

# ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 224. Winter 2023

## You can give the gift of support this Christmas & double your impact

Find out more  
about the  
Christmas  
Challenge  
on pages  
12 & 13



This year, you've taken two more steps towards ataxia diagnosis. See page 7

- Ataxia people • Ataxia awareness • Research
- Fundraising • Adapting to life • Living with ataxia
- Health & wellbeing • Services

# ATAXIA

Ataxia UK

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## CEO's Introduction

**Winter is nearly here and before we know it 2024 will be upon us. Before it arrives, on Tuesday 28th November, our Big Give Christmas Challenge will open for just one week. Please see p12 & 13 to understand how it works and what doubling your generous gifts will do to help support people with ataxia.**

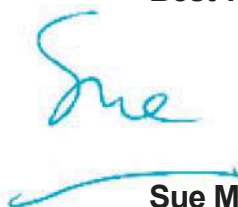
October saw our Annual Conference gathering in person and online. This event gives so much inspiration and encouragement to me and the staff team. If you missed it you can read about it on p4 & 5 and lots of the talks will be available on our website by early December: [www.ataxia.org.uk](http://www.ataxia.org.uk)

As I write at the beginning of October, we are still waiting for an application to the UK authorities for the approval of Skyclarys as a drug treatment for Friedreich's ataxia. However, the completion of the acquisition of Reata Pharmaceuticals by Biogen has just been announced. Biogen is a much larger, more experienced company, and we hope this will portend good news for the submission sooner rather than later.

In other news, we wanted to congratulate our **Research Manager, Emily** on giving birth to a beautiful baby boy, **Arlo**. We're sad to say goodbye to **Bella**, whom you may know from helping Branches & Support groups, and **Hannah**, our **Events & Community Officer**. We thank them both for their dedication and hard work and hope to see them again soon. We would also like to welcome the new **Volunteering and Community Program Intern – Matilda**, whom some of you met at the Conference.

I hope you enjoy the festive period and have a Happy New Year.

**Best wishes,**



Sue Millman





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### Seasonal opening times:

**Please note:** the Helpline will be closed over Christmas and New Year. We close at 2.30pm on Thursday 21st December and re-open on Wednesday 3rd January at 10.30am.

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# Annual Conference and awards

**After 3 years of the Annual Conferences being held virtually due to the pandemic, it was an incredibly joyous occasion to be back together in person for this year's Annual Conference. Over 100 Friends joined us at the Radisson Blu in East Midlands, as well as over 50 virtual attendees!**

Highlights included **Eshika Haque's** talk on having a family, **Ben Spencer's (4) It Works For Me** video on exploring London's Underground stations, and a furry friend joining us from **Dogs for Good** to demonstrate how assistance dogs can support people living with ataxia.

We're so grateful for everyone who was able to join us (both in person and online) and we really hope you enjoyed it. We would like to say a huge thank you to all of our speakers, clinicians, breakout leaders, staff, volunteers and committee members who helped us make this such a special conference.

*If you attended, don't forget to complete and return your feedback survey that **Anastasia** sent to you by email. If you have any questions or need a new link sent to you, please contact the team at [conference@ataxia.org.uk](mailto:conference@ataxia.org.uk).*

**It's always a pleasure to be able to show our appreciation to members of our community who have gone above and beyond to support people with ataxia, by presenting three awards at the Conference.**

**Ceri Pepper (2)** was awarded our **Ernie Heath Award** for her fierce and relentless campaigning to secure the rights and support needed for her daughter **Jade's** education and healthcare. As well as advocating for Jade, Ceri has been involved in various awareness campaigns, raising funds and increasing public understanding of ataxia, which has inspired others to join the cause. Ceri's exceptional dedication and unwavering support embody the spirit of Ernie Heath.

The deserving recipient of this year's **Matthew Law Award** is **Tim Kahn (3)**. Tim's involvement in Ataxia UK takes many forms, including proofreading this magazine and serving as a clinic volunteer at the London Ataxia Centre, offering vital support to those navigating the often daunting path of a new diagnosis. In addition to this, he is a volunteer on the Helpline and has run the **South London Support Group** for many years, providing a welcoming and supportive environment for people to share their experiences. We congratulate Tim on receiving this award, and thank him for his tireless dedication to improving the lives of people with ataxia.

The **Branch & Support Group award** went to the **Farnham Support Group**. Started in 2013 by dedicated volunteer **Derek Wood (1)**. The group has gone from strength to strength. During the pandemic, they embraced virtual meetings, allowing them to stay connected through a difficult time, and engage with other support groups across the UK. In addition to providing advice and support to each other, the group members are passionate about raising awareness of ataxia in their local community, and have hosted fundraising stalls at their local hospital, lido and Morrisons. We congratulate them on their success in creating such a strong group.







Our inaugural **Excellence in Ataxia Research and Care award** goes to **Professor Paola Giunti**, who has shown tremendous commitment to ataxia research for over 30 years, extending to a very wide range of common and ultra-rare ataxias. She has led clinical and lab-based research at the only UK site for EU-wide natural history studies on FA and SCAs, the **London Ataxia Centre**. Her team was involved in clinical and lab work leading to the Skylarys approval. Paola had the idea of setting up the first Ataxia Centre in the UK back in 2005. It has since expanded significantly, supporting around 1,200 patients today. She established a successful multidisciplinary clinic including physios, speech and language therapists and occupational therapists and recently founded a **Children's Ataxia Clinic** together with **Dr Shpresa Pula**. We are indebted to her for all she does for the ataxia community! *Images for the awards recipients can be found here: <http://alturl.com/n9tqa>*

### **RAREMINDS: RARE DISEASE AND MENTAL HEALTH**

**We were lucky to have Rareminds join us again this year as part of our Annual Conference virtual programme to talk to us about the mental health impacts of living with a rare condition.** Rareminds is the first specialist, non-profit counselling and psychotherapy service for those living with rare diseases in the UK. Started in 2014 by psychotherapist **Kym Winter** following her own experience of dealing with her family's experience of rare disease diagnosis, the organisation aims to provide access to affordable counselling and campaign for the recognition of specialised counselling for the rare disease community. They work with a number of rare disease charities to provide counselling, training and resources.

This year Kym's colleague and **UKCP Accredited Specialist Counsellor, Zubyda Azzam**, joined us from the Rareminds team. As part of her talk at this year's Annual Conference, Zubyda explored some of the particular psychological impacts of living with a rare disease. These included the burden of having to be an expert in your own condition, due to low disease awareness. She particularly emphasised the emotional toll that a long diagnosis process can have, and the uncertainty that emerges from this. It was also recognised that the psychological stresses that come along with a rare condition can build up when added to our everyday stresses and challenges that we face in life, and the importance of being able to recognise when our 'stress bucket' is full.

Zubyda offered helpful tips and strategies for managing difficult feelings and how to look after our mental health when living with a rare condition, including increasing one's own awareness of what makes us feel better and focusing on what can be controlled, rather than the aspects of our life over which we have less control. The talk was well attended and the feedback from attendees was that it was really helpful. Rareminds will be assisting Ataxia UK to develop an **All About Ataxia PLUS Mental Health** session, and we're thrilled to present the first one on Friday 24th November from 1pm to 2:30pm.

