

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 223. Autumn 2023



Last chance to
book your
tickets for the
first-ever
hybrid
conference

on **October 20th & 21st!**
See pages 4 & 5 for more info

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ATAXIA

Ataxia UK

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CEO's Introduction

As October approaches the excitement at the Ataxia UK office is building in anticipation of our first in-person Annual Conference in four years, amplified by the fact that this will be our first-ever hybrid Conference.

I'm looking forward to welcoming many of you to the East Midlands Airport Radisson on 20th and 21st October. (See p4 & 5) If you haven't booked yet, don't miss it! There's still time to secure your place at the in-person conference, or online. The hotel's discount on accommodation has finished, but Ataxia UK is subsidising bedroom costs, and at the time of writing, there are still bursaries available for people on means-tested benefits.

July saw the start of our second National Lottery Community Fund grant which is funding the development of our information services and in early 2025, and the commencement of our **Specialist Ataxia Nursing Service** in the South West of England (See p21). We are grateful to the Community Fund for awarding us £499,251 to be spent over the next 5 years and we are busy raising funds to complete the project. See p14 & 15 for information on this year's **Big Give** campaign.

Finally, our thanks go to **Rebecca Holt** for 5½ years' service as our **Fundraising and Events Manager**, **Ruby Wallis**, **Senior Research Officer** and **Rosie Gilbey**, **PA to CEO & Office Manager**. They left us for pastures new and will be very badly missed. With their departure, we would like to welcome many new (& old) faces to the Ataxia UK team – **Mary Barron** as **Research Officer**, **Hanif Abdulmuhit** as the **Fundraising & Community Events Manager**, **Scarlett Parr-Reid** as **Science Comms Intern**, **Lucy Porter** as **PA to CEO & Office Manager** and **Anastasia Georgousis**, who will work on all the **upcoming conferences**.

We're also excited for Rebecca to join us at the Ataxia Classic, and Ruby will be back for Annual Conference. I hope to see you there too!

Best wishes,

Sue Millman



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Last chance to book for Annual Conference 2023!

The Annual Conference is now just around the corner! Tickets are still available for both Friday 20th and Saturday 21st October, but make sure you book as soon as you can to avoid disappointment.

So, far we've seen an amazing uptake on Conference booking and we're very excited to meet so many new and old Friends in person. However, if you cannot attend the conference in-person at the Radisson Blu, East Midlands Airport, do not fret!

For the first time ever, we're holding a hybrid conference, meaning you can watch the platform speeches, a choice of FA or CA talks and Doctor's Q&As, as well as the afternoon breakout sessions, including a choice of pilates or hypnotherapy. **You can secure your virtual ticket for only £15!** And the best part? All of this will be streamed in high resolution with a multi camera set-up, putting you right at the heart of the conference.

TO BOOK YOUR TICKETS, AND FOR MORE INFORMATION HEAD OVER TO <http://alturl.com/9vvyw>

Our special bedroom rate at the Conference hotel (Radisson Blu) has now expired and changed to the 'best available rate'. We recommend checking Booking.com to see if the Radisson Blue, East Midlands Airport bedroom rate is cheaper there. Don't forget, there is also a wide range of overflow hotels nearby that may offer a variety of cheaper rates and accessible rooms. Visit our website for more information.

If you require an ambulant or fully accessible bedroom, please let us know using the booking form on the Conference page on our website at: <http://alturl.com/9vvyw>, or email conference@ataxia.org.uk and one of our team will be in touch to discuss your requirements.

Please note: the Radisson Blu offers free cancellation up to 7 days before your stay and the overflow hotels offer free cancellation up to 3 days before your stay.

ROOM SUBSIDY

For those staying over at the Conference, whether in the Conference or overflow hotels, we will be offering a £30 per room per night subsidy.

This will be reimbursed to you after your stay at the conference, once you send receipt of your stay to conference@ataxia.org.uk

*If you have any questions about the bedroom subsidy, please email Ataxia UK directly on conference@ataxia.org.uk or call **0207 582 1444***

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BURSARIES

There are still some bursaries available for conference attendees in receipt of means-tested benefits. A bursary will allow you to be reimbursed 50% of all conference costs. This includes your travel, bedrooms and all conference tickets. If you are on means-tested benefits and are interested in applying, please indicate this when filling in your booking form on the Ataxia UK website.

If you have already booked your conference tickets but would like to apply for a bursary, please email our team at conference@ataxia.org.uk. We will then ask you for some further information and allocate the bursaries on a first-come-first-served basis.

PROGRAMME

We are so excited to share details of our the Annual Conference programme! You can expect...

Friday 20th October

From 11.30am: An in-person **All About Ataxia** session run by **Shana de Figueiredo Scholtz** and our wonderful volunteers!

Evening: There will be a street food buffet from 7.15pm, and a 16-30s Group Social Evening.

Saturday 21st October:

From 8.30am: The conference will begin with a welcome from the superb **Paul Coia**. There will be an Ataxia UK update from our CEO, **Sue Millman**, and a talk from innovative social research platform, **NeuroLife Now. It Works for Me** will be delivered by people with ataxia looking at IVs and FA, modelling and acting, and collecting Underground stations, and also an assistance dog demonstration!

We will have FA and CA research updates from Ataxia UK's research team, and a talk delivered by **Anne Neumann** from **Biohaven**. There will also be Doctor's Q&A sessions with **Prof Paola Giunti**, **Dr Shpresa Pula** and **Prof Andrea Nemeth**.

There will be afternoon breakout sessions on mindfulness, neurophysio, genetic testing, make-up tutorials, benefits and speech therapy, as well as virtual sessions for pilates and hypnotherapy!

A talk from the CEO of **Disability Rights UK**, **Kamran Malick** and presentation of awards will conclude the day, followed by a seated dinner with entertainment from our Conference favourite, the enigmatic **Steve Price!**

We really hope to see you all at the Annual Conference. A full agenda with times will be added to our website shortly, so keep an eye out! *If you have any questions about the conference, please email conference@ataxia.org.uk*

Euro-ataxia conference 2023

Euro-ataxia, of which Ataxia UK is an active member, is the federation of 20 European ataxia patient organisations. Every year, Euro-ataxia organises a conference to enable patient groups across Europe to network and hear updates on research for the ataxias.

The 2023 Euro-ataxia research conference was held in Pieria, Greece, on the 20th May. More than 50 participants attended physically, including patient organisation representatives, people with ataxia, researchers, clinicians and pharmaceutical company representatives, as well as more than 20 who followed the event online. The event was organised by the Greek patient group (HEFAA) and Euro-ataxia, with support from Ataxia UK.

