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Winter 2015
No. 51

A-T Society News

In this latest edition

- We welcome new trustees to the board
- New guidance on lung health
- Study into new A-T like condition
- Research news from Beijing workshop
- New fundraising ideas and achievements

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

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

Cover picture: Brae Sewell

Just William

William Davis, chief executive of the A-T Society, reflects on the recent A-T workshop in Beijing

I have just returned from Beijing, where I attended the latest A-T research conference. The A-T Workshop (ATW) series always tends to focus on the basic science – that is research in the laboratory seeking to understand the role of the ATM protein and how its absence causes the symptoms of A-T.

There are some really able and committed scientists working in the A-T field and it was good to meet up with them and hear about their latest work and thinking. I was struck again by the passion they clearly feel for the subject and their determination to get answers to the fundamental questions. It was also really positive to hear how many different approaches are being explored and to share the ‘buzz’ as they discuss how others’ findings might illuminate their own work or theories.

However, while hearing of their latest discoveries is fascinating and listening to their arguments and deductions is exciting, I could not avoid coming away with a sense of frustration. For all the advances being made and for all the cutting-edge science being developed and used, answers to the questions remain stubbornly out of reach.

The main question focused on at this conference was why and how the absence of the ATM protein leads to the neurological symptoms of A-T. As a question, it seems simple enough, but answering it is anything but.

Initially it was thought that it must be a question of repairing double-strand breaks to DNA. Everyone recognises that ATM has a role in this as do many of the other proteins whose loss gives rise to conditions with similar neurological problems (e.g. MRE11 or the proteins involved in AOA1 or AOA2).

However it turns out that such breaks are not that common and that ATM is involved in many other processes which if not carried out properly can lead to cells dying. Indeed scientists have now identified over 1,000 different substances within cells which are affected by ATM.

So some scientists then decided it might be ATM’s anti-oxidation function, or role in fixing single-strand breaks, or opening up the DNA structures to be read or cleaning up debris in cells that was key, and devised experiments to show that these functions were critical to cell survival.

However, a consensus now seems to be growing that it is not one single function that is responsible for the damage, but that it is the loss or inefficiency of many different functions that leads to cells being lost.

I am not a scientist, but I follow A-T and other medical research with a keen interest and I have to say that to me this feels right. It is consistent with the experience of people living with A-T – that A-T is a complex multifaceted condition, which does not feel like the result of one particular process going wrong. So this does seem to me to be an advance in our understanding.

Nevertheless, we still don’t have any clear answers to the question and until we do, it seems that the possibility of developing targeted therapies is still some way off.

> **“Our best hope is to focus on developing and sharing good clinical practice and studying the effects of existing drugs, and this is where the A-T Society will be focusing its efforts”**

In the meantime, our best hope is to focus on developing and sharing good clinical practice and studying the effects of existing drugs, and this is where the A-T Society will be focusing its efforts. Our clinical guidance and the clinical research conferences we organise ensure that the most effective treatments are recognised and shared. We are supporting a number of projects looking at the effectiveness of existing drugs such as steroids and metformin. And we are making good progress with our work to establish an international patient registry, to bring together and learn from data from hundreds rather than tens of patients.

So while progress in the laboratory is steady but slow, we don’t have to and are not waiting for this to push ahead with research.

First impressions from the new Chairman

The A-T Society appointed Mike Detsiny as the new Chairman in April. Here he tells us a bit about why he has taken on the role and what he hopes to achieve

I was invited to join the Board of Trustees on 22nd April 2015 and Lian officially handed over the reins to me on 7th June at the family weekend.

I guess the first question is why would I want to take on this role? After all, as with the vast majority of charity trustees, it involves giving up a fair amount of personal time for no financial gain. In addition, no member of my family or any of my friends has Ataxia-Telangiectasia.

The answer for me is quite simple. I think those of us who are lucky enough to have lived a good life, largely free from serious illness, have a duty to try and put something back into society. It's a chance to put experience and skills that have been acquired over the years to good use.

I am struggling to find the words to articulate what I feel about my very short time in this role. I think I can best describe it as a "deeply humbling and enriching experience."

"Humbling " because any problems that I may feel I personally have are absolutely nothing compared with the daily struggle of those who live with A-T and the tremendous love and care given to them by their families is awe-inspiring.

"Enriching" because what I see all around me from the families and, of course, the staff and volunteers at the A-T Society, is genuinely uplifting and a tribute to the human spirit.

My principal contact is with the team at the charity offices and, readers of this newsletter will know far better than I, that their efforts go way beyond all reasonable expectations. To them this is a vocation rather than a job.

You will all appreciate the dedication of Kay Atkins to improving the lives of our families and battling daily to secure for them every benefit and service they are entitled to. Most of you will also be deeply grateful to Suzanne Roynon who, almost single handed, helps to raise the money that enables us to commission research as well as continue our work with families.

You will be less well acquainted with some of the newer members of staff Anne Murray, Kate McEleney, Jo Reader and Eve Audis. They all work part time but put amazing effort and enthusiasm into everything they do.

My principal day-to-day contact is with William our CEO. I will spare his blushes by not even attempting to describe the scope of his activities. Suffice to say that the A-T Society could not have a better leader.

My overall impression, as you may have gathered, is of a happy and efficient organisation determined to improve the lives of those it serves. Your Board of Trustees is important in creating a great working atmosphere and it is clear that my predecessor, Lian, was instrumental in achieving this. I was going to write she will be a hard act to follow. "An almost impossible act to follow" might be more accurate!

My hope for the future is that we will continue to work tirelessly in your service and that one day, sooner rather than later, the funds we raise for research will prove vital in the battle against A-T.

I hope I can play a small part in this effort.

> **"My overall impression of the A-T Society is of a happy and efficient organisation determined to improve the lives of those it serves"**

Music to our ears

The Hertfordshire Chamber Orchestra has organised a wonderful evening of music in aid of the A-T Society. Soloist Jennifer Pike, a renowned violinist and the youngest-ever winner of BBC Musician of the Year will be joining the orchestra for this special evening. Jennifer will play the Brahms Violin Concerto accompanied by our very own chief executive, William Davis, on double bass. With pieces from Beethoven, Brahms and Bizet, concert goers will be whisked away into a world of classical music to banish the darkest January evening.

The concert will take place on Sunday 17th January at 6.30pm in Harpenden. Book your tickets online today and be part of this musical evening.

6.30pm Sunday 17 January 2016
St George's School, Harpenden, AL5 4TD

Beethoven: Ruins of Athens Overture
Brahms: Violin Concerto
Bizet: Symphony in C

In aid of Harpenden children's charity The A-T Society

Hertfordshire Chamber Orchestra

Conductor : Graham Ross
Violin Soloist : Jennifer Pike
(winner BBC Young musician of the year)

TICKETS £15 from atsociety.org.uk or 01582 760 733

Perfect Christmas gifts

If you're searching for that perfect present or a stocking filler for Christmas then look no further... We've got loads of lovely new things in stock.

For children
Silky soft cuddly A-T teddy bear. Available in three colours and only £5. A perfect stocking filler.

For those who like their drinks hot!
Why not buy an insulated travel mug? Available in a choice of three bright colours for only £6. Perfect for keeping warm on the go or whilst standing on the sidelines at sporting events.

For sporting heroes and athletes
Our new smokey grey water bottle is perfect for staying hydrated. It includes a flip-up straw for spill-free drinking on the go and a lid grip so you can hold the bottle whilst exercising or hang it off a buggy or wheelchair. Only £6 and available in a choice of three colours.

Visit our online shop to purchase
www.atsociety.org.uk/products

Xmas opening hours

Please note that the A-T Society office will be closed over Christmas, from 25 December until 3 January. We'll be back in the office on 4 January with our New Year's resolutions and expanded waistlines! If during this period you need to speak to us urgently, please call our main phone number 01582 760 733 and your call will be diverted to one of us – we will never leave anyone in need without support.

Dates for your diary

2015	**6/7/8 November**	Adult Activity Break – Milton Keynes
	21 November	Pentagon Shopping Centre Parade – Chatham, Kent
2016	**25 December - 3 January**	A-T Society office closed
	4 January	A-T Society office open
	17 January	Hertfordshire Chamber Orchestra Concert
	17 April	Brighton Marathon & 10K
	10 June	A-T Lola's Enchanted Ball – Plymouth
	17/18/19 June	Family Weekend – Heathrow
	10 July	British 10K London Run
	31 July	RideLondon 100

Beijing A-T workshop

Every two years the world's leading researchers into A-T and the role of the ATM cell come together at a big international conference, this year in Beijing. Here is our full report

This year's ATW (A-T workshop) was supported by the A-T Society, the A-T Children's Project and BrAshA-T.

