

Spring 2019
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A-T Society News



Just William

The A-T Society turns 30 this year! **William Davis** reflects on this big milestone.

This year brings the A-T Society's 30th anniversary. It was in 1989 that a group of families living with A-T first met together in Birmingham and decided to create a formal organisation to provide information and support to families and promote research.

Today, the A-T Society is the longest established A-T organisation in the world and one of the most active. It is the only organisation to have a full-time programme of family support and advocacy and plays a leading role in coordinating and promoting research internationally to improve treatments for A-T.

Anniversaries like this are bitter-sweet. As an organisation, we would love not to exist. That would mean that we had found a cure for A-T and dealt with all the problems that before that moment A-T had caused. And over the years we have dealt with many serious and upsetting problems, and lost many friends.

However, rather than focus on what we have not yet achieved, I want us to use this as a chance to celebrate together how much we have achieved. A-T is a cruel

condition and brings plenty of problems with it, so it is good to have a chance to celebrate the positives.

In October I attended our Activity Weekend (*see page 10*), where 15 young people with A-T and their carers came together in Birmingham for a range of activities. One of the most positive and uplifting things for me was the way that using social media, the group had planned out the evening social events for themselves, choosing and booking a bar for the Saturday night and a restaurant for the Sunday.

Now this may not sound like much, but those familiar with A-T will recognise that it is a major step forward for people to be organising themselves in this way. And more generally, the buzz of conversation and level of engagement with each other over the weekend were at a level that my colleagues and I have never seen before.

This is just one small example, but in so many ways we are streets ahead of where we were back in 1989. We are putting together our plans for the year, which will include a party at the



Family Weekend, and we hope a reception in Parliament and a ball, not to mention some fundraising ideas around the idea of 30.

However, we would love to hear from you. How do you think we should mark the occasion? What have been the highlights for you of your time with the Society? What ideas do you have for how we can use the occasion to raise more money to fund our work in the future? You can call me at the office (01582 760733) or email me at william@atsociety.org.uk. I look forward to hearing from you.

About the A-T Society

Ataxia-telangiectasia, or A-T, is a neurodegenerative, genetic condition which affects many parts of the body, causing increasingly severe physical disability. The A-T Society is a national charity providing information and support to people affected by A-T and funding and promoting research. Our positive

philosophy of Live well with A-T expresses our commitment to provide the information and support to enable people with A-T and their families to live their lives to the full. At the same time, we work to improve treatments and to stimulate and fund research which will ultimately find a cure.



You can contact us on:

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Registered charity no: 1105528

ATTeST (Erydex) trial

I am pleased to report some good news for those hoping to participate in the ATTeST trial after what was a very frustrating year. The stop to new recruitment, which has been in place since the beginning of the year, has now been lifted. This means recruitment can begin again.

The trial, which is taking place in over 20 centres around the world, began last summer (2017). The UK trial centre in Nottingham was just about to begin screening potential participants in January 2018, when the FDA – the organisation which oversees drug trials for the US and thus effectively for the rest of the world – told the organisers to halt the recruitment of new participants, though those already on the trial were able to continue.

The stop was imposed after bacterial contamination was found

in a small number of samples taken for testing during administration of the procedure – a trial-requirement imposed by the FDA itself.

It quickly became clear that this limited contamination was a result of the testing procedure itself, and did not involve the actual treatment process. No participants were directly affected. Nevertheless, the FDA required changes to the trial protocol and then wanted to see that these changes were effective in eliminating the contamination. This all took time, and it was not until the end of the summer that the FDA allowed the trial to continue.

For the Nottingham team, with no participants enrolled yet, this meant a long period of inactivity, so there is work to do before screening can resume. Work is now underway and screening will begin in January.

We share the frustration of families who are eager to find out whether this treatment might work for their child. We are working closely with the team at Nottingham to do what we can to speed up the process. Nevertheless, it is vital that the trial is carried out safely and correctly. The worst possible outcome would be a trial that seemed to have a positive effect, yet where the reliability of the data were called into question.

We would like to hear from families with a child with A-T who can walk independently or with occasional brief support off and on over 10 metres, coming up to six years of age or more, who may want to participate.

Please visit attest-trial.com or call us on 01582 760733 for details.

Could ASOs ‘cure’ a child with A-T?

The A-T Society recently made a \$13,000 grant to the A-T Children's Project to fund their ASO- therapy project. This aims to use cutting-edge therapy, which has recently been used in successful treatments for muscular dystrophy and spinal muscular atrophy, to treat (initially) a single child with A-T.

ASOs are short sections of synthetic RNA. RNA is essentially a slightly modified copy of DNA. It is the RNA copy, rather than the DNA original, that is used by cells to carry out its various functions.

In simple terms, the ASO can be targeted to an area of RNA where there is an incorrect sequence of bases (the basic units of RNA). Once there, it attaches itself to mask the mistake, a bit like a tiny piece of sticking plaster. In the case of A-T, this would allow the RNA to function correctly and produce

functioning ATM protein. To reach the areas of the brain affected, the drug containing the ASO would be injected into the cerebrospinal fluid.

Initially at least, the therapy can only be used for particular mutations that affect the splicing of RNA – the process by which the long length of RNA is cut down to make a functional molecule. And it has to be said that these mutations are not particularly common. The ASO will also need to be made for each individual mutation.

If successful, this would be the first treatment to correct the neurological problems of A-T by producing a functioning ATM protein. It would show that it is possible to get drugs to the right areas of the brain from the cerebrospinal fluid. It could open the doors to new treatments, whether with ASOs, gene therapy or other approaches.



The project is being led by Dr Timothy Yu (*above*) of Harvard and Boston Children's Hospital. But the fact that it is taking place is due to the drive and vision of Brad Margus of the A-T Children's Project.

Dr Yu's team have already shown that ASOs can cause cells from people with A-T to produce ATM protein in a laboratory dish.

