

A-T Society News

In this summer special....

- **Families gather in the East Midlands for the annual Family Weekend**
- **Ellie's quest to find accessible sports**
- **Latest news on A-T research**
- **Fantastic fundraising efforts**



Ataxia-telangiectasia is a rare, genetic, neurodegenerative disease. It starts in early childhood and affects many parts of the body causing severe disability.

The A-T Society was established in 1989 and is committed to helping, supporting and advising families affected by A-T. While they may face more challenges than many, people with A-T have lives to live, and the Society's aim is to ensure they have the support they need to live them to the full. We do this through funding research, providing information, practical support and financial assistance, working to improve clinical management and raising awareness.

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Editor's Comments

Many thanks to all contributors. The copy date for the next issue is 1st November 2015. Please send comments, ideas, articles and pictures to:

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Cover picture: Melik Dziri



Just William

William Davis, chief executive of the A-T Society, wonders how family members and carers can be involved in the consultations that young adults with A-T have with professionals.

I write this having only recently received the amazing injection of emotion and energy that always comes from attending our Family Weekend. Hearing about all the different ways that people have found to live their lives to the full despite the best efforts of A-T to restrict them is a source of inspiration. Equally, the difficulties and challenges that people are facing makes me more determined that the Society should do even more to help them.

One issue that came up in different ways was how and when family members and carers are involved in the consultations young adults with A-T have with professionals. At the open forum, a number of parents said that they felt that doctors or other professionals were sometimes unwilling to involve them as they and their child wished in discussing their care.

This is not a black and white issue. Like any adult, people with A-T who have reached the age of 18 are entitled and expected to make decisions for themselves about their care. It is also important that they feel able to live their lives as independently as possible – which means being able to manage their lives and the care they receive as they see fit.

However most people with A-T are very close to their families and value highly the care and support they receive from them. This often creates closer bonds to their families than is the case for other young people. While this is clearly positive, it can create its own problems. For instance many A-T parents find it very hard to 'let

go' of children they have cared so much for – and some don't manage to do this.

Having grown up with A-T, some people take much for granted and may not know (or care) much about the condition except for how it affects them. They may have little interest in drugs or treatments, choosing not to see themselves as 'patients', or choosing to focus on the here and now rather than looking into an uncertain future. They may lack confidence. Growing up with A-T offers little help in building self-confidence and assertiveness. Thus they may be more comfortable leaving medical details and decisions to others.

Often, there is no issue and if the person has said that they want their parent, friend or carer to be involved in discussions, professionals accept this with good grace and get on with it. However some have a rather more rigid and formal attitude, not wanting parents or others to be present. One mother told me her 16-years-old's school didn't tell her of a visit her son was to have with a health professional. Without her prompting, he didn't raise issues that needed addressing and an opportunity to resolve these was missed.

At the Family Weekend I promised that the Society would seek to help people navigate all this. My thoughts for now are that it shouldn't be difficult to establish some sort of simple 'partnership in care' agreement that people can set up to ensure that relatives or carers of their choice can be involved in their care – always with the proviso that they can



It is important that adults with A-T feel able to live their lives as independently as possible – which means being able to manage the care they receive as they see fit

have privacy around any or all matters at any time they should choose.

I will be contacting other organisations and professionals to seek their views. But I would be very glad to hear your views, whether as a person with A-T, a family member, carer or professional. Do ring or write to me at the office and let me know your views or experience of this.

See the next six pages for a full write up of the A-T Family Weekend.

Family weekend 2015

More than 45 families, as well as professionals and friends, joined us at East Midlands Airport in June for our annual family get together. It was an action-packed weekend with inspiring presentations, informative talks and plenty of entertainment for the children.

This year we were at the Raddison Blu hotel. It was a great venue for us, access-friendly and with very comfortable bedrooms. The windows into the bathroom, the vibrant wallpaper and all the colourful birds perched in the lampshades certainly provided talking points!

The weekend started with a barbeque on the Friday night which was a chance to welcome new families and for old friends to get reacquainted. The conversation flowed well into the night before everyone was finally in bed.

Saturday was a day of presentations for the adults, starting with a talk and discussion on nutrition and swallowing, followed by a very practical presentation on the importance of correct posture to allow the body to function properly.

There was a rich afternoon of research talks. Dr Rob Dineen told of the good progress they are making with the CATNAP imaging project. There were updates on the Erydel drug trial and the Cambridge synthetic viability project. Drs Ewan Pearson and Laura McCreight from Dundee told us about their planned research to understand the link between the ATM gene and diabetes. The afternoon



Lily having fun with balloons

concluded with an informative Q&A session with our panel of experts who imparted their knowledge and offered advice. (Visit www.atsociety.org.uk/news/86/family-weekend-qas for their responses.)

While this was going on, the children were making a successful trip to the Space Centre, with its interactive and informative displays. They got the chance to launch a rocket into space, discover how much a tin of beans would weigh on each planet and decide what they would pack to take to space with them. Most decided that they would pack treats like chocolate and presents and left no room for the essentials like oxygen. A highlight of the trip was the Planetarium, where everything was 3D and it felt like they were in space.

Saturday night's entertainment started early with Ged Simpkin bravely offering to have his hair and beard shaved off all in the name of charity, while the children enjoyed a visit from Father Christmas who stopped in on his way to his summer holiday. Once the excitement was over and Ged looked 20 years younger, it was time to relax and enjoy the banquet.

Between the courses we were entertained by a magician who visited each table and astounded us with a few magic tricks and there were squeals of delight as raffle prizes were claimed! The children moved next door to enjoy a disco and making balloon animals, and they felt like models when they had their photos professionally taken.

We were joined for dinner by one of our new corporate partners, Pizza Hut Delivery, who spoke about how



Kaid and Kira

excited they were to be supporting the A-T Society. The conversation and drink flowed well into the early hours of the morning and a good time was had by all.

Following a short AGM, our speakers on Sunday morning were some of our Adults with A-T who spoke of their lives, hobbies and achievements. They certainly drew in the crowds and the sound of laughter could be heard in the break out area. Thank you Tom, Becky and Helen for your inspiring talks and honesty – your words touched us all.

The children were given the chance to put their new-found space knowledge to the test with a creative workshop run by one of our parents, Jo James and her friend Fiona Bell. There was paint, glitter, glue and much creativity.

At the end of the morning it was sadly time to go home and catch up on some sleep! It really was a very enjoyable weekend. Everyone left with a smile on their face and some new friends.

The weekend in pictures....



Clockwise from top left: family banquet; Kayleigh Aris and family, much-needed coffee break; a close shave for Ged; the creative space-themed workshop; Emma Stewart presents at the conference

Clockwise from top left: families at the conference; the Yarlett and Carrington families; Chardanai and her family; the Ferguson and Aris families; Claire and her sister Jackie;



Clockwise from top left: a presentation on how A-T affects eating and drinking; stargazing at the Space Centre; Joe, Rupert and friends show us their jazz hands; Father Christmas pays the children an early visit!



Spotlight on families

We caught up with a few of our families and asked them to tell us a bit about themselves and how they found the Family Weekend.

Amandeep Sharma

Why did you come to the A-T Family Weekend? To meet the other families and hear from the professionals.

Best thing about the weekend? The kids were entertained. I especially enjoyed the Sunday talks from young adults with A-T.

What makes you laugh? A bad joke.

Favourite pop star? Pharrell.

Favourite TV show? Match of the day.

One interesting thing from the weekend? Tips on portable wheelchairs.

What do you enjoy doing? Playing sport

What's your worst lesson at school? Religious Studies because it was boring.

Favourite food? Curry.



The Sharma Family

Favourite treat? Relaxing in the bath

What are you looking forward to? Summer holiday.

Rupert**Age:** 30 years**Why did you come to the A-T Family Weekend?** To meet up with old friends.**What was the best thing about the weekend?** The Sunday talks from young adults with A-T.**Favourite pop star/band**
David Bowie**What's your favourite TV Show?** Dr Who.**One interesting thing from the weekend?** I learnt to like saunas – after a previous experience I thought I didn't! I also learnt you can have a Peg [feeding tube] fitted in any place you want.**What do you enjoy doing?**
Going to the BFI and getting out generally.**What was your worst lesson at school?** History as I didn't like remembering dates.**Favourite treat?** Time to myself.**Who is your superhero?**
Beatrice my twin sister because we get on really well and our relationship changes all the time but it's all good.**Did you make new friends at the weekend?** Yes and it was nice to see old ones too!

