ACTION FOR A-T

**Funding research, finding hope**


# FINANCIAL ACCOUNTS 2016

# Legal And Reference Information

## Patrons

Jonny Wilkinson CBE
Roger Black MBE
Jeremy Guscott MBE
Simon Shaw MBE

## Chief Executive

Sean Kelly

## Trustees at the date of approval

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

## Appointed during the year or since year end

None

## Research Advisory Committee

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

## Patient Representatives

Mr Amandeep Sharma
Mr Joe Day

## Charity Registration Number

United Kingdom Registered Charity number: 1145303

## Registered Office

Aruna House
2 Kings Road
Haslemere
Surrey
GU27 2QA

## Operational Address

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

## Professional Advisers

Solicitors
Bingham McCutchen LLP
41 Lothbury
London
EC2R 7HF

## Bankers

HSBC Bank
110 High St
Godalming
Surrey
GU7 1DP

## Accountants & Auditors

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

# Contents

# Chairmans 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

2016 was a landmark year for Action for A-T which saw us take major strides forwards in our development financially, organisationally and in terms of our scientific processes. This progress helped us to deliver a record level of research investment during the year and also saw us pass the major milestone of funding over £1 million of A-T related research across 23 projects around the world since our launch in 2012.

Emily and Toby Read

Our funding of so many exciting and important A-T studies has created momentum within the medical research community which shows no signs of slowing. Action for A-T is now receiving a record number of high quality applications for funding and we are particularly encouraged to see that our activities have generated a significant increase in A-T related research applications from the UK.

Three main principles help to guide our work: the stimulation and support of innovative medical research; the provision of a bridge between families affected by A-T and the research community; and the development of knowledge, understanding and potential therapies for the condition.

Our progress so far simply would not have been achieved without the incredible help and support of so many organisations and individuals who have given their time, effort and donations so generously and are too numerous to thank by name here. We are also fortunate and very grateful to Sparks and the A-T Children's Project charities for their collaborative approach to the joint funding of research initiatives this year in the Netherlands and the UK.

We will work with the UK and international medical research communities, partner organisations and all our donors and supporters to continue to accelerate the pace of research into A-T. Our belief remains that every high-quality A-T research project constitutes progress towards a better understanding of A-T and ultimately, brings a treatment or a cure for this devastating condition closer. We have challenged ourselves to double our total research commitment to more than £2 million before the end of 2018. This is an ambitious target. However, the surge of interest in A-T from the medical research community make it a challenge we are duty bound to try to meet and one which, with your continued support, we hope is achievable.

From everyone at Action for A-T, thank you for your continued support.

**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 2016.*

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, July and October in 2016. 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
- Raising public awareness about A-T
- Building Collaborative Partnerships

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

## Identifying High-Quality Research into A-T

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

**Our Aims**

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

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

## Our Performance

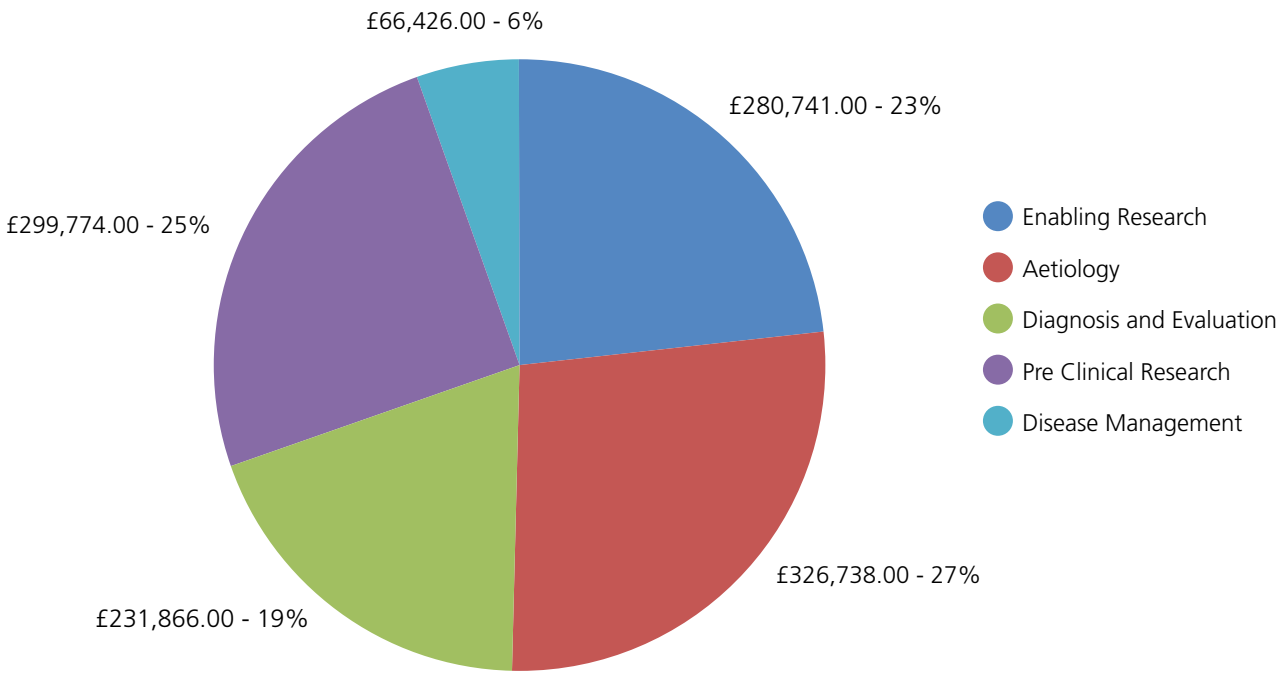
**Continuing our investment in A-T research**

We made new grant commitments of £530,039 in 2016 bringing our total research investment since the Charity was established, to £1.2million. These funds have been committed to 23 global projects under five main research headings.

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

The amount invested in each specific area is shown below.

## Total Research Spend Since 2012




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

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

In 2016, Action for A-T administered its second full grant round and a record number of applications were received from a variety of global research institutions. These applications were subject to our rigorous award winning peer review process to ensure that the money generously raised by our donors is put to the best possible use and to provide assurance to our Trustees.

Our Research Advisory Committee (RAC) 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 2016, our Chief Executive and Research Manager met with a number of key figures from the A-T research community to explore possible funding opportunities and further understand which areas of A-T research may provide the most promising outcomes. Our Chief Executive attended a number of workshops throughout the year and the Bi-annual A-T Clinical Research Conference in Poland.

Non A-T researchers who specialise in related conditions were also contacted to drive future research projects and create further interest in the condition. This strategy proved very successful and enabled us to significantly increase the number and demographic of 'who' we advertise our grant rounds to.

As a direct result of this proactive approach, we were able to significantly increase the number of applications from UK based institutions and fund three new UK based projects with a combined cost of £382,660.

## Project outcomes and sharing knowledge

We believe that sharing project outcomes and knowledge is a fundamental requirement for the development of new research strategies which will ultimately benefit those living with the condition. This is why we insist that all of our researchers use the Global Research Impact Assessment Platform called Researchfish to report on their projects periodically and several years after their grant has ended.

We also encourage all of our researchers to publish their findings in medical journals and where possible, make these open source. The outputs of research such as publications usually occur after a research project ends and it can take many years to translate research ideas into new treatments or therapies to improve quality of life.

