the Ataxian

THE MAGAZINE FOR PEOPLE AFFECTED BY ATAXIA
WINTER 2008 ISSUE NO.164

Matthew Law's family – Chelsea Football Club's official family of the year

Joe Cole, Carlo Cudicini, Terry Law, David Law, Stuart Law and Matthew Law

Photographer: Darren Walsh

Spotlight

Mary Harney opens the Ataxia UK Scientific Conference

This year Ataxia UK's Annual Scientific Conference was organised in partnership with Friedreich's Ataxia Society Ireland (FASI) and took place in Dublin. The event was opened by Mary Harney, Minister of Health in the Irish Government.

Ataxia UK belongs to *euro*-ATAXIA, an alliance of ataxia patient organisations from across Europe. Our Chief Executive, Sue Millman, is the Secretary General. The annual *euro*-ATAXIA Conference was held immediately after the Scientific Conference in Dublin and was attended by delegates from 11 member organisations.

Indian Ball

Guy and Kate at the Indian Summer Ball

The Indian Summer Ball, organised by Madeleine and Damian Cardozo, turned a wet West Country evening into an Indian themed extravaganza, complete with sitar player, belly dancers and a delicious selection of Indian cuisine. The event raised £40,000 for Ataxia UK. A huge thanks to everyone involved, especially Madeleine and Damian.

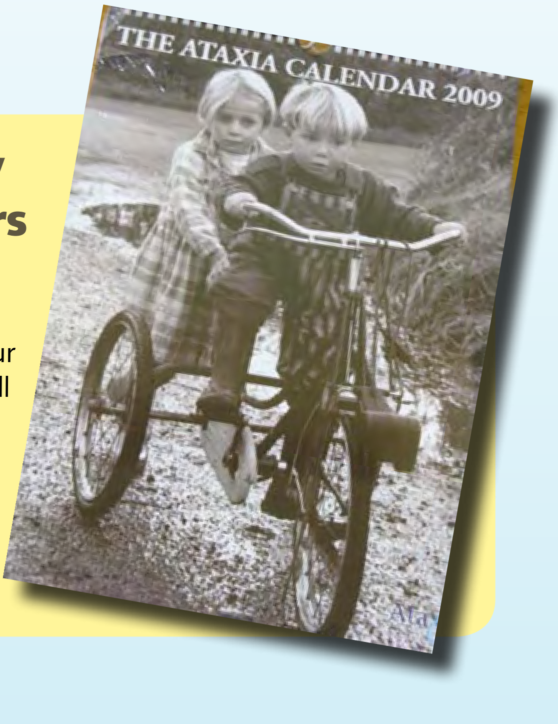
Law Family – Chelsea's family of the year

On 5 October 2008, Matthew Law and his family were made Chelsea Football Club's family of the year. A display of their family memorabilia and photos is on show at the entrance of the Club's museum and will be seen by approximately 100,000 fans during this season. Matthew's family has supported Chelsea since the 1930s when his grandfather regularly attended matches, so they are delighted to be honoured in this way.

Don't forget to buy your 2009 calendars from Ataxia UK

Photos and design are by one of our members, Madeleine Cardozo, and all proceeds go directly to the charity.

They are £6 each or 2 for £10. Phone Ataxia UK on **020 7582 1444** or email **fundraising@ataxia.org.uk** for details.



In this issue

Features

Regulars

An apology

We would like to apologise for an error we made in the last issue. We mentioned Joanna Lumley's friend Robes, who had FA and was the inspiration for Joanna becoming a patron. Robes' actual name was Christopher Rowbottom and we would like to apologise in particular to Joanna and his wife Joan for our mistake.

What is ataxia?

The ataxias are a group of neurological disorders. The early symptoms are mild and include clumsiness and loss of coordination. As ataxia progresses it can erode mobility and independence. Many forms of ataxia are inherited.

Ataxia UK

Ataxia UK helps people affected by many kinds of ataxia. We have Friends throughout Great Britain and Northern Ireland. Our aims are to:

- **stop the symptoms of ataxia starting or progressing**
- **repair the damage that has been caused to nerve and muscle cells**
- **help people live with the effects of ataxia in the meantime**

We support world class research to help us understand the causes of ataxia so we can develop treatments. We also help with:

- **information such as leaflets, magazines, reports and our website**
- **our advice and support helpline**
- **the Ataxia UK advocacy service**
- **branches, support groups and meetings**
- **welfare grants**

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Ataxia UK, Lincoln House, Kennington Park
1-3 Brixton Road, London, SW9 6DE
Tel: **020 7582 1444**
Helpline No: **0845 644 0606***
(10.30am - 3.30 pm Mondays - Thursdays
10.30am - 1pm Fridays)
Fax: **020 7582 9444**
email: **office@ataxia.org.uk**
website: **www.ataxia.org.uk**

*If you have a free local calls package with your telephone company or are calling from a mobile, it is usually cheaper to call 020 7582 1444

Patrons

Chris de Burgh, Paul Coia, Bobby Davro, Maureen Lipman CBE, Lord Morris of Manchester, Kim Wilde, Prof R Williamson

Acknowledgements and disclaimers

Photos sent to The Ataxian will be returned on request. Please send contributions by email wherever possible. Digital photos at a minimum of 250 dpi.

Policy Note

Appreciations of people who have died are normally restricted to those who have contributed significantly to Ataxia UK and are well-known.

Update Update Update Update

Ataxia UK Welfare Grants

Due to high demand we have now exhausted this financial year's funds. Unfortunately this means that we cannot accept any requests for welfare grants until 31 March 2009.

Other organisations such as your local library, local church, voluntary sector council, citizen advice bureau or an independent advice centre may be able to help you source funds from grant making trusts and charities.

There are also benevolent funds for people who've had a particular career such as electricians, librarians, teachers, plumbers, fire fighters and so on. Your local library may be able to help you do a search to find out more.

Candidates for the Ataxia UK Board of Trustees

Thank you for sending in nomination forms for the Board elections. There are four places available on the Board and six notifications have been received. You will find a ballot form enclosed with this issue of *The Ataxian*. Please choose four people on the ballot form that you would like to nominate for election.

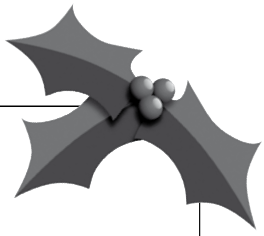
Professionals working with neurological conditions

The MS Society, along with the Brain and Spine Foundation, have launched a project that explores the training needs of professionals working with people with neurological conditions who have communication difficulties.

Researchers are interested in the challenges medical professionals face when communicating as part of their work. The project is also looking at a wide range of neurological conditions including Parkinson's, stroke and dementia. Findings will be use to develop a training course and toolkit.

