

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.

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Editor's Comments

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

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

Cover photo: Alecia Yarlett at the Family Day

We are very sorry to report the death of Liam Murphy.
We send our condolences to his family.



**David Owens,
modelling the
A-T Society polo shirt**

“May I urge readers to help raise the profile of A-T and the Society, by passing on copies of the newsletter to other people”

Chairman's letter

Once again I feel compelled to include in my introduction to this issue of A-T Society News a considerable number of votes of thanks.

Looking back..

Looking back to the Youth meeting I offer my thanks and appreciation to all members of our Youth Group who gave me the opportunity to see “Mama Mia” after their combined meeting with the Trustees in March. As on previous occasions this meeting was a most useful, instructive and enjoyable event.

For the Family Day, congratulations and many thanks go not only to our Family Support Worker Kay Atkins, but to all those staff, trustees and helpers involved in the planning, organisation and delivery of yet another successful event. The speakers and presenters played their part, as did those available for formal and informal discussion and individual support; and especially all the families, friends and supporters attending.

We were honoured by and benefited greatly from the presence of Dr Tom Crawford from the United States on the day, as well as at the Friday clinic and the family dinner. It was good to hear the positive account from Rupert Prokofiev of his visit to the Papworth Clinic and to know that this is going well. We are grateful to Dr Exley and Dr Shneerson and their colleagues for establishing

this new service for young adults with A-T.

Trustees Maureen Hammond, Alan Hammond and Lorraine Birch have retired and I would like to take this opportunity to say how much we appreciate all their considerable efforts on behalf of the Society. Having said that they have retired, I know that we shall continue to benefit from their efforts, particularly in fund raising. I would like formally to welcome Lian Yarlett to the Board, elected at the AGM.

The fund raising sub group, set up to review the Society's income generation, has had several fruitful meetings. One aspect of our fund raising strategy we have been discussing is the provision of support, advice and material to a network of local fund raising groups, or individuals raising funds throughout the country. We have also been looking at the possibility of widening and strengthening our support base by seeking the addition of “celebrities” or others whose presence would enhance our efforts in raising of profile and funds.

The group is still working on both matters but we would be pleased to hear from anyone who may need further help and advice in fund raising, or who has contact with, or access to, people or organisations we may wish to approach for support.

Once again many thanks and congratulations go to all the

runners of the London Marathon for their achievement and great effort on behalf of the Society.

Looking forward.....

We look forward to the Hydro Active Women's Challenge in September and in advance I would like to pass on my appreciation and admiration for all those taking part.

Also in September will be the Ataxia Awareness day. I know that a lot of people are preparing for various events and fund raising activities around that time.

I have requested that if we have to have a photo of myself in this magazine, it should be of me in a recently acquired A-T polo shirt, one of the items on our list of merchandise, which we intend to expand. Many of you, I am sure, will be buying (or selling) what is on offer in support of the Society.

Finally may I give my heartfelt thanks to our staff and Trustees and to all those who work on behalf of or who support the Society and our families for making possible our continued progress on all fronts. We are so very grateful to have the goodwill of so many kind people.

David Owens

News



Goodbye - but not completely!

Many of you have met Dr Susan Ritchie at the A-T Clinic in Nottingham. Sadly for the Society, Dr Ritchie has relinquished her post at Nottingham City Hospital and returned to General Practice last February. Dr Ritchie has been involved with the A-T Clinic since its beginnings in 1993, playing a central role in its development and success as well as being extremely supportive of many other aspects of the Society's work. At the Family Day 2007 we presented her with an engraved bowl as a token of our appreciation.

We are delighted to report however that Dr Ritchie has agreed not to leave us completely! We will still be able to call upon her as a medical adviser from time to time. We thank her for all her support over the years and look forward to our relationship continuing in a new way. We wish her all the best in her new post as a GP.

Welcome!

We welcome Dr Mohnish Suri, consultant clinical geneticist, to the Nottingham A-T Clinic. We are delighted that he has agreed to join the clinic team and thank him for his commitment to the A-T cause.

Patrons

We are delighted to welcome back to the fold as our patrons, two former chairmen of the Society, Archdeacon Derek Hayward OBE and the Rev Canon Paul Thomas OBE.

We thank them for their continued support for the Society and look forward to working with them in the future.

Email forum for Clinicians

There is a new facility available to clinicians dealing with A-T patients.

It is an international emailing forum specifically for them. The idea is that they will be able to seek advice from other A-T experts should they need it.

The forum is administered by the A-T Children's Project.

Any clinicians wishing to register should contact Jennifer Thornton, Director of the A-T Children's Project, by email:

Jennifer@atcp.org

Ataxia Awareness Day

Each year, International Ataxia Awareness Day is celebrated on 25 September. It is supported by the A-T Society, along with Ataxia UK and other organisations around the world.

The aim of the day is to tell more people about ataxia, help people to understand the effects of ataxia, and help raise funds for research into treatments.

If you are thinking of organising a fundraising event this year, how about doing it on or around Tuesday 25 September? Perhaps you could run a coffee morning to raise funds for the A-T Society.

For help with planning your event, you can call the office. We can supply you with leaflets and publicity materials.

Family Day funding

This year's Family Day was supported by the Barbara Ward Children's Foundation. We are very grateful for their generous donation towards the costs of the day.

Below: the 'alternative agenda' at the Family Day in May



Research Update

A quantitative neurological assessment of Ataxia-Telangiectasia



Dr Venkat Srinivasan, (centre) with Dr Nick Davies (left), Neurologist at Queen Elizabeth Hospital in Birmingham, in conversation with a parent.

At the Family Day, Dr Venkat Srinivasan, the Society's Clinical Research Fellow, spoke about his project, which is investigating links between the rate of neurological deterioration and the type of A-T mutations.

This is a summary of his talk.

ATM protein is necessary for good health. We know that people without ATM protein, or with a very small amount of this protein, have Ataxia-Telangiectasia. The function of this protein is to allow our cells to respond correctly to DNA damage.