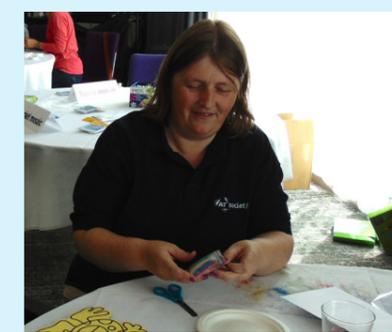
Rupert with his superhero sister Bea. She later told us Rupert is her superhero too!

Becky Simpkin**Age:** 23**Why did you come to the A-T Family Weekend?** I love to meet other families like ours**What makes you laugh?**
My cousins**Favourite pop star/band** Pink.**What's your favourite TV****show?** Soaps!**What do you enjoy doing?**

Horse riding, swimming, drinking, going to the cinema and night clubbing.

Favourite food? Pancakes.**Favourite treat?** Chocolate.**Graham High****Why did you come to the A-T Family Weekend?** Because it's always a good weekend and also we wanted to support our A-T affected family member and the charity. It's also great to link up with other families for mutual support.**What do you think of the hotel/your room?** Very good, particularly good facilities with a good pool and sauna, great food and friendly staff. The weekend really made a good break for us.**What was the best thing about the weekend?** The BBQ on the first night and a good mix between care-orientated presentations and research projects. Incidental events were also good like the magician and the charity head shave.**One interesting thing you learnt from the weekend?** The swallowing video really helped us understand what aspirate means. Also the way the OT and physio introduced posture and its implications was really interesting as it meant that we all thought about ourselves in relation to posture – it was inclusive.

Graham with his wife Frances

What's your favourite TV Show? Slings and Arrow (Canadian TV Comedy), Borgen, Nordic Noir and Frasier.**What do you enjoy doing?**
Walking, drawing, reading, gardening and going to exhibitions.**What's your worst lesson at school?** Latin – the Latin master wrote my negative reports in Latin so I told my parents it meant 'excellent'!**Favourite treat?** Being by the sea in our beach hut.**Who is your superhero?**
David Attenborough – such a campaigner for the natural world.**Hussain family****Why did you come to the A-T Family Weekend?** Our children enjoy the day out whilst we get the chance to be updated in detail on the latest research developments and healthcare advice.**What's the best thing about the weekend?** A day out for the children and dining with other parents like us.**What makes you laugh?**
Good company**Favourite pop star/band**
One Direction**Favourite TV show?** Friends**Favourite treat?** Five minutes peace and quiet with a cup of tea.**What are you looking forward to?** Starting to work from home.**Jo (pictured) and Fiona****Why did you come to the A-T Family Weekend?** As part of the James family party.**What do you think of the hotel/your room?** Lovely. But windows in the bathroom – bizarre!**What was the best thing about the weekend?** We loved the whole thing.**What makes you laugh?**
My daughter.**Can you pronounce Ataxia-Telangiectasia?**
Yes!**Clare Gallagher****Why did you come to the A-T Family Weekend?** For a break, to meet parents who understand and to find out about the latest research.**What was the best thing about the weekend?** Meeting up with other parents.**What makes you laugh?**
My dogs**What's your favourite TV Show?** Anzac Girls**What do you enjoy doing?**

Walking the dogs, and helping people find new jobs or courses as part of my job.

What's your worst lesson at school? Maths – horrible teachers and PE too for the same reason.**Favourite food?** Curry/Chinese depending on my mood.**Favourite treat?** Very dark 85% chocolate and a cup of coffee.**Who is your superhero?** My dad – he made me the person I am now.**Jenni Gallagher****Age:** 11 years**Why did you come to the A-T Family Weekend?** I love comfy beds and nice hotels.**What did you enjoy about the space centre?** The shop!**What was the best thing about the weekend?** My hotel room and the food.**What makes you laugh?**
My dogs.**Favourite pop star/band**
Katy Perry.**Favourite TV Show?**
My Little Pony.**What do you enjoy doing?**
Going to the cinema and watching TV.**What's your worst lesson****at school?** English and Humanities because I have to do a lot of writing on my iPad/computer.**Favourite treat?** Going on Holiday and to Pizza Hut.**What are you looking forward to?** The end of term.**Who is your superhero?**
Caitlin my big sister and Foxie my little dog.

Changes to the Board

There have been a number of changes to the Board since the last A-T Society News came out. Three trustees have stepped down, and three others have joined the Board.

Farewell

Back in January, the responsibilities of a new and more time-consuming job combined with those of looking after a young family meant that **Laura Rafferty** felt she could not give the necessary time to being treasurer. Laura joined the Society at a time of transition and as treasurer oversaw the introduction of new accounting and budgeting systems. She leaves the Society in a strong financial position with robust procedures in place.

Viv Levy, who leaves us in July, brought a wide range of skills, an invaluable knowledge of medical research and very useful contacts within the pharmaceutical industry. In addition to her commitment to research, we will miss her analytical skills and ability to focus on the heart of an issue.

Travelling down from Scotland for Board meetings, in spite of his A-T, was just one indication of **Ian McInnes'** (pictured) commitment to the Society. We will miss his insights into the reality of living with A-T, his broad understanding of disability matters and his ability to see things from a very different perspective, not to mention his warmth and good humour.



We are very grateful to all three for all that they have done for the Society and for people living with

A-T, and wish them all the very best for the future.

Welcome!

While we are sad to be losing Laura, Viv and Ian, we are delighted to welcome three new faces to the Board:

Andrew Mills has taken over as treasurer. A trained accountant, Andrew now runs a financial research company and is an expert on the UK financial sector. He has previous experience of working with a charity, having been for some years treasurer of an international development charity as it went through a period of rapid growth.

Linda Clarke has more than 25 years' experience working for charities – as volunteer, manager and trustee. For some 10 years, she was the director of a small national charity providing specialist services for disabled people, and she is currently trustee of an organisation providing housing and supported living for disabled adults and vulnerable people.

Mike Detsiny has had a long career in business, where he specialised in marketing and communications. He has had senior roles in a number of big companies, such as Cadbury and Allied Breweries, as well as setting up and running his own advertising company. Recently he, too, has had both voluntary and paid roles with charities, having been chief executive of a small charity for people with learning disabilities and chairing a branch of the MS Society.

A change of chair

At the AGM it was announced that Lian Yarlett is stepping down as chairman of the Society after five years in the role. Lian has been an incredibly dedicated and supportive chairman. She has led the Society through a period of transformation and growth. She has built up a board with a wide range of skills and has always been very supportive of staff and volunteers. Lian has done a great job and everyone involved with the Society owes her a debt of gratitude.

However the good news is firstly that Lian will be staying on the board as a trustee, and secondly that Mike Detsiny will be taking over as chair. With such a strong board and leadership, we can look ahead with confidence to a future of great achievements.



Mike will be replacing Lian as Chair

Sad news

We are very sad to say that Glen Henry from Wales passed away in May 2015. Our thoughts are with his family and friends at this very sad time.

New members of the team

Those of you who attended the Family Weekend this year, or who have called the office recently, may be aware that there are a number of new faces and voices in the office.

Recognising both the need for more help for Kay in her support and advocacy work and to raise more funds to increase our investment in research to find treatments for A-T, the Board agreed to recruit a number of new part-time posts.

We are delighted to welcome:

Family support coordinator

Anne Murray joins us as family support coordinator to work alongside Kay three days a week. Anne has a lot of experience in health and social care and will over time get involved in all the different areas of work that Kay is involved in.

Having Anne will mean that we are able to respond to requests

and enquires more quickly than has sometimes been possible in the past. We will also be able to support families in ensuring that their child is getting care that meets the clinical guidance and we hope to be expanding the range of written information we produce. Turn to page 14 to find out more about Anne and how she is finding her new role..

Corporate and major-donor fundraiser

To raise more funds so that we can expand our research work, we need to focus on the areas where we have most scope to increase our income.

Eve Audis has worked as a corporate fundraiser for major charities such as the NSPCC and British Heart Foundation. She has also worked on the 'other side' having been charity account manager for the Dixons group. Eve has hit the ground running, building up a strong relationship with Pizza Hut (see page 20 for more information).

Fundraising assistant

There's a lot of administrative work involved in fundraising and Jo Reader joins us to help ensure it is carried out quickly and efficiently. Jo is really over-qualified for the role, having been a systems manager for a number of large holiday companies, but we are hoping she will help us get even more organised and make better use of the database that we have.

Marketing assistant

Kate McEleney applied to be fundraising assistant but when we saw her background in marketing for major companies such as Argos, Tesco and T-Mobile, we knew we had to make use of her many skills in this area. Kate has already helped publish our annual report, has worked on this newsletter and will be working to help revamp our website.

Eve, Jo and Kate are each working 16 hours per week.



Here come the girls: Marketing assistant Kate; corporate and major-donor fundraiser Eve; and fundraising assistant Jo

Diabetes and metformin study

Prof Ewan Pearson and Dr Laura McCreight of the University of Dundee gave an interesting talk at the Family Weekend.

