

The Ataxia-Telangiectasia Society  
Annual Report and Accounts 2017

# Building a stronger future





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## Chairman's statement

**We are the only charity in Europe that not only helps care for those affected by ataxia-telangiectasia but seeks, via research, to find a cure for this cruel condition.**

The acid test for any charity is to ask itself would it be missed if it didn't exist. We know, from the feedback we get from families living with A-T, that we would be very greatly missed; ours is a unique contribution, in the range, depth and ambition of the support we provide.

One major challenge we face is how best to spend our precious funds. The A-T Society both provides an unparalleled level of care to people living with A-T and funds and promotes high-quality research. Every penny we spend on helping those with A-T is one less that can be spent on research. Both are extremely important and we strive constantly to get the balance right.

William, our Chief Executive, will give a much more comprehensive overview of our challenges and future aspirations. I would however like to highlight the new strategy and programme we are calling *Live well with A-T*. This is a positive philosophy and will underpin the provision of effective support to everyone affected by A-T throughout the course of this condition.

We are now financially in a far stronger position than we have been for many years and will therefore be able to commit significant funds

**"The A-T Society both provides an unparalleled level of care to people living with A-T and funds and promotes high-quality research."**



to research. But of course, this in itself raises questions about which of the many potential research avenues we should follow to treat a complex condition like A-T. However, collaboration is at the heart of our research strategy and we have been consulting, both with researchers and other organisations that fund A-T research, to ensure that we make the most efficient use of our funds and achieve the biggest possible impact.

The Chairman always has the need to thank staff for their efforts in the year under review. Our dedicated team have an emotional roller-coaster ride working for the A-T Society. They personally know virtually all those struggling with the condition as well as their families and carers. Theirs is no ordinary job; their contribution always exceeds what might be reasonably expected. We are so very grateful to them.

Finally, I would like to say a sincere thank you to my fellow trustees. They all lead busy lives and yet manage to find the time to make an invaluable contribution to the work of the A-T Society.

We look forward with confidence and optimism to the challenges that lie ahead.

**Mike Detsiny**  
Chairman

"The financial report will show that financially this has been the best year ever for the Society – and by a long way."



## An exceptional year

### Welcome to the A-T Society's annual report for what has been an exceptional year for the Society.

Even a cursory glance at the financial report will show that financially this has been the best year ever for the Society – and by a long way.

At the same time, the year was marked by the loss of a number of people with A-T, several with long and close relationships with the Society, others at much too young an age. This drives home the message that there can be no let-up in our efforts to improve health-care and develop new treatments for A-T.

That our income was so strong is in large part due to unusually high legacy income. This included a restricted donation from former trustee Rupert Prokofiev, who died at the start of the year, to be spent to support young adults with A-T in living independently. This was something that Rupert was passionate about, and had spoken about several times at Family Weekends. I am delighted that his generous donation will help the Society to take forward this work over the coming years.

Even without legacy income, 2017 would still have been an excellent year. Another outstanding contribution was the £90k grant from Global Make Some Noise. This was over three times the amount we had requested and were expecting. Its award is a tribute to the enthusiasm and commitment with which the Society and people living with A-T, urged on by our Fundraising Manager Suzanne Roynon, participated in the Make Some Noise Day fundraising campaign.

Our family support and advocacy work continued to play a vital role in many families' lives. The strong financial performance enabled us to increase significantly the amount we spent on financial grants. This is of greater importance with each passing year as local authority budgets are stretched to breaking point. A highly successful activity break in the Lake District saw young adults

with A-T pushing their boundaries and surprising themselves and their carers. And then another well-attended Family Weekend was again the high point of the year for many families.

The work that has taken place this year has made us acutely aware that we need to do more to address the psychological and emotional impact of the condition. In particular, we need to do more to support young adults with A-T to live as actively and independently as they choose. We are therefore launching *Live well with A-T*, a new programme which will enable us to engage with these issues at each stage of life with A-T. It will be a major focus for our support work over the years to come and involve the review and revision of existing resources and forms of support as well as the development of new ones.

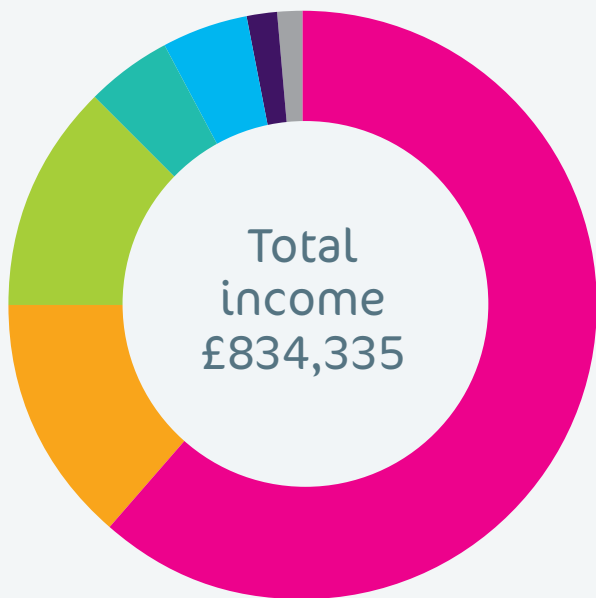
On the research side, expenditure was kept in line with the budget with the main focus on the International A-T Patient Registry. However, in the latter part of the year, when the strong financial position became clear, a lot of preparation and planning work took place and the 2018 report will show a strong increase in research activity.

The future then looks busy and exciting, but we are aware of the challenges, too. We are keen to make sure that our success this year, although much of the income is restricted, does not have an impact on our ability to fundraise from other sources. We do not want this to happen; we want this year's success to be a catalyst for the future, something that enables us to do more and deliver something special for people living with A-T.

We will do all we can to achieve this and I urge you, and all our supporters, big and small, to work with us and keep supporting us. Together, over the next few years, we can take a huge step forward in improving quality of life for all those living with A-T.

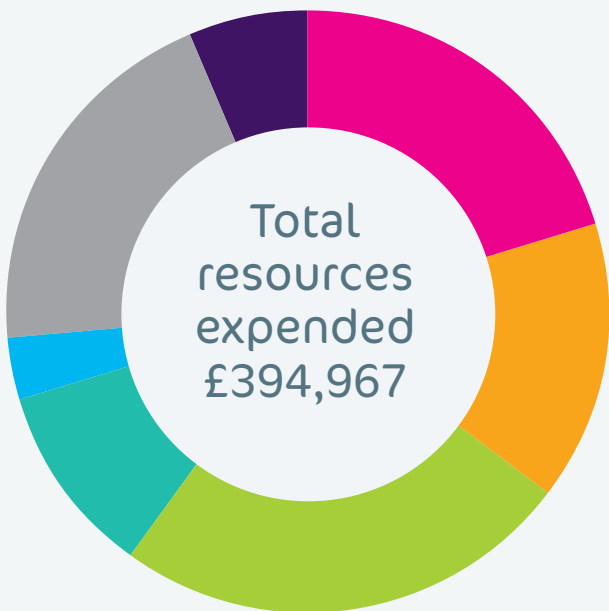
**William Davis**  
Chief Executive

How we raised the money



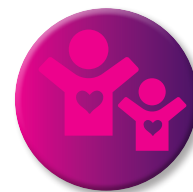
- Donations from individuals and companies, including legacies £513,420
- Donations from trusts £113,823
- Fundraising activities £104,456
- Grant from European Commission £38,241
- Grant from NHS £38,916
- GiftAid £14,856
- Other £10,623

How we spent the money



- Research £69,057
- Clinic £50,640
- Welfare £109,638
- Information £30,057
- Education £17,309
- Fundraising £99,105
- Governance £19,161

The Family Support team have nearly 40 years of experience in health and social care between them.



## Supporting families living with A-T

Supporting families is at the heart of what we do, and plays a vital role in helping families cope with the reality of living with A-T.

Our Family Support team, Kay Atkins and Anne Murray, are on hand to support individuals and their families at all stages of their journey living with A-T, from the shock of initial diagnosis through to the everyday reality of living with the condition. With nearly 40 years of experience in health and social care between them, they are able to help families navigate their way through the complexities of health, social care, education and housing and find practical solutions to difficult issues.