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

Presentations and posters about the research we fund are actively encouraged. The 2016 International Child Neurology Congress in Amsterdam and the A-T Clinical Research Conference in Poland included various presentations on the research we have funded and are currently funding.

## 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. Recognising the need for professional guidance, we recruited a Scientific Advisor to assist the Research Manager in overseeing and evaluating the effectiveness of our ongoing research portfolio. In addition, the Scientific Advisor also signs off on our completed projects ensuring that the research aims stated in the original application have been fulfilled.

Dr Kathryn Johnson took up the role on a voluntary basis and joined our Research Advisory Committee in October 2016. Kathryn is a neonatal paediatrician working at the Leeds Teaching Hospitals NHS Trust and a member of the Scientific Advisory Committee for the rare disease patient network Findacure. She has a long standing interest in neonatal/paediatric rare disease and is committed to supporting research into such conditions with the ultimate aim of improving the lives of babies, children and families. She has a strong research delivery record within the neonatal service and as an executive committee member for the British Paediatric Surveillance Unit has a unique experience and insight into surveillance for paediatric rare disease.

# 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 2016. The outcomes of these were as follows:

# Developing a new model for testing drugs to treat Ataxia Telangiectasia

**Principal Researcher: Professor Richard Gatti**
**Project Completion Date: December 2015**

## Project Overview

Professor Gatti and his colleagues aimed to develop a class of drug called "read-through compounds" to treat A-T. These drugs target one specific class of mutation in the ATM gene (the gene that carries a mutation in A-T) called a nonsense mutation. This is when one letter of the DNA sequence code is changed to another letter thereby creating a STOP signal in the middle of the gene.

Read-through compounds encourage the cells to ignore this STOP signal so they will start to produce the ATM protein in a similar way to healthy cells. The aim of this project was to develop a new mouse model that carries a nonsense mutation in the ATM gene. In order to fully investigate if these drugs might be effective in A-T and safe for clinical trials, they will need to be tested in animal models of A-T. This new mouse strain will be used for other A-T research as well.

Professor Richard Gatti

## Project Outcome

The team have completed the first steps in developing a mouse colony of ATM mice that carry a nonsense mutation. They have carried out some preliminary testing of a number of read-through compounds in these models and as they continue to build the mouse colony, will be able to fully test these and other compounds for their effectiveness at reducing the A-T symptoms that the mice possess. Read-through compounds could also have similar beneficial effects in other genetic conditions that are caused by a nonsense mutation. Thus, with just a few drugs that can read through nonsense mutations, patients with many genetic diseases may hope to benefit.

## Publications

The team plan to publish the details of developing the new mouse strain along with its usefulness for evaluating drug candidates. This would be expected to occur in 2017-18.

# Childhood Ataxia Telangiectasia Neuroimaging Assessment Project - The Catnap Study

**Principal researchers: Dr Rob Dineen and Professor Dorothee Auer**
**Project Completion Date: August 2016**

## Project Overview

This study jointly funded with the A-T Children's Project aimed to understand what happens in the brains of children who have A-T. The Nottingham based team used the latest techniques in MRI scanning to look at the brains of children with A-T with a view to developing biological markers which would measure the underlying disease process and assess whether future new treatments work. Nottingham University were uniquely placed to carry out this research as the UK National A-T Children's clinic is located in the city. Due to their proximity to the clinic, the research team were able to recruit more A-T children than would be practically possible in other larger countries, leading to the biggest study of its kind in the world.

Tania Wheeler and Dr Rob Dineen

## Project Outcome

The initial findings from the CATNAP study have shown that:

1. Detailed brain MRI is feasible in paediatric A-T, including the measurement of the antioxidant glutathione, which is an important and naturally occurring brain chemical that helps to protect the brain
2. It is possible to carry out detailed measurement of the volume of different brain structures that are important in A-T, and that some of these measurements reflect the levels of neurological disability that children and young people with A-T experience.

## Publications

Preliminary results from the study were presented at the 2016 A-T Clinical Research Conference, Warsaw. Presentations on study design and recruitment updates were also given at the 2015 British Paediatric Neurology Association Meeting, Newcastle and at the 2015 Ataxia-Telangiectasia Workshop, Beijing.

A methods paper regarding the spectroscopy technique has been submitted and is now undergoing revision following reviewer comments and the main manuscript presenting the volumetric, spectroscopic, diffusion and perfusion analyses from the CATNAP study is under preparation.

# Studying how genetic factors might reduce the severity of A-T

**Principal researcher: Professor Steve Jackson and Dr Rimma Belotserkovskaya**
**Project Completion Date: 30th September 2016**

## Project Overview

Professor Jackson and Dr Belotserkovskaya proposed to study cells derived from an Ataxia Telangiectasia (A-T) patient with unusually mild symptoms even though the patient had complete loss of ATM (the protein affected in A-T). The patient therefore appears to have "resilience" to A-T. The basis of the research was to determine whether there is something special or different about the cells and genetic background of the patient that decrease A-T disease severity.


Professor Steve Jackson & Dr Rimma Belotserkovskaya

## Project Outcome

This project had three main objectives:

1. Sequence analyse the DNA isolated from this patient – DNA was prepared and subjected to whole genome sequencing at the Wellcome Trust Sanger Institute. This was successfully achieved.

2. Generate pluripotent stems cells and differentiate these cells into neurons – by using recently established techniques this has been successfully achieved for this patient, "regular" A-T patients and healthy controls. This work is ongoing but at the time of writing the final report the team had successfully differentiated the isolated cells into neuroprogenitor cells in at least one of the cell lines.

3. To analyse DNA damage responses in the stem cells and neurons – there was a delay in receiving the pluripotent stem cells at the Gurdon Institute so this has not yet been completed. Cells were expected to be established by December 2015 but were only imported into the Gurdon Institute in August 2016. As a result, this work is currently ongoing.

## Publications

There are currently no publications from this work; it is at an early stage and we would not expect an output at this point.

## References

1. Worth, P. F. et al. Very mild presentation in adult with classical cellular phenotype of ataxia telangiectasia. Movement Disorders 28, 524-528 (2013).

# Treating cancer in A-T without exacerbating central nervous damage

**Principal researcher: Professor Mark Noble**
**Project Completion Date: December 2016**

## Project Overview

Children with A-T have an increased incidence of developing cancers, primarily leukaemia and lymphoma. These children also bear the additional risk that the mutation causing A-T makes cells more susceptible to agents that cause DNA damage and are therefore at risk of developing secondary cancers as a result of their cancer treatment.

The goal of Professor Noble and his colleagues was to develop safer, but effective treatments for cancer in individuals with this condition.

## Project Outcome

The funding provided by Action for A-T allowed Professor Noble and his team to make a number of important discoveries:

Using research models, the team's work highlighted a common weakness in several types of cancer cells that could be exploited as a therapeutic approach. This novel approach to cancer treatment may offer a greater margin of safety than current chemotherapeutic agents.

1. They found drugs already in clinical use which can take advantage of this weakness in the cancer cells. As these approaches are based on discovering new properties of drugs already approved for other purposes, this would enable a quicker and less expensive transition to the clinic than for brand new drugs.

2. A combination of drugs may make cancer cells in A-T more vulnerable to currently used treatments and thus would allow smaller and therefore less toxic doses to be used. This general treatment strategy also looks very promising for breast cancer, which occurs with increased frequency in individuals with A-T.

