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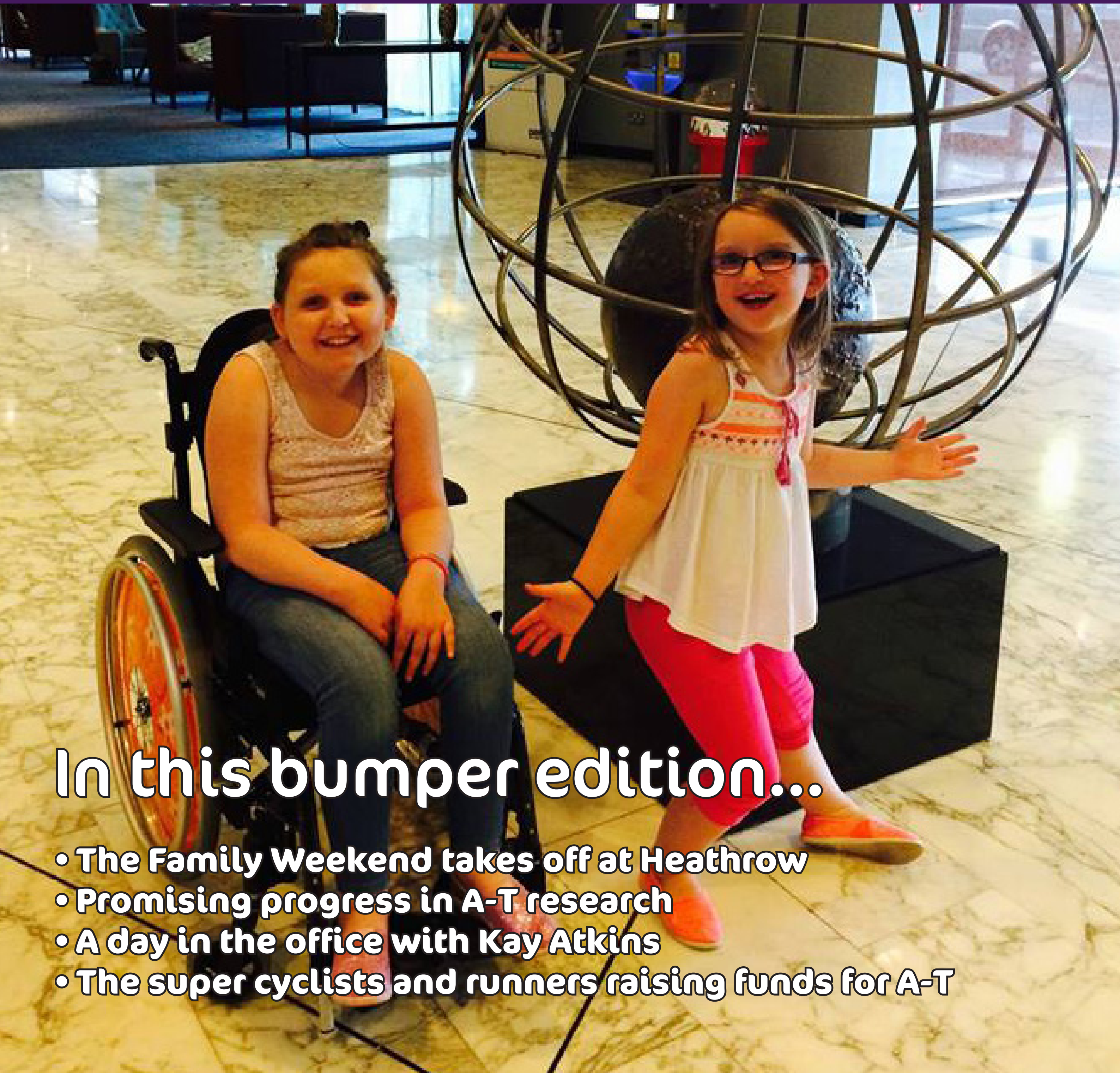
A-T Society News



In this bumper edition...

- The Family Weekend takes off at Heathrow
- Promising progress in A-T research
- A day in the office with Kay Atkins
- The super cyclists and runners raising funds for A-T

AT society
awareness research care

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

The A-T Society was established in 1989 and is committed to helping, supporting and advising families affected by A-T. While they may face more challenges than many, people with A-T have lives to live, and the Society's aim is to ensure they have the support they need to live them to the full. We do this through funding research, providing information, practical support and financial assistance, working to improve clinical management, and raising awareness.

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Editor's Comments

Many thanks to all contributors. The copy date for the next issue is 1st April 2015. Please send comments, ideas, articles and pictures to:

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Cover picture: Cleo Brady with her sister Lola at the A-T Society Family Weekend in June.

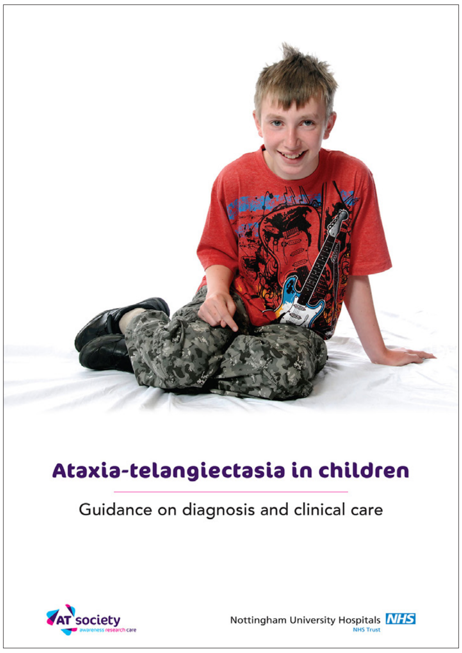
Just William

William Davis, chief executive of the A-T Society, welcomes the publication of a new document that will give clinical guidance on the diagnosis and treatment of A-T – the first of it's kind.

This month, we are publishing the first-ever clinical guidance on the diagnosis and treatment of A-T in children. Now, you may not think that sounds very exciting, but in my view this document could make a very big difference to the health of all children with A-T.

For the first time ever, A-T specialists have set out in detail, in a single document, the care that every child with A-T should be receiving. It specifies which professionals should be seeing the child and how often, and advises them on how they should be assessing and treating those in their care.

Currently, we know that the care children receive between visits to the Nottingham clinic varies hugely. The new guidance will help parents ensure that, in future, their child gets the care that they need, based on the experience built up by the world's longest-running A-T centre.


Ataxia-telangiectasia in children

Guidance on diagnosis and clinical care

AT society

Nottingham University Hospitals NHS Trust

For instance, at the moment many children rarely, if ever, see a respiratory expert, except when they go to Nottingham. However, experience from other conditions that affect the lungs, such as cystic fibrosis, suggests that regular monitoring and aggressive treatment of infections can make a huge difference to lung-health .

Those of you who came to the family day will have heard both Jayesh Bhatt from Nottingham and Stefan Zielen from Frankfurt stressing the importance of lung care. This guidance recommends that every child has a respiratory review every three months, and more often if they are poorly. If we can make this happen it is likely to lead to significant improvements in lung health and to quality and length of life.

The document is written for local doctors and therapists and we will be sending it out to all those that we know are looking after a child with A-T. However, it will also be an invaluable tool for parents to make sure that their child is (or children are) getting the best possible monitoring and care. We will therefore provide a copy to every family. Further copies will be available both in printed form and to download from the website.

This is the first ever document of its kind for A-T and I very much expect that it will be much used abroad, particularly in countries that don't have a centre of expertise. We will be promoting it at the international clinical research conference in Holland in November and through the A-T Clinical Research Network.

It may well take some time and effort to get the guidelines taken up. It will be interesting to see the attitude of local doctors. But the Society will be doing all it can to help make sure they are implemented. We will be looking to parents to tell us when the guidance is not being taken and we will work with them to make sure each child does get the care that they need.

If we are successful in this work, and if the views and experience of experts like Jayesh Bhatt prove right, we could in future look back on this month as a very significant moment in the fight against A-T.

For the first time ever, A-T specialists have set out in detail, in a single document, the care that every child with A-T should be receiving.

Family Weekend 2014 takes off at Heathrow

Around 50 families, as well as friends and professionals, gathered at a hotel in Heathrow Airport in June for the annual Family Weekend. It was a great success, full of informative and inspiring talks.

It was a very busy weekend, with many people arriving on the Friday. The most important aspect for most people was the chance to meet up with others and share their experiences; so we had an evening get-together on the Friday for families (particularly new families) to meet up and chat informally.

The agenda included a number of inspiring presentations featuring adults who live with A-T talking about their sporting achievements and hobbies. The talks covered an incredible range of activities and included a practical wheelchair-football demonstration.

Our special-guest speaker, the Paralympian cyclist Roxy Burns (who lives with mild variant A-T), had come all the way from South Africa. She gave a fascinating and moving account of her life and experiences as an international sportswoman with A-T.

Families and clinicians gather in the lecture hall to watch the talks

The afternoon of research talks included Dr Rob Dineen of the Nottingham CATNAP imaging project, Dr Jayesh Bhatt talking about lung health and Prof Mauro Magnani, from the drug company Erydel, talking about the first-ever large-scale clinical trial for A-T that is being planned. We also had a very useful talk from Jane Flint, who is the psychologist at our Nottingham Clinic, on the subject of how to talk to your child about A-T.

The children were entertained throughout the weekend with a creative workshop, live animal encounter (including snakes and lizards!), giant Wii screens, music and games. For the adults we had a sculpture workshop, back massages, facials and manicures – very relaxing!

The special evening banquet marked 25 years of the A-T Society. We were honoured to be joined by Maureen and Vincent Poupard and their two daughters – one of the families that set up the Society 25 years ago and did so much to help it grow into what it is today. Prof Malcolm Taylor gave a very entertaining talk about the "old days" and it was great to have so many families (old and new) with us.

The evening banquet commences

Between courses, the children were entertained with a disco and games while, for the adults, a magician worked his way around the tables doing close-up magic tricks.

We were also joined at the dinner by the soldiers of 20 Squadron Royal Logistics Corps who gave a presentation of their experience in the Washington Marine Corps Marathon, which raised a very impressive £6,000 for us. They then stayed around for the next day's photo shoot for our 2015 Calendar (*see page 18*) and helped to entertain the children!

It was a fantastic weekend and everyone went away happy and a little tired! In 2015 we will be in the Midlands for the weekend of 6/7 June, so do put the date in your diary.

