

# ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 212. Winter 2020

## Ataxia Classic ready, set, cycle!



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

# ATAXIA

Ataxia UK

HELLO



Hi, I'm **Ruby Wallis** and I'm the new **Research Officer**. Previously, I studied for a PhD in neuroscience at the University of Sheffield where I researched Parkinson's disease. I also worked as a scientific editor. I'm excited to join Ataxia UK as I love communicating exciting advances in research and helping others!

HELLO



Hi, I'm **Anastasia Georgousis** and I'm the new **InControl Community Programme Officer**, covering **Shana's** maternity leave. I'm really excited to meet many Ataxia UK Friends at the InControl activities we're running, and work with existing and new volunteers.

GOODBYE FOR NOW



We wish **Shana De Figueiredo Scholtz** and **Emily Cutting** the best of luck as they both enter the next chapters of their lives on maternity leave. Our 'virtual' office won't be the same without you and your cheery smiles!

## Welcome

Dear Friends,

**It's hard to believe the changes in our lives since I wrote the introduction to this a year ago; and as the turn of the year approaches, many of us will be glad to see the back of 2020, and look forward to 2021 with hope that it will be different.**

Somehow lots of people affected by ataxia are finding the energy to keep their lives going and support others. See p.4. Others have been lending their support to Ataxia UK itself, to ensure that the charity survives this challenging time. See Fundraising thank-yous, p.14.

Against all odds we held our first Ataxia Classic Cycle in Yorkshire on 27 September, supported by 33 amazing participants and volunteers, to whom we're very grateful. See p.15.

We're looking forward to the Big Give (see p.12 and 13) with hope that our supporters are able to help us meet the target of £60k for research and the development of our information and advice services.

See p.21: I hope that you like Ataxia UK are adapting to the 'virtual world', and are able to join us online for the various events we will be holding during the festive season. Keep your eyes open for the next e-news or look on the website for all our events.

Best wishes, **Sue Millman**



### KEY CONTACTS

- **Sue Millman**  
- Chief Executive  
[smillman@ataxia.org.uk](mailto:smillman@ataxia.org.uk)

### Services

- **James Atkins**  
- InControl Community Programme Manager  
[volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk)
- **Sheila Benneyworth**  
- Helpline and Membership Officer  
[helpline@ataxia.org.uk](mailto:helpline@ataxia.org.uk)  
0800 995 6037

### Research

- **Dr Julie Greenfield**  
- Head of Research  
[research@ataxia.org.uk](mailto:research@ataxia.org.uk)

### Fundraising & Communications

- **Dan Beacon**  
- Head of Fundraising and Communications
- **Kelvin Gichohi**  
- Individual Giving Manager
- **Rebecca Holt**  
- Community Fundraising Manager  
[fundraising@ataxia.org.uk](mailto:fundraising@ataxia.org.uk)
- **Leanna Coleman**  
- Communications Officer  
[communications@ataxia.org.uk](mailto:communications@ataxia.org.uk)  
*For queries or feedback please contact Leanna Coleman.*

### Contact our office

[office@ataxia.org.uk](mailto:office@ataxia.org.uk)

020 7582 1444

Ataxia UK, 12 Broadbent Close  
London N6 5JW

[www.ataxia.org.uk](http://www.ataxia.org.uk)

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## Join a virtual Branch or Support Group meeting



**As lockdowns across the UK continues, Ataxia UK's Branches and Support Groups are continuing support virtually via Zoom.**

Pictured above right is the South London Support Group who met virtually for the second time. It has enabled them to see friendly faces, discuss any concerns and feel connected.

**Tim Kahn, South London Support Group Leader**, said: "I think that by the end of the first meeting, all participants were familiar enough with Zoom that they could do things like unmute themselves when they wanted to speak." The groups will carry on virtually in the months ahead. We recently sent out a survey to find out how some of our groups are getting along with the virtual meeting experience. From the feedback, it was clear that they found Zoom relatively easy to use, and most have been booking their meetings with the Ataxia UK account, which enables a longer meeting time.

**Tony Kaye and Talita Banoori, leaders of the North London Branch**, said: "We are still able to sustain our support to members through the pandemic... We are reaching members who previously we did not see at face-to-face meetings as they were unable to attend meetings in person due to obstacles." The support groups listed below are meeting virtually, please get in touch with the support group leader for more information.

**Derek Taylor, West of Scotland Branch**, said: "I think people are grateful for staying in contact. Some people didn't know Zoom existed, so some set up their own accounts during lockdown to keep in touch with friends and family."

*If you would like to volunteer as a Support Group Leader, or you are a Support Group and would like to deliver virtual group meetings, please contact [volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk)*



Group	Leader	Email Address	Contact number
Bishop's Stortford & Ware	<b>Barry Munday</b>	<i>barrymunday22@outlook.com</i>	<b>01279 843 687</b>
Essex	<b>Dawn Wooldridge</b>	<i>tynckas@msn.com</i>	<b>01268 545 584</b> or <b>07539 061 075</b>
Farnham	<b>Derek Wood</b>	<i>woody1404@live.co.uk</i>	<b>07776 188 877</b>
Ipswich & Colchester	<b>Patsy Riggs</b>	<i>patsy.riggs42@gmail.com</i>	<b>07801 544 974</b>
Leicester	<b>Claire Huggett</b>	<i>chmrh.charjen2@yahoo.com</i>	<b>01162 848 201</b>
Lincoln	<b>Chris Weston</b>	<i>westonchris45@gmail.com</i>	<b>07887 662 667</b>
London North-Central	<b>Barry Munday</b>	<i>barrymunday22@outlook.com</i>	<b>01279 843 687</b>
North West London	<b>Talita Banoori</b>	<i>talitap@icloud.com</i>	<b>07940 166 672</b>
South London	<b>Tim Kahn</b>	<i>1timkahn@gmail.com</i>	<b>07903 599104</b>
Southampton	<b>Gina Lawrence</b>	<i>Gina_Lawrence@btinternet.com</i>	<b>07786 226 404</b>
West County	<b>Becky Downing</b>	<i>westcountry.ataxia@outlook.com</i>	<b>07773 940 586</b> or <b>01392 660 398</b>
West of Scotland	<b>Derek Taylor</b>	<i>ataxiakwestofscotland@gmail.com</i>	

## Mark Dower Trust grant

**Thanks to the Mark Dower Trust, earlier this year, Tallulah was awarded a grant to set up a YouTube channel and Emma, a grant for an exercise bike.**

**Tallulah** (right) said: "I was delighted that my application had been successful. Through this I received a fantastic camera, which came with a memory card and a ring light. Since being diagnosed I have wanted to raise awareness about ataxia and life with a chronic illness or disability. Receiving this equipment has enabled me to do so.

