

# ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 219. Autumn 2022

**Join us for the  
Virtual Annual Conference  
on 7th & 8th October!**

From fantastic speakers, interactive classes  
and entertainment, we've got something for everyone

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Adaptations • Living with ataxia • Services

# ATAXIA

Ataxia UK

# In the office



Over the last quarter, we've welcomed some fantastic additions to our rapidly-growing team. Firstly, we're saying 'hello' to **Bella**, our new **Volunteering and Community Program Intern**. Bella will be helping the Services Team develop and deliver virtual activities and supporting our volunteers. We're also welcoming **Hannah**, our new **Events and Community intern**, who will be ensuring community events are running smoothly and that our fantastic fundraisers receive all the support they need. Last, but most certainly not least, our wonderful **Social Media and Content intern, Irmak**, whom many of you may know as the person responding to messages and queries on our social channels, has been promoted to a **Social Media and Content Officer**.

## CEO's Introduction

It was wonderful to attend the **Ataxia UK Scottish Conference** in June in Edinburgh. Our first face-to-face conference since lockdown. As nearly 50 of us gathered in the hotel for the first session, it evoked memories of 'how life used to be'. For better or worse, we have now entered a period of 'living with Covid-19' without enforced mitigations against contracting the illness, but with many people remaining nervous about what catching it would mean for them – even with the prospect of emergency anti-viral medication for some, and vaccination available to all.

Ataxia UK continues to grapple with this new environment and how to best serve and support all our Friends. The lockdown brought the discovery of Zoom and gave us the ability to hold events and support people online, a clear positive for those with mobility difficulties and it's certain that we'll continue to use virtual meetings and streaming for many purposes including meetings of the Trustees, conferences, activities, and our range of support functions including the Helpline.

However, we also want to offer opportunities for people to meet, and attend events, in-person and we know that some branches and support groups are already doing this. This year we have decided that we don't have an appetite for the financial risk involved in holding an Annual Conference for 200 people, and in view of the success of the 2022 Scottish Conference and previous regional conferences we are considering whether to prioritise these next year – perhaps holding 2 to 3 across the country to reduce costs for attendees, and Ataxia UK. **Your views on this are very welcome.**

The lockdown has also opened our eyes to new ways of working in the office – and ensuring that our current office remains big enough, even though we are adding new roles to the team. We are developing the HR policies and procedures required to establish our team as hybrid – i.e. some days at home and some office-based, and anticipate that everybody will be working a few days a week from the office from the autumn.

In the meanwhile, we are seeing continued spikes in Covid-19 across the country, with continuing impacts on NHS services. You can read an article about patients' views of the neurological services they receive from the NHS, and learn about the **'Together for the 1 in 6' campaign** to improve neurology on page 5. Neurology patients urgently need to see plans for improvements to services and be consulted about them. You can join the campaign and make a difference.

Best wishes, Sue Millman



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Sue

Our Scottish Conference took place in person on 18th June, and it was a wonderful event. We heard from Ataxia UK's CEO, **Sue Millman**, about the exciting **Nurse Specialist** project we are working on within Scotland. Our delegates got to experience **Chair Pilates** and **Mindfulness** in our workshop sessions and the Research updates have received excellent feedback so far. We want to thank everyone who attended, we hope you all had a wonderful time. We certainly enjoyed finally seeing you all in person as well as our brief time in Edinburgh! *If you attended and haven't yet completed your feedback form, there is still time, please email **Lucy Porter**, [lporter@ataxia.org.uk](mailto:lporter@ataxia.org.uk).*

Our next big event is the **Annual Conference** which takes place over two days – **Friday 7th October & Saturday 8th October**. Exact times are still to be confirmed. **Following last year's successful conference, we are hosting this year's virtually, too!**

Our conference will begin on Friday morning with a welcome from our CEO, **Sue Millman** and a talk from Rare Minds about handling diagnosis. Then our **Research sessions** will begin; this year we will be covering **Friedreich's ataxia, Cerebellar ataxia & DRPLA**. Each session will include an update by our Research team followed by a Doctors Q&A with our Neurologists.

On Saturday, the legendary **Paul Coia** will be our host. We have invited some very exciting speakers this year to talk about a variety of topics. This includes **Kamran Mallick** CEO of *Disability Rights UK* who, as many of you will remember, couldn't attend last year due to illness. So, we are grateful he can join this time to talk to us. We also have our Friend, **Chris Graves**, talking to Paul Coia about his award-winning micro-farm in Wales & how he is dealing with his ataxia diagnosis.

We have a really exciting line up for our **It Works For Me** sessions presented by people directly affected by ataxia.

This year, our entertainment night will be hosted by the fabulous **Steve Hewlett**, a comedy ventriloquist whom we believe was the last live entertainment we held at Ataxia UK back in 2019. We hope he can bring laughter and smiles to the whole audience. And **Jamie Raven**, our patron who entertained us last year online, is being interviewed by Paul Coia this year. Sadly, he won't be making champagne bottles appear out of thin air this time but nonetheless, it will be an exciting chat. Friends of Ataxia UK, **Dan Stott & Lucas Schofield**, will be interviewed by Paul and you will hear about their amazing feat last year when they walked 1000 miles from John O'Groats to Lands' End.

Our **workshops** this year include **Mindfulness, Chair Yoga, Benefits, Aids & Adaptations** & more...

*We really hope to see you all at the annual conference. A full agenda with times and a booking form can be found by going to:*

**[www.ataxia.org.uk/virtual-annual-conference-2022](http://www.ataxia.org.uk/virtual-annual-conference-2022)**

*If you have any questions about the conference, please email **lporter@ataxia.org.uk***



## Working with national neurological alliances to drive recovery and change in UK neurological services

This year has seen all of the UK's neurological alliances (Neurological Alliance of Scotland, Wales Neurological Alliance, The Northern Ireland Neurological Charities Alliance, and The Neurological Alliance - England) working in collaboration to deliver a survey of people with neurological conditions, previously undertaken every other year by The Neurological Alliance in England. The results of My Neuro Survey have now been published with helpful breakdowns by condition and country.

### 8,500 people, (including around 1% with ataxia), reported:

- **Delays to diagnosis leave life in limbo.** More than a third of adults reported waiting more than a year between first experiencing symptoms and getting a diagnosis. 1 in 5 waited more than 12 months between first seeing a GP and seeing a neurologist. 3 out of 10 children and young people reported waits of more than 12 months between first experiencing symptoms and getting a diagnosis.
- **Delays to treatment and care can change your life.** 55% of adults and 60% of children and young people living with a neurological condition experienced delays to routine appointments with specialists in the last year.
- **Most people with a neurological condition are unable to access the mental well-being support they need.** 40% reported their mental well-being needs are not being met at all.
- **Finding out you have a neurological condition is scary and confusing.** Receiving the right information and support can make a real difference. 2 in 10 were not given any explanation of their diagnosis. Almost 4 in 10 adults reported not being given any information at all.

