ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 214. Summer 2021

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

ATAXIA

Ataxia UK

In the office

HELLO

Adeela Ahmad

Hi, I'm **Adeela Ahmad** and I'm the new Research Officer. I have completed a Biomedical Science BSc (Hons) at King's College London, and Genomic Medicine MPhil at the University of Cambridge. I'm delighted to join Ataxia UK as I am excited to support the charity in delivering its strategic aims in research to find effective treatments for people with ataxia.

Welcome

Dear Friends,

Welcome to our June magazine. I hope it portends a summer full of face-to-face encounters with your families, friends and the wider world.

It also includes a number of opportunities for you to be involved in the work and activities of Ataxia UK in small or big ways. Have you got a new diagnosis? Come to **All About Ataxia** (p.5). We need two **Trustees** (p.23); do you have the skills to support the governance of Ataxia UK? We are still working remotely but are hopeful that over the summer we can start a gradual migration back to the office, and finally meet face to face with our colleagues who have been recruited whilst we've been away. Nonetheless we have decided not to risk a face-to-face Conference this year; you can read about the **Virtual Annual Conference** and about our **Wellness Week** on p.10.

I hope you have a wonderful summer with lots of opportunity to be with your friends and family.

Sue Millman

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KEY CONTACTS

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

Services

James Atkins
- InControl Community Programme Manager
volunteering@ataxia.org.uk

Sheila Benneyworth
- Helpline and Membership Officer
helpline@ataxia.org.uk
0800 995 6037

Research

Dr Julie Greenfield
- Head of Research
research@ataxia.org.uk

Fundraising & Communications

Dan Beacon
- Head of Fundraising and Communications

Kelvin Gichohi
- Individual Giving Manager

Rebecca Holt
- Community Fundraising Manager
fundraising@ataxia.org.uk

Leanna Coleman
- Communications Officer
communications@ataxia.org.uk

For queries or feedback please contact Leanna Coleman.

Contact our office

office@ataxia.org.uk

020 7582 1444

Ataxia UK, 12 Broadbent Close
London N6 5JW

www.ataxia.org.uk

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Right: **Patsy** with her husband, **Ken,** who has been very supportive of her work in running the group.

Thank you, Patsy!

Patsy Riggs has run the Ipswich and Colchester Support Group since 2006, but in 2020 she stepped down as coordinator. Here Patsy reflects on her time as a group leader.

When I initially joined Ataxia UK, I was invited to start a support group. It has run since July 2006. I will be 79 in November and have stood down to allow younger people to be involved with supporting those affected by ataxia.

Our group met in the lounge bar of Holiday Inn hotels. They were very informal and allowed for general chat. Fortunately, the Holiday Inn provided beverages and biscuits for a small fee for a charity, and drinks were available to buy from the bar. Occasionally, we had a speaker such as a physio or someone from Social Services, a neurologist, or even an MP, all of whom gave their time free.

When members didn't interact or attend meetings, I never saw that as a failure of the group, but rather that I/we helped them to feel less isolated with their diagnosis of ataxia, and now they are able to get on with their life in a positive way.

Volunteering with the group was like therapy for me as I had something to focus on. Before I retired, I was a word processing secretary and still enjoyed using a proper keyboard. I liked typing a monthly newsletter for the group members which kept those unable to attend meetings in touch.

As a group we engaged in special events such as the Wheely Wobbly Walks and International Ataxia Awareness Day stalls. Some of the members also met outside of the group to go on fishing holidays. These are all happy memories for me.

Since stepping down as coordinator, I am a befriender volunteer for Ataxia UK. So far, I've had one befriendee. I like to think I am there for anyone who wants a chat. I am so grateful to Ataxia UK for being there when I was first diagnosed, so I want to volunteer to help others.

During the time that I have been engaged with Ataxia UK, there has been a rapid cycle of old and new members and I feel it very important that some of us stay and support the organisation. **Sue Millman**, CEO of Ataxia UK, has been a great inspiration to me.

My catchphrase is stay safe and don't forget to smile!

Anne Ford Cup & Ernie Heath Shield

Since 1992 we have awarded the Anne Ford Cup to 29 exceptional people with ataxia who have made a special contribution to the ataxia community. In 2007 we introduced the Shield in memory of **Ernie Heath** the founding Chairman of the newly constituted Ataxia UK, and have honoured a further 17 outstanding individuals all of whom (except one) do not have ataxia. But both the Cup and Shield are now full of names which you can find at **www.ataxia.org.uk/support-services/ataxia-uk-conferences/cup-and-shield-winners**. We will introduce the new awards at our Virtual Annual Conference (p.10) .

Ataxia UK Awards

Do you know someone who has made an outstanding contribution to the lives of people affected by ataxia? Please help us to recognise them by nominating them to be one of the first recipients of our new awards at Annual Conference.

(Please note Trustees and staff are not eligible.)

If you have someone to nominate, please contact ***Lucy Porter*** *on* ***lporter@ataxia.org.uk (0207 582 1444)****.*

Upcoming All About Ataxia Online Seminar

Our 'All About Ataxia' seminars are for people newly diagnosed with ataxia. They are also useful for those who already have a diagnosis. The seminars offer you the chance to understand what can help you, hear how the facilitators live with ataxia, learn from other participants how they are facing their diagnosis and understand how Ataxia UK can help.

Our next online session is **Saturday 21 & Sunday 22 August 2021** (2 days - 2½ hours per session).

"I got a lot out of the advice and shared experiences and now have plenty of food for thought. I shall be spending the next few days writing to my GP and consultant to try and progress things, but more importantly I now know how much I can do for myself to manage this condition."

