

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 225. Spring 2024

The Big Give Christmas Challenge.

Over 300 Friends of Ataxia UK came together to give the ataxia community the vital gift of support. Find out more on page 14.

Thank you
for giving the
gift of support

£47,659 RAISED

BREAKING NEWS

Skyclarys® treatment for FA
now approved for use in the EU
(see page 6)

- Ataxia people
- Research
- Ataxia awareness
- Health & wellbeing
- Fundraising
- Adoptions
- Living with ataxia
- Services

ATAXIA

Ataxia UK

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

CEO's introduction

The first few weeks of 2024 saw a continuation of the trend that was developing in 2023: at Ataxia UK we are having to spend more and more time providing the patient voice in the process to approve drugs for the ataxias.

Skyclarys® (for FA) is making its way through the European approval process, (see p6) and we have now had reassurance and confirmation from Biogen, the pharmaceutical involved, that they will submit it for approval in the UK very soon, following the 12th February approval from the European Medical Agency (EMA).

As trailed by Anne Neumann of Biohaven, Troriluzole (a drug they have trialled for SCA3), in her platform speech at our conference, has also been submitted to the EMA for approval. Ataxia UK provided evidence for this submission via our role in Euro-ataxia.

In the last few months of 2023 and the first few months of 2024, we were also pleased to welcome a couple of new faces to the ataxia community. We were joined by our new **Events & Community Intern, Louise Cheong**. We've also seen some changes to our Board of Trustees, with **Rob Perkins** leaving, and we've co-opted a new **Trustee, Olivia Wood**, who brings with her a wealth of knowledge in Fundraising and a personal connection to ataxia, too.

We are well into the preparations for the Ataxia UK roadshows which are coming soon to the capital cities of the devolved nations (see p4). We hope that lots of you will come to meet people affected by ataxia who are local to you and face similar challenges.

Best wishes,



Sue Millman



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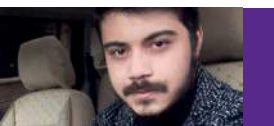
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Ataxia UK Roadshow

Ataxia UK is coming to you! We'll be travelling around the UK to the capitals of the devolved nations to connect with Friends in a series of one-day events featuring an action-packed programme.

WHAT TO EXPECT

The programme will be similar in each location, with some sessions tailored specifically to that country, so there is no need to attend in more than one of these locations. It will include 'It Works For Me' talks from Ataxia UK's Friends, research updates, a Doctor's Q&A, a presentation from Sue Millman, Chief Executive of Ataxia UK, and interactive breakout sessions.

This is a great opportunity to meet up with other people living with ataxia near to you, connect with local Support Groups and find out more about how Ataxia UK can support you.

Cardiff – Saturday 20th April 2024 10:00-16:30

Venue: **The Clayton Hotel**
St Mary's Street, Cardiff, CF10 1GD

Belfast – Thursday 20th June 2024 10:00-16:30

Venue: **The Hilton Hotel**
4 Lanyon Place, Belfast, BT1 3LP

Edinburgh – Saturday 22st June 2024 10:00-16:30

Venue: **Novotel Edinburgh Park**
15 Lochside Avenue, Edinburgh, EH11 4DG

BOOKING

You can find out more about the Roadshow events and book your tickets at <http://alturl.com/8uhji>. Tickets cost £34.00 and include lunch and refreshments.

BURSARIES

We have limited bursaries available on a first-come, first served basis to cover 50% of ticket prices and travel costs, including for carers. To be eligible for a bursary, you must receive means-tested benefits. Recipients will pay for their travel and tickets in advance, and then be reimbursed after the conference, within 4 weeks of providing their receipts. If you would like to apply for a bursary, please contact Anastasia using the contact details below.

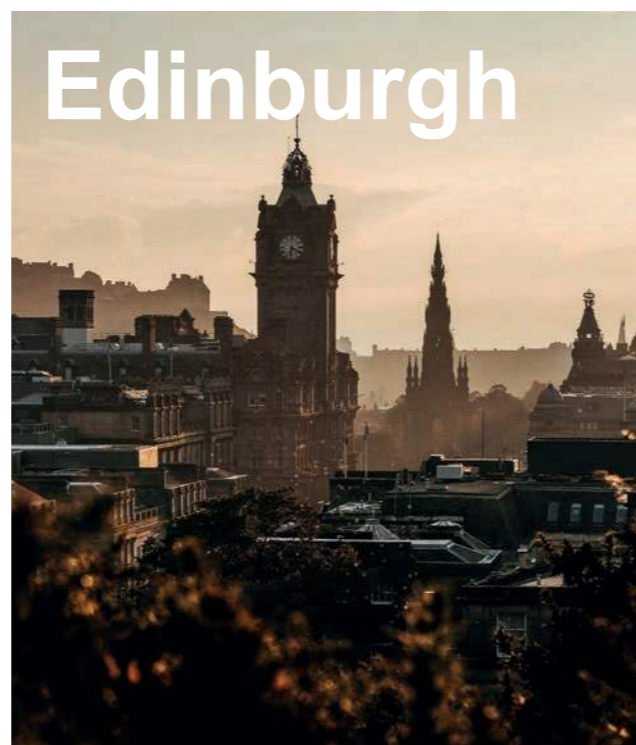
If you have any questions about these events or would like assistance with booking a ticket please contact **Anastasia** at conference@ataxia.org.uk or call **020 3196 0440**



Cardiff



Belfast



Edinburgh



Annual Conference online

Ataxia UK Virtual Annual Conference 2024 – Save the date.

Saturday 28th September

This year's Annual Conference will be taking place online, with a jam-packed programme brought directly to you in the comfort of your own home!

Keep an eye on our social media, newsletters and the next magazine for more information.

