

ATAXIA MAGAZINE

The magazine for people affected by ataxia

Issue 203. Autumn 2018



Smashing
the misconceptions
of ataxia in Derby

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

ATAXIA

Ataxia UK

In the office

HELLO



Catherine Scrace

A warm welcome to Catherine Scrace, our new **Research Communications Intern**. Catherine specialised in neuroscience at university and has since gained experience working in Communications; now she's looking to unite these specialisms within the medical research charity world by supporting our Research department and the ataxia community. Welcome on board, Catherine!

HELLO



Renata Da Silva

Renata Da Silva joins Ataxia UK as our new **Fundraising Administration Intern**. She has a background in law, but has mainly worked in the healthcare field in Brazil. She is currently studying for a Master's Degree in Bioethics and Medical Law. Renata has been a long-time supporter of our work as she has a relative who has ataxia. She is excited to join us and support the Fundraising department!

HELLO



Dan Beacon

Hello to Dan Beacon, our new **Head of Fundraising and Communications**! Dan has managed a variety of fundraising departments across charities both large and small and we're excited to see what expertise he brings to Ataxia UK, as John Williams becomes Head of Development.

Welcome

What a summer it's been! With the **Scottish Conference, Belper Games** and the **Derby awareness campaign** (p. 10) keeping us busy, we've enjoyed one of our best summers yet. Thank you to everyone who has gifted us their time, energy and sponsorship these past few months.

Looking ahead, we're getting ready for the **Annual Conference**, which will take place at **East Midlands Airport Radisson Blu** - we're excited to seeing some new and old faces, and hearing from you directly as to what you need from us moving forward. After the Conference, we'll also be meeting our two new Trustees; let us know who you think they should be by filling in the voting slip you'll find in your magazine.

Elsewhere in this issue, **we'll be announcing a potential new treatment for a rare form of ataxia, SCA38** (p. 8) and a **new collaborative study for SCA3 taking place in Europe** (p. 6-7).

Our awareness plans for September's **International Ataxia Awareness Day** are outlined on page 10, and how you can help us make them a great success (p. 13). You can also find a teaser about our next **Big Give match-funding campaign** this Christmas (p. 13) - please hold onto your generous donations until you can double them for no extra cost! - and our thanks to all of you who have fundraised for us this summer. We couldn't offer the support, advice and information we strive to without you.

Regards

A handwritten signature in blue ink that reads "Sue".

Sue Millman



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The helpline is open at the following times:
 Mon-Thurs **10.30am - 2.30pm**
 Friday **Closed**

Ataxia UK works across the whole of the UK and is a charity registered in Scotland (no SC040607) and in England and Wales (no 1102391) and a company limited by guarantee (4974832). We have made every effort to ensure that the information in this magazine is up-to-date and accurate. We hope that any advice given will complement any professional advice you receive. Please do talk to your health and social care team or contact our helpline if you are worried about any aspect of living with ataxia. © Ataxia UK 2018

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FEEDBACK

Please help us improve Ataxia Magazine by completing a short survey about this issue. You can find the survey at www.surveymonkey.com/s/ataxiomagazine203

ACCESSIBILITY

If you would prefer a large print or email version of this magazine, please let us know.

CONTACT US

We are always looking for great stories and photos for Ataxia Magazine. If you have an experience you would like to share or a topic you think we should feature, please write to the Editor at office@ataxia.org.uk. If you would like to reproduce any content from Ataxia Magazine, please contact the office.

A wedding to remember



Above:
Signing the register

Below:
Wendy and her new husband, **Laurence**

Back in edition 199, **Wendy Hurst** wrote about the challenges involved in planning a fully accessible wedding. Here, she updates us on how it all went and talks about her experience of married life so far.

The big day has come and gone. I had a mini-honeymoon. Now I'm a married woman and totally not grown-up enough for it.

Some of you may remember that I wrote an article a few issues ago on the troubles I was having organising a fully accessible wedding. My husband (scary word) and I started planning right after our engagement three years ago, but the pressure really ramped up six months before the big day until we were tearing our hair out a week before. It didn't help that everything else in our lives chose that week to go wrong, too! You've got to laugh, though. Go on, laugh!

On the big day my cousin brought strawberries and bubbly for me while I was getting ready and we actually managed to make me pretty - a task I thought would take much more than an hour. I spent the whole day in my new power chair and my family were too busy staring at that to notice me! **It was a slightly silly ceremony; light-hearted, fun, definitely unique.** The service took longer than expected and we had to rush everyone out to their cars to go for the afternoon tea. Luckily the weather wasn't great so nobody wanted to hang around for photos.

