

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 221. Spring 2023

Thank you for giving the gift of support this Christmas

295 Friends of Ataxia UK came together to give the ataxia community the vital gift of support. *Find out more on page 10.*

£38,542

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**Christmas
Challenge**

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ATAXIA

Ataxia UK

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In the office

Let's all welcome **Rosie Gilbey** to Ataxia UK & the ataxia community. As of December, Rosie is the **PA to CEO and Office Manager**, while **Lucy** (who is missed dearly by all of us) is on maternity leave. Congratulations to Lucy and her partner **Joe** on their beautiful baby boy, **Finlay**. While we're at it, more congratulations are in order. This time to **Bella Black, Hannah Cohen & Kieran Fearnley**, all of whom got promoted to officers – well done!

CEO's Introduction

Happy New Year!

Like many people, I find that the turn of the year provokes in me both reflection and planning. This January I've been doing plenty of both regarding Ataxia UK's work for our Friends. We have **plenty to celebrate in terms of what we achieved in 2022** despite austerity and the legacy of the pandemic. To mention just a few things: we commenced the **expansion of our Helpline** and started **piloting our Advocacy Service** (p23); co-hosted an amazing **International Congress for Ataxia Research (ICAR)** in Dallas (p6); held a well-attended and successful **Virtual Annual Conference**; and introduced regular placements for **Occupational Health students**. In the meanwhile, things continued to standstill or go downhill in NHS Neurological Services, whilst the cost of living mounted in an extraordinary fashion and for the most part benefits stood still producing yet more challenges for people affected by ataxia. **For information about help with benefits, see page 19.** We are delighted to announce the **accreditation of a specialist ataxia centre for adults and children in Oxford**, and a **children's ataxia clinic in London** (See more on p7).

Going forward, Ataxia UK's mission to support people with ataxia requires us to rise to this challenge, and we're delighted to announce that we have secured two years of funding for our new **Scottish Advice Service** which will be provided to all Scottish Friends in partnership with Glasgow Parkhead Citizens Advice Bureau. As I write, a member of staff is being recruited and we expect the service to be launched in April or May this year.

We are also starting to make arrangements for the next **International Congress for Ataxia Research (ICAR)** which will be in London in November 2024. Finally, this year we promise (barring unforeseen events,) that there will be a **face-to-face Annual Conference** on 20th/21st October at the Radisson East Midlands (see p4). I hope that many of you will come and join us and help create a wonderful reunion of Friends.

Best wishes, Sue Millman



Sue

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Ataxia people

- 2023 Annual Conference: Savethe date!
- Get involved in shaping 2023 Annual Conference! - 4



Research

- Highlights from ICAR
- Omaveloxolone update ————— 6



Fundraising

- The Big Give 2022: update
- Fundraising thank-yous ————— 10



Ataxia awareness

- Meet the Loach family
- The Tube Snapper ————— 14



Adaptations

- My diet and cooking with ataxia
- How an occupational therapist can help you ————— 16



Services

- Occupational Therapy Students
- The Blue Badge Scheme ————— 18



Living with ataxia

- Me & Voice Banking by Laura ————— 20



Health & wellbeing

- Wellbeing Survey Feedback
- Accessing Counselling Services ————— 21



The 2023 Annual Conference in East Midlands – Save the Date!

We're hoping 2023 Annual Conference will be our first in-person conference since 2019! The success of the virtual Annual Conference 2022, means we would be thrilled to bring you another exciting programme, this time hosted back at the Radisson Blu Hotel, East Midlands Airport on Friday 20th & Saturday 21st October 2023.

From Friends' feedback, we know that many people who couldn't attend a face-to-face conference were pleased to find it online. We are looking into ways of streaming some of the talks, seminars & entertainment into your living room. We will bring you more news on this in the next issue of the magazine and in our monthly eNews.

Let's make this an event for the entire family!

Interested in bringing your little ones along? If we get enough interest, we'll seek to provide a crèche for children up to 5-years old and the usual trip for up to 15-year-olds. If you would like to make use of either (or both) please email the team at: conference@ataxia.org.uk to register your interest. While we can't make any promises, we'd love to make this an event for the entire family and will look into whether this is possible.

We want to gauge the interest in attending the conference face-to-face. We're aware that finances for many people are tight. Please go to this page for more information and to tell us if you are interested in attending the conference in person or virtually: www.ataxia.org.uk/conference-signup. We look forward to bringing you further details, including programme updates, ticket booking, accommodation and bursaries in the coming months.

'All About Ataxia' at the 2023 Annual Conference

If you're affected by a recent diagnosis, or know someone who might be, come to learn more about the condition in our 'All About Ataxia' seminar at Conference, led by people with ataxia.

To register your interest in attending a face-to-face All About Ataxia session, please email the team at: conference@ataxia.org.uk

For more information on All About Ataxia, please visit: www.ataxia.org.uk/ataxia-uk-events/all-about-ataxia



Conference Involvement Group

Get involved in shaping the 2023 Annual Conference! Apply to join the Conference Involvement Group & help shape this year's programme and so much more.

The Group is open to Friends of Ataxia UK, regardless of whether you have previous volunteering experience or not.

The group will meet 2-3 times in the lead-up to October 2023 to review all aspects of the conference.

If you would like to be involved, please email Shana De Figueiredo Scholtz at: volunteering@ataxia.org.uk by Monday 3rd April, providing the following information:

- Name
- Contact number
- Whether or not you can commit to 2-3 meetings between now and October?
- Have you ever been to an Ataxia UK Conference?
- When you (or your family member/friend) were diagnosed

