ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 233. Spring 2026

Policy and Influencing Group:

Update from our meeting at Westminster

Georgia and mother Bev together with Sue Millman and Dr Julie Greenfield

Fundraising • Gluten free • The Big Give • Research • Ataxia people • Events • Services

ATAXIA
Ataxia UK

In the office

Ruja Ashrafi

Hello! I'm really pleased to be joining Ataxia UK as the new **Volunteering and Community Programme Intern**. In my role I'll be supporting the coordination and development of Ataxia UK's volunteering network and community events, helping to strengthen support for people affected by ataxia.

I recently completed a Master's degree in Medical Law and Ethics, following an undergraduate degree in Sociology and Criminology. My education has shaped a strong interest in access to healthcare, social justice and the barriers people can face when navigating support systems. I care deeply about helping people feel listened to and supported, particularly within healthcare and community settings. So, what excites me most about joining Ataxia UK is the organisation's commitment to their community, as well as meaningful, person-centred support.

I've already been very lucky to meet many members of the Ataxia UK community and to work alongside them. Thank you so much for the warm welcome; I'm grateful to be part of the team.

CEO's introduction

It's a New Year, and we hope we can all achieve great things for the ataxia community!

2025 ended in a fabulous Big Give fundraising effort in which we exceeded our target by £30,000 (See Kieran's article on p10-11). This is an amazing achievement. Many thanks to all those who contributed to it – we couldn't do it without you!

In 2026 we anticipate committing lots of our energy to the ongoing campaign to make Omaveloxolone available everywhere in the UK to everyone with FA, and getting the assessment system changed so that future treatments have a fairer assessment that considers the rarity of the ataxias. Many of you have contacted your local MP to get them to engage with us, and we are in the process of forging the links between them and with us. We hope to have many more meetings with MPs and Policymakers. Please sign up to our Omav newsletter and keep a lookout on socials and here in future editions of the Magazine for updates. You can find an update on the campaign on p16-17.

We will provide face-to-face updates on our campaign to those who are able to come to our Roadshows, the first of which will be hosted by Paul Coia in Basingstoke on 21 March. If you want to come to this, please book now! The others will be in Glasgow and Liverpool (see p18). I look forward to seeing you in person!

Sue

Best wishes, Sue Millman

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Sky Dive Ataxia Day

When: Saturday 28 March 2026

Why: Ready for a once-in-a-lifetime adrenaline rush? Jump from 10,000 feet, hit 120 mph, whilst raising vital funds for ataxia and contributing to groundbreaking medical research.

Picture it: the aircraft door slides open. Engines roaring. Wind in your ears. Fields stretching out below. Then… you lean forward and let go. Free-fall. Pure exhilaration. Total freedom.

No experience needed. You'll be securely strapped to a fully qualified instructor for a tandem skydive, who'll guide you every step of the way.

"It was absolutely amazing!! I loved every second!" – Frankie

"I really enjoyed myself (even if I did feel a bit sick for an hour afterwards!). I loved the freefall and could get quite addicted!" – Susan

How: Sign up online with our quick and easy form, then choose one option:

1. Self-Funded – Pay for your jump yourself. Every penny you raise goes straight to Ataxia UK. No minimum sponsorship target.

2. Charity-Funded – Raise £500+ and your jump is covered (target varies by location). A £70 registration fee applies, which you pay yourself.

To sign up for any event, email:
fundraising@ataxia.org.uk

Brighton & Hove 10K

Sunday 12 April 2026

Be part of Brighton Marathon Weekend with this fast, scenic 10K along the seafront. With just 57 feet of elevation, it's the perfect blend of challenge, views, and atmosphere.

London to Brighton bike ride

Sunday 21 June 2026

The iconic 54-mile ride from Clapham Common to Brighton Seafront is back, or try the new shorter 20.5-mile route, starting halfway at Ardingly to the Brighton finish line.

The London Big Half

Sunday 6 September 2026

Join thousands of runners at one of London's most vibrant and inclusive half marathons. The route passes through Tower Hamlets, Southwark, Lewisham and Greenwich, celebrating the incredible communities that make our city so special, finishing beside the iconic Cutty Sark.

Fundraising thank-yous

A massive thank you to everyone of our fundraisers who've raised money through community-led events, challenges or who have simply sent us donations. We are immensely grateful to all of you!

DONATIONS

Deane Morrice (£200), **Kevin Moss** (£10), **Joan Williams** (£211.20), **Mastermind Club** (£340), **Stuweb Chip Timing Services** (£35), **Carl Jones** (£91), **Stuart Taylor** (£30), **Newline Group** (£6,000) and **Georgina Ford** (£100)

COMMUNITY-LED EVENTS

Chelsea Higgot (1) - tabletop sale and pub quiz (£1310.50), **Paul McLaughlin and the JP All Star Brass** - pub concert (£500), **Stuart Taylor** - birthday event (£325), **Patricia Curtis** - breakfast event (£1120), **Sasha Seddin** - cake bake (£116.85), **Jon Lane, Ian Smith and the Worcestershire golf club** (£10,364), **Sandeep Sharma** - Crazy Hands event (£4009), **Cidney Rigney** - candlelight yoga (£300) and **Shannon Johnson** (below) - Country Fringe (£1606.06)

