

# the Ataxian

THE MAGAZINE FOR PEOPLE AFFECTED BY ATAXIA

SPRING 2008 ISSUE NO.161



**Farr to go: We launch the Jerry Farr Travel Fellowship for people with ataxia**

## Sparkling Crystal Ball

Thank you to all those who supported the Crystal Ball on 24 November. Over 350 people came and we raised more than £33,000!



## Who's that girl?

Sian Rhys, Sheila Benneyworth and Sheena Bettsworth at the London – South Downs Christmas lunch. See page 16.



## Real-time Bells

Congratulations to Alice (now Spivey), founder of the Virtual group, and Tim, who sets up the Sunday chat room. Tim and Alice, who both have ataxia, got married last year. They first met (off line) at an Ataxia UK annual conference!



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## Hold the date!

Ataxia UK's 2008 Annual Conference will be  
**10 – 12 October in Stansted, Essex.**

Booking forms will be in the next issue of *The Ataxian*.

## Spring Raffle, £250 Top Prize

**W**e are currently running a fabulous Spring raffle. There are lots of great prizes on offer including £250 cash, an iPod shuffle, high street shopping vouchers, a luxury Fortnum & Mason food hamper (worth £100) and a camcorder.

Our aim is to sell 10,000 tickets, which represents one for each adult in the UK affected by ataxia.

Tickets come in books of five and cost £1 per ticket. The draw will take place on 12 May, so contact us today if you'd like to help us sell tickets. At the same time, we'll also hold a draw for ticket sellers for a Bric's leather holdall worth £100. For pictures of the prizes, please visit our website..

**To order your tickets, email [fundraising@ataxia.org.uk](mailto:fundraising@ataxia.org.uk)  
or call us on 020 7582 1444.**

# What is ataxia and what are our aims?

The ataxias are a group of neurological disorders. The early symptoms are mild, with clumsiness and loss of co-ordination, but as ataxia progresses it can destroy mobility and independence. Many forms of ataxia are inherited.

Ataxia UK helps people affected by many kinds of ataxia. We have Friends throughout Great Britain and N. 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 through leaflets, magazines, reports and our website
- an advice and support Helpline
- branches, support groups and meetings
- welfare grants
- personal contacts

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Published quarterly by Ataxia UK

Registered charity: 1102391.

A company Limited by Guarantee.

Registered in England & Wales 4974832

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Photographs sent to *The Ataxian* will be returned on request. Please send contributions by email wherever possible, digital photographs at minimum 250 dpi.

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## 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

## Subscriptions

The Board has decided that Ataxia UK will stop charging subscriptions to existing Friends of Ataxia UK from 1 April this year – up to now, there's been an annual charge of £25 or £15 to be a Friend. Subscriptions at their current levels have become uneconomic for us to administer but we don't believe it's fair to raise the cost of subscriptions for all – some people can afford to pay more, others cannot. It seems more reasonable to let Friends decide for themselves what they can pay and give it as an annual donation. But please be reassured that if you cannot afford a donation, you will remain a Friend of Ataxia UK, and will continue to receive *The Ataxian*, unless you tell us otherwise.

We calculate that the amount we save on administration, coupled with the donations we will receive in lieu of subscriptions, will mean that Ataxia UK does not lose out. Friends joining in the last few months have not been asked to pay a subscription but to give a regular donation and we have found that our income has actually increased as a result.

People join Ataxia UK because they're interested in finding out more about ataxia and accessing our specialist support and information. They also want to support what we do. They make a commitment by signing up to become a Friend, either by requesting a form from the Office or downloading one from the website. We know that those in a position to do so help us to continue our work by donating, volunteering, fundraising and sometimes all three!

## Direct Debits

Naturally, we hope that people will give regularly. If you do give, using direct debit helps us plan ahead and reduce admin costs. If you already make a regular donation to Ataxia UK, please consider setting up a direct debit. A form is enclosed with this issue of *The Ataxian*. Your contributions enable us to continue to provide our many (and increasing) free services, as well as to fund vital research into causes and treatments.

Please contact the Office if you have any queries about your present subscription or about setting up a direct debit.

## *Pit Rink* Chair

## Jerry Farr Travel Fellowship

We are delighted to announce that a new grant from Ataxia UK is now available. This enables a person with ataxia to undertake an adventurous trip abroad.

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

adventure and love of travel to live on through the experiences of others.

The winner will receive a maximum of £4,000 to cover all the pre-agreed costs of a trip on which the traveller can be accompanied by a carer if required. The destination and purpose of the trip is up to you! The only requirement is that it provides a personal challenge for you. This competition will be judged by a panel and the closing date for entries is 4 April 2008.

To find out more and to enter online, visit our website, [www.ataxia.org.uk](http://www.ataxia.org.uk). Alternatively call the Office for more details.

***The Ataxian* is also available in large print and on audio tape. Contact [helpline@ataxia.org.uk](mailto:helpline@ataxia.org.uk) or phone the Office.**

# Update Update Update Update

## Residential camps for young people

**O**ver The Wall is a charity that organises residential camps in Dorset, the Midlands and Perth, Scotland, for UK children and young people aged 8 to 17 who are affected by a serious illness. This includes siblings. Campers experience a variety of activities during the week, for example, drama, arts and crafts, technology, swimming, sports and games. Not to mention the sensational Camper Talent Night!

For further details visit [www.otw.org.uk](http://www.otw.org.uk) or telephone **01420 82086** or write to

**Over The Wall  
Charwell House  
Wilsom Road  
Alton  
Hampshire  
GU34 2PP**

## Security Against Theft

**O**ver 6,000 Blue Badges were stolen from parked cars during 2006, and this figure appears to be rising. After the break-in, which can cause great distress, it may take up to six weeks to replace the disabled badge.

The Blue Badge Protector provides effective security for all badge holders. Single and double protectors are available, for either badge or badge and clock. Badges are locked into a rigid protector sleeve and a flexible, sturdy lock attaches to the steering wheel.

Readers of *The Ataxian* will receive a free copy of the UK Road Atlas for Blue Badge Drivers (worth £12.99) when ordering a Blue Badge Protector.

To order your protector and claim a free copy of the UK Atlas for Blue Badge Drivers call 0870 444 5435 and quote the reference PIEUK01. Alternatively send a cheque for £23.12 for the single protector (to safeguard the badge) or £28.63 for the double protector (for the badge and the clock) payable to PIE Enterprises and quoting the reference PIEUK01 to:

**PIE Enterprises Ltd,  
The Bridge,  
12-16 Clerkenwell Road,  
London EC1M 5PQ**

You can also order online at [www.parkingforbluebadges.com/shop](http://www.parkingforbluebadges.com/shop)

## Balancing Against Walls

**B**alancing Against Walls by writer and poet Hayley Smith who has Friedreich's ataxia is a rich insight into her life and includes many of her poems. We have copies at the Office and ask for £2 to cover the cost of postage.

## If Only They Knew

**T**his is the title of Peter Cordwell's autobiography, which is scheduled to be published by Olympia Press this April. Peter hopes the book will help more people to become aware of ataxia and Friederich's ataxia – "It would make Ataxia UK's job a lot easier and also help raise funds."

## Press Office

**I**f you have a story to tell and would be prepared to talk to a carefully vetted journalist, please contact press officer Barnaby Levy via the Office.

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## Driving

There's recently been a lot of discussion within the Virtual Ataxia group about driving if you have ataxia, what happens during a driving assessment, and the aftermath. We're planning to cover this topic in the next issue of *The Ataxian*.

If you have any comments or tips, or want to share your own experience, please write to Hillary at the London office, either by post or email [hbox@ataxia.org.uk](mailto:hbox@ataxia.org.uk).

# Taking Control

**Chief Executive Sue Millman on a joint campaign by the Neurological Alliance, Ask about Medicines and the Association of the British Pharmaceutical Industry.**

It is encouraging that the Neurological Alliance, the collaborative forum of a wide range of neurological charities, including Ataxia UK, recently decided to focus on the information needs of people with neurological conditions. The Alliance has now conducted a survey and, as a result, launched a campaign 'Taking Control' at the end of last year.

The findings of the Taking Control survey of 1,000 people, including people with ataxia, are strikingly similar to those from the research carried out by Ataxia UK, which is reported in this edition of *The Ataxian* 'Diagnosis & Referral Project' (page 7).

It will be no surprise to readers that people with neurological conditions don't get adequate information about their condition or their treatment.

43 per cent of the people surveyed left after initial diagnosis without any clear understanding of what is meant, and nearly 70 per cent did not receive any advice on where to get any further information.

