ISSN: 1366-0209

December 2006
No. 35

A-T Society News

The Ataxia-Telangiectasia Society

Ataxia-Telangiectasia is a rare, inherited, neurodegenerative disease which affects many parts of the body and causes 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

International Workshop 4
News from the A-T Childrens Project 8
Prevenar Vaccine 9
Canine Partners 10
Papworth Clinic 12
Fundraising 14
Hydro Active Womens Challenge 16
A Measure of Scotch 18
Using the Web 19
Straw Thing 20
Trip to Keilder 21
Holiday in Spain 22
Travel...Blue Badge 24
In Brief 26
Letters 27

Editor's Comments

Once again, many thanks to all contributors. The copy date for the next issue is ***1st April 2007***
Please send comments, ideas, articles and pictures to the newsletter editor:

Jo Child, 54 Aston St, Oxford OX4 1EP
tel 01865 242690 joanna.child@ukgateway.net

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
atcharity@aol.com
website: atsociety.org.uk

Registered Charity No.1105528

cover photo: A-T Society supporters at Hyde Park for the HydroActive Women's Challenge

We are very sorry to report the deaths of Karolinka Sosnowska, from Poland, who died in July, and Catherine Akinnola, who died in September.
We send our condolences to their families and friends.

David Owens, Chair of the A-T Society, at the Hydro Active Women's Challenge in Hyde Park

Chairman's letter

Many thanks to all the contributors to this winter edition of the A-T Society News and to our Editor, Jo Child. I am sure you will find it yet again greatly informative and entertaining and commend to you its wider distribution as another means of raising the profile of A-T and of the Society.

Talking of raising the profile, the highlight for me in the last six months was the Hydro Active Women's Challenge in Hyde Park in September. No I did not take part, as promised, but I noticed one man did sneak in right at the end! It was gratifying to see the number of young people involved and also those a little older - including those for whom it was a new experience - making a great effort on behalf of the Society, (possibly inspired by the lovely photograph on the front of the last A-T Society News.)

A group has been tasked by the Trustees with reviewing our fundraising strategy and it is hoped that runs, marathons and a wide range of other fund-raising activities will continue to take place throughout the country. This would be helped by the setting up of local fund-raising and support groups, the feasibility of which we are currently studying.

In view of the operational changes necessary to tackle the two challenges mentioned in previous newsletters, we will also be looking at how those who want to can be involved in a possible new structure and play an active part in ensuring a sustainable future for the Society.

Disability Equality Duty

You may know that the disability equality duty (DED) comes into force on 5th December 06. This means that the Disability Discrimination Act 2005 will now place a duty on all public authorities, such as central or local government, schools, health trusts or emergency services, to pay "due regard" to the promotion of equality for disabled people in every area of work. They must do away with discrimination and harassment, promote equality of opportunity and positive attitudes toward disabled people and take steps to meet their needs.

It will be interesting to see how successful it will be as there are many concerns that some public bodies are not ready for the change.

Further information can be obtained from the Disability Rights Commission,
tel: 08457 622 633 or visit: www.drc-gb.org.

David Owens

RESEARCH UPDATE

2006 International Workshop on Ataxia-Telangiectasia (A-T) and ATM

Banff, Canada September 8-12, 2006

Professor Malcolm Taylor reports on the conference in Banff:

The backdrop for this years A-T conference, hosted by Drs. Susan Lees-Miller and Steve Meyn, was the rather idyllic location of Banff, situated in the Canadian Rockies.

There were approximately 150 participants from Europe, Israel, North America, Australia and Japan. The meeting was essentially devoted to the role of the ATM protein in the cell and, therefore, much of the conference was concerned with the biochemistry of the ATM protein and the techniques used to investigate this. The use of animal models was much in evidence. Mice have been bred to mimic many of the features of ataxia telangiectasia and of course their tissues are more readily available for study. Many other proteins interact with ATM in our cells and mice lacking these interacting proteins were also described and how this in turn affected the function of ATM.

One focus of the meeting was the question of how A-T might be treated although no potential new drugs were described. There was, however, a report from Howard Lederman (Baltimore) on the results of a small trial involving two drugs on A-T patients. He indicated that there did not appear to be any important changes produced in A-T patients by these drugs.

One of the problems with trying to treat A-T patients is the necessity of being able to measure a genuine small improvement or indeed worsening of the clinical features in an objective manner. Tom Crawford (Baltimore) reminded everyone of the neurological problems in A-T patients and he and a colleague described unusual eye movements in A-T patients that might be used to register such changes in an objective manner following treatment.

Turning to the A-T mouse and whether it could be treated, Dr. Nuri Gueven (Brisbane) provoked a lot of interest by describing an antioxidant inhibitor called CTMIO, that delayed the development of tumours in A-T mice. More remarkably the inhibitor could correct the neurological defects seen in these mice, including the ataxic gait. It appeared to have no side effects in the control mice also given the inhibitor. These observations provide a very exciting glimpse at potential therapeutic agents for treating A-T in humans.

Dr. Mike Kastan (Memphis) used the mouse model of ATM as a starting point to investigate further the link between insulin and diabetes in A-T patients.

