



**ACTION
FOR A-T**

**FUNDING
RESEARCH,
FINDING HOPE**

Annual Report & Financial Statements for the year ended 31st December 2017

Action for A-T - Charity registered number 1145303
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

Chief Executive

Sean Kelly

Trustees at the date of approval

Toby Read (Chairman)
 Emily Read
 William Rowberry (Treasurer)
 Tomos Shillingford
 Maria Leonard
 Samantha Cornell
 Chris Askew
 Dr Mark Toms

Appointed during the year or since year end

None

Research Advisory Committee

Dr Mark Toms
 Dr Kathryn Johnson
 Professor David Attwell
 University College London (UCL)
 Associate Professor Esther Becker
 Dr Simon Boulton
 Dr Lisa Bunn
 Professor Sophie Hambleton
 Professor Karl Herholz
 Dr Richard Kay
 Dr Ian Kill
 Dr Guy Makin
 Dr Kevin Southern
 Professor Maria Grazia Spillantini
 Professor Grant Stewart
 Dr Alastair Wilkins

Patient Representatives

Mr Amandeep Sharma
 Mrs Clare Gallagher

Charity Registration Number

United Kingdom Registered Charity number: 1145303

Registered Office

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Chairman's Report

Action for A-T is the UK's leading A-T medical research charity. We exist to harness world leading medical science to help improve the lives of those affected by Ataxia Telangiectasia.

To all of our supporters

Another year passes and I wanted to take this opportunity to comment on how far this amazing charity has come and to highlight the potential I believe it has to make a tangible difference to those living with Ataxia-Telangiectasia ("A-T").

The charity was started by two parents after receiving the devastating news that their child not only had this terrible degenerative condition, but that it was incurable. After scouring far and wide to understand what research was being done to understand the condition and find a cure it was clear that medical research technologies were evolving at pace but that there simply were not enough funds targeted to these research opportunities. Consequently, Action for A-T was founded.



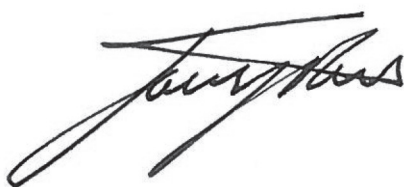
Emily and Toby Read

From small acorns do mighty oaks grow. Since those first early days the charity has gone from strength to strength evolving into what it is today, a major funder and respected partner to the A-T medical research community worldwide. These 2017 Annual Accounts amply demonstrate the incredibly important work that we are now able to support.

I am often asked by people "how is the research going". The answer is that progress is being made but more work needs to be done. The more we understand about A-T, the better we can apply what we have learnt to new technologies that offer real hope. It remains a simple equation: the more research we can fund, the less time to find a treatment or cure.

The Charity's work continues to depend on the commitment and contribution of so many people. In addition to the legions of supporters and donors, we have so many volunteers assisting our dedicated staff all of whom go above and beyond to generate the research funds so vitally needed. The Charity is also hugely indebted to the expert team of medical research advisors and talented Trustees board, all of whom freely give their time and expertise so generously to ensure that the donations are spent only on world class medical research that provides the best chance of helping people with A-T.

Thank you to everyone involved in making a difference and continuing to support us on the journey towards a cure or treatment.



Toby Read
Chairman, Action for A-T

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 2017.

The Trustees confirm that the annual report and financial statements of the Charity comply with Charities Act 2011, The Charities (Accounts and reports) Regulations 2008 and have been prepared in accordance with the Statement of Recommended Practice on Accounting and Reporting by Charities (Charities SORP FRS102).

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 January, April, July and October in 2017. 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 8 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 and Achievements

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"

In order to further that mission, the Charity focuses on four key areas:

- Identifying High Quality Research into A-T
- Funding High Quality Research into A-T
- Building Collaborative Partnerships
- Raising public awareness about A-T

Our aims and performance in these four areas are set out in more detail in the following pages.

Identifying High-Quality Research into A-T

Supporting High Quality Research is at the heart of Action for A-T's activities.

Our Aims

Action for A-T will only fund medical research into A-T that is:

- Of the highest quality;
- Will be fully peer reviewed and has clear aims;
- Is relevant to furthering Action for A-T's objectives; and
- That we are confident (so far as possible) will be able to achieve the research team's stated aims.

Our Performance

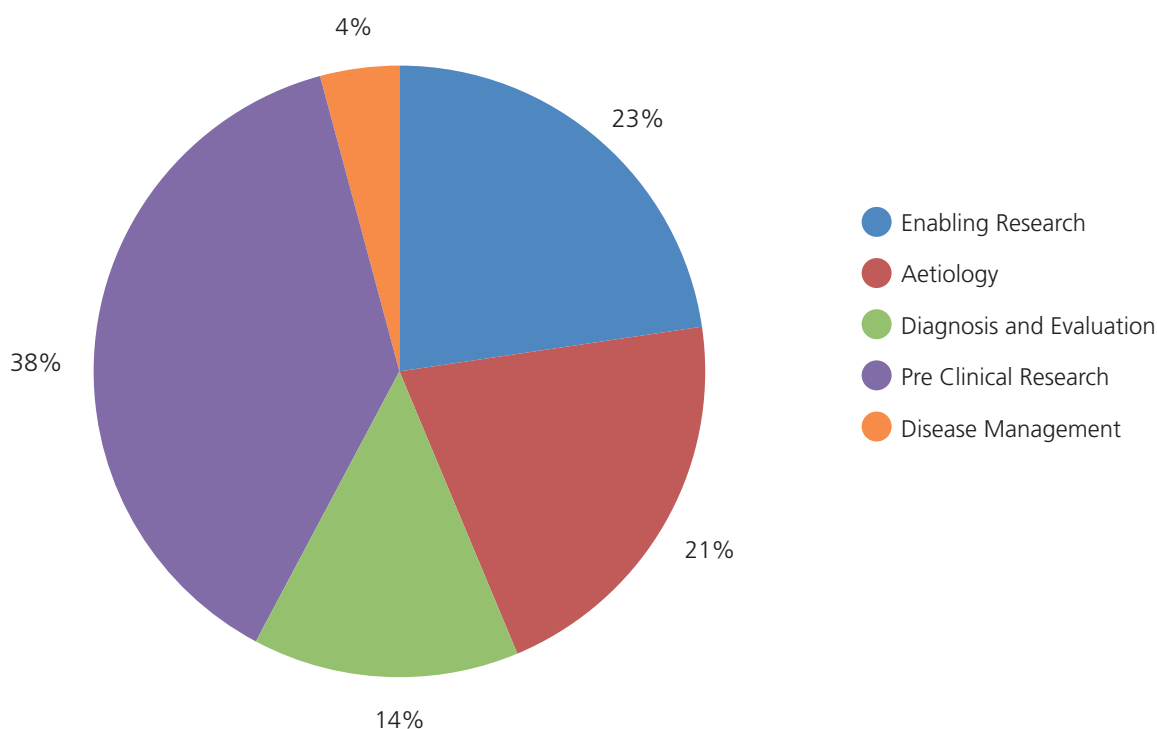
Continuing our investment in A-T research

We made new grant commitments totalling £528,132 in 2017, bringing our total research investment since the Charity was established to £1.7million. These funds have been committed to 27 global projects under five main research headings.

