

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 201. Spring 2018

A sunny, sponsored walk in South Wales

with Vicky Gee, cousin Abigail Stone
and members of the
South Wales Support Group



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

ATAXIA

Ataxia UK

In the office

HELLO



Rebecca Holt

Hello, everyone! I'm **Rebecca, Ataxia UK's new Community Fundraising Manager**. I'll be working with you, our community and supporters, to make sure our fundraisers have everything they need to achieve their goals; that members of the Branches and Support Groups are supported as much as possible, and that everyone enjoys working on their campaigns and challenges while doing their crucial work for Ataxia UK.

It's wonderful to be a part of this charity; I've been here since December and everyone has been so welcoming and warm, which seems to be the nature of Ataxia UK. Having started my career in the private sector, I quickly fell in love with charitable work, as I developed a Corporate Social Responsibility team for a large property consultancy and managed Charity of the Year partnerships. I therefore decided to move into the third-sector by joining the Children's Heart Federation as Family Support and Events Officer, and then moved onto Wings for Life UK in Community Fundraising and Relationship Development.

I am really looking forward to getting to know you all and working together to increase our reach and awareness of ataxia, the charity and of the research being undertaken, together with building our fundraising. If you have any questions or would just like to get in touch, you can email me on rholt@ataxia.org.uk or call the office on **020 7582 1444**.

Welcome

With spring on the way, the new year has truly begun, and it's a busy one for Ataxia UK.

Thanks to the generosity of you, our pledge funders and the **Hospital Saturday Fund**, we've begun 2018 on the triumphant tail of a great Christmas campaign. Thank you to everyone who contributed to an astonishing **£58,338.34** that came to us at the end of last year (p.12)!

This is a fantastic start for our **two new Fundraising Managers** who have joined us as part of our new Fundraising Strategy, which aims to double our income over five years - and more than double our impact on research and support for people affected by ataxia! Please continue to lend us your support this year and help us achieve this goal.

Meanwhile, our calendar features **two** conferences for 2018: our **Scottish Conference**, for which bookings are now open (p.10), and our **Annual Conference** in October, for which we return to Derby.

Read about an interesting new research project we're funding on **episodic ataxia type 1** (p. 6) and a new clinical trial with **REATA** (p. 7) which is recruiting patients with FA in the leaflet you'll find enclosed.

You'll also find tickets for our **Annual Spring Raffle**

(p.15) with this issue, which you can sell to friends and family to give them a chance at winning some fantastic prizes while supporting the charity. The best of luck to everyone who takes part!

Finally, we are in the process of recruiting a **new Treasurer for Ataxia UK** (p.5), as we look for a replacement for current Treasurer and Trustee, Russell Brown, who is stepping down. You can read more about who we are looking for on page 5.

We wish you a lovely spring and great start to 2018.

Regards

Sue Millman



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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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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/ataxiomagazine201

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.

Sharing your story at school



Georgia Harvey-Adcock, aged 17, was diagnosed with Friedreich's ataxia in August 2016. She had mobility issues prior to this and like many people with FA, wasn't diagnosed straight away. Bullied by school peers who didn't understand her condition, Georgia took a bold step: she prepared a speech about living with ataxia to be read out during assembly. It changed everything.

Georgia's diagnosis came in the middle of her GCSE examinations. She was angry and resentful at what it could mean for her, especially when she transitioned into a wheelchair. The support that she's received from the staff at **Lincoln Castle Academy** is testament to **the impact that a school can have on a young person's wellbeing**.

"It's been a day-by-day evolving story and picture," says **Emma Drury** (Special Educational Needs Coordinator). "We've adjusted to whatever she's needed. We'd already put things in place because of her walking as it became more of an issue, but when it became apparent that a wheelchair was necessary, Georgia was worried how people in her year would see her and how they'd react."

So that's when her **Head of Year, Mr. Jones, spoke in an assembly** to tell her peers about the condition and read out **a speech that Georgia had prepared**. Everyone there was very moved and it had a huge impact on the year group - they suddenly realised what she had been going through and how life can change for any of us in an instant."

"She did one of the bravest things I've ever seen, doing that assembly," says **Andrew Thomas** (Assistant Head Teacher). "It's been a rapid change since her diagnosis and she knew that things were going to get more difficult, but her attitude has been exceptional."

Georgia was extremely grateful for the chance to make people in the school aware of ataxia. "It's so frustrating that not enough people know about it, which is what led to bullying. My attitude has always been that 'I don't want your sympathy, just treat me the way I am.' **As soon as I did that assembly, the bullying stopped**. It's been amazing how the whole school have been fine with it," she says.

Georgia's mother, Kath, has been glowing in praise for the school staff: "They've had to manage both the physical and emotional levels of ataxia ... they've done an amazing job. They brought a bed so she could lie down, gave her a laptop, and have been flexible with her hours. This is the first time they've had a child in a wheelchair admitted ... and it's been a feather in their cap."

Georgia's experience has also inspired the school staff to fundraise for Ataxia UK, which you can read more about on page 14.

Emma advises that to create the best possible environment for someone like Georgia, "you need to work very closely with the parents and above all be very flexible. It's important to know what the student is going through, to be patient with them and to not be scared or overwhelmed by all the information that you're given."

Having seen how Georgia's bravery and support from staff has changed Georgia's wellbeing, Ataxia UK are putting together an ataxia awareness pack for secondary schools, making it easier for parents and pupils with ataxia to ask for support from staff. If your child is having a difficult time at secondary school, and is happy for ataxia to be openly discussed with their peers, get in touch with Steph Marley (communications@ataxia.org.uk) and express your interest in a pack. We also have packs for primary schools and younger children, which can also be requested from Steph.



An afternoon with the Sheffield Branch

Rebecca Holt, our new Community Fundraising Manager, recently went to visit the **Sheffield Branch** for a New Year meal and get together. They had a lovely afternoon and discussed their upcoming plans for 2018. Rebecca will be in touch with each and every Branch and Support Group in the near future, so expect to hear from her soon!

