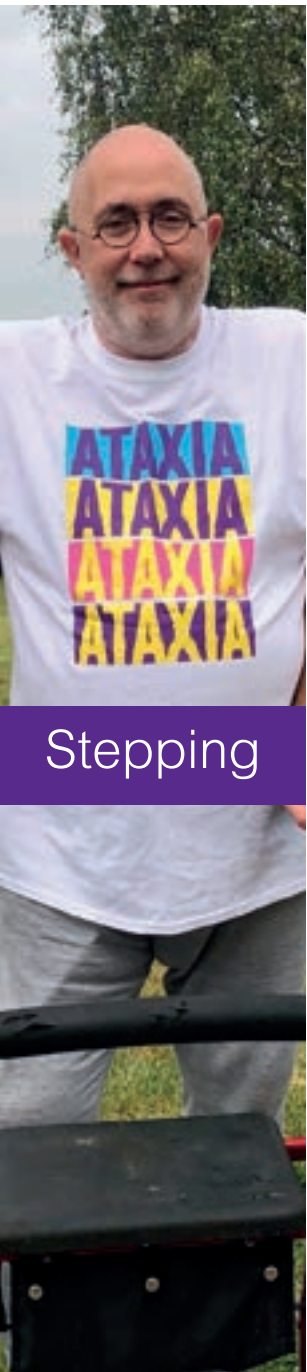


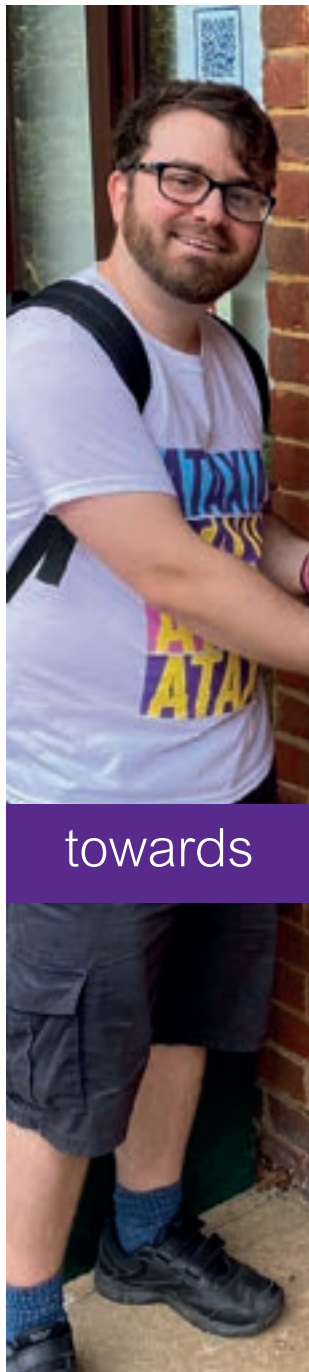
ATAXIA MAGAZINE

The magazine for people affected by ataxia

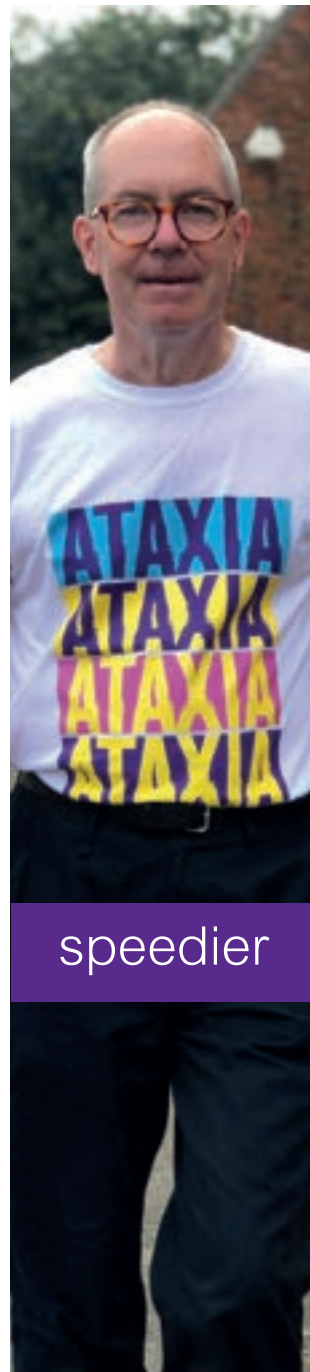
Issue 216. Winter 2021



Stepping



towards



speedier



ataxia



diagnosis!

Read more
on p.10 ...

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

ATAXIA

Ataxia UK

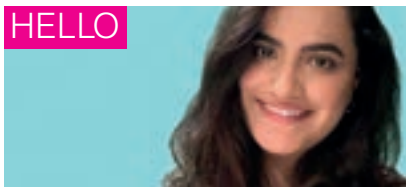
In the office

GOODBYE



With heavy hearts we say goodbye to **Kelvin Gichohi** who has been our **Individual Giving Manager** for four years. Kelvin has provided incredible work and will be sadly missed. We wish him all the best in his next steps at Crohn's and Colitis UK.

HELLO



Hi friends, I'm **Irmak Dogan**, the new **Social Media & Content Producer Intern**. Before joining Ataxia UK, I worked as a runner for the BAFTA-winning show *Life & Rhymes*, hosted by Benjamin Zephaniah. Having the opportunity to work with Ataxia UK is exciting and I am looking forward to creating some amazing things with the brilliant Communications team!

Welcome

Dear Friends,

Welcome to our Magazine. It's packed with tips on how to rise to the challenges ataxia throws at people, information about the latest research and our services, and ways to get involved with supporting the work of Ataxia UK. I hope you came along to our Annual Conference and enjoyed it. Next year's Annual Conference will be over a weekend in **October** so look out for the date. **Scottish Friends** will also get an in-person Conference on **18 June 2022 in Edinburgh**.

We've been giving a lot of thought to the results of our **Friend's Survey (p.22)** conducted over the summer. It clearly shows that more services are needed than we're able to provide! We will continue to press for improvements to statutory services and fundraise to supplement what's available ourselves. Most importantly, we're making progress with developing the **Helpline and Advocacy Service; you can read about this on (p.20)**. Finally, I'd like to add my personal thanks to **Andy Downie**, for his service as a Trustee, and to **Richard Brown** for his service as Trustee and then Co-Chair. Both of them have shown amazing commitment to Ataxia UK and been hugely supportive to the staff team.

Best wishes,
Sue Millman

*You have received this magazine as you expressed an interest in receiving it from us. If this is incorrect, (we apologise) or if you have changed your mind and no longer want to receive the magazine, please let us know by emailing **communications@ataxia.org.uk** or by writing to us at **Ataxia UK, 12 Broadbent Close, London, N6 5JW** and we will stop sending the magazine to you.*



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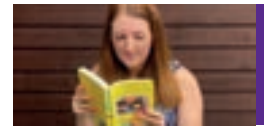
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Ataxia people

- What Cally reads
- Network updates ————— 4



Research

- Project to study DRPLA natural history
- Progress towards first approved treatment for FA — 6



Ataxia awareness

- You stepped towards speedier ataxia diagnosis — 10



Health & wellbeing

- What is hypnotherapy? ————— 11



Fundraising

- Ataxia UK's Big Give Challenge
- Winter Wonderwheels ————— 12



Adaptations

- Accessible venues to visit
- Travel and gadgets ————— 16



Living with ataxia

- Moving forward
- Diagnosis shouldn't mean you give up hope — 18



Services

- Unlocking services
- Wellbeing Week: January 2022 ————— 20



What Cally reads

Our Friend, Cally, talks about her love of reading and how it has helped her escape from her disability.

I'm Cally, I'm 30 years old and have Friedreich's ataxia (FA). I was diagnosed with FA when I was 19.

Like so many people, I found lockdown and the pandemic difficult. I was placed on furlough from my office job and then eventually made redundant. I have always enjoyed reading (particularly thrillers and romcoms) and, because of my circumstances, I had more free time to indulge in this. Then a friend inspired me to set up a Bookstagram account – an Instagram account specifically for books where you share reviews and recommendations with your followers. I have been lucky enough to receive advance copies of books to read and review.