While it is attended by both laboratory researchers and clinicians, it is primarily a 'hard science' conference, looking at the molecular basis for the disease. By contrast the series of conferences set up by the A-T Society focus more on clinical research and practice.

The conference was very well organised with an interesting programme and by the end participants felt that it had been extremely valuable. The only slight disappointment was that problems with internet access and restrictions on the use of social media meant that the A-T Society wasn't able to cover the event as it happened.

One very positive feature of this year's event was that one of the two introductory presentations was made by Howard Lederman, director of the US A-T clinic at Johns Hopkins hospital in Baltimore. Howard made sure that delegates had a very clear understanding of how A-T affects those who have it and set out the issues that people living with A-T most want an answer to.

This was later reinforced by Luciana Chessa, who is both doctor and researcher (and whose work is partly funded by the A-T Society). She showed films of children with A-T who were participating in research in Italy.


16th Ataxia-Telangiectasia Workshop
(ATW2015)
Beijing, China, October 11-14th 2015

The major theme of this year's conference was trying to understand how the lack of ATM leads to neuro-degeneration, which is such a feature of A-T. In the past, there has been a tendency to focus on the role of ATM in repairing double-strand breaks in DNA.

However the consensus at this meeting seemed to be that ATM has a much wider and more complex role, all of which could be important. Likewise, the neurological aspects of the disease may be much more closely related to other areas, such as the immunological or metabolic problems. There was much discussion of networks, systems and interdependency.

Yossi Shiloh, the Israeli researcher whose team was the first to identify the ATM gene, said that while he believed that the loss of Purkinje cells in the cerebellum was a key issue, we need to recognise that ATM has a broad role in maintaining genome stability within cells, rather than focusing exclusively on one specific function or another.

Another Israeli, Ari Barzilai, emphasised that Purkinje cells are dependent on other types of brain cell for support and that these too are affected by ATM. Once we start to recognise this we start to see connections not just to other aspects of A-T, but also to other neurodegenerative conditions such as spino-cerebellar ataxias, MS or Alzheimer's disease.


Sara Biagiotti and William Davis looking at the Dexamethazone effects on Oxidative Stress in A-T cells

Karl Herrup, who spoke at our 2012 Family Weekend, focuses on a rather particular area of ATM function. However he too is looking more widely at this role and has identified some significant overlaps with what happens in Alzheimer's, though of course this affects cells in a different part of the brain. (Given how much money is currently going into Alzheimer's research, it would be nice if this could lead to an opportunity for some joint projects!)

Mike Kastan from Duke University in the USA made a compelling case for considering A-T a metabolic disease, i.e. one affecting the basic processes of the cell, not just the protection of DNA. Mike's research has underlined the importance of ATM to what happens in the mitochondria, the cells-within-a-cell which provide its energy. It also shows how this links to other known problems, including diabetes and liver function.

Similar findings have also been made in interesting research by Alexander Bishop of the University of Texas San Antonio, which was presented in a poster.

Malcolm Taylor, from the University of Birmingham, looked at the neurological variability of A-T between individuals and how this related to their specific mutations and with the suggestion that other genes might be influencing this. He underlined how much there was to be learned from comparing people with related conditions and from analysing the relationship of gene function to symptoms.

There were many other interesting presentations and posters, which we cannot list here, including one on the CATNAP imaging project at Nottingham – though there is not yet much data available from this. Another issue looked at in detail was producing an animal model which will help us understand the neurodegeneration in A-T.

There was also a lot of discussion between participants, which it is to be hoped will lead to new ideas and new projects. It was striking that even when taken by the hosts to visit the Great Wall, the conversation on the bus was mostly of cells, pathways, screening and so on.

So what can we say in conclusion? We have to acknowledge that there is still a way to go to understand exactly why the lack of the ATM gene leads to all the symptoms of A-T and in particular the neurodegeneration.

However on the positive side researchers are now focusing on the complex interactions of ATM with a range of other cells and processes and our understanding of these is progressing significantly. This accords well with the experience of people living with A-T who live with the complexity of the condition.

Dr Michele Menotta of the University of Urbino explaining the Dexamethazone effects on blood gene expression research

It also opens the doors to exploiting research and insights into other conditions such as mitochondrial or metabolic disease or other neurodegenerative disorders. And this more complex and interdependent model of the disease also offers the possibility that we might be able to find existing treatments that while not 'curing' the condition, may have a positive impact upon it – as seems to be the case with steroids.

So overall the message is positive: there is still much to do to understand and effectively treat A-T but additional avenues of research, described at the meeting, widen the possible ways of approaching this.

Society grant to study new A-T like condition

Prof Malcolm Taylor is one of the world's leading authorities on the genetics of A-T and related conditions. He played a central role in the work that led to the identification of the gene responsible for A-T itself and some years ago a team in his lab identified the condition A-T like disorder (ATLD), caused by the loss of the closely related MRE11 gene.

Now his team believe they have identified another gene whose loss leads to a condition similar to A-T and thanks to a grant from the A-T Society are now working to characterise the condition and see what light it can throw on A-T.

They made the discovery when they were sent a sample from a patient to test for A-T. Initial tests suggested that the patient might have a 'mild-variant' form of A-T, but when they looked for A-T mutations, they were unable to find any. Subsequent analysis led them to find mutations on another gene that helps regulate ATM. They are now trying to identify another similar patient in Europe.

Given the complexity of A-T and the difficulties in understanding how loss of the ATM protein leads to the detailed symptoms, there is a lot that can potentially be learned from studying the effects of losing proteins that interact with A-T. So this work is not only of interest in revealing a new condition, but should help us make progress in understanding and thus being able to treat A-T itself.

Don't wait when it comes to lung care

Nottingham respiratory expert Jayesh Bhatt welcomes the publication of an international statement on the need for good lung care in A-T

Dr Jayesh Bhatt is the paediatric respiratory consultant at the Nottingham A-T centre. He was the first expert on lung health to be part of the clinic and over the years he has added a respiratory nurse and physiotherapist to the team. He is often joined by Professor Andy Bush, the renowned expert in children's lung health and diseases, who has an interest in A-T.

Together, the two contributed the respiratory section to the clinical guidance document published by the Society last year. But Jayesh has now gone a step further. Last year, with the support of the A-T Society, he set up and led, together with the Dutch expert Peter Merkus, a Task Force of the European Respiratory Society to produce an international statement on lung care in A-T.

Jayesh explains why he set up the Task Force "The ERS is an important body that helps professionals working with lung disease network and learn from each other. A task force with the backing of the ERS carries a lot of weight. It has an organised and systematic approach and the members comprise health professionals across a range of disciplines from different countries in Europe and Israel.

One of the members of the task force is a 'methodologist' who looks very critically at the methods you apply to come to the decisions you are making. In his view, because of the lack of evidence that there currently is for A-T, we can only call this a "statement" on the multidisciplinary management of lung disease in ataxia-telangiectasia – not a "consensus" or a "guideline".

Jayesh believes that this statement is very important: "This is our current state of knowledge based on what research has been done on managing lung disease in A-T, and it has been put together by clinicians who have the most experience of looking after people with A-T. That's why it is important. It also highlights the gaps in our knowledge and needs for research."

He thinks our understanding of A-T is improving: "Certainly mine has over the time I have been involved and everybody I see teaches me something new. We are extrapolating a lot from other conditions but what we are doing is common sense, basic things. As treatments and outcomes have improved in other conditions the hope is that it will be similar in A-T."

Does he believe that the interventions that he is now making based on his increasing knowledge are starting to make a difference? "That's certainly the impression I have got myself and also the impression that parents have been giving us. Just at this last clinic, we saw one child whose lung problems I had been very worried about a year ago. We put some interventions in place, then saw the child again about 4 months after that. Now, a year later, I am a lot less worried and the parents feel that the child is a lot better."

What are the things that he would most like to understand that he doesn't at the moment? "I am a chest specialist so that is what I would want to understand. We know if you have an immune problem you get a bad chest and if you have aspiration problems you get a bad chest. However, there are some children we see who have a bit of both but the lung disease we see is worse than you would expect – it's more than the sum of its parts - so is there something else apart from the problems with the immune system and with aspiration? I don't know whether we understand that. I don't.