The presentations covered a wide range of topics, including gene discovery, improvements in diagnosis, emerging and existing therapeutics, natural history studies, and biomarkers of ataxia. Prof Marios Hadjivassiliou from the Sheffield Ataxia Centre started the day with an overview of the ataxias, and recent advances in diagnosis and treatment. Prof Paola Giunti from the London Ataxia Centre presented her work on biomarkers for the spinocerebellar ataxias (SCAs). Prof Jörg Schulz discussed the importance of natural history studies, including the European Friedreich's ataxia study (EFACTS), taking place in a number of countries across Europe, including in the UK at the London Ataxia Centre. Prof Anja Lowit, speech and language therapist, and Mariana Kotzamanidou, physiotherapist, gave updates on their research into managing the symptoms of ataxia.

Flash talks from four early career scientists were included to promote their research findings. Engaging junior scientists in a patient-centered research event such as this is beneficial in broadening their perspectives on the needs of people with ataxia, highlighting the importance of their research and encouraging them to continue their careers in ataxia research. The conference also included a patient panel, where two people affected by ataxia and one family member were able to describe their experiences. This valuable contribution highlighted the impact of living with ataxia to researchers and clinicians. Interviews were also conducted with patient group representatives, researchers and clinicians in order to get their perspective on important issues facing the ataxia community.

Recordings of these interviews will soon be available on the Euro-ataxia website, along with the full conference agenda and some of the presentations: www.euroataxia.org/research-overview

The conference received funding from the European Union's Horizon 2020 research and innovation programme under the EJP RDCOFUND-EJP N° 825575, and we were pleased to receive sponsorship from PTC Therapeutics, Biohaven, Vico Therapeutics, Ariti and Ardius.



SKYCLARYS update

On 28th February 2023 Omaveloxolone (now known as SKYCLARYS) was approved for the treatment of Friedreich's ataxia (FA) in over 16s in the US. Since then, we have been updating the ataxia community with news of Reata Pharmaceutical's plans to get regulatory approval in other countries, and the current situation in the US.

Reata applied for approval to the EU regulators (the EMA) at the end of 2022. They received a list of questions from the EMA and plan to provide responses in the third quarter of 2023. If the EMA approves SKYCLARYS this will not automatically result in approval in the UK. To make SKYCLARYS available in Great Britain, Reata Pharmaceuticals will need to apply to the UK regulators (the MHRA). In Northern Ireland drugs currently go through EMA approval, but under the Windsor Framework (a post-Brexit legal agreement between the EU and the UK) this will change, and medicines will be regulated by the MHRA. Ataxia UK is doing everything we can to support and encourage Reata Pharmaceuticals to seek approval for SKYCLARYS in the UK.

Currently, SKYCLARYS is only approved for people with FA in the US aged 16 and above. In the US, Reata are planning to request a meeting with the FDA to discuss expanding the approval to those under 16. They plan to conduct an initial paediatric study in the US in the final quarter of 2023. This will look at the safety of SKYCLARYS and how it is processed by the body in those with FA under 16. In the EU, Reata has received a positive opinion from the EMA on their paediatric investigation plans and they have recently requested scientific advice from the EMA on the study design. An additional paediatric study will be finalized once Reata has received feedback from the EMA and FDA.

On 28th July 2023, Reata Pharmaceuticals announced that they have entered into an agreement under which Biogen will acquire Reata. We will be keeping you up-to-date with what this means for the FA community. For updates, register to receive our SKYCLARYS newsletter:

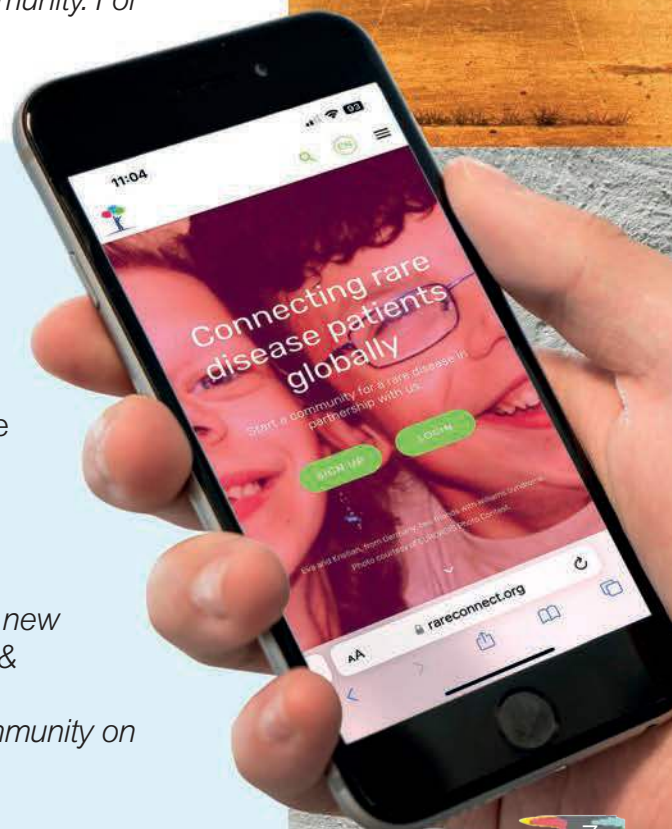
www.ataxia.org.uk/omav-updates

RareConnect platform is closing

RareConnect is an online platform which allows people with rare conditions to connect on a global level.

Unfortunately, the owners of RareConnect have decided to retire the platform. From 1st December 2023, RareConnect will become view-only. Users will be able to read posts made before 1st December, but they won't be able to create new posts or use the private messaging function. RareConnect includes forums for several types of ataxia (e.g. ARSACS, DRPLA).