A-T and metformin

In 2011, Prof Ewan Pearson and his team of researchers at the University of Dundee were investigating how an individual's genetic code might affect their response to certain medical treatments. One treatment of particular interest to the team was metformin – an oral medication with glucose-lowering effects, which is widely prescribed as a first-line treatment for Type 2 Diabetes.

Whilst investigating metformin response, they found a surprising genetic link with a region of DNA that includes the Ataxia Telangiectasia Mutated (ATM) gene. This gene is important in the repair of DNA damage, and loss of its function is responsible for A-T.

A-T and insulin resistance

A-T had previously been linked to an increased risk of diabetes and resistance to the action of insulin in case reports from the 1970s. So, Prof Pearson teamed up with Dr Andrew Exley and Dr John Shneerson of the A-T specialist centre at Papworth Hospital to investigate this further.

Ten adults with A-T and ten adults

without A-T, who were similar in weight and age, were studied using oral glucose tolerance tests. The results confirm, for the first time, that adults with A-T do have an impaired ability to handle sugar and are resistant to the effects of insulin. This work, which was funded by the Anonymous Trust, Dundee, was shortlisted for the prestigious Nick Hales Young Investigator Award at the Diabetes UK conference in 2014.

Mice lacking ATM

Since then, a scientific paper has described the link between ATM deficiency and insulin resistance in mice. They demonstrated that mice lacking ATM tended to be insulin resistant, have higher levels of fat around their abdominal organs, and increased liver fat content. However, they had less peripheral fat. It also showed that treatment with metformin can improve the insulin sensitivity of these mice, and another drug used to treat diabetes – pioglitazone – can improve the fat distribution and insulin sensitivity. This mouse study highlighted potential mechanisms by which ATM causes “fatty liver” and insulin resistance, and warrants further investigation in humans.

Future research

The research team at the University of Dundee are in the process of setting up a new

study to assess insulin sensitivity and metformin response in A-T patients. Volunteers with A-T will need to be studied on three separate occasions, three months apart including at least one trip to Dundee. During these days, several different types of investigation will take place, including a “clamp” study (which involves lying on a hospital bed for eight hours with a cannula in each arm – one for insulin and glucose infusions, the other for blood sampling), an MRI, a fat biopsy, and blood samples.

They hope to recruit up to 20 individuals with A-T, over the age of 16. These individuals do not need to be diabetic to take part in the study. All travel and accommodation expenses would be covered by the research team.

They hope to start this research in February 2016, but are keen to hear from anyone who may be interested in taking part, or to answer any questions you may have regarding their work or A-T and Diabetes. Please get in touch via the A-T Society or with the research team directly by emailing:

- Dr Laura McCreight:
laura.mccreight@nhs.net
- Prof Ewan Pearson:
ewan.pearson@nhs.net

Synthetic viability

For the past two years, the Society has been funding a project at the Steve Jackson laboratory in Cambridge looking at the potential of synthetic viability to treat A-T. This approach is based on the finding that sometimes damage caused by the non-functioning of one gene can be prevented by switching off another gene.

The team, led by Josep Forment, is screening for genes that might have this effect on the ATM gene. To do this they take a collection of cells deficient in ATM and treat them in such a way as to ‘turn off’ one different other gene in each cell. They then expose the cells to an environment that would normally kill cells without ATM and see which, if any, survive. They then

take any that do survive and look to analyse which other gene has been mutated, and run further tests.

This may not sound complicated but it is at the very forefront of genetic research and the team is creating some of the techniques as it goes.

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However, they are making good progress. With one set of cells, derived from mice, they have carried out two screens, using the revolutionary new “CRISPR-Cas9” technology to create mutations. They have identified a number of cells of interest and they are now proceeding with DNA sequencing based studies to identify the mutations in these cells. They have also established conditions for another, complementary screening approach with “haploid”

ATM-deficient cells – that is cells with only one copy of each gene.

They have also carried out two initial screens using human cells, and have identified ATM-deficient cells that can survive in the presence of DNA damage. They have identified some candidate suppressor genes that they are now seeking to analyse.

They believe that they are well on track to establish, by late this year, whether their work has been successful in identifying genetic mechanisms to compensate for ATM deficiency.

Erydex trial

Work is continuing to set up the proposed clinical trial of Erydex, the steroid dexamethasone delivered by being infused into the patient's own blood cells. The safety studies required by the US drug regulation authorities have been carried out and the company that manufactures the machine is now waiting for permission to proceed with the trial.

Given the various steps that need to be gone through, it is unlikely that a trial will start until the beginning of 2016. The trial will be open to children over the age of six who are able to walk, even if they need support to do this.

In the meantime, good progress is being made with recruiting centres to the trial. Given the small number of people with A-T and the need to recruit 180 participants there will be quite a few centres spread around the globe. Site visits are currently being carried out at centres that will be participating.

The A-T Centre in Nottingham is one of the centres involved and the site visit took place there in April. Our chief executive William Davis was there with representatives of the hospital and



Mauro Magnani, chief scientific officer of Erydel

the company to discuss how the Society will support the trial.

At our Family Weekend, Dr William Whitehouse, the paediatric neurologist who will be leading the UK arm of the trial, held a consultation workshop with parents, which gave him some very useful feedback. The A-T Society is also looking to set up a children's consultative group for the trial, so if this is something that you or your child might be interested in, do please contact us.

Some positive news about the treatment is that a number of children have now been on it for over two years and appear to have no side effects. Not only that, but the improvement in their symptoms seems to be continuing over time.

Neurological symptoms of A-T

At the recent International Congress for Radiation Research in Kyoto, Japan, Prof Martin Lavin from Brisbane gave a very interesting talk, in which he described his latest work on a rat model for A-T.



Prof Martin Lavin

One major drawback to A-T research is that ATM-deficient mice do not show the neurological symptoms (e.g. ataxia) that are so important in A-T in humans.

The cells in the rats Martin has bred display radiosensitivity but more important the rats themselves shows ataxia, with hind leg paralysis and curvature of the spine. This may finally provide a model system for evaluating the basis underlying ataxia in A-T patients. If so, it marks a major step forward. It also provides a model for evaluating drug therapies and Martin described results of relevance in both these areas.

Although the rat cerebellum showed no obvious abnormalities, they showed a number of features suggesting an altered immune response and inflammation. As a step towards analysis of potential therapies, Martin treated the rats with betamethasone, an anti-inflammatory steroid, and observed increased survival of ATM-/- rats, and reduced inflammation.

This represents a potentially significant advance in our understanding of A-T, and also provides hope that some of the current strategies based on agents similar to betamethasone could yield beneficial outcomes.

We're fighting your corner

One of the most important areas of our work is advocacy, that is helping families get the support they need and are entitled to. We get involved in more than 40 advocacy cases each year, with some taking longer than others to resolve. Here are a few Kay has been working on recently.

Educational support

A family in the North of England recently contacted Kay as their young daughter is due to start school soon. Kay travelled to attend the meeting with the school to help with the transition. She was able to give an overview of A-T to the staff and answer questions. Kay is now in the process of liaising with the local authority to push for full-time 1-to-1 support for the child, as at present they are only offering 8 hours per week. This may lead to an appeal at the educational tribunal where Kay will represent the family if she is needed.

Adapting a home

A family in the Midlands had recently moved from privately rented accommodation to a housing association property. They were then visited by an occupational therapist from the local council to look at adapting the

house by applying for a 'disabled facilities grant'. This would provide their young daughter (who has A-T) with a downstairs bedroom and wet room as, at present, they have to carry her up and down the stairs. The council approved the grant, however the housing association then refused to adapt the property using legal loopholes. At this point the family contacted Kay for help. Kay is now making an appeal to the director of the council (who have a duty of care to the family) and asking the MP to intervene to get it resolved as quickly as possible.

Benefit applications

A mum in the west of England contacted Kay to ask for help with benefit applications. She has two adult sons living with A-T and had been asked to fill in some forms for a benefit review; however the Department of Work and Pensions then stopped all benefits. When

she called Kay she was distraught and didn't know what to do. Kay reassured her that it would get sorted and asked her to send in all the paperwork. Kay completed all the relevant forms of appeal, together with supporting letters about A-T. She also arranged for a letter to be sent from the A-T Clinic at Papworth to add weight to the application. After a month of waiting the family were relieved to hear that all benefits to both sons had been reinstated and that back-payments would be processed.

If you are having problems getting the support or services you need locally – whether it's care, education, housing, benefits or anything else – or if you are not sure what support is available to you, please contact us on 01582 760 733 or support@atosociety.org.uk

New family support coordinator

Anne Murray, who started as Family Support Coordinator at the end of May, is enjoying getting to grips with her new role. "I've felt welcomed by everyone I've met", she says, "and I am really excited about working to support people living with A-T."