- Enabling Research - Developing new tools and techniques for conducting research
- Aetiology - Understanding the causes of A-T
- Diagnosis & Evaluation - Tests for diagnosing and monitoring patients with A-T
- Pre-Clinical Research - Studies to identify new treatments for A-T
- Disease Management - Managing the symptoms of A-T

The amount invested in each specific area is shown below.

Total Research Spend Since 2012



All of our research applications undergo a rigorous peer review process and only those deemed to be of the highest quality (as agreed by our Research Advisory Committee) are passed for funding.

Management of our grant application, peer - review and evaluation process

In 2017, Action for A-T administered its third full grant round and a record number of applications were received from a variety of global research institutions. These applications were subject to our rigorous award winning peer review process to ensure that the money generously raised by our donors is put to the best possible use and to provide assurance to our Trustees.

Our Research Advisory Committee (RAC) is part of this process and is made up 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.

Occasionally, members of our RAC also submit funding applications or may work alongside other potential applicants. In these instances, RAC members who may have a conflict of interest play no part in the review of the applications and are asked to leave the room when the projects are discussed. This was the case with Professor Grant Stewart when he received funding towards the cost of a replacement microscope for his lab and when his colleague Professor Malcolm Taylor was awarded a grant for his research study at the University of Birmingham.

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.

Expanding our reach within the A-T research community and beyond

Throughout 2017, our Chief Executive and Research Manager met with key figures from the A-T research community and representatives from other medical research charities 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 further interest in the condition. This strategy proved very successful and enabled us to significantly increase the number and demographic of 'who' we advertise our grant rounds to.

As a direct result of this proactive approach, we were able to significantly increase the number of applications from UK based institutions and fund a further three UK based projects with a combined cost of £421,776.

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. This is why we insist that all of our researchers use the Global Research Impact Assessment Platform called Researchfish to report on their projects periodically and several years after their grant has ended.

We also encourage all of our researchers to publish their findings in medical journals and where possible, make these open source. The outputs of research such as publications usually occur 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 of the research we have funded are displayed on our website under our 'Completed Research' section. Where applicable, these posts also include links to any online publications. In addition to the website, we also share project information via our social media channels and in communications to our supporters.

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 the projects which were completed to help ensure that the original research aims stated in the application were fulfilled.

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 Aims

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

A number of previously funded projects came to a conclusion in 2017. The outcomes of these were as follows:

Understanding Dexamethasone action in Ataxia Telangiectasia

Principal Researcher: Professor Luciana Chessa
Project Completion Date: 31st December 2016

Project Overview

Recent studies have shown that the steroid drug, Dexamethasone (Dexa), can improve some of the neurological symptoms experienced by patients with Ataxia Telangiectasia (A-T). But why Dexa works and how it affects A-T cells is unknown. A better understanding of how, and why, the drug works could help to improve existing treatment or identify targets for new ones.

In order to understand the exact mechanism of Dexa, Professor Luciana Chessa and her team undertook a series of intricate experiments which looked at different processes within A-T cells and compared them to healthy cells.



Professor Chessa and lab team

Project Outcome

Overall, A-T cells showed significant differences in their response to Dexa, compared to healthy cells. The beneficial effect seems to be a result of a reduction in damage to cells, caused by an increase in molecules that protect the cells from harmful molecules called reactive oxygen species.

Publications

Chessa L, Micheli R, Molinaro A. Focusing New Ataxia Telangiectasia Therapeutic Approaches. J Rare Dis Diagn Ther. 2016, 2:2.

Biagiotti, S. et al. Dexamethasone improves redox state in ataxia telangiectasia cells by promoting an NRF2-mediated antioxidant response. The FEBS Journal. 2016.

Menotta, M. et al. Nano-Mechanical Characterization of Ataxia Telangiectasia Cells Treated with Dexamethasone. Cell Biochem Biophys (2017) 75:95–102.

A possible new role for ATM in maintaining healthy mitochondria

Principal Researcher: Professor Mike Kastan
Project Completion Date: February 2017

Project Overview

Mitochondria are tiny compartments found within cells. They perform different and important functions to keep us healthy. They convert energy locked in food into energy that the cell can use. Mitochondria are often referred to as the powerhouses of the cells. They generate the energy that our cells need to do their jobs.

Previous observations from Professor Kastan's lab suggested that many of the symptoms in A-T may arise from mitochondrial dysfunction and an incorrect response to metabolic stress. The work carried out in this grant was to try and understand why mitochondria are dysfunctional in cells lacking ATM (the protein which is missing or not functioning completely in A-T), as well as how ATM helps cells respond to metabolic stress.



Dr Adam Brown and Prof Mike Kastan

Project Outcome

Several important and encouraging observations were made. There were also some unexpected findings which were not the initial focus of the research. These unexpected results have altered how the original key questions of the study were viewed and addressed. Therefore, Professor Kastan's work has not concluded and is ongoing, and the lab is currently working with collaborators to understand these findings. Their finished work will likely have a significant role in building up the mitochondrial knowledge base in A-T.

Publications

There is no published output from this work to date. This is not unexpected given that work is ongoing and that important scientific findings can take years to come to fruition. Action for A-T will be in regular contact with the lab over the next few years to ascertain the results.

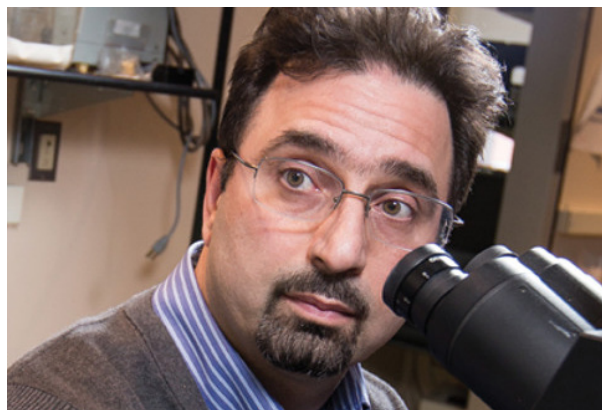
PCD Mice as an animal model of Ataxia in A-T

Principal Researcher: Professor Kamran Khodakhah
Project Completion Date: July 2017

Project Overview

One of the symptoms of Ataxia Telangiectasia (A-T) is a progressive loss of muscle coordination called Ataxia. Unfortunately, no current treatments can prevent this process.