3. The treatment strategy appears, in research models, to be remarkably safe for vulnerable cells of the brain, even in the models that lack functional ATM protein.

## Publications

Campbell A, Krupp B, Bushman J, Noble M, Pröschel C, Mayer-Pröschel M. Hum Mol Genet. 2015 Nov 15;24(22):6331-49. Epub 2015 Aug 26 A novel mouse model for ataxia-telangiectasia with a N-terminal mutation displays a behavioural defect and a low incidence of lymphoma but no increased oxidative burden.

**During the 2016 accounting period the following grants for A-T research projects were approved and allocated for funding:**

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

**Principal researcher: Dr Vincenzo Costanzo**
**Institute: IFOM – The FIRC Institute of Molecular Oncology, Milan, Italy**
**Start Date: December 2016**

## Project Summary

Dr Vincenzo and his research team will test 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 impairment of these processes might be one of the causes of the health problems associated with A-T. Nucleotides are essential components of DNA and RNA, which are molecules that store and generate the information needed for all cellular functions. Lack in nucleotide production might impair the production of other cellular components, such as proteins, and lead to poor DNA repair and DNA duplication causing problems in cell growth, cell duplication and cell survival under stress. These defects might be responsible for some of the problems typical in A-T patients such as neurological degeneration, immunodeficiency, radiation sensitivity, pulmonary infections and increased risk for cancer. Nucleotide defects could be the target of novel strategies aimed at restoring their levels in order to correct the cellular defects present in A-T cells.

The team will use several scientific methods to study the metabolic steps of the nucleotide pathways in A-T cells and study novel strategies to try to restore nucleotide balance in A-T cells. They will study the molecular reactions required to produce nucleotides, which could be directly controlled by ATM. This will provide further understanding of how these defects occur and how they could be corrected. The relevance of these metabolic alterations will be directly tested by manipulating and restoring altered metabolic pathways in A-T cells with existing compounds that are already known to impact on nucleotide metabolism. These studies will be important to understand how ATM controls cell survival and might be helpful to design novel therapeutic interventions to restore cellular functions controlled by ATM, which are altered or absent in A-T cells, bypassing the requirement for the ATM gene.

This project was made possible, in part, 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.

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

**Principal researchers: Dr Jayesh Bhatt and Dr Andrew Prayle**
**Institute: Nottingham University Hospitals NHS Trust**
**Start Date: April 2017**

## Project Summary

The Nottingham team will scan the lungs of a group of children and young people with Ataxia-Telangiectasia (A-T) with a cutting-edge lung scanning technique called Oxygen Enhanced Magnetic Resonance Imaging (OEMRI), and to measure lung function with a technique not previously used in A-T called Lung Clearance Index (or LCI).

The researchers are confident that OEMRI will be a very valuable tool to look inside the lungs of people with A-T, because it does not use x-rays (no exposure to radiation from x-rays). Also, the scan does not require the patient to hold their breath – they just lie down in the scanner and breathe. This makes the scan much easier for people who may struggle to hold their breath or breathe in or out when asked, which is needed for other types of scans. Finally, the team believe that the OEMRI scans will allow them to look at both the structure and the function of the lungs in one test.

Studies have already shown that LCI is a very good test in some other conditions, and their hypothesis is that it will also be helpful in A-T. It may technically be an easier test to perform than the currently performed lung function test (spirometry). LCI mainly tells us if the small airways within the lungs are working well, but also allows us to calculate some measurements of lung volume. Like OEMRI, it does not require breathing manoeuvres, and the team have adapted their equipment to use a face mask rather than a mouthpiece for people with A-T who are unable to make a good seal around a mouth piece. Unlike OEMRI, LCI can be measured with table-top equipment. So, in the future, LCI could potentially be measured at clinic appointments.

# A zebrafish model of Ataxia Telangiectasia (A-T)

**Principal researcher: Dr Andrew Grierson**
**Institute: Sheffield Institute for Translational Neuroscience (SITraN) & The Bateson Centre, University of Sheffield**
**Start Date: April 2017**

## Project Summary

The aim of this project is to genetically engineer zebrafish carrying mutations in the ATM gene that causes A-T in human patients.

Zebrafish are small tropical fish that are gaining popularity for academic and industry-led research into human diseases. A large proportion of human disease genes (approx. 70%) have an equivalent in zebrafish. While humans and zebrafish may not look alike, they are similar. Zebrafish are vertebrates (have a spinal cord) which is critical for modelling disorders of the nervous system such as A-T. Zebrafish are also highly fertile and it is possible to generate many fish in a short time.

There are limitations with conventional animal models of A-T as they do not develop the neurological characteristics that an A-T human patient does. To develop therapies or gain further insight into what goes wrong, researchers need to consider new models to investigate the mechanisms of A-T. The team want to study these fish in order to try and understand what "goes wrong" in the brain of A-T patients and use these fish to look for new therapeutic drugs that may slow down or limit the development of the neurological symptoms in A-T.

The team aim to produce genetically engineered zebrafish that carry ATM mutations using CRISPR-Cas9 gene editing techniques. CRISPR-Cas9 is a technology that has often been described as a pair of molecular scissors – it enables researchers to efficiently edit parts of the genome by removing, adding or altering sections of the DNA sequence.

The researchers hope to use these fish to better understand the disease process, and eventually to test new therapies for future use in A-T patients. Currently, there are no therapies for A-T. This project aims to make progress towards the development of therapies by establishing a zebrafish model that develops A-T. If successful, thousands of drugs can be tested in the zebrafish, to look for drugs that might be beneficial in A-T patients.

# Identifying potential mechanisms to suppress A-T pathologies

**Principal researchers: Professor Steve Jackson and Dr Rimma Belotserkovskaya**
**Institute: The Gurdon Institute, University of Cambridge**
**Start Date: May 2017**

This research project follows on from the previous work carried out by Professor Steve Jackson and his team (details on page 10) which was completed in September 2016. This project will be jointly managed and funded with the US-based A-T Children's Project and their first payment towards the study will be received at the end of 2017.

## Project Summary

Ataxia-telangiectasia (A-T), caused by mutations in the ATM gene, is a disease associated with various pathologies, particularly progressive loss of certain nerve cells and defective DNA repair. Building on their recent progress, the team aim to determine how changes in other genes might alleviate symptoms of A-T in cells, with the hope that these changes could also alleviate patient symptoms.

Professor Jackson and his team will work with cells they have obtained from patients who, despite possessing inactivating ATM mutations, have strikingly mild symptoms. Having determined the DNA (genome) sequence of these patients, they are now identifying possible mutations (in genes other than the ATM gene) that might alleviate A-T symptoms. Having already "reprogrammed" cells from mild A-T patients into induced pluripotent stem cells, they will next differentiate them into nerve cells and compare their properties and functions with cells derived from control patients with or without A-T. They also plan to couple this work with revolutionary CRISPR-Cas9 gene editing methods, which they have recently used to identify genes that, when mutated, alleviate DNA repair defects of ATM-defective mouse cells.

The proposed work could identify modifiers of A-T, therefore improving the ability of clinicians to counsel/advise patients and their families regarding their disease and its likely progression. It is also possible that the proposed work will identify opportunities for clinicians to advise on how the progression of A-T might be slowed down by drugs or other agents.

