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A-T Society News

In this buoyant edition...

- The Society flies its new colours
- A-T research: on the right tack
- Richard Gatti has his eye on the horizon
- Top lawyers join the crew

AT society
awareness research care

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

The A-T Society was established in 1989 and is committed to helping, supporting and advising families affected by A-T. 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.

Editor's Comments

Many thanks to all contributors. The copy date for the next issue is 1st October 2011
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Cover picture: Natalie Fall at the helm of the Lord Nelson on an activity break supported by the Society

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View from the chair

Introducing the A-T Society's newly appointed chairman **Lian Yarlett**

Halfway through the year and the sun is shining. Let's hope it stays with us for a while! With the re-branding now well underway, and the Vision and Mission clearly stated, the A-T Society is raising its profile.

William has been busy forming workable and achievable strategies to underpin our services, and providing a more structured plan to help achieve the aims of our Mission.

With so much to be done we are in the process of expanding the Board of Trustees to bring on board a wider range of skills.

The first to join us is Lynda Finn, who was elected at the AGM. I offer a very warm welcome to her and also my personal thanks to all the trustees and other volunteers, who commit their time and experience for the benefit of us all.

We had our biggest attendance ever at this year's Family Information Day and I am really pleased that so many were able to join us (and to those who could not – we hope to see you next year). Huge thanks go to everyone involved in the organisation, but especially to Kay Atkins who oversaw it all.

It is, for me as a parent, ironic that something so terrible can also bring people together and that just listening or talking with another family can bring so much benefit.

With informative talks and valuable open discussion, along with the opportunity to speak to professionals and people living with A-T directly, there was so much to be gained.

"It is, for me as a parent, ironic that something so terrible can also bring people together"
Lian Yarlett

And it's not just the participants that were affected. I was very touched and cheered to hear that the gentleman providing technical support on the day and also some of the hotel staff were moved to offer to take part in events for the A-T Society too. The power of raising awareness!

However, I know there were also a few problems. Your feedback has been important and some of the issues raised are addressed in this newsletter.

Something else very encouraging has been the level of involvement of families and supporters who have held a number of fantastic awareness and fundraising events so far this year – and huge thanks go to all involved.

We would love to see everyone taking a part in spreading the word about what we do and why we are doing it. Remember that research into A-T may hold a valuable key within the medical world to help treat certain cancers and other progressive and degenerative disorders.

This condition that affects so few could actually be of benefit to many and we have to make sure others know this.

So please have a think about how you could help spread the word – whether it's a charity box in the local shop, climbing a mountain or asking someone else if they would be interested in doing something – the rewards are there.

The A-T Society rebrands

We're proud to reveal our new branding, which is introduced on p6. Our new logo even featured in *Design Week* magazine (below).

Just William

William Davis, chief executive of the A-T Society, reflects on the recent Family Information Day and shares his excitement on the establishment of an international A-T Clinical Research Network

Two weeks have gone since the Family Information Day and I am still feeling slightly breathless from it. It was amazing to see so many people living with A-T together in one place and there was a real energy about the event. It was only sad that there was not enough time to chat properly to more people.

One of the main things I got from the event was a renewed sense of the urgency of our work. Time waits for none of us, but with A-T there is a particularly pressing need to get on and do things. Whether it's research to find a cure, improving medical treatments or just getting on with pushing back the limits A-T tries to impose and living life to the full, there is no room to hang about.

One of the things that holds us up in our race to find a cure for A-T is the fact that it is relatively rare. Almost all the clinical experts in A-T, wherever they may be, spend the majority of their time with patients who have other conditions. We are very fortunate in the UK in having a group of particularly dedicated and knowledgeable doctors and researchers, who frequently go beyond the call of duty and give up their free time to help fight A-T. But even so, we have to recognise that they can only spend a part of their working life on A-T.

For me, this is one of the most important things that the A-T Society can do – to keep the pressure on, to keep pushing for more; to make sure that everyone working in the field of A-T feels that same sense of urgency and to find ways to draw in new people and resources to help us. We also have to make sure that no money and no efforts go wasted.

"We are very fortunate in the UK in having a group of particularly dedicated and knowledgeable doctors and researchers who frequently go beyond the call of duty and give up their free time to help fight A-T"

As I said in my talk at the Family Information Day, research is going to be a big priority in the years ahead. Clearly part of this is about getting more money into support for first class research, whether it's money we have raised or money we can persuade others to invest. But equally important is using what influence we have to try and push the whole A-T research agenda forward.

There is a lot of clinical research going on in different countries. The Frankfurt Workshop, featured later in this newsletter, is proof of this. But often this research is rather piecemeal and people in one country or institute are not always aware of what others are doing. Also many clinicians have access to a relatively limited number of patients. And many don't have the time to find out what is going on elsewhere.

That is why I am so excited about the establishment of an international A-T Clinical Research Network. By sharing information better and more quickly, we can make sure that researchers know what else is happening and can learn from each other. We can also ensure that time is not wasted planning or carrying out research that has been done by others and identify opportunities for collaborating in new projects.

The planned series of international clinical research workshops will strengthen this too. By bringing together doctors, researchers, therapists and people living with A-T, it will help keep people motivated and focused and ensure that this sense of urgency is shared and turned into faster progress towards new treatments and a cure for A-T. And there is nothing more important than that.

Sophie, Charlie and Arthur at Chessington

Chessington draws the crowds

This year's Family Information Day was held at Chessington World of Adventures. More than 220 attended, making it our largest ever gathering of people with A-T in the UK and probably Europe

On Saturday May 21, over 220 people crowded into the conference suite at the Holiday Inn Chessington. There were so many people that at times it was hard to get through the crowd. And yet there was a great atmosphere and a real buzz about the place. As one parent told us: "The day was amazing. My daughter and I were overwhelmed by everything."

With some 50 families present and more than 80 children, this was never going to be a quiet event. With the excitement of meeting friends and going to the park, it certainly wasn't that. But thanks to the hard work of Kay, Caryl, Suzanne and the team of volunteers, the day went smoothly.

In the morning, while the children were entertained with a magician, face-painting and so on, young adults went into a workshop of their own and the others attended the AGM and review of the year. This was introduced by the Society's new chairman Lian Yarlett and included a presentation of the Society's new branding. The morning closed on an unusual note with the presentation to the Society of a 14ft Canadian Luggage Canoe *(see page 7)*.

After lunch, the younger attendees went into the park, accompanied by carers from NESCOT college and a few parents. The remaining adults were treated to a series of excellent talks and workshops with a range of experts, including Prof. Malcolm Taylor and Drs Mohnish Suri and Andrew Exley, directors respectively of the Nottingham and Papworth clinics. The day finished with an Open Forum and the chance to ask the experts questions.

Throughout the day, a photographer was available and proved a very popular draw. There were also stands selling books, cards and other items in aid of the Society's funds, including cards made by the late Shirley Marshall. Many adults with A-T took the opportunity for a little pampering in the hotel's Spa, in a deal supported by the Society.

Families were free to make their own arrangements for dinner, most choosing to eat in the hotel, where the restaurant looked out over a field of zebras, ostriches and other animals, or in the Money Puzzle restaurant. After dinner, most gathered in the conference room where there was a bar, a family quiz and a chance to chat to others.

The next day almost everyone took the opportunity to go into the park. This was the one major disappointment for a number of people, particularly the teenagers and adults with A-T and those with them. In spite of all the assurances we had had that the park welcomed disabled visitors, many found they were refused entry to nearly all but the tamest of rides. This was a problem we did not have at Alton Towers in 2009 and one which we have complained to the Park about. For some, this was a frustrating end to what had otherwise been, in the words of participants, "a fantastic day for the family", "brilliant", "the best Family Day ever!".