For effective therapeutics to be developed, it is crucial that the biological mechanisms which may cause Ataxia are fully understood. The cerebellum region of the brain plays an important role in muscle coordination, where neurons within the deep cerebellar nuclei (DCN) are the main output of movement related information. It is known that Ataxia can be caused by the degeneration of a type of neuron, called a Purkinje cell, within the cerebellum. It is thought that the information required for muscle coordination is encoded in the activity of Purkinje cells and transferred to the DCN neurons. Professor Kamran Khodakhah and his research team aimed to monitor the change in activity of DCN neurons within mice, as purkinje cells degenerate, in order to decipher the Ataxia mechanism.



Professor Kamran Khodakhah

Project Outcome

Neurons propagate information by generating electrical pulses. Professor Kamran Khodakhah and his research team evaluated the change in firing rate of the DCN neurons as Purkinje cells degenerated. They report that as Purkinje cells were lost in mice, the firing rate became more erratic. Based on these results, Professor Khodakhah hypothesises that anything that induces an erratic firing rate from the DCN neurons will likely contribute to Ataxia in mice (and by extension, humans).

Publications

Professor Khodakhah presented this research at the Society of Neuroscience conference and at the National Ataxia Foundation's Ataxia Investigators Meeting. He plans to publish the results within an international peer reviewed journal once more data is collected.

During the 2017 accounting period the following grants for A-T research projects were approved and allocated for funding:

Development of CRISPR/Cas Genome Editing as a Treatment for Ataxia Telangiectasia

Principal Researcher: Professor Rafael Yáñez-Muñoz
Institute: Royal Holloway, University of London
Start Date: November 2017

Project Summary

Mutations in the ATM gene affect the production or the activity of the ATM protein, leading to the symptoms associated with A-T. Fixing the faulty gene permanently will give the cells a chance to produce the correct protein. In the last few years, CRISPR has revolutionised the field of genome editing and shown remarkable success in progressing treatments for many genetic diseases that also rely on the correction of faulty genes. The team will therefore use CRISPR technology in an attempt to repair ATM mutations.

Professor Yáñez-Muñoz and his team will attempt to repair the faulty ATM gene using several different CRISPR genome editing strategies. First, they will test these in human cells that are easy-to-grow in the lab. Next, they will move on to cells that have been derived from people affected by A-T, which harbour ATM gene mutations. Finally, they will test the most efficient genome editing approaches in human blood stem cells.



Professor Yáñez-Muñoz

Currently, there are no treatments for A-T, and this project aims to pave the way for future gene and cell therapies. The team will use genome editing to repair the faulty ATM gene, which is the root-cause of the condition. During the second year of the study they will test their genome editing strategies in blood stem cells, which when re-infused in the body can regenerate the entire blood and immune system. If the planned gene repair studies are successful, follow-up work can explore the strategies in blood stem cells taken from people affected with A-T. The team hope to develop this avenue as a possibility for treating the immune defects seen in A-T patients in the long term.

Unravelling the antibody deficiency in Ataxia Telangiectasia

Principal Researcher: Associate Professor Mirjam Van der Burg
Institute: Leiden University Medical Centre (LUMC), The Netherlands
Start Date: January 2018

Project Summary

Professor Van der Burg and her team will try to unravel the cause of the immunoglobulin production defect in patients with A-T. With a combination of different cellular and molecular techniques, they will investigate the effect of ATM mutations on the formation of B-cells in bone marrow and on the production of immunoglobulins by B-cells. This will contribute to a better understanding of the condition, and potentially identify new targets for therapy, which is important for improvement of clinical management of the antibody deficiency in A-T.

Understanding why the immunoglobulin production is hampered in patients with A-T will contribute to better understanding of the condition and could lead to identification of potential targets for therapy, which will contribute to improved clinical management. Earlier and more targeted treatment for A-T patients with severe antibody deficiency could prevent or reduce the number of severe infections and potential organ damage.

The team will investigate the role of ATM in B-cell development in humans and attempt to discover what causes the diverse antibody deficiency by:

Determining the role of ATM on the formation of B-cells in bone marrow and to investigate why or to what extent the production of B-cells in bone marrow is affected in A-T patients. For this they will be using cell lines, culture systems and bone marrow samples from A-T patients.

Investigating the role of ATM in B-cell differentiation in blood and to investigate the potential of B-cells of A-T patients to produce antibodies in culture, and the focusing on the role of mutant ATM on precursor B-cell development.

By combining these results, the team aim to gain further insight into the mechanism causing the antibody deficiency in patients with A-T.



Associate Professor Mirjam Van der Burg

Identifying new therapies for blood cancers in patients with A-T

Principal Researcher: Professor Malcolm Taylor
Institute: University of Birmingham
Start Date: February 2018

Project Summary

Patients with Ataxia Telangiectasia (A-T) have an increased risk of developing blood cancers. These patients do not have a protein called ATM which is important for response to chemotherapy treatment. Consequently, A-T patients experience substantial toxic effects when receiving chemotherapy for their blood cancers. Therefore, new less toxic, blood cancer-specific therapies are urgently required.

Professor Taylor and his team have developed an animal model in which new treatments can be tested. In this model all the mice lack the ATM protein and have reduced development of T cells, a combination which allows them to develop a variety of blood cancers that occur in human A-T patients. Upon investigation of these blood cancers the team noted that a protein called c-Myc



Professor Malcolm Taylor and Team

is particularly active in cancer cells. In this study they will explore different ways of suppressing the action of c-Myc. They will use animals with developed blood cancers to test whether the addition of small molecules that inhibit c-Myc can stop cancer progression, and if these molecules can be used in combination with low doses of chemotherapy. They are hoping that this study will provide new, non-toxic, and effective strategies for the treatment of blood cancers in A-T patients.

The team will test small molecule inhibitors that are already in clinical trials. Given that these new compounds are already being assessed in other patients, they anticipate that following completion of this study, they will be in a position to directly inform optimal treatment of the most frequent blood cancers in A-T patients. If any of these new inhibitors prove to be efficient, the reduced toxicity associated with their use will be hugely beneficial for A-T patients. It will lessen problems associated with toxicities such as infection and bone marrow depletion.

Longitudinal brain changes in childhood A-T

Principal Researcher: Dr Rob Dineen
Institute: University of Nottingham
Start Date: April 2018

Project Summary

In their previous CATNAP study, Dr Rob Dineen and his team carried out brain MRI scans on 24 children with A-T and 24 without A-T. They found that measurements on the brain scan were markedly different between participants with and without A-T and some measurements showed a close relationship to the severity of the nervous system problems.

The Nottingham team will invite children and young people who participated in the previous CATNAP study to re-attend for a further MRI scan and clinical assessment. There will be an average gap of 3 years (ranging from around 2 to 4 years) between the first and second visits for these participants, and this time interval will allow them to see how the MRI measurements have changed compared to healthy children, and how the changes in the MRI measurements reflect changes in the levels of disability.



Caroline Blanchard (Research Fellow) & Dr Rob Dineen

They will also invite very young children with A-T who are referred to the UK Paediatric A-T Clinic in Nottingham to take part in the study. These children will have the standard clinical assessment of their neurological disability. They will then undergo careful preparation by a play specialist using Nottingham's new MRI simulator. Having an MRI can be challenging for young children, but they hope to make the experience a positive one, allowing them to obtain the MRI measurements from this age group.