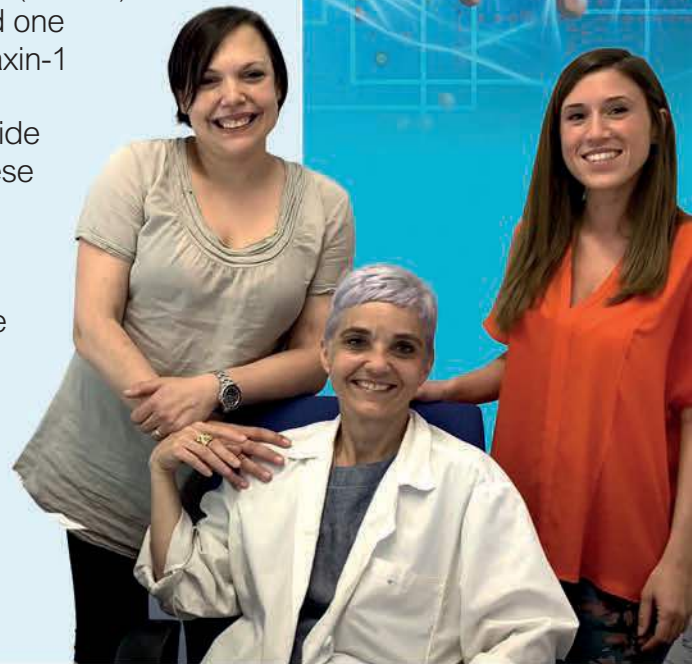
If you use RareConnect for support, and would like to find a new source of support, please consider looking into our Branch & Support Group network and our online support groups:
www.ataxia.org.uk/support-services or join the ataxia community on Health Unlocked: **<http://alturl.com/w4ege>**



Personalised gene editing approach for the treatment of spinocerebellar ataxia type 1

This project led by Dr Salvatori at the University of Ferrara is aimed at developing a future treatment for spinocerebellar ataxia type 1 (SCA1).

SCA1 is a genetic ataxia caused by a mutation in the ataxin-1 (ATXN1) gene. People with SCA1 have one mutated ATXN1 gene, and one healthy ATXN1 gene. The mutated gene produces a toxic ataxin-1 protein. This project aims to identify differences between the healthy and unhealthy genes; these are called single nucleotide polymorphisms (SNPs). The researchers can then exploit these newly identified SNPs to specifically cut out only the mutated ATXN1 gene, thus preventing production of the toxic ataxin-1 protein. To identify SNPs, the researchers are currently sequencing the DNA of fourteen people with SCA1. They are then using a gene editing technique called CRISPR/Cas9 to cut out the mutated gene. The team will assess how well the production of the toxic ataxin-1 protein has been reduced by using a label, called an antibody, for the ataxin-1 protein. The grant from Ataxia UK will enable the group to purchase a custom-made antibody to carry out these experiments. This strategy will be tested on cells taken from people with SCA1, before being tested in animal models.



New Ataxia UK-funded research into Friedreich's ataxia

This project builds upon research in Niemann Pick Type C (NPC) (a rare condition that can cause ataxia) which has led to a discovery that may be relevant to Friedreich's ataxia (FA).

In NPC, cholesterol (a type of fat) reacts with an unstable molecule known as reactive oxygen species (ROS) in cells. This reaction produces specific bile acids, the levels of which are raised in NPC. It is known that in FA, there are increased levels of ROS which causes oxidative stress and damage to cells. This could lead to an increase in bile acids, as in NPC. Previously, researchers at the London Ataxia Centre found raised levels of specific bile acids in a person with FA. They hypothesise that this increased level of bile acids could be a good indicator of the damage caused by the ROS.

This project will investigate whether levels of specific bile acids are also increased in other individuals with FA, by testing blood samples from 50 people with FA. They will also investigate whether measuring specific bile acids levels could act as a biomarker in FA. Biomarkers are a measure that give us information about either disease progression, or how well a disease has responded to treatment. Biomarkers are crucial to the development of successful clinical trials.



Positive results from a study of non-invasive brain stimulation in ataxia

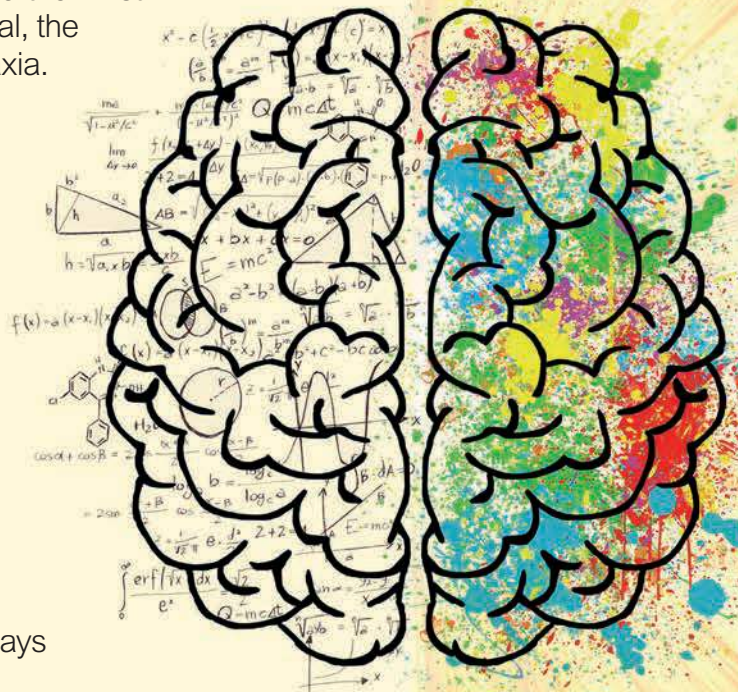
Dr Barbara Borroni and colleagues at the University of Brescia, Italy (below), have recently completed a small, pilot study comparing two techniques of non-invasive brain stimulation (NIBS) in people with ataxia

NIBS involves applying a portable machine to a person's scalp with the aim of changing the activity of brain cells. The two techniques studied were transcranial direct current stimulation (tDCS) and transcranial alternating current stimulation (tACS). Both techniques use the same machine to apply a low electrical current to the scalp. They vary in the way the electrical current is applied.

This is the second trial conducted by Dr Barbara Borroni and colleagues assessing NIBS in people with ataxia. We described their first trial in issue 215 of Ataxia Magazine. In their first trial, the researchers assessed only tDCS in people with ataxia. They found that tDCS therapy improved the clinical rating scales used to measure ataxia. tACS has not previously been studied in ataxia. Ataxia UK funded this second trial where the researchers aimed to reveal whether tACS lead to a greater improvement in ataxia compared to tDCS.

The researchers enrolled 26 people with a diagnosis of neurodegenerative ataxia. The study consisted of three different treatments: tDCS, tACS and a placebo. Every participant received all three treatments in a crossover study. The researchers randomly divided the participants into three treatment groups. Each treatment group received the three treatments in a different order. A treatment session lasted sixty minutes and seven days were left before administering a different treatment.