Fun in the sun at Chessington

The A-T Society rebrands

Those at the Family Information Day will have seen the new branding 'in all its glory'. Everyone else will presumably have seen some of it in this newsletter or in the annual report. We hope that you'll agree with the Board and staff that it gives the Society a stronger, more modern look.

Our old logo had done really good service – but it was a bit tired looking. It suggested to many people that we were primarily a scientific organisation, while the pale blue colour didn't stand out much. This is not very helpful when you want to make a loud noise in the world and be remembered.

The new logo is bright and strong. It says clearly what we do. The off-balance triangles suggest the problems of balance and coordination that come with the A-T. The letters spell our name in a font that is strong, modern, purposeful but approachable. All of these are qualities of the A-T Society.

We were very lucky in finding Gosling Design to work with on the project. They took the time to understand Society and what it is and what it wants to achieve, and to help us express that. And because they were impressed with what we were trying to do, they supported us both by working for very low rates and also by making us their Christmas charity. Furthermore, work on the logo was featured in leading publication *Marketing Week*.

At the moment we are rolling out the new design – some items have been redesigned and others will follow. Fortunately we don't have large stocks of merchandise or stationery in the old design, so waste will be minimal, but it will take time to get it all done.

Following the AGM the question was raised as to whether the format of the Annual Report might seem a bit too 'slick and professional' and make it seem to potential donors that we have plenty of money

As it happens, the cost of the report, including design work which will serve us for the future, the cost of the report was only slightly greater than that of last year's. However, the trustees feel that the new format shows a charity that is clear in its aims, is confident and professional in its work and above all provides real benefit to the people it serves and real value for money. And the response from most people has been extremely positive.

National A-T clinics in transition

As reported in the last A-T Society news, plans are going ahead for the Papworth centre to receive national funding, as Nottingham does.

While this will make little direct difference to the service the individual receives, what it means is that local GPs will no longer have to pay the cost of sending patients to Papworth out of their own budgets, which they have had to do up until now. This has meant that some have been reluctant to refer people.

The agreement with NHS Specialised Services means that from now on Nottingham will provide a paediatric service only, with all adult patients attending Papworth. To ensure a smooth transition between the two, the centres have agreed to hold one joint clinic each year.

This transition clinic will be held at Nottingham but will be attended by staff from both clinics. It is intended for teenagers in the 14-18 age-group for whom this is likely to be the final visit to Nottingham.

It will enable them to meet staff from Papworth before they go there and will also enable the doctors to 'hand the patients over' with a proper discussion, rather than just passing on notes.

A-T researchers to meet in UK next year

The A-T Society has agreed to host an international workshop on clinical research in 2012. The event will take place in May or June, probably in Cambridge. This will be the first in a series of clinical research workshops to take place over coming years.

The idea of establishing a programme of regular clinical research workshops was put forward by the A-T Society and the A-T Children's Project. The aim is to promote the sharing of experience and findings among clinicians and researchers, identify opportunities for research and collaboration, and lead to improvements in patient care.

International conferences on A-T research are already held; the last one was in Los Angeles in 2010. While very useful, these conferences tend to focus on laboratory research into the behaviour and biochemistry of the ATM protein; there is not enough time available to discuss how this can lead to improved treatments for the condition. The clinical research workshops will fill this gap.

Top law firm names us charity of the year

Thanks to a remarkable campaign by lawyer Natalie Wardle and her team, we have been adopted as the Charity of the Year for the UK Law Firm of 2010, Berwin Leighton Paisner.

As well as being one of the UK's leading law firms, BLP has a number of international offices and works with clients in 118 different countries. It has a very strong commitment to supporting charities and more than 30 percent of its staff give their time to volunteering.

In addition to raising funds for the Society, the company is keen to offer the expertise and support of its staff in particular areas, such as Marketing, IT, planning and so on.

All in all, this looks like being a really significant partnership for the Society and we look forward to working with them over the year ahead.

Two's company at Papworth

In response to feedback from patients and the A-T Society, the specialist A-T centre at Papworth has made changes to its format. As of May, appointments will regularly be made for two patients at a time. Both patients will continue to be seen individually and will have their own rooms, but this arrangement should ensure that there is a higher profile for the A-T clinic and will also potentially mean more company during periods where there is little happening.

In the early days at least, it may not always happen that two patients are booked in together. But as the number of people attending grows, it will happen more and more frequently.

Another change to the service is that the requirement for a follow-up visit six weeks after the first session is being removed. People will from now on only need to attend once a year.

And a final piece of news is that the team has a new Neurologist. Dr Anke Hensiek has taken over from Graham Lennox. We take this opportunity to thank Dr Lennox for his many years helping people with A-T, and we also wish Dr Hansiek well in her new role.

Farewell... and Welcome!

One sad moment at the AGM, which took place during the Family Information Day, saw Joan Bridger stepping down from the Board. Joan, whose son had A-T, was a trustee for seven years but has been a volunteer for much longer than that.

She has been an excellent fundraiser – her efforts brought in many thousands of pounds for the Society – and a wise and always positive voice on the Board.

Maureen Poupard spoke to those at the meeting about Joan's achievements and expressed the Society's warmest thanks for all her efforts. We would like to echo those thanks here and to wish Joan every good thing in the future.

At the same meeting, Lynda Finn was confirmed in the role of trustee. Lynda brings the Society a wealth of experience of the health-related voluntary sector and a deep commitment to ensuring that people living with A-T have access to the best possible care and support.

New member of the Nottingham team

There has been a change of personnel in Nottingham, too. The team's psychologist, Van Tran, has now left and his place has been taken by Jane Flint. Again, we thank Van Tran for his work with people with A-T and wish Jane Flint well in her new role.

Paddling our own Canoe!

One of the most unusual donations we have ever received was presented to the A-T Society at the Family Weekend.

A team of young men attending placements at Opportune Engineers in Lincolnshire had built a 16' Canadian Luggage canoe for us to use in fundraising.

Graham Dyer, his wife Sarah, Dave Thompson, the Head of Solutions 4, and three of the lads made the long journey to Chessington to hand over the canoe and, in a brief ceremony, the canoe was named 'Louisa' after Louisa Hill who has dedicated great time and effort to making cards for the charity in the last two years.

The team presents 'Louisa' to the Society

Steps forward in Frankfurt

Sixty-five world experts on A-T met for a workshop on clinical research. Here's how they got on

The last weekend in January, some 65 of the world's experts on A-T gathered in Frankfurt for a two-day workshop on clinical research. Organised by Stefan Zielen and Ralf Schubert from the Goethe University, the event attracted leading clinicians and researchers from as far as the United States and Australia.

A team of experts on A-T pose at the workshop on clinical research in Frankfurt

The workshop split into 3 streams, giving participants a chance to focus on either the neurology of A-T, its immunology or susceptibility to cancer. Given the limited number of patients that most doctors see, this was an extremely valuable opportunity to share experiences, discuss cases and compare treatment approaches and outcomes. There were also presentations on a number of recent and ongoing research projects, including the following:

• **Professor Richard Gatti** presented research he is doing into so-called nonsense mutations *(see p14)*. In A-T, the gene which gives instructions to produce and regulate the ATM protein is damaged by one of a number of different mutations. In the case of nonsense mutations, the body can 'read the instructions' codified on the gene until it reaches the mutation, but then gets blocked. Without the full 'instructions' the resulting protein is incomplete. Gatti's team is looking at drugs that can help to 'read across' the mutation to enable the complete (or virtually complete) instructions to be read.

