

**The Ataxia-Telangiectasia Society**  
Annual Report and Accounts 2015

# Progress in partnership





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**"The Erydex trial offers the first ever hope of a treatment that might improve the condition of those with A-T."**



## Welcome

**Welcome to our 2015 Annual Report which highlights our work and successes during the year. Despite a number of challenges, it has been a year of considerable achievement with several exciting developments underway.**

I was invited to become Chairman of the A-T Society in April 2015. I succeeded Lian Yarlett, her dedication and example make her an extremely hard act to follow.

An Annual Report is designed to give all stakeholders a comprehensive review of the past year's activities. It therefore seems to me to be pointless to repeat the comments of William Davis, our Chief Executive, which immediately follows my contribution.

Suffice to say that some of the achievements he highlights really do provide the opportunity to make real progress in understanding and treating A-T. The A-T registry will create a major database to track how the condition develops and manifests itself thus providing a real platform for future research. The Erydex trial, which the A-T Society worked hard to help get established, offers the first ever hope of a treatment that might improve the condition of those with A-T. This has therefore been a year of considerable achievement.

However, I would like to pen a few words about my very short time in this role. I can best describe my experience as deeply humbling and enriching. 'Humbling' because one sees the daily struggle of those who live with A-T, the strain this puts on

their families and the selfless care and dedication provided by those families. 'Enriching' because I witness the tireless work of our staff for whom this is a vocation rather than just a job and see how with their help, families come together to strengthen and support each other. This is a real tribute to the human spirit.

Usually one pays passing tribute to the hard work of one's staff. However since we are a small organisation I think it appropriate to personally thank Kay Atkins, Suzanne Roynon, Anne Murray, Kate McEleney, Jo Reader and Eve Audis for working way beyond the call of duty. William Davis, our CEO, is an inspiration.

Finally, I would like to thank my fellow trustees for the support they have given me in my early days as Chairman and for the time and effort they devote to furthering the work of our charity.

With such a great team I'm sure progress in this battle will be made and I look forward to being part of it.

**Mike Detsiny**  
Chairman



“For people with A-T, the most significant achievement of the year was probably the award of a €6 million grant to fund the first-ever international clinical trial of a treatment for A-T.”



## A Step Forward

**A very warm welcome to the A-T Society's Annual Report and Accounts for 2015. While there have been some challenges this year, particularly around income, the year is much more strongly marked by good news and positive achievements.**

For people with A-T across the world, the most significant achievement of 2015 was probably the award of a €6 million grant by the European Commission to fund the first-ever international clinical trial of a treatment for A-T. The award was won by an international consortium of seven organisations, of which the A-T Society was the only voluntary organisation. We played a key role in the success of the application, which ensured that the trial will be able to start in 2016.

As part of the grant, the A-T Society will receive a total of €250,000 to establish an A-T patient registry. A-T research is held back by the fact that A-T is a variable and very rare condition. It is therefore difficult to get enough data together to really understand how the disease progresses – what we call its Natural History. A patient registry has been discussed for years, but will now become a reality, opening the door to new understanding and potential treatments.

These achievements show the value of the A-T Society's strategy of building collaboration and partnerships to make the most of the limited funds which we and our sister charities around the world are able to invest in A-T research.

Another example of our international impact was in raising standards of clinical care. In 2015, our Clinical Guidance document on treating children with A-T was translated into French by our sister organisation in France, APRAT, and circulated in France and other French-speaking countries. On top of this, a European Respiratory Society (ERS) task force, set up with the support of the A-T Society, published a statement on the respiratory care of people with A-T. This is effectively clinical guidance on the care of the lungs in A-T and

backed by the ERS carries real clout.

Our day-to-day work supporting families through the different stages of life with A-T was busier than ever. In this time of cuts to health and social care services, the advocacy support we give to help families access the services and resources they need is vital and time-consuming. We were therefore delighted that in 2015, supported by Jeans for Genes, we were able to employ a second part-time member of our family support team.

Other generous support came from Pizza Hut Delivery, who have contributed amazingly both in fundraising and through support from their staff. In particular, they hosted a pizza-making session for 21 adults with A-T as part of a very successful Activity Weekend. We are also grateful to the support of the Pentagon Shopping Centre in Chatham, which has selected us as their 'charity of the year' for a third year running.

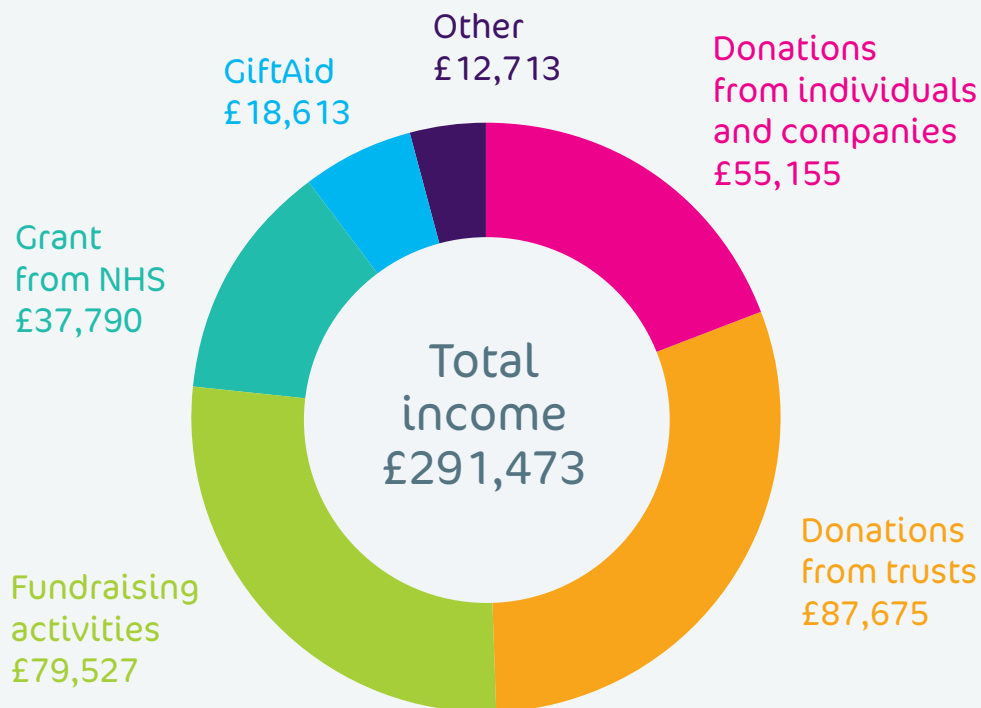
Overall, however, income was significantly lower than in 2014, leading to a deficit for the year that was higher than planned. This is largely due to a fall in income from events and individual donations. There are a number of factors in this: increased competition for funds; the difficulty of sustaining high levels of supporter activity year after year; the low number of diagnoses and thus new supporters over the last 18 months; and the increased pressure on families from cuts to services and the general financial situation.

In response the Board has adopted a new fundraising strategy which will strengthen these and other income streams, giving us a more diversified and stable income. Together with the investment in extra fundraising support made during 2015, this has enabled us to set a surplus budget for 2016 and to look forward to a future of growth.

