# ATAXIA MAGAZINE

The magazine for people affected by ataxia

**Issue 197.** Spring 2017

## Fun Footy in Farnham

ATAXIA 2020 VISION

Ataxia people • Research
Health & wellbeing • Fundraising
Adaptations • Living with ataxia

ATAXIA
Ataxia UK

# In the office

GOODBYE

## Jonathan Evans

What will we do without him? Jonathan leaves Ataxia UK for a communications management post at the **Association of British Healthcare Industries** - an amazing and well-deserved position. We'll miss you, Jonathan!

HELLO

## Sara Mohammadi

Please welcome Sara, our wonderful new **Finance Assistant**! Sara joins us after a career at **CRU International** and has already proved to be a warm and efficient member of the team. We're very happy to have her!

HELLO

## Zoe Lonergan

A warm welcome to Zoe Lonergan, our new **Fundraising Intern**. She recently graduated from **Sussex University**, specialising in psychology, and has experience in the charity sector. We are delighted to have you on board, Zoe!

HELLO

## Oliver Roberton

Qualified journalist Oliver joins Ataxia UK as **Communications Intern**! We warmly welcome Oliver and the skills he will bring to the Ataxia Magazine. He'll likely be in contact with the Ataxia UK community a great deal and looks forward to working with you!

# Welcome

And just like that, we're already into the third month of a new year!

2016 was big in various ways and like many charities we stepped into 2017 not knowing what changes it might bring. What we do know, however, is that, by working together as we always have, the future is looking good for Ataxia UK's mission.

Firstly, we'd like to thank you for the pouring-in of donations for the **Christmas Appeal**; your generosity delights us each and every year. You can find the grand total on page 15!

2017's calendar is bursting: the **London Marathon** is one of our biggest events, and in this edition you can meet the six lucky runners who qualified to run for us (p. 13). You'll also notice that you've received tickets for our **Annual Raffle** with your magazine – don't miss out on taking part! Spring will of course bring the annual **Spring Classic** (p. 12) and we have a new look for a traditional event, in our **City Parks Challenge** for September's **Ataxia Awareness Day** (p. 12).

We'll be making big strides in **Raising Awareness** in June, when the **Exeter Branch** splash 'ataxia' all over the city in an incredibly exciting **PR campaign** (p. 5). Meanwhile, the **16-30's Project** progresses this summer with a stand-alone event (p. 10); supporting our Friends is, as always, a major priority. As for the charity itself, we're finalising our **strategic plan** for the next three years.

Lastly, as 2017 brings changes to how charities are allowed to approach their supporters, we would like to ask for your assistance: please help us to continue to be in touch with you by responding to the letter that you'll be receiving from us shortly. And with that, let the Spring begin another fantastic year of fundraising, support and fun!

Regards

Sue

**Sue Millman**

# WHAT'S INSIDE. Issue 197, Spring 2017

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## OFFICE

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## HELPLINE

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The helpline is open at the following times:

| | |
|---|---|
| Mon-Thurs | **10.30am - 2.30pm** |
| Friday | **Closed** |

Ataxia UK works across the whole of the UK and is a charity registered in Scotland (no SC040607) and in England and Wales (no 1102391) and a company limited by guarantee (4974832)

We have made every effort to ensure that the information in this magazine is up-to-date and accurate. We hope that any advice given will complement any professional advice you receive. Please do talk to your health and social care team or contact our helpline if you are worried about any aspect of living with ataxia.

## FEEDBACK

Please help us improve Ataxia Magazine by completing a short survey about this issue. You can find the survey at **www.surveymonkey.com/s/ataxiamagazine197**

## ACCESSIBILITY

If you would prefer a large print or email version of this magazine, please let us know.

## CONTACT US

We are always looking for great stories and photos for Ataxia Magazine. If you have an experience you would like to share or a topic you think we should feature, please write to the Editor at **office@ataxia.org.uk**. If you would like to reproduce any content from Ataxia Magazine, please contact the office.

# A different kind of sport

Above:
**George Ransome**

**George Ransome** wrote to us about wheelchair rugby, a sport which he's been playing since Ataxia UK helped him to get a grant from **The Headley Trust** for a new wheelchair. Conclusion? He loved it.

Below:
**The Dorset Destroyers in action**

Hi! My name is George and I was diagnosed with FA as a teenager. I have awesome parents who have always encouraged me never to give up! Having had issues since birth, I did physiotherapy from a very early age. My physiotherapist recently classified me (gave me a score of how physically able I am), and I'm nearly the lowest score.

I'd never tried a team sport until last year. A friend, Justin, had been to a **wheelchair rugby** taster day. It sounded interesting and I'd loved watching the **murder-ball** (as wheelchair rugby is known) when the Paralympics was on, so I went along to see what the deal was. It's so much fun and it has taken my fitness to the next level!

Wheelchair rugby was originally called **quad rugby** - designed by people with spinal injuries that meant they were too disabled to play wheelchair basketball. It doesn't rely on balance and the ball skills are a chance to practise (and improve!) coordination. Oh yes, I am rubbish; I'm not fast, but I'm learning. I'm 40 years old and for the first time in years I have learnt a new skill: how to catch a ball!

With the help of mum and dad and a grant from The Headley Trust I have been able to commission **Roma** to make me a custom-fit defensive chair (christened **Florence**). Florence is awesome, turns so quickly and fits me like a glove (even with scoliosis!) The adaptable measuring rig they have at Roma for fitting wheelchairs is brilliant - for the first time in 20 years I have a wheelchair that fits me properly.