We also know people with A-T have different levels of neurological disability. Some have early manifestations of cerebellar signs and some late. Some progress very slowly and others quickly.

From this research, which I am doing with Professor Malcolm Taylor, we are hoping to find out

whether the degree of neurological deterioration is related to the level of ATM protein activity or mutations.

This study consists of doing two things:

First, we will measure the neurological manifestations, the variation in presentation and the progression of the disease in patients with A-T. This is done by a clinical examination.

Second, we will assess ATM levels in the same patients, in the lab, using blood samples. We will then try to find a correlation between ATM levels and neurological progression.

Are you willing to take part in this research?

What to expect

You would be seen in the Neurology Clinic at Queen Elizabeth Hospital, Birmingham. Or you could have a home visit, if you prefer.

In the Neurology clinic we will do a complete neurological examination - just a normal exam - to assess:

- eye movements
- adventitious movements
- gait
- head alignment
- speech

standing
sitting
swallowing ability
strength of muscles and coordination
sensations and reflexes
weight for height

Each of these measures would give a score, and these scores would be combined to give an overall score. This is based on the methodology devised by Dr Thomas Crawford, from the Department of Neurology, John Hopkins Hospital, Baltimore, Maryland, USA.

We would also take some blood samples to find out mutations, assess the ATM protein levels and its activity.

We would then have a score comparing differences in sub-groups of A-T according to their age, sex, neurological manifestations, mutations, protein activity. We can also compare variations within families and variations between families.

We hope to be able to use this information to provide an accurate neurological prognosis, for parents, of newly diagnosed patients.

Prevenar Study

At the Family Day, Dr Graham Davies gave an update on his research. This is summarised below.

Many of you will already know about the Prevenar Study, which is now nearly complete.

Prevenar is a vaccine against the germ pneumococcus which is a common cause of chest infections in people with A-T. The vaccine contains extracts from seven of the most common types of streptococcus pneumoniae bacteria.

The study was undertaken to find out if the vaccine could be of benefit to people with A-T.

It was hoped that after receiving the vaccine, patients with A-T would show an increased level of antibodies against pneumococcus. This should result in fewer chest, sinus and ear infections, and a reduced need for antibiotics. A further outcome of the study would be a better understanding of immune response in people with A-T.

How the study was run

Participants in the study were selected who were over two years old and had never had Prevenar. Anyone who had had immunoglobulin was excluded from the study.

A blood sample was taken before the vaccine was given, and then four weeks afterwards.



Dr Graham Davies (left) with Professor Malcolm Taylor

These blood samples were tested to measure levels of antibodies to pneumococcus. Another blood sample would be taken six to eight months later, to see whether the initial responses to the vaccine were maintained over time. In the later sample, the quality of antibodies would be tested.

Results

35 patients were recruited to receive the vaccine, ranging in age from 2 to 49 years. These were randomly selected for a single or double dose of the vaccine. 17 patients received a single dose, and 18 patients received a double



dose. So far, 26 pre- and early post vaccine samples have been analysed. Samples are still being collected.

A different group of 20 patients, who had had the vaccine before the study started, were not given the vaccine, but were also tested for antibodies. These patients ranged in age from 4 to 26 years. In this group, samples are still being collected.

Side effects of Prevenar

A number of side effects were noted. These were: soreness or small redness of arm (11 patients), itchy rash (1) and mild fever/general aches and pains (1). There were no other side effects.

Response to the vaccine

A response to the vaccine was taken as:

- Doubling of antibody level to a minimum of 0.35mcg/ml **or**
- Achieving a level of >1 mcg/ml

22 out of the 26 subjects responded to six or more of the seven serotypes or already had protective levels of antibody.

4 subjects (two each receiving double & single doses) failed to respond to three or more of the serotypes.

There were no differences observed between single or double doses.

Conclusions

At this stage, the results are preliminary and partial.

These preliminary results show that the vaccine is well tolerated in people with A-T. In most patients, the vaccine is effective in producing a good early antibody response.

There is no significant benefit of 2 doses over one.

However, further analysis is needed.

Future

If patients show a poor response to a single dose, they will be given a second dose. If there is a poor response to two doses, preventative antibiotics should be considered.

Further analysis needs to be done to see if antibody levels are maintained.

Antibody affinity information will help doctors to predict the lasting effect of the vaccine (immunological memory).

A follow up study may be done in approximately five years' time.

In the UK, all infants are now routinely immunised with Prevenar.

Acknowledgements

Dr Davies recorded his thanks to families involved in the study, to Maureen Poupard and Kay Atkins, and to the A-T Society, for helping with the research.

He also acknowledged the contributions of his personal assistant, Claire Core; the staff of the Nottingham A-T Clinic; Lindsay Ashton; David Goldblatt ;and Wyeth Pharmaceuticals.

Open Forum

The Open Forum at the Family Day in May offered people a chance to put questions to a panel of experts. The following is a summary of some of the issues discussed. The remaining questions will be covered in A-T News in December.

Do Pedro boots do any good? How?

The purpose of Pedro boots is to stabilise the ankle, minimise the movement of the mid foot, and help prevent tiptoeing. They have been used in the management of unstable feet in children for many years. Whether they do any good depends on the individual in question.

The young person with A-T uses their foot movement to help maintain their balance when walking. However, we are aware that the altered movement pattern may lead to altered postures of the foot, which may become permanent. Pedro boots may help to prevent this. The outcome of wearing them differs in each child. They may have the desired effect of improving foot posture, increasing stability and minimising falling. If so, no problem – provided that the amount of walking is not also reduced. However, if they make walking more difficult, and reduce independence, this is not so good, since maintaining function and independence should always come first. If Pedro Boots are used, the time in them must be balanced with using other shoes and with walking barefoot.

Night time splinting may be more effective and easier to manage. Above ankle trainers may be as effective and have more street cred than Pedros.



Is it common for children with A-T to have bad dreams and become upset during the night?