*Sheffield's next meeting is on 8 March; if you live in the area and are looking for some support and socialising fun, why not get in touch with **Toyah Wordsworth** at wtoyah@hotmail.com*



Spring on the South Downs

The **South Downs Support Group** and **Andy Downie**, Trustee, are hot on the wheels planning this year's **Ataxia Spring Classic** on **13 May 2018**, and the application for entries is now open! Join members of the Support Group for 100km or 11km rides across the scenic South Downs in support of Ataxia UK. Families and people of all abilities welcome. Read more about how to reserve a place at www.ataxiaspringclassic.co.uk, or get in touch with Andy at andy@downies.plus.com to express your interest!



Ataxia UK seeks a new Treasurer

The current Treasurer of Ataxia UK, **Russell Brown** (left), has announced his intention to step down from the role during 2018. The Board of Trustees have decided that the post should be filled by interview and co-option to the Board. The successful candidate will be professionally qualified as an accountant and ideally have some previous experience of working with charity accounts.

Could this be you?

Ataxia UK is a charity and a limited company. We currently have a turnover of £1m - £1.5m pa. As Treasurer, you would be a Trustee of Ataxia UK and attend our five or six Board Meetings per year, mostly in London on a Saturday. Travel expenses will be covered, plus overnight accommodation when necessary (including for a carer if this is required).

In addition to Board Meetings, the Treasurer liaises with the CEO and Head of Finance between meetings and needs to attend additional meetings relating to budget preparation, etc.

An application pack with further information about the role can be obtained from our website: www.ataxia.org.uk/work-for-ataxia-uk. If you wish to apply please send us a CV and a covering letter explaining how you meet the person specification. An informal discussion with **Sue Millman**, CEO, or **Ataxia UK Chairman, Harriet Bonney**, can be arranged by contacting Sue Millman via email: smillman@ataxia.org.uk, or by calling the Ataxia UK office and requesting to speak to Sue on **020 7582 1444**.

New project funded by Ataxia UK: novel pharmacological approach to treat episodic ataxia type 1

A new grant has been awarded to **Dr Paola Imbrici** and her team (below) from the **University of Bari** in Italy to study episodic ataxia type 1.

Episodic ataxia (EA-1) is a rare form of ataxia that gets diagnosed in early childhood and is characterised by short attacks (seconds or minutes) of incoordination, slurred speech and twitching of muscles (myokymia). Attacks can occur spontaneously or be triggered by rapid movements, fatigue or anxiety. Although there are some medications for EA-1, the response is variable, with limited efficacy in some people and adverse side-effects as well. "There is a need to develop more selective drugs that are safe and more effective for patients. This is the overall aim of our research," says lead researcher Dr Paola Imbrici.

It is known that episodic ataxia type 1 is caused by mutations in a gene coding for a specific potassium channel.

This leads to it not functioning properly and letting less potassium through the channel. This creates problems in transmitting nervous impulses in the cerebellum and peripheral nerves, leading to the ataxia symptoms.

The research team is planning on targeting the opening of the specific potassium channel by testing the effect of compounds found in tree resins in a cell model system. Although these compounds are pharmacological tools and don't have the safety requirements to be used as drugs in EA-1, if these molecules work in this laboratory setting, it would give us an understanding of the type of drug and mechanism of action that might be useful in EA-1. This could pave the way to developing more selective potassium channel-opener drugs as a future potential treatment.





A clinical study designed for patients with Friedreich's ataxia

Friedreich's ataxia trial recruiting now

We are pleased to announce that researchers at the **London Ataxia Centre** are now recruiting people with Friedreich's ataxia for a trial called **MOXIe**, supported by the pharmaceutical company **Reata**. This featured in a previous magazine (Issue 199). Please see the **leaflet insert** (left) with this magazine for further details and to find out how to take part.

RESEARCH



Research videos now available

We reported in the last issue of the magazine that we would be publishing some videos from the **International Ataxia Research Conference**, held in Pisa in September 2017 and was the largest research conference on ataxia ever organised. You can now find **videos of research presentations and interviews of researchers** on our YouTube channel: www.youtube.com/user/AtaxiaUKonline

Hear updates on spinocerebellar ataxias, immune-mediated ataxias and FA, and keep an eye out for upcoming videos that will be available soon. Ataxia UK is very grateful to **Jason Alhuwalia, Friend of Ataxia UK** and talented photographer and videographer, who kindly offered his services pro-bono at the conference.



Ataxia UK's partnership with Pfizer and three UK universities: an update

We previously reported on the launch of a **collaborative drug discovery** project looking at **Friedreich's ataxia (FA)** between **Oxford University, University College London, Imperial College London** and the pharmaceutical company **Pfizer** (Ataxia magazine 190). Ataxia UK initially brokered the creation of a consortium consisting of researchers with complementary expertise from the three UK universities, and supported them in designing a programme of research that was proposed to Pfizer. The project was funded by Pfizer with a contribution from Ataxia UK. We have continued to remain involved in this three-year project and have contributed to discussions with the project team.

Pfizer and the three UK universities are working towards identifying a compound that could increase levels of **frataxin**, the protein that is reduced in people with FA. Towards that end:

- Pfizer screened a focussed library of compounds to see if any increased the level of frataxin protein. To support characterisation of some of the compounds identified by Pfizer, investigators in the consortium tested the robustness of tests in patient-derived cells in order to select the best ones to use for further research. The results of this project, once published, may provide useful data for all researchers in the field.
- The consortium, with additional support from **Friedreich's Ataxia Research Alliance (FARA)**, is currently attempting to identify genes that increase frataxin levels. This work involves the use of new, exciting, gene-editing techniques. Identified genes, if any, may provide new targets to enable discovery of potential therapeutics.

Dr Nick Clarke, Head of External Development, Rare Diseases at Pfizer, says: "Pfizer continues to be committed to FA research. We are encouraged by the progress being made on this research project and value our collaboration with Ataxia UK and the three academic groups."