Playing rugby has helped my stamina for flying no end (I fly hang gliders and paragliders and help out at **www.flyability.org.uk** - we get disabled people into hang-gliding and paragliding by reducing barriers in the flying schools). I recommend anyone with any ataxia to give it a go! I play for the **Dorset Destroyers (www.thedorsetdestroyers.co.uk)**; we train at **Rossmore Leisure Centre** near **Poole** every Sunday 11-2. Why not come down and watch people in wheelchairs smash into each other?!

Right
**George** at home herding his chickens

# Branch Updates

## Video Stars

We've been making stars out of our Friends this year, and intend to do so even more in 2017! For our **new video series**, the **Derby Support Group** invited **Steph Marley** and **Henry Amor** to join in. Along with the rest of the video series, you can see the **Ataxia Support Groups** video via our website or **YouTube** channel (**www.alturl.com/s7vsv**)

## On the buses

2017 promises a lot more public coverage of ataxia. In June, we're going down to Exeter where the **Exeter Branch** have been preparing a city-wide **Awareness Campaign**. Busily funding, planning and sharing their stories, the Branch will be splashing 'ataxia' on the backs of buses, in railway stations and all over the local media. Please give them your utmost support - they're working incredibly hard! - and keep an eye out on social media to see the progress of their campaign.

## Network chat

### Ataxia UK Branches and support groups

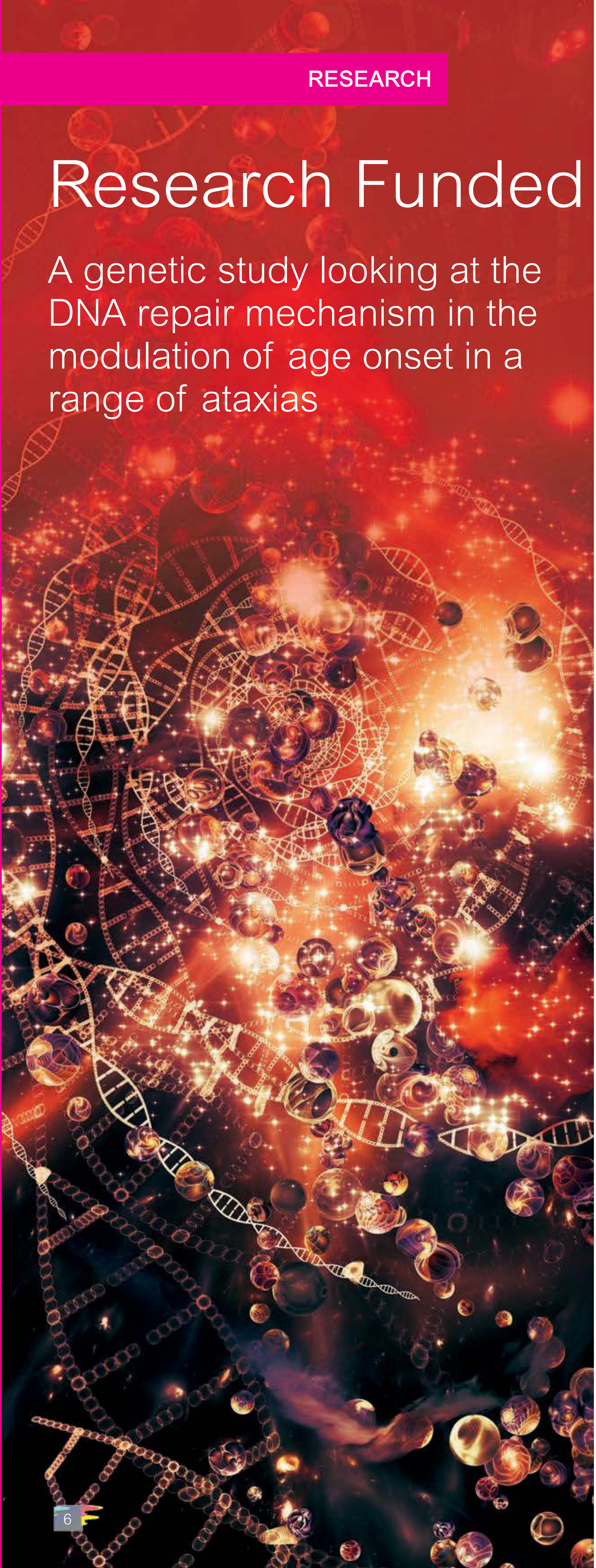
Would you like to be put in touch with your local Branch or support group, or maybe even set one up of your own? You can contact **branches@ataxia.org.uk** for more information, or call the office on **020 7582 1444**.

## Cornberg Grant

Get your application in early for the next round of the Cornberg Grant! If you need some financial help for making adaptations to your home, then visit the **Ataxia UK website** here to read about how to apply: **www.ataxia.org.uk/news/cornberg-grant1**. You can read about a recent recipient, **Barnaby Levy**, and how much the grant has helped him adapt his bathroom on page 17.

# Research Funded by Ataxia UK

## A genetic study looking at the DNA repair mechanism in the modulation of age onset in a range of ataxias



We are pleased to announce a new project led by **Dr Conceição Bettencourt** and **Prof Henry Houlden** at the **UCL Institute of Neurology**, which focuses on a group of ataxias.

These include six **spinocerebellar ataxias (SCAs)**, known as **polyglutamine** diseases, which are genetic disorders that can be transmitted from one generation to another and are caused by expansions in the genes which cause the ataxia.

All genes are made up of **nucleotides** that are held together in a chain. Each nucleotide is identified by a letter (A, T, C or G). In this group of SCAs the gene is extended because of extra copies of a series of nucleotides (identified by the letters C-A-G.)

