

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 209. Spring 2020

Raising awareness in the Scottish Parliament



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

ATAXIA

Ataxia UK

HELLO

**Jessica Lewis**

We're very pleased to have Jess on board as the new **Communications Intern**. She will be working on social media and the magazine. If you'd like to feature in the magazine or on our social media platforms, get in touch!

HELLO

**James Atkins**

A warm welcome to James, our new **InControl Manager**. He has a background in working for charities and is looking forward to working closely with everyone in the ataxia community, and hopefully meeting you soon.

CONGRATS

**Shana De Figueiredo Scholtz**

Congratulations to Shana who was our Admin Assistant, but has now moved teams, to assist James delivering the InControl volunteer project as **InControl Officer**. She is excited to be working more closely with you all!

Welcome

Happy New Year to all.

As we stand looking forward into another year, I dare to hope that 2020 might prove just as positive as 2019 for people with ataxia. The conclusion of the decade marked an end to our **2020Vision** aspirations launched in 2012, which sought a treatment or cure for one or more of the ataxias by 2020. It seemed very optimistic at the time, and lots of people believed it wouldn't be achieved. Although a potential treatment for SCA38 was found by 2017; celebrating a cure when there are no patients with SCA38 in the UK seemed to be cheating! We were therefore delighted at Reata's announcement last November that their drug trial of **OMAV** in Friedreich's ataxia has had positive topline results. Ataxia UK's job now is to provide any support needed as OMAV makes its way through all the licencing and approval stages in the UK and into the neurologists' prescribing repertoire, to be accessible to all FA patients.

Things have also gone really well for Ataxia UK, with the opening of our first **Children's Clinic** in **Sheffield**; a successful Lottery bid to develop volunteering in England; amazing fundraising and giving from you, our supporters; and the wonderful success of the **Big Give** enabling us to start developing **'Virtual Ataxia Clinics'** in the **NHS**.

Here's to another successful year for all of us!

Kind regards,
Sue Millman



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“Winning the European Team Silver Medal was indescribable, a dream come true”

Here is **Mari Durward-Akhurst** to tell the story of her incredible achievement, and the roots of her riding.

I'm 26 years old and have cerebral palsy, a chromosome disorder, ataxia and dystonia. Until recently, I have struggled to find satisfaction with the medical aid I've received.

I have faced many challenges due to my disability, but I have overcome these and believe this has made me into the person I am today. Being proud of my achievements, I have decided it's time to share my story by becoming a public speaker and hopefully inspiring others to follow their dreams.

I started riding at my local **Riding for the Disabled Centre (RDA)** as therapy, and since then have won many awards. I was 11 at my first RDA competition, then qualified for the **RDA National Championships** the following year. I was talent-spotted at a local **Paralympics** competition and since 2007 I have represented **Great Britain at Junior and Young Rider level in International Competition**. In 2016 I won the **Grade 3 Restricted Winter Championships** and in 2019 I won the **European Team Silver Medal at Para Dressage European Championships**.

I was different to other children which made it hard for me to make friends growing up. Riding changed things for me; it helps me physically and mentally; it's something I excel at. The horses are my best friends; they don't judge me. They give me the freedom from using a wheelchair full time.

My riding journey has been full of ups and downs. But the downs are sent to try us and you have to stay strong. My life with disabilities means that I have to fight every day, but thankfully I am a good fighter! There are three thoughts that have helped me, especially on a bad day; following my dreams, everything happens for a reason and, finally, my focus. My ultimate dream is to win a gold medal at a Paralympics and I'm striving towards selection for the **Tokyo Paralympics** this year and going for gold!

If you want to try something new, then go for it and see what happens; at least you tried. I would be lost without my horses and my sport. I forget everything else and smile and enjoy the time with my horses. So, if there is something you have always fancied doing, give it a try!



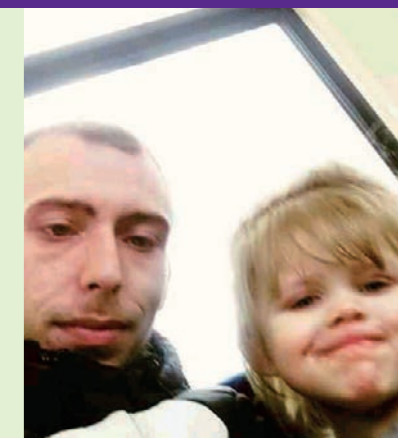
#DisorderedNotDrunk campaign continues ... turning the bad into good

by **Terry Wigzell** (right)

Last August I was treated with disrespect by **TfL** staff when travelling on the **Docklands Light Railway (DLR) line**. Whilst on the train I felt an ataxia attack come on, with little I could do about it, falling to the floor and unable to speak. Two passengers picked me up and dumped me at the next station, assuming I was drunk. The police were called and despite showing my 'I'm not drunk' card to them, I was still accused of taking drugs.

Afterwards, I was very persistent in contacting TfL to complain, with them eventually inviting me to the DLR headquarters for a meeting to discuss raising awareness of ataxia. I met with the head of DLR and a mental health nurse, and my partner and I explained what ataxia is and the effects it has.

The successful meeting concluded with TfL agreeing to display an ataxia poster on their electric billboards and add ataxia into their training programme! I'm so pleased with this result and will continue to hand out leaflets to raise awareness of ataxia, with the hope that it becomes better known. *Find out more about the new ID cards on p.23.*



Group updates

Our **Leicester Support Group** meet at the **Local Hero** to enjoy lunch and catch up. In their last meeting they discussed how exercise is key for mobility and staying in control. **Claire Huggett** said: "Swimming or walking in water is great for keeping muscles toned. I do Tai Chi which helps to calm me down and keep me relaxed. I use my walker to steady me when I'm standing, and a chair for certain moves!"

They next meet on Thursday 26 March, please contact Claire at: chmrh.charjen2@yahoo.com or 01162 848 201.



The **East Branch**, included a helpful tip in their latest newsletter which we thought you might like to hear too:

"When carrying drinks, unsteady walking or wheelchair movements often result in spillage. Drink covers solve this ... I've found the best is a **12cm Diameter Clear White Silicone Cup Cover Knob Airtight Cap Lid on eBay**". Large enough for most cups, they form a good seal when pressed into place. The best price they found was £1.50 for two with free postage. "These covers are also good for keeping flies ... from 'swimming' - besides making it practical to carry them outside in the first place!"

