ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 229. Spring 2025

Christmas Challenge

BigGive

Thank you to all our supporters

You have raised over

£57,500

- Research
- Ataxia people
- Ataxia awareness
- Fundraising
- Living with ataxia
- Services

ATAXIA

Ataxia UK

In the office

We are sorry to say goodbye to our wonderful **Viktor Elzer**, our **Senior Brand and Communications Manager**. His leadership in managing the website, design work, and ensuring our brand stayed true to its vision is invaluable. We wish him all the best in his next chapter. Thank you so much for all your hard work!

We are sorry to say goodbye to **Irmak Dogan**, our **Communications Officer**, who has been with us for three years, working on the Ataxia Magazine, social media and interacting with Friends. Best of luck to Irmmy in her next role at Duchenne UK.

Welcome to **Yolande Joubert**, our **Chief Operating Officer**, who will be overseeing key areas, including Finance, fundraising, Digital and HR, ensuring seamless coordination among various departments.

Welcome to **John Graham**, who has joined as **Director of Fundraising and Communications** and will oversee the delivery of fundraising, marketing and communications within the charity.

We're also welcoming **Camilla Notley**, who has joined as our **Ataxia Specialist Nurse** and will connect with patients to learn about their needs and how she can support them.

CEO's introduction

Welcome to our first magazine of 2025! On p4-7 you can read about the recent ICAR Conference hosted by Ataxia UK, where the current optimism and energy in ataxia research was reflected in many of the presentations and among the delegates. Many remarked upon the air of excitement at the conference. The feedback from every direction, has been overwhelmingly positive about all aspects of the event – programme and content; venue and location; logistics and arrangements. At 602 attendees, with a further 100 turned away, and 50 online, from 32 difference countries this was the largest ataxia conference ever held. Ataxia UK's involvement in the conference as the leading host was very evident and much complimented, and served to raise our profile with scientists, clinicians and with pharmaceutical companies.

As 2025 unfolds we hope that the optimism inspired by ICAR will translate into progress towards one or more treatments being made available for one or more ataxias in the UK. We are working hard to ensure that the voices of people affected by ataxia are heard during the forthcoming regulatory procedures. Please support our efforts by responding to requests for case studies, information or by completing our surveys. Very little information on the ataxias and their impact is collected by health authorities and what you tell us is important to inform decisions on whether drugs get licenced or paid for by the NHS.

Best wishes,

Sue

Sue Millman

KEY CONTACTS

- **Sue Millman**
- Chief Executive
smillman@ataxia.org.uk

Services

- **Wendy O'Mant**
- Head of Services
womant@ataxia.org.uk

Contact our helpline:
help@ataxia.org.uk
0800 995 6037

Research

- **Dr Julie Greenfield**
- Head of Research
research@ataxia.org.uk

Fundraising & Communications

- **John Graham**
- Director of Fundraising and Communications
jgraham@ataxia.org.uk

- **Hanif Abdulmuhit**
- Events and Community Fundraising Manager
fundraising@ataxia.org.uk

- **Communications**
communications@ataxia.org.uk
For queries or feedback please contact the Communications team

Contact our office

office@ataxia.org.uk

020 7582 1444

Ataxia UK, 12 Broadbent Close
London N6 5JW

www.ataxia.org.uk

Research

Ataxia People

Ataxia awareness

Fundraising

Living with ataxia

Services

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)

Highlights of ICAR 2024

The 2024 International Congress for Ataxia Research (ICAR) took place in London from 12th – 15th November. This was the biggest ICAR yet, with 600 in-person attendees and 50 attending online from 32 countries, including researchers, clinicians, representatives from the pharmaceutical industry and patient organisation representatives.

The congress brought together researchers from the ataxia field to share knowledge through talks, workshops, debates and poster presentations. Around 350 scientific research posters were presented, and over 80 invited talks were given. Members of the Ataxia UK research department were involved as authors on six posters and one talk. You may have seen more about some of these publications in our December 2024 e-newsletter.

ICAR 2024 included sessions on disease mechanisms, models of the ataxias, and preclinical and clinical research, showcasing many innovations in the field of ataxias, from gene therapies to new measures of ataxia progression. Here, we summarise some of the highlights from the Congress.

We are grateful to the 14 pharmaceutical companies and two patient advocacy organisations whose sponsorship made ICAR 2024 possible. ICAR's presenting sponsor, Biogen, hosted a breakfast meeting for clinicians in countries where Omaveloxolone is now approved for the treatment of Friedreich's Ataxia (FA). Throughout the conference, Ataxia UK had an information stall available to all at the conference, at which we shared a range of leaflets and information, including the Ataxia UK medical guidelines, which were well received. Members of the research team had discussions with numerous researchers and companies, enabling Ataxia UK to build upon and initiate new collaborations. Ataxia UK's **Head of Research**, Julie Greenfield, reflected, *'This has been the largest ever meeting of ataxia researchers, with around 600 people attending. Ataxia UK has been proud to organise this conference alongside our colleagues at Friedreich's Ataxia Research Alliance (FARA), National Ataxia Foundation (NAF) and the Ataxia Global Initiative (AGI)'.*

ICAR 2024 showcased a range of research projects, from understanding the basic science of the causes of ataxias, to advances towards treatments for ataxias. In FA research, there were a number of presentations about Omaveloxolone. Data was presented on the safety of Omaveloxolone and how well its effects can be tolerated in the body. Biogen also discussed plans for a further study assessing the long-term safety of Omaveloxolone in people with FA.

A number of other developments were discussed, including research trials testing potential new therapies for FA such as:

- **Nomlabofusp** - a treatment which aims to replace the frataxin protein, which is reduced in FA. Nomlabofusp is being developed by Larimar Therapeutics, and is currently in phase 2 clinical trials
- **Vatiquinone** - a treatment developed by PTC Therapeutics that targets a process called oxidative stress in the body which occurs in FA. It is currently in phase 3 clinical trials. PTC submitted a new drug application for Vatiquinone to the FDA in December 2024
- **DT216-P2** – a potential treatment that targets the frataxin gene, to restore function. Design Therapeutics plan to start phase 1 clinical trials of DT216-P2 in 2025
- **CAP-004** – a gene therapy developed by Capsida Therapeutics currently being tested in animals. In mice with FA, the therapy can reach the brain with just a single injection into the veins, without affecting other parts of the body such as the liver. This may potentially avoid the need for invasive brain surgery.

