

# A-T Society News



## This sparkling issue celebrates

- The start of the Erydex trial
- The International A-T registry
- Achievements of people with A-T
- Inspirational fundraisers



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

The A-T Society was established in 1989 and is committed to helping, supporting and advising families affected by A-T. While they may face more

challenges than many, people with A-T have lives to live, and the Society's aim is to ensure they have the support they need to live them to the full. We do this through funding research, providing information, practical support and financial assistance, working to improve clinical management and raising awareness.

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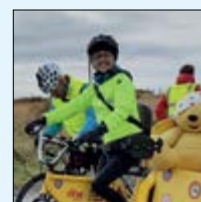
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## Editor's comments

Many thanks to all contributors. The copy date for the next issue is 1st October 2017. Please send comments, ideas, articles and pictures to:

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Champagne  
cycle ride

## Just William

**William Davis**, chief executive of the A-T Society, reflects back on a busy few months

Having returned a couple of weeks ago from cycling from St Albans to Champagne to raise money for the Society I feel that the last six to nine months have something in common from riding across Normandy. You go riding across the sunny uplands for a while and then it's down into a deep valley with a long climb out and then once again you're rolling across beautiful flat countryside.

We've had some great highs. For a start, there was all the coverage we got on national Radio in the run-up to Global's Make Some Noise Day. A number of our young people and their families did a great job of talking about life with A-T on the various stations.

There was Ebony Robinson, who took part in BBC The One Show's Rickshaw Challenge – the first ever wheel-chair user to do so. Her enthusiasm and her openness about the challenges of life with A-T moved and endeared her to people across the nation. Read more about this on page 34 and 35.

There was the touching film about the twins Brae and Broghan Sewell and their parents. While the film highlighted the difficulties A-T brings, it was lit up by the obvious love between the brothers and within the whole family. And this in turn brought nearly a whole page of coverage in the Sun as well as television features.

And of course there was that incredible moment when the £26k cheque from Global magically morphed into one for a staggering £90k. There was the buzz of cheering on our runners in the Brighton Marathon. And there was the fantastic experience of riding 350 miles with an amazing group of cyclists to raise funds for the Society.

But alongside all these and many other uplifting events, there have also been moments of real sadness, in particular the loss of a number of people who have been very influential for the Society.

Many people will remember Rupert Prokofiev, who died at the beginning of the year. Apart from being a trustee of the Society, Rupert had spoken at a number of Family Weekends, talking about independent living and most recently leading a workshop on the language used to talk about A-T. His engaging personality, positive attitude to life and willingness to speak out were a huge inspiration to me and to many other people.

We also lost Siân Watkins, another person who had lived many years with A-T. Siân's family were very closely involved in setting up the A-T Society and her father Geoff was chairman for a number of years. It is as a result of their efforts that the A-T clinic was first established in Nottingham, where the family lives. We publish an article by Siân on page 20.

Another sad loss was that of Mireille Gervasoni, Chair and driving force behind the French A-T group APRAT. Mireille set up APRAT when her son David was diagnosed with A-T and it became the most active and effective A-T organisations in continental Europe. Mireille admired and worked very closely with the A-T Society, translating our clinical guidance and other documents into French and jointly funding projects.

So it's been very up and down, but then that reflects life with A-T. Looking ahead, though, the Society is currently putting together a strategy which is inspired by and rooted in the commitment of



**“There was that incredible moment when the £26k cheque from Global magically morphed into one for a staggering £90k.”**

people like Siân and Rupert to living fulfilled and independent lives with A-T.

Our strategy will look to address the psychological and emotional needs of people with A-T and their families at the different stages of their lives and in particular to focus on adults with A-T and help them build the confidence and skills to take control of their lives and manage them as they wish.

This is an ambitious programme, but one that I am convinced is becoming more and more urgently needed given the advances in care for people with A-T and the increasing number of adults living with the condition. We will of course be working closely with people with A-T and their families as we develop the strategy and in doing so we will be taking forward the legacy of Siân, Rupert, Mireille and many others – and that to me is really important.



## Erydex trial now underway

The first major clinical trial of a treatment for the symptoms of A-T gets underway – but not yet in Nottingham

After all the talking, planning and preparations, the trial of the Erydex System is finally underway. Now known as the ATTeST (A-T Treatment with the Erydex SysTem), this study is the first major international trial for a treatment for the neurological symptoms of A-T. As we go to press some 20 people with A-T out of the 180 required have been recruited in 8 centres in Europe and the USA.

The A-T centre at Nottingham will be participating in the trial and aims to be recruiting participants later this year. The centre is receiving its final site-visit from the trial organisers in July. However, at the moment it is not possible

to say exactly when recruitment will start.

The issue is that Nottingham will be one of the largest centres in terms of numbers of participants. This, and the complexity of the trial, involving as it does monthly visits to the centre and a range of tests and assessments to be carried out, mean that they need to recruit a research fellow. It is this recruitment and the bureaucratic processes of the NHS and University which are taking time.

Many families have been in contact with the A-T Society to find out what is happening, having heard that the trial is underway in other countries. We understand

their frustration and have been in regular touch with the Nottingham team to offer any assistance we can to help speed things up. We are also in constant contact with the sponsors of the trial who are fully engaged and committed to providing all the support needed to solve the issues encountered in Nottingham.

However, while we don't know the exact start date, we are nevertheless confident that the trial will go ahead and also that there is an excellent team in place in Nottingham to carry it out. As soon as we have any more information about a start date, we will let people know.

## A-T Registry



The A-T Registry has now been launched and is starting to collect clinical data on people with A-T. As it was set up with a grant from the European Commission as part of the Horizon 2020 grant which is helping fund the ATTeST trial, data collection is therefore beginning with participants in the trial. The Registry is managed by the A-T Society, with much of the work being done by Registry Coordinator, Jo Reader.

We are in touch with all the centres that are participating in the study and are in the process of translating the necessary information and consent forms into the different languages required. We are also working on ways to simplify the uploading of existing data.

The registry will contain clinical data uploaded by doctors and as such it will complement the data being collected by the Global A-T Family Data Platform which is provided by individuals with A-T and their families. In addition to data on people with A-T, it will also collect data on people with related conditions, such as A-T-like disorder, AOA1 and AOA2 and Nijmegen breakage syndrome, which are even rarer than A-T.

Because A-T is so rare and patients so spread out, and also because symptoms vary from patient to patient, it is difficult to be able to answer with the certainty required by science, questions such as: how many people experience certain symptoms, at what age certain features appear or whether particular symptoms are linked to others. By bringing together data from hundreds of patients, a registry will help answer these questions and in doing so help us understand A-T better and thus help treat it better.

For more information, you can visit the Registry website [www.atregistry.eu](http://www.atregistry.eu) or email [admin@atregistry.eu](mailto:admin@atregistry.eu).

## About the ATTeST trial

In a number of small-scale studies in Italy, steroids have been shown to improve the neurological symptoms of A-T. This means that children who have taken steroids have shown improvements in things like walking, balance, movements and speech.

However, conventionally delivered steroids have significant side-effects, which rules out prolonged use in people with A-T. The Erydex system is a novel way of delivering the steroid dexamethasone, which seems to avoid these side-effects. A small amount of the individual's blood is removed, the red cells are separated out and the drug is infused into these red cells. They are then injected back into the individual, where the drug is released slowly over the next few weeks.

A previous smaller-scale trial showed that the treatment was effective in improving the neurological symptoms in children with A-T and had no major side-effects. In a few children who have been on the treatment for several years, it also appears that the positive effect continues, and that the treatment is well tolerated.



However, for the treatment to be approved as safe and effective, the licensing authorities require a larger trial, involving 180 patients. This is now being carried out in 24 centres around the world, including Nottingham.

To participate in the trial, you must be at least six years old with a diagnosis of A-T, weigh over 15 kilos and be able to walk independently or with occasional use of a support. There are also a number of other criteria regarding health and immunological status.

It must also be remembered that this study is placebo-controlled. This means that while all participants will undertake the treatment, not all will be receiving the actual drug. Patients will be divided at random into one of three equal-sized groups. One group will get the drug at a higher dosage, one at a lower dosage

and one will get the placebo, i.e. no active drug.

However, the trial is double-blinded, which means that neither the participants nor the doctors running the trial will know which group they are in.

After six months, and again at nine months, the number of participants in the placebo group will be reduced. After 12 months, the formal trial will be over and assuming that there have been no adverse events, anyone who wishes to will be able to continue on the treatment. At this point everyone, including those who have remained in the placebo group will get the active drug.

More information is available on the trial website [attest-trial.com](http://attest-trial.com). If you would like to talk to us about it, or express an interest in participating, please contact Anne or Kay on **01582 760733**.

## Diabetes and A-T: the Dundee RAMP study

Laura McCreight gives an update on the RAMP study (Response of Individuals with Ataxia Telangiectasia to Metformin and Pioglitazone).

### A-T and Metformin

In 2011, Prof Ewan Pearson and his team of researchers at the University of Dundee, were investigating how an individual's genetic code might affect their

response to certain medical treatments. They were particularly interested in metformin – a medication with glucose-lowering effects, widely prescribed for type 2 diabetes.

Whilst investigating the body's response to metformin, they found a surprising genetic link with a region of DNA that includes the ATM gene, the gene which does not function in people with A-T.

### A-T and Insulin Resistance

Case reports from the 70s had previously linked A-T to an increased risk of diabetes and resistance to the action of insulin, so Prof Pearson teamed up with doctors at the A-T specialist centre at Papworth, to investigate this further.

They studied ten adults with A-T and ten adults without A-T

of similar weight and age using oral glucose tolerance tests. The results confirmed, for the first time, that adults with A-T do have an impaired ability to handle sugar and are resistant to the effects of insulin.

### Mice lacking ATM

Since then, a scientific paper has described the link between ATM deficiency and insulin resistance in mice. It demonstrated that mice lacking ATM tended to be insulin-resistant, have higher levels of fat around their abdominal organs, and increased liver fat content. However, they had less peripheral fat. The paper also showed that treatment with metformin can improve the insulin sensitivity of these mice, while another diabetes drug, pioglitazone, can improve the fat distribution and insulin sensitivity.

This mouse study identified potential mechanisms by which ATM deficiency causes “fatty liver”, something which is now being found in many people with A-T, and insulin resistance. The team felt this warranted further investigation in humans.

### The RAMP study

The RAMP study investigates how individuals with A-T respond to metformin and pioglitazone, compared to “healthy” controls. Participants visit Dundee on three occasions – once at baseline, the second visit after eight weeks of metformin treatment, and the final visit after eight weeks of pioglitazone treatment.

At the initial visit, an abdominal MRI is carried out to measure fat distribution in the abdomen and a fat biopsy is taken. These images and tissue samples will allow investigation into the link between A-T and fat metabolism and turnover.



*One of our volunteers wearing the indirect calorimetry ‘hood’, which measures the oxygen and carbon dioxide in the exhaled breath of the wearer.*

The main part of the study is a “dual tracer mixed meal” test, which involves the participant lying on a hospital bed for eight hours, with a glucose infusion (drip) running in one arm. After two hours of this infusion, a liquid meal is given. Both the drip and the liquid meal have glucose tracer added – meaning these glucose sources are “labelled” and can be distinguished from the glucose already in the blood stream. During the eight-hour study, multiple blood tests are taken from the other arm, and gas exchange is measured. This tracer study is repeated at each visit.

From the tracer study, measurement of blood glucose levels and hormones such as insulin and glucagon, allow the team to calculate the individual’s insulin sensitivity and how this changes in response to each of the diabetes medications.



*Blood bottles ready for the eight hour tracer study – 55 blood tubes in total!*

### Recruitment update

Recruitment for the RAMP study has now finished. In total, 9 individuals with A-T, and 18 control participants were recruited. The final study visit will be at the end of August, and results will be published at the beginning of 2018. The team are hoping that they will gain new insights into the causes of diabetes and fatty liver in people with A-T and that the results will help improve the treatment of diabetes in A-T.

### With thanks

The research team in Dundee have worked closely with the A-T Society throughout the study, and would like to pass on sincere gratitude to all the staff. The help they provided with recruitment and support of the study has been indispensable and greatly appreciated.

