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A-T Society News

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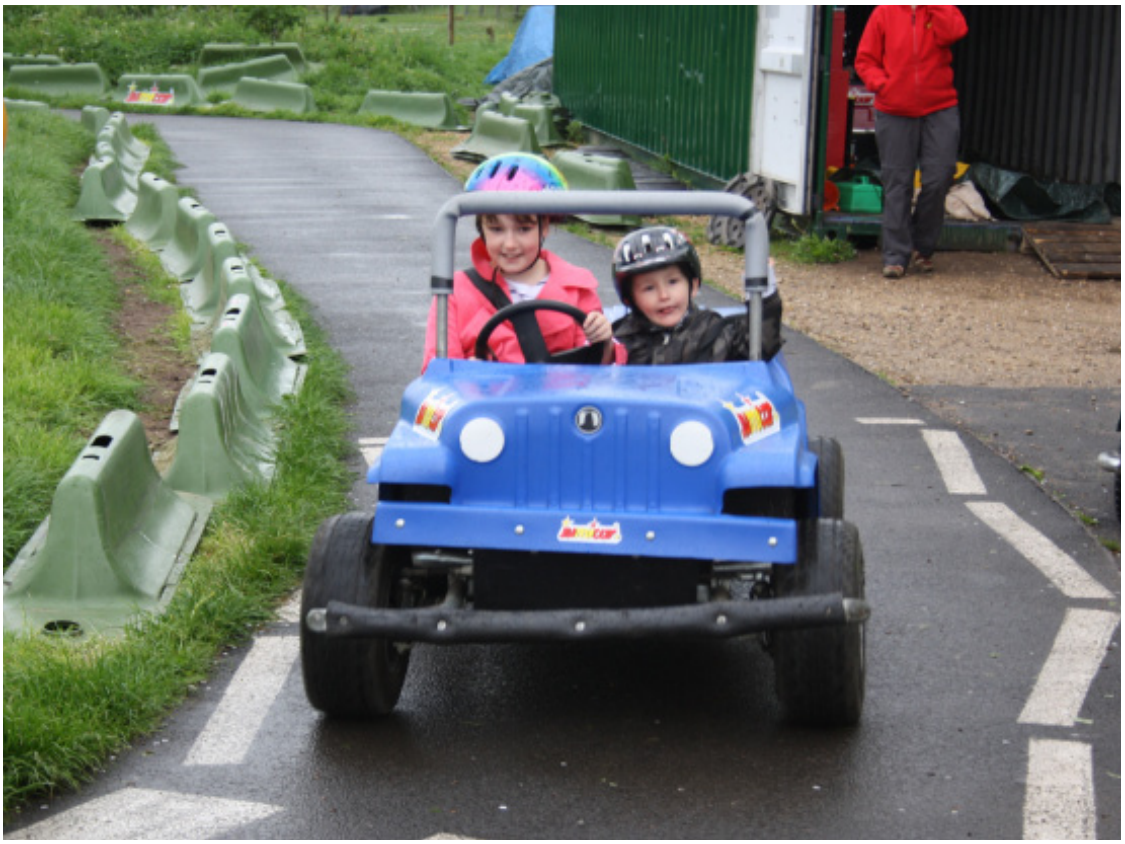

The Ataxia-Telangiectasia Society

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

The A-T Society was established in 1989 and is committed to helping, supporting and advising families affected by A-T. The Society aims to alleviate the distress and suffering that A-T causes by working to improve quality of life now and in the future. We do this through funding research, supporting families, working to improve clinical management, and raising awareness.

Contents

Editor's Comments

Many thanks to all contributors. The copy date for the next issue is 1st October 2010
Please send comments, ideas, articles and pictures to the newsletter editor:

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Cover picture: Going for a spin at the Family Day

News from the Society

The Society is delighted to welcome new Chief Executive, William Davis

About William

At the beginning of May, William Davis started work as the A-T Society's first Chief Executive. William has worked for the last 14 years, both as volunteer and professional, with charities that support people with health problems and disabilities. He worked for 12 years for the Multiple Sclerosis Society, where he became Head of Local Support, and more recently worked for the Guide Dogs for the Blind Association. As a volunteer he has worked for charities such as AFASIC, the Parkinson's Disease Society and the Queen Elizabeth's Foundation for Disabled People.

Having lived and worked closely with people with disabilities for many years, William is passionate about ensuring that society gives them the opportunities and support they need to live their lives independently and to their full potential. He also believes strongly in the value volunteers bring to organisations like the A-T Society.

In his free time, William plays the double bass (which he describes as a cross between a violin and a wardrobe). He also likes getting out in the country and looking at nature and enjoys good food, especially from the Mediterranean.

A message from William

The first thing to say is that I am delighted and honoured to have been offered this role. I am so impressed by how much has already been achieved by such a small organisation! There is a fantastic team of people here, volunteers, staff, people affected by A-T and professionals. It is a real privilege to have this opportunity to make sure people affected by A-T get the support and information they need. I hope to take some decisive steps towards finally defeating this condition.

Starting a job like this means learning huge amounts very quickly and I have been very lucky in this respect, as in my first week I was able to attend the 2-day clinic at Nottingham's City Hospital and the annual Family Day. This was a fantastic opportunity to talk to people living with A-T and start to get a sense of the impact that it has on them and their families. I was also able to meet a number of expert professionals and I was immediately very impressed by the knowledge, commitment and friendliness of all those I met.

What people probably want to know is how I see the way ahead for the A-T Society? In short, I want to see an organisation that is energetic and effective in meeting the real needs of people affected by A-T. So my first priority is going to be to talk to as many people as I can. Hearing things direct from people is the best way to learn.

I want to find out from people affected by A-T how the Society could help them better, from doctors how we can support them and improve services and from researchers, how we can best use our money and influence to ensure progress towards finding a cure. I am particularly keen to hear from young people growing up with A-T about the many challenges they face. It is a key part of our role to do all we can to enable people with A-T to live their lives to the full.

After that, on the basis of these views, I will work with the Board to agree what I hope will be an ambitious strategy for the next few years, setting out what we want to achieve, how we are going to do so and how we will pay for it. I also intend to raise our profile

and tell more people about A-T and our work. The crucial thing for me, though, is that everything we do must focus on meeting the needs and aspirations of people affected by A-T. If it doesn't, I will want to know why we are doing it.

As part of this process, we will later this year be circulating a questionnaire which I urge everyone to fill in. However, I am also very keen to hear from you directly, so please do get in touch with me and let me know what the Society does well to help you or what it does badly and to give me your ideas for what we should be doing in future. You can call me on 01582 760733 or e-mail **william@atsociety.org.uk**.

WE WANT TO HEAR FROM YOU

If you have thoughts about what the Society could do to support you better, what we should be focusing on, or even of better ways that we could raise funds, please take a few minutes to contact William and let him know.

A-T Family Day Nottingham, May 2010

Everyone at the A-T Society hopes that you will join us in thanking BBC Children In Need for providing the funding for this year's Family Day on 8 May.

Despite the weather, the day was a great success. We had an open forum, talks from new Chief Executive William Davis and experienced traveller Ian McInnes, as well as several clinicians who reported on the latest A-T research.

Workshops were held by our counsellor, social worker, and our physiotherapy and occupational therapists.

A group went bowling and another headed to Ferry Farm - both agreed they had a wonderful time.

Over the next few pages are some photos from the day. You can find more on the A-T Society Facebook group page (go to **www.facebook.com** then search 'A-T Society')

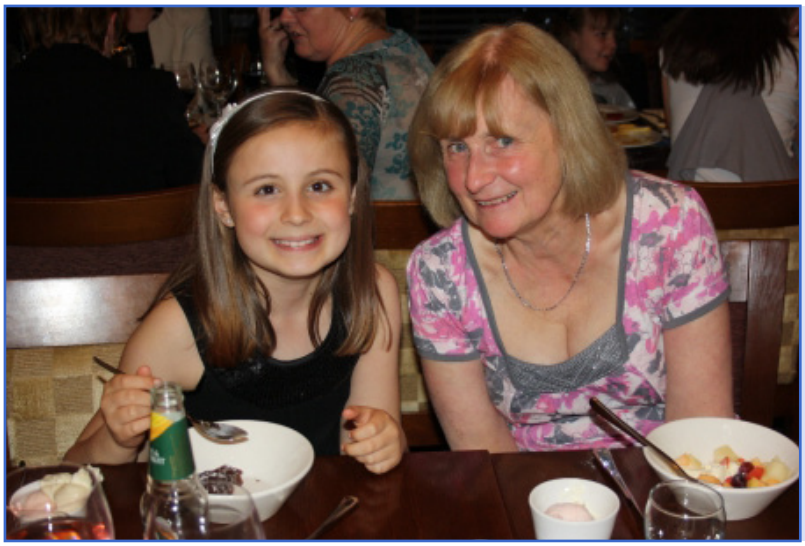
Many thanks to everyone working behind the scenes for making this such a successful day.

It is with great sadness that we announce the deaths of Louise Robinson and Elisha Shaw who both had A-T. We send our deepest condolences to both families.

We have a Memory Book of children with A-T who have died. If anybody would like a copy please contact Maureen, at the A-T office, on 01582 760733.