We are at the moment trying to pull different pieces from different parts, trying to build the picture. In some instances, like where there is a definite immune problem and we put in regular antibiotics or regular immunoglobulin infusion, we have certainly slowed down the chest disease from progressing so we are doing some things right."

Jayesh became interested in A-T almost by chance. "I was given an opportunity to interpret some lung function tests on a Friday afternoon which was meant to be my non-clinical session. I could have used it do some office work but I chose to do the clinical bit and here we are! I came in by chance but I am passionate about it now. It has led to so much that I have been able to learn and so much experience I have been able to gather."

"Now with the task force we are looking at a few other things like weight in A-T, and presentation and diagnostic delay. We are presenting at upcoming conferences and are hoping to publish soon. I have thoroughly enjoyed what I have been doing and I hope that I am contributing something useful."

In the view of the A-T Society, Jayesh is certainly doing something extremely useful. Lung disease is one area of the condition where we can hope to make a real difference and by learning from other conditions and bringing together the experience of other A-T experts he is showing the way forward.

Finally, does he have a key message for those caring for a child with A-T? "Care should be multidisciplinary, proactive and aggressive – don't wait around for things to happen, make sure they have regular assessments."

The statement of the ERS task force will be published and available in December. There will be a link on our website.

A-T Society Christmas Raffle

We are delighted to be running a Christmas Raffle this year with all proceeds going directly to the A-T Society. We have lined up some great prizes including:

- One week's stay at a villa in Majorca for up to 10 people
- A night's stay for two adults at the famous Randolph Hotel in Oxford
- Limited edition children's 'Frog' bike
- Gas BBQ

And many more prizes...

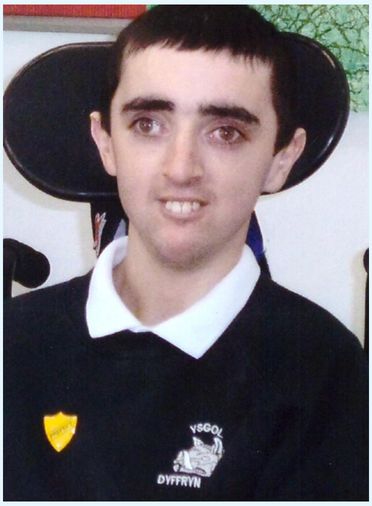
We will be sending out raffle tickets to our families and supporters with this newsletter. Please sell them to your friends, neighbours, colleagues, local contacts etc and don't forget to send back your ticket stubs and money to Suzanne by Friday 18th December. If everyone sells their raffle tickets we will raise an amazing £10,000 for the A-T Society! If you would like more raffle tickets please contact us and we will post them out to you. The raffle will be drawn on Wednesday 23rd December.

Up for grabs: (from top to bottom) Randolph Hotel, 'Frog' bike, Villa Majorca

Sad news

Glen Henry from Wales sadly passed away this year. His family would like to thank everyone who made a donation to Glen's A-Tribute fund.

Our thoughts are with his family and friends who miss him very much.



A day in the life of: The A-T Society

The A-T Society office is always a hive of activity and no day here is ever the same. As well as answering phone calls and e-mails from our families, fundraisers and professionals, and prioritising our day-to-day workload, we also spend time on a variety of other projects.

To give you an idea, we thought we would give you a snapshot of what the A-Team were up to on Thursday 17th September, the day before Jeans for Genes Day.

After a very early start, Anne, our family support coordinator, arrived at Nottingham Hospital in plenty of time to support our families through their day at the A-T Clinic. She spent time with each family and discussed what support they might need from the charity and provided a listening ear to each of them. She also talked to several of the clinical staff to get some answers to the questions that had been raised by some of our other A-T families.

William, our chief executive, was also up early to get to the Nottingham clinic to catch up with the doctors and families. He made the clinic aware that they would be receiving two new referrals from Great Ormond Street who would need their medical support and care. Over lunch he discussed progress on the upcoming Erydex trial with the doctors and therapists present and filled them in on the planning for the 2016 Clinical Research Conference.

In the afternoon, William and Anne found themselves sitting on the floor 'making stew' out plastic meat and vegetables to cheer up a little girl with A-T who was missing her parents as they talked to one of the specialists. Later William interviewed Dr Bhatt for the article in this newsletter, and on the train home in the evening, discussed cases with Anne and caught up with emails.

The real A-Team: (from left) Eve, Jo, William, Kate and Suzanne

Meanwhile, back at the office.....

Fundraising Manager Suzanne was celebrating the achievements of our fundraisers by writing about their shenanigans for this very newsletter (*see pages 23-27*) and smiling whilst she wrote all about our lovely supporters. Always ahead of the game, Suzanne was also busy planning the events for next year and securing places for events such as the Brighton Marathon, British 10k London and RideLondon100. By the time it was nearly dark and before she went home, Suzanne took advantage of some peace and quiet to write to some grant-giving trusts to ask them to support the charity.

Jo, our fundraising administrator, was busy sending out fundraising packs to our new fundraisers as well as publishing posts on Facebook to encourage or thank our amazing supporters. Queen of our database, she also updated all of the monies received from Trusts.

Caryl, our amazing volunteer, was diligently booking hotels and accommodation for the next clinic day at Papworth as well as filing and some general admin so that the office would be ship shape for Kay's return from holiday.

Kate, our communications officer, was busy liaising with our web agency about the redesign of our homepage for the website. An ongoing project, Kate has been working hard to ensure that the new homepage communicates our key messages and highlights the work of the charity.

She was also talking to Hannah at Genetic Disorders UK about the recent press coverage that our families had received in the run up to Jeans for Genes Day and how to maximise on the stories that had been published. With news that the A-T Society's Jeans for Genes press release had been featured in the local press, she was also desperately trying to get hold of a copy of the printed article to share on our Facebook page.

Our corporate fundraiser, Eve, was liaising with Pizza Hut to rebook their skydive. They were all disappointed that they didn't get to jump on Saturday due to the weather and now have to face their fears once again at the airfield! Eve was also contacting our local supporters and businesses to promote a fundraising event in Harpenden and persuade businesses to donate raffle prizes.

On holiday somewhere in the sun...

Meanwhile Kay, our family support manager, was recharging her batteries and having a well-deserved relaxing holiday somewhere warm.

Nottingham Hospital, where the A-Team go to support our families through their day at the A-T Clinic

Back to school for Kay

Kay's in-depth knowledge of ataxia-telangiectasia is often called upon to help advise healthcare and education professionals on how they can best support a person who has A-T. In September Kay was invited to visit two schools to talk to the teaching staff about the condition and how they could best support the child with A-T.

Both the schools found Kay's advice invaluable and wrote to Kay to express their gratitude.

Wendy – Acting Head Teacher from a school in Scunthorpe wrote:

"Thank you for coming up to Scunthorpe and meeting with us. Having the opportunity to talk to you about A-T was extremely valuable. It has opened our eyes to the challenges that this little boy and his family have faced and will face in the future and certainly gave us food for thought on how we can effectively support them whilst he is at our school. The staff that are currently working with him certainly feel more confident about how best to enable him to access the curriculum e.g. rest breaks before and after PE. I cannot thank you enough for spending the time to share your expertise with us."

Jill, SEN coordinator at a school in Cheshire, wrote:

"Many thanks for coming to our staff meeting on Tuesday. It was very informative and everyone who attended felt that it was a valuable insight into how we can support this little girl through her years at the school. I don't think that anyone had realised until then the complexities of her difficulties, and having the meeting has made everyone far more aware of her needs on a day-to-day basis. Thank you for your support, and it's good to know that there is someone to turn to if any questions or problems arise that we're not sure about."

It's nice to think that Kay can help to make an A-T child's experience of school a happy one.

