

THE ATAXIA-TELANGIECTASIA SOCIETY

England & Wales · Charity number 1105528

Details

Other names THE A-T SOCIETY

Status Registered

Legal form Charitable company

Company number [05177145](#)

Registered 2004-08-18

Register [View on the Charity Commission register](#)

Contact

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Website www.atsociety.org.uk

Activities

Objects: THE RELIEF OF SICKNESS AND DISTRESS AMONG PERSONS SUFFERING FROM ATAXIA-TELANGIECTASIA.

Activities: Ataxia Telangiectasia (AT) is a progressive genetic condition which from early childhood causes increasingly severe disability, and shortens lives. The AT Society is dedicated to improving quality of life and quality of care for people living with AT while actively promoting research to lengthen lives and ultimately bring about a cure.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability, Arts/culture/heritage/science
- **Who:** People With Disabilities

Geography

- **Area of benefit:** NATIONAL
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£657,491	£571,908	£485,316	9
2023-12-31	£478,337	£662,593	-	-
2022-12-31	£429,145	£481,406	-	-
2021-12-31	£368,340	£500,634	-	-
2020-12-31	£320,758	£505,594	-	-

Trustees

Name	Role	Appointed
Rachel Poupard	Chair	2021-07-15
David Macdonald		2021-07-15
Dr Jayesh Bhatt		2021-07-15
Jhilna Shah		2018-01-24
Joe Powell		2021-07-15
LIAN CECILIA YARLETT		
Nicholas Gull		2018-06-30
Penny Jeggo		2014-01-28

Accounts

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'.

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.

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

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

PO Box 289

West Malling

Kent ME19 4TA

Auditors

Hicks & Company

Chartered Accountants

Statutory Auditors

Vaughan Chambers

Vaughan Road

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. Charity No. 1105528
Reg. Company No. 5177145



Registered with
**FUNDRAISING
REGULATOR**

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

Accounts

The Ataxia Telangiectasia Society
Trustees' Report and Accounts 2023



ADVOCATING

* Ataxia Telangiectasia

COLLABOR

DEDICATED

* Ataxia Telangiectasia

TRANSFORM



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, sweeping horizontal line 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/

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:

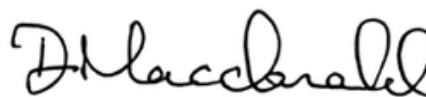
- So far as we are aware there is no relevant audit information of which the company's auditors are unaware
- As the trustees of the company, we have taken all the steps that we ought to have taken in order to make ourselves aware of any relevant audit information and to establish that the charity's 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. 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 £
Income and endowments from:					
Donations and legacies	2	280,293	174,418	454,711	421,986
Charitable activities					
Welfare	5	-	14,396	14,396	3,425
Other trading activities	3	1,385	-	1,385	1,592
Investment income	4	7,845	-	7,845	2,142
Total		289,523	188,814	478,337	429,145
Expenditure on:					
Raising funds	6	147,711	-	147,711	117,439
Charitable activities					
Research	7	149,379	34,370	183,749	58,357
Clinic		38,438	59,233	97,671	91,498
Welfare		9,376	128,659	138,035	120,649
Information		32,851	1,500	34,351	38,812
Education		23,096	-	23,096	21,555
Governance		37,980	-	37,980	33,096
Total		438,831	223,762	662,593	481,406
Net (expenditure)/income		(149,308)	(34,948)	(184,256)	(52,261)
Reconciliation of funds					
Total funds brought forward		364,843	219,146	583,989	636,250
Transfers between funds		87,766	(87,766)	-	-
Total funds carried forward		303,301	96,432	399,733	583,989

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

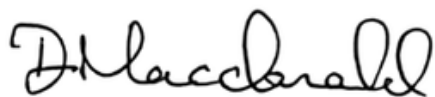
Year ended 31 December 2023

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.23 £	Total funds 31.12.22 £
Fixed assets					
Tangible assets	14	1,722	-	1,722	2,251
Current assets					
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
Creditors:					
Amounts falling due within one year	16	(12,683)	(49,785)	(62,468)	(70,959)
Net current assets		301,579	96,432	398,011	581,738
Total assets less current liabilities		303,301	96,432	399,733	583,989
Net assets		303,301	96,432	399,733	583,989
Funds:	18				
Unrestricted funds		303,301	-	303,301	364,843
Restricted funds		-	96,432	96,432	219,146
Total funds		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 £
Cash flows from operating activities:			
Cash used in operations	a	(121,299)	(56,162)
Net cash used in operating activities		(121,299)	(56,162)
Cash flows from investing activities:			
Purchase of tangible fixed assets		(833)	(1,284)
Proceeds from sale of fixed assets		378	-
Interest received		7,845	2,142
Net cash used in investing activities		7,390	858
Change in cash and cash equivalents in the reporting period		(113,909)	(55,304)
Cash and the cash equivalents at the beginning of the reporting period		558,559	613,863
Cash and cash equivalents at the end of the reporting period		444,650	558,559

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 £
Net expenditure for the reporting period as per the statement of financial activities	(184,256)	(52,261)
Adjustments for:		
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)
Net cash used in investing activities	(121,299)	(56,162)

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	-	-
	454,711	421,986

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
	161,447	212,521

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
	14,396	3,425

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
	147,711	117,439

7. Charitable activities costs

	Research £	Clinic £	Welfare £	Information £	Education £	Governance £	2023 Total £	2022 Total £
Costs directly allocated to activities								
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
Grant funding of activities	140,160	-	19,747	-	-	-	159,907	47,090
Support costs allocated to activities	2,891	11,890	16,329	7,037	5,202	4,678	48,027	51,971
	183,749	97,671	138,035	34,351	23,096	37,980	514,882	363,967

8. Analysis of grants

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

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
	140,160

*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	-	-	-	-
	-	-	16,038	21,904

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
	288,732	245,546

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 £
Income and endowments from:			
Donations and legacies	206,327	215,659	421,986
Charitable activities:			
Welfare	-	3,425	3,425
Other trading	1,592	-	1,592
Investment income	2,142	-	2,142
	210,061	219,084	429,145
Expenditure on:			
Raising funds	117,439	-	117,439
Charitable activities:			
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
Net movement in funds	(85,598)	33,337	52,261
Reconciliation of funds			
Total funds brought forward	324,532	311,718	636,250
Gross transfers between funds	125,909	(125,909)	-
Total funds carried forward	364,843	219,146	583,989

14. Tangible fixed assets

	Equipment £	Furniture £	Total £
Cost			
At 1 January 2023	18,082	4,472	22,554
Additions	833	-	833
Disposals	(378)	-	(378)
At 31 December 2023	18,537	4,472	23,009
Depreciation			
At 1 January 2023	16,867	3,436	20,303
Charge for the year	561	518	1,079
Disposals	(95)	-	(95)
At 31 December 2023	17,333	3,954	21,287
Net book value at 31 December 2023	1,204	518	1,722
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
	62,468	70,959

	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)
Grant liability at 31 December 2023	2,890	38,973	41,863

18. Movement in funds

	At 1.1.23 £	Net Movement in funds £	At 31.12.23 £
Unrestricted funds			
General fund	156,088	61,702	217,790
Designated research fund	208,755	(123,244)	85,511
	364,843	(61,542)	303,301
Restricted funds			
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
Total funds	583,989	(184,256)	399,733

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
	3,500	143,660

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 £
Unrestricted funds				
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)
Restricted funds				
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)
Total funds	478,337	(662,593)	-	(184,256)

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

Website: 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^{*}SOCIETY.ORG.UK

*Ataxia Telangiectasia



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Reg. Charity No. 1105528
Reg. Company No. 5177145



Registered with
**FUNDRAISING
REGULATOR**

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

Accounts

The Ataxia Telangiectasia Society Trustees' Report and Accounts 2022



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 or treatment. 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.

“Our greatest strength has been our network of fantastic supporters; fundraisers, donors, medics, scientists, and families affected by AT.”

Mike Detsiny
Chair of Trustees

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Chair of Trustees' statement

For most people, 2022 was another extremely challenging year. On top of COVID, which continued to impact the lives of everyone in the UK in all sorts of ways, most households also experienced financial pressure from unprecedented price increases and rising inflation. Sadly, people affected by ataxia telangiectasia, were disproportionately adversely affected by this turbulence.



The higher cost of specialist equipment, use of everyday essentials and energy, all made it harder for AT households to meet the extra cost of disability. Added to these tensions, the increasing pressures on NHS mental health teams, have made it considerably harder for people affected by AT to gain access to services even though living with a rare disease substantially impacts mental health.*

At the same time, we also faced another year of risks to income as the economic crisis impacted on donors' giving capacity, and our own costs increased. Whilst we had some terrific fundraising success stories – grants from Trusts and Foundations increased and support from companies increased ninefold from the previous year meaning overall we increased income by 16.5% – at the same time individual donations fell by 20% and event income remains woefully below pre-pandemic levels.

In the expectation that these economic pressures and the enormous social welfare restrictions will continue, we have invested in fundraising to help to continue to lift income, we have managed our operational costs and reduced our deficit, and we have taken steps to ensure our reserves are invested at a level to maximise returns, so that we can face the future with some optimism and achieve our ambitious plans for the years ahead.

So, for now, let's take a moment to celebrate our successes. We are proud of what we've achieved in 2022 with our partners and supporters, and the impact we've had. We have responded to over 800 vital phone calls from individuals with AT and family members in crisis, increased our professional counselling support by 8%, and helped young people and families to feel less alone because of the advice, support, and social connections we've provided.

We have joined other charities in the fight for disability equality, and provided 30 emergency grants to help families pay for fuel bills, specialist mobility equipment, urgent housing adaptations and respite activities. We have answered 216 urgent calls from health and social care professionals, and held 197 zoom meetings, so that professionals can effectively and sensitively recognise and address patients' and carers' health, education, housing, and financial needs. And to catch up on the covid-backlog, additional specialist AT medical clinics were organized through the year with our NHS partners, increasing our associated costs by 40%.

In 2022, we also committed to funding new research studies to advance our understanding of the condition, and we supported people with AT to participate in clinical trials where affordability prevented them from doing so. Together with our international scientific, medical, and financial partners we are pleased that we are moving closer towards finding treatments and ultimately a cure for AT.

Our greatest strength has been our network of fantastic supporters; fundraisers, donors, medics, scientists, and families affected by AT. Thank you for being with us. And thank you to all our volunteers and staff who have worked with skill, determination, and heart to achieve the things we've been able to. You have all played a vital part in helping to provide care and support for today and hope for tomorrow, and we are forever grateful.

Mike Detsiny
Chair of Trustees

*90% of individuals with a rare disease and their carers, feel anxious, stressed, and depressed. 36% of patients and 19% of carers had had suicidal thoughts. (BMC Health Services Research, vol 22, 2022, Spencer Tansley et al.)

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 2022.

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

The purpose of the Society, 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.

During 2022, we ensured the Society's objectives were always in line with our mission.

In undertaking our work, we are dedicated to ensuring people affected by AT can live the best lives possible, and are supportive, empowering, respectful, and professional in all we do. Where we come up against barriers, we seek agile and innovative solutions to ensure we can be there for those who need us.

And we are collaborative, working in partnership with AT experts in the UK and across the world to maximise influence, awareness, and knowledge.

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

The Memorandum of Association sets out the charitable purposes for public benefit. The trustees review the Society's aims, objectives and activities each year 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 accordance with the Charity Commission's guidance.

