

A-T Society News

Inside:

Nottingham Clinic expansion p4

The A-T Society's 20 Year Anniversary at the House of Lords - pictures and speeches p5-13

Coming to terms with having a child with A-T p12-13



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	
Nottingham Clinic expansion	4
House of Lords reception in pictures	5-8
House of Lords Speeches	9-13
Wheely Wobbly Walk	14
Holiday Homes	15
Spotlight on Fundraising	16-21
Paula's visit to Papworth	22
Home learning & Walks with wheelchairs	23
Holiday & leisure	24-26
In Brief	27

Editor's Comments

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

Beatrice Forrest
71 Regency Court, Withdean Rise, Brighton, East Sussex, BN1 6YH
01273 746462

email bmpforrest@googlemail.com

If you would like to receive this newsletter by email as a pdf file, please let us know.

A-T Society
IACR-Rothamsted
Harpenden, Herts AL5 2JQ

tel 01582 760733 fax 01582 760162
atsociety@btconnect.com
website: atsociety.org.uk

Registered Charity No.1105528

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

Cover picture: Ian (ex-trustee) from Scotland, celebrated his 40th birthday on Saturday 22nd August
with many friends and family. Happy Birthday Ian from all your friends at the A-T Society!

News from the Society

Like many charities, our income has seen a substantial reduction this year as a result of the effects of the recession.

Being a small charity supporting a rare condition, we feel the loss of income more keenly than some larger, better known organisations. We rely heavily on grant-giving trusts for support, but they too are experiencing reduced cash flows as a result of recent poor investment performance. It is clear that, as a Society, we need to develop other ways of attracting funds, so the fund-raising strategy group led by trustee Lian Yarlett, is endeavouring to do just this.

I regret, therefore, that in 2010 we will not be able to fund an activities weekend for adults with A-T, nor will we be able to offer respite care breaks at a Winged Fellowship Home, as we did in 2008.

On a brighter note, the next international A-T Research Workshop will be held in Los Angeles in April 2010. We congratulate BrashAT, the Australian A-T support group, on successfully negotiating with the Australian Government and health authorities to establish a multi-disciplinary Clinic in Brisbane; this is scheduled to open in February 2010. The Society

and the clinic teams at Nottingham and Papworth are giving advice and support to the Australians. We look forward to cementing good working relations with them and wish them all the best.

Our thanks go to all those families who sent in case studies in response in my request and those who wrote to their MPs urging them to attend the 20th Anniversary awareness-raising reception held at the House of Lords in June. We were very pleased to have several politicians attend. You may recognise a few of them among the photographs in this Newsletter.

Thank you.

Maureen Poupard
Hon. Secretary

BBC Radio 4 Appeal

Congratulations and a big thank you to trustee Lian Yarlett who read the BBC Radio 4 Appeal on behalf of the Society on Sunday 15 November.

The Appeal has raised an impressive £9,000 so far.



Nottingham Clinic expansion

The Nottingham Clinic is now run as a partnership between the NHS, Nottingham City Hospital and the A-T Society. This arrangement came into place on the 1st April 2009. We have been able to expand the clinic as a result to offer families more consultations with specialists which means that the clinic now takes place over two days. Families are accommodated at either the Patient Hotel on site or in a nearby hotel.

These photos show families relaxing in the large reception area at the Children's Centre where all the consultations take place. As you can see there are plenty of toys to keep everybody entertained while they are waiting!



'The elephants went in 2 by 2'



Ebony with her parents and Kay Atkins, Family Support Worker



'Does it go here?'



Sophie with her mum Mindy



Guests mingled and enjoyed the view from the balcony

Reception at the House of Lords

On 2 June 2009, a reception was held at the House of Lords to mark the 20th Anniversary of the A-T Society and to raise awareness.

Our genial hosts were Lord and Lady Parkinson. The 150 guests included a representative mix of families, patrons, politicians, clinicians, researchers, trustees, former trustees, supporters and representatives from other charities with whom we are affiliated.

The three speakers were Professor Malcolm Taylor, University of Birmingham, Lian Yarlett, trustee and Vincent Poupard, acting chairman. Their speeches are included from page 9.

We were incredibly lucky as the weather was wonderful!

A huge thank you to the following sponsors who made this event possible:

- **CSL Behring UK Ltd**
- **Wyeth UK**
- **Pax Travel Ltd**
- **Z & B Vintners Ltd**
- **CCL Label (Ashford) Ltd**
- **Head & Short Podiatrists Ltd, Harpenden**
- **Tufnuts Hair Designers, Harpenden**
- **Wayside Dental Practice, Harpenden**
- **Skye Optometrists, Harpenden**
- **Spire Healthcare, Harpenden**

The day in pictures...



Lord Parkinson welcomes everybody to the House of Lords



George comes face to face with..... George!



