

**ACTION  
FOR A-T**

**FUNDING  
RESEARCH,  
FINDING HOPE**



## **Annual Report & Financial Statements**

**for the year ended 31st December 2023**

Action for A-T - Charity registered number 1145303

[www.ActionforAT.org](http://www.ActionforAT.org)



## Legal And 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  
 Dr Mark Toms  
 Joseph Frost

### Appointed during the year or since year end

None

### Research Advisory Committee

Dr Mark Toms, Chairman  
 Dr Kathryn Johnson, Scientific Advisor, Consultant Neonatologist and Research Lead  
 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  
 Bruno Salomone Gonzalez de Castejon, Research Associate, Bristol Medical School (THS)  
 Dr Richard Kay, Medical Statistician  
 Dr Nizar Mahlaoui, Paediatrician specialising in Immuno-Haematology, Necker-Enfants Malades Hospital, Paris and Coordinator of the French National Reference Centre for Primary Immune Deficiencies (CEREDIH)  
 Dr Guy Makin, Senior Paediatric Oncology Lecturer, University of Manchester  
 Dr Andrew Prayle, Clinical Assistant Professor, University of Nottingham  
 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

### Operational Address

Action for A-T  
 Carlton House  
 19 West Street  
 Epsom  
 Surrey  
 KT18 7RL

### Professional Advisers

Solicitors  
 Bingham McCutchen LLP  
 41 Lothbury  
 London  
 EC2R 7HF

### Bankers

HSBC Bank  
 110 High St  
 Godalming  
 Surrey  
 GU7 1DP

### Accountants & Auditors

A & N (Haslemere) Limited  
 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 of Action for A-T for the year ended 31 December 2023.*

The Trustees present their report with the financial statements of the charity for the year ended 31 December 2023. The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

## 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, October, and December in 2023. 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).

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 7 to 12.

Our Trustees have considered how our work may most effectively further our charitable objectives for the benefit of the public, in particular all those affected by Ataxia Telangiectasia, and have had regard to the Charity Commission's guidance on public benefit when reviewing activities against objectives set and in planning future activities.

## 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 2023:

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

## Strengthening our Capacity and 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 infrastructure 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

2023 was our most successful fundraising year to date as we were able to deliver a full portfolio of events and activities without any of the previous Covid restrictions. Various new events were introduced alongside existing activities and 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 and allowed us to scale up many of the activities to increase the amount of funds raised. Many of these successful activities were data led as the previous investment in a good CRM system enabled us to reach key target audiences and manage relationships more effectively.

We continued to explore and implement new technologies to improve our fundraising and communicate with our stakeholders. We also upgraded our IT infrastructure to incorporate the latest 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, no cost extensions were granted as some studies were experiencing 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 and 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 2023, our Chief Executive staged online 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 were able to support four new research studies throughout 2023 thanks to a new technology-based grant round calling for proof of concept style studies and a collaboration with the Spanish based A-T charity AEFAT. In addition to investing £88,835 in four new studies, we also opened a new grant round in September 2023 in collaboration with NATA (Nucleic Acid Therapy Accelerator) and BrAshA-T (Australian based A-T charity) with a view to awarding grants in April 2024.

## 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 £4,073,550 in 50 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 and Diagnosis** - Tests for diagnosing and monitoring patients with A-T

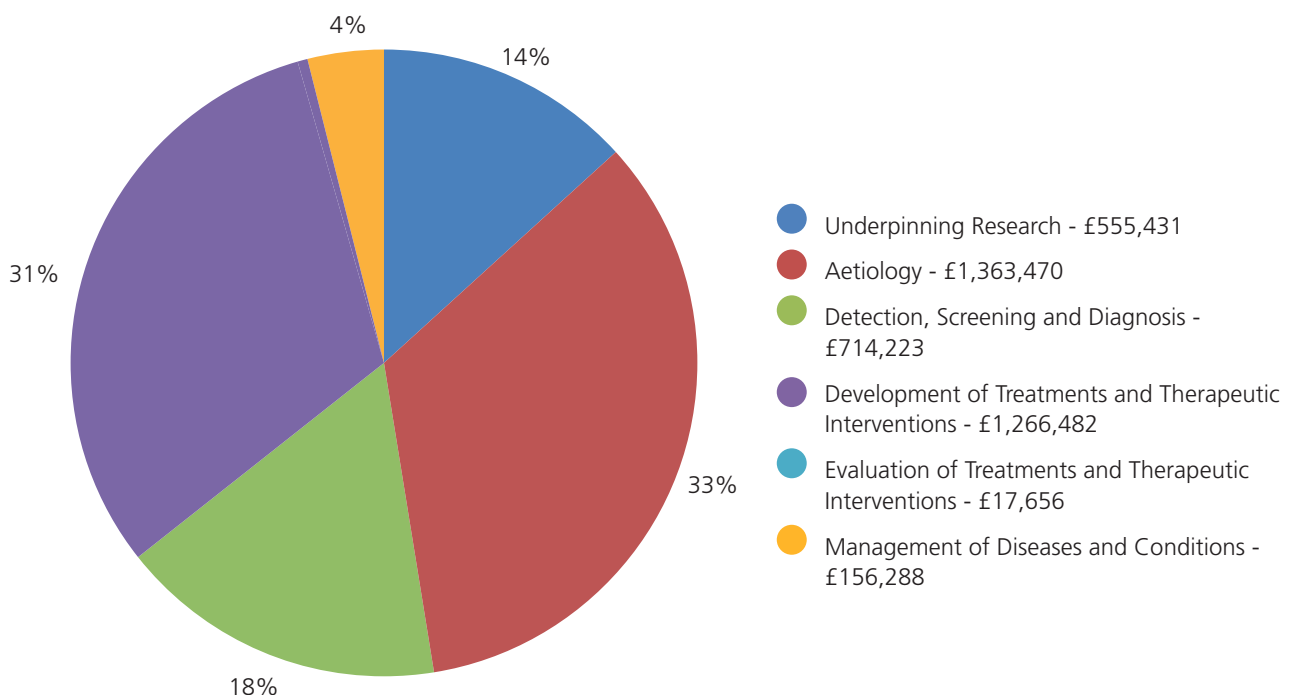
**Development of Treatments and Therapeutic Interventions** - Studies to identify new treatments for A-T

**Evaluation of Treatments and Therapeutic Interventions** - Studies to prove how new treatments work and understand how to use them

**Management of Diseases and Conditions** - Managing the symptoms of A-T

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

### Total Research Spend Since 2012



The following grants were awarded by the Trustees in 2023:

## STIM A-T Pilot Study

**Principal Researcher:** Dr Caroline Blanchard  
**Institute:** Medicine, Clinical Neuroscience, Nottingham University  
**Cost:** £20,270 over 6 months  
**Start Date:** 1st of September 2023

### Project Overview



Dr Caroline Blanchard

Dr Blanchard and her team will conduct a pilot study called STIM A-T to explore a new approach for reducing involuntary movements in people with ataxia-telangiectasia (A-T). These movements, such as muscle spasms and tremors, greatly affect their daily activities and quality of life and current treatment options are limited, so they are looking for non-invasive alternatives. Recent groundbreaking research has shown that stimulating a nerve in the wrist called the median nerve can reduce motor tics in Tourette syndrome. The team will see if this method can also help to reduce unwanted involuntary movements in individuals with A-T.