Ataxia UK continues to have an open dialogue with Pfizer and we are exploring other potential opportunities for working together.

Results and follow-up study of European

With the support of European Union funding, a European consortium of basic and clinical researchers was created in 2011, with the goal of better understanding Friedreich's ataxia (FA) and developing a structured network to test potential therapies for FA.

This group is called the **European Friedreich's Ataxia Consortium for Translational Studies (EFACTS)**, and now involves 18 centres from seven European countries including the **London Specialist Ataxia Centre** as the UK site.

The EFACTS researchers have established a European database of individuals with FA, which contains detailed clinical information that is updated annually, and a collection of biological samples

that allow the study of relevant disease markers (biomarkers). At the same time, the network researchers have made important advances in understanding disease mechanisms, establishing relevant cellular and animal models and developing potential therapies. In summer 2013, only two years after the launch of the consortium, we published in our magazine the great news that EFACTS had reached its target of recruiting 600 people living with FA. In addition, the network has validated a clinical tool for evaluation of ataxia (**Scale for the Assessment and Rating of Ataxia – SARA**); which as a result is now being extensively used.

In 2015 when funding for this Consortium came to an end, Ataxia UK and four other ataxia patient groups came together as part of a **euroataxia** initiative to provide a grant to continue part of this important project. The plan was to expand the database and continue to collect annual data. In fact, EFACTS has identified the need to extend the



EFACTS
Research For a Better Future

Friedreich's ataxia consortium (EFACTS)

clinical network by including new sites to cover unrepresented areas and promote the inclusion of children.

Another aim is to identify relevant biomarkers and work towards optimised trial design, which is invaluable information for the planning of well-designed trials. In addition, support from a pharmaceutical company has been secured, with more potentially to follow. The interest from many stakeholders illustrates the importance of the outcome of this project for the progress of research.

Five years after its inception, EFACTS has progressed by developing new tools of clinical evaluation and biomarkers that will serve for future drug trials in FA. They have expanded the European FA biorepository (biological samples repository) and to date, there are 817 FA patients and 56 controls (i.e.: people without ataxia) recruited to the EFACTS database. The four-year follow up visits are coming

to an end, but five-year and six-year follow-up visits are continuing.

At the same time, the development and laboratory testing of new therapies for FA has continued to be the objective of related studies by EFACTS partners in collaboration with academic and industrial researchers throughout the world.

Overall, this large study is making a major contribution towards shedding light on the clinical features and progression of FA. It is using the information gained in order to design successful clinical trials with good protocols that maximise the chance of success in eventually developing a treatment for FA.

In addition, the clinical network of sites with specific expertise in Friedreich's ataxia provides an essential infrastructure for clinical trials, allowing efficient patient recruitment and assuring the best quality in conducting treatment trials.

EUROPEAN FRIEDREICH'S ATAXIA CONSORTIUM FOR TRANSLATIONAL STUDIES



Our **Scottish Conference** will take place on **Saturday 23 June 2018** at the **Stirling Court Hotel**. It's packed full of events tailored to our Scottish delegates.

You can visit our website (www.ataxia.org.uk/Event/stirling-conference-2018) to discover more, book your tickets and find out how to apply for a bursary.

WHAT'S IN STORE?

Professor Rita Horvarth from **Newcastle's Specialist Ataxia Centre** will be on the platform for our **Doctor's Q&A**, and our Research Officer **Dr Julie Vallortigara** will host our research updates. **Natalie Frankish**, the Scottish representative of **Genetic Alliance**, will tell us about their rare disease work in Scotland and the **Scottish Huntington's Disease Association** will talk about the financial advice project we are hoping to launch with them in Scotland. Registration opens at 9.30am and the conference begins at 10.00am.

Various people will also be sharing their tips on coping with ataxia in our **'It Works for Me'** sessions; if you're affected by a recent diagnosis, you can learn more about the condition in our **'All About Ataxia'** breakout. There will also be a breakout on relaxation techniques and we hope to have someone available to provide massage sessions.

We aren't planning to host a children's event or a Conference Dinner; if you are interested in dining together on Friday evening, please indicate this in your booking.

BOOKING

Early bird tickets go on sale on **1 February**. Book online at www.ataxia.org.uk/Event/stirling-conference-2018 or call the office on **020 7582 1444** to order a paper booking form. Regular rates will apply from 21 May, so don't miss out!

Tickets	Early bird rate	Regular rate (from 21 May)
Delegates with ataxia	£34	£37
Delegates without ataxia	£36	£39

Please note: If you book tickets online or over the phone with a member of staff, you should receive an email confirmation from us that your booking has been successful (if you **don't** have an email address or are booking your tickets with a paper form, you should receive a confirmation letter in the post.) If you don't receive confirmation two weeks after you made your booking, **please call the office to check that your booking has been successful.**

BURSARIES

We have a limited number of bursaries to help with travel and attendance costs; applications must be in by **1 May** and are awarded on a first come, first served basis. An individual can only be awarded **one bursary per calendar year**, so if you are awarded one for the Scottish Conference, you will be unable to apply for another for October's Annual Conference. You can download the bursary form from the website or call the office to request a paper form.

ACCOMMODATION

There are a **limited number of adapted rooms** available at the hotel (www.stirlingcourthotel.co.uk) and these must be booked through **Mike Garrett** (mgarrett@ataxia.org.uk) or by calling **Steph Marley** on **020 7582 1444**. When all of these rooms are booked, we can advise on other adapted accommodation in the area.

Please only reserve an adapted room **if it is essential** as others may be in greater need. All other bookings can be made directly with the hotel on **01786 451 712** and please **quote the reference 187106** to get our negotiated price.

LOGISTICS

Parking is free and plentiful at Stirling Court and we've reserved all available Blue Badge spaces but these are limited in number. All parking is close to the hotel, however, and there is room for drop-offs.