Patient groups, other patients, specialist doctors and specialist nurses are all excellent sources. But people

with neurological conditions are not routinely given advice about where to obtain information, and access to specialists is limited.

## Patient organisations

However, 40 per cent of respondents obtained 'very useful' information from patient groups such as Ataxia UK. That's why it's so important that people are given contact details for patient organisations immediately.

Specialist doctors had proved a source of 'very useful' information for 33 per cent of respondents, as did specialist nurses, such as the ones we have at the Sheffield and London Ataxia centres. Yet getting advice from them was very hard. "We know that there are not enough specialist nurse posts, and it is deeply worrying that many of those that do exist are currently under threat," said the researchers. Over a third of diagnosed people had received no information from their GP at all.

Many people rely on their own reading and research for information. The internet is a popular source. But in a world awash with information, people with ataxia need advice on



finding and judging the quality of information about their condition and available treatments.

## Policy far from reality

Existing policy is not having the desired effect on the health service. Although there are clear standards, set out in the National Service Framework for Long-Term Neurological Conditions, the Neurological Alliance research shows that the reality is still very far from the aspirations set out in the NSF.

These findings underline the need for a national network of Ataxia Centres and for more specialist ataxia nurses.

As *The Ataxian* went to press, the Alliance was holding a summit to develop a plan to address its targets towards achieving this reality. The summit involves people with a long term neurological condition, health professionals, commissioners, managers and policy-makers. We will keep you informed of any progress.

## Audit tools

Ataxia UK is also participating in the Quality Neurology project, which will be described in more detail in the next *Ataxian*. Quality Neurology is a joint project between Ataxia UK, the MS Society, Parkinson's Disease Society and The Motor Neurone Disease Association. We are nine months into this two year project, which is being undertaken in collaboration with researchers from the University of York.

The aim is to develop an audit tool for health services to evaluate their implementations of the National Service Framework for Long Term Conditions. Friends from Ataxia UK are involved in steering the project and in consultations on the audit tool itself. This project complements the work being carried out by the Neurological Alliance.

## Other projects

Around the UK, there seem to be a number of projects covering the same broad territory. We recently discovered a project in Oldham working along similar lines but specific to people with speech difficulties. Our concern is that these projects should not duplicate effort and should be aware of each other's work. It is important, therefore, that Ataxia UK looks at the 'bigger picture' as well as highly focused activities.

*By the time this issue of The Ataxian reaches you, I will have been with Ataxia UK for nearly a year - and what a challenging, exhilarating and stimulating year it has been. As well as my regular meetings with the Board, I have met Friends around the UK at group and branch meetings, at the annual conference, at fundraising events and other functions. In the coming months, I hope to meet many more of you. I enjoy coming to branch and support group events, although I can't promise always to attend. (I have a young family and three sons who are all ardent Sunderland supporters.) Meanwhile, if there is anything you would like to raise with me, do call the Office or email me and I will try to respond as quickly as possible.*

*Sue Millman*

## New Grants awarded

*At the end of 2007, two new research projects were approved for funding by Ataxia UK.*

### Developing non-invasive therapeutic technology to improve motor coordination in cerebellar ataxias

*Professor David Lee, Dr Benjamen Schögler, Perception Movement Action Research Centre, the University of Edinburgh.*

#### The Project

This award was given for a three-year research project looking at movement control in patients with ataxia. The researchers are working on the theory that purposive movement is directed by 'formulae' generated in the brain, which use perceptual information to close 'gaps' between effectors and objects (eg between your hand and a cup when reaching for a drink), and that in cerebellar ataxia there are problems generating or managing these movement formulae.

#### Project aims

To create a device to mimic these formulae using 'sonic movement guides' which use sound of varying pitch or volume to represent closure of the 'gaps'.

#### What researchers hope to achieve

- To create a technique to improve a person's control of movements by learning to recreate the sounds in their heads to accompany movements.
- This may lead to practical techniques for patients and new ways of assessing movement impairments in ataxia.

### Development of high throughput genetic testing for cerebellar ataxias

*Dr Andrea Nemeth, Dr Kevin Talbot, Dr Jenny Taylor, Dr Anneke Seller, John Radcliffe Hospital, Oxford.*

#### The Project

Obtaining a genetic diagnosis of a specific type of inherited ataxia can be very important for patients. It may have an impact on the prognosis and treatment of the condition, as well as providing vital information about inheritance and contributing to research knowledge. However, it can be difficult to get a genetic diagnosis of inherited ataxia, particularly for the autosomal recessive cerebellar ataxias. There are so many different genes involved and not everyone can access these tests.

#### Project aims

To use new technology and expertise to develop a pilot 'high-throughput' testing service for the autosomal recessive ataxias. This will analyse more samples at a time than standard systems, is faster and more comprehensive.

#### What researchers hope to achieve

- It is hoped this will demonstrate that wider genetic testing for the ataxias can be made accessible to everyone
- Make genetic diagnoses possible for more patients.

## Genetic testing

*New guidelines will help best practice in labs*

*By Laura Rooke*

In October 2007, Ataxia UK was given a unique chance to represent our Friends and all families affected by ataxia by participating in the creation of new guidelines for best practice in genetic testing.

The number of genetic tests available for spinocerebellar ataxias seems to be increasing all the time. In order to ensure that, wherever people are, they get access to the same tests and the same level of service, standardised guidelines need to be developed to help laboratories carrying out genetic testing operate in the best way.

The European Molecular Genetics Quality Network (EMQN), in

conjunction with EuroGentest, held a meeting in Portugal to bring together leading Molecular Geneticists representing countries worldwide to contribute to a set of guidelines.

Ataxia UK was invited to represent the interests of patients and individuals undergoing genetic testing. As part of our contribution, I was also invited to give a talk to the collected Geneticists about Ataxia UK and our work, and about the importance of accessible genetic testing to patients.

Small groups worked on recommendations for the guidelines. Topics included what types of spinocerebellar ataxia to offer tests for,

methods and materials to use for the best results, and patient counseling to accompany testing.

At the end of the meeting the core team of writers, including Chair Jorge Sequeiros and Joanne Martindale from Sheffield, stayed on to draft the actual document. Since then the document has been made available online to everyone who attended to look it over and make any suggestions so we could all continue to have a say on the contents.

The Guidelines will be completed shortly and submitted for publication in a scientific journal with a high impact among geneticists.

# Diagnosis and Referral Project

A diagnosis of ataxia is often a long, slow and problematic process. In May 2007, Ataxia UK funded a project to explore individuals' experiences of getting a diagnosis. This project was conducted by Nikki Joule and Ros Levenson, healthcare policy consultants who have expertise of working with medical charities (such as the Neurological Alliance). The issues were discussed at group meetings between individuals with ataxia and their carers in Peterborough (Ataxia–East group), Uckfield (East Sussex and Kent group) and Edinburgh (East of Scotland group).

## Results of the project

### Diagnosis

Everyone agreed that getting a diagnosis is important because it brings an end to uncertainty and misunderstanding,

*“I just needed to know what it was, that I was not imagining it”*

A clear diagnosis enables individuals to explain their problem and help others to understand,

*“It is a relief. Most people say, what the hell is that? And it's good to be able to tell them”*

Ataxia is often misdiagnosed and symptoms dismissed or ignored in the early stages,

*“I couldn't keep my balance, but thought it was just stress”*

Unsteady gait is a very common symptom and has many different causes, some of which are spontaneously resolved over time. There may be a lack of awareness of ataxia among healthcare professionals because it is so rare.

Another common problem is the long delays experienced between the onset of symptoms and the diagnosis,

*“It has been a gradual process. This all started in 1976 and I got a diagnosis in the mid 80s”*

In most cases, people were unhappy with the way they received their diagnosis. Often, it was not properly explained or even named. Doctors seemed uncomfortable with the fact that ataxia is a progressive condition that cannot be cured.

To improve this, it was suggested that the diagnosis should be given by a specialist neurologist or fully informed GP, possibly with the help

of a specialist nurse. Information on the range of services available for help should also be given. It was a common observation that having a definite diagnosis was advantageous in accessing the necessary help.

### Referral: The pathway to the best possible care

It was felt that an opportunity for further discussion, shortly after the initial diagnosis, should be routinely offered. Referral to accredited specialist centres was rare, but those who attended found it extremely beneficial and suggested that it should be more widely available,

*“It's better if you go to a specialist centre. You are better informed”*

It was thought essential that genetic counselling was offered, social care needs for both the present and the future were discussed, information about possible financial support was given and access to therapists and specialist nurses was made readily available.

