

The Ataxia Telangiectasia Society  
Trustees' Report and Accounts 2023



ADVOCATING

\* Ataxia Telangiectasia

COLLABORATING

DEDICATED

\* Ataxia Telangiectasia

TRANSFORMING



# Welcome to the Ataxia Telangiectasia (AT) Society

We are a small, national charity supporting children, adults and their families whose lives have been shattered by a diagnosis of AT, a rare, degenerative, life limiting condition for which there is no cure. Our purpose is to improve the quality of life and quality of care for people living with AT while actively promoting research to improve treatments and ultimately bring about a cure. We are the only charity in the UK providing specialist, practical and therapeutic support for people affected by AT.

**“Together we can really  
make a difference and ensure  
there is hope for the future  
and support for today.”**

**Mike Detsiny**  
Chair of Trustees

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# Chair of Trustees' statement

Dedicated to providing support for today and hope for tomorrow

As I look back at the AT Society's performance over the past year, it's clear that 2023 has been a year of investment and of achievements, during what has remained an uncertain time as we tackled the aftermath of the pandemic and rising costs.

The year began positively with our BBC Lifeline Appeal, which raised valuable funds and increased awareness, thanks to the bravery of our three families who publicly told their stories. The financial uplift continued in the months that followed with some extraordinarily generous donations, an increase in fundraising events, and the receiving of some large grants. Thanks to these kind supporters, the income growth meant we were able to commit to spending more on service delivery this year than before, helping 225 individuals with AT and over 800 family members, as well as increase our medical research funding to deepen our understanding of AT.

These actions were essential because there was no escaping the fact that the cost-of-living crisis continued to have a disproportionately negative effect on people with AT. With rising bills and increasing health and social care complications, adding to the already daily frustrations, depression and anxiety that living with AT can bring, it meant that we've never delivered more support to more people as we attempted to keep up with increasing needs.

Nearly half of our emergency grants during the year helped families with rising rent and fuel costs. The rest went towards emergency housing modifications, disability equipment, respite care, and compensation for income loss associated with having a disabled child. We provided therapeutic support for young people and their parents, regularly distributed new information and resources, and organised social events to increase connections. We helped to fund international research studies, worked with organisations to help them to make AT clinical trials a reality, and with hospital teams to schedule more AT clinics, reduce waiting times, and fulfil our patient advocacy contract with NHS England. That was not all. We provided training for professionals, we advocated daily for individuals and we ran our helpline.



More can be read about these achievements in the following pages, and in our 2023 Impact Report that complements these accounts:



As we go into our 35th year and we look to the future, the external environment is likely to continue to challenge us, and prudent financial planning will continue to be as important as income generation. If we are to make great strides towards reducing inequalities, ending barriers to good health and wellbeing, and making scientific breakthroughs, then working together with the AT community, our supporters, partners, the NHS, local authorities, schools, and the scientific community, remains as important as ever.

I am most grateful to everyone who joins us and supports our work, in all the many marvellous ways you do, and ask that you please continue to do so. Together we can really make a difference and ensure there is hope for the future and support for today.

Finally, I would like to thank our dedicated staff team who continuously work beyond the call of duty to improve the lives of those affected by AT. Great people make a great charity.

A handwritten signature in black ink, appearing to read 'Mike Detsiny', with a long horizontal flourish extending to the right.

Mike Detsiny  
Chair of Trustees



# Trustees' report

The AT Society's Board of Trustees have pleasure in presenting their report, together with the Society's audited financial statements for the year ended 31 December 2023.

This report has been prepared in compliance with the duty in Section 17 (5) of the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission.

The trustees, who are directors of the company for the purposes of the Companies Act, 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 (Charities SORP FRS 102) (effective 1 January 2019).

## Objectives and activities

### Ensuring the Society's work achieves its aims and delivers public benefit

The purpose of the Society and its public benefit as set out in the company's Memorandum of Association, is "the relief of sickness and distress among persons suffering from ataxia telangiectasia".

#### Vision

A world where no one need suffer from the devastating effects of AT.

#### Mission

To improve the quality of life and quality of care for people living with AT while actively promoting research to improve treatments and ultimately bring about a cure.

We do this by:

- Providing specialist information, support, care and advocacy to meet the challenges of living with AT
- Speaking out to ensure that the voices of people affected by AT are heard
- Raising awareness of AT
- Working to achieve better, more informed, and more coordinated health and social care services across all sectors
- Promoting and commissioning high quality AT research.

In deliverance of our work, each year the trustees review the Society's aims, objectives and activities during the planning cycle. This review examines the activities of the previous year and measures the outcomes of those activities against the objectives of that year's plan by reference to the benefits delivered to people affected by AT.

It also serves to ensure that the Society's aims and objectives remain focused on its stated purpose and enables the trustees to consider how the Society's activities further its charitable purposes for the public benefit, in particular all those affected by AT, in accordance with the Charity Commission's guidance.

In pursuit of these objectives, the Society has a formal budgeted business plan for the year, which is reviewed regularly. The Society's activities and achievements in 2023 are detailed below and our 2023 Impact Report, provides further illustrations of our work during the year to complement this report.



## Achievements and performance

The year got off to a welcome start with our BBC Lifeline Appeal to help raise essential funds and to be able to tell thousands of people about this unknown condition on the world's leading broadcaster. This was quickly followed by rare disease collaborations and promotions, our first ever golf day, and all manner of new, fun and exciting fundraising and awareness events.

This positive financial start to 2023 was essential to ensure we could provide the specialist information, care and advocacy to support families coping with the everyday pressures of living with AT, and who were also the very people hit hardest by the cost-of-living crisis. We committed to spending more on service delivery this year than before. Over a third of our emergency grants were provided to help families pay for the sharp increases in rent and fuel bills. We helped to fund urgent housing adaptations and disability equipment, respite care for families to create happy memories in difficult times, and the loss of earnings that having a disabled child brings.