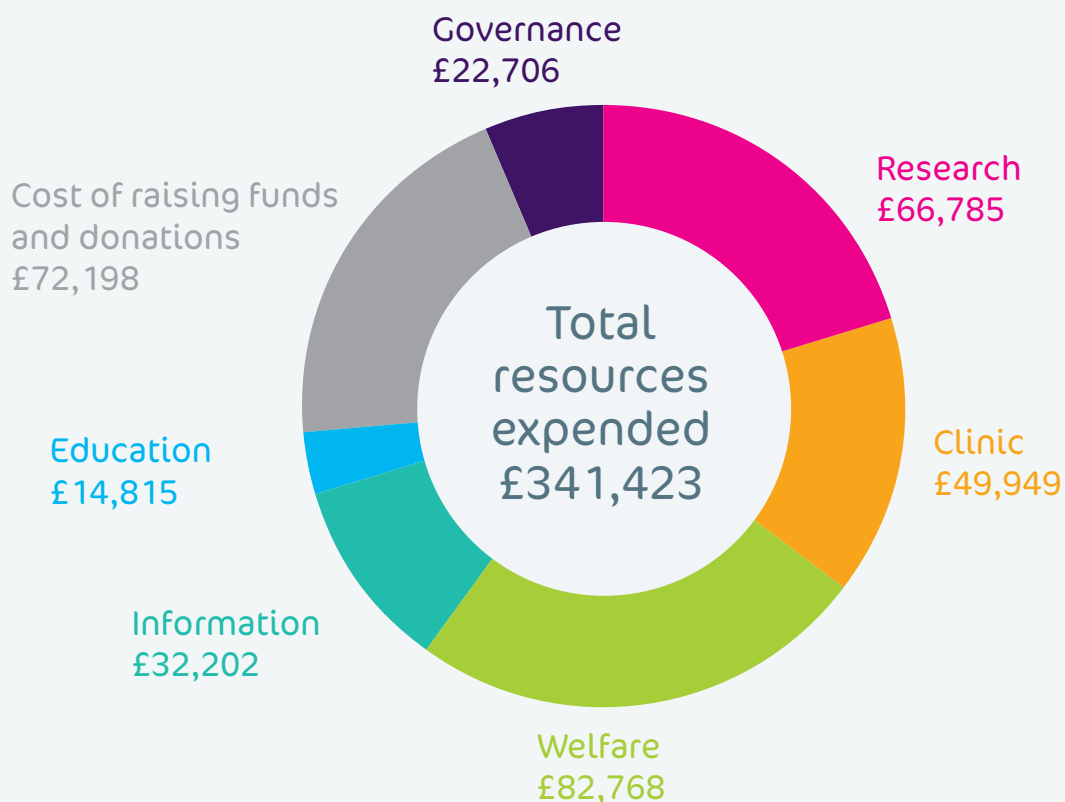
I therefore invite you to review our considerable achievements during 2015 and to look forward with us to our many plans for the future.

**William Davis**  
Chief Executive

## How we raised the money



## How we spent the money



At the end of 2015, 163 people in the UK with A-T or a related condition were registered with the A-T Society.



## Supporting people affected by A-T

The support function of the A-T Society is at the core of the charity and plays an invaluable role in the lives of many people living with A-T.

Our Family Support team provide vital support and advice to families living with A-T and professionals seeking further information about this rare condition. During the second half of 2015 we increased the capacity of the team, employing Anne Murray to support Kay Atkins, whose workload had become increasingly unsustainable due both to the continuing rise in the number of families registered with the charity and the increasing complexity of government-funded social care. With over 25 years of experience in health and social care between them, Kay and Anne are able to offer practical and workable solutions to even the most complex issues.

During 2015 their workload included:

- 1,649 support phone calls
- 40 advocacy cases
- 7 new diagnoses
- 12 medical interventions
- 12 family visits nationwide
- 9 school visits/talks
- 10 support grant requests
- 6 social services meetings
- 6 Nottingham clinics
- 46 adults booked to attend Papworth Clinic

### Support to individuals and their families

At the end of 2015, 163 people in the UK with A-T or a related condition were registered with the A-T Society. Seven new families, with a recent diagnosis, also contacted the charity for advice and support. Sadly two children and one young adult with the condition passed away during the year.

During the year the Family Support team received over 1,600 phone calls in their support role, around 80% of these calls were from people and families living with A-T. The team spend a considerable amount of time on the phone providing information, practical and emotional support to families living with A-T or those going through the ordeal of a new or potential diagnosis.





Jane contacted the A-T Society for support and advice when her 2 year old son was diagnosed with classic A-T. The family had never heard of the condition and the news came as a bit of a shock.

“Thank you for calling earlier. Sorry if I bombarded you a bit! I think sometimes you don’t realise how many things are floating about in your head to ask until you get started... As always you were so patient, kind and understanding and I can’t tell you how much I appreciate it.”

The team also receive calls from families seeking advice on housing issues, benefit applications, health concerns, educational assessments etc. Other calls are evenly split between calls from professionals or calls about the clinics.

## Advocacy

As well as providing guidance and emotional support, Kay and Anne are very much involved in helping people access the support and health services they need. During 2015 they were involved in 40 Advocacy cases - 18 were completed by the end of the year and 22 are still ongoing. 15 of the ongoing cases are housing-related issues which are taking an increasingly long time to complete due to the shortage of suitable housing stock and high demand in areas where there are real housing shortages.

The tenacity of our Family Support team enabled them to access nearly £185,000 worth of support for families from external sources in the form of grants for equipment, benefits, educational support, respite care etc. This means that over £5 worth of extra support was generated for every £1 the charity spent on advocacy work in 2015.

For every pound we spent on advocacy, we leveraged more than £5 of extra funding from social services, education and housing.



## Advocacy case studies

### *Settling into a new school*

The family of 4 year-old girl (Classic A-T) asked for our help to facilitate the smooth transition of their daughter from nursery to primary school. Kay met with the nursery to ascertain her requirements and then attended a meeting at the new school to plan the transition. Kay outlined all the issues the little girl would face and advised on the support needed. All the key professionals who would be involved in her education attended the meeting. The LEA awarded the school the maximum number of hours of support per week so that she will have a teaching assistant at all times including break. Kay also applied to the LEA for an Education and Health care plan. The family were grateful for Kay’s input as the plan was in place before their daughter started school.

### *Adapting the home to make it more suitable*

One of our young adults contacted us for assistance to get her property adapted to meet her needs - the ramps hadn’t been maintained, the driveway had access issues and the kitchen was unsuitable for a wheelchair user. Furthermore, she had, with our help, been allocated a powered wheelchair which she desperately needed but the authorities wouldn’t release this until the appropriate adaptations had been made. Responses from social services were frustratingly slow and it was impacting her daily life. Anne did a joint home visit with an OT to assess the situation and wrote numerous e-mails and reports to the housing association and wheelchair services. Within two months of the initial visit, the housing association agreed to all Anne’s recommendations and work has commenced.





“We would like to thank you for coming to meet with us today. Having the opportunity to talk to you about A-T was extremely valuable. It has opened our eyes to the challenges that our pupil and his family have faced and will face in the future. It has certainly given us food for thought on how we can effectively support them whilst he attends our school.”

W. Howlett, Acting Head Teacher, Primary School in North Lincolnshire.

## Support to Health and Social Care Professionals

The Family Support team play a crucial role in liaising with local health and social care professionals putting them in touch with experts, where necessary, to ensure that they understand the full implications of living with A-T so that they can best meet the needs of the person with A-T. For example, a parent contacted Kay when their child was ill in hospital with a chest infection and the medical team there had no experience of A-T. At Kay's request, our respiratory physician, Dr Bhatt, contacted the medical team and advised them on the most effective antibiotics to prescribe for a child with A-T.

## Support Grants

The cost of living with a condition like A-T becomes much higher as the condition progresses. The A-T Society's support grants can be a lifeline for families who are struggling to pay for all the mobility equipment required or who need a break from the stress of living with A-T. As the charity has limited means, every funding request is considered carefully and all avenues for fulfilling the request explored. Using the relationships we have built up with a number of charitable trusts and our in-depth knowledge of the different grants available, we are often able to secure external funding or fund expensive items in partnership. In 2015, 30% of the support grants we awarded were partially or fully funded by an external source.

The A-T Society awarded support grants to the value of £6,300 during 2015 to help meet a wide variety of needs such as horse riding, specialist equipment for mobility and the home, respite breaks and counselling. Each of these grants can make a substantial difference to the life and well-being of the person living with A-T and their families.

## Counselling

Counselling support is available for anyone affected by A-T. Our Counsellor, Helen Hart, has been supporting people with A-T and their families for over 20 years. She has vast experience in helping people cope with all the different stages of living with A-T and understands the strain it can put on relationships within families. In 2015 Helen gave counselling support to 5 families, 23 sessions in total.

