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A-T Society News

In this majestic issue

- The fabulous A-T Adult Weekend
- International A-T registry
- Super schools raising funds for A-T
- Inspirational A-T fundraisers

AT society
awareness research care

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 October 2016. Please send comments, ideas, articles and pictures to:

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Cover picture: Orla and Finn

Just William

William Davis, chief executive of the A-T Society, reflects back on a successful Family Weekend

I write this just after the Family Weekend, regularly the high-point of the A-T Society's year. This year people from 48 families living with A-T came together at the Park Inn near Heathrow, almost one third of all those in the UK. It's a very special occasion and a real pleasure to see so many people, though I admit I also find it frustrating that being very busy, I never find the time to chat to as many people as I would like.

Nevertheless, a recurring theme with those people I did talk to was how important the A-T Society had been to them and how much they valued coming together in this way. One lady said to me: "Without the A-T Society I don't know where my family would have been – in a black hole, I think." Another told me how she had seen her young son, who had been becoming rather withdrawn as his A-T progressed, really come out of himself and have a great time with other children there.

In recent years, I have come to value particularly the Sunday morning session, with its focus on people who have A-T and their families and carers. Last year, three young adults with A-T spoke about their lives, at times having the audience in gales of laughter. The way they overcame their nervousness at the prospect of speaking to an audience of over 100 people – hard even for people who don't have problems with their speech – was impressive and inspiring.

This year it was the Dads' turn. Three fathers, two accompanied on stage by their daughters, spoke movingly about the rewards and pleasures, perhaps unexpected but very real, of bringing up children with A-T. Although A-T made many things more difficult, it didn't stop them having fun, active family lives which they shared with the audience.

After this, Rupert Prokofiev, who has A-T and is a trustee of the Society, led a session. People in groups discussed the language that is used to describe A-T and, those that have it, which terms they dislike and why – for example calling A-T "a disease" – and which terms they are happy with.

Finally, there was a screening of a short film made at the last activity weekend. In this film a number of people with A-T talk about their lives, how people treat them and how this makes them feel. As the film rolled, there was lots of emotion amongst those watching, recognition of experiences and challenges, but also enjoyment in seeing how people lived their lives in different ways.

This session left me feeling very uplifted. People with A-T were not only speaking from the podium and leading sessions, but they were also speaking from the floor. While this last point may not seem like much, it is possibly the first time that I remember this happening at a Family Weekend – where it is normally parents or carers who take the microphone to ask questions or give views.

One of the aims of the Society is to help make sure the voice of people with A-T is heard. This is a real challenge for people with a condition that not only makes speech difficult, but tends to stifle self-confidence and make social interactions hard. However, judging from what I heard and saw at the Family Weekend, people with A-T are starting to become more confident, to feel they have something to say and are becoming more willing to speak out.

'People with A-T were not only speaking from the podium and leading sessions, but were also speaking from the floor'

On top of this, I think that quite a number of parents, particularly those coming to terms with a relatively recent diagnosis, found it uplifting to hear these voices and see that people with A-T live lives that are as unique and individual as anyone else's, which are active and rewarding, and engage in a wide range of different activities.

This is just the beginning of a process. I know that hearing people with A-T speak last year gave some the confidence to do so this year. Hopefully, seeing people talking on the film will help others feel they can do something similar in future. Bringing people with A-T together to talk and share experiences is helping develop self-confidence. And the result is that people with A-T are starting to develop a voice and that voice is starting to be heard. And that is really good to see!

From pizza to piste: A-T adults rise to challenge

The A-T adult activity weekend, which took place in November 2015, was judged by participants to have been a big success. 21 adults with A-T were able to practise new skills, experience the thrills of skiing in real snow, and share experiences and socialise with their peers in an environment where A-T is normal.

On Saturday the head office of Pizza Hut Delivery was turned into a pizzeria with all our adults designing and making their own pizzas and cooking them in Pizza Hut's specialist pizza kitchen. With the sound of laughter echoing around the place, some fake Italian accents and the smell of freshly cooked pizzas, you could almost imagine yourself in a pizzeria in the back streets of Naples! The head office staff volunteered their time and energy to help prepare and cook the pizzas and make the day a memorable one.

The evening meal provided the chance for everyone to kick back and relax and, as usual, the socialising went on well into the small hours of the morning.

On Sunday it was off to Ski School and an opportunity for our adults to experience the thrills and spills of flying down the snowy mountains of Hemel Hempstead. Casting aside their wheelchairs and having the chance to experience something totally different was liberating. Lots of smiling faces came slaloming down the mountain leaving a flurry of snow in their wake. It was a major adrenaline rush and, thanks to the support and expertise of Disability Snowsport UK, the experience went without a hitch.

Between these activities, there was plenty of time to sit and talk to people who also live with A-T. For many, this is almost the most important part of the weekend. It's not just about being able to share with each other. It's about being somewhere where A-T is normal, where people have the time to listen to you, and the interest. And for some, it is a rare opportunity to get out and socialise at all.

Film maker Sharon Woodward spent the weekend filming the events and interviewing our adults with A-T. They were given the chance to talk about what it's really like to live with A-T. The powerful film is now available to view on our website (*see next page for details*).

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

Having done free-fall (Air-Kicks), canoeing, archery and now skiing, we reckon that some adults with A-T will be thinking about applying for their '00' secret agent licences, soon...

What the adults say

Charlie Stubbs: 'I really enjoyed it. It was an event where I didn't feel different. The pizza making was fun and provided a good chance to talk to other people. Skiing was great fun. I had never tried it before and I really enjoyed it.'

Jilly Shah: 'Such an amazing weekend, so glad I got the chance to meet some wonderful new people. My first time skiing was amazing. Looking forward to the next one!'

Kayleigh Aris: 'The A-T Society did it again! They hosted yet another fantastic adult activity weekend. I just tried skiing for the first time, standing up (!!), and absolutely loved it. Great experience!'

Alecia Yarlett: 'I had never done this before – I was so scared but I had a brilliant time, it was amazing.'

Rupert Prokofiev: 'It was great to get out of my chair and onto the ski-slope.'

Becky Simpkin: 'Everyone's in the same boat. It's just like one big family.'

Amy Cooper: 'Sharing these experiences as an A-T adult, it makes us happy.'

Lorna Robinson: 'Had a wonderful weekend away with the amazing young adults from our A-T family. Lots of fun and lots of giggles. Thanks to the A-T Society for doing all the hard work to make it possible.'

Leigh Rybak-Rajewski: 'I really enjoyed the entire thing. My first time will not be my last!'

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1. Jilly Shah; 2. Emily Woodward; 3. Kath Bugby; 4. Helen Carter; 5. Alecia Yarlett with Aquila from Pizza Hut; 6. Ian McInnes; 7. Leigh Rybak-Rajewski; 8. Amy Cooper; 9. All eyes on Lee from Pizza Hut; 10. Evening socialising

Our film 'People like me' is now available to view on our website at **www.atsociety.org.uk/peoplelikeme** . The film, which gives a powerful insight into what it's really like to live with A-T, was created at our adult activity weekend last Autumn and funded by Pizza Hut Delivery. In the film the adults talk candidly about their lives and experiences and the importance of meeting up with other people with A-T.

Volunteering at the A-T Adult Weekend

By Gayathri Harikrishnan

I am someone who has never met anyone affected by A-T before, or by any other conditions. To be honest, I only knew that this condition existed after the A-T Society became one of our chosen charities at Pizza Hut UK Ltd.

When it was announced in our office that they were looking for volunteers for an event for 'Young Adults with A-T' I had no hint of what to expect. However, I wanted to be there and help out to the best of my ability.

I was a bit nervous when I found out that participants might need my help in creating their own pizzas. I worried if people would understand me, or if I would be able to understand their speech and if not, whether they might be offended if I asked them to repeat what they'd said.

So I was a bit hesitant at first, but it was astonishing to see how confident people were and how clear about what they liked and what they wanted. They even gave us some new ideas for pizza toppings and a few of them won special prizes for this as well.

It was great to able to be help people do something they wouldn't normally be doing.

The same day, people were being interviewed for the film and it was fascinating to listen to the responses. Each person revealed their own personality. Some were humorous and witty, some were nervous, others were adventurous and enthusiastic. They were asked what they tell other people about themselves and how they cope with having A-T. Mainly their answers were not to be scared and to treat them the same as any other person – something which spoke to me. They try to do the same things as anyone else, but have to adopt different methods that might require some practice and patience.

I also felt great admiration and appreciation for the parents and family members of these young adults. I am a mother and was once told by doctors that my five-year-old might grow up with a disability as a result of a particular condition. Fortunately my son grew out of the condition but as a parent I was completely devastated and in a state of shock when I heard the news. So I was able to relate at least in part to what those parents would have gone through. The acceptance, the perseverance and the strength that they show were all to me very commendable.

I took away a lot from meeting the young adults and their families. What most impressed me was their resilience. They aren't frightened; they believe in themselves, and they believe in life. They have a mind-set that they can accomplish something more each day. They might not be physically strong but mentally they are the toughest.

The A-T Society is doing a tremendous job in supporting them, which is very encouraging and inspirational. We at Pizza Hut UK Ltd are thrilled, excited and honoured to be a part of your noble work. I wish the organisation and the families living with A-T the very best in every possible way. And finally, thank you for giving me this opportunity to share my experience of the Activity Weekend.

Possible research into cannabinoids

There has been a lot of interest on social media about the potential benefits of drugs derived from cannabis on A-T. The issue was also raised at the Family Weekend.

The A-T Society has had initial talks with the company that markets one particular drug, which is used in another neurodegenerative condition, to see if they might be interested in a study with A-T. While they expressed potential interest, there are a lot of issues to overcome, in particular the small size of the population that could potentially benefit and the question of using the drug in adults or children – for which it is not yet approved.

There is a question, too, of capacity. With the Erydex trial likely to be running over the next 18 months or so, there is unlikely to be the capacity both in terms of neurologists and people with the condition. There is also a study of the drug currently taking place in children with epilepsy, and it may be helpful to see the outcome of this and whether approval is given for the drug to be used in children, before considering a study in A-T.

Nevertheless, this is something that we will keep looking at, as long as there is any indication that it might be beneficial for treating A-T.

Family Weekend 2016

The beginning of July saw families gathering once again at the Park Inn Hotel at Heathrow for the 2016 Family Weekend. Nearly a third of all families with a diagnosis of A-T in the country attended, with people flying in from Scotland and Northern Ireland.

The weekend followed a familiar course with the children and young adults going off on trips on the Saturday so their parents could concentrate on presentations on some of the support available to families and find out the latest research news.

This year there were two trips: Legoland for the younger children and Harry Potter World for everyone else. Both were a great success though there were some frustrations that the Harry Potter shop was not more accessible.

Those who stayed behind enjoyed a varied programme of talks, including the latest on the upcoming Erydex trial and some preliminary findings from the CATNAP MRI imaging project in Nottingham. Over lunch there also was a chance to look at displays and equipment from Whizz-Kidz and the Aidis Trust and to talk to an expert from Contact a Family. The afternoon finished with the traditional Open Forum and the chance to ask questions of the assembled experts.

The evening banquet this year involved a fancy-dress competition open to children and adults alike. There were some stunning costumes which made it very difficult for the judges to pick winners. Then while the children were kept entertained by a magician, balloon modelling and a disco, adults were able to sit and chat together – for many, one of the most important parts of the weekend.

