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A-T Society News

Blood, sweat and tears

Read about our inspirational supporters who have gone more than the extra mile for the A-T Society this year

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. The Society aims to alleviate the distress and suffering that A-T causes by working to improve quality of life now and in the future. We do this through funding research, supporting families, working to improve clinical management, and raising awareness.

Editor's Comments

Many thanks to all contributors. The copy date for the next issue is 15th April 2014. Please send comments, ideas, articles and pictures to:

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Cover picture: Trevor Sanderson carries the flag up yet another sand dune during his six-day run across the Sahara.

Contents

The A-T Society is extremely grateful to the team at Gosling, Harpenden, for their assistance in producing this magazine and their generous financial support for it.

Just William

William Davis, chief executive of the A-T Society, reflects on how much the A-T Society has achieved and what remains to be done.

Next year, 2014, the Society will be 25 years old. It will be a quarter of a century since Maureen Poupard and Dr Geoff Wood sent out a letter to families inviting them to a meeting at Birmingham Children's Hospice. Twenty- two families expressed an interest in meeting and thirteen turned up in Birmingham. It was there that the A-T Society was born.

Thinking about this brings mixed emotions. It is uplifting to think of all the achievements over those 25 years. So many people who have gained strength and hope from meeting others living with the disease; so many for whom the support and information they received from the Society has been a real life-line; the impact of the clinics we established in advancing understanding and treatment of A-T both in the UK and around the world; the funding that has been put into research; the amazing achievements of people living their lives with A-T.

And yet at the same time one can't help feeling deeply frustrated that after 25 years we are still here. People are still being diagnosed with A-T and families are still living with its devastating effects.

It's a very reasonable question to ask if we should we be celebrating an anniversary when there is still so much to do.

My considered answer is 'yes'. While none of us wants to be here, and we'd be delighted to close down the moment nobody is affected by A-T, that time has not yet come.

> **"Thinking about those 25 years brings mixed emotions. We should be proud though not complacent."**

A-T is a severe and complex condition. It is also very rare and only in the last 30 years has it become widely known. A-T was never going to be an easy condition to treat or cure.

At nearly 25, the A-T Society is the oldest organisation for people with A-T in the world. But compared with organisations that support people with more common complex conditions such as MS (60 years old), or Parkinson's (44 years old) it is a spring chicken.

Like them we have not yet found a cure, but we have made a major contribution to some amazing advances.

- Our understanding of the best treatments for people with A-T has improved hugely, largely due to the expertise gathered by the Nottingham clinic, established by the A-T Society, and other clinics that have followed its model.
- While hard to show scientifically in such a small population, it seems clear that life expectancy is increasing with many more people with A-T living well into adulthood.
- Research we supported at the University of Birmingham has made a significant contribution to the discovery of the ATM gene and subsequently to understanding the ATM protein.
- People with A-T are living increasingly independent and active lives often aided by the equipment paid for by the Society or grants gained with our help.

An anniversary like this is not of itself of much interest to the world at large. But for us it should be an occasion to look at what we have achieved and be proud, though not complacent.

We must celebrate our successes not for themselves but to show the world that we are a strong and effective organisation.

We must use the opportunity to draw in new supporters and new funds and re-launch our work to ensure that this is the last milestone anniversary we have to celebrate before the day when we can shut up shop for good.

We already have ideas for how to mark our 25th birthday, but if you have others, please do let us know, either by contacting individual members of staff, by e-mailing info@atsociety.org.uk or by ringing the office number.

Family Weekend 2013 Heading North!

Around 45 families, as well as friends and professionals, gathered in Manchester in June for the annual Family Weekend.

Big smiles all round in Manchester

This year we were very happy to be in Manchester, making it easier for those living further north to attend the event. After last year's success it was great to see so many people from all over the UK and southern Ireland.

For many, the most important aspect was the chance to meet up with others and share experiences. Our 'getting to know you' session on the first day was very helpful with this, particularly for the eight new families. They really valued the opportunity to chat to people who knew what they were going through.

The agenda on the Saturday included Professor Malcolm Taylor, giving an overview of A-T in the UK and Dr Emma Ross talking about her respiratory research. We also had our usual panel of doctors and therapists answering your questions in our Q&A session, which led to some very interesting discussions.

Sunday saw a number of breakout sessions, including a session on living independently and a first-aid course. Particularly popular was the demonstration from Canine Partners, including our own Kayleigh Aris with Kris. The two dogs were given lots of attention.

The children were entertained with games, music, dance and a creative workshop, where they made their own bags and keepsake boxes. This was messy, but great fun. Others went out to the local bowling alley where competition was keen. Some of our adults with A-T took the chance to indulge in spa treatments, including manicures and relaxing massages.

The Saturday evening banquet was a special occasion with a relaxed atmosphere. The children were entertained between courses with a disco and games and a magician worked his way around the tables doing tricks which were unbelievable even seen close up.

All in all it was a fantastic weekend and people went home happy but exhausted.

As one parent said: "We love attending the family weekends. It is great to see everyone. We all need to stick together! Thank you to everyone who helped to make it a great weekend".

The 2014 family weekend will be the Park Inn at Heathrow Airport from 27-29 June. Put it in your diary now!

Working hard and playing hard

Young adults with A-T get together for a weekend of discussions and activities

On a cold, snowy weekend in March ten young adults with A-T, aged between 16 and 26, met in Milton Keynes to discuss the findings of the My Life project, which looked at the views and experiences of young adults with A-T.

Many of those present had participated in the project which was led by Bryony Beresford from York University, who facilitated two discussion sessions. These gave people the opportunity to talk to each other about their own experiences of living with A-T and their future hopes and goals.

The group came up with lots of ideas about how the Society could better support them, future events they would like to see, the Papworth clinic, the newsletter and communicating between each other.

These were then fed back to the Society and we have already started to implement some of their ideas. You will see, for example, that there are lots of items from and about the activities of people with A-T in this edition.

But it wasn't all work and talk. We had a welcome meal on the Friday evening followed by a getting to know you session, including games and on the Saturday evening we went off to 'Airkix', a giant wind tunnel where you can learn to 'fly'. You experience the feeling of jumping out of an aeroplane and with the help of an instructor go flying up thirty feet or so into the air.

This was great fun and it was wonderful to see everyone enjoying themselves, including some of the carers. As you can see in the photos, some very odd safety hats were required!

Funny hats and serious chats in Milton Keynes

By the Sunday morning everyone was tired but some still had energy for ten-pin bowling or hitting the big stores in the town centre before heading home.

There were lots of friendships made and renewed. A contact list has been put together so people can keep in touch and all are looking forward to the next event!

Radiation workshop in France

In November this year, the French A-T Society hosted a two-day workshop on radiation and A-T at Clermont Ferrand.

The conference attracted speakers and delegates from Europe and the United States. It looked at what the latest research tells us about the risks of radiation both to people with A-T and to carriers of a single copy of the A-T gene.

While the formal outcomes of the event have yet to be published, the broad outlines are that the guidance should remain much the same. People with A-T should avoid having x-rays and scans where they can, but if these are clinically required, they should be carried out. Medical X-rays in particular involve low doses of radiation. However repeated exposure to the same parts of the body at close intervals should be avoided.

For carriers of the gene, there is no evidence of any raised risk from exposure to radiation. However radiation is not good for anyone, and so should be avoided unless strictly necessary.

The UK guidance on the breast-screening of female carriers from the age of 40, and women with A-T over the age of 25, is soundly based on a close study of the available evidence. This guidance can be found on our website in the About A-T section.

Interns move on

Many readers who have contacted the Society over the summer or who attended our 2013 Family Weekend will have spoken to one or both of our two excellent and delightful interns Molly Owens and Jess Miller.

After making a fantastic contribution over the summer, both have now moved on. Jess we are delighted to say has got a job in Brussels, while Molly has returned to the final year of her degree at university.

We send them both a big thank-you and wish them all the very best for the future.

We remember

It is with great sadness that we announce the deaths of the following people:

Nicole Matthew

from Montrose, Scotland, died in 2012.

Lee Gallagher

from Derbyshire, died in May 2013.

Alex Evans

from Mid Glamorgan, Wales, died in May 2013.

Zobia Mahmood

from Lancashire, died in August 2013.

Aled Pritchard

from Wrexham, Wales, died in November 2013.

The whole Society shares in their loss and we send our sincere condolences to their families and friends.

Trustees

During 2013 there have been a number of changes to the Board of Trustees.

We were very sorry to lose the experience and wisdom of Marian Barber who stepped down for personal reasons.

As well as long experience of living with A-T, Marian had worked extensively in the voluntary sector and brought a great knowledge of the issues facing organisations like ours.

We are likewise very sorry to lose the drive and energy of Tania Wheeler, and her commitment to A-T research.

The good news, however, is that Tania will still be working in the field as she has been appointed research coordinator for Action for A-T.

We wish her all the very best in her new role and look forward to working closely with her in this capacity.

We are delighted though that earlier in the year Alexei Lioutyi joined the Board.

Alexei came to us from BLP, the legal firm for whom we were charity of the year until April 2012.

Alexei is a business manager and brings extensive business skills and experience of business development, strategy and international project management.

Cambridge project attracts support

The A-T Society's biggest investment in A-T research this year has been the project being carried out by Josep Forment, part of Steve Jackson's team at the Gurdon Institute in Cambridge.

The project started in June this year. Having made a commitment to fund the project with the support of the Thomas Appeal, a charity dedicated to A-T research, we were delighted to hear in September that the trustees of the Masonic Samaritan Fund were so impressed with the project that they had agreed to fund it in its entirety.

We are extremely grateful to the Fund for their appreciation of the importance of this project and for the generosity of their support.

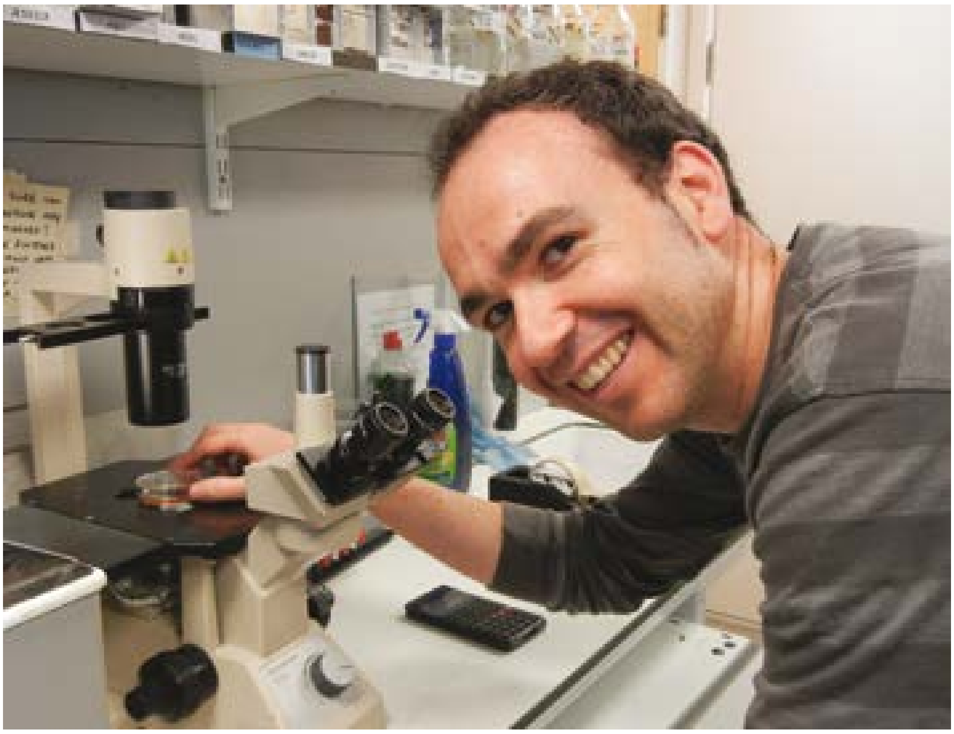
The project

The aim of the project is to identify whether there are other genes which, when 'switched off' could reduce the sensitivity to DNA damage of cells which do not produce ATM (ie the cells of people with A-T). If such genes are identified, they could represent new targets for drugs to improve the symptoms of Ataxia.