Tea was even better than I could have hoped, and served in a creative, just-this-side-of-hipster way. **The venue had left enough room for people with wheelchairs to move between tables and**

left a double-wide seating space at the table.

I had spent months asking for this but I was still impressed it had been done as most places think they know better than the person at the sharp end. There were a couple of minor hitches: a few of the guests didn't turn up; the hand dryer in the accessible toilet had a sign beneath it, so I could not use it; some bright spark had hidden a trolley under the table cloth on the cake table, so I kept crashing into it. None of those things were hugely important though and, after all our effort, it was as perfect as we could have hoped for. The lingerers were not-quite-politely ejected at 8 o'clock that evening and Laurence wanted to help the staff clear up. As expected, the staff told him to stop being ridiculous, so we loaded me into our hired WAV (wheelchair accessible vehicle) and went home, although I was so tired I kept driving off the edge of the ramp. The plan was just to get a takeaway on the way home and open a bottle of wine but, in exhaustion, we just went to sleep.

The next few days were filled with visiting friends, fading adrenaline and terrible colds.

It was nice just to have that week of recovery before we went on a mini-moon to Cardiff and then Butlins. There were a few problems with the accommodation at both places, but nothing that couldn't be worked around. We did so many nice things that it more than made up for any minor issues. For a proper honeymoon, our wedding guests contributed to a fund so we can do something extra special at a later date.

It's all over now and, to be honest, nothing has changed but my surname.

It took a few days to sink in that I'm married now, but I'm still going to run over toes if I don't like you, I'm still going to eat far too much junk food and I'm still going to wear things as hats that are not hats. The only change is that Laurence can no longer deny he knows me. Mwah hah hah haaah!





Support in North West London

Our friendly **North West London Branch** held their June meeting at the **Frogmore Paper Mill** in **Apsley, Hertfordshire**, and enjoyed a fish and chips lunch. Our **Community Fundraising Manager Rebecca** joined the group for a tour of the mill, learning all about the history of paper and seeing how it is made. The mill still produces its own speciality paper, including those with rose petals added to them - or alternatively, rhino poo! You can read more about the day on the Branch's website (<https://ataxiaknorthwestlondon.wordpress.com/frogmore-paper-mill>) or contact **Talita** for more information on the Branch on: nwlondon.supportgroup@live.co.uk or **07940 166 672**.

John Williams

John Williams, our previous **Head of Fundraising and Development**, steps into the new, part-time position of **Head of Development**.

He will be raising funds from Trusts, Foundations and Corporates for the charity and developing new projects in line with our **Strategic Plan** to improve and increase the support we offer you.



Getting social

All this year we've been expanding our online activity and support services to engage those of you who are online as directly as possible, whilst raising awareness of ataxia and increasing support for our cause.

Back in June we had some real success when a tweet went viral. Our post about a new character on **Emmerdale** who has **ataxic cerebral palsy** was re-tweeted by the show, potentially reaching their 1.2M followers. Getting the word 'ataxia' on the minds of so many people who otherwise might never have heard of the condition is an excellent outcome. None of this would have been possible without the excellent support of all of you, re-tweeting and sharing our posts. It makes a massive difference when we're able to build momentum and create a bit of a stir. Thank you!

Through this, however, we realised that the differences between ataxia as a condition, and as a symptom of other conditions (such as MS, Parkinson's and cerebral palsy), may not be as well understood by our community as it could be. So, going forward, we intend to create a new information series of videos on ataxia, as well as some new advice and support videos. Keep a look out!

Instagram

In July, following on from our success on Facebook and Twitter, we (re)launched our **Ataxia UK Instagram page**. We're now using the platform as an informal space for the ataxia community to share stories, images and ideas. The platform got off to a bang when it was (re)launched in conjunction with our **Derby awareness campaign**. Why not join us there?

You can connect with us on Instagram by going to www.instagram.com/ataxia_uk and clicking 'follow'.



Annual meeting of the European Spinocerebellar Ataxia Type 3 /Machado-Joseph Disease Initiative (ESMI)

Ataxia UK's **Head of Research Julie Greenfield** attended the annual meeting of the **European Spinocerebellar Ataxia Type 3/ Machado-Joseph Disease Initiative (ESMI)** project that encompasses research on SCA3 and is funded by the EU joint programme for neurodegenerative disease research.

She has been on the **Steering Committee** of the project for the last two years as a patient group representative and is pleased to report much progress.

