ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 228. Winter 2024

From lab to treatment - your gift, their future

Christmas Challenge

BigGive

Double your donations at no extra cost to you or Ataxia UK this festive season with the **Big Give Christmas Challenge!**

Find out more on p4 & 5

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

ATAXIA
Ataxia UK

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In the office

A warm welcome to the newest member of the **Fundraising & Communications Team** at Ataxia UK, **Amna Nahim**. Amna joins us as our new **Fundraising Administrator**, so anyone from the community who will be taking part in fundraising activity will probably get a knock from her at some point in the coming months! Amna previously worked with Accountability Lab as Project and Administrative Coordinator, where her work largely focused on highlighting corruption and increasing transparency within international politics, often at times being posted abroad. She also has experience working in the financial sector as a researcher, where she researched and reported on HNWI and monitored their investments.

CEO's Introduction

At the end of August, we reached a staging post on the way to the first drug for an ataxia available through the NHS. We attended our first meeting with NICE in connection with its assessment of Omaveloxolone, the drug for the treatment of Friedreich's ataxia in over 16s, which will decide whether the NHS will purchase it. Please turn to p6 for an update.

Thank you to all who participated in events to mark **International Ataxia Awareness Day** on 25th September. In that week, it became clear that more meetings with NICE may be in store! We had exciting news of **two potential drugs for ataxia!** Troriluzole is a drug being developed for the Spinocerebellar ataxias (SCAs) by Biohaven, (see p7,) and Intrabio announced that the FDA in the USA had approved their drug Levacetylleucine (Aqneursa) for the treatment of Niemann-Pick Disease Type C. (See p8). Assembling the evidence to represent people with ataxia during drug approvals processes takes time and money, and we are optimistic that before too long we will have to devote lots of time to it as the number of drugs multiplies – please look at p4&5 to see how you can unlock funds for Ataxia UK to do this and continue providing all our support services.

Finally, I'm sorry to have to tell **Dan Beacon** is leaving Ataxia UK. Dan has been with us for just over half a decade as our **Head of Fundraising and Communications**, providing management, support and leadership to the fundraising / communications team. We wish him the very best in his next role at Your Place.

I hope you have a very happy festive period, and that the promise of 2024 turns into treatments for ataxia in 2025.

Sue

Best wishes, Sue Millman

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Ataxia people

Research

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From lab to treatment - your gift, their future - welcome to the Big Give 2024 Christmas Challenge

Set your alarms for the upcoming 2024 Big Give Christmas Campaign which goes live from **midday Tuesday 3rd December running until midday Tuesday 10th December!**

It gives us great pleasure to announce we have raised a dynamic £12,500 in pledges from six wonderful pledgers. Thank you to those pledgers who turned up to help support the ataxia community.

Just to remind you how the Big Give works: Every year a small number of supporters pledge to give us a donation, the total of which is then matched by our Big Give Champion sponsor, The Big Give Trust. So, this will take that £12,500 already in the Campaign Pot up to £22,500! Throughout the Big Give Campaign week, all donations made by you and other 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 our target of £45,000 through the Big Give 2024 Campaign.

So, let's say you donate £100 through the official Big Give Website, well then, that donation is matched using the Campaign Pot, doubling your donation to £200 which is then increased to £225 through Gift Aid*.

Throughout the Big Give Christmas Campaign week, we need your support to achieve the wonderful £45,000 total from the Campaign Pot. Your generosity this festive season will support those affected by ataxia, through the From Lab to Treatment appeal.

There has never been a better time for ataxia research and treatments, with three drugs on the horizon and others in the research pipeline. This Challenge aims to support efforts in making these drugs available in the UK ASAP, whilst enabling us to continue providing support to you and the community. To help highlight why your support is so important this Christmas, our friend **Carol** (right) has generously shared her story. Carol was fortunate with her Friedreich's ataxia diagnosis in that her GP was excellent and though they explained the process and timescales – she didn't realise at the time that you couldn't just ask to be tested for FA.

After receiving her diagnosis, she worked hard *"to stay positive and motivated. I was diagnosed in the November and by February the following year I was training in order to slow deterioration in my trunk and balance. I set a goal, to complete the Inca trail to Machu Picchu and white-water raft down the Amazon. I completed that in the June of that year. However, things began to slowly deteriorate and managing fatigue between activities and work became a big issue. I was told that staying active would help but the activities that were meaningful for me, and motivated my involvement, became harder to do.* ***As well as losing my capacity to balance and carry out fine movement with my hands, my speech deteriorated. Knowing, at the time, there was no treatment was something that raised its head often in my thoughts and I couldn't escape that reality – I had to find a way to live with this uninvited disease.****"*

Because Carol is a French resident, she is able to receive Skyclarys, the drug to help treat FA, through the French health system. *"It's not a cure, it's a treatment. Importantly, for me though, it has reversed some of my symptoms. Most noticeable was my speech - within a matter of days my speed and clarity improved. I returned to conversations in social circles more animated and confident. Balance started to improve from week one. Ultimately Omaveloxolone has given me hope and motivation, hope that it will hold the disease until a cure is found."*

And though Carol is grateful to have access to Skyclarys, that gratitude comes with ample frustration. *"Frustration is a general feeling, along with anger, that red-tape stands in the way of making a significant difference to the lives of people with Friedreich's ataxia. On a more personal note, I feel tremendous guilt in being able to access a drug that my brother, in the UK, needs more than me. I even asked my consultant could I share the medication with him, but it was a big 'no'. It is a double-edged sword telling people I am being treated with Omav. Although responses are positive and people wish me well, I can see disappointment in their eyes – they have every reason to feel crest-fallen. They are islands within an Island."*