Magazine Editorial Group

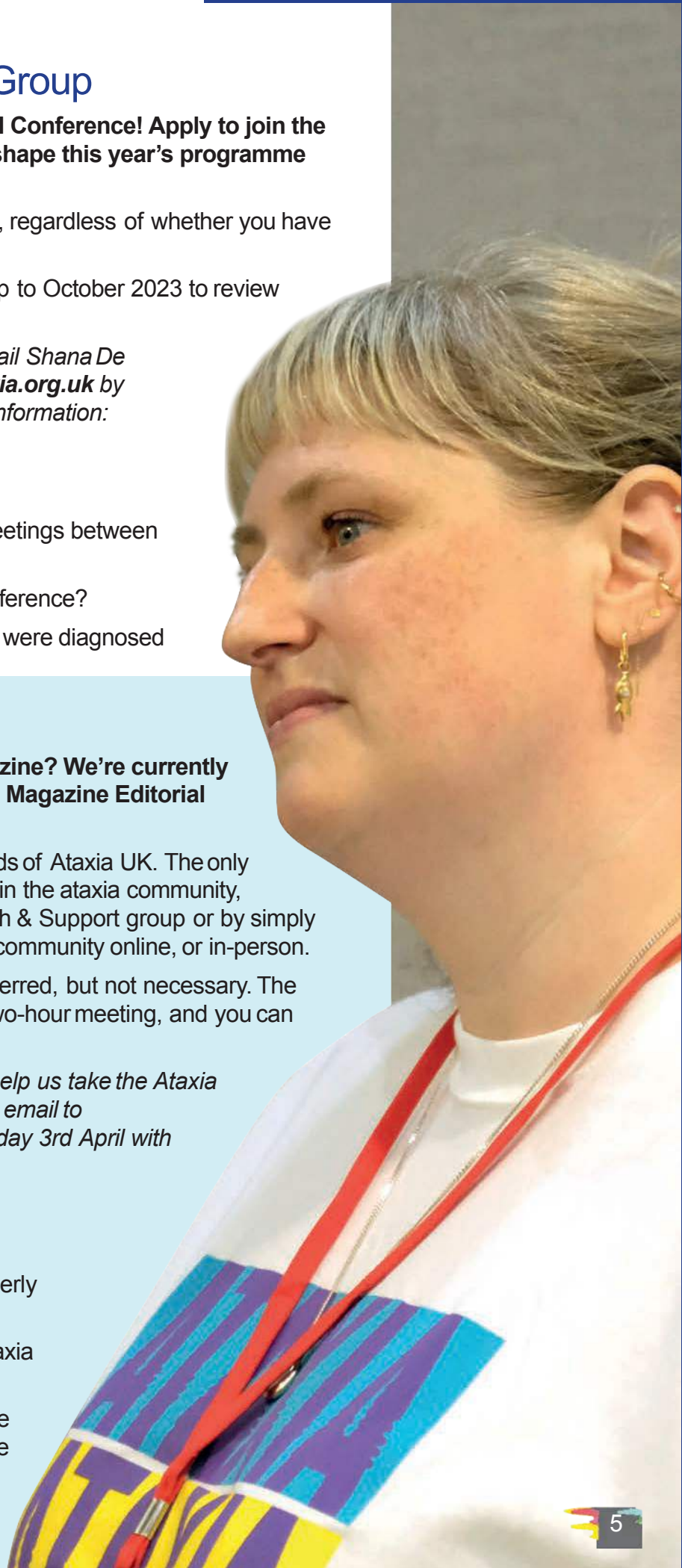
Want to shape the future of Ataxia Magazine? We're currently looking for a volunteer to join the Ataxia Magazine Editorial Group.

This volunteering position is open for Friends of Ataxia UK. The only requirement is that you're actively involved in the ataxia community, either as a volunteer, a member of a Branch & Support group or by simply keeping up with the latest news within the community online, or in-person.

Some editorial or writing experience is preferred, but not necessary. The group meets quarterly for a short one-to-two-hour meeting, and you can join virtually, via Zoom or Microsoft Teams.

If you would like to become involved and help us take the Ataxia Magazine to the next level, simply send an email to communications@ataxia.org.uk by Monday 3rd April with the following details:

- Name
- Contact number
- Are you committed to attending the quarterly editorial meetings?
- What's your current involvement in the ataxia community?
- Please tell us five things you like about the Ataxia magazine and five things you'd like to see change.



Highlights from ICAR 2022

Between November 1st – 4th 2022, Ataxia UK, the National Ataxia Foundation (NAF), and the Friedreich's Ataxia Research Alliance (FARA) co-hosted the International Congress for Ataxia Research (ICAR) in Dallas, Texas, USA. The conference was a hugely successful event.

Over 450 people attended from 19 different countries, making this one of the largest gatherings of ataxia researchers to date. This included researchers, pharmaceutical companies, and patient advocacy organisations. Here are some of the highlights:

New genetic cause of late-onset ataxia discovered

In the late-breaking news session, research was presented by two international research groups on a recently identified genetic cause of late-onset ataxia. Researchers think a newly discovered mutation in the FGF14 gene might be a common cause of late-onset ataxia. The discovery of this genetic mutation may lead to more diagnoses for people with ataxia of unknown cause. The test for the FGF14 mutation is not yet widely available. However, if your neurologist contacts researcher Dr David Pellerin, they can provide more information about genetic testing as part of their research project.

Contact details: Dr David Pellerin and Professor Henry Houlden, Institute of Neurology, Queen Square, London WC1N 3BG

david.pellerin.21@ucl.ac.uk | david.pellerin2@mcgill.ca

You can read more about this research here: <http://alturl.com/twf2a>

Panel discussion on living with ataxia

Ataxia UK Trustee, Carol McCudden participated in the panel. Carol said "I think it's useful for researchers and people involved in research to get an insight into the lives of people with ataxia. It's also important for people with ataxia to engage with researchers to let them know what we want and need."

Poster sessions

Over 200 posters of research projects were presented, including some on projects undertaken or supported by Ataxia UK. These projects included the results of Ataxia UK surveys on the impact of COVID-19 on people with ataxia, attitudes of people with ataxia towards clinical trials, and the DRPLA patient registry.

Ataxia UK travel grant awardees

Ataxia UK awarded travel grants to nine UK-based ataxia researchers to help them attend the conference. This was a great opportunity for them to showcase their research on many different types of ataxia.

92% of ICAR attendees thought the conference was extremely useful or very useful for advancing their work, and 96% made new contacts whilst attending.

Ataxia UK are so pleased to have co-hosted such a successful conference, and we are working hard on bringing ICAR to the UK in 2024.



Announcing an Ataxia UK-accredited specialist centre in Oxford

We are delighted to announce the accreditation of the specialist ataxia centre in Oxford, at the **John Radcliffe Hospital**. All Ataxia UK-accredited Specialist Ataxia Centres are centres of excellence, where people with ataxia receive the best quality of care from ataxia experts and a coordinated service combining diagnosis, treatment, support, and research. The **Oxford Ataxia Centre** offers a specialised service for adults and children with suspected or confirmed ataxia. The service is provided by a multidisciplinary team including adult neurologists, clinical geneticists, and a paediatric neurologist.

Specialist centres provide longer appointments (45-60 minutes), continuity of care, support between clinic visits, and streamlined referrals to other specialists. Referrals to the Oxford Ataxia Centre are accepted from GPs and neurologists throughout the UK.

Contact details for referrals:



Prof George Tofaris, Prof Carlo Rinaldi (Adult Neurologists)
 Department of Neurology, John Radcliffe Hospital, Oxford OX3 9DU
 Secretary to Prof Tofaris: **Tel. 01865 231295**



Prof Andrea Nemeth (Clinical Geneticist, sees adults and children)
 Department of Clinical Genetics, Churchill Hospital, Oxford OX3 7LJ
 Secretary to Prof Nemeth: **Tel. 01865 220624, Option 5**



Dr Martin Smith (Paediatric Neurologist)
 Department of Paediatric Neurology, Oxford Children's Hospital OX3 9DU
 Secretary to Dr Smith: **Tel. 01865 221579**

New children's ataxia clinic at the London Ataxia Centre

The Paediatric Ataxia Clinic brings a new service to the London Ataxia Centre, at the **National Hospital for Neurology and Neurosurgery (NHNN)**, enabling children with ataxia to receive care at this centre of excellence. The clinic team at the Paediatric Ataxia Clinic includes **Professor Paola Giunti, Dr Shpresa Pula (consultant in Paediatric Neurology)** (far left), and **Katarina Manso (ataxia nurse)** (left).

