

**ACTION
FOR A-T**

**FUNDING
RESEARCH,
FINDING HOPE**



Annual Report & Financial Statements

for the year ended 31st December 2019

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
 Leon Haslam

Chief Executive

Sean Kelly

Trustees at the date of approval

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

Resigned during the year

Samantha Cornell 1st December 2019

Appointed during the year or since year end

Joseph Frost 1st January 2020

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 Guy Makin, Senior Paediatric Oncology Lecturer, University of Manchester
 Dr Andrew Prayle, Clinical Assistant Professor, University of Nottingham
 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.

Professor Matthew Wood, Professor of Neuroscience and Deputy Head of the Medical Sciences Division at the University of Oxford

Patient Representatives

Mr Amandeep Sharma
 Mrs Clare Gallagher

Charity Registration Number

United Kingdom Registered Charity number: 1145303

Registered Office

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Bankers

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 Godalming
 Surrey
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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

At the time of writing we are all doing our best to cope with the changes the COVID-19 Virus has forced upon us. The pandemic continues to have a seismic impact on all of the people who the Charity comes into contact with. Our thoughts are with the A-T families, all our researchers, the Action for A-T team and all our supporters.

In common with many organisations, the Charity has had to adapt to a much changed operational landscape. We have taken prudent decisions to ensure we can meet our significant ongoing research funding commitments and enormous credit goes to our CEO Sean Kelly, whose exceptional resourcefulness has steered the charity through the last few difficult months and put us on a firm footing as life starts to return to normal.

Hopefully, the highly innovative emergency fundraising that has taken place despite the lock-down restrictions, will soon be replaced by our traditional programme of social, challenge and fun events that have put us in position to fund so much important research over the last 8 years.

Looking back to 2019 and the Charity once again had a highly productive year. The Trustees were pleased to be able to approve further significant funds for a number of exciting new research initiatives. In doing so the Charity passed the major milestone of providing over £2 million of funding to enable 35 research studies into A-T worldwide. This is a fantastic achievement and testament to the huge amount of effort put in by everyone involved in the Charity.

As proud as I am for all the vital research we have been able to support so far, I'm equally encouraged that 2019 saw the Charity receive record levels of new A-T research funding applications. There is a growing level of focus in the medical research community into tackling this condition and I have no doubt that Action for A-T's long term commitment to providing research funding is incentivising more experts to commit to this medical field. We must continue to work to ensure the funds are available to fund the highest quality research and to maintain this momentum.

As ever, a huge thank you goes to our army of supporters, donors, volunteers, staff, medical advisors, partners, Trustees, Patrons and Ambassadors. All of the fantastic progress we have made is because of you. Together, we will continue to reduce the time until a treatment or a cure for A-T is identified.



Emily and 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 2019.

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, May, September, and November in 2019. 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 14.

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

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;
- Relevant to furthering Action for A-T's objectives; and
- We are confident (so far as possible) will be able to achieve the research team's stated aims.

Our Achievements & Performance

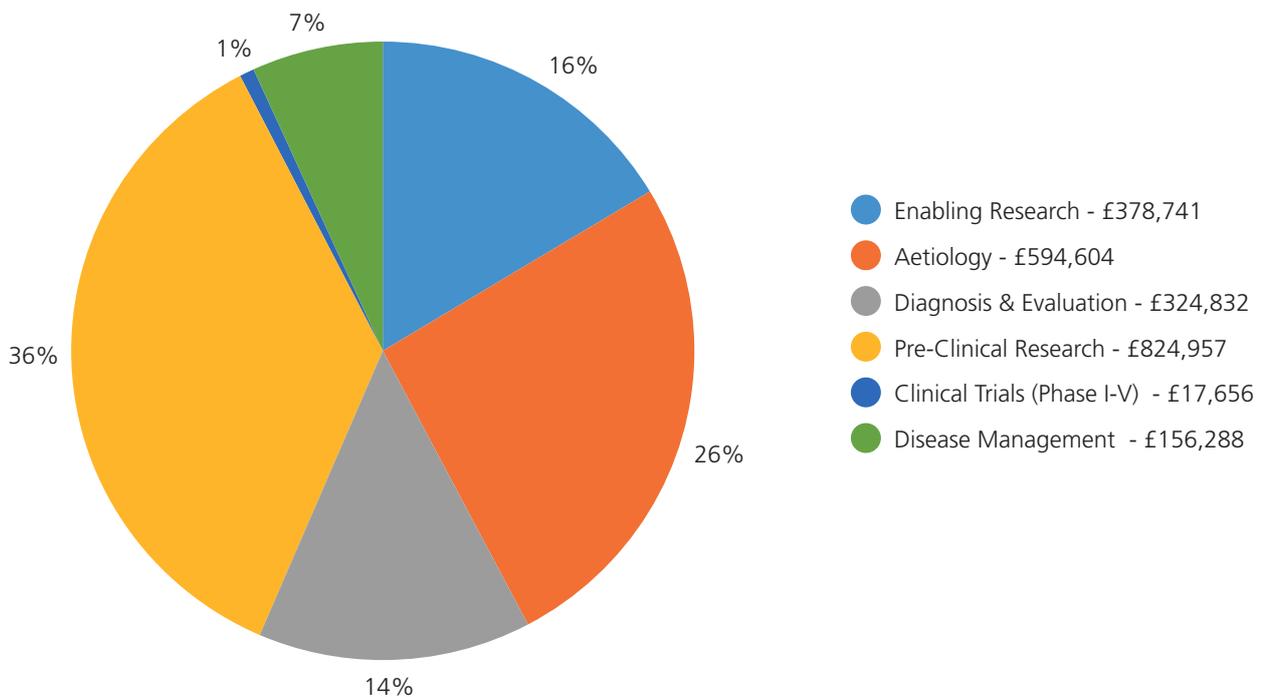
Our specific objectives for the year were to continue our funding of research into A-T, strengthen and increase our fundraising activities, work more closely with other A-T charities, and increase public awareness of the condition. The following pages show our achievements and performance in these areas:

Continuing our investment in A-T research

We made new grant commitments totalling £570,828 in 2019, bringing our total research investment since the Charity was established to £2,297,078. These funds have been committed to 35 global projects under six 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
- Clinical Trials (Phase I-V) - Studies to prove how new treatments work and understand how to use them

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

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 several key criteria including available funds, strategic alignment and existing research commitments.