Please take a few minutes to complete our online questionnaire and contribute to this much needed research. The questionnaire will be online until 18 December 2008.

Go to the research section of **www.ataxia.org.uk** and click on the link to 'MS Society and Brain and Spine Foundation survey'.



Christmas opening times

The Ataxia UK Helpline will be closed from 25 December to 5 January

Ataxia UK office opening hours will be:

Christmas Eve	**9am – 1pm**
Christmas Day and Boxing Day	**Closed**
29 December 2008 – 4 January 2009	**Closed**

Ataxia UK office and Helpline re-open on 5 January

The Ataxian **is also available in large print and on audio tape. Contact helpline@ataxia.org.uk or phone 020 7582 1444.**

Meet the fundraising team

Ataxia UK fundraising

Fundraising is a big part of Ataxia UK. It covers applying to trusts and grants, developing corporate and major donor relations, implementing appeals, organising events such as our annual ball, managing legacies, promoting fundraising activities like parachuting and trekking, and anything else that comes our way!

Kate Pearson,
Fundraising Manager

I have been working for Ataxia UK since September 2007, and took over as Fundraising Manager in June this year - I absolutely love it!

I previously worked in Stirling as a technical writer (boring!), and have worked as a volunteer for various charities throughout the years. For example, in 2007 I helped to fundraise for, organise and run an English language camp in my home town of Peebles for North Korean refugees currently living in South Korea. But nothing beats Ataxia UK and hearing from all our amazing fundraisers.

Guy Bower,
Fundraising and Events Assistant

I joined the Ataxia UK team in September this year, after running participatory photography projects for disadvantaged young people in Kosovo and Syria. I'm here to support anyone who wants to fundraise for us, especially people who want to do treks, running events or who have their own fundraising ideas. Contact me if you need anything to do with fundraising, I am looking forward to hearing from you.

Ataxia UK's amazing fundraisers

The most important part of both Guy's and Kate's roles is to be there for you. We are lucky to have a huge gang of fantastic fundraisers, organising anything from supermarket collections to treks across Peru, from Wheely Wobbly Walks to 24-hour rowing challenges. Last year you raised £280,000, and donated a further £222,000. This money is used to fund vital research into the ataxias, and provide our range of unique services to our members.

Without you we would not have been able to fund the great variety of projects we did last year. Well done!

Ataxia UK Office Staff

Sue Millman, Chief Executive
smillman@ataxia.org.uk

RESEARCH
Dr Julie Greenfield
Research Projects Manager
jgreenfield@ataxia.org.uk
Alison Stevenson,
Research Officer
astevenson@ataxia.org.uk

SERVICES
Tina Thatcher
Branch Support & Development Officer
tthatcher@ataxia.org.uk
Lyn Smith
Helpline & Advocacy Services Manager
Helpline 0845 644 0606
helpline@ataxia.org.uk
lsmith@ataxia.org.uk
Sharon Stockley
Helpline & Advocacy Services Officer
sstockley@ataxia.org.uk
Sheila Benneyworth
Helpline & Friends Services Officer
sbenneyworth@ataxia.org.uk

FUNDRAISING
Kate Pearson
Fundraising Manager
kpearson@ataxia.org.uk
Guy Bower
Fundraising & Events Assistant
gbower@ataxia.org.uk

MARKETING & COMMUNICATIONS
Barnaby Levy
Press Officer
blevy@ataxia.org.uk

ADMINISTRATION
Asantwaa Brenya
Resources & Facilities Manager
abrenya@ataxia.org.uk

Anbu Dhanushkodi
Database Administrator
adhanushkodi@ataxia.org.uk

Deborah Micheletti
Office Administrator
dmicheletti@ataxia.org.uk

Ataxia UK Board of Trustees

Our vision is for a world free from ataxia.

We work towards this every day.

Our vision

Ataxia UK funds relevant research into all of the ataxias in the UK and, where possible, abroad. In addition, we continually develop and improve the vital and unique support services we offer to people with ataxia, their carers and friends.

We can only do this with your support.

Your achievements

This year alone **you** have:

- invested in 21 research projects
- opened four new branches and five new support groups
- sent six families to Alton Towers for the annual Family Day
- enabled 23 people to purchase aids, equipment and respite care to make living with ataxia easier

We need your help

We are asking you to help us raise an extra £15,000 so that we can carry on with this important work. It's a difficult economic climate and we appreciate that this year times may be a bit harder than last. But even small amounts can have wonderful results.

- **£5** can pay for three copies of our medical guidelines, enabling three doctors to understand, diagnose and help patients with ataxia
- **£15** can provide five young people with DVDs to help them understand and cope with their condition
- **£40** can fund an hour of medical research into finding a cure. Every hour is vital.

Please give an extra gift to Ataxia UK this year.
Your gift really will make a difference.

Please complete the enclosed form and send your donation straight away.

"The staff of Ataxia UK are a constant source of support and help."

Darran

"As a branch we support each other by sharing experiences and knowledge. When you join a branch you don't feel so different, you don't feel like you're alone in this."

Tina
South Wales Branch

"The emotional support that the Ataxia UK volunteer at the London Ataxia Centre provides is a very important part of a patient's well-being."

Deanna

"The responsiveness of Ataxia UK and its willingness to fund outstanding researchers has enabled new research to investigate state-of-the-art therapeutic technologies for ataxia."

Matthew
Researcher, Oxford

"The Ataxia UK grant helped me a great deal, as it enabled me to buy my trike, take part in a half marathon, and raise funds for Ataxia UK. It will help me to keep fit and strong."

David

This year the Ataxia UK research conference was held in conjunction with FASI (Friedreich's Ataxia Society Ireland) on 25 September at the Stillorgan Park Hotel, Dublin, Ireland.

It was followed, on 26 and 27 September, by the *euro*-ATAXIA AGM and conference at the same venue, which was hosted by FASI.

***euro*-ATAXIA is a federation of ataxia charities around Europe of which Ataxia UK is a member. Both events were attended by researchers and healthcare professionals from Ireland, the UK and the rest of Europe as well as further afield.**

euro-ATAXIA Research Conference

The *euro*-ATAXIA conference focused on research updates for lay people and also included a session on living with ataxia, talks about specialised ataxia centres in Ireland, UK and Australia and presentations from therapists. For more information on the Ataxia UK conference go to **www.ataxia.org.uk**

FASI and Ataxia UK Research Conference

Friedreich's ataxia (FRDA) research

Professor Richard Festenstein, Imperial College, London, spoke about his research into the regulation of the FRDA gene, which has opened up a new potential therapeutic avenue. In FRDA the gene coding for the protein frataxin is silenced (or 'switched off') resulting in reduced levels of this essential protein. Research now aims to find modifiers which will interfere with the process so that genes could be 'unsilenced'. However it will be important to check that the regulation of other genes is not adversely affected. Based on this approach, some compounds that may be potential treatments for FRDA have been identified and will be studied further in mouse models using funds from the Medical Research Council.