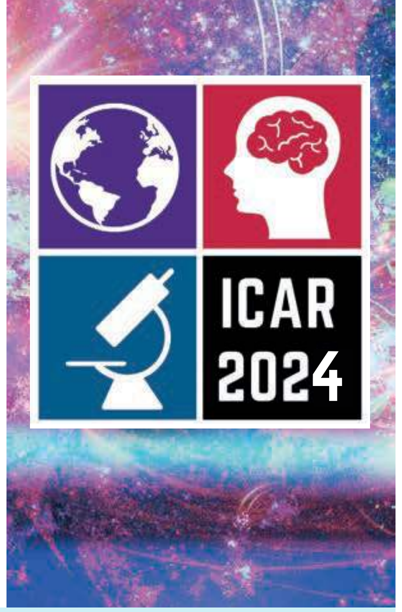
These developments highlight that a number of potential treatments for FA are being tested in clinical trials, or in later stage research in the laboratory.

In 2022, a new type of ataxia called **SCA27b** was discovered, and data was presented on it at ICAR 2022. At ICAR 2024, 10 talks and 6 posters featured research into SCA27b, highlighting the growing interest in understanding the condition and conducting clinical trials for new treatments. One of these treatments is a compound called 4-aminopyridine which you can read about on our website.

In the **SCAs**, research was presented on a potential treatment called VO659, which is an antisense oligonucleotide (ASOs) being developed by Vico Therapeutics. VO659 targets the message from the genes that cause SCA1, SCA3 and Huntington's disease. In the UK, the London Ataxia Centre is recruiting participants for this trial.

Dr Stefan Pulst and his laboratory at the University of Utah presented their research that led to discovery of the gene mutation that causes SCA4, which you can read more about on our website. This discovery paves the way for new treatments for SCA4.

On the first day of the Congress, Ataxia UK's **CEO Sue Millman** hosted a discussion panel (right) where a number of participants with ataxia, or who care for someone with ataxia, shared their experiences and perspectives.



The panel shared their experiences of taking part in research, from surveys to the clinical trials of Omaveloxolone, as well as the lived experience of being a parent of someone with ataxia. Including the experience of people living with ataxia is important to highlight the impact of the condition to researchers and clinicians. 84% of ICAR attendees who responded to the feedback survey said that the patient perspectives included within the conference were extremely valuable or very valuable. Some of the feedback we received from researchers about ICAR is shown in the infographic below.

ICAR Feedback Survey results

91% of respondents made new contacts at the conference

88% of respondents said that they think new contacts they made would be likely or very likely to enhance their work

The second day of the conference featured a clinical Grand Round, where ataxia clinicians presented unique and challenging ataxia cases to educate researchers and other clinicians. For example, one case featured the temporary deterioration in ataxia symptoms following caffeine consumption in a patient with SCA27b, highlighting the importance of lifestyle modifications which can be used to manage ataxia symptoms.

On the third day of the conference, Ataxia UK's **Senior Advocacy and Community Programme Officer**, **Shana De Figueiredo Scholtz**, gave a presentation. Shana, who lives with SCA3, spoke about patient perspectives on clinical trials of drugs designed to prevent onset of symptoms or delay symptom progression. Her talk featured insights from four people with different ataxias who attended a focus group hosted by Ataxia UK.

The Congress ended with a late-breaking research session, designed to allow researchers to share exciting new data. In this session a representative from the pharmaceutical company Biohaven presented results from their phase 3 clinical trial testing the drug Troriluzole in people with SCA. Troriluzole is currently under review by the European Drug Regulators, the European Medicines Association (EMA) for the treatment of SCA3. Biohaven planned to submit a New Drug Application (NDA) to the US drug regulators, the Food and Drug Administration (FDA) for Troriluzole in the treatment of all SCAs by the end of 2024.

We will be running a series of articles spotlighting some of the research presented at ICAR 2024 on our website. Head to the ***'Research News'*** *section to read more.*

Updates from the DRPLA Research Programme in partnership with CureDRPLA

CureDRPLA engaged Ataxia UK about five years ago to leverage their expertise in the ataxia field and we have been working together since then.

The DRPLA Research Programme is fully funded by CureDRPLA and Ataxia UK provides advice to CureDRPLA. The mission of CureDRPLA is to connect families, physicians and scientific investigators to further Dentatorubral-pallidoluysian atrophy (DRPLA) research and work towards a treatment for this ultra-rare type of ataxia.

2024 was a remarkable year for the DRPLA community, filled with meaningful progress and milestones. Almost a year ago, CureDRPLA announced the first clinical trial for people with DRPLA who are living in the United States (US). These are not the standard clinical trials in which a large number of people take part. Instead, only a handful of people will be able to participate in these trials, also called N-of-1. CureDRPLA collaborated with the n-Lorem Foundation, and this Foundation has started two N-of-1 clinical trials for two people with DRPLA and has accepted a third patient for treatment. N-of-1 clinical trials are possible because in the US there is a path established by the Food and Drug Administration (FDA) to develop new drugs for rare diseases that affect a very small number of individuals. *Find out more about these trials by reading this press release:* ***http://alturl.com/durgw***

To honour the five-year anniversary since CureDRPLA was incorporated, we produced an impact report that highlights achievements and progress in key areas like research and global outreach. Scientists, clinicians, individuals with DRPLA, and their caregivers were invited to share their stories and testimonials in this report, as we wanted to hear directly from them how these five years have made a difference in their lives. *Download the impact report here:* ***http://alturl.com/v8857***

In October 2024, CureDRPLA hosted the annual DRPLA Research Conference in Boston. Drs. Silvia Prades and Julie Greenfield from the Ataxia UK Research Department attended this conference, with 24 participants in total. This conference brought together scientists funded by CureDRPLA, healthcare professionals and representatives of pharmaceutical companies. Dr. Silvia Prades presented an overview of the DRPLA Research Program, setting the scene for the day by outlining CureDRPLA's current status and future goals, followed by talks from selected scientists showcasing the latest findings in DRPLA research.