Stem Cell Transplantation for A-T - Project Extension

Principal researcher: Professor Ralf Schubert
Institute: Goethe University, Frankfurt
Project Extension: November 2017

Project Extension Summary

Additional funding was provided to Professor Schubert and his team so that they could continue with their study exploring stem cell transplantation for A-T patients. The project extension allowed the team to perform the analysis of oxidative stress and damage in the lungs of the mice transplanted under a different condition regimen. Oxidative stress and damage is a very important issue in A-T and recent data of their group underlines the sensitivity of the pulmonary tissue to reactive oxygen species and oxidative stress.

In addition, they are now able to add analysis of inflammatory cytokines in the serum of the mice differently transplanted (syngenic, allogeneic and haploidentical), which in their opinion is important for the detection of GvHD especially after allogeneic transplantation.



Professor Ralf Schubert

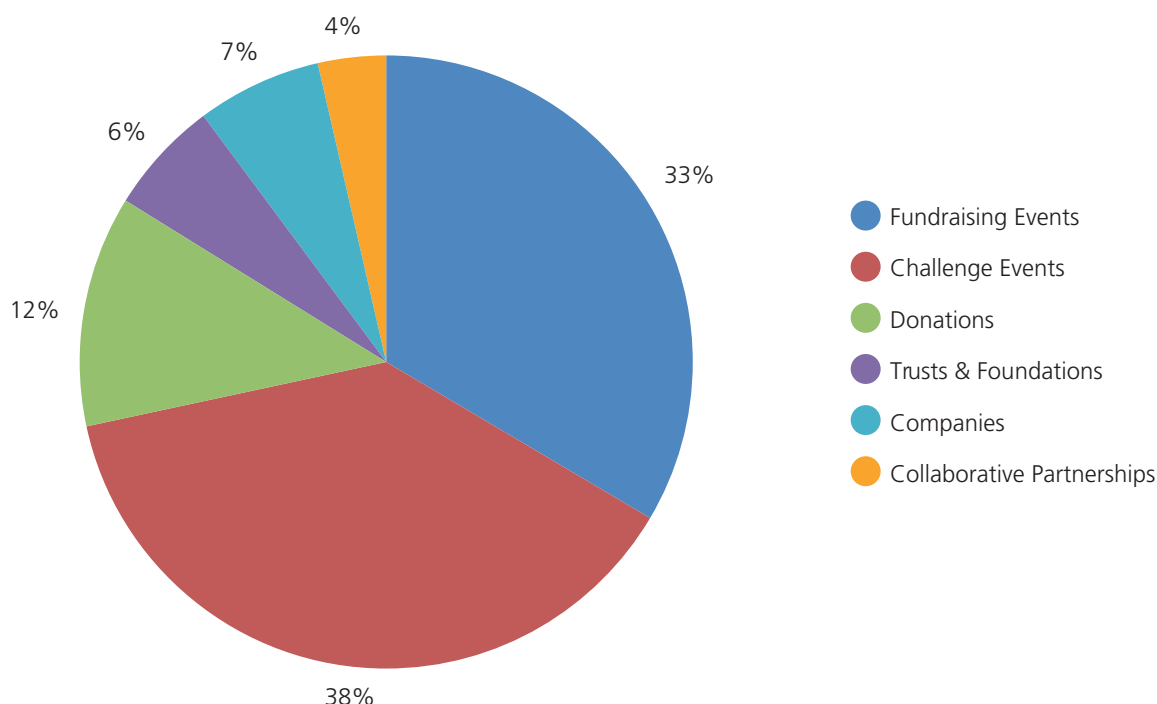
To view all of our current and complete research projects, please visit actionforAT.org

Grant Round

The Trustees currently stage one grant round per year. The application process opens in the late summer / autumn of one year and closes in the spring of the following year. 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 a number of key criteria including available funds, strategic alignment and existing research commitments.

Fundraising for Research

Action for A-T receives all of its funding from voluntary sources, including individuals, companies, trusts and foundations. We also purchase places in a number of physical challenges as well as staging and benefiting from a series of other social and sporting events. The pie chart below shows the percentage splits of each of our areas of fundraising in 2017.



In line with our fundraising strategy we continued to broaden our income base to ensure that we are not solely dependent on any one source of funding.

Challenge and social events remained a key source of income during 2017 generating more than 71% of the Charity's income but other fundraising initiatives, such as company fundraising and trust and foundation applications, provided additional new funds. A number of new fundraising activities took place throughout the year and we are especially grateful to BCA for their support during 2017 as their London to Paris cycle ride generated £93,416. In addition, we would like to thank Quest Professional, GFI, Barclays and St James's Place for their generous corporate support.

We would also like to record our thanks to all of 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 all of the trusts and foundations who have provided grants throughout the year for specific research projects (these are listed on page 38). We are keen to work with other trusts, foundations and corporate funders who might be interested in supporting our work.

Action for A-T is registered with the Fundraising Regulator (previously the Fundraising Standards Board) and is committed to upholding the code of fundraising practice.

Building Collaborative Partnerships

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 third party organisations that may have overlapping aims or objectives to our own. To this aim, we actively seek out like minded organisations and where possible, enter into collaborative partnerships.

Our Performance

Co-funding A-T Research Projects with 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 projects:

- "Optimising lung imaging in people with A-T" - Dr Peter Merkus at the Radboud University Medical Centre, Netherlands
- "Stem Cell Transplantation for A-T" - Dr. Ralf Schubert at the Goethe University Frankfurt, Germany

In addition to the above, the Trustees agreed to partner with Sparks and Great Ormond Street Hospital Charity for their current national funding call which opened on the 31st May 2018. Project grant applications for child health research will be requested from researchers across the UK. The emphasis of this call will be on complex childhood illness, including rare diseases.

Co-funding A-T Research Projects with the US Charity the A-T Children's Project

Action for A-T believes it can benefit from a strong relationship with the leading A-T research charity in the United States, The A-T Children's Project (A-TCP).

A-TCP was established in 1993 and has been the vanguard of global research into A-T, including providing funding for the work that led to identification of the ATM gene which is defective in people with A-T.

Action for A-T and the A-T Children's Project joined forces at the end of 2016 to fund a new gene therapy study at The Gurdon Institute at the University of Cambridge. Both organisations are jointly funding and managing the following project:

- "Identifying potential mechanisms to suppress A-T pathologies". - Professor Steve Jackson and Dr Rimma Belotserkovskaya, The Gurdon Institute at the University of Cambridge

The 2-year study began in May 2017 and there is an agreement in place for the A-T Children's Project to meet half the cost of the research. Their contribution of £99,555 was recognised in full in the 2016 accounts and treated as a restricted donation. The A-T Children's Project made their first contribution (£23,260) to Action for A-T in 2017.

