Annual Report & Financial Statements

FOR YEAR END 31ST DECEMBER 2024

WWW.ACTIONFORAT.ORG

Action For A-T Charity registered number 1145303

Legal & Reference Information

Patrons

Jonny Wilkinson CBE
Roger Black MBE
Jeremy Guscott MBE
Simon Shaw MBE
Rachel Morris MBE
Naga Munchetty
Leon Haslam

Chief Executive

Sean Kelly

Trustees at the date of approval

Toby Read (Chairman)
Emily Read
William Rowberry (Treasurer)
Tomos Shillingford
Maria Leonard
Chris Askew, OBE
Dr Mark Toms
Joseph Frost

Appointed during the year or since year end

None

Research Advisory Committee

Dr Kathryn Johnson, Scientific Advisor, Consultant Neonatologist and Research Lead, Chairperson

Professor David Attwell, Neuroscientist and Jodrell Professor of Physiology at the University College London

Associate Professor Esther Becker, Professor of Translational Neuroscience at the University of Oxford

Dr Simon Boulton, Principal Group Leader at The Francis Crick Institute

Dr Lisa Bunn, Associate Professor of Neurological Rehabilitation at the University of Plymouth

Professor Keith Caldecott, Professor of Genome Stability at the University of Sussex

Dr Richard Kay, Medical Statistician

Dr Guy Makin, Senior Paediatric Oncology Lecturer, University of Manchester

Dr Andrew Prayle, Clinical Assistant Professor, University of Nottingham

Bruno Salomone Gonzalez de Castejon, Research Associate, Bristol Medical School (THS)

Professor Grant Stewart, Professor of Cancer Genetics, School of Cancer Sciences, University of Birmingham

Professor Matthew Wood, Professor of Neuroscience at the University of Oxford, and Director of the Oxford Harrington Rare Disease Centre

Patient Representatives

Mr Amandeep Sharma
Mrs Clare Gallagher
Mrs Natasha Schneider

Charity Registration Number

United Kingdom Registered Charity number: 1145303

Registered Office
Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

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

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Trustees' Report

The Trustees of Action for A-T present their annual report and the financial statements for the year ended 31 December 2024.

These have been prepared in accordance with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008, and the Statement of Recommended Practice: Accounting and Reporting by Charities (SORP), applicable to charities preparing their accounts in accordance with FRS 102 (effective 1 January 2019), the Financial Reporting Standard applicable in the UK and Republic of Ireland.

Reference and Administrative Details

Action for A-T is a charity registered in England and Wales (No. 1145303). The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. The Trustees met in February, April, September, and November in 2024. The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

Public Benefit

Action for A-T's charitable objectives are set out in its governing Trust Deed, summarised in the "About Us" section on our website and include undertaking rigorously evaluated and properly conducted medical research into finding a cure or new treatment for the rare genetic condition Ataxia Telangiectasia (A-T), a rare genetic condition.

During the year, the charity has continued to manage its ongoing research portfolio as well as committing funds to a variety of new A-T related research projects. Details of this work can be seen on pages 5 to 18.

Our Trustees have considered how our work may most effectively further our charitable objectives for benefit of the public, in particular all those affected by Ataxia Telangiectasia. In doing so, they have adhered to the Charity Commission's guidance on public benefit (Public Benefit: Running a Charity (PB2) and Public Benefit: Reporting (PB3)), ensuring that all activities align with our mission and that no undue private benefit arises.

Environmental Considerations

While not subject to statutory reporting on greenhouse gas emissions, the charity remains mindful of its environmental impact. Measures taken include minimising paper use, promoting digital communications, and working with research partners committed to sustainable practices.

Objects, Achievements & Performance

Action for A-T's mission is: "To speed up the process of identifying a cure for A-T or treatments that delay or prevent the disabling effects of this childhood condition"

To further that mission, the charity focused on the following key areas in 2024:

- Strengthening our Capacity and Capabilities
- Continuing our Investment in Medical Research in the UK and Abroad
- Ensuring that our research is of the highest quality, is well managed and has clear and achievable aims
- Strengthening and Increasing our Fundraising Activities
- Working closely with others to meet our objectives
- Increasing awareness of our work and the condition
- Board Composition

The Trustees confirm that all activities undertaken align with the charity's objectives and provide clear public benefit, in accordance with the Charity Commission's guidance.

Strengthening our Capacity & Capabilities

Our Aim

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us achieve our charitable mission. Since the Charity was initially established in 2012, a great deal of governance and capacity building work has already taken place, but continued development is required to ensure that we are more efficient, productive and well positioned for the future.

Our Performance

2024 was another record-breaking year with our largest investment in new A-T research alongside our largest fundraising total. As in previous years, our ability to be flexible, innovative and capitalise on new opportunities enabled us to deliver a strong fundraising result.

Increased volunteer support helped us deliver the new planned activities and existing fundraising initiatives efficiently and effectively, allowing us to scale up many activities and increase funds raised. Many of these successful activities were data-led, as our previous investment in a good CRM system enabled us to reach key target audiences and manage relationships more effectively. In line with SORP 10.20, the value of general volunteered time has not been recognised in the financial statements, as it is not practicable to measure this contribution reliably.

We continued to explore and implement new technologies to improve our fundraising and communicate with our stakeholders. We also refreshed our IT infrastructure to strengthen our cyber security protocols and ensure that digital resources can be easily shared across the organisation.

We proactively managed our research relationships especially relationships with our grant holders to ensure that they had the required resources to complete their projects as expediently as possible. Where appropriate, some studies were granted extensions with no further cost to the charity as some investigators experienced recruitment issues due to various micro and macro-economic factors.

Our ability to adapt was only possible due to our size and structure and the hard work of a small but highly skilled team which we retained in full during the year. They have once again gone above and beyond to deliver a record-breaking fundraising year and the Trustees are very grateful for their incredible efforts.

Continuing our Investment in Medical Research in the UK & Abroad

Our Aim

Action for A-T aim to build a community of A-T research leaders and increase the amount of research that is taking place globally. Although we will always fund the highest quality applications wherever they are from; our key focus is to invest in projects and people based in the UK wherever possible.

Our Performance

Throughout 2024, our Chief Executive attended various meetings with key figures from the A-T research community and representatives from other medical research charities and patient groups to explore possible funding opportunities and further understand which areas of A-T research may provide the most promising outcomes.

Non-A-T researchers who specialise in related conditions were also contacted to drive future research projects and create greater interest in the condition. This strategy is repeated from year to year to improve the quality of applications and increase the number and demographic of 'who' we advertise our grant rounds to.

We concluded our latest grant round in April 2024 joining forces with various like-minded charities and patient organisations to award six new research grants. These projects required a combined total investment of £1,270,048 and will take place at renowned research institutions and university hospitals in the United Kingdom, USA and the Netherlands.

In addition to the main grant round, we also joined forces with NATA (Nucleic Acid Therapy Accelerator) to award a £249,615 grant to a team based in Birmingham and Hamburg as well as investing an additional £59,195 in three new proof of concept studies at various institutions in the United Kingdom.

Social Responsibility & Community Engagement

Action for A-T is committed to supporting families affected by A-T, raising awareness, and fostering collaboration with researchers and medical professionals. Beyond funding research, we actively engage with the community to ensure our work has a broad and lasting impact.

1. Community & Public Engagement: We work closely with families, researchers, and donors to advance A-T research and

awareness.

2. Volunteering & Fundraising: Our fundraising efforts are strengthened by dedicated volunteers and corporate partners, whose support is invaluable.

3. Commitment to Inclusion & Governance: We ensure fairness, transparency, and ethical governance in all aspects of our

Funding High-Quality Research into A-T

In addition to supporting and funding research aimed at improving the understanding of A-T, there are many innovative and exciting medical research opportunities that raise the prospect of real progress in combating the effects of genetic conditions such as A-T.

Our Aim

Action for A-T's aim is to be able to make grants to hospitals and universities throughout the world for the purpose of conducting research across all therapeutic areas related to A-T, with an emphasis on research that is likely to have a clear clinical application within the foreseeable future and/or which evaluate innovation in medical techniques which may have a potential benefit for children with A-T.

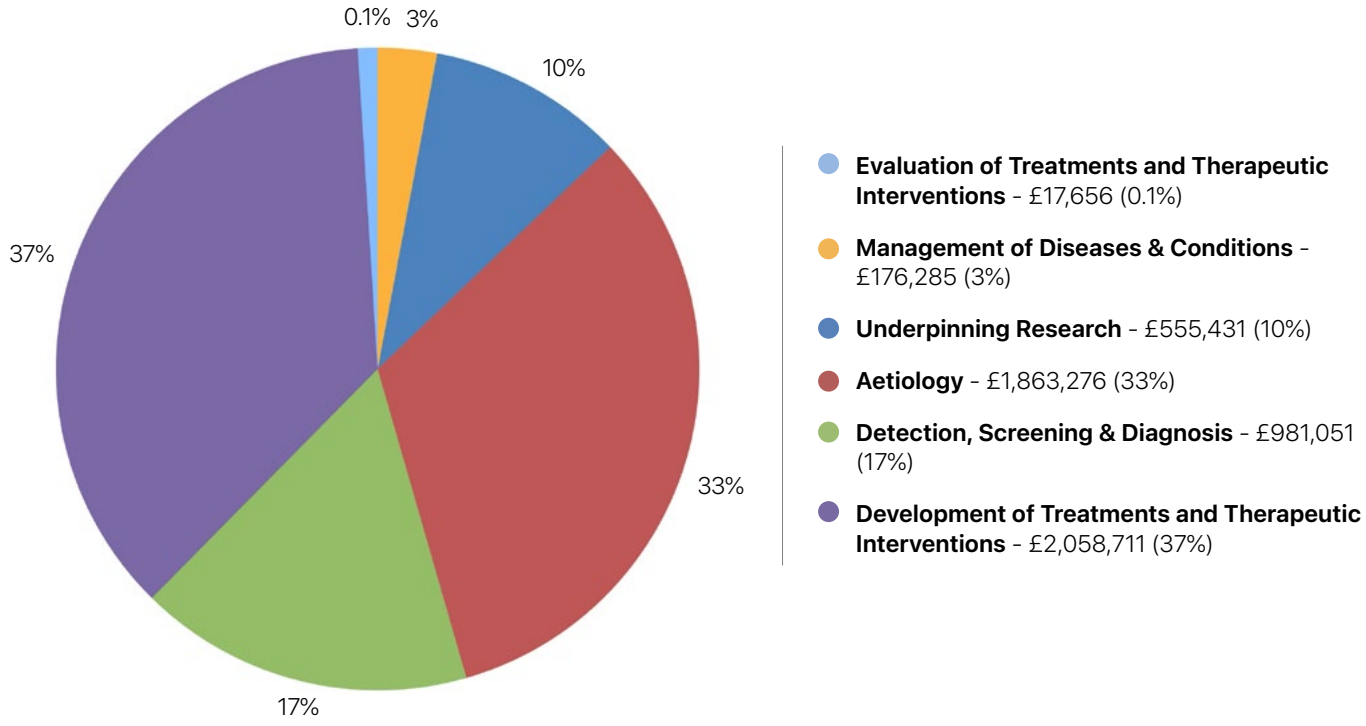
Our Performance

Since Action for A-T was established in 2012, we have invested £5,652,410 in 60 global research projects under six main research headings categorised using the UK Clinical Research Collaboration Health Research Classification System.

- **Underpinning Research** - Developing new tools and techniques for conducting research
- **Aetiology** - Understanding the causes of A-T
- **Detection, Screening & Diagnosis** - Tests for diagnosing and monitoring patients with A-T
- **Development of Treatments and Therapeutic Interventions** - Studies to identify new treatments for A-T
- **Evaluation of Treatments and Therapeutic Interventions** - Studies to prove how new treatments work and understand how to use them
- **Management of Diseases & Conditions** - Managing the symptoms of A-T

Total Research Spend Since 2012

The chart below shows the historic allocation of our research investment portfolio and our total investment in each of the six research categories listed above.