### Healthcare professionals

Another issue was the treatment from specialists in other areas of medicine. Several patients found themselves educating the healthcare professionals who looked after them about ataxia,

*“Even though they had ataxia written down, they didn't know what effect it had”*

Information and support from Ataxia UK were mentioned as very important factors in helping people access the appropriate care pathways after diagnosis,

*“You get more information in one support group meeting than they [doctors] can ever give you”*

## Recommendations

There is a need to define and distribute clear guidelines surrounding what care and support is required for people diagnosed with ataxia. There is also a need to improve GPs and other clinicians' awareness, the circumstances in which diagnoses are given and what help is offered afterwards. All patients should be made aware of Ataxia UK and the support and information it can offer as soon as a diagnosis is made. Information may need tailoring to personal needs, although most of the people with ataxia said they wanted to know as much as possible,

*“I would like to ask what's going to happen to me. If you know what to expect, you can make plans”*

Finally, the needs of the carers for people with ataxia need to be considered, and carers should be offered their own assessment.

Ataxia UK will be acting on some of these recommendations in order to improve the access to a diagnosis and ongoing care for people with ataxia.

For example,

- we will continue with our awareness raising of ataxia with healthcare professionals,
- provide specific information for newly diagnosed individuals on care pathways
- and suggest changes to the Clinical Guidelines for the management of ataxia.

This study also provides further support for the creation of more Ataxia UK accredited Ataxia Centres of excellence, which is one of our aims for the next few years.

*Thanks to Frances Harrison for her help in preparing this article.*

# Euro-Ataxia Conference 2007

Laura Rooke reports on the Paris conference.

November 2007 saw the annual conference of Euro-Ataxia, the organisation which brings together ataxia patient groups around Europe. This year the conference was held in Paris, organised by the French Friedreich's ataxia association (AFAF) and attended on behalf of Ataxia UK by our Chief Executive Sue Millman and myself. Altogether around 60 scientists were present along, with 30 representatives of charities or patient organisations.

Here I will summarise what we learned on the first day, which was solely about research. For more details on the individual presentations from each researcher, see the full report on our website or contact the Office.

### Spinocerebellar ataxia

There are two groups established between researchers and clinicians investigating the autosomal dominant cerebellar ataxias; the SPATAX network (for spastic paraplegia and ataxia) and EUROSCA. Both groups involve the prominent ataxia researchers in Europe (including many researchers currently working with Ataxia UK) and allow them to collect and share information on the ataxias from their own research and from patients they see.

The current activities in SPATAX and EUROSCA were presented by Dr Alexandra Dürr and Professor Thomas Klockgether respectively.

**Data on symptoms and other variables**, such as onset from patients, which has been collected by researchers in the SPATAX network have revealed useful information about symptoms that manifest with different genetic abnormalities. This could be extremely helpful for deciding which genetic tests to carry out to diagnose someone with an inherited ataxia.

Prof Klockgether announced that a registry of around 4,000 patients has been created by the EUROSCA project and mentioned several **drug targets in the pipeline** for the SCAs. We may hear more of them in future; they include lithium, HDAC inhibitors (which have been worked on for Friedreich's ataxia, see box), and compounds that stimulate autophagy (the metabolic breakdown of unwanted complex structures).

Several **newly-found genes** that cause spinocerebellar ataxia were presented to the audience. Dr Paola Giunti introduced research that is being carried out in London on the newly-identified SCA11 and which was described in issue 159 of *The Ataxian* (Autumn 2007). Dr Franco Taroni then described SCA28, which has been studied in 17 individuals in Italy with a very wide age range, from 12 to 64.

An informative talk on animal models for SCA3 was given by Olaf Reiss. He described how **animal models** can be used to help us learn more about the biological function of proteins, such as ataxin 3, which is abnormal in SCA3.

### Friedreich's ataxia

In the afternoon we heard from researchers working primarily in the field of Friedreich's ataxia, beginning with Hélène Puccio and Pierre Rustin. Both talked about **iron-sulphur (Fe-S) clusters** and how proteins that contain Fe-S clusters may be deficient when there is reduced Frataxin (as in Friedreich's ataxia). It is important to know more about these Fe-S proteins as they may have an effect on how damage is caused and on treatments being investigated.

Next Joel Gottesfeld, the man behind the research into **histone deacetylase (HDAC) inhibitors** at the Scripps Institute in California, gave us an update of his research. HDAC inhibitors

have generated much excitement in the past year and you may have read about research Ataxia UK is funding that is also looking at the possibility of these compounds being developed as a treatment (see box page 9).

The pharmaceutical company Repligen, has now entered into a licensing agreement involving the specific HDAC inhibiting compounds which Gottesfeld's team have been working on. Repligen is focusing on the pharmacokinetics (how they behave in the body) and safety of these compounds, and if there are derivatives of the compounds which are more effective.

Other researchers talked about **clinical trials which are beginning for Friedreich's ataxia**. Isabelle Husson described a trial starting in France looking at pioglitazone, which is a treatment currently used in diabetes mellitus, while Arnold Munnich talked about the deferiprone trial which is beginning in various countries and was mentioned in more detail in the previous issue of *The Ataxian* (160, Winter 2007).

Finally, Barbara Schieber-Mojdehkar presented a trial in Austria studying **rhuEPO** (recombinant human erythropoietin), which has now been extended. This treatment is known for its use in stimulating blood cell production in patients undergoing dialysis for kidney failure. Its potential benefit for Friedreich's ataxia was recognised when unexpected neuroprotective and cardioprotective properties were found. It is still not properly understood how rhuEPO exerts this effect. But so far research has shown that as well as the protective benefits, rhuEPO injections appear to increase expression of Frataxin protein in many patients studied.

The talks closed with Paul Konanz from the Friedreich's Ataxia Parent's Group (FAPG) in the US. His enthusiastic presentation was about how **patient organisations and researchers can work together to produce faster results**.

Following this there was the chance for the collected scientists, patients and charity representatives to ask each other questions and further discuss working together. Konanz and many others could be heard saying how wonderful it was to have so many people working for the same cause gathered together in one place.



# The Annual Meeting of the Association of British Neurologists

A report by Barnaby Levy

Last November saw the 75th Anniversary of the Association of British Neurologists, with its three day annual meeting at the Queen Elizabeth Conference Centre in central London. I went, as both a layman and a representative of Ataxia UK, to the opening day, entitled "Patient Organisations & Neurology". Not being a neurologist myself but being a person with ataxia, I felt I had a vested interest in the outcomes of such a conference, attended, as it was, by the brightest and best of both our own neurologists and those of Norway too!

Ataxia UK is a Patient Organisation and as such I was invited, along with representatives from other charities (big and small), to see the neurologists in action! Because I have no medical training and know very little about neurology beyond the basics of my own condition (SCA 6, if you were wondering), much of what went on passed over my head! But I was in good company as most of the other Patient Organisation representatives themselves were limited to knowledge of the conditions they were representing, and the day

had been specially designed to cater for people such as us.

That's not to say the day had been totally dumbed down. And thanks to the auspices of Dr Angus Kennedy of the Chelsea & Westminster Hospital in London, it proved to be informative and quite revealing. After registration at the unholy time of 8am, Dr Kennedy gave a short introduction in which he set the unlikely template that all further speakers were destined to follow, namely that being a scientist needn't preclude you from being an excellent orator!

For me the highlight of the day was a special production, staged exclusively for us, by the National Theatre and comprising of three actors. Billed as a 'forum theatre workshop developed by the NT and the General Medical Council', Forecast: Fog explored some of the issues facing people in the early stages of Alzheimer's Disease, their doctors and their carers. In particular, the workshop was concerned with communication and consent in medical situations, and was designed to spark debate and encourage audience participation

– which, when you have an audience primarily made up of doctors and people with first-hand experience of neurological disorders, was not only highly successful, but also really rather informative.

A common thread running through most of the lectures was how healthcare in this country, and particularly the parts of the NHS which deal specifically with chronic neurological complaints, have evolved through time to reflect the models set for them by the Patient Organisations concerned. So, just as the NHS now employs many MS-specialist nurses (ie nurses trained to deal with all aspects of MS), one day it may also employ many ataxia-specialist nurses – not just the excellent Debi Holm in Sheffield (who, by the way, previously worked as an MS nurse for many years). By funding Debi's appointment at the Ataxia Centre in Sheffield, Ataxia UK is merely following a template set for it by other, larger charities over the years and in its own way, therefore helping to shape the NHS for future generations.