Anne has always worked in health and social care. She most recently worked as an OT with a disabled children's team. She has also worked overseas, which she feels has given her valuable experience in working with people from different cultures and backgrounds.

Anne had not come across A-T before, but when she started to

research the condition, she was moved by the stories of people living with A-T and impressed by what she could see of the Society and its work on the web. She is keen to get involved with advocacy and support work and is looking forward to being able to work outside the constraints of the state sector, where she feels things can sometimes get bogged down with bureaucracy and red tape.

Anne was able to come along to the Family Weekend for a few hours. "What struck me was how many inspirational people I met," she says. "Despite living with such a devastating condition, people were

so positive. Many of them had a real spark in their eyes."

Anne has attended a Nottingham clinic and is starting to work on her first cases. "I've still got lots to learn about A-T and living with it, but working with the A-T Society provides the chance to build more long-term relationships with people and learn directly from them. It feels a real privilege to be doing this.

Anne will work alongside Kay for three days a week.



My remarkable family

By Lynda Warren

I always enjoy reading the A-T Society Newsletter and so I wanted to share my story about my sister Sylvia, brother in law Trav and my nephews Travis and Dale. It's a story of inspiration, challenges, positivity and highs and lows.

Both of my nephews have spent their whole lives coping with A-T. In the early 60s very little was known about A-T. The family went from one specialist to another trying to get a diagnosis and never giving up hope that someone would identify what was wrong with them. There were several diagnoses over the years ranging from Cerebral Palsy to Friedreich's Ataxia.

The family moved to America hoping that the medical teams over there would be able to offer them a cure. They sought advice at the Doman Delicardo Institute in Philadelphia and my nephews spent a year having intensive exercises to retrain the brain which

unfortunately did little to improve their condition.

By their early teens both Travis and Dale needed to use wheelchairs and they decided to move back to England to be near family. It was only then, 16 years on, that they were finally diagnosed with A-T, after their consultant recognised their symptoms and organised the definitive A-T blood test.

Despite the challenges of living with A-T, Travis and Dale have always lived their lives to the full. Sylvia has never said 'No' to any of their requests, instead saying 'Ok, how can we make this happen?'

Dale is the adrenaline junky – taking on abseiling, parachuting, adventure holidays and raising money for A-T along the way. Now in his early 50s Dale is still active in the community and an avid letter-writer for disabled rights.

Similarly, being disabled wasn't going to stop Travis from enjoying



Travis and Dale

his life and his passion for music, rock festivals, disco wheelchair dancing, partying all night and generally having a great time. In his 50s now, he enjoys a slightly slower pace of life, visiting the cinema and listening to talking books – but he is still always up for a good time.

They all still live together as Sylvia and Trav are their sole carers. Their house is always full of laughter, warmth and happiness. Travis and Dale would not have had such remarkable lives without such loving, motivated parents. I find my family to be such an inspiration and I am proud to be part of their lives.

Information available

We have a wide range of publications available that you can download from our website www.atosociety.org.uk/publications or contact us and we can post out printed copies to you. These will help you explain A-T to friends, schools and healthcare professionals.

About A-T

A small leaflet with a brief introduction to A-T and the work of the Society. It also encourages people to make a donation to support our work.

About A-T in Adults

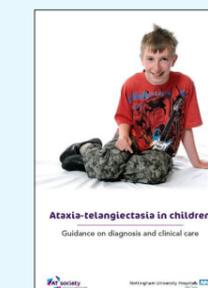
The same leaflet as About A-T but adapted to make it more suitable for use by adults with A-T.

Living with A-T

A new booklet that explains in more detail the symptoms of A-T and talks about how it can affect people's lives. It is aimed at people who are coming across A-T for the first time and want to understand how it affects people.

Guidance on diagnosis and clinical care for A-T patients

This document is primarily aimed at doctors and health professionals and sets out the recommendations of the experts at the A-T Specialist Centre in Nottingham on how children with A-T should be monitored and treated. It is essential reading for families who want to make sure their children are getting the best possible treatment.



My juggling act and quest to find handcycle hire

By Eleanor Hewitt

I'm going to tell you about the balancing act between life and OU study. As you will know from previous issues of this magazine, I am an Open University student. I passed my Psychology module with a Grade 3 Pass. This entailed no exam and, as exams are not my strong point, I was pretty confident that I had passed.

However, for this year's module I chose Human Biology. I knew that this course was assessed by exam but I was so interested in the subject areas that I completed the course with great enthusiasm – though not without trials and tribulations.

Early in the year I was put behind due to circumstances beyond my control. This occurred just before my first assignment was due. Despite all my life circumstances and the worry that I wouldn't achieve this first assignment, I passed with 73%. WOW! I was so pleased.

But there was one small problem: as I had been granted an extension, I would constantly be behind with my reading and therefore need extensions on other assignments. Not a good way to start a course, I thought to myself.

However, my interest in the subject drove my determination to complete the other two assignments, which I did gaining 78% in each. I also managed to catch up with the reading about half way through the course – at the cost of nearly burning myself out (not good!)

When the final examination came I struggled to keep focused on revision as by that time I was attending various gym and fitness classes and had found a new passion for handcycling. There just



Ellie has discovered a passion for handcycling

weren't enough days in the week to get everything done! However, by the time it came to sit the exam I felt quietly confident.

The OU allowed me to sit the exam in my own home, making use of my PC and assistive software. This was combined with extra time, an amanuensis and rest breaks. Diligently, I worked my way through the paper and by the end I was typing so frantically that my fingers didn't know what had hit them. At the conclusion I finished all associated exam admin and sent it back to the university. Phew! I can now put my heart and soul into my diet and exercise regime until I get the results and decide what to study next!

The challenge of finding accessible sport

I researched recumbent trikes a few years ago and found that groups have been set up for disabled children with not only physical impairments but learning/social disabilities too. I for one do not like being pigeon-holed or grouped with an inappropriate age group

but I suppose everyone in the A-T community is a 'one off' and we can't expect all organisations to understand individual needs. We are a minority group so I have just decided I need to do my own thing where sports are involved!

My passion for handcycling has led me to find alternative ways to become involved in the cycling scene. On my hunt for accessible cycling opportunities I came across a national charity 'Wheels for All' (WFA) www.cycling.org.uk/wfa/ who run sessions nationwide for all ages.

I went to one of their sessions in Bristol but it was very much aimed at children and was set in an adventure playground – you were limited in the space you could ride in. However I then tried a WFA session in Bath, which involved cycling on a circuit that was a mile in length. I found this excellent.

I attend classes at my local MS Therapy Centre www.msntc.org.uk/centresearch, which is open to all types of medical conditions, not just MS. I obtained useful information from my 'Everyone Active' (independent fitness initiative) gym www.everyoneactive.com who provide gyms nationwide that have accessible machinery.

I was also signposted to www.wheelpower.org.uk. This is a very informative website that enables you to enter various parameters and suggests locations to play your ideal accessible sport. Check local councils too! There is also sailing if you fancy that. Sailability: www.sailability.org.

Personally I prefer my feet on terra firma, and with my new found interest for hand-cycling, watch out for me – I could be cycling up and down the country before long!

My life living with A-T

By Becky Simpkin

My name is Rebecca but I like to be called Becky. I am 23 years old and have A-T. I live with my mum, dad, brother Sam and our two dogs. I used to be able to walk and run but as I have got older I can't do the things that I used to be able to do. I'm now in a wheelchair so getting around can be more challenging. However, I don't let it stop me from having a busy social life.

I love going shopping but I'm trying to stop as my wardrobe is rather full. I'm a real magpie and love bargains, hats and all things glittery and shiny.

My week is rather busy and mum and dad provide a good taxi service to get me to all of my social events. On Tuesdays I go swimming, on Wednesdays I go to the gym or if I'm not at the gym then I'm horse riding. I go to the

cinema on Friday nights and I also go nightclubbing or out to the pub with my friends. I love catching up with my friends and we have great fun. I enjoy my music and I'd love to run a nightclub one day but just need some help to do so. If there's any budding entrepreneurs out there that would be interested then let me know!

I find having A-T frustrating at times. I find feeding myself food like roast dinners and soup difficult. I can do buffets and snacks like chocolate but even they are now getting more difficult for me to manage unaided. Luckily I have great friends so they help me and hold my drinks for me so that I can still enjoy having a night out.

