# ACTION FOR A-T

England & Wales · Charity number 1145303

## Details

| | |
|---|---|
| **Other names** | ACTION FOR A-T, THE EVIE READ CHARITABLE TRUST - ACTION FOR A-T |
| **Status** | Registered |
| **Legal form** | Trust |
| **Registered** | 2012-01-06 |
| **Register** | View on the Charity Commission register |

## Contact

| | |
|---|---|
| **Address** | Action For A-T<br>Aruna House<br>2 Kings Road<br>Haslemere<br>Surrey<br>GU27 2QA |
| **Phone** | 01428853313 |
| **Email** | info@actionforAT.org |
| **Website** | www.actionforAT.org |

## Activities

**Objects:** THE OBJECTS OF THE CHARITY (THE OBJECTS) ARE THE RELIEF OF SICKNESS AND THE PROMOTION AND PRESERVATION OF GOOD HEALTH IN THE UNITED KINGDOM, IN PARTICULAR BUT NOT EXCLUSIVELY, BY:A) THE FUNDING AND PROMOTION OF MEDICAL AND/OR SCIENTIFIC RESEARCH INTO ATAXIA TELANGIECTASIA (A-T) WITH THE AIM OF DEVELOPING A CURE FOR THE CONDITION AND TO IDENTIFY LINKS BETWEEN A-T AND OTHER GENETIC DISEASES OR CONDITIONS AND TO PUBLISH THE USEFUL RESULTS ARISING FROM SUCH RESEARCH;B) PREVENTING A-T, INCLUDING THROUGH, BUT NOT LIMITED TO, ANTENATAL SCREENING FOR A-T;C) THE PROVISION OF INFORMATION, ADVICE, SUPPORT AND WHERE, APPROPRIATE, FINANCIAL ASSISTANCE TO ANYONE IN THE UK AFFECTED BY A-T (INCLUDING, WHERE APPROPRIATE, THE FUNDING OF EQUIPMENT WHICH CAN BE USED FOR THE DIAGNOSIS OR DETECTION OF A-T OR FOR TREATING, MITIGATING OR RELIEVING THE SYMPTOMS OF A-T); AND D) ADVANCING THE EDUCATION OF THE PUBLIC ABOUT A-T.

**Activities:** The chairty's main aim is the identification and funding of high quality peer-reviewed medical research into finding a cure or treatment that will delay or prevent the disabling effects of Ataxia-Telangiectasia ("A-T"). Additionally the charity works to raise public awareness of A-T and to build

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collaborative partnerships with other organisations to help advance the understanding of A-T.

## Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Other Defined Groups, The General Public/mankind

## Geography

- **Area of benefit:** NATIONAL
- Throughout England And Wales

## Finances

| Period end | Income | Expenditure | Assets | Employees |
|---|---|---|---|---|
| 2025-12-31 | £905,048 | £444,162 | £697,231 | 2 |
| 2024-12-31 | £1,168,113 | £1,846,493 | £236,345 | 2 |
| 2023-12-31 | £1,092,490 | £384,330 | £914,725 | 3 |
| 2022-12-31 | £949,804 | £1,106,145 | £226,804 | 2 |
| 2021-12-31 | £593,451 | £440,191 | £383,145 | 2 |
| 2020-12-31 | £458,645 | £839,221 | - | - |

## Trustees

| Name | Role | Appointed |
|---|---|---|
| **TOBY READ** | Chair | 2011-10-18 |
| Christopher Richard Thompson Askew | | 2014-03-26 |
| EMILY READ | | 2011-10-18 |
| Joseph Frost | | 2020-01-01 |
| MARIA LEONARD | | 2011-10-18 |
| MARK TOMS | | 2014-03-26 |
| Tom Shillingford | | 2015-08-01 |
| WILLIAM ROWBERRY | | 2014-03-26 |

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**ACTION FOR A-T**

England & Wales - Charity number 1145303

# Accounts




# Annual Report & Financial Statements

FOR YEAR END 31ST DECEMBER 2025

**WWW.ACTIONFORAT.ORG**

Action For A-T Charity registered number 1145303

# Legal & Reference Information

## Patrons

Jonny Wilkinson CBE
Roger Black MBE
Jeremy Guscott MBE
Simon Shaw MBE
Rachel Morris MBE
Naga Munchetty
Leon Haslam

## Chief Executive

Sean Kelly

## Trustees at the date of approval

Toby Read (Chairman)
Emily Read
William Rowberry (Treasurer)
Tomos Shillingford
Maria Leonard
Chris Askew, OBE
Dr Mark Toms
Joseph Frost

## Appointed during the year or since year end

None

## College of Experts

Dr Kathryn Johnson, Chair, Scientific Advisor
Professor David Attwell
Professor Esther Becker
Dr Lisa Bunn
Professor Keith Caldecott
Dr Richard Kay, Medical Statistician
Dr Guy Makin
Dr Andrew Prayle
Bruno Salomone Gonzalez de Castejon
Professor Grant Stewart
Professor Matthew Wood
Dr Alex Whitworth
Professor Andy Bush
Dr Anke Hensiek
Professor Sam Behjati
Munira Khan
Dr Rebecca Gil Garzon
Dr Shlomit Keler
Dr Alex Krauthammer
Professor Yossi Shiloh
Dr Peter Olbrich
Dr Peter Soler Palacin
Felipe Cortés
Dr David Gómez Andrés
Dr Borja Sáez
Professor David Coman

## Patient Representatives

Amandeep Sharma
Clare Gallagher
Natasha Schneider
Kelly Saponaro
Casey Beveridge
Henrik Bergrem

## Charity Registration Number

United Kingdom Registered Charity number: 1145303

**Registered Office**
Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

**Operational Address**
Action for A-T
Carlton House
19 West Street
Epsom
Surrey
KT18 7RL

**Professional Advisers**
Solicitors
Bingham McCutchen LLP
41 Lothbury
London
EC2R 7HF

**Bankers**
HSBC Bank
110 High St
Godalming
Surrey
GU7 1DP

**Accountants & Auditors**
A & N (Haslemere) Limited
t/a A & N Chartered Accountants and Registered Auditors, Aruna House 2 Kings Road
Haslemere
GU27 2QA

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# Trustees' Report

**The Trustees of Action for A-T present their annual report and the financial statements for the year ended 31 December 2025.**

The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

## Reference and Administrative Details

Action for A-T is a charity registered in England and Wales (No. 1145303). The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. The Trustees met in February, May, September, and November in 2025. The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

## Public Benefit

Action for A-T's charitable objectives are set out in its governing Trust Deed, summarised in the "About Us" section on our website and include undertaking rigorously evaluated and properly conducted medical research into finding a cure or new treatment for the rare genetic condition Ataxia Telangiectasia (A-T), a rare genetic condition.

During the year, the charity has continued to manage its ongoing research portfolio as well as committing funds to a variety of new A-T related research projects. Details of this work can be seen on pages 8 to 11.

Our Trustees have considered how our work may most effectively further our charitable objectives for benefit of the public, in particular all those affected by Ataxia Telangiectasia. In doing so, they have adhered to the Charity Commission's guidance on public benefit (Public Benefit: Running a Charity (PB2) and Public Benefit: Reporting (PB3)), ensuring that all activities align with our mission and that no undue private benefit arises.

## Environmental Considerations

While not subject to statutory reporting on greenhouse gas emissions, the charity remains mindful of its environmental impact. Measures taken include minimising paper use, promoting digital communications, and working with research partners committed to sustainable practices.

## Objects, Achievements & Performance

Action for A-T's mission is: "To speed up the process of identifying a cure for A-T or treatments that delay or prevent the disabling effects of this childhood condition"

To further that mission, the charity focused on the following key areas in 2025:

- Strengthening our Capacity and Capabilities
- Continuing our Investment in Medical Research in the UK and Abroad
- Strengthening and Increasing our Fundraising Activities
- Working closely with others to meet our objectives
- Increasing awareness of our work and the condition
- Board Composition

The Trustees confirm that all activities undertaken align with the charity's objectives and provide clear public benefit, in accordance with the Charity Commission's guidance.

# Strengthening our Capacity & Capabilities

## Our Aim

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us achieve our charitable mission. Since the Charity was initially established in 2012, a great deal of governance and capacity building work has already taken place, but continued development is required to ensure that we are more efficient, productive and well positioned for the future.

## Our Performance

2025 was another strong fundraising year with better-than-expected results from many of our activities. As in previous years, our ability to be flexible, innovative and capitalise on new opportunities enabled us to deliver a strong fundraising result.

Increased volunteer support helped us deliver the new planned activities and existing fundraising initiatives efficiently and effectively, allowing us to scale up many activities and increase funds raised. Many of these successful activities were data-led, as our previous investment in a good CRM system enabled us to reach key target audiences and manage relationships more effectively. In line with SORP 10.20, the value of general volunteered time has not been recognised in the financial statements, as it is not practicable to measure this contribution reliably.

We continued to explore and implement new technologies to improve our fundraising and communicate with our stakeholders. Throughout the year, we upgraded our CRM data base, invested in new IT equipment and strengthened our cyber security protocols to ensure that the data we hold is stored safely.

We proactively managed our research relationships especially relationships with our grant holders to ensure that they had the required resources to complete their projects as expediently as possible. Where appropriate, some studies were granted extensions with no further cost to the charity as many investigators experienced recruitment issues due to various micro and macro-economic factors or delays in recruiting study participants or fibroblasts.

Our ability to adapt was only possible due to our size and structure and the hard work of a small but highly skilled team which we retained in full during the year. They have once again gone above and beyond to deliver another successful fundraising year and the Trustees are very grateful for their incredible efforts.

# Continuing our Investment in Medical Research in the UK & Abroad

## Our Aim

Action for A-T aim to build a community of A-T research leaders and increase the amount of research that is taking place globally. Although we will always fund the highest quality applications wherever they are from; our key focus is to invest in projects and people based in the UK wherever possible.

## Our Performance

In 2025, Action for A-T continued to fund and manage a focused portfolio of ongoing research projects aimed at improving diagnosis, treatment and long-term outcomes for people living with Ataxia-Telangiectasia. Our commitments span therapeutic development, drug discovery, clinical research and innovative technologies that support families today while driving progress toward future treatments. These studies include gene therapy, suppressor tRNA, and ATM-splicing modulation work that target the underlying cause of A-T as well as supporting high-throughput screening programmes designed to identify potential treatments that could move quickly toward clinical use. Our portfolio also addresses urgent medical needs, such as cancer risk, immune dysfunction, and biomarkers for early diagnosis in young children. Together, these projects reflect our commitment to accelerating scientific progress and bringing meaningful hope to families affected by A-T.

We provided sponsorship for the A-T Clinical Research Conference which took place at Loughborough University in June and arranged for the speakers' presentations to be filmed and shared with the wider A-T community. The conference was the first in person meeting bringing together the global A-T research community since the pandemic and offered the perfect opportunity to catch up with many of our grant recipients as well as discussing new ideas and opportunities with other researchers.

Following a consultation with the Association of Medical Research Charities (AMRC), we expanded our Research Advisory Committee (RAC) to form a College of Experts. The COE is a distinguished group of clinicians, scientists, and sector specialists who provide independent, evidence-based guidance to ensure our research funding is rigorous, ethical, and focused on the greatest potential for patient impact. Their collective insight strengthens our decision-making, safeguards scientific quality, and helps us invest in research that truly moves the field forward. Experts from this group whose skillsets most closely match the applications we receive, will be selected for future grant rounds. This will ensure better understanding of each application, help in committee rotation and should reduce ▸

possible bias during the review process.

We opened a new drug repurposing grant round in March 2025 and members from the COE helped to review a new application from the Ataxia research team at UCL looking at Omaveloxolone as a potential treatment for Ataxia Telangiectasia. The application required some minor amendments and the team were advised to resubmit via the joint grant round with Action Medical Research which opened in December 2025.

In addition to the drug repurposing grant round, we also joined forces with Dr Andrew Prayle at Nottingham University for our third Sandpit event. A record amount of applications was received resulting in an investment of £58,188 in three new proof of concept studies. We also awarded a further £58,253 to Dr Sam Nayler at the QIMR Berghofer Medical Research Institute, Queensland, Australia to continue his work for a further 12 months exploring potential drug targets using mini brain organoids. This grant was made in partnership with BrAshA-T.

### Social Responsibility & Community Engagement

Action for A-T is committed to supporting families affected by A-T, raising awareness, and fostering collaboration with researchers and medical professionals. Beyond funding research, we actively engage with the community to ensure our work has a broad and lasting impact.

1. Community & Public Engagement: We work closely with families, researchers, and donors to advance A-T research and awareness.
2. Volunteering & Fundraising: Our fundraising efforts are strengthened by dedicated volunteers and corporate partners, whose support is invaluable.
3. Commitment to Inclusion & Governance: We ensure fairness, transparency, and ethical governance in all aspects of our work.

## Funding High-Quality Research into A-T

In addition to supporting and funding research aimed at improving the understanding of A-T, there are many innovative and exciting medical research opportunities that raise the prospect of real progress in combating the effects of genetic conditions such as A-T.

### Our Aim

Action for A-T's aim is to be able to make grants to hospitals and universities throughout the world for the purpose of conducting research across all therapeutic areas related to A-T, with an emphasis on research that is likely to have a clear clinical application within the foreseeable future and/or which evaluate innovation in medical techniques which may have a potential benefit for children with A-T.

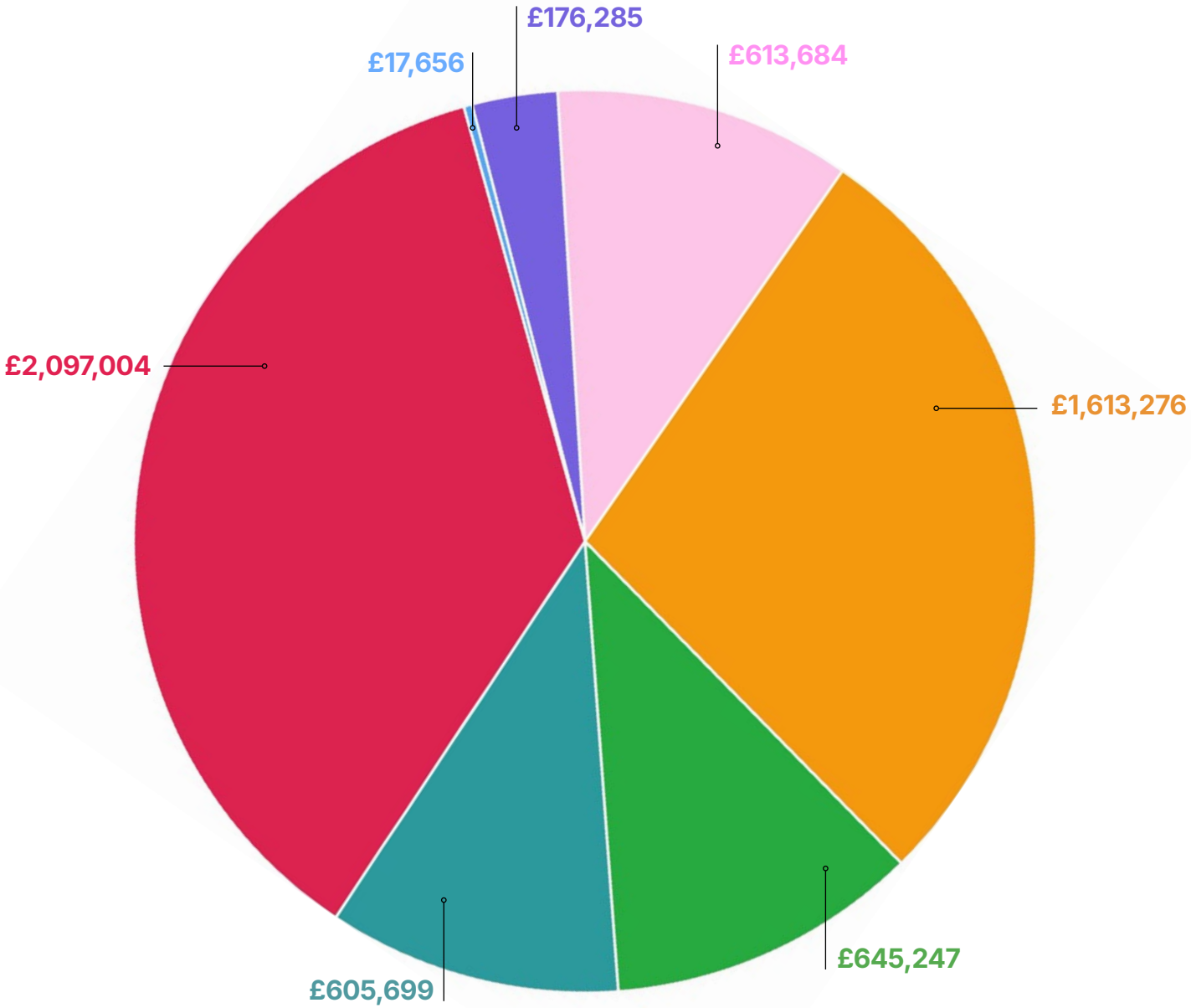
### Our Performance

Since Action for A-T was established in 2012, we have invested £5,768,851 in 64 global research projects under seven main research headings categorised using the UK Clinical Research Collaboration Health Research Classification System.

- **Underpinning Research -** Developing new tools and techniques for conducting research
- **Aetiology -** Understanding the causes of A-T
- **Prevention of Disease & Conditions -** Studies to identify new treatments for A-T
- **Detection, Screening & Diagnosis –** Tests for diagnosing and monitoring patients with A-T
- **Development of Treatments and Therapeutic Interventions -** Creating drugs and Therapies to alleviate the symptoms of A-T
- **Evaluation of Treatments and Therapeutic Interventions -** Studies to prove how new treatments work and understand how to use them
- **Management of Diseases & Conditions -** Managing the symptoms of A-T

# Total Research Spend Since 2012

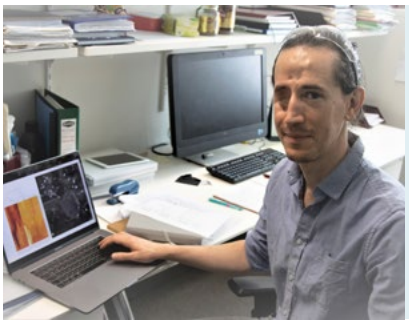
The chart below shows the historic allocation of our research investment portfolio and our total investment in each of the six research categories listed above:




- Underpinning Research
- Aetiology
- Prevention of Disease and Conditions
- Detection, Screening & Diagnosis
- Development of Treatments and Therapeutic Interventions
- Evaluation of Treatments and Therapeutic Interventions
- Management of Diseases & Conditions

# The following grants were awarded by the Trustees in 2025:

## Dose response and mechanistic profiling of two candidate neuroactive drugs in A-T cerebellar organoids



**Principal researchers:** Dr Sam Nayler

**Institute:** QIMR Berghofer Medical Research Institute, Queensland, Australia

**Cost:** £58,252.83 over 12 months in partnership with BrAshA-T (Australia)

**Start Date:** 1st of February 2026

### Project Overview

Having identified two features that operate differently in A-T cerebella, Dr Nayler and his team hypothesize these will be amenable to therapeutic intervention. The first is a drug which changes the way in which brain cells co-operate to balance out levels of glutamate. Glutamate is a building block but also acts an important neurotransmitter. ATM deficient cells have metabolic abnormalities, and thus this can spill over into issues affecting their balance of this neurotransmitter, driving further problems.

This process is critical to the cerebellum, and the team believe important for understanding A-T. The team have identified a drug (Riluzole) which has potential to correct this process and are also looking at a second aspect of Purkinje cell regulation, and whether targeting particular potassium channels which help regulate activity has therapeutic value. Depending on the efficacy of specific sup-tRNAs to bypass specific NSMs in the ATM and their ability to administer them efficiently to organs that are particularly susceptible to loss of ATM e.g. the cerebellum of the brain, it is possible that this therapy could potentially slow or halt progression of the neurological decline.

# Improving future treatments for Ataxia-Telangiectasia through better delivery of RNA-based therapies



**Principal researchers:** Dr James Dixon

**Institute:** University of Nottingham, UK

**Cost:** £18,938 over 9 months

**Start Date:** 1st of March 2026

## Project Overview

Dr Dixon and his team will carry out early-stage research to improve how emerging RNA-based treatments can be delivered to cells affected by A-T. It brings together an international team of experts from the UK, Germany and the USA, including researchers who are new to A-T and bring fresh expertise to the field.

The work focuses on improving antisense oligonucleotides (ASOs) small pieces of genetic material already being tested in patients by packaging them with a safe delivery system developed at the University of Nottingham. This approach aims to make these treatments work better and more consistently.

Over nine months, the team will:

- Test whether the new delivery system improves the performance of ASO treatments in cells donated by people with A-T
- Create new laboratory tools that allow researchers to quickly measure how well treatments are working
- Develop matching tools for mouse models, which are essential for future testing and treatment development
- Explore whether this approach could help a wider group of people with A-T, rather than only those with very specific genetic changes

By the end of the project, the team expect to have clear evidence that better delivery can improve the effectiveness of emerging A-T treatments and new research tools that can be shared with the global A-T research community. The findings will also provide a strong foundation for future studies, including work that could lead to clinical trials.

# Developing a Safer Immune-Based Treatment for Blood Cancers in Children and Adults with A-T



**Principal researchers:** Dr Saikit Mandal

**Institute:** University of Nottingham, UK

**Cost:** £19,905 over 12 months

**Start Date:** 16th March 2026

## Project Overview

This project explores a promising alternative: using a special type of immune cell, called γδ T-cells, which remain relatively intact in people with A-T. These cells naturally recognise and kill cancer cells without relying on the faulty ATM gene that causes A-T. This makes them a potentially safer option than standard chemotherapy.

The Nottingham based team will grow 3D “mini-tumours” (organoids) from cancer cell lines that carry the same ATM mutations seen in A-T patients. They will also expand γδ T-cells from healthy donor blood and test how effectively they kill leukaemia and lymphoma cells. The team will then assess whether combining γδ T-cells with existing immunotherapies (such as anti-PD-1 drugs) boosts their cancer-killing ability and use advanced imaging and machine-learning tools to measure how these immune cells interact with cancer cells in real time.

This will create the first pre-clinical platform specifically designed to test safer cancer treatments for A-T.

This study could be hugely beneficial to the families living with A-T as it provides a realistic pathway toward safer, less toxic cancer treatments and uses immune cells that are naturally preserved in A-T patients. It also reduces the reliance on chemotherapy, which is often life-threatening for this group and builds tools (organoids and analysis software) that can be shared with the wider A-T research community, accelerating future discoveries.

The results will provide essential preliminary data for larger applications to other funders. These future grants will support studies using patient-derived cells and move this work toward early-phase clinical trials.

# A prospective pilot study to compare lung CT and MRI in Ataxia Telangiectasia



**Principal researchers:** Dr Christabella Ng

**Institute:** University of Nottingham, UK

**Cost:** £19,895 over 12 months

**Start Date:** 1st of June 2026

## Project Overview

Dr Ng and her team aim to test whether MRI scans, which use no radiation, can replace CT scans for monitoring lung disease in A-T. The team has already developed a new type of lung MRI that works while the person breathes normally, avoiding the need for breath-holding (which is difficult for many people with A-T).

This project will compare MRI and CT scans taken on the same day in 12 adolescents with A-T. They will assess whether MRI can show lung structure and function as clearly as CT, and whether it can provide better information than standard lung function tests, which are often unreliable due to muscle discoordination.

If MRI can replace CT, people with A-T could avoid repeated radiation exposure throughout their lives. This would reduce cancer risk and provide a safer, more comfortable way to monitor lung health.

12 young people with A-T who are already scheduled for a CT scan will be recruited to take part in the study and each participant will undergo a 45-minute, free-breathing lung MRI at the University of Nottingham.

The MRI scans will be compared with CT images to see how well MRI detects lung changes. The team will explore whether MRI can measure lung function more accurately than current tests and use the findings to design a multi-centre study.

The project will also generate essential pilot data needed to secure larger national grants and to introduce MRI-based measures into future drug trials for A-T.

# Ensuring that our research is of the highest quality, is well managed and has clear and achievable aims

**Research is at the heart of what we do, and our research strategy outlines our intentions on achieving our mission.**

## Our Performance

Action for A-T were awarded their second prestigious AMRC award for best practise in medical and health research peer review in May 2021 and currently awaiting the outcome of a new audit which took place in 2025. The award confirms the robust methods used to make decisions about which research projects to fund and our support of the best researchers and the highest quality research, with the best chance of improving the lives of those affected by A-T. The award was made following a full audit of our processes which takes place every five years.

The Trustees generally stage one grant round per year where funds will allow. Applications are peer reviewed by independent external reviewers before they are passed on to our College of Experts for further review. Projects which pass the peer review process and are deemed high enough quality are passed on to the Trustees to make the final decision based on several key criteria including available funds, strategic alignment, and existing research commitments.

Our College of Experts (COE) are part of this process and consist of independent scientific experts from fields related to A-T, including clinicians, non-clinicians, and statistical expertise from a wide range of UK institutions. Lay members are also on the committee to incorporate the views of parents and patients living with A-T, bringing a valuable and unique perspective over what research should be funded. Members of our COE reviewed one of the applications we received in 2025 and their funding recommendations were passed on to the Trustees for consideration. The Trustees agreed with the COE's suggestion not to fund the "Omaveloxolone Efficacy" study and the applicants were encouraged to reapply when the next grant round is launched.

## Project outcomes and sharing knowledge

We believe that sharing project outcomes and knowledge is a fundamental requirement for the development of new research strategies which will ultimately benefit those living with the condition. Progress, annual and final reports are mandatory for all our research grants to ensure that they are reaching the agreed milestones. These reports are formally reviewed by our scientific advisor to ensure that each project is in line with its stated aims and the outcomes are then converted into lay summaries to share with our supporters.

Researchers are also encouraged to publish their findings in medical journals and where possible, make the findings freely available. The outputs of research such as publications usually occur sometime after a research project ends and it can take many years to translate research ideas into new treatments or therapies to improve quality of life.

The outcomes of all the concluded research we have funded are displayed on our website under the 'Completed Research' section. Where applicable, these posts also include links to any online publications, and we also share project information via our social media channels and in various communications to our supporters and potential donors.

## Evaluating the outcomes of our research

As with all charities, we are passionate about demonstrating the impact of our work and understand the importance of monitoring the progress and outcomes of our research. Throughout the year we continued to work with our scientific advisor and other members of our College of Experts to oversee and evaluate the effectiveness of our ongoing research portfolio. Between them, they monitored the progress of ongoing projects and signed off on any which were completed to help ensure that the original research aims stated in the application were fulfilled.

At the start of 2025 we created an impact report which highlighted some of our successes and stories over the past 12 years. The impact report was shared widely with our key stakeholders and is available to view or download from our website https://actionforat.org/12-years-of-research/

# The following studies concluded in 2025, and the initial project outcomes were as follows:

## Exploring Omaveloxone efficacy in Ataxia-Telangiectasia



**Principal researcher:** Professor Paola Giunti (pictured) and Dr Rosella Abeti

**Institute:** University College London (UCL), UK

**Completion Date:** January 2025

### Project Overview

One of the processes happening in people who have A-T is increased oxidative stress.  Oxidative stress is an imbalance of free radicals and antioxidants in your body that leads to cell damage. The team at UCL proposed to study a drug called Omaveloxolone (Omav).  This drug is known to defeat oxidative stress in patients with Fredreich's Ataxia, and the team wanted to investigate whether it could help overcome the adverse effects of oxidative stress in A-T cells.

### Project Outcome

The study achieved it's 3 milestones over the 4-month period:

1. **Growing cells from AT and non-AT individuals**
Skin cells (fibroblasts) were collected from both A-T patients and healthy individuals. These cells were then carefully grown and multiplied in the lab, creating a cell model to use in the next two stages of the research.

2. **Testing the effect of Omav on cellular stress**
Cells from A-T patients were found to produce higher-than-normal levels of harmful molecules called reactive oxygen species (ROS), which can damage cells. This suggests that A-T cells struggle to control oxidative stress. When treated with Omav, ROS levels in A-T cells dropped significantly, reaching levels similar to those found in healthy cells. This result shows that Omav is effective in reducing oxidative stress in the A-T fibroblasts.

3. **Understanding Omav effect on the Nrf2 pathway**
Western blot analysis, a technique used to measure protein levels, showed that A-T patient cells have lower-than-normal levels of Nrf2, a protein that helps cells fight oxidative stress. This deficiency may contribute to the increased oxidative damage observed in A-T.

When the cells were treated with Omav, Nrf2 levels increased and ROS, a potent toxin present in A-T cells, was reduced. This shows that the drug can activate the Nrf2 pathway, which plays a key role in antioxidant defence.

These initial findings show that A-T patient cells are highly vulnerable to oxidative stress due to defective Nrf2 signalling. However, treatment with Omav restores their antioxidant capacity, making it a potential therapeutic strategy for reducing oxidative damage in A-T. The team hope this could modulate disease progression. More in depth studies are now needed to bring this drug to clinical trials in humans.

# Further development of CRISPR/Cas Genome Editing as a Treatment for Ataxia Telangiectasia



**Principal researcher:** Professor Rafael Yáñez-Muñoz

**Institute:** Royal Holloway, University of London

**Completion Date:** March 2025

## Project Overview

This project was an extension to a previous project.  This extension funded the use of donated human blood stem cells to test methods to repair specific mutations in the gene responsible for ataxia-telangiectasia (A-T

## Project Outcome

CRISPR genome editing technology is a very effective method to introduce defined changes in the cellular genome, and hence may allow the repair of mutations causing A-T. There are hundreds of different A-T mutations, and the team worked with two specific mutations, one of which is relevant to 10-15% of UK A-T patients. In the previous project they demonstrated that they could repair these two mutations in patient cells modified to live indefinitely in the laboratory. Following these successful experiments on laboratory cells, they started using blood stem cells from donors not affected by A-T. Blood stem cells can be returned to people following genetic modification, allowing the correction of diseases affecting production of blood cells and the immune system. They used donor cells because they are much easier to obtain than stem cells from people affected by A-T, which would be the next step if the procedure was successful.

Their results indicate that they can introduce the desired genome changes in the donor stem cells. This suggests that the methods used may allow correction of the two A-T gene mutations if applied to blood stem cells from people with A-T. The team carried out analyses to check for possible negative effects of the CRISPR editing process on the genome of the treated cells. The results in this respect were also encouraging.

The team are currently sourcing blood stem cells from A-T patients with the two relevant mutations to further test their genome editing methods.

# IMAGIN-AT – advanced lung imaging and function testing in Ataxia Telangiectasia



**Principal researcher:** Dr Jayesh Bhatt and Dr Andrew Prayle

**Institute:** Nottingham University Hospitals NHS Trust

**Completion date:** May 2025

## Project Overview

In A-T, breathing problems are one of the main causes of early death. To improve outcomes, researchers urgently need better ways to measure lung health. Standard breathing tests often don't work well in AT because they require strong, coordinated breaths. Xrays and CT scans can show lung damage, but they use radiation — something that must be avoided as much as possible because people with AT already have a higher risk of cancer.

The IMAGINAT project set out to solve a longstanding challenge: how can we safely and reliably assess lung structure and function in AT, both in clinic and in future treatment trials?

## Project Outcome

The research team developed and refined a new approach using Magnetic Resonance Imaging (MRI) — a radiationfree technique — alongside an adapted version of the Lung Clearance Index (LCI) test. The work took place in three phases:

**Phase I – Feasibility -** Initial MRI scans in children with AT showed that the method was possible but also revealed technical issues such as motion artefacts and image distortions.

**Phase II – Troubleshooting -** The team paused recruitment to diagnose the problems. They tested new oxygen delivery methods, adjusted scanner settings, replaced equipment that caused artefacts, and trialled scanning children in different positions. Scans improved, but some issues remained.

**Phase III – A New Imaging Pipeline** - During the COVID19 pandemic, scanning had to stop, but the team used this time to collaborate with imaging experts and design a completely new protocol on a modern 3Tesla MRI scanner. This final pipeline combined three complementary MRI techniques to capture both lung structure and how air moves in and out of the lungs — all without requiring breathholding.

The team also adapted LCI testing using a soft face mask, making it suitable for children who cannot reliably use a mouthpiece.

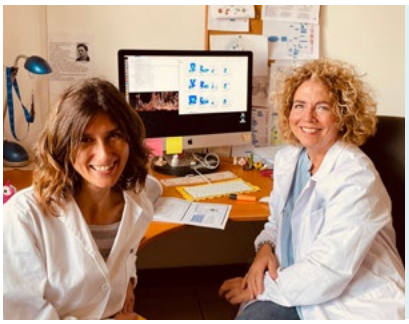
Across all phases, 21 participants took part.

**Key Outcomes**

- A robust, childfriendly MRI method for assessing lung structure and function in AT has now been developed.
- Scans are radiationfree, take under one hour, and allow children to watch a film during the procedure.
- The new imaging pipeline is resistant to movement, making it suitable for children aged 8 and above.
- LCI testing has been successfully adapted for AT using a comfortable face mask.
- The project has created reliable tools that can be used in future clinical trials to measure whether new treatments are working.

The research team are now working to bring these new tests into routine clinical practice. The portable LCI equipment can already be used in clinic, and the team is exploring how best to integrate MRI lung scans into regular AT care. The data collected through IMAGINAT will also help design and power future clinical trials, ensuring that new treatments can be tested using reliable, meaningful lung health measures.

# Study of natural killer cells in A-T pathogenesis and their therapeutic implications



**Principal researchers:** Dr Margherita Doria and Dr. Maria Giovanna Desimio

**Institute:** Bambino Gesù Children's Hospital, Italy

**Completed:** 31st December 2025

## Project Overview

This project set out to understand how natural killer (NK) cells – a key part of the immune system's defence against viruses and cancer – function in people with AtaxiaTelangiectasia (AT). Earlier work suggested that NK cells in AT may be impaired because of changes in a receptor called NKG2D, which helps NK cells recognise and destroy abnormal cells. As the report notes, "NK cells displayed reduced expression of the activating NKG2D receptor linked to plasma accumulation of cognate ligands." By studying both AT patients and an ATMdeficient mouse model, the team aimed to identify biomarkers of disease progression and explore potential therapeutic strategies that could strengthen immune responses in AT.

## Project Outcome

The study found that although NK-cell numbers were preserved and their function was significantly impaired. A-T NK cells showed reduced expression of the activating receptor NKG2D, increased expression of the inhibitory receptor PD-1, and a marked reduction in both tumour-killing capacity and cytokine production. Plasma from A-T patients contained high levels of inflammatory and immunosuppressive molecules, including IL-6 and TGF-β, with strong correlations between these factors and NK-cell dysfunction. The team also established that NK cells of A-T patients displayed impaired effector functions and that TGF-β accumulation in A-T plasma was observed for the first time. These findings suggest that chronic inflammation and soluble NKG2D ligands contribute to NK-cell exhaustion.

Importantly, the team also explored potential therapeutic strategies. When patient cells were exposed to IL-15, NK-cell receptor expression improved and cytotoxic function was partially restored, even in the presence of TGF-β. This indicates that NK-cell-based immunotherapies—already advancing in cancer treatment—may be adaptable for A-T. Overall, the study provides a detailed map of NK-cell abnormalities in A-T and identifies several promising biomarkers and intervention points that could support future clinical advances.

The team plan to focus on making the most of the rich dataset they have collected and will begin to translate their findings into future treatment possibilities. They are now applying advanced statistical methods to explore how the immune changes they observed—such as high levels of IL-6, TGF-β and soluble NKG2D ligands—relate to real-world outcomes like recurrent infections, cancer risk and immune deficiency. This deeper analysis aims to identify reliable biomarkers that could help clinicians track disease progression or tailor care more effectively.

**To view all our current and complete research projects, please visit:**
**https://actionforat.org/category/research-projects-funded/**

# Achievements and Performance, Fundraising Activities

**Action for A-T raises funds through donations, fundraising events, and corporate partnerships. No professional fundraisers or commercial participators were engaged. All fundraising is conducted in-house and monitored by the Trustees.**

The charity follows ethical fundraising standards and ensures that all activities comply with best practices. During the year, no complaints were received regarding fundraising.

## Strengthening and Increasing our Fundraising Activities

### Our Aim

Action for A-T funds high quality peer reviewed medical research to speed up the process of identifying a cure for Ataxia Telangiectasia (A-T). We endeavour to raise funds from a variety of activities which appeal to new and existing supporters. Since 2012 we have invested £5,768,851 in 64 A-T related research projects around the world, and this has only been possible thanks to our generous supporters.

### Our Performance

2025 was another strong fundraising year with most activities performing better than expected due to the generosity of our event guests and sponsors. We were able to benefit from several new fundraising events including a ball staged in Headley, Hampshire run by one of our trustees and their friends, a large scale gala event staged by an International College in Spain, a 3-day endurance cycle ride staged by friends and employees of Brightwake staged a series of events staged by the employees of Aviva Investors. The previous sizeable funding from MRC to help retain early years researchers, and NATA was not repeated and this was the main reason for the reduction of income from 2024 to 2025.

Our investment in TCS London Marathon places proved successful once again, allowing us to make a 400% return. 19 people joined our marathon team raising £66,038. Our application to secure more marathon places through the official charity ballot was successful and we now have 27 places for the 2026 event.

In line with our fundraising strategy, we delivered a robust portfolio of sporting and social events as well as developing new relationships with other funders. We also diversified our other fundraising activities to ensure that we were not solely dependent on any one source of funding. Challenge and Social events increased to 53% of our overall income (2024 - 41%). Whilst other fundraising initiatives, such as donations, funding partnerships and trust and foundation applications accounted for 39% (2024 - 51%). The remaining 8% (2024 – 8%) came from bank interest on our designated funds.

A few notable fundraising activities took place throughout the year including various golf events and the Stewart Golf and Mashie online auctions. We are especially grateful to the staff and clients of The Constellation Automotive Group yet again for taking part in a one-day endurance cycle in Oxford which raised £63,800 plus the non-riders who raised an additional £42,900 from a marathon walk. We are also indebted to the staff at Aviva Investors for their generous support throughout the year and the students of Quest Professional who raised over £17,363 at their fundraising dinner. In addition, we would like to thank Clarion Golf for raising £21,660 and Simon Toon and his friends for their ongoing and valued support.

# Raising Funds Responsibly

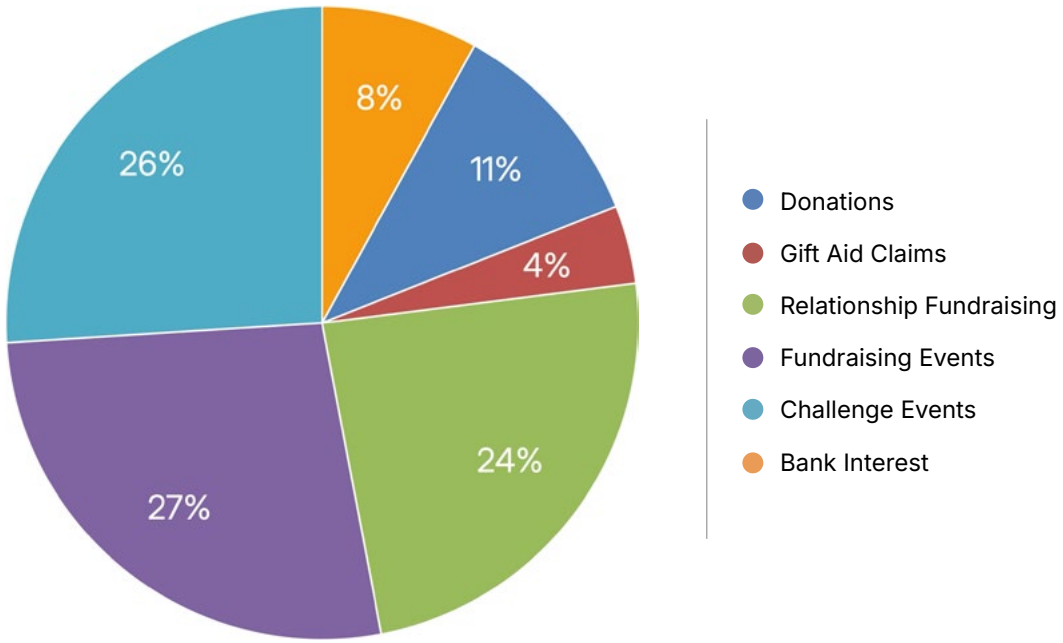


Action for A-T are registered with the Fundraising Regulator and are committed to upholding the code of fundraising practice. We receive all our funding from voluntary sources, including individuals, companies, trusts and foundations and we do not work with any professional fundraisers or commercial participators to raise funds on our behalf. Each year, we purchase places in several physical challenges as well as staging and benefiting from a series of other social and sporting events.

We want everyone we interact with to feel free from undue influence when they consider donating. Our in-house fundraising team are trained to recognise these signs, so they can manage conversations in a way that could be considered intrusive or putting repeated or undue pressure on someone to donate. We routinely monitor our fundraising materials to ensure our standards remain high and treat our supporters fairly. Supporter feedback is reviewed regularly to ensure our fundraising offer is appropriate and complies with relevant rules and regulations.

To help protect people in vulnerable circumstances, we continued to follow guidance from the Government and the Fundraising Regulator throughout 2025. We also continued to speak to more supporters to make sure our high standards were maintained.

The pie chart below shows the percentage splits of each of our areas of fundraising in 2025.




We would also like to record our thanks to all our volunteer committee members for their time and commitment in helping us achieve our mission, as well as everyone who donated their time, auction prizes and/or supported or participated in our events.

In addition to the above, we are also extremely grateful to the trusts and foundations who provided restricted funding for various research projects (these are listed on page 50). We are always keen to work with other trusts, foundations and corporate funders who might be interested in supporting our work.

# Events Since the End of The Year

Information relating to events since the end of the year is provided in the notes to the financial statements.

# Working Closely with Others to Meet our Objectives

## Our Aim

Action for A-T strongly believes that there are many opportunities to further the search for a treatment or a cure for A-T through working with others that may have overlapping aims or objectives to our own. To this aim, we actively seek out like minded organisations and where possible, create collaborative partnerships.

## Our Performance

**Co-funding A-T Research Projects with other charities and patient organisations**

Action for A-T continued to work closely with various organisations, charities, and patient organisations throughout 2025 to fund new and existing research studies. Throughout the year, we continued to manage a variety of our ongoing studies (funded in partnership with others) as well as contributing to new research. Our research partners in 2025 were as follows:

**The UK based Children's Charity GOSH**

Action for A-T continued to work closely with GOSH charity and partnered with them on their 2025/26 National Research Project Grant Call. We have agreed to contribute 25% of the cost towards any successful A-T related applications.

**The Australian charity BrAshA-T Ataxia Telangiectasia**

Action for A-T have an ongoing collaborative funding partnership with BrAshA-T who are based in Queensland, Australia. Following a joint grant call in 2023 six new research studies were passed for funding and BrAshA-T agreed to contribute £200,000 towards the total cost of five of these projects. The first payment of £100,000 was made in December 2024 and the final payment of £100,000 was made at the end of 2025.

BrAshA-T have also set aside a minimum of £130,000 to be committed towards any new research studies which are deemed fundable at the conclusion of the current Action for A-T and Action Medical Research grant round. These funds will be paid to Action for A-T in the final quarter of 2026.

**The UK based A-T Society**

A strategic partnership was established between the A-T Society and Action for A-T in 2022 to increase the overall investment in new A-T research. Following the Action for A-T grant call in 2023 six new research studies were passed for funding and the A-T Society agreed to contribute £60,000 towards the total cost of three of these projects. The full payment of £60,000 was made in the second quarter of 2025.

**The Spanish based AEFAT**

A strategic partnership was established between the AEFAT and Action for A-T in 2022 to increase the overall investment in new A-T research. Following the Action for A-T grant call in 2023 six new research studies were passed for funding and AEFAT agreed to contribute €40,000 towards the total cost of five of these projects. The first payment of €20,000 was made in December 2024 and the final payment was made in December 2025.

**The UK based Action Medical Research**

Action for A-T partnered with the children's health charity Action Medical Research (AMR) to co-fund up to £1,000,000 of A-T research in 2026. AMR will manage the application process and contribute 10% towards the costs of any successful UK based research studies. The grant round opened in December 2025 and is expected to conclude in August 2026.

Action for A-T will continue to explore additional joint funding opportunities with likeminded organisations throughout the coming year to maintain momentum and maximise the investment into A-T research.

**Working strategically with the worldwide A-T community**

The Global A-T Alliance is made up of charities and patient groups from the UK, USA, Spain, Israel, Japan, France, Turkey, Italy, China and Australia with the key objective of maximising the effort, resources and/or funding committed to finding a cure or treatments for Ataxia-Telangiectasia (A-T). The group meet virtually throughout the year to update each other on key research needs and findings as well as exploring ways in which they can work more closely together. To date, the Alliance members have jointly funded new research, met with a number of pharma companies to explore new treatment opportunities, delivered research focussed webinars for A-T families, assisted in the running of an in person clinical research conference and established a new website www.cureAT.org which brings together useful information about A-T. The Alliance members passionately believe that with increased funding and a continued global ▸

and collaborative effort, effective treatments for A-T will be developed sooner and the lives of those affected will be changed for the better.

# Increasing Awareness of our Work and the Condition

## Our Aim

As an ultra-rare disease, most people are unaware of A-T or the devastating effects of the condition. Action for A-T believes that raising awareness of the studies they fund and the impact of A-T on children and their families is an important part of increasing the potential funds available to further improve the understanding of the condition, and to progress research into possible treatments or a cure.

## Our Performance

Action for A-T has significantly increased the public awareness of the condition over the past 12 months and will continue to explore all options to promote wider understanding of A-T and why research to find a cure or treatment is so important.

The Charity's main achievements in this area to date include:

**Celebrity Support**



Our celebrity patrons have continued to help promote Action for A-T and the need for more research into the condition by championing campaigns and taking part in various activities throughout the year. As well as providing prizes for our auctions, Jonny Wilkinson created several short films which were shown at some of our events and attended the BGC trading day alongside Simon Shaw. Naga Munchetty hosted her annual golf day at Moor Park as well as the captains' charity day at Banstead Downs Golf Club and recorded a number of promotional event videos. Several other celebrities including Chris Sheasby, Leon Haslam, Kevin Whately, and Jeremy Guscott helped generate funds, awareness, and support by taking part in events and campaigns.

**Visibility at Research Institutions, Conferences and Medical Meetings**

All Action for A-T funded researchers are provided with promotional materials to display at their research facility and required to acknowledge our financial support by including our logo on any posters or presentations. Throughout 2025, several conferences and scientific meetings took place where our researchers were able to present their findings. These presentations showcased our latest projects and provided the wider A-T community with a comprehensive view of the progress made to date. We were also credited for our support in various journals and academic publications by researchers who were able to publish their findings.

**Digital Communications**

The Charity website www.ActionforAT.org remains the focal point for event sign-ups, electronic donations, and research news. The site was updated and enhanced throughout the year to provide the best possible experience for our stakeholders. After 10 years, the WordPress platform which the website currently uses is nearing its end of life so will need to be addressed in 2026.

We also continued to manage (alongside Mike Clahsen of BrAshA-T) the www.cureAT.org site which brings together key information about current & past research studies and resulting publications. The site also has sections on care and guidance, patient registries, general information about the condition and a directory of all the known patient organisations around the world. The content is available in several languages including Spanish, French, Italian and Turkish with a simplistic layout directing users to sources of useful information (e.g., websites, documents, relevant groups/meetings, etc.) rather than duplicating existing content on other websites.

Our e-newsletter continues to be a successful tool to communicate our latest news to supporters. Using Mailchimp for this proves to be cheaper than a traditional printed newsletter and has the functionality to track usage and monitor engagement. Our e-newsletter is sent to all our consenting supporters, has a clear unsubscribe function and inactive supporters are removed from the mailing list periodically.

Social media remains a key communication tool for the Charity as it is free, easily accessible and can reach wide audiences. It also allows us to engage with our supporters on a more strategic level and build additional support from their own contacts. Posts are carefully managed to ensure that the content is engaging and not repetitive and this more targeted and planned approach helped us increase our followers throughout the year. We will continue to develop our social media presence in 2025 using all available technological advancements, popular platforms, and our celebrity patrons to raise further awareness.

**National and Local News Media Coverage**

We continued to raise awareness of A-T through a series of articles and editorials in the local, national and industry press and various news websites. In addition, our chief executive and various supporters took part in local TV and radio interviews throughout the year. These helped us highlight the condition to new audiences, recruit volunteers and secure additional support and donations.

# Our Future Plans: Areas of Focus for 2026

**The Trustees believe that Action for A-T is well placed to meet its charitable objectives but have also identified the need for further development to strengthen its research activities.**

During 2026 we will continue to consolidate and diversify our fundraising activities whilst actively developing existing and seeking new funding partnerships to meet the demands of the A-T research community. We will also continue to promote A-T research to engage new audiences and maintain interest from the research community.

We will implement several measures throughout the year to ensure that the Charity continues to be fit for future purpose and to help us achieve our aim of moving closer to tangible therapies or a cure for A-T.

## Strengthening our Capacity and Capabilities

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us deliver our charitable objectives. Our size and structure enable us to adapt quickly, and we will continue to review and prioritise projects based on available resources whilst seeking out new opportunities to raise funds in a safe and sustainable manner.

## Continuing our Investment in Medical Research in the UK and Abroad

We will continue to seek out new research opportunities from the wider research community as well as focussing on key research themes related to A-T. Where possible, priority will be given to UK based projects whilst still calling for international applications where funds will allow. Our current grant round is due to conclude in August 2026, and we hope to invest circa £1,000,000 in new A-T research studies alongside our new strategic partner AMR.

We will maintain our close relationship with the Association of Medical Research Charities (AMRC) to develop and improve our peer review process and ensure that the research we fund is of the highest quality. We also hope to secure our third Excellence in Peer Review audit award at some point in 2026.

We will continue to recruit new members for our College of Experts to ensure we have a broad range of scientific experts from all areas of A-T research and additional areas of scientific technical expertise. The College of Experts will make recommendations for funding for A-T project grants, non-drug approaches and fellowship schemes. We will also secure new lay representation from various A-T families as Action for A-T strongly supports public and patient engagement in its research processes.

## Strengthening and Increasing our Fundraising Activities

We will continue to develop a pipeline of new business opportunities whilst delivering our existing portfolio of activities. We will maintain and refresh our calendar of high profile and fun events whilst also working alongside others in a benefitting capacity to reduce the financial risk to the Charity. We will continue to develop and expand our trust and foundations programme whilst actively seeking new investment from individuals, corporates, and major donors. We will also work closely with our key supporters and volunteer groups to ensure we maintain the momentum of investment in ground-breaking A-T research.

## Working Closely with Others to Meet our Objectives

We will continue to work closely with key stakeholders (especially the A-T Alliance members) as well as exploring new collaborations that will bring greater benefit to the wider A-T community. The number of promising research opportunities continues to grow steadily year on year and there are now more research themes worthy of exploration than our limited funds will allow. We will therefore continue to work with and seek out new organisations with similar objectives to our own, to help ease the financial burden and speed up the process of finding a therapy or cure for A-T.

## Increasing Awareness of our Work and the Condition

Since we were established in 2012, a key priority has been raising awareness of A-T and the work of the Charity. This has been achieved by various means including celebrity endorsement, emotive films featuring researchers and A-T ▸

families and various branding opportunities. We will continue to do all that we can to highlight A-T whilst focusing on various key projects in 2026. These projects will include maximising celebrity endorsement opportunities, the creation of a new website and other projects which help to educate and inform people about A-T.

## Board Composition

We will continue to evaluate the composition of our Trustee Board to facilitate the growth of the Charity and will consider further appointments to broaden and strengthen the Board's capabilities.

# Structure, Governance & Management

## Governing Document

Action for A-T is a charity registered in England and Wales (No. 1145303). The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

The Trustees have adopted the following policies and procedures for the recruitment, appointment, induction, and training of new Trustees:

## Trustee Recruitment and Appointment

The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. Trustees are either elected or co-opted under the terms of the Trust deed and the total number of Trustees may not be fewer than five. If a vacancy occurs or a skills need is identified, new Trustees are recommended by the existing Trustees and interviewed by the Chairman and at least one other member of the board. Election is by majority vote and potential candidates must be over the age of eighteen and eligible to act. The Trustees will continue to evaluate the composition of the Board and will consider further appointments to broaden and strengthen the Board's capabilities to facilitate the growth of the Charity.

## Trustee Induction and Training

New Trustees receive an induction pack containing a copy of the trust deed, strategy, relevant information about the Charity and its work; and a copy of the Charity Commission literature about the role and responsibilities of being a Trustee. New Trustees are also invited to meet the Chief Executive and team members to learn first-hand how the Charity operates on a day-to-day basis.

During the induction process, new Trustees are also told about the connected parties' rule, given a copy of the Charity's conflict of interest policy and asked to sign a Trustee declaration form. Where the Trustees have identified that there is a connection between the charity, or its Trustees and any third party with whom the Charity has dealt with, the Trustees will identify the relationship, and the amounts involved within the notes to the financial statements.

## Organisational Structure

The Trustees meet formally four times per year, and no business shall be conducted unless at least one-third of the total number of Trustees at the time, or two Trustees (whichever is greater) are present throughout the meeting. There are two meetings where the focus is on awarding grants for medical research and two meetings where Trustees review strategy and set operating plans and budgets. There is a review of operating and financial performance at every meeting. The Chief Executive is invited to attend all meetings of the Trustees, and the Head of Fundraising is invited to report on plans and progress at specific meetings.

While most of the business of the Charity is conducted at the scheduled Trustee meetings, there are occasional ad-hoc meetings to deal with matters of special interest and regular electronic meetings are held to review ongoing governance objectives.

The Board of Trustees delegates the exercise of certain powers in connection with the management and administration of the Charity as set out below. This is controlled by regular reporting back to the Board of Trustees so that all decisions made under delegated powers can be ratified by the full Board of Trustees in due course.

The charity considers its key management personnel to be the Trustees, Chief Executive, and senior management. Further details on remuneration are disclosed in Note 12 to the accounts.

Action for A-T is committed to the highest standards of ethical conduct in all its activities. The Trustees ensure that the charity operates with integrity, transparency, and accountability, complying with all relevant laws and regulations. While the charity's work does not typically involve high-risk environments, it maintains a zero-tolerance approach to corruption and bribery and upholds fundamental human rights principles in its partnerships and funding activities.

## College of Experts

The College of Experts (COE) is chaired by our scientific advisor. Members of the COE have a broad range of scientific expertise in areas relating to A-T. There is also lay representation on the committee as Action for A-T supports public and patient engagement in its research processes. The Trustees are very grateful to all the members of the COE for providing expert guidance and advice on a pro bono basis.

## Chief Executive

The Chief Executive is responsible for the day-to-day management of the Charity's affairs and is assisted by a small executive team who act under his direction. As well as overseeing the operations of the Charity, the Chief Executive is also responsible for implementing policies as agreed by the Board of Trustees.

## Employees, Volunteers and Contractors

The Charity aims to be an organisation where employees, volunteers and contractors enjoy a sense of fulfilment and where they feel supported and developed. All stakeholders are kept fully informed about the Charity's strategy and objectives, as well as day- to-day news and events. Individuals are encouraged to give their suggestions and views on performance and strategy.

The Charity supports equal opportunities, and a policy of recruitment and promotion based on aptitude and ability without discrimination is followed. Action for A-T is committed to the training, career development and promotion of all its employees. An individual's career development is assessed through annual appraisal and supervision. Training programmes are provided to meet any on-going needs, with the aim of developing individuals for both their current and their future roles.

## Pay and Remuneration of Key Management Personnel

The Trustees' principles are to pay staff a fair salary that is competitive within the charity sector, proportionate to the complexity of each role, it's related funding and responsible in line with the charitable objectives. Pay levels for all employees are reviewed annually and any overall percentage increases are authorised by the Board of Trustees.

Remuneration for the Chief Executive is agreed by the Trustees. Salaries are benchmarked using external data available from pay surveys (for the voluntary sector and charities located in and around London) and market conditions for the specific role and the target is the market median averages of these.

Ultimately however, salary increases relate to the funding available for each role and whether the increase will be affordable in the long term. To ensure pay is fair for all roles we are committed to paying all our employees at or above the London living wage as determined by the Living Wage Foundation.

## Engagement with Key Stakeholders

The charity recognises the importance of maintaining strong relationships with its key stakeholders, including funders, research institutions, beneficiaries, and partner organisations. During the year, we continued to work closely with medical research bodies and donor networks to ensure that our funding efforts align with the most impactful research opportunities. Trustees have actively engaged with stakeholders through regular meetings, reporting, and collaborative initiatives to advance our mission

## Risk Management

The Trustees have introduced a formal risk management process to assess business risks and implement risk management strategies. This has involved identifying the types of risks the Charity faces, prioritising them in terms of potential impact and likelihood of occurrence, and identifying means of mitigating the risks.

As part of this process the Trustees have reviewed and are satisfied with the adequacy of the Charity's current internal controls and the costs of operating controls relative to the benefits obtained. Procedures have been established for reporting failings immediately to the Chief Executive and to the Board of Trustees.

The Trustees have identified the following as the principal risks facing the charity:

• Reputational risk: the potential loss of reputation arising from error or fraud. This is mitigated through strong governance, internal controls and oversight by the Trustees.

• Income risk: the potential reduction or loss of income from donations, grants and fundraising activities. The charity mitigates this risk by maintaining a diversified funding base and actively managing relationships with donors and supporters.

• Operational capacity risk: the risk of insufficient Trustees or staff to effectively deliver the charity's objectives. This is managed through ongoing review of organisational structure and succession planning.

• Financial sustainability risk: the risk of insufficient funds to meet the charity's objectives. The Trustees manage this through regular financial monitoring, budgeting and maintaining appropriate reserves.

• Reserves perception risk: the risk that holding excessive reserves without clear justification may deter future donors and fundraisers. The Trustees address this through transparent reporting and a clearly defined reserves policy.

In addition, the Trustees recognise that the charity has ongoing commitments in respect of multi-year research grants. These commitments are carefully assessed before approval and are regularly monitored to ensure that sufficient funds are available to meet obligations as they fall due.

The Trustees also actively monitor financial risks to ensure the charity remains financially stable. Key financial risks include:

- Credit risk: the risk that committed funding may be delayed or not received. This is mitigated through careful assessment of funding sources and maintaining strong relationships with funders.
- Liquidity risk: the risk that the charity is unable to meet its short-term financial obligations. This is managed through maintaining reserves equivalent to approximately six months of operating costs and regular cash flow forecasting.
- Cash flow risk: arising from the timing of income receipts relative to expenditure commitments. Trustees monitor cash flows closely to ensure obligations can be met in a timely manner.

Based on the above, and the controls in place, the Trustees consider that the principal risks facing the charity are appropriately managed and do not pose a material threat to the charity's ability to continue as a going concern.

# Financial review

**The Trustees are satisfied with the performance of the Charity and consider that the Charity is in an excellent position to continue its activities during the coming year, and the Charity's reserves are adequate to fulfil its current obligations.**

## Income

At present, research into A-T is heavily dependent on charitable donations and by extension, Action for A-T's ability to instigate, organise and facilitate the fundraising efforts of our supporters and donors. The principal source of funding is donations from individuals, companies, and proceeds of fundraising events.

Total income raised in 2025 was **£905,048 (2024 - £1,168,113)**.

## Charitable Expenditure

Total expenditure for the year was **£444,162 (2024 - £1,846,493)**. Of this, expenditure on charitable activities was **£362,582 (2024 - £1,755,970)**, which included **£186,515 (2024 - £1,581,917)** relating to research grants and associated support costs, of which **£116,441 (2024 - £1,518,335**) was paid out to research institutions during the year (Note 8).

The cost of generating voluntary income was **£81,580 (2024 - £90,523)** whilst the cost of staging fundraising and challenge events was **£155,430 (2024 - £153,296)**.

Governance costs of **£20,637 (2024 - £20,757)** were incurred.

## General Funds

The Trustees will aim to make best use of any unrestricted funds; however they reserve the right to retain general reserves in hand until they can be used in the most efficient manner to further the objectives of the Charity. The Trustees are conscious that it should not provide funding for research where they have not been able to demonstrate that its use will offer the best opportunity to further the knowledge and treatment into A-T. Please refer to the investment policy with regard to those times where the Trustees believe general funds are in excess of the anticipated running costs of the Charity.

## Designated Funds

Designated funds of **£nil** were brought forward from 2024. In 2025, **£nil** of funds were passed on to the research projects detailed in note 8 on page 39.

As at 31 December 2025 designated funds carried forward are **£nil**.

## Restricted Funds

Restricted funds of **£96,861** were brought forward from 2024. During the year **£17,700** of restricted income was received against projects funded during 2025. During 2025, **£105,791** of funding was made to the research projects detailed in note 8 Page 39.

At 31 December 2025 restricted funds of **£8,770 (2024 - £96,861)** were carried forward and the Trustees are satisfied that the wishes of the donors were met fully. If further funds are received in the future the Trustees will ensure that those funds are used in accordance with those restrictions. Should it not prove possible to adhere to those instructions those funds will be offered back to the provider unless they indicate that they can be used for an alternative purpose.

## Investment Policy

The overall policy of the Charity is to maintain a series of designated funds deposit accounts to ring-fence any funds which the Trustees have identified as being made available for specific research projects, or other charitable activities.

The Trustees recognise the need to review this policy on an annual basis and to look at other potential opportunities whilst appropriately monitoring the available funds and being proactive in their management, to ensure the best interests of the Charity's objectives are maintained.

Funds committed for research are paid out in arrears over the duration of the project. The trustees reviewed and agreed ▸

to deposit funds in timed deposit accounts in order to obtain the best return with minimal managed risk.

During the year the Trustees transfer any funds surplus to general running costs of the Charity into an interest-bearing account which will offer a higher rate of return than holding it in the main Charity bank account. The aim is to ensure that the fund is not diminished over time due to inflation and to ensure that these funds are invested in future research projects.

## Reserves Policy

The Trustees review the reserves policy each year to ensure that all relevant risk areas are included in accordance with guidance issued by the Charity Commission. Risks included are the impact of unexpected, reduced income, and the potential impact of restructuring costs and liabilities required to downsize the organisation in an orderly manner, if a permanent income reduction was anticipated.

The review concluded that the existing reserve target level of Six months of operating costs (approx. £150,000) was sufficient to cover the risks identified in the review. This allows sufficient time for Trustees and management to take appropriate mitigating actions, if required.

The Trustees continue their commitment to develop and grow the level of investment in research into A-T, whilst maintaining a focus on managing the overall costs of the charity.

## Going concern

The Trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern. The Trustees have given consideration to the Charity's long-term future and considered what risks (see the Trustees' Report) could result in a situation where a going concern basis was not appropriate. They believe that safeguards are sufficient to ensure that both in the short and medium term the assets and reputation of the Charity are sufficiently safeguarded to ensure that the Charity is a viable going concern.

## Post Year End Events

On 12 February 2026 the Charity entered into a co-funding agreement with the Department of Health and Social Care under the Medical Research Charity Support Fund. Further details are given in Note 28. There have been no other significant events between the balance sheet date and the date of approval of these financial statements that, in the Trustees' opinion, would materially impact the financial position of the Charity.

## Statement of Trustees Responsibilities

The Trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of the incoming resources and application of resources of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in business.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the Charity and financial information included on the Charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.



Toby Read (Chairman)
Dated: 11th May 2026



William Rowberry (Treasurer)
Dated: 11th May 2026

# Auditors Report

## Independent Auditor's Report to the Trustees of Action for A-T

### Opinion

We have audited the financial statements of Action for A-T Registered Charity Number: 1145303 (the 'charity') for the year ended 31 December 2025 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- Give a true and fair view of the state of the Charity's affairs as at 31 December 2025 and of its incoming resources and application of resources, for the year then ended;
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- Have been prepared in accordance with the requirements of the Charities Act 2011.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The Trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements, or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

### Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

## Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the Trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Charity or to cease operations, or have no realistic alternative but to do so.

## Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

1. Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

2. Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Charity's internal control.

3. Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Trustees.

4. Conclude on the appropriateness of the Trustee's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report.

5. Evaluate the overall presentation, structure, and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at **www.frc.org.uk/auditorsresponsibilities**. This description forms part of our Report of the Independent Auditors.

## Use of our report

This report is made solely to the Charity's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Charity's Trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and the Charity's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.