It has been known for some time that longer coding **CAG** repeat expansions are associated with earlier disease onset. However, the difference in age at onset is not always accounted for by CAG repeat length in the DNA, which implies the existence of additional modifying factors.

A study investigating genetic modifiers in **Huntington's disease** (another polyglutamine disease caused by a similar genetic defect as these SCAs) has led to the identification of genes (acting in the DNA repair pathways) that can predispose for an earlier appearance of symptoms.

The research team at UCL has followed up this finding by looking at an independent cohort of polyglutamine diseases, including SCAs 1, 2, 3, 6, 7 and 17, and have confirmed the association of DNA repair genes with the age of onset in SCAs. With this current project, they plan to understand in more detail the molecular mechanisms behind it, with the eventual aim of finding ways of modifying the system and developing treatments.

The research team at UCL also plan to expand these findings to other ataxias (including Friedreich's ataxia, SCA8 and SCA12). Another part of the project involves working on a large number of samples from people with unidentified ataxias. As mutations in DNA repair genes are causal in some ataxias, the research team will see whether the cause of the ataxia in these patients involves the DNA repair genes.

This may lead to the identification of new genes which cause ataxia and thus specific diagnoses for patients. This project will be run by a PhD student under the co-supervision of **Dr Bettencourt** and **Prof Henry Houlden** at the Institute of Neurology and **Dr Paola Giunti** at the **London Ataxia Specialist Centre**, located in the same institute at UCL.

**Below:**
This project is being supported by the following charities:

Association Française Ataxie de Friedreich
AFAF
www.afaf.asso.fr

AISA

ATAXIA Ireland

ATAXIA
Ataxia UK

DEUTSCHE HEREDO-ATAXIE-GESELLSCHAFT

FEDAES
Federación de Ataxias de España

# Ataxia UK helps coordinate funding of **European Friedreich's ataxia** natural history study

The European Friedreich's ataxia database and natural history study is annually collecting information on FA patients to document the progression of the condition. Initially this large multi-site project, called **EFACTS**, was funded by a grant from the **European Commission** but, when that grant ended, the researchers turned to patient groups to help continue its funding.

**Euroataxia**, the umbrella organisation of ataxia charities in Europe, has under the direction of Ataxia UK coordinated a joint-funding effort. We are pleased to announce that six charities, including Ataxia UK, have agreed on the benefits of this project and are now co-funding it. In addition, one pharmaceutical company is also providing funding and the lead EFACTS researcher, along with Ataxia UK, is in talks with other companies to look at partnership opportunities.

This illustrates how the importance of this project is recognised by clinical researchers within universities (who are running this project), as well as by researchers in the industry who are planning FA trials and need the information gathered from this study to help them.

**Success so far:** there are currently around 750 people with FA taking part in this project, with a large proportion of these being from the UK site at the **London Ataxia Centre**, which is under the direction of **Dr Paola Giunti**.

There are also multiple sites in Germany, Austria, Belgium, Italy, France, Spain, Ireland and Greece. Some of the sites are new, extending the geographic coverage of the network, but they also include paediatric centres to increase the number of children involved.

Information gathered in this project to date (baseline and 2-year follow-up) has been published in two papers in the eminent medical journal **Lancet Neurology**.

Importantly, the information gained is also being used in order to help design trials. For example, the planned **nicotinamide** trial is relying heavily on the information gained in this project.

The lead researcher on this project, **Professor Massimo Pandolfo** from the **Université Libre de Bruxelles** says: 'We are delighted that many patient groups are coming together to help us take this important project forward. The data being generated is helping us design better trials in order to find effective treatments for Friedreich's ataxia.'

**Taking part:** The **London Ataxia Centre** is continually recruiting more participants to this study. If you are an adult with FA, and are interested in learning more or taking part, more information is available on the Ataxia UK website.

## Thank you

We would like to send our special thanks and condolences to **Simon Thornton's family**. Simon had Friedreich's ataxia and sadly passed away in March 2016. He had generously arranged to donate his brain and spinal cord to the **Brain Bank** in **Cambridge** in aid of ataxia research. As well as being extremely proud of Simon for helping others, **Jenny Skinner**, Simon's mother, and **Mihoko**, his wife, were very pleased by how well the process was managed.

These donations are extremely valuable to ataxia research - foremost because they are so rare: Simon is one of very few people who have made such a donation towards FA research, and has enabled us to move closer towards finding a cure. If you would like to read more about the opportunities to make a brain and spinal cord donation to ataxia research, you can read more about it in the 195 issue of the Ataxia magazine, which can be accessed online here: **www.ataxia.org.uk/news/ataxia-magazine-195** page 7.

## European partnerships in clinical trial conference

Last November, our **Research Officer Dr Julie Vallortigara** attended the **European Partnerships in Clinical Trials (PCT)** conference held in **Vienna**. PCT is an annual meeting which aims to get all partners of clinical trials together to discuss future developments, challenges and results of clinical research studies, and in this context to re-emphasise the importance of partnerships. Ataxia UK was invited to take part in a panel discussion about rare and orphan diseases, with the need to move away from traditional drug development while putting the patient first. Julie Vallortigara, together with four other representatives of organisations focusing on rare diseases, discussed the challenges in running clinical studies for patients with a rare condition. They looked at the need to involve these patients at a very early stage of such studies to ensure that the design, protocol and outcomes measures are adapted and relevant, in order to run more successful trials. The panel discussion was well received and led to interesting questions; it was very important to get the voice of patients with a rare condition heard in a large conference on trials such as PCT.