Adult Activity Weekend

Saturday 7 November to Monday 9 November

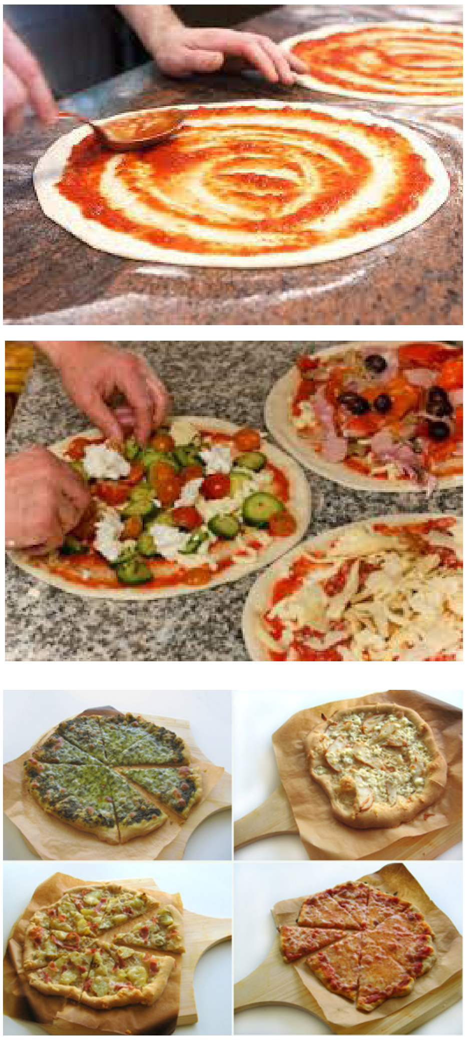
As usual, places on our annual adult activity weekend were snapped up well before the deadline and we even have a waiting list! It's always a popular event as it gives our adults living with A-T a chance to meet old friends and make new ones, try some new activities and develop new skills.

This year, on 7th November, 20 of our adults with A-T will be visiting Pizza Hut's head office and using the kitchen facilities there to design their very own pizzas. We are looking forward to some interesting new flavour combinations and perhaps some rather unusual shapes! Who knows, maybe the people at Pizza Hut will be inspired to add a new creation to their menus.

Whilst chilling out at Pizza Hut HQ we will be making a film with the help of film-maker Sharon Woodward. This will give our young adults a chance to express how they feel about having A-T, what they love about life and what they find challenging.

The evening offers the chance to socialise over a nice meal and a couple of drinks. With people so widely scattered across the country, this is an incredibly important opportunity and no doubt some will be up chatting long after the bar has closed.

This year's activities include skiing



Attendees will be given the chance to create their own pizzas at Pizza Hut HQ

Sunday is adventure day. Kay has arranged for the group to go skiing at an indoor ski slope, with the support of Disability Snowsport UK. Each person will get the chance to ski down a steep slope and experience at first hand the thrills and chills of skiing in real snow. Kay herself, though, says she will be wrapped up warm for this one with a hot chocolate.

After the skiing is over everyone will be heading back to the hotel to warm up and relax.

It really promises to be a great weekend and we will tell you all about it in the next newsletter.

Vaccines

We've recently had a few queries from parents about vaccinations. We have received the following advice from our healthcare professionals in Nottingham:

Cervical cancer and Meningitis Vaccines

Our doctors have advised that the cervical cancer and Meningitis vaccines are safe for our children with A-T because they are not live vaccines.

Flu Vaccine

Our doctors have advised the following: "The annual influenza vaccination is recommended for all people who have A-T. Currently we advise the injectable influenza vaccine rather than the 'live' nasal spray vaccine. This is not recommended as it can affect children/adults who have a severe immune deficiency."

If you have any questions about this, please contact us on 01582 760 733. Our family support team, Kay and Anne, will be happy to answer any additional questions you may have.

We would like to feature a Questions and Answers section in the newsletters. Questions can be anything from healthcare advice, education support, housing or equipment enquiries or even fundraising advice. So send in your questions please. We will consult the professionals for the answers and publish them in the next newsletter. It's your chance to ask the questions that you'd like answers to. Please note: all questions will be treated in confidence and made anonymous.

Useful websites

We’re always interested to hear about services and websites that make people’s lives easier. Here are a couple of websites that have recently been recommended to us.

DisabledGo
On this website you'll find detailed access information to thousands of venues across the UK and the Republic of Ireland: shops, pubs, restaurants, cinemas, theatres, railway stations, hotels, universities, hospitals and more.

DisabledGo visit and survey every venue on their website in person and use a survey method that over 800 groups of disabled people have fed into. They provide you with the facts so that you can make an informed choice about its suitability for you.

www.disabledgo.com

Rough Guide to Accessible Britain
The brand-new fifth edition of the Rough Guide to Accessible Britain is now available to view for free online. It’s packed with over 200 inspiring ideas for days out, with reviews, hints and tips on some of the UK’s best attractions, written by and for disabled people.

To make planning your days out easier, entries are grouped into 10 regional chapters covering everything from museums, parks and studio tours, to scenic drives and coastal towns.

Every review contains all the access information you need to enjoy your day, including disabled parking, wheelchair access and more.

www.accessibleguide.co.uk

Family Weekend: Friday 17 June to Sunday 19 June

We have reserved rooms at hotels near Heathrow airport for our next family weekend in June and are currently finalising the itinerary for the weekend. We will send out full details in the New Year. We would love to see as many of our families there as possible.

If you think you may require help financially to be able to attend then please get in touch with Kay or Anne as soon as possible (**support@atsociety.org.uk**). We may be able apply for funding for you to help with the costs. All conversations will be treated in complete confidence.

Staying safe on Social Media

There's no escaping the impact of social media on our everyday lives and, with so many of our families using social media, we thought it would be useful to provide some tips on how to stay safe.

Passwords

When it comes to practising online safety, setting up a wide variety of secure passwords is the best place to start. These secure passwords should contain a mix of capital letters and numbers and avoid key dates or words like your date of birth or "password123". Although sticking to one password across all social media platforms will make it easier to remember, it is safer to use various passwords. Norton offers a free Password Generator which you can use to ensure that you create a strong password. **www.pctools.com/guides/password/**

Remember – never give anyone your password as they could use it to impersonate you.

Facebook

Here are some top tips if you want your private life to remain private on Facebook.

1. Understand Facebook's security settings and use them
Check your security settings and take the time to learn how to use them to control what information is shared with people, applications and websites. By changing your privacy settings, you can determine who can request to be your friend and who can find your profile, as well as who can see your posts and photographs.

Access your privacy settings by clicking on "Account" in the upper right-hand corner of your Facebook page, and then click "Privacy Settings". If you want to set your privacy settings as tight as possible then can select "Friends Only". Also uncheck the box marked "Let friends of people tagged in my photos and posts see them" and then click "Apply these Settings".

2. Who's your friend?
It's not all about the numbers of friends. Remember when you accept a friend request you provide your new friend with access to lots of information about you. This includes, posts, photographs, messages and all the information you write about yourself.

3. Blocking a friend
If you want to block a friend click on their profile, then on the 'message' button dropdown and you will see the option to 'unfriend'. You can also block a person this way.

4. Be aware of those applications
Be aware that using a Facebook application can give broad permission for whoever developed that application to access your data and your friends' data.

5. Avoiding spam messages
To avoid spam messages, filtering your inbox to be either basic or strict will regulate who you can receive messages from.

Did you know….

* You can change your language on Facebook to Pirate!

* The 'like' button on Facebook was originally going to be called 'awesome'.

* Every second there are 20,000 people on Facebook. This means in just 18 minutes there are 11 million users on Facebook.

Twitter

Seven tips to keep you safe on twitter:

1. Never give out your real address or any personal details
Remember on twitter everything you say can be open to everyone.

2. Never give out your password
Also be extra careful when you sign into twitter through other websites.

3. Think before you Tweet!
Anyone can see what you say unless your profile is set to private.

4. Don't follow back people you don't know This can help protect you against Direct Message spam.

5. Make your profile private
If you don't want everyone to see everything you say on twitter visit your twitter settings and make your profile private. Only people you follow will be able to see your updates and your tweets will be hidden from the public search.

6. Location tagging If this feature is turned on people will see where you posted a tweet from. If you want your location to be private make sure this setting is turned off.

7. Prevent your Twitter account from being hacked or stolen
Sometimes people will try to take over twitter accounts so they can send spam. Don't click on links in Direct Messages unless you were expecting a link from that user. If you think your account has been hacked change your password.

Did you know….

* 500m tweets are sent a day.

* Seven of the 10 most followed accounts belong to singers.

Instagram

There are various steps you can take to make sure your experience is as safe as possible, starting with the option of a Public or Private Profile:

- **Private Profile** – this ensures only followers that you know and approve personally can see your posts.

- **Public Profile** – all posts and activity can be seen by everyone who uses the app and web version of Instagram.

By default all profiles are Public, so you must actively change your profile to Private if you want to restrict who sees your posts. Even if your posts are private, your profile is public; anyone can see your profile photo, username and bio so just be aware of the information that you are giving.

Did you know….

* The LDN Access app allows wheelchair users to find accessible stations, restaurants and various locations in and around London.

