

# ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 234. Summer 2026



## No one should walk alone

Olivia's story of care, strength and love



Olivia's story • Services • Individual giving  
• Virtual Conference • Lexeo • Research  
• Trustees • Fundraising

**ATAXIA**

Ataxia UK

# In the office



## Kevin Broadbent

Hi everyone, I recently started at Ataxia UK as the Senior Bookkeeper. This role is an interim role whilst Ataxia UK looks forward to the future. Part of this plan is to re-structure the Finance Team and, I am told, there will be a version of this role in those plans.

My current role is to keep the Charity's day-to-day finance function moving, whilst at the same time, managing the changes that are planned. This includes a new management accounting process with new reporting tools.

My background is working in charity and public sector finance, so I have seen many ways of doing things, both good and bad. Hopefully I can bring some of the good things I have learnt to my role.

## CEO's introduction

**I'm writing this following our trip to Basingstoke where eight Ataxia UK staff spent an enjoyable day at our Roadshow. Over 100 members and supporters joined us; some of them knowing what to expect, others bringing with them some concerns at coming to their first face-to-face event. Judging by the feedback on the day and subsequently, a stimulating and interesting day was had by all. We are looking forward to meeting more people in the next few weeks as we visit Glasgow and Liverpool, followed by Belfast next spring.**

The time since the start of the year has been marked by a surge of activity in the rare disease and neurological sectors around access to rare disease medicines. I have been to various online meetings, several conferences and Parliamentary receptions where it has been a topic of discussion and some signs of an impending shift have been indicated, but we must keep up the pressure. Meanwhile I have been invited to represent Ataxia UK on a Steering Group which has been invited by the Government to contribute its perspective to the next iteration of the UK Rare Diseases Framework.

This gives cause for hope that there will be a continued focus on rare diseases in all four nations.

Finally, I want to pay tribute to the work of the Ataxia UK Trustees who steer the charity wisely through calm and turbulent periods, always keeping the interests of people affected by ataxia at the centre of their decision making. If you have the skills and experience to be a Trustee, please turn to p18 to get in touch.



Best wishes, Sue Millman

## KEY CONTACTS

- **Sue Millman**  
- Chief Executive  
[smillman@ataxia.org.uk](mailto:smillman@ataxia.org.uk)

### Services

- **Wendy O'Mant**  
- Director of Services  
[womant@ataxia.org.uk](mailto:womant@ataxia.org.uk)

Contact our helpline:  
[help@ataxia.org.uk](mailto:help@ataxia.org.uk)  
0800 995 603

- **Dr Julie Greenfield**  
- Director of Research  
[research@ataxia.org.uk](mailto:research@ataxia.org.uk)

### Fundraising & Communications

- **John Graham**  
- Director of Fundraising and Communications  
[jgraham@ataxia.org.uk](mailto:jgraham@ataxia.org.uk)

- **Hanif Abdulmuhit**  
- Events and Community Fundraising Manager  
[fundraising@ataxia.org.uk](mailto:fundraising@ataxia.org.uk)

- **Communications**  
[communications@ataxia.org.uk](mailto:communications@ataxia.org.uk)  
*For queries or feedback please contact the Communications team*

### Contact our office

[office@ataxia.org.uk](mailto:office@ataxia.org.uk)  
020 7582 1444

Ataxia UK, 12 Broadbent Close  
London N6 5JW

[www.ataxia.org.uk](http://www.ataxia.org.uk)

## Olivia's story



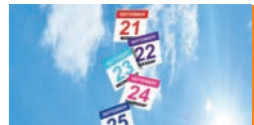
- Olivia's IVF journey: taking control in the face of ataxia 4

## Services



- Volunteers' Week / Carers Week 2026
- Thinking Ahead / Planning for the Future 6

## Individual giving



- Death in service 10

## Virtual Conference



- Virtual Conference Week 11

## Lexeo



- Getting to the heart of the matter 12

## Research



- Developing audio messages
- Speech recognition tool for people with ataxias 14

## Trustees



- Katy Rudkin
- Trustee of Ataxia UK 18

## Fundraising



- Fundraising thank-yous
- Meet Chelsea Higgott 20

## Olivia's IVF journey: taking control in the face of ataxia

**Olivia Dawson has been with her husband, Tyrell, for four years, and the couple married in May 2025. Like many at this point in their lives, they were also thinking about starting a family. But alongside the usual hopes and plans for parenthood, an added and unexpected factor was shaping their future.**

*"Dad started showing symptoms six or seven years ago. We thought maybe he'd had a stroke, but we just didn't know. Luckily, we had a GP who knew of ataxia, so we got a relatively quick diagnosis,"* Olivia explains.

SCA6 (Spinocerebellar ataxia type 6) is a rare genetic condition. It affects balance, speech, and coordination, and usually appears later in life. For Olivia and her family, this diagnosis didn't just explain her father's symptoms; it told a wider story.

### A moment that changed everything

When Olivia met her partner, she had not yet been tested for the mutated SCA6 gene that causes the condition. *"I previously hadn't really thought that it could affect me, but we realised it was genetic, and that it's affecting not just my dad, but members of his wider family too,"* she explains. Olivia proceeded to undertake genetic testing, which revealed that she has the mutated SCA6 gene. *"I was really upset when I found out I was a carrier. Shocked, and upset."*

Having SCA6 means your child has a 50% chance of inheriting the condition, as it is passed on via a dominant gene. *"Learning I have the mutated SCA6 gene changed the future,"* Olivia says. *"Not just for me, but for any child I want to have."*

During genetic counselling, Olivia learned about the possible option of undergoing IVF with pre-implantation genetic testing (PGT-M). *"It just felt like the right thing, and luckily, my husband was on the same page. It gave us some degree of control."* Instead of leaving her child a 50/50 chance of having the mutated gene for SCA6, IVF with PGT-M will allow the couple to proceed with an embryo that they know does not present the mutated SCA6 gene.

### A long and emotional journey

It took nearly two years from the time Olivia and her husband decided to pursue IVF, to reach the embryo transfer stage. The process is complicated, involving hormone treatments, procedures, long waits—and lots of uncertainty. *"The medication itself is tough both physically and emotionally for me, and then in turn for my husband. It has been a really long process, and challenging in unexpected ways."*

The most challenging moment for the couple came after egg collection. *"Out of eight eggs we retrieved, five were fertilised, and only one made it to the blastocyst stage, which meant it could then be biopsied. I felt quite defeated at that point."*



Olivia and her father, Peter

**General disclaimer: Ataxia UK is proud to share your stories. All stories represent the personal views and experiences of the author(s) only.**

With rigorous genetic screening on top of the 50% chance of passing on SCA6, the chances of success for this first round of IVF seemed low. However, their one embryo transpired not only to be viable, but also not to have the mutated SCA6 gene. *"It was a very slim chance that that one embryo would be okay. We were extremely lucky that it was,"* reflected Olivia.