CHALLENGES

Declan Rogers (2) - 25 miles over three days of walking, running and wild camping, **Edward Yap (3)** - Alton Towers Half Marathon (£1639),**Charlotte Bryne (4)** - Ealing Half Marathon (£200), **Samantha Scargall & Kerry Leslie (5)**, - climbing Ben Nevis (£816), **Chelsea Forward** - Thames Path Challenge (£508), **Daniel Fraser** - Kilt Walk (£450), **Grace O'Connell** - Battersea Half Marathon (£1587), **Rebecca Scott** - Great Scottish Run (£687.50), **Josh Baxter** - Lincoln Half Marathon (£575), **Patrick Lister** - Royal Parks Half Marathon (£1143), **Jackson Joly** - Amsterdam Marathon (£1854), **Kirsten Pettit** - Rugby Half Marathon (£1120), **Sarah Parry, & Eddy Robinson** - 100-mile walk (£1345), **Joseph Gallagher (6)** - Finsbury Park Half Marathon (£1404 and **Daniel Mabbett** - Triathlon (£563).


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Meet Mandy Race: Full-time carer, former art lecturer, artist and avid (gluten free) baker

By Maya Shukla (right)

I recently hopped on a call with **Mandy Race** (below), who cares for her husband **Malcolm**, who has gluten ataxia. For over 37 years, "long before it was trendy" Mandy has been experimenting and perfecting her craft, and bakes. This article introduces a series titled Mandy Bakes, so the whole community can enjoy Mandy's modified gluten free bakes.

MAYA SHUKLA: If your baking style had a theme song, what would it be and why?

MANDY RACE: Anything Goes by Cole Porter. I always think you shouldn't get hung up on recipes and that you can always work creatively on a recipe. You don't have all the ingredients? Improvise. You can always improvise. Do you know it? It's a bit of a sort of jazzy 1920s from a musical. I think anything goes. So, in my kitchen, anything goes.

MAYA SHUKLA: You are clearly so creative. And like you said, anything goes, and you find it quite easy to adapt to recipes. What is your superpower in the kitchen?

MANDY RACE: To be relaxed about it, to not get hung up about having the exact right things or exactly the right measurements. So, when I have been writing recipes, I had to stop and think: if you're going to pass this recipe on, you need to have a bit more accuracy. So, some of my recipes do have serious accuracy to them, depending on what they are. Quite honestly, all the nice things that I put in my cakes that compensate for the lack of other things kind of enrich it. I have a couple of secret ingredients, but one of them, not everyone can eat, is ground almonds. So yummy and it adds moisture and a different texture to baking. Making a gluten free scone is usually like cardboard, very boring and dry. You've got to bring elements that aren't traditional. I suppose there's a science to cooking.

MAYA SHUKLA: You just spoke of your scones. What is the reason behind that?

Mandy Race - continued

MANDY RACE: My mother-in-law was a brilliant baker and used to make amazing traditional scones; a recipe off her mother's back in the First World War; her husband would eat a huge scone every single day. And of course, Malcolm couldn't eat them because he couldn't tolerate gluten, so I adapted the recipe.

MAYA SHUKLA: What ingredient is the unsung hero for the scones?

MANDY RACE: Xanthan gum. It's a miracle product!

MAYA SHUKLA: What do you find that the Xanthan gum does to your bakes?

MANDY RACE: If you make the scones without Xanthan gum, they're very dry; like cardboard, they just crumble and don't keep.

MAYA SHUKLA: What is the funniest, or most chaotic thing that has ever happened to you whilst you've been baking?

MANDY RACE: Well, I remember on two occasions dropping two baked cheesecakes as I took them out of the oven and just slipping through my oven gloves, and then repeating the recipe, and the same thing happened again. My daughter reminded me, she said,"Mum, don't you remember when you accidentally spilt the rice into the mixture for rock cake" – revolting and crunchy with rice in it. So, disasters do happen.

MAYA SHUKLA: Oh gosh! What is, if you have any, your best piece of advice for anyone who wants to try gluten free recipes and then gluten free scones?

MANDY RACE: Make sure you have a freezer available. It's important if you're not baking it for a full family; it's got to last. In a week's time they might still be OK, but they're not going to be just freshly baked, you know?

MAYA SHUKLA: Finally, what is a flavour combination that you secretly love that maybe the world might not be ready for?

MANDY RACE: Well, I quite like fresh fig in the summer in my scone, sprinkled with a bit of lemon juice and brown sugar on the top, and put it under the grill, and then topped off with cream cheese.

To watch the full interview go over to our ***YouTube channel***.

Mandy Bakes: gluten free scones

My husband's favourite afternoon treat is a gluten free date and walnut scone with a cup of tea. I usually make a batch and keep them in the freezer, defrosting one at a time as needed. A single scone takes about two minutes in the microwave and comes warm, as if freshly baked (allow a little longer if defrosting more than one).

I make these scones regularly as they take just 10 minutes to prepare and 10 minutes to bake, and the added ingredients can easily be adapted to whatever you have on hand.

Utensils: Large mixing bowl, large jug, measuring scales, large metal and wooden spoon, spatula, measuring spoons, a stick blender or whisk, a fork and a sharp knife and chopping board, large flat oven tray lined with a non-stick liner, pastry brush, cooling rack.

