

ATAxia MAGAZINE

The magazine for people affected by ataxia

Issue 207. Autumn 2019

Welsh Friends strive for better care p.18 -19



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

ATAxia

Ataxia UK

GOODBYE



With heavy hearts, we wish our **Fundraising Officer, Zoe Lonergan**, the best of luck in her new role at a mental health charity and for the future. Zoe worked incredibly hard with the ataxia community and fantastic fundraisers. She will be greatly missed.

GOODBYE



After three years, we say goodbye to our wonderful **Communications Manager, Steph Marley**. Steph has brought more than many smiles to the office and with Friends at different events. We will miss Steph but wish her all the best in her next role; she'll be great!

GOODBYE



It's been a pleasure to have **Arinola Akintola-Bello** as our **Fundraising Administration Intern**. We want to thank Arinola for her hard work, and we wish her all the best with her next step!

HELLO



We are very pleased to welcome our new **Fundraising Officer, Louisa Cody**. With a background working for charity, Louisa will be working closely with you, the ataxia community, and is looking forward to meeting you at different events!

CONGRATS



Congratulations to **Leanna Coleman** who was our **Communications Intern** and is now the **Communications Officer**. Leanna is looking forward to continuing working with you all, and if you'd like to write for an issue of the magazine, get in touch!

Welcome

Dear Friends,

It has been a lovely summer indeed. Our **Cardiff Conference** was a great success. We've had many applications for **Trustee positions**. We are also pleased to say that we've had a number of unexpected and generous donations.

Looking ahead, we have the **Annual Conference** approaching quickly, taking place at **Stansted Airport Radisson Blu** - we can't wait to see you all. You can read about our plans for **International Ataxia Awareness Day** on (p. 10) and find out how can you get involved in raising awareness.

This issue has some exciting research, including a trial investigating brain stimulation as a **potential therapy for ataxia**, and a callout for a **new member on our Scientific Advisory Committee** - find more information on (p. 8).

On (p. 12) you will find a teaser post on the **Big Give match-funding campaign** this Christmas which we are pleased to be taking part in again. Please hold onto your kind donations until you can double them for free, and an enormous thank you to everyone who has taken part in fundraising this summer!

Best wishes, Sue Millman



KEY CONTACTS

- **Sue Millman** - Chief Executive
smillman@ataxia.org.uk

Helpline & Membership

- **Sheila Benneyworth**
- Helpline and Membership Officer

Contact our helpline:

helpline@ataxia.org.uk

0845 644 0606

Research

research@ataxia.org.uk

- **Dr Julie Greenfield**

- Head of Research

Fundraising & Communications

- **Dan Beacon**

- Head of Fundraising and Communications

- **Kelvin Gichohi**

- Individual Giving Manager

- **Rebecca Holt**

- Community Fundraising and Branches & Support Groups Manager

- **Louisa Cody**

- Fundraising Officer
fundraising@ataxia.org.uk

- **Leanna Coleman**

- Communications Officer
communications@ataxia.org.uk

For queries, feedback, or to request a large-print copy of the Ataxia Magazine, please contact Leanna Coleman.

Contact our office

office@ataxia.org.uk

020 7582 1444

Ataxia UK
12 Broadbent Close
London N6 5JW

www.ataxia.org.uk

Ataxia people

- Achievements alongside ataxia
- Network updates ————— 4



Research

- Targeting the gene in Friedreich's ataxia
- Results of a completed episodic ataxia type 1 study — 6



Ataxia awareness

- International Ataxia Awareness Day 2019 ——— 10



Health & wellbeing

- Ever considered music therapy? ————— 11



Fundraising

- Events
- Fundraising thank-yous ————— 12



Adaptations

- Finding the right fit for you
- Wheelchair alternatives ————— 16



Living with ataxia

- Places to change
- Improving neurological care services in Wales — 18

Achievements alongside ataxia

Deborah has many educational achievements and here she shares her pleasant experience of Open University when her ataxia made accessing education difficult.

I was never a sporty or outdoor type of child. I loved to read or play the piano and I enjoyed school. Around the time of my A-Levels I realised that something was wrong; what had started as a mere feeling of unsteadiness was now noticeable in my walking.

After a stay in hospital and going through many neurological tests, I was finally diagnosed with Friedreich's ataxia (FA). Hearing that you have a progressive and incurable neurological disease has a devastating effect on any young person and, in my case, the effect was to spectacularly fail my exams. I managed to pass English at a further education college, but it wasn't enough to get into university, so I then took a secretarial course.