Of course, even without the economic pressures, the daily frustrations, and anxiety faced by people affected by AT cannot be underestimated and we made sure we were active in supporting young people and their parents to look after their mental health. We provided play therapy, counselling, created new tools and responded to calls with a friendly listening ear to help with today's crisis, as well as with the road ahead. 75% of young people told us they felt more hopeful about their mental health after being supported to learn new skills and to connect with others.

## How we changed lives in 2023



In October we held our first Family Weekend for four years: the COVID restrictions and subsequent increased costs had temporarily prevented us from organising this previously annual event. We were pleased that 154 children, young adults and their families attended the weekend, to help forge new connections and reduce isolation, to learn from one another's experiences and to hear from the AT social, medical and scientific experts who attended, and above all, to have fun, in a safe, caring, friendly environment. Significantly the weekend helped those with a rare condition to no longer feel rare, but to feel a part of an important community.

At the end of the weekend, 83% of adults said the weekend helped them to feel happy; 75% felt less anxious, and 100% of children gave the weekend top marks!

One young person said, "I feel happy and included". A parent said "I no longer feel alone on this journey".

Working collaboratively through the year to maximise our impact and deliver our mission is essential for the AT Society, not just for raising awareness and funds, but so we could achieve better, more informed, and more coordinated health and social care services across all sectors. So as the higher cost of living continued to hit households with a disabled child hardest, we joined other disability charities to press for change and fight for equality, and we advocated at health, education, housing, benefit and social care appointments throughout the year for families who were not being heard.

We provided AT training for health and education providers to improve their awareness and knowledge of AT: 96% said their practice would be positively impacted for the benefit of families and children affected by AT. We worked closely through the year with our NHS partners to deliver regular specialist AT medical clinics; 97% of patients strongly agreed that their healthcare needs had been met this way and 100% were keen to visit again.

These dedicated AT clinics at Nottingham University Hospital (for children) and the Royal Papworth Hospital (for adults) continue to be a crucial element of our work with AT families, not only in the delivery of essential medical care by AT experts, but also in helping to join up the national service with local health and social care teams.

During the year we continued to promote and commission high quality AT research to further our understanding of the condition. There's a lot still to do. It takes considerable effort, time and money for a scientific discovery to be translated into a new treatment, particularly for a complex and rare condition like AT but there is reason to be hopeful and our role in the process is vital. We were pleased in 2023 to be able to: fund ground breaking medical research whose findings will pave the way for future clinical trials; deliver scientific talks on key topics and inform our patient group of developments to help share knowledge and improve health outcomes; work closely with medics and the pharmaceutical industry, to support recruitment to forthcoming trials; and provide funding to keep UK families involved and to ensure financial hardship is not a barrier to children's participation.

With the help of our UK and international research partners, including the other amazing international AT organisations in the AT Global Alliance, genuine progress is being made towards helping to find treatments and an eventual cure. Further information can be found here: <https://atsociety.org.uk/research/>

To strengthen our ability to campaign on behalf of and meet the needs of people living with AT, we are affiliated to the Genetic Alliance UK, Rare Disease UK, Euro-Ataxia, and are members of the NCVO and the Association of Medical Research Charities. We work closely with Ataxia UK, neurological alliances, and UK and international AT groups.

## Plans for future periods

For the last few years, we've been operating in unusual circumstances. COVID and the aftermath, a change in leadership and structure, an office move, home/hybrid working and an economic recession, have all impacted on the charity, in different ways; on our ability to raise funds, and on the services we deliver. We have risen to the challenges and have grown income each year, and controlled costs. But we are still operating in a difficult economic environment which affects everything we do and the choices we make, and we know that the situation for people affected by AT across the UK is extremely challenging. To continue to ensure we are delivering the very best services for people living with AT, in 2024 we will work towards deepening our understanding of how people with AT are experiencing the world, growing our impact, and connecting with audiences we're not yet reaching.

In what will be our 35th year, a key priority will be to develop a 3-5 year strategy which recognises and responds to the needs of people affected by AT and the economic situation that is likely to impact on the charity's operation for some years to come, and build on what has already been achieved in previous years. Running alongside this, we will:

- Work with our NHS partners to run our specialist AT medical clinics in the most effective and efficient way possible
- Deliver an Activity Weekend for young people and adults with AT to improve social opportunities and mental wellbeing
- Continue our equity, diversity and inclusion ambitions to ensure all our services are fully accessible
- Deliver opportunities for wider family networks to meet and learn about AT to help them better support their family or friend with the condition
- Continue working with, and investing in, the AT research community to advance our understanding of AT and move us closer to finding treatments and an eventual cure.

We will also continue to focus on developing our mental health work to help people to cope with the challenges that AT brings and will be led by the insights of people affected by AT.

We will provide expert and friendly advice and support to all service users, their families, and professionals, and we will fight for the overlooked needs of disabled people and stand up to the injustices that make life so much harder for people with AT.

We will develop our efforts to reduce our carbon footprint by keeping moving closer to becoming a paperless office, reducing travel by meeting online where possible; recycling waste and equipment; and buying environmentally friendly products.

## Structure, Governance and Management

The Ataxia Telangiectasia Society is a charitable company limited by guarantee, incorporated in England and Wales, in 2004, under company number 5177145. It is registered with the Charity Commission in England under the same name, registration number 1105528. The Society uses the working name "AT Society". The registered address is listed on the inside back cover. The company was established under a Memorandum of Association which defined its objects and powers; it is governed by its Articles of Association. In the event of the company being wound up members may be required to contribute an amount not exceeding £1 each.