*If you are experiencing difficulties with your mental health, it is important to discuss this with your GP or consultant. You can find out more information about Rareminds at [www.rareminds.org](http://www.rareminds.org)*

**Urgent Help: The Samaritans (116 123) [www.samaritans.org](http://www.samaritans.org)  
CALM [www.calm.com](http://www.calm.com) SHOUT [www.giveusashout.org](http://www.giveusashout.org)**



## We're very thrilled to introduce our new Trustee – Nathan Hall

**Nathan's son lives with Friedreich's ataxia, so Nathan and his family have been connected to Ataxia UK for support and advice for a number of years.**

Nathan is a lay member of the **Scientific Advisory Board**, so he joins the **Ataxia UK Board** with a great understanding of ataxia research alongside his personal understanding of the ataxia diagnosis journey.

He has extensive understanding of the NHS, having worked for 27 years as an NHS Manager, currently working at a national level for **NHS England**, improving NHS diagnostic services.

He was born and brought up in the Welsh valleys and now lives in Wiltshire with his wife **Claire** and two teenage sons.

He has established a **Community Benefit Society** that operates a community shop in his home village.

In his spare time he enjoys playing guitar and watching sport, in particular supporting Wales rugby and Aston Villa football club.

We look forward to welcoming Nathan to the Board this November.

*If you wish to find out more about Ataxia UK's Trustees, please visit our website: [www.ataxia.org.uk/board-of-trustees](http://www.ataxia.org.uk/board-of-trustees)*





# Two steps towards speedier ataxia diagnosis

**This year, we continued to take two steps towards speedier ataxia diagnosis. Monday 25th September 2023 marked International Ataxia Awareness Day (IAAD) and you have taken two steps to improve ataxia diagnosis and better care, for the third year running.**

Friends and supporters are continuing to take their steps towards speedier ataxia diagnosis by sharing the Medical Guidelines with their GPs. A huge thank you to all those that got involved. So far, over 80 copies of the Guidelines were requested to be shared with medical professionals. Thanks to this, the Guidelines were shared with GP surgeries throughout the entire UK. *To find out more about this, see the interactive map at [www.ataxia.org.uk/iaad2023](http://www.ataxia.org.uk/iaad2023)*

In addition to the stellar effort of every single Friend that decided to take part, we wanted to extend a massive thank you to those on #TeamAtaxiaUK who got sponsored and organised events, **raising over £1,260 at the time of writing!** A special mention goes to those who hosted supporting events, **Rebecca & Ava Downing, Leanne Hankin**, and some of the amazing members of our **Farnham Support Group: Derek Wood, Ed Forshaw, Carol Bullock, Kim Cottrell, and Amanda Evans.**

We shared posts about the campaign across Facebook, Twitter and Instagram and received a brilliant response! Thank you to **over 50 people who added a ribbon promoting IAAD** to their social media profile pictures.

This year's IAAD campaign might be over, but ataxia awareness is important all year round. Let's work together to end slow diagnosis.

Our Friend **Haider** says: *"I've been dealing with the challenges ataxia poses for a long time after going over a challenging decade undiagnosed. Balance and speech problems were mistaken as being drunk, and swallowing and gait problems were often mistaken for clumsiness. Slow ataxia diagnosis needs to end to make the lives of those living with undiagnosed ataxia easier and faster."*

**Make a difference by sharing a copy of the Medical Guidelines with your GP. By working together, we can increase medical professionals' awareness of ataxia and speed up not just diagnosis but access to vital care, too.**

Order the medical guidelines by visiting <http://bit.ly/3TvMJys> and please let our team ([communications@ataxia.org.uk](mailto:communications@ataxia.org.uk)) which GP surgery you shared the guidelines with, so we can update our interactive map and records.





# Ataxia UK hosts first-ever event for UK-based researchers

**On 12th September 2023, Ataxia UK hosted its first networking event for UK-based researchers in London.**

We were excited to welcome almost 50 attendees, including researchers, clinicians, Ataxia UK representatives and two people with ataxia. Representatives from research teams across the UK attended, including the Ataxia centres in London, Sheffield, and Oxford. We invited participants to present research on a range of ataxias, and share information, resources, and expertise to foster collaboration. Participant feedback was very positive; 92% of survey respondents said the event was extremely or very useful for improving their knowledge of research engagement opportunities.

**Dr Sara Anjomani-Virmouni**, who spoke at the event on her research at Brunel University, said this: *“The event provided an excellent opportunity for the scientific community in the UK to showcase their research on recent advances in the field and provided a forum for networking and exchanging ideas”.*

An example of the research presented was **Dr Natalia Gromak’s** talk on her work at the **University of Oxford** on the **role of unusual structures called R-loops in cells of people with Friedreich’s ataxia (FA)**. Despite the genetic cause of FA being identified in 1996, we do not fully understand how it causes FA, representing a major challenge in developing therapies. The team saw that R-loops form around the mutation which causes FA, contributing to development of FA symptoms. This suggests R-loops could be targeted in new FA treatments.

**Dr Rosella Abeti** and **Dr Suran Nethisinghe** shared their team’s research at the **London Ataxia Centre** into **potential treatment approaches for FA**, including lab-based studies that contributed to building evidence for the Omaveloxone, also known as SKYCLARYS®, drug approval by the US Regulators, FDA, in FA. The event sparked discussion on collaboration between physiotherapists and healthcare professionals supporting ataxia patients. **Dr Lisa Bunn, University of Plymouth**, shared her team’s success with the ‘A-team’ forum in partnership with the **Cosmic Kids Yoga** YouTube channel, **sharing physiotherapy exercises for children with Ataxia Telangiectasia** in a fun and engaging way.

## INCLUDING PEOPLE WITH ATAXIA IN RESEARCH

As part of this event **Ataxia UK hosted a Q&A on patient engagement in research** with Ataxia UK Trustee **Harriet Brown** and **Yanita Oparlakova** (right), who live with ataxia and are lay members of the **Ataxia UK Scientific Advisory Committee**. This committee comprises scientists and clinicians, advising Trustees on which research to fund. Ataxia UK invites patient engagement in research and its processes. Including people with ataxia ensures patient voices are listened to. Harriet said: *“We feel like our contributions to this committee are acknowledged as important and we are truly listened to.”*





Harriet was diagnosed with FA at 15, but when the genetic test for FA was developed, she was later told she did not have FA, so does not know the cause of her ataxia. *“When I was diagnosed with FA, just six ataxia genes were known. Now there are 100s! That shows how far we have come,”* Harriet remarked.

Harriet volunteers with Ataxia UK’s **Research Ethics Committee** reviewing research surveys to make them as ethical as possible. Harriet also represents Ataxia UK in a Medicines and Healthcare products Regulatory Agency (MHRA) patient engagement group.

Yanita was diagnosed with FA in her 20s and took part in the Omaveloxone clinical trial. She shared: *“I’m so glad I could take part in the trial and be part of the research for a drug that is now approved by the FDA.”* Yanita also featured on BBC Breakfast programme on 22nd January 2023 to highlight ataxia research and raise awareness.