For more information about the format of the Virtual Conference, watch some of the interesting content from our 2022 Virtual Annual Conference at: <http://alturl.com/vtbts>

Positive news on Skyclarys®

Positive news! Ataxia UK is delighted with the announcement on 15th December from the EMA's Committee for Medicinal Products for Human Use (CHMP), the regulatory body that makes recommendations on drug approvals in the EU. The CHMP recommended a market authorisation for Skyclarys® for people (16 and older) with Friedreich's ataxia (FA) in the EU. The final decision had to be made by the European Commission and we were happy to learn of them granting their approval for use in EU countries on 12th February. However, this was a significant hurdle to overcome. For Skyclarys® to be approved in the UK, Biogen must submit an application to the UK regulator, the MHRA. We believe EU approval will lead to a faster approval in the UK. It is worth noting that after approval, the drug must undergo the 'Health technology assessment', where decisions are made on drug funding within the NHS. Ataxia UK is collaborating with Biogen to ensure access to Skyclarys® for those with FA in the UK. A productive meeting was held with five members of the Biogen UK team on 8th December at the Ataxia UK office. Biogen plans to seek MHRA approval. They are considering several regulatory routes, including an independent filing or a new regulatory pathway called the International Recognition Procedure (IRP), a 'fast-track approval process' in place in the UK from 1st January 2024. We will continue to work with them and update you on progress.

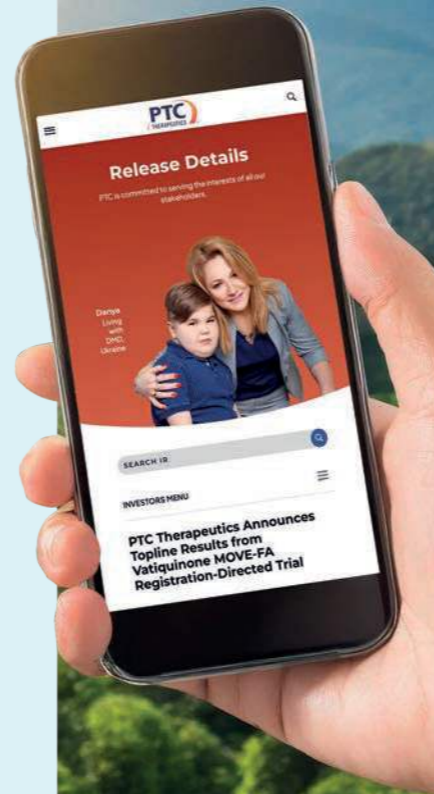
You can find Biogen's press release in our latest Skyclarys® research news article on our website at www.ataxia.org.uk/omav-updates.

Update on the PTC Therapeutics MOVE-FA programme for Friedreich's Ataxia

The pharmaceutical company PTC Therapeutics has written to the US regulatory body the Food and Drug Administration (FDA) to determine whether data from their MOVE-FA phase 3 clinical trial of vatiquinone in children and adults with FA are sufficient for a New Drug Application (NDA) for accelerated approval. The study did not meet its primary endpoint, the main measurement to show whether the drug works, as there was no statistically significant change in the overall mFARS score (a scale that measures FA progression). However, there was meaningful clinical benefit to some components of mFARS, including a slower decline in bulbar stability (of muscles in the head and neck for swallowing and coughing) and upright stability. Fatigue was also reduced with Vatiquinone.

The FDA stated that a confirmatory study would likely be needed for an NDA. PTC has requested a follow-up live meeting to address issues raised by the FDA. PTC is participating in a scientific advice procedure with the EMA, to determine if the MOVE-FA data could support a conditional marketing authorisation application in the European Economic Area (EEA).

You can read PTC Therapeutics' press release in our latest PTC news article on our website or at: <http://alturl.com/ms9yj>. For a full FA research update, see the presentation from our annual conference presented by our Research Officer, **Mary Barron**, on our website at: <http://alturl.com/frtyv>



FA research event - Frankfurt

Friedreich's Ataxia researchers based in Europe gathered in Frankfurt in November for a research retreat organised by the team at the University Hospital Aachen (who lead the EFACTS network). Ataxia UK's Research Officer, Mary Barron attended, as did a number of UK-based researchers. The programme included talks on how the frataxin protein functions in FA and discussions on the sharing of patient biosamples within the research community. Levels of frataxin proteins are decreased in FA. Frataxin proteins are needed for producing energy in part of the cells called mitochondria, and studying biosamples helps researchers to get a better understanding of FA and how the condition affects cells. This can help to identify new targets for potential FA treatments. There were also two roundtable discussions focusing on funding and strategy and a talk about the ongoing efforts to merge data collected from the FA-COMS and EFACTS natural history studies into the single FA Global Clinical Consortium.

The London Ataxia Centre is recruiting participants for the Vico Therapeutics trial of the therapy VO659 in SCA1 and SCA3

In April 2023, the Netherlands-based company Vico Therapeutics announced that they dosed the first person in their phase 1/2a clinical trial evaluating a drug they developed called VO659 for the treatment of SCA1, SCA3 and Huntington's Disease (HD) at one of their sites in Europe. VO659 is a type of therapy called an antisense oligonucleotide (ASO). ASOs are small pieces of genetic material being developed to treat several genetic conditions. ASOs act on mutated genes, influencing their ability to make proteins. In this case, the ASO targets the mutated gene causing, SCA1, SCA3 or HD, preventing it from producing a protein which ultimately causes the condition. These three conditions are all caused by the increased length of a specific sequence called 'CAG repeats', which results in the production of toxic proteins that damage cells. VO659 targets these additional CAG repeats and stops them from resulting in the production of toxic proteins.

To participate in the trial, you must be 25-60 years old and have a genetically-confirmed diagnosis of mild to moderate SCA1 or SCA3. If you or someone you know is diagnosed with SCA1 or SCA3 and is interested in taking part, contact the London Ataxia Centre by emailing uclh.ataxia@nhs.net or calling **02034 483100**. You can read more by downloading the dedicated leaflet from our website: <http://alturl.com/3md99>.

Biohaven submits application to the EMA for a new drug approval of Troriluzole for SCA3

On October 26th 2023, the pharmaceutical company Biohaven submitted an application for a new drug approval of Troriluzole to the European Medicines Agency (EMA) for the treatment of Spinocerebellar Ataxia Type-3 (SCA3). This is being reviewed by the EMA's Committee for Medicinal Products for Human Use (CHMP), the regulatory body that makes recommendations on new drug approvals in the EU. Ataxia UK is providing evidence to the EMA about the burden of illness in SCA3 via our role within EuroAtaxia. We will update you on its progress through our communications. You can read about the application on the EMA website at <http://alturl.com/hq9az>



Quality of care is higher in Specialist Ataxia Centres, European study finds

Ataxia UK worked closely with the London Ataxia Centre researchers and other experts on a research study assessing the impact of Specialist Ataxia Centres in Europe.