Work in Dr Joel Gottesfeld's lab in La Jolla, California, has also focussed on identifying drugs that will switch on the FRDA gene. His work has shown that the interaction between the active form of the FRDA gene and the inactive (silenced) form is mediated by enzymes called histone deacetylases (HDAC). Inhibition of HDAC by commercially available HDAC inhibitors revealed that one compound (BML-210) was slightly active on the FRDA gene (which means it switched the FRDA gene on). Derivatives of this compound were analysed and one promising compound (4B) was tested in a mouse model of FRDA. It was able to enter the nervous system and was active in the brain. The group have also performed biochemical analyses which will provide useful information for the design of new HDAC inhibitors to specifically target the FRDA gene. The pharmaceutical company Repligen has put together a library of HDAC inhibitor derivatives that can be screened for potential treatments and toxicity studies with these drugs are going well.

In FRDA, a deficiency of frataxin is thought to lead to cell damage due to increased iron concentration and oxidative stress. It follows that replacing the frataxin protein in cells would be a desirable treatment and this is what Dr Piyush Vyas' group from Indiana University (USA) is focussing on. The group have developed a form of human frataxin protein that can be easily introduced into the body; TAT-frataxin. Preliminary tests of TAT-frataxin gave promising results, including increased survival and improved co-ordination in a mouse model of FRDA.

Prof Dolores Cahill, University College, Dublin, Ireland, spoke about how her work studying antibody proteins in blood was being applied to FRDA. Investigating the antibody profile of FRDA patients has so far identified a number of proteins which are found in people with FRDA but not in healthy controls. However, at the moment it is not known whether these proteins are involved in the onset or the progression of the condition, or whether they may be a consequence of the disease pathway. A greater understanding of this may help point to therapeutic targets.

Prof Massimo Pandolfo from Hópital Erasme-Universite libré de Bruxelles, Belgium gave an update on antioxidant trials. We know that in FRDA cells are vulnerable to damage from oxidative stress and antioxidants have been of interest as a potential therapy for a number of years. Idebenone is a synthetic derivative of the natural antioxidant Coenzyme Q10, which has been studied extensively. A number of small studies have already been carried out testing idebenone in FRDA patients and there are currently two major phase III trials running (one in Europe and one in the USA). For details on how to take part in this trial go to the research page on **www.ataxia.org.uk**

Another treatment method being investigated in clinical trials is iron chelation - mopping up of excess iron by its binding to another compound. Iron is known to accumulate within the energy-producing compartment of cells (the mitochondria) and cause damage. Dr Arnold Munnich (Hópital Necker-Enfants-Malades, Paris, France) and his group are involved in the trial of deferiprone, an iron chelator. In a preliminary trial, humans given a low dose of deferiprone showed a measured decrease in iron deposition in the brain and there was some clinical benefit observed in the youngest patients. However there were also some serious but reversible side effects in patients taking higher doses, meaning that future studies would need to be carefully monitored. A multicentred, placebo-controlled trial has now been designed to test deferiprone over a longer period of time and to measure for any effects on the neurological symptoms of FRDA. For details on how to take part in this trial go to the research page on **www.ataxia.org.uk**

Prof Martin Delatycki, from Murdoch Children's Research Institute, Melbourne, Australia, rounded off the FRDA research session by talking about testing clinical outcome measures in FRDA. Four different rating scales were assessed and found to have good validity. Further testing of patients over time will show if these techniques can reliably track changes in symptoms and if they can be used to measure the degree of disability of patients in trials.

Cerebellar ataxia research

The EuroSCA project was funded by the European Commission to promote collaboration between researchers and clinicians in different countries in an effort to provide a greater understanding of the different types of spinocerebellar ataxias (SCAs) and geographical variations of the condition. Prof Olaf Reiss from University of Tubingen, Germany, and Dr Thomas Klockgether from University of Bonn in Germany described the results of this project.

Dr Matthew Wood, from University of Oxford has been working on a possible treatment for SCA7, which could also be applied to other SCAs. He is using a technique called RNA interference. It is a method that they have used to silence the mutant form of the gene causing SCA7, thus preventing the accumulation of toxic protein. His group have used these silencers in preliminary studies in cell models of SCA7 and they restored the appearance of the cells to that of normal cells. They have now identified a compound that appears to be safe enough to take forward for tests in cells from patients and in animal models.

Dr Sylvia Krobitsch, from the Max-Planck Institute, Berlin, Germany, talked about the characterisation of the protein ataxin-2, which is mutated in SCA2. Ataxin-2 was shown to be a component of stress granules, which appear when the cell is under stress (from oxidation or heat) and have a function in protecting the cell. Ataxin-2 was also found to have similar architecture to a yeast protein (Pbp1p) which has been extensively studied. The protein-protein interactions of ataxin-2 are predicated to be similar to those of Pbp1p. Further investigations of these interactions are hoped to reveal potential targets for treatment.

The day concluded with a topical talk from Dr Alastair Wilkins from University of Bristol who is investigating the use of bone marrow-derived stem cells for the treatment of the ataxias. Stem cells are cells that are able to self-replicate and differentiate into different cell types. Stem cells can be obtained from the bone marrow in sufficient quantities for clinical use. They have been shown to differentiate into various types of cells, and may give rise to cells of the nervous system. This makes them a possible tool for repairing damage to the central nervous system, which normally cannot repair itself.

For a more detailed report of the Ataxia UK 2008 Scientific Research Conference go to the research section of www.ataxia.org.uk

New Research Project on Genetic Testing in Ataxias

Led by Dr Andrea Nemeth and Dr Kevin Talbot (John Radcliffe Hospital, Oxford)

We are recruiting participants for a project aimed at developing new genetic tests for ataxias, particularly focussing on autosomal recessive ataxias. Tests for these ataxias are generally not currently available on the NHS.

Currently, many patients with ataxia do not know what the underlying cause is, although their doctor may suspect that it is caused by a genetic problem.

Genetic testing for ataxias is an essential part of clinical practice. It can:

- make or confirm a diagnosis
- allow patients and their families to find out the risk to other family members
- help with reproductive decisions
- identify patients who are suitable for new treatment trials as they become available

New genes causing ataxia are identified every year but genetic testing for the majority are not available because they are expensive to develop and introduce into the NHS. We don't know how many people may benefit which means funding is limited, and many of the genes are large and complicated to analyse. This is particularly true for autosomal recessive ataxia.