For more information on the East Branch please contact David on 01205 722 771 or djstuble@aol.com.



International Ataxia Research Conference 2019

The 3rd International Ataxia Research Conference, organised by Ataxia UK, FARA, FARA Australia and GoFAR, took place on 14-16 November 2019 in Washington DC. Members of the research department attended, along with CEO Sue Millman, and Trustees Barry Hunt and William Littleboy.

The conference comprised of two and a half days of updates from 250 researchers worldwide. We were also delighted to see 140 representatives from pharmaceutical companies as rare conditions, such as the ataxias, can struggle to gain attention. These 140 representatives show promise that they are interested in researching cures and treatments for the ataxias, and this is partly down to the active involvement of the ataxia community, represented by 17 different patient groups.

The research discussed ranged from early stage laboratory-based studies to clinical trials. There were updates on gene therapy studies, with researchers looking at different techniques to develop gene therapies for Friedreich's ataxia and spinocerebellar ataxias. A session highlighted lessons to be learnt from other neurological conditions, so that ataxia clinical trials can be better designed and therefore more effective. One potential method focussed on finding new biomarkers to measure ataxia. Clinical rating scales are often used to measure the severity of ataxia during clinical trials. However, the scores on these rating scales have to be measured over a very long period of time in order to detect improvements in response to treatment. Alternatively, a group in Australia presented a novel technique where ataxia patients were asked to mimic eating cereal using a spoon which measures movement. This could be a more sensitive way of measuring ataxia, equalling shorter and more informative clinical trials.

On the final day, **William Littleboy (co-chair of Ataxia UK)** took part in a platform patient panel discussion which discussed the symptoms that the panel feel are a priority for research, and their hopes for future ataxia research. As one of the organising groups, Ataxia UK was delighted that 90% of attendees thought the conference was extremely, or very, useful for advancing their work, and 97% gave the scientific content at least three out of four stars.

Thank you to everyone who submitted photos and responses to be included in a presentation shown during the conference. It provided the attendees with real-life insight from those living with ataxia and helped to demonstrate to them the importance of research.



FA Global Patient Registry

The **Friedreich's Ataxia Global Patient Registry (FAGPR)** has been launched! It has been developed by charities from across the world, including Ataxia UK, as the international registry for FA research.

What is the FA Global Patient Registry?

Ataxia UK has had a basic patient registry for many years, containing contact details for patients in the UK. Similarly, the US charity **FARA** has had a registry which has collected data from over 3,700 patients. These registries quickly identify eligible patients for clinical trials and research studies, and this quick accessibility is one of the reasons pharmaceutical companies became interested in developing treatments for FA. With our global partners we have built a new international registry: the FA Global Patient Registry (FAGPR). This pools together all the data in one place, making it a more powerful resource for research. The FAGPR will have more comprehensive information and will promote global trials, as well as eventually being available in multiple languages and devices (e.g. computer, phone, tablet etc.).

Why is a Global Registry for FA so important?

In order to develop new drugs, researchers need an understanding of the disease, its progression, and patient experiences. For successful clinical trials, ease of recruiting patients is important - especially in a rare condition where we have a limited pool of patients. The FAGPR has been built to collect patient information and match patients with studies.

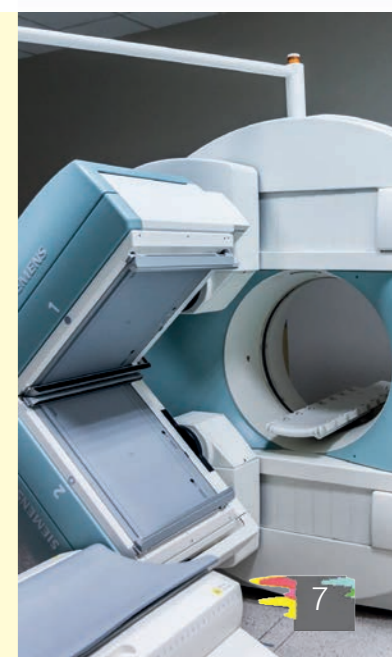
How do I register?

Go to: www.ataxia.org.uk/news/for-people-with-friedreichs-ataxia.

Head of Research Julie Greenfield says: "We are very pleased to have joined forces with charities worldwide to develop and run the FA Global registry. Ataxia UK has a lead role, together with FARA, in taking on the responsibility for the continued support of the Registry and having an active role in its governance. We hope many people with FA around the world will join and that it will be a very useful resource for researchers."

Research study into SCA2 and SCA6

Using **Magnetic Resonance Imaging (MRI)** technology, researchers at **Cardiff University** have developed new methods of looking at the brain. They aim to improve their understanding by conducting brain scans of healthy volunteers and patients with movement disorders. The researchers hope that the study will make monitoring patients easier and help to plan future clinical trials. The study is recruiting 20 people diagnosed with movement disorders, specifically including patients with **SCA2** and **SCA6**. If you want to take part, have SCA2 or SCA6 and can travel to Cardiff (travel expenses covered); please contact: **Dr Kathryn Peall, Neuroscience and Mental Health Research Institute and the BRAIN Unit, Cardiff, CF24 4HQ, tel: 029 20 688 338, email: PeallKJ@cardiff.ac.uk**.



Investigating the potential therapeutic benefit of low oxygen in FA

Several patients with Friedreich's ataxia (FA) have reported an improvement in their symptoms at high altitude, where oxygen levels are reduced. Ataxia UK is supporting a project, which will explore how low oxygen levels (known as 'hypoxia') may lead to a measurable benefit for people with FA.

The project will be led by **Professor Hugh Montgomery** from **UCL Institute for Sport, Exercise and Health**, and **Professor Paola Giunti** and **Dr Gilbert Thomas-Black** from the **London Ataxia Centre** at the **UCL Institute of Neurology**.

The UCL group reported that a person with FA, who was previously unable to sit unaided, was able to, at an ascent of 4000m with exposure to low levels of oxygen for five days. Improvements to his ataxia continued to an altitude of 5895m and remained for four to six weeks after descent to sea level. The team have since made efforts to discuss with patients who have travelled to altitudes above ~2000m. The few cases identified so far report that they felt improvements in their condition, with one going so far as to say: "It's like my ataxia is taking a holiday!". Data from cell and animal experiments have supported this evidence and provided some insight into how this might happen.

