

**ACTION  
FOR A-T**

**FUNDING  
RESEARCH,  
FINDING HOPE**



# Annual Report & Financial Statements

for the year ended 31st December 2018

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  
 Samantha Cornell  
 Chris Askew  
 Dr Mark Toms

### 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, Jodrell Professor of Physiology, Department of Neuroscience, Physiology and Pharmacology, University College London (UCL)

Associate Professor Esther Becker, Associate Professor of Neurobiology, The Becker Group, Oxford University

Dr Simon Boulton, Group Leader, DNA Damage Response Laboratory, Cancer Research UK, London Research Institute

Dr Lisa Bunn, Lecturer in Neurological Physiotherapy and Motor Control, University of Plymouth

Professor Sophie Hambleton, Professor of Paediatrics and Immunology, Institute of Cellular Medicine, Newcastle University

Dr Richard Kay, Medical Statistician

Dr Ian Kill, Director for the Cell and Chromosome Biology Centre & Senior Lecturer in Human Cell Biology, Brunel University, London

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

Dr Kevin Southern, Lead Respiratory Consultant, Alder Hey Children's Hospital, Liverpool

Professor Maria Grazia Spillantini, Professor of Molecular Neurology, John Van Geest Centre for Brain Repair, University of Cambridge

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

Dr Alastair Wilkins, Reader in Neurology, University of Bristol and Consultant Neurologist at Frenchay Hospital, Bristol.

### Patient Representatives

Mr Amandeep Sharma  
 Mrs Clare Gallagher

### 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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## 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

It has been a hugely active and productive year at Action for A-T with a significant portfolio of research studies being progressed.

I'm very encouraged to be able to report that during the course of 2018 Action for A-T was concurrently funding a record 10 ongoing research projects in laboratories around the world and also co-funded a further two US based studies through our partnership with the US Charity, the A-T Children's Project.

For a small charity, this level of research activity is a very significant achievement. To be supporting so many of the leading scientific teams in the global A-T medical community is exactly the reason this charity was founded and is testament to the efforts of everyone that supports Action for A-T.



Emily and Toby Read

For all the great work that is being done, there can be no resting on laurels. Medical research is iterative in nature and we anticipate that many of the ongoing projects will lead to follow on investigations, which we also hope to be in position to fund. Any such follow on studies will be in addition to the record 16 new research grant applications in our late 2018 grant round, demonstrating clearly the need to continue our fundraising efforts to support the A-T research community.

In addition to our own fundraising efforts, we continue to look to other sources of funding to be able to continue to build on the body of A-T understanding. I am delighted to report that in 2018 Action for A-T entered into important collaboration agreements with the Children's Medical research charities Action Medical Research and SPARKS (part of Great Ormond Street Children's Hospital). We very much look forward to identifying suitable research initiatives that we can co-fund with these highly respected research organisations.

As ever, all of the encouraging work being undertaken by Action for A-T has only been made possible because of you, our small but growing army of supporters, donors, volunteers, staff, medical advisors, partners, trustees, ambassadors and Trustees. A huge thank you to all of you for helping Action for A-T to continue to take important steps towards a treatment or a cure for A-T.

A handwritten signature in black ink, which appears to read 'Toby Read'.

**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 2018.*

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 2018. 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 6 to 11.

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

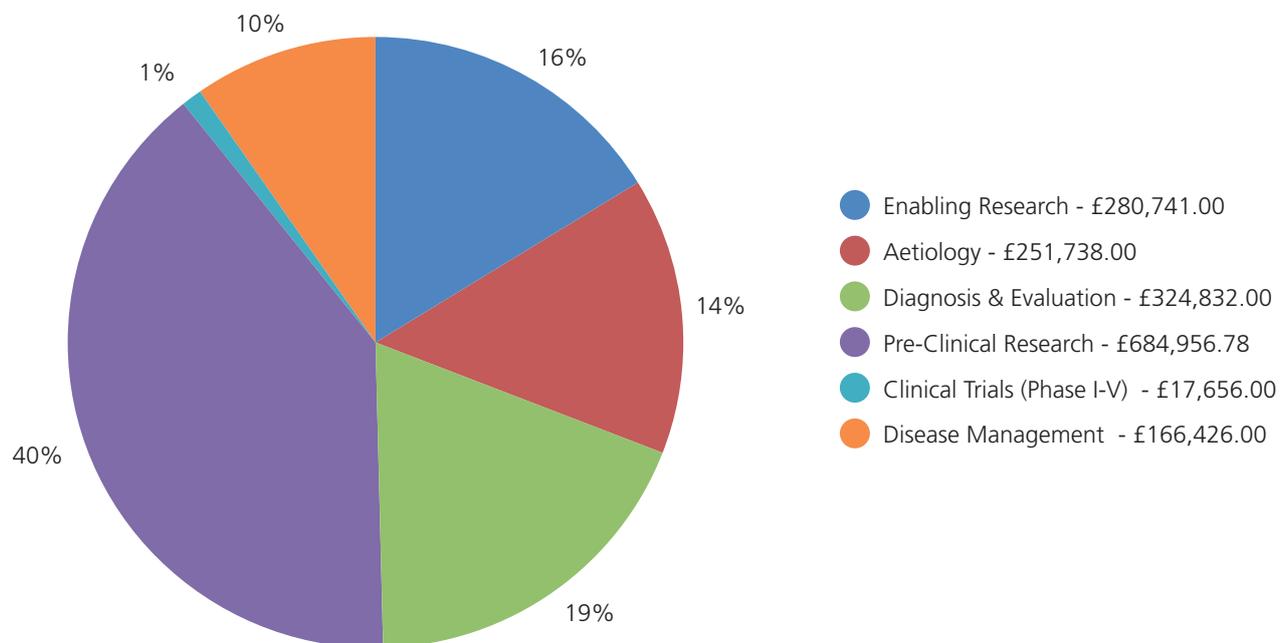
### Continuing our investment in A-T research

