

The Ataxia Telangiectasia Society
Trustees' Report and Accounts 2024



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.

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

Mike Detsiny
Chair of Trustees

Chair of Trustees' statement

Message from the Chair of Trustees, Mike Detsiny

In 2025 I will be stepping down as Chair of The AT Society after ten years in the role. It has been one of my greatest honours to have the privilege to lead this incredible charity. But ten years is too long, and it is important my successor brings new drive and thinking to the role to ensure your Society continues to improve the service we deliver to those who need us and frequently rely on us to meet their needs.

Inside this report you will find details of the many services we deliver and the increasing number of initiatives we are taking, from the new research we are involved in and the clinical trials on the horizon, to the broader support services now provided. I do hope you will find them full of hope and encouragement.

Virtually every charity will tell you that their past year has been particularly challenging; that is the nature of the charity sector. However, I would argue that the last decade has been one of almost unparalleled difficulty for the sector and for small charities in particular. COVID and the cost-of-living crisis have made fundraising incredibly hard. Many small charities have failed to survive and, whilst COVID is not currently a major threat, the financial landscape is putting ever more strain on people's ability to donate. Unfortunately, given we currently have a no-growth economy, fundraising will inevitably get increasingly difficult.

Against this challenging background we have managed to improve our range of services and, whilst our finances could always be better, they are currently strong enough for us to face the future with confidence. All this has been achieved thanks to the generosity of all of our wonderful supporters, and to the dedication of our staff team who seem to regard their efforts as a vocation rather than a job. Staff turnover is way lower than is the norm and no challenge seems too daunting to them. They are brilliantly led by Kay Atkins and Susie Norbury, and it has been my pleasure and privilege to work with them. The team's efforts have, of course, been supplemented by very many volunteers, and my fellow trustees.



A new Chair will be elected at our AGM in May and tradition demands that no announcement can be made before then. However, I am very happy to inform readers that our Board have unanimously declared that they would like Rachel Poupard to lead us through the next stage of our development. Rachel has family experience of the cruelty of AT and indeed, her parents were the founders of our charity. I could not leave the AT Society in better hands.

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

Mike Detsiny
Chair of Trustees

Trustees Annual 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 2024.

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. Reference and administrative information is set out on the inside back cover, and forms part of this report.

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".

Our vision is a world where no one need suffer from the devastating effects of AT, and 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.

We do this by:

- Providing excellent and inclusive, specialist care and support, information and advocacy to meet the challenges of living with AT
- Promoting and commissioning high quality AT research
- Raising awareness of AT and speaking out to ensure that the voices of people affected by AT are heard, improving practice, policy-making and systems so that they really work for all children and adults affected by AT
- Working to achieve better, more informed, and more coordinated health and social care services across all sectors

To fulfil our mission, the trustees undertake an annual review of the Society's goals, priorities, and initiatives as part of our planning process. We look at the previous year's performance compared to the

objectives laid out in that year's plan and examine the impact these activities have had on individuals affected by AT.

The review ensures that the Society's mission and objectives stay true to its core purpose and gives us the opportunity to evaluate how the Society's work contributes to its charitable aims for the public good, particularly for those impacted by AT, in alignment with the Charity Commission's guidance.

In working towards these priorities, the Society has a structured, budgeted business plan that is subject to ongoing review. Below, we outline the Society's efforts and accomplishments for 2024 to demonstrate how we have achieved our aims and confirm we have complied with our duty to have due regard to the guidance contained in the Charity Commission's general guidance on how we have delivered public benefit when reviewing these. Further details are available in our 2024 Impact Report at www.atsociety.org.uk/about-us.

Achievements and performance

Dedicated to providing support for today and hope for tomorrow.

2024 represented the AT Society's 35th year of operation. The anniversary was marked in a number of ways throughout the year and included an Early Day Motion in the House of Commons. In this important year, building on last year's progress, we were pleased that overall, our income grew more than expected, which was largely due to some extremely generous legacies and grants. To deliver growth and investment against the backdrop of ongoing challenges in the external world, including the cost-of-living crisis and global insecurity, is huge testament to all involved and our thanks go to all our wonderful supporters for this. The uplift has enabled us to invest in three new important medical research projects towards the end of the year and into 2025, to cover our costs, and help towards improving our investments for the year ahead.