**For and on behalf of A & N (Haslemere) Limited - Statutory Auditors**
**Aruna House**
**2 Kings Road**
**Haslemere, Surrey, GU27 2QA**

**Dated: 27th March 2026**

## Statement of Financial Activities

for the year ended 31 December 2025

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.25 Total Funds £** | 31.12.24 Total Funds £ |
|---|---|---|---|---|---|
| **Income and Endowments from** | | | | | |
| Donation and legacies | 3 | 332,656 | 17,700 | **350,356** | 593,000 |
| **Charitable Activities** | 5 | | | | |
| Fundraising & challenge events | | 481,627 | - | **481,627** | 480,466 |
| Investment income | 4 | 73,065 | - | **73,065** | 94,647 |
| Other income | | - | - | **-** | - |
| **Total** | | 887,348 | 17,700 | **905,048** | 1,168,113 |
| **Expenditure on** | | | | | |
| Raising funds | 6 | 81,580 | - | **81,580** | 90,523 |
| **Charitable Activities** | 7 | | | | |
| Fundraising & challenge events | | 155,430 | - | **155,430** | 153,296 |
| Grants | 8 | 80,724 | 105,791 | **186,515** | 1,581,917 |
| Governance costs | | 20,637 | - | **20,637** | 20,757 |
| **Total** | | 338,371 | 105,791 | **444,162** | 1,846,493 |
| **Net Income / (Expenditure)** | | 548,977 | (88,091) | **460,886** | (678,380) |
| **Reconcilliation of Funds** | | | | | |
| **Total Funds Brought Forward** | | 139,484 | 96,861 | **236,345** | 914,725 |
| **Total Funds Carried Forward** | | 688,461 | 8,770 | **697,231** | 236,345 |

## Statement of Financial Position

for the year ended 31 December 2025

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.25 Total Funds £** | 31.12.24 Total Funds £ |
|---|---|---|---|---|---|
| **Fixed Assets** | | | | | |
| Tangible assets | 18 | 216 | - | **216** | 216 |
| **Current Assets** | | | | | |
| Stocks | 19 | 13,170 | - | **13,170** | 20,863 |
| Debtors | 20 | 8,560 | - | **8,560** | 58,429 |
| Cash at bank | 21 | 2,458,710 | 8,770 | **2,467,480** | 2,316,849 |
| | | | | | 2,396,141 |
| **Creditors** | | | | | |
| Amounts falling due within one year | 22 | (519,943) | - | **(519,943)** | (815,714) |
| **Net Current Assets** | | 1,960,497 | 8,770 | **1,969,267** | 1,580,427 |
| **Total Assets Less Current Liabilities** | | 1,960,713 | 8,770 | **1,969,483** | 1,580,643 |
| **Creditors** | | | | | |
| Amounts falling due after more than one year | 23 | (1,272,252) | - | **(1,272,252)** | (1,344,298) |
| **Net Assets** | | 688,461 | 8,770 | **697,231** | 236,345 |
| **Funds** | 25 | | | | |
| Unrestricted funds | | | | **688,461** | 139,484 |
| Restricted funds | | | | **8,770** | 96,861 |
| **Total Funds** | | | | **697,231** | 236,345 |

The financial statements were approved by the Board of Trustees and authorised for issue on 11 May 2026 and were signed on its behalf by:



Toby Read (Chairman)
Dated: 11th May 2026



William Rowberry (Treasurer)
Dated: 11th May 2026

## Statement of Cash Flows

for the year ended 31 December 2025

| | Notes | 31.12.25<br>£ | 31.12.24<br>£ |
|---|---|---|---|
| **Cash flows from operating activities** | | | |
| Cash generated from operations | 1 | **89,304** | 292,341 |
| Net cash provided by operating activities | | **89,304** | 292,341 |
| **Cash flows from investing activities** | | | |
| Interest received | | **61,327** | 94,647 |
| Net cash provided by investing activities | | **61,327** | 94,647 |
| **Change in cash and cash equivalents in the reporting period** | | **150,631** | 386,988 |
| **Cash and cash equivalents at the beginning of the reporting period** | | **2,316,849** | 1,929,861 |
| **Cash and cash equivalents at the end of the reporting period** | | **2,467,480** | 2,316,849 |

# Notes to the Statement of Cash Flows

for the year ended 31 December 2025

## 1. Reconciliation of net (expenditure)/income to net cash flow from operating activities

| | 31.12.25 £ | 31.12.24 £ |
|---|---|---|
| **Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)** | **460,886** | (678,380) |
| **Adjustments for:** | | |
| Depreciation charges | - | - |
| Interest received | (61,327) | (94,647) |
| (Increase)/decrease in stocks | 7,693 | (1,878) |
| Decrease in debtors | 49,869 | (16,631) |
| Increase/(decrease) in creditors | (367,817) | 1,083,877 |
| **Net cash provided by operations** | **89,304** | 292,341 |

## 2. Analysis of changes in net funds

| | At 1.1.25 £ | Cash Flow £ | **31.12.25 £** |
|---|---|---|---|
| **Net cash** | | | |
| Cash at bank | 2,316,849 | 150,631 | 2,467,480 |
| | 2,316,849 | 150,631 | 2,467,480 |
| **Total** | 2,316,849 | 150,631 | 2,467,480 |

# Notes to the Financial Statements

## For the Year Ended 31 December 2025

## 1. Accounting Policies

### Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS102, have been prepared in accordance with the Charities SORP (FRS102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011.

The financial statements have been prepared under the historical cost convention. The accounts are prepared in £ sterling to the nearest £1.

Action for A-T meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historic cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### Accounting convention

The financial statements are prepared on a going concern basis, under the historic cost convention.

The Charity is entirely dependent on receiving income from fundraising and donations and as a consequence the going concern basis is also dependent on the continuation of such income.

### Incoming resources

All incoming resources are included in the Statement of Financial Activities under FRS102 when that receipt is probable, whereas it was previously recognised when the Charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. For legacies, entitlement is the earlier of the Charity being notified of an impending distribution or the legacy being received.

Gifts in kind, including donated professional services are recognised as income when the Charity has control over them, any conditions associated with the donated item have been met, the receipt of economic benefit from the use of by the Charity if the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS102), the general volunteered time is not recognised and refer to the Trustees' Report for more information about this contribution.

On receipt, donated professional services are recognised on the basis of the value of the gift to the Charity which is the amount the Charity would have been willing to pay to obtain that service on the open market.

Gifts in kind donated for distribution are included at fair value upon receipt under FRS102 subject to the cost of recognition outweighing the benefit provided to Action for A-T. Previously they were included at a valuation and recognised as income when they are distributed. Any donated facilities are included at the value to the Charity where this can be quantified, and a third party is bearing the cost. No amounts are included in the financial statements for services donated by volunteers.

### Resources expended

All expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs allocated to activities. Where costs cannot be directly attributed to particular activities, they have been allocated on a basis consistent with the use of the resources.

Overheads have been allocated on the basis of the activity income of the Charity.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities. Support costs are those costs incurred directly in support of expenditure on the objects of the Charity and include project management carried out by the Trustees. Governance costs are those incurred in connection with the administration of the Charity and compliance with constitutional and statutory requirements.

Grants offered subject to conditions which have not been met at the year-end date are noted as a commitment but not accrued as expenditure.

## Governance costs

Governance costs comprise all costs involving the public accountability of the Charity and its compliance with regulations and good practice. These costs include costs related to the audit, legal fees, and apportionment of overheads.

## Allocation and apportionment of costs

Fundraising Events & Challenge Events costs are allocated in their income ratio during the year.

## Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

**Computer equipment - 33% on cost**

## Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow-moving items.

## Taxation

The Charity is exempt from tax on its charitable activities.

## Fund accounting

**General Funds**

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

**Restricted Funds**

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors which have been raised by the Charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements. Any investment income, gains or losses are allocated to the appropriate fund.

Action for A-T has no designated funds as at 31st December 2025. All unrestricted funds remain available for general use at the discretion of the Trustees

**Designated funds**

Designated Funds are funds set aside by the Trustees out of general reserves for a particular purpose. The aim and use of each designated fund is set out in the notes to the financial statements. The Trustees will review the funds on an ongoing basis. At the conclusion of the purpose for the fund any excess remaining funds will be transferred back into general funds. If a shortfall arises the Trustees will consider whether any additional general funds should be transferred to designated funds. Any investment income, gains or losses are allocated to the appropriate fund.

**Foreign currencies**

Assets and liabilities in foreign currencies are translated into sterling at the rate of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling at the date of the transaction. Exchange differences if applicable are taken into the Statement of Financial Activities.

## 2. Critical accounting judgements and key sources of estimation uncertainty

### Critical Accounting Estimates And Judgements

In the application of the Charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

**1. Grant Commitments**

The Charity awards grants to support research into Ataxia Telangiectasia. The recognition of grant commitments is based on formal agreements and the likelihood of meeting performance conditions. At 31 December 2025, grant commitments totalled £1,790,933 all of which have been recognised as a liabilities there are no awarded grants left unrecognised.

**2. Provisions for Liabilities and Charges**

The Charity reviews potential liabilities arising from ongoing contractual obligations. Where a liability is probable and can be reliably estimated, a provision is recognised.

**3. Depreciation of Fixed Assets**

The Charity depreciates tangible fixed assets over their estimated useful lives. The estimated useful life of assets is reviewed annually, with the current rates as follows:

- IT Equipment: 3 years
- Fixtures and Fittings: 5 years
- Leasehold Improvements: Over the remaining lease term

**4. Accrued Income and Donations**

The recognition of income from certain fundraising events and donations is based on an assessment of whether the income is probable and can be measured reliably. Estimates are applied where donations or pledges are confirmed but not yet received.

### Key Sources of Estimation Uncertainty

The annual depreciation charge for tangible fixed assets in sensitive to changes in the estimated useful economic lives and residual value of fixed assets. The useful economic lives and residual values are reassessed on an annual basis. They are amended where deemed necessary to reflect current estimations based on physical condition, utilisation and advancement of technologies. Note 10 discloses the carrying value if the tangible fixed assets and the depreciation policy is listed above in accounting policies.

## 3. Donations and Legacies

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.25 Total Funds £** | 31.12.24 Total Funds £ |
|---|---|---|---|---|
| Donations | 79,259 | 17,700 | **96,959** | 78,147 |
| Gift aid | 33,622 | - | **33,622** | 31,837 |
| Fundraising | 219,775 | - | **219,775** | 483,016 |
| | 332,656 | 17,700 | **350,356** | 593,000 |

## 4. Investment Income

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.25 Total Funds £** | 31.12.24 Total Funds £ |
|---|---|---|---|---|
| Bank Interest | 73,065 - | - | **73,065 -** | 94,647 |

## 5. Income from Charitable Activities

| | Activity | **31.12.25 £** | 31.12.24 £ |
|---|---|---|---|
| Fundraising events | Fundraising & Challenge events | **237,043** | 266,981 |
| Challenge events | Fundraising & Challenge events | **244,584** | 213,485 |
| | | **481,627** | 480,466 |

## 6. Raising Funds

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.25 Total Funds £** | 31.12.24 Total Funds £ |
|---|---|---|---|---|
| Staff costs | 60,670 | - | **60,670** | 69,937 |
| Trusts & Foundations | - | - | **-** | 870 |
| Support costs | 20,910 | - | 20,910 | 19,716 |
| | 81,580 | - | 81,580 | 90,523 |

## 7. Charitable Activities Costs

| | Direct Costs | Grant Funding of Activities (see note 8) | Support Costs (see note 9) | Totals |
|---|---|---|---|---|
| | £ | £ | £ | £ |
| Fundraising & Challenge events | 134,520 | - | 20,910 | **155,430** |
| Grants | - | 116,441 | 70,074 | **186,515** |
| Governance cost | - | - | 20,637 | **20,637** |
| | 134,520 | 116,441 | 111,621 | **362,582** |

## 8. Grants Payable

| | **31.12.25** | 31.12.24 |
|---|---|---|
| | **£** | £ |
| Grants | **116,441** | 1,518,335 |

**The total grants paid to institutions during the year was as follows:**

| | **31.12.25** | 31.12.24 |
|---|---|---|
| | **£** | £ |
| Universities of Birmingham, UK & Hamburg, Germany – Development of suppressor tRNA-based therapeutics | **249,615** | |
| University of Nottingham, UK – Biomarkers for babies and young children with A-T | **246,867** | |
| University of North Carolina, USA – Development of a gene therapy approach to treat A-T | **249,128** | |
| Leiden University Medical Centre, Netherlands – Functional impact of Nicotinamide Riboside on the immune system of patients with A-T | **250,000** | |
| University College London, UK – Exploring Omaveloxolone efficacy in A-T | **24,915** | |
| University of Birmingham, UK – Identifying existing drugs to repurpose for treating A-T | **249,332** | |
| University of Kent, UK – Investigating the role of mutant triple T chaperone in ATM assembly in A-T | **249,806** | |
| University of Cambridge, UK - Improving diagnosis and treatment of cancer in A-T patients through whole genome sequencing | **19,960** | |
| University of Nottingham, UK – Kicking Kinases into action: A novel drug screening assay for A-T | **19,238** | |
| University of Nottingham, UK – Exploring the use of assistive robots, smart sensing & digital twin models for monitoring and support of Ataxia in non-clinical environments | **19,997** | |
| University of Granada, Spain – (Research project underspends refunded) Innovative methods for gene therapy in Ataxia-Telangiectasia | **(6,044)** | |

**The total grants paid to institutions during the year (continued)**

| | **31.12.25** **£** | 31.12.24 £ |
|---|---|---|
| University of Nottingham, UK – (Research project underspends refunded) The David Peake Study to test the feasibility of whole-body MRI for cancer surveillance in children and young people with A-T | | **(13,208)** |
| Sheba Medical Centre, Israel - Using new immunotherapy methods to treat lymphoma and leukaemia in A-T | | **(10,408)** |
| Duke University, USA - A new function for ATM and a new theory for the clinical abnormalities in A-T | | **(4,440)** |
| University of Rochester, USA - Recurrent pulmonary infections and their impact on neurological decline in A-T | | **(8,334)** |
| University of Plymouth, UK - The ATeam: Coproducing guidance and investigating a novel complex home-based intervention to optimise long-term healthy living with A-T | | **(18,089)** |
| QIMR Berghofer Medical Research Institute, Queensland, Australia – Dose response and mechanistic profiling of two candidate neuroactive drugs in A-T cerebellar organoids | 58,253 | |
| University of Nottingham, UK - Improving future treatments for Ataxia-Telangiectasia through better delivery of RNA-based therapies | 18,388 | |
| University of Nottingham, UK - Developing a Safer Immune-Based Treatment for Blood Cancers in Children and Adults with A-T | 19,905 | |
| University of Nottingham, UK - A prospective pilot study to compare lung CT and MRI in Ataxia Telangiectasia | 19,895 | |
| | **116,441** | **1,518,335** |

## 9. Support Costs

| | Management | Finance | Information Technology | Other | Wages | Governance Costs | Totals |
|---|---|---|---|---|---|---|---|
| | £ | £ | £ | £ | £ | £ | £ |
| Raising donations and legacies | 8,490 | 511 | 1,906 | 10.003 | - | - | **20,910** |
| Fundraising & challenge events | 8,490 | 511 | 1,906 | 10.003 | - | - | **20,910** |
| Grants | - | - | - | - | 70,074 | - | **70,074** |
| Governance costs | - | - | - | - | - | 20,637 | **20,637** |
| | 16,980 | 1,022 | 3,812 | 20,006 | 70,074 | 20,637 | **132,531** |

| **Activity** | **Basis of allocation** |
|---|---|
| Management | 50 % Raising Donation & legacies 50 % Fundraising & Challenge Events |
| Finance | 50 % Raising Donation & legacies 50 % Fundraising & Challenge Events |
| Information technology | 50% Raising Donation & legacies 50 % Fundraising & Challenge Events |
| Human resources | 50 % Raising Donation & legacies 50 % Fundraising & Challenge Events |
| Other | 50 % Raising Donation & legacies 50 % Fundraising & Challenge Events |
| Governance costs | 100% Governance cost |

## 10. Auditors Remuneration

Fees payable to the charity's auditor for the audit of the financial statements: **£4000 (2024: £4000)**.
Fees payable for non-audit services: **£1,498 (2024: £1,437)**.

## 11. Trustees' Remuneration and Benefits

There were no Trustees' remuneration or other benefits for the year ended 31 December 2025 nor for the year ended 31 December 2024.

**Trustees' expenses**
There were no Trustees' expenses paid for the year ended 31 December 2025 nor for the year ended 31 December 2024.

## 12. Staff Costs

| | Dec 2025 | Dec 2024 |
|---|---|---|
| | £ | £ |
| Wages and salaries | 133,575 | **140,631** |
| Social security costs | 18,133 | **14,044** |
| Pension costs | 11,277 | **11,276** |
| **Total** | **162,985** | **165,951** |

The average number of persons employed during the year was 4 (2024: 4).
The number of employees whose employee benefits (excluding employer pension costs) exceeded £60,000 was: £70,000–£80,000: 1 (2024: 1).
The total employee benefits of key management personnel were £149,685 (2024: £151,716).

## 13. Comparatives for the Statement of Financial Activities

| | Unrestricted Funds £ | Restricted Funds £ | **Total Funds £** |
|---|---|---|---|
| **Income and endowments from** | | | |
| Donations and legacies | 466,500 | 126,500 | **593,000** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 480,466 | - | **480,466** |
| Investment income | - | - | **-** |
| Other income | 94,647 | - | **94,647** |
| **Total** | 1,041,613 | 126,500 | **1,168,113** |
| **Expenditure on** | | | |
| Raising funds | 90,523 | - | **90,523** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 150,864 | - | **150,864** |
| Grants | 1,516,629 | 67,660 | **1,584,289** |
| Governance costs | 20,817 | - | **20,817** |
| **Total** | 1,778,833 | 67,660 | **1,846,493** |
| **Net income/(expenditure)** | (737,220) | 58,840 | **(678,380)** |
| **Reconciliation of funds** | | | |
| Total funds brought forward | 876,704 | 38,021 | **914,725** |
| **Total funds carried forward** | 139,484 | 96,861 | **236,345** |

## 14. Employee Benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits would be recognisable immediately as an expense when the Charity is demonstrably committed to terminate an employee's employment or to provide termination benefits.

## 15. Pension Costs

The charity participates in a defined benefit pension scheme. The pension costs charged in the financial statements represent the contributions paid by the Charity during the year amounting to £11,276 (2024 £11,312).

## 16. Financial Instruments

The Charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and are subsequently measured at their amortised cost.

## 17. Creditors and Provisions

Creditors and provisions are recognised where the Charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

## 18. Tangible Fixed Assets

| | Computer Equipment £ |
|---|---|
| **Cost** | |
| At 1 January 2025 and 31 December 2025 | 2,358 |
| **Depreciation** | |
| At 1 January 2025 and 31 December 2025 | 2,142 |
| **Net Book Value** | |
| At 31 December 2025 | 216 |
| At 31 December 2024 | 216 |

## 19. Stocks

| | **31.12.25** | 31.12.24 |
|---|---|---|
| | **£** | £ |
| Stocks | **13,170** | 20,863 |

Stocks are stated at the lower of cost and estimated selling price less costs to complete and sell. Cost includes all costs of purchase, costs of conversion and other costs incurred in bringing stock to its present location and condition. Due allowance is made for obsolete and slow-moving items.

Donated stocks are fair valued when their economic benefit is probable, it can be measured reliably, and the Charity has control over the item.

## 20. Debtors: Amounts Falling Due Within One Year

| | **31.12.25** | 31.12.24 |
|---|---|---|
| | **£** | £ |
| Deposit | **935** | 925 |
| Prepayments and accrued income | **7,635** | 57,504 |
| | **8,560** | 58,429 |

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

## 21. Cash at Bank

| | Unrestricted Funds | Restricted Funds | **31.12.25 Total Funds** | 31.12.24 Total Funds |
|---|---|---|---|---|
| | £ | £ | **£** | £ |
| Bank Current Accounts | 31,089 | - | **31,089** | 38,193 |
| Reserve Account | 556,749 | 8,770 | **565,519** | 719,111 |
| Investment Accounts | 1,870,872 | - | **1,870,872** | 1,559,545 |
| Total | 2,458,710 | 8,770 | **2,467,480** | 2,316,849 |

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of twelve months or less, and bank overdrafts. Should any bank overdrafts arise they would be shown within borrowings in current liabilities.

## 22. Creditors: Amounts Falling Due Within One Year

| | **31.12.25** £ | 31.12.24 £ |
|---|---|---|
| Grant Payable | **518,681** | 810,729 |
| Accruals and deferred income | **1,262** | 4,985 |
| | **519,943** | 815,714 |

## 23. Creditors: Amounts Falling Due After More Than One Year

| | **31.12.25** £ | 31.12.24 £ |
|---|---|---|
| Grants payable | **1,272,252** | 1,344,298 |

## 24. Leasing Agreements

During the next twelve months the Charity has operating lease commitments totalling **£14,055 (2024 - £13,014)** for contracts expiring in more than one year. The total future commitments are **£14,055 (2024 - £12,960)**

## 25. Movement in Funds

| | At 1.1.25 £ | Net Movement in Funds £ | **At 31.12.25 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 139,484 | 548,977 | **688,461** |
| **Restricted Funds** | | | |
| Restricted Fund | 96,861 | (88,091) | **8,770** |
| **Total Funds** | 236,345 | 460,886 | **697,231** |

**Net movement in funds, included in the above are as follows:**

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 887,348 | (338,371) | **548,977** |
| **Restricted Funds** | | | |
| Restricted Fund | 17,700 | (105,791) | **(88,091)** |
| **Total Funds** | 905,048 | (444,162) | **460,886** |

**Comparatives for movement in funds:**

| | At 1.1.24 £ | Net Movement in Funds £ | **At 31.12.24 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 876,704 | (737,220) | **139,484** |
| **Restricted Funds** | | | |
| Restricted Fund | 38,021 | 58,840 | **96,861** |
| **Total Funds** | 914,725 | (678,380) | **236,345** |

**Comparative net movement in funds, included in the above are as follows:**

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 1,041,613 | (1,778,833) | **(737,220)** |
| **Restricted Funds** | | | |
| Restricted Fund | 126,500 | (67,660) | **58,840** |
| **Total Funds** | 1,168,113 | (1,846,493) | **(678,380)** |

**A current year 12 months and prior year 12 months combined position is as follows:**

| | At 1.1.24 £ | Net Movement in Funds £ | **At 31.12.25 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 876,704 | (188,243) | **688,461** |
| **Restricted Funds** | | | |
| Restricted Fund | 38,021 | (29,251) | **8,770** |
| **Total Funds** | 914,725 | (217,494) | **697,231** |

**A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:**

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 1,928,961 | (2,117,204) | **(188,243)** |
| **Restricted Funds** | | | |
| Restricted Fund | 144,200 | (173,451) | **(29,251)** |
| **Total Funds** | 2,073,161 | (2,290,655) | **(217,494)** |

## 26. Related Party Disclosures

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2024 - £nil). There are no expenses paid to the Trustees in the year. No Trustee is deemed to have benefited as a result of a related party connection. All Trustees have declared all such relationships to the Chairman.

## 27. Ultimate Controlling Party

The Trustees control Action for A-T in accordance with the trust deed.

## 28. Post Balance Sheet Events

The Trustees have considered events occurring between the balance sheet date and the date on which these financial statements were authorised for issue. The following non-adjusting event has been identified for disclosure under FRS 102 Section 32:

**DHSC Medical Research Charity Support Fund**
On 12 February 2026 the Charity entered into a co-funding agreement with the Secretary of State for Health and Social Care under the Medical Research Charity Support Fund. The agreement provides for the Charity to receive £243,702.56 in respect of the initial funding year (1 April 2025 to 31 March 2026), with payment due within 30 days of signature. The funding supports seven existing research projects at UK universities to which the Charity has previously committed grant funding.

The agreement was entered into after the balance sheet date and accordingly the entitlement to the funding had not arisen as at 31 December 2025. The amount has therefore not been recognised in these financial statements and will be recognised as income in the financial statements for the year ending 31 December 2026.

**Other matters**
There have been no other significant events between the balance sheet date and the date of approval of these financial statements that, in the Trustees' opinion, require disclosure or adjustment to the financial statements.

# Detailed Statement Of Financial Activities

For the year ended 31 December 2025

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.25 Total Funds £** | 31.12.24 Total Funds £ |
|---|---|---|---|---|
| **Income and Endowments from** | | | | |
| **Donations and legacies** | | | | |
| Donations | 79,259 | 17,700 | **96,959** | 78,147 |
| Gift aid | 33,622 | - | **33,622** | 31,837 |
| Fundraising | 219,775 | - | **219,775** | 483,016 |
| | 332,656 | 17,700 | **350,356** | 593,000 |
| **Investment Income** | | | | |
| Bank Interest | 73,065 | - | **73,065** | 94,647 |
| **Charitable activities** | | | | |
| Fundraising events | 237,043 | - | **237,043** | 266,981 |
| Challenge events | 244,584 | - | **244,584** | 213,485 |
| | 481,627 | - | **481,627** | 480,466 |
| **Total Incoming Resources** | 887,348 | 17,700 | **905,048** | 1,168,113 |
| **Expenditure** | | | | |
| **Raising donations and legacies** | | | | |
| Wages | 60,670 | - | **60,670** | 69,937 |
| Trusts and Foundations | - | - | **-** | 870 |
| | 60,670 | - | **60,670** | 70,807 |
| **Charitable activities** | | | | |
| Event Campaign Costs | 120,800 | - | **120,800** | 131,146 |
| Grants to institutions | 10,650 | 105,791 | **116,441** | 1,518,335 |
| | 131,450 | 105,791 | **237,241** | 1,649,481 |
| **Support Costs** | | | | |
| **Management** | | | | |
| Wages | 16,980 | - | **16,980** | 17,111 |
| **Finance** | | | | |
| Bank charges | 1,022 | - | **1,022** | 1,273 |
| **Information technology** | | | | |
| Repairs and renewals | 3,812 | - | **3,812** | 2,663 |

## Detailed Statement Of Financial Activities (Cont)

For the year ended 31 December 2025

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.25 Total Funds £** | 31.12.24 Total Funds £ |
|---|---|---|---|---|
| **Other** | | | | |
| Rent, Rates and water | 14,055 | - | 14,055 | 13,672 |
| Insurance | 948 | - | 948 | 947 |
| Telephone | 541 | - | 541 | 544 |
| Postage and stationery | 465 | - | 465 | 372 |
| Sundries | 1,194 | - | 1,194 | 679 |
| Advertising | 1,376 | - | 1,376 | 1,022 |
| Donation collection fees | 1,427 | - | 1,427 | 1,151 |
| | 20,006 | - | 20,006 | 18,387 |
| **Wages** | | | | |
| Wages | 70,074 | - | 70,074 | 63,582 |
| **Governance Costs** | | | | |
| Wages | 15,139 | - | **15,139** | 15,320 |
| Auditors' remuneration | 4,000 | - | **4,000** | 4,000 |
| Accountancy and legal fees | 1,498 | - | **1,498** | 1,437 |
| Computer equipment | - | - | **-** | - |
| | 20,637 | - | 20,637 | 20,757 |
| **Total Resources Expended** | 338,371 | 105,791 | 444,162 | 1,846,493 |
| **Net (expenditure)/income** | 548,977 | (88,091) | 460,886 | (678,380) |

# Acknowledgements

Action for A-T relies entirely on its donors and supporters who so generously give their time and money to support vitally needed research into A-T. With their support we believe we can make a difference to all people with A-T and their families.

We would like to give special thanks to the following organisations that worked alongside us in 2025:

## Our Research Partners

BrAshA-T Ataxia Telangiectasia and their Trustees
Ataxia Telangiectasia Society
AEFAT
Action Medical Research
Great Ormond Street Hospital Charity

## Support from Companies, Trusts & Foundations

We are aware that Companies, Trusts & Foundations are often approached to support charities and are therefore extremely grateful to the following organisations and individuals for their generous support.

Ardwick Trust
Aviva Investors
Axis Capital
Barton Comms
Bellway Homes
BCA
BGC Partners
Big Give
Blyth Watson Charitable Trust
Brightwake
Cinch
Clarion Golf
Claire Buckley School of Dance
Constellation Group
Epsom Rotary Club
Enterprise Holdings
Henrik Bergrem
Hospital Saturday Fund
Mollie's Miracle Team
Monica Seccombe
Michael Cornish Charitable Trust
Michael & Anna Wix Charitable Trust
N Smith Charitable Settlement
Oakdale Trust
Quest Professional
Rawson Digital
Rest Harrow Trust
Robin Hewison
Sir Samuel Scott of Yews Trust
Syder Foundation
Stewart Golf Ltd
UKG
Woodcock Brothers

**Corporate or professional services provided by:**
A & N Chartered Accountants
Gecko Graphic Design
MPS Marketing Services Ltd

## Our Supporters

We have relied almost exclusively on our supporters, volunteers and Trustees for their time and commitment to raising money and spreading awareness about this devastating condition. Thank you to everyone who has helped us to push research into A-T forwards.

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE

Action for A-T, Aruna House, 2 Kings Road, Haslemere, Surrey GU27 2QA.

01428 853313 | info@actionforAT.org | www.actionforAT.org

**ACTION FOR A-T**

England & Wales - Charity number 1145303

# Accounts




# Annual Report & Financial Statements

FOR YEAR END 31ST DECEMBER 2024

WWW.ACTIONFORAT.ORG

Action For A-T Charity registered number 1145303

# Legal & Reference Information

## Patrons

Jonny Wilkinson CBE
Roger Black MBE
Jeremy Guscott MBE
Simon Shaw MBE
Rachel Morris MBE
Naga Munchetty
Leon Haslam

## Chief Executive

Sean Kelly

## Trustees at the date of approval

Toby Read (Chairman)
Emily Read
William Rowberry (Treasurer)
Tomos Shillingford
Maria Leonard
Chris Askew, OBE
Dr Mark Toms
Joseph Frost

## Appointed during the year or since year end

None

## Research Advisory Committee

Dr Kathryn Johnson, Scientific Advisor, Consultant Neonatologist and Research Lead, Chairperson

Professor David Attwell, Neuroscientist and Jodrell Professor of Physiology at the University College London

Associate Professor Esther Becker, Professor of Translational Neuroscience at the University of Oxford

Dr Simon Boulton, Principal Group Leader at The Francis Crick Institute

Dr Lisa Bunn, Associate Professor of Neurological Rehabilitation at the University of Plymouth

Professor Keith Caldecott, Professor of Genome Stability at the University of Sussex

Dr Richard Kay, Medical Statistician

Dr Guy Makin, Senior Paediatric Oncology Lecturer, University of Manchester

Dr Andrew Prayle, Clinical Assistant Professor, University of Nottingham

Bruno Salomone Gonzalez de Castejon, Research Associate, Bristol Medical School (THS)

Professor Grant Stewart, Professor of Cancer Genetics, School of Cancer Sciences, University of Birmingham

Professor Matthew Wood, Professor of Neuroscience at the University of Oxford, and Director of the Oxford Harrington Rare Disease Centre

## Patient Representatives

Mr Amandeep Sharma
Mrs Clare Gallagher
Mrs Natasha Schneider

## Charity Registration Number

United Kingdom Registered Charity number: 1145303

**Registered Office**
Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

**Operational Address**
Action for A-T
Carlton House
19 West Street
Epsom
Surrey
KT18 7RL

**Professional Advisers**
Solicitors
Bingham McCutchen LLP
41 Lothbury
London
EC2R 7HF

**Bankers**
HSBC Bank
110 High St
Godalming
Surrey
GU7 1DP

**Accountants & Auditors**
A & N (Haslemere) Limited
t/a A & N Chartered Accountants and Registered Auditors, Aruna House 2 Kings Road
Haslemere
GU27 2QA

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# Trustees' Report

**The Trustees of Action for A-T present their annual report and the financial statements for the year ended 31 December 2024.**

These have been prepared in accordance with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008, and the Statement of Recommended Practice: Accounting and Reporting by Charities (SORP), applicable to charities preparing their accounts in accordance with FRS 102 (effective 1 January 2019), the Financial Reporting Standard applicable in the UK and Republic of Ireland.

## Reference and Administrative Details

Action for A-T is a charity registered in England and Wales (No. 1145303). The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. The Trustees met in February, April, September, and November in 2024. The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

## Public Benefit

Action for A-T's charitable objectives are set out in its governing Trust Deed, summarised in the "About Us" section on our website and include undertaking rigorously evaluated and properly conducted medical research into finding a cure or new treatment for the rare genetic condition Ataxia Telangiectasia (A-T), a rare genetic condition.

During the year, the charity has continued to manage its ongoing research portfolio as well as committing funds to a variety of new A-T related research projects. Details of this work can be seen on pages 5 to 18.

Our Trustees have considered how our work may most effectively further our charitable objectives for benefit of the public, in particular all those affected by Ataxia Telangiectasia. In doing so, they have adhered to the Charity Commission's guidance on public benefit (Public Benefit: Running a Charity (PB2) and Public Benefit: Reporting (PB3)), ensuring that all activities align with our mission and that no undue private benefit arises.

## Environmental Considerations

While not subject to statutory reporting on greenhouse gas emissions, the charity remains mindful of its environmental impact. Measures taken include minimising paper use, promoting digital communications, and working with research partners committed to sustainable practices.

## Objects, Achievements & Performance

**Action for A-T's mission is: "To speed up the process of identifying a cure for A-T or treatments that delay or prevent the disabling effects of this childhood condition"**

To further that mission, the charity focused on the following key areas in 2024:

- Strengthening our Capacity and Capabilities
- Continuing our Investment in Medical Research in the UK and Abroad
- Ensuring that our research is of the highest quality, is well managed and has clear and achievable aims
- Strengthening and Increasing our Fundraising Activities
- Working closely with others to meet our objectives
- Increasing awareness of our work and the condition
- Board Composition

The Trustees confirm that all activities undertaken align with the charity's objectives and provide clear public benefit, in accordance with the Charity Commission's guidance.

# Strengthening our Capacity & Capabilities

## Our Aim

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us achieve our charitable mission. Since the Charity was initially established in 2012, a great deal of governance and capacity building work has already taken place, but continued development is required to ensure that we are more efficient, productive and well positioned for the future.

## Our Performance

2024 was another record-breaking year with our largest investment in new A-T research alongside our largest fundraising total. As in previous years, our ability to be flexible, innovative and capitalise on new opportunities enabled us to deliver a strong fundraising result.

Increased volunteer support helped us deliver the new planned activities and existing fundraising initiatives efficiently and effectively, allowing us to scale up many activities and increase funds raised. Many of these successful activities were data-led, as our previous investment in a good CRM system enabled us to reach key target audiences and manage relationships more effectively. In line with SORP 10.20, the value of general volunteered time has not been recognised in the financial statements, as it is not practicable to measure this contribution reliably.

We continued to explore and implement new technologies to improve our fundraising and communicate with our stakeholders. We also refreshed our IT infrastructure to strengthen our cyber security protocols and ensure that digital resources can be easily shared across the organisation.

We proactively managed our research relationships especially relationships with our grant holders to ensure that they had the required resources to complete their projects as expediently as possible. Where appropriate, some studies were granted extensions with no further cost to the charity as some investigators experienced recruitment issues due to various micro and macro-economic factors.

Our ability to adapt was only possible due to our size and structure and the hard work of a small but highly skilled team which we retained in full during the year. They have once again gone above and beyond to deliver a record-breaking fundraising year and the Trustees are very grateful for their incredible efforts.

# Continuing our Investment in Medical Research in the UK & Abroad

## Our Aim

Action for A-T aim to build a community of A-T research leaders and increase the amount of research that is taking place globally. Although we will always fund the highest quality applications wherever they are from; our key focus is to invest in projects and people based in the UK wherever possible.

## Our Performance

Throughout 2024, our Chief Executive attended various meetings with key figures from the A-T research community and representatives from other medical research charities and patient groups to explore possible funding opportunities and further understand which areas of A-T research may provide the most promising outcomes.

Non-A-T researchers who specialise in related conditions were also contacted to drive future research projects and create greater interest in the condition. This strategy is repeated from year to year to improve the quality of applications and increase the number and demographic of 'who' we advertise our grant rounds to.

We concluded our latest grant round in April 2024 joining forces with various like-minded charities and patient organisations to award six new research grants. These projects required a combined total investment of £1,270,048 and will take place at renowned research institutions and university hospitals in the United Kingdom, USA and the Netherlands.

In addition to the main grant round, we also joined forces with NATA (Nucleic Acid Therapy Accelerator) to award a £249,615 grant to a team based in Birmingham and Hamburg as well as investing an additional £59,195 in three new proof of concept studies at various institutions in the United Kingdom.

## Social Responsibility & Community Engagement

Action for A-T is committed to supporting families affected by A-T, raising awareness, and fostering collaboration with researchers and medical professionals. Beyond funding research, we actively engage with the community to ensure our work has a broad and lasting impact.

1. Community & Public Engagement: We work closely with families, researchers, and donors to advance A-T research and

awareness.

2. Volunteering & Fundraising: Our fundraising efforts are strengthened by dedicated volunteers and corporate partners, whose support is invaluable.

3. Commitment to Inclusion & Governance: We ensure fairness, transparency, and ethical governance in all aspects of our

# Funding High-Quality Research into A-T

In addition to supporting and funding research aimed at improving the understanding of A-T, there are many innovative and exciting medical research opportunities that raise the prospect of real progress in combating the effects of genetic conditions such as A-T.

## Our Aim

Action for A-T's aim is to be able to make grants to hospitals and universities throughout the world for the purpose of conducting research across all therapeutic areas related to A-T, with an emphasis on research that is likely to have a clear clinical application within the foreseeable future and/or which evaluate innovation in medical techniques which may have a potential benefit for children with A-T.

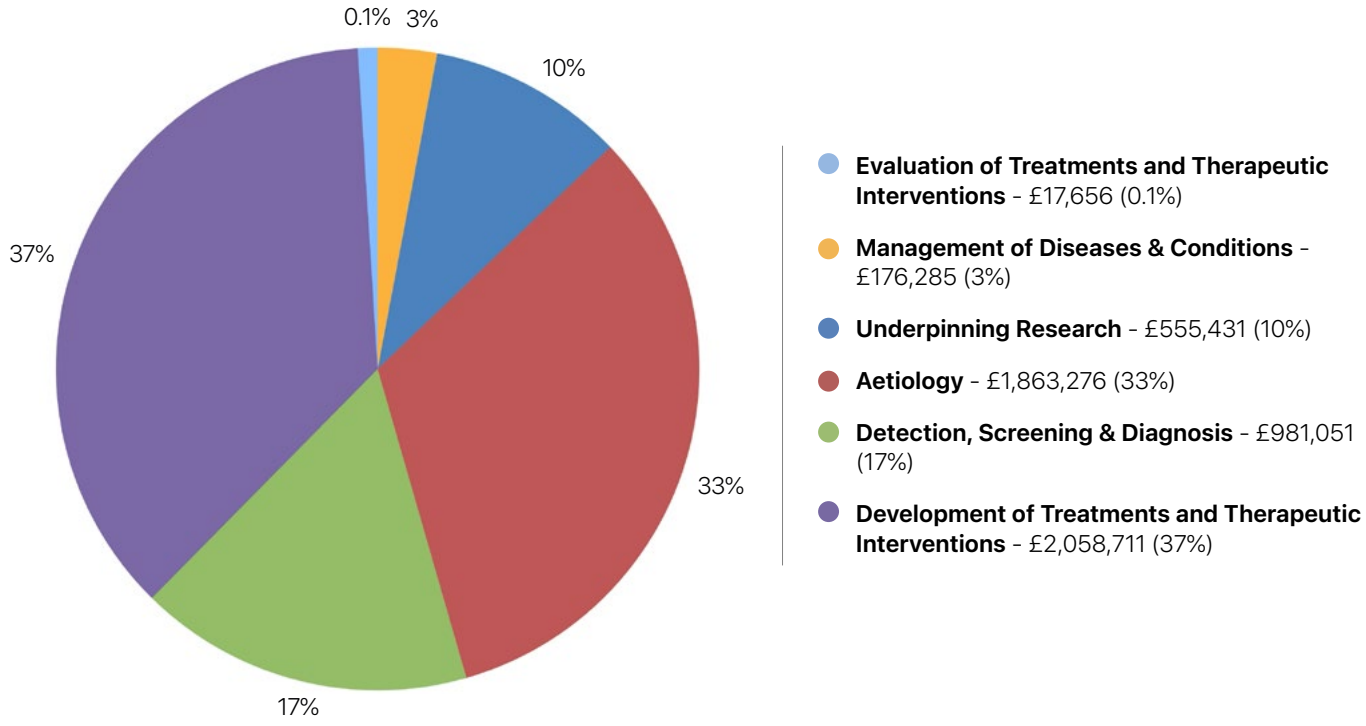
## Our Performance

Since Action for A-T was established in 2012, we have invested £5,652,410 in 60 global research projects under six main research headings categorised using the UK Clinical Research Collaboration Health Research Classification System.

- **Underpinning Research** - Developing new tools and techniques for conducting research
- **Aetiology** - Understanding the causes of A-T
- **Detection, Screening & Diagnosis** - Tests for diagnosing and monitoring patients with A-T
- **Development of Treatments and Therapeutic Interventions** - Studies to identify new treatments for A-T
- **Evaluation of Treatments and Therapeutic Interventions** - Studies to prove how new treatments work and understand how to use them
- **Management of Diseases & Conditions** - Managing the symptoms of A-T

## Total Research Spend Since 2012

The chart below shows the historic allocation of our research investment portfolio and our total investment in each of the six research categories listed above.



# The following grants were awarded by the Trustees in 2024:

## Development of suppressor tRNA-based therapeutics

**Principal researchers:** Professor Zoya Ignatova (University of Hamburg) and Professor Grant Stewart (University of Birmingham)
**Institute:** University of Hamburg and University of Birmingham
**Cost:** £249,615 over 24 months in partnership with NATA (Nucleic Acid Therapy Accelerator), Oxford
**Start Date:** 1st of June 2024


Prof Zoya Ignatova


Prof Grant Stewart

### Project Overview

Professors Ignatova & Stewart will test the efficacy of individual sup-tRNAs to bypass specific NSMs in the ATM gene and produce full-length ATM protein using patient-derived cell lines. Successful sup-tRNA that restore sufficient levels of ATM will be encapsulated in engineered viral-like particles, that are non-infectious but utilize the natural ability of viruses to enter the cells of the human body. Following validation of the ability of individual sup-tRNAs to restore ATM protein production in brain organoids (laboratory grown brains), the researchers will examine the safety of these viral-like particles using animal models.

Depending on the efficacy of specific sup-tRNAs to bypass specific NSMs in the ATM and their ability to administer them efficiently to organs that are particularly susceptible to loss of ATM e.g. the cerebellum of the brain, it is possible that this therapy could potentially slow or halt progression of the neurological decline.

## Biomarkers for Babies and Young Children with Ataxia Telangiectasia (BOBCAT)

**Principal researcher:** Professor Rob Dineen
**Institute:** University of Nottingham, UK
**Cost:** £246,867.32 over 60 months in partnership with the A-T Society (UK) AEFAT (Spain) and BrAshA-T (Australia)
**Start Date:** 1st of September 2024


Prof Rob Dineen

### Project Overview

Professor Dineen and his team will recruit families whose babies are found to have A-T following the new-born heel-prick test plus families whose baby receives an A-T diagnosis because an older sibling had already been diagnosed with A-T. These families will attend various sessions at the Nottingham A-T clinic during which the baby will have an MRI scan of the brain and lungs, recordings of eye and limb movements, and a blood test. The families will bring their children for the assessments annually, so that changes can be observed as the child grows and as they start to show the features of A-T. The research team will then compare these measures to those from infants and children without A-T.

Even in clinical trials of powerful treatments, it may take several years for effects of treatments on disability to become obvious. This means clinical trials may have to be long duration (and therefore more costly), which could stifle clinical research of new treatments. Researchers would find it very valuable to have sensitive measures (referred to as 'biomarkers') of disease progression that could allow them to detect an early benefit of a new treatment before effects of the treatment on disability become obvious. Showing an early benefit of a treatment by detecting a positive effect on a biomarker of A-T could allow researchers to select the best treatments to take forward into the longer full-scale clinical trials. However, there are currently no agreed biomarkers of A-T disease progression in infants and very young children with A-T, who are the ones who may benefit most from new treatments aiming to reduce lifelong disability in A-T.

This project will not provide immediate benefit for the participating individuals but will hopefully help infants and young children diagnosed with A-T in the future who may be included in treatment trials from a very young age.

## Development of a Gene Therapy approach to treat A-T

**Principal researcher:** Professor Samuel Young

**Institute:** University of North Carolina at Chapel Hill, USA

**Cost**: £249,128 in partnership with AEFAT (Spain) and BrAshA-T (Australia)

**Start Date:** 1st of September 2024



Prof Samuel Young

### Project Overview

Gene therapy is a way to treat or prevent a specific disease by introducing normal functioning genes into cells in place of missing or defective ones to correct genetic disorders. A common way that researchers have found to accomplish this is by using a vector. Vectors are essentially vehicles designed to deliver therapeutic genetic material, such as a working gene, directly into a cell.

Professor Young and his team will use Helper Dependent Adenoviral vectors (HdAd). These vectors have improved safety profiles and have a large capacity to deliver genetic material. HdAd provides long-term gene expression without toxicity after a single administration in multiple preclinical animal models. Due to these features, HdAd has extraordinary promise to treat A-T. Currently, its use in the cerebellum has not been explored as current HdAd vectors do not work for Purkinje Cells (large neurons found in the cerebellum that are affected in people with A-T). Therefore, a knowledge gap exists in developing HdAd gene therapy approaches to treat A-T cerebellar degeneration.

Building on the lab's decade of experience developing and using HdAd vectors in the central nervous system, the team have created a novel HdAd vector that transduces Purkinje cells and other cerebellar cell types in a mouse model. They will now carry out work to overcome the major limitations preventing the use of HdAd in the cerebellum and their objective is to develop an HdAd approach that delivers therapeutic levels of ATM and characterize their efficacy in restoring ATM function in Purkinje cells. They will use their novel viral vectors, to develop approaches for long-term expression and restoration of ATM function in Purkinje cells and other cerebellar cell types.

## Functional impact of Nicotinamide Riboside on the immune system of patients with A-T

**Principal researcher:** Dr Mirjam van der Burg

**Institute:** Leiden University Medical Centre, Netherlands

**Cost:** £250,000 over 36 months in partnership with AEFAT (Spain) and BrAshA-T (Australia)

**Start Date:** 1st of September 2024



Dr Mirjam van der Burg

### Project Overview

Dr Mirjam van der Burg and her team will initiate an international survey to collect data on the clinical status and immunophenotype of patients with A-T diagnosed via new-born screening from medical electronic patient dossiers (EPD) to create a roadmap of the natural course of immune parameters during the first years of life. They will then use laboratory culture systems, which have been proven effective models for the immune system, in combination with ATM inhibitors and different doses of NR to investigate the impact of NR on the immune system. Finally, they will develop a new model system for ATM-deficient immune cells that is based on stem cells from cord blood in which an ATM mutation has been created via a state-of-the-art technique called CRISPR-based-gene editing.

This project could make a significant difference to the lives of those affected by A-T, because more insights will be gained on the effect of NR on the immune system and as such add crucial knowledge to future (international) clinical trials on NR as a new candidate drug for improvement of both neurological and immunological clinical manifestations of the condition.

## Exploring Omaveloxolone efficacy in Ataxia-telangiectasia

**Principal researcher:** Professor Paola Giunti (pictured) and Dr Rosella Abeti
**Institute:** University College London (UCL), UK
**Cost:** £24,915 over 4 months
**Start Date:** 23rd of September 2024


Prof Paola Giunti

### Project Overview

One of the processes happening in people who have A-T is increased oxidative stress. Professor Paola Giunti and her team will study a recently approved drug called Omaveloxolone (Omav). This drug is known to defeat oxidative stress, and the team will investigate whether it could help overcome the adverse effects of oxidative stress in A-T cells. Omav activates a natural defence system in our cells that fights off damage caused by stress. To test this, they will use skin cells from A-T patients and see if Omav can lower the levels of reactive oxygen species that are generated in patients' cells, leading to oxidative stress. They will then compare the levels of reactive oxygen species in A-T patients to healthy volunteer lines to verify that Omav is effective.

If it proves to be efficacious in A-T cells, their study may lead to a potential new treatment from which A-T patients could benefit in a relatively short time.

## Exploring the Use of Assistive Robots, Smart Sensing and Digital Twin Models for Monitoring and Support of Ataxia in Non-Clinical Environments

**Principal researcher:** Professor Praminda Caleb-Solly
**Institute:** University of Nottingham
**Cost:** £19,998 over 6 months
**Start Date:** 1st of May 2025


Prof Praminda Caleb-Solly

### Project Overview

Professor Caleb-Solly and her team at Nottingham University will focus on exploring engaging ways to support children between the ages of 5 and 10 with A-T, and their parents, to better understand and self-manage their activities through the day. The aim is to investigate whether simple sensors that measure overall movement and physical activity might be able to capture information regarding levels of energy used over time. They will then co-design how this information can be communicated to the children, in a personalised, engaging and easily understandable manner, that can assist them with getting the most out of their days and balance their activities to self-manage and regulate their limited energy reserves.

The project will explore three key aspects:

1. To what extent might non-obtrusive sensors provide reliable metrics for mapping physical activities over the day

2. How could this sensor data be incorporated into a smart guidance system (such as an intelligent robot 'coach') to provide proactive support for helping to balance physical activity with energy conservation to improve overall well-being and quality of life

3. What is required and acceptable to the children, their parents and health care professionals, in terms of the data collected, clinical use of the data, and form factors of the sensors and intelligent robot coach.

This project will lay the groundwork for a larger study into the effectiveness of using intelligent robotic "toys" as "coach" to provide information regarding individual activity/energy expenditure patterns to guide with structuring and balancing daily activities.

## Identifying existing drugs to repurpose for treating Ataxia-Telangiectasia

**Principal researcher:** Dr Richard Tuxworth

**Institute:** University of Birmingham, UK

**Cost:** £249,333 over 32 months in partnership with the A-T Society (UK), AEFAT (Spain) and BrAshA-T (Australia)

**Start Date:** 1st of November 2024



Dr Richard Tuxworth

### Project Overview

Dr Tuxworth and his team will initially grow A-T nerve cells in the laboratory and test a collection of the drugs that are known to enhance recycling. If some look promising, they will then test them in two more complex models of A-T. First, they will use fruit flies that have been engineered to mirror what happens in A-T. Fruit flies, while much simpler than humans, have a complex nervous system and show complex behaviour. They will be looking to see if any of the drugs correct the structural changes to nerves that they see in their A-T flies that are due to defective recycling. They will also test if the drugs are able to correct the movement deficits the flies show.

In the final stage of the project, they will grow mini-brains in the laboratory. Over many weeks these mini-brains – known as organoids – develop into complex 3D structures with many different types of cells and features reminiscent of a brain. They know already that in brain organoids grown from A-T cells the genes associated with the autophagy recycling process are not being turned on and off correctly and that there is increased death of nerve cells. The team are hoping that the drugs shown to work in the cells and the fruit flies will be able to reverse the defective recycling in the brain organoids and protect the nerve cells from dying.

The drugs they will test have been deliberately selected to make it quicker and simpler to move into early-stage clinical trials. All the drugs are old and commonly used, meaning they are cheap with no patent issues, plus their safety profiles and any possible side-effects are well-understood. Importantly, all are known to get into the brain and several are already used to treat neurological conditions, including childhood-onset conditions such as epilepsy. If they can see positive effects of one or more drugs in their cells, fruit flies and mini-brains, they will instigate clinical trials to test if they are able to help A-T patients maintain neurological function for longer.

## Improving diagnosis and treatment of cancer in Ataxia-Telangiectasia patients through whole genome sequencing

**Principal researcher:** Dr Ramsay Bowden

**Institute:** University of Cambridge

**Cost:** £19,960 over 6 months

**Start Date:** 3rd March 2025



Dr Ramsay Bowden

### Project Overview

Dr Bowden and her team will work with doctors looking after people with A-T to collect cancer biopsy samples for genetic investigations. They will use a technique called whole genome sequencing (WGS) to study every letter in the genetic code of these samples and compare this to the genetic code of non-cancer samples. They will also invite people with A-T with and without cancer to provide a blood sample and will look for any genetic changes in this blood which may be linked to those found in cancer samples.

Understanding the genetic basis of cancer in people with A-T will help doctors make better decisions about cancer treatment. It will guide them on what treatments are most likely to be effective for improving survival. It may also suggest which treatments should be avoided because of side effects, or because they are unlikely to be effective.

Identifying genetic changes in blood may help to develop a blood test to monitor cancer treatment without needing repeated biopsies. It is possible that genetic changes will be found in blood that can be used in a blood test for early diagnosis and cancer screening. When cancers are diagnosed at an earlier stage the outcomes are generally better.

This study is unlikely to provide immediate benefits for participants going through their own cancer treatment but will hopefully improve cancer diagnosis and treatment for individuals with A-T in the near future.

## Investigating the role of mutant Triple T chaperone in ATM assembly in Ataxia Telangiectasia

**Principal researcher:** Dr Mohinder Pal

**Institute:** University of Kent, UK

**Cost:** £249,806 over 36 months partnership with the A-T Society (UK), AEFAT (Spain) and BrAshA-T (Australia)

**Start Date:** 30th April 2025



Dr Mohinder Pal

### Project Overview

Recent research shows that inherited mutations in chaperone proteins can make the ATM protein unstable, and patients develop clinical symptoms that overlap with A-T disease. Despite this, there is a need to clarify how these chaperone proteins function to stabilise ATM and how patient-associated mutations in these chaperones affect this process. Dr Pal and his team seek to define precisely how these chaperone proteins interact with ATM. Electron microscopy will produce detailed images of the atomic structure of ATM bound to the chaperone complex. From these images, it should be possible to understand how mutations in these chaperones impact the assembly of the ATM protein.

The team will visualise the natural assembly pathway of ATM protein, mediated by chaperones, with a powerful electron microscope. This approach will provide critical information to understand how different mutants of ATM protein affect its stability and activity. This information will be pivotal to potentially designing potent small drug molecules to stabilise and restore the activity of ATM to decrease the gravity of the disease.

Understanding the pathway of the ATM assembly and the role of chaperones in this process can significantly contribute to our understanding of A-T. This work could be a basis to stabilise either mutant ATM protein or mutant chaperones, which may be sufficient to slow down the disease progression in patients. It could also serve as the basis for other researchers utilising these findings to test different chemicals to push this research from the laboratory to the benefit of A-T patients.

## Kicking Kinases into Action: A novel drug screening assay for A-T

**Principal researcher:** Dr Paula Jackson

**Institute:** University of Nottingham

**Cost:** £19,238 over 12 months

**Start Date:** 3rd March 2025



Dr Paula Jackson

### Project Overview

ATM, a serine threonine kinase protein, is a key protein that is dysregulated in Ataxia Telangiectasia (A-T). ATM has a multitude of roles such as a protection against oxidative stress, the maintenance of telomeres and DNA repair. The lack of ATM in A-T leads to pathophysiology and currently, treatments only focus on managing disease symptoms rather than interfering with disease progression itself. Current interventional clinical trials for A-T include triheptanoin, nicotinamide riboside, N-Acetyl-L-Leucine, and intra-erythrocyte dexamethasone sodium phosphate. Previous trials have focused on the examination of oxidative stress markers to assess the efficacy of these pharmaceutical treatments, in example, nicotinamide riboside. Dr Jackson and her team are planning to override the ATM gene and directly activate kinases that the ATM gene should be activating when fully functional.

The ATM is important for recognising double stranded DNA damage and kickstarts several processes to repair this and ensure cell repair and survival. When there is a problem with the ATM gene this doesn't happen and DNA damage can build up causing loss of cellular function in the brain. The team want to test whether they can directly kickstart these same processes using already available compounds. Initially, cells taken from people with A-T that have the exact ATM mutation that causes A-T will be secured. These will then be tested using 5 different compounds, using cellular viability assays to identify an optimal range of doses that can be used without killing the cells. The team will then measure both metabolic activity and DNA repair in a simple assay which will indicate whether they are able to activate the DNA repair mechanisms whilst maintaining a healthy cell.

If the team can understand how to override the ATM mis-function and this data could be used to undertake a more in-depth study of the mechanisms at play. The hope at the end is to find some alleviation to symptoms, or at best a partial treatment for people with A-T.

# Ensuring that our research is of the highest quality, is well managed and has clear and achievable aims

Research is at the heart of what we do, and our research strategy outlines our intentions on achieving our mission.

## Our Performance

Action for A-T were awarded their second prestigious AMRC award for best practise in medical and health research peer review in May 2021. The award confirms the robust methods used to make decisions about which research projects to fund and our support of the best researchers and the highest quality research, with the best chance of improving the lives of those affected by A-T. The award was made following a full audit of our processes which takes place every five years.

The Trustees generally stage one grant round per year where funds will allow. Applications are peer reviewed by independent external reviewers before they are passed on to our Research Advisory Committee for further review. Projects which pass the peer review process and are deemed high enough quality are passed on to the Trustees to make the final decision based on several key criteria including available funds, strategic alignment, and existing research commitments.

Our Research Advisory Committee (RAC) are part of this process and consist of independent scientific experts from fields related to A-T, including clinicians, non-clinicians, and statistical expertise from a wide range of UK institutions. Lay members are also on the committee to incorporate the views of parents and patients living with A-T, bringing a valuable and unique perspective over what research should be funded. Members of our RAC reviewed all the applications received in 2024 and their funding recommendations were passed on to the Trustees for consideration. All ten of their recommended projects were approved by the trustees and the grants were awarded at various dates throughout the year.

## Project outcomes and sharing knowledge

We believe that sharing project outcomes and knowledge is a fundamental requirement for the development of new research strategies which will ultimately benefit those living with the condition. Progress, annual and final reports are mandatory for all our research grants to ensure that they are reaching the agreed milestones. These reports are formally reviewed by our scientific advisor to ensure that each project is in line with its stated aims and the outcomes are then converted into lay summaries to share with our supporters.

Researchers are also encouraged to publish their findings in medical journals and where possible, make the findings freely available. The outputs of research such as publications usually occur sometime after a research project ends and it can take many years to translate research ideas into new treatments or therapies to improve quality of life.

The outcomes of all the concluded research we have funded are displayed on our website under the 'Completed Research' section. Where applicable, these posts also include links to any online publications, and we also share project information via our social media channels and in various communications to our supporters and potential donors.

## Evaluating the outcomes of our research

As with all charities, we are passionate about demonstrating the impact of our work and understand the importance of monitoring the progress and outcomes of our research. Throughout the year we continued to work with our scientific advisor and other members of our Research Advisory Committee to oversee and evaluate the effectiveness of our ongoing research portfolio. Between them, they monitored the progress of ongoing projects and signed off on any which were completed to help ensure that the original research aims stated in the application were fulfilled.

# The following studies concluded in 2024, and the initial project outcomes were as follows:

## Virtual Reality in Ataxia Telangiectasia

**Principal researcher:** Professor Philip Breedon

**Institute:** Nottingham Trent University, UK

**Completion date:** December 2023



Professor Philip Breedon

### Project Overview

To reduce the rate of muscle degradation and potentially prolong the time until patients become full time wheelchair users, professor Breedon and his research team developed a bespoke virtual environment that pairs with a frictionless 360° treadmill, fitted with a rehabilitation support frame. The VR environment contains a wide selection of easy to play, non-strenuous 'mini games' each exclusively developed to target a specific muscle group, motor or cognitive function. Throughout game development, the team were in regular contact with parents of A-T patients and A-T specialist clinicians to ensure the game was made to the patient's requirements and interests.

### Project Outcome

The researchers believe the solution has the potential to play a vital role in improving patient wellbeing as it encourages independence through its ease of use, a novel approach to rehabilitation and takes away the need to complete long winded, tiresome activities. To continue their research, the team are working on a new improved study to further improve game quality, conduct in-depth patient studies and develop supplementary hardware. The teams long term goal is that the solution could be deployed into several local clinics nationwide, providing a community of active users to support one another through multiplayer gameplay and mitigating the need for families to travel long distances for physiotherapy.

## STIM A-T Pilot Study

**Principal researcher:** Dr Caroline Blanchard

**Institute:** University of Nottingham

**Completion date:** February 2024



Dr Caroline Blanchard

### Project Overview

Involuntary movements, such as muscle spasms and tremors, greatly affect daily activities and quality of life for people with A-T. Current treatment options are limited. Dr Caroline Blanchard and the team at Nottingham wanted to see if stimulating a nerve in the wrist called the median nerve could reduce unwanted involuntary movements in individuals with A-T. This pilot study aimed to show the feasibility and tolerability of, and provide preliminary evidence of the effect of, median nerve stimulation (MNS) delivered via a 'watch-like' device worn on the wrist, for reducing unwanted involuntary movements in people with A-T.

### Project Outcome

The team recruited five young adult participants for this pilot study, of whom four had classic A-T and one had a condition that overlaps with A-T called AOA-1. All participants had involuntary movements in addition to ataxia. They firstly undertook interviews with the participants about how the involuntary movements affected their lives, and what benefit they would hope to get from a non-invasive stimulation treatment. They then carried out a series of tests where they asked the participants to do a range of movement and thinking tasks, with the MNS stimulation device switched on and switched off. They filmed the participants while they were doing these tasks. The team are currently analysing the videos to look for reduced number of unwanted movements with the device switched on. It is a small sample size therefore a clear effect is not expected to be seen initially. They found that the device was well tolerated by participants and there were no safety concerns. Based on this data they now plan to apply for funding for a larger clinical trial to find evidence that this approach works as a treatment for unwanted movements in A-T and related conditions.

Through this study the team have leveraged an additional £20,000 funding from the MRC / EPSRC NeuroMod+ funding stream for a project to refine the AI-based analysis of movement disorders in A-T. This work, together with the STIM A-T pilot data, will be used to support a grant application for a larger trial of the device, with both efficacy and mechanistic study objectives.

*These two projects were funded via our Sandpit grant round which completed in March 2023. Sandpit funding is a small pot of money that we invest in both an unmet research challenge in A-T and in researchers that are new to A-T. We do this to get a new idea off the ground and to encourage new people to the field of A-T research.*

## A new function for ATM and a new theory for the clinical abnormalities in A-T

**Principal researcher:** Professor Mike Kastan

**Institute:** Duke University, North Carolina, USA

**Completion date:** December 2023



Professor Mike Kastan

### Project Overview

Ataxia Telangiectasia (A-T), results from loss of function of the ATM (Ataxia Telangiectasia, Mutated) gene. Although much is known about the function of the protein encoded by this gene, mechanistic understanding of how loss of the gene's function leads to the presentation of the disease, including neurodegeneration, cancer, lung abnormalities, etc, remains incomplete. Further understanding of ATM regulation and function is needed to help show how loss of ATM affects cellular processes and the clinical presentation of the disease. This study built on previous work and aimed to explore the interaction of ATM and a gene called SMG1 to characterise signal pathways between them.

### Project Outcome

The gene SMG1 is in the same protein family as ATM and the team made the unexpected observation that ATM protein is required for controlling SMG1 protein activity after being exposed to DNA damaging agents, like ionizing radiation. They found that ATM helps control production of alternative forms of the DNA damage-responsive and tumour suppressive protein p53, in part through negative regulation SMG1 activity. These alternative versions of p53 protein that are produced in response to irradiation in ATM intact cells, unlike in cells that have lost ATM, promote the senescence (growth arrest) of cells and triggers production of a pro-inflammatory environment around cells. They showed that ATM and SMG1 contribute to cellular senescence through the production of these alternative versions of p53 protein. They also identified another protein, DDX5, that is required for production of the alternative versions of the p53 protein and for control of cellular senescence after irradiation. In all, ATM, SMG1, and DDX5 work to promote irradiation-induced cellular senescence through production of alternative versions of the DNA damage-responsive protein p53. Alterations in this signalling pathway may contribute to the neuronal and cancer abnormalities seen in A-T patients.

While not all experiments that were proposed in the original application were successful (mainly those related to the specific biochemical mechanisms by which ATM regulates SMG1 kinase activity), the project was successful in meeting the overall objectives by formally demonstrating the role of ATM in regulating SMG1, in identifying an additional novel and interesting component of this signalling pathway (the RNA helicase, DDX5), and in demonstrating that this pathway affects a very important A-T phenotype, namely cellular senescence.

The researchers are keen to explore these unexpected new insights further and plan further work to analyse whether these new pathways could potentially account for important A-T clinical phenotypes, particularly the neurodegeneration.

### Publications

**McCann JJ, Fleenor DE, Chen J, Lai C-H, Bass TE, Kastan MB.** Participation of ATM, SMG1, and DDX5 in a DNA Damage-induced Alternative Splicing Pathway. Radiation Research, 199: 406-421, 2023. PMID: 36921295 DOI: 10.1667/RADE-22-

## Recurrent pulmonary infections and their impact on neurological decline in A-T

**Principal researcher:** Professor Margot Mayer-Proschel and Professor Michael O'Reilly

**Institute:** University of Rochester, New York

**Completion date:** March 2024



Professor Margot Mayer-Proschel

### Project Overview

A-T is a multi-organ disease, yet neurological pathologies (one of the main problems in A-T) are for the most part studied in isolation from other organs. Professors Mayer-Proschel and O'Reilly wanted to study whether lung infections exacerbate neurological decline. The team recognized this was a poorly understood and investigated correlation and aimed to understand better the role of peripheral insults and inflammation to the brain in patients with A-T.

Three aims were clearly set out and the team used a mouse model to:

- Undertake cellular analysis of the effect of a single lung infection (Influenza A)
- Undertake cellular analysis of the impact of recurrent respiratory infections on lung and brain pathology
- Characterise the functional changes after the respiratory infections

### Project Outcome

The mice were exposed to viral or bacterial lung infections and their lung and motor function tested. They found that the mice were highly sensitive to recurrent peripheral viral infections which impacted their lung function. In addition, they failed to boost their antibody response after a primary infection rendering them highly vulnerable to recurrent infections. The peripheral infections did not only affect lung function but exacerbated motor defects in a significant manner. Young animals exposed to a peripheral viral or bacterial challenge developed highly reproducible motor defects that were consistent with ataxic traits.

The researchers have established relevant behavioural endpoints that can be used to test efficiency of therapeutic drugs in the future. They aim to start the process of identifying potential drugs. If drugs are identified, they will then need to be tested to see if they prevent or revert the neurological decline that occurs in A-T. This work may ultimately assist in the development of new therapeutic approaches

### Publications

**Warren R, Dylag AM, Behan M, Domm W, Yee M, Mayer-Pröschel M, Martinez-Sobrido L, O'Reilly MA.** Ataxia telangiectasia mutated is required for efficient proximal airway epithelial cell regeneration following influenza A virus infection. Am J Physiol Lung Cell Mol Physiol. 2022 Apr 1;322(4):L581-L592. doi: 10.1152/ajplung.00378.2021. Epub 2022 Feb 23. PubMed PMID: 35196880; PubMed Central PMCID: PMC8993527.