The medical experts on the panel did not have a sense that this was any more common amongst children with A-T than other children, although several parents spoke about their children having this problem. It was suggested that if the problem is intrusive and persistent, your child should see their local neurologist or sleep physician (who is often a chest physician). By measuring the child's brain waves and oxygen levels during the night, doctors can determine whether these are night terrors or problems with the child's sleep regulation.



Pictures: Family Day

My child has recently developed a hand/arm tremor that prevents him from doing the things he likes to do, like playing with lego and colouring. It is also impacting on his limited writing and use of the computer. It seems to have a mind of its own or suddenly jerks. Is there anything that will help minimise this?

Tom Crawford spoke about a Velcro wrist band which can be attached to a fuzzy strip next to the computer, making it easy for the person with A-T to secure their wrist down and take it off again. He said this had proved very helpful with the jerk and tremor on the keyboard.

Weighted wristbands can be effective, helping to dampen the movement. Weighted pens are available too. Some children have found it helpful to have a wrist band, attached to a strip of cloth which is tethered to the front of the keyboard, so that if the arm jerks it doesn't move so much – it's easier to bring it back. The Aidis Trust and other specialists have a range of gadgets that help with computer use.

While playing or drawing, anything that keeps the other parts of the body stable might help. If your child can sit, for example, in a corner seat, with pelvis and shoulders stable, there is more hope of him controlling his hand.

There's been publicity recently about a 'Daily Pill to beat genetic diseases.' Is there any hope in this for the future of people with A-T? Are we at least heading in the right direction? Have our researchers (or the A-T Children's Project in the US) made contact with the researchers pioneering this treatment?

The drug in question is called PTC124.

A small proportion of people with A-T may be able to benefit from this kind of treatment. Other drugs which act in the same way have been around for a while, but they are very toxic. This new drug is non toxic. It attacks a specific type of genetic mutation, rather than a particular disease – hence its application to people with a range of genetic disorders. It has been used successfully on **mice** with Duchene Muscular Dystrophy. We hope that it may be effective for some people with A-T, but if so, it will only be relevant for a minority of patients with A-T (probably about 13%) who have the relevant type of genetic mutation.

We are heading in the right direction, and we are in contact with the researchers who are doing this work.

My daughter (aged 6) isn't dry – she wears nappies at night and has some urinary incontinence during the day. How common is this kind of problem, and what can we do about it?

Your daughter should be seen by a paediatric urologist. Some children are prone to recurrent infection, which can be treated. If this has been ruled out, she will probably need to have a bladder scan before and after weeing – to see how much volume is left. There are medicines which can slow the urgency, although unfortunately these can have some side effects. However, for both day time problems and bed wetting, things can be done.



Simon Rowland demonstrated a selection of specialist IT equipment available from the Aidis Trust

Reflexology



Stephen Wells enjoys a reflexology treatment from John Donovan at the Family Day

Reflexologist John Donovan gave a talk and free treatments at the Family Day in May.

You can call John on 0800 043 4570 for help and advice.

www.just1step.co.uk

Reflexology is a complementary therapy that works on the feet or hands to restore and maintain the body's natural balance and encourage healing.

The history of reflexology dates back to Ancient Egypt. In 1913 Dr William Fitzgerald introduced this therapy to the West, calling it 'zone therapy'. He noted that reflex areas on the feet and hands were linked to other areas and organs of the body within the same zone.

In the 1930s Eunice Ingham further developed this zone theory into what is now known as reflexology. She observed that congestion or tension in any part of the foot is mirrored in the corresponding part of the body.

Reflexology is suitable for people of all ages. It has been shown to be effective for back

pain, sleep disorders, arthritis, depression, respiratory conditions and other problems.

Reflexology and A-T

Reflexology may help with poor circulation or immune deficiency. If a person is being treated for leukaemia or lymphomas, reflexology can help enhance the treatment, and reduce its side effects. It can also help stressed parents.

What happens?

In a reflexology treatment, the practitioner will first have a talk with you to find out about your present and past health and lifestyle. They will then use their hands to apply pressure to your feet. The application and the effect of the therapy is unique to each person.

A professionally trained reflexologist can detect subtle changes in specific points on the feet, and by working on these points may affect the corresponding organ or system of the body. A treatment session usually lasts for about one hour, and you may be recommended to have a course of treatment, depending on your body's needs.

Reflexologists do not claim to cure, diagnose or prescribe.

The Association of Reflexologists can help you find a qualified therapist near you.

Association of Reflexologists,
5 Fore Street,
Taunton
TA1 1HX
0870 5673320

www.aor.org.uk

Fulfilling your potential

Frances Prokofiev shares her experiences of helping her son Rupert through the education system

This is a message of encouragement to those parents just starting to think about their child's education. Rupert is 22 now and still in full time education. Maybe by sharing our experiences we can help some of you, as you go through the educational journey.

I realise that everyone is different. Also, there are differences in access to facilities and good teaching, depending on where you live. But we have many concerns in common.

Education is the focus of a lot of parental anxiety and struggles. For me, it was the first place where I had to worry about my son's difference and 'special needs'. I realised that teachers who were good at working with able-bodied children might not be relied upon to be able to manage Rupert's education in the *best way for him*. I expect we have all encountered the situation where teachers address us as the experts, feeling themselves inexperienced and anxious when it comes to working with a child with a rare condition. And yet we are not trained teachers – particularly not with children with a disability - and we would like to be advised and helped ourselves.

Rupert's Education:

Nursery: Rupert went to a mainstream nursery and it was at this time that a Statement of Special Educational Need was written

Primary: he went to a mainstream primary until he was 10, by which time he began to use a wheelchair. At this point, once Rupert's disabilities were more pronounced, the school was less able to cater for all his needs and I felt we needed more specialist help. There was no physio on site for example. He stood out as different, and tended to get fussed over by primary assistants, and over-protected by his personal assistant. This special treatment irritated his sisters.

