ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 231. Autumn 2025

Wheelchair Across the Alps / Alps 4 Ataxia

A world first in manual wheelchairs

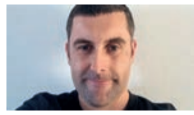
- Ataxia people • Research
- Ataxia awareness • IAAD 2025 • Fundraising
- Living with ataxia • Services

ATAXIA

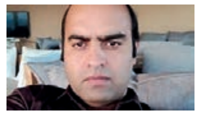
Ataxia UK

In the office

We are sad to say goodbye to **Chris Murton**, our **Charity Accountant**. We thank him for his contributions and wish him all the best in his next chapter.



A warm welcome to our new **Communications Officer**, **Conor O'Donoghue**. With a strong background in journalism and digital content, Conor has extensive experience writing for national publications, interviewing high-profile figures, and supporting successful charity campaigns.



Meet **Salman Khalid**, who joined us as **Communications and Marketing Manager**, bringing over 17 years of global experience leading campaigns across health, inclusion, and social justice.

Alice Hannaford joins our **Helpline** team with a strong background in delivering support services across the third sector. Alice has worked with a wide range of communities through roles at Perennial, Foothold, and Citizens Advice.

We're delighted to introduce **Sally Ulph**, who brings over 20 years of experience in the voluntary and charity sector to her new role on our **Helpline**. Sally has supported people living with chronic illness, disabilities, mental health issues, and homelessness.

CEO's introduction

In the last edition, I reflected on the threats and hopes for people living with ataxia. The past three months have demonstrated just how quickly these possibilities can become reality.

Skyclarys has become the first drug licensed for FA in the UK but its progress with NICE has unfortunately stalled for now. Over 10,000 people have signed our open letter to Wes Streeting, the Minister of Health, calling for a meeting to discuss the changes needed to the system so that treatments for rare diseases are assessed appropriately.

We will continue to push for a successful resolution between Biogen and NICE on Skyclarys. We also stand alongside umbrella organisations lobbying to mitigate the worst effects of the planned benefits changes.

The worst changes to PIP have evaporated but changes to Universal Credit (UC) rates, including freezing the rate of UC per week for current claimants and cutting it to £50 per week for new claimants, will have a devastating impact on some people's income. This must be urgently addressed.

In the meantime, at Ataxia UK, thanks to the wonderful efforts of our fundraisers and an unexpected legacy donation, we have been able to provide an increase in staff resources for the Helpline and the Research Department. Thank you to all of those who embark on fundraising efforts, to those who support them, and to those who so kindly think of us when creating their wills. Your generosity makes a huge difference to the work we can undertake on your behalf.

Sue

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.

Ataxia UK works across the whole of the UK and is a charity registered in Scotland (No. SC040607), in England and Wales (No. 1102391), and is a company limited by guarantee (4974832)

Ataxia UK Virtual Annual Conference 2025

Friday 3 October
and Saturday 4 October 2025

Join us for this year's Virtual Annual Conference, which will be held on Zoom and hosted by our fantastic patron, **Paul Coia**.

Our jam-packed programme will give you opportunities to learn more about ataxia, hear about the latest updates in research, put your questions to the neurologists, and participate in a variety of workshops.

Tickets cost £15 per household (one ticket covers both days).

View the full programme and book your ticket here: ***http://alturl.com/iiy7e***

RUN OF SHOW

Friday, 3 October
– afternoon – Research Day

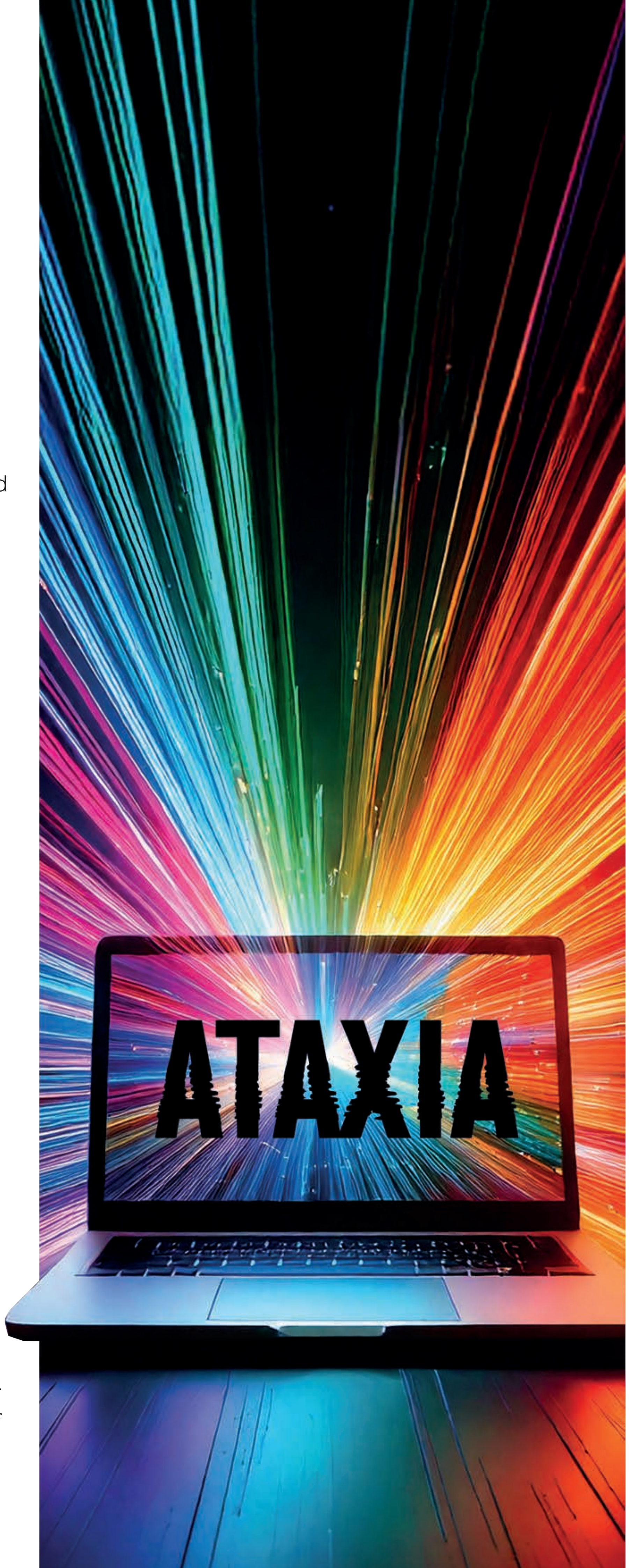
- Research Updates
- Doctor's Q&A

Saturday, 4 October – full day

- Guest speakers
- Workshops
- It Works for Me talks
- Awards ceremony
- And much more!

Any questions?

Do you have a question you'd like to ask our neurologists in the Doctor's Q&A session? If so, please email it to us at ***conference@ataxia.org.uk***



Treasurer

Are you interested in being the next Treasurer of Ataxia UK? Here, current Treasurer Kathy Jones tells us about her experience in the role.

