ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 215. Autumn 2021

Join our virtual Annual Conference this October!

Below are just some of the speakers you'll be seeing at this year's conference

Image of Mari Akhurst ©BEF/Jon Stroud Media

Ataxia people • Research • Ataxia awareness • Health & wellbeing • Fundraising Adaptations • Living with ataxia • Services

Ataxia UK

In the office

With heavy hearts we say goodbye to **Catherine Scrace** after her three years of valuable contribution. Catherine started as an intern and finished as **Research Communications Assistant**. We wish her all the best for her bright future!

After a wonderful five months, **Aaliyah Burns** our **Events and Community Fundraising Assistant**, has moved onto an incredible role as Digital Assistant at Freedom from Torture. We wish Aaliyah a very good future and we know you will be amazing!

Hello everyone, I'm **Wendy O'Mant**, the new **Helpline, Advocacy and Information Manager**. I'm excited to join the Ataxia UK family and work in our fabulous Helpline team to provide information, advocacy and support to the ataxia community.

Hi, I'm **Tegan Easterbrook**, and I've joined Ataxia UK as the **Events and Community Fundraising Intern**. My background is in adult social care and my last role was managing a team of fantastic volunteers in a substance misuse charity. I'm so excited to be working with Ataxia UK and I'm really looking forward to working on some great projects and getting to work with a lovely bunch of people!

Welcome

The measures taken to release the lockdown at a time when Covid-19 is on the rise may not have pleased the many readers who continue to feel vulnerable to the virus. The advice of our expert neurologists is that people with ataxia and their family members and close contacts should get vaccinated as soon as possible, and remain cautious even after vaccination. Thankfully, we had already decided to put the Annual Conference online! Read more on **p.23** about what there is in store for you!

We will be developing our Helpline, advocacy and information services over the coming months following the welcome arrival of **Wendy O'Mant** as Manager of the service. You can see our committed team on **p.20**. If you have skills which you would like to use as a Helpliner, please get in touch with the InControl team. And if you fancy turning your hand to some fundraising in these difficult times, the Fundraising team will welcome you with open arms. Finally, may I draw your attention to our 'Gift of Speech' project to enable us to extend online Speech Therapy, and start to offer a Voice banking service, which will be the subject of our Big Give appeal this year (**p.12**).

Enjoy what is left of the summer, and I hope to see you on screen at Annual Conference.

Stay safe, Sue Millman

Sue

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Ataxia people

Research

Ataxia awareness

Health & wellbeing

theBigGive CHRISTMAS CHALLENGE 2021

Fundraising

Adaptations

Living with ataxia

Services

Changing perceptions

Tim Kahn reflects on his childhood, specifically on his attitude towards disability.

If I had been an alien from a far-away planet looking down on my family, it would've been obvious that my dad (below) had ataxia. However, I was a child in the 1950s where my parents were secretive to 'protect' me from some 'difficult' things. So, I didn't realise that as a young child when my father, while sitting down, used a stick to hit a football towards me, it was because he could not balance and kick a ball and play football with me. And when I was a little older (though still a child), when my brother and I laughed at my dad as we watched him zigzagging his way down a hill, we were told off for laughing, but nobody told us that my dad had ataxia and could not walk in a straight line.

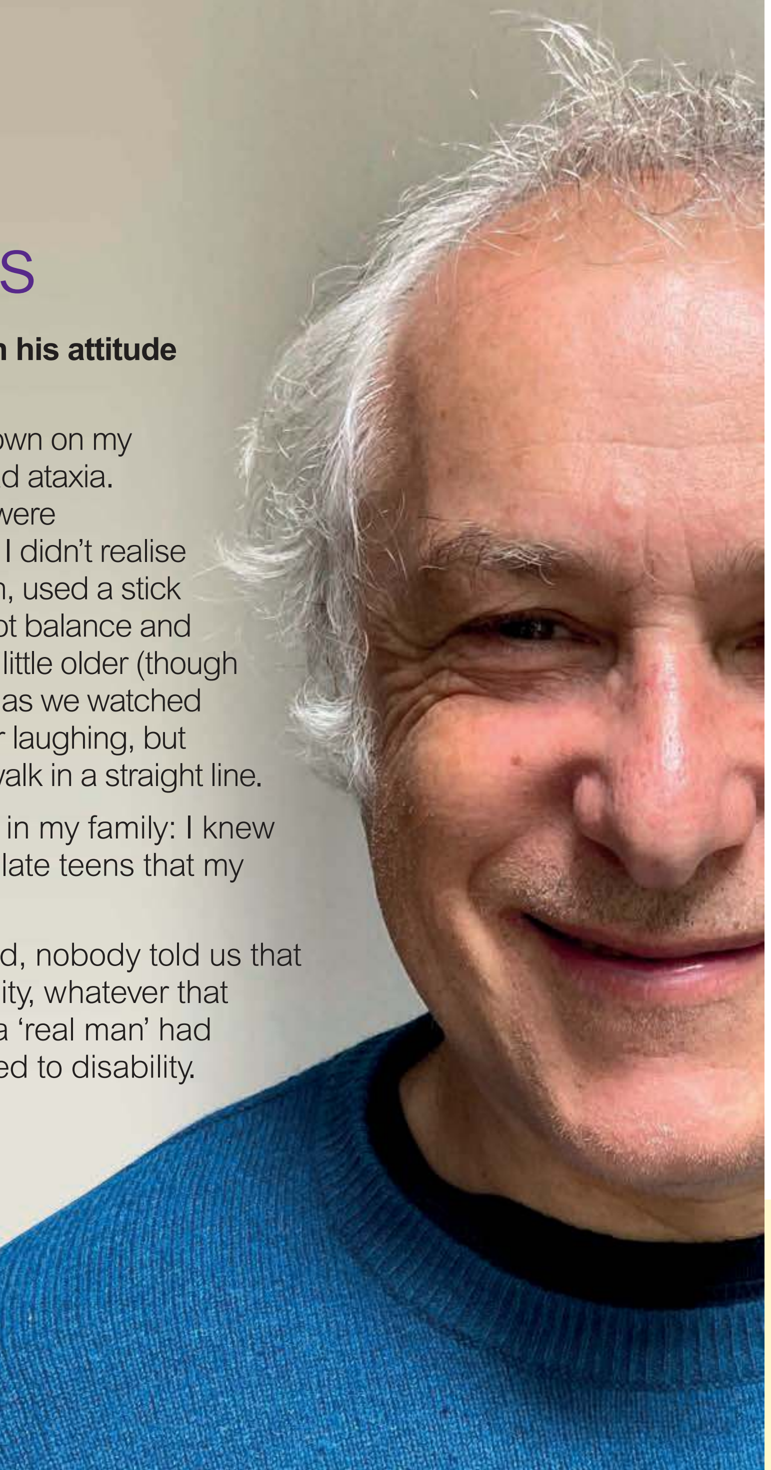
Jewishness was connected with the other big secret in my family: I knew that my family were Jewish but I didn't know until my late teens that my mum was a Jewish refugee from Nazi Germany.

Although we knew something was wrong with my dad, nobody told us that he was disabled - in order to 'protect' us from disability, whatever that meant. So, I assumed that my feeling that he wasn't a 'real man' had something to do with him being Jewish, not connected to disability.

Even in my mid-twenties, when my dad was using a wheelchair and a walking aid, and his speech was very slurred, I still didn't think of him as disabled. I wonder whether being Jewish and disabled was 'too much' for our family, so we had to 'deny' one of them; the dominant was the Jewish refugee story and the disability story got buried. I wonder if that is true for others who grew up in BAME families?