While this is an extremely positive step forward, many more studies of function and safety need to be carried out before the project can be tried on a human. We wish Dr Yu and his team every success.

Steve Cardy: my experience of A-T at Papworth

The majority of patients who attend the annual review A-T Clinic at Royal Papworth Hospital will know who I am. Some of you also know that I retired on 31 July this year after 10 years working as a Social Worker at the Hospital, and over 40 years as a qualified Social worker.

When I first came to work at Papworth I had never heard of Ataxia-Telangiectasia. In fact, it took me six weeks to learn how to say it, and another six weeks to learn how to spell it! Of course, I have been learning about it ever since.

For reasons that I really cannot remember, I found myself as the Social Work lead for the A-T Clinic, which meant it would usually be me that patients would see when they attended for the annual review. I have probably seen the majority of people who attended the Clinic in the past 10 years at least once; some many more times than that.

Although it is an advantage to know something about A-T when dealing with those affected by it, my greater interest has been in how manifestations of the condition

affect people's everyday lives, and how I might be able to look at ways in which community social-care services can make things more palatable.

I hesitate to say "suffer from it" because I know that not all of you see it that way: one patient told me, "I have A-T; A-T does not have me". I also use the phrase "social-care services" in the widest possible sense – to include benefits, housing, employment and access to activities, as well as what Local Authority Social Services Departments provide. The sense is also wide because different local authorities vary in their policies, procedures, practices and financial limitations, and some are easier to deal with than others – as many of you will know.

In my practice generally I would bring knowledge and information of a previous case to try and help with a current one. Often both cases involved someone with A-T. I never mentioned names but, because the 'A-T family' is so small, often the person I was talking to recognised



the person in the previous case. My response was along the lines of, "You may think that but I could not possibly comment!"

I never fail to be impressed by the resilience of those with A-T and their carers, and the things they all get up to – from parachuting, karting, shooting and eating their own dinner – much of which gets reported in the pages of this magazine. Plus, of course, our very own TV star of the Children in Need Rickshaw Challenge. Conversely, I feel for those whose condition and situation is much more challenging, and for the families of those who have sadly passed away.

I would like to say how much I have enjoyed meeting and working with you all, and hope that I have managed to do a little to help you along the way. It is a lot less than the A-T Society does on a day-to-day basis. I also want to say what a pleasure it has been to work with Kay, Anne and William. The Social Work Team at Papworth Hospital will continue to have input into the A-T Clinic: they are all very good at their job and will do their best to support you.

Natural history study in Nottingham

By Dr Emily Petley

At the University of Nottingham, we have started a project looking at the natural history of A-T (N-HAT).

The natural history of a condition is a detailed description of how it develops and progresses over time. This understanding is essential for determining the timing of treatments and support, and to help patients and their families understand and cope better with the condition. It can also make a valuable contribution to clinical trials.

Through many years of experience, the clinic teams in Nottingham and Papworth have an excellent understanding of A-T and when particular symptoms are most likely to occur. They have also collected a lot of data. However a formal study on the natural history of A-T has never been done.

The aim is for this study to provide more evidence and information that can help improve treatments and support and hopefully guide future studies into a cure for A-T.

Adults and young people with A-T seen in the Nottingham or Papworth clinics will have received, or will shortly be receiving, a letter with more information about the study. Initially, no active participation is required from people with A-T, however in the future we will be holding some small focus groups to determine what is important in research to patients and their families. Information will be in the letter you receive.

We are very grateful to the A-T Society for their financial and other support to the project.

Nottingham gene-therapy project making progress

A project led by Dr James Dixon (Regenerative Medicine and Cellular Therapies Division, University of Nottingham), which aims to treat A-T with an innovative gene-therapy approach, is making good progress, both technically and in terms of gaining funding and future support.

Dr Dixon's team have now engineered a synthetic full-length ATM gene into their non-viral gene therapy system and are ready to start experiments showing that they can be used to insert the gene into cells taken from people with A-T to augment the missing ATM protein.

The team have re-engineered a full-length ATM gene both to make it express the missing ATM protein more strongly and to make it resistant to being 'turned off' prematurely. This means that if a treatment for people with A-T is ultimately developed, it may not need to be given as a therapy so regularly.

Spotlight on steroids

In another interesting development, the team has also engineered a version of the so-called 'mini-ATM' which has been identified in people with A-T treated with steroids (for example with the EryDex System). This will enable them to compare the effects of this with the full ATM gene and potentially throw light on the effect steroids have on A-T.

The genes engineered are the form of a large circular loop of DNA – rather like a circle of rope. Most therapies involving genes use modified viruses as these can efficiently package genes up to a

certain size.

The ATM gene is too long for viruses so an alternative approach is needed in A-T gene therapy. Dr Dixon's technology squeezes the DNA down into a compact 'ball' (or nanoparticle), which is designed to be safer and still as effective as viruses at entering cells. It will also be cheaper and faster to develop as a medicine, which is vital to attract industry to develop the technology into a viable treatment for A-T.

The next stage will be to demonstrate that they are able to insert these ATM genes into cells from people with A-T and that it will then function to produce active ATM protein – also finding out how long it works for. In parallel, together with colleagues at Johns Hopkins University (Baltimore, USA), they have started work on how to get the vector taken up by brain cells, which is key if a treatment is to be developed.

Slowing or halting the ataxia

The initial aim is delivery of synthetic ATM genes into neurons in the brain's cerebellum because they seem to be most affected by the loss of the ATM protein. The objective would be to slow or halt the ataxia and other movement disorders in A-T. While this is still the central aim of Dr Dixon's work, as the ATM genes are now engineered, the team have also started to explore the potential for using the technique to address the immunological symptoms of A-T.

To do this, they are looking to modify cutting-edge cell therapy techniques by modifying blood cells in a similar way to powerful CAR T-Cell cancer treatment,



Dr James Dixon

licensed for the first time in 2017 and hailed as a game-changer in cancer treatment.