Finding a drug that can do this effectively involves a lot of testing and rejecting. However, they are making progress and hope to start clinical testing by 2012 – 2013.

• **Professor Luciana Chessa** spoke about a trial due to start later this year, at two sites in Italy, on the use of Dexamethasone, a cortico-steroid. Steroids have been shown in a previous trial to have a positive impact on neurological symptoms, but usually produce significant side effects. This trial aims to achieve the same positive impact while avoiding the side effects through a novel method of delivery. Small quantities of the drug are encapsulated inside red blood cells, which are then transfused directly into the bloodstream. In other treatments, this delivery method has avoided many side effects.

• **Hermann Stimm of the German Ataxia Organisation** presented the results of research he carried out which shows that there is a positive correlation between Body-Mass-Index and good health in people with A-T. Put simply, people with A-T who are well nourished, tend to have better health, particularly with regard to lung-function.

• **Dr Kate Sinclair from the A-T clinic in Brisbane** described the work they are doing to study the damage to white matter in the brain and potentially make use of deep brain stimulation. Deep brain stimulation involves the use of tiny electrodes which send electrical impulses to specific parts of the brain. It has been very effective in treating a number of other conditions involving tremor and dystonia.

• **Dr Liz McDermott of the A-T clinic in Nottingham** is studying the mechanism by which misfunctioning ATM proteins cause immune problems. Noting that immune problems are reduced in individuals who have some ATM kinase activity, they are looking at the receptors on T cells, which recognise bugs, to see if there is a normal range of variation and identify any differences between those who have some and those who have no ATM activity. Early results have not shown a big difference between groups but they are analysing more samples to see if this is true with bigger numbers.

• **A number of presentations stressed the complexity of the condition.** In particular, Professor Tom Crawford from the USA and Dr Michel Willemsen from Nijmegen underlined the complexity of the neurological component. While this is traditionally associated with damage to the cerebellum, they stressed that there are many elements to the neurological condition of people with A-T which are not typical of other ataxias

and are not associated with the cerebellum.

There were also a number of presentations from young German researchers which were exciting as they showed the amount of research going into A-T – and also the emergence of a new generation of committed researchers.

And there were yet more positives at the end of the conference when those present agreed to proposals put forward by the A-T Society and the A-T Children's project to build on the successes of this Workshop and ensure greater co-ordination of clinical research in the future.

Participants agreed that a formal A-T Clinical Research Network should be set up and also that there should in future be a continuing and planned series of clinical research workshops. These would maximise opportunities for shared learning and collaboration in designing and carrying out new research.

The next workshop will be held in the UK in the first half of 2012.

A research strategy

One of the Society's biggest priorities for the next few years is A-T research. We aim not only to invest more in research, but also to ensure that this research concentrates on the most important areas and is properly coordinated.

To help us do this, we are producing a research strategy, which will set out our priorities for research. This will help ensure our programme is focused and that we get the best possible return on the money we put in. It will also inform potential partners and funders of exactly what we aim to achieve in our programme and will hopefully encourage them to work with us.

To advise us on setting up and implementing this strategy, a number of eminent researchers and clinicians have agreed to form a scientific advisory committee. At its first meeting, the group agreed an outline for our initial strategy.

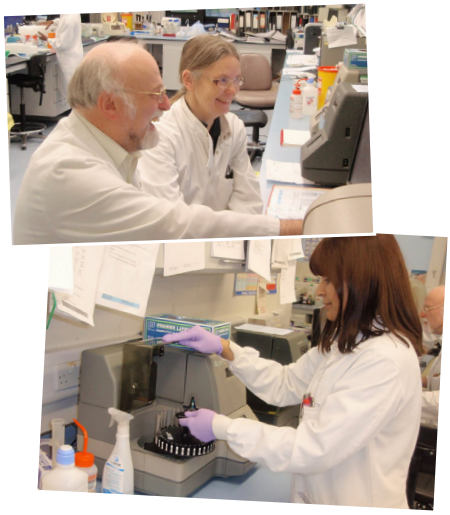
The key objectives will be:

- to better understand the relationship between the genetic profile of ATM and the physical manifestations of A-T;
- to identify and develop clinical or therapeutic interventions which can slow, prevent or undo the effects of A-T and improve quality of life;
- to promote cooperation between individuals and institutions with a clinical or research interest in A-T, within or beyond the UK, to help achieve our aims more rapidly.

Areas of particular focus will be:

- clinical and translational research, ie, research aimed at improving clinical care and developing treatments, rather than pure laboratory research;
- better understanding of the basic mechanisms of A-T and how the particular genetic mutations lead to the various different manifestations of the condition;
- Treating and preventing lung disease, which is so often fatal;
- improved administrative support; it is particularly difficult for doctors involved in clinical research to find the time to do all necessary paperwork;
- research aimed at improving the quality of life of people with A-T.

The full strategy should be completed later this year. Once it is, we will use it to try and encourage more organisations to work with us, whether by becoming actively involved in research or by providing money or other forms of support.



Our researchers get to work in the lab

International support for research project

At its June meeting, the Board of Trustees agreed to fund a research project at the University of Brighton, in partnership with the A-T Children's Project.

The project, led by Dr Emma Ross *(pictured above)* and supported by doctors from both Nottingham and Papworth, aims to evaluate whether inspiratory muscle training can help improve breathing and the ability to cough for people with A-T and so help improve quality of life.

The study will involve 15 patients of between six and 30 years old and will involve using a simple hand-held device to exercise their breathing muscles *(pictured below).*

Those participating will carry out two training sessions of fifteen minutes a day, six days a week. This technique has been shown to improve breathing and health-related quality of life in people with a number of other conditions.

It is hoped that the study will start later this year and that the results will be available in 2012.

New guidance on breast cancer screening

Guidelines for women with A-T and A-T carriers, approved by the NHS Cancer Screening Programme

It has been known for some time now that women who carry the A-T gene but don't have A-T themselves, for example the mothers of people with A-T, have a small increased risk of developing breast cancer. However, the majority of women who carry the A-T gene will not develop breast cancer in their lifetime. There is also evidence that women who have A-T themselves have an increased risk of breast cancer.

The NHS has been looking at its guidance on breast cancer screening for both women who carry the gene and for women who have A-T. We have recently been informed by the director of the Cancer Screening Service that the following guidelines have now been approved for both groups of women in England. The new guidance is as follows:

Women who carry an A-T gene mutation

It is recommended that women carrying the A-T gene who are between the ages of 40 and 50 should be offered mammographic screening every 18 months. At 50, they will join the normal screening programme, which begins at that age and from then on will be screened every three years.

Women over the age of 70 are encouraged to continue with breast screening but will need to request an appointment through their GP or local screening unit, as they will no longer be automatically invited for mammographic screening.

All screenings should be performed using the lowest dose of radiation and two-view digital mammography. Where possible this should be carried out using a full field direct digital mammography machine (FFDM), which should ensure that the lowest possible doses of radiation are used to achieve the required quality of mammogram.

Women who have A-T

It is recommended that women with A-T should be offered annual MRI screening from the age of 25, or from the time of diagnosis should this be later. It is not recommended that mammography be carried out on women with A-T for routine surveillance, although it may have a role in assessing an abnormality found on MRI. This screening should continue throughout their lives.

"Over their life time, an ATM mutation carrier has a one-in-six chance of developing breast cancer compared to a one-in-eleven chance for the general population"

While this guidance, which applies only to England, has been agreed, it has not yet been formally published. As soon as this is done, we will send a copy to all families affected.

Women carriers between the ages of 40 and 50, and women with A-T over the age of 25 who live in England are advised to go to their GP and ask to be referred to the breast cancer screening programme. It might be advisable to take this article with you, to show your GP.

