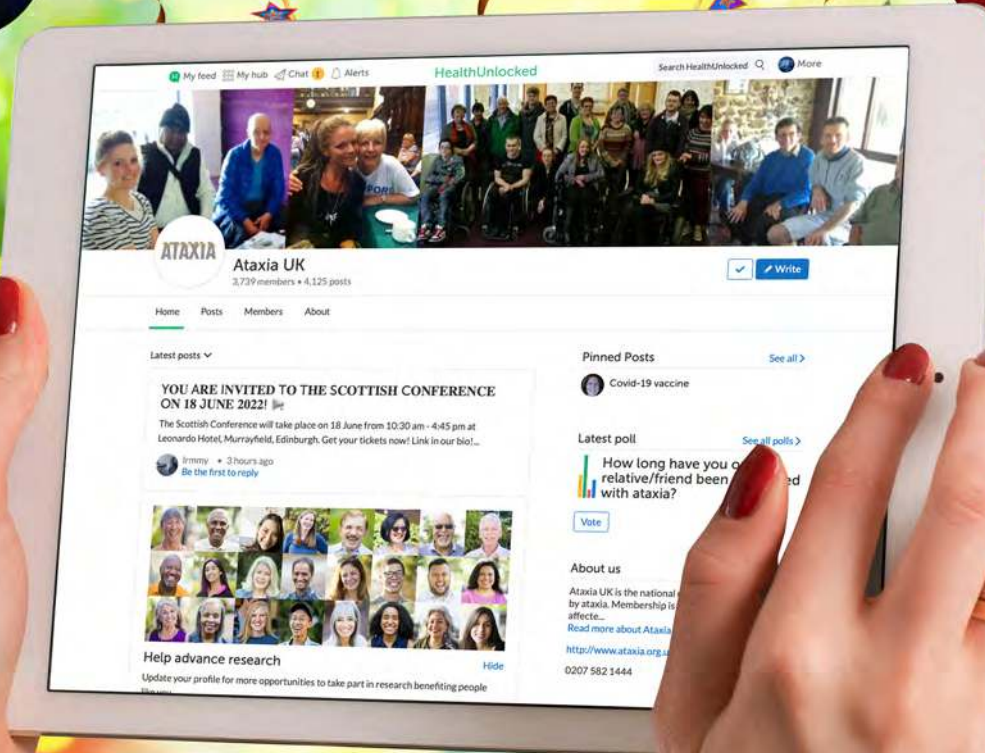


# ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 218. Summer 2022



Happy 10th Birthday  
Ataxia UK on HealthUnlocked

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

**ATAXIA**

Ataxia UK



### Welcome to Viktor Elzer

Viktor joins us as the **Communications Manager** and brings with him a wealth of knowledge and experience from his most recent role at Richer Sounds.



### Welcome to Jessica Sugden

Jessica will be joining the Services Team as **Helpline and Advocacy Officer**, providing advice, information and support to our Friends in the ataxia community.

### Welcome to Kieran Fearnley

Kieran joined us in May as the **Individual Giving Intern**. One of the key tasks that he will assist with is ensuring everyone is thanked quickly for their generous donations.

# Welcome

Dear Friends,

It was a tough call to make the decision to convert this year's **Annual Conference** to a virtual event – I know there are lots of people clamouring for the opportunity to meet. You can read why we took the decision in the article on p10. I know there isn't long to go before the **Scottish Conference**, but do consider coming if you can; we have laid on a varied agenda, and you will be amongst a group of friendly people to whom you won't have to explain ataxia!!

We have a number of changes at the office and are pleased to be getting back towards a full staff compliment enabling us to maintain not only our **Helpline services**, but also provide **Advocacy for Friends** who need our support. These services are especially important in these times of austerity and inflation and we will be continuing to develop them over the next few years to meet the needs of the ataxia community. Any fundraising you can do to help this work is very much appreciated and we are grateful to all those who continue to financially support us.

Hoping to see you in Edinburgh.

Best wishes, Sue Millman

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



## KEY CONTACTS

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

### Services

- **Wendy O'Mant**  
- Head of Services  
[womant@ataxia.org.uk](mailto:womant@ataxia.org.uk)

Contact our helpline:  
[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
- **Rebecca Holt**  
- Events and Community Fundraising Manager  
[fundraising@ataxia.org.uk](mailto:fundraising@ataxia.org.uk)
- **Viktor Elzer**  
- Communications Manager  
[communications@ataxia.org.uk](mailto:communications@ataxia.org.uk)

*For queries or feedback please contact Viktor Elzer*

### 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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## Why I became a trustee

### Rachel Harrison

Hi, I am Rachel. I was elected as a trustee of Ataxia UK last summer and formally joined the board at the last AGM in November 2021. I have been involved with Ataxia UK for 20 years and first attended a conference in 2002 in Blackpool. I have been inspired by so many people in the Ataxia community, whether it be fund raising for the charity or achieving goals in life that are made more difficult by ataxia.

So why now? With the pandemic the board has been operating online. My ataxia is now at a point where travelling is difficult (particularly fatigue). The board has agreed that meetings will either be online or hybrid. I hope that in the future this will encourage others in the community who have useful skills but are limited by ataxia and/or location.

There is a lot of reading to do as a trustee. There is a lot to learn about running an effective charity. Both Ataxia UK and the charity commission provide a lot of useful information. I feel that my 'world' has grown with this opportunity, especially having been even more isolated throughout the pandemic; it is a challenge, but one I am enjoying.

### Angela Hosie

I became a trustee of Ataxia UK last year and was delighted to be appointed to the Board at the AGM in November along with fellow new trustee Rachel Harrison. I became more closely involved with Ataxia UK's activities in the last couple of years, whilst I have been a friend of Ataxia UK for 10 years I had previously been working almost fulltime.

When I saw last summer that Ataxia UK had advertised for the upcoming trustee vacancies with the departure of 2 long-serving trustees at the end of their term of office I felt drawn to find out more and excited at the idea that my skills and previous experience could be useful to the charity.

There are many statutory duties the Board hold, and responsibilities it must hold the charity to account with - and these cannot be understated. However the work that the Board does is crucial in helping Ataxia UK improve the lives all those affected by ataxia - and this part of the role really drives me!

The impact of items on the Board's agenda each meeting is significant and has the potential to be life-changing for those with ataxia. In making informed decisions about supporting research proposals into diagnosis and treatment right through to supporting Ataxia UK's senior management in the services they provide to Friends on a daily basis, such as the Helpline and InControl project - these decisions on allocating funds and resources well really do make a difference.