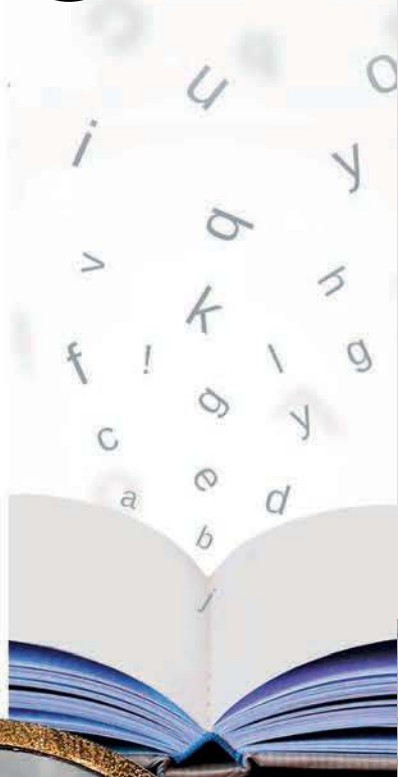
I had a few office jobs until I got married and had my daughter. I enjoyed being a mother and the physical challenges it brought, however, I thought an **Open University (OU) degree** could be the mental focus I needed. The OU had great adaptations, such as a word prediction programme; **comb-bound units** (a page that stays open without having to use your hand); exams at home with extra time, and breaks and helpers when I needed them. The BA structure allowed me to choose music courses and gave me the confidence to start teaching the piano to children, which I did until I lost the ability to play.

After graduating in 1995 I received an **Adult Learner Award** for educational achievers and I was able to study (and pass!) a postgraduate diploma in law at a local university. I didn't go on to legal practice because of my increasing mobility problems and, together with fatigue and speech problems, it was logistically impossible; I had to accept my physical limitations.

In 2009/10 I completed two **OU postgraduate courses**, receiving help with typing up essays, which I dictated. I found it more convenient to submit them online rather than wheeling as fast as I could to the post office to catch the last post (20 years earlier it had been like that!).

I am so grateful to the OU for helping me achieve so much and I'm proud to be associated with this great institution as it celebrates its 50th year. I also led the **Ataxia UK Support Group for SE Wales** for eight years. I don't intend to do any more OU studying ... but you never know!

You can find out more about the Open University here: www.open.ac.uk and more information on extra support and funding here: <https://help.open.ac.uk/topic/disability>



Support in East Durham

For many years, co-ordinator of the **East Durham Support Group**, **Phil Whitwell** (right), has been working with his local community in **Seaham** to raise awareness and funds for those affected by ataxia.

Part of this has been by taking the **Ataxia UK Medical Guidelines** (aimed at healthcare professionals for managing patients with ataxia; you can request a copy by emailing office@ataxia.org.uk) to his GP surgery and encouraging those in his Support Group to do the same. Phil has also involved his local pubs with **The Crow's Nest** (manager: Kim - below right), **The Marlborough** and **The Times Inn** all having collection tins on their bars and regularly making donations. The Times Inn also hosts the group's meetings.

Thank you so much to the community of Seaham, together with Phil and everyone at the Support Group for all their support. The group meets every three months in Seaham, offering local support to those with ataxia and their families.

You can contact our friendly East Durham Support Group by emailing philipwhitwell@sky.com or telephone **01915 819 995**. To order a collection tin for your local shop or pub, contact: fundraising@ataxia.org.uk



Have your say

Thank you to everyone who has applied or nominated an individual to stand for our **Trustee** elections. You will find the descriptions of four candidates enclosed in this magazine, and a ballot form on which you can provide your vote.

There were two places for people with experience in finance, and experience in health or medical issues. Two people were nominated unopposed for these positions.

This means there are now three places left to fill within the category of Friends of Ataxia UK and/or someone with ataxia, and four candidates to choose from. All those who are Friends living in your household can vote online (www.surveymonkey.co.uk/r/QDSM3P3) or via the paper ballot form (make copies if necessary) and freepost envelope enclosed.

For any queries, please contact the office on **020 7582 1444** or email: office@ataxia.org.uk



Targeting the gene in Friedreich's ataxia

Ataxia UK is pleased to announce that a research grant has been awarded to Dr Natalia Gromak at the University of Oxford. Dr Gromak and her team (below) will be studying the gene that causes Friedreich's ataxia (FA) in a project co-funded by the Rosetrees Trust.

FA is caused by mistakes (or mutations) in the frataxin gene, which contains instructions for how to make the frataxin protein. The mutation in the gene results in the production of less frataxin protein, which causes the symptoms associated with FA.

Genes are a code made up of the letters A, T, G and C. A specific region of the frataxin genetic code contains the letters 'GAA' usually repeated in a chain up to 33 times. For people with FA, the genetic code '**GAA is repeated up to 1,000 times**'. Even though this high number of 'GAA' repeats was discovered as the genetic cause of FA in 1996, we still do not fully understand how this repeat causes FA.

This gap in our knowledge represents a major challenge in the development of efficient therapies for FA.