Although I didn't know that I had a disabled dad, I learnt a lot about disability, as if through osmosis. I think that's often true for those of us who grew up with disability in the family – it is not a big issue, it is a fact of life. Perhaps I feel quite comfortable having inherited my dad's ataxia because I grew up with a disabled father.

I know life does not stop when you have a disability, and being open about my disability helps others to be more accepting of disabled people.



Start planning your application!

Calling out to those aged between 16 and 30 with ataxia, or to anyone that knows someone who may be interested!

The *Mark Dower Trust* offers a financial grant that aims to support young people with ataxia, who are seeking independence, to develop and enjoy hobbies and activities, or to enhance their skills through further education. The Trust was set up in memory of Mark Dower, who had Friedreich's ataxia (FA) and sadly passed away in 2003, aged 41. The grant of up to £3,000 was inspired by Mark's independent and fierce spirit and is shared among the year's awardees. Applicants must be between the ages of 16-30, have ataxia and reside in the UK.

Applications open in **November 2021** until **31 January 2022**. Successful applicants will hear back by the end of February 2022.

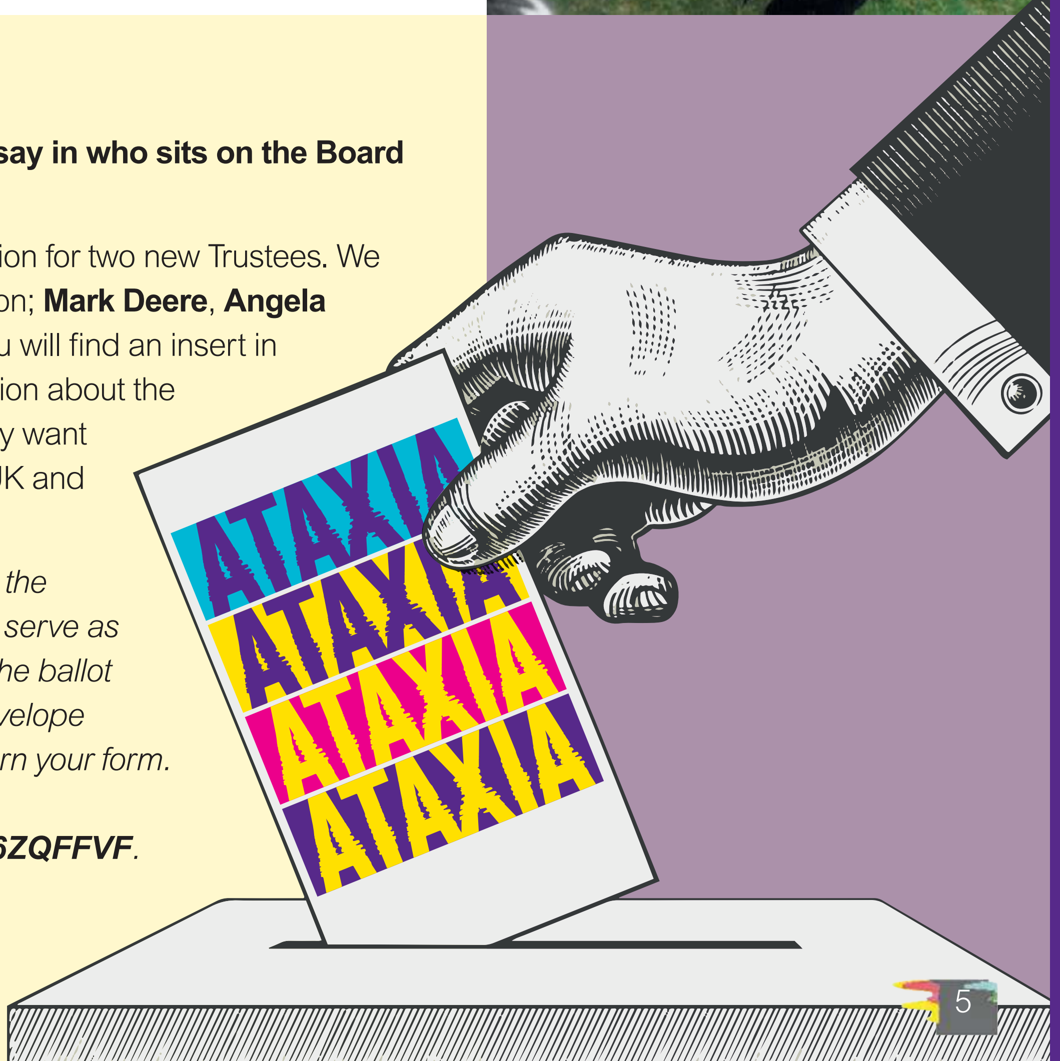
Don't miss this opportunity! Fill in the application form at: ***www.ataxia.org.uk/news/mark-dower-trust****.* *You can also request a copy by emailing* ***communications@ataxia.org.uk****.*

Trustee Elections

This is your chance to have a say in who sits on the Board of Trustees for Ataxia UK.

This September there is an election for two new Trustees. We have three standing for nomination; **Mark Deere**, **Angela Hosie** and **Rachel Harrison**. You will find an insert in this magazine including information about the candidates. Read about why they want to become a Trustee for Ataxia UK and their skills and experience.

Then have your say by voting for the two candidates you think should serve as Trustees of Ataxia UK. Vote via the ballot form and use the FREEPOST envelope included in this magazine to return your form. Alternatively, vote online at ***www.surveymonkey.co.uk/r/6ZQFFVF****.* *Please vote by* ***Tuesday 21 September 2021****.*



Euroataxia Research Conference 2021

Euro-ataxia is a federation of 20 ataxia charities around Europe who work together to help people with progressive ataxia lead their best lives. Euro-ataxia aims to accelerate research and treatments for people with ataxia. Ataxia UK is an active member of Euro-ataxia. We organised a virtual research conference in June, which was also open to Ataxia UK Friends. Researchers from universities and pharmaceutical companies were invited to talk about recent ataxia research developments.

Prof Klockgether, Bonn University, presented results from the European spinocerebellar ataxia type 3/MJD Initiative (ESMI). Information in Ataxia magazine 211. An outlook of promising treatment approaches, e.g. antisense oligonucleotide-based therapy and gene therapy, was also given.

Dr Toonen shared how the company uniQure are developing a gene therapy treatment for spinocerebellar ataxia type 3. Currently they are investigating distribution and efficacy in non-human primates. *For more information, visit:* ***https://bit.ly/2UM4NLm***.

Dr Antonijevic explained that Triplet Therapeutics are developing an antisense oligonucleotide therapy for Huntington's disease (HD), which may also be a candidate treatment for spinocerebellar ataxias. They hope to start HD clinical trials soon, and once information on HD safety and dose level is collected, they want to start ataxia studies. *More information here:* ***https://bit.ly/3kc7D7f***.

Dr Brais, Universite' McGill, introduced TREAT-ARCA, a new EU funded consortium for autosomal recessive cerebellar ataxias (ARCA). The aim is to accelerate finding and testing new treatments in animal models for ARCAs.

Dr Graessner, University of Tubingen, talked about the purpose of the Ataxia Global Initiative. *More information here:* ***http://ataxia-global-initiative.net***.

Prof Schultz, Uniklinik RWTH, Aachen, gave an update on the European Friedreich's Ataxia Consortium for Translational Studies (EFACTS). Reported in Ataxia magazine 214. An update was given on the two-year NICOFA clinical trial (***https://clinicaltrials.gov/ct2/show/NCT03761511***), which will test nicotinamide, a potential FA treatment. This is a European multi-centre trial with sites in London. Unfortunately, due to several difficulties, it has not started yet, but the plan is to start the trial in January 2022.

Dr Stoyas, Reata Pharmaceuticals, provided an update on the omaveloxolone study in Friedreich's ataxia. *More information here:* ***https://bit.ly/3yjOlw3***.