The ATM genes is one of a whole 'family' of genes that produce proteins involved in responding to DNA damage in the body's cells and this approach has already been shown to work for other related genes.

Another of these genes is BRCA1, the breast-cancer causing gene which was in the news recently when it was revealed that film-star Angelina Jolie has it.

The team at the Gurdon Institute will be working on ATM and BRCA1 side by side (though obviously we are only paying for the ATM part of the study.)



Progress

In order to carry out their study, the team have had to find a way to create mutations in the entire genome. That is, they need to obtain cell populations where every single gene of the genome is mutated at least once, so that they can see whether the suppression of each gene makes a difference to the survival of cells with no ATM.

They have now successfully done this in two different ways. Their next step will be to look at the effects of some different DNA-damaging agents on ATM-deficient cells and then apply the different mutations to these cells to isolate any that make them resistant to the agents. They will then use DNA sequencing to identify these mutations.

Pictured in order of appearance:
Researcher Josep Forment
Steve Jackson receives a cheque from Rodney Wolverson, provincial Grand Master of Cambridgeshire
At work in the lab

The project is due to last a year. We will be providing more detailed information and updates on our website.

Possible clinical trial of Erydex

Over the last 18 months we have been doing our best to keep people living with A-T informed of progress towards a possible trial of Erydex. As we go to print it is looking increasingly hopeful, though by no means certain, that a multi-centre clinical trial will be established during 2014, and that there will be an arm of the trial in the UK.

Erydex is a slow-release means of delivering the steroid dexamethasone. In a number of small scale studies in Italy, children with A-T given steroids have shown a significant improvement in their neurological symptoms, though the effect only lasts while they are on the drug. The slow release helps avoid the side effects normally associated with long-term steroid use.

A multi-centre trial would be the first large-scale clinical trial of a treatment for A-T and as such would be very welcome. It would hopefully give us more information about the effectiveness of steroids and if they are shown to have a real effect, could lead to greater understanding about the mechanisms of A-T and open the way to new treatments.

At the beginning of the year, the Italian company that produces Erydex, confusingly named Erydel, got a licence to test their product from the US authorities (the Food and Drug Administration or FDA) and what was effectively permission to fast-track the testing regime.

As many readers will know, Erydex is a means of treating people with the steroid dexamethasone by infusing it into the individuals own red blood cells. Blood is taken from the patient and the red cells are removed, cleaned and infused with the drug. They are then mixed back into to the blood, which is returned to the patient's body.

While the process is fairly simple from the patient's perspective, requiring only for blood to be taken and later put back, it does take several hours and needs to be carried out every four weeks or so.

However, delivering the drug in this way means that it is released very gradually into the body and thus almost entirely avoids the very significant side-effects of long-term steroid use. These can include weight-gain, a 'moon-face', increased risk of infection, high blood pressure, eye problems and bone weakening.

Patents on a small scale trial six-month in Italy showed virtually no side-effects. Some of these people who were allowed to continue the treatment on 'compassionate grounds' because it had had a positive effect have now been using Erydex for nearly two years and continue to be free of side effects.

Erydex machine

During 2012 Erydel has been carrying out a number of phase 1 trials, on volunteers who do not have A-T, looking in detail at safety issues and how the body reacts to the treatment. They are also undertaking a project to ensure that existing scales for measuring how people are affected by ataxia are valid for children.

The A-T Society is working with Erydel to try and ensure that the trial takes place as quickly as possible and that the UK is involved.

Nevertheless, Erydel is a commercial company and as such commercial considerations will be at the forefront of all the decisions they make.

If you would like to find out more about Erydel visit:

www.erydel.com

Three-charity fund

Last year the A-T Society together with Action for A-T and the children's medical research charity Sparks set up a joint A-T research. The fund is hosted by Sparks, but all three charities contribute equally to it. The fund made an initial grant of £90,000 to Prof Ignacio Molina at the University of Granada, who is working on a gene-therapy approach to treating A-T. While this is an approach with a lot of potential, there are still very many barriers to overcome.

The second grant round closed in September and as we go to press, four projects are being peer-reviewed.

Scientific Advisory Board

The A-T Society's new Scientific Advisory Board had its first meeting earlier this year. The Board consists of experts from a range of backgrounds with knowledge of both specific A-T research and wider related fields of research.

The role of the Board is to advise the Society on its research strategy and priorities and to ensure that it keeps up to date with the latest advances in research into A-T and related areas.

It will also assess applications for research funding, once these have been peer-reviewed, and make recommendations to the Board of Trustees on what research to fund.

The Board brings together members with an expertise in specifically A-T research and those with experience in related fields. It also has a balance of experience of clinical, laboratory and applied research.

The current members of the Board are:

Prof. Penny Jeggo (Chair), the Genome Damage and Stability Centre, University of Sussex

Prof Malcolm Taylor, University of Birmingham

Prof Bobby Gaspar, University College London

Dr Rick Livesey, Gurdon Institute, University of Cambridge

Dr William Whitehouse, University of Nottingham and A-T Centre Nottingham

Dr Anke Hensiek, University of Cambridge and A-T Centre Papworth

Dr Emma Ross, University of Brighton and Trustee of A-T Society

The Board's priorities include:

- Developing a strategy to answer the question: why do some brain-cells die in the absence of ATM but not others?
- Supporting the establishment of more small-scale clinical studies of existing drugs
- The need to develop more expertise in the UK on treating cancer in A-T patients
- Opportunities for partnership with researchers in other conditions
- Approaches to better recording and sharing data on AT patients

Work will continue between meetings, with the next scheduled for early 2014.

European survey goes global

One unexpected but extremely welcome outcome of the A-T Workshop 2013, held at the University of Birmingham in July, was the very positive meeting of 11 European clinicians specialising in A-T, from 8 countries, and their commitment to working together more closely in future.

While there has been much talk in the past of closer co-operation, it has rarely gone beyond the ideas stage.

This time, however, some concrete steps were agreed and with the help of the A-T Society, these are now starting to take place.

The first big step forward was to start to collect and share non-personal information about numbers of patients, their types of A-T and how they are affected by this. To do this, the A-T Society put together and circulated an on-line survey to gather this information.

While Europeans at the meeting had already signed up to the survey, we sent the link out to clinicians in other countries and have had positive responses from the USA and Japan.

As we go to press, the deadline for the survey has not yet been reached, but once it has the data will be circulated within the group and decisions made about how to make use of it.

The data will almost certainly be made available more widely and it is likely to the subject of discussion at the 2014 clinical research conference in the Netherlands.

Imaging project to start in Nottingham

A new project, using the latest magnetic resonance imaging (MRI) technology to see inside the brains of children with A-T will be starting in 2014 in Nottingham.

This project stems directly from the clinical research conference which we organised in Cambridge last year. It aims to identify bio-markers - biological indicators which can help us understand and measure the progress of neurological problems in A-T and assist in the development of new treatments.

The two-year project will be looking to recruit 30 patients from the Nottingham A-T clinic and 20 children without A-T. MRI does not use radiation, so is completely safe for people with A-T. We will be writing out to families in 2014 with more information.

Keep calm and carry on researching

Brad Margus tells William Davis that despite his frustrations he remains hopeful that evolving technology will help us defeat A-T.

Brad Margus is the founder and President of the A-T Children's Project. He is also the father of two sons who have A-T. Few would deny that he has had a bigger influence on A-T research than any other non-scientist.

Over the years, as a volunteer, he has lobbied for and funded A-T research, raising and spending tens of millions of dollars. He has persuaded new researchers into the field, organised conferences and established clinics.

Yet when I asked Brad to do this interview, he couldn't understand why people might be interested, suggesting that they would be more interested if I interviewed a neuroscientist.

I asked him how he came to set up the A-T Children's Project.

"In the early 90s life was pretty good. Vicki and I had 3 sons. I was running a shrimp processing company and knew nothing about A-T or molecular biology. However, we noticed our second son Jarrett was wobbly and started on the journey many A-T families take, where many things are suspected but not confirmed. It wasn't till a year later, when our third son Quinn presented with the same symptoms, that A-T was diagnosed.

"Like any family, we suffered the grief of not having the perfectly healthy children we thought we had. But after a month or two spent grieving and hugging each other, we wanted to do something. We knew there were organisations already funding A-T research but it seemed this really needed additional effort so we started the A-T Children's Project.

"I was really naïve. I read all I could find on the Internet, but I didn't know how to evaluate it. There were so many things I didn't know: how to fundraise, how a scientist's career works, the importance of publication or how to lobby the government."

So Brad made a list of these things, broke it into little pieces and set to going through it. With help from some scientists, he started to learn the science, "not so well that I could do research but so I wouldn't waste a scientist's time by asking him to explain what a gene was." Later, as A-T research advanced beyond genetics to proteins, model organisms, neurobiology and drug discovery, Brad relentlessly expanded his learning into each new area.

A couple of principles from his business background helped. One was to map out the obstacles to research. "Initially I assumed that funding is the most important thing, but quickly I learnt that there were other things that would slow research. For instance, while some researchers had access to tissue samples or cell lines, they weren't always that cooperative in sharing.

"Persuading labs to share resources and setting up a tissue bank turned out to be nearly as important as funding."

The other principle was to minimise bias. "To an immunologist, immunological factors are crucial; talk to a cerebellar expert, and they'll convince you that you can pretty much remove the rest of the brain and it doesn't matter. You need really objective advice so I focused on finding people who were experts in science – not necessarily in the A-T field – to give us that." Remarkably, over the years, highly respected scientists across many fields have helped when Brad has called on them, including several Nobel Laureates.

I ask if his view of the obstacles to research has changed over time?

"In the early days, all we wanted was to apply to our kids' disease the same approaches and technologies that were being applied to the big common diseases. Today I'd say that around the world, we've been pretty good at exposing A-T to a lot of different researchers and when a new technology comes along, we are able to assess its applicability to A-T much better. However, we are still limited on funding and end up having to choose a subset.

So what, I ask him, does he see as the most promising lines of research?

"In our strategy, we look at the different kinds of A-T patients that we want to benefit …

"The first group is A-T children who haven't been born yet. As DNA technologies get cheaper, we may some day be able to screen the whole population and prevent any more A-T children from being born.

“Then there are children who are just diagnosed but still running around. For these kids, there are many strategies such as neuro-protection, either antioxidants or growth factors, things that might help their brain cells live a little longer.