Dr Gromak, at the University of Oxford, intends to bridge this gap by studying the role of unusual gene structures, called **R-loops**. R-loops are made of genetic material and accumulate around certain genes, interfering with normal cellular processes. Dr Gromak and her team have previously shown that 'GAA' repeats cause R-loops to accumulate in the cells of people with FA. They think that this accumulation of R-loops is what triggers a chain of events that eventually leads to the neurodegeneration seen in FA.

In this new project, they will study the chain of processes that occur following R-loop accumulation. They will examine which other proteins are involved, and how R-loops influence the severity of the FA condition. This research project hopes to make a significant impact on our understanding of the underlying cause of FA and, in the long term, this could lead to new treatment approaches.

Dr Gromak said: "We are very grateful to Ataxia UK and Rosetrees Trust for funding our project on R-loops and contributing towards our understanding of FA pathology. We hope that our research will help us to understand the pathology of FA on a cellular level, and ultimately to design the therapeutic interventions to treat this disorder."



Results of a completed episodic ataxia type 1 study

An Ataxia UK-funded project seeking to better understand the mechanism of drugs used to treat episodic ataxia type 1 (EA-1) has been completed by Dr Paola Imbrici (below) and her team.

EA-1 is a rare form of ataxia that is characterised by short attacks of incoordination, slurred speech and twitching of muscles. EA-1 is caused by mutations in a gene coding for a specific potassium channel, known as the Kv1.1 channel. These mutations prevent Kv1.1 from functioning properly, leading to the symptoms of EA-1.

Ideally, EA-1 would be treated with drugs that activate only the Kv1.1 channel and no other channels. When drugs act on channels other than the desired target, this is known as 'off target effects' and often leads to side-effects. However, there are not currently any drugs available that only target Kv1.1.

Some people with EA-1 are treated with carbamazepine (also called CBZ). Although this drug can be effective towards reducing EA-1 symptoms, it doesn't work for everyone with the condition and is associated with some side effects. The main way that CBZ works as a drug is to block sodium channels. However, Dr Imbrici and her team have shown in this project that CBZ is also able to activate the Kv1.1 channel.

Interestingly, the researchers tested two different mutations in the Kv1.1 channel that cause EA-1. These mutations are known as E283K and V404I. In their study, CBZ was able to activate channels containing the E283K mutation, but not those containing the V404I mutation. However, the researchers noted that **CBZ was able to reduce symptoms in people whose EA-1 was caused by either of these mutations**. This suggests that although CBZ activates the Kv1.1 channel in the lab, this is unlikely to be the mechanism by which CBZ reduces symptoms when given to people with EA-1.

Also in this study, the researchers showed that a tree resin known as DHAA is able to activate the Kv1.1 channel. DHAA does not have the properties required to be used as a drug. However, the information learned from using this as a tool in the laboratory could be very valuable when designing new drugs to treat EA-1.

These are exciting findings because CBZ and DHAA can now be used as starting points from which to **design new drugs that act specifically on the Kv1.1 channel**. In the future, this could lead to more effective drugs for EA-1 that have fewer side-effects.



Ataxia UK funds new trial investigating non-invasive brain stimulation as a potential therapy for all ataxias

For most ataxias there is no treatment available, but recent studies have reported that applying a low electrical current to the scalp may alleviate symptoms. This technique is known as **cerebellar transcranial Direct Current Stimulation (tDCS)**. TDCS is a portable, painless, non-invasive and easy-to-perform technique which induces activity in the brain. Repetitive stimulations, for example on a daily basis for two weeks, can induce long-lasting effects.

Researchers in Italy have recently conducted a small pilot study in patients with neurodegenerative ataxia to evaluate the potential benefit of tDCS in reducing symptoms, with very promising results. They delivered tDCS to the cerebellum and the spinal cord for two weeks in a double-blind study (i.e. some patients received real tDCS, while others received placebo tDCS with the device switched off). The people that received real tDCS showed a significant improvement in cerebellar symptoms and quality of life compared to those who received placebo tDCS. After two weeks of tDCS treatment, this improvement could be detected for up to three months.

This is the first time this technique has been tested in the ataxias and it is now gaining interest from other research groups around the world. The research team will soon begin a second study in Italy to confirm and extend these preliminary findings, which will be funded by Ataxia UK. This time, they will include a larger number of patients and will repeat the treatment after a three-month break to establish if the effects of the treatment last on a longer-term basis.

People with **Friedreich's ataxia (FA)**, **spinocerebellar ataxia (SCA)**, or **multiple system atrophy (MSA)** will undergo two weeks of treatment with cerebellar/spinal cord tDCS (real treatment) versus placebo treatment. The effects of tDCS will be assessed for three months. After three months, all subjects will undergo an additional two weeks of treatment with real tDCS, and effects will be further assessed for another three months.

The project lead **Barbara Borroni** (right), from the **University of Brescia**, tells us: "This project might open a new avenue of therapeutic care for those with neurodegenerative ataxia, and show whether multiple tDCS sessions are able to delay progression of ataxia."