### Misunderstood choices

Reactions from some people surprised Olivia. Some people questioned the ethics of their decision. Some misunderstood the science.

*"People will ask things like, 'Are you designing how your baby will be?' or 'Can you decide if it's a boy or a girl?' Of course, the answer is no."* For Olivia, the process is not about perfection; it's about giving her child the best chance for a healthy future. *"Ataxia can be cruel; we all know that. If I can prevent it from happening to my child, why wouldn't I?"*

Her decision-making process is shaped by lived experience. *"I have so much love for my dad, and I see what this condition is doing to him. People have their opinions, but unless they live it, it's hard for them to understand."*

Even though IVF is now widespread, Olivia has found her specific experience of it to be isolating at times. *"There are gaps in support for people going for IVF for genetic reasons,"* she says. *"It is actually quite a different process if it's for infertility."* Friends, family, and others may be able to relate to parts of the process, but they do not understand her full experience. Olivia believes there is a lot more that needs to be done to create space for conversations around the choices prospective parents might make around IVF, genetic conditions, and their future children's health.

### There are no right or wrong answers

While scaling this learning curve, Olivia's message is loud and clear: *"There is no right and wrong choice in this,"* she says. *"Everyone is trying to do their best, in the way that suits their own needs."* She takes ownership of this deeply personal decision—whilst understanding that others may choose differently. *"If this feels like the right thing to do, then go for it, and if it doesn't, it's okay too."* Olivia wanted to share her story with the Ataxia UK community so that people can learn more about the options that exist, make decisions with more clarity, or support family or friends who may be going through something similar.

### Looking forward

Olivia's IVF journey is ongoing. While looking back at it now, she pauses.

*"When you actually talk about it, say it all out loud... you realise how much it is. But that's how life is, it presents you with different challenges and choices, and you get on with it, don't you?"*

For her, this is not a story about what is right but rather about awareness, choice, and hope. *"Seeing my dad makes me scared for the future, but I try not to dwell on it too much. You don't know how SCA6 is going to present, and there's no point worrying about that when you've got today to live for. But for me, the option of IVF and pre-genetic screening made me feel that I had some element of control and options."*

## Volunteers' Week 2026

Every year, during the first week of June, organisations across the country come together to celebrate something truly special: their volunteers. Volunteers' Week is a nationwide moment to pause, reflect, and say a massive thank you to the people who generously give their time, energy and hearts to their community.

Here at Ataxia UK, our volunteers are at the centre of everything we do. Their kindness and dedication shape the services we offer and make our community stronger.

From 1–7 June, we'll be celebrating our volunteers. Join us throughout the week as we give thanks by hosting a few virtual sessions in their honour. These will include Chair Pilates, an information session on the basics of using a computer by AbilityNet and a musical celebration to end the week with our long-serving volunteer, Tony Kaye. *For more information and to book:* [www.ataxia.org.uk/volunteers-week-2026](http://www.ataxia.org.uk/volunteers-week-2026)

During this week we will shine a spotlight on our incredible volunteers, share their stories, and show our appreciation for all the ways they contribute to our community here at Ataxia UK.

This is what our volunteer **Dawn Wooldridge** had to say about volunteering with Ataxia UK in her role as Support Group Leader, Helpline Volunteer, and All About Ataxia Facilitator.

### What do you love most about volunteering?

“Chatting to and meeting different people, sharing my experiences to help others. I was helped so greatly by Ataxia UK when I was first diagnosed — by a very special lady, even before we had a helpline. I've remembered her kindness and just want to 'pay it forward' and try to help others who are now in the position I once was.”

### How have you benefited from volunteering?

“Volunteering has given me greater confidence in myself and my abilities. I've benefited from the training provided by Ataxia UK. Volunteering has allowed me to challenge myself within my own limits, and to find acceptance for who I am — but for me it's the sense of achievement I get. I'm at home 99% of the time; if I'm not in my craft shed, I'd be watching TV and not being very productive. My ataxia has been with me for 60 years. If I can help someone by sharing my journey with them, or even just listen and meet them where they're at, hopefully the little I do may make a difference to someone.”

If you would like to find out more about volunteering for Ataxia UK, please visit: <http://alturl.com/spoms>. Or if you have any questions, please get in touch by emailing [volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk)



## Carers Week 2026

Carers Week is an annual campaign to raise awareness, highlight the challenges faced by carers and recognise their contribution to communities across the UK.

This Carers Week, we are shining a light on our unsung heroes who dedicate themselves to caring for loved ones.

A carer is anyone who provides unpaid support to a family member, partner or friend — though being a carer is more than a title. While the role is born out of compassion, the impact is significant. Caring responsibilities can take a heavy toll on a person's physical and mental health.

We asked Jane, a long-term carer in our community and our wonderful Carers Support Group leader, about her experience as a carer and what she has found most useful:

“The most important thing about being a carer is a sense of humour. On a more practical level, I'd say trying to keep positive, maintaining a good diet, and resting wherever possible — both mentally and physically.”

Jane's message is a reminder that to care for others effectively, you must care for yourself too.

One of the hardest parts of caregiving isn't just the physical demands — it's the sense of becoming invisible or losing oneself. When your life is dedicated to the needs of another, it is easy for your own identity to fade into the background.

At Ataxia UK, carers are integral to our community, but they shouldn't have to carry the weight alone. Our Carers Support Group is a space for carers to support one another. Whether you are seeking practical advice or simply need a place where you don't have to explain your exhaustion, you are welcome here.

To celebrate Carers Week (8–12 June), we are hosting a range of virtual activities designed to support you:

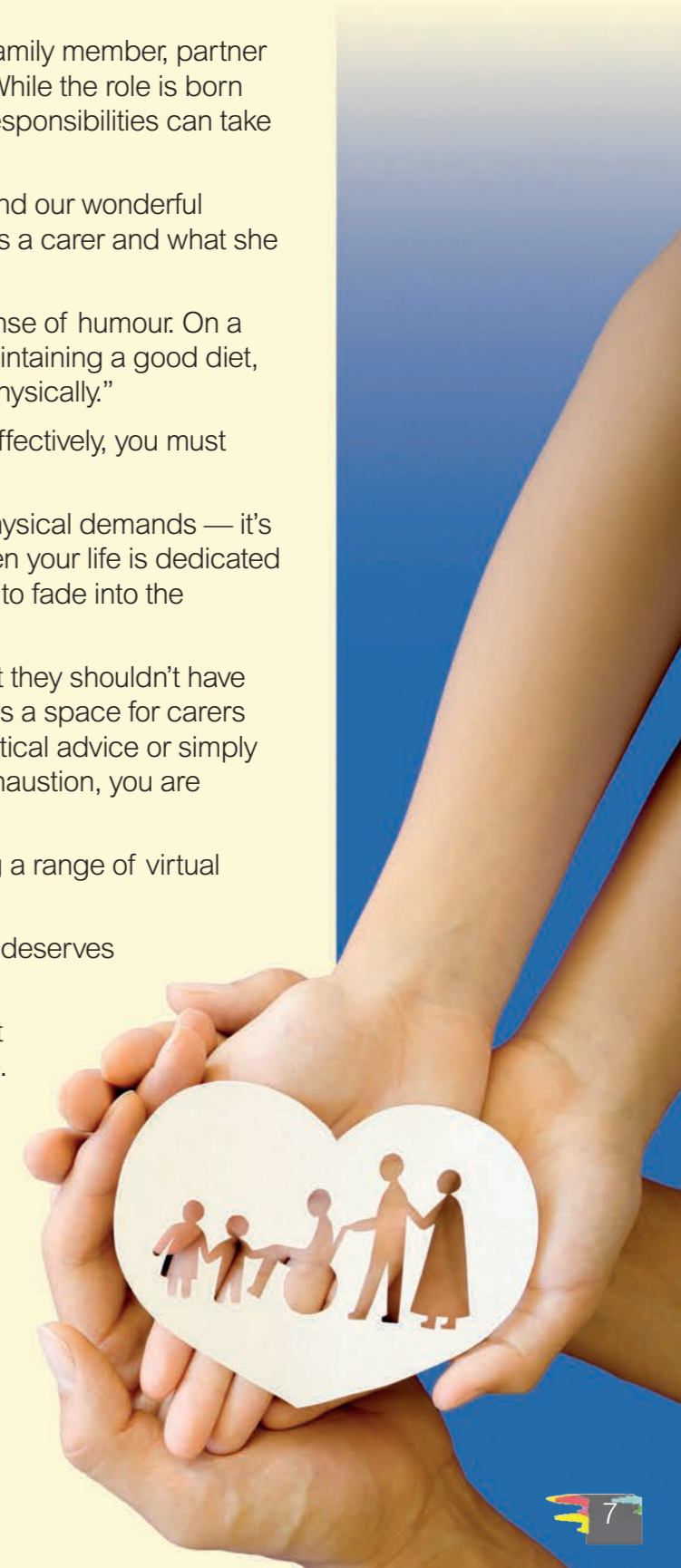
**9 June. Mindfulness Session** - because every carer deserves a moment of calm to recharge.

**10 June. Support Group Meeting** - a chance to meet other carers, share stories, practical advice, and more.

**12 June. Navigating Care Needs** - a practical workshop focused on managing the complexities of long-term care.

*Don't carry the load alone. For more information on our events or to join the Support Group, please contact us at [volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk).*

*If you are a carer looking for more information on the support available to you, please visit the Carers UK website: <http://alturl.com/qgnq3> or contact our Helpline at [help@ataxia.org.uk](mailto:help@ataxia.org.uk).*



## Thinking ahead to plan for the future

**For many people affected by ataxia, thinking about the future can feel complicated.**

You might have found yourself thinking, “I should probably plan ahead” — and then not known where to start, or just not felt ready. That’s completely normal. It’s not an easy topic and it’s something lots of people put off.

That said, from conversations at our recent events, we’ve seen how helpful it can be to think about these things in a way that feels manageable — and on your own terms.

Planning ahead doesn’t have to mean making big decisions or having everything figured out. Often, it’s about small steps that help you feel a bit more prepared and a bit more in control.

For some people, that might simply be starting a conversation — talking to someone you trust about what matters to you or how you’d like to be supported in the future. For others, it could be looking into practical things like making a will, setting up a power of attorney or finding out what options are out there when it comes to future care.

You might also want to think about work, finances, or what support could be available if your needs change over time. There’s no pressure to make decisions straight away — but having a sense of what’s possible can make things feel a bit less uncertain.

There isn’t a ‘right’ time to do this. Some people prefer to plan early, while others come back to it bit by bit. The important thing is that it happens at a pace that feels right for you.

It’s also worth saying that planning ahead isn’t about expecting the worst. Often, people tell us that once they’ve taken that first step — however small — it brings a sense of relief, even if nothing needs to change right now.

*If it’s something you’d like to start thinking about, you don’t have to do it on your own. The Ataxia UK Services Team can talk things through with you and help you explore your options. You can find out more, including some practical tips, on our website: <http://alturl.com/ua06t>*

*If you’d like to speak to someone, you can contact our Helpline, Monday to Friday, 10:30am to 2:30pm, on **0800 995 6037** or by email at [help@ataxia.org.uk](mailto:help@ataxia.org.uk).*

And if now doesn’t feel like the right time, that’s okay too. It’s something you can come back to whenever you’re ready.

Sometimes, just knowing where to start is enough.



## Have Your Say: Ataxia UK Wellbeing Survey

**We would really value your feedback on Ataxia UK services, including the Helpline.**

Our 2026 Wellbeing Survey is now open and is an important opportunity for you to share your experiences. Whether you have used the Helpline or not, your views will help us understand what is working well, what could be improved, and how we can better support people affected by ataxia. The survey is completely anonymous and takes around 20–30 minutes to complete.

**You can complete the survey:**

- **online:** <http://alturl.com/nmdmk>
- **using the paper version included with this magazine**
- **over the phone**

*If you have any questions, would like help completing the survey, or need additional copies, please contact the Ataxia UK Helpline at [help@ataxia.org.uk](mailto:help@ataxia.org.uk) or **0800 995 6037**.*

Your feedback is incredibly important and will help shape future support for the ataxia community.