(Pictured, right: Becky horseriding and at the pub with friends)



My hobby: horse riding

By Rachel Ferguson

I started riding when I was about 10 years old and have been riding ever since. I ride partly to strengthen my core and legs and to help my balance but mainly I because I love it and it's fun. When I'm riding it's like the horse is my legs and I'm in total control of them and it's great to have the freedom to roam and explore.

Since I started riding I have discovered dressage which is like dancing on horseback. You teach the horse to perform a variety of tricks and create a routine which you perform in the ring. My horse Daisy and I have been perfecting our dressage routines.



Rachel on horseback; and with her Rosette

In my first dressage competition I was awarded first place and won my first ever rosette. It was an amazing feeling.

I am now keen to learn more routines and I plan to keep competing and teaching Daisy new tricks.

My Life as a volunteer for Stray Aid

By Helen Carter

My name is Helen, I'm 22 years old and have A-T. For the past four years I've worked as a volunteer in a charity shop called Stray Aid. Stray Aid raises money to support a local cats and dogs home. I love animals and love my job and am very glad to have been given the opportunity to volunteer two to three days a week at the shop.

At 17 I left college and I started my search for a job just after my 18th birthday. My mum and my carer, Joanne, thought that volunteer work might be a suitable fit for me as it offers flexible working hours. I was initially offered a 12-week course by Connexions who trained me in first aid, health and safety and

food hygiene and gave me a few new skills. After approaching a few charity shops and not having any luck, I was getting a bit disheartened but luckily I met Bernice and she offered me a volunteering role at the Stray Aid Shop.

My job has given me so much. I have more confidence when meeting people, I feel like I have a purpose and a reason to leave the house and I really enjoy my job. We have regular customers who visit with their dogs and drop them off whilst they shop in the co-op next door and over the years I have made lots of new friends. I've also bought lots of clothes, jewellery and bags for myself from the shop, so much so that my wardrobe is now overflowing!



So my advice to other people in a similar situation to me is to give volunteering a go and persevere until you find something that will work for you. It will make a difference not only to your life but also to the life of others.

Lola's adventures

Lola gives a helping hand

It was all hands on deck at Lola's granddad's farm during lambing season. Lola and her cousins helped to look after twin lambs born that day. She loved giving them cuddles and really enjoyed her day helping out.



Lola the bridesmaid

It was a day of celebration last August as Lola was bridesmaid at her Dad's wedding. She's pictured here in her lovely bridesmaids dress with her brother, Alfie, looking gorgeous and happy.



Do you have a story you'd like to share? Send it to the editor at atsocietynews@gmail.com and see it printed in the next newsletter!

Motivating people to fundraise for the A-T Society

Elliot found out about the Society at A measure of Scotch last autumn (see page 21) and came to do a week of work experience with us in May. We asked him to write something to inspire people of his age to get involved in fundraising. Here is part of what he wrote.

By Elliot Brinkworth

My name is Elliot and I am 15 years old. I have spent a week at the A-T Society on work experience. Being here I have started to understand the hard life children and young adults who have the condition have to struggle with in their everyday lives. The A-T Society works to make the public more aware of what these people are dealing with, in the hope of raising awareness about A-T.

A-T affects about 200 people in the UK. Although that doesn't sound like a lot, I'd like you to think about all of your family or people you live with and all of your friends from school and clubs. That's a vast number of people who would also be affected if you were diagnosed with A-T. Many people are heartbroken when they lose a loved one, so it affects more than just 200.

When a child is diagnosed, what they need most is three things: support, love and care. But rather than focusing on all of the stuff that they might not get to do in their lives, think of the diagnosis more as an excuse for them to get on with their hopes and dreams. It's important to try and make anything that they have ever wanted to do in their life possible.

There are some really easy ways to fundraise for the A-T Society: you could run a cake sale at school or work, you could be sponsored to do an event like climbing a mountain or running a certain distance, or you could do the old-fashioned cleaning your neighbour's car. Anything that you can think of to raise money and make others aware of A-T is perfect. If you cleaned five cars charging £5 each and sold 20 cakes for £1 each, then you have already made £45, and if a class of 30 were to do that, then they would immediately raise £1,350.

Now I'm not writing this to tell you to go home and wash half the cars on your street or spend your evening baking cakes, but for you to know a little more about the A-T Society and the amazing, life-changing work that they do. They are already a step closer to finding a cure for this horrible condition. Money raised goes towards care, research and welfare support. Anything that you manage to raise will make these children's lives better.

If you don't want to spend your time cleaning cars or running marathons, then there are two much simpler, more direct ways to help the A-T Society. You can be very straightforward and donate



money by either calling the charity or doing it via the website. Or you can buy one of the branded merchandise for reasonable prices, and come away with a new hoodie, a new t-shirt in a variety of colours, a new cycling or running jersey, a new mug or a bag, a new water bottle, an A-T Society tie or something else from the wide variety of different products.

Believe me, your fundraising is so important to this wonderful charity. It changes these children's lives for the better and they could not thank you enough. But it's still not enough. I won't dictate to you what is required because it's always better for you to do whatever you can manage. If you can raise just £1 then that's amazing but obviously the more you can the better.

Thank you for taking this time to read this article and thinking of these children, and thinking of the A-T Society, because none of this would be possible without you.

Dates for your diary	
2015	2 August Ride London
	18 September Jeans for Genes Day
	25 September Ataxia Awareness Day
	6/7/8 November Weekend Adult Activity Break, Milton Keynes
2016	17 April Brighton Marathon

Corporate fundraising

The tusp charity golf day

One of our corporate supporters, tusp, held a golf day in July for clients and contractors who work with them. The day was co-hosted with Civil Rail Solutions (CRS), who are a partner organisation of tusp's, and they both agreed that they would like to fundraise for the A-T Society at this event.



one day with extra funds in the donation pots that are still to be counted!

A spokesperson for tusp said, "We are very happy to have raised so much for the A-T Society and we really hope it helps as many families affected by the condition as possible."

The A-T Society is a charity close to the heart of a member of staff at tusp, whose friend has a young daughter with A-T. With the help of our corporate fundraiser Eve Audis, tusp were supplied with banners, balloons, donation pots and information cards to promote the charity and to inspire as many donations as possible.

tusp and CRS raised £730 in just

Company support

By Eve Audis

As the new corporate fundraiser at the A-T Society, I will be focusing on finding new companies to support us. If you or any of your family or friends work for a company, big or small, can you find out if your company would fundraise for us or has a Charity of the Year that we could be nominated for?

Many companies choose a charity each year to support for 12 months or longer which could generate awareness and money for A-T research and family support.

I'm happy to provide you with fundraising ideas and to contact your company with information, but I know from experience that it is always best if the first ask is made by employees! With this in mind,



please also ask your friends if they too could nominate us for Charity of the Year where they work.

Please get in touch with me on 01582 760 733 or at eve@atsociety.org.uk if you would like further advice.

Pizza Hut Delivery adopts us as their local charity

We are thrilled to have Pizza Hut Delivery as one of our new charity partners. The team at Pizza Hut Delivery were very moved by the stories we presented to them and were inspired by the sheer determination of the children and families to live as normal a life as possible despite the challenges A-T brings. They were equally impressed by how much we have managed to achieve as a small charity with only three full-time members of staff.

The company's staff are keen to support us by offering their time and commercial expertise, as well as their energy to fundraise for the A-T Society. We are very much looking forward to working in partnership with them to raise funds, awareness and engage with their customers to encourage them to support us. We have a number of great fundraising activities already planned through the year and look forward to getting our message out to a wider audience.

Pizza Hut have more than 350 delivery stores in the UK and employ over 3,000 staff. This is a really wonderful opportunity for us and we are excited about what we can achieve by working together.

Lee Porter from Pizza Hut said, "Pizza Hut is a globally recognised brand but it generates its income on a local level. We are proud to work with the A-T Society as it enables us to give back on a [local level]. We look forward to a long and fruitful relationship."



Fundraising

Dancing the StrA-Thspey

The A-T Society's offices are in Harpenden, Hertfordshire, hundreds of miles from the mountains and glens of the Scottish Highlands. But strange to relate, every summer Rothamsted Park (just behind our offices) is host to a Highland Gathering complete with pipe bands, caber-tossing, sheep-dogs and all the rest.

The town also boasts a thriving Scottish dance school, the Hiel'and Toe Club, which is one of the Society's longest-standing and most generous supporters. Every two years, since the Society was set up in 1989, the Club has organised a public show of Scottish dancing and music called A Measure of Scotch. And every time, all profits from the show are donated to the Society – along with the takings from collections at the event.

Over the years, the club has raised many thousands of pounds for the Society. This year alone they raised £3,000. In doing so they have also done a lot to raise the profile of the Society in the local area, and so encourage other support.

