

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 199. Autumn 2017

Here come the suds!

Taking on the Gauntlet Games



ATAXIA
2020 VISION

Ataxia people • Raising awareness • Research
Annual Conference • Health & wellbeing • Fundraising
Adaptations • Living with ataxia

ATAXIA

Ataxia UK

In the office



Dom Joly: our new patron!

Dom Joly is a multi-award winning television comedian, journalist and travel writer. Since a close family friend was diagnosed with Friedreich's ataxia in 2017, Dom has lent his support to Ataxia UK as **our new patron**. Dom is best known for his hit series *Trigger Happy TV*, a larger-than-life hidden camera show which received critical acclaim and went on to be sold to over 70 countries worldwide. He's written columns for a number of broadsheets and tabloids throughout his career, including a 15-year stint as a columnist at the Independent, and now writes a weekly column for the Metro. He has a variety of exciting current and upcoming projects, including a new series of *Trigger Happy TV*. Dom has expressed a hope to help raise awareness of ataxia, and we couldn't be more thrilled to work with him!



Henry Amor

We wish all the best to our **Fundraising Officer Henry Amor**, as he steps up to become a Fundraising Manager for a new charity that works with musicians and mental health, something that has always been close to his heart. Henry came into Ataxia UK like a whirlwind, making strong connections with support groups and Branches across the Ataxia UK network, and we'll miss him! Goodbye, Henry!

Welcome

What a fantastic summer it's been for so far for Ataxia UK.

Every year we're grateful for the generosity, time and determined dedication of our fantastic fundraisers in organising summertime events, and they've excelled themselves this year: read about what they've been getting up to on p.14.

I must also say a big thank you to **our support groups and Branches**, who have been working hard at raising funds (p. 13) and to get the word 'ataxia' out on the streets.

Market research done after our **South West Branch's** month-long awareness campaign in Exeter shows that their hard work has made a huge difference to local awareness (p.6).

We look now to the autumn ahead and with our **International Ataxia Research Conference** in Pisa, Italy, the **Westminster Parks Challenge** (p.12)

and **Annual Conference** on 20-21 October (p.10) there's plenty going on. Make sure to check the upcoming deadlines for Conference booking and arrangements.

We're taking suggestions for recipients of the **Cup and Shield awards**, which will be announced at the Conference. Who do you think has made a wonderful contribution to Ataxia UK over the years? Read p.10 to find out how to nominate them.

You'll find a ballot paper for our Trustee elections with this issue. Please vote for who you think should help govern your charity, and return it to us via the instructions given on the form.

Thank you for your continuing generosity. We can only support people affected by ataxia and look for treatments and cures with your help!

Regards

Sue Millman. CEO



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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.

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Ataxia people

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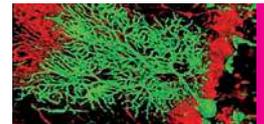
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Living with ataxia

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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/ataxiomagazine199

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.

Attacking it back

Ant Brown is the **co-chair** of Ataxia UK's **South West Branch**. He's recently presented to over 60 healthcare and medical professionals from across the South West to share with them how ataxia affects his everyday life.

Hi, my name is Anthony Brown, Ant to my friends! I was diagnosed with Friedreich's ataxia back when the earth was considered flat, and a full English was a nutritious way to start the day - well, it seems that long ago! It was in 1990. I was 13; the internet wasn't widely available; mobile phone design hadn't evolved beyond being the size of a house-brick, and more importantly, people newly diagnosed with ataxia had virtually no access to information about their condition.

Which is why I felt the opportunity to address a medical conference on ataxia during June's **Awareness Campaign** in **Exeter** was too good to turn down. I was tasked with trying to present a different side of ataxia, one that wasn't in the text books: namely, my experiences living with

a debilitating condition. Bear in mind the room was full of neurologists, GP's and physio's, and whilst they knew a little bit about ataxia - what was in their dictionaries - they knew nothing about **what it meant to live with ataxia**; the daily struggle of living with a crumbling body, the heartbreak of watching friends and loved ones fighting a battle they can never win; most crucially, the frustration of having a condition that the medical profession simply doesn't know enough about.

As a young teen diagnosed with ataxia, I was given no information about ataxia or how to live with it - doctors simply had no awareness of it. It affected absolutely everything in my life at the time: my studies, forming friendships with people (ataxia can make you very introverted), forming physical relationships and, crucially, what I wanted and expected from myself in the future. I guess it's a similar story for a lot of people with ataxia. Ataxia invariably takes these and many similar options away, forcing you to re-shape your life.

Knowing that my hopes and dreams were always going to be restricted by my physical limitations, I tried to find a pursuit that could be achieved with or without ataxia. After attending university later in life, I found I was good at - and, more importantly, enjoyed - writing. I have written a few plays for the stage and radio, and while I am not, or probably never will be, a raging success, I get simple enjoyment from it. What finer thing is there for anybody, someone with ataxia or not, to do with their life than simply enjoy it!

So, next time you are given the opportunity to parade in front of a gaggle (what is the collective term for a group of med students? 'A confusion' maybe?) of medical students, or scarily speak to a room full of doctors, don't think twice, because raising awareness of ataxia for the next generation of sufferers is perhaps the noblest thing anyone with ataxia can do. Maybe you can't cure ataxia on your own, but by raising awareness in the relevant places, you can ease the transition for the next generation.