The research team would like to give special thanks to all the fantastic people who took part, along with their families and carers. Without your help, none of the research would be possible! It has been a pleasure to get to know all of you, and we look forward to catching up with all of you at the A-T Family weekend.

*(Photos used with permission of the volunteer).*



## A-T clinical research conference

October 2014 saw many of world's leading specialists in treating A-T gathering in Warsaw for the 3rd A-T Clinical Research Conference. Also present were a number of top research scientists with an interest in understanding and treating A-T, as well as representatives of the A-T Society, A-T Children's Project, BrAshA-T and patient groups from Poland, France and Spain.

Over three days sessions looked all key areas of A-T: immunology, neurology, respiratory care, cancer and metabolic disorders. For each of these areas there were presentations both on the basic science and on clinical aspects. Other sessions focused on issues such as next-generation research, emerging treatments and unusual cases.

As always with these clinical research conferences, presentations are kept short to ensure maximum time for group discussions. This is something which participants always value very highly and discussions often went on well into the coffee-breaks.

While there were sadly no reports of major breakthroughs in understanding and treating A-T, the main aim of conferences is to share knowledge, encourage debate and spark new ideas and there was a lot of this.

The neurology session looked at data from Nottingham and Johns Hopkins detailing neurological deterioration over time in their patient groups. The Frankfurt team had found a correlation between neurological deterioration and the presence of specific brain proteins. These findings underlined the importance of a standardized scale for measuring neurological impairment, as well as the need for

an international registry in order to produce an accurate natural history.

It was also good to get the first presentation of data from the CATNAP imaging project in Nottingham. While there is still a lot of work to do to analyse all the data from the scans, one interesting finding is that the volume of a particular part of the brain (the 4th ventricle) becomes enlarged as the cerebellum shrinks and this appears to grow in parallel with neurological deterioration, which means that there is a possibility that this could be used as an outcome measure, for example in clinical trials.

There was lots of discussion around the biggest unanswered question in A-T: why does the loss of ATM protein lead to the loss of neurons in the cerebellum? There are many mechanisms that might be responsible: the effects of unrepaired DNA damage, failure to deal with oxidative stress, abnormal processes of autophagy and mitophagy, problems with the network of cells that support neurons and so on. Different researchers hold different views, but there was general agreement that it would be beneficial to be able to develop ATM-deficient neurons which could be studied in the laboratory, and researchers are making good progress towards doing this.

Immunology is a complex area and in A-T the pattern of which antibodies are low high or normal varies considerably between patients. Discussion focused on the significance of these variations and what they can tell us about A-T and about the course of the condition for individual patients. Delegates also debated the role

of inflammation and what the current evidence tells us about this. While there were no concrete conclusions, this is clearly an area that needs more work and data from the A-T Registry will play an important role in this.

Another major topic was bone-marrow transplant. Four operations have now been carried out in people with A-T in Poland and Germany. The transplants were carried out for different reasons but mainly to improve immune function and reduce the risk of cancer. While all those who had the transplant seem to be doing well, it is not clear what long term benefits there are and there seems to be little evidence of any major impact on the neurological symptoms. Significant questions remain about the circumstances in which one would choose to transplant.

The respiratory session emphasised the importance of the recommendations of the 2015 ERS statement on the management of lung disease in A-T for aggressive, proactive monitoring and treatment of lung disease. There were two presentations on MRI studies of the lungs. One from Rome showed some extremely interesting images and the other in Nottingham is due to start shortly. There was also a report of an interesting study into oxidative stress in lung disease which is currently underway in Australia – though there was no data as yet.

The cancer session contained a lot of detailed discussion of treatment of cancers in A-T which is difficult to summarise here. Some key points though were that while some people respond well to reduced-intensity treatment, approach. This requires a detailed pre-treatment assessment, which

should include a brain MRI and consultation with A-T experts and a major supportive care package. For the future, we should be working to get more information on cancer in A-T with information in registries and if possible the collection of tissue samples.

This would then aid the development of more targeted therapies.

There were many other areas of discussion and presentation, and feedback from participants was overwhelmingly positive. Nevertheless, there were a number of ideas about how we can make

the next conference, to be held in Naples in November 2018, even better. The planning group led by Cynthia Rothblun-Oviatt of the A-T Children's Project and William Davis is working to incorporate these into the programme for that event, which we are already putting together.

## ATW 2017 in Milan

**William Davis** reports on the latest A-T research conference

April 2017 saw another conference on A-T research, this time the A-T Workshop, which took place in Milan. This conference, which takes place every two years is much more focused on laboratory research than the Clinical Research Conference. Given that this was only six months after the Warsaw conference, there were few clinicians present and the A-T Society was the only patient organisation from outside Italy.

The conference was opened by Yossi Shiloh, whose team first identified the ATM protein back in 1995. He started by expressing his frustration that 22 years after the ATM gene was first discovered, we still don't understand how loss of the gene and its ATM protein leads to neurodegeneration – which makes it difficult to develop targeted treatments. He underlined the need for a holistic view of effects of ATM deficiency to understand the neurodegeneration in ATM. He sees DNA repair as the critical area of ATM activity but this is a very complex area in which ATM interacts with hundreds of other proteins.

Most of the other presentations focused on cell processes that were in some way related to ATM, and some speakers suggested that particular functions might be responsible for neurodegeneration.



*Italian families attending the Milan Conference*

The difficulty at the moment though is telling who, if anyone is right. What was more encouraging though was that compared to the first conferences I went to six years ago, researchers are looking much more at the bigger picture, and trying to see how these various functions work together to cause the symptoms of A-T. This certainly feels intuitively more sensible and is more in line with how people with A-T experience the condition.

From the A-T Society's perspective it was good to be able to speak to researchers and to catch up on where their research is. I was able to discuss an exciting and significant research project which is currently being considered by the Society's Scientific Advisory Board. I was also able to film interviews with a number of researchers and put these on line.

They are currently available on our website.

A personal highlight for me was being asked to chair a bilingual Q and A session for 20 or so Italian families with doctors and researchers, similar to the one we have at our Family Weekend. Although it was complicated having to translate between Italian and English, the families greatly appreciated this opportunity, which they don't usually get, and there was very positive feedback from some of the professionals, too. I was also able to have supper with and chat to the families at a nearby restaurant, which was very enjoyable.

I also helped William Whitehouse (the Nottingham Neurologist) run two workshops as part of a project to identify some 'Core Outcome Sets' for A-T trials. This means a series of measures (for example how far you can walk unaided or fatigue) which would be measured in every clinical trial for A-T and would enable the results of different trials to be more easily compared. The measures need to be agreed by all parties involved, people with the condition, doctors, researchers and so on, so not a simple process. However, it is something which if it can be done, is potentially very useful.



## Adult activity weekend 2017

Friday 8th September – Monday 11th September

Our adult activity weekends provide a great opportunity for adults with A-T to get away for a few days, take part a range of exciting activities, and relax in the evening with other people with A-T.

We're excited to announce that this year our adult activity weekend will take place in the Lake District at the Bendrigg Trust, an outdoor learning and activity centre especially designed for people with disabilities. The Bendrigg Trust provides the perfect place for people to try something new and face up to new challenges. From canoeing, indoor or outdoor climbing and abseiling, zip wire, sailing, orienteering to arts and crafts, film nights, disco and campfires – there's so much to do.

This three night experience has proved very popular and all 15 places were taken within the



first week of the booking letter being sent out last month. We're currently working with the team at the Bendrigg Trust to plan the agenda for the three days and will confirm more details nearer the time.

For a sneak preview of the facilities and the activities available please visit their website [www.bendrigg.org.uk](http://www.bendrigg.org.uk).

## Family weekend

Saturday 14th October – Sunday 15th October 2017



Our annual family weekend will be held at the Radisson Blu Hotel near Stansted Airport, Essex on 14th and 15th October. As usual, an action-packed agenda has been planned. The children will be

visiting Paradise Wildlife Park on the Saturday and will be visited by 'Dennis the Fire Engine' as part of an Emergency Services and First Aid workshop on the Sunday. With a magician, fancy dress competition and disco there will be plenty of entertainment to keep the children busy over the weekend.

For parents, carers and other adults the presentations on Saturday will include talks about using adapted computers and technology and the changes to disability benefits. The focus of the afternoon will be on research including talks from Prof. Steve

Jackson and Dr Anke Hensiek on mild variant A-T. On Sunday we'll be focusing on Psychological and Mental Health issues and also our adults with A-T will be talking about their experiences.

Of course we have allowed plenty of time in the schedule for people to catch up. We know that this is one of the most appreciated parts of these weekends as it gives a chance for families to socialise and support each other. Further details about the weekend will be published on our website once they are finalised.

## PIP assessments

There has been talk in the media recently about possible future cuts to disability services and benefits. This is clearly a matter of concern to people living with A-T and to the A-T Society. It comes at a time when the Department of Work and Pensions is rolling out the change from Disability Living Allowance (DLA) to Personal Independence Payments (PIP) across the country. Many families are receiving complicated forms to fill in and being invited to an assessment interview. This can be very stressful, particularly as the system seems to be operating in an environment where there is pressure to find that people are able to work or are not eligible for the allowance.

The A-T Society is very aware of these problems. We consider it ridiculous that so many people with A-T are being required to undergo an assessment visit, for a condition as severe as A-T, and when they have previously had a lifetime award of DLA. We have spoken to ATOS and to the DWP about this. However, it is currently a matter of policy that everyone with a disability, regardless of what it is or its severity, has to go through an assessment, unless a doctor states that they are unable to do so. Trying to change this policy is not something we can do on our own, but we will work with others to try and do so. And if you have a chance to raise the issue with your MP, that can only be helpful.

In the meantime, though, if you are sent the forms, please do contact us before you fill them in. Likewise, if you are invited to an assessment, please get in touch, so that we can advise or support you. You can either email [support@atsociety.org.uk](mailto:support@atsociety.org.uk) or ring us on **01582 760733**.

And finally, try not to worry. A-T is a seriously disabling condition, and with the support of the A-T Society, we will be able to make them see that. But if you are worried, please do contact us.



## Direct payments

Have you considered applying to the government for direct payments? Direct payments let you choose and buy the services you need yourself, or the person you are caring for, instead of getting them from your council. If you, or someone you care for, receive help from social services then you can apply for direct payments.

A direct payment is the amount of money that the local council/trust has to pay to meet the needs of you or the person you are looking after, and which is given to enable you/them to purchase services that will meet your/their needs (as assessed by the local council/trust). Many of our adults, for example, use them to employ a personal assistant for a few hours a week to enable them to enjoy social activities such as going out to the cinema or shopping.

Direct payments are available to people over 16 living in England, Scotland and Wales. You can only get direct payments if you've been assessed by social services as needing care and support services.

Direct payments can be made to:

- disabled people aged 16 or over (with short or long-term needs)
- disabled parents for children's services
- carers aged 16 or over (including people with parental responsibility for a disabled child)
- elderly people who need community care services

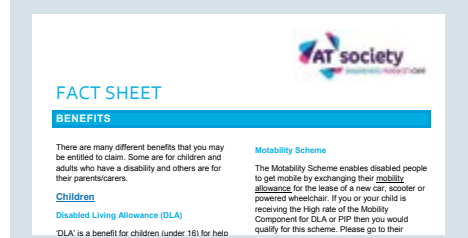
Applying for direct payments is not compulsory and so, if you would rather, you can continue to have the local council/trust continue to arrange your support. Further detailed information can be found

at [www.carersuk.org](http://www.carersuk.org).

If you would like to apply for direct payments visit the government website: [www.gov.uk/apply-direct-payments](http://www.gov.uk/apply-direct-payments).

### Benefits fact sheet

Our benefits fact sheet provides a comprehensive overview to the benefits system and the different types of benefits available. Hard copies are available from Kay and Anne and each family will receive a copy with this newsletter. To download the factsheet as a PDF visit [www.atsociety.org.uk/factsheets](http://www.atsociety.org.uk/factsheets).



## Wheelchair maintenance advice from A-T clinic therapists

This article aims to provide a reminder to manual wheelchair users, (and their families) about the importance of maintenance of the wheelchair regardless of how frequently the chair is used. It is based on our experience from the A-T Clinic in Nottingham, over the years.