The meeting took place in the **Azores Islands**, where the prevalence of SCA3 is astoundingly high. The meeting consisted mostly of researchers from the countries that are taking part in this project (UK, Portugal and a few sites in Germany and The Netherlands). In addition, representatives from patient groups in Israel and the Azores also attended. There is a very active group of researchers in the Azores Islands who run SCA3 clinics and are focusing much effort on research; they organised and hosted the meeting. Interestingly, they have been running a predictive genetic testing programme in the Azores for a number of years with a very high participation rate, meaning people are very keen to find out if they have inherited the faulty gene causing SCA3.

The main aim of this three-year project is to get ready for high-quality clinical trials in SCA3. To this end the following work is taking place:

- Creating a large database of SCA3 patients in the participating centres and merging the data from two pre-existing databases. We now have recruited 175 individuals as part of this study. By combining data from different databases, we also have information from 422 individuals on the same database.
- Seeing patients annually and doing standardised assessments of the ataxia (eg. ataxia rating scales) to understand how the ataxia changes with time, and to use this information when designing trials.
- Collecting blood samples and samples of cerebrospinal fluid (the fluid that surrounds the brain and spinal cord) to test for potential 'markers' for SCA3 that can be used to test the effect of a treatment in a trial.
- Performing brain scanning on people with SCA3 over time to see if we can detect changes that again can be used in trials.

The meeting was an opportunity to discuss the latest results and future plans. Another important component was a training session on the use of the **'Scale for Assessment and Rating of Ataxia' (SARA)**. This is a standard scale being used as part of this study and used in many trials to test the effect of treatments. Two people with SCA3 kindly volunteered to be assessed as part of this training programme, and the group was asked to individually give a score for each assessment. Julie said: "The subtle differences in each scoring to the untrained eye really emphasised to me the importance of doing these training sessions as part of this project and indeed when running trials." This need is very much recognised by the researchers and, as part of this project, an online training tool is being developed to help with training; to date, they have 70 videos of



individuals being assessed with the SARA.

A US researcher, **Dr Paulson**, also attended the meeting and spoke about a research consortium in the US that recently obtained a five-year research grant from the **US National Institute of Health** for a project on SCA1 and SCA3. Importantly, the protocol for the US study is very similar to this European study. This is very useful as it gives us international continuity and the ability to pool results. Dr Paulson presented his work in mice tested with '**antisense oligonucleotides**' (read more below) which is a genetic therapy approach that directly targets the gene affected in SCA3. The results showed that the co-ordination of the mice with SCA3 improved. Others have also reported similar findings in a SCA2 mouse model. More research is needed, but the hope is that this research could be translated into humans as has happened for Huntington's disease (where the first human trials of antisense oligonucleotides took place in London recently), and spinal muscular atrophy (where an antisense drug is now approved and available for patients).

It was very encouraging that the pharmaceutical company **Biogen** (who have developed the drug that is now approved for spinal muscular atrophy) attended the meeting and expressed their interest in SCAs. They are working with the US consortium on SCA3.

Julie Greenfield gave a talk to the group about the role of patient groups, such as Ataxia UK and euroataxia, in promoting and facilitating research. In addition, she reported some of the results of the Ataxia UK member survey, which were well received. In particular, she focused on the symptoms that people reported had the most impact on their lives, such as balance, coordination, speech and fatigue, which can all be measured in trials. The Azores patient group also gave a talk and explained that they are able to provide much support to their SCA3 patients via weekly meetings, due to funding support from the government. Julie was interviewed by the local TV and radio station to spread awareness locally.

Researchers also highlighted the importance of not only recruiting participants with SCA3, but also 'control' subjects who do not have ataxia. In addition, there is

a need for more people to volunteer to have lumbar punctures in order to collect more cerebrospinal fluid (CSF) samples. Although you can learn a lot from blood samples, being able to have access to the fluid around the brain and spinal cord can be useful in understanding what happens in the brain. This is particularly important now as we are looking at the possibility of developing 'antisense oligonucleotides' as a potential therapy, which would have to be delivered in the form of an injection in the spine.

TAKING PART IN THIS STUDY

If you are interested in taking part in this project, the **London Ataxia Centre** is still recruiting participants with SCA3, as well as 'control' participants who do not have SCA3 (such as a spouse for example). The **Head of the London Ataxia Centre, Prof Giunti**, would like to thank all those who have already taken part. The London site has recruited a large proportion of participants for this project. For more details, please visit our website: www.ataxia.org.uk/news/for-people-with-cerebellar-ataxia or contact **Hector Garcia** on Hector.Garcia@uclh.nhs.uk or **Nita Solanky** on n.solanky@nhs.net, Tel: **0203 448 4130**.