Funding

Funding for the project has come from a range of sources. The A-T Society funded the vector-engineering work and the A-T Children's Project have awarded a grant to take this work forward into A-T cells and the brain. The team are currently applying to other funders for their work on the immunological problem in A-T. They have received a grant from the Birmingham-Nottingham Strategic Collaboration Fund for partnership work on the project with the University of Birmingham to develop the therapy platform.

Dr Dixon was interviewed about his work by Brad Margus at the A-T Society's Family Weekend in June. While nothing in research can be taken for granted, there is a good deal of interest in this work and it is certainly one of the most promising areas of research focused on developing a treatment for people with A-T.

Research is the key to unlocking a cure for A-T. It costs £5,000 a month to fund a researcher. Please donate to help fund projects seeking new treatments.

Race running by Eleanor Hewitt

As some of you know, I have been heavily involved in sports and exercise since my diagnosis at the age of 16: that is 17 years of exercise! It seems a long time when you put it like that but from a young age I have firmly believed that prevention is better than cure. I believe that with my healthy lifestyle and can-do attitude, I am slowing or halting the progression of A-T. A healthy diet helps but remember that whatever your ability, where there's a will there's a way!

Anyway since getting my recumbent trike (which I love!), I have been working more on stabilising the muscles of my legs and ankles. Over time, I found that the nerves to the ankle and foot muscles and the muscles were degenerating. With my can-do attitude, I started to fix the root of the problem. If you don't use them you lose them. My thinking is that if I can maintain the muscle strength I can also prevent/slow the nerves from dying by stimulating them.

After a few months of strengthening these muscles I could see results on my foot/leg positioning on the bike. I heard of a children's gym opening near me that was going



to be equipped with upright cross trainers that the user is strapped into. This obviously enthused me and inspired me to look up a walker that I could use. I saw one such thing, a sports walker, from a company I knew of that sells sports equipment. I found out that they were called RaceRunners. Within a short space of time and a few internet searches, I had found a local (ish!) club and a whole community surrounding it. As RaceRunning has lots of health benefits I've found a new goal!

RaceRunning is run by CPSport. Visit their website for details: www.cpsport.org/sports/racerunning/

Sophie reviews disabled friendly places in magazine

Sophie Wood lives for part of the year in Fuerteventura in the Canaries and it was while she was looking for activities



to keep her busy that she saw an opportunity to help others with restricted mobility visiting the island.

Sophie became a writer for "The Voice" magazine in Fuerteventura and was given her own column called 'Sophie's Choice'. She now spends some of her free time visiting tourist attractions, restaurants and testing out excursions, assessing their facilities and then reviewing them in the magazine.

Sophie hopes that her recommendations will help people with restricted mobility and their carers to navigate their way around the resorts more easily. Visit her page at www.bit.ly/SophiesChoiceFV

Cause for celebration

Congratulations to George Keibel who has reached his first big milestone since the end of his chemotherapy treatment earlier on this year.

To celebrate reaching the official end of his cancer treatment, this epic milestone after enduring three years of treatment, George was invited to "ring the bell". His school also held a party for him to celebrate this occasion with his friends and teachers.



Well done George – you are a superstar!



Helen and George enjoy their 'Willow Special Days'

Helen heads to the West End

By Joy Carter

The Carter family applied for a Special Day for Helen after the charity Willow came along to our Family Weekend last year and explained about the 'Special Days' they organise for people aged 16-40 with life-threatening illnesses.

Helen, her carer Joanne and I had a great time at the Lion King show in London on a trip organised by Willow's 'Special Day' team. They organised everything; even when we had

to cancel the first time due to the bad weather, they just rearranged everything for another day.

The team did an excellent job and thought of everything. They arranged tickets for the show, an overnight stay at a Premier Inn with breakfast, train tickets and even taxis to and from the station and the theatre.

We arrived in London on Friday by train and went out for dinner before the show. Helen really enjoyed spending time getting ready for the Lion King and the show was wonderful.



It was such a lovely break and so well organised – we had a great time and Helen loved her 'Special Day' out. I would highly recommend applying to the Willow charity to build your own 'Special Day'.

George celebrates his birthday in style

By Michele Keith

George loves drama, music and the performing arts, so when I asked what he would like for his Willow Special Day he said that he would love to go and see Aladdin the Musical in London. We were contacted by our coordinator, who set about booking the tickets, hotel for overnight stay and high-speed train tickets to London. All was confirmed by letter and about a month before the trip we were sent all the tickets and information we needed along with contact numbers in case we had any problems.

We chose the weekend of George's birthday to go so it was a double celebration. The Saturday morning arrived and we

got the train to London, checked into our hotel and then were picked up by taxi to take us to the theatre. When we arrived at the theatre the staff were extremely helpful and helped us to our seats via a disabled entrance and stored George's wheelchair away safely!

The show was absolutely fantastic and I would highly recommend it to anyone, George loved it. When we came out of the theatre it was pouring with rain so by the time we arrived in Covent Garden we were soaked! We had a lovely meal at Flat Iron, well worth the wait, and we were then picked up by a taxi and taken back to our hotel, where we had a few cocktails to end the day.

We returned home the following lunchtime after a lazy late breakfast. We would like to thank all those at The Willow Foundation for a lovely Special Day, one to treasure and have great memories



of. We certainly didn't let the wet weather spoil it for us!

It was George's 22nd birthday on the Monday so he rounded off celebrations with a night out at his local nightclub for adults with special needs, disabilities and learning difficulties held at Gillingham Football Club, called GBeatz! The theme for the night was Hippy! He had a great time with all his friends and his PA. Needless to say he had a sore head the next day!! All in all he had a fantastic birthday weekend.

Willow's Special Days are designed to provide an uplifting and positive experience to be shared with family or close friends. From afternoon tea and theatre trips to sporting events or theme parks, there's a 'Special Day' experience to suit everyone. To apply visit www.willowfoundation.org.uk.