The Paediatric Ataxia Clinic leads a large translational research programme, which aims to put research findings into practice. It's primarily focused on the genetic basis of ataxias, particularly Friedreich's ataxia. They recognise the importance of clinical registries and gathering natural history data, so that when therapeutic trials are offered, their service is "trial-ready".

Children referred to the Paediatric Ataxia Clinic will need to be monitored and supported by local healthcare professionals between visits.

Referrals for children aged 8-18 can be made by GPs and neurologists throughout the UK. In order to meet the research aims of the clinic, referrals will be selected on a case-by-case basis. Initially, priority will be given to children with a diagnosis of a genetic ataxia.

Contact details for referrals:



Prof Paola Giunti, National Hospital for Neurology and Neurosurgery
 Queen Square, London WC1N 3BG **Tel. 0203 448 3100**
 Please note GPs should use the 'choose and book' system for referring patients

For more information on Ataxia UK-accredited ataxia centres, including referral details, visit our website: www.ataxia.org.uk/newly-diagnosed/specialist-ataxia-centres

Omaveloxolone update

At the time of writing, the FDA had not announced a decision on whether to approve Omaveloxolone for the treatment of Friedreich's ataxia (FA) in the US. We hope that when you are reading this, in March 2023, the FDA has approved Omaveloxolone, and that it will soon be available to adults with FA in the US. Ataxia UK is doing everything it can to encourage Reata Pharmaceuticals to seek approval for Omaveloxolone in the UK.

For approval in Great Britain, they will have to apply to the MHRA, and to the European regulators (EMA) for approval in Northern Ireland. We are pleased that Reata submitted an application to the EMA in December.

Under a scheme announced post-Brexit, the MHRA currently conducts a 'light-touch review' of drugs approved by the EMA. Planning to submit to the MHRA under this scheme could result in faster approval in the UK. Ataxia UK's Chair of Trustees recently wrote to the CEO of Reata, encouraging them to make use of this scheme, which is due to expire in December 2023.

For the most up-to-date information, including the FDA decision, expected by 28th February, and to sign up to our Omav-only newsletter, visit our website: www.ataxia.org.uk/omav-updates

Positive results from Ataxia UK-funded speech therapy project

Professor Anja Lowit (University of Strathclyde) and the team have published positive results from their study of a new approach to speech therapy, called **ClearSpeechTogether**. In this Ataxia UK-funded project, people with ataxia had a small number of individual speech therapy sessions. This was followed by group meetings of people with ataxia to practise speaking together. All sessions in the study were held online. The nine participants had a range of ataxias, including spinocerebellar ataxias, Friedreich's ataxia, CANVAS, autoimmune ataxia, and ataxia of unknown cause. The results showed that, overall, participants experienced reduced vocal strain, improved intelligibility and increased participation and confidence. Post-therapy Interviews with the participants highlighted a range of both social and speech benefits.

The next step in this research is to run a larger trial. The researchers are currently testing a different speech therapy treatment called **LSVT Artic**. The results from both these studies will help them decide the best treatment option for the larger trial.

Thank you to Friends of Ataxia UK who took part in this research. Ataxia UK is now offering a speech therapy service which combines individual and group practise. If you are interested in taking part, please email volunteering@ataxia.org.uk





Participants needed for a DRPLA research study

DRPLA (Dentatorubral-pallidoluysian atrophy) is a progressive disorder of ataxia, involuntary movements throughout the body, epilepsy and cognitive decline. Advances in DRPLA research will inform other ataxias, particularly the more common spinocerebellar ataxias because they have many similarities. Ataxia UK and the US Foundation CureDRPLA are coordinating the DRPLA Natural History and Biomarker Study, funded by CureDRPLA.

The DRPLA Natural History and Biomarkers Study has three main objectives:

1. Characterise how the symptoms of DRPLA change over time (natural history).
2. Identify genetic factors and biomarkers that could predict disease progression. Biomarkers can be measured as an indicator of the progression of a condition, or in response to a medication.
3. Provide useful information to support the design of future clinical trials.

This study will collect health information from people with DRPLA over three years to understand how this condition develops over time. The study also recruits participants without ataxia, so that they can compare how individuals with DRPLA differ from those without. Participating in this study will involve annual appointments at the clinics, during which the neurologists will carry out some clinical assessments. (e.g. ataxia scales, questionnaires, brain MRI, blood collection, etc.). *Find out more about this study in the flyer on our website: <http://alturl.com/2fu97>*

This is a global study, including a UK site at the London Ataxia Centre, which is now recruiting participants. **If you have DRPLA**, this is a great opportunity for you to participate in research. **The study is also recruiting participants without ataxia**, that come forward as volunteers to participate in research projects. *If you live in the UK and would like more information about participating, please contact:*

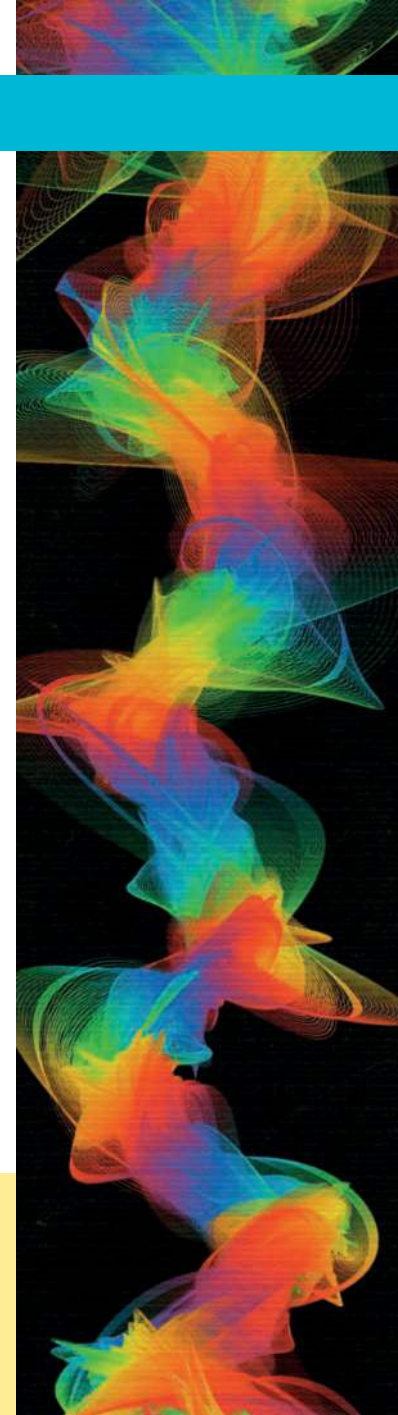
Dr Hector Garcia-Moreno and Ms Ola Volhin
 UCL Queen Square Institute of Neurology
 Email: hector.garcia-moreno@nhs.net & o.volhina@nhs.net
 Phone: +44 (0) 2034 483 100.