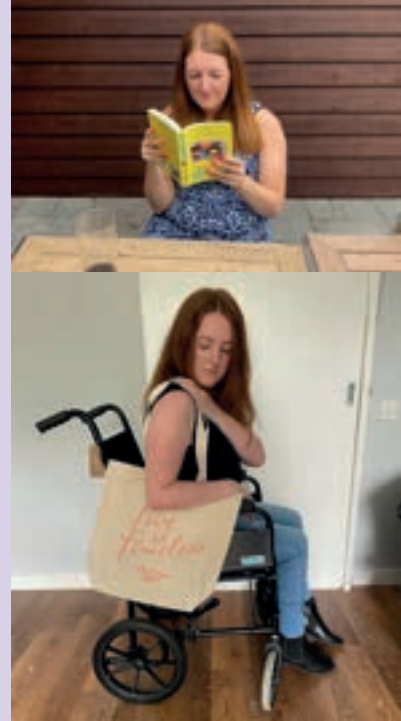
I've now had my Bookstagram for over a year and I find it interesting how many accounts I reach. At the time of writing this, I have 2,170 followers and in the past 30 days I have reached over 6,000 accounts!

The Bookstagram community have been amazing and I have made friends with people all over the world. I have also used the platform to speak about ataxia and how it affects me. The response I received was fantastic; so many people sent me messages of support and thanked me for educating them on something they didn't know about. I even received messages from two people to say that they have ataxia too. I find it helpful speaking to people who are going through the same things as me. It reminds me that I am not alone.

I find reading to be a great escape from dwelling too much on having a disability. It is a hobby I can do even on those days where I don't feel great – I can stay in my pj's and read! If you have ataxia or, in fact, any long-term condition, I strongly recommend finding a hobby that interests you. I find reading has such a positive effect on my mental health as it relieves stress and helps me focus my mind.

I try not to let having ataxia stand in the way of living a happy and fulfilled life. I know I am very fortunate to have great family and friends to support me.

*If you wish to follow my **Bookstagram**, my username is **@whatcallyreads**.*



Goodbye to Trustees Richard and Andy

Richard Brown

"I've had an amazing adventure with Ataxia UK as a Trustee over the last eight years. I would like to thank all the Trustees and staff I've worked with for their help and support. My being awarded an MBE this year for services to disabled people and to my community shows that we can achieve anything with genuine support like this. I will use my role as Ambassador for Ataxia UK to ensure that we all get the support we need. There is more to come!"

Andy Downie

"I've been an Ataxia UK Trustee for eight years and some of my achievements include: helping to create and approve the fundraising strategy; helping the Fundraising and Communications teams to become more professional and data driven; being part of the Fundraising and Communications group, which I'm still involved in, and taking part in a wide variety of events. I've enjoyed meeting and working with Ataxia UK staff and gaining an understanding of the breadth of Ataxia UK activities, particularly learning more about our services and their value to our Friends."

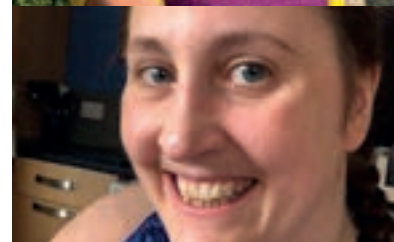
Hello to new Trustees, Rachel and Angela

Rachel Harrison

"I'm excited to join the Trustees of a growing charity and to use my experience to help make a difference to the quality of life and hopes of people affected by ataxia across the UK."

Angela Hosie

"I'm really delighted to be joining the Trustees of Ataxia UK. I have known about ataxia for ten years now, finding out about ataxia like so many of us only when you (or a family member) are diagnosed with the condition. The work Ataxia UK do to bring greater awareness of the disease is so important, with this comes improved services, speed of diagnosis - and hopefully soon a cure."



Our #TeamAtaxiaUK champions

GREAT NORTH RUN

A massive thank you to our **Great North Runners** who ran the streets of Newcastle absolutely smashing their fundraising and the 13.1 miles! Thank you so much **Claire Robson (1)**, **Joel de Gesso (2)**, **Emma Foster (3)**, **Michael Broome**, **David Whittall**, **Dave Moran**, **David Platt** and **Steve Tew (4)**, you're all absolute stars! Together you have raised over £8,948 plus Gift Aid!

BRIGHTON MARATHON

A ginormous thank you to the incredible **Sinead Pellatt (5)**, **Ryan Mason (6)** and **Becky Ingram (7)** who triumphantly completed the **Brighton Marathon** with smiles on their faces! They've collectively raised over £1,904 - a brilliant achievement!



Ataxia UK and CureDRPLA collaborate to launch a project to study Dentatorubral-pallidoluysian atrophy's (DRPLA) natural history

Ataxia UK is pleased to have awarded grants to a number of researchers in the United Kingdom and the United States to further DRPLA research. Researchers in Japan will also be awarded a grant. All the funding from this project is provided by CureDRPLA, a US-foundation that aims to find a treatment for this rare ataxia.

The DRPLA Natural History and Biomarkers Study (DRPLA NHBS) will launch later on this year and is an international collaborative effort. This project was developed and will be led by CureDRPLA and Ataxia UK.

Firstly, researchers will characterise the natural history of DRPLA, that is to say, how the condition changes over time. Secondly, this study will identify genetic factors and biomarkers that could predict disease progression. A biomarker is any variable that informs of physiological processes, pathological processes or responses of a treatment in clinical trials. Lastly, this study will provide useful information to support the design and conduct of clinical trials in the future. This study will improve the researcher's understanding of DRPLA so it will improve the information that doctors are able to give out to patients in clinic regarding prognosis and quality of life, and will allow better planning of therapeutic trials, which may lead to better treatments.

Health information from DRPLA individuals will be collected over three years to understand how this condition develops over time. **The study also recruits participants without DRPLA**, so that they are able to compare how individuals with DRPLA differ from those without. **Participating in this study will involve annual appointments at the clinics where the neurologist will collect some information** (e.g. demographics, medical history, quality of life, etc.) and do some clinical assessments (e.g. ataxia scales, speech assessment, brain imaging, blood collection, etc.).

In the UK, the participating doctors are **Prof. Paola Giunti** and **Prof. Henry Houlden** from University College London. DRPLA individuals from other countries in Europe and elsewhere might be able to participate remotely. As soon as this study starts recruiting participants, we will advertise it on all our platforms.

*In the meantime, if you have any questions about this project do not hesitate to contact **Dr. Silvia Prades**, our **DRPLA Research Manager**, on spradesabadias@ataxia.org.uk.*

Ataxia UK funds further research into non-invasive brain stimulation

In the previous issue of the *Ataxia Magazine*, we described how Dr Barbara Borroni (right) and colleagues at the University of Brescia, Italy, had completed a trial assessing a brain stimulation technique called transcranial direct current stimulation (tDCS) in people with ataxia.

tDCS is a non-invasive and portable technique where a low electrical current is applied to a person's scalp and is thought to work by stimulating cells of the nervous system. The trial showed that tDCS treatment led to an improvement in clinical rating scales used to measure ataxia.

Ataxia UK has recently funded an additional study by Dr Borroni and colleagues to research a different type of non-invasive brain stimulation technique called transcranial alternating current stimulation (tACS). This uses the same machine that was used in the team's previous study, but the electrical current is applied in a different way.

The aim of the study is to evaluate the effect of tACS on movement in people with ataxia to identify a possible rehabilitation method. The researchers propose that tACS could potentially be a more effective brain stimulation technique than tDCS. This is because tACS can synchronise the patterns of electrical activity that are produced by brain cells.

The researchers plan to enroll approximately 20 people with a diagnosis of neurodegenerative ataxia from their clinic in Italy. Participants will be put into three treatment groups: the first group will be given tACS, the second group will be given tDCS, and the third group will be given a placebo treatment. After the groups have received their first treatment, they will be given a different treatment after one week and a third treatment after a second week, meaning that study participants will receive all three treatments. This is known as a crossover study.