New member needed for SAC

Ataxia UK's **Scientific Advisory Committee (SAC)** is recruiting a new lay member. This role involves **attending Committee meetings three times a year** to discuss research grant applications and contributing to the SAC's discussions on which projects to recommend for funding to the **Board of Trustees**. The Committee consists of **seven to eight scientific members** and **three lay members**. No scientific background is requested; however, you should be interested in the research done on ataxia, be willing to read research project applications (all of which have lay summaries attached) and attend meetings.

More information about the research application process and selection can be found on our website: www.ataxia.org.uk/news/apply-for-funding. If you are interested in becoming a lay member of the Committee, please contact our **Head of Research, Julie Greenfield**, at research@ataxia.org.uk or call the office on **020 7582 1444**.



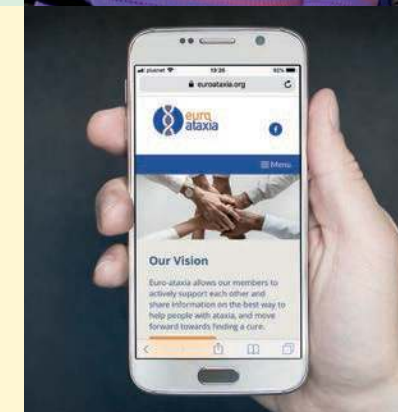
Healthcare professional Q+A videos

Ataxia UK is in the process of producing a series of videos for the **Ataxia UK YouTube channel**. In our latest videos, **Professor of Neuroaudiology Doris-Eva Bamiou** (right) talks to us about the various auditory disorders that occur in Friedreich's ataxia (FA) and other ataxias, and **Dr Antonis Pantazis** discusses cardiac problems experienced by patients with FA. Find these and other videos on the Ataxia UK YouTube channel: www.youtube.com/user/AtaxiaUKonline



Euro-ataxia patient charter

Euro-ataxia is the federation of 19 European ataxia patient groups for which Ataxia UK provides the administration and is an active member. We believe that all ataxia clinical studies **should involve the input of people affected by ataxia** (patients and their parents or carers) and patient group representatives. We have recently developed a **patient charter** which outlines our vision for this, explains why it is important and discusses strategies for how it should be implemented. *The Patient Charter can be found on the Euro-ataxia website: <http://alturl.com/kgw57>*



Patient attitudes to clinical trials in ataxia

Researchers at the **London Ataxia Centre** (Queen Square Institute of Neurology and University College London Hospitals NHS Foundation Trust) have developed a survey in collaboration with Ataxia UK and FARA (US) to investigate **the attitudes of patients towards clinical trials in ataxia in the UK and US**. This survey is important for helping to design better trials for patients and we would value your input. Anyone with ataxia is invited to take part, and the survey may be completed on behalf of someone with ataxia by a carer, partner or parent. *If you are interested in taking part, you can access the survey on our website in the section on 'Taking part in research', or go to this link: www.surveymonkey.co.uk/r/V6CJPLQ*



International Ataxia Awareness Day 2019

It's that time again: time to raise the bar of ataxia awareness across the world for International Ataxia Awareness Day on 25 September. Will you join us?

Awareness is still one of the biggest challenges faced by the ataxia community. In the UK, **only 15% of the population recognise ataxia as a medical condition.** We've heard of people with ataxia being kicked out of clubs, arrested for drunk driving and even detained overnight in airports due to public misconceptions about them being drunk. International Ataxia Awareness Day is the biggest opportunity of the year to tackle the misunderstandings, discrimination and prejudice faced by people with ataxia.

TRIED AND TESTED

This time last year, thanks to those of you who shared our awareness campaign online, **almost 400% more people visited our website** and **over 23 times as many people saw your stories** about living with ataxia on their **Facebook** news feeds.

Thanks to a number of our **Support Groups** and **Branches** braving the wind and rain and taking on an IAAD walk, countless members of the public across the UK learned about ataxia in person. Both online and offline you made a change. Will you again?

INTERNATIONAL ATAXIA AWARENESS DAY 2019

This summer, you helped raise money for brand new ID cards that explain what ataxia is. Now, we're getting that message out there online and disrupting the misconceptions. Want to share your story? Join our **#DisorderedNotDrunk** campaign on 25 September and get your voice heard.

HOW TO TAKE PART

- **Share your story.** Have you ever been mistaken for being drunk? What happened, and how did that feel? Tell us, and we'll share it.
- **Follow and like** our Facebook, Twitter and Instagram profiles so you can see, like and share our campaign posts throughout the day.
- **Sign up to our e-newsletter** if you haven't already, and get a goody pack of ready-made campaign materials to share on social media.
- **Use the hashtag #DisorderedNotDrunk** when engaging with this topic online.
- **Join a Support Group or Branch** in raising awareness on the streets of your local community (read more on p. 13 or contact the Fundraising team).

Contact us at communications@ataxia.org.uk or call the office on **020 7582 1444** for more information and advice on any of the above.