This has boosted my confidence when talking about my illness. Knowing that others are going through the same thing and having strangers' comment and share my videos is such a good feeling. Hearing positive feedback from recently diagnosed people is amazing.

I wanted to start my YouTube channel because when I was a young girl; scared and afraid of this diagnosis, I felt like ataxia was unheard of. When I went to university, all the YouTube videos reflected a 'normal' person's experience. I wanted to change this and, thanks to this award, I can."

**Emma** (right) said: "This grant has meant everything to me. Exercise has become a huge part of my life, both for my physical and mental wellbeing. I would go as far as saying it has changed my whole attitude to life.

When lockdown hit, I worried all my efforts at the gym would be wasted. The social aspect of gym classes became important to me, but now I had no choice but to switch to home workouts. My ataxia means I am limited with my range of movements and require support for certain exercises.

Despite ordering a spin bike within the first week of lockdown, it seems everyone had the same idea and I had to wait months for it to become available. Luckily, it was well worth the wait. The bike has exceeded all of my expectations and is in a different league to the ones I'm used to using at the gym. I can't thank the Mark Dower Trust enough."

*The Mark Dower Trust offers a grant to anyone with ataxia between 16 and 30 years old. Mark Dower had ataxia and was fiercely independent. This grant gives the opportunity for others to be independent too. If you would like to apply or find out more information, visit:*

**[www.markdowertrust.org.uk](http://www.markdowertrust.org.uk)**



## Grant awarded to natural history study on spastic ataxias (PROSPAX)

**Ataxia UK is pleased to have awarded a grant to Prof Rita Horvath, University of Cambridge, for her role in the PROSPAX study.**

*We previously wrote about the PROSPAX project in issue 210 of the Ataxia Magazine. This update contains information on how to get involved in the study, and details of a grant awarded by Ataxia UK to support patient participation.*

PROSPAX stands for **PRO**gression chart of **SPA**stic **ataX**ias. The aim of the PROSPAX project is to gain a better understanding of how spastic ataxias progress over time. Neurologists from Canada and Europe (including the UK) are taking part, and will carry out clinical examinations of patients recruited to the study over the course of three years.

This ambitious project includes brain imaging, looking at markers of disease progression in blood, and the development of animal models. The PROSPAX project focuses on ARSACS and SPG7, and will establish research methods that will be applied to other spastic ataxias in the future.

The study is being led by a group in Germany, and is funded by the European Joint Programme on Rare Diseases (EJP-RD), for which the UK is not eligible. Nevertheless, Prof Horvath has joined the project and will run the UK arm of the study.

**Prof Horvath** said: “The PROSPAX project is an important initiative for spastic ataxias, and we are pleased that the UK is able to be a part of this collaborative global effort. Thanks to the grant from Ataxia UK, we can reimburse patients that take part in the study, and we are looking forward to starting recruitment.”

**If you have ARSACS or SPG7 and are interested in taking part in the study, please contact:**

**Rita Horvath MD, PhD** (above right)

Director of Research (Clinical), Genetics of Rare Neurological Disorders  
Department of Clinical Neurosciences, University of Cambridge  
John Van Geest Cambridge Centre for Brain Repair, The ED Adrian Building  
Forvie Site, Robinson Way, Cambridge CB2 0PY  
Email: rh732@medschl.cam.ac.uk Tel: +44 (0) 1223 762092

**Heather Biggs** (right)

Research Project Manager  
Department of Clinical Neurosciences, University of Cambridge  
Neurology Unit Level 5 'A' Block Box 165  
Addenbrooke's Hospital, Hills Road Cambridge CB2 0QQ  
Email: hb292@cam.ac.uk Tel: +44 (0) 1223 331506



## Testing etravirine as a potential treatment for Friedreich's ataxia

**We are pleased to announce that Ataxia UK has awarded funding to an exciting project led by Dr Alessandra Rufini at Fratagene Therapeutics, based at the University of Rome “Tor Vergata”, Italy. Dr Rufini and her team will be studying etravirine and similar drugs as potential treatments for Friedreich's ataxia (FA).**

FA is the most common form of inherited ataxia and is caused by a fault in the frataxin gene. This faulty gene means that lower levels of frataxin protein are produced in people with FA, thereby leading to the symptoms of FA. Therefore, FA treatment aims to increase the levels of frataxin protein.

Recently, researchers have been looking at whether approved drugs for treating other conditions may also be useful to treat rare conditions, such as ataxias. This is known as drug re-purposing. Etravirine is an antiviral drug, which is used as a treatment for HIV. Dr Rufini's team previously found that etravirine increased frataxin protein levels in mice and in heart cells derived from people with FA, suggesting that it might also be an effective treatment for FA.

In this Ataxia UK-funded project, Dr Rufini and her team will test drugs that have a similar structure or function to etravirine. Three of these drugs are approved as HIV treatments, and one is currently being evaluated as an antiviral therapy. The information gained from this study will allow us to better understand how etravirine increases the levels of frataxin in cells. It's important to understand this when designing and testing treatments. The drugs used in this study will also be tested to see whether they are more effective than etravirine at increasing frataxin. In the future, any drugs identified as more effective than etravirine could be further studied as potential treatments for FA.

The same researchers are currently testing etravirine in a Phase 2 clinical trial to study its safety and efficacy in people with FA. In this clinical trial, 30 people with FA will be treated with etravirine over a four-month period. The researchers will measure the frataxin protein levels present in the participants' blood and the severity of ataxia symptoms before and after treatment. Recruitment for this clinical trial, which will take place in Italy, was completed in July 2020 and we are looking forward to following the progress of this promising drug.



## Physical Activities in Rare Conditions (PARC) project

People with rare, neurological conditions may find it difficult to access physical activity, and it is uncertain which interventions could help people increase their physical activity. The Physical Activity in Rare Conditions (PARC) initiative aims to facilitate engagement in physical activity and exercise for people with rare, neurological conditions, including the ataxias. This project is led by researchers in London (National Hospital for Neurology and Neurosurgery, UCLH) and Cardiff University together with 12 co-investigators in different universities and hospital settings through a grant from the National Institute of Health Research for an exploratory project.