“The third group is patients who are older and have already lost many brain cells. You can’t prevent cell death that has already happened, but maybe you could replace cells with stem-cell therapy, or perhaps you could correct circuitry, using deep brain stimulation or even pharmacological intervention.”

Another approach is working out how the disrupted gene leads to all the problems of A-T. “We’ve invested a lot here because, although it seems slow, you are least likely to waste money. People like Yossi Shiloh in Israel do great work in this area. Every time a new technology emerges, they go get it and then collaborate with other researchers around the world.

“But figuring out the biology of A-T could take 50 more years. So we allocate part of our portfolio to more speculative research. While it’s high risk, there’s a possibility you could have something in just a few years. And our foundation is also about providing hope.”

They are following areas like DNA read-through technology, that Richard Gatti at UCLA and several companies are advancing. There are also areas of science that come into vogue, lose favour and then come back again.

“When gene therapy was first out, everybody got very excited about it. Then it had some major set-backs -- it was difficult to deliver the very large A-T gene into the brain and there were some very adverse effects in other diseases. For a while, it was low priority.

Brad Margus with Son Quinn

Today the delivery vectors have advanced remarkably and we now feel it’s time to return to gene therapy. It’s important to keep your finger in all areas because a field can make progress and suddenly it can be relevant to A-T again.”

Growth factors are another area of promise he feels. And we need to focus more on how cell death in the brain eventually leads to ataxia. “I remain very frustrated that we don’t engage enough neuroscientists in A-T research.”

What, I ask, do you say when people ask if we are going to find a cure?

“In business, you can make a plan and say that over this time we will accomplish these things. In research you can’t do that. Even in the hands of the greatest scientists, experiments can fail. You can’t predict when breakthroughs will come.

“So the good news and the bad news is that we may find something in a year or two that we could rush to the clinic, or it could take us 30 years. But if you look at other discoveries, often they come out of nowhere very quickly. What’s most important is to have as many brilliant scientists aware of and thinking about A-T as much as possible.”

So does he think we could do more to work together internationally?

Brad thinks that our organisations work well together, even though they’re small and may focus differently. “But if we were doing clinical trials, suddenly we would really need every A-T family and every A-T organisation in the world to work together. Even now, it’s very helpful if we can all compare notes on what we have funded to date, and our experiences with researchers. There are also speculative projects, where no one wants to invest heavily, but if you split those 2 or 3 ways it makes more sense.”

So, what are his biggest frustrations apart from the fact that we haven’t found a cure yet?

“Well that’s the big one. I worry every day that our organisation has missed something, or that we didn’t follow it up, and that 20 years from now we will realise that it was the answer and we just passed over it.

I’m frustrated that sometimes it’s difficult to get certain experiments performed for us, particularly to confirm the results of another lab.

We often have to give a grant where we fund something else on condition they replicate an experiment for us. Some days I wish we had our own institute or laboratory.

"Another big frustration is that in 2009 I started a biotechnology company, focusing on developing drugs for more common neurological diseases. Just 3 years after we started, we had 2 exciting new drugs for neurological diseases and then a major drug company bought my company. For me it was bittersweet. I was able to build a company that developed new drugs for these other conditions but I still can't find a treatment for A-T."

I ask him about what seems to have been a change of direction in his professional career over the last year since he sold his company.

"As whole-genome sequencing becomes much cheaper, researchers and clinicians are beginning to generate a tremendous amount of genomic data, and I want the entire world to be able to use those data. So I've helped to set up a global alliance of over 110 stakeholder organisations in 17 countries to develop technical and ethical standards for storing that data so it can be freely shared. At the same time, I have also founded a non-profit organisation called Genome Bridge and hired software engineers to develop a cloud-based technology platform for securely storing, sharing and learning from genomic data – including something like an app store that will offer data analysis tools developed by scientists around the world.

"We can use this big data approach to learn a lot about genetics and how drugs interact with them. In A-T there is a lot of variability between patients and families. There must be modifier genes that affect how severe the disease is. I would love for us to be able to look at the whole genomes of A-T patients and see if there are other genes that modify how severe or mild it is. I would also love to examine the A-T gene in a million healthy people to see if anyone who should have A-T doesn't."

So his drive for this new initiative is still A-T?

"My day-job has to focus more broadly on accelerating all medical research, but I'm confident that being surrounded by brilliant physicians and scientists will pay great benefits for A-T research. I get to hear and think about approaches to many other diseases, but to be clear, when I go to sleep at night or when I take a shower in the morning, the first thing I'm thinking about is A-T research."

Between his professional and A-T work does he have any free time at all?

"I do give a lot of priority to my sons. As we've learned to manage the cancer and lung problems in A-T a little better, allowing longer life spans, a new issue has emerged because adults with A-T want to have goals, jobs and responsibilities."

I spend a lot of time with my sons trying to entertain them and make life fun but I don't have hobbies like golf or anything like that. When you are passionate about something, you don't mind giving up those other things."

Brad is keen to find other A-T parents with an appetite for learning more about the science. "I'm thrilled to spend as much time with them as I can, telling then what we've been struggling with, what we are doing, what we're excited about."

But doesn't he think his example might be rather scary to others?

He laughs. "Remember, I was a shrimp guy. Before A-T entered my life, my business was shrimp processing. It's just that if you're really driven to do something, and if you break every big challenge into lots of little pieces, you can do it – what's that British thing 'Keep Calm and Carry on!'. I love that, I feel like the UK stole that from the A-T Children's Project! It's a great motto."

Brad is positive about how much is going on. "I'd have loved to have known so much about A-T back when my children were diagnosed. It's still frustrating that we don't have great animal models of A-T, it's challenging to raise money, a clinically-relevant assay for drug screening has eluded us, and brain imaging hasn't produced quite enough information for me to be satisfied, but there are some really promising technologies. Like nanotechnology which may deliver drugs or genes more effectively than viruses, or gene therapy, where there are a lot of new strategies. And a drug developed for a completely different disease could suddenly be found to help A-T. Viagra was developed as a heart drug but at the end of the clinical trials, none of the men wanted to turn in the extra pills…"

While refusing to ever give up, the bottom line he feels is that we have failed to date. "We've been able to extend the life-span of kids with A-T some, but their quality of life is still poor, the tremendous potential of our kids is being lost, and families are perpetually exhausted. We need to make more progress.

Every time we lose an A-T kid, it kills me. It's a very promising time for research, but we can't celebrate at all yet. Sometimes at meetings, I get a little impolite with some of the researchers, but it's only because I remain impatient and want people to move faster."

"It's up to families and parents to constantly remind people why we are doing this. We don't want to; we're just doing it because we have to and we need to move as quickly as possible."

Changes to benefits

The benefit system can be a bit of a minefield and understanding what you may be entitled to and filling in all the forms can be very daunting.

This year there have also been some changes to the benefit system, including the introduction of:

Personal Independence Payment:

(PIP) this will eventually replace Disabled Living Allowance (DLA). If you are currently receiving DLA you are unlikely to be re assessed for PIP until 2015. The criteria are likely to be similar to that for DLA.

'Bedroom Tax':

This may affect you if you rent your home, claim housing benefit and are considered to be under-occupying your home.

Universal Credit:

This will eventually replace Jobseekers Allowance, Employment & Support Allowance (ESA), Income Support, Working & Child Tax Credit & Housing Benefit and will be introduced gradually between now and 2017.

Your local Department for Work & Pensions (DWP) will write to you if and when you are affected by these changes and probably ask you to complete an assessment and/or some forms.

However, if you do have any concerns, or you would like help in completing your benefit forms or just general advice on what benefits you may be able to claim then please do contact Kay, who can help with suggestions on what benefits you might be eligible for, give hands-on help with the application and provide supporting letters to confirm you have A-T and explain the condition.

It you haven't recently (or have never) reviewed what benefits you are receiving, it would also be sensible for you to contact Kay. A-T is a changing condition and you may now be entitled to benefits that you weren't before.

The following websites may also be of help:

www.gov.uk/browse/benefits

www.gov.uk/disability-benefits-helpline

www.cafamily.org.uk/know-your-rights/benefits-and-tax-credits

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Sports: Go on, have a go!

Since the success of the Paralympics last year there has been great interest in disability sports. Not all sports may suit everyone but why not have a look and see what is on offer. The following websites may help:

Parasport (disability sport)
Designed to help you find a sport to suit you, with its own self assessment wizard.

www.parasport.org.uk

Riding for the disabled
Horse riding for children and adults with all forms of disability.

www.rda.org.uk

Beyond Extreme
Paragliding for all, and tandem flights for people with disabilities

www.beyondextreme paragliding.co.uk

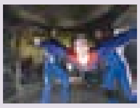
Ski 2 Freedom Foundation
Snow sport and mountain activities.

www.ski2freedom.com

Disabled Snowsport UK (DSUK)
www.disabilitysnowsport.org.uk

Calvert Trust
Adventure sports holidays for people with disabilities.

www.calvert-trust.org.uk



Airkix
Indoor skydiving for children and adults.

www.airkix.com

Royal Yachting Association
Sailing for able-bodied and disabled alike.

www.rya.org.uk

Disability Sport Federations
Each of the four nations has an organisation that provides leadership and support to the development of disability sports

England: www.efds.co.uk

Scotland: www.scottishdisabilitysport.com/sds/

Wales: www.disabilitysportwales.org

N. Ireland: www.dsni.co.uk

Papworth Clinic Visit July 2013

Charlie (17) and his Mum Tina describe their visit to the Papworth Clinic in July.

It was our first visit to the Papworth Adult A-T Clinic following the transition clinic in Nottingham last year, where we met some of the Papworth team.

We were all a little anxious, not fully understanding what was going to happen, what results we would get, and if anything would hurt.

We arrived on a Sunday afternoon, checked in and were shown to Charlie's room. It was nice and cool, with adjustable air conditioning. My husband and my other son went to book into a local bed and breakfast.

The room had everything we needed: a television, a nice comfortable fold-away bed for the guest and our own en-suite wet room.

There were various tests over the three days.

- They took blood from behind Charlie's ear, to test for oxygen levels in the blood. We were scared, and asked for some numbing cream. But we needn't have worried. Charlie said the noise was the most frightening thing, it didn't actually hurt.
- The sleep study was set up on the Sunday evening. The machine kept bleeping and flashing different numbers which made us a bit nervous, and we found it difficult to sleep, so Charlie was glad when it was morning.
- There were some respiratory blowing tests, which Charlie found quite fun and challenging.
- He was a bit concerned about the CT scan as he didn't know what to expect, and the bed moves during the scan, but it was soon over and he was fine.

- They took some more bloods. The doctor who did this was fantastic

We had lots of appointments with various doctors and therapists over the few days and spent time talking things through with them. We found out lots of new information and had tests that had not been done before, which were really useful.

On the Monday evening, after a long day, we decided to take Charlie out for dinner. We ended up in St. Neots at The Bridge House pub; it is about a 15 minute drive from Papworth.