To summarise all the achievements from 2024 and to report on how the N-of-1 clinical trials are going, Dr Silvia Prades prepared a talk in non-scientific terms talking about these topics and more. Watch the recording of her talk here: ***http://alturl.com/h65eg***

Ataxia UK welcomes Camilla, our new Specialist Nurse

Our new Specialist Nurse, Camila Notley, started with us at the end of January. Here, Ataxia UK's Wendy O'Mant (Head of Services) has asked her a few questions so that we can get to know her a bit better:

Can you tell us a bit about yourself and your professional background?

I qualified as a nurse in 2007. My career started in trauma and orthopedics and then I moved to work in neurosurgical and trauma intensive care. In 2011 I specialised in organ donation and spent 10 years working with families and patients who were experiencing acute trauma and supported them with the process of their loved ones becoming an organ donor as an End-of-Life Decision. More recently I have been working in intensive care and the emergency department which has given me many opportunities to meet lots of different patients and relatives and work with them to find the best pathways for their care. In my personal life I enjoy tennis, walking and swimming in the sea. I am a keen rugby supporter and love relaxing with a good book.

What has drawn you to specialising in ataxia care?

I have a friend whose child has Friedreich's ataxia. I have watched their journey from diagnosis, and I have been in awe of the strength that the whole family have shown throughout. I am aware of the challenges that they have been facing, and I am keen to make a difference for the patients living with Ataxia in the Southwest.

What previous experiences have prepared you for this role?

I have spent a lot of my career working with different trusts and advocating for patients. I believe that the experience I have had will stand me in good stead for working with the multiple care providers that make up the team of support for my patients. I have also worked in Neurosurgery for a long time which has given me a good foundation to build my knowledge base of Ataxia.

What excites you most about joining Ataxia UK as a specialist nurse?

I have been so impressed with the charity's focus on making a difference for the people in the UK with Ataxia. The work that has gone in to creating this role in the Southwest shows me how much patients are being heard by Ataxia UK and that they will work with me to make a positive difference.

What are your main priorities in this role?

When I start the role, my main priority will be to connect to the patients in my area and find out what it is that they need, what they are struggling to access and how I can help them. Alongside that I will be building relationships with the caregivers in my area to ensure we can make effective changes that will suit the patients' individual needs.

How do you think the service will make a difference in the lives of people with ataxia?

There is reduced access to Specialist Ataxia services for those people who live in the Southwest. In my new role I plan to play a pivotal role in linking up services. I plan to signpost individuals to available support and over time I anticipate encouraging more access to specialist services being provided in the hospitals of our area.

What kind of support can people with ataxia and their families expect from you?

In the early days of my new role, I wish to hear from the people and their families about what they need from me. But I am their Specialist Nurse so I am here to support as much as I can. Though the area I am covering is geographically large, I hope to create a community for us and then we can all help one another, especially as access to service provision eases and we all come across support in different areas that could help one another. I won't be able to physically be alongside you all but I will be on the end of the phone or the computer, so it will be possible to 'virtually' take me to appointments with you, and I am also here to talk through any concerns, challenges, or successes we have along you and your families' journeys.

What can the community do to help you in your role?

The most help I need is for you to communicate with me what your needs and challenges are. This is going to be a team effort where you, as the patients and families, alongside me as the nurse, mould the service I and the local healthcare provision provide in order to optimise your quality of life.

What do you see as the biggest challenges in providing care for people with ataxia?

The biggest challenge for me in this role will be the geographical distance. I am more used to working with people face to face and so I am grateful for technology enabling me to access my patients and their healthcare support from afar. I am aware of the number of different complications and challenges that those with Ataxia face and I hope that my new service will help to reduce the additional pressures that my patients and their families are currently handling themselves.

What are your long-term goals in this role?

My long-term goal is to have a service in the Southwest that enables people with Ataxia, and their families to have access to specialist services. I want the Neurology centres and hospitals in our areas to have more specialised information of Ataxia and to have slick pathways that ensure our patients get the right care at the right time.

What would you like to say to the Ataxia UK community as you begin this journey?

Thank you for welcoming me into your community. I am really looking forward to meeting with you all and working together to improve the provision of care for those with Ataxia in the Southwest.

Rare Disease Day 2025

Rare Disease Day takes place annually on 28 February (or 29 February in leap years).

In 2024, we highlighted how rare conditions are far more common than most people think. With the support of our friends, the Rare Disease Day campaign was a success.

For Rare Disease Day 2025, our aim was to share your powerful and unique experiences and remind the community that ataxia is *'more challenging than they can imagine'*.

In the UK, there are 3.5 million people living with a rare condition and over 7000 identified rare conditions. These conditions are not only about physical symptoms, but they can also impact a person's mental, emotional| and social wellbeing.

Many of our Friends who live with ataxia have told us that doing their daily activities can at times be challenging. Depending on what type of ataxia someone has, it can present in different ways, with coordination, balance and speech being affected in most cases. With your help, we want to raise awareness and help people understand the challenges of ataxia.

Our Friend, **Gillian's husband**, **Andrew** (61), has Spinocerebellar ataxia type 2. Gillian said, *"We have faced serious life-threatening challenges…but have pulled through together, striving for the best care for a deeply gratifying experience."*

Ava, living with a rare metabolic disease, and her mum Tammie from Australia.
Raising awareness and generating change for the 300 million people worldwide living with a rare disease, their families and carers.
Visit rarediseaseday.org or scan the QR code to learn more.

Through sharing your stories, we want to remind the community that managing daily challenges of living with ataxia can be far more challenging than they can imagine. The more we understand, the more we can support one another.