I have been Treasurer for the last 7 years, and Board rules mean I must stand down in the Autumn next year. My husband has ataxia, specifically SPG7, and I have very much enjoyed the opportunity to use my finance skills to give something back to the charity that has given both of us a great deal of help and support. It has proved to be a very interesting role, which has enabled me to understand how much Ataxia UK does.

We would like to find the right person for the role soon so that they can join the Finance Sub-Committee and shadow me from January 2026 before joining the Board in October/November 2026.

We are looking for someone with an accountancy qualification, and it would be preferable for them to have worked in a reasonably senior finance position. Having a charity or not-for-profit background would be helpful but is not essential.

The Treasurer plays a vital part in ensuring the financial stability and integrity of the charity. They are also a Trustee and work closely with the Chief Executive and Chief Operating Officer to oversee all aspects of the financial management of the charity, providing strategic guidance and ensuring compliance with regulatory requirements.

Financial governance skills are therefore important. The Treasurer is not required to do any accounts preparation – this is all done by the in-house Finance team.

The right person for the role will have the ability to work as part of a team. They will also be able to communicate clearly and explain complex financial information in lay terms to other trustees.

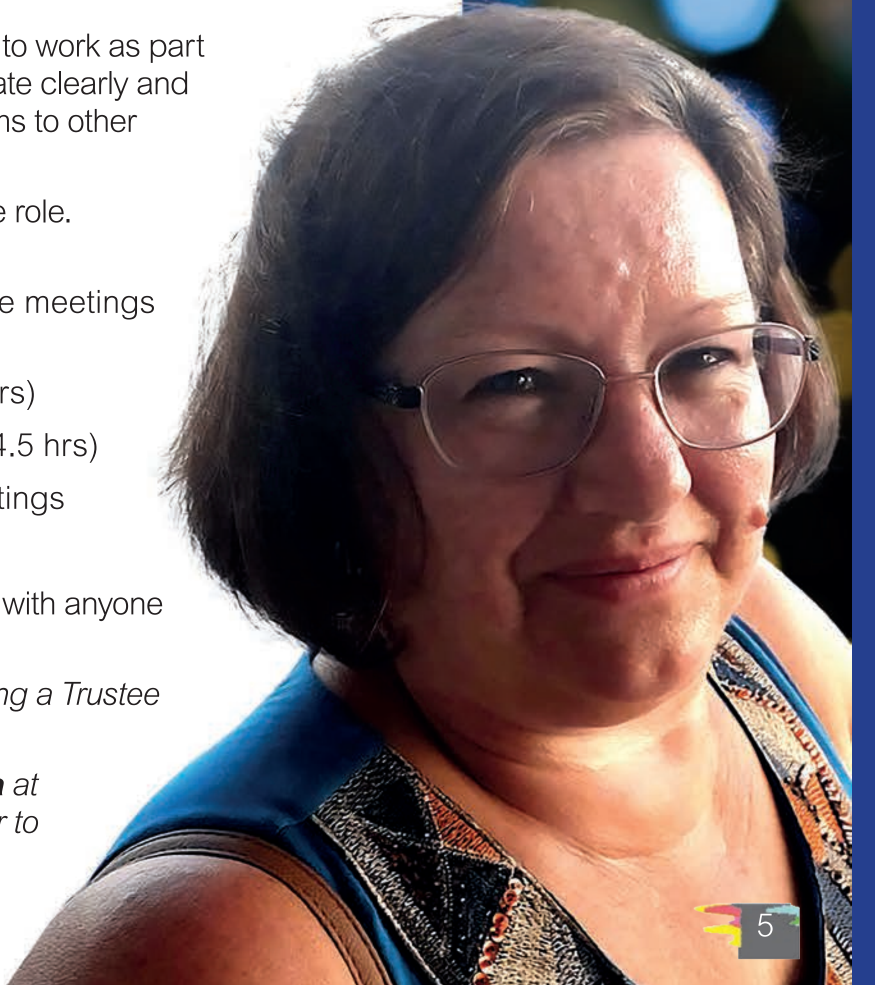
The Treasurer needs to have the time to fulfil the role. During a year, the requirements are:

- Chair monthly online Finance Subcommittee meetings (2 hrs each)
- One in-person budget-setting meeting (4 hrs)
- 4 online and 1 in-person Board meetings (4.5 hrs)
- Time to read the papers for the above meetings
- Ad hoc meetings with the Chair/CEO/COO

I would be very happy to have an informal chat with anyone interested.

Find out more about the Treasurer role and being a Trustee here: ***http://alturl.com/im3if***

If you are interested, please contact ***Anastasia*** *at* ***ageorgousis@ataxia.org.uk*** *by 30 September to express your interest.*



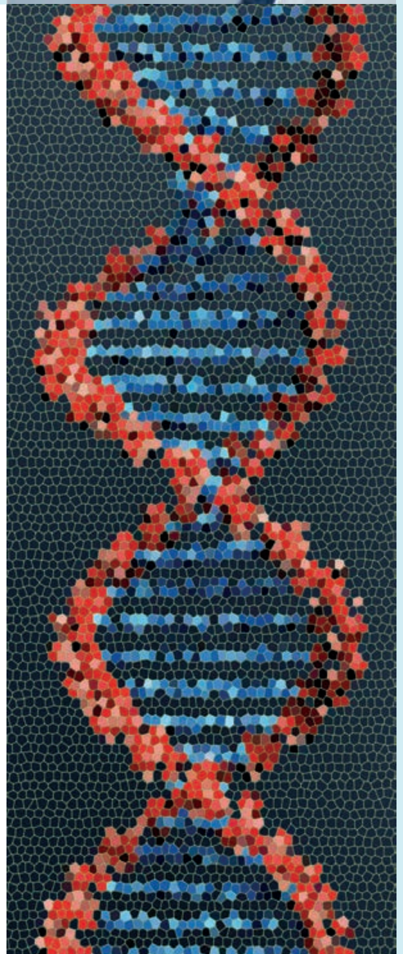
Ataxia UK funds a project using augmented reality in the rehabilitation of ataxias

Ataxia UK has recently awarded funding for a project led by Dr Boubker Zaaimi at Aston University, as well as researchers at Newcastle University, Birmingham University, and the Birmingham Community Healthcare NHS Trust.

Current rehabilitation methods, such as physiotherapy, can help improve balance, but they require regular access to specialists and clinics, which is not always possible for everyone. This research aims to improve balance and reduce falls in people with ataxia by using augmented reality (AR) to provide real-time visual feedback on movements. Taking part in this study will involve an initial assessment, followed by 8-12 weeks of AR-based balance training (twice weekly, for 20 minutes each), followed by a post-intervention assessment. By helping the brain learn to correct posture more effectively, this approach could enhance mobility and independence. The researchers hope to recruit 10-15 people with ataxias and 10-15 people without ataxia. If successful, it could lead to a widely accessible rehabilitation tool that improves quality of life for people with ataxia.

This study is due to start in November 2025, so if you would like to take part in the project when it starts, please email the researchers on ***b.zaaimi@aston.ac.uk*** *Read more here:* ***http://alturl.com/xruvi***

Gene therapy survey for people with genetic ataxias



You are invited to participate in an online research survey regarding gene therapy for genetic ataxias. The purpose of this survey is to collect opinions about gene therapy research from people diagnosed with a genetic ataxia from a number of countries.