Ataxia UK has been one of the patient groups involved in this study and has two representatives: **Dr Julie Greenfield, Head of Research**, and **Carol McCudden, Ataxia Ambassador**. The project has involved interviews, attending workshops and discussions. The Ataxia UK representatives also provided advice for designing a survey to capture information on the current level of physical activities, and questions around potential challenges and barriers to being physically active. Ataxia UK circulated the survey to capture opinions from people with ataxia and their carers. Thank you to all Friends of Ataxia UK who participated.

In total, survey data from 225 people with rare, neurological conditions and carers, including 60 people with ataxia, were analysed. The results found that most people participated in regular physical activity but needed motivation to maintain regular activity. The survey also found that many people felt they lacked the required knowledge to keep physically active and that resources and support were lacking. A second survey was designed and circulated to healthcare professionals to get their input, who overwhelmingly agreed that people with rare, neurological conditions should be physically active but there was a lack of evidence and resources. Rare disease charities were also interviewed about barriers to physical activity. These interviews found that there were three main barriers: 1) healthcare organisation and inaccessible community exercise facilities; 2) healthcare professionals and carers lacking the required knowledge; and 3) individual physical, cognitive and psychological challenges.

The PARC project explored current practice, care pathways and research sites, and made key decisions in relation to the design of a future physical activity intervention trial (including how to measure the outcome of the intervention). The aim of the PARC project was to gather information prior to developing the PARC intervention. A funding application has been submitted to develop and test it out. The intervention would be a self-management programme to support physical activity in rare, neurological diseases, including ataxias, with a focus on increasing the wellbeing of people with rare neurological conditions. We will let you know whether the funding for this intervention is successful.



## Ataxia UK and CureDRPLA are launching a patient registry

We are delighted to announce that Ataxia UK and CureDRPLA are the lead organisations in The **CureDRPLA Global Patient Registry**. This registry aims to collect data from Dentatorubral-pallidoluysian atrophy (DRPLA) patients worldwide. DRPLA patients, families and caregivers will be asked to complete a series of questionnaires to include information on diagnosis, medical history, willingness to take part in research, functional mobility, quality of life and health economics. The CureDRPLA Global Patient Registry has been set up to better understand DRPLA progression, monitor the quality of health, and as a way of informing people of the opportunity to take part in future clinical trials. We will advertise the registry, once it is live, on our social media and the Ataxia UK DRPLA support group on Facebook. To join the Facebook group please visit:

[www.facebook.com/groups/787219575010909](https://www.facebook.com/groups/787219575010909)

Other than the patient registry, the DRPLA Research Programme is developing other initiatives too. We are working with researchers and pharmaceutical companies to develop potential treatments for DRPLA, with a special focus on antisense oligonucleotides and gene therapy. If you would like to know more about our work, please watch the talk by **Dr Silvia Prades**, Ataxia UK's Research Officer, for the DRPLA programme, from the Ataxia UK conference. You can access the recording here:

[www.youtube.com/user/AtaxiaUKonline](https://www.youtube.com/user/AtaxiaUKonline)



# Let's talk about diagnosis ... the results!

**Thank you to everyone for joining our social media campaign to get 'ataxia' out there – together you raised so much awareness.**

Just like every year, for International Ataxia Awareness Day 2020, we campaigned across social media to raise awareness of ataxia and this year we focused on the challenges around an ataxia diagnosis.

Thank you to everyone who completed our survey and shared the experiences of your ataxia diagnosis. This helped to portray the rarity of ataxia and how vital it is to be recognised by medical professionals in order for improvements around diagnosis.

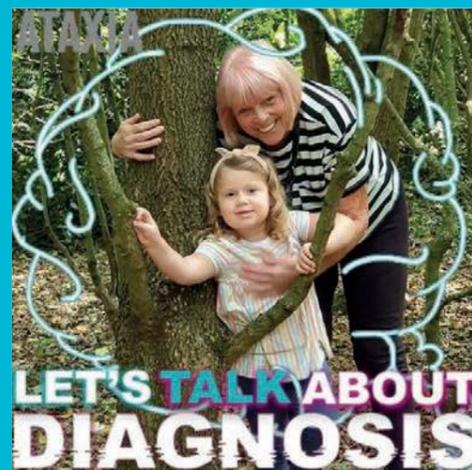
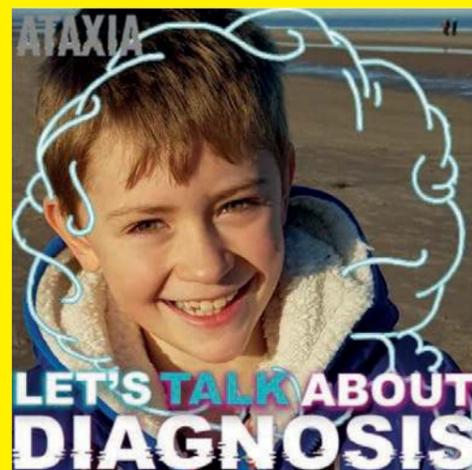
On Facebook, we shared stories from people with ataxia and their diagnosis story (plus a whole lot of other posts around ataxia). Over the week of International Ataxia Awareness Day, we reached over 30,000 people, which means over 30,000 people saw the word ataxia. Four of the stories that we shared reported that over 800 people clicked on one of the stories, which means over 800 people have read about ataxia and its difficulties of being diagnosed.

On Twitter, we tweeted the same content, including stories from the ataxia community, and findings from our survey. Around the same week reported from Facebook, our tweets have been seen 17,100 times, likely by different people to those on Facebook. This is incredible awareness of ataxia.

Then on Instagram, we posted less content, but our posts were seen over 10,000 times over the week of International Ataxia Awareness Day.

Our Twibbon frame was used over 400 times, which means ataxia on the frame has been seen by the friends of 400 people... that's a lot of people! A big thank you to Andy Hopkinson for creating the frame.

Friends of Ataxia UK shared their diagnosis stories on social media, while some of our partner organisations joined the campaign to raise awareness too. Whether you changed your photo, shared your story or shared our posts; you have contributed to the thousands of eyes who have seen *ataxia* this International Ataxia Awareness Day.



## B . R . A . I . N . *by Karen Wilson (right)*

**In this rather surreal time, we have the choice to either succumb to our fears or pivot our worries to hope, health and gratitude.**

It's a challenge no doubt, so here is an acronym to guide you to discover your happy! I truly believe this has built back the health and joy in my life, since my diagnosis of ataxia.