From left: Hasita (trustee), Suraen, Supema and Shinali



From left, Maureen Poupard (trustee) with Lord Cotter and Marian whose daughter Emily has A-T



Mr Geoff Hoon MP for Ashfield talks to Siân and her father Jeff



Joe enjoys a joke with Lady Parkinson



Left: Lord and Lady Parkinson in conversation with Dr Tanja Stankovic who leads a team of researchers at the University of Birmingham investigating the role of DNA damage response genes in lymphoid tumours

Right: Dr Andrew Exley (left), Consultant Immunologist, Papworth Hospital, in conversation with Dr Nick Davies (centre), Consultant Immunologist, Queen Elizabeth Hospital, Birmingham



From left, Elaine (ex-trustee), Jeff (ex-chairman), Siân and John



Above: Tina whose son Charlie has A-T with the Rt Hon Michael Mates, MP for East Hampshire

What is A-T? What we know so far

Professor Malcolm Taylor outlines the research that has been carried out on A-T and the importance of the A-T Society

Good afternoon, ladies and gentlemen, my name is Malcolm Taylor, I work at the University of Birmingham and have been involved in research on ataxia telangiectasia for thirty years. I shall take just 5 minutes to say what A-T is.

Ataxia telangiectasia is a progressive neurodegenerative disorder that affects children and it is caused by a defect in the ATM gene resulting in absence of the ATM protein.

These children are of normal intelligence - it is just that the degeneration in the back of the brain severely affects movement and speech. Ataxia telangiectasia is mostly diagnosed in the first two years of life and has a similar natural history in many patients – losing function of both upper and lower limbs – so that these children have to resort to wheelchair use before teenage.

They have other serious problems including an increased risk of developing a leukaemia.

Some patients, however, have a slightly milder form of ataxia telangiectasia. And there is much that we can learn from these more unusual patients.

Over the 20 years of its existence the Ataxia Telangiectasia Society has helped families in different



ways. It established and funded a clinic for A-T children. This year, following some hard work, the Society was rewarded with an agreement from the National Health Service that it would take over the funding of the Ataxia Telangiectasia National Clinic from April 1st 2009.

The Society also funds research into the disorder. At present it is supporting a young doctor to relate the neurological score of patients to their particular ATM mutations, whether some patients have any ATM protein left and what activity remains. Using this knowledge base we will then be able to tell parents with some confidence the path that A-T will take in their child.

With regard to research, I am pleased to let you know that a few days ago, Dr Grant Stewart was awarded one of three

2009 Lister Prizes awarded nationally. I mention this because, Grant started his career with a Postgraduate Research Studentship, awarded by the Ataxia Telangiectasia Society. His major find then, was that another gene, MRE11, could also cause ataxia telangiectasia.

The A-T Society also has important social functions. I will just mention the annual Family day, which is attended by more and more families, and where there is an opportunity to meet other families and to talk to doctors and scientists working on ataxia telangiectasia. It is clear that families find both support and reassurance from the work of their Self Help Group.

Ataxia telangiectasia may be a rare disorder, but the impact on biology and medicine, of our understanding of the role of the

ATM gene, has been enormous. We all rely on the ATM gene and its protein to protect our cells – to protect us as individuals - from damage to our genetic material.

If we consider the general population for a moment now, and NOT ataxia telangiectasia patients, we know that some cases of breast cancer and also some leukaemias in the general population carry mutations in the ATM gene. In other words ATM is a cancer susceptibility gene in the general population. It isn't just ataxia telangiectasia patients that it affects. Its impact as a disease gene, therefore, is much, much wider.

And at this point I would like to acknowledge that Cancer Research UK have been consistently supportive of research over many years involving A-T patients.

We are here today for the Ataxia Telangiectasia Society. Where now? For the Ataxia Telangiectasia patients we have to find ways of stopping the progression of the neurodegeneration. Referring back to Beveridge - this our Giant. We know a great deal about what the ATM protein does in various cells, but unfortunately this does not include brain cells. We know very little. This is because we do not have access to human brain cells. However, the recent advances in inducing adult cells to revert to stem cells, may help here. We may be able to get mature cells from an A-T patient to revert to being stem cells and then get these stem cells to develop into neuronal cells that we can study.

Despite our lack of knowledge about what happens in the brains of children with A-T, we still have to think of treatments that will arrest the deterioration in the brain. There is a range of possibilities – some more immediate - like the use of existing drugs, to counter the effects of damage in cells where there is no ATM protein.

Although loss of ATM causes ataxia telangiectasia, we can at least survive without this protein. This may mean that some other genes might be able to compensate for its loss. Can we 'turn up' such a gene?

Overall, I believe that during its 20 years the A-T Society has seen important improvements for Ataxia Telangiectasia families. For parents, some of the uncertainties about the diagnosis have gone and the care of patients is improved.

Thirteen years after the gene for Ataxia Telangiectasia was identified, however, it is time that we were on the threshold of understanding Ataxia Telangiectasia the disorder and starting to treat patients.