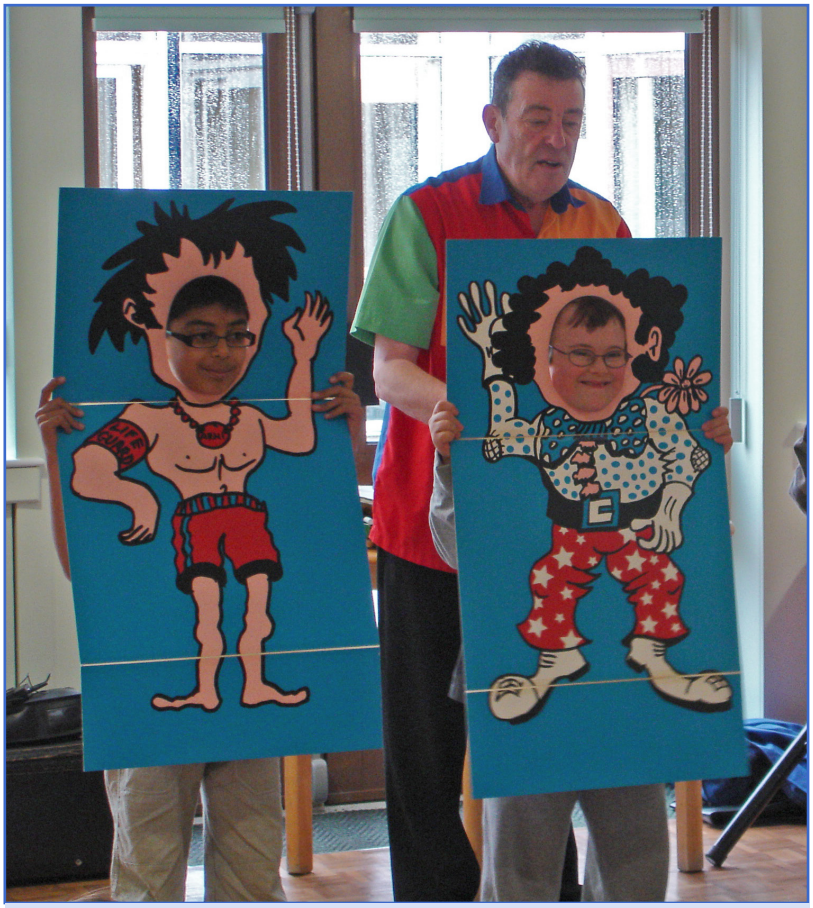
New chief executive William Davis speaks to globe trotter Ian McInnes

Emily checks out the IT equipment demonstrated by Julian Lee of the Aidis Trust

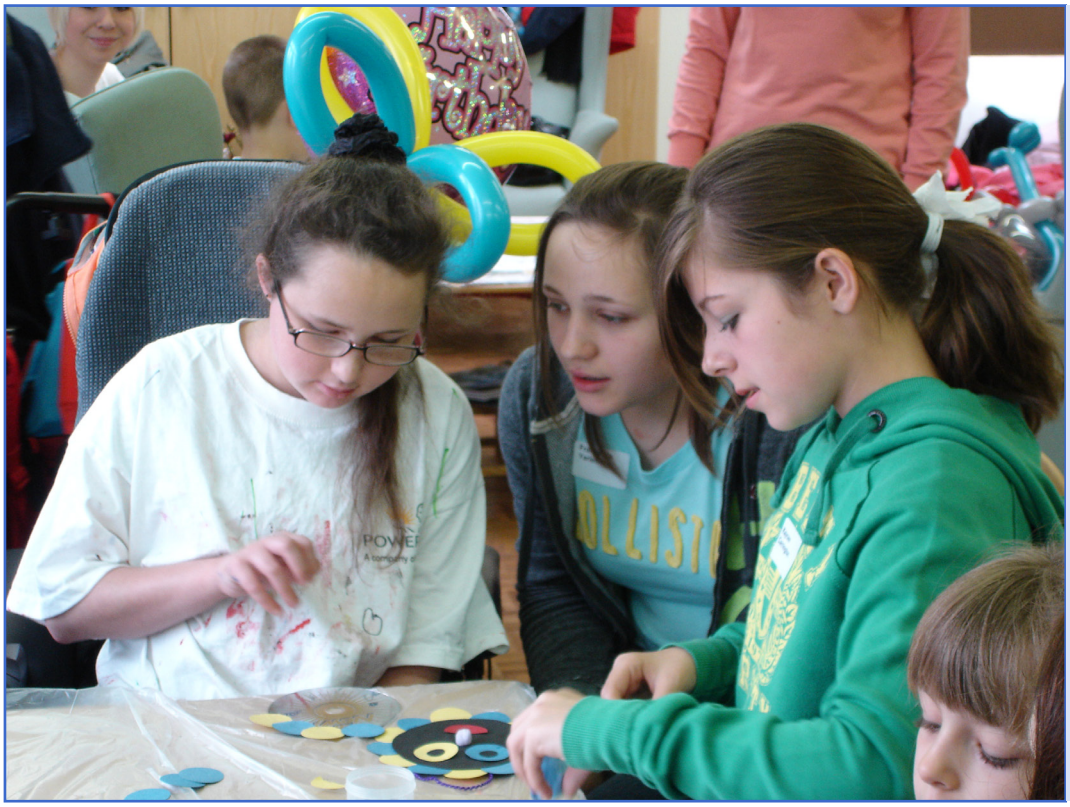


Enjoying dessert at the Family Meal Friday evening

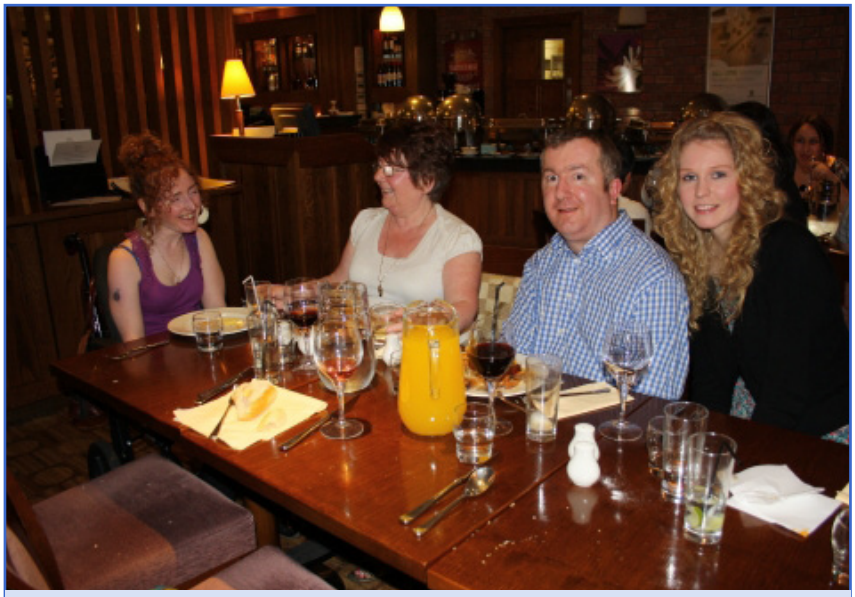
We have been racing around all day and we just needed a rest!



Marvo the Magician entertains



Alecia (1st left) and friends enjoy the craft activities



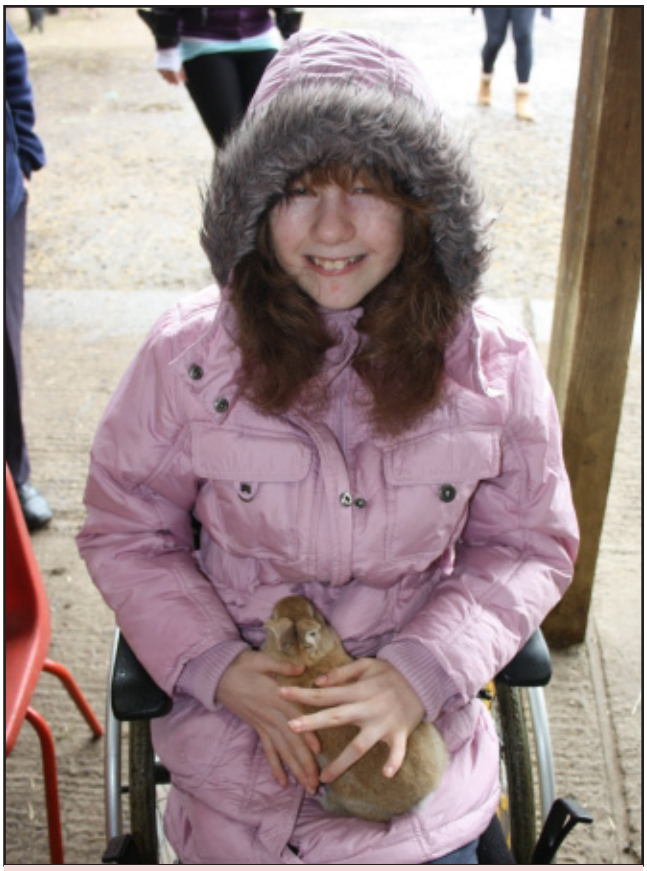
Above: Paula with her mum Anne, Ian and his support worker Kirsten

Joan (pictured) and Molly did sterling work selling plants, cards, tea towels and raffle tickets

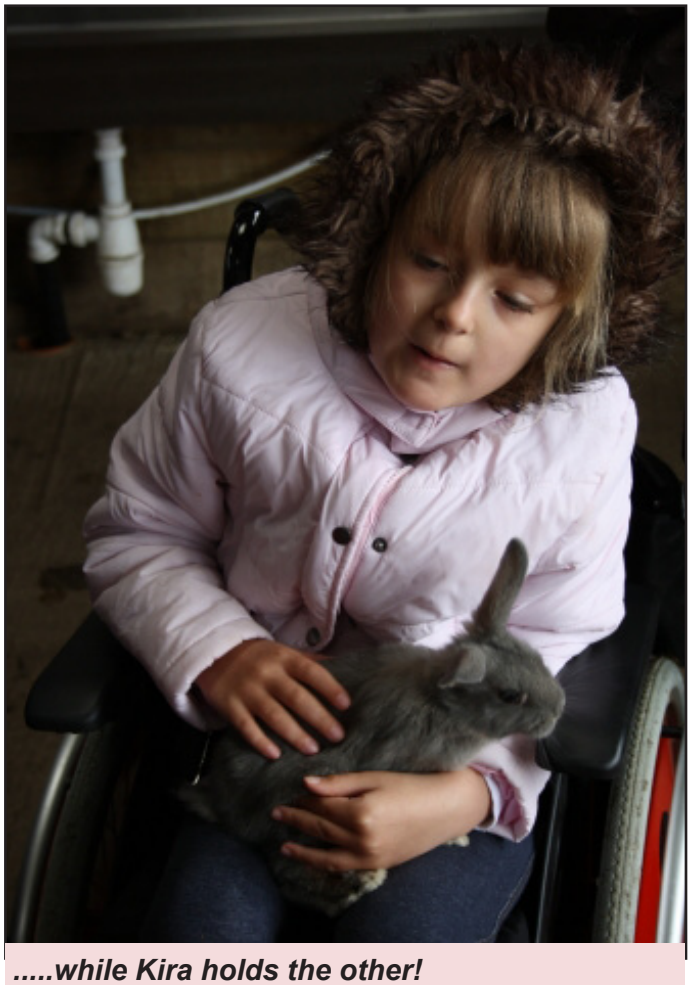
Families enjoying the buffet dinner

That was a great joke!