*Respite Break* In 2015 we booked a respite break for a low-income family with an 11 year old daughter with classic A-T. The mum had been widowed and didn't have any spare funds to go away. Kay organised a short break for them to give the family an opportunity to spend some quality time together, away from the stresses of daily life.

*A new Trike* A family with an 8 year old boy with classic A-T contacted us for help. Their son used to love going out to play on his bike with his siblings however, as his condition progressed, he could no longer join them as he couldn't stay on his unsuitable bike. He was left sitting watching from the window as his siblings played outside. The A-T Society made a grant towards the cost of a new trike and now he is able to race around with them.

*Counselling Support* We were approached by a family whose 5 year-old daughter has classic A-T. The dad was struggling to deal with his daughter's diagnosis and unable to look beyond the shock of the initial diagnosis to the future. His demeanour was affecting family life and, after spending over a year on an NHS waiting list for counselling, the family turned to us for help. We funded 5 private counselling sessions to help the dad to come to terms with his daughter's condition and enable him to move forward. It has made a huge difference to family life.



The A-T Society was active in supporting plans for the first ever international clinical trial of a treatment for A-T.



## Research: understanding and treating A-T

The Society supports research into A-T both financially and by engaging with researchers, clinicians and pharmaceutical companies to provide practical support. This includes identifying targets for research, bringing scientists and clinicians together, helping develop projects, researching and applying to potential funders, identifying participants, communication and engagement with patients and/or clinicians and so on.

In 2015 there were seven active research projects funded either wholly or in part or supported in other ways by the Society. In addition we were active in helping prepare several projects to start in 2016. We also supported the A-T Workshop 2015 conference in Beijing in October and led the planning for the next clinical research conference to be held in Warsaw in 2016.

### Erydex trial

The Society was active in supporting plans for the first ever international clinical trial of a treatment for A-T, which will start in summer 2016. The trial will test the effectiveness of the steroid dexamethasone, delivered in a novel manner which eliminates side-effects, on the neurological symptoms of A-T.

The Society formed a consortium with the company planning the trial and a number of specialist A-T Centres and played an active role in submitting a bid for funding from the European Horizon 2020 programme. The bid was not only successful, but was scored very highly by the European Commission. The award ensures that the trial will be able to go ahead. Over the course of the year we also assisted with communications with patients and clinicians, including holding a patient-involvement workshop at our Family Weekend.

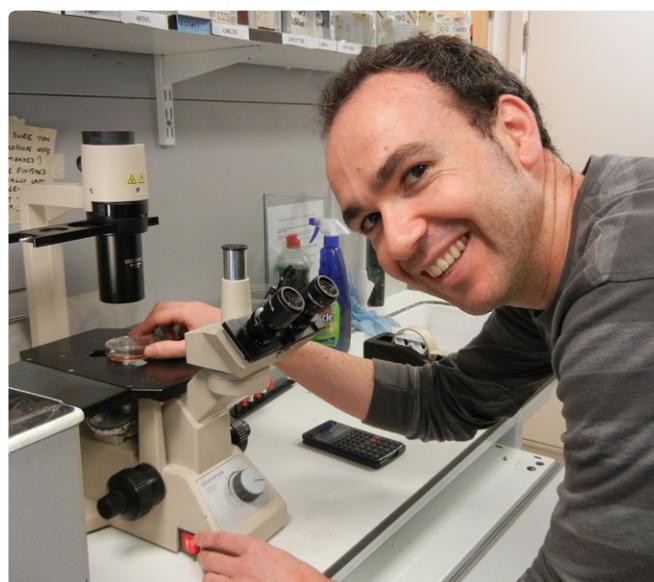
### Patient registry

The A-T Society submitted a request for funding for an International A-T patient registry as part of the Horizon 2020 bid. In December 2015 the project was awarded a grant of over €250,000 and the Society will be leading on the establishment of the project in 2016.

By bringing together data from patients from different countries, the registry will deepen our understanding of A-T, help identify effective treatments and aid the planning of and recruitment to clinical trials.

### A-T Workshop 2015

The A-T Workshops are a series of international conferences seeking to understand the role of the ATM gene which is responsible for A-T. It brings together an illustrious group of researchers from around the world. The A-T Society gave a grant to help support the 2015 conference which was in Beijing. We also published reports in lay-language and filmed interviews with speakers from the conference to give families from around the world access to the latest research information.



The Patient Registry will deepen our understanding of A-T and help identify effective treatments.



## Clinical research conference

In 2012, the A-T Society established a series of A-T Clinical Research Conferences with the aim of bringing together clinicians and researchers with an interest in developing treatments for A-T. The information shared at these conferences are particularly important for a condition as rare as A-T, where few centres see more than a few patients.

During 2015, we selected Warsaw as a venue for the third conference in 2016 and worked with clinicians there to help organise the event and put together a programme.

## Clinical research network

Established by the A-T Society in 2011 in partnership with the A-T Children's Project in the USA, the clinical research network links clinicians and researchers from around the world with an interest in developing treatments for A-T. Several bulletins were issued to well over 100 members, with updates on research, conferences, potential funding opportunities, recently published papers and so on.

## Projects supported

### Synthetic Viability

In June, the A-T Society concluded its two-year funding of a project at the Steve Jackson laboratory in Cambridge, exploring a new approach to treating A-T. Synthetic viability seeks to alleviate problems caused by loss of one protein by inhibiting the function of another. The project was funded with the generous support of the Masonic Samaritan Fund (MSF).

While our funding has ended, the project itself continues into 2016, as a number of promising target proteins were identified, and more research is required to analyse these. This potentially very exciting work should be written up and published in 2016. We continue to liaise closely with the project with a view to funding ongoing work.

### Potential new disorder related to A-T

We made a grant to Prof Malcolm Taylor to investigate and further characterise cells from two patients who have a condition which produces a low level of the ATM protein along with ataxia, and other features similar to A-T, but which appears to be caused by mutations in a different gene. As well as identifying a new condition, this work may throw new light on how the ATM mutation causes the symptoms of A-T.

### Gene Therapy

In 2013, the Society made a grant through the A-T Research Fund, set up jointly with Action for A-T and children's medical research charity Sparks, to support a gene therapy project led by Professor Ignacio Molina at the University of Granada. Work on this project continues into 2016.



“ By bringing experts together, encouraging new projects and partnerships and funding ground-breaking research, the A-T Society is having a big impact on A-T research.”

Professor Malcolm Taylor, University of Birmingham

The study demonstrated that at least in the laboratory, ATM-deficient cells can be restored by gene therapy, using a lentiviral vector to carry the gene. The project also created for the first time a panel of long-term primary T cells from A-T patients. This will be a valuable tool for future studies of immunological defects in A-T.

### Two studies into the effects of steroids

2015 saw the completion of two other studies in Italy also funded through the A-T Research Fund which aim to understand the mechanism by which steroids seem to alleviate the neurological symptoms of A-T.

The study led by Prof Luciana Chessa has provided some evidence that dexamethasone treatment can up-regulate the antioxidant capacity of A-T cells and affect abnormalities in glucose metabolism. This could provide an explanation for the clinical benefit of dexamethasone in patients although further studies are required.

Prof Claudio Pignata investigated the role of ATM in ‘autophagy’, the cell’s internal cleaning-up process which prevents the build-up of toxic waste products and which, if not working properly, can cause cells to die. This process has also been reported to be abnormal in other neurodegenerative disorders. The study has provided the first demonstration that the ATM protein plays an important role in autophagy, which suggests the possibility of a new approach to treating A-T and opens the way to more research.

### Stem-cells and genome sequencing

We continued to recruit participants for a project led by Dr Serena Nik-Zainal at the Sanger Institute which is sequencing the genome and creating stem cells from the blood of people

with A-T and related conditions. While the project itself is not primarily about A-T, the stem-cells and information it produces will be extremely valuable.