Clockwise from top left: Pink Ladies, Amy, Alecia and Brooke; Hannah Hussain; Nick and Rachel Ferguson take to the stage; Dermot from Whizz-Kidz; heading off to Legoland

Like last year, Sunday morning was focused on the experiences of people living with A-T. There were a series of talks from fathers – two of them accompanied by their daughters – giving their perspective on life with A-T. They gave a vivid, moving and often humorous picture of how the challenges of living with A-T can be overcome and how full and active their families' lives are.

Rupert Prokofiev, who has A-T and is a trustee of the Society, organised a discussion on the terms that people do or don't like being used in relation to A-T (*as mentioned on page 3*). One of the frustrations that came up during discussions was when people addressed their carers rather than them. This is a discussion that will be carried on in future, online and at other meetings.

Synthetic viability study

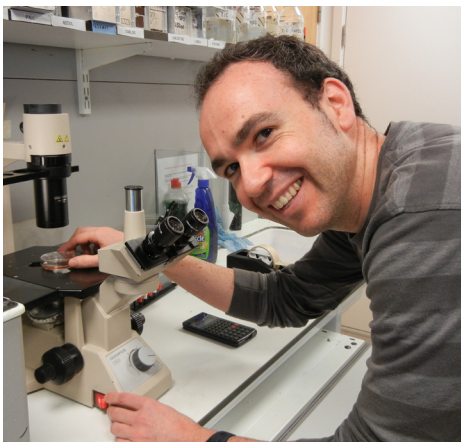
Work by Dr Josep Forment at the Steve Jackson laboratory in Cambridge looking into synthetic viability as a potential treatment for A-T has continued into 2016. The study was funded by the A-T Society, with the generous support of the Masonic Samaritan Fund.

Synthetic viability is a novel approach to treating genetic disorders, in which the damage caused by one malfunctioning gene is reduced by 'switching off' another gene. While this may seem an unlikely strategy, there are good scientific reasons for it (*for more details, visit our website www.atsociety.org.uk/synthetic-viability-project-in-cambridge*).

The concept is so new that the team first of all had to develop new technology to enable them to carry out screens to identify potential genes which, when switched off, may protect ATM-deficient cells.

The good news is that the team have identified a number of genes that appear to do this and have analysed and tested them in A-T deficient cells. They are currently finalising the details and preparing their findings for publication.

While this appears to be a very positive outcome, there are many more questions to be answered before we can think about possible therapeutic use. The ATM protein plays a role in a lot of different processes within the cell, giving rise to the wide range of symptoms experienced by people with A-T. It is not clear how many and which symptoms could potentially be rescued by this approach or indeed if it will work in the body as well as in cells.



Nevertheless, it is very good to have a new potential approach to treating A-T and, in addition, the technology developed by the team will enable the technique to be used to look at treating other conditions.

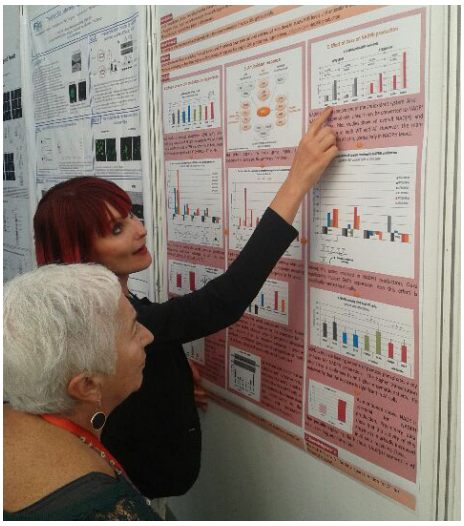
More details to come once the paper has been published.

Clinical research conference

In October, clinicians and researchers from around the world with an interest in developing treatments for A-T will come together at the A-T clinical research conference in Warsaw. This will be the third conference in the series inaugurated by the A-T Society with the one we organised in Cambridge in 2012.

While the ATW (A-T Workshop) conferences, such as the Beijing meeting featured in our last newsletter, focus more on 'hard' science and understanding cellular processes, this series puts the focus on treating A-T.

The programme has been put together by an international committee supported by the A-T Society's William Davis and Cynthia Rothblum-Oviatt of the A-T Children's Project. The programme includes sessions on all the main areas of A-T – neurology, immunology, lung-care, cancer and so on – but also sessions looking at what is being learnt from basic science studies, emerging treatments and unusual cases. We aim to have news of the discussions and presentations in our next newsletter.



Dates for your diary

2016

17 September
Colour Run, Brighton

1 October
A-T Hope Ball, Luton Hoo, Bedfordshire

7 October
Global Make Some Noise Day

2017

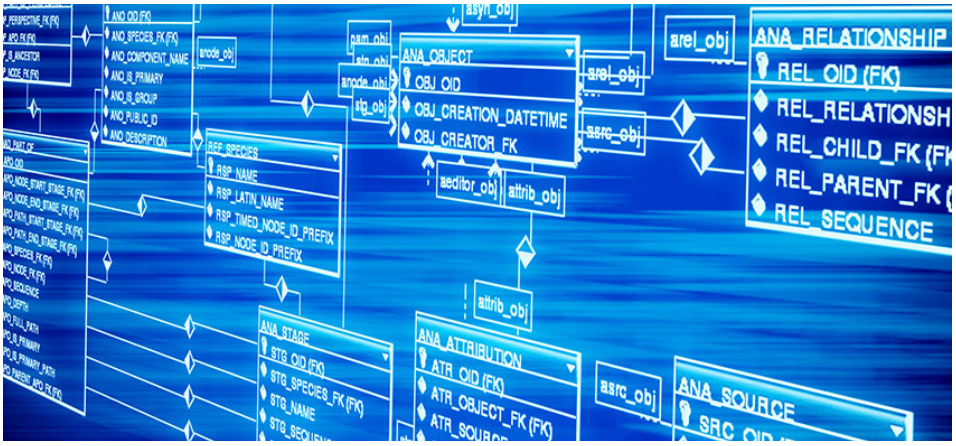
9 April
Brighton Marathon & 10k

23 April
London Marathon

10-14 May
Champagne Supercycle, St Albans to Epernay

October
A-T Concert, Caritas Harmony Choir

Gathering data to push forward research



At the beginning of the year, the A-T Society was awarded a grant of €250,000 by the European Commission to fund the establishment of an international registry of people with A-T.

The registry will bring together in one place clinical data on people with A-T and related conditions from around the world. This will make it an invaluable tool in trying to answer the many questions that still puzzle doctors and scientists about how and why A-T develops in the way it does, and why it varies so much from patient to patient.

The grant was awarded to the Society as part of a wider €6m grant to fund the Erydex clinical trial. This grant was made to an international consortium which, in addition to the A-T Society, includes EryDel, the company that makes EryDex, and the A-T clinical centres at Johns Hopkins, Tel-Aviv and Frankfurt universities.

The registry will be managed by the A-T Society and located in the UK, although the data it holds and questions relating to its use will be overseen by an international scientific advisory board. Work is already well under way and it should be in operation by the autumn.

As A-T is so rare, and because it can vary quite markedly from one individual to another, it is difficult for one centre to see enough patients repeatedly to build up statistically reliable data on how A-T affects people and how it develops over time. Creation of the registry, which will allow data to be added over time, will finally give us the ability to compare, in a systematic way, the symptoms of hundreds of different individuals. It will also make it much easier to find people for future studies or clinical trials.

At the same time that the registry is being set up to collect clinical data, the Global A-T Family Data Platform has been launched, with the support of the A-T Children's Project in the USA. This will collect information provided directly by people living with A-T, as well as data from a major genome sequencing project. The two projects are thus complementary and work is ongoing to make sure data can be brought together in future.

Research project on diabetes in A-T

The research project looking at diabetes and liver-function in A-T, led by Laura McCreight and Ewan Pearson of the University of Dundee, is now recruiting participants. The research team is investigating the link between A-T and diabetes and fatty liver, and aims to work out how best to treat these conditions, to improve the health and quality of life of those with A-T.

In descriptions of A-T, diabetes is almost always quoted as a potential symptom. However, while diabetes does occur, and in a form that is distinct to people with the condition, there are not a high number of cases. Recent studies not yet published however show that fatty liver, not directly related to diet, is much more common in people with A-T.

If you add to this the fact that in people with A-T the levels of a protein called alpha-fetoprotein, which is produced in the liver, is also unusually high, it is clear that there is much to understand about this organ.

While the study itself aims to improve our understanding of how best to treat diabetes, it should also increase our understanding of how A-T affects the liver, and thus of the condition more generally.

The team is looking to recruit people between the ages of 18 and 30 who have classic A-T, do not have diabetes and also are of white European descent. These quite restrictive criteria mean there are only a small number of people potentially suitable for this study, so if you are one of these, please do give serious consideration to taking part. You can get more details by contacting the office or emailing **support@atsociety.org.uk**

Deep brain stimulation

By Anke Hensiek, Consultant Neurologist, Papworth Hospital

Deep brain stimulation (DBS) is a surgical procedure that involves placing electrodes in the brain in order to treat certain movement disorders and psychiatric conditions. The electrodes deliver targeted impulses to specific areas of the brain and thereby affect brain activity in these regions. This can then lead to an improvement of the neurological symptoms that are relevant for the targeted brain region.

DBS is most commonly used as a treatment for certain movement disorders (so called 'extrapyramidal' movement disorders). These include dystonia, tremor or Parkinsonism. DBS can be extremely effective in patients who exhibit such symptoms because the relevant brain regions can easily be accessed and manipulated with electro-stimulation. However, other movement disorders, such as ataxia or myoclonus, would not unfortunately be amenable to this treatment because it is currently not possible to target the brain regions responsible for these symptoms in the same way.

DBS is often used as a very effective treatment for individuals with some hereditary movement disorders, particularly hereditary dystonias. However, in A-T this treatment has only been used in an extremely small number of individuals and it has not been formally evaluated. The reason for this is that the vast majority of A-T patients exhibit clumsiness, unsteadiness and tremor that are caused by dysfunction of multiple neurological systems – i.e. a combination of ataxia (cerebellar dysfunction), neuropathy (peripheral nerve dysfunction), myoclonus (sudden jerks) and dystonia (irregular tremor/muscle spasm).

DBS would treat the dystonic part of the problem, but would be unlikely to affect the main disability, which is due to dysfunction of other systems. In this situation it would not be justified to expose individuals to the risks of brain-surgery and the potential side effects of the procedure, as the benefit is likely to be very limited.

A-T has a very broad range of clinical presentations, which we have only recently started to understand and classify. We now know that there is a small proportion of people with A-T who have very different symptoms compared to those we usually see in A-T. These individuals have only minimal or no ataxia and their main clinical problem relates to dystonia. Many people within this specific group respond to standard dystonia treatment, i.e. medication or botulinum toxin injections. However, if this is not the case, a referral for assessment of DBS can be considered.

Deep brain stimulation (photo credit: Michael J Fox Foundation)

Anybody who has or cares for someone with A-T and wants to find out more about DBS or whether it would be useful in their case, should consult a neurologist for a detailed assessment and further discussion. This can be arranged by a local neurologist or by one of the neurologists based at the National A-T clinics in Papworth and Nottingham.

My DBS story

My name is Gregory Michael Crossan and I live in the north west of Ireland. As a child I was unsteady in my movement and had poor balance and as a teenager I developed a jerky head movement. My writing and walking gradually deteriorated. I became more self-conscious and nervous with jerky movements and tremor predominantly of my trunk and upper limbs. In 1994, age 19, I was diagnosed with generalised dystonia. My symptoms worsened if under stress. At this time I was also found to have abnormal liver function tests.