The situation for the other nations varies. While the guidelines don't formally apply, the same advice as for England applies to women in Northern Ireland. Women in Scotland should ask their GP to be referred to the regional genetics unit, where they will be assessed for appropriate screening. In Wales, only routine screening from the age of 50 is currently available. However, this is an issue that we will be taking up urgently with the NHS in Wales.

Wherever you live, if you have any problems accessing the screening service, please do contact us on 01582 760733; we will do all we can to support you. It would also be very helpful to hear what experiences you have, positive or negative, in accessing the service.

The incidence of breast cancer

Although work is being done in this area, given the relatively small numbers of people with A-T, it is hard to collect very accurate data. With regard to carriers, the best information comes from a large study carried out in the UK some years ago, which looked at 1,160 relatives belonging to 139 A-T families with 169 A-T patients.

This study, very much in line with other smaller studies, predicts a moderate increase in the relative risk of breast cancer in women known to be carrying the ATM mutation.

This UK study estimated the overall lifetime risk of developing breast cancer to be slightly more than twice as great (2.23 times greater) for an A-T carrier than for a member of the general population.

Over their life time, an ATM mutation carrier has about a one-in-six chance (16.6 percent) of developing breast cancer compared to the one-in-eleven chance for the general population (at the time the study was conducted).

However, the chance of developing

breast cancer by the age of 50 for an ATM mutation carrier is about one in 11 (8.8 percent). This is nearly five times higher than the risk for the general population at this age.

With regard to women with A-T, a new study is about to be published looking at this issue. The figures here are even smaller but broadly it appears that the risk for adult women with A-T is significantly higher than it is for carriers.

It should be stressed that the figures above apply only to women. Men in the general population are at a very low risk of breast cancer anyway, but we do not know what the risk is to a male A-T patient.

To put this into perspective, more than 48,000 new cases of breast cancer are diagnosed in the general population in the UK each year, of which only 340 or so (less than 1 percent) are in men.

Are there risks from radiation?

It is well known that people who have A-T are more sensitive to the effects of radiation of the kind that is used in x-rays and radiotherapy, and some carriers have wondered whether they too may have increased sensitivity to radiation.

People with A-T

People with A-T are highly sensitive to radiation. If someone with A-T receives radiation in the large doses that are used for radiotherapy, this is likely to have an extremely serious, possibly life-threatening, effect.

However with the much lower doses that are received for diagnostic purposes such as x-rays, there is not the same risk, though it cannot be excluded that even these smaller doses might carry long-term risks, as a result of the radiation causing some unrepaired damage.

However, we do not have sufficient knowledge about this and it is a matter of balancing the immediate needs of the patient and any possible long-term effects.

It is recommended that women carrying the A-T gene who are between the ages of 40 and 50 should be offered mammographic screening every 18 months

In any case, the new guidance recommends that women with A-T should be offered a regular MRI scan rather than mammography. As MRI uses magnetic fields rather than radiation, there is no risk in having regular scans.

Carriers of the ATM mutation

In the case of carriers, there is no good evidence to suggest that their cells will be more sensitive to x-rays than cells from anyone else. Radiotherapy is regularly given to carriers who have developed breast cancer and there is no increased clinical sensitivity of normal tissue to the x-rays.

Likewise, there is no reason to think that radiation doses received through surveillance (mammography) will increase breast cancer rates over and above what is already to be expected. Furthermore, the benefits of earlier breast cancer detection by screening are expected to outweigh any possible extra risks from exposure to medical radiation.

Are you a carrier?

While it is not yet possible to test members of the general public to see if they are carrying an ATM gene mutation, it is usually* possible to test someone closely related to a person with A-T. If you are a relative, and you are worried that you may be a carrier, you should first consult your GP. Your GP can arrange either for you to see a genetic counsellor or for a blood test to be organised.

If you have children who may potentially be carriers, it is again usually possible to arrange for them to be tested. However, given that there is little that can be done in the short term to change the situation, and this is an issue that will affect them as adults, it would be advisable first to see a genetic counsellor and talk through the issues. In any case, your GP should be your first port of call.

*(*providing both mutations have been identified for the person with A-T)*

Keeping well

If you are an ATM mutation carrier, then there is nothing you can do to reduce the small extra risk of breast cancer associated with this. However, you are of course still at the same risk of breast cancer, and any other cancers, as women without an ATM mutation.

Broadly speaking, many of the factors that can increase risks for breast or any other cancer are known. These include excessive body weight, cigarette smoking, excessive alcohol consumption and so on. Adjusting your lifestyle to reduce these exposures can only be beneficial in minimising the risk of developing cancer as well as other health conditions.

More information can be found on the Cancer Research UK website at http://info.cancerresearchuk.org or at NHS Choices http://www.nhs.uk.

To discuss any of these matters, contact Kay Atkins at the A-T Society on 01582 760633.

Are you getting all the help you need?

Find out how the Society has been supporting people affected by A-T, and how they can help you

One of the Society's main areas of work is to help people access all the services and support that a child or adult with A-T, or their families, might need. Kay Atkins, our Family Support Worker, spends much of her time providing this type of support.

The help people need varies considerably from simply listening and giving a different perspective on problems, through providing information or putting people in touch with experts, to offering active support at meetings or tribunals. The more involved work is sometimes called 'Advocacy'. We thought it might be helpful to give examples of how Kay has helped people recently:

• A family in Nottinghamshire, who have a daughter with A-T aged 8, called the Society for advice on their daughter's educational needs. Although her School was very supportive, they had very little knowledge of A-T and what support they should put in place. Kay spoke directly to the school on the family's behalf, wrote supporting letters and attended two meetings at the school.

The child concerned is now receiving the support and help that she needs and the school has a much better understanding of A-T. The school continues to ask for support and advice from the Society and are putting a 'Statement of Educational Needs' in place.

• The mother of an eight-year-old girl contacted us recently. Her daughter had been coughing for 2 months but her GP just wasn't taking this seriously. The mum spoke to Kay, who was able to get hold of a letter from the Respiratory Expert at the National Clinic in Nottingham, setting out what treatment he advised for her. Armed with this letter, the mother returned to the GP. The girl was admitted to hospital straight away and diagnosed with Pneumonia. She made a good recovery.

• A family in Yorkshire contacted us as they were having serious housing problems. Their daughter is 15 years old and has A-T and her mother is also a wheelchair user. They could no longer manage in their home and the family had been forced to split up with the mother moving to an adapted flat.

The council finally agreed to convert a bungalow to accommodate the whole family; however, with different departments arguing about whose responsibility it was, no one was willing to cover the cost of the rent on this new property while the adaptations were being carried out. Unable to afford three rents, the family were at risk of losing the new property.

The Society persuaded a senior manager in Social services to step in and resolve the issue. The extra funding was found and the family will move in shortly.

There are many other ways that the Society can help. For example:

Support Grants

The Society's Support Grant scheme can help families with such things as powered wheelchairs, specialist trikes, computers, respite care breaks, bathroom equipment, etc. If you are in need of equipment or a respite break and your local authority are not able to help, you may be able to apply for a support grant from the Society *(see page 13 for details)*.

Benefits

Are you receiving the correct amount of benefits? Do you need help understanding which benefits you can apply for? Do you need help applying for benefits? The Society can help fill in forms and with benefit assessments.

Emotional Support

Helen Hart, the A-T Society Counsellor, is available on the telephone, to talk through any issues regarding coping with the affects of A-T within the family.

Contact with others

The Society can put you in touch with other people of a similar age who have A-T or other parents for support.

Information and Advice

We can provide literature and advice about A-T to families or to health care professionals; we can also liaise with our specialist doctors and therapists to provide medical advice to the local care team.