Directors of the company are also trustees for the purposes of charity law. The directors are normally referred to as 'trustees' and meet formally as a Board 4 times each year. This Board of Trustees is the governing body of the Society. It determines the overall strategy for the organisation and the policies and procedures for the implementation of this strategy. It also oversees the effective and equitable use of the Society's resources and ensures that it meets all its legal, regulatory and ethical obligations.

Vetting and checks of trustees are carried out in line with Charity Commission guidance. All new trustees receive an information pack outlining their legal obligations under charity and company law, a copy of the previous year's annual report and accounts, a copy of the annual plan, a copy of the company's Memorandum & Articles of Association and a representative selection of the Society's current literature. Inductions take place with all staff, and conflicts of interest always declared.

The Board has a positive approach to its own training and development, regularly reviewing skills and needs and organising appropriate training, whether for the group or for individuals. All trustees complete safeguarding training appropriate for their role and all are encouraged to keep abreast of developments both in charity governance and in current issues concerning AT.

The AT Society has two sub-committees that report into the Board, both consisting of volunteer scientific experts in the field and lay AT family members. Our Scientific Advisory Board, chaired by Professor Rob Dineen, advise on our research strategy and rigorously assess projects to maximise our investments into the highest quality research. Our new Clinical Trials sub-committee, chaired jointly by Dr Rita Horvath and Dr Anke Hensiek, was set up this year, to keep abreast of the different trials on the horizon, provide information for families and improved connection with Principal Investigators conducting trials, and to provide input from patients in enabling new trials and trial design.

Under the terms of the Memorandum and Articles of Association, directors may either be appointed by the Board to fill a casual vacancy or are to be elected by the Society's members at the annual general meeting to serve a 3-year term of office. All appointed directors must submit themselves to election at the annual general meeting immediately following their appointment. The Board of Trustees may consist of between 3 and 20 members. We currently have 9 trustees and in accordance with our aim to be a user-led organisation, over half of our Board have experience of living with AT.

All directors of the company give their time voluntarily and receive no benefit from the charity by virtue of the office they hold. Any expenses reclaimed from the charity are set out in note 11 to the accounts. Where a director is a potential beneficiary of the charity, the holding of his office will not be a bar to his or her being an actual beneficiary. In such circumstances, the director declares his interest and takes no part in the discussion or decision concerning his or her application for benefit.

The Director of Fundraising and Operations shares leadership of the charity with the Head of Services and Head of Research. Remuneration of the Society's staff team of 9 is reviewed annually against performance and affordability. We are a Living Wage Employer which means we ensure pay is fair for all roles and are committed to paying all our employees at or above the London living wage as determined by the Living Wage Foundation.

The team organises and provides most of the services delivered by the Society and manages and supports the Society's volunteers. During the year we enjoyed the support of office, administrative, event volunteers and volunteers from companies who gave communications and design support, legal and administrative help, for which we are immensely grateful.



The Society values its staff and aims to be an exemplary employer of a skilled and committed workforce. It does not discriminate in any way in the recruitment, training or retention of employees, and actively encourages its staff to enhance and extend their skills, particularly with regard to its charitable objectives; learning and personal development are central to the appraisal process.

All trustees, members of the sub-committees, and staff active in 2023 are listed on the inside back cover of this report.

## Financial review

During the year we were pleased to have increased our income and controlled costs.

The AT Society received income of £478,337 (2022: £429,145) and spent £662,593 (2022: £481,406). The Society therefore had an overall planned deficit for the year of £184,256 (2022: £52,261) in recognition of the investment in research and support services that the Society committed to.

With funds brought forward from previous years, the Society will carry forward £399,733 in reserves (2022: £583,989). Unrestricted general funds carried forward have decreased to £303,301 (2022: £364,843). The Society also carries forward restricted funds of £96,432 (2022: £219,146), which the trustees consider to be at an appropriate level.

Of the Society's total income some 61% was received in donations from individuals, companies and trusts; 34% in grants from NHS England, the Medical Research Council and Trusts. The remaining income came from welfare charitable activities, trading and investment income.

## Investment policy

The trustees recognise their duty to maximise the financial returns generated from the way in which the charity's assets are invested and do so responsibly and ethically in a way that is consistent with the aims and values of the AT Society. In 2022 the trustees evaluated the investment returns and agreed to move funds from a deposit account with the Charities Aid Foundation, to a deposit platform with Flagstone, still managed by CAF, and which involves investing in UK banks with higher interest-bearing returns and no risk of capital loss. The trustees review this policy on an annual basis to look at other potential opportunities. The senior management and trustees proactively monitor the performance of investment opportunities regularly and in 2023 our investments generated £7,845 in income, helping towards achieving our objectives.

## Reserves policy

The AT Society maintains free unrestricted reserves:

- To provide a level of working capital that protects the continuity of our core work
- To provide a level of funding for unexpected opportunities
- To provide cover for risks such as unforeseen expenditure or unanticipated loss of income.

The Board of Trustees regularly review the above criteria with reference to the AT Society's strategy and Annual Plan and determine the target level of free reserves to meet these.

Given the economic climate and the risks to income and cost increases, in 2022 the Board considered it prudent for a charity of this size, heavily reliant upon voluntary income, to maintain a minimum level of 9 months of operational costs. This policy was adopted again in 2023, although we finished the year below our target, with just 7 months of free reserves. The Trustees deemed this to be an acceptable short-term situation but will closely monitor it in 2024. As part of the process, a new 3-5 year strategy will be developed in 2024 for the Society which will include developing robust plans for income development and cost reduction.

The Board of Trustees will at times designate funds from free reserves for significant project costs or replacement of major assets. The charity also holds restricted reserves which represent the excess of restricted income over restricted expenditure. Restricted reserves are closely monitored to ensure they are used in accordance with the terms specified when the funds were received.