## HDAC Inhibitors – a brief history

We know that in Friedreich's ataxia there is a deficiency of the protein Frataxin - an essential protein for the proper functioning of mitochondria (the energy-producing components of cells). This is because the gene responsible for producing the protein appears to be 'switched off'. HDAC inhibitors are being talked about as a possible way of switching the gene back on. Research by Professor Festenstein in London demonstrated that the abnormal GAA repeats in the Friedreich's ataxia gene led to the DNA becoming unusually packaged by

dense heterochromatin structures, preventing the DNA from being read. Thus researchers were inspired to investigate whether substances which prevent the heterochromatin binding to DNA could reverse the silencing of the gene.

Last year Joel Gottesfeld's team published the results of a study showing that HDAC inhibitors could reverse Frataxin silencing in the lab using cells from patients. This group of compounds is now being looked at by several groups of researchers, including Professor Festenstein, and Professor Pandolfo in Brussels, to try and identify potential treatments from this group of compounds that have

the most favourable properties and to test them in animal models of Friedreich's ataxia. It has also been suggested that this mechanism could be looked at for some types of spinocerebellar ataxia (eg SCA1, SCA2, SCA6) and other neurodegenerative conditions resulting from a CAG repeat expansion type of genetic defect.

For more information see Dr Everett's article in issue 148 (Winter 2004) of *The Ataxian*, or see issues 157 (Spring 2007) and 159 (Autumn 2007) for summaries of Professors Pandolfo and Festenstein's research.



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

### Dear Editor,

I wonder if *Ataxian* readers are aware of the following achievement which I read on the Ataxia UK website Forum, posted by 'Pommy'.

*Patsy Riggs*

I was so nervous! We had a meeting at the Aldwych Theatre. There was my sister (she had bought the tickets) and I, two managers from the theatre and the disability conciliation guy. After lengthy discussions (three hours!) the theatre agreed to make the relevant structural changes and accommodate a wheelchair space.

I looked at the plans. They are great and the theatre will pay for me and

my sister to attend the show when the work is done, to christen the new space! Manager Bryan Lewis was nice, he apologised for the way that I was treated and said thank you for forcing them to provide better facilities for the disabled!

*'Pommy'*

### Dear Editor,

Having enjoyed a Christmas Lunch with the South Downs and London Groups at Guildford, we would like to thank everyone who made us so welcome on our first meeting. We've been involved with various school and charity organisations for most of our lives and realise what is involved in arranging such an event. We appreciate the attention to detail and all the effort that was put into this lovely occasion.

*Jeanette and Peter Risley*

### Dear Editor,

There are no specific drugs for the ataxias and we are often medicated for conditions associated with our ataxia. We are also heirs to the many illnesses of mankind. Medication may be necessary to alleviate symptoms but slowing of thought processes and reduction of attention span may be signs of over-medication and

should be discussed with your GP or specialist

I am careful to fulfil my sleep requirements, look after my physical fitness and on alternate days have places to go or things to do. I try to work my body hard and maintain it well – as you might a machine!

*Peter Smeaton*

### Dear Editor,

We held our bi-monthly meeting on 26 January and this time were blessed with the presence of two ladies from the Office – Sue Millman and Tina Thatcher

Sue gave a very informative talk and stressed the benefits of becoming a branch – which, after we've been a support group for 17 years was, I felt, very brave of her!

We sensed a different, more welcoming attitude and everyone enjoyed the visit and the conversation with both ladies after the talk. Altogether an enjoyable day! We all hope our visitors had the same impression!

*Jack Hinchcliffe, Bradford*

*Indeed, I had a wonderful time meeting everyone and hope my words on becoming a branch bear fruit!*

*Sue Millman*

## It works for me!

Fed up with stretching down to the floor to pick up your post from the carpet?

I was! Attach a 'stroller net bag' (designed for attaching to the back of baby push chairs £4.99) to the back of your letterbox. Secure the top part of the bag with hooks.



So when the postman drops letters through your door, the letters fall into the bag and not to the floor. You can then simply take them out the bag, avoiding the potential of tipping out your chair!

*Matthew Law*

## Don't forget!

- If your ataxia makes using telephone directories difficult, you can access free Directory Enquiries. Dial 195 and you'll be instructed how to apply.
- Frances Thomas writes: I applied for free prescriptions (form FP92A, available from your GP) on the basis that I am "a person with a continuing disability" and that I "cannot go out without the help of another person". The form must be signed by your GP. Only a couple of weeks later, I received in the post a Medical Exemption Card.



*Thanks to Hampshire Support Group for these tips*

## Equal Partners - have you signed up?

The 'Equal Partners' initiative from Carers UK helps carers to campaign and get involved in local services. Equal Partners is free for carers and former carers. Sign up at <http://www.carersuk.org/Getinvolved/EqualPartners/SignuptoEqualPartners>

## Publications

*Looking after someone 2007/8: a guide to carers' rights and benefits* was launched on Carers Rights Day in December. Carers have certain legal rights to benefits and other help yet each year, £740 million of carers' benefits are unclaimed. This new guide from Carer's UK give details of financial help, practical help and help with combining work and caring. To order a free copy 0808 808 7777 or download a copy from the Carers UK website (see page 13).

# Skiing with ataxia

*My parents took me skiing over Christmas, Anna Pettman writes. I used an adapted biski and had lessons and had a fantastic time.*

We decided to go on holiday skiing for a week, something we all wanted to do. There was one problem. Where could we go and learn to ski on a family holiday that would cater for

## **Personal and friendly approach**

my family and me (with Friedreich's ataxia)? We looked on the net for places offering lessons using adapted skiing equipment alongside able-bodied ski equipment. Pretty much everywhere that met our criteria was in the USA or Canada, which was beyond our budget and not very helpful if you're only going for a week. But there was one other company we found - Redpoint. They are a British company based in a small town called Fügen in Austria, a lot closer than the USA.

## **Reassured**

We booked our holiday and were immediately reassured by the personal and friendly approach, enabling us to phone the actual ski instructors who laid all our (well, Mum's) concerns to rest.

Although we were offered airport transfers, Dad is an explorer at heart so we hired a car and drove to the hotel. On our arrival, we were greeted by Nina, co-founder of Redpoint, who showed us the clever tunnel that

## **Apparently, I needed a helmet.**

linked our rooms to the main building where all the meals were. So we didn't need to tramp around outside and wrap up warm.

Later on Nina came to the ski hire shop with us for my brother and Dad to get skis. Apparently, I needed a helmet. Mum hadn't mentioned this. I immediately envisaged falling down a steep snowy hill being chased by lots

of adapted ski equipment. However, after dinner Sara, the adaptive ski instructor, came to talk to me and told me about all the equipment I'd be using. She'd got a good idea of my abilities from a questionnaire she'd sent me when we booked.

## **Apprehensive**

The next day was my first lesson and despite my talk with Sara I was still a little apprehensive. The next morning we started gently using a bi-ski on some almost level snow on Spieljoch.

Sara guided me telling me which direction to go. Two attachments called tethers helped me not fall over. As I got braver, we went on a button

## **I got braver...**

lift using a special harness to attach the bi-ski to the lift. We were on a blue run and on the gentler bits Sara helped me steer and slowed me down, but on the steeper bits she helped me a lot, skiing holding the bi-ski until I was more confident, and occasionally having to help me up when I tipped the bi-ski over.

The next day we continued on the same slope and I developed my steering as my control increased. I felt exhilarated and excited. The views were truly breathtaking but with the element of speed and self-determination it was really a fantastic experience.

## **In control**

That day was also Christmas Eve. The hotel gave us a gala meal and a traditional Austrian celebration. The next day we went to Hochfügen. Because of my late night my steering was

really bad and so I fell over lots. Despite this, Sara didn't tell me off or get cross and continued to challenge me. By my last lesson I was fairly confident skiing, only tipping the bi-ski twice in my last

## **Speed and determination**

lesson of two and a half hours, usually to stop myself crashing into people as Sara wasn't shouting directions any more! I still had the tethers on but I couldn't feel Sara steering for me so much and it was great to be in so much control.

## **Sara wasn't shouting directions any more**

The skiing was fantastic and the staff were all wonderful, even helping with emergency repairs on my wheelchair. They bent over backwards to make sure we could all have different lessons at the same time.

In fact I enjoyed it so much I'm saving up to go again!

See colour picture of Anna in action on page 19.



# Making a difference on the web

## How to e-campaign

By Matthew Law

Back in 2004, I attended a 'The Beautiful South' concert at the Hammersmith Apollo with my good friend and fellow Ataxia UK webmaster Katie Henderson. The group were fantastic but the view we had from our wheelchairs located at the back of the auditorium was worse than poor. 'Do you think I should write to them and let them know of our disappointment' Katie asked me. 'No' I replied 'I wouldn't bother, you'll be wasting your time.'