*ANTISENSE OLIGONUCLEOTIDES AS POTENTIAL NEW TREATMENTS FOR SCA3

Antisense oligonucleotides are small snippets of modified DNA that are manufactured in the lab. They can be injected into the brain or nervous system where they target the mutated gene and are being explored as treatments for a number of genetic neurological conditions, such as the spinocerebellar ataxias. In SCA3 and some other SCAs, the mutant gene contains instructions for cells to make toxic proteins. This code is copied by a messenger molecule and is dispatched to the cell's protein-making machinery. The antisense drugs work by intercepting the messenger molecule and destroying it before the harmful protein can be made, effectively silencing the effects of the mutant gene.



Potential treatment with a dietary supplement found for a rare ataxia: SCA38

Research presented at the **International Ataxia Research Conference** in September 2017 and published in a medical journal, highlights a treatment option for a very rare form of ataxia.

WHAT CAUSES SCA38?

A team at the **University of Brescia** in Italy first found the gene causing SCA38 in three Italian families with late-onset, slowly progressive ataxia. Most of these patients also had nystagmus, pes cavus and a reduced sense of smell. Following on from that discovery in 2014, they studied the cellular mechanisms that cause the condition. The researchers found that SCA38 is caused by mutations in a gene called **ELOVL5**, which codes

for an enzyme that makes polyunsaturated fatty acids, including one called docosahexaenoic acid (DHA). Usually, this enzyme is found in high levels, mostly in the cerebellum. In SCA38, however, the enzyme's function is affected and might be harmful, as it reduces the levels of DHA.

This important discovery has led the team to carry out a treatment trial with 10 of their SCA38 patients, testing the effect of supplementing DHA (a dietary fatty acid supplement). The rationale for the trial is two-fold: firstly, to compensate for the reduction in DHA; secondly, because of the low level of DHA in SCA38, levels of the ELOVL5 enzyme are increased. This enzyme is the mutated, harmful version; therefore, increasing DHA levels should decrease the levels of the harmful ELOVL5 mutated protein.

TREATMENT TRIAL SHOWS POSITIVE RESULTS

A four-month, double-blind

and placebo-controlled trial was performed in 10 people with SCA38 (five on treatment and five on placebo). This was followed by a 40-week period in which every participant took the DHA supplement. Results showed a statistically significant change in the ataxia symptoms among the treatment group, as measured by the SARA ataxia rating scale (but not the ICARS rating scale), compared to the placebo group. The assessment made with the SARA and ICARS in the 40-week second phase also showed that there was a statistically significant difference between the scores at the start and at the end of the trial. The researchers also measured results by using a brain scanning technique, which reported a change in the cerebellum's metabolism after the 40-week treatment, compared to baseline. There were no side effects reported.

IMPLICATIONS OF THE RESULTS

Although the trial was very small, the lack of side effects and the fact that the treatment is an inexpensive dietary supplement which makes up for the insufficient natural levels, suggests that this could be a treatment option for neurologists to consider for SCA38 patients.

Lead researcher, neurologist **Dr Barbara Borroni**, told Ataxia UK: "All participants of the trial have chosen to continue taking the DHA supplementation after the trial ended and we are pleased with the continued improvement in their condition. At this stage we are not planning further trials but we would recommend any patients diagnosed with SCA38 to be treated with DHA under the supervision of their neurologist. Due to genetic screening being done in some hospitals in Italy, we are now aware of two further people having been diagnosed with SCA38 and treatment with DHA has been initiated."

IMPLICATIONS FOR PEOPLE IN THE UK

At the moment, SCA38 is thought to be very rare; neither Ataxia UK nor members of the **Medical Advisory Panel** are aware of anybody diagnosed with SCA38 in the UK. However, it could be present but under-diagnosed. At the **Oxford clinic**, the ataxia gene panel does include the gene for SCA38. Please contact the Ataxia UK office if you have a diagnosis of SCA38. In addition, if anyone is taking part in the whole genome sequencing project - the **100,000 Genome Project** described in the last Ataxia Magazine and on the Ataxia UK website (www.ataxia.org.uk/news/unknown-cause), SCA38 will be included. **Please note the 100,000 genome project will stop recruiting at the end of September 2018.**

This research highlights the importance of getting a specific diagnosis. It is also a very positive step towards a treatment of this rare form of ataxia.

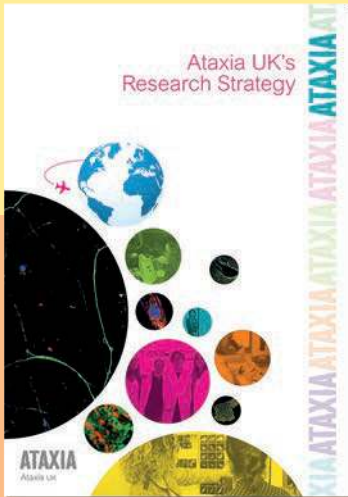


New Friedreich's ataxia trial started in the US



We reported previously about the pharmaceutical company **Takeda** having an interest in ataxia and developing a drug that targets the cerebellum.