There is still time to support this year's Rare Disease Day Campaign by sharing your ataxia stories. Don't forget to check out our website: Rare Disease Day 2025 - Ataxia UK for more information and to find out how to get involved. You can also contact us at ***communications@ataxia.org.uk****.*

The Big Give 2024

Over in the Individual Giving team, 2024 was wrapped up with a successful ending thanks to the Big Give Campaign.

If you are subscribed to our emails, you might already know, but the recent Big Give Campaign was an overwhelming success. With a huge thanks to our 6 generous Pledgers, whose pledges were boosted by our Champions – The Big Give Trust - our target to hit the challenge was set slightly higher than last year with £45,000.

However, you and the rest of the Ataxia UK family were able to come together and support each other to help raise a total exceeding more than £57,500 when offline donations & Gift Aid are taken into account. This is truly a fantastic achievement.

A quick glance at the 2024 Big Give Challenge shows that perhaps things are starting to return to a pre-pandemic normality. By the 72nd hour of the challenge we had already used up all of the money in the matching pot, and yet still the donations from supporters came flowing in. One lesson we want to address in the 2025 campaign is making our match-pot as big as it can be, so supporters can continue to challenge their friends and family to donate and unlock the full available pot throughout the week.

Though we can't complain. Because everyone in the community did a tremendous job of donating at the right time, contributing the donations from their fundraising events, and digging deep to ensure 2025 sets off with a great start.

We shared several stories over the Big Give – and we thank everyone who courageously offered up their words – but one story really highlighted what we hope these donations mean for the community.

Our Trustee **Nathan** (pictured with his son) spoke about his involvement with Ataxia UK and the need for drugs and treatments here in the UK. August 13th is the planned date for NICE to publish their recommendations of the approval of Omav in FA patients in the UK. Your generosity throughout the Big Give Challenge means we can continue to build relationships with pharmaceutical companies and set the stage for the next ataxia drugs to come through the system. With every development in treatments, Ataxia UK is learning how best to navigate the process to benefit the ataxia community. Additionally, your generosity means support continues to reach those within the community who need it, while we await more treatments.

We can take a moment to pause before the planning for the 2025 Big Give Challenge begins, however, if you think you would make a good pledger for next year's challenge then contact ***Kieran*** *on* ***fundraising@ataxia.org.uk***

Run for a cure 2025

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

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

Why choose to run for Ataxia UK?

Every step you take with us comes with free entry, an exclusive running vest, and a comprehensive support package to power your journey and fundraising efforts. More importantly, you join a community committed to a singular goal: to bring us closer to a cure and to uplift those affected by ataxia. Spaces are limited, so grab your running shoes and secure your spot. Together, let's race towards a future free from ataxia. Every stride counts!

Here are some of the amazing runs to choose from:

MARATHONS: Barcelona – 16 Mar • **The Brighton Marathon** – 6 Apr • **Manchester / Shakespeare** – 27 Apr • **Gateshead** – 4 May • **Leeds** – 11 May • **Edinburgh** - 25 May.

HALF MARATHONS & 10K RUNS: Paris – 9 Mar • **Nottingham / Chester 10k** • **Kettering / Cambridge** – 9 Mar • **Surrey** 16 Mar • **Hampton Court Palace / Reading / Sheffield** – 23 March • **Coventry** – 27 Apr • **The iconic Hackney Half** – 18 May • **Edinburgh** – 25 May.

*For more information, and to SIGN UP contact us at **fundraising@ataxia.org.uk** or call **0207 091 1594**.*

Sky-High Challenge 2025

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

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

Join forces with us to make a significant impact in the lives of those affected by ataxia. Assemble your team — be it friends, colleagues, or family — and experience a jump that's both thrilling and meaningful. We invite corporate groups to step out of the office and into the sky for a team-building experience that promises to be unforgettable!

Date: *29 March 2025.* ***Drop Zones:*** *Nationwide – a place near you!*

Sign up today and let's jump for a cure: ***http://alturl.com/75z5j***

London to Brighton Cycle 2025

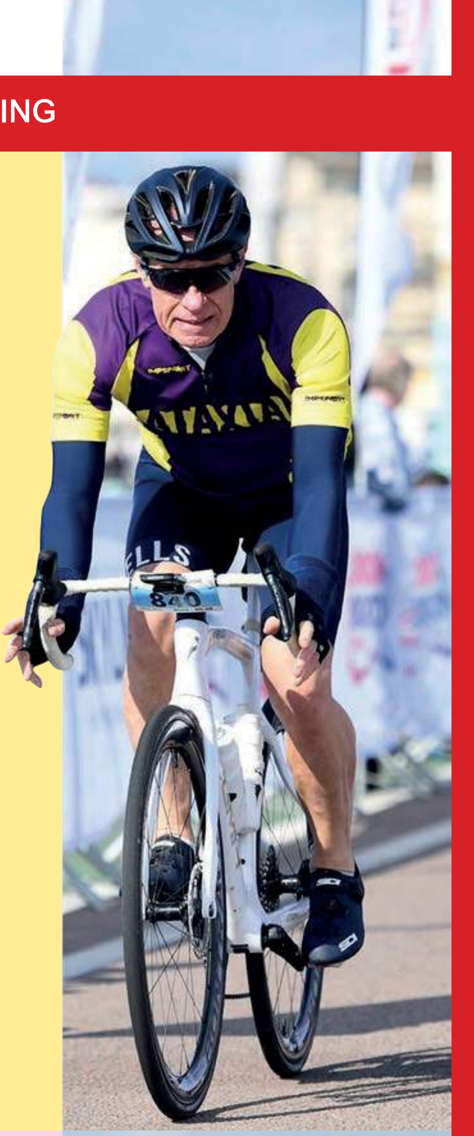
Are you ready to take on an unforgettable challenge? The London to Brighton Cycle is just around the corner! This iconic ride spans 54 miles, taking you from the bustling streets of London to the stunning Brighton seafront.