The club is run by the energetic and charismatic Glenday Thomas and her husband Michael. Glenday has been a committed supporter of the club ever since she discovered that the wobbliness of two of her young pupils, children of the Society's founder members Maureen and Vincent Poupard, was due to their having A-T. From that day forward, Glenday has been a determined and enthusiastic supporter of the Society.

In addition to their shows, the Club holds regular ceilidhs and it was at one of these that our chief executive William was recently invited to pick up a cheque – not to mention stumble through a quick reel. After thanking them for their amazing commitment and generosity to the Society over so many years, William said, "It is a fantastic and uplifting experience to be here. I can hardly think of any other activity where people of every age, from four to 84, join in together so enthusiastically and as equals and all have such a great time."

So good health to the Hiel'and Toe Club – or as they say in the Highlands, slàinte mhath!



Looking back over the past six months, there have been many changes at the A-T Society with new faces, wonderful new families to work with and fundraisers to welcome with open arms.

Supporting us with admin on and off through this time we've been fortunate to have Molly Owens, our intern from 2013, who ensured the office ran smoothly and again joined us for the Family Weekend, ably assisted by 'Queen of Shops' Laura Balcombe, one of our 2014 interns.

The interns have been able to use their work experience with us as a foundation for their ongoing university studies or a stepping stone towards their chosen careers.

However, much as we love our interns, we've realised that admin support needs to be year round if we are going to give our fundraisers the support they so richly deserve. I'm delighted to be joined by Jo Reader who will be working 16 hours a week to manage the 'back room' tasks that take so much time but are an essential part of a well-managed charity. This means I can be more proactive in working with our fundraisers rather than being 'bogged down' in admin as has been the case for the past couple of years.

Suzanne

Keep on running

Here are some of the fantastic runners who have been supporting the A-T Society this year.



Julia (pictured, right) and Mike Tribbeck of Phoenix Cards put their stamp on the Southampton Half Marathon. Meanwhile Tracey Coyne, Mel McCarthy and Kirstine Derrick (left) each achieved personal bests in the London Bupa 10000 in May.



As a change from running up and down scales, international double bass star Leon Bosch donned his running shoes to complete the Manchester Marathon.



Jayne Rainbow turned her hair A-T purple and brought some colour to the hilly Plymouth Half Marathon.



James Mallon, representing Northern Ireland, kicked off a year of running events with the Kaiser Permanente San Francisco Half Marathon.

Stepping out for A-T

You know the summer is coming when, inspired by the Ferguson family, Tim and Annette Hughes stride out on the 22 mile Bridgnorth Walk.

On a day of sunshine and gentle breezes, and joined by 2015 team

members Sue and Lloyd Evans, Chloe Hand, David Benham, Amanda Smith and Elizabeth Hughes, they set off to complete the hilly route from Bridgnorth to the summit of the Brown Clee – the highest point in Shropshire – and back again.



Doing it for Kaid

Two friends of the inimitable Jo Betts and son Kaid made a year-long commitment to raise money and awareness for the A-T Society.

Sorrel Hodgson (pictured, far right) runs 5km every day, even during summer holidays! She has taken part in the Great North Swim and plans other events later in the year.

Jo Saxton (pictured with Kaid) started off with a hangover-curing 5K on New Year's Day, followed by two virtual 10Ks, a Family Fun Day at the Royal Oak, Watnall and has gone on to the Carsington 7+ and the Wollaton Park 10K and a half marathon.

Both unstoppable ladies have plans to keep at it through 2015 despite having incredibly busy lives and families of their own.



Social climbing

Brian Freeston has quite remarkable motivational skills and, only months after his sponsored cycle, decided to rope in a group of friends to climb Mount Snowdon – the highest peak in Wales. We wanted him to explain in his own words (on his online fundraising page) why it matters so much for him to support the A-T Society.

"The only hope for Jake and Max to have a future is to find treatments to extend their lives and keep them well so that the medical researchers can work hard and find a cure for them in time.

That's where the A-T Society comes in. They fund top quality research to search for a cure.

More than that, they give support to the families of children with A-T,

helping them get the right medical care, help at school and with adapted housing and giving them a shoulder to cry on – and when you have a kid with A-T, there's a lot of crying. The A-T Society have been there for Jake and Max's Mum and Dad from the day they got their diagnosis. This charity is the only one that can help these little lads.

So I'm asking you to put your hand in your pocket, pull out your card and make a donation. Make it as big as you like. No one minds if you want to show off. When you've done that, check down the back of the sofa and in your old jeans to see if you can find any loose change and donate that too."

So a mountain of thanks to Brian and his team – Mike Sherwin, Dave Lewis-Shaw, Diane Lewis-



Brian and some of the heroic Snowdon climbers

Shaw, Robert Thomson, Ryan Somers, Jess Harvey, Connor Sherwin – all of whom made their first ever mountain climb for the A-T Society.

Mega Tri & Brighton Marathon

When a message from Kevin McGregor pings into the mailbox, we know it's going to be something exciting! True to form, he came up with a cracker when he planned the MegaTri 2015.

Combining a 2.4 mile swim, 100km cycle through the West Sussex countryside and culminating in the Brighton Marathon, our participants could take part in one, two and – for the especially hardy – all three events over the weekend.

The team came together from as far afield as Plymouth, Derbyshire and Italy, congregating at our base, the Umi Hotel on the seafront.

Saturday morning dawned grey and slightly drizzly. With furrowed brows we packed wet-weather gear and set off for the first element at the swimming pool in Eastbourne. Here we were joined by the youngest members of the team – 7-year-old Lucas and teens Ellica and Elina, who are evidently half human, half fish and left the adults trembling in their wake as they powered through the water. The swimmers completed almost 50 miles between them in just under two hours, cheered on by a rowdy group of supporters and the pool staff.

After pulling on the newly branded sports vests sponsored by Communis and carb-loading with a much-needed snack, the cycle team gathered for photos and, as the sun had driven the rain away, a frantic sun-screening of knees for James Buchanan, Has Al Hasani and Charlotte Gibb. With Mark and Julie in the lead car and Adrian with first aider Kay following behind, with a back-up vehicle driven by Mike Perry, the cyclists set off through Eastbourne and out towards the beautiful South Downs.

Aside from adding an extra five miles due to a tiny re-routing glitch, the team made excellent



Clockwise from top left: Mega Tri superheroes; Michele and Chiara; some well-earned beer; Pizza Hut after the race!

time and it was a challenge for our photographer to get ahead of them. Taking turns to lead the peloton the cyclists flew through the pretty lanes and villages, cheered on by the locals.

Our new corporate supporters Pizza Hut had arranged a feast for the half-way point in Uckfield and by the time the team arrived a table was groaning with stacks of pizza, chicken, breads and drinks provided by sponsors Britvic. We had a great time chatting with 'Manny' Shahidul Islam and Muhammad Ali of Pizza Hut Delivery who have decided they want to do much more for the A-T Society in the future.



With everyone's hunger satisfied and another 50km beckoning, the team saddled up again and set off up a particularly unwelcome steep hill out of town. The South Downs were now at their highest and the peloton split into two groups... with a surprising lead cyclist speeding ahead of the others. Steve Perry, who bought his bike specifically to do the event, had been training on the moors of Devon and the steep inclines were perfectly normal for him!

A clash of wheels saw one small spill onto a convenient soft grassy verge. Kay leapt from the follow vehicle clutching her first-aid kit, only to find a completely

unscathed cyclist keen to jump straight back onto his bike.

As the road signs ticked down the miles towards Brighton, the supporters congregated at the end of the pier. They were joined by early arrivals for the marathon and Jo and Lola Bloomer who had travelled from Devon to thank the team personally for their support. With beer supplied by sponsors Cobra and loud cheers, the cyclists with William bringing up the rear, swung around the final roundabout and onto the Prom.

Two elements down and everyone safe and well. Fantastic!

Brighton Marathon day starts with the Brighton 10K and the support team were out waving our runner Adrian Johnson on his way. Then with the distant echo of the starting klaxon it was off to our first cheer point where Gary Worsley surprised us by storming through with the super-elite runners. With five cheer points around the course and the handy Brighton app to tell us when to expect them, the team certainly knew we were there! Superman Martin Hine and Batman Kevin McGregor got a lot of attention on the course, and Italian A-T researchers Michele and Ciara were clearly enjoying every step, high fiving as they ran in the spring sunshine. Johanna Fetahu, Ann McGregor and Daisy Hollingdale were all competing in their first marathons along with Nick Meier, while Charlie Clements and Ian Corns proved that RAF discipline is great preparation for a MegaTri!

This was a really wonderful event to be part of – even just watching from the sidelines! This amazing team pulled out every stop to raise money for people living with A-T, coming together as one regardless of their speed, fitness levels and even whether they had met previously. Truly an A-Team to be proud of.