It is really encouraging to see that this work has now progressed to the human trial stage with a trial testing the effect of their drug, called **Tak-831**, in people with Friedreich's ataxia. This is a placebo-controlled trial in 65 people with FA for 12 weeks and their main aim is to test the effect on the function of the arms and hands and manual dexterity (using the nine-hole peg test). They will also test a number of other measures. More information can be found on the Ataxia UK website: www.ataxia.org.uk/Blogs/latest-research-news. Ataxia UK has been actively supporting Takeda by providing advice and information on the patient perspective, and introductions. We are hoping to hold a meeting of European patient groups soon to assist in the advancement of the programme. **Dr Hao Wang, Senior Scientific Director** at Takeda in the US, says: "We are happy to be partnering with Ataxia UK and other patient groups, as we believe it is an essential aspect of the development of successful treatment".



Research strategy

We are excited to launch the new edition of our **Research Strategy**.

This document has been developed through extensive consultation with numerous stakeholders, including people affected by ataxia. It highlights some of our achievements and plans for research activities going ahead. The Research Strategy is written in lay language in order to be accessible to a wide audience. You can find a link to download the electronic version on our website here:

www.ataxia.org.uk/news/our-research-strategy

Fion Bremner on eye disorders and FA

Recently we went along to the **Neurology Department** at **University College Hospital London** to interview **Ophthalmologist Fion Bremner**.

We asked him questions which were passed on to us by parents with sons and daughters who have FA. The questions concerned how ataxia, and FA in particular, affects the eyes. Dr Bremner gave his opinion on the use of supplements as a treatment and how gathering information through research is vitally important. The interview was filmed by our supporter, **Jason Ahluwalia**, whose daughter was recently diagnosed with FA. Jason very kindly lent us his time and his filmmaking skills to record and edit the film which can be viewed on the Ataxia UK YouTube channel: <https://bit.ly/2Jzej9x>

We have many research videos on our YouTube channel, including footage taken from the International Ataxia Research Conference held in 2017, as well as a variety of advice videos from our Specialist Ataxia Centre neurologists. Visit the channel to take a look.





DERBY AND BEYOND

In July we ran ‘Fractured Lives’, our **Derby Ataxia Awareness Campaign**. Now we’re looking ahead to **International Ataxia Awareness Day** on 25 September with a digital, nationwide **Fractured Lives** campaign. Will you be taking part?

The Fractured Lives campaign aims to spread awareness and understanding of ataxia. Currently only 10% of the UK population have heard of it. This often leads to misunderstandings of the symptoms of the condition; we’ve heard of far too many instances of people with ataxia being accused of being drunk, thrown out of shops and even arrested. **These instances happen chiefly due to a lack of understanding among the general public.** We are determined to change this so that people with ataxia do not have to live in fear of the symptoms of their condition being misinterpreted and misunderstood.

We created the concept of ‘ataxia fractures lives’ for our Derby awareness campaign that ran throughout July. With this slogan we intend to highlight the challenges that come with ataxia to the general public, while showing through case studies and interviews how people with ataxia don’t let the condition fracture their lives entirely.

THE DERBY CAMPAIGN, JULY 7

The Derby campaign kicked off on 7 July and ran throughout the month. The official launch took place at the **Intu shopping centre**. An awareness stall was manned throughout the day by Ataxia UK staff and our Friends from the **Derby Support Group**. They did a fantastic job of spreading the word about ataxia. **On the day we spoke to over 200 Derby locals**, many of whom had never heard of ataxia. Posters of **Kerry and Jim Bull**, who run the Derby Support Group and are the founders of **The Belper Games**, one of our Friends’ largest annual fundraising events, featured on buses throughout the city. The poster, and all of the campaign artwork, was developed by our partner **TBWA**, the world-renowned advertising agency. The campaign was covered by local media, including the **Derby Telegraph** and the **Derby Gazette**, and was backed by **Derby Theatre**. **We’d like to say a big thank you to everyone who got involved in the campaign via social media throughout the month.** Your support was invaluable and helped to maintain momentum throughout July; it also meant that ataxia awareness stretched much further afield than it otherwise would have.

