

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 230. Summer 2025

Shining bright: a summer of strength, connection and hope

From nature's healing power to groundbreaking research, we find hope and the courage to continue the fight for a brighter tomorrow.



Read about
Biohaven's visit to
Ataxia UK's office
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ATAXIA

Ataxia UK

In the office



A warm welcome to **Maya Shukla** who has joined our Events & Community Fundraising Team as a **Fundraising Administrator**. With a family history of ataxia, Maya is ready to get stuck in and contribute towards change within the charity and the ataxia community.



And a big welcome to **Shalane Stoute** who joins the team as our **Charity Accountant**, overseeing the day-to-day finance operations for the charity.

CEO's introduction

Over the last few months, we have been told that 'the world is changing'. None of us at Ataxia UK can remember a time of so much threat and promise for people affected by ataxia in the UK. The promise of hope is offered by the many steps forward in research and the pipeline of potentially useful drugs lining up for licensing in the next few years. No doubt there will be plenty of bumps in the road, with frustration, rejections and delays. But it's certain that over the next decade some of the hope will be realised and treatments will benefit many; and that Ataxia UK will play an important role in advocating for you in this.

In the meanwhile, one proposal after another threatens the income, status, and rights of people with disabilities. Sadly, our Helpline has never been busier with streams of enquiries about negotiating the welfare benefits system and struggles in obtaining finance to get much needed aids and adaptations, or diagnosis. Our Scottish advice service at Parkhead CAB in Glasgow reports that their ataxia clients have deeper and more complex problems than their average clients. There are cases of serious family hardship exacerbated by ataxia right across our community emphasising the increased importance of our advice and advocacy services.

While Ataxia UK doesn't have the resources to actively campaign on benefits and rights issues, we frequently lend our support to campaigns led by other charities. We are members of the Disabled Children's Partnership, a coalition of more than 100 organisations, which campaigns for improved health and social care for disabled children, young people and their families. In early March, the disability charity SCOPE assembled a letter to the Chancellor of the Exchequer, explaining the value and importance of PIP (Personal Independence Payment) and urging her to protect disability benefits, which I signed, together with over 120 charity leaders. As members of Disability Rights UK we also support their excellent campaigns: <http://alturl.com/ex98j>

Thank you for all the support you provide to enable us to provide services today, and hope for tomorrow.

Best wishes,

Sue Millman



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You have received this magazine as you expressed an interest in receiving it from us. If this is incorrect, (we apologise) or if you have changed your mind and no longer want to receive the magazine, please let us know by emailing communications@ataxia.org.uk or by writing to us at Ataxia UK, 12 Broadbent Close, London, N6 5JW and we will stop sending the magazine to you.



Updates from Euro-ataxia & the work it does for the ataxia community

What is Euro-ataxia?

Euro-ataxia is an umbrella organisation made up of 22 European patient groups, which like Ataxia UK, represent and support those living with ataxia across 16 countries in Europe. These organisations range in size, from being small groups led by highly dedicated volunteers, to larger organisations with paid staff. Together, we represent the voices of over 6000 patients. Euro-ataxia does not employ any paid staff, and Ataxia UK supports it by providing administrative services.

Participating in discussions on research and drug developments

Representatives from its member organisations meet regularly to discuss the latest research and drug developments, provide news updates from their respective countries, share information and support each other by providing guidance and skill-sharing.

Writing letters of support for funding applications

Euro-ataxia also writes Letters of Support for researchers and clinicians to support their funding applications; for example, last year we wrote a letter in support of the creation of a new gene therapy research centre at the University of Coimbra, which has since been successful.

Providing representatives for committees and research consortia

Euro-ataxia is a member of the European Organisation for Rare Diseases (Eurordis) and the European Federation of Neurological Associations (EFNA), thus providing input on policy at a European level. In addition, Euro-ataxia representatives are actively involved in many European research consortia, providing the perspective of people with ataxia in advancing research. *Read more at:* <http://alturl.com/z2t2d>. It has also coordinated the funding of research projects involving a number of Euro-ataxia members. *We have recently updated the Euro-ataxia website to make it more user friendly – take a look to find out more about the work that Euro-ataxia does:* <https://www.euroataxia.org>

2024 Euro-ataxia Annual Conference

The 2024 Euro-ataxia Annual Conference took place in London on 15-16 November, organised by Ataxia UK. The conference was a great success; 14 ataxia patient groups, as well as researchers and pharmaceutical company representatives, gathered to share best practice in healthcare and research.

Talks included updates from clinical trials, patient group presentations, and panel discussions. On the first day, there was a panel discussion chaired by Ataxia UK's Director of Research, Julie Greenfield. The panel of industry representatives discussed the development of outcome measures in ataxia clinical trials, and the journey of building effective co-operation with medicines regulatory agencies such as the FDA and EMA. Later that day, Professor Paola Giunti shared the results from a European project she led



that demonstrated the benefits of Specialist Ataxia Centres in the UK, Italy and Germany, in terms of symptom management, co-ordination of care and referrals, and opportunities to take part in research. Read about the results of this research on the Ataxia UK website.

Several junior researchers gave lay talks on their research, on topics including research on brain changes in SCA3 and modelling sensory neurons in FA using stem cells. You can see slides of some of these talks on the Euro-ataxia website.