Another successful Family Weekend

Families gathered at Stansted's Radisson Blu Hotel in June for an informative and fun-filled weekend.

At the end of June over a third of our A-T families, friends and carers attended our annual Family Weekend. The event started this year on a Friday night with an informal BBQ followed by an informative fireside chat with Brad Margus (Chairman of the A-T Children's Project in the USA). In an engaging and easy-to-follow manner, Brad interviewed James Dixon of Nottingham University about his 'Gene Therapy' project. After the chat there was plenty of time to catch up with old friends, meet new ones and celebrate Vanika and Vanshika's 15th birthday. The music and chatting went on well after the sun went down and the stars were out.

On Saturday the children headed off to Paradise Wildlife Park while the adults with A-T attended workshops about 'Living well with A-T' in the morning. This was followed in the afternoon by some 'me' time. Some adults opted for a makeover in the 'look good, feel great' workshop and a therapeutic massage, while others signed up for an adrenaline rush in the virtual-reality suite where they could experience the sensation of terrifying roller-coaster rides or overtaking the field in an F1 race at Silverstone.

"The family weekend is the only time we never have to explain why our family is the way it is."

For the parents and carers, a full agenda of presentations and workshops were planned for the day. Disability rights campaigner

and actress Samatha Renke opened the talks on Saturday with an upbeat speech about living with disability and challenging public perceptions. Her talk was peppered with personal anecdotes which many in the audience could relate to and she answered lots of questions from the floor at the end of her talk. She was a hard act to follow but our doctors and researchers held their own with updates on the latest research projects, from stem-cell research to the Catnap study and the ATTest Trial.

After lunch the research and medical team were on hand to answer questions from the floor. These ranged from questions about medical issues such as skin conditions and blood testing to questions on research and developing treatments.

A thought-provoking focus group run by Dr Andrew Prayle and James Dixon about potential new treatments for A-T and how they might be administered followed. A workshop on 'How to talk to your child about A-T', which gave parents the chance to share their experiences and learnings, proved to be a positive but emotional event.

After a busy day, it was time for everyone to socialise and let their hair down at the banquet dinner. Magic Frostie amazed us with his wizardry and a slideshow highlighted all of the amazing fundraising events our families have organised on behalf of the A-T Society over the past year. After dinner it was time to party and the dance floor was busy with

an eclectic mix of song requests flying in from the dance floor. Everyone danced the night away, with Ebony Robinson even taking on a slot as guest DJ.

"For us, the Family Weekend is invaluable. It's a chance for us to see old friends, meet new people, have a break from day-to-day life and share tips and ideas with other A-T parents."

Over a buffet breakfast on Sunday morning our inspirational adults with A-T shared their experiences of the activity weekend and Rachel gave a funny and moving personal account of her life growing up with A-T. William Davis, the Society's Chief Executive, closed the weekend with a speech highlighting the work that the charity does and the Society's plans for the future. Then it was time to say goodbye, with lots of emotional farewells and promises to catch up before the next family weekend – which we're already planning!



Our flagship event this year was made possible by a sizeable grant from Global's Make Some Noise, who funded over half the cost.

A donation of £50 could cover the cost of a child at the Family Weekend enjoying the day's excursion with their carer while their parents attend workshops and informative talks.



From left, row 1: Brae and Kira; Chilling out; Alecia having a makeover; Vanika and Vanshika. Row 2: Brooke happy to be here; Brooke, Hannah and Ryan; Brae and Kaid. Row 3: Kaid; Charlie having his makeover; Sam Renke. Row 4: Rachel on stage; Girls (and William) on stage; Vanika and Vanshika birthday celebrations. Right: Brad and James fireside chat.

Fun and laughter on the A-T adult weekend away

In October we headed up to Birmingham for a fun-filled weekend! (At people's request it was a more sedate and relaxed event compared to last year's activities in the Lake District.) The main thing that people wanted to get out of it was a chance to meet up, socialise with each other and to share their experiences.

It started on a very blustery wet Friday. Travelling by train or car, 14 adults with A-T and their carers battled their way through 'Storm Callum'. Thankfully everyone arrived safely! Kay, Kevin, William and Ann Highley were on hand to meet and greet everyone. We were staying in a hotel in Brindley Place in Birmingham which was a great location. The area was very accessible and pedestrianised so it was easy for everyone to get out and about and explore. Some people headed off to the nearby Sealife Centre to meet the penguins and apparently some very old turtles!

On Friday evening we all got together for a welcome buffet dinner, a few drinks and some ice-breaker games. We called it 'speed meeting'. It was great fun and a good way for everyone to get to know each other.

On Saturday morning we had a workshop called 'Good and Bad Days' facilitated by Rob Michael-Phillips. This was an opportunity for people with A-T to talk about things together and share the things that frustrate them. The discussions will help us in planning future work of the Society and our 'Live well with A-T' project.

In the afternoon there was an opportunity to try a 'Virtual Reality Experience', featuring rollercoasters, car racing and go karting. We also had board games and some of the ladies



Clockwise from top left: Charlie and Grant; girls strike a pose; party crew; Catherine and her sister; all aboard the wheeltrain!

took themselves off for a spot of retail therapy!

In the evening there was a banquet dinner and then it was off to a nightclub. This was organised by the group themselves – the staff opted out! All had a great time and rolled in at around 2.30am!

We took it easy on Sunday morning, with a lie in and late breakfast. We then boarded an accessible coach and headed off to the Dudley Canal Trust. It was pouring with rain but everyone was in high spirits – until the coach broke down! However, we got there in the end and had a great time on

the canal boat going through the Dudley tunnel. The boat was very easy to access so it was reasonably straightforward getting everyone on board. The rain stopped and a good time was had by all; some of the carers even had a go at 'Legging' (pushing the boat with their feet on the walls!).

On the Sunday evening we all headed off to 'Jimmy Spices Global Buffet' – great food and company, then into the bar for a few drinks!