A.M.R.Taylor,
Professor of Cancer Genetics,
School of Cancer Sciences,
University of Birmingham,
Vincent Drive, Edgbaston,
Birmingham, B15 2TT
Tel: 0121-414-4488
FAX: 0121-414-4486



Marking 20 years of the Society



Acting Chairman Vincent Poupard reflects back on how the A-T Society has progressed in 20 years and looks to the future

Your invitation states we are here to “celebrate” the 20th anniversary of the Ataxia-Telangiectasia Society. On reflection though, I wonder should we instead have chosen the phrase “to mark the 20th anniversary”?

To “mark” has a wide range of connotations. A teacher “marks” a pupil’s work, we can “mark time”, be “on our marks”, or we can “make our mark” and so on. Which meaning applies to us?

Probably, I think, most of them.

When our children, Gregory and Caroline, were first diagnosed with Ataxia-Telangiectasia the shock and confusion were, I am sure, no different from that experienced by newly diagnosed parents today. The fundamental difference now, however, is that the present day newly diagnosed child and family have, in the Society, an infrastructure dedicated to their welfare, in the broadest sense of that word; Professor Taylor has kindly referred to some of our achievements. In this respect, I suppose, we have made our mark. Yet we tell ourselves that, like the teacher’s comment on the school child’s work, we can and we must do better.

The Society is engaged as if on a marathon. It is 20 years since we were called to our marks, told to get set and were sent on our way. We’ve left the euphoric stage behind where we were fresh enough to delight in the landmarks en route - the first Clinic, the first PhD student, the first Newsletter. We’ve hit the wall but we’ve kept going, taking encouragement from other A-T groups around the world, but most especially from our supporters here who have

provided sustenance and the motivation to keep us pushing forward and not be content simply to mark time.

We are now within sight of the finishing straight. We have already begun to prepare for clinical trials and the very real prospect of, if not curing, then at least arresting and perhaps even reversing, the neurological deterioration which causes such devastation.

Professor Taylor has described the quest to arrest the progression of the disease as “our giant”. It is an apt phrase, especially if one recalls how a quick witted Jack, taking an axe to a beanstalk, dealt with his own giant. A metaphor, perhaps, for the application of thought to technology in research laboratories around the world.

But I call to mind a different kind of giant; Oscar Wilde’s “Selfish Giant” who was brought to an understanding of what love is by the sight of a suffering child. “Love”, like “mark” is also charged with many meanings. A parent’s love for his or her child is, as those of us who are parents know, unconditional and so it is not really a surprise that organisations like the A-T Society are generally established by parents; often, they have no choice. But I would argue that altruistic love, an extreme example of which is the love that prompts a man, in the words of the Gospel, “to lay down his life for his friends” – that sort of love - is more noble.

Exactly 100 years ago, in 1909, Lord Hugh Cecil said: “Virtue does not consist in doing right, but in choosing to do right”. The majority of you are here today because you have chosen to do

right. You provide the resources which enable the care of, and bring hope to, severely disabled young people who have no claim on you, save that of a shared humanity. And your support is bringing closer the day when what is now a relentless process of increasing disability will be halted and even reversed. You have and you will change lives.

As I have already said, we are tantalisingly close; it is too late now to abandon the race with the finish in sight. Stay the course, tell your friends, continue to support us so that, when next we meet like this, we can truly celebrate.

Vincent Poupard
Acting Chairman, A-T Society



Lian giving her speech

Coming to terms with having a child with A-T

Trustee Lian Yarlett shares her experience of her daughter Alecia's A-T diagnosis and the journey that followed

Good afternoon, my name is Lian, I am a trustee for the A-T Society. My husband Shane and I have 4 daughters, the youngest – Alecia has Ataxia-Telangiectasia.

From the age of 6 months we started to notice that Alecia was not developing as one would expect. She continually suffered from high temperatures and sickness. Alecia never really walked, it was more of a run and stagger – she fell so many times and her face or head always hit the ground first. She was consistently unwell and her speech was often slurred. By the age of 4 Alecia had a terrible choking cough and was diagnosed with bronchiectasis (lung damage), and soon after a diagnosis of primary immune deficiency, in layman's terms, an immune system that did not function correctly which meant Alecia would be prone to infections. Trips to our local and London hospitals were taking over our lives, each appointment exhausting for Alecia and emotionally draining for us. But we still felt which the doctors knew, that we hadn't yet got a full diagnosis.

“Trips to our local London hospitals were taking over our lives”

Alecia started at Junior School aged 7 and by this time needed a wheelchair, her eye movements had altered and whilst helping her get ready one morning I noticed her first grey hair. It was at this point that we actually put together the pieces of the puzzle, which is what A-T seems to comprise of – many different factors that gradually add up to a full picture, hard to diagnose and not always easy to spot, many of these individual factors conditions within their own right. On top of this she also has a high risk of certain cancers. The day of the appointment when the neurologist confirmed Ataxia-Telangiectasia was a terrible day that absolutely devastated us and changed our lives forever.