This was part of the Value of Treatment (VOT) project supported by the European Brain Council, a non-profit organisation which promotes brain research to improve the lives of Europeans with brain conditions.

The project highlights the impact of neurological disorders and improves care and outcomes for Europeans with conditions including ataxia.

Ataxia UK's Head of Research **Julie Greenfield** says, "This project involved many partners, including researchers, policy experts and patient groups in Italy and Germany. We are also very grateful to all the people affected by ataxia who took part in this important research".

A large survey was administered to people with ataxia in the UK, Germany and Italy, to gather information about diagnosis and management of their ataxias and healthcare resource use and costs per person in specialist ataxia centres (SACs) or non-specialist settings. The results of the study are published in the Orphanet Journal of Rare Diseases as two separate papers,

For the first part of the study, 552 people with several ataxias (or their parents/ caregivers) in the UK (277), Germany (101) and Italy (174) shared their experience of the diagnosis and management of their ataxias in SACs or non-specialist settings. Satisfaction was higher in the SAC group, across understanding of their condition, management of their ataxia, delivering care adapted to needs, co-ordinating referrals to healthcare specialists, and offering opportunities to take part in research.

For those who had not been to an SAC, or stopped attending, there were two key barriers to attending in all three countries. These were difficulties travelling to an SAC and a lack of a re-referral system to an SAC.

In the UK, over half of respondents said primary healthcare practitioners neither had a good understanding of their ataxia nor had a good knowledge of treatments. 91% of the SAC group gave positive feedback on the SAC in understanding of ataxia, and 85% gave positive feedback on knowledge of healthcare practitioners about ataxia treatments.

Feedback was less negative for patients' experiences of visits to secondary healthcare practitioners (including neurologists), in all three countries. In the UK, for the understanding of the management of their ataxia, there was negative feedback by 37% of participants, and in terms of knowledge about treatments, negative feedback was given by 52% of participants.



Survey participants shared how they thought their treatment and care could be improved:

- Earlier specific diagnosis
- Improvement and sharing of information about the condition and available treatments
- Advice to feel in control of the condition, and practical advice on living with the condition
- Better access to therapies and better management of their symptoms
- Advice on adapting their home
- Advice on maintaining the level of healthcare when SAC visits are no longer possible

The results highlight the need to improve access to SACs, as participants felt ataxia management was better overall in SACs compared to non-specialist secondary care settings. The second part of the project aimed to compare average healthcare resource use and costs per person for those who attended SACs and those who did not in the past 12 months. The experience of 320 people with ataxia within the same cohort (or their parents/ caregivers) across the UK (181), Germany (43) and Italy (96) was collected with the same survey. Healthcare costs per person were similar in both groups in all three countries. Within countries there was little variation in resource use for the SAC group compared to the non-SAC group, but there were variations between countries in some types of healthcare contact. The highest number of SAC visits occurred in Italy, then Germany and the UK. Physiotherapy visits were the most common type of healthcare contact in all three countries.

Dr Julie Vallortigara, research fellow at the Ataxia centre, who worked on this project: "We consider this data to be of great importance for the future of people living with ataxia in the UK and other European countries, by providing key insights about people's experience and feedback about their care, and by making recommendations based on evidence to improve treatment and care".

Prof Paola Giunti, who led the project, says: "This study demonstrates the value and benefits of specialist ataxia centres in the management of patients with ataxia".

Following the project, the researchers set out key healthcare policy recommendations to support ataxia management and care. The research papers were published in the **Orphanet Journal for Rare Diseases** (Orphanet J Rare Dis, 2023; 18: 328 and Orphanet J Rare Dis, 2023; 18: 382). For information on UK Specialist Ataxia Centres and how to get a referral, visit <http://alturl.com/ahx44>.

Healthcare policy recommendations from this study

Provide whole genome sequencing to give a diagnosis sooner

Increase the availability of multidisciplinary team clinics

Improve rare disease training for healthcare professionals

Ensure centres have a research focus as well as symptom management

Implement telemedicine in existing SACs and increase the number of SACs

Increase access to SACs by improving awareness of them and ensure referrals to SACs are part of national care pathways

Rare Disease Day

Rare Disease Day takes place on 29th February each year.

In 2023, we highlighted how well-coordinated care can make a real difference in people's quality of life. With the support of our friends, the Rare Disease Day campaign was a success. We were pleased to receive so much enthusiasm and support from our friends for this year's Rare Disease Day campaign. Thank you all for sharing your stories.

For the 2024 Rare Disease Day, we wanted to remind you that although rare conditions may be individually rare, they are collectively common.

In the UK, there are 3.5 million people living with a rare condition and over 7000 identified rare conditions. Despite their individual rarity, these conditions collectively impact a significant portion of the UK population. Did you know that 1 in 17 people will be affected by a rare condition at some point in their lives? With your help, we want to raise awareness and help break down barriers.

Our friend Jilly said, "I suppose I never thought of it like that. It's like a rare disease community where understanding and non-judgement is a given, as well as support and knowing you are not alone."

On average, it takes over four years to receive an accurate diagnosis of a rare condition, and currently, they have no effective treatment. In addition, 95% of people living with a rare condition have one of the most common 400 rare conditions.

When viewed collectively, we see that rare conditions emerge as a shared experience that binds individuals through their unique health challenges. Let's work together to raise awareness about the challenges faced by people living with a rare condition. The more awareness we raise, the more likely we are to see change and an improved support system for those affected.



Our friend Ali (left) said, "This is a great opportunity to inform people and raise awareness because it's true that, collectively, rare conditions are not very rare."

Though the condition is rare, so are the stories behind it. Our aim is to highlight the importance of seeing beyond people's rare conditions and understanding their rare needs. It's time to build a common ground where rare stories can be voiced.

There is still time to support this year's Rare Disease Day Campaign by sharing your ataxia stories. Don't forget to check out our website: <http://alturl.com/bmjy> for more information and to find out how to get involved. You can also contact us at communications@ataxia.org.uk.



How our services can help you

People affected by ataxia can struggle with their mental as well as physical health. Due to how rare this condition is and how debilitating it can be, it can leave people feeling isolated, anxious, and lonely. The services offered by Ataxia UK have gone far in helping people affected by ataxia fight these feelings and build a sense of community and friendship.