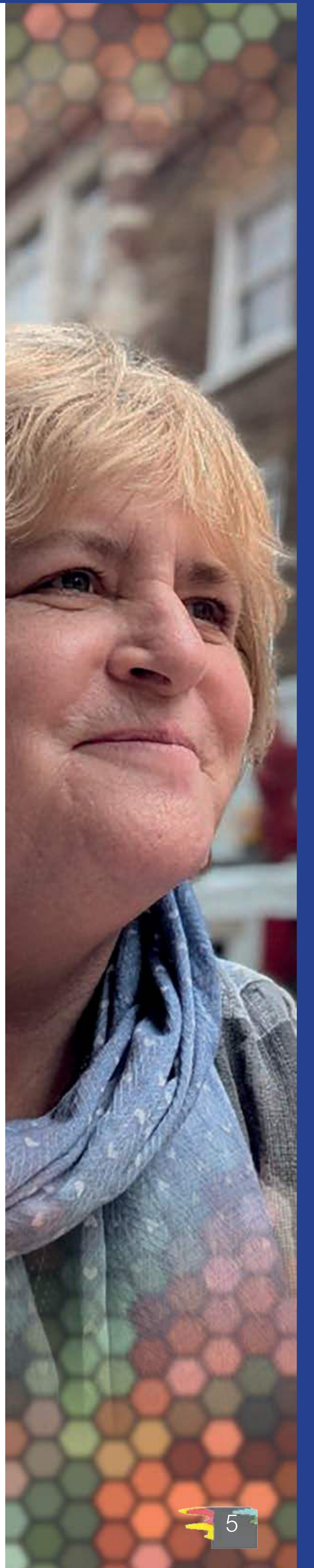
Your support this Christmas can help set the stage for the next steps of ataxia treatment and help us as a Patient Advisory Group to advocate for Skyclarys here in the UK.

However, this year's Big Give encompasses more than just setting the stage for ataxia drug approval in the UK. While we work on navigating the drug approval process with pharmaceutical companies, we also want to continue to support those affected by ataxia until treatments are found (and for as long as that support is needed).

Carol received support from Ataxia UK whilst living in the UK. *"Ataxia UK guided me towards accessing a specialist ataxia clinic. This gave me the opportunity to feel understood, treated as a person and contribute to research for Friedreich's ataxia. This began my road to purpose again. Their newsletters helped me to realise that there was a wider community and 'people like me' out there and their conferences embraced me and gave me a sense of belonging. Their support and encouragement gave me the confidence to become an ambassador for them, representing them, lobbying for them and educating people for them."*

To find out more about this year's Big Give Christmas Challenge, and to double your generosity this festive period, visit the Big Give Webpage here: http://alturl.com/ovetr and remember – only gifts donated through the link above will be doubled.

***Normal T&Cs for Gift Aid apply, and these can be found on the Big Give Website when donating.**



Update on the evaluation of Omaveloxolone for use in adults with FA in the UK

In July we shared an update on the timeline for the UK regulatory process, which you can find on the Omav updates section of our website. An important step is the evaluation by the National Institute for Health and Care Excellence (NICE), which assesses the cost effectiveness of new medicines in England, with Wales and Northern Ireland also being able to adopt NICE recommendations.

On 30th August, NICE held a scoping meeting, attended by representatives of Ataxia UK, Biogen, as well as clinicians specialising in ataxia. This is a key step in order to decide the details of how Omaveloxolone will be evaluated by NICE.

It was a good opportunity for Ataxia UK to represent people with FA in this process. We are now waiting to hear from NICE regarding the timing of the next steps and will update you through our communication channels.

To learn more about the NICE process for Omaveloxolone and find out more about the UK drug approval process, watch our webinars in the research news section of our website and sign up to the dedicated Omav newsletter at: ***www.ataxia.org.uk/omav-updates/***

Do you or does someone you know have a confirmed diagnosis of FA, and want to help contribute to the NICE evaluation process for Omaveloxolone?

If you or someone you know has a confirmed diagnosis of FA and are aged 16 and above, we want to hear from you!

As part of the NICE evaluation process for the appraisal of Omaveloxolone to treat people with FA aged 16 and above, we are inviting adults with FA to share case studies of the impact of FA on their lives.

To take part, email ***research@ataxia.org.uk*** *with the subject* ***'FA case studies'*** *and we will send you a list of questions.*

Do you currently take Omaveloxolone or did you take part in the Omaveloxolone clinical trial in London?

If you or someone you know took part in the Omaveloxolone clinical trial in the UK, we want to hear from you.

We are collecting feedback from people who have taken or are taking Omaveloxolone for their FA, to support the NICE evaluation process.

To share your experience, email ***research@ataxia.org.uk*** *with the subject* ***'My experience taking Omav for FA'****, and we will send you a list of questions.*

Positive results in Biohaven study of Troriluzole for spinocerebellar ataxia (SCA)

In September the pharmaceutical company Biohaven announced positive topline results from their study of the drug Troriluzole to treat SCAs.

Those with SCA who were treated with Troriluzole showed a 50 – 70% slowing of disease progression, compared to those with SCA who were untreated over a 3-year study period. This represents a 1.5 – 2.2 years delay in disease progression over the 3 years. The study compared results of people on the Biohaven troriluzole trial (including people with SCA1,2,3,6,7,8 and 10) with data from people on natural history studies, such as the European study EuroSCA. Many people from the UK took part in EuroSCA at the London Ataxia Centre; we are grateful to these study participants for their vital contribution to research that can lead to the development of treatments.

Following these results, Biohaven plans to submit a new drug application for Troriluzole for all types of SCAs to the US Food and Drug Administration (FDA) in the last quarter of 2024. As we reported previously, Troriluzole is also being evaluated by the European Medicines Agency (EMA) to treat SCA3, and we are awaiting information on the outcome of this. This new data should provide additional evidence on the benefit of the drug. Ataxia UK will be encouraging Biohaven to seek approval in the UK and we will share any information as soon as we have it.

The results of this study will be presented at the International Congress for Ataxia Research (ICAR) in London in November.

Read the press release from Biohaven on their website:
http://alturl.com/e6dq5

Update on the availability of genetic testing for SCA27B

In 2023, the gene that causes a type of spinocerebellar ataxia called SCA27B was discovered. Since then, researchers have been developing a genetic test for the condition, which they plan to make available in the UK.