The researchers want to assess if these findings can be replicated in a controlled experiment. The study will involve a small number of patients with FA, all of whom have previously been to high altitude (>3000m) without any problems. The researchers will perform a number of examinations to assess the effect of the exposure to low oxygen. If data from this initial study supports the claim that hypoxia may have therapeutic benefits in FA, further studies will be needed.

Below. Iain Fryatt atop Kilimanjaro



Speech therapy project shows success

In a project funded by Ataxia UK and the Swiss Association of Friedreich's Ataxia (ACHAF), Professor Anja Lowit (right) showed positive results using Lee Silverman Voice Treatment (LSVT) for ataxia.

Many people with ataxia have slurred speech (**dysarthria**) which makes communication difficult. Few studies have been conducted to test speech therapy interventions on people with ataxia, and none have provided evidence to advise speech and language therapists about how to best help people with ataxia.

A research team from **Strathclyde University** investigated the effectiveness of LSVT in improving communication in 20 people with ataxia, including FA, SCA6, idiopathic CA and spastic paraplegia type 7 (SPG7). LSVT has previously shown positive results in people with Parkinson's disease.

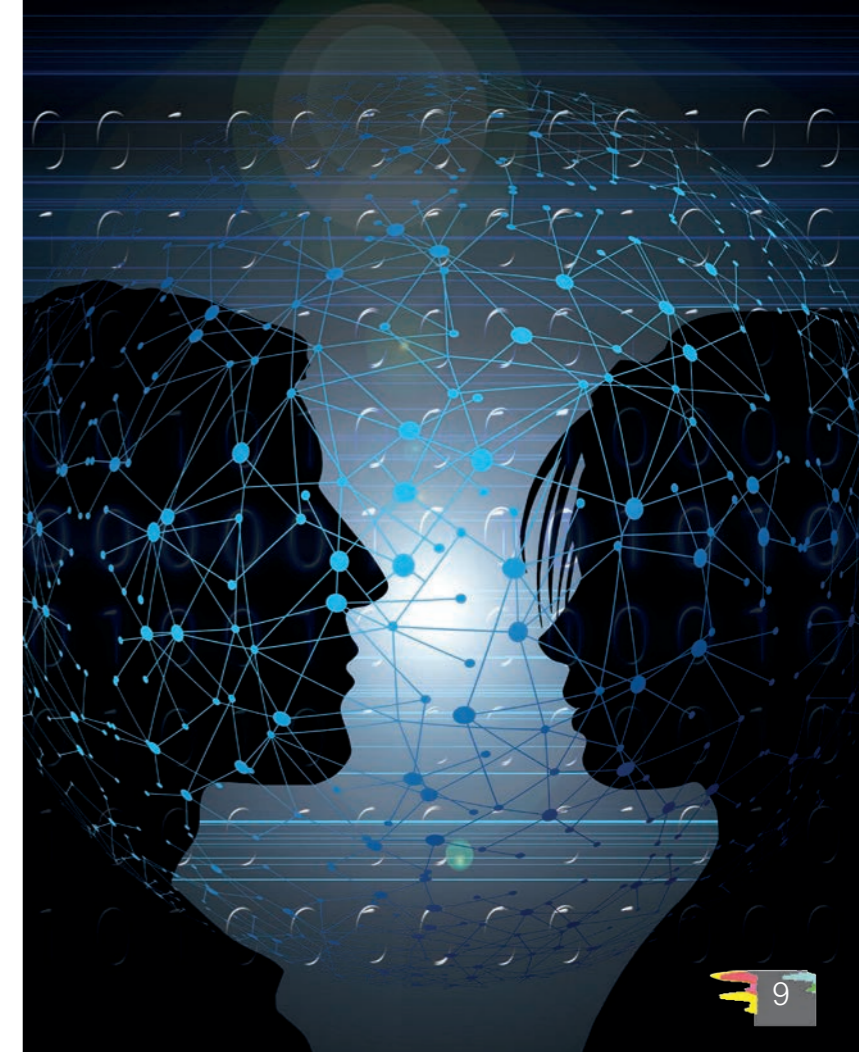
Sessions of 50-60 minutes were administered via Skype, twice a week over eight weeks and patients were advised to practise another four or five times a week.

This study represents the largest speech therapy treatment trial conducted on people with hereditary ataxia, and the results are very encouraging. After therapy, participants had more breath available to speak, resulting in improvements in their voices which sounded less strained. The study did not show improvements in ability of others to understand participants when listening to recordings, but many felt they sounded clearer or had to repeat themselves less, and were more confident when communicating. Outcomes reported by the participants demonstrate that they felt less anxious while communicating or required reduced effort for speaking, and were important factors that can be used as a measure of success of the treatment.

Professor Lowit said: "We are excited about the outcomes of our study as it shows that people with ataxia can improve their communication with the help of speech therapy. Although the treatment could not improve everybody's speech, the majority of our participants reported benefits and we now plan to do further research to be able to help a wider group of people with ataxia."

The researchers suggest that speech and language therapists consider providing LSVT treatment for people with ataxia, provided that the impact of the treatment is closely monitored.

Speak to your speech and language therapist, or contact **Professor Lowit** (a.lowit@strath.ac.uk), if you would like to know if this treatment might work for you.



Our Scottish Conference will take place on Saturday 6 June 2020 at the Leonardo Hotel, Edinburgh, EH12 6UG. The conference will be packed full of events tailored to our Scottish delegates. You can visit our website <https://bit.ly/2FVMsRK> to discover more, book your tickets and find out how to apply for a bursary.

WHAT'S IN STORE?

Hear the results of our **Financial Inclusion Survey**; help to design our **Scottish Money Advice Service**; research updates; Scottish improvements to NHS neurological and rare diseases services; **'It Works for Me'** sessions, plus more. Registration opens at 9.30am and the conference begins at 10.00am until 5.00pm. If you would like to do an 'It Works for Me' 10-minute presentation please contact **Sue Millman** at the office.

We have brand new **'All About Ataxia'** videos to showcase in our seminar on Friday (5 June) afternoon giving information on the progression of the condition for those who are newly diagnosed. It will go ahead if 10 people are interested. Please let us know you're interested by emailing conferences@ataxia.org.uk. There will be other breakouts so watch this space for more information.