This study has the potential to make a significant difference in the lives of people with Ataxia-Telangiectasia (A-T). By exploring the feasibility and effectiveness of Median Nerve Stimulation (MNS) as a non-invasive treatment, this study aims to provide new hope and potential relief for these individuals. If successful, MNS could offer a non-pharmacological approach to suppressing unwanted movements in A-T. This would be a groundbreaking development, as there are no good treatment options currently. By demonstrating the feasibility and tolerability of MNS, along with preliminary evidence of its effectiveness, this research could pave the way for larger clinical trials.

Ultimately, the findings of this study could lead to improved management of involuntary movements in people with A-T, enhancing their ability to perform daily tasks, engage in social interactions, and improve overall quality of life.

## Virtual Reality in Ataxia-Telangiectasia

**Principal Researcher:** Professor Philip Breedon  
**Institute:** Science and Technology Department, Nottingham University  
**Cost:** £18,565 over 6 months  
**Start Date:** 1st of July 2023

### Project Overview



Professor Philip Breedon

Professor Breedon and his team are embarking on a research project to explore how Virtual Reality (VR) technology can benefit children and young adults with Ataxia-Telangiectasia (A-T). By creating a virtual world through VR, they can provide A-T patients with interactive games, exercises, and rehabilitation activities. This immersive experience not only keeps people mentally engaged but also helps slow down the decline of their physical abilities. VR systems are versatile and adaptable, allowing them to be easily incorporated into the patients' daily lives. Parents can acquire the VR equipment for home use, or the systems can be set up in local clinics, making it convenient and accessible for patients in between visits to specialized centres. The team believe that Virtual Reality (VR) technology can bring about significant improvements in the lives of children with Ataxia-Telangiectasia (A-T). Currently, these children face challenges in accessing specialized care due to limited availability of A-T centres in the UK. This creates complexity and high costs for patients and their families. To address this, they aim to utilize VR as an accessible and engaging solution.

The VR system in this study could make a real difference in the lives of people with Ataxia-Telangiectasia (A-T) as the VR system has the potential to improve physical and mental well-being, provide convenient care, and enhance social interactions for people with A-T, making a positive impact on their daily lives.

## Modelling Ataxia Telangiectasia pathogenesis and therapeutics using human pluripotent stem cells and genetic engineering

**Principal Researcher:** Dr Núria Montserrat

**Institute:** Institute for Bioengineering of Catalonia, Spain

**Cost:** €150,000 over 24 months in partnership with AEFAT (Spain). Our contribution £25,000

**Start Date:** 1st of January 2024

### Project Overview



Dr Núria Montserrat

A-T is caused by mutations in the ATM gene. The most debilitating symptom of the condition is the progressive neurodegeneration of the cerebellum. Those with A-T also have a higher chance of developing cancer. The molecular mechanisms driving neurodegeneration and cancer susceptibility remain unclear, due to limitations of current disease models. The team aim to generate ATM-defective human pluripotent stem cell lines (hPSCs) via CRISPR/Cas9\* as a disease model for A-T. A-T will be studied in this model. The team will carry out work to validate their model as a drug-screening platform by identifying several compounds that improve cell survival of ATM-defective hPSCs and differentiated products. They also hope to identify predictive biomarkers for A-T patients.

This project aims to explore the impact of ATM mutations by testing ATM protein expression in patient cells. This will be crucial for the generation of unique cellular models capturing A-T genetic backgrounds via genetic engineering in human pluripotent stem cells and organoids. If successful, this will be a unique in vitro platform and will enable the team to study A-T cellular phenotypes and potential therapeutics. This is very early-stage research, but the aim is to understand how to mitigate and alleviate the effects of A-T to move to ultimately developing a curative option.

*\*CRISPR/Cas9 is a gene-editing technology. It makes it possible to correct errors in the genome and turn on or off genes in cells and organisms quickly, cheaply and with relative ease. CRISPR/Cas9 has potential to be used to treat genetic disorders caused by single gene mutations, like A-T.*

## Preclinical Assessment of Intrathecal rAAV9-Mediated miATM Therapy for Ataxia Telangiectasia In Mouse Models

**Principal Researcher:** Professor Hilde L. Nilsen

**Institute:** Oslo University Hospital, Norway

**Cost:** €150,000 over 24 months in partnership with AEFAT (Spain). Our contribution £25,000

**Start Date:** 1st of January 2024

### Project Overview



Professor Hilde L. Nilsen

This preclinical study utilizes an injection of Recombinant Adeno Associated Virus 9 (rAAV9) to deliver a therapeutic mini version of ATM into mice. ATM is the gene missing or not functioning completely in A-T. The aim is to provide safety and efficacy data for the rAAV9 mini-ATM therapy to be able to proceed to phase I/II clinical trials. Efficacy meaning how well the injection delivers the mini-ATM into the mice and if it produces the expected result. Measurements will be conducted to observe survival, motor function, weight gain, and histopathological changes. A range of further comprehensive examinations, observations and measurements will be implemented including those to monitor signs of toxicity, tumour development, and organ damage. Particular attention will be given to the cerebellum and liver damage as it is commonly affected in AAV therapies\*. This approach aims to provide valuable insights into the safety and potential use of this therapy as a treatment for A-T.

It is hoped that this preclinical study may pave the way for transformative treatments for individuals suffering from A-T in the long-term\*. The utilization of this gene therapy to deliver a therapeutic mini version of ATM could potentially rectify the underlying genetic defects associated with the disease and may alleviate symptoms. If successful, this could lead to a significant improvement in the quality of life for A-T patients.

*\*AAV therapies - 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. Adeno-associated viral (AAV) vector is a platform for delivering gene therapies. These vectors introduce therapeutic genes into patient cells to treat diseases.*



## 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 Aim

Through our award-winning research process, we aim to only fund projects of the highest-quality that have the greatest chance of advancing our understanding of A-T, improving treatment and management, and accelerating benefits to patients.