To find out more and sign up, head to ***www.ataxia.org.uk/ataxia-uk-events***

Doctors Q&A from Ataxia UK's Virtual Conference 2020

Dr Rajith de Silva (Queen's Hospital, Romford), Dr Priya Darshni Shanmugarajah and Emma Foster (Sheffield Ataxia Centre) joined Ataxia UK's Virtual Conference to answer questions from people with cerebellar ataxias. Here are a couple of their insights:

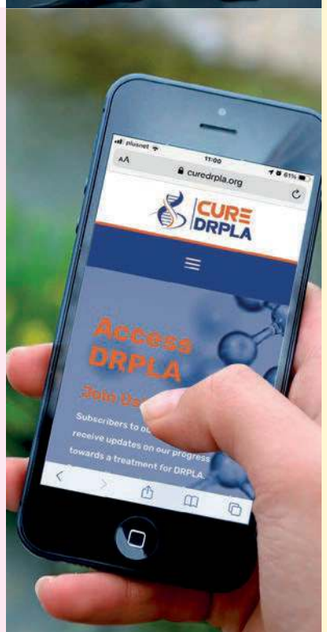
What advice would you give to minimise the progression of the disease?

We don't have a lot of data on the benefits of exercise in ataxia, but we know in the field of Parkinson's disease that doing exercise can maintain or reduce the rate of decline as time goes on. We assume, therefore, that similar mechanisms may operate in ataxia as well. I emphasise the importance of focusing on your core strength, since this is vital for maintaining function, in its broadest sense. Even if your ability to get around is restricted, doing exercises, even in a static setting, to maintain core strength is essential.

Is it usual for too much heat or sunshine to weaken the muscles in your legs?

There is no organic reason as to why being out in the sun would cause a weakness in your muscles. What's likely happening is that your body temperature rising is fatiguing, and your body struggles under the stress of heat. Whilst sun is highly beneficial to our wellbeing and our vitamin D, and I recommend it, if used safely, it's about having the balance. Have cold drinks, ice cubes to suck, and a fan nearby, so that you may still enjoy a bit of sun, but then have cooler showers to cool down, so that your body can recover.

The CureDRPLA Global Patient Registry is live!



Ataxia UK and the US Foundation CureDRPLA have set up and are the lead organisations of the CureDRPLA Global Patient Registry. This registry aims to collect data on as many Dentatorubral-pallidoluysian atrophy (DRPLA) patients as possible to better understand DRPLA development and monitoring the quality of health - both are essential for future clinical trials.

The registry will collect information on demographics, specifics of diagnosis, medical history, research, functional mobility, quality of life, and health economics. We will ask everyone that joins the registry to update their information once a year. We encourage all patients and families with DRPLA to join this registry. It is available in English and it will shortly be available in French, Italian, Japanese, Korean, and Portuguese.

If you would like to participate, please visit ***https://curedrpla.org/en/global-patient-registry****, and if you have any questions email Ataxia UK's Research Officer* ***Dr Silvia Prades*** *on* ***drplaregistry@ataxia.org.uk****.*

Latest results from the European Friedreich's Ataxia Consortium for Translational Studies (EFACTS) project: a 4-year cohort study

Friedreich's ataxia (FA) is a progressive, neurodegenerative disease and, generally, onset occurs around puberty. Currently, no cure or approved treatment is available. However, various potential treatment approaches are being developed and robust clinical trial designs are needed.

The EFACTS project investigates the natural history of FA, based on an ongoing and open-ended registry. FA patients have been assessed annually at 11 clinical centres in seven European countries. A paper published in March 2021 analysed data collected over four years. The main measurements taken were SARA (Scale for the Assessment and Rating of Ataxia), and ADL (the activities of daily living) scale. SARA monitors clinical deterioration and the patient-reported outcome, ADL, measures functional decline. The researchers analysed annual progression of the condition for the whole group, and subgroups defined by age of onset and ambulatory abilities. The objective of the project was to assess the progression characteristics and to identify patient groups with differential progression rates based on four-year data, to guide upcoming clinical trial designs.

The key findings were that annual progression rates for SARA were higher in patients who were ambulatory than non-ambulatory. Patients in both these groups had similar ADL progression rates. Although differences in progression slopes were not significant, SARA and ADL showed slightly greater worsening in the patients with symptom onset at ≤24 years, than with patients with symptom onset ≥25 years.

Additionally, the project was used to calculate the number of patients required in certain trial designs and ADL was highlighted as valuable for upcoming study designs.

The researchers concluded that the findings are valuable for clinicians and researchers as they provide reliable outcome measures to monitor progression of the condition and help in deciding how many participants are needed in future trials. The findings are useful in improving the feasibility of FA clinical trials.

The London Ataxia Centre is one of the main contributors of the EFACTS project. **Professor Paola Giunti** (right), Head of the Centre and a principal investigator of the project, said: "Thank you to all the participants of the EFACTS study, many of whom are from the London Ataxia Centre. This study has generated interesting data that will be important in designing future Friedreich's ataxia clinical trials."

Please visit ***https://pubmed.ncbi.nlm.nih.gov/33770527*** *to find the full published paper.*

Ataxia UK and the National Ataxia Foundation (NAF) co-fund SARA^{home} project

We are pleased to announce that Ataxia UK and NAF have awarded funding to a research project involving a number of groups in Europe.

The project is coordinated by Dr Marcus Grobe-Einsler and Professor Thomas Klockgether at the German Center for Neurodegenerative Diseases (DZNE) Bonn, Germany. In this project, the researchers will use a newly developed video-based assessment tool called **SARAhome** to study the severity of ataxia in the home environment. This study will involve people with **spinocerebellar ataxia type 3 (SCA3)**.