My older sister Rosemary had a similar movement disorder but also had severe swelling of her joints and was very thin. In 1996, age 26, Rosemary died of liver cancer over a six-week period.

In 2010 I was assessed in Oxford for Deep Brain Stimulation (DBS). At this time, my abnormal liver function tests were investigated in Dublin and it was discovered that I had highly elevated Alpha Feta Protein (many A-T patients have elevated AFP) and highly elevated Ferritin levels. A liver biopsy confirmed that I had Haemochromatosis (iron overload).

I later read various medical literature on Ataxia-Telangiectasia

and recognised some similarities with my condition and requested an A-T gene test. My bloods were sent to Professor Malcom Taylor in Birmingham who performed the test. In March 2011 I was informed of the test result which was positive confirming I had variant A-T.

It is almost certain that Rosemary also had A-T and a more severe type of Haemochromatosis, which undiagnosed contributed to her premature death.

The DBS team in Oxford were willing to proceed with surgery but I was not entirely happy and needed more time to consider my options.

Then, in February 2013 I was seen by Professor Patricia Limousin at Queen Square in London and was later assessed by the DBS team there. After much deliberation I decided to proceed. By the time of my surgery I was finding daily tasks such as walking, writing, using utensils to eat and drink, and holding a telephone increasingly difficult.

I underwent DBS surgery on Friday 12th September 2014, the date coinciding with the A-T Society's Charity Cycle, covering the entire length of Ireland from Malin Head at the northernmost tip to Mizen Head the southernmost tip. My younger brother Shane completed the cycle along with a group of his close friends.

Back: my nephews Alex (5) and Adam (8). Front: my brother Alan, mother Pauline, me, my brother Shane and my niece Laura Rosemary (2).

I was to be the first A-T patient in the world to undergo Deep Brain Stimulation surgery.

Two holes were drilled into my skull and two electrodes placed deep within my brain, one on the left side and one on the right. A wire then connected the electrodes to a battery pack inserted on the left side of my chest under the skin. The battery was to send a signal to the electrodes thus stimulating a certain part of the brain and it was hoped that this would help control some of my movement disorder symptoms.

The stimulator was first switched on the following Monday morning. I was warned that I might feel something such as a tingling sensation in my face or limbs but I felt nothing. Professor Limousin told me any improvement would be gradual and this has proved to be correct.

Since then I have been back at Queen Square on three occasions to review my progress. Professor Limousin worked with Dr. Dejan Georgiev to determine the optimum settings at which to stimulate the electrodes. Each electrode has eight separate points which may be stimulated.

After six months I had shown a 60-70% improvement in my symptoms and after 12 months this improvement proved to be sustained and so the procedure was deemed a success. What this actually means for me is that I am much more relaxed in general and I look healthier in appearance. I can use eating utensils much better. I am more relaxed walking. The tremor and jerky movements have greatly improved. I have not experienced any side effects from the surgery or the stimulation.

I am glad I made the decision to have DBS. It has improved my life in many ways and it has enabled me to be more independent and confident. I feel incredibly fortunate

From left: my brother Shane, mother Pauline, brother Alan and me

that the surgery has worked out so well for me. My faith in God has helped me greatly along the way and I am thankful to the many people who prayed for me at the time and continue to do so.

Dr Georgiev has written an article which details my case history and has been published in the journal, *Movement Disorders Clinical Practice*.

I would like to take this opportunity to thank the surgeons who performed the procedure, Mr Ludvic Zrinzo and Mr Jonathon Hyam. I would also like to thank my neurologist, Professor Patricia Limousin and Dr. Dejan Georgiev who determined the optimum settings for the stimulator. Thanks also to the specialist nurses, Catherine Milabo and Joseph Candelerio, and all those who cared for me during my hospital stay. A special thank you to Professor Marwan Hariz who is Head of the Department of Functional Neurosurgery at Queen Square and who came to see me in my room after the surgery.

Finally, I would like to remember and pay tribute to my sister Rosemary who was not as fortunate in this life as me, but will always have a special place in our family. I would also like to remember my father Michael who also died of cancer in 2005. I am certain he would be very happy to see how well I have benefited from DBS.

Visiting the Nottingham Clinic for the first time

Visiting the clinic for the first time can be daunting for families. Not only the logistics of getting to clinic and organising child care for any siblings left at home but also the unknown: what will the doctors say? Will I understand everything that they are telling me? What questions should I ask? Will they tell me things I don't want to hear?

Caroline O'Sullivan, mum of Erin (9), wanted to share her experience of her first trip to the clinic. As she lives in Ireland, the logistics of getting her there were slightly more challenging!

Erin and family out and about in Nottingham

"It was very raw when we first went to the clinic as Erin was only diagnosed a few months before, but the A-T Society were extremely helpful as it was a nightmare to get funding. As we live in Ireland we have to have an E112 form approved so that we can receive funded treatment abroad (under EU regulations). The team at Nottingham clinic filled in the form which then had to be approved by the Irish Health Board before we were able to attend clinic. The whole process took a while and involved several emails back and forth to get it completed and approved.

"As well as liaising to get the E112 form completed, the A-T Society also helped with our travel arrangements. Kay made sure that we had assistance at the airport so that getting onto the airplane was reasonably straightforward and she organised accessible transport and hotel rooms for our stay at Nottingham. Kay's organisation took the stress out of travelling and was one less thing for us to have to worry about.

"At first we found the prospect of attending Nottingham clinic very daunting as we didn't know what to expect. We were extremely nervous and anxious about the whole experience. We went through a very difficult and harrowing experience when Erin was being diagnosed so we were understandably apprehensive about the visit.

"However, as soon as we arrived at the clinic we were made very welcome and overall we found the whole experience very positive. No matter what question was asked – small, big or even silly – they were answered by the team. Erin loved every minute of it and was very happy about the whole experience as it was not like a hospital setting at all. The travel arrangements worked well and we were relieved at how well it all went.

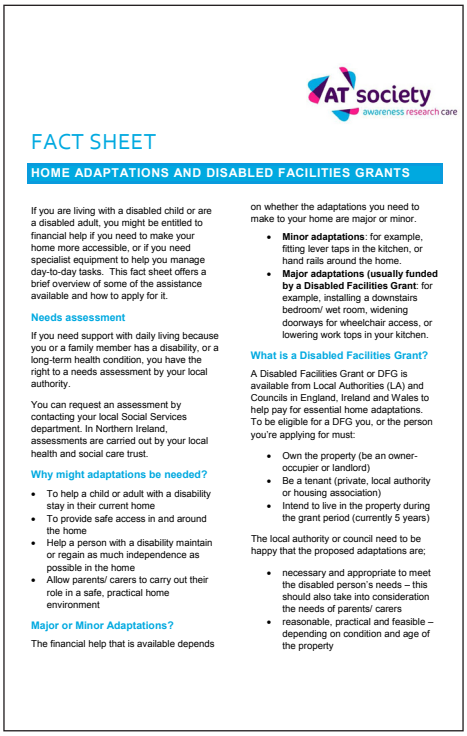
"We met new people there and we were put in touch with other families and groups through social media. The one most important thing that came out of the whole first visit was realising that we are not alone."

A-T fact sheets available

We are in the process of creating some handy fact sheets that provide a comprehensive overview of topics relevant for people living with A-T.

The first two fact sheets on Vaccines and Home Adaptations and Disabled Facilities Grants are now available to download for free from our website. Over the summer we will be working on fact sheets for Education, Benefits and Equipment, which we hope will be available from September.

To download these fact sheets as PDFs visit **www.atsociety.org.uk/factsheets**



FACT SHEET

HOME ADAPTATIONS AND DISABLED FACILITIES GRANTS

If you are living with a disabled child or are a disabled adult, you might be entitled to financial help if you need to make your home more accessible, or if you need specialist equipment to help you manage day-to-day tasks. This fact sheet offers a brief overview of some of the assistance available and how to apply for it.

Needs assessment

If you need support with daily living because you or a family member has a disability, or a long-term health condition, you have the right to a needs assessment by your local authority.

You can request an assessment by contacting your local Social Services department. In Northern Ireland, assessments are carried out by your local health and social care trust.

Why might adaptations be needed?

- To help a child or adult with a disability stay in their current home
- To provide safe access in and around the home
- Help a person with a disability maintain or regain as much independence as possible in the home
- Allow parents/ carers to carry out their role in a safe, practical home environment

Major or Minor Adaptations?

The financial help that is available depends on whether the adaptations you need to make to your home are major or minor.

- **Minor adaptations**: for example, fitting lever taps in the kitchen, or hand rails around the home.
- **Major adaptations (usually funded by a Disabled Facilities Grant**: for example, installing a downstairs bedroom/ wet room, widening doorways for wheelchair access, or lowering work tops in your kitchen.

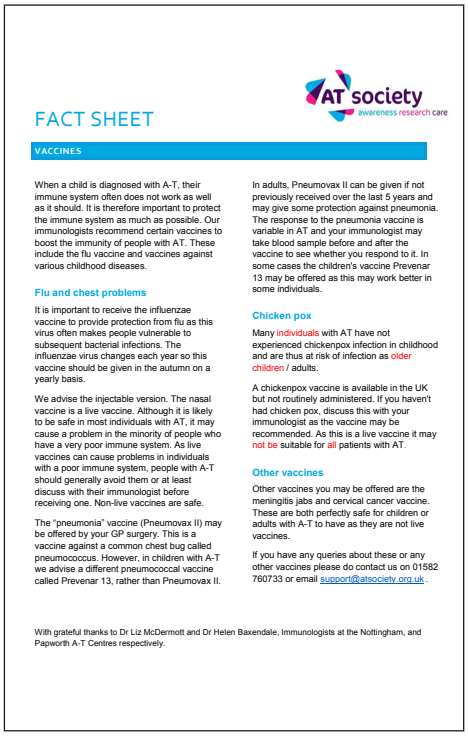
What is a Disabled Facilities Grant?

A Disabled Facilities Grant or DFG is available from Local Authorities (LA) and Councils in England, Ireland and Wales to help pay for essential home adaptations. To be eligible for a DFG you, or the person you're applying for must:

- Own the property (be an owner-occupier or landlord)
- Be a tenant (private, local authority or housing association)
- Intend to live in the property during the grant period (currently 5 years)

The local authority or council need to be happy that the proposed adaptations are;

- necessary and appropriate to meet the disabled person's needs – this should also take into consideration the needs of parents/ carers
- reasonable, practical and feasible – depending on condition and age of the property



FACT SHEET

VACCINES

When a child is diagnosed with A-T, their immune system often does not work as well as it should. It is therefore important to protect the immune system as much as possible. Our immunologists recommend certain vaccines to boost the immunity of people with AT. These include the flu vaccine and vaccines against various childhood diseases.

Flu and chest problems

It is important to receive the influenzae vaccine to provide protection from flu as this virus often makes people vulnerable to subsequent bacterial infections. The influenzae virus changes each year so this vaccine should be given in the autumn on a yearly basis.

We advise the injectable version. The nasal vaccine is a live vaccine. Although it is likely to be safe in most individuals with AT, it may cause a problem in the minority of people who have a very poor immune system. As live vaccines can cause problems in individuals with a poor immune system, people with A-T should generally avoid them or at least discuss with their immunologist before receiving one. Non-live vaccines are safe.

The "pneumonia" vaccine (Pneumovax II) may be offered by your GP surgery. This is a vaccine against a common chest bug called pneumococcus. However, in children with A-T we advise a different pneumococcal vaccine called Prevenar 13, rather than Pneumovax II.