*If you have any queries about the booking process or conference in general, please contact **Steph Marley** at communications@ataxia.org.uk or call the office. We look forward to seeing you there!*



Being mobile: suggested apps to help to plan accessible trips



Some types of ataxia require the use of wheelchair assistance and other mobility aids but it is not always easy to find suitably accessible toilets, parking and other services at home or abroad. We've found two apps that can help.

Many of you will have this issue close to heart and no doubt know the locations of your local accessible points. However, at the times when you are travelling or visiting unfamiliar places, the following apps can help you prepare.

WheelMate is an app that lets wheelchair users around the world locate wheelchair-accessible toilets and parking spaces. The WheelMate app currently has more than 30,000 locations across 45 countries and locations are added and verified by fellow wheelchair users. This app is very basic: when looking for toilets and parking spaces in your location, it will come up with grey signs for unverified services and black signs for verified ones.

Another useful app is **AccessNow**. It's in a similar vein to WheelMate, but focuses on displaying accessible establishments such as hotels, restaurants and bars. AccessNow displays a map with four different indicators: 'accessible', 'partially accessible', 'patio access only' and 'not accessible,' and contains around 10,000 locations across 16 different countries. Many of the locations pinned on the map will also have detailed instructions or comments from users.

In comparing the two, Accessnow is an excellent app and more user friendly than WheelMate. Its database appears to be more up to date and continuously growing, with useful instructions on UK-based hotels, in particular. WheelMate is effective in its simplicity; the app certainly has a wider reach than AccessNow but seems to be functioning off an older system, as it's a little slow to use.

Both are free, so we would encourage you to download them if accessibility issues apply to you. They are both available through either IOS or Android Phones.

Combatting isolation online: Ataxia UK virtual Support Groups

Ataxia UK has built a wide array of virtual support networks over the years to combat the feelings of isolation that ataxia can cause. Today we're introducing our new groups, which you can request to join anytime.

As well as our page on **HealthUnlocked** (a forum to share medical queries, information and advice), there is: 'Your Blog' (a space on our website where people with ataxia can write their own articles, advice and stories); a break-away 16-30's website (where young people with ataxia can meet others, socialise and plan events); an Ataxia UK Twitter newsfeed (where we share wider information on ataxia and disability

in general) and an Ataxia UK Facebook page. We also currently run two closed FB support groups:

- **Parents of children with ataxia:** a place for parents of children with ataxia to share advice for supporting their child(ren).
- **16-30's:** a social space for young people with ataxia.

You can read more about these groups on the Ataxia UK website: www.ataxia.org.uk/Pages/FAQs/Category/online-support-and-forums

NEW GROUPS

This year, we're making **three new closed FB groups** to cater for those whose needs are not quite met by existing support networks. They include:

- **Parents with ataxia:** a support group for parents who have ataxia
- **Spouses and partners:** a support group for spouses and partners of people with ataxia
- **Carers:** a support group for carers of people with ataxia.

HOW TO JOIN

If you would be interested in joining any of the above groups, you can send an email to **Steph Marley** at communications@ataxia.org.uk, specifying which group you would like to join. If you have specific needs that none of these groups cater for, do get in touch to suggest a group that would be beneficial for you. We will consider your suggestion if there is enough demand.



A Big Give big thank you

Back in December 2017, Ataxia UK took part in the **Big Give Christmas Challenge**, the UK's largest match-funding campaign where, for one week only - and thanks to two pledge donations of £5,000 from our own supporters, and £5,000 from **The Hospital Saturday Fund** - donations made to Ataxia UK were doubled.

The response from our Friends and supporters was unbelievable. Thanks to your generosity, we smashed our £30,000 target, hitting this milestone within just a couple of days of the Challenge starting. By the end of the week, you helped us raise an amazing **£43,785!**

But the excitement didn't end there: your support kept coming in. In addition to our Big Give online match-funding campaign, we had **the best ever Ataxia UK Christmas Appeal**,

which brought in **£14,553.34**: in total, your donations this Christmas came to an incredible **£58,338.34!**

Your donations will not only help fund much needed research projects for the estimated 10,000 people living with ataxia in the UK, but also support future generations through the ataxia **16-30's project**, helping to provide advice and coping techniques on health, mental wellbeing and independence for young people living with ataxia.

This could not happen without the generosity of Friends like you. Once again, from all of us at Ataxia UK thank you for your support!

*"To us, the 16-30's group is worth its weight in gold. Alia has forged some genuinely close relationships. Now that she has friends with ataxia who encourage her to stay positive, give advice and who believe in her, the whole family feels less alone and part of a like-minded community." - **Anneli**, mother of 16-30's group member **Aila**.*



Chance to win winners

1st. £250
Ray Owen

2nd. £150
Katie Henderson

3rd. £100
Joyce Darlington

This year, Ataxia UK is spoilt by the number of runners who are tackling the **London and Manchester Marathons** to support us!

We'd like to introduce some of them to you, and find out why they've chosen to challenge themselves and support Ataxia UK.

45-year-old **Vandna Batchelor** is preparing for the London Marathon by running four times a week. She chose Ataxia UK because it's a charity close to her heart as a relative was recently diagnosed with FA. She plans to fundraise for us online and is thinking about hosting a coffee morning to raise funds. She is hoping to complete her marathon in four hours. All the best, Vandna!

Just over a year ago **Andy Frank** (left) discovered that his nephew, **Oliver**, had been diagnosed with Friedreich's ataxia after failing a routine medical for the Ministry of Defence Police. Andy is inspired by how Oliver is dealing with having ataxia, and decided that he wanted to do something extra to support him - so chose the Manchester Marathon. Training is going well so far for Andy, but he said that after getting up to 12 miles it does get tough on the legs and mind. He's also doing brilliantly with his fundraising, having already raised over £1,000! Go for it, Andy!