As part of the PCT conference, Ataxia UK got the opportunity to host a webinar entitled **'Involving patients and patients groups in clinical research'**. The webinar was a precursor to the **'Partnerships in Clinical trials' (PCT)** conference and took place in our offices in October 2016. **Ataxia UK member and Trustee Richard Brown** took part in this, as well as the **Clinical Geneticist of the Oxford clinic, Dr Andrea Nemeth**. The webinar was recorded and can be re-watched here: **www.alturl.com/g9paz**.

Also, Ataxia UK was able to make a film highlighting the functions of the ataxia centres. This video focuses on the **Specialist Ataxia Clinic** in **London**, a centre combining cutting-edge research with a patient-centric approach, to care for those affected by the disorder. The video is now up on YouTube here: **alturl.com/ehwkt** and has been disseminated widely by the agency organising the conference; you can read a blog post here: **www.alturl.com/rgruf**.

## Results of ataxia trials:

### Promising results of SCA3 pilot trial

The biotechnology company **Bioblast Pharma Ltd**. announced in January the results of a six-month, open-label, **Phase 2a trial**, which investigated **trehalose** in patients with **Spinocerebellar Ataxia Type 3 (SCA3)**. The objectives of the study were to establish safety and tolerability of two doses of trehalose, as well as to assess the effect of the drug on reducing the rate of clinical decline. This open-label study evaluated 14 SCA3 patients over a six-month period receiving two different doses of the drug intravenously. Investigators and patients were blinded to the dose administered. They found that the drug was safe and well-tolerated and that patients remained stable over the six-month period with no change on the **Scale for Assessment and Rating of Ataxia (SARA)** score (the commonly used clinical tool for measuring the effect of the condition). There was an extension of the study and five patients received treatment for as long as 12 months and continued to remain stable on the SARA scale. This suggests that the drug might stabilise progression of the condition, as you would expect the SARA scale to get slowly worse over time; however further trials are now needed to see if this is really the case.

**Below:**
**Dr Julie Vallortigara**
(2nd from right)
is part of the panel
discussion on rare
diseases

**Bioblast** has a patent for this drug to be used in SCA3 and they also received orphan drug designation for use in the US and Europe. The rationale for using this drug is that it was shown to reduce the number of toxic protein aggregates, which are thought to cause the condition. This research was presented at our **International Ataxia Research conference** in 2015 (see Ataxia magazine 190).

## Interferon gamma trial 1b trial results in FA

**Horizon Pharma's Phase 3 clinical trial, STEADFAST**, evaluating **ACTIMMUNE (interferon gamma 1b)** for Friedreich's ataxia, unfortunately did not meet its primary endpoint. In addition, the secondary endpoints did not meet statistical significance. This was a placebo-controlled, six-month trial that took place in the US, with the primary endpoint being the effect of ACTIMMUNE versus placebo, on the change from baseline to Week 26 in the modified **Friedreich's Ataxia Rating Scale** (FARS-mNeuro, a rating scale that measures coordination of movements). Further analysis of other data collected is currently on-going in order to help inform future research efforts, as well as future data presentation or publication. We will keep you updated as more information becomes available.

## Cost of care and healthcare savings - developing Ataxia UK's collaboration with **Findacure**

**Below: Annabel Griffiths (Costello Medical Consulting)** presenting the research at **ISPOR conference**

Last year Ataxia UK started a partnership with Findacure, a charity focusing on getting treatments into use for rare diseases, that has developed a **social impact bond (SIB)** model to fund clinical trials using repurposed drugs. This model aims to pay for the cost of successful trials, using the money that effective low cost treatments could save the NHS.

Following the success of the pilot trial in FA using **nicotinamide**, Ataxia UK has been working on an application for a larger trial, to be funded using the Findacure SIB. We were delighted that following evaluation by **Findacure's Scientific Committee**, they decided to choose Ataxia UK's project as one of three to test their model. In this context we have been supporting them in working on a cost of illness model for FA, in order to build a case to put to NHS England. More information on this model can be read on **www.findacure.org.uk/drug-repurposing**.

For the economic side of the model, Findacure is working in collaboration with a medical consultancy called **Costello Medical Consulting**. The project was discussed at **Ataxia UK's Medical Advisory Panel** meeting, where both Findacure and Costello were invited to join and present the model. We also hosted a meeting with Friends affected by FA and Findacure to discuss the challenges, costs and the impact of ataxia, the current treatment options, and the design of future trials. This workshop has allowed Findacure to collect very useful and relevant data to build a solid model for FA, and to evaluate the benefits that a treatment could have for patients living with the condition. Ataxia UK is very grateful for those who attended and helped us. This workshop has led to the production of a report made by **Rick Thompson (Head of Research at Findacure)**. This report is available to you on request - please visit **www.findacure.org.uk/resources** to download it.

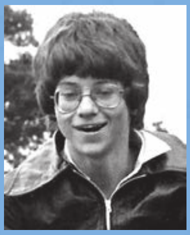
We will keep you informed of any progress made on this project and funding of the trial. Other options for funding are also being explored by researchers. However, this partnership is already producing relevant outcomes. Indeed, we were pleased to see the study of cost of illness of FA being presented at the **International Society of Pharmacoeconomics and Outcomes (ISPOR)** last November in Vienna, by the Costello Medical Consulting team. The ISPOR conference is seen as one of the largest conferences in this field and it was great to get some coverage there. There is also a plan to get this study published in a journal, expanding the reach of this important research. Ataxia UK acknowledges the importance of good collaborations and the benefit of working with helpful and dedicated organisations.