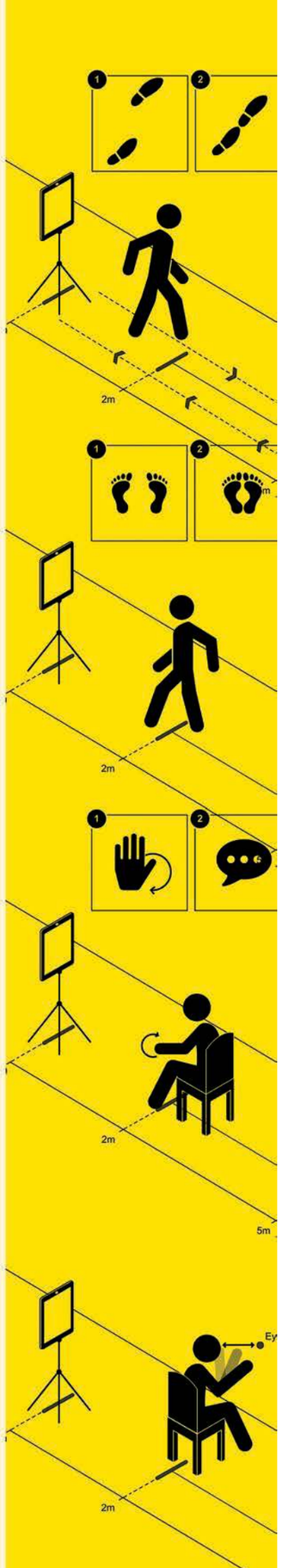
Currently, the severity of ataxia is measured using clinical scales such as SARA (the Scale for the Assessment and Rating of Ataxia). SARA is made up of eight assessment items, (for example, sitting, speech, nose-finger test etc.) and is applied by trained professionals in a clinical setting such as a hospital. However, ataxia symptoms can change from day-to-day and throughout each day. Therefore, it is important to be able to assess the severity of ataxia in a home setting. Assessing ataxia in a home environment may also be more convenient for people with ataxia than visiting a hospital and allows the collection of data for clinical trials in the event of government lockdowns.

SARAhome is a video and device assisted rating of ataxia that is performed at home. It contains almost the same assessment items as the traditional SARA and people with ataxia can be trained to apply SARAhome themselves. SARAhome instructions are given on a tablet screen and the performance of the different assessment items are video recorded on the tablet. This recording is then transmitted to be rated.

People with SCA3 from the European Spinocerebellar Ataxia Type 3/ Machado-Joseph Disease Initiative (ESMI) cohort will be involved in this research project. ESMI has multiple study sites across Europe in Bonn, Tübingen, Aachen, Essen, Heidelberg (Germany), London (UK), Azores and Coimbra (Portugal), Nijmegen and Groningen (Netherlands), and Santander (Spain).

During their project the researchers will: assess the severity of ataxia under real-life conditions, investigate daily changes in ataxia severity and what may cause these, demonstrate the feasibility of SARAhome, and identify the minimum number of days home assessment is needed to assess ataxia severity.

Overall, this project aims to give us further insight into assessing ataxia severity in a home environment and the changes in ataxia severity. Although this project focuses on SCA3, SARAhome could be used in the future for other types of ataxia.



Healx launches partnership with Ataxia UK and FARA to find treatments for rare neurodegenerative condition

Ataxia UK and Friedreich's Ataxia Research Alliance (FARA) are excited to announce a partnership with Healx.

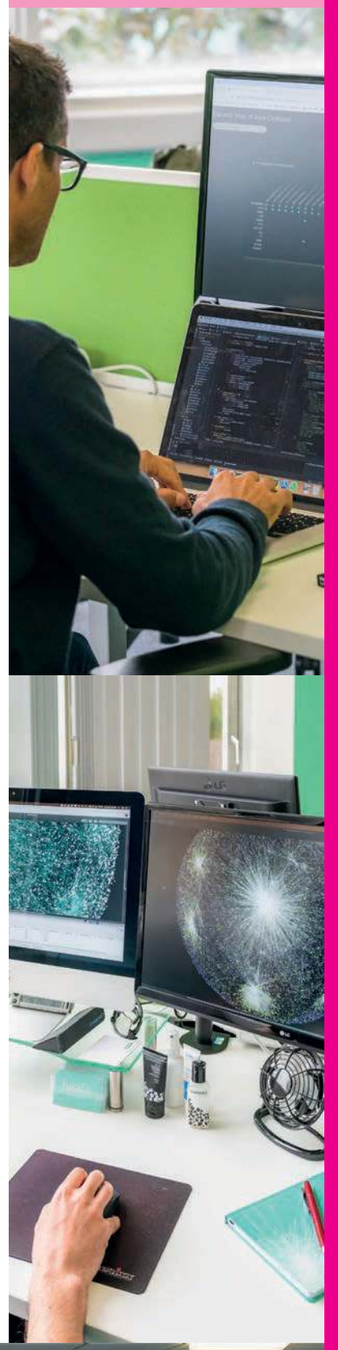
Healx is an artificial intelligence (AI)-powered, patient-inspired technology company, accelerating the discovery and development of rare disease treatments at scale. Working in collaboration with Ataxia UK and FARA, Healx will leverage its state-of-the-art AI platform and drug discovery expertise to develop novel treatments for Friedreich's ataxia (FA).

FA is a progressive, inherited form of ataxia and is caused by a genetic fault in a gene that encodes a protein called frataxin. Unfortunately, there is currently no cure or approved pharmacological treatment specifically for FA but there are some treatments available to manage the symptoms. This partnership will aim to find, and accelerate to the clinic, some of the world's first disease-modifying treatments for the condition.

To do this Healx will leverage its cutting-edge technology and innovative drug-repurposing approach and combine this with Ataxia UK and FARA's unrivalled patient and scientific insight. At the heart of Healx's technology is Healnet - their AI drug-discovery platform. As one of the only AI companies in the world to focus specifically on rare diseases, Healx has developed the world's most comprehensive biomedical knowledge graph for rare diseases which comprises millions of data points from clinical, pharmacological and scientific literature. This graph is analysed by more than 10 different AI models to rapidly uncover novel connections between drugs, diseases and other relevant medical information. These AI models have been specially trained to predict the effectiveness of repurposing and combining drugs for rare disease treatments and, in the case of this project, the team have developed a novel, metabolic model that they can use to identify drug candidates.