## Have you the vision, commitment and experience to be a Trustee of Ataxia UK?

**The Trustee Board governs and sets the strategic direction of Ataxia UK. The Board is made of up Friends of Ataxia UK; seven who are elected by Friends of Ataxia UK and three who are appointed by the Board.**

We have vacancies on the board for Trustees. There is an additional place for someone with fundraising or marketing experience who will be appointed by co-option. All posts are subject to interview and the elections take place in September. *You can find more information including a Job Description by visiting [www.ataxia.org.uk/work-for-us/trustee-jd](http://www.ataxia.org.uk/work-for-us/trustee-jd). Anyone interested will be welcomed at an online information seminar with the Chairs of Trustees and Sue Millman, please let Sue know of your interest by emailing [smillman@ataxia.org.uk](mailto:smillman@ataxia.org.uk).*

### If you're not ready to be a Trustee, how about joining an Ataxia UK sub-group?

**In order to ensure that our strategies, and their implementation, are scrutinised in sufficient detail, we have a number of sub-groups and sub-committees with vacancies, which support the work of the Board and the staff. They are each attended by, at least, one Trustee and a number of interested Friends, plus the senior staff members.**

Friends of Ataxia UK can apply to join the group(s) in which they have interest and experience, and will have an interview with the Chair/members of the group(s). If they gain a place we will provide induction into the governance structures of Ataxia UK and have opportunities to attend training.

The sub-committees and groups meet between once a month or two-monthly via Zoom during the day for a maximum of 2 hours - but usually the meetings are shorter. The groups with current vacancies are: Services Committee; Fundraising Committee; HR Committee; and the Equalities, Diversity and Inclusion Services Strategy group. *If you wish to apply to join one of these, or want more information, please contact Sue Millman on **020 7582 1444** or email [smillman@ataxia.org.uk](mailto:smillman@ataxia.org.uk).*

Whether you have aspirations to become a Trustee in the future, or if you are simply interested in our work ... we are interested in hearing from you.

## Project identifies unmet needs in the management of the ataxias

The European Brain Council (EBC) is a not-for-profit organisation which aims to promote brain research and improve the lives of Europeans living with brain conditions. The EBC recently released results from the Value of Treatment (VOT) project.

The aim of the VOT ataxia project was to understand if existing specialist ataxia centres provide better management of ataxia and more coordinated care, compared to non-specialist settings. Three countries with existing specialist centres were involved in the study: UK, Germany and Italy. The VOT ataxia project is part of a larger project which includes other rare conditions.

The VOT team conducted a survey to collect information from patients about the diagnosis and management of their ataxia, and carried out a review of published articles on treatment for ataxias in Europe.

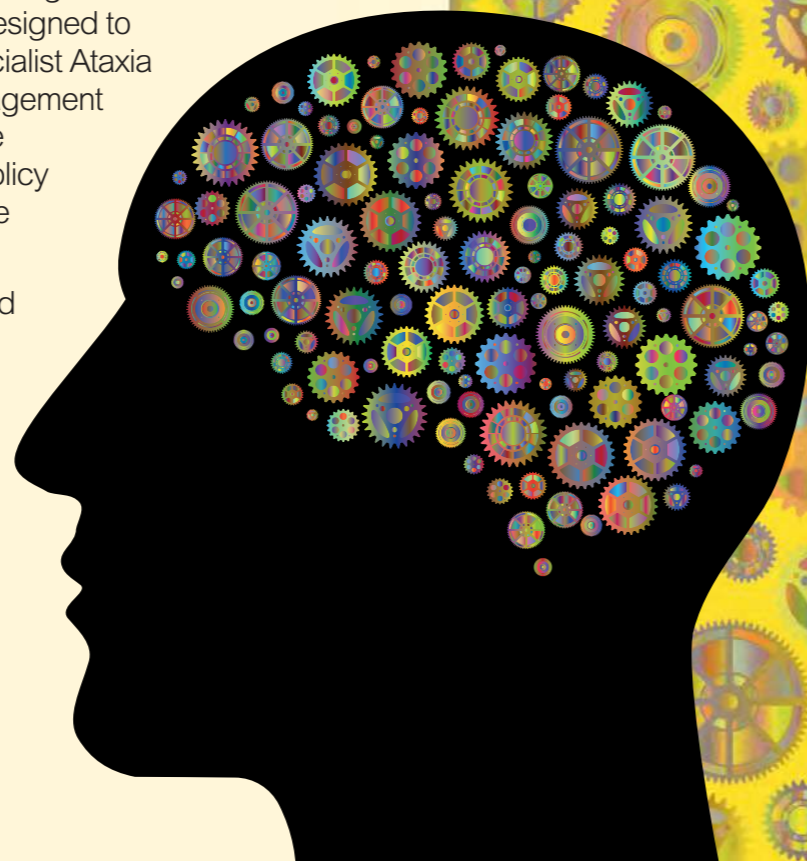
Patients reported better overall treatment and care in Specialist Ataxia Centres, with positive feedback on the management of the condition, coordination of referrals and offers to participate in research. Given this positive feedback, it is concerning that across the three countries, 20-50% of respondents had never visited a specialist centre. This was due to challenges in travelling to the centres, and lack of awareness amongst healthcare professionals for referrals. Participants also felt there was a lack of understanding of ataxia in primary care. Overall, participants who were not seen in specialist centres expressed more needs for improvements in their care compared with those who were.

The results of this project highlight the value of coordinated care and specialist centres to address the challenges for people living with ataxia. Based on these results, the ataxia case study working group together with the EBC made a number of recommendations designed to increase access to, and raise awareness of, Specialist Ataxia Centres, as well as improving education on management of the ataxias amongst primary care settings. The results of the VOT project will be used to make policy recommendations which we hope will improve the healthcare of people with ataxia.

The VOT Project ataxia case study was conducted by Dr Vallortigara and Prof Giunti, leader of the project, at the London Ataxia Centre, with representation on the working group from Ataxia UK. Thank you to Friends of Ataxia UK who took part in the VOT survey. This project was made possible by grants from two pharmaceutical companies, Takeda and Reata.

For information on Specialist Ataxia Centres, including how to get a referral, visit:

[www.ataxia.org.uk/newly-diagnosed/specialist-ataxia-centres](http://www.ataxia.org.uk/newly-diagnosed/specialist-ataxia-centres)



## Ataxia UK funds project developing nanobodies as a potential therapy for SCA3

We are pleased to announce that Ataxia UK has awarded funding to Dr Alexandra Silva at the Instituto de Invesigação e Inovação em Saúde i3S, Portugal for a project looking at whether nanobodies can be used as a treatment for Spinocerebellar Ataxia Type 3 (SCA3).