## Fundraising

Whilst the AT Society engages in public fundraising, it does not use external professional fundraisers or commercial participators for this. However, professional fundraisers are used for fundraising from Trusts and Foundations. The charity observes and complies with the relevant fundraising regulations and codes and is a member of the Fundraising Regulator.

The AT Society is committed to safeguarding any personal fundraising data that we process, ensuring that it is stored and shared safely and securely. We are compliant with GDPR and review all data privacy and protection policies regularly to ensure that they remain strong and effective.



## Risk management

The trustees have a risk management process which includes an annual review of the risks to which the charity may be exposed, and the establishment and implementation of systems and procedures designed to mitigate the impact on the charity of the risks identified. The risk register is reviewed frequently, and key risk areas identified for 2024 include:

- Insufficient funds to allow the charity to meet its objectives
- Information security and data protection
- Safeguarding children, young people and vulnerable adults
- Loss of key staff.

## Safeguarding

Protecting the welfare of children, young people and vulnerable adults who receive the services we provide is central to our culture and is a governance priority. Everyone who works or volunteers for the AT Society has a responsibility to safeguard and promote service users' welfare, alongside a duty to recognise, respond and share concerns or worries about possible abuse and harm in a timely fashion. This is reflected in our safeguarding policies and procedures, which include safe recruitment measures and clear training requirements, which are regularly reviewed by our safeguarding leads.

## Grant-making policies

The Society makes two types of grants to meet its objectives:

- Research grants
- Individual support grants

### Research grants

The Society is a member of the Association of Medical Research Charities (AMRC) and works to AMRC standards in its research grant programme. Our Scientific Advisory Board ensure that research grants undergo a robust peer-reviewed process and confirm that:

- The project has scientific merit and meets the aims of the Society's research strategy
- The proposed study does not duplicate other current or recent research
- The Society is spending its research funds in the most effective way

The AT Society's research strategy and procedures are reviewed by the SAB and reported to the trustee board, with priorities agreed to ensure the greatest possible impact for its research programme.

For the next few years, the AT Society is primarily focusing its research efforts on understanding and treating the neurological problems caused by AT and the loss of the ATM protein. This is the feature of AT which has the greatest impact on everyday life for people with AT. It not only affects movement and manual dexterity, but also speech, eating and nutrition, posture and potential scoliosis and it also contributes significantly to the development of lung disease.

In line with our research strategy, during 2023 we supported the following research projects:

- Natural History of AT (N-HAT), and a statistical consultancy, University of Nottingham
- Brain-penetrating ATM gene therapy, University of Nottingham
- Study of natural killer cells in AT pathogenesis and their therapeutical implications, Tor Vergata University of Rome
- Digital drug prediction informed by genetic analysis of stem cell-derived mini brains from AT patients, QIMR Berghofer Medical Research Institute
- Understanding and correcting glucose metabolism defects in AT, The FIRC Institute of Molecular Oncology
- Trial REadiness in AT, University of Cambridge
- Modulation of RELB/p52-dependent NF-kB activities to improve neurodegenerative symptoms of AT, University of Cambridge

Our full research programme can be viewed at:

[www.atsociety.org.uk/research/](http://www.atsociety.org.uk/research/)

### Individual support grants

The Society provides financial support grants to any individual affected by AT, to assist with the cost of items that they need as a result of the condition but cannot easily afford, and for which they cannot get help from other sources. An application form is used and there are formal criteria for the assessment and awarding of grants, approved by the AT Society Support Team. Applicants need the support of an appropriate professional and need to demonstrate what efforts have been made to obtain statutory or other funding.

## Statement of Trustees' responsibilities

The trustees (who are also the directors of The Ataxia Telangiectasia Society for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice). Company law 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 charitable company and of the incoming resources and application of resources, including the income and expenditure of the charitable company for that period. In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the charity SORP
- Make sound judgements and estimates that are reasonable and prudent
- Prepare the financial statements on the going concern basis, unless it is inappropriate to presume that the Society will continue on that basis.

The trustees are responsible for keeping proper accounting records which 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 Companies Act 2006. The trustees 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.

In accordance with company law, as the directors of the company, we certify that:

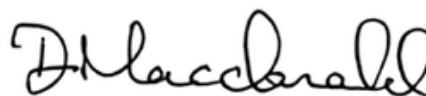
- So far as we are aware there is no relevant audit information of which the company's auditors are unaware
- As the trustees of the company, we have taken all the steps that we ought to have taken in order to make ourselves aware of any relevant audit information and to establish that the charity's auditors are aware of that information.

## Auditors

Hicks and Company, the auditors, were re-appointed as the charitable company's auditors during the year and have expressed their willingness to continue in that capacity. A resolution will be proposed at the annual general meeting that they be re-appointed as auditors to the charity for the ensuing year.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by the Board of Trustees on 15 July 2024 and signed on its behalf by:



David MacDonald  
Treasurer

# Independent auditor's report

## Independent auditor's report to the members of the Ataxia Telangiectasia Society

### Opinion

We have audited the financial statements of the Ataxia Telangiectasia Society (the 'charitable company') for the year ended 31 December 2023 on pages 12 to 20. 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 charitable company's affairs as at 31 December 2023 and of its incoming resources and application of resources, including its income and expenditure, 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 Companies Act 2006.

### 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 Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company 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 charitable company'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 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, 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.

### Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- The information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- The Report of the Trustees has been prepared in accordance with applicable legal requirements.

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

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees. We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- Adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- The financial statements are not in agreement with the accounting records and returns; or
- Certain disclosures of trustees' remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit; or
- The trustees were not entitled to take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Report of the Trustees.

## Responsibilities of trustees

As explained more fully in the Statement of Trustees' Responsibilities set out on page 8, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they 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 charitable company'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 charitable company or to cease operations, or have no realistic alternative but to do so.