One of the biggest examples of this is in our peer support groups located all over the UK, including Scotland, Wales, and Northern Ireland. Each group has its unique way of running its meetings, but whether it be in person or online you'll be welcomed regardless of where you're from in the UK. Through the meetings these groups hold, you can meet and bond with other people with ataxia, share tips and advice for living with the condition and talk in a safe and understanding environment.

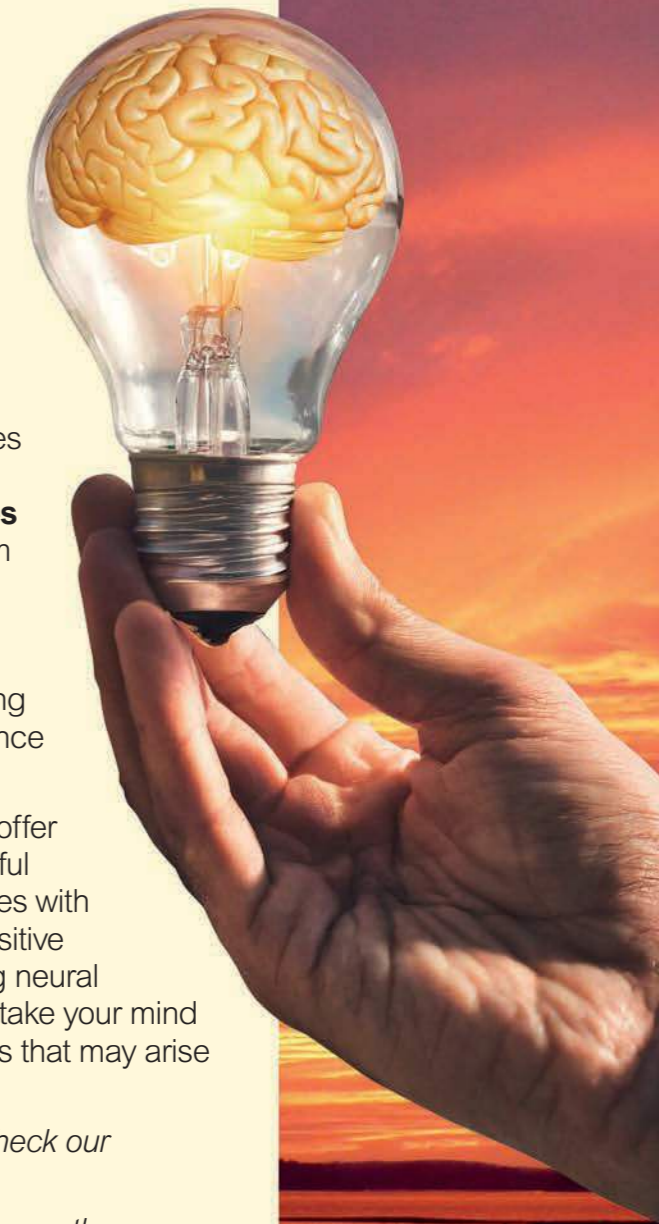
We also offer several online support groups, including the virtual support group, which is known to have members worldwide. Other support groups are tailored to someone's condition or situation, such as the **Episodic Ataxia Support Group** and **Autoimmune & Gluten Ataxia Support Group**. To join these groups, simply contact the Support and Branch Group leader: <http://alturl.com/6n449>

Alongside this, we provide regular and one-off virtual activities throughout the year tailored to helping people with ataxia emotionally, socially, and physically. Through our **Chair Pilates** sessions run by **Sonia Forde**, people with ataxia can perform exercises tailored to their condition from the comfort of their own home over Zoom. Using only a chair and occasionally a cushion or pillow, Sonia will take you through several Pilates exercises designed to ease ataxia symptoms by strengthening core muscles and helping to keep the coordination and balance systems of the body working as well as possible.

The regular **Mindfulness** sessions hosted by **Lucy Holland** offer coping strategies to help deal with difficult thoughts or stressful situations. These sessions often combine breathing techniques with meditation, stretch and release exercises, body scan and positive affirmations. These methods involve the entire body, including neural highways, circulatory and respiratory system. They can help take your mind to a place of inner peace to help you deal with the challenges that may arise in daily life.

To find details of our upcoming virtual activities, be sure to check our webpage for up-to-date information: <http://alturl.com/ej6pi>

If you have any questions or suggestions for how we can improve the services we offer, then our services team would love to hear from you at: volunteering@ataxia.org.uk. If you would like to find out more, or talk to a member of the team, please get in touch by calling **0800 995 6037** or by emailing help@ataxia.org.uk.



Through my gaze

Virtual Art Exhibition Fundraiser. 4th to 31st March 2024.

We are delighted to be inviting you to take part in the third-ever edition of our Virtual Art Exhibition & Fundraiser 'through my gaze' taking place this March. As part of this exciting fundraiser we have unique one-off pieces of art sold through our website. As well as an opportunity for new, budding or experienced artists, hobbyists, photographers and creative minds to show off their talent, it's a unique and exciting opportunity to support a fabulous community.

Show your support! Head over to our website to browse art and purchase your truly unique artwork today. Visit <http://alturl.com/2ik7d> – be quick, once these one-off pieces of art are gone, they're gone. Contact us at: fundraising@ataxia.org.uk.

Ataxia Classic 2024!

We will be heading back to the beautiful countryside of Yorkshire for our very own cycling event, the Ataxia Classic, on 22nd September 2024! We invite those who took part in 2023 and those who did not to get your bikes out and start pedalling away and join us for a cycling adventure like no other! Andrew, who has taken part in every single one of our cycling events, said: "I've enjoyed riding my bike for Ataxia UK for many years and helping in a small way with the planning for this year's Ataxia Classic in Yorkshire."

To take part, visit our website or get in touch with the team at fundraising@ataxia.org.uk for more information. You will receive a cycling vest, fundraising pack and 1st class support all the way to the finish line! Those signing up early will also receive an exclusive, early-bird discount, so visit our website today: www.ataxia.org.uk/ataxia-classic-2024

STEP TOWARDS SUPPORTING PEOPLE WITH ATAXIA!

When you sign up for one of the exciting running, walking, trekking, or cycling events, you will receive an exclusive running/cycling vest or t-shirt to flaunt your support while you conquer those miles. Not to mention our support, which will be with you every step of the way to the finishing line & beyond! Plus, every fundraiser gets **FREE** entry, courtesy of Ataxia UK!