Using the A-T mouse model, he presented evidence that these mice have symptoms similar to those observed in patients with metabolic syndrome, which includes increased blood pressure, type II diabetes and increased cholesterol. He then went on to look at a proper mouse model for metabolic syndrome that has had the ApoE gene knocked out. By treating these mice with a drug called chloroquine to activate ATM without inducing DNA damage, this could alleviate the symptoms of metabolic syndrome in these mice.

This suggests that ATM plays a role in the insulin-dependent signalling pathway that helps to suppress metabolic associated disease.

Dr. Junjie Chen (Mayo, Rochester) presented data about the MDC1 knockout mouse generated in his laboratory. MDC1 is another gene whose protein is involved in repair of damage to the cell, just like ATM. Interestingly, the MDC1 knockout mouse exhibits a number of features similar to A-T patients, that is, increased radiosensitivity, increased genetic instability, abnormal antibody production, an increased risk of developing tumours and surprisingly, premature aging.

These features fit with the proposed function of MDC1 as a molecule regulating the function of ATM.

There was an important session on “How the ATM protein is activated“ and the involvement of another protein complex called MRN in this activation process. The ATM protein acts as an intermediary between damage caused to the DNA and the cell’s response to this damage. The type of damage that the ATM protein recognises is breakage of both strands of the DNA - a double strand break. Indeed ATM sits at a point determining how the cell will respond to this damage.

An important finding by Dr Mike Kastan (Memphis) and his colleagues was that ATM itself becomes modified as part of this response process. The modified ATM is called ATMser1981.
At the meeting Dr. Kastan described a cell system in which he could induce a DNA double strand break in a defined site in a chromosome, at will. ATM is brought directly to the DNA break, a process that is enhanced by another protein hMre11 and its partners (MRN). Once at the break ATM becomes activated and this, in combination with the hMre11, can open up regions of the chromosome surrounding the break so that repair enzymes can gain access. ATM leaves the break but remains bound to the regions surrounding the break, presumably to oversee its repair and ‘zipping back up’ of the chromosome.

This was a very nice demonstration of how the ATM protein works.

Dr. Martin Lavin (Brisbane) also provided evidence that ATM can modify itself but at sites additional to ATMser1981, and that all these modifications were required for it to be fully activated.

However, intriguingly, Dr. Andre Nussenzweig, (Bethesda, Maryland) used transgenic mouse technology to derive a mouse whose ATM could not be modified to the ATM ser1981 form. Bizarrely, these mice were still able to activate their ATM quite normally.

So, on the one hand the ATMser1981 is required in human cells to activate the ATM protein, but on the other, the mouse does not require this modification to make its ATM protein work.

Why there is this disparity between mouse and man is not clear, but everyone at the meeting realised the contribution that solving this conundrum would make to an understanding of how ATM works.

On the same theme, Dr. Ji-Hoon Lee Austin, Texas) gave a talk a showing a role for the product of the breast cancer susceptibility gene, BRCA1, in helping ATM become activated following the induction of DNA damage, thus adding another level of complexity to the biology of ATM activation.

In addition to the failure of repair of DNA double strand breaks being linked to neurological defects, as in ataxia telangiectasia, there has been much interest in the role of a break in just one of the two strands of DNA also being involved in neurological disorders.

Dr. Peter McKinnon (Memphis) presented data about this so called DNA single strand break repair, and the nervous system.

He showed that knocking out a gene called XRCC1, in the mouse, whose function is critical to single strand break repair, specifically in the brain, esulted in mouse that was prone to fatal seizures.

Neurological examination of the brains of these mice, showed that unrepaired DNA single strand breaks during the development of the brain were converted to DNA double strand breaks, which ultimately resulted in loss of specific neurones. It is likely that loss of these neurones contribute to the severe seizures in these mice. This highlights the importance of DNA single strand break repair as well as double strand break repair in the developing nervous system.

Dr. Keith Caldecott (Sussex) gave some new insight into DNA single strand break repair. He provided some exciting data that was generated in collaboration with Dr. Steve West about the function of the APTX protein, whose gene is mutated in an A-T-like sydrome called AOA type 1. It appears that the APTX protein helps the DNA ligase stick the two DNA ends together by modifying one of the DNA ends. In addition, Dr. Caldecott provided some tantalising evidence of an AOA1 knockout mouse.

Another important session was on the role of ATM in tumour formation. Dr. Thanos Halazonetis (Geneva) presented an interesting hypothesis of how cellular barriers exist to prevent the transformation of a pre-malignant or benign lesion into a tumour. He described an important normal function for ATM was to suppress tumour growth. One feature of potential tumour cells is their ability to keep on dividing and growing in number. A by-product of this runaway growth is that damage occurs to the DNA because of the number of times that it has to replicate. The DNA damage activates ATM and ATM in turn signals arrest of growth; thus ATM functions to suppress the growth of potentially tumourigenic cells. If the ATM gene

The meeting was a great success in terms of the number of participants, and the breadth and quality of the presentations on all aspects of the function of the ATM protein.

or protein is subsequently lost then this check to growth is also lost. Cell growth will continue as will damage to the DNA. The DNA damage, or mutation, can produce a more malignant tumour. Therefore, the role of the normal ATM in inducing this check to growth may contribute to its function of preventing cancer.