Gene therapy is a potential treatment for genetic ataxias, and as such the views of people with the condition are invaluable in the design of future research and clinical trials. The results of this research will provide information to the ataxia research community about opinions on gene therapy, which will help when designing future treatment trials.

People diagnosed with a genetic ataxia, or their family members, are eligible to complete the survey. Minors are required to complete the survey with a parent or guardian. We expect the survey will take roughly 30 minutes to complete, and the data collected will be anonymous.

If you have any questions about this research, contact Ataxia UK's research department at ***research@ataxia.org.uk***

For more information, visit: ***www.ataxia.org.uk/gene-therapy-survey***

Thank you to those who signed our open letter calling for access to omaveloxolone

Thank you so much to those who have signed our open letter calling for access to omaveloxolone — the first treatment approved for use in people aged 16 and over with Friedreich's ataxia.

Thanks to you, more than 10,000 people have already joined this call. It's an incredible show of support — but we're not done yet. Now we need to make sure your MP hears this message loud and clear. Let's keep this momentum going. Together, we are fighting for fair, urgent access to treatment. Thank you for standing with us.

Sign the letter here: ***http://alturl.com/ki9kk***

Will you take the next step and contact your MP today? It only takes a minute. Send a letter to your local MP urging them to support access to omaveloxolone: ***https://members.parliament.uk/FindYourMP***

Update on access to omaveloxolone in Scotland

On 2nd June, the Scottish Medicines Consortium (SMC) accepted Biogen's new drug application for omaveloxolone (a treatment for Friedreich's ataxia). The SMC is the committee that evaluates the cost-effectiveness of medicines in Scotland.

Dependent upon the New Drug Committee - NDC (A committee within SMC) recommendation, Biogen will be given the opportunity to request a Patient and Clinician Engagement (PACE) meeting where patients/ caregivers and clinical experts are given a forum to express their views and experiences living with FA. These will then be considered in decision-making by the SMC (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).

As the SMC have now accepted the submission, clinicians may be able to make individual funding requests for patients to be prescribed omaveloxolone under the PACS-2 process. If you are living in Scotland and are interested, you could talk to your neurologist about this.

Generally, this whole process can take 18-22 weeks from the date that the NDC meeting is scheduled, although it can take longer. We understand the NDC meeting should take place in November.

We shared how the SMC evaluation process for medicines works in our previous webinar on the Health Technology Appraisal process for UK medicines here: ***https://tinyurl.com/55uc5cfu***

Ataxia UK co-funds a project on caring for people with progressive ataxias

Ataxia UK recently co-funded a project at Strathclyde University, led by Prof Anja Lowit and Prof Christopher Graham. Their project is focused on supporting those who care for people with progressive ataxias.

People with ataxia face many challenges every day, from medical to psychological. In turn, those caring for people with ataxia – many of whom are family carers – also face several challenges to their quality of life. So far, no research has been done to identify the challenges faced by family carers of people with ataxia and how these might vary depending on the type of ataxia, stage of their life, or other possible influencing factors.

The project aims to co-develop a support package for carers of those with progressive ataxias by working together with family carers and people with ataxia. The support package will be distributed to the community via Ataxia UK.

The project will consist of four key phases. First, the project will review the current research on family and carer experiences and challenges in other neurological conditions. Then, a panel will meet consisting of family carers, people with ataxia, Ataxia UK representatives, and healthcare professionals. This panel will explore the key issues faced by those caring for someone with ataxia. After this, the researchers will conduct a survey, follow-up focus groups and interviews (20-30 people) to understand how the issues identified by the panel affect people with ataxia and their carers. This will then inform the development of a carer support package, which will be piloted in those who took part in the interviews, and eventually, if beneficial, it will be distributed through Ataxia UK.

This project is due to begin on October 1, 2025. Opportunities to take part in this project through surveys and interviews will be advertised in our newsletter and magazine.

If you are interested in taking part in this project once it starts, email our research team at ***sparr-reid@ataxia.org.uk*** *with your name and whether you are a carer or someone living with ataxia, to be added to the waiting list to be involved in a panel of patients and carers when recruitment to the study begins. Read more here:* ***http://alturl.com/qfay7***

NfL may be a potential biomarker in Friedreich's ataxia

New research that stemmed from a collaboration between the London Ataxia Centre and the Children's Hospital of Philadelphia has identified the rise of a protein called NfL, as a potential early biomarker of Friedreich's ataxia (FA). The study was funded by the US organization Friedreich's Ataxia Research Alliance (FARA) and the National Institute for Health and Care Research UCLH Biomedical Research Centre at University College London Hospitals.

Biomarkers are very relevant for clinical trials. A biomarker is a measurable characteristic that reflects the clinical condition. When drugs are tested in clinical trials, we need reliable biomarkers as a measure of whether the drug is effective or not. Biomarkers are also used as a measure of progression in conditions like FA.

NfL, or Neurofilament Light Chain, is a protein that is released into the cerebrospinal fluid (CSF), which is the fluid surrounding the nervous system, connecting it to the blood. To assess whether NfL could be a useful biomarker for FA, the researchers measured NfL levels in blood (plasma) from 187 people with FA and 127 people without a neurological condition (controls). People with FA were recruited from two natural history studies where the progression of FA has been studied (EFACTS in Europe and FACOMS in the US).

The researchers found increased levels of NfL in the plasma of people with FA compared to people who do not have FA. They conclude that NfL is a sensitive biomarker in younger people with FA. However, they saw that the difference in NfL levels decreased with age of 40. This means that whilst NfL could be used as a marker of FA progression, or in clinical trials, this age-dependent pattern would have to be carefully considered. A greater understanding of how NfL levels are increased in FA is required, and NfL would likely need to be used as a biomarker in combination with other measures of FA progression.

Prof Paola Giunti, **Consultant Neurologist** at the London Ataxia Centre at the National Hospital for Neurology and Neurosurgery (above), and UCL Queen Square Institute of Neurology, who was involved in the research, reflects,

"We are really excited about the results of this research project, which indicates that NfL could be a useful measure for clinical trials in Friedreich's ataxia, measuring the effectiveness of the drug. We are in debt to all our patients who were willing to participate in this research exercise, and we highly value their contribution."

A paper was recently published on this research in the Movement Disorder Journal, which you can read here: ***http://alturl.com/zknts***

Biogen begins global phase 3 trial of omaveloxolone in children with FA aged 2-15, with UK sites opening soon

This BRAVE trial will study the effects and long-term safety of the drug in this population.

The London Ataxia Centre, Sheffield Ataxia Centre and Oxford Ataxia Centre are UK sites for this trial, and will begin recruiting participants soon. We will provide further information on our website as soon as the UK trial sites open recruitment.

Individuals interested in taking part should speak to their healthcare provider.
Read more on ***ClinicalTrials.gov***

From lab to people: Removing barriers to treatment

Last Winter, thanks to your support and the hard work of the community, you were able to raise over £57,500 for our 2024 Big Give Christmas Challenge.

One way in which your generosity throughout the campaign has impacted our work is through allowing us to continue building relationships with pharmaceutical companies and setting the stage for the next ataxia drugs to come through the system.

