

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 208. Winter 2019

Exciting news about a
Friedreich's ataxia
trial inside!



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

ATAXIA

Ataxia UK

HELLO

**Shana de Figueiredo Scholtz**

We're very pleased to have Shana as our new **Administration Assistant**. Shana has SCA3 and wants to make a difference.

HELLO

**Julia Schaff**

A warm welcome to Julia who is excited to join us as **Communications Intern**. She will be working on our social media and the magazine.

HELLO

**Ann Opara**

We are delighted to announce that Ann's position as **Finance Officer** is now permanent. Ann is a joy to have in the office and always brightens up the day!

Welcome

Dear Friends,

As I write, the office is still basking in the glow of a very successful **Annual Conference**, where we renewed relationships with old Friends and got to know new ones. It was packed with interesting information and plenty of fun. If you haven't been to one yet, look out for the announcement of our **Scottish Conference** in the next magazine, or reserve the 2 and 3 October 2020 to join us at Radisson Blu at East Midlands Airport.

At Conference I was pleased to be able to announce our success in securing a grant from the **Community Fund** for our volunteering project called '**In Control**'. We expect it to be up and running in the new year, and that the **Sheffield Children's Ataxia Centre** will have its formal opening by the end of the year (keep an eye on the website and our e-news for updates).

We expect this will be followed by a **London Children's Centre** in the New Year. These children's clinics have been made possible by last year's generous donations to the **Big Give** which we hope will be even more successful this year (read more about the Big Give on pg. 12.)

I hope you have a peaceful festive season and that 2020 brings progress in research, better treatment and care, and lots of opportunities for you to volunteer with us!

Kind regards,
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

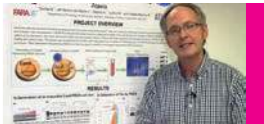
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Board of Trustees

We say goodbye to some incredible people and a warm welcome to those new.

Goodbye and thank you to Harriet Bonney (1) who has been Chair for the last seven years.

“Although I have retired from the Board, I am continuing to reply to emails on the helpline, moderate **HealthUnlocked**, sitting on the **Medical Advisory Panel** and hopefully a few other things in the future. And I will see everyone at the conferences in 2020!”

Farewell and thank you to Howard Marshall (2) who has been associated with Ataxia UK since 1979.

“It has been good to see the way in which Ataxia UK has grown into an effective charity since 1979.”

Hello to William Littleboy (3) who has been a Trustee for one year and is now Co-Chair.

“I’m delighted to be appointed as Co-Chair at this time. Richard and I have complementary skills and work well together. I became a Trustee of Ataxia UK a year ago, shortly after retiring from my job in financial services. I have genuine empathy with those affected by ataxia, I can be a powerful advocate for our many causes and I have many related interests, in particular dealing with mental health issues such as anxiety and confidence, to contribute. I look forward to the next few years.”

Hello to Richard Brown (4) who has been a Trustee since 2013 and is now Co-Chair.

“It is 28 years since my diagnosis, and I have learned a lot about myself and disability. I hope to bring my commitment to showing disabled people can and should lead the organisations that represent them. I want us to take Ataxia UK forwards together. I am looking forward to working alongside and developing a great working-relationship with William, our excellent staff team and our friends.”

Hello to Gemma Fish (5) who has re-joined the Board of Trustees.

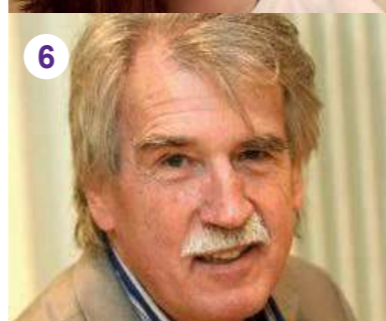
“I’m most looking forward to being on the front line of the decision making and giving people with ataxia a voice.”

Hello to Terence McCaw (6) who has joined the Board of Trustees.

“I hope to bring my experience from the ‘inside’ of previous boards which will be beneficial to the decisions Ataxia UK makes, whilst also understanding my duties and responsibilities of an Ataxia UK Trustee.”

Hello to Carol McCudden (7) who is now on the Board of Trustees.

“I am looking forward to building on the good work and being part of exciting times ahead. There are new Trustees with fresh blood and research is bringing treatments closer to our grasp - an exciting time to be on board!”



Network updates

Mark Dower Trust

Are you **16 to 30 years old with ataxia** looking to spread your wings? Well, look no further. The Mark Dower Trust offers a financial grant that aims to support young people with ataxia, who are seeking independence, to develop and enjoy hobbies and activities, or to enhance their skills through further education.

The Trust was set up in memory of Mark (right), who had Friedreich’s ataxia (FA) and sadly passed away in 2003, aged 41. At 19, when the local authority rejected his application for funding to live away from home and to attend college with other young people, Mark conducted a ‘sit-in’ at the council offices until the officers reviewed their decision. He won his fight and spent an incredible few years making great creative achievements.

The grant of up to £3,000 was inspired by Mark’s independent and fierce spirit and can be shared among each year’s awardees. Applicants must be between the ages of 16-30, have ataxia and reside in the UK. **Applications are open now until 31 January 2020.** Successful applicants will hear back by the end of February.

Take a chance and fill in the application form at www.ataxia.org.uk/news/mark-dower-trust. You can also request a copy by emailing communications@ataxia.org.uk.



Support in St Austell

Thank you to **Ann Truscott, Stephanie** and **Mick** (above) for welcoming **Community Fundraising and Branches & Support Group Manager Rebecca Holt** to their Support Group meeting in **Fraddon, Cornwall**.

Everyone gave updates on how their care was going, and raised any issues and questions. They also shared some tips on mobility aids they were finding useful, such as gutter crutches rather than standard ones as they are much more supportive of your arms.

*As well as having a great chat and catch up, they talked about the great support from the group. Please contact **Ann** on: masontruscott@gmail.com or contact the office on **020 7582 1444**.*

VERY exciting top line results from the world's largest Friedreich's ataxia (FA) trial

In October **Reata Pharmaceuticals Inc** announced exciting top line findings from their trial of Omaveloxolone (Omap) in patients with FA.