Read **Tara's** case study on our website: www.ataxia.org.uk/Blog/disorderly-not-drunk-taras-story

Ever considered music therapy?

Leanna Coleman (LC) from Ataxia UK talks to **Tony Kaye (TK)**, co-ordinator of the NW London Branch and Ataxia UK Trustee, and **Elaine McGregor (EM)**, a music therapist at *Nordoff Robbins*.

LC: Firstly, Elaine, what is music therapy?

EM: Music therapy aims to facilitate physical and emotional wellbeing, while developing and retaining communication skills. A wide range of instruments can be used, including the voice, and the music created is often improvised. Music therapists support people to develop their own ways of being musical in order to help them explore their potential and connect with the world.

LC: Brilliant, so, how can music therapy help someone with ataxia?

EM: Broadly speaking, music is processed in many parts of the brain, which makes music therapy an excellent tool for people living with ataxia. It can play a crucial role in rehabilitation, enhancing connections between the motor and auditory systems. Making music together can help patients combat depression and help provide a sense of community.

LC: For anyone who may be interested in trying music therapy, what advice would you give?

EM: *Nordoff Robbins* is the largest independent music therapy charity in the UK and has music therapists all over the country. I would always recommend trying music therapy, but please don't hesitate to contact us if you have questions!

LC: Tony, congratulations on your 10-year anniversary of the NW London Branch! What inspired you to choose music therapy?

TK: As luck would have it, our friend's fiancé used to work for *Nordoff Robbins* and she put us in touch with Elaine.

LC: How did everyone respond to playing with instruments during the party?

TK: Whenever there is food, particularly scones, the atmosphere is always good! When Elaine handed out instruments, we were greeted with smiles and laughs as everyone had fun bashing drums and cymbals in time to her singing.

LC: After hearing Elaine talk, how do you think music therapy could benefit someone living with ataxia?

TK: Music appears to cut through things and even if you have speech difficulties you may be able to hit a cymbal or bash a drum and get involved in something creative. We could see that everyone went away in good spirits.

LC: This year's Annual Conference has a breakout session on music therapy. What advice would you give to encourage people to go along?

TK: Like most things in life, if you don't give it a try, you won't know, and music is a universal language that we all understand. You don't need any pre-existing skills to participate. There is something really great about bashing a drum - just ask my wife, Deanna!

For more information, visit *Nordoff Robbins*' website here: www.nordoff-robbins.org.uk or call their head office on **020 7267 4496**.



#DisorderedNotDrunk

Are you ready for the Big Give?

It's that time of the year again, folks! One donation, twice the impact. We're so pleased to be entering the Big Give again this Christmas, and here's how you can get involved.

Thanks to your amazing support and the success of last year's Big Give Christmas Challenge, we are pleased to announce we'll be taking part in the campaign again this December! From **12pm on 3 December to 12pm on 10 December 2019**, any donations made online to Ataxia UK will be doubled for no extra cost.

Save the date!

There are currently two Ataxia UK accredited **Specialist Ataxia Centres** across England, but it's not enough for everyone to access this care. Following last year's drive for funds to open children's clinics (more news of this later in the year), this year's goal is to raise **£68,000** to improve access to diagnosis and treatment for ataxia patients. Our feedback from patients is that our centres offer the best support and care available. With your help to raise enough money, additional clinics can be opened to support the 10,500 people with ataxia across the four home countries where there is a neurologist expert in ataxia.

We aim to increase and improve the availability of these services, for example, by trying to set up a virtual clinic to enable people to access them at long-distance, or to establish new clinics. When we've done this, whether you're visiting one of our existing or new centres in person, or the virtual clinic, we hope you'll be able to receive the specialist support and care you deserve.

If you're thinking of making a donation towards the Big Give Challenge this Christmas, remember to get the most out of the campaign and donate between **3 and 10 December 2019 to double your donation**. If you donate **£50** online and you're a UK taxpayer and you **Gift Aid** your donation, your gift towards the establishment of a new ataxia centre will be worth an incredible **£125** at no extra cost!

Stay tuned for more information on taking part in this year's **Big Give Christmas Challenge** in the next issue of *Ataxia Magazine* and monthly e-newsletters.



Want to join a fundraising event this year? We've got something for everyone. Whether you adore the outside or you're a baker at heart, join **#TeamAtaxiaUK** and get involved!

International Ataxia Awareness Day: Walk Together 2019

On 25 September, we hope as many people as possible will come together across the UK for **International Ataxia Awareness Day (IAAD)** on the day or over the weekend. After the fantastic result of 2018, why not join this year and organise your own walk? Think of the awareness and funds we can raise through individual walks across the UK to make it the biggest collective walk yet! From Land's End to John O'Groats and Belfast to Cardiff, let's get ataxia out there. So gather your families, friends, colleagues and local Branch or Support Group, to show off your colourful t-shirts and walk, skip or push (or do all three!) to come together. We will support you all the way, so get in touch and we can chat through your brilliant ideas, and get you started!