On Monday morning everyone headed home, tired but happy, all asking 'What are we doing next year'? Watch this space...



Clockwise from top left: Last night meal; Becky and Jilly; Catherine and Henry, Grant and Martin at the bar; Canal boat; Henry, Ebony and Charlie; Amy and Alecia laughing; Becky never stops, except to shop!



"I had such a great time at the Activity Weekend. The best thing I got out of it was meeting up with everyone and having a chance to chat and have fun together. I really like sharing ideas with each other and finding out what they do and how they do it."

The best bit for me was going out to the club on the Saturday evening. We had decided where to go between us and we had organised and reserved a space (thanks to Jilly). We all got dressed up and off we went! We were having a great time and I noticed a group of people next to us and I smiled at them. One of the girls came over to us and asked if they could join us, they said they weren't sure how to approach us at first, but they saw we were having a great time and wanted to join in! It was great as they danced and drank with us and I felt really good, we were just like everyone else, having a night out on the town!

Following that we have now created a 'WhatsApp' group and we are now planning to get together again for another fun night out!"

Becky Simpkin

Back to school!

The new school year has started and lots of our children are off to school. We are proud of you all!

Kay and Anne (our support team) give advice to many schools/ colleges on the issues that children with A-T may have and they can arrange visits to give a talk about A-T to the staff, (which includes an overview of A-T and health issues).

In the past year they have visited 14 schools and colleges, from Scotland to the South West of England and everything in between!

The main difficulty schools/ colleges have is understanding the complexity of A-T and how it affects the children. It is easy to look at a child and say, 'They are not too bad just a bit wobbly'; however we know there is a lot more going on than that and the child needs a lot of support. We talk to the school/ college about issues such as:

1:1 Support: We recommend that all children with A-T have full-time 1:1 support for help in the classroom, getting around the school and break/lunchtimes.

EHCP: We recommend that every child has an EHCP (Education and Health Care Plan) put in place. We can provide supporting evidence for the school to help with this.

Fatigue: We talk about how this will affect everything the child does in school and give advice on limiting the amount of lessons/school work as well as having regular breaks and snacks to keep up energy levels.

Reading & Writing: Advice on how reading will be difficult and how aids like a book board and large print can help; we also recommend early intervention of IT support to take the pressure off writing and to find alternative ways to record work.



From left to right, row 1: Max; Cian; Brae and Broghan. Row 2: Jake; Daisy; Erin. Row 3: Jessica; Toni-Jo; Brooke.

Posture and Seating: We recommend supported seating in the classroom and in the dining room (as good posture can help with fatigue and give good support while eating safely).

Emotional Support: It is vital that as well as practical help the child is also offered emotional support, whether that is from services within the school or outside agencies, as they come to terms with their deteriorating condition. (Obviously

with permission of the parents). There are many other things that we can help with. We produce a leaflet specifically for schools (which can be downloaded here www.atsociety.org.uk/about-us/our-publications-and-films/factsheets).

We also offer ongoing advice from here in the office and we can Skype into meetings as necessary (unfortunately we cannot travel to every meeting). Please do contact us for information and support.

‘Live well with A-T’ project

By Anne Murray

Every life is priceless and unique for what it is, not what it isn't, and the A-T Society places a strong focus on the possibilities of living full and active lives with A-T.

As you know, the daily support and advocacy work carried out by Kay and I is core to the A-T Society's philosophy. This work starts from diagnosis and continues for as long as the individual or family wants or needs it.

Most of us are also already aware that the transition from children's services to adult services is epic – some liken it to 'falling off the edge of a cliff'! Particular issues begin to crop up as the young person leaves full-time education and finds themselves without meaningful activity and with reduced opportunity for regular contact with friends and/or other people their own age. This often leads to social isolation, which is universally known to have a negative impact on a person's overall health and wellbeing.

The A-T Society has long wanted

to broaden its scope and develop a support project which focuses on adults living with A-T. The need for this focus is even more apparent due to ongoing cuts to local services in recent years: cuts which have led to loss of funding for many aspects of local provision.

So, with this in mind, our 'Live well with A-T' programme is currently being developed. The project aims to recognise and celebrate the achievements of adults with A-T and find new ways to encourage and support them in living their lives their way.

Over the past 12 months we have hosted several consultation meetings to gather thoughts, views and experiences on this topic. Contributions have been made by a variety of external professionals as well as many adults living with A-T and their parents/family members. Kay and I have also been gathering anecdotal evidence from our advocacy and support work. A recent series of home visits to spend time with several young adults has also helped us to better understand what is important to

adults living with A-T.

We have identified three young adults in need of immediate support and we are working on ways in which to assist them to meet their needs. Their thoughts, views and experiences will help us to develop a framework for this project.

To supplement the limited resources we have in-house, we have drafted in additional expertise from people such as Ann Highley. For those of you who aren't aware, Ann was Rupert Prokofiev's care coordinator. We know that increasing our focus on adults 'living well with A-T' was something very close to Rupert's heart (as it is ours) and we are committed to further develop this area of our work both in honour of Rupert and all other adults living with A-T.

As a result of this collaboration, one of the main aims identified so far is to hire a Personal Assistant to help each of these three young people access meaningful activities locally....and, to quote one young woman, "get a life"! Please watch this space for further updates.

Date for your Diary!

Family Weekend 2019

A-T Society 30th Anniversary Year!



28-30th June 2019

East Midlands



In 2019 it will be 30 years since the A-T Society was born! So please do put the date in your diary for our Family Weekend. We will be at the Radisson Blu Hotel – East Midlands Airport.

We are planning lots of exciting activities and international speakers. There will be a fancy-dress theme of 'The Eighties' so get planning!

More information coming out to you soon.

Fundraising

THANK YOU! We think you're all AMAZING!



Alecia Yarlett celebrated her 20th birthday with a sponsored 52-metre ascent up and over the iconic O2 Arena in London.



Jackie and Alan Blount, Adam and Paul Doyle, Gary McAllister and Julia Macartney formed a winning London 10K team.