To assess the impact of the treatments on ataxia, the researchers first used two clinical rating scales: the scale for the assessment and rating of ataxia (SARA) and the international cooperative ataxia rating scale (ICARS). They also used wearable sensors to measure more subtle changes in movements. Additionally, they used magnetic fields to assess the activity of an area of the brain called the cerebellum. This produced a measure called cerebellar brain inhibition (CBI). The researchers found that both tDCS and tACS significantly improved all measures of ataxia compared to no treatment. They additionally found that tDCS led to a significantly better improvement in SARA, ICARS and CBI compared to tACS. The findings of the two trials opens the door to more research into NIBS in ataxia. Dr Borroni said *'The next stage for this research is to conduct a larger study. We would also like to test the safety of using this device in the home environment, as this has not yet been shown.'*



Two steps towards speedier ataxia diagnosis

With the International Ataxia Awareness Day coming up this September 25th, we take a moment to reflect on last year's awareness-raising campaign.

As part of last year's effort, Friends and supporters shared copies of the Medical Guidelines with their GPs to speed up ataxia diagnosis. **Over fifty** people have requested **over one hundred** copies. Friends were also able to **participate virtually** by sharing a digital version of the Guidelines with their GP, and **over thirty** copies were downloaded from the Ataxia UK website last year.

Sharing awareness of ataxia is crucial. As our Friend Ed put it: ***"Ataxia awareness is important every day, but IAAD is a great time for those affected by ataxia to raise awareness together. Delivering the Medical Guidelines should result in earlier diagnosis and better ongoing care in the community"***.

The Medical Guidelines, created by Ataxia UK and healthcare professionals with expertise in ataxia, aim to provide recommendations for healthcare professionals on the diagnosis and management of people with progressive ataxia.

"Hi, my name is Hannah, and I have lived with an undiagnosed form of ataxia with sensory neuropathy for 17 years. Not knowing the exact nature of my condition or how it will progress has been tough. However, it is comforting to know that although we might be rare, we are not alone. Ataxia UK has allowed me to access a great support network, so I can talk about my symptoms and gain information."
- **Friend of Ataxia UK**

This year, we're encouraging Friends to share a copy of the guidelines with their local GP surgeries on or around 25th September to make sure no GP is left without these guidelines.

The Two Steps Towards Speedier Ataxia Diagnosis campaign creates an opportunity to make a difference and help bring an end to stories like Hannah's by **improving awareness of ataxia and in turn faster diagnosis and better care for the ataxia community with just two simple steps.**

So, what are these two steps, you ask? They're simple:

- 1.** Sign up for the challenge on our website at www.ataxia.org.uk/iaad2023 and we will send you an information pack with the medical guidelines.
- 2.** Get sponsored to walk, wheel, run or simply cover the distance to your local GP and give or email them a copy of the Medical Guidelines around 25th September. You can fly solo or take part with your family and friends.

That's it! If you're online, don't forget to take photos for social media with the hashtags **#Step2AtaxiaDiagnosis** **#IAAD** and tag Ataxia UK. Please also add our Twibbon (a badge that is shown on your profile photo) to raise awareness of ataxia. For everyone, whether you are online or offline, ask others to get involved! Be part of the change this year and help speed up diagnosis for the ataxia community with just two steps. Don't forget to gather friends and family to help raise funds and awareness.

For more information, email: communications@ataxia.org.uk or visit our website at: www.ataxia.org.uk/iaad2023



All About Ataxia PLUS Life Hacks

Have you ever been to an All About Ataxia seminar? If you have, you'll know how informative and supportive they are. If you haven't then we highly recommend them. All About Ataxia seminars aim to bring people who have a relatively recent diagnosis together to share information about ataxia, although we know that people who have been diagnosed much longer have also found them useful.

"Things really started to make sense during the seminar. I have significant fatigue and never knew that this could be caused by ataxia. I have eye symptoms that I can't explain and didn't know that they can also be caused by ataxia. The seminar has given me lots to think about and I hope that I can manage to get a referral to the ataxia centre in Sheffield where I might get more answers. I felt empowered by the incredible women in my break out group - Harriet, Rachel and Gemma. I think Ataxia UK is an incredible organisation and I hope to do my bit to help raise awareness and funds in the future."

– **Mary Owen (right)**

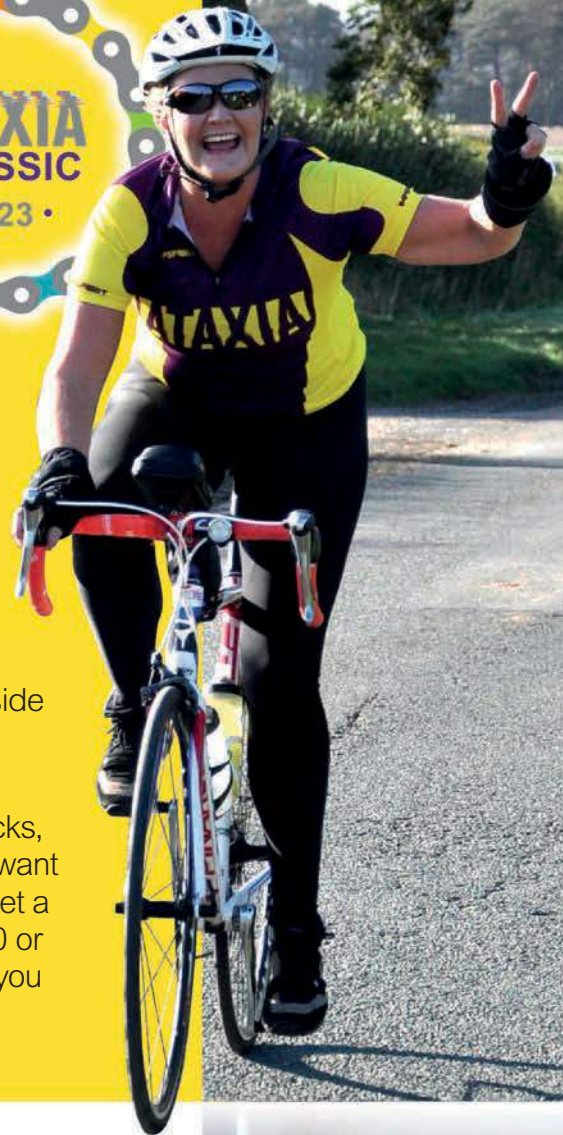
Many other members of the ataxia community that participated in an All About Ataxia seminar tend to agree how extremely useful they are in supporting them during the early diagnosis stage. This is why we're working on All About Ataxia PLUS. Just like All About Ataxia, All About Ataxia PLUS will bring people in the community together (whether you have ataxia, or know someone who does) to share information about a topic and provide the opportunity to connect with other people in a similar situation as you, sharing experiences and hopefully some tips!