Healx is unique in the AI drug-discovery space in its creation of novel treatment opportunities through already approved drugs. This repurposing approach shortens and de-risks the path to clinical trials - since the safety profile and mechanisms of action of the drugs are usually well-characterised meaning people in need can get effective treatments earlier and at a more reasonable cost.

Ataxia UK are also working with Healx to facilitate drug-repurposing in other types of ataxia through connecting them with academic partners, researchers, and clinicians in our network.



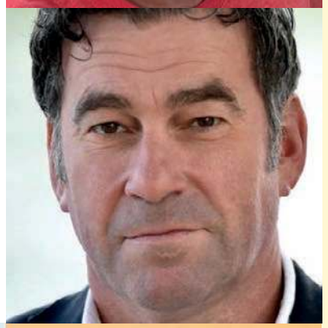
Ataxia UK Virtual Annual Conference 2021

Last year's online Annual Conference was such a success that we've decided to avoid risk and make Conference virtual again this year!

To relieve Zoom-burn-out, it will be spread over three days **Fri 15 Oct (afternoon) - Sun 17 Oct**. Friday afternoon will comprise ataxia research and medical Q&A sessions focused on the most common ataxias; Birds of a Feather will enable you to link up with people with your ataxia, or in similar circumstances; and it concludes with Bingo in the evening.

Saturday and Sunday will be hosted by our Patron **Paul Coia** and include an interview with Irish Bronze Paralympian dressage medal holder **Helen Kearney**, and British rider **Mari Akhurst**; Patron **Dom Joly** meeting actor **Robert Perkins** (Trustee); It Works for Me; other speakers TBA and breakout sessions on both days; with entertainment on Saturday evening.

Based on your feedback, we will have a re-run of the breakouts on Sunday; plus guest speakers, It Works for Me, and the presentation of our NEW awards. (p.5) Every day will include opportunities for you to meet other delegates. The per-screen-charge is £20 for the weekend. Bookings open **14 June**. Visit the website **www.ataxia.org.uk/latest-news/virtual-conference-2021** and see the e-newsletter for the speakers as they are announced.



Ataxia UK Wellbeing Week

From 21- 25 June 2021 our InControl team are hosting a wellbeing-focused activity each day from 1-2pm.

Practicing **mindfulness** involves breathing methods, guided imagery, and other practices to relax the body and mind and help reduce stress.

Hypnotherapy is an alternative medicine in which hypnosis is used to create a state of focused attention, and guided imagery are used to help overcome concerns and issues.

Involvement is an opportunity for you to become directly involved in Ataxia UK's work. We have a variety of flexible projects.

Speech therapy techniques are used to improve communication. We have been delivering a pilot virtual speech therapy project with University of Strathclyde since April and hope to present our findings. We will also talk about how we hope to deliver this as a regular service in future.

Our **quiz** will replicate the style of BBC's Pointless. We will ask you to guess the least known answer from a list collated from members and volunteers. A prize will be provided for the winner.

*Further information on Wellbeing Week can be found by visiting **www.ataxia.org.uk/ataxia-uk-news/wellbeing-week**. Alternatively, please email **volunteering@ataxia.org.uk***

Saying goodbye to gluten

After seven years of suffering with a mystery illness, Hayley was diagnosed with gluten ataxia at 29 years old. She talks about living a gluten free lifestyle.

I had never heard of gluten ataxia. I couldn't believe that something so simple made me so ill and was overlooked for so long. I certainly couldn't believe that bread was causing brain damage! I loved anything with gluten in it; I was known as the carb queen. I was devastated and relieved at the same time. Going gluten free sounds simple, but it was emotional.

I first became ill at 23; I had been riding that day. I came home and suddenly the room began to spin and I felt very ill - I believe it was triggered by food poisoning. I lost 1.5 stone in a week and sadly the GP wasn't helpful, despite my symptoms. Over the next few years, I was passed around hospital departments from gastroenterology, brain physio to audiology.

My symptoms affected my gut, balance and eyesight. I had constant waves of what felt like a panic attack mixed with vertigo, I slurred my words and had constant brain fog.

I was eventually referred to Prof Marios Hadjivassiliou who confirmed gluten ataxia. He told me to follow a very strict gluten free diet, stricter than a usual coeliac gluten free diet. I had my last meal from my local bakery and sobbed, but I was relieved to find the answer.

I have been following a strict gluten free diet for almost six years now. I am so sensitive to trace amounts of gluten that our entire home is gluten free, including the dog! I can't kiss my husband if he has eaten gluten and I can't work with products that contain wheat protein (which many hair products have). In fact, I had to remove myself from my own hair salon for a few years and now I run a gluten free studio alongside my main salon. Being allergic to your business isn't fun.

Now I live relatively symptom free, as long as I stay away from gluten. I have a brain scan once a year and blood tests every six months to keep an eye on my condition. Due to the damage gluten ataxia can cause, our son has been tested and also lives a gluten free lifestyle.

*For more information on how to live a gluten free lifestyle, visit my website: **www.glutenfreefabulousme.co.uk** and my Instagram page: **www.instagram.com/glutenfreefabulousme***

Join Chance2Win today!

Your ticket takes us a step closer to a future without ataxia.

The Chance2Win raffle is a wonderful way for Friends of Ataxia UK to help fund research into finding new treatments and cures for the ataxias and support services for thousands of people affected by ataxia across the UK - all from the comfort of your own home.

As the world opens up, we know that not everyone feels ready to take part in an outdoor fundraising event just yet - but that doesn't mean there aren't other ways you can help make a difference without lifting a finger!

Join the Chance2Win raffle today and from just £2 a month, you can purchase a one-ticket entry for each of our four quarterly prize draws throughout the year. For each prize draw, three winning names are picked at random to win one of three cash prizes:

1st Prize - £500, 2nd Prize - £250, 3rd Prize - £150

HOW TO GET INVOLVED

Step 1: Complete your contact and Direct Debit details on the enclosed Chance2Win leaflet. Choose how many tickets you would like to buy. **Each ticket entry costs £2 a month**.