The researchers will use two clinical rating scales to assess the treatments: the scale for the assessment and rating of ataxia (SARA) and the international cooperative ataxia rating scale (ICARS). They will also use wearable sensors so that they can measure more subtle changes in ataxia. In particular, they will look at changes in participant's steps and the smoothness of movements.

This study will help determine whether tACS could be a more effective brain stimulation technique for ataxia for use in future trials.



Progress towards first approved treatment for Friedreich's ataxia

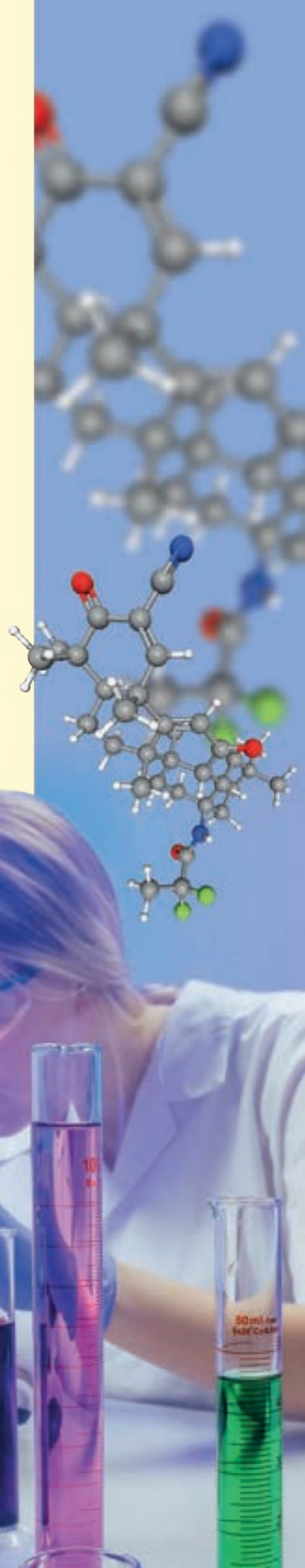
Reata Pharmaceuticals has been investigating the benefits of a drug called Omaveloxolone (Omap) – a potential therapy for Friedreich's ataxia (FA). In the Winter 2019 edition of the *Ataxia Magazine*, we reported that Reata had announced exciting initial findings from their trial of Omap in patients with FA.

In the trial, Reata used the modified Friedreich's Ataxia Rating Scale (mFARS) to measure the symptoms of those taking Omap vs those taking a placebo. The mFARS results showed that patients taking Omap for 48 weeks had a statistically significant improvement in their symptoms associated with FA than those on the placebo trial. One of the trial sites for the study was the London Ataxia Centre, and Ataxia UK assisted in the trial recruitment process.

In order for Omap to be passed for use in the USA, it must be approved by their Regulators, the Food and Drug Administration (FDA). In November 2020, the FDA concluded that the results did not show enough evidence to support Reata's submission for drug approval of Omap, and that an additional study may be required. Following this announcement, Ataxia UK provided support for a campaign by Friedreich's Ataxia Research Association (FARA), which asked people to sign an open letter to the FDA and Reata. The letter requested that Reata submit a New Drug Application (NDA) and for the FDA to consider approval of the drug with the current data. This letter was signed by over 74,000 people worldwide. Furthermore, in May 2021, Reata announced further positive results from their Omap study 'Extension phase'.

Following this, Reata announced that they had received communication from the FDA stating that a pre-New Drug Application (pre-NDA) meeting would be the most appropriate format for a discussion of the development program for Omap. A pre-NDA meeting is a specific meeting to discuss the content of an NDA. This represented a positive step forward for the potential approval of Omap by the FDA. In September 2021, Reata announced that they had completed their pre-NDA meeting and are planning to submit an NDA in the first quarter of 2022. They are not planning to conduct a second pre-approval clinical trial prior to the submission.

If the NDA is successful, Omap has the potential to be the first approved treatment for FA. Approval in the USA may hasten approval in other countries, including the UK, and Ataxia UK will do all it can to make this happen.



Ataxia UK funds an online knowledge platform: SCAsource

SCAsource is a website that provides information on ataxia and spinocerebellar ataxia (SCA) research that is written in plain language by ataxia researchers.



The goals of SCAsource are to make ataxia research more accessible and understandable to patients and families, and to provide opportunities for ataxia researchers to develop their communication skills. The SCAsource initiative is run entirely by volunteers, mainly graduate students and postdoctoral fellows who research ataxia. It was launched in 2018 and as of September 2021, the website has published 145 lay articles and received over 70,000 views worldwide.

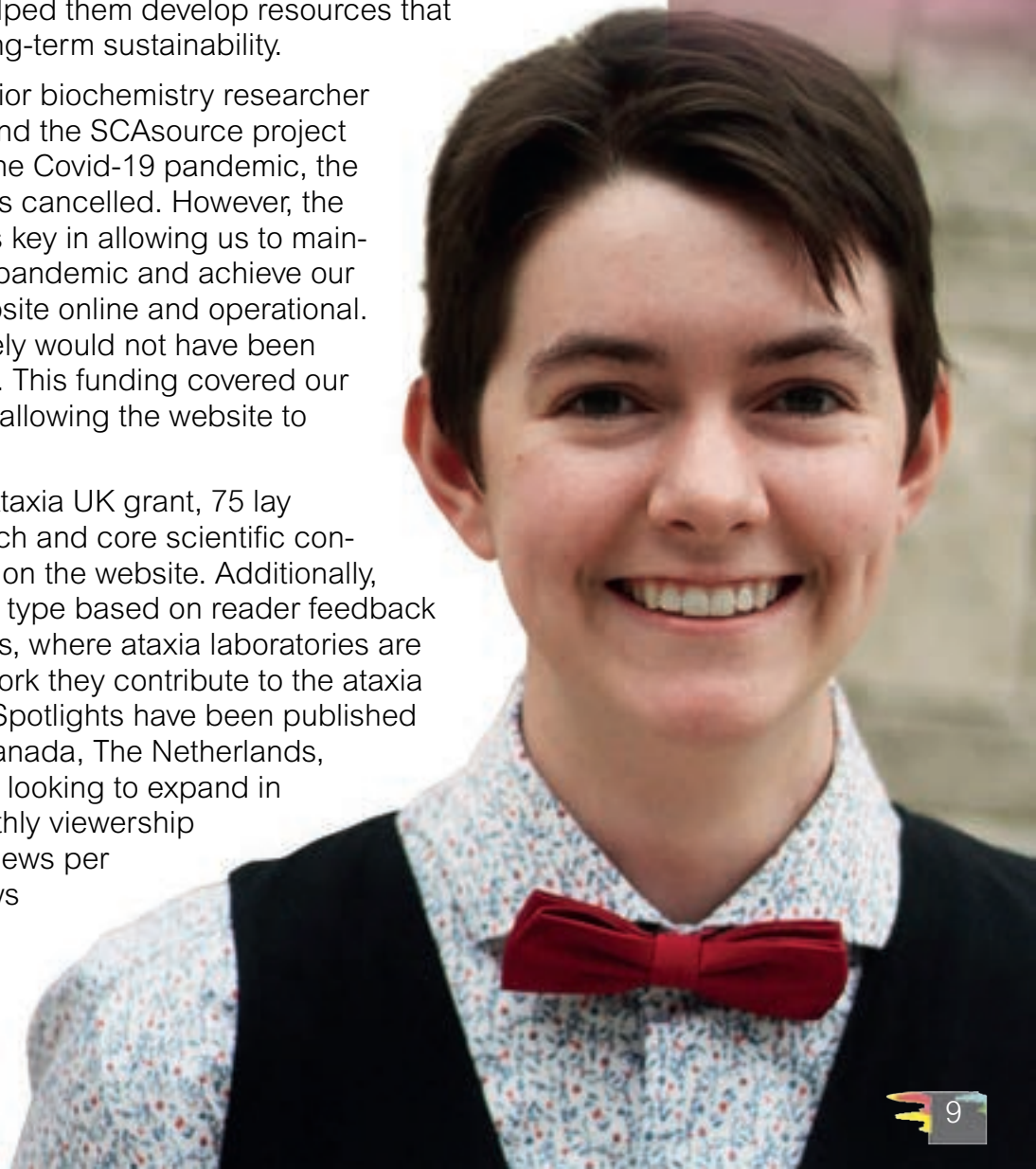
For the past year, a £1,200 grant from Ataxia UK has been funding the SCAsource website. They had two main goals for the grant. The first was to allow them to cover the expenses required to keep the website online and operational, giving them more time to seek out new funding sources. The second, to increase their chances of success for a specific larger grant, which would have helped them develop resources that could be used to ensure long-term sustainability.