## Innovative methods for gene therapy in Ataxia-Telangiectasia

**Principal researcher:** Professor Ignacio Molina & Dr García-Pérez

**Institute:** University of Granada, Spain

**Completion date:** March 2024



Professor Ignacio Molina & Dr García-Pérez

### Project Overview

Gene therapy is a technique for correcting genetic defect by inserting a healthy copy of a gene into cells (replacing a faulty gene). To deliver a gene into cells, scientists use delivery systems called vectors.

In a previous study, Professor Molina's team demonstrated that this technique could cure A-T cells. However, the extremely large size of the ATM gene (the gene missing or not functioning completely in A-T) means most delivery systems are inefficient. To overcome this, the team studied whether a new type of vector called transposons would be suitable. Transposons can carry large genes and deliver them into target cells, and thus the team wanted to see if this approach could introduce a healthy ATM gene into A-T patient cells.

### Project Outcome

The researchers introduced the full-length ATM gene into patient cells and found that whereas transposons could be introduced into deficient cells, the efficiency was not higher than that previously obtained by other viral methods and unfortunately considered insufficient to start clinical trials. Since the transfection efficiency was greatly affected by the size of the transgene, they then designed a mini-ATM gene that was about half the size of the full-length ATM gene. Transfection efficiency obtained with the mini gene was greatly enhanced and they detected a presence of the truncated mini protein. This was a relevant achievement since they considered that such construction could result in an unstable protein. They then analysed if the cellular defects typical of A-T had been rescued in mini-ATM transfected patient cells. After a detailed analysis they concluded that the truncated ATM protein was unable to revert the defects related to A-T.

Although the researchers were not successful with their gene therapy strategy, the findings are still important. It is now known that this approach to gene therapy has been tested and found at present to be ineffective. Within this fast moving and rapidly expanding field of gene therapy testing of any potential hypotheses are important.

### Publications

There are no publications at this current time.

## Optimizing lung imaging in people with Ataxia Telangiectasia applying improved MRI techniques

**Principal researcher:** Dr Peter Merkus

**Institute:** Radboud University Medical Centre, the Netherlands

**Completion Date:** August 2024



Dr Peter Merkus

### Project Overview

Many children and adults with Ataxia Telangiectasia (A-T) suffer from recurrent infections and some develop malignancies. This is responsible for a large burden for these patients and their families/caretakers and may cause severe symptoms and even death. In order to improve treatment, it is necessary to be able to monitor the condition of the lung better. Lung function measurements are difficult to carry out reliably for many people with A-T, and imaging of the lungs with conventional radiology of the chest involves ionizing radiation that should be avoided whenever possible. Magnetic Resonance Imaging (MRI) does not involve ionizing radiation, and improved MRI would be the ideal tool to obtain reliable structural information of the lungs. However, MRI scanning used to be less suitable for lung imaging till recently because of poor resolution. Furthermore, MRI is not a quick procedure and patients with A-T often have uncoordinated movements that preclude optimal imaging.

### Project Outcome

Dr Merkus and his team, aimed to improve the resolution of the MRI images, to correct for movement during the procedure and to reduce the time needed to obtain images of the lungs. The goal was to enhance and standardize a technique suitable for routine clinical care of patients with A-T, also the severe and the young.

Although the project suffered considerable delays, the team were successful in reaching their stated goals/milestones. Furthermore, they now also have a tool to assess ventilation and perfusion of the lungs during tidal breathing, so not only are they now able to make images of the structure of the lungs, but also of their function.

The quality of the imaging is clearly better than using conventional Chest X-rays. Through optimizing duration of procedure and resolution using the software developed in the past few years, MRI quality is now far better than previously possible. The team believe that their work will contribute to better monitoring and treating people with A-T, thereby enhancing the quality of their lives. They have subsequently decided that they will introduce the MRI as a part of the annual visit to the outpatient clinic. This will require serious planning and preparation of patients but is considered important. They will also develop a protocol aimed at accepting the MRI scanning better (for instance through distraction with MRI – Compatible VR glasses).

### Publications

The team are currently working on a manuscript for publication.

## The ATeam: Producing healthcare guidance for children with A-T

**Principal researchers:** Munira Khan & Dr Lisa Bunn

**Institute:** University of Plymouth

**Completion Date:** August 2024



Munira Khan

### Project Overview

This project aimed to develop evidence-based guidance for healthcare professionals managing Ataxia Telangiectasia (A-T), focusing on nursing, physiotherapy, and occupational therapy. Historically, these disciplines have been integral to A-T management but lacked guiding research evidence. A large team of parents, academics and clinicians who are interested in A-T research was assembled to conduct this project and they named themselves 'the ATeam'.

### Project Outcome

Following a compilation of all available evidence that could guide the management of A-T (Khan et al., 2024) the ATeam co-designed:

**My A-T Pack:**

A child- and family-owned healthcare pack to support communication and care. Its design was informed by focus groups and iterative feedback, including live illustrations during sessions (and My A+ Pack: A version tailored for broader ataxia disability needs).

**A Home-Based Exercise Intervention:**

A flexible, remotely supported exercise program was co-developed to suit daily life demands and manage fatigue. This included Yoga adapted videos and co-produced a "breathing exercise movie" for use with the 'Breather' device aimed to enhance respiratory health. This intervention included mindfulness options to ensure participant inclusivity and reduce perceived failure risks.

A feasibility randomized controlled trial tested the intervention's acceptability and effectiveness with seven participants. Four completed the program, reporting high enjoyment and perceived benefits. Engagement rates varied, and improvements were noted in balance and respiratory function. This project developed and trialed the first non-medical therapy intervention for children and young people with A-T, which, following amendment and rapid evaluation, will also be freely available to download freely for accessible use.

The project has advanced A-T care by addressing gaps in evidence and creating family-centered tools and interventions. Ongoing refinement and collaborations aim to scale its impact globally.

### Publications

Khan et al., The Cerebellum: "Care and Management of Children with A-T by Nurses and Allied Health Professionals."

https://doi.org/10.1007/s12311-023-01555-z

Manuscript on My A-T Pack under review.

**To view all our current and complete research projects, please visit**

**https://actionforat.org/category/research-projects-funded/**

# Achievements and Performance, Fundraising Activities

Action for A-T raises funds through donations, fundraising events, and corporate partnerships. No professional fundraisers or commercial participators were engaged. All fundraising is conducted in-house and monitored by the Trustees.

The charity follows ethical fundraising standards and ensures that all activities comply with best practices. During the year, no complaints were received regarding fundraising.

## Our Aim

Action for A-T funds high quality peer reviewed medical research to speed up the process of identifying a cure for Ataxia Telangiectasia (A-T). We endeavor to raise funds from a variety of activities which appeal to new and existing supporters. Since 2012 we have invested £5,652,410 in 60 A-T related research projects around the world, and this has only been possible thanks to our generous supporters.

## Our Performance

2024 was our most successful fundraising year to date as we were able to deliver a full portfolio of events. Most activities performed better than expected as our event guests were incredibly generous, and we were able to benefit from several new fundraising events including an overseas cycle ride with the Wasps Legends, a sponsored walk staged by the employees of Aviva Investors and a charity of the year partnership with the captains of Banstead Downs Golf Club. We also received further funding from the MRC to help retain early years researchers, plus a sizeable donation from Aviva Investors and continued our funding partnership with NATA.

Our investment in Virgin London Marathon places proved successful once again, allowing us to make a 421% return. 15 people joined our marathon team raising £60,070. We have secured 15 places for the 2025 London Marathon and applied for an additional 12 places (27 in total) which can be used from 2026 onwards.

In line with our fundraising strategy, we delivered a robust portfolio of sporting and social events as well as developing new relationships with other funders. We also diversified our other fundraising activities to ensure that we were not solely dependent on any one source of funding. Challenge and Social events accounted for 41% of our overall income (2023 - 50%). Whilst other fundraising initiatives, such as donations, funding partnerships and trust and foundation applications increased to 51% (2023 - 47%). The remaining 8% (2023 – 3%) came from bank interest on our designated funds. A few notable fundraising activities took place throughout the year including various golf events and the St Martin's Junior Trailblazers Walk. We are especially grateful to the staff and clients of The Constellation Automotive Group yet again for taking part in the three-day cycle from Surrey to Arras, France which raised £75,000 plus the non-riders who raised an additional £29,200 from a marathon walk. We are also indebted to the staff at Aviva Investors for their generous support throughout the year and the students of Quest Professional who raised over £14,000 at their drinks and canapes evening. In addition, we would like to thank Simon Toon and his friends for their ongoing and valued support and the captains and members of Banstead Downs Golf Club for raising over £48,000.

## Raising Funds Responsibly

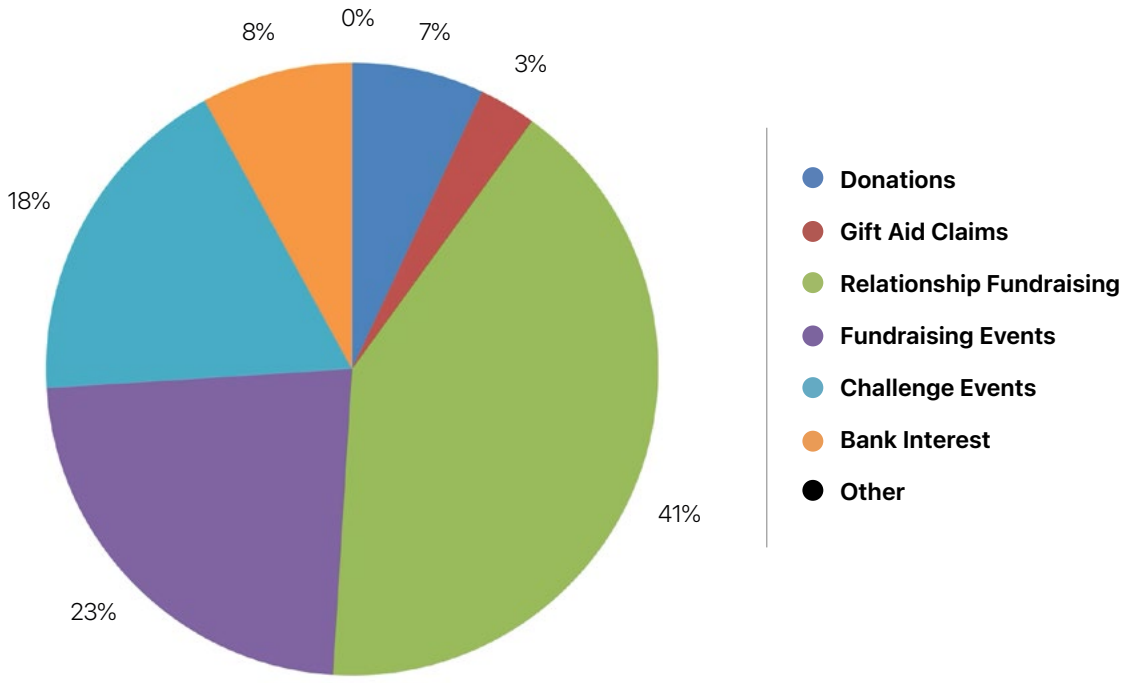



Action for A-T are registered with the Fundraising Regulator and are committed to upholding the code of fundraising practice. We receive all our funding from voluntary sources, including individuals, companies, trusts and foundations and we do not work with any professional fundraisers or commercial participators to raise funds on our behalf. Each year, we purchase places in several physical challenges as well as staging and benefiting from a series of other social and sporting events.

We want everyone we interact with to feel free from undue influence when they consider donating. Our in-house fundraising team are trained to recognise these signs, so they can manage conversations in a way that could be considered intrusive or putting repeated or undue pressure on someone to donate. We routinely monitor our fundraising materials to ensure our standards remain high and treat our supporters fairly. Supporter feedback is reviewed regularly to ensure our fundraising offer is appropriate and complies with relevant rules and regulations.

To help protect people in vulnerable circumstances, we continued to follow guidance from the Government and the Fundraising Regulator throughout 2024 and only carried out public fundraising when we considered it safe to do so. We also continued to speak to more supporters to make sure our high standards were maintained as we returned to normal activities following the pandemic.

The pie chart below shows the percentage splits of each of our areas of fundraising in 2024.




We would also like to record our thanks to all our volunteer committee members for their time and commitment in helping us achieve our mission, as well as everyone who donated their time, auction prizes and/or supported or participated in our events.

In addition to the above, we are also extremely grateful to the trusts and foundations who provided restricted funding for various research projects (these are listed on page 51). We are always keen to work with other trusts, foundations and corporate funders who might be interested in supporting our work.

## Events Since the End of The Year

Information relating to events since the end of the year is provided in the notes to the financial statements.

# Working Closely with Others to Meet our Objectives

## Our Aim

Action for A-T strongly believes that there are many opportunities to further the search for a treatment or a cure for A-T through working with others that may have overlapping aims or objectives to our own. To this aim, we actively seek out like minded organisations and where possible, create collaborative partnerships.

## Our Performance

**Co-funding A-T Research Projects with other charities and patient organisations**

Action for A-T continued to work closely with various organisations, charities, and patient organisations throughout 2024 to fund new and existing research studies. Throughout the year, we continued to manage a variety of our ongoing studies (funded in partnership with others) as well as contributing to new research. Our co-funding partners in 2024 were as follows:

**The UK based Children's Charity GOSH**

Action for A-T continued to work closely with GOSH charity as they were managing the following jointly funded research project which concluded in August 2024.

• "Optimising lung imaging in people with A-T" - Dr Peter Merkus at the Radboud University Medical Centre, Netherlands

**The Australian charity BrAshA-T Ataxia Telangiectasia**

Action for A-T have an ongoing collaborative funding partnership with BrAshA-T who are based in Queensland, Australia. Following a joint grant call in 2023 six new research studies were passed for funding and BrAshA-T agreed to contribute £200,000 towards the total cost of five of these projects. The first payment of £100,00 was made in December 2024 and the final payment of £100,000 will be made in the final quarter of 2025.

**The UK based A-T Society**

A strategic partnership was established between the A-T Society and Action for A-T in 2022 to increase the overall investment in new A-T research. Following the Action for A-T grant call in 2023 six new research studies were passed for funding and the A-T Society agreed to contribute £60,000 towards the total cost of three of these projects. The full payment of £60,000 will be made in the second quarter of 2025.

In addition, the A-T Society made their final contribution of £30,000 towards the five studies previously funded following the joint grant call in 2022. This payment was received in full in March 2024.

**The Spanish based AEFAT**

A strategic partnership was established between the AEFAT and Action for A-T in 2022 to increase the overall investment in new A-T research. Following the Action for A-T grant call in 2023 six new research studies were passed for funding and AEFAT agreed to contribute €40,000 towards the total cost of five of these projects. The first payment of €20,000 was made in December 2024 and the final payment will be made in the final quarter of 2025.

In addition, Action for A-T partnered with AEFAT to fund two research projects in Spain and Norway which began in January 2024. Action for A-T paid AEFAT £25,000 towards these projects at the end of 2023 and the remaining £25,000 will be paid in the first quarter of 2025.

**The MRC Nucleic Acid Therapy Accelerator (NATA)**

Our joint funding partnership with NATA was reconfirmed in 2024 and a grant round was opened calling for new nucleic acid therapies (NATs) related research applications. Both NATA and Action for A-T set aside £125,000 each to cover the full £250,000 cost of any new projects which

were deemed fundable by the RAC. Action for A-T managed the application and peer review process and one study totalling £249,615 was passed for funding. The 24-month study got underway in June 2024 and full details are available online https://actionforat.org/suppressor-trna-based-therapeutics/. The £125,000 contribution from NATA was received in full in August 2024.

Action for A-T will continue to explore additional joint funding opportunities with likeminded organisations throughout the coming year to maintain momentum and maximise the investment into A-T research.

**Working strategically with the worldwide A-T community**

The Global A-T Alliance is made up of charities and patient groups from the UK, USA, Spain, Israel, Japan, France, Turkey, Italy and Australia with the key objective of maximising the effort, resources and/or funding committed to finding a cure or treatments for Ataxia-Telangiectasia (A-T). The group meet virtually throughout the year to update each other on key research needs and findings as well as exploring ways in which they can work more closely together. To date, the Alliance members have jointly funded new research, met with a number of pharma companies to explore new treatment opportunities, delivered research focussed webinars for A-T families and established a new website www.cureAT.org which brings together useful information about A-T. The Alliance members passionately believe that with increased funding and a continued global and collaborative effort, effective treatments for A-T will be developed sooner and the lives of those affected will be changed for the better.

# Increasing Awareness of our Work and the Condition

## Our Aim

As an ultra-rare disease, most people are unaware of A-T or the devastating effects of the condition. Action for A-T believes that raising awareness of the studies they fund and the impact of A-T on children and their families is an important part of increasing the potential funds available to further improve the understanding of the condition, and to progress research into possible treatments or a cure.

## Our Performance

Action for A-T has significantly increased the public awareness of the condition over the past 12 months and will continue to explore all options to promote wider understanding of A-T and why research to find a cure or treatment is so important.

The Charity's main achievements in this area to date include:

**Celebrity Support**




Our celebrity patrons have continued to help promote Action for A-T and the need for more research into the condition by championing campaigns and taking part in various activities throughout the year. As well as providing prizes for our auctions, Jonny Wilkinson created several short films which were shown at some of our events and attended the BGC trading day alongside Simon Shaw. Naga Munchetty hosted her annual golf day at Moor Park as well as the captains' charity day at Banstead Downs Golf Club and recorded a number of promotional event videos. Several other celebrities including Chris Sheasby, Leon Haslam, Kevin Whately, Phil Vickery, and Jeremy Guscott helped generate funds, awareness, and support by taking part in events and campaigns.

**Visibility at Research Institutions, Conferences and Medical Meetings**

All Action for A-T funded researchers are provided with promotional materials to display at their research facility and required to acknowledge our financial support by including our logo on any posters or presentations. Throughout 2024, several conferences and scientific meetings took place where our researchers were able to present their findings. These presentations showcased our latest projects and provided the wider A-T community with a comprehensive view of the progress made to date.

**Digital Communications**

The Charity website www.ActionforAT.org remains the focal point for event sign-ups, electronic donations, and research news. The site was updated and enhanced throughout the year to provide the best possible experience for our stakeholders.

We also continued to manage (alongside Mike Clahsen of BrAshA-T) the www.cureAT.org site which brings together key information about current & past research studies and resulting publications. The site also has sections on care and guidance, patient registries, general information about the condition and a directory of all the known patient organisations around the world. The content is available in several languages including Spanish, French, Italian and Turkish with a simplistic layout directing users

to sources of useful information (e.g., websites, documents, relevant groups/meetings, etc.) rather than duplicating existing content on other websites.

Our monthly e-newsletter continues to be a successful tool to communicate our latest news to supporters. Using Mailchimp for this proves to be cheaper than a traditional printed newsletter and has the functionality to track usage and monitor engagement. Our e-newsletter is sent to all our consenting supporters, has a clear unsubscribe function and inactive supporters are removed from the mailing list periodically.

Social media remains a key communication tool for the Charity as it is free, easily accessible and can reach wide audiences. It also allows us to engage with our supporters on a more strategic level and build additional support from their own contacts. Posts are carefully managed to ensure that the content is engaging and not repetitive and this more targeted and planned approach helped us increase our followers throughout the year. We will continue to develop our social media presence in 2025 using all available technological advancements, popular platforms, and our celebrity patrons to raise further awareness.

**National and Local News Media Coverage**

We continued to raise awareness of A-T through a series of articles and editorials in the local, national and industry press and various news websites. In addition, our chief executive and various supporters took part in local TV and radio interviews throughout the year. These helped us highlight the condition to new audiences, recruit volunteers and secure additional support and donations.

# Our Future Plans: Areas of Focus for 2025

**The Trustees believe that Action for A-T is well placed to meet its charitable objectives but have also identified the need for further development to strengthen its research activities.**

During 2025 we will continue to consolidate and diversify our fundraising activities whilst actively developing existing and seeking new funding partnerships to meet the demands of the A-T research community. We will also continue to promote A-T research to engage new audiences and maintain interest from the research community.

We will implement several measures throughout the year to ensure that the Charity continues to be fit for future purpose and to help us achieve our aim of moving closer to tangible therapies or a cure for A-T.

## Strengthening our Capacity and Capabilities

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us deliver our charitable objectives. Our size and structure enable us to adapt quickly, and we will continue to review and prioritise projects based on available resources whilst seeking out new opportunities to raise funds in a safe and sustainable manner.

## Continuing our Investment in Medical Research in the UK and Abroad

We will continue to seek out new research opportunities from the wider research community as well as focussing on key research themes related to A-T. Where possible, priority will be given to UK based projects whilst still calling for international applications where funds will allow. Due to the significant investment in new research studies in 2024, our next full grant round is unlikely to reach its conclusion until early 2026.

Alongside the other members of the A-T Alliance, we will help to deliver the 2025 A-T Clinical Research Conference. The conference will be the first in-person clinical meeting since the Covid 19 pandemic and will bring together A-T researchers and clinicians from all over the globe. The conference will take place in June 2025 and is being staged within the Loughborough University complex.

We will maintain our close relationship with the Association of Medical Research Charities (AMRC) to develop and improve our peer review process and ensure that the research we fund is of the highest quality. We will take part in the AMRC Excellence in Peer Review audit in 2025 and hope to secure our 3rd award.

We will update our current RAC panel to a College of Experts model formed of scientific experts from all areas of A-T research and additional areas of scientific technical expertise. The new College of Experts will make recommendations for funding for A-T project grants, non-drug approaches and fellowship schemes. Membership of the new College of Experts will be continually reviewed to ensure that we have a broad range of scientific expertise in areas relating to A-T as well as early years researchers who are likely to become future research leaders. We will also secure new lay representation from various A-T families as Action for A-T strongly supports public and patient engagement in its research processes.

## Strengthening and Increasing our Fundraising Activities

We will continue to develop a pipeline of new business opportunities whilst delivering our existing portfolio of activities. We will maintain and refresh our calendar of high profile and fun events whilst also working alongside others in a benefitting capacity to reduce the financial risk to the Charity. We will continue to develop and expand our trust and foundations programme whilst actively seeking new investment from individuals, corporates, and major donors. We will also work closely with our key supporters and volunteer groups to ensure we maintain the momentum of investment in ground-breaking A-T research.

## Working Closely with Others to Meet our Objectives

We will also continue to work closely with key stakeholders (especially the A-T Alliance members) as well as exploring new collaborations that will bring greater benefit to the wider A-T community. The number of promising research opportunities continues to grow steadily year on year and there are now more research themes worthy of exploration than our limited funds will allow. We will therefore continue to work with and seek out new organisations with similar objectives to our own, to help ease the financial burden and speed up the process of finding a therapy or cure for A-T.

## Increasing Awareness of our Work and the Condition

Since we were established in 2012, a key priority has been raising awareness of A-T and the work of the Charity. This has been achieved by various means including celebrity endorsement, emotive films featuring researchers and A-T families and various

branding opportunities. We will continue to do all that we can to highlight A-T whilst focusing on various key projects in 2025. These projects will include maximising celebrity endorsement opportunities, the creation of new promotional films and other projects which help to educate and inform people about A-T.

## Board Composition

We will continue to evaluate the composition of our Trustee Board to facilitate the growth of the Charity and will consider further appointments to broaden and strengthen the Board's capabilities.

# Structure, Governance & Management

## Governing Document

Action for A-T is a charity registered in England and Wales (No. 1145303). The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

The Trustees have adopted the following policies and procedures for the recruitment, appointment, induction, and training of new Trustees:

## Trustee Recruitment and Appointment

The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. Trustees are either elected or co-opted under the terms of the Trust deed and the total number of Trustees may not be fewer than five. If a vacancy occurs or a skills need is identified, new Trustees are recommended by the existing Trustees and interviewed by the Chairman and at least one other member of the board. Election is by majority vote and potential candidates must be over the age of eighteen and eligible to act. The Trustees will continue to evaluate the composition of the Board and will consider further appointments to broaden and strengthen the Board's capabilities to facilitate the growth of the Charity.

## Trustee Induction and Training

New Trustees receive an induction pack containing a copy of the trust deed, strategy, relevant information about the Charity and its work; and a copy of the Charity Commission literature about the role and responsibilities of being a Trustee. New Trustees are also invited to meet the Chief Executive and team members to learn first-hand how the Charity operates on a day-to-day basis.

During the induction process, new Trustees are also told about the connected parties' rule, given a copy of the Charity's conflict of interest policy and asked to sign a Trustee declaration form. Where the Trustees have identified that there is a connection between the charity, or its Trustees and any third party with whom the Charity has dealt with, the Trustees will identify the relationship, and the amounts involved within the notes to the financial statements.

## Organisational Structure

The Trustees meet formally four times per year and no business shall be conducted unless at least one-third of the total number of Trustees at the time, or two Trustees (whichever is greater) are present throughout the meeting. There are two meetings where the focus is on awarding grants for medical research and two meetings where Trustees review strategy and set operating plans and budgets. There is a review of operating and financial performance at every meeting. The Chief Executive is invited to attend all meetings of the Trustees, and the Head of Fundraising is invited to report on plans and progress at specific meetings.

While most of the business of the Charity is conducted at the scheduled Trustee meetings, there are occasional ad-hoc meetings to deal with matters of special interest and regular electronic meetings are held to review ongoing governance objectives.

The Board of Trustees delegates the exercise of certain powers in connection with the management and administration of the Charity as set out below. This is controlled by regular reporting back to the Board of Trustees so that all decisions made under delegated powers can be ratified by the full Board of Trustees in due course.

The charity considers its key management personnel to be the Trustees, Chief Executive, and senior management. Further details on remuneration are disclosed in Note 11 to the accounts.

Action for A-T is committed to the highest standards of ethical conduct in all its activities. The Trustees ensure that the charity operates with integrity, transparency, and accountability, complying with all relevant laws and regulations. While the charity's work does not typically involve high-risk environments, it maintains a zero-tolerance approach to corruption and bribery and upholds fundamental human rights principles in its partnerships and funding activities.

## Research Advisory Committee

The Research Advisory Committee (RAC) is chaired by a member of the Board of Trustees. Members of the RAC have a broad range of scientific expertise in areas relating to A-T but are not generally active researchers in the field of A-T to minimise bias and conflicts of interest. There is also lay representation on the committee as Action for A-T supports public and patient engagement in its research processes. The Trustees are very grateful to all the members of the RAC for providing expert guidance and advice on a pro bono basis.

## Chief Executive

The Chief Executive is responsible for the day-to-day management of the Charity's affairs and is assisted by a small executive team who act under his direction. As well as overseeing the operations of the Charity, the Chief Executive is also responsible for implementing policies as agreed by the Board of Trustees.

## Employees, Volunteers and Contractors

The Charity aims to be an organisation where employees, volunteers and contractors enjoy a sense of fulfilment and where they feel supported and developed. All stakeholders are kept fully informed about the Charity's strategy and objectives, as well as day-to-day news and events. Individuals are encouraged to give their suggestions and views on performance and strategy.

The Charity supports equal opportunities, and a policy of recruitment and promotion based on aptitude and ability without discrimination is followed. Action for A-T is committed to the training, career development and promotion of all its employees. An individual's career development is assessed through annual appraisal and supervision. Training programmes are provided to meet any on-going needs, with the aim of developing individuals for both their current and their future roles.

## Pay and Remuneration of Key Management Personnel

The Trustees' principles are to pay staff a fair salary that is competitive within the charity sector, proportionate to the complexity of each role, it's related funding and responsible in line with the charitable objectives. Pay levels for all employees are reviewed annually and any overall percentage increases are authorised by the Board of Trustees.

Remuneration for the Chief Executive is agreed by the Trustees. Salaries are benchmarked using external data available from pay surveys (for the voluntary sector and charities located in and around London) and market conditions for the specific role and the target is the market median averages of these.

Ultimately however, salary increases relate to the funding available for each role and whether the increase will be affordable in the long term. To ensure pay is fair for all roles we are committed to paying all our employees at or above the London living wage as determined by the Living Wage Foundation.

## Engagement with Key Stakeholders

The charity recognises the importance of maintaining strong relationships with its key stakeholders, including funders, research institutions, beneficiaries, and partner organisations. During the year, we continued to work closely with medical research bodies and donor networks to ensure that our funding efforts align with the most impactful research opportunities. Trustees have actively engaged with stakeholders through regular meetings, reporting, and collaborative initiatives to advance our mission

## Risk Management

The Trustees have introduced a formal risk management process to assess business risks and implement risk management strategies. This has involved identifying the types of risks the Charity faces, prioritising them in terms of potential impact and likelihood of occurrence, and identifying means of mitigating the risks.

As part of this process the Trustees have reviewed and are satisfied with the adequacy of the Charity's current internal controls and the costs of operating controls relative to the benefits obtained. Procedures have been established for reporting failings immediately to the Chief Executive and to the Board of Trustees.

It is recognised that internal controls can only provide reasonable but not absolute assurance that major risks have been adequately managed. In the opinion of the Trustees the key risks are:

- The loss of reputation due to error, or fraud.
- The loss of income due to error, or fraud.
- Insufficient numbers of Trustees or staff to allow the Charity to continue.
- Insufficient funds to allow the Charity to meet its objectives.
- Excessive reserves without justification deterring future donors and fundraisers.

In the opinion of the Trustees the policies and procedures are currently adequate to mitigate financial and reputation loss due to error or fraud whilst maintaining a viable future financially.

## Financial Risk Management

The Trustees actively monitor financial risks to ensure the charity remains financially stable. The primary risks considered are:

**Credit Risk:** The charity relies on grants and donations from individuals, trusts, and corporate sponsors. While funders are carefully vetted, there remains a risk that committed funding may be delayed or not received. The charity mitigates this by diversifying income sources and maintaining close relationships with funders.

**Liquidity Risk:** To safeguard operations, the charity maintains reserves equivalent to six months of operating costs (£90,000). This allows flexibility to respond to financial uncertainties.

**Cash Flow Risk:** The timing of income receipts varies based on grant disbursements and fundraising cycles.

Trustees closely monitor cash flows to ensure financial obligations can be met in a timely manner.

Given the financial controls in place and the charity's reserves policy, the Trustees believe these risks are well managed and do not pose a material threat to the charity's ability to operate as a going concern.

# Financial review

**The Trustees are satisfied with the performance of the Charity and consider that the Charity is in an excellent position to continue its activities during the coming year, and the Charity's reserves are adequate to fulfil its current obligations.**

## Income

At present, research into A-T is heavily dependent on charitable donations and by extension, Action for A-T's ability to instigate, organise and facilitate the fundraising efforts of our supporters and donors. The principal source of funding is donations from individuals, companies, and proceeds of fundraising events.

Total income raised in 2024 was **£1,168,113 (2023 - £1,092,490)**.

## Charitable Expenditure

The cost spent on Charitable Activities Was **£1,846,493 (2023 - £404,569)** of which **£1,584,289 (2023 – £139,427)** was for grants provided for funding of research projects.

The cost of generating voluntary income was **£90,523 (2023 - £87,806)** whilst the cost of generating income from charitable events was **£150,864 (2023 - £157,097)**

Governance costs of **£20,817 (2023 - £20,239**) were incurred.

## General Funds

The Trustees will aim to make best use of any unrestricted funds, however they reserve the right to retain general reserves in hand until they can be used in the most efficient manner to further the objectives of the Charity. The Trustees are conscious that it should not provide funding for research where they have not been able to demonstrate that its use will offer the best opportunity to further the knowledge and treatment into A-T. Please refer to the investment policy with regard to those times where the Trustees believe general funds are in excess of the anticipated running costs of the Charity.

## Designated Funds

Designated funds of **£nil** were brought forward from 2023. In 2024, **£nil** of funds were passed on to the research projects detailed in note 8 on page 40.

As at 31 December 2024 designated funds carried forward are **£nil**.

## Restricted Funds

Restricted funds of **£38,021** were brought forward from 2023. During the year **£126,500** of restricted income was received against projects funded during 2024. During 2024, **£67,660** of funding was made to the research projects detailed in note 8 Page 40.

At 31 December 2024 restricted funds of **£96,861 (2023 - £38,021)** were carried forward and the Trustees are satisfied that the wishes of the donors were met fully. If further funds are received in the future the Trustees will ensure that those funds are used in accordance with those restrictions. Should it not prove possible to adhere to those instructions those funds will be offered back to the provider unless they indicate that they can be used for an alternative purpose.

## Investment Policy

The overall policy of the Charity is to maintain a series of designated funds deposit accounts to ring-fence any funds which the Trustees have identified as being made available for specific research projects, or other charitable activities.

The Trustees recognise the need to review this policy on an annual basis and to look at other potential opportunities whilst appropriately monitoring the available funds and being proactive in their management, to ensure the best interests of the Charity's objectives are maintained.

Funds committed for research are paid out in arrears over the duration of the project. The trustees reviewed and agreed to deposit funds in timed deposit accounts in order to obtain the best return with minimal managed risk.

During the year the Trustees transfer any funds surplus to general running costs of the Charity into an interest-bearing account which will offer a higher rate of return than holding it in the main Charity bank account. The aim is to ensure that the fund is not diminished over time due to inflation and to ensure that these funds are invested in future research projects.

## Reserves Policy

The Trustees review the reserves policy each year to ensure that all relevant risk areas are included in accordance with guidance issued by the Charity Commission. Risks included are the impact of unexpected, reduced income, and the potential impact of restructuring costs and liabilities required to downsize the organisation in an orderly manner, if a permanent income reduction was anticipated.

The review concluded that the existing reserve target level of Six months of operating costs (approx. £90,000) was sufficient to cover the risks identified in the review. This allows sufficient time for Trustees and management to take appropriate mitigating actions, if required.

The Trustees continue their commitment to develop and grow the level of investment in research into A-T, whilst maintaining a focus on managing the overall costs of the charity.

## Going concern

The Trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern. The Trustees have given consideration to the Charity's long-term future and considered what risks (see the Trustees' Report) could result in a situation where a going concern basis was not appropriate. They believe that safeguards are sufficient to ensure that both in the short and medium term the assets and reputation of the Charity are sufficiently safeguarded to ensure that the Charity is a viable going concern.

## Post Year End Events

The Trustees confirm that there have been no significant events since the year-end that would materially impact the financial position of the charity.

## Statement of Trustees Responsibilities

The Trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of the incoming resources and application of resources of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in business.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the Charity and financial information included on the Charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Approved by order of the Board of Trustees on 14th May 2025 and signed on its behalf by:



Toby Read (Chairman)

Dated: 14th May 2025



William Rowberry (Treasurer)

Dated: 14th May 2025

# Auditors Report

## Independent Auditor's Report to the Trustees of Action for A-T

### Opinion

We have audited the financial statements of Action for A-T Registered Charity Number: 1145303 (the 'charity') for the year ended 31 December 2024 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- Give a true and fair view of the state of the Charity's affairs as at 31 December 2024 and of its incoming resources and application of resources, for the year then ended;
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- Have been prepared in accordance with the requirements of the Charities Act 2011.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The Trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements, or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

### Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

## Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the Trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Charity or to cease operations, or have no realistic alternative but to do so.

## Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

1. Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

2. Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Charity's internal control.

3. Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Trustees.

4. Conclude on the appropriateness of the Trustee's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report.

5. Evaluate the overall presentation, structure, and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at **www.frc.org.uk/auditorsresponsibilities**. This description forms part of our Report of the Independent Auditors.

## Use of our report

This report is made solely to the Charity's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Charity's Trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and the Charity's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.



For and on behalf of A & N (Haslemere) Limited - Statutory Auditors
Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

Dated: 14th May 2025

## Statement of Financial Activities

for the year ended 31 December 2024

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.24 Total Funds £** | 31.12.23 Total Funds £ |
|---|---|---|---|---|---|
| **Income and Endowments from** | | | | | |
| Donation and legacies | 3 | 466,500 | 126,500 | **593,000** | 514,985 |
| **Charitable Activities** | 5 | | | | |
| Fundraising & challenge events | | 480,466 | - | **480,466** | 549,677 |
| Investment income | 4 | 94,647 | - | **94,647** | 27,828 |
| Other income | | - | - | **-** | - |
| **Total** | | 1,041,613 | 126,500 | **1,168,113** | 1,092,490 |
| **Expenditure on** | | | | | |
| Raising funds | 6 | 90,523 | - | **90,523** | 87,806 |
| **Charitable Activities** | 7 | | | | |
| Fundraising & challenge events | | 150,864 | - | **150,864** | 157,097 |
| Grants | 8 | 1,516,629 | 67,600 | **1,584,289** | 139,427 |
| Governance costs | | 20,817 | - | **20,817** | 20,239 |
| **Total** | | 1,778,833 | 67,600 | **1,846,493** | 404,569 |
| **Net Income / (Expenditure)** | | (737,220) | 58,840 | **(678,380)** | 687,921 |
| **Reconcilliation of Funds** | | | | | |
| **Total Funds Brought Forward** | | 876,704 | 38,021 | **914,725** | 226,804 |
| **Total Funds Carried Forward** | | 139,484 | 96,861 | **236,345** | 914,725 |

## Statement of Financial Position

for the year ended 31 December 2024

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.24 Total Funds £** | 31.12.23 Total Funds £ |
|---|---|---|---|---|---|
| **Fixed Assets** | | | | | |
| Tangible assets | 18 | 216 | - | **216** | 216 |
| **Current Assets** | | | | | |
| Stocks | 19 | 20,863 | - | **20,863** | 18,985 |
| Debtors | 20 | 58,429 | - | **58,429** | 41,798 |
| Cash at bank | 21 | 2,219,988 | 96,861 | **2,316,849** | 1,929,861 |
| | | 2,299,280 | 96,861 | **2,396,141** | 1,990,644 |
| **Creditors** | | | | | |
| Amounts falling due within one year | 22 | (815,714) | - | **(815,714)** | (422,367) |
| **Net Current Assets** | | 1,483,566 | 96,861 | **1,580,427** | 1,568,277 |
| **Total Assets Less Current Liabilities** | | 1,483,782 | 96,861 | **1,580,643** | 1,568,493 |
| **Creditors** | | | | | |
| Amounts falling due within one year | 23 | (1,344,298) | - | **(1,344,298)** | (653,768) |
| **Net Assets** | | 139,484 | 96,861 | **236,345** | 914,725 |
| **Funds** | 25 | | | | |
| Unrestricted funds | | | | **139,484** | 876,704 |
| Restricted funds | | | | **96,861** | 38,021 |
| **Total Funds** | | | | **236,345** | 914,725 |

The financial statements were approved by the Board of Trustees and authorised for issue on 14th May 2025 and were signed on its behalf by:



Toby Read (Chairman)

Dated: 14th May 2025



William Rowberry (Treasurer)

Dated: 14th May 2025

## Statement of Cash Flows

for the year ended 31 December 2024

| | Notes | 31.12.24<br>£ | 31.12.23<br>£ |
|---|---|---|---|
| **Cash flows from operating activities** | | | |
| Cash generated from operations | 1 | **292,341** | 273,723 |
| Net cash provided by operating activities | | **292,341** | 273,723 |
| **Cash flows from investing activities** | | | |
| Interest received | | **94,647** | 29,171 |
| Net cash provided by investing activities | | **94,647** | 29,171 |
| **Change in cash and cash equivalents in the reporting period** | | **386,988** | 302,894 |
| **Cash and cash equivalents at the beginning of the reporting period** | | **1,929,861** | 1,626,967 |
| **Cash and cash equivalents at the end of the reporting period** | | **2,316,849** | 1,929,861 |

## Notes to the Statement of Cash Flows

for the year ended 31 December 2024

### 1. Reconciliation of net (expenditure)/income to net cash flow from operating activities

| | **31.12.24** | 31.12.23 |
|---|---|---|
| | **£** | £ |
| **Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)** | **(678,380)** | 687,921 |
| **Adjusments for:** | | |
| Depreciation charges | - | - |
| Interest received | (94,647) | (29,171) |
| (Increase)/decrease in stocks | (1,878) | (11,235) |
| Decrease in debtors | (16,631) | (23,329) |
| Increase/(decrease) in creditors | 1,083,877 | (350,463) |
| **Net cash provided by operations** | **292,341** | 273,723 |

### 2. Analysis of changes in net funds

| | At 1.1.24 | Cash Flow | **31.12.24** |
|---|---|---|---|
| | £ | £ | **£** |
| **Net cash** | | | |
| Cash at bank | 1,929,861 | 386,988 | 2,316,849 |
| | 1,929,861 | 386,988 | 2,316,849 |
| **Total** | **1,929,861** | **386,988** | **2,316,849** |

# Notes to the Financial Statements

## For the Year Ended 31 December 2024

## 1. Accounting Policies

### Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS102, have been prepared in accordance with the Charities SORP (FRS102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011.

The financial statements have been prepared under the historical cost convention. The accounts are prepared in £ sterling to the nearest £1.

Action for A-T meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historic cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### Accounting convention

The financial statements are prepared on a going concern basis, under the historic cost convention.

The Charity is entirely dependent on receiving income from fundraising and donations and as a consequence the going concern basis is also dependent on the continuation of such income.

### Incoming resources

All incoming resources are included in the Statement of Financial Activities under FRS102 when that receipt is probable, whereas it was previously recognised when the Charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. For legacies, entitlement is the earlier of the Charity being notified of an impending distribution or the legacy being received.

Gifts in kind, including donated professional services are recognised as income when the Charity has control over them, any conditions associated with the donated item have been met, the receipt of economic benefit from the use of by the Charity if the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS102), the general volunteered time is not recognised and refer to the Trustees' Report for more information about this contribution.

On receipt, donated professional services are recognised on the basis of the value of the gift to the Charity which is the amount the Charity would have been willing to pay to obtain that service on the open market.

Gifts in kind donated for distribution are included at fair value upon receipt under FRS102 subject to the cost of recognition outweighing the benefit provided to Action for A-T. Previously they were included at a valuation and recognised as income when they are distributed. Any donated facilities are included at the value to the Charity where this can be quantified, and a third party is bearing the cost. No amounts are included in the financial statements for services donated by volunteers.

### Resources expended

All expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs allocated to activities. Where costs cannot be directly attributed to particular activities, they have been allocated on a basis consistent with the use of the resources.

Overheads have been allocated on the basis of the activity income of the Charity.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities. Support costs are those costs incurred directly in support of expenditure on the objects of the Charity and include project management carried out by the Trustees.  Governance costs are those incurred in connection with the administration of the Charity and compliance with constitutional and statutory requirements.

Grants offered subject to conditions which have not been met at the year-end date are noted as a commitment but not accrued as expenditure.

## Governance costs

Governance costs comprise all costs involving the public accountability of the Charity and its compliance with regulations and good practice. These costs include costs related to the audit, legal fees, and apportionment of overheads.

## Allocation and apportionment of costs

Fundraising Events & Challenge Events costs are allocated in their income ratio during the year.

## Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

**Computer equipment - 33% on cost**

## Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow-moving items.

## Taxation

The Charity is exempt from tax on its charitable activities.

## Fund accounting

**General Funds**

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

**Restricted Funds**

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors which have been raised by the Charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements. Any investment income, gains or losses are allocated to the appropriate fund.

Action for A-T has no designated funds as at 31st December 2024. All unrestricted funds remain available for general use at the discretion of the Trustees

**Designated funds**

Designated Funds are funds set aside by the Trustees out of general reserves for a particular purpose. The aim and use of each designated fund is set out in the notes to the financial statements. The Trustees will review the funds on an ongoing basis. At the conclusion of the purpose for the fund any excess remaining funds will be transferred back into general funds. If a shortfall arises the Trustees will consider whether any additional general funds should be transferred to designated funds. Any investment income, gains or losses are allocated to the appropriate fund.

## Foreign currencies

Assets and liabilities in foreign currencies are translated into sterling at the rate of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling at the date of the transaction. Exchange differences if applicable are taken into the Statement of Financial Activities.

## 2. Critical accounting judgements and key sources of estimation uncertainty

### Critical Accounting Estimates And Judgements

In the application of the Charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

**1. Grant Commitments**

The Charity awards grants to support research into Ataxia Telangiectasia. The recognition of grant commitments is based on formal agreements and the likelihood of meeting performance conditions. At 31 December 2024, grant commitments totalled £2,215,550 all of which have been recognised as a liabilities there are no awarded grants left unrecognised.

**2. Provisions for Liabilities and Charges**

The Charity reviews potential liabilities arising from ongoing contractual obligations. Where a liability is probable and can be reliably estimated, a provision is recognised. The Trustees have considered legal and contractual exposures and have determined that provisions of £12,960 are appropriate at the year-end (see note 24 on page 46).

**3. Depreciation of Fixed Assets**

The Charity depreciates tangible fixed assets over their estimated useful lives. The estimated useful life of assets is reviewed annually, with the current rates as follows:

- IT Equipment: 3 years
- Fixtures and Fittings: 5 years
- Leasehold Improvements: Over the remaining lease term

**4. Accrued Income and Donations**

The recognition of income from certain fundraising events and donations is based on an assessment of whether the income is probable and can be measured reliably. Estimates are applied where donations or pledges are confirmed but not yet received.

### Key Sources Of Estimation Uncertainty

The annual depreciation charge for tangible fixed assets in sensitive to changes in the estimated useful economic lives and residual value of fixed assets. The useful economic lives and residual values are reassessed on an annual basis. They are amended where deemed necessary to reflect current estimations based on physical condition, utilisation and advancement of technologies. Note 10 discloses the carrying value if the tangible fixed assets and the depreciation policy is listed above in accounting policies.

## 3. Donations and Legacies

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.24 Total Funds £** | 31.12.23 Total Funds £ |
|---|---|---|---|---|
| Donations | 78,147 | - | **78,147** | 91,706 |
| Gift aid | 31,837 | - | **31,837** | 35,530 |
| Fundraising | 356,516 | 126,500 | **483,016** | 387,749 |
| | 466,500 | 126,500 | **593,000** | 514,985 |

## 4. Investment Income

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.24 Total Funds £** | 31.12.23 Total Funds £ |
|---|---|---|---|---|
| Bank Interest | 94,647 | - | **94,647** | 27,828 |

## 5. Income from Charitable Activities

| | Activity | **31.12.24 £** | 31.12.23 £ |
|---|---|---|---|
| Fundraising events | Fundraising & Challenge events | **266,981** | 323,820 |
| Challenge events | Fundraising & Challenge events | **213,485** | 225,857 |
| | | **480,466** | 549,677 |

## 6. Raising Funds

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.24 Total Funds £** | 31.12.23 Total Funds £ |
|---|---|---|---|---|
| Staff costs | 69,937 | - | **69,937** | 65,471 |
| Trusts & Foundations | 870 | - | **870** | 3,534 |
| Support costs | 19,716 | - | **19,716** | 18,801 |
| | 90,523 | - | **90,523** | 87,806 |

## 7. Charitable Activities Costs

| | Direct Costs | Grant Funding of Activities (see note 8) | Support Costs (see note 9) | Totals |
|---|---|---|---|---|
| | £ | £ | £ | £ |
| Fundraising & Challenge events | 131,146 | - | 19,718 | **150,864** |
| Grants | - | 1,518,335 | 65,954 | **1,584,289** |
| Governance cost | - | - | 20,817 | **20,817** |
| | 131,146 | 1,518,335 | 106,489 | **1,755,970** |

## 8. Grants Payable

| | **31.12.24** | 31.12.23 |
|---|---|---|
| | **£** | £ |
| Grants | **1,518,335** | 74,683 |

**The total grants paid to institutions during the year was as follows:**

| | **31.12.24** | 31.12.23 |
|---|---|---|
| | **£** | £ |
| Universities of Birmingham, UK & Hamburg, Germany – Development of suppressor tRNA-based therapeutics | **249,615** | |
| University of Nottingham, UK – Biomarkers for babies and young children with A-T | **246,867** | |
| University of North Carolina, USA – Development of a gene therapy approach to treat A-T | **249,128** | |
| Leiden University Medical Centre, Netherlands – Functional impact of Nicotinamide Riboside on the immune system of patients with A-T | **250,000** | |
| University College London, UK – Exploring Omaveloxolone efficacy in A-T | **24,915** | |
| University of Birmingham, UK – Identifying existing drugs to repurpose for treating A-T | **249,332** | |
| University of Kent, UK – Investigating the role of mutant triple T chaperone in ATM assembly in A-T | **249,806** | |
| University of Cambridge, UK - Improving diagnosis and treatment of cancer in A-T patients through whole genome sequencing | **19,960** | |
| University of Nottingham, UK – Kicking Kinases into action: A novel drug screening assay for A-T | **19,238** | |
| University of Nottingham, UK – Exploring the use of assistive robots, smart sensing & digital twin models for monitoring and support of Ataxia in non-clinical environments | **19,997** | |
| University of Granada, Spain – (Research project underspends refunded) Innovative methods for gene therapy in Ataxia-Telangiectasia | **(6,044)** | |

**The total grants paid to institutions during the year (continued)**

| | **31.12.24** £ | 31.12.23 £ |
|---|---|---|
| University of Nottingham, UK – (Research project underspends refunded) The David Peake Study to test the feasibility of whole-body MRI for cancer surveillance in children and young people with A-T | **(13,208)** | |
| Sheba Medical Centre, Israel - Using new immunotherapy methods to treat lymphoma and leukaemia in A-T | **(10,408)** | |
| Duke University, USA - A new function for ATM and a new theory for the clinical abnormalities in A-T | **(4,440)** | |
| University of Rochester, USA - Recurrent pulmonary infections and their impact on neurological decline in A-T | **(8,334)** | |
| University of Plymouth, UK - The ATeam: Coproducing guidance and investigating a novel complex home-based intervention to optimise long-term healthy living with A-T | **(18,089)** | |
| University of Nottingham, UK - Virtual Reality in Ataxia-Telangiectasia | | 18,565 |
| University of Nottingham, UK - STIM A-T Pilot Study | | 20,270 |
| Institute for Bioengineering of Catalonia, Spain - Modelling Ataxia Telangiectasia pathogenesis and therapeutics using human pluripotent stem cells and genetic engineering | | 25,000 |
| Oslo University Hospital, Norway - Preclinical assessment of intrathecal rAAV9-mediated miATM therapy for Ataxia Telangiectasia in mouse models | | 25,000 |
| University of Birmingham, UK - (Research project underspends refunded) Assessment of the frequencies and types of cancers occurring in A-T patients | | (14,986) |
| University of Birmingham, UK - (Research project underspends refunded) Deciphering the molecular mechanism linking Ataxia-Telangiectasia and Ataxia-Telangiectasia-Like Disorder | | (29) |
| University of Nottingham, UK – Sandpit Event | | 863 |
| | **1,518,335** | 74,683 |

## 9. Support Costs

| | Management | Finance | Information Technology | Other | Wages | Governance Costs | **Totals** |
|---|---|---|---|---|---|---|---|
| | £ | £ | £ | £ | £ | £ | **£** |
| Raising donations and legacies | 8,555 | 636 | 1,332 | 9,193 | - | - | **19,716** |
| Fundraising & challenge events | 8,556 | 637 | 1,331 | 9,194 | - | - | **19,718** |
| Grants | - | - | - | - | 65,954 | - | **65,954** |
| Governance costs | - | - | - | - | - | 20,817 | **20,817** |
| | 17,111 | 1,273 | 2,663 | 18,387 | 65,954 | 20,817 | **126,205** |

| **Activity** | **Basis of allocation** |
|---|---|
| Management | 50 % Raising Donation & legacies 50 % Fundraising & Challenge Events |
| Finance | 50 % Raising Donation & legacies 50 % Fundraising & Challenge Events |
| Information technology | 50% Raising Donation & legacies 50 % Fundraising & Challenge Events |
| Human resources | 50 % Raising Donation & legacies 50 % Fundraising & Challenge Events |
| Other | 50 % Raising Donation & legacies 50 % Fundraising & Challenge Events |
| Governance costs | 100% Governance cost |

## 10. Auditors Remuneration

Fees payable to the charity's auditor for the audit of the financial statements: **£4,000 (2023: £4000).**
Fees payable for non-audit services: **£1,437 (2023: £1,412).**

## 11. Trustees' Remuneration and Benefits

There were no Trustees' remuneration or other benefits for the year ended 31 December 2024 nor for the year ended 31 December 2023.

**Trustees' expenses**
There were no Trustees' expenses paid for the year ended 31 December 2024 nor for the year ended 31 December 2023.

## 12. Staff Costs

Only one employee received emoluments in excess of **£60,000**.

The Charity considers its key management personnel to be the Trustees, Chief Executive and senior management. The total employment benefits of the key management personnel were **£165,951 (2023 - £156,996**). Only one employee had employment benefits falling between **£65,000** and **£80,000 (2023 - 1)**.

## 13. Comparatives for the Statement of Financial Activities

| | Unrestricted Funds £ | Restricted Funds £ | **Total Funds £** |
|---|---|---|---|
| **Income and endowments from** | | | |
| Donations and legacies | 501,985 | 13,000 | **514,985** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 549,677 | - | **549,677** |
| Investment income | 27,828 | - | **27,828** |
| Other income | - | - | **-** |
| **Total** | 1,079,490 | 13,000 | **1,092,490** |
| **Expenditure on** | | | |
| Raising funds | 87,806 | - | **87,806** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 157,097 | - | **157,097** |
| Grants | 78,962 | 60,465 | **139,427** |
| Governance costs | 20,239 | - | **20,239** |
| **Total** | 344,104 | 60,465 | **404,569** |
| **Net income/(expenditure)** | 735,386 | (47,465) | **687,921** |
| **Reconciliation of funds** | | | |
| Total funds brought forward | 141,318 | 85,486 | **226,804** |
| **Total funds carried forward** | 876,704 | 38,021 | **914,725** |

## 14. Employee Benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits would be recognisable immediately as an expense when the Charity is demonstrably committed to terminate an employee's employment or to provide termination benefits.

## 15. Pension Costs

The charity participates in a defined benefit pension scheme. The pension costs charged in the financial statements represent the contributions payable by the Charity during the year.

At the reporting date, there was no material pension liability or asset that would impact the financial position. The scheme is fully funded, and no additional contributions are required beyond regular employer contributions.

The charity has no pension commitments for past trustees, as all trustees remain in office.

## 16. Financial Instruments

The Charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and are subsequently measured at their amortised cost.

## 17. Creditors and Provisions

Creditors and provisions are recognised where the Charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

## 18. Tangible Fixed Assets

| | Computer Equipment £ |
|---|---|
| **Cost** | |
| At 1 January 2024 and 31 December 2024 | 2,358 |
| **Depreciation** | |
| At 1 January 2024 and 31 December 2024 | 2,142 |
| **Net Book Value** | |
| At 31 December 2024 | 216 |
| At 31 December 2023 | 216 |

## 19. Stocks

| | **31.12.24** | 31.12.23 |
|---|---|---|
| | **£** | £ |
| Stocks | **20,863** | 18,985 |

Stocks are stated at the lower of cost and estimated selling price less costs to complete and sell. Cost includes all costs of purchase, costs of conversion and other costs incurred in bringing stock to its present location and condition. Due allowance is made for obsolete and slow-moving items.

Donated stocks are fair valued when their economic benefit is probable, it can be measured reliably, and the Charity has control over the item.

## 20. Debtors: Amounts Falling Due Within One Year

| | **31.12.24** | 31.12.23 |
|---|---|---|
| | **£** | £ |
| Deposit | **925** | 925 |
| Prepayments and accrued income | **57,504** | 40,873 |
| | **58,429** | 41,798 |

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

## 21. Cash at Bank

| | Unrestricted Funds | Restricted Funds | **31.12.24 Total Funds** | 31.12.23 Total Funds |
|---|---|---|---|---|
| | £ | £ | **£** | £ |
| Bank Current Accounts | 38,193 | - | **38,193** | 46,480 |
| Bank Current Accounts (US $) | - | - | **-** | - |
| Reserve Account | 622,250 | 96,861 | **719,111** | 410,848 |
| Investment Accounts | 1,559,545 | - | **1,559,545** | 1,472,533 |
| Total | 2,219,988 | 96,861 | **2,316,849** | 1,929,861 |

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of twelve months or less, and bank overdrafts. Should any bank overdrafts arise they would be shown within borrowings in current liabilities.

## 22. Creditors: Amounts Falling Due Within One Year

| | **31.12.24** £ | 31.12.23 £ |
|---|---|---|
| Grant Payable | **810,729** | 415,417 |
| Accruals and deferred income | **4,985** | 6,950 |
| | **815,714** | 422,367 |

## 23. Creditors: Amounts Falling Due After More Than One Year

| | **31.12.24** £ | 31.12.23 £ |
|---|---|---|
| Other creditors | **1,344,298** | 653,768 |

## 24. Leasing Agreements

During the next twelve months the Charity has operating lease commitments totalling **£13,014 (2023 - £12,485)** for contracts expiring in more than one year. The total future commitments are **£12,960 (2023 - £12,960)**

## 25. Movement in Funds

| | At 1.1.24 £ | Net Movement in Funds £ | **At 31.12.24 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 876,704 | (737,220) | **139,484** |
| **Restricted Funds** | | | |
| Restricted Fund | 38,021 | 58,840 | **96,861** |
| **Total Funds** | 914,725 | (678,380) | **236,345** |

**Net movement in funds, included in the above are as follows:**

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 1,041,613 | (1,778,833) | **(737,220)** |
| **Restricted Funds** | | | |
| Restricted Fund | 126,500 | (67,660) | **58,840** |
| **Total Funds** | 1,168,113 | (1,846,493) | **(678,380)** |

**Comparatives for movement in funds:**

| | At 1.1.23 £ | Net Movement in Funds £ | **At 31.12.23 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 141,318 | 735,386 | **876,704** |
| **Restricted Funds** | | | |
| Restricted Fund | 85,486 | (47,465) | **38,021** |
| **Total Funds** | 226,804 | 687,921 | **914,725** |

**Comparative net movement in funds, included in the above are as follows:**

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 1,079,490 | (344,104) | **735,386** |
| **Restricted Funds** | | | |
| Restricted Fund | 13,000 | (60,465) | **(47,465)** |
| **Total Funds** | 1,092,490 | (404,569) | **687,921** |

**A current year 12 months and prior year 12 months combined position is as follows:**

| | At 1.1.23 £ | Net Movement in Funds £ | **At 31.12.24 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 141,318 | (1,834) | **139,484** |
| **Restricted Funds** | | | |
| Restricted Fund | 85,486 | 11,375 | **96,861** |
| **Total Funds** | 226,804 | 9,541 | **236,345** |

**A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:**

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Fund | 2,121,103 | (2,122,937) | **(1,834)** |
| **Restricted Funds** | | | |
| Restricted Fund | 139,500 | (128,125) | **11,375** |
| **Total Funds** | 2,260,603 | (2,251,062) | **9,541** |

## 26. Related Party Disclosures

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2023 - £nil). There are no expenses paid to the Trustees in the year. No Trustee is deemed to have benefited as a result of a related party connection. All Trustees have declared all such relationships to the Chairman.

## 27. Ultimate Controlling Party

The Trustees control Action for A-T in accordance with the trust deed.

# Detailed Statement Of Financial Activities

For the year ended 31 December 2024

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.24 Total Funds £** | 31.12.23 Total Funds £ |
|---|---|---|---|---|
| **Income and Endowments from** | | | | |
| **Donations and legacies** | | | | |
| Donations | 78,147 | - | **78,147** | 91,706 |
| Gift aid | 31,837 | - | **31,837** | 35,530 |
| Fundraising | 356,516 | 126,500 | **483,016** | 387,749 |
| | 466,500 | 126,500 | **593,000** | 514,985 |
| **Investment Income** | | | | |
| Bank Interest | 94,647 | - | **94,647** | 27,828 |
| **Charitable activities** | | | | |
| Fundraising events | 266,981 | - | **266,981** | 323,820 |
| Challenge events | 213,485 | - | **213,485** | 225,857 |
| | 480,466 | - | **480,466** | 549,677 |
| **Other Income** | | | | |
| Exchange rate difference | - | - | **-** | - |
| **Total Incoming Resources** | 1,041,613 | 126,500 | **1,168,113** | 1,092,490 |
| **Expenditure** | | | | |
| **Raising donations and legacies** | | | | |
| Wages | 69,937 | - | **69,937** | 65,471 |
| Trusts and Foundations | 870 | - | **870** | 3,534 |
| | 70,807 | - | **70,807** | 69,005 |
| **Charitable activities** | | | | |
| Event Campaign Costs | 131,146 | - | **131,146** | 138,063 |
| Grants to institutions | 1,450,675 | 67,660 | **1,518,335** | 74,683 |
| | 1,581,821 | 67,660 | **1,649,481** | 212,746 |
| **Support Costs** | | | | |
| **Management** | | | | |
| Wages | 17,111 | - | **17,111** | 16,264 |
| **Finance** | | | | |
| Bank charges | 1,273 | - | **1,273** | 1,310 |
| **Information technology** | | | | |
| Repairs and renewals | 2,663 | - | **2,663** | 2,647 |

## Detailed Statement Of Financial Activities (Cont)

For the year ended 31 December 2024

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.24 Total Funds £** | 31.12.23 Total Funds £ |
|---|---|---|---|---|
| **Other** | | | | |
| Rent, Rates and water | 13,672 | - | **13,672** | 13,014 |
| Insurance | 947 | - | **947** | 1,115 |
| Telephone | 544 | - | **544** | 693 |
| Postage and stationery | 372 | - | **372** | 480 |
| Sundries | 679 | - | **679** | 526 |
| Advertising | 1,022 | - | **1,022** | 887 |
| Donation collection fees | 1,151 | - | **1,151** | 899 |
| | 18,387 | - | 18,387 | 17,614 |
| **Wages** | | | | |
| Wages | 65,954 | - | 65,594 | 64,744 |
| **Governance Costs** | | | | |
| Wages | 15,380 | - | **15,380** | 14,827 |
| Auditors' remuneration | 4,000 | - | **4,000** | 4,000 |
| Accountancy and legal fees | 1,437 | - | **1,437** | 1,412 |
| Computer equipment | - | - | **-** | - |
| | 20,817 | - | 20,817 | 20,239 |
| **Total Resources Expended** | 1,778,833 | 67,660 | 1,846,493 | 404,569 |
| **Net (expenditure)/income** | (737,220) | 58,840 | (678,380) | 687,921 |

# Acknowledgements

**Action for A-T relies entirely on its donors and supporters who so generously give their time and money to support vitally needed research into A-T. With their support we believe we can make a difference to all people with A-T and their families.**

We would like to give special thanks to the following organisations that worked alongside us in 2024:

## Our Research Partners

BrAshA-T Ataxia Telangiectasia and their Trustees
Ataxia Telangiectasia Society
AEFAT
Great Ormond Street Hospital Charity
NATA

## Support from Companies, Trusts & Foundations

We are aware that Companies, Trusts & Foundations are often approached to support charities and are therefore extremely grateful to the following organisations and individuals for their generous support.

Ardwick Trust
Aviva Investors
Axis Capital
Banstead Downs Golf Club
Barton Comms
Bergqvist Charitable Trust
BCA
Big Give
Broyst Foundation
Cinch
Clarion Golf
Constellation Group
Enterprise Rent A Car
Global Entertainment
Henrik Bergrem
Horton Park Golf Club
Kent College
Medical Research Council
Mollie's Miracle Team
Monica Seccombe
NATA
Quest Professional
Rawson Digital
Robin Hewison
Royal Grammer School Guildford
Syder Foundation
Stewart Golf Ltd
Junior Trailblazers
The WASPS Legends Charitable Foundation
Woodcock Brothers

**Corporate or professional services provided by:**
A & N Chartered Accountants
Gecko Graphic Design

## Our Supporters

We have relied almost exclusively on our supporters, volunteers and Trustees for their time and commitment to raising money and spreading awareness about this devastating condition. Thank you to everyone who has helped us to push research into A-T forwards.

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE

Action for A-T, Aruna House, 2 Kings Road, Haslemere, Surrey GU27 2QA.

01428 853313 | info@actionforAT.org | www.actionforAT.org

**ACTION FOR A-T**

England & Wales - Charity number 1145303

# Accounts

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE




# Annual Report & Financial Statements

## for the year ended 31st December 2023

Action for A-T - Charity registered number 1145303

www.ActionforAT.org

# Legal And Reference Information

## Patrons

Jonny Wilkinson CBE
Roger Black MBE
Jeremy Guscott MBE
Simon Shaw MBE
Rachel Morris MBE
Naga Munchetty
Leon Haslam

## Chief Executive

Sean Kelly

## Trustees at the date of approval

Toby Read (Chairman)
Emily Read
William Rowberry (Treasurer)
Tomos Shillingford
Maria Leonard
Chris Askew
Dr Mark Toms
Joseph Frost

## Appointed during the year or since year end

None

## Research Advisory Committee

Dr Mark Toms, Chairman

Dr Kathryn Johnson, Scientific Advisor, Consultant Neonatologist and Research Lead

Professor David Attwell, Neuroscientist and Jodrell Professor of Physiology at the University College London

Associate Professor Esther Becker, Professor of Translational Neuroscience at the University of Oxford

Dr Simon Boulton, Principal Group Leader at The Francis Crick Institute

Dr Lisa Bunn, Associate Professor of Neurological Rehabilitation at the University of Plymouth

Professor Keith Caldecott, Professor of Genome Stability at the University of Sussex

Bruno Salomone Gonzalez de Castejon, Research Associate, Bristol Medical School (THS)

Dr Richard Kay, Medical Statistician

Dr Nizar Mahlaoui, Paediatrician specialising in Immuno-Haematology, Necker-Enfants Malades Hospital, Paris and Coordinator of the French National Reference Centre for Primary Immune Deficiencies (CEREDIH)

Dr Guy Makin, Senior Paediatric Oncology Lecturer, University of Manchester

Dr Andrew Prayle, Clinical Assistant Professor, University of Nottingham

Professor Grant Stewart, Professor of Cancer Genetics, School of Cancer Sciences, University of Birmingham
Professor Matthew Wood, Professor of Neuroscience at the University of Oxford, and Director of the Oxford Harrington Rare Disease Centre

## Patient Representatives

Mr Amandeep Sharma
Mrs Clare Gallagher
Mrs Natasha Schneider

## Charity Registration Number

United Kingdom Registered Charity number: 1145303

## Registered Office

Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

## Operational Address

Action for A-T
Carlton House
19 West Street
Epsom
Surrey
KT18 7RL

## Professional Advisers

Solicitors
Bingham McCutchen LLP
41 Lothbury
London
EC2R 7HF

## Bankers

HSBC Bank
110 High St
Godalming
Surrey
GU7 1DP

## Accountants & Auditors

A & N (Haslemere) Limited
t/a A & N Chartered Accountants and Registered Auditors,
Aruna House, 2 Kings Road, Haslemere. GU27 2QA

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# Trustees' Report

## *The Trustees of Action for A-T present their annual report and the financial statements of Action for A-T for the year ended 31 December 2023.*

The Trustees present their report with the financial statements of the charity for the year ended 31 December 2023. The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

## Reference and Administrative Details

Action for A-T is a charity registered in England and Wales (No. 1145303). The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. The Trustees met in February, April, October, and December in 2023. The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

## Public Benefit

Action for A-T's charitable objectives are set out in its governing Trust Deed, summarised in the "About Us" section on our website and include undertaking rigorously evaluated and properly conducted medical research into finding a cure or new treatment for the rare genetic condition Ataxia Telangiectasia (A-T).

