

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 213. Spring 2021

Big Give 2020 Christmas Challenge

£71,657 raised to help fund the Helpline and ataxia research!

£71,657

theBigGive

Thank you!

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

ATAXIA

Ataxia UK

In the office

HELLO



Hello, I'm **Aaliyah Burns** and I've joined as an **Events and Community Fundraising Intern**. I have recently finished my master's degree in Gender, Violence and Conflict and, since then, I have run the social media for a charity which provides English lessons to Refugees and Asylum Seekers. I'm excited to help raise money for a great cause and to get to know the inspiring people who fundraise.

HELLO



Hello, I'm **Mia Krikler** and I'm excited to work as an **Events and Community Fundraising Intern**. Previously, I worked in the arts, as well as in communications for The Climate Coalition. I also volunteer for the Dutch NGO, HealthNet TPO, which aims to integrate mental health and psychosocial services into national healthcare systems in countries like Afghanistan and Colombia. I'm looking forward to working with the inspiring people who fundraise for us, as well as the larger team at Ataxia UK.

Welcome

Dear Friends,

I hope you are optimistic about the prospects for a return to a more normal life when the vaccine against Covid-19 eventually becomes available to us all. Our expert neurologists are encouraging people with ataxia to take the earliest opportunity they can, to receive the vaccine. Please see our detailed statement on Covid-19 vaccines on our website www.ataxia.org.uk/latest-news/covid-19-vaccine-update.

Sadly, as I write in mid-January, it looks as if it will be quite a while before we can meet face-to-face, and Ataxia UK will continue to offer as many online and remote services as we can, to support people during this difficult time. On p.12 you can read about the wonderful success of our Big Give Christmas Challenge to develop our advice and information services, and for research into treatments and cures. We are grateful to all of you who supported this appeal. Other articles demonstrate the work that your ongoing support enables us to provide: the launch of our peer support speech therapy research project (p.9) and an appreciation of our online forum HealthUnlocked (p.23). In bleak times it is good to celebrate all positive steps forwards, and the resilience and benefits of participating in a diverse ataxia community (p.4). I hope you too, will find something in this magazine to celebrate.

Best wishes, **Sue Millman**

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How to become - and continue to stay - diverse

The South London Support Group was given an award at the Virtual Annual Conference for being a diverse group. Tim Kahn, Coordinator, writes about the group.

Some principles I keep in mind when running the group, which may have enabled our diversity:

- When people contact me, I talk with them about ataxia. I give them useful information *and* tell them about the benefits of support group meetings – but only a minority of people choose to attend the support group and many come only once.
- Pre-lockdown, we met in a community centre. People paid to attend meetings (to cover the rent) and charges were flexible to reflect that poorer folk may not have much cash compared to richer ones.
- Frances and I model kindness and we intervene (often behind scenes) to ensure that everyone treats people well.

When thinking about diversity, either *we treat all people the same* or *we treat them each according to their needs*. I lean towards the latter and think about the following issues:

- As a Jew, I remember that Jews have difficulty (learnt from our experience through history) trusting others. I try to counter this by consulting with others, particularly Frances (from Jamaica) who started the group and thinks brilliantly and very differently from me - we complement each other.
- As a man, I remember that men have felt the right to speak while women have not developed the confidence to hold the floor. Thus, I am keen to encourage female voices and discourage men from 'taking over'.
- As a white person, I remember that we think our voices are more important than those of our BAME brothers and sisters, so I encourage *us* to listen to *them* talking.
- We have a deaf person in our group, so I encourage people to indicate when they are speaking so he can look at them, lip read and feel included.
- One of our members has a learning difficulty. I try to ensure he understands everything.

My disabled friends have taught me that real inclusion only happens when one addresses these kinds of issues. I encourage you to join me in creating an inclusive world. That world is much more interesting than a world of the same people.

Perhaps most important of all is that people like and care for each other. There is real kindness in the group among people who have known one another for years and others who joined recently. My role is to encourage this more than anything else.



Conference feedback - involvement opportunity

Do you usually attend our **Annual Conference**? Did you come to the Virtual Conference in October 2020? If so, we'd like to hear your ideas and feedback on how we can make this year's Mini Conference and Annual Conference even better. The Annual Conference is **15-17 October 2021**.

We are looking for four **Ataxia UK Friends** with different perspectives to be a part of a focus group that will influence the content and delivery of the conferences. Participants will be asked to commit to attending monthly meetings (which will last around one hour), between February-October 2021.

We aim to run an inclusive involvement programme so meetings will be held on Zoom, with the option to use the chat function if preferred. We want to ensure our meetings and conferences are accessible to all of our supporters, so if you have any other accessibility requirements let us know.

*If you would like more information or to apply, please head over to the **Get Involved** section on our website or email the InControl team on volunteering@ataxia.org.uk. Applications will close on **Monday 15 March 2021**.*