### CATNAP

The *Children’s Ataxia Telangiectasia Neuroimaging Assessment Project* uses the latest magnetic resonance imaging (MRI) technology to reveal the processes underlying the neurological symptoms in A-T and to identify bio-markers which can show the progress of neurological problems in A-T and will be very useful in testing new treatments.

While we do not fund this project, we played a key role in setting it up and continue to support it by recruiting families to take part and publicising it through a presentation at our Family Weekend and articles in the newsletter. The project will conclude in 2016.





**"I just tried Skiing for the first time and I absolutely loved it!"**

**Kayleigh Aris**



## Supporting one another

### Family Weekend

Our family weekend is the one opportunity a year for families and people with A-T to get together with people who understand them, to share experiences and to develop the support networks which are so essential for those who live with rare conditions. This year our family weekend, held at the Radisson Blu hotel East Midlands, was attended by over 45 families.

Our thought-provoking presentations ranged from practical advice on nutrition and the importance of maintaining good posture to research talks about the progress of the Erydex drug trial, the CATNAP imaging project and the Cambridge synthetic viability project. The Q&A session with medical experts and researchers gave our families and carers the opportunity to get their burning questions answered and sparked some healthy debates. The talks from young adults with A-T about their hobbies, lives and aspirations were emotional and inspiring. They received the biggest applause of the weekend.

For our children with A-T and their siblings, the weekend was action-packed. The programme this year included a trip to the Space Centre, balloon modelling, evening disco and a 'space workshop'. For many, the opportunity to try new experiences and the chance to meet with other children just like them and feel 'normal' for a couple of days is what made the weekend so memorable.

### Adult Activity Break

Our Adult Activity Breaks are always oversubscribed. As well as the chance to try something new, the weekends offer plenty of time for our adults to sit and talk to others who also live with A-T. For many, this is almost the most important part of the weekend. For some, it's a rare opportunity to get out and socialise.

Thanks to the generosity of one of our corporate supporters, this year 21 adults came to the headquarters of Pizza Hut Delivery to try their hand at making their own unique pizzas. With friends old and new to catch up with, and some creative pizza-design, the building was soon awash with the sound of laughter. The following day it was off to ski-school and the chance for our adults to cast aside their wheelchairs and experience something totally different. Lots of smiling faces came slaloming down the mountain and, those who felt out of their comfort zone at the beginning, were soon enjoying the adrenaline rush.

Film maker Sharon Woodward spent the weekend filming the events and interviewing our adults with A-T. Many valued the opportunity to get their views across and talk candidly about what it's like to live with the condition. The films will be available to view in 2016.

We were able to fund the weekend with support from various grant-giving Trusts who recognise the value and importance of respite, activity and quality of life for disabled people.



**"Had a fantastic weekend away with the amazing young adults from our A-T family, lots of fun and giggles. Thanks to the A-T Society for making it possible."**

**Lorna Robinson**



We have over 3,000 active followers on Facebook.

## Communicating our messages

### Website

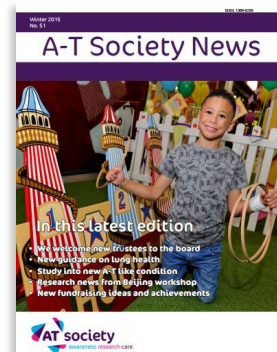
Our website continues to be an important resource for the charity. It's often the first point of contact for professionals and parents who are new to A-T and need information about the condition. In the last quarter of 2015 we overhauled the homepage, encompassing space to promote our fundraising events, adding in our Twitter feed, and improving navigation. As a result the homepage is more dynamic and informative. There are a few more enhancements to the website planned for 2016 which will improve the visitor experience and ensure the site continues to communicate well what we do and how we can help.

Our website attracts a global audience, with 16,350 people visiting the website at least once during the year. Of these 66% are based in the UK, 10% in the USA and the remainder across the globe. After the Homepage the most frequently visited section continued to be 'About A-T' followed by 'examples of advocacy support' and then the section for 'Professionals', reflecting the importance of the website as a source of information about Ataxia-Telangiectasia and the support available.

Our website works in partnership with Facebook and Twitter to communicate our messages.

### Social media

We are extremely active on Facebook and frequently use our pages to promote events, support our fundraisers and communicate our latest news. Our followers include many of our families, fundraisers and supporters who regularly engage with our content and interact with us and other followers. In 2015 the number of people who 'liked' one or other of our Facebook pages averaged 3,050. Our posts delivering the latest news on our research projects generally caused substantial spikes in our 'reach' and received



the most shares and comments. During 2015 we changed the Facebook headers to include our 'text to donate' number and added a 'donate now' button to the pages. In 2016 we plan to bring our 2 Facebook communities together by merging our 2 pages.

Our Twitter messages largely mirror our posts on Facebook. In 2015 we increased the number of active twitter followers from 450 to 526 and we look to continue this trend in 2016. We also created an Instagram account which we will develop in 2016 to reach a younger audience.

At the end of 2015 we created a LinkedIn account to increase our reach in the corporate sector. In 2016 we will be using it to connect with our corporate supporters and establish connections with new businesses.

### Newsletter

Our A-T Society newsletters are hugely informative and highlight all of the valuable work undertaken on behalf of the charity. In 2015 we published 2 which were sent to our A-T families, supporters and professionals within the UK and globally. These newsletters included articles about research, the latest healthcare advice, candid and inspirational stories from people living with A-T, fundraising events and news. A-T Society News is always well received and we often get requests for additional copies.

80 children/adults with A-T attended a specialist A-T clinic in 2015.



## Improving standards of care

### The two excellent specialist A-T clinical centres in the UK continued to be an important focus for our work.

The world's first specialist A-T clinic was established at Nottingham City Hospital by the A-T Society in 1993. In 2009, the NHS took over the funding. The adult A-T specialist centre at Papworth was set up in 2012 with the support of the A-T Society. The Nottingham centre is now entirely paediatric, while adults are seen at Papworth.



The A-T Society continues to work closely with both centres, making arrangements for people to attend clinics, organising their travel and accommodation and where needed, providing funding for these. We collect and collate feedback, attend regular review meetings and work with staff to improve the service.

We also liaise with local professionals and experts at the specialist centres. Most local doctors or therapists have little in-depth knowledge about the care of A-T so we put them in contact with the appropriate specialist, whether in the UK or abroad, which is an invaluable service.

Through our close relationships with the individual clinicians, we ensure that they are aware of all developments in clinical care and research and conversely that their knowledge and views feed into projects and initiatives. Examples of this in 2015 included keeping them informed on progress of the planned Erydex clinical trial, getting their input into the programming of the A-T Clinical Research Conference 2016 and the scope and contents of the new patient registry.

### Nottingham

The Nottingham centre has a high international reputation for its understanding and treatment of A-T. Over two half-days, those attending see ten different specialists, with others available if needed. Staff from the A-T Society are always on hand to talk to families, provide information and deal with any issues that arise.

The 6 clinics each year, allow up to 36 children to be seen. The July clinic is designated as a transition clinic, where those about to move onto adult services are seen jointly by staff from Nottingham and Papworth. Given the high



number of new diagnoses it is currently around two and half years before children are recalled to the clinic. In 2015, 34 children attended with their families.

### Papworth

The adult centre is at Papworth, a hospital specialising in lung and heart disorders, which has particular expertise in dealing with the lung and respiratory problems which affect many people with A-T and are a frequent cause of premature death. However, the centre offers a strong neurology service too and is carrying out MRI scans of the brain, which are starting to provide valuable new insights into how A-T affects the brain.

Attendance is on an in-patient basis with a one or two night stay. Patients receive a visit from either a member of the A-T Society's staff or our volunteer visitor Maureen Jenkins. 46 adults attended the centre in 2015. As with the Nottingham centre, feedback from patients is very positive and where there are suggestions for improvement, these are noted and acted on.