The results showed patients taking Omap for 48 weeks had a statistically significant improvement in their symptoms associated with FA over those on the placebo trial (a placebo has no therapeutic effect, and is used as a control in testing new drugs) – not just a slowing down or halt in progression, but an improvement!

This is a truly wonderful result. Reata say Omap has the potential to be the first approved treatment for FA.

Prof Paola Giunti, Head of the London Ataxia Centre, says: "We are excited by these promising results of the trial and hope this will lead to the development of a much-needed approved treatment for FA. I am so grateful to all the people with FA who have taken part in this trial."

SOME DETAIL FROM THE STUDY:

This was the largest global interventional study in patients with FA so far; undertaken at a number of sites around the world including the London Ataxia Centre. Half of the participants received 150mg of Omap per day and half received a placebo for 48 weeks. To measure the impact of Omap, patient progression was measured using mFARS – a scale for rating movement in people with FA. Patients are scored on a scale from 0 to 99. Diagnosis is usually in teenage years when patients have a score of 25-35; and this gradually worsens (increases), on average by 1-2 points every year.

What's so exciting about the results of this trial is that patients taking Omap showed a **decrease in their score**. So, not only is it halting or slowing down progression, but actually improving it!

Those taking Omap also showed improvements in other areas including speech, swallowing, personal hygiene, and walking; and also exhibited a 65% reduction in frequency of falls.

Reata believe Omap may be applicable to a broader set of neurodegenerative diseases including other ataxias.

Sue Millman, Ataxia UK CEO welcomed the news: "In 2014 we launched our **2020 Vision Campaign** looking for a treatment or cure for at least one ataxia by 2020. We're delighted that this trial provides the prospects of a result to celebrate before 2020 has arrived!"

ATAXIA 2020 VISION



Targeting the genetic cause of DRPLA

We are delighted to announce funding of an exciting project targeting the genetic cause of a rare form of ataxia, to be carried out by Dr Stevanin (image, right) and Dr El-Hachimi (image, left) at ICM in Paris, and Dr Fanto (image, centre) at Kings College London. This project has been made possible by a donation from Andrea and Paul Compton, who have a son affected by DRPLA, and have created a foundation called CureDRPLA.

Dentatorubro-Pallidoluysian Atrophy (also called DRPLA) is a rare form of inherited ataxia that leads to progressive loss of motor control and, in the most aggressive forms, also to epilepsy. There is currently no cure.

DRPLA is caused by a mutation in the **Atrophin-1 gene**. Genes are a code made up of the letters A, T, G and C. This code contains instructions for how to make proteins. In DRPLA, a section of the code reading 'CAG' is mistakenly repeated many times, resulting in the incorrect code for making the protein called Atrophin-1. Production of the incorrect Atrophin-1 protein leads to the symptoms associated with DRPLA.

Targeting the genes that cause genetic conditions, also known as gene therapy, has been gaining a lot of attention in recent years. One form of gene therapy uses molecules called **antisense oligonucleotides** or '**ASOs**' which can be designed to prevent a specific gene from being read to make a protein. In this project, the researchers will design ASOs to specifically block the Atrophin-1 gene from being read. They hope this will result in the production of less Atrophin-1 protein.

DRPLA is similar in its genetic cause to **Huntington's Disease (HD)**. ASOs are currently being tested in people with HD, with preliminary results showing success. We are very pleased that this approach, which is providing hope for people with HD, is now being looked at for DRPLA. A number of spinocerebellar ataxia (SCA) research project are also being carried out using ASOs (see pg. 9).

This group will test how effective this treatment is, using a mouse model of DRPLA. The group hopes that at the end of this project, it may be possible to translate this therapy into a clinical trial for DRPLA patients.

Dr Fanto at Kings College London, says: "We are excited to contribute to this project towards a preclinical treatment for DRPLA. We thank Ataxia UK for their support and look forward to starting this work."



Friedreich's ataxia research project identifies new drug targets

This project, funded by Ataxia UK, uses an innovative gene editing approach.

Friedreich's ataxia (FA) is the most common inherited ataxia. In FA, there is an expansion of a fragment of the DNA genetic code in the **frataxin (FXN)** gene. This results in the depletion of the FXN protein, leading to the disease. Increasing FXN protein levels is therefore key to treating the condition.

Although there has been progress towards understanding the molecular mechanisms underlying FA, there are no drugs approved to treat the condition. According to researchers at the University of Oxford: "There is a clear need to find new molecular targets that can pave the way to the developing drugs to increase FXN levels."

These researchers have developed a new approach to perform genome-wide screening to discover new molecular pathways that could be involved in increasing FXN levels using a new and exciting gene editing technique called **CRISPR Cas-9**. This method works by simultaneously switching off the genes within a group of cells, whereby one gene is switched off in each cell at a time. The cells are then analysed to see which ones contain more FXN protein, and those with increased levels of FXN protein have their genes sequenced. This gives the researchers information about which genes contributed to the increase in protein levels and reveals new biological pathways that may be useful to target with drugs to regulate FXN protein expression.

This project is a part of the collaborative drug discovery consortium between Ataxia UK, **Oxford University, University College London, Imperial College London** and the pharmaceutical company, **Pfizer**. The aim of that Consortium, funded by Pfizer with a contribution from Ataxia UK, was to work towards identifying a compound that could increase FXN levels in patients with FA (Ataxia Magazine 190 and 201). The project later evolved, with additional funding from **Friedreich's Ataxia Research Alliance (FARA)** to investigate the genes that increase FXN levels (Ataxia Magazine 201).

The researchers managed to generate a list of genes that control FXN expression and identify a total of 23 new biological pathways and molecules that could be targeted to restore FXN protein levels in patients. They have prioritised and confirmed two of these targets.

Head researcher **Richard Wade-Martins (right)** said: "Moving forward, priority will be given to targets for which drugs already exist. One approach could maybe even be to use a drug which is already in use for another disease as that represents a quicker way to translate our findings into the clinic."



Growing evidence for ASOs as a potential treatment for SCAs

As already mentioned (on p. 6), antisense oligonucleotides or 'ASOs' are molecules that can target faulty genes and stop them from making toxic versions of certain proteins, which can lead to a variety of disorders such as DRPLA. ASO drugs are currently approved for treatment of spinal muscular atrophy, and have also shown success in amyotrophic lateral sclerosis (ALS) and Huntington's disease clinical trials.