Ready to ride for a cause? Whether you're an experienced cyclist or looking for a new adventure, this is the perfect way to test your endurance and raise vital funds for Ataxia UK. Every mile you pedal helps us move closer to finding a cure and supporting those living with ataxia.

- Free Entry – we pay while you pedal for a cure!
- Free technical cycling jersey
- Free water bottle
- First class support all the way to the finish line!
- Water stops
- Medal & entry to Brighton Village

Date: *Sunday 15th June 2025.* ***Distance:*** *54 miles*
Starting Point: *Clapham Common.* ***Finish Line:*** *Brighton Seafront*

Register your interest by emailing ***fundraising@ataxia.org.uk***



Kiltwalk 2025

Join us for Kiltwalk 2025 to help make a difference with Ataxia UK!

With affordable registration fees and the addition of the new Big Stroll route, it's easier than ever to step up for vital research and support for those affected by ataxia.

Why Walk for Ataxia UK?

- Every step you take helps improve lives
- Support essential research to find a cure
- Receive an Ataxia UK t-shirt and full fundraising pack
- Get the encouragement and tools you need to achieve your fundraising goals

Event Dates:

- **Glasgow** – April 26-27
- **Aberdeen** – June 1
- **Dundee** – August 17
- **Edinburgh** – September 14

Register for FREE with Ataxia UK and be part of a powerful community. Rally your friends, family, and colleagues, and let's make 2025 unforgettable!
To get involved email us at: ***fundraising@ataxia.org.uk***

Fundraising thank-yous

A massive round of applause for **Ian Smith (1)**, who completed the epic Southwest Coast Path and raised a staggering £5811.25 (inc GA). That's an amazing achievement worth celebrating.

A heartfelt shout-out to **Paul & Lauren Robinson (2)** for smashing the Lyke Wake Walk and raising an impressive £1210. Your dedication is truly inspiring.

Thank you to **Derek Wood (3)** for hosting the IAAD Stall and raising £44. Your dedication to the cause shines brightly!

Kudos to **Eileen Baker (4)** for gathering support through your Family Collection and contributing £30. Every bit makes a difference.

A warm thank you to **Denise Walters (5)** for hosting the Annual Yoga Summer School and raising a fantastic £165. 'Namaste' for your generosity!

Thanks, and congratulations to **Andre Van der Schyff (6)** for the amazing achievement of completing the London Big Half and raising an incredible £115!

Huge appreciation to **Gayle Morrison (7)** for lacing up for the Kilt Walk Edinburgh and raising a wonderful £406 with Gift Aid. Much appreciated!

A special cheer for **Emily Banks (8)** for bravely completing a Sky Dive and raising an incredible £988 with Gift Aid. What a courageous feat!

An enormous round of applause for **Ewan Barker, Gabriella McGrath, & Jack Doherty (9)**, who completed the Great Scottish Run and raised an outstanding £3803 with Gift Aid. What a team effort!

Thank you so much to **Lydia Howell (10)** for combining a Cake Bake Walk and Litter Pick for IAAD, raising an incredible £1355 (inc GA). Such creativity and dedication!

A big cheer for **Jayne Cowie (11)**, who took on the Kilt Walk Edinburgh and raised an excellent £422 with Gift Aid. Brilliant work.

A massive well done to **Anna Hipwell (12)** for completing the Manchester Half Marathon and raising a phenomenal £2295 with Gift Aid. What an amazing achievement!

A big thank you to **Craig Prickett (13)** for also completing the London to Brighton and raising a great £212.50 with Gift Aid. Keep up the amazing work!

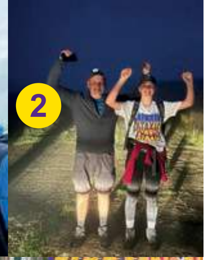
A huge thank you to **Meria Sukanen & Kevin Burgess (14)** for their amazing show at the Superhero event raising an amazing £1,000!

A huge thank you to **Sarah Campbell (15)** and mum **Patricia Curtis** for bravely taking on the Barefoot Walk, raising a phenomenal £4450 with Gift Aid. What an incredible effort.

Thank you to **Lucie, Amelia Dews & Family (16)** for conquering the Worcester City Runs Half Marathon and raising a fantastic £1503 with Gift Aid. Your teamwork is amazing.

Our heartfelt thanks to **April Austen (17)** for supporting the cause through the Quaker Meeting, raising a fantastic £1020. We are so grateful for your kindness and support!


1


2


3


4


5


6


7


8


9


10


11


12


13


14


15


16


17

A massive well done to **Jade Abraham (18)** for bravely taking on a Sky Dive, raising a breathtaking £1670 with Gift Aid. Your courage inspires us all!

We are so grateful to **Daniel Fraser (19)** for completing the Kilt Walk Edinburgh and raising an outstanding £1342 with Gift Aid. Way to go!

A big thank you to **SQS Ltd** via **Martin Jones & Pam Scott (20)** for your thoughtful donation of £214. Your generosity makes a real impact!

We would like to thank **Lucy & Thomas Riley (21)** for completing the junior and mini–Great North Run in aid of Ataxia UK. Raising an awesome £2366 inc Gift Aid (GA).

A big round of applause to the **North Cornwall Whist Holiday Group (22)** for their generous Draw, contributing £600. Your continued support is invaluable!

An enormous thank you to **Cody Embley (23)** for your generous donation of £1124. Your kindness is making a real difference.

High fives to **Nigel Foster (24)** for tackling the London to Brighton challenge and raising an incredible £1994 with Gift Aid. What an achievement.

A special thank you to **Thomas Fraser (25)** for taking part in the Kilt Walk Edinburgh and raising £250 with Gift Aid. You're making a real difference.

Kudos to **Yvette Loach (26)** for taking part in the IAAD Walk with support from Puretone Ltd raising an amazing £210. Every contribution helps make a difference—thank you!

Well done to **Shirley Fraser** (right) for stepping up and completing the Kilt Walk Edinburgh, raising a fantastic £322 with Gift Aid. Superb effort.