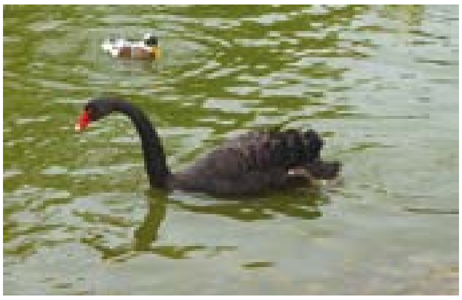
I must say they were very welcoming and served the best pub food we have ever had – at a very reasonable price!

We had fantastic steak, and the chocolate brownie finished it off a treat. We went back to Papworth to settle down for the night and both had a much better night's sleep.

The next day was our last and we had some important meetings with the Doctors to discuss results.

Everyone was very down to earth and answered all the queries we had.

We mentioned the sleep study and were told that as Charlie's sleep study was ok, we wouldn't need to have it done next time, if we didn't want too. Suggestions were made about services before our next visit in 12 months time.



After all our appointments we went outside to the pond and fed the black swans and the fish! We were on our way home by lunchtime.

We certainly thought this visit was very worthwhile and will definitely return next year.

Tina and Charlie

Beauty in ‘hell’: a personal journey

Trevor Sanderson will never be the same after 6 days running across the Sahara for the A-T Society

The tension was palpable. 297 Brits in the departure lounge for the specially chartered flight to Morocco, all of us to attempting to hide our nerves. We were flying out to participate in the infamous Marathon des Sables (MdS). 28 years ago, when ex Foreign Legionnaire Patrick Bauer had the crazy idea of running 250km through the Sahara Desert, 26 competitors set off. This year, 1124 would cross the start line.

Had I prepared enough? No. Had I done enough research? No. Did I have the best kit? No. Did I have plenty of race experience? Never even run a half marathon. But I believed I had something that many do not. The RAF esprit de corps, that self-belief born out of tough experience that would keep me going…right?

What makes the MdS so tough and unique is its totally self-sufficient nature. From departure onward, my 30-litre backpack contained everything I needed to get me through the next 6 days, including food, spare socks, hypodermic needles, Friars Balsam for blisters, salt tablets, anti-venom pump and a distress flare. The only thing we would be given was water and as it turned out never enough!!

On the morning of day 1, a noticeable rise in temperature was a shock and any delusions of grandeur regarding my performance evaporated with the moisture in the air.

We had 39km to trot on day 1. Setting off with the very apt Highway to Hell blasting out of the sound system I felt good. I was making good on a promise to a friend and his little girl and was excited beyond words.

“Taking part in the MdS will change your life forever”
Trevor Sanderson

My three mates and I had agreed to take it easy: only a fool would go too hard on day 1. But yes, you guessed it. I finished day 1 in 291st place, tired, hot and with a few tiny blisters, but otherwise feeling great. Day 2 was only 30km; the shortest day. Surely those horror stories had been exaggerated!

Day 2 is still a blur. I don’t know exactly where it started to go wrong. By Check Point 1 at 12km, I was exhausted, nauseous and peeling off white socks that had turned blood red. I was in agony. We had been going over mountains, not hills. Taping up the blisters that had formed on every inch of my feet took half an hour. Mountain after mountain, sand dune after sand dune I had never felt worse in my life.

It took 7 hours to reach the end of one of the most physically and mentally difficult days in my life. I had no choice but to visit the doctors. Both big toe nails and all on the left foot had turned black, with blood blisters forming under the nails. Fortunately, these docs do feet like nowhere else on Earth. They work behind a curtain, but curtains can’t hide screams…

Day 3 dawned. On attempting to rise, I had pain in my hips, knees and shoulders and my feet didn’t feel like mine. I wasn’t sure how I was going to get my trainers on let alone do 38kms.

The first hour and a half was purgatory. Being passed by runner after runner was a huge blow. After 2 hours the pain faded to numbness and I began to feel better. Calling on Gunner spirit I cracked on, finishing the stage in a not too shabby time in around the 450 position.

Sadly, though, mental resolve and physical well-being don’t go hand in hand in the MdS. My feet were obliterated. Not wanting to go back to the Docs I ‘self-aided’ with the use of knife, syringe and Friars Balsam disinfectant. If you want to see a grown man cry, I have the video footage… Nevertheless, after the burning had stopped, my feet felt a little better. Only 80km to cover tomorrow. What could go wrong?

Waking to searing heat and a broken body, I struggled to the start. The pain was indescribable and I won’t lie I was concerned.

It took me 4 and half hours to make 20k's and at Checkpoint 2 the temperature was 55°C. Blood was coming through my thick trail trainers, so I did the sensible thing and had my feet treated.

It took the beautiful French doctor Veronique an hour and a half to sort my feet and tape each toe individually using a metric ton of zinc oxide tape.

9 hours and I had only travelled 35km. However, as dusk approached, I suddenly felt better and I had my second moment of the race. I covered the next 45km in roughly 7 hours powering through the desert night, using Polaris as a guide.

I felt good until the last 5km where strange sensations took over. I knew I was taking far too many pain killers and probably too many electrolytes but that wasn't going to stop me. Nothing was.

Crossing the finish line, I knew I was in bad shape. I was being constantly sick, had pins and needles all over and moments of blackout. I must have passed out when I went to the toilet, as it took me over an hour to find my tent, only 20 metres away.

It took till 4 in the afternoon the next day before I was compos mentis and able to sip some water and eat some food. I now understood why it's called the toughest footrace on Earth.

The hobble to the start line for day 6, the traditional marathon distance, did nothing to dampen spirits. I knew I'd cracked it, though the temperature pushed 54 again and the breeze, felt like someone had opened the oven door.

Coming over a mountain top to see the final camp site in the distance was one of the greatest sights I have ever seen. However, as with everything in this race the last 5km was deceptive and soul destroying and the end never seemed to come. When it did and I received my traditional 2 cheek kiss and medal from Patrick Bauer on the finish line, I muttered something incoherent to the webcam and was close to tears. The emotion and enormity of the moment almost overtook me as the realisation of a dream being achieved struck home.

This short report doesn't cover the experience itself. For this isn't really a race. It's a journey and one unlike any other. You share moments with people and yourself that will be etched in the memory forever. On a tattooed man, the MdS is a tattoo for the soul.

A man much smarter than me once said:

"one who pushes himself too far is the only one who ever really finds out how far one can go".

I found some of my answers on day 4. Taking part in the MdS will change your life forever. In my 34 years it's the most beautiful thing I've ever seen on this massive blue green planet.

A little bit about me

By Eleanor Hewitt

I enjoy learning so much, but it can be a challenge. I have tried brick-built universities but found issues with accessing material and with fatigue, so I recently turned to the Open University.

I am pursuing an open degree of free choice modules and have not found any accessibility issues. I'd urge anyone who is thinking of continuing their education to degree level to consider the OU.

I have done a nutrition module and passed, and my exam for health sciences is coming soon. They're honestly really good.

I love animals and particularly cats, I care for my cat, Jet, at home. I love looking after him and he is a great comfort when times are hard!

I use an mp3 player to listen to audio books from Audible (audible.co.uk). One of my favorites is 'A Street Cat Named Bob' by James Bowen.

I won't spoil it for you but it's a must for animal lovers – I challenge anyone not to cry!

A summer of sport 2013

By Joe Bromwich

It is some time since I wrote to the newsletter but I have had a busy summer I thought I would tell you about.

Sailing

I still go sailing using access boats most weekends, which I have done for the past 10 years. There should be an RYA Sailability club near to you. If you are interested in sailing, just look on the RYA website. People will be very helpful and up for a challenge.

Paragliding

I was 21 this year and Mom and Dad paid for me to go paragliding. We made the arrangements for a flight in May with Mark Dann from Beyond Extreme. Mark has an excellent approach to things. A simple phone call, no drama, no over-the-top risk assessments, and we are ready for action.

We met Mark and the team at a garden centre and followed them up to the Long Mynnd. Then we had to get in their Land Rover for the next bit, and that's when the real fun started. The off-roading was almost as exciting as the jump.

The weather was good so we got to take off almost straight away. I was strapped to Mark and we ran down the hill to get the wind – well he did – with the help of some assistants.

We took off and were up for about 20 minutes before we landed in a field down below. It was a real experience as I don't like heights. But once we took off I was ok. I could see the clouds above and the fields, trees and sheep below. It is a good feeling when you are up there.

The landing felt just like someone walking off a step. We touched down gently on the grass with none of the 'bum dragging' I expected. Mark folded the chute around me so I could sit up and wait for everyone else to arrive in the Land Rover to collect us.

It was a good day and I would recommend it to anyone, if only to hear your Mom shout "Oh my god" as they push you off the hill.

If interested, take a look at the website:

www.beyondextreme.co.uk

Karting

Next I went karting at Wilton Mill where they have a hand controlled kart. The handlebars have a lever to accelerate and one to brake. I found this out on the internet as injured soldiers go there to try karting. I started off lapping carefully whilst I got used to the controls and then gunned it. (I was going to say floor it, but there's nothing to floor when you're not using your feet).

I also go karting locally, but I do have trouble keeping my feet on the pedals and the hand controls were loads easier for me. I have booked to go back in September.

If you are looking to do a sport, have a look what injured soldiers are doing. There seems to be a lot out there for them that we could hijack.

Boating

This year's family holiday was in Beadnell Northumberland. We took my speed boat, but I will let my Dad tell the tale.

"We set off at 5am for Northumberland in glorious weather, the hottest day of the year at the time, towing Joe's boat.

After making good time my car conveniently informed me it was overheating. No amount of water and rest helped it and the AA was needed.

"When we tried to call only one out of our four mobile phones had a signal. When we finally got through to the operator and the conversation went something like this:

AA	Where are you broken down?
Me	Don't really know. Somewhere on the A1 north of Alnwick.
AA	Okay we'll get someone to you as soon as we can.
Me	By the way. we are towing a boat.
AA	Oh what size is the boat?
Me	Blah blah.
AA	Okay, we will get someone to you as soon as we can.
Me	By the way we have a wheelchair as well.
AA	Oh can the person transfer.
Me	Blah Blah.
AA	Okay, we will get someone to you as soon as we can.
Me	By the way, we also have a dog with us!!!!
AA	Okay, we will get someone to you as soon as we can.

You can image the control room at the AA thinking is this a training scenario, or you've been framed; No it was just us on holiday!

Anyway, we finally got there and had a great week assisted by Jim the tractor launcher on the beach, a good bloke when you have a boat and no car!

We saw porpoises, dolphins and lots of puffins and grey seals whilst out on the North Sea around the Farne Islands."

Well that's all from me and my Dad, hope you had a good summer too.

Remember it isn't disability, its differently-abled that matters.

Community Build

Keith Johnson, who lives with his mother Rose in Crosby, Liverpool, is 41 years old but was only diagnosed with A-T a few years ago.

Although Keith was struggling to use the stairs and there was no downstairs toilet in the house, Social Services would not build a downstairs bedroom/bathroom for Keith. They would provide a downstairs bathroom but asked Keith to use the living room as his bedroom).

Despite a battle involving the A-T Society and the local MP, the Council refused to budge. In the end the family felt they couldn't fight anymore and would have to accept the Council's decision, as Keith was having constant falls.

However they didn't reckon on their friend, Keith Harwood. A builder himself, Keith said: "Well if they won't do it, we'll do it ourselves".