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

**Principal researcher: Dr Peter Merkus**
**Institute: Radboud University Medical Centre, the Netherlands**
**Start Date: TBC – pending ethical approvals**

This project is funded in partnership with Sparks charity and our contribution to the project was paid in full in December 2016.

## Project Summary

Almost all children and adults with Ataxia Telangiectasia (A-T) suffer from respiratory symptoms, recurrent or chronic lung disorders. This is responsible for a large burden on these patients and their families, and can often be fatal. In order to improve treatment, it is necessary to be able to monitor the condition of the lung. Lung function measurements are difficult to carry out reliably for many people with A-T, and standard imaging techniques involve the use of ionising radiation which should be avoided whenever possible in A-T patients. Magnetic Resonance Imaging (MRI) does not involve ionising radiation and improved MRI would be the ideal tool to obtain reliable structural information about the lungs. However, up until recently MRI was not a very suitable technique for lung imaging in A-T due to several reasons: poor resolution and contrasts, being a lengthy procedure and patients with A-T often having uncoordinated or involuntary movements due to ataxia which prevents optimal imaging.

MRI Scanner Lego model

The Dutch team will study how they can develop improved lung imaging in A-T patients using advanced MRI techniques instead of conventional chest X-ray or CT imaging. They want to facilitate the possibility of obtaining useable lung images whilst patients breathe normally instead of holding their breath. They also hope to create high quality images of the lungs even when patients are unable to keep completely still.

Initially, the team will see how they can best program the MRI scanner to obtain the best lung images based on comparisons with lung imaging using CT scans, in patients with lung disease who do not have A-T. The result of this first part will indicate the optimal MRI settings to be used for lung imaging.

In the second part of the study, they will explore how they can obtain good quality lung MRI images using these settings, whilst correcting for breathing and small movements that the patients make; this part will be carried out in patients with A-T.

**To view all of the research projects we have funded to date, please visit actionforAT.org**

## Grant Round

The Trustees currently stage one grant round per year. The application process opens in the late summer / autumn of one year and closes in the spring of the following year. Applications are peer reviewed by independent external reviewers before they are passed on to our Research Advisory Committee for further review. Projects which pass the peer review process and are deemed high enough quality are passed on to the Trustees to make the final decision based on a number of key criteria including available funds, strategic alignment and existing research commitments.

## Fundraising for Research

Action for A-T receives all of its funding from voluntary sources, including individuals, companies, trusts and foundations. We also take places in a number of physical challenges as well as staging and benefiting from a series of other social and sporting events. The pie chart below shows the percentage splits of each of our areas of fundraising in 2016.

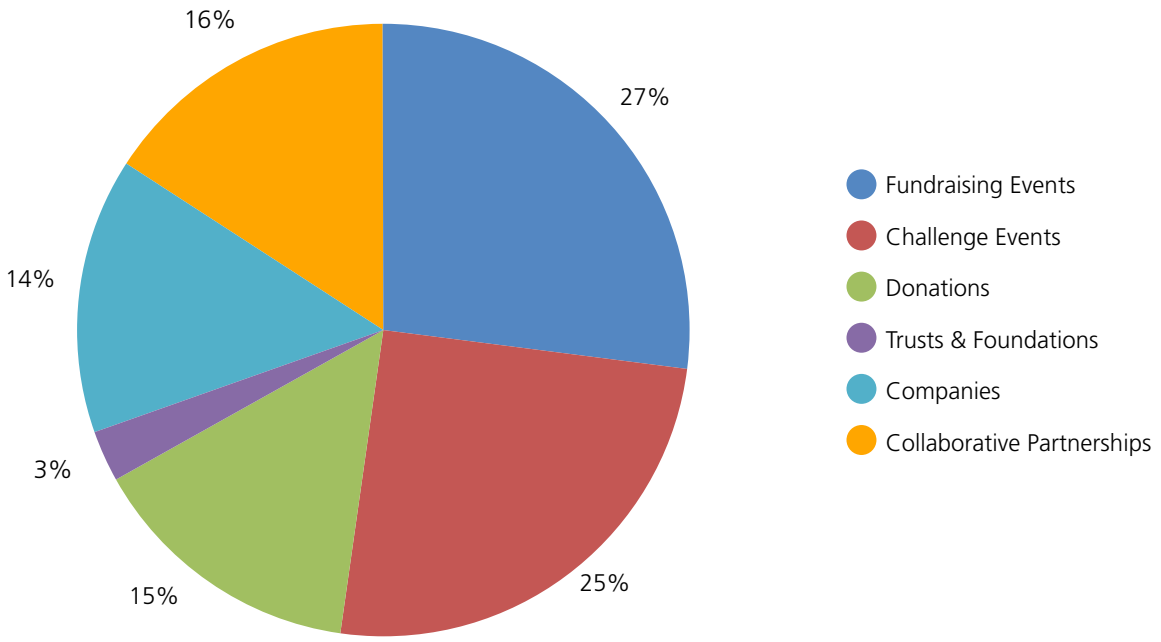
In line with our fundraising strategy we continued to broaden our income base to ensure that we are not solely dependent on any one source of funding.

Challenge and social events remained a key source of income in 2016 generating more than 52% of the Charity's income but other fundraising initiatives such as company fundraising and trust and foundation applications, provided additional new funds. A number of new fundraising activities took place throughout the year and we are especially grateful to Ed and Jess White of Scumrun Ltd for their corporate partnership during 2016 which generated £55,000. In addition, we would like to thank House of Fraser, Quest Professional, Grant Thornton, Barclays and St James's Place for their ongoing corporate support.

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

In addition to the above, we are also extremely grateful to all of the trusts and foundations who have provided grants throughout the year for specific research projects (these are listed on page 38). We are keen to work with other trusts and foundations who might be interested in supporting our work.

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



# Raising Public Awareness about A-T

## Our Aim

A-T is currently little known in the general population. 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 made real progress in raising public awareness about A-T over the past 12 months and will continue to explore options to promote wider understanding of what A-T is and why research is so important.

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

## 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 a charity information leaflet highlighting the need for research into A-T, a simple postcard with an overview of the condition, a calendar which was sent to all of our warm supporters and a series of materials to assist individuals with the promotion of their fundraising activities. We also increased our investment in branded clothing for challenge participants and signage and banners for use at events.

## Visibility at Conferences and Medical Meetings

Throughout the year, representatives from the Charity and the research community gave speeches at various medical conferences and events. These speeches showcased our latest research projects, provided an overview on how we are investing donated funds and provided information about the condition and its effects on the children who have A-T.

## 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 and national press and news websites. These have helped us to highlight the condition to new audiences, recruit volunteers and secure donations.

## Celebrity Support

We have continued to work with our existing celebrity patrons to help promote Action for A-T and the need for research into the condition. Following on from the sizeable donation from our lead patron's (Jonny Wilkinson) testimonial activities in December 2015 we also received considerable celebrity support at a variety of events throughout the year from the likes of Sir Trevor Brooking, Alan McInally, Tiff Needell and Chris Sheasby.

Jonny Wilkinson, CBE

## Digital Communications

Our website which incorporates the functionality of our CRM system was launched in January 2016. The site has specific areas for a variety of stakeholders and is easier to navigate than the old site. It also incorporates Google analytics which enable us to monitor traffic and make amendments or enhancements where necessary. Over the year, we have seen a steady increase in website traffic, electronic donations and event sign ups. We received external recognition for the quality of our website as we were finalists in 2017 Surrey Digital Awards in the best school or charity website category.