There is growing evidence that they may also prove useful in treating some types of spinocerebellar ataxia (SCA). In a mouse model of SCA2, researchers have shown that ASOs successfully reduce the disease-causing protein, and improve motor function. ASOs have also been shown to reduce toxic protein levels in mouse models of SCA3 and SCA1 (see the research news article 'Toxic protein production reduced in SCA3 and SCA1 by genetic approach' on the Ataxia UK website for more info), and to restore visual function in SCA7 mice with retinal disease.

These results, along with the success in other conditions, gives us hope for future clinical success in SCAs.



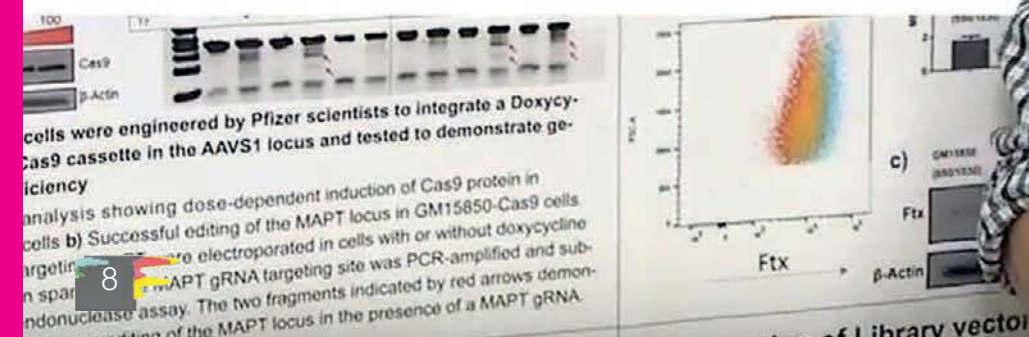
Launch of the Friedreich's Ataxia Global Patient Registry (FAGPR)

To complement our patient registry and FARA's, global partners have now come together to build a new international registry – the FA Global Patient Registry (FAGPR). This is a global effort of patient groups around the world working together and pooling information in once place, making it a much more powerful resource for research. *The FAGPR has now been launched. See the Ataxia UK website for more details and information about how to register.*



New website launched for SCA global and ARCA global

We have been collaborating with ataxia experts in the development of two new global initiatives to progress research into the inherited ataxias: SCA global and ARCA global. Visit **www.ataxia-global-initiatives.net** and see the new website with a video describing the initiatives, featuring Ataxia UK Friend **Maja Jefferies** whose son has the rare ataxia DRPLA.



International Ataxia Awareness Day 2019

Once again, International Ataxia Awareness Day was a huge success in getting ataxia out there and seen by thousands of new people.

DISORDERED NOT DRUNK: YOUR STORIES ...

Continuing from the earlier ID card crowdfunding campaign this year, Disordered Not Drunk, Friends told their stories about the times they have been accused of being drunk. Thank you to everyone who shared your own and other's stories and contributed to making the day count.

Emmerdale actor **James Moore** kindly shared his personal story too, and was one of almost **800 people who changed their profile photo to support the campaign**. James' story reached 40,000 accounts. This means **40,000 people saw the word ataxia on their Facebook** and possibly learnt about those with ataxia who are misjudged for being drunk.

From 24 September to 2 October, our **tweets about ataxia were seen 17,400 times**. On Instagram, we reached almost **15,000 people**. IAAD saw **1,400 people on our website**: 771 came from social media and 374 directly searched for the website.

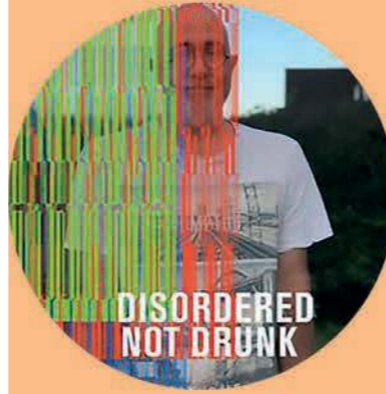
WE TOOK AWARENESS TO THE STREETS

We planned our own five-mile walk from the Ataxia UK office in Highgate to the **Specialist Ataxia Centre** in London. We packed a bag of leaflets, took Hope the Bear out for a stroll, sported the Ataxia UK t-shirts and admittedly had some stares! One lady stopped her car and shouted 'what is ataxia?'.

AND SO DID MANY OF YOU ACROSS THE UK ...

A huge thank you to those of you who gathered your friends and family, and walked to increase awareness and funds! Thank you to the **South East Wales Support Group** who joined together for a lovely awareness day walk. **Helen** and **Beth**, along with friends **Allison**, **Kay** and **Sam** got involved too with their 'wheely wobbly' walk raising over £1,600! Another thanks to the **Ipswich and Colchester Support Group** where **Patsy Riggs** held a fundraising stall at their meeting, and to **Sam Hyde** and the **West Country Branch** who held a stand in **Exeter High Street**. Doing something different was **Lydia Hallet** who streamed her live 'hoopathon' and raised £775! A big thank you to **Crosshills Social Club** in **Keighley** and to **Anita Robertson** and **Carol Ellison** who gathered together for their friend **Tracy Carr** and hosted a **Breakfast Weekend** raising £259! Finally, thank you to **Toyah** and our **Sheffield Branch** who held a **Race Night** raising £1,800 for **IAAD**!

If you haven't read the brilliant stories from our Friends yet, please visit: www.ataxia.org.uk/Blogs/our-friends-blog/Category/members-blog.



16-30s open and honest

The 16-30's Conference explored a new and personal topic this year: intimacy and relationships.

We heard talks by **Sir Tom Shakespeare, Professor of Disability Research**, and **Emily Yates, Disability Consultant and Blogger**. Tom led a fantastic talk about connection and relationships and had us all thinking about our own experiences. Emily works at **Enhance the UK**, a charity that is run by people with disabilities aiming to change society's views on disability, she talked and hosted a breakout about intimacy and disability.