In adults, Pneumovax II can be given if not previously received over the last 5 years and may give some protection against pneumonia. The response to the pneumonia vaccine is variable in AT and your immunologist may take blood sample before and after the vaccine to see whether you respond to it. In some cases the children's vaccine Prevenar 13 may be offered as this may work better in some individuals.

Chicken pox

Many individuals with AT have not experienced chickenpox infection in childhood and are thus at risk of infection as older children / adults.

A chickenpox vaccine is available in the UK but not routinely administered. If you haven't had chicken pox, discuss this with your immunologist as the vaccine may be recommended. As this is a live vaccine it may not be suitable for all patients with AT.

Other vaccines

Other vaccines you may be offered are the meningitis jabs and cervical cancer vaccine. These are both perfectly safe for children or adults with A-T to have as they are not live vaccines.

If you have any queries about these or any other vaccines please do contact us on 01582 760733 or email support@atsociety.org.uk .

With grateful thanks to Dr Liz McDermott and Dr Helen Baxendale, Immunologists at the Nottingham, and Papworth A-T Centres respectively.

Have you heard about Contact a Family?

Contact a Family is a national charity that helps families who need some extra support because of their child's disability or medical diagnosis. They provide help to these children whatever their disability or health condition.

Expert advisers on Contact a Family's freephone helpline – 0808 808 3555 – can help you with any aspect of raising your child including education, welfare benefits, specialist equipment, holidays and leisure, learning and behaviour, short breaks services, transport and local services.

As well as providing information, advice and support for families with disabled children, Contact a Family also bring families together so that they can support each other through regular workshops and family events around the country.

For further details about how Contact a Family can help, including information about the wealth of free parent guides and factsheets, visit **www.cafamily.org.uk.**

A new home for Neil and Stephen

Brothers Neil and Stephen have been living in a residential home in Harrow for more than 10 years and have been desperate to move back to their home town in Aylesbury. They started their search for suitable accommodation over seven years ago and have been patiently waiting for a new home. Kay has been helping to find them somewhere suitable but, due to a lack of suitable housing stock in the area, it's been a very long wait.

Neil and Stephen with Kay Atkins (top left) and their mum Kay

Happily, SeeAbility started building purpose-built accessible accommodation in Aylesbury last year and so Neil and Stephen are delighted to finally be moving home. They move into their brand new accommodation on 1st October 2016 and can't wait.

SeeAbility provide supported living and residential care services for people with sight loss and multiple disabilities. They have a number of supported living, outreach services and residential homes in the south of England. For further information visit their website **www.seeability.org** or give them a call on 01372 755 000.

In memory of Jenni and Chardanai

It is with great sadness that we announce the passing of two remarkable children, Jenni and Chardanai, who both took everything in their stride and faced their illnesses with such bravery.

Jenni's mum Clare said, "Jenni was witty, intelligent, observant, loving and empathetic. She also had a very dry sense of humour and an amazing talent for remembering where we had put things if we had 'lost' them." Jenni is very much missed by her mum and dad, her brothers and sister and grandparents.

Chardanai was such a beautiful girl with a lovely smile which would light up the room. Her family call her Princess Chards as she was so special to them all. Her mum Kerry said 'I'm so proud of my girl – her strength, courage and determination.' Chardanai is very much missed by her parents, brothers, family and their dog.

Jenni

Our thoughts are with the families and friends of these two incredible girls.

Chardanai

Living life to the max!

Sixteen-year-old Jordan has A-T and uses a wheelchair but he doesn't believe that his condition should define him or prevent him from taking on a challenge or two. He is certainly living proof that everyone should take every opportunity to live their life to the full.

Jordan recently enjoyed a passenger driving experience as part of his 18th birthday present and took part in a camping trip for his Duke of Edinburgh award. He wanted to share his experiences:

"For my 18th birthday I was bought a passenger driving experience because I love fast cars. Top Gear was one of my favourite programs – until they changed it.

The day of my driving experience was nice and sunny but also really windy – though not enough to spoil the day. Luckily when I got in the car they had heated seats.

I had a ride in a Ferrari and an Aston Martin DB9. The man who drove me around used to be a professional racing driver and drove at over 100mph. It was really good fun.

With help, I was able to get in and out of the cars OK and everyone was really friendly and helpful. I really enjoyed my day and would like to go again – but maybe when it's a bit warmer...

The experience day was booked through iCAN Experiences and facilitated by Everyman Racing.

This year at college I took part in the Duke of Edinburgh scheme. As part of the award I undertook a camping trip. This involved two trips: one was a practice on the college campus and the other was on a proper campsite.

I was a little worried at first that I would not be able to take part as well as others. But it turned out this was not the case and I was able to help put the tents up and set up camp. On the practice camp we had a campfire and toasted marshmallows. However, we weren't able to have a campfire on the actual trip as the campsite didn't allow them. Whilst camping I did miss my soft bed and pillow, as we slept in sleeping bags and roll mats. It also rained quite a bit which made it a little cold but it was ok.

One of my favourite things we did whilst away was walking along an abandoned railway line. The track had been concreted so I was able to get through with my electric chair which was good. We had to walk through the abandoned tunnels – they were creepy, dark and damp, dripping with water.

I really enjoyed the experience and am proud that I completed it. I made new friends and it showed how many things I can do. I would strongly recommend it to others. If I can do it you can do it!"

News from Emily Chanter

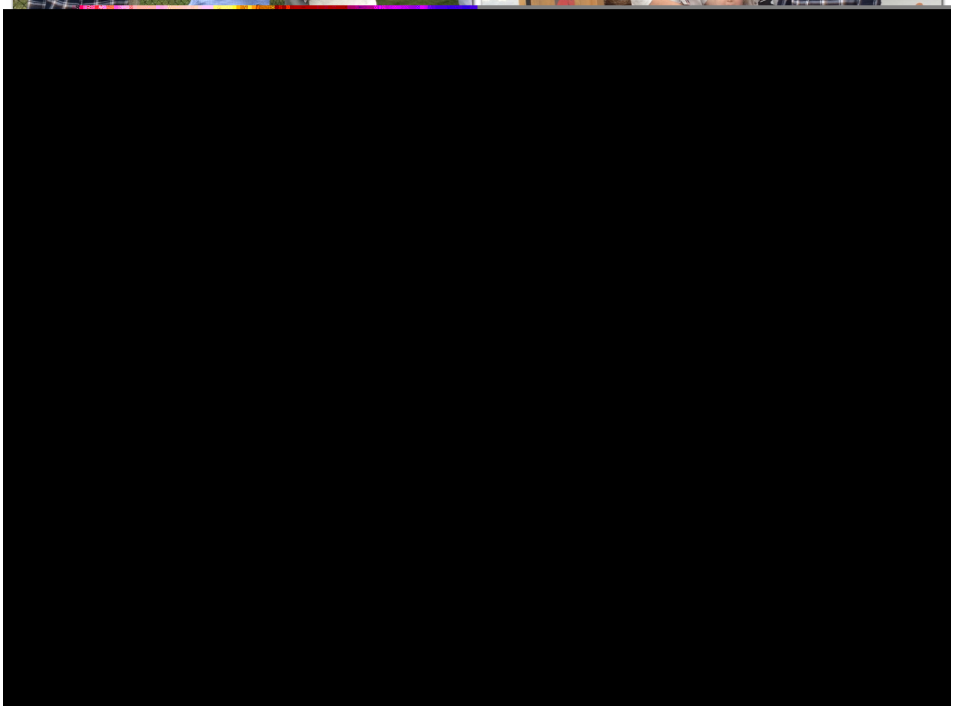
Hi. I'm Emily, I am 36 years old and I live in Lockleaze, Bristol. I moved to my new accommodation recently so I'm still settling in. I enjoy reading, listening to music and exercise – there is a Zumba class for people in wheelchairs on Thursdays which I really enjoy. I also like to go to a weekly coffee morning where I can get involved in art.

In January I gave a talk to the Rotary Club of Weston-super-Mare. I told them about how much I enjoy the fully accessible facilities that ReVitalise holidays provide and the club very kindly gave a donation. I am going on holiday at the end of the month for a week and the theme is murder mystery which sounds fun and I'm really looking forward to it.

Emily at the Rotary Club

Orla starting school

By Mrs Whiston, Orla's teacher



Orla with her teachers and on her beloved bike

Orla is a very popular member of the class. She has settled in beautifully and is not defined by having A-T. She actively participates in every activity, including class trips. As the year has progressed, Orla has grown in self-confidence and has made many new friends. She is on everyone's party list!

Orla's parents, grandparents and members from the A-T Society have supported and advised us as to how we can fully include and celebrate Orla as the feisty young lady that she is, without her condition being compromised or coming first. We have really welcomed that communication as it has enabled us to treat Orla like everyone else in the class, with discreet measures in place to support her. Having a wonderful 1:1 in place from day one has been essential in ensuring that Orla can be one of the 'gang' and be safe.

Because Orla requires an adapted chair, she is assigned a buddy each day to sit next to her, which is a role that is eagerly filled by her classmates.

Orla enjoys creative activities art and music and often leads the class with dancing at music time. She is achieving in all areas of learning and is making great progress. Orla has a fantastic sense of humour and enjoys playing tricks on friends. All of the children understand that Orla may take her time to respond to them, but they wait patiently and accept without question.

Orla has enriched our class. She is fiercely independent, determined and full of fun and mischief. She is undoubtedly a huge asset to our class and the whole school. Our philosophy is 'Where there's a will, there's a way'. Orla certainly has the will and we find 'the way'

My curry night

By Dale Phillips

On 18th May at about 5pm I went out to an Indian restaurant called Viceroy with my carer Dalpat and my two friends Steve and Sandra. We met outside the restaurant, went in and were shown to our table, which I had booked the previous evening. We all sat down then ordered the drinks and food. I had onion bharji with mango chutney for starters and lamb rogan josh for mains, plus a pint of lager to wash it down. It was a very pleasant evening with good company and a lot of laughter.

Pentagon Shopping Centre

Thanks to a variety of fun events and the generosity of local shoppers in Chatham in Kent, the Pentagon Shopping Centre raised £1,720 for us during 2015 and we are delighted they have decided to continue supporting us in 2016! The first half of the year is going well with their PR contact securing a donation of £482 from a company that used the shopping centre for a photo shoot, and the Yarlett family baked and sold cakes as part of the centre's 'One Great Day' fundraising.

At a photo shoot with the local Kent paper in February, Centre Director Martyn Stone said "We're so happy to present this cheque because the A-T Society is an extremely worthy charity providing crucial support to local families with this heartbreaking condition. Here at the Pentagon we favour a more interactive form of fundraising, so we enjoy working

with the A-T Society as they are so easy to work with and fully commit to our colourful, interactive events. They deserve every penny."

Tiesplanet

We are delighted that Tiesplanet have designed a new tie for the A-T Society in our colours. The tie will be launched in August 2016 and will cost £10. Please get in touch with us in the office on 01582 760733 if you would like to buy one. We have 10 ties currently in stock and one of the older style left.

Pizza Hut Delivery

Pizza Hut has a fundraising day each month with each department taking a turn to run an event. In April, Pizza Hut volunteers came to our offices to help transform our store room (*see page 17*). They also supported our Family Weekend by helping us to make up packs, prepare name badges and providing pizzas and side dishes for 100 people on the Friday night.