### 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 2023 and their funding recommendations were passed on to the Trustees for consideration. All four 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 2023 and the initial project outcomes were as follows:

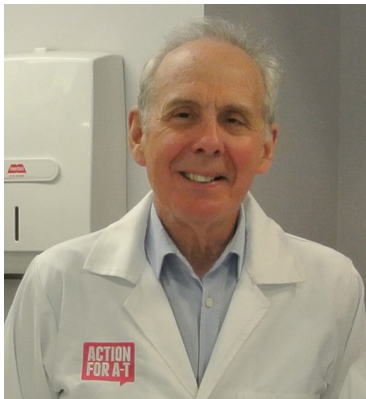
## Assessment of the frequencies and types of cancers occurring in A-T patients

**Principal researchers:** Professor Malcom Taylor

**Institute:** University of Birmingham

**\*Project Completion Date:** 31st March 2023

### Project Overview



Professor Malcom Taylor

The primary aim of the project was to identify the cancers present in Ataxia Telangiectasia patients alive today in ~200 families in the UK as well as those who had passed away in the past 10 years. The team looked at past and present families affected and families were given the opportunity to opt out of their data being shared. The records of 48 A-T individuals in the UK were studied and of these 48 there was a total of 52 tumours.

### Project Outcome

33 of the tumours occurred in 31 patients with classic A-T. 18 of these were lymphoid tumours and 15 non-lymphoid. Of the 15 non-lymphoid tumours, 14 were carcinomas. This data revealed that the median age for diagnosis of the tumour in classic A-T patients was 14–15-years old. 19 of the tumours were identified in 17 patients with a mild variant of A-T. 4 of these were lymphoid and 15 non-lymphoid. This data revealed that the median age for diagnosis of the tumour in mild variant A-T patients was 38 years old.

With respect to the types of tumour identified, 17 out of the 20 children (under the age of 16 years old) had lymphoid tumours. Plus the following:

- 28 Carcinomas, 14 in classic A-T and 14 in mild variant A-T. 3 of these were pancreatic tumours in mild variant A-T.
- 6 Esophageal tumours (5 in classic A-T). This appears to be a new observation.
- There were at least 5 breast cancers and 2 myeloid tumours.

The data confirms the increased risk of cancer in both classic and mild variant A-T but the team identified a difference in the spectrum of tumours between them. The spectrum of tumour types in UK patients reflects the ATM mutation types seen in UK A-T patients.

This work will help to support future decision making in clinical practice and assist other research groups looking to make early cancer diagnoses.

### Publications

A manuscript is currently being prepared.

## Deciphering the molecular mechanism linking Ataxia-Telangiectasia and Ataxia- Telangiectasia-Like Disorder

**Principal Researcher:** Professor Grant Stewart

**Institute:** University of Birmingham

**\*Project Completion Date:** 5th of October 2023

### Project Overview



Professor Grant Stewart

Individuals with Ataxia-Telangiectasia (A-T) and the related disorder Ataxia-Telangiectasia-Like Disorder (ATLD), which are caused by mutations in the ATM gene and MRE11 gene respectively, suffer from progressive degeneration of the cerebellum (the region of the brain that is responsible for coordinating voluntary muscle movements and regulating balance). The aim of this project was to gain a further understanding of the DNA repair deficiencies that are responsible for this neurodegeneration and to pinpoint what type(s) of DNA damage are involved.

### Project Outcome

A unique ATLD patient with a mutation in the Mre11 protein was studied in this project to understand the cellular processes in cell death in the cerebellum in more detail. The team acknowledged at the outset this is basic research and therefore would not have a medium- or short-term impact on individuals and families affected by A-T / ATLD.

The project had the following objectives:

- Identify and characterise the cellular defect/s present in ATLD cells with the MRE11 mutation.
- Investigate the cellular defects in 15 ATLD cell lines
- Investigate the impact of the pM26T mutation on MRE11 function.
- Define the nature of the TOP2 DSB repair defect in cells carrying the mutation.

The first objective demonstrated that the inability in the ATLD patient to repair DNA damage in the presence of the MRE11 mutation was not due to defects in ATM activation. Secondly, in the 15 ATLD cell lines available the team have demonstrated that inability to activate ATM is not a common cellular phenotype in ATLD.

The pM26T mutation was not shown to have any deleterious effect on its ability to activate ATM. However, this may have been due to the techniques used and work is ongoing to modify this.

The team found no evidence that the ATLD cells expressing the mutation demonstrated any defects in the repair of DNA breaks. Work is ongoing on this third objective.

Although the initial hypothesis was disproved, this research has delivered some useful information which could be built into future projects. Some work is still ongoing and therefore there are no current plans to publish.

### Publications

No publications are planned at this date

# The David Peake Study to test the feasibility of whole-body MRI for cancer surveillance in children and young people with Ataxia Telangiectasia

**Principal Researcher:** Professor Rob Dineen

**Institute:** University of Nottingham

**Project Completion Date:** 30th of September 2023

## Project Overview

Dr Rob Dineen and his team believed that the combination of an MRI scan of the whole body together with a blood test would be a good way to find hidden cancers in children and young people with the inherited disease Ataxia Telangiectasia (A-T).

## Project Outcome



Professor Rob Dineen

18 children with A-T were recruited to take part in the study and 16 successfully completed the MRI scans. Two very young children were not willing to go in the MRI scanner despite play preparation and audiovisual distraction. During the scans, no malignancies were found which is obviously very good for the participants and their families, but it does mean that the team do not have any preliminary evidence of efficacy of this approach.

Non-cancer findings were identified in 4 children. Granulomas were identified in two (one localized, one disseminated requiring further investigations and biopsy). Two children had localized sub-cutaneous edema, which on further questioning turned out to be due to recent injections. One of these children also had altered bone marrow signal at a single bone site, for which further investigations at the local hospital were recommended.

The team also interviewed adults with A-T and parents of children with A-T to find out their views on cancer screening, and for those whose children had the scan, how they found the experience. They learned that the possibility of cancer caused anxiety and a screening programme would be welcomed because it would mean the families weren't the only ones watching out for the development of a cancer. As well as working with families, the team also worked with A-T experts to get their views on cancer screening, and there was strong support for doing more research so that guidelines can be put in place.

Although this study will not immediately change clinical practice, the team have shown that their approach is feasible and supported by patients, families, and clinical A-T experts around the world. They are now planning a follow-on trial which will seek preliminary evidence of efficacy of the approach and in turn hopefully trigger a large, definitive international trial. They are currently applying to the NIHR for funding for the next stage as considerable investment will be required.

In addition, the work has raised further awareness of the current evidence and knowledge gaps regarding cancer screening in A-T and has stimulated several exiting new collaborations in this area.