On the second day, representatives of 6 ataxia patient groups shared new projects and best practice in providing support to those living with ataxias. This included a talk from the director of the SCA27b Foundation, Mary Hogan. The SCA27b Foundation was set up by the Darby/Nye family in the US in May 2023. The SCA27b Foundation is currently working with the pharmaceutical company Solaxa on a clinical trial of the drug 4-Aminopyridine to treat SCA27b. You can find out information about SCA27b, including the 'SCA27b For Me' educational tool on the SCA27b Foundation website. For information on genetic testing for SCA27b in the UK, visit the 'Research News' section on the Ataxia UK website. *If you or someone you know has a genetic diagnosis of SCA27b, please let us at Ataxia UK know by emailing sparr-reid@ataxia.org.uk, so we can plan for future trials.*

The President of Euro-ataxia, Andreas Nadke, had this to say:

"It is great to see how many people in Europe are pursuing the same goal, fighting against the disease and supporting those affected. For the future, I would like to see even closer co-operation with researchers, pharmaceutical companies and the regulators in the respective countries in order to further improve the lives of people affected. We are happy to support research and the authorisation of new drugs".

Ataxia UK funds two new research projects

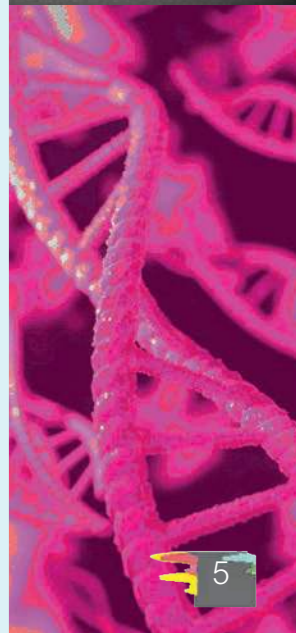
Ataxia UK funds project looking at genetic factors affecting age of onset and disease progression in SCA27b

Ataxia UK has recently awarded funding to researchers at the University of Miami and University College London on spinocerebellar ataxia 27b (SCA27b). The researchers will analyse the DNA of 1,000 people with SCA27b to look at genetic variations that might influence the onset and progression of SCA27b, which may potentially identify new targets for treatments. *Read a summary of the project on our website on the **Research Funded by Ataxia UK** section of our website.*



Ataxia UK funds project to study potential compounds called antisense oligonucleotides to target the Ataxin-3 gene in SCA3

Ataxia UK has recently awarded funding to Dr Stefan Hauser and his research team at the German Center for Neurodegenerative Diseases on spinocerebellar ataxia type-3 (SCA3). People with SCA3 inherit one mutated version of the SCA3 gene from one parent and one healthy version of the gene from their other parent. This is known as dominant inheritance. The researchers hope to find suitable drug compounds known as antisense oligonucleotides (ASOs) to target only the mutant protein in SCA3 without affecting the healthy version. To do this, the researchers plan to use brain-like cells formed from skin cells from those with SCA3 to test a range of ASOs. *Read the summary of the project on our website. This project builds on work that was previously funded by Ataxia UK, which you can read about on our website.*



An interview series with the London Ataxia Centre Multidisciplinary Team – Part 2

In conversation with London Ataxia Centre Specialist Ataxia Nurse, Suzanne Booth

Suzanne has worked as a neurology specialist nurse for 19 years, supporting people with a range of long-term neurological conditions. She has recently completed an MSc in Advanced Clinical Practice, and is also an APPI qualified Pilates Instructor, with a special interest in helping people of all abilities to engage in and experience the benefits of regular exercise.

"I have worked as a specialist neurology nurse for around 19 years, initially in Creutzfeldt-Jakob Disease (CJD) research at the National Hospital for Neurology and Neurosurgery, UCLH, London. I then went on to work as an MS specialist nurse for a number of years before returning to Queen Square to work with people with neuromuscular diseases. I joined the London Ataxia Centre in 2018 – it seemed to be a role that combined aspects of all my previous experiences into one!"

Read the interview in the 'Research News' section of our website.

In conversation with the London Ataxia Centre Speech and Language Therapist, Lucie Hogger

Lucie Hogger has worked in adult speech and language therapy since 2008 in hospital, rehabilitation and community settings. She recently completed her PhD on the medicines practices of people with dementia and their carers, and works clinically in the ataxia service and the facial rehabilitation service at the National Hospital for Neurology and Neurosurgery, UCLH, London. She is passionate about supporting people with communication difficulties to flourish in their conversations and social relationships.

"I've been working with the London Ataxia Centre since the beginning of August 2023. I work within outpatient neurology alongside three other speech therapists who also have expertise in ataxia. From a speech therapy point of view, some people will come through to our online group therapy. Group speech therapy sessions are for people who have a mild-to-moderate ataxic dysarthria (speech difficulty), and they run online over five weeks for one hour per week. There are usually three or four people per group in addition to me."

Read the interview on our website.



An update on genetic testing in ataxia

There are many different types of ataxia, with numerous causes. For example, ataxia can be genetic, occur due to an autoimmune response (e.g. gluten ataxia) or when we do not know what has caused an individual's ataxia, it is called "idiopathic".

If you fall into the last category, you might still turn out to have a genetic form. The genetic tests used to try and diagnose you may not have identified the abnormality present in your genes as yet.

Genetic ataxias are caused by changes in the genetic code which eventually leads to symptoms of ataxia. Currently well known forms of genetic ataxias include the Spinocerebellar Ataxias (SCAs), Friedreich's ataxia (FA), and Episodic Ataxia type 2 (EA2). Over the last three decades, laboratories all over the world have been discovering more forms of genetic ataxia.