Through the year we continued to work collaboratively to achieve more informed, and more coordinated health and social care services across all sectors. We provided bespoke AT training for health and education providers to improve their awareness and knowledge of AT: 100% said their knowledge of AT had improved considerably and 97% said their work with families and children affected by AT would significantly improve as a direct consequence. We worked closely with the public sector to help local teams implement national advice; and with our

international partners in the AT Global Alliance, we co-funded important medical research projects, as well as shared knowledge, expertise and best-practice to keep developing our collective skills.

We committed to spending more on service delivery this year. A large part of this increased investment was on supporting access to specialist health care and advice and helping towards funding the 28% increase in the number of children and adults attending the AT medical clinics throughout the year. The clinics are based at Nottingham University Hospital and Royal Papworth Hospital and enable the progression of AT to be monitored and managed closely by AT professionals, helping enormously to improve individual lives. Of parents attending with their children, 72% came away with new approaches to better manage this complex condition.

93% of parents attending the children's AT specialist clinics said they were extremely useful and 87% of parents felt their concerns were addressed.

Working closely with medics and the pharmaceutical industry, we have also invested time and money to support long-anticipated clinical trials. We have funded travel and overnight stays, to ensure financial hardship is not a barrier to a child's participation; disseminated information and hosted meetings to keep families informed; and worked closely with hospital teams to help recruitment to new trials. We were pleased that the first, NEAT, (<https://quincetx.com/pipeline/>) started at the end of the year for children aged 6-9 years old and aims to slow the disease progression. A second, IB1001, (<https://intrabio.com/clinical-trials/>), which aims to improve the ataxia, will begin in 2025. Both trials represent significant milestones and strengthen our communities' hope for the future.

Throughout the year, we remained committed to advancing high-quality AT research, deepening our understanding of this complex condition. In 2024, we were proud to commit to funding groundbreaking medical research taking place in the UK from 2024 – 2028 that will lay the foundation for future clinical trials. We also delivered key talks and hosted international scientific discussion on important topics and kept our patient group informed throughout. While significant challenges remain, there is genuine reason for optimism, and our role in investing in research continues to be essential.

We provided and developed expert and accessible information, advocacy and care to support 235 UK individuals coping with the everyday pressures of

living with AT and their 800+ family members and carers, many of whom were also the very people hit hardest by the cost-of-living crisis. Nearly 40% of the emergency support grants provided were needed to help families pay for escalating cost of housing adaptations, utility bills and food bills; 30% were on disability equipment and increased transport costs. In 2024 100% of parents said the advice and support received to navigate their way through a crisis or to address specific and pressing issues around housing, benefits, and education needs was 'extremely helpful'.

Beyond financial struggles, the emotional toll of living with AT can be overwhelming: anxiety, frustration, and uncertainty often weigh heavily on young people and their families. Recognising these challenges, we remained dedicated to offering meaningful support that prioritised mental well-being. Through play and art therapy, we provided children with a safe space to express their emotions, while counselling services equipped parents with coping strategies to manage stress and build resilience. We also developed useful tools to help families navigate their emotional journey.

"I don't know how we would get through this without the AT Society".

The year saw a 5% increase in new diagnosis, and using a combination of friendly home visits, online meetings and telephone calls, we were able to provide space where new families felt safe, respected and able to access services. It's imperative that we continue to reach families early, creating person-centred and responsive approaches, and thanks to our supporters, we achieved this and continued to have an open-door approach that meant no one was turned away.

"From the very beginning, the AT Society was there. They didn't just offer support — they were part of the light that helped guide us. They stepped in with school visits, home visits, advice about housing, and support in ways we hadn't even thought about. We are forever grateful for everything they've done — not just for our daughter, but for our entire family."

In June we held an activity weekend in Cumbria for adults with AT, which was an overwhelming success. It promoted inclusion and belonging by connecting 39 individuals to each other and to wider opportunities and support. It helped those with a rare condition to no longer feel rare, but to feel a part of an important community. Friendships were made, challenges were conquered, and a lot of fun was had.