### B is for Beliefs

Our beliefs shape our everyday thoughts, which has a profound impact on our wellbeing. A victim mentality of "why me / who to blame?" became my every day, until I realised how damaging it was. Try to catch negative thoughts and challenge yourself to choose a different outlook. For me, I choose to believe I am worthy of living a happy, healthy life full of love and bucketfuls of belly laughter. My future will not be defined by my past trauma.

**Ask yourself: What do I want to believe about my life?**

### R is for Rest and Rejuvenate

At night our brains detox through our glymphatic system and our bodies work to repair and heal. Therefore, you need a re-charge of seven to eight hours. Create a relaxing bedtime routine; try to replace screen time with a relaxing bath, book, meditation or gratitude journal. **Write down your bedtime routine ideas to test them.**

### A is for Active

If boosting your mood, focus, strength, balance and energy appeals to you, then engage in creative ways to explore these two tiers safely. I love variety, so I mix up exercises like, physio, yoga, dog walking, gardening, a crossword or Sudoku. **What could you explore each day to challenge yourself both physically and mentally?**

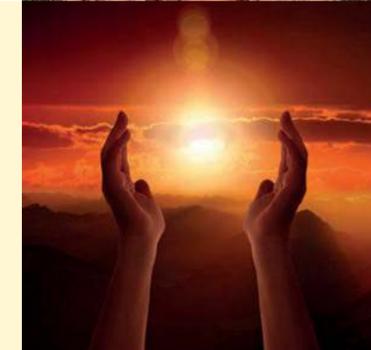
### I is for Irrigation

Water is life. On a cellular level, it is integral to our health, so let's all stay hydrated! Aim to drink 2L of water throughout the day. **Try it for 30 days, and ask: How do I feel?**

### N is for Nourish

Switching my nutrient-poor diet to a rainbow plant food one has been a game changer. Ask yourself ... **Which nutrient void foods can I cut out? Which fruits, vegetables, nuts, herbal teas and spices can I add in to nourish my body?**

**Don't feel limited by your circumstances, be kind to yourself and stay curious. Don't feel bad if your ideas don't go to plan. Dust yourself off and keep trying until the hard work sticks (according to research, three weeks to break habits).**



# The Big Give 2020 Ataxia UK Christmas Challenge

**One week, one donation, double the impact**

**Save the date: 12pm, Tuesday 1 Dec - 12pm, Tuesday 8 Dec**

Since 2017, your matched donations through The Big Give Christmas Challenge has achieved some amazing results. From the establishment of the Ataxia: 16-30s group – a thriving platform for young people affected by ataxia to meet online and talk about similar issues, to the funding of the UK's first ataxia paediatric clinic at the Sheffield Ataxia Centre; your matched donations have raised, in total, an incredible **£151,452** to help support families living with ataxia and fund ground-breaking ataxia research.

## WHAT CAN YOUR DOUBLED DONATION DO?

**Between 12pm on Tuesday 1 December and 12pm on Tuesday 8 December** we are calling on your support to help double your donations and raise **£60,000** to expand helpline advice services for people living with ataxia, and fund ataxia research. Our goal for this campaign is to ensure that people with ataxia understand, in detail, the relationship between the impact of the condition, its progression, and the benefits they're entitled to, and if they need support to appeal decisions we will be there to guide and support them. We want to enhance the Helpline service by providing access to independent advisors who understand what ataxia means, and can advise on how you can move forward with your financial affairs.

This is just one example of the support you can help make possible, other areas include:

- Employment and pension rights
- Advice and support focused on housing rights, aids and adaptations
- Accessing accurate information about potential entitlement to different benefits, about how their condition relates to and triggers that entitlement
- Provide information about sources of mainstream advice to people with ataxia facing debt issues.

**You can help establish this service - which any one of us might need one day.**

In these challenging times, we have no doubt the demand for these kind of information services will grow over the next few months and years in the ataxia community, as it will across society as a whole.

You can help provide people living with ataxia, the knowledge and confidence they need to find their way forward.



[www.ataxia.org.uk/the-big-christmas-challenge-2020](http://www.ataxia.org.uk/the-big-christmas-challenge-2020)

## HOW DOES THE BIG GIVE CHRISTMAS CHALLENGE WORK?

Donate between 12pm on Tuesday 1 December and 12pm Tuesday 8 December to **DOUBLE** your donations and help raise **£60,000** to fund:

- The Ataxia UK **Helpline** to ensure it remains fully staffed throughout 2021 and beyond
- An **Advice and Financial Information Service** providing financial assistance to families affected by ataxia, during the lockdown and current recession
- **World-class ataxia research** into finding treatments and cures for the ataxias.

Thanks to the commitment of our pledge donors and the support of our Champion funder, **The Reed Foundation**, from **Tuesday 1 December until Tuesday 8 December**, Ataxia UK will have a **match pot of £30,000 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 2020 Big Give donation page: [www.ataxia.org.uk/the-big-christmas-challenge-2020](http://www.ataxia.org.uk/the-big-christmas-challenge-2020) from **12pm on 1 December until 12pm on 8 December** to double your donations.

If you are a UK taxpayer, please tick the Gift Aid box when you donate online, as your donation 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 our goal of raising **£60,000**.

**PLEASE NOTE:** Unfortunately, we are not allowed to help you process donations to the Big Give via telephone or accept cheques during the week of the Challenge. Your gift will **NOT** be matched if you donate online after these specific dates, or if you decide to send a donation by cheque.

So, if you are planning on making a gift to Ataxia UK this year - **make the most out of your donation, at no extra cost to yourself** by clicking our Big Give donation page link between the 1 and 8 December.

**Your donations will go a long way towards protecting and improving vital services for the most vulnerable people in our community.**

## HOW IT WORKS

### STEP 1

Click the donation link here, between **12pm on Tuesday 1 December and 12pm Tuesday 8 December ONLY**

### STEP 2

You donate, say **£50**



### STEP 3

Our major donor pledgers and champion donor: **The Reed Foundation** match your donation with another **£50**



### STEP 4

And if you tick the Gift Aid box, you'll add a further **£25** at no extra cost!



## RESULT:

**£50 becomes £125!**  
**MORE THAN DOUBLE THE IMPACT!**

## Fundraising thank-yous

**Congratulations and a big thank you to our wonderful fundraisers for your creativity and commitment!**

Thank you to **Holly Ryan (1)** and the **ladies at Liverpool John Moores University Women's Rugby Union** who walked over 800 miles and raised £400 in memory of their dear friend, **Emily**.