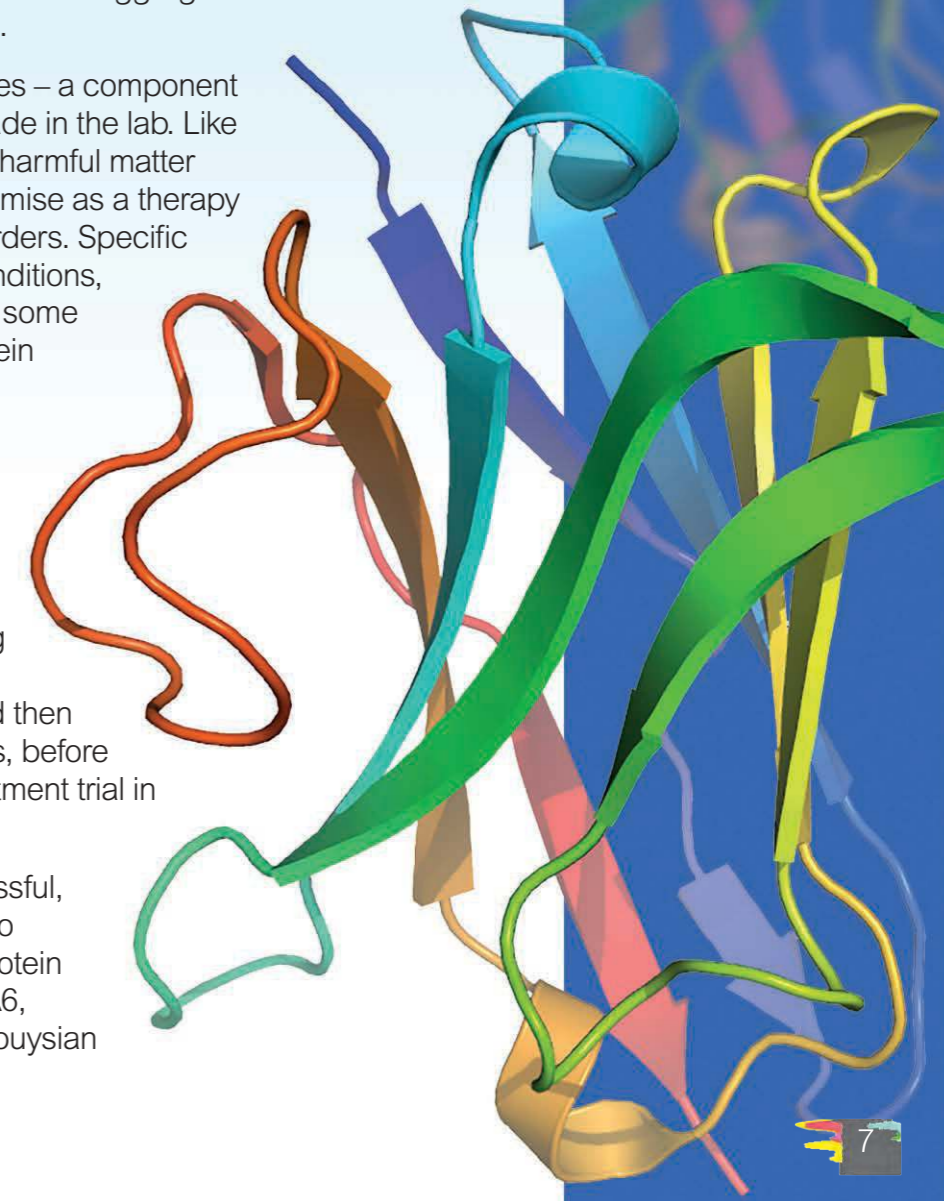
In February 2022 we sent out a fundraising appeal to Friends of Ataxia UK, and we would like to thank all those who contributed to the funding of this project! This project has also been co-funded with other ataxia organisations across Europe, including Plataforma R+SCAs, AISA (Associazione Italiana per la lotta alle Sindromi Atassiche), ACAH (Catalan Association of Hereditary Ataxias) and the Swedish SCA-network.

SCA3 is caused by a defect in a gene, which causes a protein, called ataxin 3, to become sticky and clump together. These toxic clumps are called protein aggregates. They cause damage to cells, and stop the cells functioning properly, eventually leading to the symptoms of SCA3. Researchers believe the removal of these toxic aggregates could be a treatment for SCA3. The team in Portugal have some preliminary results to show that they can decrease the ataxin 3 toxic aggregates in cells using specific nanobodies they created.

Nanobodies are small parts of antibodies – a component of our immune system – that can be made in the lab. Like antibodies, nanobodies help to destroy harmful matter found in the body. They have shown promise as a therapy in a number of neurodegenerative disorders. Specific nanobodies are needed for specific conditions, and the research team have developed some for SCA3, which target the ataxin 3 protein aggregates.

The research involves testing the effect of these nanobodies in a commonly used fly model of SCA3. They also will modify the nanobodies to increase their safety, reduce side effects and increase the likelihood of them reaching the brain. If this project is successful, then these optimised nanobodies would then need to be tested in further experiments, before eventually being tested in a clinical treatment trial in people with SCA3.

Should this therapy ultimately be successful, then it has the potential to be modified to work across other ataxias caused by protein aggregates, such as SCA1, SCA2, SCA6, SCA7, SCA17 and Dentatorubral-pallidouysian atrophy (DRPLA).



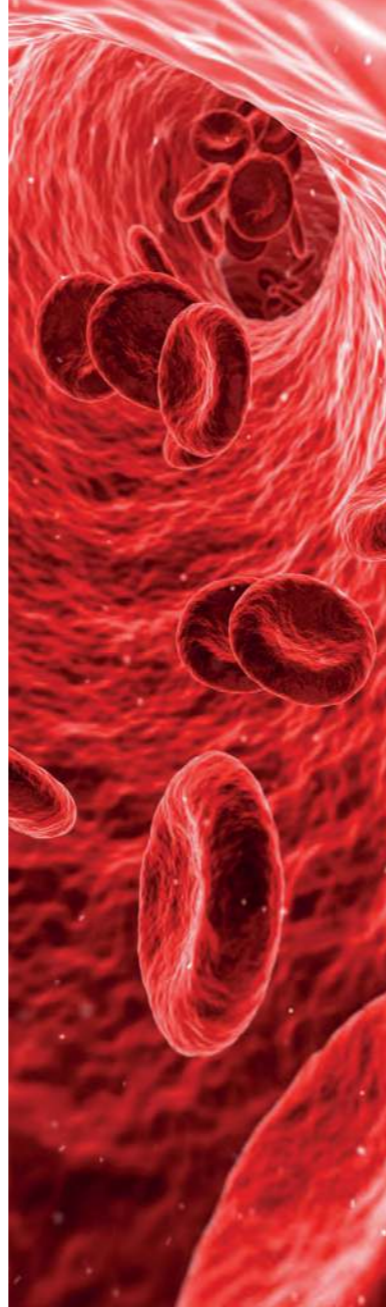
## Ataxia UK funds project on heart cell model of Friedreich's ataxia

**Ataxia UK has awarded funding to Professor Festenstein and Dr Ping Kei Chan at Imperial College London for a project on Friedreich's ataxia (FA). This project is focused on developing and understanding a heart cell model of FA.**

It is important to develop good models of FA so that we can understand the condition and test potential treatments. Heart problems can be a symptom of FA, so Professor Festenstein's team have been developing a heart cell model so they can learn more about why FA affects the heart.