## Our responsibilities for the audit of the financial statements

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 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:

Based on our understanding of the entity and sector in which it operates, we identified the principal risks of non-compliance with laws and regulations relating to charitable companies and the application of charitable funds. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements.

We communicated identified laws and regulations throughout our team and remained alert to any indications of non-compliance throughout the audit. We assessed the susceptibility of the charity's financial statements to material misstatement, including obtaining an understanding of how fraud may occur, by making enquiries of the trustees and management as to where they considered there was susceptibility to fraud and considering the internal controls in place to mitigate fraud risks and non-compliance with laws and regulations.

In response to the risk of fraud through management bias (including the risk of override of controls) and the risk of irregularities and non-compliance with laws and regulations, we designed procedures which included, but were not limited to:

- Performing analytical procedures to identify unusual or unexpected transactions
- Assessing whether judgements and assumptions made in determining accounting estimates were indicative of potential bias
- Reviewed a sample of transactions from the client's records for proper authorisation
- Performing completeness of income tests
- Test checking the appropriateness of journal entries
- Agreeing financial statement disclosures to the underlying supporting documentation
- Checking for correspondence with the Charity Commission
- Reading the minutes of Trustees' meetings
- Checking for any actual and potential litigation and claims including inspecting legal costs.

There are inherent limitations in our audit procedures outlined above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures to identify non-compliance with laws and regulations to enquiry of the trustees and other management and the inspection of regulatory and legal correspondence, if any. Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion. We are not responsible for preventing non-compliance and cannot be expected to detect non-compliance with all laws and regulations.



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](http://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 company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's 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 company and the company's members as a body, for our audit work, for this report, or for the opinions we have formed.

*Philip Dean*

Philip Dean  
Senior Statutory Auditor

For and on behalf of Hicks and Company

Chartered Accountants and Statutory Auditor  
Vaughan Chambers  
Vaughan Road  
Harpenden  
Hertfordshire AL5 4EE

15 July 2024

# Statement of financial activities

## Year ended 31 December 2023

	Notes	Unrestricted funds £	Restricted funds £	Total funds 2023 £	Total funds 2022 £
<b>Income and endowments from:</b>					
Donations and legacies	2	280,293	174,418	<b>454,711</b>	421,986
<b>Charitable activities</b>					
Welfare	5	-	14,396	<b>14,396</b>	3,425
Other trading activities	3	1,385	-	<b>1,385</b>	1,592
Investment income	4	7,845	-	<b>7,845</b>	2,142
<b>Total</b>		<b>289,523</b>	<b>188,814</b>	<b>478,337</b>	<b>429,145</b>
<b>Expenditure on:</b>					
Raising funds	6	147,711	-	<b>147,711</b>	117,439
<b>Charitable activities</b>					
Research	7	149,379	34,370	<b>183,749</b>	58,357
Clinic		38,438	59,233	<b>97,671</b>	91,498
Welfare		9,376	128,659	<b>138,035</b>	120,649
Information		32,851	1,500	<b>34,351</b>	38,812
Education		23,096	-	<b>23,096</b>	21,555
Governance		37,980	-	<b>37,980</b>	33,096
<b>Total</b>		<b>438,831</b>	<b>223,762</b>	<b>662,593</b>	<b>481,406</b>
<b>Net (expenditure)/income</b>		<b>(149,308)</b>	<b>(34,948)</b>	<b>(184,256)</b>	<b>(52,261)</b>
<b>Reconciliation of funds</b>					
<b>Total funds brought forward</b>		<b>364,843</b>	<b>219,146</b>	<b>583,989</b>	<b>636,250</b>
<b>Transfers between funds</b>		<b>87,766</b>	<b>(87,766)</b>	<b>-</b>	<b>-</b>
<b>Total funds carried forward</b>		<b>303,301</b>	<b>96,432</b>	<b>399,733</b>	<b>583,989</b>

The statement of financial activities includes all gains and losses in the year.  
All incoming resources and resources expended derive from continuing activities.

The notes on pages 15 to 20 form part of these financial statements.

# Statement of financial position

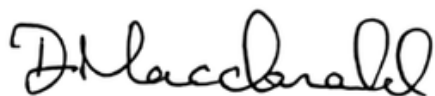
## Year ended 31 December 2023

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.23 £	Total funds 31.12.22 £
<b>Fixed assets</b>					
Tangible assets	14	1,722	-	1,722	2,251
<b>Current assets</b>					
Debtors	15	8,829	7,000	15,829	94,138
Cash at bank		305,433	139,217	444,650	558,559
		314,262	146,217	460,479	652,697
<b>Creditors:</b>					
Amounts falling due within one year	16	(12,683)	(49,785)	(62,468)	(70,959)
<b>Net current assets</b>		301,579	96,432	398,011	581,738
<b>Total assets less current liabilities</b>		303,301	96,432	399,733	583,989
<b>Net assets</b>		303,301	96,432	399,733	583,989
<b>Funds:</b>	18				
Unrestricted funds		303,301	-	303,301	364,843
Restricted funds		-	96,432	96,432	219,146
<b>Total funds</b>		303,301	96,432	399,733	583,989

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

The notes on pages 15 to 20 form part of these financial statements.