Well done to **Ashley Benvie (2)**, her partner **Lillian** and dog **Misty** who covered 300 miles in 30 days – over 600,000 steps! Thank you, ladies and congratulations on raising £310!

Thank you to **Claire Jane (3)** who raised £344 by spending a whole month doing active challenges, with everything from walking to dancing!

A big round of applause to **Liam Foster (4)** who had the whole of Sproatley Village supporting him for his first marathon in support of his family friend with ataxia, raising £425!

A very Happy 50th Birthday and thank you to **Anita Robertson (5)** who chose to celebrate by fundraising at her party and raising £400!

Well done to **Neil Weaver (6)** who virtually rowed over 100km from Otley to Retford and back, raising over £200!

Congratulations **Seb Hardy** and **Dan Anderson (7)** for completing a 100km trek of the Peak District to support Seb's cousin, **Aila**, and raised £475!

Thank you so much **Phil Hughes (8)**, who shaved his head and beard to support his granddaughter **Molly**, raising £2,465!

Thank you to the band **Erica**, their Manager **Jez Sprigg**, and our Patron **James Moore** for taking donations from their song, Not Alone, raising £210!

Happy Birthday and thank you to **Ellie Thompson** and **Phil Maries** who fundraised for their birthdays, raising £230 and £357.81 respectively!

Thank you to **Tina Lysford** who creatively held an online charity event week and collected donations in exchange for her drawings, raising £877!

Congratulations to **Michael (Shads) Palmer** and **Julian Phillips** who completed an impressive 24 hour virtual climb of Everest and raised £150!

Thank you so much **John Iuan Jones** who held a beautiful classical concert in memory of **Scarlett**, raising £767!

A big thank you to **Janice** and **Roddy Souter** and their wonderful friend, **Kathleen Robbie**, who raised £7,000 by organising a Going for Gold themed Ladies Day!

A big shout out to **Lucy Capps** (right) who cut her beautiful long locks to support her brother **Jack**, raising £363! Thank you so much Lucy - we look forward to seeing your new do!



### Chance2Win Winners

**1st Prize: £500**  
**John Atkinson**

**2nd Prize: £250**  
**Martin Wagstaff**

**3rd Prize: £150**  
**Gary Groves**  
*Gary has kindly donated his winnings back to Ataxia UK*

## Ataxia Classic 2020

**Thank you for making the Ataxia Classic an exceptional day.**

On Sunday 27 September, 26 cyclists rode the 56.8km and 100km routes from the beautiful **Kilnwick Percy Golf Club** in Pocklington for the Ataxia Classic. A big thank you to **Gavin Dalton** who tirelessly mapped the routes and imparted local knowledge and recommendations, to Trustee, **Andrew Downie**, who together with **Howard Marshall** and **Richard Bradford** provided event support. It was a very special day bringing staff, supporters and those we support together from across the UK. There was a real spirit of camaraderie from cheering each other from the start line, through the stunning countryside, and up the testing hills to the finish line.

A round of applause to our wonderful cyclists; **Jenny Thompson, Howard** and **Jade Marshall, Malcolm Roger, Tom Barnes, Jennifer Edwards, Lyndsey Sansom, Richard Bretherick, Stephen Wood, Rick Ainley, Jamie Husband, Mel Bailey, Alex Stuart, Andrew Downie, Mark Johnston, Strafford Watson, Alison and Martin Dorsett, Gerry O'Keefe, Gavin** and **Matt Dalton, Simon Jenkinson, Ken Cowdell, Peter Lawley** and **Daren Suggitt**. Congratulations **Laura** and **Tom Hind** and **Lisa Waistell** who completed their Ataxia Classic at home in the Peak District, and to **Victoria** and **Kevin Delaney** in Berkshire! Good luck to **Steve Capps** who will be completing his own soon!

*"We thoroughly enjoyed the day, and big thanks ... for organising such a great event. The highlight ... was the friendliness and camaraderie of the cyclists who stopped for a chat with my son **Zac**, who has Friedrich's ataxia, and my two daughters, who were on the route cheering us all."* **Stephen**

A sterling effort from everyone, who together have raised an impressive £24,960 plus gift aid so far! Thank you too **Trudy** and **Steve Pickersgill** who kindly volunteered, and were heroes throughout the day. Riders were congratulated with their medals and goodie bags including gifts from **Crankalicious, Hebden Tea** and **Tesco** who generously donated to support the cause. Thank you everyone for gearing up to cycle towards a cure. We are in awe of your commitment, enthusiasm and your achievements.

## At Home Superheroes

Congratulations to **Brian Davis** and family (far right), and nine-year-old **Kieran Hankin** (right), who raised a smashing £790 and £2,700 respectively! Brian swam, cycled, walked and skydived, while Kieran, who has Friedrich's ataxia, cycled on his trike at least 2.8km every day, hitting over 70km! Well done and thank you so much.



## Being a dad with Friedreich's ataxia

This issue I thought I would talk about being a dad with ataxia.

I love being a dad; it has changed my life in so many ways. I count myself lucky and don't take being a parent for granted. There have been times which have been so hard, probably the hardest of my life. Other times of complete joy. I have re-evaluated what is important. I have learnt to let more things go and to concentrate on what I can do. Ataxia affects mine and my wife's life so much in so many ways; I really try to not let it affect Liam's too much. He knows that there are things we can't do together, and I think now that he is starting school and as he sees what other kid's dads can do, he might be disappointed and frustrated, as I can't do traditional 'Dad' stuff.

When Liam was at pre-school, I was asked to go in to chat with the kids, as they had been asking about Liam's daddy's wheelchair. I told them about ataxia and that my legs and body don't do what I tell them. Kids are very accepting and I believe the next generation will accept and understand disability better than our generation. The kids just wanted to know what the buttons on my power-chair did!

During lockdown, although not easy for anyone, I got to spend quality time with Liam, which I might not have again. Our relationship definitely got stronger. Last week was the first time we left the house just us two with no back up. My wife is now back at work part-time and I am doing the school run twice a week, on my power-chair with Liam on my lap. I have, only recently, had the confidence he will listen and come to me when called. He has just started school and at the moment he loves it - I'm not sure if he will listen or sit on my lap on a rainy morning in January!

Hope everyone is safe.