To think that my daughter is ageing faster than me is a very difficult thing to bear. Having to tell our other children was not easy, but for me the hardest of all was telling my parents that they may outlive their granddaughter.

We were introduced to the A-T Society, invited to the clinic in Nottingham and to the family day. At the Clinic we were met by some of the A-T Society office staff which made us instantly feel more at ease, faces to put with those voices at the end of the phone. I suppose we expected just another usual hospital visit but this was different, there were speech, occupational and physiotherapists; neurologist, respiratory consultant,

immunologist, geneticist and others. It had taken us 6 1/2 years to get the diagnosis, and here we were with every person possible in one place talking with us, supporting every aspect of Alecia's care. They all knew about A-T and would keep our local medical staff informed too.

“Here we were with every person possible in one place talking with us, supporting every aspect of Alecia's care.”

On the evening of the Family Day we were invited to informal drinks. Shane stood outside initially, Alecia and I went in to meet other families, and staff from the Society and doctors from the clinic were there too. I went to see if Shane was OK and I found that he was with other family members that also did not want to talk to anyone – all talking to each other. You could not have planned it if you tried. The informality of the evening was the key to its success. At the Family Day, the children all played and were fully entertained and looked after, as were the brothers and sisters. Parents and relatives had the opportunity to talk without the

children present, everyone met together for lunch and later in the day a very informative afternoon of talks & discussions whilst the children were taken out for an afternoon of fun. We came home from this feeling as if doors had been opened, more secure knowing that there was a support network for us all. At this point although I could relate to the immense organisation needed I had not given any thought to the fact that

the clinic and Family Day had been possible because the A-T Society had funded it.

“We came home from this feeling as if doors had been opened, more secure knowing that there was a support network for us all.”

I was asked 18 months ago to become a trustee, and have really enjoyed supporting the Society in this way. I hope that I bring a families perspective together with new ideas. Locally I continue to raise awareness and funds.

This is a journey which is a completely gradually progressive

neurological degeneration of someone you love, the only certainty being that you love them unconditionally and cannot change the fact that A-T will be their downfall. Alecia is now 11 years old, unlike our other children is dependant on us or others for help with every aspect of daily life, from the time she wakes helping her into her wheelchair to the time she goes to bed. Fully aware of the things that she used to be able to do with ease and now cannot, fully aware that the gap between herself and her friends is widening.

We as a family are very grateful for all the hard work that has been put in over the last 20 years and especially to those who have lead the charity along the way. The support and information they are able to provide is invaluable, raising awareness of this condition and supporting research

programmes paramount. All this is helping to provide the best care for our daughter now. We feel sure that as a direct result of the A-T Society's work, the future for sufferers of ataxia-telangiectasia and for the families is brighter than the past.



Alecia (far right) on the balcony at the House of Lords with (from left) her sister Beth, Nick and George

Wheely Wobbly Walk

A team of 42 from the A-T Society turned out to support the walk at Victoria Park, East London. This event took place on Sunday 27th September and was held to raise awareness and funds.

We worked collaboratively with Ataxia UK with the organization of this event. The weather was very kind to us, it was a glorious day and everyone had a great time.



Above: the wheely wobbly walk commences!



Above and below: members of the team with their certificates



Fancy a change of scenery?

We have had a fantastic idea put forward from one of our families about 'Holiday Homes'.

This would consist of a scheme where families would offer their homes to other families, for 1 or 2 weeks a year (or even short breaks), therefore giving families, who don't often get away, the chance to enjoy a break somewhere different.

If you are going away next year, maybe you can offer your home to another family? Or maybe you are hoping to

get away next year but are finding it difficult?

We would compile a list of all those who are interested in taking part in the scheme, whether looking to offer their home, or looking for a break!

We would then post everyone a copy of the list.