Dr Martinell, Minoryx, presented an update on the development of leriglitazone, a potential Friedreich's ataxia treatment. Reported in Ataxia magazine 213. They are currently preparing for the next study but before launching, they will discuss the study design with regulators in the US (FDA) and Europe (EMA).

Presentations available by visiting: ***www.ataxia.org.uk/ataxia-research/research-conferences***. *For more information on Euro-ataxia visit:* ***www.euroataxia.org/research-overview.***

Active form of vitamin D, calcitriol, improves function of mitochondria and increases frataxin levels in cell models of Friedreich's ataxia

In a project funded by Ataxia UK, ACAH (Associació Catalana d'Atàxies Hereditàries) and Ataxia Ireland, Dr Joaquim Ros and colleagues from Universitat de Lleida, Spain, found that treatment with the active form of vitamin D, called calcitriol, led to improvements in Friedreich's ataxia (FA) cell models.

FA is caused by mutations in the frataxin gene that cause cells to produce less of a protein called frataxin. Frataxin is found in the mitochondria, which is the part of the cell which produces energy. These low levels of frataxin cause the symptoms of FA.

In their study, the researchers found that in rat neurons with low levels of frataxin, there were low levels of protein called ferredoxin 1, which is also found in the mitochondria. Ferredoxin 1 interacts with frataxin and is essential for making calcitriol, the active form of vitamin D. Lower ferredoxin 1 levels were also seen in cells of people with FA compared to cells from people without FA. These results suggested that calcitriol may be important in this condition.

The researchers then performed calcitriol treatment to see whether this led to any improvement in neurons with low levels of frataxin. These neurons were obtained from dorsal root ganglia, one of the most affected tissues in FA. They found that treatment with calcitriol increased levels of ferredoxin 1 and improved the function of the mitochondria. They also found that calcitriol improved survival of these cells. Importantly, the researchers found that treatment with calcitriol increased the levels of frataxin in not only neurons, but also rat heart cells and in cells of people with FA.

The findings from this research study have been published in the *Biochemical Journal*. Due to these positive findings, the group will be starting a pilot clinical trial of calcitriol in Spain in September 2021. The group will aim to treat 20 people with FA with calcitriol for one year to see whether it helps improve their FA symptoms. Trial participants will be 16-65 years of age and the trial will assess the safety of calcitriol, changes in frataxin levels, and effects on their daily life activities and quality-of-life. Ataxia UK look forward to seeing how this trial progresses.

Ataxia UK-funded tDCS trial shows improvement in symptoms of ataxia

Dr Barbara Borroni and colleagues at the University of Brescia, Italy, have completed a trial assessing transcranial direct current stimulation (tDCS) in people with ataxia. This trial has shown positive results and Dr Borroni's group have published their findings in the scientific research journal, Brain.

tDCS is a non-invasive and portable technique where a low electrical current is applied to a person's scalp. tDCS is thought to work by stimulating cells of the nervous system. In this trial, tDCS was applied to the cerebellum and spine, which are commonly affected in different types of ataxias.

The study included 61 people with ataxia; 24 had spinocerebellar ataxia (5 with SCA1, 12 with SCA2, 1 with SCA14, 1 with SCA28, 5 with SCA38), 10 people had multiple system atrophy with cerebellar phenotype (MSA-C), 7 had Friedreich's ataxia, 17 had sporadic adult-onset ataxia, and 3 had cerebellar ataxia with neuropathy and vestibular areflexia syndrome (CANVAS).

In the first phase, participants were given either real tDCS or placebo tDCS 5 days a week for 2 weeks. At week 12, all participants were then given real tDCS treatment 5 days a week for 2 weeks. Clinical measures were then taken before the study, and at weeks 2,12, 14, 24, 36 and 52.

The researchers found that after treatment with real tDCS, there was a significant improvement in both clinical rating scales used to measure ataxia in this study. The rating scales used were the scale for the assessment and rating of ataxia (SARA) and the international cooperative ataxia rating scale (ICARS). The improvements in these scales were particularly seen in posture, gait and limb coordination. There were also improvements in cognition and quality-of-life scores. This improvement was increased when participants had two treatments of real tDCS compared to only one treatment and lasted on average between 3 and 6 months.

These results are encouraging as it suggests that tDCS may be useful in multiple types of ataxias, and helps with both the motor and cognitive symptoms of ataxia. Further research is needed in this area, and both the researchers and Ataxia UK are currently investigating what the next steps should be to take forward this research.

New research suggests a reason for a delayed age of onset in some people with Friedreich's ataxia

Below: Simplified diagram of an interruption (in red) in the GAA repeat sequence in the FXN gene

A new paper on Friedreich's ataxia (FA) from the team lead by Prof Giunti at the London Ataxia Centre has been recently published: *www.mdpi.com/1422-0067/22/14/7507*.

Genes are made of a chain of components, identified by a letter (A, T, C or G). In FA, the FXN gene has excessive copies of repeated G-A-A. Interruptions can occur in this continuous sequence of GAA repeats.

This study of 101 FA patients identified short interruptions at both ends of the GAA repeats. Small interruptions were found more commonly, and those towards the end of the GAA repeats being most frequent. Interruptions towards the end of the GAA repeat sequence were associated with later ages of disease onset.

The interruption towards the end of the GAA sequence is predicted to delay onset of symptoms by approximately nine years relative to those lacking interruptions. This study highlights the role of interruptions in modulating the FA condition and prognosis.

Dr Suran Nethisinghe (right) is joint first author of the paper and a postdoctoral research associate at the London Ataxia Centre. He said: *"These results are exciting as interruptions will help in understanding how FA will unfold for individuals. This is the first step to possibly translate these findings in clinical practice. It will possibly help with grouping FA patients in clinical trials. We are grateful for the participation of patients in this study. After my PhD, I was eager to work in research that has the potential to have a real impact on patient care."*

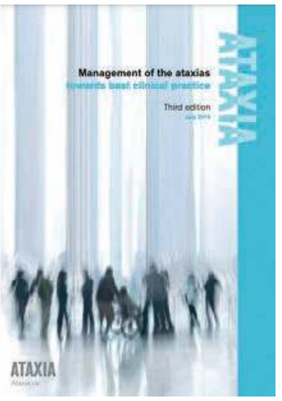
We are looking for a new lay member for Ataxia UK's Scientific Advisory Committee

Ataxia UK's Scientific Advisory Committee (SAC) is recruiting a new lay member. This role involves **attending Committee meetings three times a year** to discuss research grant applications and contributing to the SAC's discussions about projects to recommend for funding to the Trustees.

The Committee consists of **seven to eight scientific members** and **three lay members** who provide the perspective of people affected by ataxia. No specific scientific background is requested; however, you should be interested in the research done on ataxia, be willing to read research project applications (all of which have lay summaries attached) and attend meetings

More information about the research application process and selection can be found on our website: ***www.ataxia.org.uk/ataxia-research/research-grants****. If you are interested, please contact* ***Julie Greenfield, Head of Research*** *(****research@ataxia.org.uk****).*

Two steps towards speedier ataxia diagnosis



Management of the ataxias

towards best clinical practice

Third edition

ATAXIA

As we approach International Ataxia Awareness Day on 25 September 2021, we are striving towards faster and easier diagnosis and better care for those affected by ataxia.

Too many people with ataxia have struggled to receive a diagnosis. Due to its rare nature, many medical professionals are unaware of what ataxia is and how to treat it. The Medical Guidelines (above), 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.

"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

This International Ataxia Awareness Day you can help improve diagnosis and care for the ataxia community. How, you ask? In just two steps!

1. **Sign up** for the challenge on our website at **www.ataxia.org.uk/iaad2021** and we will send you an information pack with the medical guidelines.