If you have any suggestions for articles please email me, **James Downie** on [downstar@mac.com](mailto:downstar@mac.com)



## Responsible Travel

Although travel is not an option for everyone right now, we talked to **Justin Francis, Co-founder and CEO of Responsible Travel, a travel company committed to making tourism a more caring and accessible industry: [www.responsibletravel.com](http://www.responsibletravel.com)**

### What's the idea behind Responsible Travel?

I love travel but too much of it damages the environment, culture and communities. I believed tourism could create better places to live in and visit.

### How do you follow through as an activist travel company?

We've campaigned on issues from aviation to over-tourism and animal welfare. That's included encouraging less flying, stopping orphanage tourism and elephant rides. We've published the first holiday carbon audits, and are pressing for greater carbon data transparency around holidays. I'm also proud of our Trip for a Trip initiative - when someone takes a holiday with us, we fund a great day out for a child.

### Could the challenges posed by Covid-19 and the increase in UK based travel help accelerate improvements for those with disabilities?

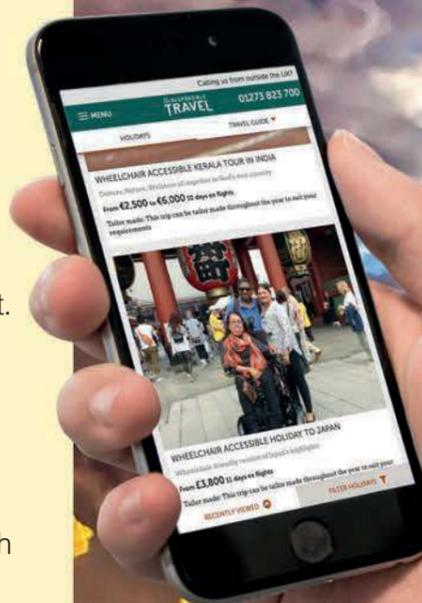
Through the pandemic, we've seen that change is possible and can happen very quickly. And while travel has been devastated by Covid-19, there's a widespread sense that we don't want to go back to how things were - tourism needs to rebuild responsibly. Improved accessibility has to be part of that, but there's a danger it gets sidelined during the recovery. It's important to keep pressing so that doesn't happen.

### How do you get more tourism providers on board?

We've worked to identify specific areas for improvement and hurdles to progress. Part of the problem is an obvious lack of available information - but there's also no universal understanding on what true accessibility means. And while accommodation may be accessible, what about the booking process, the flights, the in-destination transport and sights? Globally, we need to see better industry coordination - and tourism boards need to better plan for, and advise travellers of, routes and sights that meet their needs. Some people and businesses want to do more, but feel daunted and unsure where to start. It's important to show the demand is there, and get people and businesses talking honestly.

### Within England, you have two holidays catering for limited mobility. Will this increase?

I certainly hope we'll see more, and not only in the UK. In travel - and more broadly - there's still work to do to increase awareness, as well as information and infrastructure, on accessibility.



## Sharing experiences

**Uzo contributed to issue 204 of the *Ataxia Magazine* about caring for her husband Chris. Here she shares her new projects.**

A lot has happened since my last article in 2018 - Chris's eyesight and mobility became more compromised, I created *i\_Authentic* and the **Love As Is Marriage** Series, Covid-19 happened to the world ... those were the big things. And yes, there were small things also.

The pandemic and other activities have impacted my perspective on life more than I could think. And Chris? He hasn't allowed the progression of his symptoms prevent him from doing stuff, like attending Bible Institute. We are both in our second year of Bible Institute and it is a great testament to the resilience in our family and the impact the course has had on our lives.

I wrote about life giving us something new to learn. I so believe that will continue as long as one is still alive. We have learned to hold on to our faith more. We learned to enjoy more moments. I learned to find my safe place; my happy place. And when my job contract ended and I couldn't find work, I learned to enjoy being with Chris even more. Then Covid-19 happened and we learned how to enjoy being with our children and enjoy more family life. During lockdown, we found different games to play which included Chris, like the Logo game he loves.

I mentioned my two new creations since 2018 - *i\_Authentic* and *Love As Is*. Well, I always kind of knew that I was meant to share my experiences but I didn't know how. Then last year it hit me - create a forum. *i\_Authentic* is a support forum for people who have partners battling disability or ill health and with young families. There were other forums, but I wanted one where people were like me; working professionals with a young family. I decided to create a safe place for people where we could hang out and share tips. I have a private Facebook for that purpose, as well as being in the process of creating a private page on my website: [www.uzonwuga.com](http://www.uzonwuga.com).

So far, I have released several videos on my website and *i\_Authentic* YouTube channel featuring Chris, our children and guests. Then this year, I felt a new direction for *i\_Authentic*, which is a platform where people share their experiences of having a disabled partner, raise awareness of conditions, and help others know they are not alone. *Love As Is* is as the name implies, loving your spouse as they are - in their disability or ill health. It started off with live videos on Instagram where guests share their experiences, and is now on Facebook. If you feel like sharing your experiences, please contact me on [i.authentic@gmail.com](mailto:i.authentic@gmail.com).

It is empowering to hear how the videos have inspired people. For Chris and me, the impact has been huge. It has strengthened our marriage and our communication has improved greatly. I thought I was aware of my husband, but this is now greatly heightened. We don't feel alone in our challenges as we hear the experiences of others and we learn new things.

*i\_Authentic*



REMEMBER TO  
FILL YOUR  
CUP.  
because you  
CAN'T POUR  
from an  
EMPTY CUP.



Although I have a very busy life, I ensure I create time for myself. Please read my blog *Refill your cup* (<https://uzonwuga.com/blog/f/refill-your-cup>), which talks about how it is important to create and ensure you have time for yourself.

I am very intentional about my time and protect it. Otherwise I would go to pieces. I try not to put myself under pressure because life is already challenging as it is.

I would like to leave you with this - if you can't find what you need, then look at creating the space or platform for what you need.

You'd be surprised how many others are out there like you.

I did it and so can you.

**Uzo Nwuga**



## Pregnancy and labour with Friedreich's ataxia

**We spoke to Lynne, who is 28, lives in Northern Ireland and has two daughters, Alix and Ivie, about her pregnancy journey with FA.**

I won't forget how I was diagnosed. The news was delivered poorly by my neurologist and I couldn't stop thinking: "I will never have children, I will never get to change my baby's bum" - it's funny how our mind perceives things. After some education, I followed some amazing people on Instagram and realised it was possible.