Fun for all the family (clockwise from top left): Sophie Wood is very happy; fun on the dance floor; Lola Bloomer and Brooke Sprawling dressing up; Gracie Potter the princess with Batman; Jilly Shah trying out the 'Bergan' with Corporal Dan Woodvine; Brae and Brogan Sewell with Dad making friends with a Snake!

Audience moved by sculpture

Sculptor and A-T mother Allison Wilson had the audience in tears when she presented her sculpture to mark the 25th anniversary of the Society at the Family Weekend.

Allison described in moving terms how the inspiration for her sculpture was the family living with A-T and also the support that she felt had always been there for her family from the A-T Society. The forms suggest the mother and father and the baby in the womb while the hand and the circle symbolise support and the hope the Society gives.

Allison also led a sculpture workshop for adults with A-T, which resulted in the production of some amazing pieces. Given that she seems to have unearthed some real talent this is something we may well be looking to organise again in future.

Sculptures made by people with A-T

Alison's sculpture

International A-T patient registry

Because A-T is such a rare condition, with very few countries having a centralised A-T service like the one here in the UK, we have very little idea how many people have been diagnosed around the world. This makes it hard to say with confidence how common particular symptoms are or to see patterns in the way A-T affects people.

There has been a lot of talk over the years about the need for a registry of people with A-T, but now the A-T Society is starting to make this happen. We have set up an international steering group of doctors and researchers and this had its first meeting just before our Family Weekend in June.

A registry is essentially a database of people with A-T. The group aims to set up a registry that will record key details of each person's symptoms and also of the particular mutations that they have. This will make the registry valuable as a research tool as well as building up a picture of how many people there are with A-T and where they are.

To get the project off the ground, we need to be able to employ someone to work on it. The group is applying for funding for this from the European Union. To strengthen the application we are making a joint application with a number of other partners including EryDel, the company planning an international trial of the steroid dexamethasone to treat A-T. We should hear whether we have got through the first stage of the application later this year. Fingers crossed!

Members of the steering group committee for the registry include (from left) Doctors Stefan Zielen, Anke Hensiek and Luciana Chessa.

Respiratory data published

Earlier this year, Jayesh Bhatt and Andew Bush, the two respiratory experts at the A-T Centre in Nottingham, published the initial findings from their work with children with A-T in the *European Respiratory Journal*.

The data comes from 70 children seen over four years, around half of them seen two or three times. What is particularly significant is that the children were seen at scheduled appointments, not because they were ill. This gives insight into what may be happening while the child is seemingly well. In fact, in 9% of the samples taken bacteria were identified and in 32% of samples, viruses.

In the authors' view, the data suggests that all children should undergo regular and routine microbiological testing, even when there does not appear to be anything wrong. They also propose the aggressive treatment of any infection with antibiotics.

These recommendations have been incorporated into the recently published clinical guidance document.

New A-T information leaflet published

Around the time this magazine goes to print, we will be publishing a new information leaflet on A-T. *Living with A-T* is a general introduction to A-T. It is aimed at people who are new to the condition but want to find out what it is and how it affects people living with it.

The leaflet will replace the old *Overview of A-T*. It is likely to be mainly used by people who are finding out about A-T as a possible diagnosis or by the family and friends of someone who has been diagnosed.

It will be available both in printed form and as a PDF that can be downloaded from our website. For now it is only available in English but we hope over time to have versions available in other languages. We will also make the text available to other A-T organisations around the world so that they can translate or adapt it.

New trustees

Since the last magazine went out, we have lost and gained two trustees from the Board. Naz Hussain and Emma Ross have both reluctantly stepped down due to the combined pressures of a new and challenging job and the demands of a young family. They have both made significant contributions to the Board and the Society and we will miss their knowledge and enthusiasm. We thank them and wish them all the best.

We are, though, delighted to welcome two new trustees. Penny Jeggo (*pictured, below*) is a very distinguished scientist, known and respected around the world for her work in understanding the way cells respond to DNA damage. ATM is at the heart of this process. Penny has for some time been chair of our Scientific Advisory Board and now, with a little more time free as she winds down towards retirement, she brings her invaluable knowledge and experience to the Board.

Jill Burder is an experienced fundraiser who, until recently, led fundraising for the national charity Abbeyfield, which provides quality homes and care for older people. She has recently taken up a new position at CAMRA, the Campaign for Real Ale. Good fundraisers are like gold-dust and the Society is very lucky to have Jill on the Board. She lives not far from the Society's offices in Hertfordshire, which is perhaps why she allowed us to twist her arm…

Cambridge project making progress

The ground-breaking research project that the A-T Society is funding at the Gurdon Institute in Cambridge is continuing for a second year. Prof Steve Jackson was granted a year's extension to the project, which is looking at a completely new approach to the treatment of A-T. The extension is jointly funded by the A-T Society and the Masonic Samaritan Fund, which very generously funded the first year's work.

The project looks at whether the problems caused by the absence of the ATM protein, which is produced by the ATM gene, can be relieved by suppressing another gene. While this may sound counter-intuitive, there are good reasons to suppose this might be the case and the approach has been shown to work with related genes.

To test this, the team have to create a colony of ATM-deficient cells and knock out a different gene in each one. They will then treat the cells in a way that would normally kill an ATM-deficient cell, and look to see which cells survive. Any that do will be analysed to see which gene has been knocked out in that cell, and whether the absence of that gene contributed to the cell's survival.

There are many challenges in doing this, but perhaps the biggest is that the team have to work with a form of cell that has only one set of genes, whereas all animal and plant cells have two sets. This approach has previously been used in yeasts, which only have one set.

Creating a stable colony of single-gene cells from a mammal is very difficult and at the very cutting edge of science. However, the team have managed to do this. They have also been testing the technology for knocking out other genes and are ready to proceed with the first screenings. They hope to have their first data by the end of the year.

Of course we can't be certain whether or not genes will be found that when suppressed can relieve the harm caused by the absence of ATM. But if they are, this opens up a potential new approach to treating not just A-T, but a range of other genetic disorders. And, in any case, we are likely to learn much more about the way the ATM protein interacts with others in the cell.

Clinical research conference

November sees the second A-T Clinical Research Conference take place in the Netherlands. This is the second conference in the series established by the A-T Society when we organised the first in Cambridge in 2012.

Whereas other scientific conferences tend to focus on laboratory science and understanding the processes at work inside cells, these conferences focus on how we can use science to treat A-T, and also to give the doctors and therapists treating A-T a chance to compare their experiences.

The programme looks at a wide range of clinical issues and there is space for discussion. The subjects to be worked on include respiratory care, treating cancers, bone-marrow transplant and the use of antibiotics and immunoglobulin replacement.

The Society's chief executive William Davis is chairing the final session to try and ensure that there are clear and positive outcomes from the conference. It will also be an opportunity to promote our new clinical guidance document. Information will be published on our website.

US scanning project publishes results

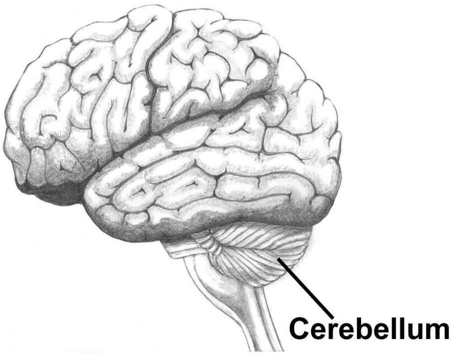
One of the most significant features of A-T is neurodegeneration. Many brain-imaging studies have shown that Individuals with A-T suffer a loss of cells in the cerebellum, the part of the brain that coordinates movement. This loss is particularly high in a type of cell called Purkinje cells.

However, damage to the cerebellum does not account for other neurological symptoms such as motor control dysfunction. This suggests that other areas of the brain are also affected.

In a recent study in the USA, carried out by Dr Nora Volkow and funded by the A-T Children's Project, individuals with A-T were scanned using a type of brain imaging called a PET scan. This measures the level of glucose metabolism in the brain, that is the rate at which different parts of the brain take up glucose, which is the brain's basic 'fuel'. This gives an indication as to whether a particular part of the brain is functioning and whether it is over- or under-active. The study included relatives (siblings and parents) to assess whether having a mutation in one copy of the ATM gene is associated with changes in brain function.

This study is the first to show that other areas of the brain are affected in people with A-T. A significant result showed that there were changes in a sub-section of the globus pallidus, which controls motor function. This could explain the decline in motor control seen in individuals with A-T. The globus pallidus has been implicated in other movement disorders such as Parkinson's disease and offers another potential target for certain therapies such as deep brain stimulation.

Deep brain stimulation is a process in which high frequency electrical stimulation is targeted to certain brain structures in order to improve motor control while minimising any side effects. This treatment is used in a number of neurological conditions including movement disorders and psychiatric illnesses.



Identifying other regions of the brain that are impaired in individuals with A-T provides a further insight into the processes triggered by loss of the ATM protein and gives us more options for developing future treatments.

Bone-marrow transplantation – Professor Zielen

At our Family day we heard from Professor Stefan Zielen, who is a specialist in paediatric medicine at the Goethe University hospital in Frankfurt. His presentation focused mainly on his research on lung disease in individuals with A-T, looking at the different factors that contribute to this airway disease and which treatments work best.

However, at the end of his talk Prof Zielen discussed stem-cell transplantation as a potential treatment for Ataxia-Telangiectasia. He discussed a recent case in which a five-year-old boy with classic A-T received a hematopoietic stem-cell transplant from his younger sister who was a blood match.

Hematopoietic stem cells are cells that can self-renew and turn themselves into a variety of specialised blood and immune cells. They are located within the bone marrow and blood. Hematopoietic stem-cell transplants are routinely used to treat patients with certain cancers and other disorders of the blood and immune system. A successful transplant requires a donor who is a blood match in order to prevent rejection.

Two years on from the transplant, the child has a marked increase in immune cells. This improvement in immunity should in theory decrease the risk of lung infections and therefore improve quality and possibly length of life.

Prof Zielen was upbeat in his assessment, and this case does raise the possibility that bone-marrow transplantation might be a promising therapy for A-T. However it must be stressed that this is only one case and it requires more time to determine whether these encouraging results continue, and what if any impact they may have on the course of the condition.

It must also be said that bone-marrow transplantation is a complex process and incurs substantial risks. On top of that, there is the need to find a matching donor. Nevertheless, this is a very interesting case and we will follow this and any other cases with close interest.