The following grants were awarded by the Trustees in 2024:

Development of suppressor tRNA-based therapeutics

Principal researchers: Professor Zoya Ignatova (University of Hamburg) and Professor Grant Stewart (University of Birmingham)
Institute: University of Hamburg and University of Birmingham
Cost: £249,615 over 24 months in partnership with NATA (Nucleic Acid Therapy Accelerator), Oxford
Start Date: 1st of June 2024


Prof Zoya Ignatova


Prof Grant Stewart

Project Overview

Professors Ignatova & Stewart will test the efficacy of individual sup-tRNAs to bypass specific NSMs in the ATM gene and produce full-length ATM protein using patient-derived cell lines. Successful sup-tRNA that restore sufficient levels of ATM will be encapsulated in engineered viral-like particles, that are non-infectious but utilize the natural ability of viruses to enter the cells of the human body. Following validation of the ability of individual sup-tRNAs to restore ATM protein production in brain organoids (laboratory grown brains), the researchers will examine the safety of these viral-like particles using animal models.

Depending on the efficacy of specific sup-tRNAs to bypass specific NSMs in the ATM and their ability to administer them efficiently to organs that are particularly susceptible to loss of ATM e.g. the cerebellum of the brain, it is possible that this therapy could potentially slow or halt progression of the neurological decline.

Biomarkers for Babies and Young Children with Ataxia Telangiectasia (BOBCAT)

Principal researcher: Professor Rob Dineen
Institute: University of Nottingham, UK
Cost: £246,867.32 over 60 months in partnership with the A-T Society (UK) AEFAT (Spain) and BrAshA-T (Australia)
Start Date: 1st of September 2024


Prof Rob Dineen

Project Overview

Professor Dineen and his team will recruit families whose babies are found to have A-T following the new-born heel-prick test plus families whose baby receives an A-T diagnosis because an older sibling had already been diagnosed with A-T. These families will attend various sessions at the Nottingham A-T clinic during which the baby will have an MRI scan of the brain and lungs, recordings of eye and limb movements, and a blood test. The families will bring their children for the assessments annually, so that changes can be observed as the child grows and as they start to show the features of A-T. The research team will then compare these measures to those from infants and children without A-T.

Even in clinical trials of powerful treatments, it may take several years for effects of treatments on disability to become obvious. This means clinical trials may have to be long duration (and therefore more costly), which could stifle clinical research of new treatments. Researchers would find it very valuable to have sensitive measures (referred to as 'biomarkers') of disease progression that could allow them to detect an early benefit of a new treatment before effects of the treatment on disability become obvious. Showing an early benefit of a treatment by detecting a positive effect on a biomarker of A-T could allow researchers to select the best treatments to take forward into the longer full-scale clinical trials. However, there are currently no agreed biomarkers of A-T disease progression in infants and very young children with A-T, who are the ones who may benefit most from new treatments aiming to reduce lifelong disability in A-T.

This project will not provide immediate benefit for the participating individuals but will hopefully help infants and young children diagnosed with A-T in the future who may be included in treatment trials from a very young age.

Development of a Gene Therapy approach to treat A-T

Principal researcher: Professor Samuel Young

Institute: University of North Carolina at Chapel Hill, USA

Cost: £249,128 in partnership with AEFAT (Spain) and BrAshA-T (Australia)

Start Date: 1st of September 2024

Prof Samuel Young

Project Overview

Gene therapy is a way to treat or prevent a specific disease by introducing normal functioning genes into cells in place of missing or defective ones to correct genetic disorders. A common way that researchers have found to accomplish this is by using a vector. Vectors are essentially vehicles designed to deliver therapeutic genetic material, such as a working gene, directly into a cell.

Professor Young and his team will use Helper Dependent Adenoviral vectors (HdAd). These vectors have improved safety profiles and have a large capacity to deliver genetic material. HdAd provides long-term gene expression without toxicity after a single administration in multiple preclinical animal models. Due to these features, HdAd has extraordinary promise to treat A-T. Currently, its use in the cerebellum has not been explored as current HdAd vectors do not work for Purkinje Cells (large neurons found in the cerebellum that are affected in people with A-T). Therefore, a knowledge gap exists in developing HdAd gene therapy approaches to treat A-T cerebellar degeneration.

Building on the lab's decade of experience developing and using HdAd vectors in the central nervous system, the team have created a novel HdAd vector that transduces Purkinje cells and other cerebellar cell types in a mouse model. They will now carry out work to overcome the major limitations preventing the use of HdAd in the cerebellum and their objective is to develop an HdAd approach that delivers therapeutic levels of ATM and characterize their efficacy in restoring ATM function in Purkinje cells. They will use their novel viral vectors, to develop approaches for long-term expression and restoration of ATM function in Purkinje cells and other cerebellar cell types.

Functional impact of Nicotinamide Riboside on the immune system of patients with A-T

Principal researcher: Dr Mirjam van der Burg

Institute: Leiden University Medical Centre, Netherlands

Cost: £250,000 over 36 months in partnership with AEFAT (Spain) and BrAshA-T (Australia)

Start Date: 1st of September 2024

Dr Mirjam van der Burg

Project Overview

Dr Mirjam van der Burg and her team will initiate an international survey to collect data on the clinical status and immunophenotype of patients with A-T diagnosed via new-born screening from medical electronic patient dossiers (EPD) to create a roadmap of the natural course of immune parameters during the first years of life. They will then use laboratory culture systems, which have been proven effective models for the immune system, in combination with ATM inhibitors and different doses of NR to investigate the impact of NR on the immune system. Finally, they will develop a new model system for ATM-deficient immune cells that is based on stem cells from cord blood in which an ATM mutation has been created via a state-of-the-art technique called CRISPR-based-gene editing.

This project could make a significant difference to the lives of those affected by A-T, because more insights will be gained on the effect of NR on the immune system and as such add crucial knowledge to future (international) clinical trials on NR as a new candidate drug for improvement of both neurological and immunological clinical manifestations of the condition.

Exploring Omaveloxolone efficacy in Ataxia-telangiectasia

Principal researcher: Professor Paola Giunti (pictured) and Dr Rosella Abeti
Institute: University College London (UCL), UK
Cost: £24,915 over 4 months
Start Date: 23rd of September 2024


Prof Paola Giunti

Project Overview

One of the processes happening in people who have A-T is increased oxidative stress. Professor Paola Giunti and her team will study a recently approved drug called Omaveloxolone (Omav). This drug is known to defeat oxidative stress, and the team will investigate whether it could help overcome the adverse effects of oxidative stress in A-T cells. Omav activates a natural defence system in our cells that fights off damage caused by stress. To test this, they will use skin cells from A-T patients and see if Omav can lower the levels of reactive oxygen species that are generated in patients' cells, leading to oxidative stress. They will then compare the levels of reactive oxygen species in A-T patients to healthy volunteer lines to verify that Omav is effective.

If it proves to be efficacious in A-T cells, their study may lead to a potential new treatment from which A-T patients could benefit in a relatively short time.

Exploring the Use of Assistive Robots, Smart Sensing and Digital Twin Models for Monitoring and Support of Ataxia in Non-Clinical Environments

Principal researcher: Professor Praminda Caleb-Solly
Institute: University of Nottingham
Cost: £19,998 over 6 months
Start Date: 1st of May 2025


Prof Praminda Caleb-Solly

Project Overview

Professor Caleb-Solly and her team at Nottingham University will focus on exploring engaging ways to support children between the ages of 5 and 10 with A-T, and their parents, to better understand and self-manage their activities through the day. The aim is to investigate whether simple sensors that measure overall movement and physical activity might be able to capture information regarding levels of energy used over time. They will then co-design how this information can be communicated to the children, in a personalised, engaging and easily understandable manner, that can assist them with getting the most out of their days and balance their activities to self-manage and regulate their limited energy reserves.

The project will explore three key aspects:

1. To what extent might non-obtrusive sensors provide reliable metrics for mapping physical activities over the day

2. How could this sensor data be incorporated into a smart guidance system (such as an intelligent robot 'coach') to provide proactive support for helping to balance physical activity with energy conservation to improve overall well-being and quality of life

3. What is required and acceptable to the children, their parents and health care professionals, in terms of the data collected, clinical use of the data, and form factors of the sensors and intelligent robot coach.

This project will lay the groundwork for a larger study into the effectiveness of using intelligent robotic "toys" as "coach" to provide information regarding individual activity/energy expenditure patterns to guide with structuring and balancing daily activities.

Identifying existing drugs to repurpose for treating Ataxia-Telangiectasia

Principal researcher: Dr Richard Tuxworth

Institute: University of Birmingham, UK

Cost: £249,333 over 32 months in partnership with the A-T Society (UK), AEFAT (Spain) and BrAshA-T (Australia)

Start Date: 1st of November 2024

Dr Richard Tuxworth

Project Overview

Dr Tuxworth and his team will initially grow A-T nerve cells in the laboratory and test a collection of the drugs that are known to enhance recycling. If some look promising, they will then test them in two more complex models of A-T. First, they will use fruit flies that have been engineered to mirror what happens in A-T. Fruit flies, while much simpler than humans, have a complex nervous system and show complex behaviour. They will be looking to see if any of the drugs correct the structural changes to nerves that they see in their A-T flies that are due to defective recycling. They will also test if the drugs are able to correct the movement deficits the flies show.

In the final stage of the project, they will grow mini-brains in the laboratory. Over many weeks these mini-brains – known as organoids – develop into complex 3D structures with many different types of cells and features reminiscent of a brain. They know already that in brain organoids grown from A-T cells the genes associated with the autophagy recycling process are not being turned on and off correctly and that there is increased death of nerve cells. The team are hoping that the drugs shown to work in the cells and the fruit flies will be able to reverse the defective recycling in the brain organoids and protect the nerve cells from dying.

The drugs they will test have been deliberately selected to make it quicker and simpler to move into early-stage clinical trials. All the drugs are old and commonly used, meaning they are cheap with no patent issues, plus their safety profiles and any possible side-effects are well-understood. Importantly, all are known to get into the brain and several are already used to treat neurological conditions, including childhood-onset conditions such as epilepsy. If they can see positive effects of one or more drugs in their cells, fruit flies and mini-brains, they will instigate clinical trials to test if they are able to help A-T patients maintain neurological function for longer.

Improving diagnosis and treatment of cancer in Ataxia-Telangiectasia patients through whole genome sequencing

Principal researcher: Dr Ramsay Bowden

Institute: University of Cambridge

Cost: £19,960 over 6 months

Start Date: 3rd March 2025

Dr Ramsay Bowden

Project Overview

Dr Bowden and her team will work with doctors looking after people with A-T to collect cancer biopsy samples for genetic investigations. They will use a technique called whole genome sequencing (WGS) to study every letter in the genetic code of these samples and compare this to the genetic code of non-cancer samples. They will also invite people with A-T with and without cancer to provide a blood sample and will look for any genetic changes in this blood which may be linked to those found in cancer samples.

Understanding the genetic basis of cancer in people with A-T will help doctors make better decisions about cancer treatment. It will guide them on what treatments are most likely to be effective for improving survival. It may also suggest which treatments should be avoided because of side effects, or because they are unlikely to be effective.

Identifying genetic changes in blood may help to develop a blood test to monitor cancer treatment without needing repeated biopsies. It is possible that genetic changes will be found in blood that can be used in a blood test for early diagnosis and cancer screening. When cancers are diagnosed at an earlier stage the outcomes are generally better.

This study is unlikely to provide immediate benefits for participants going through their own cancer treatment but will hopefully improve cancer diagnosis and treatment for individuals with A-T in the near future.

Investigating the role of mutant Triple T chaperone in ATM assembly in Ataxia Telangiectasia

Principal researcher: Dr Mohinder Pal

Institute: University of Kent, UK

Cost: £249,806 over 36 months partnership with the A-T Society (UK), AEFAT (Spain) and BrAshA-T (Australia)

Start Date: 30th April 2025

Dr Mohinder Pal

Project Overview

Recent research shows that inherited mutations in chaperone proteins can make the ATM protein unstable, and patients develop clinical symptoms that overlap with A-T disease. Despite this, there is a need to clarify how these chaperone proteins function to stabilise ATM and how patient-associated mutations in these chaperones affect this process. Dr Pal and his team seek to define precisely how these chaperone proteins interact with ATM. Electron microscopy will produce detailed images of the atomic structure of ATM bound to the chaperone complex. From these images, it should be possible to understand how mutations in these chaperones impact the assembly of the ATM protein.