For further details and advice on all the above please contact Kay Atkins, Family Support Worker, at the A-T office.

You can reach her by calling 01582 760733 or emailing kay@atsociety.org.uk.

Attending a national clinic

Nottingham City Hospital (Children)

If your child hasn't been to a clinic for approximately two years, or you are concerned about their health, you may wish to book a space at one of the clinics below.

22/23 September 2011
(Transition Clinic) This will be a special clinic for 15-18 year olds, attended by staff from both clinics to help with the transition to the adult service at Papworth.

17/18 November 2011
26/27 January 2012
8/9 March 2012

Papworth Hospital – Cambridge (Adults)

If you are an adult with A-T and have never been to the Papworth Clinic, we would encourage you to book an appointment.

These appointments are arranged throughout the year on a weekly basis, with admission on a Sunday afternoon (as an inpatient), until the Tuesday lunchtime.

Help can be provided with arrangements for transport and accommodation for carers. Just contact Kay for more details.

Note

If you live outside the UK but within the EU, you may still be able to attend one of the above Clinics and have the costs paid by your country's medical board.

Your consultant needs to fill in form S2 (which used to be called E112).

For further details of the above clinics and to book your appointment please contact Kay Atkins, Family Support Worker, on 01582 760733, or email kay@atsociety.org.uk

Individual support grants

You may not be aware but the Society can make available Financial Support Grants to people living with A-T. The grants are there to assist people with the cost of items that they need as a result of the condition, but cannot easily afford, and for which they cannot get help from other sources.

Grants can be made to cover a variety of different costs. These include:

- mobility equipment, such as wheelchairs, scooters, trikes, special terrain buggies, stair lifts, through-lifts or ramps
- specialist furniture or equipment for the house
- IT equipment
- respite or holiday breaks
- courses

Adaptive technology can help with using computers

However, this is not a complete list and the Society is willing to consider other appropriate applications.

Grants can only be made to meet a need which is a direct result of A-T and all applications must be supported by an OT or other health or social care professional.

We will not fund things that other organisations have a duty to fund and where possible we will look to obtain funding from other sources. For instance, we often work with the AIDIS trust to support applications for IT equipment.

If you are interested in applying for a grant or would like to discuss the possibility, please contact Kay on 01582 760733.

There's a bright future...

After a lifetime in A-T research, **Richard Gatti** tells William Davis he is optimistic about the future

In the field of A-T research, few names are bigger than that of Professor Richard Gatti, which will be familiar to almost everyone with an interest in the subject. Professor Gatti was in the headlines earlier this year when his laboratory was awarded nearly $2 million by the California Institute for Regenerative Medicine for its research programmes.

Professor Gatti spoke to me by phone, from his house overlooking the Pacific Ocean in California. Though it was 9.00am there, he had already been working for a couple of hours. His enthusiasm and energy were apparent as he launched into a passionate, detailed and wide-ranging description of his current research.

At the moment, his lab is focusing on a particular type of gene mutation known as 'nonsense mutation' (sometimes also called a 'premature termination codon' - *see box for more information*). This kind of mutation blocks the process used by the cell to produce the ATM protein. Their aim is to identify a compound which will help the protein-making mechanism in the cell to 'read across' the mutation, effectively ignoring the blockage, and thus finish producing a complete ATM protein.

Similar drugs have already been developed for other conditions which have nonsense mutations. However, a drug for Duchenne's Muscular Dystrophy, called Ataluren, had disappointing results when trialled in patients and was withdrawn. Gatti is very positive about the progress his team are making with the new drug.

While this is an exciting project and one that Gatti clearly believes offers great hope, it must be underlined

"I'm very positive. We are more in touch than ever as a global unit"
Professor Richard Gatti

that it will not help everyone with A-T. This approach can only help those people who have a nonsense mutation. Nonsense mutations only make up about 15 percent of mutations, though they are more common in certain areas of north Africa and central America. However, each person with A-T has two mutations and in areas of mixed population, such as Europe and North America, these are likely to be two different mutations, so the number of people who have at least one nonsense mutation and could thus potentially be helped could be up to about 30 percent.

In order to identify suitable candidates, Gatti's laboratory has been working its way through a library of 75,000 compounds. They have now narrowed down their interest to a handful of compounds. They have been testing these on a number of key genes, including those responsible for A-T and Muscular Dystrophy, and results have been very encouraging.

One of the challenges particular to A-T is that you need to get your compound into the brain – to the cerebellum to be precise – and the brain is protected by a very effective structure, called the blood-brain barrier. This, as its name implies, is a kind of membrane designed to keep chemicals and cells from the blood away from the brain and the central nervous system.

So at the moment, Professor Gatti and his lab are working to develop ways to get these compounds through the very small 'doors' that exist in the barrier.

Once they can do this they will be able to move towards starting clinical trials, and Professor Gatti is hopeful that this is not far off. "I will be very disappointed if by the end of 2012 we are not moving into making an IND application," he says. An IND (Investigational New Drug) application is the first stage on the route to clinical evaluation and hopefully eventual licensing of a drug.

But as he recognises they "will be entering a whole new world of commercialisation, where there are many obstacles and many sharks swimming around", to get a drug through the whole obstacle course of testing, approval and ultimately production and marketing will need the support and resources of a pharmaceutical company. And there is the challenge of getting a company interested in a drug that will help a very rare condition.

Professor Gatti is undaunted. "The fact that these compounds can potentially treat a number of genetic conditions is in our

favour. And of course we own the rights to them – that's essential for the pharma companies to be interested." And he has a number of potential strategies in mind: "We might be able to 'piggy-back' on the interest for treating other conditions, for example Muscular Dystrophy; alternatively we may be able to stipulate in a contract that while they go initially for licensing for another condition, they do A-T second; or we may be able to go for off-label use for A-T."

And he's looking for help from wherever he can get it. He has engaged students from the prestigious Anderson Business School at UCLA where he is based to work on the project, looking at how to develop a strong business case and mitigate the risks for potential investors.

The above is a brief summary of a two-hour conversation, which moved ceaselessly from one project or idea to another, leaving this amateur journalist struggling to keep up. Professor Gatti certainly has a huge range of interests, far too many to fit into this article.

I ask him what he is most proud of in his career; he laughs: "Surviving, I guess! No, really, I think the real achievement is having been able to move from a position where we didn't really understand immunodeficiency at all to identifying and localising the genes responsible for this and to working out how mutations can be repaired. That's thirty years of hard work."

He first became interested in A-T when he was a young man, studying with the world-renowned immunologist Professor Robert Good in Minnesota. It was becoming clear that cancer was much more prevalent in children with immunodeficiency conditions and the young Gatti became interested in the links between them. When he eventually began to do his own research, he chose to study A-T, because it caused both immunodeficiency and cancer. He became more and more fascinated by the condition and its underlying mechanisms and has been working on it ever since.

I asked him if he had research interests beyond A-T? He thought for a bit: "Not really though there are other things I find fascinating in A-T, like the whole issue of sensitivity to radiation.

How does he see the situation of A-T research more generally. "I'm very positive" he says. "We are more in touch than ever as a global unit". And he considers meetings like the one in Frankfurt or that to be hosted by the A-T Society next year as vital, not just for the formal proceedings but for the chance they give experts to talk and spark off new ideas over a coffee or beer.

He also thinks that new technologies are opening up new opportunities. "For example, the great improvements in MRI (Magnetic Resonance Imaging) are potentially very significant for A-T. I'm going to a meeting next week to look at proposals for research using Diffusion Tensor Imaging to look at the nerve tracts that lead from one part of the brain to the next. As well as leading to advances in our understanding of A-T, this could prove very helpful in measuring the impact of new treatments." He's also interested in work being done on drugs which affect splicing, another type of problem caused by A-T mutations.