He immediately got to work with the planning department, some council funding and local tradesmen to put the project together. It took many months of hard work but thanks to Keith Harwood's never-ending determination, and the support of all the people who volunteered their time and materials, the project went forward.

Keith outside the newly refurbished house

The whole community pitched in. Many different tradesmen donated their time and materials, such as skips, concrete, sand, roofing materials etc. Men and women who had already done a full day's work would turn up in the evenings and at weekends to put in the time and effort needed to get the job done.

Every single one of them went far beyond the call of duty and made a huge contribution to transforming Keith's life.

In just a few months the project was finished. Keith now has his own downstairs bedroom and a large wet room, as well as ramps to the front and back of the house. They even managed to build a small utility room for Rose.

Keith and Rose were overwhelmed by how many people supported the project and gave up their spare time to help. They said:

"We were very upset when the Council turned us down and we were going to have to just accept the situation. Then, when our friend Keith Harwood suggested the Community Build, we couldn't quite believe that it was going to happen. But it did! We are amazed that so many people gave their time and materials to help us. It is very humbling. There are not enough words to express how grateful we are to everyone. Keith is now very independent and can get about on his own without any help or danger. For that we will be forever grateful to everyone involved."

On his travels! – with Ian McInnes

I mentioned at the end of my last talk on the stage at one of the family days that I was going on a cruise round the Caribbean.

If that sounds like tropical relaxation, it didn't start like that! We stayed overnight in a hotel next to Glasgow Airport, as we had to get up about 3am to catch our flight to Montego Bay in Jamaica.

While we were waiting in Glasgow airport, having got up before dawn, we found out that our aircraft was still in Bristol. Eventually it landed on the tarmac in Glasgow, and in the time that it took us to board the plane, the engine froze because it was -5 degrees. So we then had to wait again for them to defrost the engines before we could go.

It took around 10 hours to get to Montego Bay, where we boarded our cruise ship. We made first port of call in Georgetown in the Cayman Islands where, due to the tenders, I could not get off the ship. However one of my helpers did.

Other places we visited were Havana in Cuba, Tortola in The British Virgin Islands and St Lucia, which was by far the best port. We also called into, Antigua, Honduras and the Dominican Republic.

We flew back from Barbados. To our surprise at Glasgow airport it was blowing a gale and lashing down with rain and was -3 degrees. That's Scotland for you.

Last year I went to Cyprus for 2 weeks which I have to say is not really my kind of place because everywhere you go you had adverts for either a full English breakfast or Fish n Chips. We did the usual sightseeing things, including going on a firework cruise.

On the last day all 3 of us were having a drink and a chat in my room and one of my helpers saw a 4 legged friend (a mouse). This made the helper leap on the bed and scream like a banshee, while in turn myself and the other helper were both creasing ourselves laughing.

Me and my software

By Robert Soper

My hands have been deteriorating for a long time threatening my continued use of the computer my two nephews, Phillip and Michael, gave me for my birthday in 2009.

Over the last couple of years they have deteriorated to the extent that I can't use my mouse or keyboard so Tony from the Aidis Trust came down from Manchester.

He set up The Grid 2 and Star Talker on my computer. The Grid 2 uses on screen grids made up of cells. The keyboard is then on the screen. Star Talker is a grid that is used for verbal communication and will speak a word or phrase.

This is a quite mind-bending piece of equipment to use. Both keyboard and mouse are replaced by a single button which operates my entire computer.

I am writing this article, my first article, with Star Talker. As a user, you have to learn how to think "outside the box". It consists of a dozen different keyboards in one and I am constantly having to stop and think about which keyboard I need to use.

It is operated by hitting a button once to select your keyboard, again to select the direction you want the cursor to go on the selected keyboard and a third time to select the key.

The system is surprisingly easy to use and it has given me back what I thought I was going to lose. Using a computer has always been important to me. I began using one in the 1980's at COMPAID, which was based at the old Pembury Hospital in Kent.

It has been quite a steep learning curve for me but I like a challenge. Writing is something I have always enjoyed and I enjoy using Star Talker, so I will be able to enjoy my writing again.

Robert's software was provided with grants provided by the A-T Society and the Aidis Trust. If you are interested in finding out more about Grid 2 and Star Talker, please do contact Kay in the office.

Me and A-T

Rachel at her prom with friends

Rachel is 16 and has classic A-T. This year, having gained 8 GCSEs with excellent grades (2 As 2 Bs and 3 Cs) she is embarking on a new challenge, a level 3 BTEC in health and social care at a local college.

In preparation for this, she created a Powerpoint presentation for teachers and students on A-T and her life with it.

We can't fit it in here but to see the presentation, please visit the 'Living with A-T' session on our website.

Fundraising

What an incredible year so far! We've been blessed with many new and dynamic fundraisers keen to support the A-T Society, and these wonderful people have organised and taken part in exciting events across the UK and far beyond. You can read more about them in the forthcoming pages.

We also welcomed two summer interns, Jessica Miller and Molly Owens who gave up their summer break from University to gain experience working with us.

Jessica made use of her skills in Science Communication to prepare information on research projects for the family weekend and website as well as organising the British London 10K Run. Molly organised 'Ride London' and covered lots of tasks in the office. They both helped increase our social media profile.

We were also able to offer shorter work experience placements to Beth Gratton and Antonia Hunter.

All of our student placements proved a joy to work with a huge asset to the A-T Society. They allowed me to get out and meet trust funders, fundraisers and event organisers and lay the foundations for our work in 2014.

Fundraising Volunteers: Antonia, Jessica, Molly, Beth

I also need to offer an apology in advance. I fell and broke my hip at the end of September, just as we were putting the newsletter together. This meant I was away from the office at a very busy time for fundraisers and events and these pages have been prepared at the very last minute.

If I have missed your name or event, or not given you the coverage you expected, or deserved, please accept my profuse apologies and contact me for inclusion in the next issue. Thanks

Suzanne

Moving for-Ward

When Sinead and Craig Ward first heard the words 'Ataxia-Telangiectasia', and the implications of the diagnosis were explained, time seemed to stop.

Walking back to the car with 2-year-old daughter Orla, they faced the fears all A-T families face about her future but also the possibility that baby Finn, just 6 months old, might have A-T.

Contacting the A-T Society for more information, Sinead spoke to Kay who arranged for Orla to be seen at the Nottingham clinic and for Finn to be tested. Over the coming weeks Sinead spoke regularly to Kay and via the Facebook group was introduced to many other A-T families in the UK and elsewhere. This is Sinead's story…

"We were so grateful for all the help and support we received from the word go. I can't imagine how awful it would have been if the A-T Society hadn't been there. Kay gave us all the time we needed and came to visit us at home to meet Orla, Finn, Craig and my Mum, and talk through Orla's situation face to face. She answered all our questions very sensibly and it was so comforting to have her explain things to us.

We decided almost straight away that we wanted to start fundraising for the A-T Society. It was our way of both saying 'Thanks for being there' but also, by raising money for research, of giving Orla hope of a future. We just couldn't sit on our hands and assume someone else would do it. Fundraising gave us a focus and helped to spread the word about A-T locally. We had no idea it would generate so much kindness and support for us as a family, and also valuable funds for the A-T Society. “

As soon as they heard about Orla’s diagnosis, friends and family wanted to get involved. Mum’s friends Janet and Alan Brown raised sponsorship for a walk around the coast of Anglesey and Martin Wilson shared his matched funding for the walk. My mother-in-law Gail sold wristbands in her beautiful Magic Box toy shop. Tracy Coyne and Naomi Odling joined me to run the Manchester 10K and Naomi went on to climb Kilimanjaro.

Suddenly it seemed everyone wanted to do something to help. Many collection pots were distributed locally with some friends and family using them to collect and donate their loose change!

Martjin Kruithof set himself a number of half marathon and marathon challenges, Crumbals Tea Shop did a ‘guess-the-baby’s-weight’ competition, Angela and Stephen Grimes hiked in the Lake District and great-grandad Peter donated money from his hiking expeditions.

Craig’s work colleague Elzbieta is running a tuck shop and donating all the profits, Rachael Slater collected money for her ‘syn free’ slimming world snacks. Liam Neevin did a 5k run, the local Playworld hosted a collection pot, Clare Gallagher, friend Noelle and I did a cake stall at a local Christmas Fayre and David Salt gathered a team for a Tough Mudder race.

I’d read about Family Fun Days in other parts of the country and felt really inspired by the parents who had arranged them.

They obviously realised that the way to make sure our children have all the welfare, research for treatments and a cure and practical support they need with school and everyday life is to ensure the A-T Society is there to help.

I decided to ask my friends and their friends to help me with a Family Fun day at the local Funky Monkey Café, which had been offered as a venue free of charge. Before I knew it my head was buzzing with ideas and offers of help were rolling in.

Fundraiser Suzanne was full of advice and useful ideas. She gave me the confidence to talk to our local newspaper to help with publicity. The coverage we got for the Steve Jackson research project led to yet more support being offered and an interview on Red Shift Radio. My local MP, Edward Timpson agreed to open the Fun Day and before I knew it we had an amazing day lined up.

Friends Louise and Mary Burke travelled over from Ireland to help. Fellow A-T Mum Clare Gallagher brought daughter Jenni to run a stall. Friends and family ‘dug deep’, offering time, energy, resources and money. We had an oil painting donated, a signed Manchester United Shirt and a large remote control car. Those who were unable to come on the day made generous donations via our fundraising page. It really was a fantastic day.

I wanted to use this article to say a huge thank-you to all the friends, family, colleagues and strangers, too, who opened their hearts to us and to everyone who has supported us and will do so in the future.

My husband Craig is working on a virtual Christmas campaign to raise funds for the A-T Society and I hope everyone involved with the charity will make a donation and send the campaign to their friends. You can find it at www.helpcure-at.co.uk

We’re already looking ahead to 2014. My friend Kerrie Stringer will be throwing herself out of a plane to celebrate her birthday in June. Our local Mums and Babies group and Slimming World are getting involved. Mum’s friend Colette Cook is holding a coffee morning, Craig has another team of 5 colleagues to do a Tough Mudder in the summer, and we are gathering a team to ‘bag pack’. We are also planning another big event.

With a little determination anyone can achieve great things! We will always be grateful to the A-T Society for being there for us every step of the way. We know so well that research is the key to the future for children like Orla, but we also know the only place we can get sensible, informed family support is the A-T Society. For that reason we made the decision to use Orla’s photo on an advertising campaign poster which went out in October in north-west England.

And, to finish on a high note, I’m delighted to say that Finn’s tests proved negative and he is clear of A-T.”

In Good Company; Corporate Support for the A-T Society

Allington Hughes Golf Day

A prime example of getting contacts involved resulted in Emma Simoes' employers, the renowned Chester Law Firm Allington Hughes inviting the A-T Society to be part of their annual fundraising Golf Day.

Sharing the glory with a local organisation, the North Wales Crusaders, and a local charity B.I.R.D. A-T Society CEO William Davis received an enthusiastic welcome from the Golfers taking part and the representatives of Allington Hughes including Gareth Evans, Ian Evans, Director of Allington Hughes, Andy Mousdale, Captain of North Wales Crusaders and Louie Middlehurst at the spectacular Carden Park Golf Course in Cheshire.

We thank Allington Hughes for the opportunity to meet some of their clients and extend awareness of A-T within an area which has a higher than average number of people living with the condition.