The Society has a formal budgeted business plan for the year, which is reviewed regularly, in accordance with the key objectives above.

The Society's activities and achievements in pursuit of these objectives in 2022 are detailed below. We have set out specific examples of activities in our Impact Report, which complements this report (www.atsociety.org.uk/about-us).

Achievements and performance

This was an exceptional year as the continuation of COVID and uncertainties around future restrictions, the increased mental health issues, the severe lack of government funding of social care, and the beginnings of double-digit inflation resulted in tough times for many, and none more so than those affected by ataxia telangiectasia.

Throughout the year people affected by AT continued to face unfair extra costs. The higher cost of specialist equipment, higher usage of everyday essentials and energy, the continuous fight to receive the correct disability benefit, all made it harder for AT households to meet the extra cost of disability. Refugee families affected by AT especially faced a disproportionate struggle to get the right support and respect.

Against that backdrop, it can be easy to lose hope, but at the AT Society optimism continued to shine.

In furtherance of our aims, we supported 225 individuals with AT and their family members, representing a 5% increase on last years numbers.

How we changed lives in 2022



We increased the emergency financial support we were able to provide to help with food and energy bills, respite care and housing support, and we increased our bespoke mental health provision to ensure that as NHS waiting lists for mental health care kept growing, we were able to be there for people with AT.

We are proud that we ensured that families affected by AT felt less alone, because of the advice and support we were able to give; that young people were able to stay connected and felt more fulfilled because of the social activities we ran; that medical queries were answered as the number of AT specialist clinics doubled to deal with the backlog

from the pandemic; and that parents with a newly diagnosed child were given hope because of the investments in medical research we have been able to make in the year.

The AT Society clinic continues 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.

Our involvement in the two unique, dedicated AT clinics at Nottingham University Hospital and the Royal Papworth Hospital, is essential to their operation. From the organisation of families' transport and individual appointments with clinicians, to the funding

of accommodation and food and the attendance of our team being on-hand to offer emotional support, advice and professional counselling, this bespoke service is extremely valuable. Feedback demonstrated that 100% of families attending the clinics would be keen to visit again in future and 83% reported valuing meetings with our Family Support team prior to their medical appointments.

The COVID backlog put increased pressure on this service and as a result we ran 3 extra clinics in the year and will do so again in 2023 to ensure that everyone in the UK with AT can reap the benefits of AT clinics.

"We're so grateful to receive emotional, physical and mental support from professionals who understand about AT."

This year we were pleased to be able to create a series of films showing our specialist clinics. These are designed for children and their families new to clinic, to reduce any anxieties prior to attending and increase their understanding of what to expect.

Thanks to our wonderful supporters and to the excellent AT research community, we have also been able to continue investing in medical research. In 2022, we committed to supporting 6 new important research studies and to continuing to fund 4 ongoing projects. All of these studies are essential in advancing our understanding of the condition, driving us towards better treatments and moving us closer to a cure for AT.

Some examples of the work we are funding are detailed in our Impact Report, and can be found here: www.atsociety.org.uk/about-us/our-publications-and-films/our-annual-report-and-accounts/

It was also an exciting year in the field of clinical trials, as some encouraging results were reported, and new trials discussed. EryDel's international trial to assess a treatment to slow the progression of ataxia in AT, for instance, reported positive outcomes; IntraBio announced optimistic results in alleviating ataxia symptoms; and Adrestia Therapeutics continued their journey towards their development of new drugs to correct the underlying disease biology of AT.

In the year we diverted some of our funding to keep UK families involved and to ensure financial hardship was not a barrier to their children's participation.

We have not achieved this alone. As part of our everyday work we've worked in partnership with experts across the world and across different

sectors, to make this happen. Our experts include people with lived experience of AT, who have been, and always will be, central to all we have achieved. Our Board of Trustees with 55% representation of lived experience, our user consultations, our WhatsApp groups with young people with AT, and our Scientific Advisory Board with parent representatives, all ensure that the delivery of our services is shaped by those who know best.

Plans for future periods

The Society's plans for 2023 and the following years are built around our priority areas of:

- › Supporting people affected by AT to live well with AT
- › Improving provision of information and active communication around AT
- › Increasing the impact of our research programme and strengthening cooperation across the AT research community
- › Strengthening and increasing the diversity of our fundraising.

We will do this by continuing 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 harder for people with AT.

Key priorities will be to: work with our NHS partners to run more of our specialist AT medical clinics to continue catching up on the COVID backlog; deliver in person events with beneficiaries to improve social opportunities and mental wellbeing; progress our work to ensure all our services are fully accessible; continue our equity, diversity and inclusion ambitions and develop an action plan to guide our next steps in this area; recruit a part-time fundraiser and organise new fundraising events.

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

Financial review

During the year we were pleased to have increased our income, controlled costs and significantly reduced our deficit.

The AT Society received income of £429,145 (2021: £368,340) and spent £481,406 (2021: £500,634).

The Society therefore had an overall deficit for the year of £52,261 (2021: £132,294). With funds brought forward from previous years, the Society will carry forward £583,989 in reserves (2021: £636,250).

Unrestricted general funds carried forward have increased to £364,843 (2021: £324,532). The Society also carries forward restricted funds of £219,146 (2021: £311,718), which the trustees consider to be at an appropriate level.

Of the Society's total income some 49.6% was received in donations from individuals, companies and trusts; 49.5% in grants from NHS England, the European Commission, the Medical Research Council and Trusts. The remaining income came from 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 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. The senior management and trustees monitor the investments regularly.

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 turbulent 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. In 2023 this will amount to unrestrictive reserves of approximately £350,000.

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.

Our operational budget currently includes a planned deficit in recognition of the investment in research and support services that the Society committed to during the year.

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.

Structure

The Society is a charitable company limited by guarantee, incorporated in England and Wales, and registered with the Charity Commission in England. 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 in normal years meet formally as a Board 4 times each year. Through the pandemic trustees met monthly in order to keep abreast of challenges the coronavirus brought. The Board of Trustees is the governing body of the Society. It agrees 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.

Our research work is overseen by our Scientific Advisory Board, who report to the main Board. The membership of the SAB is listed on the inside back cover of this report. Our research applications undergo a rigorous peer reviewed process and only those deemed to be of the highest quality are passed for funding. We are regulated by the Association of Medical Research Charities.

The Society's staff team is based at the offices in Harpenden. The Director of Fundraising & Operations shares leadership of the charity with the Head of Services and Head of Research. Remuneration of the Society's staff team of 8 is reviewed annually against performance and affordability. The team organises and provides the vast majority of the services delivered by the Society and manages and supports the Society's volunteers.

Governance and management

The Board of Trustees may consist of between 3 and 20 members. 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.

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 10 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.

All trustees active in 2022 are listed on the inside back cover of this report. In accordance with our aim to be a user-led organisation, over half of our Board have experience of living with AT.

Trustee induction and training

Vetting and checks of trustees is 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.

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.

Staff

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.

The Society actively encourages its staff to enhance and extend their skills, particularly with regard to its charitable objectives, and learning and personal development are central to the appraisal process.

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.

Collaborations

The Society is a national organisation operating throughout the UK and collaboration is at the heart of what we do. It is essential that we work closely with all organisations and individuals connected to AT and we are proud that joining with experts across the world and across different sectors is part of our everyday work.

Our involvement in establishing the Global A-T Alliance in 2020, is a good example (www.cureat.org/). The Alliance has a strong collective belief that together we are stronger and through 2022 delivered a range of shared activities. The connections give small international AT organisations access to vital skills, knowledge, and experience, while working towards the same overall vision: to improve lives for people affected by AT and to find a cure.

To strengthen our ability to campaign on behalf of and meet the needs of people living with AT, we are affiliated to:

- Genetic Alliance UK
- Rare Disease UK
- The Association of Medical Research Charities ("AMRC")
- Euro-Ataxia

We are members of the NCVO and we work closely with Ataxia UK. For instance, the Head of Ataxia

Research assists the AT Society in the implementation of the AT Society's research strategy.

Our long-established AT Clinical Research Network brings together researchers, clinicians and patient organisations from around the world and is a very active and useful body.

Our AT clinics (the world's first) provide an integrated service for people living with AT, funded and supported by NHS England. We work closely with the professional arms of the service: the specialist AT centres at Nottingham University Hospital (paediatric), the Royal Papworth Hospital (adult) and the diagnostic services. The centres of excellence have developed a unique expertise in this field and provide multi-disciplinary AT clinics.

Our specialist clinics and our strong links with those medics in the world with expertise in AT mean that we can successfully act as an important point of contact for local professionals seeking expert opinion. Most have little in-depth knowledge of AT and so our role here is imperative. Equally we help ensure recommendations from clinic professionals are understood and implemented by patients' local health teams to speed up access to health.

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. In the current challenging times, the risk register is reviewed frequently. Key risk areas identified for 2023 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 grant to meet its objectives:

- Individual support grants
- Research 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 2022 we supported various research projects. Some we are co-funding and some we fund alone:

- Natural History of AT (N-HAT), and a statistical consultancy, University of Nottingham
- The use of ultrasound in the assessment of people with AT's ability to swallow versus use of video fluoroscopic, Royal Papworth Hospital
- 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
- › Functional and metabolomic analysis of iPSC-derived Purkinje neurons from AT patients, FIRC Institute of Molecular Oncology, Milan.

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 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.

Legal and administrative information

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.

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 17 July 2023 and signed on its behalf by:

David MacDonald
Treasurer

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 2022 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 2022 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. 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

17 July 2023

Statement of financial activities

Year ended 31 December 2022

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.22 £	Total funds 31.12.21 £
Income and endowments from:					
Donations and legacies	2	206,327	219,084	425,411	367,087
Charitable activities					
Other trading activities	3	1,592	–	1,592	1,190
Investment income	4	2,142	–	2,142	63
Total		210,061	219,084	429,145	368,340
Expenditure on:					
Raising funds	5	117,439	–	117,439	92,811
Charitable activities	6				
Research		57,278	1,079	58,357	179,939
Clinic		34,592	56,906	91,498	65,210
Welfare		602	120,047	120,649	81,756
Information		31,097	7,715	38,812	30,132
Education		21,555	–	21,555	17,987
Governance		33,096	–	33,096	32,799
Total		295,659	185,747	481,406	500,634
Net (expenditure)/income		(85,598)	33,337	(52,261)	(132,294)
Reconciliation of funds					
Total funds brought forward		324,532	311,718	636,250	768,544
Transfers between funds		125,909	(125,909)	–	–
Total funds carried forward		364,843	219,146	583,989	636,250

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 2022

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.22 £	Total funds 31.12.21 £
Fixed assets					
Tangible assets	13	2,251	–	2,251	1,931
Current assets					
Debtors	14	16,641	77,497	94,138	157,258
Cash at bank		357,460	201,099	558,559	613,863
		374,101	278,596	652,697	771,121
Creditors:					
Amounts falling due within one year	15	(11,509)	(59,450)	(70,959)	(136,802)
Net current assets		362,592	219,146	581,738	634,319
Total assets less current liabilities		364,843	219,146	583,989	636,250
Net assets		364,843	219,146	583,989	636,250
Funds:	17				
Unrestricted funds				364,843	324,532
Restricted funds				219,146	311,718
Total funds				583,989	636,250

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 17 July 2023 and were signed on its behalf by:

David MacDonald
Treasurer

Statement of cash flows

Year ended 31 December 2022

	Notes	31.12.22 £	31.12.21 £
Cash flows from operating activities:			
Cash used in operations	a	(56,162)	(175,693)
Net cash used in operating activities		(56,162)	(175,693)
Cash flows from investing activities:			
Purchase of tangible fixed assets		(1,284)	(504)
Interest received		2,142	63
Net cash used in investing activities		858	(441)
Change in cash and cash equivalents in the reporting period		(55,304)	(176,134)
Cash and cash equivalents at the beginning of the reporting period		613,863	789,997
Cash and cash equivalents at the end of the reporting period		558,559	613,863

Notes to the statement of cash flows

Year ended 31 December 2022

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

	31.12.22 £	31.12.21 £
Net expenditure for the reporting period as per the statement of financial activities	(52,261)	(132,294)
Adjustments for:		
Depreciation charges	964	794
Interest received	(2,142)	(63)
(Increase)/decrease in debtors	63,120	(115,487)
Increase/(decrease) in creditors	(65,843)	71,357
Net cash used in operating activities	(56,162)	(175,693)

Notes to financial statements

Year ended 31 December 2022

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 (FRS 102) (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 2022

2. Donations and legacies

	31.12.22 £	31.12.21 £
Donations	118,846	79,178
Grants	212,521	199,590
Fundraising activities	82,422	64,845
Income tax refund	11,622	23,439
Other income	–	35
	425,411	367,087

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

	31.12.22 £	31.12.21 £
Grants from NCG	56,886	55,310
Grants from European Commission	(4,551)	43,256
Grant from Medical Research Council	72,686	60,107
Grants from Trusts	87,500	40,917
	212,521	199,590

3. Other trading activities

	31.12.22 £	31.12.21 £
Sale of merchandise	1,592	1,190

4. Investment income

	31.12.22 £	31.12.21 £
Deposit account interest	2,142	63

5. Raising funds

	31.12.22 £	31.12.21 £
Staff costs	71,113	46,562
Information, literature, publicity etc.	3,521	6,106
Merchandise	949	330
Other direct costs	16,456	20,941
Support costs allocated to activities	25,400	18,872
	117,439	92,811

6. Charitable activities costs

	Research £	Clinic £	Welfare £	Information £	Education £	Governance £	2022 Total £	2021 Total £
Costs directly allocated to activities								
Staff costs	13,687	48,371	55,845	22,593	15,919	18,018	174,433	154,558
Support events	–	–	636	–	–	–	636	2,706
Newsletter	–	–	906	906	–	–	1,812	1,442
Welfare, equipment, respite etc.	–	–	23,597	–	–	–	23,597	3,200
Research costs and conference	14,777	–	–	–	–	–	14,777	19,469
Clinic costs	–	30,193	–	–	–	–	30,193	18,850
Information, literature, publicity	250	–	1,321	7,715	–	–	9,286	–
Other direct costs	–	–	–	–	–	10,172	10,172	10,074
Grant funding of activities	25,713	–	21,377	–	–	–	47,090	139,904
Support costs allocated to activities	3,930	12,934	16,967	7,598	5,636	4,906	51,971	57,620
	58,357	91,498	120,649	38,812	21,555	33,096	363,967	407,823

7. Analysis of grants

	31.12.22 £	31.12.21 £
Grants to institutions	25,713	121,673
Grants to individuals	21,377	18,231
	47,090	139,904

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:

	£
Natural History of Ataxia-Telangiectasia	(7,787)
Royal Papworth Hospital – the use of ultrasound (USS) in the assessment of people with Ataxia-Telangiectasia's ability to swallow versus use of videofluoroscopic swallow studies (VFSS)	3,500
Joint funding of 5 research projects*	30,000
	25,713

* research projects funded: 1) Brain-penetrating ATM gene therapy, 2) Study of natural killer cells in AT pathogenesis and their therapeutic 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

9. 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	
	2022	2021	2022	2021
Less than one year	–	15,819	5,866	5,866
Two to five years	–	–	16,038	20,143
More than five years	–	–	–	1,761
	–	15,819	21,904	27,770

10. Trustees' remuneration and benefits

No member of the Board of Trustees received any remuneration during the year (2021: £Nil).

Trustees' expenses

Travel expenses of £Nil were reimbursed during the year (2021: £Nil).

8. Net expenditure

Net expenditure is stated after charging:

	31.12.22 £	31.12.21 £
Auditors' remuneration	5,040	4,560
Depreciation – owned assets	964	794
Operating lease rentals – land and buildings	27,288	22,894
Operating lease rentals – equipment	5,845	5,885

11. Staff costs

	31.12.22 £	31.12.21 £
Salaries	217,424	178,504
Social security costs	16,089	12,007
Pension provision	12,033	10,609
	245,546	201,120

No employees had emoluments in excess of £60,000 (2021: none).

During the year the Society paid £54,010 in employee benefits to key management personnel for their services to the charity (2021: £52,022).

Notes to financial statements

Year ended 31 December 2022

11. Staff costs (continued)

During the year, the Society employed the equivalent of 6.5 full-time staff (2021: 5.5 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 £10,286 (2021: £8,786).

12. Comparatives for the statement of financial activities

	Unrestricted funds 2021 £	Restricted funds 2021 £	Total funds 2021 £
Income and endowments from:			
Donations and legacies	150,906	216,181	367,087
Charitable activities:			
Other trading activities	1,190	–	1,190
Investment income	63	–	63
	152,159	216,181	368,340
Expenditure on:			
Raising funds	92,811	–	92,811
Charitable activities:			
Research	137,291	42,648	179,939
Clinic	9,717	55,493	65,210
Welfare	8,037	73,719	81,756
Information	30,132	–	30,132
Education	17,987	–	17,987
Governance	32,799	–	32,799
	328,774	171,860	500,634
Net movement in funds	(176,615)	44,321	(132,294)
Reconciliation of funds			
Total funds brought forward	441,869	326,675	768,544
Gross transfers between funds	59,278	(59,278)	
Total funds carried forward	324,532	311,718	636,250

13. Tangible fixed assets

	Equipment £	Furniture £	Total £
Cost			
At 1 January 2022	16,798	4,472	21,270
Additions	1,284	–	1,284
At 31 December 2022	18,082	4,472	22,554
Depreciation			
At 1 January 2022	16,420	2,919	19,339
Charge for the year	447	517	964
At 31 December 2022	16,867	3,436	20,303
Net book value			
At 31 December 2022	1,215	1,036	2,251
At 31 December 2021	378	1,553	1,931

14. Debtors: amounts falling due within one year

	31.12.22 £	31.12.21 £
Trade debtors	4,784	–
Prepayments and accrued income	86,461	154,365
Other debtors	2,893	2,893
	94,138	157,258

Other debtors include a franking machine deposit of £200 which falls due in more than one year. Accrued income relates primarily to a grant of £72,686 from the Medical Research Council.

15. Creditors: amounts falling due within one year

	31.12.22 £	31.12.21 £
Support grants payable	2,270	4,791
Institutional grants payable	50,031	119,305
Trade creditors	1,099	956
Accruals and deferred income	12,260	7,849
Taxation and social security	5,299	3,901
	70,959	136,802

Grant funding commitments	Support grants £	Institutional grants £	Total £
Grant liability at 1 January 2022	4,791	119,305	124,096
Grants awarded in the year	21,377	25,713	47,090
Grants paid in the year	(23,898)	(94,987)	(118,885)
Grant liability at 31 December 2022	2,270	50,031	52,301

16. Contingent liabilities

Research grant funding	31.12.22 £	31.12.21 £
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	30,000
Modulation of RELB/p52 – dependent NF-κB activities to improve neurodegenerative symptoms of AT	80,160	80,160
Joint funding of 5 research projects (see note 7)	30,000	–
	143,660	113,660

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. It is anticipated that these contingent liabilities will be funded from designated research funds (see note 17) during 2023 and 2024.

17. Movement in funds

	At 1.1.22 £	Net movement in funds £	At 31.12.22 £
Unrestricted funds			
General fund	143,572	12,516	156,088
Designated research fund	180,960	27,795	208,755
	324,532	40,311	364,843
Restricted funds			
Research	7,014	11,185	18,199
Welfare, support, equipment	294,704	(96,542)	198,162
Information	10,000	(7,215)	2,785
	311,718	(92,572)	219,146
Total funds	636,250	(52,261)	583,989

Notes to financial statements

Year ended 31 December 2022

17. Movement in funds (continued)

	Incoming resources £	Resources expended £	Transfers in/(out) £	Movement in funds £
Unrestricted funds				
General fund	210,061	(256,677)	59,132	12,516
Designated research fund	–	(38,982)	66,777	27,795
	210,061	(295,659)	125,909	40,311
Restricted funds				
Research	79,041	(1,079)	(66,777)	11,185
Clinic costs	56,906	(56,906)	–	–
Welfare, support, equipment	82,637	(120,047)	(59,132)	(96,542)
Information	500	(7,715)	–	(7,215)
	219,084	(185,747)	(125,909)	(92,572)
Total funds	429,145	(481,406)	–	(52,261)

Purpose of restricted funds

Research

Restricted research income relates primarily to a grant received from the Medical Research Council to fund research projects. A transfer back to unrestricted designated funds has been made as the cost of these research projects was originally funded from unrestricted designated funds.

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 young adult activity 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.

A transfer of £59,132 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 2022, £38,982 (2021: £88,803) has been spent from this fund on research. A transfer of £66,777 has been made back to unrestricted designated reserves from restricted funds 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 during 2023 and 2024.

18. 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.

19. Ultimate controlling party

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

20. 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



Andrew Mills
Treasurer
(resigned
October 2022)



David
MacDonald
Treasurer
(appointed
October 2022)



Dr Jayesh
Bhatt



Nicholas Gull



Professor
Penny Jeggo



Joe
Pemberton-
Powell



Rachel
Poupard



Jhilna Shah



Lian Yarlett

Patrons

Mrs Joan Bartholomew

The Lord Bilimoria of Chelsea CBE DL

Mr Brian Conley

The Lady Parkinson DL

The Revd Canon Paul Thomas OBE

Senior Management

Susie Norbury

Director of Fundraising & Operations

Kay Atkins

Head of Services

Professor Penny Jeggo

Head of Research

Scientific Advisory Board

Professor Rob Dineen

Chair

Dr Anke Hensiek

Professor Penny Jeggo

Professor Rick Livesey

Dr Cynthia Oviatt-Rothblum

Professor Laurence Pearl

Natasha Schneider

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.

Registered office and operational address

AT Society
Unit 54

Thrales End Business Centre

Thrales End Lane

Harpenden

Hertfordshire AL5 3NS

Telephone: 01582 760733

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

Auditors

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

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

**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.**

To find out how you, or your organisation
can get involved in our work and help
change lives, please visit us:

AT^{*}SOCIETY.ORG.UK

*Ataxia Telangiectasia



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Reg. Charity No. 1105528
Reg. Company No. 5177145



amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

Accounts

The Ataxia-Telangiectasia Society Trustees' Report and Accounts 2021



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 or treatment. 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.

“We will ensure our responsiveness and adaptability of this year will continue into next and will use our resources in the most effective way possible for the benefit of the individuals and families we support.”

Mike Detsiny
Chair of Trustees

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2021 was another very difficult year for everyone but whilst we were all in the same COVID-related storm, we most definitely were not in the same boat; the impact of COVID-19 for children, young people and adults with AT, and their families, was severe. Their mental health, finances and social wellbeing were hit hard. It was essential that as a charity, we remained entirely steadfast throughout the year in our focus on meeting the needs of the most vulnerable individuals and families.