If you or someone you know has a genetic diagnosis of SCA27B, please let us at Ataxia UK know by email: ***sparr-reid@ataxia.org.uk****, so we can plan for future trials. You can read more information on SCA27B on the research news section of our website:* ***http://alturl.com/2ydqq***

Intrabio announces FDA approval of their drug Levacetylleucine (Aqneursa) for the treatment of niemann-pick disease type C

In September, the pharmaceutical company IntraBio announced that the FDA in the US has approved their drug levacetylleucine for the treatment of niemann-pick disease type C (NPC).

NPC is a rare lysosomal storage disorder, in which ataxia is a hallmark symptom. The FDA approval follows positive data from their phase III placebo-controlled clinical trial which showed significant improvement in neurological symptoms and functional benefits in adults and children with NPC taking Levacetylleucine within 12 weeks of administration, including on the Scale for the Assessment and Rating of Ataxia (SARA) and Spinocerebellar Ataxia Functional Index (SCAFI).

IntraBio's Chief Development Officer Taylor Fields commented, *"IntraBio has been dedicated to bringing novel treatments to patients with extremely high unmet medical needs like NPC. We remain committed to ensuring that all patients who can benefit from this novel treatment will have the opportunity to do so. Based on our clinical research, we believe that Levacetylleucine may hold potential for treating other rare and common neurodegenerative and neurodevelopmental disorders, and we will continue to rapidly develop Levacetylleucine for these additional indications."*

IntraBio's Phase IIb clinical trials on levacetylleucine for NPC and GM2 Gangliosidosis showed positive results, with improved symptoms, including better SARA scores. The treatment was safe and well-tolerated with no serious drug-related adverse events. The trials were conducted in the USA, EU, and UK. IntraBio has presented this data at Ataxia UK's patient conference and is also exploring the drug's potential in other inherited cerebellar ataxias, such as Ataxia-Telangiectasia and Spinocerebellar ataxias, offering future hope. Find out more here: http://alturl.com/yet24

In conversation with Dr Yi Shiau Ng, Consultant Neurologist, and Clinical Senior Lecturer at Newcastle University

Our research intern, Scarlett Parr-Reid (top right), sits down with Dr Ng (below right) to discuss his research into mitochondrial disease and spinocerebellar ataxia type-6 (SCA6).

Tell me a bit about yourself and your journey into the field of ataxia research.

I'm a consultant neurologist with research interests in natural history, outcome measures and clinical trial endpoints in hereditary ataxia and primary mitochondrial disease (PMD). My research journey started at the Wellcome Centre for Mitochondrial Research, Newcastle University.

When I reviewed adult patients with PMD in the clinic, I noticed that many patients are significantly affected by ataxia, in addition to other multi-system involvement. What we have often observed is that individuals with PMD lose the ability to walk safely because of ataxia rather than muscle weakness. This led to my first clinical project focusing on the assessment of ataxia several years ago.

Could you talk about the research you and your team at Newcastle University have conducted so far into mitochondrial disease and SCA6?

Through my research, I first tried to characterise ataxia in those individuals with primary mitochondrial disease (PMD) compared to healthy participants. This was to ensure that existing clinical rating scales and gait laboratory measures can reliably distinguish between those with ataxia and healthy controls.

The next question that led to is whether those with PMD and ataxia have a unique characteristic profile in terms of their walking pattern and balance control compared to other forms of hereditary ataxia. This is important as, if there are any similarities, then any interventions we look at might be applicable for both disease groups.

We chose SCA6 patients as a disease control group, as these individuals have what is called pure cerebellar syndrome, meaning that their symptoms are primarily driven by cerebellar degeneration. This means we could compare their balance and gait profiles to those with PMD to see what is caused by cerebellar degeneration and what is separate in mitochondrial disease. Ataxia UK and Academy of Medical Sciences (AMS) co-funded this project, **'Balance and Gait abnormalities in adult patients with mitochondrial disease and spinocerebellar ataxia type 6'.**

What are the next steps for your research?

My research team and I have recently received funding from Ataxia UK for our project 'A feasibility study of Remote Patient-Reported Outcome measures in Mitochondrial Disease and Spinocerebellar ataxias (R-PROMS)'. It is a collaboration between Newcastle University and Monash University in Australia. This project will study the feasibility of conducting online assessments of how ataxic symptoms change over time and questionnaires on quality of life. There will only be one face-to-face visit at the beginning of the study to conduct a physical examination of participants.

The hope is that this project will provide a research opportunity for people who do not normally take part in studies due to severe physical disability, as well as those with very rare genetic causes. We aim to use the findings from this project to show whether online assessments are suitable and reliable to show how ataxic symptoms change over one year, which will help inform the design of clinical trials.

As this is a feasibility study, how do you plan to capture the feasibility of remote assessments of ataxia symptoms?

Because this project is a feasibility study, we will need to carry out post-study surveys and virtual focus groups involving participants who complete the study. However, it is important to also explore why some patients decline to take part in the study. We need to ensure that individuals have not been excluded based on their access to computer or laptop.

Host your own premiere of UN(CONQUERED)

This International Ataxia Awareness Day, we celebrated what makes us unconquered, and we asked you to organise a screening of our documentary, Un(CONQUERED).

UN(CONQUERED) is a new documentary produced by Ataxia UK's Viktor Elzer, that tells the powerful story of Ben, a man diagnosed with progressive cerebellar ataxia.

It is time to make a difference, and we can only do this with your help! Have your popcorn, nachos, and soft drinks ready and get the show started!

This year, we are asking our Friends to host their very own home premiere. Organise a screening of the documentary in the comfort of your home, your community centre, or your cinema.
Raise awareness of living with ataxia through the eyes of Ben.

We would also encourage you to raise some vital funds to support those in the ataxia community.

Here is what makes our Friend, Dunc (right)**, unconquered:** *"I guess I'd say that my determination to live an independent life and to keep travelling the world with my trusty wheelchair Priscilla means ataxia hasn't conquered me."*

You can still share your stories and tell us what makes you unconquered! Get in touch by emailing ***communications@ataxia.org.uk***

Take action by visiting our website:
http://alturl.com/afegk

Exciting new Specialist Nurse Service set to launch in the Southwest

We are excited to announce the upcoming launch of a new, independent specialist nurse service dedicated to supporting individuals with ataxia in the Southwest of England.