Ingredients - 12 scones.

340g / 12oz gluten free Doves farm self-raising flour, 85g / 3oz dairy free margarine or goat's butter, 1tsp Xanthan gum, 1tsp gluten free baking powder, 42g / 1 ½ oz golden sugar

2 large free-range eggs, 200 ml cold water, and few drops of vanilla essence. Optional additions: Roughly 80g (2 ¾ oz) of any dried fruit, dates, 1¾ cups walnuts, sultanas or raisins, dried apricots, and dried cherries (about 50 g each).

Method

- Heat the oven to 220c/425f/Gas Mark7 and line a baking tray.
- Place all the dry ingredients in a large mixing bowl and roughly combine these with the butter or margarine and sugar, using a fork to break up into small chunks.
- Chop and add the dried fruit and disperse evenly with the fork until fine and crumbly.
- Place the eggs, water and vanilla in the jug and whisk lightly until blended.
- Then pour almost all the wet mixture into the dry and stir lightly. It will thicken up a little.
- Place 12 spoonfuls, evenly on the baking tray. Dip a metal spoon in cold water and carefully smooth the top of each scone keeping the shape round and rustic. Note this is a wet mixture and doesn't resemble a traditional scone. You can brush the tops with a little egg water, but it's not essential.
- Lower the oven temperature to 200°C or equivalent. Place in the middle of the oven and bake for 10-12mins or until golden.
- Allow to cool on a rack. Serving suggestions: home-made jam and lactose-free cream cheese or whatever you fancy. Freeze spare scones during the week. I often make these for visitors.

You helped Ataxia UK reach new heights with our biggest fundraising campaign of the year!

Over one week in December, Ataxia UK takes part in the Big Give Christmas Challenge which has historically been our biggest fundraising campaign over the year. Last year, we were raising money for our campaign From Lab to People: Removing Barriers to Treatment. This project was the result of months of careful planning and development, running alongside our growing policy, advocacy and influencing work.

Back in April, the MHRA (Medicines and Healthcare products Regulatory Agency) approved Omav for use in FA patients over 16 here in the UK, which was really positive news, however, at the same time there was disappointment because it isn't yet available for reimbursement on the NHS. The drug approval and reimbursement process is often long and complex, with technicalities causing delays and frustrations when it comes to accessing drugs. Ataxia UK wants to keep doing more for the ataxia community so that once drugs reach the market, they get into the hands of those who need them, as soon as possible. When progress towards treatments stalls, we come together. Not just for the drugs we cannot access now, but to improve the approval processes for the drugs to come.

We were hoping to raise £60,000 across 7 days, to support this work and help us use our position to advocate for the ataxia community, expand our engagement with policy stakeholders and encourage change.

The Big Give only works thanks to a small number of Pledgers who pledge to donate a generous amount to the ataxia community. This number is then boosted by a Champion sponsor: The Reed Foundation. This combined total was already a wonderful £30,000.

But something amazing happened within the first 8 hours – the ataxia community donated a further £30,000 to support this project.

You and other Friends of Ataxia UK banded together and collectively raised more than £60,000. Your support for this campaign emphasised its importance and so we didn't slow down or stop there!

We entered new ground as a charity, as we had never before been in the position to grow our campaign pot through the Big Give, but thanks to a last-minute gift from another generous Pledger, we were able to drive another £10,000 before the weekend was over.

It was wonderful as a charity watching every target we set for this Campaign be smashed by the community.

By the end of the week-long campaign you had helped raise £82,593 online. However, once we factor in Gift Aid and offline cash donations, we can surmise for now that almost £90,000 has been generously raised to support this project.

This is a wonderful achievement and makes this the biggest Big Give Christmas Challenge Ataxia UK has taken part in. So, here's just a snippet of how that generosity will be reinvested back into the community to support you.

- Patients have waited too long to gain access to life-changing treatments. Our policy and advocacy work is an essential part of achieving the changes to the system that patients with rare and ultra-rare diseases deserve. We aim to use funds raised to continue to develop and grow our advocacy work. In July our CEO was invited to an All-Party Parliamentary Group on Genetic and Rare Conditions to speak on the issues of drug approval and reimbursement in the UK. And then later in 2025 members of the team met with the Department of Health and Social Care to discuss this further. We aim to use your support to help us continue this work.
- We aim to expand our engagement with crucial policy stakeholders through a range of activities, events, and policy-response.
- We will continue to support those affected by ataxia until treatments are available here in the UK. We will continue to provide support through our Helpline & Advocacy service, offer Speech Therapy & Voice Banking services, build a community through Branches and Support Groups.

A lot of people went into making this campaign a success for the ataxia community. Firstly, I'd like to thank everyone who shared their stories, but particularly our Friends:

Annaleigh, **Harry** and **James** (left) – your story helped galvanise our community and highlighted how 'From Lab to People' will make a difference.

Darren and **Mathew** (above) - your efforts to demand the attention of those with the capacity to bring about change is courageous and inspiring.

Our anonymous Pledgers to this Campaign. We thank you for your continued generosity and commitment to supporting those affected by ataxia. And finally, our Big Give 2025 Champions, The Reed Foundation.