We are delighted to announce the first in the series is ready to go ahead! All About Ataxia PLUS Life Hacks is debuting on the morning of Wednesday 4th October. This session will focus on the range of gadgets, aids and adaptations available to help people with ataxia live their best life. There will be tips on choosing the right gadgets and equipment and getting help to pay for things. And of course, there will be opportunities to connect and chat with other people in the community, ask questions and share advice, in breakout sessions facilitated by the fabulous Ataxia UK volunteers, all of whom have a diagnosis of ataxia themselves.

*The session will be hosted online, via Zoom, and we hope to see as many of you as possible there. You can sign up here: <http://alturl.com/de24f> but **HURRY**, as places are limited! If you have any questions at all please do get in touch. You can reach us via the Helpline by emailing help@ataxia.org.uk or calling **0800 995 6037**.*



Pump up your tyres, oil your chain and join us for the Ataxia Classic 2023!



There's still time to join us in Pocklington, Yorkshire on 24th September for this one-of-a-kind cycling event, hosted by Ataxia UK! Now certified by British Cycling, you can take on a demanding 102.6km challenge, a 51.6km adventure or a shorter 12km accessible route; ideal for those with adapted bikes.

You will have the opportunity to pedal through the Yorkshire countryside while raising vital funds. If you love cycling and want a brand-new challenge, the Classic is perfect for you!

Prepare to be amazed by breathtaking scenery, enjoy delicious snacks, and connect with fellow riders, making this a weekend you wouldn't want to miss. Every participant will receive a medal, and fundraisers will get a limited-edition Ataxia Classic water bottle! Everyone who raises £200 or more will also receive a high-performance cycling jersey - What are you waiting for? Sign up for the Ataxia Classic today at www.ataxia.org.uk/ataxia-classic-2023

The Big Ataxia Cake Bake 2023!

We are thrilled to invite you to our most delectable event of the year – The #BigAtaxiaCakeBake2023!

Due to the success of last year's Cake Bake, we encourage all avid bakers to join us for another year of baking shenanigans.

This year's Cake Bake will run from 6th November to 8th December. You can host a Bake Sale from your home, a local event, your workplace or make it a competition and host a Bake Off with your friends and family! The winner will win an awesome prize just in time for Christmas. Ataxia UK will send you an exclusive cake bake pack, free t-shirt and materials to help with your event!



To sign up for either event or for more information; contact Hannah via email at fundraising@ataxia.org.uk or call 0207 091 1594.

A big thank you to our fantastic fundraisers, who have shown great dedication these past few months.

Fundraising thank-yous

A soaring congratulations to **Frankie Hurley-Peet** (above) who took on a skydive, raising £1,000!

Thank you, **Kirsty Bennett (1)** who raised £940 and hosted a Dance-a-thon! Happy 21st Birthday **Henry Bowers (2)** and thank you to his Mum **Debbie Heritage** for hosting a casino and raffle party, raising £4,000!

Thank you, **Elliott Link (3)** for raising £1,184 by completing the Ironman 70.3.

Joanne McDougall and her awesome friends **Helen, Sally, Simon & Andrew (4)** raised £1,183 running the Manchester Half.

A Royal well done to **Fred & Max Worwood (5)** who made and sold crowns for the King's Coronation and raised £50!

Thank you **Westly Spenceley & John Carrol (6)** for organising teams in a football tournament at Chatham Town FC, raising an incredible £1,250.

Huge congratulations to **Grant Harris (7)** who raised £2,046 by taking on the Ironman Hamburg.

Well done **Helen Lydall, Craig & Kathryn (8)** who swam the Great North Swim, raising £850 in memory of their friend **Danielle**.

Congratulations to the newly wed **Lou Proctor (9)** who raised £260 by collecting donations at her wedding.

Thank you **Ann Truscott** for raising £150 at her scrumptious afternoon tea.

Joan Lashbrook, Estelle Gallagher and the **Parkhouse Patchwork group (10)** hosted a quilt raffle and exhibition, raising £1,200.

A big thank you **Kyle Thomas & Scott Wallis (11)** who sped to the Edinburgh Marathon finish line, raising £1,562 and £2,570 respectively.

Congratulations to our fantastic **North West London Branch (12)** raising £1,020 with their Quiz Night.

Well done **Norbert Cauvas** who raised £2,662 at Parallel Windsor.

A gold medal for **Sue Deane (13)** who completed the Royal Sutton Fun Run, raising £400. Thank you, Sue!

Thank you so much **Tracy Taylor (14)** who raised £2,565 at her Disco Event 'Denim and Diamonds' in memory of her daughter **Danielle**.

A speedy congratulations to **Penny Hall, Laura Stead, Martin Stead, David Crow, Jon Vernoum & Matt Banks (15)** who ran the Hull Half raising £1,811.

Thank you so much **Sandra Creamer** and the ladies at **Porthmadog Golf Club (16)** who held a charity day raising £887!

Thank you **Janifer Redpath, Adam, Dave, Brian & Ernest** for their Family Football Fans fundraiser, raising £112.50!

Congratulations **Scott Amit, Kieran Ferrie, Brian Totten, Steven Thompson, Billy Wylie, Gerard Fox, Scott Devine & Gary Syme (17)** who cycled from Glasgow Hydro to Loch Lomond and did a Tough Mudder, raising £1,584!

Congratulations **Caitlin Watson** (right) who raised a wonderful £2,500 with her parachute jump!



Give the gift of support this Christmas

It's time to add another important date to your diary because this year's Big Give Christmas Challenge will take place **from midday Tuesday 28th November until midday on Tuesday 5th December**.

Over the next few weeks and months we will be working hard on this year's Big Give Christmas Challenge. **The week-long challenge is vital to charities like Ataxia UK. During this seven-day match-funding event all your generous donations go even further as they are worth twice their value! Double the value, double the impact. This year, Ataxia UK's Christmas Challenge aim is focused on raising funds to expand the provision of support services. Read on to find out more...**

We recently received funding from the National Lottery (see p21) to help with the five-year project of expanding Ataxia UK's support services. This grant will provide Ataxia UK with a wonderful £499,251 over the course of this project, the aims of which include:

- Help for people with ataxia to navigate the NHS and care & support services
- Support for people affected by ataxia with employment issues e.g discrimination, reduced hours, reasonable adjustments, pension planning & retirement
- Assistance with support planning so people get better care, or respite
- Access to specialist nursing for people with ataxia in Southwest England, where we're currently engaged with many people with ataxia who need greater support
- Improved understanding of ataxia among people with ataxia, families & carers

These highlights are just some of the many ways this project sets out to support the ataxia community. While securing the Lottery funding is a wonderful start, our focus now shifts to match-funding this project, which is where this year's Big Give Christmas Challenge comes into play.