We made new grant commitments totalling £67,656 in 2018, bringing our total research investment since the Charity was established to £1,726,349.78. These funds have been committed to 29 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
- Clinical Trials (Phase I-V) - Studies to prove how new treatments work and understand how to use them
- 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 vigorous peer review process and only those deemed to be of the highest quality (as agreed by our Research Advisory Committee and Trustees) are passed for funding.*

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

In the summer of 2018, Action for A-T entered into collaborative funding partnerships with the charities Action Medical Research and Sparks in order to maximise the potential investment into A-T research. Each organisation ran open grant rounds including calls for research applications into A-T on the understanding that Action for A-T would contribute towards the cost of any successful applications. We were encouraged to see A-T specific research project applications were generated through these channels, although on this occasion none of the applications passed the stringent peer review processes operated by the various organisations.

Action for A-T administered its own full grant round at the end of September 2018 with a view to awarding grants in early summer 2019. A record number of applications (16) were received from a variety of global research institutions which will

undergo our rigorous award winning peer review process to provide assurance to our Trustees and ensure that the money generously raised by our donors is put to the best possible use.

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.

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 2018, our Chief Executive 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 greater 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 received a record number of new applications for funding with a combined investment requirement of more than £1.6million.

## 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 concluded 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 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 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

There were no previously funded projects which concluded in 2018. Full details of the following ongoing projects can be found on our website:

#### Longitudinal brain changes in childhood A-T

**Principal researcher:** Dr Rob Dineen  
**Institute:** University of Nottingham  
**Start Date:** April 2018  
**Website:** <https://actionforat.org/brain-changes/>

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

**Principal researcher:** Professor Malcolm Taylor  
**Institute:** University of Birmingham  
**Start Date:** February 2018  
**Website:** <https://actionforat.org/blood-cancers/>

#### 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  
**Website:** <https://actionforat.org/unravelling-antibody-deficiency-ataxia-telangiectasia/>

#### Stem cell transplantation for A-T – Project extension

**Principal researcher:** Professor Ralf Schubert  
**Institute:** Goethe University, Frankfurt  
**Start Date:** November 2017  
**Website:** <https://actionforat.org/stem-cell-transplantation-for-a-t/>

#### 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  
**Website:** <https://actionforat.org/crispr/>

## Optimising lung imaging in people with Ataxia Telangiectasia (A-T) applying improved MRI techniques

**Principal researcher:** Dr Peter Merkus

**Institute:** Radboud University Medical Centre, the Netherlands

**Start Date:** November 2017

**Website:** <https://actionforat.org/optimising-lung-imaging-in-people-with-ataxia-telangiectasia-applying-improved-mri-techniques/>

## IMAGIN-AT – Advanced lung imaging and function testing in Ataxia Telangiectasia

**Principal researcher:** Dr Jayesh Bhatt and Dr Andrew Prayle

**Institute:** Nottingham University Hospitals NHS Trust

**Start Date:** October 2017

**Website:** <https://actionforat.org/imagin-a-t/>

## Identifying potential mechanisms to suppress A-T pathologies

**Principal researcher:** Professor Steve Jackson and Dr Rimma Belotserkovskaya

**Institute:** The Gurdon Institute, University of Cambridge

**Start Date:** May 2017

**Website:** <https://actionforat.org/identifying-potential-mechanisms-suppress-t-pathologies/>

## A Zebrafish model of A-T

**Principal researcher:** Dr Andrew Grierson

**Institute:** Sheffield Institute for Translational Neuroscience (SITraN) & The Bateson Centre, University of Sheffield

**Start Date:** April 2017

**Website:** <https://actionforat.org/zebrafish-model-ataxia-telangiectasia/>

## The Stephen Green project for the study and treatment of DNA production defects in Ataxia Telangiectasia

**Principal researcher:** Dr Vincenzo Costanzo

**Institute:** IFOM – The FIRC Institute of Molecular Oncology, Milan, Italy

**Start Date:** December 2016

**Website:** <https://actionforat.org/the-stephen-green-project/>

During the 2018 accounting period, Action for A-T made the following contributions towards research projects managed by the A-T Children's Project in the USA

## Non-viral gene therapy for Ataxia Telangiectasia

**Principal researcher:** Dr James Dixon

**Institute:** University of Nottingham

**Start Date:** September 2018

**Action for A-T have provided £50,000 towards this project**

### Project Summary

Non-viral gene therapy has the potential to safely and cheaply deliver new copies of genes to correct neurodegenerative disorders such as Ataxia Telangiectasia (A-T). Dr Dixon (University of Nottingham, UK) and his team aim to develop and then deploy a system to supply new ATM genes (the gene mutated in A-T patients) and provide a universal therapy for many aspects of the disease, but specifically in this grant the neurodegeneration seen in the brain (cerebellum).