Sri Lankan curry night's a hot ticket

On a wet, windy evening at the end of January, what better way to cheer and warm yourself up than an evening trying out dishes prepared by an award-winning Sri Lankan chef? Thanks to the generous support of our trustee Hasita Senanayake and his colleagues at London's Carlton Club, that is just what 80 supporters of the Society were able to do.

Chef Krishna Kumar has won several awards at Sri Lanka's prestigious Culinary Arts Competition including 'Best Sri Lankan Meal'. For the Society's supporters he prepared a range of Sri Lankan specialities including King Fish in White Curry Sauce, Tempered Dhal, String-hoppers and Cashew-nut Curry.

Warmed by new flavours, with the Cobra beer flowing (generously provided by our Patron Lord Bilimoria) in a room decorated with Sri Lankan objects and banners, it was possible to forget for a while that you had come in from the damp streets of London and not some tropical garden beside the Indian Ocean.

Sri Lanka-born Ramesh Murugupillai, who attended with other members of his family, said: "The food was really excellent. The flavours took me right back to my young days growing up near Colombo".

After dinner, guests were treated to a thought-provoking talk from Sir Paul Judge, successful businessman and founder of the Judge Business School in Cambridge. They were also able to

admire the splendid interior of the club, with its many portraits and objects of historical interest.

With venue and food supplied by the Carlton Club, and the staff volunteering their time, the evening raised a considerable amount of money for the Society as well as drawing in new supporters. Our warmest thanks go to all those who supported the evening and made it such a success. Certainly most of the guests went away asking if we would be doing this again...

Fundraising

The past six months have flown by and as usual our fundraisers have gone the extra mile to support us. There have been a few changes here in the fundraising team. Jo Reader is now working alongside William setting up and running the international patient registry. Her expertise in building and managing databases will be invaluable in this role. Jo's shoes have been filled by Sophie Arnold who has a background in publishing and is a whizz on social media. Sophie has already hit the ground running and has taken to her new job like a duck to water. Joseph Craft has joined the team for the summer as our fundraising intern. As well as supporting the fundraising team, Joseph will also be concentrating on claiming back gift aid. His warm, outgoing personality made a big impression at the Family Weekend.

Tough Mudder teamwork

The Building Technical Services team from Luton Borough Council are no strangers to muddy building sites, but the Belvoir Castle 12-mile Tough Mudder was a whole new experience for Jason, Keith, Lee, Craig, Liam, Mikey, Mark, Andrea, Scott and Jordan.

The team rounded up support from colleagues, friends and suppliers and had constant encouragement from A-T mum Nicola Woodward who works with them. Here's what Nicola had to say about the event:

"I work for a local authority dealing with various aspects of building maintenance and new builds. Part of my role is dealing with communication within the Division. Recently I was approached by one of the operatives who wanted to take part in the 'Tough Mudder' challenge and he wondered if there were others within the organisation that would also be interested in taking part.

For those of you not aware of the Tough Mudder challenge it is advertised as 'Probably the toughest event on the planet'. Tough Mudder is a 10-12-mile mud and obstacle course designed to drag you out of your comfort zone by testing your physical strength, stamina, and mental grit. With no podiums, winners, or clocks to race against, it's not about how fast you can cross the finish line. Rather, it's a challenge that emphasises teamwork, camaraderie, and accomplishing something almost as tough as you are.

"Initially there were 15 people up for the challenge and it became apparent that none of them had a charity they wanted to support so I suggested the A-T Society.

"Suzanne agreed to help and organised the registrations and prepared fundraising packs. They were given a target to raise £3,000 and Suzanne set up a My Donate page for them. I emailed the team regularly checking how their fundraising was going and giving words of encouragement. Unfortunately some people did drop out and eventually we had a team of 11 people made up of managers, operatives, surveyors and even spouses. Suzanne came to our depot very early on the day before the event to thank everyone for supporting the A-T Society.

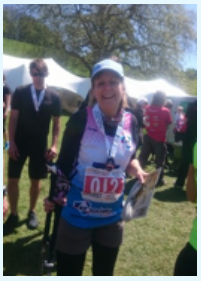
"On the Monday after the event every single one of them told me it was the hardest thing they had ever done and they would not be

doing that or anything like that again! However, over the week the photos began to appear on the Tough Mudder website and their talk turned to how much fun it was. Then we held our staff briefing for all 260 employees and this event was mentioned as a good team-building exercise and they all started to talk of taking part in other events and to continue to support the A-T Society."

Craig, who took part in the event, said, "We really wanted to raise money for the A-T Society because we have seen the great work they do in supporting the daughter of one of our colleagues and we wanted to be able to help them to do the same for other children with A-T and their families."

The BTS Team are determined that this will be the first of many fundraising events for the charity.

Every step you take



Anne Saunders commenced her retirement with a mammoth 50-mile walk for the A-T Society. Travelling 150 miles from her home in Wiltshire to take part in the Hope24 event in Plymouth, she walked for 23 hours through the night and into a sparkling Sunday morning. This is the first event of Anne's fundraising year in support of her great-niece Gracie.

Far away in Cumbria, Gemma Grayburn, whose little sister Toni-Jo has A-T, set out on a five-day 75-mile trek across the Lake District in Cumbria. Carrying all her clothes, food and camping gear on her back Gemma, with the support of great friend Claire, finished the hike in the beautiful town of Ulverston.

In Norfolk, Brooke's Toddle for Treats was a walk in the park. With a field including local TV presenter Becky Jago taking part this year, the cakes and goodie bags at the end were a huge bonus.

Classical concert

We started the year with a beautiful classical concert in Harpenden. The Hertfordshire Chamber Orchestra, with our own William Davis on double bass, was joined by conductor Graham Ross and the amazing violin soloist Jennifer Pike whose performance sent shivers of joy through the entire audience on a snowy evening in January.

Jennifer was so moved by the stories of A-T families that she offered to return and perform again with the Orchestra in 2017. If you'd like to come and see this virtuoso performance and meet up with us in Harpenden for an exquisite classical programme, put a date in your diary for 14 January 2017.

Standing up for A-T

Our patron Brian Conley visited St Albans with his touring one-man show. At the end of a uniquely funny night, he encouraged the audience to give generously to the charity with a bucket collection. We are immensely grateful to Brian for his support, not just to the A-T Society but also to our families who enjoy meeting him after his shows.

Annual Ceilidh

The skirl of pipes and the swirl of kilts made the Hiel and Toe Club's annual Ceilidh a night to remember for everyone who attended. The club, led by the indomitable Glenday Thomas (*pictured*), has supported the A-T Society for well over 20 years and are a firm fixture on our calendars.

British bake off

Darren Haynes and Roberta Saldanha presented a bake off for friends and colleagues in Devon.

Tasty treats at LTI

Nav and Amy Cooper, along with Aunt Pinkey, created an indulgent Indian lunch for staff at LTI Metaltech in Abingdon, where Tim Cooper works. The spicy delights were followed up with a range of cakes provided by LTI's Claire Spires whose creations rounded off a perfect team-building fundraiser for the company and of course the Cooper Family!

Super schools

Three schools in Cheshire, Somerset and Kent have done great things for A-T recently. Engaging children with charities helps them understand how a small action can make a really positive difference and is a great way to develop young minds. Non-uniform days are always a winner and raise a lot of money for the A-T Society quickly and with very little effort for either the school or parents. Ask your child's school if they will do one too!

Blackbrook Primary School

Down in Somerset, Gracie Potter's school, Blackbrook Primary in Taunton, organised a Mufti Day and allowed the children to indulge in a very splendid cake sale to celebrate the end of half term. Huge thanks to new headteacher Mr Rycroft for making this happen, and to Sheryl Potter and friends for organising the cake stall.

Haslington Primary School

Haslington School near Crewe has set out to raise awareness of A-T within the school to promote a greater understanding of the condition and raise valuable funds. The school sold knitted Easter Chicks bulging with creme eggs and plan a non-uniform day later in the year.

(You can read more about the school in Mrs Whiston's article about welcoming Orla into her class on page 16).

Kingfisher Primary School

When Shannon and Killian, two 11-year-olds from Chatham with no direct link to A-T, wrote to their headteacher Miss Panesar and asked to do a fundraising day, Miss Panesar and the staff realised how much it meant to them. The dynamic duo created a poster and sent a letter to parents requesting their support. The resulting fun-day involved face painting, games, stalls, cakes and not a school uniform in sight!

Shannon, Olivia and Killian

The letter home opened both parents' and children's eyes to the challenges of life with A-T and talented swimmer 6-year-old Olivia Callaghan decided to undertake a sponsored 5km swim for the Society. She completed her challenge in just 3 hours 15 minutes.

Unbeknown to Oliva, our charity of the year partners Pentagon Shopping Centre recognised an Olympian-in-the-making and offered to match-fund her sponsorship. They presented Olivia with a cheque and a Zoggs swimsuit at a surprise presentation in the centre (*see below*).

None of this would have happened without Shannon and Killian's determination to support the A-T Society. These extraordinary young people have shown compassion and humanity in their actions, and it's clear these values will have been instilled both at school and at home. The school can be justifiably proud of all they have achieved.

On your marks...

In this Olympic year we have our own crop of champion runners eating up the miles for A-T. We never underestimate the time, effort and training that goes into a big run. Every step on the day will have been preceded by hours of long runs, often in the dark after work or at weekends. Every one of these people is a hero to us all.

Hastings Half Marathon

Joe Powell, Richard Bentley and Amanda McGuinness rocked the Hastings Half Marathon in March. This beautiful photo includes little Winston who inspires them all.

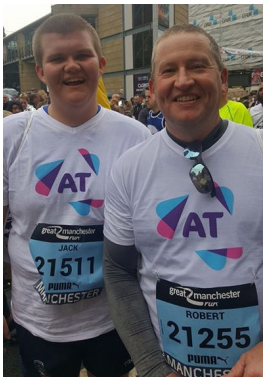
London Marathon

Michelle Corp, who has two cousins with A-T, put her London Marathon ballot place to great use. After the completing the 26.2 miles, she said,
"I'm all done and celebrating. Thank you to everyone for the lovely messages of support and to my fabulous family for looking after me."

Bedgebury 10k

Claire Clarke spent a beautiful day in the countryside for the Bedgebury 10k in Kent. She combined her fundraising for A-T with support for a local hospice and was congratulated at the end of her race by Winston, who has A-T.

The Great Manchester Run



The Great Manchester Run had a magnificent crop of A-T runners with Eddie Cullie, David Forbes, Rob Davies and Jack Davies (who were a lovely surprise in the post-race photos!) running for Orla Ward and A-T research, and Suzie Hadfield championing Cleo Brady.

This event gets bigger every year and it's great to have such wonderful supporters out on the sunny streets of Manchester!

Cambridge Half Marathon

By Amy Ashlee

Three months before the Cambridge Half Marathon I could barely run a 3k. But, when my friend suggested that we run a half marathon, I agreed, and nervously laughed the whole way through signing up. My friends and family couldn't believe it when I told them.

While I was working with Siobhan Kelly I was learning about A-T and meeting the boys, now aged seven. I was so inspired by their strength, courage and positive outlook.

Knowing that I was fundraising for such a worthwhile charity has helped with my training and has made the challenge worthwhile. Running a half marathon is a rewarding experience I will never forget.

Brighton Marathon, 10k and Mini Mile

The Brighton Marathon weekend is a highlight of our calendar. The event brings together keen runners from all over the country to run a course described as 'the best marathon in the UK'. In the past five years the event has grown visibly, not just in terms of competitors, but also the crowds who fill the streets to cheer the runners on. All this against the backdrop of the sea and the enticing aroma of fish and chips!