Celeste Suart (right), a junior biochemistry researcher from McMaster University and the SCAsource project co-ordinator said: “Due to the Covid-19 pandemic, the larger grant competition was cancelled. However, the funding from Ataxia UK was key in allowing us to maintain the website during the pandemic and achieve our first aim of keeping the website online and operational. Without this support, we likely would not have been able to continue the project. This funding covered our most basic, essential costs allowing the website to continue to exist.”

Since they applied for the Ataxia UK grant, 75 lay summaries of ataxia research and core scientific concepts have been published on the website. Additionally, they launched a new article type based on reader feedback called SCAsource Spotlights, where ataxia laboratories are featured, showcasing the work they contribute to the ataxia community. 10 SCAsource Spotlights have been published (including laboratories in Canada, The Netherlands, Italy and USA) and they are looking to expand in this area. The average monthly viewership has increased from 1,800 views per month in 2019 to 2,500 views per month in 2021.

Please visit the SCAsource website:

<https://scasource.net>



You stepped towards speedier ataxia diagnosis!



Saturday 25 September 2021 marked International Ataxia Awareness Day (IAAD) and together you stepped to improve ataxia diagnosis and better care.

For this year's IAAD campaign we asked Friends and supporters to step towards speedier ataxia diagnosis by giving the Ataxia UK Medical Guidelines to their GP to raise awareness of ataxia. We want to say a **huge thank you** to everyone who got involved and gave them a copy. So far, **over 30 people** have requested a copy to inform their GP.

A special thank you to supporters on #TeamAtaxiaUK who additionally got sponsored to walk to their local GP surgery: **Derek Wood, Phil Baines, Tracy and Scarlett Cromwell, Emma Willis, Edward Forshaw, Jason Baxter, Taryn Cotton, Gemma Fish and David Woods!** So far, you have collectively raised over **£10K plus Gift Aid!** An absolutely incredible amount of funds that will go towards supporting those affected by ataxia and raising funds for ataxia research.

On social media we shared posts about the campaign across Facebook, Twitter and Instagram and received a brilliant response to get **ataxia** out there! Thank you to the 119 people who changed their profile photos to reflect IAAD – that's sharing about IAAD to all of their Facebook and Twitter friends.

From 20 to 26 September, we reached **47,098 people on Facebook, 5,473 people on Twitter** and **7,148 people on Instagram**. That's a whopping **59,719 people altogether!**

The campaign is not over yet. We would love for you to get involved if you haven't already and order or download a copy of the Medical Guidelines to give to your GP. Together, we can inform medical professionals about ataxia, so they diagnose patients more easily and gain access to vital care. Sign up for the campaign by visiting: **www.ataxia.org.uk/iaad2021**.

Order the Medical Guidelines by visiting:
www.ataxia.org.uk/shop/information-and-advice/medical-guidelines

Or download a copy by visiting:
www.ataxia.org.uk/shop/information-and-advice/management-of-the-ataxias-towards-best-clinical-practice



What is Hypnotherapy?

One workshop at our virtual Annual Conference this year was hypnotherapy which aims to improve your wellbeing. The session was led by Kristin Hayward (below) whose husband has ataxia.

The session began with Kristin discussing the power of the mind and the benefits of hypnosis in improving your outlook on life. The mind and body are interconnected, so having a positive attitude will positively impact your physical wellbeing, as well.

Hypnotherapy involves hypnosis and you are always in control of yourself. With self-hypnosis, you can switch off and dream, relax deeply, disconnect from your immediate surroundings and access your subconscious mind.

Hypnotherapy is very accessible and can be practised anywhere – on the train on your way to work, in the bath, before bed or first thing in the morning. It is your secret weapon because nobody knows you are doing it, and it is for you and only you!

SO, HOW DO YOU PRACTICE HYPNOTHERAPY?

- Find somewhere quiet where you are comfortable
- Take a few long deep breaths and notice where your breath is going in your body
- Count when breathing, keep it slow and regular
- Imagine drifting into a zone where you feel safe, no-one/nothing can bother you here
- Bring in images and feelings to visualise/imagine a future event as positive, to release stress, to see yourself as the amazing person you are
- Enjoy a few minutes or longer in your zone before either going to sleep or counting yourself back to full awareness
- Practice hypnosis/visualisation every day.

BUILD IT INTO YOUR ROUTINE

- Visualise the event – use hypnosis
- Focus on breathing, step into your power zone
- Set up triggers
- Use relaxation techniques to keep calm
- Keep things in perspective
- Work with a friend, support each other.

If you're interested in finding out more, please see Kristin's website: www.kristinhayward.co.uk.



Give the gift of speech this Christmas

This December marks the 5th year Ataxia UK has participated in the Big Give Christmas Challenge; the UK's largest match-giving campaign, and this year you can help give the gift of speech as well as help to fund vital ataxia research by DOUBLING your Christmas gift at no extra cost to you!

WHAT CAN YOUR DOUBLED DONATION DO?

For people living with ataxia, the impact of the pandemic on their mobility, mental health and speech has been especially difficult. The vital and reduced opportunity to practise everyday conversations with people, as well as a lack of access to speech and language therapy services during the pandemic, has had a detrimental effect on many people's speech and communication.

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

And 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 voices. Speech therapy can prevent deterioration 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 December, **between midday on Tuesday 30 November – midday on Tuesday 7 December**, YOU can help give a voice back to one of thousands of people who face losing their natural speech and identity by taking part in the Ataxia UK Big Give Christmas Challenge.

HOW DOES THE BIG GIVE CHRISTMAS CHALLENGE WORK?

Between **midday on Tuesday 30 November – midday on Tuesday 7 December only**, you can **DOUBLE** the value and impact of your gift at no extra cost to you. Your doubled impact will:

1. Help people living with ataxia communicate more effectively using a dual approach through:
 - An online speech therapy course in a peer support group setting.
 - Offering people who may lose their natural voice the opportunity to continue speaking and communicating by banking (recording) their voice to use if, in the future, they need to speak using IT support, rather than speaking with an electronic voice.
2. Ensure scientific research into finding treatments and cures for the ataxias continues to be funded.



Chance2Win Winners

1st Prize: £500
Melva Powell

2nd Prize: £250
Geoffrey Jennings
(who has donated his money back)

3rd Prize: £150
Richard and Jane Busk

HOW IT WORKS

Thanks to the commitment of our pledge donors and the support of our Champion funder, from **Tuesday 30 November until Tuesday 7 December**, Ataxia UK will have a match pot of **£26,250** of available funds to **DOUBLE YOUR DONATIONS!**

Donate online between those dates only and your donation will be doubled at no extra cost to you, and worth even more if you Gift Aid your donation.

HOW TO JOIN

To double your donation, please visit our 2021 Big Give donation page: www.ataxia.org.uk/the-big-give-2021 from **12pm on 30 November until 12pm 7 December** to double your donations.

Don't forget, if you are a UK taxpayer, please tick the Gift Aid box when you donate online, as your matched gift will be **worth an additional 25% to Ataxia UK** at no extra cost to you.

For example, a donation of **£100** during the week of the challenge will be worth an incredible **£225** towards reaching the target goal of raising **£52,500** to fund research and the gift of speech for people living with ataxia.

PLEASE NOTE: Unfortunately, Ataxia UK is not allowed to help you process donations to the Big Give via telephone or accept cheques for Big Give. Your gift will NOT be matched if you donate on our Big Give page after the week of the challenge, or if you decide to send a donation by cheque, though of course we are grateful for all donations!

STEP 1

Visit the donation link between midday **Tuesday 30 November** and midday **Tuesday 7 December**

www.ataxia.org.uk/the-big-give-2021

STEP 2

Donate, say, **£100**



STEP 3

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



STEP 4

Tick the Gift Aid box to add a further **£25**.