Masonic
Charitable Foundation

Financial support for Ataxia UK from Freemasons

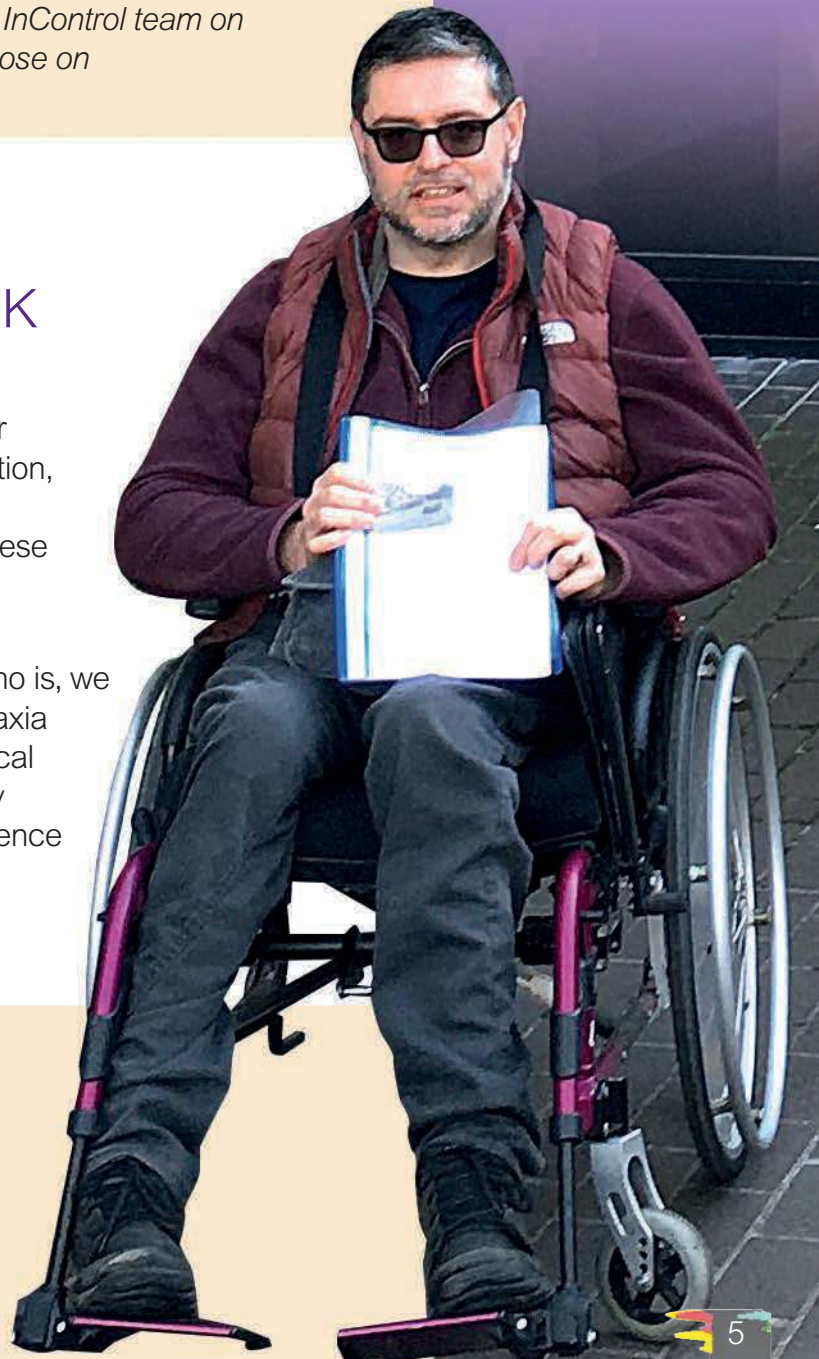
Due to high demands, it is difficult to gain small or large grants from the Masonic Charitable Foundation, however, we often get small amounts of financial support from local Masonic Lodges in the UK. These small grants can mount up over the year and any support is always appreciated.

If you are a Freemason, or you know someone who is, we will be very grateful if you will consider putting Ataxia UK forward for a small support grant from your local Lodge. In these difficult times, where every penny counts, these small grants can make all the difference to us in maintaining our much-needed services.

If you can help, please let us know by emailing office@ataxia.org.uk.

Well done, Richard!

We are so pleased and proud that **Co-Chair of Ataxia UK, Richard Brown** (right), has been appointed an MBE in the New Years Honours for services to people with disabilities. Congratulations, Richard. Very much deserved!





New projects aim to understand SPAX8

We are pleased to announce the funding of two projects on a rare type of ataxia called spastic ataxia 8 (SPAX8).

A PhD Studentship has been awarded to **Dr Viorica Chelban** and **Prof Henry Houlden** (above) at **University College London (UCL)**, and funding for a research project has been awarded to **Dr Jacques Tremblay** (right) at **Laval University, Canada**. These grants were made possible by a donation of over £100,000 from the DVS Foundation (www.dvsproperty.com/foundation).

SPAX8, which leads to stiffness and problems with coordination, is caused by mutations in a gene called NKX6-2. There is currently no treatment for SPAX8, or way to reliably measure its progression.

In their project, Dr Chelban and Prof Houlden (who identified the gene causing SPAX8) will conduct a natural history study using clinical information from people with SPAX8. A natural history study involves collecting health information over a period of time in order to understand how a condition progresses. They will also use samples (blood samples) from patients to find an accurate way of measuring the progression of the condition.

Dr Chelban and colleagues will also study gene therapy for SPAX8 by growing cells donated by patients, and designing ways in which the mutated NKX6-2 gene can be replaced with a healthy version of the gene. They will package the healthy version of the gene into a virus, which is able to infect cells but cannot cause any virus-related health problems. Once the healthy gene has been introduced into the virus, they will carry out tests on the cells to see if this could work as a potential future treatment for SPAX8.

In their project, Dr Tremblay and colleagues will test a different method of gene therapy called gene editing to see whether this can be used to treat mutations in the NKX6-2 gene. DNA is made up of four different molecules called nucleotides, which come in pairs. In SPAX8, there is a mutation which



means that one of the pairs of nucleotides in the NKX6-2 gene is incorrect. The Tremblay group will use a gene editing technique called PRIME editing, where it is possible to change any pair of nucleotides into any other nucleotide pair. They will use this technology in cells with a mutation in the NKX6-2 gene to change the incorrect nucleotide pair, and therefore correct the mutation.

These projects will improve our understanding and begin to develop gene therapies for SPAX8. If successful, the researchers hope to test these gene therapies on animal models of SPAX8 in the future. These techniques are being studied for many conditions and offer hope for the future of gene therapy.

DVS Foundation said: “We are delighted to be working with Ataxia UK and two world renowned institutions in advancing research in this very exciting area of science. Although this research is aimed to advance research in SPAX8 and the gene NKX6-2, if successful, we are hopeful that the methods of science and technology that are being implemented will have a positive impact on advancing research across many conditions.

“Following a chance meeting with Julie Greenfield at the Ataxia UK conference in October 2019, Ataxia UK launched a global call for research proposals and we are able to support research from two different teams.

“We are hugely impressed with the work and dedication shown by the Ataxia UK team. They have positively progressed this project in a relatively short space of time, especially given the restrictions we have all been faced with during much of 2020. Through their experience, specialist knowledge base, and vast global networks of medical professionals and institutions, Ataxia UK have mobilised two cutting edge projects.”