I am immensely proud to say that given the challenges faced, the AT Society continued to perform well in 2021. We increased our investments in improving mental health, and we provided specialist information, care, and support to meet the challenges of living with AT, which helped to offset some of the trauma experienced. When one young person told us "You have helped me to be me again", and a mother said, "You have helped us to become stronger parents", we knew we were making a difference.

We took advantage of the growing global understanding of the importance of medical research and with the help of some generous supporters, we increased our investment in research by 8% during the year. Our international scientific, medical, and financial partners worked collaboratively with us, and continue to do so, to provide hope for the future, by investigating the improvement of treatments and moving us a small step closer to finding a cure.

Whilst we grappled throughout the year with being able to meet the rise in demand for our services, we also faced considerable insecurity around raising enough income to fund this work. Our normally profitable events and activities were inevitably

curtailed, and their income fell by 20%. But thanks to the generosity of our wonderful supporters, and a prudent approach to our financial reserves, we ended the year in a more hopeful position. Of course, the looming cost of living crisis and economic pressures mean that this very real challenge is unlikely to go away anytime soon but we will ensure our responsiveness and adaptability of this year will continue into next and will increase our efforts to use resources in the most effective way possible for the benefit of the individuals and families we support.

I am extremely proud to be able to Chair this wonderful charity and grateful to the dedicated team who work so hard to make it successful, and to all the supporters that make our work possible. We can't change the AT diagnosis, but with so much generous support behind us, we can help those affected by AT to live the best lives possible.

Mike Detsiny

Mike Detsiny
Chair of Trustees

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 2021.

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

The purpose of the Society, 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 information and support to meet the challenges of living with AT
- Working to achieve better, more coordinated health and social care services
- Promoting and funding high quality AT research
- Speaking out to ensure that the voices of people affected by AT are heard
- Raising awareness of AT and gathering supporters and resources to help achieve our vision.

During 2021, we ensured the Society's objectives were always in line with our mission.

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

The Memorandum of Association sets out the charitable purposes for public benefit. The trustees review the Society's aims, objectives and activities each year 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 accordance with the Charity Commission's guidance.

The Society has a formal budgeted business plan for the year, which is reviewed regularly, in accordance with the key objectives above.

The Society's activities and achievements in pursuit of these objectives in 2021 are detailed below. We have set out specific examples of activities in our Impact Report, which complements this report (www.atsociety.org.uk/about-us).

Achievements and performance

2021 was another difficult year for many, but especially for children and adults with AT, and their families. Their mental health, finances and social wellbeing was hit hard during the continuing pandemic. Endless disruption to education, long periods of isolation, losing support networks, struggling to access services and the increased disability inequalities faced, all had a huge impact. We particularly saw the needs of many young people, who were already struggling, rapidly increase.

At the same time, managing the economic consequences of the pandemic within the charity, including a reduction in our fundraised income, and ongoing staff shortages, made our work even more challenging. But thanks to the generosity of our wonderful supporters, we are pleased that in 2021 we provided support, care and hope for brighter futures for more individuals affected by AT than ever before.

To summarise the year, we worked with 13.4% more individuals in 2021 than in 2020 and we provided 35 emergency grants for disability equipment, emergency respite, and end of life support. A total of 39 social care injustices were resolved and we joined other disability charities to press for change and fight for equality.

During the year we worked closely with our NHS partners to run specialist AT clinics, enabling 55 children and adults to receive expert medical attention. We also focused on improving mental wellbeing and increased our investment in therapy by over 300%. 120 counselling sessions were delivered to safeguard mental health and we created digital social groups with young people.

A total of 197 virtual support and training events were delivered, all shaped by user feedback, and we directly advised and supported over 267 people.

The impact of COVID on people affected by AT continued to cause concern and the AT Society hosted an international AT Clinical Research Meeting mid-way through the year with clinical specialists, scientists, and experts from around the world, to focus on this. Following a survey of those affected by AT, we were delighted to find that, although several cases were reported, there were no serious COVID-related illness or deaths in AT individuals, and we were able to circulate important advice to families on vaccinations, shielding and risks associated with COVID following this.

We also continued to promote and commission high quality AT research and advanced our understanding of AT. In addition to three ongoing projects, we were pleased to fund two new projects following a rigorous selection process, towards the end of the previous year. Both are progressing well and their details can be found in our Impact Report 2021 at www.atsociety.org.uk/about-us.

It was an exciting year in the field of clinical trials, as some encouraging results were reported, and new trials set up. We provided regular support throughout the year for several of these trials. ATTeST, the first major trial assessing a potential treatment to slow the progression of ataxia in AT, reported positive outcomes. The trial was undertaken internationally by EryDel, involving red blood cells being loaded with the steroid dexamethasone. We have supported UK families to attend the trials, established a registry of AT individuals from different parts of the world, and surveyed patients' experience of participating in the trial. The results will be published in 2022 but interim findings are hopeful, and significant in representing the first treatment to provide benefit to individuals with AT, as one parent said:

"The Erydel drug trial has completely changed the life of our son... It has given us hope where we had very little before he started the trial. The impact of the treatment on his condition has been miraculous and we feel blessed to have been able to access the treatment and arrest the effects of AT on our little boy."

Similarly, we have supported some individuals with AT to be involved in Intrabio Inc's N-Acetyl-L-Leucine trial, an amino acid which are the building blocks of proteins which our bodies need to function properly. Intrabio recently announced positive results in alleviating the ataxia symptoms of

two other conditions, which is promising for the AT trial. Following delays due to the pandemic, this trial is progressing in the UK at the Royal Papworth Hospital for adults over 18, and in the US, Germany and Spain. It will not treat the root cause of AT but will hopefully provide symptomatic relief and offer a long-term neuroprotective effect.

At the December AT Clinical Research Network meeting, led by AT Society Trustee, Professor Penny Jeggo and Cynthia Oviatt in the US, further therapeutic interventions were closely reviewed by AT experts from around the world. Penny disseminated a useful layman's summary for all AT families, which can be seen here: www.atsociety.org.uk/research/clinical-trials

As part of our mission to ensure people affected by AT fully understand the condition, Professor Penny Jeggo delivered a series of scientific talks through the year and produced new materials to help individuals with AT and their families. AT is such a rare and complex genetic disorder, affecting several different systems within the body, so this initiative was an important way of helping families, and will be repeated again in 2022. One family member said:

"It's definitely the kind of information I've been needing. It all makes way more sense now."

Plans for future periods

The Society's plans for 2022 and the following years are built around our priority areas of:

- Supporting people affected by AT to live well with AT
- Improving provision of information and active communication around AT
- Increasing the impact of our research programme and strengthening cooperation across the AT research community
- Strengthening and increasing the diversity of our fundraising

We will do this by continuing 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 organise an in-person event for young adults with AT. And we will fight for the overlooked needs of disabled people and stand up to the injustices that make life harder for people with AT.

A key priority will be to work with our NHS partners to run more of our specialist AT clinics

at Nottingham University Hospital and the Royal Papworth Hospital in Cambridge, to deal with the increase in demand and the growing waiting list as a result of the pandemic.

We will also support people with AT to participate in clinical trials where affordability prevents them and keep investing in research to accelerate breakthroughs. Following the success of our scientific talks in 2021, we will again deliver on key topics to help share knowledge with families and improve health outcomes.

We are passionate about developing our equality, diversity, and inclusion strategies and in 2022 will implement throughout the organisation, and we will take action to improve our carbon footprint.

Financial review

During the year the AT Society received income of £368,340 (2020: £320,758) and spent £500,634 (2020: £505,594).

The Society therefore had an overall deficit for the year of £132,294 (2020: £184,836). With funds brought forward from previous years, the Society will carry forward £636,250 in reserves (2020: £768,544).

Unrestricted general funds carried forward have decreased to £324,532 (2020: £441,869). The Society also carries forward restricted funds of £311,718 (2020: £326,675), which the trustees consider to be at an appropriate level.

Of the Society's total income some 45% was received in donations from individuals, companies and trusts; 54% in grants from NHS England, the European Commission, the Medical Research Council and Trusts. The remaining income came from 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 2021 the trustees have continued to hold funds on a deposit account with the Charities Aid Foundation rather than investing them where there would be the risk of a capital loss. The trustees will continue to monitor the Society's cash position carefully and will ensure funds are moved whenever possible to a higher interest-bearing deposit account.

Reserves policy

The policy aims to ensure that the Society is maximising its charitable expenditure in any given year, whilst at the same time maintaining financial prudence to ensure its sustainability and capacity to manage unforeseen expenditure or unanticipated loss of income. We seek, at all times, to provide a level of working capital that protects the continuity of our core work.

The Board of Trustees review the policy with reference to the AT Society's strategy and Annual Plan and determine the target level of free reserves to meet these. The Board of Trustees will at times designate funds from free reserves for significant project costs or replacement of major assets. Given the current unpredictability in income levels the reserves policy will be monitored on an ongoing basis and adjusted as the trustees deem necessary.

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.

Our operational budget currently includes a planned deficit in recognition of the investment in research and support services that the Society committed to during the year. In light of our drop in income, the trustees also approved appropriate cost-cutting measures and income generating activities to work towards achieving a balanced budget in 2022, whilst retaining the desired level of reserves. However given the financial challenges ahead, this target date is now under review and we anticipate spending more of our reserves in 2022 and moving towards a balanced budget in 2023.

Fundraising

Whilst the AT Society engages in public fundraising, it does not use external professional fundraisers or commercial participators. The charity nevertheless 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.

Structure

The Society is a charitable company limited by guarantee, incorporated in England and Wales, and registered with the Charity Commission in England. 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 in normal years meet formally as a Board four times each year. Through the pandemic trustees met monthly in order to keep abreast of challenges the coronavirus brought. The Board of Trustees is the governing body of the Society. It agrees 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.

Our research work is overseen by our Scientific Advisory Board, who report to the main Board. The membership of the SAB is listed on the inside back cover of this report. Our research applications undergo a rigorous peer reviewed process and only those deemed to be the highest quality are passed for funding. We are regulated by the Association of Medical Research Charities.

The Society's staff team is based at the offices in Harpenden. The Director of Fundraising & Operations shares leadership of the charity with the Head of Services and Head of Research. Remuneration of the Society's staff team of 8 is reviewed annually against performance and affordability. The team organises and provides the vast majority of the services delivered by the Society and manages and supports the Society's volunteers.

Governance and management

The Board of Trustees may consist of between 3 and 20 members. 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 three year term of office. All appointed directors must submit themselves to election at the annual general meeting immediately following their appointment.

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 10 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.

All trustees active in 2021 are listed on the inside back cover of this report. On 15 July 2021, Dr Jayesh Bhatt, Rachel Poupard, David Macdonald and Joe Powell were appointed, and Linda Clark and Lynda Finn resigned, as trustees. In accordance with our aim to be a user-led organisation, 50% of our Board have lived-experience of the condition.

Trustee induction and training

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.

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.

Staff

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.

During the pandemic we redeployed members of our dedicated staff team to ensure frontline services were not compromised, and new virtual fundraising could take place. We did not furlough any members of staff during this period.

The Society actively encourages its staff to enhance and extend their skills, particularly with regard to its charitable objectives, and learning and personal development are central to the appraisal process.

During the year we enjoyed the support of occasional office and administrative volunteers and benefitted a lot from corporate volunteers who

gave communications and design support, legal and administrative help, for which we are immensely grateful.