Even the humble fruit fly has been put to the service of research on A-T. A rather interesting talk by Stacey Rimkus (Madison) using a fruit fly model of A-T demonstrated the existence of modifying genes that could alleviate or increase the severity of the symptoms caused by loss of ATM. This rather elegant system provided the first experimental evidence showing the existence of genes, which have been hypothesised to exist to explain why A-T patients with the same mutations or lack of protein can show variation in disease severity.

What we have written, we hope gives a flavour of this range of topics; we have not tried to list everything. The meeting was a great success in terms of the number of participants, the breadth and quality of the presentations on all aspects of the function of the ATM protein. Even the weather was warm and sunny all the time that we were there, although the snow arrived just a day or two after we left.

The next A-T workshop is to be held in Kyoto in Japan. It is certain that by that time there will be other important advances in research on A-T.

Grant Stewart
Malcolm Taylor

CR-UK Institute for Cancer Studies
University of Birmingham
Vincent Drive, Edgbaston
Birmingham
B15 2TT

News from the A-T Children’s Project

Thanks to Cynthia Rothblum-Oviatt, at the A-T Children’s Project, who has sent us this update on the research that the Project is involved in.

The international community of clinicians who treat patients with A-T is aggressively pursuing life-improving therapies for this disease.

In 2005, the A-T Clinical Center at Johns Hopkins Hospital, USA conducted a small, safety trial to help determine if an antioxidant therapy represents a potential treatment option for A-T. Fourteen participants, aged 12-20 years, received a combination of the antioxidant alpha-lipoic acid and a weak PARP-1 inhibitor, nicotinamide.

Results from this trial demonstrated that two markers of oxidative stress were significantly improved when participants took both compounds.

Encouraged by these results the Hopkins clinicians are now planning an expanded, dose-finding trial using these same compounds. It is hoped that this combination of drugs will be able to ultimately slow the neuro-degeneration seen in A-T.

The data from the Hopkins trial was recently presented at an A-T Clinical Research Workshop held in Bethesda, Maryland, USA near the National Institutes of Health (NIH).

Developing clinical assessment measures

This international meeting of industry representatives, A-T clinicians and basic scientists was co-sponsored by the National Institute for Neurological Disorders & Stroke/NIH, the Office of Rare Diseases/NIH and the A-T Children’s Project. The goal of the workshop was to develop a minimal standard protocol(s) for the clinical assessment of A-T.

Following this meeting, which was held in March of 2006, the NIH and the A-T Children’s Project have been facilitating continuing discussions amongst the participants to help finalise the clinical assessment measures.

Developing neurological assessment measures

In addition, the A-T Children’s Project, in collaboration with the National Institutes of Health, will be organising another workshop where neurologists and a cross-section of patients with A-T will be brought together to develop novel neurological assessment measures for this disease.

Clearly defined clinical measures for A-T will help clinicians world wide plan and implement effective clinical trials when the time comes to test potential therapeutic compounds for this rare, but devastating disease.

Cynthia Rothblum-Oviatt, PhD
Science Coordinator
A-T Children’s Project
Deerfield Beach
Florida
USA

www.atcp.org

Prevenar Vaccine

Dr Graham Davies gives an update on his research

I am happy to report that the Prevenar Vaccine study has gone extremely well and is now nearing its conclusion. For those who have not heard about it, this is a study using a vaccine against the germ pneumococcus which is a common cause of chest infections in people with AT. So far 30 people with AT have participated in the study to receive the vaccine and in addition another 18 who had already received Prevenar in the past have agreed to supply a blood sample so that we can check antibody levels. In many cases, myself or one of our nurses have travelled to the family home where we have always received a very warm and friendly welcome.

The preliminary results of the study are now coming through and we have results of the antibody levels on the first 25 individuals. These results show that most people did respond well to the vaccine, although a small number had poor responses. In the study some people received one dose of vaccine and some received two. It is too early to say how much better two doses were than one and this will need further analysis. However, in those individuals who received only one dose and had a poor response, I am contacting the family and GP asking that another dose of Prevenar be given, not as part of the study, but just as part of routine clinical care. There is no reason why this should not be given at the same time as the flu vaccine, but in the other arm.

We are still in the process of collecting late blood samples from everyone who had the vaccine to see whether the initial responses to the vaccine are maintained over time.

I am extremely grateful to all the families who have participated and to the A-T Society for its practical support helping organise the study.
I should also mention that none of this would have been possible without the hard work of Claire, my Personal Assistant, who has unfailingly managed to organise me, the vaccine and the family all to be in the same place at the same time, wherever that was in the UK or Ireland.

I should say that we still have a number of doses of vaccine left and could include further individuals in the study if anyone was interested. If so, please give Claire a call on 020 7813 8121. We also feel that there must be more people with A-T who have already received Prevenar in the past who we would like to know about, so that we could collect the single blood sample to look at antibody levels against the germ pneumococcus. Again, if you are willing to participate, please get in touch with Claire.

Glossary of Scientific Terms

We continue our regular feature explaining the meaning of some of the scientific terms you may come across.

Cells

The cell is the smallest structional and functioning unit of all living organisms. Cells are often called the building blocks of life. There are many different types of cells and they become specialised in different parts of the body such as in the blood, the nerves, muscles and bone. We humans have millions of cells.