Grants for studying steroids

Earlier this year the three-way A-T research fund – a partnership between the A-T Society, Action for A-T and children's medical research charity Sparks – made two grants to projects based in Italy that are seeking to understand how it is that steroids seem to have a positive effect on A-T.

Professor Claudio Pignata (pronounced "Pin-yata") of the University of Naples has a long interest in A-T. It was his team that carried out the first two studies that showed that steroids such as betamethasone appear to improve the neurological symptoms of A-T. This finding ultimately led to the development of the Erydex treatment (*see page 4*), which is likely to start clinical trials next year.

Prof Pignata believes that the loss of cells in the cerebellum is caused by the failure of the cell's internal cleaning-up process called "autophagy". This critical process helps to prevent a build-up of toxic-waste products in cells and, if it doesn't work properly, cells can die. It has been suggested that the disruption of this process may contribute to other conditions such as Parkinson's disease and Alzheimer's disease.

The ATM protein, which is lost in people with A-T, appears to play an important role in autophagy and it is this that the team wants to investigate. If it is shown that this process is linked to the symptoms of A-T, it will not only increase our understanding of how A-T affects people but could also offer a new pathway on which to focus efforts to develop a therapy.

The fund also made a grant to professors Luciana Chessa (pronounced "Kessa") of the La Sapienza University in Rome and Mauro Magnani ("Man-yani") of the University of Urbino. Prof Chessa, who spoke at our Family Day in 2012 and was present at this year's, led the first small-scale clinical trial of Erydex.

> **In seeking to understand how steroids affect A-T – the only drug so far to have done so – Prof Pignata could make great strides forward in our understanding of A-T**

The project will be carrying out a wide range of tests on cells from people with A-T. However, one particular area of focus will be to test their theory that steroids enable the production of a shortened version of ATM, which is able to carry out some of the functions of proper ATM.

Professor Claudio Pignata

Welcoming the announcement, A-T Society chief executive William Davis said, "We are very excited to be supporting these two innovative projects. In seeking to understand how steroids impact on A-T – the only drug so far to have done so – they can potentially make great strides forward in our understanding of A-T. It's also extremely encouraging for people with A-T to see this collaborative investment in research."

Prof Pignata's project has already started, while the other is due to start shortly. Updates on progress will be available through the website.

Cognitive study nearing completion

Dr Gemma Cummins of the University of Cambridge has been undertaking a study of the effects of A-T on mood and thought patterns in adults with A-T. This is an area that has received little attention up to now, but has a major impact on the day-to-day lives of people with A-T.

Dr Cummins study, which is supported by a grant from the A-T Society, is part of a wider study looking at a number of neurodegenerative conditions, such as Parkinson's and Huntington's diseases. During the study, she has interviewed 22 adults living with A-T and related conditions.

She is currently analysing her findings and will be giving a preliminary report on them at the A-T Clinical Research Conference in Nijmegen, in November. As soon as the results are published, we will be making them available on our website.

Dr Cummins expressly asked that we should give her warmest thanks to all those who agreed to participate in the study.

CATNAP project almost ready

By William Davis

The CATNAP imaging project in Nottingham will shortly be ready to start recruiting participants.

The project involves doing MRI scans of the brains of children with A-T and of others without. MRI scans do not involve radiation so there is no risk to those with A-T. The scans will then be compared to see what is different between them.

The project involves a number of different types of scan. These will look at a number of things. The aim is to identify measures (called biomarkers) that can help us to evaluate the processes at work in the brains of people with A-T and measure the progress of the disease. Biomarkers are a vital tool to enable us to develop and test A-T treatments. They will help us better understand the mechanisms of A-T and potentially show us where to target new treatments. They will play a key role in clinical trials, allowing us to effectively assess whether or not a treatment or drug works.

This project arose as a result of the Clinical Research Conference that the A-T Society held in Cambridge two years ago, inspired by presentations there from related projects in the US and Australia. I organised a couple of follow-up meetings involving the Nottingham team and Dr Kate Sinclair from Brisbane and the project took shape. Cynthia Rothblum of the A-T Children's project very kindly let me persuade her to accept a late application for funding and that was that. The project is now being funded by the A-T Children's Project and Action for A-T.

I was delighted to meet Felix Rausch who has been taken on to carry out the study. The work will be breaking new ground and Felix is currently testing the techniques that he will use. He will be looking for the presence of chemicals called metabolites and at the moment he is scanning these in bottles and using his friends as volunteers to refine the techniques.

The project should be starting to involve people in the new year. In the near future, though, they will be sending out a questionnaire to families of children with A-T asking for their input to the project. They are keen, where they can, to use the siblings of participants as their non A-T "controls".

Given the importance of what is happening in the brain to the course of A-T, and how little we currently know about what is happening there, this is an extremely exciting project, and I for one cannot wait for them to start acquiring and interpreting data.

The team is extremely capable and committed and I think that this could be the start of very significant piece of work.

A-T breathing study helps other athletes

The study by Dr Emma Ross and Paula Elison into the effects of training the muscles used in breathing was completed earlier this year. The findings of the study are now being written up and it is hoped that they will be published by the New Year.

The study found that there were particular challenges for some people with A-T to use the equipment (*pictured*) correctly, but when this was done, the muscle training did increase respiratory muscle strength and quality of life. This benefit was more marked in younger participants. There was a mixed picture of its effects on cough function. There was no measurable improvement in cough strength, but participants reported an improvement in cough effectiveness.

The findings of the study have already been used to help para-athletes in other sports played by athletes with a high level of disability. For example, a study is now being set up to look at the potential to increase performance in Boccia, incorporating many findings from the A-T study.

Once the findings are published, we will be making them available on the Society's website.

Adults' meeting

Before the family day in June, a group of adults with A-T got together for a meeting with William, the Society's chief executive, to talk about how the Society supports them and what more it could do.

The short answer appears to be that broadly the people there were happy with what the Society does. All had relatively active lives, attending the gym and getting out, though obviously this wasn't always as easy as people would have liked. A few were involved in volunteer work, which they enjoyed. One had an ambition to set up a company to run a night-club!

They felt that problems often arose from other people's attitudes, rather than any difficulties that they had directly. For example people often ignored them or spoke to the person they were with rather than to them.

Clearly this is a wider social problem – and not something that the A-T Society alone could do a lot about. Some said that the answer was just to be confident and ignore it. They agreed they would like to see more awareness about disabled people but were unsure how that could be achieved.

They felt that the key to independence was getting the right support in place. If you could get a group of people to go out with, that was particularly helpful. The problem is finding out what is available in your area, as it varies so much, and it isn't always easy to find out.

They valued very much the support they get from being with their peers, eg at Family Weekends or activity breaks and would be keen to see more of the latter – though there was a divide between those who were keen on the more challenging outdoor-type activities, such as paragliding, and those who preferred more social and urban activities.

They also valued hearing about the different things that people were doing – from the newsletter, or from direct communication.

Get your voice heard

If you're an adult with A-T and you have something to add to this, please email or call us and we'll see what we can do to support you.

New leaflet

We have a new version of our basic introductory leaflet, which covers A-T in adults.

Entitled "About A-T in adults", it is available to download from our website, **www.atsociety.org.uk**. Click on "how we can help" and then "publications". If you would like hard copies, please contact us and we will be very happy to send you some.

Special Educational Needs Statements

In September 2014 the new Education, Health and Care (EHC) Plan replaced the old statements of special educational needs. All eligible children who have not as yet had a statement will now be assessed for an EHC plan instead. However, there will be a transitional period of up to three years, during which existing statements can be transferred into EHC Plans. In the meantime current statements will still be valid.

There are a number of changes in these plans. In particular, they are intended to include the child's health and care needs as well as their educational needs. They also aim to give the child and their family a greater say in drawing up the plan.

For more information see links below for Contact a Family or contact Kay in the office.

www.cafamily.org.uk/advice-and-support/resource-library/guidance-on-the-top-children-and-families-bill-myths-part-2/

www.cafamily.org.uk/advice-and-support/resource-library/guidance-on-the-top-children-and-families-bill-myths/

A day in the office: Kay Atkins, family support officer

Many of you will have talked to Kay or had her support in sorting out some aspect of living with A-T. We thought it would be interesting to ask her to describe a typical day in the office.

8.30am – Arrive at the office and first things first – cup of tea to keep me going! Then check in with Suzanne and William to see what is happening and what the plan is for the day.

8.45am – Check and answer emails (about 10 this morning) in order of urgency. Notice one from a family whose child has been admitted to hospital for IV antibiotics – need to check this out with our doctors at Nottingham.

9.00am – A few phone calls between Nottingham doctors and family with child in hospital. Family reassured that child is getting best care and they can call me back if they are concerned.

9.30am – Phone rings – a man in his 20s, who has A-T, has been sent a letter and a form to fill in to review his benefit. Advised him to complete all he can and then send to me so I can fill in the detail about A-T and do a supporting letter to go with it.

9.45am – Start some advocacy work. Today I am writing a letter of complaint to a social services department in the south of England, and asking their local MP to intervene. The local council have taken a year to complete a care plan for a young woman with A-T and it has still not been received by the family. I forward my letter to the MP's office and speak to the case worker there; they are going to contact the council on the family's behalf.

11.45am – Two more phone calls, one regarding a possible support grant application for a wheelchair and another from a teaching assistant at a school looking for information on A-T.

Great, William has bought in some cakes – there goes the diet!

12.15pm – Start a support grant application for a family whose son needs some adaptations to his computer. He has been assessed by the Aidis Trust and we will part-fund with them. I send the application and assessment to the trustees and await their decision.

12.20pm – Phone call from a mother who is struggling. Her son is deteriorating and there are issues around home adaptations and support in school. We talk things through for a while and then think about a plan of action. I offer to call social services and the school to start discussions about what support is needed.

1.15pm – While phone is quiet I take a sandwich at my desk and catch up with the day's news!

1.40pm – I try to contact social services for the family I have just spoken to, and get put through to lots of different departments until eventually I get to speak to the duty social worker. I ask them to open a case for an assessment for the family to see what adaptations they need at home.

2.00pm – I have a discussion with William about next year's Family Weekend: we are looking at the Midlands for 2015 and we need to start looking at venues. We use an outside agency to help us do this and they know our requirements. We make a date to see some venues.

2.30pm – I call a family whose daughter has recently been diagnosed. We've spoken before and now need to sort out some details for their visit to the Nottingham clinic. They have lots of questions and concerns. We make a date for me to visit them at their home and meet them face to face.