Whether you're new to the Big Give or just need a little reminder, here's how the Christmas Challenge works: Every year a small number of supporters pledge to give us a donation; the total of 'Pledgers' is then matched by our Big Give Champion sponsor. The combined total of the Pledgers & Champion funding will then create our Campaign Pot. Throughout the Big Give Campaign week, all donations made by you and our supporters online, through the Big Give website, will be matched using the Campaign Pot. Offline donations, either over the phone or via cheque, are not considered for matching. Though any donations will still help support those affected by ataxia, to double your support, we recommend donating directly through the Big Give official webpage when it goes live.

We can now proudly introduce the Big Give 2025 Christmas Challenge: From Lab to People: Removing Barriers to Treatment – Which will run from 2-9 December 2025.

Over the last year we have watched with elated eyes as the prospective drug pipeline (the pipeline being the number of drugs and treatments we know of that are currently making their way through research trials and testing) has become increasingly populated. However, the process for drug approval for use on the NHS is not making available the licensed treatments to ataxia patients. While we all celebrated the announcement that the MHRA approved Omav for use in the UK, unfortunately, the process for evaluation of cost effectiveness by NICE (and thus access on the NHS) has stalled. You can read more on our website Omav page.

Omav isn't our sole focus; only it exemplifies the systemic issues with the drug approval process with regards to rare and ultra-rare conditions. There are more treatments in the pipeline that will one day have to navigate the difficulties of drug approval and reimbursement in the UK.

Friends of Ataxia UK have waited for 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 need to expand our engagement with crucial policy stakeholders through a range of activities, events, and policy responses whilst similarly increasing our work to support patients with any of the ataxias across the UK.** We want to continue to empower the ataxia community to raise awareness of these conditions whilst growing our role as champions for the ataxias amongst decision-makers.

One example of how we have recently used our platform as a vital and trusted platform for advocacy for the community happened in July when our CEO, Sue Millman, attended an All-Party Parliamentary Group on Genetic and Rare Conditions to highlight the issues with the drug approval process and advocate for change to those who can make a difference. We want to continue growing our work in this advocacy space and your support for this year's Big Give Challenge can help us do just this!

People with rare conditions in the UK must not be kept waiting unnecessarily for treatments which are available in other countries, whilst their condition deteriorates.

It would be amazing to smash last year's target and raise over £60,000 for this project. Let's set our ambitions high, but only you can help us get there!

So now that you're armed with the dates and details, to support all of those affected by ataxia, **we need you** to get ready to share the Big Give links on your social media, speak with friends and family about why we need their generosity, save up that loose change and fundraised income, and support the ataxia community this Christmas.

You can preview and bookmark the official Ataxia UK Big Give webpage here: ***http://alturl.com/tqn8m***

Get ready for International Ataxia Awareness Day 2025!

This September 25th is IAAD 2025, and Ataxia UK is inviting you to join us in a day of awareness raising and action!

For 60 years, Ataxia UK has been working with and for the ataxia community. This is your day. This is a day to come together. This year, our themes are designed to raise awareness of the ataxias; to shine a spotlight on the amazing stories from across our community; and to congratulate the winners, the riders, the runners, the divers and everyone who keeps going, and keeps us going.

Our IAAD 2025 themes are:

CREATE

EDUCATE

CELEBRATE

And we need YOU to help us!

Planning a fundraiser or other event for IAAD 2025? We want to hear from you!

Got a funny joke, whacky cartoon or beautiful artwork? Send it over!

Running an assembly or writing a blog about your experience of the ataxias? Let us know!

You can contact us and send us your ideas and your content here: ***communications@ataxia.org.uk***

At Ataxia UK we've been with you ***every day*** *for 60 years. This International Ataxia Awareness Day is YOUR day. Get in touch with us to help us tell your story.*

#IAAD25

IAAD2025

CREATE

We want you to send us your **creations**. It could be a work of art, a poem, an amazing recipe…really anything that we could publish online and share across social media

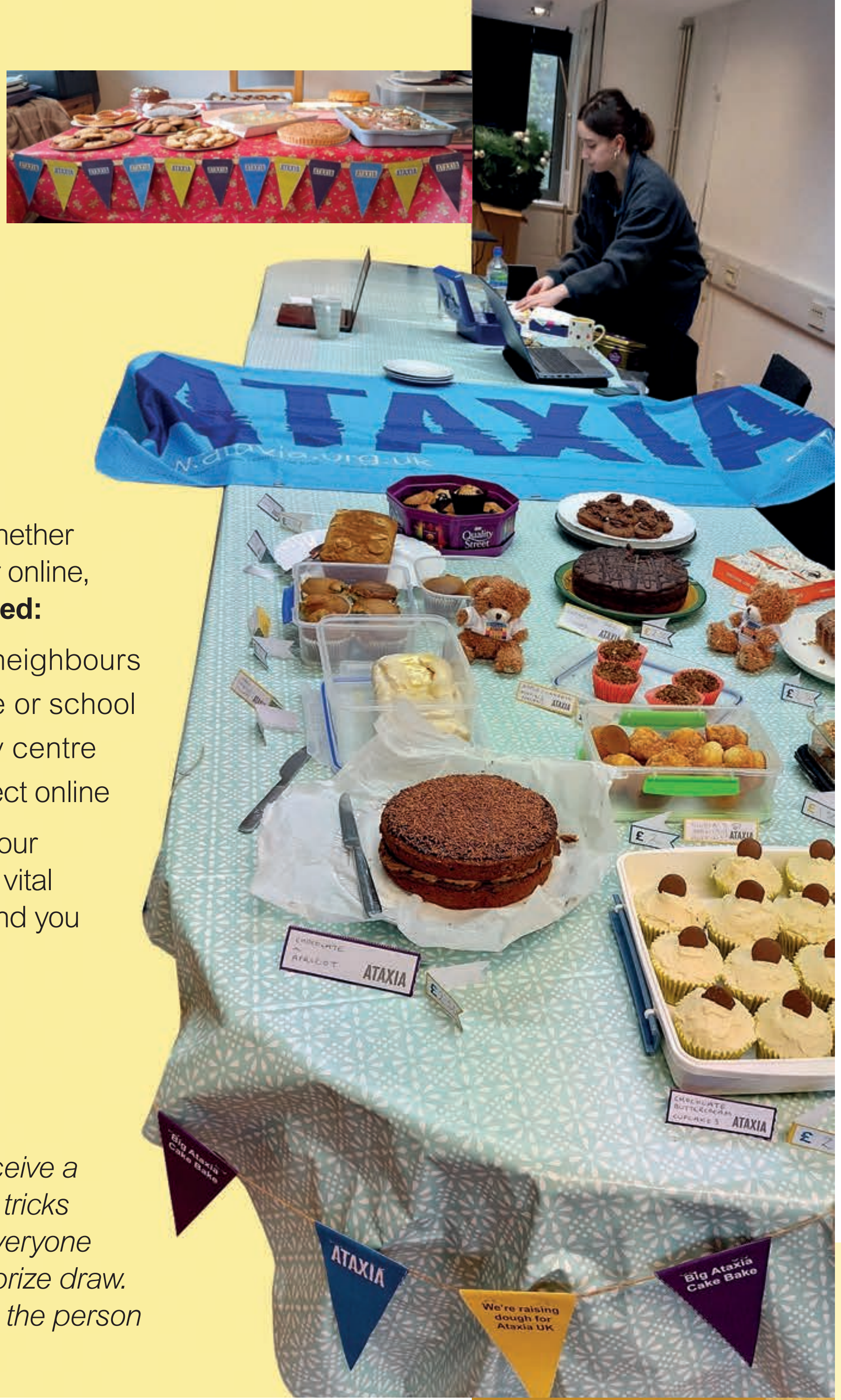
EDUCATE

We need you to help us **educate** the public and practitioners by sharing information packs and medical guidelines and by helping us to tell your stories of living or caring for people with the ataxias