The financial statements were approved by the Board of Trustees on 15 July 2024 and were signed on its behalf by:



David MacDonald  
Treasurer

# Statement of cash flows

## Year ended 31 December 2023

	Notes	2023 £	2022 £
<b>Cash flows from operating activities:</b>			
Cash used in operations	a	(121,299)	(56,162)
<b>Net cash used in operating activities</b>		<b>(121,299)</b>	<b>(56,162)</b>
<b>Cash flows from investing activities:</b>			
Purchase of tangible fixed assets		(833)	(1,284)
Proceeds from sale of fixed assets		378	-
Interest received		7,845	2,142
<b>Net cash used in investing activities</b>		<b>7,390</b>	<b>858</b>
<b>Change in cash and cash equivalents in the reporting period</b>		<b>(113,909)</b>	<b>(55,304)</b>
<b>Cash and the cash equivalents at the beginning of the reporting period</b>		<b>558,559</b>	<b>613,863</b>
<b>Cash and cash equivalents at the end of the reporting period</b>		<b>444,650</b>	<b>558,559</b>

### Notes to the statement of cash flows

#### Year ended 31 December 2023

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

	2023 £	2022 £
<b>Net expenditure for the reporting period as per the statement of financial activities</b>	<b>(184,256)</b>	<b>(52,261)</b>
<b>Adjustments for:</b>		
Depreciation charges	1,079	964
Profit on sale of fixed assets	(95)	-
Interest received	(7,845)	(2,142)
Decrease/(increase) in debtors	78,309	63,120
(Decrease)/increase in creditors	(8,491)	(65,843)
<b>Net cash used in investing activities</b>	<b>(121,299)</b>	<b>(56,162)</b>



# Notes to financial statements

## Year ended 31 December 2023

### 1. Accounting policies

#### Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) '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 Companies Act 2006. The financial statements have been prepared under the historical cost convention.

#### Income

All incoming resources are included in the Statement of Financial Activities when the charity is entitled to the income and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

- Voluntary income is received by way of grants, donations and gifts. Donations and gifts are included in the Statement of Financial Activities when received. Grants are included when receivable. Grants, where entitlement is conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to them
- Donated services and facilities are included at the value to the charity where this can be quantified. The value of services provided by volunteers has not been included in these accounts
- Investment income is included when receivable. Bank interest is included when received
- Tax refunds (e.g. gift aid) are accounted for when receivable
- Trading income is accounted for on a receivable basis.

#### Expenditure

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes VAT, which cannot be recovered, and is reported as part of the expenditure to which it relates:

- Costs of generating funds comprise the costs associated with attracting voluntary income
- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them

- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees. All costs are allocated between the expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resources. Costs relating to a particular activity are allocated directly, other costs are apportioned on an appropriate basis e.g. estimated usage.

#### Leases

Rentals payable under operating leases are charged to the Statement of Financial Activities evenly over the period of the lease.

#### Grants payable

Grants payable are charged in the year when the offer is conveyed to the recipient except in cases where the offer is conditional, such grants being recognised as expenditure when the conditions are fulfilled.

#### Allocation and apportionment of costs

Costs have either been directly allocated or have been allocated on the basis of an estimate of time spent.

#### Tangible fixed assets

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

Equipment	25% on cost
Furniture	20% on cost

#### Taxation

The charity is exempt from corporation tax on its charitable activities.

#### Fund accounting

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity.

Designated funds are unrestricted funds earmarked by the Board of Trustees for particular purposes.

Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of appeal.

#### Pension costs and other post-retirement benefits

The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

# Notes to financial statements

## Year ended 31 December 2023

### 2. Donations and legacies

	2023 £	2022 £
Donations	154,330	115,421
Grants	161,447	212,521
Fundraising activities	119,634	82,422
Income tax refund	19,300	11,622
Other income	-	-
	<b>454,711</b>	<b>421,986</b>

Grants received, included in the above, are as follows:

Grants from NCG	59,233	56,886
Grants from European Commission	-	(4,551)
Grant from Medical Research Council	17,356	72,686
Grants from Trusts	84,858	87,500
	<b>161,447</b>	<b>212,521</b>

### 3. Other trading activities

	2023 £	2022 £
Sale of merchandise	1,385	1,592

### 4. Investment income

Deposit account interest	7,845	2,142
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### 5. Welfare

Restricted income from family meetings	14,396	-
Restricted income from adult activity breaks	-	3,425
	<b>14,396</b>	<b>3,425</b>

### 6. Raising funds

Staff costs	91,701	71,113
Event support, publicity and literature	13,086	3,521
Merchandise	2,149	949
Other direct costs	12,399	16,456
Support costs allocated to activities	28,376	25,400
	<b>147,711</b>	<b>117,439</b>

### 7. Charitable activities costs

	Research £	Clinic £	Welfare £	Information £	Education £	Governance £	2023 Total £	2022 Total £
<b>Costs directly allocated to activities</b>								
Staff costs	14,620	52,619	65,228	27,144	17,894	19,526	197,031	174,433
Newsletter	-	-	170	170	-	-	340	1,812
Welfare, equipment, respite etc.	-	-	36,561	-	-	-	36,561	24,233
Research costs and conference	25,821	-	-	-	-	-	25,821	14,777
Clinic costs	-	33,162	-	-	-	-	33,162	30,193
Event support, publicity and literature	257	-	-	-	-	-	257	9,286
Other direct costs	-	-	-	-	-	13,776	13,776	10,172
<b>Grant funding of activities</b>	140,160	-	19,747	-	-	-	159,907	47,090
<b>Support costs allocated to activities</b>	2,891	11,890	16,329	7,037	5,202	4,678	48,027	51,971
	<b>183,749</b>	<b>97,671</b>	<b>138,035</b>	<b>34,351</b>	<b>23,096</b>	<b>37,980</b>	<b>514,882</b>	<b>363,967</b>

## 8. Analysis of grants

	2023 £	2022 £
Grants to institutions	140,160	25,713
Grants to individuals	19,747	21,377
	<b>159,907</b>	<b>47,090</b>

Grants to individuals are made to provide financial support grants to any individual affected by AT, to assist with the cost of items they need as a result of the condition. Grants to institutions are made to fund research.