3.30pm – Cup of tea and some more emails. I need to sort the next Nottingham Clinic, so I email some families about the arrangements and start booking hotel rooms.

3.55pm – Phone call from a lady whose sister has A-T. She is interested in the genetics and is concerned about starting her own family. I email her some literature and suggest she speaks to her GP about a referral to her local genetic service.

4.10pm – I make a call to a mother who needs a letter of support for her employer, as she needs some time off for appointments and her employer is not being particularly helpful. I promise to do this week.

4.15pm – A man in his 30s calls. He is due to the Papworth clinic soon and needs help with transport. I will pass this onto Caryl (our wonderful volunteer) to sort as soon as she can.

4.30pm – I start to clear my desk, ready for the next day. A phone call comes in, just a quick query from a young lady who wants some information. I sort the outgoing post and head out of the office, leaving a list on my desk for tomorrow morning!

Review of Kindle Fire HD

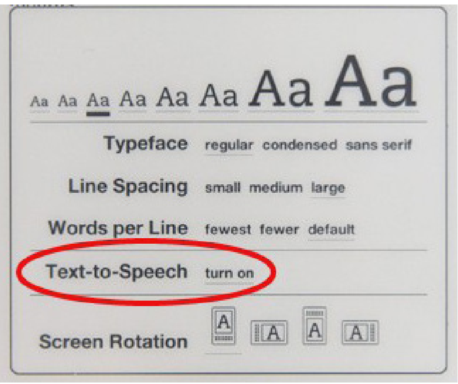
By Ellie Hewitt

I am going to review the accessibility features, focusing on the “Text-to-Speech” function of the Kindle Fire HD.

Owing to my sight problems, I have difficulty tracking and following printed text so the Text-to-Speech function was an essential feature when buying a Kindle. Text-to-Speech is the Kindle’s ability to read a book aloud to you. This is available on most Kindles but is only understandable as a human voice in the Fire models. The voice uses IVONA’s speech engine.

When you open a book on the Fire HD (2013), there are options to increase the text size of the book. These are located by touching a page of an open book and then touching the “Aa” symbol. When you touch “more options”, there is an option for turning on Text-to-Speech. This is different to voiceover which reads out the whole of the screen.

To listen to the text of the book, touch the open page and a bar appears at the bottom of the screen that allows you to play or pause the open page. The one thing people may find frustrating, however, is that when you pause speech and restart it, it restarts from the top of the open page.



Aa Aa Aa Aa Aa Aa Aa Aa

Typeface regular condensed sans serif

Line Spacing small medium large

Words per Line fewest fewer default

Text-to-Speech turn on

Screen Rotation

Personally, I do not find this an issue as I like being reminded of where I am in the book.

One thing that frankly got on my nerves was the American accent and I thought that there was no option for changing the voice. However, a few weeks after purchasing the Kindle, I was playing about in the settings application and found a way of altering the accent to a British one.

To do this, you open up the Apps program and follow >settings >language and keyboard>Text-to-Speech>Download additional voices. It then shows you all available voice engines for you to select. To change the Kindle’s default voice, go to the previous screen and select “default voice”. You will now see a list of all voices installed on the Kindle. Select your preferred default voice and go to a book page. It will now speak text in your preferred voice.

I am a student and as my eye-sight does not allow me to read paper-based study books, the University adapts them to PDF’s for me to access. This works well on a PC using Adobe reader but as Adobe has not yet developed the read-aloud accessibility function for use on the Fire HD, I have found a way to email PDF files via the personal documents section on the kindle.

Every kindle owner is assigned an “@free.kindle.com” email address. Messages sent to this address are sent directly to the documents section of the Kindle, which is located by touching the tab on the top portion of the home screen. To have PDFs converted to Kindle format, attach the PDF file to an email and send it to the “@free.kindle.com” address with “Convert” in the subject field. After doing this, the now converted document will appear in the documents section of the Kindle, where it can be opened and read as a book. This service allows the PDF to be sent over a wi-fi connection and converted by Amazon into Kindle book format. If there is no wi-fi connection, it is sent through Whispernet, Amazon’s 3G, and there is a charge of 20p/MB.

The converted file is accurate and using the Kindle’s voice to read the text is fine. As the conversion process does not allow for diagrams, however, the diagram labels are read out without viewing the diagram. This can be distracting from the main text but personally, as most of my reading is done at a computer, I have found this feature a useful go-between but imagine it would be useful for classroom-based activities.

Another tip I have found useful is locking the screen orientation to landscape. This allows for slightly larger keys on the keyboard so if, like me, you have difficulty in accurate figure movements this makes input slightly easier.

I hope you have found my review helpful and informative!

A-T National Clinic, Nottingham

As you may know, the Nottingham Clinic is now NHS-funded, which means we can offer a much more comprehensive clinic over two days. We hold six clinics per year, with six children seen at each one, so a total of 36 children per year.

However, as we have had many new diagnoses recently we are in need of more places and would like to have at least one extra clinic per year. We are asking the NHS to fund this, but given the tight restraints they are under, it is not yet clear whether we will get it.

For the moment this means we cannot recall children as often as we would like. Ideally we will recall every two years, but with demand for places being so high, this is likely to be nearer to every two and a half to three years.

We appreciate that this is not ideal and if a child is in particular need, we will certainly do all we can to slot them in earlier.

In the meantime we ask that you bear with us and we will keep you informed of progress. We appreciate that, at times, parents have to cancel appointments due to illness and we understand this cannot be helped. However we would ask that where possible you stick to the appointments you are given as spaces are so sought-after.

If you have any queries about the Clinic or your child's next appointment, please do contact Kay in the office. Thank you.

Vitalise respite breaks

Vitalise is a national charity providing short breaks and holidays (respite care) for adults with physical disabilities.

Emily Chanter (who lives with mild variant A-T) recently took a break with them and had a great time. Emily says, "I love going to Vitalise, I really enjoy meeting new people and I like the fact that there are carers to look after you. There are three centres in Southampton, Southport and Essex to choose from."

For more information, go to www.vitalise.org.uk or contact Kay in the office.

Employment and Support Allowance

What is employment and support allowance?

You can get an employment and support allowance (ESA) if your ability to work is limited by ill health or disability. ESA has two elements, contributory ESA and income-related ESA. You may receive either one of these, or both together, depending on your circumstances. (ESA is replacing incapacity benefit).

Recently Kay helped one of our young adults living with A-T sort out a problem with his ESA application. He had been allocated to the "work-related group" rather than the "support group" (which most people living with A-T are allocated to).

"After finding myself having problems with the ESA form (as they don't seem to understand the symptoms and implications of A-T), I contacted Kay to get a letter explaining A-T. I then resubmitted the claim and found that the problem had been resolved – thank you."

Find out more

You can download the following factsheet to find out more about ESA or contact Kay in the office.

www.disabilityrightsuk.org/employment-and-support-allowance-overview

My life as an OU student

By Eleanor Hewitt

Firstly, I would like to thank everyone at the A-T society for giving me this space to tell you about the trials and tribulations of my life as an OU student.

In the last issue of the magazine, I told you I was an Open University student and I had just completed and passed my last level 1 module (which is level 4 of a conventional uni), entitled Health Sciences: A Case Study Approach.

It involved seven books that I listened to at my computer using Adobe reader v9 with the PDF Aloud facility enabled, which even highlights the text being read for you.

The course itself was mostly biology, with a bit of chemistry, physics and healthcare thrown in for good measure. It was primarily about the seven most prevalent world health problems. I took the exam at home with a reader and extra time.

“Yes!!!” I thought, “On to level 2.” I chose my next module: The Science of the Mind: Investigating Mental Health. The synopsis looked intriguing and I thought, “Great, a really interesting course.”

My enthusiasm was short lived. Well, I was right initially on the “interesting” part. However, as the course progressed I quickly found out that the psychology element (on which the course was based!) was not for me. I’m sure others like learning about how people tick but it’s not for everyone. Still, I battled my way on and at the end of May I submitted my end of module assessment.

Cornish adventure

On a different note, I went to stay with my father, who lives just outside Truro in Cornwall. It’s a lovely part of the country with a number of accessible walks. The people in Cornwall are so friendly and helpful and just want everyone to access and enjoy the countryside.

On Portreath beach two people (yes, TWO!) informed us of the Beach Hut where they loaned out one of their two “sand buggies”. This was essentially a wheelchair with huge air-filled tyres that allowed me to go to the sea edge with my Dad. It was great: it made the impossible possible!

The second walk we went on was in the Penrose Estate at Loe Poole. Dad had booked a vehicle called a Tramper owned by Countryside Mobility and rented to various locations in the UK. This was an all-terrain mobility scooter and enabled us to walk for two hours. It was tiring but at least it saved Dad’s back and gave me independence!

If you would like to know more about my experience or would like photos of the vehicles mentioned, please contact me on eleanor.hewitt1@gmail.com. I am always happy to help if I can. Next issue I hope to update you on my studies and tell you a bit more about accessibility with the OU and beyond!

The day I met Forest captain

By Lisa Grigg

I thought that I would tell you about the great day I had when I met Chris Cohen, the captain of Nottingham Forest Football Club. Earlier this year I had won a raffle prize to meet him so me and my nephew Jason went.

We arrived at the luncheon, had some finger buffet food and waited in a room that was set out with tables so the other team players could meet their sponsors as well. The players were introduced, I was nervous and excited as I had only seen these players on television or on the pitch and now I was a few feet from them. We had our photos taken with them and got many autographs. Chris was a very nice person to talk to; he answered all our questions and was one of the last to leave.

I have been a Nottingham Forest supporter for 34 years and this was an excellent day for me and one I won't forget.

Cruising with the stars

By Catherine Marshall

Three years ago, after losing my dearly beloved Mum, me, my Dad and my brother Richard went on a Mediterranean cruise to cheer ourselves up.

Our first port of call was Malaga in Spain which has a beautiful harbour with panoramic views all around. From there we went on to Corfu and Zakinthos, two popular Greek islands, before staying overnight in Venice. Venice, known as the "floating city", is not at all wheelchair friendly as there are a lot of steps to negotiate; I often had to get out of my chair so my brother could carry it up the steps. Before heading home the ship docked at Gibraltar where we had a pleasant morning sight-seeing and shopping.

The entertainment on board the Arcadia was second to none with a show every night, ranging from dazzling West End-style performances to comedy. The food was of five-star quality, ranging from buffets and barbeques to cuisines from around the world. There were plenty of bars and lounges where I could sit and unwind over a glass of wine or two!