*As some of you may recall we did an ataxia wellbeing survey last year, which explored the issues people with ataxia face in the UK. You can read the ataxia report in full on our website: <https://bit.ly/3J4MciV>. The findings of it, sadly, supported those of the **My Neuro Survey**.*

In launching the report 'Together for the 1 in 6' and a campaign to demand change, the Chairs of Neurological Alliance of Scotland, Wales Neurological Alliance, The Northern Ireland Neurological Charities Alliance, and The Neurological Alliance (England) made the following plea:

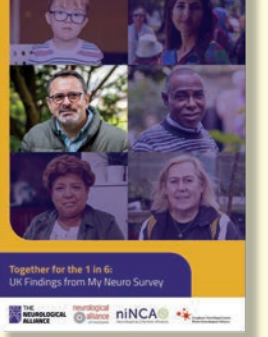
"We call on the UK Government, Scottish Government, Welsh Government and Northern Ireland Executive to prioritise services for people with neurological conditions and establish a Neuro Taskforce. The Taskforce would bring together relevant departments, health and social care bodies, professional bodies, people affected by neurological conditions and the voluntary sector to:

- Assess the current neuroscience workforce and set out plans to ensure it is fit for the future.
- Share approaches to common problems, such as addressing long-standing barriers to accessing mental, emotional and cognitive support, driving down waiting lists for elective care, improving the quality and analysis of health and care data and supporting transition between paediatric and adult neuroscience services.
- Assess the level of investment in research into the causes, impacts and possible cures of neurological conditions and set out plans to level up investment in areas that do not receive a fair share currently."

*You can read the full 'Together for the 1 in 6 – UK Findings from my Neuro Survey' report here: <https://bit.ly/3zyHpDj>*

### Ataxia UK backs the 'Together for the 1 in 6' campaign

*The situation for neurological patients must change. You can join us and the patient organisations representing other neurological conditions from across the UK, in backing the 1 in 6 campaign. Sign the petition now at: <https://bit.ly/3vcw6hx> and share it on social media. **#BackThe1in6***



## New speech therapy project launched

**Ataxia UK is pleased to award funding to Prof Anja Lowit (below) at Strathclyde University to continue her important research on speech and language therapy for people with ataxia.**

Evidence for the effectiveness of speech treatment to improve communication for people with ataxia is steadily increasing. Over the last five years Prof Lowit and her team have contributed critical studies to this topic, by testing different speech treatments for people with ataxia. In their first study, they showed that **Lee Silverman Voice Treatment Loud (LSVT Loud)** had some benefits for people with ataxia. Participants in the study have shown improved voice quality and confidence in communicating. Unfortunately, the most important outcome measure, intelligibility, did not show any improvement. In the next study, they added a peer support element, which enabled participants to practise in a group setting every day for four weeks. Intelligibility improved for almost everyone that took part, and communication confidence improved for all participants.

Whilst both of these studies showed promise, the important next step is to run a large trial which will conclusively show whether speech therapy is effective for people with ataxia, and which approach works best. Before the team can plan this large trial, they will carry out one more small pilot study of a newly developed speech treatment called **LSVT Artic**. This Ataxia UK-funded project will help them decide the best treatment option for a larger future trial.

Evidence suggests that LSVT Artic, which focuses on articulation rather than a loud voice, might be more appropriate for people with ataxia. The LSVT Artic treatment is administered intensively over a period of four weeks. They will study whether this has the potential to achieve better outcomes than the treatments used previously and whether intensive speech therapy is feasible for people with ataxia.

Prof Lowit, with support from LSVT Global – the developers of LSVT Artic – will initially work with six individuals with FA to explore the treatment potential. If the treatment turns out to be promising, they plan to increase the number of participants further, to collect more supporting evidence.

At the end of this project, the team will have established whether LSVT Artic is a viable treatment option for people with progressive ataxia, allowing them to plan a large-scale trial using the treatment which evidence shows is the best option for people with ataxia.

*The researchers are looking for people with FA to take part in this trial. To see the criteria required to participate, and for information on taking part, see our website: <https://bit.ly/3delskd>*



## The TREAT-ARCA Project

**TREAT-ARCA** is a global preclinical research project, led by Dr H el ene Puccio from Universit e de Lyon, focused on two rare ataxias: Autosomal Recessive Spastic Ataxia of Charlevoix-Saguenay (**ARSACS**) and **COQ8A-ataxia** (also known as Autosomal Recessive Cerebellar Ataxia type 2 ARCA2, and ataxia caused by CoQ10 deficiency). This three-year project received funding from the EU's Horizon 2020 research and innovation programme.

**The TREAT-ARCA project has four objectives:**

1. Test two promising repurposed drugs in mouse models of ARSACS and COQ8A-ataxia. Repurposed drugs are those which are already approved for another condition.
2. Test novel drugs for ARSACS in a mouse model.
3. Test gene therapy for COQ8A-ataxia in a mouse model.
4. Identify and validate biomarkers, which are a way of measuring whether a treatment is working during a clinical trial. When preparing for ataxia clinical trials in the future, it is crucial that neurologists have a reliable biomarker. Failure to identify a good biomarker can even be the cause of a failed clinical trial.

This planned, preclinical work could help identify potential treatments for ARSACS and COQ8A-ataxia. These could then be tested in future clinical trials. Euro-ataxia (with support from Ataxia UK), German patient group DHAG, and Ataxia Charlevoix-Saguenay Foundation (based in Montr el) are representing patients on this project. They will lead a programme of patient engagement activities, including a regular blog and webinar series. Ataxia UK encourages anyone with these types of ataxias to join the ARSACS or COQ8A-ataxia RareConnect forums for regular updates. *Please see our website: [www.ataxia.org.uk/support-services/online-support-forums](http://www.ataxia.org.uk/support-services/online-support-forums)*

## 2022 CureDRPLA Research Conference

Drs. Silvia Prades and Julie Greenfield from Ataxia UK's Research Department attended the 2022 CureDRPLA Research Conference on 11th May. Dentatorubral-pallidoluysian atrophy (DRPLA) is a rare form of ataxia. Ataxia UK is part of a partnership with CureDRPLA to research this very rare condition. The conference was attended by over 30 people, including medical professionals, researchers, and representatives from pharmaceutical companies. There were a few presentations showcasing the research that has taken place since we started this collaboration in 2019 and plenty of time for Q&A and brainstorming ideas for projects that we could take on. It was a great opportunity to share knowledge across all the DRPLA projects and discuss the best strategy to advance DRPLA research and work towards finding a treatment for this condition.