"I don't feel so lonely now. I've never met anyone with AT before and I've made good friends from this event."

"You got me doing things I wouldn't normally do. Being in a wheelchair won't stop me! Not anymore."

We were also pleased to start our strategic review mid-way through 2024, which will be completed in 2025. We began this by surveying and collecting data from our AT families through the year, deepening our understanding of how people with AT are experiencing the world, to ensure we can meet their needs and connect with audiences we're not yet reaching. The end strategy will likely involve proactively investing in medical research, broadening our care and support reach and accessibility, and increasing our fundraising investment to increase capacity and growth.

We would like to thank everyone who has supported us to make this all possible in our 35th year. Every donation, no matter how big or small, makes a difference in our determined efforts to help people affected by AT to deliver a service that provides the best support now and hope for the future.

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, in 2004, registration number 1105528. The Society uses the working name "AT Society".

The company was established under a Memorandum of Association which defined its objects and powers, and 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 and are the governing body of the Society. They meet formally as a Board of Trustees a minimum of four times each year and determine the overall strategy for the organisation and the policies and procedures for the implementation of the strategy. The Board also oversee the effective and equitable use of the Society's resources and ensures that it meets all its legal, regulatory and ethical obligations.

Under the terms of the Memorandum and Articles of Association, trustees (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 trustees can serve a maximum of two terms of office, and in very exceptional circumstances, the Board may agree to extend this to three terms. All appointed trustees 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. At the time of writing, we have 9 trustees and in accordance with our aim to be a user-led organisation, over half of our Board have lived experience of AT.

Vetting and checks of trustees are carried out in line with Charity Commission guidance. All new trustees receive an information pack which includes their legal obligations under charity and company law, the annual report and accounts, the annual plan and budget, the company's Memorandum & Articles of Association, all mandatory policies and a representative selection of the Society's current literature. Induction meetings take place with the Chair, and with all staff, and a conflict 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 are DBS checked every 3 years and complete safeguarding training appropriate for their role every 2 years, and all are encouraged to keep abreast of developments both in charity governance and in current issues concerning AT.

All trustees 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. Beneficiaries are not prevented from being trustees, but in such circumstances, the trustee declares their interest and takes no part in the discussion or decision that they may benefit from. All conflicts of interest are declared at the start of each meeting.

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 Clinical Trials sub-committee, chaired jointly by Dr Rita Horvath and Dr Anke Hensiek, was set up in 2023, 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.

Day to day operational and fundraising management is delegated to the Director of Operations, Susie Norbury. Our Family Support work is led by the Head of Services, Kay Atkins and our research programme is led, voluntarily, by our trustee and scientific advisor Professor Penny Jeggo. 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 living wage as determined by the Living Wage Foundation.

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 regarding its charitable objectives; learning and personal development are central to the appraisal process.

The staff team organise and provide most of the services delivered by the Society and manage and support the Society's volunteers. During the year we enjoyed volunteer support to help with administrative duties, fundraising and beneficiary events, communications and design support, and legal advice, for which we are immensely grateful. The hours of voluntary support totalled approximately 1,000 through the year, representing a cost saving of around £10,000.

All trustees and members of the sub-committees active in 2024 are listed on the inside back cover of this report.

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 ("AMRC"). We work closely with Ataxia UK, neurological alliances, and UK and AT groups.

Financial review

During the year we were pleased to have increased our income whilst controlling costs.

The AT Society received income of £657,491 (2023: £478,337) and spent £571,908 (2023: £662,593). The Society therefore had an overall surplus for the year of £85,583 (2023: deficit of £184,256). The large deficit in 2023 was due to a commitment we made in the year to use our reserves to invest in new research studies and in our support services.

With funds brought forward from previous years, the Society will carry forward £485,316 in reserves (2023: £399,733). Unrestricted general funds carried forward are at £404,744 (2023: £303,301). The Society also carries forward restricted funds of £80,572 (2023: £96,432), which the trustees consider to be at an appropriate level.