Special School: This was in the adjacent borough, and he was collected by taxi each day. It was a challenge getting him into this school but we were supported by the Educational Psychologist. Here he was offered more variety in the curriculum, more fun and adapted sport, and more appropriate educational support. He gained a sense of there being others like himself to identify with. He could ask for assistance when he needed it, with several helpers around.

Secondary: As Rupert progressed in special school to Secondary age, he was able to combine some lessons in this school with some in the neighbouring mainstream comprehensive. He took a limited number of GCSEs, doing particularly well in maths and science.

“I expect we have all encountered the situation where teachers address us as the experts”

Sixth Form: He then went to Lord Mayor Treloar Residential Sixth Form College, which has had quite a few students with A-T. In the first year, he shared his time between Alton College, a mainstream Sixth Form College nearby, and Treloars, where he had physiotherapy and learned IT and independence skills.

More time for homework, less for personal development

The problem here was that attending a mainstream college meant more time for homework, and less time for personal development and for the carefully adapted education that a specialist college can offer. In the second year there was a re-think and a complete change. Rupert found a new subject – media – in which he took a GNVQ, and which became a passion, especially with the opportunity to create films. He went on to have a third year, becoming much more independent and making good links with the careers advisor to plan his next step without our help.

At Treloars Rupert had to share an academic assistant, and this meant doing some of his typing for himself. Although it was slower, it meant he had to learn to manage his studies in a not too pressurised environment. He shared a study with four others, going there in the evenings to continue sometimes because he was enjoying it.

Although Rupert had the capacity to be academic, it didn't mean this was the best thing to strive for - as his experience of Alton College at this particular time in his education showed - although at the time I was, perhaps mistakenly, keen to make this possible. It was wonderful that the money was forthcoming from the Learning and Skills Council for a total of 3 years at this college.

Further Education: Rupert is now at Hereward College, which is an integrated further education college with residential provision for students with disabilities. He has done film studies, TV and Video access, European Computer Driving Licence, and computer graphics. Here he has learned more independence skills – organising washing, cooking, travel, personal training etc. As college life improves and his independence increases, Rupert is becoming less satisfied with being in Specialist Education and is now looking at higher education, thinking of an HND or a degree at university.

You can't guarantee that all the possibilities will be presented to you...

Some Key Points about Education for our Children

Because of the range of challenges encountered by individuals with A-T, I have sometimes felt that it is only we parents who are involved enough to take the time to imagine what our children need. I have also felt I have to really understand and get my head round the issues in order to get the best for my child. This is particularly the case in mainstream education. You need to research what's available, and how it can be paid for, as you can't guarantee that all the possibilities will be presented to you. For example, when Rupert needed to move into special education, we originally thought that the only option was residential school. It was later that we found out about the local special school.

Essential independence skills

The Special Education element in Rupert's education has proved to be an essential part of the transition to adulthood – the teaching of independence skills that is available there in particular has been crucial.

Assistants: At mainstream schools Rupert had one person assigned to help him all the time. There were problems with this. At primary school his assistant tended to anticipate what he needed and to pre-empt his having autonomy and making decisions. At

secondary school I sometimes felt that Rupert's assistant was doing the work for him, and not writing down his own work.

Education for our children has a distinct aim, which I would call 'real education'. It's about a discovery of what they can do, what strengths they have and what skills they can achieve. Rupert has discovered that he has strengths, and found out what they are. He's discovered that he can be creative in a family of artists, once he's found the right medium. He has only just realised it's possible for him to get a degree. Possibilities only reveal themselves at certain points and it's important to take one step at a time. There may even be a job at the end, but this is not the whole point.

Good times

These are good times for our children. Education is now more accessible than ever before for disabled students. There are fewer exams and more practical assessments. The emphasis on the computer is more user friendly for them. With the government target of 50% attending university, more colleges are keen to overcome difficulties in making their courses accessible for disabled students – even if it takes lots of adjustments. This is also a legal requirement.

Rupert's education at college level has had big pay-offs. Through a lot of his time in mainstream school, he was low on energy. Life was a struggle - and who knows, maybe our despondency and worry may

have contributed to this. But his recent college experience has clearly contributed to new energy levels in his enthusiasm. Aside from the academic learning, there has been his increased independence and achievements. Even planning snacks and shopping for them has made him think more about eating regularly and eating what he likes – so his weight (sometimes a real worry in the past) has gone up. He takes responsibility for his physiotherapy and knows that exercise makes a difference to his health. The new adult A-T clinic at Papworth seems to echo this emphasis on personal management and independence. His whole attitude to himself as a 'can-do' person has been affected.

In relation to education, it is hard for the parent not to be one of their child's 'key workers'. I am glad to have given the time because it has made a difference – it *has* been a lot of time though.

But I have benefited too by learning more about how to conduct my relationship with Rupert since he was at the colleges - through seeing how staff do not jump to help before they are asked and that what seems like kind empathy can be a mistaken way of reducing autonomy for my son.

His independence is becoming mine too.

Rupert's view

I'm happy with all the decisions I've made.

Treloars helped me build up my independence and confidence – things like practising speaking on the phone. Travel trips to learn skills included having to ask strangers in the street for directions.

I'm now doing things I wouldn't have dreamed of: booking trains on my own; a return train trip I'm proud of; booking cinema tickets in advance; getting train tickets sent to me. Recently I discovered I could do a degree.

I've been out from Hereward a few times this term leaving a carer behind.

Current skills – in my written work I'm aware of dictating then proof-reading more.

I used to feel embarrassed dictating in creative writing (personal stuff).

Being at Special Ed colleges has meant there has been so much death in my life already.

Without my experience of the two residential colleges I would not be as independent as I am today.

Fundraising

Hydro Active Women's Challenge

Sunday 16 September

Last year more than thirty women and girls participated in this event on behalf of the A-T Society. It was a fabulous day and we raised around £5,000.

We are looking for more ladies this year. If you are looking for a challenge, why not join us? You'll be guaranteed a memorable day out.