The following grants to institutions have been made in the year:

	£
Modulation of RELB/p52 - dependent NF-kB activities to improve neurodegenerative symptoms of AT	80,160
Functional and metabolomic analysis of iPSC-derived Purkinje neurons from AT patients	30,000
Joint funding of 5 research projects*	30,000
	<b>140,160</b>

\*research projects funded: 1) Brain-penetrating ATM gene therapy, 2) Study of natural killer cells in AT pathogenesis and their therapeutical implications, 3) Digital drug prediction informed by genetic analysis of stem cell-derived mini brains from AT patients, 4) Understanding and treating AT 5) Trial REadiness in AT

## 10. Operating lease commitments

The charity's total future minimum lease payments under non cancellable operating leases are as follows for each of the periods:

	Land & buildings		Equipment	
	2023	2022	2023	2022
less than one year	-	-	5,866	5,866
Two to five years	-	-	10,172	16,038
More than five years	-	-	-	-
	-	-	<b>16,038</b>	<b>21,904</b>

Subsequent to the year end, a new lease agreement was signed for the office at Thrales End. This is a two year lease from 1st February 2024. Monthly rent payable under the lease totals £2,316 per month.

## 11. Trustees' remuneration and benefits

No member of the Board of Trustees received any remuneration during the year (2022: £Nil).

### Trustees' expenses

Travel expenses of £Nil were reimbursed during the year (2022: £Nil).

## 9. Net expenditure

Net expenditure is stated after charging:

	2023 £	2022 £
Auditors' remuneration	5,040	5,040
Depreciation	1,079	964
• owned assets		
Operating lease rentals	27,288	27,288
• land and buildings		
Operating lease rentals	5,866	5,845
• equipment		

## 12. Staff costs

	2023 £	2022 £
Salaries	255,372	217,424
Social security costs	19,153	16,089
Pension provision	14,207	12,033
	<b>288,732</b>	<b>245,546</b>

No employee had emoluments in excess of £60,000 (2022: none).

# Notes to financial statements

## Year ended 31 December 2023

### 12. Staff costs (continued)

During the year the Society paid £57,141 in employee benefits to key management personnel for their services to the charity (2022: £54,010). During the year, the Society employed the equivalent of 7 full-time staff (2022: 6.5 FTE). The company operates a defined contribution pension scheme in respect of the employees. The scheme and its assets are held by independent managers. The pension charge represents contributions due from the company and amounted to £12,821 (2022: £10,286).

### 13. Comparatives for the statement of financial activities

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total funds 2022 £
<b>Income and endowments from:</b>			
Donations and legacies	206,327	215,659	421,986
<b>Charitable activities:</b>			
Welfare	-	3,425	3,425
Other trading	1,592	-	1,592
Investment income	2,142	-	2,142
	210,061	219,084	429,145
<b>Expenditure on:</b>			
Raising funds	117,439	-	117,439
<b>Charitable activities:</b>			
Research	57,278	1,079	58,357
Clinic	34,592	56,906	91,498
Welfare	602	120,047	120,649
Information	31,097	7,715	38,812
Education	21,555	-	21,555
Governance	33,096	-	33,096
	295,659	185,747	481,406
<b>Net movement in funds</b>	(85,598)	33,337	52,261
<b>Reconciliation of funds</b>			
Total funds brought forward	324,532	311,718	636,250
<b>Gross transfers between funds</b>	125,909	(125,909)	-
<b>Total funds carried forward</b>	364,843	219,146	583,989

### 14. Tangible fixed assets

	Equipment £	Furniture £	Total £
<b>Cost</b>			
At 1 January 2023	18,082	4,472	22,554
Additions	833	-	833
Disposals	(378)	-	(378)
<b>At 31 December 2023</b>	<b>18,537</b>	<b>4,472</b>	<b>23,009</b>
<b>Depreciation</b>			
At 1 January 2023	16,867	3,436	20,303
Charge for the year	561	518	1,079
Disposals	(95)	-	(95)
<b>At 31 December 2023</b>	<b>17,333</b>	<b>3,954</b>	<b>21,287</b>
<b>Net book value at 31 December 2023</b>	<b>1,204</b>	<b>518</b>	<b>1,722</b>
At 31 December 2022	1,215	1,036	2,251

### 15. Debtors: amounts falling due within one year

	31.12.23 £	31.12.22 £
Trade debtors	5,240	4,784
Payments and accrued income	7,696	86,461
Other debtors	2,893	2,893
	15,829	94,138

Other debtors include a franking machine deposit of £200 which falls due in more than one year.



## 16. Creditors: amounts falling due within one year

	31.12.23 £	31.12.22 £
Support grants payable	2,890	2,270
Institutional grants payable	38,973	50,031
Trade creditors	1,957	1,099
Accruals and deferred income	12,175	12,260
Taxation and social security	6,473	5,299
	<b>62,468</b>	<b>70,959</b>

	Support grants £	Institutional grants £	Total £
Grant funding commitments			
Grant liability at 1 January 2023	2,270	50,031	52,301
Grants awarded in the year	19,747	140,160	159,907
Grants paid in the year	(19,127)	(151,218)	(170,345)
<b>Grant liability at 31 December 2023</b>	<b>2,890</b>	<b>38,973</b>	<b>41,863</b>

## 18. Movement in funds

	At 1.1.23 £	Net Movement in funds £	At 31.12.23 £
<b>Unrestricted funds</b>			
General fund	156,088	61,702	217,790
Designated research fund	208,755	(123,244)	85,511
	364,843	(61,542)	303,301
<b>Restricted funds</b>			
Research	18,199	(14,688)	3,511
Welfare, support, equipment	198,162	(107,026)	91,136
Information	2,785	(1,000)	1,785
	219,146	(122,714)	96,432
<b>Total funds</b>	<b>583,989</b>	<b>(184,256)</b>	<b>399,733</b>

## 17. Contingent liabilities

Research grant funding	Total funds £	Total funds £
Natural History of Ataxia-Telangiectasia – Statistics Consultancy	3,500	3,500
Functional and metabolomic analysis of iPSC-derived Purkinje neurons from AT patients	-	30,000
Modulation of RELB/p52 – dependent NF-kB activities to improve neurodegenerative symptoms of AT	-	80,160
Joint funding of 5 research projects (see note 8)	-	30,000
	<b>3,500</b>	<b>143,660</b>

The above contingent liabilities relate to research grant funding where payment of the remaining funding is contingent on receipt of a satisfactory progress report from the institution in receipt of the award.