Professorship for Paola Giunti

We're pleased to announce that **Dr Paola Giunti** has been awarded a **Professorship** by the **UCL Institute of Neurology**. The internationally renowned ataxia expert and former winner of the **European Health Professional of the year award**, has worked with Ataxia UK for many years and has run a specialist ataxia clinic since 2005. Congratulations Professor Giunti!



New look

You will have noticed by now that our website has been revamped and given a fresh new layout. We have done this to make it easier for people to navigate their way around the site to find the resources and advice they need. We're always trying to improve how we interact with our supporters and those who are new to the ataxia community. Please let us know what you think.



New support group in Preston

A warm welcome to the new Ataxia UK support group in **Preston** which had its first meeting in late July. **Arran Rigney**, a newcomer to Ataxia UK, has taken the bull by the horns to begin this group; if you live in the Preston area and would like to grab those bull's horns too, get in touch with Arran at info@arraneleanorcreative.com or by emailing the office at office@ataxia.org.uk to request to join!



Going Farr to South Africa

Congratulations to the winner of this year's **Jerry Farr Travel Fellowship, Aila Figura!** Aila is a keen photographer but since her studies came to an end, she hasn't had the opportunity to continue her craft.

Thanks to winning the award, Aila is now able to go to South Africa with **Access 2 Africa Safaris** where she intends to create a new wildlife photography portfolio.

Aila's choice of destination is particularly fitting for the last Jerry Farr award, as it was Jerry Farr's own trip to the country that inspired the Farr family to put together the award in his memory and help people with ataxia experience world travel.

"I just wanted to say thank you very much to the Farr family for awarding me the Jerry Farr travel grant," says Aila.

"This has given me an opportunity to do something I wouldn't have been able to do otherwise. I will make the most of the experience, not just for my sake but in memory of Jerry Farr."

Aila travels with her mother next May - we look forward to hearing about her experience upon her return!



On Tuesday 20 June, **The Old Vic** held a reading of **Exceptional Mercy**, a play in development and written by **Rebecca Crookshank** which centres on the real-life story of a man with Friedreich's ataxia, named in the play as Jay Ricardo-Marsh.

The production focuses on Jay's close relationship with his mother, Eva, and his carer, Arash, following Jay's arrest for drug-smuggling. The unflinching portrayal of Jay's struggles with ataxia whilst he's in detention for his crime and the physical challenges he deals with are underpinned by a warm but rambunctious relationship with Arash. The bleaker moments of the reading were balanced by high-spirited language and a terrific performance from the ensemble cast, with **Josie Lawrence** in particular excelling in her portrayal of Eva.

Ataxia UK Chair Dr Harriet Bonney and **Research Officer Julie Vallortigara** advised the creative team and cast on the physical interpretation of ataxia and its challenges. The reading was performed to a well-attended house where Ataxia UK staff members were on hand to publicise the charity and spread the word about the condition.

Exceptional Mercy marked a milestone for disability within the arts due to The Old Vic being renovated to accommodate a lead actor in a wheelchair, while the events the play is based upon highlight how woefully ill-equipped the justice system is to cope with the needs of the disabled.

Since this performance, **Daniel** (upon whose story Exceptional Mercy is based) has unfortunately become very ill. We send him our best wishes for a speedy recovery.

Exceptional Mercy

Exeter campaign success

only familiar with the word 'ataxia', but also know that it is a medical condition (a fifth of whom also understood specifically that it affects balance, co-ordination and movement).

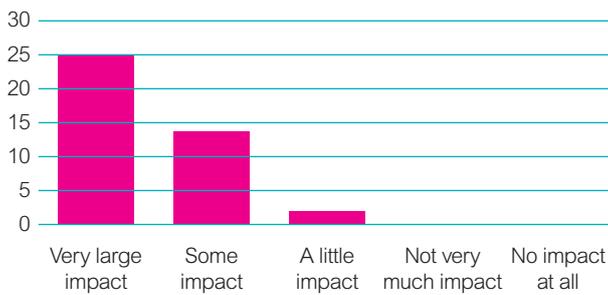
Thanks to **Pauline Lampshire's Ataxia Pilates fundraiser** (below left), a person who was interviewed randomly knew what the condition was in detail; a handful of people had also heard about the campaign on the radio. 15 interviewees said that they wanted to investigate further after seeing the campaign posters around the city, which tallies with a rise in website viewings after the posters went up. The campaign slogan we chose was quite controversial but it evidently achieved its purpose by inspiring people to look further into ataxia. These results bode very well for localised campaigns that Ataxia UK and their Branches may wish to carry out in the future. Our biggest thanks go to the **South West Branch** and former **Mayor of Exeter Rachel Lyons** for their enthusiasm, hard work and dedication towards making the campaign such a success!



Ataxia UK's **South West Branch**, co-chaired by **Anthony Brown** and **Rebecca Downing**, ran an awareness campaign in Exeter throughout June. After a month of posters on the buses and rail platforms; a promotional video; fundraising and awareness-raising events and a medical training seminar (**Ataxia Training Day**) for healthcare professionals across the South West, we measured the effectiveness of the campaign through a survey conducted in early July. 300 people of different ages, genders and ethnicities were interviewed at random at various locations. To our delight, the results demonstrate that the campaign was a huge success! Through previous surveys, Ataxia UK knows that less than 10% of the national population is aware of ataxia. Following our localised campaign, we are happy to report that **41% of the population of Exeter** is now not



What impact will this seminar have on your future practice of treating/supporting people who have ataxia?