## SCA6 research project – recruiting participants

**Ataxia UK is pleased to award funding to Dr Yi Shiau Ng (below) and his team at Newcastle University, for their project studying balance and gait in SCA6.**

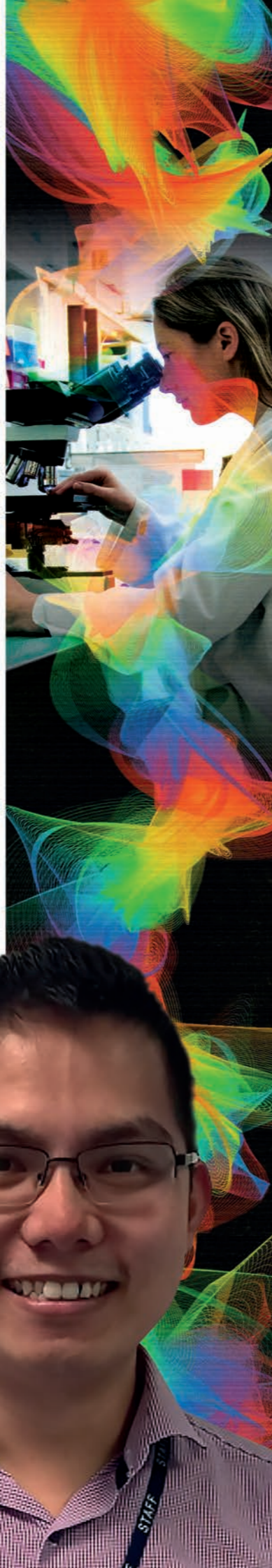
Dr Ng and his colleagues (Dr Newman, Dr Alcock and Dr Del-Din) are studying a group of genetic conditions called mitochondrial disease. People with mitochondrial disease often have similar symptoms to people with ataxia, such as an unsteady gait and impaired balance. These symptoms are usually caused by cerebellar dysfunction.

When measuring balance and gait in people with mitochondrial disease, Dr Ng and his colleagues found that other co-existing neurological symptoms such as nerve damage (neuropathy) and muscle weakness, can also cause problems with gait and balance for these patients. Dr Ng and his team want to know specifically which changes in gait are caused by degeneration of the cerebellum, and which are caused by other neurological symptoms. In order to better understand this, they plan to measure gait in people with spinocerebellar ataxia type 6 (SCA6). SCA6 is caused by degeneration of the cerebellum, and unlike mitochondrial disease it does not cause the other co-existing neurological symptoms.

Instruments used to measure changes to gait are emerging as promising tools to measure and track the symptoms of ataxia. Developing sensitive ways of measuring the symptoms of ataxia is important for the design of clinical trials, as clinicians need objective ways of measuring whether a treatment in a trial improves the ataxia symptoms. As well as undergoing tests designed to measure gait and completing questionnaires at a hospital appointment, participants will also wear a small sensor on the lower back for seven days whilst at home. This will allow the researchers to gather data on gait in people with SCA6 in their home environment, and compare this with measures taken at the hospital.

At the end of this project, Dr Ng and his team hope to better understand which changes to gait are caused by degeneration of the cerebellum (as seen in SCA6), and which are caused by other co-existing symptoms of mitochondrial disease. The researchers expect that this project will also generate useful data in support of using gait measurements in future clinical trials.

*They intend to assess 16 people with SCA6 (aged between 16 to 70 years old) who are able to walk without any walking aids for a short distance. Participants will be asked to attend Newcastle University for one visit, and wear a sensor for seven days at home. If you have been diagnosed with SCA6 and would like more information on taking part in the study, please contact the study team via email: [mito.ataxia.study@ncl.ac.uk](mailto:mito.ataxia.study@ncl.ac.uk).*



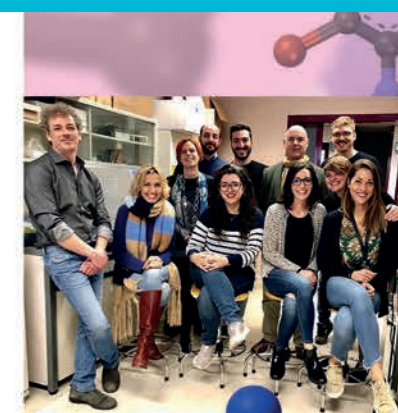
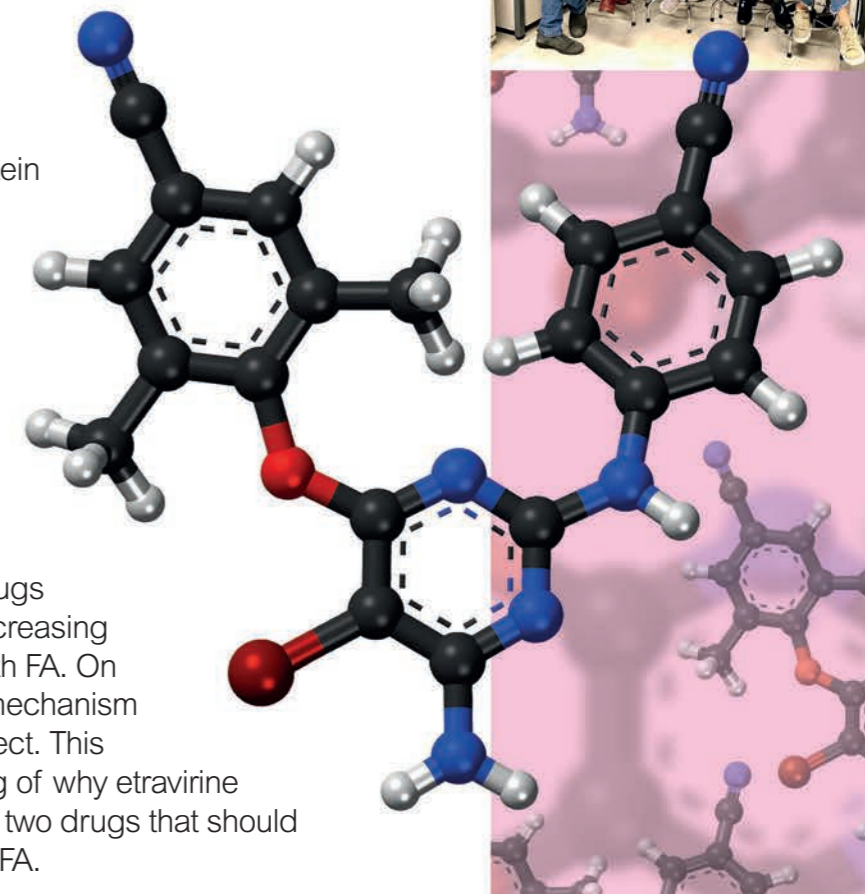
## Studying etravirine and similar drugs as potential treatments for Friedreich's ataxia

**Dr Alessandra Rufini and team (right) at Fratagene Therapeutics, based at the University of Rome "Tor Vergata", Italy have recently completed their Ataxia UK-funded project looking at etravirine and similar drugs as potential treatments for Friedreich's ataxia (FA).**

Etravirine is an antiviral drug which is used as a treatment for HIV. Previously, the team's cell and animal work showed that etravirine increased frataxin protein levels. Frataxin protein is decreased in people with FA. The team are currently testing etravirine in a Phase 2 clinical trial in Italy to study its safety and efficacy in people with FA. The results of this study are expected in the first half of 2023.