Of the Society's total income some 42% was received in donations and legacies from individuals, and donations from companies and trusts; 39% in grants from NHS England, the Medical Research Council and Trusts; and 17% from fundraising challenges and events. The remaining income came from trading and investments.

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 more flexible 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. We have continued to use this system during 2024, and were pleased to have generated £13,875 in investment income, representing a 77% growth on the previous year. However, the trustees review the investment policy on an annual basis and in 2025 will be exploring whether there are other more beneficial opportunities to maximise our returns.

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 this 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, 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. In 2023 we committed to new research studies and made the conscious decision to allow our reserves to temporarily fall to 7 months. By the end of 2024 the Society built this back up to having unrestricted reserves of 8.5 months.

The Board of Trustees will at times designate funds from free reserves for significant project costs or replacement of major assets. In 2019 the trustees designated £350,000 to invest in medical research projects, of which we now have £93,330 remaining. It is anticipated that the majority of the remaining designated funds will be spent in 2025 on new research studies.

The charity also holds restricted reserves of £80,572 which represent the excess of restricted income over restricted expenditure. These restricted reserves are closely monitored to ensure they are used in accordance with the terms specified when the funds were received.

Fundraising

During the year, the AT Society engaged in public fundraising, but did not use external professional fundraisers or commercial participators for this. However, professional fundraisers are used on occasion for fundraising from Trusts and Foundations. The charity continued to observe and comply with the relevant fundraising regulations and codes and is a member of the Fundraising Regulator. In 2024 the charity received no complaints relating to its fundraising practice.

Grant-making policies

The Society makes two types of grants to meet its objectives: research grants and 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 (SAB) 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.

The research projects we supported in 2024 can be seen on page 17 of the accounts. Our full research programme can be viewed at:
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 because 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.

Principal risks and uncertainties

Overall responsibility and accountability for risk lies with the Board of Trustees, who review it formally on an annual basis, and regularly throughout the year. The AT Society's approach to risk management centres on identifying 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 them. Our approach is informed by guidance provided by the Charity Commission, including its overarching definition of risk:

"the uncertainty surrounding events and their outcomes that may have a significant impact, either enhancing or inhibiting any area of a charity's operations."

The key risks areas identified remain the same as the previous years, and 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.

To mitigate these risks, we have a fundraising strategy that we monitor closely to address underperforming income streams. Being a small national charity always means our resources are spread thinly, but it also means we are agile enough to respond immediately to challenges. Whilst donations under-performed in the year, an increase in legacy income presents opportunities to review our investment strategy, as well as invest in fundraising resource for longer term growth.

The AT Society is committed to safeguarding any personal and 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. All staff receive annual training in managing data risks and updates on protection, and we have additional cyber-security insurance to moderate these risks and their associated costs.

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 beneficiaries' 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, senior staff and Board of Trustees.

We have a committed and loyal staff team and turnover is well below the sector norm, however the loss of anyone would be significant for the charity and so to reduce these risks the AT Society works hard to be an employer where everyone feels they belong, and feels valued, supported, and motivated to stay. We provide flexible and hybrid working, a positive and inclusive work environment, wellness programs and professional development. Whilst we are a Living Wage employer, salaries are far from high, especially for those based in the southeast. The Board of Trustees have committed to a salary review in 2025 and for adjustments to be made where necessary.

Plans for future periods

To continue to ensure we are delivering the very best services for people affected by AT, in 2025 we will continue progressing the work we began in 2024 to deepen our understanding of how people with AT are experiencing the world, grow our impact, and connect with audiences we're not yet reaching.

A key priority will be to complete 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.

Mid-way through the year we will hold our first, international AT clinical research conference since 2018. This will be a landmark event and will bring together the world's leading AT scientists and clinical experts to collaborate, share ideas and drive forward solutions to improve patient outcomes. Scientists, medical professionals and charities have been calling for this face-to-face meeting, which will lead into the AT Society Family Weekend, where UK families affected by AT come together for support, connection, and learning.