RESEARCH



Exeter Ataxia Training Day for healthcare professionals is a success

As part of the **Exeter campaign**, we held an **Ataxia Training Day** for healthcare professionals in July at the **Met Office**. We partnered with **ACPIN (Association of Chartered Physiotherapists with Interest in Neurology)** for the event, meaning many physiotherapists attended. Around 60 delegates learned about the diagnosis and management of the ataxias and heard the views of two people with ataxia. In addition, they were able to gain **Continued Professional Development (CPD) credit points** from the **Royal College of Physicians** and were given copies of the **Ataxia Medical Guidelines**. Many also joined our **Registry of Healthcare Professionals** with interest in ataxia, so that we can keep them regularly updated. The day was successful and feedback from delegates was very positive. Read more about Ataxia Training Days here: www.ataxia.org.uk/get-training.

Below:

The team's research has shown that under experimental conditions, bone marrow cells can integrate into the brain. This image shows that bone marrow cell genes - in this case, 'marker' genes which make the cell appear green - are found in cells of the cerebellum. These cerebellar cells otherwise appear to be healthy and functioning.

New research project funded by Ataxia UK

Studying 'Granulocyte colony stimulating factor' (GCSF) as a potential treatment for Friedreich's ataxia

A new research project on Friedreich's ataxia is starting at the **University of Bristol**. We are delighted to be co-funding this project with the US charity **FARA**. This project is also being supported by the University of Bristol.

Background

This project builds on **Dr Alastair Wilkins'** research team's work on bone marrow stem cells as a treatment for Friedreich's ataxia (FA). Ataxia UK funded this group a few years ago who then succeeded in getting a grant from the **Medical Research Council** to pursue the studies further. Following promising results from the last few years, it is now the time to move to the next stage.

An alternative to transplanting bone marrow cells, and avoiding the need for bone marrow harvest and infusions, would be to use **bone marrow stem cell mobilising drugs**. These drugs are used in clinical practices which activate stem cells within the bone marrow and induce them to circulate around the body. The Bristol researchers believe that increasing the circulation of

the body's own stem cells is a promising approach for therapeutic success.

Progress so far

Experimental studies undertaken within Dr Wilkins' laboratory indicate that bone marrow stem cells protect nerve cells and induce repair of the nervous system. They have recently completed a major study of a mouse model of FA in which the bone marrow stem cell mobilising drug **GCSF** protected mice from neurological damage. This type of drug has potential in neurodegenerative conditions and represents a novel therapeutic possibility for FA.

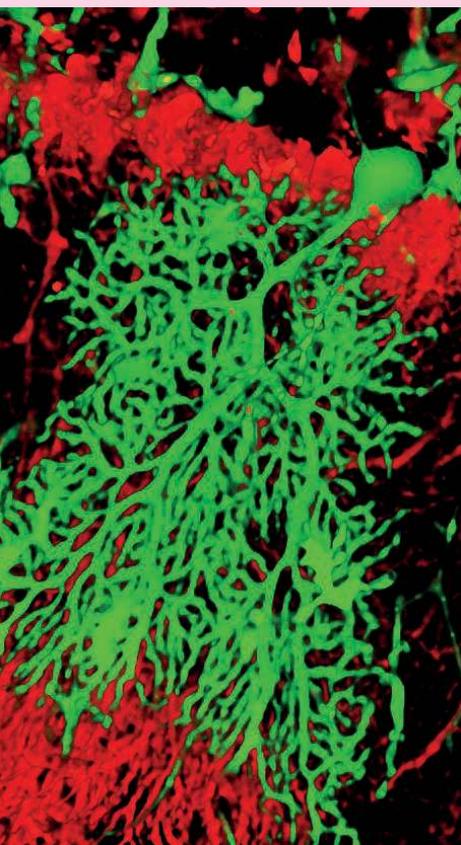
Aims of this study

In this 18-month project they plan to:

- i) Test the effect of the drug GCSF in human cells (to see if they get the same response as in mice)
- ii) Do a pilot trial in seven people with FA to test safety, dosage and get information for a larger trial.

Taking part in the study

The second part of the study will require seven people with Friedreich's ataxia to take part in a short trial. The trial is still being planned and is therefore not currently recruiting participants. Ataxia UK will be part of the **Trial Steering Committee** and any opportunities to take part will be publicised. The research team hopes to involve people who live locally in the trial to reduce travel time and costs. More information on this will follow. If you are interested in knowing more, please contact Dr Alastair Wilkins at this email: alastair.wilkins@bristol.ac.uk. The lead researcher Dr Alastair Wilkins says: "It is a very exciting time for our studies and we are extremely grateful to Ataxia UK and FARA for funding this project."



New Friedreich's ataxia trial

starting at the **London Ataxia Centre**: We are delighted to announce a new trial that is recruiting participants at the London Ataxia Centre. *See information below:*

Call for patients with Friedreich's Ataxia Phase 2 Trial with RTA 408

The Institute of Neurology and The National Hospital for Neurology and Neurosurgery, University College London are recruiting patients with Friedreich's ataxia (FA) in the United Kingdom for a Phase 2 clinical trial studying the safety and effects of RTA 408 (also called Omaveloxolone, a semi-synthetic triterpenoid, an Nrf2 activator with antioxidant properties) in FA.

This study is sponsored by **Reata Pharmaceuticals, Inc.** This study includes several sites in the United States, Austria, Australia and the UK, including **The Institute of Neurology** and **The National Hospital for Neurology and Neurosurgery**.

We are looking for patients between the ages of 16 and 40 years who have Friedreich's ataxia.