The team will re-engineer a full-length ATM gene both to make it express the missing protein strongly and to make it resistant to being 'turned off' prematurely. These new genes will be packaged into Dr. Dixon's system and tested for activity in patient cells culture and in models of A-T. The team will attempt to deliver the therapy by directly injecting into the brain or through less invasive routes such as lumbar puncture to reach and correct gene defect in the cerebellum.



Dr James Dixon

The initial aim is delivery of synthetic ATM genes into neurons in the brain's cerebellum because they seem to be most affected by the loss of the ATM protein. The objective would be to slow or halt the ataxia and other movement disorders in all A-T patients. While this is still the central aim of Dr. Dixon's work, the engineered ATM gene delivery system could also be used to address the lung infection and cancer symptoms of A-T.

## Genetically tailored splice-modulating therapy for A-T

**Principal researcher:** Dr Timothy Yu

**Institute:** Harvard and Boston Children's Hospital

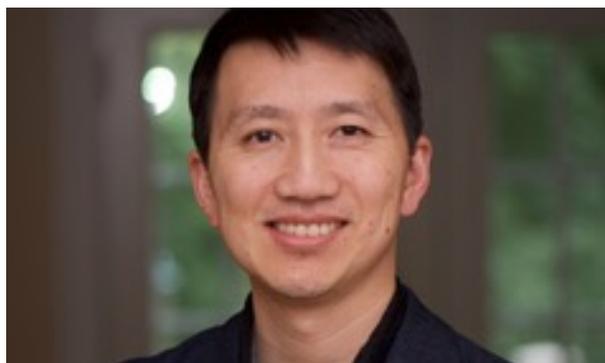
**Start Date:** April 2018

**Action for A-T have provided \$23,000 towards the initial "Design and Test" stage of a new ASO study**

### Project Summary

Several ASO drugs have already been approved by the FDA for other rare diseases such as Duchenne muscular dystrophy, spinal muscular atrophy and cytomegalovirus retinitis and Dr Yu and his team have recently developed an ASO therapeutic for a neurodegenerative disorder named Batten disease.

Dr Yu and his team aim to develop and then deploy an ASO-based splice modulating therapy for Ataxia Telangiectasia as there are currently no effective treatments for A-T, and the size of the ATM gene poses challenges to traditional gene replacement therapy approaches. Antisense oligonucleotide (ASO) therapies have recently come to the fore as a promising therapeutic strategy for genetic disorders of the central nervous system and as ASO drugs are already in existence for other rare conditions, there is a possibility that one could be developed for A-T.



Dr Timothy Yu

Initially, the Boston based team will screen A-T patients with clinically and molecularly confirmed diagnoses to identify at least three patients who bear molecular mutations that may be treatable via splice modulating ASOs. They will then design and test ASOs both in vitro and in animal models, to block abnormal splicing. If these initial tests prove successful, Dr Yu will then seek FDA permission to launch and conduct an N-of-1 clinical trial.

ASO therapy could potentially produce the functional ATM protein that is missing within the cells of children with A-T. Initially, only the youngest A-T kids who have lost the fewest brain cells and who carry a certain type of mutation would be treated with this approach, using personalised drugs for each mutation.

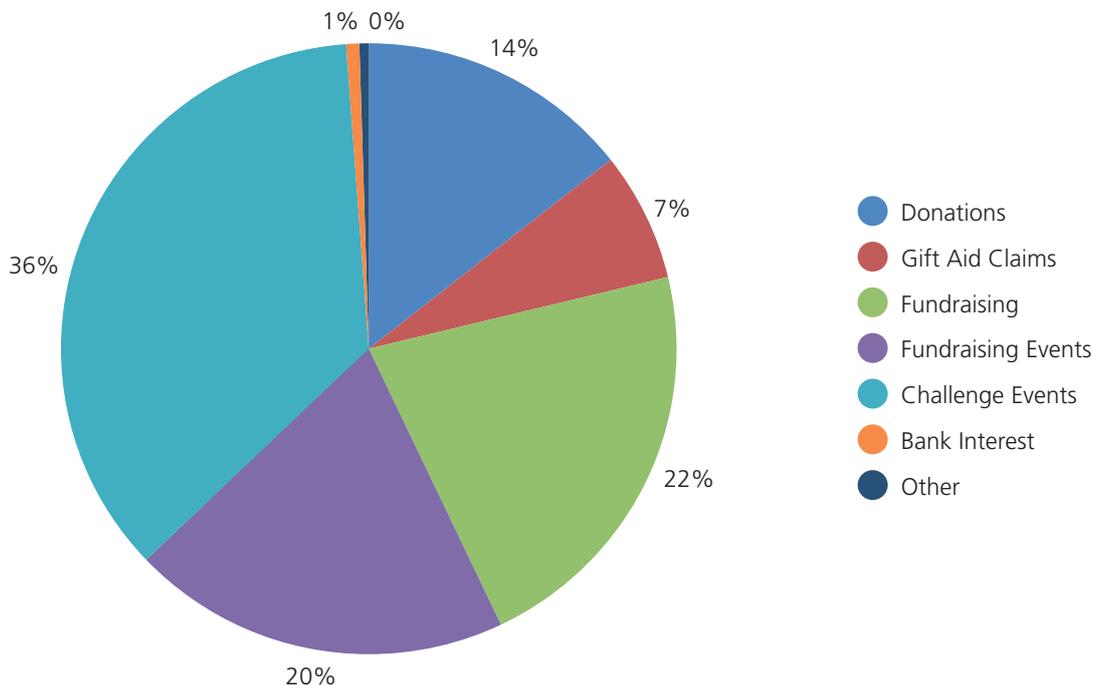
**To view all of our current and complete research projects, please visit [actionforAT.org](http://actionforAT.org)**

## Grant Round

The Trustees generally 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 secure charity 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 2018.