CELEBRATE

And we want to **celebrate** all this community does to support the work of Ataxia UK and the inspiring stories of courage, resilience and strength that you live every day

Big Ataxia UK Cake Bake returns



1 November – 31December 2025

Join supporters across the UK for the **Big Ataxia UK Cake Bake**, raising funds and awareness for people affected by ataxia. Whether you're hosting at home, at work, at school or online, everyone can take part. **Ways to get involved:**

- Hold a bake sale with friends, family or neighbours
- Organise a cake bake at your workplace or school
- Run a stall at a local event or community centre
- Take part in a virtual cake bake and connect online

Prizes for top fundraisers, plus entry into our festive prize draw! Every bake helps to fund vital research and support. When you sign up, and you take part, you'll be making a real difference.

Ready to Get Started? Register here: ***http://alturl.com/fjy5h***

*For more information, contact us at **fundraising@ataxia.org.uk** or call us on **0207 091 1594**. When you register, you'll receive a glorious Cake Bake pack filled with tips and tricks for a successful flour-powered fundraiser. Everyone who raises over £150 will be entered into a prize draw. Additionally, a **GRAND** mystery prize awaits the person or team who raises the most funds!*

Ataxia UK christmas cards!

Support Ataxia UK this festive season by choosing from our delightful range of Christmas cards. Each purchase helps us continue our important work.

HANDMADE CARDS BY GEMMA SHEEN

We are thrilled to partner once again with Gemma Sheen, who crafts wonderfully festive, bespoke, handmade cards. Each card is an original piece of Christmas cheer, perfect for spreading joy to your loved ones. She also offers bespoke cards for all occasions throughout the year! Remember, 100% of all sales will be donated to Ataxia UK (excluding P&P).

*Explore Gemma's designs at **http://alturl.com/njaiw** For more information, visit our website or contact us at **fundraising@ataxia.org.uk** or call **0207 091 1594**. Thank you for making a difference this Christmas!*

Sky dive for Ataxia UK

Looking for your next big challenge? Why not jump out of a plane for a cause that truly matters?

On **Saturday 28 February 2026**, Ataxia UK is hosting its nationwide Sky Dive Action Day. Participants will experience the thrill of tandem skydiving while raising vital funds to support people living with ataxia.

Whether you're a thrill-seeker, marking a milestone, or planning a team-building day with a difference, this is a chance to do something unforgettable. With **drop zones across the UK**, you can take part from wherever you are or even select a different date that suits you better. Your jump will help fund essential services, research, and support for families across the UK.

Teams of friends, families, and **corporate groups** are especially welcome. It's a brilliant way to bond outside the office and make a lasting impact.

Event Details:

Date: Saturday 28 February 2026 (or a date of your choosing)
Locations: Drop zones nationwide. *Email: **fundraising@ataxia.org.uk***

Take the leap. Raise awareness. Help us soar towards a cure.

Other Christmas activities to look out for this year:

SANTA IN THE CITY 2025

Sign up and pledge to raise funds for Ataxia UK and we will reimburse your entry fee cost and send you a fundraising pack including your very own Ataxia UK t-shirt!

*Read more here: **http://alturl.com/3qza2***
*or contact us at **fundraising@ataxia.org.uk***

CHRISTMAS JUMPER DAY

Get dressed up in your finest silly sweater and join in with Christmas Jumper Day! Pick your own date & location and get stuck into the festive fun!

*Read more here: **http://alturl.com/sxpky***
*or contact us at **fundraising@ataxia.org.uk***

ORGANISE A CHRISTMAS PUB QUIZ!

Grab your friends, family, colleagues and sports team & head to your lovely local for a Christmas Pub Quiz in support of Ataxia UK!

*Read more here: **http://alturl.com/xgh4z***
*or contact us at **fundraising@ataxia.org.uk***

Wheelchair Across the Alps / Alps 4 Ataxia: A world first in manual wheelchairs

Ben Spencer and Peter Smorthit have made history, becoming the first people to cross the Alps in manual wheelchairs. Over the course of 18 days, they covered 420km, pushing through some of Europe's most challenging terrain. The dynamic duo were supported from start to finish by fellow Ataxian Phil Bosworth, who also raised £1000s in corporate sponsorship to support their journey.

The route took them from Montreux in Switzerland, ending in Lake Como, Italy, across steep climbs, long descents, and remote mountain passes. It was a test of both physical and mental endurance, which was made tougher by unpredictable weather, with soaring temperatures near 40c and dealing with the effects of Ataixa driven fatigue. Yet, each push of the wheel was driven by a clear purpose: to raise awareness and funds for people affected by ataxia.

Another fellow Ataxian, Emily Fishwick and her partner, came out to drive the support car for the first week of the challenge. Ben said "We wanted to involve as many ataxians as posible and we also had a team of Ataxians in the UK helping with content and sharing the challenge on social media".

Alps 4 Ataxia is more than a fundraising challenge. It's a powerful demonstration of what's possible with planning, perseverance, and the right support. For many, this journey has shed light on a condition that often goes unnoticed and offered hope to those who live with its impact every day.

"We wanted to show people that you can do anything regardless of disability," said Ben. "We trained full time for a year, It was difficult, but that was the point."

To date, the challenge has raised more than £16,500 with more to come for Ataxia UK, helping to fund research, provide support, and increase public understanding. **Thank you, Ben and Peter, Phil, Emily and Claudia, for continuously showing us that disability does not mean inability.**

If you fancy taking on a challenge, let us know. It doesn't have to be moving mountains to make a difference.

Celebrating Andy Grant's birthday!!!

A massive Thank-You to Andy Grant, who completed a Skydive, a 60km Cycle, 40km Row, 21km run, and finally a 2 km Swim across the month of May – 5 in 5.

Andy (on the right in the picture) has raised a whopping £21,719.12 in honour of his 60th th birthday. What a way to start a new decade! We wish you the best in all your endeavours, and thank you for all your determination and grit and for raising awareness and visibility for Ataxia UK. We are so honoured to have you part of our community.

Fundraising thank-yous

Thank you, **Mark Ward** (right) for raising a staggering £1,900 by completing the Olympic Triathlon challenge.

Thank you to **Yolande Joubert**, **Ataxia UK CFO** for completing her first half for Ataxia UK.

Thank you to **McKesson Global** and **ClarusONE** for choosing Ataxia UK as their charity partner – and for raising an outstanding £30,000!