Below: The Derby Support Group at the Intu shopping centre in Derby



INTERNATIONAL AWARENESS DAY, SEPT 25

It’s now time to look ahead to International Ataxia Awareness Day on 25 September. This is such an important event in terms of raising awareness and understanding of ataxia, and this year we’re aiming to make a bigger splash than ever before. Once again we’ll be calling on the expertise of TBWA and launching an online campaign using social media. And once again we need your help! **So on 25 September please tweet, post, share, like and re-tweet everything related to ataxia, attaching our excellent campaign artwork.** We’ll be calling in favours from everyone we know up and down the land, asking them to get involved. If we all take to social media at the same time, we’ll be impossible to ignore.

For every post you share, please include the hashtag: **#ataxiafractureslives**. This will ensure that everyone talking about the campaign will be using the same topic tag, helping create a bigger impact!

And why not use these examples below as inspiration:

Over 10,000 people in the #UK have a rare neurological condition called #ataxia. It affects balance, speech and co-ordination and can even lead to heart failure. #ataxiafractureslives and the voices of those affected have gone unheard for far too long.

#ataxia is a neurological condition that affects balance, speech and coordination. Only 10% of people in the UK know what ataxia is, and how #ataxiafractureslives. We need you to help spread the word. Please #talkataxia (or #tweetataxia)

#ataxia is a rare neurological condition that affects balance, speech and coordination. People with ataxia are often mistakenly accused of being drunk. Next time you’re not sure, #thinkataxia #ataxiafractureslives

90% of the general public have never heard of #ataxia, a rare condition that affects balance, speech and co-ordination. Many people are often accused of being drunk, thrown out of shops and some have even been arrested. Help make #Britain #ataxiaaware #ataxiafractureslives

Today is International Ataxia Awareness Day #IAAD. Over 10,000 people in the UK have #ataxia, but the vast majority of the #UK public have never heard of it. Are you #ataxiaaware? #ataxiafractureslives

And perhaps give the following hashtags a go? #talkataxia #tweetataxia #thinkataxia #ataxiaaware

Not online? Not an issue. Our Fundraising team have prepared a fun way for you to get involved offline on Awareness Day - jump to page 13 to read all about it.

For more information on how you can get involved and to request campaign materials please email us: communications@ataxia.org.uk. Together we can take control of how the British public perceive and understand ataxia. Let’s make it happen!



Bloggging

Tallulah shares how writing her ataxia story has impacted her wellbeing, and helped her friends and family understand her condition all the better.

It was around this time last year that I got the news that I had ataxia. Hearing I had a condition I'd never heard of brought fear, but also relief at the fact that I would no longer have to spend endless days in tears, wondering what in the world was going on with me. Why I wasn't as able as I used to be, or as those around me? And why did everything feel so much more difficult?

Before I was diagnosed, I spent months - if not a few years - wondering why I found things more difficult than others my age; why my writing was like that of a five year old and why it took me longer to carry out a simple task. So, to no longer be in a constant state of despair was a silver lining, to say the least. But, of course, for any self-conscious 19-year-old girl, being told that you have a chronic illness that will only get worse in time is not ideal. I wondered how I would fit in, whether my friends would treat me as they normally would, let alone how society would.

I live in Bristol, a wonderful city, which to my surprise is very accessible (I say 'to my surprise' as prior my diagnosis I was not aware of this). The type of ataxia I have is called AOA2 (also known as SCAR1). In a nutshell, it is a recessive form of spinocerebellar ataxia. Despite my condition, I carried on with my university application and now attend Sheffield University, studying education, culture and childhood. **I have found that being upfront and honest about my condition has enabled me to make friends who not only make me feel good, but accept me for how I am and understand if I'm having a bad day.** I found it tricky coming to terms with my condition, and I don't want to pretend that every day is amazing, because it's not; but through time I have learnt that it is okay to feel sorry for myself and to not take for granted what I do have, which is an amazing family and a supportive group of friends.

Last October I started a blog called '**Ataxic Fantastic**'. This blog has really helped me come to terms with my condition and has also allowed me to connect with other people who are going through similar things as me, not just on a national scale, but internationally. **I would recommend blogging to others who are looking for an outlet.** I started my blog in the hope that those reading wouldn't only be others with illnesses and disabilities, but also friends and family who had previously found it hard to understand and relate to my situation. In my posts, I try to talk about my condition in a way which I hope the vast majority of people can understand and relate to. **I enjoy discussing topics related to my age group, but also enjoy eliciting conversation amongst others, who may be from other generations.** This is just one way of coping; I'm not saying it will work for everyone, and it is definitely not the only way, but it works for me. Why don't you give it a go?!