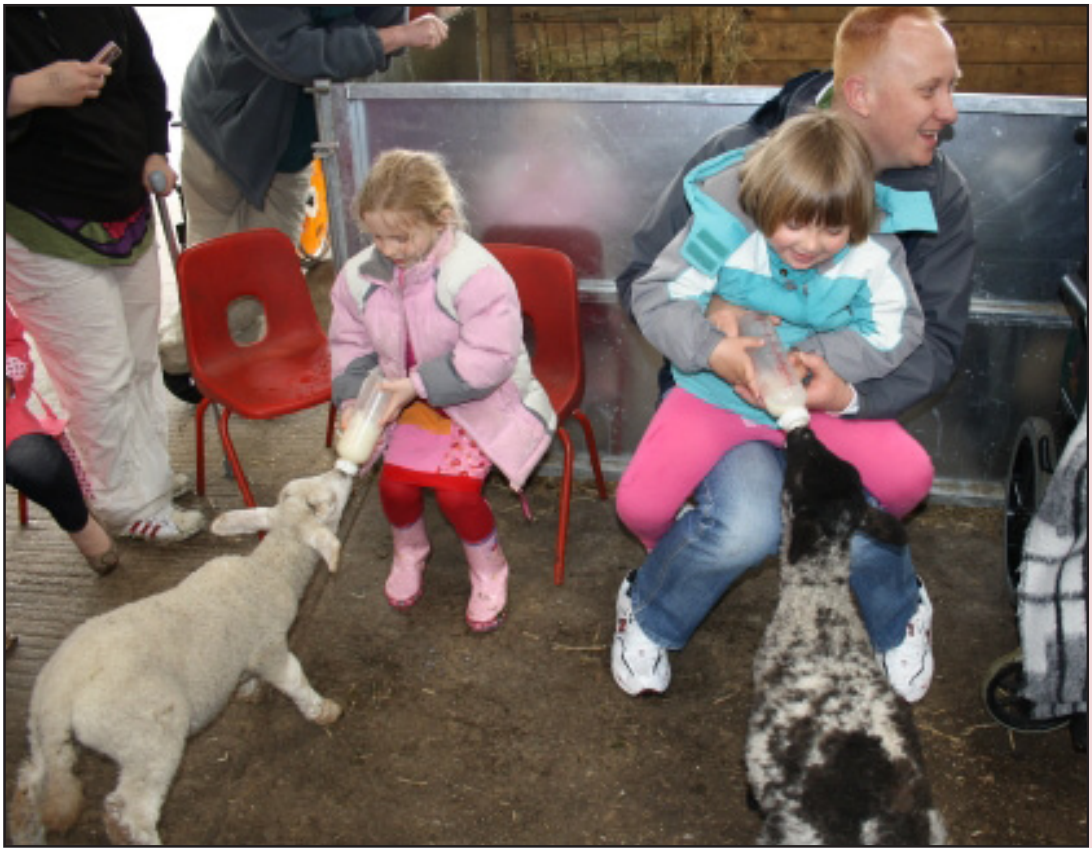
Trip to Ferry Farm...



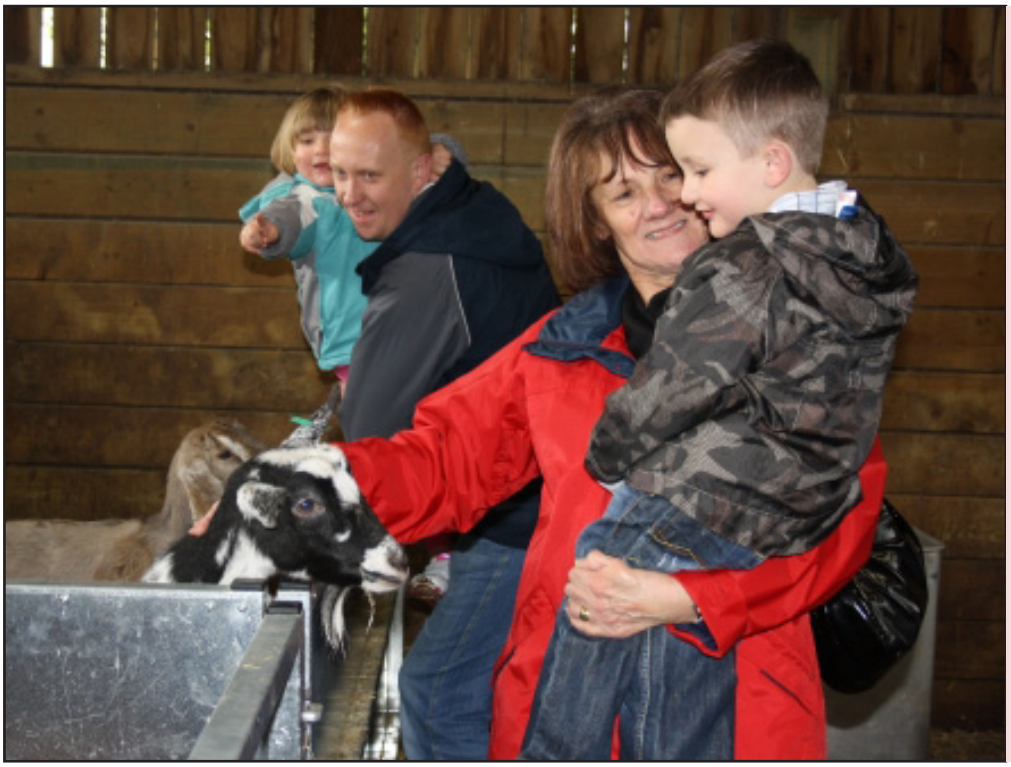
Rachel holds one rabbit...



.....while Kira holds the other!



Hold tight! Those lambs are thirsty!



A goat says hello to Kaid and his Gran

Becky holds a kitten

Kaid rides a horse

Open Forum

An Open Forum was held during the Family Day in May, offering people a chance to put questions to experts on the clinical management of A-T.

Electrical Circulation Boosters

What are your thoughts on electrical circulation boosters? Do you think they could help an individual with A-T considering the poor circulation to extremities? (Electrical circulation boosters can apparently stimulate the muscles and help to keep the blood circulating.)

• I suggest identifying the problem of poor circulation and cold feet at one of the A-T Clinics in Nottingham or Papworth in order to understand what is behind the problem.
It may lead to a simple practical intervention. So flag up the issue of cold feet at the clinic or with your local clinician.
• As nothing is known about the boosters they are probably not validated.
• Try ski socks - these seem to help.
• Try using a foot spa. They are relaxing and pleasant.
• Poor circulation can be a secondary symptom in neurological conditions. Lack of circulation is partly due to being stationary for a while.
• It is important that the feet are inspected regularly for pressure sores and for in-growing toenails. We would advise visiting a chiropodist regularly.

Diets and Exercise

Do you or other parents have any general advice in regard to vitamins, diets, exercises etc? Is there something I should be doing from day to day to help improve my child's life?

Diet: A child with A-T uses up more calories owing to the twitching and spasms. I suggest adding extra calories to food (e.g. butter to potatoes, cream into gravy etc). Allowing the school to give snacks (milk and banana, chocolate bars etc) between meals can make a difference.
• The Body Mass Index (BMI) is important and should be maintained within the range. If the person puts on weight the BMI will rise. The BMI is crucial - refer to a BMI chart. If the BMI is at the top of the range then try to restrict the weight. People with neurological problems don't need excess weight.
• If the patient is underweight, it has a negative effect on the immune system, so try to avoid that.
• Make sure that the basic nutrition is correct. After that, it is just fuel and doesn't matter.

Exercise: Be careful to guard against fatigue. Exercise little and often so that you don't get too tired. Regular exercise is good but try not to over-tire the person with A-T. Swimming is a good long-term activity. Try to find a pool with warmer water which is preferable to a cooler one.

Fingers and thumbs locking

My child's fingers and thumbs keep locking up, is this normal for a child with A-T? After writing the thumb locks inwardly, towards the palm. Is that a natural tendency in A-T? Should a splint be used overnight to strengthen the thumb?

• This is a movement disorder. Writing, like feeding, involves fine motor skills and with A-T the person has to overcome the A-T movements first. The muscles tense up and have to work harder. The muscle locks up while the person concentrates on reducing the A-T movements.
• Try a thicker pen to give a better grip. The person with A-T has to work harder when using a thinner pen.
• Aim for a good sitting posture when writing. See a neurologist for a diagnosis as to why the thumb is locking up. There is limited success in handwriting as it's difficult to achieve the natural rhythm and flow.

Diabetes

What effect do you think diabetes will have on a child who suffers from A-T?

• Diabetes has none of the neurological effects seen in A-T. Diabetes may have an immunological and a nutritional effect. There is no increase in the risk of developing cancer.
• Having to pay more attention to healthy nutrition and

exercise could be a good result as a spin off.
• Not many individuals with A-T have overt diabetes.
• Some features e.g. insulin resistance are being studied which may open a window of opportunity for treatment not currently available.

Skin problems and hair loss

Some people with A-T have difficulty with skin problems and hair loss; could these be side effects of A-T weakening their immune systems?

• Hair loss may be an auto-immune problem.
• Beware of sun sensitivity particularly in children with A-T. Give them protection.
• A-T can sometimes lead to skin conditions. These may be largely cosmetic, like café-au-lait spots, but occasionally may be more serious. If in doubt, consult your doctor.
• Some individuals with A-T are affected and some are not. The auto-immune component is related to other genes. There are a number of factors interacting in some families. It's not seen across the board. Like the inherited component in diabetes, the problem may partly relate to other genes.

Baclofen

In a recent newsletter it was said that Baclofen is being tested in A-T patients, for reducing unwanted movements. My adult son has been taking Baclofen for a number of years (3 times a day). However the effect wears off before the next dose and increasing the strength has made little difference. We have heard of a Baclofen pump which administers the drug as needed, We wondered if this had been tested on people with A-T and if you have any advice about this method?

• Baclofen is used to reduce spasticity and muscle spasms. It is delivered directly into the cerebrospinal fluid via a pump and has a long-lasting effect. We are not aware of any problems with Baclofen and see no reason why it would not be of benefit, provided neurological advice is taken.
• I would advise seeking neurological and neurosurgical opinion. There is no reason why Baclofen would not help. In one patient it seems to help but it is not taking away a lot of the problems.
• The pump itself might cause issues. Explore the use of Baclofen further and discuss it with a neurologist.

Botox

I understand that some people with A-T have tried Botox for various problems with muscle spasms. Do you recommend trying Botox with people who have A-T?

• There would need to be a careful clinical assessment carried out to ascertain precisely what the problem is. Botox may be useful in some instances but not in others. For example, Botox may be of benefit with dystonia (twisting/ jerking movements of parts of the body). Again, we suggest seeking clinical advice.

Thank you!

Thank you to the experts who gave advice at the Open Forum

A big thank you to all those who worked so hard behind the scenes and to all those who provided prizes for the Family Day raffle

Dr Venkat Srinivasan spoke about the link between A-T mutations and the clinical picture. A full write up will come in the newsletter's December issue

Benefits and financial support explained

Every April, the government makes a number of changes to the rules governing the benefits system and other forms of financial support for families.