Both charities will continue to explore additional joint funding opportunities throughout 2017.

Co-funding A-T Research Projects with the Australian charity BrAshA-T Ataxia Telangiectasia

At the end of 2017, Action for A-T established a new collaborative funding partnership with BrAshA-T who are based in Queensland, Australia. BrAshA-T will contribute towards the following new UK based research projects in 2018.

- "Identifying new therapies for blood cancers in patients with A-T" - Professor Malcolm Taylor, University of Birmingham
- "Longitudinal brain changes in childhood A-T" - Dr Rob Dineen, University of Nottingham

BrAshA-T was founded in 2007 by Sean and Krissy Roebig after two of their young children, Brady and Ashleigh, were diagnosed with A-T. Determined to do something about their situation, the Roebigs created the charitable foundation to raise money to support research into finding a cure and as a means for creating a support network for other families dealing with A-T. Through working together, both charities believe more can be achieved to help develop treatments and work towards a cure for A-T.

Raising Public Awareness about A-T

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 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 A-T research at various events throughout the year. Numerous celebrities attended our golf days and several joined some of our beneficiaries at the GFI Charity Trading Day in September. These included Jeremy Guscott, Jason Leonard, Simon Shaw and Naga Munchetty. Naga has since agreed to become a charity Patron and is taking part in several cycling events in 2018. Jeremy Guscott also chose Action for A-T as the benefiting charity at another City of London event in November.



Naga Munchetty

Visibility at Conferences and Medical Meetings

All Action for A-T funded researchers are provided with a wall plaque to display at their research facility and required to acknowledge our financial support by including our logo on any presentations. Throughout the year, representatives from the Charity and the research community gave speeches at various medical conferences and events. These speeches showcased our collaborative partnerships, latest research projects as well as providing an overview on how we are investing donated funds. They provided information about the condition and its effects on the children and families who live with the effects of A-T.

Digital Communications

The Charity website actionforAT.org remains the focal point for event sign-ups, electronic donations and research news. We update and enhance the site on an ongoing basis to provide the best possible experience for our stakeholders. At the end of 2017 we upgraded the events pages to enhance the user experience and make the area easier to navigate.

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 has helped us increase our Facebook likes 5% throughout the year as well as continuing to increase our Twitter following. We will continue to develop our social media presence in 2018 using all available technological advancements and popular platforms to raise further awareness.



Stamford Green Primary School Pupil

Branded Materials

The Charity continued to develop a variety of branded materials for distribution to potential and existing supporters and for use at events. These materials included charity information leaflets and postcards, a calendar which was sent to supporters and a series of materials to assist individuals with the promotion of their fundraising activities. We also increased our investment in pull up and pop up banners for use at events and continued to invest in branded clothing for our challenge event participants.

National and Local News Media Coverage

We have 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. These have helped us to highlight the condition to new audiences, recruit volunteers and secure additional support and donations.

Film

With no new fundraising films produced in 2017, we adapted and used existing material so that it could be used at various events or sent directly to potential supporters. We increased our portfolio of research films throughout the year featuring some of the UK researchers we are currently funding. These films are available to view alongside the project information on our website and provide an overview of specific areas of research as well as highlighting some of the complications of the condition.

All of our awareness raising, and fundraising films are available to view on our website, Vimeo and YouTube channels.

vimeo.com/actionforat/videos

www.youtube.com/channel/c/ActionforatOrg

Our Future Plans: Areas of Focus for 2018

The Trustees believe that Action for A-T has a sound financial basis upon which to build for the future but have also identified the need for further development if we are to strengthen our research activities. During 2018 we will increase our fundraising activities and actively seek out other funding partnerships to meet the demands of the A-T research community. We will also continue to explore opportunities to promote A-T research rather than simply responding to applications for grant funding.

We will implement a number of 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.

Building 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 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 well positioned for the future. In 2018 we will:

- Prioritise key projects based on available resources
- Developing our data management and communication processes to ensure that we meet or exceed the needs of the new GDPR data regulations
- Explore new and enhance existing fundraising Initiatives to provide the maximum return on investment
- Ensure that we have the necessary skills throughout the organisation to deliver our organisation wide objectives
- Keep up to date with current trends and remain flexible so that change can be implemented quickly if required

Working Closely with Others to Meet our Objectives

As our reach expands throughout the A-T world, we are less able to meet the increasing demands of the research community. The number of funding applications we receive continues to grow steadily year on year and we often have more fundable research projects than we can afford. 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 for A-T.

Strengthening and Increasing our Fundraising Activities

Our Head of Fundraising will continue to develop a pipeline of new business opportunities whilst delivering our existing portfolio of activities. We will maintain 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 build on the initial successes of our trust and foundations programme whilst developing the funds generated from individual and major donors. We will also work closely with our key supporters and volunteer groups to meet the increased demand from the research community.

Including our Beneficiaries in our Fundraising Efforts

Since the charity was established in 2012, thousands of supporters have taken part in our events to help raise funds for A-T research but most of these events have not been suitable for individuals with disabilities. In 2018, we will establish a series of physical activities which will accommodate all supporters including the children and families living with A-T. Planned activities scheduled to date include: A child with A-T completing a full Marathon in an adapted wheelchair and twins with A-T attempting to reach the summit of Mount Snowdon. Both families will be assisted by a large team of supporters.



The Big Push Team

Making our Funds Work Harder

Funds committed to research projects are normally paid out in arrears and are currently safely deposited in the Charity bank account. As we receive minimal interest on these deposits we will explore alternative investment opportunities to ensure that our allocated funds gain a better return with minimal risk.

Continuing our Investment in Medical Research in the UK and Abroad

We will continue our investment in the highest quality A-T research around the globe whilst actively seeking out new funding opportunities here in the UK. Where possible, we will continue to collaborate with other research charities whilst actively seeking new partners.

We will maintain our close relationship with the Association of Medical Research Charities (AMRC) and work alongside our Scientific Advisor to develop and improve our peer review process and to 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 a number of A-T experts around the globe.

We will review and refresh the membership of our Research Advisory Committee to ensure that we have a broad range of scientific expertise in areas relating to A-T as well as lay representation from various A-T families as Action for A-T supports public and patient engagement in its research processes.

We will build on our existing relationships within the research community here in the UK to increase our UK based research portfolio and will continue our investment in UK based research fellowships with a view to producing the next generation of A-T researchers.

Board Composition

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

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.

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 also 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 main focus is on awarding grants for medical research and two meetings where Trustees review strategy and set operating plans and budgets. There is a review of operating and financial performance at every meeting. The Chief Executive is invited to attend all meetings of the Trustees and the Head of Fundraising is invited to report on plans and progress at specific meetings.

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

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

The 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 in order 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 of 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 on the basis of 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

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 particular 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.

Investment Policy

The overall policy of the Charity is to maintain a designated funds bank account 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

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.

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 principle source of funding is donations from individuals, companies, and proceeds of fundraising events.