In their Ataxia-UK funded study, the team tested drugs that have either a similar structure to etravirine or the same mechanism of action against HIV.

They found that the two structurally similar drugs were even more effective than etravirine in increasing frataxin levels in cells derived from people with FA. On the other hand, the two drugs with a similar mechanism of action against HIV as etravirine had no effect. This research has given us a better understanding of why etravirine increases frataxin levels. It has also identified two drugs that should be further studied as potential treatments for FA.



## New Ataxia UK leaflets

**Along with our expert advisors, Ataxia UK has written two new medical leaflets.**

**The first leaflet talks about receiving fluids intravenously for people with Friedreich's ataxia (FA).** It is important that medical professionals are made aware of your FA diagnosis before you undergo medical procedures that involve receiving fluids. They should be made aware of the effect that FA can have on the heart and consult with your cardiologist or neurologist.

To download a copy of this leaflet visit: <https://bit.ly/3bi2EQq>

**The second leaflet talks about a type of ataxia called CANVAS (Cerebellar ataxia, neuropathy and vestibular areflexia syndrome).**

CANVAS is a genetic condition, which can be caused by a defect in the RFC1 gene. The identification of this genetic mutation could mean that more people with late-onset ataxia receive a genetic diagnosis for their condition. It is thought to be a relatively common form of genetic ataxia.

To download a copy of this leaflet visit: <https://bit.ly/3vpHHKc>



## Two steps towards speedier ataxia diagnosis 2022

As we approach International Ataxia Awareness Day on 25th September, we reflect on last year's campaign, which was a great success thanks to all those that got involved by getting a copy of the ataxia Medical Guidelines to their local GP surgery.

Due to its rare nature, many medical professionals are unaware of what ataxia is and how to treat it. Getting the Medical Guidelines to all GP surgeries is a step towards faster and easier diagnosis and better care for those affected by ataxia. 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.

*"I found the Guidelines very comprehensive and useful. As a GP, I will definitely be referring to them in the future. It's good to have the summary too. Having guidelines for children with ataxia is also helpful."* – **Meryem Kaya, GP**

Experiences of slow diagnosis are far too common.

*"At primary school, when I was initially displaying symptoms, I was told I was faking it. This made me feel very confused. I felt that I must be making up my symptoms as adults were telling me so."* - **Friend of Ataxia UK**

*"My diagnosis process was incredibly slow, difficult and horrendous. I was passed from specialist to specialist. The doctors did not seem to believe me at all. It was very humiliating and frustrating."* - **Friend of Ataxia UK**

**This International Ataxia Awareness Day you can be the part of change and help bring an end to stories like these by improving diagnosis and care for the ataxia community with just two easy steps.**

So, what are these two steps, you ask? It's simple:

**1. Sign up** for the challenge on our website at [www.ataxia.org.uk/iaad2022](http://www.ataxia.org.uk/iaad2022) 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 to 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, please email: [communications@ataxia.org.uk](mailto:communications@ataxia.org.uk)



## Movement and ataxia

**There's a mountain of evidence showing that movement and exercise is great for us. It's great for our physical and mental health, helps us sleep better, and can be beneficial in maintaining movement. While exercise is important for everyone, research has shown it is even more important to those with a disability. However, sometimes disabilities can create barriers to exercise and movement resulting in adults with disabilities doing approximately half as much regular physical activity as those without disabilities.**

It's important to recognise that movement can be difficult for some members of the ataxia community and finding the type of exercise that works for you is crucial. We often get asked about the types of exercises which are particularly helpful for people with ataxia. Our medical guidelines suggest that general fitness training, yoga and pilates are particularly helpful to maintain strength, flexibility, and balance.

Ataxia UK has been encouraging and providing exercise opportunities for the ataxia community regularly, by hosting online chair yoga and chair Pilates sessions. The next Chair Pilates class will be on 20th September – we'd love to see you! *Book your ticket here:* <https://bit.ly/3BXwILZ>

### About Chair Pilates

The classes are led by Sonia who is a trained Pilates practitioner and specialises in working with people with a variety of abilities including those with ataxia. The classes are all chair-based, so everyone can participate from any type of chair (wheelchair, armchair, kitchen chair). The classes focus on mobilising and stretching the whole body, as well as exploring optimal body alignment to improve body awareness and alleviate muscular tension.

During the session, Sonia sees all participants and suggests alternative exercises tailored to individuals' needs. This means we have to limit the classes to around 20 attendees per session. The feedback from many participants has been that they like that the movements are tailored to their abilities, and they can exercise alongside other people with ataxia, making them feel less self-conscious than they might in another setting.

*If you have any questions about Chair Pilates or exercise in general, please contact the **Helpline** on **0800 995 6037** or email [help@ataxia.org.uk](mailto:help@ataxia.org.uk). **PLEASE ALWAYS consult your DOCTOR before beginning this or any other exercise program.***



Since 2017 we have participated in The Big Give Christmas Challenge. This is a match-funding campaign run around the festive season. During this time, we have raised over £277k for a range of projects supporting the ataxia community, including:

- **Helpline** – In 2020, £34k was raised to help keep the helpline open, provide information and support throughout the pandemic and to start providing financial information support.
- **Paediatric centre** – In 2018, £21k was raised to help set up a new paediatric centre. In 2019, the UK's first Ataxia Centre for Children was opened!
- **Ataxia Clinics** – in 2019, £68k was raised to help establish additional accredited ataxia centres and to improve access to extended services at all existing and new ataxia centres, which will include the development of a virtual ataxia clinic. The virtual clinic has stalled due to a number of factors including a global pandemic, but there are plans in place to help make this a reality – more to be revealed soon!
- **Research** – 2017 to 2021 - £103k was raised – helping to fund research projects into treatment and cures for the ataxias.
- Most recently by supporting “**The Gift of Speech**” project which has gotten off to a flying start. You can read all about it on pages 20-21.

### We are thrilled to announce that we will be taking part again this year!

This year the campaign target is £60k and it will be used to help fund and grow the support services to the ataxia community. This includes the provision of information & support through the Helpline, increased Advocacy support, Anxiety & motivation workshops, Online Speech Therapy, Mindfulness & hypnotherapy sessions, Friends Connect & more.