We have continued to communicate with our supporters via a structured monthly e-newsletter. These electronic communications are much cheaper and easier to produce than traditional printed newsletters and have embedded tools which allow us to monitor engagement. We are able to send targeted marketing to a large proportion of our supporters as we are aware of their personal preferences and also send generic content to keep donors informed of our latest research as well as promoting campaigns and fundraising events. Our e-newsletter is sent to all of 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 has the ability to 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 by more than 16% throughout the year as well as increasing our Twitter following significantly. We will continue to develop our social media presence in 2017 using all available technological advancements and popular platforms to raise further awareness.

## Film

We created two new short films in 2016 to communicate and celebrate our £1million investment in A-T research since the Charity was established in 2012. The first of these was a short animation film entitled "The Story So Far" which explained the basic symptoms of the condition, thanked supporters for helping us reach the £1million mark and communicated our future plans. The film has been shared on a variety of digital platforms and continues to be popular as it has been viewed more than 5,000 times so far. It has also been screened at various events and sent directly to potential supporters to help them understand the condition and learn more about Action for A-T.

Action for A-T cyclists

Our second film entitled "One Word" showcased a wide variety of our stakeholders holding up message boards displaying a key word which best described what Action for A-T meant to them. Researchers, celebrity patrons, A-T families and a variety of donors and supporters all took part and their messages were unprompted. The film was shared via a variety of digital channels shortly after our £1million research investment announcement and sends a powerful and moving message.

In addition to the above we also produced a series of short films featuring some of the UK researchers we are funding. These films are available to view alongside the project information on our website and provide an overview of specific areas of research as well as highlighting some of the complications of the condition.

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

vimeo.com/actionforat/videos

www.youtube.com/channel/ActionforAT

# Building Collaborative Partnerships

## Our Aim

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

## Our Performance

Ongoing collaboration work with the Children's Medical Research Charity Sparks

Action for A-T continued to work closely with UK Children's Medical Research Charity Sparks who are currently managing the following jointly funded research projects:

Understanding dexamethasone action in Ataxia Telangiectasia – Professor Luciana Chessa at the Sapienza University of Rome, Italy

Stem Cell Transplantation for A-T – Dr. Ralf Schubert at the Goethe University Frankfurt, Germany

In addition to the above, the Trustees agreed to joint fund a new project with Sparks in November 2016. Full details of this study are provided on page 14. The cost of €110,000 will be shared between both charities and the project is due to start in the summer of 2017 when Professor Merkus receives the necessary ethical approvals.

In February 2017 Sparks joined Great Ormond Street Hospital Charity as a subsidiary. Together GOSH Charity and Sparks aim to fund more pioneering national research to find new ways to diagnose, treat and cure childhood diseases. Action for A-T will continue to work with both organisations moving forward as long as opportunities to joint fund A-T related research projects exist.

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

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

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

At the end of 2016, Action for A-T and the A-T Children's Project combined forces to joint fund a new project at The Gurdon Institute at the University of Cambridge. Entitled "Identifying potential mechanisms to suppress A-T pathologies", this 2 year study follows on from Professor Jackson's and Dr Belotserkovskaya's previous work (full details can be found on page 13). Action for A-T will fund the full cost of the project (£199,111) and there is an agreement in place for the A-T Children's Project to meet half the cost of the research. Their contribution of £99,555 has been recognised in these accounts and treated as a restricted donation.

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

# Our next steps: areas of focus for 2017

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 2017 we will increase our fundraising activities and actively seek new funding partners to meet the demands of the A-T research community. We will also continue to seek opportunities to promote A-T research rather than simply responding to applications for grant funding.

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

## Building our Capacity and Capabilities

As a small charity, we have limited resources and must therefore think very carefully before choosing to invest in new activities or personnel to help us achieve our charitable mission. Since the Charity was initially established in 2012, a great deal of infrastructure work has already taken place but continued development is required to ensure that we are well positioned for the future. In 2017 we will:

- Prioritise key projects based on available resources
- Secure volunteer help to assist with various administrative duties and development work
- Further develop fundraising initiatives which provide sustainable and repeatable sources of income
- Ensure that we have the necessary skills throughout the organisation to deliver our organisation wide objectives
- Keep up to date with current trends and remain flexible so that change can be implemented quickly if required

## Exploring Additional Collaborative Funding Opportunities

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 has grown steadily year on year and we have now reached a point where we have more fundable research projects than we can afford. It is vital that we continue this momentum to help speed up the process of finding a therapy or cure for A-T and we will therefore explore additional joint funding opportunities with other likeminded research organisations to help ease the financial burden.

## Strengthening and Increasing our Fundraising Activities

Our Head of Fundraising (appointed in February 2016) will continue to develop a pipeline of new business opportunities whilst delivering our existing portfolio of activities. We will continue to deliver a series 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 further develop our sustainable giving program and work closely with our key supporters to meet the increased demand from the research community.

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

We will continue our investment in the highest quality A-T research around the globe with a key focus on projects which are carried out here in the UK. We will develop new partnerships with other medical research charities to help us meet the demands of the A-T research community whilst continuing to work with our existing research partners.

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

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

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

## Board Composition

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

# Structure, Governance & Management

## Governing Document

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

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

## Trustee Recruitment and Appointment

The Trustees listed on page 26 have overall responsibility for the strategic direction and effective governance of the Charity. Trustees are either elected or co-opted under the terms of the Trust deed and the total number of Trustees may not be fewer than five. If a vacancy occurs or a skills need is identified, new Trustees are recommended by the existing Trustees and interviewed by the Chairman and at least one other member of the board. Election is by majority vote and potential candidates must be over the age of eighteen and eligible to act.

## Trustee Induction and Training

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

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

## Organisational Structure

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

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

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

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

## Chief Executive

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

## Employees, Volunteers and Contractors

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

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

## Risk

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

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

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

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

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

## Investment Policy

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

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

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

# Financial review

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

## Income

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

Total income raised in 2016 was £626,779 **(2015 - £573,574).**

## Charitable Expenditure

The cost spent on Charitable Activities Was £568,691 **(2015 - £321,797)** of which £540,615 **(2015 – £289,862)** was for grants provided for funding of research projects.

The cost of generating voluntary income was £59,783 **(2015 - £48,580)** whilst the cost of generating income from charitable events was £146,657 **(2015 - £127,471)**

Governance costs £12,799 **(2015 - £10,171)** 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 £400,000 were brought forward from 2015

In 2016, £212,664 of funds were passed on to the research projects detailed in note 8 on page 33.

As at 31 December 2016 designated funds carried forward are £nil.

## Restricted Funds

Restricted funds of £nil were brought forward from 2015. During 2016, £341,393 of funding was made to the research projects detailed in note 8 Page 33.

At 31 December 2016 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 Trustee report included in the previous pages

Signed on behalf of the charity's Trustees.

Toby Read (Chairman)

William Rowberry (Treasurer)

Dated: 8/8/17

Dated: 8/8/17

# Auditors Report

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

We have audited the financial statements of Action for A-T for the year ended 31 December 2016 which comprise (the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Generally Accepted Accounting Practice including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

This report is made solely to the Charity's Trustees, as a body, in accordance with regulations made under section 154 of the Charities Act 2011. Our audit work has been undertaken so that we might state to the Charity's Trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and the Charity's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

## Respective responsibilities of Trustees and auditor

As explained more fully in the Trustees' Responsibilities Statement set out on page 23, the Trustees are responsible for the preparation of financial statements which give a true and fair view.