The team will visualise the natural assembly pathway of ATM protein, mediated by chaperones, with a powerful electron microscope. This approach will provide critical information to understand how different mutants of ATM protein affect its stability and activity. This information will be pivotal to potentially designing potent small drug molecules to stabilise and restore the activity of ATM to decrease the gravity of the disease.

Understanding the pathway of the ATM assembly and the role of chaperones in this process can significantly contribute to our understanding of A-T. This work could be a basis to stabilise either mutant ATM protein or mutant chaperones, which may be sufficient to slow down the disease progression in patients. It could also serve as the basis for other researchers utilising these findings to test different chemicals to push this research from the laboratory to the benefit of A-T patients.

Kicking Kinases into Action: A novel drug screening assay for A-T

Principal researcher: Dr Paula Jackson

Institute: University of Nottingham

Cost: £19,238 over 12 months

Start Date: 3rd March 2025

Dr Paula Jackson

Project Overview

ATM, a serine threonine kinase protein, is a key protein that is dysregulated in Ataxia Telangiectasia (A-T). ATM has a multitude of roles such as a protection against oxidative stress, the maintenance of telomeres and DNA repair. The lack of ATM in A-T leads to pathophysiology and currently, treatments only focus on managing disease symptoms rather than interfering with disease progression itself. Current interventional clinical trials for A-T include triheptanoin, nicotinamide riboside, N-Acetyl-L-Leucine, and intra-erythrocyte dexamethasone sodium phosphate. Previous trials have focused on the examination of oxidative stress markers to assess the efficacy of these pharmaceutical treatments, in example, nicotinamide riboside. Dr Jackson and her team are planning to override the ATM gene and directly activate kinases that the ATM gene should be activating when fully functional.

The ATM is important for recognising double stranded DNA damage and kickstarts several processes to repair this and ensure cell repair and survival. When there is a problem with the ATM gene this doesn't happen and DNA damage can build up causing loss of cellular function in the brain. The team want to test whether they can directly kickstart these same processes using already available compounds. Initially, cells taken from people with A-T that have the exact ATM mutation that causes A-T will be secured. These will then be tested using 5 different compounds, using cellular viability assays to identify an optimal range of doses that can be used without killing the cells. The team will then measure both metabolic activity and DNA repair in a simple assay which will indicate whether they are able to activate the DNA repair mechanisms whilst maintaining a healthy cell.

If the team can understand how to override the ATM mis-function and this data could be used to undertake a more in-depth study of the mechanisms at play. The hope at the end is to find some alleviation to symptoms, or at best a partial treatment for people with A-T.

Ensuring that our research is of the highest quality, is well managed and has clear and achievable aims

Research is at the heart of what we do, and our research strategy outlines our intentions on achieving our mission.

Our Performance

Action for A-T were awarded their second prestigious AMRC award for best practise in medical and health research peer review in May 2021. The award confirms the robust methods used to make decisions about which research projects to fund and our support of the best researchers and the highest quality research, with the best chance of improving the lives of those affected by A-T. The award was made following a full audit of our processes which takes place every five years.

The Trustees generally stage one grant round per year where funds will allow. Applications are peer reviewed by independent external reviewers before they are passed on to our Research Advisory Committee for further review. Projects which pass the peer review process and are deemed high enough quality are passed on to the Trustees to make the final decision based on several key criteria including available funds, strategic alignment, and existing research commitments.

Our Research Advisory Committee (RAC) are part of this process and consist of independent scientific experts from fields related to A-T, including clinicians, non-clinicians, and statistical expertise from a wide range of UK institutions. Lay members are also on the committee to incorporate the views of parents and patients living with A-T, bringing a valuable and unique perspective over what research should be funded. Members of our RAC reviewed all the applications received in 2024 and their funding recommendations were passed on to the Trustees for consideration. All ten of their recommended projects were approved by the trustees and the grants were awarded at various dates throughout the year.

Project outcomes and sharing knowledge

We believe that sharing project outcomes and knowledge is a fundamental requirement for the development of new research strategies which will ultimately benefit those living with the condition. Progress, annual and final reports are mandatory for all our research grants to ensure that they are reaching the agreed milestones. These reports are formally reviewed by our scientific advisor to ensure that each project is in line with its stated aims and the outcomes are then converted into lay summaries to share with our supporters.

Researchers are also encouraged to publish their findings in medical journals and where possible, make the findings freely available. The outputs of research such as publications usually occur sometime after a research project ends and it can take many years to translate research ideas into new treatments or therapies to improve quality of life.

The outcomes of all the concluded research we have funded are displayed on our website under the 'Completed Research' section. Where applicable, these posts also include links to any online publications, and we also share project information via our social media channels and in various communications to our supporters and potential donors.

Evaluating the outcomes of our research

As with all charities, we are passionate about demonstrating the impact of our work and understand the importance of monitoring the progress and outcomes of our research. Throughout the year we continued to work with our scientific advisor and other members of our Research Advisory Committee to oversee and evaluate the effectiveness of our ongoing research portfolio. Between them, they monitored the progress of ongoing projects and signed off on any which were completed to help ensure that the original research aims stated in the application were fulfilled.

The following studies concluded in 2024, and the initial project outcomes were as follows:

Virtual Reality in Ataxia Telangiectasia

Principal researcher: Professor Philip Breedon

Institute: Nottingham Trent University, UK

Completion date: December 2023

Professor Philip Breedon

Project Overview

To reduce the rate of muscle degradation and potentially prolong the time until patients become full time wheelchair users, professor Breedon and his research team developed a bespoke virtual environment that pairs with a frictionless 360° treadmill, fitted with a rehabilitation support frame. The VR environment contains a wide selection of easy to play, non-strenuous 'mini games' each exclusively developed to target a specific muscle group, motor or cognitive function. Throughout game development, the team were in regular contact with parents of A-T patients and A-T specialist clinicians to ensure the game was made to the patient's requirements and interests.

Project Outcome

The researchers believe the solution has the potential to play a vital role in improving patient wellbeing as it encourages independence through its ease of use, a novel approach to rehabilitation and takes away the need to complete long winded, tiresome activities. To continue their research, the team are working on a new improved study to further improve game quality, conduct in-depth patient studies and develop supplementary hardware. The teams long term goal is that the solution could be deployed into several local clinics nationwide, providing a community of active users to support one another through multiplayer gameplay and mitigating the need for families to travel long distances for physiotherapy.

STIM A-T Pilot Study

Principal researcher: Dr Caroline Blanchard

Institute: University of Nottingham

Completion date: February 2024

Dr Caroline Blanchard

Project Overview

Involuntary movements, such as muscle spasms and tremors, greatly affect daily activities and quality of life for people with A-T. Current treatment options are limited. Dr Caroline Blanchard and the team at Nottingham wanted to see if stimulating a nerve in the wrist called the median nerve could reduce unwanted involuntary movements in individuals with A-T. This pilot study aimed to show the feasibility and tolerability of, and provide preliminary evidence of the effect of, median nerve stimulation (MNS) delivered via a 'watch-like' device worn on the wrist, for reducing unwanted involuntary movements in people with A-T.

Project Outcome

The team recruited five young adult participants for this pilot study, of whom four had classic A-T and one had a condition that overlaps with A-T called AOA-1. All participants had involuntary movements in addition to ataxia. They firstly undertook interviews with the participants about how the involuntary movements affected their lives, and what benefit they would hope to get from a non-invasive stimulation treatment. They then carried out a series of tests where they asked the participants to do a range of movement and thinking tasks, with the MNS stimulation device switched on and switched off. They filmed the participants while they were doing these tasks. The team are currently analysing the videos to look for reduced number of unwanted movements with the device switched on. It is a small sample size therefore a clear effect is not expected to be seen initially. They found that the device was well tolerated by participants and there were no safety concerns. Based on this data they now plan to apply for funding for a larger clinical trial to find evidence that this approach works as a treatment for unwanted movements in A-T and related conditions.

Through this study the team have leveraged an additional £20,000 funding from the MRC / EPSRC NeuroMod+ funding stream for a project to refine the AI-based analysis of movement disorders in A-T. This work, together with the STIM A-T pilot data, will be used to support a grant application for a larger trial of the device, with both efficacy and mechanistic study objectives.

These two projects were funded via our Sandpit grant round which completed in March 2023. Sandpit funding is a small pot of money that we invest in both an unmet research challenge in A-T and in researchers that are new to A-T. We do this to get a new idea off the ground and to encourage new people to the field of A-T research.

A new function for ATM and a new theory for the clinical abnormalities in A-T

Principal researcher: Professor Mike Kastan

Institute: Duke University, North Carolina, USA

Completion date: December 2023

Professor Mike Kastan

Project Overview

Ataxia Telangiectasia (A-T), results from loss of function of the ATM (Ataxia Telangiectasia, Mutated) gene. Although much is known about the function of the protein encoded by this gene, mechanistic understanding of how loss of the gene's function leads to the presentation of the disease, including neurodegeneration, cancer, lung abnormalities, etc, remains incomplete. Further understanding of ATM regulation and function is needed to help show how loss of ATM affects cellular processes and the clinical presentation of the disease. This study built on previous work and aimed to explore the interaction of ATM and a gene called SMG1 to characterise signal pathways between them.

Project Outcome

The gene SMG1 is in the same protein family as ATM and the team made the unexpected observation that ATM protein is required for controlling SMG1 protein activity after being exposed to DNA damaging agents, like ionizing radiation. They found that ATM helps control production of alternative forms of the DNA damage-responsive and tumour suppressive protein p53, in part through negative regulation SMG1 activity. These alternative versions of p53 protein that are produced in response to irradiation in ATM intact cells, unlike in cells that have lost ATM, promote the senescence (growth arrest) of cells and triggers production of a pro-inflammatory environment around cells. They showed that ATM and SMG1 contribute to cellular senescence through the production of these alternative versions of p53 protein. They also identified another protein, DDX5, that is required for production of the alternative versions of the p53 protein and for control of cellular senescence after irradiation. In all, ATM, SMG1, and DDX5 work to promote irradiation-induced cellular senescence through production of alternative versions of the DNA damage-responsive protein p53. Alterations in this signalling pathway may contribute to the neuronal and cancer abnormalities seen in A-T patients.

While not all experiments that were proposed in the original application were successful (mainly those related to the specific biochemical mechanisms by which ATM regulates SMG1 kinase activity), the project was successful in meeting the overall objectives by formally demonstrating the role of ATM in regulating SMG1, in identifying an additional novel and interesting component of this signalling pathway (the RNA helicase, DDX5), and in demonstrating that this pathway affects a very important A-T phenotype, namely cellular senescence.

The researchers are keen to explore these unexpected new insights further and plan further work to analyse whether these new pathways could potentially account for important A-T clinical phenotypes, particularly the neurodegeneration.

Publications

McCann JJ, Fleenor DE, Chen J, Lai C-H, Bass TE, Kastan MB. Participation of ATM, SMG1, and DDX5 in a DNA Damage-induced Alternative Splicing Pathway. Radiation Research, 199: 406-421, 2023. PMID: 36921295 DOI: 10.1667/RADE-22-

Recurrent pulmonary infections and their impact on neurological decline in A-T

Principal researcher: Professor Margot Mayer-Proschel and Professor Michael O'Reilly

Institute: University of Rochester, New York

Completion date: March 2024

Professor Margot Mayer-Proschel

Project Overview

A-T is a multi-organ disease, yet neurological pathologies (one of the main problems in A-T) are for the most part studied in isolation from other organs. Professors Mayer-Proschel and O'Reilly wanted to study whether lung infections exacerbate neurological decline. The team recognized this was a poorly understood and investigated correlation and aimed to understand better the role of peripheral insults and inflammation to the brain in patients with A-T.

Three aims were clearly set out and the team used a mouse model to:

- Undertake cellular analysis of the effect of a single lung infection (Influenza A)
- Undertake cellular analysis of the impact of recurrent respiratory infections on lung and brain pathology
- Characterise the functional changes after the respiratory infections

Project Outcome

The mice were exposed to viral or bacterial lung infections and their lung and motor function tested. They found that the mice were highly sensitive to recurrent peripheral viral infections which impacted their lung function. In addition, they failed to boost their antibody response after a primary infection rendering them highly vulnerable to recurrent infections. The peripheral infections did not only affect lung function but exacerbated motor defects in a significant manner. Young animals exposed to a peripheral viral or bacterial challenge developed highly reproducible motor defects that were consistent with ataxic traits.