* IPhone users can now set up a Medical ID in cases of emergency and in situations where someone needs to get hold of someone's next of kin. The health app which is a default app on the phone will allow you to enter details such as date of birth, emergency contacts and medical conditions.

Sharing and posting content

There are 3 different posting options:

1. Public – the most relaxed profile setting. All photos and videos are searchable and can be viewed and commented on by all users.

2. Private – videos and photos are only seen by 'approved followers'. All followers must be approved by you.

3. Direct – Instagram has an option to send content directly to up to 15 people. Messages are deleted after 2 weeks if they remain ignored.

Other tips….

- Location tagging – tagging a location when posting will show where the photo or video was. It's turned off by default, but once turned on, it stays on until you turn it off. Think about whether you really want people to know where it was taken and be aware of advertising to people that you are away, especially if your profile is public.

- Unfollow a user – if you no longer want to see someone's content you can simply unfollow them by tapping on the green 'following' button on their profile page and then selecting unfollow.

- Block a user and/or report their content as inappropriate – a user can be blocked, or their content reported as inappropriate, by tapping the menu button in top right-hand corner of their profile. Select 'Block User' and/or 'Report Inappropriate Content'. Once you block someone they can't tag you, contact you directly or mention you in comments and they also won't be able to see your profile or search for your account.

Did you know….

* On average 70m photos are shared each day on Instagram.

* The minimum age for Instagram users is 13.

Information for this article was taken from www.internetmatters.org and www.bullying.co.uk/cyberbullying.

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AT society

Catch ups with our families

It’s September and back to school we go....

With new haircuts, smart new shoes and beautifully labelled uniforms, it’s time to head back to school and catch up with friends.

Starting Year 2 is not in the least bit scary, especially when you have your twin brother with you. Here are Brae and Broghan starting school.

It’s a big thumbs up from Max, who looks ready for a new school year!

Starting school is a huge milestone for every little person living with Ataxia-Telangiectasia. We think Orla looks smashing in her uniform and ready for whatever the new school year brings!.

From left: Orla with her brother; Max; twins Brae and Broghan

New pink trike for Toni-Jo

Thanks to some great fundraising efforts from Toni-Jo’s friends and family and her pre-school, Treetops, Toni-Jo now has a lovely new pink trike to cycle around on.

The staff at Treetops organised collections at their sports day and summer concert, and sold lots of cakes. They even persuaded the ice-cream man to donate some money too. This is the second fundraising event that they have organised for Toni-Jo and the A-T Society. They always do their utmost to raise awareness of A-T and tell people Toni-Jo’s story.

Mum Anna said, “It’s a fantastic pre-school and the staff are amazing. They support Toni-Jo and her family in so many different ways. They have helped her become such a confident little girl who's happy to play with her friends now. I really can't express how much they have all done for us since she started there.” As for the new trike, it’s priceless. “Toni-Jo is so happy. She hasn’t stopped smiling.”

Brooke to star in Great Ormond Street Hospital booklet

Last year the doctors at the A-T Clinic advised that Brooke might benefit from Immunoglobulin treatment and so she was referred to Great Ormond Street Hospital and began her treatment in December.

While the family were at the hospital, they were asked to be part of a booklet that was being created to explain to other families what having the Immunoglobulin treatment entails. Mum Justine explained that at first the treatment seemed quite daunting. There was a lot of information to digest and they had to learn how to administer it at home. However, 6 months later, the family find the process very straightforward and fit it into their weekly routine at home. It takes a maximum of 2 hours to complete and Brooke watches TV or plays games on her iPad, while the cat often climbs onto her lap for a cuddle.

The family were more than happy to be involved with the creation of the booklet. The step-by-step guide should make the whole process look less daunting to parents and, with children like Brooke featuring in the leaflet, it will hopefully help show children that having the treatment isn’t that scary.

We look forward to seeing the booklet when it’s finished and will of course post a copy of it on our website. Well done Brooke!

Summer holiday snaps

Northern Ireland is not renowned for its day-after-day sunshine, so it was off to sunny Spain for Cian (*left*) with Mum and Dad, Lynda and Christopher. The family had a fun holiday in Salou, where Cian enjoyed spending time on the beach and cooling down in the swimming pool.

However, Brae and Broghan found that Northern Ireland is a great place for a holiday. They visited Malin Head (*right*) on a day trip to see their granny and grandad, who have a caravan there. The family had a fun day out exploring the area and after climbing to the top of the mountain they were rewarded with chips and ice cream!

What's your news?

We'd love to hear your news and feature more of our families in our newsletters. Please send photos and stories to **kate@ atsociety.org.uk**.

Rupert joins the Board as a trustee

As we reported in the last newsletter, there have been some changes within the A-T Society Board, such as long-time trustee Ian McInnes moving on. Now joining the Board is 30-year-old Rupert Prokofiev, who has A-T and who many of you may know.

We caught up with Rupert to hear about his life, interests and what becoming a new trustee for the A-T Society means to him.

Tell us a bit about yourself

I've been living in my flat in Greenwich for five years with my cousin and a rotation of five PAs. My hobbies include watching Charlton Athletic FC (I have a season ticket but we're not doing very well at the moment!) and watching films (I'm a member of the BFI, which shows good old films). I also go to a lot of live shows at the O2, which is just down the road. I'm applying for a course in Graphic Design at a college nearby which would take place three days a week.

How does having A-T affect your life?

My views on A-T have changed so much. When I was young I was probably in denial; I didn't want to be under the "disabled" umbrella. But as I've got older I've learnt to embrace my situation. A-T is part of who I am.

How has the A-T Society helped you?

I've enjoyed meeting up with other A-T affected families and knowing that there are other "me's" out there – so it's not just my journey, it's our journey. The support of the office team has been invaluable. I ring up Kay or Suzanne quite often and that's been helpful. They're good people to listen and give input.

What do you hope to achieve as a trustee?

I'd like to get my ideas out there, and listen too. I know I can help because I have the inside knowledge (literally). I can offer other skills to the Board, such as computer skills and design. I think the A-T Society could use some fresh ideas. As an adult with A-T I'm aware of the challenges. I know the Board valued Ian's input, so hopefully I can take up the baton and give my first-hand experience and come up with solutions.

By the time you're reading this I will have been to my first Board meeting so I'll know more about how it's run. I'm looking forward to my Trustee responsibilities and having more of an influence.

Q&A with Roxy Burns

We caught up with the marvellous South African Paralympic cyclist Roxy Burns to find out what she's training for at the moment, what she does to wind down and how A-T affects her life

By Beatrice Prokofiev

Many of you will remember Roxy Burns, who has a mild form of A-T and spoke to us at the A-T Family Weekend back in June 2014. She inspired and moved us all with the story of her life and success as a Paralympic cyclist. So what has Roxy been up to since? We thought we would do a follow-up story to hear her news and fill in those who missed the pleasure of hearing her speak last year.

Firstly, how are you?
I'm good thanks...

Can you give a little background about yourself for those who didn't hear you speak before?
I was born on 21 october 1988, diagnosed at the age of 18 months after getting the diagnosis of CP. My parents knew it was more because my mum's pregnancy was good and there were no complications at birth. I attended a special needs school from the age of 6 (grade 1) to grade 6 and this is where I started sport. I did everything – track and field and netball as well as cycling. In grade 6 I was selected for the provincial team to go to nationals (for track and field as well as cycling). From then on I've been in the provincial team until now.

Roxy in the zone!

In 2002 I started high school in a local, mainstream school where I matriculated in 2006.

In 2005 I was selected to go overseas for cycling (CPISRA) in the USA. It was then that I had to make the decision to focus on cycling – and I got my first international medals. Later that year I went to the European championship in the Netherlands. My next competition was Beijing in 2008 which was the most exciting experience. From then on I was often part of Team SA. We went to world champs, world cups and international races around the world yearly.

London Paralympics was another great highlight of my career: so many supporters and an atmosphere of admiration for all the athletes.

In 2007 after matriculating I started studying BA Sport Science at Stellenbosch University, which I completed in 2011. I then started my Education Certificate (PGCE) through UNISA (University of South Africa). I completed that in 2014. This year I've started my Honours in Education (educational support).

Are you training for anything at the moment? How's it going?
At the moment I'm focusing on the World Champs in March 2016, which will be last chance to qualify for Rio. In order to qualify for Worlds though, we have to do well in Manchester next month (November) – so you could say I'm focusing on that... I, along with my team mates, have been selected to attend a training camp in Switzerland for 10 days leading up to the competition in Manchester. I'll be in Switzerland from the 2-12 November and in Manchester from 12-16 November.