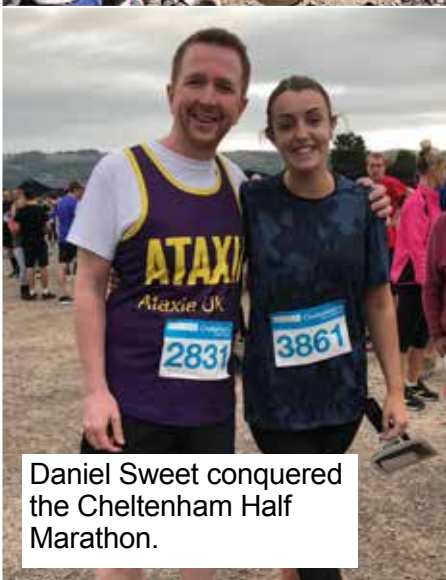
Cheryl Williams ran a popular A-T Society stall at Hosted School Fete.



Charlotte Pethen and her sister Liz have taken part in 26 Park Runs as part of her ongoing fundraising efforts.



Justine Sprawling and her Gung-Ho! Gang of friends – Sandra Eglington, Judith Mears, Susan Semrau and Kris Wagg – took on the 5K assault course in Earlham Park, Norwich.



Daniel Sweet conquered the Cheltenham Half Marathon.



Congratulations to John Arnold and everyone who helped make Chard Rock our favourite festival this summer!



Claire and Gemma Magee took on the Manchester Half Marathon.



Cadence and Concordia Choirs teamed up for a very well-attended evening of song in Bridgnorth.



Dingle School sold Easter chicks made by knitting Nora (Orla Ward's Granny) and friends.



Helen Skippen at Equiniti motivated all her colleagues to raise money by dressing down for work.



Annette Hughes and Sue Evans took part in Bridgnorth walk.



Finn McCann and his classmates in year 10 at St Patricks Academy in Dungannon organised a day of fundraising sports and activities plus a popular cake sale and summer sports day.



Richard Picton pedalled all the way from Wolverhampton to Aberdovey.

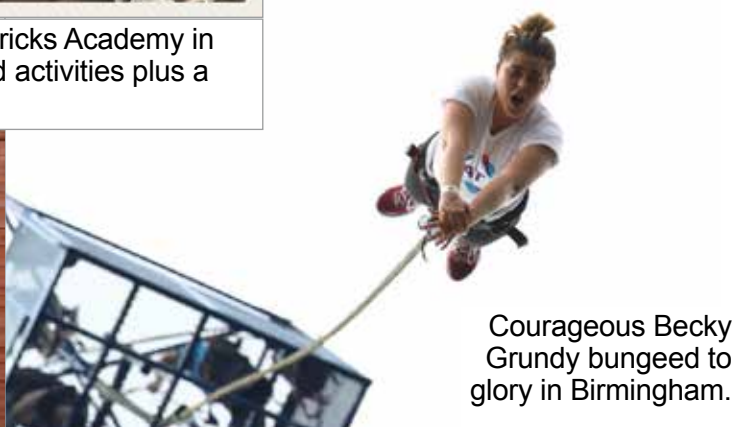


Telford College generously supported us as their Charity of the Year.

Pizza Hut hosted a very successful tea and cake fundraiser.



Thank you to all those who have used Facebook to think of us and raise money by asking friends and family to donate money instead of giving birthday gifts.



Courageous Becky Grundy bungeed to glory in Birmingham.

Jim Thompson organised an evening river-boat trip from Totnes to Dartmouth to view the Regatta firework display.





Mark Nolan-Smith pulled out all the stops for the English Half Marathon in Warrington



Sinead Ward had a circus-themed 'Hook a Duck' stall at Haslington Village Fete.



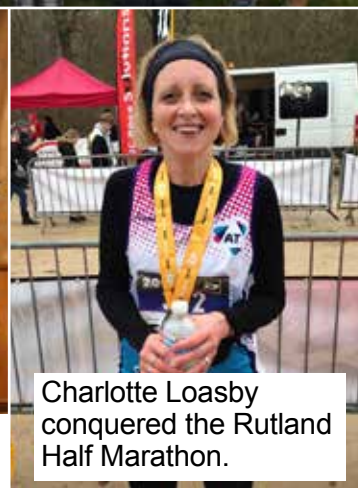
Inspired by Winston, Joe Powell and 'Team Hulk' ran the Hastings Half Marathon.



Lee and Terri Goble, Vickie Dobson, Darren Shultz and Sarah and Jim Hyde took on the Yorkshire 3 Peaks Challenge with gusto, climbing a total distance of 24.5 miles.



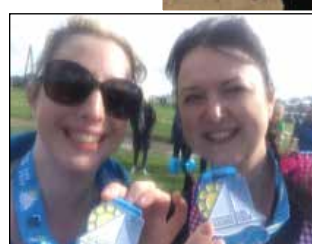
A wonderful evening was had by all who attended the Magic Voices Choir Concert at St Nicholas' Church, Harpenden.



Charlotte Loasby conquered the Rutland Half Marathon.

Swanton Morley V.C. Primary School

Swanton Morely Primary School held a very popular 'dress down or dress up' day



Sinead Ward and Helen Higham gave the Southport seaside 10K their all.

London Marathon superstars

We were super proud to have two runners representing us in this year's London Marathon! Ben Protheroe was inspired to take on the challenge by his good friend Henry Wright, and Charlie Johnston chose to support us in memory of his friend since childhood, Ian McInnes.

Together, Ben and Charlie raised more than £10,000 by completing the hottest London Marathon on record! They certainly deserved the impressive medals they were awarded at the finish!

Henry, his mum Karen and Ben's then fiancé (now wife) Claris set up a cheering station on the route complete with A-T coloured balloons and an enthusiastic team of supporters,



Ben and Charlie's cheering station; Ben Protheroe; Charlie running past the palace; a hug for Henry.

including Community and Events Fundraiser Sarah Ajder and her husband Milorad.