The Big Give Christmas Challenge works by having a “match pot” made up of individual donors and “champions”. When donations are made in December they are doubled from this pot. The 1st phase of the campaign is to find £15k in pledges from individuals which helps secure the champion funds and complete the match pot.



## London Landmarks Half Marathon

Following on from the success of 2022, we are re-entering the London Landmarks on 2nd April 2023 and we want you to be on the Team.

From cultural landmarks and heritage to the City's quirky and hidden secrets, you'll get to see the best of London on a closed-road route like no other. The London Landmarks is the only half marathon to go through both the City of London and City of Westminster, and with a supportive, friendly, positive crowd cheering and awesome live music playing along the way, this is the event to be part of.

*“My brother, Jonah, and I ran the LLHM for Ataxia UK in 2022, and we loved it. Well, perhaps one of us was slightly less keen on the final 5km than the other... But there is no feeling better than having completed a huge challenge like a half-marathon through the streets of London - especially when you're doing it for such a fantastic cause as improving care for people with ataxia! The team at Ataxia UK were absolutely lovely, and we saw them a few times on our run around the course. It really helped to have such a great team behind us, encouraging us through the training, the fundraising, and then the race itself. All around, it was a wonderful experience!”* **Rory Cockhaw.**

Grab your place now – email [fundraising@ataxia.org.uk](mailto:fundraising@ataxia.org.uk) or call **0207 091 1597** to find out more.



## Try something different with an abseil

Abseiling is a spectacular challenge, and you can take part across the UK. Here are just a some of the places you could do yours.

**The ArcelorMittal Orbit in London** where a lift takes you 80m above ground, all the way to the top. **Philippa Campbell** who completed hers recently said:

*“My abseil went amazing, I loved it! I let them know I had a disability [and] when I arrived all of the staff were very helpful and accommodating. Abseil instructors kit you up and use the safest rigging system possible. They look after you and get you ready for a truly breath-taking experience!”*

**Becca Snell** abseiled from the **Newport Transporter Bridge**:

*“I was excited and nervous. Mostly over all the steps [but] staff reassured me they'd be on hand to help, I just need to be comfortable managing the steps. They were really supportive and encouraging. They brought my frame over as soon as I got to the bottom so I could sit whilst unhooked. I practised the steps in the gym for a few weeks before to be sure! It was really fun, and I'd definitely do it again!”*

*I'd recommend anyone that can should do it! If, like me, you have ataxia make sure the organisers are aware of you, and where you might need help. Chat with them beforehand so you feel confident that you'll get the support you need. The great thing about this abseil is you only have to walk up the steps, and as down is always harder with ataxia, an abseil is the perfect solution!”*

Contact us now to find out more: [rholt@ataxia.org.uk](mailto:rholt@ataxia.org.uk)



# Fundraising thank-yous

From music festivals to night cycling and everything in-between, here are just some of the wonderful fundraising achievements of our Friends. Thank you to all.

A golden thank you to our Guinness world record-breaking **Ivor Button** (above) who completed a **WingWalk** becoming the World's oldest WingWalker at a sprightly 95. Ivor has raised over £1,870 – congratulations Ivor!

A super round of applause to **Matt Tolson** and **Jack Greaves (1)** for trekking the epic **Jurassic Coast!** They smashed it and raised a whopping £1,690. Thank you so much to you both!

Congratulations to our marvellous **cake bakers Sharon Pearson, Samantha & Lucy Byrne** and **Liam Patient (2)** who raised a delicious £115. Thank you to the **Canewdon Village community** too for all your support!

Well done to **Sheena Betsworth (3)** who organised another successful fundraiser, this time with her **Colour Lucky Dip** raising a creative £281.50. Thank you so much for your continuing support and hard work Sheena!

A hattrick of congratulations to **Michelle, Bethany, Noah** and all the **Mccaffrey family (4)** for organising a **Football Day** and raising a goal-scoring £430! Noah, who has cerebellar ataxia gave cookies to supporters and kept everyone smiling. Thank you too to **Cheesy Waffles FB** and **New Derby FC** for their awesome support – what an amazing community effort.

A sunny rainbow of thanks to **Erika Allamand** and **Caroline Johnson (5)** who dashed through coloured foam and powder and 20 obstacles in the **Windsor Colour Rush** to support **Erika's son** who has ataxia, raising a vibrant £1,559 in the process. What a dynamic duo and congratulations to you both. Thank you too to **Vicky Creed** who was a star and helped Erika train!

A trophy for **Ayfer Yildiz** (below) as she completed her first-ever half marathon with the **Hackney Half** and raised a magnificent £160. Congratulations Ayfer, and thank you for all your hard work!

A nimble congratulations to speedy **Thomas Castledine** who took on the **Royal Sutton Fun Run**, raising a fantastic £590 for the Ataxia UK West Midlands Birmingham Branch. A massive thank you, Thomas!

Congratulations to **Braeden Jones**, who has already done the Royal Parks Half for Ataxia UK, now also added the **Brighton Marathon** under his belt. Thank you so much for your dedication, Braeden and for raising a smashing £974!

A very Happy 80th Birthday and thank you to **Martin Davies** for choosing to support Ataxia UK through his beautiful **boat party celebrations**, which raised over £115! Thank you too to **Lisa Davies** for all her organising.



A big well done to **Rhiannon Garrity** who **Walked 10k a day** in April, May and into June to support her friend who has ataxia, and raised a super £520!

A medal for **Michael Atkins** and **Gillian Ward Stokes (6)** as they triumphed at the **Milton Keynes Half Marathon**, raising a speedy £868 and £357 respectively. Thank you so much to you both and what an achievement!

**LottieFEST (8)** took place in June, and was a wonderful celebration of **Lottie Rapson (7)**. With a day of fantastic music in Devizes, the **Rapson family** very kindly chose Ataxia UK as one of the charities to support, raising over £800. Such a wonderful way to remember Lottie, and Thank you so much to **James, Anne, Luke** and **George Rapson, Devizes RFC** and all their friends, family and local community.

A big thank you to **Trevor Fleet (9)** and his fab team of friends and family; **Ruth Fleet, Hannah Fleet, James Frodsham, Tom Wright, Gavin Edge, Jon Whittaker, Andrew Stoneman, Kat Simkins, Simon Long** who completed the stunning 21-mile **Coniston to Barrow walk** in just under seven hours and have raised over £4,000. What an awesome team you all make, and massive congratulations all-round!