**Dr Esther Becker**, who presented a talk on the research into Cerebellar ataxias at the University of Oxford, reflected on patient engagement: *“I especially valued meeting patients with ataxia and learning about their day-to-day experience with the disease. Hearing from patients gives us researchers extra inspiration and motivation to go back to the laboratory and help find a cure.”*

## Results of study on new method to overcome frataxin deficiency in Friedreich’s ataxia

**A study on Friedreich’s ataxia (FA) carried out by Dr Benoit D’Autr aux (right) at the Institute for Integrative Biology of the Cell, CNRS-CEA-Universit  Paris, France has released promising results.**

FA is a neurodegenerative condition caused by a mutation in the frataxin gene, containing instructions to make the frataxin protein. This mutation causes less frataxin protein to be produced. People with FA have 5-10% of the frataxin protein compared to cells of those without FA. Frataxin proteins help cells produce energy, so a lack of frataxin damages energy production centres called mitochondria. The main therapeutic strategies under development for FA are gene therapies to replace mutated frataxin, increase frataxin levels or diminish problems caused by decreased frataxin. This group has been working on a different strategy, aiming to develop drugs to replace frataxin function or enhance activity of residual frataxin in FA patients. Until recently, this strategy could not be explored due to difficulty measuring frataxin activity. An experiment developed by these researchers made this possible.

Now these researchers can measure frataxin activity, they have tested over 80,000 compounds to identify which could function in place of frataxin, and which could enhance frataxin activity, finding eight positive hits. This research is jointly funded by Ataxia UK and **Friedreich’s Ataxia Research Alliance (FARA)**. Dr D’Autr aux has successfully gained further funding for the eight compounds to be tested in animal models of FA and modified to improve their efficiency. The researchers hope these compounds could be tested as FA treatments.



# Biohaven update on the SCA3 Troriluzole treatment programme

**Biohaven is a pharmaceutical company developing Troriluzole to treat Spinocerebellar Ataxia Type-3 (SCA3).**

In May 2023, Biohaven submitted a New Drug Application (NDA) to US regulators, the (Food and Drug Administration, FDA), for approval of Troriluzole to treat SCA3. Unfortunately, the FDA decided not to review the NDA, following inconclusive results. Together with the US National Ataxia Foundation (NAF), Ataxia UK campaigned to encourage flexibility in NDA approvals by the FDA. The FDA needs to hear from the ataxia community to help understand why applying regulatory flexibility is needed, and why reviewing the full clinical trial data is in the best interest of patients. The NAF and Ataxia UK asked for feedback from anyone affected by ataxia or neurodegenerative disease, to share with the FDA, receiving over 3,000 responses. 97% agreed the FDA should apply regulatory flexibility and accept the NDA filing for Troriluzole for full review. The FDA has said Biohaven can request a meeting to discuss the FDA's concerns. Biohaven continues to apply for approval, hoping Troriluzole will become available to those with SCA3.

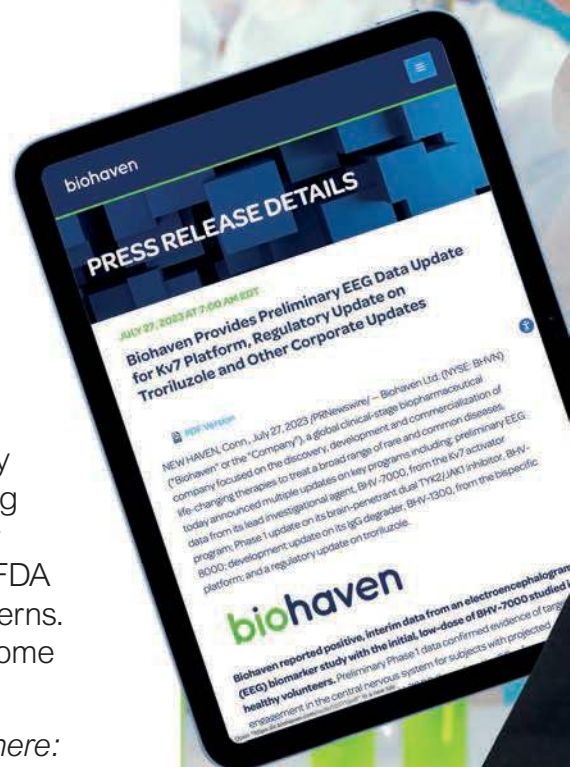
Find out more about the Troriluzole treatment programme for SCA3 here: <http://alturl.com/8jb3t>. We will keep you up to date on the Troriluzole approval developments in our monthly eNews and upcoming issues of the magazine.

## Biogen acquires Reata Pharmaceuticals

**On 26th September 2023, the global biotech company Biogen officially acquired the pharmaceutical company Reata Pharmaceuticals.**

Reata is the company that developed **SKYCLARYS®** (the US brand name for **Omaveloxone**) – the first ever FDA-approved drug for adults with Friedreich's Ataxia. In July, **Christopher Viehbacher**, Biogen's **President** and **CEO** said that they "look forward to leveraging Biogen's rare disease expertise and capabilities to work together with Reata colleagues as one team to bring SKYCLARYS® to patients living with this devastating disease." Ataxia UK is making every effort to encourage and support Biogen in seeking UK regulatory approval. In addition, we are discussing other ways to cooperate to gather useful information from people with FA in the UK.

To read the full Biogen press release, visit <http://alturl.com/camvs> or sign up to our dedicated Omav-only newsletter at: <http://alturl.com/6vtvg>





Below: Main picture: Dr Stefan Hauser  
Below: Inset picture: Jacob Helm,  
a PhD student in Dr Hauser's laboratory

# Ataxia UK awards new funding for study to turn off faulty genes in Spinocerebellar Ataxia Type-3

**Ataxia UK has awarded funding to Dr Stefan Hauser and his colleagues at the German Center for Neurodegenerative Diseases, Tübingen, Germany, paving the way for a technique to switch off faulty ataxin-3 genes in Spinocerebellar Ataxia Type-3 (SCA3) without turning off healthy versions, which could help slow the progression of SCA3.**

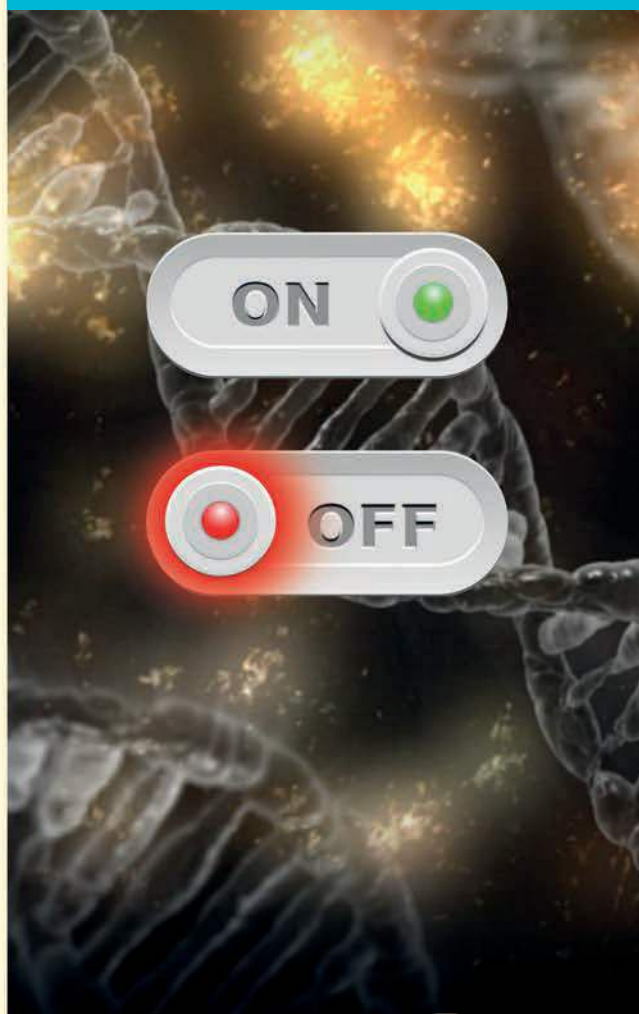
This is called gene silencing. The method uses synthetic sections of DNA called antisense oligonucleotides (ASOs), which bind to instructions for the gene sequence including faulty ataxin-3, and break it down, keeping only healthy ataxin-3.