2. **Get sponsored to walk, wheel or run** with family and friends, or fly solo, to your local GP surgery on or around **25 September** and give them the Medical Guidelines.

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!

"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

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, email **communications@ataxia.org.uk**.*

Wellbeing Week

The InControl team hosted our first Wellbeing Week from 21-25 June. We provided daily, virtual wellbeing workshops, designed specifically for people affected by ataxia. We had over 70 participants throughout the week take part in the following sessions.

HYPNOTHERAPY

Hypnotherapy aims to achieve a relaxed state of mind, to be more present and train the mind to enhance the positives and eliminate the negatives. It can be used to treat a range of issues including anxiety, phobias, insomnia and stress. This session was led by Clinical Hypnotherapist Kristen Hayward who is running a Hypnotherapy workshop at our Annual Conference.

INVOLVEMENT AND VOLUNTEERING WITH ATAXIA UK

Involvement and Volunteering can provide new skills, structure and is a natural way to release endorphins and reduce stress. James Atkins, our InControl Community Programme Manager, provided an overview of the various options available with Ataxia UK.

POINTLESS QUIZ

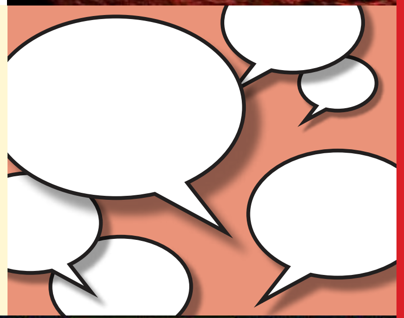
Undertaking a quiz is a great way to improve memory, release dopamine and connect with people. Our Pointless-style quiz asked people to identify the least known answers provided by 100 people to different questions.

MINDFULNESS WORKSHOP

Mindfulness is a form of meditation to be fully present and not overwhelmed by what is happening around us. This session was run by experts from the South London and Maudsley (SLAM) Hospital.

*If you would like to hear about upcoming InControl activities, please contact the InControl team on **volunteering@ataxia.org.uk**.*

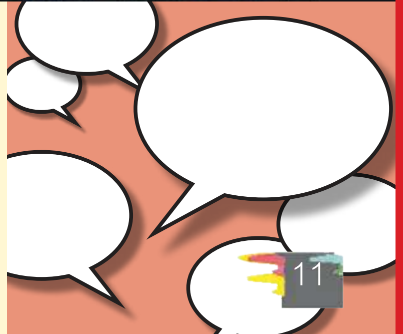
Speech therapy



Many of our members reported that their speech ability has declined throughout the lockdowns. Therefore, in partnership with University of Strathclyde, we have delivered a pilot peer support speech therapy programme. Over the course of several months, two groups of five participants performed daily exercises via Zoom designed to improve their speech. This was paired with weekly support from a trained speech therapist.

"I found both the 1-1 sessions and group sessions useful - encouraging you to slow down the speech, pronounce every syllable, speak louder and breathe appropriately. I would definitely recommend."

"Could I please express my gratitude to Ataxia UK for making this project possible. I have found the group therapy sessions most rewarding and have gained a great boost to my knowledge."



Both groups continue to meet weekly to maintain their progress. Dr Anja Lowit and her team at University of Strathclyde are compiling their findings into a report. This will be available in due course. Ataxia UK are also working on securing funding to maintain this project on an ongoing basis.

*You can view a recording of some of the Wellbeing Week sessions on our YouTube Channel (**www.youtube.com/user/AtaxiaUKonline/videos**).*

Ataxia UK's Big Give Challenge returns this December!

theBigGive
CHRISTMAS CHALLENGE
30 NOV—7 DEC 2021

Give the gift of speech and help fund ataxia research.

This season you can help fund vital ataxia research and the gift of speech for the ataxia community by DOUBLING the value of your Christmas gift at no extra cost to you.

Save the date: Midday on Tuesday 30 November until midday on Tuesday 7 December 2021. One donation, double the gift, twice the impact!

For people living with ataxia, the impact of the pandemic on movement, mental health and speech communication, in particular, has been especially difficult during the past 18 months. The vital and much reduced opportunity to have everyday conversations with people, as well as a lack of access to speech and language therapy services, have had a significant detrimental effect on many people's speech and communication.

This December, you can give the gift of speech to those who face losing their natural speech and identity by taking part in this year's Big Give Christmas Challenge.

Those living with progressive ataxias frequently rank **speech and communication problems as one of the top three symptoms**, which can be incredibly debilitating and have a negative impact on their ability to communicate effectively.

So, as we slowly return to normality, people living with ataxia may continue to experience a deterioration in their speech and mental health as they work to rebuild their voice. Speech therapy can prevent this by improving communication, strengthening oral muscles and boosting people's self-confidence. Sadly, very few people across the country are offered or have access to this type of therapy intervention via the NHS.

This Christmas, between **midday on Tuesday 30 November until midday on Tuesday 7 December only**, you can DOUBLE the value and impact of your gift at no extra cost.

Your matched donations will help to fund and accelerate research towards finding new treatments and a cure, as well as give a voice to those in the ataxia community who face not being able to communicate effectively.

This December you can help raise £70,000 to fund:

1. **Vital ataxia research**
2. **An Ataxia UK online speech therapy course and access to voice-banking technology.**

Following the success of a speech therapy trial conducted on people with hereditary ataxia earlier this year, it was demonstrated that therapy focusing on voice production can significantly help improve people's speech and their confidence communicating with others. Part of your matched gift this Christmas will help to permanently establish **a new online speech therapy course and peer support group for the ataxia community**.

This course will enable a group of participants at a time to undergo an intensive course to compensate for the impact that the reduced opportunity to meet people has had on their speech over the past 18 months. Secondly, the funding will make available **voice banking technology** to people with ataxia who need it, so they can record and preserve their natural voice in case they eventually need to talk using synthesised speech created from a computer.

SAVE THE DATE

This year from **midday on 30 November until midday on 7 December only**, Ataxia UK urgently needs your help to raise **£70,000** to:

1. **Help people living with ataxia communicate more effectively using a dual approach of providing online speech therapy courses in a group setting with peer support.**
2. **Offer people facing the prospect of losing their natural voice and speech the opportunity to continue speaking and communicating, not only by using speech synthesis as a voice companion, but also by using their own voice, synthetically re-created, helping to maintain their identity.**
3. **Commission research into finding treatments and a cure for the ataxias during these tough times.**

If you are thinking of making a donation to Ataxia UK this December, please remember to save the date and donate using our online web page link between **30 November and 7 December 2021** to double your donation and help fund ataxia speech therapy and research.

For example, if you donate **£50** on our online Big Give donation webpage between **30 November and 7 December** and **Gift Aid** your donation, your gift will be worth an **incredible £125!**

For one week only, you will have the opportunity to more than double the value of your donations towards restoring speech and improve the quality of life for people living with ataxia.

Please stay tuned for more information on this year's campaign, as well as details of the online URL link you will need to donate and take part in Ataxia UK's Big Give Christmas Challenge in the next issue of Ataxia Magazine and monthly e-newsletter.

One donation, double the gift, twice the impact.

Chance2Win Winners

1st Prize: £500
Jon Brooks

2nd Prize: £250
Joyce Darlington

3rd Prize: £150
Sheila Mai Jones

10.5 Challenge is back!

Following the success of the 2020 challenge, the 10.5 Challenge returns and you can be a part of it throughout October.

WHY 10.5 FOR 10.5?

10.5 represents the 10,500 people in the UK with ataxia. By doing 10.5 for 10.5 during the month of October, you are helping to work towards improving the lives of those with ataxia and their families by raising funds and awareness across the UK.