Combining the pledges made by long-time Friends and supporters of Ataxia UK and The Big Give champion create a match-funding pot worth up to £30,000.

Here's where your help is needed the most. Only your generous donations can help double this pot by donating on The Big Give website throughout the week of the Christmas Challenge (**Tuesday 28th November – Tuesday 5th December**). As a Friend of Ataxia UK you've probably seen the wonderful impact The Christmas Challenge has had on developing services. Here are just some of the many successes achieved thanks to your generosity during previous Christmas Challenges. These truly show just how crucial the campaign is at helping support those affected by ataxia:

2022: THE GIFT OF SUPPORT

Matched total raised including Gift Aid: £42,335.75

The impact of the campaign is still to be fully seen, but donations have been helping a variety of Support Services projects including but not limited to; advancing the information, advice & support via the Helpline; increasing advocacy support; running online speech therapy projects; providing mindfulness and hypnotherapy sessions, as well as other information sessions.

2021: THE GIFT OF SPEECH

Matched total raised including Gift Aid: £62,738.25

As well as helping support those with ataxia through speech therapy, donations helped create a partnership with the company SpeakUnique. Thanks to this, Friends are now able to 'bank' their voice – preserving it for the future – and choose between three synthetic voice options depending on the level of deterioration of their natural voice when it is recorded. Thanks to the 2021 Christmas Challenge, we can provide funding for those people with ataxia who need to download their banked voices, which has so far benefited 14 of our Friends.

2020: FUND THE HELPLINE AND ATAXIA RESEARCH

Matched total raised including Gift Aid: £76,634.75

50% of donations were put towards the Helpline to ensure it is fully staffed through all the opening hours and our information provision further developed to better allow our Helpline to provide support to people affected by ataxia. An important service that has continued to grow because of this initial development. While the 50% for research contributed towards providing research grants to a number of different research projects into the ataxias.

In the coming weeks we'll be sending out more information about the 2023 Big Give Christmas Challenge, but in the meantime, you can help by spreading the word and asking your friends and family to support those affected by ataxia by donating during this week-long fundraising drive.

For more information on this year's Christmas Challenge, please contact the fundraising team at fundraising@ataxia.org.uk or visit www.ataxia.org.uk/tbg23

STEP 1

Visit the donation link:
www.ataxia.org.uk/TBG23
between midday Tuesday 28th
November and midday
Tuesday 5th December

STEP 2

Donate, say, £100



STEP 3

Our major donor pledgers
and champion donor match your
donation with another £100



STEP 4

Tick the Gift Aid box to add a further £25.
So, you give £100 but we get £225!



The importance of caregiving and caregivers

Being someone's 'carer' may only be part of the relationship. You may also be a parent, partner, sibling, child, grandchild, friend or other relative. This relationship can be just as, if not more, important to you. You may also have other caring roles, for example, taking care of your children. You may even have a diagnosis of ataxia yourself.

Every one of us will likely have caring responsibilities at some point in our lives, with the challenges faced by carers taking many forms.

We interviewed Trevor Fleet, a retired GP and NHS ambassador for Ataxia UK during Carer's Week. Abigail, Trevor's daughter, aged 29, has had ataxia for fifteen years.

Trevor says: *"I am trying to get involved with the NHS to highlight ataxia as a condition which is very rare and isn't really known much by some of the general public and certainly by GPs. So I just want to increase awareness of ataxia within the medical world, including spreading the guidelines."*

"Despite being a doctor, I received very little information about a diagnosis for a rare condition. In the area, there aren't many people with ataxia the same age as Abigail, who she knows, so we are only meeting people who have ataxia through Ataxia UK."

The roles and responsibilities that carers have to provide vary widely - they can range from help with everyday tasks, like getting out of bed, and personal care, such as bathing, to emotional support, like helping someone cope with the mental health impacts of living with ataxia.

Trevor points out the importance of reaching out and talking to someone. He says *"being a caregiver for someone close to you can bring certain stresses. There is a physical aspect to caring, but you also have an emotional side, and it is not like a profession. There's no way just to get rid of it, and it's there 24/7. Finding someone you can talk to who's going through the same thing as you can make things easier."*

Many carers juggle their caring responsibilities with work, study and other family commitments. Some, in particular younger carers, are not known to be carers.



They don't tell relatives, friends or health and care professionals about their responsibilities because they fear separation, guilt, pride or other reasons.

During our interview, Trevor opened up about acceptance: *"I think acceptance is crucial. My daughter still hasn't accepted her ataxia. She's very annoyed and angry at times. We go through the process of anger and denial. But also, as a caregiver, you need to accept it as well."*

The mission of Ataxia UK is to support anyone affected by ataxia. This is why we started our Carers Support Group. The group met for the first time on the 15th June and were joined by Renee & Peter from Carers First. They gave us an informative presentation about the general benefits a carer may be entitled to and how to access them. *If you missed the meeting, you may watch the presentation on the following link: <http://alturl.com/npjv>*

If you'd like to see what benefits you may be entitled to as a carer, please see the following website for more information: <http://alturl.com/rg2up>

There are a few charities that provide some more information on caring and being a carer. Here are a few:

- 1. Carers UK – 020 7378 4999 – www.carersuk.org/contact-us**
- 2. Carers First – 0300 303 1555 – www.carersfirst.org.uk**
- 3. Carers Trust – 0300 772 9600 – <https://carers.org>**

If you're struggling to access support, or you're unsure where to look, please contact your local HealthWatch in your area. You can find your local HealthWatch here:

www.healthwatch.co.uk/your-local-healthwatch/list

We would also love to see you at one of our regular Carers Support Group meetings. For more information about the group as well as upcoming dates, please email volunteering@ataxia.org.uk and keep an eye out on our socials, eNews and website.



Angela's story

Angela is a devoted Ataxia UK friend who has Episodic and Gluten ataxia. Angela's daughter, Chelsea, actively volunteers and fundraises for Ataxia UK, and as a family, they do their utmost to help raise awareness. Their relationship and dedication to raising awareness is truly awe-inspiring, which is why we wanted to introduce you to them in this issue...

Angela first experienced her symptoms in her early thirties, while these were occasional, she knew something wasn't right. The symptoms, despite being irregular at first, made her worried.