Did you take part in 100,000 Genomes Project?

The **100,000 Genomes Project**, launched in 2013, aimed to sequence **100,000 genomes from people with rare conditions, such as ataxia, or cancer.** The project has contributed to ground-breaking discoveries and continues to improve our understanding of genetic conditions. Genomics England hosted a webinar in which they explain the achievements of the project, and the ongoing work to find diagnoses for families involved.

If you took part and you didn't receive a diagnosis, they explain how you might receive a diagnosis in the future, as they make more discoveries about genetic conditions: <http://alturl.com/ihn2u>

Genomics
 england



The Big Give Christmas Challenge 2022 - Update

Between 29th November and 6th December 2022, 295 Friends of Ataxia UK came together to help fund vital ataxia services. This was done by donating to the match-funding The Big Give Christmas Challenge. In the process, you raised a wonderfully festive £38,542, exceeding the original target by £742.

These generous donations will help fund the Ataxia UK Helpline and provide the ataxia community with increased advocacy support, online speech therapy, mindfulness & hypnotherapy sessions, other well-being & information sessions and so much more...

We cannot even begin to express our gratitude for having such wonderful Friends that pull together despite the difficult times. Thank you for coming together and supporting the ataxia community. *To find out more about the many ways your donations will benefit the community, please visit: www.ataxia.org.uk/tbg22*

Spring Raffle 2023

Be in with the chance of winning our top cash prize of £200 by taking part in the Spring Raffle!

Ataxia UK's Spring Raffle is making a comeback in 2023 and with it a fantastic opportunity to win up to £200! You will find two Ataxia UK raffle books, containing 10 tickets each, enclosed with this issue of the magazine. Sell these to your friends, family, and colleagues, or simply buy them yourself.

At just £1 each – every ticket you buy gets you closer to a chance of winning one of three fantastic prizes, with the top prize of £200. The best part? It's not just you who can win! By taking part you're also helping people in the ataxia community by providing support where it's most needed and funding ataxia research, in a fun way! We encourage you to take this opportunity to talk to as many people as possible to sell tickets and raise awareness.

HOW TO PLAY

Step 1: Fill in the full name, postal address and telephone number on each individual ticket purchased by the raffle player(s). 1 raffle ticket costs £1 and a book of 10 tickets costs £10.

Step 2: Send your cash or cheque amount along with the purchased raffle ticket(s) to Ataxia UK using the enclosed FREEPOST envelope. Please write the buyer's name on each purchased ticket. This must arrive no later than Monday 1st May.

Please note: If you sell all your tickets and would like to order more, you can request additional raffle books by contacting us at fundraising@ataxia.org.uk or on 020 7582 1444.

Would you, or someone you know, prefer to take part online? No problem. To purchase tickets online, simply visit: www.ataxia.org.uk/get-involved/spring-raffle. The Spring Raffle is open to UK residents only aged 16 and above. The Ataxia UK 2023 Spring Raffle draw takes place on **Monday 15th May 2023.**

Great North Run 2023

This is the perfect athletic event for both running newbies and seasoned pros. Join us on 10th September and be part of #TeamAtaxiaUK.

Known as the best and biggest Half Marathon, you will begin in Newcastle and end by the beautiful seaside in South Shields. You'll have a run-tastic time with this iconic route!

If you're not convinced yet, see what Elaine Sinclair had to say about her 2022 experience

"I honestly loved every minute of running the Great North Run for Ataxia UK. I was completely blown away by the support from everyone. It really meant so much to me knowing that I was doing something to help a cause that now affects not only my stepdad's life but my family's lives too..."

Sign up now by filling out our online form here:

<http://alturl.com/s5kmb> or email Rebecca at rholt@ataxia.org.uk



Through My Gaze: Virtual Art Exhibition

Due to its success in 2021, Ataxia UK will once again be hosting an online Art Exhibition fundraiser from 6 to 31 March 2023.

The theme this year is *'through my gaze'*, which encourages the audience to consider how people's lived experiences can affect how they see the world. The theme can be interpreted from the perspective of someone with or without ataxia and allows the artist to tell their story, and show the audience life; through their gaze.

Take part in this unique and exciting online exhibition, as an artist or a buyer by following this link to sign up: www.ataxia.org.uk/gallery or contact Hannah at hcohen@ataxia.org.uk / 0207 091 1594



Ataxia Classic, Sunday 24 September 2023

Gear up for a 4-5km, 50km or 100km cycle in the stunning Yorkshire countryside as we return to Pocklington!

Taking on the roads to cycle together over the weekend of International Ataxia Awareness Day, you'll pedal parts of the renowned Tour de Yorkshire.

Whether you're a super or standard cyclist, or just fancy an exciting challenge – this is the cycle for you. Don't take it from us, hear from our 2020 team...

"Great day out - beautiful scenery, great course and the wind gave the event full Yorkshire authenticity. Many thanks to the team for the very detailed and thoughtful organisation"

"We thoroughly enjoyed the day, and big thanks to your team, such a great event. The highlight was the friendliness and camaraderie of all the cyclists."

Contact the team on fundraising@ataxia.org.uk / 0207 582 1444 for more information and to sign up!



Fundraising thank-yous



From skydives to marathons, you have all been amazing. Working so incredibly hard, and we'd like to say a **BIG Thank You**.

A Celebratory thank you to **Jenna Dobson & Shauna McKeown** (above) who chose to buy Ataxia UK pins as wedding favours, raising a stunning £250 and £169 respectively.

Thank you so much, **Octavia Thomas (1)** and **Gemma Prisk (2)** who sped through the London to Brighton cycle raising £4,792 and £437 respectively.

Ava Downing & her friend Ash (3) were superstars, running 2.5km near their home and raising an awesome £710.

Congratulations to **Lorna Cook (4)** who ran the Rutland Half Marathon and raised a speedy £663!

A year of thank yous to **Jane Maries (5)** and **Margaret Morris (6)** for being community fundraising stars, and continuing to sell cards, jams and plants!

A giant congratulations to **John Potter & his team** who mastered the Three Peaks and raised a fantastic £385!

A round of applause to **Lukas Garcia (7)** who raised £360 by completing the Cheshire Triathlon in memory of his dear friend **Kevin Madeley**.

A soaring thank you to **Peter Williams, Ian Haigh & Robert Wilkinson (8)** for their skydive, raising a spectacular £6,007! Thank you too **Joan Williams** for all her organising and fundraising mastery!

We can't thank **Whitehead Primary School** enough for their wonderful school fundraiser, raising £5,080.

Thank you so much **Nathan Moore** who epically ran the Spar Craic 10k, Antrim Coast Half Marathon and the Great North Run supporting his **brother** and raising £2,268!

Well done to Edinburgh Kiltwalkers **William, Alison (9) & Chris Littleboy (10)** together raising a mammoth £3,020 topped up by the **Hunter Foundation** to give a total of £4,530!