On our first night at dinner we found to our dismay that we were sitting by ourselves. But the following night as we appeared for dinner, I recognised a familiar face at the table… It was Sue Holderness, who plays Marlene in Only Fools and Horses, with her husband and sister. I was over the moon to share my table with a celebrity and to be chatting with the one and only Sue Holderness! One evening she gave a talk about her role in TV, theatre and cinema. It was really interesting to hear about her upbringing and how she became famous.

The Lido and Promenade were the main decks for entertainment and relaxation. Getting outside on the Promenade deck was difficult for me because there were heavy fire doors but someone was often around to help. I also used the high-tech gym where I astonished many passengers by getting out of my wheelchair to use the equipment. The looks of bewilderment on their faces were priceless!

There were wheelchair-accessible cabins but we booked an ordinary one as I am not confined to my chair. This meant I had to get out of my chair each time I came in or out as it was too wide for the door!

The staff and crew were very friendly and attentive. While I was able to get around independently, the decks had carpet which made it difficult to push myself along. However staff, and sometimes even passengers, would often give me a push... a bit too far sometimes but their hearts were in the right place!

All in all it was an amazing trip. Meeting Sue and sitting on her table gave me a much-needed boost. The signed photo she gave me and the photo I had taken with her will ensure that I treasure these memories forever!

Clockwise from top left: Catherine with Sue Holderness; Catherine with her dad and brother Richard; the star-studded table

Torch bearer

Ian McInnes (who lives with mild variant A-T) was very proud to be asked to carry the torch for the recent 'Commonwealth' Games in Scotland. He is pictured here with his mother Elisabeth

Making the calendar

“Wouldn’t it be great” said intern Molly Owens during summer 2013, “if we could do a calendar with the soldiers and some people with A-T”. Looking back, it’s funny to think this passing comment took on a life of its own and changed the whole course of 2014.

The men of 20 Transport Squadron The Royal Logistic Corps immediately offered to strip off along the lines of “The Calendar Girls” but were gently reminded the A-T Society is a charity supporting disabled children.... sorry ladies! However, the idea grew over the winter, and with photographer Frances Newman offering her skills gratis, and Bournemouth Colour Press being incredibly supportive about the printing, the plan began to take shape.

Fast forward to March and work experience student Becci Uden met with Frances and the soldiers at Regents Park Barracks to talk through ideas for the Family Weekend photo shoot at Heathrow. Props – including five uniform variations for each soldier, camouflage netting and a landrover – were requisitioned and Sgt. Lilley made contact with Max Gilbert of the Worshipful Company of Hackney Carriage Drivers, a London Cab driver with a particularly handsome Taxi. Various companies and helpful people made or donated props and costumes and The Royal British Legion were happy to get involved.

We realised the project had to be completed in just two hours on Sunday morning, and that to achieve this we needed a second photographer. Step up Andy Wilkinson, who made a great impression at Manchester in 2013 and offered his services without hesitation.

The next months were a hive of activity as the storeroom filled with boxes of Christmas jumpers and Easter Eggs. The Halloween spider was a particularly unwelcome guest! The plan was fine tuned, each month themed, and the shooting schedule finalised. All of the families attending the weekend were invited to get involved.

The Family Weekend arrived and Saturday evening saw Superheroes and Princesses transforming the hotel into Gotham City. It’s no joke trying to get 30 children to look at a single photographer when their parents are all snapping away and the resulting picture (May) is one you will have seen on Facebook soon after the event.

By 9am on Sunday, two studios had been set up and tables overflowing with props were laid out to make the photoshoot as efficient as possible. Children arrived with their costumes, the photographers were ready to go.... but where were the soldiers? Step forward five rather sheepish interns who admitted to hustling drinks from the men until 3am! “They might be a bit tired” said Zena looking as though butter wouldn’t melt in her mouth!

But just a few minutes later the men of 20 Transport Squadron in full uniform marched in to save the day and, with quick changes of kit, raced from studio to studio to help create most of the pictures you will see in the calendar.

The August picture was taken outside, and there was a brief panic when the bicycle for Paralympian cyclist Roxy Burns to use for the Ride London shot was misplaced. While Mac McIntyre hunted it down we chatted to Max Gilbert and admired his cab. You might have seen it during the opening ceremony of the London Olympics when Max drove Spice Girl Geri Halliwell into the stadium, with the roof of the cab matching that very famous Geri dress.

Calendars cost £9.99 + p&p and are the perfect Christmas gift.

Purchase options:

- Online: www.atsociety.org.uk/products
- By card over the phone: 01582 760 733
- By cheque to the office*

*postage depends on the number of calendars ordered so please ring us before sending a cheque.

The landrover was driven into the exhibition hall and, before we knew it, Dads and children were swarming all over it. There was plenty of dressing-up kit to go around and even the coolest of young adults couldn’t resist pulling on the gear and posing for the shot which became the back cover.

The remaining pictures were taken at the end of the morning session and included everyone who wanted to be part of the fun.

We’d like to say a big thank you to everyone involved, and to those families who couldn’t be there but sent pictures to include in the montage page.

We hope you like the calendar and that you will buy many copies to share with your family, friends, work colleagues, teachers, local press....... the list is endless!

Interning with the A-T Society

We have been fortunate to intern with the A-T Society for three unforgettable months! None of us knew what to expect, but we couldn't have wished for a warmer welcome and immediately felt part of the A-T team.

All at different stages of education, we each had our own skills and ideas to contribute. Right from the start, with support and guidance from Suzanne, Kay and William we got involved in the charity's work, and there was never a dull day! Whether in the office, at one of our many events or out meeting families and supporters, we were always kept busy.

The Family Weekend was one of the highlights of our interning. It was wonderful to meet some of the families living with A-T. It made us realise just how important the Society's work for all the families is. From setting up and running the shop to hosting tables at the banquet in the evening, we were always busy but enjoyed every minute of it – can we come back again next year?!

Another perk was going to see the band Chvrches, at Somerset house. As the band supports the A-T Society we were given VIP tickets! It was a fantastic concert and we made sure the A-T banner was flying for the crowds to see.

Skills we have gained

The variety of work we get to do is huge. Along with valuable office experience, we have honed our social media proficiency to keep the charity prominent on Facebook and Twitter. Our aim is to get #ATsociety global! Other interesting and unforeseen tasks include wrapping numerous raffle prizes and assuming the identity of Atey bear! Coming up with innovative fundraising ideas, a key part of the role, helped develop business skills and enterprise, while raising the profile of the charity and its work.

From left: Amy, Laura, Danny, Antonia, Chantal and Zena

Project Pimms

We had great fun putting our heads together to produce the "Pimms Party" pack this summer. "My liaising with the chair of the local cricket club lead to the 'Pimms Party' idea being taken to the next level, and we were able to represent the A-T Society at a huge classic car rally," says Danny. Cue the unexpected task of baking 700 cupcakes and scones to sell for donations at our stall: "I never thought a 24-hour baking marathon would be a part of my internship, but I was so happy to put my baking skills to good use!", says Laura.

Sporting Success

Our role included keeping our enthusiastic fundraisers on track and motivated in the charity's key events this summer, which included the Malin to Mizen Cycle Ride (*see page 30*). Other ventures included plans for next years Mega-Triathlon and the RideLondon100 (book your place for next year now!). Some of us have signed up to take part in events for the A-T Society next year – wish us luck!

We would all like to say a massive thank you to Suzanne, Kay and William who are incredible and made such a great effort to ensure we are truly part of the A-T family.

Our internship programme

Our internship programme has grown dramatically this year, with two students from the University of Hertfordshire, Becci Uden and Beata Micholc, joining us one day a week during the spring.

For the summer we were able to offer university student internships in Research (Amy Roberts), Family Support (Chantal Estevez-Carrera) and Fundraising (Danny McGrinder, Laura Balcombe and Zena Lopez). You may have met them at the Family Weekend.

Each of the interns has provided invaluable support to the charity, whilst developing and strengthening the work skills regarded as essential in many careers. At the same time they have used their hobbies and interests to extend our fundraising, family support and research capacity. Laura's secret passion for baking worked beautifully with Danny's Pimm's events which gave Zena the perfect opportunity to practice her networking!

Amy, who has a Masters and practical experience in bioscience research, has started working with William on supporting our research work and communications.

Finally, Chantal has supported Kay throughout the summer to update the database and help with the complex logistics of the family weekend. She attended a very busy Nottingham clinic and helped William Whitehouse with the video trials for the A-T NEST validation project.

We wish all of our interns success, either on their return to university studies or as they enter their chosen careers.

Fundraising

A close shave for Paul O'Sullivan

Think back to the heat of summer 2015 and imagine what it would have been like to have a "Grizzly Adams" head of hair and beard you could hide your lunch in. That's what Paul O'Sullivan lived with for nine months in preparation for a head and beard shave. The day finally dawned with wife Caroline and daughters Louise, Erin and Megan wondering what Paul actually looked like underneath!

With radio and newspaper interviews under their belts and a huge amount of support from their wonderful, caring community, Paul went under the razor in Woodies DIY Store in Tralee, Co. Kerry – which also hosted entertainment, face-painting and lots of family fun.

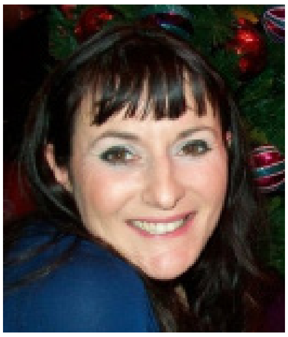
Daughter Louise finished off the day by releasing A-T balloons for all the children who are no longer with us. A thoughtful gesture, which meant the world to her parents and their many Facebook friends.

Paul before (top) and after (bottom) with daughter Erin

Virgin Active fundraiser and Dartmoor Cycle

John Pritchard says: "Many thanks to The Lord Roborough Lodge No 5789 and those from my local community who kindly sponsored these two charity events. The first was at the Devonshire Virgin Active Sports Club, where staff and members joined me for a 10-hour static cycle in March. This was followed in April by a long day in the saddle for me as I cycled 50km over Dartmoor, dodging torrential rain and ponies."

John received fantastic coverage in the Plymouth press, and along with other local Masons has been a great friend to some of our Devon families. We're delighted to work with them again in the future.



2014 has flown by, with more families than ever before asking their friends and colleagues to get involved with fundraising and support for the A-T Society. Clearly those families value the high-quality research we inspire and fund and the support they receive from Kay and want to give something back.