James Tattersal (left) has always enjoyed a challenge. He completed two marathons last year (one of which he ran for us) and is now looking to complete 12 marathons in 2018 for Ataxia UK, including this year's Manchester Marathon. To prepare, James says the hardest part has been "drastically reducing the amount of beer I drink!" He wants to raise awareness as his girlfriend's sister was diagnosed with Friedreich's ataxia in 2004, and he aims to raise £2,500. James asks that: "If you see me running anywhere in 2018, please give me a shout and I'll run faster!"

Physiotherapist **Paul Joyce** (left) is running his second London Marathon this year. This time it's in memory of his father, **John Joyce**, who had cerebellar ataxia and multiple systems atrophy. He feels a strong connection to the London Marathon, as his dad attended and supported him in his last race. He hopes to complete the marathon in three hours and is taking a more traditional approach to fundraising by raising money offline; he also plans to go to his local support group to talk about his father's story. The best of luck, Paul!

Sophie Kennedy and her boyfriend **Nathan** will be taking part in their first ever marathon this year. Sophie's brother, **Fraser**, and sister, **Rebecca**, both have FA, which is why Sophie and Nathan want to take on the challenge. They've both fundraised for us before, taking part in the **Big Bad Bike Ride** which was set up by Sophie's family; to fundraise for the London Marathon Sophie will be hosting dinner parties. She is hoping to complete the marathon in less than five hours and her target time is 4:30. Good luck, Sophie and Nathan!



FUNDRAISING

22-year-old graduate **Ryan Gibbons** is running the London Marathon for us this year as his twin brother **Frankie** was diagnosed with FA when he was five. Ryan has been running to and from work to prepare for the challenge, and he has fundraised for us before by taking part in the **Tough Mudder Half Marathon** and **London to Brighton Bike Ride**. He hopes the money he has raised can be put towards FA research. All the best, Ryan!

Singer and newlywed **Max Fox** is running the London Marathon because his mother and uncle both have a rare form of cerebellar ataxia (AOA2.) He will be fundraising at his theatre shows and online, and wants the money he raises to go towards research. Max has hired a personal trainer and hopes to complete the Marathon in less than five hours. Good luck, Max!



Fundraising than

We're so thankful to all of our hard-working fundraisers who took the time to fundraise for Ataxia UK this quarter.

Although we cannot feature everyone, we appreciate all of your fantastic efforts!

We would like to say a massive thanks to the **Sterling Dental Foundation** for holding a recent 'Fun Day' in aid of Ataxia UK, which raised an incredible £1,845!

The day consisted of face painting, magic and balloonist shows, Bollywood Dance workshops, food and cake stalls and a raffle.

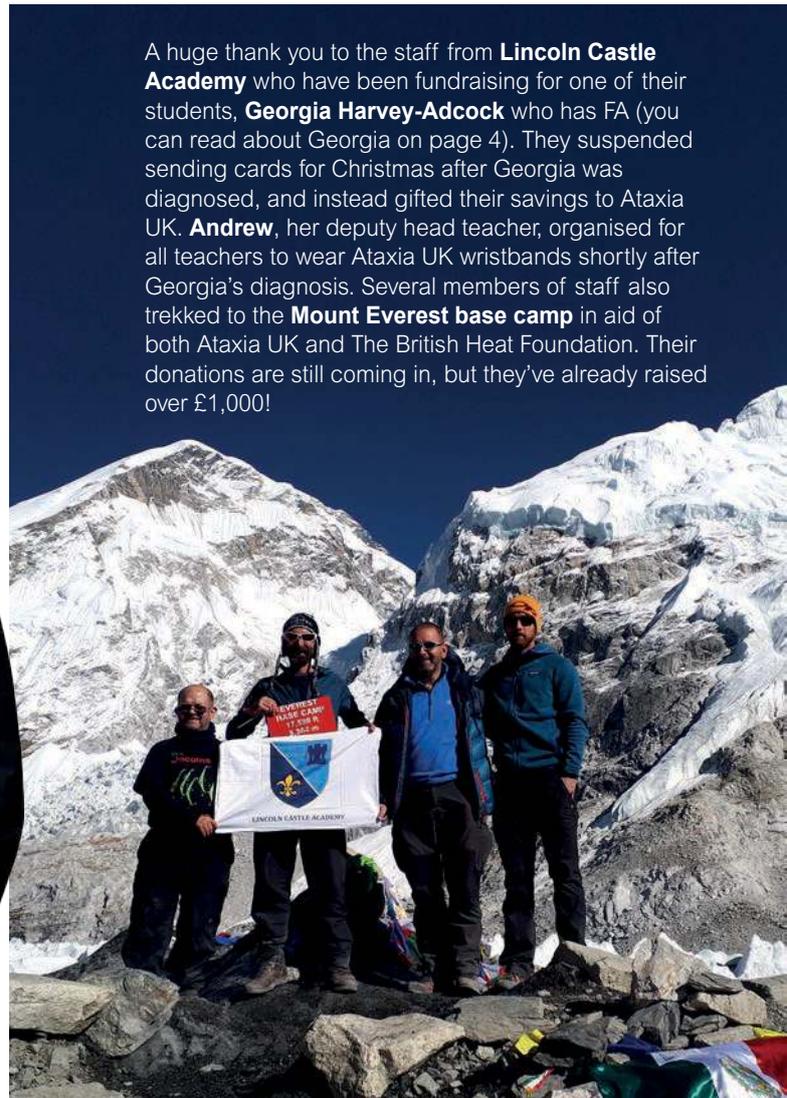
The local community came together to support nine-year-old **Ronnie Jafrate** who has cerebellar ataxia (pictured below with **Mr Virendra Sharma, MP of Ealing Southall**.) Our thanks go to **Julie Saunders** (Ronnie's grandmother), **Amy Bola** and **Moni Pengali** for their involvement in making the day such a success.