So, you give **£100** but we get **£225!**



Winter Wonderwheels

Choose to accept your mission **At Home** between **20 November** and **5 December** or do the **Live Event** on **5 December** in **Windsor!**

AT HOME WINTER WONDERWHEELS, 20 NOVEMBER - 5 DECEMBER

Get your capes and costumes ready to clock up kilometres to help Santa deliver his presents this December! You'll dash round the world delivering presents from your own homes and neighbourhoods!

- ☀️ Take on any challenge you choose - walk, peddle, push, swim, skip, or use your super senses!
- ☀️ Fly solo or get friends and family to be your trusty sidekicks to accompany you on the adventure.
- ☀️ Complete it in one go, over a few days, or two weeks!

LIVE EVENT - DORNEY LAKE, WINDSOR, 5 DECEMBER

- ☀️ Take part in Windsor and choose from three super distances (1, 5, or 10km).
- ☀️ Choose what you'd like to do and call your team of sidekicks to join the action.
- ☀️ There are no cut-off times and you can use any gadget or gizmo to help you complete your mission (as every superhero would!).

All fundraisers will receive a free place in these festive extravaganzas!

*Ready to accept your mission? Contact **Rebecca** on rholt@ataxia.org.uk*



London Landmarks Half Marathon 2022

Run on #TeamAtaxiaUK in Central London's Half Marathon through Westminster and the City on 3 April 2022!

From cultural landmarks and heritage to the city's quirky and hidden secrets, runners get to explore the capital on a route like no other on this closed-road, central London run!

Starting by The Strand and finishing by Downing Street, the run has fabulous views of London's most iconic landmarks including Big Ben, St Paul's Cathedral, the Shard and the Tower of London. Just pledge to raise a minimum of £500 and you will receive your place for free. Be quick though as we only have a limited number available!

Contact **Mia** on mkrikler@ataxia.org.uk or call **020 7091 1597**.

When you sign up to be part of #TeamAtaxiaUK for either of these events, you'll receive your own running vest or t-shirt and support every step or swoop of the way!



Fundraising thank-yous

Thank you **Andy Perkins (right)** and **Nathan** who raised £580 with their 'Paddle for Ataxia', kayaking 100km in the Great Glen Canoe Trail! Thank you too **Nikki** and **Mel** who supported them and even spotted Nessie!

Congratulations **Christian Marks (1)**, **Nicola Gould**, **Rhydian Williams**, **Paul Broad**, **Rhodri Thomas**, **Dale Evans** and **Geth Young** who completed their 55-mile Brecon Beacons to Cardiff Bay cycle to support Christian's sister **Shelley**, raising £1,790!

Well done and thank you **Lucy Byrne (2)** and **colleagues** at **Halls of Ivy Hair** who raised £230 as part of their Beauty Level 3 Course with massages and nail treatments!

A massive thank you to **Bishop's Cannings Cricket Club**, **James Rapson (3)** and his **team** and lead sponsors **Gore Brown Investment Management** for their Clay Day, raising a whopping £25,300! Thank you so much and to everyone who attended.

A huge hurrah for **Millie Mae Ormsby (4)** who triked for three hours and raised £642 in support of her dear friend **Emily Adams**, who would have turned 21 this year, and her **Mum Elaine**. Thank you to Millie's friends and family who took part too!

A big thank you to **Connor Kidd (5)** for running the York 10k, raising £330 in memory of his grandfather **Hugh**.

Thank you and congratulations to **Emily** and **Joshua Banks (6)** who smashed the Yorkshire Three Peaks challenge, raising £460!

A shining thank you to **Deborah Jackson (7)** who bravely did an extreme abseil, raising a smashing £388!

A big thank you to **Geraint Williams (8)** who climbed Ten Y Fan 10 times on his mountain trike, raising over £1,400 – such a huge achievement!

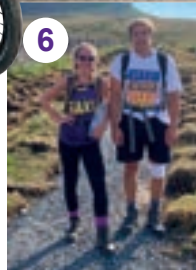
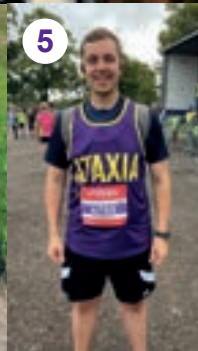
Well done **Natasha Giddings** who held a stunning Garden Party with stalls in support of her daughter, **Lyla (9)**, raising £1,248 - thank you!

Well done and a big thank you **Tom Dunn (10)**, who completed the Land's End to John O'Groats cycle, taking on 100 miles a day and raising £1,983!

A great big thank you to **Sheena Betsworth (11)** who held a lucky dip - it was such a success, raising over £200!

A huge round of applause to **Grace Moore** who walked 70 miles around the Isle of Wight, raising £615 in memory of **Abi Stone** who "was like a sister" to Grace.

A round of applause to **Pippa Eden**, **staff** and **Year 3-6 pupils** of **Waverley School (below)** for their *Race for Emily* in memory of their friend **Emily Adams**, raising £1,550. A lovely way to remember her and you all did so well.



Accessible venues

As events open again, James Downie, who has Friedreich's ataxia (FA), writes about sports and music events he has attended and his favourite, accessible venues.

GETTING TO KNOW THE VENUE

Over the years I have been very lucky to attend many events; the proximity and ease to travel to London from where I live has helped greatly. For every event my carer goes free, and I normally go with family or friends, and they usually drive. I visit venues I know and try to get the same seats. Having knowledge of where I am located puts me more at ease as I know the accessibility and toilet situation. I prefer venues that use RADAR keys as the toilets are normally in a better condition.

THE O2 ARENA

The O2 arena is my favourite venue for music and indoor sports. From Kanye West to Liam Gallagher, National Basketball Association (NBA) to tennis. The O2 has a wheelchair platform really close to the stage and, if you get those tickets, the view is incredible. There is lots of hospitality in and around the O2, plus it is all flat and accessible. The toilets are OK and use a RADAR key, but you have to remember to shut the door properly, otherwise everyone uses the toilet!

WIMBLEDON

I have been to the tennis at Wimbledon every year since 2010 and, pre-Covid, we always joined the queue before 7am! Court One has the best view, while sitting in Centre Court means you either sit at the very front or right at the back of the stadium. There are decent toilets dotted around the grounds of various sizes and the staff are very helpful. However, accessibility is an afterthought because it is an old venue. There are hills and steep ramps everywhere and I can't get around independently without battery power, so that's something to think about if you are visiting Wimbledon.

WEMBLEY STADIUM

I have been to many events at Wembley Stadium. Before Covid-19 I went to all the National Football League games and was lucky enough to go to the football EURO Semi-Finals and Final this year. Wembley has good access and many toilet options all using a RADAR key.

Other stadiums with great access are the American Express Stadium (Brighton and Hove Albion) and the Tottenham Hotspur stadium.

If you have any questions or if I can help in anyway, let me know! downsar@mac.com



Travel and gadgets

MAKING ACCESSIBLE TRAVEL EASIER

Accessible travel can be difficult and time-consuming to arrange. If you find this challenging, there is a Passenger Assistance App which helps. The App was created by **Transreport** who collaborated with disabled passengers. The app allows you to set up a profile which means your accessibility needs are saved each time you request assistance. You can also add an optional profile photo to make it easier for station staff to spot you.

1. Download the Passenger Assistance App. Go to the App Store if you're using an Apple device or Google Play Store if you're using an Android device.
2. Set up your profile and provide as much information as you'd like – you're in control of your profile. Whatever your accessibility needs, there's space for it all to be listed.
3. When you're planning a journey, put in your travel details; where to/ from and what day and time. This way station staff will have all the details they need to make your journey run smoothly.
4. Send your request via the app. This will be sent directly to the train operator who will arrange assistance for you. The app will confirm your booking. Then all you have to do is book your ticket and you're on your way.

The app was tested by disabled passengers. Transreport are always looking for ways to improve and update it in collaboration with disabled people. Go to www.passengerassistance.com for more information.