To participate, you must:

- Have genetic confirmation of your FA;
- Be willing to maintain a consistent exercise routine and stable medication doses throughout the study;
- Be willing to discontinue taking all antioxidant supplements and vitamins, or any other medication intended to treat Friedreich's ataxia before beginning this study drug and throughout your participation in the study;
- Use an acceptable form of contraception throughout the study.

In addition, you must NOT:

- Have any clinically relevant medical or surgical condition that could interfere with the administration of the study drug or compromise your safety or wellbeing.
- Be pregnant, planning a pregnancy, or breastfeeding.

About the study:

- Participation in the study is for up to seven months, including 24 weeks of treatment.
- Approximately 172 patients will be enrolled across all sites
- The study has two different parts:

Part 1: Dose ranges from 2.5mg up to 300mg,

placebo-controlled: cohorts of eight participants are assigned to receive RTA

408 or placebo for 12 weeks. The study doctor will let you know what dose of RTA 408 your group may receive. **Enrolment in Part 1 is complete.**

Part 2: Parallel doses, placebo-controlled: participants are assigned to receive placebo or 150 mg of RTA 408 for 24 weeks. The RTA 408 dose for Part 2 was selected from the dose levels tested in Part 1.

• Extension

Participants completing either Part 1 or Part 2 of the study will have the option of entering an extension portion of the study. Eligible participants will receive open label RTA 408 (150 mg) until RTA 408 is commercially available.

All individuals in the study would be asked to complete eight visits at the Institute of Neurology and The National Hospital for Neurology and Neurosurgery, along with two telephone calls. Please note that some study assessments will be performed at the **Royal Brompton Hospital** and individuals will have to complete six visits here (these will be scheduled alongside the main visits to the **National Hospital for Neurology and Neurosurgery**).

Once you enrol, your travel costs to the Institute of Neurology and The National Hospital for Neurology and Neurosurgery, and to the Royal Brompton Hospital will be reimbursed up to a specific amount, as allowed by Reata Pharmaceuticals, Inc.

You may not directly benefit from participating in this study, but you and other participants may make an important contribution to advancing the understanding and treatment of FA.

Please call the study coordinator below to learn more about what study procedures are involved and if you may be eligible to participate.

Study Coordinator: Mila Resuello-Dauti

Tel: **020 3448 4531**

Email: **Mila.Resuello-Dauti@uclh.nhs.uk**

Thank you for your on-going support of clinical research into Friedreich's ataxia.

University College London Hospitals 
NHS Foundation Trust

 **MOXie**
a study in Friedreich's ataxia

 **REATA**
PHARMACEUTICALS

Adapting arm movements in symptomatic and pre-symptomatic individuals with SCA6

A group of researchers from the University of Oxford and the University of Birmingham have recently investigated how individuals with Spinocerebellar Ataxia Type 6 (SCA6) and pre-symptomatic individuals (i.e. those who know they have inherited SCA6 but do not show any clinical symptoms of ataxia yet) learn to adapt their arm movements.

The cerebellum is responsible for motor control; this includes coordination of movement and adaptation. As SCA6 affects the cerebellum, it's possible that the ability for people with SCA6 to adapt their movement will have to be modified. The researchers have designed a 'movement task' to assess the adaptation of arm movements:

- One of the aims of the study is to determine whether this task could be used as a more objective measure of the general motor symptoms of SCA6, complimenting the more commonly-used clinical testing methods, such as the **International Cooperative Ataxia Rating Scale (ICARS)**, which can be more subjective.
- Another aim is to identify whether the task is sensitive to subtle changes in movement performance in individuals with SCA6 who have not yet presented clinical symptoms according to the subjective clinical scales.

The researchers found that individuals with clinical symptoms of SCA6 performed the task in accordance with the severity of their symptoms as evaluated with the ICARS. This suggests that this type of task could be a useful quantitative indicator of disease progression. Moreover, the team also showed that pre-symptomatic individuals performed worse in the task compared to the control group who don't yet exhibit their symptoms.

SCA6 symptoms become evident late in life (50s-60s); these results suggest that this assessment of movement could detect changes happening within the cerebellum before the first clinical symptoms of SCA6 can be observed.

Further research could help better identify these subtle initial changes in cerebellar function.

Ataxia UK has been helping the team find participants to take part in this study and we are extremely grateful to those who did. This study has been published in the prestigious journal **Scientific Reports**, a journal from the publishers of Nature, and can be found on the following website:

<http://alturl.com/457vq>



Above:

This photo shows a member of the research team doing the movement task used in this research study



Updates, Early Birds, cups & shields



Above:
Kerry Bull,
winner of the
2016
Anna Ford
Cup

Below:
Peter Souter,
winner of the
2016
Ernie Heath
Shield

Our Annual Conference has stepped up a gear this year: find out how below. We've already had many bookings come in, so make sure you don't miss out from the Early Bird prices!

Read below for a reminder on how to request bursaries and book accommodation, and to find out what's in store for delegates. You can book tickets on the events page of the **Ataxia UK website** or via a paper form until the **12 October**; please email or call the office if you would like to receive a paper form.

EARLY BIRD PRICES REMINDER

Event	Early Bird Rates	Regular Rates
All About Ataxia	£25	£28
Day Delegate with ataxia	£36	£40
Day Delegate without ataxia	£39	£43
Dinner	£32	£36
Under-12's Dinner	£15	£18
Friday Buffet	£15	£18

BURSARIES

Help with the cost of the conference is available for eligible people with ataxia. Up to 50% of the cost of travel, accommodation and delegate registration fees can be paid against receipts. The deadline for applications is **10 September** but there are limited funds available. We can award one bursary per person, per calendar year.