Collaborations

The Society is a national organisation operating throughout the UK and collaboration is at the heart of what we do. It is essential that we work closely with all organisations and individuals connected to AT and we are proud that connecting with experts across the world and across different sectors is part of our everyday work.

Our involvement in establishing the Global A-T Alliance in 2020, and developing this in 2021, is a good example (<https://cureat.org/>). The Alliance has a strong collective belief that together we are stronger and through 2021 delivered a range of shared activities. The connections give small international AT organisations access to vital skills, knowledge, and experience, while working towards the same overall vision: to improve lives for people affected by AT and to find a cure.

To strengthen our ability to campaign on behalf of and meet the needs of people living with AT, we are affiliated to:

- › Genetic Alliance UK
- › Rare Disease UK
- › The Association of Medical Research Charities ("AMRC")
- › Euro-Ataxia

We are members of the NCVO and we work closely with the charity Ataxia UK. For instance, Head of Ataxia Research, assists the AT Society in the implementation of the AT Society's research strategy.

Our long-established AT Clinical Research Network, brings together researchers, clinicians and patient organisations from around the world, and is a very active and useful body.

Our AT clinics (the world's first) provide an integrated service for people living with AT, funded and supported by NHS England. We work closely with the professional arms of the service: the specialist AT centres at Nottingham University Hospital (paediatric), the Royal Papworth Hospital (adult) and Professor Malcolm Taylor's laboratory at the University of Birmingham, which provides diagnostic services. The centres of excellence have developed a unique expertise in this field and provide multi-disciplinary AT clinics.

Our specialist clinics and our strong links with those medics in the world with expertise in AT mean that we can successfully act as an important point of contact for local professionals seeking expert opinion. Most have little in-depth knowledge of AT and so our role here is imperative. Equally we help ensure recommendations from clinic professionals are understood and implemented by patients' local health teams to speed up access to health.

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. In the current challenging times, the risk register is reviewed frequently. Key risk areas identified for 2022 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 grant to meet its objectives:

- › Individual support grants
- › Research 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 every-day 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 2021 we funded three ongoing research grants and commissioned two new grants:

- Functional and metabolomic analysis of iPSC-derived Purkinje neurons from AT patients, with the FIRC Institute of Molecular Oncology, Milan
- Natural History of Ataxia-Telangiectasia (N-HAT), University of Nottingham
- Statistical consultancy on the Natural History of Ataxia-Telangiectasia (N-HAT), University of Nottingham
- Modulation of RELB/p52-dependent NF-κB activities to improve neurodegenerative symptoms of AT, University of Cambridge
- AT cerebellar neurodegeneration and inositol phosphate signalling, University of Texas at Austin

Our full research programme can be viewed at:
<https://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 Grants Sub-Committee. Applicants need the support of an appropriate professional and need to demonstrate what efforts have been made to obtain statutory or other funding.

Legal and administrative information

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.

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 13 July 2022 and signed on its behalf by:

Andrew Mills

Andrew Mills
Treasurer

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 2021 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).

This report is made solely to the charitable 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 charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

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 2021 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 7, 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.

Philip N 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

13 July 2022

Statement of financial activities

Year ended 31 December 2021

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.21 £	Total funds 31.12.20 £
Income and endowments from:					
Donations and legacies	2	150,906	216,181	367,087	317,820
Charitable activities					
Other trading activities	3	1,190	–	1,190	2,227
Investment income	4	63	–	63	711
Total		152,159	216,181	368,340	320,758
Expenditure on:					
Raising funds	5	92,811	–	92,811	102,133
Charitable activities	6				
Research		137,291	42,648	179,939	167,748
Clinic		9,717	55,493	65,210	54,506
Welfare		8,037	73,719	81,756	87,905
Information		30,132	–	30,132	33,185
Education		17,987	–	17,987	24,293
Governance		32,799	–	32,799	35,824
Total		328,774	171,860	500,634	505,594
Net (expenditure)/income		(176,615)	44,321	(132,294)	(184,836)
Reconciliation of funds					
Total funds brought forward		441,869	326,675	768,544	953,380
Transfers between funds		59,278	(59,278)	–	–
Total funds carried forward		324,532	311,718	636,250	768,544

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 2021

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.21 £	Total funds 31.12.20 £
Fixed assets					
Tangible assets	13	1,931	–	1,931	2,221
Current assets					
Debtors	14	21,125	136,133	157,258	41,771
Cash at bank		316,542	297,321	613,863	789,997
		337,667	433,454	771,121	831,768
Creditors:					
Amounts falling due within one year	15	(15,066)	(121,736)	(136,802)	(65,445)
Net current assets		322,601	311,718	634,319	766,323
Total assets less current liabilities		324,532	311,718	636,250	768,544
Net assets		324,532	311,718	636,250	768,544
Funds:	17				
Unrestricted funds				324,532	441,869
Restricted funds				311,718	326,675
Total funds				636,250	768,544

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 13 July 2022 and were signed on its behalf by:

Andrew Mills

Andrew Mills
Treasurer

Statement of cash flows

Year ended 31 December 2021

	Notes	31.12.21 £	31.12.20 £
Cash flows from operating activities:			
Cash used in operations	a	(175,693)	(161,484)
Net cash used in operating activities		(175,693)	(161,484)
Cash flows from investing activities:			
Purchase of tangible fixed assets		(504)	(2,589)
Interest received		63	711
Net cash used in investing activities		(441)	(1,878)
Change in cash and cash equivalents in the reporting period		(176,134)	(163,362)
Cash and cash equivalents at the beginning of the reporting period		789,997	953,359
Cash and cash equivalents at the end of the reporting period		613,863	789,997

Notes to the statement of cash flows

Year ended 31 December 2021

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

	31.12.21 £	31.12.20 £
Net expenditure for the reporting period as per the statement of financial activities	(132,294)	(184,836)
Adjustments for:		
Depreciation charges	794	699
Interest received	(63)	(711)
Increase in debtors	(115,487)	(19,313)
Increase in creditors	71,357	42,677
Net cash used in operating activities	(175,693)	(161,484)

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 (FRS 102) (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 2021

2. Donations and legacies

	31.12.21 £	31.12.20 £
Donations	79,178	77,595
Grants	199,590	142,081
Fundraising activities	64,845	80,831
Income tax refund	23,439	17,313
Other income	35	–
	367,087	317,820

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

	31.12.21 £	31.12.20 £
Grants from NCG	55,310	54,333
Grants from European Commission	43,256	15,748
Grant from Medical Research Council	60,107	–
Grants from Trusts	40,917	72,000
	199,590	142,081

3. Other trading activities

	31.12.21 £	31.12.20 £
Sale of merchandise	1,190	2,227

4. Investment income

	31.12.21 £	31.12.20 £
Deposit account interest	63	711

5. Raising funds

	31.12.21 £	31.12.20 £
Staff costs	46,562	60,261
Information, literature, publicity etc.	6,106	1,440
Merchandise	330	1,683
Other direct costs	20,941	19,818
Support costs allocated to activities	18,872	18,931
	92,811	102,133

6. Charitable activities costs

	Research £	Clinic £	Welfare £	Information £	Education £	Governance £	2021 Total £	2020 Total £
Costs directly allocated to activities								
Staff costs	28,177	33,321	41,031	21,270	13,431	17,328	154,558	178,893
Support events	–	–	2,706	–	–	–	2,706	1,873
Newsletter	–	–	721	721	–	–	1,442	3,664
Welfare, equipment, respite etc.	–	–	3,200	–	–	–	3,200	1,670
Research costs and conference	19,469	–	–	–	–	–	19,469	22,070
Clinic costs	–	18,850	–	–	–	–	18,850	13,484
Other direct costs	–	–	–	–	–	10,074	10,074	10,813
Grant funding of activities	121,673	–	18,231	–	–	–	139,904	124,862
Support costs allocated to activities	10,620	13,039	15,867	8,141	4,556	5,397	57,620	46,132
	179,939	65,210	81,756	30,132	17,987	32,799	407,823	403,461

7. Analysis of grants

	31.12.21 £	31.12.20 £
Grants to institutions	121,673	96,795
Grants to individuals	18,231	28,067
	139,904	124,862

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:

	£
Natural History of Ataxia-Telangiectasia	16,557
Natural History of Ataxia-Telangiectasia – Statistics Consultancy	2,437
Modulation of RELB/p52 – dependent NF-kB activities to improve neurodegenerative symptoms of AT	80,160
AT cerebellar neurodegeneration and inositol phosphate signaling	22,519
	121,673

9. Operating lease commitments

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

	2021	Land & buildings 2020	2021	Equipment 2020
Less than one year	15,819	22,894	5,392	4,379
Two to five years	–	15,819	12,077	7,174
More than five years	–	–	1,761	–
	15,819	38,713	19,230	11,553

In September 2020 the AT Society moved office premises and entered into a new two year property lease. It is anticipated that this lease will be renewed thereafter.

10. Trustees' remuneration and benefits

No member of the Board of Trustees received any remuneration during the year (2020: £Nil).

Trustees' expenses

Travel expenses of £Nil were reimbursed during the year (2020: £50 to one Trustee).

11. Staff costs

	31.12.21 £	31.12.20 £
Salaries	178,504	211,954
Social security costs	12,007	14,906
Pension provision	10,609	12,294
	201,120	239,154

8. Net expenditure

Net expenditure is stated after charging:

	31.12.21 £	31.12.20 £
Auditors' remuneration	4,560	4,560
Depreciation – owned assets	794	699
Operating lease rentals – land and buildings	22,894	8,692
Operating lease rentals – equipment	6,021	3,654

No employees had emoluments in excess of £60,000 (2020: none).

During the year the Society paid £52,022 in employee benefits to key management personnel for their services to the charity (2020: £54,797).

During the year, the Society employed the equivalent of 5.5 full-time staff (2020: almost 6 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 £8,786 (2020: £10,989).

Notes to financial statements

Year ended 31 December 2021

12. Comparatives for the statement of financial activities

	Unrestricted funds 2020 £	Restricted funds 2020 £	Total funds 2020 £
Income and endowments from:			
Donations and legacies	166,361	151,459	317,820
Charitable activities:			
Other trading activities	2,227	–	2,227
Investment income	711	–	711
	169,299	151,459	320,758
Expenditure on:			
Raising funds	102,133	–	102,133
Charitable activities:			
Research	151,671	16,077	167,748
Clinic	173	54,333	54,506
Welfare	21,373	66,532	87,905
Information	33,185	–	33,185
Education	24,293	–	24,293
Governance	35,824	–	35,824
	368,652	136,942	505,594
Net movement in funds	(199,353)	14,517	(184,836)
Reconciliation of funds			
Total funds brought forward	641,222	312,158	953,380
Total funds carried forward	441,869	326,675	768,544

13. Tangible fixed assets

	Equipment £	Furniture £	Total £
Cost			
At 1 January 2021	16,294	4,472	20,766
Additions	504	–	504
At 31 December 2021	16,798	4,472	21,270
Depreciation			
At 1 January 2021	16,144	2,401	18,545
Charge for the year	276	518	794
At 31 December 2021	16,420	2,919	19,339
Net book value			
At 31 December 2021	378	1,553	1,931
At 31 December 2020	150	2,071	2,221
14. Debtors: amounts falling due within one year			
	31.12.21 £		31.12.20 £
Prepayments and accrued income	154,365		38,379
Other debtors	2,893		3,392
	157,258		41,771

Other debtors include a franking machine deposit of £200 which falls due in more than one year. Accrued income of £151,084 relates to grants of £136,132, and gift aid receivable of £14,952.