HOW DO I TAKE PART?

1. Decide on your 10.5 challenge
Challenge yourself to do 10.5 or 10,500 of something – anything you like! Walk, run, cycle, wheel, bake, sing, sell or spin - and everything in between! Take part individually or with friends and colleagues - just make it 10.5 or 10,500.

2. Register your challenge
*Go to our website at **www.ataxia.org.uk/10.5** or email the team (see below) to register your challenge and receive your supporter pack, which includes a free t-shirt or sports vest, and we will support you every hop, skip, jump, bounce and bake of the way!*

*Email **Rebecca**, **Mia** and **Tegan** on **fundraising@ataxia.org.uk**. Register now to make your mark and support those 10,500 in the UK and their families.*

Saddle up for the Virtual Ataxia Classic throughout September - take part from home!

With distances from 5km to 500km and a month to complete it, whether you are a seasoned cyclist or a weekend wanderer, this is the event for you!

Just select your distance, grease up your chain, saddle up and get cycling to clock up the kilometres to support those with ataxia and their families. Everyone who takes part will receive an exclusive medal and certificate, and fundraisers are given the opportunity to get their hands on a free high-performance Ataxia UK cycling jersey!

HOW DO I TAKE PART?

- Select your distance, and choose whether to do it in one day, or over a number of days
- Pay your entry fee
- Complete your challenge between **1 and 30 September**, clocking your kilometers through Strava or uploading manually.
- Fundraise! You get your very own fundraising page when you register, and fundraising means we can pedal faster towards treatments and a cure for the ataxias, and to support those with ataxia and their families more.

Be part of something incredible, cycling across the UK for the same cause and supporting one another as one team.

*To register and find out more, go to **www.ataxia.org.uk/ataxiaclassic2021** or contact the team on **fundraising@ataxia.org.uk** / **0207 582 1444**.*

Fundraising thank-yous

From online cookalongs to skydiving, here are some of our fantastic fundraisers…

Congratulations to everyone who joined **Sarah Matchett's** online dance-fit fundraiser, which was a huge success, raising £230!

Suzanne Blakemore (1) raised over £630 by running the Burton Leonard 10k for her 30-year-old nephew, **Ben**, who has Friedreich's ataxia. We are so grateful, thank you.

Thank you so much to **Hannah**, **Rosie** and **Kadie (2)** who skydived in memory of their friend **Emily Adams** and raised an impressive £1,170! *"Emily was an adrenaline junkie ... she would have loved to do a skydive ... that's why I [was] so keen to do this to raise money for such an important charity."*

Speedy thanks to **Abby Harris** who didn't let Covid-19 cancelling the Royal Parks Half Marathon stop her taking part in the virtual race, raising over £250!

Congratulations **Fred Finch (3)**, for teaching Ataxia UK's first online cookalong, raising £90. We loved hosting a new, creative fundraiser.

A big well done to **Holly Gledhill** and **Steve Jones** who raised £599 by walking the Yorkshire Three Peaks to help those like Steve's Dad, **Phil**, who have ataxia.

Congratulations to our Virtual Kiltwalkers, **Barbara Taylor (4)**, **Derek Taylor** and members of the **West of Scotland Branch**, who altogether with **Linda**, **Ronnie** and **Ross Docherty (5)** raised over £1,400!

A whopper of a thank you to **Nicola Miles** and **Sam Clark-Keen (6)** who are doing a year of fundraising, raising over £7,000 to date. Most recently walking 100km from London to Brighton and are now warming up for the Royal Parks Half Marathon!

A shining thank you to **Jude**, **Louie** and **Willow (7)** who grew and sold sunflowers to support their friend **Darcy**, raising £564! Such a marvellous idea and what fantastic friends you are!

A big thank you to **Geraint John (8)** who raised £255 by cycling 5,000 miles around Britain's coast despite a broken bike!

A big round of applause to **Fiona Bull** and **Sam (9)** who walked the 293-mile Cornwall South West Coast Path carrying everything on their backs! They walked for Fiona's Dad who has cerebellar ataxia and in memory of their friend **Sally**. Thank you and congratulations on raising over £2,200 with donations still coming in.

Congratulations to **Angelica Giugno** (right) for running a half marathon, raising a smashing £904!

A huge thank you to **Amanda Heyes (10)**, who was diagnosed with ataxia four years ago, for skydiving to support others also affected by ataxia, raising £550!

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Staying active with ataxia

James Downie, who has FA, writes about how he tries to stay fit and healthy. It is not a must or must not do, but what works specifically for him.

I have been a wheelchair user for around 20 years, full-time for roughly 15. Before that, I was very active and, as a child, I played and enjoyed most sports, especially football. During my late teens I often went to the gym.

My jobs since using a wheelchair have mainly been working with young people, either youth work or a wheelchair skills trainer. Although my job as a wheelchair skills trainer was only two days a week, it was enough to keep me active as I literally had to chase kids around all day in wheelchairs - please note this was playing games!

Now I try to remain reasonably active and drive myself to work three days a week, putting my manual chair in the car. Most of the time I use a manual chair and self-propel as much as possible. Around once every six weeks I see a masseur to help keep me straight as I hunch over more than I used to, as I am on a computer for a significant amount of time.

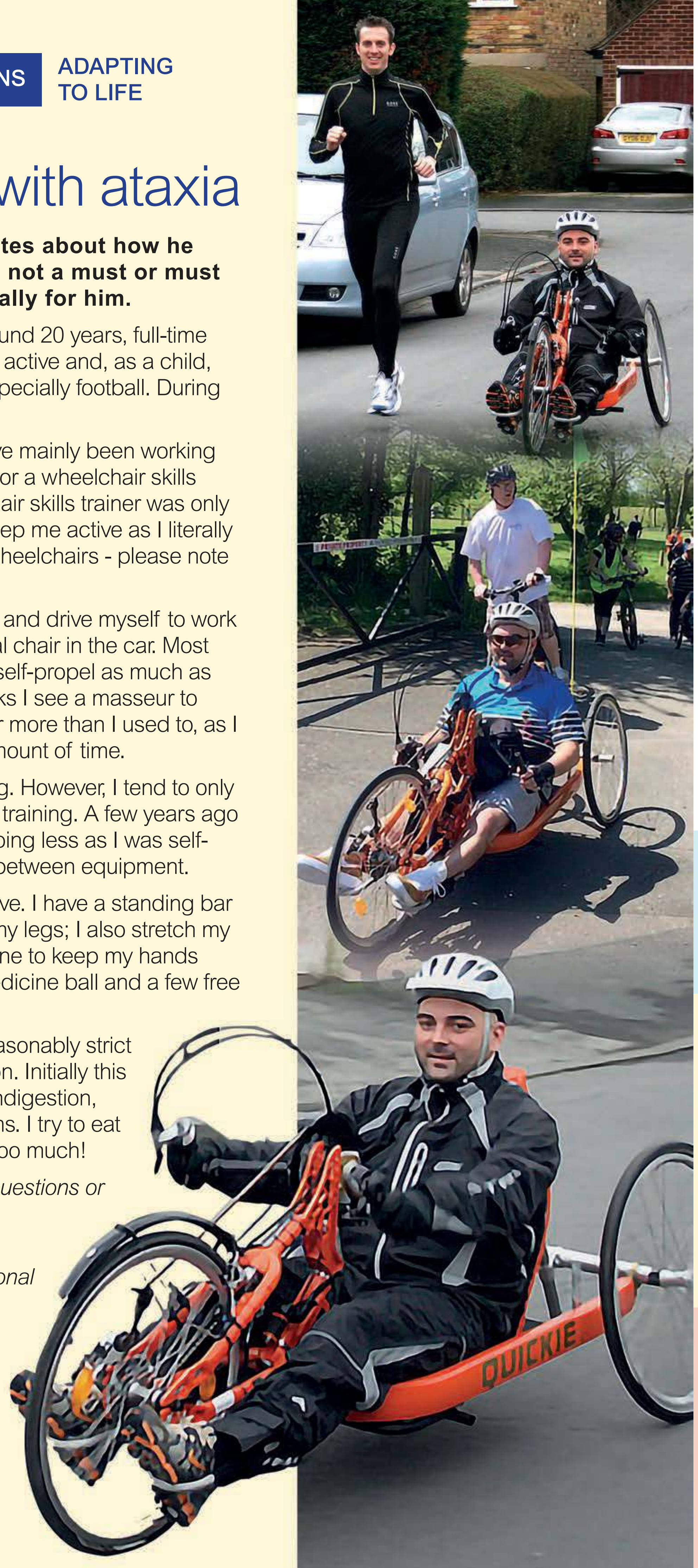
I have a hand trike which I enjoy riding. However, I tend to only ride for ataxia fundraising events and training. A few years ago I went to the gym but found myself going less as I was self-conscious and found it hard moving between equipment.