Emily encouraged everyone to break up into small groups and discuss topics such as dating a disabled partner vs a non-disabled partner, and whether or not you would disclose your disability on a dating app. These topics initiated a long discussion and interesting answers and opinions from everyone. It allowed people to create friendships within the session and spark new ideas.

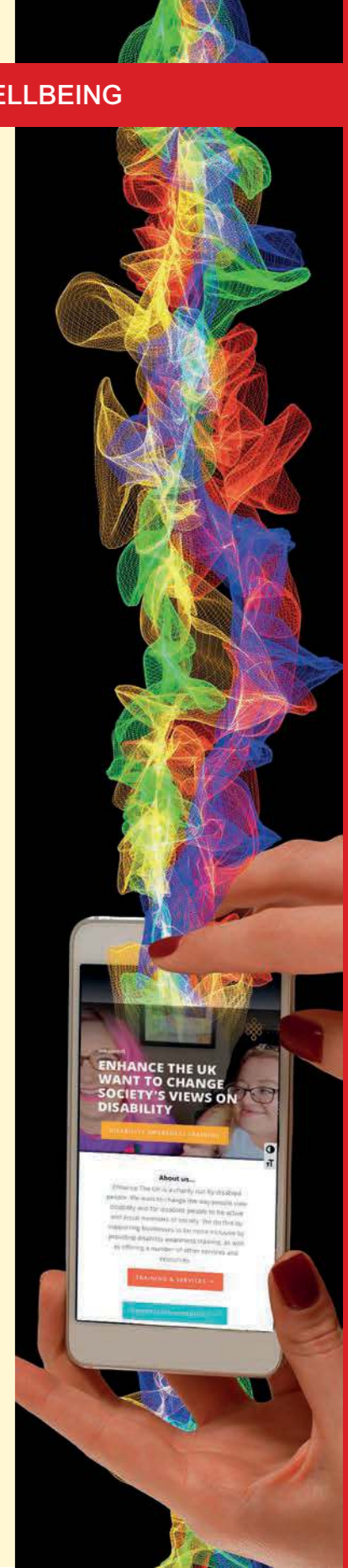
In the afternoon, Emily hosted a breakout: a live '**Love Lounge**'. The Love Lounge is a platform created by **Enhance the UK**, where people can send in questions (for example on love, loneliness, relationships, friendships) which get answered by Emily and her colleague. They call themselves the '**non-expert sexperts**'. In the live session at the Conference, everyone bounced off each other's questions and answers. Everyone engaged in intimate questions that are not often discussed.

Much of the discussion linked to mental wellbeing, particularly around topics such as relationships and love and its connection to disability. The session was a confidential but open and inviting space for people to talk with others who may be in a similar situation, which became apparent as people opened up more. The breakout was a chance for people to talk about any issues and receive support on the spot from both Emily and others in the group.

Georgia, who attended the conference, said: "I loved the 16-30s group this year! It's definitely been my favourite year so far. It was really interesting, and I loved how comfortable everyone felt despite some of the topics, and it seemed much more age-appropriate than normal!"

Emily, who joined the breakout, said: "I really enjoyed it, it was a safe space to express concerns or ask questions. Emily was approachable, relatable and empathetic. Intimacy isn't really something that's talked about in society, let alone with a disability, so it was a breath of fresh air."

You can find out more about **Enhance the UK** on their page: www.enhancetheuk.org.





The Big Give 2019 Christmas Challenge

Improving access to diagnosis and treatment

Last year, your generosity helped raise an incredible £53,803 to help fund the establishment of an ataxia paediatric centre and ataxia research programme. Thanks to your support, we are delighted to announce that the first **Accredited Ataxia Specialist Centre for children** is now up and running at the **Sheffield Children's Hospital!** (Read more on pg. 21). **A truly amazing achievement which would not have been possible without your support!** However, there is still more to be done to increase the accessibility of specialist ataxia neurologists across the country. Along with the new paediatric centre, there are currently two **adult Specialist Ataxia Centres** across the UK, so we understand it's not possible for all ataxia patients to travel there.

WHAT CAN YOUR DOUBLED DONATION DO?

This December we are calling on your fantastic support and generosity to help raise **£68,000** to fund a truly ground-breaking project to develop the establishment of **virtual ataxia clinics**, which will make accessing specialist support much easier for people living with ataxia.

Our vision is to provide patients with access to online video consultations with expert ataxia neurologists at Ataxia Centres. With your support, we want to ensure that every ataxia patient across the UK is able to access a neurologist who has experience and expertise in ataxia at points when they need it the most, such as diagnosis. Along with piloting the virtual clinic, the funds from this year's Big Give will also help expand patient access to appropriate healthcare.

HOW DOES THE BIG GIVE CHRISTMAS CHALLENGE WORK?

From **12pm on 3 December until 12pm on 10 December**, we will have a matching pot of £34,000, thanks to pledged funds generously donated by **major donor supporters** and funds contributed by our **Champion donor, Candis Club**. When you give online during these dates, your donation will be doubled!

HOW TO JOIN

To double your donation, please visit our **Big Give Donation Page: www.ataxia.org.uk/the-big-christmas-challenge-2019** from **12pm on 3 December until 12pm on 10 December**. If you are a UK taxpayer, please **tick the Gift Aid box** when you donate online as your donation will be worth 25% more at no extra cost to you. For example, a donation of £100 during the week will be worth an incredible £225 towards reaching our goal of raising £68,000. **Unfortunately, this year Ataxia UK will not be allowed to help supporters process donations to the Big Give via telephone or accept cheques, so please see a full explanation of the Big Give Christmas Challenge online donation process on our website: www.ataxia.org.uk/the-big-christmas-challenge-2019.**

HOW IT WORKS

STEP 1

You donate, say £50



STEP 2

Our major donor pledgers and champion donor: **Candis Magazine** match your donation with another £50



STEP 3

And if you tick the Gift Aid box, you'll add a further £25



RESULT:

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



E V E N T S

Super fundraisers

A special thank you to supporters taking part in the **Kiltwalks, Great North Run and Superhero Tri** making up our biggest Ataxia UK teams in these events than ever before!