The biggest cheer was when Ben was spotted and a hero's welcome given when he stopped



briefly to give Henry a hug. A truly remarkable and memorable day.

A winning walking team

The City Ground Walk was organised by Mark and Hayley Carrington who rallied a large team of family and friends to put their best foot forward and walk 17 miles from Sutton-In-Ashfield to the Nottingham Forrest Ground in April.

Their combined sponsorship, plus a collection along the route and a grant from Asda – where Hayley works – all helped to raise nearly £4,000!

The original plan was to watch a match at the end of the walk but the 'Beast from the East' caused



the walk to be postponed. True commitment was shown and the team turned out in full force on the new date, with a couple of friends walking it solo who were unable to make the new date.

Very well done to everyone in the City Ground team. You are top of our league!



Donations in lieu of presents make any birthday or anniversary special. Facebook now offer the facility or set up a 'celebrate someone special' fundraising page with BT MyDonate to reach family and friends near and far. See website for details.

Joe's marathon camping trek challenge

Joe Bromwich wanted a challenge. He initially considered the Brighton Marathon but logistics ruled that out. Undeterred, Joe created his own local marathon distance challenge with an overnight camping stop to break up the distance travelled each day. With the support of his key worker Richard, the plan was hatched and carer Trevor offered to join them too.

The overnight camp was set up by Richard's fellow residents and their key workers ready for when they arrived. They all enjoyed a barbeque together before leaving the weary travellers to get some sleep.

The going was tough in places, especially on the second day, but together this fabulous team raised more than £1,500! What a great inspiration they are!



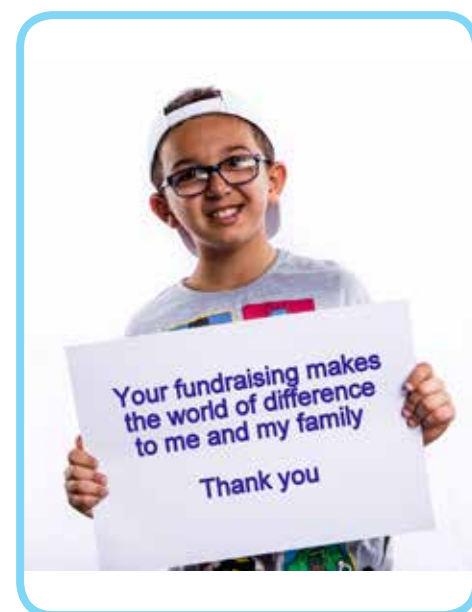
Clockwise from left: Richard Davies, Joe Bromwich and Trevor Dunn; home for the night; Joe clocking up the miles.

Jilly's wedding cake is a hit

Richard Marshall, brother of Catherine, married Helen in September. His firm request to his wedding planner (Helen!) was that Jilly Shah should make the cake. This was after seeing her presentation with her sister at the A-T Family Weekend a couple of years ago.



The result was a spectacular three-tier cake with alternating lemon and chocolate layers and pink sugar roses. For any celebration that needs a cake, which you can pick up from Harrow, please contact Jilly. All funds go to the AT Society.



Over the course of a year a gift of £5 a month could pay for information packs to be sent to 12 new families.



Nora Roe's fantastic fundraising efforts

Inspired by the recent diagnosis of her grandson Jack, Nora Roe has tirelessly been drumming up support amongst her colleagues at BT, with some fantastic results.

They have organised a variety of successful fundraising events, such as a quiz night and an appeal for donations at a business conference. Nora has also encouraged friends and family to get involved in fundraising too.

Gunge a Goldstar!

Good sports Tyler Maycock and Tony Allford win the prize for the most imaginative and messy way to fundraise this year!

Friends of Becky Simpkin, these lovely lads work as Goldstars at Golden Sands Holiday Park, Towyn and raised more than £1,000 during the summer season by having buckets of green slime tipped over their heads every week!



An art exhibition remembers Rupert

Many of you will have met or read about Rupert Prokofiev, who died in January 2017. Rupert was a greatly-loved member of the A-T community, a friend and inspiration to many, and a strong supporter of the A-T Society.

In January 2019, his mother, the artist Frances High, is putting on an exhibition of prints and drawings in Rupert's memory at the White Box Art Gallery in Blackheath. Entitled A history in portraits: drawings of Rupert and his Family, the

exhibition runs from the 6th to the 27th of January. The gallery is open from 11 to 6 at weekends and from 2 to 5 on Thursdays and Fridays.

Frances and her family extend a warm invitation to come and see the exhibition.



Corporate fundraising

Meet the brilliant companies that have chosen to support and raise funds for the A-T Society.

Jarvis Home

We were blown away by the dedication of staff at Jarvis Homes to fundraise for us when a team of 28 of them signed up to skydive! Read a full account of this extraordinary event on page 22.

Staff from the A-T Society office joined staff from Jarvis Homes for a rousing sing-along at a wonderful event in Harpenden organised by Mike Hodge. Guests were treated to an eclectic mix of songs from the 60's, 70's and 80's and everyone sang their hearts out! This fun event raised over £4000 for the A-T Society.



Countrywide Nottingham

Members of staff from the Nottingham office of Countrywide chose us as one of their two charities of the year. They organised a cake sale and a quiz night to raise awareness and funds. Our huge thanks to Lisa-Marie Cousins for spreading the word and to everyone at Countrywide for their support. Kira and Hayley Carrington went to thank the team and collect a rather splendid cheque.



M&S Bridgnorth

Bridgnorth M&S is a shining example of community support in action. They chose the A-T Society for the second year running as their Charity of the Year.

Staff and customers have been unfailing in their support, with various fundraising events and activities including staff raffles, carol singing, sponsored walks, a challenging walk up Mount Snowdon, collection pots on tills, and a cheque for £1,000 from carrier-bag donations.