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 fundraising events remained a key source of income during 2018 generating 56% (2017 - 71%) of our overall income whilst other fundraising initiatives, such as corporate partnerships and collaborative funding partnerships accounted for 22% (2017 - 29%). Several new fundraising activities took place throughout the year including a BBC Radio 4 Appeal and a climb of Mount Snowdon which included some of our beneficiaries. We are especially grateful to staff and clients of BCA as their Bedford to Amsterdam cycle ride generated £100,065. In addition, we would like to thank AXIS Capital, 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 36). We are keen to work with other trusts, foundations and corporate funders who might be interested in supporting our work.

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



BCA Bike Ride

## 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 charity Action Medical Research

Action for A-T joined forces with Action Medical Research (AMR) at the end of 2017 and an agreement was put in place for each organisation to contribute £250,000 towards any successful A-T related research applications agreed for funding in 2018. The application process was managed by AMR and all grants were subject to their peer review process. They received six A-T applications and four of these were shortlisted for the final peer review meeting in June but due to various factors, none of these projects were recommended for funding.

Action for A-T will be working with AMR again in 2019 to fund a research training fellowship. Each charity will contribute 50% should a suitable candidate be selected.

#### 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

In addition to the above, the Trustees agreed to partner with Sparks and Great Ormond Street Hospital Charity for their national funding call which opened on the 31st May 2018. Only a few applications were received and none of these were taken forward for full peer review.

We will be partnering with Sparks again in 2019 for their national rare disease funding call which opened at the start of June.

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

Action for A-T and the US based A-T Children’s Project joined forces at the end of 2018 to fund two new research projects. Both studies are being managed by the A-TCP and Action for A-T has agreed to contribute towards each project. The studies are as follows:

- “Non-viral gene therapy for Ataxia Telangiectasia” – Dr James Dixon at the University of Nottingham, United Kingdom
- “Genetically tailored splice-modulating therapy for A-T” – Dr Timothy Yu at the Harvard and Boston Children’s Hospital, USA

Action for A-T have committed £50,000 towards the “Non-viral gene therapy” project and £17,656 (\$23,000) towards the “Genetically tailored splice-modulating therapy”.

In addition to the above, both organisations are jointly funding and managing a project entitled “Identifying potential mechanisms to suppress A-T pathologies” at the Gurdon Institute at the University of Cambridge.

The 2-year study is being carried out by Professor Steve Jackson and Dr Rimma Belotserkovskaya and will conclude in April 2019. There is an agreement in place for the A-T Children’s Project to meet half the cost of the research and 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 further contributions to Action for A-T in 2018 totaling £24,764.

### 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 chose to contribute £50,000 towards the following UK based research projects in 2018 and early 2019.

- “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

A payment of £24,988 was made to Action for A-T in October 2018 and the remaining £25,012 was paid in April 2019.

Action for A-T will continue to explore additional joint funding opportunities with likeminded organisations throughout 2019 to maximise the investment into A-T research.

## 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.



Kevin Whately and Lilly Day

### 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 by championing campaigns and attending various events throughout the year. Kevin Whately provided the voice for our BBC Radio 4 Appeal and Naga Munchetty hosted a golf day, completed the Prudential Ride 100 and cycled from Bedford to Amsterdam. Paralympian Rachel Morris completed the Brighton Marathon alongside a large group assisting an A-T child and numerous other celebrities attended or hosted our golf days including Jeremy Guscott, Leon Haslam, Simon Shaw and Sir Trevor Brooking. 2018 British Superbike Champion Leon Haslam has since agreed to become a charity Patron and he and many other celebrities (including our lead patron Jonny Wilkinson) have provided us with amazing prizes for our event auctions.

### 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 2018 representatives from the research community funded by Action for A-T presented their findings at various medical conferences such as the A-T clinical conference in Naples, Italy. The Action for A-T CEO also spoke on “Innovative Funding Partnerships” at the 9th European Conference on Rare Diseases and Orphan Products in Vienna, Austria. These speeches showcased our collaborative partnerships, latest research projects and provided further details of how we are investing donated funds.

## Digital Communications

The Charity website [actionforAT.org](http://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. In April 2018, the site was upgraded to ensure that we were GDPR compliant, enhance the user experience and assist with navigation.

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.

All of our digital communications were reviewed fully throughout 2018 to ensure that they are GDPR compliant.

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 throughout the year as well as continuing to increase our Twitter and Instagram following. We will continue to develop our social media presence in 2019 using all available technological advancements and popular platforms to raise further awareness.



George Kebell

## 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 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 redesigned our challenge event running and tech tops.

## 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

We created two new films in 2018. The first was entitled "Brighton Heroes" which was created to showcase the incredible efforts of the Brighton Marathon Big Push team who helped an A-T child complete the 26.2mile course. The two part film features our new patron, Rachel Morris (a multi medal winning Paralympian) and was shown on the large screens around the Brighton marathon course. It was also included on the Brighton Marathon official website and in the Big Push section of our website. To date, it has been shared widely on various social media sites by multiple stakeholders including the event organisers.