Set to launch in early 2025 and funded by the National Lottery Community Fund, this service represents a significant milestone for those living with ataxia, particularly in areas with limited access to specialist care.

The Southwest has long been underserved in terms of ataxia services. With no local accredited specialist ataxia centres and a shortage of neurologists with expertise in ataxias, people in this region have faced significant challenges in accessing the care they need. The nearest ataxia centre, located in Oxford, is distant and costly to reach, creating further barriers to diagnosis and treatment. The introduction of the Ataxia UK Specialist Nurse service aims to overcome these challenges by providing much-needed support closer to home.

Managed by Ataxia UK, the service is designed to complement existing NHS services while remaining independent. The Specialist Nurse will work alongside NHS professionals, assisting individuals from initial diagnosis through ongoing care. The nurse will also serve as an advocate, ensuring that people with ataxia and their families are fully informed, connected to relevant services and supported throughout their healthcare journey.

The specialist nurse will provide personalised, face-to-face, and remote support tailored to the needs of each individual. This includes coordinating access to essential therapies such as physiotherapy, speech therapy, and occupational therapy, which are crucial for managing ataxia symptoms and improving quality of life. The service is designed to ensure that individuals receive the right support at the right time, helping them navigate the complexities of living with ataxia more effectively.

The service has been developed with input from clinicians and nurses, people with ataxia, their families, and carers to ensure it meets the real needs of those it aims to support. The specialist nurse will work closely with existing support groups in the Southwest, offering guidance and resources to strengthen these networks.

The introduction of our specialist nurse service marks a significant step forward in the care and support of individuals with ataxia in the Southwest. We look forward to seeing its positive impact on the ataxia community in the Southwest and, if it's successful, rolling it out to other areas of the UK.

Run for a cure in 2025!

Imagine crossing the finish line at one of 2025's most prestigious marathons, the crowd cheering, your heart pounding with pride — not just for the physical achievement but for the incredible cause you're supporting.

In 2025, Ataxia UK is offering spots in major marathons and half marathons across the UK and beyond — from the scenic Brighton Marathon to the historic streets of Edinburgh, the bustling streets of London Hackney, and even the vibrant Barcelona Half Marathon.

Sign up: ***fundraising@ataxia.org.uk***

Christmas is just 'round the corner

There is still time to send season's greetings! Get your Christmas cards from us and 100% proceeds will be donated to Ataxia UK!

BUY NOW:
http://alturl.com/trnwn
or ***http://alturl.com/x7yqr***

Sky-high challenge - dare to dive!

Mark your diary for 29 March 2025 and get ready for an incredible day of skydiving with Ataxia UK's Sky-High Challenge!

Whether you're a thrill-seeker or searching for an extraordinary group activity, this event is tailor-made for you. Dive into excitement at various prime locations across the country, all while supporting ground-breaking research and services for the ataxia community!

Join forces with us to make a significant impact in the lives of those affected by ataxia. Assemble your team - be it friends, colleagues, or family - and experience a jump that's both thrilling and meaningful.

We invite corporate groups to step out of the office and into the sky for a team-building experience that promises to be unforgettable!

Date: ***29 March 2025***
Drop Zones: ***Nationwide***
– a place near you!
Sign up: ***http://alturl.com/a79cc***

Sign up today and let's soar for a cure!

Big Ataxia Cake Bake 2024

There is still time to get involved in the Big Ataxia Cake Bake!

Sign up: ***http://alturl.com/22ttd***

Fundraising thank-yous

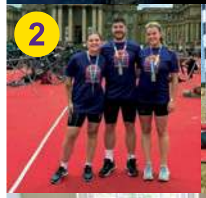
A huge thanks duo **Sean Hevey & Caroline Tarlton** (right) for completing the Birmingham 10k and raising an amazing £1450 inc. GA.

Thanks to everyone at **Rhiwbina Trefoil Guild** for your generous donation of £100!

Thank you, **David Laydon (1)** who works onboard the Deep Blue pipelay vessel, for your very generous donation of £540 to support the ataxia community.


1

Thanks and congratulations to trio **Jessica Steel**, **Bethanie Cundy** and **Ben Costin (2)** for their tremendous achievement at completing the Blenheim Palace Triathlon and raising a whopping £4095 inc. Gift Aid


2

Lucy & Codie Byrne (3) another awesome mother & son team have conquered the 5k Inflatable Obstacle Run challenge and raised an amazing £112 inc. GA. Well done and thank you!


3

Thank you to **Susan Thompson (4)** & grand-daughter **Ellie** for another amazing Plant Sale, raising £500!


4

A huge thanks to **Jayne & Martin Townley** for their amazing fundraising at the Santa UK convention, raising an awesome £350!

Well done and a huge thanks to **Christine Daly, Abigail Eden & Jade Andrews (5)** for completing the Peak District Ultra and raising an awesome £3,520 inc. GA; £1,546 inc. GA & £400 respectively.


5

Thanks to **Natasha Breindel** & everyone at **RBC GAM UK** for your very generous donation of £1000!

Leni Donaldson (6), thank you for organising your fundraiser raising an amazing £378 for the ataxia community.


6

We're absolutely thrilled to extend a heartfelt thank you to the incredible **Ed (7) & Jane Masters** for completing their Paddleboard Challenge and raising over £7,000 inc. GA. You two are truly making waves for a great cause.


7

Karly Johnson organised the Ladies in Red Charity Dinner for her daughter **Brogan (8)** who has Friedreich's Ataxia. They raised an amazing £655! Thank you so much for commitment to rid this world of ataxia, Karly.


8

Peter Smeaton (9), thank you for holding your Coffee Morning for Ataxia UK and raising £307 and all the amazing awareness.


9

Thank you, **Graham Sykes**, for you very generous donation of £630!

A huge thanks to **Joanne Wilson (10)**, her daughter **Kelly** and grand-daughter **Alicia** for raising an amazing £1181 inc. GA at Alicia's Summer Fete. Well done!