New technology, known as 'high throughput sequencing', is now available which can help to analyse large quantities of genetic material much more quickly. The John Radcliffe Hospital in partnership with Oxford University has recently been funded by the Department of Health to install two of these new machines as a result of becoming one of five UK Biomedical Research Centres. A grant from Ataxia UK means that we will have a dedicated scientist working full time for two and a half years to use the new machines. Our aim is to test genes causing ataxia which are not currently available on the NHS to work out which of these tests should be made available. We also hope to find out whether the new high throughput sequencers are the best way to do the analysis. So taking part in this project may result in you getting a specific diagnosis of which type of ataxia you have.

Who can take part

We are looking for anyone who has an undiagnosed ataxia which developed under the age of 50, whether they have affected family members or not. But we are particularly keen to see people whose ataxia is likely to be genetic and inherited in an autosomal recessive way – which means there may be affected brothers, sisters, or cousins, but not affected parents.

We are particularly interested to hear from people with childhood onset, teenage onset or young adult onset cerebellar ataxia which may have been thought to be Friedreich's ataxia but turns out not to be on genetic testing. We are also interested in analysing samples from patients with a condition called Joubert syndrome, which is a very rare cause of ataxia in children. We are aiming to test as many genes as possible during the project so we are happy to hear from anyone interested in taking part.

This project is not relevant for people with a confirmed diagnosis of Friedreich's ataxia.

More information

For more information on autosomal recessive ataxias see Ataxia UK's leaflet on 'Genetics and ataxia' on the website. Generally if you have an autosomal recessive ataxia your parents do not have ataxia but they are carriers for the condition.

If your ataxia started over 50 and you are still interested in taking part

Please do get in touch with us. If we are able to show that the new machines are useful in clinical practice, then we will start testing more genes inherited in different ways. We will contact you as soon as we are able to offer further tests.

Next steps

Your GP, neurologist or doctor will be able to tell you if your ataxia, or your child's ataxia is likely to be autosomal recessive, or is suspected to be, or if it is likely to be inherited in some other way.

If you are willing to travel to Oxford you can ask your GP to refer you to our Ataxia clinic and send any clinical information including details of any genetic or other tests you or your child has already had. We will send you an information sheet and arrange to see you or your child and take a small blood test which we can use to extract some genetic material to analyse.

If you are unable to travel to Oxford then you can ask your GP, neurologist, geneticist, paediatrician or other doctor to contact us at the address below. We can send patient information sheets, and forms to get blood taken at your own clinic and sent to our laboratory in Oxford.

Any blood samples will be sent to the Oxford Regional Genetics Laboratory at the Churchill Hospital, in Oxford. From there the DNA is extracted, the sample is given a numbered code and is then transferred to the Wellcome Trust Centre for Human Genetics where the laboratory work will take place.

Contact

Dr Andrea Nemeth and
Dr Kevin Talbot

Department of Clinical Neurology
3rd Floor,
West Wing,
John Radcliffe Hospital,
Oxford
OX3 9DU

Email:
andrea.nemeth@imm.ox.ac.uk

Secretary numbers:

Dawn Eeley for Dr Nemeth
01865 226020

Sandra Steeples for Dr Talbot
01865 231893

More research opportunities

A new study at the University of Manchester is recruiting people with Friedreich's ataxia to study hearing and speech perception.

To take part in this, or other research projects, visit **www.ataxia.org.uk** and go to the research pages or phone **020 7582 1444**.

Jeremy Farr Travel Fellowship

People with ataxia can apply for £3,000 to cover all the pre-agreed costs of a trip, or up to £5,000 if they are accompanied by a carer, thanks to the Jeremy Farr Travel Fund.

The fellowship has been made possible by the generosity of friends and family of Jeremy Farr who passed away in August 2007. Jeremy was diagnosed with Friedreich's ataxia at the age of nine. According to his brother, "Jeremy remained determined, positive, focused, energetic, loving and fun" throughout his life. This memorial fund is a way for Jeremy's spirit of adventure and love of travel to live on through the experiences of others.

So if you have ataxia and have a passion for travel, this could be the chance you've been waiting for.

The destination and purpose of the trip is completely up to you.

To apply, visit our **www.ataxia.org.uk** or call **020 7582 1444** and ask for an application form.

This competition will be judged by a panel and the closing date for entries is 3 April 2009.

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Ataxia UK Family Day 28 March 2009

Chessington World of Adventures

The Family Day is an excellent opportunity for families to come together, share their experiences and form support networks.

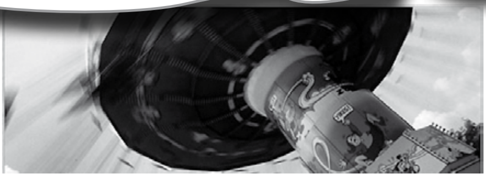
If you would like to attend the Ataxia UK Family Day 2009, please contact Asantwaa Brenya on 020 7582 1444 or email office@ataxia.org.uk

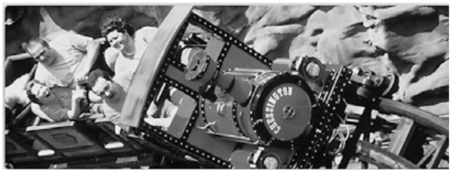
Prices

Accommodation £199 + VAT for a twin room including breakfast and dinner.
Theme park and zoo pass £21 per person with group discount.
Places are limited and are offered on a first come first served basis.

Book early to avoid disappointment.

Children under 12 stay and eat for free!





Ataxia UK Friends Conference 2008

Nearly 200 Friends of Ataxia UK attended this year's conference at the Radisson Hotel, Stansted.

The feedback we've had about the conference this year has been very positive. Many people have commented on the quality of the programme as well as the location – it seems Stansted is a manageable location for many of our Friends. For some of the delegates it was the first time they had come to the conference. They were unsure of what to expect but they said that they found it valuable for establishing relationships with other members. We also got useful comments and suggestions from Friends about how we can improve in the planning and administration of the conference in the future. We'll take those comments into account when we plan next year's event.

As well as regular favourites such as the research update and the Drs' question and answer time, there were new elements to the programme that Friends said they enjoyed.

You said:

"I thought the Drs' Question and Answer session was excellent"

"I am assured of what the specialists are doing for ataxia sufferers"

"You did a grand job, I came away happy"

Young Friends

This year, thanks to sponsorship from Jeans for Genes, we were able to run a Children's Agenda alongside the main conference programme. Younger Friends went to Sea Life Adventure Park on the afternoon of the conference.