Whatever your fitness level, we have a number of prestigious runs in Europe to suit your needs: Paris Marathon: 7 April 2024, Amsterdam Half & Full Marathon: 20 October 2024

In the UK, we have scores of runs, marathons and half-marathons throughout the country. Here are just a few: Shakespeare Marathon: **April 2024**, Edinburgh Running Festival including Marathon: **May 2024**, Leeds Half & Marathon: **May 2024**, The Great North Run: **September 2024**, The Great South Run: **October 2024**, The Great Scottish Run: **October 2024**. See the full selection of upcoming runs here: <http://alturl.com/q72sr>. For more info, contact **Hanif** or **Louise** at fundraising@ataxia.org.uk.



Our super-hero fundraisers ended 2023 with some amazing achievements! We are immensely grateful to each and every one of them.

Fundraising thank-yous

Afsha Mohamed and son **Hashim (1)** who has ataxia, organised a stall to celebrate his 10th birthday by raising awareness and funds for Ataxia UK! They raised an amazing £350! Thank you, Hashim, for being so brave!

Thank you to **Chelsea Higgott (2) & family** for their pub quiz night with family, friends, and everyone at the local pub raising £420!

Hannah Way (3), who ran the Cardiff Half raised a staggering £2146 with match funding from her employer. Thank you, Hannah, for your fabulous contribution!

Luke Martin (4), thank you for running the Loch Ness Marathon and raising over £3000, which will go a long way to support people living with ataxia!

Scott Forsyth (5), you are a legend! After 6 months, 12 half - marathons, raising a staggering £5,532! You are an inspiration to us all. Thank you so much for your amazing resilience, determination & commitment.

We had **42 cycling heroes** (left) pedalling through the beautiful Yorkshire countryside to make the **2023 Ataxia Classic** a tremendous success. Together they raised a whopping £20,000! A huge thanks to all of them, including all our volunteers, and the family members who came along to support the riders.

A special thanks to **Tesco in Pocklington** for their generous contribution with refreshments and water for the riders. Thanks also to **Pocklington Rugby Union Club** for hosting the event.

A huge thanks to everyone at **Furness Rugby Union Club (6)** and **Craig McKinnon** for their continued support and raising £250 during a day which they call Ataxia Day over the Christmas period!

Thank you to **Samuel Biddiscombe (7)** for taking the punches and boxing his way to a cure for ataxia. Samuel raised £250 at UWCB Boxing event!

The **2023 Big Ataxia Cake Bake (8, 9)** was a huge success this year! Thanks to everyone who participated! Total raised this year was over £1500 with a couple more events still left to do. The fundraising challenge prize was won by **Julie Ryder** who raised a sweet total of £584.75.

A superhero thanks to **Nick Fairlie** (left) for his achievement in completing the Ironman 70.3 Portugal Triathlon challenge and raising over £4000!

Phil Hobbs (10) raised over £2000 zipping his way down the Snowdonia Zipline! Thank you, Phil, for your brave achievement!

Lucy Holland, (right) thank you for hosting your annual fundraiser, 'Relax & Restore' a Candlelit Yoga Evening raising a fantastic £700 from the sold-out event! Well done!



The Big Give

Thanks to your overwhelming support, 2023 was wrapped up with a successful ending thanks to the Big Give Christmas Challenge.

If you are subscribed to our emails, you might already know, but the recent Big Give Campaign was an overwhelming success. We initially set our target for the 2023 Big Give at £37,500, but with a huge thanks to our generous pledgers and our Champion Supporters – **The Reed Foundation** – we were able to push our target up to £44,000. However, you and the rest of the ataxia community were able to come together and support each other to help raise a total exceeding more than £55,000 to support the expansion of Services provided to those affected by ataxia.

In the last few issues of the Ataxia Magazine, we reported on the wonderful grant we received from the National Lottery and how this would allow for the expansion of the support services provided the community. However, this grant falls short of the total we need to finance the completion of this expansion project. It's your support that helped us smash this target with all funds received through the Christmas Challenge allowing the expansion of these services.

Gifts towards the Christmas Challenge will help progress several of our services, including, providing timely, appropriate, and high-quality information, advice and support on a range of issues impacting all aspects of the lives of people affected by ataxia. This will happen both by creating a more specific series of All About Ataxia Seminars and increasing the range / quality of advice & information via print, website & Helpline. Your gifts throughout this Christmas Challenge will also ensure our capacity to provide more casework support and provide advice and advocacy to more people increases – so everyone who needs support can access it.

Although we are still wrapping up last year's Christmas Challenge, we must also start looking forward to the 2024 appeal. As with previous years, planning this campaign begins with looking for pledgers. Pledgers should start to register interest now but won't need to fulfil that pledge until early 2025! If you are interested in being a pledger next year, then you can reach out to us at fundraising@ataxia.org.uk. Alternatively, you can sign up for more news and information on the 2024 Christmas Challenge.

Christmas
Challenge

BigGive



Put a spring in your step

The Ataxia UK 2024 Spring Raffle draw takes place on Monday 13th May 2024. Be in with the chance of winning the top cash prize of £200 by taking part in the Spring Raffle no later than Wednesday 1st May!

Ataxia UK's blooming awesome Spring Raffle is growing back in 2024, and with it a fantastic opportunity to win! You will find two Ataxia UK raffle books, containing 10 tickets each, enclosed with this issue of the magazine. Sell these to your friends, family, and colleagues, or simply buy them yourself.

At just £1 each – every ticket you buy gets you closer to a chance of winning one of three fantastic prizes: A £200 voucher, a handy 'ability' hamper, or an experience voucher! The best part? It's not just you who can win! By taking part, you're also helping people in the ataxia community by providing support where it's most needed and funding ataxia research, in a fun way! We encourage you to take this opportunity to talk to as many people as possible to sell tickets and raise awareness.

HOW TO PLAY

Step 1: Fill in the full name, postal address and telephone number on each ticket purchased by the raffle player(s). 1 raffle ticket costs £1, and a book of 10 tickets costs £10.

Step 2: Send your cash or cheque amount along with the purchased raffle ticket(s) to Ataxia UK using the enclosed FREEPOST envelope. Please write the buyer's name on each purchased ticket. This must arrive no later than Wednesday 1st May.