# Statement of financial activities

## Year ended 31 December 2023

### 18. Movement in funds (continued)

	Incoming resources £	Resources expended £	Transfers in/(out) £	Movement in funds £
<b>Unrestricted funds</b>				
General fund	289,523	(315,587)	87,766	61,702
Designated research fund	-	(123,244)	-	(123,244)
	289,523	(438,831)	87,766	(61,542)
<b>Restricted funds</b>				
Research	19,682	(34,370)	-	(14,688)
Clinic costs	59,233	(59,233)	-	-
Welfare, support, equipment	109,399	(128,659)	(87,766)	(107,026)
Information	500	(1,500)	-	(1,000)
	188,814	(223,762)	(87,766)	(122,714)
<b>Total funds</b>	<b>478,337</b>	<b>(662,593)</b>	<b>-</b>	<b>(184,256)</b>

### Purpose of restricted funds

#### Research

Restricted research income relates primarily to a grant received from the Medical Research Council to fund research projects.

#### Clinic costs

Represents amounts received from NHS England in relation to our work supporting the specialist AT clinics run at Nottingham University Hospital and the Royal Papworth Hospital.

#### Welfare, support and equipment

The balance remaining represents provisions to fund work to support adults with AT to live more independently, plus funds restricted to particular items of equipment and geographical areas and to our welfare and communications work more broadly. Amounts spent in the year include the funding of a Family Weekend event, emergency support grants, grants towards equipment for adults and young people, grants towards counselling, grants towards housing modifications and the funding of family support staff.

A transfer of £87,766 has been made from the restricted welfare fund back to general funds in respect of core costs advance funded from general funds but subsequently offset against a restricted legacy fund, the terms of which permit the funds to be used towards the core costs of the charity.

#### Information

The balance carried forward at the year end relates to funds to be used for the production of information materials in respect of AT.

#### Designated research fund

During 2019, the Board of Trustees designated £350,000 for research. During 2023, £123,244 (2022: £38,982) has been spent from this fund on research. It is anticipated that the remaining designated funds will be spent in coming years as we continue to commit to medical research and develop our funding programme for this. By using some of these funds towards co-funding research projects, as we have in 2022 and 2023, the likely expenditure will occur in 2024 and 2025.

### 19. Related party disclosures

No trustee or any other person related to the charity had any personal interest in any contract or transaction entered into by the charity during the year or the previous year save as a potential beneficiary of the charity in the normal course of its activities.

### 20. Ultimate controlling party

In the opinion of the trustees, there was no controlling party during the year.

### 21. Statutory information

The Ataxia Telangiectasia Society is a private company, limited by guarantee, registered in England and Wales. The company's registered number and registered office address can be found on the facing page.

# Trustees, patrons and advisors

## Directors/Trustees



Michael Detsiny  
Chair of Trustees



David Macdonald  
Treasurer



Dr Jayesh Bhatt



Nicholas Gull



Jhilna Shah



Professor Penny Jeggo



Joe Pemberton-Powel



Rachel Poupard



Lian Yarlett

## Senior Management

Susie Norbury

Director of Fundraising & Operations

Kay Atkins

Head of Services

Professor Penny Jeggo

Head of Research

## Patrons

Mrs Joan Bartholomew

The Lord Bilimoria of Chelsea CBE DL

The Lady Parkinson DL

The Revd Canon Paul Thomas OBE

## Registered office and operational address

AT Society

Unit 54

Thrales End Business Centre

Thrales End Lane

Harpenden

Hertfordshire

AL5 3NS

Email: [info@atsociety.org.uk](mailto:info@atsociety.org.uk)

Website: [www.atsociety.org.uk](http://www.atsociety.org.uk)

Company Registered in England and Wales,  
Number: 5177145

Charity Commission Registered in England,  
Number: 1105528

## Scientific Advisory Board

Professor Rob Dineen

Chair

Dr Anke Hensiek

Professor Penny Jeggo

Professor Rick Livesey

Dr Cynthia Oviatt-Rothblum

Professor Laurence Pearl

Professor Malcolm Taylor

Erik Thomassen

Dr William Whitehouse

Our Scientific Advisory Board expertly provide independent scientific advice on our research priorities, all in a voluntary capacity, to help shape AT research for the future.

## Bankers

The Co-operative Bank

PO Box 250

Skelmersdale WN8 6WT

HSBC Bank plc

1 High Street

Harpenden

Herts AL5 2RS

CAF Bank Ltd

PO Box 289

West Malling

Kent ME19 4TA

## Auditors

Hicks & Company  
Chartered Accountants  
Statutory Auditors  
Vaughan Chambers  
Vaughan Road  
Harpenden  
Herts AL5 4EE

**“Our vision is a world  
where no one need suffer  
from the devastating  
effects of AT”**

**“Our mission is to  
improve the quality of life  
and quality of care for people  
living with AT while actively  
promoting research to  
improve treatments and  
ultimately bring  
about a cure”**

**AT<sup>\*</sup>SOCIETY.ORG.UK**

\*Ataxia Telangiectasia



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