## Our Helpline hours are expanding to Fridays!

**The Helpline phone lines are now open Monday to Friday, 10:30am to 2:30pm. You can call us on **0800 995 6037** or email [help@ataxia.org.uk](mailto:help@ataxia.org.uk) at any time — we aim to respond within three working days, often sooner.**

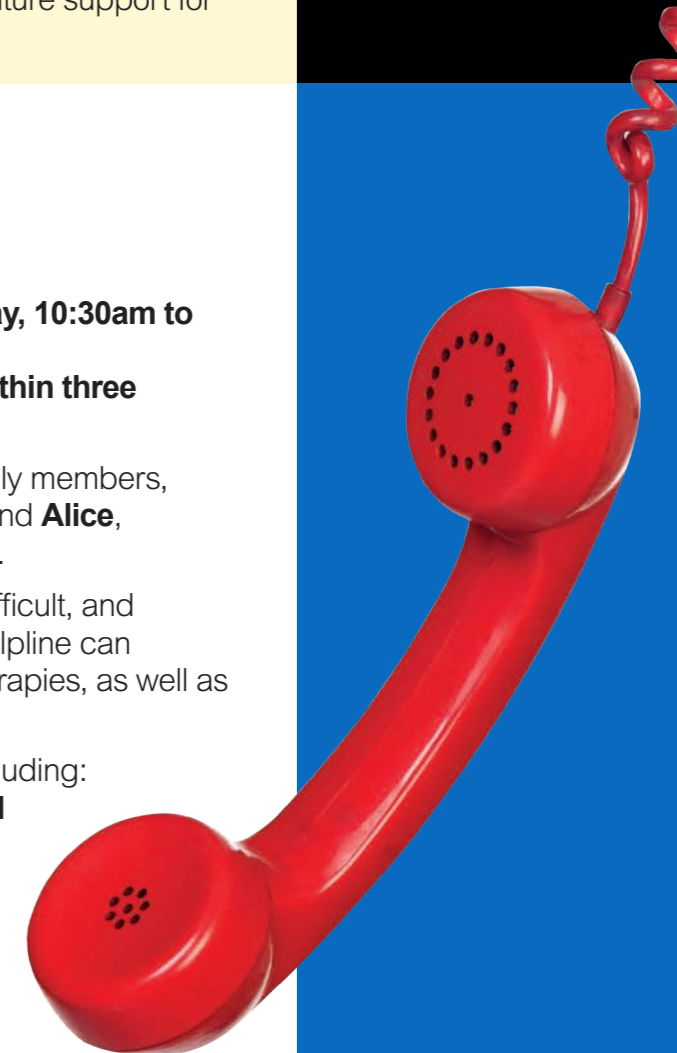
The Helpline is for anyone affected by ataxia, including family members, carers and friends. It is run by our Helpline Officers, **Sally** and **Alice**, alongside trained volunteers with lived experience of ataxia.

We know that knowing what to do after diagnosis can be difficult, and people are often left to navigate things on their own. The Helpline can provide practical information about accessing care and therapies, as well as emotional support if you need someone to talk to.

We can also help with a wide range of everyday issues, including:

- **benefits and finances** • **housing** • **employment** • **mental health** • **aids and adaptations** • **travel, insurance and driving** • **social care**

*We can also signpost you to other organisations, support grant applications, and help with referrals to specialist services. Where needed, we can refer you to Ataxia UK’s Advocacy Service for more ongoing support.*



## Death in service

Many employers in the UK offer a 'Death in Service' payment as a benefit of working for them.

Employers pay a tax-free cash sum if their employee dies while on the company payroll. The employee can normally choose who receives the money.

Though it's not exactly pleasant to think about, have you checked to see if your employer offers a Death in Service benefit? If so, have you listed someone as a recipient?

Leaving Ataxia UK as a beneficiary of your life insurance or work-related 'Death in Service' policy is a straightforward way to create a lasting legacy without impacting your day-to-day finances.

The Ataxia community was recently gifted more than £13,000 after a Friend of Ataxia UK left us as a partial recipient of their 'Death in Service' payment. This was an incredibly generous and thoughtful act, and one that will have a lasting impact on those affected by ataxia.

*Should you choose to list Ataxia UK as a recipient of your 'Death in Service' payment, you are under no obligation to tell us. You just need the following details: **Ataxia UK, Registered Charity Number England and Wales (1102391) & Scotland (SC040607)**. However, it would give us great joy to be able to thank you for listing us as a beneficiary, while we can.*

There are some things we have no control over. But where choice presents itself, make sure you make the decisions you are happy with.



## Ataxia Together Week

This year, we're doing things a little differently. We've taken on board your feedback from the last Virtual Annual Conference, where many attendees reported online fatigue. While we all got used to being on Zoom for longer periods of time during the pandemic, our habits have shifted and we understand how tiring it can be to stay engaged while sitting in front of a screen for a whole day.

Therefore, we've decided to adapt our Virtual Annual Conference into a week-long event: Ataxia Together Week! The same key sessions and content, but spread into shorter sessions across a week, leading up to International Ataxia Awareness Day (25th September). This follows on from the success of our Wellbeing Week format, which many of you have attended.

**Ataxia Together Week**  
**Monday 21 - Saturday 26 September**

We'll be coming together for a week of connection, support and celebration of the ataxia community – because nobody should face ataxia alone. The full programme is to be confirmed, but sessions will include:

- Research updates and Q&As with specialist ataxia healthcare professionals
- Therapies and management of ataxia symptoms
- Practical advice and support for living well with ataxia
- All About Ataxia workshop
- The ataxia community, including information about support groups and a celebration of our volunteers and community

Tickets: one ticket gives you access to all sessions throughout the week. Pay what you feel, from £5, £10, or £15.

For more information about the programme and when bookings open, visit our page: <https://tinyurl.com/3jbu5zk2>, and keep an eye on social media and our newsletters.

SEPTEMBER

21

MONDAY

SEPTEMBER

22

TUESDAY

SEPTEMBER

23

WEDNESDAY

SEPTEMBER

24

THURSDAY

SEPTEMBER

25

FRIDAY

SEPTEMBER

26

SATURDAY

# Getting to the heart of the matter

Lexeo therapeutics shares with Ataxia UK how they are raising awareness of heart health in FA and describe their research programme

## About Friedreich ataxia (FA)

Friedreich ataxia (FA) is a genetic, progressive multisystem disease that significantly impacts the heart, brain, and muscles. FA can affect many parts of the body, including movement, coordination, speech, sensation, and heart function. An estimated 15,000 people worldwide have FA.

## Why is heart health important in FA?

When most people think about FA, they picture classic symptoms like movement difficulty and muscle weakness. What's less often recognized is how FA impacts the heart. Approximately 60% of individuals with FA develop cardiac hypertrophy (thickening of the heart muscle). Cardiac hypertrophy can cause the heart to become stiff and less flexible, making it harder for the heart to fill and pump blood. Over time, this can lead to FA-cardiomyopathy (FA-CM), a form of heart disease seen in FA. Common symptoms of FA-CM, such as shortness of breath, fatigue, and dizziness, can be overlooked or attributed to other aspects of FA. Symptoms and severity of FA-CM can vary widely, even in the same family.

Although FA-CM may develop without clear early warning signs, it can lead to serious complications, including abnormal heart rhythms, heart failure and shortened lifespan. That's why regular heart monitoring is an essential part of FA care. Expert-developed guidelines recommend that people with FA have regular evaluations of their hearts, even if they do not have symptoms of FA-CM. Evaluations may include imaging to look at the structure and function of the heart (echocardiogram and cardiac MRI) and tests to monitor heart rhythms (electrocardiogram, also known as ECG or EKG). Additional screenings and tests may be done depending on an individual's symptoms and other health history.