SCA and ARCA Global Conference 2020

The SCA and ARCA Global Conference took place online on 19-21 October 2020. Members of the Ataxia UK Research department attended.

The conference was organised by two ataxia initiatives; SCA Global, an initiative for research in Spinocerebellar Ataxias (SCAs), and ARCA Global, an initiative for research in Autosomal-recessive Cerebellar Ataxias (ARCAs). Dr Julie Greenfield from Ataxia UK is on the steering committee for both initiatives and was part of the organising committee for the conference.

The conference included presentations on laboratory-based and clinical research. There were presentations about different biomarkers for ataxias, including brain imaging, speech, and blood biomarkers. Biomarkers are measurable characteristics that can be used to measure the progression of a condition and to determine the effect of treatments in clinical trials. There were also presentations on clinical trial readiness, as well as updates on trials from pharmaceutical companies. Other sessions included mechanisms that may cause SCAs and ARCAs, and a clinical rating scales training session.

Ataxia UK also attended the ARCA working group session on policies and patient organisation engagement. Overall, it was encouraging to see the progress being made in ataxia research.



Minoryx Therapeutics release results from clinical trial investigating novel FA drug 'leriglitzzone'

Back in October 2019, Ataxia UK reported on a new orphan drug designation granted to Minoryx Therapeutics for a novel treatment for Friedreich's ataxia (FA).

The drug, leriglitzzone, also known as MIN-102, has been tested in cell and animal models of FA and shown to increase levels of frataxin (that is reduced in FA) and protects cells from neurodegeneration. A paper has been published in January 2021.

Minoryx have now released results from their phase 2, multicentre, double blind, placebo controlled clinical trial known as the FRAMES study. During this study, leriglitzzone was tested on 39 patients with FA, 32 of whom completed the study. The results found that leriglitzzone prevented decline in upper limb ataxia in FA patients compared to placebo and was shown to be well tolerated among the FA patients. There was also a reduction in iron accumulation in the brain. The effect of the drug on the spinal cord, the primary outcome measure of the study, was unfortunately inconclusive.

Professor Alexandra Durr, the principal investigator and coordinator of the FRAMES study, says that the drug shows promise: "Clinical results from the Minoryx Phase 2 FRAMES clinical trial are promising. Specifically, the reduction in decline in upper limb ataxia in Friedreich's ataxia patients demonstrate the potential of meaningful benefit in tackling this neurodegenerative condition."

In their press release Minoryx say that full and detailed results from the study will be presented in the next few months. The study data are being used to design an additional confirmatory study. Marc Martinell, CEO of Minoryx, added: "We intend to initiate discussions with regulatory agencies to define the clinical development path forward to deliver this therapy to Friedreich's ataxia patients as quickly as possible."

Find out more at: <http://bit.ly/3sCf1L4>.

Innovative project on speech therapy and online group & peer support

Ataxia UK is pleased to announce the start of this new research project lead by Prof Lowit.

PROJECT INVESTIGATING ONLINE GROUP AND PEER SUPPORT SPEECH THERAPY STUDY

Communication problems are a frequent consequence of ataxia, but there is currently no effective treatment for speech problems that has been properly evaluated. However, a number of small pilot studies have recently demonstrated that speech therapy can help people with ataxia with their communication.

In one of those studies, we demonstrated that speech therapy focusing on good voice production can help some people with ataxia to improve their speech and their confidence in communicating with others. This treatment was delivered online in participants' homes. We are now looking to fine-tune this therapy model in response to participants' comments with another small group of people before investigating its effectiveness on a larger scale. Altogether, participant's involvement will last around four months in total including assessments, six weeks of these involve actual regular therapy input. This study is funded by Ataxia UK and carried out by researchers at Strathclyde University in Glasgow in collaboration with NHS Greater Glasgow and Clyde.

The participants fulfil the following criteria:

- Have a confirmed diagnosis of progressive ataxia
- Experience mild to moderate speech or voice problems, i.e. not be completely unintelligible to people who don't know you very well
- Not have any other neurological or speech problems
- Be aged 16 or over
- Have access to the necessary technology (good internet connection, access to a computer, tablet or smartphone that allows you to use video conferencing software and has a microphone input - we will provide the microphone)
- Have good English speaking skills.

*If you are interested in participating in this research in the future, please contact **James Atkins** on volunteering@ataxia.org.uk.*



Upcoming All About Ataxia online seminar

Over the years, we have run 'All About Ataxia' seminars for people newly diagnosed with ataxia.

They are also useful for others who received a diagnosis a while ago but would like further information and the opportunity to hear other people's experiences. They are based around videos made with the clinicians and therapists at the **Sheffield Ataxia Centre** and presented by people who are affected by ataxia.

The seminars offer the opportunity to:

- Understand the medical implications of ataxia and what can help you.
- Hear how the facilitators have learned to live with ataxia and remain active.
- Learn from other participants how they are facing the diagnosis.
- Understand what support and services Ataxia UK offers.

When the risk of Covid-19 has receded, we will offer the opportunity to attend the All About Ataxia seminars in person. Meanwhile, our next online session will be **Tuesday 18 & Wednesday 19 May 2021** (2 days - 2½ hours per session). Tickets cost £5 each and you can book yours via the website at the at the end of this article.