A huge High-Five to **Lucy Gill** for her Charity Day and to her **Dad** for his epic skydive. Together they raised over £1,162.

Thank you so much, **Phil & Brenda Whitwell, Courtney Lewis & The Crow's Nest Pub (11)** who ran a charity night and raffle, raising £350.

A heartfelt thank you to **Stephanie Youle (12)** who raised £2,661 by walking 1,000 miles in 10 months in support of her **sister**.

Congratulations **Ian Wharin** (below) for completing his Skydive in support of his **son** and raising a whopping £1,570!

A big cheer to **Charlotte Berrington (13)** who sped through the New York Marathon and raised £2,841.

Thank you, **Jayne Townley-Corrigan (14)**, for holding another awesome Christmas display, this time with Candyland making a lovely £62!

Thank you so much **Gemma Sheen (15)** for raising £375 by selling her beautiful homemade Christmas cards.





A massive well done to **Francesca Smith, Ed Smith & Tom Morris (16)** for raising £1,560 with their epic 100km South Coastal Trek.

A huge congratulations to **Lucy & Matthew Holland (17)** who celebrated their Silver Wedding Anniversary, raising a fantastic £1,865!

A huge cheer for **Jonathan Woods (18)** who trekked the Yorkshire Three Peaks in three days, and to all his friends who together raised £4,809!

A very speedy congratulations to **Mark Tenn (19)** who smashed the Marine Corp marathon in Washington DC raising an amazing £1,589.

Well done to **Danny Curtis (20)** for running the Chester Marathon and raising an incredible £1,530.

A round of applause to **Xander Wrigley & family (21)** for completing the Clarendon Pushchair Marathon; zooming with his daughters and raising £4,124!

Thank you so much, **Yvette Loach & Vanessa Bartlett (22), Amy Loach, Vicky & family** for supporting Ataxia UK with their Celebration evening in memory of their much-missed **James Loach**, raising £6,000. Thank you too to their **MP Rehman Chishti (23)** for completing the Medway 10k raising £648!

Congratulations on another successful Christmas Raffle to **Sheena Betsworth (24)** raising a fabulous £563! Thank you, Sheena.

A warm thank you to **Rebecca Davy (25)** for raising £170 with her Office Christmas Jumper day; thank you so much everyone at the **South East Coast Ambulance Service** for getting involved!



LONDON MARATHON 2022 SUPERSTARS

A huge round of applause to the outstanding #TeamAtaxiaUK London Marathon runners; **Martin Joy (26), Joe Campbell (27), Andy Franks (28), Matt Dalton (29), Sara Szabo (30), Sara Daly (31), Chloe Hilton (32), Sally Kiddie (33), Sarah Ewart (34)** and **Danielle Williams** (right).

Their perseverance and commitment were astounding, and together they raised over £30,000! Incredible! The atmosphere was fantastic. The team smiled and waved as they sped through Woolwich Dockyard, whizzed past Big Ben and leapt to the finish at Birdcage Walk! **We are so grateful to you all, and a huge Congratulations on your awesome achievement.**



Meet the Loach family, raising awareness in memory of James

The Ataxia UK staff interviewed Yvette Loach (below left) and Vanessa Bartlett (below right), the mother and auntie of James Loach (right). James, a loving young man who passed away in 2012 at the age of 19, has left a lasting legacy that his family is striving to uphold.

The Loach family has been very involved in supporting Ataxia UK and its community over the past decade. They raised over £6,000 in 2022 alone, but more importantly, they have been actively raising awareness about the condition. Yvette, James' mother, is always eager to get involved and make a difference. She tells us *"It's always bittersweet for me because on the one hand, you're helping other people, which of course, is our aim and we want to keep this going as long as we can, but it's heart-breaking because of the reason we're doing it."*

Ataxia UK is 'very much their family and friends' chosen charity' and they have been actively involved within the community. In September 2022, a very special evening was held by his family and friends in memory of James in which over £6,000 was raised. Not to mention, it was a wonderful way to honour James' life & legacy.

They have tried their best to make a difference at every opportunity as Ataxia UK is a charity close to their heart. Vanessa, James' aunt, elaborates: *"One thing I can say, I love about Ataxia UK is that you are so personable, and that is a beautiful way to run a charity. It's so incredible and you don't get that from every charity"*. The family, including two of his sisters, Claire and Amy, mum Yvette, aunts Annette and Georgina and uncle Andrew, supported the RoyalParks Challenge in 2018. They raised £1,600 collectively, and in 2020 they joined the 2.6 challenge and raised £400 as a family including a challenge from James's nephew Jack. Throughout the years, they have supported the community through their donations to The Big Give, Ataxia UK Spring Raffles, and their regular donations via the website.

Loach family members have also participated in Ataxia UK's annual International Ataxia Awareness



Day (IAAD) campaigns. In addition to supporting IAAD, they have been doing community fundraisers, including birthday fundraisers such as sister Rebecca's £250 raffle from her masquerade ball and hosting collection tins. The Loach family's partnership with Ladbrokes led to a £2,500 award to Ataxia UK for research. Ladbrokes has also donated sums of £500 on several occasions.

Yvette and Vanessa both take pride in raising awareness. As Yvette puts it, *"the word is getting out there"* and they will continue to do what they can to reach as many people as possible because *"ataxia is not taking your mind but it's taking your body bit by bit."* Yvette hopes that they will find a cure. She says, *"I'm going to be so over the moon for anybody that it can help"*.

Additionally, Yvette and Vanessa are active in running the Rainham and Gravesend Support Group, providing the group members with every possible support. Vanessa says: *"through Ataxia UK we created a support group. I wanted to do it because if James had wanted to have found a support group, I wanted there to be one"*. Several new supporters have been welcomed and made to feel at home by the group.

Here's a message Yvette and Vanessa would like to share with the Ataxia UK community

Yvette: *I was looking for motivation for anyone suffering with Friedreich's and other ataxias and I found this and thought it was so apt: It's not the strength of the body that counts, but the strength of the spirit.*

Vanessa: *Because of Ataxia UK, you're not alone. People shouldn't feel alone because they shouldn't feel that they're going through a journey where no one's going to understand it. I think that's why Ataxia UK is excellent.*

'Tube Snapper' - raising ataxia awareness

Ataxia UK's Friend Ben – also known as Tube Snapper on Instagram – has started a very unique way of raising ataxia awareness. He decided to travel to and photograph every single one of the 272 stations on the London Underground network.

As he puts it: *"I'm raising awareness of Ataxia and the challenges it presents by visiting and photographing all of London's 272 Tube Stations. In order to highlight access and disability issues of travelling on the underground, I'm getting off at each station, exiting and entering the station to experience the stairs, escalators, ramps and lifts while I'm on my two sticks for walking and still able to access non-step-free stations."*

As of 11th February, Ben has managed to visit every single one of the 272 stations. To keep up with Ben's inspiring journey and to find out what's next, follow his Instagram handle [@tube.snapper](https://www.instagram.com/tube.snapper) or read his blog at:

www.ataxia.org.uk/your-blog/tubesnapper



My diet and cooking with ataxia

In the latest issue of his column, our Friend James Downie talks us through some of his diet and cooking tips. Let's hear from James himself...