On page 16, David Lowe advocates fighting for your rights. Someone with ataxia also recently posted a forum message (via [www.ataxia.org.uk](http://www.ataxia.org.uk)) and managed to get a theatre to change its policy for disabled people (see Letters page 10). The National Association of Disabled Supporters is constantly campaigning on their website ([www.nads.org.uk](http://www.nads.org.uk)), at Wembley and on the radio, for improved facilities for disabled supporters at football grounds. The Association of Wheelchair and Ambulant Disabled Supporters ([www.awads.co.uk](http://www.awads.co.uk)) continually urges football grounds to review their disabled access by encouraging supporters of each football club to post their comments directly to the site.

### Petitions

These are all examples of ways we can all make a difference - or try to make a difference. I can't pretend that you're always going to be successful, but have a go! For those with a little knowledge of HTML, you will find a useful web tool at Bravenet ([www.bravenet.com](http://www.bravenet.com)) which you can add to your own site to record the answers to questions you set. You can then present the answers to interested parties. Yahoo also has a useful site enabling users to pose questions and get answers at <http://uk.answers.yahoo.com>

However, if you want an online petition site where you can set up a petition and enable others to see what your petition is, as well as add their names

to it, then look no further than [www.thepetitionsite.com](http://www.thepetitionsite.com). So I could gain an insight into how the site works, I have taken the liberty of setting up my own petition. Wheelchair users should log in to [www.thepetitionsite.com/petition/580485798](http://www.thepetitionsite.com/petition/580485798) and sign if they agree to it. Perhaps we can find out the power of the internet by seeing how many sign up.

To help support you in promotion of your petition, each person who signs will automatically receive an email message to confirm their signature. It recommends they take a moment to tell a few friends about your petition.

You don't have to use [www.thepetitionsite.com](http://www.thepetitionsite.com), of course. You could try one of these (they probably all do a similar thing and are all free) [www.ipetitions.com](http://www.ipetitions.com), [www.gopetition.co.uk](http://www.gopetition.co.uk), [www.petitionthem.com](http://www.petitionthem.com).

### Other tools

Other ways of spreading the word using the internet could include:

- emailing a petition announcement to your friends and supporters
- submitting your petition page to major search engines
- promoting the petition in appropriate news groups, online forums and discussion groups
- adding it to your email footer

Please do not send unsolicited bulk mail messages ('junk mail' or 'spam'), though. In fact, if you do so, you may be in danger of being blacklisted by your internet service provider, and your email account suspended.

### Does it work?

It's all very well getting a petition signed but will an online petition be officially recognised? A House of Commons committee recently met to gather evidence on the wisdom of giving electronic petitions the same status as paper ones. 10 Downing Street's e-petitions site launched in November 2006 and is still under trial, but has at least gained public support - 41,000 people signed up recently

Matt in the snow this winter at Trondheim, Norway



to make Jeremy Clarkson Prime Minister! The Scottish Parliament and several local authorities have also experimented with e-petitions.

Paper petitions can be presented formally by a Member of Parliament during an adjournment debate. Petitions can also be presented informally by dropping them in a green bag behind the Speaker's Chair.

### Proof of the pudding

Last year I returned to the Hammersmith Apollo to see Ricky Gervais. The view from my wheelchair was fantastic. The disabled access had been improved beyond recognition. The wheelchair balcony was much higher and was accessed via a lift. It was totally co-incidental of course that three years before, Katie had written that letter and not received a reply. Or was it? Maybe Katie did make a difference.

*Matthew Law*

### The virtual group

To join Ataxia UK's internet group, go to [www.virtualataxia.co.uk](http://www.virtualataxia.co.uk), click on the link to the Yahoogroups site and follow the instructions!

Alice, who set up and runs the virtual group, and Tim, who manages the Sunday chat, were married last year. See the colour photo on page 2. There is also a lovely photo album at [http://spiveyworld.net/wedding/categories.php?cat\\_id=1](http://spiveyworld.net/wedding/categories.php?cat_id=1)

### What are you watching?

Tell us about your favourite websites. Email [marketing@ataxia.org.uk](mailto:marketing@ataxia.org.uk)

## New National Carers' Strategy anticipated

In 2007, Gordon Brown announced that the Government would review the National Carers Strategy and publish a new version in 2008, outlining a framework for carers' services over the next decade. He said it would involve "the biggest ever consultation with carers."

According to Carers UK, carers' priorities are:

### Better recognition by professionals and inclusion in society

Carers do not feel valued for the contribution they make. They want a special status in society - reflected in the benefits system. Professionals should be given proper training so that they understand the expert role carers play.

### Better quality services for carers and those they care for

In return for the unpaid care they provide, carers expect services to support their caring role and fit around their lives.

In reality, many carers have to subsidise care packages, and are forced to put up with inadequate, inflexible services. Services such as breaks, transport and equipment constantly let carers down.

### Income for the under 65s

Carers feel passionately that the benefits system is outdated and in

need of a radical overhaul. It needs to change from one based loosely on income replacement, to one which properly recognises their contribution to society.

Carers recognised that things were getting better for many working carers, but the services and support to enable them to stay in work too often fell short.

### Income for the over 65s

Carers jobs may finish when they retire but their caring doesn't. Carers were extremely angry that their Carer's Allowance stops when they reach retirement age. They want a proper pension to which they have contributed all their lives, as well as financial recognition, in the shape of Carer's Allowance, for continuing to care.

### Carers' health

Many carers said they go without a break, health checkup, or any back-up if anything happens to them. The Government needs to look after carers and give them support to carry out the sort of tasks that health professionals would receive years of training to do.

The new National Strategy is expected to be published in Spring or Summer this year. Read the full article at [www.carers.org](http://www.carers.org)

## Carers Week 9-15 June 2008

The Neurological Alliance is one of the charities organising this year's Carers Week. The theme is "Carers can't afford to be ill."

If you are a carer, please complete the online questionnaire at [www.carersweeksurvey.org.uk](http://www.carersweeksurvey.org.uk).

To find out more about Carers Week, including free leaflets, posters and promo materials, visit [www.carersweek.org](http://www.carersweek.org)

## Carers support organisations

### Carers UK

Campaigning, policy and information organisation for carers

20-25 Glasshouse Yard  
London EC1A 4JT

T. 020 7490 8818 F. 020 7490 8824

CarersLine T. 0808 808 7777

(Wednesday and Thursday  
10am-12pm and 2pm-4pm)

[info@carersuk.org](mailto:info@carersuk.org) [www.carersuk.org](http://www.carersuk.org)

Membership is free and there is a quarterly print magazine and email newsletter to keep you up to date with developments. Carers UK publishes a wide range of factsheets and booklets covering benefit entitlements, work, study, coming out of hospital and getting a break. Downloadable free or you can order a free single copy of each publication of each publication by post, if you are a carer. Publications line 0845 241 0963 during office hours.

### Princess Royal Trust for Carers

Carers' support services through a network of 122 independently managed Carers' Centres and interactive websites, Carers.org and YCNet for Young Carers. The website directory page links through to all the key topics and articles about caring (eg benefits, holidays, taking care of yourself, transport, employment, bereavement), which in turn signposts you to the best information available on the Internet. If you can't find what you're looking for, email your question to their Help Desk or phone the London office. 142 Minories, London EC3N 1LB  
T. 020 7480 7788 F. 020 7481 4729  
[info@carers.org](mailto:info@carers.org) for publications  
[help@carers.org](mailto:help@carers.org) for Help Desk  
[www.carers.org](http://www.carers.org)

### Crossroads Association

Provides a tailored service to allow carers to have some time for themselves.

10 Regent Place, Rugby  
Warwickshire CV21 2PN

T. 0845 450 0350 F. 0845 450 6556  
[www.crossroads.org.uk](http://www.crossroads.org.uk)

## Taking control

### The 'landmark case' of Sharon Coleman

Sharon Coleman, a carer from London, has won the initial stages of her case at the European Court of Justice. This could give new rights to millions of carers.

The Advocate-General agreed in January that Sharon had suffered "discrimination by association".

Sharon worked as a legal secretary for a law firm. She left her job and took her employer to court for constructive dismissal claiming she had suffered disability discrimination because she had a disabled son. This is termed 'discrimination by association'.

Sharon claimed that her employer treated her less favourably than parents of non-disabled children. When her son was born disabled, she felt her employers began to treat her differently. When she asked for time off to deal with her caring responsibilities she was described as 'lazy'. She said she was not allowed as much flexibility as parents of other children. She said her manager had commented that her child was always sick, and had accused her of trying to use his condition to get out of work. Eventually she felt she had no choice but to resign and bring a case under Disability discrimination laws.