You sound very busy! How do you have time for training? What does it entail?
Training for me entails one session a day, because I get tired quickly and I have to study. Normally I train in the gym or on my bike on a stationary trainer. I also go through to the velodrome once a week for technical training.

Can you describe a typical day off?
A day off..... Sleep in, and just veg! I love movies and books so I'll read, catch up on series or work.

Do you have a special diet for training?

No special diet – healthy and balanced, with the occasional burger/pizza :-) I have recently started taking whey protein after training sessions for recovery.

Do you have much contact with the A-T Society?

The A-T society was a great help to my parents when I was newly diagnosed. We flew over in 1990ish to get information and to have me properly assessed, etc. Now we get the newsletters but don't have that much to do with the Society. Because I'm so mildly affected, I personally don't need as much support as typical cases.

Is there much support for A-T in South Africa?

There's no support in SA. I'd like to start a society or something to assist with the race for a cure, but will seriously start thinking about it once I've finished cycling...

How does A-T affect your life and sport?

In a way I've been blessed with A-T; if I didn't have it I wouldn't be able to compete as I have and I wouldn't have met so many great people. I've been blessed to have such a mild strain of it that I can lead a relatively normal life. I've been in a mainstream school with no assistance, except for extra time for tests, etc. The only way I can see A-T affecting me is my balance and coordination. It's by God's grace that I am able to live my life as I am.

Disabled and proud

By Leigh Rybak-Rajewski

I'm Leigh Rybak-Rajewski and I have a mild variant of A-T. In September this year I set up a group on Facebook called 'Disabled and Proud'. I would love more people to join the group and become supporters. Who knows where it might lead...

I initially wanted to set up some kind of group years ago for people like me with a disability, so we could communicate with one another and share our experiences. I also hoped that the group would appeal to the families, friends and carers of people with a disability. From a young age I knew I had a disability but didn't know exactly what it was until recently. It's taken 27 years to finally have a confirmed diagnosis and I wanted to find a way to be in touch with people in the same boat as me.

I never expected to have such attention from an organisation like the A-T Society. Kay and Anne visited my Mum and me at home, which we found very positive and uplifting. My Mum describes it as 'like seeing a light at the end of the tunnel'!

I've always tried to cope with my disability and have learned to live with it by trying not to take life too seriously and having sense of humour. Of course it sometimes gets me down, but I know that's just part of life as well. I recently made contact with a cousin I haven't seen in a long time and she was amazed that I finally have a diagnosis…we laughed about it a lot!

I have lots of interests, but like many people with a disability I find it difficult to find suitable/accessible activities.

I'm very interested in tracing my family tree and our Polish Heritage. I went to Poland this summer with my Dad to try and find out more about my Grandad, Adam Rybak. I wanted to see where my ancestors came from and visit some of the famous historical sites. My Dad exchanged emails with a Polish man we met on our journey and we're hopeful he will be able to give us some more information. I have an Uncle who does lots of research into our family history, so it would be good to be able share information from our trip.

I'm also interested in Japanese culture. I would love to learn to speak a difficult language like Japanese (or Polish or German!) Maybe this is something the A-T Society can help me find?!

So please join my group – and if you speak Japanese, Polish or German then maybe you can teach me a few words.

www.facebook.com/groups/890490757685783/

Letitia's story

Letitia lives in Wales and has a diagnosis of mild variant A-T. She has recently undergone several life-changing experiences that the A-T Society and the medical team at Papworth have been part of

By Letitia

Being diagnosed with mild variant A-T three years ago came as quite a shock, especially as I had never even heard of the condition. I am so grateful to have the A-T Society as they have helped me loads. From small things like having someone to talk to on the phone to helping me get access to the things I need.

My mother especially likes to be able to have Kay to talk to as there is nothing down where we live (i.e. support groups) and it's great to know that there's always a friendly voice at the end of the phone when we need advice.

I'm also thankful that the A-T Society organise annual family weekends. It's such a great opportunity for me to meet and talk to other people who know what I'm going through. And the support that's on offer from the A-T Society – professionals and all the families that attend – I'm amazed by it all because this time 3 years ago I had no idea what A-T was, let alone all the support that's out there!

An A-T Society loom band that Tish is now able to make

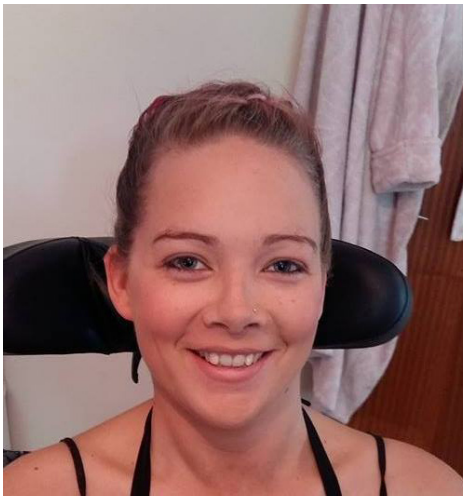
Family weekend

A lot has changed in my life for the better since the last family weekend in June. I'm so thankful that I went. Some of you may recall seeing me in a very unsuitable wheelchair with no headrest and I was really struggling to sit up for any length of time. I was taking numerous drugs but none of them seemed to be making me feel any better and everyday life was hard work. Little did I know that coming to the family weekend would be the turning point.

As soon as Kay saw me at the family weekend, she booked me an urgent appointment at Papworth so that they could review all of my medication and assess what was going on. The staff at the hospital were very good and answered all of my questions and concerns and explained everything so clearly to make sure I could understand. The doctors changed my medication and this has made such a huge difference to my life.

Onwards and upwards

For the first time in two years I have been able to walk from my living room to my kitchen. Anyone who is a wheelchair user will appreciate just how much that achievement really means. And it's being able to do the little things that have made such a difference to me. I have been able to drink out of a cup and stand in my kitchen and fry an egg! Yes, not quite Masterchef standard yet, but it's a start. The change in my medication has given me back some of my independence and it's made me so happy.



"The annual family weekends are such a great opportunity to meet and talk to other people who know what I'm going through"

The other amazing thing that happened as a result of the family weekend was that Kay put plans into place to organise a new wheelchair for me with a headrest. My mum was getting nowhere trying to get one from the local health authority and was caught up in a load of red tape. It had been an ongoing battle for over a year. Plus Anne is helping me to get adaptations for the house to enable me to get around in a powered chair and get the assessments that I need to live as independently as possible.

So a lot has changed since June and so have I. I am happy, mobile and living life to the full. I'm so grateful to have such great support from my family, friends and the A-T Society. Can't wait to see you all at the next Family Weekend.

Corporate fundraising

Harpenden Cricket Club and Pizza Hut support us at Classics on the Common

Wednesday 22nd July brought crowds in their thousands to Harpenden Common to view the spectacular array of some 1,200 classic cars, scooters and motorbikes. The Cricket Club provided us with the opportunity to have a cake and Pimm's stall and very kindly donated the Pimm's! Pizza Hut provided 600 cakes and scones and enthusiastic volunteers to help man the stall and did an amazing job. We raised more money than last year and spread the word about A-T!

We couldn't have done it without the fantastic support from Harpenden Cricket Club and Pizza Hut.

Best of St Albans

The A-T Society are now a community partner of the Best of St Albans. The Best of St Albans champion the best businesses in St Albans and the surrounding villages and select Community Partners to support and promote their events. They have been promoting local A-T Society events on their website and Facebook and Twitter feeds, helping us to generate more awareness of A-T and the Society.

thebestofstalbans

When they're not making pizzas they're busy raising funds!

Pizza Hut have been very busy raising funds for us. In the school holidays they held a retro-themed family fun day with lots of stalls and games. Children and adults took part in an egg and spoon race, sack race, tug of war and assault course followed by an auction and jumble sale before enjoying a BBQ.

A brave team of 14 skydivers travelled to the Skydive Centre together only for the weather to disappoint. Half of their team have since been and jumped, hurrah, with a few more people still to make the return journey to the Skydive Centre.

Maria Swift's Great North Run efforts; the brave Pizza Hut skydive team

Pizza Hut employees have been busy at the weekends too: Maria Swift trained and fundraised hard for the Great North Run which she completed in just under two and half hours despite it being rather warm for the runners! And Alan O'Brien overcame injuries to complete the Human Race Duathlon at the iconic Olympic venue in Eton Dorney! Well done and congratulations everyone!