I would like to start this article by saying I am by no means particularly healthy, or particularly good at cooking, but I do try!

In terms of my diet, I am mainly gluten-free, only eating gluten-free pasta and bread. Being predominantly gluten-free doesn't particularly help with my FA but stops me from feeling bloated and helps my digestion.

I rarely eat meat at all and never cook with it. I do eat cheese (way too much!) but don't drink milk. Occasionally we eat fish at home. I will eat meat when I am out or for a takeaway. The reason I have little meat and dairy is partly to do with health reasons and also the environment and the future of our planet.

I still cook frequently but normally cook only pretty easy meals. I don't like using the oven or the microwave as things tend to get really hot and hard to handle. I wouldn't say I enjoy cooking, but I don't mind it, as long as it's simple!

For everything I cook, I like to use only one or two pans on the hob. Preferably one! I normally use one really big pan with high sides (see pic). I use a pan like this to cook almost everything. You can boil and fry using this pan. You can also use the spatula and push against the sides without things falling out.

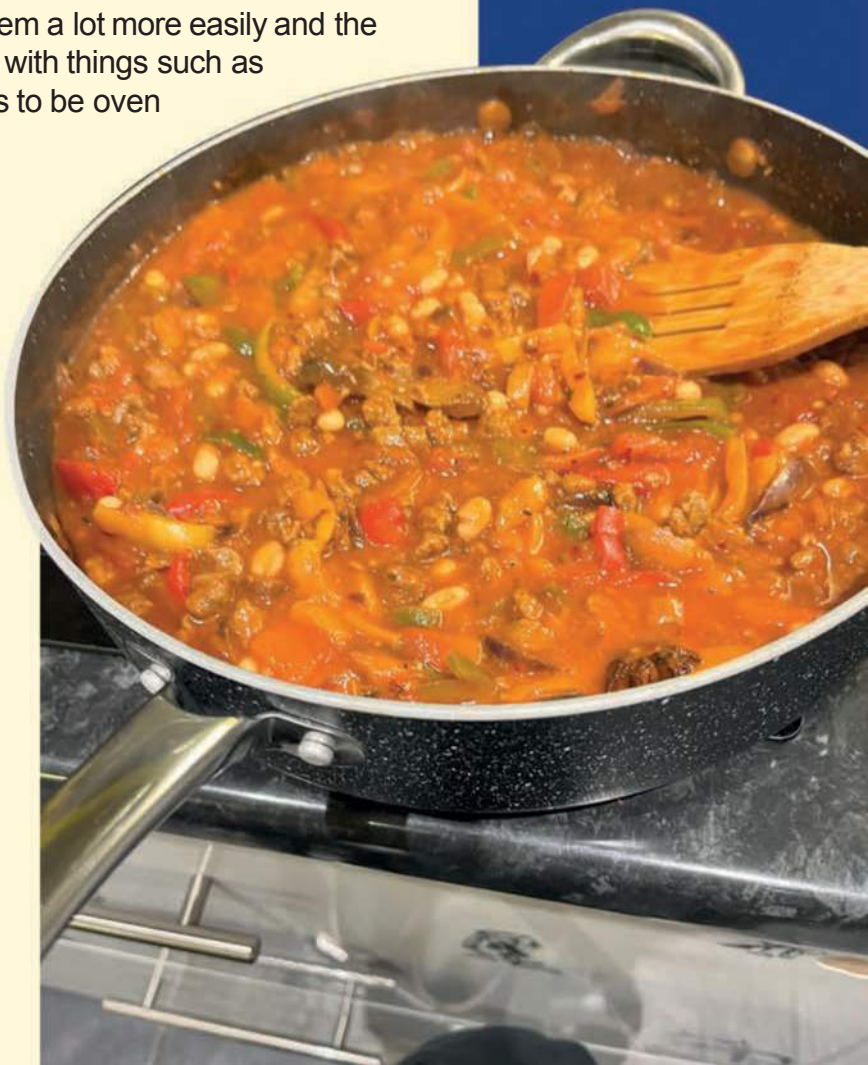
My hobs have been lowered so I can get to them a lot more easily and the kitchen has been set up for me. My wife helps with things such as pasta which need draining or if something has to be oven cooked.

For cooking, I use as many lazy products as I can. I use lazy chilly and lazy chopped garlic. I also use frozen chopped peppers, chopped onions and mushrooms for convenience. This saves having to use knives or any chopping utensils this also greatly reduces preparation time.

For me everything is about preparation. I have every ingredient ready before I start. Normally I will cook a few meals in one and split the leftovers to reheat at a later date.

There are lots of great cookbooks available using one pan and many cookbooks for people with disabilities. I can't really recommend one as I just Google and use online recipes if needed.

*Thanks for reading. If you have any questions or suggestions please email me:
downstar@mac.com*



How an occupational therapist can help you

People with ataxia often find that they struggle to do everyday activities. In many cases, aids and adaptations can help. Whether it is grabrails and ramps to help you get around safer and easier at home or using adapted equipment to help you continue participating in a hobby. There are often things which can make a task easier or more accessible. Some aids are more obvious and common, but there are also some surprising gadgets out there, like adapted instruments and sports equipment.

With the wide variety available, it can be difficult to know where to start. If you are not sure which aid or equipment is right for you, or if a friend has recommended something but you're not sure it is right for you, an occupational therapist can help.

Everyone is unique and has their own strengths and needs. Something which works for one person may not work for someone else. In some cases, using the wrong piece of equipment can have a negative impact by taking away a strength you already have or encouraging negative adaptive strategies. **Occupational therapists will assess you and the tasks you want to do and prescribe aids and equipmentspecificallysuitablefor you** to enable you to do that activity safely and in a way which doesn't cause harm. In addition to prescribing aids and equipment, they can help with strategies to address fatigue or cognitive issues such as memory loss.

You can ask your GP for a referral to an occupational therapist in your area if you think you would benefit from one. You can also contact your local council's Health and Social Services team to get you in touch with an occupational therapist. If you are under the services of one of the Specialist Ataxia Clinics in the UK, you can also ask there about getting an occupational therapy referral. Finally, if you have the financial means, the Royal College of Occupational Therapists have an online tool where you can find a qualified occupational therapist in your area.

www.rcot.co.uk/about-occupational-therapy/find-occupational-therapist

We're thrilled to have occupational therapists joining us at Ataxia UK – read more on the next page! *If you would like to discuss occupational therapy or if you would like help accessing an occupational therapist, please get in touch with the Helpline on 0800 995 6037 or help@ataxia.org.uk*

Occupational Therapy Students at Ataxia UK

Ataxia UK is delighted to welcome two more Occupational Therapy students who will be joining us on placement from 27th February until 21st April 2023.