Genetic testing has changed dramatically in recent years

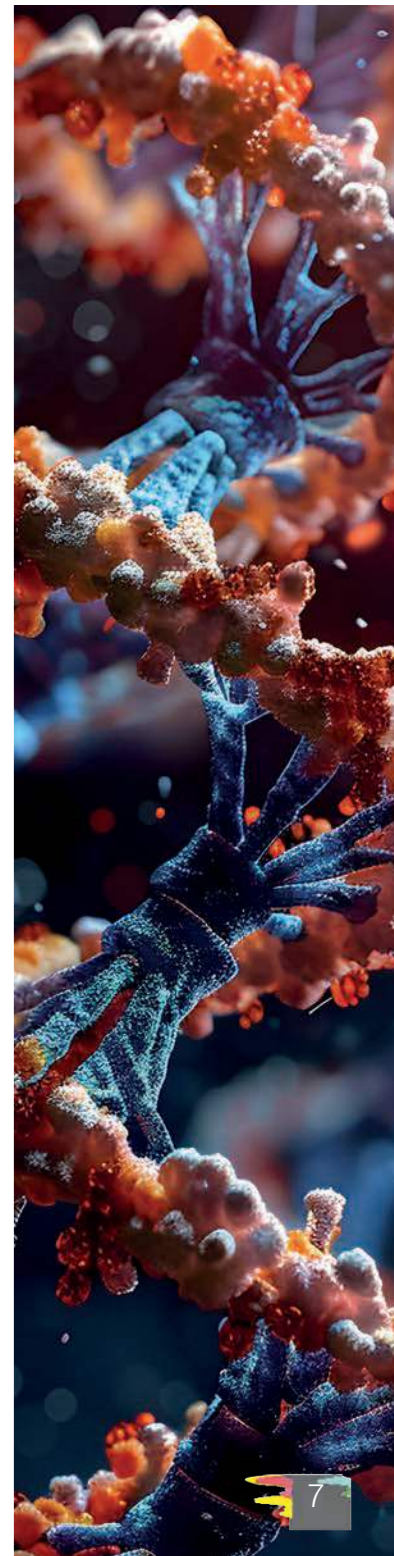
An important breakthrough in genetic testing has been a technology called whole genome sequencing (WGS). The new technologies enable hundreds of genes to be checked in individuals simultaneously (earlier, doctors used to check individual genes, sometimes one at a time, based on their clinical suspicions.) These advances have meant that cases previously designated as "idiopathic" ataxia have turned out to be of genetic cause. If you had genetic tests many years ago but did not receive a genetic diagnosis (and remain "idiopathic"), it might be worth being tested again. Even in middle-aged and older individuals with idiopathic ataxia, new genetic forms of ataxia such as CANVAS and GAA-FGF14/SCA27B appear to account for significant numbers.

As more ataxias have been identified, the chance of receiving a specific diagnosis through genetic testing has increased. This is becoming increasingly important as treatments for the ataxias start entering clinical trials, and even in some cases being approved by the regulators. In order to access trials or treatments which could be relevant for you, it is important to have a specific diagnosis.

Even now, there are a handful of targeted treatments available in inherited ataxias. Niemann Pick Type C (NPC), for example, is a condition which has ataxia as a symptom. There is already an approved treatment for NPC in the UK, and two more treatments were approved by the US regulators (the FDA) in 2024. NPC1 and NPC2 can be diagnosed by a genetic test. Treatments like these provide a justification for a GP or neurologist to arrange further genetic tests, especially in cases where genetic testing has not been carried out for many years.

Identifying the cause of ataxia in a family may enable individuals at risk of acquiring ataxia to undergo "pre-symptomatic" testing (if they so wish). In families where this information is known, younger generations can also make better-informed reproductive decisions.

If you have not received a specific diagnosis for your ataxia, and have not had genetic tests for many years, speak to your GP or neurologist about being tested again. If you have any questions about this, or want information about referrals to Specialist Ataxia Centres, please email the Ataxia UK Helpline at help@ataxia.org.uk



Biohaven visit Ataxia UK

In March 2025, two members of the US team from Biohaven Pharmaceuticals visited Ataxia UK at our offices in London. Here, Anne Neumann shares her reflections on the visit.

Who are you and what brought you to the Ataxia UK offices?

My name is Anne Neumann RN, BSN (right). I am the Global Patient Advocacy lead for Biohaven Pharmaceuticals headquartered in New Haven, Ct. USA. I was joined by my colleague Laura Heller, PharmD, Vice President, Medical Affairs (below, far right), and we were visiting the UK as part of our work to continue to build our relationship with the Ataxia UK patient community, staff and neurologists in the area.

What reflection do you have on your conversations with SCA patients?

As we reflect on the conversations with SCA patients we had during our visit a few things stand out. Everyone's story is different, but so many of the challenges SCA patients face are the same and what really comes across is the resilience and the hope, as well as the vital role that Ataxia UK plays in bringing the community together.

Why are personal stories from the ataxia community so important to your work?

Personal stories are important for our work because not all our colleagues can speak with and hear patients' stories and struggles. Bringing these stories back to our research teams gives them a face to their research; there is no substitute for that.

What is your message to the Ataxia community?

Biohaven's message to the community is Hope. Hope for the research in development, hope for treatments, hope for an Ataxia free future.

What fun thing did you do or discover on your visit to the UK?

While in London we went to Kensington Palace and saw the exhibit of royal clothes and jewellery. We as Americans love the gowns and jewels.