You can walk, jog, run or skip, the option is yours. So join in - and encourage your family, friends and colleagues to take part too!

The entry fee is £15 - and £5 of this goes directly to the A-T Society.

If you are interested, we would love to hear from you. Call Angie in the office on 01582 760733. You can also obtain further details and enter on line at www.womenschallenge.co.uk.

It's worth getting your entry in early to ensure you secure a place.



We hope to see you there!

LONDON MARATHON

Congratulations to Jonathon Smith, Dan Thompson, Gill Duffy, Dave Pennycock and Steve Hayes, who ran the 2007 London Marathon for the A-T Society.

Jonathon completed the marathon in 5 hours and 17 minutes, which was an exceptional achievement.

Dan completed the marathon in 6 hours 20 mins. Special thanks must go to Dan for completing this gruelling challenge because on the tenth mile, Dan damaged his knee and was unable to run any further. However, Dan wouldn't give up and decided to walk the remaining distance, which was a fantastic achievement!

Gill crossed the finish line in 4 hours 49 mins, which was a fantastic time.

Dave was one of our first runners from the A-T Society team to cross the finish line at an incredible 4 hours 12 minutes.

Steve wasn't far behind Dave, clocking an excellent time of 4 hours 40 mins.



Gill Duffy (pictured above with her training partner) writes about her experience:

My London Marathon feat began sometime last year when, in a moment of weakness - or drunkenness! - I foolishly agreed to entering. Once the seed was sown I decided it should be for a good cause and, therefore, opted for the A-T Society. Up until two years ago, I had never heard of A-T, but was made aware of it through a friend, and work colleague, whose son has A-T..... Joe Bromwich take a bow here please!

The training programme was hard, and, as the runs got longer, the alcohol consumption reduced, unheard of thus far in my life! I don't think I ever got used to the weekend alarm going off at 6.30am so I could have my bowl of porridge before undertaking a 2 - 3 hour run.

All too soon the day itself arrived and although I was nervous, I knew I had done the necessary training, so was as ready as I could be. Messages from friends and family kept coming through on my mobile phone, but the one that gave me the most motivation and inspiration was a good luck message from Joe himself.

It was a hot day, and an incredibly hard run, but the support from the crowds and fellow runners was tremendous and gave me the lift I needed, especially when I hit 'the wall' at about 21 miles.

At about the 8 mile mark a woman ran alongside me and asked if I was running for the A-T Society, having seen the logo on the back of my vest. We chatted for a while (yes, believe it or not it is possible to hold a conversation even when running 26 miles!) and it transpired that she fundraises for the A-T Children's Project in America – small world.

The highlight of the race was Tower Bridge where the noise from the crowd was awesome, which put a bounce back into my step and a smile on my face. This is also where the main race cameras are, so it is important to look your best at this point. The low part was when I was beaten

to the finish by Scooby Doo and a Sunflower (who later revealed himself to be a grey haired 60 year old man!). I think Scooby Doo was actually the real thing, or maybe at that point I was hallucinating.

The final mile passed in a blur as I was so focused on just getting to the finish line, but I finally made it in a quite respectable 4hrs and 49mins, and I have to say it was the proudest moment of my life.

All in all it was a fantastic and memorable day, and I hope that the monies raised will go some way to assisting the Society. Keep up the good work!

Gill Duffy

Below: runner Steve Hayes at the London Marathon



E-fundraising

Everyclick.com

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

Everyclick.com is a search engine that gives half of the revenue it generates to charity. If you are not already using it, please give it a try - it's a great way to give 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. You can then use it whenever you search the web or shop online.

Since our registration last year we have raised £193.68. We would like to double that figure this year.

Please give it a go and if you like it as much as we do - pass the message on!

The more you use it, the more we earn

Help us spread the word.
Tell your friends about everyclick.com



MissionFish

You can also raise money for the A-T Society by selling any unwanted items on line.

eBay.co.uk has teamed up with registered charity **MissionFish** to create a selling scheme for charities. By selling an item on eBay you can donate as little or as much as you wish of the final sale price to the A-T Society.

Clean out that cupboard or loft – you can sell practically anything on eBay

Here's how it works:

1. Visit www.ebay.co.uk/ebay-for-charity
2. Register for your eBay and MissionFish seller accounts
3. Choose an item to sell
4. Write an item title and description
5. List your item on eBay and indicate that it will benefit the A-T Society
6. Complete your transaction – MissionFish will collect your donation, claim the Gift Aid (if you declared it) and pass both on to us



Raise funds for the A-T Society today!

Legacies

Joan Bridger writes:

Like an awful lot of people, Tony and I hadn't even thought about making a will until we had our son, Luke.

When he was diagnosed with A-T it really made us think about the future and besides ensuring his interests were covered we wanted to make a bequest to the A-T Society.

If you haven't made a will do think about it (look out for 'Will Week' when a number of solicitors offer reduced prices!)

If you have already done so, please consider adding a codicil to include a bequest to the A-T Society. Your legacy could make a huge difference to our children and young people who live with A-T every day of their lives.

Have you made a will?

Perhaps you could consider making a bequest to the A-T Society.



Joan Bridger, above, left, with Maureen Jenkins and Molly Lane at the A-T Society Family Day.

Money in Lieu of Flowers

Thank you to those of you who chose to make a donation to the Society in memory of recently deceased friends and relatives instead of sending flowers to the funeral.

These donations are much appreciated.

Line dance and raffle



Alecia Yarlett and George Keith with family and friends at the Line Dance and Raffle, January 2007.

Over £4,500 was raised for the A-T Society.

We need you!!

The Line Dance for January 2008 is booked!

Now we need some tempting raffle prizes for the national A-T Society raffle, which will be drawn on the night. Can you get a prize from your local area? This would make the raffle more attractive throughout the country and assist ticket sales, thus raising more funds for the A-T Society. It is surprising what a few telephone calls or letters to local companies/retailers can generate.



Please contact the office if you can help. Thank you.