We have been appointed as auditor under section 145 of the Charities Act 2011 and report in accordance with regulations made under section 154 of that Act. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

## Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of:

- Whether the accounting policies are appropriate to the Charity's circumstances and have been consistently applied and adequately disclosed;
- The reasonableness of significant accounting estimates made by the Trustees;
- And the overall presentation of the financial statements.

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

## Opinion on financial statements

In our opinion the financial statements:

- Give a true and fair view of the state of the Charity's affairs as at 31 December 2016, 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 applicable to Smaller Entities; and
- Have been prepared in accordance with the requirements of the Charities Act 2011.

## 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 Trustees' Annual Report 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.

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

Dated: 8/8/17

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

ACTION FOR A-T

# Statement of Financial Activities

Incorporating income and expenditure for the year ended 31 December 2016

| | Notes | Unrestricted 2016 £ | Restricted 2016 £ | **Total Funds 2016 £** | Total Funds 2015 £ |
|---|---|---|---|---|---|
| **Incoming resources** | | | | | |
| Voluntary income: | 2 | | | | |
| Donations and legacies | | 95,826 | 112,805 | **208,631** | 169,125 |
| Activities for generating funds: | 3 | | | | |
| Charitable events | | 387,172 | 27,360 | **414,532** | 402,189 |
| Investments: | 4 | | | | |
| Investment income | | 616 | - | **616** | 260 |
| Other Income: | 5 | | | | |
| Sundry income | | 3,000 | - | **3,000** | 2,000 |
| **Total income** | | 486,614 | 140,165 | **626,779** | 573,574 |
| **Resources expended** | | | | | |
| Costs of generating voluntary income: | 6 | | | | |
| Voluntary income | | 59,783 | - | **59,783** | 48,580 |
| Costs of activities for generating funds: | 7 | | | | |
| Charitable events | | 146,657 | - | **146,657** | 127,471 |
| Costs of charitable activities | | 227,298 | 341,393 | **568,691** | 321,797 |
| Other expenditure: | 9 | | | | |
| Governance costs | | 12,779 | - | **12,779** | 10,171 |
| **Total resources expended** | | 446,517 | 341,393 | **787,910** | 508,019 |
| **Net income / (expenditure)** | | 40,097 | (201,228) | **(161,131)** | 65,555 |
| Transfers between funds | | (201,228) | 201,228 | **-** | - |
| **Net Movement in funds** | | (161,131) | - | **(161,131)** | 65,555 |
| **Total funds at 1 January 2016** | | 654,583 | - | **654,583** | 589,028 |
| **Total funds at 31 December 2016** | | 493,452 | - | **493,452** | 654,583 |

The net movement in funds referred to above is the net incoming resources as defined in the Statement of Recommended Practice for Accounting and Reporting issued by the Charity Commission for England and Wales and is reconciled to the total funds as shown in the Balance Sheet on page 27 as required by the said statement.

ACTION FOR A-T

# Balance Sheet

At 31 December 2016

| | Notes | **2016** | | 2015 | |
|---|---|---|---|---|---|
| | | **£** | £ | £ | £ |
| **Current assets** | | | | | |
| Stock | | **6,171** | | 11,478 | |
| Debtors | 10 | **153,256** | | 83,506 | |
| Cash at bank | | **914,068** | | 813,805 | |
| | | **1,073,495** | | 908,789 | |
| **Liabilities** | | | | | |
| Amounts due within one year | 11 | **307,609** | | 254,206 | |
| **Total assets less current liabilities** | | | 765,886 | | 654,583 |
| **Creditors: Amounts falling due after more than one year;** | 11 | | (272,434) | | - |
| **Net assets** | | | 493,452 | | 654,583 |
| Charity funds | | | | | |
| Restricted funds | 13 | **-** | | - | |
| Unrestricted funds | 13 | **493,452** | | 654,583 | |
| | | | 493,452 | | 654,583 |

The Trustees declare that they have approved the financial statements.

Signed on behalf of the charity's Trustees.

Toby Read (Chairman)

William Rowberry (Treasurer)

Dated: 8/8/17

Dated: 8/8/17

ACTION FOR A-T

# Cashflow Statement

At 31 December 2016

| | Notes | **Total Funds 2016 £** | Prior Year Funds 2015 £ |
|---|---|---|---|
| **Cash flows from operating activities:** | | | |
| Net cash provided by operating activities | 19 | **99,647** | 248,165 |
| **Cash flows from investing activities:** | | | |
| Interest | | **616** | 260 |
| Fixed assets | | **-** | - |
| Net cash provided by investing activities: | | **616** | 260 |
| **Cash flows from financing activities:** | | | |
| Net cash provided by financing activities | | **-** | - |
| **Change in cash and cash equivalents in the reporting period** | | **100,263** | 248,425 |
| **Cash and cash equivalents brought forward** | 20 | **813,805** | 565,380 |
| **Cash and cash equivalents carried forward** | 20 | **914,068** | 813,805 |

# Notes to the financial statements

At 31 December 2016

## 1. Accounting Policies

### Basis of preparation of financial statements

The financial statements have been prepared in accordance with Accounting and Reporting by Charities Statement of Recommended Practice applicable to charities preparing their accounts in accordance with Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS102) issued on 16 July 2014 and with the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS102) and with the Charities Act 2011. In the previous year the financial statements had been prepared under the historical cost convention, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008).

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

### Reconciliation with previous Generally Accepted Accounting Practice

In preparing the financial statements the Trustees have considered whether in applying the accounting policies required by FRS102 and the Charities SORP FRS102 a restatement of comparative item was required. No such restatement has been required. In accordance with the requirements of FRS102 a reconciliation of opening balances and net income / (expenditure) for the year is provided with the net income / (expenditure) under previous GAAP.

### Reconciliation of reported net income

| | £ |
|---|---|
| Net income / (expenditure) as previously stated | 65,555 |
| No adjustments necessary | - |
| 2015 net income as restated | 65,555 |

### Accounting convention

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

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

### Going concern basis

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

### Fund accounting

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

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

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

# Accounting Policies (cont)

## 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.

## Foreign currency

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

## Governance costs

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

## Taxation

The Charity is exempt from tax on its charitable activities.

## Irrecoverable VAT

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

## Financial instruments

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

## Stocks

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

# Notes to the financial statements

At 31 December 2016

## 2. Income From Donations And Legacies

| | Unrestricted 2016 £ | Restricted 2016 £ | **Total Funds 2016 £** | Total Funds 2015 £ |
|---|---|---|---|---|
| Donations | 62,754 | 8,000 | **70,754** | 37,114 |
| Gift aid claims | 9,730 | - | **9,730** | 10,897 |
| Fundraising | 23,342 | 104,805 | **128,147** | 121,114 |
| Legacies | - | - | **-** | - |
| | 95,826 | 112,805 | **208,631** | 169,125 |

## Volunteer Services

No volunteers provided unpaid services to the Charity during the year. During the previous year (2015) 120 hours were provided which the Trustees valued at £10.50 per hour.