Joy, James, and Rachel Ferguson also made the most of the A-T Society's second stint as Charity of the Year, with several in-store collections. Huge thanks to Sara and everyone else who works and shops at M&S Bridgnorth!



If you work for or know of an organisation that would be interested in fundraising for the A-T Society, then we would love to hear from you. Please email william@atsociety.org.uk or call the office for a chat on 01582 760733.

Taking to the skies

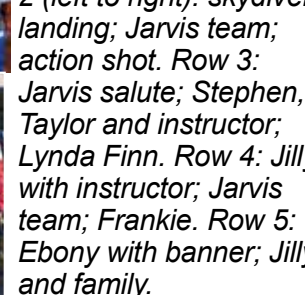
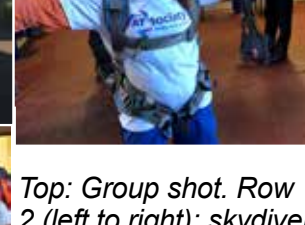
Looking for a new challenge with an adrenaline rush, Ebony Robinson signed herself up for a tandem skydive and managed to persuade Mike Peters, CEO of Jarvis Homes, to join her. Mike met Ebony when he sat next to her at a dinner in support of the A-T Society hosted by local MP Bim Afolami. When Ebony, who uses a wheelchair, told Mike a skydive was on her bucket list, he replied that he was frightened of heights. "Well, if I can do it, I'm sure you can!" came Ebony's challenge. And with a bit of arm-twisting, Mike duly signed up!

Moved by Ebony's story and their boss's courage, many of his colleagues signed up in support, and competition ensued between different teams within the Jarvis group to see who could raise the most money for the A-T Society.

The skydive was booked in for September. It was shared on social media and we were overjoyed to get more interest. We now had another seven fantastic adrenaline junkies wanting to join in, bringing the total to 36. This included some people with A-T and their families: Alecia Yarlett's sister Frankie was one of the first to sign up. Alongside Ebony we had Jilly Shah with her brother Arjun and brother-in-law Anuj and Stephen Wells and his cousin Taylor. We were also thrilled that one of our Trustees Lynda Finn courageously got involved.

On the day of the event, we couldn't have been luckier. The weather was absolutely glorious and clear blue skies were forecast for the whole day, which is obviously what you want when you are jumping out of a plane at 15,000 feet!

Our first batch of intrepid skydivers were kitted out in jumpsuits and very fetching helmets and set off in the aircraft by about 10am. Everyone was cheering them



Top: Group shot. Row 2 (left to right): skydiver landing; Jarvis team; action shot. Row 3: Jarvis salute; Stephen, Taylor and instructor; Lynda Finn. Row 4: Jilly with instructor; Jarvis team; Frankie. Row 5: Ebony with banner; Jilly and family.

on from the ground and, as the weather was so perfect, we could see them clearly as they jumped from the plane. One of the first people back on the ground was Mike from Jarvis who said, "It was pretty hairy actually!"

The day continued as smoothly as it had begun, with a number of teams of five skydivers all taking to

the skies. We watched group after group tumbling out of the plane and drifting slowly to the ground. As nervous as they had been on the way up, all of them found the actual experience thrilling. Some of them even wanted to do it again! And all were proud that they'd been able to share the experience with friends and colleagues and to contribute to the work of the A-T Society.

Help us celebrate our 30th anniversary

In 2019 it will be 30 years since the A-T Society was born and we've come a long way since then! We are planning lots of exciting activities throughout the year and would love for as many of our supporters as possible to get involved and help mark the occasion. Every penny raised makes such a difference to the people and research projects we support. Here's some '30' themed fundraising ideas we've had – some are more energetic than others!

- Run or walk 30 miles over a week
- Get sponsored to lose 30 pounds
- Give up something you love for 30 days e.g. chocolate, smoking, Coronation Street, social media...
- 30 challenges in 30 days
- Swim 30 lengths
- Invite 30 friends over for a coffee morning
- Bake and sell 30 cupcakes at school
- Wash 30 cars
- Do 30 good deeds
- Go to 30 exercise classes
- Raise £30

Other fundraising ideas

Are you an online shopper? Why not register with Give as you Live? Every time you shop online at more than 3,900 online stores, including Amazon, eBay, Tesco, John Lewis, Sainsburys and the trainline, Give as you Live will make a donation to the A-T Society.

www.giveasyoulive.com/charity/atsociety

If you shop on Amazon, did you know you can sign up to Amazon

Smile and select the A-T Society as your chosen charity? That way we get a donation from them every time you shop! All you need to do is start your shopping at smile.amazon.co.uk. The donation will be made at no extra cost to you.



Forthcoming challenge events:

Brighton Marathon, Sunday 14th April

The Brighton Marathon is the second-largest marathon in the UK. With fresh sea air to invigorate you and a flat route that takes in the stunning coastline, it's perfect for seasoned runners and beginners. Our A-Team will help us celebrate 30 years of making a difference with a post-race tea party by the sea! www.atsociety.org.uk/events.



Ride London, Sunday 4th August 2019

Beginning at the Queen Elizabeth II Olympic Park, the route passes through central London. It then heads out to the scenic Surrey countryside and some testing climbs, before coming back into London to



finish in front of Buckingham Palace. Register for just £30 with no minimum fundraising commitment but an incentive of a free cycling jersey when you raise £300 plus.



We would love you to support us at any of the numerous sporting and fun events taking place all over the country throughout the year. Keep an eye on our Facebook page for ideas of events and book your place to become a fundraising hero for the A-T Society!

Contact us on 01582 760733 or email info@atsociety.org.uk.

Or for more details visit our website www.atsociety.org.uk/events.

The opinions expressed in the A-T Society News are those of the individual authors and not necessarily those of the A-T Society.

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!

We would like to keep your details and use them to inform you occasionally about our activities. We will not pass your details to any other organisation. If you are happy for us to do this please tick this box ☐