Benefactors 2006

Many thanks to all our benefactors in 2006:

29 Regiment Royal Logistics Corps
 The Accenture Foundation
 Maureen Ainsworth
 Mrs Akerman
 In memoriam - Catherine Akinola
 The Alchemy Foundation
 Mrs MA Alexander
 Alexander Maritime Charity
 The Ammco Trust
 Anonymous
 Ashcroft High School
 Mrs Kay Atkins
 Ms Imogen Atkins
 In memoriam - Mary Austen
 In memoriam - Raymond Austin
 AM Bailey
 Mrs HM Baker
 DJS & JM Barber
 Bartle Family Charitable Trust
 The Betterware Foundation
 Ms JM Biggs
 MF & L Birch
 The GE Birtwistle Memorial Trust
 The Sydney Black Charitable Trust
 Sir Arthur Black Charities
 Arnaud Blanchard
 Mrs D Bowes
 Edith Boyes
 Bradford Abbas Brownies
 Mrs Eileen Bridger
 Mrs Joan Bridger
 Brockenhurst College
 Mr R Bromwich
 Mrs Lee Bromwich
 Mrs Valerie Brown
 R Brownless Charitable Trust
 BUPA - matched funding
 In memoriam - Vera Byatt
 Cannon-Brookes Charitable Trust
 Carluke High School
 Mr & Mrs RJ Carson
 Miss RDT Carter
 Chapman Charitable Trust
 SF Child
 Jo Child & Esther Turpin
 JM & PE Turpin
 The Childwick Trust
 Chinook Integrated Team
 Miss G Christie
 Mrs E Claxton
 In memoriam - Doug Collins
 Como Group
 Mr & Mrs Cooper
 The Cornerstone Charitable Trust
 The Coutts Charitable Trust
 D&C Crosley
 Danbury Antiques

In memoriam - Paul Dancy
 Mrs VEM Deith
 In memoriam - Anupam Dhirani
 K Dhirani
 DM Charitable Trust
 BB & GC Dodge
 LT & RA Dorins
 The Mildred Duveen Charitable Trust
 Ebchester C E Primary School
 Kim Edwards
 The Epigoni Trust
 Mrs WG Evans
 Eveson Charitable Trust
 I & R Farns
 AC Farrell
 Findel plc
 The Fitton Trust
 Mrs Nicola Fitzhugh
 DS Forsyth
 Sister Francis
 C & A Frizzell Charitable Trust
 N&P Frost
 In memoriam - Mrs B Galiegue
 Penelope Gluckstein
 Mr & Mrs P Goodwin
 In memoriam - Ben Gorton
 Greek Orthodox Community
 Prof MHL Green
 Tom Hall Charitable Trust
 Mr MS Hammond
 Alan & Maureen Hammond
 Harpenden Round Table
 Adrian Harrison
 In memoriam - Harry Hunt
 In memoriam - Andrew Hart
 The Hart Family
 Havan Ladies
 Mr & Mrs Hawkes
 Sir John & Lady Heathcoat-Amory
 Charitable Trust
 Mrs A Hendrick
 Mrs D Hewes
 S Hewitt
 Hiel & Toe Club
 Frances High
 Jacqui Hill
 Beverley & Peter Hodson-Cottingham
 Mr SC Hollingdale
 Mrs Monica Horne
 Staff of HSBC Stockport
 Miss J Hudson
 Mr A C Hunt
 MJ & LC Hunt
 Albert Hunt Trust
 In memoriam - Andrew Pearson
 Ann Jackman
 Sir Robin Jacob

Rev MP James
 The Jarvis (Harpenden) Charitable
 Trust
 Mrs Maureen Jenkins
 Matthew Johns
 Mr & Mrs S Kemp
 DM Kenny
 Mr S Kildea
 RC Kingsley
 The Kobler Trust
 In memoriam - Faye Larkin
 A&S Lass Charities
 Mrs RV Lawson
 Diane Le Maistre
 Mr JG Lockwood
 The London Law Trust
 In memoriam - Mr & Mrs Long
 Mrs KS Luke
 Mr Simon Lynn
 The Lynn Foundation
 Germaine Maguire
 Mrs Liane Mallett
 Marsh Christian Trust
 Mr & Mrs GW Marshall
 Mrs Mary Maunsell
 SA Meadows
 The Tony Metherell Charitable Trust
 Michaelis Charitable Trust
 AJCP Midwood
 The Victor Mishcon Charitable Trust
 Mrs Pravina Modha
 V Moore
 Jim Moore
 Sheila & Gerald Morel
 Staff of Morgan Stanley
 Morgan Stanley - matched funding
 Multithon Trust
 Murphy-Neuman Charity Company
 Mr & Mrs Neary
 LA Nesbit
 The Oak Trust
 Oakley Charitable Trust
 Kerry & Sue O'Brien
 Caroline & Angus Ogilvie
 KA Oppenheim Charitable Settlement
 Dr R Owen
 D&D Owens
 PR Owens
 RC & JM Owens
 Mrs J Owens
 Mrs Pabary
 The Paristamen Foundation
 The Parivar Trust
 RH Parsons
 Mrs VM Pearce
 M J Penelrick
 Travis Phillips

Dale Phillips
 Sylvia Phillips
 Mr MG Picton
 Mr JD Piper
 Janet Pollard
 Mr Martin Poupard
 Mr Peter Poupard
 Mrs Maureen Poupard
 Miss Rachel Poupard
 Mrs Frances Prokofiev
 Mr & Mrs JA Pye's Charitable Trust
 Gordon Ramsey Holdings
 ZVM Rangoonwala Foundation
 Mr & Mrs Redford
 DL Rhys
 Muriel E Rickman Charitable Trust
 The Rind Foundation
 DM Roberts
 In memoriam - Mrs Ivy Robinson
 Round Table - Market Deeping
 AE Rowley
 The Royal Union Pub
 Ruislip Whiteheath Townswomen's Guild
 Mrs Lita Rundle
 JD & HS Sabel