Hats on, it's time to bake

With Halloween, Guy Fawkes night and St. Andrew's Day just around the corner, now is the perfect time to get baking and raise some dough for a great cause. There will be a lucky prize for the best cake bake, so get competitive and you can have your cake and eat it! Get started now by requesting your very own free scrummy **Cake Bake Pack** from the **Fundraising team**. Contact: fundraising@ataxia.org.uk

Superhero Winter WonderWheels

Do something fun and festive to keep you motivated during the colder months by signing up for the Superhero Winter WonderWheels on 1 December 2019. Walk, run, push or anything in-between around Dorney's spectacular Lake in Surrey to complete the course.

There is something for everyone at this fully inclusive event for all ages, where all gadgets and gismos are welcome. Choose from 1km, 5km or 10km and if you have ataxia, you can also sign up a friend or two (your sidekicks) to push or guide you!

Make sure to add plenty of Christmas sparkle to those Superhero costumes!

For more information on all of these events, contact: fundraising@ataxia.org.uk or call **020 7582 1444** **#TeamAtaxiaUK**



Fundraising thank-yous

Congratulations and an enormous thank you for all your generous fundraising. Your dedication continues to support ataxia research, and care and support services.

Thank you to **Hannah Roberts (4)** for her **dedicated haircut** and raising £350, as her **nain** has a rare form of ataxia.

A huge thanks to **Amanda Evans (5)**, **Diana Kilmartin**, **Chloe Kilmartin** and the team for taking part in the **5k Colour Rush**, raising an incredible £732. An extra thanks to Amanda who has cerebellar ataxia, for organising the event.

Special thanks to **Anthony**, **Dionne** and **Havana Ide (1)** for climbing **Mount Snowdon** in just over four hours. The family has raised an amazing £2,677 in memory of their dear niece, **Natasha**.

A big thank you to **Martin Black (2)** for completing the **Stanwick 10K Road Race** and raising £780. Martin ran in memory of his **mum** who had cerebellar ataxia and who loved going to Stanwick Lakes.

Well done **Heidi Oldfield** for completing the **Chester Half**, which she did as many of her family have ataxia, raising a smashing £545!

An enormous thank you to **Henry Sallitt (6)** and team at FPE Capital for raising an outstanding £11,000 so far by tackling the **100km Jurassic Coast walk**. A remarkable effort from everyone and congratulations to you all.

Well done to **Aynslye Stevenson (7)** and her team for taking on the mighty **Tough Mudder 5k Scotland**, raising £802.

Another big thank you goes to **Diane Wiles** and everyone at **Incorporatewear Ltd** for kindly supporting us for 10 years and recently raising £1,823 with a fun day and fun run!

Congratulations to **Ian Morley (8)** and his team for organising the terrific **#AtaxiaCC walk** from **Middleton Sports Club** to **Portslade Cricket Club**, raising £2,776. Thank you to the cafés who kept the team going!

A big thank you to **David Lawrence** and **Bluebird Care** for a very successful collection at **Tesco** which raised £419.

We were honoured to be chosen as **York Golf Club Ladies' Charity of the Year**. Thank you to the ladies' Captain, **Philippa Ashley (9)**, for all her hard work and everyone at the club for raising an impressive £4,433.

A round of applause goes to **Holy Trinity Primary School (3)** in **Lincoln** for raising £423 with a **Football Fundraising Day**, celebrating the achievements and determination of one of their pupils who has ataxia.



A loud Hooray! to **Joe Betts (17)** and the **Brewhouse Streetly** team for raising £865 by combatting **Hadrian's Wall** together - thank you and go team!

Thank you to **Olivia Clark** and friends for taking part in a fantastic **Clothes Swish**, selling unwanted clothes and raising £625! Thank you too to the **White Stuff** for match funding Olivia £250.

Thank you **Neil Dearnley (14)** for completing the **Leeds Half Marathon** in 1 hour 45 minutes, raising £1,177. Well done to **Olivia Corkery** who also did the Leeds Half, raising £185, and scored a shout-out to Ataxia UK by the host.

Congratulations to head teacher **Sarah Hearn** and teacher **Russ Varnam (15)** for completing the **Lee Valley Velo Park Half**, raising a whopping £1,498. One of their pupils at **Haynes Lower School** has ataxia. The school have fundraised as part of the efforts too - thank you!

A HUGE thank you goes to our incredible **#TeamAtaxiaUK runners (13)** who completed the **London Marathon 2019** and have raised a whopping £20,000! Thank you **Teresa, Natalie, Elin, Nicki, Debbie, Sophie, Heather, Christopher, Danica** and **Andrew** - we are so proud of you. You all made a huge effort with your training and fundraising, and pushed the boat out to boost your donations. Also, thank you to our brilliant volunteers, **Nicolette, Louise** and **Sarah**, who were a great support on the day.