For ASOs to bind to faulty ataxin-3, differences between faulty and healthy versions must be identified. This is essential for developing ASOs that target only the faulty ataxin-3. The team will use human brain cells that have been created in the laboratory from skin samples taken from patients with SCA3. The advantage of using cells from someone with SCA3 is that they contain identical gene sequences to the patient.

The team found that the level of faulty ataxin-3 was reduced by 80% in the cells following the treatment compared to untreated cells. *“By identifying novel targets, my team hopes to increase the likelihood of safe and selective degradation of faulty ataxin-3. Future projects will investigate the safety and tolerability of the method, and its long-term effects on brain cells. This method could help slow progression of SCA3”*, says Dr Hauser.

**For more information on Dr Hauser's research, visit:**  
**<http://alturl.com/2cimo>**  
& **<http://alturl.com/5egyh>**

## RESEARCH



# Christmas Challenge

## One donation, twice the impact

**Set your alarms! This year's Big Give 2023 Christmas Challenge is around the corner. Going live from midday Tuesday 28th November and running until midday Tuesday 5th December, your donations will be doubled at no extra cost to you.**

In the last Magazine we brought you the exciting news that this year we're taking part in The Big Give Christmas Challenge again. We're thrilled to announce that this year's Christmas Challenge is backed by seven very generous pledgers, raising a festive £14,500. A huge thank you goes to all those pledgers who turned up in strength to help support the ataxia community.

### How does the Christmas Challenge work?

Every year a small number of supporters pledge to give a donation, which is then topped with £7,500 by our Big Give Champion – **The Reed Foundation**. This will take the already generous £14,500 in the Campaign Pot to £22,000! Throughout the Christmas Challenge week, all donations made by you and our supporters online, through the Big Give website, will be matched using the Campaign Pot. We need you to spread the word this Christmas and help us reach the target of £44,000 through the Big Give 2023 Christmas Campaign.

Let's say you donate £100 during the Christmas Challenge week through the official Big Give website. Well then, that donation is matched using the Campaign Pot, doubling its value to £200, which can then be increased to £225 through Gift Aid\*.

**It's only through your generous donations this £44,000 festive target can be reached, helping provide the ataxia community with the much-needed gift of support.**

Your doubled donations made during the 2023 Christmas Challenge will directly benefit the five-year service expansion aimed at providing vital support to the ataxia community.

This plan, which is part-funded by the National Lottery grant, received in the summer of 2023, will help improve crucial support and reduce feelings of isolation for people like **Bayram** (right), **who has managed to connect with others through being a Friend of Ataxia UK. The Friendship provided Bayram with a number of FREE benefits, including the Ataxia Magazine.**

# BigGive

**During the Christmas Challenge week, donate, say, £100**



**Our major donor pledgers and champion donor match your donation with another £100**



**Tick the Gift Aid box to add a further £25. So, you give £100 but we get £225!**



*For more info, visit:*  
[www.ataxia.org.uk/tbg23](http://www.ataxia.org.uk/tbg23)





Bayram told us that he's *"so grateful that Ataxia UK exists. Thanks to Ataxia UK, I've felt less lonely and I know that I can always reach out to someone if I need support. You are doing such an amazing job helping us, and I am so grateful to have found you – it is a welcoming community. I wish I had joined earlier."*

**Another service that will see improvements from your generous gifts is the Ataxia UK Helpline, which will be expanded in both reach and effectiveness.** Our friend **Lauren** (right) recently used the Helpline after being faced with difficulties when her dad was diagnosed with ataxia: *"With no support and no idea who to turn to for help regarding ataxia – I Googled and got in touch with Ataxia UK. Since then, Jess, who works on the Helpline, has been amazing! Her compassion, knowledge and personal service has been like a breath of fresh air for me and the family. She has sent me information regarding ataxia, Zoom call meetings and chased up the referral. Without Jess we would still be none the wiser to ataxia, still have no referral for Sheffield and still feel lost and unsupported. I hope she knows how much of a difference she has made."*

**Another aspect of the Support Services that will be improved thanks to your Christmas Challenge donations are Branch & Support Groups.**

One of the many services our wonderful supporter **Amanda** (right) has used includes the B&SGs which she told us have been amazing in reducing her feelings of isolation through having others around her who truly understand how it feels to have ataxia. *"Lack of awareness creates isolation and so support groups are amazing and really helpful!"*

Hopefully you can see why Support Services are such a vital component to Ataxia UK and supporting the ataxia community.

*The key focus of the first year of the services expansion project is on Information, Helpline & Advocacy. You can read more on the impact your donations will have on the Ataxia UK Christmas Challenge page:*  
<http://alturl.com/4pyva>

**How can you double your impact? Throughout the Christmas Challenge week, which runs from midday Tuesday 28th November to midday Tuesday 5th December 2023 get into the festive spirit and contribute generously through the Big Give website to help expand the services for the ataxia community.**

You can help by sharing your stories of ataxia with your friends, family, colleagues and neighbours and highlighting the need for Support Services for the ataxia community. With this you can ask them to donate generously to the expansion of the Information, Helpline and Advocacy Services at Ataxia UK.

Donations must be made directly through the Big Give website to qualify for doubling! We look forward to updating you on the success we know you will make of the 2023 Big Give Christmas Campaign.

*\*If you qualify for Gift Aid and we have a valid Gift Aid Declaration for you then an additional 25% will be added to your gift! If you are not sure if we have a valid Gift Aid Declaration for you, contact **Kieran** at [fundraising@ataxia.org.uk](mailto:fundraising@ataxia.org.uk) and we will send you a form to fill out!*



Christmas  
Challenge

BigGive



# Big Ataxia Cake Bake 2023!

**The tastiest (& everyone's favourite) event of the year is making a return in 2023!**

Get ready to fire up your oven from 6th November to 8th December. Host your Bake Sale at home, turn your local community space into a sugary wonderland, or even challenge your friends and family to a Bake-Off competition.