You can read Tallulah's blog (<https://ataxicfantastic.blogspot.com/2018/03/what-health.html>) and some of her stories, which are featured on the Ataxia UK blog, written by people with ataxia, for people with ataxia (www.ataxia.org.uk/Blogs/our-friends-blog). We want as many of your voices heard as possible; the more stories we share, the more chance we have of getting ataxia out there and challenging some of the misconceptions you face. Writing for blogs not only reaches a wider audience than our own community, but it also costs less, meaning we can feature your stories all the faster.

*You don't have to be an online user to blog - you can send **Steph Marley** or **Adam Harley** from **Communications** your story in the post to **Ataxia UK, 12 Broadbent Close, London, N6 5JW**. Don't forget to include a photo and your own address, so we can get in touch with you! Similarly, if you already write a blog and would like to see it hosted on our website, you can email us at communications@ataxia.org.uk.*

Facebook: www.facebook.com/AtaxiaUK Twitter: <https://twitter.com/AtaxiaUK>





The Chance2Win Lottery doubles its prize

What would you do with an extra £500?

The Ataxia UK **Chance2Win** Lottery is now bigger and better than ever before! Join today for just £2 a month, and starting from this October, you could now win up to **£500** every three months. All three prizes have increased. First prize is now **£500**, 2nd prize is now **£250** and 3rd prize is now **£150**.

HOW IT WORKS

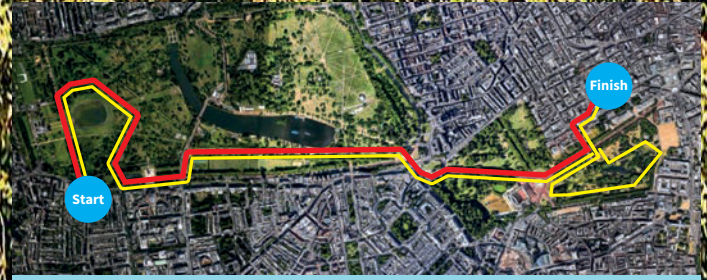
For just £2 a month, your name will be entered in our prize draw every three months. For each draw, three winning names will be picked out at random and prize cheques will be posted directly to the winners.

HOW TO JOIN - TWO EASY STEPS

Step 1: Complete your personal details on the enclosed **Chance2Win** reply slip

Step 2: Fill in your Direct Debit details, select whether you'd like to pay £2 every month or £24 once a year, then simply sign and return the form to our freepost address: **12 Broadbent Close, London, N6 5JW. FREEPOST RTUG-CLKB-RGJE**

By supporting Ataxia UK's Chance2Win Lottery, you have the chance to win up to £500 and help fund research towards treatments and a cure for ataxia. So it's not just you who could win - by entering our lottery you could help change the lives of thousands of people across the UK. To enter, please fill in the enclosed Chance2Win form and return it to our address.



The Royal Parks Challenge, 2018

Celebrating International Ataxia Awareness Day in attention-grabbing style!

For **International Ataxia Awareness Day**, we're taking to London again with our annual walk - this time, it's the '**Ataxia UK Royal Parks Challenge**'

Preview the route for our Royal Parks Challenge, taking place on **Sunday 23 September** through the Royal Parks of London (see map above). The walk is happening two days before **International Ataxia Awareness Day**, and is a great opportunity to come and see some wonderful London landmarks, all whilst raising vital awareness and funds for Ataxia UK.

Let us know if you'd like to take part and we'll send you a free Ataxia UK t-shirt and supporter pack. The more of us join together on the day, the bigger an impact we will have. So please join us as we take to the streets of London for what promises to be a cracking event (see last year's event below).

THE ROUTE

Starting at Palace Gate at **10.00am**, the walk will take you through **Kensington Gardens, Hyde Park, Green Park** and **St James's Park** before finishing at the **Army and Navy Club** for complimentary food and drinks! We have two routes for you to choose from; our short route is approximately 3.9 miles and our longer route is 5 miles long. The routes are fully wheelchair-accessible, so anyone with ataxia can take part. If you would like more information or would like to sign-up, please contact fundraising@ataxia.org.uk.





The UK-wide International Ataxia Awareness Day Challenge

Can't make it to London? Don't worry! If you'd like to be part of something collaborative, fun and fund-raising, then why not organise your own Challenge for International Ataxia Awareness Day?

Whether it's a bake sale, sports event or your own walk, give it a go!

We'll send you your very own supporter pack which includes t-shirts for those taking part, sponsorship forms and advice to help you make the most of the day.

We're looking for Support Groups and Branches, families and friends to get together, pop on their colourful t-shirts and make a splash all over the UK.