ACCOMMODATION

You will need to book non-adapted rooms directly with the hotel. Contact them on **01279 661012** and quote **Ataxia UK** by **20 September** in order to receive discount room rates from the hotel. Prices include breakfast and VAT as follows:

Single occupancy	£77
Double occupancy	£87
Some family rooms are available at	£125

ADAPTED ROOMS

The adapted rooms at the Radisson have currently all been reserved, but contact the office (office@ataxia.org.uk) to check for cancellations. We've

negotiated special rates at the nearby **Hampton by Hilton Hotel**, which has 18 adapted rooms that all include adapted wet rooms, double beds and sofa beds; they can therefore accommodate up to three people. The flat rate for these rooms is £85.00 which includes breakfast, VAT and Wi-Fi. Unfortunately, none of the accessible rooms are interconnecting. Please visit here to book: <http://alturl.com/rsgfg>. Click on "Add Special Rate Codes" and enter "ATX" in the Group Code Box to get the discounted rate. This will also ensure that an adapted room is allocated to your booking.

CHILDREN'S ACTIVITIES

We will be providing care and exciting activities for our younger delegates including a **fantastic trip out to a wildlife park**. In order that we may best organise the activities that suit the age range, please can you register your interest or complete the booking for your family members to attend by **10 September** at the latest.

VOLUNTEERS

If you'd like to help at the conference in any way, please contact the Ataxia UK office (office@ataxia.org.uk). We need assistance on the registration desk, the merchandise and fundraising stalls and help with people getting in and out of the conference hall.

THINGS TO LOOK FORWARD TO

- Mental wellbeing session
- Introduction to **Disability Rights UK** and the services they offer
- **'It Works for Me'** session, kids trip, research updates and doctors Q&A (usual fixtures)
- Breakouts include: Mindfulness, Pilates, Health Unlocked with **Ataxia UK Chair Dr Harriet Bonney** and an introduction to Ataxia UK's new research strategy
- We'll also be having a stand-alone **16-30's agenda** that includes sessions on employment and university, financial aid opportunities, confidence building workshops and hearing from people with ataxia about their careers. Group members: please keep an eye out on the 16-30's website (www.ataxia16to30.org.uk) for a schedule of events, which will be released this month!



The Anne Ford Cup and Ernie Heath Shield

Every year at the **Annual Conference**, Ataxia UK recognises two people who have made outstanding contributions to the work of the charity: the **Anne Ford Cup** is given in recognition of the commitment of a person with ataxia, and the **Ernie Heath Shield** is given to someone who does not have ataxia but has made a big impact on our community. To make a suggestion as to who should win either of these awards, please contact **Sue Millman** by 6 October (smillman@ataxia.org.uk), explaining why your suggested person should receive the award.

Paraorchestra

Organisations like the **British Paraorchestra** are helping to open up the arts to people with a range of abilities.

The British Paraorchestra is the world's first professional ensemble for disabled musicians. It was set up in 2011 by musical director **Charles Hazlewood** and television director **Claire Whalley**. Their world debut was accompanying **Coldplay** at the closing ceremony of the 2012 Paralympics and the orchestra are at the forefront of a global movement to recognise and showcase disabled musicians with extraordinary abilities.

Just as the growing success and media interest in Britain's Paralympic team has started to change the public's perceptions surrounding disability in sport, the Paraorchestra hopes to replicate this by highlighting the potential for disabled people to excel in music and the arts.

The orchestra believes they have a unique set-up which will not be familiar to audiences more accustomed to traditional classical music ensembles. This is something they pride themselves in and it has not lessened their ambitions. Founder Charles Hazlewood is a passionate advocate for a wider audience for orchestral music and has conducted some of the world's greatest orchestras, including the Swedish Radio Symphony and the Copenhagen Philharmonic. "Music is the most universal language that we have," said Hazlewood during a TEDx Talk in Brussels, where he outlined his vision for The Paraorchestra and his hopes for similar groups forming across the globe.

One of The Paraorchestra's biggest performances to date was at last year's Glastonbury Festival, where they performed Philip Glass' *Heroes Symphony*, a modern classical reinterpretation of David Bowie's seminal 1977 album. The recital was described by Will Hodgkinson in *The Times* as: "One of the quietest sets at Glastonbury and also one of the most affecting".

The orchestra has also worked in conjunction with the **South-West Open Youth Orchestra (SWOYO)**, who are the UK's only disabled-led regional youth orchestra. SWOYO's instruments have been developed and adapted for them by **OpenUp Music**, an organisation specialising in making orchestras, instruments and repertoire accessible to young disabled musicians.

SWOYO member **Bradley Warwick** plays the clarion, an instrument for the disabled which has been eight years in development. The clarion's innovative design means it can be adapted for the musician, allowing the player to alter the shape, position, and colour of the notes, as well as the ways in which they are played. Bradley plays the clarion with eye movements which are interpreted through an eye-tracking computer programme. In an interview on BBC Radio 3, Bradley said through an electronic communication aid that he "get[s] a buzz playing music in front of people. I love being part of the South West Open Youth Orchestra. I feel a kind of freedom and belonging. I meet lots of new people. Disability should never be a barrier to enjoying music and getting involved."