Step 2: Simply return the completed leaflet using the enclosed FREEPOST envelope to our office address: **Ataxia UK, FREEPOST RTUG-CLKB – RGJE, 12 Broadbent Close, London, N6 5JW**.

AM I A WINNER?

We'll let you know whether you are one of our three cash prize winners by phone. You will then receive a confirmation letter through the post including your prize cheque.

WHY A REGULAR GIFT?

By taking part in the Chance2Win raffle, your regular gift will play an important role in helping Ataxia UK plan for ataxia research projects as well as improve medical and social care for people living with ataxia.

A regular gift allows us to plan for the future because we know, day in day out, that we have a steady income stream that can be relied on.

"My husband was recently diagnosed with cerebellar ataxia. We joined Ataxia UK because we wanted to make a financial contribution towards ataxia research following his diagnosis. We were both very surprised by the lack of awareness there is about ataxia amongst healthcare professionals. This is why we decided to donate to Ataxia UK on a regular basis. I was so surprised to have won because we had only been taking part for a few months." ***- 1st prize winner, Patricia Bartholomew (Friend of Ataxia UK)***

We want to add, it's not just YOU who could win. But by joining Chance2Win today, you are guaranteed to help fund research towards treatments and a cure for thousands of people across the UK, and you may win the Chance2Win top cash prize!

Don't forget to give family and friends the Chance2Win too! Simply visit: ***www.ataxia.org.uk/get-involved/make-a-donation/chance2win*** *to join and purchase your raffle tickets online.*

Chance2Win Winners

1st Prize: £500
Helen Downey

2nd Prize: £250
Virginia Strong

3rd Prize: £150
Phil Palmer

The Classic is back!

Following the success of its first year, the Ataxia Classic is returning to Yorkshire on Saturday 11 September!

There is a shorter and longer route to choose from, with the shorter route approximately 50km to 55km and the longer route approximately 100km. So, whether you are a super or standard cyclist, fancy a new challenge or took part last year and can't wait to be part of it again, this is the cycle for you!

Starting and finishing at Allerthorpe Golf and Country Golf Club, we have built on the popularity of the 2020 routes, retaining sections of the renowned Tour de Yorkshire and, of course, the spectacular East Yorkshire scenery. Allerthorpe is an idyllic spot, just 30 minutes-drive from historic York, so you can make a weekend of it exploring the city and county alike.

The Ataxia Classic brings together existing and new friends to beat ataxia side-by-side and is a crucial way to raise funds for research and support for those affected by ataxia. We would love you to be part of it, and make it even better than 2020!

We will support you with your fundraising target and will be with you every pedal of the way, from registration to cheering you over the finish line! Those supporting you on the day can enjoy the serene surroundings while you cycle, and as everyone welcomes you back and celebrates together, there will be lunch and refreshments as well as the all-important medals.

The routes are being finalised and registration is open from mid-May on our website. Please just contact Rebecca for more information and to be kept updated.

This September be part of Team Ataxia UK and cycle your way towards a cure for ataxia. Contact ***Rebecca*** *on* ***rholt@ataxia.org.uk***
Visit the website: ***www.ataxia.org.uk/ataxiaclassic2021***

PARTNERS AND SPONSORSHIP

Could your company or employer be an official event partner? Corporate sponsorship not only brings funds to Ataxia UK, but puts your company in front of a new audience, providing promotion and advertising, as well as a being a tool to engage staff and boost morale and motivation. We have lots of opportunities that we would love to explore with your connections, so do get in touch to find out more.

Fundraising thank-yous

From growing your mo to raffles, here are some of our fantastic fundraisers ...

Congratulations to **Amy Chamberlain (1)** and her three girls, who ran, walked and rode a mile a day in March to support daughter **Darcy**, raising over £4,000!

Many thanks and congratulations to **Ellie** and **Susan Thompson (2)** for raising an amazing £1,011 in their Easter raffle!

Congratulations to **Roberta Cucuzza (3)** and **Kellye Coffyn** who handmade a fabulous fedora hat for their raffle, raising a smashing £695!

Well dones to **Paul**, **Mason** and **Ollie Elliott (4)** on raising £800 with their own running and jumping challenges, totting-up 25 and 28 miles together with 100 kick-ups!

Friends of **Scarlett Salisbury** gathered together to fundraise in her memory throughout March. **Guto** and **Noa Williams (5)** raised £1,540 and £1,921 respectively, with Guto running 2km every hour for 24 hours, and Noa running 10km. **Emily Harrison (6)** ran 104km for Scarlett, raising £1,312 so far. Thank you all so much.

A huge round of applause to **Jessica Hawkins (7)** for completing a 100-lap cycle of her road, inspired by Captain Tom and raising a massive £1,111!

Congratulations **Wayne Elson (8)**, who ran four miles every four hours for 48 hours, raising over £1,100! Such a big challenge and achievement, thank you.

A big thank you to **Emma Stamp** for completing her birthday fundraiser, raising £397!

We'd like to say a sensational well done to 12-year-old **Thomas Riley (9)** who has raised over £7,600 by walking 28 miles in 28 days – such a huge achievement, Thomas!

A big thank you to the **White Stuff Foundation** for their continued support raising over £905 to date! Thank you to **Olivia Clark** for organising the collaboration - a great way to raise awareness and funds.

Leonora Donaldson raised £1,900 with her lockdown cookbook full of her own scrumptious recipes and contributions from friends and family! We are so grateful, thank you.

Well done and thank you to **Caspar Collis** and family for raising £1,552 from their Journey to Luxembourg fundraiser!

Congratulations to **Dan Beacon** (right), Head of Fundraising and Communications at Ataxia UK, for growing a moustache as a fundraiser, raising £355! Also... good luck Dan in running the London Landmarks in August!

Driving with a disability

In this article I talk about my driving, adaptations and Motability.