KILTWALKS

Taryn Cotton, Ally and Donna Mitchell (1) completed the **Glasgow Kiltwalk** and raised nearly £300 and **Isobel Munro (2)** raised £95. Well done and thank you ladies, a superb effort! Congratulations to **Diane Hocking and Janette Duncan (3)**, **Antonia Hoolihan** and **Sasha Carroll** for completing the **Dundee Kiltwalk**, raising £950 and £1,589 respectively - thank you all, what a fantastic team!

GREAT NORTH RUN

A MASSIVE thank you and congratulations to our incredible **Great North Run (4-7)** team who smashed it and raised over £4,290! The awesome team: **Mark Aaron, Lisa Armes, Caroline Cooper, Sarah Prescott, Philip Smith, Emma Booth-Rigby, Amelia Dore, Becky Norton, Angela Harrison, Sonya Loadman, Kate Skelton** and her mum, **Mandy**. Emma said: "I can't believe I did it; I still feel very emotional! On the way round, I reminded myself why I was doing it - for my dad and, of course, Ataxia UK. That saw me through, as well as the incredible atmosphere."

SUPERHERO TRI

A HUGE HURRAH and congratulations to the superheroes who took part in the **Superhero Tri at Dorney Lake (8-9)**. **Sian Rhys** and friends **Amelia Ross** and **Adrian McBreen** completed the course as a team, with Sian and Amelia raising a smashing £140! **Meria Sukannen** and **Kevin** aka 'Ataxia Man' flew over the finish line and raised £295! **Geraint Williams** together with his son and daughter, **Sam** and **Lexie**, and friends, **Alex** and **Adrian**, also completed the course in style. Well done everyone for an incredible day!

Still to come!

WINTER WONDERWHEELS - SUPERHERO SANTA DASH: 1 DEC 2019

Don your festive attire and sign-up to this family event and walk, run, cycle or push 1km, 5km or 10km beside the beautiful **Dorney Lake!** With no cut-off time and all mobility aids welcome - from day chairs and hand cycles to frames, trikes and bikes, **there's something for everyone!** Take part by yourself or bring a friend or relative (your 'sidekick') to help you around the course, or gather together to form a team! You, or at least one of your team members, must have ataxia to take part. If you'd like to be in a team but don't have one, we can connect you with others! *Find out more by emailing fundraising@ataxia.org.uk or calling 020 7582 1444.*



Fundraising thank-yous

An enormous thank you to all the incredible fundraisers for your impressive efforts to support those affected by ataxia and your loved ones. Here are some brilliant stories and photos of everyone.

Well done and thank you to **Tina Cade (1)** for running in the **Hull 10k** and raising a fantastic £400, and **Toni Davis (2)** for raising a wonderful £420 by taking part in the **Total Warrior 10K** and **Yorkshire Strongest Team competition**.

Congratulations and a huge thank you to **Helen Howells** and her colleagues at **EE (3)** for raising a superb £300 through completing a bike ride around Cardiff!

A huge thank you to **Karl Miles (4)** and **William Lambson (5)** for being so brave and joining our **'19 in 19' skydive team!** Congratulations to Karl for raising £480 and William for raising £315.

Congratulations to **Peter Williams** and **Alan Graham (6)** for doing their **'Old Gimmer's bike ride'** and raising a brilliant £590.

Marie Scammell and **friends (7)** teamed up as the **'Jock Squad'** to complete the **Hull Inflatable 5k**, which they did for Marie's dad, **Jock**, who had ataxia. Well done team and thank you for your top fundraising efforts, raising £1,201!

Thank you to the **Crows Nest Pub** in **Seaham** and the bands, **Stoney Broke** and **Coastline**, for a great music night, raising over £300. Thank you too to **Phil Whitwell (8)** and everyone who attended for their wonderful support.

Thank you to **David Clough** and **Adam Brunskill (9)** for taking on the gruelling **Ironman** challenges – David with **Bolton Ironman** and Adam with **Ironman Austria**. David raised over £560, and Adam over £1,000. Adam and his friend, **Andrew**, travelled through a vicious storm, dealt with a downhill puncture, to then soar over the finish line, burning a whopping 5652 calories!

Thank you to **Barbara** and **John Price (10)** and friends for holding a beautiful **Garden Party** in **Rhyl** with cake, plant, book stalls, a raffle and live music. They raised an incredible £1,027! We're glad you all had a fabulous day.

A big thank you to **Karen Bunt** for taking part with her gorgeous furry friends in the **Woodland Dog Shows (11)** two years running, raising a whopping £1,000!

Well done and thank you **Hannah Jardine (12)** and the team at **Istoria Group** for their collection at **Bristol Temple Meads Station**, and taking snack box donations in the office to raise over £500! We are Istoria's Charity of the Year, and staff are continuously working hard on fundraising ideas.



Congratulations to **Rob Stevens, Simon Hodgson, Martin Cousins, John McPhee, Lee Callaghan, Dave Griffiths, Neil Roast, Richard Selkirk, Conrad Thomas** and **Navin Gurung** from **DHL (13)** who completed the **Yorkshire Three Peaks** raising an awesome £840. DHL are also kindly making a donation through their 'Match It' scheme. Thank you very much!

Steve and **Julie Stubbs** also organised a **Garden Sale** and raised a fantastic £520 – thank you so much!

The pupils of **Sevenoaks School** organised a **'Sing-off' Evening**, selling tickets and cakes to raise more than £2,600! Thank you everyone and we hope you had a fantastic time.

Jenna Ingham and **Stephanie Critchley (14)** organised a **Concert Night** at **Garswood Hall Bowling and Community Club** in **Wigan**, raising an outstanding £1,540! They also did **'Play your Cards Right'**, a **raffle** and **bingo!** Thank you to both clubs and all your friends and family for their support.

Congratulations and thank you to **Chelsea Higgott**, her mum, **Angela**, and the **Chadwick Arms** on another very successful **quiz night** raising an impressive £200 for our **West Midlands Branch**.

Thank you to **Sean** and **Tracy Carroll** for raising a fantastic £171 through having collection tins at various bars in **Broughty Ferry, Dundee**.

Thank you to **Tredegar Constitutional Club** for displaying a tin and collecting £30 whilst raising awareness among their members. Also to **Deborah** and **Dave Poyser** for kindly getting them involved.

Thank you **Joan Rowbottom** and friends and family for their continued support at the annual **Robes Inebriation Society**. Together they raised a wonderful £250 and had a lovely time remembering their dear **Robes**.