FINDING A SMARTPHONE

Abilitynet's website has information about accessible mobile phones. They recommend phones such as the *Doro 8030* or the *Synaptic Diamond* models, which offer features that a smartphone has, through a simplified and more intuitive interface on a large, clear LCD display.

Smartphones such as Apple and Android have useful features, such as:

- Voice-control. If you struggle with hand-function but your speech is strong, you can control your phone by **using your voice**.
- Switches to text/browse easier. There are all sorts of different ways of setting a switch up for **Apple** or **Android**, including buttons.

Go to <https://abilitynet.org.uk/news-blogs/using-mobile-phones-if-you-have-mnd> to find out more.

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.*



Moving forward

We talked to Georg Herdt about his incredible motivation for exercise.

I had never seen the words 'Friedreich's ataxia' (FA) until I received my diagnosis letter at 35 years old. I received no further information about the condition and I didn't know what to do. I wasn't showing obvious symptoms: I was able to walk and run unaided.

I was developing my academic career and suspended exercising due to a lack of time. However, within a year after the diagnosis, I started showing symptoms fast – my walking declined and my vision blurred.

I made a tough decision to end my professional career but I began to increase exercise. A friend of mine encouraged me to run, as walking needed improving. I have been an advocate for exercise my whole life and I have a long history of competitive sport. I was born into a family of keen rowers and rowed from the age of six.

Although I never knew I was living with FA until my diagnosis, my physical decline must have been present early on. Due to my exceptional physical ability symptoms were limited and those that came to the fore were shrugged off as clumsiness. However, the decline was very slow and I continued with sport at university. I completed a marathon and took part in rowing competitions. I believe this is what kept my FA at bay.

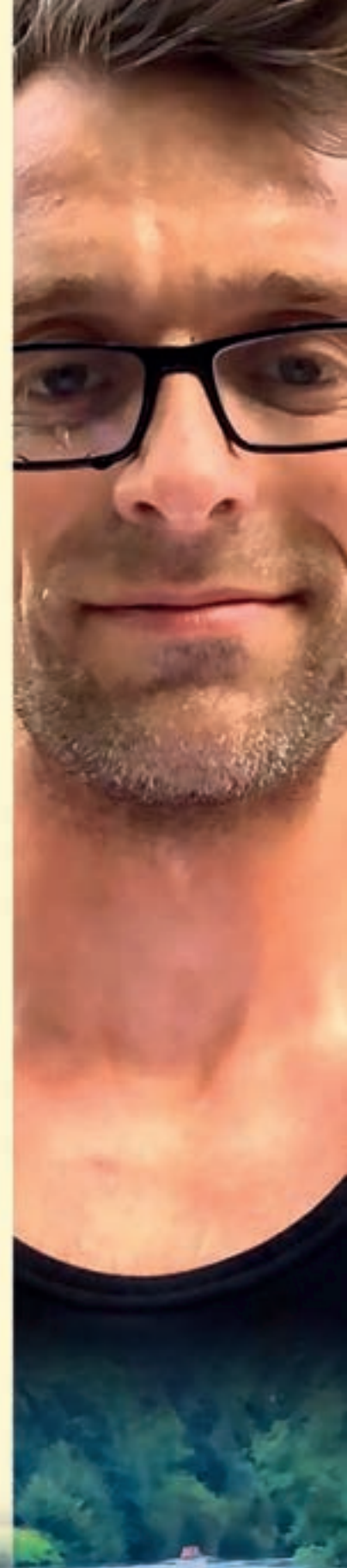
After a brief interlude in academia, Oxford Brookes University approached me as a potential Sports Ambassador. They have supported me on the journey to combat the physical degeneration that my FA causes. I am still a keen and ambitious rower with a dream. Currently I row at Hinksey Sculling School in Oxford: Their programme includes me, not as a disabled outsider, but as a member of their squad. That is the kind of world I dream of. I can only be as good as my environment allows me to be.

I train two to four hours every day doing different exercises and the more training I do, the more control I gain. When my ataxia says no, I say yes. Sport will not cure me, but exercise is what keeps me on my feet.

Follow Georg's story on Instagram: [@AtaxiaAthlete](#)

Thanks to Oxford Brookes University for some content.

Disclaimer: This article is written by Georg Herdt and represents his own personal view. Please consult your physio, GP or neurologist for advice around exercise as ataxia affects everyone individually.



Diagnosis shouldn't mean you give up hope

Despite Olie Frank's diagnosis being a difficult time, he writes about how he changed his perspective.

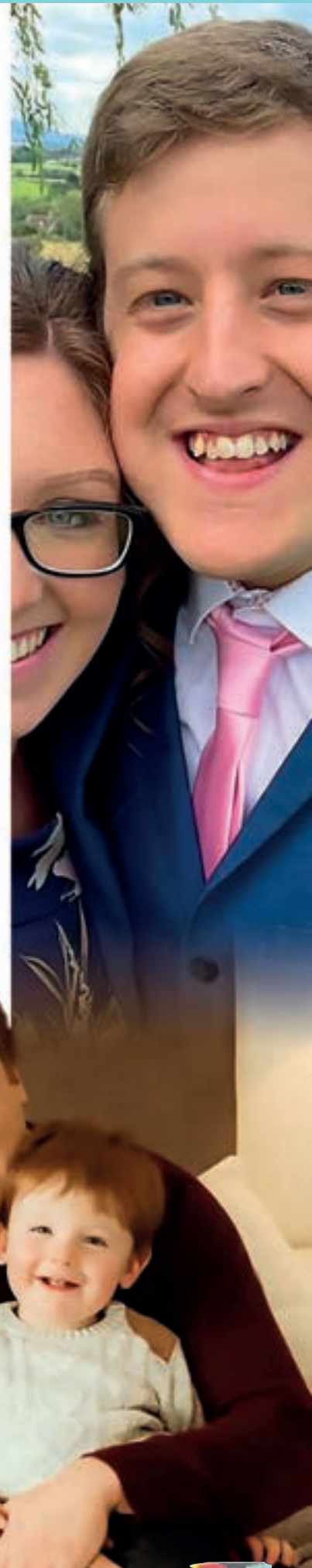
Six years ago at 21 years old, I was about to begin an exciting career in the police force. However, while completing the medical test, the doctor noticed issues with my balance and senses. In order to investigate this, I attended appointments with neurologists, had brain scans and other tests. Being 21 and generally healthy, I assumed this was unnecessary.

Therefore, when I received my results, I did not anticipate being diagnosed with Friedreich's ataxia: something I had never heard of, and that I would likely use a wheelchair within ten years. The immediate impact was shattering to my family and me. I was unable to complete my police training; the final stage in the recruitment process for the job I had already been offered, after studying police sciences. I quickly lost hope for the future and any plans that I once had.

Then something changed. I started taking things day by day and tried to stop worrying about the future. It's a hand I have been given but it's not what defines me. I realised I had two options, to feel sorry for myself and have others feel sorry for me, or to set goals on what I can achieve and work towards it. Ataxia still makes me feel upset and angry when I think about it too much, but day to day I focus on what I can do and what makes me happy.

It has given me a mature outlook on life and has helped to establish present and future goals. I am incredibly lucky to be surrounded by a supportive family and I won't let it take over my life. I can still achieve both personal and professional goals even if I must alter these slightly.

Six years on from my diagnosis, my life is very positive and I am proud of what I have achieved - even if things haven't worked out as I expected! I own my home and have worked hard to qualify as a financial advisor. Most importantly I now have my own family; my wife Amy and two wonderful children: Louie has just turned two and Penny is five months. Right now my condition is progressing slowly and, although the future is daunting, I am grateful to be well and living a very happy life.





Unlocking services

This year's virtual Annual Conference theme was **Ataxia Unlocked**. It was wonderful to see familiar and new faces, but it is no substitute for an in-person event and we hope to meet live next year.

"The staff did an unbelievable job in delivering an amazing conference. Despite it being virtual the warmth from people could still be felt which is an incredible feat to have achieved."