### Clinical guidance

One of the A-T Society's priorities is to ensure that people with A-T receive the best possible care locally, not just when they attend a national clinic. In October 2014, the charity published the first ever clinical guidance document on treating A-T. The guidance sections were written by experts from Nottingham and by Professor Malcolm Taylor from the University of Birmingham and the work was introduced and edited by the A-T Society.

The document was very well received by doctors and therapists as well as by families. The charity has continued to work with both groups to ensure that the guidance is being observed and we

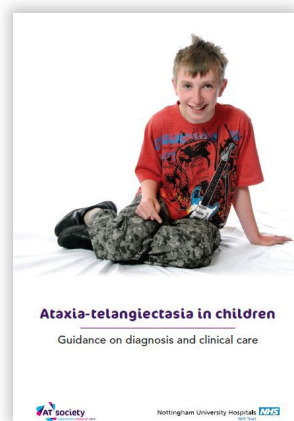
have many examples of it having led to positive changes in the care provided.

A French translation of the document was published in 2015 and was well received by the French-speaking clinicians. We also gave permission for an Arabic version to be produced.

In parallel with this, the Task Force of the European Respiratory Society, set up with the support of the A-T Society and led by Dr Jayesh Bhatt from Nottingham, published its findings in 2015. The statement on the multi-disciplinary respiratory management of ataxia-telangiectasia is in effect a clinical guidance document on caring for lung disease in A-T, produced with the backing of a major international clinical body.

### Fact Sheets

During 2015 we produced the first in a new series of fact sheets covering different aspects of caring for someone with A-T. Aimed at families living with A-T, the sheets will provide them with the information necessary to ensure that they are getting the support or services they need and are entitled to. The first two sheets cover vaccines and housing.



Corporate and Community Fundraising grew strongly in 2015.



## Raising the money

As ever, our families and supporters were at the heart of our fundraising during 2015.

Their fundraising efforts provided 27% of our total income for the year - £79K. The enthusiasm and dedication of our remarkable supporters, along with the valuable charity of the year relationships and the hard work of our fundraising team all played a substantial role in helping us achieve this. In 2015 we increased the capacity of our fundraising team, employing a part-time Fundraising Coordinator, Jo Reader, and a part-time Corporate Fundraiser, Eve Audis.



Throughout 2015, we will be establishing relationships with local companies, building up local corporate support, and endeavouring to persuade a few national companies to support us.

Sporting challenges were very popular this year with supporters signing up for physical challenges such as running, walking, cycling, climbing, swimming and skydiving. The running calendar started on New Year's Day with a 5km running event which was swiftly followed by large scale televised events such as; the Brighton Marathon, Manchester Marathon, London 10k and Great North Run, as well as smaller scale events including the Southampton Half Marathon, 5km Color Run, Wollaton Park 10k and Plymouth Half Marathon where our fundraiser dyed her hair purple to stand out in the crowd. Some of our runners even took part in events abroad so the A-T Society was represented at the San Francisco Half Marathon and the Midnight Sun Marathon in Norway. One of our runners was a true inspiration to us all, running 5km every day of the year, no matter what the weather, to support the A-T Society.

Our cyclists pedalled miles for us cycling from London to Windsor, taking part in duathlons and triathlons and enduring the arduous Surrey hills at the RideLondon 100 event. Similarly our walkers tramped miles and endured extreme weather and blisters all for the best of causes. The 22 mile Bridgnorth walk and Brooke's 5km toddle have become an annual event for several of our families.

Adventure and endurance also featured heavily in the fundraising efforts of our supporters. Several swimmers braved the freezing cold temperatures of Lake Windermere for the Great North swim, while a group of work colleagues experienced a huge adrenaline rush by skydiving, or squelched through the mud at the gruelling and challenging Tough Mudder events. Amateur golfers yearned



“Today has been one of the best ever! If someone had told me last year I would run a marathon in 2015, I would have laughed, but I completed the marathon for the A-T Society today and I loved it! Knowing how much every little penny means for this charity really kept me motivated when the going got tough!”

Daisy Hollingdale

for a birdie at a charity golf day while Tri-athletes pushed themselves to the limit at our Mega-Tri event in Brighton. Determined 14 year old Merry James, who has A-T, even organised her own triathlon event – combining rock climbing, swimming and cycling to raise awareness and money for the A-T Society.

Aside from sporting events, our families and supporters also organise many local initiatives and events which raise considerable amounts of money and help to increase the profile of the charity and awareness of Ataxia-Telangiectasia. 2015 fundraising initiatives included; a Bingo night, sponsored head and beard shaves, Knitting Nanas, bake sales, charity car wash, mufti days, choral concert, ladies pamper evening, family fun days, handmade Easter cards, BBQs, donations in lieu of wedding presents and second-hand book sales. These events make a valuable contribution to the charity’s fundraising income and can lead to new fundraisers joining us. We know how much passion and hard work our families and supporters put into organising these events and we really appreciate having such dedicated support. Every penny raised is important to us and allows us to continue to change lives for the better.

We are fortunate to have benefitted from the support of many companies this year. Pizza Hut Delivery have been incredibly active fundraisers with monthly fundraising days such as 50 shades of Pizza, auctioning off experiences with the Senior Leadership team such as Wine and Cheese

with the Chief Executive, organising a retro sports day, and holding auctions at supplier days. Staff also volunteered their time to help mail out the newsletter, pack up for the Family Weekend and host a group of young adults at our Activity weekend.

Lloyds Banking Group Northern Ireland are keen to generate awareness of A-T in the province. In 2015 they kicked their fundraising off with two very brave men taking part in ‘it’s a Rip-off’ - a sponsored chest wax! - which generated a lot of attention. The Pentagon shopping centre continued to support us as their charity of the year by organising several innovative fundraising events, while Harpenden Cricket Club kindly provided us with the opportunity to be part of ‘Classics on The Common’ for the second year running and donated goods for the cake stall. Our corporate partners continue to delight us with their fundraising efforts and commitment to helping the charity and everyone with A-T.

Trust funds contributed 30% of our total income in 2015. Whilst researching and providing the information required for applications can take up a considerable amount of Suzanne’s time, it is clear that this enables trusts to see and appreciate the value of our work. This is shown, for example, in the grant we received from Genetic Disorders UK which enabled us to appoint our Family Support Co-ordinator. We will continue to concentrate on building up this vital income stream in 2016.





In 2016 our main focus will be establishing the world's first international A-T patient register.



## Plans for the future

The A-T Society's Board has identified a number of priority areas for the next three years. These include:

- Increasing our research spending 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.

However, the Board also recognises that to enable significant progress to be made in delivering these, we need an increased and secure income, we will therefore also focus on:

- Strengthening and increasing the diversity of our fundraising

### Research

Over the next few years we intend to build on the wide range of projects we have initiated and supported over recent years. We will continue to ensure that the principal focus of our work is on developing effective therapies and treatments for A-T and related conditions. In 2016 we will focus on:

- Establishing the world's first international A-T patient register. This will help provide much more detailed evidence on the course of A-T and the range of symptoms and effects it produces. As well as inspiring cooperation and new research, the registry will enable the production of a natural history of A-T.
- Supporting the setting up and running of the UK arm of the Erydex clinical trial. We will ensure effective engagement with families and assist with providing information and recruiting people to take part in the trial. We will also assist with

travel and accommodation for those attending the trial centre.

- Building on the interest in A-T research we generated in Cambridge, developing projects and partnerships to take forward the findings from the project we funded at Steve Jackson's lab in Cambridge and also exploiting the stem cells and genomic data from the Sanger Institute.
- Providing practical support to projects we are funding or assisting with at the universities of Nottingham and Birmingham.
- Supporting the establishment of a research project at the University of Dundee looking at diabetes in A-T and the response of people with A-T to treatments for diabetes.
- Organising the third in our Clinical Research Conference series in Warsaw in October 2016, using the A-T Clinical Research Network to create new research partnerships and collaborations and drive up standards of clinical care.



# Looking ahead

We will continue to work to ensure that people with A-T are receiving the best possible health care.