During 2017, Kay was absent for several months on sick-leave, a period which Anne nobly covered. The year also saw Anne increase her hours from three days a week to full-time.

During 2017 their workload included:

- 1,806 support phone calls
- 80 advocacy cases
- 6 new diagnoses
- 37 medical support and advice requests
- 9 family support visits nationwide
- 7 school/college talks
- 14 support grant requests
- 2 education and healthcare plan meetings
- 6 social and housing meetings
- 6 Nottingham clinics
- 44 adults booked to attend Papworth clinic

### Support to individuals and their families

At the end of 2017, 167 people in the UK with A-T or a related condition were registered with the A-T Society. Six new families, with a recent diagnosis, also contacted the charity for support and advice. Sadly two children and six adults with the condition passed away during the year.

The Family Support team handled 1,806 phone calls in their support role during the year. 75% of these calls were from individuals and families living with A-T who called for information, practical and emotional support or advice on housing issues, benefit applications, health concerns, educational assessments etc. The remainder of the calls received were from health and social care professionals, education providers and the national A-T clinics.

The team made personal visits to meet four of the newly-diagnosed families and met another from South Africa at the A-T Society offices. They also made regular trips to attend meetings at schools and with social services and other local agencies.

### Advocacy

In addition to providing guidance and emotional support, Kay and Anne are very much involved in assisting people to access the necessary health and support services. In 2017 they were involved in 80 Advocacy cases – 43 were completed by the end of the year, with 37 still ongoing. One of the biggest challenges they faced this year was helping people navigate the change from Disability Living Allowance (DLA) to Personal Independence Payments (PIP). This required assistance in filling in the detailed forms, support in undergoing the statutory assessment and in some cases help with the appeals process.



“The family weekend was brilliant. It’s so good for the families to get together for support, and for the children and adults with A-T to build confidence.”

### Ensuring effective health care

Given the rarity of A-T, local clinicians and therapists are often unfamiliar with the wide variety of symptoms it can produce. The family support team play an important role bridging this knowledge gap and putting local professionals in touch with specialists.

One symptom of A-T is the greatly raised risk of cancer, and in 2017 we supported 13 people with cancer and their families. One particular feature of the year was that we had 4 cases, where what appeared to us likely to be symptoms of cancer, were not being investigated with any urgency by local clinicians. In all four cases we had to push hard to get proper tests carried out, and in all four cases cancer was eventually diagnosed.

### Support Grants

The cost of living with A-T becomes much higher as the condition progresses and mobility deteriorates. The A-T Society’s support grants can provide invaluable help with families struggling with the expense of buying specialist equipment or who need extra support such as counselling or a respite break to help them cope with the stresses of living with A-T. We also give grants to help people with A-T take part in activities to build confidence and strength. Each funding request is carefully evaluated and, where possible, we always seek to gain funding from other sources or fund expensive items in partnership with other organisations.

During the year we awarded 12 support grants to the value of £21,358 to help meet a wide variety of needs such as specialist IT Equipment, adaptations to the home, an adapted trike, riding lessons and counselling. These grants can make a significant difference to the well-being of the person living with A-T and their families.

### Counselling

This year saw the retirement of our volunteer counsellor, Helen Hart. For over 20 years Helen helped many, many people affected by A-T to cope with all the different stages of living with the condition, both with telephone counselling and face-to-face sessions. We are extremely grateful to her and wish her well in future.

### Advocacy case studies

#### *Support and equipment at school*

A young boy in the south of England was starting school for the first time. The Education and Health Care Plan proposed by the local authority only provided part-time educational support. Anne and Kay helped get that changed to full-time support. They also persuaded the school to provide the specialist seating, the boy needed, which they had been unwilling to do. In the end they provided two seats. The little boy is now very happy and enjoys going to school.

#### *Help with benefit applications*

As the change from DLA to PIP rolls out across the country, all disabled adults on DLA are being invited to apply for PIP and then undergo a statutory assessment. This is a difficult and stressful process as the application form is long and complex and undergoing an assessment can be intimidating. Kay and Anne have helped 11 adults to fill in the form to make sure they do so in a way that accurately reflects their condition. They have also supplied information on the condition and talked to people undergoing assessment to reassure them. In a couple of cases they have also had to help with appeals. With their help, everybody who has gone through the process has ultimately been awarded PIP at an appropriate level.

For the moment we are not seeking to replace Helen, but we continue to fund counselling through our grants programme and will be developing our counselling provision through the *Live well with A-T* programme.

### Family Weekend

As always, our annual A-T Family Weekend was well attended this year, with 45 families gathering at the Radisson Blu, Stansted. The weekend provides families with the chance to get together with people who understand their situation and many find the strength and support they gain from each other at the weekend invaluable.

This year saw presentations from other charities offering special breaks and specialist equipment as well as a range of talks on A-T research and clinical trials, including presentations from Prof Steve Jackson and Dr Laura McCreight on major projects supported by the A-T Society. The Q&A session with medical experts and researchers provided the opportunity to ask questions about A-T.

A highpoint of the weekend was the presentations from Becky, Kayleigh and Jilly, young women with A-T, about their lives and activities. Another very well-received session was from psychotherapist Jane Flint on looking after one's own emotional health.

For our younger children with A-T and their siblings, there was a fun-filled day at the zoo and a visit from a real fire engine. At the gala dinner, an audience full of super heroes and princesses enjoyed both Ebony's talk about her time in the BBC's *The One Show* Rickshaw Challenge team for Children in Need and her squeals of delight at a surprise reunion of the team.

### Activity Weekend

In September, 11 adults with A-T and their carers spent a weekend at the Bendrigg Trust activity centre in the Lake District. The programme included climbing, canoeing, archery, zip-wires and camp-fire activities, as well as time for socialising.

The climbing and canoeing in particular gave almost everyone – including carers – the chance to really stretch and surprise themselves. People who spend most of the time in a wheelchair found themselves 20 foot from the ground or paddling through open water in Lake Windermere. Mealtimes and evenings were a chance to talk, share experiences and laugh together with people who understood living with A-T.

The weekend was both inspiring and emotional for participants, carers and staff alike. At the final feedback session, everyone spoke out positively, everyone had achieved something that they were proud of and everyone had a funny memory. Eleven adults with A-T left with a confidence and 'swagger' that hadn't been there on arrival.

### Counselling Support

We were approached by a father of a young child who was suffering from depression, which as well as affecting him was starting to put his marriage under pressure. We funded a series of counselling sessions which had a really positive impact and changed his outlook. As a result both father and family are much happier and more stable.

### Riding lesson

The parents of a young girl with A-T were worried that she did not want to go out much. When she discovered that the girl loved animals, Kay suggested a trial riding lesson with the Riding for the Disabled Association. This was a great success, so the Society paid for a block of 10 lessons. The girl now rides regularly and loves it and her confidence and posture have both improved markedly.



During 2017 the International A-T Registry started collecting its first data on patients.



## Research

Research is a central element of the A-T Society's work. We support research in many different ways so that the impact of our research work cannot be solely measured by the physical amount of money spent on research as reported in the accounts.

We fund research projects and researchers directly, and help find other sources of funding. We support researchers and research projects to promote them, recruit and provide help to participants and provide other forms of practical assistance. We engage with pharmaceutical companies, institutes and researchers to promote A-T research and encourage and support the development of new projects. And we bring researchers and clinicians together, directly through our biennial A-T Clinical Research Conferences and virtually via the A-T Clinical Research Network. And of course we bring researchers and people living with A-T together through our Family Weekends and other meetings.

In terms of research, 2017 was a year of planning and preparation for the Society. Research spending was focused on the International A-T Registry and the ATW 2017 conference in Milan in March. We continued to be actively involved in the organisation of the ATTeST trial and in supporting a number of other research projects. We also started programme planning for the 4th in our series of international Clinical Research Conferences, to be held in Naples in 2018.

### International A-T Registry

Funded by a Horizon 2020 grant from the European Commission, the International A-T Registry is led by the A-T Society. During 2017 the registry started collecting its first data on patients, which in this registry is supplied by doctors.