## Publications

Neves R, De Dios Perez B, Panek R, Jagani S, Wilne S, Bhatt JM, Caputi C, Cirillo E, Coman DJ, Dückers G, Gilbert DL, Kay Koenig M, Mansour L, McDermott E, Pauni M, Pignata C, Perlman SL, Porras O, Betina Porto M, Schon K, Soler-Palacin P, Nick Russo S, Takagi M, Tischkowitz M, Wainwright C, Dandapani M, Glazebrook C, Suri M, Whitehouse WP, Dineen RA. Development of cancer surveillance guidelines in Ataxia Telangiectasia: A Delphi-based consensus survey of international experts. *Cancer medicine*. 2023 Jul;12(13):14663-14673. doi: 10.1002/cam4.6075

Neves R, Perez BD, Tindall T, Fernandez NS, Panek R, Wilne S, Suri M, Whitehouse W, Jagani S, Dandapani M, Dineen RA, Glazebrook C. Whole-Body MRI for cancer surveillance in Ataxia Telangiectasia: A qualitative study of the perspectives of people affected by A-T and their families. *Health Expect*. 2023 Jun;26(3):1358-1367. doi: 10.1111/hex.13756

Dineen R. Whole-body MRI for cancer surveillance in children and young people with Ataxia Telangiectasia: Protocol for mixed methods cross-sectional interventional feasibility study. Nottingham Research Data Management Repository. <http://doi.org/10.17639/nott.7288>

The team also have three other manuscripts in draft as follows:

Neves R, Panek R, Clarkson K, Panagioti O, Wilne S, Suri M, Whitehouse WP, Jagani S, Dandapani M, Glazebrook C, Dineen RA. Feasibility of whole-body MRI for cancer surveillance screening in children and young people with Ataxia Telangiectasia: a mixed methods cross-sectional study.

Stephens M, Bourigault E, Neves R, Panek R, Suri M, Fairbank J, Ather S, Jamaludin A, Dineen RA. Feasibility of AI-based quantification of scoliosis using MRI in ataxia telangiectasia: a novel ionising radiation free approach in a disease with increased radiosensitivity.

Kumasaka S, Panek R, Neves R, Jagani S, Suri M, Dineen RA. MRI-based quantification of liver fat deposition in ataxia telangiectasia.

To view all our current and complete research projects, please visit <https://actionforat.org/category/research-projects-funded/>



## Investing in People as well as projects

### Our Aim

As the A-T research community is relatively small in comparison to other disease areas, a pipeline of new talent is required to continue the quest for treatments or a cure for A-T and to build on the existing research findings. Action for A-T are passionate about supporting individuals on their trajectory to becoming future leaders in health and research and have taken various steps to support individuals at various points of their development.

### Our Performance



In 2023, we provided several funding opportunities to encourage new and existing researchers to take an interest in A-T. This funding was in addition to our project grant round and included a “sandpit” event at the University of Nottingham which brought together experienced researchers for a one-day event to promote multidisciplinary translational research. Attendees learned more about the complexities of the condition and were encouraged to think creatively and broadly around the field of A-T, with the intention of applying for one of two £20,000 pump priming grants. The event was highly successful, and two grants were awarded to the new researchers for their technology-based projects (details on pages 6 & 7). Due to its success, another Sandpit event will be held in January 2024.

We also staged our first Fellowship grant round in collaboration with the MRC Nucleic Acid Therapy Accelerator (NATA) to drive high quality research in the application and translation of nucleic acid therapies in A-T. We received very few applications for the fellowship post and no candidates were appointed. We did however secure a sizable grant from NATA to support the work being carried out by Dr Rita Horvath and Dr Anke Hensiek at the University of Cambridge. Full details of this study can be seen on our website <https://actionforat.org/treat-at/>

In addition to the above, we also appointed an early-stage post doc researcher to our Research Advisory Committee (RAC) to provide a different perspective to our review meetings. The opportunity will help them expand their knowledge of A-T and build collaborative networks whilst enhancing their skills and supporting career development through training, mentoring, networking, and research involvement opportunities. We plan to recruit other younger members of the RAC moving forwards.

## Strengthening and Increasing our Fundraising Activities

### 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 £4,073,550 in 50 A-T related research projects around the world, and this has only been possible thanks to our generous supporters.

### Our Performance



2023 was our most successful fundraising year to date as we were able to deliver a full portfolio of events and activities without any of the previous Covid restrictions. Nearly all our activities performed better than expected as our event guests were incredibly generous, and we were able to benefit from several new fundraising events including a fundraising dinner for an international school in Spain, high-profile construction industry ball and a series of new endurance events. We also received another MRC grant to help retain early years researchers, plus a sizeable legacy donation and secured a collaborative funding partnership with NATA.

Our investment in TCS London Marathon places proved successful once again allowing us to make a 450% return. 19 people joined our marathon team and between them they raised £68,071. We have 15 places available for the 2024 London Marathon and hope to achieve a similar strong fundraising outcome.

In line with our fundraising strategy, we delivered a strong portfolio of sporting and social events to meet the heightened demand from our supporters 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 were the most successful fundraising activities accounting for 64% of our income (2022 - 59%). Whilst other fundraising initiatives, such as donations, funding partnerships and trust and foundation applications increased to 26% (2022 - 28%). The remaining 10% (£109,700) was generated from the Medical Research Council grant to help retain early years researchers. A few notable fundraising activities took place throughout the year including various golf events and the Trailblazers 10 Peak Challenge. We are especially grateful to the staff and clients of BCA and Cinch yet again for taking part in the three-day cycle from Kent to Brussels which raised £101,100 plus the non-riders who raised an additional £33,900 on the marathon walk and £5,500 from the Endure 24 event. We are also indebted to the students of Quest Professional who raised over £29,700 at their fundraising dinner. In addition, we would like to thank Simon Toon and his friends for their ongoing and valued support and the late Javier Garzon and his family for their generous legacy totaling £12,192.

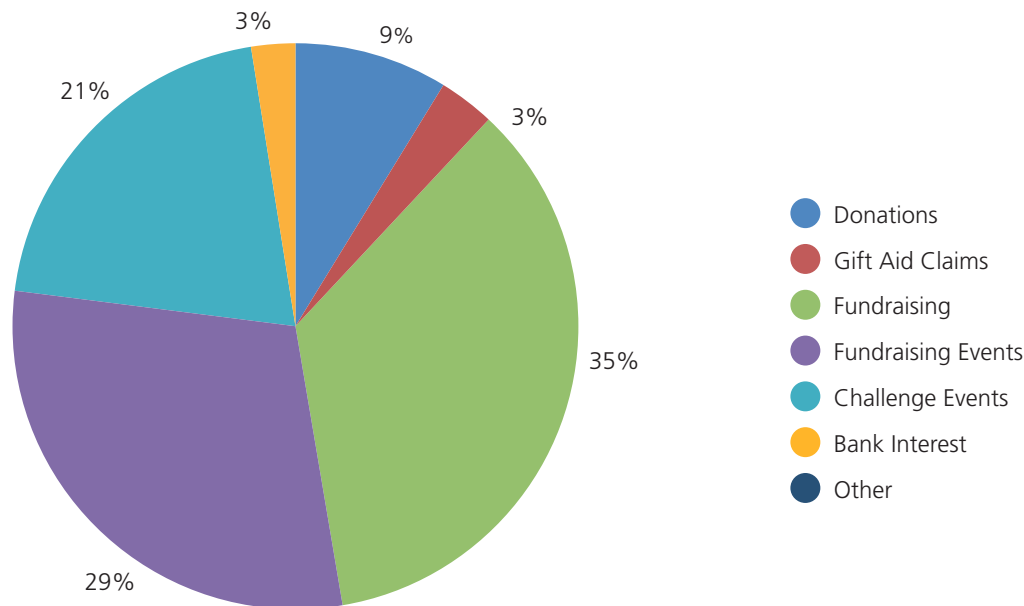
### Raising Funds Responsibly

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. No complaints relating to our fundraising activities were logged with the Fundraising Regulator throughout the year.