The researchers have established relevant behavioural endpoints that can be used to test efficiency of therapeutic drugs in the future. They aim to start the process of identifying potential drugs. If drugs are identified, they will then need to be tested to see if they prevent or revert the neurological decline that occurs in A-T. This work may ultimately assist in the development of new therapeutic approaches

Publications

Warren R, Dylag AM, Behan M, Domm W, Yee M, Mayer-Pröschel M, Martinez-Sobrido L, O'Reilly MA. Ataxia telangiectasia mutated is required for efficient proximal airway epithelial cell regeneration following influenza A virus infection. Am J Physiol Lung Cell Mol Physiol. 2022 Apr 1;322(4):L581-L592. doi: 10.1152/ajplung.00378.2021. Epub 2022 Feb 23. PubMed PMID: 35196880; PubMed Central PMCID: PMC8993527.

Innovative methods for gene therapy in Ataxia-Telangiectasia

Principal researcher: Professor Ignacio Molina & Dr García-Pérez

Institute: University of Granada, Spain

Completion date: March 2024

Professor Ignacio Molina & Dr García-Pérez

Project Overview

Gene therapy is a technique for correcting genetic defect by inserting a healthy copy of a gene into cells (replacing a faulty gene). To deliver a gene into cells, scientists use delivery systems called vectors.

In a previous study, Professor Molina's team demonstrated that this technique could cure A-T cells. However, the extremely large size of the ATM gene (the gene missing or not functioning completely in A-T) means most delivery systems are inefficient. To overcome this, the team studied whether a new type of vector called transposons would be suitable. Transposons can carry large genes and deliver them into target cells, and thus the team wanted to see if this approach could introduce a healthy ATM gene into A-T patient cells.

Project Outcome

The researchers introduced the full-length ATM gene into patient cells and found that whereas transposons could be introduced into deficient cells, the efficiency was not higher than that previously obtained by other viral methods and unfortunately considered insufficient to start clinical trials. Since the transfection efficiency was greatly affected by the size of the transgene, they then designed a mini-ATM gene that was about half the size of the full-length ATM gene. Transfection efficiency obtained with the mini gene was greatly enhanced and they detected a presence of the truncated mini protein. This was a relevant achievement since they considered that such construction could result in an unstable protein. They then analysed if the cellular defects typical of A-T had been rescued in mini-ATM transfected patient cells. After a detailed analysis they concluded that the truncated ATM protein was unable to revert the defects related to A-T.

Although the researchers were not successful with their gene therapy strategy, the findings are still important. It is now known that this approach to gene therapy has been tested and found at present to be ineffective. Within this fast moving and rapidly expanding field of gene therapy testing of any potential hypotheses are important.

Publications

There are no publications at this current time.

Optimizing lung imaging in people with Ataxia Telangiectasia applying improved MRI techniques

Principal researcher: Dr Peter Merkus

Institute: Radboud University Medical Centre, the Netherlands

Completion Date: August 2024

Dr Peter Merkus

Project Overview

Many children and adults with Ataxia Telangiectasia (A-T) suffer from recurrent infections and some develop malignancies. This is responsible for a large burden for these patients and their families/caretakers and may cause severe symptoms and even death. In order to improve treatment, it is necessary to be able to monitor the condition of the lung better. Lung function measurements are difficult to carry out reliably for many people with A-T, and imaging of the lungs with conventional radiology of the chest involves ionizing radiation that should be avoided whenever possible. Magnetic Resonance Imaging (MRI) does not involve ionizing radiation, and improved MRI would be the ideal tool to obtain reliable structural information of the lungs. However, MRI scanning used to be less suitable for lung imaging till recently because of poor resolution. Furthermore, MRI is not a quick procedure and patients with A-T often have uncoordinated movements that preclude optimal imaging.

Project Outcome

Dr Merkus and his team, aimed to improve the resolution of the MRI images, to correct for movement during the procedure and to reduce the time needed to obtain images of the lungs. The goal was to enhance and standardize a technique suitable for routine clinical care of patients with A-T, also the severe and the young.

Although the project suffered considerable delays, the team were successful in reaching their stated goals/milestones. Furthermore, they now also have a tool to assess ventilation and perfusion of the lungs during tidal breathing, so not only are they now able to make images of the structure of the lungs, but also of their function.

The quality of the imaging is clearly better than using conventional Chest X-rays. Through optimizing duration of procedure and resolution using the software developed in the past few years, MRI quality is now far better than previously possible. The team believe that their work will contribute to better monitoring and treating people with A-T, thereby enhancing the quality of their lives. They have subsequently decided that they will introduce the MRI as a part of the annual visit to the outpatient clinic. This will require serious planning and preparation of patients but is considered important. They will also develop a protocol aimed at accepting the MRI scanning better (for instance through distraction with MRI – Compatible VR glasses).

Publications

The team are currently working on a manuscript for publication.

The ATeam: Producing healthcare guidance for children with A-T

Principal researchers: Munira Khan & Dr Lisa Bunn

Institute: University of Plymouth

Completion Date: August 2024

Munira Khan

Project Overview

This project aimed to develop evidence-based guidance for healthcare professionals managing Ataxia Telangiectasia (A-T), focusing on nursing, physiotherapy, and occupational therapy. Historically, these disciplines have been integral to A-T management but lacked guiding research evidence. A large team of parents, academics and clinicians who are interested in A-T research was assembled to conduct this project and they named themselves 'the ATeam'.

Project Outcome

Following a compilation of all available evidence that could guide the management of A-T (Khan et al., 2024) the ATeam co-designed:

My A-T Pack:

A child- and family-owned healthcare pack to support communication and care. Its design was informed by focus groups and iterative feedback, including live illustrations during sessions (and My A+ Pack: A version tailored for broader ataxia disability needs).

A Home-Based Exercise Intervention:

A flexible, remotely supported exercise program was co-developed to suit daily life demands and manage fatigue. This included Yoga adapted videos and co-produced a "breathing exercise movie" for use with the 'Breather' device aimed to enhance respiratory health. This intervention included mindfulness options to ensure participant inclusivity and reduce perceived failure risks.

A feasibility randomized controlled trial tested the intervention's acceptability and effectiveness with seven participants. Four completed the program, reporting high enjoyment and perceived benefits. Engagement rates varied, and improvements were noted in balance and respiratory function. This project developed and trialed the first non-medical therapy intervention for children and young people with A-T, which, following amendment and rapid evaluation, will also be freely available to download freely for accessible use.

The project has advanced A-T care by addressing gaps in evidence and creating family-centered tools and interventions. Ongoing refinement and collaborations aim to scale its impact globally.

Publications

Khan et al., The Cerebellum: "Care and Management of Children with A-T by Nurses and Allied Health Professionals."

https://doi.org/10.1007/s12311-023-01555-z

Manuscript on My A-T Pack under review.

To view all our current and complete research projects, please visit

https://actionforat.org/category/research-projects-funded/

Achievements and Performance, Fundraising Activities

Action for A-T raises funds through donations, fundraising events, and corporate partnerships. No professional fundraisers or commercial participators were engaged. All fundraising is conducted in-house and monitored by the Trustees.

The charity follows ethical fundraising standards and ensures that all activities comply with best practices. During the year, no complaints were received regarding fundraising.

Our Aim

Action for A-T funds high quality peer reviewed medical research to speed up the process of identifying a cure for Ataxia Telangiectasia (A-T). We endeavor to raise funds from a variety of activities which appeal to new and existing supporters. Since 2012 we have invested £5,652,410 in 60 A-T related research projects around the world, and this has only been possible thanks to our generous supporters.

Our Performance

2024 was our most successful fundraising year to date as we were able to deliver a full portfolio of events. Most activities performed better than expected as our event guests were incredibly generous, and we were able to benefit from several new fundraising events including an overseas cycle ride with the Wasps Legends, a sponsored walk staged by the employees of Aviva Investors and a charity of the year partnership with the captains of Banstead Downs Golf Club. We also received further funding from the MRC to help retain early years researchers, plus a sizeable donation from Aviva Investors and continued our funding partnership with NATA.

Our investment in Virgin London Marathon places proved successful once again, allowing us to make a 421% return. 15 people joined our marathon team raising £60,070. We have secured 15 places for the 2025 London Marathon and applied for an additional 12 places (27 in total) which can be used from 2026 onwards.

In line with our fundraising strategy, we delivered a robust portfolio of sporting and social events as well as developing new relationships with other funders. We also diversified our other fundraising activities to ensure that we were not solely dependent on any one source of funding. Challenge and Social events accounted for 41% of our overall income (2023 - 50%). Whilst other fundraising initiatives, such as donations, funding partnerships and trust and foundation applications increased to 51% (2023 - 47%). The remaining 8% (2023 – 3%) came from bank interest on our designated funds. A few notable fundraising activities took place throughout the year including various golf events and the St Martin's Junior Trailblazers Walk. We are especially grateful to the staff and clients of The Constellation Automotive Group yet again for taking part in the three-day cycle from Surrey to Arras, France which raised £75,000 plus the non-riders who raised an additional £29,200 from a marathon walk. We are also indebted to the staff at Aviva Investors for their generous support throughout the year and the students of Quest Professional who raised over £14,000 at their drinks and canapes evening. In addition, we would like to thank Simon Toon and his friends for their ongoing and valued support and the captains and members of Banstead Downs Golf Club for raising over £48,000.

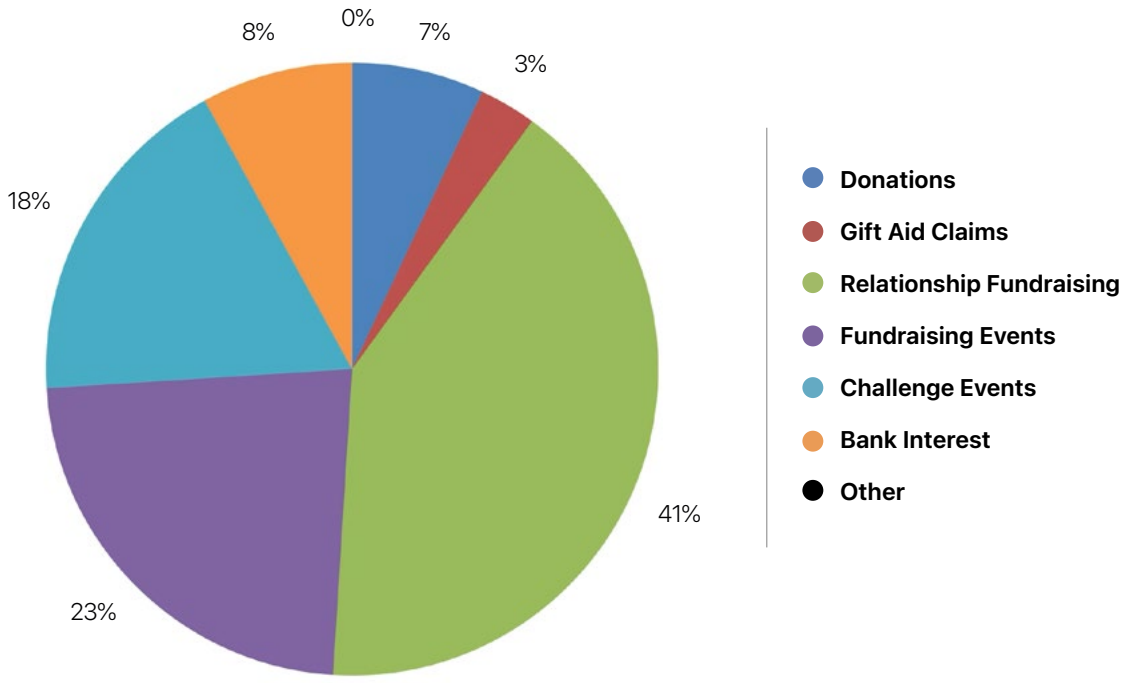
Raising Funds Responsibly

Action for A-T are registered with the Fundraising Regulator and are committed to upholding the code of fundraising practice. We receive all our funding from voluntary sources, including individuals, companies, trusts and foundations and we do not work with any professional fundraisers or commercial participators to raise funds on our behalf. Each year, we purchase places in several physical challenges as well as staging and benefiting from a series of other social and sporting events.