Before the start of this project, the team used blood stem cells taken from people with and without FA, to make heart cells in their lab. Stem cells are cells which, under certain conditions in the laboratory, can become other types of cells. The researchers saw that there were differences between the heart cells generated from people with FA compared to heart cells generated from people without FA. For example, there was a higher number of FA-generated heart cells that were smaller and more rounded.

In their Ataxia-UK funded project, the team will use a technique called single-cell RNA sequencing to examine these heart cells further. This technique allows researchers to study each individual cell in detail. This experiment will allow the team to see whether heart problems in FA could be caused by the underdevelopment of heart cells, and help them understand more about the mechanisms underlying heart problems in FA. Learning more about these mechanisms is important for finding potential therapies, and in the future this heart cell model could be used to test new potential therapies.



## Partnership between Academia and Pharma to study SCA3

**The European Spinocerebellar Ataxia type 3/Machado-Joseph disease Initiative (known as ESMI), is a research initiative involving researchers from five countries, led by Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE) in Germany, and including University College London. Originally established using public funding, ESMI has now entered into a partnership with French pharmaceutical company Servier Laboratories for continued funding for the next three years.**

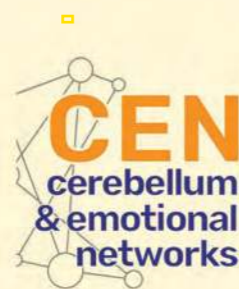
The ESMI project involves a well-characterised group of more than 450 people, most of whom are carriers of the mutation which causes SCA3. The ESMI researchers have developed standardised procedures for clinical examination, and identified a biomarker for SCA3. Biomarkers are vital for measuring the progression of the condition and the success of treatments in clinical trials. This partnership aims to pave the way to SCA3 drug trials.

Dr Julie Greenfield, Ataxia UK's Head of Research, is on the ESMI Steering Committee as a Euro-ataxia representative. The London Ataxia Centre at the National Hospital for Neurology and Neurosurgery/UCLH is the UK site for this study, and is recruiting participants. *If you have SCA3 and are interested in being involved in this study contact Dr Hector Garcia at [hector.garcia-moreno@nhs.net](mailto:hector.garcia-moreno@nhs.net).*



## Cerebellum and Emotional Networks Project

**The Cerebellum and Emotional Network (CEN) recently received funding from the European Research Council, to study the role of the cerebellum in emotion. The CEN involves eight academic partners, and nine non-academic partners, including Ataxia UK as a patient representative.**



The cerebellum has long been known to be involved in coordination and movement, but other brain areas have been the focus of research into emotion. However, as the cerebellum is a complex structure, these researchers think it is likely to be involved in other functions, such as emotion.

One of the aims of the CEN is to understand how the cerebellum contributes to emotion when the brain is affected by a condition such as ataxia, which is caused by degeneration of the cerebellum. The researchers hope that a better understanding of the role of the cerebellum will open the door to new treatments.



## Research funding for rare ataxia

**Ataxia UK is pleased to award research funding to Prof Giunti (right) at UCL Queen's Square Institute of Neurology, for the study of Cowchock syndrome.**

Cowchock syndrome is a rare genetic condition, which causes ataxia as well as other symptoms such as deafness and cardiomyopathy. It is caused by mutations in a gene called AIFM1, which codes for the AIFM1 protein. In this project, Prof Giunti and her team will study the role of the AIFM1 protein in the central nervous system, and test a potential treatment, using brain tissue donated by a person that had Cowchock syndrome. Better understanding of AIFM1 and how it is affected in this condition will help researchers and clinicians to better understand Cowchock syndrome, and to design treatment strategies for people with this condition in the future.

The son of John and Ann Chapman, Friends of Ataxia UK, was affected by Cowchock syndrome. They said "Our son Christopher was diagnosed with Cowchock syndrome by Prof Giunti. He had always wanted to be involved in research, but unfortunately there were no research opportunities before he died in December 2008. We wanted to contribute to this project to give something back to Prof Giunti after all her efforts not just for Christopher, but for all her patients. Supporting this research project would have delighted Christopher"



## 2022 Conferences Update



Throughout the charity sector and beyond, it is being found following two years of the pandemic people are reluctant to commit themselves to events very far in advance with many planned events being cancelled. This is Ataxia UK's experience too! Despite a number of people expressing interest in coming to the Scottish Conference on 18th June, we have less than 20 confirmed attendees.

In many ways this isn't surprising. People are continuing to be cautious about potential exposure to Covid-19; some have been financially badly affected by the pandemic; and others by inadequate welfare benefit increases; and everybody is being subjected to inflation and huge rises in energy and fuel costs. In this context, we have been thinking very carefully about whether we can go ahead with the planned Scottish and Annual Conferences.

Once again, we will hold this year's Annual Conference online. To proceed with a face-to-face Annual Conference would incur significant cancellation costs as soon as the beginning of July; which in the current climate, is long before we can expect to have enough bookings to know if the Conference would be viable. In addition, due to increases in hotel costs, attending the Annual Conference would be much more expensive than previous years, which many may not be able to afford in the present financial situation. We know that a virtual conference will be very disappointing to many who are looking forward to meeting up with friends and acquaintances after such a long time apart, but we also know from feedback from the last two online Conferences that many people appreciate being able to attend online when they could not come in person.

If you want to come to an in-person Conference don't despair!!! **The Scottish Conference will definitely go ahead in person** no matter how many people confirm in advance! So if you want to come to a face to face conference come to the **Leonardo Hotel on Saturday 18th June**, head to [www.ataxia.org.uk/support-services-ataxia-uk-conferences](http://www.ataxia.org.uk/support-services-ataxia-uk-conferences) and make your booking!

The Leonardo has some disabled accessible bedrooms and we have investigated other local hotels with disabled accessible rooms; you will find a list on the booking page.

*Please remember that if you are on means tested benefits you can apply for a bursary to cover 50% of the costs of someone with ataxia and their carer to travel and attend the conference (including accommodation if distance requires it). The bursary application procedure is on the **Scottish Conference web page**.*



## Mindfulness

As part of January's Wellbeing Week here at Ataxia UK, we were joined by Lucy Holland who volunteered to do a session on Mindfulness.