This is a huge event for Brighton and starts on Saturday with the junior events. For the first time, we were thrilled to have an A-Team runner in the children's Mini Mile. Eleven-year-old Melissa Day, whose little sister Lilly has A-T, made a four-hour rail journey to take part. Melissa ran a brave race with loud support from Mum Viviane and Dad Joe.

North London Half

Three men jumped off their big red bus and into their stride as Mark Bolton, Dave Kenny and Tony Thomas, who have connections with Transport for London's Merton Bus Garage, joined friends and junior supporters Broghan and Brae to master the route of the North London Half Marathon.

We were also able to field a team of five in the Brighton 10k which is run just before the Marathon. We bellowed our support for two A-T researchers from the University of Sussex; Penny Jeggo and Keith Caldecott, A-T Society treasurer Andrew Mills and Will Smith and Ellie Cooper of Pizza Hut Delivery. After their victory Penny, Andrew and Will joined the A-T cheer squad for the Marathon.

Then came the big one! Our 2016 Marathon team included Carrie Stanley; Dawn Baron; Paul Samat; Ashley Knight; Simon Monaci and Adam Spurdle from the London communications giant Communisis, who with Anne-Marie Francis of ITV were inspired by Lola Bloomer to take part; Claire Chadwick and Sarah Cooke, friends of Kaid Betts, who travelled from Nottingham; and regular volunteer Adrian Johnson. They were joined by experienced marathon runners Julian Thomas, who works for our corporate partner Pizza Hut Delivery; Alejandro Pena, an A-T researcher; and Kevin McGregor, who provided training hints and encouragement to prepare everyone for the big day. The final team member was Heather Bush, a friend of Lisa Baricella, and the Fox family in Dublin who travelled from Norfolk and was supporting both the A-T Society and Tommy's.

All of these wonderful people came together for A-T children and their families.

The entire team finished well and achieved their marathon dreams and excellent times. It's always an honour to support fundraisers to complete their first marathon and this was a weekend of some very special firsts.

After a fantastic race in sparkling sunshine with a gentle breeze, our runners met up with their families, friends and supporters at our post-race event. It's a wonderful opportunity to share the details of the race, congratulate one another and have a massage and a couple of well-deserved drinks and bite to eat before heading home wearing their Marathon medal with pride.

If you have a marathon dream and you'd like to be part of our Brighton A-Team in 2017, this is the perfect time to contact suzanne@atsociety.org.uk and reserve your place.

Brighton runners: their experiences

Some of our Brighton runners wanted to share their experience to encourage people to take up running or even sign up for a different challenge. Here are their inspirational comments.

What motivated you to take part in the event?

Simon Monaci: I've always wanted to take part in a Marathon event but never fancied the crowded London marathon. Kevin came with the suggestion and I was in. After that, the info pack from the A-T Society and website information convinced me of the worthy cause and saw me through the long, lonely training runs during the dark winter nights.

Ellie Cooper: I like to help the smaller charities out so they can have their name heard. When I first heard about the A-T Society I'd never heard of the condition before and it really saddened me to hear about A-T and how it shortens lives so drastically. I enjoyed running from time to time but wanted to take part in an event to push me to run further and faster.

Julian Thomas: My brother-in-law ran the Brighton Marathon in 2015 and the support and atmosphere really motivated me to run this year. My son turned 18 in December 2015 and we always said that we would run a marathon when he was old enough. My wife also joined the party so we had a great team approach.

Julian: 'As I ran around the course it was great to see so many people running for so many great causes. The support from the crowd was for you and your families'

Will Smith: I wanted to help raise funds for the A-T Society and a few options were presented at a 'Hut Huddle' at work. I had just started running again after a long break so I thought the 10k would be a good way to help. I thought the marathon would be a step too far!

Have you done anything like this before?

Simon: I've competed in a few non-fundraising endurance obstacle races at much shorter distances and I've also done a few fundraising events like the London Hospital Abseil and some It's A Knockout events.

Andrew Mills: I have taken part in quite a few sponsored events over the years but never something involving running!

Penny Jeggo: Yes (two half-marathons) – but over 25 years ago when I was not a 'senior citizen'.

Tell us about your training?

Andrew: I don't really like running so training in the winter was a bit of a chore. But that was positive in a way – a reminder to keep small problems in perspective.

Simon: Long, cold and dark. I joined a running club which was probably the best thing to do as all necessary training run groups and meets are geared towards marathon events. However, it was the regular building of long runs I struggled with and, with a young family, couldn't make all the club meets so did most of them solo – this was the hardest part for me.

Penny: 'Scientists will be able to find a route to alleviating A-T – amazing advances are being made. Do not give up hope'

Alejandro: 'Lots of researchers are giving their all to find a new discovery which will provide a step forward in the comprehension of a final cure for A-T'

Will: Started off mostly as a few laps round the lake after work with colleagues for fun, a couple of times a week. As I became a little fitter I built up my distance and worked on improving my times.

Alejandro Pena: The training was really hard because I started in January and, because of my work, I only could do it during the night. Also, the weather conditions did not help very much because of

the cold, the wind and the rain. Fortunately, when spring came the weather improved and some of the weekend training was very good.

Ellie: At first I found it quite difficult especially when it was sub-zero outside and raining! When the sponsorship started coming in I found I was much more motivated. I also set myself a target of completing the 10k in under and hour so once that was set I was really determined!

Penny: I was building up beautifully (I only ran 10k) when I made a mistake of sailing my son's laser in strongish winds – that caused aching in my upper legs (quadriceps) – but I thought this was OK because it was just muscle ache so I kept training. That was a mistake since before long I had non-muscle pains. So the rest of my training was about balancing building up with not causing rebellion from my knees. It was only in the last two weeks that they started to give up fighting against me and began to support me.

How did you feel in the run up to the event?

Penny: Nervous whether I would be able to do it – and whether I would finish miles behind everyone and be caught up by the Marathon runners!

Ellie: Nervous and excited but mostly determined!

Andrew: A bit nervous about my fitness as I had been away for a while and unable to train as much as I should have!

What was the atmosphere like during the run?

Andrew: The atmosphere was outstanding. Brighton was looking at its best and the crowds and the team from the A-T Society were fantastically supportive to all the runners whatever their levels of fitness.

Andrew: 'The atmosphere was outstanding. Brighton was looking at its best and the crowds were fantastically supportive'

Simon: Absolutely amazing! I felt highly emotional at points to see the sheer amount of people out to support, and families who had prepared goodies and cut fruits for the runners. It was unbelievable! I was truly moved. Beautiful weather highlighted lovely scenery for a fantastic day.

Will: The atmosphere was brilliant and it really helped having my name on my running vest as lots of random people were cheering me on!

Julian: The atmosphere was excellent. The A-T Society cheerleaders across Brighton really did motivate. The people of Brighton and Hove also came out in great numbers and the sweets and oranges on route really did help energy levels.

How did you feel after you'd completed the event?

Simon: Elated, tired, sore and relieved all rolled into one. I'd just come out of a deep cramp suffering zone around mile 25 and thought I'd be barely hobbling over the line

Simon: 'Alecia was a superstar on the day and her strength on a daily basis pales my efforts of jogging around town waving for four hours... People with A-T are the real elite athletes, fighting in multiple marathons daily'

if at all. Alecia was a superstar on the day and her strength on a daily basis pales my efforts of jogging around town waving for four hours.

Julian: Fantastic. We had many family members along the route and even had a friend visit from Canada. Giving high fives to them all on the final 500 metres was great.

Ellie: Great to have made my goal and achieved something not only for myself but also beating my fundraising target (I also felt absolutely exhausted!)

Andrew: Very relieved to have finished, very pleased to have beaten my sponsorship target and pleased with my performance on the day.

Do you have a message for the A-T Society and people with A-T?

Simon: After doing an endurance event that had me in tough mind scenarios throughout training and

the day gave me a fragment of emotional mountains scaled on a daily basis by people with A-T. Knowing this makes me even more proud of the importance of my fundraising and achieving the targets we had for the charity. I wish the charity every success with its medical research breakthroughs and striving to offer better lives for people with A-T – or athletes as I believe they are – fighting in multiple marathons daily, the real elite athletes.

Penny: Scientists will be able to find a route to alleviating A-T – amazing advances are being made. Do not give up hope.

Julian: To Suzanne and the whole team at the A-T Society I say a massive 'Thank you'. The planning and organising that went into Brighton was amazing. You could not have supported more and the feeling of being part of your team on the day certainly gave me a huge boost.

To the brave and courageous people with A-T (and their families) I say never give up hope. The work of the Society and the wider medical community will I am sure make great strives as more

Ellie: 'In the run up to the event I felt nervous and excited but mostly determined!'

Will: 'The atmosphere was brilliant and it really helped having my name on my running vest as lots of random people were cheering me on!'

and more is learned about the condition.

As I ran around the course it was great to see so many people running for so many great causes. Do know that the support given to us on the day from the crowd was for you and your families.

Alejandro: You must have strength and hope. I work in healthcare research with Penny and some of the projects in our institution are related with A-T, studying some proteins involved in the disease. I want the families to know that lots of researchers are giving their all to find a new discovery which will provide a step forward in the comprehension of a final cure for A-T.

If you have been inspired to take on a fundraising challenge then please do get in touch with Suzanne or Sophie – we'd love to have you on our team!

So, you're going to run a marathon...

Emma Ross, head of Physiology at The English Institute of Sport and former A-T trustee, gives us some advice about training for and competing in a marathon.

The first thing I need to tell you is: It. Will. Hurt. It will take time, dedication and will power. It will require sacrifice, there will be temptation. But I promise you, when you reach your goal, it's worth it! After all, if it was easy everyone would be doing it – by putting yourself through this personal challenge for such a good cause, you have officially reached the status of Awesome! I'd like to give you a few tips that might help you plan and prepare for the big day:

Training

1. Follow a programme. There are lots of good marathon training plans available online (e.g. Runners World) which will help you do the right types of training, and get the right recovery in the weeks leading up to the race.

2. Remember the principles of training:

• **Specificity**: the more specific to your performance training can be the better. Running is the best training for running. You might want to use some 'cross training' like cycling or swimming, especially if you are injury prone, but ultimately to get better at running, you need to run.
• **Progression**: to improve and achieve the 26.2 mile goal, your training needs to get progressively harder. This will mean extending the length of your long runs weekly, and increasing the speed of your shorter runs as you become fitter.
• **Reversibility**: you de-train very

quickly if you stop exercising. Keep the momentum in your fitness improvements up by training regularly and consistently. However, do make sure you stop training if you are injured or ill – putting your body under stress in these conditions may ultimately lead to more time out of training, or worse still, not being able to reach the start line.

• **Tedium:** training must be varied to keep you motivated and ensure you keep improving. Try different running routes and different terrain (get off the pavement and explore your local footpaths). Your training should include different types of sessions, including slow and steady running (usually your weekly long run), high-intensity interval training (repeated short high-intensity bursts of between 1 and 4 minutes, interspersed with a low-intensity recovery period) and high-intensity endurance running (shorter distances of between 5 and 10k performed as fast as you can).

3. Recover well. The recovery period following training is where the adaptation to be fitter happens, so use it wisely. Try and stay off your feet following a very long run. Compression garments help promote blood flow through your tired leg muscles. Eat (protein and carbohydrates) and drink well following training, and get a good night's sleep.

Competition preparation

1. Don't do anything on race day that you haven't tried in training. Use all your kit in training (including your race t-shirt) and use your long runs to practise what and when you will eat and drink. Just like your muscles have to be trained for a marathon, your gut does too – your stomach has to become used to taking on board food and drink and digesting it so that it can be useful to your tired muscles.