Biohaven team meet AUK staff and patients in Highgate, London

Ataxia UK Virtual Annual Conference 2025 – save the date!

Friday 3 October and Saturday 4 October 2025

Join us for this year's Annual Conference, which will be held online and hosted by our wonderful patron Paul Coia. As always, we'll be bringing you an action-packed programme which will include guest speakers, research updates, doctor's Q&A sessions and a range of online workshops.

Find out more information here: <http://alturl.com/s6qc9>

Friday 3 October - afternoon – Research Day

- Research Updates
- Doctor's Q&A

Saturday 4 October – Main Day

- Guest speakers
- Workshops
- 'It Works for Me' talks
- and much more!

We are looking for volunteers to take part in our Conference Involvement Group to help us shape this year's programme. This will involve attending between 2 and 3 online meetings in June and July. *If you're interested in taking part or have more questions, contact Anastasia at conference@ataxia.org.uk*

Award nominations needed!

Every year at the Annual Conference, Ataxia UK gives out three awards to celebrate particular achievements or commitment to the ataxia community. These are awarded to:

1. A Branch or Support Group
2. Someone affected by ataxia (the Ernie Heath Award)
3. Someone who has the condition (the Matthew Law Award)

If you'd like to nominate a person or group for any of these awards, please send your nominations to conference@ataxia.org.uk

Please include the nominee's name and a few sentences about why you've nominated them and their contributions to the ataxia community.



Finding freedom in nature

In this article, Rebecca tells us how she finds freedom in nature through her Trumper, an all-terrain scooter that helps her embrace the outdoors.

I'm Rebecca, and I'm 40, living in Devon with my partner, my 11-year-old, and our eight guinea pigs. I also run the West Country branch of Ataxia UK. I've been living with Friedreich's Ataxia for a long time, and over the past 14 years, I've been fortunate enough to have many wonderful personal assistants who assist me with everything from home and garden tasks to school runs, gym sessions, and spending time with friends and family. These PAs aren't just assistants—they've become a part of my life. We've created deep, hybrid relationships that allow me to live fully and enjoy life as best as I can.

One of the most life-changing things I've discovered along the way is the 'Trumper', an all-terrain mobility scooter. A friend with Ataxia let me try theirs, and I immediately thought, "If only I could afford one!" Then I found out about Countryside Mobility, which provides safe, off-road scooter hire for people who have difficulty walking. In 2018, my dad surprised me with a Trumper, wanting to give me the freedom to explore his farm and experience more of the outdoors. It's been an incredible gift, and I've even organized accessible walks for the West Country branch, bringing my own Trumper along with a few others to share.

The Trumper is built in the UK by a family-run business, and it's been designed to let people like me go off the beaten path—whether that's through the countryside, along the coast, or into the woods. What I love most is how eco-friendly it is, being powered by a battery that doesn't make noise or pollute the environment. It aligns perfectly with the world I want to help create.

In August 2023, I met Jake, who owns a second-hand wheelchair-accessible taxi. It's just big enough to fit both my Trumper and my electric chair in. Jake is a true gem—he's strong from his job lifting heavy equipment, so he helps me get in and out of the van and onto my Trumper with ease. He's also a nature lover with a wealth of knowledge about amazing spots in Devon. Jake researches places in advance to make sure they're accessible, and together we explore beautiful locations like Dartmoor, local forests, beaches, and even places like Stonehenge.

For the last seven years, I've been drawn to nature therapy, also known as ecotherapy or green therapy. It's all about using nature to improve physical and mental well-being, and I've found that spending time in nature—whether 'walking', gardening, or just being outside—has made a huge difference to my life. Since meeting Jake and embracing nature therapy more fully, I've noticed I'm sleeping better, feeling happier, stronger, and more able. I've found a new lease of life, and with the freedom to travel and explore on my own terms, I feel more empowered than ever before.



I want to see Ataxia UK continue its important work, which is why I intend to leave you a gift in my will – Dave

Legacy, Wills, Estate, Death. These are not easy topics to think about and discuss at the best of times, and discussing these topics with a charity is often even harder. But it doesn't have to be.

Having a conversation with our Fundraising team can help put your mind at ease and provide you with important information about legacy gifts to Ataxia UK.

Legacy gifts are so important to every small charity, but for Ataxia UK they are instrumental in ensuring the work we begin has longevity and projects will have sustainability. Money pledged now helps us to plan for future projects when we can predict what our legacy supporters will leave to the charity to help further our mission and aims.

Leaving a legacy gift in your Will to support Ataxia UK and those affected by ataxia is straight-forward. Once this is done, you don't need to worry about this or keep checking back in on it. Ataxia UK will benefit for years and decades to come, all from this small effort and your pledge today to become a legacy supporter.

We hope that our supporters live long and happy lives and have many good years after making their Will and declaring their intentions to leave a legacy gift to Ataxia UK. But it is important to put the work in now and speak to you about why leaving a legacy gift is vital to the continuation of Ataxia UK's work.

We recently caught up with our Friend, Dave, who intends to leave a legacy gift to Ataxia UK. Dave hopes that in sharing his story, more people will have these difficult conversations now and pledge to become a legacy donor to Ataxia UK and the ataxia community.

"I'm Dave. I was diagnosed with Cerebellar Ataxia early in 2018 when I was 53. However, I didn't contact Ataxia UK until September 2022 when I stopped working. I worked from home during the pandemic which worked for me, but I gave up work because anxiety took over. My speech and handwriting were getting worse, and the ataxia symptoms were starting to be a problem.