The registry is invaluable because given the rarity and variability of A-T, individual doctors and even centres don't have enough data to build up scientifically-valid knowledge of how A-T develops or how different aspects of the condition may relate to each other or to particular mutations. Gathering data from many centres will enable us to build up a detailed understanding of A-T, which will help develop new treatments, test the effectiveness of therapies and help identify participants for future studies and clinical trials.

Discussions were also held with our sister organisation in the USA, which runs a data platform of patient-provided information, about what we need to do to share data in the future.

### ATW 2017 research conference

The A-T Society gave a grant to support the ATW 2017 research conference held in Milan in March. While the focus was on laboratory science, this is an important area of A-T research as there is still much we need to understand better to help develop new treatments.

The Society had a significant presence. Two members of our Scientific Advisory Board, Prof. Penny Jeggo and Prof. Malcolm Taylor were speakers, while another, Dr William Whitehouse ran a workshop on core outcome measures for A-T clinical trials. Our chief executive William Davis, chaired and translated for a session where international scientists and clinicians met and answered questions from Italian families living with A-T.

One excellent concrete outcome of the meeting was that discussions held there led subsequently to a proposal for a project to use stem cells from people with A-T to create Purkinje cells, the neurons that die off in people with A-T, in the laboratory. This proposal was later formally



The ATTeST Trial is the first ever large-scale trial of a treatment which could improve major aspects of the condition.



submitted to the Society and peer-reviewed, and in early 2018 we agreed to fund it.

## ATTeST trial

The A-T Society is the only patient-organisation in the consortium of organisations which was awarded a Horizon 2020 grant to fund a world-wide clinical trial of a product called the Erydex System to treat neurological effects of A-T. This is the first ever large-scale trial of a treatment which could improve major aspects of the condition.

The EryDex System is an innovative means of delivering the steroid dexamethasone, by removing a small quantity of the patient's own blood, infusing the drug into the red blood cells and then putting it back. The drug is gradually released over a few weeks, giving the clinical benefit without the usual serious side-effects. Small scale trials have shown a positive effect on the neurological symptoms of A-T.

We continued to play a role in the central governance of the project, in communicating with people with A-T and potential participants and in supporting the team at the UK trial site, Nottingham. This included running an information session at our Family Weekend and supporting the recruitment and induction of a clinical fellow to help manage the trial.

## RAMP study, University of Dundee

2017 saw the completion of the RAMP trial, looking at the effects of two different diabetes drugs on people with A-T. It is becoming clear that there is a strong link between A-T, diabetes and liver problems. This study aimed both to make recommendations on the best way to treat diabetes in A-T and also to throw light on the

underlying mechanisms.

The final results of this study, which the Society supported practically rather than financially are still to be published, but there was an initial report at the 2017 Family Weekend.

## A-T Clinical Research Conference 2018

Following the successful A-T Clinical Research conference held in Warsaw in October 2016, work began on planning the next one in Naples in November 2018. This will be the fourth in the series inaugurated by the A-T Society in 2012. These conferences, which bring together clinicians and therapists with scientists who have an interest in developing treatments for A-T, were first proposed by our chief executive, William Davis.

The focus in these conferences is on keeping presentations short and maximising time for group discussion. The programme being developed for Naples aims to bring in people from different fields beyond A-T, to see what can be learned from them to help A-T research.



Approval and funding were gained for both an MRI study of the lungs and a three-year project to produce a Natural History of A-T.



## Improving health and social care

The A-T Society plays a key role in the UK A-T Service, commissioned and funded by the NHS. In 2017, we continued to work closely with our partner organisations to provide an integrated service for people living with A-T, which has few, if any, rivals in the world. The professional arms of the service are the two specialist A-T centres at Nottingham (paediatric) and Papworth (adult) and Professor Malcolm Taylor's laboratory at the University of Birmingham, which provides diagnostic services.

The A-T Society liaises with patients and invites them to attend clinics, arranging and funding travel and accommodation. Our staff and volunteers attend all clinics to make available our information, support and advocacy. We gather regular feedback and ensure that this is used to develop the service.

An important part of our role is to act as a first point of contact for local professionals seeking the opinion of specialists, as most have little in-depth knowledge of A-T. The Society has an excellent knowledge of experts and available resources and can be easily contacted by local professionals.

We also make sure clinicians and therapists are up to date with developments in research and care from around the world and likewise that their views and experience feed into other international projects, such as the A-T Clinical Research Conference series or the International A-T Registry.

### Nottingham

Set up by the A-T Society in 1993, the Nottingham A-T Centre is a world leader in paediatric care for A-T. It provides a comprehensive multidisciplinary service to children with A-T every two to three years.

Children attending one of its 6 annual clinics see

10 different specialists over two half-days, with others available if needed. A-T Society staff are present to pick up other support needs. The July clinic is a transition clinic where 16-18 year olds are seen by staff from both Nottingham and Papworth. In 2017, 35 children attended with their families. Feedback was very positive.

The centre continues to be very active in research. The CATNAP study of MRI scans of the brain concluded in 2017 but plans were immediately made for a follow-up CATNAP 2 project. In parallel to this approval and funding were gained for both an MRI study of the lungs and a three-year project to produce a Natural History of A-T. The centre is the largest centre to be participating in the international ATTeST trial and during the course of the year recruited a clinical fellow to work on this.

### Papworth

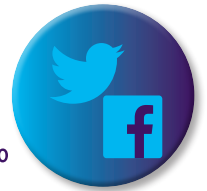
The world's only centre specialising in adults with A-T, Papworth is developing a unique expertise in this field. Those attending see a multi-disciplinary team as well as a representative of the Society. In 2017 44 people attended the clinic.

Papworth, too, is becoming more research-active. The service offers regular MRI scans, and is now building up significant data in this area. The team worked on major papers on Variant A-T and liver function which will be published in 2018.

### Cancer care

Cancer continued to be a major issue for us in 2017, with new and ongoing cases, including several where we had to push hard to get a diagnosis made. In partnership with the Universities of Newcastle and Birmingham we developed plans for a specific registry of A-T in cancer, which we hope will be developed during 2018.

The number of people following our Facebook page and the number of active Twitter followers grew by 8% over the year.



# Communicating our messages

## National Media

In 2017 we released a short film featuring the Sewell family. The film featured twins Broghan and Brae and poignantly demonstrated the impact that the condition has - Broghan is a talented junior player with Chelsea FC juniors and Brae has A-T so struggles to keep up with his brother. Their story was picked up by Channel 5 news and The Sun newspaper as well as by the local press and the resulting coverage increased awareness of the condition.

## Website

Following an unprecedented year in terms of media coverage for the charity in 2016, our website user figures dropped back slightly in 2017, tracking in line with where we would expect them to be for such a rare condition. The website is usually the first point of contact for professionals and parents who are new to A-T and want to understand more about the condition and also establish the resources available to them. Our families also visit the website when they are looking for some specific information about the condition or research project updates or fundraising inspiration.

Our homepage continued to be the most frequently visited page followed by pages about A-T and living with A-T, reflecting the importance of our website as a trusted source of information about ataxia-telangiectasia.

In 2018 we will be moving the website over to a new content management system which will allow us to redesign the website to be responsive. This will improve the user experience as the content will automatically resize to fit the screen size on mobile phones, tablets or desktops.

## Social Media

We are very active users of social media and use both Facebook and Twitter to promote events, support our fundraisers, celebrate the accomplishments of our A-T families, and update our followers on the latest news from the charity. Our followers include many of our families, fundraisers and supporters who regularly engage and share/retweet our content and interact with us and other supporters.

The number of people following our Facebook page grew by 8% over the year with 3,364 followers by the end of 2017. Similarly the number of people 'liking' our Facebook page grew by 9.5% with 3,695 people 'liking' our Facebook page. Posts featuring the film created about the Sewell boys, and the subsequent media coverage that followed, caused substantial spikes in our 'reach' as did posts for Rare Disease Day and International Ataxia Day.

Our Twitter messages largely mirror our posts on Facebook. In 2017 we increased the number of active twitter followers by 8% to 700 followers.