During the year, the charity has continued to manage its ongoing research portfolio as well as committing funds to a variety of new A-T related research projects. Details of this work can be seen on pages 7 to 12.

Our Trustees have considered how our work may most effectively further our charitable objectives for the benefit of the public, in particular all those affected by Ataxia Telangiectasia, and have had regard to the Charity Commission's guidance on public benefit when reviewing activities against objectives set and in planning future activities.

## Objects, Achievements & Perfomance

**Action for A-T's mission is:**

**"To speed up the process of identifying a cure for A-T or treatments that delay or prevent the disabling effects of this childhood condition"**

To further that mission, the charity focused on the following key areas in 2023:

- Strengthening our Capacity and Capabilities
- Continuing our Investment in Medical Research in the UK and Abroad
- Ensuring that our research is high quality, peer reviewed and has clear and achievable aims
- Investing in people as well as projects
- Strengthening and Increasing our Fundraising Activities
- Working closely with others to meet our objectives
- Increasing awareness of our work and the condition
- Board Composition

## Strengthening our Capacity and Capabilities

### Our Aim

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us achieve our charitable mission. Since the Charity was initially established in 2012, a great deal of infrastructure work has already taken place, but continued development is required to ensure that we are more efficient, productive and well positioned for the future.

### Our Performance

2023 was our most successful fundraising year to date as we were able to deliver a full portfolio of events and activities without any of the previous Covid restrictions. Various new events were introduced alongside existing activities and our ability to be flexible, innovative and capitalise on new opportunities enabled us to deliver a strong fundraising result.

Increased volunteer support helped us deliver the new planned activities and existing fundraising initiatives efficiently and effectively and allowed us to scale up many of the activities to increase the amount of funds raised. Many of these successful activities were data led as the previous investment in a good CRM system enabled us to reach key target audiences and manage relationships more effectively.

We continued to explore and implement new technologies to improve our fundraising and communicate with our stakeholders. We also upgraded our IT infrastructure to incorporate the latest cyber security protocols and ensure that digital resources can be easily shared across the organisation.

We proactively managed our research relationships especially relationships with our grant holders to ensure that they had the required resources to complete their projects as expediently as possible. Where appropriate, no cost extensions were granted as some studies were experiencing recruitment issues due to various micro and macro-economic factors.

Our ability to adapt was only possible due to our size and structure and the hard work of a small but highly skilled team which we retained in full during the year. They have once again gone above and beyond to deliver a record-breaking fundraising year and the Trustees are very grateful for their incredible efforts.

## Continuing our Investment in Medical Research in the UK and Abroad

### Our Aim

Action for A-T aim to build a community of A-T research leaders and increase the amount of research that is taking place globally. Although we will always fund the highest quality applications wherever they are from; our key focus is to invest in projects and people based in the UK wherever possible.

### Our Performance

Throughout 2023, our Chief Executive staged online meetings with key figures from the A-T research community and representatives from other medical research charities and patient groups to explore possible funding opportunities and further understand which areas of A-T research may provide the most promising outcomes.

Non-A-T researchers who specialise in related conditions were also contacted to drive future research projects and create greater interest in the condition. This strategy is repeated from year to year to improve the quality of applications and increase the number and demographic of 'who' we advertise our grant rounds to.

We were able to support four new research studies throughout 2023 thanks to a new technology-based grant round calling for proof of concept style studies and a collaboration with the Spanish based A-T charity AEFAT. In addition to investing £88,835 in four new studies, we also opened a new grant round in September 2023 in collaboration with NATA (Nucleic Acid Therapy Accelerator) and BrAshA-T (Australian based A-T charity) with a view to awarding grants in April 2024.

# Funding High-Quality Research into A-T

*In addition to supporting and funding research aimed at improving the understanding of A-T, there are many innovative and exciting medical research opportunities that raise the prospect of real progress in combating the effects of genetic conditions such as A-T.*

## Our Aim

Action for A-T's aim is to be able to make grants to hospitals and universities throughout the world for the purpose of conducting research across all therapeutic areas related to A-T, with an emphasis on research that is likely to have a clear clinical application within the foreseeable future and/or which evaluate innovation in medical techniques which may have a potential benefit for children with A-T.

## Our Performance

Since Action for A-T was established in 2012, we have invested £4,073,550 in 50 global research projects under six main research headings categorised using the UK Clinical Research Collaboration Health Research Classification System.

**Underpinning Research** - Developing new tools and techniques for conducting research

**Aetiology** - Understanding the causes of A-T

**Detection, Screening and Diagnosis** - Tests for diagnosing and monitoring patients with A-T

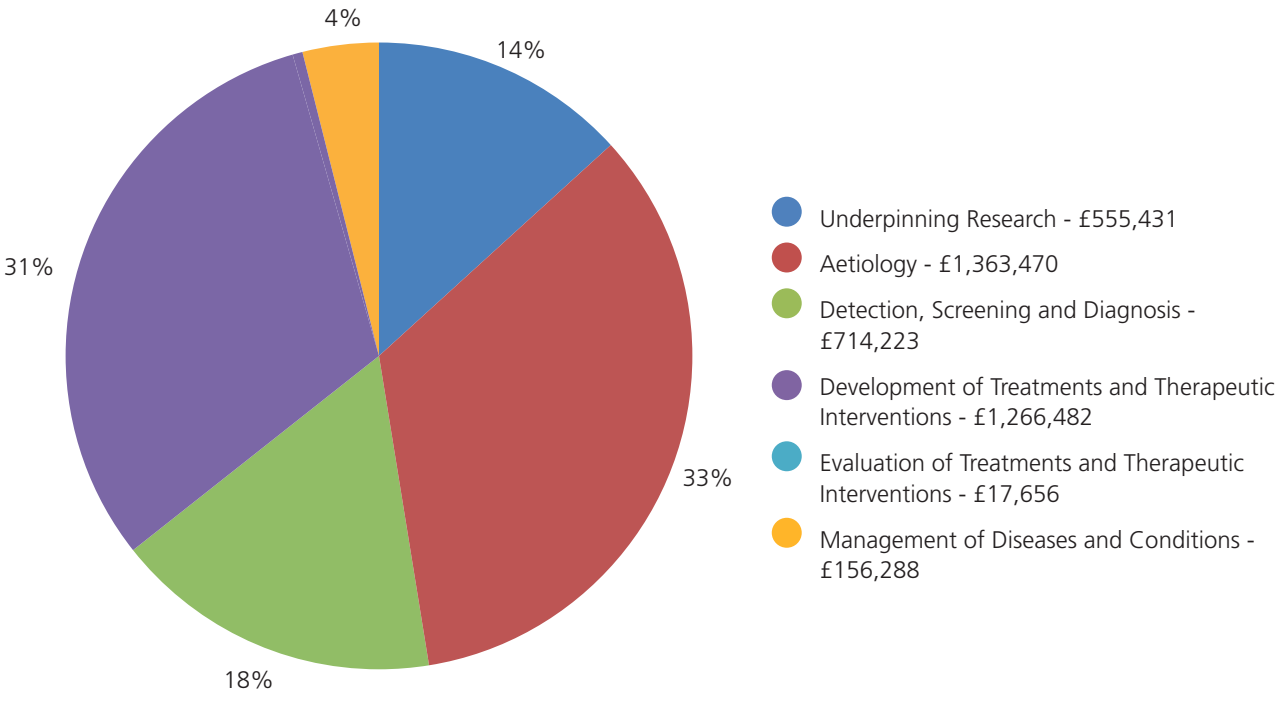
**Development of Treatments and Therapeutic Interventions** - Studies to identify new treatments for A-T

**Evaluation of Treatments and Therapeutic Interventions** - Studies to prove how new treatments work and understand how to use them

**Management of Diseases and Conditions** - Managing the symptoms of A-T

The chart below shows the historic allocation of our research investment portfolio and our total investment in each of these six research categories listed above.

## Total Research Spend Since 2012



The following grants were awarded by the Trustees in 2023:

## STIM A-T Pilot Study

**Principal Researcher:** Dr Caroline Blanchard
**Institute:** Medicine, Clinical Neuroscience, Nottingham University
**Cost:** £20,270 over 6 months
**Start Date:** 1st of September 2023

### Project Overview



Dr Caroline Blanchard

Dr Blanchard and her team will conduct a pilot study called STIM A-T to explore a new approach for reducing involuntary movements in people with ataxia-telangiectasia (A-T). These movements, such as muscle spasms and tremors, greatly affect their daily activities and quality of life and current treatment options are limited, so they are looking for non-invasive alternatives. Recent groundbreaking research has shown that stimulating a nerve in the wrist called the median nerve can reduce motor tics in Tourette syndrome. The team will see if this method can also help to reduce unwanted involuntary movements in individuals with A-T.

This study has the potential to make a significant difference in the lives of people with Ataxia-Telangiectasia (A-T). By exploring the feasibility and effectiveness of Median Nerve Stimulation (MNS) as a non-invasive treatment, this study aims to provide new hope and potential relief for these individuals. If successful, MNS could offer a non-pharmacological approach to suppressing unwanted movements in A-T. This would be a groundbreaking development, as there are no good treatment options currently. By demonstrating the feasibility and tolerability of MNS, along with preliminary evidence of its effectiveness, this research could pave the way for larger clinical trials.

Ultimately, the findings of this study could lead to improved management of involuntary movements in people with A-T, enhancing their ability to perform daily tasks, engage in social interactions, and improve overall quality of life.

## Virtual Reality in Ataxia-Telangiectasia

**Principal Researcher:** Professor Philip Breedon
**Institute:** Science and Technology Department, Nottingham University
**Cost:** £18,565 over 6 months
**Start Date:** 1st of July 2023

### Project Overview


Professor Philip Breedon

Professor Breedon and his team are embarking on a research project to explore how Virtual Reality (VR) technology can benefit children and young adults with Ataxia-Telangiectasia (A-T). By creating a virtual world through VR, they can provide A-T patients with interactive games, exercises, and rehabilitation activities. This immersive experience not only keeps people mentally engaged but also helps slow down the decline of their physical abilities. VR systems are versatile and adaptable, allowing them to be easily incorporated into the patients' daily lives. Parents can acquire the VR equipment for home use, or the systems can be set up in local clinics, making it convenient and accessible for patients in between visits to specialized centres. The team believe that Virtual Reality (VR) technology can bring about significant improvements in the lives of children with Ataxia-Telangiectasia (A-T). Currently, these children face challenges in accessing specialized care due to limited availability of A-T centres in the UK. This creates complexity and high costs for patients and their families. To address this, they aim to utilize VR as an accessible and engaging solution.

The VR system in this study could make a real difference in the lives of people with Ataxia-Telangiectasia (A-T) as the VR system has the potential to improve physical and mental well-being, provide convenient care, and enhance social interactions for people with A-T, making a positive impact on their daily lives.

## Modelling Ataxia Telangiectasia pathogenesis and therapeutics using human pluripotent stem cells and genetic engineering

**Principal Researcher:** Dr Núria Montserrat
**Institute:** Institute for Bioengineering of Catalonia, Spain
**Cost:** €150,000 over 24 months in partnership with AEFAT (Spain). Our contribution £25,000
**Start Date:** 1st of January 2024

### Project Overview


Dr Núria Montserrat

A-T is caused by mutations in the ATM gene. The most debilitating symptom of the condition is the progressive neurodegeneration of the cerebellum. Those with A-T also have a higher chance of developing cancer. The molecular mechanisms driving neuro degeneration and cancer susceptibility remain unclear, due to limitations of current disease models. The team aim to generate ATM-defective human pluripotent stem cell lines (hPSCs) via CRISPR/Cas9* as a disease model for A-T. A-T will be studied in this model. The team will carry out work to validate their model as a drug-screening platform by identifying several compounds that improve cell survival of ATM-defective hPSCs and differentiated products. They also hope to identify predictive biomarkers for A-T patients.

This project aims to explore the impact of ATM mutations by testing ATM protein expression in patient cells. This will be crucial for the generation of unique cellular models capturing A-T genetic backgrounds via genetic engineering in human pluripotent stem cells and organoids. If successful, this will be a unique in vitro platform and will enable the team to study A-T cellular phenotypes and potential therapeutics. This is very early-stage research, but the aim is to understand how to mitigate and alleviate the effects of A-T to move to ultimately developing a curative option.

**CRISPR/Cas9 is a gene-editing technology. It makes it possible to correct errors in the genome and turn on or off genes in cells and organisms quickly, cheaply and with relative ease. CRISPR/Cas9 has potential to be used to treat genetic disorders caused by single gene mutations, like A-T.*

## Preclinical Assessment of Intrathecal rAAV9-Mediated miATM Therapy for Ataxia Telangiectasia In Mouse Models

**Principal Researcher:** Professor Hilde L. Nilsen
**Institute:** Oslo University Hospital, Norway
**Cost:** €150,000 over 24 months in partnership with AEFAT (Spain). Our contribution £25,000
**Start Date:** 1st of January 2024

### Project Overview


Professor Hilde L. Nilsen

This preclinical study utilizes an injection of Recombinant Adeno Associated Virus 9 (rAAV9) to deliver a therapeutic mini version of ATM into mice. ATM is the gene missing or not functioning completely in A-T. The aim is to provide safety and efficacy data for the rAAV9 mini-ATM therapy to be able to procced to phase I/II clinical trials. Efficacy meaning how well the injection delivers the mini-ATM into the mice and if it produces the expected result. Measurements will be conducted to observe survival, motor function, weight gain, and histopathological changes. A range of further comprehensive examinations, observations and measurements will be implemented including those to monitor signs of toxicity, tumour development, and organ damage. Particular attention will be given to the cerebellum and liver damage as it is commonly affected in AAV therapies*. This approach aims to provide valuable insights into the safety and potential use of this therapy as a treatment for A-T.

It is hoped that this preclinical study may pave the way for transformative treatments for individuals suffering from A-T in the long-term*. The utilization of this gene therapy to deliver a therapeutic mini version of ATM could potentially rectify the underlying genetic defects associated with the disease and may alleviate symptoms. If successful, this could lead to a significant improvement in the quality of life for A-T patients.

**AAV therapies - Gene therapy is a technique for correcting genetic defect by inserting a healthy copy of a gene into cells (replacing a faulty gene). To deliver a gene into cells, scientists use delivery systems called vectors. Adeno-associated viral (AAV vector is a platform for delivering gene therapies. These vectors introduce therapeutic genes into patient cells to treat diseases.*

# Ensuring that our research is of the highest quality, is well managed and has clear and achievable aims

Research is at the heart of what we do, and our research strategy outlines our intentions on achieving our mission.

## Our Aim

Through our award-winning research process, we aim to only fund projects of the highest-quality that have the greatest chance of advancing our understanding of A-T, improving treatment and management, and accelerating benefits to patients.

## Our Performance

Action for A-T were awarded their second prestigious AMRC award for best practise in medical and health research peer review in May 2021. The award confirms the robust methods used to make decisions about which research projects to fund and our support of the best researchers and the highest quality research, with the best chance of improving the lives of those affected by A-T. The award was made following a full audit of our processes which takes place every five years.

The Trustees generally stage one grant round per year where funds will allow. Applications are peer reviewed by independent external reviewers before they are passed on to our Research Advisory Committee for further review. Projects which pass the peer review process and are deemed high enough quality are passed on to the Trustees to make the final decision based on several key criteria including available funds, strategic alignment, and existing research commitments.

Our Research Advisory Committee (RAC) are part of this process and consist of independent scientific experts from fields related to A-T, including clinicians, non-clinicians, and statistical expertise from a wide range of UK institutions. Lay members are also on the committee to incorporate the views of parents and patients living with A-T, bringing a valuable and unique perspective over what research should be funded. Members of our RAC reviewed all the applications received in 2023 and their funding recommendations were passed on to the Trustees for consideration. All four of their recommended projects were approved by the trustees and the grants were awarded at various dates throughout the year.

## Project outcomes and sharing knowledge

We believe that sharing project outcomes and knowledge is a fundamental requirement for the development of new research strategies which will ultimately benefit those living with the condition. Progress, annual and final reports are mandatory for all our research grants to ensure that they are reaching the agreed milestones. These reports are formally reviewed by our scientific advisor to ensure that each project is in line with its stated aims and the outcomes are then converted into lay summaries to share with our supporters.

Researchers are also encouraged to publish their findings in medical journals and where possible, make the findings freely available. The outputs of research such as publications usually occur sometime after a research project ends and it can take many years to translate research ideas into new treatments or therapies to improve quality of life.

The outcomes of all the concluded research we have funded are displayed on our website under the 'Completed Research' section. Where applicable, these posts also include links to any online publications, and we also share project information via our social media channels and in various communications to our supporters and potential donors.

## Evaluating the outcomes of our research

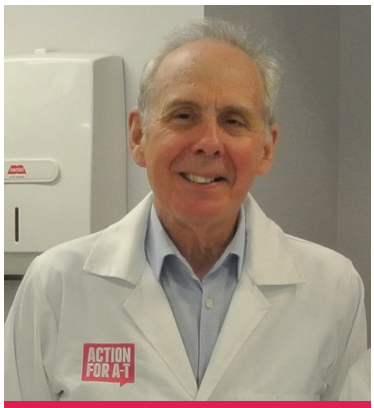
As with all charities, we are passionate about demonstrating the impact of our work and understand the importance of monitoring the progress and outcomes of our research. Throughout the year we continued to work with our scientific advisor and other members of our Research Advisory Committee to oversee and evaluate the effectiveness of our ongoing research portfolio. Between them, they monitored the progress of ongoing projects and signed off on any which were completed to help ensure that the original research aims stated in the application were fulfilled.

**The following studies concluded in 2023 and the initial project outcomes were as follows:**

# Assessment of the frequencies and types of cancers occurring in A-T patients

**Principal researchers:** Professor Malcom Taylor
**Institute:** University of Birmingham
***Project Completion Date:** 31st March 2023

## Project Overview



Professor Malcom Taylor

The primary aim of the project was to identify the cancers present in Ataxia Telangiectasia patients alive today in ~200 families in the UK as well as those who had passed away in the past 10 years. The team looked at past and present families affected and families were given the opportunity to opt out of their data being shared. The records of 48 A-T individuals in the UK were studied and of these 48 there was a total of 52 tumours.

## Project Outcome

33 of the tumours occurred in 31 patients with classic A-T. 18 of these were lymphoid tumours and 15 non-lymphoid. Of the 15 non-lymphoid tumours, 14 were carcinomas. This data revealed that the median age for diagnosis of the tumour in classic A-T patients was 14–15-years old. 19 of the tumours were identified in 17 patients with a mild variant of A-T. 4 of these were lymphoid and 15 non-lymphoid. This data revealed that the median age for diagnosis of the tumour in mild variant A-T patients was 38 years old.

With respect to the types of tumour identified, 17 out of the 20 children (under the age of 16 years old) had lymphoid tumours. Plus the following:

- 28 Carcinomas, 14 in classic A-T and 14 in mild variant A-T. 3 of these were pancreatic tumours in mild variant A-T.
- 6 Esophageal tumours (5 in classic A-T). This appears to be a new observation.
- There were at least 5 breast cancers and 2 myeloid tumours.

The data confirms the increased risk of cancer in both classic and mild variant A-T but the team identified a difference in the spectrum of tumours between them. The spectrum of tumour types in UK patients reflects the ATM mutation types seen in UK A-T patients.

This work will help to support future decision making in clinical practice and assist other research groups looking to make early cancer diagnoses.

## Publications

A manuscript is currently being prepared.

# Deciphering the molecular mechanism linking Ataxia-Telangiectasia and Ataxia- Telangiectasia-Like Disorder

**Principal Researcher:** Professor Grant Stewart
**Institute:** University of Birmingham
***Project Completion Date:** 5th of October 2023

## Project Overview


Professor Grant Stewart

Individuals with Ataxia-Telangiectasia (A-T) and the related disorder Ataxia-Telangiectasia-Like Disorder (ATLD), which are caused by mutations in the ATM gene and MRE11 gene respectively, suffer from progressive degeneration of the cerebellum (the region of the brain that is responsible for coordinating voluntary muscle movements and regulating balance). The aim of this project was to gain a further understanding of the DNA repair deficiencies that are responsible for this neurodegeneration and to pinpoint what type(s) of DNA damage are involved.

## Project Outcome

A unique ATLD patient with a mutation in the Mre11 protein was studied in this project to understand the cellular processes in cell death in the cerebellum in more detail. The team acknowledged at the outset this is basic research and therefore would not have a medium- or short-term impact on individuals and families affected by A-T / ATLD.

The project had the following objectives:

- Identify and characterise the cellular defect/s present in ATLD cells with the MRE11 mutation.
- Investigate the cellular defects in 15 ATLD cell lines
- Investigate the impact of the pM26T mutation on MRE11 function.
- Define the nature of the TOP2 DSB repair defect in cells carrying the mutation.

The first objective demonstrated that the inability in the ATLD patient to repair DNA damage in the presence of the MRE11 mutation was not due to defects in ATM activation. Secondly, in the 15 ATLD cell lines available the team have demonstrated that inability to activate ATM is not a common cellular phenotype in ATLD.

The pM26T mutation was not shown to have any deleterious effect on its ability to activate ATM. However, this may have been due to the techniques used and work is ongoing to modify this.

The team found no evidence that the ATLD cells expressing the mutation demonstrated any defects in the repair of DNA breaks. Work is ongoing on this third objective.

Although the initial hypothesis was disproved, this research has delivered some useful information which could be built into future projects. Some work is still ongoing and therefore there are no current plans to publish.

## Publications

No publications are planned at this date

# The David Peake Study to test the feasibility of whole-body MRI for cancer surveillance in children and young people with Ataxia Telangiectasia

**Principal Researcher:** Professor Rob Dineen
**Institute:** University of Nottingham
**Project Completion Date:** 30th of September 2023

## Project Overview

Dr Rob Dineen and his team believed that the combination of an MRI scan of the whole body together with a blood test would be a good way to find hidden cancers in children and young people with the inherited disease Ataxia Telangiectasia (A-T).

## Project Outcome


Professor Rob Dineen

18 children with A-T were recruited to take part in the study and 16 successfully completed the MRI scans. Two very young children were not willing to go in the MRI scanner despite play preparation and audiovisual distraction. During the scans, no malignancies were found which is obviously very good for the participants and their families, but it does mean that the team do not have any preliminary evidence of efficacy of this approach.

Non-cancer findings were identified in 4 children. Granulomas were identified in two (one localized, one disseminated requiring further investigations and biopsy). Two children had localized sub-cutaneous edema, which on further questioning turned out to be due to recent injections. One of these children also had altered bone marrow signal at a single bone site, for which further investigations at the local hospital were recommended.

The team also interviewed adults with A-T and parents of children with A-T to find out their views on cancer screening, and for those whose children had the scan, how they found the experience. They learned that the possibility of cancer caused anxiety and a screening programme would be welcomed because it would mean the families weren't the only ones watching out for the development of a cancer. As well as working with families, the team also worked with A-T experts to get their views on cancer screening, and there was strong support for doing more research so that guidelines can be put in place.

Although this study will not immediately change clinical practice, the team have shown that their approach is feasible and supported by patients, families, and clinical A-T experts around the world. They are now planning a follow-on trial which will seek preliminary evidence of efficacy of the approach and in turn hopefully trigger a large, definitive international trial. They are currently applying to the NIHR for funding for the next stage as considerable investment will be required.

In addition, the work has raised further awareness of the current evidence and knowledge gaps regarding cancer screening in A-T and has stimulated several exiting new collaborations in this area.

## Publications


Neves R, De Dios Perez B, Panek R, Jagani S, Wilne S, Bhatt JM, Caputi C, Cirillo E, Coman DJ, Dückers G, Gilbert DL, Kay Koenig M, Mansour L, McDermott E, Pauni M, Pignata C, Perlman SL, Porras O, Betina Porto M, Schon K, Soler-Palacin P, Nick Russo S, Takagi M, Tischkowitz M, Wainwright C, Dandapani M, Glazebrook C, Suri M, Whitehouse WP, Dineen RA. Development of cancer surveillance guidelines in Ataxia Telangiectasia: A Delphi-based consensus survey of international experts. Cancer medicine. 2023 Jul;12(13):14663-14673. doi: 10.1002/cam4.6075

Neves R, Perez BD, Tindall T, Fernandez NS, Panek R, Wilne S, Suri M, Whitehouse W, Jagani S, Dandapani M, Dineen RA, Glazebrook C. Whole-Body MRI for cancer surveillance in Ataxia Telangiectasia: A qualitative study of the perspectives of people affected by A-T and their families. Health Expect. 2023 Jun;26(3):1358-1367. doi: 10.1111/hex.13756

Dineen R. Whole-body MRI for cancer surveillance in children and young people with Ataxia Telangiectasia: Protocol for mixed methods cross-sectional interventional feasibility study. Nottingham Research Data Management Repository. http://doi.org/10.17639/nott.7288


The team also have three other manuscripts in draft as follows:


Neves R, Panek R, Clarkson K, Panagioti O, Wilne S, Suri M, Whitehouse WP, Jagani S, Dandapani M, Glazebrook C, Dineen RA. Feasibility of whole-body MRI for cancer surveillance screening in children and young people with Ataxia Telangiectasia: a mixed methods cross-sectional study.

Stephens M, Bourigault E, Neves R. Panek R, Suri M, Fairbank J, Ather S, Jamaludin A, Dineen RA. Feasibility of AI-based quantification of scoliosis using MRI in ataxia telangiectasia: a novel ionising radiation free approach in a disease with increased radiosensitivity.

Kumasaka S, Panek R, Neves R, Jagani S, Suri M, Dineen RA. MRI-based quantification of liver fat deposition in ataxia telangiectasia.


To view all our current and complete research projects, please visit https://actionforat.org/category/research-projects-funded/

# Investing in People as well as projects

## Our Aim

As the A-T research community is relatively small in comparison to other disease areas, a pipeline of new talent is required to continue the quest for treatments or a cure for A-T and to build on the existing research findings. Action for A-T are passionate about supporting individuals on their trajectory to becoming future leaders in health and research and have taken various steps to support individuals at various points of their development.

## Our Performance



In 2023, we provided several funding opportunities to encourage new and existing researchers to take an interest in A-T. This funding was in addition to our project grant round and included a "sandpit" event at the University of Nottingham which brought together experienced researchers for a one-day event to promote multidisciplinary translational research. Attendees learned more about the complexities of the condition and were encouraged to think creatively and broadly around the field of A-T, with the intention of applying for one of two £20,000 pump priming grants. The event was highly successful, and two grants were awarded to the new researchers for their technology-based projects (details on pages 6 & 7). Due to its success, another Sandpit event will be held in January 2024.

We also staged our first Fellowship grant round in collaboration with the MRC Nucleic Acid Therapy Accelerator (NATA) to drive high quality research in the application and translation of nucleic acid therapies in A-T. We received very few applications for the fellowship post and no candidates were appointed. We did however secure a sizable grant from NATA to support the work being carried out by Dr Rita Horvath and Dr Anke Hensiek at the University of Cambridge. Full details of this study can be seen on our website https://actionforat.org/treat-at/

In addition to the above, we also appointed an early-stage post doc researcher to our Research Advisory Committee (RAC) to provide a different perspective to our review meetings. The opportunity will help them expand their knowledge of A-T and build collaborative networks whilst enhancing their skills and supporting career development through training, mentoring, networking, and research involvement opportunities. We plan to recruit other younger members of the RAC moving forwards.

# Strengthening and Increasing our Fundraising Activities

## Our Aim

Action for A-T funds high quality peer reviewed medical research to speed up the process of identifying a cure for Ataxia Telangiectasia (A-T). We endeavor to raise funds from a variety of activities which appeal to new and existing supporters. Since 2012 we have invested £4,073,550 in 50 A-T related research projects around the world, and this has only been possible thanks to our generous supporters.

## Our Performance



2023 was our most successful fundraising year to date as we were able to deliver a full portfolio of events and activities without any of the previous Covid restrictions. Nearly all our activities performed better than expected as our event guests were incredibly generous, and we were able to benefit from several new fundraising events including a fundraising dinner for an international school in Spain, high-profile construction industry ball and a series of new endurance events. We also received another MRC grant to help retain early years researchers, plus a sizeable legacy donation and secured a collaborative funding partnership with NATA.

Our investment in TCS London Marathon places proved successful once again allowing us to make a 450% return. 19 people joined our marathon team and between them they raised £68,071. We have 15 places available for the 2024 London Marathon and hope to achieve a similar strong fundraising outcome.

In line with our fundraising strategy, we delivered a strong portfolio of sporting and social events to meet the heightened demand from our supporters as well as developing new relationships with other funders. We also diversified our other fundraising activities to ensure that we were not solely dependent on any one source of funding. Challenge and Social events were the most successful fundraising activities accounting for 64% of our income (2022 - 59%). Whilst other fundraising initiatives, such as donations, funding partnerships and trust and foundation applications increased to 26% (2022 - 28%). The remaining 10% (£109,700) was generated from the Medical Research Council grant to help retain early years researchers. A few notable fundraising activities took place throughout the year including various golf events and the Trailblazers 10 Peak Challenge. We are especially grateful to the staff and clients of BCA and Cinch yet again for taking part in the three-day cycle from Kent to Brussels which raised £101,100 plus the non-riders who raised an additional £33,900 on the marathon walk and £5,500 from the Endure 24 event. We are also indebted to the students of Quest Professional who raised over £29,700 at their fundraising dinner. In addition, we would like to thank Simon Toon and his friends for their ongoing and valued support and the late Javier Garzon and his family for their generous legacy totaling £12,192.

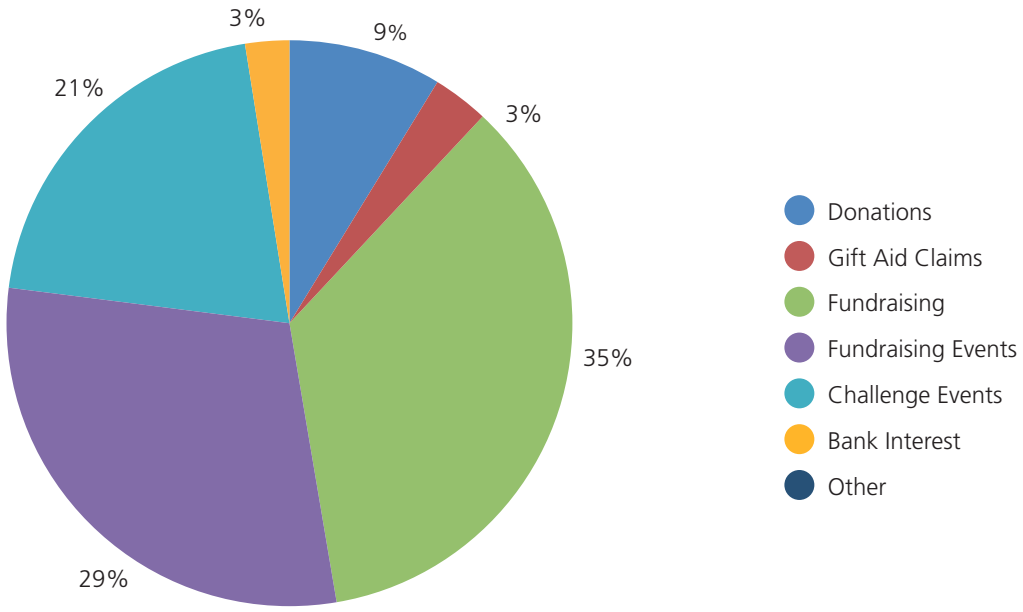
## Raising Funds Responsibly

Action for A-T are registered with the Fundraising Regulator and are committed to upholding the code of fundraising practice. We receive all our funding from voluntary sources, including individuals, companies, trusts and foundations and we do not work with any professional fundraisers or commercial participators to raise funds on our behalf. Each year, we purchase places in several physical challenges as well as staging and benefiting from a series of other social and sporting events. No complaints relating to our fundraising activities were logged with the Fundraising Regulator throughout the year.

We want everyone we interact with to feel free from undue influence when they consider donating. Our in-house fundraising team are trained to recognise these signs, so they can manage conversations in a way that could be considered intrusive or putting repeated or undue pressure on someone to donate. We routinely monitor our fundraising materials to ensure our standards remain high and treat our supporters fairly. Supporter feedback is reviewed regularly to ensure our fundraising offer is appropriate and complies with relevant rules and regulations.

To help protect people in vulnerable circumstances, we continued to follow guidance from the Government and the Fundraising Regulator throughout 2023 and only carried out public fundraising when we considered it safe to do so. We also continued to speak to more supporters to make sure our high standards were maintained as we returned to normal activities following the pandemic.

The pie chart below shows the percentage splits of each of our areas of fundraising in 2023.




*We would also like to record our thanks to all our volunteer committee members for their time and commitment in helping us achieve our mission, as well as everyone who donated their time, auction prizes and/or supported or participated in our events.*

In addition to the above, we are also extremely grateful to the trusts and foundations who provided restricted funding for various research projects (these are listed on page 47). We are always keen to work with other trusts, foundations and corporate funders who might be interested in supporting our work.

## Events Since The End Of The Year

Information relating to events since the end of the year is provided in the notes to the financial statements.

# Working Closely with Others to Meet our Objectives

## Our Aim

Action for A-T strongly believes that there are many opportunities to further the search for a treatment or a cure for A-T through working with others that may have overlapping aims or objectives to our own. To this aim, we actively seek out like minded organisations and where possible, create collaborative partnerships.

## Our Performance

**Co-funding A-T Research Projects with other charities and patient organisations**

Action for A-T continued to work closely with various organisations, charities, and patient organisations throughout 2023 to fund new and existing research studies. Throughout the year, we continued to manage a variety of our ongoing studies (funded in partnership with others) as well as contributing to new research. Our co-funding partners in 2023 were as follows:

**The UK based Children's Medical Research Charity Sparks**

Action for A-T continued to work closely with UK Children's Medical Research Charity Sparks which joined forces with Great Ormond Street Hospital Charity as a subsidiary in February 2017. Sparks are currently managing the following jointly funded research project which is due to end in early 2024:

- "Optimising lung imaging in people with A-T" - Dr Peter Merkus at the Radboud University Medical Centre, Netherlands

**The Australian charity BrAshA-T Ataxia Telangiectasia**

Action for A-T have an ongoing collaborative funding partnership with BrAshA-T who are based in Queensland, Australia. A joint grant call was launched at the start of 2022 to increase the investment in new A-T research and 13 funding applications were received and peer reviewed by Action for A-T. Upon completion of the grant round in May 2022, the two charities combined their resources to fund five new research studies. BrAshA-T contributed £150,000 towards the £765,815 total cost of all five projects. The final payment of £75,000 was made towards the end of 2023 and the total funds committed by BrAshA-T was split equally amongst each of the five projects.

BrAshA-T have also partnered with Action for A-T for our latest grant round which opened in September 2023. At the time of writing these accounts, 24 new funding applications have been received and grants will be awarded to successful applicants in April 2024. BrAshA-T will contribute a similar amount (TBC) towards the cost of any new studies in 2024 and 2025.

**The UK based A-T Society**

A strategic partnership was established between the A-T Society and Action for A-T in 2022 to increase the overall investment in new A-T research. Upon completion of the grant round in May 2022, the two charities combined their resources to fund five new research studies. The A-T Society agreed to contribute £60,000 towards all five of the studies and £30,000 was paid to Action for A-T in 2023. The remaining £30,000 will paid in Q2 2024 and the payments will be split equally amongst each of the five projects managed by Action for A-T.

**The Spanish based AEFAT**

A strategic partnership was established between the AEFAT and Action for A-T in 2022 to increase the overall investment in new A-T research. Upon completion of the grant round in May 2022, the two charities combined their resources to fund five new research studies. AEFAT agreed to contribute €50,000 towards all five of the new research studies and a funding agreement was put in place. The first payment of €25,000 was made in September 2022 and the remaining payment was made in September 2023. The total funds committed by AEFAT was be split equally amongst each of the five projects which are managed in full by Action for A-T.

In addition, Action for A-T have partnered with AEFAT for their recent grant round and made available £50,000 to fund two new research projects in Spain and Norway (full details of these studies are on page 8). £25,000 was paid at the end of 2023 and the remaining £25,000 will be paid in 2024.

**The MRC Nucleic Acid Therapy Accelerator (NATA)**

A joint funding partnership was established with NATA in October 2022 to fund a joint Fellowship. The purpose of the 2-year Fellowship was to drive high quality research in the application and translation of nucleic acid therapies in A-T. No fellowships were awarded but NATA kindly agreed to contribute £125,000 towards the Trial REadiness in Ataxia Telangiectasia (TREAT-AT) being run by Dr Rita Horvath and Dr Anke Hensiek at the University of Cambridge. Full details of this study can be seen on our website https://actionforat.org/treat-at/. NATA made the full £125,000 payment to Action for A-T in February 2023.

An additional funding partnership was established in 2023 which called for new nucleic acid therapies (NATs) related research applications. Both NATA and Action for A-T will contribute £125,000 towards the full £250,000 cost of any new projects which are deemed fundable by the RAC. Action for A-T will manage the application process and funds will be made available for projects focusing on the management or treatment of A-T. The peer review process will be managed through the Action for A-T system. Representatives from NATA will join the Action For A-T Scientific Advisory Panel to review the applications and assist with the peer review of the relevant projects. The final grant award/s will be made in Q2 2024.

Action for A-T will continue to explore additional joint funding opportunities with likeminded organisations throughout the year to maintain momentum and maximise the investment into A-T research.

**Working strategically with the worldwide A-T community**

Recognising the need for the global A-T community to work more closely together, Action for A-T played a key role in establishing the Global A-T Alliance at the start of 2021. The Alliance is made up of charities and patient groups from the UK, USA, Spain, Israel, Japan, France, Italy and Australia with the key objective of maximising the effort, resources and/or funding committed to finding a cure or treatments for Ataxia-Telangiectasia (A-T). The group meet virtually throughout the year to update each other on key research needs and findings as well as exploring ways in which they can work more closely together. To date, the Alliance members have joint funded new research, met with a number of pharma companies to explore new treatment opportunities, delivered research focussed webinars for A-T families and established a new website www.cureAT.org which brings together useful information about A-T. The Alliance members passionately believe that with increased funding and a continued global and collaborative effort, effective treatments for A-T will be developed sooner and the lives of those affected will be changed for the better.

# Increasing Awareness of our Work and the Condition

## Our Aim

As an ultra-rare disease, most people are unaware of A-T or the devastating effects of the condition. Action for A-T believes that raising awareness of the studies they fund and the impact of A-T on children and their families is an important part of increasing the potential funds available to further improve the understanding of the condition, and to progress research into possible treatments or a cure.

## Our Performance

Action for A-T has significantly increased the public awareness of the condition over the past 12 months and will continue to explore all options to promote wider understanding of A-T and why research to find a cure or treatment is so important.

The Charity's main achievements in this area to date include:

## Celebrity Support




Our celebrity patrons have continued to help promote Action for A-T and the need for more research into the condition by championing campaigns and taking part in various activities throughout the year. As well as providing prizes for our auctions, Jonny Wilkinson created several short films which were shown at some of our events. Naga Munchetty hosted our "Spotlight on A-T Research" webinar alongside Dr Mark Toms as well as her annual golf day. Several other celebrities including Chris Sheasby, Leon Haslam, Kevin Whately, Will Greenwood, and Jeremy Guscott helped generate funds, awareness, and support by taking part in events and campaigns or starring in promotional social media videos.

## Visibility at Research Institutions, Conferences and Medical Meetings

All Action for A-T funded researchers are provided with promotional materials to display at their research facility and required to acknowledge our financial support by including our logo on any posters or presentations. Throughout 2023, a number of conferences and scientific meetings took place where our researchers were able to present their findings. These presentations showcased our latest projects and provided the wider A-T community with a comprehensive view of the progress made to date.

## "Spotlight on A-T Research" Webinar

Action for A-T staged the third "Spotlight on A-T" virtual event in conjunction with the A-T Alliance to showcase some of the current A-T research projects which are taking place around the world. Key stakeholders from the global A-T community provided an easy to understand, concise overview of their current projects as well as answering audience questions. The webinar took place on the 27th of March 2023 and was hosted by Broadcaster, Journalist and Action for A-T Patron, Naga Munchetty and chair of the Research Advisory Committee, Dr Mark Toms.

There were six presentations broadcast live in English from various research teams and over 190 families, clinicians and other stakeholders tuned in to the event. The webinar was very popular and will be repeated at some point in the future in conjunction with the A-T Alliance members.

## Digital Communications

The Charity website www.ActionforAT.org remains the focal point for event sign-ups, electronic donations, and research news. The site was updated and enhanced throughout the year to provide the best possible experience for our stakeholders.

We also continued to manage (alongside Mike Clahsen of BrAshA-T) the www.cureAT.org site which brings together key information about current & past research studies and resulting publications. The site also has sections on care and guidance, patient registries, general information about the condition and a directory of all the known patient organisations around the world. The content is available in several languages including Spanish, French, Italian and Turkish with a simplistic layout directing users to sources of useful information (e.g., websites, documents, relevant groups/meetings, etc.) rather than duplicating existing content on other websites.

Our monthly e-newsletter continues to be a successful tool to communicate our latest news to supporters. Using Mailchimp for this proves to be cheaper than a traditional printed newsletter and has the functionality to track usage and monitor engagement. Our e-newsletter is sent to all our consenting supporters, has a clear unsubscribe function and inactive supporters are removed from the mailing list periodically.

Social media remains a key communication tool for the Charity as it is free, easily accessible and can reach wide audiences. It also allows us to engage with our supporters on a more strategic level and build additional support from their own contacts. Posts are carefully managed to ensure that the content is engaging and not repetitive and this more targeted and planned approach helped us increase our followers throughout the year. We will continue to develop our social media presence in 2024 using all available technological advancements, popular platforms, and our celebrity patrons to raise further awareness.

## National and Local News Media Coverage

We continued to raise awareness of A-T through a series of articles and editorials in the local, national and industry press and various news websites. In addition, our chief executive and various supporters took part in local TV and radio interviews throughout the year. These helped us highlight the condition to new audiences, recruit volunteers and secure additional support and donations.

# Our Future Plans: Areas Of Focus For 2024

The Trustees believe that Action for A-T is well placed to meet its charitable objectives but have also identified the need for further development to strengthen its research activities. During 2024 we will continue to consolidate and diversify our fundraising activities whilst actively developing existing and seeking new funding partnerships to meet the demands of the A-T research community. We will also continue to promote A-T research to engage new audiences and maintain interest from the research community.

We will implement several measures throughout the year to ensure that the Charity continues to be fit for future purpose and to help us achieve our aim of moving closer to tangible therapies or a cure for A-T.

## Strengthening our Capacity and Capabilities

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us deliver our charitable objectives. Our size and structure enables us to adapt quickly and we will continue to review and prioritise projects based on available resources whilst seeking out new opportunities to raise funds in a safe and sustainable manner.

## Continuing our Investment in Medical Research in the UK and Abroad

We will continue to seek out new research opportunities from the wider research community as well as focussing on key research themes related to A-T. Where possible, priority will be given to UK based projects whilst still calling for international applications where funds will allow. Due to a record-breaking fundraising year in 2023, we hope to make our largest research investment to date in 2024.

We will maintain our close relationship with the Association of Medical Research Charities (AMRC) and work in conjunction with our research advisory committee (RAC) to develop and improve our peer review process and ensure that the research we fund is of the highest quality. This will include constant evaluation of our systems and processes as well as enlisting the help and support of various A-T experts around the globe.

Membership of the RAC will be continually reviewed to ensure that we have a broad range of scientific expertise in areas relating to A-T as well as early years researchers who are likely to become future research leaders. We will also secure new lay representation from various A-T families as Action for A-T strongly supports public and patient engagement in its research processes.

## Strengthening and Increasing our Fundraising Activities

We will continue to develop a pipeline of new business opportunities whilst delivering our existing portfolio of activities. We will maintain and refresh our calendar of high profile and fun events whilst also working alongside others in a benefitting capacity to reduce the financial risk to the Charity. We will continue to develop and expand our trust and foundations programme whilst actively seeking new investment from individuals, corporates, and major donors. We will also work closely with our key supporters and volunteer groups to ensure we maintain the momentum of investment in ground-breaking A-T research.

## Working Closely with Others to Meet our Objectives

We will also continue to work closely with key stakeholders (especially the A-T Alliance members) as well as exploring new collaborations that will bring greater benefit to the wider A-T community. The number of promising research opportunities continues to grow steadily year on year and there are now more research themes worthy of exploration than our limited funds will allow. We will therefore continue to work with and seek out new organisations with similar objectives to our own, to help ease the financial burden and speed up the process of finding a therapy or cure for A-T.

## Increasing Awareness of our Work and the Condition

Since we were established in 2012, a key priority has been raising awareness of A-T and the work of the Charity. This has been achieved by various means including celebrity endorsement, emotive films featuring researchers and A-T families and various branding opportunities. We will continue to do all that we can to highlight A-T whilst focusing on various key projects in 2024. These projects will include maximising celebrity endorsement opportunities, the creation of a new promotional film and other projects which help to educate and inform people about A-T.

## Board Composition

We will continue to evaluate the composition of our Trustee Board to facilitate the growth of the Charity and will consider further appointments to broaden and strengthen the Board's capabilities.

# Structure, Governance & Management

## Governing Document

Action for A-T is a charity registered in England and Wales (No. 1145303). The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

The Trustees have adopted the following policies and procedures for the recruitment, appointment, induction, and training of new Trustees:

## Trustee Recruitment and Appointment

The Trustees listed on page (2) have overall responsibility for the strategic direction and effective governance of the Charity. Trustees are either elected or co-opted under the terms of the Trust deed and the total number of Trustees may not be fewer than five. If a vacancy occurs or a skills need is identified, new Trustees are recommended by the existing Trustees and interviewed by the Chairman and at least one other member of the board. Election is by majority vote and potential candidates must be over the age of eighteen and eligible to act. The Trustees will continue to evaluate the composition of the Board and will consider further appointments to broaden and strengthen the Board's capabilities to facilitate the growth of the Charity.

## Trustee Induction and Training

New Trustees receive an induction pack containing a copy of the trust deed, strategy, relevant information about the Charity and its work; and a copy of the Charity Commission literature about the role and responsibilities of being a Trustee. New Trustees are also invited to meet the Chief Executive and team members to learn first-hand how the Charity operates on a day-to-day basis.

During the induction process, new Trustees are also told about the connected parties' rule, given a copy of the Charity's conflict of interest policy, and asked to sign a Trustee declaration form. Where the Trustees have identified that there is a connection between the charity, or its Trustees and any third party with whom the Charity has dealt with, the Trustees will identify the relationship and the amounts involved within the notes to the financial statements.

## Organisational Structure

The Trustees meet formally four times per year and no business shall be conducted unless at least one-third of the total number of Trustees at the time, or two Trustees (whichever is greater) are present throughout the meeting. There are two meetings where the focus is on awarding grants for medical research and two meetings where Trustees review strategy and set operating plans and budgets. There is a review of operating and financial performance at every meeting. The Chief Executive is invited to attend all meetings of the Trustees and the Head of Fundraising is invited to report on plans and progress at specific meetings.

While most of the business of the Charity is conducted at the scheduled Trustee meetings, there are occasional ad-hoc meetings to deal with matters of special interest and regular electronic meetings are held to review ongoing governance objectives.

The Board of Trustees delegates the exercise of certain powers in connection with the management and administration of the Charity as set out below. This is controlled by regular reporting back to the Board of Trustees so that all decisions made under delegated powers can be ratified by the full Board of Trustees in due course.

## Research Advisory Committee

The Research Advisory Committee (RAC) is chaired by a member of the Board of Trustees. Members of the RAC have a broad range of scientific expertise in areas relating to A-T but are not generally active researchers in the field of A-T to minimise bias and conflicts of interest. There is also lay representation on the committee as Action for A-T supports public and patient engagement in its research processes. The Trustees are very grateful to all the members of the RAC for providing expert guidance and advice on a pro bono basis.

## Chief Executive

The Chief Executive is responsible for the day-to-day management of the Charity's affairs and is assisted by a small executive team who act under his direction. As well as overseeing the operations of the Charity, the Chief Executive is also responsible for implementing policies as agreed by the Board of Trustees.

## Employees, Volunteers and Contractors

The Charity aims to be an organisation where employees, volunteers and contractors enjoy a sense of fulfilment and where they feel supported and developed. All stakeholders are kept fully informed about the Charity's strategy and objectives, as well as day-to-day news and events. Individuals are encouraged to give their suggestions and views on performance and strategy.

The Charity supports equal opportunities and a policy of recruitment and promotion based on aptitude and ability without discrimination is followed. Action for A-T is committed to the training, career development and promotion of all its employees. An individual's career development is assessed through annual appraisal and supervision. Training programmes are provided to meet any on-going needs, with the aim of developing individuals for both their current and their future roles.

## Risk Management

The Trustees have introduced a formal risk management process to assess business risks and implement risk management strategies. This has involved identifying the types of risks the Charity faces, prioritising them in terms of potential impact and likelihood of occurrence, and identifying means of mitigating the risks.

As part of this process the Trustees have reviewed and are satisfied with the adequacy of the Charity's current internal controls and the costs of operating controls relative to the benefits obtained. Procedures have been established for reporting failings immediately to the Chief Executive and to the Board of Trustees.

It is recognised that internal controls can only provide reasonable but not absolute assurance that major risks have been adequately managed. In the opinion of the Trustees the key risks are:

- The loss of reputation due to error, or fraud.
- The loss of income due to error, or fraud.
- Insufficient numbers of Trustees to allow the Charity to continue.
- Insufficient funds to allow the Charity to meet its objectives.
- Excessive reserves without justification deterring future donors and fundraisers.

In the opinion of the Trustees the policies and procedures are currently adequate to mitigate financial and reputation loss due to error or fraud whilst maintaining a viable future financially.

## Reserves Policy

The Trustees review the reserves policy each year to ensure that all relevant risk areas are included in accordance with guidance issued by the Charity Commission. Risks included are the impact of unexpected, reduced income, and the potential impact of restructuring costs and liabilities required to downsize the organisation in an orderly manner, if a permanent income reduction was anticipated.

The review concluded that the existing reserve target level of Six months of operating costs (approx. £90,000) was sufficient to cover the risks identified in the review. This allows sufficient time for Trustees and management to take appropriate mitigating actions, if required.

The Trustees continue their commitment to develop and grow the level of investment in research into A-T, whilst maintaining a focus on managing the overall costs of the charity.

## Investment Policy

The overall policy of the Charity is to maintain a series of designated funds deposit accounts to ring-fence any funds which the Trustees have identified as being made available for specific research projects, or other charitable activities.

The Trustees recognise the need to review this policy on an annual basis and to look at other potential opportunities whilst appropriately monitoring the available funds and being proactive in their management, to ensure the best interests of the Charity's objectives are maintained

Funds committed for research are paid out in arrears over the duration of the project. The Trustees reviewed and agreed to deposit funds in timed deposit accounts in order to obtain the best return with minimal managed risk.

During the year the Trustees transfer any funds surplus to general running costs of the Charity into an interest-bearing account which will offer a higher rate of return than holding it in the main Charity bank account. The aim is to ensure that the fund is not diminished over time due to inflation and to ensure that these funds are invested in future research projects.

## Pay and Remuneration of Key Management Personnel

The Trustee's principles are to pay staff a fair salary that is competitive within the charity sector, proportionate to the complexity of each role, it's related funding and responsible in line with the charitable objectives. Pay levels for all employees are reviewed annually and any overall percentage increases are authorised by the Board of Trustees.

Remuneration for the Chief Executive is agreed by the Trustees. Salaries are benchmarked using external data available from pay surveys (for the voluntary sector and charities located in and around London) and market conditions for the specific role and the target is the market median averages of these.

Ultimately however, salary increases relate to the funding available for each role and whether the increase will be affordable in the long term. To ensure pay is fair for all roles we are committed to paying all our employees at or above the London living wage as determined by the Living Wage Foundation.

# Financial Review

The Trustees are satisfied with the performance of the Charity and consider that the Charity is in an excellent position to continue its activities during the coming year, and the Charity's reserves are adequate to fulfil its current obligations.

## Income

At present, research into A-T is heavily dependent on charitable donations and by extension, Action for A-T's ability to instigate, organise and facilitate the fundraising efforts of our supporters and donors. The principal source of funding is donations from individuals, companies, and proceeds of fundraising events.

Total income raised in 2023 was **£1,092,490 (2022 - £949,804).**

## Charitable Expenditure

The cost spent on Charitable Activities Was **£404,569 (2022 - £1,106,145) of which £139,427 (2022 – £804,239)** was for grants provided for funding of research projects.

The cost of generating voluntary income was **£87,806 (2022 - £81,134)** whilst the cost of generating income from charitable events was **£157,097 (2022 - £201,167)**

Governance costs of **£20,239 (2022 - £19,605)** were incurred.

## General Funds

The Trustees will aim to make best use of any unrestricted funds, however they reserve the right to retain general reserves in hand until they can be used in the most efficient manner to further the objectives of the Charity. The Trustees are conscious that it should not provide funding for research where they have not been able to demonstrate that its use will offer the best opportunity to further the knowledge and treatment into A-T. Please refer to the investment policy with regard to those times where the Trustees believe general funds are in excess of the anticipated running costs of the Charity.

## Designated Funds

Designated funds of **£nil** were brought forward from 2022. In 2023, **£nil** of funds were passed on to the research projects detailed in note 8 on page 37.

As at 31 December 2023 designated funds carried forward are **£nil.**

## Restricted Funds

Restricted funds of **£85,486** were brought forward from 2022. During the year **£13,000** of restricted income was received against projects funded during 2023. During 2023, **£60,465** of funding was made to the research projects detailed in note 8 Page 37.

At 31 December 2023 restricted funds of **£38,021 (2022 - £85,486)** were carried forward and the Trustees are satisfied that the wishes of the donors were met fully. If further funds are received in the future the Trustees will ensure that those funds are used in accordance with those restrictions. Should it not prove possible to adhere to those instructions those funds will be offered back to the provider unless they indicate that they can be used for an alternative purpose.

## Trustees' Responsibilities

The Trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of the incoming resources and application of resources of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP 2015 (FRS 102);
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the Charity and financial information included on the Charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

The Trustees declare that they have approved the Trustees report included in the previous pages

Signed on behalf of the charity's Trustees





Toby Read (Chairman)

William Rowberry (Treasurer)

Dated: 23rd April 2024

Dated: 23rd April 2024

# Auditors Report

## Independent Auditor's Report to the Trustees of Action for A-T

### Opinion

We have audited the financial statements of Action for A-T Registered Charity Number: 1145303 (the 'charity') for the year ended 31 December 2023 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2022 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern:

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The Trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

## Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

## Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

## Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- Conclude on the appropriateness of the trustee's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charity to cease to continue as a going concern.
- Evaluate the overall presentation, structure, and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

## Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



A & N (Haslemere) Limited Statutory Auditor
Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

Dated: 23rd April 2024

A & N (Haslemere) Limited is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

# Statement Of Financial Activities

for the year ended 31 December 2022

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.23 Total Funds £** | 31.12.22 Total Funds £ |
|---|---|---|---|---|---|
| **Income and Endowments from** | | | | | |
| Donations and legacies | 3 | 501,985 | 13,000 | **514,985** | 377,170 |
| **Charitable Activities** | 5 | | | | |
| Fundraising & challenge events | | 549,677 | - | **549,677** | 559,411 |
| Investment income | 4 | 27,828 | - | **27,828** | 10,043 |
| Other income | | - | - | **-** | 3,180 |
| **Total** | | 1,079,490 | 13,000 | **1,092,490** | 949,804 |
| **Expenditure on** | | | | | |
| Raising funds | 6 | 87,806 | - | **87,806** | 81,134 |
| **Charitable Activities** | 7 | | | | |
| Fundraising & challenge events | | 157,097 | - | **157,097** | 201,167 |
| Grants | 8 | 78,962 | 60,465 | **139,427** | 804,239 |
| Governance costs | | 20,239 | - | **20,239** | 19,605 |
| **Total** | | 344,104 | 60,465 | **404,569** | 1,106,145 |
| **Net Income / (Expenditure)** | | 735,386 | (47,465) | **687,921** | (156,341) |
| **Reconciliation of Funds** | | | | | |
| **Total funds brought forward** | | 141,318 | 85,486 | **226,804** | 383,145 |
| **Total Funds Carried Forward** | | 876,704 | 38,021 | **914,725** | 226,804 |

The notes form part of these financial statements

# Statement Of Financial Position

for the year ended 31 December 2023

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.23 Total Funds £** | 31.12.22 Total Funds £ |
|---|---|---|---|---|---|
| **Fixed Assets** | | | | | |
| Tangible assets | 17 | 216 | - | **216** | 216 |
| **Current Assets** | | | | | |
| Stocks | 18 | 18,985 | - | **18,985** | 7,750 |
| Debtors | 19 | 41,798 | - | **41,798** | 18,469 |
| Cash at bank | 20 | 1,891,840 | 38,021 | **1,929,861** | 1,626,967 |
| | | 1,952,623 | 38,021 | **1,990,644** | 1,653,186 |
| **Creditors** | | | | | |
| Amounts falling due within one year | 21 | (422,367) | - | **(422,367)** | (491,139) |
| **Net Current Assets** | | 1,530,256 | 38,021 | **1,568,277** | 1,162,047 |
| **Total Assets Less Current Liabilities** | | 1,530,472 | 38,021 | **1,568,493** | 1,162,263 |
| **Creditors** | | | | | |
| Amounts falling due after more than one year | 22 | (653,768) | - | **(653,768)** | (935,459) |
| **Net Assets** | | 876,704 | 38,021 | **914,725** | 226,804 |
| **Funds** | 23 | | | | |
| Unrestricted funds | | | | **876,704** | 141,318 |
| Restricted funds | | | | **38,021** | 85,486 |
| **Total Funds** | | | | **914,725** | 226,804 |

The notes form part of these financial statements

The financial statements were approved by the Board of Trustees and authorised for issue on 23rd April 2024

and were signed on its behalf by:



Toby Read (Chairman)

Dated: 23rd April 2024



William Rowberry (Treasurer)

Dated: 23rd April 2024

# Statement of Cash Flows

for the year ended 31 December 2023

| | Notes | **31.12.23** **£** | 31.12.22 £ |
|---|---|---|---|
| **Cash flows from operating activities:** | 1 | | |
| Cash generated from operations | | **273,723** | 254,184 |
| Net cash provided by operating activities | | **273,723** | 254,184 |
| **Cash flows from investing activities:** | | | |
| Purchase of tangible fixed assets | | **-** | - |
| Interest received | | **29,171** | 10,043 |
| Net cash provided by investing activities | | **29,171** | 10,043 |
| **Change in cash and cash equivalents in the reporting period** | | **302,894** | 255,227 |
| **Cash and cash equivalents at the beginning of the reporting period** | | **1,626,967** | 1,371,740 |
| **Cash and cash equivalents at the end of the reporting period** | | **1,929,861** | 1,626,967 |

# Notes to the Statement of Cash Flows

for the Year Ended 31 December 2023

## 1. Reconciliation of net (expenditure)/income to net cash flow from operating activities

| | **31.12.23** **£** | 31.12.22 £ |
|---|---|---|
| **Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)** | **687,921** | (156,341) |
| **Adjustments for:** | | |
| Depreciation charges | **-** | 108 |
| Interest received | (29,171) | (10,043) |
| (Increase)/decrease in stocks | (11,235) | 1,782 |
| Decrease in debtors | (23,329) | 18,670 |
| Increase/(decrease) in creditors | (350,463) | 391,008 |
| **Net cash provided by operations** | **273,723** | 245,184 |

## 2. Analysis of changes in net fund

| | At 1.1.23 £ | Cash Flow £ | 31.12.23 £ |
|---|---|---|---|
| Net cash | | | |
| Cash at bank | 1,626,967 | 302,894 | 1,929,861 |
| | 1,626,967 | 302,894 | 1,929,861 |
| Total | **1,626,967** | **302,894** | **1,929,861** |

# Notes to the Financial Statements

for the Year Ended 31 December 2023

## 1. Accounting Policies

### Basis of preparation of financial statements

The financial statements of the charity, which is a public benefit entity under FRS102, have been prepared in accordance with the Charities SORP (FRS102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011.

The financial statements have been prepared under the historical cost convention. The accounts are prepared in £ sterling to the nearest £1.

Action for A-T meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historic cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### Accounting convention

The financial statements are prepared on a going concern basis, under the historic cost convention.

The Charity is entirely dependent on receiving income from fundraising and donations and as a consequence the going concern basis is also dependent on the continuation of such income.

### Incoming resources

All incoming resources are included in the Statement of Financial Activities under FRS102 when that receipt is probable, whereas it was previously recognised when the Charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. For legacies, entitlement is the earlier of the Charity being notified of an impending distribution or the legacy being received.

Gifts in kind, including donated professional services are recognised as income when the Charity has control over them, any conditions associated with the donated item have been met, the receipt of economic benefit from the use of by the Charity if the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS102), the general volunteered time is not recognised and refer to the Trustees' Report for more information about this contribution.

On receipt, donated professional services are recognised on the basis of the value of the gift to the Charity which is the amount the Charity would have been willing to pay to obtain that service on the open market.

Gifts in kind donated for distribution are included at fair value upon receipt under FRS102 subject to the cost of recognition outweighing the benefit provided to Action for A-T. Previously they were included at a valuation and recognised as income when they are distributed. Any donated facilities are included at the value to the Charity where this can be quantified, and a third party is bearing the cost. No amounts are included in the financial statements for services donated by volunteers.

### Resources expended

All expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs allocated to activities. Where costs cannot be directly attributed to particular activities, they have been allocated on a basis consistent with the use of the resources.

Overheads have been allocated on the basis of the activity income of the Charity.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities. Support costs are those costs incurred directly in support of expenditure on the objects of the Charity and include project management carried out by the Trustees. Governance costs are those incurred in connection with the administration of the Charity and compliance with constitutional and statutory requirements.

Grants offered subject to conditions which have not been met at the year-end date are noted as a commitment but not accrued as expenditure.

# Notes to the Financial Statements

for the Year Ended 31 December 2023

## Governance costs

Governance costs comprise all costs involving the public accountability of the Charity and its compliance with regulations and good practice. These costs include costs related to the audit, legal fees, and apportionment of overheads.

## Allocation and apportionment of costs

Fundraising Events & Challenge Events costs are allocated in their income ratio during the year.

## Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Computer equipment - 33% on cost.

## Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

## Taxation

The charity is exempt from tax on its charitable activities.

## Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors which have been raised by the Charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements. Any investment income, gains or losses are allocated to the appropriate fund.

Designated funds are funds set aside by the Trustees out of general reserves for a particular purpose. The aim and use of each designated fund is set out in the notes to the financial statements. The Trustees will review the funds on an ongoing basis. At the conclusion of the purpose for the fund any excess remaining funds will be transferred back into general funds. If a shortfall arises the Trustees will consider whether any additional general funds should be transferred to designated funds. Any investment income, gains or losses are allocated to the appropriate fund.

## Foreign currencies

Assets and liabilities in foreign currencies are translated into sterling at the rate of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling at the date of the transaction. Exchange differences if applicable are taken into the Statement of Financial Activities.

# Notes to the Financial Statements

for the Year Ended 31 December 2023

## 2. Critical Accounting Judgements and Key Sources of Estimation Uncertainty

### Critical accounting estimates and judgements

In the application of the charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

### Key sources of estimation uncertainty

Grants payable are recognised when sanctioned and the total amount is split into due within one year and after one year based on current year amounts paid during the year.