## Support people affected by A-T to live their lives to the full

As demand for the services of our Family Support team continues to grow, we will look to increase their capacity to provide the support needed. We will continue to work to ensure the new clinical guidance is implemented and that people with A-T are receiving the best possible health care.

We will build on the success of our family weekends, in providing information for people living with A-T and helping them engage with professionals, researchers and the charity. We will also continue to develop our support for adults with A-T, encouraging them to make their voices and views heard and by working with expert clinicians, we intend to publish clinical guidance on A-T in adults.

We will use our activity breaks, grants programme and communications to encourage people with A-T to participate in new physical and social activities. In the longer term we plan to establish a course on living well with A-T.

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

Our website is already one of the most detailed and authoritative sources of information on A-T in the world. In 2016 we will continue to refresh the design, review and update the web copy and address areas that are currently inadequately covered on our website.

A number of new information sheets, both for people living with A-T and for the professionals working with them, are planned for 2016 including, in particular, more extensive information on cancer in A-T.

We will publish and promote two films featuring the achievements and views of adults living with A-T. We will also make more use of videos

on our website and social media platforms, for information and promotional purposes and also to report on conferences.

We will do more to show the range and impact of our work and increase the reach of our communications, both through existing channels and new ones. We will promote our publications more actively both in the UK and abroad and increase the range of available subjects.

## Increasing our income

We aim to strengthen our fundraising in those areas that are underperforming, focusing on events in particular. We also intend to increase our corporate and major-gift fundraising and continue building the level of our engagement with the local community around the A-T Society's offices. For the longer-term, we will seek to increase our 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 2015.

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.

## 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.

## Financial review

During the year the A-T Society received income of £291,473 (2014: £361,402) and spent £341,423 (2014: £371,669).

The Society therefore had an overall deficit for the year of £49,950 (2014: £10,267). With funds brought forward from previous years, the Society will carry forward £103,286 in reserves (2014: £153,236).

Unrestricted general funds carried forward have been reduced to £59,187 (2014: £111,825). The Society also carries forward restricted funds of £44,099 (2014: £41,411).

Of the Society's total income some 30% (2014: 25%) was donated by grant-giving trusts, 19% (2014: 15%) by individuals or corporate matched funding and 27% (2014: 31%) by the fundraising activities of our supporters (i.e. individuals provided some 46% (2014: 46%) of the Society's total income). The remaining 24% (2014: 29%) came from some small amounts of interest income and trading receipts and also from the NCG contribution towards the Nottingham Clinic.

## 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 2015 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 2016 and the following years are built around a number of priority areas. These include:

- Strengthening and increasing the diversity of our fundraising
- 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

More information about these priorities can be found in the Plans for the future section on pages 18 and 19 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.



# Trustees' report

## Structure

As set out above, 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. 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.

## The Board

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 10 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 2015 are listed on page 34.

## 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. Learning and personal development are central to the appraisal process.

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.

## 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.

## 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 2015 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 2015 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, Registered 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 13 June 2016 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

We have audited the financial statements of The Ataxia-Telangiectasia Society Limited for the year ended 31 December 2015 which comprise the statement of financial activities, the balance sheet and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and the Financial Reporting Standard for Smaller Entities (effective January 2015) (United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities).

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.

## Respective responsibilities of trustees and auditors

As explained more fully in the Statement of Trustees' Responsibilities, 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.

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 charitable company'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 Report of the Trustees 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 charitable company's affairs as at 31 December 2015 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 applicable to Smaller Entities; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

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

In our opinion 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.

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

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 prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemption from the requirement to prepare a Strategic Report or in preparing the Report of the Trustees.

**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

14 June 2016



# Statement of financial activities

Year ended 31 December 2015

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.15 £	Total funds 31.12.14 £
<b>Income and endowments from</b>					
Donations and legacies	2	144,295	134,465	<b>278,760</b>	347,651
<b>Charitable activities</b>	5				
Welfare	-	-	9,350	<b>9,350</b>	6,583
Other trading activities	3	3,190	-	<b>3,190</b>	6,593
Investment income	4	173	-	<b>173</b>	575
<b>Total</b>		<b>147,658</b>	<b>143,815</b>	<b>291,473</b>	<b>361,402</b>
<b>Expenditure on</b>					
Raising funds	6	72,198	-	<b>72,198</b>	71,493
<b>Charitable activities</b>	7				
Research		30,136	36,649	<b>66,785</b>	85,074
Clinic		12,059	37,890	<b>49,949</b>	49,124
Welfare		32,795	49,973	<b>82,768</b>	110,507
Information		30,402	1,800	<b>32,202</b>	39,589
Education		-	14,815	<b>14,815</b>	-
Governance		22,706	-	<b>22,706</b>	15,882
<b>Total</b>		<b>200,296</b>	<b>141,127</b>	<b>341,423</b>	<b>371,669</b>
<b>Net income/(expenditure)</b>		(52,638)	2,688	<b>(49,950)</b>	(10,267)
<b>Reconciliation of funds</b>					
<b>Total funds brought forward</b>		111,825	41,411	<b>153,236</b>	163,503
<b>Total funds carried forward</b>		<b>59,187</b>	<b>44,099</b>	<b>103,286</b>	<b>153,236</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.

# Balance sheet

Year ended 31 December 2015

	Notes	Unrestricted funds £	Restricted funds £	Total funds 31.12.15 £	Total funds 31.12.14 £
<b>Fixed assets</b>					
Tangible assets	13	1,632	-	<b>1,632</b>	-
<b>Current assets</b>					
Debtors	14	7,024	-	<b>7,024</b>	17,366
Cash at bank		59,753	44,099	<b>103,852</b>	160,120
		66,777	44,099	<b>110,876</b>	177,486
<b>Creditors:</b> amounts falling due within one year	15	(9,222)	-	<b>(9,222)</b>	(24,250)
<b>Net current assets</b>		57,555	44,099	<b>101,654</b>	153,236
<b>Total assets less current liabilities</b>		59,187	44,099	<b>103,286</b>	153,236
<b>Net assets</b>		<b>59,187</b>	<b>44,099</b>	<b>103,286</b>	<b>153,236</b>
<b>Funds</b>					
	16				
Unrestricted funds				<b>59,187</b>	111,825
Restricted funds				<b>44,099</b>	41,411
<b>Total funds</b>				<b>103,286</b>	<b>153,236</b>

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 and with the Financial Reporting Standard for Smaller Entities (effective January 2015).

The financial statements were approved by the Board of Trustees on 13th June 2016 and were signed on its behalf by:

.....  
Andrew Mills Treasurer-Trustee

The notes form part of these financial statements.

# Notes to the financial statements

Year ended 31 December 2015

## 1. Accounting policies

### Basis of preparing the financial statements

The financial statements of the charitable company have been prepared in accordance with the Charities SORP (FRSSE) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities (the FRSSE) (effective 1 January 2015)', the Financial Reporting Standard for Smaller Entities (effective January 2015), 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 not 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 2015

## 2. Donations and legacies

	31.12.15 £	31.12.14 £
Donations	142,830	143,751
Grants from NCG	37,790	37,790
Fundraising activities	79,527	112,011
Income tax refund	18,613	54,099
	278,760	347,651

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

	31.12.15 £	31.12.14 £
Other grants	37,790	37,790

## 3. Other trading activities

	31.12.15 £	31.12.14 £
Sale of merchandise	3,190	6,593

## 4. Investment income

	31.12.15 £	31.12.14 £
Deposit account interest	173	575

## 5. Income from charitable activities

	Activity	31.12.15 £	31.12.14 £
Family meetings and conferences etc	Welfare	9,350	6,583

# Notes to the financial statements

Year ended 31 December 2015

## 6. Raising funds

	31.12.15 £	31.12.14 £
Staff costs	43,009	30,542
Information, literature, publicity etc.	3,560	26,163
Merchandise	6,187	-
Other direct costs	2,061	-
Support costs allocated to activities	17,381	14,788
	<b>72,198</b>	<b>71,493</b>