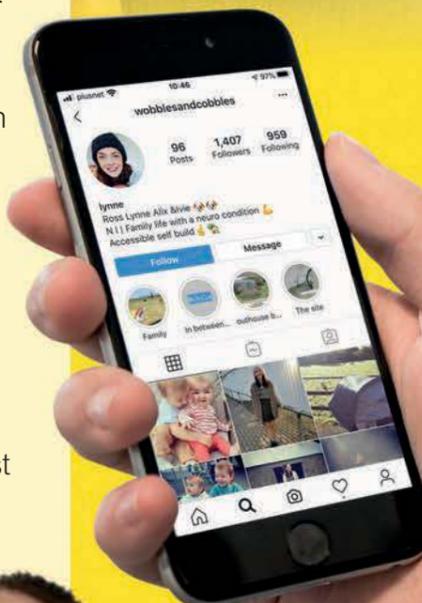
I met my husband at 24 years old. He was the most amazing, positive and inspiring person. I was a bit wobbly, but I realised quite soon that he was 'the one', so I unwillingly told him all about myself and what it could mean for our future. We wanted to start a family right away while I was still independent. I was scared. My husband didn't have genetic testing; we decided FA is autosomal recessive and hoped for the best, and we didn't want a stigma on our baby. We had no trouble to conceive and became pregnant four months after we married.

Due to my low energy levels and advanced scoliosis, I assumed I couldn't push, so I planned to have a C-section. However, I went into a very quick labour the night before the planned birth with no issues and Alix was born safely. It was scary at the time, but I am glad it happened. Recovering from a C-section would have been a lot harder for me. During both pregnancies I have fallen over - at 35 weeks with Alix on a bathroom floor, and at 36 weeks with Ivie and broke my left ankle. They were fine, but with Ivie it was the worst thing to happen me. I gave birth in a cast and was so proud of myself. The pain of a broken bone was worse than labour itself, but my ankle has recovered and it is my confidence that has taken a hit.

The consultant and midwives were amazing. I had gestational diabetes - a common trait in pregnant women with ataxia. I was seen at the hospital every two weeks from 28 weeks, which was reassuring. The nine months flies by and the little baby who sees you as their whole world at the end is totally worth it.

I am trying to raise some awareness through my Instagram:

**@wobblesandcobbles**  
- please follow!



## Supporting the ataxia community

**Since April, our InControl team have been delivering weekly virtual activity sessions on a Friday and everyone is welcome. We are delighted that over 350 people have joined our sessions.**

We look at music, TV series, books and films; all the choices are suggested from the ataxia community. **Emma**, who is one of our regular attendees, said: "It's been 125 days since I last had any physical contact with anyone. It was my sister giving me a hug goodbye after lunch. I am so glad that I found these sessions; it allows me to be a part of something and gives me a purpose for reading/watching a film etc ... learning and hearing the opinions of others. It is just a small thing but it is invaluable to me right now. Thank you, genuinely thank you. This has meant a lot to me so please don't ever doubt that your efforts are completely worth it."

The screen on the right is from a session in September where we imitated playing an instrument for *Brassed off*. To join a virtual activity session, email [volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk)



## Ataxia UK Wellbeing Survey

In June, the InControl Project launched a survey to understand 'wellbeing' among people affected by ataxia, review people's experiences of Covid-19 and find out what services you would like us to develop in the years ahead. We received over 200 responses - thank you to everyone who submitted their feedback.

You can find the report on the Wellbeing survey here:  
[www.ataxia.org.uk/wellbeingsurveyreport](http://www.ataxia.org.uk/wellbeingsurveyreport)

Having analysed the results, the main themes of services you would like us to focus on include:

- Wheelchair/home adaptations guidance - what are the best options for people living with ataxia
- Mentoring/peer support
- Day to day coping techniques/tailored exercise routines
- Employment advice - how to apply/find suitable employment opportunities
- Counselling service; specifically, around issues such as bereavement
- Volunteering opportunities that are flexible to people affected by ataxia.

We are looking at these results alongside the results of the recent survey of the financial circumstances of people with ataxia (more on this next issue), and developing a Services Strategy.

We are looking to grow our *Telephone Befriending service* in line with people's feedback. We have also launched online group speech therapy sessions, which we hope will be attractive to many people as lots of Friends have said their speech has been affected during lockdown and Covid-19.

If you would like to hear more about the InControl team, contact [volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk)



## Virtual Annual Conference

**After a disappointing decision to cancel our Annual Conference this year, we were pleased to host our first ever Virtual Annual Conference over three days.**

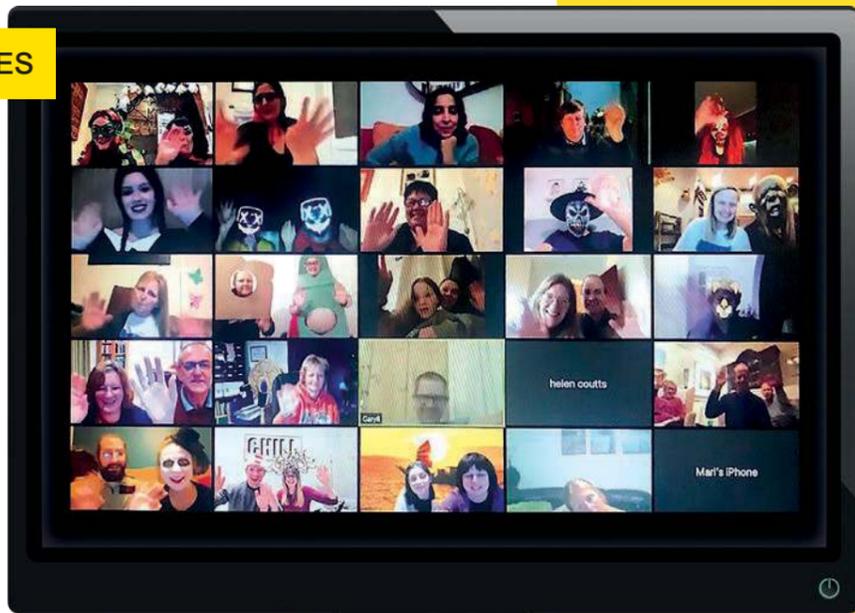
The conference began on Friday 16 October with research updates and doctors' Q&As. There were many new and familiar faces logged on to hear the latest in research, and a variety of questions answered by neurologists and nurses. The day continued with a life update from **Patron of Ataxia UK, James Moore** (right).