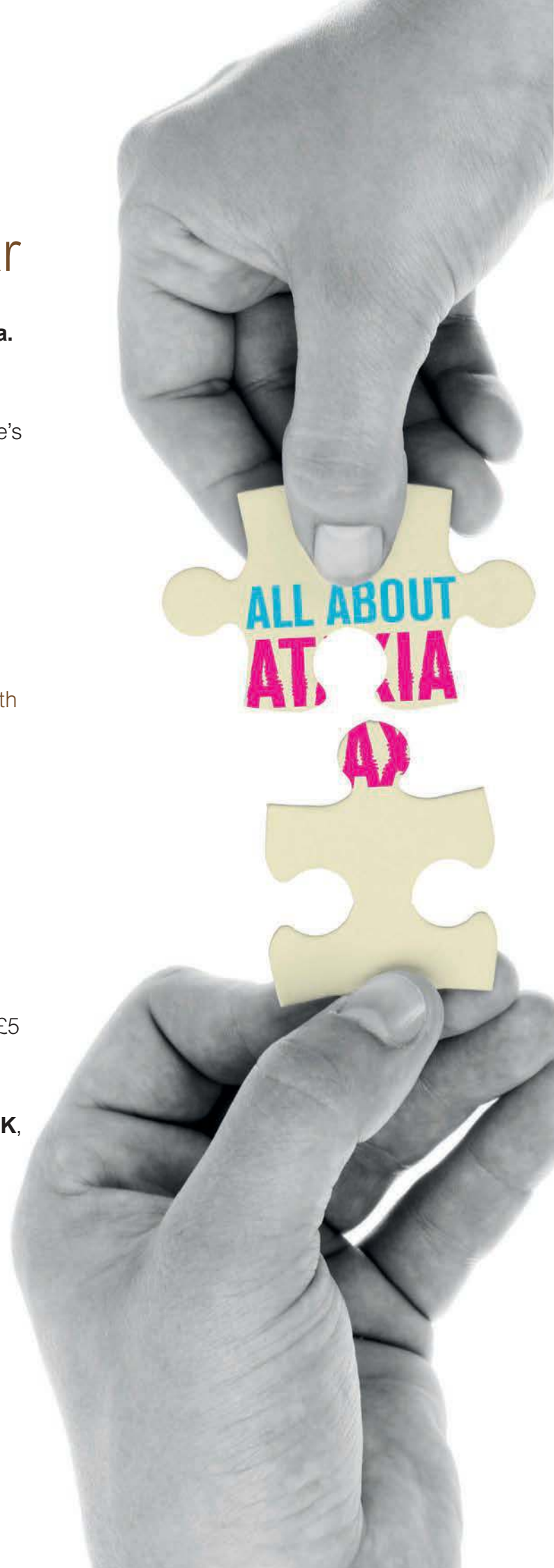
Our thanks to **Robert Perkins, Trustee of Ataxia UK**, who has filmed, directed and edited these videos, and to the staff of Sheffield Ataxia Centre who offered their time to be interviewed.

Previous participants have said:

"Loads of good information", "Our facilitators were very well informed and helped to make the day a success", "Meeting others with ataxia was inspirational".

To find out more information and sign up for the sessions, head to

www.ataxia.org.uk/ataxia-uk-events



Mindfulness with Annabel, our Media Ambassador

We all need to take time to slow down and relax - now more than ever! And what better way to do this than to introduce mindfulness into your daily routine? Whether you are always on the go or prefer a slower pace of life, everyone can make the time to stop, breathe, and slow down busy minds.

WHAT IS MINDFULNESS?

Mindfulness is a form of meditation where you focus deeply on being in the moment, become acutely aware of your surroundings and heighten all the senses you are feeling. It can help to move your attention away from any negative thoughts or stressful feelings and allow you to calm your mind to focus on the present. Practising mindfulness helps you to not become overwhelmed with what is going on around you, and encourages you to pause and take in the environment you are in.

HOW CAN I PRACTISE MINDFULNESS?

Mindfulness helps to slow our reactions to things that happen and allow you to take a moment to process what is around you.

Here are a few ways in which you can practice mindfulness throughout the day:

1. Try and set aside some time, in a place that is calm and quiet.
2. You don't need to do it for a long period of time, especially if this is your first time. Five or ten minutes will do!
3. Become aware of your body. Notice your breathing, your heart rate, how you are sitting, how you are holding yourself. Notice the sensations you are feeling in your body.
4. Focus on your breath, and the sensation when you inhale and exhale. How does this feel? Use your breathing as an anchor to the present.
5. When your mind wanders and thoughts enter your head, try to bring your attention back to your breathing. But don't put too much pressure on yourself - it is natural to think!

You can do this as often as you like, and the more you do it the more you will focus your mind to your immediate surroundings. If you do not have the time to set aside, just taking 20 seconds to concentrate on your breathing can calm your mind and bring back your attention.

It's as simple as that! Practise this and you will be sure to see your stress levels reduced and your attention levels increased.

Head to **www.mind.co.uk** to find more information and techniques on mindfulness.



A Big Give thank you!

Last Christmas, the generosity of the ataxia community helped raise an incredible £71,657!

A huge and heartfelt thank you to everyone who donated, shared our social media posts and supported the Big Give Christmas Challenge 2020. Despite the challenges of 2020, the support you offered during the week of the Big Give Challenge was nothing short of amazing!

Ataxia UK first participated in the Big Give Christmas Challenge in 2017 and, since then, the support received from the ataxia community has been fantastic. Last year was no different. Over 400 Friends of Ataxia UK doubled their gifts to fund vital ataxia research and establish a new Advice and Financial Inclusion service via the Helpline.

The donations made to the Big Give Challenge will provide support in two ways:

1. To ensure the Helpline is able to continue supporting the community throughout 2021 and beyond, extending the service by offering independent financial advice on welfare benefits, employment and housing rights, grants, and tax and debt counselling.
2. To continue funding research into finding treatments and cures for the ataxias to ensure progress isn't impeded by the impact of the pandemic.

Thanks to the feedback last year, we know that the demand for financial information services is vital. The introduction of these services will be even more important in the aftermath of the pandemic and beyond.

Which is why we are so grateful for your support. Your matched gifts will help equip anyone living with ataxia with the knowledge and confidence to improve their understanding and self-management of their condition, along with the financial implications and their rights as their ataxia progresses.

A truly worthwhile service which anyone living with ataxia could need one day.

No matter what life stage you're at, our goal for this new service is to ensure that anyone living with ataxia is not left financially impoverished due to their condition and they are able to confidently progress with their lives in a positive direction - whatever the problem.

Thanks to **your generosity, our match-funders, The Reed Foundation, and Ataxia UK's major donor pledgers**, your gift will help bring significant and positive change to thousands of families living with ataxia.

This could not happen without the generosity of friends like you. We deeply appreciate your support, and on behalf of everyone who will benefit from your generosity - thank you.

Watch this space for more information on the progress of this vital project in the coming months.