15. Creditors: amounts falling due within one year

	31.12.21 £	31.12.20 £
Support grants payable	4,791	5,232
Institutional grants payable	119,305	28,305
Trade creditors	956	13,103
Accruals and deferred income	7,849	13,620
Taxation and social security	3,901	5,185
	136,802	65,445

Grant funding commitments	Support grants £	Institutional grants £	Total £
Grant liability at 1 January 2021	5,232	28,305	33,537
Grants awarded in the year	18,231	121,673	139,904
Grants paid in the year	(18,672)	(30,673)	(49,345)
Grant liability at 31 December 2021	4,791	119,305	124,096

16. Contingent liabilities

	31.12.21 £	31.12.20 £
Research grant funding		
Natural History of Ataxia-Telangiectasia	–	16,558
Natural History of Ataxia-Telangiectasia – Statistics Consultancy	3,500	6,750
Functional and metabolomic analysis of iPSC-derived Purkinje neurons from AT patients	30,000	30,000
Modulation of RELB/p52 – dependent NF-κB activities to improve neurodegenerative symptoms of AT	80,160	160,321
	113,660	213,629

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.

It is anticipated that these contingent liabilities will be funded from designated research funds (see note 17) during 2022 and 2023.

17. Movement in funds

	At 1.1.21 £	Net movement in funds £	At 31.12.21 £
Unrestricted funds			
General fund	188,664	(45,092)	143,572
Designated research fund	253,205	(72,245)	180,960
	441,869	(117,337)	324,532
Restricted funds			
Research	3,351	3,663	7,014
Welfare, support, equipment	313,324	(18,620)	294,704
Information	10,000	–	10,000
	326,675	(14,957)	311,718
Total funds	768,544	(132,294)	636,250

17. Movement in funds (continued)

	Incoming resources £	Resources expended £	Transfers in/(out) £	Movement in funds £
Unrestricted funds				
General fund	152,159	(239,971)	42,720	(45,092)
Designated research fund	–	(88,803)	16,558	(72,245)
	152,159	(328,774)	59,278	(117,337)
Restricted funds				
Research	105,588	(42,647)	(59,278)	3,663
Clinic costs	55,493	(55,493)	–	–
Welfare, support, equipment	55,100	(73,720)	–	(18,620)
	216,181	(171,860)	(59,278)	(14,957)
Total funds	368,340	(500,634)	–	(132,294)

Purpose of restricted funds

Research

Restricted research income and expenditure relates to a three year Horizon 2020 grant from the European Commission to build and run an international AT patient registry, a grant received from Medical Research Council to fund research projects and grants, donations and income restricted to research.

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 emergency support grants, grants towards equipment for adults and young people, grants towards housing modifications, virtual online events 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 2021, £88,803 (2020: £96,795) has been spent on research. A transfer of £16,558 has been made back to unrestricted designated reserves in respect of research expenditure initially made from unrestricted

designated funds which was subsequently funded by restricted income received in the year. A transfer of £42,720 has been made from the restricted research fund back to general funds in respect of core costs advance funded from general funds but subsequently covered by restricted income from the European Registry Grant. It is anticipated that the remaining designated funds will be spent during 2022 and 2023.

18. 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.

19. Ultimate controlling party

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

20. 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



Andrew Mills
Treasurer



Linda Clark
(resigned
15 July 2021)



Lynda Finn
(resigned
15 July 2021)



Dr Jayesh
Bhatt
(appointed
15 July 2021)



Rachel
Poupard
(appointed
15 July 2021)



Nicholas Gull



Professor
Penny Jeggo



Jhilna Shah



Lian Yarlett



David
Macdonald
(appointed
15 July 2021)



Joe Powell
(appointed
15 July 2021)

Patrons

The Lady Parkinson DL

Mrs Joan Bartholomew

The Lord Bilimoria of Chelsea CBE DL

Mr Brian Conley

The Revd Canon Paul Thomas OBE

Senior Management

Susie Norbury

Director of Fundraising & Operations

Kay Atkins

Head of Services

Professor Penny Jeggo

Head of Research

Scientific Advisory Board

Professor Penny Jeggo
Chair

Dr Anke Hensiek

Professor Rick Livesey

Dr Cynthia Oviatt-Rothblum

Professor Laurence Pearl

Professor Malcolm Taylor

Dr William Whitehouse

Registered office and operational address

AT Society

Unit 54

Thrales End Business Centre

Thrales End Lane

Harpenden

Hertfordshire AL5 3NS

Telephone: 01582 760733

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

Auditors

Hicks & Company

Chartered Accountants

Statutory Auditors

Vaughan Chambers

Vaughan Road

Harpenden

Herts AL5 4EE

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

**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.**

To find out how you, or your organisation
can get involved in our work and help
change lives, please visit us:

AT^{*}SOCIETY.ORG.UK

*Ataxia Telangiectasia



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Reg. Charity No. 1105528
Reg. Company No. 5177145



amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

Accounts

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

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 or treatment. 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.

“I am proud to say that during this last year, the charity continued to perform well and to focus efforts on meeting the needs of children, young people and adults with AT, in their hour of need.”

Mike Detsiny
Chair of Trustees

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Chair of Trustees' statement

2020 was one of the hardest years we have faced at the AT Society, and yet, as Chair of Trustees I am proud to say that during this last year, the charity continued to perform well and to focus efforts on meeting the needs of children, young people and adults with AT, and their families.



When the COVID-19 crisis took hold, the AT Society had to respond quickly to an urgent and unprecedented demand for help from families caring for children with complex health needs, as well as develop innovative solutions to our research programme which was hard hit, and navigate a forced, unplanned office move during this period. All the while the charity faced a significant loss of income as fundraising events were cancelled and activities reduced.

After the quick diversifying of income streams, and the generosity of our wonderful supporters, the actual loss of income was curtailed. These results and the prudent financial management and cost-cutting measures during the year mean that we retain a healthy level of reserves and are able to respond proactively to the needs of the children and their families now, and in the future.

Our colleagues worked hard to support families in their hour of need and the whole Board is extremely proud of their response to the crisis, and their enduring commitment to the charity's values.

During this time we have learned a great deal. We have reviewed our risk management and taken action to strengthen it, we have increased the training the team receive to ensure that our people have the very best learning opportunities, we have adapted our policies and procedures and strengthened our governance – and we are better placed to deal with the challenges that lie ahead.

With the brilliant help from communications consultancy Madano, we have also strengthened our campaign materials. We have introduced our 'We're AT' campaign, where the 'AT' letters within specifically selected words draw out and highlight the AT Society's involvement, engagement and goals. We hope you like it.

Thank you to all our supporters for getting us through one of the most uncertain and challenging years in the charity's history. Whilst we celebrate the great impact we've had in an uncertain year, our families and our organisation still face an equally challenging year ahead. There is significant uncertainty in the economic outlook, which is likely to affect our fundraising income. We will monitor the environment closely and increase our efforts to use resources in the most effective way possible for the benefit of the individuals and families we support.

I and my fellow trustees are extremely proud to be able to help this wonderful charity and grateful to the dedicated team who work so hard to make it successful.

Mike Detsiny

Mike Detsiny
Chair of Trustees

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 2020.

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

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

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 information and support to meet the challenges of living with AT
- Working to achieve better, more coordinated health and social care services
- Promoting and funding high quality AT research
- Speaking out to ensure that the voices of people affected by AT are heard
- Raising awareness of AT and gathering supporters and resources to help achieve our vision.

During 2020 the Society's high-level objectives matched with these points.

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

The Memorandum of Association sets out the charitable purposes for public benefit. The trustees review the Society's aims, objectives and activities

each year 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 accordance with the Charity Commission's guidance.

The Society has a formal budgeted business plan for the year, which is reviewed regularly, in accordance with the key objectives above.

The Society's activities and achievements in pursuit of these objectives in 2020 are detailed below. We have set out specific examples of activities in our Impact Report, which complements this report (www.atsociety.org.uk/aboutus).

Achievements and performance

The AT Society is the only charity in the UK providing specialist, practical and therapeutic support for people affected by AT, which we do through a range of activities including advocacy, outreach, respite, counselling and medical interventions. We also fund research to improve treatments and find a cure.

2020 was an exceptionally challenging year. The measures taken by the UK government to control the spread of the coronavirus involved a high degree of social disruption, impacting on the delivery of and demand for the activities of the AT Society, and the availability of staff for work. COVID-19 had a disproportionately negative effect on people living with AT and we were forced into rethinking our plans both for the work we do to support families affected by AT, and the way we raise funds to pay for it. Our programmes adapted and expanded through the year to take on the challenges presented to us, including rapidly modifying our working practices to a virtual model, so that our frontline staff could work from home safely and our helpline could still operate no matter where we were.

The implications meant that our forecasted income significantly fell during the year as fundraising events were cancelled and activities considerably reduced. We implemented cost cutting measures to offset the loss and focused efforts on other income streams, ending the year with the deficit as originally predicted. The trustees express their sincere gratitude to all grant-giving trusts, including those who provided emergency grants, individual donors and fundraisers, who have made our work possible over the last 12 months both by their

financial support and by the generous giving of their time. Their support is always crucial, but never more than during a pandemic.

At a time when the volume of work increased dramatically, the size of our staff team decreased. We did not need to furlough anyone during this period. We provided flexible and supportive working solutions and took the opportunity to upskill staff and expand capabilities, embracing technology and digital events. The Society remain incredibly grateful to the team's enduring commitment to the cause during the difficult year.

A significant challenge faced by many families during the year was a lack of clear information and guidance specific to their needs. The AT Society worked hard to develop a library of online resources and provided daily updates to help families navigate their way through the crisis safely – from how to cope with shielding, advice about the vaccine, to preparing to go back to school or to one of our specialist AT clinics. The resources became vital sources of information for the AT community and visits to our website increased by 117% and new visitors by 58%.

We worked closely with health and social care services throughout the year. We resolved 161 educational, housing and benefits injustices, championing human rights and addressing inequalities. We delivered 25 training events to improve pupils' schooling and we worked closely with NHS England to reopen our specialist AT clinics at Nottingham University Hospital and the Royal Papworth Hospital, for essential medical consultations.

Existing support was tailored in response to the pandemic's devastating impact on mental wellbeing. We knew that families, young adults with AT living alone, and families with a newly diagnosed child, would need our support when they didn't have their networks around them, so we made sure we personally contacted everyone, provided expert advice and information throughout the year, set up online social events to connect to one another and increased our therapeutic provision and practical support. We were pleased that moving our social support events online amid shielding helped to address severe isolation; 86% said we had significantly reduced their feelings of isolation.

To offset financial and social losses, 27 emergency grants were provided and helped towards providing disability equipment, essential housing adaptations, technical equipment and grocery bills. 99,000 minutes were spent providing a friendly and listening ear to people in crisis needing to talk and we ran

emergency surgeries for families struggling. 100% declared feeling more empowered and better able to cope after these interventions.

We took part in the first global AT awareness campaign: "Ataxia telangiectasia is difficult to say. It is more difficult to live with" reaching thousands across the world. And we joined other UK disability charities to press for change and fight for equality.

We continued to promote and commission high quality AT research and advanced our understanding of AT. Three existing research projects progressed through the year, albeit at a slower pace given the lockdown restrictions and the temporary closure of laboratories, and after implementing an innovative and rigorous assessment process with our Scientific Advisory Board & Review Panel we also identified two new research projects for 2021. Further information on these projects can be found in our Impact Report 2020.