Many parents report that they find it very difficult to keep abreast of these new rules and initiatives. Here, **Contact A Family** explains the changes that may be of interest to parents with disabled children

Additional Child Trust Fund payments

Extra Child Trust Fund payments for disabled children
From April 2010 the government will start to make extra payments into the Child Trust Fund accounts of disabled children. The extra payment will be £100 per year, or £200 per year if a child is on the care component of Disability Living Allowance at the highest rate.

Will all disabled children receive these extra payments?
No. In order to qualify for an additional payment from the government your child must have been in receipt of Disability Living Allowance (DLA) at some point in the previous year. In addition, only children born on or after 1st September 2002 have Child Trust Fund accounts.

My child gets DLA. What steps do I need to take to ensure my child receives these extra payments into their account?
The government expects to automatically identify those children who have both DLA and a child trust fund and will then make a payment directly into each child's account. Parents will receive a letter telling them once a payment has been made.

When will my child be able to get the money in their account?
A child must normally wait until they reach 18 years of age to access the money in their account. However if your child has a terminal illness and their death could be reasonably expected within six months, you can get early access to buy things that your child needs.

The Savings Gateway - government help to boost your savings

A new government backed savings scheme called the Savings Gateway has been introduced. Aimed at people of working age who are on lower incomes, the government will give you 50 pence for each £1 you save into your Savings Gateway account.

Am I eligible for a Savings Gateway account?
You will qualify for an account if you getting one of the following benefits or tax credits: Income Support; Incapacity Benefit; Severe Disablement Allowance; Employment and Support Allowance; Job Seekers Allowance; Child Tax Credit (your income must be below £16,040 - this limit may increase after April) or Carers Allowance (you must actually get this, not just have an underlying entitlement).

How do I apply for an account?
Her Majesty's Revenue and Customs (HMRC) will write to everyone who is eligible, inviting them to apply for an account and telling them how to go about doing this. Savings Gateway accounts will be offered by a range of banks, building societies and credit unions. You can only open one savings gateway account during the course of your lifetime – so you need to think about when would be the best time for you to do so.

How much can I save into my account?
You can save whatever you like - up to a maximum of £25 a month. At the end of the two years the government will then add a reward of 50 pence for each £1 you've saved.

Carer's Allowance earnings limit to increase

Carer's Allowance is the only state benefit specifically aimed at carers. However in order to get Carer's Allowance one of the rules is that your earnings must be no more than £95 per week. This earnings limit has been unchanged since October 2007. However from 6th April 2010 the government is to increase this figure to £100 per week.

How are my earnings calculated for Carer's Allowance?
In working out your weekly earnings certain deductions can be made from your gross wages. For instance any tax and national insurance you pay is deducted, alongside half of any pension contributions you make.

What about if I have to pay someone to look after my children while I am at work?
If because of your work you have to pay someone else to care for the person you look after, or to look after your children, you may also be able to deduct these costs from your earnings. However the maximum amount that you can deduct for alternative care costs is 50% of what would otherwise have been your earnings. No deduction is allowed if the person you pay is a close relative.

These rules may allow some carers to qualify for Carer's Allowance even though they are earning slightly more than £100 per week.

What are the other Carers Allowance rules?
You must be at least 16 to claim and you can only get Carer's Allowance if the person you look after is in receipt of the care component of Disability Living Allowance at the middle or highest rate or Attendance Allowance (a benefit for elderly people). You cannot claim if you are a student involved in 21 hours or more supervised study.

If you are looking after a disabled adult then in certain circumstances an award of Carer's Allowance could lead to a reduction in that disabled person's benefits. Parents with disabled children who are working and who want to know if the change in the earnings rule will help them claim Carer's Allowance should call Contact a Family's free Helpline on 0808 808 3555.

Child maintenance payments to be ignored

From 12th April, child maintenance payments will no longer be treated as income when working out if you are entitled to means tested benefits such as income support, income based job seekers allowance or income related Employment and Support Allowance. These payments are already ignored as income for housing and council tax benefit and for tax credits.

This will allow thousands of parents to qualify for benefits such as income support for the first time.

If you receive child maintenance payments and were told in the past that your income was too high to receive a means tested benefit, you may find that these new rules allow you to qualify for the first time. To find out whether this applies to you seek further advice.

For more information on any of these changes, phone the Contact a Family helpline free on 0808 808 3555

From Rome to Paris: Tips from a globe trotter

Ian pictured with support worker Kirsten, who joined him on the trip

Ian McInnes, who has A-T, spoke at the Family Day about the joys and challenges during his trip to Paris and Rome last Summer

We took off from Edinburgh airport to Rome with Lufthansa. We were met by our taxi driver with no problem but we were all amazed that the hotel was outside the city centre. At the time of booking I had been assured that this was a city centre hotel. It was not a walkable distance and so we had to rely on taxis and buses. As there were no obvious accessible toilets in the city centre, this could have been a problem for me, but as I am a bit of a camel where this is concerned, I was able to wait the majority of the day to use the facilities back at the hotel!

The other thing was that the room I was allocated in the hotel was not what we would call accessible. The only real difference in the room was that it had wider doorways. So not everyone's view of what is accessible is the same.

The company I booked through was Thomson's, who arranged flights, airport transfers, insurance and accommodation. I haven't had any problems with Thomson's in the past, or with my current trips for the future. However, they did compensate me on my return for the problems we had. It made us realise how lucky we are in the UK, but this did not dampen our spirits because I enjoy a challenge.

Rome

We went on a bus tour around the city, which was useful to get our bearings from. Some of the tour buses had disabled access signs on them. We went on one and found that there was a limited view because you could only access the lower deck. Also, there was no ramp to get on the bus, but we managed without one, and the tour was worthwhile.

We visited places such as the Colosseum, Trevi Fountain, the Pantheon and the Vatican. It was possible to hop on and off the bus where you chose. When we visited the Colosseum, we were waiting in the entrance area and a chap spotted us and asked us if we wanted to join an English tour party, which we did, but the guide of this party did not appreciate that being in a wheelchair took some more time to get places. The gentleman who had picked us out of the crowd was not very happy that we were being left behind the

> "Not everyone's view of what is accessible is the same"

group. So he gave us back, in full, our entrance fees and also gave us a couple of audio guides, and told us we could wander about on our own, which meant we could

do things at our own pace. The Colosseum itself, it is amazing how much of it is left intact, and you can also get to the higher levels because there is a lift. If you look down towards where the arena floor used to be, it is quite amazing how many pens there are underneath the arena floor for holding animals, equipment and men, because the Romans were fantastic at their lift systems.

The Trevi Fountain is very impressive and apparently a very romantic spot. There were quite a few people though, so you were jostling for a view.

The Pantheon is a chapel which is very ornately decorated inside with an amazing circle left open in its domed roof. Like most buildings in Rome, its outside is impressive, with three columns at the front.

> "The person pushing needs to be prepared for a work-out"

The outside space before you get to the Vatican is very impressive, including St Peter's Square, with all it's columns and statues. Most of this is either flat or ramped. We went into the Sistine Chapel; it was a real experience to see the ceiling, painted by Michelangelo. We could hear screaming children and flash photography though, which is not really allowed.

To summarise, the week in Rome was not without its challenges, but as I have said, I thrive on challenges. It is possible to push a manual wheelchair around the centre of Rome, and we managed just fine, but the person pushing needs to be prepared for a work-out because of the cobbles and blocked ramps. The good things about Rome were the excellent wine and the food. They also had very good ice cream. But my everlasting memory of Rome would be cobbles and yet more cobbles.

Paris

After our week in Rome, we flew up to Paris with Squeezyjet, who ended up losing my luggage, which wouldn't be too bad, but the luggage had my footplates in it. So for the first day or so we could not go that far afield. My main reason for going to Paris, apart from, again, the good food and wine, was to meet up with a good friend of mine called Mike (aka El Pillock!) He lived in the outskirts of Paris and our hotel was in the centre, and again, we were told this hotel was accessible, but the room that I had was not really accessible.

An example of inaccessibility in the hotel was the bath. It was an ordinary bath, not much use to me, but with a bit of encouragement, the hotel manager came up with a solution and they made a temporary seat for it, which I could then use over the bath.

The days we met up with Mike, we went down to the Bateau Mouche (boats on the river) and there were two flights of very steep stairs, which even though my friend has two knees that are shot, it still didn't stop him from tipping me back and bumping me down the stairs at high speed. I am sure he just does that to see the reaction on my face, and Elliot, 5, (his son) loved it!

Another time we all met up, we went to a wine shop, which Mike knew, because he knows the owners. He got us places in a wee back room where you could have meats, cheeses and obviously wines, and my friend, much to my disgust, force fed me cheese, which I do not like. After this torture had finished, we went down the road to a local pub, where we had a delicious meal, consisting of escargot (snails) and the most amazing salads. On the final night, we went down to Mike's house, where he cooked delicious duck, but little did I know the hard bit was still to come, because he started force feeding me Russian Vodka, straight, and he was also getting me to speed drink it, which I found very hard!

> "I thrive on challenges!"

The transport in Paris is not that easy, but on the last night when we were going to Mike's, we did get a train, but this was through Mike telling us what numbers to get. Although the route we took was accessible, few of them are.

We walked most places, occasionally getting taxis. The pavements in central Paris are good for pushing a manual wheelchair. They are generally flat, smooth, and have ramped corners, although the corners are often blocked by vehicles. If you intend to go around the city in a manual wheelchair, it is advisable to go with two people who can share the pushing. It might be too tiring for one person on their own. With two people, it also means one person can map read etc, while the other pushes.

We also walked to the Eiffel Tower, which was not very far away from our hotel, and there is an accessible lift, which unfortunately due to bad weather could only take us half way up to the middle viewing deck, but still, you got a pretty good view of Paris from there.

After the two weeks, I think we all enjoyed it, because I know I did!

International Workshop on Ataxia-Telangiectasia, April 2010

The International A-T Workshop (ATW2010) was held on 11-14 April at Redondo Beach in Los Angeles. Below, Trustee Emma Ross gives a report of the workshop

Dr Richard Gatti and his organising committee hosted what was a stimulating and informative conference, offering delegates who ranged from basic scientists to clinicians, the opportunity to share cutting edge research in to this complex disease.

Pamela Smith, president of the A-T Medical Research Foundation (A-TMRF), welcomed the 180 delegates. Pamela and George Smith founded A-TMRF after they met with Dr Gatti and Eleanor Boder shortly after their daughter had been diagnosed with A-T. A-TMRF was a major sponsor of this meeting along with support from A-T societies worldwide.

A-T: A neurodegenerative or developmental disease?