The cell has 3 main parts: **membrane**, **cytoplasm**, and **nucleus**:

The Cell Membrane

This is like a thin skin that encloses the cell. It can control to some extent which substances pass through it.

The Cytoplasm

All those parts of the cell enclosed by the membrane, **other than the nucleus.** It contains all of the components (enzymes etc.) needed for the cell to function.
(Enzyme-a protein that assists chemical processes)

The Nucleus

This contains chromosomes. The chromosomes contain DNA (short for **d**eoxyribo**n**ucleic **a**cid). DNA carries genetic information.
The nucleus has its own membrane.

Maureen Poupard

Canine Partners

Canine Partners is a charity which aims to transform the lives of people with disabilities, enabling them to lead more independent lives, by providing them with highly trained assistance dogs.
A Canine Partner can respond to around one hundred commands, including opening and shutting doors, switching lights on and off, drawing the curtains, retrieving items such as keys or the phone, passing over the purse and items at checkouts and helping to stabilise during wheelchair transfers.

James Rose is a university student currently doing a degree in Broadcasting. He has Cerebral Palsy which affects his motor skills in the arms and legs meaning that he uses an electric wheelchair. He has been partnered with Nemo for 12 months. When James is not living in the halls of residences at University College Falmouth in Cornwall, he lives at home with his parents and two sisters in Hampshire near Southampton.

"*Before Nemo came along, I was finding it hard to socialise with people my own age. People saw my 'disability' rather than 'me' and found it hard to approach me. Now with Nemo by my side, it is much easier to get into conversation and my social life and confidence levels are improving. Walking him has got me used to driving over rough terrain without being nervous about tipping over.*

Nemo is such a quick learner and he can now open a door without his tuggy rope by jumping at the handle and walking backwards. He is so clever that in doing that he has mastered one of basic laws of physics!! He never stops surprising me - he's a dude! Nemo is like a part of me now, and to be honest, I could never be able to live without him because (in the words of Tina Turner) he's "simply the best"!"

Sarah and Hazel
Sarah, 23, used to spend most of her days alone at home. She could not even make a trip to the local shops on her own using her wheelchair because she experienced a great deal of pain when she tried to pick up and carry objects unaided. Before getting help from Canine Partners, she said "One of my main aims is that in the future I will be able to consider living alone with the minimum of support. My mother is my only carer and I would hope that my having the support and companionship of a dog would give her peace of mind to leave me alone more often".

Since being partnered with Golden Retriever, Hazel, Sarah's hopes and wishes have become a reality. With Hazel's assistance, she can go out on her own whenever she wants, meet new friends and do her own shopping. Her mother can rest assured that Hazel will always be there to give Sarah help when she needs it.

A Canine Partner is totally reliant on its human partner for feeding, grooming, exercise and play. Partners must be willing to undertake the majority of these responsibilities as it is not appropriate for others to manage an assistance dog. Partners with mobility problems have been very resourceful in finding strategies to complete these tasks.

They also need to give lots of praise to their Canine Partner: the dogs enjoy learning new tasks which will help their Partners, but in return they need love and affection.

If you are interested in finding out more, contact

Canine Partners
Mill Lane
Heyshott
Midhurst
GU29 0ED

tel 08456 580 480

email:
info@caninepartners.co.uk

www.caninepartners.co.uk

Direct.gov

information for disabled people and carers

Direct.gov is the place to turn to for the latest and widest range of public service information.

Find a wealth of information online for disabled people and carers covering:

- independent living , including equipment & home adaptations
- financial support
- caring for a disabled child
- NHS Wheelchair Service and voucher schemes
- disability rights and accessibility
- work schemes and programmes
- and much more

There is also information on health, education as well as links to charities and other helpful organisations.

For public services all in one place, visit:

www.direct.gov.uk/disability

www.direct.gov.uk/carers

Papworth Clinic

Rupert Prokofiev was the first to try out the new Papworth Clinic for young adults with A-T.

The Papworth Clinic offers a complete consultation including respiratory, immunological and neurological assessments.

The initial visit to Papworth is for 2-3 days as an in-patient, and Rupert is pictured here in the private room provided, where there is enough space for a fold-down bed for a family member or friend. There is also a small ensuite toilet and there is a bathroom down the corridor.

Rupert had a very full two days in the clinic, undergoing a lot of tests and meeting clinicians from all disciplines. His mother Frances, who went with him, said ‘It was quite tiring but we felt it was an extremely thorough assessment and all the people we met were very helpful. At the end of the visit we were told we could contact the hospital any time with questions, which is very good to know. As a parent/carer I was treated well too.’

Since Rupert’s visit, another person with A-T has been to the clinic, and it is hoped that * people will go over the next year. The Society can pay travel expenses for the person with A-T and a family member or carer.

A second visit follows about 6 weeks later which includes an overnight stay and a consultation with feedback and advice about the results, and after this, patients are offered an annual review.

Young people over 16 and adults with A-T can be referred to the clinic by their local GP or hospital doctor.

They can also be referred by Dr Susan Ritchie, Nottingham City Hospital, if they have attended the A-T Clinic based there.

Referrals should be addressed to Dr Exley (consultant immunologist) and Dr Shneerson (consultant chest physician),
Adult A-T Services,
Papworth Hospital NHS Foundation Trust,
Papworth Hospital,
Papworth Everard,
Cambridge
CB3 8RE.