If you wish to share your ataxia story and get involved with a fundraising appeal, email ***kfearnley@ataxia.org.uk***

Update: Omaveloxolone for FA

Omaveloxolone (a treatment for people 16 and over with FA) is currently under review by the Scottish Medicines Consortium (SMC). The SMC is the committee that evaluates the cost-effectiveness of medicines in Scotland. In November, Ataxia UK submitted a patient group report which is considered during the SMC's decision-making process. This report represents views and experiences of people with, and affected by, FA and helps the SMC understand how omaveloxolone could impact their quality of life.

The next step was a Patient and Clinician Engagement (PACE) meeting in early 2026, in which Ataxia UK representatives participated. The PACE meeting is an opportunity for patients, caregivers, expert clinicians and patient group representatives to express their views and experiences of FA, and how omaveloxolone could benefit them.

This information is considered in the SMC decision-making at the SMC committee meeting (in addition to other decision-making flexibilities granted under the Orphan pathway, which is applied for drugs that have an Orphan Designation, such as omaveloxolone).

Following the PACE meeting, an SMC committee meeting took place, which also included participation from an Ataxia UK representative. A final decision is usually released around a month after the meeting.

At the time of writing this article we do not have a final decision from the SMC, but this is expected in early March. Check our communication channels for updates.

As communicated previously, clinicians are able to make individual requests for patients to be prescribed omaveloxolone under the PACS Tier 2 process. If you live in Scotland and are interested, you could talk to your neurologist about this.

Read more on the 'Omav Updates' page of our website.

Ataxia UK continues to call for urgent access to omaveloxolone for all adults with FA in the UK.

Recruitment for the BRAVE paediatric clinical trial of omaveloxolone for FA has begun.

Recruitment has begun at the UK sites for Biogen's BRAVE study, a global Phase 3 clinical trial of omaveloxolone in children aged 2-15 years, with the first UK patient enrolled in early January 2026.

The trial will study the effects and long-term safety of omaveloxolone in the paediatric population. The London Ataxia Centre, Sheffield Ataxia Centre and Oxford Ataxia Centre are UK sites for this trial. Individuals interested in taking part should contact the Ataxia Centres. *Please see our website for details.*

Pharma news updates

Larimar Therapeutics announces positive results from their phase 2 trial of Nomlabofusp for FA

Nomlabofusp is designed to increase levels of the frataxin protein, which is reduced in FA. So far, 65 people have been dosed with nomlabofusp, with 14 having taken it for over six months and eight for over a year. In 10 participants with data at six months, they saw an increase in frataxin to 50% of frataxin levels seen in people without FA. This is similar to the level of frataxin seen in carriers (people with one copy of the FA-causing gene, who don't have symptoms). This was measured in skin cells, so we don't know the frataxin protein levels in cells relevant to FA.

Improvements across several clinical rating scales were seen in participants who received treatment in the shorter term and longer term, compared to people in the FACOMS natural history study not on the treatment. Larimar plans to submit a new drug application to the FDA in the second quarter of 2026. *Read more on the 'Research News' section of our website.*

FDA does not approve new drug application for troriluzole for spinocerebellar ataxias

In 2024, Biohaven announced positive results from their study of troriluzole to treat SCAs 1,2,3,6,7,8 and 10. Following this, they submitted a new drug application (NDA) for troriluzole for all types of SCAs to the US regulators, the FDA.

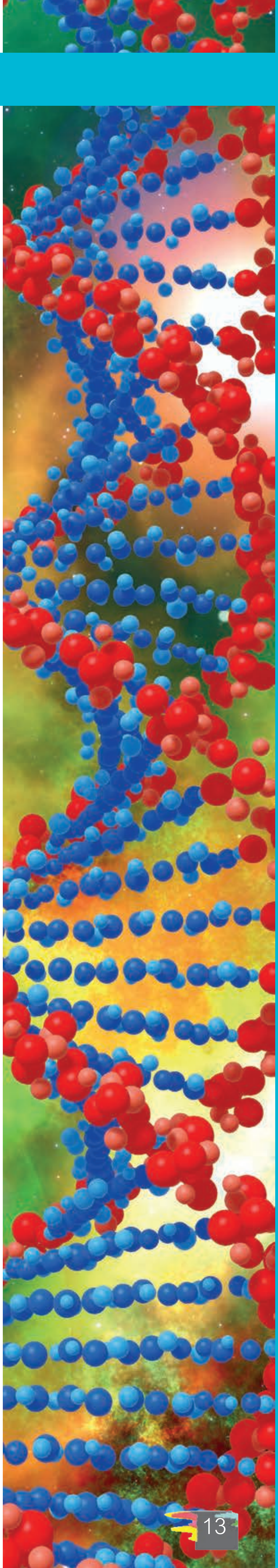
Unfortunately, in November 2025 Biohaven announced that the FDA issued a complete response letter to Biohaven informing them that they have not approved the NDA. The FDA recommended that Biohaven meet with them to discuss the evidence needed for Biohaven to re-submit an NDA. Biohaven is requesting a meeting with the FDA as soon as possible to discuss potential next steps and say they are committed to working with the FDA to achieve new drug approval of troriluzole.