## 7. Charitable activities costs

	Direct costs	Support costs (see note 8)	Total
	£	£	£
Research	66,785	-	66,785
Clinic	49,949	-	49,949
Welfare	82,768	-	82,768
Information	32,202	-	32,202
Education	14,815	-	14,815
Governance	-	22,706	22,706
	<b>246,519</b>	<b>22,706</b>	<b>269,225</b>

### Analysis of direct costs:

	Research £	Clinic £	Welfare £	Information £	Education £	Total £
<b>Costs directly allocated to activities</b>						
Staff costs	20,900	20,472	30,637	24,780	8,923	105,712
Support events	-	-	27,454	-	-	27,454
Newsletter	-	-	945	945	-	1,890
Welfare, equipment, respite etc.	-	-	15,871	-	-	15,871
Research fees and conference	43,080	-	-	-	-	43,080
Clinic costs	-	24,311	-	-	-	24,311
Information, literature, publicity etc.	-	-	-	3,913	-	3,913
Other direct costs	-	198	259	-	122	579
<b>Support costs allocated to activities</b>	2,805	4,968	7,602	2,564	5,770	23,709
	<b>66,785</b>	<b>49,949</b>	<b>82,768</b>	<b>32,202</b>	<b>14,815</b>	<b>246,519</b>

# Notes to the financial statements

Year ended 31 December 2015

## 8. Support costs

	Governance costs £
Governance	22,706

Support costs, included in the above, are as follows:

### Governance costs

	31.12.15 £	31.12.14 £
Auditors' remuneration	3,000	3,000
Staff costs	11,811	6,474
Other direct costs	4,952	4,147
Support costs allocated to activities	2,943	2,261
<b>Total</b>	<b>22,706</b>	<b>15,822</b>

## 9. Net income/(expenditure)

Net income/(expenditure) is stated after charging/(crediting):

	31.12.15 £	31.12.14 £
Auditors' remuneration	3,000	3,000
Depreciation - owned assets	544	-

## 10. Trustees' remuneration and benefits

No member of the Board of Trustees received any remuneration during the year (2014: £Nil).

### Trustees' expenses

Travel expenses amounting to £1,332 (2014: £1,980) were reimbursed to 5 (2014: 4) trustees.



# Notes to the financial statements

Year ended 31 December 2015

## 11. Staff costs

	31.12.15 £	31.12.14 £
Salaries	141,914	113,445
Social security costs	11,464	10,389
Pension provision	7,154	5,663
	160,532	129,497

No employees had emoluments in excess of £60,000 (2014: 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 worker.

During the year, the Society also employed 4 part-time staff, equivalent to 2 full-time staff (2014: None).

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 £7,154 (2014: £5,663).

## 12. Comparatives for the statement of financial activities

	Unrestricted funds 2014 £	Restricted funds 2014 £	Total funds 2014 £
<b>Income and endowments from</b>			
Donations and legacies	212,371	135,280	347,651
<b>Charitable activities</b>			
Welfare	-	6,583	6,583
Other trading activities	6,593	-	6,593
Investment income	575	-	575
	219,539	141,863	361,402
<b>Expenditure on</b>			
Raising funds	71,493	-	71,493
<b>Charitable activities</b>			
Research	15,815	69,259	85,074
Clinic	11,334	37,790	49,124
Welfare	65,685	44,822	110,507
Information	39,589	-	39,589
Governance	15,882	-	15,882
	219,798	151,871	371,669
<b>Net income/(expenditure)</b>	(259)	(10,008)	(10,267)
<b>Transfers between funds</b>	(7,787)	7,787	-
<b>Net movement in funds</b>	(8,046)	(2,221)	(10,267)

# Notes to the financial statements

Year ended 31 December 2015

## 12. Comparatives for the statement of financial activities - continued

	Unrestricted funds 2014	Restricted funds 2014	Total funds 2014
	£	£	£
<b>Reconciliation of funds</b>			
Total funds brought forward	119,871	43,632	<b>163,503</b>
<b>Total funds carried forward</b>	<b>111,825</b>	<b>41,411</b>	<b>153,236</b>

## 13. Tangible fixed assets

	Equipment £	Furniture £	Total £
<b>Cost</b>			
At January 1 2015	13,058	1,883	<b>14,941</b>
Additions	2,176	-	<b>2,176</b>
<b>At December 31 2015</b>	<b>15,234</b>	<b>1,883</b>	<b>17,117</b>
<b>Depreciation</b>			
At January 1 2015	13,058	1,883	<b>14,941</b>
Charge for the year	544	-	<b>544</b>
<b>At December 31 2015</b>	<b>13,602</b>	<b>1,883</b>	<b>15,485</b>
<b>Net book value</b>			
<b>At December 31 2015</b>	<b>1,632</b>	<b>-</b>	<b>1,632</b>
<b>At December 31 2014</b>	<b>-</b>	<b>-</b>	<b>-</b>

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

	31.12.15 £	31.12.14 £
Other debtors and prepayments	<b>7,024</b>	17,366

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

	31.12.15 £	31.12.14 £
Other creditors and accruals	<b>9,222</b>	24,250

# Notes to the financial statements

Year ended 31 December 2015

## 16. Movement in funds

	At 1.1.15	Net movement in funds	At 31.12.15
	£	£	£
<b>Unrestricted funds</b>			
General fund	111,825	(52,638)	59,187
<b>Restricted funds</b>			
Research	13,020	(9,669)	3,351
Welfare, support, equipment	28,391	12,357	40,748
	<b>41,411</b>	<b>2,688</b>	<b>44,099</b>
<b>Total funds</b>	<b>153,236</b>	<b>(49,950)</b>	<b>103,286</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	147,658	(200,296)	(52,638)
<b>Restricted funds</b>			
Research	26,980	(36,649)	(9,669)
Clinic costs	37,890	(37,890)	-
Welfare, support, equipment	78,945	(66,588)	12,357
	<b>143,815</b>	<b>(141,127)</b>	<b>2,688</b>
<b>Total funds</b>	<b>291,473</b>	<b>(341,423)</b>	<b>(49,950)</b>

### Purpose of restricted funds

**Research** - the balance remaining represents the unexpired costs of a research project using magnetic resonance imaging to investigate the range and depth of neurological disability in A-T. The balance is being held pending the second stage of the research. Incoming resources represent amounts received in donations and fundraising restricted to research spending by the donor. These amounts have been spent in the year.

**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 equipment for young people below the age of 18 years, the support of education of young people, the funding of a family support coordinator plus a range of funds restricted to particular items of equipment and geographical areas. 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.



# Notes to the financial statements

Year ended 31 December 2015

## 17. 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.

## 18. Ultimate controlling party

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

# The team

The A-T Society is run by a handful of staff and volunteers backed up by a nationwide team of creative, dedicated and enthusiastic supporters.

In the course of 2015, the volunteers and staff consisted of:

## Directors/Trustees

Jill Burder  
Linda Clarke (from April 2015)  
Mike Detsiny (From June 2015) (Chairman)  
Lynda Finn  
Penny Jeggo  
Vivienne Levy (Resigned April 2015)  
Alexei Lioutyi  
Ian McInnes (Resigned June 2015)  
Andrew Mills (Treasurer)  
Rupert Prokofiev (From November 2015)  
Hasita Senanayake  
Lian Yarlett (Chairman until June 2015)

## Staff

William Davis	Chief Executive
Kay Atkins	Family Support Officer
Suzanne Roynon	Fundraising and Relationship Manager
Eve Audis	Corporate Fundraiser (part-time from May)
Kate McEleney	Communications Officer (part-time from April)
Anne Murray	Family Support Coordinator (part-time from June)
Jo Reader	Fundraising Assistant (part-time from May)
Denise Ganley	Book-keeper (part-time)
Molly Owens	Fundraising Assistant (part-time to April)

## Patrons

The Lady Parkinson DL  
Mrs Joan Morecambe  
Dr Miriam Stoppard  
Ms Susannah Harker  
Lord Bilimoria  
Mr Brian Conley

## Scientific Advisory Board

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

## Volunteers

Volunteers make a huge contribution to almost every area of our work and without their commitment, skill and enthusiasm the A-T Society would not be here.