Fundraising

Lian Yarlett

writes about organising a coffee morning and raffle for Ataxia Awareness Day.

Coffee Morning 25.September?
That's my birthday too, so yes lets!

Up went the very large poster at school at the beginning of September, made by our daughters, and that is when it all began. Initially having spoken with a friend, Michelle Keith, (mother of George) I was hesitant when she suggested having a raffle – I wasn't sure that anyone would be interested. Boy was I wrong!

Once people started to tell others, prizes started being offered for the raffle. I wrote to some local companies and some friends actually just asked when they were out -shops/gyms/friends. It was amazing. We ended up with 116 raffle prizes, over 25 home-made cakes for the table and some quiz sheets for people to have a go at.

I asked for a £1 donation for entry and everyone could drink as much tea & coffee as they wanted and help themselves to cake. The raffle ticket books sold out, some sold prior to the event both in the playground and with people taking them to work to sell. The raffle itself raised just under £1000.

From a little coffee morning to over 60 people

It mushroomed from a little coffee morning to us having over 60 people in our house. The atmosphere was friendly and relaxed, everyone that came knew of us or our daughter (Alecia) and were very supportive. It was not until that day that most people actually knew the diagnosis that we had been given some months before. We had a table with information about the condition and Michelle and her mum Lorraine had a table selling A-T branded goods and sold over £200 worth.

Everyone that offered to do something I said yes to - so the actual load was therefore spread between lots of people. Alecia's school also joined in by doing a tag day and allowing children to wear their own clothes for a £1 donation.

School network

The school network is something to behold – you have immediate indirect contact with a large number of people who may be able to support in some way, or they will know someone that knows someone and so it goes on.

In total the sum was raised was £2603.44! Plus gift aid - quite fantastic!. Also our local BUPA hospital supported the event and because of this BUPA Connections very kindly donated £2000 in addition.

I will do it again next year. I am not sure if it would be such an amazing success, but who knows, if you don't start off with high expectations then you won't be disappointed but you might be very surprised.

Everyclick.com

Raise money for the A-T Society just by searching the web.

www.everyclick.com is an internet search engine with a difference –
it donates half its revenues to charity!

It's a great way to give to the A-T Society every day and it doesn't cost you a penny!

All you have to do is choose the A-T Society as the charity of your choice
and make everyclick your home page, then use it whenever you search the web or shop online.

Help us spread the word. Tell your friends about everyclick.com
The search engine that helps charity

Hydro Active Women's Challenge

Caption:

More than thirty women and girls turned out on Sunday 3 September for this year's Hydro Active Women's Challenge on behalf of the A-T Society.

This 5k women-only event takes place annually in London, Liverpool and Birmingham and can take the form of a serious run, jog, walk or leisurely stroll. The increasingly popular event is organised by the team responsible for the world famous London Marathon and is designed for runners of all abilities and aspirations.

It attracts over 20,000 entrants, the vast majority of which are raising funds for charity.

Maureen Jenkins, Esther Turpin &Maureen Ainsworth

This year, the day dawned damp and wet, but by the time we had arrived at Hyde Park, the weather had improved and as we waited with anticipation on our approach to the start line, the sun came out and the conditions were absolutely perfect.

Everyone who took part on the Society's behalf agreed that they had really enjoyed the experience and plan to enter again next year. The spirit of the event is overwhelming; looking around at the sea of ladies taking part with their brightly coloured charity vests or t-shirts is really very heart-warming.

If you would like to join us in 2007, then **call Angie in the office on 01582 760733.**

I will take your details and contact you again when registration begins.

Angie Sherry

Meanwhile, in Liverpool…

Nav and Aimee Cooper and Zoe Harwood took part in the Hydro Active Women's Challenge in Liverpool on the same day, and raised £421 for the A-T Society.

Another caption

Pam Goodwill and friends

A Measure of Scotch

Seen in the photo are the Mayor of St Albans, Alison Steer with Richard Wooster and Niambh MacDonald.

"A Measure of Scotch" is an event to showcase the talents of 150 dancers of a Scottish country dancing school (the Heil' and Toe Club) which is based in Harpenden. Dancers are from age 3 to over 60!

The show took place on Saturday 14th October.

Better put something in here about how they raised money for the A-T Society.

Have you written a will?

Could you consider giving a legacy to the A-T Society?

A gift in your will to the A-T Society will help us improve quality of life for young people with A-T, provide practical support to families and fund vital research.

Legacy pledges can allow us to plan for the future. Knowing what funds may become available helps us to feel more secure about planning long-term projects.

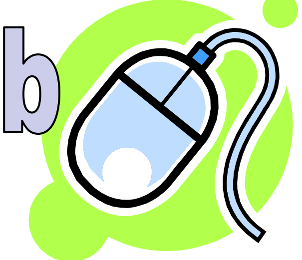
Any time your circumstances change, a birth, death, marriage, divorce – it's important to have a look at your finances, especially your will.

Having a will allows you to choose who should benefit from your estate and can also identify ways to save money through tax effective planning.

Not only can you leave money to the A-T Society but at the same time reduce your inheritance tax bill.