Please note: If you sell all your tickets and would like to order more, you can request more raffle books by contacting us at fundraising@ataxia.org.uk or on **020 7582 1444**. To purchase tickets online, visit <http://alturl.com/94rur>. The Spring Raffle is only open to UK residents aged 16 and above, for full Terms & Conditions, please see our website.



2024
Spring
Raffle

Regular Giving

Can you commit to becoming a regular giver at Ataxia UK?

We know that with the New Year, many charitable givers like to reassess their contributions. If you're looking to give back to a charity that has helped support you or a loved one, then choosing a small charity like Ataxia UK could make all the difference. Your regular support allows for sustainable expansion of services provided to those that need it most. It's only through your regular gifts that we can predict certain levels of income, meaning we can plan and launch projects for those affected by ataxia, well into the future.

Visit our website at: <http://alturl.com/adx8a>, to sign up to a Direct Debit with Ataxia UK and become a committed regular giver – helping ensure sustainability of support and research for those affected by ataxia. Alternatively, if you want more information or assistance with setting up your regular gift, please contact **Kieran** at kfearnley@ataxia.org.uk



Adapting to my ataxia

Louise, in her blog post, explains her ataxia journey and reminds us to be inspired by our courageous resilience.

My name is Louise, and I was born in Ceredigion, Wales, in 1961 to a family of six. I trained and worked as a neurology nurse in England. My father was diagnosed with cancer, which resulted in my return to Wales in 1990. There are no neurology nursing work or resources near my family. I started my mental health nurse training but faced challenges in 1992. I was diagnosed with ataxia in 2014, but the cause is unknown. I live with my husband and our dog, Gwen, in Carmarthenshire. Writing, speaking, singing, walking and being an active voice for neurology keeps me busy.

In September 2023 I agreed to participate in research and a six-month wait is expected for the genetic results. In 2015 a neuropsychologist confirmed no active mental illness. Psychometric testing is insightful to my processing problems in memory and communication. The neuropsychology team and others have said and documented how inspiring they have found my resilience. I keenly aim to prevent others on a similar journey from feeling their vulnerability is invisible.

Making sense of my general health and neurology history and past links to psychiatry has helped me adjust my life and has made it easier to move forward. I was grateful to receive the ataxia nurse support letter, they had used straightforward language and offered guidance. I found this to be super helpful since I could reach out to the health professionals when needed.

A disabled shower room supports my needs. A profiling bed has made a huge difference. Profiling bed helps me as it reduces headaches - especially in the mornings. It also helps my vertigo since I can elevate the back and get accustomed to upright posture. Helps with bone and muscle pain. I have gained freedom to walk outdoors just by using my four-wheeled rollator which has a seat. It keeps my body and mind at ease.

My husband, Stephen, and I became Ataxia UK members in 2014. A helpful person on the Helpline was experienced, compassionate and confident. This contained my multiple questions and vulnerability. I was given suggestions and guidance in a sensitively manageable manner. The website and other online information, plus Facebook offers excellent and straightforward awareness. The newsletter and email updates are most informative.

My advice to you is to invest in your strengths. Use your talents. Be flexible and understanding since this can reduce pressure and frustration. Good humour guides well. Show kindness and patience towards the people around you, as they may also be scared and confused. We should allow our abilities to thrive and befriend disabilities. Accept help offered as needed. Ataxia is tough, but with confidence building, you can be in charge. Be amazed and inspired by your courageous resilience. Use opportunities such as quality relationships, contacts with connections to belong, hobbies and your defined work within capacity. We are stronger together going forward. Conserve energy wisely to optimise health and wellness.



Desert island aids

Harriet Brown is a trustee of Ataxia UK, and she is involved with the organisation and the ataxia community in lots of other ways, including volunteering regularly on our Helpline. Here Harriet talks about her must-have gadgets and aids.

My name is Harriet Brown, and I was diagnosed with Cerebellar ataxia over 30 years ago. I didn't use any aids for quite a few years but following an assessment with an occupational therapist about 10 years after my diagnosis, I was recommended to use a number of things which I subsequently found brilliant. It precipitated a conversation at the time with a friend who also has ataxia-if we were stuck on a desert island, what three aids would we want with us. It led to a very thought-provoking and entertaining discussion!

As the years have passed by, I have accrued many more aids, adaptations and gadgets to help me live the life I want to in the easiest and safest way possible. In preparing this article, I struggled to select my top three now. Instead, I kept my top three, which are actually as valid now as they were then.

My first would be my walking stick. I started using it occasionally to let others know I had mobility difficulties. Now, I wouldn't set foot outside without it. When I first started using it, I thought if I had to use one, I would use a nice one! I have built up a collection of sticks of different colours over the years. I consider them now more of a fashion accessory than a mobility aid. They must, as far as possible, co-ordinate with my outfit!

The second would be my bed rail. This is an 'L' shaped frame with the horizontal arm fitting under the mattress and the vertical arm sticking up as a grab rail. It helps massively with getting out of bed, helping with all of turning and pulling myself up to sit on the side of the bed from a lying position, pulling myself up into a standing position and helping to get my balance (as much as possible!) before setting off walking.

The third would be my raised toilet seat frame. Before I had this, I would regularly 'slam down' when sitting on the toilet seat, which was neither good for my pelvis/back nor the toilet seat itself. I now lower myself down gently using the handles on the frame and don't have as low to lower. It makes going to the toilet a much kinder experience for all concerned.

Thank you to Harriet for sharing her desert island aids! If you have any questions about gadgets, aids and adaptations, please don't hesitate to contact the Ataxia UK Helpline on 0800 995 6037 and help@ataxia.org.uk



Baking & positive thinking is Jilly's way forward

Meet our friend Jilly, who shares her story with us and reminds us of the importance of seeking help and expressing our emotions.

My name is Jilly and I have Ataxia Telangiectasia (AT). I am 35 years old.

I am a qualified pharmacist, however I had to stop practising in 2017 as my ever-progressing ataxia symptoms were making being a pharmacist very difficult.

I now spend my days baking and have my own home cake business. I started Jilly's Cupcake House in October 2015 and donate 100% of the proceeds. I also enjoy working out, going to concerts, the cinema, the theatre and going out to eat. I am a MASSIVE foodie.