Angela says: "As time went on, my symptoms worsened, and I was sent to several different hospitals. It was a hard time as they were unable to give me a diagnosis and some of the doctors just said it was all in my head! (Eye-roll) I knew it was not. You know when your body is not right, don't you? I loved working but I had to stop when I was quite young, but I coped. I have always been so independent and have always taken care of family and friends. I was finding it very difficult to drive home and have stopped since my diagnosis in 2012. I have also been registered as sight impaired."

Angela was eventually referred to the Royal Hallamshire Hospital in Sheffield, where she was seen by Professor Marios Hadjivassiliou, who diagnosed her with Episodic ataxia, type 2. *"When I got my diagnosis, I was relieved that they had found something, and I was not going mad! It was also very upsetting as I knew I was not going to get better. Having the tests, I found out it is hereditary, and my mother also has it, she has been ill for many years now, but nobody knew what it was back then, classing it as a medical mystery. I just hope my daughter, Chelsea, does not carry the gene."*

Since Angela and her family became Friends of Ataxia UK and members of the ataxia community, she says she's felt very welcome and supported. *"We are so grateful for Ataxia UK because they are only a phone call or email away. We can contact them if we have any problems or enquiries. I find that the research news at Ataxia UK provides excellent help. Knowing that, even though it is so rare, there is still hope for us in the future. What helps me a lot is that I have a local support group to go to, which Sue Deane runs. She is brilliant, informative, helpful and a lovely lady, and she has also become a dear friend of ours. Things are never too much trouble for her, and it is lovely to meet other people with ataxia and discuss the different daily challenges we face... and it is nice to get out of the house."*

Please check out our website for details about your local support groups: www.ataxia.org.uk/support-services/branches-support-groups



Through thick and thin

Recently we sat down Aleisha, who completed the London Landmarks Half Marathon with her best friend, Kaisha. Their friendship, however, spans well beyond this half-marathon. It goes back to their early childhood and it's a story of extraordinary perseverance and support...

Kaisha is twenty-three years old and has Friedreich's ataxia. Her and Aleisha are childhood friends. They grew up together and became "more like sisters." Aleisha tells us: *"As children me and Kaisha would spend our days browsing through Argos catalogues marking house items we would like to have in our home when we grew up. We both have accomplished that, and I could not be prouder. Kaisha loves Lego and Harry Potter. She is a remarkable person and someone I look up to, as she is a massive inspiration to many people."*

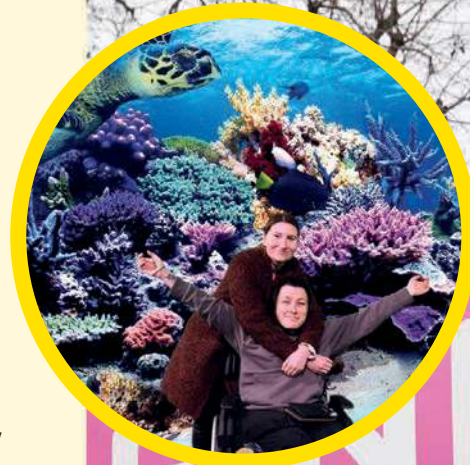
Kaisha received her diagnosis at the age of ten and prior to this, she experienced fatigue when walking far and had poor balance. As Aleisha puts it, *"I can only remember Kaisha going to the hospital. After numerous tests, they diagnosed her with FA. At that age we did not really know what it was or meant. I can remember the first day she came out of the hospital, she called for me, and I can just remember giving her the biggest hug ever."*

Kaisha believes: *"Ataxia UK is such a good way to tell people about ataxia, and they also offer a lot of support and meetings. If I knew about Ataxia UK when I got diagnosed, it would have definitely made the diagnosis so much easier"* and Aleisha adds, *"if it wasn't for them there would have been no way me and Kaisha would have been able to participate in the half marathon."*

Here is a message Kaisha and Aleisha would like to share with the Ataxia UK community:

Kaisha: *"Just accept it is happening and do not beat yourself if you cannot do something other people find easy to do. Ataxia is rare, so that means we are rare."*

Aleisha: *"Throughout the years, I have learnt to let Kaisha give things a go and let her try and do them before I help. Try and push them to be independent and show them that they can do things, but sometimes it just takes a little longer."*



Meet Eilidh from Parkhead CAB

In the last edition of the magazine we shared the wonderful news that Rare Conditions Adviser, Eilidh Clark (below) has joined the ataxia community.

Eilidh is employed by Parkhead CAB and works closely with the Ataxia UK Helpline Team to provide information, advice and support to people affected by ataxia in Scotland. We're seeing praise of Eilidh's work from our Friends already, including this one:

We were very pleased with the service provided by Eilidh Clark in relation to my wife's medical condition of Spinocerebellar ataxia. Eilidh is very knowledgeable about Ataxia as she has attended Ataxia UK's HQ in London. We secured a parking space right outside the premises and Eilidh was ready to meet with us at the appointed time. The building is wheelchair accessible, clean and modern.

In this issue, we're bringing you an interview with Eilidh who tells us a bit more about herself and her work with the ataxia community...

1. Could you please tell us a bit about yourself and what you do?

My name is Eilidh and I work and live in Glasgow as an adviser for Parkhead Citizens Advice Bureau. I have studied law at university and have worked in social welfare and disability rights for almost 5 years. I love working in this area of law as it is very fulfilling and I feel it is extremely important to ensure that everyone has access to their rights, no matter their social or economic status.

2. What kind of support do you provide to the community, and what are some of the limitations?

I provide advice on benefits, healthcare rights/costs, energy issues, debt, housing, social care, immigration, consumer, employment, issues relating to courts/legal aid and family/relationship disputes. I also do casework in many of these areas including the completion of forms, contacting agencies on a client's behalf and representation at benefit appeals. I am unable to provide legal or medical advice but can signpost clients to someone else who is qualified.

3. Do you have the relevant resources to provide the best possible services?

The Citizens Advice network provides an extensive database of social welfare resources as well as access to information published by organisations like CPAG and Disability Rights UK. However, there is minimal information provided by the NHS about the framework for cross-border health care referrals which is an issue faced by many ataxia clients.

4. What is your favourite thing about interacting with the Ataxia community?

How positive they are despite the struggles they face with their condition! I think the support they get from Ataxia UK and each other in the community makes such a difference to the morale of many of my clients and has made my role a very positive experience due to the strength of the community.

5. What are some of the common issues you come across and how can these be addressed?

One of the most common issues I come across relates to accessing community care assessments, adaptations in the home and the costs associated with these. This can be addressed through liaising with the relevant social care and health partnership to find out the local authority's policies and how this interacts with a client's economic status.