The second film is entitled "Jenni's Story" and tells the tragic story of Jenni Gallagher who lost her battle with A-T aged 12 years old. The film includes an interview with Jenni's mother and Professor Malcolm Taylor at the University of Birmingham as he and his team are looking to develop a non-toxic therapy for blood cancer in A-T patients. The content is hard hitting and designed to raise awareness about the devastating effects of A-T as well as raising funds for our research programme. It has been played at various events, included on our website and shared widely on various social media channels.

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

<https://vimeo.com/actionforat/videos>

<https://www.youtube.com/channel/c/ActionforatOrg>

## Our Future Plans: Areas of Focus for 2019

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 2019 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 promote A-T research to increase interest in the condition and drive new applications from the research community.

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 taken place but continued development is required to ensure that we are well positioned for the future. In 2019 we will:

- Prioritise key projects based on available resources
- 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 or cure for A-T.

### 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 meet the increased demand from the research community.

### Making our Funds Work Harder

We will continue to ensure that our funds which are ring fenced for future research projects gain the best possible return with minimal risk. The fixed rate deposit accounts where our funds are held will be reviewed at the end of their 12-month lock-in period to ensure that they still offer the best rate of return and are fit for purpose. In June 2019, the Trustees agreed to reinvest the original capital plus interest back into the three initial deposit accounts. The Trustees will also consider any outstanding research institution payments and at this point, decide if it is appropriate to commit the funds for a further fixed period.

## Continuing our Investment in Medical Research in the UK and Abroad

We will continue our investment in high 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 funding partners with similar objects to our own.

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 an appropriate standard and delivers on our research strategy. 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.

## 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 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 series of deposit accounts to ring-fence any designated 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.

## 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 2018 was **£824,504 (2017 - £648,392)**.

### Charitable Expenditure

The investment into Charitable Activities was **£121,751 (2017 - £593,406)** of which **£59,166 (2017 - £547,953)** was for grants provided for funding of research projects (including a £8,490 refunded underspend on a project from 2012).

The cost of generating voluntary income was **£59,225 (2017 - £61,776)** whilst the cost of generating income from charitable events was **£161,966 (2017 - £179,291)**

Governance costs **£22,590 (2017 - £13,858)** 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 2017

In 2018, £nil of funds were passed on to the research projects detailed in note 8 on page 31, however £8,490 was refunded to the Charity due to an underspend on a project previously funded from designated funds.

As at 31 December 2018 designated funds carried forward are £nil.

### Restricted Funds

Restricted funds of £nil were brought forward from 2017. During the year **£144,764** of restricted income was received against projects funded during 2017. During 2018, **£67,656** of funding was made to the research projects detailed in note 8 Page 31.

At 31 December 2018 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.

## 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: 30/8/2019

Dated: 30/8/2019

## 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 2018 which comprise (the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Generally Accepted Accounting Practice including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2018, 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 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 and the overall presentation of the financial statements.

## Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement (set out on page 19) 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.

(Continued)



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

Dated: 04/9/2019

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

## Financial Statements:

Incorporating income and expenditure for the year ended 31 December 2018

	Notes	Unrestricted 2018 £	Restricted 2018 £	<b>Total Funds 2018 £</b>	Total Funds 2017 £
<b>Incoming resources</b>					
Voluntary income:	2				
Donations and legacies		217,274	136,161	<b>353,435</b>	163,358
Activities for generating funds:	3				
Charitable events		453,378	8,603	<b>461,981</b>	481,225
Investments:	4				
Investment income		6,088	-	<b>6,088</b>	537
Other Income:	5				
Sundry income		3,000	-	<b>3,000</b>	3,272
<b>Total income</b>		<b>679,740</b>	<b>144,764</b>	<b>824,504</b>	648,392
<b>Resources expended</b>					
Costs of generating voluntary income:	6				
Voluntary income		59,225	-	<b>59,225</b>	61,776
Costs of activities for generating funds:	7				
Charitable events		161,966	-	<b>161,966</b>	179,291
Costs of charitable activities:	7				
Charitable activities		54,095	67,656	<b>121,751</b>	593,406
Other expenditure:	9				
Governance costs		22,590	-	<b>22,590</b>	13,858
<b>Total resources expended</b>		<b>297,876</b>	<b>67,656</b>	<b>365,532</b>	848,331
<b>Net income / (expenditure)</b>		<b>381,864</b>	<b>77,108</b>	<b>458,972</b>	(199,939)
Transfers between funds		77,108	(77,108)	-	-
<b>Net Movement in funds</b>		<b>458,972</b>	<b>-</b>	<b>458,972</b>	(199,939)
<b>Total funds at 1 January 2018</b>		<b>293,513</b>	<b>-</b>	<b>293,513</b>	493,452
<b>Total funds at 31 December 2018</b>		<b>752,485</b>	<b>-</b>	<b>752,485</b>	293,513

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 24 as required by the said statement.