Total income raised in 2017 was **£648,392 (2016 - £626,779)**.

Charitable Expenditure

The cost spent on Charitable Activities Was **£593,406 (2016 - £568,691)** of which **£547,953 (2016 - £540,615)** was for grants provided for funding of research projects.

The cost of generating voluntary income was **£61,776 (2016 - £59,783)** whilst the cost of generating income from charitable events was **£179,291 (2016 - £146,657)**

Governance costs **£13,858 (2016 - £12,779)** 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 2016

In 2017, **£419,142** of funds were passed on to the research projects detailed in note 8 on page 33.

As at 31 December 2017 designated funds carried forward are **£nil**.

Restricted Funds

Restricted funds of **£nil** were brought forward from 2016. During 2017, **£128,811** of funding was made to the research projects detailed in note 8 Page 33.

At 31 December 2017 no restricted funds 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.

Auditors

A resolution to re-appoint A&N (Haslemere) Limited will be proposed at the next trustees meeting.

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: 1/10/2018

Dated: 1/10/2018

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 for the year ended 31 December 2017 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement 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, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (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 2017, 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.

In addition, we read all the financial and non-financial information in the Trustees' Annual Report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the 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

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charity's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the trustees' annual report, other than the financial statements and our auditor's report 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 there is a material misstatement in the financial statements or a material misstatement of the other information. 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 in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

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

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement [set out on page 21], the trustees are responsible for the preparation of 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.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with regulations made under section 154 of that Act.

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 an auditor's report 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.

As part of an audit in accordance with ISAs (UK), we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- 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 trustees' 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.
- We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

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 auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the 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: 1/10/2018

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

Financial Statements:

Statement of Financial Activities for the year ended 31 December 2017

	Notes	Unrestricted 2017 £	Restricted 2017 £	Total Funds 2017 £	Total Funds 2016 £
Incoming resources					
Voluntary income:	2				
Donations and legacies		116,185	47,173	163,358	208,631
Activities for generating funds:	3				
Charitable events		481,225	-	481,225	414,532
Investments:	4				
Investment income		537	-	537	616
Other Income:	5				
Sundry income		3,272	-	3,272	3,000
Total income		601,219	47,173	648,392	626,779
Resources expended					
Costs of generating voluntary income:	6				
Voluntary income		61,776	-	61,776	59,783
Costs of activities for generating funds:	7				
Charitable events		179,291	-	179,291	146,657
Costs of charitable activities:	7				
Charitable activities		464,595	128,811	593,406	568,691
Other expenditure:	9				
Governance costs		13,858	-	13,858	12,779
Total resources expended		719,520	128,811	848,331	787,910
Net income / (expenditure)		(118,301)	(81,638)	(199,939)	(161,131)
Transfers between funds		(81,638)	81,638	-	-
Net Movement in funds		(199,939)	-	(199,939)	(161,131)
Total funds at 1 January 2017		493,452	-	493,452	654,583
Total funds at 31 December 2017		293,513	-	293,513	493,452

The statement of financial activities includes any gains and losses recognised in the year.
All income and expenditure derives from continuing activities.

The net movement in funds referred to above is the net incoming resources as defined in the Statement of Recommended Practice for Accounting and Reporting issued by the Charity Commission for England and Wales and is reconciled to the total funds as shown in the Balance Sheet on page 26 as required by the said statement.

Financial Statements: Balance Sheet

At 31 December 2017

	Notes	2017 £	£	2016 £	£
Fixed assets					
Tangible fixed assets	10	600		-	
			600		-
Current assets					
Stock		9,702		6,171	
Debtors	11	156,637		153,256	
Cash at bank		1,110,134		914,068	
		1,276,473		1,073,495	
Liabilities					
Amounts due within one year	12	396,880		307,609	
Total assets less current liabilities			879,593		765,886
Creditors: Amounts falling due after more than one year;	12		586,680		(272,434)
Net assets			<u>293,513</u>		<u>493,452</u>
Charity funds					
Restricted funds	14	-		-	
Unrestricted funds	14	293,513		493,452	
			<u>293,513</u>		<u>493,452</u>

The Trustees declare that they have approved the financial statements.

Signed on behalf of the charity's Trustees.



Toby Read (Chairman)



William Rowberry (Treasurer)

Dated: 1/10/2018

Dated: 1/10/2018

Financial Statements: Cashflow

At 31 December 2017

	Notes	Total Funds 2017 £	Prior Year Funds 2016 £
Cash flows from operating activities:			
Net cash provided by operating activities	20	196,429	99,647
Cash flows from investing activities:			
Interest		537	616
Fixed assets		(900)	-
Net cash provided by investing activities:		(363)	616
Cash flows from financing activities:			
Net cash provided by financing activities		-	-
Change in cash and cash equivalents in the reporting period		196,066	100,263
Cash and cash equivalents brought forward	21	914,068	813,805
Cash and cash equivalents carried forward	21	1,110,134	914,068

Financial Statements: Notes to the Financial Statements

At 31 December 2017

1. Accounting Policies

Basis of preparation of financial statements

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2015), Charities SORP FRS102, the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102).

Assets and liabilities are initially recognised at historic cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Legal form

The Charity is an unincorporated registered charity defined by its governing document.

Accounting convention

The financial statements are prepared on a going concern basis, under the historic cost convention. The Charity is a Public Benefit Entity as defined by FRS102.

The accounts have been prepared in sterling, which is the functional currency of the Charity. Monetary values in these financial statements are rounded to the nearest £.

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.

Going concern basis

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

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.

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.

Financial Statements: Notes to the Financial Statements

At 31 December 2017

Accounting Policies (cont)

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.

Foreign currency

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.

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.

Taxation

The Charity is exempt from tax on its charitable activities.

Irrecoverable VAT

Irrecoverable VAT is charged against the expenditure heading for which it was incurred.

Financial instruments

The Charity only has financial assets and liabilities which qualify as basic financial instruments. These are initially valued at their transaction value and subsequently measured at their settlement value.

Stocks

Stock is valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items. Cost is based on the purchase price of the item plus any additional costs of enhancement to bring the item to the point at which it is auctioned or provided as technical wear to challenge event participants using a first in first out basis.

Tangible fixed assets

Depreciation is provided at the following annual rate in order to write off the cost less estimated residual value of each asset over its estimated useful life.

Office equipment 33.33% straight line depreciation

Pension costs

Employees are automatically enrolled into a money purchase scheme unless they exercise their right to opt out of the scheme. The contributions are charged to the SOFA in the period to which they relate.

Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees may be required to make assumptions, estimates and judgements about the carrying values of assets and liabilities that are not readily apparent from other sources.

These are based on previous experience and other factors that are considered by the trustees to be relevant. Ultimately, actual results may differ from these estimates.

Any such estimates and assumptions are subject to review on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the revision takes place where the revision affects only that period, or in the period of the revision and any future periods where the revision affects both current and future periods.