A big thank you goes to our loyal supporters, **Joan Williams** and her family, for raising a fantastic £570 at the **Hensall Carnival**.

Thank you so much to **Leni Donaldson** for raising an amazing £700 at her pop-up clothes shop, **Maggie Rose Clothing**.

Special thanks to the **Harvey-Adcock** family for organising a disco evening and raising an incredible £755.

Thank you **Patricia Rak** for organising two coffee mornings at **The United Reformed Church of Eastcote and Northwood Hills** and raising £170.

Thank you **Margaret Gregory** and her family for organising a **tea party** and raising a fantastic £100.



Chance2Win Winners

- 1st Prize: £500
Judy Trim
- 2nd Prize: £250
Anthea Young
- 3rd Prize: £150
Wendy Heath



Making your tech more accessible

As the weather turns colder, many of us will spend days inside, huddled with a blanket and hot drink, maybe around our favourite tech device. So, we asked Matt Law how to make using them easier and more accessible.

I began using a computer seriously in about 1990 for work. Windows for PCs was just about beginning and I remember feeling disappointed that sometime in the future I would have to manoeuvre a pointer around a screen with a mouse, instead of using cursor buttons on the keyboard. This required no coordination, so using a computer in those early days was as easy for me as it was for everyone else. Using a pointer and a mouse proved a challenge from day one, but I knew this was the way PCs were going, so I just got on with it.

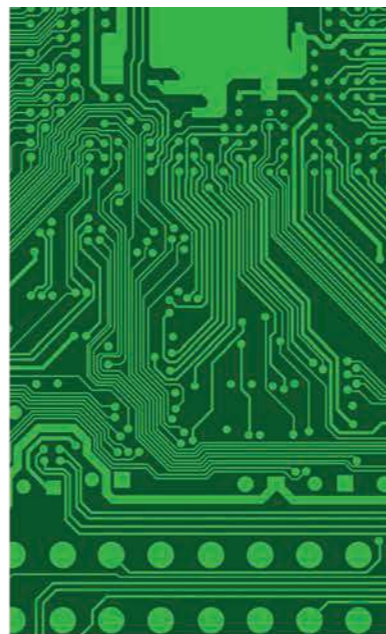
Within a few months, I became frustrated because my hands could not control the mouse. To combat this, I used a mouse with a trackball which required movement in my thumb, rather than my whole arm. This worked for me for many years, until about ten years ago, when I started to find that my fingers were accidentally pressing the click buttons while I was moving the trackball with my thumb. I tried all sorts of trackballs but it didn't work for me in the end.

After leaving work, I realised that I would still be using a computer, so I changed to using a joystick controller. This device is simple to control, but slower. You can adjust the speed, but the faster you have it, the greater the dexterity that is needed in your movement, so I have accepted that moving the cursor is going to take longer. There is a cable attached to this joystick which runs to a button that acts as a left click which makes life much easier, too.

Using the keyboard has become far more difficult over the years and, instead of typing all the time, I now use DragonDictate software. This types out exactly what I say into a microphone. I am using that now and so everything you are reading has been said and not typed. Occasionally, it does not type out exactly what you said, so if anything that you have read does not make sense, then you should blame DragonDictate software and not me!



Matthew Law
matthewlaw1968
@yahoo.co.uk



Supporting Friends in Scotland

This exciting project will focus on helping Friends who have financial needs in Scotland.

We are pleased to say we have been approached by **Scottish Huntington's Association (SHA)** with a view to enter a partnership with them. SHA would provide a money advice service to **Friends** of Ataxia UK living in Scotland, which they already provide to their own members.

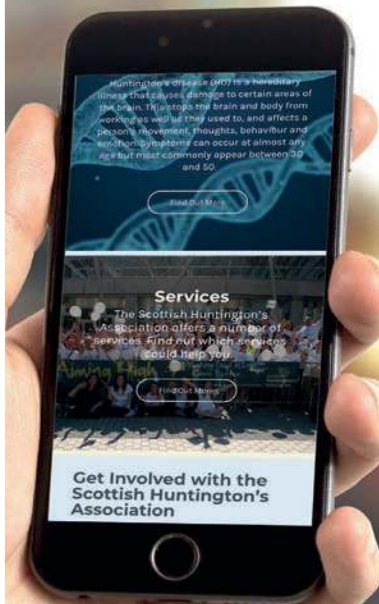
A money advice service aims to support anyone with a financial need; including areas around welfare benefits, debt, bank accounts, insurance, pensions and mortgages. This service would be available to those affected by ataxia and who are signed up as a Friend of Ataxia UK.

Crucial to the foundation of this service is for us to understand the financial circumstances of people affected by ataxia in Scotland. We will achieve this, with your help, by conducting a survey of all Friends right across the UK.

We will then focus on the Scottish service to meet people's needs. Hopefully, armed with the results of the research, we will be able to approach a Trust to give us the funds to set up the **Money Advice Service** in Scotland, which, if successful we will hope to mirror elsewhere in the UK.

We encourage anyone who is not already a Friend of Ataxia UK to sign up to ensure you are involved. Signing up is free and easy, visit our website for more information: www.ataxia.org.uk/forms/joinataxiak. You can also find out more about SHA by visiting their website: hdscotland.org.

scottish
huntington's
association



Eating 'out' with a walking frame

Kizzy cares for her mum, Kathy (right), who has spinocerebellar ataxia. They enjoy trying new activities and getting outside. Here they share their experience of eating 'out' with a walking frame.

For the most part, eating out has always been an enjoyable activity for mum and me. However, in recent years when mum has become dependent on her walking frame, it has been less spontaneous and more considered. As I am mum's only carer, the responsibility of assessing a potentially suitable restaurant lies with me. Now, I am not suggesting we pre-plan everything or avoid random trips to fast food restaurants, but we have learnt through trial and error that a little thought leads to a much more enjoyable outing.

During early days with the walking frame, we thought that getting in the door and settling at a table would always be the tricky part. We have since learnt that there are other factors which have proved more problematic. When I know we are going somewhere specific and there is an option to book a table, I do so and ask for extra room around the table to accommodate the frame. Some restaurants take the request in their stride but others seem as though they have panicked a little; we have so much room around the table you could sail a small ship.