Ataxia UK understands that this news will be disappointing for the SCA community. We will continue to do what we can to advance treatment development for the ataxias. We will continue our dialogue with Biohaven and provide further updates as soon as possible. *Read their press release via our article on the 'Research News' section of our website.*

IntraBio to conduct phase III trial in SCA6 and Episodic Ataxia Type 2

In September 2024, the US drug regulator, the FDA, approved IntraBio's symptom-relief drug levacetylleucine (or AQNEURSA) for the treatment of Niemann-Pick Type C (NPC). This drug has also recently been approved for the treatment of NPC by the European drug regulator, the EMA. *Read more in the 'Research News' section of our website.*

IntraBio now plans to trial levacetylleucine in disorders related to the CACNA1A gene, including SCA6 and episodic ataxia type 2. They hope to start a trial in 2026 and are exploring potential UK sites. *When we know more, we will share through our communications channels.*



Reflections on CTAX and the International Ataxia Patient Conference

In October, representatives from Ataxia UK attended the first Clinical Trials in Ataxia (CTAX) conference in Amsterdam. CTAX was organised by Ataxia UK, the National Ataxia Foundation (NAF), the Friedreich's Ataxia Research Alliance (FARA), and the Ataxia Global Initiative (AGI). CTAX was followed by the International Ataxia Patient Conference, hosted by Euro-ataxia. Here, we reflect on the impactful discussions that came out of these events.

CTAX

CTAX was attended by 120 invited researchers, patient groups, pharmaceutical companies, and representatives from drug regulators (the EMA and FDA). The aim was to discuss lessons learned from clinical research, and build a consensus around outcome measures and biomarkers. These central areas of research are common to all ataxias, and they become increasingly important when potential treatments enter clinical trials.

Biomarkers

Biomarkers are required to measure progression of ataxia, as well as the effect of potential treatments being tested in clinical trials. We heard from researchers studying a range of biomarkers, to be used in trials and monitoring of ataxias. Whilst progress is being made, we need more biomarkers that are sensitive to change, and their clinical relevance needs to be defined.

Outcome measures

Day one ended with a session on the clinical meaningfulness of outcome measures. These are the measures used in clinical trials to determine whether the treatment being tested improves symptoms or slows progression of ataxia. Clinical researchers and regulators agree that outcome measures need to be clinically relevant, meaning that a person with ataxia taking a potential medication needs to feel an improvement or stabilisation in their health or day-to-day living. Clinical meaningfulness is important when it comes to gaining regulatory approval for potential treatments.

Learning from other conditions

Day two included speakers from other neurological conditions, including ALS and Huntington's Disease. As potential ataxia treatments are reaching late-stage clinical trials, we can learn from other conditions that have faced the same problems as the ataxia research field.

In summary
The success of potential ataxia treatments depends on sensitive biomarkers, high quality natural history data, and clinically meaningful outcome measures. Together, these topics underline the importance of good clinical trial design. We ended the conference by discussing how we can move forward together to ensure that we are ready for late-stage clinical trials and the drug regulatory process. The CTAX Steering Committee plans to pull together the topics from the conference for a consensus paper, and Ataxia UK will continue to represent the interests of people affected by ataxia as we support this work.

INTERNATIONAL ATAXIA PATIENT CONFERENCE

The International Ataxia Patient Conference, hosted by Euro-ataxia, was attended by representatives from 18 patient organisations from Europe and North America, six pharmaceutical companies, and some ataxia researchers.

We heard updates on clinical programmes from Lexeo Therapeutics, Biogen, Biohaven, IntraBio, Solaxa and Larimar Therapeutics. We were joined by specialists in accessing treatments, who discussed the new Joint Clinical Assessment route being rolled out in the EU. We heard experiences from those working in Muscular Dystrophy, who recently undertook a range of projects aimed at getting access to treatment. To end day one, two researchers described their work ensuring that rating scales (SARA and mFARS) are clinically meaningful to people with ataxia.

We heard about burden of illness studies by Biohaven (on SCAs) and Biogen (on FA). Representatives of patient organisations in Greece (HEFAA), the UK (Ataxia UK), and France (AFAF) presented their experiences supporting the Health Technology Assessment (HTA) process. HTA is the process by which individual countries decide whether to provide a treatment on their health service. Although the process is individual to each country, the information required and lessons learned are applicable across countries and different ataxias.

To end the meeting, we discussed the next steps required to ensure we are ready for future trials and potential treatments. This includes harmonising information collected across countries, so we can gather high quality data with which to represent the ataxia community. The event was a great success, and we look forward to continuing our work with the international ataxia community to amplify the voices and experiences of people affected by ataxia. We are grateful to the event sponsors Biogen, Lexeo Therapeutics and Biohaven.

Policy and Influencing Group: Update

Ataxia UK has been working collaboratively with families, clinicians, policymakers and parliamentarians to press for access to a licenced treatment – omaveloxolone (Omav) - for those affected by Friedreich's ataxia (FA) aged 16 years and over.

As treatments are developed, we're ensuring that Ataxia UK is connected and positioned to advocate for the interests of people affected by ataxia everywhere. This includes establishing an internal Policy and Influencing Group to help steer our work and engagement with the wider health and rare disease ecosystems and working more closely with stakeholders in all the devolved nations.

The government is committed to reviewing a range of policies affecting our community, and we are representing the views and interests of people affected by ataxia at every stage - from responding to consultations on proposals to how NICE cost-effectiveness thresholds are changed, to engaging with the All-Party Parliamentary Group on Rare Disease - we are working tirelessly to ensure that any changes create better outcomes for patients, carers and families.