### Physical maintenance tips:

- Wheelchairs last longer if maintained correctly.
- Are the tyres correctly or fully inflated? If not this will make it harder to push or propel the wheelchair and can affect the ability of the chair to stay straight when moving.
- On a monthly basis, check the tyre treads: are they still visible? Or have they been worn smooth? If bald (smooth) patches are present or the tyres do not look the same all the way round, you need to inform your local therapists and/or contact your local wheelchair services for a review, replacement. NB: worn tyres do not grip effectively and can affect the performance of the wheelchair when being self-propelled or pushed.
- Do the brake handles move easily into place? Are they effective at keeping the wheelchair stationary when on a slope? If not the brakes may need tightening or other adjustment.
- Are the footplates level and do they remain so when weight is put onto them?
- If a lap strap is attached is it a) in place and b) still able to be secured? It should fit snugly but not be too tight. In winter accommodation is needed for coats etc.
- Is the wheelchair still the correct size for the child/adult? Growth or other physical issues including comfort can influence this.

### Postural management tips:

Postural management refers to how the body positions and maintains itself against gravity, in all positions. In sitting, alignment in an upright position is optimum, with good symmetry on the right and left at the hips. The trunk should be in midline with the head aligned above as much as possible. This position needs to be maintained when still or moving in the wheelchair and be sustainable over time too.

Good postural management is preventative of pain or muscle contractures whilst enhancing functional independence and comfort.

- Observe the child/adult when seated in the wheelchair. What does their positioning look like? If they cannot keep upright over time, extra trunk support may be required. (It is important to be seated as symmetrically as possible).
- Is the backrest offering enough support? If it is a soft backrest, is it fastened (velcro is common) as firmly as possible?
- Is the backrest too high or too low, from a comfort perspective or when self-propelling?
- Seat width and depth; is this still correct (i.e. no more than two finger widths from back of knee to the seat)? Seat is not too narrow or too wide.
- Seat cushions; is the seat cushion still keeping its shape and not going too saggy?
- For gel or other pressure-relieving cushions, ensure they are stored level not on their side and that the gel has not become lumpy. When pressure is applied and released does the cushion bounce back into shape? If not, this needs replacing. NB: old cushions can increase the risk of pressure problems, discomfort and postural asymmetry of the pelvis, which impacts on spinal position.

- Are the knees level when looking from the front, the same length and positioned in the centre facing forwards? Can this be maintained when moving in the wheelchair, if not self-propelling? If the knees sweep to one side consult your local therapist.
- Footrests – are these the correct height? Is the knee bent at 90 degrees in sitting as it should be? (If too long or too short these need adjusting).
- Are the push handles at the correct height for the carer?
- Check the wheelchair is stable when the individual is seated in it. Check size and weight remains correct for the chair, as this can affect stability and safety, especially on uneven surfaces.

If the individual uses a powered wheelchair for a majority of the time, it is likely the manual wheelchair only has occasional use. This in turn means that postural review in the manual wheelchair is often overlooked or infrequent. It is essential that all wheelchairs be reviewed regularly. (Keep a record of when this is due and book in advance). A useful time scale would be 12-18 months, depending on growth, usage and postural changes. A service on a wheelchair should be undertaken by a suitably qualified and experienced professional either via wheelchair services for NHS-provided equipment (no cost incurred), or via an independent provider for privately-purchased equipment, (which the individual or family would need to fund).

If in doubt about any aspect of the manual wheelchair, contact your local Occupational Therapist or Physiotherapist.

This article has been devised and written by the Nottingham A-T Clinic Therapists, Janet Corderoy and Sarah Jessop. Please contact us through the A-T Society if you have any queries.





## Breast screening in women with A-T

This article is based on an information leaflet produced by the team at the Papworth A-T Centre.

### Cancer risks in A-T

It is widely known that people with A-T have an increased risk of developing various types of cancer. While in children the cancers are predominantly blood cancers – lymphomas or leukaemias – in adult life the range is more varied including breast cancer, blood cancers, endocrine tumours, brain tumours, and hepatocellular carcinoma (primary liver cancer).

While it is sensible to keep an eye on the health of a person with A-T and consult a doctor when there are any unexplained symptoms or unexplained ill-health, the only formal screening programme currently recommended is for breast cancer.

### Breast cancer risk

Breast cancer affects about one in eight women in the general population (12%) most commonly after the menopause. Women with A-T have a substantially higher risk of developing breast cancer from age 25 years. It has been estimated that nearly half all women with A-T will develop breast cancer by the age of 50 years but this number is based on very small studies so we do not know how accurate it is. The level of risk may be different for women with milder forms of A-T, but again we cannot be sure about this.

### Screening recommendations

NHS England guidelines recommend screening using an MRI scan of the breasts once per year, starting when a woman is 25 years old. Breast screening aims to detect any developing breast cancers at an early stage so that they can be treated more easily. However, it may also find abnormalities which turn out to be non-cancerous and do not require treatment.

Screening by mammography is not recommended for women with A-T due to their increased sensitivity to X-rays, although mammography may have a role in assessing an abnormality found on MRI. If a woman is unable to tolerate MRI scanning, she should be given information about breast awareness and ask her GP to refer her on should she suspect any changes.

### There are a number of ways to access screening

You may wish to see a Clinical Geneticist or Genetic Counsellor to discuss your genetic status (types of gene alterations), implications for other family members (or planning a pregnancy) and cancer risks. This can be done either locally or when you attend Papworth:

1. Your GP can refer you to your local genetics service, who will then arrange the breast screening after your appointment at your local breast unit. Be aware, though, that you may have to inform them about the guidelines for A-T as they may well not have come across them before.
2. Alternatively, you can see a Clinical Geneticist as part of your regular A-T review at the National adult A-T service, Papworth. Your screening can then be done either at Addenbrooke's Hospital in Cambridge during your visit to Papworth or through referral to your local breast unit.

If you live in Scotland, Wales or Northern Ireland and wish to have breast screening done locally, your local genetics service will need to make the referral.

### Advice for other family members

Women who are carriers of the A-T gene mutation have a moderately increased risk of breast cancer. Mothers of people with A-T are always carriers, while other female family members such as sisters

or aunts may be and can request testing, by asking their GP to refer them to their local Clinical Genetics Service.

Current guidelines recommend that carriers of the A-T mutation should be offered a mammogram every 18 months from the age of 40 until the age of 50 years, after which they will get three-yearly mammograms as part of the regular NHS Breast Screening Programme. A full assessment of the family history of cancer will help guide whether any additional screening above this baseline is required. Women carrying the c.7271T>G mutation may be at higher risk of breast cancer. Genetic counselling is particularly important for families of A-T patients with this mutation. They may be offered additional MRI screening based on their family history.

Any of these routes should result in your being able to access regular screening. Once again though, your GP or local screening service may not be familiar with the guidance. If you have any problems please get in touch with Kay or Anne at the A-T Society on [01582 760733](tel:01582760733).

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

If you, or anyone you know, has been affected by cancer then you may wish to visit the Macmillan cancer support website. Macmillan offer advice on living with cancer whether that be practical, medical or financial, as well as help and support for the patient and family and friends who are supporting them.

[www.macmillan.org.uk](http://www.macmillan.org.uk)

## Rachel lands her first paid job

Rachel Ferguson has classic A-T but she hasn't let A-T get in her way of pursuing her dreams and, with much grit and determination, she has overcome every hurdle to get to where she is today. She achieved seven GCSEs at school and has recently graduated from Telford College of Arts and Technology. Rachel passed her three year BTEC level 3 course in Health and Social Care with flying colours.

Rachel was recently interviewed for her college newsletter and had this to say:

"When I started college, the staff centred the whole course around me. They put me in a normal group of students, gave me a reduced timetable, let me have study time after lunch to get on with any work I had, and allowed me to go home at 3pm.



Finishing my course took a lot of effort and I couldn't have completed it without the support of my tutors. As well as supporting me, they also became my friends."

The staff at the college were so impressed with the way that Rachel embraced the course, her determination to be like all the other health students and

her resilience in completing her placements. They also recognised that Rachel has an amazing sense of humour which shone through when the wrong bus turned up without a wheelchair lift for a college trip. Determined to go Rachel told her friend and teachers to just 'manhandle her up the steps' which they obligingly did!

Since leaving college Rachel has embarked on her next challenge - her first ever job. She is now employed as a part time website administrator working with the Bridgnorth and Morville Parishes Team Ministry.

Her mother Joy said: "We now have a website administrator in the family! Hopefully this is just the start of an exciting new chapter in her life - I'm so proud of my daughter for landing her first paid job."

## Jordan's flying high



Jordan has always had a sense of adventure and doesn't believe that his condition should prevent him from tackling a challenge or two; in fact he featured in the last newsletter describing his driving experience riding in sports cars.

He recently went on holiday with his family to the Calvert Trust adventure centre in the Lake District. The Calvert Trust offer challenging outdoor adventures



for people with disabilities and believe it's what a person can do that counts! With so many activities and new challenges on offer, Jordan had a hard time choosing which activities to do and tried to fit in as much as possible on his break.

His grit and sheer determination to try everything really shone through as he tackled the assault course, zip wire, climbing wall and



archery. He had the time of his life and loved every minute. He did however, give his mum a fright when his wheelchair decided to do a wheelie on the assault course but Jordan wasn't in the least bit phased and found that it added to the adventure.

Jordan has now decided what he really wants is his own crossbow! We can't wait to see what adventure he has lined up next!



## A new addition to the family



Congratulations to Bea and Dan who have become proud parents to baby Luca born in December last year. Looking after Luca is keeping Bea very busy but it's the best job in the world watching her little man grow and explore the world. Crawling and solid foods are next on his agenda. Many of you will know Bea as she's



Rupert Prokofiev's twin sister, a regular attendee at the family weekend and wonderful editor of this newsletter. Rupert was a very proud uncle who enjoyed his cuddles with Luca and a lovely Christmas together before he very sadly passed away in January.



## Flying the flag for Great Britain



On 7th June 2017 Spencer had the honour to be the GB flag bearer for the European Clay Pigeon Shooting Championships at Lulworth Castle. Spencer is a well-known shooting enthusiast, so was asked to bear the flag by Graham Brown who runs Purbeck Shooting School and led out the Great Britain team. Well done Spencer – a much-deserved honour.

## A baby sister for Winston



Winston is the very proud brother of baby sister Wren who was born in June last year. They are definitely keeping mum, Sara, on her toes and are all having a lot of fun together. They dressed up as skeletons for Bonfire night and, judging by the smiles on their faces, they had a fearfully good time!





### George's colour run

George took part in his very first colour run in June organised by his school. As you can see from the big grin on his face, he loved every minute of it. His wheelchair was multi coloured by the end of it but luckily it didn't take too long to clean.



### Jake's heading off to high school in September

It only seemed like yesterday to Jake's mum when Jake started primary school but in September he's off to high school. His family are so proud of him as he's making another big jump all by himself, going to a new school with none of his friends! He's so excited and has already had his first taster day at his new school.



### Orla joins Rainbows

Orla joined Rainbows last summer and made her Rainbow promise just before Christmas. Joining Rainbows has been a really positive experience for Orla – she's made new friends, tried lots of new activities and challenges and her Rainbow unit have been very inclusive.



### A new baby sister for Ibraheem

Ibraheem was so excited to meet his new baby sister, Juwairiyah, born in December last year. As the photos prove it's very hard to get everyone smiling at the same time! We hope they both have many fun adventures together.



## Erin's new pink wheelchair – Taylor Swift

Anne interviewed the delightful Erin recently whilst she was waiting at Nottingham A-T Clinic for her appointment. Anne found out all about school and Erin's new wheelchair which she has named Taylor Swift. Here's her story with little a bit extra from Erin's wonderful school special needs assistant Áine.

**Anne:** So Erin, I hear 'Taylor Swift' has come into your life recently, what's the story?!

**Erin:** Well, I've always loved the name Taylor and I also like Taylor Swift's songs. So when I first saw my new pink wheelchair I said 'That's not a wheelchair, that's Taylor Swift!' And we've been together ever since.

**Anne:** What a brilliant idea. What kind of things do you get up to with Taylor then?

**Erin:** Well sometimes I'll say 'Come on Taylor, lets go for a ride' and off we go to the park, the shops or whatever. Sometimes I ride 'IN' Taylor. Get it?!!!