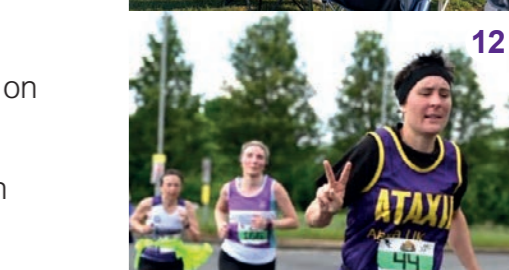
A big thank you to the **Burstner UK Owners Club (11)**, who raised £1,570 with everything from Bingo to selling chutney in memory of **Rhys (10)**, who had ataxia and sadly passed away. Such a special way to remember him, and thank you for your support.

Thank you so much **Joyce Lindsay** who conquered the beautiful **West Highland Way Walk** and raised a brilliant £590!

Thank you so much to **Martin & Ann Roberts** who held a **Quiz Night** at their local pub, and raised a winning £560! Such stars, and well done on such a victorious event!

Well done to **Emma Asquith Ellis (12)** who ran the **Northampton 10k** in 57mins 45secs and has raised over £300. Thank you so much, Emma!

A whooper of a well done to our star **Nightrider cyclists, Andrew Thompson & Edek Figura (13), Alick Varma & Manoj Tank (14), Attish Khmbatta & Mahesh Patel (15), Westly Spencley (16), Martin & Alison Dorsett, Amy & Scott Chamberlain** (right) and **Camilla Grundy**. Pedalling around London through the night, they took it up a gear past the Houses of Parliament and over Tower Bridge to raise an outstanding £10,382 with a further £530 in matched giving from Mahesh and Attish's employers. We are so impressed by your achievements, thank you so much our cycling heroes!





## Air Ataxia

By James Downie

**In this issue, I am going to write about my experiences travelling by air as someone with Ataxia, positive and negative, and a few tips!**

As we all know planning is key! I have been lucky enough to do lots of travelling abroad. As a wheelchair user I have been to New Zealand, the USA, Vietnam, South Africa, Spain and France. Please note all were pre-covid. To get wheelchair users and disabled passengers on planes you go in what I describe as a small portacabin on wheels. This is driven next to the plane then the portacabin raises to the height of the plane. You are then wheeled onto the plane using a special wheelchair to your seat. Your personal wheelchair (if you use one) is then put into the hold. Then you hope it is put on the plane and arrives in one piece at your destination!

I flew to New Zealand and the US on my own as a wheelchair user but then my ataxia was not what it is now. I recall when I was getting a connecting flight in the US and being told they would not let me board as I was too drunk! My speech was very slurred, having already been on a nine-hour flight. It was resolved as I stayed calm and asked for the manager. Inside, I was shouting!

One of my best friends got married in Vietnam in 2012. It was quite an experience. Dodging the traffic in Hanoi in my manual wheelchair with my wife pushing is a memory that will stay with me!

I went to Florida on my honeymoon in 2013 (see pics). For this trip we went using a travel agent and it all went well with flights and accommodation. Back then I used the toilet on the plane. Although most staff don't know where the aisle chair is, all planes have one! I used an aisle chair and with help transferred into the toilet.

In 2017 I went to South Africa on a safari with my Dad. On the plane, I didn't use the facilities as I took a wee tablet (tolterodine tartrate) and didn't drink much. For the safari, we used a company called **Epic Enabled** [www.epic-enabled.com](http://www.epic-enabled.com) and visited the Kruger national park. Looking back, the trip was great, the accommodation was mixed, to say the least, and the word accessible does not mean the same worldwide! On shorter flights around Europe, I never plan to use the toilet.

Most airlines put disabled passengers on first. However, Ryanair and possibly a few others put you on last. Being put on last is not great as if it's a busy flight everyone is staring and maybe thinking it's you holding the departure up. After landing I have been waiting for assistance for well over an hour before. The best thing is to stay patient, they will come as they don't want you on the plane forever! Before travelling check the airport's policy on helping disabled passengers. All large airports have a team which helps with checking in, passport control and getting you on the plane. *If you have any questions or if I can help in any way, let me know!*  
**downsar@mac.com**



## Communication Aids

Ataxia disrupts the body's ability to coordinate its muscles, including those used to speak and communicate, so communication can be difficult for some people with ataxia. Speech therapy can help manage the symptoms and improve communication and you can learn about **Ataxia UK's Online Speech Therapy Service** on page 20.

Sometimes the disruption is so severe that the person struggles to talk, and it can be difficult for them to make themselves understood; fatigue is a common symptom of ataxia, and this can make it even harder. When this is the case people may want to consider using a communication aid.

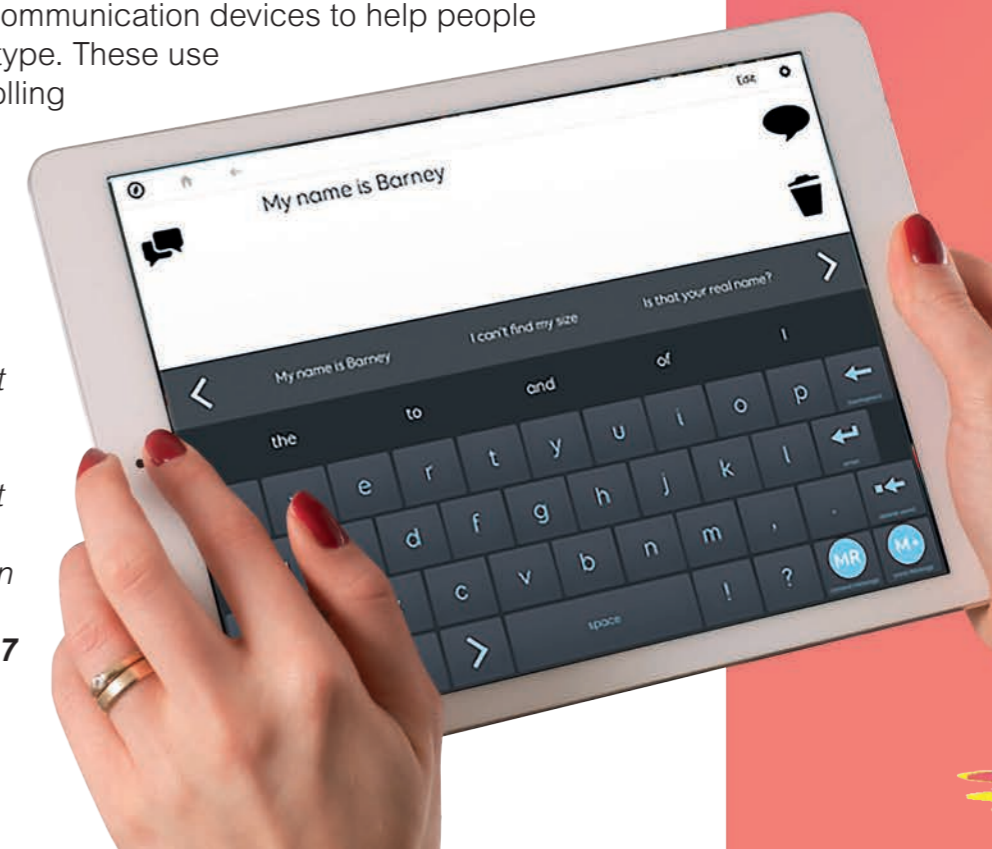
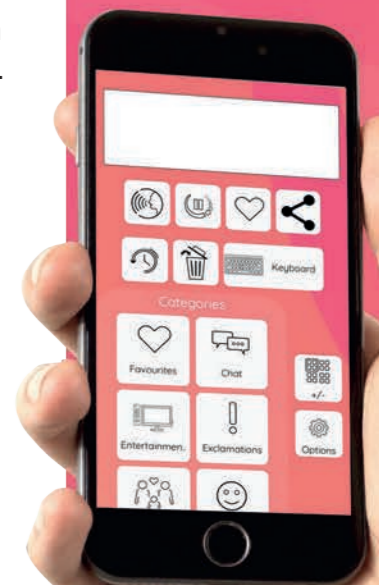
Ataxia UK is working with a company called SpeakUnique (see page 21 for more information), which specialises in pre-recording or 'banking' your voice. They can even create one for you if you can't record your voice! Once your voice is created, you can use software that has been developed to turn your smartphone, tablet, or computer into a communication aid.