The first day began with presentations on the neurological aspects of A-T. Dr Tom Crawford (John Hopkins Hospital, Baltimore) opened this session with the question: 'Is A-T a developmental or a neurodegenerative disease?' In a degenerative disease, the child develops normal neurological function, but then begins to lose it over time. In a developmental condition, full function is never present. The problem with trying to address this important question is that in studying children we are presented with a 'shifting baseline'- they are ever changing by nature of being a developing child. Because diagnosis is often delayed until ataxia is recognised as abnormal (rather than just being a 'wobbly toddler') it is hard to know if A-T children ever had some normal neurological function. Dr Crawford emphasised the need for an array of outcome measures by which we can test degeneration of neurological function. The development of the A-T Neurological Examination Scale Toolkit (A-T NEST) is an example of such an outcome measure. These tests will also prove vital in measuring improvements in neurological function when promising drugs get to clinical trial.

Dr Harry Vinters (UCLA) discussed the loss of nerve cells in the cerebellum (the part of the brain thought to most affected in A-T). In response to Dr Crawford's earlier question, Dr Vinters described A-T as a neurodegenerative disease 'superimposed onto a developmental disease'. Dr Youngsoo Lee (St Jude Hospital, Memphis) explained how his laboratory are using an ATM 'double mutant' mouse model to research the loss of nerve cells in the cerebellum. Drs Wang (Jena, Germany) and Pandita (University of Texas Southwest, Dallas) went further into how mice models and cell studies are proving very useful in researching the neurological changes seen in A-T.

Tanja Stankovic (University of Birmingham, UK) chaired a session on the role of the ATM gene in cancer predisposition. Other sessions included basic science research into the immunobiology of A-T and the presentation of recent findings about the structure and function of the ATM gene.

Molecular and cellular research

The second day of the workshop saw more molecular and cellular research being presented; specifically investigation of the double strand DNA breaks which are characteristically seen in the cells of those with A-T. Whilst this seems a long way from affecting the lives of those with A-T (translating cellular research into drug therapies can take over 15 years and up to £500 million!), it provides the essential foundation on which to build promising drug therapies. For example, Samuel Bunting (National Institute of Health, Bethesda) spoke about how in cell research and mouse models it has been shown that a compound called 53BPi is pivotal in inducing breast and ovarian cancer in ATM heterozygous individuals (A-T gene 'carriers'); thus a drug which could inhibit the action of this compound could be important in preventing tumours in these people (who have been shown to be slightly more susceptible to developing breast cancer than the 'normal' population).

Penny Jeggo (University of Sussex, UK) chaired a session on how A-T related syndromes might prove useful models by which to study A-T. For example, the condition known as Ataxia Occulomotor Apraxia, might provide a useful insight into the neurodegeneration seen in A-T.

What we have learnt from A-T

To close the second day of the conference, Dr Richard Gatti had been invited by the organising committee to give the first A-T workshop 'Special Honorary Lecture' which he entitled 'What we have learnt from A-T'. Dr Gatti gave an eloquent overview of the history and current standing of research into A-T. Dr Gatti has a personal interest in A-T patients, their care and their well-being.

Dr Gatti was first involved with localising the A-T gene by linking it to Chromosome 11, before Professor Yossi Shiloh in Israel and his team later identified it. He spoke of receiving feedback from the funding body to whom he applied to finance the research to identify the gene – they commended his idea, but said it was a 'Herculean' task that may never be fulfilled. With what he describes as a little luck and hard work, international scientists were able to identify the single defective gene that causes A-T. The ATM gene, with its missing ATM protein was identified in 1995.

Dr Gatti described A-T as a prototype for a new disease paradigm. Once considered an orphan disease, A-T might now be the key to identifying and understanding a host of related disorders which all show common characteristics; radiosensitivity (to X rays), predisposition to cancer, immune deficiency, neurological impairment and hereditary (passed down through familial DNA). He calls it XCIND syndrome.

Developments in A-T research

Dr Gatti finished his engaging lecture by talking about the most current developments in A-T research. An interesting breakthrough is the research from Dr Gatti's lab where drug therapies are being developed to treat individuals with what is known as 'nonsense ATM mutations'. This type of genetic mutation is seen in about 30% of those diagnosed with A-T. In the process of translation, a cell converts its DNA into working proteins (which are used for essential cell functioning). Nonsense mutations create what is recognised by the cell as a 'stop sign' in the middle of making a new protein, which stops its proper formation. In the case of A-T this means that the ATM protein never gets translated properly in the cell, and this ATM deficiency causes A-T. Dr Gatti's lab have screened 35,000 compounds to see which ones might be good at stopping the creation of this 'stop sign' in the middle of ATM production. They found 12 leading candidate compounds, and published these findings 6 months ago. From these promising candidates, further investigation in vitro and work with chemists singled out two compounds that were worthy of much further investigation (only known now as compounds #13 and #14!).

Extended work with these compounds has demonstrated that #13 increases ATM production in cells by removing the 'stop sign', which was preventing ATM protein being synthesised. It also reduced the radiosensitivity of the cells. Since this work, #13 has been tested in the mouse model for Duchennes Muscular Dystrophy, and it does not appear to be toxic to the animals, and improves their ataxic symptoms. Dr Gatti is very optimistic that more animal studies will be carried out with this compound in the next 12 months, with an aim of getting FDA approval to try the compounds in human clinical trials within the next two years.

Promising therapies for A-T

The final day of the conference returned to the clinical research with presentations on promising therapies for A-T. Andreea Nissenkorn (Tel Aviv, Israel) presented some early observations from a study using Amantadine to treat movement disorders in A-T. In children aged 4-12 years, 5-8 mg/kg of Amantadine was administered daily for 8 weeks with various neurological assessments before and after the intervention. Improvements were seen in ataxia, involuntary movement and 10m walking time following the 8-weeks of Amantadine. These are promising results, but Dr Crawford added that until we test this therapy using a blinded trial (where participants don't know if they are receiving the intervention drug, or just a placebo) we can't be sure this is not a placebo effect in some of the patients. More studies are planned for the future.

Stefan Zielen (Frankfurt, Germany) presented on interstitial lung disease in A-T. He described that A-T patients often presented with recurrent respiratory tract infections and bronchiectasis, aspiration and respiratory muscle abnormalities, and interstitial lung disease, making the picture rather complex! He noted that patients with advanced lung disease always have increased muscle wasting and poor nutritional status (and consequently a low BMI). Preventing this decline in body mass may be a way to slow down the progression of the lung disease.

The final presentation was by Claudio Pignata (Naples, Italy) who has been investigating the effect of Bethamethasone therapy in A-T. This glucocorticoid steroid has been shown to be effective in improving ataxic symptoms and Dr Pignata's work is now looking at finding the minimal effective dose of this steroid, to avoid the contraindications often observed with long term steroid use. This study showed that with a dose of 0.03 mg/kg, similar responses to that of the larger 0.1 mg/kg dose were observed. Thus the positive effect on neurological symptoms is still present at a low dose, potentially reducing the negative side effects of such supplementation.

The future of A-T research

To close the conference, a panel comprised of Drs Gatti, Lavin, Lowry, McBride, McKinnon, Meyn, Shiloh and Whitehouse gave their thoughts on important future directions for A-T research. These included:

- To understand the oxidative stress aspect of A-T and its relation to its neuropathy. Future research might focus of mitochondrial function and revisit oxidative stress and ATM function.
- To address the issue of radiosensitivity, and whether we fully understand the cause of the persistent damage that radiation causes in A-T patients.
- To investigate whether neurological problems in A-T are developmental or degenerative.
- To address issues of care, to ensure that every patient with A-T has access to optimal A-T therapy. This will include measures such as educating doctors, and the establishment of an international registry of the natural history of all diagnosed A-T patients with data sets from all international A-T clinics.
- To work on developing rigorous outcome measures of neurological function, and perform well controlled (double blind, placebo, multi-centred) trials.
- To work on the long term effect of therapies, and not just look at improving function by short-term interventions.
- To understand the array of physiological functions of the ATM gene, and to be open to new concepts.
- To understand the basis of selective vulnerability; this is not a degenerative disease affecting all of the brain – some cells decline and some don't.
- The need for more clinical discussion at the conference; the emphasis of this LA conference was basic science (work in isolated cells and animals). In the future, presentation of clinical work should be integrated with the basic science, and scientists should be encouraged to engage with clinicians to foster translational research.

After a very full 3 days, the 2010 A-T workshop was called to a close. The baton was handed over to the Indian A-T research group, who hope to host the next workshop in November 2011. The conference reflected the wealth of knowledge and enthusiasm that is ploughed into A-T research, whether it is at the lab bench or in the clinics. We are making progress into understanding, treating and potentially curing this complex disease.

International A-T Workshop Report: Presentations

Elaine Willmore, from the Newcastle Cancer Centre at the Northern Institute for Cancer Research, Newcastle University, also attended the International Workshop in April. Below is her summary of three presentations:

A. Nissenkorn et al, A-T Clinic, Israel

Amantadine Sulfate for treatment of movement disorder in A-T

There have been few clinical studies on improving the cerebellar ataxia that becomes very disabling in A-T patients. Some studies have focused on the use of steroids to treat movement disorder, but there has been little success and one of the challenges is knowing how to measure and monitor improvements following treatment.

One new agent that is being studied is Amantadine. This is a drug that has previously been used in Parkinson's disease and Huntingdon's disease, with relatively few side effects. Amantadine is a dopaminergic drug, which means that it works by altering the nerve systems in the body that use dopamine to transmit nerve signals. Changes in dopamine neurotransmission have several effects, including muscle rigidity, blood flow and thought disorder.

This study tested the effectiveness of amantadine in 17 A-T patients. Treatment was given over 3 visits to the clinic, with two doses of the drug (5-8mg/kg).

Scales were used to try and estimate the effectiveness of the drug. These included the 'international cooperative ataxia scale (ICARS)', the 'unified Parkinson disease rating scale (UPDRS)' and the 'abnormal involuntary movement scale (AIMS)'. One of the difficulties is that none of the current scales are optimal, and in the A-T field, there is a current working party to try and develop a new, unified, A-T- specific scale (this was described in abstract 196, by Dr Whitehouse et al). Patients were monitored on day 1, day 28 and then 8 weeks into the study. The tests carried out on patients included

hand tapping (for 30 seconds) to assess fatigue, and timing of a 10m walk.

Despite the difficulty with measuring improvement in the patients, the study was able to show that there was at least a 'moderate' improvement in the majority of the patients. This was very encouraging, since both the clinical assessment and the patient's assessment measured a positive effect. The most improved symptom was the ataxia, and the 10m walk, with the eyes, general movement and speech improving mildy. There were some side effects in about half of the patients, including stomach ache, sickness and constipation or rash, but most of these were relatively mild.