Your support for this is crucial. Since launching the Omav campaign, many of you have written to your MPs, who have reached out to us. We have seen a question asked at Prime Ministers' Questions, and personal stories covered on the BBC, ITV, STV and other media. Though change takes time and often appears to stall, or be going in the wrong direction, in reality policymakers can't create change overnight. That's why we are in this together, for the long haul. Every engagement matters, every story shared helps to grow support.

On December 10th last year, we were joined by Georgia Hart, who lives with FA, and her mother, Bev, for a meeting organised at our request by Jonathan Brash their MP with the Department of Health and Social Care. Georgia and Bev's

powerful testimony reflected the deeper realities of the condition. For Georgia, the meeting offered a vital opportunity to speak directly about her lived experience, explaining to Dr Ahmed, the Parliamentary Under Secretary of State for Health Innovation and Safety, that "being able to tell my story and highlight how feelings of isolation are made worse by disparities in treatments and outcomes is really important to me."

Bev spoke about the urgency of the situation for patients and families with FA unable to secure Omav and the importance of sustained support, highlighting that "Jonathan's and Ataxia UK's support for us has been amazing, helping to raise awareness at this crucial time provides hope that change will happen."

The meeting agreed the following next steps:

- **Interim access:** The minister agreed to instruct NHS England to initiate discussions with the manufacturer (Biogen) to explore options for an interim access pathway for Omav in England for adults with FA while the company prepares to re-submit its proposal to NICE for approval.
- **Prevalence and data gaps:** Dr Ahmed acknowledged the lack of prevalence data for the ataxias and rare diseases more broadly and committed to looking into the matter.
- **Wider rare disease barriers:** Dr Ahmed expressed a commitment to look at some of the barriers affecting the evaluation of medicines for rare diseases that were discussed at the meeting.
- **Continued dialogue:** All the stakeholders agreed on continuous dialogue and sustained engagement.

This is a major milestone in the Omav campaign and, more widely, has supported Ataxia UK's Policy and Influencing group to convene a coalition of policymakers to support our work to secure better outcomes for everyone living with ataxia. Our work with them will continue to grow and to become more strategic.

Please follow our socials or sign up to our newsletter for the latest updates.

Ataxia UK Roadshows

Thank you to the sponsors of this event, Lexeo and Biohaven.
We're continuing our road trip around the UK to bring Ataxia UK to you!

BASINGSTOKE ROADSHOW

Saturday 21 March 2026

The Hampshire Court Hotel, Basingstoke, RG24 8FY

Join us for an information-packed day, hosted by Ataxia UK patron Paul Coia. The programme will include:

- An update from Ataxia UK CEO Sue Millman
- Find out what Ataxia UK can do to support you
- All About Ataxia workshop
- The opportunity to connect with others living with ataxia
- Other workshops and talks to be confirmed

Who this event is for:

- Those with a new or existing diagnosis of ataxia
- Families, friends and carers of people living with ataxia
- Local healthcare professionals working with ataxia patients, or with an interest in ataxia

Tickets: £30.00 for adults, £12.50 for ages 13-18 and free for under 12s (Includes buffet lunch and refreshments).
Bookings close on Thursday 12 March.

Accommodation: If you would like to stay at the event venue, you can contact the hotel's central reservations team on **0330 107 1599**.

*To find out more and book your tickets, head to **http://alturl.com/5aadf***
*If you have any queries please email us at **conference@ataxia.org.uk***
*or call **020 3196 0440**.*

THE ROADMAP

Don't worry if you're not local to Basingstoke or the South East. Here are our next stops:

- **Liverpool. Sunday 7th June**
- **Glasgow. Saturday 9th May**
- **Belfast. Early 2027**
- *We also have many other virtual events coming up throughout the year so keep an eye on our Events page and newsletters for more information.*

Mark Dower Trust Grant goes live

The Mark Dower Trust is a financial grant that aims to support young people with ataxia who are seeking independence, through further studies, employment, specialist equipment or hobbies/skills. This year's grant applications will open on the 1st of March 2026 and close on the 30th of April 2026.

The Mark Dower Trust was set up in memory of Mark, who sadly passed away in 2003, aged 41. Mark had FA and was fiercely independent and driven, truly living his life to the full. Though he loved his family and his home he wanted the same autonomy which other young people yearn for; the ability to make his own choices and to have his own space. The Mark Dower Trust aims to help similarly independent young people between the ages of 16-30 who have been diagnosed with ataxia to develop and enjoy hobbies and activities or to enhance their skills through further education.

Inspired by Mark's independent spirit and appetite to try new things, The Mark Dower Trust offers a small annual grant of up to £3,000 to share among each year's awardees.

The average award is around £500 per person. The aim is to support young people by enabling them to pursue skills, hobbies or further educational opportunities and hence allow them to maximise their independence.

In the past awards have been given for sports equipment, musical instruments and art lessons. The trust does not award grants for medical aids or mobility equipment as there are already grant organisations that provide for these things.