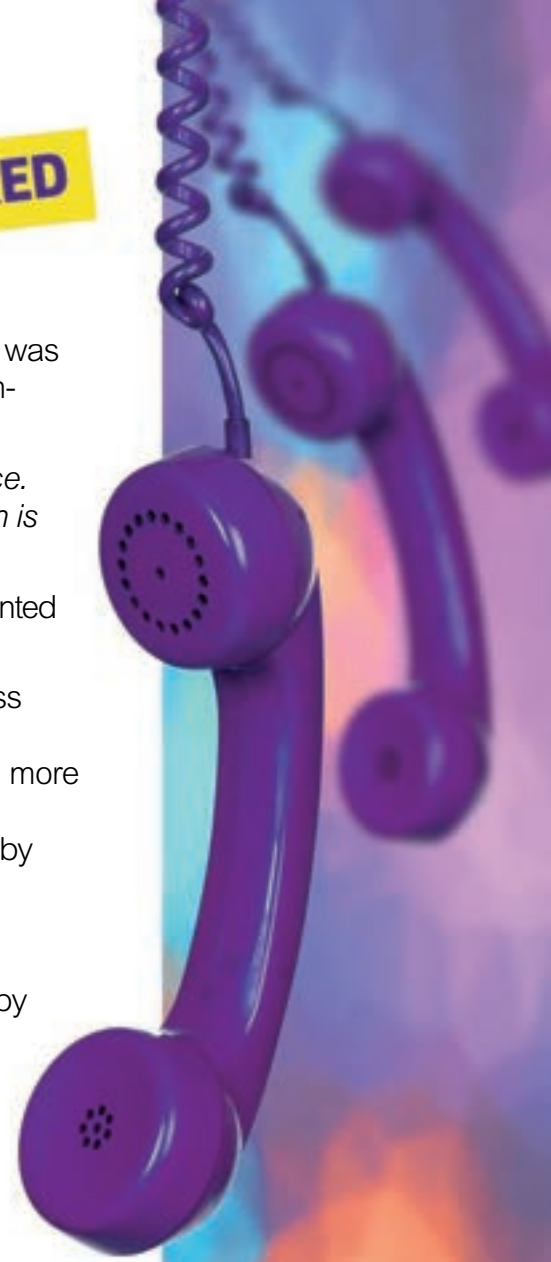
Our Helpline, Advocacy and Information Manager, **Wendy O'Mant**, presented the future plans of our Helpline and Advocacy service. **WE AIM TO:**

- Do everything we can to support those affected by ataxia to access information, advice and support.
- Increase the number of contacts to the Helpline so we are helping more people in the ataxia community.
- Be the go-to organisation to help all people whose lives are affected by ataxia.

WE HOPE TO ACHIEVE THIS BY:

- Making the helpline more accessible through other channels and by opening additional hours.
- Covering more issues such as benefits.
- Publicising the Helpline and the Advocacy Service so everyone with ataxia knows we're here to help.
- Recruiting more volunteers to help – could this be you?

Email help@ataxia.org.uk for more information.



Wellbeing Week: January 2022

Back in June the InControl team held our first Wellbeing Week. We hosted a wide range of events with the aim of increasing the ataxia community's wellbeing. Due to the success of the sessions, we plan to deliver another Wellbeing Week in January 2022.

From 21-25 January we will provide a daily workshop with a range of speakers and topics. On 23 January we will look at our new volunteer role of *Regional Support Coordinator*. This new volunteer role will be working with our Branch and Support Groups. These groups provide vital peer support for people living with ataxia. Each group is different but with the overarching aim of breaking the cycle of people affected by ataxia feeling isolated.

As we leave lockdown restrictions, we are looking to develop our support with volunteers engaging with Branch and Support groups within their local area. This will involve attending Branch and Support group meetings, offering guidance, information and ensuring best practice standards.

This is a varied and interesting role that can make a real difference to our volunteers and the wider ataxia community. Full training and guidance will be provided by the InControl Team. *If you would like to attend the workshop, or would simply like to hear more, please contact volunteering@ataxia.org.uk.*



Dr Julie Greenfield:

Celebrating her 20-year anniversary with Ataxia UK

In July Dr Julie Greenfield, Head of Research, marked her 20-year anniversary at Ataxia UK. We thank Julie for her invaluable dedication and commitment to people affected by ataxia.

Julie started at Ataxia UK in 2001 as the Research Department's only member. Since then, she has assembled a skilled and committed research team, and developed our varied research programme. Her work has included:

PROJECTS AND COLLABORATIONS

Julie develops and manages our research grants programme. She promotes and facilitates research on ataxia and has developed numerous partnerships. Her work with researchers, healthcare professionals and pharmaceutical companies has had a significant impact on awareness of the ataxias and the search for treatments. She has organised numerous research conferences and established partnerships with other ataxia charities across the world.

She has been involved in both European and global initiatives, and is on the Steering Committee for the Ataxia Global Initiative, a research platform facilitating the development of therapies for ataxia.

SUPPORTING PEOPLE WITH ATAXIA

Julie manages the research communications to Friends, ensuring they are provided with information regarding research developments and have opportunities to be involved in research projects and trials. She continuously advocates for patient involvement in research.

In addition, she has answered Ataxia UK Helpline calls for 20 years and managed the Helpline for the last seven years; supporting countless ataxia patients and families with their queries.

Ataxia UK promotes good practice in treatment and care, and Julie has played a crucial role in the establishment of the Ataxia UK Accredited Specialist Ataxia Centres and coordinating the production of our Medical Guidelines for the Clinical Management of People with Ataxia.

Professor Barry Hunt, Ataxia UK Trustee and Scientific Advisor said:

“Julie has become an exemplary champion for the ataxias. She is outstanding as Head of Research and has established a highly successful link for patients, parents and carers with the global community of researchers. She is known for her conscientious and caring approach. She is a member of many steering groups that coordinate research on the ataxias and is a prominent representative of the global network of patient groups. She has forged links with pharmaceuticals, ensuring that they understand the needs of ataxia patients.”