We would like to thank **Jenny Southey** for her on-going support for Ataxia UK over the years. She has fundraised for our charity at many village fairs, and her most recent fundraising event took place at the **Southwark Cathedral Christmas Fair** which raised £300. She plans to continue fundraising throughout 2018; her dedication to our cause is appreciated by all at Ataxia UK.

A massive congratulations to **Georg and Katharine Herdt**, and their friends **Bodo, Lutz, Niko, Piers, Jenny, Dan, Daniel, Hari, Reece** and **Sam** for taking part in the **Oxford Half Marathon** and raising over £2,500 for Ataxia UK. Georg was diagnosed with FA in 2015. Despite this, he remains very active and finds that sports and exercise have helped him to keep on top of some of his symptoms. Next year they plan to complete the event again with a bigger team!

A huge thank you to the staff from **Lincoln Castle Academy** who have been fundraising for one of their students, **Georgia Harvey-Adcock** who has FA (you can read about Georgia on page 4). They suspended sending cards for Christmas after Georgia was diagnosed, and instead gifted their savings to Ataxia UK. **Andrew**, her deputy head teacher, organised for all teachers to wear Ataxia UK wristbands shortly after Georgia's diagnosis. Several members of staff also trekked to the **Mount Everest base camp** in aid of both Ataxia UK and The British Heart Foundation. Their donations are still coming in, but they've already raised over £1,000!



k-yous



Our **Head of Fundraising, John Williams**, was delighted to visit **Supreme Home Care** in Telford to pick up a cheque for over £350 raised at a recent fun-day. Their client, **John Mytton**, has ataxia, and Supreme Home Care have been fundraising for us throughout 2017. We would like to thank John, senior carer **Pat Hall**, **Coral Chaproniere** and **Registered Care Manager Amy Hutchings** for all of their involvement.



The Camelford and District Agricultural Association and the family and friends of **Stuart Retallack**, who sadly passed away in December 2016, have raised thousands of pounds in Stuart's memory. **Karen Bunt**, Stuart's sister, has collected many donations and fundraised for us, and the Association kindly presented us with a cheque of £250. Thank you to the Association and to everyone who donated, as well as to our former Trustee **Ann Truscott** for representing Ataxia UK at the cheque presentation.

Victoria Gee has supported Ataxia UK for many years, as her cousin **Abigail Stone** has FA.

In 2017 she organised her second **Sponsored Walk in Wales**, from Barry to Cardiff (pictured on the front cover) which raised over £3,000 for Ataxia UK.

We would like to thank Vicky and Abigail, members of the **South Wales Support Group** who went along, and her lovely friends and family for their ongoing support.



The Ataxia UK Annual Spring Raffle

Our annual raffle is back this Spring, and you'll find your tickets included with this magazine! Sell as many as you can to friends, families and loved ones to heighten their chances of winning some of our wonderful prizes, including vouchers, wine and £200! All ticket sales will help support our work. Good luck, everyone!



Why should I make a Will?

Writing a Will is one of those things in life - like life insurance or saving into a pension - which many of us would prefer not to think about.

But, if you don't make a Will, the law decides who will inherit your assets and possessions. This could mean that your possessions don't go to the people you want them to.

Writing a Will is the best possible way of taking control and ensuring your money and possessions are passed on to the people and causes you care about. Although the process can seem daunting and costly, setting up your Will is a lot easier and more affordable than you might think.

At Ataxia UK, gifts our supporters leave us in their Wills contribute and underpin every aspect of our research, support services and awareness campaigns. Whatever their size, these special gifts make a huge difference.

A gift in your Will can help accelerate ataxia research and help thousands of people to live longer, healthier lives.

There is no obligation to leave a gift in your Will to Ataxia UK, but after looking after your loved ones, we do hope you will consider leaving a gift to Ataxia UK and help us continue our essential work in the future.

To find out more about leaving a gift to Ataxia UK in your Will, please free to call our legacy team on **020 7582 1444**, email us at:

giftsinwills@ataxia.org.uk, or visit our website **www.ataxia.org.uk/leave-a-gift-in-your-will**

Adapting to life



Those that know me well or have read my book will know that the biggest thing in my life is Chelsea FC. To be asked to write an article about my relationship with the club is an absolute honour for me.

I cannot remember watching my first game, but I'm guessing it was in about 1976. My dad used to take me as a young boy and it's a passion that's stayed with me ever since. I have had a season ticket since the 1987/88 season and I've only missed a handful of home games in that time.

I could discuss my support for the club until the cows come home, but I'm afraid there's no room for that here. But I have been to three winning European finals (Stockholm, 1998; Munich, 2012 and Amsterdam, 2013.) Also 24 other European trips to 23 European cities to watch matches as well as to six winning FA Cup finals, four winning League Cup finals and nearly every home and many away league games every season for the last 30 years (including five

championship winning seasons). I also have every home and neutral match programme since 1947.

As my ataxia has affected my mobility over the years, **the viewing positions** I have had at the stadium have varied. When I was able to stand, I'd do so in The Shed at Stamford Bridge (now the South stand); when I was unable to stand, I'd transfer down to the benches in the old West stand. When I became unable to walk unaided, I'd go with my dad to the West stand, before transferring our tickets to the opposite side of the stadium in the East stand when I began using crutches and a wheelchair. For a few seasons, I chose to transfer out of my chair and into a seat in the back row of the lower tier of this stand. When this became too difficult, I sat in the North stand (now called the Matthew Harding stand) where I could remain in my wheelchair.

In July 2003 Chelsea was bought by **Roman Abramovich** who's transformed the club from being a top English club into a European superpower. Since 2006, he's abolished charges for all disabled home fans, created a separate ticket policy for disabled fans and created the **Chelsea Disabled Supporters Association (CDSA)**. I applied to be on the CDSA's first committee, as I believed that I had a good understanding of various levels of disability and was keen to play an active role in what the club was trying to do for its disabled fans.