We want everyone we interact with to feel free from undue influence when they consider donating. Our in-house fundraising team are trained to recognise these signs, so they can manage conversations in a way that could be considered intrusive or putting repeated or undue pressure on someone to donate. We routinely monitor our fundraising materials to ensure our standards remain high and treat our supporters fairly. Supporter feedback is reviewed regularly to ensure our fundraising offer is appropriate and complies with relevant rules and regulations.

To help protect people in vulnerable circumstances, we continued to follow guidance from the Government and the Fundraising Regulator throughout 2024 and only carried out public fundraising when we considered it safe to do so. We also continued to speak to more supporters to make sure our high standards were maintained as we returned to normal activities following the pandemic.

The pie chart below shows the percentage splits of each of our areas of fundraising in 2024.



We would also like to record our thanks to all our volunteer committee members for their time and commitment in helping us achieve our mission, as well as everyone who donated their time, auction prizes and/or supported or participated in our events.

In addition to the above, we are also extremely grateful to the trusts and foundations who provided restricted funding for various research projects (these are listed on page 51). We are always keen to work with other trusts, foundations and corporate funders who might be interested in supporting our work.

Events Since the End of The Year

Information relating to events since the end of the year is provided in the notes to the financial statements.

Working Closely with Others to Meet our Objectives

Our Aim

Action for A-T strongly believes that there are many opportunities to further the search for a treatment or a cure for A-T through working with others that may have overlapping aims or objectives to our own. To this aim, we actively seek out like minded organisations and where possible, create collaborative partnerships.

Our Performance

Co-funding A-T Research Projects with other charities and patient organisations

Action for A-T continued to work closely with various organisations, charities, and patient organisations throughout 2024 to fund new and existing research studies. Throughout the year, we continued to manage a variety of our ongoing studies (funded in partnership with others) as well as contributing to new research. Our co-funding partners in 2024 were as follows:

The UK based Children's Charity GOSH

Action for A-T continued to work closely with GOSH charity as they were managing the following jointly funded research project which concluded in August 2024.

• "Optimising lung imaging in people with A-T" - Dr Peter Merkus at the Radboud University Medical Centre, Netherlands

The Australian charity BrAshA-T Ataxia Telangiectasia

Action for A-T have an ongoing collaborative funding partnership with BrAshA-T who are based in Queensland, Australia. Following a joint grant call in 2023 six new research studies were passed for funding and BrAshA-T agreed to contribute £200,000 towards the total cost of five of these projects. The first payment of £100,00 was made in December 2024 and the final payment of £100,000 will be made in the final quarter of 2025.

The UK based A-T Society

A strategic partnership was established between the A-T Society and Action for A-T in 2022 to increase the overall investment in new A-T research. Following the Action for A-T grant call in 2023 six new research studies were passed for funding and the A-T Society agreed to contribute £60,000 towards the total cost of three of these projects. The full payment of £60,000 will be made in the second quarter of 2025.

In addition, the A-T Society made their final contribution of £30,000 towards the five studies previously funded following the joint grant call in 2022. This payment was received in full in March 2024.

The Spanish based AEFAT

A strategic partnership was established between the AEFAT and Action for A-T in 2022 to increase the overall investment in new A-T research. Following the Action for A-T grant call in 2023 six new research studies were passed for funding and AEFAT agreed to contribute €40,000 towards the total cost of five of these projects. The first payment of €20,000 was made in December 2024 and the final payment will be made in the final quarter of 2025.

In addition, Action for A-T partnered with AEFAT to fund two research projects in Spain and Norway which began in January 2024. Action for A-T paid AEFAT £25,000 towards these projects at the end of 2023 and the remaining £25,000 will be paid in the first quarter of 2025.

The MRC Nucleic Acid Therapy Accelerator (NATA)

Our joint funding partnership with NATA was reconfirmed in 2024 and a grant round was opened calling for new nucleic acid therapies (NATs) related research applications. Both NATA and Action for A-T set aside £125,000 each to cover the full £250,000 cost of any new projects which

were deemed fundable by the RAC. Action for A-T managed the application and peer review process and one study totalling £249,615 was passed for funding. The 24-month study got underway in June 2024 and full details are available online https://actionforat.org/suppressor-trna-based-therapeutics/. The £125,000 contribution from NATA was received in full in August 2024.

Action for A-T will continue to explore additional joint funding opportunities with likeminded organisations throughout the coming year to maintain momentum and maximise the investment into A-T research.

Working strategically with the worldwide A-T community

The Global A-T Alliance is made up of charities and patient groups from the UK, USA, Spain, Israel, Japan, France, Turkey, Italy and Australia with the key objective of maximising the effort, resources and/or funding committed to finding a cure or treatments for Ataxia-Telangiectasia (A-T). The group meet virtually throughout the year to update each other on key research needs and findings as well as exploring ways in which they can work more closely together. To date, the Alliance members have jointly funded new research, met with a number of pharma companies to explore new treatment opportunities, delivered research focussed webinars for A-T families and established a new website www.cureAT.org which brings together useful information about A-T. The Alliance members passionately believe that with increased funding and a continued global and collaborative effort, effective treatments for A-T will be developed sooner and the lives of those affected will be changed for the better.

Increasing Awareness of our Work and the Condition

Our Aim

As an ultra-rare disease, most people are unaware of A-T or the devastating effects of the condition. Action for A-T believes that raising awareness of the studies they fund and the impact of A-T on children and their families is an important part of increasing the potential funds available to further improve the understanding of the condition, and to progress research into possible treatments or a cure.

Our Performance

Action for A-T has significantly increased the public awareness of the condition over the past 12 months and will continue to explore all options to promote wider understanding of A-T and why research to find a cure or treatment is so important.

The Charity's main achievements in this area to date include:

Celebrity Support

Our celebrity patrons have continued to help promote Action for A-T and the need for more research into the condition by championing campaigns and taking part in various activities throughout the year. As well as providing prizes for our auctions, Jonny Wilkinson created several short films which were shown at some of our events and attended the BGC trading day alongside Simon Shaw. Naga Munchetty hosted her annual golf day at Moor Park as well as the captains' charity day at Banstead Downs Golf Club and recorded a number of promotional event videos. Several other celebrities including Chris Sheasby, Leon Haslam, Kevin Whately, Phil Vickery, and Jeremy Guscott helped generate funds, awareness, and support by taking part in events and campaigns.

Visibility at Research Institutions, Conferences and Medical Meetings

All Action for A-T funded researchers are provided with promotional materials to display at their research facility and required to acknowledge our financial support by including our logo on any posters or presentations. Throughout 2024, several conferences and scientific meetings took place where our researchers were able to present their findings. These presentations showcased our latest projects and provided the wider A-T community with a comprehensive view of the progress made to date.

Digital Communications

The Charity website www.ActionforAT.org remains the focal point for event sign-ups, electronic donations, and research news. The site was updated and enhanced throughout the year to provide the best possible experience for our stakeholders.

We also continued to manage (alongside Mike Clahsen of BrAshA-T) the www.cureAT.org site which brings together key information about current & past research studies and resulting publications. The site also has sections on care and guidance, patient registries, general information about the condition and a directory of all the known patient organisations around the world. The content is available in several languages including Spanish, French, Italian and Turkish with a simplistic layout directing users

to sources of useful information (e.g., websites, documents, relevant groups/meetings, etc.) rather than duplicating existing content on other websites.

Our monthly e-newsletter continues to be a successful tool to communicate our latest news to supporters. Using Mailchimp for this proves to be cheaper than a traditional printed newsletter and has the functionality to track usage and monitor engagement. Our e-newsletter is sent to all our consenting supporters, has a clear unsubscribe function and inactive supporters are removed from the mailing list periodically.

Social media remains a key communication tool for the Charity as it is free, easily accessible and can reach wide audiences. It also allows us to engage with our supporters on a more strategic level and build additional support from their own contacts. Posts are carefully managed to ensure that the content is engaging and not repetitive and this more targeted and planned approach helped us increase our followers throughout the year. We will continue to develop our social media presence in 2025 using all available technological advancements, popular platforms, and our celebrity patrons to raise further awareness.

National and Local News Media Coverage

We continued to raise awareness of A-T through a series of articles and editorials in the local, national and industry press and various news websites. In addition, our chief executive and various supporters took part in local TV and radio interviews throughout the year. These helped us highlight the condition to new audiences, recruit volunteers and secure additional support and donations.

Our Future Plans: Areas of Focus for 2025

The Trustees believe that Action for A-T is well placed to meet its charitable objectives but have also identified the need for further development to strengthen its research activities.

During 2025 we will continue to consolidate and diversify our fundraising activities whilst actively developing existing and seeking new funding partnerships to meet the demands of the A-T research community. We will also continue to promote A-T research to engage new audiences and maintain interest from the research community.

We will implement several measures throughout the year to ensure that the Charity continues to be fit for future purpose and to help us achieve our aim of moving closer to tangible therapies or a cure for A-T.

Strengthening our Capacity and Capabilities

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us deliver our charitable objectives. Our size and structure enable us to adapt quickly, and we will continue to review and prioritise projects based on available resources whilst seeking out new opportunities to raise funds in a safe and sustainable manner.

Continuing our Investment in Medical Research in the UK and Abroad

We will continue to seek out new research opportunities from the wider research community as well as focussing on key research themes related to A-T. Where possible, priority will be given to UK based projects whilst still calling for international applications where funds will allow. Due to the significant investment in new research studies in 2024, our next full grant round is unlikely to reach its conclusion until early 2026.

Alongside the other members of the A-T Alliance, we will help to deliver the 2025 A-T Clinical Research Conference. The conference will be the first in-person clinical meeting since the Covid 19 pandemic and will bring together A-T researchers and clinicians from all over the globe. The conference will take place in June 2025 and is being staged within the Loughborough University complex.

We will maintain our close relationship with the Association of Medical Research Charities (AMRC) to develop and improve our peer review process and ensure that the research we fund is of the highest quality. We will take part in the AMRC Excellence in Peer Review audit in 2025 and hope to secure our 3rd award.

We will update our current RAC panel to a College of Experts model formed of scientific experts from all areas of A-T research and additional areas of scientific technical expertise. The new College of Experts will make recommendations for funding for A-T project grants, non-drug approaches and fellowship schemes. Membership of the new College of Experts will be continually reviewed to ensure that we have a broad range of scientific expertise in areas relating to A-T as well as early years researchers who are likely to become future research leaders. We will also secure new lay representation from various A-T families as Action for A-T strongly supports public and patient engagement in its research processes.

Strengthening and Increasing our Fundraising Activities

We will continue to develop a pipeline of new business opportunities whilst delivering our existing portfolio of activities. We will maintain and refresh our calendar of high profile and fun events whilst also working alongside others in a benefitting capacity to reduce the financial risk to the Charity. We will continue to develop and expand our trust and foundations programme whilst actively seeking new investment from individuals, corporates, and major donors. We will also work closely with our key supporters and volunteer groups to ensure we maintain the momentum of investment in ground-breaking A-T research.

Working Closely with Others to Meet our Objectives

We will also continue to work closely with key stakeholders (especially the A-T Alliance members) as well as exploring new collaborations that will bring greater benefit to the wider A-T community. The number of promising research opportunities continues to grow steadily year on year and there are now more research themes worthy of exploration than our limited funds will allow. We will therefore continue to work with and seek out new organisations with similar objectives to our own, to help ease the financial burden and speed up the process of finding a therapy or cure for A-T.

Increasing Awareness of our Work and the Condition

Since we were established in 2012, a key priority has been raising awareness of A-T and the work of the Charity. This has been achieved by various means including celebrity endorsement, emotive films featuring researchers and A-T families and various

branding opportunities. We will continue to do all that we can to highlight A-T whilst focusing on various key projects in 2025. These projects will include maximising celebrity endorsement opportunities, the creation of new promotional films and other projects which help to educate and inform people about A-T.

Board Composition

We will continue to evaluate the composition of our Trustee Board to facilitate the growth of the Charity and will consider further appointments to broaden and strengthen the Board's capabilities.

Structure, Governance & Management

Governing Document

Action for A-T is a charity registered in England and Wales (No. 1145303). The Charity is governed by the terms of its Trust Deed adopted on 6 January 2012 and as amended on 2 February 2012.