Thank you for your support.

using the web



Thank you to Ataxia UK for permission to copy this article from their magazine ‘The Ataxian’

Thank heavens for the World Wide Web. The internet is an absolute godsend for anyone who has mobility problems and especially when those problems are increased for whatever reason.

As things have happened in my life today, I have made a mental note of them and will share them with you now so you can see just how much an internet connection has become paramount in my life.

After having got up and changed, the first thing I did was to check my emails. Thanks to a program called ‘Mailwasher’ (**www.mailwasher.net**) checking all my emails is simple because the program does it for you. Every five minutes, it checks all the accounts you have told it to look at and reports back with any unread emails.

My car was collected at 9am by a contractor in order to take it to Cowal Mobility Aids to have the roof top wheelchair hoist and the hand controls removed. This is because the car has to be returned to Motablity ‘in the condition in which you received it’. The contractor inspected the vehicle before he drove off. He found and noted three pieces of minor damage which have to be removed before I hand the vehicle back. I google bashed (**www.google.co.uk**) the following site: **www.repairmagic.co.uk**, filled in the online form and sent the request for a quote and an appointment.

Immediately after breakfast I checked all my bank accounts and credit card balances. If you have an egg card (**www.egg.co.uk**) then the hassle of remembering and entering all your passwords and pin numbers is saved. Their site sets up a key safe which is stored on your hard disk and accessed when required. Checking all my accounts took me two minutes...and hey...good news: no-one had taken money from my account since yesterday. But had news: no-one had put any in!

Wednesday is Cleaner day for me. Doreen arrives at about 9.45 to do her weekly house clean. Today she asked me to buy some refuse sacks and some bin liners, as I was running low. I immediately went into **www.tesco.com** and added them to next week’s delivery.

My gardener also came round this morning (or should I say ‘my personal assistant who assists me with garden duties’). She re-potted one of the hanging baskets in the back garden and then told me that as it is more difficult for me to water those in the front garden (there being no outside tap at the front), I may want to consider some artificial hanging baskets. So I got straight on to eBay (**www.ebay.co.uk**) and was amazed at the quantity and variety of baskets available. The postage costs are quite significant but I am now waiting until one minute before the bidding period ends to bag a bargain!

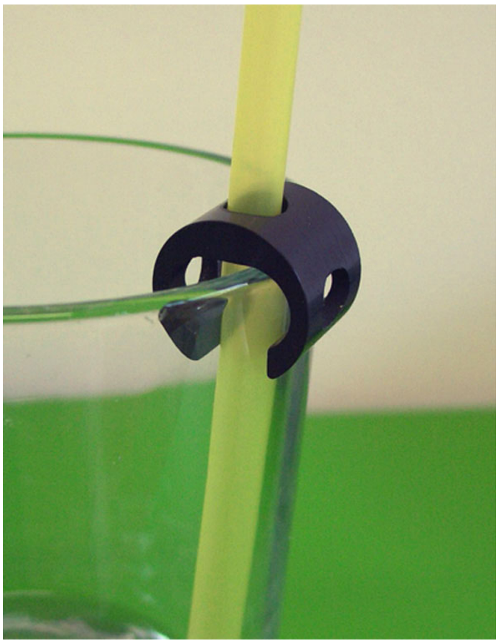
My post then turned up (did you know that you can order your first and second class stamps on-line—delivered to your door from **www.royalmail.com**?) Whilst we’re on the subject did you know you can send a parcel without leaving your front door, no matter what size or shape the parcel is, for £10? DHL will pick it up from your address and deliver it anywhere within the UK. All just by typing on your keyboard! See **www.parcel2go.co.uk**.

Any information that you need or anything you want to buy is available somewhere on the internet and the above gives you some examples of how you can manage your everyday life without even leaving your computer. You might also wish to visit **www.keepable.co.uk** for a variety of mobility and lifestyle ideas.

Happy clicking!

Matthew Law

The Straw Thing



Kay spotted a clever idea at a recent show.

Here David Buckley, one of the designers of the Straw Thing, describes what it is.

Isn't it often said that it's the little things in life that can make a big difference? At Such and Such Design we certainly hope that's the case as we launch our first and probably smallest product, the 'Straw Thing'.

Straw Thing is a new and incredibly simple invention to hold a straw in a glass or mug. When attached to the side, Straw Thing lightly clamps the straw and prevents it spinning around inside the glass. It also holds the straw at your chosen level within the glass, so when you get to the last sips of your drink the straw can stay in the liquid, even when the glass is tipped!

The need for a straw holder was first suggested to us by occupational therapists working at the National Spinal Injuries Unit at Stoke Mandeville Hospital. Straw Thing is currently being manufactured in the UK, and we hope to have it available to buy at the end of December.

Prices start at £3.50 for two, plus postage and packing, and Straw Thing will be available to purchase online from our website, or by mail order, and will hopefully be available through UK health-care distributors in the New Year.

Such and Such Design is a team of two design engineers, David Buckley and Hayley Smith, both of whom have worked in the field of design for disability for a number of years. We decided to set up our own company a year ago as we wanted to take a different approach to the design and production of so called 'disability products'.

Having met and worked with many people with various different disabilities, we came to understand the frustration of many with the apparent trade off between attractive, desirable products and purely functional items. We want to do things differently; to design inclusive, attractive products that meet and fulfill real needs. And we're always on the look out for more product ideas and feedback!