Pizza Hut also hosted pizza making at this month's Young Adult weekend at their head office in St Albans.

More corporate fundraising stories on the next page....

Ladies pamper evening

At the beginning of October over 50 ladies attended our Ladies Pamper Evening at Gatsby & Miller hairdressers in Harpenden. Gatsby & Miller and Emerald Brows generously donated their time and expertise to ensure all the ladies left looking and feeling lovely.

We had make-up expertise provided by Emma Burden from Arbonne showing us how to create smoky eyes and luscious lips ready for the party season. Our raffle had some luxurious prizes so proved very popular and everyone was very generous, ensuring that it was a truly fabulous fundraising event!

Lloyds: it's a rip-off

The amazing Neal and Thomas from Lloyds in Northern Ireland braved pain and the amusement of their colleagues in August when they had their chests and backs waxed at their office to raise money for the A-T Society. The activity seemed to grab everyone's attention and they did fantastically well with their fundraising. Above and beyond boys, well done! The A-T Society is very dear to Neal's heart as his very good friend's son, Finn, is one of the 8 people with A-T in Northern Island..

Pentagon Shopping Centre turns 40

Regular supporter Pentagon Shopping Centre celebrated its 40th Birthday on 3rd October with traditional fun and games including a coconut shy, buzz wire, Punch & Judy shows, Clown Town, mini-golf challenge, live music, ball in a bucket and stand the bottle with our lovely A-T volunteers running the stalls and collecting donations! It was lots of fun and helped raise awareness of A-T!

Fundraising

A quintessentially English evening

We were delighted to receive photographs of Robin and Judy's cheese and wine evening in the garden of their chocolate box cottage in Somerset.

Robin explains: "In our kitchen we provided a buffet of choice cheeses, accompanied by a variety of breads, sausages, sausage rolls, salads and pate, whilst in the 16th century sitting room guests found an assortment of excellent cakes. Outside on the lawn there was a selection or a dozen red wines, a dozen white wines and some rose complimenting the bouquet of the summer bloom.

We also had an excellent raffle with prizes provided by locals and a quiz to stretch the grey matter! We had around 60 guests for a very enjoyable evening and raised over £600 for the A-T Society."

Buttoning up the British 10K

Without a doubt the A-T Society's team comprising Nottingham's finest – Steph, Courtney and Jordan Button along with Sarah Bradbury – was the most glamorous on the British 10K course this year.

Gentle sisterly love was overtaken by breathless rivalry as Steph and Courtney took part in their first running event, determined to beat the more experienced runner Jordan. However, the dynamic Sarah left buttons in her wake as she challenged for a personal best in the event.

Well, autumn crept up pretty quickly this year! Here in A-T HQ we're getting used to having our wonderful new part-time staff to share some of the workload which is a great thing. For us it's really important to be able to stay in touch with the people who help us to help you. A phone call here or a quick note there can make a huge difference and having Jo, Kate, Eve and Anne 'in our corner' means there's a little more of a very valuable commodity: time!

We love to hear about your plans for fundraising in the coming months and year. With the Brighton Marathon, a ball, Tough Mudders and all sorts of awesome events in the planning stages, we're really looking forward to working with you in 2016.

Suzanne

Resonate

Companies that engage the services of Resonate for their recruitment needs can choose the A-T Society to benefit from 20% of Resonate's fees. If you or anyone you know works in HR please introduce them to Resonate. Resonate works at market-rate fees and only charges companies fees if they place a candidate who commences employment. If they don't deliver, you don't pay. Resonate has already donated £500 to the A-T Society so please help us to promote them and raise funds for A-T!

Chris goes the extra mile for A-T

There's no such word as 'can't' in Chris Hughes' vocabulary and if someone tells him that he can't or shouldn't do something then he loves to prove them wrong.

27 years ago, Chris was knocked off his bar stool in a pub and suffered a severe blow to his head. He was rushed to hospital, but ended up losing part of his brain and was very ill for a long time.

Chris has made remarkable progress. He is physically able to do most things. However, he suffers from tunnel vision and can't read and write as well as he used to. But his sheer determination to never give up has made him strong and he has surpassed even the most optimistic expectations of the medical teams.

Once Chris was fit and able, he started taking part in running events and slowly built up his stamina till he could run half marathons. After completing four of these, Chris signed up for the Robin Hood Marathon in Nottingham.

Chris heard about Kaid Betts who has A-T and was in desperate need of a new wheelchair. Moved by Kaid's story, he got in touch with the A-T Society and decided to run for us. The six months of dedicated training paid off. Chris, who at one point wasn't sure he would be able to walk ever again, completed the marathon in 4 hours and 5 minutes.

Chris says that this was definitely his first and last marathon. The training was very time intensive and the marathon was very hard going. However, while he rests and enjoys his achievement, he is already thinking about his next challenge. He won't say what it is yet, but it's sure to be a tough one. So thank you Chris. We are truly honoured that you chose to fundraise for the A-T Society. You really are an inspiration.

A-T Lola's Enchanted Ball

10th June 2016

Holiday Inn, Plymouth

Tickets £40/head or

£350/table of ten

Arrival drink & three course meal

From: www.atsociety.org.uk/LolaBall

Charity no. 1105528

Chasing the midnight sun

The amazing Mr Danny Ford, a great friend to the charity, travelled more than 2,000 miles to take part in the Midnight Sun Marathon in Tromso, a good way beyond the Arctic Circle. Danny's dedication to the charity has raised thousands of pounds over the past three years and we're pleased he managed to avoid hungry polar bears this time!

Bash in the barn

This very tasty event takes place every two years in a huge barn in the wilds of North Yorkshire. This is a magical place, where the nearest neighbours are sheep and street lights are non-existent. Organised by 3 day eventing supremo, horsewoman Sara Metcalfe and her family, this year's Bash saw guests travelling from all over the country to enjoy the party atmosphere, auction, disco and a hog roast featuring the pig with the biggest smile ever seen on a swine. Sara's son Jasper turned heads with his blue hair which was shaved off as part of the evening's fun.

True colours shining through

The Color Runs (yes, spelt that way!) are a series of bright 5K runs around the country. We've been lucky enough to have teams in two events, Belfast with Tresca Mallon and Maria Hagan tinting the Titanic quarter (*top*) and Lee and Claire Arnold (*bottom*) daubing Derby in their quest to paint the towns red!

When the going gets Tough

These two fragrant ladies have been waiting some time to show the world how brave they really are! Donna Reilly, along with daughter Krystyn Andrews took on the Tough Mudder at Malpas in Cheshire. This tricky test of mucky madness would tax the strongest of men, but the two ladies – with Krystyn also carrying a shoulder injury – left competitors trailing in their wake as they triumphed in honour of Jake and Max Noscoe.

Tough Mudder Krystyn and Donna with friends

Eaton Park Family 5K

The one thing you can say about Stefan and Justine Sprawling is that they don't ever quit! They have passed this determination on to son Caleb and daughter Brooke who threw themselves into this lovely, friendly 5K event in September. Although Brooke can't walk very far any more, she took the lead to encourage friends and family to take part on a stunning September Sunday.

Family Fun Day

The Sewell and Kelly families sure do know how to throw a party! For the third fabulous year they pulled off a magnificent fun day with endless entertainment for kids and adults alike. Out of respect for the faint hearted among us we won't show you photos of the brightly coloured snakes and reptiles the children were playing with, but they were clearly having a good time and the children enjoyed it too!

Sewell Family Fun Day: Brian and his four wonderful children

Merry James Triathlon

It's always very special when someone with A-T embarks on fundraising for the charity. Fourteen-year-old Merry gave us all a touch of vertigo when she planned her own 'triathlon' with a difference. The elements were rock climbing, swimming and cycling. Merry showed us that A-T isn't about what you can't do.... it's about the amazing things you CAN!

Fearless Merry rock climbing

The Incredibles –just keep on keeping on!

There are a group of people who have dedicated their time and copious amounts of energy to fundraising for us with a variety of different events throughout the year. As we're a tiny bit tight on space in this issue and, all bar one of them featured last time, we can't squeeze their pictures in this time. Nevertheless, please applaud loudly for Siobhan Pope, Nick Walsh, Glen Walsh, Sorrel Hodgson and Jo Saxton who keep on running and swimming for us. A mention too for the wonderful (but camera shy) Mr Ged Coyle who cycled from London to Windsor for us in August.