BOOKING

Book online at <https://bit.ly/2FVMsRK> or call the office on **020 7582 1444** and ask for **Shana** or **James** who will take your booking. Booking closes **25 May**; if you need to book a ticket after the closing date, there will be a £10 admin fee per person per ticket.

Tickets for Delegates ...	All About Ataxia (if enough are interested)	Rate (incl. lunch) up to 25 May	Rate (incl. lunch) after 25 May
with ataxia	£25	£36	£46
without ataxia	£25	£39	£49

Please note: If you book tickets online or over the phone with a member of staff, you should receive an email confirmation from us that your booking has been successful. If you don't receive confirmation two weeks after you made your booking, please call the office to check that your booking has been successful.

BURSARIES

We have limited bursaries which cover half of delegates' fees and travel costs for those on means-tested benefits. Applications must be in by **1 May** and are awarded on a first-come, first-served basis. (Half of accommodation costs can also be met through a bursary, if accommodation is required to attend). **Only one claim** for a bursary can be made per year for conferences.

ACCOMMODATION

Ataxia UK has negotiated rates of £99 for a single room and £109 for a double/twin room including VAT and breakfast. Secure yours by calling the hotel on **0131 535 9988** and quote **'Ataxia UK'**. There are 2 fully-accessible wet rooms at the hotel, held for our delegates. There are also a number of cheaper alternatives nearby. Parking is complimentary, with lots of space. Any queries, please call **020 7582 1444**. We look forward to seeing you there!



Special guest, Tom Clouse, visits the South Downs Support Group

Rocana Bishop, from the South Down's Support Group, recalls her experience meeting Tom Clouse.

When I was finally diagnosed with ataxia, after many years of tests, the first thing I did was search the internet for hope and support. I found the support through Ataxia UK and hope of alternative techniques through Tom's website.

In October last year, 21 of us gathered for an afternoon with Tom. He was diagnosed with spinocerebellar ataxia type 14 (SCA14) just three years after qualifying as a surgeon, and had to give up the job he loved. When his movement got worse, he would only go for walks when it was dark because he was embarrassed to be seen 'stumbling around'.

In 2003 he was advised to get a walker, but now, 16 years later, he doesn't even need a walking stick. Through observing how those with ataxia walk and move, and how other people walk and move, he has re-trained his movement and posture. Since then he has spent many years trying to teach others the same.

I emailed him and asked if he had any plans to come to the UK and when he replied to say that he would be coming over in October and that he could come down to Eastbourne, it was too big an opportunity to miss. A group of 21 people joined from all over the south of England and one person even came up from Cornwall to see him.

Tom spent five hours with us, helping us feel stronger and sturdier on our feet. He managed to help us individually to walk better, to get in and out of a chair more easily and how to play golf better. He brought along a lovely physiotherapist friend called **Diane** (from London) who also worked with us, and is training in his technique.

Learning to become more stable will require us to work hard, but having seen Tom's achievements, I am optimistic, and after our one session I am feeling more stable and balanced already. Tom is bringing out a book which will offer some alternative methods with the aim to help all of us with ataxia, as well as working on a new website which will have videos to demonstrate his techniques.

You can visit Tom's current website: <http://walkingwithataxia.com>.



Spring Raffle 2020

Ataxia UK's Spring Raffle is back! Take part today and help transform the lives of thousands of people across the UK living with ataxia. You'll find two raffle books enclosed in this issue (please request yours if you're viewing this by email). Each book contains 10 raffle tickets which are sold at £1 each and a book of 20 tickets cost £20. The money raised will help fund Ataxia UK's support services and ataxia research. Sell as many tickets as you can to friends and family to increase the chance of winning one of our wonderful prizes, including a **top cash prize of £200!**

HOW TO PLAY

Step 1: Fill in the full name, postal address and telephone number on each ticket purchased by the raffle player. Please use BLOCK CAPITALS.

Step 2: Send your donations along with the purchased raffle ticket(s) to Ataxia UK using the enclosed FREEPOST envelope, by **Monday 4 May 2020**. Please note: you can request more raffle books by emailing fundraising@ataxia.org.uk or call us on **020 7582 1444**.

The Spring Raffle draw will take place on **Monday 11 May 2020** at the Ataxia UK office.

A very Big Give thank you!

Last December Friends of Ataxia UK helped to raise an incredible **£78,472** to improve access to diagnosis and treatment.

Your amazing generosity concluded the campaign as one of the most successful Christmas campaigns you have helped to support.

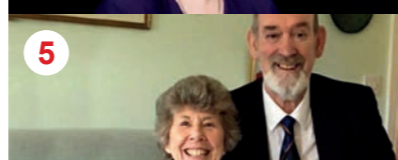
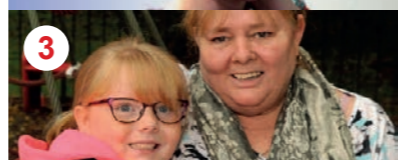
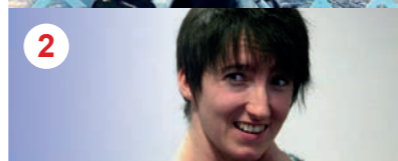
Thanks to all those who donated, our major donor pledgers and our match-funders (**The Candis Club**). We hit our **Big Give Christmas Challenge** target of £68,000 to improve access to diagnosis and treatment by piloting a virtual ataxia clinic within six days! An amazing accomplishment which we would not have achieved without your support.

We'd also like to say a BIG thank you to **Georgia Hart (1)**, **Taryn Cotton (2)**, **Ceri** and **Jade Pepper(3)**, **Gemma Fish(4)**, and **Ann** and **Bill Truscott (5)** for sharing their own experiences in accessing local support. We know that many Friends could relate to them.

Please stay tuned for more information on the virtual ataxia service in future issues of Ataxia Magazine.

Big Give Christmas Challenge 2020

After the success of the 2019 challenge (raising £78,472), Ataxia UK is now applying for the Big Give 2020. If you would like to contribute as a pledger towards our matching pot of available funds, which will be used to double supporter donations this December, please contact fundraising@ataxia.org.uk or call **020 7582 1444** for more information.



E V E N T S

Manchester Half Marathon

A huge thank you and congratulations to our impressive Manchester Half Marathon runners who not only conquered the course, but raised over £10,300 - with donations still coming in! Well done you absolute stars **James Riley, Adam Caulfield, Isobel Holt, Grace Turner, Scott Jones, Matt Gough, Matt Dobson, Maddie Clark, Briony Wills, Victor Choules, Dawn Cortlett, Michelle Ellis** and **Mark Fraser**. A big thank you to **Don Cortlett** too, who did some exceptional fundraising for the team.