Action for A-T administered its own full grant round at the end of September 2018 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 was put to the best possible use and provide assurance to our Trustees.

Our Research Advisory Committee (RAC) are part of this process and 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 2019, 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 cost of more than £2.8million and were able to fund six new projects with a combined cost of £570,728.44 as they passed our rigorous peer review process.

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

A number of previously funded projects came to a conclusion in 2019. The outcomes of these were as follows:

Identifying potential mechanisms to suppress A-T pathologies

Principal researchers: Professor Steve Jackson and Dr Rimma Belotserkovskaya

Project Completion Date: April 2019

This research project was jointly managed and funded with the US-based A-T Children's Project.

Project Overview

Ataxia-telangiectasia (A-T), is caused by mutations in the ATM gene. This research project jointly funded with the A-T Children's Project aimed to determine how changes in other genes (not the ATM gene) might alleviate symptoms of A-T in cells, with the hope that these changes may have the potential to alleviate A-T patient symptoms.

Project Outcome

Professor Jackson & team's work has in the main achieved what they set out to do, to identify suppressors of ATM inactivity both in vitro and in samples from a patient with atypical, mild A-T disease. Understanding these processes has clear future potential therapeutic effects. The first part of the work has identified gene products that could potentially affect the physical symptoms of A-T. This work has already been published (see below). Having experimentally identified potential modifier genes in experimental models, the team moved on to their second objective using the patient with severely inactivation ATM mutations but with mild disease symptoms. The team used iPSCs from the patient and compared them to healthy matched controls. Unsurprisingly given the mild phenotype, in the patient with mild disease DNA damage signalling in response to oxidative stress was more similar to people without A-T than people with classic symptoms of A-T.

Follow on work from the findings of this project is ongoing. There is planned collaboration with the team in Oxford (Dr Sam Nayler) in order to specifically look at the cerebellum in relation to the findings described above.

Publications

Gabriel Balmus, Domenic Pilger, Julia Coates, Mukerrem Demir, Matylda Sczaniecka-Clift, Ana C. Barros, Michael Woods, Beiyuan Fu, Fengtang Yang, Elisabeth Chen, Matthias Ostermaier, Tatjana Stankovic, Hannes Ponstingl, Mareike Herzog1, Kosuke Yusa, Francisco Munoz Martinez, Stephen T. Durant, Yaron Galanty, Petra Beli, David J. Adams, Allan Bradley,



Dr Rimma Belotserkovskaya & Professor Steve Jackson

Emmanouil Metzakopian, Josep V. Forment & Stephen P. Jackson; ATM orchestrates the DNA-damage response to counter toxic non-homologous end-joining at broken replication forks. Nature Communications volume 10, Article number: 87 (2019).

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

Principal researcher: Dr Vincenzo Costanzo

Project Completion Date: November 2019

This research project was jointly managed and funded with the US-based A-T Children's Project.

Project Overview

The primary aim of this project was to look at the hypothesis that ATM (the protein which is missing or not functioning completely in A-T) controls the chemical reactions required for the production of nucleotides, which are the building blocks of DNA and other cellular components. The team looked at the impairment of these processes and if/how they contribute to the health problems associated with A- T.



Dr Vincenzo Costanzo

Project Outcome

Dr Constanzo and his team were able to provide evidence about metabolic effects occurring at cellular level in the absence of ATM and demonstrate multiple defects. Using cells affected by other conditions relevant to the metabolic processes studied, they were also able to further explain any defects and then move on to how these defects might be addressed with existing drugs. One unexpected finding was a "family signature" present in carriers. The team therefore believe that "metabolic defects could be largely compensated" and that residual levels of ATM are needed for pathways to compensate.

They now plan to look specifically at how their hypothesis might involve cells of the cerebellum as future research to test potential beneficial drugs could lead to clinical impact in the moderate term.

Publications

A publication is currently being prepared.

**This project was made possible thanks to the funds raised by the 2016 Scumrun participants and donations made in memory of Stephen Green. Stephen was riding for Action for A-T when he suffered a fatal heart attack during the 2015 Prudential Ride 100 cycle event.*

During the 2019 accounting period, the following grants for A-T research projects were approved and allocated for funding:

Natural History of Ataxia-Telangiectasia (N-HAT)

Principal researchers: Dr William Whitehouse & Dr Emily Petley

Institute: University of Nottingham

Cost: £177,866 over 24 months in partnership with the A-T Society and BrAshA-T

Start Date: August 2019

Project Overview

Dr William Whitehouse, along with Dr Emily Petley and professionals from the two UK national A-T clinics, are going to document the natural history of A-T. They will do this by using data from the national paediatric and adult A-T clinics in Nottingham and Papworth to understand what the most common problems are, how frequently, and at what age they present. This study will be the first to define the life-course of A-T in the whole population with results that will help families all over the world. The NHS set-up in the UK provides this unique opportunity.

Dr Petley will initially review the clinical notes of everyone with A-T seen in the adult and paediatric A-T clinics since 2001, (approximately 170 people), extracting data on infections; immune deficiencies; cancers; lung disease; brain and nervous system disorders; growth; nutritional status; mortality; and genetics. This data will then be statistically analysed to determine links between signs and symptoms as well as describing how A-T progresses.

This study will provide more information to people with A-T and their families about the progression of A-T, what to expect in the future, and what complications to look out for. Understanding the natural history and progression of A-T will enable clinicians to help patients and their families get the services they require; more support at school, equipment at home to make activities of daily living easier, more emotional support for the patient and their family and career advice. This study will generate information that will be used by clinicians to improve the care they provide to their patients with A-T, including looking at how different aspects of A-T may impact on each other, for example nutrition on respiratory function. The team also hope that this study will inform future clinical trials, working towards symptomatic treatment and cures.