## 3. Donations and Legacies

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.23 £** | 31.12.22 £ |
|---|---|---|---|---|
| Donations | 78,706 | 13,000 | **91,706** | 107,903 |
| Gift Aid | 35,530 | - | **35,530** | 31,768 |
| Fundraising | 387,749 | - | **387,749** | 237,499 |
| | 501,985 | 13,000 | **514,985** | 377,170 |

## 4. Investment Income

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.23 £** | 31.12.22 £ |
|---|---|---|---|---|
| Bank interest | 27,828 | - | **27,828** | 10,043 |

## 5. Income from Charitable Activities

| | Activity | **31.12.23 £** | 31.12.22 £ |
|---|---|---|---|
| Fundraising events | Fundraising & Challenge events | **323,820** | 358,874 |
| Challenge events | Fundraising & Challenge events | **225,857** | 200,537 |
| | | **549,677** | 559,411 |

## 6. Raising Funds

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.23 £** | 31.12.22 £ |
|---|---|---|---|---|
| **Raising donations and legacies** | | | | |
| Staff costs | 65,471 | - | **65,471** | 61,071 |
| Trusts & Foundations | 3,534 | - | **3,534** | |
| Support costs | 18,801 | - | **18,801** | 20,063 |
| | 87,806 | - | **87,806** | 81,134 |

## 7. Charitable Activities Costs

| | Direct Costs £ | Grant funding of activities (see note 8) £ | Support Costs (see note 9) £ | **Totals £** |
|---|---|---|---|---|
| Fundraising & challenge events | 138,063 | - | 19,034 | **157,097** |
| Grants | - | 74,683 | 64,744 | **139,427** |
| Governance costs | - | - | 20,239 | **20,239** |
| | 138,063 | 74,683 | 104,017 | **316,763** |

## 8. Grants Payable

| | **31.12.23 £** | 31.12.22 £ |
|---|---|---|
| Grants | **74,683** | 743,455 |

The total grants paid to institutions during the year was as follows:

| | **31.12.23 £** | 31.12.22 £ |
|---|---|---|
| University of Nottingham, UK - Virtual Reality in Ataxia-Telangiectasia | **18,565** | - |
| University of Nottingham, UK - STIM A-T Pilot Study | **20,270** | - |
| Institute for Bioengineering of Catalonia, Spain - Modelling Ataxia Telangiectasia pathogenesis and therapeutics using human pluripotent stem cells and genetic engineering | **25,000** | - |
| Oslo University Hospital, Norway - Preclinical Assessment of Intrathecal rAAV9-Mediated miATM Therapy for Ataxia Telangiectasia in Mouse Models | **25,000** | - |
| University of Birmingham, UK - (Research project underspends refunded) Assessment of the frequencies and types of cancers occurring in A-T patients | **(14,986)** | - |
| University of Birmingham, UK - (Research project underspends refunded) Deciphering the molecular mechanism linking Ataxia-Telangiectasia and Ataxia-Telangiectasia-Like Disorder | **(29)** | - |
| University of Nottingham, UK – Sandpit Event | **863** | - |
| University of Nottingham, UK - Brain-penetrating ATM gene therapy | **-** | 147,304 |
| Bambino Gesù Children's Hospital, Italy - Study of natural killer cells in A-T pathogenesis and their therapeutic implications | **-** | 91,000 |
| QIMR Berghofer Medical Research Institute, Queensland, Australia - Digital drug prediction informed by genetic analysis of stem cell-derived mini-brains from A-T patients | **-** | 151,690 |
| University of Cambridge, UK - Trial REadiness in Ataxia Telangiectasia (TREAT-AT) | **-** | 250,000 |
| IFOM – The FIRC Institute of Molecular Oncology, Milan, Italy - Understanding and correcting glucose metabolism defects in Ataxia-Telangiectasia | **-** | 125,821 |
| Nottingham University Hospital, UK – (Research project underspends refunded) Natural History of A-T | | (22,360) |
| | **74,683** | 743,455 |

## 9. Support Costs

| | Management | Finance | Information Technology | Other | Wages | Governance Costs | **Totals** |
|---|---|---|---|---|---|---|---|
| | £ | £ | £ | £ | £ | £ | **£** |
| Raising donations and legacies | 8,132 | 664 | 1,324 | 8,681 | - | - | **18,801** |
| Fundraising & challenge events | 8,132 | 664 | 1,323 | 8,933 | - | - | **19,034** |
| Grants | - | - | - | - | 64,744 | - | **64,744** |
| Governance costs | - | - | - | - | - | 20,239 | **20,239** |
| | 16,264 | 1,310 | 2,647 | 17,614 | 64,744 | 20,239 | **122,818** |

| **Activity** | **Basis of allocation** |
|---|---|
| Management | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Finance | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Information technology | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Human resources | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Other | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Governance costs | 100% Governance cost |

## 10. Trustees' Remuneration And Benefits

There were no Trustees' remuneration or other benefits for the year ended 31 December 2023 nor for the year ended 31 December 2022.

## Trustees' Expenses

There were no Trustees' expenses paid for the year ended 31 December 2023 nor for the year ended 31 December 2022.

## 11. Staff Costs

Only one employee received emoluments in excess of £60,000.

The Charity considers its key management personnel to be the Trustees, Chief Executive and senior management. The total employment benefits of the key management personnel were £156,996 (2022 - £147,225). Only one employee had employment benefits falling between £65,000 and £80,000 (2022 - 1).

## 12. Comparatives for the Statement of Financial Activities

| | Unrestricted Funds £ | Restricted Funds £ | **Total Funds £** |
|---|---|---|---|
| **Income and endowments from** | | | |
| Donations and legacies | 357,010 | 20,160 | **377,170** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 559,411 | - | **559,411** |
| Investment income | 10,043 | - | **10,043** |
| Other income | 3,180 | - | **3,180** |
| **Total** | 929,644 | 20,160 | **949,804** |

| | Unrestricted Funds £ | Restricted Funds £ | **Total Funds £** |
|---|---|---|---|
| **Expenditure on** | | | |
| Raising funds | 81,134 | - | **81,134** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 201,167 | - | **201,167** |
| Grants | 804,239 | - | **804,239** |
| Governance costs | 19,605 | - | **19,605** |
| **Total** | 1,106,145 | - | **1,106,145** |
| **Net income/(Expenditure)** | (176,501) | 20,160 | **(156,341)** |
| **Reconciliation of funds** | | | |
| Total funds brought forward | 317,819 | 65,326 | **383,145** |
| **TOTAL FUNDS CARRIED FORWARD** | 141,318 | 85,486 | **226,804** |

## 13. Employee Benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits would be recognisable immediately as an expense when the Charity is demonstrably committed to terminate an employee's employment or to provide termination benefits.

## 14. Pension Costs

The pension costs charged in the financial statements represent the contributions payable by the Charity during the year to a multi-employer defined benefit pension scheme.

# Notes to the Financial Statements - continued

for the Year Ended 31 December 2023

## 15. Financial Instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and are subsequently measured at their amortised cost.

## 16. Creditors and Provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

## 17. Tangible Fixed Assets

| | Computer Equipment £ |
|---|---|
| **Cost** | |
| At 1 January 2023 and 31 December 2023 | 2,358 |
| **Depreciation** | |
| At 1 January 2023 and 31 December 2023 | 2,142 |
| **Net Book Value** | |
| At 31 December 2023 | 216 |
| At 31 December 2022 | 216 |

## 18. Stocks

| | **31.12.23 £** | 31.12.22 £ |
|---|---|---|
| Stocks | **18,985** | 7,750 |

Stocks are stated at the lower of cost and estimated selling price less costs to complete and sell. Cost includes all costs of purchase, costs of conversion and other costs incurred in bringing stock to its present location and condition. Due allowance is made for obsolete and slow-moving items.

Donated stocks are fair valued when their economic benefit is probable, it can be measured reliably, and the charity has control over the item.

## 19. Debtors: Amounts Falling Due Within One Year

| | **31.12.23** **£** | 31.12.22 £ |
|---|---|---|
| Deposit | **925** | 925 |
| Prepayments and accrued income | **40,873** | 17,544 |
| | **41,798** | 18,469 |

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due

## 20. Cash at Bank

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.23 Total Funds £** | 31.12.22 Total Funds £ |
|---|---|---|---|---|
| Bank Current Accounts | 8,459 | 38,021 | **46,480** | 25,084 |
| Bank Current Accounts (US $) | - | - | **-** | - |
| Reserve Account | 410,848 | - | **410,848** | 291,944 |
| Investment Accounts | 1,472,533 | - | **1,472,533** | 1,309,939 |
| Total | 1,891,840 | 38,021 | **1,929,861** | 1,626,967 |

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of twelve months or less, and bank overdrafts. Should any bank overdrafts arise they would be shown within borrowings in current liabilities.

## 21. Creditors: Amounts Falling Due Within One Year

| | **31.12.23** **£** | 31.12.22 £ |
|---|---|---|
| Grant Payable | **415,417** | 489,475 |
| Accruals and deferred income | **6,950** | 1,664 |
| | **422,367** | 491,139 |

## 22. Creditors: Amounts Falling Due After More Than One Year

| | **31.12.23 £** | 31.12.22 £ |
|---|---|---|
| Other creditors | **653,768** | 935,459 |

## 23. Leasing Agreements

During the next twelve months the Charity has operating lease commitments totalling £13,014 (2022 - £12,485) for contracts expiring in more than one year. The total future commitments are £12,960 (2022 - £12,960)

## 24. Movement in Funds

| | At 1.1.23 £ | Net Movement in Funds £ | **At 31.12.23 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 141,318 | 735,386 | **876,704** |
| **Restricted Funds** | | | |
| Restricted Funds | 85,486 | (47,465) | **38,021** |
| Total Funds | 226,804 | 687,921 | **914,725** |

**Net movement in funds, included in the above are as follows**

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 1,079,490 | (344,104) | **735,386** |
| **Restricted Funds** | | | |
| Restricted Funds | 13,000 | (60,465) | **(47,465)** |
| Total Funds | 1,092,490 | (404,569) | **687,921** |

**Comparatives for movement in funds**

| | At 1.1.22 £ | Net Movement in Funds | **At 31.12.22 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 317,819 | (176,501) | **141,318** |
| Restricted Funds | 65,326 | 20,160 | **85,486** |
| Total Funds | 383,145 | (156,341) | **226,804** |

## 24. Movement in Funds - Continued

Comparative net movement in funds, included in the above are as follows:

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 929,644 | (1,106,145) | **(176,501)** |
| **Restricted Funds** | | | |
| Restricted Funds | 20,160 | - | **20,160** |
| Total Funds | 949,804 | (1,106,145) | **(156,341)** |

A current year 12 months and prior year 12 months combined position is as follows:

| | At 1.1.22 £ | Net Movement in Funds | **At 31.12.23 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 317,819 | 558,885 | **876,704** |
| **Restricted Funds** | | | |
| Restricted Funds | 65,326 | (27,305) | **38,021** |
| Total Funds | 383,145 | 531,580 | **914,725** |

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 2,009,134 | (1,450,249) | **558,885** |
| **Restricted Funds** | | | |
| Restricted Funds | 33,160 | (60,465) | **(27,305)** |
| Total Funds | 2,042,294 | (1,510,714) | **531,580** |

## 25. Related Party Disclosures

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2022 - £nil). There are no expenses paid to the Trustees in the year. No trustee is deemed to have benefited as a result of a related party connection. All trustees have declared all such relationships to the Chairman.

## 26. Ultimate Controlling Party

The Trustees control Action for A-T in accordance with the trust deed.

# Detailed Statement of Financial Activities

for the Year Ended 31 December 2023

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.23 £** | 31.12.22 £ |
|---|---|---|---|---|
| **Income and Endowments** | | | | |
| **Donations and legacies** | | | | |
| Donations | 78,706 | 13,000 | **91,706** | 107,903 |
| Gift aid | 35,530 | - | **35,530** | 31,768 |
| Fundraising | 387,749 | - | **387,749** | 237,499 |
| | 501,985 | 13,000 | **514,985** | 377,170 |
| **Investment income** | | | | |
| Bank interest | 27,828 | - | **27,828** | 10,043 |
| **Charitable activities** | | | | |
| Fundraising events | 323,828 | - | **323,828** | 358,874 |
| Challenge events | 225,857 | - | **225,857** | 200,537 |
| | 549,677 | - | **549,677** | 559,411 |
| **Other income** | | | | |
| Other income | - | - | **-** | - |
| Exchange rate difference | - | | **-** | 3,180 |
| **Total incoming resources** | 1,079,490 | 13,000 | **1,092,490** | 949,804 |
| **Expenditure** | | | | |
| **Raising donations and legacies** | | | | |
| Wages | 65,471 | - | **65,471** | 61,071 |
| Trusts and Foundations | 3,534 | - | **3,534** | - |
| | 69,005 | - | **69,005** | 61,071 |
| **Charitable activities** | | | | |
| Event campaign costs | 138,063 | - | **138,063** | 181,101 |
| Grants to institutions | 14,218 | 60,465 | **74,683** | 743,455 |
| | 152,281 | 60,465 | **212,746** | 924,556 |
| **Support costs** | | | | |
| **Management** | | | | |
| Wages | 16,264 | - | **16,264** | 15,241 |
| **Finance** | | | | |
| Bank charges | 1,310 | - | **1,310** | 1,465 |
| **Information technology** | | | | |
| Repairs and renewals | 2,647 | - | **2,647** | 5,420 |

# Detailed Statement of Financial Activities

for the Year Ended 31 December 2023

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.23 £** | 31.12.22 £ |
|---|---|---|---|---|
| **Other** | | | | |
| Rent, rates and water | 13,014 | - | **13,014** | 12,485 |
| Insurance | 1,115 | - | **1,115** | 1,066 |
| Telephone | 693 | - | **693** | 849 |
| Postage and stationery | 480 | - | **480** | 461 |
| Sundries | 526 | - | **526** | 813 |
| Advertising | 887 | - | **887** | 956 |
| Subscription | - | - | **-** | 474 |
| Donation collection fees | 899 | - | **899** | 899 |
| | 17,614 | - | **17,614** | 18,003 |
| **Fundraising** | | | | |
| Wages | 64,744 | - | **64,744** | 60,784 |
| **Governance costs** | | | | |
| Wages | 14,827 | - | **14,827** | 14,015 |
| Auditors' remuneration | 3,300 | - | **3,300** | 3,300 |
| Accountancy and legal fees | 2,112 | - | **2,112** | 2,182 |
| Computer equipment | - | - | **-** | 108 |
| | 20,239 | - | **20,239** | 19,605 |
| Total resources expended | 344,104 | 60,465 | **404,569** | 1,106,145 |
| Net (expenditure)/income | 735,386 | (47,465) | **687,921** | (156,341) |

# Acknowledgments

Action for A-T relies entirely on its donors and supporters who so generously give their time and money to support vitally needed research into A-T. With their support we believe we can make a difference to all people with A-T and their families.

We would like to give special thanks to the following organisations that worked alongside us in 2023:

## Our Research Partners

BrAshA-T Ataxia Telangiectasia and their trustees

A-T Children's Project (USA) and their Medical Research Team

Ataxia Telangiectasia Society

AEFAT

Great Ormond Street Hospital Charity

NATA

## Support from Companies, Trusts & Foundations

We are aware that Companies, Trusts & Foundations are often approached to support charities and are therefore extremely grateful to the following organisations for their generous support.

Adrestia Therapeutics
Astor Foundation
Barton Comms
BCA
Big Give
Blyth Watson Charitable Trust
Charity Escapes
Cinch
Clarion Golf
Constellation Group
Epsom Rotary Club
Enterprise Rent A Car
Global Entertainment
Henrik Bergrem
James Tudor Foundation
James Wise Charitable Trust
Kent College
Medical Research Council
Michael and Anna Wix Charitable Trust
Mollie's Miracle Team
Moe's Ices
Monica Seccombe
Personal Agent
Quest Professional
Rawson Digital
Robin Hewison
Sheppard Piling
Syder Foundation
Stewart Golf Ltd
Trailblazers
Woodcock Brothers

**Corporate or professional services provided by:**

A & N Chartered Accountants
Akin Gump
Chris Stanton
Gecko Graphic Design

## Our Supporters

We have relied almost exclusively on our supporters, volunteers and Trustees for their time and commitment to raising money and spreading awareness about this devastating condition. Thank you to everyone who has helped us to push research into A-T forwards.

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE

Action for A-T, Aruna House, 2 Kings Road, Haslemere, Surrey GU27 2QA.
01428 853313 | info@actionforAT.org | www.actionforAT.org
Registered Charity number: 1145303

**ACTION FOR A-T**

England & Wales - Charity number 1145303

# Accounts

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE




# Annual Report & Financial Statements

**for the year ended 31st December 2022**

Action for A-T - Charity registered number 1145303

www.ActionforAT.org

# Legal And Reference Information

## Patrons

Jonny Wilkinson CBE
Roger Black MBE
Jeremy Guscott MBE
Simon Shaw MBE
Rachel Morris MBE
Naga Munchetty
Leon Haslam

## Chief Executive

Sean Kelly

## Trustees at the date of approval

Toby Read (Chairman)
Emily Read
William Rowberry (Treasurer)
Tomos Shillingford
Maria Leonard
Chris Askew
Dr Mark Toms
Joseph Frost

## Appointed during the year or since year end

None

## Research Advisory Committee

Dr Mark Toms, Chairman

Dr Kathryn Johnson, Scientific Advisor, Consultant Neonatologist and Research Lead

Professor David Attwell, Jodrell Professor of Physiology, Department of Neuroscience, Physiology and Pharmacology, University College London (UCL)

Associate Professor Esther Becker, Associate Professor of Neurobiology, The Becker Group, Oxford University

Dr Simon Boulton, Group Leader, DNA Damage Response Laboratory, Cancer Research UK, London Research Institute

Dr Lisa Bunn, Lecturer in Neurological Physiotherapy and Motor Control, University of Plymouth

Professor Keith Caldecott, Professor of Biochemistry 'Royal Society Wolfson Research Merit Award Holder', and Deputy Director of the Genome Damage and Stability Centre, University of Sussex

Dr Richard Kay, Medical Statistician

Dr Nizar Mahlaoui, Paediatrician specialising in Immuno-Haematology, Necker-Enfants Malades Hospital, Paris and Coordinator of the French National Reference Centre for Primary Immune Deficiencies (CEREDIH)

Dr Guy Makin, Senior Paediatric Oncology Lecturer, University of Manchester

Dr Andrew Prayle, Clinical Assistant Professor, University of Nottingham

Professor Grant Stewart, Professor of Cancer Genetics, School of Cancer Sciences, University of Birmingham

Professor Matthew Wood, Professor of Neuroscience and Deputy Head of the Medical Sciences Division at the University of Oxford

## Patient Representatives

Mr Amandeep Sharma
Mrs Clare Gallagher
Mrs Natasha Schneider

## Charity Registration Number

United Kingdom Registered Charity number: 1145303

## Registered Office

Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

## Operational Address

Action for A-T
Carlton House
19 West Street
Epsom
Surrey
KT18 7RL

## Professional Advisers

Solicitors
Bingham McCutchen LLP
41 Lothbury
London
EC2R 7HF

## Bankers

HSBC Bank
110 High St
Godalming
Surrey
GU7 1DP

## Accountants & Auditors

A & N (Haslemere) Limited
t/a A & N Chartered Accountants and Registered Auditors,
Aruna House, 2 Kings Road, Haslemere. GU27 2QA

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# Trustees' Report

## *The Trustees of Action for A-T present their annual report and the financial statements of Action for A-T for the year ended 31 December 2022.*

The trustees present their report with the financial statements of the charity for the year ended 31 December 2022. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

## Reference and Administrative Details

Action for A-T is a charity registered in England and Wales (No. 1145303). The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. The Trustees met in February, April, September, and November in 2022. The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

## Public Benefit

Action for A-T's charitable objectives are set out in its governing Trust Deed, summarised in the "About Us" section on our website and include undertaking rigorously evaluated and properly conducted medical research into finding a cure or new treatment for the rare genetic condition Ataxia Telangiectasia (A-T).

During the year, the charity has continued to manage its ongoing research portfolio as well as committing funds to a variety of new A-T related research projects. Details of this work can be seen on pages 7 to 13.

Our Trustees have considered how our work may most effectively further our charitable objectives for the benefit of the public, in particular all those affected by Ataxia Telangiectasia, and have had regard to the Charity Commission's guidance on public benefit when reviewing activities against objectives set and in planning future activities.

## Objects, Achievements & Perfomance

**Action for A-T's mission is:**

**"To speed up the process of identifying a cure for A-T or treatments that delay or prevent the disabling effects of this childhood condition"**

To further that mission, the Charity focused on the following key areas in 2022:

- Building our Capacity and Capabilities
- Continuing our Investment in Medical Research in the UK and Abroad
- Ensuring that our research is high quality, peer reviewed and has clear and achievable aims
- Strengthening and Increasing our Fundraising Activities
- Working closely with others to meet our objectives
- Increasing awareness of our work and the condition
- Board Composition

## Building our Capacity and Capabilities

### Our Aim

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us achieve our charitable mission. Since the Charity was initially established in 2012, a great deal of infrastructure work has already taken place, but continued development is required to ensure that we are well positioned for the future.

### Our Performance

As virtually all pandemic restrictions were dropped at the start of 2022, we were able to plan for most activities with some degree of certainty. An early decision was made to relocate an annual corporate bike ride to the UK as overseas group travel was still complicated and for the first time since the pandemic, we were able to plan and deliver several new mass participation fundraising activities.

In addition to delivering all the events which were previously postponed due to the pandemic, we were able to benefit from a variety of new events such as golf days, a large-scale sponsored walk and a new construction industry ball at the Royal Automobile Club. Our ability to be flexible, innovative and capitalise on new opportunities enabled us to deliver a strong fundraising result.

We incorporated more volunteer support than ever before throughout the year to help us deliver the new planned activities and fundraising initiatives efficiently and effectively. This allowed us to scale up many of the activities and in most cases increase the amount of funds raised.

We continued to explore and implement new technologies to improve our fundraising and communicate with our stakeholders. We also upgraded our CRM database to make better use of our fundraising data and to incorporate the latest cyber security protocols.

We stayed in close contact with all our grant holders to ensure that they had the required resources and were able to restart their projects as expediently as possible. Where appropriate, no cost extensions were granted as some studies requiring patient involvement were still experiencing recruitment issues as many Covid related restrictions were still in place at various university hospitals.

Our ability to adapt was only possible due to our size and structure and the hard work of a small but highly skilled team which we retained in full during the year. They have gone above and beyond to deliver a record-breaking fundraising year and the Trustees are very grateful for their incredible efforts.

## Continuing our Investment in Medical Research in the UK and Abroad

### Our Aim

Action for A-T aim to build a community of A-T research leaders and increase the amount of research that is taking place globally. Although we will always fund the highest quality applications wherever they are from; our key focus is to invest in projects and people based in the UK wherever possible.

### Our Performance

Throughout 2022, our Chief Executive staged online meetings with key figures from the A-T research community and representatives from other medical research charities and patient groups to explore possible funding opportunities and further understand which areas of A-T research may provide the most promising outcomes.

Non-A-T researchers who specialise in related conditions were also contacted to drive future research projects and create greater interest in the condition. This strategy is repeated from year to year to increase the number and demographic of 'who' we advertise our grant rounds to.

We concluded our latest grant round in April 2022 joining forces with various like-minded charities and patient organisations to award five new research grants. These projects required a combined total investment of £765,815 and will take place at renowned research institutions and university hospitals in the United Kingdom, Italy, and Australia.

# Funding High-Quality Research into A-T

*In addition to supporting and funding research aimed at improving the understanding of A-T, there are many innovative and exciting medical research opportunities that raise the prospect of real progress in combating the effects of genetic conditions such as A-T.*

## Our Aim

Action for A-T's aim is to be able to make grants to hospitals and universities throughout the world for the purpose of conducting research across all therapeutic areas related to A-T, with an emphasis on research that is likely to have a clear clinical application within the foreseeable future and/or which evaluate innovation in medical techniques which may have a potential benefit for children with A-T.

## Our Performance

Since Action for A-T was established in 2012, we have invested £3,984,715 in 46 global research projects under six main research headings categorised using the UK Clinical Research Collaboration Health Research Classification System.

**Underpinning Research** - Developing new tools and techniques for conducting research

**Aetiology** - Understanding the causes of A-T

**Detection, Screening and Diagnosis** - Tests for diagnosing and monitoring patients with A-T

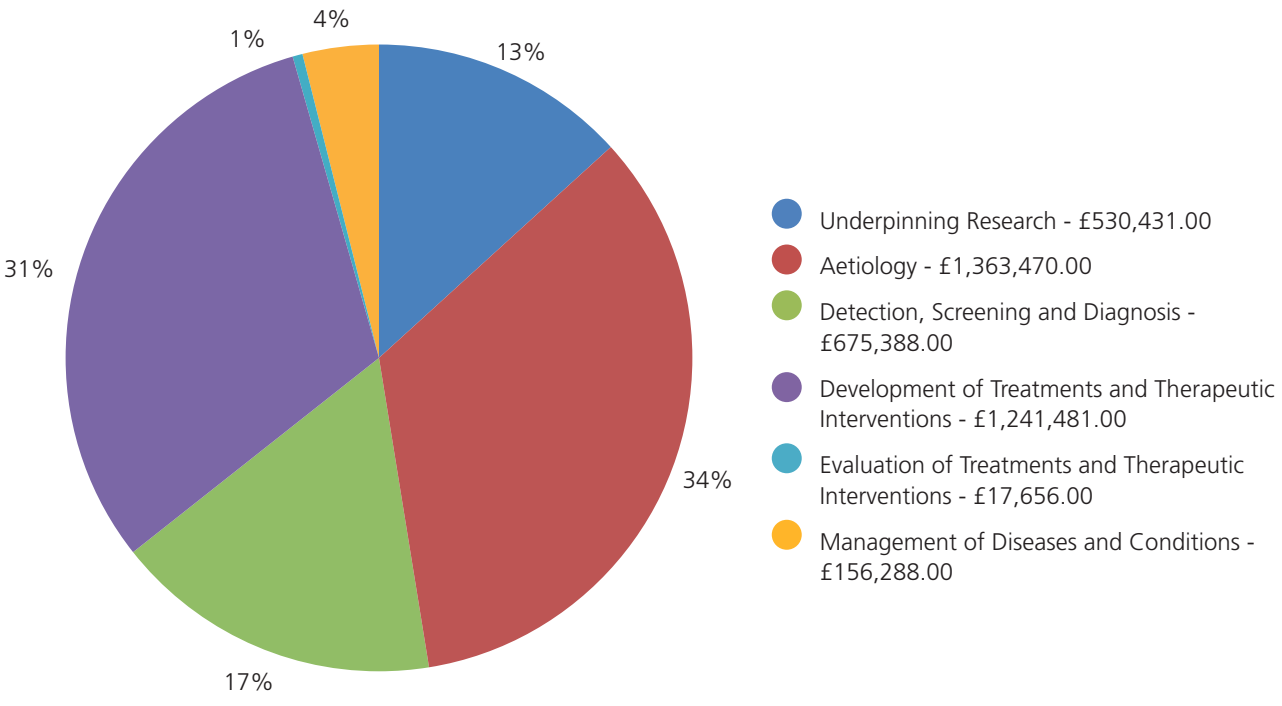
**Development of Treatments and Therapeutic Interventions** - Creating drugs and therapies to alleviate the symptoms of A-T

**Evaluation of Treatments and Therapeutic Interventions** - Studies to prove how new treatments work and understand how to use them

**Management of Diseases and Conditions** - Managing the symptoms of A-T

The chart below shows the historic allocation of our research investment portfolio and our total investment in each of these six research categories listed above.

## Total Research Spend Since 2012



The following grants were awarded by the Trustees in February 2022:

## Brain-penetrating ATM gene therapy

**Principal Researcher:** Dr James Dixon
**Institute:** University of Nottingham, UK
**Cost:** £147,304 over 24 months in partnership with the AEFAT, A-T Society and BrAshA-T
**Start Date:** 5th of September 2022

### Project Overview


Dr James Dixon

Dr James Dixon and team propose to combine gene therapy and editing to engineer an effective therapy to treat A-T in the brain. Their focus is to combine novel nanoparticle chemistry with state-of-the-art gene editing technology to replace faulty A-T genes and 'molecularly cure' any A-T mutation as a medicine for all patients. In their lab, they have demonstrated that delivering genes to A-T patient cells can correct aspects of the disease, and that their gene therapy is effective when injected into healthy mouse brains. They now aim to improve how the medicine penetrates through brain tissue. In parallel they will use the most advanced gene editing technologies to replace defective A-T genes, or to provide extra 'active' copies. A-T patient cells will be used to determine if their proposed treatment corrects the disease permanently. With success they will progress to deliver the therapy to brain slices and then into healthy mice. This research is in its infancy but if successful will pave the way for future trials of their technology.

## Study of natural killer cells in A-T pathogenesis and their therapeutic implications

**Principal Researcher:** Dr Margherita Doria (right) and Dr. Maria Giovanna Desimio
**Institute:** Bambino Gesù Children's Hospital, Italy
**Cost:** £91,000 over 24 months in partnership with the A-T Society (UK), AEFAT (Spain) and BrAshA-T (Australia)
**Start Date:** 1st of November 2022

### Project Overview


Dr. Maria Giovanna Desimio & Dr Margherita Doria

The aim of this project is to identify alterations in blood immune cells of people with A-T that could serve as predictors of cancer development and targets of novel anti-cancer immunotherapies. By studying a small group of A-T patients, the team at the Bambino Gesù Children's Hospital (Rome, Italy) recently identified some defects in cells of the innate immune defence against tumours and viruses that are called 'natural killer' (NK) cells. Specifically, A-T NK cells showed features that are typical of 'exhausted' cells and displayed reduced expression and function of the activating NKG2D receptor correlated with the increase of its ligands (NKG2DLs) in the plasma of patients. The expression of NKG2DLs, normally absent, is induced by tumorigenic transformation, infection and, in general, when cells undergo a 'stress', a condition that typically occur in A-T due to genetic defects of the ATM enzyme. The present study aims to verify the hypothesis that persistent engagement of stress-induced NKG2DLs may result overtime in NKG2D down-regulation and, consequently, in the loss of anti-tumour and anti-viral efficacy of NK cells during A-T disease progression.

# Digital drug prediction informed by genetic analysis of stem cell-derived mini-brains from A-T patients

**Principal Researcher:** Dr Sam Nayler
**Institute:** QIMR Berghofer Medical Research Institute, Queensland, Australia
**Cost:** £151,690 over 36 months in partnership with the A-T Society (UK), AEFAT (Spain) and BrAshA-T (Australia)
**Start Date:** 1st of December 2022

## Project Overview


Dr Sam Nayler

In a previous study, Dr Sam Nayler and his team performed genetic sequencing on single cells from mini-brains made from A-T patient cells. They have predicted from these data which genes are disrupted in the absence of ATM (the gene missing or not functioning completely in A-T), with a focus on key genes which could be targeted with drugs. However, further analysis is required to understand how the different cell types of the brain are affected, and as a result which drugs might elicit restorative effects, while minimizing side effects. They will now perform a much deeper analysis of this data aiming to classify the cell types at the highest resolution possible using the latest statistical advances, relevant data in the field and best-current practice. This will enable fine-grained analysis of specific cell types (i.e. astrocyte, granule, Purkinje neuron) between A-T patients and controls. The team will share these with other interested researchers. Three major pathways have been identified as being disrupted in A-T mini brains which the team will confirm by establishing cerebellar organoid technology. They will validate these pathways using a variety of biochemical approaches which will form the basis of a testing pipeline for drugs computationally-predicted to restore these pathways. In addition to this work they will also functionally characterize neuronal activity. They will examine the contribution of an important immune cell, the microglia, which has not previously been possible.

# Trial REadiness in Ataxia Telangiectasia (TREAT-AT)

**Principal Researcher:** Dr Rita Horvath and Dr Anke Hensiek
**Institute:** University of Cambridge, UK
**Cost:** £250,000 over 36 months in partnership with the A-T Society (UK), AEFAT (Spain) and BrAshA-T (Australia)
**Start Date:** 1st of January 2023

## Project Overview


Dr Rita Horvath and Dr Anke Hensiek

Dr Horvath and her team have identified a particular A-T mutation (the 'UK mutation') that causes a condition type that may be treatable with a new genetic treatment called antisense oligonucleotide (ASO) therapy. Early phase 1 trials with a US-based patient with A-T have already begun, but the interpretation of the results has been hampered by the current inability to assess meaningful clinical improvement. One of the major limiting factors in assessing effectiveness of the ASO treatment is the lack of a clear understanding of the natural history of the condition and disease biomarkers (biological molecules found in blood, other body fluids or tissues that are indicators of the disease condition, which can be easily measured and used to monitor the disease).

This study aims to explore the progression of neurological symptoms using 10 years of existing data (tracking people with A-T) whilst gathering additional new data from people with the UK mutation. The resulting data will be used to establish optimal biomarkers for future clinical trials (there are plans for a phase 1 ASO trial here in the UK) and to further understand the natural history of A-T. The study results will allow rapid progression to trial-readiness for therapies, such as ASO, by offering better outcome measures for disease severity and progression.

# Understanding and correcting glucose metabolism defects in Ataxia-Telangiectasia

**Principal Researcher:** Dr Vincenzo Costanzo
**Institute:** IFOM – The FIRC Institute of Molecular Oncology, Milan, Italy
**Cost:** £125,821 over 36 months in partnership with the A-T Society (UK), AEFAT (Spain) and BrAshA-T (Australia)
**Start Date:** 1st of April 2023

## Project Overview


Dr Vincenzo Costanzo

Dr Costanzo and his team will test the hypothesis that ATM controls the chemical reactions required for the correct use of glucose. Glucose usage defects could lead to glycogen accumulation, which might be toxic for brain cells. They will study the molecular reactions controlled by ATM that promote correct glucose usage and assess possible toxicity of glycogen accumulation to understand how these defects occur and how they can be corrected. The team will monitor glucose metabolism in primary AT cells directly measuring the activity of enzymes controlling key regulatory reactions in glucose processing. The team will also measure and monitor mitochondrial function to understand whether glucose usage defects are linked to mitochondrial impairments. They will also explore the impact of known enzymes involved in glycogen accumulation and AT cell survival to identify possible alterations in pathways controlling energy metabolism in AT cells. Finally, the team will use Purkinje neurons derived from normal and A-T human in vitro reprogrammed cells to validate the impact of the alterations linked to impaired glucose metabolism. The information resulting from this study could help Ataxia-Telangiectasia managing clinicians to better understand how to treat the disease.

# Ensuring that our research is of the highest quality, is well managed and has clear and achievable aims

Research is at the heart of what we do, and our research strategy outlines our intentions on achieving our mission.

## Our Aim

Through our award-winning research process, we aim to only fund projects of the highest-quality that have the greatest chance of advancing our understanding of A-T, improving treatment and management, and accelerating benefits to patients.

## Our Performance

Action for A-T were awarded their second prestigious AMRC award for best practise in medical and health research peer review in May 2021. The award confirms the robust methods used to make decisions about which research projects to fund and our support of the best researchers and the highest quality research, with the best chance of improving the lives of those affected by A-T. The award was made following a full audit of our processes which takes place every five years.

The Trustees generally stage one grant round per year where funds will allow. Applications are peer reviewed by independent external reviewers before they are passed on to our Research Advisory Committee for further review. Projects which pass the peer review process and are deemed high enough quality are passed on to the Trustees to make the final decision based on several key criteria including available funds, strategic alignment, and existing research commitments.

Our Research Advisory Committee (RAC) are part of this process and consist of independent scientific experts from fields related to A-T, including clinicians, non-clinicians, and statistical expertise from a wide range of UK institutions. Lay members are also on the committee to incorporate the views of parents and patients living with A-T, bringing a valuable and unique perspective over what research should be funded. The RAC reviewed all the applications received in our 2022 grant round and their funding recommendations were passed on to the Trustees for consideration. All five of their recommended projects were approved by the trustees and the grants were awarded in May 2022.

## Project outcomes and sharing knowledge

We believe that sharing project outcomes and knowledge is a fundamental requirement for the development of new research strategies which will ultimately benefit those living with the condition. Progress, annual and final reports are mandatory for all our research grants to ensure that they are reaching the agreed milestones. These reports are formally reviewed by our scientific advisor to ensure that each project is in line with its stated aims and the outcomes are then converted into lay summaries to share with our supporters.

Researchers are also encouraged to publish their findings in medical journals and where possible, make the findings freely available. The outputs of research such as publications usually occur sometime after a research project ends and it can take many years to translate research ideas into new treatments or therapies to improve quality of life.

The outcomes of all the concluded research we have funded are displayed on our website under the 'Completed Research' section. Where applicable, these posts also include links to any online publications, and we also share project information via our social media channels and in various communications to our supporters and potential donors.

## Evaluating the outcomes of our research

As with all charities, we are passionate about demonstrating the impact of our work and understand the importance of monitoring the progress and outcomes of our research. Throughout the year we continued to work with our scientific advisor and other members of our Research Advisory Committee to oversee and evaluate the effectiveness of our ongoing research portfolio. Between them, they monitored the progress of ongoing projects and signed off on any which were completed to help ensure that the original research aims stated in the application were fulfilled.

The following studies concluded in 2022 and the initial project outcomes are as follows:

# Non-viral gene therapy for Ataxia Telangiectasia

**Principal researchers:** Dr James Dixon
**Institute:** University of Nottingham
**Cost:** £105,183 over 36 months
***Project Completion Date:** June 2022

## Project Overview


Dr James Dixon

Gene therapy is a method to replace faulty genes with new copies. This is not readily applicable to the treatment of A-T due to the disease gene (ATM) being too large to deliver by the most developed systems using viruses. There are non-viral systems based on nanoparticles that can deliver such large genes, but they are generally poor and the benefit does not last, meaning that gene therapy to molecularly cure A-T will be a very difficult task. This is even more so since the primary tissue for treatment is the brain (Cerebellum) which is difficult to reach even with the most effective systems.

The team developed a new platform of nanoparticles that can deliver engineered ATM genes to cells in the laboratory. The main aim of this project was to test if this therapy is effective enough in A-T patient cells to correct the sensitivity to radiation caused by the lack of the ATM protein. Also to test the system using mouse models and determine if their system can express genes in the correct part of the brain safely and effectively.

## Project Outcome

Dr. Dixon and his team have shown that ATM gene engineering is possible, and this can be effectively delivered to A-T patient cells in the laboratory and show positive effects on restoring the normal function of the ATM gene in helping repair DNA after damage. The demonstration that genes can be delivered and expressed in mice brains also confirms the possibility that this approach should be further explored as a potential future therapy.

## Publications

A paper is in preparation and will be submitted for publication at a later date.

*This study was funded in partnership and managed by the A-T Children's Project in the USA

# Natural History of Ataxia-Telangiectasia (N-HAT)

**Principal Researcher:** Dr William Whitehouse & Dr Emily Petley
**Institute:** University of Nottingham
***Project Completion Date:** August 2022

## Project Overview

Dr William Whitehouse, along with Dr Emily Petley and professionals from the two UK national A-T clinics, aimed to document the natural history of A-T as the NHS set-up in the UK provided a unique opportunity to do such a study. Dr Petley reviewed the clinical notes of everyone with A-T seen in the adult and paediatric A-T clinics since 2001, extracting data on infections; immune deficiencies; cancers; lung disease; brain and nervous system disorders; growth; nutritional status; mortality; and genetics. The data was statistically analysed to determine links between signs and symptoms and describe how A-T progresses.

## Project Outcome


Dr Emily Petley & Dr William Whitehouse

The project has documented the pattern of disease of ataxia-telangiectasia (A-T) in 173 people. The outcome has determined at what age manifestations of the disease occur in the UK A-T population, and how common each manifestation of the disease is. This will help doctors and healthcare professionals pre-empt complications of the condition, so that they can aim to treat them early. It is hoped that this will result in a better outcome for people with A-T, for example detecting cancer earlier. This study will also find links between manifestations of the condition. This study has raised questions and theories that clinicians are currently unable to answer without further research. However, raising these questions and theories will enable further research to be carried out, potentially finding treatments or in the long term a cure for the condition. By understanding the condition in more detail, the team behind the study hope to help people with A-T and their families to have a greater understanding of what to expect at what age. This will help them to plan their future, for example education, housing, and careers.

Most of the aims of this project were met successfully. COVID-19 did have an impact on meeting with families and the development of focus groups. A plan to approach this in 2023 has been made.

## Publications

Petley E, Yule A, Alexander S, Ojha S, Whitehouse WP. The natural history of ataxia-telangiectasia (A-T): A systematic review. PLoS One. 2022 Mar 15;17(3):e0264177. doi: 10.1371/journal.pone.0264177. PMID: 35290391; PMCID: PMC9049793.

The team are currently preparing manuscript of descriptive data on natural history of ataxia-telangiectasia.

*This study was managed by Action for A-T and funded in partnership with the A-T Society and BrAshA-T

# A-T cerebellar neurodegeneration and inositol phosphate signalling

**Principal Researcher:** Professor Tanya Paull
**Institute:** The University of Texas at Austin, USA
**Project Completion Date:** September 2022

## Project Overview


Professor Tanya Paull

This proposal was based on a previous finding from the Paull laboratory that the cerebellum obtained from deceased A-T individuals has reduced levels of expression of proteins that are involved in calcium signalling, which is known to be important for cerebellar function. One goal of this proposal was to examine whether this was also observed at the mRNA level (that is the transcript level), with mRNA being the cellular molecule used to make proteins. This would help to provide insight into the basis underlying such changes. A second goal was to examine how loss of ATM affects calcium signalling using human neurons in culture.

## Project Outcome

The findings of this study demonstrate that ATM has a unique role in the cerebellum and are consistent with the notion that loss of ATM affects the expression of genes that are critical for cerebella function. They suggest that oxidative damage may have an additive impact on impairing ATM function in the cerebellum. Although further studies are required to gain insight into the precise mechanism, they suggest that agents that prevent oxidation-induced DNA damage have the potential to diminish the impact of ATM loss. They provide important insight into the unique or special function of ATM in the cerebellum, which, if clearly understood, could help target treatment.

## Publications

The research team are currently writing up these results into a manuscript.

To view all our current and complete research projects, please visit https://actionforat.org/category/research-projects-funded/

# Strengthening and Increasing our Fundraising Activities

## Our Aim

Action for A-T funds high quality peer reviewed medical research to speed up the process of identifying a cure for Ataxia Telangiectasia (A-T). We endeavor to raise funds from a variety of activities which appeal to new and existing supporters. Since 2012 we have invested £3,984,715 in 46 A-T related research projects around the world, and this has only been possible thanks to our generous supporters.

## Our Performance

2022 was our most successful fundraising year to date as we were able to take full advantage of the relaxation of all Covid restrictions and were able to deliver our full portfolio of fundraising activities. Nearly all our activities performed better than expected as our event guests were incredibly generous, and we were able to deliver several new fundraising activities including a high-profile construction industry ball and a large-scale sponsored walk. We also benefitted from a UKRI grant to help retain early years researchers in their roles plus a sizeable legacy donation.

Our investment in Virgin London Marathon places proved successful once again allowing us to make a 360% return. 22 people were initially recruited for the event, four of these withdrew due to injury or other health concerns, but between them they raised £45,691. We have 20 places available for the 2023 London Marathon and hope to achieve a similar strong fundraising outcome.

In line with our fundraising strategy and as a direct result of the easing of pandemic restrictions, we quickly increased our events offering to take advantage of the heightened demand from our supporters. We also diversified our other fundraising activities to ensure that we were not solely dependent on any one source of funding. The lack of any pandemic restrictions meant that Challenge and Social events recovered well from the previous year, accounting for 59% of our income (2021 - 51%). Whilst other fundraising initiatives, such as donations, funding partnerships and trust and foundation applications decreased to 28% (2021 - 40%). The remaining 13% (£121,000) was generated from the Medical Research Council grant to help retain early years researchers. A few notable fundraising activities took place throughout the year including a large-scale marathon walk with wine tasting, a golf event in partnership with Stewart Golf Ltd and a fundraising dinner for various stakeholders within the construction industry sponsored by Sheppard Piling. We are especially grateful to the staff and clients of BCA and Cinch yet again for taking part in the three-day South Coast cycle event which raised £109,000 plus the non-riders who raised an additional £24,500 on the marathon walk. We are also indebted to the students of Quest Professional who raised over £34,000 at their fundraising dinner. In addition, we would like to thank Simon Toon and his friends for their ongoing and valued support and the late Margaret Claire Seccombe and her sister Monica for their generous legacy and donations totaling £40,000.

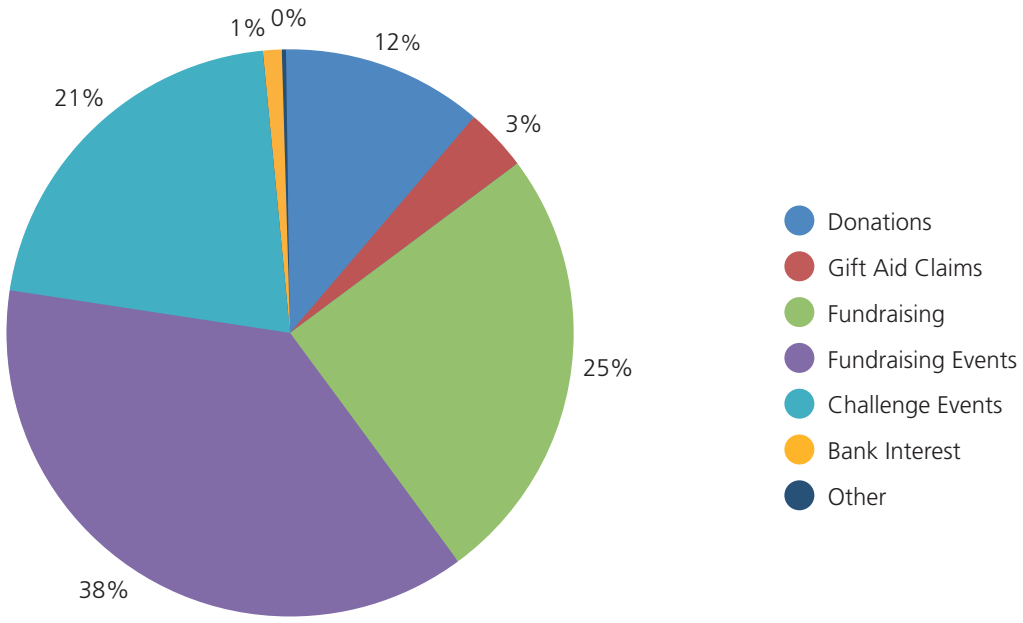
## Raising Funds Responsibly

Action for A-T are registered with the Fundraising Regulator and are committed to upholding the code of fundraising practice. We receive all our funding from voluntary sources, including individuals, companies, trusts and foundations and we do not work with any professional fundraisers or commercial participators to raise funds on our behalf. Each year, we purchase places in several physical challenges as well as staging and benefiting from a series of other social and sporting events. No complaints relating to our fundraising activities were logged with the Fundraising Regulator throughout the year.

We want everyone we interact with to feel free from undue influence when they consider donating. Our in-house fundraising team are trained to recognise these signs, so they can manage conversations in a way that could be considered intrusive or putting repeated or undue pressure on someone to donate. We routinely monitor our fundraising materials to ensure our standards remain high and treat our supporters fairly. Supporter feedback is reviewed regularly to ensure our fundraising offer is appropriate and complies with relevant rules and regulations.

To help protect people in vulnerable circumstances, we continued to follow guidance from the Government and the Fundraising Regulator throughout 2022 and only carried out public fundraising when we considered it safe to do so. We also continued to speak to more supporters to make sure our high standards were maintained as we returned to normal activities following the pandemic.

The pie chart below shows the percentage splits of each of our areas of fundraising in 2022.




*We would also like to record our thanks to all our volunteer committee members for their time and commitment in helping us achieve our mission, as well as everyone who donated their time, auction prizes and/or supported or participated in our events.*



In addition to the above, we are also extremely grateful to the trusts and foundations who provided restricted funding for various research projects (these are listed on page 38). We are always keen to work with other trusts, foundations and corporate funders who might be interested in supporting our work.

At the time of writing these accounts, the COVID-19 pandemic continues to impact the way in which every organisation operates around the world and new variants bring further uncertainty as they are discovered. As a result, we are constantly having to adapt and are less able to plan future fundraising activities with any certainty. The vaccination programme has allowed us to return to near normal, enabling us to stage and benefit from many of our planned activities. But as new COVID variants are discovered which may evade the protection of the vaccines it is hard to predict the potential impact that the ongoing pandemic will have on our overall income. We will continue to adapt to the ever-changing situation and further diversify our fundraising activities as well as staying mindful of our costs to ensure that there are no going concern issues.

## Events Since The End Of The Year

Information relating to events since the end of the year is provided in the notes to the financial statements.

# Working Closely with Others to Meet our Objectives

## Our Aim

Action for A-T strongly believes that there are many opportunities to further the search for a treatment or a cure for A-T through working with others that may have overlapping aims or objectives to our own. To this aim, we actively seek out like minded organisations and where possible, create collaborative partnerships.

## Our Performance

**Co-funding A-T Research Projects with other charities and patient organisations**

Action for A-T continued to work closely with various charities and patient organisations throughout 2022 to fund new and existing research studies. Throughout the year, we continued to manage a variety of our ongoing studies (funded in partnership with others) as well as contributing to new research. Our co-funding partners in 2022 were as follows:

**The UK based Children's Medical Research Charity Sparks**

Action for A-T continued to work closely with UK Children's Medical Research Charity Sparks which joined forces with Great Ormond Street Hospital Charity as a subsidiary in February 2017. Sparks are currently managing the following jointly funded research project which is due to end in 2023:

- "Optimising lung imaging in people with A-T" - Dr Peter Merkus at the Radboud University Medical Centre, Netherlands

**The Australian charity BrAshA-T Ataxia Telangiectasia**

Action for A-T have an ongoing collaborative funding partnership with BrAshA-T who are based in Queensland, Australia. A joint grant call was launched at the start of 2022 to increase the investment in new A-T research and 13 funding applications were received and peer reviewed by Action for A-T. Upon completion of the grant round in May 2022, the two charities combined their resources to fund five new research studies. BrAshA-T contributed £150,000 towards the £765,815 total cost of all five projects. The first payment of £74,915 was made in October 2022 and the remaining payment will be made towards the end of 2023. The total funds committed by BrAshA-T will be split equally amongst each of the five projects which will be managed in full by Action for A-T.

**The UK based A-T Society**

A strategic partnership was established between the A-T Society and Action for A-T in 2022 to increase the overall investment in new A-T research. Upon completion of the grant round in May 2022, the two charities combined their resources to fund five new research studies. The A-T Society agreed to contribute £60,000 towards all five of the studies and a funding agreement was put in place whereby two payments of £30,000 each will be made in 2023 and 2024. The total funds committed by the A-T Society will be split equally amongst each of the five projects which will be managed in full by Action for A-T.

Action for A-T will continue to explore additional joint funding opportunities with likeminded organisations throughout the year to maintain momentum and maximise the investment into A-T research.

**The Spanish based AEFAT**

A strategic partnership was established between the AEFAT and Action for A-T in 2022 to increase the overall investment in new A-T research. Upon completion of the grant round in May 2022, the two charities combined their resources to fund five new research studies. AEFAT agreed to contribute €50,000 towards all five of the new research studies and a funding agreement was put in place. The first payment of €25,000 was made in September 2022 and the remaining payment will be made around the same time in 2023. The total funds committed by AEFAT will be split equally amongst each of the five projects which will be managed in full by Action for A-T.

**The MRC Nucleic Acid Therapy Accelerator (NATA)**

A joint funding partnership was established with NATA in October 2022 to fund a joint Fellowship. The purpose of the 2-year Fellowship is to drive high quality research in the application and translation of nucleic acid therapies in A-T and each organisation will contribute £125,000 towards the full £250,000 cost.

Action for A-T will manage the application process in full and joint funds from NATA and Action for A-T will be made available for projects focusing on nucleic acid therapies (NATs) for the management or treatment of A-T. NATA will assist Action for A-T with the promotion of the Fellowship opportunity and applications will be received and managed by Action for A-T. The peer review process will be managed through the Action for A-T system. Representatives from NATA will join the Action For A-T Scientific Advisory Panel to review the applications, interview the candidates and assist with the peer review of the relevant projects. The final fellowship award will be made in late 2023.

Action for A-T will continue to explore additional joint funding opportunities with likeminded organisations throughout the year to maintain momentum and maximise the investment into A-T research.

**Working strategically with the worldwide A-T community**

Recognising the need for the global A-T community to work more closely together, Action for A-T played a key role in establishing the Global A-T Alliance at the start of 2021. The Alliance is made up of charities and patient groups from the UK, USA, Spain, France, Italy and Australia with the key objective of maximising the effort, resources and/or funding committed to finding a cure or treatments for Ataxia-Telangiectasia (A-T). The group meet virtually throughout the year to update each other on key research needs and findings as well as exploring ways in which they can work more closely together. To date, the Alliance members have joint funded new research, met with a number of pharma companies to explore new treatment opportunities, delivered research focussed webinars for A-T families and established a new website www.cureAT.org which brings together useful information about A-T. The Alliance members passionately believe that with increased funding and a continued global and collaborative effort, effective treatments for A-T will be developed sooner and the lives of those affected will be changed for the better.

# Increasing Awareness of our Work and the Condition

## Our Aim

As an ultra-rare disease, most people are unaware of A-T or the devastating effects of the condition. Action for A-T believes that raising awareness of the studies they fund and the impact of A-T on children and their families is an important part of increasing the potential funds available to further improve the understanding of the condition, and to progress research into possible treatments or a cure.

## Our Performance

Action for A-T has significantly increased the public awareness of the condition over the past 12 months and will continue to explore all options to promote wider understanding of A-T and why research to find a cure or treatment is so important.

The Charity's main achievements in this area to date include:

## Celebrity Support

Our celebrity patrons have continued to help promote Action for A-T and the need for more research into the condition by championing campaigns and taking part in various activities throughout the year. As well as providing prizes for our auctions, Jonny Wilkinson represented Action for A-T in a promotional video for the "Big Give" campaign. The film was used to recruit potential campaign donors for Action for A-T and other charities and was shared widely online and via various social media platforms. We received £15,700 from STV in March 2022 due to Naga Munchetty taking part in the celebrity edition of the TV gameshow "Catchphrase" and Naga also hosted our "Spotlight on A-T Research" webinar alongside Dr Mark Toms. Several other celebrities including Chris Sheasby, Leon Haslam, Kevin Whately, Simon Shaw, Colin Charvis and Jeremy Guscott helped generate funds, awareness and support by taking part in events and campaigns or starring in promotional social media videos.

## Visibility at Research Institutions, Conferences and Medical Meetings



All Action for A-T funded researchers are provided with promotional materials to display at their research facility and required to acknowledge our financial support by including our logo on any posters or presentations. Throughout 2022, most in-person conferences and meetings were cancelled due to the pandemic, but researchers funded by Action for A-T were able to present their findings at various webinars and online events. These presentations showcased our latest projects and provided the wider A-T community with a comprehensive view of the progress made to date.

## "Spotlight on A-T Research" Webinar

Action for A-T staged the second "Spotlight on A-T" virtual event in conjunction with the A-T Alliance to showcase some of the current A-T research projects which are taking place around the world. Key stakeholders from the global A-T community provided an easy to understand, concise overview of their current projects as well as answering audience questions. The webinar took place on the 7th of March 2022 and was hosted by Broadcaster, Journalist and Action for A-T Patron, Naga Munchetty and chair of the Research Advisory Committee, Dr Mark Toms.

There were six presentations broadcast live in English from various research teams and over 150 families, clinicians and other stakeholders tuned in to the event. The webinar was very popular and will be repeated in 2023 in conjunction with the A-T Alliance members.

## Digital Communications

The Charity website www.ActionforAT.org remains the focal point for event sign-ups, electronic donations, and research news. The site was updated and enhanced throughout the year to provide the best possible experience for our stakeholders.

We also continued to manage (alongside Mike Clahsen of BrAshA-T) the www.cureAT.org site which brings together key information about current & past research studies and resulting publications. The site also has sections on care and guidance, patient registries, general information about the condition and a directory of all the known patient organisations around the world. The content is available in several languages including Spanish, French, Italian and Turkish with a simplistic layout directing users to sources of useful information (e.g., websites, documents, relevant groups/meetings, etc.) rather than duplicating existing content on other websites.

Our monthly e-newsletter continues to be a successful tool to communicate our latest news to supporters. Using Mailchimp for this proves to be cheaper than a traditional printed newsletter and has the functionality to track usage and monitor engagement. Our e-newsletter is sent to all our consenting supporters, has a clear unsubscribe function and inactive supporters are removed from the mailing list periodically.

Social media remains a key communication tool for the Charity as it is free, easily accessible and can reach wide audiences. It also allows us to engage with our supporters on a more strategic level and build additional support from their own contacts. Posts are carefully managed to ensure that the content is engaging and not repetitive and this more targeted and planned approach helped us increase our followers throughout the year. We will continue to develop our social media presence in 2023 using all available technological advancements, popular platforms, and our celebrity patrons to raise further awareness.

## National and Local News Media Coverage

We continued to raise awareness of A-T through a series of articles and editorials in the local, national and industry press and various news websites. In addition, our chief executive and various supporters took part in local TV and radio interviews throughout the year. These helped us highlight the condition to new audiences, recruit volunteers and secure additional support and donations.

# Our Future Plans: Areas Of Focus For 2023

The Trustees believe that Action for A-T is well placed to meet its charitable objectives but have also identified the need for further development to strengthen its research activities. During 2023 we will continue to consolidate and diversify our fundraising activities whilst actively developing existing and seeking new funding partnerships to meet the demands of the A-T research community. We will also continue to promote A-T research to engage new audiences and maintain interest from the research community.

We will implement several measures throughout the year to ensure that the Charity continues to be fit for future purpose and to help us achieve our aim of moving closer to tangible therapies or a cure for A-T.

## Strengthening our Capacity and Capabilities

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us deliver our charitable objectives. Our size and structure enabled us to adapt quickly to the ever-changing environment in 2022 but as we continue to operate in tumultuous conditions, we will:

- Review and prioritise projects based on available resources whilst seeking out new opportunities to raise funds in a safe and sustainable manner
- Invest in the necessary skills, tools and resources to meet our organisation wide objectives
- Continue to review and refine all of our systems to meet the demands of the charity
- Explore new and enhance/review existing fundraising initiatives to ensure the maximum return on investment
- Keep up to date with current trends and remain flexible so that change can be implemented quickly if required

## Continuing our Investment in Medical Research in the UK and Abroad

We will continue to seek out new research opportunities from the wider research community as well as focussing on key research themes related to A-T. Where possible, priority will be given to UK based projects whilst still calling for international applications where funds will allow. If funds will allow, we plan to call for new research applications towards the end of 2023.

We will maintain our close relationship with the Association of Medical Research Charities (AMRC) and work in conjunction with our research advisory committee (RAC) to develop and improve our peer review process and ensure that the research we fund is of the highest quality. This will include constant evaluation of our systems and processes as well as enlisting the help and support of various A-T experts around the globe.

Membership of the RAC will be continually reviewed to ensure that we have a broad range of scientific expertise in areas relating to A-T as well as lay representation from various A-T families as Action for A-T strongly supports public and patient engagement in its research processes.

## Invest in People as well as Projects

The A-T research community is relatively small in comparison to other disease areas and a pipeline of new talent is required to build on the existing research findings. Throughout 2023, we will provide several funding opportunities to encourage new and existing researchers to take an interest in A-T. This funding will be in addition to our project grant round and will include a "sandbox" event which will provide in depth information about the condition and an opportunity to apply for small pump priming grants to kick start future large scale projects. We will also be staging our first Fellowship grant round in collaboration with the MRC Nucleic Acid Therapy Accelerator (NATA) to drive high quality research in the application and translation of nucleic acid therapies in A-T.

## Strengthening and Increasing our Fundraising Activities

We will continue to develop a pipeline of new business opportunities whilst delivering our existing portfolio of activities. We will maintain and refresh our calendar of high profile and fun events whilst also working alongside others in a benefitting capacity to reduce the financial risk to the Charity. We will continue to develop and expand our trust and foundations programme whilst actively seeking new investment from individuals, corporates, and major donors. We will also work closely with our key supporters and volunteer groups to ensure we maintain the momentum of investment in ground-breaking A-T research.

## Working Closely with Others to Meet our Objectives

We will also continue to work closely with key stakeholders (especially the A-T Alliance members) as well as exploring new collaborations that will bring greater benefit to the wider A-T community. The number of promising research opportunities continues to grow steadily year on year and there are now more research themes worthy of exploration than our limited funds will allow. We will therefore continue to work with and seek out new organisations with similar objectives to our own, to help ease the financial burden and speed up the process of finding a therapy or cure for A-T.

## Increasing Awareness of our Work and the Condition

Since we were established in 2012, a key priority has been raising awareness of A-T and the work of the Charity. This has been achieved by various means including celebrity endorsement, emotive films featuring researchers and A-T families and various branding opportunities. We will continue to do all that we can to highlight A-T whilst focusing on various key projects in 2023. These projects will include maximising celebrity endorsement opportunities, the creation of a new promotional film and delivering another family focussed A-T research webinar in conjunction with the A-T Alliance.

## Board Composition

We will continue to evaluate the composition of our Trustee Board to facilitate the growth of the Charity and will consider further appointments to broaden and strengthen the Board's capabilities.

# Structure, Governance & Management

## Governing Document

Action for A-T is a charity registered in England and Wales (No. 1145303). The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

The Trustees have adopted the following policies and procedures for the recruitment, appointment, induction, and training of new Trustees:

## Trustee Recruitment and Appointment

The Trustees listed on page (2) have overall responsibility for the strategic direction and effective governance of the Charity. Trustees are either elected or co-opted under the terms of the Trust deed and the total number of Trustees may not be fewer than five. If a vacancy occurs or a skills need is identified, new Trustees are recommended by the existing Trustees and interviewed by the Chairman and at least one other member of the board. Election is by majority vote and potential candidates must be over the age of eighteen and eligible to act. The Trustees will continue to evaluate the composition of the Board and will consider further appointments to broaden and strengthen the Board's capabilities to facilitate the growth of the Charity.

## Trustee Induction and Training

New Trustees receive an induction pack containing a copy of the trust deed, strategy, relevant information about the Charity and its work; and a copy of the Charity Commission literature about the role and responsibilities of being a Trustee. New Trustees are also invited to meet the Chief Executive and team members to learn first-hand how the Charity operates on a day-to-day basis.

During the induction process, new Trustees are also told about the connected parties' rule, given a copy of the Charity's conflict of interest policy, and asked to sign a Trustee declaration form. Where the Trustees have identified that there is a connection between the charity, or its Trustees and any third party with whom the Charity has dealt with, the Trustees will identify the relationship and the amounts involved within the notes to the financial statements.

## Organisational Structure

The Trustees meet formally four times per year and no business shall be conducted unless at least one-third of the total number of Trustees at the time, or two Trustees (whichever is greater) are present throughout the meeting. There are two meetings where the focus is on awarding grants for medical research and two meetings where Trustees review strategy and set operating plans and budgets. There is a review of operating and financial performance at every meeting. The Chief Executive is invited to attend all meetings of the Trustees and the Head of Fundraising is invited to report on plans and progress at specific meetings.

While most of the business of the Charity is conducted at the scheduled Trustee meetings, there are occasional ad-hoc meetings to deal with matters of special interest and regular electronic meetings are held to review ongoing governance objectives.

The Board of Trustees delegates the exercise of certain powers in connection with the management and administration of the Charity as set out below. This is controlled by regular reporting back to the Board of Trustees so that all decisions made under delegated powers can be ratified by the full Board of Trustees in due course.

## Research Advisory Committee

The Research Advisory Committee (RAC) is chaired by a member of the Board of Trustees. Members of the RAC have a broad range of scientific expertise in areas relating to A-T but are not generally active researchers in the field of A-T to minimise bias and conflicts of interest. There is also lay representation on the committee as Action for A-T supports public and patient engagement in its research processes. The Trustees are very grateful to all the members of the RAC for providing expert guidance and advice on a pro bono basis.

## Chief Executive

The Chief Executive is responsible for the day-to-day management of the Charity's affairs and is assisted by a small executive team who act under his direction. As well as overseeing the operations of the Charity, the Chief Executive is also responsible for implementing policies as agreed by the Board of Trustees.

## Employees, Volunteers and Contractors

The Charity aims to be an organisation where employees, volunteers and contractors enjoy a sense of fulfilment and where they feel supported and developed. All stakeholders are kept fully informed about the Charity's strategy and objectives, as well as day-to-day news and events. Individuals are encouraged to give their suggestions and views on performance and strategy.

The Charity supports equal opportunities and a policy of recruitment and promotion based on aptitude and ability without discrimination is followed. Action for A-T is committed to the training, career development and promotion of all its employees. An individual's career development is assessed through annual appraisal and supervision. Training programmes are provided to meet any on-going needs, with the aim of developing individuals for both their current and their future roles.

## Risk Management

The Trustees have introduced a formal risk management process to assess business risks and implement risk management strategies. This has involved identifying the types of risks the Charity faces, prioritising them in terms of potential impact and likelihood of occurrence, and identifying means of mitigating the risks.

As part of this process the Trustees have reviewed and are satisfied with the adequacy of the Charity's current internal controls and the costs of operating controls relative to the benefits obtained. Procedures have been established for reporting failings immediately to the Chief Executive and to the Board of Trustees.

It is recognised that internal controls can only provide reasonable but not absolute assurance that major risks have been adequately managed. In the opinion of the Trustees the key risks are:

- The loss of reputation due to error, or fraud.
- The loss of income due to error, or fraud.
- Insufficient numbers of Trustees to allow the Charity to continue.
- Insufficient funds to allow the Charity to meet its objectives.
- Excessive reserves without justification deterring future donors and fundraisers.

In the opinion of the Trustees the policies and procedures are currently adequate to mitigate financial and reputation loss due to error or fraud whilst maintaining a viable future financially.

## Reserves Policy

The Trustees review the reserves policy each year to ensure that all relevant risk areas are included in accordance with guidance issued by the Charity Commission. Risks included are the impact of unexpected, reduced income, and the potential impact of restructuring costs and liabilities required to downsize the organisation in an orderly manner, if a permanent income reduction was anticipated.

The review concluded that the existing reserve target level of Six months of operating costs (approx. £90,000) was sufficient to cover the risks identified in the review. This allows sufficient time for Trustees and management to take appropriate mitigating actions, if required.