A Mega Thank You to all our courageous runners who completed the TCS London Marathon this year: **Mark Burden** - £4877; Micheal Ball - **£7711.45**; Saminah Fazil - £**4259.74**; Stuart Croft - **£5212.65**; Bradley Minns - **£4950.84**; Christian Keogh - **£2900.25** and Graham Fryatt **£2181.25** (all inc. GA)!

Thank you, **Susan Fuller** (right) for raising an incredible £787 at the Hull 10k.

A flying tribute to all our heroes who dared to jump out of a plane for the Ataxia UK Sky Dive Action Day to raise funds to support the ataxia community: A team led by **Dan Pettit** with **Alex Roberts**, **Vicky Roberts**, **Laura Stanton**, and **Tom Harris** raised a heavenly £6,515 and **Jade Andrews**, **Paul Burgess**, **Rebecca Bingham**, **Craig Elliot**, **Helena Murphy**, and **Liam Murphy** together raised an amazing £6,126. Making the total for the Sky Dive Action Day a whopping £12,641!

Thank you, **Hannah Smith**, for completing the Paris Half Marathon raising an amazing £1,153!

Massive round of applause to **DJ Pavan** & **Applegarth Primary School** for your combined donation of £470.

Elizabeth Gregory & **Bella Fishwick** completed the Hampton Court Palace Half Marathon, raising an awesome £418 & £1030 respectively! Thank you both.

Thank you, **Elaine Adams**, for organising an amazing donation of £520 from **Reddam House School**

Thanks, **Lydia Howell**, for completing the 18.5-mile Vale Coastal Races, raising a breezy £387!

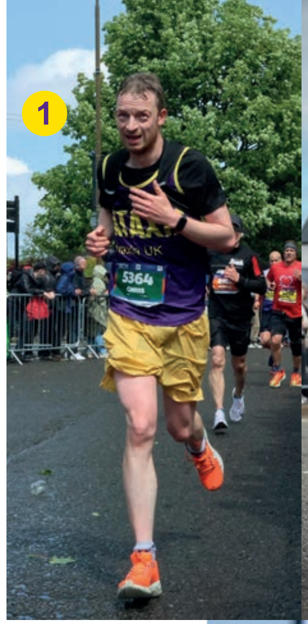
A huge well done to **Stephen Sturt**, **Hannah Smith** & **Joanna Ward** for completing the Brighton Marathon, raising an amazing £438, £1,969 & £1,955 respectively!

Chelsea Higgott, thank you so much for organising your Pub Quiz raising a lovely £559!

Thank you, **Amy Jones**, for walking the West Highland Way and raising an incredible £1,711.

A huge congratulations to **Kulraj Bains** for completing the epic Paris Marathon and raising a staggering £1,572!

Fundraising thank-yous



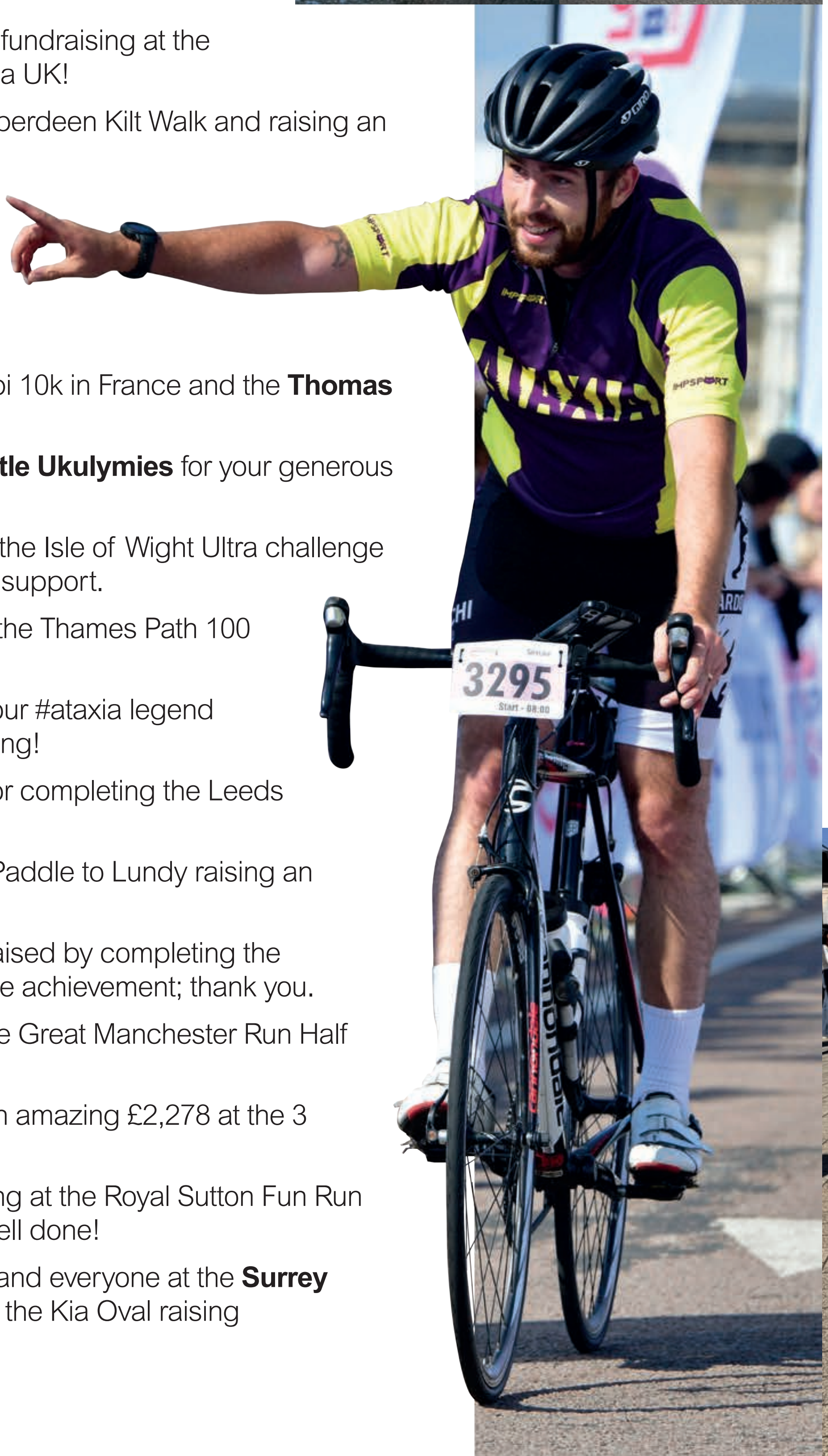
Chris Littleboy (1), you are simply amazing for completing the Edinburgh Marathon, raising an incredible £2,576. Thank you!

Massive thanks to **Maegan Barker** & **Callum Aktar (2)** for completing the Manchester Marathon raising £1,583 & £2,332 respectively.

Thank you, **Gillian Welch**, for raising an awesome £60 from your fundraising event.

Thank you, **Zoe Heaney** for your amazing fundraising at the Glasgow Kilt Walk, raising £1,017 for Ataxia UK!

Thanks, **Erica Wood** for completing the Aberdeen Kilt Walk and raising an amazing £1,065!