Mrs LK Saunders
 Sir Samuel Scott of Yews Trust
 MH Senanayake
 Mr MM Shah
 Mr & Mrs K Sherry
 SK Shuttleworth
 Mrs SL Sibley
 Anita Siddle
 AAL & MM Silver
 Mr LG Sims
 N Smith Charitable Settlement
 Mrs P Smyth
 JI Soper
 The Souter Charitable Trust
 South West Charitable Giving
 Ms FM Spalding
 St Albans Abbey
 St Stephen's Church Chatham
 St Thomas More Ladies
 BJ Standing
 JSE Staughton
 Jill Stevenson
 Tina Stubbs
 Swale Charity
 John Swire 1989 Charitable Trust

The Charles & Elsie Sykes Charitable Trust
 Glenday Thomas
 Tivoli Stores
 Michaela Turner
 Upton Cross Masonic Lodge 4454
 The Valentine Charitable Trust
 FJ Wallace Charitable Trust
 Mr DCE Watson
 Mary Webb Trust
 Mrs Kay Wells
 Mr Robert Wells
 Western Foils Charitable Trust
 Mr William Wheeler
 SA Windsor
 The Michael & Anna Wix Charitable Trust
 Mrs Pam Woodford-Smith
 Mr & Mrs JG Woodward
 Emily & Amy Woodward
 Mrs Patricia Wooler
 The Woolf Charitable Trust
 Mrs L Yarlett
 Yellow Rose Spiritual Centre

Nottingham Clinic

These pictures, taken at the Nottingham A-T Clinic in May, give an impression of what happens there. If you wish your son or daughter to attend the clinic at Nottingham, please contact Kay Atkins, Family Support Worker at the A-T Society, on 01582 760733.



Some of the clinic team whom you will meet when you visit

From left: Caroline, clinic nurse, Patricia, clinical physiologist, Kerry, genetic counsellor, Mary, clinic nurse, Jo, nursery nurse



A therapy session (physiotherapy, occupational therapy, dietetics, speech & language) in full swing for the Keith family



Rebecca getting ready for some respiratory tests

Tea party at number 10



*Natalie with Cherie Blair
at Number 10*

Natalie Fitzhugh writes:

Last year I was very lucky to be invited to a Christmas party for the Francis House Hospice, being held at 10 Downing Street by Cherie Blair.

On the day my Mum and I got up very early and when we arrived at Francis House the coach was already there. It was a lovely coach especially as all my friends and carers from Francis House were there and of course my mum who had taken time off work for this special occasion.

It was a long journey which took 5 hours. Luckily Sister Maureen had brought lots of food and drinks to keep us going. When we arrived, the coach took us to

the front door which was special as the public are not allowed at the front door. I felt very grand.

It was a lovely big house with very big rooms and with surprisingly a floor to floor lift and a step lift for my wheelchair. Cherie Blair walked past as I was using the step lift and asked my name, she then said are you pleased Natalie that we have got all the mod cons at number 10 for your wheelchair. I was a bit surprised to see her so I just smiled and said yes.

When the party started there were lots of clowns and party food, but most importantly there was Father Christmas giving out lots of Christmas presents.

Cherie Blair came round with her son Leo to talk to everyone, and we all told her what a fantastic party it was.

As the party ended we all went outside (including Cherie) next to the big Christmas tree with Kirsty (who does lots of fundraising for Francis House), Sue Johnston the actress and the choir. We all sang carols while the press took photographs, it was a lovely end to a lovely day.

On the way home I was so tired I fell asleep, when I woke up Mum said that we had been on the TV on the local news.

I did not mind missing seeing it on the news as I knew I would remember this special day for ever.

Resources for Siblings

Thank you to Contact a Family, who gave us permission to reproduce this from their summer 2007 newsletter

There is an increasing amount of support for the brothers and sisters of children who have a disability or long-term health condition. Local projects have been set up across the UK, usually called young carers projects because they are for children who have a family member who is ill or disabled. Some of them run sibling-only support groups.

Young carers projects offer different activities depending on where they are and who runs them. The sorts of things to expect are help with home work, evening clubs, weekends away, days out and holidays. They are run by skilled workers who will listen to your children and can usually give information and advice for the whole family.

The **Children's Society's Young Carers Initiative** website has information for brothers and sisters, parents and professionals and lists local projects. See www.youngcarer.com

The **Princess Royal Trust for Carers** also has a website for young carers. www.youngcarers.net With information for children, parents and professionals. There is an 'agony aunt' page and children can sign up for the discussion boards, register to join a discussion, ask questions and join live chats, all moderated by a police-checked adult.

Sibs is a UK-wide organisation for both adult and young siblings who grow up with a brother or sister with special needs,

disability or chronic illness. They run workshops and conferences, produce factsheets and information for siblings, parents and professionals. For support or information on sibling issues, contact them at

Sibs
Meadowfield
Oxenhope
Keighley
BD22 9JD
tel 01535 645453
email: info@sibs.org.uk

www.sibs.org.uk

For more information on these and other resources for siblings, see the Contact a Family factsheet, 'Siblings' which is packed with information, resources, and hints and tips. It is available free to parents from the CAF helpline, 0808 808 3555.

The **Letterbox Library** has a catalogue of books for children which are helpful in promoting understanding and explaining 'difference' for all ages from 0-12+. They can be bought as 'book packs' or individually. As well as many disability-related publications, they have produced comprehensive booklists on particular themes.

Letterbox Library
71-73 Allen Road
Stoke Newington
London
N16 8RY

020 7503 4801
www.letterboxlibrary.com



Out and About



Are you a rugby fan?

The **Rugby Football Union** provides 300 wheelchair spaces within Twickenham Stadium to enable both wheelchair supporter and carer/companion to attend free of charge. Accessible car parking is also included in the wheelchair package.