The Trustees continue their commitment to develop and grow the level of investment in research into A-T, whilst maintaining a focus on managing the overall costs of the charity.

## Investment Policy

The overall policy of the Charity is to maintain a series of designated funds deposit accounts to ring-fence any funds which the Trustees have identified as being made available for specific research projects, or other charitable activities.

The Trustees recognise the need to review this policy on an annual basis and to look at other potential opportunities whilst appropriately monitoring the available funds and being proactive in their management, to ensure the best interests of the Charity's objectives are maintained

Funds committed for research are paid out in arrears over the duration of the project. The Trustees reviewed and agreed to deposit funds in timed deposit accounts in order to obtain the best return with minimal managed risk.

During the year the Trustees transfer any funds surplus to general running costs of the Charity into an interest-bearing account which will offer a higher rate of return than holding it in the main Charity bank account. The aim is to ensure that the fund is not diminished over time due to inflation and to ensure that these funds are invested in future research projects.

## Pay and Remuneration of Key Management Personnel

The Trustee's principles are to pay staff a fair salary that is competitive within the charity sector, proportionate to the complexity of each role, it's related funding and responsible in line with the charitable objectives. Pay levels for all employees are reviewed annually and any overall percentage increases are authorised by the Board of Trustees.

Remuneration for the Chief Executive is agreed by the appropriate remuneration committee. Salaries are benchmarked using external data available from pay surveys (for the voluntary sector and charities located in and around London) and market conditions for the specific role and the target is the market median averages of these.

Ultimately however, salary increases relate to the funding available for each role and whether the increase will be affordable in the long term. To ensure pay is fair for all roles we are committed to paying all our employees at or above the London living wage as determined by the Living Wage Foundation.

# Financial Review

The Trustees are satisfied with the performance of the Charity and consider that the Charity is in an excellent position to continue its activities during the coming year, and the Charity's reserves are adequate to fulfil its current obligations.

## Income

At present, research into A-T is heavily dependent on charitable donations and by extension, Action for A-T's ability to instigate, organise and facilitate the fundraising efforts of our supporters and donors. The principal source of funding is donations from individuals, companies, and proceeds of fundraising events.

Total income raised in 2022 was **£949,804 (2021 - £593,451).**

## Charitable Expenditure

The cost spent on Charitable Activities Was **£1,106,145 (2021 - £440,191)** of which **£804,239 (2021 – £262,572)** was for grants provided for funding of research projects.

The cost of generating voluntary income was **£81,134 (2021 - £82,281)** whilst the cost of generating income from charitable events was **£201,167 (2021 - £76,057)**

Governance costs of **£19,605 (2021 - £19,281)** were incurred.

## General Funds

The Trustees will aim to make best use of any unrestricted funds, however they reserve the right to retain general reserves in hand until they can be used in the most efficient manner to further the objectives of the Charity. The Trustees are conscious that it should not provide funding for research where they have not been able to demonstrate that its use will offer the best opportunity to further the knowledge and treatment into A-T. Please refer to the investment policy with regard to those times where the Trustees believe general funds are in excess of the anticipated running costs of the Charity.

## Designated Funds

Designated funds of £nil were brought forward from 2021. In 2022, £nil of funds were passed on to the research projects detailed in note 8 on page 37.

As at 31 December 2022 designated funds carried forward are £nil.

## Restricted Funds

Restricted funds of **£65,326** were brought forward from 2021. During the year **£20,160** of restricted income was received against projects funded during 2022. During 2022, **£nil** of funding was made to the research projects detailed in note 8 Page 37.

At 31 December 2022 restricted funds of **£85,486 (2021 - £65,326)** were carried forward and the Trustees are satisfied that the wishes of the donors were met fully. If further funds are received in the future the Trustees will ensure that those funds are used in accordance with those restrictions. Should it not prove possible to adhere to those instructions those funds will be offered back to the provider unless they indicate that they can be used for an alternative purpose.

## Trustees' Responsibilities

The Trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of the incoming resources and application of resources of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP 2015 (FRS 102);
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the Charity and financial information included on the Charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

The Trustees declare that they have approved the Trustees report included in the previous pages

Signed on behalf of the charity's Trustees





Toby Read (Chairman)

William Rowberry (Treasurer)

Dated: 25th April 2023

Dated: 25th April 2023

# Auditors Report

## Independent Auditor's Report to the Trustees of Action for A-T

### Opinion

We have audited the financial statements of Action for A-T Registered Charity Number: 1145303 (the 'charity') for the year ended 31 December 2022 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2022 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern:

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

## Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

## Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

## Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- Conclude on the appropriateness of the trustee's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charity to cease to continue as a going concern.
- Evaluate the overall presentation, structure, and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

## Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

(Continued)



A & N (Haslemere) Limited Statutory Auditor
Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

Dated: 25th April 2023

A & N (Haslemere) Limited is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

# Statement Of Financial Activities

for the year ended 31 December 2022

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.22 Total Funds £** | 31.12.21 Total Funds £ |
|---|---|---|---|---|---|
| **Income and Endowments from** | | | | | |
| Donations and legacies | 3 | 357,010 | 20,160 | **377,170** | 234,149 |
| **Charitable Activities** | 5 | | | | |
| Fundraising & challenge events | | 559,411 | - | **559,411** | 305,409 |
| Investment income | 4 | 10,043 | - | **10,043** | 11,452 |
| Other income | | 3,180 | - | **3,180** | 42,441 |
| **Total** | | 929,644 | 20,160 | **949,804** | 593,451 |
| **Expenditure on** | | | | | |
| Raising funds | 6 | 81,134 | - | **81,134** | 82,281 |
| **Charitable Activities** | 7 | | | | |
| Fundraising & challenge events | | 201,167 | - | **201,167** | 76,057 |
| Grants | 8 | 804,239 | - | **804,239** | 262,572 |
| Governance costs | | 19,605 | - | **19,605** | 19,281 |
| **Total** | | 1,106,145 | | **1,106,145** | 440,191 |
| **Net Income / (Expenditure)** | | (176,501) | 20,160 | **(156,341)** | 153,260 |
| **Reconciliation of Funds** | | | | | |
| **Total funds brought forward** | | 317,819 | 65,326 | **383,145** | 229,885 |
| **Total Funds Carried Forward** | | 141,318 | 85,486 | **226,804** | 383,145 |

The notes form part of these financial statements

# Statement Of Financial Position

for the year ended 31 December 2022

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.22 Total Funds £** | 31.12.21 Total Funds £ |
|---|---|---|---|---|---|
| **Fixed Assets** | | | | | |
| Tangible assets | 17 | 216 | - | **216** | 324 |
| **Current Assets** | | | | | |
| Stocks | 18 | 7,750 | - | **7,750** | 9,532 |
| Debtors | 19 | 18,469 | - | **18,469** | 37,139 |
| Cash at bank | 20 | 1,541,481 | 85,486 | **1,626,967** | 1,371,740 |
| | | 1,567,700 | 85,486 | **1,653,186** | 1,418,411 |
| **Creditors** | | | | | |
| Amounts falling due within one year | 21 | (491,139) | - | **(491,139)** | (448,986) |
| **Net Current Assets** | | 1,076,561 | 85,486 | **1,162,047** | 969,425 |
| **Total Assets Less Current Liabilities** | | 1,076,777 | 85,486 | **1,162,263** | 969,749 |
| **Creditors** | | | | | |
| Amounts falling due after more than one year | 22 | (935,459) | - | **(935,459)** | (586,604) |
| **Net Assets** | | 141,318 | 85,486 | **226,804** | 383,145 |
| **Funds** | 23 | | | | |
| Unrestricted funds | | | | **141,318** | 317,819 |
| Restricted funds | | | | **85,486** | 65,326 |
| **Total Funds** | | | | **226,804** | 383,145 |

The notes form part of these financial statements

The Trustees declare that they have approved the financial statements.

Signed on behalf of the charity's Trustees.



Toby Read (Chairman)

Dated: 25th April 2023



William Rowberry (Treasurer)

Dated: 25th April 2023

# Statement of Cash Flows

for the year ended 31 December 2022

| | Notes | **31.12.22** **£** | 31.12.21 £ |
|---|---|---|---|
| **Cash flows from operating activities:** | 1 | | |
| Cash generated from operations | | **254,184** | (137,316) |
| Net cash provided by operating activities | | **254,184** | (137,316) |
| **Cash flows from investing activities:** | | | |
| Purchase of tangible fixed assets | | **-** | - |
| Interest received | | **10,043** | 11,452 |
| Net cash provided by investing activities | | **10,043** | 11,452 |
| **Change in cash and cash equivalents in the reporting period** | | **255,227** | (125,864) |
| **Cash and cash equivalents at the beginning of the reporting period** | | **1,371,740** | 1,497,604 |
| **Cash and cash equivalents at the end of the reporting period** | | **1,626,967** | 1,371,740 |

# Notes to the Statement of Cash Flows

for the Year Ended 31 December 2022

## 1. Reconciliation of net (expenditure)/income to net cash flow from operating activities

| | **31.12.22** **£** | 31.12.21 £ |
|---|---|---|
| **Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)** | **(156,341)** | 153,260 |
| **Adjustments for:** | | |
| Depreciation charges | **108** | - |
| Interest received | **(10,043)** | (11,452) |
| (Increase)/decrease in stocks | **1,782** | (4,719) |
| Decrease in debtors | **18,670** | 14,710 |
| Increase/(decrease) in creditors | **391,008** | (298,553) |
| **Net cash provided by operations** | **245,184** | (137,316) |

## 2. Analysis of changes in net fund

| | At 1.1.22 £ | Cash Flow £ | 31.12.22 £ |
|---|---|---|---|
| Net cash | | | |
| Cash at bank | 1,371,740 | 255,227 | 1,626,967 |
| | 1,371,740 | 255,227 | 1,626,967 |
| Total | **1,371,740** | **255,227** | **1,626,967** |

# Notes to the Financial Statements

for the Year Ended 31 December 2022

## 1. Accounting Policies

### Basis of preparation of financial statements

The financial statements of the charity, which is a public benefit entity under FRS102, have been prepared in accordance with the Charities SORP (FRS102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011.

The financial statements have been prepared under the historical cost convention. The accounts are prepared in £ sterling to the nearest £1.

Action for A-T meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historic cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### Accounting convention

The financial statements are prepared on a going concern basis, under the historic cost convention.

The Charity is entirely dependent on receiving income from fundraising and donations and as a consequence the going concern basis is also dependent on the continuation of such income.

### Incoming resources

All incoming resources are included in the Statement of Financial Activities under FRS102 when that receipt is probable, whereas it was previously recognised when the Charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. For legacies, entitlement is the earlier of the Charity being notified of an impending distribution or the legacy being received.

Gifts in kind, including donated professional services are recognised as income when the Charity has control over them, any conditions associated with the donated item have been met, the receipt of economic benefit from the use of by the Charity if the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS102), the general volunteered time is not recognised and refer to the Trustees' Report for more information about this contribution.

On receipt, donated professional services are recognised on the basis of the value of the gift to the Charity which is the amount the Charity would have been willing to pay to obtain that service on the open market.

Gifts in kind donated for distribution are included at fair value upon receipt under FRS102 subject to the cost of recognition outweighing the benefit provided to Action for A-T. Previously they were included at a valuation and recognised as income when they are distributed. Any donated facilities are included at the value to the Charity where this can be quantified, and a third party is bearing the cost. No amounts are included in the financial statements for services donated by volunteers.

### Resources expended

All expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs allocated to activities. Where costs cannot be directly attributed to particular activities, they have been allocated on a basis consistent with the use of the resources.

Overheads have been allocated on the basis of the activity income of the Charity.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities. Support costs are those costs incurred directly in support of expenditure on the objects of the Charity and include project management carried out by the Trustees. Governance costs are those incurred in connection with the administration of the Charity and compliance with constitutional and statutory requirements.

Grants offered subject to conditions which have not been met at the year-end date are noted as a commitment but not accrued as expenditure.

# Notes to the Financial Statements

for the Year Ended 31 December 2022

## Governance costs

Governance costs comprise all costs involving the public accountability of the Charity and its compliance with regulations and good practice. These costs include costs related to the audit, legal fees, and apportionment of overheads.

## Allocation and apportionment of costs

Fundraising Events & Challenge Events costs are allocated in their income ratio during the year.

## Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Computer equipment - 33% on cost.

## Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

## Taxation

The charity is exempt from tax on its charitable activities.

## Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors which have been raised by the Charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements. Any investment income, gains or losses are allocated to the appropriate fund.

Designated funds are funds set aside by the Trustees out of general reserves for a particular purpose. The aim and use of each designated fund is set out in the notes to the financial statements. The Trustees will review the funds on an ongoing basis. At the conclusion of the purpose for the fund any excess remaining funds will be transferred back into general funds. If a shortfall arises the Trustees will consider whether any additional general funds should be transferred to designated funds. Any investment income, gains or losses are allocated to the appropriate fund.

## Foreign currencies

Assets and liabilities in foreign currencies are translated into sterling at the rate of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling at the date of the transaction. Exchange differences if applicable are taken into the Statement of Financial Activities.

## 2. Critical Accounting Judgements and Key Sources of Estimation Uncertainty

### Critical accounting estimates and judgements

In the application of the charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

### Key sources of estimation uncertainty

The annual depreciation charge for tangible fixed assets in sensitive to changes in the estimated useful economic lives and residual value of fixed assets. The useful economic lives and residual values are reassessed on an annual basis. They are amended where deemed necessary to reflect current estimations based on physical condition, utilisation, and advancement of technologies. Note 17 discloses the carrying value if the tangible fixed assets and the depreciation policy is listed above in accounting policies.

## 3. Donations and Legacies

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.22 £** | 31.12.21 £ |
|---|---|---|---|---|
| Donations | 87,743 | 20,160 | **107,903** | 196,586 |
| Gift Aid | 31,768 | - | **31,768** | 12,163 |
| Fundraising | 237,499 | - | **237,499** | 25,400 |
| | 357,010 | 20,160 | **377,170** | 234,149 |

## 4. Investment Income

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.22 £** | 31.12.21 £ |
|---|---|---|---|---|
| Bank interest | 10,043 | - | **10,043** | 11,452 |

## 5. Income from Charitable Activities

| | Activity | **31.12.22 £** | 31.12.21 £ |
|---|---|---|---|
| Fundraising events | Fundraising & Challenge events | **358,874** | 106,007 |
| Challenge events | Fundraising & Challenge events | **200,537** | 199,402 |
| | | **559,411** | 305,409 |

## 6. Raising Funds

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.22 £** | 31.12.21 £ |
|---|---|---|---|---|
| **Raising donations and legacies** | | | | |
| Staff costs | 61,071 | - | **61,071** | 59,786 |
| Support costs | 20,063 | - | **20,063** | 22,495 |
| | 81,134 | - | **81,134** | 82,281 |

## 7. Charitable Activities Costs

| | Direct Costs £ | Grant funding of activities (see note 8) £ | Support Costs (see note 9) £ | **Totals £** |
|---|---|---|---|---|
| Fundraising & challenge events | 181,101 | - | 20,066 | **201,167** |
| Grants | - | 743,455 | 60,784 | **804,239** |
| Governance costs | - | - | 19,605 | **19,605** |
| | 181,101 | 743,455 | 100,455 | **1,025,011** |

## 8. Grants Payable

| | **31.12.22 £** | 31.12.21 £ |
|---|---|---|
| Grants | **743,455** | 207,960 |

The total grants paid to institutions during the year was as follows:

| | **31.12.22 £** | 31.12.21 £ |
|---|---|---|
| University of Nottingham, UK - Brain-penetrating ATM gene therapy | **147,304** | - |
| Bambino Gesù Children's Hospital, Italy - Study of natural killer cells in A-T pathogenesis and their therapeutic implications | **91,000** | - |
| QIMR Berghofer Medical Research Institute, Queensland, Australia - Digital drug prediction informed by genetic analysis of stem cell-derived mini-brains from A-T patients | **151,690** | - |
| University of Cambridge, UK - Trial REadiness in Ataxia Telangiectasia (TREAT-AT) | **250,000** | - |
| IFOM – The FIRC Institute of Molecular Oncology, Milan, Italy - Understanding and correcting glucose metabolism defects in Ataxia-Telangiectasia | **125,821** | - |
| Nottingham University Hospital, UK – (Research project underspends refunded) Natural History of A-T | **(22,360)** | - |
| University of Texas, USA - A-T cerebellar neurodegeneration and inositol phosphate signalling | **-** | 22,519 |
| Duke University, USA - A new function for ATM and a new theory for the clinical abnormalities in A-T | **-** | 249,854 |
| University of Birmingham, UK - (Research project underspends refunded) Identifying new therapies for blood cancers in patients with A-T | **-** | (33,437) |
| Nottingham University Hospital, UK - (Research project underspends refunded) longitudinal brain changes in childhood A-T | **-** | (7,124) |
| Imagin Institute Paris, France - (Research project underspends refunded) - Does irregular repair of DNA damage in Neurons and Lymphocytes cause cellular degeneration in A-T patients? | **-** | (7,371) |
| Oxford University, UK - (Research project underspends refunded) - The use of patient stem cell-derived mini-brains to study A-T | **-** | (16,481) |
| | **743,455** | 207,960 |

## 9. Support Costs

| | Management | Finance | Information Technology | Other | Wages | Governance Costs | **Totals** |
|---|---|---|---|---|---|---|---|
| | £ | £ | £ | £ | £ | £ | **£** |
| Raising donations and legacies | 7,620 | 732 | 2,710 | 9,011 | - | - | **20,063** |
| Fundraising & challenge events | 7,621 | 733 | 2,710 | 9,002 | - | - | **20,066** |
| Grants | - | - | - | - | 60,784 | - | **60,784** |
| Governance costs | - | - | - | - | - | 19,605 | **19,605** |
| | 15,241 | 1,465 | 5,420 | 18,033 | 60,784 | 19,605 | **120,518** |

| **Activity** | **Basis of allocation** |
|---|---|
| Management | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Finance | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Information technology | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Human resources | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Other | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Governance costs | 100% Governance cost |

## 10. Trustees' Remuneration And Benefits

There were no Trustees' remuneration or other benefits for the year ended 31 December 2022 nor for the year ended 31 December 2021.

## Trustees' Expenses

There were no Trustees' expenses paid for the year ended 31 December 2022 nor for the year ended 31 December 2021.

## 11. Staff Costs

Only one employee received emoluments in excess of £60,000.

The Charity considers its key management personnel to be the Trustees, Chief Executive and senior management. The total employment benefits of the key management personnel were £147,225 (2021 - £124,481). Only one employee had employment benefits falling between £65,000 and £70,000 (2021 - 1).

## 12. Comparatives for the Statement of Financial Activities

| | Unrestricted Funds £ | Restricted Funds £ | **Total Funds £** |
|---|---|---|---|
| **Income and endowments from** | | | |
| Donations and legacies | 168,823 | 65,326 | **234,149** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 305,409 | - | **305,409** |
| Investment income | 11,452 | - | **11,452** |
| Other income | 42,441 | - | **42,441** |
| **Total** | 528,125 | 65,326 | **593,451** |

| | Unrestricted Funds £ | Restricted Funds £ | **Total Funds £** |
|---|---|---|---|
| **Expenditure on** | | | |
| Raising funds | 82,281 | - | **82,281** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 76,057 | - | **76,057** |
| Grants | 220,110 | 42,462 | **262,572** |
| Governance costs | 19,281 | - | **19,281** |
| **Total** | 397,729 | 42,462 | **440.191** |
| **Net income/(Expenditure)** | 130,396 | 22,864 | **153,260** |
| **Reconciliation of funds** | | | |
| Total funds brought forward | 187,423 | 42,462 | **229,885** |
| **TOTAL FUNDS CARRIED FORWARD** | 317,819 | 65,326 | **383,145** |

## 13. Employee Benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits would be recognisable immediately as an expense when the Charity is demonstrably committed to terminate an employee's employment or to provide termination benefits.

## 14. Pension Costs

The pension costs charged in the financial statements represent the contributions payable by the Charity during the year to a multi-employer defined benefit pension scheme.

# Notes to the Financial Statements - continued

for the Year Ended 31 December 2022

## 15. Financial Instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and are subsequently measured at their amortised cost.

## 16. Creditors and Provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

## 17. Tangible Fixed Assets

| | Computer Equipment £ |
|---|---|
| **Cost** | |
| At 1 January 2022 and 31 December 2022 | 2,358 |
| **Depreciation** | |
| At 1 January 2022 and 31 December 2022 | 2,034 |
| Charge for year | 108 |
| At 31 December 2022 | 2,142 |
| **Net Book Value** | |
| At 31 December 2022 | 216 |
| At 31 December 2021 | 324 |

## 18. Stocks

| | **31.12.22 £** | 31.12.21 £ |
|---|---|---|
| Stocks | **7,750** | 9,532 |

Stocks are stated at the lower of cost and estimated selling price less costs to complete and sell. Cost includes all costs of purchase, costs of conversion and other costs incurred in bringing stock to its present location and condition. Due allowance is made for obsolete and slow-moving items.

Donated stocks are fair valued when their economic benefit is probable, it can be measured reliably, and the charity has control over the item.

# Notes to the Financial Statements - continued

for the Year Ended 31 December 2022

## 19. Debtors: Amounts Falling Due Within One Year

| | **31.12.22** **£** | 31.12.21 £ |
|---|---|---|
| Deposit | **925** | 925 |
| Prepayments and accrued income | **17,544** | 36,214 |
| | **18,469** | 37,139 |

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due

## 20. Cash at Bank

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.22 Total Funds £** | 31.12.21 Total Funds £ |
|---|---|---|---|---|
| Bank Current Accounts | 4,924 | 20,160 | **25,084** | 44,804 |
| Bank Current Accounts (US $) | - | - | **-** | 14,374 |
| Reserve Account | 226,618 | 65,326 | **291,944** | 435,940 |
| Investment Accounts | 1,309,939 | - | **1,309,939** | 876,622 |
| Total | 1,541,481 | 85,486 | **1,626,967** | 1,371,740 |

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of twelve months or less, and bank overdrafts. Should any bank overdrafts arise they would be shown within borrowings in current liabilities.

## 21. Creditors: Amounts Falling Due Within One Year

| | **31.12.22** **£** | 31.12.21 £ |
|---|---|---|
| Grant Payable | **489,475** | 438,757 |
| Accruals and deferred income | **1,664** | 10,229 |
| | **491,139** | 448,986 |

## 22. Creditors: Amounts Falling Due After More Than One Year

| | **31.12.22** **£** | 31.12.21 £ |
|---|---|---|
| Other creditors | **935,459** | 586,604 |

## 23. Leasing Agreements

During the next twelve months the Charity has operating lease commitments totalling £12,485 (2021 - £12,442) for contracts expiring in more than one year. The total future commitments are £12,960 (2021 - £12,442)

## 24. Movement in Funds

| | At 1.1.22 £ | Net Movement in Funds | **At 31.12.22 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 317,819 | (176,501) | **141,318** |
| **Restricted Funds** | | | |
| Restricted Funds | 65,326 | 20,160 | **85,486** |
| Total Funds | 383,145 | (156,341) | **226,804** |

**Net movement in funds, included in the above are as follows**

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 929,644 | (1,106,145) | **(176,501)** |
| **Restricted Funds** | | | |
| Restricted Funds | 20,160 | - | **20,160** |
| Total Funds | 949,804 | (1,106,145) | **(156,341)** |

**Comparatives for movement in funds**

| | At 1.1.21 £ | Net Movement in Funds | **At 31.12.21 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 187,423 | 130,396 | **317,819** |
| Restricted Funds | 42,462 | 22,864 | **65,326** |
| Total Funds | 229,885 | 153,260 | **383,145** |

## 24. Movement in Funds - Continued

Comparative net movement in funds, included in the above are as follows:

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 528,125 | (397,729) | **130,396** |
| **Restricted Funds** | | | |
| Restricted Funds | 65,326 | (42,462) | **22,864** |
| Total Funds | 593,451 | (440,191) | **153,260** |

A current year 12 months and prior year 12 months combined position is as follows:

| | At 1.1.21 £ | Net Movement in Funds | **At 31.12.22 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 187,423 | (46,105) | **141,318** |
| **Restricted Funds** | | | |
| Restricted Funds | 42,462 | 43,024 | **85,486** |
| Total Funds | 229,885 | (3,081) | **226,804** |

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 1,457,769 | (1,503,874) | **(46,105)** |
| **Restricted Funds** | | | |
| Restricted Funds | 85,486 | (42,462) | **43,024** |
| Total Funds | 1,543,255 | (1,546,336) | **(3,081)** |

## 25. Related Party Disclosures

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2021 - £nil). There are no expenses paid to the Trustees in the year. No trustee is deemed to have benefited as a result of a related party connection. All trustees have declared all such relationships to the Chairman.

## 26. Ultimate Controlling Party

The Trustees control Action for A-T in accordance with the trust deed.

# Detailed Statement of Financial Activities

for the Year Ended 31 December 2022

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.22 £** | 31.12.21 £ |
|---|---|---|---|---|
| **Income and Endowments** | | | | |
| **Donations and legacies** | | | | |
| Donations | 87,743 | 20,160 | **107,903** | 196,586 |
| Gift aid | 31,786 | - | **31,768** | 12,163 |
| Fundraising | 237,499 | - | **237,499** | 25,400 |
| | 357,010 | 20,160 | **377,170** | 234,149 |
| **Investment income** | | | | |
| Bank interest | 10,043 | - | **10,043** | 11,452 |
| **Charitable activities** | | | | |
| Fundraising events | 358,874 | - | **358,874** | 106,007 |
| Challenge events | 200,537 | - | **200,537** | 199,402 |
| | 559,411 | - | **559,411** | 305,409 |
| **Other income** | | | | |
| Other income | - | - | **-** | 4,000 |
| HMRC JRS Grant | - | - | **-** | 38,441 |
| Exchange rate difference | 3,180 | | **3,180** | |
| | 3,180 | - | **3,180** | 42,441 |
| **Total incoming resources** | 929,644 | 20,160 | **949,804** | 593,451 |
| **Expenditure** | | | | |
| **Raising donations and legacies** | | | | |
| Wages | 61,071 | - | **61,071** | 59,786 |
| **Charitable activities** | | | | |
| Event campaign costs | 181,101 | - | **181,101** | 56,234 |
| Grants to institutions | 743,455 | - | **743,455** | 207,960 |
| | 924,556 | - | **924,556** | 264,194 |
| **Support costs** | | | | |
| **Management** | | | | |
| Wages | 15,241 | - | **15,241** | 14,817 |
| **Finance** | | | | |
| Bank charges | 1,465 | - | **1,465** | 2,036 |
| **Information technology** | | | | |
| Repairs and renewals | 5,420 | - | **5,420** | 2,945 |

# Detailed Statement of Financial Activities

for the Year Ended 31 December 2022

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.22 £** | 31.12.21 £ |
|---|---|---|---|---|
| **Other** | | | | |
| Rent, rates and water | 12,485 | - | **12,485** | 14,853 |
| Insurance | 1,066 | - | **1,066** | 1,036 |
| Telephone | 849 | - | **849** | 736 |
| Postage and stationery | 461 | - | **461** | 312 |
| Sundries | 813 | - | **813** | 1,746 |
| Advertising | 956 | - | **956** | 998 |
| Subscription | 474 | - | **474** | 512 |
| Donation collection fees | 899 | - | **899** | 899 |
| | 18,003 | - | **18,003** | 21,092 |
| **Fundraising** | | | | |
| Wages | 14,015 | - | **14,015** | 55,720 |
| **Governance costs** | | | | |
| Wages | 14,015 | - | **14,015** | 13,969 |
| Auditors' remuneration | 3,300 | - | **3,300** | 3,300 |
| Accountancy and legal fees | 2,182 | - | **2,182** | 2,322 |
| Computer equipment | 108 | - | **108** | - |
| | 19,605 | - | **19,605** | 19,601 |
| Total resources expended | 1,106,145 | - | **1,106,145** | 440,191 |
| Net (expenditure)/income | (176,501) | 20,160 | **(156,341)** | 153,260 |

# Acknowledgments

Action for A-T relies entirely on its donors and supporters who so generously give their time and money to support vitally needed research into A-T. With their support we believe we can make a difference to all people with A-T and their families.

We would like to give special thanks to the following organisations that worked alongside us in 2022:

## Our Research Partners

BrAshA-T Ataxia Telangiectasia and their trustees

A-T Children's Project (USA) and their Medical Research Team

Ataxia Telangiectasia Society

AEFAT

Great Ormond Street Hospital Charity

NATA

## Support from Companies, Trusts & Foundations

We are aware that Companies, Trusts & Foundations are often approached to support charities and are therefore extremely grateful to the following organisations for their generous support.

Barton Comms
BCA
Big Give
Blyth Watson Charitable Trust
Broyst Foundation
Cast Media
Charity Escapes
Cinch
Claws Consultants
Clarion Golf
Constellation Group
Epsom Rotary Club
Eveson Charitable Trust
Global Entertainment
Henrik Bergrem
Hospital Saturday Fund
International Racing Club
Medical Research Council
Michael and Anna Wix Charitable Trust
Mollie's Miracle Team
Monica Seccombe
Openwork Foundation
PIB Community Trust
Quest Professional
Rawson Digital
Rest-Harrow Trust
Robin Hewison
Sheppard Piling
Sir Roger Manwoods School
Sir Samuel Scott of Yews Trust
Stewart Golf Ltd
Tonbridge School
Trak Employment Solutions
Waitrose
Weatherall Foundation Trust
Woodcock Brothers

**Corporate or professional services provided by:**

A & N Chartered Accountants
Akin Gump
Chris Stanton
Gecko Graphic Design

## Our Supporters

We have relied almost exclusively on our supporters, volunteers and Trustees for their time and commitment to raising money and spreading awareness about this devastating condition. Thank you to everyone who has helped us to push research into A-T forwards.

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE

Action for A-T, Aruna House, 2 Kings Road, Haslemere, Surrey GU27 2QA.
01428 853313 | info@actionforAT.org | www.actionforAT.org
Registered Charity number: 1145303

**ACTION FOR A-T**

England & Wales - Charity number 1145303

# Accounts

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE




# Annual Report & Financial Statements

**for the year ended 31st December 2021**

Action for A-T - Charity registered number 1145303

www.ActionforAT.org

# Legal And Reference Information

## Patrons

Jonny Wilkinson CBE
Roger Black MBE
Jeremy Guscott MBE
Simon Shaw MBE
Rachel Morris MBE
Naga Munchetty
Leon Haslam

## Chief Executive

Sean Kelly

## Trustees at the date of approval

Toby Read (Chairman)
Emily Read
William Rowberry (Treasurer)
Tomos Shillingford
Maria Leonard
Chris Askew
Dr Mark Toms
Joseph Frost

## Appointed during the year or since year end

None

## Research Advisory Committee

Dr Mark Toms, Chairman

Dr Kathryn Johnson, Scientific Advisor, Consultant Neonatologist and Research Lead

Professor David Attwell, Jodrell Professor of Physiology, Department of Neuroscience, Physiology and Pharmacology, University College London (UCL)

Associate Professor Esther Becker, Associate Professor of Neurobiology, The Becker Group, Oxford University

Dr Simon Boulton, Group Leader, DNA Damage Response Laboratory, Cancer Research UK, London Research Institute

Dr Lisa Bunn, Lecturer in Neurological Physiotherapy and Motor Control, University of Plymouth

Professor Keith Caldecott, Professor of Biochemistry 'Royal Society Wolfson Research Merit Award Holder', and Deputy Director of the Genome Damage and Stability Centre, University of Sussex

Dr Richard Kay, Medical Statistician

Dr Nizar Mahlaoui, Paediatrician specialising in Immuno-Haematology, Necker-Enfants Malades Hospital, Paris and Coordinator of the French National Reference Centre for Primary Immune Deficiencies (CEREDIH)

Dr Guy Makin, Senior Paediatric Oncology Lecturer, University of Manchester

Dr Andrew Prayle, Clinical Assistant Professor, University of Nottingham

Professor Maria Grazia Spillantini, Professor of Molecular Neurology, John Van Geest Centre for Brain Repair, University of Cambridge

Professor Grant Stewart, Professor of Cancer Genetics, School of Cancer Sciences, University of Birmingham

Professor Matthew Wood, Professor of Neuroscience and Deputy Head of the Medical Sciences Division at the University of Oxford

## Patient Representatives

Mr Amandeep Sharma
Mrs Clare Gallagher
Mrs Natasha Schneider

## Charity Registration Number

United Kingdom Registered Charity number: 1145303

## Registered Office

Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

## Operational Address

Action for A-T
Carlton House
19 West Street
Epsom
Surrey
KT18 7RL

## Professional Advisers

Solicitors
Bingham McCutchen LLP
41 Lothbury
London
EC2R 7HF

## Bankers

HSBC Bank
110 High St
Godalming
Surrey
GU7 1DP

## Accountants & Auditors

A & N (Haslemere) Limited
t/a A & N Chartered Accountants and Registered Auditors,
Aruna House, 2 Kings Road, Haslemere. GU27 2QA

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# Trustees' Report

*The Trustees of Action for A-T present their annual report and the financial statements of Action for A-T for the year ended 31 December 2021.*

The trustees present their report with the financial statements of the charity for the year ended 31 December 2021. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

## Reference and Administrative Details

Action for A-T is a charity registered in England and Wales (No. 1145303). The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. The Trustees met in February, April, September, and November in 2021. The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

## Public Benefit

Action for A-T's charitable objectives are set out in its governing Trust Deed, summarised in the "About Us" section on our website and include undertaking rigorously evaluated and properly conducted medical research into finding a cure or new treatment for the rare genetic condition Ataxia Telangiectasia (A-T).

During the year, the charity has continued to manage its ongoing research portfolio as well as committing funds to a variety of new A-T related research projects. Details of this work can be seen on pages 7 to 12.

Our Trustees have considered how our work may most effectively further our charitable objectives for the benefit of the public, in particular all those affected by Ataxia Telangiectasia, and have had regard to the Charity Commission's guidance on public benefit when reviewing activities against objectives set and in planning future activities.

## Objects, Achievements & Perfomance

**Action for A-T's mission is:**

**"To speed up the process of identifying a cure for A-T or treatments that delay or prevent the disabling effects of this childhood condition"**

To further that mission, the Charity focused on the following key areas in 2021:

- Adapting to the new environment
- Identifying & funding research into A-T
- Ensuring that our research is high quality, peer reviewed and has clear and achievable aims
- Diversifying and consolidating our fundraising capabilities
- Working closely with others to meet our objectives
- Increasing awareness of our work and the condition

## Adapting to the New Environment

## Our Aim

As a small charity, we have always remained flexible and regularly explored new ways of working to meet our charitable objectives. Since the start of the pandemic, it has become increasingly difficult to plan with any certainty and the need to adapt quickly and cleverly has never been greater. Recognising that the pandemic recovery would take some time, one of our key focuses for 2021 was continuing to adapt to this new environment.

## Our Performance

At the beginning of 2021, further pandemic restrictions were enforced which led to the cancellation and postponement of many of our planned fundraising activities. Thankfully, we were able to reschedule most of the fundraising events to the latter

part of the year and adapt the way in which they were run to ensure that they were operated in line with the current guidelines. An early decision was made to relocate our overseas events to the UK due to ongoing travel restrictions as this provided a level of certainty to the participants and some larger scale in person social events were cancelled due to an increased risk of infection.

In addition to delivering most of the postponed events, we also created some new fundraising activities which capitalised on the full unlocking of restrictions. These included golf days, a sponsored walk and a large-scale property awards event held at a well-known London night club. Our ability to be flexible, innovative and adapt quickly to change enabled us to almost reach our full year budget when we were only able to fully operate in the final four months of the year.

We continued to explore new technologies to improve our fundraising and communicate with our stakeholders and many new digital tools were incorporated throughout the year. These helped us increase our online fundraising by 20% and stay in regular contact with our supporters, researchers, and funding partners.

We stayed in close contact with all our grant holders to ensure that they had the required resources and keep project delays to a minimum. Where appropriate, no cost extensions were granted as many of the studies requiring patient attendance were unable to continue as planned due to the pandemic restrictions.

Our ability to adapt was only possible due to our size and structure and the hard work of a small but highly skilled team which we retained in full during the year. They have gone above and beyond on many occasions and the Trustees are very grateful for their incredible efforts.

## Identifying High-Quality Research into A-T

### Our Aim

Action for A-T aim to build a community of A-T research leaders and increase the amount of research that is taking place here in the UK. Although we will always fund the highest quality applications wherever they are from; our key focus is to invest in projects and people based in the UK wherever possible.

### Our Performance

Throughout 2021, our Chief Executive staged online meetings with key figures from the A-T research community and representatives from other medical research charities and patient groups to explore possible funding opportunities and further understand which areas of A-T research may provide the most promising outcomes.

Non A-T researchers who specialise in related conditions were also contacted to drive future research projects and create greater interest in the condition. This strategy is repeated from year to year to increase the number and demographic of 'who' we advertise our grant rounds to.

We opened a new grant round in October 2021 alongside our research partner BrAshA-T who will contribute up to £100,000 towards any projects which pass our award-winning peer review process. The deadline for applications was the 4th of January 2022 and at the time of writing this report, we have received 13 requests for funding.

# Funding High-Quality Research into A-T

*In addition to supporting and funding research aimed at improving the understanding of A-T, there are many innovative and exciting medical research opportunities that raise the prospect of real progress in combating the effects of genetic conditions such as A-T.*

## Our Aim

Action for A-T's aim is to be able to make grants to hospitals and universities throughout the world for the purpose of conducting research across all therapeutic areas related to A-T, with an emphasis on research that is likely to have a clear clinical application within the foreseeable future and/or which evaluate innovation in medical techniques which may have a potential benefit for children with A-T.

## Our Performance

Since Action for A-T was established in 2012, we have invested **£3,202,620** in 41 global research projects under six main research headings categorised using the UK Clinical Research Collaboration Health Research Classification System.

**Underpinning Research** - Developing new tools and techniques for conducting research

**Aetiology** - Understanding the causes of A-T

**Detection, Screening and Diagnosis** - Tests for diagnosing and monitoring patients with A-T

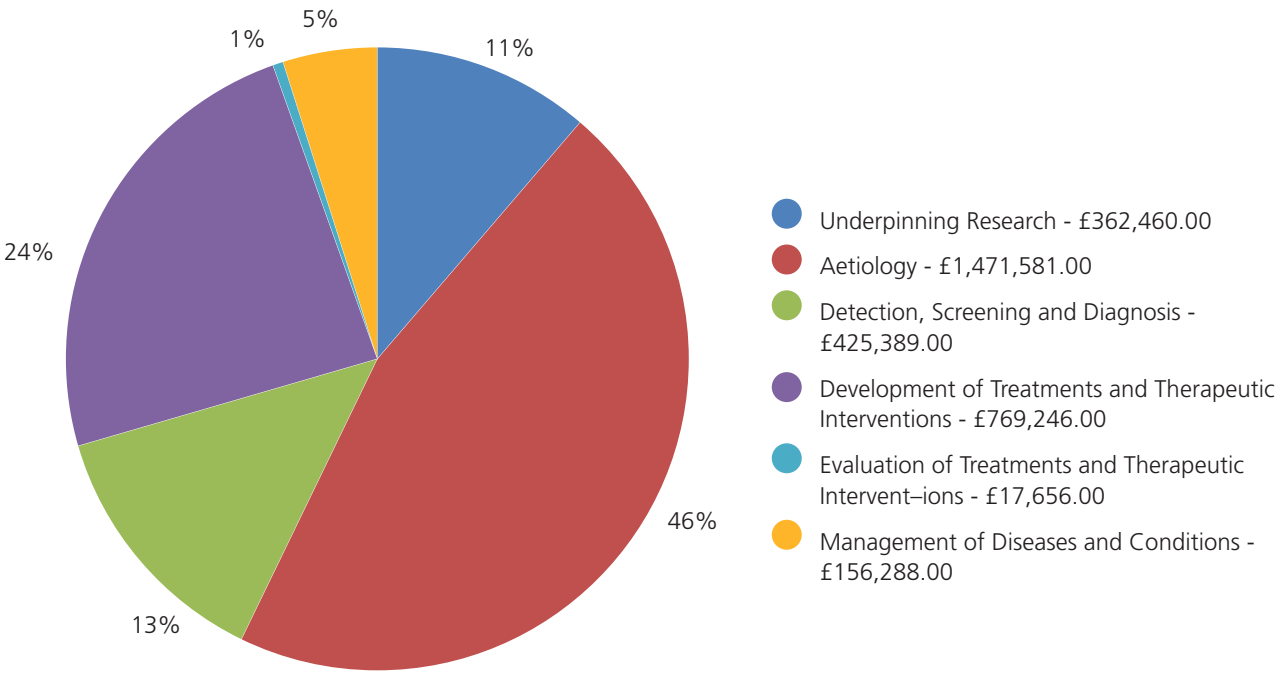
**Development of Treatments and Therapeutic Interventions** - Creating drugs and therapies to alleviate the symptoms of A-T

**Evaluation of Treatments and Therapeutic Interventions** - Studies to prove how new treatments work and understand how to use them

**Management of Diseases and Conditions** - Managing the symptoms of A-T

The chart below shows the historic allocation of our research investment portfolio and our total investment in each of these six research categories listed above.

## Total Research Spend Since 2012



The following two grants were awarded by the Trustees in February 2021:

## A new function for ATM and a new theory for the clinical abnormalities in A-T

**Principal Researcher:** Professor Michael Kastan
**Institute:** Duke University, USA
**Cost:** £249,854 over 36 months
**Start Date:** 1st of January 2021

### Project Overview


Professor Mike Kastan

A-T is caused by mutations in the ATM gene and results in progressive neurodegeneration, greater susceptibility to cancer, immune deficiencies, and other clinical manifestations. While much is known about the roles of the ATM protein in cells, definitive explanations for the clinical abnormalities in A-T patients remain incomplete. Thus, effective approaches to minimising these clinical problems remain limited. Professor Kastan's lab recently discovered a new function of the ATM protein in repression of the RNA* surveillance factor SMG1 activity in the setting of DNA damage. As a result, they are proposing to characterise how ATM is involved in the regulation of SMG1 activity and determine the effects of SMG1 regulation on A-T phenotypes.

*RNA (Ribonucleic acid) is an important biological macromolecule that exists in all biological cells. It carries the messenger instructions from DNA. DNA contains all the genetic instructions for the development and maintenance of life.

The team will attempt to identify how ATM regulates SMG1 by mapping which areas of the SMG1 protein are affected by ATM activity and exploring proteins regulated by ATM that affect SMG1 kinase activity. As SMG1 was initially described as a factor involved in reducing inappropriate RNA, they will identify what RNA molecules differ with SMG1 loss in A-T cells. Finally, they aim to address how SMG1 could potentially drive some A-T phenotypes, including defining the role of SMG1 in oxidative stress responses as well as inflammatory responses.

As effective approaches to mitigate the clinical manifestations in A-T remain limited, the team aim to define how SMG1 functions are altered in the setting of ATM deficiency. They will explore the possibility that the inability to repress SMG1 activity could contribute to A-T phenotypes. As a result, demonstration of the importance of ATM repression of SMG1 activity would lead to novel avenues of research to approach targeting A-T clinical phenotypes.

## A-T cerebellar neurodegeneration and inositol phosphate signalling

**Principal Researcher:** Professor Tanya Paull
**Institute:** The University of Texas at Austin, USA
**Cost:** *£22,518.50 over 12 months in partnership with the A-T Society (UK), AEFAT (Spain) and BrAshA-T (Australia)
**Start Date:** 1st of June 2021

### Project Overview


Professor Tanya Paull

This project builds on work that has already been carried out by Professor Paull. Previous research in her lab looked at cerebellum and neocortex brain tissue from A-T patients and matched controls that showed marked differences in protein aggregation** in A-T cerebellum as well as the overall loss of specific proteins involved in calcium signalling. This pathway of calcium signalling is already known to be disrupted in familial forms of another form of ataxia, spinocerebellar ataxia.

** protein aggregation – when disordered proteins or mis-folded proteins accumulate and clump together. Protein aggregation has been implicated in a wide variety of neurodegenerative conditions.

Professor Paull will further investigate the changes in protein levels in A-T brain tissue by determining if these arise from changes in gene expression. She will also use a human neuronal system to determine if calcium signalling proteins are regulated by ATM or its activity. Her work is aimed at increasing our understanding of the cause/s of protein abnormalities that have been observed in A-T brain tissues.

Ultimately, only by understanding why neurodegeneration occurs in A-T will researchers be able to start the development of potential treatments. Treatment strategies targeting neurodegeneration would make a huge impact on the quality of life of those living with A-T.

**This study is being managed by the A-T Society and being funded equally by four A-T charities including Action for A-T. The total study cost is £90,074*

## Ensuring that our research is of the highest quality, is well managed and has clear and achievable aims

Research is at the heart of what we do, and our research strategy outlines our intentions on achieving our mission.

### Our Aim

Through our award-winning research process, we aim to only fund projects of the highest-quality that have the greatest chance of advancing our understanding of A-T, improving treatment and management, and accelerating benefits to patients.

### Our Performance

amrc
PEER REVIEW AUDIT
2020

The Trustees generally stage one grant round per year where funds will allow. Applications are peer reviewed by independent external reviewers before they are passed on to our Research Advisory Committee for further review. Projects which pass the peer review process and are deemed high enough quality are passed on to the Trustees to make the final decision based on several key criteria including available funds, strategic alignment, and existing research commitments.

In May 2021, Action for A-T was awarded its second prestigious AMRC award for best practise in medical and health research peer review. The award confirms the robust methods used to make decisions about which research projects to fund and our support of the best researchers and the highest quality research, with the best chance of improving the lives of those affected by A-T. The award was made following a full audit of our processes which takes place every five years.

Action for A-T opened a new grant round in October 2021 in partnership with the Australian based A-T charity, BrAshA-T. The deadline to submit applications was the 4th of January 2022 and a number of applications were received from a variety of global research institutions. These applications will be subject to our rigorous award-winning peer review process to ensure that the money generously raised by our donors is put to the best possible use and provide assurance to our Trustees.

Our Research Advisory Committee (RAC) are part of this process and consist of independent scientific experts from fields related to A-T, including clinicians, non-clinicians, and statistical expertise from a wide range of UK institutions. Lay members are also on the committee to incorporate the views of parents and patients living with A-T, bringing a valuable and unique perspective over what research should be funded. The RAC will meet in April 2022 to formally review all the applications and their funding recommendations will be passed on to the Trustees with a view to final awards being made in May 2022.

## Project outcomes and sharing knowledge

We believe that sharing project outcomes and knowledge is a fundamental requirement for the development of new research strategies which will ultimately benefit those living with the condition. Progress, annual and final reports are mandatory for all our research grants to ensure that they are reaching the agreed milestones. These reports are formally reviewed by our scientific advisor to ensure that each project is in line with its stated aims and the outcomes are then converted into lay summaries to share with our supporters.

Researchers are also encouraged to publish their findings in medical journals and where possible, make the findings freely available. The outputs of research such as publications usually occur sometime after a research project ends and it can take many years to translate research ideas into new treatments or therapies to improve quality of life.

The outcomes of all the concluded research we have funded are displayed on our website under the 'Completed Research' section. Where applicable, these posts also include links to any online publications, and we also share project information via our social media channels and in various communications to our supporters and potential donors.

## Evaluating the outcomes of our research

As with all charities, we are passionate about demonstrating the impact of our work and understand the importance of monitoring the progress and outcomes of our research. Throughout the year we continued to work with our scientific advisor and other members of our Research Advisory Committee to oversee and evaluate the effectiveness of our ongoing research portfolio. Between them, they monitored the progress of ongoing projects and signed off on any which were completed to help ensure that the original research aims stated in the application were fulfilled.

The following studies concluded in 2021 and the initial project outcomes are as follows:

# Using new immunotherapy methods to treat lymphoma and leukaemia in A-T

**Principal researchers:** Dr Elad Jacoby
**Institute:** Sheba Medical Centre, Israel
**Cost:** £105,183 over 36 months
**Project Completion Date:** 1st October 2021

## Project Overview


Professor Elad Jacoby

Immunotherapy is a type of treatment for cancer which prompts the body's own immune system to identify and destroy cancerous cells. The main players are called T-cells, which are a type of white blood cells that play a central role in immune response. CAR-T cell therapy, a form of immunotherapy with specialised T-cells, is a novel treatment for leukaemia and lymphoma. These are made from the patient's own blood cells, which are modified to produce special structures called chimeric antigen receptors (CARs) on their surface. CAR T cells have been shown to be extremely effective in the therapy of blood cancers, without producing the usual side-effects resulting from chemotherapy.

The main aim of this project was to test if this therapy is suitable and feasible in A-T patients and whether it could provide a suitable non-toxic treatment of lymphoma and leukaemia in A-T patients.

## Project Outcome

Initially, blood samples were taken from some A-T patients along with heterozygote family members – to be used as controls. The team were able to create CAR-T cells from the collected mononuclear cells and in sufficient amounts for a therapeutic cell dose; the first aim of the project.

They then assessed the cytotolxic function of these cells in the lab; the research showed that the collected cells were able to kill their targets. It was noted however that the toxic activity of the CAR-T cells from the A-T patients was lower than controls.

The effectiveness of the cells was then tested in mice; anti leukaemic activity was shown in the mice and work on this aspect of the project is still ongoing. The genetic integration of the CAR into the cells of A-T patients was also investigated and this work is also ongoing.

Dr Jacoby and his team acknowledge some challenges regarding their findings in terms of the genetic integration analysis as some concerning clonal changes were seen however the early findings are being explored further.

## Publications

A paper is in preparation and will be submitted for publication at a later date.

# Development of CRISPR/Cas Genome Editing as a Treatment for Ataxia Telangiectasia

**Principal Researcher:** Professor Rafael Yáñez-Muñoz
**Institute:** Royal Holloway, University of London
**Project Completion Date:** 30th June 2021

## Project Overview


Professor Rafael Yáñez-Muñoz

The aim of this project was to begin early research to explore the use of genome editing technology, known as CRISPR, to look at ways to permanently repair the ATM gene. The Royal Holloway based team hoped to use the technology to test ways to repair the faulty gene responsible for A-T (the ATM gene). Although the study offered much hope, it was widely acknowledged that the varied mutations in the disease could potentially make gene editing challenging.

## Project Outcome

Professor Rafael Yáñez-Muñoz and his team attempted to repair the faulty ATM gene using several different CRISPR genome editing strategies. They then tested these in human cells that are easy-to-grow in the lab. Next, they moved on to cells that have been derived from people affected by A-T, which harbour ATM gene mutations. Finally, they looked at genome editing approaches in human blood stem cells.

The first study objective was to attempt to replace the first or second half of the faulty gene dependent on where the ATM mutation was located. This was shown to be feasible but there was no evidence that the gene could be fixed. Work is ongoing to look at how this may be successfully achieved.

When they looked at repairing mutations relatively common in A-T using patient cell lines grown in the lab, they were able to detect correction of the ATM gene in several cases. Following this, changes in the cells suggest that there was successful fix of the gene.

There were some challenges with a lack of success with some of the repair templates used. Different vectors are now being explored to test the feasibility of achieving this (using Adeno-associated viral vectors). The group acknowledge that this was a technical challenge rather than a change of objective and their work in this field is ongoing with a master's student.

Although the original study has now concluded, work continues as described above using AAV vectors and further gene editing using blood stem cells to test where the likely initial target for clinical application would be.

The team were very clear at the outset that this project involved very early research and unlikely to lead clinical applicability in the foreseeable future. There is a lot of work to be done to pave the way for a viable treatment option but with advances in CRISPR techniques and gene editing such research and the research that follows from it will be vital if gene editing in A-T is to be successful.

## Publications

No publications are being proposed at this time.

# Does irregular repair of DNA damage in Neurons and Lymphocytes cause cellular degeneration in A-T patients?

**Principal Researcher:** Dr Jean-Pierre De Villartay
**Institute:** The IMAGINE Institute for Genetic Diseases, Paris
**Project Completion Date:** 30th June 2021

## Project Overview


Dr Jean-Pierre De Villartay

The ATM protein is one of the critical components necessary for the repair of DNA damage in human cells. In patients with A-T, who have mutations in the ATM gene, cells of the brain and the immune system are both affected (called neurons and lymphocytes). One important aspect of A-T is the progressive nature of these clinical symptoms, which suggests that "time" is a critical factor. Dr Jean-Pierre De Villartay and his team wanted to test the idea that the abnormal repair of such DNA damage, especially over time, may explain the progressive cellular degeneration seen in A-T patients. The main goal of the study was to test this hypothesis both on a mouse model (neuron) and in the lab (on lymphocyte cells) from A-T patients and their families.

## Project Outcome

The first aim was to look at ATM deficiency and neurodegeneration. In this part of the project, the team investigated how ATM deficiency affected live neurons responding to repeated activating signals in the test tube. They mapped out the pattern of DNA damage that occurs across the genome of nerve cells in response to a repeated signal. They compared how DNA damage is repaired in the presence or absence of ATM. They also measured the impact of accumulated damage on how easily the cell can access the information contained in DNA ("genes").

Results from the first aim have shown that the deficiency is indeed associated with cellular changes and modification of gene expression. The team suggest that this may be the basis for the neurodegeneration in A-T however as this is very early research, further work to explore this is required.

The second aim was to explore ATM deficiency and the immune function. The team tested their hypothesis that lymphocytes might also undergo DNA damage during their normal activities. They tested this with signals that activate lymphocytes. These cells were obtained from both A-T patients and mice with A-T and compared with healthy cells (from parents or A-T carriers) for the pattern of DNA damage and associated changes in gene function.

Work on the second aim provided interesting results. It is well known that lymphocytes from A-T patients are highly radio sensitive, what has not been previously described is that parents (and carriers of an A-T mutation) also display a degree of sensitivity to ionising radiation. This may have clinical importance for A-T carriers.

The initial aims of this projects were completed as planned but as this area of work is in its infancy, more research at a laboratory level is now required to explore the initial findings.

## Publications

A paper is in preparation and will be submitted for publication later.

To view all our current and complete research projects, please visit https://actionforat.org/category/research-projects-funded/

# Diversifying and Consolidating our Fundraising Activities

## Our Aim

Action for A-T funds high quality peer reviewed medical research to speed up the process of identifying a cure for Ataxia Telangiectasia (A-T). We endeavor to raise funds from a variety of activities which appeal to new and existing supporters. Since 2012 we have invested more than £3,200,000 in 41 A-T related research projects around the world, and this has only been possible thanks to our generous supporters.

## Our Performance

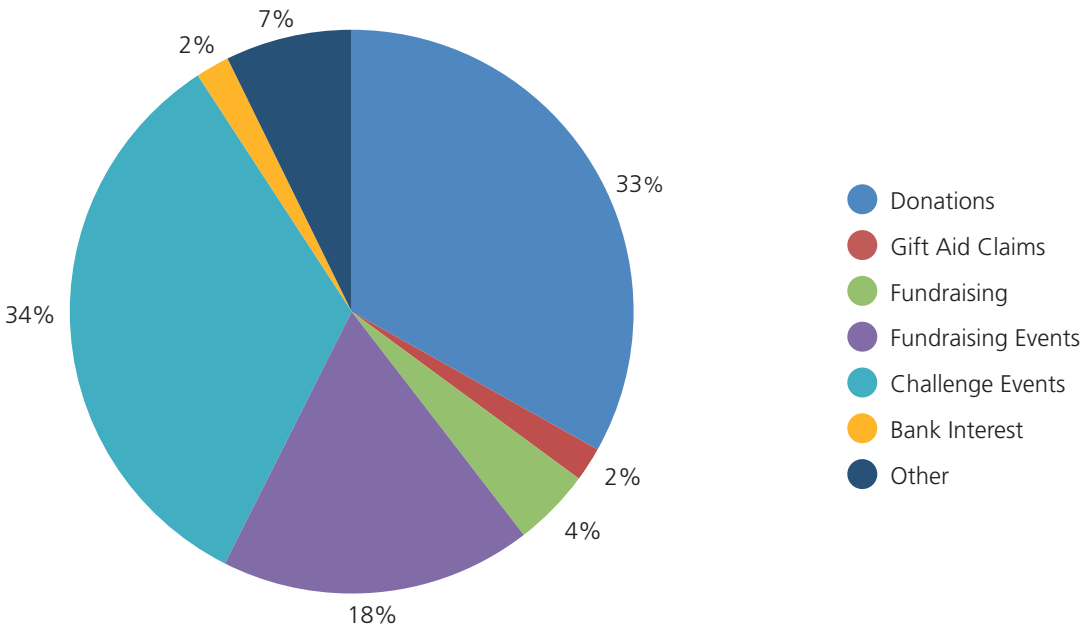
Action for A-T are registered with the Fundraising Regulator and are committed to upholding the code of fundraising practice. We receive all our funding from voluntary sources, including individuals, companies, trusts and foundations. We also purchase places in several physical challenges as well as staging and benefiting from a series of other social and sporting events.

2021 was another difficult year for fundraising as we were forced to cease most of our event activities until the pandemic restrictions were eased in the late summer. The vaccination programme which began in December 2020 enabled us to plan with some certainty for the latter half of 2021 and early decisions were made to cease all planned overseas activities and relocate them to the UK. We made an early decision to reschedule events which were planned for the first half of the year, pushing them back to the late summer and autumn. This led to a very busy period towards the end of the year where numerous activities were staged before the winter months. As a result, 80% of our annual income was generated in the final four months of the year. As well as raising funds, we also reduced our overheads by taking advantage of the government led furlough scheme up until August and reducing our general and administrative expenses during the same period.

In 2020 the Virgin London Marathon was cancelled and the places we had previously purchased were carried forward to the 2021 event. The ongoing pandemic restrictions meant the marathon was postponed until October and this date change impacted our ability to recruit runners. 16 people were initially recruited but four of these withdrew due to injury or other health concerns but between them, they raised £47,551 allowing us to make a 375% return on our original investment. We were also able to carry forward the unused places meaning that we have 21 places available for the 2022 London Marathon.

In line with our fundraising strategy and as a direct result of the pandemic restrictions, we diversified our income base to ensure that we were not solely dependent on any one source of funding. The easing of pandemic restrictions meant that Challenge and Social events recovered well from the previous year, accounting for 51% of our income (2020 - 30%). Whilst other fundraising initiatives, such as donations, funding partnerships and trust and foundation applications decreased to 40% (2020 - 56%). A few new fundraising activities took place at the end of the year including a marathon walk with wine tasting, a pairs golf event and a property awards ceremony entitled the Proper Awards. We are especially grateful to the staff and clients of BCA and Cinch yet again for choosing to stage their three-day cycle event in the Yorkshire Dales (instead of their planned overseas ride) which raised over £100,000. We are also extremely grateful to the National Association of Motor Auctions (NAMA) who held their annual AGM in September and raised £30,500 from a charity auction. In addition, we are indebted to Simon Toon and his friends for their ongoing and valued support plus Quest Professional, Epsom & Ewell Borough Council and Claws Consultants for their generous corporate support.

The pie chart below shows the percentage splits of each of our areas of fundraising in 2021.



*We would also like to record our thanks to all our volunteer committee members for their time and commitment in helping us achieve our mission, as well as everyone who donated their time, auction prizes and/or supported or participated in our events.*



In addition to the above, we are also extremely grateful to the trusts and foundations who provided restricted funding for various research projects (these are listed on page 44). We are always keen to work with other trusts, foundations and corporate funders who might be interested in supporting our work.

At the time of writing these accounts, the COVID-19 pandemic continues to impact the way in which every organisation operates around the world and new variants bring further uncertainty as they are discovered. As a result, we are constantly having to adapt and are less able to plan future fundraising activities with any certainty. The vaccination programme has allowed us to return to near normal, enabling us to stage and benefit from many of our planned activities. But as new COVID variants are discovered which may evade the protection of the vaccines it is hard to predict the potential impact that the ongoing pandemic will have on our overall income. We will continue to adapt to the ever-changing situation and further diversify our fundraising activities as well as staying mindful of our costs to ensure that there are no going concern issues.

### Events Since The End Of The Year

Information relating to events since the end of the year is provided in the notes to the financial statements.

## Working Closely with Others to Meet our Objectives

### Our Aim

Action for A-T strongly believes that there are many opportunities to further the search for a treatment or a cure for A-T through working with others that may have overlapping aims or objectives to our own. To this aim, we actively seek out like minded organisations and where possible, create collaborative partnerships.

### Our Performance

Action for A-T continued to work closely with various charities and patient organisations throughout 2021 to fund new and existing research studies. Throughout the year, we continued to manage a variety of our ongoing studies (funded in partnership with others) as well as contributing to new research. Our co-funding partners in 2021 were as follows:

**The UK based Children's Medical Research Charity Sparks**

Action for A-T continued to work closely with UK Children's Medical Research Charity Sparks which joined forces with Great Ormond Street Hospital Charity as a subsidiary in February 2017. Sparks are currently managing the following jointly funded research project which is due to end in 2022:

- "Optimising lung imaging in people with A-T" - Dr Peter Merkus at the Radboud University Medical Centre, Netherlands

**The US Charity the A-T Children's Project**

Action for A-T and the US based A-T Children's Project joined forces at the end of 2018 to fund two new research projects. Both studies are being managed by the A-TCP and Action for A-T has contributed towards each project. The studies are as follows:

- "Non-viral gene therapy for Ataxia Telangiectasia" – Dr James Dixon at the University of Nottingham, United Kingdom
- "Genetically tailored splice-modulating therapy for A-T" – Dr Timothy Yu at the Harvard and Boston Children's Hospital, USA

Action for A-T have committed £50,000 towards the "Non-viral gene therapy" project (The final £25,000 was paid at the end of 2020) and £17,656 ($23,000) towards the "Genetically tailored splice-modulating therapy" (this was paid in full at the end of 2018).

**The Australian charity BrAshA-T Ataxia Telangiectasia**

Action for A-T have an ongoing collaborative funding partnership with BrAshA-T who are based in Queensland, Australia. BrAshA-T agreed to support the patient stem cell-derived mini-brains study being carried out by Dr Sam Nayler at Oxford University and their agreed contribution totalling £29,460 was paid in full in December 2019. This project concluded at the end of 2020 and cost less than originally budgeted so a refund of £4,713.60 was made to BrAshA-T at the end of 2021.

In addition to partnering on existing research studies, BrAshA-T formed a strategic partnership with Action for A-T to increase the investment in new A-T research. The two charities will combine their resources to fund new research following a joint grant call in October 2021. Action for A-T will manage the grant round and any projects which pass the peer review process and BrAshA-T will contribute £100,000 to the funding pot. Payments will be made to Action for A-T at various stages throughout 2022 and 2023 as and when project invoices are received.

**The Australian charity BrAshA-T Ataxia Telangiectasia and the UK based A-T Society**

At the start of 2019, Action for A-T established a new collaborative funding partnership with BrAshA-T and the A-T Society in connection with the Natural Histories Study being carried out Dr William Whitehouse and Dr Emily Petley at the University of Nottingham. Throughout 2021, each organisation contributed £22,605.72 towards the cost of this study. As the project is scheduled to conclude in 2022, the final contributions will be paid in 2022.

**The UK based A-T Society**

Following completion of their grant round at the start of 2021, the A-T Society approached various A-T charities to support one of the projects which had passed peer review. Four organisations (including Action for A-T) agreed to equally fund the study being carried out by Tanya Paull at the University of Texas, each contributing £22,518.50. Action for A-T contributed £5,629.63 towards the study in September 2021. The remaining payments will be made in 2022 when the 12-month study managed by the A-T Society concludes.

Action for A-T will continue to explore additional joint funding opportunities with likeminded organisations throughout the year to maintain momentum and maximise the investment into A-T research.

**Working strategically with the worldwide A-T community**

Recognising the need for the global A-T community to work more closely together, Action for A-T played a key role in establishing the Global A-T Alliance at the start of 2021. The Alliance is made up of charities and patient groups from the UK, USA, Spain, Italy and Australia with the key objective of maximising the effort, resources and/or funding committed to finding a cure or treatments for Ataxia-Telangiectasia (A-T). The group meet virtually throughout the year to update each other on key research needs and findings as well as exploring ways in which they can work more closely together. To date, the Alliance members have joint funded new research, delivered a research focussed webinar for A-T families and established a new website www.cureAT.org which brings together useful information about A-T. The Alliance members passionately believe that with increased funding and a continued global and collaborative effort, effective treatments for A-T will be developed sooner and the lives of those affected will be changed for the better.

# Increasing Awareness of our Work and the Condition

## Our Aim

As an ultra-rare disease, most people are unaware of A-T or the devastating effects of the condition. Action for A-T believes that raising awareness of the studies they fund and the impact of A-T on children and their families is an important part of increasing the potential funds available to further improve the understanding of the condition, and to progress research into possible treatments or a cure.

## Our Performance

Action for A-T has significantly increased the public awareness of the condition over the past 12 months and will continue to explore all options to promote wider understanding of A-T and why research to find a cure or treatment is so important. The Charity's main achievements in this area to date include:

## Celebrity Support

Our celebrity patrons have continued to help promote Action for A-T and the need for more research into the condition by championing campaigns and taking part in various activities throughout the year. As well as providing prizes for our auctions, Jonny Wilkinson represented Action for A-T in a promotional video for the "Big Give" campaign. The film was used to recruit potential campaign donors for Action for A-T and other charities and was shared widely online and via various social media platforms. We received £15,700 from STV in March 2021 due to Naga Munchetty taking part in the celebrity edition of the TV gameshow "Catchphrase" and Naga also hosted our "Spotlight on A-T Research" webinar alongside Dr Mark Toms. Several other celebrities including Chris Sheasby, Leon Haslam, Kevin Whately, Simon Shaw, Colin Charvis and Jeremy Guscott helped generate funds, awareness and support by taking part in events and campaigns or starring in promotional social media videos.