## Summary of Ataxia Medical Guidelines for GPs

Having recently published the third edition of the **Ataxia Medical Guidelines**, we are pleased to announce that we now also have a summary document aimed at GPs. We have worked with the editors of the online publication 'Guidelines' to produce this summary aimed at primary care, which they have publicised amongst their extensive readership in primary care. You may find it helpful to inform your GP of this new publication which can be downloaded from our website.

# The 16-30's Summer Spin-Off

If you have ataxia and are between 16-30 years old, then you're formally invited to our Summer event!



**Above:**
**Mark Dower**

**The Mark Dower Trust** and Ataxia UK have teamed up to bring you a break-away weekend. Start the Summer by meeting old friends and making some new ones!

Mark Dower was a man who lived as independently as he could whilst having Friedreich's ataxia. In his memory, sister **Alison Halls** has created the Mark Dower Trust, which gives grants to support young adults with ataxia who're aiming to increase their independence (eg. studying at university).You can hear more about the Trust at the weekend from Alison herself.

There is also an opportunity for you to take part in a **Q&A** with **James Downie**: 42, husband, father and career man who has FA. If you have any worries about the future, or are wondering how to best make ataxia work with you, then why not ask a man who has done it all already? We will be taking your questions (anonymously if you wish) in advance of the weekend, and you'll be able to hear his replies during the event.

James works with young people and has personal experience of living with FA; no question is off-limits, so why not make the most of this opportunity? Keep a look out on the 16-30's website and Facebook page to hear how to get involved.

As well as other activities, good food and some general socialising, we also want to use this weekend to plan ahead; the 16-30's project belongs to you: we want to hear your thoughts and help us to shape its future. If you have ideas and hopes for the project, this is your opportunity to share them with us.

# Opening up: ataxia and mental health

**Above and Below: Beverley Vickery** (left) and her best friend

**Beverley Vickery** talks to Ataxia UK about the depression she experienced after her SCA6 diagnosis, and how counselling has helped her to reach the healthier state of mind she has today. *Please be aware that this article contains some difficult topics.*

My name is Beverley, or Bev. I live in Gravesend, Kent with my husband, three hormonal teenage boys, and my West Highland Terrier, **Reg**. I'm 52 and was diagnosed with SCA6 about four years ago. Until recently, I was a care home manager for a disability charity, but I lost my job after 15 years because they wouldn't make any more reasonable adjustments for my needs.

Before my ataxia began to affect me, I had an active life of work, socialising, walking my dog and dancing - God, I loved to dance! The onset of my symptoms was gradual; I suffered from complications following some surgery and after a genetic test, I was diagnosed with hereditary SCA6. My Mum has lived with the same condition for years, but her GP misdiagnosed her with vertigo. She doesn't want to make a fuss though, and is happy to believe it!

Since then, I've struggled with severe depression. I've been admitted to a psychiatric hospital twice because I couldn't come to terms with my ataxia. It felt like the illness had taken my life away and everything that I enjoyed.

I've even struggled with my family, putting them through hell and back - heavy drinking, terrible mood swings … I even attempted suicide - something I feel very ashamed of.

However, things have got better. I was lucky enough to be referred for counselling through the mental healthcare system, which helped me immensely. My counsellor enabled me to look at my condition differently and encouraged me to start writing my feelings down a couple of times a week. Although I feel I'll never come to terms with my ataxia, counselling has helped me to gradually understand that even though I'm the same person, some things are different; I have to do things differently; that was then, and this is now.

My experience has been like a grieving process. Even though I still have the odd meltdown, I am managing better now. I recently went on holiday with my best friend to New Orleans, Memphis and Nashville! We visited Graceland and took a paddle steamer on the Mississippi. Yes, every day was hard, but I did it. I do what I can when I can and get help when I have to. Next year it's Route 66 for my silver wedding anniversary!

I'm far more relaxed about everything now. Counselling, using forums like **Heath Unlocked** and Ataxia UK have helped me immensely, and I would advocate all of the above for anyone who is struggling. My motto is: **I have ataxia; it doesn't have me!**

# Dates for your diary

Some exciting and nature-filled opportunities for fund-and-awareness -raising are on the calendar this year. Keep an eye on the website, or give us a call at the Head Office, to read more and book your place!

## City PARKS Challenge 2017

It seems like only yesterday that 100 ambassadors for ataxia descended upon the streets and bridges of London to take part in the **2016 City Bridges Challenge**. The day was a huge success and we're delighted to announce the return of the event … but this time with a twist! We welcome a new theme this year: the bridges are out (well, most of them anyway) and the parks are in! This time around we'll be starting near **Kensington Palace** and zig-zagging our way through as many parks as possible, before finishing once again at the wonderful **Oxo Tower**. The route and date of the event are still being finalised, but keep your eyes and ears open for updates over the coming months.

## The Ataxia UK Annual Raffle

Ataxia UK are delighted to announce that the **Annual Raffle** is back this spring. With this magazine you'll find some tickets included: please sell as many as you can to friends, families and loved ones. There are many wonderful prizes on offer and all ticket sales will help support our work. We hope you'll take part!

## Freemasons

We are hoping to make an application for funding to the **Masonic Charitable Foundation**, and it would really strengthen our bid if we were able to tell them how many masons and their families have ataxia. If you have any connections with freemasonry, do let us know. Any information supplied will be strictly confidential.

## Back to the Downs

The annual **Ataxia Spring Classic** (below) is one of the fundraising highlights of Ataxia UK's year, and it's fast approaching on 14th May. Enjoy the beautiful views over the South Downs and help to raise money for Ataxia UK by joining **Andrew Downie** and the **South Downs Branch** for a brilliant day out. There are two routes to choose from: 11 miles or 65 miles to suit your needs or preferences.