**Anne:** Yep I get it. I guess Taylor comes in handy when you get tired.

**Erin:** Did you hear about my speeding fines in school?

**Anne:** Erm, no! Please tell me more.

**Erin:** The head teacher was always telling me 'Erin you need to be slowing down now'. But I kept going too fast, so he's started giving me fines!

**Anne:** Really? I bet you've slowed down now then, to stop getting into trouble?

**Erin:** No, I just hand the fines to Áine and tell her to pay them! Áine's my special needs assistant in school and she helps me out when I need it.

**Anne:** Well she's going above and beyond if she's paying fines for you... I think I'd like to find out more about this story from Áine!

On further investigation, it seems Erin can indeed be seen speeding around with her walker, both inside and outside of school. No amount of telling her to slow down worked. So in an attempt to reduce her speed, her head teacher resorted to issuing Erin with speeding tickets whenever he spotted her zooming along too fast!



Each speeding ticket costs 20 cents but according to Áine none of the fines have been paid yet and there are lots of them!!!

Áine also reported that Erin's class mates are very caring towards her. They never leave her out of any activities, which is wonderful.

As for Erin's mobility equipment; the other kids don't even notice it! They see Erin, not her walking frame or wheelchair (oops sorry, I mean Taylor Swift!)



## Annie's dedication recognised by Pride of Gwent Award Judges

Annie Wills, whose daughter Alexandra has A-T, won the Carer Award in the Pride of Gwent awards run by her local paper South Wales Argus. Her family are so proud of her and say she always goes the extra mile for her daughter Alexandra. Despite working part-time she visits and cares for her daughter nearly every day. Annie's other daughter, Terrie, nominated her for the award as she felt her mum deserved to know just how amazing she was. Terrie said: "I don't know where she gets the energy or strength from. My mum is the most selfless, kind and giving person I know." Annie wasn't expecting the award at all so it was a lovely surprise. Annie said "I did think 'why me?' because as a mum you do what you do without questioning anything. I would

do anything for my daughter to make her life easier. My daughter enjoys going out so I take her out and arrange things like hospital appointments."

When she found out that she had won the Carer Award, Annie said:

"I felt in the beginning that if anyone should win the award it should be my daughter, but some people say that I do wonders and I have two other daughters who also say that I go all out for Alexandra." The most important thing about winning the award for Annie is realising how much she is appreciated and how much her daughters think of her and for that she is really thankful although she still sees it as being part and parcel of a mum.



*N.B This is an extract of the story printed by South Wales Argus paper – the full story can be found online on their website.*



## Toni-Jo's Boccia victory

Five year old Toni-Jo should be extremely proud of herself after being awarded a medal, certificate and receiving a very loud cheer from the whole of her school.

In November Toni-Jo and her three team mates played in a Boccia tournament. (Boccia is a disability sport that tests muscle control and accuracy. Players propel balls to land close to a target ball). Toni-Jo's team came first out of the primary schools and 7th overall (most were secondary schools). They won a trophy for their school and came away from the event full of excitement and pride.

A big round of applause to such superstars!



## End of an era for James

Congratulations to James Ferguson who has just finished secondary school. Over the past few months he has been diligently studying for his GCSE's, and had to sit a two-hour Physics exam on his 16th birthday! James's hard work has been recognised and he has been awarded a special award called the 'Carroll Bennett Prize for Endeavour'. James enjoyed his time at secondary school and he was fortunate to have some very supportive teaching assistants and teachers. We wish him the very best of luck with his results.



## Becky receives the Inspire Scholarship

Congratulations to Becky Simpkin for being awarded the Inspire Scholarship. 24 year old Becky has an active and busy life and works hard at keeping strong and healthy.

In November 2016 she was awarded the Inspire Scholarship by her local gym, Gym & Tonic. The Inspire Scholarship gives free gym access to an inspirational member of the community. Becky impressed the team at Gym & Tonic with her sheer determination to work hard to achieve her fitness goals and they awarded her the scholarship in recognition of her efforts.

Using the gym helps with the ataxic movements, helps keep her lungs working properly and aids general fitness and well-being. Also, because she is in a wheelchair full time, it is important to strengthen her arms and legs.

Becky said "I was doing pay as you go at Gym & Tonic once a week with trainer Kate and we did a mixture of things including the bike, the arm bike, resistance machines and free weights. Kate has recently introduced me to Boxing which I love!!! Since joining the gym I have actually put on weight & I'm getting stronger which is great for me and something I need to retain!"



## Rowing for charity

by Eleanor Hewitt



On the 22nd May 2017, I completed a 10,000m (6 mile) row for Meningitis Research in memory of my friend, Vicki, who passed away from bacterial meningitis and would have been supportive of my challenges. I decided to uphold the work of the charity who can help prevent the same tragedy happening to others. I successfully raised £150 for Meningitis Research and know my friend would be proud of my achievement.

After appearing in a local sporting paper, a local radio station became aware of my fundraising challenge and followed my training for my row. They even made a video clip of me which is on Facebook.

I believe my diet and lifestyle to be a large contributing factor in the explanation as to why my A-T hasn't deteriorated for years.

I have a very active life which includes going to the gym twice a week as well as fitting in other sporting events. On my recent

visit to the Papworth Clinic, I found that I had improved my lung capacity which is one of the body systems that deteriorates in A-T. I believe this to be a result of my cardiovascular training I do at the gym. Like I say, I firmly believe a healthy diet/lifestyle to be instrumental in slowing the A-T progression in my case and would love there to be a holistic diet and lifestyle approach on prescription for people with A-T to follow.

Anyway, the media interviews earlier this year and my many sporting challenges have led to local status as an 'inspiration'.

My advice to parents of children with A-T or people with A-T themselves is to not give in. Prevention is better than cure. No matter how long it takes or how small the benefit, keep persisting as small steps make big changes.

## A place to call home

We are proud to have been able to work closely with Maldon District Council and Balmoral Property Services to help a family desperately in need of major home adaptation. It's been a long and stressful process, but finally the work is complete and the family are loving their 'new' home. So what was this mum's dream? Enough space for a dining table. The adaptations have given her that, so now her family can enjoy mealtimes together, plus the children have a place to play games and do their homework.

Here's excerpt of the letter that the family wrote to express their gratitude.

*Dear Maldon District Council Home Improvement Team, Balmoral and the A-T society,*

*I needed to write to you to describe how having the adaptations done to our property has been and try to explain how life-changing it is. It is very difficult trying to express just how much you have all changed our lives... When you're told that your child has a condition such as ataxia-telangiectasia. (or A-T for short) that is so life changing and has no cure, it stops you dead in time.*

*When I started to see what the future holds for my child it hit me that the place I call home will become her prison, a place she can't move around or be safe in. I knew that something had to be done to provide her with a house she could feel safe and secure in and we could eventually all call home.*

*The whole process started a couple of years ago. Maldon District Council Home Improvement Team came in took measurements and made plans for the house and showed us how and why things were being done for us. Even down to things I wouldn't have ever thought of. Once plans were confirmed it all went ahead so quickly. We were very lucky to be decanted into the property next door, which the Maldon District Council Home Improvement Team & the A-T Society sorted out for us. This meant that my children were able to see all the works done and were able to get to know the Balmoral team, who have not only done a fantastic job with the house but have also supported the family through what could have been a really very stressful time. They even took the time to tell the children what was happening and why, which meant a lot to them and us.*

*Our home is now a safe, open planned, welcoming place that I'm able to care for both the disabled people in my life. You have given me back the ability to be able to care for my child in a way she deserves. I have the room to fully complete her physiotherapy and give her a place to be able to rest freely. I have the facilities to wash her safely and for her to be able to get around the whole property from inside to outside, front to back without having to have someone doing it for her. This will allow her to be as independent as she possibly can be, especially when she is fully wheelchair bound. I know I am so very lucky to have had support from Maldon District*

*Council Home Improvement Team, Balmoral & the A-T Society.*

*I will never be able to thank any of you enough ever. You have taken my fears away and given me back my own pride to know that I will be able to care for my child. We may have a hard road ahead of us all, but being in this home I know it will be that bit easier now.*

*You have given us a home to be happy in and make the most precious memories. Thank you all so much from the bottom of our hearts x*

## A new home at last!

After a lot of letters, reports, telephone calls and sheer unremitting determination, our family support manager Kay was finally able to get Neil and Steven Wells into new purpose built residential accommodation close to their family in a brand new Seeability development in Aylesbury. They moved in in October 2016 and have thoroughly enjoyed settling into their new home. They even have neat little gardens outside their rooms which they look forward to using this summer.

Neil and Steven were at an event celebrating the opening of Waterside House to which Suzanne was invited. When they had all stopped eating cake, they popped outside for a picture!





## Amy passes her degree course with flying colours



Congratulations to Amy Cooper who has just been offered a place on a Masters degree course in Social Work at Swansea University. Amy had to participate in a 3 part interview which she passed with flying colours. Amy had this to say:

"I am a fun, caring person and have a good sense of humour, I always say follow your dreams and don't let anything stop you from doing what you love! I have been told that I'm a fighter. I have been studying in Swansea for three year at university for degree in Health and Social Care, I received some fantastic news that I passed. At the end of my second year, I was nominated by my tutors and the Dean of faculty for an award from Ede & Ravenscroft for 'best student of the year'. I'm now going on to study my Masters in Social work."

## In memory of Usman, Rupert, Siân, and Wayne



*Usman*

It is with great sadness we announce the passing of three of our adults with A-T; **Siân Watkins**, **Rupert Prokofiev** and **Usman Khan**. They will all be very much missed by their family and friends and have left a huge hole in their hearts. Our thoughts are with them all at this sad time.

Usman Khan's mum, Neelum, said "Usman sadly passed away in January this year. He will be remembered as a lovely young man with a smile that lit up a room."



*Rupert*

Rupert Prokofiev sadly died on 2nd January after two years of deteriorating health, during which time he carried on determinedly in his usual independent way.

He was a trustee on the A-T Society board, a new role for him in which he was beginning to see how he could make his own contribution. He spoke on stage at the family weekends several times and was keen for others with A-T to speak up too. He thought of A-T as an essential part of who he was. The A-T Society was very important to Rupert and his family, providing much support as well as a sense of belonging to a warm community. Rupert especially enjoyed having fun with his peers at the adult activity weekends. He leaves behind a proud family, many friends and a wonderful team of carers.

Siân Watkins died on 23rd January 2017. This June she would have been 37. Of course all her family and friends miss her dreadfully. She was tough, stubborn, clever, and funny. Above all else, she was extremely proud of living alone and determined to be as independent as possible. She wrote a piece that she wanted to publish in the A-T newsletter, but never got around to sending it in.

Her family say it is how she would want to be remembered, so we publish it now, as they request, with her own spelling and punctuation.

*March 08*

*I started looking for somewhere else to live about 6 years ago. I was living with my Mum and Dad at this point and I didn't want to move too far away, plus all my family live in Nottingham and I wanted to be close to them.*





Siân

*In Nottingham we have a group called the Independent Living Team (Part of Nottingham city council) and their job is to give help and support to disabled people who want to live independently.*

*Someone told me about a system where you can bid for a property, a flat, a house or bungalow. I made three bids for a bungalow and my third bid was accepted, that was in October 2004 so you can see it's been a long process to get too where I am today.*

*Someone arranged with me to go and view the bungalow, I had about a week to accept or decline, I accepted the offer. That was two and a half years ago.*

*The bungalow needed adapting for my needs. The bathroom had to be ripped out and now I've got a wet room with a shower, there was an airing cupboard that took up half the space, that's gone. The kitchen also had to be dipped, new units and lower work surfaces and an electric door opening system. It took over a year to get that done.*

*June 09*

*All the adaptation was finished about 3 years ago, then I could start getting things ready to move in. At first I only stayed for the odd weekend and then I gradually started to build it up to a week and so on.*

*July 09*

*I have been living in my bungalow for just over a year now and I love it. It's been a lot of hard work but it's been worth it. So don't let anyone tell you, you can't because if you really want it; you can, I did it!!!*

*I have two carers (personal assistants) who both do 24 hours a week, that's 7 hours a day. They do 52 hours between them but sometimes they go early because they've done everything. They help me with things such as cooking, cleaning and helping me to have a shower.*

*They come about 10.00 and leave at 4.00. We also go out a lot. We go shopping in town or if I need to go shopping for food we go to the Co-op or Asda or we sometimes just walk up to the local shops. There is a café there where we sometimes go for lunch. They leave my tea when they go and a snack for later and a couple of drinks.*

*We have even been to the theatre and we have been on day trips so we have lots of fun as well.*

*Nov 09*

*There were times when I thought I couldn't do it but I did it!! I couldn't do it without my family's and my P.A's help and support and I'm glad I did because I love it.*

*Who knows maybe one day you'll do it too?*

We also sadly announce the passing of Wayne Bugby, the beloved husband and carer of one of our adults with A-T, Kath. Many of you will remember Wayne from our family weekends. Wayne attended all of the events with Kath, including all of the adult activity weekends and was well known within the Society. There was nothing he liked better than watching Kath enjoying herself, particularly when she had the opportunity to try canoeing for the first time and loved it. They laughed together the whole day! Wayne will be very much missed by Kath, all the children and family.