Royal Parks Half Marathon

A massive thank you and congratulations to our amazing Royal Parks Half Marathon runners for raising over £15,000! - our biggest running team yet! **Alex Barraclough, Karen Wilson, Cydney Adams, Rachel Drinkwater, Rowan Shukla, Maya Shukla, Taha Gulamhusein, Glenn Trafford, Debbie Foreman, Gemma Whitehead, Emma Worwood, Harriet Dunstan, Tony Morrison, Alicia Edgar, Cassie Luttig** and **Sarah Graham** - you absolutely smashed it!



Birmingham Half Marathon

Congratulations and thank you to our wonderful team at **Lambert Smith Hampton** in **Birmingham** who chose Ataxia UK as their charity of the year, raising over £2,000! The team took on the **Great Birmingham Half**: **Louise, John, Ankur, Scott, Gavin, Tim, Natalie, Louisa, Thomas, Dean, Colin, Henry, Andy, Patrick, Ewa** and **Mark!** We are so grateful to you all - thank you!



Edinburgh Kiltwalks

A big round of applause and thank yous to our kingpin Edinburgh Kiltwalkers: **Jan, Donald, Connor** and **Elizabeth McLeod, Mike** and **Irene Ewing, Maureen** and **David Coyle, Bojan** and **Michael Jones** and **Jacqueline** and **John Fletcher** who teamed up as **Clan McLeod**, and great friends **Maya Remoy** and **Alexandra Clinton** who together raised a whopping £17,000 with the support of the **Hunter Foundation**. An outstanding effort, thank you.



Shorts for days

Thank you also to **David Arnold** who spent 2019 wearing shorts to raise funds in memory of his niece. David smashed his target of £1,000 and has now raised more than £5,000! Not only has he raised funds, but awareness through news coverage, including the **BBC!**



Fundraising thank-yous

A huge thank you to all the amazing fundraisers and their impressive efforts to support those affected by ataxia. Let's take a look at some of their achievements!

Thank you so much **Declan McGurk, Joe Hodrien** and the team at **The Savoy** who raised a fantastic £1,347 in a thoughtful tribute to **Natasha Graffen** who sadly passed away last year. They created a non-alcoholic cocktail in her memory. Thank you too to **Seedlip Drinks** for matching those donations, and to everyone who donated, raising £2,894 in total.

A big thank you to **Stephen Marsh** and the team at **Three Piggies (1)** in **Liverpool** who chose Ataxia UK as their charity of the year and raised a fantastic £3,270 through their popular weekly quiz nights! Not only have they raised crucial funds but have also raised awareness of ataxia.

Thanks a million to **Carole Stagg (2)** for bravely taking on a **Wing Walk** soaring through the skies and raising £1,583! We look forward to hearing when you book the Loop the Loop!

A big thank you to **Alice** and **Daniel Eland** who trekked the **Three Peaks** as their niece has FA, raising a terrific £510 and completing it in 10 hours 44 minutes! Thank you so much for your support.

Congratulations to **Bee Barbini** who ran the **Richmond Marathon** raising a smashing £170! Bee's **son**, who has ataxia, also did the family mile - thank you for all your hard work.

Well done **Gary Ward** and **Chloe (3)** who cycled an astounding 516 miles of the **Scottish Northern Highlands**, raising an impressive £4,563 – thank you!

Matt Bembridge and all at **Gym Professor (4)** raised £202 by selling tickets and t-shirts at their **OLO RAW** inclusive strength competition in memory of **Darran Stanesby**. A great way to remember Darran and thank you to everyone involved.

A huge congrats to **Lucy Hurley (5)** who climbed to **Mount Everest Base Camp** in memory of her dear friend **Glen**. Lucy has been on the radio raising awareness and raised £4,000! What a great achievement, thank you!

Congratulations to **Craig Lowe** and **family (6)** who gathered together with **Cockerham Sands Country Park** to raise £1,637 from donations, raffles, auctions and charity bingo. Their final fundraising event included **Britain's Got Talent semi-finalists Faye** and **Martin Gregory Lambert!**

Thank you **Roseanne Donegan (7)** who completed the **Bournemouth Marathon** and hosted afternoon tea too! She ran in memory of her friends **Lisa & Micheal McKernan**, raising over £1,100!



Congratulations and thank you **Emma Grist (8)** for taking part in the **Tonbridge half marathon**, raising a fantastic £811!

Thank you to **Elishia Philips (9)** and **Henry Salisbury** who completed a Tough Mudder in memory of their dear **Scarlett**, raising a fantastic £1,983! **Paul Hollingsworth (10)** also ran in memory of Scarlett by completing the **Chester Marathon** and raising a whopping £8,000. Congratulations Paul and thank you for all your work with the local press too raising awareness. A lovely way for you all to remember Scarlett.

Rhydian Hoogewerf organised a white-collar boxing match to raise awareness and £696, as two of his nieces and one of his nephews suffer from ataxia. Congratulations and thank you for all your support and bravery!

A big thank you to **John** who organised a **5-mile walk** from **Baildon Bridge** and raised a wonderful £201. A great achievement!

Thank you to **Alison Cavanagh** and **colleagues** at **Place UK Ltd** for holding an **Office Bake Sale**, raising a brilliant £180 in memory of their friend **Monika Kolodziejuk**. Also thank you to **Inca Charlamow (11)** for holding a **Cake Bake**, raising a fantastic £200! Inca also won our **Cake Bake Competition!**

Congratulations and thank you **Erin, Jack** and **Sophie (12)** for completing the **Thames Bridges Trek** and raising an amazing £1,000!

Special thanks to our **Ataxia UK colleague, Leanna Coleman (13)**, for taking part in a **'Dog Jog'** with her lovely dog **Tilly**, and raising £315.

A big thank you to all of the **schools** and **colleges** supporting Ataxia UK, including **Ullswater Community College** who organised a **Talent Show** and raised a fantastic £717 and everyone at **Wildern Secondary School** for holding a **Non-Uniform Day**, raising a brilliant £250.