Clarke Willmott, Bristol Office

We are now coming towards the conclusion of our two year 'Chosen Charity' link with top Bristol law firm, Clarke Willmott.

You may recall the connection was made through a treasured friend of Tania Wheeler, Philippa Hann, who has been a keen advocate and supporter of the A-T Society.

This year has seen a wide range of fundraising opportunities, with Philippa herself taking part in the Bristol Half Marathon. Rhiannon Radcliffe and Clare Titchner cycled from London to Paris, Graham McIntyre ran his first marathon and made it extra special by taking one of our four places in the London Marathon. Clarke Willmott are sponsors of the Business Challenge, part of the Bristol 10K and had a strong presence in the event.

However, it's not all about sport! The Monopoly Challenge, an almost legendary event of skullduggery and cunning, pits teams from companies throughout the city against one another. The office quiz, raffles, dress down days, competitions and much more besides show that Clarke Willmott lead from the front in terms of fundraising and support for the A-T Society and their local charity, Jessie May.

Thank you to every member of staff who has put their time, energy and effort into making a very significant difference, not only in financial terms, but also in raising awareness of A-T locally.

It is also important to recognize the legal support provided to A-T parents who have used the professional services of Clarke Willmott's specialists to write wills and create trust funds to ensure the long term future of their children is secure.

The feedback we have received from parents is that Clarke Willmott have handled this delicate situation capably and with the utmost consideration and thought. We are very grateful to the team at Clarke Willmott for all their help and are pleased that a key part of their own legacy to the A-T Society is to emphasize the importance of tackling this difficult but very necessary subject in a proactive way.

Pictured: Claire Titchner and Rhiannon Radcliffe from Clarke Willmott

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Barclays, Kent

Scott Wilkins, Area Business Manager from Barclays has been rallying his area team to support the A-T Society throughout 2013. Following a Quiz Night and a collection at Maidstone Football Ground, five employees took part in the Dirty Dozen event on 19th October at Paddock Wood.

Barclays has a fantastic community investment programme which encourages employees to get involved in causes that are important to them. "It's about giving back skills, time, and energy to support our local communities – so we're thrilled to be raising funds for the AT Society" explains Scott.

Barclays will match the amount each individual raises up to £750. Scott continued "We are delighted to be involved and helping to make a positive contribution to our local charities and ensuring children with A-T have the best possible chance for a better life".

Pictured: Barclays Team

Pentagon Shopping Centre, Kent – extended for another year!

Fundraising Volunteers: Penny the Dragon and volunteers at the Pentagon Centre

The Pentagon Centre in Chatham has been raising awareness and support amongst staff and the general public and generating great local publicity. We are very grateful for this support and very excited to announce that they would like to continue this through 2014.

With Pentagon's mascot Penny the Dragon being seen about the place in her A-T tee-shirt, staff having their heads shaved, regular fundraising days and a huge Christmas procession, Pentagon is very much at the heart of Chatham's daily life.

We would love to have some local Kent families and friends helping us out with this, please contact the office if you think you may be able to spare an occasional hour, thank you.

20 Squadron Royal Logistics Corps

Many years ago while based in Germany, Warrant Officer Mac McIntyre of 20 Squadron Royal Logistics Corps was friendly with the Murphy family whose son Liam had A-T. Sadly Liam passed away in 2007, but Mac has never forgotten the A-T Society and when the opportunity to take a team to the United States Marine Corps Marathon arose, Mac suggested us as their chosen charity.

Mac explains "I am being joined by Sergeant Jim Lilley and Corporals Rob Clifford, Gav Keen, Kirk Wilson & Dan Woodvine as we travel to the USA to take part in this demanding event. Just to make the 26.2 miles around Washington DC a little more challenging, the team will be in full Military Uniform carrying 30lbs in weight. This is no mean feat as for five members of the team this will be their first ever marathon."

The team wanted to learn more about A-T and give a focus to their fundraising, so they invited Alecia Yarlett and mum Lian along with Suzanne and Molly to visit them at The Wellington Barracks in London.

Alecia was given red carpet treatment from the moment she arrived. The team lined up at the entrance to the Sergeant's Mess to be introduced to her before escorting her into the formal dining room so Alecia could answer their questions. With an official photographer on hand and the staff of the Sergeant's Mess bending over backwards to make it special, Alecia certainly was 'Queen for a day'.

Warrant Officer McIntyre presented Alecia with a RLC T-shirt and wings to wear in support of the team when they ran their marathon on October 27th 2014. Then she posed for many photographs before sitting down to lunch in the Mess.

It's fair to say Alecia didn't stop smiling all day and she made six wonderful new friends.

The following week Sergeant Jim Lilley and Corporal Gavin Keen travelled to Harpenden to meet William and Kay and learn more about the intense support new families require, as well as the day to day challenges of living with A-T.

Jim and Gavin returned to barracks more determined than ever to raise money and awareness of A-T both now and with events in the future.

Mac and the team trained hard for the marathon and were seen in the best places around London as they spread the word about their fundraising.

On 27 October, having bumped into Matt Cardle and taken Twitter by storm, the men of 20 Squadron crossed the finish line in Washington, completing an awesome challenge for both themselves and the A-T Society.

Pictured in order of appearance:

20 Squadron Badge
20 Squadron Alecia receives shirt
20 Squadron at Downing Street
20 Squadron Matt Cardle
20 Squadron Washington Marathon

Fundraising trip to Northern Ireland

It's a challenge to stay in touch with fundraisers around the country, so when a fundraising support visit to Northern Ireland was requested, I wanted to be sure I met as many of the people who work so hard to support us as possible.

Touching down in Belfast on a Thursday morning it was off to pretty village of Camlough to meet Aiden and Maria Boyle and their sons Matthew and three year old Connor who was recently diagnosed with A-T.

The family have big fundraising plans for the coming year, starting with a Race Night before Christmas and then a Family Fun Day in May. Aiden is looking forward to taking the lead in the Malin to Mizen cycle ride in September the family hope to organise a Ball and auction during the autumn of 2014.

As we chatted through the "who do you know" exercise, and how it could help Aiden and Maria involve the extended family and many friends and contacts in the local community, Maria's parents arrived to say 'hello' and Connor showed off his football skills.

Before I knew it, three hours had flown by and it was time to take my leave of this lovely family with promises to return another time.

Off then to Armagh to catch up with Allison Wilson and hear all about John and his determination to beat disability prejudice and get his local authority to give him a work experience placement. John's perseverance won through and while Allison and I were chatting, John was busy at work.

Allison had arrived laden down with bags and I was a little curious about their contents - and slightly worried I might have to bring them home on the plane! Allison opened them to reveal three amazing sculptures which she had made from a variety of recycled fabrics and oddments. Photos don't do them justice, but they were absolutely stunning and I wasn't surprised to learn that Allison's work is now selling in galleries around the province. Allison is not only incredibly creative, she also enjoys sharing her knowledge and teaches classes for local disabled people to learn how to create art of their own.

All too soon, I was following winding country roads, rugged hills and moors across the wild mountains to the city of Derry to meet Lynda McIntyre and SeanTaylor who planned to present money raised by this year's Astroturf League Competition.

Sean explained how consistently generous the people of Derry have been. After the 'photocall', Lynda informed me that my plans for a quiet dinner and early night were history, and that instead we were off to the Fleadh - a festival of song and Guinness which takes over the centre of Derry for a week each year.

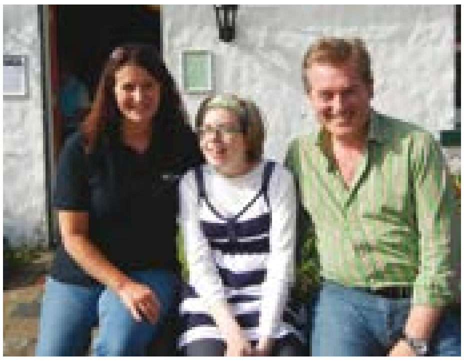
Over dinner at Bentley's by the famous city walls, I met the owners who have donated prizes and offered their support to the A-T Society on many occasions. Lynda hopes they may host an event at the restaurant in the future and if you find yourself nearby, do your best to get there - it's a welcome you won't forget!

The next morning I drove north along the stunning winding coast road past Portrush and The Giant's Causeway to Ballycastle.

Arriving in Ballycastle the lovely Lynn family had arranged visits to some of the local businesses hosting A-T Society collection pots.

With brief visits to Haughey's and the Northern Furniture Company under my belt we drove out to the Red Door Tea Room at Ballintoy to meet Joanne, Nigel and Jeanette for a cup of tea and possibly the most enormous slice of cake ever.

The team here actively fundraise for us asking every customer to support the charity. As people come from far and wide to visit this hidden treasure, they raise awareness of A-T with people who would not otherwise know about it.



People like Ulster TV personality and journalist Mark Carruthers, who happened to pop in for tea and cake whilst we were there.

He asked lots of questions and happily posed for photos with a slightly star-struck Sophie.

Late on Friday evening, as I flew away from Northern Ireland and the four wonderful families who had made me so welcome, I took with me their hopes and plans for future fundraising.

I'm sure we will be hearing much more of our Northern Ireland families in the coming year.

Pictured in order of appearance:

The Boyle Family
Allison Wilson Sculpture
The Fleadh
Red Door Tea Room
Sophie with Mark Carruthers

Thank you!

We are always looking for opportunities to raise the profile of A-T and the A-T Society and the research project in Cambridge led by Steve Jackson was just that.

Many families worked with us to generate publicity, placing stories in over 20 local papers and radio stations.

Papers love human stories and at the heart of each of these was a family willing to tell their story.

"Going public" is always a big step, but we worked closely with each family to ensure they were comfortable with the direction of the article.

This was especially important as for the first time we involved some of our teenagers and young adults in publicity which laid the facts about A-T on the line.

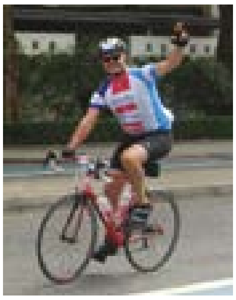
An enormous 'thank you' to every family for working with us and their local journalists to share news of this exciting project.

If you think you might like to be involved in publicity in the future, please contact the office.

Ride London 2013

The first-ever Prudential Ride London-Surrey 100 cycle event saw a large team of riders raising serious money for the Tripartite A-T Research Fund.

While each rider was supported by one of the three charities involved, they wore shirts displaying together the logos of the A-T Society, Action for A-T and Sparks.



Our team comprised: Kevin Attridge, Pete Black, Garry Dalton, Ramesh Dalton, William Davis, David Fitt, Stephen Hopkins, Michael Larkin, Thomas Linley, David Seddon, John Stephenson, Martin Wild and lastly (and fastest A-T team member) Matt Wright.

August 4th was a warm sunny day, but a touch chilly when our riders made their way to the Olympic park at 6am for the start of their 100 mile challenge event out to the hills of Surrey.

Gathering pace in the biggest Peleton the UK has ever seen, our intrepid cyclists made light work of the famous Box and Leith Hills before tracking back through Kingston and along the path of the Thames back into central London where they crossed the finish line in glory on The Mall, in front of Buckingham Palace.