2. In the week before the race, you should reduce the volume of training (that is, cut down the distance and/or the frequency of training sessions) but maintain the intensity.

3. Don't overdo it at the Expo. Try and stay off your feet as much as you can the day before, maybe taking a gentle stroll into registration to collect your number – don't hit the shops or decide to do a sightseeing tour by foot!

4. Eat carbohydrate-rich foods in the 24 hours prior to racing, but don't have a big heavy dinner or breakfast that you will still be digesting as you cross the start line.

5. Keep well hydrated at all times, but especially in the days leading up to the race. Sip on water and isotonic drinks, don't guzzle large volumes in one go.

6. Don't worry if you feel a bit sluggish in the days preceding the race – reducing training and eating carbs tends to make you feel like that. Believe in your training and come race day, you'll be raring to go.

Race Day

1. Get to the start line. Sounds obvious, but staying illness and injury-free right up until competition day, so that you are able to start, is one of the biggest challenges to actually finishing the race.

2. Have a race schedule. From your training you will know what pace/marathon time is achievable for you to aim for. Don't expect to suddenly find super powers on the day that will allow you to run significantly quicker than that. Hitting the wall is an unpleasant experience, and it happens when you set off too fast and run out of fuel before the end of the race. Stick to your planned pace, and if you still have energy left over the last 5km to speed up, that's when you can use it!

Emma Ross

3. Fuel to plan, drink to thirst. Every hour, try and consume 30-60g of carbohydrate and 200-400ml of fluid. Don't drink just because you are passing a water station. Over-hydration is just as dangerous as dehydration.

4. Vaseline is your friend! Blisters and friction burns are very painful, and lubricant in the appropriate areas can help prevent this. Under arms, around the groin, nipples, toes and even on your eyebrows to act as a barrier to sweat running into your eyes.

5. Know where your spectators will be. Seeing friends, family, and your charity supporters along the route is the biggest motivation you'll find. Know where they will be standing so you can look forward to seeing them – it will make the miles pass a bit quicker.

6. Enjoy it. This is your moment. This is what all the training has been for. You are running because someone else can't. You are awesome. Soak up the atmosphere, high five the crowds, and however painful it gets remember every step is a step closer to that wonderful feeling of crossing the finish line and saying "I did it!"

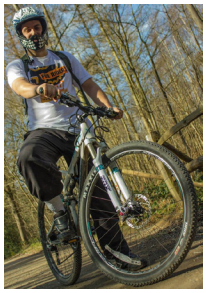
Kingsbridge Estuary Rotary Club Golf Day

We were honoured to be selected as one of two charities to be the beneficiaries of this wonderful day hosted at the spectacular Thurlestone Golf Club on the Devon coast. Members of the Rotary Club went above and beyond in support of the A-T Society and the local disability charity Hannah's. Many thanks to all involved.

Blenheim Triathlon

Brothers Jon and Patrick Turpin, whose cousin has A-T, competed in the Blenheim Triathlon to raise funds and awareness of the condition. Jon said afterwards, "It was a great experience, and doing it for the A-T Society definitely helped me push through the last few kilometres when it got really hard!"

Friends rising to the challenge!



Aron Okines took part in the 'On Yer Bike' event organised by the Rotary Club of St Leonard's-on-Sea. Aron is a man of many talents and we look forward to working with him again soon – so watch this space!

Stephanie Button, daredevil and adrenaline junkie, pulled on her jumpsuit and climbed onto the wings of a biplane to wingwalk for A-T. We're told her screams of exhilaration could be heard across three counties! If you would like to Wingwalk, just let us know and we'll organise an experience for you.

Will Lloyd, for whom swimming is a real challenge, set himself a target of half a mile for a sponsored event in support of his friends **Rachel** and **James Ferguson**. He generated huge support locally and did a really brave and fantastic job of his swim.

Nancy Smith celebrated her 80th birthday with a family party and shared the joy with the A-T Society by requesting donations in lieu of gifts. We're told it was a glorious day, although secretly none of us believe the stunning lady in the centre of this family group is anything like 80 years old!

The Royal Lions held a Football Tournament on Spring Bank Holiday Monday and invited **Brae Sewell** along to share the soccer glory. The teams had a great day to finish off the football season.

Our Mums are the best!

You may not know this, but it's a test of skill and dexterity to hook a single duck, let alone catch a whole flock and put them in a pond! **Sinead Ward** is the undisputed Duck Wrangling title holder 2016 and she proved this in style at the Haslington Village fete. Sinead didn't stop there though. Ably assisted by friends and family, she hosted a stall overflowing with A-T treats and a royal theme.

Meanwhile, over at Belvoir Castle in Lincolnshire, things were getting very mucky indeed! **Anita Rose** and her friend **Samantha Goldsmith** took on the Tough Mudder Half, a rampaging riot across a variety of obstacles. We think it's safe to say those shirts will never pass the whiter whites test!

Across in Taunton, **Sheryl Potter** organised a Disco, Quiz and Karaoke Night at the Wyvern Club, providing masses of entertainment for the local community. The time and effort added up to a really successful night.

Joy Ferguson did a talk to her local U3A Group and received a speaker's donation as well as the proceeds of fundraising and a raffle. Here she is with daughter Rachel receiving the cheque.

Joy has also been very busy selling a huge library of paperback books for us, so if you like a good read, contact Joy via Facebook and she'll can provide you with all your holiday reading!

With the support of her wonderful friends, A-T mum **Jo Bloomer** organised Lola's Enchanted Ball in Plymouth. An impressive total of 300 people danced the night away with special appearances from Cinderella, who made sure Lola was the belle of the ball, and Dave Benson-Phillips of Playbus who compered the evening.

Trooping the colours for A-T

For some, the May Bank Holiday means BBQs, a lazy long weekend or a chance for a spot of DIY. For the Troopers 4 A-T it means it's time for their annual sponsored 22 mile Bridgnorth walk. Come rain or shine they have donned their walking boots to raise awareness and funds for A-T. Founding member of the Troopers 4 A-T, Tim Hughes, comments:

"I am pleased to report that the weather was fair, perhaps a bit on the warm side in places, although as we reached the Brown Clee there was a refreshing breeze to cool us down a bit. I can't deny it – we ache a lot with the added blister or two but I am pleased to report that we all made it back. Thank you so very much to everyone who supported us and spurred us on towards the finishing line. A particular well done goes to Chris, who was walking for the first time."

So thank you Lloyd & Sue Evans, Tim, Annette & Becky Hughes, Mandy Smith & Dave Benham and Bridgnorth newbie Chris Madden – your dedication is very much appreciated.

Boxing challenge

In Shotts prison, four inmates succeeded in organising an event that involved hitting punch bags for two hours non-stop: all in an effort to raise money for the A-T Society. Barry, Billy, Neil and Willie completed this impressive feat of endurance on 27th March. In their efforts, they managed to raise the sum of £384. This is especially impressive and many of their fellow inmates were willing to donate 25 to 50 percent of their weekly income.

Willie said that the guys were happy to "take the opportunity to do something constructive and raise some money for people in need" and are keen to continue doing what they can for the charity. The date for the next charity event has already been set for June 2017 and they are currently brainstorming for additional ways of helping the A-T Society. We would like to thank them profusely for their efforts and congratulate them on doing what they can to be proactive. We would also like to wish Barry Thompson good luck when receiving his Open University exam results.

Inspirational A-T fundraisers

It is both inspiring and motivating to see people with A-T getting involved in fundraising for the A-T Society and achieving some truly amazing things. These remarkable individuals have shown how raising money can be approached in so many different ways, from taking on personal challenges and pushing individual boundaries to using their unique skills and talents to make a difference. They proved that you don't need to run a marathon or climb a mountain to be a top-notch fundraiser!

Kira Carrington

Kira inspired her school-mates and teachers to get involved in fundraising for the A-T Society. This April five students from her class took part in a sponsored 10-mile bike ride at Sherwood Pines. Kira motivated them to smash their fundraising target and she arranged her own bake sale in the school on the same day. Everyone had great fun working to support Kira and the A-T Society together, it was a true testament to friendship!

Merry James

Fifteen-year-old Merry James planned her own Triathlon as part of her Duke of Edinburgh Award Scheme. She made it happen with sheer determination, patience and the support of her family and friends. First she used her especially adapted trike to cycle the hills of Cumbria, then she walked 100m with assistance from her walking frame, completing an overall distance of 3km. Then, to top it all off, she challenged her brain to co-ordinate her limbs and completed a near vertical climb. Her achievement was captured on film thanks to Trapeze Film who spent the day following her. You can watch her inspirational film on YouTube - **www.youtube.com/user/ATSuzanne**

Charlie Stubbs

As part of Charlie Stubbs' Business Enterprise Course at Treloar's College he was able to nominate a charity and organise an event to raise funds. Charlie chose the A-T Society as he said they have always helped him and his family. He arranged an auction for some artwork that had been created by other students at the college and also held a raffle with handmade jewellery and a gingerbread house donated by a relative of a member of staff at the college. Charlie was very pleased with what he raised, as was everyone at the A-T Society!

The A-T Society's philosophy is that everyone with A-T should have the opportunity to live their life to the full. These young people are not letting A-T get in the way of their fundraising and have shown how awareness and funds can be raised in so many different ways. They are an inspiration and an example to us all! If we've inspired you to organise a fundraising event or to set yourself a new challenge then do get in touch with Suzanne or Sophie on 01582 760733 who will be happy to advise and support you.

My fundraising achievements

By Eleanor Hewitt

On Monday 27th June 2016, I embarked on a massive physical fitness challenge. This event was to row 3000m, arm bike 6.4km (4 miles) and cycle 9 miles. The primary purpose of this journey was to raise awareness of A-T. However, it turned out to be a fundraiser with people donating to the A-T Society as a result of my work.

As I trained in my local gym fellow gym goers would say that I inspired them to continue with their activity in the gym. I would like to think that I have raised more awareness as a result of my training and other efforts.

As a result of my passion for health and fitness, I have raised more than £500 for the A-T Society and completed my challenge in 1 hour 57 minutes! I have also since completed the Bristol Race for Life 5km on a hand cycle. The route was half grass and half road and took just 57 minutes! There will be many more fitness challenges for me and this just shows that everyone can participate in exercise if they want to. 'Where there's a will there's a way!'

I can only hope that my 'can do', 'prevention is better than cure' attitude rubs off on people and my successes give hope for newly diagnosed families and individuals.

Jilly Shah and her delicious cakes

Jilly has a passion for baking and all things 'cake-ish'! Her cupcakes are wonderfully intricate, beautifully creative and totally delicious! For Jilly, baking is a form of escapism from the difficulties she faces with A-T, a 'bubble' for her to relax in, as well as a way to put a smile on other people's faces. She has taken this scrumptious pastime and used it to raise money for the A-T Society by setting up Jilly's Cupcake House. Jilly has donated 100% of her profits to the charity. What a wonderful way to put her culinary talent to good use!

The Champagne Tour

Join the team and round up your friends and colleagues to take part!

10-14 May 2017

With distance road cycling now a favourite pastime of people from all generations, we're delighted to be able to offer a brand new tour for keen cyclists.

The Champagne Tour is unusual in that it has two starting points. North of London, people can start in the picturesque town of St Albans, just along the road from the A-T offices in Harpenden. We have been invited to launch the tour from the grounds of the famous St Albans Cathedral where cyclists will be cheered on their way by staff from Pizza Hut Delivery and the A-T Society.