However, the fundamental challenges of A-T research remain. And what are these? "The rarity of A-T, the complexity of its effects and what remains a fundamental lack of knowledge of some of the basic processes, such as how and why the cerebellum is affected and leads to the neurological symptoms."

And as he approaches the age when most people would be thinking of retiring, I ask about the future; who's going to take over the torch? "We have that covered" he replies confidently. "There are a number of really good people in my lab who will be taking forward the work." There are experts on stem-cells and on the clinical side, as well as someone with a special interest in radio-sensitivity. But far from putting his feet up, he's looking forward to retirement as an opportunity get on with more research. It means he can bow out of all the other tasks and just focus on the research that he loves .

But driven as he clearly is, he does find a little time for relaxation. Richard Gatti is a fine pianist – he studied at the world-famous Juilliard School of Music in New

Explaining the science

Nonsense mutation or premature stop codon

A-T is caused by a mutation (or 'fault') in one particular gene. This gene is rather like a code or recipe for making a particular protein, called ATM. When a person has A-T, they effectively have a mistake in the recipe as a result of which the ATM protein isn't produced or else turns out wrong and doesn't work – and that's what causes all the problems.

There are different types of mutation. In a nonsense mutation, a particular group of chemicals, which normally appears at the end of the gene and tells the protein-making process to stop, appears in the middle of the gene. It's as if we got halfway through our recipe and came to the words 'the end'. The result is that the production of the protein stops in the middle, leaving an unfinished protein, which can't do what it is supposed to.

York and will sit for hours at one of his collection of pianos playing from memory. And if he's not at the keyboard of his piano or computer, you are likely to find him working in his garden or, true to his Italian roots, sharing a bottle of wine with friends.

As we closed our conversation, I asked him what message he has for people with A-T: "Remain hopeful" he says.

"We are entering a new era of opportunity for technologies for looking into the brain and body non-invasively, and for understanding and treating genetic processes. There are a lot of ideas, a lot of opportunities for research and a lot of skilled people around. We are coming together now as never before and if we work together we are going to make real progress".

Sean Roebig: a loss to the whole A-T community

In January this year, Sean Roebig, co-founder with his wife Krissy of the Australian A-T charity BrAshA-T, lost his battle with malignant melanoma.

BrAshA-T has achieved a huge amount to improve the lives of people living with A-T in Australia and to support research, and Sean's death is a real loss, not just to his family but to the whole A-T community. Sean's contribution to BrAshA-T will be his legacy and will live on.

The many people who know Krissy either in person or through Facebook, will have witnessed her incredible inner strength and fortitude during the difficult last weeks of Sean's life. It seems appropriate to let the last words be hers:

"Life is going to be very hard without Sean in it. Raising kids alone is going to be hard. Running the foundation is going to be hard. Going back to work in my shop is going to be hard. Having two sick kids with a disability is going to be hard.

"Getting them to start school for the year is going to be hard. Smiling again is going to be hard... BUT as hard as all of these things will be, it will happen because Sean had faith in me from the day he met me. He loved me. We will be ok..."

Meet Keck, the assistance dog

By Maureen Poupard

I was delighted to meet the Laage family when I attended the A-T Clinical Research Workshop in Frankfurt last January. Beate and Andreas have one son Christian who is 11 and has A-T. Keck is Christian's assistance dog.

Keck is two and a half years old and he gives a lot of practical help to Christian. First thing in the morning, Keck finds Christian's shoes and clothes and brings them to him. He ferries items from mum and dad to put into Christian's school bag and then accompanies him to school.

There he acts as an intermediary helping Christian make friends. He has increased Christian's confidence, concentration and independence. With Keck at his side, Christian was able to give a presentation to his class about the Romans, something that would not have happened before.

Keck with Christian and his parents Beate and Andreas Laage

Keck was trained by the German organisation Vita Assistance Dogs. He is a lively golden Labrador, enjoys being petted enormously and very much has his own personality!

He is great at making friends and is an excellent companion.

Christian controls and praises Keck and feeds him but it is always Beate or Andreas who tell Keck off (if necessary)! This way Christian and Keck always enjoy a good relationship.

Certainly bringing a dog into the family is a big commitment and not for everybody but should you wish to explore this further please contact:

Dogs for the Disabled
01295 252600
www.dogsforthedisabled.org

Fundraising

It's been an exhilarating six months at fundraising central, and the number of new fundraisers, events and activities has really kept me on my toes!

It was fun to meet so many new faces at the Family Weekend and from feedback, it's clear lots of people plan to get more involved with raising money for the A-T Society in the coming year. Remember it's my role to support you, so please don't hesitate to get in touch.

This month's newsletter is crammed with articles about incredible people, a range of unusual fundraising ideas, an update on our newly branded products including the much requested hoodies, and details of a change in our online donation site provider to replace Justgiving.

Happy reading and stay in touch!

Suzanne

Troopers4AT and the Bridgnorth Walk 2011

The Troopers4AT Team braved wet and almost wintry conditions to complete the arduous 22 mile course on Spring Bank Holiday in May.

Despite the heavy going, all the team managed to complete the course without mishap and were very proud of their overall performance.

In terms of sporting prowess it was the ladies who showed us the way with Jayne finishing as the second fastest lady. Our Junior Walker, Oscar, finished in a very creditable 22nd place.

Even more pleasing is to report that we exceeded our £1,000 target and to date have raised £1,135 for the A-T Society.

Despite the blistered feet and aching legs – roll on next year!!

• **NB** there was another group of walkers supporting the A-T Society, and we hope to feature them next time (once they have dried out!).

Power walkers: (from left) Becky Hughes, Annette Hughes, Sue Evans, Tim Hughes, Deb Waterson and Jayne Seal

Exxon Mobil tackle the 62 mile race!

A team of nine from Roc D84, a division of Exxon Mobil, took part in the 62 mile cycle race from Knutsford, Cheshire to Blackpool on 11 June.

The group included:

Adrian Roberts, Beth Richardson, Dave Ablott, James Sykes, Phil McCann, Stuart Jones, Dan Robson, Carey Manger and Dilan Burkath.

Dilan explained: "We now have new-found respect for cyclists on the road. There were some cramps, sun burns etc, but overall a brilliant day and the weather was gorgeous too.
"We're all suffering a bit now with sore bums and tight thighs, but it was so worthwhile and we want to say a big thank you to all our sponsors".

At the time of going to press the team had already raised more than £2,300.

Hayley and Mark come out fighting

By Hayley Radford and Mark Carrington

Kira was diagnosed with A-T in 2004. She was fine until 2010 when her balance and coordination really started to deteriorate. People were used to Kira running and playing, so when she started to use her wheelchair we got questions and puzzled looks.

This is when we decided to do the Fun Day. We got the local press involved. Kira was then front page news and from that day on the response has been GREAT!

Lots of friends, family schools and businesses got involved by donating raffle prizes, doing sponsored events, holding collections and just giving their time to help. The Fun Day and surrounding events raised massive awareness of A-T in and around our town, as well as lots and lots of money for the A-T Society.

Kira is now a little star in Sutton in Ashfield. People understand more about what is going on with her and it's helped us with our process of coming to terms with her illness. We take each day as it comes. I say to Kira every day: "Don't worry about the things you can't do, let's have fun doing the things you can".We are thankful every day knowing we have the support of our friends, family and the A-T Society.