Dr Emily Petley & Dr William Whitehouse

The use of patient stem cell-derived mini-brains to study A-T

Principal researcher: Dr Samuel Nayler

Institute: University of Oxford

Cost: £98,200 over 12 months in partnership BrAshA-T

Start Date: September 2019

Project Overview

Dr Nayler and team are proposing to make cerebellar organoids or 'mini-brains' from induced pluripotent stem cells (iPSCs). iPSCs have been made from the skin of patients with A-T, some of which have had 'genetic correction', meaning the faulty ATM gene has been restored to normal. They will make mini brains using established protocols in the Becker lab at the University of Oxford using iPSCs supplied by Malcolm Taylor and Steve Jackson in the UK, and Ernst Wolvetang in Australia. Cells from cerebellar organoids will be sequenced at the Wellcome Trust Centre for Human Genetics. Data will be analysed in a collaborative initiative to provide insight into the dysfunction of Purkinje cells in the



Dr Sam Nayler & Esther Becker

cerebellum. This will enable the team to pinpoint the dysfunctional cellular machinery in Purkinje cells allowing them to identify compounds which may be therapeutically viable in A-T.

Animal models of the 'cerebellum' (a part of the brain that coordinates and regulate muscular activity) do not accurately demonstrate the neurological aspect seen in human A-T. Therefore, they cannot be used to further understand A-T and offer limited use in testing drugs that may be effective in human A-T patients. Organoids provide the most relevant model of the human brain which can currently be created. The team have demonstrated that they can derive cell types among those affected in the disease of A-T, including Purkinje neurons (cells that are affected in the cerebellum of A-T patients). They will use cutting edge sequencing technologies to isolate thousands of cells, individually from multiple organoids, to gain the clearest picture yet of the functional consequence of ATM deficiency (the gene affected in A-T). This will allow them to pinpoint defective cellular machinery that could be targeted with drugs to treat the neurological dysfunction in A-T.

iPSCs will be grown and differentiated into cerebellar organoids using a defined protocol which makes use of molecules that reproduce development of the cerebellum in vitro (in a dish). Organoids will be validated using a variety of biochemical and immunohistochemical techniques. This involves testing of genetic material and cutting/staining sections of the mini brains to assess they have made the right cell types to learn about the cerebellum. Organoids will be prepared for single-cell sequencing, in collaboration with the core facility at the Wellcome Trust Centre for Human Genetics. This means the team can examine one cell at a time, from thousands of replicates, from large numbers of organoids, giving them the best resolution to dissect out the genetic basis of dysfunctional ATM in Purkinje neurons. Data will be analysed both in-house and with collaborators.

Innovative methods for gene therapy in Ataxia-Telangiectasia

Principal researcher: Professor Ignacio Molina & Dr García-Pérez

Institute: University of Granada

Cost: £100,000 over 36 months

Start Date: November 2019

Project Overview

Gene therapy is a technique for correcting genetic defect by inserting a healthy copy of a gene into cells (replacing a faulty gene). To deliver a gene into cells, scientists use delivery systems called vectors. Gene therapy has cured a significant number of children suffering from primary immunodeficiencies. In a previous study, Professor Molina's team demonstrated that this technique also cures A-T cells. However, the extremely large size of the ATM gene (the gene missing or not functioning completely in A-T) means most delivery systems are inefficient. Therefore, applying this therapy to A-T patients is currently not possible. To overcome this, the team now plan to study whether a new type of vector called transposons are suitable. Transposons may carry large genes and deliver them into target cells very efficiently, and thus represent an innovative approach to introduce a healthy ATM gene into A-T patient cells.



Professor Ignacio Molina & Dr García-Pérez

There is no cure for A-T and therapeutic options are limited therefore it is vital to develop innovative approaches to design new treatments for the disease. Transposons are a new type of gene-delivery vector that have demonstrated their capacity for carrying large DNA fragments. In addition, they are very safe and efficient, and are becoming a sound alternative to traditional vectors, whose efficiency is severely limited with large genes. Transposons could be an ideal tool to introduce a healthy ATM gene into A-T patient cells. With this procedure, the team hope to reverse the functional defects found in A-T patient cells.

Professor Molina and Dr García-Pérez will introduce a healthy ATM gene, into patient cells by chemical or electrical means using an in vitro (controlled environment in the lab) experimental system. Once the gene is integrated into the host cell

DNA, they will analyse whether the modified deficient cells fully recover from the defects associated to the disease. If they can demonstrate the system is efficient, they will obtain human haematopoietic stem cells (cells that can develop into all types of blood cells) to attempt their reconstitution by using a similar strategy. This is particularly important because future clinical trials will target these cells, which are capable of restoring the immune system. Demonstrating an in vitro cure of A-T haematopoietic stem cells is one of the main objectives of the project and a key preclinical requirement prior advancing into human trials.

Does irregular repair of DNA damage in Neurons and Lymphocytes cause cellular degeneration in A-T patients?

Principal researcher: Dr Jean-Pierre De Villartay

Institute: The IMAGINE Institute for Genetic Diseases, Paris

Cost: £65,000 over 12 months

Start Date: February 2020

Project Overview

The ATM protein is one of the critical components necessary for the repair of DNA damage in human cells. In patients with A-T, who have mutations in the ATM gene, cells of the brain and the immune system are both affected (called neurons and lymphocytes, respectively). One important aspect of A-T is the progressive nature of these clinical symptoms, which suggests that “time” is a critical factor. It was recently shown that DNA damage may be triggered in neurons, and possibly white blood cells, in the course of normal cellular activities. Dr Jean-Pierre De Villartay and his team will test their idea that the abnormal repair of such DNA damage, especially on a recurrent basis, may explain the progressive cellular degeneration seen in A-T patients. This will be studied in the test tube using cells from human A-T patients and mice with A-T.



Dr Jean-Pierre De Villartay

The project has two aims:

Aim1: ATM deficiency and neurodegeneration: In this part of the project, the team will investigate how ATM deficiency affects live neurons responding to repeated activating signals in the test tube. They will first map out the precise pattern of DNA damage that occurs across the genome of nerve cells in response to a repeated signal. Then they will compare how faithfully DNA damage is repaired in the presence or absence of ATM. The team will also measure the impact of accumulated damage on how easily the cell can access the information contained in DNA (“genes”).