As our AT International Clinical Research Conference, due to be held in October 2020, was cancelled, we instead led meetings with leading USA, UK and European clinicians and scientists, to increase our collaborative working across the international AT community and to keep sharing expertise and findings. We also worked collaboratively to create the 'AT Global Alliance'. This is a group of AT organisations from across the world, currently consisting of The AT Society (UK), Action for AT (UK), BrAshA-T (Australia), Aefat (Spain) and the A-T Children's Project (US). As AT is such a rare condition, it is critical that our resources committed to finding a cure are maximised and that we achieve this through a coordinated effort with other AT organisations.

The AT Society continued to participate in international clinical trials with Intrabio and Erydel, both of which are developing therapies for the treatment of AT to improve quality of life. Whilst the pandemic slowed recruitment down for these trials, progress is being made and we are hopeful of some positive results in 2021.

Plans for future periods

The Society's plans for 2021 and the following years are built around our priority areas of:

- Supporting people affected by AT to live well with AT
- Improving provision of information and active communication around AT
- Increasing the impact of our research programme and strengthening cooperation across the AT research community

► Strengthening and increasing the diversity of our fundraising

We will: deliver our new 'Building Resilience' project, to help improve mental health and cope with the challenges AT brings; extend our existing work with children and teenagers and develop new services with them; continue to provide expert and friendly advice to service users, their families, and professionals; stand up to the injustices and remove barriers that make life harder for people with AT.

A key priority will be to work with our NHS partners to run more of our specialist AT clinics at Nottingham University Hospital and the Royal Papworth Hospital in Cambridge. In 2020 the number of adults able to attend a clinic fell by 58% during the year as medical and administrative staff were redeployed and for children, it fell by 15%, with approximately one third of appointments taking place online.

We will also keep developing new materials to improve awareness, understanding and management of the condition; increase our investment into research to accelerate the breakthroughs we are all seeking; and hold international AT clinical meetings, prioritizing the impact of COVID-19.

We will work collaboratively and launch the AT Global Alliance (www.cureat.org), the first international directory for AT, and we will deliver regular science talks for families to improve understanding of AT.

Our digital offering for both service users and funders will be further expanded, and opportunities for increased income generation continuously explored.

We will continue to ensure everything we do is measured objectively and led by the insights of people affected by AT. And we will make the most of our assets by building a culture of excellence at all levels within the charity to ensure we have a strong organisation for many years to come. We are extremely proud of our long serving and highly skilled staff and will invest further in their development and work hard to retain our most important asset – our people.

Financial review

During the year the AT Society received income of £320,758 (2019: £1,061,873) and spent £505,594 (2019: £553,027).

The Society therefore had an overall deficit for the year of £184,836 (2019: surplus of £508,846). With funds brought forward from previous years, the Society will carry forward £768,544 in reserves (2019: £953,380).

Unrestricted general funds carried forward have decreased to £441,869 (2019: £641,222). The Society also carries forward restricted funds of £326,675 (2019: £312,158), which the trustees consider to be at an appropriate level.

Of the Society's total income some 29% (2019: 8%) was donated by grant-giving trusts, 18% (2019: 69%) by individuals and companies and 25% (2019: 13%) by the fundraising activities of our supporters (i.e. individuals and companies provided some 43% (2019: 82%) of the Society's total income). The remaining 28% (2019: 10%) came from NHS England's contribution towards the AT specialist clinics, the European Commission grant for the development of the International AT Registry and also some small amounts of interest income and trading receipts.

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 2020 the trustees have continued to hold funds on a deposit account with the Charities Aid Foundation rather than investing them where there would be the risk of a capital loss. The trustees will continue to monitor the Society's cash position carefully and will ensure funds are moved whenever possible to a higher interest-bearing deposit account.

Reserves policy

The policy aims to ensure that the Society is maximising its charitable expenditure in any given year, whilst at the same time maintaining financial prudence to ensure its sustainability and capacity to manage unforeseen expenditure or unanticipated loss of income. We seek, at all times, to provide a level of working capital that protects the continuity of our core work.

The Board of Trustees review the policy with reference to the AT Society's strategy and Annual Plan and determine the target level of free reserves to meet these. The Board of Trustees will at times designate funds from free reserves for significant project costs or replacement of major assets. Given the current unpredictability in income levels the reserves policy will be monitored on an ongoing basis and adjusted as the trustees deem necessary.

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.

Our operational budget currently includes a planned deficit in recognition of the investment in research that the Society has committed to. In light of our drop in income, the trustees have also approved appropriate cost-cutting measures and income generating activities to work towards achieving a balanced-budget in 2022, whilst retaining the desired level of reserves.

Fundraising

Whilst the AT Society engages in public fundraising, it does not use external professional fundraisers or commercial participators. The charity nevertheless observes and complies with the relevant fundraising regulations and codes and is a member of the Fundraising Regulator. During the year the AT Society was compliant with these regulations and codes, and the charity did not receive any complaints relating to its fundraising practice.

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.

Structure

The Society is a charitable company limited by guarantee, incorporated in England and Wales, and registered with the Charity Commission in England. 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 in normal years meet formally as a Board four times each year. Through the pandemic trustees met monthly in order to keep abreast of challenges the coronavirus brought. The Board of Trustees is the governing body of the Society. It agrees 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.

Our research work is overseen by our Scientific Advisory Board, who report to the main Board. The membership of the SAB is listed on the inside back cover of this report. Our research applications undergo a rigorous peer reviewed process and only

those deemed to be the highest quality are passed for funding. We are regulated by the Association of Medical Research Charities.

The Society's staff team is based at the offices in Harpenden. Until June 2020 this was under the leadership of the Chief Executive, who was responsible for implementing the strategy and policies agreed by the Board. From September 2020, following the departure of the Chief Executive, many of these responsibilities were delegated to the Director of Fundraising & Operations. Remuneration of the Society's staff team is reviewed annually against performance and affordability. The team organises and provides the vast majority of the services delivered by the Society and manages and supports the Society's volunteers.

Governance and management

The Board of Trustees may consist of between three and 20 members. 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 three year term of office. All appointed directors must submit themselves to election at the annual general meeting immediately following their appointment. There is no limit to the number of terms a director may serve, subject to approval of the membership in general meeting. One third of the directors must retire by rotation at each annual general meeting and each retiring director may offer himself for re-election.

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.

All trustees active in 2020 are listed on the inside back cover of this report.

Trustee induction and training

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.

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.

Staff

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.

During the pandemic we redeployed members of our dedicated staff team to ensure frontline services were not compromised, and new virtual fundraising could take place. We did not furlough any members of staff during this period.

The Society actively encourages its staff to enhance and extend their skills, particularly with regard to its charitable objectives, and learning and personal development are central to the appraisal process.

In normal times the Society benefits from the support of volunteers. 2020 was an exception to this as regular event volunteers and office volunteers were unable to help. We did enjoy the support of occasional office and administrative volunteers and corporate teams to assist with an office relocation, for which we are immensely grateful.

Collaborations

The Society is a national organisation operating throughout the UK and collaboration is at the heart of what we do. It is essential that we work closely with all organisations and individuals connected to AT and we are proud of the partnerships we have developed. In 2020 we were definitely stronger together.

To strengthen our ability to campaign on behalf of and meet the needs of people living with AT, we are affiliated to:

- › Genetic Alliance UK
- › Rare Disease UK
- › The Association of Medical Research Charities ("AMRC")
- › Euro-Ataxia

The Society also enjoys good relations with other AT support groups around the world. In 2011 it established the AT Clinical Research Network, to bring together researchers, clinicians and patient organisations from around the world, and this

network was still active throughout 2020. We are also a key member of the newly formed AT Global Alliance.

Our AT clinics (the world's first) provide an integrated service for people living with AT, funded and supported by NHS England. We collaborated weekly and often daily through the pandemic with the professional arms of the service: the specialist AT centres at Nottingham City Hospital (paediatric), the Royal Papworth Hospital (adult) and Professor Malcolm Taylor's laboratory at the University of Birmingham, which provides diagnostic services. The centres of excellence have developed a unique expertise in this field and provide multi-disciplinary AT clinics.

Our specialist clinics and our strong links with those medics in the world with expertise in AT mean that we can successfully act as an important point of contact for local professionals seeking expert opinion. Most have little in-depth knowledge of AT and so our role here is imperative. Equally we help ensure recommendations from clinic professionals are understood and implemented by patients' local health teams to speed up access to health care.

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. In the current challenging times, the risk register is reviewed frequently. Key risk areas identified for 2021 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, and they are regularly reviewed by our safeguarding leads.

Grant-making policies

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

- › Individual support grants
- › Research 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 regularly 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 every-day 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 2020 we funded three ongoing research grants and assessed two new grants for funding in 2021, namely:

- › Functional and metabolomic analysis of iPSC-derived Purkinje neurons from AT patients, with the FIRC Institute of Molecular Oncology, Milan
- › Natural History of Ataxia-Telangiectasia (N-HAT), University of Nottingham
- › Statistical consultancy on the Natural History of Ataxia-Telangiectasia (N-HAT), University of Nottingham
- › Modulation of RELB/p52-dependent NF- κ B activities to improve neurodegenerative symptoms of AT, University of Cambridge (2021)
- › AT cerebellar neurodegeneration and inositol phosphate signalling, University of Texas at Austin (2021)

Our full research strategy can be viewed at: www.atsociety.org.uk/wp-content/uploads/2020/05/A-T-Society-Research-Strategy-2020-1.pdf

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 Grants Sub Committee. Applicants need the support of an appropriate professional and need to demonstrate what efforts have been made to obtain statutory or other funding.

Legal and administrative information

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.

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 2021 and signed on its behalf by:



Andrew Mills
Treasurer

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 2020 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).

This report is made solely to the charitable 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 charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

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 2020 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 pages 7–8, 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.