From top: The team before the big swim; bikes and beers; Ann and Johanna (left); Daisy

Four very special people missed out on the MegaTri through injury and were desperately disappointed not to be able to take part. With fundraising inspired by little Lilly Day and Alecia Yarlett, a big shouty thank you (and 'see you

next year!') to the Kent contingent Caroline Anderton, Steve Inett, Scott Wilkins and Craig Wilkins.

Be part of the 2016 Brighton Marathon team – see page 29.

Speaking of Caroline & Steve....

If Carlsberg made fundraisers it would be these two! Caroline Anderton and Steve Inett (with back-room support from Will and Kathie) threw themselves into fundraising for their Brighton Marathon places. Their enthusiasm resulted in cake sales, local schools involvement, a quiz and lots more. It's going to be great to see them restored to health and showing Brighton how it's done in 2016.



Burnley Lions

Following a wonderful article in the "Lion" magazine, our friends from Burnley Lions Club continue their year of fundraising for the A-T Society. If you are local to Burnley or drop in on a visit, do please look out for Frank Seed and this dedicated group of fundraisers who do all they can to support the community.



School non-uniform days

For every family with children of school age, requesting a non-uniform day is a likely winner for both the pupils and the A-T Society. Three Kent schools channelled their fundraising in support of Lilly Day this spring. We'd like to thank Castle Community College, Downs C of E Primary and Hornbeam Primary, all of which went 'mufti' for A-T. **Jump on board and ask your child's school to do a non-uniform day for A-T!**

Jon Mann and Launceston Choral Society

The soaring notes and harmonies of Haydn's Creation rang out across Cornwall courtesy of the Launceston Choral Society and soloists, guided by organist and steam-train enthusiast Jonathan Mann. With a significant contribution to the A-T Society, the concert raised awareness for a whole new audience.



Ware Inner Wheel

We always welcome the opportunity to meet people who have no connection with the charity and talk to them about the condition, its impact on families and the ways our care – and in particular our research – impacts on A-T and other genetic, cancer and neurological diseases.

Suzanne jumped at the invitation to speak to members of Ware Inner Wheel at their dinner meeting in May and introduced them to many of our families by using the calendar to bring individual stories to life. The ladies embraced our work and, in addition to making a generous donation on the night, they plan a further grant and will encourage other Inner Wheel clubs to get involved.



Coffee morning in Durham

A tiny village hall in Northumberland was the venue for a quite extraordinary morning of Coffee and Cake hosted by Mo Seal and Sara Metcalfe. In just two hours the ladies and their team of volunteers raised an astonishing amount for the charity. Thank you to everyone who went along and gave their time and money so generously.



Car wash

A spur of the moment decision by young Luca Baricella saw the drive of his home transformed into a car wash as he and his friends grabbed buckets and chamois to shampoo and polish every vehicle that came their way. The boys worked incredibly hard, did a great job and well and truly cleaned up for A-T!



Thornton's chocolate heaven

Chocolate has truly been the food of love this season, with Thornton's stores in Bridgnorth and Stafford providing delicious support and huge quantities of chocolate as raffle prizes in support of a variety of events.



Yes, but bring some plasters...

When Sue Simpkin rang to say that husband Ged was growing his hair and beard long with a plan to have it all shaved off at the Family Weekend, we were taken by surprise. After all, Family Weekend entertainment tends to follow a regular pattern and suddenly we had a new piece of "performance art" to include. With Kay's support we found a prime slot on the agenda, and a chance conversation netted us the barbering duo of Ben and Tina Stubbs.

Saturday evening saw Suzanne and a couple of Hendricks girls

on their knees battling with large sheets of plastic and duct tape to protect the carpets from hair and blood spatter ahead of the arrival of Ged, hirsute and primed for battle. Next came Tina, clippers charged and lined up ready for the fray, and finally Ben, blades glinting in the harsh overhead light.

Like a Gladiator stepping into the ring, Ged settled nervously into his seat. The crowd fell silent as the clippers whirred against Ged's skull revealing the pale skin of a man protected from the sun for many months... Some time later,

with enough fleece on the floor to cover a woolly mammoth, Ged had a buzzcut, but the dynamic duo weren't finished, and with a flourish Ben reached for the razor...

After a short first aid intermission, a lot of shaving foam and a whole pack of razors, a new Ged stood to salute the now huge and admiring crowd. Looking 20 years younger, cranium glowing, applause ripped through the Radisson Blu and Sue rediscovered the man she married! Huge thanks to Ged, Tina, Ben and of course to Sue for putting up with the contents of the beard!

Easter Toddle

Brooke Sprawling and her family are determined not to let the grass grow under their feet. Since Brooke's diagnosis, which came whilst her father was serving with the British Forces in Afghanistan, they have pulled together to raise awareness in their local area, and those all-important funds to make sure that Brooke and every child like her always has the support of the A-T Society.

Each year Mum Justine organises an 'Easter Toddle' around a local park. The last two events have seen local TV celebrity Becky Jago starting the event and taking part with her own children.



Justine explains "All we do is contact the local authority to ask permission to use the park and we ask some friends and volunteers to support the event. Each child

makes a donation to join in and that's the money we send to charity. We make sure there are cakes and goody bags at the end and it's a lovely fun time for everyone."

Granny-power

There are all sorts of ways to raise money if you feel the urge, and housebound grandmother Margaret Lloyd wasn't going to let anything stand in her way. Firstly she tackled her costume jewellery and sent items she never wears to be recycled or valued by a trusted jeweller. Then she sorted through her books and arranged for them to be collected and sold. Finally, putting her knitting needles to good use and encouraging her friends join her, Margaret was able to despatch two boxes of exquisite baby wear and knitted toys to be sold with all proceeds to the A-T Society. Margaret said, "I was feeling quite helpless, but then I realised I had all sorts of ways to raise money for the charity quite literally in my hands. Suddenly I was able to take control again and it was a very good feeling!"



Scottish Police College

Fergus Loughrey and Probationary Constables training at the Scottish Police College selected the A-T Society as their course charity. Thanks to Fergus, awareness of A-T has been spread to towns and villages throughout Scotland by the 48 new constables who are now on the beat.



Joy's books

When you speak to Joy Ferguson, you can't help but be inspired by her heartfelt support for the charity. Quite simply, she never stops thinking about ways to raise money, who she can speak to and ideas to put into action. She has a wealth of understanding and appreciation of the work of the A-T Society and how Kay works tirelessly to make life brighter for everyone living with A-T. So you can imagine, we always look forward to hearing from Joy!



Her latest money-raising exercise is to invest in the power of social media to sell off huge numbers of paperback books, mainly novels by a variety of authors. You can find the group on Facebook if you search for 'Books for A-T'.

Magic Mary

Mary Messer from Crewkerne, Somerset, is a great friend of the Arnolds and a big fan of Lola! She has generated hundreds of pounds using collection pots in the shop where she works, and she also organised a Bingo Night in a local club where the A-T Society hit the Jackpot!



Weddings

It's been a joyful spring with two generous couples asking their wedding guests to make a donation to the A-T Society in lieu of wedding gifts. For their family members who live with A-T this is a gesture that brings them to the heart of the ceremony. For the charity it is a rare and precious opportunity to raise awareness of the condition in a beautiful and positive way. We thank Richard and Nikki (below) and Katherine and David and wish both couples a lifetime of happiness and good health.



Pentagon

We were highly delighted to hear from Penny the Dragon and her friends at the Pentagon Shopping Centre that they wanted to extend their charity support into a third year. The centre has done sterling work in raising awareness of A-T in an area with a particularly high number of A-T cases and we look forward to working with Martyn and the team through 2015.



Brighton Marathon 2016

"A non runner can train to run a marathon in as little as four months". Or so we are reliably informed by people who know much more about marathon running than those of us built for comfort rather than speed!

Everyone needs a goal and, with eight months to go until the 2016 Brighton Marathon, we'd like to issue you – YES YOU! – with an invitation to be part of the A-T Society marathon team on Sunday 17 April. If you want to make this a family event, there is a mini mile event for children and a 10K too!