Thank you, **Sarah Campbell** & **Rob Dowie** (right) for your amazing achievement of completing the London to Brighton Cycle raising an amazing £1,521 & £1137 respectively.

Thanks to **Sam Sba** for completing the Albi 10k in France and the **Thomas Pesquet Cake Sale** raising £185.

A huge thanks to everyone at the **Newcastle Ukulymies** for your generous donation of £250.

Thank you, **Tina Southby**, for completing the Isle of Wight Ultra challenge and raising £291, thanks **Paul** also for the support.

Well done, **Russell Crane** for completing the Thames Path 100 Mile Ultra, raising an amazing £948.

Thanks to **State Street Bank** for support our #ataxia legend **Scott Forsyth** with £1,503.45 match funding!

A massive well done to **Sheleen Lawler** for completing the Leeds Marathon and raising over £1,404!

Elliot Wood, thank you for your amazing Paddle to Lundy raising an awesome £584.

Michael Barker your staggering £4,405 raised by completing the Edinburgh Marathon is simply an awesome achievement; thank you.

Daniel Grant, thank you for completing the Great Manchester Run Half Marathon, raising an awesome £358!

Thanks, **Lawrence Glennon**, for raising an amazing £2,278 at the 3 Castles Race – well done!

Susan Deane, your magnificent fundraising at the Royal Sutton Fun Run was a great achievement, raising £266. Well done!

A huge thanks **Sarah** & **David Campbell** and everyone at the **Surrey Cricket Club** for hosting the Ataxia Day at the Kia Oval raising an awesome £1,496.95!

A massive thanks to **Ellie** & **Susan Thompson** for organising the Easter Raffle, raising an amazing £240.

A flying congratulations to **Carys Evans (3)** & **Kev Clark** (right) **Lucy Riley (4)** & **James Riley (5)** raising £4,281, £796, £1,703 & £930 respectively!

A huge well done to **Westley Spencley** for organising your Football Tournament raising an amazing £596.

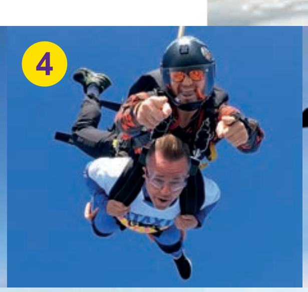
Yvette Loach, thank you for your high-flying wing walk, in the clouds, raising a whopping £3,903!

Thank you, **Katie Mitchell** for your Obstacle Course 10K achievement raising £1,726!

Kieran Campion, thanks so much for your amazing fundraising of £1591 at the Peak District Ultra!

Thank you to our amazing fundraisers for your most recent collections: **Joan Williams** (£105.60); **Rosie Morgan** (£216.89) & **Julie Ryder** (£33)

A huge Thank You to all our finishers for the London Landmarks Half Marathon **(6)** this year: **Phillipa Craig** - £1673.75; **Lucy West** - £788.25; **Victoria Dobson** - £955; **Ian Fearnley** - £356.25; **Constance Smith** - £1763.14; **Sophie Devizio** - £1586.25; **Lucie Sarcone** - £1341.25; **Russell Golf** - £1757.81; Grace Wise - **£1100**; Rob Hurst - **£2236.25**; Poppy West - **£923.75**; Lisa Culleton - **£1321.25** (all inc. GA)!



Thank you, **Daniel**, **Thomas**, **Sirley** & **Leo Fraser (7)** for completing the Glasgow Kilt Walk and raising an awesome £658!

All about autoimmune and gluten ataxia

“Fatigue, Tiredness & Diet”

Hi, I’m Carol, and I run the “Autoimmune and Gluten Ataxia” support group for Ataxia UK. I was diagnosed with ‘possibly ataxia’ and, following research, tried a gluten-free diet to see what the effect was on my ataxia symptoms.

I find the fatigue I experience is hard to explain. I must plan my day carefully, pacing myself.

Even talking to my friends, being in a busy place or unfamiliar surroundings, and making phone calls, in fact, anything that is a little stressful, exacerbates my symptoms.

Those who do not have ataxia may take these seemingly trivial tasks for granted.

We all know how important it is to keep up exercise. ‘Use it or lose it,’ ‘pace or bust,’ and ‘little and often’ are all familiar to us.

Personally, ‘little and often’ suits me best but we are all different with individual needs.

What is perhaps not so familiar is the term ‘Blood Sugar Balance’. If you have diabetes type II, you may be familiar with this. This term could be misinterpreted; sugar or sugary foods are the last thing I find I want to eat to increase or improve my energy level.

When my energy level dips, sometimes a quiet sit down helps me, but other times a hot drink with a gluten-free, low sugar oaty based biscuit (low Glycaemic Index—GI) helps to keep me going.

This is an example of a low GI snack, though some people with gluten ataxia also avoid gluten-free oats.

I choose low GI carbohydrate foods which release energy gradually into the bloodstream and keep my blood sugar levels more balanced. This helps to avoid the ‘high peaks’ and ‘low dips’ of energy.

Glycaemic Index (GI)

Find a private dietitian near you:

Search by Postcode, City or Country

Carbohydrates (carbs) are digested at different rates and this has an effect on your blood glucose (blood sugar) levels. The Glycaemic Index (GI) is a ranking from 1-100 and relates to how quickly these foods make your blood glucose levels rise after eating them.

What is GI?

The amount of carbohydrate in the reference and test food must be the same.

Each time you eat or drink something sugary or starchy, the blood glucose level in your body rises. Some of these are quickly digested and cause quick and sharp rises in your blood glucose levels - they are called high GI foods and drinks. Low GI foods and drinks are more slowly digested and will make your blood glucose rise more slowly. These are sometimes called ‘slow release’ carbs.

Starchy and sugary food and drinks contain carbohydrates:

Starchy foods such as bread, pasta, chapattis, potatoes, yam, noodles, rice and cerea

- Starchy foods such as bread, pasta, chapattis, potatoes, yam, noodles, rice and cerea
- Fruit and fruit juice.
- Some dairy products such as milk and yogurts.
- Sugar and other sweet foods.
- Non-diet soft drinks

Further information

Food Fact sheets on other topics including healthy eating, sugar and carbohydrates are available at www.bda.uk.com/foodfacts

This Food Factsheet is a public service of The British Dietetic Association (BDA) intended for information only. It is not a substitute for proper medical diagnosis or dietary advice given by a dietitian. If you need to see a dietitian, visit your GP for a referral or find a private dietitian. To check your dietitian is registered check www.hcpc-uk.org

*(Those who are gluten sensitive must remember to make gluten-free low GI choices; this BDA fact sheet: **http://alturl.com/g5n34** is a generic diet sheet for all).*

Sweet foods and low–fibre carbohydrate choices such as gluten-free white bread/white pasta/sugary cereal and white rice have a higher GI, so I eat these less often. Including them in moderation as part of a balanced meal with plenty of vegetables and a healthy protein will help to reduce the glycaemic index. Eating a balanced diet, having regular meals, a good fluid intake, and making low glycaemic index choices for the carbohydrate part of the diet may help to stave off cravings.