10

We would like to thank everyone at **St Edward's Church (11)** for your regular contribution raised from Concerts held at the church. The latest donation of £172.33 is gratefully received.


11

A huge thanks to **Shane Darbey (12)** for his awe-inspiring effort in jumping out of a plane! Shane, your courage not only soared through the skies but also raised an amazing £477 for the ataxia community.


12

Susan Fuller (13) smashed it at the Hull 10K raising an amazing £1236 inc. GA. Thank you, Susan, for all your efforts.


13

Thank you to **Susan Deane (14)** for running at the 41st Royal Sutton Fun Run and raising awareness and funds for Ataxia UK, raising an awesome £211 inc. GA.


14

Thank you, **Shauna Considine (15)** & mum **Leanne**, for your tremendous bravery, jumping out of plane to raise awareness and funds to support crucial research and services for the ataxia community! You raised an amazing £1483 inc. GA.


15

Warmest thanks and congratulations to **Mr & Mrs Maurice & Jayne Stephenson (16)**, newly married couple for your generous fundraising at your wedding which raised an amazing £956 inc. GA.


16

Fae Sarcone, thank you for your generous donation of £35!

The awesome mother & son team **Carly & Kingsly Davis** (below) raised an amazing £1293 inc. GA at the Superhero Tri this summer! Thank you and well done!

A huge thank to **Elizabeth Maxwell** for the collection & donation of £229, it is truly appreciated.

A huge thanks to everyone at **St Mary's Methodist Church** Bright Hour for their generous donation of £139 from our very own Freda Burley's Book Sale

Thank you and congratulations to **Hasan Basyildiz** for completing Bristol Walk and raising an amazing £1395 inc. GA.

Thank you, **Kevin Moss**, for your kind donation of £5 from the KLM Prize Box.

Our star fundraiser **Joan Williams**, thank you, and everyone at the following for the latest collection and donation: **Eggborough Post Office** - £31.25; £503 from the **Red Lion at Kellington**; £145 from **P&M Stores in Havercroft** & £35 from **Happy & Team at Londis**.

Thank you to everyone at the **Centura Golf Society** for your generous collection and donating £200!

Thank you, **Tina Dalby**, for your latest donation of £300 from your collection tins.

Thank you to everyone at the **Woodhouse Community Music Groups** for your generous donation of £140!

All about autoimmune and gluten ataxia

Hi, I'm Carol and I run the "Gluten Ataxia and Autoimmune" support group as a volunteer. I have no medical training but when diagnosed with "possibly ataxia" out of desperation to learn about the condition, I turned to Google. Where else!

This article is about how to do your own research. It can be time consuming, but the reward will be a better understanding and the knowledge to ask relevant questions at appointments.

Online searches often come up with easy-to-read information. These can be misleading so don't always believe what you read particularly if the site includes pop-ups, adverts or selling something.

If you are not familiar with PubMed then this is a reputable place to start researching. It is the National Library of Medicine in the US. It contains over 37 million literatures from science journals and online books with the aim of improving health. The review and research papers can make difficult reading using medical terminology and words that need looking up. Don't be deterred, these words will become familiar.

The "PubMed User Guide" has a FAQs section to help you find your way around.

Review papers are a review of several research papers that are relevant to each other and read together they come to conclusive evidence.

Research papers are a research, study or trial. It could involve small numbers of patients or many participating in the research over a short period or many years.

Helpful pointers to look for:

Date: when the research was carried out, recent is best and under 5 years old unless of special interest to you.

Who: carried out the research. Some names will become familiar.

Where: what country and the institution. Eg. Sheffield Hospital and Professor Hadjivassiliou.

Funding: who funded the research and are there any conflict of interests.

Always read the "conclusions" at the end.

Abstract: is a shortened version and the Full Text often needs opening via being a member of an institution (so a subscription is needed) or buying the article. I personally never buy a research paper; they can be disappointing when fully opened and there are usually ways to read the full paper in another location.

There will be various references throughout the paper and the corresponding list will be found at the end of the paper and is associated with the research by specialist or condition.

Also, the "Health Unlocked" forum has a hub for Ataxia UK and questions can be answered here.

The Ataxia UK helpline is open Monday to Thursday, 10.30am to 2.30pm on 0800 995 6037 or by email: ***help@ataxia.org.uk***

Bongo: the online racing community

Our Friend, Philip, is part of a lovely online racing community called 'Bongo' and he has chosen to write about his journey.

My name is Philip, and I am 55 years old. I was diagnosed with SCA6 in 2018. My Mum and auntie also have SCA6. I live alone with my dog Wilson. I have two grown up daughters and one beautiful granddaughter.

I raced motorcycles and worked in the racing paddock most of my life. I started racing online in 2019, after I started to get bored with staying indoors all the time as my balance is a problem.

I moved from a PS5 (PlayStation) to a huge PC setup in 2020. I found bongo racing and its proprietor, Mr Robin Tate, on YouTube in late 2023 and was drawn to them because of their older gentlemen driver ethos. It was from then on that I met some wonderful gentlemen from across the world: USA Netherlands, France, Belgium, etc.

We race two or three times a week with practice in-between. We all have special car liveries to use in-game, I have my livery designed by a lovely French gentleman called Laurent from Whalenapp design which took him a few weeks to do.

I then progressed on to using a virtual reality headset to race in and wow it's like sitting in a real car on a real racetrack. I use a Meta Quest 3, and I've just got a Pimax Crystal Light headset too.

Looking back now, I'm not sure where I'd be without SIM racing; the community aspect has become very important to me and, looking forward to hearing and chatting to the guys and gals each evening, tends to get me through.

I would advise anyone to start a hobby, if they have ataxia. It has helped with muscle retention and keeps my mind active all the time.

My consultant at The National Hospital for Neurology and Neurosurgery, London thinks it is critical I carry on as long as possible.

My enemy is fatigue and without having to spend the day after racing to recover I would be racing more.

Let's hope I have many more years racing and I wish everyone finds their hobby to help their mind.