Karishma (above right) and **Lara** (right) are both **MSc students** from the University of Brighton and will be with us for seven weeks. **There will be opportunities to get involved** and Karishma and Lara hope to be able to meet some of you during their time here.

Karishma and Lara will be promoting occupational therapy and **how it can help you live your best life**. Occupational therapy is all about overcoming challenges with completing activities in your daily life – both work and play!

Occupational therapists work with you to understand what meaningful activities you want to do, need to do or are expected to do and develop a care plan with YOU at the centre.

Karishma and Lara will be interested in learning more about ataxia and how it affects you in your day-to-day life, to help them understand how occupational therapists can best support this community.

Some of you may have met **Sue** and **Leona**, who were on placement with us in November and December last year. Sue and Leona joined support group meetings to provide information sessions about occupational therapy, explaining the process, what to expect from an occupational therapist and how to access occupational therapy in your area. They started developing a project around telehealth, which explores options for delivering occupational therapy remotely. They ran a therapeutic, creative arts group and they provided one-to-one occupational therapy assessments to Friends of Ataxia UK whilst on placement.

Sue and Leona enjoyed working with Ataxia UK and the ataxia community so much that they came back to join us as volunteers to deliver an occupational therapy session for wellbeing week and we hope to see them again soon.

Whilst on placement at Ataxia UK our occupational therapy students receive support and supervision from our **Head of Services, Wendy O'Mant**, and from **Carol McCudden** who is a **consultant occupational therapist** and a person with ataxia as well as being a member of the Ataxia UK board of trustees.

If you have any questions about occupational therapy, please get in touch by calling the Helpline on 0800 995 6037 or emailing help@ataxia.org.uk



The Blue Badge Scheme

The Blue Badge Scheme is designed to help disabled people park near places they are going.

Some people are automatically entitled to a blue badge:

- People who are on the higher rate mobility component of Disability Living Allowance (DLA).
- Some PIP claimants-
 - Those who can't walk more than 50 metres and who therefore got 8 points or more in response to questions about the moving around activity.
 - Those who get the mobility component and got 10 points because they are unable to undertake any journey because to do so would cause 'overwhelming psychological distress'.

The schemes in Scotland and Wales have broader criteria.

In Scotland and Wales, you can get a Blue Badge if you scored 12 points in relation to questions about planning and following a journey.

In Scotland, you can also get a Blue Badge if:

- You previously got the higher rate of mobility component for DLA indefinitely.
- You had a Mandatory Reconsideration against a PIP decision accepted by the Department of Work and Pensions (DWP).

The gov.uk website states you may also access a Blue Badge if you are in one of the following situations. Many of these might apply to families affected by ataxia:

- You cannot walk at all, or you cannot walk without help from someone else or using mobility aids.
- You find walking very difficult due to pain, breathlessness, or the time it takes to walk is dangerous to your health and safety.
- You have a terminal illness, which means you cannot walk or find walking very difficult and have a DS1500 form.
- You have a severe disability in both arms and drive regularly but cannot operate pay-and-display parking machines.
- You have a child under the age of 3 with a medical condition that means the child always needs to be accompanied by bulky medical equipment.
- You have a child under the age of 3 with a medical condition which means the child must always be kept near a vehicle in case they need emergency medical treatment.
- You are constantly a significant risk to yourself or others near vehicles, in traffic or car parks you struggle severely to plan or follow a journey.
- You find it difficult or impossible to control your actions and lack awareness of the impact you could have on others.
- You regularly have intense and overwhelming responses to situations causing temporary loss of behavioural control.
- You frequently become extremely anxious or fearful of public/open spaces.

If you can see your household situation described on this list, and you aren't a claimant already, you should consider applying for Disability Living Allowance, Personal Independence Payment or Attendance Allowance as soon as possible. We're here to help!

If you need support to apply for a blue badge or any of the benefits mentioned here, please contact the Helpline on 0800 995 6037 or by emailing help@ataxia.org.uk



Me & Voice Banking by Laura

As you may know, Ataxia UK offers funding for Friends to bank their voices. Our Friend & Helpline volunteer Laura talks us through her Speak Unique voice banking experience. Let's hear from Laura...

I was introduced to SpeakUnique by Ataxia UK. Having Friedreich's Ataxia (FA) my voice is slightly slurred but at this stage not a huge issue. This said I decided to 'bank' my voice should my voice deteriorate in the future.

As for the process, I simply went to www.speakunique.co.uk and selected the option to 'sign up / login'. Signing up is completely free and takes just a few minutes. You need to confirm a few details such as your condition, date of birth, if you have an accent etc. You then have the option to build, design, or repair your voice. I selected the 'build voice' option.

There is a tutorial lasting about 4 minutes. This very clearly explains what to do and what not to do. Common sense stuff really. When you progress to recordings you are given a choice of book – I went for the Jungle Book! You then simply record a minimum of 150 sentences which are snippets from the book. Each recording can be played back and if you are unhappy with it simply delete and re-record. I'm not going to lie this is quite time-consuming. **However, you can save your progress at any point and return later.** As I was in no huge rush, I did the whole process over a few weeks.

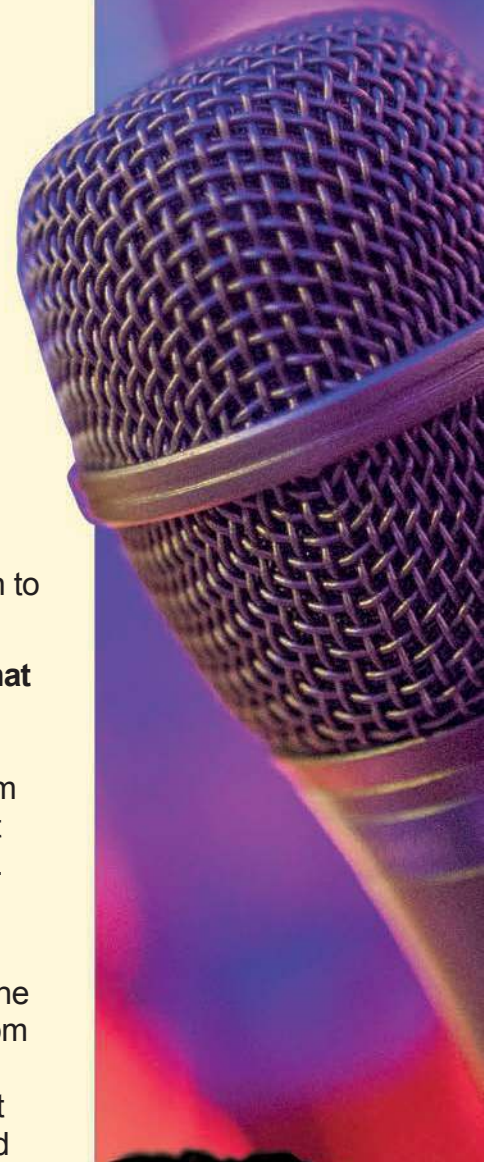
The only issue I experienced was an error message which read 'microphone too near mouth'. After moving my laptop literally to the other side of the room and still getting this message I realised there must be something wrong! I mentioned this to Ataxia UK and they gave me an email address to contact straight away. Within 24 hours I received a reply confirming my settings had been 'relaxed'. I then returned to my recordings and haven't seen the error message again.