Financial Statements: Notes to the Financial Statements

At 31 December 2017

2. Income From Donations And Legacies

	Unrestricted 2017 £	Restricted 2017 £	Total Funds 2017 £	Total Funds 2016 £
Donations	61,517	47,173	108,690	70,754
Gift Aid claims	17,283	-	17,283	9,730
Fundraising	37,385	-	37,385	128,147
Legacies	-	-	-	-
	116,185	47,173	163,358	208,631

Volunteer Services

No volunteers provided unpaid services to the Charity during the year. During the previous year (2016) no hours were provided. Trustees have previously valued voluntary hours at a rate of £10.50 per hour.

3. Income From Charitable Activities

	Unrestricted 2017 £	Restricted 2017 £	Total Funds 2017 £	Total Funds 2016 £
Fundraising events	232,883	-	232,883	174,503
Challenge events	248,342	-	248,342	240,029
	481,225	-	481,225	414,532

4. Income From Investments

	Unrestricted 2017 £	Restricted 2017 £	Total Funds 2017 £	Total Funds 2016 £
Bank interest	537	-	537	616
	537	-	537	616

5. Other Income

	Unrestricted 2017 £	Restricted 2017 £	Total Funds 2017 £	Total Funds 2016 £
Employment allowance	3,000	-	3,000	3,000
Sundry receipts	272	-	272	-
	3,272	-	3,272	3,000

6. Costs Of Generating Voluntary Income

	Unrestricted 2017 £	Restricted 2017 £	Total Funds 2017 £	Total Funds 2016 £
Voluntary Income:				
Film	600	-	600	1,200
Administrative Costs	23,841	-	23,841	23,387
Donation Collection Fees	11,913	-	11,913	12,690
Insurance	843	-	843	554
Telephone	2,107	-	2,107	1,874
Bank Charges	2,610	-	2,610	1,653
Subscriptions	252	-	252	569
Sundry Expenses	672	-	672	430
Information Technology	1,848	-	1,848	1,383
Office Rent	12,269	-	12,269	11,086
Marketing	2,212	-	2,212	3,781
Printing And Stationery	2,609	-	2,609	1,176
	61,776	-	61,776	59,783

7. Costs Of Activities For Generating Funds

	Unrestricted 2017 £	Restricted 2017 £	Total Funds 2017 £	Total Funds 2016 £
Cost of Charitable Events:				
Event costs	179,291	-	179,291	146,657
	179,291	-	179,291	146,657
Costs of Charitable Activities:				
General Funds:				
Research support costs	44,039	-	44,039	49,724
Designated Funds:				
Grants to research institutions (Note 8)	419,142	128,811	547,953	540,615
Exchange losses/(gains)	1,414	-	1,414	(21,648)
	464,595	128,811	593,406	568,691

8. Grants To Research Institutions

	Unrestricted 2017 £	Restricted 2017 £	Total Funds 2017 £	Total Funds 2016 £
Restricted Funds:				
University of Birmingham - Prof. Malcolm Taylor	-	128,811	128,811	-
University of Nottingham - Dr Bhatt & Dr Prayle	-	-	-	94,839
University of Cambridge - Prof. Steve Jackson	-	-	-	199,111
Radboud University Netherlands - Dr Merkus	-	-	-	47,443
Designated Funds:				
Duke University - Prof. Mike Kastan	19,898	-	19,898	-
Goethe University, Frankfurt - Prof. Ralph Schubert	6,355	-	6,355	-
Leiden University Medical Centre (LUMC), The Netherlands - Prof. Van der Burg	100,000	-	100,000	-
Royal Holloway University of London - Professor Rafael Yáñez-Muñoz	200,000	-	200,000	-
University of Nottingham - CATNAP Study Part 2	92,966	-	92,966	24,018
University of Sheffield - Dr Grierson	-	-	-	88,710
The FIRC Institute Milan - Dr Constanzo	-	-	-	99,936
Research project underspends refunded				
University of Cambridge - Prof. Steve Jackson	(77)	-	(77)	-
University of Nottingham - CATNAP Study Part 1	-	-	-	(9,028)
University of Granada - Prof. Molina	-	-	-	(3,266)
Sparks A-T Network Fund	-	-	-	(1,148)
	419,142	128,811	547,953	540,615

9. Other Expenditure

	Unrestricted 2017 £	Restricted 2017 £	Total Funds 2017 £	Total Funds 2016 £
Governance costs:				
Salaries	7,525	-	7,525	7,407
Auditors remuneration	3,280	-	3,280	2,910
Accountancy	1,250	-	1,250	1,550
Professional fees	655	-	655	426
Travel	67	-	67	486
Sundry	781	-	781	-
Depreciation	300	-	300	-
	13,858	-	13,858	12,779

10. Tangible Fixed Assets

Cost

Additions
Disposals

At 31 December 2017

Depreciation

Charge for the year
Eliminated on disposal

At 31 December 2017

Net Book Value

At 31 December 2017
At 31 December 2016

Office Equipment £	Total £
900	900
-	-
900	900
300	300
-	-
300	300
600	600
-	-

11. Debtors: Amounts Falling Due Within One Year

Other debtors
Restricted donations

At 31 December 2017

2017 £	2016 £
80,339	53,701
24,764	49,778
105,103	103,479

Debtors: Amounts Falling Due After One Year

Restricted donations

At 31 December 2017

2017 £	2016 £
51,534	49,777
51,534	49,777
156,637	153,256

12. Creditors: Amounts Falling Due Within One Year

Grants
Other taxes and social security
Accruals and deferred income
At 31 December 2017

2017 £	2016 £
371,135	302,373
471	-
25,274	5,236
396,880	307,609

Creditors: Amounts Falling Due After One Year

Grants

At 31 December 2017

2017 £	2016 £
586,680	272,434
586,680	272,434

13. Corporate Taxes

The Charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

14. Statements Of Funds

	Brought Forward £	Incoming Resources £	Resources Expended £	Transfers In/(Out) £	Carried Forward £
University of Sheffield - Dr Grierson	-	2,250	(-)	(2,250)	-
University of Nottingham - Dr Bhatt & Dr Prayle	-	38,200	(-)	(38,200)	-
University of Cambridge - Prof. Steve Jackson	-	1,000	(-)	(1,000)	-
University of Birmingham - Prof. Malcolm Taylor	-	5,723	(128,811)	123,088	-
					-
Restricted funds	-	47,173	(128,811)	£81,638	-
Designated funds					
University of Nottingham CATNAP Study - Dr Robert Dineen	-	-	(92,966)	92,966	-
Leiden University Medical Centre (LUMC), The Netherlands - Prof. Van Der Burg	-	-	(100,000)	100,000	-
Royal Holloway University of London - Prof. Yáñez-Muñoz	-	-	(200,000)	200,000	-
Goethe University, Frankfurt - Prof. Ralph Schubert	-	-	(6,355)	6,355	-
Duke University - Mike Kastan	-	-	(19,898)	19,898	-
University of Cambridge - Prof. Steve Jackson	-	-	77	(77)	-
General funds	493,452	601,219	300,378	(500,780)	293,513
Unrestricted funds	493,452	601,219	719,520	(81,638)	293,513
Total Funds	493,452	648,392	848,331	-	293,513