Wheelchair Supporters Annual Ballot for International Matches

An annual ballot form is posted out in July/August prior to the start of the forthcoming season. There are currently over 700 wheelchair supporters registered for the ballot for tickets for the Major International matches, which includes the RBS 6 Nations Championship.

To register you have to submit a written request to the Ticket Office, (address below) providing mailing address, telephone number and email address and including some form of documentation confirming registered wheelchair status.

For non international matches, application forms are available on request to tickets@rfu.com or by fax (see number below).

Car Parking

All those successful in the wheelchair ballot are provided with a TESCO car park label for major international matches. Car parking is provided for other matches at Twickenham, this can include TESCO, NORTH or other on-site parking.

For any additional information contact

Rugby Football Union
Ticket Office
Rugby House
Rugby Road
Twickenham
TW1 1DS

tel 020 8831 6666
 fax 020 8831 6670
 email tickets@rfu.com

Thinking of going to an event at Wembley? Here's some information about accessibility.

The stadium has 310 wheelchair accessible spaces with an equal number of adjacent seats for companions. The seats are on all 5 levels of the Stadium, and are available in all areas of the seating bowl, including halfway line, corner and behind the goals. There are over twenty lifts and thirty sets of escalators.

Each wheelchair platform has a dedicated steward to provide assistance where required. All event-day disabled parking is pre-booked, and is only available for Blue Badge holders.

Tanni Grey-Thompson

recently went to check out the disabled facilities and was pleased with what she found: "I'm pretty impressed with it, to be honest," she said. "Sometimes, what's good for blind people is not good for wheelchair-users, but it seems to be good for everyone. There are 147 accessible toilets, which is amazing. You go to some places and they have two. As a wheelchair-user you get a bit obsessed about toilets. When I was young I had to go before I left the house, or crawl upstairs somewhere. It's better now, but I still get quite excited about toilets."

In Brief

New leaflets for families

Contact a Family has produced three new leaflets for parents of disabled children. These are:

Sleep:improving your child's sleep

Providing advice on encouraging good sleep habits in children, breaking bad habits and information about where to go for further help

Feeding and Eating

Explaining the problems that can occur for disabled children and giving hints on managing mealtimes

Toilet training

Providing information to aid families of disabled children when toilet training their child.

The leaflets were developed with the help of parents, speech and language therapists, specialist nurses and clinical psychologists, and will shortly be available on the CAF website translated into six other languages.

To get a copy of any of these leaflets, call Contact a Family on 0808 808 3555

or view the leaflets online:
www.cafamily.org.uk/paptinfo.html

Help if you are in debt

If you are struggling to pay debts, or worried about your finances, there are ways to get help.

Contact a Family has set up debt advice services for families with a child who has a disability. These are in Gateshead, Rotherham, Greater Manchester, Sheffield, Stoke-on-Trent, Liverpool, London, Wolverhampton, and Bradford.

Home visits are often possible. To make an appointment, call Contact a Family on 0808 808 3555.

More on money advice..

If you don't live in one of these areas, you can still get free money advice.

The Community Legal Service has a directory of all legal information and advice providers. You can find details of your local advisor by calling 0845 345 4 345.

Or you can search for a money advisor on their website:

www.clsdirect.org.uk

If you qualify for legal aid you can get free advice over the phone:0845 345 4 345 (Minicom 0845 609 6677).

Debt advice online

CLS Direct has teamed up with the Consumer Credit Counselling Service (CCCS), the UK's leading debt charity, to offer a debt advisory service on the web.

This can help to provide a solution to your money problems – whatever your situation.

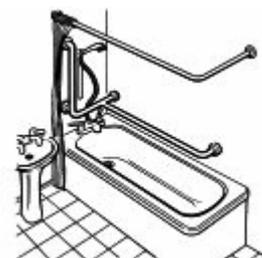
Fill in a questionnaire and you will be given a debt remedy tailored to your personal circumstances. You don't have to give your name, and the service is free.

www.cccs.co.uk/DebtRemedy/

Bathing made easy

The Disabled Living Foundation, a national charity that provides advice about products for disabled people, has recently launched a new web guide to bathing.

www.dlf.org.uk/bathing is a free, impartial search and comparison website for walk-in baths, bath seats, showers, grab rails and other personal care products for disabled people.



Mobility Road Show

The Mobility Roadshow will be at Kemble Airfield between Gloucester and Swindon, from 19 to 21 July. With a wide range of exhibits of motoring and mobility products and services for disabled people, this is billed as a day out for all the family. There are opportunities to test drive vehicles. This year there will be a Holiday Village and life-style, sports and leisure zones.

www.mobilityroadshow.co.uk
tel 0845 241 9390

Accessible coaches



National Express have introduced new easy access coaches on three new routes: between Blackpool and Bournemouth via Manchester and Bristol, between Coventry and Paignton via Bristol and between Burnley and Torquay via Manchester and Birmingham. The coaches have a lift built into the passenger entrance, and a space for a passenger in a wheelchair.

Easy access coaches are already running between Leeds and Gatwick Airport, Liverpool and Cambridge, Newcastle and Torquay, The Midlands and Scotland and Nottingham and Stansted Airport.

National Express also runs a coach from Bath to London which has a side lift.

To make a reservation, contact the Disabled Persons' Travel Helpline: **0121 423 8479**.

www.nationalexpress.com/why_choose/disabled/access.cfm

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

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		1	3				7	4
	3		1					

Merchandise

T-Shirts

Ladies skinny fit (pink)
£8.50

Mens/unisex (blue)
£8.50

Polo Shirts (pink or black)
£12.00

Running vests
(pink or black)
£7.00

*Pictured: left: skinny fit t-shirt
Right: polo shirt*



Mugs (various designs)
£5.00

Lapel Badges
£1.00

Balloons
free (for 10 or less)

Collection boxes and buckets
free

Interested?
Place an order today by phoning
the A-T Society on the number below.
These prices are exclusive of
postage and packing.

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

atcharity@aol.com

tel 01582 760 733 fax 01582 760 162

Reg Charity No 1105528