Aim2: ATM deficiency and immune function. Based on what happens inside neurons, Dr Villartay and team suggest that lymphocytes might also undergo DNA damage in the course of their normal activities. This is a new idea that can be tested in a similar way to Aim1, but with signals that activate lymphocytes. These cells will be obtained from both A-T patients and mice with A-T, and compared with healthy cells for the pattern of DNA damage and associated changes in gene function.

This project looks at very basic scientific questions aimed at increasing our knowledge of how ATM deficiency leads to the disease A-T. However, it’s possible that insights into the impact of various different ATM mutations on cellular degeneration will help predict the clinical progress of patients early in the disease.

A Team approach to producing healthcare guidance for children with Ataxia Telangiectasia (A-T)

Principal researcher: Munira Khan & Dr Lisa Bunn

Institute: University of Plymouth

Cost: £89,862 over 36 months

Start Date: February 2020

Project Overview

Dr Lisa Bunn and her large team of collaborators with specialist experience of A-T or related disorders will work together to produce the first comprehensive up-to-date healthcare guidance for people with A-T. The guidelines will focus on non-medical and non-surgical healthcare such as physiotherapy, occupational therapy, dietetics, etc. and will report on the best available evidence for therapies and treatments.

As well as producing evidence based allied healthcare guidelines, the team will also develop the “MyATeam Pack” specifically designed in conjunction with and for A-T children to help them better understand themselves and their condition. This pack is designed to be shared on their terms, with parents and key workers in education and healthcare.



Munira Khan

The study will also include the design and delivery of a randomised (delayed start) controlled clinical trial of a complex home-based intervention. The trial will involve an 8-week programme of whole-body exercise (yoga) and breathing exercises for 10 A-T children and an online group approach wrapping around the twice weekly yoga sessions. The online approach will provide peer support and promote open information sharing regarding acceptability and feasibility of the programme.

The Yoga journeys will be supplied directly from an organisation called Cosmic Kids www.cosmickids.com to avoid children being exposed to online advertisements in YouTube. This will also enable the team to plan a progression for children across the 8-week programme to minimise muscle soreness and the impact of fatigue which are both major issues in 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

Cost: £40,000 over 4 months

Start Date: April 2020 (Extension granted in September 2019)

Project Overview

Ataxia Telangiectasia (A-T) is caused by mutations in the ATM gene and more than 600 different mutations have been identified in patients. The aim of this project is to use the most proficient genome editing technology, known as CRISPR, to develop strategies to permanently repair the ATM gene.

The 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 Rafael Yáñez-Muñoz

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 have therefore decided to use CRISPR in an attempt to repair ATM mutations.

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

Fundraising for Research

Our Aim

Action for A-T funds high quality peer reviewed medical research to speed up the process of identifying a cure for Ataxia Telangiectasia (A-T). We endeavor to raise funds from a variety of activities which appeal to new and existing supporters. Since 2012 we have invested just under £2,300,000 in 35 A-T related research projects around the world and this has only been possible thanks to your generous support.

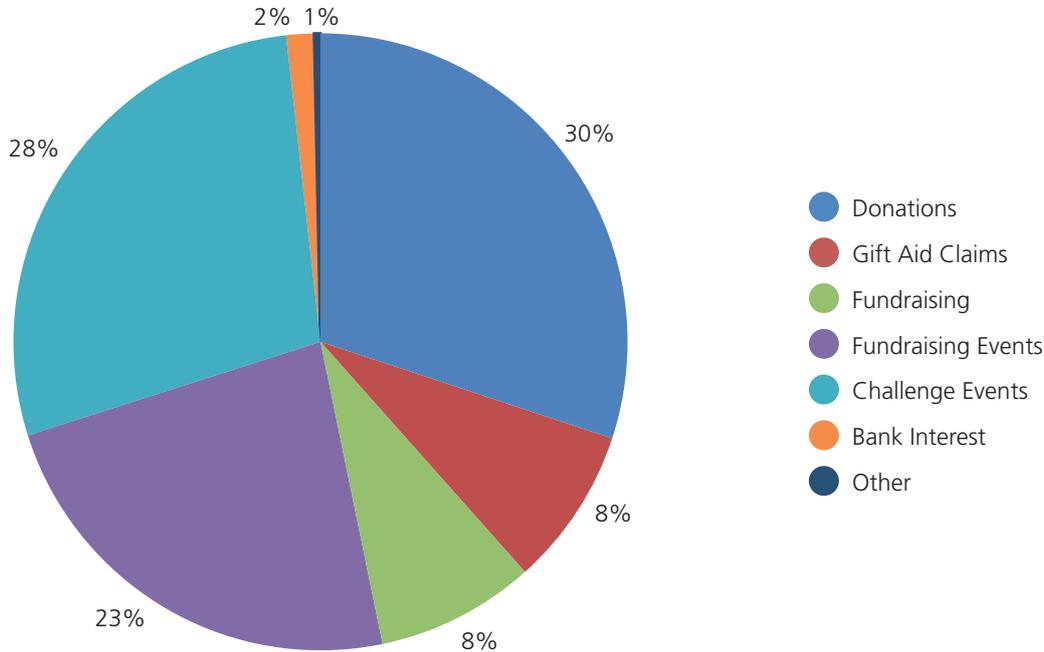
Our Performance

Action for A-T registered with the Fundraising Regulator (previously the Fundraising Standards Board) and are committed to upholding the code of fundraising practice. We receive all our funding from voluntary sources, including individuals, companies, trusts and foundations. We also purchase places in several physical challenges as well as staging and benefiting from a series of other social and sporting events. In 2018 places were purchased for the 2019 Virgin London Marathon and the Prudential Ride 100 events. The London marathon generated £37,000 representing a 59% return on investment but we struggled to fill our Prudential Ride 100 places and £3,900 was generated representing a 56% loss. The unused Prudential Ride 100 places will be used in 2020 and no further places have been purchased. A material investment was agreed by the Trustees and an advertising package which includes 9 places was purchased for the 2020 London marathon.

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 2019 generating 59% (2018 - 56%). Whilst other fundraising initiatives, such as corporate partnerships and collaborative funding partnerships increased to 29% (2018 - 22%). Several new fundraising activities took place throughout the year including a Summer Ball organised by the Parents of Downsland School and an abseil from the ArcelorMittal Orbit which included some of our

beneficiaries. We are especially grateful to the staff and clients of BCA as their Paddock Wood to Bruges cycle ride generated £141,922. In addition, we would like to thank AXIS Capital, Quest Professional, Psigma Investment Management, Barclays and St James’s Place for their generous corporate support.