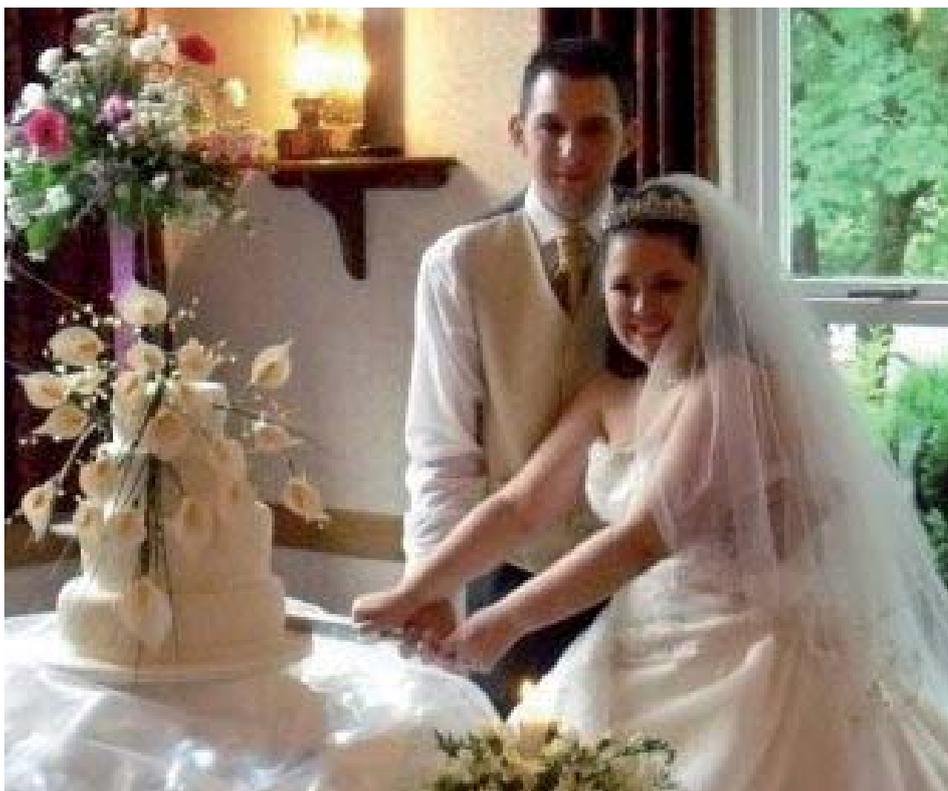
Please note that although the A-T Society will compile the list, we would not be

responsible for any private arrangements that are made, as this would be purely

between the two parties concerned.

If you are interested in the first instance, to discuss this further, then please contact Kay Atkins on 01582 760733, or email:

kay@atsociety.org.uk



Congratulations Alexandra!

Congratulations to Alexandra Wills who recently married her childhood sweetheart, Gavin.

Alex, who has A-T, celebrated her big day on August 28th at the Glen-Yr-Afon hotel in Wales. They had a wonderful, fairytale wedding.

The happy couple recently bought their first house together and Alex is now training to be a teacher.

We wish them all the best and a very happy future together.

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.



The A-T Team pick up the pace!

Dragon Boat Race

4 October 2009

The day had finally arrived from booking the boat some 6 months earlier to finding 17 volunteers; here we were at Basin 2 Medway Maritime. My 17 crew arrived and having turned down one suggestion of them all wearing mankini's, agreed to don the blue wigs. Batman and Robin brought a smile to everyone's face and we were hoping that their superpowers would help us on especially as few had previous experience of rowing..

The event itself was organised by our Kent Messenger who gave full support and supply of equipment on the day, necessary documentation including sponsorship forms, advice and publicity.

There were 3 heats, all timed; in 2 of these we found ourselves racing against an army squadron. Our crew started the morning by adopting the attitude that it is the taking part which is important, and by the time they had their training brief, they were psyched up and ready for really giving it their all.

Supporters came to watch as they rowed across the basin to practice their synchronising of oars. Joined

by 2 other boats they waited for the starting horn and the loud music of Hawaii 5 O! We all cheered and chanted 'A-T, A-T'. They came a very close second to the army team and we were all rather impressed.

They came out of the boat somewhat wet but very positive that they could get a faster time in their next heat - clearly the competitiveness had set in!

Two more races were held and we finished a very proud 7th out of 16 teams, rather impressive for 2 teenagers and 15 middle aged men. It was a wonderful day, the sun was shining and we had a big crowd rallying our troops.

The crew did a marvellous job, the atmosphere was friendly and fun, and we were on target to raise £2000... Our crew managed to raise an amazing £3800 and have even offered to row again next year!

Is there a Dragon Boat race in your area next year? Contact us and we can help you to get a team together.

Lian Yarlett

The A-T Team (including Batman & Robin) celebrate their great dragon boat race result



London Marathon

Hayley Radford's close friend Chris Taylor ran the London Marathon and raised £400 for the A-T Society. He is pictured above with Kira and the cheque!



Triathlon

Rob Colville took part in the 'King Sturge Property Triathlon' at Dorney Lake Eton on Friday 3 July. This included a 750m swim, 20km bike ride and 5km run. He completed the race in 1 hour 23 mins and has raised a total of £345 for the A-T Society. Great job Rob!

Parachute Jumpers

So far 13 very gutsy people have been brave enough to jump for the A-T Society:

Rachel from Cambridge; Bethany, Kelly, Rob, Chris and Jake from Kent; and Chris, Ruth, Bryan, Stephanie, Jordan, Aiden and Helen from Nottingham!

Altogether they have raised a fantastic £5,500. Congratulations guys!



Ruth Crisford celebrates after landing



Helen Chamberlain prepares to jump!



Bryan Rouse celebrates



The Kent group



The Nottingham group

A very special donation

The former Mayor of St Albans, Cllr Bert Pawle, hosted a special evening event on 16 October to present the £20,865 raised during his mayoral year to his three chosen charities: Grove House Day Hospice, St Albans; Keech Cottage Children's Hospice, Luton; and the A-T Society.