Please do get in contact with us via email at info@suchandsuchdesign.co.uk

or see our website for updates, www.suchandsuchdesign.co.uk.

Such and Such Design Ltd
259 Beckenham Road
Beckenham
Kent
BR3 4RP
United Kingdom

020 8123 8274

My trip to Keilder

Natalie Fitzhugh describes the 'best trip ever' : a week in Keilder

On a cloudy day in May we all set off from Francis House (the hospice where I sometimes stay) to Keilder, an activity centre which is wheelchair friendly. We travelled in a van which was very full, mostly of luggage and food. When we arrived we got the key to our lodge and unpacked. The lodge was lovely and there were people from other hospices in lodges as well.

During the day we did activities such as archery, rides in the golf buggies and speed boat. We saw some waterskiers when we were in the speed boat but they weren't as good as my mum as she has been waterskiing for quite a few years now.

Zip Wire

There was also an adventure course which was really good fun. I went down the zip wire [see above!] on my own - as I was feeling brave it was great but my helper Jackie from Francis House didn't think so as she doesn't like heights and screamed all the way down!

Afterwards we relaxed in the hydro pool. I told my helper not to panic if I went under the water, but panic if I didn't come up again! She had a look of panic on her face then started laughing!

Each evening the Hospices took it in turn to cook a meal. Our hospice made curry but my favourite was the barbecue with burgers and hotdogs.

All too soon it was time to pack and go home. There was a lot less to load up the van with as we had eaten all the food. We returned back to Francis House in the afternoon and we all decided it was the best trip ever.

I hope I am lucky enough to be invited again.

My holiday in Spain

Dale Philips writes:

My week long holiday in Spain began on Thursday 21 September when my dad drove us (myself and my helper, Eddie, from Ipswich) to Manchester airport at about 7am.

After checking in and getting a drink, we finally boarded the plane about 10. The porters transferred me to another chair and took me to my seat on the plane. They then lifted me into my seat. The flight went quite smoothly - even so we had a bacon baguette and a drink to calm the nerves!

Two hours later we landed in Malaga.

We were met by Adrian and Hannah – a couple I had met on previous holidays. They came in a wheelchair accessible vehicle and drove us to their villa which was about an hour's drive away.

The guest house was completely adapted for wheelchair users with ramps and wide doors. They had thought of everything - they even had a pool with a hoist to get you in.

The food was excellent. One of the best meals we had was a seafood barbecue.

They took the group out on four of the seven days, sightseeing, to tapas bars, and beach cafes – we even went for a picnic up in the mountains. On the days we did not go out we just sat by our pool catching some rays or going in for a dip.

In the evening, after the meal, we sat outside on the patio drinking and just chatting or playing games.

I thoroughly enjoyed the experience and hopefully will be going back next year.

Dale stayed at Las Piedras, a small guesthouse in the Axarquia region of Southern Spain, just 25 minutes from the coast.

Las Piedras has four air-conditioned rooms, all totally wheelchair accessible including en-suite bathroom. It is run by Adrian and Hannah Stone, who had many years working in tourism, and specialised in running touring holidays for disabled people, before settling in Spain. "Through our experiences we appreciate what is important for the disabled traveller and that the really good accessible properties are few and far between. With this in mind we have created our own guest house with excellent facilities for disabled people."

Travellers can choose between a full board package with transfers to and from Malaga airport, and four excursions, or a bed and breakfast package.

Or you can hire the whole house for a self-catering holiday.

For more information see their website www.laspiedras.co.uk
Or phone 00 34 952 033 100.

Have you had a good holiday that you would like to tell us about?

Do you have any travelling tips?

Write to us and tell us your story!

Travel

Taxicard

Taxicard is a door-to-door transport service for Londoners with serious mobility problems who have difficulty using public transport.

Financed by the London boroughs and the Mayor of London, the scheme provides subsidised trips in licensed London taxis.

If you receive the higher rate mobility component of Disability Living Allowance, you're eligible to apply for a card.

With a subsidy from your local borough council, you're likely to pay an average fare of about £3.50 per trip. A trip that normally costs £14 could be as little as £3.70.

For more information or an application form contact 020 7484 2929 or visit the website **www.taxicard.co.uk**

Once you've got your taxicard, you can even choose to book your taxi online.

Holiday cottages

SECOND SPACE is a new charity which enables people with second homes to offer one week a year to families with disabled children.

The charity then arranges free respite holidays for parents, with or without their child, depending on circumstances.

Second Space
Portobello Studios
138 Portobello Road
London
W11 2DZ

020 7792 9043

www.secondspace.net

National Trust

The National Trust produces a free access guide to all their properties. You can order the guide by phone on

01793 817634

or see it on the website

www.nationaltrust.org.uk/accessforall

Using a Blue Badge

New regulations came into effect on 29 September giving police, traffic wardens and other enforcement officers the power to inspect blue badges. Failure to produce a badge when parking on a yellow line or using an on-road space reserved for badge holders could lead to a £1000 fine.

Officers can also check for stolen, forged, altered and out-of-date badges.

The Department of Transport has prepared a guidance booklet for blue badge holders on this power and the way in which it should be exercised.