Without your fundraising support, there would be no A-T Society. It's a tough but necessary message to give and we want to be sure we are always here for every family who need us.

The research we fund is making great strides in the care of people with A-T and each new project we inspire or fund brings a cure closer. But no amount of research will help people with A-T if parents don't ensure they attend clinics.

As long as the A-T Society is here, family support and quality research towards treatments and a cure will be our priority.

Suzanne

Mud Monsters!

Running through a quagmire, wading through raging torrents, carrying logs and bog-snorkelling is a new and filthy trend in fundraising. We were captivated by the accounts of Will Preston and his team in the 'Dirty Weekend' at Burghley; Paddy and George in the 'Mad Monk' at Derby; Lisa Capper, Heidi Rudd, Juliet Marshall and Donna Curtis in the Kamikaze Run in Kent; and Siobhan, Nick and Tim in the Total Warrior.

Clockwise from left: Will Preston and Chris Hughes; Kamikaze Run; Siobhan, Nick, Tim, Total Warrior

In brief

- Great friends of the Noscoe family, Tracy Nolan Smith and her niece Courtney (*pictured, right*) climbed Mount Snowdon to support both Testicular Cancer and the A-T Society.
- The Merton Lions FC team are fundraising for us throughout the year.
- Lisa Baker ran a book stall at her local school fete.
- The Lynn Family fundraised at the Amory Road Race motorcycle event in Ballycastle.

Street collections

A tiny reminder to all fundraisers that before you arrange a street collection, you must apply for a permit from your local authority Licensing Office. It is illegal to collect money on public property without a permit so please, if you are planning sponsored walks or any event where you want to carry a collecting pot in a public place, make sure you have permission to do so.

St Patrick's fundraiser

The St Killian's Gaelic Football Club organised a charity night of music, feasting, Irish dancing and an enormous auction in Whitecross, Co. Down, Northern Ireland. The whole community came out to support the Boyle family and celebrate St Patrick's Day in uniquely Irish style. Truly a weekend to remember!

Kerrie's spectacular skydive

Jumping out of a plane on your birthday wouldn't be everyone's idea of a good time, but for Kerrie Palin it was the perfect way to mark a special day! At the same time she raised money for research towards a cure for A-T. A job well done Kerrie!

Santander Hyde and the Phillips family's big BBQ

A chance conversation between mum Sylvia Phillips and Kirsten Day, the manager of Santander's Hyde Branch, resulted in the bank choosing to support the A-T Society for their Easter fundraising raffle. Dale Phillips, who has A-T, tells us the story:

"On 28 June we hosted a big charity BBQ.The ladies from Santander did lots of baking and arranged a gazebo, which came in very handy!

"The day was a great success with a raffle, cake, book stalls, and even a magician who was very good. The cloudy weather didn't put anyone off and we entertained 60-70 people, raising more than £1,300 on the day. We couldn't believe the generosity of our brilliant friends and neighbours and were so pleased to have done something special for the A-T Society."

Fizz Fashion Show

The North West is quite a hub for fashion, so Sinead Ward backed a winner when she asked Fizz Fashion of Manchester to show off their stunning range of clothes for a keen audience in Cheshire. The ladies revelled in purchasing from the summer and autumn ranges, with many 'mother of the bride' and 'races' outfits taking pride of place in their wardrobes.

Georgette Butler – The Virgin London Triathlon

Back in January, Georgie and her friend Claire signed up to take part in the Virgin London Triathlon. This event isn't for the faint hearted and the girls set out to raise money for the A-T Society and Macmillan Cancer Care. Unfortunately Claire had to pull out, but determinedly pushed on with fundraising and encouraging Georgie with her training. Georgie was delighted with her achievement and her incredibly hard work paid off for both charities.

24-hour snooker marathon

Daniel Fox and his good friend Phil Browne pushed themselves to the limit in March when they played snooker non-stop for 24 hours at the Setanta GAA club.

The Prudential Ride London 100

By Frances High

You may remember a call in early 2014 for cyclists to take part in the Prudential 100-mile charity race and raise funds for the A-T Society? The route was similar to the Olympic route, starting at Olympic Park and ending in Pall Mall via Surrey and its hills, cycling initially through the City and central London with all the roads closed to traffic.

Our own chief Executive, William Davis, took up the challenge in the previous year and was prepared to do it again – so I signed up, having no idea that there would be a limit on the amount of time allowed to cycle the 100 miles. Imagine my horror when I filled in the form, to find that 8.5 hours was the maximum time allowed – this meant a speed of at least 12 mph. So no slowing down or stopping for lunch!

Nevertheless, this account is intended to encourage people to consider it for next year. Before 2014, I was an ordinary cyclist, past my prime, who used my bike to get from A to B. I had enjoyed the odd week's cycling holiday of up to 50 miles a day, with stops to eat Mars bars and look at the view. By the time I had succeeded in crossing the line on 10th August within the time limit, I had joined a cycle club; bought the full lycra regalia and a better bike; started wearing my helmet more correctly and learnt to eat energy gels and drink water while riding! This was a life-changing experience and at times really exhilarating!

Clockwise from top left: 6.30am and worried at the drop-off point; greeted by friends as I passed Tate Britain; meeting Graham at Leatherhead; sodden about halfway round; about to go over the finishing line in the Mall

Training

From May to August, training dominated my life. The organisers sent out a series of magazines with advice on training and diet as well as practical plans about the route. They advised getting some cycling practice with a group. So I joined the Sidcup cycle club and tried to do their Saturday morning rides as often as I could – three to four-hour trips into Kent or along the Thames. This was useful as the leaders and many members had so much experience and the bike shop itself became my Mecca to check on correct footwear and wet weather gear and procuring easier brakes.

I was now in the cycle club email circle and intrigued by the conversations – especially those between the advanced riders (the ones who cycle at 18mph). A number of them took part in the Prudential 100 and I was amazed when in one email there was the question about what someone's planned 'rate' would be - the answer was 145, which turned out to be 'heart rate'. I can thank the club for getting me cycling quicker, not getting off and walking up the hills and understanding the concept of cycling as an athletic sport.

I was staying in Norfolk in May and set out to do fast, one-hour rides every other day as a readily do-able bit of training. The lanes I chose were quiet and I could vary my routes; I kept going throughout the hour to try to beat my times. I followed the Prudential instructions to cycle in lower gears with my legs going round more quickly (this was in complete contrast to what I'd always done before – getting into higher gears as soon as I could and pedalling in a more leisurely fashion – which apparently tires the legs more and is actually slower overall).

In May my sister Katy and I did the Coast 2 Coast ride in four days (140 miles from the west to the east of England across the Lakes and Pennines) in order to get some hill practice and longer distances.

The day of the race

It was a very wet day with winds brought by Hurricane Bertha. Even before the start, as cyclists rode from all directions to the Olympic park, people were stopping to mend punctures! – but not me thank goodness! I finished the Ride feeling fine and arrived in Pall Mall at 4pm in sunshine. There were over 20,000 riders.

It took me 7 hours 38 minutes though that wasn't all cycling as we were forced to walk about a mile through Richmond Park where the road had become a dangerous torrent of rainwater. In fact the whole ride was more about coping with the weather than the famous Surrey hills as the organisers decided to cut out Leith Hill and Box Hill because of the danger of descents in the wet conditions. This reduced the distance to 86 miles, but with wet feet and indistinct view through my dripping and clouded glasses and some riding through water up to knee-deep, we had a different challenge. My time was quicker than I could have hoped though some completed it in less than 5 hours!!

It was intriguing to see what difference training can make as I had no previous experience of anything similarly physical. So – the message is: If I can do it, so can anyone who can fit in regular cycling in the 12 weeks leading up to the event! And well done William, who was much faster than me and apparently cycles on jam and peanut butter sandwiches!

The Sewell Fun Day

Brian Sewell and fiancée Siobhan Kelly took great delight in organising their Annual Fun Day in Croydon in early September. With their amazing extended family and masses of friends, it was always going to be a towering success. And with guest appearances from Commonweath Middleweight Boxing Bronze Medal winner Connor Kelly and Rough Copy – who made a great impression on their fans and cornered the market in 'selfies' – it was certainly a day to remember.


FAMiLY FUN DAY

In Aid of Brae Sewell
who has
Ataxia Telangiectasia,
a rare Degenerative condition.
Our goal is to raise as much money as possible
to raise awareness and one day a cure,
to donate to the A.T.Society.....

Food + Drink to purchase

Fun events throughout the day:

Bouncy Castle, Wet Sponge, Penalty Shootout,
Face Painting, Raffles etc.
D.J. Disco and BBQ in the evening.

Date: 06-09-2014
Time: 3pm - 11pm
Place: Sir Phillip Game Centre
38 Morland Avenue
Croydon
Surrey CR0 6EA

Katie's Great London Swim

Katie Poupard trained hard all summer to compete in this fantastic event and was one of 2,500 very disappointed swimmers when the event was cancelled at the 11th hour due to problems with water quality in the Thames. However, with typical Poupard determination, Katie went to the outdoor, unheated Parliament Hill Lido and without a wetsuit, despite intense cold, completed her swim in a time of 33 minutes 17 seconds.