Wayne

## Share your news

Our next newsletter will be out before Christmas so please send any stories, updates or photos to [kate@atsociety.org.uk](mailto:kate@atsociety.org.uk) by 1st October 2017 if you'd like to be included.

## My journey to employment by Kayleigh Aris

31 year-old Kayleigh Aris was diagnosed with mild A-T when she was 26. She has never let her condition define her and has always been determined to live as normal a life as possible. Kayleigh wanted to share her journey to employment and the challenges she faced to find a job.

My ambition was to be a Primary School Teacher, so I undertook a degree in Childcare and in 2009 I achieved a BA (Hons) in Education, but to be honest this put me off working with children full stop! So I decided to have a career change. I applied for lots of jobs and had a number of interviews but had the feeling that my disability had a bit to do with me not getting the job. All I ever wanted was for an employer to give me a chance and see that my condition only affected me physically; I did have a brain and I could use it! I do firmly believe that this is all each person with a disability wants - to be seen as a person who has a disability and not a person who is disabled.

I started hearing really good things about Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust (RJA), what a good employer they were so I was determined to get a job at the Trust too. I had many interviews here, but was always second in line to getting the job. Determination to work at RJA saw me through and I successfully got offered a job in the Clinical Governance Department – beating 60 other candidates for the post!

When I started working in the department, Kris, my assistance dog, and I came as a team so steps were taken to ensure that he would be made welcome and a part of the team too. During my induction day at the very beginning of my employment, a member of staff came up to me and offered



Kris a bowl of water whilst I was sitting listening to various talks on how the Trust operated – I knew at this point that I was in safe hands and that this was the place of work for us both.

In terms of the practicalities, I was given a bigger desk so that I could get a dog bed under it and the Estates Department put up a poo bin on the field for him – being an assistance dog Kris is so well-trained, but I still haven't managed to train him to clean up after himself as of yet, or to input comment cards, but believe me I am working on it!

Kris is very well known in the hospital; in fact the staff here quite often know his name over mine. For example, I can be walking down the corridor and people will acknowledge Kris first – it's really quite funny actually, but talk about stealing the limelight!

The Trust has been so supportive of my disability, I have longer lunch-breaks so I can exercise Kris on the field, away from the Heli-pad I must add, and they are flexible with my days off. Also I am allowed to have time-off for my annual trip to Papworth Hospital and for yearly breast-screening too. I also have Access to Work, which is where the government

supports me financially to have a taxi to and from work.

I feel lucky that I was given a chance when I started working at RJA and my line manager, Alison, has never judged me. Instead she encourages me in all aspects of my work and I will always be very grateful to her for that. Following a Leadership course that Alison undertook, she had to develop a member of her team who showed potential - she decided to develop me, which made me very happy. As a result of this, my role has changed dramatically since I first started working here; I now have much more responsibility.

I do really enjoy my job and I believe this has helped me in my achievements. I have become much more confident and developed many new skills. However, it hasn't been all plain sailing – for example, I have had to learn to work as part of a team, which has been a challenge at times and is frustrating.

One day I would like to have my own consultant to look after, being his/her secretary as I do like to nurture people and take them under my wing.

# Fundraising

Goodness, a whole year has passed with barely a moment to draw breath since the last newsletter. There have been some staff changes, with Eve leaving and Sophie Arnold joining the team to provide excellent admin and Trust support.

As our responsibilities increase with more A-T diagnoses and

families asking for help with housing, education, medical care, equipment and mental health we either have to take our fundraising to a new level or make some difficult decisions about what we can fund in future. For this reason we are widening our fundraising opportunities by taking on a community and events fundraiser to provide new zest

and enthusiasm to support the wonderful people who fundraise with us. In the meantime, Suzanne and Sophie are here for anyone and everyone who wants to assist the A-T Society with fundraising and donations, and we would love to hear your great ideas for events and raising funds in the coming year.

## Corporate supporters



We are delighted to continue our corporate partnership with our friends at **Pizza Hut Delivery**. They have been immensely supportive over the last couple of years, including opening their test kitchen for our young adults and offering space for the trustees meetings. It's great to know that every time someone orders a pizza online from [www.pizzahut.co.uk](http://www.pizzahut.co.uk) they have the option to make a donation to Children in Need and the A-T Society.

The staff at the company's head office in St. Albans are planning various fundraising activities through the coming year and we hope to involve some A-T children and young people in at least one of them.



It was very exciting to learn that a friend of the Goble family had suggested the Houghton Regis division of **Aggregate Industries**, a national aggregates company, support the A-T Society this year. Suzanne went along to meet some of the team to hear about their exciting plans. She remembered that this isn't the first time Aggregate Industries have offered their support for an A-T family – back in 2012 the company donated supplies to a DIY SoS building project in Liverpool to extend a home for a young man with A-T...coincidentally, the lady who organised that donation was none other than Lisa Noscoe, whose eldest son Jake was diagnosed with A-T that year.



**Hello Baby** is a fabulous online baby store based in St Albans. They recently opened a retail space in the town and are planning various fundraising events in support of local charities including a coffee morning for the A-T Society. They have also made some very helpful donations of products to support our fundraising for which we are incredibly grateful.

If you have a baby, or want to shop for one, you can find the store at [www.hellobabydirect.com](http://www.hellobabydirect.com).





Another company providing valuable assistance is the local branch of national Chartered Accountants **Mercer and Hole**. They have been generous with raffle prizes, sponsorship of the ball and shared lots of cake on a 'dress down and eat cake day'.



**Nisbet's, Bristol** Luke Harrison organised a team cake sale in support of Simone Kelly's Champagne Tour fundraising.

The company plan to support us again later in the year.



**M&S Bridgnorth**

The amazing team at Marks and Spencer's Simply Food in beautiful Bridgnorth have gone above and beyond in their charity of the year support for the A-T Society. With Joy and Rachel Ferguson regularly invited to the store and carrier bag charge money added to a fabulous fundraising total, it's been a bumper year. We are doubly delighted to have been chosen for a second time with the store and look forward to working with the team again through to summer 2018.



The Internet Watch Foundation work internationally to make the internet a safer place for everyone who uses it. We are very honoured to have been selected as their 2017/18 Charity of the Year and look forward to meeting staff later in the summer. Their first fundraising event took place in June with many more to follow.



**Oxford Children's Hospital** had a dress down day and raffle for us. The mouth-watering prizes on offer were most distracting and the team raised an excellent amount for A-T.



**Tarmac** Wolverhampton's staff are hard-core fundraisers, they don't settle for being 'middle of the road' and their dress down days are great fundraisers for the A-T Society!



**Convergys** is a global customer services company with a base in Derry, Northern Ireland. Staff there organised a raffle in honour of Brae Sewell and raised a splendid sum for the A-T Society. Brae and his twin Broghan went along to draw the raffle and make lots of new friends.



2017 marks the completion of a magnificent five year Charity of the Year Partnership with the **Pentagon Shopping Centre** in Chatham. The Medway area has a high number of A-T diagnoses and the centre has been a fantastic way to share information and raise awareness of ataxia-telangiectasia. We've enjoyed dressing up in a variety of costumes and taking part in parades and fun days. We thank the Pentagon Management team and all of the stores for their generosity and wish them success in the future.



**Local support**

Our home town of Harpenden has active **Inner Wheel and Rotary Clubs** and we were welcomed by both last year to speak about our work and the special link with Harpenden where the charity was founded in 1989. It means a lot to us to establish a connection with these two wonderful local groups. Suzanne was invited to the June meeting of Harpenden Village Inner Wheel to receive a cheque for £1,000. This was followed by a donation from the Rotary Club just a few days later.



**Costa Coffee Kings Lynn**

have been very active in their support of the A-T Society via our friends at Kings Lynn Cycle Club. They have organised fundraising days and supported the club with their dynamic fundraising for us.

We would also like to thank a number of other national and local companies who also provide match funding and more low-key support for the charity. We very much appreciate their engagement with us.

**Chelsea film**

Some of you may know that our Chairman, Mike Detsiny is a huge fan of Premiership Champions Chelsea FC. When he heard that Broghan Sewell was being scouted to join Chelsea Juniors, Mike was able to secure funding for a short video to be made about the very different futures Broghan and his twin Brae (who has A-T) will have.

The film, 'A Game of Two Halves' also features Mum and Dad, Siobhan and Brian Sewell and was shot entirely on location in and around the home they had moved into only days earlier! Talented Film Producer Tom Worsley created a very special video which was featured in The Sun and on Channel 5 news when Broghan officially signed for Chelsea FC.



Photo-credit Olivia West



Photo-credit Olivia West

You can find the film on our A-T Society YouTube channel and on our website.

**Make a £5 donation by texting FOOTY to 70500**



## Global Make Some Noise



When we were adopted as one of the Global Radio 'Make Some Noise' charities last summer, we never imagined for a moment all of the wonderful things which would happen during our amazing year.

It all started with a group of five young adults being invited to visit the radio station for interviews and VIP tours, meeting a smattering of celebrities along the way. For Merry, Ebony, Jordan, Charlie, Amy and their mums this was an opportunity to tell their stories ready for broadcast in the run up to Make Some Noise Day – October 7th.



On Make Some Noise Day itself, Suzanne was up bright and early ready for a 7.30am live interview with Nick Ferrari on LBC. Before Suzanne's knees had stopped knocking, Lian Yarlett was giving a mother's perspective for LBC's breakfast audience.

It was quite a party at the Global HQ with Mylene Klass playing the piano in reception and rock and pop stars wandering through. As Kay couldn't be there, Aled Jones

recorded a lovely 'get well' video clip to speed her recovery. But the best was yet to come... there was an air of excitement, little whispers and giggles as Lian and daughter Alecia, dressed loud in honour of the day, were escorted into the Heart FM studio to meet Stephen Mulhern and Emma Willis. As they chatted away about Alecia's adoration for a particular megastar, who should walk in but the man himself, Mr Michael Buble. If you haven't seen the video Global made, check out their website and see, for the first time ever, Lian utterly speechless as Michael Buble charmed his way still deeper into Alecia's heart!

As the money poured in to Make Some Noise, the interviews with our five young adults were on air across the country, raising awareness of A-T for everyone who heard them. We loved being there and being part of something quite extraordinary.

But that wasn't all! Global were determined to keep giving people with A-T a voice and Rupert Prokofiev along with composer brother Gabriel and William Davis were interviewed by John Brunning on Classic FM, talking about the condition and their grandfather, Sergei Prokofiev. Rupert loved taking part, and his words took on



a new significance for the charity and his family when Rupert died suddenly in January this year.

Other visits were arranged for people with A-T who asked to be shown around the radio station. They were made welcome and mentioned on air during their studio tours.





In January Suzanne was asked to speak at a huge Make Some Noise fundraising Burns Night event along with Globals' Jenni Falconer. Suzanne held an audience of 500 spellbound whilst she explained the impact on families of life with A-T. At the end of the evening the event had raised a whopping £30,000 more than anticipated for Make Some Noise and William had shown us all how to dance a Scottish jig!