Our two regular office volunteers continue to offer invaluable support. Caryl Guest gives two days per week to help Kay and Anne with family support work while Jill Curl gives a day per week to help Suzanne with fundraising.

While we didn't recruit any interns in 2015, it was very pleasing to note that four of our interns from 2014 have used their experience with the A-T Society to get jobs in the voluntary sector.

Helen Hart MBE provides counselling support which is an invaluable benefit to many people struggling with the stresses of living with A-T. Helen works largely by telephone, but also holds regular sessions at our Family Weekend. Maureen Jenkins' regular visits to patients at Papworth are extremely valuable. Adrian Johnson is a versatile and committed volunteer, while other volunteers help out at the Family Day and other events.

On top of their formal responsibilities to oversee the A-T Society, each of our trustees makes specific contributions to particular areas of work. We have a really strong Board with a wide range of skills. In a small organisation like the A-T Society this is extremely valuable. Our trustees also help out at events and raise valuable funds for us.

We would love to thank by name each and every one of our many supporters and fundraisers across the UK, Ireland and beyond, however this is clearly impractical. Without them we could not operate. They continue to amaze and inspire us.

They have cycled, run, climbed, walked and swum, braved mountains, hills, fjords, wind, rain, sun; worn lycra, thermals, boots, jeans, ball-gowns; dressed as Elsa, bears, elves, small clowns; sold curries, sausage-rolls, Pimms, cakes, collected at birthdays, weddings, wakes; they've sung, swung, rock-climbed, danced with zest, planted flowers, trod catwalks, shaved heads and chests. Their invention and commitment leave us all breathless and we thank and honour them all.

And finally we owe a great debt to the doctors, therapists and researchers, in the UK and beyond, who do so much to help people affected by A-T and the A-T Society. We greatly appreciate them all but would especially mention:

- The skilled and dedicated teams in Nottingham, and at Papworth, doing all they can to help people living with A-T and to share their knowledge
- Professor Malcolm Taylor in Birmingham, whose contribution from analysing and researching A-T is, like his dedication to supporting people with AT, second to none.
- Professor Penny Jeggo, and her colleagues on the Scientific Advisory Board who are helping shape A-T research for the future
- Dr Cynthia Rothblum-Oviatt of the A-T Children's Project is always generous with her time and expertise
- The clinicians at the A-T centres in Baltimore, Rome, Tel Aviv, Frankfurt, Warsaw, Oslo, Nijmegen and Brisbane who together with their UK colleagues are doing so much to improve care of people with A-T

# Donors and supporters

## Thank you

**The Board and the A-T Society are extremely grateful to everyone who has contributed to our funds, however large or small their donation.**

While we would love to be able to thank everyone individually who has supported us in 2015, for reasons of space, we are unable to do so. Nevertheless, we would particularly like to mention the following:

### In memoriam or legacy donations

Gifts were given in memory of:

Anne Mitchell  
Anupam Dhirani  
Doreen Owens  
Enid Emily Gratton  
Faye Larkin  
Glen Henry  
Iris Ray  
Janet Harper  
Joan Holgate  
John Forster  
John Richard Owens  
Kate Akinola  
Maria Silver

### Corporate Donations

AIG  
Asda, Sutton in Ashfield  
Avenue Stores, Crewkerne  
Bargain Booze (Haslington)  
BCMY Recycling  
BLP  
Britvic Soft Drinks Ltd.  
Bupa, Tadworth Grove  
C & S (Chirk) Limited  
Easyfundraising Limited  
Easyjet Airline Company Ltd  
Erydel  
Everyclick Limited  
Furniture Store  
Gatsby & Miller  
Go Ahead London  
I D Integrated Security  
ICI Slough  
Insite Development Ltd  
JM Traders, Bala  
Legal and General Investment Management  
Lloyds Banking Group Northern Ireland  
LTI Metaltech  
Mobile World  
Pentagon Shopping Centre  
Pizza Hut UK & Ireland  
Premier Convenience Store, Oswestry

Premier Stores, Churchill Drive  
Rehau Limited  
Resonate-rse  
Sainsbury's, Stockport  
Southsea Post Office  
Steve Turzynski & Co.  
Tesco Express, Bridgnorth  
The Ultimate Solution Partnership  
W F Senate

### Trusts and foundations

A M Pilkington Charitable Trust  
Annie Tranmer Charitable Trust  
Bartle Family Charitable Trust  
Bellasis Trust  
Bruce Wake Charitable Trust  
D M Charitable Trust  
IBB Charitable Trust  
Jarvis (Harpenden) Charitable Trust  
Middlesex Sports Foundation  
Mrs Penelope Gluckstein Charity Trust  
Reuben Foundation  
Sovereign Health Care Charitable Trust  
St James's Place Foundation  
Stephen Clark 1957 Charitable Trust  
The Adrian Swire Charitable Trust  
The Albert Hunt Trust  
The Anna and Colin Frizzell Charitable Trust  
The Armourers' and Brasiers' Gauntlet Trust  
The Benham Charitable Settlement  
The Bothwell Charitable Trust  
The Camelia Trust  
The Catherine Cookson Charitable Trust  
The Clare Milne Trust  
The D'Oyly Carte Charitable Trust  
The Dr and Mrs A Darlington Charitable Trust  
The Felicity Wilde Charitable Trust  
The Fitton Trust  
The Girdlers' Company Charitable Trust  
The Grocers' Charity  
The Hugh Fraser Foundation  
The J Reginald Corah Foundation Fund  
The Jessie Spencer Trust  
The Keith Coombs Trust  
The Laspen Trust  
The Merchants' House of Glasgow  
The Metropolitan Masonic Charity  
The Michael and Anna Wix Charitable Trust  
The Multithon Trust  
The Murphy-Neumann Charity Company Ltd  
The Parivar Trust  
The Pennycress Trust  
The Prince of Wales's Charitable Foundation  
The Rank Foundation  
The Rest-Harrow Trust  
The Russell and Mary Foreman Charitable Trust  
The Shanly Foundation  
The Sir James Roll Charitable Trust

The Sobell Foundation  
The Souter Charitable Trust  
The Strangward Charitable Trust  
The Sylvia and Colin Shepherd Charitable Trust  
The Tom Hall Charitable Trust  
The Wakefield Trust  
The Walker Trust  
The Wilfred and Elsie Elkes Charity Fund

Plus other trusts which prefer to remain anonymous

### Individuals and organisations who raised over £500 in 2015

Berkeley Junior School  
Bromwich Family  
Ferguson Family  
Harpenden Round Table  
Hele's School  
Logistica Masonic Lodge No. 9804  
Lynn Family  
Mrs D Ganley  
Mr & Mrs J Garton  
Mr & Mrs Michael and Glenday Thomas  
Mr & Mrs Phil and Sara Metcalfe  
Mr & Mrs Richard and Nikki Hewison  
Mr & Mrs Tim and Annette Hughes  
Mr Bill Child  
Mr D Hills  
Mr Danny Ford  
Mr David Owens  
Mr Ged Simpkin  
Mr Graham Lawrence  
Mr J Camblin  
Mr Robin Hewison  
Mr Rupert Prokofiev  
Mrs Joan Arnold  
Mrs Charlie Horton  
Mrs Claire Arnold  
Mrs Katherine Sunderland  
Mrs Katherine Welton  
Mrs M Bassil  
Mrs Maureen Seal  
Mrs Sorrel Hodgson  
Ms Frances Prokofiev  
Ms Jo Saxton  
Ms Krystyn Andrews  
Ms Rachael McMichael  
Ms Tara Camm  
Penelrick Family  
Plymouth and West Devon Combination  
Football League  
Sewell and Kelly Family  
Stubbs Family  
Wells Family  
Yarlett Family

## Contact us

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JEANS FOR GENES DAY