I use equipment at home to keep active. I have a standing bar which I use every day to strengthen my legs; I also stretch my calves and ankles. I use a grip machine to keep my hands and fingers flexible. Then I have a medicine ball and a few free weights which I use at home, too.

For the last two years I have had a reasonably strict gluten-free diet to help with indigestion. Initially this helped with weight loss and to stop indigestion, but it doesn't help my ataxia symptoms. I try to eat healthily but life is too short to worry too much!

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

Please consult your medical professional about exercise before changing your routine. Our Medical Guidelines provide guidance for exercise which you can read about on our website: ***www.ataxia.org.uk/healthcare-professionals/resources-for-healthcare-professionals/medical-guidelines***



Home adaptations

There are hundreds of adaptations out there to try, including a spoon to help with eating, a cup holder to prevent spills and a handrail to support on the stairs.

GYENNO SPOON

If your ataxia causes tremors or sudden movements which hinder your ability to eat and enjoy food, you could try new technology to make mealtimes easier and more comfortable. The Gyenno Spoon is a utensil that's been developed to help those with tremors at mealtimes. The innovative device contains a stabilising sensor that detects hand motion and an on-board computer that distinguishes tremors from the intended movement of the hand. The spoon weighs just 130g and has been ergonomically designed for ease of use with a patented TritanTM medical grade coating and antibacterial silicon. The spoon can be detached and replaced by a fork which is included with the device. It has a rechargeable battery which can store enough power for use with three meals, holding 180 minutes of run-time off a single charge. The device will also power down automatically when not in use. *The Gyenno Spoon is available to order online:* ***https://attainability.co.uk/gyenno-spoon***.

SPILLNOT

The SpillNot is a mug holder which your drink will not spill from, regardless of how it's used. You can use the SpillNot to transport hot beverages from the kitchen to living room without spilling a drop. *Find it on Amazon:* ***http://alturl.com/ifa5k***.

STAIRSTEADY

The StairSteady is a high-quality handrail with a supporting bar that is movable when pushed but locks firmly into place when weight is applied. It acts as a support aid for travelling up and down the stairs, similar to a walking frame, but with the added bonus of folding away when not in use. *For more information check the company website:* ***www.stairsteady.net***.

Do you use adaptations to support with ataxic symptoms? If so, please let us know and we will share in the next issue of the Ataxia Magazine. Email ***communications@ataxia.org.uk***.

Disclaimer: *This article is for guidance purposes only and, while every care is taken to ensure its accuracy, no guarantee of accuracy can be given. Individual professional advice should be sought before taking or refraining from taking any action based on the information contained in this article and nothing should be construed as professional advice given by Ataxia UK.*

Growing old with ataxia

Patsy Riggs writes about her personal journey with ataxia and her adaptations.

When I was diagnosed with ataxia, my first thoughts were: how will I progress and adapt? I was born in 1942 and diagnosed with ataxia in 2006 and, on reflection, I had problems from childhood that were dismissed. At four years old I was prescribed 'wedged' shoes; my parents had one pair made and, when I outgrew those, I just managed, unconcerned about my inward growing foot. I was a fast runner and competed in school sports but I didn't seek help for frequent falls until 2002.

Of course, each of us has a different journey with ataxia, but we can adapt for an optimum lifestyle. I like to think my slow progression is due to my healthy lifestyle; for me, keeping weight down but spirits up is most important.

KEEP CONNECTED

Joining Ataxia UK and attending a support group are the first steps to feeling less isolated. Every day I log into HealthUnlocked (***https://healthunlocked.com/ataxia-uk***) which keeps me in touch with like-minded people. I am also very active on many other social media sites, such as Facebook and Twitter.

STAY ACTIVE

Personally I have found that exercising first thing in the morning is essential, otherwise it doesn't get done. I have used an electric vibro plate for many years. For me it's the easy option to get my circulation going and, by using the handrail, I can do squats and heel toes. It has a 10-minute timer and I cast 1950s music on the bedroom smart speaker. I sing along which gives my lungs exercise and helps with night-time coughing. However, it's important to pace yourself when coping with fatigue. A neuro-physiotherapist will help you aim for that optimum goal within exercise.

SUPPORT SYSTEM

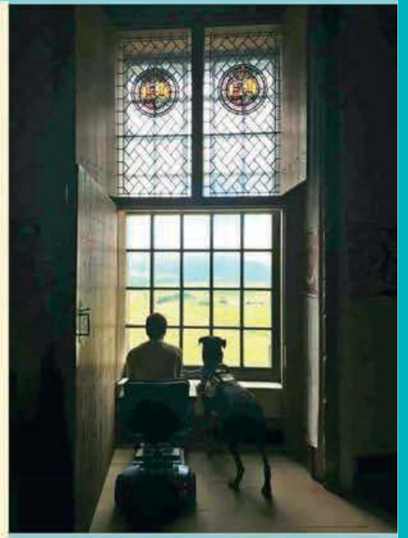
My husband, Ken, is now 80 and old age has brought him symptoms similar to ataxia. However, there is a huge difference between us. He is my carer and rock. Ken talks things through with me and helps me to work out the logistics of keeping my independence. He now manages the household (with just a few tips from me!), thus preventing me from accidents wherever possible. If you need support, ask for a home assessment which is carried out by an occupational therapist to enable necessary adjustments to your home.

Don't despair, you can cope, you just need to work out the logistics.

Archie, you will be missed!

Our Friend, Taryn Cotton, writes about the super support she received from her assistance dog, Archie.

Most people know assistance dogs as organisation-trained, but you can train them yourself with the help from organisations such as Dog AID and Support Dogs. I went down this route due to a few reasons. My ataxia-related conditions didn't meet the organisation's criteria, being required to travel and stay for weeks to train with a dog, no choice over the breed or if mobility assistance is needed.