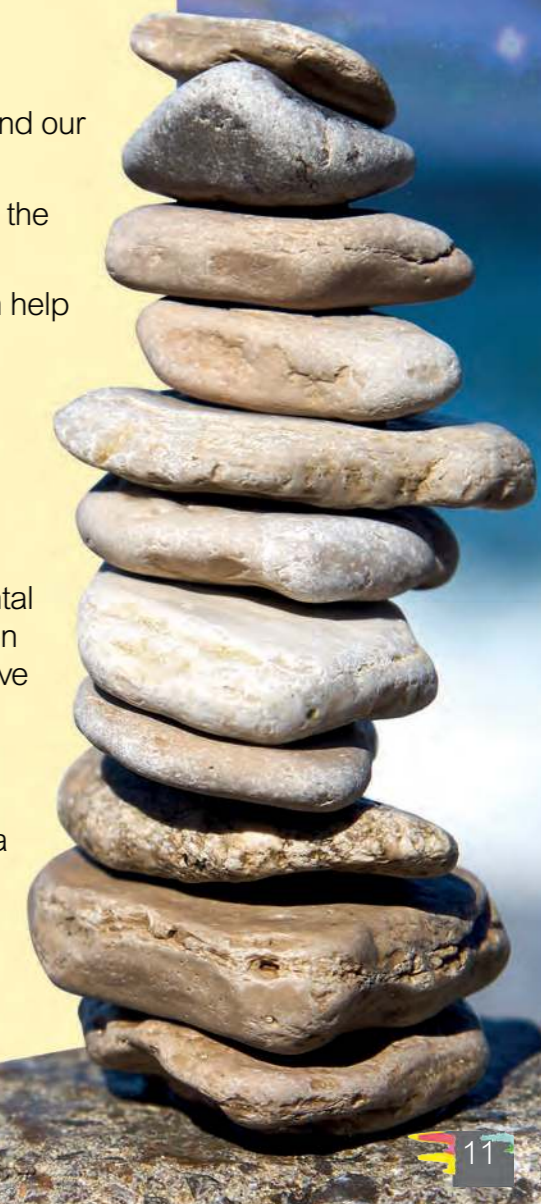
The benefits of yoga and mindfulness have been a constant in Lucy's life for over 20 years and she has been sharing her experience through her teaching since 2017. Ataxia UK is a charity close to her family's heart and she has organised several fundraising yoga and mindfulness classes.

Lucy has now held two Mindfulness workshops for Ataxia UK, in which she explained some of the benefits of practising mindfulness. She described how mindfulness can be used to relax the body (including our central nervous system) as well as calming the mind. For those living with a health condition such as ataxia, or their families and carers, it can help with coping with fatigue and stress, as well as an approach to pain management. Its focus on increased self-awareness and self-acceptance also helps with some of the mental health aspects of living with a long-term health condition or disability.

During the sessions, Lucy led participants through a few different types of mindfulness practice:

- **Gentle movements and stretching**
- **Self-massage of acupressure points**
- **Positive affirmations** - Finding a positive approach to ourselves and our bodies, to boost self-care and self-esteem.
- **Mantras** – a sound vibration or repeated word or phrase to protect the mind, repeated over and over during meditation.
- **Breathing exercises** including Bee Breath and 3:4:5 Breath which help to release stress, relax and help with insomnia.
- **Yoga Nidra ('Yogic Sleep')** - a relaxation technique in the conscious state between waking and sleeping including the **tensing and releasing** of muscles, and a mental **body scan** (guiding your awareness from the feet up).
- **Meditation** - Think of meditation as a journey through the layers of your being. It's not just about your physical body but also your mental and energetic body. Think of it as gaining a sense of control or even escapism, taking you on a journey which helps you develop effective coping strategies.
- **Somatic tracking** – a technique to help with pain management which involves teaching the brain to reinterpret signals from your body, change the mindset around uncomfortable sensations from a place of safety and curiosity rather than judgement or fear.

As Lucy explained, mindfulness works differently for everyone and is about finding what works for you. If you'd like to give some of these techniques a go, please look out for upcoming sessions which will be advertised in our monthly newsletters and on social media.



## Become an Ataxia Angel

The concept of a “guardian angel” is one that persists. From Greek mythology, world religions and pop culture, guardian angels are there to support and look after their charges.

Ataxia Angels are special individuals who decide to take Ataxia UK under their charge and make a commitment to helping make a world free of ataxia a reality. And until this happens, they help support all those affected by ataxia.

Could you be an Ataxia Angel or do you know someone who might be suitable?

### WHAT DOES IT MEAN TO BE AN ATAXIA ANGEL?

Ataxia Angels are individuals who can commit to giving a minimum amount of £1,000 or more on an annual basis. Helping to ensure that vital research into treatments and cures continues, and that people can be supported until these are found.

### WHAT WILL MY IMPACT AS AN ANGEL BE?

Your annual commitment and generosity will help to;

- invest in scientific research to have the maximum impact on the future development of treatments and cures
- develop resources and provide information services for those affected by ataxia at key stages of their diagnosis including the provision and updating of medical guidelines
- ensure services such as the helpline continue to be available for all who need them.

### WHAT BENEFITS DO ANGELS RECEIVE?

As an Ataxia Angel, you will receive

- An exclusive Ataxia Angel pin badge
- Regular updates on the impact of your support
- Your name engraved on the Ataxia Angel plaque of honour in the office
- Invitations to events
- Acknowledgement in the Annual Report (although you can give anonymously if you wish)

### HOW CAN I MAKE MY DONATION AND BECOME AN ANGEL?

You can make your annual commitment by a number of ways. Direct debit, credit or debit card, cheque or standing order.

To become an Angel, either visit [www.ataxia.org.uk/ataxia-angels](http://www.ataxia.org.uk/ataxia-angels) or email Dan at [dbeacon@ataxia.org.uk](mailto:dbeacon@ataxia.org.uk)

### CAN I RAISE MY COMMITMENT THROUGH FUNDRAISING?

We are incredibly grateful for everyone who raises money for us. Unfortunately, the Ataxia Angels programme is designed for those wanting to make an annual personal donation.



## The Kiltwalk is back!

Calling all Scottish Striders, Strollers and Wanderers! The KiltWalk is back and The Hunter Foundation are topping up fundraising by 50%!

The KiltWalks bring everyone together across Scotland, and Ataxia UK are offering **free places to fundraisers!** Not only that, but The Hunter Foundation will top-up your fundraising by 50%!