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 2023 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 2023.



*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 47). 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 2023 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 2023 were as follows:

#### The UK based Children's Medical Research Charity Sparks

Action for A-T continued to work closely with UK Children's Medical Research Charity Sparks which joined forces with Great Ormond Street Hospital Charity as a subsidiary in February 2017. Sparks are currently managing the following jointly funded research project which is due to end in early 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. A joint grant call was launched at the start of 2022 to increase the investment in new A-T research and 13 funding applications were received and peer reviewed by Action for A-T. Upon completion of the grant round in May 2022, the two charities combined their resources to fund five new research studies. BrAshA-T contributed £150,000 towards the £765,815 total cost of all five projects. The final payment of £75,000 was made towards the end of 2023 and the total funds committed by BrAshA-T was split equally amongst each of the five projects.

BrAshA-T have also partnered with Action for A-T for our latest grant round which opened in September 2023. At the time of writing these accounts, 24 new funding applications have been received and grants will be awarded to successful applicants in April 2024. BrAshA-T will contribute a similar amount (TBC) towards the cost of any new studies in 2024 and 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. Upon completion of the grant round in May 2022, the two charities combined their resources to fund five new research studies. The A-T Society agreed to contribute £60,000 towards all five of the studies and £30,000 was paid to Action for A-T in 2023. The remaining £30,000 will be paid in Q2 2024 and the payments will be split equally amongst each of the five projects managed by Action for A-T.

#### 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. Upon completion of the grant round in May 2022, the two charities combined their resources to fund five new research studies. AEFAT agreed to contribute €50,000 towards all five of the new research studies and a funding agreement was put in place. The first payment of €25,000 was made in September 2022 and the remaining payment was made in September 2023. The total funds committed by AEFAT will be split equally amongst each of the five projects which are managed in full by Action for A-T.

In addition, Action for A-T have partnered with AEFAT for their recent grant round and made available £50,000 to fund two new research projects in Spain and Norway (full details of these studies are on page 8). £25,000 was paid at the end of 2023 and the remaining £25,000 will be paid in 2024.

#### The MRC Nucleic Acid Therapy Accelerator (NATA)

A joint funding partnership was established with NATA in October 2022 to fund a joint Fellowship. The purpose of the 2-year Fellowship was to drive high quality research in the application and translation of nucleic acid therapies in A-T. No fellowships were awarded but NATA kindly agreed to contribute £125,000 towards the Trial REadiness in Ataxia Telangiectasia (TREAT-AT) being run by Dr Rita Horvath and Dr Anke Hensiek at the University of Cambridge. Full details of this study can be seen on our website <https://actionforat.org/treat-at/>. NATA made the full £125,000 payment to Action for A-T in February 2023.



An additional funding partnership was established in 2023 which called for new nucleic acid therapies (NATs) related research applications. Both NATA and Action for A-T will contribute £125,000 towards the full £250,000 cost of any new projects which are deemed fundable by the RAC. Action for A-T will manage the application process and funds will be made available for projects focusing on the management or treatment of A-T. The peer review process will be managed through the Action for A-T system. Representatives from NATA will join the Action For A-T Scientific Advisory Panel to review the applications and assist with the peer review of the relevant projects. The final grant award/s will be made in Q2 2024.

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

### **Working strategically with the worldwide A-T community**



Recognising the need for the global A-T community to work more closely together, Action for A-T played a key role in establishing the Global A-T Alliance at the start of 2021. The Alliance is made up of charities and patient groups from the UK, USA, Spain, Israel, Japan, France, 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 joint 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](http://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. Naga Munchetty hosted our "Spotlight on A-T Research" webinar alongside Dr Mark Toms as well as her annual golf day. Several other celebrities including Chris Sheasby, Leon Haslam, Kevin Whately, Will Greenwood, and Jeremy Guscott helped generate funds, awareness, and support by taking part in events and campaigns or starring in promotional social media videos.

### 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 2023, a number of 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.

### "Spotlight on A-T Research" Webinar

Action for A-T staged the third "Spotlight on A-T" virtual event in conjunction with the A-T Alliance to showcase some of the current A-T research projects which are taking place around the world. Key stakeholders from the global A-T community provided an easy to understand, concise overview of their current projects as well as answering audience questions. The webinar took place on the 27th of March 2023 and was hosted by Broadcaster, Journalist and Action for A-T Patron, Naga Munchetty and chair of the Research Advisory Committee, Dr Mark Toms.

There were six presentations broadcast live in English from various research teams and over 190 families, clinicians and other stakeholders tuned in to the event. The webinar was very popular and will be repeated at some point in the future in conjunction with the A-T Alliance members.

### Digital Communications

The Charity website [www.ActionforAT.org](http://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](http://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 2024 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 2024

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 2024 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 enables 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 a record-breaking fundraising year in 2023, we hope to make our largest research investment to date in 2024.

We will maintain our close relationship with the Association of Medical Research Charities (AMRC) and work in conjunction with our research advisory committee (RAC) to develop and improve our peer review process and ensure that the research we fund is of the highest quality. This will include constant evaluation of our systems and processes as well as enlisting the help and support of various A-T experts around the globe.

Membership of the RAC 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 2024. These projects will include maximising celebrity endorsement opportunities, the creation of a new promotional film 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.

### 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.

## 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 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.

## 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.

## 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.

## Pay and Remuneration of Key Management Personnel

The Trustee's 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.

## 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 2023 was **£1,092,490 (2022 - £949,804)**.

### Charitable Expenditure

The cost spent on Charitable Activities Was **£404,569 (2022 - £1,106,145) of which £139,427 (2022 - £804,239)** was for grants provided for funding of research projects.

The cost of generating voluntary income was **£87,806 (2022 - £81,134)** whilst the cost of generating income from charitable events was **£157,097 (2022 - £201,167)**

Governance costs of **£20,239 (2022 - £19,605)** 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 2022. In 2023, **£nil** of funds were passed on to the research projects detailed in note 8 on page 37.

As at 31 December 2023 designated funds carried forward are **£nil**.

### Restricted Funds

Restricted funds of **£85,486** were brought forward from 2022. During the year **£13,000** of restricted income was received against projects funded during 2023. During 2023, **£60,465** of funding was made to the research projects detailed in note 8 Page 37.

At 31 December 2023 restricted funds of **£38,021 (2022 - £85,486)** 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.



## 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 2015 (FRS 102);
- 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 operation.

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.