A special thank you to those people who helped with our event: Lorraine Orton – Julie Sharp – Sophie Orton – Rose Clowse – Courtney Hallam – Janis Carringon – Lorraine Unwin – Gayle Wharton – Carrie Ann Roberts – Gemma Wharton – Mickaela Carrington – Lianne Aldred – Kate Taylor and of course Amy and Kaycee!

To purchase photos visit: www.justgiving.com/steve-white0

Making 'time' count

The walls of Her Majesty's Prison Shotts were no barrier to fundraising when William Sinclair arranged a sponsored event for the A-T Society.

William, along with fellow inmates Neil Murray and Barry Thompson, took part in a three-hour Heavy Punchbag Boxing Challenge raising a total of £354 from their hard labour.

The prison officers were supportive and helped with arrangements before and after the event, even sending the money on to the A-T Society after William was transferred in preparation for release.

William explained that the average weekly wage for a prisoner is around £10 and some of their sponsors had donated their wage packet to the charity.

There aren't many people who would be willing to give up their entire weekly salary for charity, and we offer the inmates and staff of HMP Shotts our sincere thanks for their support.

If you go down to the woods today...

By Jackie Edge

I'm Jackie Edge and I am a teaching assistant at Abingdon School in Reddish. A gorgeous little girl in my class called Cleo Brady unfortunately suffers from A-T.

She is always smiling and never lets anything get her down and everyone at school, myself included, loves her to bits. Cleo tries so hard with everything she does.

The children all love her and argue about who is going to push her in her wheelchair in the playground and who is going to hold her hand to go to assembly, among other things.

Me, my daughter Nicky (who has never actually met Cleo, but listens to all my stories about her and has fallen in love with her), Cleo's teacher Beccy and another

Cleo (centre) with Sarah, Becky, Jackie and Nicky

teacher from school Sarah, decided that we really wanted to try and do something to help Cleo and other A-T sufferers and so we decided to make up our own walk and ask for sponsors.

So on Saturday July 2nd we are walking in Macclesfield Forest doing a 'challenging 10K walk' and I can assure you it will be challenging as none of us are particularly used to much exercise!!! I have been walking at weekends to try and get myself a little bit fit!

We all have our own sponsor sheets and a joint one at school and so far I have collected £250 on my own sheet and I know we have quite a good amount on the joint sheet and the other 3 have their own sheets too.

We really hope to raise a good amount of money for your organisation to try and help children like our special Cleo. I will let you know how we get on.

Editor's note: We can inform you that Jackie and her team successfully completed the walk and raised a total of almost £1,000.

'Spooker Stars'

Nerys Middleton is a remarkable lady! Not only does she work part-time in her local hospital, she is a professional cup cake maker, Dannii Minogue lookalike and has now become an accomplished GHOSTBUSTER in aid of the A-T Society!

Nerys wanted to get involved after her friend's twins Zach and Ruben were diagnosed with A-T, but she wanted to do something a little different to raise money in her local area.

Plas Teg is renowned as the 'most haunted' house in Wales.

Even Cheryl Cole and Girls Aloud were scared witless when they visited the very creepy mansion for a TV programme. Nerys's team of brave souls soon turned to jelly as they explored the haunted house Nerys said...

"I got touched on the back of my neck, Kate got her hair touched and the chair she was on moved. When we tried table tipping, the table flipped right over and slammed to the floor.

"Some rooms were ice cold and you could see your breath even though it was a warm night.

"We saw unexplained lights on the ceiling in one room and in another room it kept getting darker and then we saw a mist on the ceiling. It was all very bizarre, but a great night for us all!"

If you would like to organise a

A brave team: Nerys (left) with friends who dared to visit Plas Teg

Ghost Hunt for you and your friends, contact Compass Paranormal at: www.compassparanormalevents.co.uk who can arrange and promote a charity event for you.

Alnmouth Village Golf Club
A Texas Scramble team event was held at Alnmouth Village Golf Club in Northumberland, raising an impressive £1,000 for the A-T Society. Sisters Beatrice and Cordelia Prokofiev travelled up to collect the cheque. Many thanks to the Captain Norman Luke (pictured) for organising the event and choosing the Society!

Counting the days

The charity calendar organised by Flicks Bar in Fuerteventura, Canary Islands and supported by Thomas Cook and Oasis Hotels, generated a donation to the A-T Society of €1,300. We also benefitted from ongoing publicity for the A-T Society through the involvement of 'tattoo man' James Bourner.

The picture above shows Sophie Wood receiving the cheque on behalf of the charity.

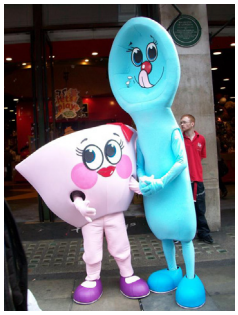
Lloyd Morris Electrical Ltd
Staff at Wrexham-based Lloyd Morris Electrical Limited donated £1,470 in a recent collection. The company added an additional £250 to the total which is to be used for research into finding a cure for A-T.

Racing ahead
2623 Squadron RAuxAF, based at RAF Honington, hosted a race night and raised a magnificent sum for the A-T Society. The picture below shows Stefan Sprawling receiving the cheque from his colleagues.

Ulster Gaelic Athletic Association Writers
The Ulster GAA Writers Association presented a cheque to Conor and Aedamar McCann for €2,410 which was raised as part of the charity envelope collection at their Annual Awards Dinner.

Recycling
Thank you to everyone who routinely recycles printer cartridges and mobile phones. We are delighted to say the total raised through Recycle4charity so far is £1,861.44. Envelopes are always available from the office and boxes for larger cartridges can be requested direct from the company.

Natalie Fall
Natalie's remarkable 2010 Fundraising Year raised in excess of £10,400, but Natalie, ably assisted by mum Helen, is not ready to stop there! 2011 has already seen a Car Wash, a Dinner, and match funding from Barclays to add to a significant donation from the famous 'Betty's Tea Rooms' in Harrogate (pictured below), with more events to follow.

Hamleys

The Kids Cooking Company of Kingsbridge, Devon invited us to join them for their product launch at Hamleys, the flagship toy store in Central London. Mascots the Dish and the Spoon attracted a lot of attention, and we not only raised awareness of A-T, but also gained a new volunteer, Jeneen Hippolyte!

Nothe Fort Ghost Hunt
The second A-T Spook-a-thon took place on 24 June in Weymouth.

Marathons!
Congratulations to Claire Tierney and her team for taking part in the Dublin Women's Mini Marathon in early June *(see below)*.

Great North Swim
Nick Walsh and Marcus Harding braved the chill waters of Lake Windermere in the Great North Swim, in June.

British 10K London Run
Ten runners represented the A-T Society in our first British 10K London Run on 10 July *(see below)*. The run includes part of the Olympic Marathon route and takes in many of the most historic sites in London... Not that our runners had time to see them!

Upcoming events

Welsh peaks
Twelve-year-old Kalisha Redican is taking part in a two day Welsh peaks event. On the first day she will take on Glyder Fawr (3,277ft), the fifth-highest peak in England and Wales, and Y Garn, the 10th-highest. The next day, Kalisha will climb Yr Wyddfa (Snowdon). At 3,559ft, this is the highest peak in both England and Wales. On the same day she will walk up the second highest, Crib Y Ddysgul (3,494ft). Kalisha does not believe people she doesn't know will support her in this amazing feat... Let's prove her wrong! www.justgiving.com/Jane-Redican.

Three Peaks challenges
There are two teams taking on British peaks during summer 2011. For those who didn't take part in the Family Weekend quiz, the 'Three Peaks Challenge' comprises Ben Nevis, Snowdon and Scafel Pike, the highest peaks in Scotland, Wales and England, all of which have to be climbed within 24 hours! A team from Heath Lambert UK Construction made the climb in June *(see clipping, p20)*. The 'Brady Bunch' team based in Stockport are climbing the 25 mile 5,000ft 'Yorkshire Three Peaks' in September. Good wishes to all for a blister-free experience.