## Financial Statements: Balance Sheet

At 31 December 2018

	Notes	2018 £	£	2017 £	£
<b>Fixed assets</b>					
Tangible fixed assets	10	<u>1,272</u>		<u>600</u>	
			1,272		600
<b>Current assets</b>					
Stock		<b>9,005</b>		9,702	
Debtors	11	<b>133,256</b>		156,637	
Cash at bank		<u><b>1,372,146</b></u>		<u>1,110,134</u>	
		<b>1,514,407</b>		<b>1,276,473</b>	
<b>Liabilities</b>					
Amounts due within one year	12	<u><b>358,073</b></u>		<u>396,880</u>	
<b>Total assets less current liabilities</b>			1,156,334		879,593
<b>Creditors: Amounts falling due after more than one year;</b>	12		405,121		586,680
<b>Net assets</b>			<u>752,485</u>		<u>293,513</u>
<b>Charity funds</b>					
Restricted funds	14	-		-	
Unrestricted funds	14	<u><b>752,485</b></u>		<u>293,513</u>	
			<u>752,485</u>		<u>293,513</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: 30/8/2019

Dated: 30/8/2019

## Financial Statements: Cashflow

At 31 December 2018

	Notes	<b>Total Funds 2018 £</b>	Prior Year Funds 2017 £
<b>Cash flows from operating activities:</b>			
Net cash provided by operating activities	20	<b>257,382</b>	196,429
<b>Cash flows from investing activities:</b>			
Interest		<b>6,088</b>	537
Fixed assets		<b>(1,458)</b>	(900)
Net cash provided by investing activities:		<b>4,630</b>	(363)
<b>Cash flows from financing activities:</b>			
Net cash provided by financing activities		-	-
<b>Change in cash and cash equivalents in the reporting period</b>		<b>262,012</b>	196,066
<b>Cash and cash equivalents brought forward</b>	21	<b>1,110,134</b>	914,068
<b>Cash and cash equivalents carried forward</b>	21	<b>1,372,146</b>	1,110,134

# Financial Statements: Notes to the Financial Statements

At 31 December 2018

## 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). In the previous year the financial statements had been prepared under the historical cost convention, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008).

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.

### 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

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.

## Financial Statements: Notes to the Financial Statements

At 31 December 2018

### 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.

### Cash and cash equivalents

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.

### Stocks

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

### 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.

Computer equipment 33.33% straight line depreciation

## Debtors

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

## 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.

## 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.

## 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.

## 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.

## 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

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

## Financial Statements: Notes to the Financial Statements

At 31 December 2018

### 2. Income From Donations And Legacies

	Unrestricted 2018 £	Restricted 2018 £	<b>Total Funds 2018 £</b>	Total Funds 2017 £
Donations	117,662	1,500	<b>119,162</b>	108,690
Gift Aid claims	55,746	294	<b>56,040</b>	17,283
Fundraising	43,866	134,367	<b>178,233</b>	37,385
Legacies	-	-	-	-
	<b>217,274</b>	<b>136,161</b>	<b>353,435</b>	<b>163,358</b>

### Volunteer Services

No volunteers provided unpaid services to the Charity during the year. During the previous year (2017) no hours were provided. Trustees have previously valued voluntary hours at a rate of £10.50 per hour.

### 3. Income From Charitable Activities

	Unrestricted 2018 £	Restricted 2018 £	<b>Total Funds 2018 £</b>	Total Funds 2017 £
Fundraising events	156,524	8,603	<b>165,127</b>	232,883
Challenge events	296,854	-	<b>296,854</b>	248,342
	<b>453,378</b>	<b>8,603</b>	<b>461,981</b>	<b>481,225</b>

### 4. Income From Investments

	Unrestricted 2018 £	Restricted 2018 £	<b>Total Funds 2018 £</b>	Total Funds 2017 £
Bank interest	6,088	-	<b>6,088</b>	537
	<b>6,088</b>	<b>-</b>	<b>6,088</b>	<b>537</b>

### 5. Other Income

	Unrestricted 2018 £	Restricted 2018 £	<b>Total Funds 2018 £</b>	Total Funds 2017 £
Employment allowance	3,000	-	<b>3,000</b>	3,000
Sundry receipts	-	-	-	272
	<b>3,000</b>	<b>-</b>	<b>3,000</b>	<b>3,272</b>

## 6. Costs Of Generating Voluntary Income

	Unrestricted 2018 £	Restricted 2018 £	<b>Total Funds 2018 £</b>	Total Funds 2017 £
<b>Voluntary Income:</b>				
Film	1,200	-	<b>1,200</b>	600
Administrative Costs	15,738	-	<b>15,738</b>	23,841
Donation Collection Fees	20,044	-	<b>20,044</b>	11,913
Insurance	742	-	<b>742</b>	843
Telephone	1,053	-	<b>1,053</b>	2,107
Bank Charges	2,114	-	<b>2,114</b>	2,610
Subscriptions	746	-	<b>746</b>	252
Sundry Expenses	232	-	<b>232</b>	672
Information Technology	2,808	-	<b>2,808</b>	1,848
Office Rent	11,428	-	<b>11,428</b>	12,269
Marketing	1,290	-	<b>1,290</b>	2,212
Printing And Stationery	1,830	-	<b>1,830</b>	2,609
	<b>59,225</b>	-	<b>59,225</b>	61,776

## 7. Costs Of Activities For Generating Funds

	Unrestricted 2018 £	Restricted 2018 £	<b>Total Funds 2018 £</b>	Total Funds 2017 £
<b>Cost of Charitable Events:</b>				
Event costs	161,966	-	<b>161,966</b>	179,291
	<b>161,966</b>	-	<b>161,966</b>	179,291
<b>Costs of Charitable Activities:</b>				
<b>General Funds:</b>				
Research support costs	63,566	-	<b>63,566</b>	44,039
<b>Designated Funds:</b>				
Grants to research institutions <b>(Note 8)</b>	(8,490)	67,656	<b>59,166</b>	547,953
Exchange losses/(gains)	(981)	-	<b>(981)</b>	1,414
	<b>54,095</b>	<b>67,656</b>	<b>121,751</b>	593,406