## Branch Lines

### Focus on Thames Valley branch

The Thames Valley Group was formed about five years ago, initially to serve the Berkshire area but has grown to include members from Middlesex to Oxford, and from north and east Hertfordshire to parts of Hampshire.

Covering such a large area, it's not surprising that many members have difficulty in attending our meetings but we do keep in touch with our newsletter and, for those on-line, by email. With the help of Tina Thatcher, the group attained Branch status recently and is looking forward to organising official fundraising events for the branch and for Ataxia UK.

Michelle Spratt, who is well known to Ataxia UK having

been a trustee, was one of the founders of the group and has just recently taken up a temporary teaching post in, of all places, Venezuela! She has never let being in a wheelchair hold her back and we wish her well in her new venture. She will be more than welcome to come back as she is sorely missed.

Our Christmas lunch was well attended last December in spite of some members succumbing to winter flu. It was great to meet some of our newer members and, of course, to meet up again with our 'regulars'.



The committee is now busy planning our first year's events since becoming an official branch of Ataxia UK, and has some exciting ideas for fundraising, both for Thames Valley and for Ataxia UK. The Thames Valley Branch meets every other month, usually at Knowl Hill village hall. Easy to find, Knowl Hill is about five miles west of Maidenhead on the A4 and it is also geographically central to the majority of our members. During the summer (?) months we normally arrange one or two outside events such as a pub lunch (very popular - I wonder why?)

In 2008, we hope to organise a boat trip on the river Thames.

At our April AGM, we'll have an opportunity to discuss plans in more detail with our members. For confirmation of dates and venues, please visit our web page on the [www.ataxia.org.uk](http://www.ataxia.org.uk) site or contact Bob (details p15). We are always pleased to welcome newcomers.

### Focus on Milton Keynes support group

Milton Keynes is a new support group meeting every other month and the membership is informal. It welcomes everyone, those with ataxia and carer alike. Gary (Betty's son - one of our members) and his friend come to generally spoil us, make delicious sandwiches and cake and whatever we want to drink. Betty lives in Everglades sheltered housing on the Eaglestone housing estate, where we meet. It's a lovely light, airy large room with tables and comfortable chairs and its own kitchen. French doors open onto gardens where there are also benches. We are very fortunate as it is free, which helps keep the costs down, as well as saving me the headache of finding somewhere to meet every time. Our grateful thanks to Betty.

As with any new group, members are still exploring whether it is for them, so the numbers tend to fluctuate. There is a freedom to find the right kind of support. No-one stands on ceremony, but we do share our concerns.

Our last meeting was a big one and was enjoyed by all. Laura Rooke from Ataxia UK's London office came to talk to us about research. She was clear and gave us valuable information and the event was very successful.

Some of the members arrive with their carers. There's Janet Harrison with Lennon, a beautiful golden retriever who usually arrives sporting his special carer's coat. Lennon helps Janet do her daily tasks, from taking washing out of the machine to rescuing her if she falls, by pushing her into a sitting position, so that she can grab a chair to pull herself up. Lennon provides the sort of loyal

companionship you would only find in such an adoring canine!

Mia is coming up to five and now proudly goes to school. She arrives with her mum who is usually quite exhausted at the end of meetings, keeping her from falling and being generally vigilant. At our last meeting she wanted to sit next to everyone!

Nick arrives with his carer, a very jolly lady with a good sense of humour who keeps the group amused.

You can see we're a very varied crowd so if you haven't yet found your support group, you'd be welcome to come and join us!



Meetings at Everglades normally start at 1pm on Saturdays and a light lunch (sandwiches, cakes, tea and coffee,) is provided. Membership is free but a small donation towards the cost of refreshments is appreciated.

For details of future meetings, either email Joan at [jj5@talktalk.net](mailto:jj5@talktalk.net) or phone 01908 222618.

*Joan Johnson*

*At our January meeting, where the star is undoubtedly Lennon, Janet's assistance dog, pictured here directly in front of the speaker, Laura!*

# Tina Talk

*Hi everyone,*

I've heard ataxia mentioned on TV three times now in past month – which is great for increasing awareness! Although it seems a long way away, we're planning the contents of an events pack for branches and groups for International Ataxia Awareness Day (25 September – a Thursday this year).

Following our successful branch officers' weekend last year, we're holding another 11-13 April at Leicester University. Places are getting snapped up and I hope to see some new faces. This event is entirely free.

I would like to welcome our two new branches. The North West group met for the first time in January (see below) and is very excited about becoming a branch and being able to fundraise for their members and Ataxia UK. And the turnout for Newcastle was equally excellent (see Breaking News). Welcome, both, to The Branch Network.

Best wishes to you all,

*Tina*



## Short cuts

- Ataxia-East – the branch held a collection at the Queensgate Centre in Peterborough
- Ipswich - two new members came to our Christmas lunch as a result of Patsy Riggs broadcasting details on BBC Radio Suffolk!
- North West group – the first meeting was on 30 January in Bolton and 19 people attended! The new group has decided to be a branch. John Gurhy, who has late onset ataxia, was elected Chair. And from this meeting also came offer of another branch for Cheshire and Staffordshire! Watch this space.

*Continues page 16*

## Breaking News!

The first meeting of the Newcastle group in February was attended by 25 people, a fantastic response. Instigator (and now Chair) Louise Nugent was going to set up as a support group. However, because of the brilliant turn out and enthusiasm, all agreed a branch would be better!

## Branch and Group Contacts

Branch/Group	Contact Name	Tel/Email
Ataxia East	Dave Stubley	01205 722771 djstubble@aol.com
Central	Brian Doody	01902 783381 Brian@doody.wanadoo.co.uk
Derby	Marta Hancock	martaehancock@aol.com
E 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	Julie Fallon and	
Huddersfield	Michael Williams	jkfjules@btinternet.com
Ipswich	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 (New)	Louise Nugent	0191 291 2741 louise@atyourside.org.uk
North West (New)	John Gurhy	johngurhy@btinternet.com 07984 512383
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 Downs	James Downie	james@downstar.co.uk 07884 186906
South West	Graham Fickling	fickling2002@blueyonder.co.uk
Thames Valley	Bob Robson	bob-robson@ntlworld.com 01438 747160
West Country	Becky Downing	becs2737@yahoo.co.uk
N Yorkshire	Stewart Newhouse	01756 795258 newhousehev@aol.com
<b>N Ireland</b>	Margaret Evans	magsevans9@yahoo.co.uk
<b>Scotland</b>		
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
<b>Wales</b>		
North Wales	Chris Hobson	chris_hobson@hotmail.com
South Wales	Tina Evans	bontwelshgirl@hotmail.com
<b>Virtual Ataxia</b>	Alice Spivey	alice@spiveyworld.net
<b>Other ataxia groups</b>		
Ataxia self-help group Bradford	Dennis Boland	01274 735662 Pbeddard@ntlworld.com

Rose Selway, a Friend and volunteer with cerebellar ataxia, can be contacted by phone after 6pm. Telephone 01472 316783.

# Dave Lowe urges others to challenge wrongful decisions



**I**n May 2003, at the age of 50, I was diagnosed as having cerebella ataxia. Tests carried out found it was not any of the known SCAs. So it is classed as sporadic idiopathic cerebellar ataxia, 'sporadic' meaning it has not been identified in my family history. My symptoms are with me continually.

From the very outset of being diagnosed, I was faced with being told I couldn't continue with my job. My employer tried to put me into an unsuitable alternative job role, reducing my salary and saying I would not be able to claim ill health retirement. When I would not comply with this, I was put on a precautionary suspension and subjected to a humiliating health assessment by a private neurologist hired by the firm.

### **Humiliated**

The neurologist told me to take off all my clothes and when I refused he commented that he did not know how anyone could have made a diagnosis without seeing me undressed. My wife made some comment about my cerebellum being in my head and

having an MRI scan. He then asked me to prance up and down the room on my tiptoes like a performing monkey. I presume he originally wanted me to do this in the nude, but no way was I having that. Still on suspension after 12 months, my condition was much worse and I then fought for ill health retirement, which I have received from September 2004.

### **DLA Challenge**

Subsequently this fight gave me the strength to challenge the right to DLA which I had been refused. I took this to the tribunal panel who gave me the lower rate of care and mobility. My doctor had refused to sign a form to enable me to get a Blue Badge and I enlisted the help of Welfare Rights who were successful in getting this for me.