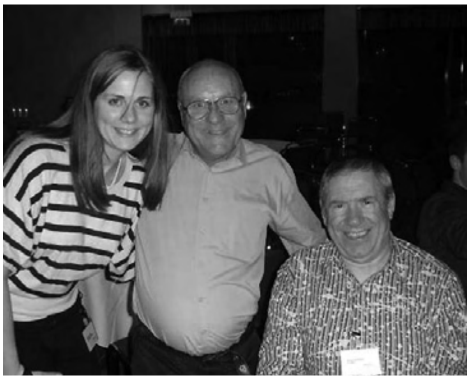
Trustee Pit Rink presents Graham Fickling with the Anne Ford Cup

Treasurer Christopher Bunton gives the financial update

"I saw a big fish!" Kieran tells his Grandpa

"We had a great time at the beach," say Kieran and Chloe

'YMCA' gets everyone on the dance floor



Fundraising Manager, Kate Pearson with Allan Carre and Michael Piper

The conference was a great opportunity for staff, trustees and Friends to get together. Thank you for coming and making it a successful event. We hope to see you all again next year.

Changes to Welfare Benefits – Employment and Support Allowance (ESA)

Lyn Smith, Helpline and Advocacy Services Manager

As part of the Welfare Reform Act 2007, from 27 October 2008 Incapacity Benefit, Severe Disablement Allowance and Income Support (claimed on grounds of incapacity), was replaced by Employment and Support Allowance – or ESA – for all new claimants.

People already claiming Incapacity Benefit, Severe Disablement Allowance and Income Support (claimed on the grounds of incapacity due to disability or long term illness) will initially continue to receive their existing benefits – as long as they continue to satisfy the entitlement conditions – and will start to be transferred to the new system from April 2010. The new system will consider what an individual is capable of doing, and what help and support they will need to manage their condition and return to work.

Why is the system changing?

With the introduction of Employment and Support Allowance, the Department for Work and Pensions aims to improve the package of support to help people return to the workplace. Employment and Support Allowance builds on the New Deal for Disabled People and Pathways to Work, which provide the practical support needed to help people into work.

The Department for Work and Pensions states that there is evidence which shows being out of work can contribute to poor health, whereas being in work can deliver real benefits, not only financially, but in terms of people's health and well-being, their self-esteem and the future prospects.

How is Employment and Support Allowance different from other benefits?

Employment and Support Allowance offers personalised support and financial help for people who are not working due to an illness or disability. One of the most important aspects of Employment and Support Allowance is the new medical assessment which examines what the claimant can do, rather than what they can't do.

ESA is supported by the work of a personal adviser who can provide access to a range of financial support, return-to-work programmes such as the New Deal for Disabled People, and specialist provision, including access to the Condition Management Programme.

The Condition Management Programme is delivered by healthcare professionals and helps people to manage and cope with their illness or disability in a work context. The personal adviser can also help an individual to find the right job with the support needed to sustain employment.

Employment and Support Allowance is focused on support, and people will not be forced to take a job, or undertake any other work-related activity which may be detrimental to their health.

To apply for Employment and Support Allowance or find out more, phone, apply online or visit your local Job Centre.

Phone: 0800 055 6688
Textphone: 0800 023 4888
http://www.dwp.gov.uk/esa/

For Northern Ireland contact the Department for Social Development in Northern Ireland:

Phone: 028 9033 6958
www.dsdni.gov.uk

What happens after an application?

When someone becomes entitled to Employment and Support Allowance they enter a 13-week assessment phase. During this period they will receive a basic rate payment of up to £60.50 a week for a single person aged 25 or over, £47.95 a week for a single person aged under 25, or, where income-related Employment and Support Allowance is payable, £94.95 a week for a couple. Additional financial support components may be added on completion of the assessment phase.

Healthcare professionals (either a doctor or nurse appointed by the Secretary of State, not your own GP) will carry out a Work Capability Assessment. People who are able to undertake some form of work-related activity will also take part in a 'work-focused health-related assessment' as part of the Work Capability Assessment, which explores their views about moving into work and identifies any health related support that may help with this transition.

As soon as possible after week eight of the assessment phase, you will be contacted to arrange a work focused interview, during which a personal adviser will discuss your entitlement to benefits, your views on returning to work, and the package of support that may be required to help you into work.

Is there anybody who doesn't have to attend a Work Capability Assessment?

Some claimants will not need to attend the full Work Capability Assessment, including individuals with a terminal illness and those identified as having limited capability for work, or limited capability for work-related activity without the need for them to take part in the full assessment.

People with a terminal illness will be fast-tracked into the Support Group of Employment and Support Allowance to ensure that they receive everything that they are entitled to as quickly as possible. They will not be required to participate in a work-focused health-related assessment or any other work-related activity.

Wheely Wobbly Walks

On 28 September we held our first ever Wheely Wobbly Walks in aid of International Ataxia Awareness Day.

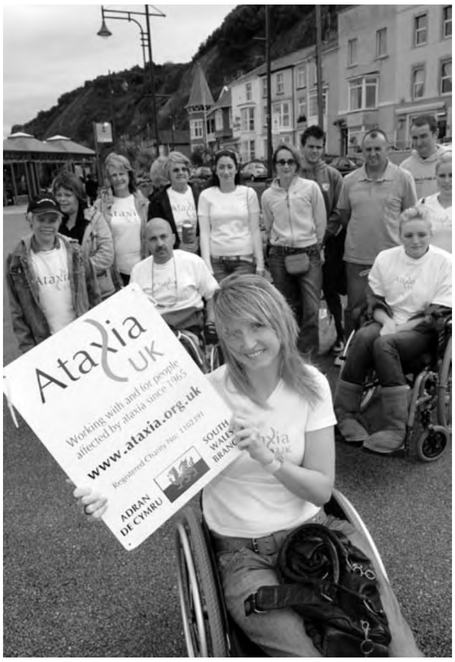
In London, 27 people turned out on one of the last beautiful days of summer, to collectively walk, run and pedal over 100km in total. Damian Jones and his dog Milo won the 10km running in the morning. We had a wonderful day – thank you to everyone who turned up and completed an inspirational Wheely Wobbly Walk.

Our branches and members organised walks all over the country including Patsy Riggs and the Ipswich support group, and Tina Evans leading the South Wales branch. Melanie Priest-Taylor even completed a walk on the deck of a cruise ship in the Caribbean raising over £700 and spreading awareness of ataxia across the globe!

Currently, the events have raised over £2,800 for Ataxia UK and people with ataxia have travelled over 200km this International Ataxia Awareness season!