## Newsletter

In 2017 we produced one bumper edition of our newsletter which was posted out to our A-T families, supporters and professionals. This edition featured the latest news on the ATTeST trial, the launch of the International A-T Patient Registry, inspirational stories about children and young adults living life to the full with A-T and celebrated the achievements of our fundraisers.



2017 saw the highest number of fundraisers and fundraising events we have seen for many years.



## Raising the money

2017 was our strongest ever year for fundraising with most areas showing a significant increase on the previous year.

All areas performed strongly, with almost every line showing an increase on 2016. The one exception was Staff and Trustee fundraising, due to the fact that we did not hold a ball this year. This success is built on the unflagging commitment of our amazing families and supporters combined with the hard work and determination of the fundraising team.



As a result of a generous grant from the Childwick Trust we were pleased to appoint a new community and events fundraiser in June 2017. This gave new and much needed capacity within fundraising for the second half of the year, enabling the team to offer an increased level of input to individuals and companies wishing to work with us.

2017 saw the highest number of fundraisers and fundraising events we have seen for many years. Supporters and family members threw themselves into a wide variety of sporting achievements and took on many personal challenges and activities.

Community and school fundraising initiatives also reached new heights. We were delighted to see young people with A-T representing the charity by talking to local groups about their condition and the value they receive as a result of our work.

Corporate support and interest continues to grow with companies and their staff offering both Charity of the Year engagement and one-off fundraising events.

Trust fund income enabled us to offer a higher level of support for disability equipment, family and welfare support. An unexpectedly generous grant from Global's Make Some Noise Appeal enabled us to partially fund the salaries of our family support team, the 2017 Activity Weekend and the 2018 Family Information Weekend.

Generous in memoriam donations during the year provided a bittersweet boost to our income, as did valuable income from legacies.

The charity offers heartfelt thanks to the companies, individuals and trusts which make our work possible.



We are designing a Live well with A-T strategy and a programme of resources and support based around a series of key life stages.



## Plans for the future

The A-T Society's current priority areas of work identified by the Board are:

- Supporting people affected by A-T to live well with A-T
- Improving provision of information and active communication around A-T
- Strengthening our investment in research and cooperation across the A-T research community
- Strengthening and increasing the diversity of our fundraising

### Support people affected by A-T to live well with A-T

Enabling people to live well with A-T and to build meaningful and autonomous lives involves not just practical support but dealing with emotional and psychological issues. We recognise that to do this effectively means providing the right information, guidance or support at every stage of the journey from before diagnosis until after bereavement. We are therefore designing a Live well with A-T strategy and a programme of resources and support based around a series of key life stages, which we will develop over the next 3 years.

With demand for the services of our Family Support team higher than ever, we will ensure that we continue to provide first-class and personalised support and advocacy, to enable families with A-T to obtain the housing, education, equipment and services they need to live the lives they aspire to.

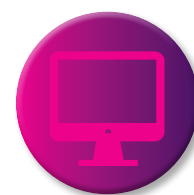
We will continue to organise first-class events for families and for adults with A-T, ensuring that they are effective in offering peer-support and learning, in building skills and confidence and providing information and a chance for discussion.

We will continue to work with our smaller sister organisations around the world, enabling them to make use of our information and resources. This will both help strengthen their work and increase the impact of our own.

### Improve the provision of information and active communication around A-T

We launch our new website in 2018 and will seek to make this and our other information resources the most authoritative and respected source of reliable, up-to-date and user-focused information on A-T in the world.





## We will develop a specific and detailed registry of cancer in A-T.

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We will continue to develop our social media presence both to publicise the Society, its work and resources and to strengthen engagement with families that need us and with our other supporters.

We will introduce regular communications via e-mail with supporters who wish to be communicated with in this way and will review and redesign our paper-based communications.

We will increase the number of our information sheets and information resources both for people living with A-T and for professionals, in accordance with our Live well with A-T strategy.

We will continue to build on our successes in getting publicity about A-T and the Society into the national media and build awareness of the condition, both at national and local level. We will make use of case studies, films and videos to do this, developing new ones whenever we can.

## Strengthening our investment in research and cooperation across the A-T research community

We will continue to develop the International A-T Registry and work closely with specialist clinicians and A-T centres around the world to ensure that data is collected on as many patients as possible. We will also continue to build links with other related databases, in particular the A-T Families Global Data Platform.

We will develop a specific and detailed registry of cancer in A-T, if possible with an associated library of tissue samples.

We will review and refocus our research strategy and look to significantly increase our funding of research projects which contribute to this. The overriding aim will be to bring effective treatments for A-T closer.

We will take active steps to ensure regular communication and meetings with other A-T

research-funding charities. Where possible we will fund in partnership with others.

We will work with the Nottingham A-T centre to ensure the success of the arm of the ATTeST trial based there. We will also continue to play an active role on the board of the consortium managing the Horizon 2020 grant which funds the trial, ensuring that the views and needs of participants are central to the project.

We will continue to lead the planning process for the 2018 A-T Clinical Research Conference, in Naples, and to support the organisers on the ground to ensure the event is successful and has a concrete impact. We will then take steps to plan for the next conference, in the light of the outcomes of this one and of lessons learned.

We will continue to provide practical support to the projects we support or fund at the universities of Nottingham, Birmingham and Dundee.

We will continue to develop the A-T Clinical Research Network to maximise its effectiveness in ensuring active communication between researchers and clinicians, and promoting research to improve clinical treatments and outcomes.

## Strengthening and increasing the diversity of our fundraising

We will build on the recent reorganisation of our fundraising team to ensure that we have a broad-based and sustainable fundraising portfolio for the years ahead. In particular we will continue to strengthen our corporate and major-gift fundraising and to take advantage of the opportunities offered by social media and new technologies. We will also continue to build on our successes in engaging with the local community and to build our potential for legacy income.



# Trustees' report

**The Board of Trustees, who are directors of the company for the purposes of the Companies Act, have pleasure in presenting their report, together with the Society's audited financial statements for the year ended 31 December 2017.**

This report has been prepared in compliance with the duty in Section 17 (5) of the Charities Act 2011 to have due regard to public benefit guidance published by The Charity Commission.

The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

## Aims and objectives

The purpose of the Society, as set out in the company's Memorandum of Association, is "the relief of sickness and distress among persons suffering from A-T". In March 2011 the Society agreed the following Vision and Mission:

### Vision

A world where no one need suffer from the devastating effects of A-T.

### Mission

To improve quality of life and quality of care for people living with A-T while actively promoting research to lengthen lives and ultimately bring about a cure.

We do this by:

- providing information and support to meet the challenges of living with A-T
- working to achieve better, more coordinated health and social care services
- promoting and funding high quality A-T research
- speaking out to ensure that the voices of people affected by A-T are heard
- raising awareness of A-T and gathering supporters and resources to help achieve our vision

## Activities, achievements and performance

Details regarding our activities, achievements and performance are set out in our Review section on pages 5-14.

## Financial review

**During the year the A-T Society received income of £834,335 (2016: £391,793) and spent £394,967 (2016: £351,395).**

The Society therefore had an overall surplus for the year of £439,368 (2016: £40,398). With funds brought forward from previous years,

the Society will carry forward £583,052 in reserves (2016: £143,684).

Unrestricted general funds carried forward have been reduced to £89,410 (2016: £95,964). The Society also carries forward restricted funds of £493,642 (2016: £47,720), which the trustees consider to be at an appropriate level.

Of the Society's total income some 14% (2016: 20%) was donated by grant-giving trusts, 62% (2016: 20%) by individuals and companies and 13% (2016: 29%) by the fundraising activities of our supporters (i.e. individuals and companies provided some 75% (2016: 49%) of the Society's total income). The remaining 11% (2016: 31%) came from the NCG contribution towards the Nottingham clinic, the European Commission grant for the development of the international A-T registry and also some small amounts of interest income and trading receipts.

## Investment policy

Apart from retaining a prudent amount in reserves, most of the Society's funds are spent on its charitable purposes each year or set aside for already commissioned work or projects, consequently there are few funds available for long term investment. In 2017 the trustees have continued to hold funds on a deposit account with CAF rather than investing them where there would be the risk of a capital loss. Moving forward, the trustees will monitor the Society's cash position carefully and move funds whenever possible to a higher interest bearing fixed term deposit account.