More recently, I challenged the rights to extra Direct Payments, which had been refused. I took this to a Stage Two of the Social Services Complaints Procedure, after which I was granted the extra hours. A song I frequently used to play during these times was Bob Marley's "Get up, Stand up, Stand up for your rights".

### **Confident**

The last few years have been extremely hard and I felt I was not in control of my life. But with each success, I have become more confident in challenging and questioning the decisions of those in authority. I would advise anyone in a similar situation to get as much advice, information and support as possible to enable them to fight for their rights and not to give up at the first hurdle. If you truly believe you have a right to something go out there, take the bull by the horns and kick ass.

### **My rock**

Finally I would like to say I have had the unreserved support of my wife Glenys. She has spent an enormous amount time, effort and patience. She wrote endless letters and researched the law regarding my rights and entitlements. She is my rock and keeps me focused and sane.

*Dave Lowe*

## New Direct Debit Scheme

**E**nclosed with this magazine is a direct debit form. As you'll read on page 3, rather than subscriptions, we're now asking for annual optional donations, preferably by direct debit. Alternatively, you could make a quarterly or monthly donation which may help you to manage your own finances more effectively. Direct debits help us to plan our work and enable us to make better use of our resources.

We are extremely grateful for any support you can provide and hope you'll find that direct debits are a convenient way for you to support our work.

If you choose to make an annual donation of £15 - £25, we would be grateful if you could make this an annual rather than a monthly donation, to reduce bank costs to us to a minimum.

## Short cuts extra: More branch news

- **London** – held a great Christmas Lunch jointly with South Downs Branch, which also included members of Thames Valley and East Sussex and Kent, and Sheila Benneyworth, Tina Thatcher and Barnaby Levy from the Office. The turn-out was an impressive 58!
- **West of Scotland** – had a great Christmas meeting, with entertainment, to round off the year. 2008 kicked off with February's meeting, and should be even more lively.
- **Thames Valley** - latest bulletin from ex Chair Michelle: she's now teaching in Honduras!

## Ask the Physio

**I**n the next *Ataxian*, we'll be introducing a new section where readers can get answers on exercise questions from a qualified physiotherapist with specialist knowledge of the ataxias. If you have a question, write to **Ask the Physio** at the London office or email your query to [research@ataxia.org.uk](mailto:research@ataxia.org.uk) and put 'ask the physio' in the header. You must provide your full name and address but only your first name will be published.

## The Giving Machine

We know a growing number of Friends shop online. Ataxia UK has teamed up with TheGivingMachine™ to generate cash donations for us every time you shop online. It won't cost you anything apart from the extra click to go via [www.thegivingmachine.co.uk](http://www.thegivingmachine.co.uk) into the online shop. Every purchase generates a cash donation



and it quickly adds up to a significant amount. It is estimated that 1,000 online shoppers 'donating for free' to Ataxia UK via TheGivingMachine™ would generate around £15,000 - £20,000 a year.

You'll find more than 100 different shops at TheGivingMachine™, including all the high street favourites.

## Don't bin your old mobile!

Another new fundraiser - we've teamed up with Re:cycle Your Mobile who recycle your unwanted phones for cash.

Just put your old mobile phone into the freepost envelope provided in this issue of *The Ataxian* and post it to the freepost address already on the envelope. For every handset received, up to £10 is donated to Ataxia UK. (Pass the envelope on if you can't use it.)

Recycling with Re:cycle Your Mobile guarantees that even items that cannot be reused or resold will not end up in landfill. Mobile phones



and their batteries contain elements such as mercury, cadmium, nickel and gallium arsenide. If not disposed of carefully, they can be extremely harmful to the environment.

You can also request a single freepost envelope for your own phone. Several bags (in a display box if you need one) can be placed in public areas for customers or fellow workmates to use. For more envelopes, call freephone 0800 970 5097 or visit the Ataxia UK page at [www.recycleyourmobile.co.uk](http://www.recycleyourmobile.co.uk)

## Everyclick

Everyclick ([www.everyclick.com](http://www.everyclick.com)) search engine works just like Yahoo, Google or MSN but it also generates money for Ataxia UK. Last year Ataxia UK supporters raised nearly £500 just by searching through



Everyclick. All you need to do is make Everyclick.com your homepage, select Ataxia UK as your chosen charity and let them do all the work!

## A Gift of a Lifetime

Once you have provided for your family and friends, we ask that you think of leaving a gift in your Will to Ataxia UK. Our vision is to live in a world which is free from ataxia. We believe that through the funding of world-class medical research, a cure can be found. A gift in your Will is truly a gift of a lifetime and will enable us to move one step closer to our vision. It is suggested that you should update your Will on a regular basis. A gift of any size is much appreciated – it doesn't need to be a large amount. The information you will need to include Ataxia UK in your Will is as follows:

Official Name: Ataxia UK

Registered Address:

9 Winchester House,  
Kennington Park, Cranmer Road,  
London, SW9 6EJ

Registered Charity No. 1102391

There are different types of legacies to consider:

- Residuary, usually shown as a percentage of what is left over after all other gifts have been made, debts and expenses deducted and inheritance tax paid.
- Pecuniary, a specified amount of money
- Specific, a gift that can be in almost any form, for example, a house, land, painting, jewellery.
- Contingent, a gift that depends upon the occurrence of an event. For example, the death of a relative.

## Running Events Round Up

### The British 10km London Run

Please join Kate from the Ataxia UK Office on Sunday 6 July to take part in this 10km run in London. We have five spaces available. For details go to [www.thebritish10klondon.co.uk](http://www.thebritish10klondon.co.uk), or call Kate to reserve your space.

### Just Walk South Downs

The Just Walk event takes place on 10 May in the South Downs. You can walk 20km or 60km in aid of Ataxia UK. More details from [www.just-walk.co.uk](http://www.just-walk.co.uk).

### Do It For Charity - something a little less strenuous!

Do It For Charity has launched three 5km races across the country: Birmingham on 27 April, London on 11 May, and Manchester on 8 June. Register at [www.doitforcharity.com](http://www.doitforcharity.com).

### Great North Run

The Great North Run takes place on Sunday 5 October. The ballot has now closed for entry but we have two spaces available. Please contact Kate at the Office for more details and visit [www.greatrun.org](http://www.greatrun.org) for race information.

# Fundraising from November 2007 – January 2008

## RAFFLES & COLLECTIONS

Betty Rapson, Alness - collection tin .....	£296.00
Ronald Hill, Andover Winemaking Circle - raffle and supper.....	£440.00
Diana Knight, Lowestoft - collection tin 98 .....	£100.00
Leslie Fryatt, Surrey - collection tin 116 .....	£23.50
Jenny Miles, Somerset - collection tin 267 .....	£25.00
Susan and Robert Wallis, Richmond - collection.....	£62.15
Chapman & Myers, Kidderminster - raffle at Christmas party.....	£220.00
Michael Gould, Cheshunt - collection tin .....	£1.50
Jean Ive, Polegate - collection tin 839.....	£60.00
Coronation Press, Chester-le-Street, Collection tin 44 ....	£65.00
Kevin Fulcher, The Waterfront Inn - collection tins 210 & 211.....	£30.00
Graham Kennedy, York - collection tin .....	£27.00
Alan Reed, Isle of Wight - collection tins.....	£87.87
Sunderland Youth Offending Service - collection .....	£60.00
Geoff & Ella Marshall, Cumbria - collection tin 318.....	£30.00
Barbara Lea, Flixton - collection tins 104,105, 106 and 107 .....	£184.53
David Lowe - collection tins 564 and 565 .....	£73.60
<b>Total Raffles and Collections.....</b>	<b>£1,786.15</b>

## SPONSORED EVENTS

Steve McCool, Cardiff - Cardiff Half Marathon.....	£2,029.00
James Waggott, Dave Price, Beth Routt - race across Africa .....	£5,752.52
Dr Barry Hunt - Chicago Marathon.....	£1,860.88
Michael Stuble, Frampton - skydive .....	£155.00
Mathew Dawson, Wyberton - skydive.....	£135.00
Adam Dawson, Wyberton - skydive .....	£135.00
Hector Murray, Perth - the Great Scottish Walk .....	£12.50
Simmene Amir-Mohammadi - Great North Run 2008....	£69.00
Linda Marshall - sponsored marathon walk at Foxhills Golf Club ....	£1,855.00
<b>Total sponsored events.....</b>	<b>£12,003.90</b>

## SALES AND FETES

Melanie Priest-Taylor, West Midlands - Ebay sales .....	£220.71
Anne Eyre, Northallerton - Christmas card sales.....	£50.00
Sarah Mair, Edinburgh - sale of ornaments at a coffee morning.....	£50.00
Penny Downen, Carolyn Hamerton & Holly Hipwell, Norwich - clothing sale and lunch.....	£195.00
<b>Total Sales and Fetes.....</b>	<b>£1,143.00</b>