Above:
Charles Hazlewood,
Director of
Paraorchestra

Below Top:
**The South-West
Open Youth
Orchestra
(SWOYO)**

**Below Bottom
& Right:**
SWOYO member
Bradley Warwick



A day in the park



Remaining places are limited for our annual awareness-raising fundraiser the **Westminster Parks Challenge**, held the day before **Ataxia Awareness Day** on 24 September, which takes our walkers through the **Royal Parks of London** this autumn.

To add to the excitement of the day, we have the **Lord Mayor of Westminster Ian Adams** (left) hosting a celebratory buffet just for us at his **Mayoral Parlour** overlooking **Trafalgar Square!** Book your place by heading to our website (www.ataxia.org.uk/news/westminster-parks-challenge),

or give us a call **(020 7582 1444)** or email fundraising@ataxia.org.uk to receive an application form and your free Ataxia UK t-shirt.

We ask our walkers to raise or donate a minimum of £20 to cover the costs of the walk but this is not compulsory for you to take part. If you would like some help with setting up a fundraising page, then get in touch!

We are also looking for volunteers to help navigate our walkers along the route, making sure they stay on track. If you think you can lend us just a little of your time on the day, then please let us know.

Below. Map of the route.

Long route is red, short route is yellow.



Chance to win

If you haven't heard already, you could be winning up to **£250** whilst also raising vital funds for Ataxia UK by taking part in our quarterly **Chance To Win scheme!** All you have to do is pay £2 a month or £24 a year to be in with a chance of winning. The draw happens every three months; winners are personally notified as well as published on our website and in the Ataxia Magazine. Get in touch with the office if you'd like to take part!

Winners

- 1st. £250. **Jan Owen**
- 2nd. £150. **Mr Peter Allen**
- 3rd. £100. **John Ford**

Superb support groups and brilliant Branches

Our support groups and Branches have been in top fundraising form over the summer. Let's take a closer look at what they've been getting up to ...



The Belper Games (left) celebrated its sixth year with the biggest and best games yet! Thirty-two teams competed in the Games with live music, freshly cooked food and activities for all across the weekend. Much of the Games' success is down to the hard work of event organisers **Kerry and Jim Bull** and help from members of the **Derby support group**. Thank you to everybody who came along and made this year's Games so successful!

From supermarket charity schemes to bake sales, the **North-West London Branch** have had a busy few months of fundraising. The Branch applied for their local Waitrose's '**Community Matters**' scheme and were rewarded with a fantastic donation of £320 (left). Branch treasurer and **Ataxia UK**

Trustee Tony Kaye donated his speaker's fee from a number of photography and camera lectures to Ataxia UK whilst the whole Branch came together to host a 'cake bake' at the **National Hospital for Neurology**

and **Neurosurgery, London**. Their combined fundraising efforts stand at almost £800!

The South Downs support group are bringing back their annual BBQ this summer and are hosting a fundraising tombola, too!

The Dudley support group welcomed the start of the sunny season with a summer fayre. The fayre was full of all sorts of activities, including a bake sale, tombola and an Ataxia UK merchandise stand. A great day was had by all and a wonderful £800 was raised in the process! Twenty members and friends of the Dudley support group also travelled to Cardiff in late July to take on **The Gauntlet Games** (below), a brutal obstacle course patrolled by a team of battle-hardened gladiators. The rain was pouring, the mud was thick and the obstacles were not for the faint-hearted, yet the team prevailed, conquering all the obstacles and taking down every last gladiator!

A big thank you to everybody involved, but especially to **Melanie Priest** of the Dudley support group for recruiting her unstoppable team and a special thank you also to **Deborah Poyser** of the **Cardiff support group** for coming along to cheer on the team from Dudley.

If you are part of a support group or Branch and would like some fundraising help or advice, then contact one of our team at fundraising@ataxia.org.uk. For more information about our Branches and support groups, please visit www.ataxia.org.uk/a-list-of-branches-support-groups



The summer summary



The summer may be sadly coming to an end, but it has been a very successful one for Ataxia UK with many of you fundraising for us!

We can't feature all of you but, on behalf of everyone at Ataxia UK, thank you to all of our fundraisers who have helped to make this a summer to remember.

Our very own interns **Oliver Roberton** and **Zoe Lonergan** (left) took part in the British 10K this July, along with our dedicated fundraiser **Donna Vant**. Overall they raised over £1,000.

Donna (far left) is planning on completing a number of runs this year and we are so impressed by her dedication!

Jennifer Miremadi (below far left) walked 6,783 steps along 'La Ruta de los 6,000 Escalones' in Spain at the end of June to fundraise for us.

She picked this challenge because walking is something most people take for granted every single day and don't think twice about.

Thank you Jennifer for raising a marvellous £1,716!

We would also like to thank the **Evans family** (left) for recently completing a zip wire challenge and raising £535 for Ataxia UK.

Special thanks go to **Amanda** who has cerebellar ataxia; not only did she face her fears and complete the zip wire but she is also collecting donations for us at her workplace!

A big thanks goes to **Tansy Boyd** for hosting the Chelsea Street Party (right) for the third year running! It was such a fun event where all profits raised were donated to Ataxia UK. In total over £8,000 was raised.

Tansy's friend **Lukyn** has ataxia, which is what motivates Tansy to put on this incredible party every year! Thank you for all of your hard work, Tansy.



of fundraising ...



Many thanks to **Rita Fong** (far left), who ran the Manchester 10K race at the end of April. Not only did she raise £365, but she did this whilst being 19 weeks pregnant!