On route they passed supporters from Sparks and Action for A-T and further into London a cheer squad led by Molly Owens who had been tied to a lamp-post to make sure the banner could be seen by all our riders.

A special mention goes to our rider John Stephenson, who spied an opportunity when he spotted Mayor of London Boris Johnson on a leafy road in Surrey.

John diligently stuck with Boris and his efforts ensured an A-T cyclist featured on TV and on the front cover of The Times in post event publicity.

Also thanks to Rebecca Tomlinson and Matthew Buck of Sparks whose organization ensured the combined team were looked after throughout the process.

The event has boosted the A-T Tripartite Research Fund by over £50K!

Pictured in order of appearance:

An A-T rider nears the finish
Boris with A-T team rider

Jo Bloomer writes: My Story just the way it was

Wow, what a roller coaster ride I've been on, and I don't mean a visit to Alton Towers either! May 22nd 2012 was the day I received Lola's diagnosis. A day I'm sure no parent could ever forget.

That day, Lola and my lives changed forever. I'm sure you vividly remember the day you received the news, how you felt your life was falling apart. But after days of tears came strength. What could I do to fight back, to help my beautiful daughter stand a chance of a better future? Do something. The decision was easy - and so it started.

Plan a Charity Ball? Oh 'eck! How do I do that? We needed money to start the ball rolling so friends on Facebook helped organise a bazaar in our local church hall. Others gave bric-a-brac, cupcakes, tea and coffee. £700. Hurrah!

Now I could book venue, band, comedian and photographer, design the tickets and posters and then the easy bit, sell the tickets.

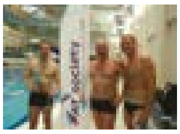
In the meantime, my local paper interviewed me about A-T. The fantastic article they did was picked up by local TV, the Daily Mail and Daily Express. Things started going viral.

Brian Conley, performing in Oliver at the Theatre Royal, saw the article and invited us to meet him and the cast. They offered to perform a one-night show and donate half the proceeds to the A-T Society.

Before the show, I had to stand on stage with Brian and Suzanne and tell 500 people about A-T and our work. It was so scary I was sure they could hear my knees knocking! But the night was amazing and Brian so funny, and we raised £11,000.

Next my lovely friend Kevin McGregor, in Singapore, read about Lola on Facebook. I wasn't looking for sympathy. I just wanted to raise awareness and see if any mad friends might do something for the charity. Boy, did Kevin do something mad!

The "For Lola Mega Tri" involved swimming 2.5miles, cycling from Plymouth to Brighton and running the Brighton Marathon. The planning was very intense with Kevin being so far away, but friends old and new friends joined in.



Julie, Darren, Dave, Jayne, Suzanne, myself and many others, along with Lola's big brother, Will (12yrs old) took part in the gruelling 2.5mile swim and cheered the runners along the streets of Brighton. It was all so worth it as Kevin and friends raised a whopping £23,000. What stars!

Alongside this came more generosity than I could have ever imagined. Year 13 students at the Heles School in Plympton, where my son Will goes, raised £300. My mum's Golf club raised £800. The college where I work put on a hair show and the St Mellion Mother and baby show held a raffle.

Preparations for the Charity Ball went on. Letters and begging calls produced a return flight to New York, a diamond, a weekend in a top hotel, a beautiful painting, and other gifts. And of course I treated myself to a new frock!

The ball was unforgettable the most amazing evening ever. 290 people in their bright A-T coloured dresses strutted their stuff and showed us their stylish moves. The auction and raffle made £5,500. Total raised £11,000. Another whoop whoop!

The year brought so many other contributions. Kevin's buddy Marv Hine started the year running a month of marathons in Afghanistan with his RAF colleagues, then ran the Marathon dressed as Peppa Pig, and the 'Race to the Stones' as a Spamalot knight.

Kirsten Koh and her friends in Australia fundraised month by month. Lola's granny told everyone visiting her B&B about A-T while her grandad celebrated his birthday with a big fundraising party. Dave Kelman and the Plymouth Blitz American Football Team waxed their chests (and more!). Mark Rayment did a half marathon.

Lola's nursery started fundraising as did the local chemist's. Novahomes sponsored two charity football matches at which Lola and Richard Penelrick, who has A-T and lives nearby, presented the trophies.

Not content, Kevin McGregor took on the Norseman –the 'toughest Ironman event in the world'. The pictures alone terrify me, but in his A-T Society wetsuit he took the freezing water of a Norwegian fjord in his stride. And back in Singapore, he is raising yet more money in other events!

So many people have been inspired to support us, and if I've missed you in the emotion of these memories, please know how very special you are to me and to every family living with A-T.

It's now October and my head has stopped spinning. The adrenaline rush has gone. Things are nearly back to normal, except for the general mayhem of life! And then comes the call, "you've been nominated for the Pride of Plymouth award". Wow,again, along with a cheque and a fabulous night out

But I didn't do any of the above for any recognition or awards; it was for my beautiful Lola. And this is where I silently cry again

Joanne Bloomer

So what can I do?

The incredible networks of friends, families and work contacts of, believe it or not, just 35% of UK A-T families mean that the A-T Society can continue to support everyone living with A-T and lead from the front in terms of instigating new treatments and medical research to give real hope of a future without A-T.

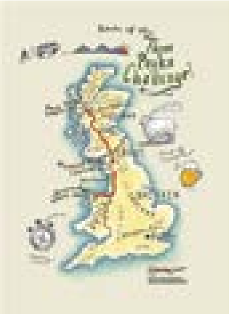
Can you imagine what could be achieved if each and every family got involved? Your A-T Society could go from strength to strength and not only continue to offer the care and support which is vital to so many people, but also engage with an even wider range of scientists and specialists to generate new treatments and research towards a cure.

Getting involved with fundraising is a great way to raise interest and awareness of the condition in your community and also to be part of changing the future for the better.

Every family can be part of this and you would be amazed how your participation can snowball.

Let's take a look at some of the friends and contacts of some of our families who did just that...

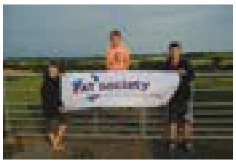
Gill's Three Peaks



Gill Duffy works with Gary Bromwich whose son Joe has A-T. With her eye on a new challenge, Gill decided to tackle the three highest peaks in the UK - Scafell Pike in Cumbria, Mount Snowdon in North Wales and Ben Nevis in Scotland.

Any one of these climbs would be more than enough for most of us, but Gill did them in less than 24 hours in June, racing between the mountains with friends Sarah, Ryan and Mick. The team was generously provided with a support vehicle by Volvo, ably driven by Kev Woodley.

All Metcalfe's Great and Small!



Sara and Phil Metcalfe farm 300 acres of Yorkshire on the edge of "Herriot Country", Sara also runs Foxberry Chasers, an equestrian cross country course used by some of the British riders to train ahead of last year's London Olympics.

More importantly, Sara is Mum to Jasper, a veteran A-T Society Fundraiser at the tender age of 12, and aunt to Charlie and Arthur Seal who have A-T.

Sara and Phil organised a "Bash In the Barn" with disco, bar, bouncy castle and raffle to raise money for the A-T Society and a local Hospice. On a dazzling July evening friends, family and locals gathered for a fantastic party which included Jasper having his head shaved after raising over £500 in sponsorship, and a guest appearance from Elvis!

Each charity received over £2500, a testament to the generosity of everyone who attended and the local businesses which donated prizes and services for the event.

Dyna-Mo

Not to be outdone, Charlie and Arthur's 'Granny Mo' Seal, who has been raising money with Grid Games in her Durham village for a couple of years, arranged a Saturday Coffee Morning at her local Village Hall in early September. There can't be many people in Boldron who haven't heard of A-T thanks to Granny Mo's enthusiastic support for the charity.

The Wonderful World of the Walshes

Would you squeeze into a wetsuit and voluntarily immerse yourself in the freezing water of Lake Windermere? Thought not! But for Glen Walsh, son Nick and his girlfriend Siobhan Pope the lure of the dark depths was irresistible. There was a bit of a grudge match too, as Siobhan was determined girl power would prevail and she would beat Nick in the mile long open water swim event.

Firstly though there was fundraising to be done, and Glen recruited the family, including grand-daughter Katelin who has A-T, to pull out all the stops and raise as much money as they could. Katelin proved to be very persuasive during a supermarket bag pack, and became the team's secret weapon, ensuring they exceeded their target.

Fast forward to a really chilly day in June when the grudge came to a head! With everything to play for Siobhan was at peak fitness and swam her way to success, beating Nick by 30 seconds but being pipped for the fastest time by Glen who took the champion's crown.

Not one to be crushed by coming last, Nick bounced back and took part in the Total Warrior, a cross country mud and strength challenge which saw him strain every muscle and sinew over a 10K course to triumph in the field.

Pictured in order of appearance:
Walsh bag packing with Katelin
Great North Swim Glen Siobhan and Nicky
Nicky – Total Warrior

London Marathon

Thanks to determined campaigning by our former Trustee Tania Wheeler, the A-T Society was granted three places in the London Marathon from the medical research charity, Sparks. By coincidence, our ‘once in five years’ Silver Bond place came up for 2013, giving us four runners raising funds for A-T research in this world renowned event.

Our team comprised James Sloan, Ian Barnes and Vera Hall, all of whom live in the North West of England, together with Graham McIntyre of our Charity of the Year partners, Clarke Willmott, Bristol.

The minimum fundraising target for the event was £2000 and our determined runners got involved in a range of activities including a 12 hour Spinathon, 24 hour runathon and various collections, sales and raffles to reach their goal.

The day dawned relatively warm and sunny and from our vantage point on Canary Wharf we waved and cheered as our runners battled through to achieve fantastic times.

It was great to meet up with James, Graham and Ian at the Sparks post race reception and to be able to congratulate them in person. The combined total for their fundraising including Gift Aid was £9000

London Marathon places are quite tough to come by, and we were extraordinarily grateful to Sparks for providing us with a unique opportunity to have our first ‘team’ in the event as part of an initiative to help small associated medical research charities.

For 2014 our Marathon plans we are focusing on the Brighton Marathon on 6 April. Read more about it on page 31.

Clockwise from top left:

Graham McIntyre; Vera Hall; James Sloan; and Ian Barnes

The Vintage Tractor Run

John and Helen Proudlove who live in Malpas, are friends of the Pritchard family. They are also the organisers of the Malpas Vintage Tractor run which involves around 80 tractors travelling in convoy around the fields and lanes of the beautiful Cheshire countryside.

Each driver makes a donation to take part with the proceeds coming this year to the A-T Society. Our CEO William was invited to attend and was able to ride on a tractor, meet lots of drivers, and experience the event first hand.

With guest appearances from the Pritchard and Bromwich families at the lunchtime barbecue it was a day when strong links were made with new friends.

Sponsored walk to the City Ground

When Mark Carrington gets an idea he’s rather like a tornado, whisking everything and everyone into his path.

That’s what happened with this year’s Walk to the City Ground when over 50 friends and family members made the 16 mile walk inspired by Mark’s daughter Kira who also took part.

Raising over £4000 and having a fantastic community event bringing so many wonderful people together meant the world to Mark and his family. We’re hearing rumours of another event next year.