The Trustees declare that they have approved the Trustees report included in the previous pages

Signed on behalf of the charity's Trustees



Toby Read (Chairman)



William Rowberry (Treasurer)

Dated: 23rd April 2024

Dated: 23rd April 2024

## 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 2023 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 2022 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.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- 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.
- 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.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- 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. However, future events or conditions may cause the charity to cease to continue as a going concern.
- 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](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our Report of the Independent Auditors.

## Use of our report

This report is made solely to the 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.



A & N (Haslemere) Limited Statutory Auditor  
Aruna House  
2 Kings Road  
Haslemere  
Surrey  
GU27 2QA

Dated: 23rd April 2024

A & N (Haslemere) Limited is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

## Statement Of Financial Activities

for the year ended 31 December 2022

	Notes	Unrestricted Funds £	Restricted Funds £	<b>31.12.23 Total Funds £</b>	31.12.22 Total Funds £
<b>Income and Endowments from</b>					
Donations and legacies	3	501,985	13,000	<b>514,985</b>	377,170
<b>Charitable Activities</b>					
Fundraising & challenge events	5	549,677	-	<b>549,677</b>	559,411
Investment income	4	27,828	-	<b>27,828</b>	10,043
Other income		-	-	-	3,180
<b>Total</b>		<b>1,079,490</b>	<b>13,000</b>	<b>1,092,490</b>	<b>949,804</b>
<b>Expenditure on</b>					
Raising funds	6	87,806	-	<b>87,806</b>	81,134
<b>Charitable Activities</b>					
Fundraising & challenge events	7	157,097	-	<b>157,097</b>	201,167
Grants	8	78,962	60,465	<b>139,427</b>	804,239
Governance costs		20,239	-	<b>20,239</b>	19,605
<b>Total</b>		<b>344,104</b>	<b>60,465</b>	<b>404,569</b>	<b>1,106,145</b>
<b>Net Income / (Expenditure)</b>		<b>735,386</b>	<b>(47,465)</b>	<b>687,921</b>	<b>(156,341)</b>
<b>Reconciliation of Funds</b>					
<b>Total funds brought forward</b>		<b>141,318</b>	<b>85,486</b>	<b>226,804</b>	<b>383,145</b>
<b>Total Funds Carried Forward</b>		<b>876,704</b>	<b>38,021</b>	<b>914,725</b>	<b>226,804</b>

The notes form part of these financial statements



## Statement Of Financial Position

for the year ended 31 December 2023

	Notes	Unrestricted Funds £	Restricted Funds £	<b>31.12.23 Total Funds £</b>	31.12.22 Total Funds £
<b>Fixed Assets</b>					
Tangible assets	17	216	-	<b>216</b>	216
<b>Current Assets</b>					
Stocks	18	18,985	-	<b>18,985</b>	7,750
Debtors	19	41,798	-	<b>41,798</b>	18,469
Cash at bank	20	1,891,840	38,021	<b>1,929,861</b>	1,626,967
		1,952,623	38,021	<b>1,990,644</b>	1,653,186
<b>Creditors</b>					
Amounts falling due within one year	21	(422,367)	-	<b>(422,367)</b>	(491,139)
<b>Net Current Assets</b>		1,530,256	38,021	<b>1,568,277</b>	1,162,047
<b>Total Assets Less Current Liabilities</b>		1,530,472	38,021	<b>1,568,493</b>	1,162,263
<b>Creditors</b>					
Amounts falling due after more than one year	22	(653,768)	-	<b>(653,768)</b>	(935,459)
<b>Net Assets</b>		876,704	38,021	<b>914,725</b>	226,804
<b>Funds</b>	23				
Unrestricted funds				<b>876,704</b>	141,318
Restricted funds				<b>38,021</b>	85,486
<b>Total Funds</b>				<b>914,725</b>	226,804

The notes form part of these financial statements

The financial statements were approved by the Board of Trustees and authorised for issue on 23rd April 2024 and were signed on its behalf by:



Toby Read (Chairman)

Dated: 23rd April 2024



William Rowberry (Treasurer)

Dated: 23rd April 2024

## Statement of Cash Flows

for the year ended 31 December 2023

	Notes	<b>31.12.23</b> £	31.12.22 £
<b>Cash flows from operating activities:</b>	1		
Cash generated from operations		<b>273,723</b>	254,184
Net cash provided by operating activities		<b>273,723</b>	254,184
<b>Cash flows from investing activities:</b>			
Purchase of tangible fixed assets		-	-
Interest received		<b>29,171</b>	10,043
Net cash provided by investing activities		<b>29,171</b>	10,043
<b>Change in cash and cash equivalents in the reporting period</b>		<b>302,894</b>	255,227
<b>Cash and cash equivalents at the beginning of the reporting period</b>		<b>1,626,967</b>	1,371,740
<b>Cash and cash equivalents at the end of the reporting period</b>		<b>1,929,861</b>	1,626,967

## Notes to the Statement of Cash Flows

for the Year Ended 31 December 2023

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

	31.12.23 £	31.12.22 £
<b>Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)</b>	<b>687,921</b>	(156,341)
<b>Adjustments for:</b>		
Depreciation charges	-	108
Interest received	(29,171)	(10,043)
(Increase)/decrease in stocks	(11,235)	1,782
Decrease in debtors	(23,329)	18,670
Increase/(decrease) in creditors	(350,463)	391,008
<b>Net cash provided by operations</b>	<b>273,723</b>	245,184

### 2. Analysis of changes in net fund

	At 1.1.23 £	Cash Flow £	31.12.23 £
Net cash			
Cash at bank	1,626,967	302,894	1,929,861
	1,626,967	302,894	1,929,861
<b>Total</b>	<b>1,626,967</b>	<b>302,894</b>	<b>1,929,861</b>

## Notes to the Financial Statements

for the Year Ended 31 December 2023

### 1. Accounting Policies

#### Basis of preparation of 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.

## Notes to the Financial Statements

for the Year Ended 31 December 2023

### 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 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 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.

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.



## Notes to the Financial Statements

for the Year Ended 31 December 2023

### 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.

#### Key sources of estimation uncertainty

Grants payable are recognised when sanctioned and the total amount is split into due within one year and after one year based on current year amounts paid during the year.