The Society received a magnificent £6,629.22 and offers its sincere and very grateful thanks to Cllr Pawle.



Cllr Pale (centre) presents the three cheques to his chosen charities (Maureen is to his right!)

Golden Wedding donation

Malcolm and Lorraine celebrated their Golden Wedding on 5 September with a lunch for family and friends. Rather than have presents ("At our age, we have everything we need already!" said Lorraine), they invited their guests to make donations instead to the A-T Society and the Muscular Dystrophy Campaign.

A magnificent £1,400 was raised so each charity received £700. Thank you to the happy couple and congratulations!

Fun Day in Bradford

Zeenat Ulnisa and Naz Hussain organised a Family Fun Day in Bradford on Saturday 1st August in aid of the A-T Society and Martin House Hospice.

Despite the rotten weather over £2,000 was raised. Thank you!



Fun on the Bouncy Castle



Families and supporters at the event

Glasgow Half Marathon

James Ashe completed the Glasgow half marathon in 1 hour 45 min 40 sec and raised £100 for the A-T Society.

Here he is before the race (with his son James) and after!



Royal Star & Garter Homes donation

£278.66 was raised by the Royal Star & Garter Homes. It was presented to the A-T Society by Bob Wells who works there and is also Stephen & Neil's Dad.

Shown in the photo is Kay Atkins with Stephen, Neil and Bob Wells, being presented with a cheque for £278.66.

Thanks very much from the Society!

Donation in Lieu of Flowers

A donation was made to the Society in lieu of flowers by Terry Paterson in remembrance of his former Mother-in-Law, Senora Rina Pita.

Thank you Terry for choosing to remember Rina in this way so that children with A-T will benefit.





St Patrick's and St Brigid's Primary School, Ballycastle with a cheque to the A-T Society

A very special thanks to:

The 'Havan Ladies' who send us regular donations.

Diana Bowes who regularly sends in donations.

Mike Lane who did a run in May and raised £351.00.

Regular donations from Morrish & Partners – donations given from staff for tea and coffee.

Tony Gormley who organized a charity football match and raised a total of £1,161.60. In addition to this we also received a further £200 from the Charities Trust Royal Mail Corporate Charity who donated a further £200 of matched funding (up to £200).

Mrs Joan Bridger who continually sends in donations from monies raised from Jumble Sales and the sale of Jam.

Donation of £423.28 raised by Neale Jagoe who completed the Great Wall Marathon in China.

Alan Hall who did a cycle ride in memory of Ryan Lecky and raised £1,155.

Schools who have raised money:

Wimbledon High School, London - £1,200.

St Patrick's and St Brigid's Primary School, Ballycastle - £400 (shown above).

Queen's Park Junior School, Bournemouth - £633.45.

Music Concert

On Saturday 11 July, Winchmore String Orchestra (an amateur string orchestra based in North London) presented a concert of music in aid of the A-T Society featuring the works of Aaron Copland, George Gerswhin and Felix Mendelsohn, amongst others. Many thanks go to Dr Louise Izatt and friends. £230 was raised and the concert was great!



Lian held a Coffee Morning on Fri 25 September to mark Ataxia Awareness Day and raised £800. Well done to Lian!

Paula's visit to Papworth

Last July, Paula, accompanied by her Mum, sister and niece, visited Papworth A-T Clinic for her regular check-up. These photos give you an idea of what the check-ups entail.



Paula with Jenny, the occupational therapist



Paula and Family at the A-T Clinic



In discussion with Dr Andrew Exley, consultant immunologist



With Steve, the social worker

Swine flu vaccine for people with A-T

As you may know, people with underlying medical conditions such as A-T are now being called to have the 'swine flu vaccine'.

Our Immunologists have confirmed that children/adults with A-T should have this vaccine. The vaccine is not a live vaccine and therefore you cannot catch swine flu from it.

For more information, please go to www.direct.gov.uk and go to the swine flu section.

If you have any further queries about this please contact Kay Atkins, Family Support Worker on 01582 760733 or email kay@atsociety.org.uk

The benefits of studying from home

Lisa Gregg, who is 41 years old and has A-T, describes how she has been able to develop her professional skills from the comfort of her home

I'm interested in figure work so I decided to do a Home Study Course in bookkeeping.

My first port of call was the internet to find an organisation that produced these courses. I settled on the Home Learning College and enrolled on a Sage Payroll course because I could do most of the work on my computer.

You were supplied with all the materials you would need, tutor support via e-mail or telephone and you didn't have to rush as you had plenty of time. The learning literature was set out in two work books with easy-to-follow instructions which took you through the course. After you had completed a new section you were given an assignment to see if you understood what you had learnt. At the end I took an exam which I also sat at home (you were allowed two weeks to complete it, so no rush).

I achieved my Level III in Payroll Management not for work prospects but for a challenge. I enjoyed the course and will now be doing another one. However, you do not get any financial help with the cost and they are expensive!