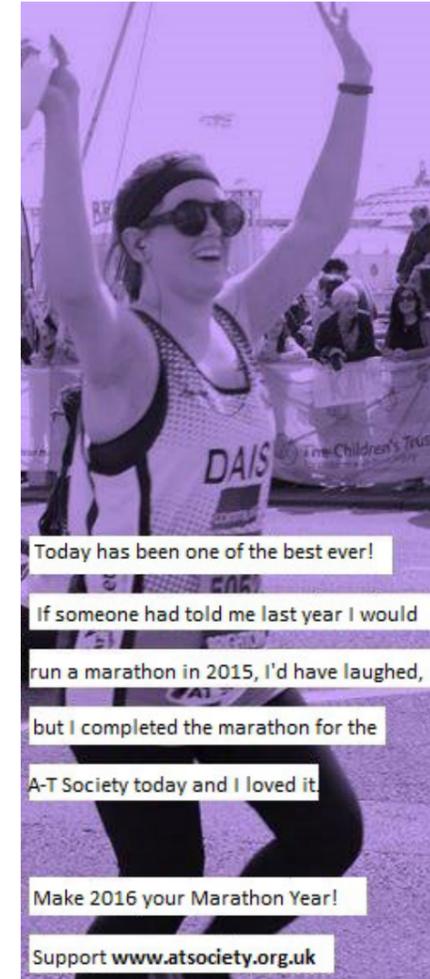
This is said to be the finest marathon on the UK circuit with a gentle, mainly flat course through the town and out along the sea front, finishing with a fanfare at Brighton Pier. You and your family then join the A-T Society's 'after-show party' and catch up with other members of the team to share the experience and a fabulous, well-earned sports massage.

Sign up right now by calling us on 01582 760 733 or emailing info@atsociety.org.uk to reserve your place. You are part of a great team!

School support

Year 7 students from Hele's School in Plympton, Devon, made and marketed gifts that sold for an amazing £1,610 at their Sustainable Gifts Fair. Students selected their beneficiary charity based on presentations given by their classmates. Milly and Jenna, who know Lola Bloomer, talked about the A-T Society.

Their words resulted in unanimous support for our work and Suzanne was invited to Hele's school to receive a very handsome cheque.



Today has been one of the best ever!
 If someone had told me last year I would run a marathon in 2015, I'd have laughed, but I completed the marathon for the A-T Society today and I loved it!
 Make 2016 your Marathon Year!
 Support www.atsociety.org.uk



Swimmers

The Great North Swim is enticing more rubber-suited swimmers to brave the dark depths of Lake Windermere each year. First timers Rebecca Ross and Sorrel Hodgson represented Nottingham's Kaid Betts, and celebrated their achievement with their support team and a lot of champagne!



Meanwhile, Nick Walsh led a team – which included his dad Glen, fiancé Siobhan, brother-in-law (to be) Lawrence and friend Jonny – in the annual inter-family grudge match to see who leaves the others in their wake.



Jeans for genes

Around a quarter of our income comes from applications to charitable trusts. We thought you'd like to know just how much work went into one such (this time successful) application.

We all remember Jeans for Genes day from school – that glorious day when, abandoning the all-too-strict dress code, you could discard knee-length skirts and sensible shoes in favour of your most glam jeans and carefully hidden stiletto heeled boots (or was that just William?).

But we didn't realise then the importance Jeans for Genes has for genetic conditions, and in particular for every family living with A-T in 2015. We thought you might be interested in finding out about the grant process and how important it has been for the A-T Society this year.

The money raised on Jeans for Genes Day funds a range of initiatives that improve the quality of life of children affected by genetic disorders. To access this money, charities are asked to make an initial written application within a tightly defined timescale.

For quite some time Kay's workload has increased massively, and families have had to wait longer than any of us wanted to receive the support they need. By September 2014, her desk was groaning under the piles of advocacy cases, to say nothing of dealing with new diagnoses and organising the family weekend and young adults respite break.

It was clear that the best application we could make would be to ask for funding for a new part-time family support coordinator to take on some of the workload and learn from the person in the world with the most extensive knowledge of how best to support people living with A-T.

Suzanne set to work on the detailed

and very complex application process, almost memorising the 13 pages of guidance notes, while William and Kay considered the person specification and job description to be included with the bid. Two weeks later, after draft and redraft, the application was despatched by email to Jeans for Genes.

We knew there were further stages to the process but October was spent with Suzanne uncomfortably on tenterhooks, waiting to see what happened. We were very thrilled when we got the email to say we had made it onto the final shortlist of 15 major grant applications.

This meant giving a talk and presentation about the project to a highly prestigious panel including medical experts, geneticists, politicians and journalists. We knew we had to 'hit the spot' because we were up against equally deserving projects from other charities and genetic organisations.

After what seemed like endless rehearsing, tweaking and at one stage wholesale re-writing, Suzanne and William set off to meet their Waterloo – well, to a conference centre near Waterloo actually.

You know on The Apprentice, where you see the team sitting in a rather dodgy café waiting to go into the boardroom? Then you can picture Suzanne and William, who at Suzanne's insistence had arrived an hour early in case of delays, and were twitching nervously before their allotted time slot.

The presentation took place in a room on the 17th floor with spectacular views across London – a 10 minute mix of information, background and

just a little laughter. We were pleased the panel asked many pertinent questions to ensure they understood exactly what we needed and why. Resisting the urge to gaze out of the window we headed for the lift and the long ride down.

Then it was over, and we waited... and waited...

Two months passed then late on a Thursday afternoon we received the call. "The Panel loved your presentation, it really stood out. We are pleased to be able to offer you a grant for your new member of staff".

And that, dear reader, is when the work really started! We had to identify families who were willing to share their stories in the media but had not done so before. Then we worked with them to summarise their experiences and put a press pack together to help Jeans for Genes with their 2015 media campaign. We are incredibly grateful to the Noscoe, Nie, Gallagher and Sharma families for their endless support and enthusiasm in helping this happen.

Please look out for their stories and let us know if you see them before we do!

We are hugely grateful to the staff and trustees of Jeans for Genes for their generous support and will be actively supporting their campaign throughout 2015. We would also ask every family to consider getting involved in fundraising for Jeans for Genes Day – which this year is on Friday September 18th.



Easy ways to raise money

You don't have to run a marathon, cycle 100km or jump out of a plane to raise money for us (although we appreciate those who do). There are some really simple ways to get involved and every penny raised can make a difference.

Register with Give as You Live

Every time you shop online at more than 3,900 leading online stores – including Amazon, eBay, Tesco, John Lewis, Sainsburys, and thetrainline – Give as You Live will make a donation.

Ask your company if they do Payroll Giving

It's a tax efficient way to donate money every month from your salary.

Order a collection pot from us

Put your loose change into your collection pot every time



you empty your pockets. It soon adds up.

Recycle

Contact us for free envelopes and recycle your old printer cartridges, mobile phones, cameras, unwanted or broken jewellery or watches, or foreign currency. We receive a donation with every envelope filled so it pays to clear your clutter!

Set up a monthly direct debit

Make a regular donation via your bank. You will find a standing-order form on the back page.

Consider leaving the A-T Society a gift in your will

When you have taken care of your family and friends, consider leaving a gift for the charities that you care about.

Challenge yourself and give something up

Whether it's chocolate, alcohol, cigarettes or takeaways, why not give it up for a month and donate

the money you would have spent to the A-T Society.

Organise a coffee morning, cake sale or car wash event

It's a fun way to raise money with your friends.

Send a text

Simply text ATGIVE3, ATGIVE5 or ATGIVE10 to 70500 to donate £3, £5, or £10 to the A-T Society.*

* The A-T Society (registered charity no. 1105528) will receive 100% of your donation. You may be charged for one text message at your network's standard or charity rate.

Full terms and conditions can be found here www.atsociety.org.uk/donate



Sainsburys Stockport

The staff and customers at Sainsburys in Stockport have been busy raising money for the A-T Society, who they adopted as their charity of the year 2014/15. They

have raised more than £3,300 by organising tombolas and events in store and holding a fashion show for the staff, which was a great success.



Card craft

Fourteen year-old James Ferguson got creative and made a range of cards in the run up to Easter, which he sold in school. His hard work netted a smashing amount and he donated it all to the A-T Society.





Standing Order Form

To: (insert name of your bank)

Bank Address: _____

Sort Code: ___/___/___ Account No: _____

Please pay a regular gift to the A-T Society of: (tick appropriate box)

£3 £5 £10 £25 £100 Other Amount

I wish to donate £ _____

(please also state the amount in words) _____

each month to The A-T Society

Please start on ___ / ___ / ___ and each month until further notice.

Signature: _____ Date: ___/___/20___

The A-T Society Bank Details are as follows:

HSBC, 1 High Street, Harpenden, AL5 2RS.

Sort code: 40 -23-11 Account: 41248693

Your details to set up the standing order:

(Please complete in BLOCK CAPITALS)

Title: _____ Name: _____

Address: _____

Post code: _____ Phone: _____

Email: _____



Tick this box

to add an extra 25p to every £1 you give at no extra cost

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify.

I understand the charity will reclaim 28p of tax on every £1 that I gave up to 5 April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.

Please return this form to:

The A-T Society
Rothamsted,
Harpenden, AL5 2JQ

Thank you!