Weeks later we were invited to bring 'someone who loves cooking' to The CEO Cookoff, a feast of a fundraising event for Jamie Oliver's charity. Step forward Jilly Shah who has raised over £2,000 for the charity with her 'Jilly's Cupcake House' fundraising page. Jilly had a riot, meeting various chefs and celebrities including Jamie Oliver, Emma Bunton and she even caught a smile from the Duchess of Cornwall!

But the best was still to come. Our grant request to Make Some Noise was for £26,000 and we knew that would make a big difference to our family support in 2017. Global had other ideas and asked us to round up a small group of people to attend 'an event' at the station in mid-March. Media-savvy Ebony and Amy were joined by Gracie, Brae, Broghan and Kira and their Mums along with Mark and



Kaycee Carrington. As we stood in reception mouths dropped open and more than one chin hit the floor when Take That walked past us. The hyperventilating ladies amongst the party were swiftly escorted into a room equipped with a camera crew and a lot of Global staff who were clearly very excited. Kay and Suzanne were miked up ready to be interviewed by our friend Jenni Falconer and the cameras started to roll...

"Now" said Jenni, "you asked us for £26,000 so here's a cheque for that amount". We all cheered and Suzanne clutched the cheque very tightly.

"But" Jenni went on, ripping the cheque out of Suzanne's hand with barely concealed glee, "we thought we could do better than

that, so instead we want to give you this" She handed over a huge presentation cheque which none of us could see... Then turned it round to reveal £90,000! Hands flew to mouths (fortunately covering a few excited expletives), Kay hugged everyone and there wasn't a dry eye in the room – even behind the cameras!

What a finale to our year with our wonderful friends at Global, especially Hannah and Kara who with constant good humour encouraged and supported us throughout the process.

Check out the celebration film made by Make Some Noise here: [www.makesomenoise.com/thank-you](http://www.makesomenoise.com/thank-you).





## Inspirational fundraisers

### Challenge Sara 50:50 for A-T! by Sara Metcalfe

On nearing 49 in September 2016 I decided to do something challenging and different for a year to mark my upcoming 50th Birthday. As a family we have organised big Bash in the Barn Fundraisers every two years when the proceeds are split between the A-T Society and the MS Society. This was to be different and I would spend my year fund raising by completing challenges as a mark of respect for my gorgeous nephews, Charlie and Arthur, who face challenges every day with their A-T life. My husband has MS and some people did wonder why the donations were not to be shared with the MS Society but I can help make his life easier on a daily basis whereas we live miles away from the boys.



Challenges were to be set by friends and family and they had to be involved in the challenge as well while donating to my cause. My husband set the very first one – to get into my wedding dress after 17 years of marriage and he would try to do all the buttons up! Challenge one complete!

Friends got involved and soon after came a 5km run dressed as Mrs Elastica from The Incredibles film. The lycra suit was a tad short, very hot and with a full face mask and awful wig! This was a competitive 5km race and I was the only one dressed up – needless to say I got



some strange looks and it was only at the finish when runners actually began to ask what on earth I was doing.

As more and more people heard of my idea the challenges started coming in thick and fast – a Roseberry Topping walk that I assumed I was doing with just my challenger, Mel, turned into virtually a full village outing and they were all waiting to surprise me in the car park as I pulled up. This made me quite emotional at the thought of so many people supporting not just me but my nephews and of course the charity so close to my heart.

On a frosty Sunday morning in December you would have seen elves, Santas, reindeer and “real” dogs running around my cross country course, jumping over jumps and into the water jump for a fantastic, fun filled hour. Warm mince pies and mulled wine followed to warm us all up. The sight of Phil dressed as Santa with a very full white beard zooming along the top of the hill on his mobility scooter is one none of us will forget.

One of the highlights was catching up with the Rickshaw from Children in Need when it was in

the North and meeting Ebony who was doing a massive challenge herself. When I caught up with them I was already halfway through a four-day “Dress as a Teletubby” challenge so the look on Matt Baker’s face when LaLa jumped out of the car in front of him was a picture! I got quite emotional again talking to Ebony and her Mum in the support bus and it spurred me on to make sure I raised as much money as I could.



LaLa and Tinky Winky have made various appearances over the past few months as people heard how much my 15 year old son, Jasper, is embarrassed by it! Picking him up from school in a bright yellow suit has amused everyone except him on a number of occasions...

I have completed runs, cycles, walks, cooked stews, made fruit vodka, helped at horse events and bathed Shetlands. I have clung to rock faces in the Lake District while hyperventilating and crying



with fright and jumped into the sea on New Year's Eve dressed as Mrs Claus, all pushing boundaries that some friends did not even realise I had. I have "cantered" round the dance floor at the A-T Hope Ball while wearing pink Dr Martens (thank you Suzanne Roynon for that one!) Why? Because whatever Challenges I get set until September 2017 will in no way, shape or form match those that A-T can deal the people and families affected by it. Those that they overcome are far more

challenging and I just want to do something to show how much respect and love I have for them all, while raising vital funds to support the Society that supports them.

If anyone reading this has a challenge they would like to do and would like me to come along and support them while raising money for A-T then Challenge Sara 50:50 for A-T !!! Contact Suzanne or Sophie at the A-T Society and they can pass on the message and put us in touch!

## Walking for A-T - a family affair by Anne Saunders

It was May 2014 after I had taken part in the Hope 24 event in Plymouth when the idea came to me. I thought why not take something I enjoy and from that develop a plan to raise money for a charity that's so important to our family. When my beautiful great niece Gracie was diagnosed with A-T it was, as all families hearing this know, a really difficult time dealing with the heart-breaking news. For the next few years my thoughts kept turning to 'how can I do something to help?'

At the start of 2015 I looked at events I could take part in to set myself walking challenges whilst raising much needed funds for the A-T Society. I've always enjoyed walking and in fact it became a very big part of my recovery

process (on the advice of my physiotherapist) after having had two spinal operations in 2006. Walking gives me time to reflect, time to put things into perspective and at 64 years old is a very good way of keeping fit.

A couple of weeks after making this decision my plans were halted – I had an argument with the solid wooden leg of an armchair, which I lost, ending up with a broken toe! This took more weeks than I expected to heal so I had to postpone my plans. When 2016 arrived, I was even more determined and came up with the idea of taking part in a series of walking events over the space of a year to cover a total of 300 miles. It seemed appropriate to start the series with Hope 24, a challenge



to complete as many 5 mile circuits as you can/want to within 24 hours set in beautiful Newnham Park. I completed 10 circuits including some through the night; a new experience for me walking with only a headtorch to light my way.





I took part in six more events in the following 12 months; the longest and most challenging being the 62-mile Race to the Stones which was a non-stop walk over 21 hours along The Ridgeway ending at Avebury Stones. I've been very lucky to have amazing support from family and friends during all the events and in fact two of them were organised by my children, Matthew and Aimi, who have both been such strong emotional support through all the challenges. Matthew and his wife planned and accompanied me on a 30 mile walk along the SW Coast Path from Millbrook to Fowey. Just a stroll along the coast path I thought – I could not quite believe how many steps there were up from Polperro to the cliff top, followed by many steps back down, to be followed by even more steps back up again and so it continued..... really tough on my legs but such stunning scenery and all pain soon forgotten by the promise of a pint of Cornish Ale waiting for me at the end! Aimi's planned walk was a total contrast – together we walked a 16 mile circuit around Bristol, taking in the Clifton Suspension Bridge, Observatory, Cumberland Basin and many more sights that I've driven past, not realising how remarkable they were. We finished

with a Gin in a Tin at Cabot Tower.....wonderful!

My final challenge, and the most important to me, was to walk the 65 miles from home to Gracie's front door. Over two and a half days I walked a route I had planned using Ordnance Survey and Google maps, with the whole family (including my 8 month old Grandson) supporting me. An emotional journey, a very appropriate finale and with a lot of plugging to friends and friends of friends it (along with the other challenges) has raised money which will be ploughed into research to extend lives and eventually find a cure.

Looking back on the last year and remembering that first 'long' walk I took after my surgery – only three miles (but a very important three miles) – I'm proud of what I've achieved and I'm proud of my family for rallying to the cause and helping me make this last year's 300 mile journey such a success. Every step I took and every penny raised was not just for Gracie but for every young person living with this devastating condition.

My plans for the future? To keep walking and if another challenge presents itself...



## Prudential RideLondon 2016

by Aisling Patterson

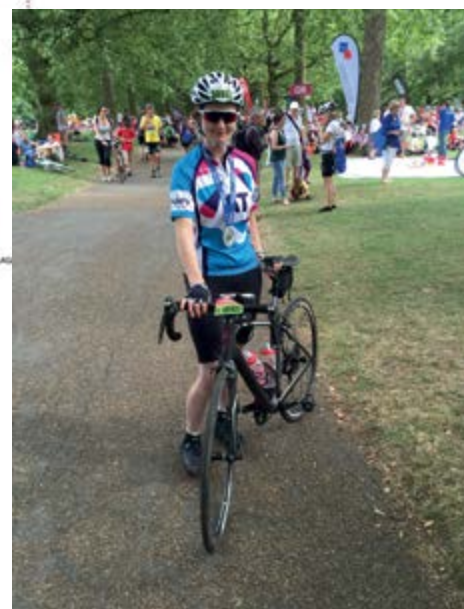
In summer 2015 I set myself a challenge to cycle 100 miles in a day by taking part in RideLondon 100. I had never cycled 100 miles before, my closest was 90 and RideLondon would be a fitting event to reach this milestone. I offered my support to a small charity with a big heart at its centre, the A-T Society.

I went to meet the A-Team, who were lovely, warm and so supportive. They provided lots of ideas for fundraising. We spoke about A-T and their work. I was extremely touched and humbled by the impact and the difference to so many young lives this wonderful charity made, their tireless work and the passion that drives it.

It was new fundraising on my own. I set up an online donation site and sent emails to friends and family pleading with all to part with their money. I hosted a cake sale, baked 100 gingerbread bikes and held a coffee morning, and it all came together. I reached my target on 7th July and I thought 'GREAT I can concentrate on training now!'

10 days before RideLondon, I took a MASSIVE tumble when I hit a band of gravel. I somehow landed underneath my bike and my elbow took the impact and deep gashes, but my first concern was my bike... did I scratch it! No. Phew! One of my cycling buddies suggested I defer my place as I was on antibiotics, but I thought 'NO WAY!' I wasn't going to let my injuries rob me of riding. My fundraising efforts and everything I had trained for and anticipated meant I was adamant to ride.

The day dawned with a very early start on a wonderful course! It follows a 100 mile route on closed roads through the capital and into



stunning countryside made famous by the 2012 Olympics. There are 26,000 riders and the first thing that strikes you about the event is quite how well organised it is. The signage into the starting pens, the marshalling at the start is excellent, loading bays are colour coded, there are porta loos in the pens for those nervous bladders!

I was in awe. I just remember thinking to myself this is it, this is 'RideLondon' hold onto this moment. We set out from the heart of London towards Richmond park with its stunning views and then onwards and downwards to the Surrey hills. The first 40 miles roll

out in front of you, nice and flat. I have never experienced anything like the fast and furious SPEED of the event. Riders need to reach certain points around the course on time or face diversion or even getting swept up as a backmarker. I marvelled at the average speed showing on my Garmin...24mph on those flat miles. I kept thinking I just wanted to make it around the course without incident or injury. It was about keeping safe and staying focused and constant risk assessing.

We soon faced the first and shortest of our 3 big climbs.... Newlands corner, this was a gentle

*continued overleaf*





climb, next up was Leith Hill at mile 55. It is just under 2 miles long. The gradient varies constantly, and the road winds and it's impossible to see more than 100 yards ahead.

Next it was on to Box Hill at mile 65, on its approach crowds gathered and cheered, music filled the air, guitars strumming, all singing 'Sweet Caroline' it gave us a great mental boost.

I must say I enjoyed the Box Hill climb, 3 miles long with an ascent of 557ft. It is a lovely smooth tarmac zig-zag climb, open with stunning views and a pretty constant gradient. It was a pacy climb and there was a feed stop at the top. I wasn't going to stop but then I saw a rider drinking a nice chilled can of COKE! At that moment in time I couldn't have imagined anything better, I was craving a sugar and caffeine hit... so I caved in. I was in HEAVEN with my ice cold can of full sugar and then I was off again.