Thankfully, most restaurants have some form of disabled toilets, although this doesn't change the fact that watching Mum weave her way through the restaurant has almost become a real-life version of Mario cart. Unfortunately, the toilet doors can be too heavy and awkward for Mum and her frame, but I am always on hand to assist. Another tricky factor is the floor. We have learnt a lot of places have tiled or wooden floors which is easy for the walking frame, but a layer of cleaning product causes a slippery scene. We are yet to work out how to get around the slippery floor scenarios but, for now, Mum just takes things slow and steady.

Our experiences prove that eating out is still a lovely treat. We continue to try and explore different restaurants and cafés on our travels, especially where afternoon tea is involved!

To read more about Kizzy and Kathy's adventures, visit our website www.ataxia.org.uk/Blogs/our-friends-blog/Category/members-blog.



Being involved: a patient's perspective

Being involved as a patient can be a rewarding experience and help to raise awareness of ataxia within the medical profession.

Patients can become involved in the training of healthcare professionals in a number of different ways, including volunteering at **Objective Structured Clinical Exams (OSCEs)**, communications workshops and role-playing scenarios for medical school applicants. OSCEs and workshops usually require a student or trainee doctor to take in patient history and talk about a condition, in order to try and diagnose a patient. This is the most common way someone can become part of patient involvement. Role-playing scenarios can be used as part of medical school applications, in which the patient-volunteer and applicant role-play a situation, such as a doctor's appointment.

Liz Dalby (right), who coordinates the **East of Scotland Branch and Support Group** with her husband, **Peter**, has volunteered at a hospital to raise awareness of ataxia to trainee doctors for 12 years. Liz was diagnosed with spinocerebellar ataxia type 8 (SCA8) in 1995. One day, Liz's GP asked if she would be interested in a patient involvement opportunity, to which Liz replied she definitely was.

Around three times a year, Liz visits the **Western General Hospital** in **Edinburgh**. Trainee doctors are put to the test by trying to diagnose Liz; some diagnose her correctly but some completely miss, Liz told us. Either way, each trainee doctor that sees her, will leave, having heard of ataxia and, therefore, raise awareness of the condition in the medical sector. "It isn't going to help me, but it will hopefully help younger generations," Liz said.

We spoke to **Jo Colbert**, **Undergraduate Assessment Manager at Anglia Ruskin School of Medicine**.

Jo explained that every teaching hospital and medical school is different. There are no standard requirements for patient involvement but the **General Medical Council**, who regulate medical degrees and doctors, see it as important for students to have active patient involvement in their medical course.

Some medical schools have patient involvement programmes, whilst others might have a more informal approach to patient involvement. If you are interested in an opportunity like this and have not been offered one, you can contact your local medical school (hospital and university) and ask if they have any opportunities for patient involvement.





Taking Control

Ataxia UK gains three-year support from the Community Fund for its programme to study isolation and loneliness in the ataxia community and develop volunteering in England: 'Taking Control of your ataxia'.

One of the key elements of our **Strategic Plan** is to enable people to feel supported, and in control of their circumstances, despite being affected by ataxia. Over the next three years, we will seek to understand the extent of the challenges of isolation, loneliness and mental wellbeing in the ataxia community and develop volunteering opportunities. Studies show that loneliness makes people more prone to depression and other mental health issues. The Programme will address this by developing services, including volunteering, to decrease loneliness, isolation and exclusion, and thus improve mental wellbeing.

We are appointing a **Community Programme Manager** to engage with the ataxia community; support **Branches and Support Groups** and develop our volunteering opportunities, including our **16-30's Group** and **Ambassadors Programme**. To oversee the project, we are establishing a steering group consisting of a diverse group of people affected, or engaged with Ataxia UK in a variety of ways.

In the coming months we will carry out an extensive survey of **Friends** using the **Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)** to determine the levels of loneliness and isolation, taking into account the different types of ataxia and milestones as the condition worsens. In addition, we will conduct a number of semi-structured interviews with various segments of the community to understand the challenges to mental wellbeing and potential remedies in more depth.

We are delighted that we have been given the opportunity by the **Community Fund** to both carry out the research and develop our services in support of the Ataxia community.



Children's Ataxia Centre in Sheffield

We are delighted to announce that the first Ataxia Specialist Centre for children has opened at the Sheffield Children's Hospital NHS Foundation Trust.

Following the generosity of everyone who gave to last year's Big Give campaign, the UK's first **Ataxia Specialist Centre for children has been opened!** **Dr Santosh Mordekar, Paediatric Neurologist** with expertise in ataxia, will be running the Centre with the support of **James Bull, Paediatric Ataxia Specialist Nurse**.

This Centre has been accredited by Ataxia UK, which means it complies with the same criteria as the two currently-existing adult Centres (in London and Sheffield). Centres must have a neurologist with expertise in ataxia, provide continuity of care and regular follow-ups as well as referrals to appropriate healthcare professionals. At the Sheffield Children's Hospital there is excellent support from physiotherapists and Dr Santosh Mordekar runs a monthly multi-disciplinary clinic for the treatment of spasticity.

The **Paediatric Centre** will provide expertise in ataxia for children, access to an ataxia nurse and other services such as speech therapy and physiotherapy. This would speed up diagnosis and ensure that parents and children receive the best possible support.

Another important aspect of the Centres is providing ongoing support in-between annual appointments by the neurologist which will be provided by the Specialist Nurse. Ataxia research is an important aspect and Dr Mordekar is already involved in collaboration with **Professor Hadjivassiliou** and is ambitious for more involvement e.g. global ataxia initiatives such as **SCA global** and **ARCA global**.

Initially there will be Specialist Ataxia Clinics four times a year but this is likely to increase as more children get referred. The Centre will see children and young people up to 18 years old.

Dr Mordekar says: "I've been seeing children with various movement disorders including ataxia for 13 years and am delighted that our Centre has now been accredited as the first Children's Ataxia Centre in the UK. We are extremely thankful to Ataxia UK. I have been working closely with Professor Hadjivassiliou and Dr Shanmugarajah, (at the Centre in Sheffield) doing combined clinics for 17-18 year olds to ensure smooth transition to adult care. We are collaborating with a few research projects in ataxia which will help these patients."