In 2025 we will also:

- Disseminate findings from our clinical conference and set up international legacy working groups to take forward key areas of development
- 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

Trustees' report

- Provide expert and friendly advice and support to all service users, their families, and professionals
- Fight for the overlooked needs of disabled people and stand up to the injustices that make life so much harder for people with AT
- Work with our NHS partners to run our specialist AT medical clinics in the most effective and efficient way possible
- 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 our equity, diversity and inclusion ambitions to ensure all our services are fully accessible
- 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
- Work with pharmaceutical and biotech companies to help advance clinical trials and support patients to understand and access those trials
- 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.

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
- State whether applicable UK Accounting Standards and statements of recommended practice 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 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 19 May 2025 and signed on their behalf by:



David MacDonald
Treasurer

Independent auditor's report

Independent auditor's report

Opinion

We have audited the financial statements of The Ataxia Telangiectasia Society (the 'charitable company') for the year ended 31 December 2024 on pages 14 to 22. 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 2024 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.

Independent auditor's report

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:

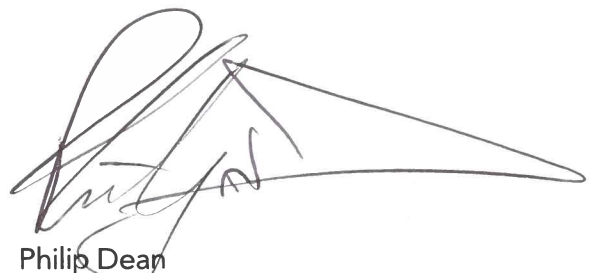
- Performing analytical procedures to identify unusual or unexpected transactions
- Assessing whether judgements and assumptions made in determining accounting estimates were indicative of potential bias
- Reviewed a sample of transactions from the client's records for proper authorisation
- Performing 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. 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
Senior Statutory Auditor

For and on behalf of Hicks and Company

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

19 May 2025

Statement of financial activities

Year ended 31 December 2024

	Notes	Unrestricted funds £	Restricted funds £	Total funds 2024 £	Total funds 2023 £
Income and endowments from:					
Donations and legacies	2	391,471	248,510	639,981	454,711
Charitable activities					
Welfare	5	-	3,200	3,200	14,396
Other trading activities	3	435	-	435	1,385
Investment income	4	13,875	-	13,875	7,845
Total		405,781	251,710	657,491	478,337
Expenditure on:					
Raising funds	6	145,354	-	145,354	147,711
Charitable activities					
	7				
Research		74,337	22,801	97,138	183,749
Clinic		41,131	62,894	104,025	97,671
Welfare		23,039	107,602	130,641	138,035
Information		32,870	4,153	37,023	34,351
Education		24,580	-	24,580	23,096
Governance		33,147	-	33,147	37,980
Total		374,458	197,450	571,908	662,593
Net income/(expenditure)		31,323	54,260	85,583	(184,256)
Reconciliation of funds					
Total funds brought forward		303,301	96,432	399,733	583,989
Transfers between funds		70,120	(70,120)	-	-
Total funds carried forward		404,744	80,572	485,316	399,733

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 2024

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.24 £	Total funds 31.12.23 £
Fixed assets					
Tangible assets	14	1,614	-	1,614	1,722
Current assets					
Debtors	15	125,372	19,143	144,515	15,829
Cash at bank		294,145	138,487	432,632	444,650
		419,517	157,630	577,147	460,479
Creditors:					
Amounts falling due within one year	17	(16,387)	(77,058)	(93,445)	(62,468)
Net current assets		403,130	80,572	483,702	398,011
Total assets less current liabilities		404,744	80,572	485,316	399,733
Net assets		404,744	80,572	485,316	399,733
Funds:					
Unrestricted funds	19	404,744	-	404,744	303,301
Restricted funds		-	80,572	80,572	96,432
Total funds		404,744	80,572	485,316	399,733

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 19 May 2025 and were signed on its behalf by:



David MacDonald
Treasurer

Statement of cash flows

Year ended 31 December 2024

	Notes	2024 £	2023 £
Cash flows from operating activities:			
Cash used in operations	a	(24,598)	(121,299)
Net cash used in operating activities		(24,598)	(121,299)
Cash flows from investing activities:			
Purchase of tangible fixed assets		(1,295)	(833)
Proceeds from sale of fixed assets		-	378
Interest received		13,875	7,845
Net cash used in investing activities		12,580	7,390
Change in cash and cash equivalents in the reporting period		(12,018)	(113,909)
Cash and the cash equivalents at the beginning of the reporting period		444,650	558,559
Cash and cash equivalents at the end of the reporting period		432,632	444,650

Notes to the statement of cash flows

Year ended 31 December 2024

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

	2024 £	2023 £
Net income/(expenditure) for the reporting period as per the statement of financial activities	85,583	(184,256)
Adjustments for:		
Depreciation charges	1,403	1,079
Profit on sale of fixed assets	-	(95)
Interest received	(13,875)	(7,845)
(Increase)/decrease in debtors	(128,686)	78,309
Increase/(decrease) in creditors	30,977	(8,491)
Net cash from operating activities	(24,598)	(121,299)

Notes to financial statements

Year ended 31 December 2024

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 2024

2. Donations and legacies

	2024 £	2023 £
Donations	71,269	154,330
Legacies	180,616	-
Grants	256,514	161,447
Fundraising activities	109,328	119,634
Income tax refund	22,254	19,300
	639,981	454,711

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

Grants from NCG	62,894	59,233
Grant from Medical Research Council	70,120	17,356
Grants from Trusts	123,500	84,858
	256,514	161,447

3. Other trading activities

	2024 £	2023 £
Sale of merchandise	435	1,385

4. Investment income

Deposit account interest	13,875	7,845
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5. Welfare

Restricted income from family meetings	-	14,396
Restricted income from adult activity breaks	3,200	-
	3,200	14,396

6. Raising funds

Staff costs	98,777	91,701
Event support, publicity and literature	4,667	13,086
Merchandise	499	2,149
Other direct costs	11,003	12,399
Support costs allocated to activities	30,408	28,376
	145,354	147,711

7. Charitable activities costs

	Research £	Clinic £	Welfare £	Information £	Education £	Governance £	2024 Total £	2023 Total £
Costs directly allocated to activities								
Staff costs	15,084	54,729	68,995	29,217	19,203	20,524	207,752	197,031
Newsletter	-	-	139	139	-	-	278	340
Welfare, equipment, respite etc.	-	-	17,401	-	-	-	17,401	36,561
Research costs and conference	19,020	-	-	-	-	-	19,020	25,821
Clinic costs	-	37,059	-	-	-	-	37,059	33,162
Event support, publicity and literature	-	-	-	368	-	-	368	257
Other direct costs	-	-	-	-	-	7,614	7,614	13,776
Grant funding of activities	59,994	-	27,670	-	-	-	87,664	159,907
Support costs allocated to activities	3,040	12,237	16,436	7,299	5,377	5,009	49,398	48,027
	97,138	104,025	130,641	37,023	24,580	33,147	426,554	514,882

8. Analysis of grants

	2024 £	2023 £
Grants to institutions	59,994	140,160
Grants to individuals	27,670	19,747
	87,664	159,907

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	(6)
Joint funding of 3 research projects*	60,000
	59,994

*Research projects funded: 1) Investigating the role of mutant Triple T chaperone in ATM assembly in Ataxia Telangiectasia: A structural perspective, 2) Identifying existing drugs to repurpose for Ataxia Telangiectasia, 3) Biomarkers for Babies and Young Children with Ataxia Telangiectasia

9. Net income

Net income/(expenditure) is stated after charging:

	2024 £	2023 £
Auditors' remuneration	5,400	5,040
Depreciation	1,403	1,079
• owned assets		
Operating lease rentals	27,750	27,288
• land and buildings		
Operating lease rentals	5,866	5,866
• equipment		

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	
	2024	2023	2024	2023
Less than one year	27,792	-	5,392	5,866
Two to five years	4,632	-	4,780	10,172
More than five years	-	-	-	-
	32,424	-	10,172	16,038

11. Trustees' remuneration and benefits

No member of the Board of Trustees received any remuneration during the year (2023: £Nil).