I got my life back after my diagnosis

Our Friend, Frankie, has kindly shared her diagnosis journey with us and what it meant to her.

I am a 38-year-old female. Married with 2 dogs and 2 cats, and very career-oriented with a sporty background. I previously played tennis (until that was scuppered with multiple shoulder surgeries). I tried running; I was not great, but I have done a marathon and triathlon.

In 2017, we were staying with my in-laws as we were renovating our house. It was Good Friday, so we had been out with some friends. In the night, I woke up and went to the toilet but passed out at the top of the stairs and woke up on the bathroom floor. I didn't wake anyone, as I thought they would just think I was drunk. The next day I lost feeling in my left leg but just put that down to poor circulation, which was always bad.

Over the next week the leg stayed feeling numb, but we were on holiday, so I just ignored it. A week later, I returned to work, and the numbness spread - up the left side of my body and face and down my arm.

My GP sent me to the hospital who did inconclusive tests and just asked me to go back for more the next week since my results went missing.

Within weeks, I had numbness and buzzing in my left side. My walking was wonky, my grip was altered, and I started saying the wrong words. For example, I would use mashed potatoes a lot, and I told the dogs nettles would burn them instead of stinging them.

Next time at the hospital, they told me in front of everyone in the waiting room that they thought I had MS and needed more tests.

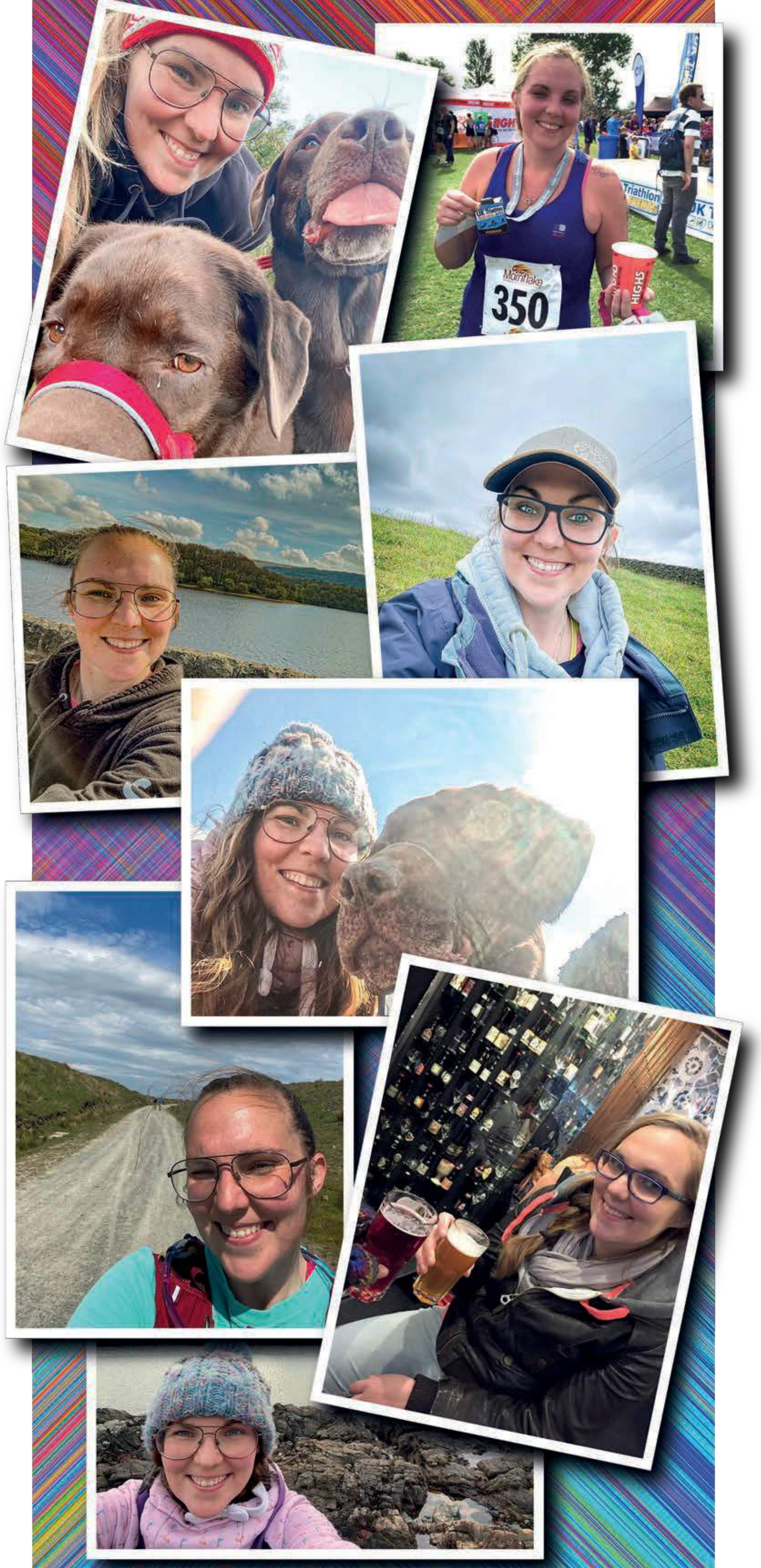
Luckily, I had private health insurance, so I was able to bypass the long wait (2 weeks) and book myself an appointment. The neurologist did all sorts of tests and he thought I had some kind of blood vessel issue. When I questioned all the issues in my upper body and head, he said that was just stress. I wasn't convinced.

More tests later - I was diagnosed (by an assistant) with Functional Neurological Disorder. Then later with myalgic encephalomyelitis / chronic fatigue syndrome.

Now my symptoms are awful - I also have awful fatigue and joint pain - buzzing and all the above plus loads more - I can't function and constantly feel drunk.

My wife researched, and we started a low-carb diet, which seemed to really help - until I found low-carb bread and cakes, which made me worse.