The second starting point is at Portsmouth where cyclists who would prefer a shorter ride, or are only able to take two days off work, can meet up with the rest of the team, sailing across the English Channel to start the ride on French soil.

Over the next three days riders will visit Caen, Rouen, Compiègne and finish the ride in sparkling style at the heart of the Champagne region – the city of Epernay where they will enjoy a celebration meal in the cellars of a specialist Champagne vineyard.

The ride is fully supported by our friends from Sport Ecosse, who provide kit transfer, mechanicals, accommodation and return travel. All you have to do is turn up and enjoy the ride!

Participants can either join the tour as a fundraiser, or treat it as a cycle tour holiday and pay to take part.

William Davis, who did the Malin-to-Mizen ride two years ago said, "This will be a terrific event. A challenging ride but with the support and camaraderie of a great group of people, backed up by the wonderful Sport Ecosse team. I'm looking forward to it."

If you are interested in joining the tour or you have friends who you think could be persuaded to support you and the A-T Society, please contact us without delay.

You can find further details and a reservation form at **www.atsociety.org.uk/champagne**

global's Make some NOISE to change young lives

Global wants you to Make Some Noise about A-T!

We are very excited to have been selected as one of the national charities for the Global Make Some Noise Day in the autumn.

Global's radio stations include Capital, LBC, Heart FM, Gold, Smooth and Classic FM – definitely something for everyone there!

Global is keen to work with our families and invite them to take part in programmes around the country in the run up to Make Some Noise Day. All interviews will be pre-recorded at your convenience and families will be supported to tell their stories and explain how the A-T Society makes a difference to their lives.

If you would be happy to be on local radio and tell the world about A-T, then please email **suzanne@atsociety.org.uk** who will be on hand to support you every step of the way.

Pig, Swig and Jig or Bash in the Barn checklist

If you're thinking about organising a large charity event then you'll definitely need a checklist. Queen of Big Barn events **Sara Metcalfe** has compiled one full of useful tips to help get you started.

Year before if possible!
Set the date in the diary to ensure most people are around.

Start putting the word out there that you need raffle prizes, sponsorship and that there will be a head shave or other fundraiser on the night.

Book the disco/band
Book a marquee, tables, tents, gazebos – beg, borrow or steal all of these!

Two/three months to go
Contact local supermarkets to see if they will discount/fund alcohol and food.

Start confirming any sponsors of food, provider of pig, hog roast chef or equipment if doing it yourself.

Ask local pubs if they will donate a barrel.

Set up a My Donate page for those fundraiser events or for far-flung friends who cannot attend but want to donate.

Get helpers confirmed: door staff, cooks, servers, bar staff, raffle sellers, compere if needed.

If buying booze, start looking for best deals and stock piling.

Sell tickets in advance if needed or advise that it is 'pay on the door'.

Place posters everywhere.

Facebook advertising.

Get in touch with a newspaper to do an article two weeks before with photos.

Contact the lovely Suzanne at the A-T Society for wrist bands, balloons, leaflets and other merchandise.

One month to go at least!
Apply for a temporary event notice with selling of alcohol and music licence if needed. Apply at least 28 days before your event. Costs about £30.

Double check you have the bar covered: alcohol, plastic cups, soft drinks, bar staff, an actual bar or tables, float, tins to put money in. Someone to take cash at regular intervals to somewhere locked like a safe or a house.

Double check food: who is cooking it, who is butchering the pig, who is providing said pig, tables to serve it on, bread buns, apple sauce, stuffing. How are people going to get the food – carvery style, served at tables, help yourself, do they need a ticket or is it one free and pay for a second? Float if paying for food and not in ticket price. Plates, cutlery, serving utensils.

Check you have tables for A-T merchandise, the raffle, food, the door.

Double check floats – entrance – raffle – bar- A-T items.

Raffle: if it's a noisy event then it's quicker to draw the raffle quietly during the event and just call out the winning tickets rather than try to get everyone's attention to draw it while the event is buzzing.

On the night: good money raiser is "Roll the Coin" to the whisky/ champagne bottle.

Check you have a temporary licence.

Contact your insurance company to advise that you are holding a charity event BUT make sure they don't charge you for it as is a charity function. Ask for any extra cover to be free of charge.

Sara's family and friends

Day Before
Set up and pray that your helpers turn up as do your friends and neighbours! Make sure everyone knows who pays to get in and if all helpers are free, then make sure the door staff are aware of that.

Organise a tidy-up group for the day after!

Fundraising at your school

The A-T Society is completely funded by grants and donations and we would love you to get your school involved. Here are some ideas to whet your appetite!

Cake Sale

Whip up something tasty for friends. If you're not much of a baker, pop to the shops, buy some treats and do your bit. It's the cakes that count! In the summer months you could sell drinks and ice lollies after school too – it's very popular with the children and easy to do as you can keep them cold in a big cool bag.

Book sale

A book sale is not only a great way to raise money, but it also has the advantage of encouraging reading amongst children at the school. Asking teachers, parents and local community members or businesses to donate books for sale at the school will help increase donations too. Any books that aren't sold could then be used in the school library or classrooms.

Non-uniform day

If your school usually has a dress code or if uniforms are compulsory, a dress-down day is a particularly popular choice amongst pupils. Charging a fixed donation to everyone who takes part throughout the school can raise lots of money for minimum effort!

Bad Hair Day

Everyone knows you need to look smart for school, but for one day teachers and students all across the country can let their hair down (or up!) with Bad Hair Day! Celebrate with a zany hairstyle, from pretty pigtails to marvellous mohawks to wacky wigs – the crazier, the better!

Custard pie your head teacher

We think this would be a popular one! Ask for donations in return for throwing custard pies at your headteacher or class teacher.

Do a sponsored something!

Why not do a sponsored walk, run, silence or coin trail?

How many sweets/ chocolates/1p coins in a jar?

Ask your school friends to guess how many sweets/chocolates/1p coins are in the jar and charge them 10p or 20p per guess. The person who guesses correctly wins the jar.

Use your creative skills

Make friendship bracelets, greetings cards or loom band keyrings and sell them at school.

Guess the name of the teddy bear

Get a sheet of paper and put 50 teddy bear names on it. Ask your school friends to pay 20p and sign their name next to the name of the teddy bear they have chosen. Don't forget to choose the winning teddy name in advance and place it in a sealed envelope.

Pudsey Pudsey Pudsey, oi oi oi!

Children in Need have pulled out all the stops to ensure children attending the annual A-T Society Family Information Weekend get to enjoy the event to the max.

Pudsey funded all of the children's entertainment, including transfers and trips to Legoland and The Harry Potter Experience (we think he might have used the Mobiliarbus charm for this). He even ensured the Hogwarts theme continued with a magician at the Banquet and Sunday Wizarding workshop.

For both Children in Need and Pudsey it is very special to see A-T children and their siblings having lots of fun together. Pudsey loves to know his transforming spells give children and teenagers with A-T and their siblings a voice and that they get to spend a magical time together.

BBC Children in Need

Give as you Live

Did you know you could raise a free donation for us every time you shop online at places like John Lewis, Tesco, ASOS and Amazon?

Give as you Live®

Simply shop via @giveasyoulive. Find out more at **www.giveasyoulive.com/join/atsociety**

Why you shouldn't put off writing your Will

By Louise Pavoni of Remember A Charity

Pablo Picasso, Abraham Lincoln, Amy Winehouse and Robert Burns. Well known figures who all died without making a Will.

Making a Will is one of the most important decisions you will ever make. But why is it so low on our priorities?

Writing a Will means acknowledging our mortality. Our circumstances change throughout life and making decisions can be difficult. We worry about the cost attached, and fear that we have nothing of worth in our estate.

If you haven't taken the time to write yours, you're certainly not alone. More than half of the UK population and almost four in 10 over-50s haven't made a Will. This means risking part or all of your estate going to people who you never intended to benefit, and the people you love being forgotten.

If anything, making a Will is all the more important for the parents of disabled children. Who will take care of them if you are no longer around to do so? Where will they live? And how do you balance their needs against those of their siblings? To help you get your affairs in order, here are some key points to consider.

Invalid Wills

It is easy and inexpensive to have a Will drafted by a qualified solicitor or Will writer. They will guide you through the process, ensuring everything is covered and arranged as you would like. Speak to The Law Society, who represent high-calibre solicitors across England and Wales, or find a local practitioner via **www.rememberacharity.org.uk/find**

Drawing up your own Will can be complex and risky as mistakes can render the Will invalid. It is possible to have it written online, but remember that a Will is a document that is specific to you, and a website may not cater to your needs.

Surviving spouse

It's worth bearing in mind amendments to the intestacy laws in October 2014. Under the new rules, if a person who is married or in a civil partnership dies and they have no children, the surviving spouse receives the whole estate. Previously a portion went to the deceased's blood relatives.

For couples with children, the surviving partner receives the first £250,000 plus half of the remainder of the estate, which originally reverted to the children when he or she died. The remaining assets are held for the children.

Remember that if you are not married to your partner or in a civil partnership, if you do not leave a will they have no entitlement to any part of your estate, pension, life insurance or even to arrange your funeral. Making a Will is an act of love that lives on, even after you have gone.

In light of this, it is arguably more important than ever to make a Will and be clear about your final wishes.

Another important consideration is the appointment of your Executors – the people who will deal with your estate in the event of your death. Ideally, these should be business-minded family or friends, or could be professional advisers.

Lasting legacies

After you've looked after family and friends, why not consider a cause close to your heart?

74% of the UK population support charities and when asked, 35% of people say they'd happily leave a gift in their Will once family and friends had been provided for. The problem is only 7% actually do.

It's a common myth that only the rich and famous leave money to charity when they die. The reality is that without gifts left in Wills by people like you, many of the charities we support wouldn't exist.

There is no inheritance tax (40%) payable on charitable legacies. In addition, if you leave 10% or more of your estate to charity, your inheritance tax reduces to 36%. Every gift, however large or small, helps to ensure charities like the A-T Society's work can continue long into the future.

Take action today

Why not make the first steps by speaking to your local professional adviser. Search via Remember A Charity's network of trusted solicitors and Will-writers, and start planning for your future and that of your children today by visiting **www.rememberacharity.org.uk/find**

Remember A Charity Week is 12-18 September. Become a Living Legend and share your story on the Remember A Charity website.

REMEMBER A CHARITY IN YOUR WILL WEEK

12-18 September 2016

AT society
awareness research care

Standing order form

To: {insert name of your bank}

_____

Bank address: _____

_____

Account name: _____

Sort code: ___/___/___ **Account no:** _____

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

☐ £3 ☐ £5 ☐ £10 ☐ £25 ☐ £50 ☐ Other amount

I wish to donate £ _____ **(please also state amount in words)** _____

each month to the A-T Society

Please start on ___/___/___ **and pay this amount 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 no. 41248693**

Your details to set up the standing order:

Title: _____ **Name:** _____

Address: _____

_____

Post code: _____ **Phone:** _____

Email: _____

giftaid it

Boost your donation by 25p for every £1 you donate

Gift aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK tax-payer.

I am a UK tax-payer and understand that if I pay less Income Tax and/ or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations, it is my responsibility to pay any difference.

I wish to Gift Aid my donation to the A-T Society ☐

Please notify the charity if you:

- want to cancel this declaration
- change your name or home address
- no longer pay sufficient tax on your income and/ or capital gains

If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

Please return this form to:

The A-T Society
Rothamsted
Harpenden, AL5 2JQ

Thank you!