The Trustees have adopted the following policies and procedures for the recruitment, appointment, induction, and training of new Trustees:

Trustee Recruitment and Appointment

The Trustees listed on page 2 have overall responsibility for the strategic direction and effective governance of the Charity. Trustees are either elected or co-opted under the terms of the Trust deed and the total number of Trustees may not be fewer than five. If a vacancy occurs or a skills need is identified, new Trustees are recommended by the existing Trustees and interviewed by the Chairman and at least one other member of the board. Election is by majority vote and potential candidates must be over the age of eighteen and eligible to act. The Trustees will continue to evaluate the composition of the Board and will consider further appointments to broaden and strengthen the Board's capabilities to facilitate the growth of the Charity.

Trustee Induction and Training

New Trustees receive an induction pack containing a copy of the trust deed, strategy, relevant information about the Charity and its work; and a copy of the Charity Commission literature about the role and responsibilities of being a Trustee. New Trustees are also invited to meet the Chief Executive and team members to learn first-hand how the Charity operates on a day-to-day basis.

During the induction process, new Trustees are also told about the connected parties' rule, given a copy of the Charity's conflict of interest policy and asked to sign a Trustee declaration form. Where the Trustees have identified that there is a connection between the charity, or its Trustees and any third party with whom the Charity has dealt with, the Trustees will identify the relationship, and the amounts involved within the notes to the financial statements.

Organisational Structure

The Trustees meet formally four times per year and no business shall be conducted unless at least one-third of the total number of Trustees at the time, or two Trustees (whichever is greater) are present throughout the meeting. There are two meetings where the focus is on awarding grants for medical research and two meetings where Trustees review strategy and set operating plans and budgets. There is a review of operating and financial performance at every meeting. The Chief Executive is invited to attend all meetings of the Trustees, and the Head of Fundraising is invited to report on plans and progress at specific meetings.

While most of the business of the Charity is conducted at the scheduled Trustee meetings, there are occasional ad-hoc meetings to deal with matters of special interest and regular electronic meetings are held to review ongoing governance objectives.

The Board of Trustees delegates the exercise of certain powers in connection with the management and administration of the Charity as set out below. This is controlled by regular reporting back to the Board of Trustees so that all decisions made under delegated powers can be ratified by the full Board of Trustees in due course.

The charity considers its key management personnel to be the Trustees, Chief Executive, and senior management. Further details on remuneration are disclosed in Note 11 to the accounts.

Action for A-T is committed to the highest standards of ethical conduct in all its activities. The Trustees ensure that the charity operates with integrity, transparency, and accountability, complying with all relevant laws and regulations. While the charity's work does not typically involve high-risk environments, it maintains a zero-tolerance approach to corruption and bribery and upholds fundamental human rights principles in its partnerships and funding activities.

Research Advisory Committee

The Research Advisory Committee (RAC) is chaired by a member of the Board of Trustees. Members of the RAC have a broad range of scientific expertise in areas relating to A-T but are not generally active researchers in the field of A-T to minimise bias and conflicts of interest. There is also lay representation on the committee as Action for A-T supports public and patient engagement in its research processes. The Trustees are very grateful to all the members of the RAC for providing expert guidance and advice on a pro bono basis.

Chief Executive

The Chief Executive is responsible for the day-to-day management of the Charity's affairs and is assisted by a small executive team who act under his direction. As well as overseeing the operations of the Charity, the Chief Executive is also responsible for implementing policies as agreed by the Board of Trustees.

Employees, Volunteers and Contractors

The Charity aims to be an organisation where employees, volunteers and contractors enjoy a sense of fulfilment and where they feel supported and developed. All stakeholders are kept fully informed about the Charity's strategy and objectives, as well as day-to-day news and events. Individuals are encouraged to give their suggestions and views on performance and strategy.

The Charity supports equal opportunities, and a policy of recruitment and promotion based on aptitude and ability without discrimination is followed. Action for A-T is committed to the training, career development and promotion of all its employees. An individual's career development is assessed through annual appraisal and supervision. Training programmes are provided to meet any on-going needs, with the aim of developing individuals for both their current and their future roles.

Pay and Remuneration of Key Management Personnel

The Trustees' principles are to pay staff a fair salary that is competitive within the charity sector, proportionate to the complexity of each role, it's related funding and responsible in line with the charitable objectives. Pay levels for all employees are reviewed annually and any overall percentage increases are authorised by the Board of Trustees.

Remuneration for the Chief Executive is agreed by the Trustees. Salaries are benchmarked using external data available from pay surveys (for the voluntary sector and charities located in and around London) and market conditions for the specific role and the target is the market median averages of these.

Ultimately however, salary increases relate to the funding available for each role and whether the increase will be affordable in the long term. To ensure pay is fair for all roles we are committed to paying all our employees at or above the London living wage as determined by the Living Wage Foundation.

Engagement with Key Stakeholders

The charity recognises the importance of maintaining strong relationships with its key stakeholders, including funders, research institutions, beneficiaries, and partner organisations. During the year, we continued to work closely with medical research bodies and donor networks to ensure that our funding efforts align with the most impactful research opportunities. Trustees have actively engaged with stakeholders through regular meetings, reporting, and collaborative initiatives to advance our mission

Risk Management

The Trustees have introduced a formal risk management process to assess business risks and implement risk management strategies. This has involved identifying the types of risks the Charity faces, prioritising them in terms of potential impact and likelihood of occurrence, and identifying means of mitigating the risks.

As part of this process the Trustees have reviewed and are satisfied with the adequacy of the Charity's current internal controls and the costs of operating controls relative to the benefits obtained. Procedures have been established for reporting failings immediately to the Chief Executive and to the Board of Trustees.

It is recognised that internal controls can only provide reasonable but not absolute assurance that major risks have been adequately managed. In the opinion of the Trustees the key risks are:

- The loss of reputation due to error, or fraud.
- The loss of income due to error, or fraud.
- Insufficient numbers of Trustees or staff to allow the Charity to continue.
- Insufficient funds to allow the Charity to meet its objectives.
- Excessive reserves without justification deterring future donors and fundraisers.

In the opinion of the Trustees the policies and procedures are currently adequate to mitigate financial and reputation loss due to error or fraud whilst maintaining a viable future financially.

Financial Risk Management

The Trustees actively monitor financial risks to ensure the charity remains financially stable. The primary risks considered are:

Credit Risk: The charity relies on grants and donations from individuals, trusts, and corporate sponsors. While funders are carefully vetted, there remains a risk that committed funding may be delayed or not received. The charity mitigates this by diversifying income sources and maintaining close relationships with funders.

Liquidity Risk: To safeguard operations, the charity maintains reserves equivalent to six months of operating costs (£90,000). This allows flexibility to respond to financial uncertainties.

Cash Flow Risk: The timing of income receipts varies based on grant disbursements and fundraising cycles.

Trustees closely monitor cash flows to ensure financial obligations can be met in a timely manner.

Given the financial controls in place and the charity's reserves policy, the Trustees believe these risks are well managed and do not pose a material threat to the charity's ability to operate as a going concern.

Financial review

The Trustees are satisfied with the performance of the Charity and consider that the Charity is in an excellent position to continue its activities during the coming year, and the Charity's reserves are adequate to fulfil its current obligations.

Income

At present, research into A-T is heavily dependent on charitable donations and by extension, Action for A-T's ability to instigate, organise and facilitate the fundraising efforts of our supporters and donors. The principal source of funding is donations from individuals, companies, and proceeds of fundraising events.

Total income raised in 2024 was **£1,168,113 (2023 - £1,092,490)**.

Charitable Expenditure

The cost spent on Charitable Activities Was **£1,846,493 (2023 - £404,569)** of which **£1,584,289 (2023 – £139,427)** was for grants provided for funding of research projects.

The cost of generating voluntary income was **£90,523 (2023 - £87,806)** whilst the cost of generating income from charitable events was **£150,864 (2023 - £157,097)**

Governance costs of **£20,817 (2023 - £20,239**) were incurred.

General Funds

The Trustees will aim to make best use of any unrestricted funds, however they reserve the right to retain general reserves in hand until they can be used in the most efficient manner to further the objectives of the Charity. The Trustees are conscious that it should not provide funding for research where they have not been able to demonstrate that its use will offer the best opportunity to further the knowledge and treatment into A-T. Please refer to the investment policy with regard to those times where the Trustees believe general funds are in excess of the anticipated running costs of the Charity.

Designated Funds

Designated funds of **£nil** were brought forward from 2023. In 2024, **£nil** of funds were passed on to the research projects detailed in note 8 on page 40.

As at 31 December 2024 designated funds carried forward are **£nil**.

Restricted Funds

Restricted funds of **£38,021** were brought forward from 2023. During the year **£126,500** of restricted income was received against projects funded during 2024. During 2024, **£67,660** of funding was made to the research projects detailed in note 8 Page 40.

At 31 December 2024 restricted funds of **£96,861 (2023 - £38,021)** were carried forward and the Trustees are satisfied that the wishes of the donors were met fully. If further funds are received in the future the Trustees will ensure that those funds are used in accordance with those restrictions. Should it not prove possible to adhere to those instructions those funds will be offered back to the provider unless they indicate that they can be used for an alternative purpose.

Investment Policy

The overall policy of the Charity is to maintain a series of designated funds deposit accounts to ring-fence any funds which the Trustees have identified as being made available for specific research projects, or other charitable activities.

The Trustees recognise the need to review this policy on an annual basis and to look at other potential opportunities whilst appropriately monitoring the available funds and being proactive in their management, to ensure the best interests of the Charity's objectives are maintained.

Funds committed for research are paid out in arrears over the duration of the project. The trustees reviewed and agreed to deposit funds in timed deposit accounts in order to obtain the best return with minimal managed risk.

During the year the Trustees transfer any funds surplus to general running costs of the Charity into an interest-bearing account which will offer a higher rate of return than holding it in the main Charity bank account. The aim is to ensure that the fund is not diminished over time due to inflation and to ensure that these funds are invested in future research projects.

Reserves Policy

The Trustees review the reserves policy each year to ensure that all relevant risk areas are included in accordance with guidance issued by the Charity Commission. Risks included are the impact of unexpected, reduced income, and the potential impact of restructuring costs and liabilities required to downsize the organisation in an orderly manner, if a permanent income reduction was anticipated.

The review concluded that the existing reserve target level of Six months of operating costs (approx. £90,000) was sufficient to cover the risks identified in the review. This allows sufficient time for Trustees and management to take appropriate mitigating actions, if required.

The Trustees continue their commitment to develop and grow the level of investment in research into A-T, whilst maintaining a focus on managing the overall costs of the charity.

Going concern

The Trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern. The Trustees have given consideration to the Charity's long-term future and considered what risks (see the Trustees' Report) could result in a situation where a going concern basis was not appropriate. They believe that safeguards are sufficient to ensure that both in the short and medium term the assets and reputation of the Charity are sufficiently safeguarded to ensure that the Charity is a viable going concern.

Post Year End Events

The Trustees confirm that there have been no significant events since the year-end that would materially impact the financial position of the charity.

Statement of Trustees Responsibilities

The Trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of the incoming resources and application of resources of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in business.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the Charity and financial information included on the Charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Approved by order of the Board of Trustees on 14th May 2025 and signed on its behalf by:

Toby Read (Chairman)

Dated: 14th May 2025

William Rowberry (Treasurer)

Dated: 14th May 2025

Auditors Report

Independent Auditor's Report to the Trustees of Action for A-T

Opinion

We have audited the financial statements of Action for A-T Registered Charity Number: 1145303 (the 'charity') for the year ended 31 December 2024 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- Give a true and fair view of the state of the Charity's affairs as at 31 December 2024 and of its incoming resources and application of resources, for the year then ended;
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- Have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The Trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements, or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the Trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

1. Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

2. Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Charity's internal control.

3. Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Trustees.