The pie chart below shows the percentage splits of each of our areas of fundraising in 2019.



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

In addition to the above, we are also extremely grateful to all of the trusts and foundations who have provided grants throughout the year for specific research projects (these are listed on pages 10 to 14). We are keen to work with other trusts, foundations and corporate funders who might be interested in supporting our work.

At the time of writing these accounts, the Covid-19 pandemic has significantly impacted the way in which every organisation operates around the world. As a result, we have been forced to cease most fundraising activities and all our events due to the ever-changing situation relating to the outbreak. It is unclear how much of an impact this will have on our overall income for the year, but we are unlikely to meet the fundraising budget which was signed off by the Trustees in January. We have reacted quickly to the crisis and further diversified our fundraising activities to ensure that there are no going concern issues.



Events since the end of the year

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

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, create 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 start of 2019 with a view to co funding a training fellow. The application process was managed by AMR and all applications were subject to their peer review process. They did not receive any applications from individuals looking to work in the A-T research field, so no grants were awarded.

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 project which is due to end in November 2020:

- "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 2019. Only a few applications were received and none of these were taken forward for full peer review.

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 contributed 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 (£25,000 was paid in 2019) and £17,656 (\$23,000) towards the "Genetically tailored splice-modulating therapy" (this was paid in full at the end of 2018).

In addition to the above, both organisations were 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 was carried out by Professor Steve Jackson and Dr Rimma Belotserkovskaya and concluded in April 2019. A funding agreement was in place whereby the A-T Children's Project met 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 final contributions totalling £51,102.73 in 2019.

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 collaborative funding partnership with BrAshA-T who are based in Queensland, Australia. BrAshA-T chose to contribute £50,000 towards the UK based research projects shown below and the final payment of £25,000 was paid to Action for A-T in April 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

In addition to the above, BrAshA-T agreed to support the patient stem cell-derived mini-brains study being carried out by Dr Sam Nayler at Oxford University and their agreed contribution totaling £29,460 was paid in full in December 2019.

Co-funding A-T Research Projects with the Australian charity BrAshA-T Ataxia Telangiectasia and the UK based A-T Society

At the start of 2019, Action for A-T established a new collaborative funding partnership with BrAshA-T and the A-T Society in connection with the Natural Histories Study being carried out Dr William Whitehouse and Dr Emily Petley at the University of Nottingham. Each organisation (including Action for A-T) will contribute equally to the cost of the study contributing £59,288

each throughout 2020 and 2021.

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 by championing campaigns and attending various events throughout the year. Naga Munchetty represented Action for A-T on the game shows "The Chase" and "Who wants to be a millionaire" winning £32,000 as well as taking part in our charity abseil from the ArcelorMittal Orbit and hosting her annual golf day. Numerous other celebrities attended or hosted our golf days including Jeremy Guscott, Leon Haslam, Kevin Whately and Sir Trevor Brooking.



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 2019, representatives from the research community who are funded by Action for A-T, presented their findings at various medical conferences including the International Ataxia Research Conference (IARC) where Dr Sam Nayler won a poster prize for the work we are currently funding. These speeches showcased our latest projects and provided the research community with a comprehensive view of the projects which are currently being funded.

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. In 2019, further upgrades were made to 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.

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 2020 using all available technological advancements and popular platforms to raise further awareness.

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, flyers, postcards and a series of materials to assist individuals with the promotion of their fundraising activities. We also redesigned and secured new pull up and pop up banners for use at events thanks to the generous support of Cast Media Ltd.

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 highlight the condition to new audiences, recruit volunteers and secure additional support and donations.



Film

In July 2019, Action for A-T featured in a YouTube video created by a group known as the F2Freestylers. The film has been viewed 33.8 million times (as of May 2020) and received 697,000 likes and 14,121 comments. Since it was posted, we have received donations and messages of support from various individuals located all over the world and in the first few weeks the traffic to our website increased significantly.

We also filmed a series of interviews with the UK researchers we are currently funding. These films are available to view alongside the project information on our website to help provide an overview of specific areas of research as well as highlighting some of the complications of the condition. They are also available to view on our Vimeo and YouTube channels.

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

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

Our Future Plans: Areas of Focus for 2020

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 2020 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 already taken place, but continued development is required to ensure that we are well positioned for the future. In 2020 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
- Review our existing IT setup and upgrade or replace where necessary to ensure that the equipment is fit for purpose
- Keep up to date with current trends and remain flexible so that change can be implemented quickly if required

Increasing Awareness of our Work and the Condition

Since we were established in 2012, a key priority has been raising awareness of A-T and the work of the charity. This has been achieved by various means including celebrity endorsement, emotive films featuring researchers and A-T families and various branding opportunities. We will continue to seek out new ways in which we can highlight A-T whilst focusing on two key projects in 2020. Firstly, we will increase our celebrity endorsement opportunities by actively engaging our existing patrons and other celebrity supporters whilst also establishing an A-T family ambassadors programme. We will also invest in at least one new promotional film to help engage with our existing and new event audiences as our existing films have proved extremely effective in securing additional support, awareness and funds for our research programme.

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 and individuals 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. This will include refreshing 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 charitable trusts and foundations programme whilst actively seeking new investment and support 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.

Continuing our Investment in Medical Research in the UK and Abroad

We will continue to seek out new research opportunities from the wider researcher community as well as focussing on key research themes related to A-T. Where possible, priority will be given to UK based projects whilst still calling for international applications. We will also 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 in conjunction with our research advisory committee (RAC) to develop and improve our peer review process and ensure that the research we fund is of the highest quality. This will include constant evaluation of our systems and processes as well as enlisting the help and support of various A-T experts around the globe.

Membership of the RAC will be continually reviewed to ensure that we have a broad range of scientific expertise in areas relating to A-T as well as lay representation from various A-T families as Action for A-T strongly supports public and patient engagement in its research processes.

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

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.

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.

Research Advisory Committee

The Research Advisory Committee (RAC) is chaired by a member of the Board of Trustees. Members of the RAC have a broad range of scientific expertise in areas relating to A-T but are not generally active researchers in the field of A-T 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.