I was accepted and became a committee member originally for two years. I created a website for the CDSA (www.chelseadsa.com) and obtained an email address which I still man to this day (chelseadsa@yahoo.co.uk). The club has kept me on the committee (they now call me an honorary committee member), so I still have a degree of responsibility, as well as being a supporter. The CDSA meets with the club three times a year to discuss any issues that any of the disabled fans might have. Over the years we have made tweaks to the disabled ticketing policy, installed radar locks to all the accessible toilets, improved signage around the stadium and installed lowered counters at food outlets and ticket booths, to name just a few things.

Only by the club listening to its disabled supporters, can all disabled fans enjoy their days out at football just like everyone else. In six and a half years' time, the club will be playing its home matches in a brand-new stadium, located on the same site. This new stadium is still in the planning stage, and the CDSA will be playing an active role in ensuring that the stadium is totally accessible for all.

Matthew Law
matthewlaw1968@yahoo.co.uk

Below:

Me on Christmas Day wearing my Chelsea Christmas Jumper and my Chelsea Santa hat



Applying for PIP and ESA made easy with c-App

Personal Independent Payment (PIP) and **Employment and Support Allowance (ESA)** have been in the national press a lot recently, with many people not getting the support they need. A new web app has been released that will help you prepare for a PIP or ESA assessment and let you know what to expect.

As many of you will be aware, it can be a difficult process to access the PIP and ESA to which you may be entitled. An assessment is made by a healthcare professional to find out how your illness or disability affects your ability to work, and a decision by the **Department for Work and Pensions (DWP)** to estimate how much money you are able to claim (between £22 and £141.10) is reached. This is often followed by a 'mandatory reconsideration', whereby the assessed party can challenge that decision if they feel it is unfair.

The Government's recent inquiry into the effectiveness of this process has uncovered serious flaws in both the assessment and appeal stages. There was an overwhelming public response to this inquiry which shared a general consensus: that PIP and ESA assessments were militaristic and showed a lack of understanding of various conditions. For ataxia this is particularly relevant, as symptoms can vary in severity from day to day and be difficult to use as

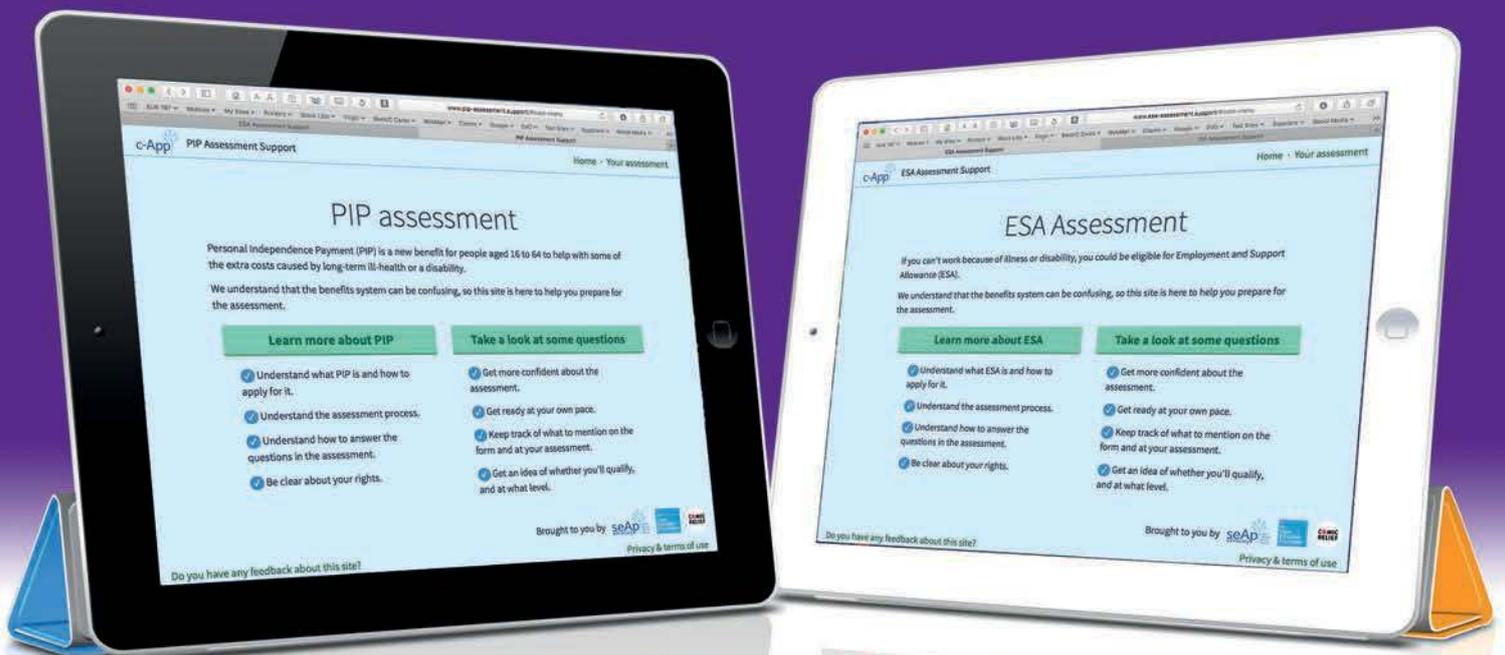
evidence for the support required; feelings of fatigue or dizziness, for example, cannot easily be quantified by an assessor.

Written evidence from the Public and Commercial Services Union (www.data.parliament.uk) has echoed this public concern: "Our members report that there are regular examples where the level of expertise of the person carrying out the assessment does not appear to match the requirements of the health condition being assessed ... It is much easier to confirm the original decision than change it during an appeal."

C-APP CAN HELP

Despite the many issues that accompany PIP and ESA, there is a new web app that can help prepare you for your assessment, giving you the best chance of getting the support that you need: the **c-App** was created to alleviate some of the stress that can come with having an assessment by guiding you through the process, so you feel confident to communicate the full extent of your condition.