This, of course, is not the whole picture because ‘my ataxia’ impacts on my energy levels, but the above may go some way in helping to sustain energy levels, avoiding those ‘highs’ and ‘lows’. **Remember, life is for living. I adopt an 80/20 principle, which allows for treats and social occasions.**

*Thank you, Carol, and thanks also to **Gillian Goddard, Dietitian at the Sheffield Ataxia Centre** for her support with this article.*

The Ataxia UK helpline is open Monday to Thursday, 10 am to 2.30 pm.

*on **0800 995 6037***

*or by email: **help@ataxia.org.uk***

The gift of speech: Restoring voices and rebuilding confidence

For many people with ataxia, speech changes are one of the most difficult parts of the condition. They can make everyday conversations harder, and that can knock confidence, increase isolation, and make people feel like they're losing part of who they are.

That's why Ataxia UK created the **Gift of Speech** project. Thanks to the generosity of supporters during our Big Give campaign in 2022, we've been able to run two services: a specialist online speech therapy course and funding for personalised synthetic voices through our partnership with SpeakUnique.

With the current funding coming to an end, we want to share how these services are helping people and encourage anyone in the community who could benefit to get involved.

Speech Therapy

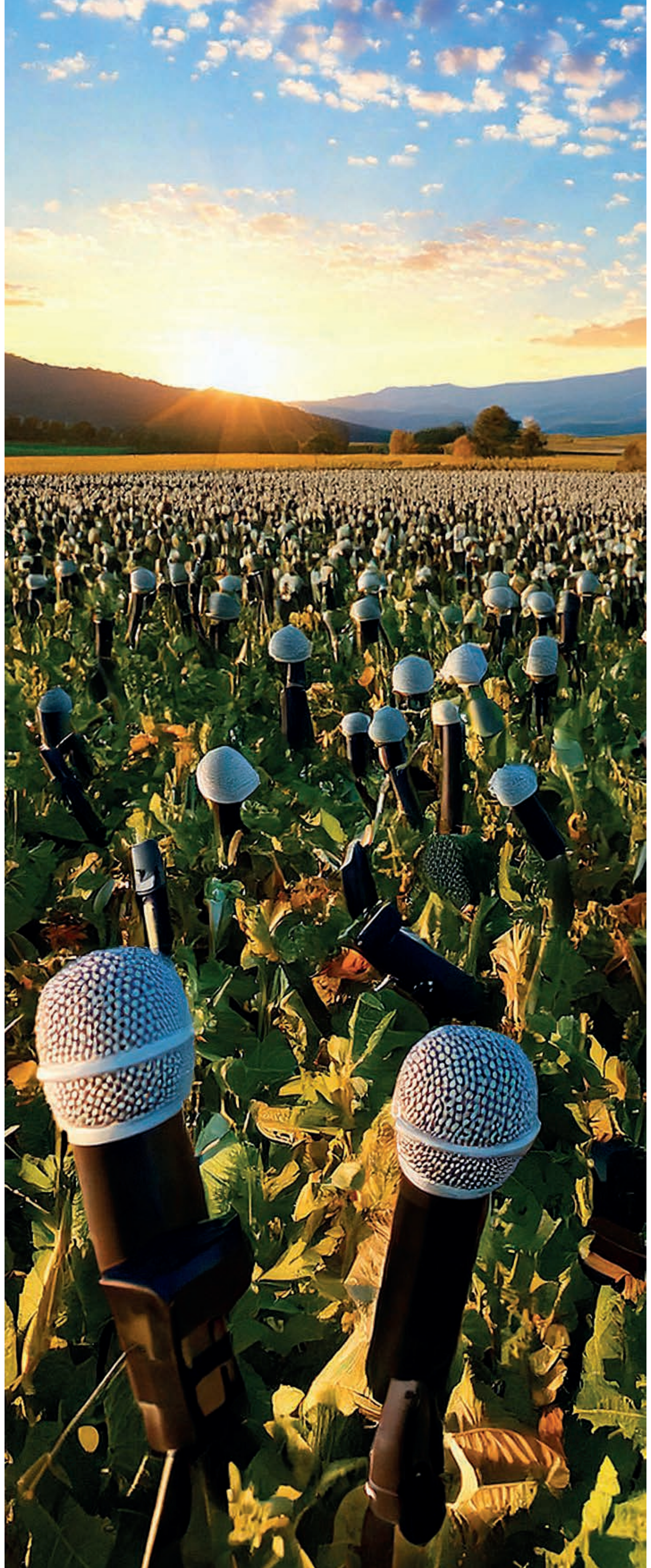
Ataxia can affect the coordination of the muscles used to speak. People often say they feel frustrated, lose confidence, or avoid conversations altogether.

In response, we worked with **Professor Anja Lowit** from the **University of Strathclyde** to develop a six-week online course specifically for people with ataxia. The programme combines one-to-one sessions with group practice, helping people develop simple techniques—like speaking louder and more clearly—and building confidence through regular use.

The group sessions have proved just as valuable as the speech work itself, as participants often connect with others facing similar challenges. Jenny, who joined one of the groups, said:

"Not only have you helped me with my speech, but the experience as a whole made such a difference. We developed our own little support group and shared things no one else would understand. Without Ataxia UK, I don't know what I would have done."

*Due to its success, we now have a waiting list for the course—but places are still available. If you or someone you know might benefit, don't hesitate to get in touch. Email **volunteering@ataxia.org.uk** to begin the process.*



Voice banking: Preserving 'you'

We also offer funding for voice banking through SpeakUnique. This service allows people to create a personalised synthetic voice that can be used on a communication device if their speech becomes harder to understand.

Depending on your needs, there are three options:

- **Voice Build** – for people whose speech is unaffected now but may change in the future.
- **Voice Repair** – for those already noticing changes like slurring or breathiness.
- **Voice Design** – for people who can no longer speak clearly, using voice donors or old recordings to create a new voice that feels like your own.

The process is flexible and can be done at your own pace. Laura, who used the Voice Design service, told us:

"It has been a life-changing experience not being able to speak as I developed what is thought to be SCA 27B—rare, like me! I'll be able to talk again and argue with David, which I'd given up on because it was just too much effort."

We usually ask that a speech therapist approves your funding application, but don't let that stop you from getting started – you can still bank your voice. When the time comes, if you don't have a therapist to support your application, contact our Helpline and we'll guide you through it.

The Future of the Gift

We're delighted to say that new fundraising has allowed the Gift of Speech to continue for the next two years. We're especially grateful to McKesson Medical Supplies and their employees, who chose Ataxia UK as their charity of the year and helped raise a significant amount to support this work.

Thanks also go to everyone who donated during our Spring Appeals—and to **Ian** and **Esther**, who shared their experiences and helped bring the campaign to life.

How to Get Involved

If you're living with ataxia and your speech is changing—or you want to prepare for the future—there's support available.

- *To ask about the speech therapy course, email: **volunteering@ataxia.org.uk***
- *To explore voice banking, visit: **www.speakunique.co.uk***
- *Or call our Helpline for more information: **0800 995 6037** or email **help@ataxia.org.uk***

We know how much speech matters. Whether it's having a chat with family, taking part in meetings, or just feeling more like yourself, being able to communicate makes a big difference.

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