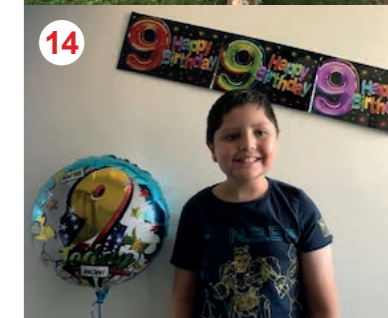
A special thank you to **Kieran Hankin (14)** for asking for donations instead of presents for his 9th birthday and raising a brilliant £160.

A big thank you to **Yvonne Porteous** and **colleagues** at **Matalan** in **Glasgow** for collecting donations and raising an incredible £2,000.

Thank you to **Malcolm Long** for selling **recycled golf balls** and raising a fantastic £140 so far!

A massive thank you to the **Von Dinther family (15)** for organising a **coffee morning** and **sponsored hair dye event** in **Marbury**, raising an incredible £2,445.

A huge well done and thank you to **Michael Fraser (16)** for taking a leap of faith and skydiving, raising a fantastic £164 so far.



Chance2Win Winners

- 1st Prize: £500
Anon (name withheld)
- 2nd Prize: £250
Louise Ames
- 3rd Prize: £150
Sheila Thompson



Matt's journey to living independently

It was in the early months of 1993, shortly after being diagnosed with Friedreich's ataxia, that I applied for my first property. I remember a meeting at my parents' house with a housing officer from **Surrey Heath housing association**. I explained to her that due to my walking difficulties (at the time I was still stumbling around using crutches) I needed my own place that was wheelchair accessible.

I was on the waiting list for seven months and took the first property that was offered to me in a small village called Chobham in Surrey. I moved in on 25 October 1993. Of course, I had no preconceived ideas of what it was like to live on my own and you could say I had a rather steep learning curve to negotiate. But I soon came to realise that it was quite possible for me to live alone, even if I knew that things would take me far longer than they have done before.

I was quite happily working full-time as well as paying my own rent and I can proudly say that it was still the case some nine years later. I suppose in those nine years I came to realise that the property was not really suitable for me at all. Having not seen the kitchen prior to moving in, the narrow size of it became an increasing issue.

On the 7 May 2002 I moved from Chobham to my current bungalow in Lightwater, Surrey. From the experience I had gained living in Chobham, I knew exactly what I needed in my new place. Thanks to the council, their builders did a brilliant job in getting the place to my recommendation. Their major work consisted of knocking down a wall between the kitchen and living room to make it open plan, as well as putting a new back door into the bedroom and blocking up the old back door which was in the kitchen. This enabled me to have plenty of cupboard space and a large turning circle in the kitchen.

Since moving in here some 18 years ago, much has changed for me but, with the help of PAs, I am still able to live on my own, which I enjoy very much.

If you are looking for some help with adaptations in your own home, you can contact Independence at Home for advice:

www.independenceathome.org.uk/our-work.html



Matthew Law
matthewlaw1968@yahoo.co.uk



SpillNot

Physics may not be your forte, but this invention could be. Reviews rave about this saucer stopping your drink from spilling, even when swinging it around!

Carrying a drink from one room to the other can become a challenge for those with ataxia. If your ataxia prevents you from holding and carrying drinks, there could be something out there for you to try. You may have tried various cups that claim to not spill, but 'SpillNot' actually lives up to its promise. It was recommended by a **HealthUnlocked** member and has a five-star review on Amazon including over 30 fantastic comments, with its only downfall the costly price. It is made in America and it costs \$14.95 plus shipping.

You can check out the gadget here: <https://spillnot.myshopify.com> and read some reviews on Amazon.



CEA card

There are various different schemes for those with disabilities, and we think a free ticket for a carer when visiting the cinema is a brilliant one.

Have you heard of a CEA card? It's a national scheme card developed by the **UK Cinema Association** for people with disabilities to use at cinemas across the UK. The CEA card entitles you to one free ticket for your carer once you buy a ticket for yourself. The free ticket is provided on the assumption that the person who accompanies you can provide you with appropriate assistance.

You can visit their website to find out if you are eligible for the card. It costs £6 and you can order one here: www.ceacard.co.uk/apply.



Richard Farrant: “The world is your oyster”

Ever considered travelling but worried your ataxia would get in the way? Read Richard’s inspirational story about his travels to 35 different countries, despite his ataxia.

I was first diagnosed with Friedreich’s ataxia (FA) at eight years old, and my walking became progressively worse throughout my school years. By the time I started university at 19 years old, I had lost the ability to walk. At this point in my life I knew some people who were travelling the world and enjoying their experience; I listened to their stories and admired them, so I started to want that experience. Then two years later, at the age of 21, I decided to travel the world and I have never looked back. I have visited beautiful places and have loved every minute.

At the start of my travels and despite my FA, I chose to travel solo because I wanted to experience complete freedom. I was able to decide where I wanted to go, when and how I would make it. I had to travel on a tight budget, so would often stay in hostels rather than hotels, and I would travel by any means available: hitch hiking or being towed around Asia behind a motorbike ... you may call me inventive!

Unfortunately, my travels couldn’t stay solo forever; as the years went by, it became harder to do things on my own. Being able to control my wheelchair was a big part of my independence and, as that decreased with my condition, it made it impossible for me to continue my solo experience.

Most of my experiences have been good on different levels, but when visiting Asia, particularly the Philippines and Thailand, my disability wasn’t an issue for them and I was made to feel the same as everyone else. I was very comfortable in my surroundings in those two places.

My website **GlobeWheeling.com** has been active for a few years but the travel journal, photos and basic documentation has been collected over 25 years.

I hope Globe Wheeling will show people the possibilities of a full and active life if you take away the constraints associated with having a disability. I hope my experience, knowledge and love for the world will inspire people to create their own experiences. *Please feel free to email me through <http://globewheeling.com>.*



Scottish Parliament hears Connor’s story

Connor Beveridge has lived with Friedreich’s ataxia (FA) since he was nine years old. At 24 years old, he has faced challenges with the welfare system; however, recently his story was read out in the Scottish Parliament by his Member of Scottish Parliament (MSP), Jenny Gilruth.

The most vulnerable people in society always bear the brunt from the ‘blame game’ caused by austerity.

Although I was diagnosed with FA when I was nine, my parents chose not to tell me about the condition until I was 16. I blamed all my symptoms prior to this on my aggressive scoliosis. When I did find out about FA, I was unable to deal with it; I shut it out and used all my energy to focus on my studies. After school, I went on to study a degree in accountancy at my local college which helped to continue the deflection.