I've been driving since I was 17 years old, before I knew I had ataxia. I love driving as it offers me a sense of freedom. I don't feel as disabled when I am driving, although things are getting harder. I also dislike driving at night and, if I have to, I use night driving glasses to help with the glare.

Over the years I have had various adaptations on my cars. I passed my driving test in a manual car, then changed to driving an automatic and now my car has hand controls.

I used to have a roof box for my wheelchair (right), which was a very cool gadget. It lifted my chair onto the roof and laid it flat. This was great as it kept the chair out of the car; however, the choice of wheelchair was limited as it had to fold flat.

Now, I use a rigid wheelchair and remove the wheels before putting my wheelchair on the passenger seat, by lifting it over my body when I am in the driver's seat. This does take time and effort but I get to use a rigid wheelchair. If I am with someone, the wheelchair can easily fit in the boot. There are so many amazing adaptations, from many suppliers, helping people with all sorts of disabilities to keep driving.

I use hand controls which are cables and levers connected to the pedals (automatic cars only). Pull to go, push to stop. I used this system for my last four cars, but my current car has a trigger to accelerate and push to break. The trigger is wired straight into the engine making it less effort to accelerate. I use a ball to steer and indicate using a switch on the hand-control lever.

The **Motability scheme** enables you to exchange mobility allowance to lease a new car or powered mobility equipment. They cover insurance and servicing, which means you only have to pay for fuel. They also pay for standard adaptations, and subsidise most others. You can get some cars with no advanced payment or get a car with high advanced payment depending on specifications and make/model. The choice is very impressive. The lease lasts three or five years depending on your specifications and adaptations.

*Find out more by visiting **www.motability.co.uk**. If you have any questions, please email me, **James Downie**, on **downstar@mac.com**.*

Home adaptations

Adaptations for your home to help with household chores, accessible devices and everyday tasks.

ROBOT HOOVER

Hoovering can be a challenge for people with mobility issues due to the inaccessibility of many hoovers. However, for a range of prices, a robot cleaner takes care of the vacuuming for you. It is designed to clean carpets and hard flooring, including climbing over door ledges, for up to 100 minutes. Some are compatible with your smartphone and you can set a cleaning schedule too! There are different types of robot hoovers available from online stores, such as Currys.
*Visit **https://bit.ly/3uMFzt1***

AMAZON ECHO DOT

You may have heard of Amazon's speaker devices before - the Amazon Echo Dot is their new smart, sleek and compact device. It is designed to listen to your commands; whether you want a joke or to set an alarm, the Echo Dot will listen! You just say: "Alexa, tell me a joke." or "Alexa, set an alarm for 8am tomorrow." The speaker is compatible with your smartphone which means you can play and control music through your phone. So, whether you are looking for a voice-activated device or hosting a garden party with the easing of restrictions, this speaker is an accessible one!
*Visit **https://amzn.to/3df8DDX***

TAP TURNERS

Reaching for taps may be difficult for some people with ataxia. Gripping can be difficult too, if they are particularly tough. With the crosshead tap turners, you can reach and grip the taps, making it easier to turn them. The turners are compatible with an X type tap.
*Visit **www.completecareshop.co.uk/kitchen-aids/knob-turners/crosshead-tap-turners-pair***

***Disclaimer:** This article is for guidance purposes only and, while every care is taken to ensure its accuracy, no guarantee of accuracy can be given. Individual professional advice should be sought before taking or refraining from taking any action based on the information contained in this article and nothing should be construed as professional advice given by Ataxia UK.*

Diagnosis Day

Georgia Hart took part in the European Patient Forum advocacy programme (EPF) last summer and has been busy working on her 'Diagnosis Day' campaign. Let's find out more.

Why did you start Diagnosis Day?

In the last couple of years I've come to terms with my condition and feel much happier talking about it. However, for the first few years after diagnosis I struggled to accept myself and find the motivation to work at something. Unfortunately, I think a lot of that resulted from my 'Diagnosis Day'. Anyone with a health condition like ataxia knows that **no story is ever the same**. More often than not, these are 'horror' stories or so ridiculous it's borderline funny. So, I wanted to find out why this was, why was there no standardised procedure when it came to diagnosing people. Why was compassion not a priority? And does it really need to take someone six years to get over their Diagnosis Day, like it did for me?

How did you carry out Diagnosis Day?

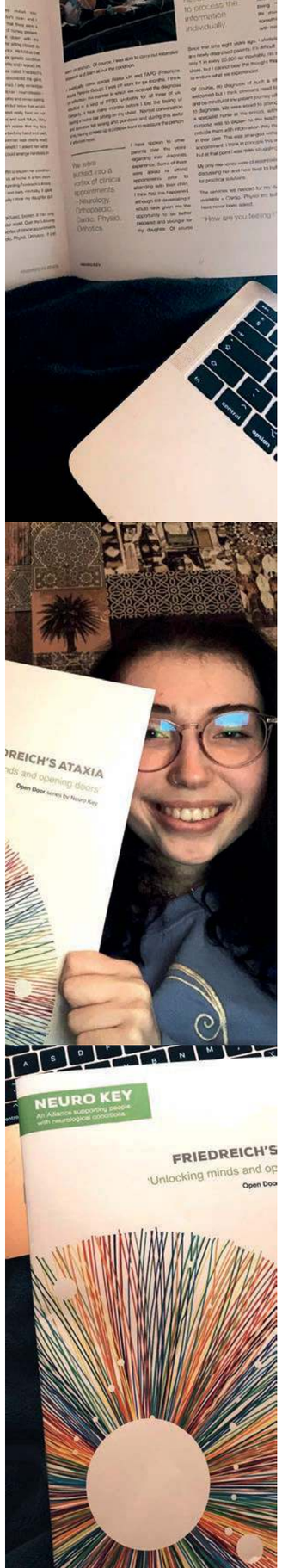
I started speaking to as many people as I could about their diagnosis stories. I learnt diagnosis was a bigger issue than I thought. I found that, through my own research into NHS procedures (or lack thereof), the information was not available for a 'regular' person like me. I then spoke to my MP who helped me contact people I didn't even know existed but, due to Covid-19, everything is delayed. I did two workshops at the 2020 Ataxia UK conference with Co-Chair, **Richard Brown**, to discuss more stories concerning diagnosis and what people think needs improving.