Hats off to **Darren Ashton-Lake** for your efforts in the collection, raising £252. Your commitment is so appreciated!

We extend our heartfelt gratitude to **The Lodge of Harmony and Progress** for your generous Donation of £250. Your support means the world to us!

Hats off to **Rhiannon Garrity** for smashing the Great Scottish Run 10K, raising an impressive £907 with Gift Aid. Your hard work shines brightly!

Well done to **Ella O'Neill** for finishing the Amsterdam Half Marathon and raising a fantastic £697 with Gift Aid. Your determination is inspiring!

A tremendous shout-out to **Manisha Bains, Amandeep Athwal & Sandeep Sahota** for taking on the Half Marathon Morun and raising a breathtaking £4564 with Gift Aid. Incredible teamwork!

A warm thank you to **Deane Morrice** for your generous donation of £200. Your kindness makes a difference!

A heartfelt thank you to **Amy Hall** for hosting a wonderful Jewellery Stall and raising £50. Your efforts are truly appreciated!

A special thank you to **Joan Williams** for the Tin Collection in November, raising a fantastic £320.33. Your dedication and effort are so appreciated!


18


19


20


21


22


23


24


25


26

All about autoimmune and gluten ataxia

The gluten free diet

Hi, I'm Carol (below left) and I run the "Autoimmune and Gluten Ataxia" support group for Ataxia UK. I was diagnosed with 'possibly ataxia' and my friend Amanda (below right) told me that eating gluten can cause ataxia in some of us, so I did lots of reading and tried a gluten-free (GF) diet.

The GF diet is a way of life! For those with gluten ataxia it needs adhering to 100% of the time. Thoughts of 'just one crusty roll won't hurt' because it will! I have been GF now for over four years, it isn't easy and I am still learning. It messes up your social life and family celebrations. When we have positive signs that our symptoms of ataxia have stabilised and our TG6 test is negative then that gives us the motivation to continue to be GF.

A dietitian from Coeliac UK talked to our group about 'cross contamination'. Someone spreads their toast with butter and dips the knife back in the butter and so contaminates it with gluten. Using the same toaster for ordinary bread and GF bread etc, and don't forget your pet's food. Unless you have a true gluten free kitchen then cross contamination can happen.

Food production lines are another source of cross contamination, crisps are a good example. It is not enough to read the label and note that there are no gluten containing ingredients because the many varieties of products companies produce mean it can all be on the same production lines, so contamination is possible'

Coeliac UK have an app that is useful for those newly GF but that brings into question the <20ppm rule (less than 20 parts per million rule). We know it applies to coeliacs but does this apply to gluten ataxia too? We don't know. We are all different and our tolerance levels will vary. Can <20ppm gluten free food build up in the body? Again, we don't know, for some it will, and others will be able to tolerate it.

Being "gluttoned" is the expression we use when we have eaten gluten by accident, and it has a detrimental effect. Digestion, dizziness, balance is worse, walking and speech too, fatigue and coordination can all be affected. We are all different and any of these or more symptoms could affect you when "gluttoned". You try and think back to what might have caused it? Coeliacs have a reaction time quickly, usually within three hours but those with gluten ataxia and neurological problems it can be one to four days or even longer and certainly these symptoms can take a long time to reverse.

Everyone's body is dynamic and ever changing so what we eat on one occasion might have no effect - but might do at another time. It's complicated and if newly gluten free then it might help to keep a food diary and note how you feel day by day too.

The Traditional gluten free diet will be replacing a normal loaf of bread with the GF version, replacing normal pasta with GF pasta, and so on. This is the case in gluten free ready meals too. However, some neurologists are now warning us, do not go down the FREE FROM aisle to buy these replacement foods. These foods can contain emulsifiers, gums, rice flour and corn flour, cheap ingredients that mimic the action of gluten and can have a negative effect on some of us. A good rule is if you can't pronounce even one of the ingredients then don't eat it!

It would be helpful for some to have structured guidance or GF eating plans, but we are all different and so need to do what is right for us, our own health and wellbeing. Yes it's hard and complicated and what a headache this all is and we live with ataxia too!

If your symptoms do not respond positively to a GF diet then it might be worth avoiding all ultra processed foods (UPF) which is becoming popular now, and not just with the GF community. This means sticking to eating foods that are in their most natural form as possible eg. vegetables, fruit, meat, poultry and fish, nuts and seeds. It can be expensive, mean lots of shopping trips, being imaginative with recipes and planning in advance meals that take time cooking.

Again, we are all different and this 'one step' further will not be necessary for those who can tell by their symptoms that a 'Traditional' gluten free diet is working for them. But if your TG6 test is not yet negative then a natural whole food and UPF diet is worth considering, also cross contamination too.

The ultimate aim for us all is to stabilise or even reverse ataxia!

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

Riding beyond limits: Mari's journey to victory

My name is Mari Durward-Akhurst. I have ataxia caused by a very rare condition that nobody knows very much about! I am a full-time wheelchair user; my condition affects all four limbs and my trunk.

I am a Paralympic bronze medalist and European silver medalist in Para Dressage. I am also a mentor to four up-and-coming riders and one Boccia player. I have recently become a public speaker.

I started riding when I was three years old as my Physiotherapist at the time thought it would be a good form of therapy. It was love at first sight and horses soon became a huge part of my life.

When I was younger, I used to get bullied a lot as at this point, I wasn't in a wheelchair and children couldn't see why I got to miss PE etc. Horses were and still are my paradise; they have never judged me. They are my legs and together we excel.

Riding has given me a huge sense of belonging and horses are what got me through all the bullying and the reason I get out of bed every day and keep fighting!

The whole experience was incredible, and memories were made that will last a lifetime. Everything was bigger and better than I expected, and it was just absolutely amazing competing on the World Stage with the view of the Palace of Versailles in the background and crowds all around you.

The preparation was very intense, I attended five competitions which all acted as selection events starting in March and going onto July, so we had two weeks at home and then we were off competing again. As well as all the training on the horse I also had to do lots off the horse, and I took up reformer Pilates which really helped my position on the horse. This was extremely full on, on top of everything else I already did.