With the hills behind me there was a wonderful exhilarating descent into Leatherhead. With a warm reception in Oxshott, and a gel or two, I was flying along the route from Esher past the river into Kingston and then on to Wimbledon where we faced our last climb. By now we had completed 90 miles, the end was in sight.

I felt utterly exhausted the pace was so fast and my legs had nothing left to give. It was all down to mental endurance. As I turned the last corner, the cheers from the crowd spurred me on, and I discovered a reserve of energy which pushed me on around Trafalgar Square and that was it.

A moment to savour when The Mall loomed into view with Buckingham Palace in sight. What a moment! It was magical. The cheers from the crowds, the euphoria, road lined with Union Flags, the finish line up ahead! Choked with emotion, the tears welled in my eyes, I couldn't believe I had done 100 miles in a time of 5 hours 52 minutes.

Mostly, I was just thankful to return safely and to have completed the ride for such an amazing and worthwhile charity, the A-T Society.





## Champagne ride

There was excitement, hard cycling, camaraderie and enormous satisfaction on the ride to Champagne, says William Davis

Thunder rolled around the black sky lit up by flashes of lightning, marble-sized hailstone rattled off our helmets and stung any exposed flesh but the flat fields around us offered no shelter at all as we cycled across the French countryside. By the time we reached a village, the road was under a foot of muddy brown water. We took shelter under an archway, from where a kind lady invited us in to drip in her kitchen. 20 minutes later the flood had vanished we made our way to the hotel under butter-wouldn't-melt evening sunshine.

This was a bit more excitement than we had planned on. The ride from St Albans to Epernay was supposed to be a new and original take on the traditional London to Paris or Amsterdam, which we hoped would appeal to potential supporters in the area around our offices, close to St Albans. A couple of days out of the office, a good ride and a celebration feast on arrival – naturally enough, with a glass of bubbly.

The final route was 350 miles over 4 days – with a 3-day option for those who wanted to join at Portsmouth. Two days involved rides of over 100 miles and both the English and the Normandy legs involved a lot of hills.

The group of riders was a real mixed bunch, with people from their 20s to 70s, some family or friends of people with A-T, others with no connection whatsoever. There was an amazing array of jobs too: tour-guide, beauty-



therapist, artist, gas-fitter, publican, social-worker, art-installer to name but a few. Jarno Vannucchi from Erydel, the company involved in the ATTeST trial, had come from Italy to take part.

Most of the group had set off from St Albans Cathedral early on Wednesday morning. Our friends from Pizza Hut had turned up with cheese-on-toast and coffee to wave us off, the vice-dean came out to send us on our way with a blessing and the first swifts of the year flew above us as we pedalled off in the sunshine.

The blessing prevailed and the sun shone all day, without being too hot. Still 104 miles is a long way, especially if the route seems to go across most of the hills in the south-east of England. And Garry and Dave managed to miss a turn and ended up doing an extra 12 miles. But eventually we all met up in a pub in Portsmouth for a more-than-welcome pint and food, only to be told “You’ve only got 5 minutes to eat, before we have to get on the boat!”

Cycling in France was a pleasure. The roads were wide and well-surfaced, with little traffic for the most part. The weather was mainly fine and we rode through green

countryside, with grazing cows and beautiful villages. However France is a big country with lots of big rivers in deep valleys, so there was plenty of climbing to keep us serious. And of course there was that storm and the flash flood.

We stopped every 16 miles or so to take on food and water and ensure that the front-riders didn't get too far ahead. Frances would whip out her sketch book and draw the scene, the well-equipped Jarno, would produce another bit of kit and Scottish tour-leader Kevin would tell us the hills of the next stage were “almost flat - a few wee undulations!”

When we finally rode into Epernay, we pulled up at the Moët Chandon building to take photos with the statue of Dom Perignon. And of course we popped a couple of corks for a sparkling toast, followed by a few more that evening as we enjoyed an excellent celebration meal.



Overall verdict? Hard work but extremely rewarding. And the most important thing of all: everyone raised well over their fundraising target.



## BBC One Show Children in Need Rickshaw Challenge

About this time last year we received a call from the Producer of the Rickshaw Challenge asking us if we might have anyone interested in taking part in the event. He explained that it was a complex selection process with two interviews, a fitness test and psychology assessment as well as an ability to cycle for a minimum of one hour on a heavy trike.



This gave us lots of food for thought, so we put a post on Facebook to ask families to tell us about their teens and trikes. That's the funny thing about our apparently random Facebook posts, you just never know what might be behind our questions!



Just two families responded and both Ebony Robinson and Alecia Yarlett made it through to the final assessment weekend where they met Matt Baker and other young people who hoped to represent a range of different charities. We knew with two girls in the mix we stood a very good chance of one of them being selected and we waited on tenterhooks for another week before the call came...Ebony had made the team!

The summer rushed by in a flurry as Children in Need prepared their website and filmed promo videos of the team members. Kay travelled to Ebony's home in Bournemouth to be filmed and CiN worked with the A-T Society to tell her A-T story online.

It was a real struggle to keep the big secret and quite how Ebony and her family managed, we have no idea!

As we reached mid-October the planning and pre-publicity for the Rickshaw Challenge was complete. We knew the team would be revealed on The One Show on 19th October and Ebony

spent an exciting day in the studio meeting Little Mix and enjoying her photoshoot with the other team members. We encouraged families to watch whilst we bubbled with excitement. With one flick of her long dark hair, a star was born!

On 10th November the special promotional film about Ebony gave A-T the widest TV coverage ever... so far! The donations started to roll in to Children in Need.

The next day Ebony and her mum Lorna set off for Jedburgh on the Scottish Borders, the official start of the 2016 Rickshaw Challenge.

Ebony was universally adored by her team-mates, the crew and the presenters. If anyone thought she couldn't hold her own on the trike, well they were mistaken. She did her bit through biting cold, rain, wind, storms and snow and was regularly doing over 2 hours solid cycling at a time.

Families living along the route came out to support the team with Merry James and Sara Metcalfe (dressed as a Teletubbie) waving the rickshaw through.





Ebony gave the team a fright when the rickshaw hit a large stone and tipped precariously onto two wheels before being caught by TV presenter Matt Baker and brought back to earth. Matt and the outriders were considerably more shaken than Ebony who just laughed!

On Monday night The One Show's coverage focused on Ebony as she cycled with Matt. She spoke candidly about her A-T and the impact on her life and those of the friends she has lost to the condition. She explained how she makes the best of the life she has, knowing her A-T deteriorates every day. Matt was unable to hide his emotions and broke down on camera. There were no dry eyes anywhere. That night alone, the Rickshaw Challenge raised over £1 million.

As momentum for the event grew, the team would stop at schools and to meet people in the towns on route. Each evening the Rickshaw

Challenge featured on the One Show and the nation got to know the six remarkable young people; Andy, Salar, Phoebe, Ross, Olivia and of course Ebony.

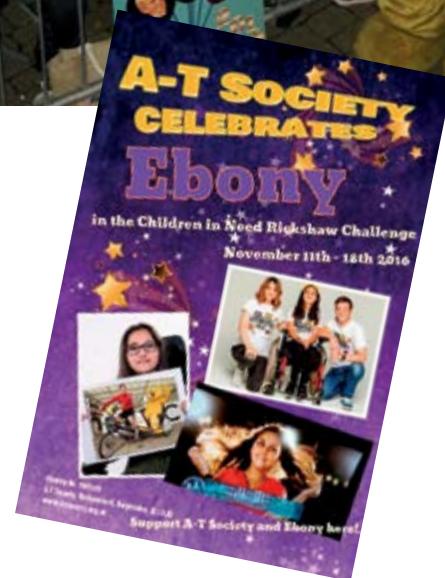
At the end of the daily 10 hour cycle one of the team 'rides in' to the destination for the night. With fanfares, cheers and an honour guard from our friends at KLCC, Ebony's arrival town was Kings Lynn and the Rickshaw was bedecked in pink and sparkles with Ebony's cycle helmet now sporting a pink tiara. Ebony's dad and brothers made the journey to surprise her and the Sprawling family were there too. It was quite a party!

By Thursday the end was in sight and the Airforce Museum at Duxford was the night's finish point. A contingent from the A-T Society and various young Ebony fans were there to greet the team. In the front row was Alecia, on great form as an honorary member

of the rickshaw team who was greeted with hugs all round.

On Children in Need Day the team cruised into London and did a circuit of the sights before reaching their final destination at BBC Broadcasting House. No one wanted it to be over, firm friendships had been made and this remarkable young team had raised over £3.5 million for Children in Need.

Stop Press: If you are attending the Family Weekend in October, Ebony will be telling her inspiring Rickshaw Challenge Story in her own words. Don't miss it, no seriously...don't miss it!





## Making a splash for A-T!

Justine Sprawling and her friend Tracy Dugdale from Dereham swam 22 miles, the equivalent of the English Channel, last September in a swimming pool. They allowed themselves six weeks to complete the challenge, raising money for Brooke and the A-T Society with every stroke!

The pool at Nuffield Health Farnborough was buzzing with A-T fundraising activity in December when Lesley Bromige and the Junior swimmers of took part in a week-long sponsored swim.

Friends Jacky Ellis and Lucy Hodge both took part in a Swimathon, each swimming 5k for Winston and raising money for the A-T Society.



## Classical concert

We had a great start to the fundraising year with a magnificent classical concert in our home town of Harpenden. The Hertfordshire Chamber Orchestra, with our own William Davis on double bass, was joined by conductor Graham Ross and the wonderful and celebrated violinist Jennifer Pike. The concert was a great success and the audience were spellbound by Jenny's lightning fingers and emotional performance.

## Dry January



We had four Dry January fundraisers this year, all enduring 31 booze-free days. Alison Baldwin, Olivia and Adam Langton and Jack Bartlett spent the whole month of January foregoing their regular tipples – they were able to save money, feel healthy and energised AND raise money while they were at it!

It doesn't just have to be alcohol you give up; super siblings Sophie and Matthew did the impossible in 2016 (in our eyes!!). For the whole year, Sophie gave up sweets and Matthew gave up chocolate, quite how they managed this is a mystery to us but we are all in awe of their amazing achievement!







## Every penny counts

One of our young supporters, Flo, donated her pocket money to The A-T Society and was really happy when she received a thank you letter back!

She is planning another fundraiser soon, a cake sale after school. Thanks Flo, every penny makes a difference to us.

## Party, party, party...

Local supporter Jacqui Doyle held a Drinks and Raffle night, everyone enjoyed the wine & cheese on offer and due to lots of fantastic raffle prizes donated, which included beauty treatments, art and champagne, lots of raffle tickets were sold!

A fantastic evening was had by all who attended the 'Fizz' fashion Show in Haslington near Crewe, organised by Sinead Ward.

Jo Betts's Aunt and Uncle had an anniversary party in Nottingham and kindly took donations on the night.

And nannas like to party too! This is our amazing Knitting-Nana Nora proving that it doesn't matter where you are, who you are or how old you are... you can make life brighter for everyone living with A-T by finding your own way to fundraise. Nora and her friends created hundreds of beautiful knitted chicks to raise money.



## We had a ball!

Our focus on building our support in the area around the office paid dividends this year.

Thanks to the hard work of our former Corporate Fundraiser, Eve Audis, the first Hope Ball was held at the glamorous Walled Gardens at Luton Hoo.

Local company, Plowman Craven, agreed to sponsor the event and the auction raised thousands, as well as the blood pressure of those who were bidding in the spectacular auction. Data management company LDex very generously matched the final auction total.





## In the running!

### Brighton Marathon

Jonny Luke, Patrick Turpin and Adrian Johnson ran the Brighton Marathon on 9th April in celebration of the life of Rupert Prokofiev. They were joined by last minute entry, Ed Reilly. The sun came out on the day and Rupert's family were there in force, cheering on our team. This event has been a fixture in our fundraising calendar for a number of years – everyone loves the seaside.



### London Marathon

Adrian Johnson – one man, TWO MARATHONS! Running a marathon is always impressive, but running two is really rather wonderful! Two weeks after he ran the Brighton Marathon Adrian got out there again and ran the London Marathon, sharing his fundraising between us and the Child Death Helpline at Alder Hey Hospital.