Choose your distance from The Mighty Stride (22.6 - 24 miles), The Big Stroll (14.5 miles) or The Wee Wander (3-5 miles) and then choose your location: Dundee 21 August, Edinburgh 18 September or Virtual KiltWalk from 7 to 9 October.

All Wee Wanders are wheelchair accessible.

Join now by Contacting Rebecca on [rholt@ataxia.org.uk](mailto:rholt@ataxia.org.uk) and see [www.thekiltwalk.co.uk](http://www.thekiltwalk.co.uk)



## Hadrian's Wall Trek

Step back in time and trek 25 miles in a day or a weekend!

Explore a UNESCO World Heritage Site and follow in the footsteps of the Roman legions on this fantastic challenge! Discover fascinating ruins of ancient Roman forts and settlements as you Trek along Hadrian's Wall through the stunning Northumberland countryside

Choose the one or three day trek:

**1 Day trek:** Brocolitia Roman Fort to Wall Town National Park Centre.  
13 August 2022

**3 Day Trek:** from Lanercost Priory to Brocolitia  
24 to 26 June Or 16 to 18 September 2022

Both treks have an option where Ataxia UK will pay your entry fee if you raise a certain amount of money. For full details of these amazing offers, see:

[www.ataxia.org.uk/get-involved/events-and-fundraising/challenges/treks/hadrians-wall](http://www.ataxia.org.uk/get-involved/events-and-fundraising/challenges/treks/hadrians-wall). Get in touch: [rholt@ataxia.org.uk](mailto:rholt@ataxia.org.uk) or 020 7582 1444.



# Great North Run

Whether you're new to running, or you're a half marathon veteran, we'd love you to join #TeamAtaxiaUK on 11 September 2022 and help make 2022 our biggest year yet for the Great North Run!

Be part of the iconic half marathon on #TeamAtaxiaUK as it returns to its traditional City to Coast route, starting on the famous Tyne Bridge and finishing along the stunning coastline at South Shields. Time to look forward to that delicious post-race fish and chips and the incredible support along the route, especially as you hit 'that view' for the final mile. It's a once-in-a-lifetime experience, and one we'd love you to have on Team Ataxia UK.

"The support and atmosphere of the GNR is electric. The geordie way is so welcoming and really lifts you, making the run ... more manageable! ... fabulous communication and support ... and it was just lovely to be cheered on by you during the day and to see you. Being on my own made that really lovely!"  
 (Emma Foster, Senior Ataxia Nurse Specialist)

"We enjoyed the crowds lining the route and the atmosphere. [Rebecca] and Tegan were fantastically helpful, ... Well organised and kept us very well informed. ... we loved the personal touch ... Thanks again for everything."  
 (Dave Whittall, running in memory of his friend Kev)

Join us now! Contact Rebecca on [rholt@ataxia.org.uk](mailto:rholt@ataxia.org.uk)

# Awesome Inflatable (5k or 10k)

Get involved in a brilliant day of fun in support of Ataxia UK.

With everyone invited from age 5 upwards and dates all the way through the year at venues including Exeter, Norfolk, Ipswich, Brands Hatch, Bristol, York, Leeds, Hertfordshire, West Sussex, Chichester, Bournemouth, Glasgow, Peterborough, Warwickshire and Stafford, now is the time to gather for a brilliant day of fun in support of Ataxia UK.

To find out more visit [www.ataxia.org.uk/get-involved/events-and-fundraising/challenges/abseils-skydives-bungee/inflatable](http://www.ataxia.org.uk/get-involved/events-and-fundraising/challenges/abseils-skydives-bungee/inflatable) or by emailing Rebecca now on [rholt@ataxia.org.uk](mailto:rholt@ataxia.org.uk).

All fundraisers taking part in an event will receive a running vest or t-shirt, supporter pack and medal.



# Fundraising thank-yous

Thank you to everyone who has fundraised on #TeamAtaxiaUK - these pages show a highlight of some fundraisers - check our social media for even more!

Thank you so much to **Aimee Donnelly (1)** and all the friends and family who took part in their 'Wobble Walk for Molly' around the beautiful Alva Park in Clackmannanshire, raising a whopping £815!

A massive cheer and thank you to **Nicola Miles & Sam Clark Keen (2)** who have raised over £8,000 by completing 12 challenges in 12 months to support **Nicola's mum**. Such an outstanding achievement all round, thank you so much and congratulations on an epic effort.

A gigantic Congratulations to **Steve Speariett (3)** who ran 5km a day for a month and raised £1,064 to support a friend with ataxia. Thank you too to his friends **Suzi** and **Keith** who joined in for some of the runs!

Congratulations **George Thomas & Lisa Kiff (4)** for completing the New Forest Off-Road Half Marathon, raising a wonderful £1,825! Such a great duo, thank you both!

A big hurray for **Nathan Moore (5)** who completed the first of his runs; the Spar Craic 10k in support of his brother **Adam**. Now working towards the East Antrim Half, he has raised £1,435 already!

A massive round of applause to **Frankie Hurley-Peet (6)** who smashed her first 10k in five years with the Tatton Park race, together with wife **Jacqui** and her cousin, raising a brilliant £220! Thank you so much to you both!

A big thank you to **Malcolm Long** for his continued support by selling discarded golf balls - he has raised over £300 in the last year!

Well done to **Joel Biddiscombe** for his second live streaming fundraising - this time raising a fantastic £70!

Gold stars all round for mum and daughter duo **Louise Hickey & Naomi Bolton** for completing the Manchester Marathon and raising £1,390 so far!

A big well done **Gemma Pridham** who remained determined to complete her challenge despite covid19 continuing to cancel events. She completed the Plymouth Half triumphantly and raised a fantastic £550!

# London Landmarks Half Marathon

A BIG CONGRATULATIONS to our London Landmarks Half Marathon Runners **Rory & Jonah Cockshaw (7)**, **Dave Whittall (8)** and **Tom Watson (9)**! Flying round the stunning course through the City and along the River, passing bands and DJs as we cheered them on! Together they have raised £1,625 so far! Thank you so much for all your hard work and dedication - you smashed it!

Contact Rebecca on [rholt@ataxia.org.uk](mailto:rholt@ataxia.org.uk) to find out about taking part in 2023!





## It's the little things ...

By James Downie

In this article I am going to write about the small gadgets and gizmos I use and would recommend for others with ataxia. Some help with specific things/tasks, some are general for everybody and some are just kind of useful and cool!

I first want to mention my wheelchair bag. The bag hangs under your legs and is attached to your wheelchair by parachute clips. They come in a variety of sizes but only in black! In my bag I carry my medication, tissues, wet-wipes, metal straw, wheelchair tools and a multitool.