## 3. Income From Charitable Activities

| | Unrestricted 2016 £ | Restricted 2016 £ | **Total Funds 2016 £** | Total Funds 2015 £ |
|---|---|---|---|---|
| Fundraising events | 147,143 | 27,360 | **174,503** | 195,137 |
| Challenge events | 240,029 | - | **240,029** | 207,052 |
| | 387,172 | 27,360 | **414,532** | 402,189 |

## 4. Income From Investments

| | Unrestricted 2016 £ | Restricted 2016 £ | **Total Funds 2016 £** | Total Funds 2015 £ |
|---|---|---|---|---|
| Bank interest | 616 | - | **616** | 260 |
| | 616 | - | **616** | 260 |

## 5. Other Income

| | Unrestricted 2016 £ | Restricted 2016 £ | **Total Funds 2016 £** | Total Funds 2015 £ |
|---|---|---|---|---|
| Employment allowance | 3,000 | - | **3,000** | 2,000 |
| | 3,000 | - | **3,000** | 2,000 |

## 6. Costs Of Generating Voluntary Income

| | Unrestricted 2016 £ | Restricted 2016 £ | **Total Funds 2016 £** | Total Funds 2015 £ |
|---|---|---|---|---|
| **Voluntary Income:** | | | | |
| Film | 1,200 | - | **1,200** | 2,171 |
| Administrative Costs | 23,387 | - | **23,387** | 16,014 |
| Donation Collection Fees | 12,690 | - | **12,690** | 6,704 |
| Insurance | 554 | - | **554** | 501 |
| Telephone | 1,874 | - | **1,874** | 1,702 |
| Bank Charges | 1,653 | - | **1,653** | 2,109 |
| Subscriptions | 569 | - | **569** | 436 |
| Sundry Expenses | 430 | - | **430** | 510 |
| Information Technology | 1,383 | - | **1,383** | 5,421 |
| Office Rent | 11,086 | - | **11,086** | 5,868 |
| Marketing | 3,781 | - | **3,781** | 5,228 |
| Printing And Stationery | 1,176 | - | **1,176** | 1,916 |
| | 59,783 | - | **59,783** | 48,580 |

## 7. Costs Of Activities For Generating Funds

| | Unrestricted 2016 £ | Restricted 2016 £ | **Total Funds 2016 £** | Total Funds 2015 £ |
|---|---|---|---|---|
| **Cost of Charitable Events:** | | | | |
| Event costs | 146,657 | - | **146,657** | 127,471 |
| | 146,657 | - | **146,657** | 127,471 |
| **Costs of Charitable Activities:** | | | | |
| **General Funds:** | 49,724 | - | **49,724** | 37,335 |
| Research support costs | | | | |
| **Designated Funds:** | | | | |
| Grants to research institutions **(Note 8)** | 199,222 | 341,393 | **540,615** | 289,862 |
| Exchange gains | (21,648) | - | **(21,648)** | (5,400) |
| | 227,298 | 341,393 | **568,691** | 321,797 |

## 8. Grants To Research Institutions

| | Unrestricted 2016 £ | Restricted 2016 £ | **Total Funds 2016 £** | Total Funds 2015 £ |
|---|---|---|---|---|
| **Restricted Funds:** | | | | |
| University of Nottingham Dr Bhatt & Dr Prayle | - | 94,839 | **94,839** | 37,810 |
| University of Cambridge Prof. Steve Jackson | - | 199,111 | **199,111** | 38,876 |
| Radboud University Netherlands – Dr Merkus | - | 47,443 | **47,443** | - |
| **Designated Funds:** | | | | |
| University of Nottingham CATNAP Study | 24,018 | - | **24,018** | 13,176 |
| University of New York Prof. Khodakhah | - | - | **-** | 100,000 |
| Duke University of North Carolina Prof. Kastan | - | - | **-** | 100,000 |
| University of Sheffield Dr Grierson | 88,710 | - | **88,710** | - |
| The FIRC Institute Milan, Dr Constanzo | 99,936 | - | **99,936** | - |
| **Research project underspends refunded** | | | | |
| University of Nottingham CATNAP Study | (9,028) | - | **(9,028)** | - |
| University of Granada Prof. Molina | (3,266) | - | **(3,266)** | - |
| Sparks A-T Network Fund | (1,148) | - | **(1,148)** | - |
| | 199,222 | 341,393 | **540,615** | 289,862 |

## 9. Other Expenditure

| | Unrestricted 2016 £ | Restricted 2016 £ | **Total Funds 2016 £** | Total Funds 2015 £ |
|---|---|---|---|---|
| Governance costs: | | | | |
| Salaries | 7,407 | - | **7,407** | 7,426 |
| Auditors remuneration | 2,910 | - | **2,910** | 1,600 |
| Accountancy | 1,550 | - | **1,550** | 720 |
| Professional fees | 426 | - | **426** | 425 |
| Travel | 486 | - | **486** | - |
| | 12,779 | - | **12,779** | 10,171 |

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

| | **2016** **£** | 2015 £ |
|---|---|---|
| Other debtors | **53,701** | 83,506 |
| Restricted donations | **49,778** | - |
| At 31 December 2016 | **103,479** | 83,506 |

## Debtors: Amounts Falling Due After One Year

| | **2016** **£** | 2015 £ |
|---|---|---|
| Restricted donations | **49,777** | - |
| At 31 December 2016 | **49,777** | - |
| | **153,256** | 83,506 |

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

| | **2016** **£** | 2015 £ |
|---|---|---|
| Grants | **302,373** | 249,994 |
| Accruals and deferred income | **5,236** | 4,212 |
| At 31 December 2016 | **307,609** | 254,206 |

## Creditors: Amounts Falling Due After One Year

| | **2016** **£** | 2015 £ |
|---|---|---|
| Grants | **272,434** | - |
| At 31 December 2016 | **272,434** | - |

## 12. Corporate Taxes

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

## 13. Statements Of Funds

| | Brought Forward £ | Incoming Resources £ | Resources Expended £ | Transfers In/(Out) £ | Carried Forward £ |
|---|---|---|---|---|---|
| Radboud University Netherlands – Dr Merkus | - | 27,360 | (47,443) | 20,083 | - |
| University of Nottingham - Dr Bhatt & Dr Prayle | - | 8,000 | (94,839) | 86,839 | - |
| University of Cambridge - Prof. Steve Jackson | - | 99,555 | (199,111) | 99,556 | - |
| University Hospital Birmingham - Prof. Grant Stewart | - | 5,250 | (-) | (5,250) | - |
| | | | | | - |
| **Restricted funds** | **-** | **140,165** | **(341,393)** | **201,228** | **-** |
| Designated funds | | | | | |
| Medical research | 400,000 | - | (-) | (400,000) | - |
| University of Granada - Prof. Molina | - | 3,266 | (-) | (3,266) | - |
| Sparks A-T Network Fund | - | 1,148 | (-) | (1,148) | - |
| University of Nottingham CATNAP Study - Dr Robert Dineen | - | 9,028 | (24,018) | 14,990 | - |
| University of Sheffield - Dr Grierson | - | | (88,710) | 88,710 | - |
| The FIRC Institute Milan - Dr Constanzo | - | | (99,936) | 99,936 | - |
| General funds | 254,583 | 473,172 | (233,853) | (450) | 493,452 |
| **Unrestricted funds** | **654,583** | **486,614** | **(446,517)** | **(201,228)** | **493,452** |
| **Total Funds** | **654,583** | **626,779** | **(787,910)** | **-** | **493,452** |