As if love of baking wasn't enough, there will be a grand prize for whoever raises the most! But wait, there's more! When you register, Ataxia UK will send you a Cake Bake kit, including essential materials and an Ataxia UK t-shirt to ensure your event's success.

Sign up today on our dedicated webpage:  
[www.ataxia.org.uk/big-ataxia-cake-bake](http://www.ataxia.org.uk/big-ataxia-cake-bake)



# Get running!

**Lace up those running shoes – it's time to hit the pavement for Ataxia UK!**

When you sign up to one of the exciting running events, you'll receive an exclusive running vest to flaunt your support while you conquer those miles. Not to mention our unwavering support, which will be with you every step of the way.

**Plus, every fundraiser gets FREE entry, courtesy of Ataxia UK!**

Whether you're a seasoned pro or just starting out on your running adventure, we have a variety of exciting races to choose from. We offer 5ks, 10ks, half marathons, and full marathons throughout the country, including;

- **Victoria Park 5k or 10k**, 2nd December 2023
- **Newcastle 10k**, 20th January 2024
- **Birmingham Running Festival**, 18th February 2024
- **Sheffield Half**, 7th April 2024
- **Leeds Running Festival**, 21st April 2024
- **Birmingham Running Festival**, 12th May
- **Edinburgh Running Festival**, 25th May 2024

Visit our website to see the full selection of upcoming runs:  
[www.ataxia.org.uk/get-involved/events-and-fundraising/challenges/runs](http://www.ataxia.org.uk/get-involved/events-and-fundraising/challenges/runs)

For more information or to sign up to an event contact our Fundraising team at [fundraising@ataxia.org.uk](mailto:fundraising@ataxia.org.uk).





Over the last few months, our amazing fundraisers went swimming, climbing, trekking, and more! We are immensely grateful to each and every one of them.

## Fundraising thank-yous

We are filled with gratitude to **David Lawrence** (right) and **Bands of Hope and Glory** for raising £332!

**Adam Lewis (1)** raised £1,164 at the Three Peaks Challenge. Well done, you nailed it!

A round of applause to **Demi Attwood (2)** who raised a fantastic £345 by completing the Black Country Half.

We really appreciate **Les Church** who used collection tins to raise £350!

Well done to **Stephen Wood (3)**, **Martha Wood (4)** & **Josh** who completed the Six Dales Trail and raised an awesome £2,057.

Thank you very much to **Alex Duncan (5)** who hosted the 'Big John Club' Breakfast and raised a wonderful £100.

Congratulations to **Sam Smeaton (6)** who bought Wedding pins and raised £180.

We are so thankful to **Sally Kiddie** who organised the Riverside Run and raised a super £2,650.

**Ben Cleak (7)** raised £1,755 cycling 186 miles in a month! We are so grateful for his support.

A speedy congratulations to **Holly McCubbin (8)** who raised £953.50 by cycling 100 miles on her holidays!

High fives to **Jack Gibson (9)** who walked 201.4 miles over the summer holidays and raised an amazing £790.

Thanks a million, to **Peter Crossley (10)**, who conquered the North Kessock Swim and raised £1,000!

**Sarah Campbell (11)** organised the Bare Your Soles event and raised an incredible £3,331. We are deeply grateful to you and your team.

**Susan Martin's** Skydive was a soaring success. She raised £605!

**Tracey Rhodes-Muir, Linda, John & Jackie (12)** raised a brilliant £1,315 by cycling from Glasgow to Brighton, reaching 463 miles!

**Megan Harvey, Amy and Dan (13)** raised £1,110 and completed the Yorkshire Three Peaks. We are so very grateful.

Hats off to **Merja Sukanen (14)** who completed the Superhero Series Triathlon for the third year in a row, raising £860.

Bravo to **Tyrell Richards (15)** who hiked the Three Peaks in 24 hours and raised £495.

Our heartfelt thanks to **Yvette Hodgson (16)** who ran the Leeds Half, raising an awesome £563.



## HATS OFF TO OUR GREAT NORTH RUN 2023 RUNNERS!

Despite the challenging weather, they raised an outstanding £6,104!

Thank you to the following 13 exceptional individuals: **Teresa Wood** (right), **Rebecca Lowes**, **Natasha Cadman**, **Amy Chamberlain**, **Gillian Ward-Stokes**, **Maddy Brown**, **Peter Nee**, **Josh Helsby**, **Mark Aaron**, **Liam Brown**, **Peter Williams**, **Lucas Ticker** and **Claire Robinson**. Thank you for your unwavering support.





For more information about the speech therapy service, visit: <http://alturl.com/xkgxi>

# Speech therapy

**Our Speech therapy service is provided over a 6-week intensive course run by Ataxia UK with our Speech Therapists Jo Lewis (1) and Mandy Mui Ngo (2).**

The course is provided via Zoom and there are six participants per group. It involves a series of individual sessions followed by four weeks of group sessions where participants work through speech and language exercises with other members of the group. The course has been hugely successful in improving speech ability and confidence among participants. **67% people who took part in our Speech Therapist course and did our evaluations survey, agreed, or strongly agreed that their communication had improved since treatment.** Another reoccurring comment people made was that their confidence increased following the completion of the course.

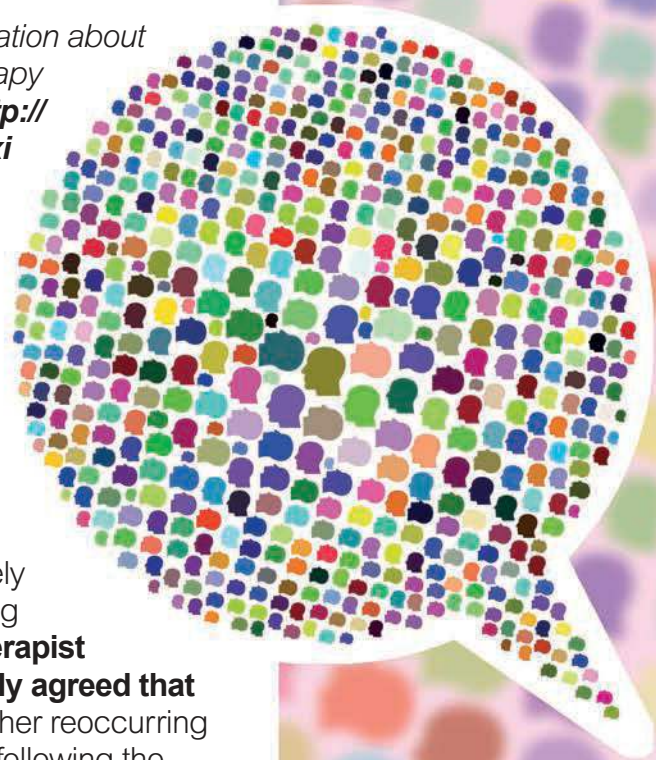
***“(the) speech therapy group has massively, positively impacted my life”***  
Peter, 70, Cerebellar Ataxia.

Holding the sessions on Zoom ensures that people from across the UK can access this free service without having to travel or disrupt their routine too much. From our survey we found that 94% of people agreed that Zoom meetings worked well for them.