4. Conclude on the appropriateness of the Trustee's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report.

5. Evaluate the overall presentation, structure, and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at **www.frc.org.uk/auditorsresponsibilities**. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the Charity's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Charity's Trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and the Charity's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

For and on behalf of A & N (Haslemere) Limited - Statutory Auditors
Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

Dated: 14th May 2025

Statement of Financial Activities

for the year ended 31 December 2024

	Notes	Unrestricted Funds £	Restricted Funds £	**31.12.24 Total Funds £**	31.12.23 Total Funds £
Income and Endowments from					
Donation and legacies	3	466,500	126,500	**593,000**	514,985
Charitable Activities	5				
Fundraising & challenge events		480,466	-	**480,466**	549,677
Investment income	4	94,647	-	**94,647**	27,828
Other income		-	-	**-**	-
Total		1,041,613	126,500	**1,168,113**	1,092,490
Expenditure on					
Raising funds	6	90,523	-	**90,523**	87,806
Charitable Activities	7				
Fundraising & challenge events		150,864	-	**150,864**	157,097
Grants	8	1,516,629	67,600	**1,584,289**	139,427
Governance costs		20,817	-	**20,817**	20,239
Total		1,778,833	67,600	**1,846,493**	404,569
Net Income / (Expenditure)		(737,220)	58,840	**(678,380)**	687,921
Reconcilliation of Funds					
Total Funds Brought Forward		876,704	38,021	**914,725**	226,804
Total Funds Carried Forward		139,484	96,861	**236,345**	914,725

Statement of Financial Position

for the year ended 31 December 2024

	Notes	Unrestricted Funds £	Restricted Funds £	**31.12.24 Total Funds £**	31.12.23 Total Funds £
Fixed Assets					
Tangible assets	18	216	-	**216**	216
Current Assets					
Stocks	19	20,863	-	**20,863**	18,985
Debtors	20	58,429	-	**58,429**	41,798
Cash at bank	21	2,219,988	96,861	**2,316,849**	1,929,861
		2,299,280	96,861	**2,396,141**	1,990,644
Creditors					
Amounts falling due within one year	22	(815,714)	-	**(815,714)**	(422,367)
Net Current Assets		1,483,566	96,861	**1,580,427**	1,568,277
Total Assets Less Current Liabilities		1,483,782	96,861	**1,580,643**	1,568,493
Creditors					
Amounts falling due within one year	23	(1,344,298)	-	**(1,344,298)**	(653,768)
Net Assets		139,484	96,861	**236,345**	914,725
Funds	25				
Unrestricted funds				**139,484**	876,704
Restricted funds				**96,861**	38,021
Total Funds				**236,345**	914,725

The financial statements were approved by the Board of Trustees and authorised for issue on 14th May 2025 and were signed on its behalf by:

Toby Read (Chairman)

Dated: 14th May 2025

William Rowberry (Treasurer)

Dated: 14th May 2025

Statement of Cash Flows

for the year ended 31 December 2024

	Notes	31.12.24 £	31.12.23 £
Cash flows from operating activities			
Cash generated from operations	1	**292,341**	273,723
Net cash provided by operating activities		**292,341**	273,723
Cash flows from investing activities			
Interest received		**94,647**	29,171
Net cash provided by investing activities		**94,647**	29,171
Change in cash and cash equivalents in the reporting period		**386,988**	302,894
Cash and cash equivalents at the beginning of the reporting period		**1,929,861**	1,626,967
Cash and cash equivalents at the end of the reporting period		**2,316,849**	1,929,861

Notes to the Statement of Cash Flows

for the year ended 31 December 2024

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

	31.12.24	31.12.23
	£	£
Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)	**(678,380)**	687,921
Adjusments for:		
Depreciation charges	-	-
Interest received	(94,647)	(29,171)
(Increase)/decrease in stocks	(1,878)	(11,235)
Decrease in debtors	(16,631)	(23,329)
Increase/(decrease) in creditors	1,083,877	(350,463)
Net cash provided by operations	**292,341**	273,723

2. Analysis of changes in net funds

	At 1.1.24	Cash Flow	**31.12.24**
	£	£	**£**
Net cash			
Cash at bank	1,929,861	386,988	2,316,849
	1,929,861	386,988	2,316,849
Total	**1,929,861**	**386,988**	**2,316,849**

Notes to the Financial Statements

For the Year Ended 31 December 2024

1. Accounting Policies

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS102, have been prepared in accordance with the Charities SORP (FRS102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011.

The financial statements have been prepared under the historical cost convention. The accounts are prepared in £ sterling to the nearest £1.

Action for A-T meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historic cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Accounting convention

The financial statements are prepared on a going concern basis, under the historic cost convention.

The Charity is entirely dependent on receiving income from fundraising and donations and as a consequence the going concern basis is also dependent on the continuation of such income.

Incoming resources

All incoming resources are included in the Statement of Financial Activities under FRS102 when that receipt is probable, whereas it was previously recognised when the Charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. For legacies, entitlement is the earlier of the Charity being notified of an impending distribution or the legacy being received.

Gifts in kind, including donated professional services are recognised as income when the Charity has control over them, any conditions associated with the donated item have been met, the receipt of economic benefit from the use of by the Charity if the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS102), the general volunteered time is not recognised and refer to the Trustees' Report for more information about this contribution.

On receipt, donated professional services are recognised on the basis of the value of the gift to the Charity which is the amount the Charity would have been willing to pay to obtain that service on the open market.

Gifts in kind donated for distribution are included at fair value upon receipt under FRS102 subject to the cost of recognition outweighing the benefit provided to Action for A-T. Previously they were included at a valuation and recognised as income when they are distributed. Any donated facilities are included at the value to the Charity where this can be quantified, and a third party is bearing the cost. No amounts are included in the financial statements for services donated by volunteers.

Resources expended

All expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs allocated to activities. Where costs cannot be directly attributed to particular activities, they have been allocated on a basis consistent with the use of the resources.

Overheads have been allocated on the basis of the activity income of the Charity.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of charitable activities. Support costs are those costs incurred directly in support of expenditure on the objects of the Charity and include project management carried out by the Trustees. Governance costs are those incurred in connection with the administration of the Charity and compliance with constitutional and statutory requirements.

Grants offered subject to conditions which have not been met at the year-end date are noted as a commitment but not accrued as expenditure.

Governance costs

Governance costs comprise all costs involving the public accountability of the Charity and its compliance with regulations and good practice. These costs include costs related to the audit, legal fees, and apportionment of overheads.

Allocation and apportionment of costs

Fundraising Events & Challenge Events costs are allocated in their income ratio during the year.

Tangible fixed assets

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

Computer equipment - 33% on cost

Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow-moving items.

Taxation

The Charity is exempt from tax on its charitable activities.

Fund accounting

General Funds

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

Restricted Funds

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors which have been raised by the Charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements. Any investment income, gains or losses are allocated to the appropriate fund.

Action for A-T has no designated funds as at 31st December 2024. All unrestricted funds remain available for general use at the discretion of the Trustees

Designated funds

Designated Funds are funds set aside by the Trustees out of general reserves for a particular purpose. The aim and use of each designated fund is set out in the notes to the financial statements. The Trustees will review the funds on an ongoing basis. At the conclusion of the purpose for the fund any excess remaining funds will be transferred back into general funds. If a shortfall arises the Trustees will consider whether any additional general funds should be transferred to designated funds. Any investment income, gains or losses are allocated to the appropriate fund.

Foreign currencies

Assets and liabilities in foreign currencies are translated into sterling at the rate of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling at the date of the transaction. Exchange differences if applicable are taken into the Statement of Financial Activities.

2. Critical accounting judgements and key sources of estimation uncertainty

Critical Accounting Estimates And Judgements

In the application of the Charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

1. Grant Commitments

The Charity awards grants to support research into Ataxia Telangiectasia. The recognition of grant commitments is based on formal agreements and the likelihood of meeting performance conditions. At 31 December 2024, grant commitments totalled £2,215,550 all of which have been recognised as a liabilities there are no awarded grants left unrecognised.

2. Provisions for Liabilities and Charges

The Charity reviews potential liabilities arising from ongoing contractual obligations. Where a liability is probable and can be reliably estimated, a provision is recognised. The Trustees have considered legal and contractual exposures and have determined that provisions of £12,960 are appropriate at the year-end (see note 24 on page 46).

3. Depreciation of Fixed Assets

The Charity depreciates tangible fixed assets over their estimated useful lives. The estimated useful life of assets is reviewed annually, with the current rates as follows:

- IT Equipment: 3 years
- Fixtures and Fittings: 5 years
- Leasehold Improvements: Over the remaining lease term

4. Accrued Income and Donations

The recognition of income from certain fundraising events and donations is based on an assessment of whether the income is probable and can be measured reliably. Estimates are applied where donations or pledges are confirmed but not yet received.

Key Sources Of Estimation Uncertainty

The annual depreciation charge for tangible fixed assets in sensitive to changes in the estimated useful economic lives and residual value of fixed assets. The useful economic lives and residual values are reassessed on an annual basis. They are amended where deemed necessary to reflect current estimations based on physical condition, utilisation and advancement of technologies. Note 10 discloses the carrying value if the tangible fixed assets and the depreciation policy is listed above in accounting policies.

3. Donations and Legacies

	Unrestricted Funds £	Restricted Funds £	**31.12.24 Total Funds £**	31.12.23 Total Funds £
Donations	78,147	-	**78,147**	91,706
Gift aid	31,837	-	**31,837**	35,530
Fundraising	356,516	126,500	**483,016**	387,749
	466,500	126,500	**593,000**	514,985

4. Investment Income

	Unrestricted Funds £	Restricted Funds £	**31.12.24 Total Funds £**	31.12.23 Total Funds £
Bank Interest	94,647	-	**94,647**	27,828

5. Income from Charitable Activities

	Activity	**31.12.24 £**	31.12.23 £
Fundraising events	Fundraising & Challenge events	**266,981**	323,820
Challenge events	Fundraising & Challenge events	**213,485**	225,857
		480,466	549,677

6. Raising Funds

	Unrestricted Funds £	Restricted Funds £	**31.12.24 Total Funds £**	31.12.23 Total Funds £
Staff costs	69,937	-	**69,937**	65,471
Trusts & Foundations	870	-	**870**	3,534
Support costs	19,716	-	**19,716**	18,801
	90,523	-	**90,523**	87,806

7. Charitable Activities Costs

	Direct Costs	Grant Funding of Activities (see note 8)	Support Costs (see note 9)	Totals
	£	£	£	£
Fundraising & Challenge events	131,146	-	19,718	**150,864**
Grants	-	1,518,335	65,954	**1,584,289**
Governance cost	-	-	20,817	**20,817**
	131,146	1,518,335	106,489	**1,755,970**

8. Grants Payable

	31.12.24	31.12.23
	£	£
Grants	**1,518,335**	74,683

The total grants paid to institutions during the year was as follows:

	31.12.24	31.12.23
	£	£
Universities of Birmingham, UK & Hamburg, Germany – Development of suppressor tRNA-based therapeutics	**249,615**	
University of Nottingham, UK – Biomarkers for babies and young children with A-T	**246,867**	
University of North Carolina, USA – Development of a gene therapy approach to treat A-T	**249,128**	
Leiden University Medical Centre, Netherlands – Functional impact of Nicotinamide Riboside on the immune system of patients with A-T	**250,000**	
University College London, UK – Exploring Omaveloxolone efficacy in A-T	**24,915**	
University of Birmingham, UK – Identifying existing drugs to repurpose for treating A-T	**249,332**	
University of Kent, UK – Investigating the role of mutant triple T chaperone in ATM assembly in A-T	**249,806**	
University of Cambridge, UK - Improving diagnosis and treatment of cancer in A-T patients through whole genome sequencing	**19,960**	
University of Nottingham, UK – Kicking Kinases into action: A novel drug screening assay for A-T	**19,238**	
University of Nottingham, UK – Exploring the use of assistive robots, smart sensing & digital twin models for monitoring and support of Ataxia in non-clinical environments	**19,997**	
University of Granada, Spain – (Research project underspends refunded) Innovative methods for gene therapy in Ataxia-Telangiectasia	**(6,044)**	

The total grants paid to institutions during the year (continued)