Since getting in touch with Ataxia UK, I've always donated to them, gifting support to the ataxia community. Helping the charity helps them to continue research, and hopefully, raise awareness of the ataxias, which unfortunately aren't as well-known as some other conditions. Certainly, I had never heard of it until I myself was diagnosed, and I think that probably is the same for a lot of people.

The same goes for legacies in Wills, which is something I intend on doing. Personally, I don't have any dependants, and I want to see Ataxia UK continue its important work. I hope this will be my legacy: supporting the continuation of Ataxia UK's important work.

Ataxia UK, like other charities, depends on legacies as an important form of funding. In order to continue their work, financial worries are one less thing for them to focus on, and my legacy can help ease their financial burden.

We have seen the Omap drug slow down the progression of Friedreich's Ataxia in some US & EU patients. That is one thing that has been made possible by research. It is important that research continues and Ataxia UK helps secure more victories for the community, and that this vital work helps with the knowledge of the disease. I hope the legacy gift I intend to leave will allow for continued research and more drugs to treat and cure the ataxias."

Thank you Dave for sharing your story, and we thank you for your intention to leave a gift in your Will to support the ataxia community.

Your legacy gift will help advance research, work to bring treatments here to the UK and provide support for those affected by ataxia until long after these treatments are available for the community.

Our Individual Giving & Legacy Manager recently attended a full-day event focusing on legacies, to understand more about the current economic climate and the impact this is having on legacy giving. He also found out more about how best to provide stewardship to legacy pledgers while they are still alive, and how best to support Executors and next-of-kin when they pass. This upskilling will benefit the ataxia community as charities across the UK become more reliant on legacy gifts to perform their day-to-day aims and activities.

We know how important it is to supporters to reassure them in advance that their legacy gift will go to supporting the ataxia community in the best way possible. And so, we have developed a specially designed Legacy Pack which aims to answer the FAQs about legacy giving to a charity.

To request a Legacy Pack please contact fundraising@ataxia.org.uk

Ready to make a difference this Summer?

Dive into a world of adventure and purpose with #TeamAtaxiaUK and stand in solidarity with thousands living with ataxia.

Exciting Challenges:

- Conquer the **Ultra Challenges** your way - run, jog or walk and embrace the thrill: Isle of Wight, Jurassic Coast, London 2 Brighton, Lake District & more...
- Navigate through exhilarating **inflatable obstacle courses** – in various locations.
- Take on the **Half Marathons** challenge in iconic locations like Edinburgh, Birmingham, Manchester, Battersea Park, the Queen Elizabeth Olympic Park, the Great Bristol Run and many more...
- Join the **Scottish Kilt** walks.
- Get mucky in a **Tough Mudder** event.
- Dare to soar with a **sky jump** or **bungee jump**. The sky's not the limit; it's just the beginning.

Join the adventure, embrace the challenge, and become a hero in the truest sense. Contact us at: fundraising@ataxia.org.uk



Be a #hero at the GREAT NORTH RUN. 7 September 2025!

Experience the world's largest half marathon, from Newcastle to South Shields, and be part of an event renowned for its inclusive atmosphere and vibrant route-side entertainment: <http://alturl.com/orfsa>

Why run with Ataxia UK?

- **Free Entry:** Secure your spot at no cost when you run for Ataxia UK.
- **Exclusive Running Kit:** Receive a free high-quality running vest to wear on race day.
- **First-class support all the way to the finish line.**
- **Make a Difference:** Every step you take brings us closer to finding a cure and supporting those affected by ataxia.

By running with us, you'll help raise vital funds and awareness for the ataxia community. Together, we can make a difference. Sign up now and let's cross that finish line together.

For more information email us at fundraising@ataxia.org.uk

#RunForACure #GreatNorthRun2025 #StepByStepForAtaxia #HalfMarathonHeroes #TogetherWeCan #AtaxiaAwareness #TeamAtaxia #RunToInspire



SUPERHERO TRI POWERED BY MARVEL. 16 August 2025 – Dorney Lake, Windsor

There are three super distances to choose from and many super ways to take part in these super-fun & flexible tri challenges. You can fly solo and take on all three stages (a swim, cycle & push/run for any tri newbies out there), share the fun in a team relay, or Superheroes can recruit Sidekick teammates to tow, push & pull them around the entire course. This summer we will be celebrating our super planet and all its natural wonders, so prepare yourself for a super-wild time! Who can join the Superhero Tri missions? Everyone is welcome. All we ask is that all solo entrants, or at least one team member, consider themselves to have a disability of any kind. Dress code: A Superhero outfit, of course!

Why be an Ataxia UK superhero:

- **FREE ENTRY** – you be the superhero and we pay the bill.
- **FREE t-shirt** for all team members.
- **Fundraising Pack** with super ideas.
- **Support all the way.**

REGISTER now for your **FREE** registration code by emailing us at fundraising@ataxia.org.uk. There are no cut-off times and all types of gadgets and gismos are welcome on the course. So grab those masks and capes, sign up and save the day!

We also have FREE places at the Winter Wonderwheels powered by MARVEL on 7 December 2025 – Dorney Lake, Windsor
More information here: <http://alturl.com/qgqu8>

#EverydaySuperhero #SuperheroSeries

JOIN THE KILT WALK FOR ATAXIA UK – Step Out for a Cause Dundee on August 17, Edinburgh on September 14

The Kilt Walk is back, and it's time to pull on your kilt and step out for Ataxia UK! Whether you're walking the 6-mile Big Stroll, 15-mile Medium Walk, or the 23-mile Warrior Walk, this is your chance to support a cause close to your heart while enjoying a fun and community-driven event. It's the perfect opportunity to get active while raising funds for Ataxia UK, supporting vital research and services for those affected by ataxia.