**Heart changes in FA may develop without obvious or noticeable symptoms. Regular heart monitoring is an important part of FA care as recommended in the Ataxia UK medical guidelines.**

## How does FA cause cardiomyopathy?

FA is caused by changes in the gene *FXN*, which provides instructions for the body to make a protein called frataxin. Frataxin plays an important role in the mitochondria, the part of the cell responsible for making energy. When frataxin levels are low, mitochondria cannot produce enough energy to support organs and tissues including the brain, muscles, and heart. Over time, heart cells can become energy-starved and vulnerable to damage, which may lead to FA-CM.

# The Heart of FA

*Below: Members of the Lexeo's FA Cardiac Advisory Council met with Lexeo's CEO and CMO in New York City, April 2026*



## An investigational gene therapy for FA-CM

There are currently no approved treatments that address the underlying cause of FA-CM. Lexeo Therapeutics is developing an investigational gene therapy for FA-CM called LX2006.

Genes are like recipes in a cookbook. Each recipe contains instructions the body uses to make proteins it needs to function properly. When an ingredient is missing or incorrect, the final result does not turn out the way it should. One type of gene therapy works by adding a working version of the recipe back into the cookbook. In this case, LX2006 is designed to deliver a working copy of the *FXN* gene so the heart has the correct instructions to make the frataxin it needs. The goal is to address FA-CM at its source, rather than only treating symptoms.

Encouraging results were seen in the LX2006 Phase 1/2 clinical studies. Improvements were seen in heart structure and function. Improvements were also seen in neurological measures, including the modified Friedreich Ataxia Rating Scale (mFARS).

## Partnering with the FA community

Meaningful research starts with listening. Lexeo is committed to engaging patients and caregivers living with FA-CM. In 2025, Lexeo formed an FA cardiac advisory council. The council brings together diagnosed individuals, caregivers, and advocacy community members to ensure the lived experience of FA-CM is heard. Through ongoing discussions, council members share insights about cardiac awareness, unmet needs, and everyday challenges, helping identify barriers and opportunities that matter most to the community. The council will provide ongoing guidance on strategic direction and will help foster collaborations that empower the FA community to address gaps in cardiac care.

Earlier this year, Lexeo also launched The Heart of FA, a community platform on Instagram. The channel was created to give the FA community a dedicated space to share their stories, connect with others, and stay informed about the science that affects their lives.

If you are a member of the FA community, join the conversation! **Find The Heart of FA on Instagram @theheartoffa.**

## About Lexeo Therapeutics

Lexeo Therapeutics is a clinical stage genetic medicine company dedicated to reshaping heart health by applying pioneering science to fundamentally change how cardiovascular diseases are treated — including FA cardiomyopathy (FA-CM).

## Reference

*Clinical Management Guidelines for Friedreich Ataxia. Chapter 4: The heart and cardiovascular system in Friedreich ataxia. Friedreich's Ataxia Research Alliance; 2022. Available at: <https://frdaguidelines.org/chp4overview/> Management of the ataxias - towards best clinical practice, Ataxia UK. Available at: <https://tinyurl.com/4tjec426>*

# Developing audio messages to help those with ataxia when making calls

**In an Ataxia UK-funded project, Dr Maria Cairney and Prof Anja Lowit at the University of Strathclyde are developing audio messages to support people with ataxia whilst making phone calls. People with ataxia can experience difficulties with their speech and can find it hard to make themselves understood on the phone. In addition, they can sometimes have difficulties understanding what others tell them. This article describes the first part of the project in which the researchers used a survey to ask people with ataxia about their experiences calling different services on the phone and asking for adjustments to make their phone calls easier (known as self-advocacy).**

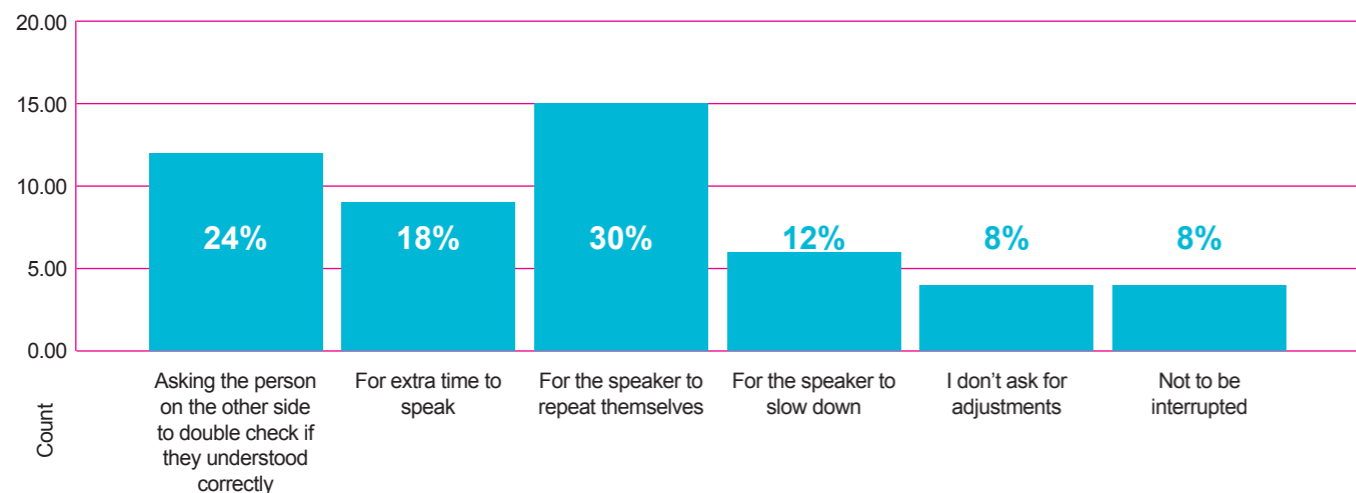
In the survey, the researchers asked people if they would be interested in an audio tool (like the physical Ataxia ID card) that could help with self-advocacy on the phone. They also asked participants what functions they think such a tool should have.

Thirty-three responses were analysed, from people aged 25-88, with a range of ataxias including FA, SCAs, idiopathic ataxia and others.

97% of participants said they would be interested in an audio tool to help with self-advocacy on the phone. Over half of the participants (52%) said it is either quite hard or very hard to make themselves understood when making a phone call. 60% do not feel very confident asking for adjustments and some wrote that they prefer to ask their partners to make the phone calls on their behalf.

Some of the most common adjustments that participants ask for (**see bar chart below**) are to be given extra time to speak (18%), and for the person on the other side to double check if they have understood them correctly (24%), as well as to repeat themselves (30%) and slow down (12%) to make them easier to follow.