It was amazing, a real dream come true, and it was so nice to meet a variety of different people all with different disabilities. We didn't stay in the Paralympic village so the majority of the people we saw were Para Dressage Riders and their support teams. We did get to go to the Paralympic village before we attended the closing ceremony, which was amazing, just very wet! It was fantastic to meet so many disabled people from all across the world using all different forms of transport such as scooters, electric chairs etc.

My ataxia has thrown a lot at me over the years, but I've always had that goal to get to the Paralympics and I've done it!

Winning a Bronze Medal was incredible, sitting on that podium hearing your name being called out and then having the medal put around my neck, it's hard to put into words how much that meant to me.

I firmly have my eyes set on the LA 2028 Paralympics and reaching the top of the podium! Short term I am aiming for next year's Europeans and then hopefully the World Championships the following year.

My main message is that if I hadn't taken every opportunity I had; I wouldn't be where I am today! So take every opportunity you are given and follow your dreams!

Ataxia has taken an awful lot away from me and left me severely disabled, but I still have been able to become a Paralympic Medalist! I like to show that nothing is impossible there is always a way to do something although it might just not be in the most conventional way.

Navigating life with ataxia through poetry

Our friend, Elizabeth, has kindly shared her ataxia journey with us and wrote a heart-warming poem.

Hi! I'm Elizabeth and I have ataxia. There was no family history, no warning. I developed it 14 years ago when I was 53. It developed very quickly. Prior to the illness I was a vice-president in banking and did mapping, business intelligence and customer profiling. I worked for a few years after the onset but resigned due primarily to a lack of energy. Because of my condition, I have moved to a one-story house, now walk instead of run, do art that doesn't require fine work, and so on. A lot has changed – but not the core of who I am.

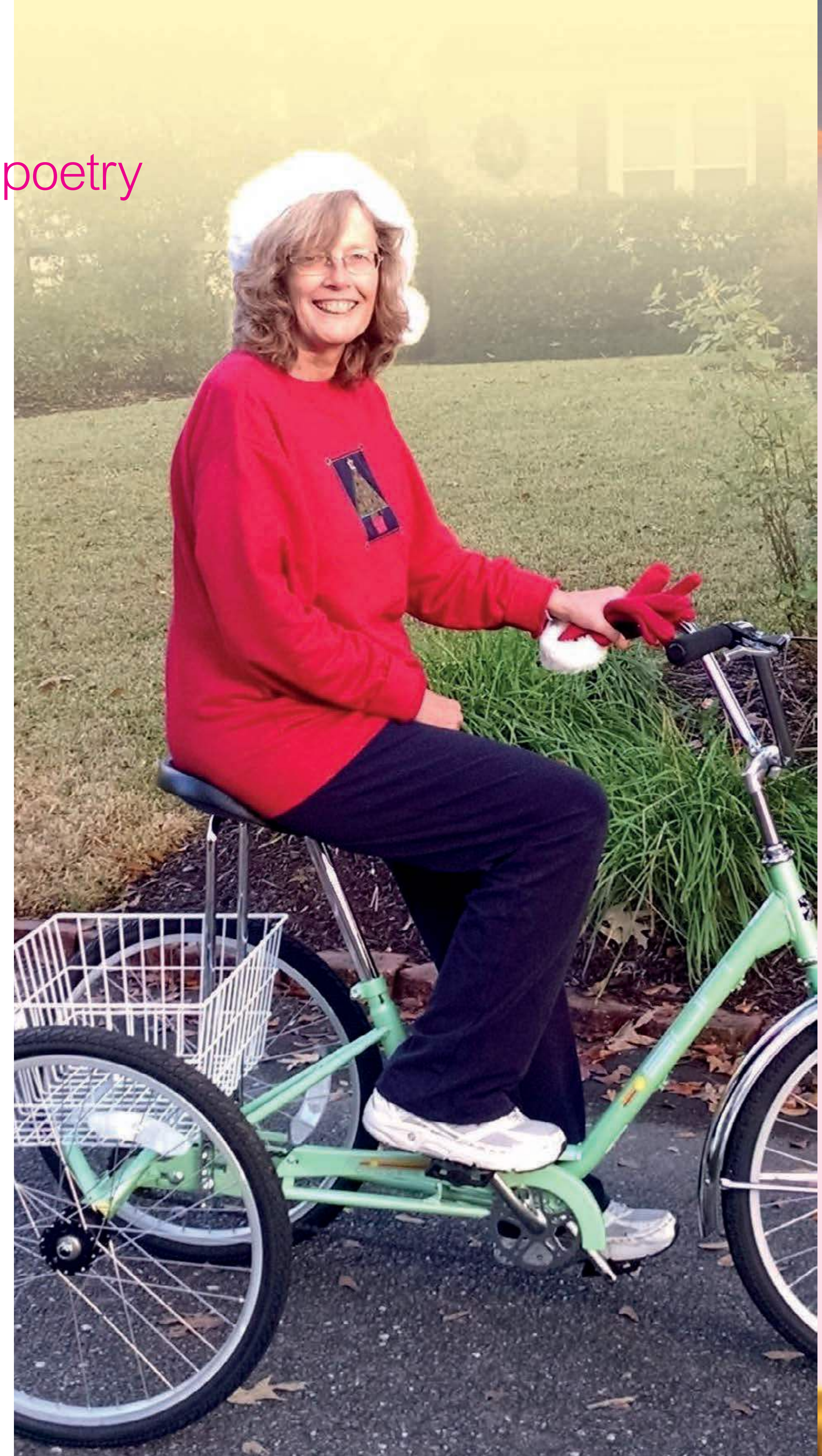
I wrote the poem, 'Differently Abled', primarily to help others understand my illness - particularly that my mind was fine, and that my limitations were mostly physical. I find people want to help the 'disabled' one – but on their terms often. I sometimes take the time to let people know that the best way to help is primarily to ask if I want some help…especially at self-checkouts where a store clerk will rush in to do it for me instead of asking if that's what I'd like. I've been 'helped' across streets when I didn't want to cross. I've had people move chairs to where I don't want to sit, and so on. I find that people will assume what's needed rather than asking what I need or desire. But sometimes I just smile and say, "Thank you." It's hard, though.