Are you interested in studying from home?

Home Learning College runs a wide range of courses in a number of different areas, from Accountancy to Web Design, IT, Business and Marketing.

All their courses lead to Industry Recognised Qualifications.

You can contact them on 0800 912 2926 or visit their website:

www.homelearningcollege.com



Walks with wheelchairs



www.walkswithwheelchairs.com

This fantastic website has been brought to our attention. It's dedicated to providing free information on routes that are suitable for wheelchair users throughout the UK.

All of the walks on their database have been tried and tested by wheelchair users.

Walks with Wheelchairs will allow you to:

- Read reviews of routes before trying them out
- Download walk directions and detailed OS maps free of charge
- Share your own routes for walking with wheelchairs
- Add your own comments for others users to view

If you visit this website and try out any of their walks, please let us know how you got on!

New York New York!

In July 2009, 24 year-old Rupert Prokofiev jetted off to NYC with his cousin Richard for a week. Here they share how they got on in The Big Apple.

Rupert's view:

Planning the trip

We did it all through a travel agent in Norfolk - she booked the flights, hotel and even tickets for a musical. The travel agent had helped arrange trips to New York for people with wheelchairs before so she was confident it would be manageable. It worked out cheaper than an online package.

Richard and I were both involved in the planning and wanted to do the same things. I wanted to go to more galleries than Richard though but that's a good reason to go back!

The highlights

Being there with Richard and no parents. I was looking forward to this from the start but I felt a bit nervous about Richard giving me the extra help. But it worked out fine and he reassured me. It would've been different if it had just been Mum and me. With Richard, he's the same age, has the same hopes and wanted to do the same activities. It was great to just be two blokes having fun.

Other highlights were going round the Statue of Liberty by boat and going up the Empire State Building at night - it was really nice seeing the city lights. There was lots of queuing though.

A major highlight for me was going to the parks - Central Park and the little Greenwich Village park. It was nice to escape the busy city streets - like being in a different place in a way.

A week was just the right length of time as we weren't rushing around.

Accessibility

It was quite busy on the 'sidewalks', especially when Michael Jackson died and when Tiger Woods promoted one of his games. But the sidewalks were nice and wide and there were plenty of drop kerbs on corner of each avenue.

We had no problems getting the wheelchair into restaurants because everything's bigger scale. Food was good especially the New York steaks!

The hotel was really nice. The only problem was that our room was on the 26th floors - every time I went up my ears popped! The staff were attentive; they



sent someone straight up when bathroom broke.

What would your advice be to someone with A-T who is thinking of doing a similar trip?

If you get a chance to do any holiday like this just do it. You've got to take risks to enjoy your life. Just go for it! If you're thinking of it, don't be afraid!



Rupert enjoying the tranquility of Central Park

Richard's view:

Rupert and I are cousins and good friends. This trip was quite ambitious as we'd never been away without parents or carers before. Both Rupert and I had quite a big commitment because it was going to be live-in caring. Rupert was great at letting me know what to do in regards to his disability and made it very easy for me to help. For me it was great - it felt like an adventure!

Getting organised

I studied maps before we got to New York so I had a rough understanding of where things were; then I could run ideas past Rupert. Luckily we have similar likes so it wasn't too hard to make decisions! It is definitely a good idea to familiarise yourself with things first.

We had a bit of a problem planning our days at the beginning of the trip because there is so much to see! We wanted to have a plan but we didn't want to be rushing from one place to the next and not taking things in. So we semi-planned and thought of a zone of Manhattan to visit each day and we left the hotel in the mornings for breakfast at about 10.30, which worked out well. The last few days were nice because we knew the place a bit more.

Getting around the city

It's quite flat in New York so that's good for pushing the wheelchair. The only thing is there are roads at the end of every block and the cars only stop when its red so u need to be quite alert.

We definitely needed the manual chair because it gets very busy. Sometimes around Times Square (where our hotel was) it got really busy but people were cooperative

if you just shouted 'coming through folks!' The subway isn't accessible for wheelchairs so we did a lot of walking. Cabs are everywhere so we used them a lot too; we would fold up the chair and put it in the boot. The cab drivers were fine with it but we usually opted to get a taxi from the hotel front door so we could get some help.

The museums had good access with lots of lifts. And they were free!

The highlights

The people! There were no false smiles - everyone seemed genuine, helpful and happy.

There are lots of good deals and carers mostly pay half price. When we went on the boat trip around the Statue of Liberty (which I would thoroughly recommend because bus tours aren't that convenient for wheelchairs) I was allowed in free.

What would be your advice be to someone with A-T who is thinking of doing a similar trip?

My advice would be to go for it. The plane was fine and staff helpful. Manhattan is great - lots to keep everyone entertained and Central Park is a great place to get away from it all. The staff everywhere are always ready to help so ask them and don't feel intimidated.

I can't lie and say it wasn't tiring; there was a lot of walking and pushing the chair around and it was quite humid. By the time the return flight was over I needed to sleep for a day! But the way I see it, it was completely worth it. It is quite a big trip to do but a great experience.