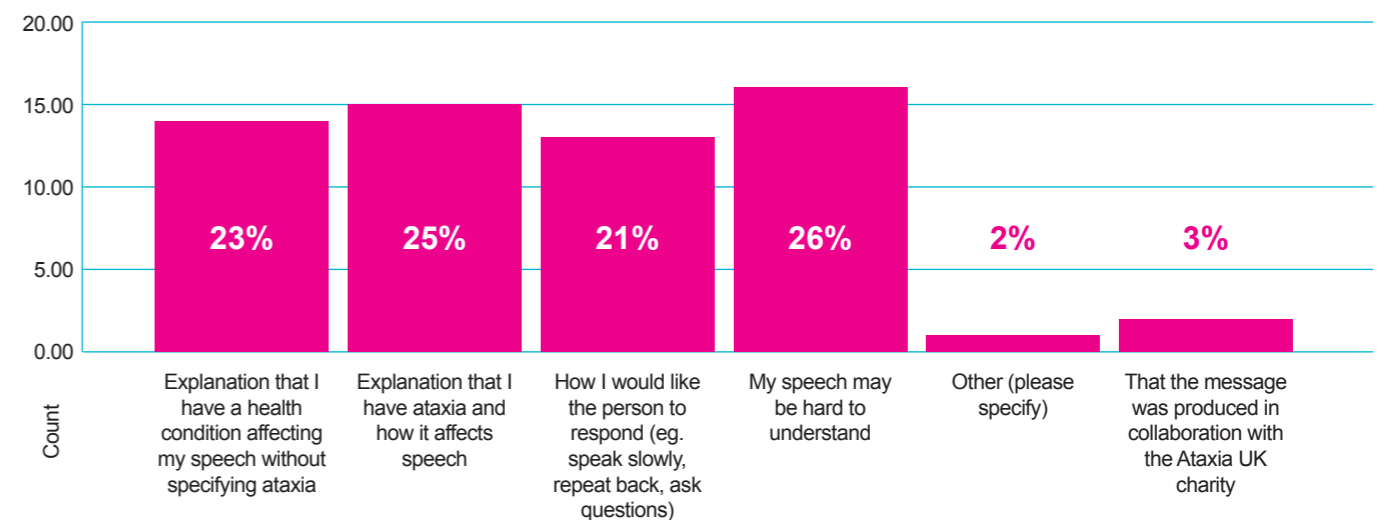
## What adjustments do you ask for most often?



Those that responded to the survey would like a tool to mention that their speech might be hard to understand and to include an instruction for the other person (e.g., to double check their understanding). Participants were roughly split between whether they want the tool to mention ataxia or not. (**see bar chart below**)

The researchers are now working with people with ataxia to refine different versions of the message that the tool should include. The next stages of the project include testing an early version of the tool and understanding the experiences of people with ataxia when using it. Thank you to Friends of Ataxia UK that completed the survey for this project. Your input and experiences are highly valuable to guide research projects such as this one.

## What information should be included in the message?



## The Scottish Medicines Consortium (SMC) announced that it has not recommended omaveloxolone for the treatment of FA in people aged 16 and over within the NHS in Scotland

**On 9 March, the Scottish Medicines Consortium (SMC) announced that it has not recommended omaveloxolone for the treatment of Friedreich's ataxia (FA) in people aged 16 and over within the NHS in Scotland.**

This news will be very disappointing for the FA community as it is for us at Ataxia UK. It is, however, encouraging and an important step that the SMC acknowledged both the clinical value of this treatment and the significant unmet need in FA. Despite this decision, as previously communicated to people with FA in Scotland, clinicians can still make individual funding requests for patients to be prescribed omaveloxolone under the PACS Tier 2 process in Scotland.

If you live in Scotland and are interested, you should talk to your neurologist about this. If your clinician intends to use the process, please let us know, as we can support them.

To read more about this, including further details on the SMC decision and Biogen's statement to Ataxia UK please go to the [Oma updates page](#) on the Ataxia UK website.

## Ataxia UK funds new project to develop a speech recognition tool for people with ataxias

**Many people with ataxia experience speech difficulties, which can make communication challenging. While voice-controlled technologies are now widely used, they often struggle to understand speech affected by ataxia, leaving many people unable to benefit from these tools.**

This project, led by Prof Lin at the University of Manchester, is a collaboration with University College London, the University of Sheffield, the University of Strathclyde and the company NVIDIA. It aims to develop speech recognition technology that is better suited to the ways people with ataxia speak.

To do this, the researchers will work with people with ataxia to collect speech data. The collected data will help researchers develop new approaches that make speech recognition more accurate and inclusive. *Read more about the project on our website.*

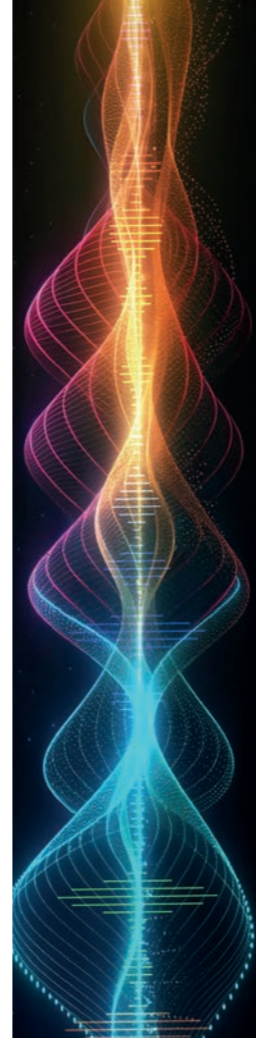
### Research at the Oxford Ataxia Centre

**The Oxford Ataxia Centre, at the John Radcliffe Hospital, is an Ataxia UK Accredited Specialist Ataxia Centre. The clinical team are Prof Nemeth (Clinical Geneticist), Prof Rinaldi and Prof Tofaris (Adult Neurologists), and Dr Smith (Paediatric Neurologist).**

The team cares for over 500 children and adults, living with suspected or confirmed ataxia. As well as providing clinical care, the team are involved in research projects ranging from laboratory-based research to clinical trials. Here we describe some of these projects, to highlight the important work of this research active ataxia centre.

The Oxford Ataxia Centre is recruiting participants for the BRAVE Phase 3 Paediatric study, which is evaluating the safety and efficacy of omaveloxolone for children with Friedreich's ataxia (FA). Prof Nemeth is undertaking a SCA44 natural history study, in collaboration with Prof Helen Dawes. Natural history studies are especially important for rare conditions, like SCA44, where there is not much information available about symptoms and progression. This involves gathering information about the way SCA44 affects a person throughout their life. This is vital to guide work towards finding treatments and improving care.