Most of my writing is poetry and about what's happening to me internally. I started as a young teen, writing about my family and my growth in faith. I also sketched and would sketch people in my life as well as some self-portraits. William Blake, a romantic poet, wrote 'Songs of Innocence and of Experience.' It shaped who I am and gave me the recognition that unless someone has experienced what I have experienced, they are incapable of truly understanding. Therefore, my poetry is not necessarily an attempt to have people understand as much as it is my attempt to help others try to have some insight and effective empathy.

Everyone has to find what works best for them to cope with ataxia. Personally, ataxia took a lot from me – but not the essence of who I am. Since creativity helps me grow, I stay creative. Thus, I now type – slowly – because my handwriting is poor. I decorate my cane to match the season. Recognising that hand tremors keep me from sketching and bead weaving, I now make cards (this doesn't require the same type of fine work). I lean on my faith a lot, too. I also take advantage of aids to help me – including physical (such as canes and rollators), occupational and speech therapies. Basically, I try not to sacrifice who I am to ataxia.

I also worked in the addictions field and in that field, it was important to have a 'relapse plan'. It was important to recognise that relapses happen and to plan what to do at that time. Likewise, this condition is HARD. We're likely to get depressed. It's important to me to have a list of things I like to do – and can do! Watching a favourite movie while eating some popcorn. Talking (albeit slowly) with a friend. Enjoying the sounds of nature around me or on a CD. Doing my limited artwork. Listening to an audio book when I'm too tired to read. When I feel down, it's hard to take action. Thus, I tell myself a baby step is okay – if I want to go for a walk, for example, I give myself permission to just make the effort to put my trainers on. Baby steps.

I try to be kind to myself. I can go to a pity party; I just can't stay there!



DIFFERENTLY ABLED

by Elizabeth Brown

I'm differently abled,
Not disabled.

Often, our world values a person
By his or her productivity.
When one becomes 'disabled',
So much changes!
"Where do you work?"
"What do you do?"
Becomes silence.

People are nice.
They reach out,
Want to help the 'disabled' one.

My body has changed
But not my mind.

"The spirit is willing
But the flesh is weak"
Has so much meaning now!

I tire easily,
But my brain is still going.
I have thoughts to share,
But forming words is hard.

So much has changed:
Singing is hard.
I no longer lector.
Beading and other artwork
Take much more time.
Walking in and of itself
Has become exercise.
Biking with a ten-speed
Has become pedalling slowly
With a three-wheeler.
But I tread on.
Even though I tire easily.

I love to do.
So, here's to me!
And to all those that support
And enable me.

How to search the internet to actually find what you're looking for!

Jess, Ataxia UK's Helpline and Advocacy Manager, has written this very helpful article about searching the internet:

I don't know if you have ever tried to search for something on the internet, you enter a word or phrase into a search engine and instead of what you were looking for up comes a lot of irrelevant information. This is time consuming as well as frustrating especially if you are looking for access to help or support it can feel very demoralizing, adding to an already difficult process. There are things that you can do to help you get to the specific information you need.

Before doing your search define your topic as completely and succinctly as possible, write down exactly what you are looking for, why you are looking for it and what you are not looking for. This will help you find the best key words for your search. Here are some tips:

Key words

A search engine looks for key words in websites when searching your enquiry and not the question you have asked, so the more key words you can provide the better. For instance, if you are looking for a neurologist with an interest in ataxia – you might search neurologist with an interest in ataxia, this though might come up with hundreds across the world so add in UK to define your search.

Put key words in quotes

Once you have your key words put them into a phrase. If you want to search a certain sequence of words together, use quotation marks on the outside of the phrase. An example of this: "neurologist with an interest in ataxia". Without the quote marks on the end of the phrase a search engine would independently search for websites containing words "neurologist" and/or "ataxia" in any order.

Make sure your phrase doesn't suggest the answer to your question: "chocolate is better than vegetables" will get you more results that say chocolate is better than vegetables and "vegetables are better than chocolate" will do the reverse.

Use + and –

If you want to limit your search further, you can use a minus (-) sign to exclude words that you want to avoid in your search. Doing so filters out stuff you don't need. So, for instance you could put neurologists with an interest in ataxia -London if you knew that you wouldn't be able to get to London for instance.

You can also add a plus (+) sign to inform the search engine of specific words that must appear in your search results. For instance, neurologists with an interest in ataxia +Sheffield.

Consider advanced search tips

You can also limit your search by type, time or country. Most search engines have tabs at the top that let you choose between websites, images, videos, news even shopping and maps. Many also have advanced search tools that let you limit your search to just one country, a certain time (the last day, week, month, year or a specific range you specify).

You can click the tools tab in Google at the top of the screen and sort by relevance, date or use the Advanced Search option.

When searching the internet for information on a particular topic it is important to consider the source of the information as there is a lot of misinformation out there. Stick to well-known trusted sites like NHS, charity websites and the government website. It is also good to remember that some search results are listings paid for by companies to promote their products or services so results may be biased towards them. These can be identified by words such as 'Ad' or 'Sponsored Results' and normally appear at the top of the page and in a column on the right of the page.

I hope that this article gives you some pointers in how to search the internet effectively and safely. If you do still struggle to find the information that you are looking for regarding, you or your loved one's diagnosis. Please do get in contact with the Helpline either by emailing us at ***help@ataxia.org.uk*** *or calling us on* ***0800 995 6037****.*

If you need any technical help to get online initially then ***Ability Net*** *might be able to help you. Ability Net is a UK charity set up to help older and disabled people access technology you can contact them for support via their website:* ***https://abilitynet.org.uk*** *or giving them a ring on* ***0300 180 0028****.*

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