If you have attended a conference before, you will know that our Breakout sessions give an opportunity to focus on something in more depth and in a smaller group. Therefore, we are grateful to the speakers who joined to allow the full range of Breakouts to happen, including Coping with Covid-19, Benefits and Grants, Ataxia UK's Constitution, Mindfulness, Speech Therapy, Diagnosis stories, Quarantine Workout and InControl. Delegates saw the first day to a close with a good ole' game of Halloween Bingo with **InControl Community Programme Manager, James Atkins**, raising £200!

We were delighted that our regular host, **Paul Coia** (right), was able to host the second day on Saturday 17 October – this made the whole event feel much more evocative of past face-to-face conferences. The agenda was busy, with inspirational It Works for Me sessions from **Friends, Georgia Hart, Emma Buckett** and **Mari Akhurst**, and **Trustee, Robert Perkins**. There were updates on various projects; the Financial Inclusion by **Researcher, Nick Hopkins**, and **Senior Financial Wellbeing Officer at Scottish Huntingdon's Association, Jo Baldock**. The Wellbeing Survey was reported on by **James Atkins** and **Genetic Alliance's Dr Jennifer Jones**. We were joined by **Dr Ossie Stuart** for an important talk on why Black Lives Matter to those with disabilities, and **Kyle Bryant** talked about his inspirational journey with ataxia. Day two finished with a Classic Comedy session hosted by **Trustee, Tony Kaye**, and **International TV Comedy Scriptwriter, Brad Ashton**!

To round off the conference, on Monday 19 October, **Dr Santosh Mordekar** (right) gave an update on the **Sheffield Children's Ataxia Centre**. Then our **Birds of a Feather** sessions grouped together people with the same type of ataxia, or those in a similar situation. Thank you to all who joined us. During a time where we cannot get together as we usually would, it was wonderful to see so many faces - new and familiar, and we hope you enjoyed it, too.

*If you missed the Conference you can find recordings of sessions here:*  
**[www.youtube.com/user/AtaxiaUKonline](https://www.youtube.com/user/AtaxiaUKonline)**



## All About Ataxia

*by Dr Harriet Bonney, volunteer facilitator*

All About Ataxia seminars aim to give people affected by ataxia (patients, carers/family members) information about ataxia: what ataxia is; how it may progress; what can be done to mitigate its effects. This is done by showing a series of videos made in collaboration with the neurologists, nurses and therapists associated with the Sheffield Ataxia Specialist Centre.

Due to Covid-19, this year's seminar, which is usually delivered the day before a regional or national conference, moved online. On the 6 and 7 October, staff and volunteer facilitators from Ataxia UK were joined on Zoom by 11 people affected by ataxia to talk, listen and discuss all about ataxia. There was a range of ages and of ataxias, with locations being far reaching, including all parts of the UK and Russia!

As well as learning from the videos, everyone had the opportunity to share their diagnosis journey and exchange experiences and tips of how they manage their own ataxia.

People's honesty and candour in these seminars is always humbling and refreshing, and this one was no exception. Feedback was very positive, and three participants have even volunteered to help deliver further sessions. What a great couple of days they were! Watch this space for the date of our next Zoom seminar ...



## Two Volunteers needed to help support Friends

**Do you have experience of making grant applications to Trusts or Foundations? Have you worked in an advice centre such as Citizens Advice?**

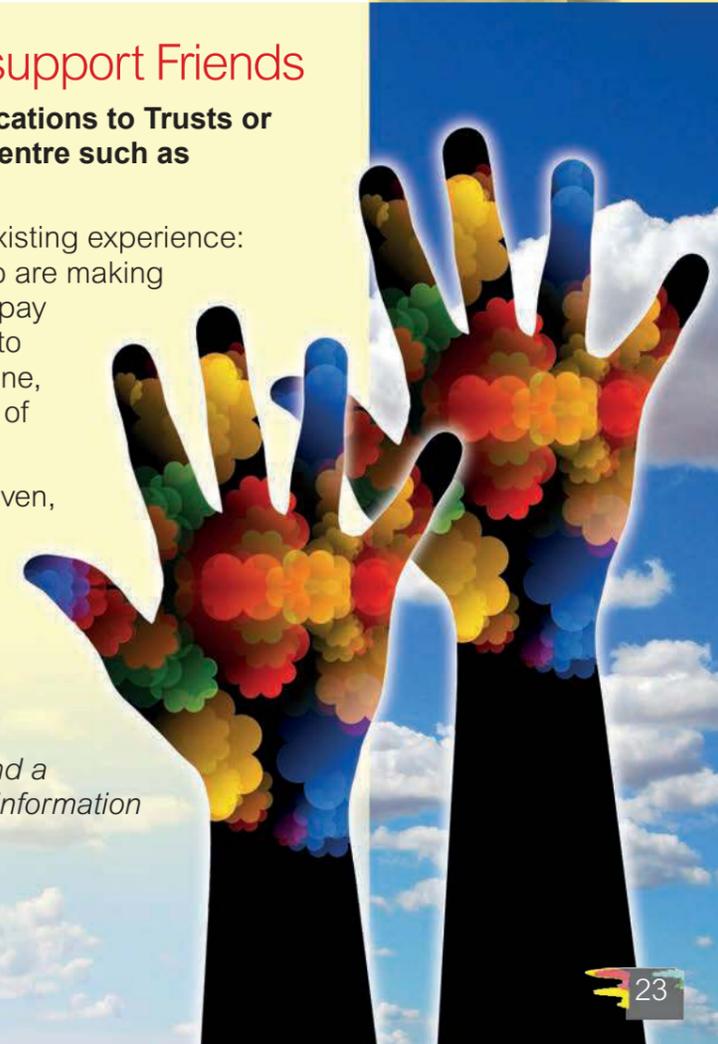
Ataxia UK is looking for two volunteers with pre-existing experience: a Grant Support Volunteer to support Friends who are making applications to Trusts or Foundations for funds to pay for aids or adaptations; and a Helpline Volunteer, to undertake a shift per fortnight, answering the phone, and dealing with Friends enquiries about a range of issues including benefits.

Training in the practicalities of each role will be given, including training to enable an advice worker to be able to work on the phone. Regular supervision and support will also be provided.

The successful candidates will need to become accredited as InControl Volunteers.

*For more information please go to **[www.ataxia.org.uk/News/roles](https://www.ataxia.org.uk/News/roles)** where you will find a detailed role description for each post and more information about volunteering with InControl.*

*If you are interested in either role please contact **[volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk)***





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

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

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

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

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