My GP made me see a nurse to up my pain meds - the nurse was fantastic - and flagged I hadn't been tested for coeliac. The test was negative, but I had only eaten gluten for two weeks, and in those two weeks my symptoms increased hugely. So, we googled, and we found gluten ataxia on Ataxia UK's website. and I demanded my GP refer me to Professor Hadjivassiliou.



Six months wait - and eight weeks eating gluten full time before my appointment. I was almost housebound and slurring my words. But on that first appointment in 2021, he told me he thought I was right. I had gluten ataxia and both other diagnoses were wrong. I should immediately cut gluten out - he arranged blood tests - and I had a functional MRI scan within an hour.

In December 2021, I got a letter confirming I had brain dysfunction, which was consistent with gluten ataxia.

Six months later, a further scan showed significant improvement on a gluten-free diet.

I am 2.5 years post diagnosis and still have a numb leg, and when I'm poorly, stressed or overexerted, my symptoms flare up. I lose my words, get confused, or stumble, but I have my life back.

Things that were affected were beyond belief. As it was the balance centre of my brain that was affected, looking back at things makes sense. My entire life I have been petrified of heights - I am not now! I don't have to hold a bannister or get my wife to hold my hand going down the stairs at the football.

All the tests were normal from April 2017 until December 2021. I was made to feel like it was in my head, but I couldn't function at all. I felt drunk without a drop of alcohol. I couldn't do anything - my life was on hold! My wife's life was on hold - because of me!

I got my life back with my diagnosis because I was lucky enough to catch my symptoms early enough that lots of the damage was reversible. I can live with what I have been left with.

My life is now a million times better and, if I can help others so that they are diagnosed before any of the damage is permanent, that's what I want - I want to make people aware of ataxia and gluten ataxia because it's awful but can be reversed if caught early!

My wife - she has been amazing. People told her to leave me, but we are a team, and we now have an amazing, albeit changed, life. Yes, it can be frustrating having to plan every meal out weeks in advance - but I would rather this life than the one I had!

They gave me my life back. It made me aware of what was wrong with me and helped me to get fixed.

Advocate for yourself. You know your body; you know what is right or wrong. Fight for the help you deserve.

Professor Hadjivassiliou is the best doctor I have ever seen; he cares; he listens and explains; find a doctor you trust. and talk - the more you talk, the more people understand - you need people in your corner.

Ataxia UK Support Groups: connecting, sharing, and supporting each other

Ataxia UK is more than a charity - it is a supportive network where individuals and families affected by ataxia can connect, share experiences and find valuable information.

Whether you're newly diagnosed or have been living with ataxia for years, there's a branch or support group for everyone. With groups meeting online, in person, or both, we hope you can access the support you need no matter where you are in the UK.

A VARIETY OF GROUPS TO SUIT YOU

Across the UK, geographical branches and support groups offer local opportunities to connect with others facing similar challenges and navigating local services. For example, the West of Scotland Branch covers a wide area and supports members across at least 10 council regions, sharing valuable advice on everything from NHS services to benefits.

For those who prefer virtual meetings, the Virtual Support Group is available entirely online, making it easy for anyone to join, no matter their location. Additionally, Ataxia UK offers specialised groups, including the Autoimmune and Gluten Ataxia Group, Carers Support Group, 16-30s Group, and Episodic Ataxia Group.

AN INSIDE LOOK AT LEADING A SUPPORT GROUP: DEREK TAYLOR'S STORY

Derek Taylor (right), who runs the West of Scotland Branch, has been involved with Ataxia UK for over 20 years. His personal journey, which started with an incorrect diagnosis of MS and eventually led to the discovery that he has Hereditary Spastic Paraplegia (HSP), mirrors the experiences of many others in the community - searching for answers and support, feeling isolated and then finding connection through Ataxia UK.

"I didn't quite know what to expect," Derek says of his first meeting with the West of Scotland Branch. *"But I found a friendly and open environment where information and experiences were shared. That was 20 years ago, and that openness hasn't changed."*

Derek's journey highlights the importance of connection in managing ataxia. Over the years, Derek has taken on various roles within the branch, from member to treasurer to chair. His dedication to the group and to Ataxia UK is driven by the sense of community he has found. ***"If someone is going through challenges with DWP, doctors, or other services, chances are someone in the branch will have already experienced those issues and can guide them,"*** he explains.

Derek is not the only one who has found comfort and strength in the group. One of the West of Scotland members shared, *"It's not just about the information. It's knowing you're not on your own. We've all been where you are, and there's a sense of relief that comes with that."*

Another group member added, *"The group gives me a place to talk openly about what I'm going through without having to explain everything from scratch. Everyone just gets it."* These experiences reflect the key role that support groups play in breaking the isolation many feel after diagnosis.

One of the most valuable aspects of being part of a support group is the shared experience. *"The first thing I would say to anyone newly diagnosed is that you're not alone,"* Derek emphasises. *"Many of us facing a rare condition think we are isolated, but we're all in it together. When you feel ready, go along to a support group. You'll meet people local to you with similar challenges, and maybe even the same doctor."*

Derek also encourages members to stay active and engaged in whatever way works for them. *"I believe in keeping active - whether it's going to the gym, walking, or doing exercises at home. And being involved in the branch helps too. It's important to stay connected, share experiences, and offer support over a cup of tea and some biscuits."*

FINDING STRENGTH IN COMMUNITY

The strength of Ataxia UK's support groups lies in the connections made and the information shared. As Derek's story shows, being part of a support group is not just about dealing with the challenges of ataxia- it's also about finding camaraderie, friendship, and a shared sense of purpose. Whether you attend regularly or drop in from time to time, you'll always be welcomed with open arms.

As one member of the West of Scotland Branch said, *"Sometimes just knowing the group is there is enough. I might not make every meeting, but I know they'll be there when I need them."*

From coffee mornings to online meetings, from social events to serious discussions about managing ataxia, the support groups offer a wide range of activities that cater to everyone's needs. As Derek puts it, *"We don't just talk about ataxia. We try to organise social events like boat trips on Loch Lomond, lunches, and Christmas dos. We're a friendly, sociable group."*

GET INVOLVED

If you're looking for information, support, or just a friendly chat, Ataxia UK's branches and support groups are here for you. Whether online or in person, these groups are a vital part of the ataxia community, offering a space where everyone is welcome, and no one has to face ataxia alone.