Congratulations to **Max Titmuss** for completing the **Great Wall of China 42km marathon** in his Leon Paul Apex fencing kit - raising £2,258! Thank you too to **Leon Paul** for their incredible support.

Many thanks to our **Trustee, Andrew Downie (10)**, for taking on the challenging **Channel to Channel cycle**, raising £4,436! Andrew's son, **James**, (former Trustee of Ataxia UK), has FA and the family continue to take on exciting activities.

Superb effort from our **Support Groups** with the **Great Midlands Fun Run (16)** - **Sue Deane** and **Patricia Castledine** gathered a team including **Kerry Burns, Megan Spilsbury, Jonathan Stone** and **Robert Castledine** for this year's event in the sunshine, with their funds still being counted. Well done!

An epic thank you to **Philip Clark (11)** for completing his first ever triathlon - the **Cotswold Triathlon** - raising just under £3,000! As a family, they have been doing numerous events over the last 18 months and we're very proud to be **Charity of the Year** for Philip's company, **Bristol Mortgages Online**.

Congratulations to the incredible **Lucy Smith** and **Mike Evans (12)** for braving the cold 14°C waters for the **Great North Swim!** They have raised over £2,700 so far and Mike's **employer** is kindly matching donations, too. Thank you for your ongoing support.

Thank you to **Carol** and **Allen Price (18)** for raising an amazing £1,118 by transforming their garage into a **department store** and hosting a **cake sale!**



Finding the right fit for you

Choosing the right kind of walking aid or wheelchair can be a challenge. We asked the ataxia community for reviews on different equipment, and here Matt shares his transition from a manual to a power wheelchair.

I began using a wheelchair in 1993 to increase my independence and live on my own. Accepting that I had to use one, however, was difficult. For someone who is not a wheelchair user, a wheelchair can represent something terrible (a devastating accident, life changing injury or a debilitating disorder). To someone who needs to use a wheelchair, however (like myself in 1993), it can remove barriers and promote ability and independence. I just had to shift from one mind-set to the other.

The only way I could live on my own was to use a wheelchair. Sure, I could get around my house by leaning on the walls and putting handrails where I needed them. But the way forward, I thought, was to become a wheelchair user. Strange it may seem, but one of the main reasons I accepted it was knowing I would be able to make myself a cup of tea and then transport it to the living room to drink. This, of course, is one of the hundreds of things that I can now do for myself, rather than having to rely on others.

It wasn't until 2002 that I needed a power wheelchair to get me out and about. It was also when I took medical retirement from work, so I could spend my days doing whatever, rather than going to an office every day. Again, the overriding thought behind this change was to increase my independence.

Then, I realised I needed a car so I could take my wheelchair out with me. With a bit of a battle lasting several years, I eventually got myself a **WAV** (wheelchair accessible vehicle). This allowed me to drive myself and I could also take my wheelchair with me. I got an internal transfer WAV, so I could transfer to the driver's seat, having entered the vehicle through the back.

For many years I used both a manual and power chair. I eventually became fed up with this and now I have a chair which is both manual and power. All I have to do is take it in and out of gear by adjusting two levers. I would say to always begin with a manual chair, then you can always try a power chair later on.



Matthew Law
[matthewlaw1968](https://www.facebook.com/matthewlaw1968)
[@yahoo.co.uk](mailto:matthewlaw1968@yahoo.co.uk)



Wheelchair alternatives

If you're currently not looking for a wheelchair, there are many other types of equipment, such as rollators, crutches and walkers that can aid your independence when getting around.

Pinjem [HealthUnlocked] has gluten ataxia and uses the Trionic Veloped rollator.

"I use the Trionic Veloped Sport rollator (right). I can sit and recover when I need to and carry my lunch or extra clothes in the carry bag. It folds to go in the car and has both pavement and rough terrain settings. The rollator gave me freedom to go outside by myself and even in the snow. It's expensive but worth the money - you may find it cheaper on eBay."

Price: £934.80. Where? www.trionic.uk/en/veloped-sport-c-8

Jason (right) is 46 and has spinocerebellar ataxia type 2 (SCA2). Jason uses crutches and a rollator.

"My physiotherapist recommended crutches which help to keep me balanced and mostly central. She also taught me to walk better with my rollator by keeping a straight back and engaging my core muscles. This has helped tremendously with my walking; both inside the house and out. I'd urge anybody who feels they are struggling with walking to ask their GP about the availability of targeted neurological physiotherapy."

Litty, 57, has spinocerebellar ataxia type 1 (SCA1) and uses various rollators.

"For walkers and rollators, definitely try to get four wheels rather than three for more stability. Good brakes are essential and the bigger the wheels the better! I use a Stannah rollator for the width (it's narrower) and the net for all my essentials. Although, it must be said the brakes aren't great!"