At the start of the sessions, **Professor Anja Lowitt** introduced Jo and Mandy by saying: *“We couldn’t do it without our brilliant Speech and Language Therapists”*

Jo Lewis replied: *“I was delighted to be introduced to Ataxia UK via Professor Anja Lowitt, Strathclyde University, having had the opportunity to provide the online group and individual therapy elements of her current research project. I am passionate about supporting individuals and their families with communication difficulties as a result of neurological disorders. Although I have recently branched out into independent practice, I continue to work within the NHS. My career spans 27 years working in specialist in-patient rehabilitation, neurosurgery, neurology, intensive care, and community settings, but mostly within the field of community neuro rehabilitation where I’ve been clinical lead within a multidisciplinary team, supporting individuals to achieve their potential for the things that matter to them, whether that is within their home, their communities, employment, or education.”*

Professor Anja Lowitt then introduced Mandy, saying: *“Mandy Mui Ngo is an Independent Speech and Holistic Therapist, based in London, UK. She graduated with a BSc (Hons) Degree in Speech Sciences from the University College of London (UCL) and Clinical Hypnosis at West London University. She has worked throughout the UK, providing services for clients with Neurological Disorders. She has travelled worldwide, helping to set up Education Centres as well as teaching the medical professionals. Mandy also provided therapies to the British Army staffs in Germany. She gets involved in the community by being a Trustee for the Stroke Action UK; working with the London Olympics 2014 Open Ceremonies, and a Heritage Champion for North London.”*



1



2





# Festive gift ideas

**It's coming round to that time of year again (we hope your year hasn't flown by quite as quickly ours!) when we start to think about gifts for our loved ones.**

When buying a gift for a disabled family member or friend it can be tricky to know what to buy them. It is a good idea to start thinking about what would actually benefit them and what activities they enjoy. There are so many useful things that could help make things a little easier or give people more independence. So, we've popped on our elf hats a little early this year to put together this list to get you started.

First on the list is a hands-free hair dryer stand – really useful for those with limited mobility, strength, or coordination. We like this one from Ability Superstore: <http://alturl.com/rhwzj>

Following on the beauty theme Kohl kreatives have produced a range of brushes called the Flex Collection that allow makeup to be accessible for people who struggle with coordination: <http://alturl.com/nmwin>

Moving on to pet owners. The no-bend pet bowl is a must for anyone struggling with their mobility to feed their pets. It has a level lift so that you can rise and lower the bowls to height suitable for you. It comes in red or grey and can also be found on Ability Superstore: <http://alturl.com/xa5bs>

For those of you that like a gadget, meet the Eko home motion sensor bin. No more trying to open the bin with a foot pedal whilst hanging onto furniture for balance. They come in a wide range of sizes and styles: <http://alturl.com/hu2te>

For the gamers in your lives, Lepmis offer disabled gamers a range of robust products that allow access to all gaming and entertainment options available through the latest videogame consoles: <http://alturl.com/rmaqy>

For the keen gardeners out there, have you ever thought of a robot mower? Not the cheapest, but maybe family members could club together for the gardeners in their lives. *Just search for **Robot lawnmower UK** on [www.amazon.co.uk](http://www.amazon.co.uk)*

Bundle Bean have a Free Wheelers range for wheelchair users from four years to adult. The range includes bags, wheelchair spokeguards, wheelchair ponchos and cosy's all in bright eye-catching designs, my favourite is the yellow zebra design: <http://alturl.com/6bt3a>

*We hope this gives you some inspiration for some more unusual present ideas as the festive season approaches and remember that your time is one of the best gifts that you can give. There are many disability cards that you could buy for your loved ones to help you and them get out and about – the CEA card for cinema's, for example, costs £6 to buy for the year and entitles the companion to a free ticket, so effectively saving 50% between you. Find out more about all sorts of disability cards and eligibility here: <http://alturl.com/wwbzt>*



## Do not give up

**Laxmi has Friedreich's ataxia (FA), and her advice for the Ataxia UK community is never stop believing in yourself and be consistent.**

**Let's hear from Laxmi in her own words:**

Hi everyone. I want to tell you a bit about myself. My childhood consisted of dancing and Taekwondo. But gradually, I started to feel weak. At first, I thought it might just be fatigue. I took vitamins, but nothing changed, and I still felt weak.

My handwriting started deteriorating, and I became slow at doing things. I began to question my situation at this point. As a result, I stopped studying because I felt unworthy.

Eventually, I stopped socialising as well. It was my mother who encouraged me to continue studying and to move forward - she gave me courage to pursue my dreams. Although I continued to study, my slow handwriting made it difficult for me to get good grades in exams.

I was diagnosed a year ago with Friedreich's ataxia (FA). Before the pandemic, I was able to walk, but now I need support. I felt quite negative about everything at the time. But my mum gave me the confidence to pursue my career and not overthink things.

With the support of my parents, I got a diploma in computing and started teaching. Through these ups and downs, I have learned that life is not easy, but if parents are supportive, the path can be good. Although my symptoms have been present for nine years, I still do not use a wheelchair. I am hopeful. I am motivated. I know this condition is progressive, but I will not let it dominate me. I exercise at home. My two sisters also have ataxia. It is thanks to Mum's courage and support that we all feel blessed.

**My message to you is:** Do not give up. We are unique in our own way – just be brave and explore. Let's show everyone that if we believe in ourselves, we can accomplish anything. You've got this. Never doubt yourselves, my friends.

It does not matter how slowly you go as long as you do not stop – be consistent. We can achieve whatever we like as long as we go for it. What is there to stop us? Of course, if need be, we can certainly ask for help and take all the support we need. Yes, I have FA, but I know I have to push myself to be the best version of myself.

*Do you have a story you'd like to share with the ataxia community? Get in touch with our Communications team:*

**[communications@ataxia.org.uk](mailto:communications@ataxia.org.uk)**





## Holly's Big Cycle for Pappy

**Holly (7) is Ataxia UK's young friend, who, during her summer holidays cycled 100 miles to raise support, funds and awareness for the ataxia community. She did this incredible fundraiser for her Pappy, David. Here is what Lee (Holly's dad) told us:**

David, aka Ben, is Holly's Pappy (paternal grandfather). David's symptoms started developing when he was in his late thirties. In 2014, following genetic testing and an MRI, he was diagnosed with Spinocerebellar ataxia type 6. Since his diagnosis, David's symptoms have progressed, and he now requires a walker indoors and a wheelchair outdoors. He is fortunate that the **Douglas Grant Rehabilitation Centre** is nearby and on hand to provide support. They have worked with him to provide neurological physiotherapists, occupational therapists, speech therapists and dietician services over the years.

**Holly is David's much-adoring granddaughter.** She is seven years old and loves riding her bike, having only learned to ride it at Easter this year. She enjoys visiting her Pappy and joining him on trips outdoors. She will always catch a ride with him in his wheelchair. Indoors, she quickly snuggles up and watches a film with her Pappy and loves playing games with him and stealing his chocolate.