Entry is only £20 for adults and £10 for kids; refreshments along the route, clearly-signed routes and maps will be provided. The fundraising target for adults is (at least) £100, and all proceeds will go straight to Ataxia UK.

You can read more about the event and success stories from previous years at **www.ataxiaspringclassic.co.uk**.

There are only 70 places on offer and it's first come, first served, so let Andrew know that you're interested via **andy@downies.plus.com**. Hope to see you there!

# Meet our Marathon Runners!

Here are our **London Marathon** runners who have won **Golden Bond** places this year. We also have several other fantastic people running the marathon for us, who have secured their places, and we want to thank all of them for taking on this amazing challenge. Good luck everyone!

### Hello Molly

**Molly Grange**, a 22-year-old student in Brighton, is running the marathon for her best friend **Holly**, who has Friedreich's ataxia. She is preparing through a 17-week training plan and by reciting motivational quotes. We asked Molly about the biggest challenge she has faced in preparation for the marathon. She said that her 'mind set is so important; being able to get my head in the right place is the biggest challenge - but I feel like I'm there now!' Good luck Molly!

### Hello Izzi

Mum of two, **Izzi Stainton**, can tick the London Marathon off her bucket list this year as she has received a place to run for Ataxia UK. Ataxia is something close to Izzi's heart; her mother was diagnosed seven years ago and unfortunately her condition has rapidly deteriorated over the past year. Izzi has already hit her fundraising target - over £5,000 already - and is hoping to finish the marathon in less than four hours.

### Hello Gosia

The 2017 London Marathon will be **Gosia Brothers**' fourth marathon! She wants the money she has raised to go towards raising awareness of and finding a cure for ataxia. She is familiar with ataxia as her brother is a scientist working in the field; she also has a friend who has the condition. She is hoping to beat her personal best of 3:59:23 this time round - you can do it Gosia!

### Hello David

**David Gothard** has a family history of ataxia and, unlike our other runners, has the condition himself. As such, David is the ataxia community's representative for this marathon! This is his second marathon and we're sure he's going to smash it. David has previously raised money for lots of different causes, but as the condition has made a massive impact on his family life (as well as on his own), David has chosen to run for Ataxia UK this year.

### Hello Rob

**Rob Wilkins** has completed many events over the years and has raised over a whopping £12,000 in total for Ataxia UK! This time he's back to take on the challenge of the London Marathon. Rob has chosen to complete this event for his close family friend, **Sophie**, who has Friedreich's ataxia. As Sophie's condition is worsening, he wants to raise her spirits whilst raising awareness of the condition.

### Hello Charlotte

**Charlotte Geen** is a **Project Support Associate** from **Medical Research Network**, who made us their **Charity of the Year** in 2016. Charlotte will be running her third **London Marathon** this year. Charlotte has a personal connection with ataxia as her close friend **Sasha** has the disorder. Having already completed a half marathon in January and currently running with **Milton Keynes Lakeside Runners**, we believe Charlotte is well on her way to beating her personal best of 4 hours and 40 seconds. She is planning to fundraise for the event by organising a race night with a casino theme - sounds exciting!

# Fundraising Updates

The holiday season hasn't slowed down our Ataxia UK fundraisers, who have been working overtime on some pretty spectacular fundraising events. A massive thank you to everybody who has fundraised for us over the past few months!

Essex-based blogger **Michelle Beagan** (top left) teamed up with her local **GAA** football team back home in Northern Ireland to arrange a festive fundraiser for Ataxia UK. The team donned Christmas outfits (left) and doled out festive cheer on the streets of **Roslea**, managing to raise an absolutely incredible £3,850! A huge thank you to Michelle, her family and everybody involved with **Roslea Shamrocks GFC**. Megan also works tirelessly to raise awareness of ataxia through her blog and twitter (**www.twitter.com/mrooney84**), which has won her a monthly writing column in her local newspaper: why not give it a read and help spread the word to your friends and family.

**Val Nailor** (left) decided to take her fundraising onto an international scale by cycling from **Ho Chi Minh City** in **Vietnam** all the way to **Angkor Wat** in **Cambodia**! That's a 400km journey through cities, over rivers and up and over countless hills that brought in over £2,200 for Ataxia UK. Well done on such a fantastic effort, Val!

**Joanna McCool**'s yearly **Halloween** fundraiser (right) in aid of Ataxia UK was another huge success. Not only was it a fun-filled evening but a fantastic £1,245 was raised through the event. Thanks Joanna and everybody who attended; now just take a minute to appreciate all of those incredible costumes!

The **NCS Autumn Team 2** did all sorts of fundraising events throughout the winter months. The team held a car boot sale, they walked dogs and they even spent two days bouncing tirelessly on trampolines, all to raise awareness and money for Ataxia UK. The group managed to raise a wonderful £578.30. Thanks for all the hard work!

The **Farnham support group** teamed up with local football side **Ash United** to organise a charity football match. **Ataxia UK's Fundraising Officer Henry Amor** attended the event to help raise awareness of the support which the charity offers. **A side** from the army took on **Ash United** in a thrilling night that ended with a whopping £1,152 being raised for Ataxia UK. A huge thank you to the army, Ash United, **Brian Paskins** and **Derek Wood**, as well as **Friends of the Farnham Support Group** (some of whom are donning the front cover!)

A huge thank you to **Cherry Lodge Golf Club** and **Ladies Captain Margaret White** for raising a total of £1,500 for Ataxia UK. Margaret arranged a ladies golf day followed by a number of games and challenges. Congratulations on such a successful day!