### 3. Donations and Legacies

	Unrestricted Funds £	Restricted Funds £	<b>31.12.23 £</b>	31.12.22 £
Donations	78,706	13,000	<b>91,706</b>	107,903
Gift Aid	35,530	-	<b>35,530</b>	31,768
Fundraising	387,749	-	<b>387,749</b>	237,499
	<b>501,985</b>	<b>13,000</b>	<b>514,985</b>	377,170

### 4. Investment Income

	Unrestricted Funds £	Restricted Funds £	<b>31.12.23 £</b>	31.12.22 £
Bank interest	27,828	-	<b>27,828</b>	10,043

## 5. Income from Charitable Activities

Activity		31.12.23 £	31.12.22 £
Fundraising events	Fundraising & Challenge events	<b>323,820</b>	358,874
Challenge events	Fundraising & Challenge events	<b>225,857</b>	200,537
		<b>549,677</b>	559,411

## 6. Raising Funds

	Unrestricted Funds £	Restricted Funds £	31.12.23 £	31.12.22 £
<b>Raising donations and legacies</b>				
Staff costs	65,471	-	<b>65,471</b>	61,071
Trusts & Foundations	3,534	-	<b>3,534</b>	
Support costs	18,801	-	<b>18,801</b>	20,063
	87,806	-	<b>87,806</b>	81,134

## 7. Charitable Activities Costs

	Direct Costs £	Grant funding of activities (see note 8) £	Support Costs (see note 9) £	Totals £
Fundraising & challenge events	138,063	-	19,034	<b>157,097</b>
Grants	-	74,683	64,744	<b>139,427</b>
Governance costs	-	-	20,239	<b>20,239</b>
	138,063	74,683	104,017	<b>316,763</b>

## 8. Grants Payable

	31.12.23 £	31.12.22 £
Grants	<b>74,683</b>	743,455

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

	31.12.23 £	31.12.22 £
University of Nottingham, UK - Virtual Reality in Ataxia-Telangiectasia	<b>18,565</b>	-
University of Nottingham, UK - STIM A-T Pilot Study	<b>20,270</b>	-
Institute for Bioengineering of Catalonia, Spain - Modelling Ataxia Telangiectasia pathogenesis and therapeutics using human pluripotent stem cells and genetic engineering	<b>25,000</b>	-
Oslo University Hospital, Norway - Preclinical Assessment of Intrathecal rAAV9-Mediated miATM Therapy for Ataxia Telangiectasia in Mouse Models	<b>25,000</b>	-
University of Birmingham, UK - (Research project underspends refunded) Assessment of the frequencies and types of cancers occurring in A-T patients	<b>(14,986)</b>	-
University of Birmingham, UK - (Research project underspends refunded) Deciphering the molecular mechanism linking Ataxia-Telangiectasia and Ataxia-Telangiectasia-Like Disorder	<b>(29)</b>	-
University of Nottingham, UK – Sandpit Event	<b>863</b>	-
University of Nottingham, UK - Brain-penetrating ATM gene therapy	-	147,304
Bambino Gesù Children's Hospital, Italy - Study of natural killer cells in A-T pathogenesis and their therapeutic implications	-	91,000
QIMR Berghofer Medical Research Institute, Queensland, Australia - Digital drug prediction informed by genetic analysis of stem cell-derived mini-brains from A-T patients	-	151,690
University of Cambridge, UK - Trial REadiness in Ataxia Telangiectasia (TREAT-AT)	-	250,000
IFOM – The FIRC Institute of Molecular Oncology, Milan, Italy - Understanding and correcting glucose metabolism defects in Ataxia-Telangiectasia	-	125,821
Nottingham University Hospital, UK – (Research project underspends refunded) Natural History of A-T		(22,360)
	<b>74,683</b>	743,455

## 9. Support Costs

	Management	Finance	Information Technology	Other	Wages	Governance Costs	Totals
	£	£	£	£	£	£	£
Raising donations and legacies	8,132	664	1,324	8,681	-	-	<b>18,801</b>
Fundraising & challenge events	8,132	664	1,323	8,933	-	-	<b>19,034</b>
Grants	-	-	-	-	64,744	-	<b>64,744</b>
Governance costs	-	-	-	-	-	20,239	<b>20,239</b>
	16,264	1,310	2,647	17,614	64,744	20,239	<b>122,818</b>

Activity	Basis of allocation
Management	90 % Raising Donation & legacies 10 % Fundraising & Challenge Events
Finance	90 % Raising Donation & legacies 10 % Fundraising & Challenge Events
Information technology	90 % Raising Donation & legacies 10 % Fundraising & Challenge Events
Human resources	90 % Raising Donation & legacies 10 % Fundraising & Challenge Events
Other	90 % Raising Donation & legacies 10 % Fundraising & Challenge Events
Governance costs	100% Governance cost

## 10. Trustees' Remuneration And Benefits

There were no Trustees' remuneration or other benefits for the year ended 31 December 2023 nor for the year ended 31 December 2022.

## Trustees' Expenses

There were no Trustees' expenses paid for the year ended 31 December 2023 nor for the year ended 31 December 2022.

## 11. 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 £156,996 (2022 - £147,225). Only one employee had employment benefits falling between £65,000 and £80,000 (2022 - 1).

## 12. Comparatives for the Statement of Financial Activities

	Unrestricted Funds £	Restricted Funds £	Total Funds £
<b>Income and endowments from</b>			
Donations and legacies	357,010	20,160	<b>377,170</b>
<b>Charitable activities</b>			
Fundraising & challenge events	559,411	-	<b>559,411</b>
Investment income	10,043	-	<b>10,043</b>
Other income	3,180	-	<b>3,180</b>
<b>Total</b>	<b>929,644</b>	<b>20,160</b>	<b>949,804</b>
	Unrestricted Funds £	Restricted Funds £	Total Funds £
<b>Expenditure on</b>			
Raising funds	81,134	-	<b>81,134</b>
<b>Charitable activities</b>			
Fundraising & challenge events	201,167	-	<b>201,167</b>
Grants	804,239	-	<b>804,239</b>
Governance costs	19,605	-	<b>19,605</b>
<b>Total</b>	<b>1,106,145</b>	<b>-</b>	<b>1,106,145</b>
<b>Net income/(Expenditure)</b>	<b>(176,501)</b>	<b>20,160</b>	<b>(156,341)</b>
<b>Reconciliation of funds</b>			
Total funds brought forward	317,819	65,326	<b>383,145</b>
<b>TOTAL FUNDS CARRIED FORWARD</b>	<b>141,318</b>	<b>85,486</b>	<b>226,804</b>

## 13. 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.

## 14. Pension Costs

The pension costs charged in the financial statements represent the contributions payable by the Charity during the year to a multi-employer defined benefit pension scheme.



## Notes to the Financial Statements - continued

for the Year Ended 31 December 2023

### 15. 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.

### 16. 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.

### 17. Tangible Fixed Assets

	Computer Equipment £
<b>Cost</b>	
At 1 January 2023 and 31 December 2023	2,358
<b>Depreciation</b>	
At 1 January 2023 and 31 December 2023	2,142
<b>Net Book Value</b>	
At 31 December 2023	216
At 31 December 2022	216

### 18. Stocks

	31.12.23 £	31.12.22 £
Stocks	18,985	7,750

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.

## Notes to the Financial Statements - continued

for the Year Ended 31 December 2023

### 19. Debtors: Amounts Falling Due Within One Year

	<b>31.12.23</b>	31.12.22
	<b>£</b>	£
Deposit	<b>925</b>	925
Prepayments and accrued income	<b>40,873</b>	17,544
	<b>41,798</b>	18,469

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

### 20. Cash at Bank

	Unrestricted Funds	Restricted Funds	<b>31.12.23</b>	31.12.22
	£	£	<b>Total Funds</b>	Total Funds
			<b>£</b>	£
Bank Current Accounts	8,459	38,021	<b>46,480</b>	25,084
Bank Current Accounts (US \$)	-	-	-	-
Reserve Account	410,848	-	<b>410,848</b>	291,944
Investment Accounts	1,472,533	-	<b>1,472,533</b>	1,309,939
Total	1,891,840	38,021	<b>1,929,861</b>	1,626,967

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.