## Reserves policy

The policy aims to ensure that the Society is maximising its charitable expenditure in any given year, whilst at the same time maintaining financial prudence to ensure its sustainability and capacity to manage unforeseen difficulties.

Given unpredictability in income levels the reserves policy will be monitored on an on-going basis alongside the Society's financial budgets and adjusted as the trustees deem necessary.

## Plans for future periods

The Society's plans for 2018 and the following years are built around a number of priority areas. These include:

- Increasing the impact of our research programme and strengthening cooperation across the A-T research community
- Supporting people affected by A-T to live their lives to the full
- Improving provision of information and active communication around A-T
- Strengthening and increasing the diversity of our fundraising

More information about these priorities can be found in the Plans for the future section on pages 13 and 14 of this report.

## Donors and supporters

The trustees express their sincere gratitude to all grant-giving trusts, individual donors and fundraisers, who have made our work possible over the last 12 months both by their financial support and by the generous giving of their time.

## Structure

The Society is a charitable company limited by guarantee, incorporated in England and Wales, and registered with the Charity Commission in England. The company was established under a Memorandum of Association which defined its objects and powers; it is governed by its Articles of Association. In the event of the company being wound up members may be required to contribute an amount not exceeding £1 each.

Directors of the company are also trustees for the purposes of charity law. The directors are normally referred to as 'trustees' and meet formally as a Board four times each year. The Board of Trustees is the governing body of the Society. It agrees the overall strategy for the organisation and the policies and procedures for the implementation of this strategy. It also oversees the effective and equitable use of the Society's resources and ensures that it meets all its legal, regulatory and ethical obligations.

The Society's staff team is based at the offices in Harpenden. Under the leadership of the Chief Executive, it is responsible for implementing the strategy and policies agreed by the Board. Remuneration of the Society's staff team is reviewed annually by the Board against performance and affordability. The team organises and provides directly the vast majority of the services delivered by the Society. It also manages and supports the Society's volunteers, whether working in or from the office or locally across the UK.

## Governance and management

The Board of trustees may consist of between three and 20 members. Under the terms of the Memorandum and Articles of Association, directors may either be appointed by the Board to fill a casual vacancy or are to be elected by the Society's members at the annual general meeting to serve a three year term of office. All appointed directors must submit themselves to election at the annual general meeting immediately following their appointment. There is no limit to the number of terms a director may serve, subject to approval of the membership in general meeting. One third of the directors must retire by rotation at each annual general meeting and each retiring director may offer himself for re-election.

All directors of the company give their time voluntarily and receive no benefit from the charity by virtue of the office they hold. Any expenses reclaimed from the charity are set out in note 9 to the accounts. Where a director is a potential beneficiary of the charity, the holding of his office will not be a bar to his or her being an actual beneficiary. In such circumstances, the director declares his interest and takes no part in the discussion or decision concerning his or her application for benefit.

All Trustees active in 2017 are listed on page 31.

## Trustee induction and training

New trustees receive an information pack outlining their legal obligations under charity and company law, a copy of the previous year's annual report and accounts, a copy of the annual plan, a copy of the company's Memorandum & Articles of Association and a representative selection of the Society's current literature.

The Board has a positive approach to its own training and development, regularly reviewing skills and needs and organising appropriate training, whether for the group or for individuals. All trustees regularly receive relevant information published by the Charity Commission and are encouraged to keep abreast of developments both in charity governance and in current issues concerning A-T.

## Staff

The Society values its staff and aims to be an exemplary employer of a skilled and committed workforce. It does not discriminate in any way in the recruitment, training or retention of employees.

The Society actively encourages its staff to enhance and extend their skills, particularly with regard to its charitable objectives, and learning and personal development are central to the appraisal process.

The Society benefits from the support of volunteers as detailed on page 31.

## Relationships with other organisations

The Society is a national organisation operating throughout the United Kingdom. To strengthen its ability to campaign on behalf of and meet the needs of people living with A-T it is affiliated to:

- Genetic Alliance UK
- Rare Disease UK
- The Association of Medical Research Charities ("AMRC")
- Euro-Ataxia

The Society also enjoys good relations with other A-T support groups in the UK, the USA, Australia, France, Germany, Israel, Morocco, Norway, Poland, and Spain. In 2011 it established the A-T Clinical Research Network, to bring together researchers, clinicians and patient organisations with an interest in clinical research into A-T from around the world.

## Risk management

The trustees have a risk management strategy which includes an annual review of the risks to which the charity may be exposed, and the establishment and implementation of systems and procedures designed to mitigate the impact on the charity of the risks identified. Key elements of this strategy include:

- the implementation of procedures for the authorisation of all financial transactions and the incurring of all financial obligations
- the setting of a reserves policy and its regular review by trustees
- the agreement of an annual business plan and budget, supported by a fundraising plan, which is regularly reviewed
- the carrying out of a full financial audit, although this is not required of a charity of this size
- procedures to ensure compliance with health and safety regulations
- all staff and volunteers undertake regularly updated child-protection training and DBS checks are made on all eligible posts

## Grant-making policies

The Society makes two types of grant to meet its objectives: individual support grants and research grants.

### Individual support grants

The Society provides financial support grants to any individual affected by A-T, to assist with the cost of items that they need as a result of the condition, but cannot easily afford, and for which they cannot get help from other sources. A standard form for the collection of information is used and there are formal criteria for application and for the assessment and awarding of grants. Applicants need the support of an appropriate professional and need to demonstrate what efforts have been made to obtain statutory or other funding.

# Trustees' report

## Research grants

The Society is a member of the Association of Medical Research Charities (AMRC) and works to AMRC standards in its research grant programme. All research grants are peer-reviewed to ensure that:

- the project has scientific merit and meets the aims of the Society's research strategy
- the proposed study does not duplicate other current or recent research
- the Society is spending its research funds in the most effective way

The A-T Society's research strategy and procedures are reviewed regularly with priorities agreed to ensure the greatest possible impact for its research programme.

## Ensuring the Society's work achieves its aims and delivers public benefit

The trustees review the Society's aims, objectives and activities each year during the planning cycle. This review examines the activities of the previous year and measures the outcomes of those activities against the objectives of that year's plan by reference to the benefits delivered to people affected by A-T. It also serves to ensure that the Society's aims and objectives remain focused on its stated purpose and enables the trustees to consider how the Society's activities further its charitable purposes for the public benefit, in accordance with the Charity Commission's guidance.

The Society has a formal budgeted business plan for the year, which is reviewed and reforecast regularly. This sets out the main objectives we set ourselves to help us achieve what is set out in our Vision and Mission statements.

During 2017 the Society's high-level objectives were:

- to provide information and support to meet the challenges of living with A-T
- to work to achieve better, more coordinated health and social care services
- to promote and fund high quality A-T research
- to raise awareness of A-T and speak out to ensure that the voices of people affected by A-T are heard
- to gather supporters and resources to enable us to achieve our vision

The Society's activities and achievements in pursuit of these objectives in 2017 are detailed in the first part of this Annual Report and Accounts.

## Legal and administrative information

The Ataxia-Telangiectasia Society is a charitable company limited by guarantee, incorporated in England and Wales, in 2004, under company number 5177145. It is registered with the Charity Commission in England under number 1105528. The Society uses the working name "A-T Society".