Reserves Policy

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

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

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

Investment Policy

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

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

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

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

Pay and Remuneration of Key Management Personnel

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

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

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

Financial Review

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

Income

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

Total income raised in 2019 was **£768,819 (2018 - £824,501)**.

Charitable Expenditure

The cost spent on Charitable Activities Was **£910,844 (2018 - £365,533)** of which **£673,985 (2018 - £114,658)** was for grants provided for funding of research projects.

The cost of generating voluntary income was **£55,576 (2018 - £59,225)** whilst the cost of generating income from charitable events was **£163,705 (2018 - £169,060)**

Governance costs of **£17,578 (2018 - £22,590)** 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 2018

In 2019, **£nil** of funds were passed on to the research projects detailed in note 8 on page 34. As at 31 December 2019 designated funds carried forward are **£nil**.

Restricted Funds

Restricted funds of **£nil** were brought forward from 2018. During the year **£169,172** of restricted income was received against projects funded during 2018. During 2019, **£570,828** of funding was made to the research projects detailed in note 8 Page 34.

At 31 December 2019 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: 13 July 2020

Dated: 13 July 2020

Auditors Report

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

Opinion

We have audited the financial statements of Action for A-T - Registered Charity Number: 1145303 (the 'charity') for the year ended 31 December 2019 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards 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 2019 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

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

Conclusions relating to going concern:

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 where the Charities Act 2011 requires us to report to you if, in our opinion:

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

Responsibilities of Trustees

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

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

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.

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

Use of our report

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

(Continued)



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

Dated: 13 July 2020

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

Statement Of Financial Activities

for the year ended 31 December 2019

	Notes	Unrestricted Funds £	Restricted Funds £	31.12.19 Total Funds £	31.12.18 Total Funds £
Income and Endowments from					
Donations and legacies	3	190,654	169,172	359,826	353,437
Charitable Activities					
Fundraising & challenge events	5	394,885	-	394,885	461,981
Investment income	4	11,108	-	11,108	6,088
Other income		3,000	-	3,000	3,000
Total		599,647	169,172	768,819	824,506
Expenditure on					
Raising funds	6	55,576	-	55,576	59,225
Charitable Activities					
Fundraising & challenge events	7	163,705	-	163,705	169,060
Grants		504,813	169,172	673,985	114,658
Governance costs		17,578	-	17,578	22,590
Total		741,672	169,172	910,844	365,533
Net Income / (Expenditure)		(142,025)	-	(142,025)	458,973
Reconciliation of Funds					
Total funds brought forward		752,486	-	752,486	293,513
Total Funds Carried Forward		610,461	-	610,461	752,486

The notes form part of these financial statements

Statement Of Financial Position

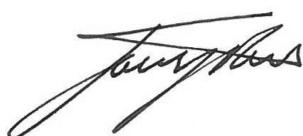
for the year ended 31 December 2019

	Notes	Unrestricted Funds £	Restricted Funds £	31.12.19 Total Funds £	31.12.18 Total Funds £
Fixed Assets					
Tangible assets	17	486	-	486	1,272
Current Assets					
Stocks	18	10,811	-	10,811	9,005
Debtors	19	79,868	-	79,868	133,257
Cash at bank	20	1,539,632	-	1,539,632	1,372,146
		1,630,311	-	1,630,311	1,514,408
Creditors					
Amounts falling due within one year	21	(422,303)	-	(422,303)	(358,073)
Net Current Assets		1,208,008	-	1,208,008	1,156,335
Total Assets Less Current Liabilities		1,208,494		1,208,494	1,157,607
Creditors					
Amounts falling due after more than one year	22	(598,033)	-	(598,033)	(405,121)
Net Assets		610,461	-	610,461	752,486
Funds					
Unrestricted funds	23			610,461	752,486
Total Funds				610,461	752,486

The notes form part of these financial statements

The Trustees declare that they have approved the financial statements.

Signed on behalf of the charity's Trustees.



Toby Read (Chairman)

Dated: 13 July 2020



William Rowberry (Treasurer)

Dated: 13 July 2020

Statement of Cash Flows

for the year ended 31 December 2019

	Notes	31.12.19 £	31.12.18 £
Cash flows from operating activities:			
Cash generated from operations	1	156,378	257,382
Net cash provided by operating activities		156,378	257,382
Cash flows from investing activities:			
Purchase of tangible fixed assets		-	(1,458)
Interest received		11,108	6,088
Net cash provided by investing activities		11,108	4,630
Change in cash and cash equivalents in the reporting period		167,486	262,012
Cash and cash equivalents at the beginning of the reporting period		1,372,146	1,110,134
Cash and cash equivalents at the end of the reporting period		1,539,632	1,372,146

Notes to the Statement of Cash Flows

for the Year Ended 31 December 2019

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

	31.12.19 £	31.12.18 £
Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)	(142,025)	458,973
Adjustments for:		
Depreciation charges	786	786
Interest received	(11,108)	(6,088)
(Increase)/decrease in stocks	(1,806)	696
Decrease in debtors	53,389	23,381
Increase/(decrease) in creditors	257,142	(220,366)
Net cash provided by operations	156,378	257,382

2. Analysis of changes in net fund

	31.12.19 £	Cash Flow £	31.12.18 £
Net cash			
Cash at bank	1,372,146	167,486	1,539,632
Total	1,372,146	167,486	1,539,632

Notes to the Financial Statements

for the Year Ended 31 December 2019

1. Accounting Policies

Basis of preparation of financial statements

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

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

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

Accounting convention

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

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

Incoming resources

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

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

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

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

Resources expended

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

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

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

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

Notes to the Financial Statements

for the Year Ended 31 December 2019

Governance costs

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

Allocation and apportionment of costs

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

Tangible fixed assets

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

Computer equipment - 33% on cost.

Stocks

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

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

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

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

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

Foreign currencies

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

Notes to the Financial Statements

for the Year Ended 31 December 2019

2. Critical Accounting Judgements and Key Sources of Estimation Uncertainty

Critical accounting estimates and judgements

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

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

Key sources of estimation uncertainty

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 17 discloses the carrying value if the tangible fixed assets and the depreciation policy is listed above in accounting policies.