Whether you're looking for local or specialised support, there's a group for you. If you have any questions or would like to start a new group, contact us at ***volunteering@ataxia.org.uk*** *or call* ***020 7582 1444****. More details can be found on our website* ***http://alturl.com/rrt2i***

Festive season opening and closing times

Over the festive season, Ataxia UK will be closed for a brief period and reopen in the new year. Our opening and closing times are listed here:

CLOSING TIMES:

Helpline: Monday 23rd Dec, 2:30pm

Ataxia UK: Monday 23rd Dec, 5pm

Helpline reopening time: Thursday 2nd January, 10:30am

Ataxia UK: Thursday 2nd January, 9am

Living with ataxia can be difficult, but we know that over the festive period it can be even harder. This time of year, can be especially hard on your mental health, potentially bringing up feelings of isolation, financial worries and stress.

*If you are struggling and need someone to talk to you can contact **Samaritans** on **116 123**. If you prefer to use text, you can text **'shout'** to **85258**.*

*If you need medical help please contact the NHS, either via your GP if they are available or by calling **NHS 111**, or by dialling **999** in an emergency.*

*If you'd like a call back from the Helpline in January, please call **0800 995 6037** and leave your name, number and a brief message, and we'll get back to you as soon as possible in the new year. Alternatively, you can reach us via email at **help@ataxia.org.uk***

Outstanding contribution awards

Thank you to the 130 Friends who joined us online for the Ataxia UK Virtual Annual Conference 2024! We were delighted to present three awards, recognizing outstanding contributions to supporting people with ataxia.

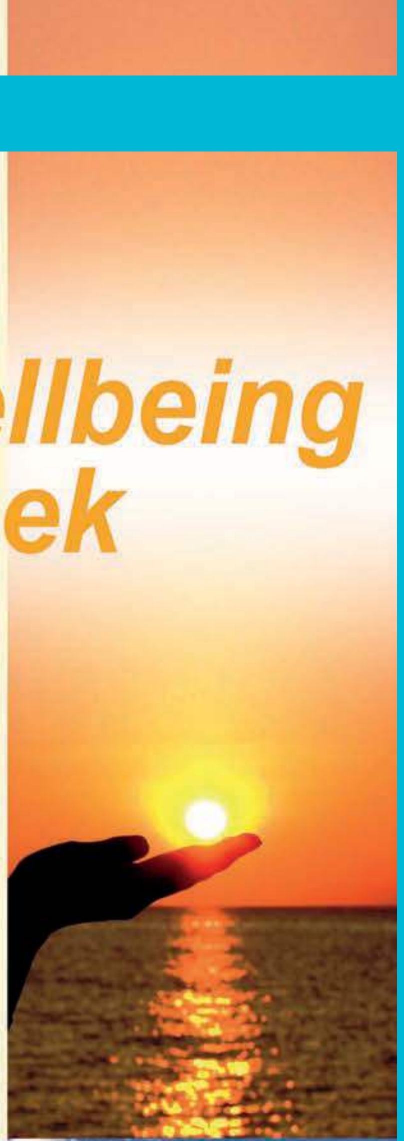
Chelsea Higgott (above right), whose mum has ataxia, received the **Ernie Heath Award** for her dedicated efforts to raise awareness and funds for the ataxia community. She always finds creative ways to engage – from bake sales, pub quizzes, and participation in the Give it Up for Lent challenge.

Rebecca Downing (right) earned the **Matthew Law Award** for her long-standing contributions, including her work with the West Country Branch, which she founded 20 years ago, and her participation in awareness campaigns.

Yvette Loach and Vanessa Bartlett, founded **The Rainham & Gravesend group** (below right) in 2015 following the death of Yvette's son, James. At this year's Conference they received the **Branch and Support Group Award** for creating a supportive, welcoming community for people of all ages.

*For a summary of the conference, and a wealth of video and presentation content, please head to the website: **http://alturl.com/tvmp9***

Join us for Wellbeing Week in February 2025!



Following last year's successful Wellbeing Week, attended by over 100 community members, we're excited to announce another inspiring lineup for 2025. Last year, we welcomed special speakers from the London Ataxia clinic, and our Head of Services, Wendy O'Mant, led an engaging session on Gadgets, Aids & Adaptations.

This year promises to be just as impactful, and we hope you'll join us for a week dedicated to enhancing emotional and physical wellbeing. Mark your calendars for 3rd to 7th February 2025! We'll be offering a variety of **FREE** virtual workshops, each designed to support different aspects of wellbeing. All workshops will be held online over Zoom, and are free to attend (donations welcome) and open to everyone.

Each day will feature a unique session, covering a range of topics which are helpful for people affected by ataxia.

*For details and to register your interest, please visit: **http://alturl.com/v989b** Or, feel free to reach out at **volunteering@ataxia.org.uk** or call **020 7582 1444**.*

Getting the most from occupational therapy

Carol McCudden, an Ataxia UK board member and consultant occupational therapist, will be sharing her valuable insights on how to make the most of occupational therapy support.

With 33 years of experience, Carol has worked across hospitals, community services, and private practice, covering a wide range of conditions. Throughout her career, she has assessed and referred people for aids and adaptations to improve their daily lives. Carol knows how home adaptations can significantly impact health, wellbeing, and independence while also reducing risks. However she has also experienced the frustrations of delays caused by the limitations of the system which determines who can access these adaptations. Did you know that the Royal College of Occupational Therapists has produced a guide offering valuable information? This guide provides guidance to several services on how they can help with adaptations without the need for an occupational therapy assessment. More importantly, it helps members of the public gain a clearer understanding of the types of adaptations available, how they can help, and who can provide them for you.

*If you're looking to avoid delays in securing adaptations, or simply want to understand the criteria and process involved, join our upcoming workshop session on **Friday 6th December, 1pm - 2pm**. You can sign up for the session here: **http://alturl.com/66nti***

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.

Your legacy can be hope for the future