Whether you're walking solo, with friends or as part of a team, you'll be joining thousands of people who are dedicated to making a difference. The Kilt Walk is all about community, fun, and raising much-needed funds. And don't forget – kilts are a must! So, lace up your walking shoes, get your kilt ready, and sign up today to get your free t-shirt, fundraising pack and help raise crucial funds for Ataxia UK.

For more details contact: fundraising@ataxia.org.uk

STOP PRESS

We are now looking for supporters who want to run for Ataxia UK in the **2026 London Landmarks Half Marathon** and the **London Marathon**. If want an application form, please get in touch at fundraising@ataxia.org.uk



Fundraising thank-yous

Huge appreciation to everyone at **Brandhall Community Choir (1)** who have donated £242.82 inc. Gift Aid (GA). Thank you all.

Hannah Smith (2) conquered Paris and completed the iconic Paris Half Marathon raising a smashing £1153 (inc. GA). What an amazing achievement, thank you Hannah and everyone who donated.

Joan Williams, thank you so much for all your efforts. Your recent Collection Tin donation of £295.49 has been received and much appreciated.

Ellie and her grandmother, **Susan Thompson (3)** organised a Christmas Raffle raising £330 to support people living with ataxia. Thank you to both for your regular and continued support.

Thanks, **Gavin Dalton**, for your generous Christmas Cards donation of £50.

Susan Sowerby organised a leaving do for colleague **Tony Croda** and raised an amazing £256 (inc. GA). Thank you, Susan, and everyone at work who contributed.

Thank you, **Phil Whitwell**, for your recent Collection Tin donation of £41.87.

Thanks to everyone at **Dalton District Girl Guiding** for organising the Carol Service and raising £187 for Ataxia UK.

Massive thanks to **Charlotte Huggett** (right) for completing the Mad Dog 10K and raising over £496 (inc. GA). Your efforts will go a long way to support the community, it is highly appreciated.

Thanks, **Dave Poyser**, for your collection and donation of £20.

Lucy Holland (4), thank you once again for your amazing annual Yoga event, raising a whopping £767 (inc. GA).

Thanks to **Ivor Button** for the Christmas donation of £10.

Congratulations to **Amy Russell** (Reeve) for completing the Gateshead Hot Chocolate 10K and raising an amazing £805 and £121 (inc. GA).



Well done and huge congratulations to our superhero **Scott Forsyth** (right) for completing a series of events culminating at the Abu Dhabi Marathon and Dubai Sky Dive. Thank you and good luck with all your fundraising efforts.

Thanks to everyone at **Harrogate Spa Town Ukes** for your very generous donation of £50.

Thank you, **Jenifer Redpath**, for your most recent Tin Collections, raising £34.

A huge cheer to **Maya Shukla (5)** for completing the Battersea Half Marathon and raising over £465 (inc. GA). Thank you for your support.

Thank you, **Anastasia Franey**, for organising the Valentines Musical Event, raising over £205 (inc. GA).

Richmond Amateur Dramatic Society (6) raised an amazing £300 to support the community. We wish to thank everyone involved. Your support means a lot.

Thank you, **Chris Lewis**, for your Christmas Card donation of £50.

Thank you, **Linda Jarvie**, for your Christmas Card donation of £50.

Leanne Sullivan has made a huge donation of £3,999. Thank you so much Leanne.

Thank you, **Eileen Judd**, for your Christmas & Birthday donation of £50.

A huge thanks to everyone at **Poeton Industries (7)** for your very generous donation of £887. It will be well used to support the ataxia community.

Thank you, **Kevin Moss**, for donating £5 from the KLM Prize Box.

Brave **Gabriel Modaresi** (below) brought together family & friends to the Attack Ataxia Skate Jam to raise funds to support the ataxia community. His uncles live with ataxia. He is an amazing inspiration to us all, thank you Gabriel. They raised an amazing £976.



Celebrating our amazing Cake Bakers of 2024!

We would like to say a huge thank you to all our fabulous cake bakers who took part in the **2024 Big Ataxia Cake Bake**. You rose to the challenge and baked for a cure and we really appreciate all your efforts.

The prize for raising the highest amount of money goes to **Mandy Sayers** (right), who raised an amazing £1633. That is an amazing achievement Mandy; thank you for all your efforts.

Julie Ryder was drawn as the winner from all the participants; well done Julie and thank you for donating back the prize, you are simply amazing.

Finally, a huge thanks to everyone else who took part and those who supported you: **Kate Rudkin; Hannah Doyle; Alberto Delle Fratte; Kali Kang** and everyone at **MD Law LLP**. Thanks to you all we raised a whopping £3407 in 2024.



Lynne Green – ataxia, access & achievements

Could you briefly introduce yourself, describe your experience with ataxia and how it has shaped who you are today?

My name's Lynne and I was diagnosed with Friedreich's Ataxia when I was 5 years old, but genetic testing since has proved that I haven't got the gene and all other tests have proved negative, so it's an unknown ataxia. I'm now 48 and my ataxia has never been an issue to hold me back; I've gone through mainstream school and sixth form, achieved a list of GCSEs, gone on to college to complete a BTEC and held a job for over 27 years. I've walked down the aisle on my dad's arm and live happily in my bungalow with my husband and dog.