Best of luck – we look forward to seeing the pictures of your own Wheely Wobbly Walks!

Damian Jones and Milo winning the 10km race



Tina Evans and the South Wales branch

Members of the London Branch enjoy the sun before setting off to complete their 5km journeys

We were very sorry to hear of the passing of Yvonne Schmid, who enjoyed taking part in the London event, and who, until recently, was on the London Branch Committee. Her personal input and support of the London Branch was strong and even extended to providing her flat as the venue for Committee Meetings and the London Branch postal address. She touched many lives and will be missed by all those who had the privilege to meet her.

Branch Lines

Focus on Ataxia East

The Æ Branch covers a large area and its members come from ten different counties to meet in Peterborough. The branch was originally called the Peterborough Branch of Ataxia when it was set up in the mid 1990s by Nigel Molesworth and his wife, Anne, but the name was changed to take advantage of regional grants. In 1997 I took over as Chair when Nigel and Anne moved away.

Because the area covered is so large, it is not possible for all our members to attend a meeting, so it is vital that our newsletter goes out to keep everyone updated. Not everyone uses email so a printed version is posted to over 30 of our members.

Today the group has over 56 members, from all over the area, and we meet at the Stanground Community Centre, Stanground, Peterborough, roughly every quarter. The meeting venue is ideal for the disabled members with all areas accessible and parking just outside the door. It is only a couple of miles from Peterborough bus and train stations, and transport is always available for those that really need it.

Meetings are usually a very sociable occasion, with the Chair updating everyone on events. Members are welcome to contribute in any way possible. We have arranged for various speakers from organisations relevant to our situation which have been really popular.

Meetings usually end with tea, biscuits and a raffle draw, which helps with the small charges we have to pay for the venue.

In summer we meet for picnics – members have met at the beautiful Ferry Meadows Country Park in Peterborough and recently at Sandringham.

Members visit Sandringham

Æ Branch meeting, October 2008

Throughout the year we raise funds by various means, from street collections to sponsored 'bag packs'. We have received a lot of support from the pupils of Deacons School, Peterborough who have made Ataxia UK the sponsored charity on many occasions. A school band won a competition and donated the £300 prize to the cause.

As Chair, I enjoy my role. It has its highs and lows, but I have come to understand that people with ataxia have good days and bad ones, you just do what you can and 'pace' yourself. Initially my biggest worry was that I would fail to get members to attend meetings, but I learnt from other branch committee members at our annual meeting at the Leicester Branch officers' weekend that 'bums on seats' is not always essential as long as members benefit and enjoy themselves.

The help of the Æ Committee is crucial to the smooth running of our branch and I would particularly like to thank Terry, Sheila, Kirstie, Lesley and Sue.

We share some of our members with some of the newer support groups that Tina Thatcher has been encouraging all over the country. I worked with Tina to initially set up the Leicester Support Group as we had several members on our list that lived in and around Leicester, and it made sense for a Leicester group to be formed. The group is run by Claire Huggett and is proving very active. I have not removed any of the Leicestershire members from the Æ list – these members have 'dual' membership and have the advantage of being able to attend whichever suits them. This all adds to good communications between branches, groups and ultimately members.

Dave Stubley

Tina Talk

It was so nice to see so many of you at the conference in Stansted! There were many representatives from our ever growing network of branches and support groups and it was great to see people from newly formed groups such as Dorset.

A few people asked me about when the next branch officers' conference would be. I know those of you that have been coming to these over the past two years find them really useful, so I will be organising another one for next April. If any branch officer has a specific area they would like some training on, or an item to discuss at the branch officers' conference then please let me know.

Look out for booking forms in the New Year as places get filled very quickly.

Tina

Email: tthatcher@ataxia.org.uk
Tel: 01782 791131

Branch and Group Contacts

Branch/Support Group	Contact Name	Telephone	Email
Ataxia East	Dave Stubley	01205 722771	djstubley@aol.com
Bradford	Dennis Boland	01274 735662	Pbeddard@ntlworld.com
Central	Brian Doody	01902 783381	Brian@doody.wanadoo.co.uk
Derby	Marta Hancock		martaehancock@aol.com
Dorset	Lorraine Richardson	077737 54565 (prefers text or email only please)	l.richardson57@ntlworld.com
East Sussex & Kent	Josephine Singer	01892 536822	fifidelabonbon@aol.com
Gloucester	Brian Davis		bctl@davfam.fsnet.co.uk
Hampshire	Jenny Rose	01590 645 739	Jenjon56@hotmail.com
Holmfirth & Huddersfield	Julie Fallon & Michael Williams		jkfjules@btinternet.com
Ipswich & Colchester	Patsy Riggs	01473 621604	pa.riggs@virgin.net
Isle of Wight	Alan Reed	01983 867946	
Kent	Gill Solly	01634 813988	
Leicester	Claire Huggett	01162 848201	Claire_huggettfamily@hotmail.co.uk
London	Jenny Kerbey		jkerbey@yahoo.co.uk
Newcastle	Louise Nugent	0191 291 2741	louise@atyourside.org.uk
North West	John Gurhy	07984 512383	johngurhy@btinternet.com
Northamptonshire	Arthur O'Neill	01536 399512	arthuroneill@hotmail.com
Milton Keynes	Joan Johnson	01908 222618	
Sheffield	Marie Unwin		munwin@talktalk.net
Shropshire	Beryl Martin		bm@whmltd.com
South Cheshire/N Staffs	Deborah Carter-Taylor	01270 829 189	marketing@splashabout.co.uk
South Downs	James Downie	07884 186906	james@downstar.co.uk
South West	Graham Fickling		fickling2002@blueyonder.co.uk
Tamworth	Sharon Lockwood	0795 800 9224	Sharon.lockwood@atkinsglobal.com
Thames Valley	Bob Robson	01438 747160	bob-robson@ntlworld.com
West Country	Becky Downing		becs2737@yahoo.co.uk
North Yorkshire	Stewart Newhouse	01756 795258	newhousehev@aol.com
Northern Ireland	Margaret Evans		magsevans9@yahoo.co.uk
Scotland			
Ayrshire	Hugh Collins	01290 422 584	hmc305@hotmail.com
East of Scotland	Derek Main	0131 477 4371	Derek@ataxia-east-scotland.org.uk
Inverness	Kerry Louise Challinor	01463 711910	
West of Scotland	Anne Green		annegreen803@hotmail.com
Wales			
North Wales	Chris Hobson		chris_hobson@hotmail.com
South Wales	Tina Evans		bontwelshgirl@hotmail.com
Virtual Ataxia	Alice Spivey		alice@spiveyworld.net

Rose Selway, a Friend and volunteer with ataxia, would like to thank all the people who have phoned her. She hopes she has been of some help and is happy to take calls from 6pm on 01472 316783.