3. Donations and Legacies

	31.12.19	31.12.18
	£	£
Donations	232,188	119,164
Gift Aid	63,530	56,040
Fundraising	64,108	178,233
	359,826	353,437

4. Investment Income

	31.12.19	31.12.18
	£	£
Bank interest	11,108	6,088

5. Income from Charitable Activities

	31.12.19	31.12.18
	£	£
Fundraising events	178,591	165,127
Challenge events	216,294	296,854
	394,885	461,981

6. Raising Funds

	31.12.19	31.12.18
	£	£
Raising donations and legacies		
Staff costs	46,821	-
Support costs	8,755	59,225
	55,576	59,225

7. Charitable Activities Costs

	Direct Costs	Grant funding of activities (see note 8)	Support Costs (see note 9)	Totals
	£	£	£	£
Fundraising & challenge events	133,565	-	30,140	163,705
Grants	-	598,034	75,951	673,985
Governance costs	-	-	17,578	17,578
	133,565	598,034	123,669	855,268

8. Grants Payable

	31.12.19	31.12.18
	£	£
Grants	598,034	59,166

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

	31.12.19	31.12.18
	£	£
Natural History of A-T (N-HAT)	177,866	-
De Villartay - Does irregular repair of DNA damage in Neurons and Lymphocytes cause cellular degeneration in Ataxia Telangiectasia patients?	65,000	-
Innovative methods for gene therapy in Ataxia-Telangiectasia	100,000	-
The use of patient stem cell-derived mini-brains to study Ataxia Telangiectasia	98,000	-
The ATeam: Producing healthcare guidance for children with Ataxia Telangiectasia including the exploration and design of a home-based exercise package	89,692	-
Development of CRISPR/Cas Genome Editing as a Treatment for Ataxia Telangiectasia	40,000	-
University of Nottingham (A-TCP)	-	50,000
ASO Project (A-TCP)	-	17,656
University of Texas	-	(8,490)
	570,828	59,166

9. Support Costs

	Management	Finance	Information Technology	Other	Wages	Governance Costs	Totals
	£	£	£	£	£	£	£
Raising donations and legacies	3,848	34	515	4,358	-	-	8,755
Fundraising & challenge events	11,545	2,203	1,545	14,847	-	-	30,140
Grants	-	-	-	-	75,951	-	75,951
Governance costs	-	-	-	-	-	17,578	17,578
	15,393	2,237	2,060	19,205	75,951	17,578	132,424

Notes to the Financial Statements - continued

for the Year Ended 31 December 2019

9. Support Costs - continued

The basis of allocation for Management, Finance, Information Technology, Other, and Wages is 25% Raising donations & legacies 75% Fundraising & challenge events. Governance costs are allocated on a 100% basis.

10. Trustees' Remuneration And Benefits

There were no Trustees' remuneration or other benefits for the year ended 31 December 2019 nor for the year ended 31 December 2018.

Trustees' Expenses

There were no Trustees' expenses paid for the year ended 31 December 2019 nor for the year ended 31 December 2018.

11. Staff Costs

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

The Charity considers its key management personnel to be the Trustees, Chief Executive and senior management. The total employment benefits of the key management personnel were £121,049 (2018 - £119,467). Only one employee had employment benefits falling between £70,000 and £79,999 (2018 - 0).

12. Comparatives for the Statement of Financial Activities

	Unrestricted Funds £	Restricted Funds £	Total Funds £
Income and endowments from			
Donations and legacies	217,276	136,161	353,437
Charitable activities			
Fundraising & challenge events	453,378	8,603	461,981
Investment income	6,088	-	6,088
Other income	3,000	-	3,000
	<hr/>		
Total	679,742	144,764	824,506
	<hr/>		

Notes to the Financial Statements - continued

for the Year Ended 31 December 2019

12. Comparatives for the Statement of Financial Activities - continued

	Unrestricted Funds £	Restricted Funds £	Total Funds £
Expenditure on			
Raising funds	59,225	-	59,225
Charitable activities			
Fundraising & challenge events	169,060	-	169,060
Grants	47,002	67,656	114,658
Governance costs	22,590	-	22,590
Total	297,877	67,656	365,533
Net income	381,865	77,108	458,973
Reconciliation of funds			
Total funds brought forward	370,621	(77,108)	293,513
TOTAL FUNDS CARRIED FORWARD	752,486	-	752,486

13. Employee Benefits

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

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

14. Pension Costs

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

15. Financial Instruments

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

16. Creditors and Provisions

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

Notes to the Financial Statements - continued

for the Year Ended 31 December 2019

17. Tangible Fixed Assets

	Computer Equipment £
Cost	
At 1 January 2019 and 31 December 2019	<u>2,358</u>
Depreciation	
At 1 January 2019	1,086
Charge for year	<u>786</u>
At 31 December 2019	<u>1,872</u>
Net Book Value	
At 31 December 2019	<u>486</u>
At 31 December 2018	<u>1,272</u>

18. Stocks

	31.12.19 £	31.12.18 £
Stocks	<u>10,811</u>	<u>9,005</u>

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

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

19. Debtors: Amounts Falling Due Within One Year

	31.12.19 £	31.12.18 £
Deposit	925	925
Prepayments and accrued income	<u>78,943</u>	<u>108,386</u>
	<u>79,868</u>	<u>109,311</u>

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

Notes to the Financial Statements - continued

for the Year Ended 31 December 2019

20. Cash at Bank

	31.12.19	31.12.18
	Total Funds	Total Funds
	£	£
Bank account no. 1	48,813	119,216
Bank account no. 2	16,017	5,236
Bank account no. 3	740,208	522,694
Bank account no. 4	734,594	725,000
	<hr/>	<hr/>
Total	1,539,632	1,372,146

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

21. Creditors: Amounts Falling Due Within One Year

	31.12.19	31.12.18
	£	£
Social security and other taxes	-	486
Grant Payable	406,569	330,562
Accruals and deferred income	15,734	27,025
	<hr/>	<hr/>
	422,303	358,073