Global skydive
The Global Skydive is booked for the weekend of 10/11 September 2011. Lynda McIntyre is hoping to get some media interest, and more participants! We have a team of jumpers at Coleraine in Northern Ireland, and one in Cambridgeshire. There is interest in taking part from America too. If you'd like to try a tandem skydive, consider booking up with your local airfield and be part of something amazing

Street Collections
Elizabeth Clark and Lisa Baricella have worked with their local councils to organise street collections in Ipswich and Bury St Edmunds this summer and autumn.

Fundraising Year
The Fox family of Dublin and their friends are pulling out all the stops to raise money in memory of Conor, with collections, runs and events planned throughout the year.

Skydive – Yorkshire
A team of Natalie Fall's friends make their second skydive for the A-T Society on 6 August.

Pampered Chef
For anyone who loves to cook and likes to have the newest gadgets, you can now combine the two with fundraising using the services of 'The Pampered Chef'. There are Pampered Chef representatives throughout the UK who would be pleased to support you with a tasty fundraising event incorporating an entertaining and informative cooking show. For more information visit: www.pamperedchef.co.uk.

Jewellery recycling
With the success of cartridge recycling, we have sought out another option to help you clear your clutter and simultaneously raise money for A-T. You can recycle your costume jewellery, broken chains, watches, single earrings, unwanted cufflinks etc, through www.jewelleryrecycling.org. Contact the A-T Office for envelopes. Happy spring cleaning!

In the media

Merry James
Merry and her family featured in an article in the Evening Chronicle.

Nicole and Cian
Mums Shona McBride and Lynda McIntyre were involved in a moving article in the *Sunday Life* paper in Northern Ireland (below).


'There is little chance of a cure - but we won't give up'
NICOLA SPURS MUM TO ACTION
Robo riled by fans over Glens' bailout

Brooke
Brooke's aunt Chantelle Bishop made sure 'The Toddle for Brooke' hit the front page of *The Norwich Evening News* (below and right).


Families toddle off to city park for fundraising event


Every game is massive now, says Holt – see Sport
Norwich Evening News
Children go for a toddle in the park
Fun for families this spring – free magazine inside
Accident?

Ebony
There can't be many people around Bournemouth who haven't seen the stories about Ebony Robinson and her great friend Adam Murry. Adam is chairman of The Murry Foundation and the charity coordinator for AFC Bournemouth. Adam has set up and is actively promoting 'The Ebony Robinson Foundation', which is dedicated to raising money for A-T Research and providing equipment for disabled children. Look out for lots more on Adam Murry in future issues.

Nerys Middleton
News of the Plas Teg House event certainly caught the eye of readers of the *Wrexham Leader* (see below).


Email our news team at news@leaderlive.co.uk
Look-a-like's spooky charity challenge
"I believe in ghosts but don't really know what to expect"

Emma Simoes
Emma pulled on her trainers for an action shot to publicise her 10K run in the *Wrexham Leader* (see below).


Solicitor all set for fundraising run in bid to aid nephews

Heath Lambert/UK Construction
The Three Peaks challenge featured in two articles in the *St Albans Review* (right).


Five set to take on three peaks challenge
St Albans Review 2/3/2011 p.18

The A-T Society
Our new logo was featured in the News and Pictures section of *Design Week* magazine, which was a coup for the charity and Gosling Design who worked with us to create the new brand.


AT Society

Kira
Kira Carrington has become a 'media babe' in her local area with several articles featuring in the *Ashfield Chad* during 2011!


Sutton parents raise awareness of their daughter's brain condition
Footy record for Kira fund
Charity match and fun day for sick Sutton girl
KIRA FIGHTS RARE BRAIN DEFECT
3 in a million have Sutton girl's disorder
THE CITY GROUND NEWS
When Kira met Nathan
Stamina test for Kira fundraiser
Fundraising help for Brave Kira
Royal day for Kira
Ashfield gets set for right Royal day!

Move to Virgin Money Giving

After many years using Justgiving for online donations, we have transferred our contract to Virgin Money Giving.

Virgin is more cost effective for the charity, and also offers a greater range of options for your donation site including photo galleries, videos and much more space to tell your story.

Go to http://uk.virginmoneygiving.com/charities/atsociety to set up your page.

Facebook

Our Facebook page currently has more than 800 members from around the world, all of whom have an interest in A-T.

It's great for friendship and advice from other parents and of course regular updates on all your fundraising exploits.

facebook

Leaving a legacy

By Maureen Poupard

The late Margaret Alexander (or Debbie as she liked to be known) was an extraordinary woman though on the face of it, very ordinary. Debbie was a great supporter of the Society. I got to know her through the 'Measure of Scotch' shows which have been raising funds for the Society for many years now. Debbie loved the shows.

This is where she learnt about A-T, became committed to our cause and started to fundraise for us. She sold our Christmas cards, T-shirts, mugs and also her own books of poetry. But Debbie was a woman of great compassion; we were in fact one of 18 small charities that she supported. Despite her deteriorating health, eyesight and poor mobility, her charities remained Debbie's consuming passion.

Sadly Debbie died last year but being the thoughtful woman that she was, she put her affairs in order so she could make one final gift to each of her charities. She was not a rich woman but she made us all small bequests in her will. The Society received the largest at £135.23.

Debbie was indeed an extraordinarily kind and selfless woman.

Legacy giving
A legacy to a charity is a gift that lives on. Once you have taken care of your friends and family, would you consider leaving a legacy to the A-T Society in your will?

Why do I need to make a will?
Making a will ensures your loved ones are provided for as you intended and your wishes are respected after you have passed away. If you don't have a valid will, the courts have to administer your affairs after you die. This can cause delays and anxiety for friends and family, and your affairs may not be handled as you would like.

Why make a gift in my will to remember The A-T Society?
A gift in your will costs you nothing during your lifetime and won't affect you now, but will one day make a huge difference to the future of people with A-T.

If you wish to remember The A-T Society in your will, we recommend that you use the following wording:
I leave... to The A-T Society, registered charity number 1105528, IACR-Rothamsted, Harpenden, Hertfordshire, AL5 2JQ

How else could I help The A-T Society?
You could help us to raise awareness about how important legacies are to our work by:
- introducing gifts in wills to your friends;
- sharing your story with others.

Merchandise

Our brand new note cards are available to purchase. The stunning photographs (right) were taken by our friend and supporter George Milford who has generously donated them for our use. Each pack includes 6 cards with two flower designs and costs £4.00 plus p&p. They are ideal for thank you letters or to keep in your desk and are the perfect gift for birthdays and Christmas.

Christmas cards

The 2011 Christmas Cards are here! This year's eyecatching design is called 'Twilight Squares'. The cards have the words 'Season's Greetings' written inside. A pack of 10 cards retails at £3.50 plus postage. We have them ready for dispatch now, so if you want to get ahead of the game – this is your opportunity!

Sunflower competition

Before we get too carried away with Christmas, a little reminder for all the children who attended the Family Weekend to plant your sunflower seeds donated by Sutton's Seeds and George Milford, and watch them grow. We are looking forward to your photographs and will have some smashing prizes for the winners of each category.

Clothes

By popular demand, we now have a range of clothing including Hoodies (£18), Adult Polo Shirts (£12), Children's Polo Shirts (£8) and Baseball caps (£6). They all carry the A-T Society logo and are a practical navy blue. For further information and sizes, please contact the office.