

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

Research grant funding	31.12.21 £	31.12.20 £
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

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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
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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. Company No. 5177145



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