Spring Raffle 2021

Everyone's a winner with the Ataxia UK 2021 Spring Raffle. Play Ataxia UK's 2021 Spring Raffle and be in with the chance of winning up to £200 plus lots of other exciting prizes!

Ataxia UK's Spring Raffle is back and inside this issue of the Ataxia Magazine you will find your two Ataxia UK raffle book tickets available to sell to family, friends and colleagues. The annual Spring Raffle raises money for the work we do at Ataxia UK. With every ticket you buy, not only do you have a great chance of winning, but you also support those affected by ataxia in a fun and simple way!

Each book contains 10 raffle tickets and sell for £1 per ticket, 100% of which is guaranteed to help fund Ataxia UK's support services and the ataxia research programme. Sell as many tickets as you can to friends, family and loved ones to increase their chance of winning our wonderful prizes, including vouchers, wine sets and a top cash prize of £200.

It's not just you who could win. By taking part in the Ataxia UK Spring Raffle today you're helping to transform the lives of thousands of people across the UK living with ataxia.

HOW TO PLAY

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

Step 2: Send your cash or cheque amount along with the purchased raffle ticket(s) to Ataxia UK using the enclosed FREEPOST envelope by **Friday 1 May 2021**.

Please note: If you sell all the tickets in your raffle book and would like to sell more tickets you can request more raffle books by emailing fundraising@ataxia.org.uk or call **020 7582 1444**.

Due to lockdown restrictions we understand you may find it difficult to physically sell your raffle tickets to family and friends. So this year, you can also purchase as many tickets as you like and share the campaign with distant friends and relatives by visiting:

www.ataxia.org.uk/get-involved/springraffle.

UK residents only.

*The Ataxia UK 2021 Spring Raffle draw takes place on **Friday 7 May 2021** at **Ataxia UK, 12 Broadbent Close, London, N6 5JW**.*

Chance2Win Winners

1st Prize: £500
Roy West

2nd Prize: £250
Michelle Mytton

3rd Prize: £150
Audrey Fry



Run your way through 2021

We have three excellent runs lined up this year with spaces available, and we are recruiting now. Will you be part of Team Ataxia UK? Not only are they a brilliant way to celebrate your personal story, but you will also be raising crucial funds to help people affected by ataxia whilst achieving your personal fitness goals.

GREAT NORTH RUN: SEPTEMBER 2021

Join #TeamAtaxiaUK for the world famous Great North Run, returning this year and celebrating its 40th event on **12 September 2021**. It is an iconic half marathon with the route going through the Centre of Newcastle, Gateshead and taking in the stunning coastline of South Shields. You can run or take part in your self-propelled and assisted wheelchairs, including racing wheelchairs. *We ask that you pledge to raise £400.*

ROYAL PARKS HALF MARATHON: OCTOBER 2021

Run in one of the UK's most beautiful half marathons on **10 October 2021** by taking part in The Royal Parks Half Marathon. A spectacular run through central London and past world-famous landmarks including Buckingham Palace, Horse Guards Parade and the Royal Albert Hall. This is a flat route where you can enjoy Spring views of four of London's eight Royal Parks: Hyde Park, Green Park, St James's Park and Kensington Gardens. *We ask that you pledge to raise £500.*

MANCHESTER HALF AND FULL MARATHONS: OCTOBER 2021

The Manchester Half and Full Marathons take place on **10 October 2021**. Starting and finishing by Old Trafford, both runs are famous for their fast and flat routes and as being two of the friendliest events you can take part in, with amazing support from the crowd. You can run or take part in your racing wheelchair or a trike and, if you have any questions, just let us know. *We ask that you pledge to raise £400 for the half and £500 for the full marathon.*

We would love you to join Team Ataxia UK and, when you do, we will cover the cost of your place and just ask that you fundraise. You will receive a free running vest and pack, support every step of the way and an exclusive medal at the finish line!

To sign up or find out more about these events and what else we have on offer, contact: fundraising@ataxia.org.uk or call us on **020 7582 1444**. If any of these events do not go ahead, we will ensure that you secure a place in the event's new date, or in another suitable event.



Fundraising thank-yous

Despite all odds, community spirit has still shone through in support of those affected by ataxia.

A special mention goes to **Jenny Southey** and **Kevin Fulcher** who have been community fundraisers for Ataxia UK for many years. From fairs to collection boxes, Jenny and her friends have raised awareness and £5,665 over 16 years, and Kevin has been fundraising since 1996 doing everything from head shaves to auctions and collection tins, raising £1,227. You are both an incredible part of the Ataxia UK team, and we are so grateful for all your hard work and efforts, thank you.

Thank you so much to **Margaret Morris (1)** for her ongoing support, kindly making and selling beautiful cards at her gym for Ataxia UK.

Congratulations to **Evanna Nash** who raised £225 from her yoga fundraiser! Such a great idea and thank you for hosting it Evanna, and to all that took part.

A huge round of applause to **Gary Ward** and **Daniel Mabbett (2)**, who took on their second epic cycle - this time with 500 miles from Edinburgh to Thurso and raising over £4,000!

A huge well done and thank you to all our Wobble Walkers who followed **Emily Barker and family (3)** outside across the UK to walk on 6 December. Thank you so much to all the **Barker and Lawson family**, and to all of you who took part, including **Marcia Toms (4)**, **Ellie Oddy (5)**, **Amy Richardson**, **Faye Clark**, **Jacqueline Barker**, **Craig Lowe** and all your friends and family who came together to raise awareness and over £4,200 plus gift aid!

Happy 30th Birthday and thank you **Cally Benvie (6)** who fundraised on her special day and raised over £700!

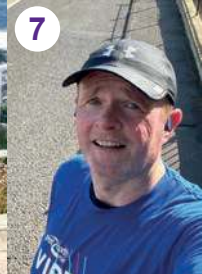
Well done to **Scott Renton (7)** who didn't let Covid-19 postponing the Great North Run stop him, by completing the virtual race and raising £806.

Congratulations and thank you **Paul, Mason** and **Ollie Elliott** who raised over £800 with Ollie and Mason running 25 miles and doing 100 kick-ups every day in December, and dad, Paul, completing a 28-mile run!