## Visibility at Research Institutions, Conferences and Medical Meetings

All Action for A-T funded researchers are provided with promotional materials to display at their research facility and required to acknowledge our financial support by including our logo on any posters or presentations. Throughout 2021, most in-person conferences and meetings were cancelled due to the pandemic, but researchers funded by Action for A-T were able to present their findings at various webinars and online events. These presentations showcased our latest projects and provided the wider A-T community with a comprehensive view of the progress made to date.

## "Spotlight on A-T Research" Webinar



Naga Munchetty & Mark Toms

As the ongoing pandemic restrictions led to the cancellation or postponement of almost all face-to-face A-T meetings and conferences, Action for A-T staged a virtual event to highlight some of the current A-T research projects which are taking place around the world. Key stakeholders from the global A-T community provided an easy to understand, concise overview of their current projects as well as answering audience questions. The webinar took place on the 29th of March 2021 and was hosted by Broadcaster, Journalist and Patron, Naga Munchetty and chair of the Research Advisory Committee, Dr Mark Toms.

There were six presentations broadcast live in English from various research teams and over 150 families, clinicians and other stakeholders tuned in to the event. The webinar was very popular and will be repeated in 2022 in conjunction with the A-T Alliance members. A recording of the webinar is available to view on our YouTube channel https://youtu.be/BYi8Vi_ETXQ

## Digital Communications

The Charity website www.ActionforAT.org remains the focal point for event sign-ups, electronic donations, and research news. The site was updated and enhanced throughout the year to provide the best possible experience for our stakeholders.

We also played a key role (alongside Mike Clahsen of BrAshA-T) in establishing a Global Directory website. The www.cureAT.org site brings together key information about current & past research studies and resulting publications. The site also has sections on care and guidance, patient registries, general information about the condition and a directory of all the known patient

organisations around the world. The content is available in several languages including Spanish, French, Italian and Turkish with a simplistic layout directing users to sources of useful information (e.g. websites, documents, relevant groups/meetings, etc.) rather than duplicating existing content on other websites.

Our monthly e-newsletter continues to be a successful tool to communicate our latest news to supporters. Using Mailchimp for this proves to be cheaper than a traditional printed newsletter and has the functionality to track usage and monitor engagement. Our e-newsletter is sent to all our consenting supporters, has a clear unsubscribe function and inactive supporters are removed from the mailing list periodically. As promotion of events and activities was limited in the first half of 2021, the e-newsletter was predominantly used to inform supporters about our work. These updates were well received and enabled us to secure various online donations, including some sizable donations via the Big Give matched funding campaign at the end of the year.

Social media remains a key communication tool for the Charity as it is free, easily accessible and can reach wide audiences. It also allows us to engage with our supporters on a more strategic level and build additional support from their own contacts. Posts are carefully managed to ensure that the content is engaging and not repetitive and this more targeted and planned approach helped us increase our followers throughout the year. We will continue to develop our social media presence in 2022 using all available technological advancements, popular platforms, and our celebrity patrons to raise further awareness.

## National and Local News Media Coverage

We continued to raise awareness of A-T through a series of articles and editorials in the local, national and industry press and various news websites. These helped us highlight the condition to new audiences, recruit volunteers and secure additional support and donations. Our CEO also recorded short film clips with various TV networks highlighting regional A-T related news stories.

## Film

Due to the ongoing pandemic restrictions, no new promotional films were made in 2021. We did, however, continue to showcase our existing films at various events, meetings and via social media to help raise awareness of A-T and the devastating impact it has on families.

All of the charity's films are available to view on our Vimeo and YouTube channels.

vimeo.com/actionforat/videos

youtube.com/c/ActionforatOrg

# Our Future Plans: Areas Of Focus For 2022

The Trustees believe that Action for A-T is well placed to meet its charitable objectives but have also identified the need for further development to strengthen its research activities. During 2022 we will continue to consolidate and diversify our fundraising activities whilst actively developing existing and seeking new funding partnerships to meet the demands of the A-T research community. We will also continue to promote A-T research to engage new audiences and maintain interest from the research community.

We will implement a number of measures throughout the year to ensure that the Charity continues to be fit for future purpose and to help us achieve our aim of moving closer to tangible therapies or a cure for A-T.

## Building our Capacity and Capabilities

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us deliver our charitable objectives. Our size and structure enabled us to adapt quickly to the ever-changing environment in 2021 but as the world slowly returns to the new normal, we will:

- Review and prioritise projects based on available resources whilst seeking out new opportunities to raise funds in a safe and sustainable manner
- Explore new and enhance existing fundraising initiatives to provide the maximum return on investment
- Ensure that we have the necessary skills throughout the organisation to deliver our organisation wide objectives
- Keep up to date with current trends and remain flexible so that change can be implemented quickly if required
- Work closely with our grantees to minimise delays and ensure projects are progressing in line with their stated aims

## Continuing our Investment in Medical Research in the UK and Abroad

We will continue to seek out new research opportunities from the wider research community as well as focussing on key research themes related to A-T. Where possible, priority will be given to UK based projects whilst still calling for international applications where funds will allow. We will also continue to collaborate with other research charities whilst actively seeking new funding partners with similar objectives to our own.

We will maintain our close relationship with the Association of Medical Research Charities (AMRC) and work in conjunction with our research advisory committee (RAC) to develop and improve our peer review process and ensure that the research we fund is of the highest quality. This will include constant evaluation of our systems and processes as well as enlisting the help and support of various A-T experts around the globe.

Membership of the RAC will be continually reviewed to ensure that we have a broad range of scientific expertise in areas relating to A-T as well as lay representation from various A-T families as Action for A-T strongly supports public and patient engagement in its research processes.

## Strengthening and Increasing our Fundraising Activities

We will continue to develop a pipeline of new business opportunities whilst delivering our existing portfolio of activities. We will maintain and refresh our calendar of high profile and fun events whilst also working alongside others in a benefitting capacity to reduce the financial risk to the Charity. We will continue to develop and expand our trust and foundations programme whilst actively seeking new investment from individuals, corporates and major donors. We will also work closely with our key supporters and volunteer groups to meet the increasing demand from the research community.

## Working Closely with Others to Meet our Objectives

As our reach expands throughout the A-T world, we are less able to meet the increasing demands of the research community. The number of funding applications we receive continues to grow steadily year on year and we often have more fundable research projects than we can afford. We will therefore continue to work with and seek out new organisations with similar objectives to our own, to help ease the financial burden and speed up the process of finding a therapy or cure for A-T.

## Increasing Awareness of our Work and the Condition

Since we were established in 2012, a key priority has been raising awareness of A-T and the work of the Charity. This has been achieved by various means including celebrity endorsement, emotive films featuring researchers and A-T families and various branding opportunities. We will continue to do all that we can to highlight A-T whilst focusing on three key projects in 2022. Firstly, we will increase our celebrity endorsement opportunities by actively engaging our existing patrons and other celebrity supporters. If restrictions allow, we will also invest in at least one new promotional film to help engage with our existing and new event audiences as our existing films have proved extremely effective in securing additional support, awareness and funds for our research programme. Finally, we will work alongside the other members of the A-T Alliance to deliver another family focussed A-T research webinar.

## Board Composition

We will continue to evaluate the composition of our Trustee Board to facilitate the growth of the Charity and will consider further appointments to broaden and strengthen the Board's capabilities.

# Structure, Governance & Management

## Governing Document

Action for A-T is a charity registered in England and Wales (No. 1145303). The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

The Trustees have adopted the following policies and procedures for the recruitment, appointment, induction and training of new Trustees:

## Trustee Recruitment and Appointment

The Trustees listed on page (2) have overall responsibility for the strategic direction and effective governance of the Charity. Trustees are either elected or co-opted under the terms of the Trust deed and the total number of Trustees may not be fewer than five. If a vacancy occurs or a skills need is identified, new Trustees are recommended by the existing Trustees and interviewed by the Chairman and at least one other member of the board. Election is by majority vote and potential candidates must be over the age of eighteen and eligible to act. The Trustees will continue to evaluate the composition of the Board and will consider further appointments to broaden and strengthen the Board's capabilities to facilitate the growth of the Charity.

## Trustee Induction and Training

New Trustees receive an induction pack containing a copy of the trust deed, strategy, relevant information about the Charity and its work; and also, a copy of the Charity Commission literature about the role and responsibilities of being a Trustee. New Trustees are also invited to meet the Chief Executive and team members to learn first-hand how the Charity operates on a day-to-day basis.

During the induction process, new Trustees are also told about the connected parties' rule, given a copy of the Charity's conflict of interest policy, and asked to sign a Trustee declaration form. Where the Trustees have identified that there is a connection between the charity, or its Trustees and any third party with whom the Charity has dealt with, the Trustees will identify the relationship and the amounts involved within the notes to the financial statements.

## Organisational Structure

The Trustees meet formally four times per year and no business shall be conducted unless at least one-third of the total number of Trustees at the time, or two Trustees (whichever is greater) are present throughout the meeting. There are two meetings where the focus is on awarding grants for medical research and two meetings where Trustees review strategy and set operating plans and budgets. There is a review of operating and financial performance at every meeting. The Chief Executive is invited to attend all meetings of the Trustees and the Head of Fundraising is invited to report on plans and progress at specific meetings.

While most of the business of the Charity is conducted at the scheduled Trustee meetings, there are occasional ad-hoc meetings to deal with matters of special interest and regular electronic meetings are held to review ongoing governance objectives.

The Board of Trustees delegates the exercise of certain powers in connection with the management and administration of the Charity as set out below. This is controlled by regular reporting back to the Board of Trustees so that all decisions made under delegated powers can be ratified by the full Board of Trustees in due course.

The Research Advisory Committee (RAC) is chaired by a member of the Board of Trustees. Members of the RAC have a broad range of scientific expertise in areas relating to A-T but are not generally active researchers in the field of A-T in order to minimise bias and conflicts of interest. There is also lay representation on the committee as Action for A-T supports public and patient engagement in its research processes. The Trustees are very grateful to all of the members of the RAC for providing expert guidance and advice on a pro bono basis.

## Research Advisory Committee

The Research Advisory Committee (RAC) is chaired by a member of the Board of Trustees. Members of the RAC have a broad range of scientific expertise in areas relating to A-T but are not generally active researchers in the field of A-T to minimise bias and conflicts of interest. There is also lay representation on the committee as Action for A-T supports public and patient engagement in its research processes. The Trustees are very grateful to all the members of the RAC for providing expert guidance and advice on a pro bono basis.

## Chief Executive

The Chief Executive is responsible for the day-to-day management of the Charity's affairs and is assisted by a small executive team who act under his direction. As well as overseeing the operations of the Charity, the Chief Executive is also responsible for implementing policies as agreed by the Board of Trustees.

## Employees, Volunteers and Contractors

The Charity aims to be an organisation where employees, volunteers and contractors enjoy a sense of fulfilment and where they feel supported and developed. All stakeholders are kept fully informed about the Charity's strategy and objectives, as well as day-to-day news and events. Individuals are encouraged to give their suggestions and views on performance and strategy.

The Charity supports equal opportunities and a policy of recruitment and promotion based on aptitude and ability without discrimination is followed. Action for A-T is committed to the training, career development and promotion of all its employees. An individual's career development is assessed through annual appraisal and supervision. Training programmes are provided to meet any on-going needs, with the aim of developing individuals for both their current and their future roles.

## Risk Management

The Trustees have introduced a formal risk management process to assess business risks and implement risk management strategies. This has involved identifying the types of risks the Charity faces, prioritising them in terms of potential impact and likelihood of occurrence, and identifying means of mitigating the risks.

As part of this process the Trustees have reviewed and are satisfied with the adequacy of the Charity's current internal controls and the costs of operating controls relative to the benefits obtained. Procedures have been established for reporting failings immediately to the Chief Executive and to the Board of Trustees.

It is recognised that internal controls can only provide reasonable but not absolute assurance that major risks have been adequately managed. In the opinion of the Trustees the key risks are:

- The loss of reputation due to error, or fraud.
- The loss of income due to error, or fraud.
- Insufficient numbers of Trustees to allow the Charity to continue.
- Insufficient funds to allow the Charity to meet its objectives.
- Excessive reserves without justification deterring future donors and fundraisers.

In the opinion of the Trustees the policies and procedures are currently adequate to mitigate financial and reputation loss due to error or fraud whilst maintaining a viable future financially.

## Reserves Policy

The Trustees review the reserves policy each year to ensure that all relevant risk areas are included in accordance with guidance issued by the Charity Commission. Risks included are the impact of unexpected, reduced income, and the potential impact of restructuring costs and liabilities required to downsize the organisation in an orderly manner, if a permanent income reduction was anticipated.

The review concluded that the existing reserve target level of Six months of operating costs (approx. £90,000) was sufficient to cover the risks identified in the review. This allows sufficient time for Trustees and management to take appropriate mitigating actions, if required.

The Trustees continue their commitment to develop and grow the level of investment in research into A-T, whilst maintaining a focus on managing the overall costs of the charity.

## Investment Policy

The overall policy of the Charity is to maintain a series of designated funds deposit accounts to ring-fence any funds which the Trustees have identified as being made available for specific research projects, or other charitable activities.

The Trustees recognise the need to review this policy on an annual basis and to look at other potential opportunities whilst appropriately monitoring the available funds and being proactive in their management, to ensure the best interests of the Charity's objectives are maintained

Funds committed for research are paid out in arrears over the duration of the project. The Trustees reviewed and agreed to deposit funds in timed deposit accounts in order to obtain the best return with minimal managed risk.

During the year the Trustees transfer any funds surplus to general running costs of the Charity into an interest-bearing account which will offer a higher rate of return than holding it in the main Charity bank account. The aim is to ensure that the fund is not diminished over time due to inflation and to ensure that these funds are invested in future research projects.

### Pay and Remuneration of Key Management Personnel

The Trustee's principles are to pay staff a fair salary that is competitive within the charity sector, proportionate to the complexity of each role, it's related funding and responsible in line with the charitable objectives. Pay levels for all employees are reviewed annually and any overall percentage increases are authorised by the Board of Trustees.

Remuneration for the Chief Executive is agreed by the appropriate remuneration committee. Salaries are benchmarked using external data available from pay surveys (for the voluntary sector and charities located in and around London) and market conditions for the specific role and the target is the market median averages of these.

Ultimately however, salary increases relate to the funding available for each role and whether the increase will be affordable in the long term. To ensure pay is fair for all roles we are committed to paying all our employees at or above the London living wage as determined by the Living Wage Foundation.

## Financial Review

The Trustees are satisfied with the performance of the Charity and consider that the Charity is in an excellent position to continue its activities during the coming year, and the Charity's reserves are adequate to fulfil its current obligations.

### Income

At present, research into A-T is heavily dependent on charitable donations and by extension, Action for A-T's ability to instigate, organise and facilitate the fundraising efforts of our supporters and donors. The principle source of funding is donations from individuals, companies, and proceeds of fundraising events.

Total income raised in 2021 was **£593,451 (2020 - £458,645).**

### Charitable Expenditure

The cost spent on Charitable Activities Was **£440,191 (2020 - £839,221)** of which **£262,572 (2020 – £677,077)** was for grants provided for funding of research projects.

The cost of generating voluntary income was **£82,281 (2020 - £97,468)** whilst the cost of generating income from charitable events was **£76,057 (2020 - £45,090)**

Governance costs of **£19,281 (2020 - £19,586)** were incurred.

### General Funds

The Trustees will aim to make best use of any unrestricted funds, however they reserve the right to retain general reserves in hand until they can be used in the most efficient manner to further the objectives of the Charity. The Trustees are conscious that it should not provide funding for research where they have not been able to demonstrate that its use will offer the best opportunity to further the knowledge and treatment into A-T. Please refer to the investment policy with regard to those times where the Trustees believe general funds are in excess of the anticipated running costs of the Charity.

### Designated Funds

Designated funds of **£nil** were brought forward from 2020. In 2021, **£nil** of funds were passed on to the research projects detailed in note 8 on page 34.

As at 31 December 2021 designated funds carried forward are **£nil**.

### Restricted Funds

Restricted funds of **£42,462** were brought forward from 2020. During the year **£65,326** of restricted income was received against projects funded during 2021. During 2021, **£42,462** of funding was made to the research projects detailed in note 8 Page 34.

At 31 December 2021 restricted funds of £65,326 **(2020 - £42,462)** were carried forward and the Trustees are satisfied that

the wishes of the donors were met fully. If further funds are received in the future the Trustees will ensure that those funds are used in accordance with those restrictions. Should it not prove possible to adhere to those instructions those funds will be offered back to the provider unless they indicate that they can be used for an alternative purpose.

## Trustees' Responsibilities

The Trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of the incoming resources and application of resources of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP 2015 (FRS 102);
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the Charity and financial information included on the Charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

The Trustees declare that they have approved the Trustees report included in the previous pages

Signed on behalf of the charity's Trustees





Toby Read (Chairman)

William Rowberry (Treasurer)

Dated: 26th May 2022

Dated: 26th May 2022

# Auditors Report

## Independent Auditor's Report to the Trustees of Action for A-T

### Opinion

We have audited the financial statements of Action for A-T Registered Charity Number: 1145303 (the 'charity') for the year ended 31 December 2021 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2021 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern:

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

## Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

## Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

## Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- Conclude on the appropriateness of the trustee's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charity to cease to continue as a going concern.
- Evaluate the overall presentation, structure, and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

## Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

(Continued)



A & N (Haslemere) Limited Statutory Auditor
Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

Dated: 26th May 2022

A & N (Haslemere) Limited is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

# Statement Of Financial Activities

for the year ended 31 December 2021

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.21 Total Funds £** | 31.12.20 Total Funds £ |
|---|---|---|---|---|---|
| **Income and Endowments from** | | | | | |
| Donations and legacies | 3 | 168,823 | 65,326 | **234,149** | 265,902 |
| **Charitable Activities** | 5 | | | | |
| Fundraising & challenge events | | 305,409 | - | **305,409** | 139,407 |
| Investment income | 4 | 11,452 | - | **11,452** | 12,130 |
| Other income | | 42,441 | | **42,441** | 41,206 |
| **Total** | | 528,125 | 65,326 | **593,451** | 458,645 |
| **Expenditure on** | | | | | |
| Raising funds | 6 | 82,281 | - | **82,281** | 97,468 |
| **Charitable Activities** | 7 | | | | |
| Fundraising & challenge events | | 76,057 | - | **76,057** | 45,090 |
| Grants | | 220,110 | 42,462 | **262,572** | 677,077 |
| Governance costs | | 19,281 | - | **19,281** | 19,586 |
| **Total** | | 397,729 | 42,462 | **440,191** | 839,221 |
| **Net Income / (Expenditure)** | | 130,396 | 22,864 | **153,260** | (380,576) |
| **Reconciliation of Funds** | | | | | |
| **Total funds brought forward** | | 187,423 | 42,462 | **229,885** | 610,461 |
| **Total Funds Carried Forward** | | 317,819 | 65,326 | **383,145** | 229,885 |

The notes form part of these financial statements

# Statement Of Financial Position

for the year ended 31 December 2021

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.21 Total Funds £** | 31.12.20 Total Funds £ |
|---|---|---|---|---|---|
| **Fixed Assets** | | | | | |
| Tangible assets | 17 | 324 | - | **324** | 324 |
| **Current Assets** | | | | | |
| Stocks | 18 | 9,532 | - | **9,532** | 14,251 |
| Debtors | 19 | 37,139 | - | **37,139** | 51,849 |
| Cash at bank | 20 | 1,306,414 | 65,326 | **1,371,740** | 1,497,604 |
| | | 1,353,085 | 65,326 | **1,418,411** | 1,563,704 |
| **Creditors** | | | | | |
| Amounts falling due within one year | 21 | (448,986) | - | **(448,986)** | (606,965) |
| **Net Current Assets** | | 904,099 | 65,326 | **969,425** | 956,739 |
| **Total Assets Less Current Liabilities** | | 904,423 | 65,326 | **969,749** | 957,063 |
| **Creditors** | | | | | |
| Amounts falling due after more than one year | 22 | (586,604) | - | **(586,604)** | (727,178) |
| **Net Assets** | | 317,819 | 65,326 | **383,145** | 229,885 |
| **Funds** | 23 | | | | |
| Unrestricted funds | | | | **317,819** | 187,423 |
| Restricted funds | | | | **65,326** | 42,462 |
| **Total Funds** | | | | **383,145** | 229,885 |

The notes form part of these financial statements

The Trustees declare that they have approved the financial statements.

Signed on behalf of the charity's Trustees.



Toby Read (Chairman)

Dated: 26th May 2022



William Rowberry (Treasurer)

Dated: 26th May 2022

# Statement of Cash Flows

for the year ended 31 December 2021

| | Notes | **31.12.21** **£** | 31.12.20 £ |
|---|---|---|---|
| **Cash flows from operating activities:** | 1 | | |
| Cash generated from operations | | **(137,316)** | (54,158) |
| Net cash provided by operating activities | | **(137,316)** | (54,158) |
| **Cash flows from investing activities:** | | | |
| Purchase of tangible fixed assets | | **-** | - |
| Interest received | | **11,452** | 12,130 |
| Net cash provided by investing activities | | **11,452** | 12,130 |
| **Change in cash and cash equivalents in the reporting period** | | **(125,864)** | (42,028) |
| **Cash and cash equivalents at the beginning of the reporting period** | | **1,497,604** | 1,539,632 |
| **Cash and cash equivalents at the end of the reporting period** | | **1,371,740** | 1,497,604 |

# Notes to the Statement of Cash Flows

for the Year Ended 31 December 2020

## 1. Reconciliation of net (expenditure)/income to net cash flow from operating activities

| | **31.12.20 £** | 31.12.19 £ |
|---|---|---|
| **Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)** | **153,260** | (380,576) |
| **Adjustments for:** | | |
| Depreciation charges | **-** | 162 |
| Interest received | **(11,452)** | (12,130) |
| (Increase)/decrease in stocks | **4,719** | (3,440) |
| Decrease in debtors | **14,710** | 28,019 |
| Increase/(decrease) in creditors | **(298,553)** | 313,807 |
| **Net cash provided by operations** | **(137,316)** | (54,158) |

## 2. Analysis of changes in net fund

| | At 1.1.21 £ | Cash Flow £ | 31.12.21 £ |
|---|---|---|---|
| Net cash | | | |
| Cash at bank | 1,497,604 | (125,864) | 1,371,740 |
| | 1,497,604 | (125,864) | 1,371,740 |
| Total | **1,497,604** | **(125,864)** | **1,371,740** |

# Notes to the Financial Statements

for the Year Ended 31 December 2021

## 1. Accounting Policies

### Basis of preparation of financial statements

The financial statements of the charity, which is a public benefit entity under FRS102, have been prepared in accordance with the Charities SORP (FRS102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011.

The financial statements have been prepared under the historical cost convention. The accounts are prepared in £ sterling to the nearest £1.

Action for A-T meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historic cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### Accounting convention

The financial statements are prepared on a going concern basis, under the historic cost convention.

The Charity is entirely dependent on receiving income from fundraising and donations and as a consequence the going concern basis is also dependent on the continuation of such income.

### Incoming resources

All incoming resources are included in the Statement of Financial Activities under FRS102 when that receipt is probable, whereas it was previously recognised when the Charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. For legacies, entitlement is the earlier of the Charity being notified of an impending distribution or the legacy being received.

Gifts in kind, including donated professional services are recognised as income when the Charity has control over them, any conditions associated with the donated item have been met, the receipt of economic benefit from the use of by the Charity if the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS102), the general volunteered time is not recognised and refer to the Trustees' Report for more information about this contribution.

On receipt, donated professional services are recognised on the basis of the value of the gift to the Charity which is the amount the Charity would have been willing to pay to obtain that service on the open market.

Gifts in kind donated for distribution are included at fair value upon receipt under FRS102 subject to the cost of recognition outweighing the benefit provided to Action for A-T. Previously they were included at a valuation and recognised as income when they are distributed. Any donated facilities are included at the value to the Charity where this can be quantified, and a third party is bearing the cost. No amounts are included in the financial statements for services donated by volunteers.

### Resources expended

All expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs allocated to activities. Where costs cannot be directly attributed to particular activities, they have been allocated on a basis consistent with the use of the resources.

Overheads have been allocated on the basis of the activity income of the Charity.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities. Support costs are those costs incurred directly in support of expenditure on the objects of the Charity and include project management carried out by the Trustees. Governance costs are those incurred in connection with the administration of the Charity and compliance with constitutional and statutory requirements.

Grants offered subject to conditions which have not been met at the year-end date are noted as a commitment but not accrued as expenditure.

# Notes to the Financial Statements

for the Year Ended 31 December 2021

## Governance costs

Governance costs comprise all costs involving the public accountability of the Charity and its compliance with regulations and good practice. These costs include costs related to the audit, legal fees, and apportionment of overheads.

## Allocation and apportionment of costs

Fundraising Events & Challenge Events costs are allocated in their income ratio during the year.

## Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Computer equipment - 33% on cost.

## Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

## Taxation

The charity is exempt from tax on its charitable activities.

## Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors which have been raised by the Charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements. Any investment income, gains or losses are allocated to the appropriate fund.

Designated funds are funds set aside by the Trustees out of general reserves for a particular purpose. The aim and use of each designated fund is set out in the notes to the financial statements. The Trustees will review the funds on an ongoing basis. At the conclusion of the purpose for the fund any excess remaining funds will be transferred back into general funds. If a shortfall arises the Trustees will consider whether any additional general funds should be transferred to designated funds. Any investment income, gains or losses are allocated to the appropriate fund.

## Foreign currencies

Assets and liabilities in foreign currencies are translated into sterling at the rate of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling at the date of the transaction. Exchange differences if applicable are taken into the Statement of Financial Activities.

# Notes to the Financial Statements

for the Year Ended 31 December 2021

## 2. Critical Accounting Judgements and Key Sources of Estimation Uncertainty

### Critical accounting estimates and judgements

In the application of the charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

### Key sources of estimation uncertainty

The annual depreciation charge for tangible fixed assets in sensitive to changes in the estimated useful economic lives and residual value of fixed assets. The useful economic lives and residual values are reassessed on an annual basis. They are amended where deemed necessary to reflect current estimations based on physical condition, utilisation, and advancement of technologies. Note 17 discloses the carrying value if the tangible fixed assets and the depreciation policy is listed above in accounting policies.

## 3. Donations and Legacies

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.21 £** | 31.12.20 £ |
|---|---|---|---|---|
| Donations | 131,260 | 65,326 | **196,586** | 175,785 |
| Gift Aid | 12,163 | - | **12,163** | 8,498 |
| Fundraising | 25,400 | - | **25,400** | 81,619 |
| | 168,823 | 65,326 | **234,149** | 265,902 |

## 4. Investment Income

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.21 £** | 31.12.20 £ |
|---|---|---|---|---|
| Bank interest | 11,452 | - | **11,452** | 12,130 |

## 5. Income from Charitable Activities

| | Activity | **31.12.21 £** | 31.12.20 £ |
|---|---|---|---|
| Fundraising events | Fundraising & Challenge events | **106,007** | 43,820 |
| Challenge events | Fundraising & Challenge events | **199,402** | 95,587 |
| | | **305,409** | 139,407 |

## 6. Raising Funds

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.21 £** | 31.12.20 £ |
|---|---|---|---|---|
| **Raising donations and legacies** | | | | |
| Staff costs | 59,786 | - | **59,786** | 60,010 |
| Support costs | 22,495 | - | **22,495** | 37,458 |
| | 82,281 | - | **82,281** | 97,468 |

## 7. Charitable Activities Costs

| | Direct Costs £ | Grant funding of activities (see note 8) £ | Support Costs (see note 9) £ | **Totals £** |
|---|---|---|---|---|
| Fundraising & challenge events | 56,234 | - | 19,823 | **76,057** |
| Grants | - | 207,960 | 54,612 | **262,572** |
| Governance costs | - | - | 19,281 | **19,281** |
| | 56,234 | 207,960 | 93,716 | **357,910** |

## 8. Grants Payable

| | **31.12.21 £** | 31.12.20 £ |
|---|---|---|
| Grants | **207,960** | 622,245 |

The total grants paid to institutions during the year was as follows:

| | **31.12.21 £** | 31.12.20 £ |
|---|---|---|
| University of Texas, USA - A-T cerebellar neurodegeneration and inositol phosphate signalling | **22,519** | - |
| Duke University, USA - A new function for ATM and a new theory for the clinical abnormalities in A-T | **249,854** | - |
| University of Birmingham, UK - (Research project underspends refunded) Identifying new therapies for blood cancers in patients with A-T | **(33,437)** | - |
| Nottingham University Hospital, UK - (Research project underspends refunded) longitudinal brain changes in childhood A-T | **(7,124)** | - |
| Imagin Institute Paris, France - (Research project underspends refunded) - Does irregular repair of DNA damage in Neurons and Lymphocytes cause cellular degeneration in A-T patients? | **(7,371)** | - |
| Oxford University, UK - (Research project underspends refunded) - The use of patient stem cell-derived mini-brains to study A-T | **(16,481)** | - |
| Sheba Medical Centre, Israel - Using new immunotherapy methods to treat lymphoma and leukaemia in A-T | **-** | 143,400 |

| | | |
|---|---|---|
| University of Rochester, USA - Recurrent pulmonary infections and their impact on neurological decline in A-T | - | 246,691 |
| University of Birmingham, UK - Deciphering the molecular mechanism linking Ataxia-Telangiectasia and Ataxia-Telangiectasia-Like Disorder | - | 105,183 |
| Nottingham University Hospital, UK - The David Peake Study to test the feasibility of whole-body MRI for cancer surveillance in children and young people with Ataxia Telangiectasia | - | 100,557 |
| University of Birmingham, UK - A survey of cancer in Ataxia Telangiectasia patients in the UK | - | 53,619 |
| | **207,960** | 649,449 |

## 9. Support Costs

| | Management | Finance | Information Technology | Other | Wages | Governance Costs | **Totals** |
|---|---|---|---|---|---|---|---|
| | £ | £ | £ | £ | £ | £ | **£** |
| Raising donations and legacies | 7,425 | 928 | 1,473 | 11,241 | 1,108 | 320 | **22,495** |
| Fundraising & challenge events | 7,392 | 1,108 | 1,472 | 9,851 | - | - | **19,823** |
| Grants | - | - | - | - | 54,612 | - | **54,612** |
| Governance costs | - | - | - | - | - | 19,281 | **19,281** |
| | 14,817 | 2,036 | 2,945 | 21,092 | 55,720 | 19,601 | **116,211** |

| **Activity** | **Basis of allocation** |
|---|---|
| Management | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Finance | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Information technology | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Human resources | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Other | 90 % Raising Donation & legacies 10 % Fundraising & Challenge Events |
| Governance costs | 100% Governance cost |

## 10. Trustees' Remuneration And Benefits

There were no Trustees' remuneration or other benefits for the year ended 31 December 2021 nor for the year ended 31 December 2021.

## Trustees' Expenses

There were no Trustees' expenses paid for the year ended 31 December 2021 nor for the year ended 31 December 2021.

## 11. Staff Costs

Only one employee received emoluments in excess of £60,000.

The Charity considers its key management personnel to be the Trustees, Chief Executive and senior management. The total employment benefits of the key management personnel were £124,481 (2020 - £121,049). Only one employee had employment benefits falling between £65,000 and £70,000 (2020 - 1).

## 12. Comparatives for the Statement of Financial Activities

| | Unrestricted Funds £ | Restricted Funds £ | **Total Funds £** |
|---|---|---|---|
| **Income and endowments from** | | | |
| Donations and legacies | 158,623 | 107,279 | **265,902** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 139,407 | - | **139,407** |
| Investment income | 12,130 | - | **12,130** |
| Other income | 41,206 | - | **41,206** |
| **Total** | 351,366 | 107,279 | **458,645** |

| | Unrestricted Funds £ | Restricted Funds £ | **Total Funds £** |
|---|---|---|---|
| **Expenditure on** | | | |
| Raising funds | 97,468 | - | **97,468** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 45,090 | - | **45,090** |
| Grants | 612,260 | 64,817 | **677,077** |
| Governance costs | 19,586 | - | **19,586** |
| **Total** | 774,404 | 64,817 | **839,221** |
| **Net income/(Expenditure)** | (423,038) | 42,462 | **(380,576)** |
| **Reconciliation of funds** | | | |
| Total funds brought forward | 610,461 | - | **610,461** |
| **TOTAL FUNDS CARRIED FORWARD** | 187,423 | 42,462 | **229,885** |

## 13. Employee Benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits would be recognisable immediately as an expense when the Charity is demonstrably committed to terminate an employee's employment or to provide termination benefits.

## 14. Pension Costs

The pension costs charged in the financial statements represent the contributions payable by the Charity during the year to a multi-employer defined benefit pension scheme.

# Notes to the Financial Statements - continued

for the Year Ended 31 December 2021

## 15. Financial Instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and are subsequently measured at their amortised cost.

## 16. Creditors and Provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

## 17. Tangible Fixed Assets

| | Computer Equipment £ |
|---|---|
| **Cost** | |
| At 1 January 2021 and 31 December 2021 | 2,358 |
| **Depreciation** | |
| At 1 January 2021 and 31 December 2021 | 2,034 |
| **Net Book Value** | |
| At 31 December 2021 | 324 |
| At 31 December 2020 | 324 |

## 18. Stocks

| | **31.12.21 £** | 31.12.20 £ |
|---|---|---|
| Stocks | **9,532** | 14,251 |

Stocks are stated at the lower of cost and estimated selling price less costs to complete and sell. Cost includes all costs of purchase, costs of conversion and other costs incurred in bringing stock to its present location and condition. Due allowance is made for obsolete and slow-moving items.

Donated stocks are fair valued when their economic benefit is probable, it can be measured reliably, and the charity has control over the item.

## 19. Debtors: Amounts Falling Due Within One Year

| | **31.12.21** **£** | 31.12.20 £ |
|---|---|---|
| Deposit | **925** | 925 |
| Prepayments and accrued income | **36,214** | 50,924 |
| | **37,139** | 51,849 |

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due

## 20. Cash at Bank

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.21 Total Funds £** | 31.12.20 Total Funds £ |
|---|---|---|---|---|
| Bank Current Accounts | 44,804 | - | **44,804** | 51,010 |
| Bank Current Accounts (US $) | 14,374 | - | **14,374** | 15,484 |
| Reserve Account | 370,614 | 65,326 | **435,940** | 865,898 |
| Investment Accounts | 876,622 | - | **876,622** | 565,212 |
| Total | 1,306,414 | 65,326 | **1,371,740** | 1,497,604 |

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of twelve months or less, and bank overdrafts. Should any bank overdrafts arise they would be shown within borrowings in current liabilities.

## 21. Creditors: Amounts Falling Due Within One Year

| | **31.12.21** **£** | 31.12.20 £ |
|---|---|---|
| Grant Payable | **438,757** | 600,198 |
| Accruals and deferred income | **10,229** | 6,767 |
| | **448,986** | 606,695 |

## 22. Creditors: Amounts Falling Due After More Than One Year

| | **31.12.21** **£** | 31.12.20 £ |
|---|---|---|
| Other creditors | **586,604** | 727,178 |

## 23. Leasing Agreements

During the next twelve months the Charity has operating lease commitments totaling £12,442 (2020 - £12,442) for contracts expiring in more than one year. The total future commitments are £12,442 (2020 - £12,442)

## 24. Movement in Funds

| | At 1.1.21 £ | Net Movement in Funds | **At 31.12.21 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 187,423 | 130,396 | **317,819** |
| **Restricted Funds** | | | |
| Restricted Funds | 42,462 | 22,864 | **65,326** |
| Total Funds | 229,885 | 153,260 | **383,145** |

**Net movement in funds, included in the above are as follows**

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 528,125 | (397,729) | **130,396** |
| **Restricted Funds** | | | |
| Restricted Funds | 65,326 | (42,462) | **22,864** |
| Total Funds | 593,451 | (440,191) | **153,260** |

**Comparatives for movement in funds**

| | At 1.1.20 £ | Net Movement in Funds | **At 31.12.20 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 610,461 | (423,038) | **187,423** |
| Restricted Funds | - | 42,462 | **42,462** |
| Total Funds | 610,461 | (380,576) | **229,885** |

## 24. Movement in Funds - Continued

Comparative net movement in funds, included in the above are as follows:

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 351,366 | (774,404) | **(423,038)** |
| **Restricted Funds** | | | |
| Restricted Funds | 107,279 | (64,817) | **42,462** |
| Total Funds | 458,645 | (839,221) | **(380,576)** |

A current year 12 months and prior year 12 months combined position is as follows:

| | At 1.1.21 £ | Net Movement in Funds | **At 31.12.21 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 610,461 | (292,642) | **317,819** |
| **Restricted Funds** | | | |
| Restricted Funds | - | 65,326 | **65,326** |
| Total Funds | 610,461 | (227,316) | **383,145** |

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 879,491 | (1,172,133) | **(292,642)** |
| **Restricted Funds** | | | |
| Restricted Funds | 172,605 | (107,279) | **65,326** |
| Total Funds | 1,052,096 | (1,279,412) | **(227,316)** |

## 25. Related Party Disclosures

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2020 - £nil). There are no expenses paid to the Trustees in the year. No trustee is deemed to have benefited as a result of a related party connection. All trustees have declared all such relationships to the Chairman.

## 26. Post Balance Sheet Events

**Covid-19 Pandemic**

At the time of writing these accounts, all Covid-19 pandemic restrictions in the UK have ended and we have resumed virtually all of our pre-pandemic activities. The trustees therefore believe that there are no ongoing concern issues.

## 27. Ultimate Controlling Party

The Trustees control Action for A-T in accordance with the trust deed.

# Detailed Statement of Financial Activities

for the Year Ended 31 December 2021

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.21 £** | 31.12.20 £ |
|---|---|---|---|---|
| **Income and Endowments** | | | | |
| Donations | 131,260 | 65,326 | **196,586** | 175,785 |
| Gift aid | 12,163 | - | **12,163** | 8,498 |
| Fundraising | 25,400 | - | **25,400** | 81,619 |
| | 168,823 | 65,326 | **234,149** | 265,902 |
| **Investment income** | | | | |
| Bank interest | 11,452 | - | **11,452** | 12,130 |
| **Charitable activities** | | | | |
| Fundraising events | 106,007 | - | **106,007** | 43,820 |
| Challenge events | 199,402 | - | **199,402** | 95,587 |
| | 305,409 | - | **305,409** | 139,407 |
| **Other income** | | | | |
| Other income | 4,000 | - | **4,000** | 3,000 |
| HMRC JRS Grant | 38,441 | - | **38,441** | 38,206 |
| | 42,441 | - | **42,441** | 41,206 |
| **Total incoming resources** | 528,125 | 65,326 | **593,451** | 458,645 |
| **Expenditure** | | | | |
| **Raising donations and legacies** | | | | |
| Wages | 59,786 | - | **59,786** | 60,010 |
| **Charitable activities** | | | | |
| Event campaign costs | 56,234 | - | **56,234** | 40,927 |
| Grants to institutions | - | - | **-** | 622,245 |
| | 221,732 | 42,462 | **264,194** | 663,172 |
| **Support costs** | | | | |
| **Management** | | | | |
| Wages | 14,817 | - | **14,817** | 14,922 |
| **Finance** | | | | |
| Bank charges | 2,036 | - | **2,036** | 1,056 |
| **Information technology** | | | | |
| Repairs and renewals | 2,945 | - | **2,945** | 3,999 |

# Detailed Statement of Financial Activities

for the Year Ended 31 December 2021

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.21 £** | 31.12.20 £ |
|---|---|---|---|---|
| **Other** | | | | |
| Rent, rates and water | 14,853 | - | **14,853** | 13,089 |
| Insurance | 1,036 | - | **1,036** | 1,036 |
| Telephone | 736 | - | **736** | 758 |
| Postage and stationery | 312 | - | **312** | 809 |
| Sundries | 1,746 | - | **1,746** | 1,976 |
| Advertising | 998 | - | **998** | 2,042 |
| Subscription | 512 | - | **512** | 932 |
| Donation collection fees | 899 | - | **899** | 1,002 |
| | 21,092 | - | **21,092** | 21,644 |
| **Fundraising** | | | | |
| Wages | 55,720 | - | **55,720** | 54,832 |
| **Governance costs** | | | | |
| Wages | 13,969 | - | **13,969** | 13,802 |
| Auditors' remuneration | 3,300 | - | **3,300** | 3,300 |
| Accountancy and legal fees | 2,322 | - | **2,322** | 2,322 |
| Computer equipment | - | - | **-** | 162 |
| | 19,601 | - | **19,601** | 19,586 |
| Total resources expended | 397,729 | 42,462 | **440,191** | 839,221 |
| Net (expenditure)/income | 130,396 | 22,864 | **153,260** | (380,576) |

# Acknowledgments

Action for A-T relies entirely on its donors and supporters who so generously give their time and money to support vitally needed research into A-T. With their support we believe we can make a difference to all people with A-T and their families.

We would like to give special thanks to the following organisations that worked alongside us in 2021:

## Our Research Partners

BrAshA-T Ataxia Telangiectasia and their trustees

A-T Children's Project (USA) and their Medical Research Team

Ataxia Telangiectasia Society

AEFAT

Great Ormond Street Hospital Charity

## Support from Companies, Trusts & Foundations

We are aware that Companies, Trusts & Foundations are often approached to support charities and are therefore extremely grateful to the following organisations for their generous support.

An Anonymous Trust
Ari Fleet UK Ltd
Barclays
Barton Comms
BCA
Bellway Homes
Big Give
Blyth Watson Charitable Trust
Cast Media
Chapman Charitable Trust
Cinch
Clarke Willmott
Claws Consultants
Epsom & Ewell Borough Council
Epsom Rotary Club
Eveson Charitable Trust
Global Entertainment
Henrik Bergrem
Hospital Saturday Fund
STV
International College Spain (ICS)
International Racing Club
Lumen Financial Ltd
Michael and Anna Wix Charitable Trust
Mollie's Miracle Team
Naga Munchetty
Niall Flanagan
Nick Rich
The Proper Awards
Quest Professional
Rawson Digital
Reed Foundation
Rest-Harrow Trust
Robin Hewison
Syder Foundation
Weatherall Foundation Trust
Work for Good

**Corporate or professional services provided by:**

A & N Chartered Accountants
Akin Gump
Chris Stanton
Gecko Graphic Design

## Our Supporters

We have relied almost exclusively on our supporters, volunteers and Trustees for their time and commitment to raising money and spreading awareness about this devastating condition. Thank you to everyone who has helped us to push research into A-T forwards.

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE

Action for A-T, Aruna House, 2 Kings Road, Haslemere, Surrey GU27 2QA.
01428 853313 | info@actionforAT.org | www.actionforAT.org
Registered Charity number: 1145303

**ACTION FOR A-T**

England & Wales - Charity number 1145303

# Accounts

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE




# Annual Report & Financial Statements

**for the year ended 31st December 2020**

Action for A-T - Charity registered number 1145303

www.ActionforAT.org

# Legal And Reference Information

## Patrons

Jonny Wilkinson CBE
Roger Black MBE
Jeremy Guscott MBE
Simon Shaw MBE
Rachel Morris MBE
Naga Munchetty
Leon Haslam

## Chief Executive

Sean Kelly

## Trustees at the date of approval

Toby Read (Chairman)
Emily Read
William Rowberry (Treasurer)
Tomos Shillingford
Maria Leonard
Chris Askew
Dr Mark Toms
Joseph Frost

## Appointed during the year or since year end

None

## Research Advisory Committee

Dr Mark Toms, Chairman

Dr Kathryn Johnson, Scientific Advisor, Consultant Neonatologist and Research Lead

Professor David Attwell, Jodrell Professor of Physiology, Department of Neuroscience, Physiology and Pharmacology, University College London (UCL)

Associate Professor Esther Becker, Associate Professor of Neurobiology, The Becker Group, Oxford University

Dr Simon Boulton, Group Leader, DNA Damage Response Laboratory, Cancer Research UK, London Research Institute

Dr Lisa Bunn, Lecturer in Neurological Physiotherapy and Motor Control, University of Plymouth

Professor Keith Caldecott, Professor of Biochemistry 'Royal Society Wolfson Research Merit Award Holder', and Deputy Director of the Genome Damage and Stability Centre, University of Sussex

Dr Richard Kay, Medical Statistician

Dr Nizar Mahlaoui, Paediatrician specialising in Immuno-Haematology, Necker-Enfants Malades Hospital, Paris and Coordinator of the French National Reference Centre for Primary Immune Deficiencies (CEREDIH)

Dr Guy Makin, Senior Paediatric Oncology Lecturer, University of Manchester

Dr Andrew Prayle, Clinical Assistant Professor, University of Nottingham

Professor Maria Grazia Spillantini, Professor of Molecular Neurology, John Van Geest Centre for Brain Repair, University of Cambridge

Professor Grant Stewart, Professor of Cancer Genetics, School of Cancer Sciences, University of Birmingham

Dr Alastair Wilkins, Reader in Neurology, University of Bristol and Consultant Neurologist at Frenchay Hospital, Bristol

Professor Matthew Wood, Professor of Neuroscience and Deputy Head of the Medical Sciences Division at the University of Oxford

## Patient Representatives

Mr Amandeep Sharma
Mrs Clare Gallagher
Mrs Natasha Schneider

## Charity Registration Number

United Kingdom Registered Charity number: 1145303

## Registered Office

Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

## Operational Address

Action for A-T
Carlton House
19 West Street
Epsom
Surrey
KT18 7RL

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# Chairman's Report

*Action for A-T is the UK's leading A-T medical research charity. We exist to harness world leading medical science to help improve the lives of those affected by Ataxia-Telangiectasia.*

## To all of our supporters


Emily and Toby Read

2020 was a year like no other due to the impact of the COVID-19 crisis upon so many aspects of our daily lives. In common with many organisations, the ambitious plans and goals we set ourselves at the start of the year were completely overtaken by events and we immediately recognised that we would need to adapt quickly to overcome the unprecedented changes the pandemic would force upon all of us.

Many of Action for A-T's traditional fund-raising activities had to be cancelled, including all face-to-face challenge and social events. This huge limitation on how we could fundraise meant the team at Action for A-T had to show enormous resilience, flexibility, creativity, and sheer hard work to find new and innovative ways to raise money. It is to their enormous credit that whilst fundraising was of course impacted, our team of talented and dedicated staff and volunteers still managed to generate significant funds for medical research in A-T. I am humbled and so grateful to have received so much continuing support from our supporters and donors who contributed both their time and money so generously, despite everyone having to cope with so many changes to their lives.

Everyone involved in Action for A-T hopes that the world will begin to return to normal before too much longer. So many people are raring to get back involved in running marathons, having cake sales, attending charity fundraising events and all the multitude of other in-person activities our supporters participate in. We look forward to turning all that positive activity into funding the A-T medical research agenda we have successfully supported for so long.

Thank you to everyone who helped to ensure that during the most difficult times in 2020, Action for A-T was able to continue to support vital research into this condition and I look forward to hopefully seeing many of you face to face during 2021.

Warm wishes



**Toby Read**
**Chairman, Action for A-T**

# Trustees' Report

*The Trustees of Action for A-T present their annual report and the financial statements of Action for A-T for the year ended 31 December 2020.*

The Trustees confirm that the annual report and financial statements of the Charity comply with Charities Act 2011, The Charities (Accounts and reports) Regulations 2008 and have been prepared in accordance with the Statement of Recommended Practice on Accounting and Reporting by Charities (Charities SORP FRS102).

## Reference and Administrative Details

Action for A-T is a charity registered in England and Wales (No. 1145303). The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. The Trustees met in February, June, September, and November in 2020. The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

## Public Benefit

Action for A-T's charitable objectives are set out in its governing Trust Deed, summarised in the "About Us" section on our website and include undertaking rigorously evaluated and properly conducted medical research into finding a cure or new treatment for the rare genetic condition Ataxia Telangiectasia (A-T).

During the year, the charity has continued to manage its ongoing research portfolio as well as committing funds to a variety of new A-T related research projects. Details of this work can be seen on pages 6 to 11.

Our Trustees have considered how our work may most effectively further our charitable objectives for the benefit of the public, in particular all those affected by Ataxia Telangiectasia, and have had regard to the Charity Commission's guidance on public benefit when reviewing activities against objectives set and in planning future activities.

## Objects, Achievements & Perfomance

**Action for A-T's mission is:**

**"To speed up the process of identifying a cure for A-T or treatments that delay or prevent the disabling effects of this childhood condition"**

To further that mission, the Charity focused on the following key areas in 2020:

- Identifying & funding research into A-T
- Ensuring that our research is high quality, peer reviewed and has clear and achievable aims
- Strengthening our fundraising capabilities
- Building collaborative partnerships
- Raising public awareness about A-T

## Identifying High-Quality Research into A-T

**Our Aim**

Action for A-T aim to build a community of A-T research leaders and increase the amount of research that is taking place here in the UK. Although we will always fund the highest quality applications wherever they are from; our key focus is to invest in projects and people based in the UK wherever possible.

**Our Performance**

Throughout 2020, our Chief Executive staged online meetings with key figures from the A-T research community and representatives from other medical research charities and patient groups to explore possible funding opportunities and further understand which areas of A-T research may provide the most promising outcomes.

Non-A-T researchers who specialise in related conditions were also contacted to drive future research projects and create greater interest in the condition. This strategy is repeated from year to year and once again proved very successful, enabling us to significantly increase the number and demographic of 'who' we advertise our grant rounds to.

# Funding High-Quality Research into A-T

*In addition to supporting and funding research aimed at improving the understanding of A-T, there are many innovative and exciting medical research opportunities that raise the prospect of real progress in combating the effects of genetic conditions such as A-T.*

## Our Aim

Action for A-T's aim is to be able to make grants to hospitals and universities throughout the world for the purpose of conducting research across all therapeutic areas related to A-T, with an emphasis on research that is likely to have a clear clinical application within the foreseeable future and/or which evaluate innovation in medical techniques which may have a potential benefit for children with A-T.

## Our Performance

Since Action for A-T was established in 2012, we have invested **£2,946,528** in 40 global research projects under six main research headings.

**Underpinning Research** - Developing new tools and techniques for conducting research

**Aetiology** - Understanding the causes of A-T

**Detection, Screening and Diagnosis** - Tests for diagnosing and monitoring patients with A-T

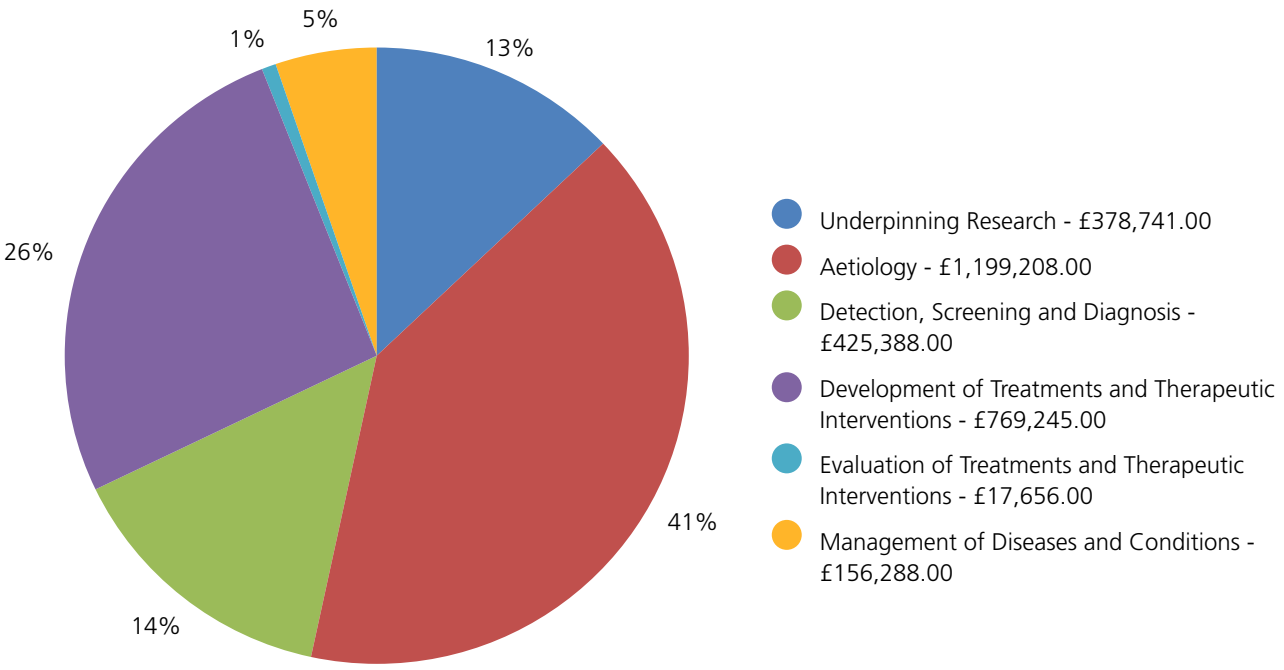
**Development of Treatments and Therapeutic Interventions** - Creating drugs and therapies to alleviate the symptoms of A-T

**Evaluation of Treatments and Therapeutic Interventions** - Studies to prove how new treatments work and understand how to use them

**Management of Diseases and Conditions** - Managing the symptoms of A-T

The chart below shows the historic allocation of our research investment portfolio and our total investment in each of these six research categories listed above.

## Total Research Spend Since 2012




The following five grants were awarded by the Trustees in February 2020:

# Using new immunotherapy methods to treat lymphoma and leukaemia in A-T

**Principal Researcher:** Dr Elad Jacoby
**Institute:** Sheba Medical Centre, Israel
**Cost:** £143,400 over 18 months
**Start Date:** March 2020

## Project Overview



Dr Elad Jacoby

In recent years, immunotherapy has revolutionised the field of blood cancer therapy. Immunotherapy is a type of treatment which prompts the body's own immune system to identify and destroy cancerous cells. CAR T-cell therapy is a form of immunotherapy that uses specially altered T-cells, which are a type of white blood cell that plays a central role in the immune response.

CAR T-cells have been shown to be extremely effective in the therapy of blood cancers, without producing the usual side-effects of chemotherapy. Currently, there is no available data regarding the feasibility and safety of CAR T-cell production in A-T patients and given high morbidity with traditional therapies, the proposed study could pave the way for safer treatments of lymphoma and leukaemia in patients with A-T.

Dr Jacoby and his team at the Sheba Medical Center believe that CAR T-cell immunotherapy for lymphoid malignancies in A-T patients is feasible and may lead to acceptable clinical results in the absence of adverse genotoxicity. The team plan to activate, transduce and expand T-cells from patients with A-T and study the feasibility of this process in-vitro, as well as analysing the CAR integration sites in the genome as part of the safety assessment. They will test this hypothesis using blood immune cells taken from 15 A-T patients and 15 healthy participants to study the viral integration of the CAR in products of CAR T-cells.

As the study is preclinical there will be no direct benefit for participating patients. However, as cellular immunotherapy is available in many countries, should the study findings prove the feasibility and safety of this method, A-T patients will be able to receive treatment either with commercial products or on clinical trials in the future.

# Recurrent pulmonary infections and their impact on neurological decline in A-T

**Principal Researcher:** Professor Margot Mayer-Proschel
**Institute:** University of Rochester, New York
**Cost:** £246,691 over 36 months
**Start Date:** July 2020

## Project Overview


Professor Margot Mayer-Proschel

Professors Mayer-Proschel and O'Reilly have previously generated a novel mouse model to study the early pathologies identified in A-T patients and established that their model recapitulates brain pathologies that mark the onset of neurological decline as seen in A-T patients. The models are also highly susceptible to recurrent respiratory viral infections and display a defective immune response that is associated with dysfunctional repair of the lung. While these defects have thus far been studied in isolation, the team propose that the vulnerability of the lung in A-T patients is an important contributor to neurological decline. They will now study whether respiratory viral infections and lung disease can affect the neurological status of patients and whether it can contribute to disease progression.

Many A-T patients suffer from chronic and reoccurring respiratory infections. While neural and lung pathologies have been studied in isolation, emerging evidence suggests that poorly controlled respiratory infections are associated with neurological decline. The team hypothesize that the neurologic decline seen in A-T individuals might be driven or exacerbated by systemic inflammatory responses that develop when the lung fails to effectively defend against infections. Subsequent studies in their developed animal model showed that these display an impaired ability to respond to recurrent respiratory viral infections and develop dysfunctional airway pathology reminiscent of those found in lung biopsies of A-T individuals.

The team have found no other reports that formally test a lung-brain connection in A-T neurologic disease and saw a unique opportunity to fill this knowledge gap. They will use state of the art techniques to analyse central nervous system and lung pathology using a combination of lab and animal-based experiments. They will work to manipulate and characterise lung and brain function in A-T and hope to yield new insights into the progression of pathology in A-T. Individual iPSCs will be grown and differentiated into cerebellar organoids using a defined protocol which makes use of molecules that reproduce development of the cerebellum in vitro (in a dish). Organoids will be validated using a variety of biochemical and immunohistochemical techniques. This involves testing of genetic material and cutting/staining sections of the mini brains to assess they have made the right cell types to learn about the cerebellum. Organoids will be prepared for single-cell sequencing, in collaboration with the core facility at the Wellcome Trust Centre for Human Genetics. This means the team can examine one cell at a time, from thousands of replicates, from large numbers of organoids, giving them the best resolution to dissect out the genetic basis of dysfunctional ATM in Purkinje neurons. This data will then be analysed both in-house and with collaborators.

# Deciphering the molecular mechanism linking Ataxia-Telangiectasia and Ataxia-Telangiectasia-Like Disorder

**Principal researchers:** Dr John Reynolds
**Institute:** University of Birmingham
**Cost:** £105,183 over 36 months
**Start Date:** October 2020

## Project Overview



Dr John Reynolds and Grant Stewart

Dr John Reynolds and his team at the University of Birmingham have recently identified a unique ATLD patient who exhibits all the clinical symptoms associated with ATLD, but in contrast cells from this patient can activate ATM efficiently and can repair IR-induced DNA damage normally. This suggests that a global inability to repair DNA double strand breaks may not be the underlying cause of the ataxia in ATLD and A-T patients as previously thought.

The team have discovered that the MRE11 mutation present in this unique ATLD patient specifically causes a defect in repairing DNA damage induced by the activity of an enzyme called Topoisomerase 2 (TOP2). TOP2 is a protein that resides in the cell and helps to relieve tangles in the DNA, called supercoils, by cutting the DNA and allowing it to unwind, before resealing the break. This activity of TOP2 is very important for regulating the expression of specific genes, particularly genes associated with brain development and function. However, in certain situations TOP2 is unable to reseal the DNA break, and as such the cell requires the activity of other proteins e.g. ATM and MRE11, to repair the damage. Therefore, it is possible that mutations in MRE11 that cause an inability to repair DNA breaks caused by the activity of TOP2, will block the expression of genes that are required for brain development and function, leading to a progressive decline in neuronal fitness.

Based on these preliminary observations, the team will study how this unique mutant MRE11 protein causes a specific defect in the repair of TOP2-associated DNA double strand breaks and how this can be linked to the neurodegeneration exhibited by patients with A-T and ATLD.

Dr Reynolds and team believe that the results from this study will benefit clinicians involved in diagnosing patients with ATLD and atypical A-T. Clinically, patients with ATLD and A-T are nearly indistinguishable, and one of the diagnostic tests for ATLD, like A-T, is a failure to activate ATM following exposure to ionising radiation. Since the implications from this work is that patients with clinical ATLD may not exhibit an inability to activate ATM, this could affect the ability of the clinician to diagnose these patients properly. Results from this study will identify which DNA damage inducing agents should be used instead of, or in addition to, ionising radiation when carrying out diagnostic research to confirm a genetic diagnosis of ATLD.

# *The David Peake Study to test the feasibility of whole-body MRI for cancer surveillance in children and young people with Ataxia Telangiectasia

**Principal Researcher:** Dr Rob Dineen
**Institute:** University of Nottingham
**Cost:** £100,557 over 24 months
**Start Date:** October 2020

## Project Overview


Dr Rob Dineen

At present, there are no guidelines on how children and young people with A-T should be screened for cancer. Scans that use x-rays, like CT scans, can be particularly harmful in people with A-T so the current practice at the UK Paediatric A-T clinic is to perform blood tests. These tests can detect most types of leukaemia but are not effective at detecting solid tumours. As highlighted in a recent international consensus statement, effective cancer surveillance strategies for A-T patients are urgently required.

Dr Dineen and his team at the Queens Medical Centre will carry out a feasibility study of cancer surveillance using modified blood tests and whole-body MRI. They will recruit 20 participants with A-T who along with their parents and carers, will be invited to participate in workshops and focus groups to fully understand the impact of the tests and any findings.

The team will use advanced MRI scanning techniques to search for signs of cancer and to establish the technical feasibility of whole-body MRI. They will also carry out radiological analysis of the spectrum of findings taking appropriate action where needed. Each study participant will be scanned, and a Band 7 NHS Research Radiographer, Band 7 NHS Paediatric nurse and health psychologist research assistant will also be appointed to coordinate the various elements of the study.

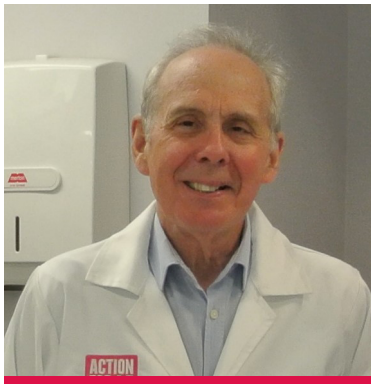
This feasibility study will equip the research team with the vital information needed to develop a larger trial to test whether cancer surveillance using whole body MRI scanning and blood tests is effective in children and young people with A-T. If successful, the proposed cancer surveillance programme could provide an effective way to identify the cancers in children and young people earlier, allowing earlier referral to the specialist centres. Because A-T is such a rare disease, and because a trial of cancer surveillance would be very difficult for other groups to deliver, it is highly likely that any guidelines developed from this UK-led trial would be adopted in many other countries.

**This research study was part funded thanks to a generous donation from the David Peake Appeal. David lost his battle with Pancreatic Cancer in 2016 and his family chose to commit the funds raised by his work colleagues at Grange Aston Martin and Cambria Automobiles PLC towards this project.*

# A new function for ATM and a new theory for the clinical abnormalities in A-T

**Principal Researcher:** Professor Malcolm Taylor
**Institute:** University of Birmingham
**Cost:** £53,619 over 24 months
**Start Date:** March 2021

## Project Overview



Professor Malcolm Taylor

Building on their initial pilot study in 2011, Professor Taylor and his team at the Institute of Cancer and Genomic Sciences will perform a detailed survey of cancer incidence in a cohort of ~300 UK individuals with A-T to gain a more accurate assessment of the tumour types that individuals develop.

The cohort of patients are registered with the national A-T clinic in Nottingham where Professor Taylor is well known having diagnosed the ATM mutations in virtually all 300 patients. Approximately 200 are still alive, some having already been treated for a cancer and of the ~100 that are deceased, 50% were due to cancer.

The data on cancers in this population will be analysed in a standard manner, in terms of the types of tumour and incidence rates of the different cancers compared to the normal population. Where tumour material is available, further molecular characterisation of the tumours using techniques such as whole genome sequencing and RNA-Seq will be performed. These will give a detailed assessment of both the mutational and transcriptional spectrum of the tumours and provide insight into the cancer phenotype within A-T, identifying the genetic drivers and biochemical pathways that promote and maintain this phenotype.

The results of the survey will enable the team to compute the risk of A-T patients developing cancer plus the full range of cancers they are predisposed to. They also hope to determine how the tumour type is related to the particular ATM mutations carried by the individuals and if there is any impact of the different types of mutation on clinical outcome.

## COVID-19

Shortly after our 2020 grant awards were made, the COVID-19 pandemic became a worldwide problem and operational restrictions were enforced on virtually all research institutions. As a result, the proposed start dates of the above studies were delayed and many existing grant recipients were forced to put their work on hold and subsequently request no costs extensions. At the time of writing this report, the pandemic continues to impact our daily lives and we expect there to be further delays to a large proportion of our research portfolio. We are monitoring the situation and working closely with our grant holders to help minimise any disruption to their work.



## Ensuring that our research is of the highest quality, is well managed and has clear and achievable aims

Research is at the heart of what we do, and our research strategy outlines our intentions on achieving our mission.

### Our Aim

Through our award-winning research process we aim to only fund projects of the highest-quality that have the greatest chance of advancing our understanding of A-T, improving treatment and management, and accelerating benefits to patients.

### Our Performance

The Trustees generally stage one grant round per year. Applications are peer reviewed by independent external reviewers before they are passed on to our Research Advisory Committee for further review. Projects which pass the peer review process and are deemed high enough quality are passed on to the Trustees to make the final decision based on several key criteria including available funds, strategic alignment, and existing research commitments.

Action for A-T administered its own full grant round at the end of July 2019 and a record number of applications were received from a variety of global research institutions. These applications were subject to our rigorous award-winning peer review process to ensure that the money generously raised by our donors was put to the best possible use and provide assurance to our Trustees.

Our Research Advisory Committee (RAC) are part of this process and made up of independent scientific experts from fields related to A-T, including clinicians, non-clinicians, and statistical expertise from a wide range of UK institutions. Lay members are also on the committee to incorporate the views of parents and patients living with A-T, bringing a valuable and unique perspective over what research should be funded. The RAC met in January 2020 to formally review all the applications and their funding recommendations were passed on to the Trustees.

## Project outcomes and sharing knowledge

We believe that sharing project outcomes and knowledge is a fundamental requirement for the development of new research strategies which will ultimately benefit those living with the condition. Progress, annual and final reports are mandatory for all our research grants to ensure that they are reaching the agreed milestones. These reports are formally reviewed by our scientific advisor to ensure that each project is in line with its stated aims and the outcomes are then converted into lay summaries to share with our supporters.