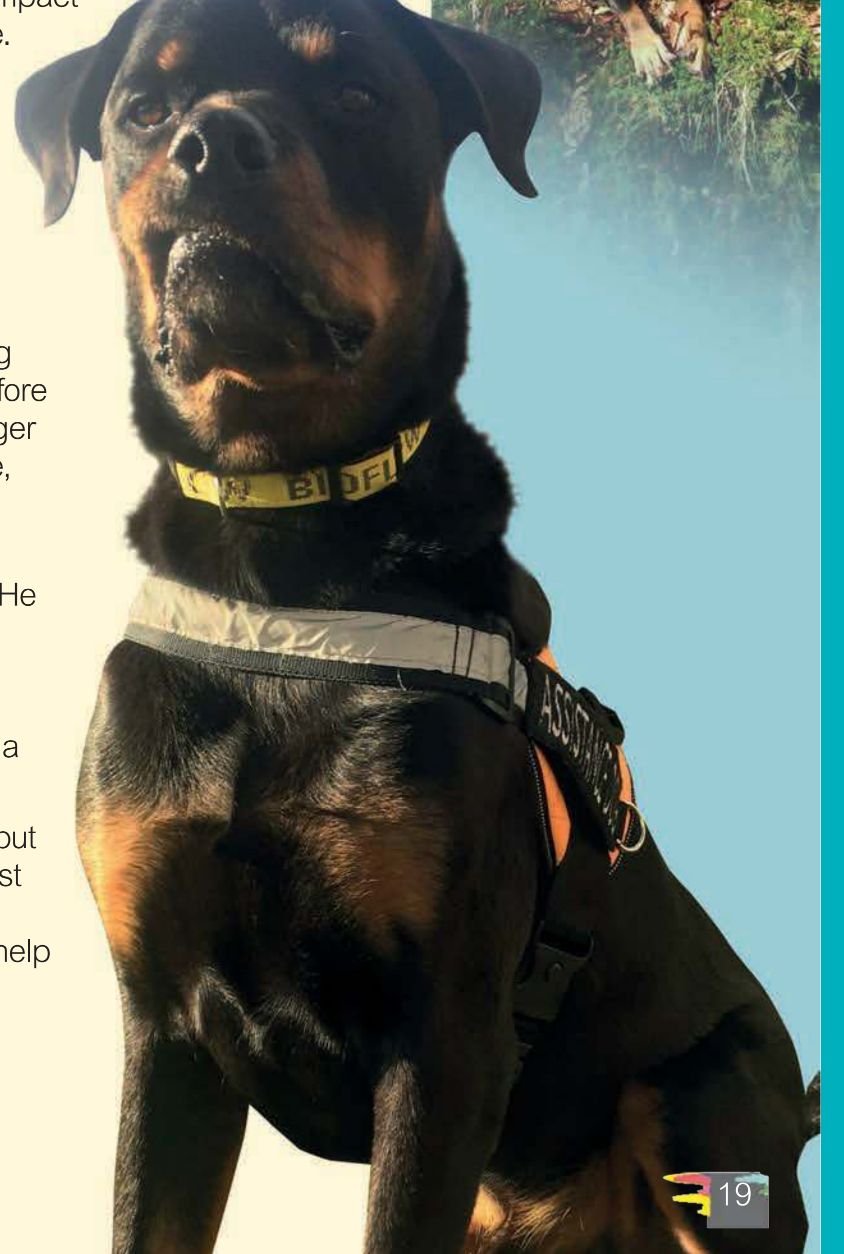
Most ataxians relate to a lack of balance, which often results in a fall, especially if a steadying person or aid is not there. If we fall, there is the conundrum of how we get back up safely and stay safe while on the floor. As Archie was owner trained, I added mobility assistance; this helped immeasurably, as he not only knew how to steady me in walking or transferring, but also how to 'brace' to help me up if I fell. He would also stand protectively over me, barking to alert or warn others that his person is in danger. All of this lessened my anxiety and panic attacks. We know how negatively that can impact ataxia, so he lessened my falls just by being there.

Archie carried out many tasks, such as: switched lights on/off, pressed buttons for me (like disabled door buttons), opened/closed doors (his size enabled him to do this with heavier ones and lighter doors sometimes went through the walls as he was very enthusiastic!), picked up items, fetched medication, calmed me, and emptied the washing machine. Ultimately, I was becoming reclusive before Archie. For this type of work I knew I'd need a larger breed of dog, so I chose a Rottweiler for their size, intelligence, loyalty, dependability and endearing character.

Archie not only touched my life but many others'. He gave me the confidence I needed to get out independently and face the world again. I felt able, both physically and mentally, to visit shops, cafes, pubs and even B&Bs/hotels. The power of a loyal, lovable, mobility-assistance dog!

I hope this is not only a tribute to fabulous Archie but will provide information to help others. Archie's zest for life and infectious enthusiasm lifted everyone's spirits, I believe a mobility-assistance dog would help many as the bond is so great!

For more information, visit Support Aids here: ***www.supportdogs.org.uk*** *and Dog AID here:* ***https://dogaid.org.uk***.



The faces behind the Ataxia UK Helpline

Our Helpline is open Monday to Thursday 10.30am-2.30pm and available by phone (**0800 995 6037**) or email (**help@ataxia.org.uk**). During 2020-2021, we answered 1,441 queries. Here is the team!

Sheila Benneyworth, Helpline and Membership Officer

"I love working on the Helpline as I get the feeling that I have helped someone with every contact made during the day, even if it is in a small way. Every day is different, and I try to do it by bringing a smile on the caller's face however far away they are. I get great satisfaction when I know I have helped someone achieve their aims and empowered them to take action."

Wendy O'Mant, Helpline, Advocacy and Information Manager

"I have been working in the charity sector for 15 years and have a background in advocacy. I'm excited to join Ataxia UK in the Helpline team. We want to ensure everyone affected by ataxia understands their rights, has access to the information and advice they need to make informed choices and is supported to feel in control of their lives. If you have any questions for me, please do get in touch."

Julie Greenfield, Head of Research

"I have been working on the Helpline since I joined Ataxia UK many years ago and during this time I have spoken to some amazing people. Having a rare condition means people often do not get answers from their GP, and they may not have met anyone else with ataxia. Being able to provide information and support that is not available elsewhere is very rewarding, and I hope we are able to make a difference to peoples' lives."

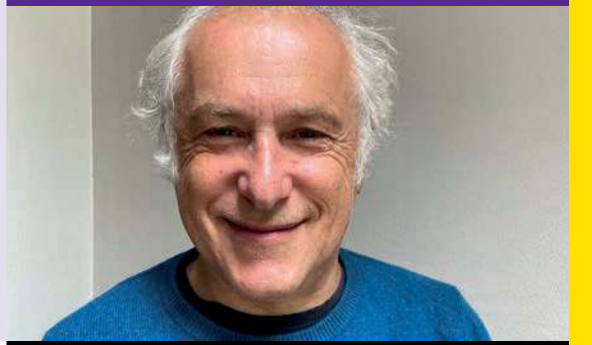
Ruby Wallis, Research Officer

"I find it very rewarding to work on the Helpline and to support people with ataxia and their families. It's been great to provide information about our fantastic resources, such as our InControl support services which have been so important in promoting wellbeing over the past year. I enjoy talking to people, providing a listening ear, and helping people to gain access to information and support."

Harriet Bonney, Volunteer

"By working on the Helpline, I hope to offer help and reassurance to people affected by ataxia that there is a wealth of support available, and they are not alone. It is humbling to be able to use all of my knowledge, skills and the experience I have gained from being diagnosed and living with ataxia for 30 years, constructively and for the benefit of others."

Tim Kahn, Volunteer



"Way back, around 1980, I worked as an advisor in a Citizen's Advice Bureau; there is much overlap between what I did then and volunteering for the Helpline now. Also, I love using my knowledge of ataxia, being gained over the years I have been involved with Ataxia UK, to support others with ataxia who at times are not seeking, or are not offered, the help they need. It feels so good to make a difference."

Dawn Wooldridge, Volunteer

"Ataxia UK have been my go-to place over many years, even before we had a Helpline. Once the Helpline was introduced, I saw first-hand the difference it made to us with ataxia. You could say I've kind of gained basic experience around ataxia over the years and want to try give something back, by listening to others and hopefully pointing people in the right direction. I look forward to chatting on the Helpline."

Ataxia Specialist Centre for children - two years on ...