### 21. Creditors: Amounts Falling Due Within One Year

	<b>31.12.23</b>	31.12.22
	<b>£</b>	£
Grant Payable	<b>415,417</b>	489,475
Accruals and deferred income	<b>6,950</b>	1,664
	<b>422,367</b>	491,139

## 22. Creditors: Amounts Falling Due After More Than One Year

	31.12.23 £	31.12.22 £
Other creditors	<b>653,768</b>	935,459

## 23. Leasing Agreements

During the next twelve months the Charity has operating lease commitments totalling £13,014 (2022 - £12,485) for contracts expiring in more than one year. The total future commitments are £12,960 (2022 - £12,960)

## 24. Movement in Funds

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

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

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

### Comparatives for movement in funds

	At 1.1.22 £	Net Movement in Funds	At 31.12.22 £
<b>Unrestricted Funds</b>			
Unrestricted Funds	317,819	(176,501)	<b>141,318</b>
Restricted Funds	65,326	20,160	<b>85,486</b>
Total Funds	383,145	(156,341)	<b>226,804</b>

## Notes to the Financial Statements - continued

for the Year Ended 31 December 2023

### 24. Movement in Funds - Continued

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

	Incoming Resources £	Resources Expended £	Movement in Funds £
<b>Unrestricted Funds</b>			
Unrestricted Funds	929,644	(1,106,145)	<b>(176,501)</b>
<b>Restricted Funds</b>			
Restricted Funds	20,160	-	<b>20,160</b>
<b>Total Funds</b>	<b>949,804</b>	<b>(1,106,145)</b>	<b>(156,341)</b>

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

	At 1.1.22 £	Net Movement in Funds	At 31.12.23 £
<b>Unrestricted Funds</b>			
Unrestricted Funds	317,819	558,885	<b>876,704</b>
<b>Restricted Funds</b>			
Restricted Funds	65,326	(27,305)	<b>38,021</b>
<b>Total Funds</b>	<b>383,145</b>	<b>531,580</b>	<b>914,725</b>

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 £
<b>Unrestricted Funds</b>			
Unrestricted Funds	2,009,134	(1,450,249)	<b>558,885</b>
<b>Restricted Funds</b>			
Restricted Funds	33,160	(60,465)	<b>(27,305)</b>
<b>Total Funds</b>	<b>2,042,294</b>	<b>(1,510,714)</b>	<b>531,580</b>

## 25. Related Party Disclosures

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2022 - £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.

## 26. 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 2023

	Unrestricted Funds £	Restricted Funds £	<b>31.12.23 £</b>	31.12.22 £
<b>Income and Endowments</b>				
<b>Donations and legacies</b>				
Donations	78,706	13,000	<b>91,706</b>	107,903
Gift aid	35,530	-	<b>35,530</b>	31,768
Fundraising	387,749	-	<b>387,749</b>	237,499
	501,985	13,000	<b>514,985</b>	377,170
<b>Investment income</b>				
Bank interest	27,828	-	<b>27,828</b>	10,043
<b>Charitable activities</b>				
Fundraising events	323,828	-	<b>323,828</b>	358,874
Challenge events	225,857	-	<b>225,857</b>	200,537
	549,677	-	<b>549,677</b>	559,411
<b>Other income</b>				
Other income	-	-	-	-
Exchange rate difference	-	-	-	3,180
<b>Total incoming resources</b>	1,079,490	13,000	<b>1,092,490</b>	949,804
<b>Expenditure</b>				
<b>Raising donations and legacies</b>				
Wages	65,471	-	<b>65,471</b>	61,071
Trusts and Foundations	3,534	-	<b>3,534</b>	-
	69,005	-	<b>69,005</b>	61,071
<b>Charitable activities</b>				
Event campaign costs	138,063	-	<b>138,063</b>	181,101
Grants to institutions	14,218	60,465	<b>74,683</b>	743,455
	152,281	60,465	<b>212,746</b>	924,556
<b>Support costs</b>				
<b>Management</b>				
Wages	16,264	-	<b>16,264</b>	15,241
<b>Finance</b>				
Bank charges	1,310	-	<b>1,310</b>	1,465
<b>Information technology</b>				
Repairs and renewals	2,647	-	<b>2,647</b>	5,420

## Detailed Statement of Financial Activities

for the Year Ended 31 December 2023

	Unrestricted Funds £	Restricted Funds £	<b>31.12.23 £</b>	31.12.22 £
<b>Other</b>				
Rent, rates and water	13,014	-	<b>13,014</b>	12,485
Insurance	1,115	-	<b>1,115</b>	1,066
Telephone	693	-	<b>693</b>	849
Postage and stationery	480	-	<b>480</b>	461
Sundries	526	-	<b>526</b>	813
Advertising	887	-	<b>887</b>	956
Subscription	-	-	-	474
Donation collection fees	899	-	<b>899</b>	899
	17,614	-	<b>17,614</b>	18,003
<b>Fundraising</b>				
Wages	64,744	-	<b>64,744</b>	60,784
<b>Governance costs</b>				
Wages	14,827	-	<b>14,827</b>	14,015
Auditors' remuneration	3,300	-	<b>3,300</b>	3,300
Accountancy and legal fees	2,112	-	<b>2,112</b>	2,182
Computer equipment	-	-	-	108
	20,239	-	<b>20,239</b>	19,605
Total resources expended	344,104	60,465	<b>404,569</b>	1,106,145
Net (expenditure)/income	735,386	(47,465)	<b>687,921</b>	(156,341)

## Acknowledgments

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 2023:

### Our Research Partners

BrAshA-T Ataxia Telangiectasia and their trustees

A-T Children's Project (USA) and their Medical Research Team

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 for their generous support.

Adrestia Therapeutics

Astor Foundation

Barton Comms

BCA

Big Give

Blyth Watson Charitable Trust

Charity Escapes

Cinch

Clarion Golf

Constellation Group

Epsom Rotary Club

Enterprise Rent A Car

Global Entertainment

Henrik Bergrem

James Tudor Foundation

James Wise Charitable Trust

Kent College

Medical Research Council

Michael and Anna Wix Charitable Trust

Mollie's Miracle Team

Moe's Ices

Monica Seccombe

Personal Agent

Quest Professional

Rawson Digital

Robin Hewison

Sheppard Piling

Syder Foundation

Stewart Golf Ltd

Trailblazers

Woodcock Brothers

#### **Corporate or professional services provided by:**

A & N Chartered Accountants

Akin Gump

Chris Stanton

Gecko Graphic Design

### 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.



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