Knitting Nanas

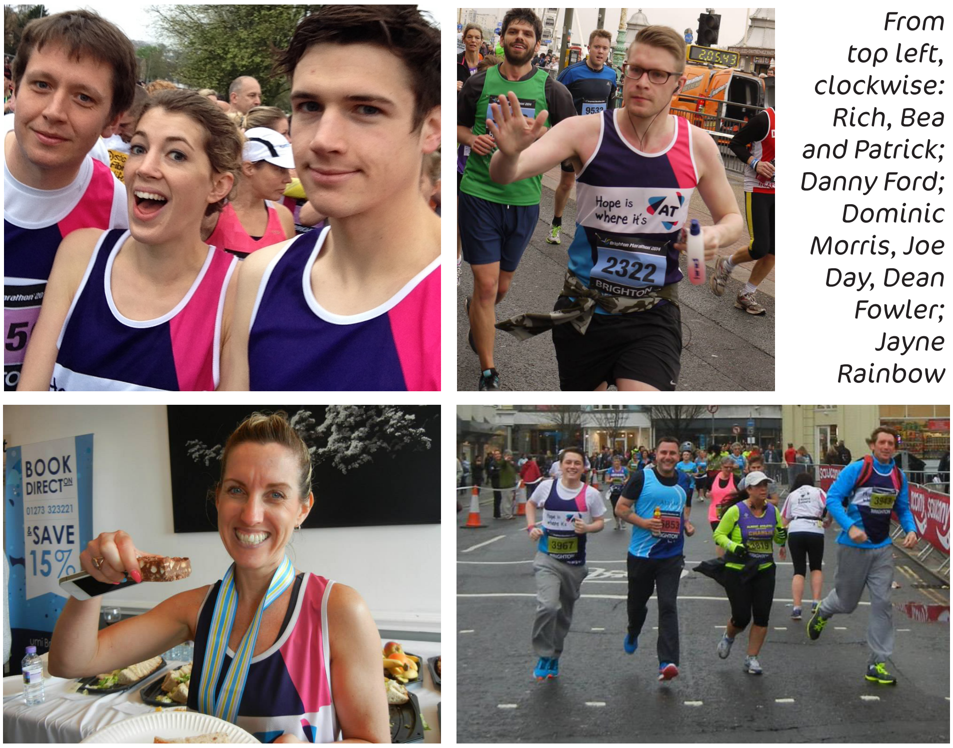
If you think Magner's cider is the only export from Clonmel, Co. Tipperary, you'd be very wrong indeed! The A-T Society's very own Knitting Nanas – Nora O'Donnell, Nellie Maddon and Margaret Ryan – cornered the Easter market with numerous baskets of eggstremely popular chicks! You'll be glad to know the Nanas have promised they'll knit more.

Marvellous Marriages

Two lovely couples tied the knot and dedicated their wedding favours to the A-T Society. We wish Karin and Kevin from Derry and Karen and Timmy from Widnes the happiest of lives together.

Terrific 10 take on the Brighton Marathon

By Dan Colombini



From top left, clockwise: Rich, Bea and Patrick; Danny Ford; Dominic Morris, Joe Day, Dean Fowler; Jayne Rainbow

On Sunday 6 April, a team of 10 runners gathered in Brighton to raise money for the A-T Society by attempting one of the most gruelling physical challenges they would ever undertake. With a stunning backdrop of the sea, all involved felt they were about to partake in something special.

“Amazing, inspiring and challenging” was how runner Beatrice Prokofiev described the experience. Although she did not get off to the most encouraging of starts. “I felt awful on the morning of the race as I’d hardly slept the night before,” she said. “But five minutes before the start I began to feel really excited!”

And so the tone was set for the A-T Society runners who had decided to put themselves through the paces for 26 miles in and around the Sussex coast. The morning was overcast and cool: conditions that appeared to be well received by the runners (the spectators looked a little more concerned!) as they made their first strides of what was to be an enthralling and – for some – somewhat painful afternoon.

Caution was the order of the day as the race got underway. “I had never actually run that far before in my life, so I knew that I was going into the unknown,” said runner Richard Luke, who has family ties with the Society. “I tried to calm myself down by remembering I was doing the marathon for such a good cause.”

Nerves were quickly cast aside as the runners picked up the pace and found their stride, urged on by tremendous support from friends and family. “The support from the A-T society was amazing! It really gave me a boost,’’ said Richard. “There were some long periods of the race where we were away from the town centre and the spectators. I looked forward to coming back into the town because I knew hearing people cheering would give me a boost. The A-T Society banners really stood out and I couldn’t help smiling, despite how tired I felt inside!”

Fellow runner Jayne Rainbow was also inspired, despite some worrying moments as the miles increased. “The support of the A-T Society was absolutely amazing! It really spurred me on. I didn’t see much of the other runners as they were quite a way ahead of me. I hit a wall at the 14/15-mile marker and was quite tempted to hail a taxi! But I just remembered the words of my eight-year-old daughter and all the money my friends and family had donated. That kept me going.”

Refreshed from the light rain, the runners made their way back to the seafront. Steely determination filled the air as the runners pounded the concrete, the finish line now agonisingly close – a sight that, for some, seemed to unearth unknown reserves of much-needed energy. Bea explained: “As we approached the finish line I felt really elated and actually sped up! Later, when I looked back at my timings online, I found out that I ran the last 5km faster than the rest of the race!”

As the runners charged across the finish line, expressions jumped from relief to delight as the magnitude of their achievements sunk in. The sun came out and everyone congregated in a nearby bar to reflect on the day’s events.

“If I had to sum it all up in three words,” said Jayne, “it would be rewarding, exhilarating and emotional.” Richard agreed: “I had expected to think ‘never again’ but actually it’s inspired me to run more. I loved the weekend and felt like I’d joined quite an exclusive club of marathon runners.”

Beatrice, Richard and Jayne were joined by Sarah Bradbury, Dean Flower, Danny Ford, Dominic Morris, Adam Murry, Bill Salkend and Patrick Turpin, who together raised a total of £13,000 for the Society. A huge thank you and congratulations to all involved!

Charity of the year

Pentagon

We have had a lot of fun working with the Pentagon Centre in Chatham who, with their PR Team, have been running events throughout the year to involve and amuse children and adult shoppers alike! We are very grateful for the support that we have received, and for the opportunity to raise awareness in an area where there are several families.

With the Model Search competition soon to come to a close, Alecia Yarlett has been chosen as Model Search Ambassador for the Pentagon Centre. Staff and customers have continued to support us throughout this 2013 and 2014 partnership and we are very grateful to them all.

Harpenden Cricket Club

A networking event gave intern Danny the opportunity to meet Geoff Newman, the chairman of Harpenden Cricket Club. As a result the team adopted the A-T Society as their charity for 2014 and have promoted our work at Pimm's events through the summer.

Sainsbury Stockport

The people of Stockport nominated the A-T Society as their local charity for 2014/15 at the Warren Street store, in support of Cleo Brady who lives nearby. Amy Wynne and her colleagues are fundraising hard with many in-store events and by taking part in a distance cycle event from Nairn to Newry.

George and Alecia at the Pentagon Mascot Races

Danny with Geoff Newman

Dill Cruise and Luke Whitehead

Burnley Lions

The plight of a local family came to the attention of Frank Seed of Burnley's magnificent Lions Club, who not only wrote a wonderful article about A-T for the Lion Magazine, but also selected the A-T Society as their charity for 2015. Intern Zena, who is at the University of Leeds, will be working with the Lions throughout the year.

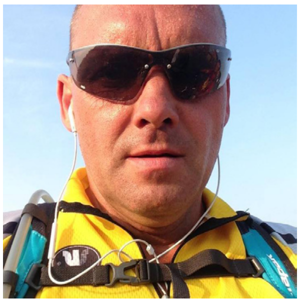
Great North Swim

Glen and Nick Walsh and Siobhan Pope continued the intergenerational family rivalry with the Great North Swim 2015. Siobhan then kept up her training with the Great Manchester Swim before joining Nick and friend Tim in the Total Warrior event.

Glen, Nick, Siobhan

Cycling

Applause to Brian Sewell for the London to Brighton ride, Mark Macauley for the Great Notts Bike ride and to Stephen Rafferty who climbed every mountain between Paris and Geneva on a marathon cycle ride across Europe.



Left to right: Mark Macauley; Brian Sewell; Stephen Rafferty

Sister Kate A-Tribute Fund

Ayo Akinola explains why the family set up an A-Tribute fund in memory of her sister: “Catherine, or ‘Kate’ as she was fondly called, was known for her big smile and infectious laugh! She was fearless and had a great sense of humour. Every day was filled with laughter and she would never turn down a ride on the tallest and fastest roller-coasters!!

“This year we decided to create A-Tribute fund for her, to raise funds in her memory so that other families can benefit from the great services that the A-T Society provide – enabling them to smile together for as long as possible. We planned a fun day at our church and a group of friends climbed ‘Up the O2’.”

Keep on running

There have been so many wonderful runners out pounding the streets, fields and footpaths in support of the A-T Society. We don't have pictures of everyone, but we'd like to congratulate:

- **Alison Grice**
  Fleet Half Marathon
- **Dave Kelman and Megan Edwards and Vicky Stacey**
  Plymouth Half Marathon
- **Sarah Bradbury** was pregnant when she achieved a scorching time in the Brighton 10K
- **Denise Ganley, Daniel Fox, Wesley Macdonald, Adrian Gentry, Anthony Cross, Sarah Holliday, Molly Owens, Laura Airey, David O'Connor and Amy Roberts** British 10K London Run
- **Aideen and Rosaline Mallon**
  Rock 'n' Roll Dublin Half Marathon
- **Fiona Bell and Kate**
  Great North Run

Walks

Tim Hughes and his intrepid team took on the Bridgnorth Walk on a beautiful May Bank Holiday Monday. For the friends of the Ferguson family, this annual walk is a sure sign summer is on its way.

Siobhan Kelly and 30 friends (*pictured, right*) jumped on a big red bus driven by fiancée Brian Sewell to reach the start of their Clapham Common to Purley Sponsored Walk. Little Brae managed to walk a good part of the way and his parents were incredibly proud of him. Siobhan and sister Ciara tell us next year's walk is already being planned, so pull on your trainers and contact Siobhan on Facebook if you'd like to take part!

Clockwise from top left: Aideen and Rosaline Mallon; Sarah Bradbury; Dave Kelman; David, Daniel, Wesley; Molly and Laura

A-Team kids take the lead!

Hooking ducks with Orla

Little Orla Ward ran the 'Hook a Duck' stall at Haslington Village Fete with the assistance of mum Sinead. Sinead has teamed up with Clare Gallagher, another A-T mum who lives nearby, to organise bake sales and bag packs in Crewe and Nantwich through the year.

The Dip at Deal

15-year-old Hayden Day clearly has a bit of a thing for cold water. Not only did he take part in the Ice Bucket Challenge, he also threw himself boldly into the Arctic conditions of the North Sea on Boxing Day dressed in a Pikachu onesie!

Easter Toddle

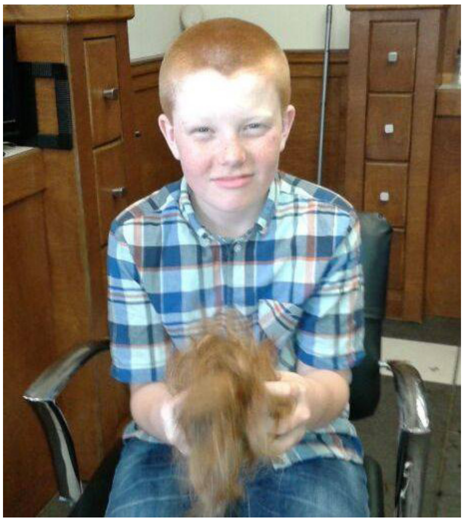
Brooke Sprawling is getting very grown up now, but being a mature 6-year-old does not prevent her from leading the way in the annual Norfolk 'Easter Toddle' organised by mum Justine.