Robin Hood Marathon and Half Marathon

Sherwood Forest was turned blue, pink and purple by three fantastic teams of A-T supporters for the Robin Hood Marathon events in September.

Nottingham Mum Jo Betts rallied four of her wonderful friends to take part in the Half Marathon event. Andrea Spencer, Claire Chadwick, Sorrel Hodgson and Aimee Bunhejee each achieved a great time in support of Jo and her son Kaid.

The Mobots, Amandeep Sharma, Sue Phillips, Dan Trindell, David Daly, Derek Porter and John Trueblood all ran the Robin Hood Half Marathon in Nottingham except for John who went the extra 13.1 miles and ran the full marathon.

Sue said "John, David, Derek and I ran the race last year for A-T but this was Amandeep's first half-marathon. His two daughters have A-T and they inspired us to run again this year."

Kayleigh Minion, whose niece has A-T describes herself as "a proper shoddy runner". Nevertheless, she ran the half marathon in support of both A-T and Macmillan, two charities very close to her heart, and plans more fundraising for the future.

Bridgnorth walk

Each year, the pretty town of Bridgnorth in Shropshire holds a mammoth sponsored walk. Tim Hughes a friend of the Ferguson family and a fifteen strong team took on the challenge in May.

Tim said afterwards "We all managed to complete the course in what was pretty good walking weather - sunny with a strong breeze. A big and sincere thank you to everyone who supported our team. With all the donations which rolled in we have now beaten our target and are looking ahead to 2014."

Sorrel Hodgson

Sorrel is a great friend to Jo Betts, and you'll see she features twice in this issue. Back in June she took part in the Great North Swim, conquering Lake Windermere for the second time.

British 10K London Run

Benjamin Baker, Jordan Button, Dan Colombini, Aidan Wilson, Joe Doig, Lucy Henderson, Beatrice Prokofiev, Hayley Carrington, Patrick Turpin and Bethany Yarlett spread A-T cheer along the route of the hot and sunny British 10K London Run in July.

This event is a riot of colour and entertainment which takes over the heart of central London and is great fun to watch as well as to take part in. It's clear from the pictures that our team of runners threw themselves into the experience.

Astroturf Football

Sean Taylor is a long term supporter of the A-T Society through his friendship with Lynda McIntyre and her son Cian. Sean and his team run an annual football tournament in Derry, Northern Ireland and it was a pleasure to meet him with Lynda during a visit to the city.

Family Fun Day has the X-Factor!

The Sewell and Kelly families and friends joined together again in September for a wonderful day of family fun. The weather didn't stop anyone from having a great day with indoor and outside activities and stalls set up around the local sports centre.

The evening saw a charity auction followed by an up close and personal performance by X-Factor Finalists Rough Copy who showed their star quality and their immense support for the A-T Society which will continue as they storm the charts.

Brian and Siobhan would like to say a very big thank you to everyone involved in helping to make this day a success and to all who supported it.

Celebration of Life Birthday Ball

Nicole Matthew and her twin Natalie would have been 21 this October.

Sadly Nicole is no longer with us, but the family wanted to ensure she was very much part of Natalie's birthday celebrations and organized an A-T Society fundraising ball at Stonehaven in Aberdeenshire.

Highlights of a spectacular event included a Slave for a Day Auction and a mammoth raffle with some highly unusual prizes.

The whole family are looking forward to doing more fundraising in the future, keeping Nicole's name and memory alive in everyone's thoughts.

Fright Hike

Scott Iceton found out earlier this year that his little girl has A-T and determined that he was going to do all he could to help her have a better future. Along with his team Lee P, Lee S, Leigh, Sam, Ollie, Malcolm, Kyle and Patrick, Scott set out into Sherwood Forest on the first ever 'Fright Hike', a 25 mile trek in the dark.

Scott said afterwards "It was the hardest physical challenge any of us had ever done, but we all wanted to make it work for the A-T Society so we kept at it, goading and egging one another on to reach the finish line."

Harpenden Rocks

Singer Anjali Rundle grew up with Gregory and Caroline Poupard in the A-T Society's 'home town' of Harpenden. Each year Anjali and a group of enthusiastic musicians organise 'Harpenden Rocks' an event bursting at the seams with great local bands and we were thrilled to be selected as the event's chosen charity.

The 2013 night promised to be 'bigger, better, band-ier and boozier than ever before'.

Anjali and Suzanne joined Martyn and Ryan of the "Low Lamps" who were featured on BBC Three Counties Radio as a prelude to the event.

With a raffle and grand auction it was an incredible night for anyone lucky enough to secure a ticket.

Thank you for the music to; Elvis Bob, Jipsy, Hubcap Moon, Caught Stealing, Riddler, The Monophonic, David Hoare, the Low Lamps and of course Anjali.

Race Night in Newry

Aiden and Maria Boyle are still reeling from son Connor's diagnosis earlier this year. This spurred them on to be part of making a better future for Connor and they organized a Race Night in Camlough, Northern Ireland in October. Maria said "It was a great night and all we raised was for such a worthy cause so once again a big thank you to everyone who came, sponsored, put on bets, bought raffle tickets and anything else that I forgot to mention. Also a special thanks to my cousin Ciara Davidson who spent the last two weeks helping to make last night a success."

Ireland Walk

We love it when our families have an opportunity to meet up and thanks to Aisling Kelly for organising a lovely walk in Ireland, A-T Mums Siobhan Kelly with Brae & Brogan and Lynda McIntyre with Cian were able to do just that. Along with a bunch of wonderful people they walked through Derry to raise awareness and funds for A-T.

Some very honourable mentions!

These wonderful people have all taken part in fundraising initiatives this year. We don't have photos to show you, but want to recognize and thank each and every one of them:

Ingo and Ambar Heinen – Donations in lieu of Wedding Gifts

Lee Barber for the Wiggle Dragon Ride

Hannah Roberts for the London-Edinburgh Cycle Ride

Liam Nevin and family in the Liverpool Fun Run

Toro Shudoke, Mum Shirley and team – Mount Snowdon climb

Richard Oatey – Great Birmingham Run

Lynne Yeoman – Wedding Day Collection

Marcus Murray, Dominic Davenport, Michaela Hall – Tough Mudder

David Salt – Tough Mudder

Chantelle Bishop and team – 5K Run for Brooke

Philip Windsor – Liverpool Fun Run

Michael John Moore – Survival of the Fittest

Vicki and Stuart Hughes – The Colour Run, Manchester

Tom Mann – 500 Miles in 72 Hours for us and two other charities

Debbie Picton – Hadrian's Wall Cycle

Claire McGrady and Jo Peterson – Half Marathons in Chester and Southport

Mark Rayment – Plymouth Half Marathon

The Lynn Family – Street Collection in Ballycastle

The Red Door Café – Gala Night

Royal Lions FC – Charity Football Match

Winscombe Nursing Home – Fundraising day

Joy Ferguson – Sainsburys Collection

Sheryl Potter – Asda Collection and Tokens

Dungannon Thomas Clark's Gaelic Football Team - sponsored walk

Tracy and George Koulouri – Birthday donations in lieu of gifts

Mathew Hollis – The San Jose Rock n' Roll Marathon, California

RAF Honington – Gala Christmas Event

Genome Damage and Stability Centre – ongoing fundraising

Naomi and Martin Heffernan – 50th Birthday fundraising

St Albans Round Table – Christmas Float

Looking ahead – what will you do?

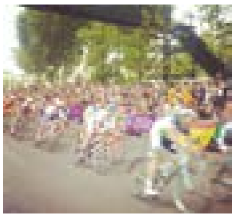
2014 is our 25th Birthday and we would love you to help celebrate 25 years of improving the quality of life and quality of care for people with A-T. These are the BIG Three events being organized by the A-T Society which you and your friends, colleagues or family might like to get involved with:

Brighton marathon – 6 April 2014

We have 25 places for this marathon which is second only to the London Marathon in participants and described as the ‘most beautiful marathon on the UK calendar”. The course runs the length of the Brighton seafront and offers plenty of space for spectators to cheer on the A-T runners.

With a minimum fundraising target of £600 we know it’s going to be a fantastic day for everyone involved. Make this your first goal for 2014!

Ride London 100 – 10 August 2014

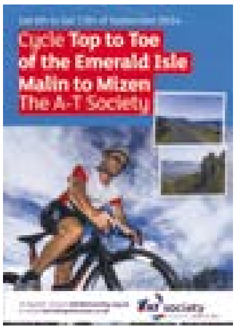


We have 21 places in the second Ride London-Surrey 100 event. Building on the success of the first event in 2013, you will start at the Olympic Park in Stratford, travelling through London and out to the challenging Box and Leith Hills in Surrey’s rolling countryside. Pushing back into central London, you’ll enjoy the relatively flat roads along the Thames enabling you to build up speed for the crowning glory of your finish on the Mall right in front of Buckingham Palace.

With a minimum fundraising target of £600 towards A-T Research and an achievement which will be hard to beat, we look forward to welcoming you and your friends to the team.

For an application form contact the office.

Top to Toe of the Emerald Isle – The Malin to Mizen cycle ride



Cycle Top to Toe
of the Emerald Isle
Malin to Mizen
The A-T Society

Discover the natural beauty of Ireland by bike whilst raising money for the A-T Society. Starting at Ireland’s most northerly point, Malin Head on 6th September 2014, you will cover 427 miles over seven days, ending the challenge at Mizen Head in the south on Saturday the 13th September.

Your meals and accommodation are covered throughout the event, and your luggage will be transferred for you, leaving you to simply enjoy the ride.

With a minimum fundraising target of £1500 this event is something special for our 25th Birthday.

The organizers have committed to finding places for as many people who want to take part, so do please reserve your place today. You will also find a leaflet enclosed with the newsletter, and we would love you to pass this on to anyone you know who enjoys a bit of a bike ride!

The Big Birthday Party – make it your own!

Something for every family – please celebrate with us by organizing your own birthday party. Whether you choose a coffee morning, afternoon tea, Come Dine with Me or a full scale party you can be part of a very special chain of events around the UK.

Gift Aid

Did you know that as a British Taxpayer, we can reclaim an additional 25% on any donation you make to the A-T Society? It might not seem much, but it really mounts up when you consider that a donation of £20 nets us an additional £5!

If you haven’t completed a form, or it’s been a while since you did so, please tear off the back page of the newsletter and fill it in. We can back date a claim for up to four years, so it really isn’t too late! Thank you.

British 10K London Run

This is a fantastic event for runners, whether you are complete novice and want to try something new and fundraise for us at the same time, or whether you are an accomplished runner with an eye on your PB.

Taking in the great sites of London and enjoying an atmosphere close to that of the London Marathon for the whole of the 10K course, it’s an event that’s fun for all the right reasons.

With a modest £200 minimum fundraising target, we’d love to have you on our British 10K London team.

Gift Aid declaration – for past, present & future donations

Please treat as Gift Aid donations all qualifying gifts of money made to The A-T Society:

☐ today ☐ in the past 4 years ☐ in the future
Please tick all boxes you wish to apply.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 28p of tax on every £1 that I gave up to 5 April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.

Donor's details

Title ------------- First name or initial(s) ---

Surname ---

Full home address ---

Postcode ----------------------------------

Date ---

Signature ---

Please notify the charity or CASC 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.

The A-T Society
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Charity No. 1105528

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