I was diagnosed at age 2. My mum noticed I was very wobbly on my feet, more so than other toddlers who were around the same age. So, she took me to see the GP. We were quite lucky that my GP at the time had heard of ataxia, so I was referred to a specialist almost immediately. I was extremely young, so I remember nothing of the diagnosis journey.

But throughout my childhood, and even my teens, my mum would take me to various doctors' appointments, hospital appointments, osteopathy appointments, hydrotherapy appointments. You name it, and we probably had an appointment booked for it.

I think the theory behind all of these appointments was, "we know it's AT, so let's do everything we can to slow down the progression of this condition".

As I entered primary school, my balance symptoms resolved, and I was completely asymptomatic until I was about 17. Since the age of 17, my symptoms slowly began worsening.

I now suffer from slurred speech, hand tremors, dystonia of the neck and jaw and poor balance.

At home, I have a shower stool and grab rails fitted in the bathroom. I can no longer use stairs without assistance, and I now have to use a wheelchair for outings or holidays abroad.

In all honesty, yes it sucks, sometimes it's hard, and I do get upset and extremely frustrated but for the most part I feel okay about using these aids and adaptations because they make my life easier.

I also think that general society has become much more accepting of disabilities.

I know that there is a lot more to be done and a lot more awareness that needs to be raised, but if I think back to my mainstream high school days, I would be so afraid and so embarrassed if I needed to use such aids, as I do now.



But now, almost 20 plus years later (gosh I'm really showing age here!!), this increase in awareness, and more specifically ataxia awareness, has given me the confidence to accept myself as I am and carry on with my life unapologetically.

I follow Ataxia UK on social media, and they post about so many interesting things including ongoing research and stories and personal accounts of inspirational people who have ataxia.

I love reading about people's personal stories and their own experiences with ataxia, as not only does it mean increased awareness being raised, but it also makes me feel more seen/represented and less alone.

My advice for anyone living with ataxia, or just newly diagnosed is to allow yourself to feel sad, angry, and frustrated. These feelings are perfectly normal and valid.

The trick is not to dwell on them. Think positive. The power of positivity works wonders and is so underestimated.

Surround yourself with family, friends and people who love and support you. Because they will be your positive power when you have no energy and feel like giving up.

If you wish to share your story with the ataxia community, please contact our team at: communications@ataxia.org.uk



My pet and me

After the amazing presentation about assistance dogs from Dogs for Good at our Annual Conference in October 2023, we thought it would be interesting to hear from the ataxia community about what benefits and support they gain from their pets. In this article, Dawn, one of our Helpline volunteers, has very kindly written about what her dog means to her.

As I have got older, my Episodic ataxia has got worse. Causing many new symptoms and challenges. At 58 life is really "Interesting."

My husband & I decided to get a pet, a dog. I found a litter of rottweilers, very local. Knowing these were my husband's favourite breed, I also know that if we went to see the litter, that we would be bringing one home. I was right, that's exactly what happened.

Bubbles joined our family, and was a great asset, the grandchildren loved her. As did we. However, it wasn't long before I had an "episode." During the episode Bubbles, laid nose to nose with me.... This went on EVERY time I had an episode. Eventually she began knocking into my knees, it took a while to realise that she was doing this just before I went into an Episode, giving me time to call my Husband for help. It was due to her being a self-appointed assistance dog, that I started taking her out with me.

Bubbles and I go to church, shopping, holidays, meals out and concerts (non-amplified music).

None of this would have been possible without her training with "ROTE" "Rottweilers Only Training Essex". I have had many different breeds of dog, but training a rottweiler has been so different. They are so clever and bright.

When we go out, people cross the road when they see a rottweiler coming towards them, which makes me sad. so many don't get to see the precious gem of a dog that we see and know she is. The breed is so misunderstood, but they make amazing pets, companions, and self-appointed service dogs.

Do you have a personal experience with a pet that helps you cope with ataxia? Let our team know! We'd love to share your story with the ataxia community. Please contact communications@ataxia.org.uk



Possible grant to stay in work

Access to Work is a government scheme that supports you to stay in work if you have a disability or physical or mental health condition.

You need to be in employment (this includes self-employed, apprentices, trainees, and supported interns, as well as others) to access the scheme. You can also apply if you have a job offer or letter confirming your interview. Your financial situation or how much you earn is not considered when applying for the grant. You are awarded the grant based on your disability.

To be able to access Access to Work, you need to be over the age of 16 and living in England, Scotland, or Wales. There is a different system in Northern Ireland, you can find out more information here: <http://alturl.com/ipnan>

The sort of help you will receive depends on your needs. The main types of grants you can apply for through Access to Work are:

- A grant to help pay for practical support with your work. Examples of this are a support worker, costs for travelling to work, adaptations to your vehicle, specialist equipment and physical changes to your workspace
- Support with managing your mental health at work. This might include a tailored plan to help you to get or stay in work or one-to-one sessions with a mental health professional. *You can apply directly to either **Able Futures**: <http://alturl.com/ot89n> or **Maximus**: <http://alturl.com/pwor8>. Both services offer up to nine months of support tailored to your needs. They're free, and you don't have to have a formal diagnosis of any kind to access these services.*
- Money to pay for communication support at job interviews, such as a BSL interpreter or communication support if you have a physical or mental health condition or learning disability

There is no set amount for an access to work grant, it depends on your specific case. There is an annual cap on the amount of support that can be provided under Access to Work, this is currently set to £60,700 per person.

When you apply for your Access to Work grant, it will depend on who pays what percentage of the grant.