Once completed, you can listen to examples of how your voice sounds. I was amazed how good the recordings were.

At this stage, you can literally save your voice and it's 'banked', which is what I did. Alternatively, you have the option to download your voice to be used on your communication device. The cost for Voice Build is £175, however, you have 2 options – 'pay now' or 'apply for funding'. If the 'apply for funding' option is selected, you will notice that Ataxia UK are an approved charity.

Overall, a pretty seamless experience and I would encourage anyone to bank their voice – whether you have Ataxia or not!

When Laura is ready to download her synthetic voice, all she needs to do is apply for funding from Ataxia UK via her SpeakUnique account. For more information about Voice Banking, visit www.ataxia.org.uk/support-services/voice-banking



Wellbeing Survey Feedback

In September we launched our Wellbeing Survey 2022. We wanted to learn about the impact our InControl project had on the lives of people with ataxia and to find out about the wellbeing of the ataxia community.

More than 300 of you responded – thank you!
Here are some of the things we learned:

About your living situation:

Almost one-third (28%) of those responding to the wellbeing survey live alone which suggests a large proportion of the community is at risk of isolation and loneliness. The work carried out by the InControl Project and continued Ataxia UK Services Team continues to play a crucial role in engaging and bringing together the community.

About your occupation:

57% of respondents are retired, 22% are unable to work due to health reasons/disability, and a further 3% are unemployed. This shows a large proportion of the ataxia community do not receive income from work and may be eligible for financial assistance. Statistics show that **there is significant underclaiming of welfare benefits and many people do not know what they are entitled to or simply assume they cannot claim anything.** Some respondents said they wanted to know more about benefits and some have asked for help to apply: *“I would benefit from benefits advice, as apart from receiving a small pension I do not have any further income.”*

What health, social care, community and voluntary services have you used since 2020?

Almost half (45%) of the respondents said they had not used any health, social care, community, or voluntary services in the last 3 years which is an alarming number from a community living with progressive neurological conditions. This suggests there is a significant proportion of the community which does not use services either because they are not aware of what is available or have struggled to access what they may be entitled to.

We're here to help!

If you, or someone you know, needs help accessing or finding out more about the range of benefits you're entitled to, please contact our Helpline team on 0800 995 6037 or help@ataxia.org.uk

28%
live alone

57%
retired

22%
unable to work

3%

unemployed

45%

not used any health, social care, community, or voluntary service in the last 3 years

Accessing Counselling Services

We are often asked by people affected by ataxia how they can access counselling. Living with, or watching someone you're close to, cope with a progressive condition can trigger a wide range of emotions. Often talking to someone outside of your family or friends can help you better understand your feelings and manage them more effectively.

Counselling, talking therapies, like cognitive behavioural therapy (CBT) and guided self-help are **available via the NHS's Improving Access to Psychological Therapies (IAPT) service in England**. You can access IAPT through your GP or you can contact them directly without talking to your GP, though you do need to be registered with a GP to apply. They are able to help with common mental health problems like anxiety and depression and if you would like to refer yourself you can do so here: <http://alturl.com/6uy3p>

If you're in **Scotland** you can find information on **NHS Mental Health Services** by talking to your GP and here: <http://alturl.com/z9cvjg>

In **Northern Ireland**, all referrals go through your GP. You can find out **more about the mental health services available here**: <http://alturl.com/v8edz>

In **Wales**, you can access online CBT courses without a referral from your GP as well as CALL Mental Health Listening Line on **0800 132 737**. All other referrals go through your GP. Find out **more about the services that are available here**: <http://alturl.com/fp77i>

You may not want to go through your GP though if you are concerned about waiting lists or looking for more specific counselling for people with a disability. This would normally mean finding a paid counsellor.

The Counselling Directory - 0333 325 2500
www.counselling-directory.org.uk

The Counselling Directory can help you find a counsellor in your area that specialises in specific types of therapy, and you can choose what type of session you would like: in person, online etc. The website also allows you to search for counsellors that offer discounts to a wide range of people, for example, if you are on a low income, state pension or unemployed. All counsellors registered on the website are fully qualified.

Disability Plus - 01932 881849
www.disabilityplus.co.uk

Disability Plus offer specialised, disabilities-focused counselling to anyone over the age of 18 who has a disability or is affected by a disability. They take referrals from the general public as well as from GPs (so definitely worth asking your GP). Their therapists have the same or similar disability as the individual or have extensive training and specialism in the service they deliver. They have a wide range of payment options, including possible access to their bespoke service funded via the NHS. Disability Plus can apply for NHS funding for people who are unable to access counselling directly from NHS IAPT due to their disability. Their waiting lists are also significantly shorter than the NHS.



The Neuro Therapy Centre - 01244 678 619

www.neurotherapycentre.org

The Neuro Therapy Centre is a charity that supports people with long-term neurological conditions and their carers. Although the centre is based in Chester they provide a lot of virtual help including counselling, support groups and exercise classes. They run a specific Parkinson's and Ataxia Support group that is run by their counsellor Glesni via Zoom. To access these services, you will need to become a member. For a person with a neurological condition, the cost per year is £24, for a carer it is £12 or you can pay them together for £32.

If you need help to access counselling or any of the services mentioned above, please contact the Helpline on 0800 995 6037 or help@ataxia.org.uk, we're here to help.

**Helpline & Advocacy service**

Our Helpline & Advocacy team is here to provide one-to-one support with a range of issues from benefits, housing, care & health needs, aids & adaptations and so much more...

Email: help@ataxia.org.uk Phone: 0800 995 6037

**Friends Connect**

An important part of what we do at Ataxia UK. Friends Connect is here to ensure that nobody ever feels alone with their ataxia.

**Speech Therapy**

A combined individual and group speech therapy course for people with ataxia who have speech difficulties

**Voice Banking**

We are delighted to announce we can now offer funding for friends of Ataxia UK to use Voice Banking via a company called Speak Unique.

**Social groups & Online Forums**

From Branches & Support Groups to virtual activities and more, there's a variety of in-person and online groups, including authorised Facebook groups.

**Online groups**

www.ataxia.org.uk/support-services/online-support-forums

Branches & Support groups

www.ataxia.org.uk/support-services/branches-support-groups

Virtual Activities

www.ataxia.org.uk/latest-news/virtual-activities

More information

Support Services: www.ataxia.org.uk/support-services

Help & Advice: www.ataxia.org.uk/newly-diagnosed/help-and-advice

Our Helpline team is here for you.

Email: help@ataxia.org.uk Phone: 0800 995 6037

Monday to Thursday, from 10.30am to 2.30pm.



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