My involvement with the welfare system came once I graduated, and the realisation of FA and my inability to work began to sink in. My initial **Disability Living Allowance (DLA)** assessment, and then a follow up **Personal Independent Payment (PIP)** assessment, although degrading, were relatively straightforward. However, my transfer from **Jobseekers Allowance (JSA)** to **Employment and Support Allowance (ESA)** was a different story.

I was on JSA for over a year before somebody at the Job Centre suggested that ESA would be more suitable for me. I always remember how that lady appeared to be given a telling off by her manager for advising me about ESA; however, that lady was moving jobs the following week so wasn’t bothered about following austerity-driven rules.

Once I applied to ESA, I was put on a waiting list for an assessment and therefore put on a reduced rate of payment. I was on the waiting list for 15 months, which was detrimental to my health as I couldn’t pay for physiotherapy, food supplements and vitamins.

I was eventually assessed for ESA and was backdated for 9 of the 15 months I was on the waiting list, and received £3,500. But due to the nature of FA, the impact of that period cannot be recovered.

*You can watch Connor’s story being told in Scottish Parliament via Twitter by visiting this page <https://bit.ly/2RkPiVA>. If you are in a difficult situation with welfare, you can take a look at **Citizen’s Advice**: <https://bit.ly/2TA42T0>.*



Long term disability: not a barrier to home ownership

We spoke to Advance, the Housing Association that provides a range of housing options for people with disabilities, learning disabilities, mental health conditions and age-related needs.

Living with a severe disability that restricts mobility is never easy, wherever you live. It's even more challenging when you are struggling to find somewhere affordable, suitable and safe to live. Advance offer a home ownership for people with long-term disabilities scheme (**HOLD**). **Paul** tells us about his family's experience of purchasing a home through HOLD.

"Home ownership can be problematic or, in some cases like ours and many others', impossible even. This is exactly the problem my wife, **Amy**, and I were experiencing until we came across the HOLD scheme. The only place we could afford was completely unsuitable for my wife's condition. This caused many issues, such as frequent falls at home when I was at work, plus a step to access the building, so she was unable to easily access the garden. We had no hope of home ownership. We tried the council but there were no suitable properties. The council then referred us to Advance. This was a life changing moment for us.

Advance came over, talked everything through with us and from that moment we felt they were totally in our corner. The team radiated determination to help us find our dream home. My understanding was that people using Advance's service are usually eligible for benefits, which can be used towards the cost of the mortgage for the HOLD scheme. We were fairly unique in so far that my wife is not eligible for the required benefits. However, there was still hope through the HOLD programme. It wasn't necessarily straightforward but the Advance team were there every step of the way to help us. From mortgage advice, help choosing the right place to live, to just talking over concerns about the purchase process, everyone in the team was so helpful.

We have been in our new home for nearly two years and the improvement to my wife's health has been life-changing. We live in a bungalow, have an accessible bathroom, hand rails throughout - all of which would be impossible in a rented property."

How can I find out more? Visit the website at www.advanceuk.org to find out more, or give the friendly **Home Ownership** team a ring on **0333 012 4307** or email: homeownership@advanceuk.org.

WHAT IS HOLD?

HOLD is a route into home ownership through a government backed scheme (England only). As a specialist provider of housing and support for people with disabilities and mental health conditions, Advance has supported more than 600 people to part-purchase a home of their choice.

ARE YOU ELIGIBLE?

If you are over 18 years old, have a recognised long-term disability and can fund a deposit and legal fees of around £20k, this could be the programme for you.

HOW DOES IT WORK?

Advance buys the property you choose and then sells a share of the equity to you under the HOLD shared ownership scheme. This means you can buy a share of the equity of a house or flat, normally between 25-75%. We will rent our share to you and provide certain maintenance and repairs to your property to ensure it stays in good condition. This is covered by a service charge to pay for essential repairs and maintenance on the property over the time you own it. You will have the option to increase your percentage share (staircasing) in the property if you wish.

Supporting you around Motability

Are you one of many who is challenged by the Motability scheme? Phil Hobbs (right) has worked in the motor industry for over 40 years and supports his wife, Sue, who has SCA6, and now he wants to support you, too.

I operate a **Fleet Cost Analysis Consultancy**, identifying areas where businesses can save money on their vehicle operation. Due to this, I have extensive knowledge throughout the motor industry and would love to utilise my skills by helping people with ataxia to receive what they deserve.

Sue and I recently attended the Ataxia UK successful **Annual Conference**. Listening to the presentation in the **Motability** breakout, then speaking with some attendees at the end of the day, we thought of an idea to support anyone with ataxia wanting to apply for a car through the **Motability Scheme**.

It's clear that there's a grey cloud around eligibility to the scheme as government benefit allowances play a big part. Some of the most common queries are:

"I get a part-payment, am I eligible for a car?"

"My allowance has changed; can I get a car?"

"I don't drive but receive an allowance; can my carer get a car?"

Also, there are people with ataxia who don't receive any allowances but need help when thinking of a car with or without any modifications.

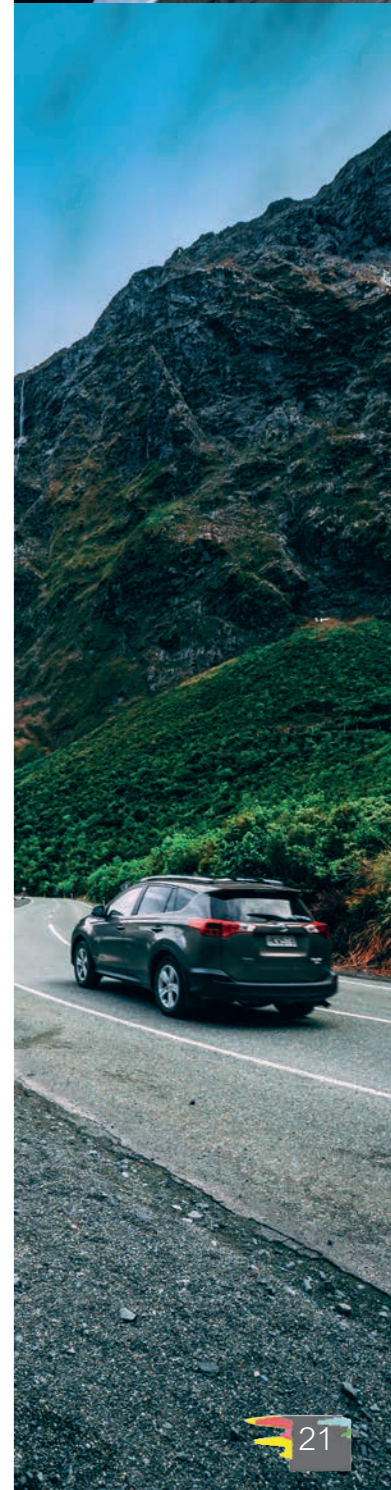
Broadly speaking, the Motability Scheme enables anyone with a higher rate mobility allowance to exchange all or part of their mobility allowance to lease a car, scooter, powered wheelchair or Wheelchair Accessible Vehicle.