## Registered office and operational address

A-T Society, Rothamsted, Harpenden, Herts AL5 2JQ  
Telephone: 01582 760733 Fax: 01582 760162  
Email: [info@atsociety.org.uk](mailto:info@atsociety.org.uk) Website: [www.atsociety.org.uk](http://www.atsociety.org.uk)

Company Registration

Registered in England and Wales, Number 5177145

Charity Commission Registration

Registered in England, Number 1105528

## Auditors

Hicks & Company, Chartered Accountants, Statutory Auditors, Vaughan Chambers, Vaughan Road, Harpenden, Herts AL5 4EE

## Bankers

The Co-operative Bank, PO Box 250, Skelmersdale WN8 6WT  
HSBC Bank plc, 1 High Street, Harpenden, Herts AL5 2RS  
CAF Bank Ltd., PO Box 289, West Malling, Kent ME19 4TA

## Statement of trustees responsibilities

The trustees (who are also the directors of The Ataxia-Telangiectasia Society Limited for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice). Company law 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 charitable company and of the incoming resources and application of resources, including the income and expenditure of the charitable company for that period. In preparing those financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the charity SORP
- make sound judgements and estimates that are reasonable and prudent
- prepare the financial statements on the going concern basis, unless it is inappropriate to presume that the Society will continue on that basis

The trustees are responsible for keeping proper accounting records which 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 Companies Act 2006.

The trustees 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.

In accordance with company law, as the directors of the company, we certify that:

- so far as we are aware there is no relevant audit information of which the company's auditors are unaware
- as the trustees of the company, we have taken all the steps that we ought to have taken in order to make ourselves aware of any relevant audit information and to establish that the charity's auditors are aware of that information

## Auditors

Hicks and Company, the auditors, were re-appointed as the charitable company's auditors during the year and have expressed their willingness to continue in that capacity. A resolution will be proposed at the Annual General Meeting that they be re-appointed as auditors to the charity for the ensuing year.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by the Board of Trustees on 21st June 2018 and signed on its behalf by:

**Andrew Mills**  
Treasurer



## Independent auditor's report

### Independent auditor's report to the Members of The Ataxia-Telangiectasia Society

#### Opinion

We have audited the financial statements of The Ataxia-Telangiectasia Society Limited (the 'charitable company') for the year ended 31 December 2017 on pages 20 to 30. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2017 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

#### Basis for opinion

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

#### Conclusions relating to going concern

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

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

#### Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

#### Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

#### Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Report of the Trustees.

#### Responsibilities of trustees

As explained more fully in the Statement of Trustees Responsibilities set out on page 17, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

# Trustees' report

## Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

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

**Philip Dean** (Senior Statutory Auditor)

For and on behalf of Hicks and Company  
Chartered Accountants and Statutory Auditor  
Vaughan Chambers,  
Vaughan Road,  
Harpenden,  
Hertfordshire,  
AL5 4EE

22nd June 2018

# Statement of financial activities

Year ended 31 December 2017

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.17 £	Total funds 31.12.16 £
<b>Income and endowments from</b>					
Donations and legacies	2	183,720	639,992	<b>823,712</b>	380,501
<b>Charitable activities</b>	-				
Welfare	5	-	7,731	<b>7,731</b>	8,119
Other trading activities	3	2,777	-	<b>2,777</b>	3,080
Investment income	4	115	-	<b>115</b>	93
<b>Total</b>		<b>186,612</b>	<b>647,723</b>	<b>834,335</b>	<b>391,793</b>
<b>Expenditure on</b>					
Raising funds	6	79,105	20,000	<b>99,105</b>	86,415
<b>Charitable activities</b>	7				
Research		26,317	42,740	<b>69,057</b>	66,654
Clinic		11,332	39,308	<b>50,640</b>	52,890
Welfare		11,146	98,492	<b>109,638</b>	79,557
Information		30,057	-	<b>30,057</b>	31,738
Education		16,048	1,261	<b>17,309</b>	13,031
Governance		19,161	-	<b>19,161</b>	21,110
<b>Total</b>		<b>193,166</b>	<b>201,801</b>	<b>394,967</b>	<b>351,395</b>
<b>Net income/(expenditure)</b>		(6,554)	445,922	<b>439,368</b>	40,398
<b>Reconciliation of funds</b>					
<b>Total funds brought forward</b>		95,964	47,720	<b>143,684</b>	103,286
<b>Total funds carried forward</b>		<b>89,410</b>	<b>493,642</b>	<b>583,052</b>	<b>143,684</b>

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing activities.

The notes form part of these financial statements.



# Statement of financial position

Year ended 31 December 2017

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.17 £	Total funds 31.12.16 £
<b>Fixed assets</b>					
Tangible assets	12	805	-	805	1,340
<b>Current assets</b>					
Debtors	13	5,465	3,243	8,708	11,129
Cash at bank		93,078	527,373	620,451	146,449
		98,543	530,616	629,159	157,578
<b>Creditors:</b> amounts falling due within one year	14	(9,938)	(36,974)	(46,912)	(15,234)
<b>Net current assets</b>		88,605	493,642	582,247	142,344
<b>Total assets less current liabilities</b>		89,410	493,642	583,052	143,684
<b>Net assets</b>		89,410	493,642	583,052	143,684
<b>Funds</b>	15				
Unrestricted funds				89,410	95,964
Restricted funds				493,642	47,720
<b>Total funds</b>				583,052	143,684

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

The financial statements were approved by the Board of Trustees on 21st June 2018 and were signed on its behalf by:

.....  
Andrew Mills Treasurer-Trustee

The notes form part of these financial statements.

# Statement of cash flows

Year ended 31 December 2017

	Notes	31.12.17 £	31.12.16 £
<b>Cash flows from operating activities:</b>			
Cash generated from operations	a	474,011	42,840
<b>Net cash provided by operating activities</b>		<b>474,011</b>	<b>42,840</b>
<b>Cash flows from investing activities:</b>			
Purchase of tangible fixed assets		(124)	(336)
Interest received		115	93
<b>Net cash used in investing activities</b>		<b>(9)</b>	<b>(243)</b>
<b>Change in cash and cash equivalents in the reporting period</b>		<b>474,002</b>	<b>42,597</b>
<b>Cash and cash equivalents at the beginning of the reporting period</b>		<b>146,449</b>	<b>103,852</b>
<b>Cash and cash equivalents at the end of the reporting period</b>		<b>620,451</b>	<b>146,449</b>

## Notes to the Statement of cash flows

Year ended 31 December 2017

### a. Reconciliation of net income to net cash flow from operating activities

	31.12.17 £	31.12.16 £
<b>Net income for the reporting period as per the statement of financial activities</b>	<b>439,368</b>	<b>40,398</b>
<b>Adjustments for:</b>		
Depreciation charges	659	628
Interest received	(115)	(93)
Decrease/(increase) in debtors	2,421	(4,105)
Increase in creditors	31,678	6,012
<b>Net cash provided by operating activities</b>	<b>474,011</b>	<b>42,840</b>

# Notes to the financial statements

Year ended 31 December 2017

## 1. Accounting policies

### Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland', the Charities Act 2011 and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

### Income

All incoming resources are included in the Statement of Financial Activities when the charity is entitled to the income and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

- Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to them.
- Donated services and facilities are included at the value to the charity where this can be quantified. The value of services provided by volunteers has not been included in these accounts.
- Investment income is included when receivable. Bank interest is included when received.
- Incoming resources from grants, where related to performance and specific deliverables, are accounted for as the charity earns the right to consideration by its performance.
- Tax refunds (e.g. gift aid) are accounted for when received.

### Expenditure

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes VAT, which cannot be recovered, and is reported as part of the expenditure to which it relates:

- Costs of generating funds comprise the costs associated with attracting voluntary income.
- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.
- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees. All costs are allocated between the expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resources. Costs relating to a particular activity are allocated directly, other costs are apportioned on an appropriate basis e.g. estimated usage.

### Allocation and apportionment of costs

Costs have either been directly allocated or have been allocated on the basis of an estimate of time spent.

### Tangible fixed assets

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

Equipment	- 25% on cost
Furniture	- 20% on cost

### Taxation

The charity is exempt from corporation tax on its charitable activities.

### Fund accounting

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity.

Designated funds are unrestricted funds earmarked by the Board of Trustees for particular purposes.

Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of appeal.