### Restricted Funds

1. Dr Peter Merkus from Radboud University Medical Centre in the Netherlands is being co-funded by Action for A-T and Sparks Charity to research Optimising lung imaging in people with Ataxia Telangiectasia (A-T) applying improved MRI techniques. This joint funded project was paid in December 2016. A donation of £27,360 was received from House of Fraser towards the study being undertaken at the Radboud University Medical Centre, the Netherlands. This donation was passed on in full during the year to Sparks Charity as they are managing the project. The balance of the contribution has been made from our unrestricted reserves.
2. Dr Jayesh Bhatt and Dr Andrew Prayle of Nottingham University Hospitals NHS Trust has been funded to the value of £94,839 for the IMAGIN-AT advanced lung imaging and function testing in Ataxia Telangiectasia research project. A gift totalling £8,000 was received from the Allergan Foundation against this research project. The balance of the contribution has been made from our unrestricted reserves.
3. Professor Steve Jackson and Dr Rimma Belotserkovskaya of The Gurdon Institute (University of Cambridge) are being funded to extend the work previously carried out by Professor Steve Jackson and his team into identifying potential mechanisms to suppress A-T pathologies. The project will be funded in full by Action for A-T but it is been agreed with US based A-T Children's Project that they will contribute towards the overall cost during the latter part of 2017 and 2018.
4. Funding of £37,810 was agreed in 2015 for Professor Grant Stewart at the University Hospital, Birmingham to pay for a replacement fluorescent microscope which is used to research and diagnose A-T. Part of the funds came via restricted donations received with the balance met from unrestricted funds by Action for A-T. The payment was made prior to receiving two further donations for the microscope. These funds have therefore been offset against the amount met from Action for A-T's unrestricted funds.

## Designated Funds

Medical Research – The Trustees agreed to ring fence £400,000 of general reserves during 2015 for suitable medical research projects. During the year this was released following approval for funding of the following projects which totalled £530,039.

5. In prior years in collaboration with Sparks, research projects were undertaken via Professor Ignacio Molina (University of Granada) and Professor Claudio Pignata (Fredrico II University). In January 2016 a refund was received for the underspend on these two projects.

6. A further contribution was made in the year to Dr Robert Dineen for the CATNAP study, Nottingham University. A refund of the underspend on conclusion of the CATNAP study was received back during the year.

7. Dr Andrew Grierson of Sheffield Institute for Translational Neuroscience (SITraN) & The Bateson Centre (University of Sheffield) has been funded to research the use of Zebrafish to study gene mutation.

8. Dr Vincenzo Costanzo of The FIRC Institute of Molecular Oncology, Milan, Italy will undertake research for the study and treatment of DNA production defects in Ataxia Telangiectasia. We refer to this as the Stephen Green project in memory of him.

## 14. Analysis Of Staff Costs

| | **2016**<br>**£** | 2015<br>£ |
|---|---|---|
| Salaries and wages | **99,867** | 74,282 |
| Social security costs | **11,164** | 8,674 |
| Pension contributions | **-** | - |
| | **110,031** | 82,956 |

| **Salary Bands** | **2016**<br>**£** | 2015<br>£ |
|---|---|---|
| £80,000 or more | **-** | - |
| £70,000 - £79,999 | **-** | - |
| £60,000 - £69,999 | **1** | 1 |

## 15. Staff Numbers

During the year the average number of employees was two (2015 – two).

## 16. Related Party Transactions And Trustees' Expenses

The Trustees all give freely their time and expertise without any form of remuneration or other benefits in cash or kind (2015 - £nil). Expenses paid to the Trustees in the year are detailed below. No trustee is deemed to have benefited as a result of a related party connection. All trustees have declared all such relationships to the Chairman.

Mr T Read, the Chairman of Action for A-T was reimbursed £nil (2015 £nil) of expenses during the year.

Mrs E Read, a Trustee of Action for A-T was reimbursed £nil (2015 £nil) of expenses during the year.

Mr W Rowberry, the Treasurer of Action for A-T was reimbursed £nil (2015 £nil) of expenses during the year.

Mr T Shillingford, a Trustee of Action for A-T was reimbursed £nil (2015 £nil) of expenses during the year.

Mrs M Leonard, a Trustee of Action for A-T was reimbursed £nil (2015 £nil) of expenses during the year.

Mrs S Cornell, a Trustee of Action for A-T was reimbursed £nil (2015 £nil) of expenses during the year.

Mr C Askew, a Trustee of Action for A-T was reimbursed £nil (2015 £nil) of expenses during the year.

Dr M Toms, a Trustee of Action for A-T was reimbursed £nil (2015 £nil) of expenses during the year.

During the year, Mrs C Wall, (the sister of Mrs E Read) invoiced and was paid £2,050 (2015 - £1,350) for marketing expenses. This was with the full agreement of the other trustees and was on an arms-length basis.

During the year Mrs S Shillingford (the wife of Mr T Shillingford) invoiced and was paid £nil (2015 - £2,037) for services, plus £590 (2015 - £623) for expenses. Mrs S Shillingford has provided these services on an arms-length basis. In 2015 her services pre-dated her husband's appointment as a trustee.

## 17. Controlling Interest

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

## 18. Operating Lease Commitments

During the next twelve months the Charity has operating lease commitments totalling £12,456 (2015 - £11,131) for contracts expiring in more than one year.

## 19. Reconciliation Of Net Movement In Funds To Net Cash Flow From Operating Actiivities

| | **Total Funds 2016 £** | Prior Year Funds 2015 £ |
|---|---|---|
| Net income for the reporting period (as per the SOFA) | **(161,131)** | 65,555 |
| Adjustments for: | | |
| Depreciation charges | **-** | - |
| Interest from investments | **(616)** | (260) |
| (Increase) / decrease in stocks | **5,307** | (2,210) |
| (Increase) / decrease in debtors | **(69,750)** | (36,774) |
| Increase/ (decrease) in creditors | **325,837** | 221,854 |
| Net cash provided by operating activities | **99,647** | 248,165 |

## 20. Analysis Of Cash And Cash Equivalents

| | **Total Funds 2016 £** | Prior Year Funds 2015 £ |
|---|---|---|
| Cash in hand | **914,068** | 813,805 |
| Termed deposits | **-** | - |
| Total cash and cash equivalents | **914,068** | 813,805 |

# Acknowledgments

Acti on 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 have helped us in 2016:

## Our Research Partners

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

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

## Support from Companies, Trusts & Foundations

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

An Anonymous Trust Fund
Allergan Foundation
Autotask
Barclays
CBRE Charitable Trust
CHK Charities Ltd
CAM Trust
Compasses Public House
Couture Travel Ltd
Cyance
DAR Group
Deutsche Bank
Givergy
Global Entertainment
Grant Thornton
Haslington Primary School
Helping Hand Foundation
House of Fraser
IAM Promotions
Jonny Wilkinson Testimonial Committee
Lady Eleanor Holles School
Lillie Johnson Charitable Trust
Michael and Anna Wix Charitable Trust
Northern Trust
Paphitis Charitable Trust
Quest Professional
Rawson Digital
ScumRun Ltd
Syder Foundation
St. James' Place Foundation
Tokio Marine Insurance
Westminister Foundation

Corporate or professional services provided by:

A & N Chartered Accountants
Akin Gump
Candyswall
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.
01428 853313 | info@actionforAT.org | www.actionforAT.org
Registered Charity number: 1145303