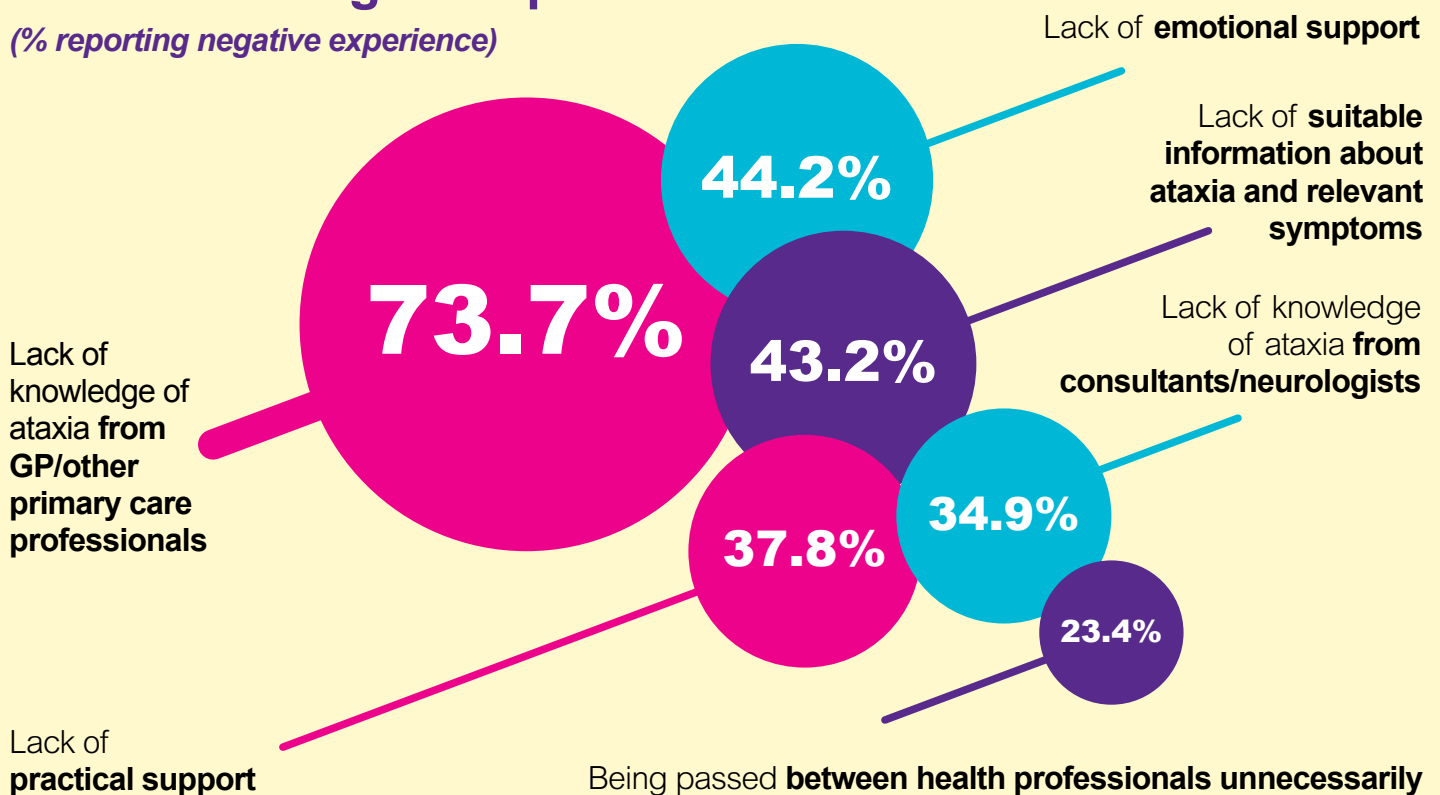
Ataxia UK 2021 survey: what you told us

In Spring 2021 Ataxia UK asked for the experiences of people living with ataxia and carers. The research comprised a survey for those living with ataxia and another for carers, we received a total of 314 surveys from people with ataxia.

This infographic covers an overview of the findings which, in the upcoming issues of the *Ataxia Magazine*, we will cover in in-depth analysis. Thank you to everyone who participated; your answers help Ataxia UK to work out our priorities and tailor our business strategy to empower and support the ataxia community.

Barriers in diagnosis process

(% reporting negative experience)



Impact on life

80.3% indicated that ataxia had an impact on their mobility outside of the home.

75.6% reported that ataxia had an impact on their ability to use public transport.

72.9% indicated that ataxia had a significant impact on their physical health and wellbeing.

71.7% had installed aids and adaptations.

70.0% indicated that ataxia had an impact on their mobility within the home.

61.8% felt that their current housing met most of their needs.

55.5% reported that ataxia had an impact on their ability to engage with friends outside their home.

51.5% specified the most significant impacts on relationships were with their spouse/partner.

Access to therapies and counselling

86.6% had accessed **physiotherapy**; **51.6%** reported that it **met most of their needs**.

56.7% had accessed **speech therapy**; **48.9%** reported that it **met most of their needs**.

16.6% had accessed **counselling**; **38.7%** noted that they **could not access counselling** or that the counselling support they did receive **met none of their needs**.

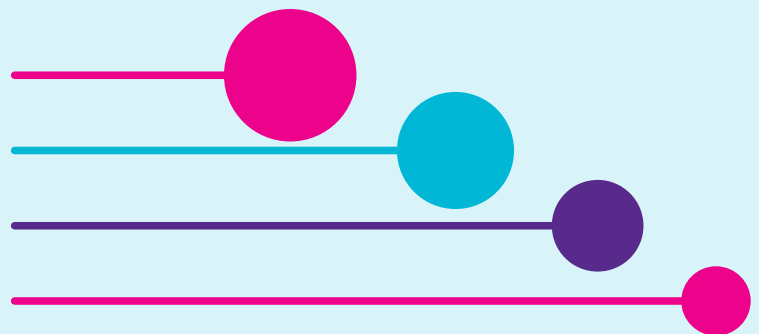
Dealing with issues at work *(% reporting negative experience)*

21.5% Negative **employer attitudes**

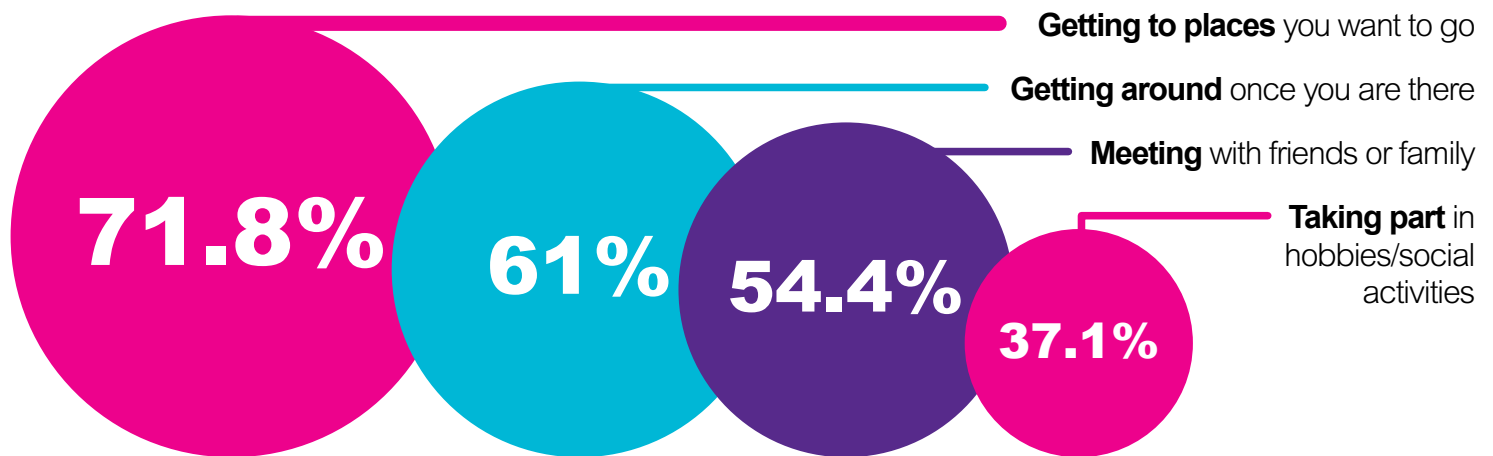
19% Issues with **physical access at work**

14.9% Negative **colleague attitudes**

11.3% Lack of **reasonable adjustments**



Informal care activities *(% reporting getting help)*



Formal care activities *(% reporting getting paid help)*

Cleaning

Bathing

Dressing

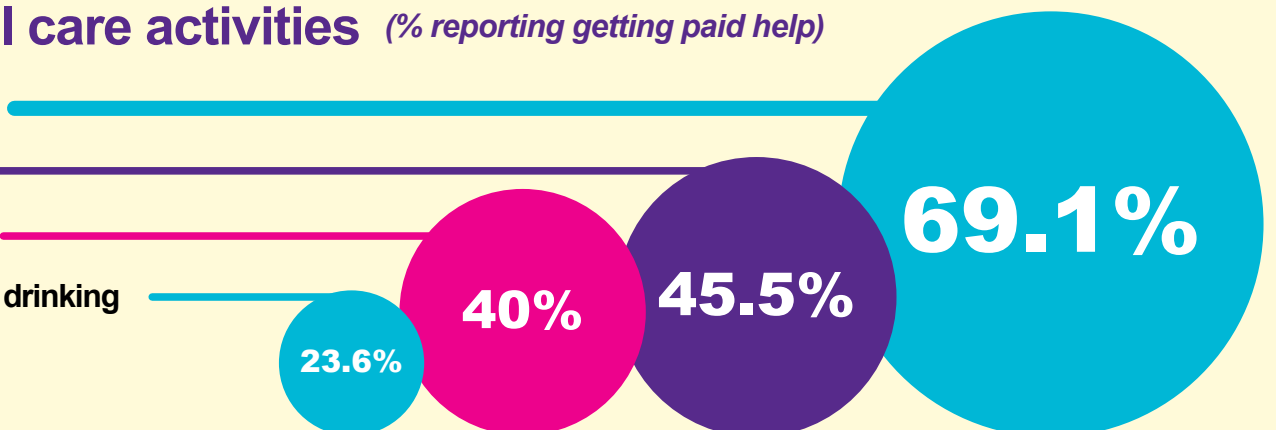
Eating and drinking

23.6%

40%

45.5%

69.1%





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