The next gadget I want to mention is my multitool (top right). It is basically a set of pliers and an array of pen knives and screw drivers. I find this very useful, especially the pliers when gripping is an issue. You do need to remember to take them out before being scanned at events or while traveling as I have had them confiscated before! Metal straws are always useful to have handy as paper straws fall apart.

Grippy stickers (right) are also very useful for a variety of things. They stick to most things you drop frequently. They come in all sorts of sizes and shapes and can be used for a multitude of purposes. I mainly use on phone cases to stop me dropping my phone. This also works on iPads, laptops, computer mice and game controllers etc. They can also be used to stop things slipping and sliding.

In the kitchen I use a big heavy pan and bottle/jar openers (below right). I find a huge heavy saucepan the best for cooking and frying. The pincer style jar and bottle openers are also great. I also use plastic glasses and pasta bowls instead of plates.

On the side of my bed I have an attached hanging bag. In this I put everything I need for the night and know I won't lose it or drop it out of reach. For example I put my phone in and always know where it is.

**Not so much a gadget but around the house wear long tops and in the summer I wear basketball tops. I find they help when carrying things. I put the item I want to carry on my lap then wrap the item in my top to stop it falling off. I sometimes use my teeth to hold for added security, but I can't recommend that!**

Sorry if what I have talked about is obvious but it might help with ideas. Any questions or ideas for future articles please contact [downstar@mac.com](mailto:downstar@mac.com)



## Aids & Adaptations

Aids and adaptations can have a huge impact on making life with ataxia easier. They can make everyday tasks easier and safer, as well as allowing you to continue with the hobbies and activities you enjoy. There is such a large number of different types of gadgets and adaptations out there that it can often seem overwhelming and costly.

### WHERE TO START

If you're finding that daily tasks are starting to become challenging, or that you're using complex workarounds to enable you to continue doing tasks, then you might start thinking about aids and adaptations. A good place to start is arranging an appointment with an Occupational Therapist (OT) who is a trained professional that assesses what your needs are and advises what adaptations will be suitable for you. Under the Care Act 2014, everyone has the right to a free assessment which is managed by your local authority, or housing associations. You can apply for this here:

[www.gov.uk/apply-needs-assessment-social-services](http://www.gov.uk/apply-needs-assessment-social-services). If your local authority has a long waitlist for assessments and you plan to pay for adaptations yourself, you might want to pay for a private OT assessment too. You can find private services here: [www.findmyhia.org.uk](http://www.findmyhia.org.uk)

### HELP WITH THE COST

There are Government and Council funding grants available to help with the cost of aids and adaptations:

- For smaller aids and adaptations, Occupational Therapists will advise if there is council funding or loan of equipment available to you.
- The Disabled Facilities Grant is a grant from your local council to make more extensive adaptations to your home. It is means tested, but offers up to £30,000 to make the necessary adaptations. You can read more here: [www.gov.uk/disabled-facilities-grants](http://www.gov.uk/disabled-facilities-grants)
- The Access to Work scheme provides grants to support people in continuing to work. This may include things like adaptations to your vehicle so you can get to work or support workers in your workplace. You can read more and apply here: [www.gov.uk/access-to-work](http://www.gov.uk/access-to-work)

There are also a number of trusts and foundations which provide grants to help with the cost of purchasing equipment. You can read more about them here: [www.ataxia.org.uk/support-services/grants](http://www.ataxia.org.uk/support-services/grants). If you would like any help with applying for these grants, our Helpline and Advocacy service will be happy to support you with this.

### FIND OUT MORE

In January 2022 we held an online workshop about Aids & Adaptations as part of our Wellbeing Week. The recording of this session is available to view on the Ataxia UK Youtube channel.



## The Big Push

**What do you know about Daniel Stott and Lucas Schofield? Friends from Yorkshire who completed 'The Big Push' covering 1,000 miles in 71 days and raised £21,500 for three charities, including Ataxia UK. Daniel on foot and Lucas in his wheelchair.**

When Lucas was 15, he was diagnosed with Friedreich's ataxia. He is now 22 and says; **"My body may be shutting down, but my mindset has never been stronger."**

### How did you come up with the idea and why?

*"By pushing yourself, you can find achievement and progress that can build your character. Once my condition kicked in at 18, it took me a while to adjust to a slower lifestyle, but four years later now in the chair, I feel like I've regained the freedom to move that I had lost. I simply found something I was good at, and I liked it, so I wanted to amplify that into a real challenge."*

### What was the best part about the Push?

*"The combination of different scenery and people that we met and saw along the way. Particularly the first 20 or so days of traveling through the Highlands were filled with incredible views. We went straight through Glen Coe Valley along the A82, and even though the cars flew by they didn't distract us from the vast expanse of grassy green mountains that closely surrounded us. As for the people, all the way down the country we were shown so much kindness and support. During our stay, we were always given tea, biscuits, a roof, a garden, water, directions, little bits of local knowledge about the area, and more reasons to keep going."*

### What motivated you to keep going?

*"We were highly motivated and eager to embark on this adventure even before we reached John O' Groats. The Push was two years in the making. I spent most of that time at the gym and the last few months were when we really started planning and buying a kit. In all that time there was no external pressure to finish it, it was up to us to motivate ourselves to complete it. Both of us felt strongly motivated to finish it!"*

### Why Ataxia UK?

*"I was diagnosed with Friedreich's ataxia at 15, so it only made sense to support it and to do my part in raising awareness of the condition. Despite the fact that it is not well known, it affects so many and, in fact, it is quite a burden to bear. Therefore, I thought it was important to show what can still be done."*

### Do you find fundraising motivating?

*"It was a constant morale booster to see the figure go up from nothing to £21,500, which was split between three excellent charities and causes. The charities are: Ataxia UK, the Butterfly thyroid cancer trust and CALM. Each charity received just over £7,200."*

*If I can push once then I can push a million times, if I can do something once*



*then I can do it again and again, as many as it takes. I tested that theory by Pushing from Leeds to Knaresborough on a twenty mile push mainly going down the M85. My experience taught me that I should have used talcum powder and sun cream but also that it was possible. We are able to move 20 miles in a day, so I knew with Dan's help, we could move 15 miles every day as many times as we needed. We finished the Push in 71 days."*

### What message would you like to send?

**Lucas:** *"Even though the odds are against you, there is an exciting life to live and that the kindness of others can be found anywhere."*

**Dan:** *"For me the best part was the relief I felt once we made it to the top of a nasty hill or the time I caught up with Lucas on the downhill, and saw he was still in one piece. Also, when I was able to help my friend achieve his insane goal of pushing the length of the country."*

*What motivated me to keep going was knowing we were raising a smashing amount for three charities close to our hearts. We were having a great time on our journey, so it was only really the final two weeks where we had to dig deep to see it off."*

**A big thank you to Dan and Lucas from all of us at Ataxia UK for undertaking this extraordinary challenge and raising money to support those affected by ataxia.**



## Happy 10th Birthday Ataxia UK on HealthUnlocked!

By Dr Harriet Bonney

**I was diagnosed with cerebellar ataxia (idiopathic) over 30 years ago and took early medical retirement about 10 years ago from the NHS in which I worked as a doctor. I was Chair of Ataxia UK 2012-2019 and now volunteer in a variety of roles within the charity.**

HealthUnlocked is a social networking service for health that currently has over 700 different health communities for a wide range of health and wellbeing conditions. The main HealthUnlocked website launched in 2011 and the Ataxia UK community was formed in 2012. The Ataxia UK community is celebrating its 10th Birthday and now has over 3700 members, all affected by ataxia in some way.