Cumbrian Coffee and Cakes

Merry's enthusiasm inspired her grandparents, Peter and Jane, to organise a coffee morning at Brampton in the beautiful Cumbrian countryside. The splendour of the scenery was the perfect accompaniment to a fantastic array of cakes, with locals and visitors alike making the most of them!

Look out behind you, Mary Berry!

We met 'pocket dynamo' Jilly Shah for the first time at the 2014 family weekend in Heathrow. In the year since, we've found – hidden behind the huge smile – a determination to recognise everything the A-T Society means for people living with A-T and to make sure the charity is there for the future. Jilly sold over 70 calendars and has baked her way into the hearts of most of north London with cake stalls at various events, raising awareness and money in the process. Jilly's enthusiasm and lovely messages could brighten the darkest day.

So to Jilly, and everyone who fundraises for us. Thank you from the bottom of our hearts! Without you, the A-T Society could not continue. There would be no family support, no medical or educational intervention, no advocacy or family weekends, no one to call when people first get a diagnosis. And whilst research might continue in other forms, without support to ensure children stay well and have the best quality of life, the research won't help the people who need it most – you and your children.

The A-T Society needs YOU!

If we've inspired you to organise your own fundraising event then please do get in touch with Suzanne or Jo who will be only too willing to help you make your event a huge success. And, if you are thinking of taking part in a sporting challenge in 2016, then why not consider training for the following events which we have places for:

The Brighton Marathon and the Brighton 10K (15th – 17th April) is one of the UK's favourites. With a stunning backdrop of the sea in one of the country's most vibrant cities, the race gets bigger and better every year. Renowned for its buzzing atmosphere and roaring crowd support, the course winds through the city streets, finishing up on the spectacular Brighton seafront.

British 10K London (10th July) "The World's greatest road race" is how this is described and we can see why, some of the iconic landmarks you will pass include Piccadilly Circus with Eros as a backdrop (three times!), Oxford Circus, Regent Street, The Strand, Big Ben and the Houses of Parliament!

RideLondon100 (30th – 31st July) The route of the RideLondon-Surrey 100 offers a perfect, traffic-free ride for a range of cycling abilities. Everyone can enjoy a challenging day in the saddle pedalling through the roads of London and Surrey. Starting from Queen Elizabeth Olympic Park in east London and ending spectacularly on The Mall.

First degree A-T Society films

Earlier this year young broadcast journalist and regular A-T Society volunteer Antonia Hunter asked if she could create a series of three short films to explain A-T, its impact on families and the A-T Society's work and research. As we don't have a video production or marketing budget, Antonia's offer was very welcome.

The films were part of a final Degree project and followed a set format to make them suitable for online or TV 'magazine programme' viewing.

Two families, the Sewells and the Yarletts, agreed to be involved. Brian Sewell and partner Siobhan Kelly spoke incredibly movingly about the 18 months it had taken to get their son Brae's diagnosis. The film showed Brae playing with his twin Brogan, who doesn't have A-T, and emphasised the differences between these two lively, happy little boys.

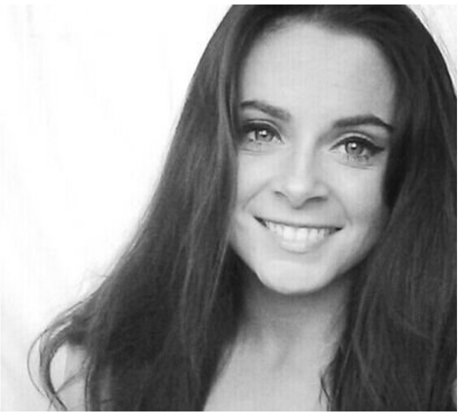

Brian and Siobhan Sewell (top); Alecia with her mum Lian

Alecia Yarlett, who is now 17, talked about her life and the things she enjoys. She explained that she likes to do 'normal things', such as putting on her make-up and going out with her friends. Mum Lian talked about what the future holds for Alecia and other young adults with A-T.

Antonia then went on to interview Professor Steve Jackson who is at the forefront of A-T research at the Gurdon Institute in Cambridge. He talked about his hopes for research to make a real difference to the future for people with A-T, and how much people are already benefiting from the research funded by the A-T Society.

Finally Antonia interviewed Kay, Suzanne and William at the office. Each explained their role within the charity and why it is essential that family support and research go hand in hand if children are to benefit from the research currently being carried out around the world.

The films explain A-T in an accessible way and generated a lot of interest and media coverage around the country.


Star student Antonia

Alecia was interviewed by BBC South East, with her video on their Facebook page receiving more than 19,000 hits.

You can find the films on our website **www.atsociety.org.uk** and on our YouTube Channel **www.youtube.com/user/ATSuzanne**

We're delighted to say that Antonia's films helped secure a first-class honours degree from the University of Salford. She also received the University Award for 'Best TV Journalist 2015'.

Finally, for the A-T Society, the films have been invaluable in communicating the heartbreak that families go through when a family member is diagnosed with A-T. They have helped enormously with educating people about the condition and what having A-T actually means, as well as demonstrating the amount of work going on behind the scenes to find a cure.

Wolverhampton DMES hosts 'running day'

The Baggeridge Country Park is the home of Wolverhampton District Model Engineering Society. It played host to a 'running day' for the A-T Society where the public could go along and ride on model trains and inspect a variety of engines. Once a colliery in the industrial heartland of England, the park has been reclaimed by nature, but machines and making things work is clearly in the blood of many a local man and boy. In particular Nick and James who loved their day on the line, along with Joy and Rachel who ran a stall and were thrilled to see an engine renamed 'A-T Society' for the day. Enormous thanks to Charlie Harthill and the members of Wolverhampton DMES.

Easy way to raise money at Christmas time

Have an ‘A-T Christmas event’ in your home, invite some friends round for some festive fun and raise money for the A-T Society at the same time!

Throw a festive tea party for your friends, but rather than tea you could serve homemade mince pies and mulled wine in exchange for a donation. You could also serve up Christmas cupcakes and star biscuits. Google ‘Christmas cupcakes’ for inspiration!

Things to do and sell at your Christmas event.

Rudolph the red nosed reindeer game – charge a small donation per go
You’ve probably played pin the tail on the donkey, but have you tried pinning the nose on Rudolph? Google ‘pin the nose on Rudolph’, print a template and you’re ready! Blindfold your friends, spin them round once or twice and give a prize to whoever is ‘on the nose’ with their attempt.

Reindeer food – charge a small donation per bag
This is simply a small envelope or jam jar containing some oatmeal or bird seed and glitter. Add a sticker of a reindeer and instructions to leave scattered on the ground on Christmas Eve. In the morning the seed will be gone with just the glitter to mark where the reindeers were!

Guess the sweets! – charge a small donation per guess
Fill a cookie jar with cookies or sweets and get friends to guess how many are in it. Whoever gets the nearest gets the jar (and its contents!)

A-T Christmas cards
Sell our Christmas cards – there are 10 cards in a pack and they cost £4. Please contact us if you would like to purchase some.

Festive fivers competition
This is such a simple idea but gives you a chance of winning some money to help with the Christmas shopping! Everyone puts their name in a hat and donates £5 – then you pick a winner. Half the money goes to the winner and half goes to the A-T Society.

Other fundraising ideas at Christmas

Christmas carols
This is a traditional fundraiser at Christmas. Get a group together and delight your friends, family, neighbours or colleagues by singing Christmas Carols to raise money. Providing you have enough strong voices try contacting your local supermarket or shopping centre to arrange permission to sing there – contact us to arrange a collection pot.

Decorate your house
Make your house an authentic Santa's Grotto with lights outside or decorations inside. Ask visitors to make a donation to admire your efforts – you can either direct guests to a MyDonate page or get in touch to request a collection pot.

Gift-wrapping service
Offer to wrap up peoples’ Christmas presents in return for a donation. Make sure your fees cover the cost of materials.

Unwanted Christmas presents?
Sell them on an online auction site such as eBay or have a post-Christmas car boot sale. Donate all proceeds to the A-T Society.

Register with Give as You Live
With the Xmas season approaching and lots of presents and food to buy, why not register with Give as you Live and do your festive shopping online? 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

Clear out your clutter before Christmas
Use the FREEPOST envelopes included with this newsletter and recycle your old mobile phones, cameras, unwanted or broken jewellery or watches and foreign banknotes. We receive a donation with every envelope that is filled so it pays to clear your clutter.