You can read more about it on their website: <https://bit.ly/38fP499>.

I would be delighted to discuss, help and assist anybody connected to our big family who is interested in acquiring a motor vehicle. It's my greatest pleasure to offer this assistance, free of charge, and in no way taking anything away from Motability UK, but as a mere go-between for anybody who would like advice or a guiding hand along the way when acquiring transport within or outside the rules of the Motability scheme.

If you would like to discuss your thoughts or situation, please call Ataxia UK on **0207 582 1444** who will set up a connection.

I am happy to attend any local Support Group meetings to give a presentation and offer support on this subject where I can. Again, this can be organised by the team at Ataxia UK, so please call the office or email office@ataxia.org.uk.



Doctor's Q&A



Q: Is depression a common feature in FA? What treatments are recommended?

Rajith De Silva: We think it's probably common but there is a paucity of data and our assumption is based on our experience with other, progressive, neurological disorders, such as Parkinson's disease. A recent study from Spain showed that in a group of 62 individuals with Friedreich's ataxia, 23% had 'mild', 23% had 'moderate' and 5% had 'severe' grades of depression. The presence of depression correlated with worse 'quality of life', so its presence matters a lot. Interestingly, there was no correlation of 'physical functioning' with depression in this study but this might have been because the degree of impairment in this group, as a whole, was quite severe. There are a variety of treatments available but my approach would be to pursue optimal psychiatric treatment for individuals with depression, calling upon the expertise of relevant specialists (Psychiatrists, Clinical Psychologists, etc.).

Paola Giunti: From my experience in the ataxia centres, depression, stress and anxiety are quite common. Reduced ability to communicate and isolation are very big components. I think it's very important, if you feel that way, to talk to a neurologist. I know that a neurologist is seen as someone to talk to about difficulties in balance, but this is very important because it can open up a possibility to refer you to a specialist psychologist.

Sue Millman: These comments support research done recently by the Neurological Alliance/Rare Disease UK. If you've been rejected by mental health services, please let us know, as we're looking for examples to show the NHS.

Q: My balance and mobility seem to have deteriorated a lot. Is there any connection with stress?

Paola Giunti: Yes. Psychological stress, as well physical stress, for example a fever, can indeed deteriorate your ataxia tremendously. The positive side is that once the cause has been removed, then you will retrieve the level of disability that you had before the stressful episode. I think it's an important message, that if the psychological stress continues, it will impact on the ataxia. Fatigue can also impact on ataxia, so it is very relevant to the lifestyle of an ataxia patient to have a very good sleep. Try to have a proper routine at bedtime and have alternative methods that you can put into place to have restful sleep. It is like recharging your battery; fatigue can make you weak and the weakness can make you more ataxic.

Disclaimer

Please note that we publish this part of Ataxia UK's Conferences for information purposes only. Readers must seek their own medical advice before taking or refraining from taking any action based on the information contained in this document, and nothing should be construed as medical advice given by the doctors, Ataxia UK or any of its officers, trustees or employees. No person shall have any claim of any nature whatsoever arising out of or in connection with the contents of this document against Ataxia UK or any of its officers, trustees or employees.



Introducing your brand new Ataxia UK ID card

We're pleased to announce that you can now request your new 'I'm not drunk' Ataxia UK ID card.

Last summer, **Friends of Ataxia UK** played a vital role in helping to raise funds for a brand new ID card printer to produce new Ataxia UK 'I'm not drunk' ID cards. The campaign was a huge success and we wouldn't have been able to reach our target goal of £1,500 without the incredible support of all those who donated. There are two types of cards to request for free: for people living with ataxia (in blue), and an ataxia awareness card for family, friends or carers (in purple).

To order by email

Email office@ataxia.org.uk with your full name, post code and photograph. Please ensure you write which ID card you'd like.

To order by post

Please complete the enclosed ID card request form and return to Ataxia UK using the FREEPOST envelope. If you would like to add a photograph to your ID card, please ensure you email it to office@ataxia.org.uk.

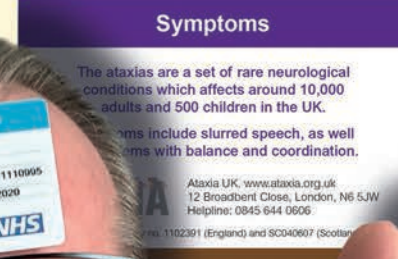
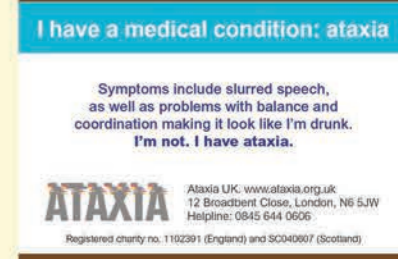
Both ID cards will also have the option to include an image of you which will then be scanned onto the front of the card. Please ensure the quality of the image meets the following criteria:

- Clear and in focus
- In colour
- At least 600 pixels wide and 750 pixels tall
- At least 50KB and no more than 10MB
- Contain no other objects or people
- Be taken against a plain, light-coloured background.

Please send your digital image to office@ataxia.org.uk.

On behalf of everyone who will benefit from the new ID card, we'd like to say a big thank you for helping to raise funds for this incredibly worthwhile cause. We are confident that the new ID card will play a crucial role in helping to break down communication barriers between people living with ataxia and the general public, as well as help spread greater public awareness about ataxia and its symptoms.

Please ensure: If you would like to include a photograph of yourself on the front of the card, please ensure the quality of the image meets the criteria provided above, and please email your digital photograph along with your full name to office@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