In conclusion, amantadine is an effective agent for helping some A-T patients with movement and has tolerable side effects. Future studies will be able to assess this drug on a bigger group of patients and measure longer term benefits.

Liutao Du et al, UCLA, USA

Arginine-rich cell-penetrating peptide dramatically enhances AMO-mediated correction of aberrant splicing in ATM transcripts.

The underlying defect in A-T is the loss of function of the enzyme, ataxia telangiectasia mutated kinase (ATM). This enzyme has many functions, acting as a signalling protein to activate other proteins. In A-T patients, it is thought that if the function of ATM could be restored, then some of the symptoms that patients suffer could be reduced.

Dr Gatti and colleagues have been investigating various ways of making the ATM protein functional again in A-T cell line models. The basic aim is to attack the machinery in the cells that makes proteins - in other words to fool it into making protein again. One way of doing this is by designing peptides (small units of protein) that interfere with the generation of the defective ATM protein. These peptides can be joined onto other molecules (called AMOs -antisense morpholino oligonucleotides) and can enter into A-T cells to disrupt production of the defective ATM.

In this study, a peptide called (RXR)4 linked to an AMO was used. This peptide was very successful, restoring activity of ATM protein up to 80% of its normal levels. Even after 20 days, the cells still retained this high level of functional ATM protein.

The study went on to use a mouse model to look at the distribution of this peptide in the body. This is important because one of the problems with this type of therapeutic approach is making sure that enough of the peptide gets into the brain cells that are affected in A-T patients.

Using the mouse model, and a fluorescent tag to allow the peptide to be visualised, this study was able to demonstrate efficient uptake into the brain, especially in the Purkinje cells, even after a single injection. There was no obvious toxicity to the animals and this approach is very promising as it could restore ATM function in those patients who have a particular type of defect in their ATM protein.

Zhi Guo et al, University of Texas, Austin, USA

ATM activation by oxidative stress

The classic model for the way that the enzyme, ATM, becomes activated, is that breaks in the DNA within cells stimulate ATM to start working. Dr Paull's lab presented data from a new study showing that there is an alternative way that ATM can become active.

All cells have ways of responding to stress (stress includes heat, cold, lack of oxygen and the type of DNA breaks that are induced by chemotherapy drugs). One form of stress that has been studied by this group is oxidative stress. Oxidative stress is the production of chemicals that can cause an imbalance of the normal metabolism of cells. Such chemicals include 'reactive oxygen species (ROS)', 'free radicals' and 'peroxides'. Some of the current herbal remedies and anti-ageing tablets are designed to work against the harmful effects of oxidative stress, and these are called 'antioxidants'. Sometimes ROS and free radicals can be converted into even more harmful chemicals and the cell has a way of dealing with this toxicity, using special proteins like one called 'glutathione'.

Recent reports in the literature have identified two important results; (a) cells lacking ATM are known to have high levels of oxidative damage; (b) the A-T mouse model, which is often used to study A-T, has some of its defects (including induction of leukaemia and shortened lifespan) reduced by treatment with

antioxidants. These two pieces of evidence point to the fact that the oxidative stress plays a big role in A-T disease (represented by cell models or mouse models).

This study looked at the activation of ATM in human cell line models cultured in the lab. They found that when they induced oxidative stress in these cells, there was a large activation of ATM. Importantly, these cells did not have any DNA breaks, suggesting that in this case, breaks were not required to activate ATM (as the classic dogma states).

As well as looking at ATM in cultured cells, this group looked at the ATM protein in a test tube to see what happened to it after oxidative damage. Again, ATM became activated, and again this was without the presence of DNA breaks. Since this activation took place in a test tube, it was also without all the other proteins and factors that normally work together to activate ATM. These data show that ATM, by itself, can become oxidised, and that this oxidation activates it.

Furthermore, this study went on to pinpoint which particular part of the ATM protein was responsible for this effect, and if they deactivated it ('mutated' the protein), it was no longer activated by oxidative damage.

This is a very important observation in the field, since it highlights for the first time, why ATM becomes active following oxidative damage, and shows that another one of ATM's roles is to respond to oxidative damage. Finding out more about how the ATM protein works like this will really advance our understanding of A-T and help us design new therapeutic strategies.

Archdeacon Derek Hayward OBE

It is with great sadness that we report the death, on April 26, 2010 at the age of 86, of the Ven. Derek Hayward OBE.

Derek had served as a trustee of the Society for 11 years, seven of these as Chairman. In this role he had a vision of where the Society could go and what it might achieve.

Among his many insights, Derek encouraged the recruitment of a fundraiser, thereby securing the resources which underpin all we do today. Metaphorically, he is the rock upon which all our present endeavours are built.

Self-effacing yet highly visible, Derek led by example, guided by an ingrained sense of duty and a deep commitment to the service of others.

Clearly, the A-T Society was but a part of Derek's very full life. He was a soldier, a priest, a father and a husband. He was a friend and wise counsel to many, to which the overflowing congregation at his memorial service bore fond and eloquent witness.

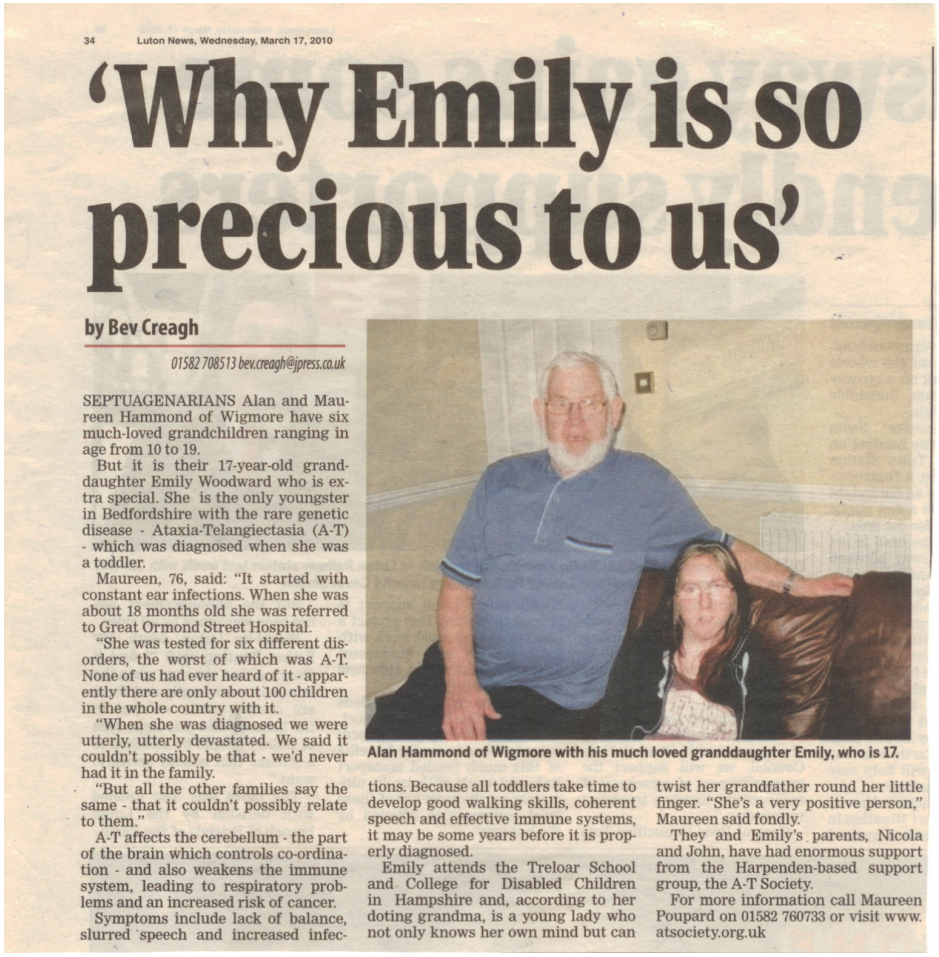
However, one suspects that it is not principally for his achievements nor for his ministry that Derek will be remembered and missed, but rather for the person he was. If there is a spark of the Divine within each of us, then in Derek it shone more brightly than in most.

In paradisum deducant te angeli.
In tuo adventu suscipiant te martyres
et perducant te in civitatem sanctam Jerusalem.
Chorus angelorum te suscipiat
et cum Lazaro, quondam paupere,
aeternam habeas requiem.

May angels lead you into Paradise.
May the martyrs receive you on your arrival
and escort you into the holy city, Jerusalem.
May the choir of angels receive you
and with Lazarus, once a poor man,
May you have everlasting rest.

A-T in the papers

Alan Hammond and his granddaughter Emily made it into their local paper, Luton News, in March. The article talked about A-T, which Emily has, describing how they dealt with the diagnosis and praising Emily's positivity.



34 Luton News, Wednesday, March 17, 2010

'Why Emily is so precious to us'

by Bev Creagh

01582 708513 bev.creagh@jpress.co.uk

SEPTUAGENARIANS Alan and Maureen Hammond of Wigmore have six much-loved grandchildren ranging in age from 10 to 19.

But it is their 17-year-old granddaughter Emily Woodward who is extra special. She is the only youngster in Bedfordshire with the rare genetic disease - Ataxia-Telangiectasia (A-T) - which was diagnosed when she was a toddler.

Maureen, 76, said: "It started with constant ear infections. When she was about 18 months old she was referred to Great Ormond Street Hospital.

"She was tested for six different disorders, the worst of which was A-T. None of us had ever heard of it - apparently there are only about 100 children in the whole country with it.

"When she was diagnosed we were utterly, utterly devastated. We said it couldn't possibly be that - we'd never had it in the family.

"But all the other families say the same - that it couldn't possibly relate to them."

A-T affects the cerebellum - the part of the brain which controls co-ordination - and also weakens the immune system, leading to respiratory problems and an increased risk of cancer.

Symptoms include lack of balance, slurred speech and increased infections. Because all toddlers take time to develop good walking skills, coherent speech and effective immune systems, it may be some years before it is properly diagnosed.

Emily attends the Treloar School and College for Disabled Children in Hampshire and, according to her doting grandma, is a young lady who not only knows her own mind but can twist her grandfather round her little finger. "She's a very positive person," Maureen said fondly.

They and Emily's parents, Nicola and John, have had enormous support from the Harpenden-based support group, the A-T Society.

For more information call Maureen Poupard on 01582 760733 or visit www.atsociety.org.uk

Alan Hammond of Wigmore with his much loved granddaughter Emily, who is 17.