## 8. Grants To Research Institutions

	Unrestricted 2018 £	Restricted 2018 £	<b>Total Funds 2018 £</b>	Total Funds 2017 £
<b>Restricted Funds:</b>				
University of Birmingham - Prof. Malcolm Taylor	-	-	-	128,811
<b>Designated Funds:</b>				
Duke University	-	-	-	19,898
Goethe University, Frankfurt - Prof. Ralph Schubert	-	-	-	6,355
Leiden University Medical Centre (LUMC), The Netherlands - Prof. Van der Burg	-	-	-	100,000
Royal Holloway University of London - Professor Rafael Yáñez-Muñoz	-	-	-	200,000
University of Nottingham - CATNAP Study Part 2	-	-	-	92,966
University of Nottingham (A-TCP)	-	50,000	<b>50,000</b>	-
ASO Project (A-TCP)	-	17,656	<b>17,656</b>	-
<b>Research project underspends refunded</b>				
University of Texas	(8,490)	-	<b>(8,490)</b>	-
University of Cambridge	-	-	-	(77)
	<b>(8,490)</b>	<b>67,656</b>	<b>59,166</b>	<b>547,953</b>

## 9. Other Expenditure

	Unrestricted 2018 £	Restricted 2018 £	<b>Total Funds 2018 £</b>	Total Funds 2017 £
<b>Governance costs:</b>				
Salaries	15,738	-	<b>15,738</b>	7,525
Auditors remuneration	3,300	-	<b>3,300</b>	3,280
Accountancy	1,530	-	<b>1,530</b>	1,250
Professional fees	672	-	<b>672</b>	655
Travel	31	-	<b>31</b>	67
Sundry	533	-	<b>533</b>	781
Depreciation	786	-	<b>786</b>	300
	<b>22,590</b>	<b>-</b>	<b>22,590</b>	<b>13,858</b>

## 10. Tangible Fixed Assets

	Office Equipment £	Total £
<b>Cost</b>		
At 1 January 2018	900	<b>900</b>
Additions	1,458	<b>1,458</b>
Disposals	-	-
	<b>2,358</b>	<b>2,358</b>
<b>Depreciation</b>		
At 1 January 2018	300	<b>300</b>
Charge for the year	786	<b>786</b>
Eliminated on disposal	-	-
	<b>1,086</b>	<b>1,086</b>
<b>Net Book Value</b>		
At 31 December 2018	1,272	<b>1,272</b>
At 31 December 2017	600	<b>600</b>

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

	2018 £	2017 £
Other debtors	<b>81,725</b>	80,339
Restricted donations	<b>30,581</b>	24,764
	<b>112,306</b>	105,103
At 31 December 2018		

## Debtors: Amounts Falling Due After One Year

	2018 £	2017 £
Restricted donations	<b>20,950</b>	51,534
	<b>20,950</b>	51,534
At 31 December 2017		
	<b>133,256</b>	156,637

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

	2018 £	2017 £
Grants	<b>280,562</b>	371,135
Restricted grants	<b>50,000</b>	-
Other taxes and social security	<b>486</b>	471
Accruals and deferred income	<b>27,025</b>	25,274
At 31 December 2018	<b>358,073</b>	396,880

## Creditors: Amounts Falling Due After One Year

	2018 £	2017 £
Grants	<b>405,121</b>	586,680
At 31 December 2018	<b>405,121</b>	586,680

### 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 Nottingham – (A-TCP)	-	-	(50,000)	50,000	-
ASO Project (A-TCP)	-	-	(17,656)	17,656	-
Royal Holloway University of London – Prof. Yáñez-Muñoz	-	31,628	(-)	(31,628)	-
University of Nottingham – Dr Bhatt & Dr Prayle	-	25,000	(-)	(25,000)	-
University of Birmingham – Prof. Malcom Taylor	-	75,488	(-)	(75,488)	-
University of Nottingham CATNAP Study Part 2 – Dr Robert Dineen	-	11,148	(-)	(11,148)	-
Jenni Gallagher Fund	-	1,500	(-)	(1,500)	-
					-
<b>Restricted funds</b>	<b>-</b>	<b>£144,764</b>	<b>(£67,656)</b>	<b>(£77,108)</b>	<b>-</b>
<b>Designated funds</b>					
M D Anderson Cancer Centre – Prof Paul Wong	-	-	8,490	(8,490)	-
General funds	293,513	679,740	(306,366)	85,598	752,485
<b>Unrestricted funds</b>	<b>£293,513</b>	<b>£679,740</b>	<b>(£297,876)</b>	<b>£77,108</b>	<b>£752,485</b>
<b>Total Funds</b>	<b>£293,513</b>	<b>£824,504</b>	<b>(£365,532)</b>	<b>-</b>	<b>£752,485</b>