Thank you so much **Helen Bridge**, who raised £500 through her company, Helen's Bridge Holidays!

10.5 CHALLENGERS

Thank you to all of our 10.5 Challengers! Including **Patsy Riggs and the Ipswich & Colchester Support Group (8)** who smiled for 10.5 seconds, **Philip Morris (9)** who devised his own triathlon, **Isobel Bowers (10)** who completed an impressive swim, **Harry Cozens (11)** who walked 10,500 steps and **Ellie von Dinther and friends (12)** who walked 10.5km. Congratulations to everyone involved! Together you have raised £11,181 smashing the £10,500 target!



Medication that works for me

Over the 19 years I have been diagnosed with FA, I have tried many medications. This article is based only on my views and what I think works for me.

SUPPLEMENTS

I have tried a few supplements. For example, when I was diagnosed with FA, I took vitamin E and CoQ10. I didn't find this helpful for my ataxia but it caused no harm and at that time it was a new discovery that doctors thought helped. I took vitamin E and CoQ10 until I joined the idebenone trial. Idebenone is a synthetic modified version of CoQ10. During the trial I had to take idebenone only. I continued taking this after the trial but had to buy it from USA through the internet. The drug trial had limited success for my ataxia, but I feel it helped my energy levels. I no longer take idebenone as it became harder to get and it didn't help significantly enough to warrant the cost and hassle.

GABAPENTIN

I saw a pain specialist about two years ago and, after much deliberation, I now take a drug called gabapentin (900mg per day). This drug stops my muscle spasms, controls my pain and reduces times when my legs give way. I think gabapentin is helpful in many respects but not for my ataxia itself. In fact, my ataxia is a bit worse. I am unable to do some little movements in my legs that I could do before. However, for me, the pros outweigh the cons.

OTHER MEDICATIONS

I take bisoprolol and ramipril for my heart, due to another illness, but many people with ataxia take them. I also take tolterodine tartrate which helps reduce trips to the toilet, allowing me a better night's sleep.

Lastly, I take paracetamol with caffeine and a shot of coffee in the morning.

This is based upon my own opinions. It's not a recommendation. Always consult your GP/ neurologist around medication.

See *Ataxia UK Guidelines* (www.ataxia.org.uk/healthcare-professionals/resources-for-healthcare-professionals/medical-guidelines) for more information on medications that can help with symptoms associated with ataxia, such as muscle spasms and bladder issues. These options can be discussed with your doctor. Unfortunately, there are no proven medications to help with the ataxia itself to date. There have been trials of idebenone and Vitamin E and CoQ10 in FA the past, but they did not conclusively show beneficial effects.

If you have any suggestions for articles please email me, James Downie on downstar@mac.com



Lit's wet room has changed our lives for the better

Lit (right) and Ian Smith had their house designed and built in 1998/99 when they knew of Lit's diagnosis of SCA1 and with her long-term needs in mind. But Lit's mobility deterioration during lockdown and shielding highlighted some flaws in their design. Her husband and carer, Ian, explains their story.

We had revamped Lit's bathroom about eight years ago but that design had underestimated her mobility issues. We had a steam shower fitted which was great, but it has a step which made it difficult for me to access to help Lit wash. Before lockdown, Lit could get there herself on her walking frame but she can no longer manage that. We've tried to keep her legs working, so I lead her with me walking backwards.

We were inspired after watching the **Doddie Weir documentary on BBC**, seeing his purpose-built wet room to deal with his motor neurone disease (MND). We found an excellent company, **Absolute Mobility**, to design and carry out the bathroom work. We also knocked the bathroom through into Lit's bedroom to make an en suite (this work was done by Lit's trainer, Marc Scriven, and friends).

The challenge was shielding Lit during this work. She moved in with our daughter, Kate, and son-in-law who live just 30 yards away. But, as Kate is a primary school teacher, we had to complete this work whilst she was at home. Then, when she started teaching in September, Lit moved back home.

We did it with about 48 hours to spare. The wet room includes a shower with a seat and lots of grab rails; a body drier; a low-level sink and grab rails and a Geberit wash dry toilet. I'd never heard of wash dry toilets before the Doddie Weir programme, but it is the best thing we have ever bought. Lit loves it; it has given her some independence and dignity back. And I have to admit, as a carer, I love it too!

This wet room was expensive, and we are very lucky that my job means we can afford something like this. However, it has completely changed our lives for the better and will mean, we hope, that Lit will never need to move out of the house as her condition progresses.

You can find out more about **Absolute Mobility** via their website: www.absolutemobility.co.uk



Tackling loneliness together

The InControl team aims to reduce social isolation and increase mental wellbeing within the ataxia community. As Covid-19 continues to affect our lives, the InControl project intends to keep the ataxia community connected through our range of services and events.

BRANCHES & SUPPORT GROUPS

Support groups are a great way to meet other people living with ataxia and receive peer support as well as sharing handy tips and advice. We've been working to get all our groups meeting online. While meetings are running virtually, they are open to all and not restricted to people living in the local area. Check social media for online meeting dates, or email volunteering@ataxia.org.uk.

FRIENDS CONNECT

Our befriending service is great for anybody who would like one-to-one discussions with someone who has experience of living with ataxia. See p.22 for more information.

VIRTUAL ACTIVITIES

Since the first lockdown, we have run over 50 virtual activity sessions looking at films, TV shows, music and books. The sessions take place every Friday from 1-2pm on Zoom. You can see upcoming sessions here:

www.ataxia.org.uk/latest-news/now-thats-what-ataxia-uk-calls-lockdown

ZOOM SUPPORT

Zoom is an online video call system which allows for individual and group calls. If you have a device with a camera, microphone and an internet connection, you can use Zoom. The InControl team are happy to offer training on Zoom.

VIRTUAL FUNDRAISING EVENTS

Following the success of our virtual quizzes and Bingo, we're planning monthly virtual fundraisers such as games nights. Look out for more details soon.

HELPLINE

Our telephone Helpline is open **Tuesday - Thursday 10.30am-2.30pm** on **0800 995 6037** or via email help@ataxia.org.uk. Whether you're looking for tips and advice or feel you are in crisis, there is help available.