The web app has two sections that explain how both ESA and PIP work; it also outlines what categories of topics and questions you could be asked by an assessor, giving you the chance to practice some questions at home. You'll then receive a summary of which of your symptoms are important to mention in the assessment. You can find the c-App for ESA here (www.esa-assessment.support/#main-menu) and for PIP: (www.pip-assessment.support/#main-menu).



Winning at a canter

The story of **Darren Ashton's** rise to prominence is a remarkable one. Just six years ago he was diagnosed with Friedreich's ataxia; now, he holds the coveted title of the **RDA (Riding for the Disabled Association) Rider of the Year award for 2017**.

Meeting Darren at the stables where he practices in Trowbridge, Wiltshire, it was easy to see why he has been so successful in taking up horse riding. At 16, Darren was a football fanatic; it was something that he did almost all the time, whether it was at home, at school or for his local team. Suddenly, he started to get multiple injuries in his knees and ankles but couldn't understand why. Eventually he visited a doctor where the diagnosis of FA was given.



From there on, Darren says that the problems snowballed: "I wasn't bothered at the time of diagnosis, but it quickly became very difficult, once I began to feel the effects of the ataxia. I was on antidepressants for a while, I had anxiety and then borderline agoraphobia at one point. It was a very unpleasant time".



A few years later, whilst Darren was trying his hand at wheelchair basketball, his mother spoke to a fellow parent who mentioned the RDA to her. After a quick bit of research, Darren thought he'd give it a go and so he joined the Hemel Hempstead branch. It struck a chord with Darren immediately, and harnessed his competitive edge. "Riding gave me a purpose, I have always liked competing, and it has **given me something to aim towards** and practice at to keep my mind busy. **When your mind isn't busy, it wanders on to bad thoughts**, it's best to always have something to keep you focused. I was pretty wobbly at the start, but by keeping it up and going every week I improved so much. **It's given me strength in my core and self-confidence.**"

Shortly after, Darren and his parents, **Stephen and Helen**, moved to Trowbridge, as their house in Watford was no longer suitable for Darren's needs. This allowed Darren to join the Saxon RDA group, which is just around the corner from their accessible bungalow.

As of the start of 2017, Darren began to enter competitions and things escalated. "The first competition was a dressage friendly, which I won. Around March they [the RDA] have regionals, so I went to that and did the countryside challenge and dressage. I came second in the countryside challenge, which granted me a place at the nationals. When I went to the nationals, I didn't feel any pressure because I felt like I shouldn't be there - I only hoped to not finish last, so to finish second was just mad!" he says.

This all happened within a matter of months and his achievements certainly did not go unnoticed, as he was soon nominated for the RDA's rider of the year. "My group leader entered me on the last day you could enter but didn't even tell me. One minute I'm riding a horse around a stable, the next I'm meeting Clare Balding and getting an award in front of 300 very rich people!"

Darren feels that riding has helped with his ataxia and highlights the importance of attitude in being willing to try and commit to something when you feel ready. "When I first went riding, I had two side walkers and someone leading me. Now I can ride easily by myself. It's good for the legs because you have to kick the horse. It's a full body workout really, but it doesn't feel like one ... You've got to want to push yourself, you can't knock anything until you've tried it. I'm not a 'horse-y' person, I used to like horses but it never really crossed my mind to ride them."

It is well known that exercise can help people with ataxia. Ask your GP for a referral to a physiotherapist or neuro-physiotherapist for some advice on what exercises you can take up to help manage your ataxia.

Getting ataxia into the press

Tallulah Clark, a student with ataxia, has recently had her story published in the **Sheffield Star**; **Derek Wood**, co-ordinator of the **Farnham Support Group**, has won a double-page spread on ataxia in Surrey's local magazine, **Vantage Point**. Contacting your local press is a great way to raise awareness about ataxia in your local community.



Towards the end of last year, we started to create a portfolio of case studies of people within the Ataxia UK community as part of the **Big Give** campaign. This involved showcasing some of your stories to share on our website and social media platforms. One of our case studies was about Tallulah Clark (left), a 19 year-old student from the University of Sheffield, who was eventually diagnosed with ataxia with **oculomotor apraxia (AOA2)**, after having been in and out of hospital for a decade with misdiagnoses.

Her infectious positive and hard-working attitude has helped her raise almost **£7,500** in just a few months, after having only been diagnosed in May last year. Speaking with Tallulah, it was clear that she was willing to do anything to raise awareness of ataxia; she was enjoying her time at University but was also facing some challenges.

As many of you will know, ataxia symptoms are often misconstrued as the acts of someone who is drunk, and this problem is exacerbated for Tallulah by public perceptions of university drinking culture. Tallulah spoke about how she had been denied entry to night clubs by bouncers who were simply not aware of her condition or wouldn't believe her. She contacted her local paper, and after a few phone calls, an interview was arranged in which Tallulah could tell her story to the Sheffield Star. She was published in December and hopes to see a difference in the local community's attitudes about her condition.

Derek Wood receives a local magazine called Vantage Point through his letterbox each quarter, and thought it might be worth getting in touch to see if they'd print something about ataxia. "My hope was to gain new members, which in turn would lead to raising awareness," Derek told us. "I consider myself generally well-educated, but had never heard of ataxia before my own diagnosis and I've never seen anything in the press about it since. So I emailed the editor."

In that email, Derek wrote a succinct description of ataxia, using everyday language and detailing its common symptoms, and gave notice of when the Support Group would next meet. The editor agreed to publish the notice of the group's next meeting, and since then, Derek has been contacted by **three new members**.

The editor also offered Derek a **450-word article to highlight ataxia as a condition** in the coming May issue. Working together on the article, Steph Marley met up with Derek and the group to plan what the article could entail, which has been very productive. The article will be published in May; look out for further news!

*Thinking about contacting your local press, and want some advice?
Get in touch at communications@ataxia.org.uk and we'll help!*

Below:
Derek Wood (third from left) and the **Farnham Support Group**.





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