In addition, we also ask researchers to use the Global Research Impact Assessment Platform called Researchfish to report on their projects periodically and several years after their grant has ended.

Researchers are also encouraged to publish their findings in medical journals and where possible, make the findings freely available. The outputs of research such as publications usually occur sometime after a research project ends and it can take many years to translate research ideas into new treatments or therapies to improve quality of life.

The outcomes of all the concluded research we have funded are displayed on our website under our 'Completed Research' section. Where applicable, these posts also include link to any online publications and we also share project information via our social media channels and in various communications to our supporters and potential donors.

## Evaluating the outcomes of our research

As with all charities, we are passionate about demonstrating the impact of our work and understand the importance of monitoring the progress and outcomes of our research. Throughout the year we continued to work with our scientific advisor and other members of our Research Advisory Committee to oversee and evaluate the effectiveness of our ongoing research portfolio. Between them, they monitored the progress of ongoing projects and signed off on the projects which were completed to help ensure that the original research aims stated in the application were fulfilled.

The following studies concluded in 2020 and the initial project outcomes are as follows:

# Identifying new therapies for blood cancers in patients with A-T

**Principal Researcher:** Professor Malcolm Taylor
**Institute:** University of Birmingham
**Project Completion Date:** January 2020

This research was funded in partnership with BrAshA-T

## Project Overview


Professor Malcolm Taylor and team

Patients with Ataxia Telangiectasia (A-T) have an increased risk of developing blood cancers. These patients do not have a protein called ATM which is important for response to chemotherapy treatment. Consequently, when receiving chemotherapy for their blood cancers A-T patients experience substantial toxic effects. Therefore, new less toxic, blood cancer-specific therapies are highly needed.

Previously, Professor Taylor and his team developed a mouse model in which new treatments could be tested. This model lacked the ATM protein and had reduced development of T-cells, a combination which allows them to develop a variety of blood cancers that occur in human A-T patients. Upon investigation of these blood cancers the team noted that a protein called c-Myc is particularly active in cancer cells. In this study the team aimed to explore different ways of suppressing the action of c-Myc. They also wanted to test whether the addition of small molecules that inhibit c-Myc can stop cancer progression, and if these molecules could be used in combination with low doses of chemotherapy.

## Project Outcome

The first objective, using a technique 'in-vitro' (experiments performed outside of a living organism such as in a test tube/petri dish), looking at inhibition of tumour cell lines (by inhibiting c-Myc) was successful. The team found inhibiting several specific pathways within the c-Myc protein particularly effective, including inhibiting Aurora kinase B, BET and mTOR. The team were also able to look at combinations of inhibitors that might have a synergistic effect.

For the second phase of testing 'in-vivo', modifications of the project had to be made as there were insufficient mice with blood cancer to test all the treatments identified in-vitro.

They were therefore able to test certain inhibitors and able to use a slightly different mouse model in bigger numbers. BET and mTOR inhibition showed particularly effective tumour inhibition. The research team recognise the need to carry out further inhibitor tests in more mouse models to make further final conclusions. In the medium term, this work provides the basis to potentially develop more treatment options for one of the commonest malignancies seen in A-T patients.

## Publications

At the time of writing this report, a publication is currently being prepared.

# A Zebrafish model of Ataxia Telangiectasia (A-T)

**Principal Researcher:** Dr Andrew Grierson
**Institute:** Sheffield Institute for Translational Neuroscience (SITraN) & The Bateson Centre, University of Sheffield
**Project Completion Date:** June 2020

## Project Overview


Dr Andrew Grierson

Almost all human disease genes (approx. 70%) have an equivalent in zebrafish. While humans and zebrafish may not look alike, they are similar. Zebrafish are vertebrates (have a spinal cord) which is critical for modelling disorders of the nervous system such as A-T. This research aimed to genetically engineer zebrafish carrying mutations in the gene, called ATM, that causes A-T in human patients. The team

aimed to explore whether zebrafish could provide an adequate animal model for A-T. There is a need for adequate models as currently there are limitations with conventional animal models of A-T. They do not develop the neurological characteristics (cerebella degeneration) of the disease that an A-T human patient does. Once the research team created the zebrafish, they planned to look at the brain abnormalities seen in A-T and look at potential therapeutic drugs that may improve such symptoms.

## Project Outcome

The team were able to generate the ATM mutant zebrafish as planned using standard CRISPR techniques. For the second part of the project, they moved on to characterizing the phenotype of the ATM mutant zebrafish, particularly in the context of the neurological characteristics seen in human A-T patients. The cerebella of 12-month-old zebrafish were examined (both A-T & non A-T types). Unfortunately, in the A-T phenotype zebrafish there was no evidence of cerebella degeneration; both pathologically and functionally (using swimming behaviour). But there were some interesting findings which may be worth further exploration. Like patients, these fish were infertile, however, while A-T patients are sensitive to radiation, these fish are not. A-T patients also have a high incidence of cancer – uncontrolled cellular growth, and the team found that the male mutant zebrafish also exhibit uncontrolled cellular growth in their testicular tissue. It was unclear whether this was due to neoplastic (cancer) changes or not. This project will not influence further research in this area but has answered the original question as to whether zebrafish generated with new CRISPR technologies can be used as a model for the ataxia seen in A-T.

## Publications

The work will now be written up as a PhD thesis. Then a paper will be written to submit for publication.

# Unravelling the antibody deficiency in Ataxia Telangiectasia

**Principal Researcher:** Associate Professor Mirjam Van der Burg
**Institute:** Leiden University Medical Centre (LUMC), The Netherlands
**Project Completion Date:** November 2020

## Project Overview


Professor Mirjam Van der Burg

A-T is characterised by progressive cerebellar ataxia, chromosomal instability, immunodeficiency and increased cancer susceptibility. Patients' lives are shortened, usually from cancer or chronic lung failure, of which the latter is partly due to recurrent infections. Patients have an increased risk of severe infections because of a defect in antibody production by B-cells. The team aimed to explore and understand the immunoglobulin/ antibody defect seen in some patients with A-T, recognising that the defect is seen variably in patients. Those patients with severe immunoglobulin defects are known to have an earlier onset disease and a higher risk of malignancy. Once the defect was better understood the team planned to use this information to explore potential therapeutic targets and hoped to identify which patients were at risk of severe antibody deficiency.

## Project Outcome

The findings of this study have the potential to be clinically useful in the short term given that A-T can be detected on Newborn Blood Spot (NBS) screening. The NBS is the heel prick test taken on all babies in the UK by the midwife on Day 5 of life. Currently in the UK SCID (and hence A-T) is not one of the 9 conditions screened for on the blood spot. Decision making on which rare conditions should be screened for is influenced by a variety factors; however, the fundamental premise is that early diagnosis should improve outcome.

It could be argued that this is currently not the case in A-T, a situation that may change as new treatments are discovered. The team from the Netherlands discussed the findings with families who universally stated despite there not being specific treatments to improve outcome in A-T they would like to know of the diagnosis early.

The impacts of the CSR and T-cell defects need to be further explored and once better understood the research team acknowledge may lead to new clues for treatments.

One of the discoveries has the potential to have clinical impact in the short term (screening). The defects in the immune system that the team discovered during this research project need further work but do in the longer term have the potential to have clinical impact via the discovery of new potential therapeutic strategies.

## Publications

The team have published 2 papers, have a third which has been accepted with some minor revisions and are preparing a 4th manuscript.

Schoenaker MHD, Blom M, de Vries MC, Weemaes CMR, van der Burg M, Willemsen M. Early diagnosis of ataxia telangiectasia in the neonatal phase: a parents' perspective. Eur J Pediatr. 2019.

Blom M, Schoenaker MHD, Hulst M, de Vries MC, Weemaes CMR, Willemsen M, Henneman L, van der Burg M. Dilemma of Reporting Incidental Findings in Newborn Screening Programs for SCID: Parents' Perspective on Ataxia Telangiectasia. Front Immunol. 2019;10:2438.

Weitering T, Takada S, Weemaes CMR, van Schouwenburg PA, Van der Burg M. ATM: Translating DSB response to adaptive Immunity. Trends in Immunology (accepted with minor revisions)

Takada S et al. Unraveling antibody deficiency in patients with Ataxia Telangiectasia (manuscript in preparation)

# Longitudinal brain changes in childhood A-T

**Principal Researcher:** Dr Rob Dineen
**Institute:** University of Nottingham
**Project Completion Date:** November 2020

This research was funded in partnership with BrAshA-T

## Project Overview


Dr Rob Dineen

Dr Dineen and his team at the Nottingham University Hospital wanted to understand longitudinal brain changes in children and young people with A-T. They wanted to know if the progression in movement and other nervous system problems is closely matched by changes in the structure of the back part of the brain that controls coordinated movements (the cerebellum) as measured on MRI scans of the brain. The cerebellum is known to be the main part of the brain to be affected by A-T, but knowing that changes over time are accompanied by changes in the movement and other nervous system problems could be very useful for trials of new treatments for A-T. In such trials, being able to show that treatments slow or stop the damage to the cerebellum will be extra evidence of a positive effect of the treatment, and that could be helpful in reducing the movement and other nervous system problems. Lastly, the team wanted to trial whether MRI scans could be carried out in very young children (aged 3-6 years) with A-T.

## Project Outcome

The team showed that young people with A-T demonstrate a greater reduction in the size of the cerebellum than older children and young adults with A-T. They found that this early reduction in the size of the cerebellum matched the time at which children with A-T experienced the most rapid increase in problems with movement and other nervous system degeneration. Their data shows that the cerebellar volume in A-T patients decreases up to the age of 12 years but then stabilises. The team replicated previous data showing the decline in clinical status occurs to a greater extent in early rather than later childhood. They were also able to show that there was a correlation between changes in cerebellar volume and neurological status.

These findings proved the original research hypothesis that changes in brain MRI metrics reflecting pathophysiological processes in A-T will predict changes in neurological status. There is potential clinical impact given that the changes on MRI and associated neurodegeneration appear to occur early in childhood (i.e. before 12 years) and therefore certain potential treatments should be targeted at this age group.

Unfortunately, the team struggled to recruit very young children to the study (not helped by recruitment having to end due to the COVID-19 pandemic), and while they found that some young children were happy to have the scan, others did not want to. This approach may work for future research studies, but clearly clinicians will need to consider each child individually and work closely with the parents / carers to make sure the child is likely to respond well to the preparation for the MRI scan.

## Publications

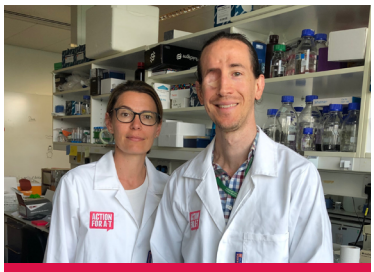
R.A. Dineen, C.V. Blanchard, S. Pszczolkowski, S. Paine, M. Prasad, G. Chow, W.P. Whitehouse and D.P. Auer (2021) Accumulation of Brain Hypointense Foci on Susceptibility-Weighted Imaging in Childhood Ataxia Telangiectasia. American Journal of Neuroradiology DOI: https://doi.org/10.3174/ajnr.A7107

# The use of patient stem cell-derived mini-brains to study A-T

**Principal Researcher:** Dr Samuel Nayler
**Institute:** University of Oxford
**Project Completion Date:** December 2020

This research was funded in partnership with BrAshA-T

## Project Overview


Dr Esther Becker and Dr Samuel Nayler

What makes a person with A-T different from you or I? Since the ATM gene was first identified in 1995, numerous teams worldwide have committed themselves to investigating this question. The most debilitating aspect of this disease, the neurological implications, arises from degeneration of the cerebellum. The cerebellum sits at the back of the brain and communicates to most other brain regions, it can be thought of as the control centre to the brain. Why though, does mutation of this gene, affect this brain region so profoundly? Dr Nayler and his team set out to make cerebellar organoids or 'mini-brains' from induced pluripotent stem cells (iPSCs) to help answer these questions.

## Project Outcome

The team were successful in creating 'mini-brains' from induced pluripotent stem cells (iPSCs) as per their aims. This is the first step in trying to find drugs which will ultimately make these differences disappear. Thanks to the data generated with these mini-brains, it will be possible to use sophisticated computational methodology to predict if there are drugs which will be effective to treat these differences. The direct clinical impact of this work is some way off as any potential treatments will take many years to research and validate, however there is a clear plan from the team going forward as to how this could happen.

## Publications

Nayler SP, Becker EBE. (2018) The Use of Stem Cell-Derived Neurons for Understanding Development and Disease of the Cerebellum. Frontiers in Cellular Neuroscience. 12:646. doi: 10.3389/fnins.2018.00646.

[Van Essen M, Nayler SP], Becker EBE, Jacob J. (2019) Deconstructing cerebellar development cell by cell. PLOS Genetics. *joint first-authors. https://doi.org/10.1371/journal.pgen.1008630

[Van Essen M, Nayler SP], Jacob J, Becker EBE (2020, In press). Modelling cerebellar development using induced pluripotent stem cells. Neuromethods.

Nayler SP, Agarwal D, Curion F, Bowden R, Becker EB (bioxriv, 2020, & In preparation). Singlecell sequencing of human iPSC-derived cerebellar organoids shows recapitulation of cerebellar development. [co-first authors]

To view all of our current and complete research projects, please visit https://actionforat.org/category/research-projects-funded/

# Strengthening and Increasing our Fundraising Activities

## Our Aim

Action for A-T funds high quality peer reviewed medical research to speed up the process of identifying a cure for Ataxia Telangiectasia (A-T). We endeavor to raise funds from a variety of activities which appeal to new and existing supporters. Since 2012 we have invested just under £3,000,000 in 40 A-T related research projects around the world and this has only been possible thanks to our generous supporters.

## Our Performance

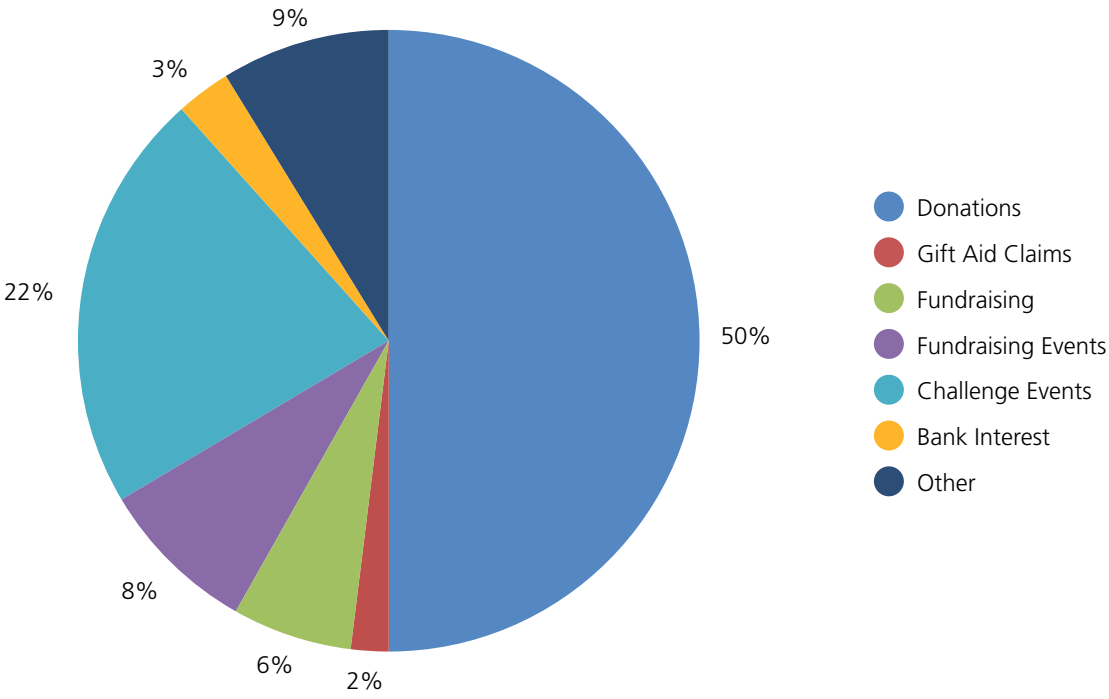
Action for A-T are registered with the Fundraising Regulator (previously the Fundraising Standards Board) and are committed to upholding the code of fundraising practice. We receive all our funding from voluntary sources, including individuals, companies, trusts and foundations. We also purchase places in several physical challenges as well as staging and benefiting from a series of other social and sporting events.

2020 was an incredibly difficult year for fundraising as we were forced to cease most of our events activities due to the ever-changing situation relating to the COVID-19 outbreak. Events usually account for approximately 60% of our total income and normally provide a steady and reliable source of funds, but restrictions on group gatherings meant they were unable to take place. We adapted to the new fundraising environment quickly, and where possible staged and benefited from virtual style events. We also significantly increased our trust and foundation applications and applied to various emergency funding schemes for support. As well as raising funds, we also reduced our overheads by taking advantage of the government led furlough scheme and making significant reductions to our general and administrative expenses.

In 2019 places were purchased for the 2020 Virgin London Marathon and 80 unused places were carried forward for the 2020 Prudential Ride 100 event. The Virgin London Marathon (along with virtually all other mass participation events) was cancelled, and the unused places were carried forward to 2021. The Prudential Ride 100 was also cancelled and due to the uncertainty about its future, we were provided with several Virgin London Marathon places for use in future years. Both event organisers staged virtual versions of their events to placate entrants and provide fundraising opportunities for participating charities. These activities enabled us to raise £56,000 allowing us to make a 360% return on our original investment, as well as providing us with several free places for future London Marathons. The Trustees also agreed a material investment in an advertising package for the 2021 London Marathon which includes a further 9 places.

In line with our fundraising strategy and as a direct result of the pandemic, we diversified our income base to ensure that we were not solely dependent on any one source of funding. Ongoing COVID-19 restrictions meant that Challenge and Social events performed far worse than in previous years, accounting for only 30% of our income (2019 - 59%). Whilst other fundraising initiatives, such as donations, funding partnerships and trust and foundation applications increased to 56% (2019 - 29%). Very few new fundraising activities took place throughout the year but some of our existing supporters were able to stage their activities in a virtual format. We are especially grateful to the staff and clients of BCA yet again for choosing to stage a virtual one-day cycle event (instead of their planned overseas ride) which raised over £30,000. We are also extremely grateful to Simon Toon and his friends for their multiple fundraising efforts throughout the year and our patron Naga Munchetty who secured a £32,000 donation after appearing on the "Who Wants to Be a Millionaire" gameshow. In addition, we would like to thank Quest Professional, Psigma Investment Management and St James's Place for their generous corporate support.

The pie chart below shows the percentage splits of each of our areas of fundraising in 2020.




## Fundraising for Research



We would also like to record our thanks to all our volunteer committee members for their time and commitment in helping us achieve our mission, as well as everyone who donated their time, auction prizes and/or supported or participated in our events.

In addition to the above, we are also extremely grateful to the trusts and foundations who provided emergency funding grants throughout the year and restricted funding for various research projects (these are listed on page 50). We are always keen to work with other trusts, foundations and corporate funders who might be interested in supporting our work.

At the time of writing these accounts, the COVID-19 pandemic continues to significantly impact the way in which every organisation operates around the world. As a result, we have been forced to cancel many of our larger scale social events and delay many of our planned activities until much later in the year. We hope that the vaccination programme will be completed towards the end of the summer, allowing us to stage and benefit from many of our planned activities. It is hard to predict the potential impact that the ongoing pandemic will have on our overall income, but it seems unlikely at this stage that we will be able to deliver the fundraising budget which was signed off by the Trustees in January. We continue to react to the crisis by further diversifying our fundraising activities and reducing our costs to ensure that there are no going concern issues.

## Events since the end of the year

Information relating to events since the end of the year is provided in the notes to the financial statements.

# Building Collaborative Partnerships

## Our Aim

Action for A-T strongly believes that there are many opportunities to further the search for a treatment or a cure for A-T through working with others that may have overlapping aims or objectives to our own. To this aim, we actively seek out like minded organisations and where possible, create collaborative partnerships.

## Our Performance

**Co-funding A-T Research Projects with the UK based Children's Medical Research Charity Sparks**

Action for A-T continued to work closely with UK Children's Medical Research Charity Sparks which joined forces with Great Ormond Street Hospital Charity as a subsidiary in February 2017. Sparks are currently managing the following jointly funded research project which is due to end in the first quarter of 2021:

- "Optimising lung imaging in people with A-T" - Dr Peter Merkus at the Radboud University Medical Centre, Netherlands

**Co-funding A-T Research Projects with the US Charity the A-T Children's Project**

Action for A-T and the US based A-T Children's Project joined forces at the end of 2018 to fund two new research projects. Both studies are being managed by the A-TCP and Action for A-T has contributed towards each project. The studies are as follows:

- "Non-viral gene therapy for Ataxia Telangiectasia" – Dr James Dixon at the University of Nottingham, United Kingdom
- "Genetically tailored splice-modulating therapy for A-T" – Dr Timothy Yu at the Harvard and Boston Children's Hospital, USA

Action for A-T have committed £50,000 towards the "Non-viral gene therapy" project (The final £25,000 was paid at the end of 2020) and £17,656 ($23,000) towards the "Genetically tailored splice-modulating therapy" (this was paid in full at the end of 2018).

**Co-funding A-T Research Projects with the Australian charity BrAshA-T Ataxia Telangiectasia**

Action for A-T have an ongoing collaborative funding partnership with BrAshA-T who are based in Queensland, Australia. BrAshA-T agreed to support the patient stem cell-derived mini-brains study being carried out by Dr Sam Nayler at Oxford University and their agreed contribution totalling £29,460 was paid in full in December 2019. This project concluded in October 2020 and the project outcomes are shown on page 18.

**Co-funding A-T Research Projects with the Australian charity BrAshA-T Ataxia Telangiectasia and the UK based A-T Society**

At the start of 2019, Action for A-T established a new collaborative funding partnership with BrAshA-T and the A-T Society in connection with the Natural Histories Study being carried out Dr William Whitehouse and Dr Emily Petley at the University of Nottingham. Throughout 2020, each organisation contributed £15,230.91 towards the cost of this study. As the project is scheduled to conclude in 2022, the remaining payments are likely to be made throughout 2021 and 2022.

As the COVID-19 pandemic will impact our ability to fund new projects in 2021, Action for A-T will continue to explore additional joint funding opportunities with likeminded organisations throughout the year to maintain momentum and maximise the investment into A-T research.

# Raising Public Awareness about A-T

## Our Aim

As an ultra-rare disease, most people are unaware of A-T or the devastating effects of the condition. Action for A-T believes that raising awareness of the impact of A-T on children and their families is an important part of increasing the potential funds available to further improve the understanding of the condition and to progress research into possible treatments or a cure.

## Our Performance

Action for A-T has significantly increased the public awareness of the condition over the past 12 months and will continue to explore all options to promote wider understanding of A-T and why research to find a cure or treatment is so important.

**The Charity's main achievements in this area to date include:**

## Celebrity Support

Our celebrity patrons have continued to help promote Action for A-T and the need for more research into the condition by championing campaigns and taking part in various activities throughout the year. As well as participating in a virtual challenge, Naga Munchetty represented Action for A-T on the game shows "Who wants to be a millionaire" and "Celebrity Catchphrase". As well as securing substantial donations, the shows provided an opportunity to highlight the charity's work to a huge TV audience. Sir Clive Woodward was the only celebrity to attend an actual event (as this took place before the COVID-19 restrictions were enforced) but several other celebrities including Chris Sheasby, Leon Haslam, Jonny Wilkinson, Simon Shaw and Mike Tindall helped generate awareness and support by taking part in virtual events and campaigns or starring in promotional social media videos.




## Visibility at Research Institutions, Conferences and Medical Meetings

All Action for A-T funded researchers are provided with promotional materials to display at their research facility and required to acknowledge our financial support by including our logo on any posters or presentations. Throughout 2020, all in-person conferences and meetings were cancelled due to the pandemic, but researchers funded by Action for A-T were able to present their findings at various webinars and online events. These presentations showcased our latest projects and provided the research community with a comprehensive view of the progress made to date.

## Digital Communications

The Charity website actionforAT.org remains the focal point for event sign-ups, electronic donations, and research news. We update and enhance the site on an ongoing basis to provide the best possible experience for our stakeholders. In 2020, further upgrades were made to enhance the user experience and assist with navigation including the introduction of interactive pictogram to explain the symptoms of A-T and a complete redesign of our home page.

Our monthly e-newsletter continues to be a successful tool to communicate our latest news to supporters. Using Mailchimp for this proves to be cheaper than a traditional printed newsletter and has the functionality to track usage and monitor engagement. Our e-newsletter is sent to all our consenting supporters, has a clear unsubscribe function and inactive supporters are removed from the mailing list periodically. As promotion of events and activities was limited in 2020, the e-newsletter was predominantly used to inform supporters about our work. These updates were well received and enabled us to secure online donations, including one for £2,000 at the end of the year.

Social media remains a key communication tool for the Charity as it is free, easily accessible and can reach wide audiences. It also allows us to engage with our supporters on a more strategic level and build additional support from their own contacts. Posts are carefully managed to ensure that the content is engaging and not repetitive and this more targeted and planned approach helped us increase our followers throughout the year. We created and participated in several large social media campaigns during 2020 including #26in26, #26steps4AT, #2.6challenge and the "What is not named does not exist" campaign. These posts were viewed and shared thousands of times around the world. We will continue to develop our social media presence in 2021 using all available technological advancements and popular platforms to raise further awareness.

## National and Local News Media Coverage

We continued to raise awareness of A-T through a series of articles and editorials in the local, national and industry press and various news websites. These helped us highlight the condition to new audiences, recruit volunteers and secure additional support and donations.

## Film

In April 2020, Action for A-T created a new awareness-raising film featuring a grandfather telling the tragic story of his granddaughter (Jenni Gallagher) who lost her battle with A-T aged 12 years old. The film includes an interview with Dr William Whitehouse who is a Clinical Associate Professor at the Queens Medical Centre, Nottingham as he and his team are carrying out a study to plot the Natural History of A-T. The film was produced to raise awareness about the devastating effects of A-T as well as raising funds for our research programme. Throughout the year, it was shared widely on various social media channels as well as being included on our website. It will also be used to raise awareness and funds at various events when the COVID-19 restrictions are eased.




All of the charity's films are available to view on our Vimeo and YouTube channels.

https://vimeo.com/actionforat/videos

https://www.youtube.com/channel/c/ActionforatOrg

# Our Future Plans: Areas of Focus for 2021

The Trustees believe that Action for A-T is well placed to meet its charitable objectives during and after the COVID-19 pandemic but have also identified the need for further development to strengthen its research activities. During 2021 we will consolidate and diversify our fundraising activities whilst actively seeking other funding partnerships to meet the demands of the A-T research community. We will also continue to promote A-T research to engage new audiences and maintain interest from the research community.

We will implement a number of measures throughout the year to ensure that the Charity continues to be fit for future purpose and to help us achieve our aim of moving closer to tangible therapies or a cure for A-T.

## Adapting to the New Environment

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us deliver our charitable objectives. Our size and structure enabled us to adapt quickly to the ever-changing environment in 2020 but as the COVID-19 pandemic will continue to impact everything we do in 2021, we will:

- Review and prioritise projects based on available resources
- Seek out new opportunities to raise funds in a safe and sustainable manner whilst reviewing existing fundraising Initiatives, prioritising those which are most likely to be deliverable
- Utilise new and existing technology to disseminate key information to the wider A-T community
- Work closely with our grantees to minimise delays and ensure projects are progressing in line with their stated aims
- Ensure that we have the necessary skills and people to deliver our organisation wide objectives
- Keep up to date with current trends and remain flexible so that change can be implemented quickly if required

## Continuing our Investment in Medical Research in the UK and Abroad

We will continue to seek out new research opportunities from the wider research community as well as focussing on key research themes related to A-T. Where possible, priority will be given to UK based projects whilst still calling for international applications where funds will allow. We will also continue to collaborate with other research charities whilst actively seeking new funding partners with similar objects to our own.

We will maintain our close relationship with the Association of Medical Research Charities (AMRC) and work in conjunction with our research advisory committee (RAC) to develop and improve our peer review process and ensure that the research we fund is of the highest quality. This will include constant evaluation of our systems and processes as well as enlisting the help and support of various A-T experts around the globe.

Membership of the RAC will be continually reviewed to ensure that we have a broad range of scientific expertise in areas relating to A-T as well as lay representation from various A-T families as Action for A-T strongly supports public and patient engagement in its research processes.

## Increasing Awareness of our Work and the Condition

Raising awareness of A-T and the work of the charity is one of our key charitable objectives. To date, we have implemented various strategies including the use of celebrities, digital and printed media and the creation of emotive films featuring researchers and A-T families. We will continue to seek out new ways in which we can highlight A-T whilst focusing on two key projects in 2021. Firstly, we will work alongside other A-T organisations to create a global A-T directory platform containing key information to assist the wider A-T community. We will also deliver a family focused interactive webinar (as face-to-face meetings and conferences are not permissible) showcasing some of the research which is currently being undertaken around the world.

## Working Closely with Others to Meet our Objectives

Ongoing research funding is critical to ensure that existing knowledge is expanded and interest in such a rare and complex condition is retained. Whilst COVID-19 restrictions continue to impact our fundraising capabilities, we are less able to meet the increasing demands of the research community. We will therefore continue to develop existing, and create new partnerships with major stakeholders across the globe including patients, their families/supporters, researchers, clinicians, and A-T patient groups and charities, to help maintain a funding pipeline and speed up the process of finding a therapy or cure for A-T.

## Diversifying and Consolidating our Fundraising Activities

As the COVID-19 pandemic is likely to impact our fundraising capabilities for the foreseeable future, we will work hard to retain key relationships and deliverable activities whilst exploring new and innovative ways to engage safely with new and existing supporters. Our events calendar will be scaled down to comply with ongoing restrictions and wherever possible, we will embrace virtual event opportunities. We will continue to develop and expand our charitable trusts and foundations programme with a key focus on emergency funding opportunities whilst actively seeking new investment and support from individuals, corporates, and major donors. We will also work closely with our key supporters and volunteer groups to raise funds in a safe and sustainable manner and only invest in new activities which are low risk with a very good chance of successful delivery. As well as seeking new opportunities to diversify our income, we will look to reduce costs where possible and stay poised to reintroduce many of our postponed events and activities as soon as restrictions are eased.

# Structure, Governance & Management

## Governing Document

Action for A-T is a charity registered in England and Wales (No. 1145303). The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

The Trustees have adopted the following policies and procedures for the recruitment, appointment, induction and training of new Trustees:

## Trustee Recruitment and Appointment

The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. Trustees are either elected or co-opted under the terms of the Trust deed and the total number of Trustees may not be fewer than five. If a vacancy occurs or a skills need is identified, new Trustees are recommended by the existing Trustees and interviewed by the Chairman and at least one other member of the board. Election is by majority vote and potential candidates must be over the age of eighteen and eligible to act. The Trustees will continue to evaluate the composition of the Board and will consider further appointments to broaden and strengthen the Board's capabilities to facilitate the growth of the Charity.

## Trustee Induction and Training

New Trustees receive an induction pack containing a copy of the trust deed, strategy, relevant information about the Charity and its work; and also, a copy of the Charity Commission literature about the role and responsibilities of being a Trustee. New Trustees are also invited to meet the Chief Executive and team members to learn first-hand how the Charity operates on a day-to-day basis.

During the induction process, new Trustees are also told about the connected parties' rule, given a copy of the Charity's conflict of interest policy, and asked to sign a Trustee declaration form. Where the Trustees have identified that there is a connection between the charity, or its Trustees and any third party with whom the Charity has dealt with, the Trustees will identify the relationship and the amounts involved within the notes to the financial statements.

## Organisational Structure

The Trustees meet formally four times per year and no business shall be conducted unless at least one-third of the total number of Trustees at the time, or two Trustees (whichever is greater) are present throughout the meeting. There are two meetings where the focus is on awarding grants for medical research and two meetings where Trustees review strategy and set operating plans and budgets. There is a review of operating and financial performance at every meeting. The Chief Executive is invited to attend all meetings of the Trustees and the Head of Fundraising is invited to report on plans and progress at specific meetings.

While most of the business of the Charity is conducted at the scheduled Trustee meetings, there are occasional ad-hoc meetings to deal with matters of special interest and regular electronic meetings are held to review ongoing governance objectives.

The Board of Trustees delegates the exercise of certain powers in connection with the management and administration of the Charity as set out below. This is controlled by regular reporting back to the Board of Trustees so that all decisions made under delegated powers can be ratified by the full Board of Trustees in due course.

The Research Advisory Committee (RAC) is chaired by a member of the Board of Trustees. Members of the RAC have a broad range of scientific expertise in areas relating to A-T but are not generally active researchers in the field of A-T in order to minimise bias and conflicts of interest. There is also lay representation on the committee as Action for A-T supports public and patient engagement in its research processes. The Trustees are very grateful to all of the members of the RAC for providing expert guidance and advice on a pro bono basis.

## Research Advisory Committee

The Research Advisory Committee (RAC) is chaired by a member of the Board of Trustees. Members of the RAC have a broad range of scientific expertise in areas relating to A-T but are not generally active researchers in the field of A-T to minimise bias and conflicts of

interest. There is also lay representation on the committee as Action for A-T supports public and patient engagement in its research processes. The Trustees are very grateful to all the members of the RAC for providing expert guidance and advice on a pro bono basis.

## Chief Executive

The Chief Executive is responsible for the day-to-day management of the Charity's affairs and is assisted by a small executive team who act under his direction. As well as overseeing the operations of the Charity, the Chief Executive is also responsible for implementing policies as agreed by the Board of Trustees.

## Employees, Volunteers and Contractors

The Charity aims to be an organisation where employees, volunteers and contractors enjoy a sense of fulfilment and where they feel supported and developed. All stakeholders are kept fully informed about the Charity's strategy and objectives, as well as day-to-day news and events. Individuals are encouraged to give their suggestions and views on performance and strategy.

The Charity supports equal opportunities and a policy of recruitment and promotion based on aptitude and ability without discrimination is followed. Action for A-T is committed to the training, career development and promotion of all its employees. An individual's career development is assessed through annual appraisal and supervision. Training programmes are provided to meet any on-going needs, with the aim of developing individuals for both their current and their future roles.

## Risk Management

The Trustees have introduced a formal risk management process to assess business risks and implement risk management strategies. This has involved identifying the types of risks the Charity faces, prioritising them in terms of potential impact and likelihood of occurrence, and identifying means of mitigating the risks.

As part of this process the Trustees have reviewed and are satisfied with the adequacy of the Charity's current internal controls and the costs of operating controls relative to the benefits obtained. Procedures have been established for reporting failings immediately to the Chief Executive and to the Board of Trustees.

It is recognised that internal controls can only provide reasonable but not absolute assurance that major risks have been adequately managed. In the opinion of the Trustees the key risks are:

- The loss of reputation due to error, or fraud.
- The loss of income due to error, or fraud.
- Insufficient numbers of Trustees to allow the Charity to continue.
- Insufficient funds to allow the Charity to meet its objectives.
- Excessive reserves without justification deterring future donors and fundraisers.

In the opinion of the Trustees the policies and procedures are currently adequate to mitigate financial and reputation loss due to error or fraud whilst maintaining a viable future financially.

## Reserves Policy

The Trustees review the reserves policy each year to ensure that all relevant risk areas are included in accordance with guidance issued by the Charity Commission. Risks included are the impact of unexpected, reduced income, and the potential impact of restructuring costs and liabilities required to downsize the organisation in an orderly manner, if a permanent income reduction was anticipated.

The review concluded that the existing reserve target level of Six months of operating costs (approx. £90,000) was sufficient to cover the risks identified in the review. This allows sufficient time for Trustees and management to take appropriate mitigating actions, if required.

The Trustees continue their commitment to develop and grow the level of investment in research into A-T, whilst maintaining a focus on managing the overall costs of the charity.

## Investment Policy

The overall policy of the Charity is to maintain a series of designated funds deposit accounts to ring-fence any funds which the Trustees have identified as being made available for specific research projects, or other charitable activities.

The Trustees recognise the need to review this policy on an annual basis and to look at other potential opportunities whilst appropriately monitoring the available funds and being proactive in their management, to ensure the best interests of the Charity's objectives are maintained

Funds committed for research are paid out in arrears over the duration of the project. The Trustees reviewed and agreed to deposit funds in timed deposit accounts in order to obtain the best return with minimal managed risk.

During the year the Trustees transfer any funds surplus to general running costs of the Charity into an interest-bearing account which will offer a higher rate of return than holding it in the main Charity bank account. The aim is to ensure that the fund is not diminished over time due to inflation and to ensure that these funds are invested in future research projects.

### Pay and Remuneration of Key Management Personnel

The Trustee's principles are to pay staff a fair salary that is competitive within the charity sector, proportionate to the complexity of each role, it's related funding and responsible in line with the charitable objectives. Pay levels for all employees are reviewed annually and any overall percentage increases are authorised by the Board of Trustees.

Remuneration for the Chief Executive is agreed by the appropriate remuneration committee. Salaries are benchmarked using external data available from pay surveys (for the voluntary sector and charities located in and around London) and market conditions for the specific role and the target is the market median averages of these.

Ultimately however, salary increases relate to the funding available for each role and whether the increase will be affordable in the long term. To ensure pay is fair for all roles we are committed to paying all our employees at or above the London living wage as determined by the Living Wage Foundation.

## Financial Review

The Trustees are satisfied with the performance of the Charity and consider that the Charity is in an excellent position to continue its activities during the coming year, and the Charity's reserves are adequate to fulfil its current obligations.

### Income

At present, research into A-T is heavily dependent on charitable donations and by extension, Action for A-T's ability to instigate, organise and facilitate the fundraising efforts of our supporters and donors. The principle source of funding is donations from individuals, companies, and proceeds of fundraising events.

Total income raised in 2020 was **£458,645 (2019 - £768,819).**

### Charitable Expenditure

The cost spent on Charitable Activities Was **£839,221 (2019 - £910,844)** of which **£677,077 (2019 – £673,985)** was for grants provided for funding of research projects.

The cost of generating voluntary income was **£97,468 (2019 - £55,576)** whilst the cost of generating income from charitable events was **£45,090 (2019 - £163,705)**

Governance costs of **£19,586 (2019 - £17,578)** were incurred.

### General Funds

The Trustees will aim to make best use of any unrestricted funds, however they reserve the right to retain general reserves in hand until they can be used in the most efficient manner to further the objectives of the Charity. The Trustees are conscious that it should not provide funding for research where they have not been able to demonstrate that its use will offer the best opportunity to further the knowledge and treatment into A-T. Please refer to the investment policy with regard to those times where the Trustees believe general funds are in excess of the anticipated running costs of the Charity.

### Designated Funds

Designated funds of £nil were brought forward from 2019 In 2020, **£nil** of funds were passed on to the research projects detailed in note 8 on page 40.

As at 31 December 2020 designated funds carried forward are £nil.

## Trustees' Responsibilities

The Trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of the incoming resources and application of resources of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP 2015 (FRS 102);
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the Charity and financial information included on the Charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

The Trustees declare that they have approved the Trustees report included in the previous pages

Signed on behalf of the charity's Trustees





Toby Read (Chairman)

William Rowberry (Treasurer)

Dated: 24th May 2021

Dated: 24th May 2021

# Auditors Report

## Independent Auditor's Report to the Trustees of Action for A-T

### Opinion

We have audited the financial statements of Action for A-T Registered Charity Number: 1145303 (the 'charity') for the year ended 31 December 2020 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2020 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern:

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

## Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

## Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

## Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- Conclude on the appropriateness of the trustee's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charity to cease to continue as a going concern.
- Evaluate the overall presentation, structure, and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

## Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

(Continued)



A & N (Haslemere) Limited Statutory Auditor
Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

Dated: 24th May 2021

A & N (Haslemere) Limited is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

# Statement Of Financial Activities

for the year ended 31 December 2020

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.20 Total Funds £** | 31.12.19 Total Funds £ |
|---|---|---|---|---|---|
| **Income and Endowments from** | | | | | |
| Donations and legacies | 3 | 158,623 | 107,279 | **265,902** | 359,826 |
| **Charitable Activities** | 5 | | | | |
| Fundraising & challenge events | | 139,407 | - | **139,407** | 394,885 |
| Investment income | 4 | 12,130 | - | **12,130** | 11,108 |
| Other income | | 41,206 | | **41,206** | 3,000 |
| **Total** | | 351,366 | 107,279 | **458,645** | 768,819 |
| **Expenditure on** | | | | | |
| Raising funds | 6 | 97,468 | - | **97,468** | 55,576 |
| **Charitable Activities** | 7 | | | | |
| Fundraising & challenge events | | 45,090 | - | **45,090** | 163,705 |
| Grants | | 612,260 | 64,817 | **677,077** | 673,985 |
| Governance costs | | 19,586 | - | **19,586** | 17,578 |
| **Total** | | 774,404 | 64,817 | **839,221** | 910,844 |
| **Net Income / (Expenditure)** | | (423,038) | 42,462 | **(380,576)** | (142,025) |
| **Reconciliation of Funds** | | | | | |
| **Total funds brought forward** | | 610,461 | - | **610,461** | 752,486 |
| **Total Funds Carried Forward** | | 187,423 | 42,462 | **229,885** | 610,461 |

The notes form part of these financial statements

# Statement Of Financial Position

for the year ended 31 December 2020

| | Notes | Unrestricted Funds £ | Restricted Funds £ | **31.12.20 Total Funds £** | 31.12.19 Total Funds £ |
|---|---|---|---|---|---|
| **Fixed Assets** | | | | | |
| Tangible assets | 17 | 324 | - | **324** | 486 |
| **Current Assets** | | | | | |
| Stocks | 18 | 14,251 | - | **14,251** | 10,811 |
| Debtors | 19 | 51,849 | - | **51,849** | 79,868 |
| Cash at bank | 20 | 1,455,142 | 42,462 | **1,497,604** | 1,539,632 |
| | | 1,521,242 | 42,462 | **1,563,704** | 1,630,311 |
| **Creditors** | | | | | |
| Amounts falling due within one year | 21 | 606,965) | - | **606,965)** | (422,303) |
| **Net Current Assets** | | 914,277 | **42,462** | **956,739** | 1,208,008 |
| **Total Assets Less Current Liabilities** | | 914,601 | 42,462 | **957,063** | 1,208,494 |
| **Creditors** | | | | | |
| Amounts falling due after more than one year | 22 | (727,178) | - | **(727,178)** | (598,033) |
| **Net Assets** | | 187,423 | 42,462 | **229,885** | 610,461 |
| **Funds** | 23 | | | | |
| Unrestricted funds | | | | **187,423** | 610,461 |
| Restricted funds | | | | **42,462** | - |
| **Total Funds** | | | | **229,885** | 610,461 |

The notes form part of these financial statements

The Trustees declare that they have approved the financial statements.

Signed on behalf of the charity's Trustees.



Toby Read (Chairman)

Dated: 24th May 2021



William Rowberry (Treasurer)

Dated: 24th May 2021

# Statement of Cash Flows

for the year ended 31 December 2020

| | Notes | **31.12.20** **£** | 31.12.19 £ |
|---|---|---|---|
| **Cash flows from operating activities:** | 1 | | |
| Cash generated from operations | | **(54,158)** | 156,378 |
| Net cash provided by operating activities | | **(54,158)** | 156,378 |
| **Cash flows from investing activities:** | | | |
| Purchase of tangible fixed assets | | **-** | - |
| Interest received | | **12,130** | 11,108 |
| Net cash provided by investing activities | | **12,130** | 11,108 |
| **Change in cash and cash equivalents in the reporting period** | | **(42,028)** | 167,486 |
| **Cash and cash equivalents at the beginning of the reporting period** | | **1,539,632** | 1,372,146 |
| **Cash and cash equivalents at the end of the reporting period** | | **1,497,604** | 1,539,632 |

# Notes to the Statement of Cash Flows

for the Year Ended 31 December 2020

## 1. Reconciliation of net (expenditure)/income to net cash flow from operating activities

| | **31.12.20 £** | 31.12.19 £ |
|---|---|---|
| **Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)** | **(380,576)** | (142,025) |
| **Adjustments for:** | | |
| Depreciation charges | **162** | **786** |
| Interest received | **(12,130)** | (11,108) |
| (Increase)/decrease in stocks | **(3,440)** | (1,806) |
| Decrease in debtors | **28,019** | 53,389 |
| Increase/(decrease) in creditors | **313,807** | 257,142 |
| **Net cash provided by operations** | **(54,158)** | 156,378 |

## 2. Analysis of changes in net fund

| | **31.12.20 £** | Cash Flow £ | **31.12.20 £** |
|---|---|---|---|
| **Net cash** | | | |
| Cash at bank | **1,539,632** | (42,028) | 1,497,604 |
| | **1,539,632** | (42,028) | 1,497,604 |
| **Total** | **1,539,632** | (42,028) | 1,497,604 |

# Notes to the Financial Statements

for the Year Ended 31 December 2020

## 1. Accounting Policies

### Basis of preparation of financial statements

The financial statements of the charity, which is a public benefit entity under FRS102, have been prepared in accordance with the Charities SORP (FRS102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011.

The financial statements have been prepared under the historical cost convention. The accounts are prepared in £ sterling to the nearest £1.

Action for A-T meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historic cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### Accounting convention

The financial statements are prepared on a going concern basis, under the historic cost convention.

The Charity is entirely dependent on receiving income from fundraising and donations and as a consequence the going concern basis is also dependent on the continuation of such income.

### Incoming resources

All incoming resources are included in the Statement of Financial Activities under FRS102 when that receipt is probable, whereas it was previously recognised when the Charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. For legacies, entitlement is the earlier of the Charity being notified of an impending distribution or the legacy being received.

Gifts in kind, including donated professional services are recognised as income when the Charity has control over them, any conditions associated with the donated item have been met, the receipt of economic benefit from the use of by the Charity if the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS102), the general volunteered time is not recognised and refer to the Trustees' Report for more information about this contribution.

On receipt, donated professional services are recognised on the basis of the value of the gift to the Charity which is the amount the Charity would have been willing to pay to obtain that service on the open market.

Gifts in kind donated for distribution are included at fair value upon receipt under FRS102 subject to the cost of recognition outweighing the benefit provided to Action for A-T. Previously they were included at a valuation and recognised as income when they are distributed. Any donated facilities are included at the value to the Charity where this can be quantified, and a third party is bearing the cost. No amounts are included in the financial statements for services donated by volunteers.

### Resources expended

All expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs allocated to activities. Where costs cannot be directly attributed to particular activities, they have been allocated on a basis consistent with the use of the resources.

Overheads have been allocated on the basis of the activity income of the Charity.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities. Support costs are those costs incurred directly in support of expenditure on the objects of the Charity and include project management carried out by the Trustees. Governance costs are those incurred in connection with the administration of the Charity and compliance with constitutional and statutory requirements.

Grants offered subject to conditions which have not been met at the year-end date are noted as a commitment but not accrued as expenditure.

# Notes to the Financial Statements

for the Year Ended 31 December 2020

## Governance costs

Governance costs comprise all costs involving the public accountability of the Charity and its compliance with regulations and good practice. These costs include costs related to the audit, legal fees, and apportionment of overheads.

## Allocation and apportionment of costs

Fundraising Events & Challenge Events costs are allocated in their income ratio during the year.

## Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Computer equipment - 33% on cost.

## Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

## Taxation

The charity is exempt from tax on its charitable activities.

## Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors which have been raised by the Charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements. Any investment income, gains or losses are allocated to the appropriate fund.

Designated funds are funds set aside by the Trustees out of general reserves for a particular purpose. The aim and use of each designated fund is set out in the notes to the financial statements. The Trustees will review the funds on an ongoing basis. At the conclusion of the purpose for the fund any excess remaining funds will be transferred back into general funds. If a shortfall arises the Trustees will consider whether any additional general funds should be transferred to designated funds. Any investment income, gains or losses are allocated to the appropriate fund.

## Foreign currencies

Assets and liabilities in foreign currencies are translated into sterling at the rate of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling at the date of the transaction. Exchange differences if applicable are taken into the Statement of Financial Activities.

## Going Concern

The financial statements have been prepared on a going concern basis as the trustees believe that no material uncertainties exist. The trustees have considered the level of funds held and the expected level of income and expenditure for 12 months from authorising these financial statements. The budgeted income and expenditure is sufficient with the level of reserves for the charity to be able to continue as a going concern.

## 2. Critical Accounting Judgements and Key Sources of Estimation Uncertainty

### Critical accounting estimates and judgements

In the application of the charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

### Key sources of estimation uncertainty

The annual depreciation charge for tangible fixed assets in sensitive to changes in the estimated useful economic lives and residual value of fixed assets. The useful economic lives and residual values are reassessed on an annual basis. They are amended where deemed necessary to reflect current estimations based on physical condition, utilisation, and advancement of technologies. Note 17 discloses the carrying value if the tangible fixed assets and the depreciation policy is listed above in accounting policies.

## 3. Donations and Legacies

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.20 £** | 31.12.19 £ |
|---|---|---|---|---|
| Donations | 68,506 | 107,279 | **175,785** | 232,188 |
| Gift Aid | 8,498 | - | **8,498** | 63,530 |
| Fundraising | 81,619 | - | **81,619** | 64,108 |
| | 158,623 | 107,279 | **265,902** | 359,826 |

## 4. Investment Income

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.20 £** | 31.12.19 £ |
|---|---|---|---|---|
| Bank interest | 12,130 | - | **12,130** | 11,108 |

## 5. Income from Charitable Activities

| | **31.12.20 £** | 31.12.19 £ |
|---|---|---|
| Fundraising events | **43,820** | 178,591 |
| Challenge events | **95,587** | 216,294 |
| | **139,407** | 394,885 |

## 6. Raising Funds

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.20 £** | 31.12.19 £ |
|---|---|---|---|---|
| **Raising donations and legacies** | | | | |
| Staff costs | 60,010 | - | **60,010** | 46,821 |
| Support costs | 37,458 | - | **37,458** | 8,755 |
| | 97,468 | - | **97,468** | 55,576 |

## 7. Charitable Activities Costs

| | Direct Costs £ | Grant funding of activities (see note 8) £ | Support Costs (see note 9) £ | **Totals £** |
|---|---|---|---|---|
| Fundraising & challenge events | 40,927 | - | 4,163 | **45,090** |
| Grants | - | 622,245 | 54,832 | **677,077** |
| Governance costs | - | - | 19,586 | **19,586** |
| | 40,927 | 622,245 | 78,581 | **741,753** |

## 8. Grants Payable

| | **31.12.20 £** | 31.12.19 £ |
|---|---|---|
| Grants | **622,245** | 598,034 |

The total grants paid to institutions during the year was as follows:

| | **31.12.20 £** | 31.12.19 £ |
|---|---|---|
| Using new immunotherapy methods to treat lymphoma and leukaemia in A-T | **143,400** | - |
| Recurrent pulmonary infections and their impact on neurological decline in A-T | **246,691** | - |
| Deciphering the molecular mechanism linking Ataxia-Telangiectasia and Ataxia-Telangiectasia-Like Disorder | **105,183** | - |
| *The David Peake Study to test the feasibility of whole-body MRI for cancer surveillance in children and young people with Ataxia Telangiectasia | **100,557** | - |
| A new function for ATM and a new theory for the clinical abnormalities in A-T | **53,619** | - |
| Natural History of A-T (N-HAT) | **-** | 177,866 |
| De Villartay - Does irregular repair of DNA damage in Neurons and Lymphocytes cause cellular degeneration in Ataxia Telangiectasia patients? | **-** | 65,000 |
| Innovative methods for gene therapy in Ataxia-Telangiectasia | **-** | 100,000 |
| The use of patient stem cell-derived mini-brains to study Ataxia Telangiectasia | **-** | 98,000 |
| The ATeam: Producing healthcare guidance for children with Ataxia Telangiectasia including the exploration and design of a home-based exercise package | **-** | 89,692 |
| Development of CRISPR/Cas Genome Editing as a Treatment for Ataxia Telangiectasia | **-** | 40,000 |
| | **649,449** | 570,828 |

## 9. Support Costs

| | Management | Finance | Information Technology | Other | Wages | Governance Costs | **Totals** |
|---|---|---|---|---|---|---|---|
| | £ | £ | £ | £ | £ | £ | **£** |
| Raising donations and legacies | 13,430 | 950 | 3,599 | 19,479 | - | - | **37,458** |
| Fundraising & challenge events | 1,492 | 106 | 400 | 2,165 | - | - | **4,163** |
| Grants | - | - | - | - | 54,832 | - | **54,832** |
| Governance costs | - | - | - | - | - | 19,586 | **19,586** |
| | 14,922 | 1,056 | 3,999 | 21,644 | 54,832 | 19,586 | **116,039** |

| **Activity** | **Basis of allocation** |
|---|---|
| Management | 90 % Raising Donation &legacies 10 % Fundraising & Challenge Events |
| Finance | 90 % Raising Donation &legacies 10 % Fundraising & Challenge Events |
| Information technology | 90 % Raising Donation &legacies 10 % Fundraising & Challenge Events |
| Human resources | 90 % Raising Donation &legacies 10 % Fundraising & Challenge Events |
| Other | 90 % Raising Donation &legacies 10 % Fundraising & Challenge Events |
| Governance costs | 100% Governance cost |

## 10. Trustees' Remuneration And Benefits

There were no Trustees' remuneration or other benefits for the year ended 31 December 2020 nor for the year ended 31 December 2019.

## Trustees' Expenses

There were no Trustees' expenses paid for the year ended 31 December 2020 nor for the year ended 31 December 2019.

## 11. Staff Costs

Only one employee received emoluments in excess of £60,000.

The Charity considers its key management personnel to be the Trustees, Chief Executive and senior management. The total employment benefits of the key management personnel were £121,049 (2019 - £121,049). Only one employee had employment benefits falling between £65,000 and £70,000 (2019 - 1).

## 12. Comparatives for the Statement of Financial Activities

| | Unrestricted Funds £ | Restricted Funds £ | **Total Funds £** |
|---|---|---|---|
| **Income and endowments from** | | | |
| Donations and legacies | 190,654 | 169,172 | **359,826** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 394,885 | - | **394,885** |
| Investment income | 11,108 | - | **11,108** |
| Other income | 3,000 | - | **3,000** |
| **Total** | 599,647 | 169,172 | **768,819** |

| | Unrestricted Funds £ | Restricted Funds £ | **Total Funds £** |
|---|---|---|---|
| **Expenditure on** | | | |
| Raising funds | 55,576 | - | **55,576** |
| **Charitable activities** | | | |
| Fundraising & challenge events | 163,705 | - | **163,705** |
| Grants | 504,813 | 169,172 | **673,985** |
| Governance costs | 17,578 | - | **17,578** |
| **Total** | 741,672 | 169,172 | **910,844** |
| **Net income/(Expenditure)** | (142,025) | - | **(142,025)** |
| **Reconciliation of funds** | | | |
| Total funds brought forward | 752,486 | - | **752,486** |
| **TOTAL FUNDS CARRIED FORWARD** | 610,461 | - | **610,461** |

## 13. Employee Benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits would be recognisable immediately as an expense when the Charity is demonstrably committed to terminate an employee's employment or to provide termination benefits.

## 14. Pension Costs

The pension costs charged in the financial statements represent the contributions payable by the Charity during the year to a multi-employer defined benefit pension scheme.

## 15. Financial Instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and are subsequently measured at their amortised cost.

## 16. Creditors and Provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

## 17. Tangible Fixed Assets

| | Computer Equipment £ |
|---|---|
| **Cost** | |
| At 1 January 2020 and 31 December 2020 | 2,358 |
| **Depreciation** | |
| At 1 January 2020 | 1,872 |
| Charge for year | 162 |
| At 31 December 2020 | 2,034 |
| Net Book Value | |
| At 31 December 2020 | 324 |
| At 31 December 2018 | 486 |

## 18. Stocks

| | **31.12.20 £** | 31.12.19 £ |
|---|---|---|
| Stocks | **14,251** | 10,811 |

Stocks are stated at the lower of cost and estimated selling price less costs to complete and sell. Cost includes all costs of purchase, costs of conversion and other costs incurred in bringing stock to its present location and condition. Due allowance is made for obsolete and slow-moving items.

Donated stocks are fair valued when their economic benefit is probable, it can be measured reliably, and the charity has control over the item.

# Notes to the Financial Statements - continued

for the Year Ended 31 December 2020

## 19. Debtors: Amounts Falling Due Within One Year

| | **31.12.20** **£** | 31.12.19 £ |
|---|---|---|
| Deposit | **925** | 925 |
| Prepayments and accrued income | **50,924** | 78,943 |
| | **51,849** | 79,868 |

Trade and other debtors are recognised at the settlement amount due after any trade discount offered.
Prepayments are valued at the amount prepaid net of any trade discounts due

## 20. Cash at Bank

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.20 Total Funds £** | 31.12.19 Total Funds £ |
|---|---|---|---|---|
| Bank account no. 1 | 8,548 | 42,462 | **51,010** | 48,813 |
| Bank account no. 2 | 15,484 | - | **15,484** | 16,017 |
| Bank account no. 3 | 865,898 | - | **865,898** | 740,208 |
| Bank account no. 4 | 565,212 | - | **565,212** | 734,594 |
| Total | 1,455,142 | 42,462 | **1,497,604** | 1,539,632 |

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of twelve months or less, and bank overdrafts. Should any bank overdrafts arise they would be shown within borrowings in current liabilities.

## 21. Creditors: Amounts Falling Due Within One Year

| | **31.12.20** **£** | 31.12.19 £ |
|---|---|---|
| Grant Payable | **600,198** | 406,569 |
| Accruals and deferred income | **6,767** | 15,734 |
| | **606,965** | 422,303 |

## 22. Creditors: Amounts Falling Due After More Than One Year

| | **31.12.20 £** | 31.12.19 £ |
|---|---|---|
| Other creditors | **727,178** | 598,033 |

## 23. Movement in Funds

| | At 1.1.20 £ | Net Movement in Funds | **At 31.12.20 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 610,461 | (423,038) | **187,423** |
| **Restricted Funds** | | | |
| Restricted Funds | - | 42,462 | **42,462** |
| Total Funds | 610,461 | (380,576) | **229,885** |

**Net movement in funds, included in the above are as follows**

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 351,366 | (774,404) | **(423,038)** |
| **Restricted Funds** | | | |
| Restricted Funds | 107,279 | (64,817) | **42,462** |
| Total Funds | 458,645 | (839,221) | **(380,576)** |

**Comparatives for movement in funds**

| | At 1.1.19 £ | Net Movement in Funds | **At 31.12.19 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 752,486 | (142,025) | **610,461** |
| Total Funds | 752,486 | (142,025) | **610,461** |

## 23. Movement in Funds - Continued

Comparative net movement in funds, included in the above are as follows:

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 599,647 | (741,672) | **(142,025)** |
| **Restricted Funds** | | | |
| Restricted Funds | 169,172 | (169,172) | **-** |
| Total Funds | 768,819 | (910,844) | **(142,025)** |

A current year 12 months and prior year 12 months combined position is as follows:

| | At 1.1.19 £ | Net Movement in Funds | **At 31.12.20 £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 752,486 | (565,063) | **187,423** |
| **Restricted Funds** | | | |
| Restricted Funds | - | 42,462 | **42,462** |
| Total Funds | 752,486 | (522,601) | **229,885** |

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

| | Incoming Resources £ | Resources Expended £ | **Movement in Funds £** |
|---|---|---|---|
| **Unrestricted Funds** | | | |
| Unrestricted Funds | 951,013 | (1,516,076) | **(565,063)** |
| **Restricted Funds** | | | |
| Restricted Funds | 276,451 | (233,989) | **42,462** |
| Total Funds | 1,227,464 | (1,750,065) | **(522,601)** |

## 24. Related Party Disclosures

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2019 - £nil). There are no expenses paid to the Trustees in the year. No trustee is deemed to have benefited as a result of a related party connection. All trustees have declared all such relationships to the Chairman.

## 25. Post Balance Sheet Events

**Covid-19 Pandemic**

At the time of writing these accounts, the Covid-19 pandemic has significantly impacted the way in which every organisation operates around the world. As a result, we have been forced to cease most fundraising activities and all our events due to the ever-changing situation relating to the outbreak. It is unclear how much of an impact this will have on our overall income for the year, but we are unlikely to meet the fundraising budget which was signed off by the trustees in January. We have reacted quickly to the crisis and further diversified our fundraising activities to ensure that there are no going concern issues. If the crisis continues until the end of the year (as predicted) we are unlikely to fund any new research projects until the end of 2021.

## 26. Ultimate Controlling Party

The Trustees control Action for A-T in accordance with the trust deed.

# Detailed Statement of Financial Activities

for the Year Ended 31 December 2020

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.20 £** | 31.12.19 £ |
|---|---|---|---|---|
| **Income and Endowments** | | | | |
| Donations | 68,506 | 107,279 | **175,785** | 232,188 |
| Gift aid | 8,498 | - | **8,498** | 63,530 |
| Fundraising | 81,619 | - | **81,619** | 64,108 |
| | 158,623 | 107,279 | **265,902** | 359,826 |
| **Investment income** | | | | |
| Bank interest | 12,130 | - | **12,130** | 11,108 |
| **Charitable activities** | | | | |
| Fundraising events | 43,820 | - | **43,820** | 178,591 |
| Challenge events | 95,587 | - | **95,587** | 216,294 |
| | 139,407 | - | **139,407** | 394,885 |
| **Other income** | | | | |
| Other income | 3,000 | - | **3,000** | 3,000 |
| HMRC JRS Grant | 38,206 | - | **38,206** | - |
| | 41,206 | - | **41,206** | 3,000 |
| Total incoming resources | 351,366 | 107,279 | **458,645** | 768,819 |
| **Expenditure** | | | | |
| **Raising donations and legacies** | | | | |
| Wages | 60,010 | - | **60,010** | 46,821 |
| **Charitable activities** | | | | |
| Event campaign costs | 40,927 | - | **40,927** | 128,307 |
| Event - fundraising & challenge | - | - | **-** | 5,258 |
| Grants to institutions | 557,428 | 64,817 | **622,245** | 598,034 |
| | 598,355 | 64,817 | **663,172** | 731,599 |
| **Support costs** | | | | |
| **Management** | | | | |
| Wages | 14,922 | - | **14,922** | 15,393 |
| **Finance** | | | | |
| Bank charges | 1,056 | - | **1,056** | 2,237 |
| **Information technology** | | | | |
| Repairs and renewals | 3,999 | - | **3,999** | 2,060 |

# Detailed Statement of Financial Activities

for the Year Ended 31 December 2020

| | Unrestricted Funds £ | Restricted Funds £ | **31.12.20 £** | 31.12.19 £ |
|---|---|---|---|---|
| **Information technology** | | | | |
| Other | | | | |
| Rent, rates and water | 13,089 | - | **13,089** | 13,523 |
| Insurance | 1,036 | - | **1,036** | 675 |
| Telephone | 758 | - | **758** | 883 |
| Postage and stationery | 809 | - | **809** | 905 |
| Sundries | 1,976 | - | **1,976** | 534 |
| Advertising | 2,042 | - | **2,042** | 1,366 |
| Subscription | 932 | - | **932** | 438 |
| Donation collection fees | 1,002 | - | **1,002** | 881 |
| | 21,644 | - | **21,644** | 19,205 |
| **Fundraising** | | | | |
| Wages | 54,832 | - | **54,832** | 75,951 |
| **Governance costs** | | | | |
| Wages | 13,802 | - | **13,802** | 11,355 |
| Auditors' remuneration | 3,300 | - | **3,300** | 3,300 |
| Accountancy and legal fees | 2,322 | - | **2,322** | 2,137 |
| Computer equipment | 162 | - | **162** | 786 |
| | 19,586 | - | **19,586** | 17,578 |
| Total resources expended | 774,404 | 64,817 | **839,221** | 910,844 |
| Net (expenditure)/income | (423,038) | 42,462 | **(380,576)** | (142,025) |

# Acknowledgments

Action for A-T relies entirely on its donors and supporters who so generously give their time and money to support vitally needed research into A-T. With their support we believe we can make a difference to all people with A-T and their families.

We would like to give special thanks to the following organisations that worked alongside us in 2020:

## Our Research Partners

BrAshA-T Ataxia Telangiectasia and their trustees

A-T Children's Project (USA) and their Medical Research Team

Ataxia Telangiectasia Society

Sparks Children's Medical Research Charity

## Support from Companies, Trusts & Foundations

We are aware that Companies, Trusts & Foundations are often approached to support charities and are therefore extremely grateful to the following organisations for their generous support.

Aviva
An Anonymous Trust
Barclays
Barton Comms
BCA
Bergqvist Charitable Trust
Big Give
Blyth Watson Charitable Trust
Broyst Foundation
Cast Media Group
Chapman Charitable Trust
Cinch
Data IQ
Ed Shanley
Epsom & Ewell Borough Council
Epsom Rotary Club
Mr & Mrs Gary Shaughnessy
Global Entertainment
Hiscox Foundation
ITV
Jones 1986 Charitable Trust
Kent Community Foundation
Lumen Financial Ltd
Michael and Anna Wix Charitable Trust
Midwood McTurk Trust
Naga Munchetty
National Lottery Community Fund
Paul & Clare Rooney
Psigma Foundation
Quest Professional
Rawson Digital
Real Golf
Reed Foundation
Rest-Harrow Trust
Robin Hewison
Sir Samuel Scott of Yews Trust
St. James' Place Foundation
Steel Charitable Trust
Syder Foundation
Tesco
Work for Good

**Corporate or professional services provided by:**

A & N Chartered Accountants
Akin Gump
Chris Stanton
Gecko Graphic Design

## Our Supporters

We have relied almost exclusively on our supporters, volunteers and Trustees for their time and commitment to raising money and spreading awareness about this devastating condition. Thank you to everyone who has helped us to push research into A-T forwards.

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE

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Registered Charity number: 1145303