Can you write a short poem for us?

What is the message of the poem and its purpose?

I've written this poem because my disability is not a problem, it's the challenges and frustrations I am forced to face on a near daily basis, because some people in society and designers of buildings need an insight and maybe need educating on how access barriers impose on the independence and dignity of people who use mobility aids.

What tips/messages would you give to those living with ataxia?

I have mostly grown up with my ataxia so I don't really remember a time when I haven't needed a mobility aid. I never wanted to use a wheelchair indoors, and in fact it took me 16 years of living independently before I accepted its help. I'd always got around on all fours or holding onto furniture, but by 37 years old it was time for more dignity and safer independence. Bringing a manual wheelchair indoors was one of the best things I've done as I no longer have to open the front door from floor level and I don't have to struggle to get down on the floor to get up again, I can transfer from the settee to my wheelchair at the same level. Where I need to stand up, I've got grab rails or fixtures to hold onto, to give safety and prevent wobbles. There isn't much I can do to avoid the challenges forced on me by access obstacles; through the years I have learnt the best routes for my journeys, which shops and buildings to avoid and the best places for accessible toilets. There are still unavoidable obstacles but there's nothing worse than holding frustration, so I often divert on pavement journeys to find a ramp, avoid a branch or dodge a parked car! So accept reality, there will be frustrations and challenges, ask for help and seek help from mobility aids to increase your independence.

Two of my proudest moments: my wedding and the student award which led to my 27 year classroom assistant's career.



Access?

*There's a slope to get in
But steps to the room
There's a lift
But not big enough for a chair to fit in,*

*There's a lip to get out the door
So it would tip my chair off the floor
Now I can't get out without help
To save me from going down with a yelp*

*There's a grab rail to hold
But it's too far away
There's a buzzer to press
In times of distress*

*There's a pull cord to call
In case you fall
But it's tied out of reach, or doesn't reach the floor
And there's no room to turn to open the door*

*The fire alarm goes off and everyone goes fast
But the exit is down steps so they all go past
I have to go back to find another way
I'll now know better for another day*

*I'm stuck in the corridor with walkers behind
But the door's too narrow for my chair to pass
Walkers come fast but they'll have to go back
My only way is to reverse back down the same path*

*There's a parked car on the pavement blocking my path
There's a branch drooping down which will poke my eye
I'll have to divert to find another way,
But now I know better for another day.*

*I lengthen my journey for slopes and the like,
But sometimes I feel it's just too much of a hike
There's challenges to overcome
Always lessons to be learnt
Frustrations may overtake me,
But they very rarely win.*



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

We have a vacancy on the board for one Trustee. We are seeking someone with professional experience in accountancy, fundraising, pharmaceuticals, the NHS, social care, or charity governance. The elections take place in early September. A Trustee's term runs for 4 years, after which they can re-stand for a further term of 4 years.

The Trustee Board governs and sets the strategic direction of Ataxia UK. Trustees oversee every aspect of Ataxia UK's operation, including finance, services we offer, the research we fund, and how we fundraise. It ensures that the charity is financially viable and has robust policies and procedures covering every area of our operation.

The Board meets 4-5 times a year mainly on Zoom and once a year face-to-face/hybrid. Meetings are from 11am – 3.30pm. Most Trustees also join a sub-group of the Board looking at finance, services, fundraising etc.

The Board is made up of Friends of Ataxia UK; seven who are elected by Friends of Ataxia UK and three who are appointed by the Board and co-opted. All prospective Board members are interviewed by two current Trustees prior to standing for election or being co-opted. We cover all costs incurred by Trustees in the course of their duties – including (when attending face-to-face meetings) those of a carer, if required.

We are keen to broaden the diversity of our board members to ensure we have a range of perspectives at meetings. We particularly encourage people who come from diverse ethnic backgrounds or are members of the LGBTQ+ community to apply for these roles. All Trustees are given an induction into the Trustee role and how the Board operates at Ataxia UK and offered opportunities for external training.

You can find more information including a Role Description by visiting www.ataxia.org.uk/work-for-us/trustee-jd. Anyone interested will have the opportunity to attend an online information session with **Sue Millman, CEO** prior to interview. Please let Sue know of your interest by the end of June by emailing smillman@ataxia.org.uk. You can also reach her via telephone on **0207 582 1444**.

Volunteers' Week 2025

Volunteers' Week is back, running from **Monday 2 to Sunday 8 June**, and it's time to shine a spotlight on the amazing contributions of our volunteers. Held annually across the UK, this week aims to celebrate the work of volunteers in their communities. At Ataxia UK, our volunteers are nothing short of superheroes! Whether they're offering a listening ear on our Helpline or boosting morale as Event Volunteers, they play a vital role in shaping our services and supporting the ataxia community. We want to say a massive thank you to our volunteers. You are the heart of everything we do.

It's so important to us that our volunteers' efforts don't go unnoticed, that's why this year we're putting on several virtual sessions to celebrate their achievements and have some fun! See below for the exciting events we have planned for the week and book your spot via the links provided.