6. If you could share any messages/tips with the Ataxia UK community, what would they be?

Don't be afraid to ask for advice or introduce yourself to me! You don't know what you don't ask about! There are no silly questions and no issue is too big or too small to bring to the helpline for advice and support.



Breaking news: Ataxia UK Receives a £499,251 National Lottery grant!

We are overjoyed to share the news that Ataxia UK has been awarded a grant of £499,251 from the National Lottery Community Fund towards funding the development of Ataxia UK Support Services. We're excited to be able to spring into action and show the positive impact they can make.

Thanks to this generous grant, support to the ataxia community will expand, as will guidance, and information services to provide more comprehensive assistance. The Helpline will increase its capacity with extended opening hours supported by additional staff members, and trained volunteers. This will allow for more help to be provided to people facing the various challenges associated with ataxia.

These services are designed to provide specialist information tailored specifically to those affected by ataxia. This funding allows for the development of valuable information resources on crucial topics such as welfare benefits, employment, finances, and housing. Additionally, we will host monthly wellbeing sessions, including Mindfulness and Chair Pilates, interactive information sessions focusing on various aspects of life affected by ataxia, such as aids and adaptations, physiotherapy and other exercise, and mental health. This grant also allows for the continued support of branches and support groups, viewed as vital peer support by many Friends. While much of this work will be conducted remotely, we also aim to connect in person by visiting Branches & Support Groups and hosting face-to-face events around the country.

We are thrilled to announce that in January 2025, Ataxia UK will appoint its first Specialist Nurse whose role will be to ensure that people with ataxia have access to appropriate treatments, therapies, care, and support when they need it.

This nurse will be based in the South West, an area currently lacking easy access to Ataxia Specialist Centres and expert neurology, but they will assist in providing information, advice, and support to the ataxia community across England.

Want to get involved? There are numerous ways you can volunteer for Ataxia UK including on the Helpline mentioned above. Please get in touch if you are interested. We're really grateful for the funds Friends have already given towards various elements of this project. We still have more money to raise but we're confident that with your support we will succeed.

We are extremely grateful to the National Lottery Community Fund for their recognition and investment in support for people affected by ataxia. For more information and to watch Sue Millman's announcement video, visit: <http://alturl.com/ankkr>



Employment and the Disability Charter

Worries about employment come up a lot on the Helpline and statistics for disabled people in employment are not great. The employment gap between disabled and non-disabled people has remained at around 30%, with disability gaps in pay, job satisfaction and work-related well-being. There is good news though! The Disability Charter 2021 has been put together as a call to government to act to address the disadvantages that disabled people face in their working lives. The charter outlines 9 main points:

1. Employment and pay gap reporting.

The government should: require all employers with 250+ employees to publish data annually on their disabled workforce.

2. Supporting disabled people into employment.

The government should: increase disabled people's access to employment programmes and apprenticeships; increase the scale, quality and awareness of supported employment programmes and supported internships; and increase the provision of tailored careers advice to disabled people.

3. Reform of Access to Work (AtW).

The government should: remove the AtW support cap; ensure application/renewal processes are efficient, personalised, and flexible; entitle disabled job-seekers to 'in principle' indicative awards; facilitate passporting of awards between organisations and from Disabled Student's Allowance to AtW; and increase awareness of AtW support.

4. Reform of Disability Confident.

The government should: require all employers at Disability Confident Levels 2 and 3 to meet minimum thresholds regarding the percentage of disabled people in their workforce; and remove accreditation from employers that do not move up within 3 years from Level 1 to Levels 2 or 3.

5. Leveraging government procurement.

The government should: ensure award decisions for all public sector contracts take into account the percentage of disabled people in the workforce of tendering organisations; require government contractors to work towards a minimum threshold regarding the percentage of disabled people in their workforce; and take failure to achieve this threshold into account in future contract award decisions.

6. Workplace adjustments.

The government should: require employers to notify employees on decisions regarding reasonable adjustment requests within two weeks; make the option to work flexibly from day one the legal default for all jobs; introduce stronger rights to paid disability leave for assessment, rehabilitation and training; and fund an increase in Statutory Sick Pay to the European average.

7. Working with disabled people and their representatives.

The government should: require employers to consult and negotiate with disabled people and their representatives on disability equality matters; and



provide trade union equality representatives and disability champions with statutory rights to time off to perform their role.

8. Advice and support.

The government should: create a 'one stop shop' portal to provide information, advice and guidance to employers on recruiting and retaining disabled people, and to disabled people on their employment rights.

9. National progress on disability employment.

The government should: take into account increasing disability prevalence in calculating the disability employment gap, and use the 'prevalence corrected' employment gap measure in monitoring national progress on disability employment. Currently 131 organisations have signed up to the charter including the Post Office and MacDonal'd's. *Find out more information about the Charter here: <http://alturl.com/o743r>*

LOOKING FOR WORK NOW? These organisations could help:

Even Break, has a job search engine with inclusive employers: www.evenbreak.co.uk or phone them on **0845 658 5717**. There is **Even Break Hive** that gives you access to relevant and accessible careers support and advice delivered by professionals with lived experience of disability. *You can find services and support in your local area: <https://hive.evenbreak.co.uk> or 0845 658 5717.*

Disability Jobs is another job search engine pairing disabled candidates with inclusive employers: <https://disabilityjob.co.uk> or **0345 057 3408**.

WORRIED ABOUT COSTS?

The **Access to Work** scheme can cover some of the costs involved with applying for jobs, getting to work and staying in work. It can pay for:

- Adaptations to your vehicle or taxi fares to get you to work
- A support worker or job coach to help you in your workplace
- Support for your mental health at work with tailored plans to help you get and stay in work as well as one-to-one sessions with a mental health professional

*You can find more information here: www.gov.uk/access-to-work or by calling your local job centre. For access to mental health help if you are currently employed your employer can fill out a referral for you or you can refer yourself here : <https://atw.maximusuk.co.uk> or **0300 456 8114**.*

If using technology is a worry or if you want to know how it might help you in the workplace for instance with an adapted keyboard or mouse, voice recognition or other communication aids then **Ability Net** is the place to go. They have lots of factsheets that might be useful to share with your employer when talking to them about reasonable adjustments. If you want to learn more about using technology they have training guides, factsheets and a free helpline: **0800 048 7642**. <https://mcmw.abilitynet.org.uk>.

*If you have any questions or concerns please do contact the Ataxia UK Helpline help@ataxia.org.uk, **0800 995 6037***





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