Campaign to End Loneliness: www.campaigntoendloneliness.org/blog/what-to-do-if-youre-feeling-lonely-during-self-isolation

Let's Talk Loneliness: letstalkloneliness.co.uk/advice

Carer's UK: www.carersuk.org/help-and-advice/coronavirus-covid-19

Samaritans: www.samaritans.org or **Helpline: 116123**

More advice and information available on our website:
www.ataxia.org.uk/covid-19/helpful-resources



I'm fine, thanks

We caught up with author, Chris Doveton, about his new book, *I'm fine, thanks*.

A touching memoir exploring one man's journey from grief and destruction to self-realisation and hope. Chris and Anne enjoyed a loving marriage in the prime of their lives, then Anne is diagnosed with Friedreich's ataxia. For ten years, Chris and Anne endure this terrible secret alone. After Anne's death, Chris, ravaged by crippling grief, realises that his survival depends upon him ridding himself of his stiff upper lip. This book pulls back the veil on ataxia and openly discusses the challenges of being a full-time carer. It candidly talks about male depression, isolation and recovery. But, ultimately, *I'm fine thanks* is a story of new beginnings, showing that things can change.

What motivated you to write *I'm fine, thanks*?

I felt compelled to talk about Friedreich's ataxia in the hope that others can learn from my experiences and, hopefully, find solace from opening up and getting support available. I couldn't find another book on this topic, so I hope *I'm fine, thanks* helps other ataxia sufferers and carers in a similar position.

What is the significance of the book's title?

Perhaps one of the most-used responses when asked "how are you?" is a simple "I'm fine, thanks". This ends any conversation and avoids talking about the one thing that should be discussed - how we're really feeling.

Was there a certain part of the book which you found more difficult to work on?

The hardest part for me to cover was, without doubt, when Anne was diagnosed with Friedreich's ataxia at the age of 50 and told by the consultant she only had 10 years to live. Reliving the experience of turning our home into a nursing home was not easy but something that was so vital to my story.

If you could choose one message that readers take away from the book, what would it be?

I hope that the book will provide encouragement to anyone facing illness, sorrow or bereavement. I hope that readers take on board the message that, however dark things are, life can become worth living again. Never give up, even in your darkest moments; there is always hope.

To find out more about Chris Doveton, visit www.chrisdoveton.com.

I'm fine, thanks can be purchased from Amazon (<https://bit.ly/chrisdoveton>), Waterstones (<https://bit.ly/chrisdovetonwaterstones>), Foyles (<https://bit.ly/chrisdovetonfoyles>) or WH Smith (<https://bit.ly/chrisdovetonwhsmith>).



Researching the circumstances of Ataxia UK Friends

We're keen to understand the circumstances of Ataxia UK Friends. A Wellbeing Survey was undertaken by the **InControl Project** last summer. We commissioned the Genetic Alliance UK to write a report and make recommendations based on the 204 responses. Topics covered by the survey included mental wellbeing, interest in volunteering, and experiences during the pandemic. The conclusions supported and complimented separate research we commissioned in late 2019, 'Financial Inclusion Experiences of People with Ataxia', by Nick Hopkins Consulting.

The reports provide a concerning picture of significant unmet needs within the ataxia community. Over 50% of respondents answered 'Never' or 'Rarely' when asked if they felt: 'optimistic about the future', 'confident', or 'useful'. 46% of respondents were 'just getting by' financially; 9% were 'not managing well'; and 3% were in 'deep financial trouble'. 3 in every 10 respondents received 80% or more of their income from benefits; with 35% of people on benefits saying their understanding of the system was 'poor' or 'very poor'.

However, they also provide a picture of the services which Friends feel could be usefully provided by Ataxia UK.

The recommendations are that Ataxia UK should:

- More effectively develop and disseminate information about the financial inclusion issues facing people with ataxia through: our website, emails and magazines, at conferences, and where necessary in print.
- Become more involved in the direct provision of advice through all channels.
- Strengthen the engagement of people affected by ataxia with mainstream advice by providing information and developing referral routes.
- Provide more mentoring/peer support.
- Provide ways to access day to day coping techniques/tailored exercise routines.
- Provide employment advice - how to apply/find suitable opportunities.
- Provide a counselling service; specifically, around issues such as bereavement.
- Provide flexible volunteering opportunities.

Visit our website to read the reports: www.ataxia.org.uk/ataxia-uk-news/wellbeing-survey-report and www.ataxia.org.uk/ataxia-uk-news/financial-circumstances.

PLANS FOR ATAXIA UK SERVICES IN 2021

In response to the reports, and following the successful Big Give Campaign (see p.12), we're appointing a Manager to further develop our Helpline and Information Services, co-ordinate their delivery, manage the Helpline volunteers and staff, and deliver some one-to-one advocacy services to Ataxia UK Friends.



Muhammad's story

Muhammad Shahid leads the Bradford Support Group. He tells us about his volunteering experience.

What's your connection to ataxia?

I was diagnosed with cerebellar ataxia in 2013 at the Specialist Ataxia Centre in London whilst working as a Drug Development Research Scientist (oh, the irony).

What motivated you to become a volunteer?

I was involved with Ataxia UK from my initial diagnosis. I was not a proactive member – staying in the background, perhaps not realising the significance of this condition. I relocated back to my home city after I parted way with my beloved job due to ataxia.

I am a very social person with a desire to help and interact with people, so I started attending the Bradford Ataxia Support Group meetings. Due to health conditions, the leader wanted to step down. Fearing the closure of the group, I volunteered to take the lead in late 2019.

What's your volunteer role?

I am the Bradford Support Group leader. Having said that, everyone in the group is an integral part of group. It wouldn't function without their efforts.

We don't have any hard or fast rules, just a relaxed and casual group atmosphere. I (with the agreement of the group) help to arrange meetings, social gatherings, share information and instigate discussions.

What's your favourite part about volunteering with Ataxia UK?

Working at my personal capacity without being pushed. I must say that this role is very rewarding with regard to personal satisfaction. My favourite part is that I feel like a valued member of group. I am never asked to do anything which I don't feel 100% comfortable with.