'Where's his Phone Number?' A GDPR Session with Yolande Joubert

Date: Tuesday 3 June. Time: 1pm-2pm

Join us as we provide an interactive and powerful session with Yolande Joubert, our new Chief Operating Officer at Ataxia UK. GDPR is a really important aspect for all volunteer roles so it would be fantastic to see as many of you there as possible. There will also be a chance to win some prizes during the session! <https://bit.ly/4hOnsuU>

Chair Pilates with Sonia Forde

Date: Wednesday 4 June. Time: 11am-12pm

Led by Sonia Forde, this seated movement class will use Pilates techniques to focus on mobilising and stretching the whole body and relaxing the mind. This class is open to all and there will be adaptations for all exercises to make them suitable to individual needs. <https://bit.ly/43ozJ5S>

Bingo with the Services Team

Date: Friday 6 June. Time: 1pm-2pm

Join us for a fun-filled round of bingo! Unlike regular bingo, our game will test your knowledge of ataxia and volunteering. There will be a few prizes to give out to our winners, so don't delay in signing up! <https://bit.ly/4hSGwlp>

While we encourage all volunteers to attend as part of their ongoing training and development as a volunteer, anyone in the ataxia community is welcome to join these sessions if any are of interest to them. *We're always on the lookout for people willing to volunteer with us. If you're interested in finding out more about volunteering, please email volunteering@ataxia.org.uk*

 VOLUNTEERS' WEEK

2nd – 8th June
2025

#VolunteersWeek



Carers Week 2025

Carers Week is an annual campaign to raise awareness of caring, highlight the challenges unpaid carers face and recognise the contribution they make to families and communities throughout the UK.

Carers perform a vital and often under-recognised role in the ataxia community. Carers Week aims to help family members and friends who don't think of themselves as having caring responsibilities to identify as carers and access much-needed financial and emotional support.

This year, Carers Week is running from the 9 –15 June. The 2025 campaign will highlight the disadvantages faced by unpaid carers across the UK.

Join us this year as we recognize and celebrate the carers in our lives and in our communities and within the ataxia community, working tirelessly without payment and taking care of their loved ones.

We will be hosting a number of virtual activities, aiming to uplift our carer community, which may be found here: <http://alturl.com/6ph7a>

Carers Support Group Meeting:

The lovely Carer Support Group will be meeting on 9 June at 2pm. It is a chance to meet other carers and exchange useful advice on caring for someone with ataxia. *To register for this meeting, please do so here: <https://bit.ly/4hPoAyy>*

Mindfulness:

Our Mindfulness sessions are led by our incredible volunteer, Lucy Holland. The benefits of yoga and mindfulness have been a constant in Lucy's life for over 20 years and she has been sharing her experience through her teaching since 2017. Ataxia UK is a charity close to her family's heart and she has organised several fundraising yoga and mindfulness classes. Join us on the 11 of June at 1pm.

To register for this session, please do so here: <http://alturl.com/sitkw>

Self-care for Carers with Glesni Roberts from the Neuro Therapy Centre

Join us for a session on self-care for carers on the 12 June at 10am. Glesni Roberts is a qualified Counsellor, and registered member of the BACP (British Association for Counselling and Psychotherapy). She currently works for the Neuro Therapy Centre, near Chester, supporting people living with neurological conditions, including ataxia, as well as their carers. She is looking forward to meeting you all.

To register for this session, please do so here: <https://bit.ly/4j8NM45>

Please email volunteering@ataxia.org.uk if you have any questions about attending the virtual activities. We look forward to seeing you there!

For information on what support you may access as an unpaid carer, please visit: <https://www.carersuk.org/help-and-advice>

And to find out more about Carers Week, see here:

<https://www.carersweek.org>



Information for benefit applicants in Scotland - BASRiS

Lynsay Banks from Parkhead Citizens Advice Bureau, who works on the Scottish Rare Diseases Advice Service, has written this informative update regarding the changes to the benefits system in Scotland.

The benefits system in Scotland has been changing. Social Security Scotland have taken control of some of the benefits that used to be managed by the Department for Work and Pensions (DWP). You may have received a letter telling you that you will now be receiving child disability payment, adult disability payment or pension age disability payment. The amount you receive should remain the same, as should the day you receive the benefit.

The regulation surrounding the move to the Scottish Benefits identified that the system needed to be more empathetic and fair. This means that there should be no need for medical assessments and persons with long term conditions may get an indefinite award, taking the uncertainty of the review period away. There is a significant change in the rules surrounding terminal illness. The DWP rules, which still apply for DWP benefits, stipulate that the terminal condition should reasonably expect to cause your death within 12 months. The form to be completed to support this is called the SR1 and the process is called claiming under special rules. For Scottish benefits, the rules are slightly different. You can apply under the special rules if:

- 1. you have a progressive or advanced condition, or a condition that can cause sudden death,**
- 2. your condition is not curative, or you have chosen not to undertake curative treatment, and**
- 3. you are in increasing need of extra care and support to manage daily activities.**

This means that persons with a progressive condition, who may have been told that their condition is life limiting, but not life threatening, may be able to claim under the special rules. The 12-month prognosis is removed entirely. This is a sensitive subject and can only be confirmed by speaking to a consultant who knows your condition and how it affects you personally.

Ataxias affect people in such varying degrees, so claiming under special rules needs supporting evidence from your registered medical practitioner. They would need to complete a Benefit Assessment under Special Rules in Scotland (BASRiS) form. If you claim under special rules, your claim will be fast-tracked and you will not need to complete the full application form. If you would like more information on this, you can look at the guidance on the Social Security Scotland website. You can also contact Ataxia UK or the Scottish Rare Diseases Advice Service which is for patients and anyone affected by ataxia in Scotland. *Find out more about this service at <http://alturl.com/b7kco>*





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