Here are a couple examples of communication software which can be used with a SpeakUnique synthetic voice:

- **SpeakUnique App** – this is a text-to-speech app that allows you to enter text and have messages played aloud using your (SpeakUnique) synthetic voice. You can input text through the keyboard or select pre-set phrases. There is an option to message bank your important phrases in the app. The SpeakUnique App can be used on specialist communication devices as well as Apple and Android devices and on your Windows computer using Windows-based communication aids.
- **Grid for iPad** – designed by Smartbox specifically for use on iPads.

There are also specialist communication devices to help people that are no longer able to type. These use various methods for controlling the device, such as eye or head movements and switches pressed by other parts of the body.

*If you have any questions about communication aids your speech therapist should be able to advise you. If you need help to access a speech therapist or if you would like to talk to us about communication aids, please contact the **Helpline** on **0800 995 6037** or email us at **help@ataxia.org.uk**.*



## Thriving with Friedreich's

**Will Street has been a Friend and an amazing supporter of Ataxia UK for years. Some of you may know him through his company WillStreetTWF. We also wanted to extend a massive thank you to him and all the fantastic support and fundraising he's provided through the sales of his electric wheelchair attachments. But, without further ado, let's hear from Will as he tells us about his life journey in this article...**

My name is Will Street. I was diagnosed with Friedreich's Ataxia when I was 13 years old. When I left school I wasn't sure what lay ahead. I didn't want to go to college as I didn't want to be different from others. I pretty much stayed at home and played on my Playstation. I finally started using a wheelchair when I was 18. For those struggling with the idea of being a wheelchair user, please take it from me it was the best thing I've ever done. I wish that I had done it sooner. At that time I couldn't have imagined the things I would be able to achieve.

I have always been a bit of an entrepreneur. When I was 14, I wanted to buy a fishing boat and needed the funds, so I started selling sweets. I bought these at wholesale and sold them at school and enlisted the help of a couple of mates as I struggled to carry them all! Every day was a sell-out, so we expanded to chocolate and cans of drink, too. Even the teachers knew where to come for a pick-me-up. After about two years we had the funds to buy a boat and many hours were spent on the water with my mates.

After school finished my mobility was worsening so I didn't go to college but I was keen to start a business. One evening my parents went out and said: "Why don't you setup a website for your business? We expect to see it finished when we get back". To their total surprise, it was! This was the start of BigWillysTackle.com. I sold something I knew about and was passionate about – fishing tackle. Money made from this enabled me to buy a sailing boat, which I raced as part of the British Sailing Team, and a van for my dad to drive all over Europe to Paralympic Sailing events. Sailing took over my life for 10 years as I campaigned towards representing GBR at the Paralympics.

The business I run now is selling Electric Wheelchair Attachments. I brought one for my own use as I would rely on being pushed (it's a coordination thing!). I was so impressed with the freedom and independence it gave me that I wanted to share this with others with disabilities. Other makes are prohibitively expensive but mine are from China and very affordable. I started selling them during lockdown and the business, **WillStreetTWF.com** (that's Will Street Thriving With Friedreich's), is going great.

I am really happy with the response from customers telling me about their new-found freedoms. The business has inspired me as it means others are finding the freedom that I have. It was never about the money, but about helping others.



### **Nothing is off limits.**

I travel a lot and made and posted many videos of my adventures on my YouTube channel, WillStreetTWF. I love to travel and see the world and meet interesting people. I get help at the airports and onto the plane using an aisle chair to get to my seat. My motto is "Nothing is off limits". The most difficult thing that I have faced is thinking that I can't do it.

### **I focus on what I can do and not what I can't.**

I am a really positive person but have found motivation harder since having Covid. I am now pushing myself physically and mentally, I am getting there but I can't deny it has been a long journey. I believe it is important to exercise regularly, or even daily. I give myself long-term targets but set smaller achievable goals along the way. I focus on what I can do and not what I can't.

My friends and family describe me as motivated, happy and inspirational. I just get on with life and enjoy every minute. I have met many people through disabled sailing from all over the world and they motivate and inspire me. I have often visited them on holidays as well as being in competition with them on the water. It was a great community and although Sailing is no longer a Paralympic sport the memories and achievements motivated me to become a world champion.

### **What would I tell anyone that finds themselves in a similar situation to mine?**

'NOTHING IS OFF LIMITS'. Get yourself out there and make dreams come true. Set achievable goals and enjoy yourself. Set the bar high and take steps towards achieving that goal. I wanted to win a Gold medal but sailing was removed from the Paralympics so I modified it to become a World Champion, which I achieved one year later. I intend to keep moving that bar.

### **If I could achieve any goal in life, what would it be?**

Stay positive and be happy.



# The Big Give 2021 – The Gift of Speech update

**As we've mentioned on page 12, thanks to all your generous donations, you raised a whopping £57k. We have used that money to provide 2 new services, Speech Therapy and Voice Banking.**

## Speech Therapy

People with progressive ataxias often rank speech and communication problems as one of the top three symptoms of their condition.

Following a successful pilot in 2021 our online Speech Therapy service was launched this May. The course is a combined individual and group practice approach for people with speech difficulties. It usually consists of four individual treatment sessions with a Speech and Language Therapist, to help identify and practise what you can do to improve your speech. The strategies include speaking with a strong, LOUD voice and articulating in a CLEAR manner.