The team is also involved in laboratory-based research, aimed at understanding the ataxias. Prof Rinaldi, together with Prof Becker and Associate Prof Toepfer, is studying how changes to the DNA at the FXN gene (changes called methylation) are linked with instability in the repeated section of the gene that causes FA. This work has important implications also for other neurological conditions caused by repeat expansion in genes, including many ataxias. *For information on referrals to the Specialist Ataxia Centres, see our website or contact the helpline: 0800 995 6037 or [help@ataxia.org.uk](mailto:help@ataxia.org.uk)*



## A novel approach to targeting SCA3 – the Target-MJD project

**Target-MJD is a preclinical SCA3 project led by Dr Patricia Maciel at the University of Minho in Portugal, and funded by 'La Caixa' foundation. Ataxia UK is playing an important role in the project, providing perspective from people with ataxia to support the research, along with the National Ataxia Foundation (NAF) in the US.**

Target-MJD is an early-stage research project, focusing on laboratory-based research to identify potential treatments for SCA3 (also known as Machado-Joseph Disease or MJD). The researchers have secured funding for three years.

SCA3 is caused by a change to a gene, called the ataxin-3 gene (or ATXN3 gene). This gene includes the instructions the body uses to produce a protein, called the ataxin-3 protein. In people with SCA3, one copy of the ATXN3 gene has an expanded section known as a CAG repeat expansion. The ataxin-3 protein produced from this expanded ATXN3 gene sets in motion a chain of events which eventually leads to the degeneration of the cerebellum and the symptoms associated with SCA3. One potential method to treat SCA3 is to remove the ataxin-3 protein from the cells of the body, and that is what the researchers in the Target-MJD project aim to achieve.

Their method is to promote the degradation of the mutant ataxin-3 protein in a selective manner, maintaining the normal version of the protein intact, and able to perform its normal activities. All cells of the body include a protein degradation system. This system is constantly in use, destroying proteins that are damaged or no longer needed in the cell. The researchers aim to harness this system, by identifying ways to move the mutant ataxin-3 protein into the protein degradation system that already exists in the cells. In this way, they aim to destroy this toxic ataxin-3 protein, preventing it from causing the damage which leads to SCA3.

They aim to test molecules for the ability to achieve this, first in cells, and eventually in animal models of SCA3.

We are looking forward to being involved in this interesting and important project, and will publicise updates from the research when available.



## Kate Rudkin

Last year, I was reading the monthly email newsletter when I came across an article asking people with ataxia, or those with a connection to ataxia, if they were interested in becoming a Trustee of the Charity. I was keen to learn more, as I have ataxia and had been looking for opportunities where my physical constraints wouldn't prevent me from taking an active role in something that gives me a sense of purpose. It felt reassuring to see that the call for Trustees included people like me, and I remember thinking how much I wanted to contribute my own lived experience to the Organisation. That article sparked something in me and inspired me to take the next step.

Having worked for many years at a senior level in the charity sector, I wondered whether I had the necessary skills, bringing with me my knowledge of health and social care. I was able to discuss this with the Chief Executive, who explained the role and provided further insight into the Charity. The conversation left me feeling excited and valued, as the Chief Executive took a genuine interest in my story and how my background could help shape the Charity's future.

The Charity Commission website provides a wealth of useful information about trustee responsibilities, and you can also find more detailed information about Ataxia UK. During my research, I found myself drawn to the Charity's history and the personal stories shared by other Trustees, which made me feel part of a community from the outset.

I was delighted when I was put forward as a potential Trustee. I was then invited to a two-day, in-person residential meeting, which included the AGM and a strategic planning event. This was a great opportunity to meet the other Trustees and staff. Almost all other meetings are held online and a few Trustees joined the residential meeting remotely too—no barriers to participation, as you'd expect. Meeting everyone face-to-face, sharing laughs and stories, made me feel genuinely welcomed and part of something meaningful. Knowing that the Charity made it so easy for people like me to get involved, regardless of mobility, was truly encouraging.

I became a Trustee because I genuinely care about what this Organisation seeks to achieve and I wanted to help make a real difference. It's also a great way to give back and to learn more about how charities work. If you're ever thinking about getting involved yourself, I would absolutely encourage you—your voice and ideas matter and you can help create positive change too. Personally, it has been both rewarding and humbling to see the impact we make together and I am grateful for the chance to connect with so many passionate people.



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

**We are looking for up to three elected Trustees. We are particularly seeking individuals with professional experience in fundraising, campaigning, influencing public affairs, pharmaceuticals, the NHS, social care or charity governance. However, these are not our exclusive criteria, so if you feel you have the governance qualities to enhance our Board, we would still love to hear from you.**

The elections take place in early September and are voted on by Friends of Ataxia UK. A Trustee's term runs for four years, after which they may stand again for a further four-year term.

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

The Board meets four to five times a year, mainly on Zoom, with one face-to-face or hybrid meeting annually. Meetings run from 10:30am to 4:00pm. Most Trustees also join a sub-group of the Board, focusing on areas such as finance, services or fundraising.

The Board is made up of Friends of Ataxia UK: seven Trustees are elected by Friends of Ataxia UK, and three are appointed and co-opted by the Board. All prospective Board members are interviewed by two current Trustees prior to standing for election or being co-opted.

We are keen to broaden the diversity of our Board to ensure a wide range of perspectives. We particularly encourage applications from people from diverse ethnic backgrounds and members of the LGBTQ+ community. We cover all reasonable costs incurred by Trustees in the course of their duties, including attending face-to-face meetings and the costs of a carer, if required.

All Trustees receive an induction to the role and to how the Board operates at Ataxia UK, and are offered opportunities for external training.

*You can find more information, including the Trustee role description, by visiting [www.ataxia.org.uk/board-of-trustees](http://www.ataxia.org.uk/board-of-trustees). Anyone interested will have the opportunity to attend an online information session with Sue Millman, CEO, prior to interview. Please contact Lucy Porter, Executive Assistant, to express your interest by early June at [lporter@ataxia.org.uk](mailto:lporter@ataxia.org.uk). You can also reach her by telephone on **0207 582 1444**.*



## 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/COLLECTIONS

**Norbert Cauvas** (on behalf of Alyson Edenborough) (£3,936 inc. GA), **Phillip Whitwell** (£64.45), **Jenifer Redpath** (£32), **Exley Wobbly Club Ltd** (£50), **Black Rock** (£400), **Irene Hempstock** (£50), **Megan Harvey** (£123), **Chris Clifford** (£380), **Kirsten Beasley** (£303.45), **Sam Sba** (£95), **Tom & Donna Mallon** (£3,575 inc. GA), **Mandy Race** (£425), **Peter Martin** (£20), **Racquel Ayers** (£75), **Suzanne Sammons** (£50), **Mark Harvey** (£2,500).