Price: £199. Where? www.dolphinliftskent.com/mobility/walking-aids/stannah-active-rollator

"For outside (where we have gravel and slopes), I need bigger wheels and better brakes, so I use the Topro Olympos." *Price: £349. Where? www.topro.co.uk/topro-olympus-rollator-4 or try Amazon for prices as low as £239.*

"Upstairs I use a Nitro Rollator (right)" *Price £159.99. Where? Search 'Drive red nitro 4 Wheeled Premium Rollator with Backrest, Seat and bag' into Amazon.*

Harriet Bonney (right) is 43 and has idiopathic cerebellar ataxia. Harriet uses a mixture of walking aids.

"I 'furniture walk' around my flat; I use a stick when outside but if I am going further than my own gate I link arms with another person as well as using my stick. I have tried to use a walker, but my feet kept getting tangled up with the wheels, leaving me feeling more unstable. If I am going somewhere and know I will have to walk a long way, stand for a long time or have to negotiate lots of obstacles/people, I use my manual or power chair."

Thank you to all who contributed to this article and shared your tips and opinions on various types of equipment.

For more discussion around this, you can sign up to the Ataxia UK Health Unlocked forum – used by over 3,000 – for free! <https://healthunlocked.com>



Places to change

Kimberley Edwards has Friedreich's ataxia (FA) and has started the campaign *Places to Change* due to the lack of accessible toilet facilities in North Wales.

My ataxic symptoms began at the age of ten when it became apparent that my sister, who is six years younger than me, had a steadier grip. I couldn't be trusted with carrying drinks or holding plates of food.

Between 11 and 19 years old my mobility slowly deteriorated and I was using an electric wheelchair by 24. I had a spinal infusion operation at the age of 30 which changed everything for me. I could no longer do things independently but had to rely on support with everyday tasks such as washing and dressing. This is difficult even at home, so the challenges are much worse out in public.

There is a desperate need for more accessible changing places across North Wales. People with disabilities can easily feel excluded from their local towns because they are not able to have their basic human needs met: to simply use the toilet.

I visited Liverpool Hospital once and their 'changing place' facility was so small you couldn't swing a cat in it. It was in the spinal department, which should have been a big clue that the toilet ought to cater for different abilities.

I am determined to campaign and raise awareness for local authorities across North Wales to pay attention, and to ensure everywhere is accessible and meets everyone's needs. That's why I've started the **Places to Change campaign**, which calls on local authorities across North Wales to ensure everywhere is disability friendly and meets the needs of everyone. I have set up a Facebook page, a steering committee and have been featured in different publications. We are now beginning to formulate a plan of action moving forward.

Having proper changing places will make disabilities visible to the public. It will help to reduce the ignorance and stigma whilst enhancing the general public's understanding of a variety of disabilities. But even more than that, it's miserable having to put a time limit on days out because I can't use the toilet and maybe you have been in this situation, too. Therefore, speaking out and making places more accessible will enable us to enjoy a day out without the stress of accessing toilet facilities, and will improve our general social inclusion.

If you think the same, then please join the campaign by visiting our Facebook page www.facebook.com/todalooo



Improving neurological care services in Wales

Ataxia UK Ambassador and Friend, Carol McCudden, tells us about a survey for patients with neurological conditions in Wales that has concluded with disappointing findings, and how the Wales Neurological Alliance is working towards providing the care patients deserve.

The **Well-being (Wales) Act 2014** was passed on 6 April 2016, but the **Wales Neurological Alliance (WNA)** still had concerns with the growing number of personal stories by those with neurological conditions, revealing an absence of care. The WNA conducted a survey and presented the findings to the **Cross-Party Group (CPG) on Neurological Conditions** (a group in Wales to improve services for people affected by neurological conditions). The findings concluded that social care in Wales is failing and people living with neurological conditions are missing out on vital support and services:

- 80% did not receive any services from a local council as a result of a care plan
- 79% have not been referred to other organisations for support
- 46% have paid out their own money for additional support.

Mark Isherwood, Assembly Member (AM), and Chair of the Cross-Party Group on Neurological Conditions said: "We are deeply concerned that a significant number of people living with neurological conditions are missing out on vital support and services."

The WNA stands to support neurological organisations to campaign together and speak with an influential voice. They get involved with research, influence policies, raise awareness, and improve services for people affected by neurological conditions. They aim for patients to have access to the best care possible, have control over their lives and be able to live free from ignorance and injustice.

Over the years, the WNA's participation has been in reviews of services for patients and assisting in policy development. Some of the key areas they have been involved in are **Neurological Conditions Delivery Plan, Wales Neurosciences Review** and **Clinical Pathways Project**. The WNA are looking for people with neurological conditions in Wales to help lobby to improve care. Can you help? The WNA uses the Cross-Party Group to petition **Welsh Government** and affect change in health and social care.

Want to know more? You can contact Carol directly at cmccudden@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

Your legacy can be hope for the future