New groups on the way – Wiltshire and Harrow – watch this space!

LETTERS TO THE EDITOR

Letters for publication should be sent by post to **The Editor** at the **Ataxia UK Office** or emailed to **marketing@ataxia.org.uk** Letters may be edited.

Dear Editor,

I am 35 years old and have FA. I am very happily married to a wonderful man. We have been trying for a family for over six years with no success, so we have decided to adopt. We have a very supportive family and know we would make terrific parents, it is just proving this to the powers that be.

I am very keen to hear from people with any form of ataxia who have been through the adoption process.

Please write to me care of Ataxia UK.

Helen Ashton

David at the Irish National Stud at Kildare

Dear Editor,

I would like to express my thanks to the trustees of Ataxia UK who recently awarded me a welfare grant. This money made it possible for my wife and I to take a tour of South West Ireland. Many thanks.

David Howard

Dear Editor,

I would like to thank you for your generous contribution of £1,000 towards the cost of my new mobility scooter. I am now able to do things like shopping and visiting the doctors. It has given me a new lease of life and wouldn't have been possible without Ataxia UK.

Andrew Taylor

Ask a Physio *– with Elizabeth Cassidy*

Our physiotherapist cannot answer individual enquiries directly; she provides general advice based on questions raised by members of Ataxia UK. The advice provided is not tailored to the needs of an individual and is not intended as a substitute for individual assessment and treatment provided by a physiotherapist who is registered with the Health Professions Council. If readers have any specific concerns please consult your GP or registered health care professional.

Question

Is treadmill training useful for people with cerebellar ataxia?

Answer

The rationale behind treadmill training is that walking on a moving belt may promote co-ordination of the legs and improve strength, balance and range of movement. There are also some psychological benefits associated with exercise. But there is limited evidence on how treadmill training may affect people with ataxia, so I don't suggest that you rush out and buy a treadmill. For those of you who are already using one, or are talking to your physiotherapist about starting, here's some useful information.

Treadmill training has been investigated as an intervention to improve mobility for people with a range of neurological conditions. Only two studies using this technique for people with ataxia have been reported.

One study* investigated the effect of four weeks treadmill training for two participants following brain injury. Although improvements in walking speed, leg speed, step length, rising from a chair and balance, were noted, all the improvements started in the baseline phase before the treadmill was introduced. Researchers concluded that the repeated practice of tasks while preparing for the study may have contributed to the improvements – a finding that is perhaps encouraging in itself.

The second study** looked at the effect of a body weight support system with treadmill training on the mobility of a 13-year-old girl with severe cerebellar ataxia, 16 months following a brain haemorrhage. Researchers noted that significant improvements were not seen until after five months of training.

So if you are already doing treadmill training perhaps as part of a gym programme, my advice is to carry on, and to build up the intensity, duration and gait speed slowly, even if that means starting off with five minutes at a time with frequent rest breaks.

Alternatively, a taster session at the local gym might be a good idea. However, it is very unlikely that a body weight support system would be available and gym treadmills often do not have the facility to go slowly enough for walking training. If you are new to this level of activity you must see your GP first to get the all clear for aerobic exercise.

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*Vaz et al, 2008 **Cernak, 2008

Toyah raises £1,500 for Ataxia UK

Toyah Wordsworth is 27 and has FA. She's a Disability Equality Trainer in Doncaster and uses a wheelchair to get around. But in July, Toyah threw herself out of an airplane several thousand feet above the ground, raising almost £1,500 in the process!

It all started in March when Toyah attended the Ataxia UK Talk-In Weekend at Alton Towers designed for people with ataxia, their carers and families. Toyah was amazed to hear about someone else with FA doing a sponsored skydive and was determined to do the same. She found a local airfield and signed up straight away.

After getting the all-clear from her GP, Toyah set up an account on the fundraising site, www.justgiving.com so that anyone could sponsor her online. She also wrote an article for her local newspaper to publicise her event, and to attract sponsors to her page.

On 20 July, conditions were perfect and Toyah jumped into the clouds. "It was one of the best experiences of my life and I'm really glad I did it," she says.

Other people with ataxia who have skydived this year to raise funds for Ataxia UK include Kerry Bull and Derek Taylor.

For more information about sky-diving to raise funds, please contact Guy Bower at Ataxia UK on 020 7582 1444. Minimum sponsorship is £395.

Cycle London to Paris

If you're a keen cyclist, or simply someone looking for an exciting challenge, this could be for you. Next summer Ataxia UK is looking for people to take part in a sponsored cycle from London to Paris. Beginning at London Bridge, you'll cross the South Downs and the Normandy countryside before finishing beneath the Eiffel Tower in central Paris. This is a challenge not to be missed – it'll be good for you, better for the environment, and most importantly, a fantastic way to raise money for Ataxia UK.

Sign up for a sponsored trek and raise funds

Ataxia UK is also running sponsored treks through the stunning Lares Valley in Peru, home of the Incas, and up Mount Kilimanjaro in Tanzania. Both promise to be real challenges with once in a lifetime rewards. Contact Guy Bower at gbower@ataxia.org.uk for more details.

Fundraising from August – October 2008

RAFFLES & COLLECTIONS

Yvonne Khan, Dog & Dog Public House, Walthamstow - raffle	£210.00
Michael Spencer, Norwich - raffle	£100.00
Ella and Geoff Marshall, Cumbria - collection box	£40.00
Hazel Konicki, Leeds - collection box	£50.00
Kathy Charton, Hampshire - collection box	£40.00
Maureen Bunn, Surrey - raffle	£98.00
Leslie Fryatt, Surrey - collection box	£60.00
Jenny Southey, Kent - collection box	£235.00
Nanette Whitman, Middlesex - collection box	£170.00
Elise Gunn, Essex - collection box	£55.00
Total Raffles and Collections	**£1,058.00**