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

16 July 2021

Statement of financial activities

Year ended 31 December 2020

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.20 £	Total funds 31.12.19 £
Income and endowments from:					
Donations and legacies	2	166,361	151,459	317,820	1,046,823
Charitable activities					
Welfare	5	–	–	–	11,968
Other trading activities	3	2,227	–	2,227	1,928
Investment income	4	711	–	711	1,154
Total		169,299	151,459	320,758	1,061,873
Expenditure on:					
Raising funds	6	102,133	–	102,133	127,406
Charitable activities	7				
Research		151,671	16,077	167,748	79,853
Clinic		173	54,333	54,506	76,788
Welfare		21,373	66,532	87,905	185,725
Information		33,185	–	33,185	38,078
Education		24,293	–	24,293	21,727
Governance		35,824	–	35,824	23,450
Total		368,652	136,942	505,594	553,027
Net (expenditure)/income		(199,353)	14,517	(184,836)	508,846
Reconciliation of funds					
Total funds brought forward		641,222	312,158	953,380	444,534
Total funds carried forward		441,869	326,675	768,544	953,380

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 2020

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.20 £	Total funds 31.12.19 £
Fixed assets					
Tangible assets	14	2,221	–	2,221	331
Current assets					
Debtors	15	9,880	31,891	41,771	22,458
Cash at bank		448,603	341,394	789,997	953,359
		458,483	373,285	831,768	975,817
Creditors:					
Amounts falling due within one year	16	(18,835)	(46,610)	(65,445)	(22,768)
Net current assets		439,648	326,675	766,323	953,049
Total assets less current liabilities		441,869	326,675	768,544	953,380
Net assets		441,869	326,675	768,544	953,380
Funds:	18				
Unrestricted funds				441,869	641,222
Restricted funds				326,675	312,158
Total funds				768,544	953,380

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 2021 and were signed on its behalf by:

Andrew Mills

Andrew Mills
Treasurer

Statement of cash flows

Year ended 31 December 2020

	Notes	31.12.20 £	31.12.19 £
Cash flows from operating activities:			
Cash (used in)/generated from operations	a	(161,484)	484,868
Net cash (used in)/provided by operating activities		(161,484)	484,868
Cash flows from investing activities:			
Purchase of tangible fixed assets		(2,589)	–
Interest received		711	1,154
Net cash (used in)/generated from		(1,878)	1,154
Change in cash and cash equivalents in the reporting period		(163,362)	486,022
Cash and cash equivalents at the beginning of the reporting period		953,359	467,337
Cash and cash equivalents at the end of the reporting period		789,997	953,359

Notes to the statement of cash flows

Year ended 31 December 2020

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

	31.12.20 £	31.12.19 £
Net (expenditure)/income for the reporting period as per the statement of financial activities	(184,836)	508,846
Adjustments for:		
Depreciation charges	699	265
Interest received	(711)	(1,154)
Increase in debtors	(19,313)	(16,364)
Increase/(decrease) in creditors	42,677	(6,725)
Net cash (used in)/provided by operating activities	(161,484)	484,868

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 (FRS 102) (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 and is included in full in the Statement of Financial Activities 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 received.
- ▶ 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 2020

2. Donations and legacies

	31.12.20 £	31.12.19 £
Donations	149,595	813,333
Grants	70,081	83,058
Fundraising activities	80,831	139,176
Income tax refund	17,313	11,256
	317,820	1,046,823

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

	31.12.20 £	31.12.19 £
Grants from NCG	54,333	51,403
Grants from European Commission	15,748	31,655
	70,081	83,058

3. Other trading activities

	31.12.20 £	31.12.19 £
Sale of merchandise	2,227	1,928

4. Investment income

	31.12.20 £	31.12.19 £
Deposit account interest	711	1,154

5. Income from charitable activities

Activity	31.12.20 £	31.12.19 £
Family meetings & conferences etc: Welfare	–	11,968

6. Raising funds

	31.12.20 £	31.12.19 £
Staff costs	60,261	78,106
Information, literature, publicity etc.	1,440	7,857
Merchandise	1,683	1,061
Other direct costs	19,818	16,765
Support costs allocated to activities	18,931	23,617
	102,133	127,406

7. Charitable activities costs

	Research £	Clinic £	Welfare £	Information £	Education £	Governance £	2020 Total £	2019 Total £
Costs directly allocated to activities								
Staff costs	39,271	32,346	41,923	25,474	18,349	21,530	178,893	166,451
Support events	–	–	1,873	–	–	–	1,873	46,922
Newsletter	–	–	1,832	1,832	–	–	3,664	4,114
Welfare, equipment, respite etc.	–	–	1,670	–	–	–	1,670	30,151
Research fees and conference	22,070	–	–	–	–	–	22,070	30,157
Clinic costs	–	13,484	–	–	–	–	13,484	40,688
Information, literature, publicity etc.	–	–	–	–	–	–	–	8,076
Other direct costs	–	–	–	–	–	10,813	10,813	6,791
Grant funding of activities	96,795	–	28,067	–	–	–	124,862	63,566
Support costs allocated to activities	9,612	8,676	12,540	5,879	5,944	3,481	46,132	28,705
	167,748	54,506	87,905	33,185	24,293	35,824	403,461	425,621

8. Analysis of grants

	31.12.20 £	31.12.19 £
Grants to institutions	96,795	9,435
Grants to individuals	28,067	54,131
	124,862	63,566

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:

	£
Natural History of Ataxia-Telangiectasia	42,732
Natural History of Ataxia-Telangiectasia – Statistics Consultancy	4,063
Functional and metabolomic analysis of iPSC-derived Purkinje neurons from AT patients	50,000
	96,795

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:

	2020	Land & buildings 2019	2020	Equipment 2019
Less than one year	22,894	–	4,297	3,333
Two to five years	15,819	–	7,174	8,198
More than five years	–	–	–	1,025
	38,713	–	11,471	12,556

In September 2020 the AT Society moved office premises and entered into a new two year property lease.

11. Trustees' remuneration and benefits

No member of the Board of Trustees received any remuneration during the year (2019: £Nil).

Trustees' expenses

Travel expenses of £50 were reimbursed to one trustee during the year (2019: £104).

12. Staff costs

	31.12.20 £	31.12.19 £
Salaries	211,954	215,842
Social security costs	14,906	16,936
Pension provision	12,294	11,779
	239,154	244,557

9. Net (expenditure)/income

Net (expenditure)/income is stated after charging:

	31.12.20 £	31.12.19 £
Auditors' remuneration	4,560	4,560
Depreciation – owned assets	699	265
Operating lease rentals – land and buildings	8,692	–
Operating lease rentals – equipment	3,878	4,175

No employees had emoluments in excess of £60,000 (2019: none).

During the year the Society paid £54,797 in employee benefits to key management personnel for their services to the charity (2019: £61,876).

At the start of the year, the Society employed the equivalent of 6.5 full-time staff. After some changes mid-way through the year, we ended the year with a staff team of almost 6 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 £10,999 (2019: £10,374).

Notes to financial statements

Year ended 31 December 2020

13. Comparatives for the statement of financial activities

	Unrestricted funds 2019 £	Restricted funds 2019 £	Total funds 2019 £
Income and endowments from:			
Donations and legacies	893,481	153,342	1,046,823
Charitable activities:			
Welfare	–	11,968	11,968
Other trading activities	1,928	–	1,928
Investment income	1,154	–	1,154
	896,563	165,310	1,061,873
Expenditure on:			
Raising funds	127,406	–	127,406
Charitable activities:			
Research	32,850	47,003	79,853
Clinic	25,185	51,603	76,788
Welfare	81,428	104,297	185,725
Information	38,078	–	38,078
Education	18,703	3,024	21,727
Governance	23,450	–	23,450
	347,100	205,927	553,027
Net movement in funds	549,463	(40,617)	508,846
Reconciliation of funds			
Total funds brought forward	91,759	352,775	444,534
Total funds carried forward	641,222	312,158	953,380

14. Tangible fixed assets

	Equipment £	Furniture £	Total £
Cost			
At 1 January 2020	16,294	1,883	18,177
Additions	–	2,589	2,589
At 31 December 2020	16,294	4,472	20,766
Depreciation			
At 1 January 2020	15,963	1,883	17,846
Charge for the year	181	518	699
At 31 December 2020	16,144	2,401	18,545
Net book value			
At 31 December 2020	150	2,071	2,221
At 31 December 2019	331	–	331

15. Debtors: amounts falling due within one year

	31.12.20 £	31.12.19 £
Prepayments and accrued income	38,379	22,458
Other debtors	3,392	–
	41,771	22,458

Other debtors includes a rent deposit of £2,693 which falls due in more than one year.

16. Creditors: amounts falling due within one year

	31.12.20 £	31.12.19 £
Support grants payable	5,232	–
Institutional grants payable	28,305	–
Trade creditors	13,103	5,323
Accruals and deferred income	13,620	11,810
Taxation and social security	5,185	5,635
	65,445	22,768

Grant funding commitments	Support grants £	Institutional grants £	Total £
Grant liability at 1 January 2020	–	–	–
Grants awarded in the year	28,067	96,795	124,862
Grants paid in the year	(22,835)	(68,490)	(91,325)
Grant liability at 31 December 2020	5,232	28,305	33,537

17. Contingent liabilities

Research grant funding	31.12.20 £	31.12.19 £
Natural History of Ataxia-Telangiectasia	16,558	59,289
Natural History of Ataxia-Telangiectasia – Statistics Consultancy	6,750	10,000
Functional and metabolomic analysis of iPSC-derived Purkinje neurons from AT patients	30,000	80,000
Modulation of RELB/p52 – dependent NF-κB activities to improve neurodegenerative symptoms of AT	160,321	–
	213,629	149,289

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.

It is anticipated that these contingent liabilities will be funded from designated research funds (see note 18) during 2021 to 2023.

18. Movement in funds

	At 1.1.20 £	Net movement in funds £	At 31.12.20 £
Unrestricted funds			
General fund	291,222	(102,558)	188,664
Designated research fund	350,000	(96,795)	253,205
	641,222	(199,353)	441,869

Restricted funds			
Research	3,351	–	3,351
Welfare, support, equipment	308,807	4,517	313,324
Information	–	10,000	10,000
	312,158	14,517	326,675
Total funds	953,380	(184,836)	768,544

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	169,299	(271,857)	(102,558)
Designated research fund	–	(96,795)	(96,795)
	169,299	(368,652)	(199,353)

Restricted funds			
Research	16,077	(16,077)	–
Clinic costs	54,333	(54,333)	–
Welfare, support, equipment	71,049	(66,532)	4,517
Information	10,000	–	10,000
	151,459	(136,942)	14,517
Total funds	320,758	(505,594)	(184,836)

Purpose of restricted funds

Research

Restricted research income and expenditure relate primarily to a three year Horizon 2020 grant from the European Commission to build and run an international AT patient registry.

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.

18. Movement in funds (continued)

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 emergency support grants, grants towards equipment for adults and young people, grants towards housing modifications, virtual online events and the funding of family support staff.

Designated research fund

During 2019, the Board of Trustees designated £350,000 for research. During 2020, £96,795 has been spent on research. It is anticipated that the remaining designated funds will be spent during 2021 to 2023.

19. Non adjusting post balance sheet event

Subsequent to the year end it was agreed that the AT Society would collaborate on a project to fund an AT cerebellar neurodegeneration and inositol phosphate signalling study.

It is expected that the AT Society will contribute £11,260 in 2021 and £11,260 in 2022 in respect of the project. Grant instalment payments are contingent on receipt of satisfactory progress reports.

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.

Trustees, patrons and advisors

Directors/Trustees



Michael Detsiny
Chair of Trustees



Andrew Mills
Treasurer



Linda Clark



Lynda Finn



Nicholas Gull



Professor
Penny Jeggo



Jhilna Shah



Lian Yarlett

Patrons

The Lady Parkinson DL

Mrs Joan Bartholomew

The Lord Bilimoria of Chelsea CBE DL

Mr Brian Conley

The Revd Canon Paul Thomas OBE

Chief Executive

William Davis (until June 2020)*

* From September 2020 leadership of the charity was delegated to: Susie Norbury, who became Director of Fundraising & Operations; Kay Atkins, who became Head of Services; and trustee Professor Penny Jeggo, who is voluntarily leading our research programme.

Scientific Advisory Board

Professor Penny Jeggo
Chair

Dr Anke Hensiek

Professor Rick Livesey

Dr Cynthia Oviatt-Rothblum

Professor Laurence Pearl

Professor Malcolm Taylor

Dr William Whitehouse

Registered office and operational address

Registered office and operational address from October 2020:

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Unit 54
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Thrales End Lane
Harpenden
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Telephone: 01582 760733

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

Auditors

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

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

**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.**

To find out how you, or your organisation
can get involved in our work and help
change lives, please visit us:

AT^{*}SOCIETY.ORG.UK

*Ataxia Telangiectasia



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Reg. Company No. 5177145



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