Holly is fundraising to help Ataxia UK raise funds for research. She hopes that the money can go towards research that will help find a cure for Ataxia and, hopefully, one day see her Pappy and others suffering from the condition cured. In her own words, she wants to *"get the scientists more money to do research and find a cure."* She is also keen to raise awareness of ataxia and knows not a lot of people know about the condition. She managed to get her local MP, **Dr Philippa Whitford**, on board; she joined Holly and her big sister on a cycle in the pouring rain and even promoted their efforts on social media. **Holly has managed to complete the 100-mile cycle and cross the finishing line on 20th August. Along the way, she made plenty of friends and smashed her original £100 fundraising target, raising a total of £477 and still counting...**

In Holly's words, *"It's important to fundraise for Ataxia UK because people who have ataxia need help, and the charity needs important funding to provide some of this help."* People can help Holly's fundraising journey by talking about ataxia, and donating to her JustGiving page, if they can spare any change. Holly knows that research can be expensive, and we have explained to her that the higher the demands, the more funding a charity receives. Given that her beloved Pappy has a rare condition, not as much funding is available. This is why it is important to raise the charity's profile, raise awareness of the condition and, where possible, fundraise. Holly is also worldly-wise beyond her years and knows that a cute wee girl doing something amazing for charity will likely make people pay attention.

**A message from Holly:** *"I hope that everyone in the ataxia community and my family is proud of me. I really want to help everyone. Thank you so much if you can spare pennies. It is going to help people like my Pappy."* She wants to thank everyone who has already donated to her JustGiving page and is very grateful due to the current cost of living crisis.



# Information on receiving IV fluids as someone living with Friedreich's ataxia

**Ataxia UK has produced a leaflet on the safe administration of fluids for people with Friedreich's ataxia (FA).**

It was written in collaboration with **Prof Paola Giunti** and **Dr Michael Parkinson, Consultant Neurologists** at the **London Ataxia Centre** at the **National Hospital for Neurology and Neurosurgery (NHNN)**, and **Dr Konstantinos Savvatis, Consultant Cardiologist** at **St. Bartholomew's Hospital**.

Some people with FA have a heart condition called cardiomyopathy. For those with cardiomyopathy, the leaflet describes that some considerations need to be made when administering fluids via IV, such as during labour, surgery and medical emergencies. Cardiomyopathy results in the heart being unable to tolerate fluids in the same way as a healthy heart. This needs to be carefully managed, for example through altering the speed that the fluid is given, or increasing monitoring of the heart during the procedure. Before undergoing such a procedure, it is a good idea for those with cardiomyopathy to have a cardiac assessment, including a recent echocardiogram. Echocardiograms can identify any problems with the heart, to inform healthcare providers on how to plan for the IV procedure. Cardiologists can be consulted to ensure that the most appropriate protocol is being followed.

For those with Friedreich's ataxia, but with no cardiomyopathy diagnosis, some steps still need to be taken to ensure safe administration of fluids. This is because the heart may have undergone changes that have not yet been detected or diagnosed. Before any procedure, those with FA should have a cardiac assessment, including a recent Echo. It is suggested that those with FA have their hearts assessed once per year.

During medical emergencies, it is not likely that there will be enough time for healthcare professionals to complete an echocardiogram, and a person with FA may not have recently had their heart assessed. In this situation, it is important to share the FA diagnosis and any diagnosis of cardiomyopathy with healthcare providers, so they can conduct extra monitoring of the heart during an emergency procedure.

*We are grateful to **Becky Downing**, Friend of Ataxia UK who has FA, for sharing her experience of the issues she had with IV fluids during her pregnancy. This led us to work with the clinicians at the London Ataxia Centre in producing a leaflet designed to be given to your healthcare practitioner to ensure you are provided with the most appropriate care and we recommend reading the full leaflet on our website at: <http://alturl.com/wfrzp> or ask the Helpline for a copy via email: [help@ataxia.org.uk](mailto:help@ataxia.org.uk) or phone **0800 995 6037**.*





# Wellbeing Week 2024

**You're invited to come along to Wellbeing Week, from 29th January to 2nd February 2024.**

We are delighted to announce we will be hosting another virtual Wellbeing Week in 2024. Wellbeing Week is a chance to focus on some of the things that can be done to improve the lives of people with ataxia. There will be a session every day from Monday 29th January to Friday 2nd February.

This will be our fourth annual Wellbeing Week and some of you may have joined us in 2021, 2022 or 2023 and we would love to see you again in 2024! Previously we have hosted wellbeing sessions including Chair Pilates, Mindfulness and Chair yoga and information sessions covering things like aids and adaptations, Occupational Therapy, Neuro Physiotherapy and more!

*You can still check out the recordings of those sessions on our YouTube channel: [www.youtube.com/user/AtaxiaUKonline](https://www.youtube.com/user/AtaxiaUKonline)*

More than 300 people in the ataxia community have participated in Wellbeing Week with 90% of attendees who fed-back to us this year rating the sessions as "very good" or "excellent". Here are some of the things you said about it so far:

*"I attended Neurophysio with Olivia. She was excellent and her presentation was very comprehensive. I've done Mindfulness and Chair Pilates before and these are always helpful."*

*"The neurophysio session was excellent. I've already amended my normal gym routine to accommodate some new exercises."*

*"All were good and would attend any that were repeated, particularly ones involving exercises."*

*"...good coverage of needs of ataxia."*

We listened to your feedback, and during the upcoming Wellbeing Week 2024 we will be offering a range of virtual workshops designed to provide tools, tips, and information to support you in different ways to improve your wellbeing.

There will be sessions focusing on wellbeing, movement and ataxia, as well as information about accessing the support which is available to help you.

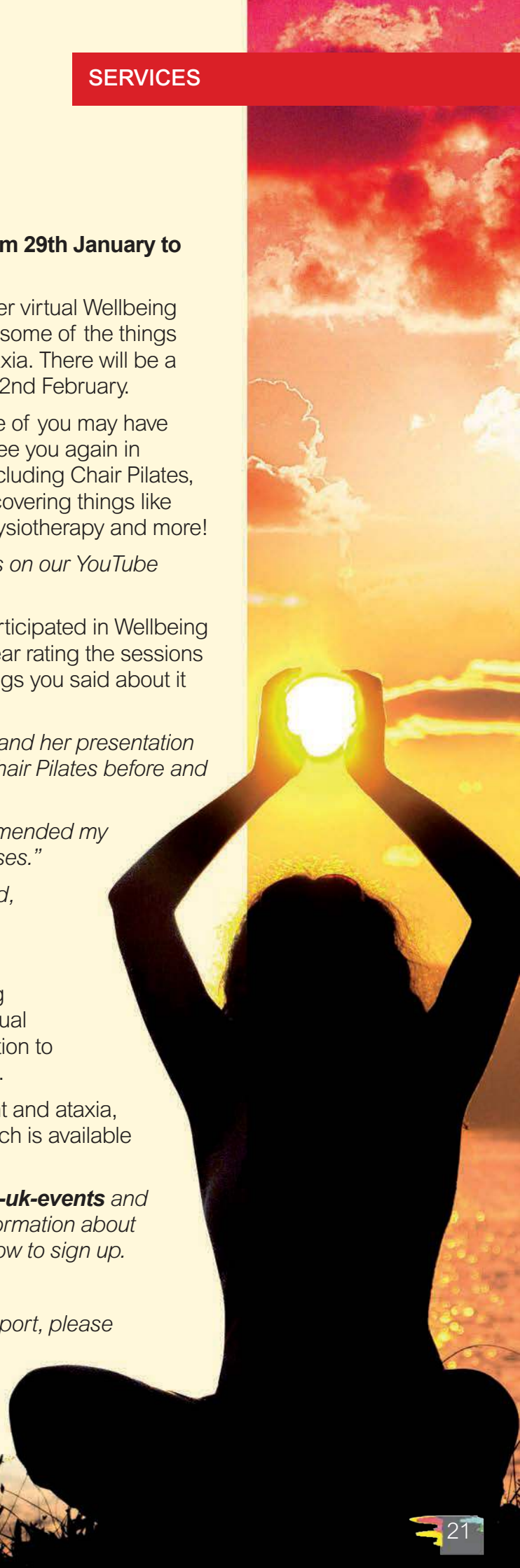
*Keep an eye on our website [www.ataxia.org.uk/ataxia-uk-events](https://www.ataxia.org.uk/ataxia-uk-events) and our social media channels where we will be sharing information about Wellbeing Week, the sessions we will be holding and how to sign up.*