My EPF team supported me throughout this. They have taught me so much about other health conditions and how advocacy is carried out in other countries.

What have you found so far?

I've summed up areas that need improvement after speaking to people about their diagnosis day.

- The way the information is presented to the patient. Is it morbid? Too technical to understand? Accessible? Age appropriate? This was something wrong with my own diagnosis. The information I received was blunt and nonchalant.
- Who is in the room when you're diagnosed? I was 15 when I was diagnosed, and my parents and I found out together. Other people under 16 were not in the room when their parents were told. Some people were alone and not advised to bring support. If the patient isn't told directly then it is up to the parent to tell them without support and, I have found, this leads to resentment in the family.
- The lack of support offered after a diagnosis. The UK claims to hand out genetic counselling for the family, signpost to charities, help with benefits and navigate occupational therapy and social care. I wasn't offered any help. I found out what FA was from Google.



How did you work with a neuropsychologist?

I study psychology and Steph was my personal tutor in my first year, so I felt comfortable speaking to her about my campaign. Clinical Psychology is her thing, so we're in the process of getting the ethics passed, then we can conduct the research and write the report!

What aims do you have?

My biggest aim is to make a difference. I want to help medical professionals understand how crucial the diagnosis day is to patients' wellbeing. Although it doesn't change how my friends and I were diagnosed, I want to make life easier for people who are diagnosed in the future. I'd also love to publish my report when it's finished and spread awareness about the campaign.

Tell us about the FA booklet.

I wanted to make something in addition to an academic report that would be **accessible for anyone to read**: ***https://bit.ly/3xT7WrY*** One of the big issues my research identified was the lack of compassion shown by doctors to their patients.

Steph also works for NeuroKey and after hearing about my campaign they asked how they could help. NeuroKey often create booklets for hospitals, GP surgeries and medical students with the intent of educating them on an unknown topic, so this was perfect. I am hoping that the diagnosis stories included in the FA booklet show that these are real people and not just potential research subjects.

Are there future plans for Diagnosis Day?

Of course! By the time you are reading this, my dissertation will be finished, so I can focus on the Diagnosis Day campaign. As well as writing the report, I hope to bring awareness to the campaign by speaking about it more.

I am also in the process of applying to the EPF advocacy programme to do it again this summer. As someone with a big interest in psychology, I am a strong believer in the way we are introduced to our illness can have an impact on how we manage it going forward.

Looking back in a positive light

Kieran featured in issue 210 when he participated in the Superheroes Challenge for Ataxia UK. Mum Leeann tell us what they have been up to.

Kieran was diagnosed with Friedreich's ataxia at six years old, almost four years ago. Now Kieran is 10, my perspective on life has changed. To begin with I was stressed and anxious. Over time, you begin to accept that life is different to what you planned. My focus is to keep Kieran active and to have equipment that makes our lives easier.

As everyone will agree, the past year has been tough. Kieran has missed his friends and extra activities, including swimming lessons, horse riding and gymnastics. It's those small connections with people (and animals) that help lift his spirit. Not to mention the negative impact lockdown has had on his physical health.

However, there are positives too. We have learnt to slow down and enjoy being present, not rushing around from one thing to the next, especially trying to get ready for school. Kieran has more time in the morning to wear his gaiters (they help by giving his hamstrings a long stretch to help reduce muscle spasticity and shrinkage) and use his stander before the online lessons start. His lessons have been fantastic. In fact, the option to have virtual lessons on days when he is too fatigued to move could benefit Kieran going forward.

We have enjoyed watching Marvel films in chronological order, the local drive-in cinema, and Kieran loves being in the fresh air on his trike. Oh, and the doughnut deliveries!

Kieran has participated in challenges too. Last year he took part in a cycling challenge with his school's fundraiser and, as a personal challenge, he cycled 14km through the Superhero Winter Wonderwheels event. Then, from March to April 2021, Kieran completed his Inca Trail Challenge fundraiser.

Kieran finds his motivation through boredom, delicious food and helping others. Positive comments and donations really spur him on. However, he has bad days. His fatigue gets him down. He experiences overtiredness, headaches and dizziness. We learn to constantly balance what he can do. After bad days, he bounces back and is ready to get back on his trike.

For anyone in a similar situation: take one day at a time. Choose one battle at a time. Share the load. Ask for help and support. Most importantly - look after yourself. There is hope with research on FA.

Hope for the ataxia community

Tony lived a fulfilling life with Friedreich's ataxia (FA) until 80 years old. His nephew Darren wants to spread hope for others.

Uncle Tony was formally diagnosed with FA at 19 years old and in a wheelchair full time by 21. In his mid-teens he had a loss of co-ordination, a wobbly walk and speech problems. He loved football matches and lived life to the full. He was a wonderful and kind man with many friends and will leave a massive gap in our family.

Although his diagnosis was a difficult period for his family, he was very accepting, and proceeded to embrace life with all he had. He decided not to marry but saw my family like his own. My father also had FA and lived a fulfilling life with his family.

Tony worked in accounts for Rolls Royce until his retirement in his 50's after 25+ years. Afterwards, he travelled the world; Israel, the Mediterranean and Europe were on his list. Throughout his life he visited America five times. He even did abseiling!

He lived with his parents until it became too challenging for them to take care of him and then moved to a nursing home. However, after his parents passed away, Tony wanted independence and stood up for his rights and was able to move back to his family home with full-time carers. He seemed happy and the muscle spasms became less as he lived at home with everything around him. This seemed to significantly help his mental wellbeing.