### Pension costs and other post-retirement benefits

The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

# Notes to the financial statements

Year ended 31 December 2017

## 2. Donations and legacies

	31.12.17 £	31.12.16 £
Donations	627,243	159,074
Grants	77,157	89,010
Fundraising activities	104,456	112,606
Income tax refund	14,856	19,811
	823,712	380,501

Grants received, included in the above, are as follows:

	31.12.17 £	31.12.16 £
Grants from NCG	38,916	38,635
Grants from European Commission	38,241	50,375
	77,157	89,010

## 3. Other trading activities

	31.12.17 £	31.12.16 £
Sale of merchandise	2,777	3,080

## 4. Investment income

	31.12.17 £	31.12.16 £
Deposit account interest	115	93

## 5. Income from charitable activities

	Activity	31.12.17 £	31.12.16 £
Family meetings and conferences etc	Welfare	7,731	8,119



# Notes to the financial statements

Year ended 31 December 2017

## 6. Raising funds

	31.12.17 £	31.12.16 £
Staff costs	52,804	47,604
Information, literature, publicity etc.	19,986	18,550
Merchandise	3,354	1,596
Other direct costs	625	879
Support costs allocated to activities	22,336	17,786
	99,105	86,415

## 7. Charitable activities costs

Analysis of direct costs:

	Research £	Clinic £	Welfare £	Information £	Education £	Governance £	Total £
<b>Costs directly allocated to activities</b>							
Staff costs	32,730	24,561	36,717	26,858	11,391	12,334	144,591
Support events	-	-	30,704	-	-	-	30,704
Newsletter	-	-	1,099	1,099	-	-	2,198
Welfare, equipment, respite etc.	-	-	32,247	-	-	-	32,247
Research fees and conference	31,455	-	-	-	-	-	31,455
Clinic costs	-	20,127	-	-	-	-	20,127
Information, literature, publicity etc.	-	-	-	169	-	-	169
Other direct costs	-	-	-	-	-	4,663	4,663
<b>Support costs allocated to activities</b>	4,872	5,952	8,871	1,931	5,918	2,164	29,708
	69,057	50,640	109,638	30,057	17,309	19,161	295,862

## 8. Net income/(expenditure)

Net income/(expenditure) is stated after charging:

	31.12.17 £	31.12.16 £
Auditors' remuneration	3,400	3,400
Depreciation - owned assets	659	628

# Notes to the financial statements

Year ended 31 December 2017

## 9. Trustees' remuneration and benefits

No member of the Board of Trustees received any remuneration during the year (2016: £Nil).

### Trustees' expenses

Travel expenses reimbursed to trustees were £86, 1 trustee (2016: £Nil).

## 10. Staff costs

	31.12.17 £	31.12.16 £
Salaries	175,527	161,318
Social security costs	12,888	11,099
Pension provision	8,980	7,683
	197,395	180,100

No employees had emoluments in excess of £60,000 (2016: None).

During the year and the previous year, the Society employed a full-time chief executive, a full-time fundraiser and a full-time family support manager, and 5 part-time staff, equivalent to 3 full-time staff (2016: 5 part-time staff equivalent to 2 full-time staff).

The company operates a defined contribution pension scheme in respect of the employees. The scheme and its assets are held by independent managers. The pension charge represents contributions due from the company and amounted to £8,980 (2016: £7,683).

# Notes to the financial statements

Year ended 31 December 2017

## 11. Comparatives for the statement of financial activities

	Unrestricted funds 2016	Restricted funds 2016	Total funds 2016
	£	£	£
<b>Income and endowments from</b>			
Donations and legacies	231,767	148,734	380,501
<b>Charitable activities</b>			
Welfare	-	8,119	8,119
Other trading activities	3,080	-	3,080
Investment income	93	-	93
	234,940	156,853	371,793
<b>Expenditure on</b>			
Raising funds	86,415	-	86,415
<b>Charitable activities</b>			
Research	12,235	54,419	66,654
Clinic	14,255	38,635	52,890
Welfare	25,317	54,240	79,557
Information	29,018	2,720	31,738
Education	9,813	3,218	13,031
Governance	21,110	-	21,110
	198,163	153,232	351,395
<b>Net movement in funds</b>	36,777	3,621	40,398
<b>Reconciliation of funds</b>			
Total funds brought forward	59,187	44,099	103,286
<b>Total funds carried forward</b>	95,964	47,720	143,684

# Notes to the financial statements

Year ended 31 December 2017

## 12. Tangible fixed assets

	Equipment £	Furniture £	Total £
<b>Cost</b>			
At January 1 2017	15,570	1,883	17,453
Additions	124	-	124
<b>At December 31 2017</b>	<b>15,694</b>	<b>1,883</b>	<b>17,577</b>
<b>Depreciation</b>			
At January 1 2017	14,230	1,883	16,113
Charge for the year	659	-	659
<b>At December 31 2017</b>	<b>14,889</b>	<b>1,883</b>	<b>16,772</b>
<b>Net book value</b>			
<b>At December 31 2017</b>	<b>805</b>	<b>-</b>	<b>805</b>
<b>At December 31 2016</b>	<b>1,340</b>	<b>-</b>	<b>1,340</b>

## 13. Debtors: amounts falling due within one year

	31.12.17 £	31.12.16 £
Other debtors and prepayments	8,708	11,129

## 14. Creditors: amounts falling due within one year

	31.12.17 £	31.12.16 £
Other creditors and accruals	46,912	15,234



# Notes to the financial statements

Year ended 31 December 2017

## 15. Movement in funds

	At 1.1.17	Net movement in funds	At 31.12.17
	£	£	£
<b>Unrestricted funds</b>			
General fund	95,964	(6,554)	89,410
<b>Restricted funds</b>			
Research	6,493	4,463	10,956
Welfare, support, equipment	41,227	441,459	482,686
	47,720	445,922	493,642
<b>Total funds</b>	<b>143,684</b>	<b>439,368</b>	<b>583,052</b>

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

	Incoming resources	Resources expended	Movement in funds
	£	£	£
<b>Unrestricted funds</b>			
General fund	186,612	(193,166)	(6,554)
<b>Restricted funds</b>			
Research	47,203	(42,740)	4,463
Clinic costs	39,308	(39,308)	-
Welfare, support, equipment	541,212	(99,753)	441,459
Fundraising	20,000	(20,000)	-
	647,723	(201,801)	445,922
<b>Total funds</b>	<b>834,335</b>	<b>(394,967)</b>	<b>439,368</b>

### Purpose of restricted funds

**Research** - the research funds include that part of a three-year Horizon 2020 grant from the European Commission to build and run an international A-T patient registry, which was received and utilised in 2017. The balance remaining represents that part of the funding for research projects which was not spent in 2017.

**Clinic costs** - represents amounts received by the NHS in relation to our work supporting the Nottingham and Papworth clinics.

**Welfare, support and equipment** - the balance remaining represents provisions to fund work to support adults with A-T to live more independently, equipment for young people below the age of 18 years, the support of education of young people, plus a range of funds restricted to particular items of equipment and geographical areas and to our welfare and communications work more broadly. Amounts spent in the year include donations restricted to respite, to the family weekend and towards equipment for adults and young people, the education of young people and the funding of a family support coordinator.

**Fundraising** - represents an amount received from a grant giving charitable trust to fund the employment of a community fundraiser.

# Notes to the financial statements

Year ended 31 December 2017

## 16. Related party disclosures

No trustee or any other person related to the charity had any personal interest in any contract or transaction entered into by the charity during the year or the previous year save as a potential beneficiary of the charity in the normal course of its activities.

## 17. Ultimate controlling party

In the opinion of the trustees, there was no controlling party during the year.

## 18. Statutory information

The Ataxia-Telangectasia Society is a private company, limited by guarantee, registered in England and Wales. The company's registered number and registered office address can be found in the Trustees' report.

Everything that the A-T Society does is carried out by a small team of staff and volunteers, with the enthusiastic backing of a great network of committed, energetic and imaginative supporters across the UK and beyond.