Top tips for a good application:

- Be clear what you want to use the grant for. Provide a link to website or an invoice for the equipment you are asking for.
- If you want to use the grant to pay towards training or fees for a course, then be clear which course/when/where and what the costs are.
- If you can contribute part of the cost of the item yourself let us know.
- Explain how the grant will benefit you; what will you learn and how will this help you?
- Demonstrate your passion and commitment to the area of interest.

To apply please fill out the application form on our website: ***http://alturl.com/hm7kf***

If you need any help, please contact the Ataxia UK Helpline on ***0800 995 6037*** *or email -* ***help@ataxia.org.uk***

How to access a wheelchair

Having access to a wheelchair can be a great way to maintain independence and continue to live life to the full when symptoms progress. However, understanding how to access a wheelchair, what support is available, and how to cover the costs can feel confusing. There are several routes you can take in the UK, and the right option will depend on your personal circumstances, mobility needs, and financial situation.

Before choosing any wheelchair, it is essential to be assessed by a qualified professional. A wheelchair that does not fit properly can cause serious problems. An expert assessment ensures the wheelchair supports your body correctly, meets your clinical needs, and is safe and comfortable to use. Whether you go through the NHS, buy privately, or apply for grants, an assessment is a crucial first step.

1. Accessing a wheelchair Through the NHS

To begin this process, you will need a referral to your local NHS Wheelchair Service. You can request this referral from your GP, physiotherapist, or another healthcare professional involved in your care.

The assessment process

Once referred, you will be invited to an assessment with the wheelchair service. During this appointment, a specialist will look at your mobility needs, daily activities, home environment, and physical measurements. They will determine whether you meet the eligibility criteria for an NHS funded wheelchair and what type of chair would best support your needs.

Who owns the wheelchair?

If you accept the wheelchair offered by the NHS:

- The wheelchair belongs to the NHS, not you.
- You are effectively borrowing it.
- The NHS is responsible for repairs, servicing, and maintenance.

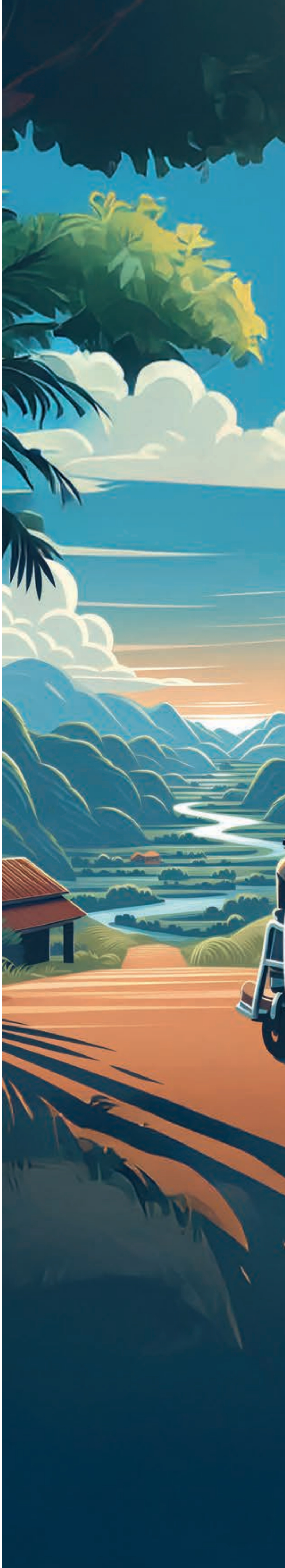
This can be a major advantage, especially if you want to avoid the cost and responsibility of maintaining the equipment yourself.

The NHS aims to provide most wheelchairs within 18 weeks of receiving the referral. However, waiting times vary significantly across the country. In some areas, delays are much longer, and around 15% of wheelchair users wait over a year. If waiting times are long in your area, you may want to consider alternative options such as Personal Wheelchair Budgets or private purchase.

2. Personal Wheelchair Budgets (PWB)

A Personal Wheelchair Budget gives you more choice and flexibility. If the NHS offers you a standard wheelchair that meets your clinical needs, they must also tell you the monetary value of that wheelchair. This amount is known as your “notional budget”.

You can then choose how to use this budget. There are three main options:



Option 1: Notional PWB

You accept the standard NHS wheelchair offered. This is the simplest option and includes NHS maintenance and repairs.

Option 2: TopUp

You choose a higher spec wheelchair from the NHS approved list and pay the difference yourself. This allows you to add features or upgrades that improve comfort, independence, or usability.

Option 3: Third Party PWB

You use your budget as a contribution toward any clinically suitable wheelchair from an approved supplier, even if it is not on the NHS list. You may need to pay extra, and you will be responsible for repairs and maintenance. This option is particularly useful in areas with long waiting lists, as it allows you to purchase a wheelchair more quickly. However, it does mean taking on more responsibility and potentially higher costs.

3. Powered wheelchairs and NHS criteria

The NHS will only fund a powered wheelchair if you need it both indoors and outdoors. If you only require powered mobility outside the home, you may not meet the criteria. In this situation, you may need to explore other funding routes such as grants or the Motability Scheme.

4. Hiring a wheelchair

If you need a wheelchair temporarily or while waiting for an assessment, charities such as the British Red Cross offer short term wheelchair hire. Hire is usually charged weekly and is a flexible, low commitment option.

5. The Motability Scheme

If you receive the higher mobility rate of certain disability benefits, you may be eligible for the Motability Scheme. This allows you to lease a powered wheelchair or mobility scooter.