For the last 17 years **Ali Green** (51), **'The Wobbly Drummer'** (left), has been performing the drums in various bands across **Berkshire**. She was diagnosed with late-onset cerebella ataxia last March, and since then, a lack of strength and fatigue have been her biggest hurdles: 'As a surprise, because I was feeling a bit low, my lovely husband contacted my old band and asked if they could organise a one-night-only reunion!' And they did! Ali and her band, **Deju**, performed live at the **Bell & Bottle** in **Reading** in November. Ali's friends used the opportunity to raise money for Ataxia UK. Ali and her friends raised £131 but, more importantly perhaps, also raised Ali's morale. Thank you for your support, Deju!

In February 2016 **Dominique** (left) set herself the challenge of running a half marathon and cycling the **Ataxia Spring Classic** and **London-Brighton** bike rides. A massive challenge for a full time mum and air hostess. Dominique's hard work in completing all three challenges has so far raised over £600. Well done Dominique!

Thank you to **Bob Collard**, **Nathan Freeman** and everybody involved with **Walmley Social Club** (left) for making Ataxia UK a beneficiary of their fundraising events! **Susan Deane** of the **Birmingham Support Group** went along to a presentation evening to collect a £500 cheque on behalf of Ataxia UK. Thanks a lot guys!

## Christmas Appeal 2016

Thank you to everyone who generously donated to our **2016 Christmas Appeal**.

We've received a wonderful £7,286 so far, and look forward to putting it to good use!

## Chance to Win winners!

Congrats to our winners this quarter! If you want a chance to win, set up a monthly direct debit with the charity for just £2 per month to enter the draw.

1st. £250. **Barry Luscombe**

2nd. £150. **Elizabeth Heather**

3rd. £100. **Barbara Grover**

# Adapting to life

by Matthew Law

## Amazon Echo

In this issue I have been asked to write about a resource that has proved helpful in my everyday life. On clarification of the word ‘resource’, it became obvious that the device I got for Christmas from my sister would fit the bill perfectly.

I saw the adverts for this device on TV just before Christmas. I have already made slight changes to the way I live my life because this little device has made many things much easier for me.

It is called an **Amazon Echo**. It is a small cylindrical box that looks a lot like a black speaker. It is constantly plugged into the mains, takes little more than ten minutes to set up and now lives next to my television in my bedroom.

The Amazon Echo is simply a voice recognition device that responds to voice commands that you make. It has a name: **Alexa**. Alexa uses your Wi-Fi to access the internet without you even realising that it’s doing it. I am now using voice recognition software on my computer much more frequently, as typing on a keyboard is becoming far too frustrating and time-consuming for me - so I do know what voice recognition is all about. It is still a complete mystery how it works though.

When you say Alexa’s name, the top circumference rim turns blue which means that it’s listening to you. Its most important use, for me anyway, is to use Alexa as a clock radio so she can wake you up each morning and can switch on your desired radio programme. On many occasions I have climbed into bed and then realised that my clock is not set for the right time. I then have to get out of bed, back into my chair and press the fiddly buttons on my radio alarm clock to set the right alarm time before getting back into bed. This would probably take me about 15 minutes. With Alexa in your room, however, all you have to do is say: ‘Alexa, set my alarm for 8am’ and it’s done. At 8am you are duly woken up and you simply say ‘Alexa, stop’ [the alarm] then ‘Alexa, play Radio 2’ and it does just that without you having to lift a finger, which for people who have ataxia is very useful indeed.

This just scratches the surface of the things the Amazon Echo can do. I will briefly list some of the other things that I have found useful - it can tell you all the distances between places in this country; convert distances and currencies; keep your diary, shopping list and ‘to-do’ list up to date*; play any song that you ask it to play** or any radio station. I also know that if I had ‘hive’ (a device which is controlled by Wi-Fi, too), I could control the temperature or light bulbs in my house merely by talking to Alexa. Of course the first question I asked it was ‘Who is top of the Premier league?’ (as a devout Chelsea fan) and it knew that too (and how many points we had!).

Please be aware that I know of one person with ataxia whose voice cannot be interpreted by Alexa. This is not to say that your voice will not be detected by Alexa, but just to put you in the picture.

It’s probably the best Christmas present I have ever had.

**Alexa app or website is recommended to view all diary/lists **Dependent on the artists’ copyright authority*

**Matthew Law (matthewlaw1968@yahoo.co.uk)**

# The Final Jerry Farr Fellowship

After ten years the **Jerry Farr Travel Fellowship** enters its final year. We take a look back at the man who inspired the grant, and the difference it has made to people with ataxia who have had the desire to travel.

Don't miss out on your last chance to apply!

Inspiring travel adventures have been undertaken by people with ataxia due to the generosity of spirit embodied in the Jerry Farr Travel Fellowship. Jerry was diagnosed with Friedreich's ataxia aged nine and despite the condition he was an energetic, loving and positive influence on all who met him. He travelled extensively throughout countries as diverse as **Brazil**, **China** and **Australia**, making many friends along the way. During these globe-trotting escapades he **white-water rafted**, **para-glided** and even experienced the nerve-shredding thrill of a **bungee-jump** in **New Zealand**.

So inspirational were Jerry's exploits that, when he passed away in 2007, his friends and family set up a fund in his honour to enable other people with ataxia to undertake the life-affirming experiences Jerry had on his travels. So far the grant has been awarded to eight individuals who have been able to participate in activities such as **swimming with dolphins** in **New Zealand**, **rainforest treks**, and **snorkelling** in the **Great Barrier Reef**!