Trustees' expenses

Travel expenses of £Nil were reimbursed during the year (2023: £Nil).

12. Staff costs

	2024 £	2023 £
Salaries	269,992	255,372
Social security costs	20,961	19,153
Pension provision	15,576	14,207
	306,529	288,732

No employee had emoluments in excess of £60,000 (2023: none).

Notes to financial statements

Year ended 31 December 2024

12. Staff costs (continued)

During the year the Society paid £59,040 in employee benefits to key management personnel for their services to the charity (2023: £57,141) and employed the equivalent of 7 full-time staff (2023: 7 FTE). The Society 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 Society and amounted to £13,500 (2023: £12,821).

13. Comparatives for the statement of financial activities

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total funds 2023 £
Income and endowments from:			
Donations and legacies	280,293	174,418	454,711
Charitable activities:			
Welfare	-	14,396	14,396
Other trading	1,385	-	1,385
Investment income	7,845	-	7,845
	289,523	188,814	478,337
Expenditure on:			
Raising funds	147,711	-	147,711
Charitable activities:			
Research	149,379	34,370	183,749
Clinic	38,438	59,233	97,671
Welfare	9,376	128,659	138,035
Information	32,851	1,500	34,351
Education	23,096	-	23,096
Governance	37,980	-	37,980
	438,831	223,762	662,593
Net movement in funds	(149,308)	(34,948)	(184,256)
Reconciliation of funds			
Total funds brought forward	364,843	219,146	583,989
Gross transfers between funds	87,766	(87,766)	-
Total funds carried forward	303,301	96,432	399,733

14. Tangible fixed assets

	Equipment £	Furniture £	Total £
Cost			
At 1 January 2024	18,537	4,472	23,009
Additions	1,295	-	1,295
At 31 December 2024	19,832	4,472	24,304
Depreciation			
At 1 January 2024	17,333	3,954	21,287
Charge for the year	885	518	1,403
At 31 December 2024	18,218	4,472	22,690
Net book value at 31 December 2024	1,614	-	1,614
At 31 December 2023	1,204	518	1,722

15. Debtors: amounts falling due within one year

	31.12.24 £	31.12.23 £
Trade debtors	15,925	5,240
Pre payments and accrued income	125,495	7,696
Other debtors	3,095	2,893
	144,515	15,829

Other debtors include an office lease deposit of £2,895 which falls due in more than one year.

16. Contingent asset

A residual legacy was left to the AT Society in 2024. As at the year end the amount bequeathed to the AT Society could not be determined. Subsequent to the year end in April 2025 a sum of £399,206 was received by the charity.

17. Creditors: amounts falling due within one year

	31.12.24 £	31.12.23 £
Support grants payable	9,570	2,890
Institutional grants payable	60,000	38,973
Trade creditors	3,116	1,957
Accruals	13,248	12,175
Deferred accruals	1,200	-
Taxation and social security	6,311	6,473
	93,445	62,468

Grant funding commitments	Support grants £	Institutional grants £	Total £
Grant liability at 1 January 2024	2,890	38,973	41,863
Grants expense in the year	27,670	59,994	87,664
Grants paid in the year	(20,990)	(38,967)	(59,957)
Grant liability at 31 December 2024	9,570	60,000	69,570

18. Contingent liabilities

Research grant funding	Total funds £	Total funds £
Natural History of Ataxia-Telangiectasia – Statistics Consultancy	3,500	3,500
	3,500	3,500

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.

19. Movement in funds

	At 1.1.24 £	Net Movement in funds £	At 31.12.24 £
Unrestricted funds			
General fund	217,790	93,624	311,414
Designated research fund	85,511	7,819	93,330
	303,301	101,443	404,744

Restricted funds			
Research	3,511	(11)	3,500
Welfare, support, equipment	91,136	(14,196)	76,940
Information	1,785	(1,653)	132
	96,432	(15,860)	80,572
Total funds	399,733	85,583	485,316

Statement of financial activities

Year ended 31 December 2024

19. Movement in funds (continued)

	Incoming resources £	Resources expended £	Transfers in/(out) £	Movement in funds £
Unrestricted funds				
General fund	405,781	(312,157)	-	93,624
Designated research fund	-	(62,301)	70,120	7,819
	405,781	(374,458)	70,120	101,443
Restricted funds				
Research	92,910	(22,801)	(70,120)	(11)
Clinic costs	62,894	(62,894)	-	-
Welfare, support, equipment	93,406	(107,602)	-	(14,196)
Information	2,500	(4,153)	-	(1,653)
	251,710	(197,450)	(70,120)	(15,860)
Total funds	657,491	(571,908)	-	85,583

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, 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.