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

	31.12.19	31.12.18
	£	£
Other creditors	598,033	405,121

23. Movement in Funds

	At 1.1.19	Net Movement	At 31.12.18
	£	in Funds	£
Unrestricted Funds			
Unrestricted Funds	752,486	(142,025)	610,461
	<hr/>	<hr/>	<hr/>
Total Funds	752,486	(142,025)	610,461

Notes to the Financial Statements - continued

for the Year Ended 31 December 2019

23. Movement in Funds - Continued

	Incoming Resources £	Resources Expended £	Movement in Funds £
Unrestricted Funds			
Unrestricted Funds	599,647	(741,672)	(142,025)
Restricted Funds			
Restricted Funds	169,172	(169,172)	-
Total Funds	768,819	(910,844)	(142,025)

Comparatives for movement in funds

	At 1.1.18 £	Net Movement in Funds	At 31.12.18 £
Unrestricted Funds			
Unrestricted Funds	370,621	381,865	752,486
Restricted Funds			
Restricted Funds	(77,108)	77,108	-
Total Funds	293,513	458,973	752,486

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

	Incoming Resources £	Resources Expended £	Movement in Funds £
Unrestricted Funds			
Unrestricted Funds	679,742	(297,877)	381,865
Restricted Funds			
Restricted Funds	144,764	(67,656)	77,108
Total Funds	824,506	(365,533)	458,973

Notes to the Financial Statements - continued

for the Year Ended 31 December 2019

23. Movement in Funds - Continued

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

	At 1.1.18 £	Net Movement in Funds	At 31.12.19 £
Unrestricted Funds			
Unrestricted Funds	370,621	239,840	610,461
Restricted Funds			
Restricted Funds	(77,108)	77,108	-
Total Funds	293,513	316,948	610,461

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

	Incoming Resources £	Resources Expended £	Movement in Funds £
Unrestricted Funds			
Unrestricted Funds	1,279,389	(1,039,549)	239,840
Restricted Funds			
Restricted Funds	313,936	(236,828)	77,108
Total Funds	1,593,325	(1,276,377)	316,948

24. Related Party Disclosures

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2018 - £nil). There are no expenses paid to the Trustees in the year. No trustee is deemed to have benefited as a result of a related party connection. All trustees have declared all such relationships to the Chairman.

25. Post Balance Sheet Events

Covid-19 Pandemic

At the time of writing these accounts, the Covid-19 pandemic has significantly impacted the way in which every organisation operates around the world. As a result, we have been forced to cease most fundraising activities and all our events due to the ever-changing situation relating to the outbreak. It is unclear how much of an impact this will have on our overall income for the year, but we are unlikely to meet the fundraising budget which was signed off by the trustees in January. We have reacted quickly to the crisis and further diversified our fundraising activities to ensure that there are no going concern issues. If the crisis continues until the end of the year (as predicted) we are unlikely to fund any new research projects until the end of 2021.

Notes to the Financial Statements - continued

for the Year Ended 31 December 2019

26. Ultimate Controlling Party

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

Detailed Statement of Financial Activities

for the Year Ended 31 December 2019

	31.12.19 £	31.12.18 £
Income and Endowments		
Donations and legacies	-	-
Donations	232,188	119,164
Gift aid	63,530	56,040
Fundraising	64,108	178,233
	359,826	353,437
Investment income		
Bank interest	11,108	6,088
Charitable activities		
Fundraising events	178,591	165,127
Challenge events	216,294	296,854
	394,885	461,981
Other income		
Other income	3,000	3,000
Total incoming resources	768,819	824,506
Expenditure		
Raising donations and legacies		
Wages	46,821	-
Charitable activities		
Event campaign costs	128,307	107,462
Event - fundraising & challenge	5,258	57,318
Sub-contractor	-	4,280
Grants to institutions	598,034	59,166
	731,599	228,226
Support costs		
Management		
Administrative costs	15,393	15,738
Finance		
Bank charges	2,237	2,114
Information technology		
Repairs and renewals	2,060	2,808

This page does not form part of the statutory financial statements

Detailed Statement of Financial Activities

for the Year Ended 31 December 2019

	31.12.19	31.12.18
	£	£
Information technology		
Other		
Rent, rates and water	13,523	11,428
Insurance	675	742
Telephone	883	1,053
Postage and stationery	905	1,830
Sundries	534	232
Advertising	1,366	1,290
Subscription	438	746
Donation collection fees	881	20,044
Film	-	1,200
	19,205	38,565
Wages		
Wages	75,951	55,492
Governance costs		
Wages	11,355	15,738
Auditors' remuneration	3,300	3,300
Accountancy and legal fees	2,137	2,766
Computer equipment	786	786
	17,578	22,590
Total resources expended	910,844	365,533
Net (expenditure)/income	-142,025	458,973

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 2019:

Our Research Partners

Action Medical Research

BrAshA-T Ataxia Telangiectasia and their trustees

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

Ataxia Telangiectasia Society

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.

AAC Golf Society
 Allergan International Foundation
 Alliance Bernstein
 AXIS Capital
 Barclays
 Barton Comms
 BCA
 B-CH 1971 Charitable Trust
 Bellway Homes
 Bergqvist Charitable Trust
 Big Give
 Blyth Watson Charitable Trust
 Cast Media Group
 Chapman Charitable Trust
 Cricket Green School
 Downsend School
 Ecclesiastical Insurance
 Enterprise Holdings Ltd
 Freemasons of Northumberland
 Giveall
 Global Entertainment
 Hiscox Foundation
 Hospital Saturday Fund
 HSBC

ITV
 James Wise Charitable Trust
 Marjorie & Geoffrey Jones Charitable Trust
 Mashie Golf
 Michael and Anna Wix Charitable Trust
 Paul & Clare Rooney
 Psigma
 Quest Professional
 Rawson Digital
 Robin Hewison
 Sir Samuel Scott of Yews Trust
 St. James' Place Foundation
 Steel Charitable Trust
 Toyota (GB) Charitable Trust
 Wasps Legends Charitable Foundation
 Work for Good

Corporate or professional services provided by:

A & N Chartered Accountants
 Akin Gump
 Chris Stanton
 Gecko Graphic Design

Our Supporters

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



Action for A-T, Aruna House, 2 Kings Road, Haslemere, Surrey GU27 2QA.
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Registered Charity number: 1145303