Rita decided to take on this challenge in memory of her auntie. Thank you so much, Rita!

One of our biggest yearly fundraisers, **The Ataxia Spring Classic**, was back again this year.

We would like to extend our sincere thanks to **Andrew Downie**, an **Ataxia UK Trustee**, for organising yet another successful cycle which raised the fantastic amount of over £15,000!

We would also like to thank all those who took part in the cycle ride, including our very own **Head of Finance, Stephanie Lawrence**, and her family (left).



Nick Cook's nephew **Tony** (left) has Friedreich's ataxia. Growing up, Tony was (and still is) football mad but, as his ataxia has progressed, he's had to come to terms with the fact that he'll lose his ability to play. Nick, who is a football coach, is fundraising at matches to take Tony to Barcelona to see his footballing hero, **Lionel Messi**. Half of the money raised will be donated to Ataxia UK. So far the appeal has raised over £2500!

Our thanks also go to **John and Linda Brown** for recently hosting a '**Charity Fun Evening**' in aid of Ataxia UK. They have managed to raise £930 in memory of **Pamela Cairns**. Their friends **Tracey** and **Jackie Rhodes** have also been raising money in memory of Pamela. Collectively the four of them have raised £1,858.

John and Linda's daughter, **Chloe**, has also raised over £500 by running this year's **Edinburgh Half Marathon**. This is fantastic; well done, guys!

Another special thank you goes to **Jack Hopwood** for organising a charity concert at his local pub in Lymington. The event showcased local musicians, including Jack himself, and a raffle was held. The night brought in £543 – thanks for your hard work, Jack!

We were kindly nominated by **Stuart House** at **The Whitby High School** to be one of their house charities. Students and teachers raised money in a variety of ways including cake sales, ice cream sales on hot days, sponsored silences and 'soak the teacher' events. Thanks to all who helped to raise £293.



Adapting to life

by Matthew Law



My adapted holiday

Matthew Law has recently returned from a holiday in Norway and here reviews his experience of an accessible cruise.

Having ataxia and being disabled certainly does not end your ability to go on holiday. Sure, it changes the places you can visit and what you can do once you are there, but it doesn't mean you have to sit at home. Adapting to a life with ataxia includes adapting to a life on holiday as well. I received the email asking for this article and suggesting a subject for it whilst I was in the middle of the **North Sea on a cruise ship heading for Norway**, so there was never any doubt to me what the subject of this article could be.

This was the first cruise I have ever been on. Many years ago I went on a cruise ship but it was just for an hour or so and it was just to see what the disabled facilities were like on board. This 'ship viewing' was arranged by **Accessible Travel (a disabled holiday travel agent)**. I went on this cruise with my **PA, Ivana**, who also has ataxia, **Jenny**, and her niece, **Hannah**. Jenny actually booked the cruise through Accessible Travel as I deemed it important to use their many years of experience. We had adjacent, outside, adapted cabins, each with their own balcony overlooking the sea. We were able to permanently open the dividing door between our two balconies so in effect we had one double-length balcony. The cabins were near the centre of the ship on deck 12 (there were 16 decks in total).



The adapted cabins were very spacious, which is very important when you are a wheelchair-user, and the bathroom was totally accessible with a roll-in shower, plenty of space under the sink and plenty of hand rails around the toilet and shower. They would even have installed an adjustable bed for me, had I thought of asking for it before we went. My only regret of the holiday was not even thinking about my sleeping comfort beforehand - as it was, I had to rely on a brandy and coke just before bedtime to get any sleep at all! The ship docked in four different ports and we arrived in each one in the middle of the night. It felt wonderful to wake up and look out to a different place on four different occasions.

I can honestly say that it was **the most inclusive holiday I have ever been on**, one where using a wheelchair had absolutely no bearing on what you could do during your time on the ship or seeing the sites of the port cities - for example, we could eat in any restaurant, go to the casino, go to the theatre or the cinema, spend time in the gym or go on any of the accessible excursions. The only time I had to get out of my chair was to get into bed or go to the toilet. I am aware, however, that many readers of this magazine will not be full-time wheelchair users and so a note for them: The ship is extremely big and to get full enjoyment you will have some long walks. I would recommend you take a chair and use it so you can conserve some energy to do the things you enjoy.

Matthew Law (matthewlaw1968@yahoo.co.uk)



Roomba robot

Few of us enjoy chores, so why not enlist the help of a robot?

For some people with ataxia, keeping a home clean and tidy can be a challenge. Most conventional vacuum cleaners are not designed for ease of use by people who have limited mobility. For some, domestic technology like the **Roomba** could be the perfect solution. The **iRobot Roomba** is a robotic vacuum cleaner that uses sensors to navigate automatically around the home. The time-saving device maps the areas of the house it's already cleaned and even puts itself back on charge when it's low on power before returning to complete the chores. The marvellous machine can also detect what type of surface it is cleaning and adjust its suction levels accordingly. The roaming robot comes in a range of models and is available to buy online: <http://shop.irobot.co.uk>



Gyenno Spoon

Mealtimes made easy

If your ataxia causes tremors or sudden movements which hinder your ability to eat and enjoy food, then there is new technology available which could help. The **Gyenno Spoon** is a utensil that's been developed to help those with tremors at mealtimes. The innovative device contains a stabilising sensor that detects hand-motion and an on-board computer that distinguishes tremors from the intended movement of the hand. The spoon weighs just 130g and has been ergonomically designed for ease of use with a patented **Tritan™ medical grade coating and antibacterial silicon**. The spoon can be detached and replaced by a fork which is included with the device. It has a **rechargeable battery** which can store enough power for use with three meals, holding 180 minutes of run-time off a single charge. The device will also power down automatically when not in use. The Gyenno Spoon is available to order online:

www.amazon.co.uk/dp/B01M6178NX

Thriving with Friedreich's

Will Street is a **Paralympian sailor with ataxia** who's recently launched his own website documenting his life.