Tony was involved with Ataxia UK (called Friedreich's Ataxia Group at the time), raising awareness in Derby, and his friend even ran the London Marathon. He looked forward to what he could do and was always smiling with a cheeky comment! I think it's partly the reason he lived so long. He was inspirational and a hero to me and the kindest guy I have ever known.

Suzanne Booth, Ataxia Nurse at London Ataxia Centre, said: "The rate of progression and life expectancy varies widely. Individual prognosis depends on factors, including the age of disease onset, severity of symptoms, other illnesses, and lifestyle factors e.g. exercise and weight management. Some with less severe symptoms of FA live until sixties, seventies or eighties, however significant heart disease can reduce life expectancy. Although FA cannot currently be cured, in our ataxia clinics we focus on symptomatic treatments to help reduce the severity of the complications associated with ataxia, and subsequently extend our patients' life span."

Lobbying for people with ataxia during the pandemic

Sue Millman CEO Ataxia UK and Board Member, Neurological Alliance and Genetic Alliance UK

We know that many Friends were concerned at the lack of priority given to people with ataxia during the Covid-19 pandemic in being assessed as Extremely Clinically Vulnerable (ECV) thereby being advised to shield, and subsequently entitled to be in Category 4 for the vaccine.

It was clear when the 'shielding letters' were originally issued, that whether people with an ataxia received a letter was hit and miss. Very soon it was apparent that it was common across a number of neurological and rare diseases. Ataxia UK was active in support of the efforts of Rare Disease UK/Genetic Alliance UK and the Neurological Alliance who made strong representations via various routes for the situation to be rectified; we received a sympathetic reception but no positive result.

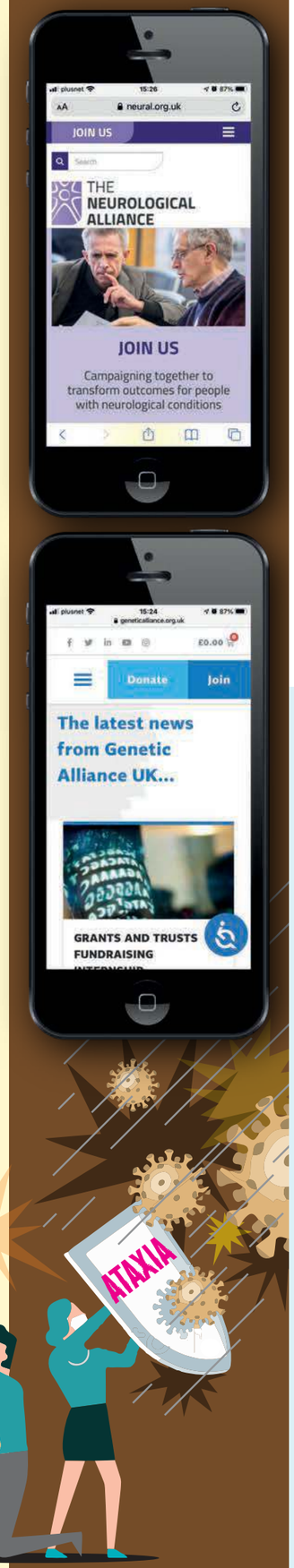
In my [**Sue Millman**] view, it was inevitable that there would be no central decision to make this happen for people with ataxia, due to the lack of data collection in NHS England on rare neurological conditions, thus when the criteria for the issuing of shielding letters was produced, it didn't include ataxia patients as they don't show within the existing codes and couldn't be extracted.

It's clear that in some areas the problem has been rectified locally, for some conditions - but it was incredibly hit and miss. In a Neurological Alliance survey answered by 1,672 people, 49% reported difficulty with shielding notification.

In this situation we assessed that the best thing for Ataxia UK to do was to support people by advising to approach their GP to explain why their status should be changed and supported people in doing so. When the vaccine became available we made a template letter available on the website. This approach was used successfully by a number of people who managed to get themselves changed to Category 4 or Category 6.

Eventually at the beginning of February 2021 the Association of British Neurologists (with which the Neurological Alliance often collaborates) issued guidance to its members clarifying the situation and specifically mentioning the ataxias, and this, together with the progress in rolling out the vaccine, seems to have dissipated the problems. If you are continuing to have problems in accessing the vaccine, please contact the Helpline.

The Neurological Alliance has launched **NeuroLifeNow** to collect data from patients with neurological conditions about their treatment, in an effort to improve services. Read more on p.23.



Have you the vision, commitment and experience to be a Trustee of Ataxia UK?

The Trustee Board governs and sets the strategic direction of Ataxia UK. The Board is made of up Friends of Ataxia UK; seven whom are elected by Friends of Ataxia UK and three who are appointed by the Board.

In September there will be an election for two Trustees, one must have ataxia. There is a third vacancy for someone (with or without ataxia) with fundraising/ marketing experience who will be appointed by co-option. Both posts will be subject to interview. *You can find more information including a Job Description by visiting* ***www.ataxia.org.uk/work-for-us/trustee-jd.*** *Anyone interested will be welcomed at an online information seminar with the* ***Chairs of Trustees*** *and* ***Sue Millman,*** *please let Sue know of your interest by emailing* ***smillman@ataxia.org.uk****.*

NeuroLifeNow app

The Brain and Spine Foundation and the Neurological Alliance have built **NeuroLifeNow** - an app and website that supports people with neurological conditions to share their experiences to influence change. The app aims to increase the level of support for people living with a neurological condition.

When you sign up to the platform, you answer a few questions each month about your access to health and care services, your wellbeing and experiences of Covid-19. NeuroLifeNow then reports the feedback from the surveys each month and the results are available for people who are responsible for funding and delivering care to read. Additionally, when you sign up, you gain access to the latest news and information about neurological conditions.

Your data and experiences are anonymous. Only representatives from the Brain and Spine Foundation and Neurological Alliance can access your data.

Get started by downloading the app or use the web platform. Visit ***https://neurolifenow.org*** *for more information.*

hank 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