We'd love to see you there!

*In the meantime, if you need information, advice or support, please contact the Helpline for a copy via email:*

***help@ataxia.org.uk*** or phone ***0800 995 6037***.

*The Helpline is open Monday to Thursday, 10.30am to 2.30pm. See page 2 for seasonal opening times.*



# Our North West London Branch

**We recently had a conversation with our North West London Branch, which happens to be one of our longest standing Support Groups (coming up to 15 years!). We wanted to hear a bit about how they operate and learn a bit about the history of the Branch.**

**Deanna** originally set up the group and continues to be involved as a Committee Member. **Talita** is the Chairperson and runs the group alongside other Committee members **Tony** (Treasurer and Deanna's husband), **Ray** (Fundraising) and **Gillian** and **Sarah** (Committee).

We spoke to Deanna, Tony, and Talita about the history of the Branch and some of the activities they have gotten up to over the years.

## 1. Tell us a bit about the group and what you do?

**Deanna:** I started a satellite support group in April 2009 with the help of one member of staff who came down to get me started at the first meeting. I ran the group organising many events such as a picnics, lunches, and quizzes. Tony helped me by coming with me to look at places to see if they were suitable for our members.

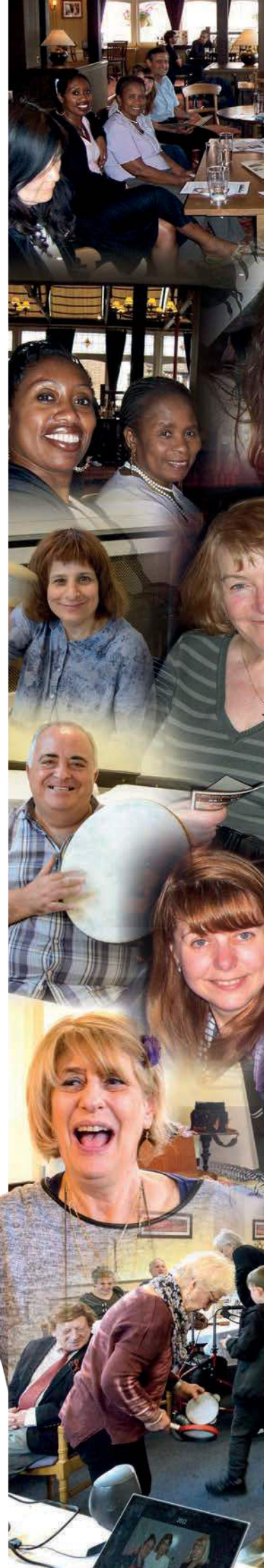
After about three to four years our group was getting so big and successful that we became a Branch with a financial officer (Tony) and a secretary, with me still running and organising it. After about three years I became ill, and I handed the branch over to Talita. She has carried on the good work for the branch (I am still on our committee), and I still organise some events and the pantomime every year.

**Tony:** I have built the website, act as treasurer and assist with organising activities.

## 2. What kind of activities do you organise and how have they helped?

**Tony:** We have arranged grants for members to help them with access and along with many events including:

- Panto outings
- Canal Boat Trips
- Lunches
- Cream teas
- Fund raising quizzes (afternoon and supper)
- Virtual activities, bingo, quizzes, music sessions
- Tour Albert Hall
- Informal get togethers in pubs
- Waitrose Community Matters fundraising
- 10th anniversary party with a music therapist
- Visit to local paper mill
- Guest speakers, Pilates, Meditation, Benefits, Ataxia Researchers, Comedy Script Writer
- Stalls to publicise ataxia at Waitrose, Local Pharmacy, RAF Museum
- Interview with local papers (Harrow Times and Jewish Chronicle)







**Talita:** Our events help people to connect with other individuals that have an understanding of what they are going through, the challenges they face and obstacles they may need to overcome but also our events give an opportunity for members to relax for a while and have a nice enjoyable afternoon. We also give our members opportunities to go to events they wouldn't normally be able to because of their limitations such as our fully accessible boat trip.

**Deanna:** When I was chair, I use to ring new members to welcome them to the group, but I remember one man who rung me, he told me his wife had ataxia and she had got so bad that she had to go into a home. He felt so lost and so alone, he did not know much about ataxia except for the symptoms his wife had he knew no others with ataxia. So, I suggested that if he came to the group and met other people it might help him, and he told me it did. I think there was another similar person, and I gave the same advice so that helped, and friendships have been made between members. There is communication and support between people in the group. The committee can offer others personal advice.

### **3. Could you tell us a bit about some of the challenges you are facing and how you are dealing with them?**

**Talita:** Since we resumed our face-to-face meetings, we have struggled to get back to the numbers we previously used to get before covid, we do, of course, realise that some may no longer be able to come due to deteriorating health and other challenges. We have been running a hybrid group of both virtual and face-to-face, but we have been struggling with numbers for both types of events.

We have organised a special Extraordinary Meeting virtually to discuss with our members what motivated them to join our group and what they are looking for in our group and anything we can do to increase the likelihood that they will come to our events.

### **4. Why do you think you are facing these challenges, and how can they be overcome?**

**Talita:** It could still be a casualty of Covid but also in the time of Covid, time passed, people aged, and health deteriorated. We have new people join our group but the new members either never come to a meeting or they come once or twice and then we never see them again. I think finding out what people's expectations from our group and what motivated them to join would help us overcome these challenges, which is the purpose of our EGM however so far, we have not had much response to our scheduled meeting of people intending to attend.

### **5. What is the best way to reach you and where can people find you?**

**Talita Banoori.** Email: [ataxiuknwlondonchairperson@btinternet.com](mailto:ataxiuknwlondonchairperson@btinternet.com)  
Branch website: <https://ataxiuknorthwestlondon.wordpress.com>  
Talita's details are listed on the Ataxia UK website under **London North West** on the **Branch and Support Groups** page.

Find your local Branch & Support Group at:  
[www.ataxia.org.uk/support-services/branches-support-groups](http://www.ataxia.org.uk/support-services/branches-support-groups)



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 several  
research projects underway,  
some of which are funded,  
at least in part, by gifts left to us.

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