Restricted Funds

1. Dr Andrew Grierson of Sheffield Institute for Translational Neuroscience (SITraN) & The Bateson Centre (University of Sheffield) has been funded to research the use of Zebrafish to study gene mutation. During the year restricted donations were received towards this funding and due to this having been funded from general reserves the restricted income was transferred to offset these general fund.
2. Dr Jayesh Bhatt and Dr Andrew Prayle of Nottingham University Hospitals NHS Trust has been funded to the value of £94,839 for the IMAGIN-AT advanced lung imaging and function testing in Ataxia Telangiectasia research project. Restricted donations totalling £38,200 were received against this funding and due to this having been funded from general reserves the restricted income was transferred to offset these general funds.
3. Professor Steve Jackson and Dr Rimma Belotserkovskaya of The Gurdon Institute (University of Cambridge) have been funded to extend the work previously carried out by Professor Steve Jackson and his team into identifying potential mechanisms to suppress A-T pathologies. The project will be funded in full by Action for A-T but it has been agreed with US based A-T Children's Project that they will contribute towards the overall cost during the latter part of 2017 and 2018. During the year restricted donations were received towards this additional research. Due to this having been funded from general reserves the restricted income was transferred to offset these general funds.
4. Funding of £128,811 was agreed during the year to fund Professor Malcolm Taylor at the University of Birmingham. During the year restricted donations were received towards this research funding. The funding was approved and contracts signed, but the funds will be paid in future periods.

Designated Funds

5. A further contribution of £92,966 was agreed in the year to Dr. Dineen for the continuation of the CATNAP study (Part 2) at Nottingham University.
6. Funding was agreed for £100,000 during the year to Professor Van der Burg in the Netherlands. No funds were paid over during the year and will be paid in future periods.
7. Funding was agreed for £200,000 during the year to Professor Rafael Yáñez-Muñoz at the Royal Holloway, University of London. No funds were paid over during the year and will be paid in future periods.
8. Funding totalling £6,355 was paid to Professor Ralph Schubert at Goethe University, Frankfurt for research. These funds were paid during the year.
9. The final funding for Professor Mike Kastan - Duke University was paid during the year.
10. There was an underspend of £77 on the conclusion of the research project carried out by Prof. Steve Jackson - University of Cambridge.

Transfer Between Funds

11. Where restricted or designated funds received are exceeded by the corresponding expenditure a transfer will be made from general reserves to ensure those funds are not held in deficit. Where designated funded projects end with surplus funds these will be transferred back to general reserves.

15. Analysis Of Staff Costs

	2017 £	2016 £
Salaries and wages	102,340	99,867
Social security costs	11,877	11,164
Pension contributions	1,595	-
	115,812	110,031

Salary Bands

	2017 £	2016 £
£80,000 or more	-	-
£70,000 - £79,999	-	-
£60,000 - £69,999	1	1

The Charity considers its key management personnel to be the Trustees and the Chief Executive. The total employment benefits of the key management personnel were £75,253 (2016 - £74,072). Only one employee had employment benefits falling between £60,000 and £69,999 (2016 - 1).

16. Staff Numbers

During the year the average number of full time employees was two (2016 - two).

17. Related Party Transactions And Trustees' Expenses

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2016 - £nil). Expenses paid to the Trustees in the year are detailed below. 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.

Mr T Read, the Chairman of Action for A-T was reimbursed £nil (2016 £nil) of expenses during the year.

Mrs E Read, a Trustee of Action for A-T was reimbursed £nil (2016 £nil) of expenses during the year.

Mr W Rowberry, the Treasurer of Action for A-T was reimbursed £nil (2016 £nil) of expenses during the year.

Mr T Shillingford, a Trustee of Action for A-T was reimbursed £nil (2016 £nil) of expenses during the year.

Mrs M Leonard, a Trustee of Action for A-T was reimbursed £nil (2016 £nil) of expenses during the year.

Mrs S Cornell, a Trustee of Action for A-T was reimbursed £nil (2016 £nil) of expenses during the year.

Mr C Askew, a Trustee of Action for A-T was reimbursed £nil (2016 £nil) of expenses during the year.

Dr M Toms, a Trustee of Action for A-T was reimbursed £nil (2016 £nil) of expenses during the year.

During the year, Mrs C Wall, (the sister of Mrs E Read) invoiced and was paid £nil (2016 - £2,050) for marketing expenses. This was with the full agreement of the other trustees and was on an arms-length basis.

18. Controlling Interest

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

19. Operating Lease Commitments

During the next twelve months the Charity has operating lease commitments totalling £12,514 (2016 - £12,456) for contracts expiring in more than one year. The total future commitments are £12,514 in total.

20. Reconciliation Of Net Movement In Funds To Net Cash Flow From Operating Activities

	Total Funds 2017 £	Prior Year Funds 2016 £
Net income for the reporting period (as per the SOFA)	(199,939)	(161,131)
Adjustments for:		
Depreciation charges	300	-
Interest from investments	(537)	(616)
(Increase) / decrease in stocks	(3,531)	5,307
(Increase) / decrease in debtors	(3,381)	(69,750)
Increase/ (decrease) in creditors	403,517	325,837
Net cash provided by operating activities	196,429	99,647

21. Analysis Of Cash and Cash Equivalents

	Total Funds 2017 £	Prior Year Funds 2016 £
Cash in hand	1,110,134	914,068
Termed deposits	-	-
Total cash and cash equivalents	1,110,134	914,068

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 2017:

Our Research Partners

The Sparks Children's Medical Research Charity and their Medical and Parents Advisory Committees

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

BrAshA-T Ataxia Telangiectasia and their Trustees

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.

An Anonymous Trust Fund
Annie Tranmer Charitable Trust
Allergan Foundation
Alliance Bernstein
Autotask
Barclays
BCA
Big Give
Chapman Charitable Trust
Compasses Public House
Cyance
DAR Group
George and Esme Pollitzer Charitable Settlement
GFI Group
Global Entertainment
Hamamelis Trust
Hospital Saturday Fund
James Wise Charitable Trust
Lillie Johnson Charitable Trust
Limoges Charitable Trust
Lumen Financial Planning Limited

Lynn Foundation
Lloyds Football Club
Mace Group
Marks & Spencer Haslemere
Michael and Anna Wix Charitable Trust
Quest Professional
Rawson Digital
Robin Hewison
Sir Samuel Scott of Yews Trust
St. James' Place Foundation
Steelcase
Wasps Legends Charitable Foundation

Corporate or professional services provided by:

A & N Chartered Accountants
Akin Gump
Candyswall
Chris Stanton
Framework Digital
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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