During the course of 2017, the volunteers and staff consisted of:

### Directors/Trustees

Linda Clarke  
Michael Detsiny, Chairman  
Lynda Finn  
Penny Jeggo  
Andrew Mills, Treasurer  
Rupert Prokofiev (deceased January)  
Hasita Senanayake  
Lian Yarlett

### Staff

Sarah Ajder	Community Fundraiser
Sophie Arnold	Fundraising Assistant (part-time)
Kay Atkins	Family Support Manager
William Davis	Chief Executive
Denise Ganley	Book-keeper (self-employed, part-time)
Kate McEleney	Communications Officer (part-time)
Anne Murray	Family Support Coordinator (part-time)
Jo Reader	Registry Coordinator (part-time)
Suzanne Roynon	Fundraising and Relationship Manager

### Patrons

The Lady Parkinson DL  
Mrs Joan Bartholomew  
The Lord Bilimoria of Chelsea DL  
Mr Brian Conley

### Scientific Advisory Board

Dr Penny Jeggo (Chair)  
Professor Bobby Gaspar  
Dr Anke Hensiek  
Dr Rick Livesy  
Professor Malcolm Taylor  
Dr William Whitehouse

### Volunteers

We couldn't do what we do without the enormous contribution made by our volunteers, who bring their skills, enthusiasm and commitment to nearly all areas of our work.

Helen Hart retired after many years as the Society's counsellor. Helen has been an invaluable source of help to people struggling to cope with the challenges of living with A-T. Many, many people have benefited from talking to her over the years and we thank her warmly and wish her well for the future.

Caryl Guest and Jill Curl continued to provide invaluable help in the office, while Maureen Jenkins visited those attending the Papworth clinic. The Atkins Family, regularly help out at Family Weekends and our Christmas collection and we appreciate the support of the families of all members of staff.

We are incredibly fortunate to have such a strong Board with such a wide set of skills, and so willing to share them and to participate in other Society activities.

But above all we depend on our many, many fundraisers and supporters, across the UK and Ireland and further afield. There are too many to name, though we would love to thank them all individually. We are left amazed and breathless but always inspired by their commitment and creativity and on them depends the future of the A-T Society.

And finally, we acknowledge a huge debt to the doctors, therapists and researchers who do so much to help people with A-T and to support the A-T Society in its work. We thank them all warmly.

# Thank you

**The Board and the A-T Society are extremely grateful to everybody who has contributed to our funds.**

We would love to be able to thank everyone individually who has supported us in 2017, however for reasons of space, we cannot do so. Nevertheless, we would particularly like to mention the following:

### In memoriam or legacy donations

Gifts were given in memory of:

Colin Baker  
Cleo Brady  
Wayne Bugby  
Anupam Dhirani  
Raymond Evans  
Brian Fairclough  
Becky Goodwill  
Dennis Hammond  
Leo Hayward  
Joan Holgate  
Harry Hunt  
Faye Larkin

Ian McInnes  
Doreen Owens  
Sylvia Price  
Rupert Prokofiev  
Margaret Ward  
Sian Watkins

### Trusts and foundations

A & S Lass Charities Limited  
Bartle Family Charitable Trust  
Children in Need (London)  
D M Charitable Trust  
Edinburgh Bar Association Benevolent Trust  
Global Make Some Noise  
Hertfordshire Community Foundation

# Donors and supporters

Leeds Building Society Charitable Foundation  
Reuben Foundation  
Sir Samuel Osborn's Deed of Gift Relief Fund  
The Bergne-Coupland Charity  
The Boshier-Hinton Foundation  
The Bothwell Charitable Trust  
The Childwick Trust  
The Clare Milne Trust  
The Edith Lilian Harrison 2000 Foundation  
The Eveson Charitable Trust  
The Foresters Charity Stewards UK Trust  
The Gloag Foundation  
The J Reginald Corah Foundation Fund  
The Jarvis (Harpenden) Charitable Trust  
The Magdalen and Lasher Charity  
The Michael and Anna Wix Charitable Trust  
The Mrs A Lacy-Tate Trust  
The Multithon Trust  
The Murphy-Neumann Charity Company Ltd  
The N Smith Charitable Settlement  
The Parivar Trust  
The Perry Watlington Trust  
The Rest-Harrow Trust  
The Roger and Jean Jefcoate Trust  
The Sir Arthur Black Charities No. 2 Trust  
The Sir James Roll Charitable Trust  
The Smith and Pinching Charitable Trust  
The Sobell Foundation  
The Sylvia and Colin Shepherd Charitable Trust  
The Tom Hall Charitable Trust  
And two trusts which request anonymity

## Individuals and organisations who raised over £500 in 2017

All Saints Church, Blackheath  
Colfe's School  
Concordia Choir  
Dr Jarno Vannucchi  
Friends of Elvetham Heath Primary School  
Harpenden Village Inner Wheel  
HM Prison Shotts  
Kings Lynn Cycle Club  
London Joy Singers  
Master Matthew Audis  
Miss Anne Saunders  
Miss Bibi Dindar  
Miss Jilly Shah  
Miss Jo Betts  
Miss Sarah Evans  
Miss Simone Kelly  
Miss Suzie Hadfield  
Mr & Mrs Betty and Barry Sharp  
Mr & Mrs Michael and Glenday Thomas  
Mr & Mrs Roger and Christine Kelly  
Mr & Mrs Tim and Annette Hughes  
Mr Adrian Johnson

Mr Aidan Wilson  
Mr Alexander Williams  
Mr Alfie Arnold  
Mr Barry Thomson  
Mr Chris Bentley  
Mr Darren Haynes  
Mr David Drury  
Mr Emmett Ives  
Mr Garry Dalton  
Mr Ivor Saunders  
Mr Jim Thomson  
Mr Jonny Luke  
Mr Josef Camblin  
Mr Lee Goble  
Mr Michael Byrne  
Mr Michael Eames  
Mr Nathan Murley  
Mr Patrick Turpin  
Mr Paul Sargent  
Mr Phil Sampson  
Mr Richard Bosson  
Mr Robert Thomas  
Mr Robin Hewison  
Mr Roddy Grant  
Mr Ron Giles  
Mr Scott Horney  
Mr Scott Robertson  
Mr Timothy Child  
Mr Tom Worsley  
Mr William Davis  
Mrs Adelle Rouse  
Mrs Catherine Muddle  
Mrs Claire Martindale  
Mrs Elisabeth McInnes  
Mrs Frances High  
Mrs Hayley Carrington  
Mrs Jayne Rainbow  
Mrs Joy Ferguson  
Mrs Katy Luke  
Mrs Lian Yarlett  
Mrs Lisa Noscoe  
Mrs Maureen Seal  
Mrs Sara Metcalfe  
Mrs Sinead Ward  
Mrs Zita Tarr  
Ms Astrid Prokofiev  
Ms Lisa Baker  
Ms Micky MacCormick  
Nuffield Health, Farnborough  
Oxford Children's Hospital, Department of Paediatrics  
Provincial Grand Lodge of Hertfordshire  
Reverend Martin James  
Rotary Club of Weston Super Mare  
St Albans Round Table  
The Cole Family  
The Dziri Family  
The Green Man  
The Moody Mare  
The Sewell Family  
The Sprawling Family

## Corporate Donations

Aggregate Industries UK Limited  
Asda, Sutton in Ashfield  
Babcock International Group, Network Rail Apprenti  
Barclays Global Community Investment Team  
BCMY Recycling  
Blunts Shoe Shop  
Castle Tearooms  
Cheshire Police HQ Winsford  
Convergys  
Co-op Ballycastle  
Costa Coffee, Vancouver Quarter  
Ernst & Young  
Food for Thought Bakery  
Gemini Hair Salon  
Gosling Design  
Greycastle  
Haslington Models  
Hicks & Company Chartered Accountants  
Internet Watch Foundation  
Jones and Champion  
KD Electrical  
LTI Metaltech  
Marks and Spencer Bridgnorth  
Marks and Spencer Carrier Bag Account  
Messrs TJ Legal Services Ltd.  
Nisbets Catering Equipment (Bristol)  
Oxford Children's Hospital, Department of Paediatrics  
Pentagon Shopping Centre  
Perranwell Post Office and Stores  
Pizza Hut UK & Ireland  
Recycle for Charity  
RSA Insurance  
Steve Turzynski & Co.  
Stort Mill Recycling Limited  
Tarmac  
The New Calley Arms  
The Udell Group  
Thorntons and Hallmark, Bridgnorth  
Town Hall Cobbler  
VMWare International Ltd.  
Waitrose Clapham Common  
Waitrose Hythe  
Waters Networking Limited  
Wayne Turner Developments Limited

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