If you just want to have a look around the forum to see what questions and posts have been written in the past, you don't need to join. That is absolutely fine. However, if you want to ask a question or write a post, you must join. This is free to do. It is anonymous, so you can use whatever username you like. You can restrict the viewing of posts to just members of the community or let everyone see it. Even if restricted to just members of the community, then potentially 3700 people all affected by ataxia in some way see the post/question and can reply if they wish. I am sure you will agree it is a fantastic resource.

The forum is moderated chiefly by me to ensure posts, questions and replies are accurate and do not cause offence or any damage, potential or otherwise, to anyone.

Members of the site say "Always handy tips", "the forum is a huge benefit to all users", "Initially I was reluctant to subscribe....now it's my favourite", "...invaluable means of contact with others", "you feel you are not alone", "very informative", "community is supportive."

You can access the Ataxia UK forum on HealthUnlocked by either clicking on the little green box with a capital 'H' in it at the bottom of Ataxia UK's website homepage ([www.ataxia.org.uk](http://www.ataxia.org.uk)) or by going to:

[www.healthunlocked.com/ataxia-uk](http://www.healthunlocked.com/ataxia-uk).

If you have any further questions about HealthUnlocked please get in contact with me by either sending me a direct message on the forum (username HarryB) or email the Ataxia UK Helpline on [help@ataxia.org.uk](mailto:help@ataxia.org.uk).



## Are you getting the welfare benefits you are entitled to?

**We can help!**

We believe it's important that everyone affected by an ataxia can access the financial support they need and are entitled to. The world of welfare benefits can be complicated and confusing, there's lots of information out there and it can feel overwhelming. You may think you are not eligible, or you could have applied already and been turned down or gotten less than you'd hoped for. Also, nearly all people with a progressive ataxia will experience a worsening of their symptoms over time, which means if you were not eligible before, you might be now.

**YOU COULD BE ENTITLED TO BENEFITS IF:**

- you are on a low income
- if you are unable to work because of a disability or because you look after someone who is disabled
- if you have a disability or if you are caring for someone who does

Some disability benefits are not means-tested, so even if your income isn't low, you could be entitled to some financial help to meet your needs and live independently.

Did you know? According to Citizens Advice, the latest government statistics show that **more than half of PIP decisions are changed after mandatory reconsideration or an appeal to a tribunal**, so do challenge the decision if you think it's wrong. It won't cost you anything to appeal.

Navigating the process can feel daunting but please don't give up! Ataxia UK is here to help. We can provide you with information and support to:

- Help you to find out what you may be entitled to. **Citizens Advice** is a good place to start. You can also try a **benefits calculator**.
- Help you to apply for benefits. For example:
  - **Disability Living Allowance (DLA)** – for under 16s
  - **Personal Independence Payment (PIP)** – for adults aged between 16 to pension age
  - **Attendance Allowance** – for adults over pension age.
  - **Carer's Allowance** – if you have a low income and are caring for someone
  - **Employment and Support Allowance (ESA)** – if you are unable to work
- Help you appeal decisions
- Help you make sure medical assessors understand how your ataxia affects you

If you would like to find out more, or talk to a member of the team, please get in touch via the Helpline, by calling **0800 995 6037** or by emailing [help@ataxia.org.uk](mailto:help@ataxia.org.uk). The Helpline is open Monday to Thursday 10.30am until 2.30pm.



# Access to Information, Advice & Support

In the last couple of issues we have been reporting on the feedback from the 2021 Friends survey into the experiences of people affected by ataxia. This edition we focus on your experiences accessing information, advice and support.



## Emotional Support

The figures below focus on the views of participants who had accessed advice from the range of sources, and the proportion who had found the emotional support to be important, very important or vital.

*Finding source of emotional support vital / very important / important*

	Ataxia UK Helpline	<b>72.5%</b>
	Engagement with Ataxia UK branch/support group	<b>65.2%</b>
	Engagement with Ataxia UK online group	<b>59.6%</b>
	Involvement with Ataxia UK event	<b>57.1%</b>
	Consultation with NHS - secondary care	<b>74.7%</b>
	Consultation with NHS - primary care	<b>70.6%</b>
<b>Other Voluntary Sector</b>	Other voluntary organisation	<b>72.7%</b>
	Health Unlocked Ataxia Forum	<b>54.1%</b>

Those respondents who did access emotional support from these sources were more likely than not to find that support at least important. They were most likely to find consultation with NHS secondary care important, almost three quarters doing so, with just under three quarters of respondents feeling the same about emotional support from other voluntary organisations, or from Ataxia UK's Helpline. Over seven out of ten of these respondents found consultations with primary care professionals important, and nearly two thirds of those engaging with the branch/support group did.

Generally speaking, respondents were more likely to need information than advice, and more likely to need advice than emotional support.

## Information Support

The figures below focus on the views of participants who had used information from a range of sources, and the proportion who had found such information important, very important or vital.

*Finding sources of information vital / very important / important*

	Ataxia UK website	<b>78.7%</b>
	Ataxia UK Magazine	<b>70.7%</b>
	Ataxia UK Helpline	<b>66.7%</b>
	Engagement with Ataxia UK branch/support group	<b>60.5%</b>
	Engagement with Ataxia UK online group	<b>58.7%</b>
	Involvement with Ataxia UK event	<b>56.9%</b>
	Consultation with NHS - secondary care	<b>79.7%</b>
	Consultation with NHS - primary care	<b>71.1%</b>
<b>Other Voluntary Sector</b>	NHS Website	<b>52.0%</b>
	Other voluntary organisation	<b>61.5%</b>
	Health Unlocked Ataxia Forum	<b>60.8%</b>
	Other voluntary sector website	<b>56.3%</b>

This set of responses suggest that where respondents have accessed information from a given source, they are more likely than not to find it of considerable importance to them. This is particularly the case for the Ataxia UK website and magazine.



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**