James Bull says: "I'm excited to be part of this new initiative. I've been a neurology specialist nurse for five years. I aim to work closely with adult ataxia nurses from Sheffield Teaching Hospital NHS Trust."

*If you are interested in attending the Sheffield Children's Ataxia Centre, a referral can be made by your GP, paediatrician or paediatric neurologist to see Dr Mordekar at **Sheffield Children's Hospital NHS Foundation Trust, Ryegate Children's Centre, Tupton Crescent Road, Sheffield S10 5DD.***

CONTACTS: Dr Mordekar 0114 2260675, Mr James Bull 0114 2717618



Dr Santosh Mordekar
Paediatric
Neurologist



James Bull
Paediatric Ataxia
Specialist Nurse



Having your say



THE NEUROLOGICAL ALLIANCE

Neurological Alliance is a coalition of over 80 organisations that work together to transform the outcomes of those living with a neurological condition in England. Throughout 2018 and 2019, Neurological Alliance sent out their National Neurology Patient Experience Survey and received over 10,000 responses. A total of 185 respondents had ataxia.

The survey is very comprehensive and asks questions on a variety of topics including diagnosis, welfare, mental health, social care and accessing support.

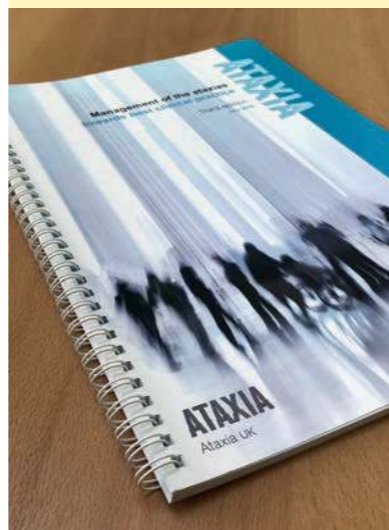
The results are fascinating, especially when you compare the results of responders with ataxia to those with other conditions. Here are some findings we thought you may find interesting.

45% of respondents with ataxia had to see their GP five or more times before seeing a neurological specialist. And after seeing their neurologist for the first time, it took 42% of people with ataxia over 12 months to receive an accurate diagnosis, compared to 21% for those with other conditions.

And sadly, after how long it takes to receive a diagnosis, 52% of people were not offered any written information about their condition and 30% were not given any information at all. On top of this, 63% of people were not told about how to find further information for themselves. When patients took to finding information themselves, they found their local authority, the NHS and charity to be most useful.

The figures above suggest that awareness and understanding of ataxia is far too low amongst health professionals. Ataxia UK are working hard to change this.

One of the key components of this change is the **Specialist Ataxia Centres**, run by specialist neurologists who hold the best knowledge of ataxia. You can ask your GP or neurologist for a referral to one of the centres and visit our website for more information www.ataxia.org.uk/Pages/News/Category/ataxia-centres.

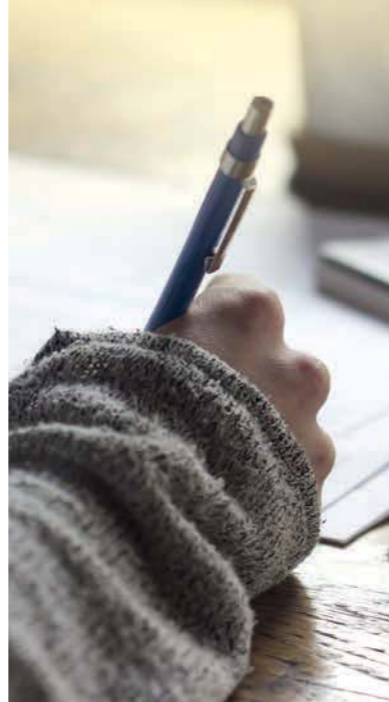


45%

of respondents with ataxia had to see their GP

5x

or more before seeing a neurological specialist



68%

of patients with ataxia were not offered support with their mental wellbeing after receiving their diagnosis



70%

of patients received help with purchasing equipment through grants from a charity, their local council or the NHS



72%

of ataxia patients have not had their local council assess them to see if they are eligible for support and care

We have also created the **Ataxia UK's Medical Guidelines** (left) that offer support and guidance to healthcare professionals. You can order a free copy from the office by emailing office@ataxia.org.uk to give to your GP or physiotherapist.

62% of patients reported to have seen an **occupational therapist (OT)**. This puts ataxia patients considerably higher than other national respondents without ataxia, who reported that only 38% of them are seeing an OT. Equally positive, **physiotherapy** and **speech and language therapy (SPL)** were offered to a higher percentage of people with ataxia, compared to the other national respondents.

One area that clearly needs improvement is **mental health and wellbeing**. 68% of patients with ataxia were not offered support with their mental wellbeing after receiving their diagnosis. A further 24% of patients would have liked to be offered counselling but were not.

Mental wellbeing was rated much lower than other areas, such as welfare and social care.

World Mental Health Day 2019 fell on the 10 October; we compiled some resources to highlight the link of ataxia and mental health, and some resources for support. Visit this page to see them www.ataxia.org.uk/News/mental-wellbeing.

The survey showed that patients with ataxia have received help with purchasing equipment they have been advised to get. 70% of patients received help with purchasing equipment through grants from a charity, their local council or the NHS.

Ataxia UK acts as a third party to support people with grants and you can find out more about by visiting www.ataxia.org.uk/Pages/News/Category/grants-for-people-with-ataxia.

Additionally, 72% of ataxia patients have not had their local council assess them to see if they are eligible for support and care. There were 19% of patients who did, and were eligible, so we encourage others to do so.

Overall, 40% of ataxia patients reported that they felt they are seen often enough for their needs, but 42% of patients felt the opposite.

As ataxia is a rare condition and goes unrecognised by many healthcare professionals, it can be difficult for patients' needs to be met.

Furthermore, there are only two Ataxia UK Accredited Specialist Ataxia Centres in the UK. This is something we are working hard to resolve and hope to open a virtual clinic to improve accessibility for patients with ataxia. You can read more about this and the **Big Give** campaign on pg.12.



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