The Rough Guide to Accessible Britain (Updated for 2010)

This guide is FREE for Blue Badge Holders. It has over 180 inspiring ideas for worry-free days out, featuring reviews and suggestions for disabled visitors, as well as accessibility information and advice

You can order your free copy from www.accessibleguide.co.uk or call 0800 953 7070, quoting ref MO400D

(Non blue badge holders pay £6.99 including p&p)

Attention all Barclays Employees

Are you an employee of Barclays? Do you know someone who is? If the answer is yes, then it could be possible for you to double the amount of money that you make through any fundraising activity that you do for the A-T Society.

Barclays has recently announced a new initiative. They will match the money raised by an employee through a fundraising event as long as it is between £100-£750.

See website for further details **https://barclays.givingforce.com/home.phtml**

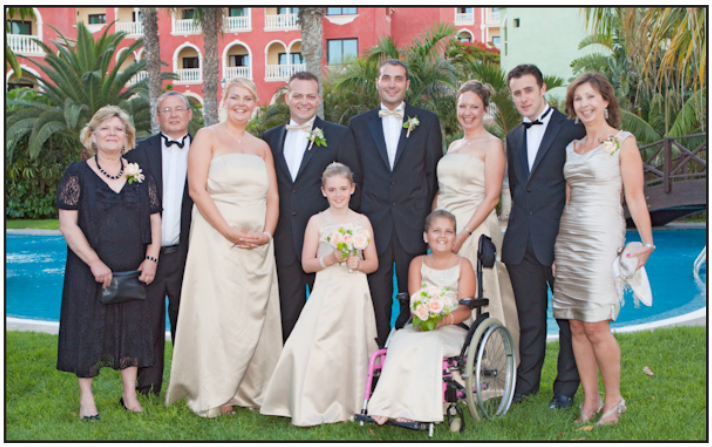
If you would like to learn more please contact Richard at the A-T Society:

Telephone: 01582-760733
E-Mail: **info@atsociety.org.uk**

Spotlight on Fundraising

The next few pages show the wonderful ways people have been raising money for the A-T Society this year. A huge thank you to all fundraisers for their fantastic efforts - without their help, the Society wouldn't be able to support families and fund research

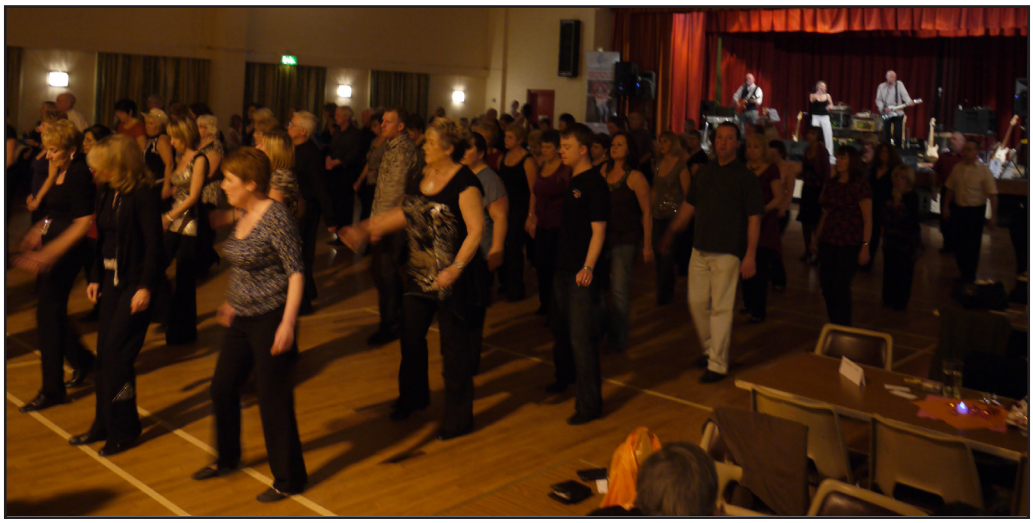
A very charitable wedding



Our warmest congratulations and thanks to Tim Hawley and David Northcote, who recently celebrated their civil partnership in Fuerteventura in the Canary Islands, attended amongst others by bridesmaid Sophie Wood, who has A-T (pictured right).

Very generously, the couple asked family and friends to donate to the A-T Society in lieu of presents. They also included an A-T badge as part of the wedding favours to their family and friends to raise awareness.

The pair has also helped the Society successfully apply for a grant of £3,000 from their employers' charity the Thomas Cook Children's Charity, which will go towards next year's Family Day. When you combine all of the money that the pair has accumulated for the Society a total of £3,500 has been raised so far! That's a great present for us all so many thanks to Tim and David. We wish you a very happy life together.



A Rootin' Tootin' good time on behalf of the A-T Society

In January 2010, Sheila Morel organised a Line Dance on behalf of the A-T Society. The Line Dancers were able to raise a total of £2,400 for the Society!

Sea Bank Marathon 2009

Last year Emma Davies took part in the Sea Bank Marathon. The 2009 marathon has been called the worst Skegness has ever seen in regards to weather. Emma had to deal with torrential rain and thunder storms as she took part in the grueling 26 miles. Despite all the hardships, Emma was able to raise £247.50 for the A-T Society. Congratulations!

Jez Smith (standing, right) presents the cheque to Spencer

Cub skip and jump

In November of last year the girls and boys of the Wool and Bovington Cub and Scout Groups raised £257.06 for the A-T Society.

To raise the money the children had to go around a circuit in their hall in as many different ways as possible, hopping, skipping, spinning etc and they were sponsored for the number of circuits they did.

All of the Scouts and Cubs had great fun and the evening was rounded off with Jennifer Owens giving a talk on A-T and answering some of their questions.

Dancing for A-T

In July 2009 the Happy Feet Dance Academy in Basingstoke held a raffle on behalf of the A-T Society and were able to raise an astonishing £1,135.40!

Pictured, from left to right. are Diane Gould, Beth Bartlett and Val Green, who were given the cheque in November 2009.

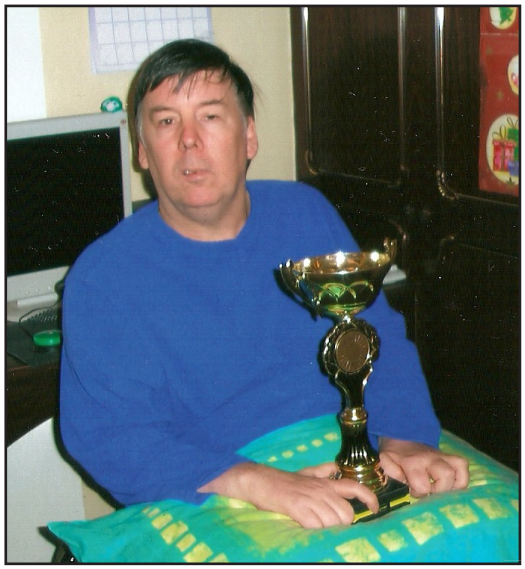
The Phab Club Quiz

By Dale Phillips

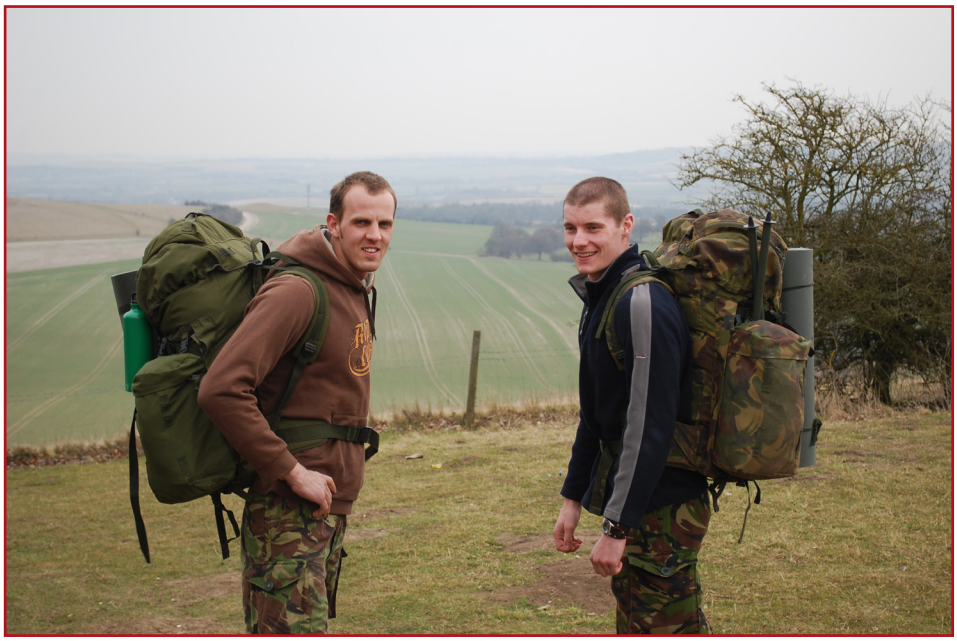
Back in October, we held our annual fundraising quiz night at Loxley House in Dukinfield. There was a raffle and some people baked. About 50-60 attended and £350 was raised.

We all divided into about ten teams of seven for a quiz. There were several different categories, mostly general knowledge. Our team's name was 'the Chippendales' and we were very surprised to find out that we won!

A few weeks later I was awarded with a very nice trophy, which came as a complete surprise! (Pictured right).



Sponsored walk: From Overton Hill to Ivinghoe Beacon in 58 hours



By Ian McBride

The walk (87 miles) started in earnest on Friday 19th March at 07:00 and was completed by 20:03 on Sunday 21st. Ross Plastow and I had an amazing experience, and one that will live long in our memories. Both of us are very proud that we were able to raise funds for the A-T Society.

As challenging as this walk was, we appreciate it is nothing compared to the day to day life of an A-T Sufferer. It was a complete pleasure to do this for the A-T Society, and something I would do again in the future.

An impressive effort

Lloyd Evans has raised an amazing £4,319 for the A-T Society by competing in two events, the 3 Peaks challenge and the Bridgnorth Walk. A big thank you from all at the Society, Lloyd!

Pictured left is Lloyd and friends who competed in the 3 Peaks challenge. (From left to right, Lloyd Evans, Rachel Ferguson, Derek Farrell, James Ferguson and Mark Mitchell.)

Office raffle

In March of this year, the staff of Steve Turzynski & Co held a raffle on behalf of the A-T Society. The staff raffled off the Christmas presents they had received but not wanted and were able to raise £101.00.