Following the generous Big Give Christmas Challenge in 2018, the first Ataxia Specialist Centre for children opened at the Sheffield Children's Hospital NHS Foundation Trust. Since its opening almost two years ago, Ataxia UK talked to Dr Santosh Mordekar, Paediatric Neurologist with expertise in ataxia, about the centre.

Dr Santosh (below right) runs the centre along with James Bull (right), Paediatric Ataxia Specialist Nurse. The Paediatric Centre provides expertise in ataxia for children, access to an ataxia nurse and other services such as speech therapy and physiotherapy. The aim is to speed up diagnosis and ensure that parents and children receive the best possible support.

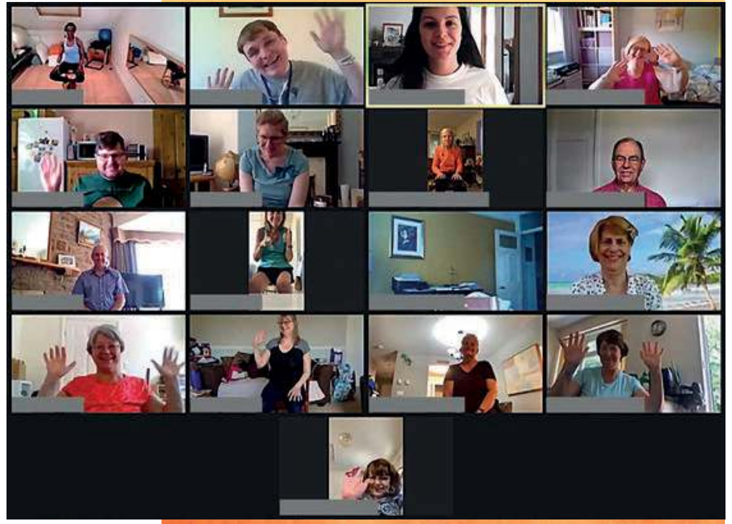
We were pleased to discover that referrals to the centre have increased by a satisfactory amount. The majority of children who visit the centre have Friedreich's ataxia (FA), but there are children attending with cerebellar ataxia, episodic ataxia and gluten ataxia. Children and their families visit from a wide range of locations too. Dr Santosh is also involved in various pieces of research at the centre, including research into gluten ataxia in children and genetic diagnostic rates in paediatric ataxias.

If you are interested in attending the Sheffield Children's Ataxia Centre, a referral can be made by your GP, paediatrician or paediatric neurologist to see Dr Mordekar at ***Sheffield Children's Hospital NHS Foundation Trust, Ryegate Children's Centre, Tapton Crescent Road, Sheffield S10 5DD****. Contacts:* ***Dr Mordekar. 0114 226 0675, Mr James Bull. 0114 271 7618***

Chair Pilates

Since March 2021, we have offered Chair Pilates for anyone affected by ataxia.

As many people will know, exercise can be really beneficial to those with ataxia, helping to maintain movement and function for as long as possible, and help manage the progression of symptoms. During the pandemic, many Friends reported that their activity levels had dropped, perhaps from not being able to do their daily outing to the park or attending their local gym. We also get many questions about the type of exercises people with ataxia should be doing.



Thus, in March 2021, we launched monthly, online Chair Pilates classes. 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. So far, they've been extremely popular with five sessions and over 90 participants.

The classes are all chair based so everyone can participate from their kitchen chair, armchair, wheelchair or deckchair (though we're yet to see that one). The class focuses on mobilising and stretching the whole body, as well as exploring optimal body alignment to improve body awareness and alleviate muscular tension. The final part of the session uses breathing techniques to relax the mind and body to leave you feeling centered, re-energised and ready to continue with the rest of your day.

The classes are capped at around 20 attendees per session so that Sonia can see all participants and suggest adjustments or alternative exercises, making it more tailored to individuals' needs. 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.

The next session is on **14 September 2021**; you can book on our website: **https://bit.ly/3i98ZPc**.

Classes cost £5 to help cover instructor costs and can be booked using the links above.

"Sonia concentrates on really opening up those areas of the body that suffer when you are less mobile. I just love these sessions as they are tailored to suit those with neurological conditions and I'm delighted to see that there are some more sessions arranged."

Ataxia Unlocked

Our Annual Conference is virtual again this year and we hope you will join us!

The conference is spread over three days - **Friday 15 October, Saturday 16 October** and **Sunday 17 October**, which means more sessions but less Zoom burnout.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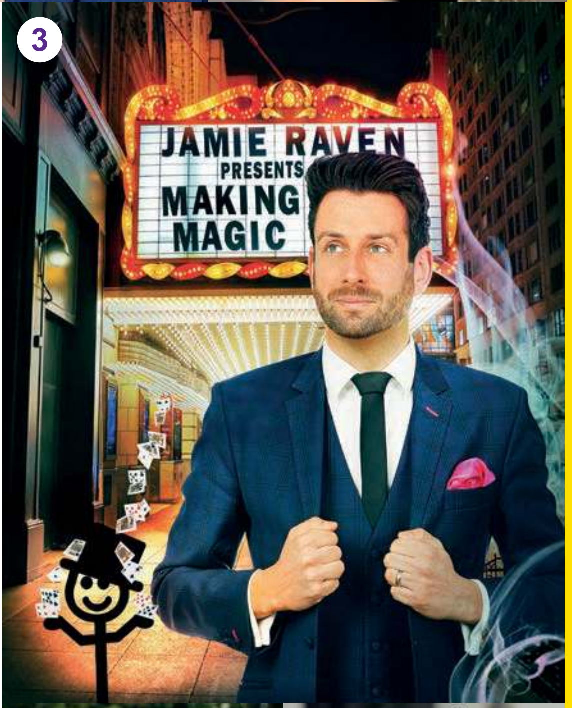
It is your opportunity to hear the latest research updates and unlock the key to information around ataxia. We have invited many, exciting speakers this year to talk about a variety of topics, including **Emma Davies (1)** from *Healx* who will discuss finding treatments through artificial intelligence. Of course, there are *It Works For Me* sessions presented by people directly affected by ataxia. Plus, the legendary host, **Paul Coia (2)**, will present the conference as always!

After the success of last year, we have increased the number of Doctor's Q&A sessions, now including gluten ataxia and ataxia in children, which will take place on the Friday. As well as the research updates covering Friedreich's ataxia, cerebellar ataxia, DRPLA a presentation on gluten and other ataxias.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The Saturday night entertainment will be hosted by our Patron **Jamie Raven (3)**, who will perform an exclusive night of magic, including an ataxia-specific trick! Jamie appeared on the 2015 series of Britain's got Talent and, since then, has performed at over 150 different venues and for **Prince Charles**.

Don't miss our exclusive interview with Paul Coia, para dressage rider, **Mari Akhurst (4)**, and Paralympic equestrian, **Helen Kearney (5)**!


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If that isn't enough, there will be *Birds of a Feather* sessions which offers you the opportunity to meet others with a similar ataxia or situation as you. There are also the *Virtual Workshop* sessions, previously known as *Breakouts*, and we have a great variety this year, including a new creative workshop.

There will be a talk about the upcoming *Mark Dower Trust* grant this year for those aged between 16 and 30 with ataxia; hear from Founder, **Alison Halls (6)**, and a previous winner of the grant.


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*We really hope to see you there. Book your tickets online (**www.ataxia.org.uk/latest-news/virtual-conference-2021**). Alternatively, send a £20 cheque to the Ataxia UK office in the FREEPOST envelope provided with your name and 'conference' on the back. Or, book your ticket over the phone on **020 7582 1444**. Any questions - please email **office@ataxia.org.uk. Bookings close at midday on Monday 4 October 2021.***

Image of Mari Akhurst ©BEF/Jon Stroud Media

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

Your legacy can be hope for the future