#### Restricted Funds

1. Professor Rafael Yanez Munoz at the Royal Holloway University of London had funding agreed to the value of £200,000 in 2017 for CRISPR Cas 9 Gene Editing research project. During 2018 restricted donations totalling £31,628 were received towards that funding and due to this having originally been funded from the general reserves the restricted income was transferred to offset these general funds.
2. Dr Jayesh Bhatt and Dr Andrew Prayle of Nottingham University Hospitals NHS Trust had funding agreed to the value of £94,839 in 2017 for the IMAGIN-AT advanced lung imaging and function testing in Ataxia Telangiectasia research project. During 2018 restricted donations totalling £25,000 were received towards that funding and due to this having originally been funded from general reserves the restricted income was transferred to offset these general funds.
3. Professor Malcolm Taylor at the University of Birmingham had funding agreed to the value of £128,811 in 2017. During 2018 restricted donations totalling £75,488 were received towards that research funding and due to this having originally been funded from general reserves the restricted income was transferred to offset these general funds.
4. Professor Robert Dineen of Nottingham University Hospitals NHS Trust had funding agreed to the value of £92,966 in 2017 for the CATNAP Study (part 2) project. During 2018 restricted donations totalling £11,148 were received towards that funding and due to this having originally been funded from general reserves the restricted income was transferred to offset these general funds.
5. Funding has been agreed for the non-viral gene therapy project carried out at the University of Nottingham Hospitals NHS Trust by Dr James Dixon.
6. Funding has been agreed for the genetically tailored splice-modulating therapy carried out by Dr Timothy Yu at the Harvard and Boston Children's Hospital.

## Designated Funds

7. There was an underspend of £8,490 on the research original funded in 2012 by Professor Paul Wong of the MD Anderson Cancer Centre in Texas.

## 15. Analysis Of Staff Costs

	<b>2018</b>	2017
	<b>£</b>	£
Salaries and wages	<b>109,658</b>	102,340
Social security costs	<b>12,316</b>	11,877
Pension contributions	<b>3,285</b>	1,595
	<b>125,259</b>	115,812

<b>Salary Bands</b>	<b>2018</b>	2017
	<b>£</b>	£
£80,000 or more	-	-
£70,000 - £79,999	-	-
£60,000 - £69,999	<b>1</b>	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 £77,924 (2017 - £75,253). Only one employee had employment benefits falling between £60,000 and £69,999 (2017 – 1).

## 16. Staff Numbers

During the year the average number of employees was two (2017 – 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 (2017 - £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 (2017 £nil) of expenses during the year.

Mrs E Read, a Trustee of Action for A-T was reimbursed £nil (2017 £nil) of expenses during the year.

Mr W Rowberry, the Treasurer of Action for A-T was reimbursed £nil (2017 £nil) of expenses during the year.

Mr T Shillingford, a Trustee of Action for A-T was reimbursed £nil (2017 £nil) of expenses during the year.

Mrs M Leonard, a Trustee of Action for A-T was reimbursed £nil (2017 £nil) of expenses during the year.

Mrs S Cornell, a Trustee of Action for A-T was reimbursed £nil (2017 £nil) of expenses during the year.

Mr C Askew, a Trustee of Action for A-T was reimbursed £nil (2017 £nil) of expenses during the year.

Dr M Toms, a Trustee of Action for A-T was reimbursed £nil (2017 £nil) of expenses during the year.

## 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 £11,644 (2017 - £12,512) for contracts expiring in more than one year. The total future commitments are £11,644 (2017 - £12,514)

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

	<b>Total Funds 2018 £</b>	Prior Year Funds 2017 £
Net income for the reporting period (as per the SOFA)	<b>458,972</b>	(199,939)
Adjustments for:		
Depreciation charges	<b>786</b>	300
Interest from investments	<b>(6,088)</b>	(537)
(Increase) / decrease in stocks	<b>697</b>	(3,531)
(Increase) / decrease in debtors	<b>23,381</b>	(3,381)
Increase/ (decrease) in creditors	<b>(220,366)</b>	403,517
Net cash provided by operating activities	<b>257,382</b>	196,429

## 21. Analysis Of Cash and Cash Equivalents

	<b>Total Funds 2018 £</b>	Prior Year Funds 2017 £
Cash in hand	<b>647,146</b>	1,110,134
Termed deposits	<b>725,000</b>	-
Total cash and cash equivalents	<b>1,372,146</b>	1,110,134

## 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 2018:

### Our Research Partners

Action Medical Research  
 BrAshA-T Ataxia Telangiectasia and their Trustees  
 A-T Children's Project (USA) and their Medical Research Team  
 Sparks Children's Medical Research Charity

### 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.

Albury Music Festival	Mace Group
All World Freight	Marks & Spencer Haslemere
Allergan International Foundation	Michael and Anna Wix Charitable Trust
Alliance Bernstein	N Smith Charitable Settlement
AXIS Capital	Paul & Clare Rooney
Barclays	Psigma
BBC Radio 4	Quest Professional
BCA	Rest-Harrow Trust
Big Give	Rawson Digital
Blythe Watson Charitable Trust	Robin Hewison
Cast Media Group	Sir Samuel Scott of Yews Trust
Charterhouse School	St. James' Place Foundation
Clive & Sylvia Richards Charity	Syder Foundation
Compasses Public House	Theo Paphitis Charitable Trust
Dudley & Geoffrey Cox Charitable Trust	United Business Group
Eveson Charitable Trust	Wasps Legends Charitable Foundation
Edith Murphy Foundation	Work for Good
Gillespie MacAndrew	
GFI Group	<b>Corporate or professional services provided by:</b>
Global Entertainment	A & N Chartered Accountants
Hiscox Foundation	Chris Stanton
Hospital Saturday Fund	Gecko Graphic Design
James Wise Charitable Trust	
Lumen Financial Planning Limited	

### 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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