	31.12.24 £	31.12.23 £
University of Nottingham, UK – (Research project underspends refunded) The David Peake Study to test the feasibility of whole-body MRI for cancer surveillance in children and young people with A-T	**(13,208)**	
Sheba Medical Centre, Israel - Using new immunotherapy methods to treat lymphoma and leukaemia in A-T	**(10,408)**	
Duke University, USA - A new function for ATM and a new theory for the clinical abnormalities in A-T	**(4,440)**	
University of Rochester, USA - Recurrent pulmonary infections and their impact on neurological decline in A-T	**(8,334)**	
University of Plymouth, UK - The ATeam: Coproducing guidance and investigating a novel complex home-based intervention to optimise long-term healthy living with A-T	**(18,089)**	
University of Nottingham, UK - Virtual Reality in Ataxia-Telangiectasia		18,565
University of Nottingham, UK - STIM A-T Pilot Study		20,270
Institute for Bioengineering of Catalonia, Spain - Modelling Ataxia Telangiectasia pathogenesis and therapeutics using human pluripotent stem cells and genetic engineering		25,000
Oslo University Hospital, Norway - Preclinical assessment of intrathecal rAAV9-mediated miATM therapy for Ataxia Telangiectasia in mouse models		25,000
University of Birmingham, UK - (Research project underspends refunded) Assessment of the frequencies and types of cancers occurring in A-T patients		(14,986)
University of Birmingham, UK - (Research project underspends refunded) Deciphering the molecular mechanism linking Ataxia-Telangiectasia and Ataxia-Telangiectasia-Like Disorder		(29)
University of Nottingham, UK – Sandpit Event		863
	1,518,335	74,683

9. Support Costs

	Management	Finance	Information Technology	Other	Wages	Governance Costs	**Totals**
	£	£	£	£	£	£	**£**
Raising donations and legacies	8,555	636	1,332	9,193	-	-	**19,716**
Fundraising & challenge events	8,556	637	1,331	9,194	-	-	**19,718**
Grants	-	-	-	-	65,954	-	**65,954**
Governance costs	-	-	-	-	-	20,817	**20,817**
	17,111	1,273	2,663	18,387	65,954	20,817	**126,205**

Activity	**Basis of allocation**
Management	50 % Raising Donation & legacies 50 % Fundraising & Challenge Events
Finance	50 % Raising Donation & legacies 50 % Fundraising & Challenge Events
Information technology	50% Raising Donation & legacies 50 % Fundraising & Challenge Events
Human resources	50 % Raising Donation & legacies 50 % Fundraising & Challenge Events
Other	50 % Raising Donation & legacies 50 % Fundraising & Challenge Events
Governance costs	100% Governance cost

10. Auditors Remuneration

Fees payable to the charity's auditor for the audit of the financial statements: **£4,000 (2023: £4000).**
Fees payable for non-audit services: **£1,437 (2023: £1,412).**

11. Trustees' Remuneration and Benefits

There were no Trustees' remuneration or other benefits for the year ended 31 December 2024 nor for the year ended 31 December 2023.

Trustees' expenses
There were no Trustees' expenses paid for the year ended 31 December 2024 nor for the year ended 31 December 2023.

12. Staff Costs

Only one employee received emoluments in excess of **£60,000**.

The Charity considers its key management personnel to be the Trustees, Chief Executive and senior management. The total employment benefits of the key management personnel were **£165,951 (2023 - £156,996**). Only one employee had employment benefits falling between **£65,000** and **£80,000 (2023 - 1)**.

13. Comparatives for the Statement of Financial Activities

	Unrestricted Funds £	Restricted Funds £	**Total Funds £**
Income and endowments from			
Donations and legacies	501,985	13,000	**514,985**
Charitable activities			
Fundraising & challenge events	549,677	-	**549,677**
Investment income	27,828	-	**27,828**
Other income	-	-	**-**
Total	1,079,490	13,000	**1,092,490**
Expenditure on			
Raising funds	87,806	-	**87,806**
Charitable activities			
Fundraising & challenge events	157,097	-	**157,097**
Grants	78,962	60,465	**139,427**
Governance costs	20,239	-	**20,239**
Total	344,104	60,465	**404,569**
Net income/(expenditure)	735,386	(47,465)	**687,921**
Reconciliation of funds			
Total funds brought forward	141,318	85,486	**226,804**
Total funds carried forward	876,704	38,021	**914,725**

14. Employee Benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits would be recognisable immediately as an expense when the Charity is demonstrably committed to terminate an employee's employment or to provide termination benefits.

15. Pension Costs

The charity participates in a defined benefit pension scheme. The pension costs charged in the financial statements represent the contributions payable by the Charity during the year.

At the reporting date, there was no material pension liability or asset that would impact the financial position. The scheme is fully funded, and no additional contributions are required beyond regular employer contributions.

The charity has no pension commitments for past trustees, as all trustees remain in office.

16. Financial Instruments

The Charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and are subsequently measured at their amortised cost.

17. Creditors and Provisions

Creditors and provisions are recognised where the Charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

18. Tangible Fixed Assets

	Computer Equipment £
Cost	
At 1 January 2024 and 31 December 2024	2,358
Depreciation	
At 1 January 2024 and 31 December 2024	2,142
Net Book Value	
At 31 December 2024	216
At 31 December 2023	216

19. Stocks

	31.12.24	31.12.23
	£	£
Stocks	**20,863**	18,985

Stocks are stated at the lower of cost and estimated selling price less costs to complete and sell. Cost includes all costs of purchase, costs of conversion and other costs incurred in bringing stock to its present location and condition. Due allowance is made for obsolete and slow-moving items.

Donated stocks are fair valued when their economic benefit is probable, it can be measured reliably, and the Charity has control over the item.

20. Debtors: Amounts Falling Due Within One Year

	31.12.24	31.12.23
	£	£
Deposit	**925**	925
Prepayments and accrued income	**57,504**	40,873
	58,429	41,798

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

21. Cash at Bank

	Unrestricted Funds	Restricted Funds	**31.12.24 Total Funds**	31.12.23 Total Funds
	£	£	**£**	£
Bank Current Accounts	38,193	-	**38,193**	46,480
Bank Current Accounts (US $)	-	-	**-**	-
Reserve Account	622,250	96,861	**719,111**	410,848
Investment Accounts	1,559,545	-	**1,559,545**	1,472,533
Total	2,219,988	96,861	**2,316,849**	1,929,861

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of twelve months or less, and bank overdrafts. Should any bank overdrafts arise they would be shown within borrowings in current liabilities.

22. Creditors: Amounts Falling Due Within One Year

	31.12.24 £	31.12.23 £
Grant Payable	**810,729**	415,417
Accruals and deferred income	**4,985**	6,950
	815,714	422,367

23. Creditors: Amounts Falling Due After More Than One Year

	31.12.24 £	31.12.23 £
Other creditors	**1,344,298**	653,768

24. Leasing Agreements

During the next twelve months the Charity has operating lease commitments totalling **£13,014 (2023 - £12,485)** for contracts expiring in more than one year. The total future commitments are **£12,960 (2023 - £12,960)**

25. Movement in Funds

	At 1.1.24 £	Net Movement in Funds £	**At 31.12.24 £**
Unrestricted Funds			
Unrestricted Fund	876,704	(737,220)	**139,484**
Restricted Funds			
Restricted Fund	38,021	58,840	**96,861**
Total Funds	914,725	(678,380)	**236,345**

Net movement in funds, included in the above are as follows:

	Incoming Resources £	Resources Expended £	**Movement in Funds £**
Unrestricted Funds			
Unrestricted Fund	1,041,613	(1,778,833)	**(737,220)**
Restricted Funds			
Restricted Fund	126,500	(67,660)	**58,840**
Total Funds	1,168,113	(1,846,493)	**(678,380)**

Comparatives for movement in funds:

	At 1.1.23 £	Net Movement in Funds £	**At 31.12.23 £**
Unrestricted Funds			
Unrestricted Fund	141,318	735,386	**876,704**
Restricted Funds			
Restricted Fund	85,486	(47,465)	**38,021**
Total Funds	226,804	687,921	**914,725**

Comparative net movement in funds, included in the above are as follows:

	Incoming Resources £	Resources Expended £	**Movement in Funds £**
Unrestricted Funds			
Unrestricted Fund	1,079,490	(344,104)	**735,386**
Restricted Funds			
Restricted Fund	13,000	(60,465)	**(47,465)**
Total Funds	1,092,490	(404,569)	**687,921**

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.1.23 £	Net Movement in Funds £	**At 31.12.24 £**
Unrestricted Funds			
Unrestricted Fund	141,318	(1,834)	**139,484**
Restricted Funds			
Restricted Fund	85,486	11,375	**96,861**
Total Funds	226,804	9,541	**236,345**

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming Resources £	Resources Expended £	**Movement in Funds £**
Unrestricted Funds			
Unrestricted Fund	2,121,103	(2,122,937)	**(1,834)**
Restricted Funds			
Restricted Fund	139,500	(128,125)	**11,375**
Total Funds	2,260,603	(2,251,062)	**9,541**

26. Related Party Disclosures

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2023 - £nil). There are no expenses paid to the Trustees in the year. No Trustee is deemed to have benefited as a result of a related party connection. All Trustees have declared all such relationships to the Chairman.

27. Ultimate Controlling Party

The Trustees control Action for A-T in accordance with the trust deed.

Detailed Statement Of Financial Activities

For the year ended 31 December 2024

	Unrestricted Funds £	Restricted Funds £	**31.12.24 Total Funds £**	31.12.23 Total Funds £
Income and Endowments from				
Donations and legacies				
Donations	78,147	-	**78,147**	91,706
Gift aid	31,837	-	**31,837**	35,530
Fundraising	356,516	126,500	**483,016**	387,749
	466,500	126,500	**593,000**	514,985
Investment Income				
Bank Interest	94,647	-	**94,647**	27,828
Charitable activities				
Fundraising events	266,981	-	**266,981**	323,820
Challenge events	213,485	-	**213,485**	225,857
	480,466	-	**480,466**	549,677
Other Income				
Exchange rate difference	-	-	**-**	-
Total Incoming Resources	1,041,613	126,500	**1,168,113**	1,092,490
Expenditure				
Raising donations and legacies				
Wages	69,937	-	**69,937**	65,471
Trusts and Foundations	870	-	**870**	3,534
	70,807	-	**70,807**	69,005
Charitable activities				
Event Campaign Costs	131,146	-	**131,146**	138,063
Grants to institutions	1,450,675	67,660	**1,518,335**	74,683
	1,581,821	67,660	**1,649,481**	212,746
Support Costs				
Management				
Wages	17,111	-	**17,111**	16,264
Finance				
Bank charges	1,273	-	**1,273**	1,310
Information technology				
Repairs and renewals	2,663	-	**2,663**	2,647

Detailed Statement Of Financial Activities (Cont)

For the year ended 31 December 2024

	Unrestricted Funds £	Restricted Funds £	**31.12.24 Total Funds £**	31.12.23 Total Funds £
Other				
Rent, Rates and water	13,672	-	**13,672**	13,014
Insurance	947	-	**947**	1,115
Telephone	544	-	**544**	693
Postage and stationery	372	-	**372**	480
Sundries	679	-	**679**	526
Advertising	1,022	-	**1,022**	887
Donation collection fees	1,151	-	**1,151**	899
	18,387	-	18,387	17,614
Wages				
Wages	65,954	-	65,594	64,744
Governance Costs				
Wages	15,380	-	**15,380**	14,827
Auditors' remuneration	4,000	-	**4,000**	4,000
Accountancy and legal fees	1,437	-	**1,437**	1,412
Computer equipment	-	-	**-**	-
	20,817	-	20,817	20,239
Total Resources Expended	1,778,833	67,660	1,846,493	404,569
Net (expenditure)/income	(737,220)	58,840	(678,380)	687,921

Acknowledgements

Action for A-T relies entirely on its donors and supporters who so generously give their time and money to support vitally needed research into A-T. With their support we believe we can make a difference to all people with A-T and their families.

We would like to give special thanks to the following organisations that worked alongside us in 2024:

Our Research Partners

BrAshA-T Ataxia Telangiectasia and their Trustees
Ataxia Telangiectasia Society
AEFAT
Great Ormond Street Hospital Charity
NATA

Support from Companies, Trusts & Foundations

We are aware that Companies, Trusts & Foundations are often approached to support charities and are therefore extremely grateful to the following organisations and individuals for their generous support.

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Banstead Downs Golf Club
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Our Supporters

We have relied almost exclusively on our supporters, volunteers and Trustees for their time and commitment to raising money and spreading awareness about this devastating condition. Thank you to everyone who has helped us to push research into A-T forwards.

ACTION FOR A-T

FUNDING RESEARCH, FINDING HOPE

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