Also wearing our colours on the iconic course was Matt Tarr, who completed his first London Marathon and dedicating his amazing run in honour of Rupert Prokofiev.

### Great Manchester Run



After months of training and a huge slice of courage she achieved her goal in Manchester this May.

A-T Society fundraiser and cousin of Cleo Brady, Suzie Hadfield ran her half marathon in style.

### North Devon Marathon



is Marv's first event as part of the Internet Watch Foundation's Charity of the Year fundraising.

Marv Hine ran the North Devon Marathon for Lola and the A-T Society, this is one of the most challenging and visually stunning events in the UK.

### Worthing 10k



She set herself the challenge and she smashed it, raising funds and awareness in support of Orla and A-T research projects with every kilometre!

Running isn't Tracy Coyne's favourite pastime, in fact she actively dislikes it! For this reason running the Worthing 10k was a truly amazing achievement for her.



### Lake Vyrnwy

Simon Roscoe took on the beautiful Lake Vyrnwy Half Marathon for stepdaughter Kayleigh to raise funds and awareness for A-T.



## Colour Run

Our very own wonderful Communications Officer, Kate McEleney, joined by her two young daughters, and husband Pete, rose to the Colour Run challenge in Brighton whilst having a lot of colourful fun along the way!



## Wolf Run

Wild running is THE new challenge in the running world. A Wolf Run is a unique combination of off-road running: mud runs, trail runs and obstacle runs. A hardcore 10k run across raw natural terrain, including open ground, woodland, cold lakes and thick mud.

David and Sean Cole, along with last minute stand-in Cameron tackled the Wolf Run in searing heat this April inspired by James and Rachel Ferguson and everyone with A-T.



## Malvern Ultra

50 miles - all cross country - over the Malvern Hills. Total ascent: two kilometres. Total descent: two kilometres!

That's what the brains behind our "A Game of Two Halves" Chelsea Video, film-maker Tom Worsley did. Inspired by Brae Sewell he took part in the Malvern Ultra in May.

The route goes all along the Worcestershire Way to the town of Malvern - a marathon distance up and down some serious hills, and all off road - then when he got there, he turned around and ran back again. That's two marathons in one go and he was still smiling at the end!



## Hastings Half Marathon

This year we had two runners in the Hastings Half Marathon, Simon Custerwell and Joe Powell did the A-T Society proud by running 13 miles, inspired by Joe's son Winston.



## Climb every mountain...

Last year two brave men conquered the world's tallest freestanding mountain.

A-T Dad, Gary Bromwich took on a mammoth challenge and climbed

to the summit of Mount Kilimanjaro in Africa. This is a difficult and dangerous trek which took Gary seven days but he took it all in his stride late in October.

Gary passed the 'Kilimanjaro baton' to Daniel Fox who also bravely took on the challenge and conquered this 5,882m beast of a mountain for his brother Conor and sister Sarah.



## Giving A-T a dressing down...



Dress-down days have become an increasingly popular way for schools and organisations to raise money for charity. They are simple to organise, everyone can get involved and of course, they can be lots of fun!

Brooke Sprawling's school, **Swanton Moreley Primary** had a dress-down day in February where pupils traded boring uniforms for their own, much more imaginative clothing!

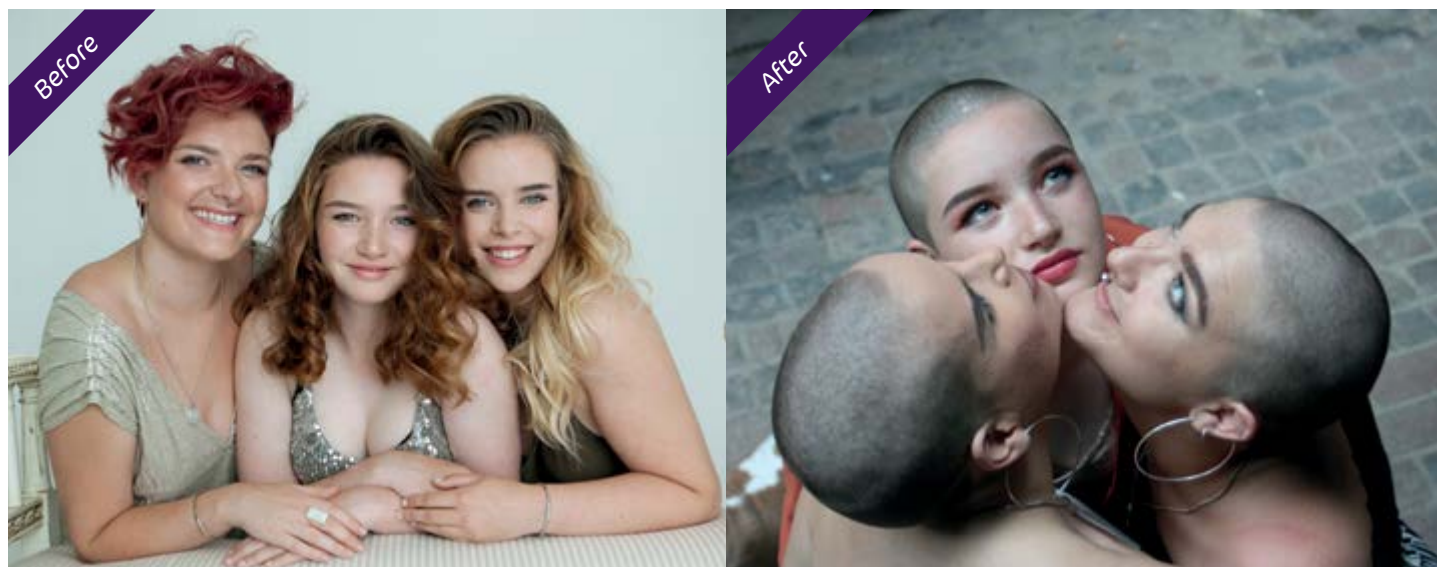
In April Nav Cooper and the Paediatric Department at **Oxford Children's Hospital** had a dress-down day and hamper raffle and Anayah Lee and **Gaelscoil Eadain Mhoir** had fun NOT wearing uniform to school all looking cool while raising money for a great cause. Ask your school to get into mufti for A-T. It's even more fun with a theme.

## Singing their hearts out!



Joy Ferguson and the Concordia Choir have been working their musical magic again! In December, they warmed the hearts of Marks and Spencer shoppers as they sang in-store at M&S Bridgnorth and got everyone in the festive mood! Their support continues in 2017 with a series of concerts in a range of local venues.

## Hair-raising fundraising



Proving that you don't need to run a marathon to raise money for charity, these fantastic folks from Hastings all got shaving!

Three amazing young girls, sisters Alice and Bibi Dindar along with their friend Lilly Cooper, decided to do something exceedingly brave to raise money. They were inspired by their friend and fellow resident of Hastings, Winston, to shave off their hair.

We interviewed the girls to find out more about why they decided to take the plunge and lose the hair!

**Whose idea was it to shave your heads?**

**Bibi:** We all had it in mind then found out about Winston and it was definite.

**Who will be up first when it comes to the big day?**

**Lilly:** Maybe Alice because she's super brave, or me because we'll then build up to Alice and Bibi's massive manes getting sheared off!! Ha-ha.

**What inspired you to shave your heads for charity?**

**Lilly:** Well, firstly I think women have a really hard time living up to today's beauty standards set by the media etc. So to defy them, and find beauty in not what the mainstream media believes, I think will be massively liberating for all of us! And then the idea of shaving our heads for Winston and the A-T Society came about, which was an amazing offer I couldn't refuse.

**How have your friends and family reacted to this amazingly brave decision?**

**Alice:** Some of my friends thought it was crazy and all of family have been very supportive.

**Why did you decide to hold this event at the pub? Do you have lots of local supporters?**

**Alice:** We know a lot of people will turn up to the event and the pub just has a very welcoming atmosphere rather than a hall, venue etc.

**What will you do with your hair after it's been shaved?**

**Lilly:** We're thinking about donating our hair!

**Are you planning any different hairstyles/looks for when your hair grows back?**

**Bibi:** I want to experiment during summer with different colours so when it grows out it can be natural but whilst it's short I want to look like Eminem.



Emmett Ives shaved off his remarkable beard for the A-T Society at The Royal Standard pub in the old town in Hastings.



## Walking on sunshine



The 'Troopers4AT' Team is made up of Lloyd & Sue Evans, Tim & Annette Hughes, Chris Madden and new boy on the block Paul Hughes.

Inspired by Rachel and James Ferguson this wonderful team took on The Bridgnorth Walk, a challenging 22-mile walk starting at Bridgnorth High Street and covering some hilly and often challenging terrain.

In spite of a testing route the terrific troopers smashed their target and triumphed for the A-T Society!

## Skydiving superstars



In support of Brae Sewell Francesca Piccolo took part in a Tandem Skydive with her brother jumping from 13,000 feet over the Palm, Dubai. The resulting photographs had us gasp in awe!

Jayne Rainbow also threw herself from a plane and dedicated her amazing feat of bravery to Lola Bloomer.



## Fighting our corner

Having never boxed before, Roddy Grant took an 8-week intensive training course and then got straight into the ring for a white-collar charity boxing match.

Armed with an impressive level of determination and his new-found skills he went on to win the event for little Daisy Goble and everyone with A-T.

Barry Thomson is currently residing at Her Majesty's pleasure in HMP Shotts in Lanarkshire. He has been a good friend to the charity and organises team fundraising events for us when he can. A prisoner can 'earn' just £11 each week, and many have sponsored more than their weekly wage, making Barry's 2017 team fundraising total of £553.

## Cycling steps up a gear

In anticipation of Sara Metcalfe's 50th birthday she decided to do something rather wonderful: she signed up to take on 50 different challenges to be put to her by friends and family to raise money.

Inspired by her two nephews who both have A-T she came up with this really unique way to raise money for the A-T Society. For her 27th challenge, Sara took part in a Mini Tour de Yorkshire which was a 45km cycle ride on a circular route. Along with some friends and supporters Sara got on her bike and cycled across Yorkshire with aplomb!



The Kings Lynn Cycle Club got busy fundraising this summer. They also did a GoRide challenge to cover the distance from John O'Groats to Paris, some 3838 laps around the athletics track to cover the exact distance.

There were stalls, activities and lots going on to ensure a fantastic time was had by everyone involved!

The following day the club were joined by cyclists from all over East Anglia as they took part in a Sportive event on a route through the West Norfolk countryside to raise money for the club and the A-T Society.

## Christmas cheer

Festive fundraising was in full force with a Christmas raffle held by Lisa Baker at the Elvetham Primary School in Fleet, while Sarah Jackson organised a Christmas Talent Show at Kings School in Worcester and the St Albans Round Table organised a Santa Sleigh Collection.



## New A-T Christmas cards on sale now!

Families were involved with the design of the 2017 Christmas Cards and we think they've done a stunning job. Our three happy angels Hope, Joy and Love will spread their light around the world. Packs of ten cards cost £4 plus postage. We sold out last year, so order your cards soon.

Purchase online from [www.atsociety.org.uk/products](http://www.atsociety.org.uk/products)





## Standing order form

To: {insert name of your bank}

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Bank address: \_\_\_\_\_

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Account name: \_\_\_\_\_

Sort code: \_\_\_/\_\_\_/\_\_\_ Account no: \_\_\_\_\_

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

£3

£5

£10

£25

£50

Other amount

I wish to donate £ \_\_\_\_\_ (please also state amount in words) \_\_\_\_\_

each month to the A-T Society

Please start on \_\_\_/\_\_\_/\_\_\_ and pay this amount each month until further notice.

Signature: \_\_\_\_\_ Date: \_\_\_/\_\_\_/20\_\_\_

### The A-T Society bank details are as follows:

HSBC, 1 High Street, Harpenden, AL5 2RS

Sort code: 40-23-11 Account no. 41248693

### Your details to set up the standing order:

Title: \_\_\_\_\_ Name: \_\_\_\_\_

Address: \_\_\_\_\_

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Post code: \_\_\_\_\_ Phone: \_\_\_\_\_

Email: \_\_\_\_\_

*giftaid it*

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

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

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

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

Please notify the charity if you:

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

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

Please return this form to:

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

# Thank you!

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