6. Access to Work

If you are employed and need a wheelchair or mobility equipment to help you stay in work, the Access to Work scheme may be able to help.

7. Grants and financial support

If you are struggling to afford a wheelchair or need to top up your Personal Wheelchair Budget, Ataxia UK may be able to help. We can apply to grant giving organisations on your behalf. Grant organisations usually require supporting evidence from a professional confirming that the equipment is suitable and cannot be provided by the NHS or social services. One person we supported with a grant shared that “their world has been opened up with their new wheelchair” after receiving grant support. *If you would like help applying for a grant, contact our Helpline on* ***0800 995 6037***
or email ***help@ataxia.org.uk***

Useful links

NHS: *Walking aids, wheelchairs and mobility scooters* ***http://alturl.com/dday6***
British Red Cross: *Hire a wheelchair* ***http://alturl.com/hzu5d***
Motability Scheme: *How it works* ***http://alturl.com/vo8zs***
GOV.UK: *Access to Work.* ***http://alturl.com/4tgmo***

Practical tips for accessible days out

Planning days out can be a great way of improving wellbeing and having something to look forward to. People in the ataxia community have a variety of mobility and other access needs, so knowing what to ask when planning days out can be helpful. Most venues will be more than happy to explain how they can improve access for you, so do call ahead if the information is not available online.

Things to consider when checking accessibility:

- Is public transport or disabled parking available at the venue?
- Are there step free access, ramps or lifts if needed?
- Are wheelchairs or scooters available to borrow?
- Is there a specific wheelchair area, and is it integrated with the audience?
- Can sensory needs be met (sign language interpreter, audio descriptions, subtitles, hearing loops)?
- Are bar, restaurant and toilet facilities accessible?

Hearing from other people who have been to venues can also be invaluable; several websites offer this:

- ***https://www.accessable.co.uk/*** *search by type of venue and location*
- ***https://access.great-days-out.co.uk/*** *lists by region and category*
- ***https://www.euansguide.com/*** *has reviews from disabled people*

On occasion, venues may ask for evidence of disability, for example to use accessible areas at gigs, the theatre or festivals. Schemes exist that provide you with an ID card that communicates your access requirements simply without the need to provide evidence or lengthy explanations. *For example,* ***https://www.accesscard.online/*** *which can also describe if a companion or carer is required. In addition, carers ID cards are available online and sometimes are given for free by registering as a carer with your local carers' association.*

Getting outside:

Enjoying historical sites and the natural beauty of the UK is more possible than ever now with big organisations like the National Trust and Forestry England offering accessibility guides. Some sites also offer accessible trails and hire of all-terrain mobility scooters.

Regional groups also offer all-terrain scooter hire, such as ***Access the Dales*** *in North Yorkshire (contact the Ataxia UK helpline to find out if there's one near you):* ***https://www.access-the-dales.com/*** *Ten further venues around the UK that offer free hire of all-terrain (push) mountain trike wheelchairs can be found here:* ***http://alturl.com/qzqen***

Whether you're wanting to plan a trip, get out to new venues or figure out if you can get back out in nature, it's well worth planning to ensure things go smoothly and you're aware of all the support that's on offer.

New Support Groups

Over the past year, we've been delighted to see new support groups launching across our community, creating more opportunities for people affected by ataxia to connect, share experiences, and support one another.

One of the newest additions is the **ARSACS Support Group**, created specifically to bring together people affected by Autosomal Recessive Spastic Ataxia of Charlevoix-Saguenay (ARSACS). Led by sisters **Natalie** and **Rachael** (right), the group offers a welcoming and understanding space for those living with the condition and their families.

The ARSACS Support Group runs a mix of online and in-person meet-ups, including bi-monthly meetings described as "an informal space to get together and connect with others who get it." The group has welcomed guest speakers, and will be holding social events in June and December, giving members the opportunity to build friendships, learn more about ataxia, and strengthen connections.

Looking ahead, we're also excited to see a new **Northampton Support Group** forming this year! The group will be led by **Martin**:

"Hi, I'm Martin and I'm excited to be setting up a new Ataxia UK support group for the Northampton region.

I was diagnosed with ataxia in 2002 after noticing increasing issues with balance and clumsiness. It wasn't until 2023 that DNA testing confirmed it as Spinocerebellar Ataxia type 42 (SCA42).

Despite this, I've always tried not to let ataxia define me or hold me back. I've travelled widely, lived overseas for many years, and embraced new adventures.

These experiences have given me an understanding of the day-to-day realities of living with ataxia, as well as the importance of encouragement, community, and a safe space to share our lived experiences openly.

I want to start this local group to create a space where people affected by ataxia can connect, share experiences, swap practical tips, and support one another. Whether you're newly diagnosed, have lived with ataxia for decades, or are caring for someone, you'll be very welcome. I'm really looking forward to meeting everyone and building a strong, supportive ataxia community in Northampton together!"

Getting involved in a support group can help you build connections, share advice, and feel part of a supportive community. Support groups offer a chance to connect at your own pace and remind you that you're not alone.

Support groups run across the UK, both online and in person, including regional branches and condition-specific groups. To find one that's right for you, visit our website page: ***http://alturl.com/3eijb***

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