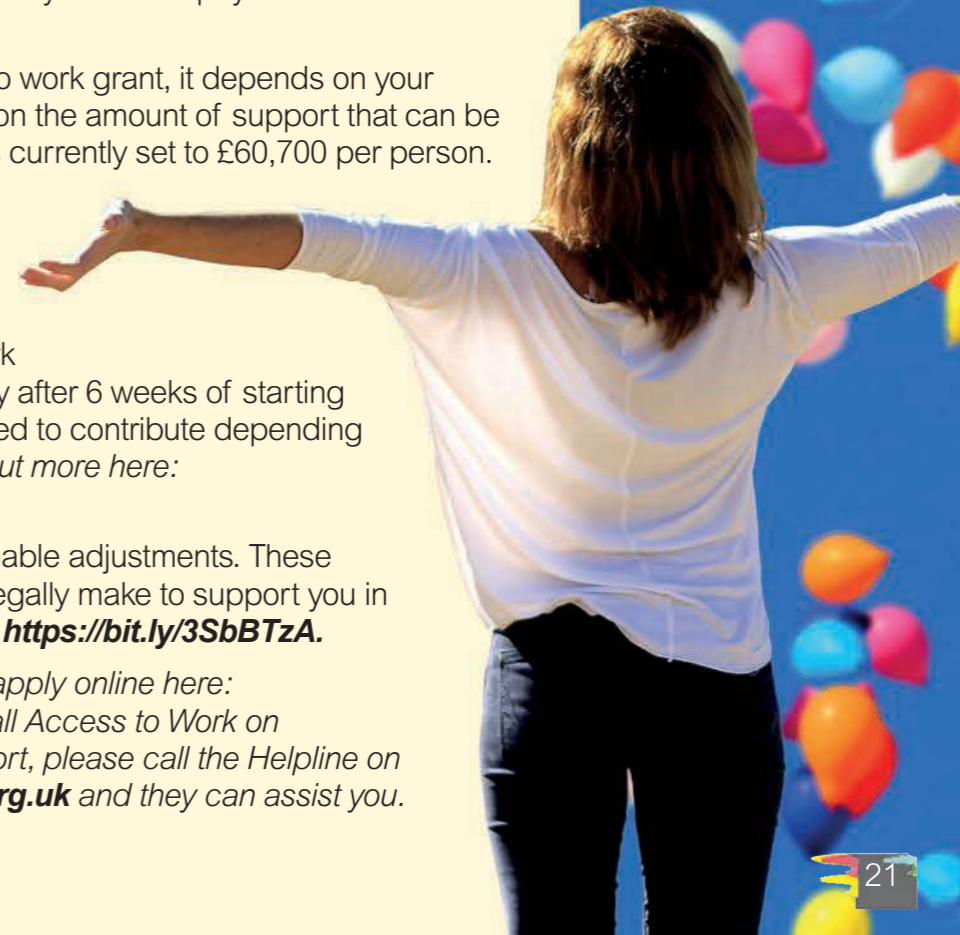
If you apply in the first 6 weeks of starting a new job, then Access to Work will pay 100% of the costs. If you apply after 6 weeks of starting a new job, then your employer may need to contribute depending on their circumstances. *You can find out more here:*

<http://alturl.com/vke7f>

Access to Work does not cover reasonable adjustments. These are the changes your employer must legally make to support you in doing your job. *See here for more info: <https://bit.ly/3SbBTzA>.*

You can check if you are eligible and apply online here:

<http://alturl.com/x3aov>, or you can call Access to Work on **0800 121 7479**. If you need any support, please call the Helpline on **0800 995 603** or email help@ataxia.org.uk and they can assist you.



Don't be put off appealing a benefit decision

The process of applying for benefits can be a stressful one: getting through to the **Department for Work and Pensions (DWP)** initially can be difficult, the forms are long, and the assessments can be anxiety-inducing. And after all that, what do you do if you aren't awarded a benefit when you think you should have been?

The first step is to apply for the DWP to look at your award again. This is called a **Mandatory Reconsideration**. Although it says that you need to apply for a Mandatory Reconsideration within one month of getting your award letter, you actually have up to a year, as long as you can explain to the DWP why it is late. Bear in mind though that your chances of a Mandatory Reconsideration being successful are low, with success rates for **Personal Independent Payments (PIP)** being under 20% and **Universal Credit (UC)** around 14%.

But do not be put off, if you are still unhappy with the decision, you can then lodge an appeal to an independent panel, called a tribunal. Although this process is long and can be difficult, it is important to know that the chances of your benefit decision being overturned at appeal stage are significantly better than with a Mandatory Reconsideration. The success rate for PIP is around 70% and for UC it is around 60%. It is important to note that you cannot lodge an appeal until you have received the results of a Mandatory Reconsideration.

The Ataxia UK Advocacy Service can help you with any part of the process. Last year, we helped L to appeal their PIP re-assessment after they had let the DWP know of their changes in circumstance as their symptoms had significantly worsened. The DWP initially didn't change L's award, so L put in a Mandatory Reconsideration that was also turned down. L turned to the Helpline for support through the appeal process. One of our **Advocacy Officers** then took on the role as Representative for L, writing their initial appeal form and then writing what is called a court submission – this is a written document that is sent to court before your hearing that outlines why you think the DWP decision is wrong and why you think that you meet the criteria for the benefit. At this stage, you can also send any new evidence that you have to support your argument. It is a good way to make sure the people assessing your case focus on the matters that are important to you. Although L found the appeal process very stressful, L was awarded the higher rate for both the daily living and mobility components of PIP as well as a lifetime award. L said afterwards: *“Thank you so much for your help – couldn't have done the process without your support.”*

Appealing a benefits decision is a lengthy process but we can help you through it and it is important to remember that at the appeal stage you have a high chance of success.

If you need any support with benefits, please call the Helpline on **0800 995 603** or email: help@ataxia.org.uk



Helpline & Advocacy service

Our Helpline & Advocacy team is here to provide one-to-one support with a range of issues from benefits, housing, care & health needs, aids & adaptations and so much more...

Email: help@ataxia.org.uk Phone: **0800 995 6037**



Speech Therapy

A combined individual and group speech therapy course for people with ataxia who have speech difficulties



Voice Banking

We are delighted to offer funding for Friends of Ataxia UK to use Voice Banking via a company called Speak Unique.



Social groups & Online Forums

From Branches & Support Groups to virtual activities and more, there's a variety of in-person and online groups, including authorised Facebook groups.

Online groups

www.ataxia.org.uk/support-services/online-support-forums

Branches & Support groups

www.ataxia.org.uk/support-services/branches-support-groups

Virtual Activities

www.ataxia.org.uk/latest-news/virtual-activities

More information

Support Services:

www.ataxia.org.uk/support-services

Help & Advice:

www.ataxia.org.uk/newly-diagnosed/help-and-advice

Our Helpline team is here for you.

Email: help@ataxia.org.uk Phone: **0800 995 6037**

Monday to Thursday, from 10.30am to 2.30pm.



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 several
research projects underway,
some of which are funded,
at least in part, by gifts left to us.

Your legacy can be hope for the future