### COMMUNITY-LED EVENTS

**Ellie & Susan Thompson** – Pre-Christmas raffle (£400), **Joanne Fowlie** – Raffle (£500), **Sheena Betsworth** – Christmas raffle (£330), **Lucy Holland** – Candlelit yoga (£948 inc. GA), **Ainsley Gommon** – 2025 Christmas fundraiser (£216 inc. GA), **Bristol Cabot Probus Club** – Charity of the Year (£1,000), **Barbara Edenborough** – Christmas event (£100), **Fiona Madeley** – Christmas charity darts and raffle (£450), **Kuldip Dahele** – Lohri dance event (£2,608), **Aqua Heat Ltd** – Work event (£575).

### CHALLENGES & RUNS

**Naoise Ker-Reid** – Running in park (£1,295 inc. GA), **Karl Patterson** – Round Sheffield Run (£2,215 inc. GA), **Matteo Kotch** – Run (£1,568.50), **Mark Siggins** – Swimming (£505), **Stacy Wilson (parent and child)** Sienna – 2-mile walk or cycle over two months (£590 inc. GA).



## Superhero Tri powered by Marvel

Saturday, 15 August 2026

Celebrate ten years of the Superhero Tri at Dorney Lake, Windsor, with a super-sized, fully inclusive triathlon. Open to all, with at least one team member identifying as having a disability, participants can take part solo, as a relay, or team up with Sidekicks. Choose from three distances and complete the course your way – adaptive equipment is fully welcomed, with no cut-off times. Expect a festival atmosphere, celebrity appearances and plenty of entertainment. All participants receive a medal, a T-shirt and a kit bag.



## The Big Half - London

Sunday, 6 September 2026

Get ready to be part of one of London's most vibrant and inclusive running events. Taking place on Sunday, 6 September 2026, The Big Half brings together runners, walkers and communities for an unforgettable 13-mile journey through the heart of the capital. This exciting, road-based flat course begins at the iconic Tower Bridge and finishes beside the historic Cutty Sark. Along the way, participants will travel through four diverse London boroughs – Tower Hamlets, Southwark, Lewisham and Greenwich – soaking up an incredible atmosphere, community spirit and city sights. Whether you're chasing a personal best or simply enjoying the experience, The Big Half offers something for everyone. Join thousands of others and be part of this inspiring celebration of fitness, inclusivity and London life.



## London to Brighton Cycle Ride

Sunday, 13 September 2026

Join one of the UK's most popular charity rides this September. The fully signposted route from London to Brighton features regular water stops, toilets and on-site mechanical support throughout. Riders receive access to pre-event training and fundraising guidance, as well as the chance to connect with others via the official community. All finishers will receive a commemorative medal, with professional photos available after the event. A well-supported, scenic challenge – perfect for cyclists of all levels.



## Meet Chelsea Higgott: Community fundraiser with a big heart and even bigger ideas

By Maya Shukla

I recently sat down with Chelsea Higgott, a dedicated fundraiser from Lichfield who has spent the past decade raising money and awareness for Ataxia UK. Inspired by her mum's diagnosis, Chelsea has turned determination into action. She's organised everything from pub quizzes to Lent challenges. With talk of skydives and 'something bigger' on the horizon, it's clear she's only just getting started.

**MAYA SHUKLA:** Let's start simple – who are you, and where are you from?

**CHELSEA HIGGOTT:** I'm Chelsea Higgott, I'm 33, nearly 34, and I'm from Lichfield in Staffordshire. I've been fundraising for about ten years now. A memory popped up recently from my first one, which made me realise how long it's been. I started fundraising for MS and then after my mum was diagnosed, I began fundraising for Ataxia UK. So yes, it's been quite a while.

**MAYA SHUKLA:** What's your "why" in a few words? Why do you fundraise?

**CHELSEA HIGGOTT:** My mum, Angela. When she was diagnosed over 13 years ago, we didn't even know what ataxia was and a lot of the doctors didn't either. Once we started researching it, I just thought: "Right, I need to do something." That's where it all started.

**MAYA SHUKLA:** Would you be happy to share a bit about your mum's diagnosis?

**CHELSEA HIGGOTT:** Yes. At first, Mum was diagnosed with episodic ataxia because her symptoms came in episodes. She knew something wasn't right, but it took a long time to get answers. There were lots of tests and a lot of uncertainty. Eventually, an ENT doctor at Derby Hospital recognised it as neurological and referred her to a specialist in Sheffield. From there, it was identified as cerebellar ataxia. Later, after testing in the family, they found it was genetic – SCA27B on my grandma's side.



General disclaimer: Ataxia UK is proud to share your stories. All stories represent the personal views and experiences of the author(s) only.

It's a lot to take in and even now it's hard to keep track of all the stages. But the main thing is that it's progressive, so it won't get better. That's something we've had to learn to live with.

**MAYA SHUKLA:** You've done so many different fundraisers over the years. What's been your go-to?

**CHELSEA HIGGOTT:** I always do something for Lent. It started as me thinking, "What can I give up?" because I don't smoke and I don't really drink. So, I usually give up sweet treats and turn that into a fundraiser.

I've also done tabletop sales and I organise annual pub quizzes, which people really enjoy. It's nice because people expect it now – they're like, "Oh, Chelsea's doing another fundraiser."

**MAYA SHUKLA:** If there were no limits, what would your dream fundraising event be?

**CHELSEA HIGGOTT:** Oh gosh... something big, I think. I've been invited to do a skydive before, which would definitely be a big one. I'm not quite there yet, but maybe one day. I even asked my dad if he'd do one with me; he said maybe in a year or so.

I think I'd just love to do something major. What I do now is lovely and people support it, but I'd like to go bigger – something that really gets people talking and raises even more awareness.

**MAYA SHUKLA:** A skydive definitely sounds like a 'next level' moment.

**CHELSEA HIGGOTT:** It really does, doesn't it? Maybe I'll get there.

**MAYA SHUKLA:** Looking ahead, what gives you hope?

**CHELSEA HIGGOTT:** I think it's becoming more well-known now than it used to be. There's more awareness, more research, and more people talking about it. If that keeps growing, then hopefully in the next ten years we'll see something real, something that gives people hope. That's what it's all about really, just getting it out there.

*Chelsea's story is a reminder that fundraising doesn't have to start with something big – it starts with care, consistency, and a willingness to act. Whether it's a pub quiz, a Lent challenge, or one day, a skydive, every effort brings the ataxia community one step closer to greater awareness, better support, and hope for the future.*



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**

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](mailto: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