The individual sessions are followed by four weeks of daily group practice without a clinician, four times a week, and one weekly clinician-led group session. Friends who have used the service have reported feeling more confident about talking. Some have made phone calls for the first time in years!

*"Since attending the group, people don't ask 'what' like they did before when I spoke, which means my speech is clearer. It has changed my life."*

*"It introduced a great group of like-minded people, and we still meet via Zoom twice a week for one hour each time – to practise, chat and provide a medium for discussing situations and getting and giving advice."*

*"It has given me more confidence to speak when in company rather than just allow the conversation to go on around me."*

The first group finished in June and the second group is already underway!

*If you are interested in taking part, email [volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk). We will send you a short survey to establish how severely your speech is affected. When you return the survey, you will be placed on our waiting list until there is a suitable group for you to join.*

## Voice Banking with SpeakUnique

**We are delighted to announce we can now offer funding for Friends of Ataxia UK to use Voice Banking via a company called SpeakUnique.**

Many people with ataxia experience problems with speech which worsen over time. Some lost the ability to speak altogether and use communication aids. Voice Banking enables you to create a personalised synthetic voice so your communication aid can sound how you want. There are 3 services to choose from so everyone can have a tailored synthetic voice:

**Voice Build** is a synthetic replica of your own voice that can be used in your communication device. This is ideal for people whose ataxia is likely to impact their speech but who have not yet had any significant symptoms.

**Voice Repair** is for people who have already noticed considerable changes in their speech. For example, if you struggle articulating some words or sound more breathy than normal, Voice Repair can repair this damage in your synthetic voice.

**Even if you have already completely lost your speech, Voice Design can help!**

**Voice Design** is for people who have no intelligible speech. It enables you to design your synthetic voice based on your chosen characteristics such as regional accent, age, and gender. To use Voice Design SpeakUnique ideally ask you to nominate two different individuals, or 'voice donors', with a voice similar to how you would like to sound, to record their voices. They then use these voices to create a new voice that you identify with. It is sometimes possible to use old recordings of your own voice.

Once you have successfully recorded your (or your donor's) voice. SpeakUnique will create up to five versions of your synthetic voice for you to listen to and choose your favourite. Once your speech therapist has said you're ready to use your synthetic voice, you can apply for funding from Ataxia UK via your Speak Unique account, and download the voice to as many devices as you wish!

*If you have questions about Voice Banking or if you do not have a speech therapist, please contact the **Helpline** on **0800 995 6037** or [help@ataxia.org.uk](mailto:help@ataxia.org.uk)*



## Volunteering

**Ever thought about volunteering?  
Did you know that volunteering could  
improve your health?**

According to the NCVO report *Time Well Spent*, **77% of volunteers said volunteering improved their mental health** with just over half (53%) saying it improved their physical health. Since our **InControl** project started in 2020, we have recruited lots of volunteers and we are now working with more than 80 volunteers from the ataxia community who support us in a range of roles. There are lots of possibilities choose from, here are just a few...

**NHS Ambassador** – raising the profile of the ataxias in the NHS at local, regional and national levels.

**All About Ataxia Facilitator** – do you have ataxia? You could help us support people who are new to ataxia to learn more about the condition and what to expect.

**Helpline Volunteer** – would you like to help us provide information, advice, and support to people in the ataxia community? We help with a range of issues.

*All our volunteers receive training about being a volunteer and training specific to their role. To learn more about volunteering for Ataxia UK and discover the roles available please check out the website*

*[www.ataxia.org.uk/get-involved/volunteer-for-ataxia-uk](http://www.ataxia.org.uk/get-involved/volunteer-for-ataxia-uk) or you can email us at [volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk). We'd love to hear from you!*

## Volunteer spotlight

This month we're shouting about our brilliant volunteer, **Rachel** who is on our board and is also an NHS Ambassador.

*'Hi, I'm Rachel and I'm an NHS Ambassador for Ataxia UK. Being an NHS Ambassador can be whatever you are interested in. We all complete regular surveys on Neuro Life and for the Neurological Alliance. I have also chosen to get involved with improving my local wheelchair service and with my local university. Last month I did a session with Occupational Therapy students on Microsoft Teams (like Zoom) where I told them about my medical history. They went on a wobbly tour of my house and saw all my aids and adaptations. We finished with questions and answers. The students really enjoyed the session and will now take knowledge of ataxia into their future careers. I have already been asked back next year.'*

*If you have any questions about our services, please contact the **Helpline: [help@ataxia.org.uk](mailto:help@ataxia.org.uk)** or by calling **0800 995 6037**.*

## Ataxia Community Wellbeing Survey 2022 – we want to hear from you!

**In 2019 Ataxia UK was awarded funding from the National Lottery Community Fund to develop a 3-year programme to support and enhance the lives of people affected by ataxia.**

The project, which became known as **InControl**, is aimed at improving peoples' wellbeing and to decrease feelings of social isolation through community activities and volunteering opportunities.

We are continuing to work with our wonderful volunteers and provide services for the ataxia community and we're already working hard to secure funding for new projects, and services. We can't wait to share these with you! In the meantime, we need your help to evaluate the work of the InControl project and to see how our Friends are faring in this new post-pandemic world.

There is an anonymous survey enclosed with this magazine which we would love for you to complete. *If preferred, we also have a digital version of this survey. You can find it by going to: [www.surveymonkey.co.uk/r/AtaxiaUKSurvey2022](http://www.surveymonkey.co.uk/r/AtaxiaUKSurvey2022).* The survey follows up on the wellbeing survey we carried out in 2020. It aims to establish the impact of InControl and services on the ataxia community. It will also help us plan and develop new services going forward.

*Please return your completed Ataxia UK Wellbeing Survey no later than 15th October 2022, to: **Ataxia UK, FREEPOST RTUG-CLKB-RGJE, 12 Broadbent Close, London, N6 5JW***

Your responses will be shared with the research team at Genetic Alliance UK to support analysis of the data. You will not be asked for your name, contact details or any identifying information about you. Your anonymous survey responses will be kept securely so that only Ataxia UK InControl team members can access them, and we will not tell anyone that you have taken part in this survey. You must be aged 16 or over to complete the survey and be located in the UK (this includes all the UK mainland, Guernsey, Jersey, Isle of Man etc..)

You must also be at least one of the following:

- diagnosed with ataxia OR
- family member or friend of someone diagnosed with ataxia OR
- current carer of someone diagnosed with ataxia

*If you have any questions about our services, please contact the **Helpline: [help@ataxia.org.uk](mailto:help@ataxia.org.uk)** or by calling **0800 995 6037**.*

*For enquiries about volunteering please email [volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk).*



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 more than  
20 research projects underway,  
all of which are funded,  
at least in part,  
by gifts left to us

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**Your legacy can be hope for the future**