SPONSORED EVENTS

Michael Halmark and Fintan Byrne, Southport - Trans-Penine bike ride	£1,488.00
Martin Hunter, London - Edinburgh and London marathons	£1,622.50
Sarah Briscoe, Barnsley - St Cuthbert's Way Walk	£50.00
Alan Reed, Isle of Wight - Off-Road bike ride along the South Downs Way	£300.00
John Wisdom, Hertfordshire - Climbing Mount Blanc	£3,050.00
Toyah Wordsworth, South Yorkshire - skydive	£1,468.00
Judith Parry & Gary Lewis, Buckinhamshire - Great Wales Run	£841.10
Kate Wallace, Buckinghamshire - Timer Triathalon	£90.00
Ellie Naselli, Fiona Naselli, James Downie, David Campbell and friends - Run to the Beat	£3,441.00
Hannah Rhys, London - Run to the Beat	£240.00
Damian Jones, London - British 10k Run	£250.00
Ross, Yorkshire - Sponsored Boxing Match	£650.00
Kate Armstrong, Northants - London Triathalon	£1,566.00
Melanie Preist-Taylor, somewhere in the Caribbean - Wheely Wobbly Deck Walk	£689.00
Mike Welch, London - Wheely Wobbly Walk	£100.00
Eileen Goodsman, Suffolk - Wheely Wobbly Walk	£74.50
Jeanette Risley, London - Wheely Wobbly Walk	£36.00
Margaret Clowes, Norfolk - Wheely Wobbly Walk	£433.20
Total sponsored events	**£14,901.30**

SALES AND FETES

Melanie Priest-Taylor, West Midlands - Ebay Sales	£223.14
Dorothy Cox, West Sussex - Fun Day	£410.00
Milne Family and Friends, Buckinghamshire - Stowe Autumn Fair	£16,000.00
Sophie Smith, Surrey - Cake Day	£280.00
Total Sales and Fetes	**£16,913.14**

MISCELLANEOUS

Mrs Crossland, Liverpool - 80th birthday celebrations	£250.00
Marta Hancock - donations in lieu of birthday gifts	£160.00
Sian John, Essex - Fundraising Week at Emerson Park School	£104.48
Sue Kendrick and Stacey Mander, Dudley - disco	£2,180.00
Garnett family, Dorset - teenage tennis match	£320.00
Kirsty McPake, Coatbridge - concert	£1,200.00
Anabel Tucker, Maidstone - concet and talk	£80.00
Peter Case, Edinburgh - bagpipe playing	£535.00
Joan Rowbottom, Leicester - The Robes' Inebriation Society Annual Reunion	£550.00
Sally McEnvoy, Lancashire - Royal Bank of Scotland Community Cashback Scheme	£500.00
Peterston Church Choir, Cardiff	£600.00
Karen Sherwood, Cambridgeshire - Midsummer Music Festival	£150.00
Cardozo family, Wiltshire - Indian Summer Ball	£40,000.00
Albert and Edna Lovelock, London - 50th Wedding Anniversary	£300.00
Brian and Eileen Harding, Surrey - Ataxia UK Golf Day	£880.00
Anthony Lue, West Midlands - Sutton Long Run	£661.00
Total Miscellaneous	**£48,060.48**

BRANCH FUNDRAISING

Hampshire Support Group - collection tin	£28.00
Total Branch Fundraising	**£28.00**

GRAND TOTAL	**£80,960.92**

Brilliant! Thank you.

In Memoriam Tributes

We are most grateful to have received tributes in memory of the following:
Christina Avery, Albert Blackmore, Jean Browne, James Bordley, Margaret Campbell, Peggy Campbell, Giles Catmur, Harry Fancott, Douglas Fox, Joanne Kellard, Jamie Kendrick, Marina Johnson, Andrew Jones, Gerald Lander, Maxine Lower, Bernard Perry, David Renshaw, Sheila Stevens, John Teasdale, Christopher Thomson, Peter Alfred Venus, Lillian S Williams

The Chance to Win winners are

Jacky Gawne

1st prize £250

Gemma Owen

2nd Prize £150

Sandra Smith

3rd Prize £100

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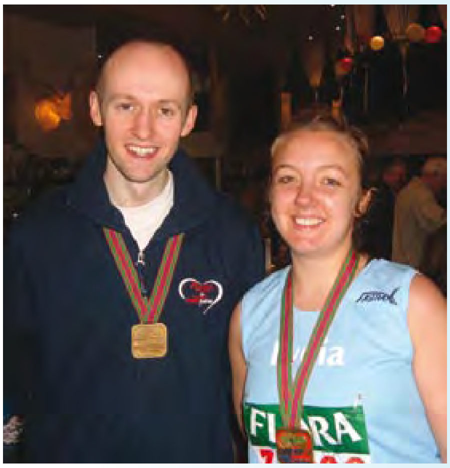
Join **CHANCE TO WIN** for only £2 per month, payable by standing order. You'll be helping to raise valuable funds for Ataxia UK. With a draw every three months, you could win up to **£1,000** a year! Ask the Office for an application form – and ask friends and colleagues to join too!

Our brilliant backers

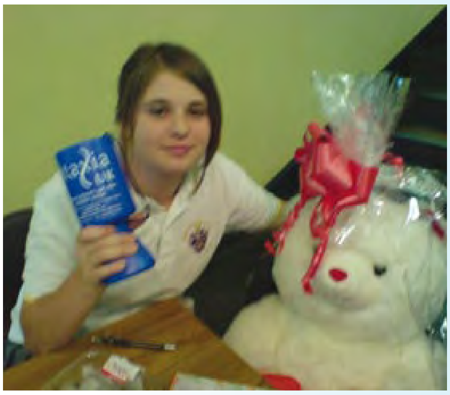
David Campbell and his friends were part of a 20-strong team of Ataxia UK runners at this year's Run to the Beat half marathon. The group hopes to raise about £4,000, and David took part on his new recumbent bike, which he purchased with the help of an Ataxia UK grant.

Tracy Dodd, husband Kevin, and his son Chris, took part in the Durham Big Ride cycle event on 21 September 2008 to raise funds for Ataxia UK, and in the memory of the late Jackie Thompson, Tracy's sister.



Running one marathon for Ataxia UK per year wasn't enough for Martin Hunter. He ran the Flora London Marathon and the Edinburgh Marathon for us, bringing home £1,600 in sponsorship money.

Sally McEnvoy gave Ataxia UK a cheque for £500 donated by the Royal Bank of Scotland. The donation was made under the bank's matched giving scheme to honour the fundraising work Sally has done for us.



Sian held a whole week of fundraising events at Emerson Park School. Her variety of sales and games raised £104 for Ataxia UK.

Mike Hallmark and Fintan Bryne's 'Trans-Pennines Bike Ride' raised £1,488 in sponsorship money for Ataxia UK.

Our brilliant backers

In September, Jane Milne and friends held a fair at the beautiful Stowe School. A unique range of designers and exhibitors were brought together to sell their innovative products and gifts, and together they raised around £16,000 for Ataxia UK.

Kirsty McPake organised her own music festival – 'T in the Garden' – and raised £1,200 for Ataxia UK, and another £1,200 for the West of Scotland Branch of Ataxia UK.

John Wisdom climbed the epic summit of Mont Blanc in aid of Ataxia UK, raising £2,425 – that's 50p for every metre of mountain!