The Blue Badge Scheme: Guidance for blue badge holders and their drivers on the power to inspect blue badges being displayed on motor vehicles should be available from many information points and issued with new and renewed blue badges.

It can also be obtained from
DfT Free Literature Service,
PO Box 236,
Wetherby LS23 7NB.
tel: 0870 1226 236. textphone: 0870 1207 405
email: dft@twoten.press.net

Or you can download the guide from the website:**www.dft.gov.uk**

Protection for Blue Badges

Blue Badges are often stolen from cars, and it's a crime that seems to be on the increase.

A Blue Badge Protector (£15.99) provides effective security for badge holders. The badge is locked into a rigid protective sleeve, and a flexible lock attaches to the steering wheel. It's a visible deterrent which saves the mess and expense of a break-in.

The Double Blue Badge Protector (price £19.99) can hold the blue badge itself and your Time of Arrival parking disc.

You can buy these protectors from Pie Enterprises Ltd,
The Bridge, 12-16 Clerkenwell Road, London EC1M 5PQ
tel 0870 444 5435

or online at **www.thepieguide.com**

Mobility UK Road Atlas

A UK road atlas customised for Blue Badge holders. This motoring guide includes 65 major UK cities, showing every Blue Badge parking location, as well as local parking regulations and concessions for over 450 local, unitary and county councils. The guide also highlights accessible beaches, accommodation and toilets.

It costs £16.54 including p&p from Pie Enterprises: details above

In Brief

Disabled Living Foundation

Free, impartial advice about thousands of items of specialist equipment from bath seats to wheelchairs, jar openers to tap turners.
Call the DLF Helpline
0845 130 9177
Monday to Friday 10 to 4
www.dlf.org.uk

Ideas just for you

Self Assessment, Rapid Access (SARA) is a web facility provided by the Disabled Living Foundation.
All you have to do is key in some information about yourself and your environment and you will be provided with a detailed report with useful hints and tips and suggestions of products that might help you. You'll be given information about where you can buy or borrow the suggested equipment too.

www.dlf.org.uk/sara

Clinic

The Nottingham A-T clinic in May is already full, but there are places in June.
If you would like to be given a place, contact Kay Atkins in the A-T office.

Letters

Dear A-T Society News:

Support for Families in Australia

I'm Judith McKay, and I first learnt about A-T when I searched the internet to try and find information about my grandchildren – I couldn't believe they were just 'clumsy children'.
I couldn't find anything based in Australia, but found quality information in the U.K. and USA.

I knew about a program that provided a range of on-line features for community groups and individuals – and our A-T community was born in mid-December last year. I believe an Australian support group needs to be web-based to allow for the demands of A-T, and because of the vast distances in Australia. Only members can see the information in the community area. People apply to join, their application is approved, and then they have full access to all the community features.

I see myself as a facilitator of this community. It will grow and become whatever its members want it to be. I'm not sure if we will ever become a formal organization due to our small numbers.

The community provides a means for A-T families and children to have contact with other A-T children and families.

We have a few newly diagnosed families who have very young children as founding members, as well as more experienced families.

I've also had some contact with some very generous A-T families, who share their knowledge and care unstintingly. If we all can follow their role and share our valuable experience and knowledge – the journey may be a little easier.

The website acts as a contact point and is located at www.mc2.vicnet.net.au/ataust/web .

My direct email is judithm@tpg.com.au.

If there are any people out there in Australia who haven't been contacted, or who want to find out more, I encourage you to either visit our website or email me.

Kind regards,

Judith McKay

Do you have an experience you would like to share with the readers of A-T News?

Have you found a solution to a problem that others might like to hear about?

Do you have anything to say arising from the articles in this newsletter?

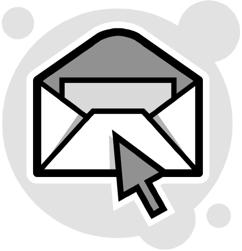
We would like to hear from you -

please send your letters to
A-T News - address on page 2.

SUDOKU

	6	9		5		2	7	
8			7		9			5
2			8		4			3
	9	2				8	6	
6								1
	8	7				4	5	
9			3		5			2
7			6		8			4
	3	8		1		7	9	

Penpal list



The penpal list, for young people with A-T, has now been updated.

We have 23 penpals on the list, ranging from age 12 to 49, from the UK, Australia, Spain, Poland, USA and Georgia. The people from abroad are very keen to hear from people in the UK.

If you are aged 12 or over and you would like to get involved, call Kay in the office on 01582 760 733.

This is a great opportunity to communicate with other people from all over the world.

Family Day 2007

The A-T Society is holding another of our popular family days on

Saturday 12 May 2007
in
Nottingham

Put the date in your diaries!

For more information, contact
Kay Atkins
at the A-T Society office

01582 760 733

Merchandise

We have the following items for sale:

Mugs £5

A-T Lapel Badges £1

T-shirts, from £7.50:
Pink womens t-shirts, sky blue gents t-shirts, black running vests

Tea-towels: £2.50

To order, please contact the A-T Society.

A-T Society, IACR-Rothamsted, Harpenden, Herts, AL5 2JQ
ATCharity@aol.com
tel 01582 760 733 fax 01582 760 162
Reg Charity No 1105528