The Jerry Farr Travel Fellowship is now in its final year, so we are looking for a great travel proposal to enable us to grant the award. We're looking for a person with ataxia seeking to broaden their horizons and exemplify the passionate spirit of discovery that Jerry personified, despite the perceived constraints of his disability.

The proposal should outline challenges that push the boundaries of what you may have previously thought possible and also detail what you hope to gain from what will be a life-enhancing experience.

You can apply via the form on the website at **www.ataxia.org.uk/news/jerry-farr-travel-fellowship**

Be careful not to miss the deadline which is approaching fast on **June 12th**.

## A new bathroom for Barnaby

**Barnaby Levy** (left) was awarded the **Cornberg Grant** of £10,000 from Ataxia UK last year to help him adapt his house for easier living. Barnaby, a former **Communications Officer** of **Ataxia UK**, long-term **Friend** and fundraiser for us, was diagnosed with SCA6 in 2006. It took a while, but now his wonderful adapted bathroom is finally complete! If you'd like some financial assistance in adapting your home, you can read about, and apply for the Cornberg Grant, on the Ataxia UK website here: **www.ataxia.org.uk/news/cornberg-grant1**

# People’s parking

## Supporting drivers with accessibility requirements

Ataxia UK welcomes a new accreditation scheme for car parks called People’s Parking. The brain-child of **Helen Dolphin MBE**, the scheme allows a driver to ascertain and find car parks which cater to their needs even before they travel.

Helen Dolphin (left, seated) is a disabled businesswoman who was tired with car parks which felt unsafe, lacked facilities or didn’t meet her needs. Her new enterprise aims to drive up the quality of car parks for everyone by having a list of accreditations which are aligned to the **Equality Act 2010**, and are awarded to those car parks which fulfil certain criteria. Some general accreditations which People’s Parking acknowledges are whether a car park:

- **is safely-lit;**
- **has safe pedestrian access, including well-marked routes to facilities;**
- **has good signage (e.g. for specialist bays, lifts and payment machines);**
- **has designated bays which are reserved for the users they were designed for.**

There are also extra accreditations which are awarded to car parks which:

- **are accessible for disabled people;**
- **are family-friendly, with wide spaces for buggies;**
- **feature charging points for electric vehicles;**
- **offer a pre-booking service.**

By using the People’s Parking website (**www.peoplesparking.org**), a driver can search for a car park which fulfils any combination or number of requirements. It also gives car parks which do make the effort to be inclusive, safe and well-managed the opportunity to promote their efforts, giving an incentive for other car parks to partake in the scheme.

Why not try out Helen’s scheme, and let us know how it worked for you?

# Spotted

A friend of ours in Sweden recently got in touch to shout about the **SpillNot**, a mug holder which doesn't spill no matter how it's used.

An excellent discovery, says **Sofie Trellman**, who purchased one for herself and her brother for Christmas, as they both have SCA3. You can use the SpillNot to transport hot beverages from kitchen to living room without spilling a drop. You can find it on Amazon here: **alturl.com/mbf4b**. Thanks for the heads up, Sofie!

# Holidays with Linda

As Spring comes round again, **Noel McCann** remembers his wife **Linda**, who had FA, and the accessible holidays they used to enjoy right here in the UK.

My wife, Linda, was diagnosed with Friedreich's ataxia when she was 16; by 24 she was pregnant with our daughter **Kelly** and by 26 she was permanently in a wheelchair. Our naivety about the condition was our help, I think, as we didn't know what to expect, so we just took each day by the scruff of the neck and shook the hell out of it. We had wonderful holidays abroad whilst airline travel was easy; we visited **Italy**, **Portugal**, **Spain**, **America** and **Corfu**; but eventually flying became more a trial more than a pleasure, so we decided to try camping in the UK.

**Devon** and **Cornwall** were our usual destinations. We loved the outdoors and the freedom those holidays allowed us: no time restrictions, no distance limitations, just enjoyment and fun. From the tent we progressed to a **folding caravan** that was pure heaven compared to beneath the canvas: a camping environment where you didn't wake up in damp clothes with a hedgehog trying to share your sleeping bag! We towed it all around the country using **Caravan Club** sites (**www.caravanclub.co.uk**) for their excellent amenities, which are very accessible.

After five years of the folder we tried hotel holidays, but they were hit and miss; the accommodation wasn't always as described. 'Lovely wide doorways and adapted bathroom,' the pages would shout, but there was no mention of the half-dozen steps up to the entrance! We took things like that in our stride because Linda just loved to be away. She never let FA get in the way of enjoying life and it did not define her as a person. As age and Linda's condition began to impact on us, our last adventures were undertaken in **motorhomes**, and this is where we felt the most comfortable. Self-contained living on wheels with glorious sunsets outside of your windscreen; snug warmth in the winter and your best buddy to share it with: perfect.

Linda McCann was my wife, my lover, my advisor and my confidant. I miss her greatly. Some days were hard work, I know, but the reward was so much worth it. Linda loved our holidays and I shall miss sharing them with her, but you can't leave your dreams on the shelf: take them off and use them - Linda did.

**Linda McCann September 1955 - May 2016**

**Above:**
**Linda** and her folding caravan

**Right:**
**Linda** and **Noel** on holiday in the Isle of Wight with their daughter and son-in-law

# Thank you to everyone who has given a donation in memory of a loved one

Leaving a legacy
is one of the most enduring ways
to make an impact

Much of our research
has been made possible
by the foresight and generosity
of our Friends and supporters
who have remembered our work
when making their will

We currently have more than
20 research projects underway,
all of which are funded,
at least in part,
by gifts left to us

**Your legacy can be hope for the future**