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 2024, £62,301 (2023: £123,244) has been spent from this fund on research.

A transfer of £70,120 has been made back to unrestricted designated reserves from restricted reserves in respect of research expenditure initially made from unrestricted designated funds which was subsequently funded by restricted income received in the year.

It is anticipated that the remaining designated funds will be spent in 2025.

20. 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.

21. Ultimate controlling party

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

22. 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.

Reference and Administration Details

The working name for The Ataxia Telangiectasia Society is the AT Society. The reference and administrative details, trustees and advisers are listed below.

Directors/Trustees



Dr Jayesh Bhatt



Michael Detsiny
Chair of Trustees



Nicholas Gull



Professor Penny Jeggo



David Macdonald
Treasurer



Joe Pemberton-
Powel



Rachel Poupard



Jhilna Shah



Lian Yarlett
Secretary

Senior Management

Susie Norbury

Director of Fundraising & Operations

Kay Atkins

Head of Services

Patrons

Mrs Joan Bartholomew*

The Lord Bilimoria of Chelsea CBE
DL

The Lady Parkinson DL

The Revd Canon Paul Thomas OBE

*Mrs Joan Bartholomew sadly died in March 2024, we are very grateful for the support she gave over the years

Scientific Advisory Board

Professor Rob Dineen

Chair

Professor Jessica Downs

Dr Julie Greenfield

Dr Anke Hensiek

Dr Rita Horvath

Dr Winnie Ip

Professor Penny Jeggo

Dr Svetlana Khorenkova

Professor Laurence Pearl

Erik Thomassen

Dr William Whitehouse

Our Scientific Advisory Board voluntarily provides expert, independent advice on AT research priorities

Clinical Trials Sub Committee

Drs Rita Horvath and

Anke Hensiek

Chairs

Emily Barker

Dr Madhu Dandapani

Professor Rob Dineen

Professor Penny Jeggo

Natasha Schneider

Dr William Whitehouse

Bankers

The Co-operative Bank

PO Box 250

Skelmersdale WN8 6WT

HSBC Bank plc

1 High Street

Harpenden

Herts AL5 2RS

CAF Bank Ltd

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West Malling

Kent ME19 4TA

Auditors

Hicks & Company

Chartered Accountants

Statutory Auditors

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Harpenden

Herts AL5 4EE

Registered office/ operational address

AT Society

Unit 54

Thrales End Business Centre

Thrales End Lane

Harpenden

Hertfordshire

AL5 3NS

Email: info@atsociety.org.uk

Website: www.atsociety.org.uk

Company Registered in England
and Wales, Number: 5177145

Charity Commission Registered
in England, Number: 1105528

28%

increase in children and adults with AT accessing specialist medical support

"I don't know how we would get through this without the AT Society"

95

children and adults with AT attended AT specialist medical clinics throughout the year

5%

increase in new diagnosis in the year

40%

of emergency support grants helped alleviate the cost of living crisis

93%

of parents attending the AT specialist medical clinics for children found them very useful

"I feel less isolated and lonely now. I've never met anyone with AT before and I've made good friends from this event."

2000+

hours of mental health support over the year

"The biggest difference this weekend made for me was watching all the young adults having fun, smiling and interacting ..."

235

people with AT in the UK supported in 2024

100%

of parents said the advice and support received to address their housing, benefits, and education needs was 'extremely helpful'

3

new medical research projects funded through the year

How we changed lives in 2024

AT^{*}SOCIETY.ORG.UK

*Ataxia Telangiectasia



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Reg. Company No. 5177145



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