How supportive is the InControl team?

All my emails are answered without any difficulty and I get regular follow-up communication. I find it helpful that a framework of support is always a call or email away. When I get a message from the InControl team, I get the sense that it is tailored to me specifically.

Did you have any concerns before volunteering?

I thought it would involve lots of paperwork, pen pushing and bureaucracy but it was nothing like that.

What would you say to others thinking of volunteering for Ataxia UK?

It is very easy-going, rewarding and friendly. Not only is it empowering, you receive free training and it's good for your CV and self-esteem. It's an opportunity to interact with people and form new friendships in a space where everyone understands our situation and condition.

If you are interested in volunteering, see our roles:

www.ataxia.org.uk/get-involved/volunteer-for-ataxia-uk.



Friends Connect rebrand

We have revamped our Telephone Befriending service, now called *Friends Connect*, for 2021.

2020 was a challenging year for everyone. Lockdowns and restrictions across the UK resulted in many people feeling increasingly isolated. This particularly affected the ataxia community as many of you were asked to shield for an extended period of time. Therefore, in response to this isolation, we created a befriending service to provide an opportunity for Friends to have one-to-one calls with volunteers who are also affected by ataxia.

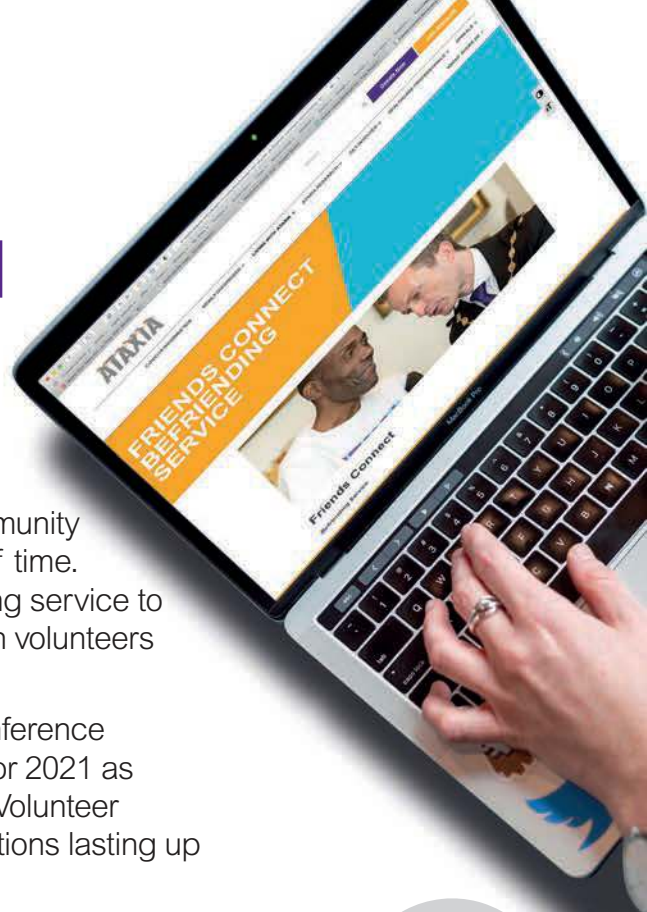
Following some very useful feedback at our Virtual Annual Conference in October 2020, we are relaunching the Befriending service for 2021 as Friends Connect. The essence has stayed the same - we pair Volunteer Befrienders and participants for weekly or fortnightly conversations lasting up to one hour.

But we've made some tweaks to ensure it is easier to get involved, including introducing more communication methods. You can now choose from telephone calls, Zoom video calls or Telegram text messaging service. We suggest starting with a block of four calls and then you can decide if you would like to continue using the service.

Friends Connect has been designed for anyone that is feeling isolated, wants to talk to someone on a one-to-one basis who has experience of ataxia, or even just fancies a social chat and the opportunity to make a new connection within the ataxia community. We always aim to pair people with similar interests to make sure you both get the most out of the calls.

If you'd like to get involved or want more information, check out our updated Friends Connect page on our website (www.ataxia.org.uk/get-involved/volunteer-for-ataxia-uk/friends-connect-befriending-service) or contact the InControl team on volunteering@ataxia.org.uk.

If you know someone who might benefit from the service, please tell them to get in touch.



Ataxia UK HealthUnlocked

Heard of it? It's an online forum for anyone affected by ataxia with over 3,400 all-time users. It is designed to be anonymous and has moderators in place, so you can ask and answer questions within a safe space.

Many people within the ataxia community have expressed their appreciation for HealthUnlocked, so we found out what they love most about the forum ...

Wobblybee

"Ataxia UK HealthUnlocked was my first experience with an Ataxia Support Group. That was way back before others sprang up on Facebook, and it was a revelation, being able to interact with like-minded people who were also looking for information about this rare disease."

Ddmagee1

"I am most thankful for the communication with like-minded people, 'battling' the same problems, or very similar problems, that comes with having these chronic ailments! I receive many good tips, and, sometimes, I comment, with others, concerning advice, and gathering information about ataxia."

Piero

"The site is vitally important for many and varying reasons. For some, its primary value is that it ends isolation, for others it's a source of advice on coping with our condition. Its 'open forum' structure allows for all this and more. Most days I visit this site, if only briefly but when I've done so I feel less alone. I'm reminded that there are many, many people out there battling the same problems as me."

Mari

"I have used the forum for the last few years; it's a great way of connecting with other people who have ataxia. At first I was undiagnosed and it was great to meet and talk to people who have similar issues and were also undiagnosed. I now have a diagnosis but I can still seek advice from other users which has been really helpful. I have made friends and we message each other regularly. I highly recommend this forum to anyone who is affected by ataxia and wants some advice, or even if you want to make some friends."

Visit the forum here: <https://healthunlocked.com/ataxia-uk>



Thank you
to everyone
who has given
a donation
in memory of
a loved one

Leaving a legacy
is one of the most enduring ways
to make an impact

Much of our research
has been made possible
by the foresight and generosity
of our Friends and supporters
who have remembered our work
when making their will

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

Your legacy can be hope for the future