Here, Will tells us about his journey through his diagnosis and his aims going forward.

I grew up in a sporting family. My mum is a trampoline coach and my dad a competitive sailor. My two elder sisters used to do gymnastics and I remember making it into the club's squad for talented children around age six. I had good balance then, even walking on the beam.

As I got older I played football and rugby although I didn't excel at those, in fact quite the opposite!

A typical weekend would involve trips to the sailing club and beach, playing around on surfboards

and boats. I loved sailing and eventually started racing dinghies when I was about 10 years old. Alongside sailing, I also started beach fishing which I really enjoyed, becoming angling club junior champion for three consecutive years.

Around this time I started to notice that my balance and co-ordination were not so good; I began to stumble a bit when walking. I realised that I was looking down all the time when walking across the beach.

I was diagnosed with FA at the age of 13. Some people thought I had dyspraxia, including some doctors, although my mum thought

otherwise. Eventually, with the help of a specialist doctor, I had tests done at **Guy's and St Thomas' Hospital**. Walking in to get my results, I was barely stumbling when they hit me with the news that I was going to be in a wheelchair before I left school: only three years away. I thought that they must be wrong; that they couldn't be talking about me. They said FA was genetic and that it affected the nerves. For me, it affected those that were furthest from my brain most severely, and this gave me poor co-ordination.



My consultant said that the condition was degenerative but that the deterioration could stabilise, which I took as a positive. I decided to just get on with life, enjoy it to the full and not even think about what the future may hold.

That was hard at times. At times I thought that life was over, that I would always be in the shadows of others unaffected by a disability ... but how wrong could I have been! Friedreich's ataxia has made me the man I am today and, although my life is not what I expected, it is better than a normal life; it just needs adjustments to make it work for me.

Earning a place on the **British sailing team** gave me a real identity and purpose to thrive. I've worked hard for my world ranking, and can honestly say it has been the best experience ever.

I've met so many people from all over the world, and have been treated as an equal on so many levels, challenging my fears of being treated differently as my condition changes.

www.WillStreetTWF.com is my new website. I have videos of my sailing events, holidays with mates in different countries and training programmes. I have filmed and edited these myself and thoroughly enjoyed the process.

I hope to keep making these as my life unfolds and hope it helps others to **'Thrive With Friedreich's'**. I don't want to think or worry about my condition, I just want to live each day and inspire others.

Further information on my sailing adventures can be found at **www.willstreet.org** or on the range of vlogs I have posted on **www.willstreettwf.com**.





Planning the big day

Wendy Crooks tells us about the difficulties she came across when planning her accessible wedding.

Planning a wedding is an absolute nightmare for anybody - in fact, weddings consistently poll in the top ten of most stressful life events - but for a wheelchair user, it's hellish. No exaggeration. Now, I'm guessing a fair few people reading this are already married and you have my utmost respect ... and I want to know how you did it without going insane!

Choosing a venue was easy for my partner and me because we wanted to use somewhere that had memories for us and catered for my access needs. We did get swept up by the idea of getting hitched somewhere fancy and elegant, but all of our initial enquiries were met with: 'there are stairs, but if you tell us when the wheelchair arrives we'll get our strongest staff members to carry it up.' That's a lovely attempt to accommodate a wheelchair, but what about the person inside it? Newer buildings often have better access but you pay through the nose. With a disability, you can't just put up and shut up because a venue is pretty - if I can't get in and around independently then sorry, no business for you.

What Laurence (the victim of my clutches) and I want is fairly simple and affordable. Once we realised that we didn't actually want the big, showy wedding everyone apparently dreams of, everything slotted into place fairly quickly.

Brides are not supposed to have disabilities. People like me don't get married. You never see girls in wheelchairs in bridal magazines unless

the editors have decided to do a disability-positive piece. Wedding dresses are largely made of stiff material, are very fitted and don't account for the fact it will be sat in: so they're rarely comfy and don't come with lots of stretchy panels so people can, y'know, breathe. Thankfully, spending the day looking like a fluffy white sheep doesn't appeal to me, so I can dodge that drama. How difficult must it be for women and men, if that's what does take their fancy, to find a bridal shop where designers know that disabled dresses need to be made differently, and have an adapted fitting room? Constantly having to be pulled into awkward and dangerous positions just to try on an outfit? I've got better things to do with my time, thanks.

I wonder if a lot of couples feel forced into having things they don't really want at their wedding. I don't know, but maybe having to always fight to make myself heard has made me more determined to get things done my way. Our caterer tried to ignore me and get Laurence to decide everything. I love him, but I don't trust him THAT much! So I stamped my tiny size three's and she realised that I actually have a mind of my own. Whether talking over my head was down to ignorance or rudeness I'm not sure, but that attitude doesn't fly with me.

What planning an accessible wedding boils down to is this - my wedding is a joint venture. My relationship thus far has been a partnership, and the fact that he can walk and I can't, has never mattered to us. Hopefully, if we can beat the doubters, it never will.



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