## COFFEE MORNING AND LUNCHEONS

Mrs Smith, Seaham - Christmas meal at Castlea Centre .	£34.50
Jeanette Randall - coffee morning .....	£50.00
Mary Duff, Kilmarnock - coffee morning and raffle.....	£700.00
<b>Total Coffee Mornings and Luncheons.....</b>	<b>£784.50</b>

## MISCELLANEOUS

Brian and Eileen Harding, Surrey - Halloween Ball.....	£3,253.00
Ruth Eary and Shirle Corfield - fundraising events....	£1,000.00

Nicola Clark, Buckinghamshire - art exhibition .....	£1,125.00
Pauline McCool, Bellshill - Halloween Ball.....	£900.00
Lizzie Tovey, London - Rubiks Cube party.....	£305.00
Robert & Graham Fickling - joint birthday party.....	£225.00
Haste Hill Golf Club, Ladies Section - competitions and events.....	£48.00
Adrian Hallmark, Cheshire - Walk around Manchester...	£85.00
The Pieces of 8 Square Dance Club, Christchurch - dances and events.....	£512.00
Chobham Golf Society, Senior Section .....	£355.00
Sophie Earle, Tesco .....	£600.00
Dai Llewllin, Narbeth - 60th birthday party.....	£500.00
Monday Craft Club, Newbury .....	£50.00
FCA and Swanley Modern Sequence Dance Club .....	£200.00
Sandie, Graham, Pete and Amy Salvin - wedding speech sweepstakes.....	£150.00
Mrs S Donohue, Manchester - Dutch auction .....	£136.00
Colburn Village Dancers - dinner dance and raffle .....	£120.00
Jeff Marshall - Foxhills Golf Club Golf Day.....	£450.00
Leslie and Nicola Hughes - donations in lieu of birthday presents .....	£6,385.00
<b>Total Miscellaneous .....</b>	<b>£16,399.00</b>

**TOTAL..... £32,116.55**

## In Memoriam Tributes

We are most grateful to have received Tributes recently in memory of the following:

Delyse Boyes, Alan Brittain, Ann Casella, Joan Dobson, Ernest Haynes, Michael McKernan, Kenneth Milne, Glenis Mitchinson, Vera Moore, Wayne Quick, Doreen Tabbitt, Stewart Thompson, Daniel Whelan, Florence Winter.

## The Chance to Win winners are



Judith Hunt

**1st prize £250**

Mrs P Ashman

**2nd Prize £150**

Philip Ingham

**3rd Prize £100**



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

## 2008 London Marathon

### Welfare Grants



Agnes with siser Betty and nephew David during the interval

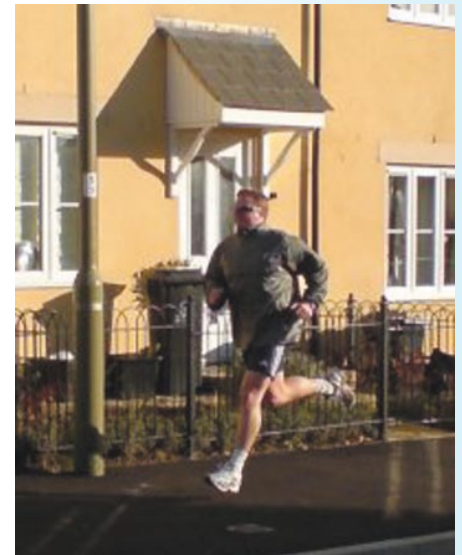
### Respite Days Out

**T**hank you very much for the grant towards a respite day out. As I live in a rural area, it's hard to get transport.

I, my sisters and their families went to the King's Theatre, Glasgow, to see *Sleeping Beauty* – the grant paid for our transport, pantomime tickets and a bite to eat afterwards.

What a great night out! Thank you very much.

*Agnes Colley*



**T**his year we have ten fantastic runners who will be taking part in the famous Flora London Marathon, on Sunday 13 April.

Our team members are Kurt Baldwin, Tom Barnes, Richard Clarke, Fred Davies, Radi Lyubenov, Wayne Maliphant, Charlotte Pennell, Hannah Rhys, Sandra Steeds and Lydia Warren.

The runners will be provided with personalised running vests, treated to a carb-loaded lunch the day before the race, and given goodie bags after they have successfully completed the 26 miles and 385 yards! This has all been kindly sponsored by Anthony Stick of TriXG.

Please come along and support our team on the day. Contact the Office for balloons and information on meeting points – we would love to see you there.

**D**arran Winfield-Stansby (below left) won the 100kg body weight class at the UK Open Bench Press Competition in January.



### Computer help

**A** big thank you to all the team at Ataxia UK who have enabled me to purchase a computer through its grant system. I am emailing this letter to you, a great support, because I can't even get to the letter box just up the road without getting the car out.

See *Dave's article and picture on page 16.*

## Sports and Leisure

### Sailing with attitude

**I** took up sailing in 2007 (see *Ataxian* 160 page 7) and was invited to the Royal Yachting Association's annual dinner by disabled sailor Geoff Holt. At the dinner, Dave Rutter, Managing Director of Artemis, invited me to try out



an Artemis 20 boat, which was great fun. Artemis believes that boats that are accessible for all. "Sailing should be something that anyone can enjoy

and we feel this is something that is more than worth promoting and building ideas for."

*Alan Thomas*

### "I'm saving up to go again!"

Read *Anna's account of a family skiing trip on page 11*



# Fundraising

## Skydivers



Michael Stubleby – son of Ataxia-East's Dave – and two of his mates, Matthew and Adam Dawson, completed a parachute jump to raise over £425 for Ataxia UK.

## To Timbuktu

James Waggott and his friend Dave Price, supported by Beth Routt, drove to Timbuktu in a car costing only £100 – and raised almost £6,000 for Ataxia UK.

James and Dave made the 5,500-mile journey to Africa in a battered twenty-year-old Mercedes estate. They joined other teams on the Plymouth to Dakar challenge, an economical tribute to the famously extravagant Paris-Dakar rally.

Co-driver Dave said: "Driving through sand is a skill in itself, a skill we did not possess.

"Drive too slow and you get stuck in the sand, drive too fast and you completely lose control."



The car survived the hazardous journey across deserts and minefields despite a catalogue of mechanical problems.

A leaking petrol tank meant that the person in the passenger seat spent the last leg of the journey with a fire extinguisher on his knee.

Well done, James and Dave!

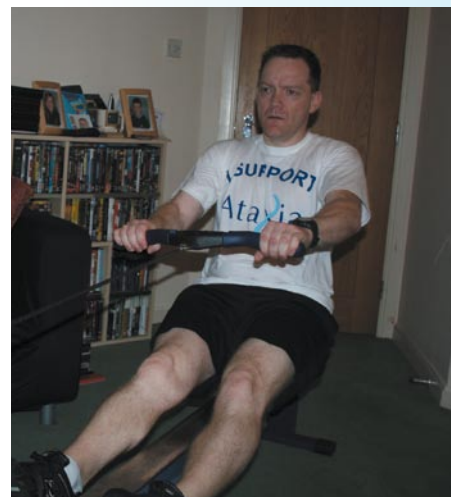
## Treadmill Triumph

In January, Linda Marshall completed a sponsored marathon power-walk on a treadmill, over the full marathon distance of 26 miles 385 yards. The power-walk took place at Foxhills Golf & Country Club and Linda completed it in a time of 5 hours, 57 minutes and 40 seconds. Her marathon efforts raised a fantastic £2,000 for Ataxia UK.

## Cheers!



## Row, Row, Row Your Boat



Niall Williams is currently taking part in a unique and gruelling challenge in aid of Ataxia UK. Between January and April, Niall is rowing one million metres (1,000km) on a rowing machine in no more than 100 days. This is the equivalent of rowing from Plymouth to Aberdeen.

On one tough day, Niall said, "Despite wanting to stop and not bother with it, I focused on all those who have donated money to the charity for this challenge and this spurred me on."

You can show your support and check on his progress by visiting <http://mmr2008.niallwilliams.co.uk>.

You can sponsor Niall at [www.justgiving.com/millionmetrerowing](http://www.justgiving.com/millionmetrerowing). You can also sponsor many of our other fundraisers, including the intrepid marathon team, through the Just Giving site. Go to <http://www.justgiving.com/ataxia/raisemoney> and click on 'See all Ataxia UK fundraisers' to see who's doing what for us.