A-T Society
Ataxia-Telangiectasia Society
Ataxia UK
Caring today, researching for tomorrow
Join us on the 26th September for the 2010
Wheely Wobbly Walk
In Victoria Park, East London
For more information:
E-mail:info@atsociety.org.uk
Call us: 01582 760733

In brief

Computer help

There are volunteers based around the country who can help disabled people get better use of their computers! Visit **www.itcanhelp.org.uk** for more information

Family Support Worker's Hours Increased

Please note Kay's new hours should you wish to contact her:

Monday	8.30 – 3.30
Tuesday	8.30 – 4.00
Wednesday	8.30 - 2.00
Thursday	8.30 – 2.00
Friday	8.30 – 12 noon

Go Kids Go! Independence through Mobility

The Association of Wheelchair Children (AWC) is a specialist national charity providing expert training and advice to wheelchair-using children and their families across the UK. No charges are made to parents for these courses.

For more information, call 0207 473 3684 or visit their website **www.wheelchairchildren.org.uk**. You can also watch a short video here **www.youtube.com/user/GoKidsGo100?feature=mhw5**

Our thanks go to Tina Stubbs for letting us know about this charity.

100 CLUB winners announced

Listed below are the '100 Club' winners so far for this year. Congratulations all!

January: Jo Child (£25), Keith Larkin (£10)

February: Kathryn Knight (£25), Lisa Atkins (£10)

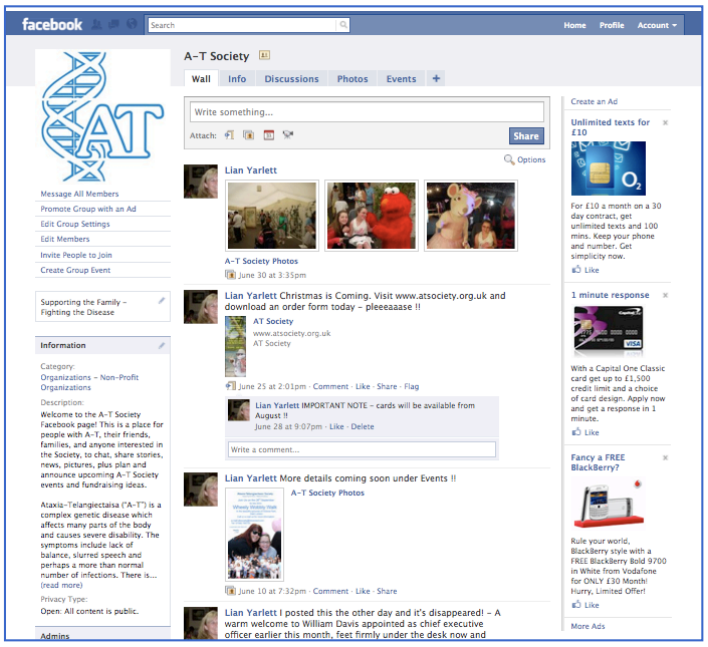
March: Travis Phillips (£25), Patricia Wooler (£10)

April: Teresa Lawson (£25), Jo Betts (£10)

May: Annette Smith (£25), Nieve Allan (£10)

Are you on Facebook yet?

There are currently 450 members in our Facebook group and we want more! It's a great place to meet people, share stories and publicise fundraising events. If you're interested but haven't got a Facebook account yet, feel free to contact me, Beatrice Forrest, on **bmpforrest@googlemail.com** and I will send you instructions on how to join.



Thank you

Our thanks go to Graham High who announced he's stepping down as a Trustee at the recent AGM. We are very grateful for his contribution to the work of the Society and wish him all the best for the future.

Donation in Lieu of Flowers

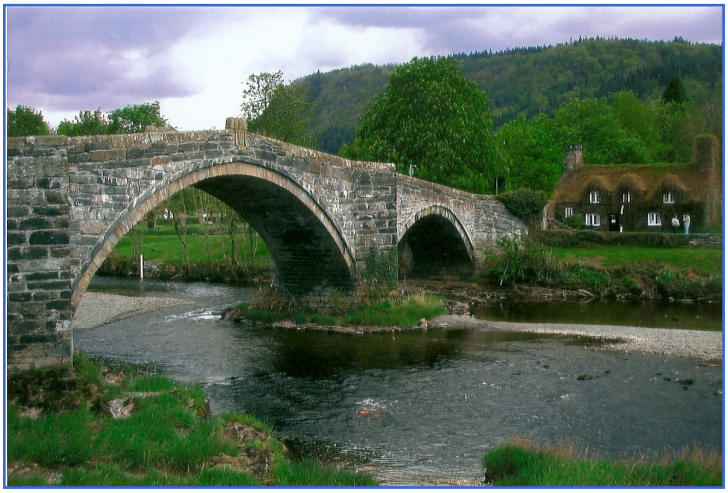
In March of this year, Peggy Alder's family made a donation to the A-T Society in lieu of flowers at her funeral. We send them our warmest thanks for their generosity.

Angela Sherry has moved on

Angie our fundraiser has left us to work for another small charity. Angie worked for the Society for nine years. We thank her for all the enthusiasm and energy she put into her work. She was very dedicated and we wish her great success in her new post.

Some of you have already spoken to Richard Daglish, a gap-year student, who has taken over Angie's role on a temporary basis. A new fundraiser will be appointed as soon as possible.

We also welcome, in addition to William Davis our new Chief Executive, Caryl Guest and Jill Curl who are both working with the Society as part-time volunteers to help with administration.



Dale's Holiday Diary

7-9 May, Llanrwst, Wales
My carer Dalpat picked me and the van up for our annual pilgrimage to the beautiful village of Llanrwst. We arrived at our destination at around 2.30 and popped into the local Somerfields to get some supplies for our two day stay.

We wandered to the local pub that evening then got some fish & chips, before hitting the sack at about 11.30.

The next day we went to Llanudno for a walk along the promenade. While having a bite to eat, a seagull swooped down and took the pork-pie I was going to enjoy out of my hand!

That night we went for an Indian restaurant which was very nice - I do like a curry every now and again!

On Sunday we packed and headed for Rhyl where we had a stroll along the front, then after a bite to eat we started on the journey home.

Benefactors 2009

Many thanks to all our benefactors in 2009:

30 Postal & Courier Squadron
The Company of Actuaries
Mrs RCR Airey
Mrs M Akerman
In memoriam - Peggy Alder
Mr Peter Alderton
Mrs M Alexander
Alexandra Maritime Charity
JMW Allison
Alison Archell
Asda Stores Charity
James Ashe
Mrs AM Bailey
Mrs HM Baker
Mrs JM Barber
Bartle Family Charitable Trust
Mrs B Bartlett
Steve Bernard Foundation
Ms Jo Betts
Mr & Mrs M Birch
The GE Birtwistle Memorial Trust
SD Black
Sydney Black Charitable Trust
Miss V Bolam
Mr & Mrs J Bowes
Mrs V Bradford
Mr Paul Brenson
Mrs JV Bridger
Mrs E Bridger
Mrs NG Brightwell
Mr A Brocklebank
Mr G Bromwich
Mr GF Bromwich
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DL & AG Brown
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Mr Alan Brown
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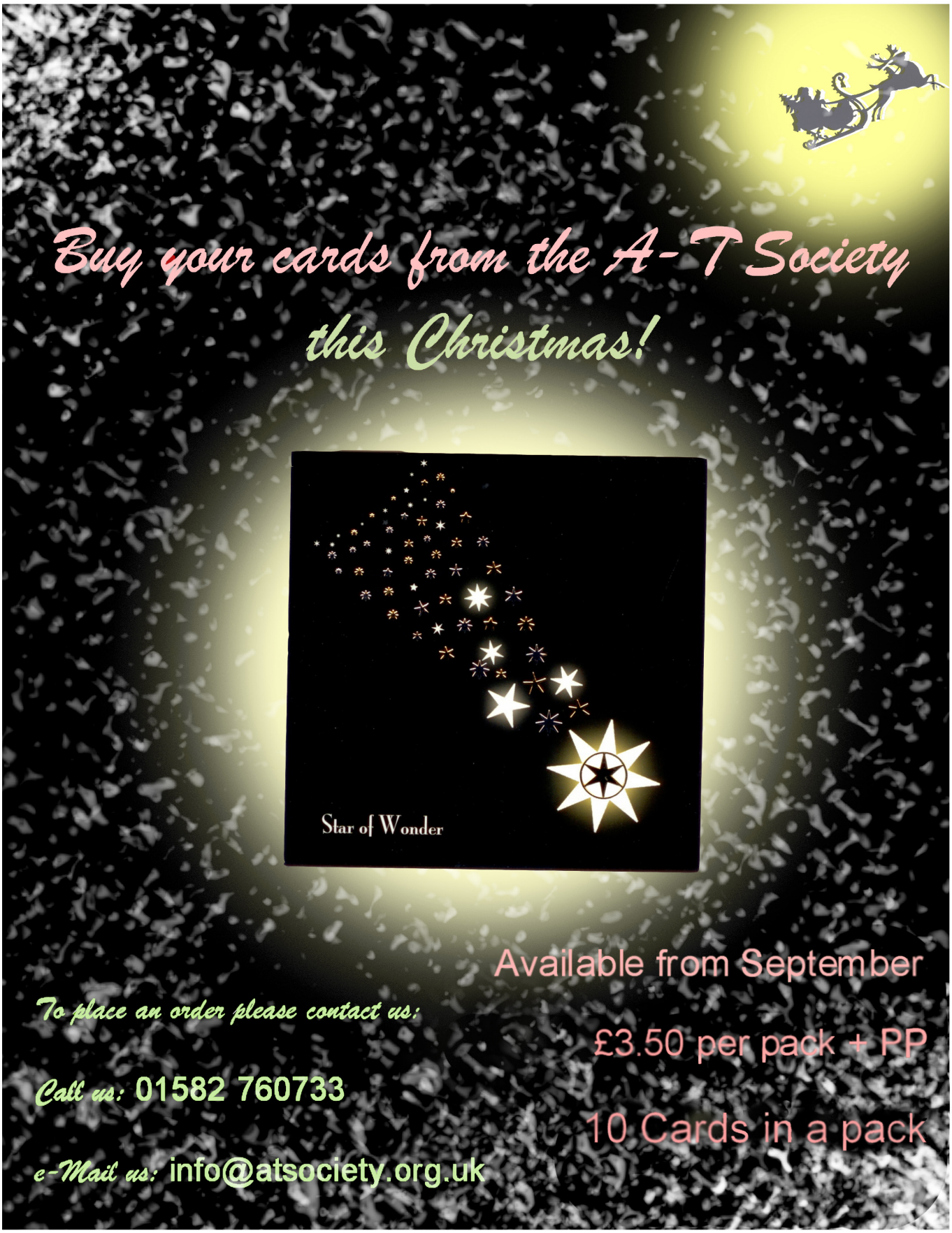
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