

**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

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Accountants & Auditors

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

Contents

Legal & Reference Information	2
Table of Contents	3
Trustees' Report	4
Reference & Administrative Details	4
Public Benefit	4
Objectives, Achievements & Performance.....	4
Identifying High Quality Research into A-T.....	5
Funding High Quality Research.....	6
Fundraising for Research	12
Building Collaborative Partnerships	13
Raising Public Awareness for A-T.....	15
Our Future Plans: Areas of Focus for 2022	17
Structure, Governance & Management	19
Financial Review	21
Auditor's Report.....	23
Statement of Financial Activities	26
Notes to the Financial Statements	30
Acknowledgements.....	43

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 & 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 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

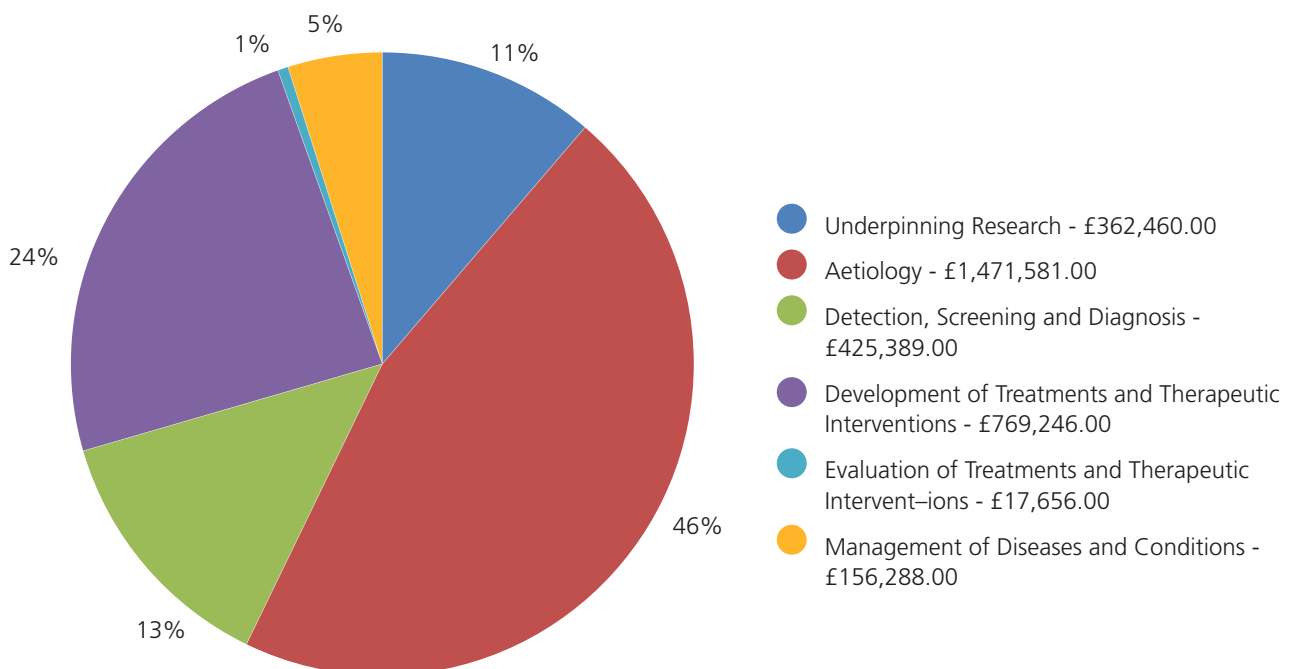
Development of Treatments and Therapeutic Interventions - Creating drugs and therapies to alleviate the symptoms of A-T

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



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 cytotoxic 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

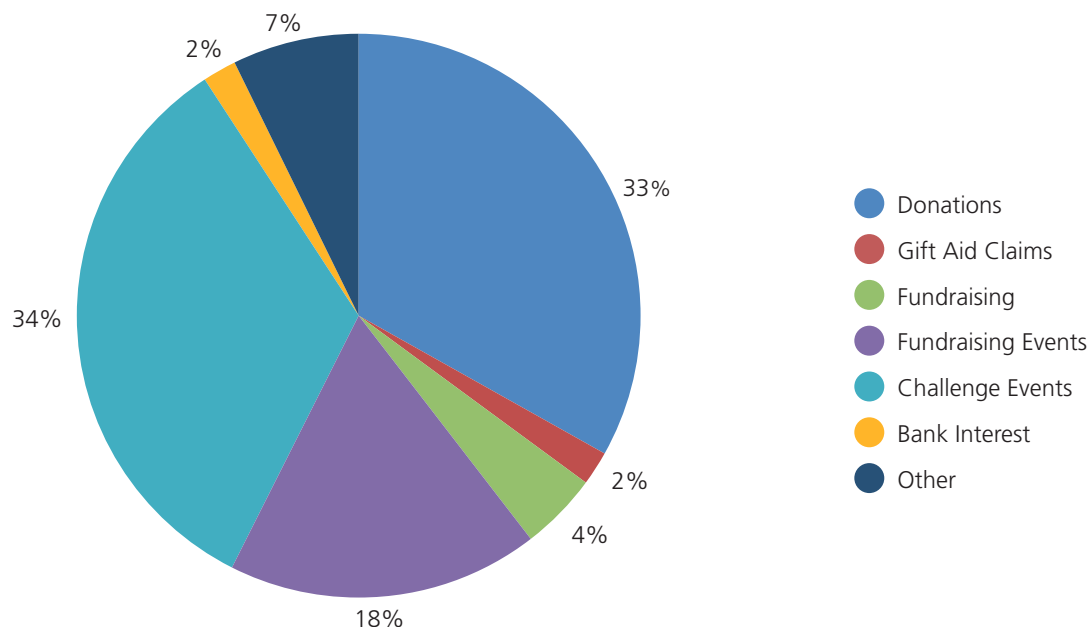
Action for A-T are registered with the Fundraising Regulator and are committed to upholding the code of fundraising practice. We receive all our funding from voluntary sources, including individuals, companies, trusts and foundations. We also purchase places in several physical challenges as well as 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					
Fundraising & challenge events	5	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					
Fundraising & challenge events	7	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

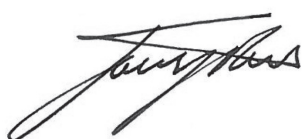
for the year ended 31 December 2021

	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:			
Cash generated from operations	1	(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 is 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 2020.

Trustees' Expenses

There were no Trustees' expenses paid for the year ended 31 December 2021 nor for the year ended 31 December 2020.

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.

Notes to the Financial Statements - continued

for the Year Ended 31 December 2021

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	606,965

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

Notes to the Financial Statements - continued

for the Year Ended 31 December 2021

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.



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Registered Charity number: 1145303