R&R's NYC Survival Guide

- **Always ask people for help! Don't be afraid to ask hotel staff or barmen for tips on where to eat, if they can get you a taxi or how much something will cost. They were always very helpful**
- **Take a small backpack in your luggage - very handy during the day for caps, sunglasses and straws**
- **Don't be too taken aback by the size of things. Just take your time and have a wander - these were some of our best memories. Having said that, you do need to make sure you see great landmarks too!**
- **Travel light! It was a bit of a struggle in the airport with the bags**

Rupert's mother's view:

I wasn't sure about New York at first. I thought it would be tricky with the wheelchair and that they'd be too far away if there was a problem. I saw how keen they were but really had to be persuaded!

The travel agent told us about 'Accessible Travel' catalogue holidays for the disabled which seemed the easiest option. But they then told us they'd provided bespoke holidays for people with wheelchairs before, at a quarter of the price. They could arrange airport pickups, pre book hotels and tourist trips. We decided to go for this option and weren't disappointed.

I hadn't realised how many places you could get to in New York by walking. Their experience made me realise anything's possible.

Alecia the adventurer!

Here's a photo of Alecia climbing the wall at the Arethusa Centre in Medway, Kent. She has also been boating there.

The Arethusa Centre specialises in adventurous outdoor learning for all ages, with many activities including archery, sailing, climbing and swimming.

They are well set up for all abilities. For more information visit www.arethusa.org.uk or call 01634 719 933.



Dale's Holiday Diary

My day trip to Chester, August '09



My day out in Chester began at about 9.30 on Friday morning when my carer Dalpat drove to our bungalow to pick me and our van up. We then drove to Droylesdon to pick up my other carer Cath, who brought a picnic.

Once we finally found a parking space, we had a brief walk around the city and then went to the park. Time was getting on so we found a bench and had our picnic - we had a bite to eat and something to drink.

It was a lovely park so we decided to explore it, until we came across the suspension bridge over the River Dee, where we took some photographs. We then sat by the river, just watching the boat and the people passing for a while, before heading back to the van.

We stopped at a shop briefly to buy some postcards of this historic city. At the van we loaded up and set off home.

Ian's trusty trike up for grabs

Ian has a recumbent trike that he no longer uses which is about 13 years old but in good condition. The trike is in Edinburgh where he lives; the transport costs would be borne by the taker. It is for an adult rider but Ian believes that some adjustments can be made.

Ian would love to see his beloved trike go to another person who has A-T. He clocked up over 1,000 miles one year!

If interested please contact Kay on 01582 760733 or email atsociety@btconnect.com



In brief

Next Family Day

The next Family Day will be on Saturday 8th of May 2010 in Nottingham (our usual venue). Kay will be writing to all families with more details in the new year.

A-T International Research workshop

Professor Richard Gatti, UCLA School of Medicine, Los Angeles, is organising the next A-T international research workshop in Los Angeles. It will take place on April 11-15 2010 in Redondo Beach, California. For more information visit <http://atw2010.pathology.ucla.edu/>

A special wedding

Congratulations to Richard Penelrick's sister who recently got married. Here they are together (right) on her big day.

New Editor becomes a Mrs!

You may have noticed on page 2 that the Editor has a new surname! I got married in June and am now Beatrice Forrest. It was a lovely day and my twin brother Rupert (p25) did a fantastic speech that I'll never forget.

Power trike looking for new home

Rupert Prokofiev is looking for someone to buy his battery powered trike. He's had many fun times on it but now feels it's time to pass it on to someone else.

It can go up to a very speedy 14mph - you change the speed by rotating the handle bar. It comes attached to a manual wheelchair so is really 2 in 1!

Frances and Rupert are asking for between £50-100 for the trike, as a donation to the Society.

If you're interested, please call Rupert's mum Frances on 020 8318 4677. She recommends you give it a test drive first, either by visiting her in

London or she can bring it along to the Family Day in May.

Rupert also has a spare electric wheelchair which needs a new owner. It is a Phoenix wheelchair with a 14" width seat. This was a very useful extra chair which he has grown out of. Again, if you're interested please contact Frances on the number provided.



Proud brother: Richard with his sister



Rupert's trike for sale

100 Club

Join the A-T Society's 100 Club!

Raise funds for us whilst giving yourself the opportunity to win a cash prize! Two winners per month!

Details will be sent shortly. If you can't wait, then phone Angie on 01582 760733 or email angie@atsociety.org.uk.

UNSUBSCRIBE

If you do not wish to receive our Newsletter any longer please fill out the form below and return to us at the A-T Society, IACR-Rothamsted, Harpenden, Herts AL5 2JQ. Alternatively email us: info@atsociety.org.uk

I no longer wish to receive the A-T Society Newsletter. Please delete me from your list.

Name _____

Address _____

Post code _____

Email _____