Melissa Cake Stall

Not to be outdone by big brother Hayden, Melissa Day and her friend hosted a cake stall at school and made mouths water with their sweet treats.

Saul Gray Head Shave

13-year-old Saul wanted to find a way to help little brother Kaid, and hit on the idea of growing a Beatle-like mop of hair and then getting Dom's Barbers of Carlton to shave it off! Saul explains, "I have seen how A-T has devastated Kaid's life. I want him to live longer and I want to help other people with A-T. I decided to do this because I have seen my little brother get a lot worse in the last year and I did not realise how bad it would get. It's hard to know he may not be here when I grow up, so I want to raise money now towards finding a cure for this horrible condition."



Ice Bucket Challenges

Many wonderful families and friends of the A-T Society threw themselves into the Ice Bucket Challenge around the country. We saw some terrific videos, heard lots of special thanks for our work, and received many donations. There are too many brave people to mention by name, so if you took part in the Challenge and nominated the A-T Society for your support, we'd like to say a huge thank you!

Walk to the City Ground

95 friends joined Mark and Hayley Carrington, along with daughter Kira, to walk 15 miles from Sutton in Ashfield to the Nottingham Forest Football Ground. Mark said, “This is the second time we’ve done the walk and the support we get is overwhelming. We just want to say a really massive thank you to everyone who took part and sponsored us. We’re looking forward to next year!”

Indoor skydivers

A-T was no barrier to 16-year-old Jordan Lyon and 18-year-old George Keith, who celebrated their birthdays in style by with sponsored Airkix indoor skydives. Jordan went to Manchester and George to Milton Keynes. Both loved their weightless experience and were really chuffed to be able to give something back to the A-T Society.

Jordan in flight (top) and George presenting his donation to Suzanne (bottom)

Brian and Michael’s magnificent cycle ride

Brian Freeston and Michael Sherwin planned a sponsored cycle from Manchester to Widnes in just three weeks. They wanted to support the A-T Society and celebrate 8-year-old Jake Noscoe having a new adapted trike which will enable him to experience some of the independence his friends have. Brian and Michael were joined by Jake for the last part of the cycle and he powered first across the finish line at the Mersey Hotel.

Premier Pensions Management

Zena and Danny were lucky enough to attend the Premier Pensions Croydon Golf Day at the Surrey National Golf Club. The event was held to raise money for Premier’s three chosen charities, of which we are thrilled to be one. Despite the tropical rainstorm which halted play early, it was a terrific day and everyone in attendance had a great time. Danny was invited to say a few words about our work and Zena chatted with the golfers until they were able finish their rounds after the rain break. We’d like to say a massive thank you to Premier Croydon, David Little, Simon Payne and everyone who attended the event.

Malin to Mizen: Ireland’s miles more beautiful

By William Davis

Under starters orders (from left) Mark Cullen, William, Jude O’Reilley, David Murtagh, Ivan Bennett, Shane Crossan, Micheàl Mac Giolla Bhride, Paul Hughes and Penny and Donna (who weren’t riding for the Society)

When Suzanne first suggested organising a cycle ride from the northern to the southernmost points of Ireland, I thought, “Yes, I’m up for that.” Seeing the beauties of Ireland at first hand and ‘rehydrating’ with a pint or two of Guinness in the evening? What more could you want in a fundraiser?

Having done the Ride London 100 last year, I knew I could do a long distance in one day. However as the start got closer, I became nervous as to how I would cope with doing this day after day. And how would I get my bike over to Ireland without taking it to bits that I wouldn’t have a hope of putting back together?

That all proved a doddle though, and on a September Saturday morning I found myself at Belfast station with a group of cheerful people from across Ireland and Scotland loading bags and bikes into vans for the three-hour drive up to Malin Head.

With the wind in our hair (in my case strictly metaphorically) and the dramatic coastal scenery, we could only feel energised and excited and after soup and sandwiches we were off. There isn’t room to describe the journey, but we had six days of glorious green landscapes. We were very lucky with the weather – not a drop of rain fell and the wind was with us. The route was chosen to avoid main roads (and steep hills!) as much as possible, so there was little traffic. And the road surfaces put those in the home counties to shame – meaning no problems with saddle-soreness!

William with Megan and Erin O’Sullivan

The organising team from Sport Ecosse were brilliant and efficient, making it feel as if the event was organised around you, not you fitting into the event. The re-fuelling stops were regular and the hotels comfortable and close to some excellent pubs!

But what makes a trip like this special is the people and I was privileged to be travelling with a fantastic group. The majority were friends and family of Greg Crossan from the Republic, who as it happened was in London for an operation to help his A-T. But there were also friends of the McCann’s in Dungannon. There was a mix of ages and levels of experience, but a great atmosphere mixing banter with support – and in the evenings liberal (but entirely ‘scientific’) dosings of the black stuff...

I will admit I hadn’t realised Ireland was so big, but when we got to Mizen Head and saw, in Seamus Heaney’s words, “the secular powers of the Atlantic thundering”, it was an exhilarating yet moving moment; a great sense of achievement mixed with thoughts about why we were doing this. Nevertheless, we celebrated with chocolate cake and spumante.

If the idea of doing this yourself sounds appealing, do get in touch – even just for a chat. We would love to run another, if there are enough people. You will need to train, but you don’t need to be an expert cyclist. And however it goes, you will have a memorable and rewarding week. Would I do it again? If I could persuade people to re-sponsor me, yes, I would!

Fergus and Danny

Fergus Loughrey, a friend of the McCann family, and Danny McAllister weren't prepared to wait until September for a chance to ride the Malin to Mizen route, so instead they hit the road over Easter. Having just graduated, they made the trip on a budget and camped overnight wherever they found a welcome. In just four days Ferg and Danny traversed Ireland and arrived on a slightly soggy Mizen Head a day earlier than planned. Ferg said, "It was an absolute slog, but what an amazing trip and I would absolutely do it again!"

Eoin Woolley

Eoin Woolley, who knows Brendan Maunsell well, was keen to join the A-T Society ride but his commitments made this impossible to achieve. Not to be defeated, however, he turned the route around, cycling from Mizen to Malin.

Eoin explained, "I had the route planned, engaged two support drivers (my Dad and my wife), booked accommodation and teamed up with a friend to cycle with me a few miles from Cork to Mallow and another friend in the North to cycle from Bucranna to Malin Head. I had no punctures or mechanical issues, and although my legs were a bit sore they were back to normal in a day or two".

Open Garden

Robin and Judy Hewison with granddaughter Jenni Gallagher worked hard through the spring months to open their exquisite Somerset garden for us in June. This rose-filled, enchanting oasis in the village of Dunster ensured a large number of visitors on the day.

Celebrating Nicole

The Matthews Family celebrated what would have been Nicole's 21st Birthday with real panache. Her twin Natalie and mum Julie planned a fabulous butterfly themed fundraising party in Aberdeenshire. The community turned out to support them and donated an enormous raffle with rare and unusual prizes. The family are continuing their fundraising through 2014 with Dave and Laura both planning fundraising events.

Tracy Koulouri and the Corfu ladies

Young Andreas Vlassi's bravery following his A-T diagnosis won the hearts of the Corfu expat community, and Tracy Koulouri, Susan Kaloudis and Harriet Lioumba organised a fun day at the Taverna on the Beach. Tracy said, "We had a bouncy castle which was donated for the day, a treasure hunt and an egg and spoon race as it was near Easter. We also had a few craft stalls and the owners donated some of their proceeds. We raised €225.00 and a great day was had by all".

Mega Tri for Lola 2015

The first Mega-Tri for Lola in 2013 raised in excess of £22,000 for the A-T Society. Mega-Tri 2 is now in the planning stages, and will take place over the weekend of 11-12 April 2015.

Adopting the familiar triathlon format of swim, cycle-ride and run, the event centres on Brighton and culminates in the fantastic Brighton marathon. Participants and supporters will take up residence in the Umi Hotel at the heart of Brighton seafront.

Details are still to be finalised, but the plan is that the Mega-Tri will consist of:

A 4km swim The Mega-Tri starts on the morning of Saturday 11th April in the University of Brighton Pool in Eastbourne.

A 100km bike ride Setting off from Eastbourne at 12:00 on Saturday, the route will take in quiet roads through the beautiful South Downs countryside to finish beside Brighton Pier. Then it's back to the hotel for a hearty meal, stories of the day, a good night's sleep and breakfast, followed by:

26.2 mile run – the Brighton Marathon Starting at 9:00 on Sunday 12th, this is one of the UK's most popular marathons, renowned for its buzzing atmosphere, great crowd support and sea-side setting.

Peppa pig leads the way in 2013!

Join the A-Team for the 2015 Mega-Tri for Lola!

Sign up today!

We aim to make this our biggest event ever. Already a good number of participants have signed up (12 swimmers, 14 cyclists, 12 runners and a few hardy fools aiming to do the whole Mega-Tri). But we would like you to come and take part, in one or more of the events either as an individual or a team.

The swim is taking place in a 25m pool in Eastbourne with plenty of supervision, so will be safe for children/teenagers as well as adults. You can sign up for the whole 4km, or if that sounds too daunting, why not put together a relay team?

The ride Confidence and experience of riding 100km will be necessary. Although this is a relatively flat route, the team will be riding as a group and the pace needs to be around 15mph, aiming to arrive in Brighton at around 5pm on the Saturday, including stops for refreshments and/or mechanicals. It may be possible to arrange a relay.

The marathon Although limited, places are still available. The team will start the run together, but complete the course at their own pace, to ensure plenty of energy remains for the after-party at the bar of the Umi Hotel!

Whatever you choose, there will be plenty of support over the weekend. Experiences range from Ironmen and seasoned competitors to those running their first marathon, or swimming 4km for the first time. And a massage will be available at the end of the marathon.

If you would like to get involved, as a participant or supporter – or even if you are just thinking about it – please get in touch with **suzanne@atsociety.org.uk**.

We'd love you to be part of what promises to be an amazing and memorable event!

If you would like to get involved, as a participant or a supporter, please get in touch with **suzanne@atsociety.org.uk**. We'd love to hear from you and have you on the Mega-Tri team!