Taking part on 23 September, tweeting, posting on Facebook or Instagram with **#IAAD**, **#ataxia**, **#ataxiafractureslives** and **#TeamAtaxiaUK**, and popping a penny in a fundraising pot can really make this day more successful than ever before.

We'll be looking to make a collage of photos on social media of all of those who take part, so why not give it a go?

Email us at fundraising@ataxia.org.uk or call the office on **020 7582 1444** and ask for **Rebecca** or **Zoe** for more information on planning your own event. We hope to see you there!



Thinking of donating a gift to Ataxia UK this Christmas?

Well, we want to give you the opportunity to make your donation worth even more to our research projects and support services - at no extra cost to you. This Christmas, Ataxia UK is once again taking part in the **Big Give Christmas Challenge**, the UK's biggest match funding campaign. **From 12 noon on 'Giving Tuesday' 27 November to midday on Tuesday 4 December, every pound donated to the Ataxia UK online page will be doubled - and worth even more with Gift Aid!**

So, please save any donations you'd like to send to Ataxia UK over the autumn or Christmas period, and donate them through our **Big Give 2018 Challenge** page instead, to help your gift have an even bigger impact on the lives of people with ataxia.

Stay tuned to the Ataxia UK Facebook page, the December issue of the Ataxia Magazine (this year published in November just before the campaign kicks off) and the ataxia e-newsletter for more information on how you can donate to our Big Give 2018 Christmas Challenge.



Other big diary dates

- **Annual Conference**, Saturday 6 October
- **Royal Parks Half Marathon**, Sunday 14 October
- **The Big Give**, 27 November-4 December



Fundraising than



One of our busiest summers has passed and we're overwhelmed with the number of people, events and ideas that have made it such a success.

It's impossible to have the space to thank everyone here but please know we are grateful to everyone who has given, supported or volunteered for us over the past three months: nothing we do could be achieved without your generosity.

Six-year-old **Sophie Upham's** grandmother has ataxia, and so Sophie ① decided to hold her very own cake and craft stall for Ataxia UK. She raised £64, so a big thank you to Sophie and everyone in the village for their support - we hope you enjoyed your sweet treats!

A special thank you also goes to **Tansy Boyd** for all the hard work and effort she put into this summer's **Chelsea Street Party** ②. It's amazing to see that the party is growing year on year. This year it managed to raise an incredible £10,204 for Ataxia UK.

A huge thank you goes to our **Trustee, Andrew Downie**, for organising yet another successful **Spring Classic Bike Ride** ③. This year the event raised over £12,000 (£15,000 including Gift Aid) for Ataxia UK! Over 50 riders took part in this fantastic event. If you'd like to get involved in a cycle ride for Ataxia UK please contact fundraising@ataxia.org.uk.

The **Cawkill family and friends** ④ organised their own **Castleton walk** in the stunning **Peak District** with **Jonathan**, who has FA, leading the group and covering seven miles. They have raised £3,700 with donations still coming in. Jonathan's brother **Matthew** is a keen footballer with **Ordsall Rangers and Retford FC**. He raised money for Ataxia UK at their family day in June. Despite terrible weather, they had a great day and raised £1,500 - they have also kindly decided to continue supporting Ataxia UK for the 2018/2019 season. Thank you to the Cawkills and everyone involved in the walk, together with the football day, including **Leigh Birch** and **Chris Woodhead** - you all make a magnificent team!

Thank you to everyone who has been supporting us with your school. Pupils at **Woodstone Primary School** held a non-uniform day and ran a mile around the school grounds, raising £330. Thank you to teacher **Natalie Franks** for organising this in support of her Uncle, **Andy Franks'** fantastic ongoing fundraising, and thanks to all the pupils who took part! **Clement Wilson** also got his school involved in fundraising by organising a **Readathon**. He raised a brilliant £245.

Also part of Andy Franks' team are **Sasha MacGregor** ⑤ and **Daniel Hughes** who did the beautiful but challenging **Cotswold Way** recently after being inspired by Andy's Manchester Marathon efforts. Andy's nephew, **Ollie** ⑥, has FA and is a great friend of **Sasha** and **Daniel**. They are very proud of him and did the walk on his behalf, raising over £900 so far. Well done both for such a great achievement.



k-yous

Chance2Win winners

- 1st. £250 **Alison Love**
- 2nd. £150 **Pete Campbell**
- 3rd. £100 **Philip Ingham**



Charlotte Tibaldi ⁸ organised a **Ball at The Essex Golf & Country Club**, raising over £1,000 through ticket sales and an auction. Thank you to all the supporters who attended the ball and to Charlotte for her hard work!

Thank you to all of you who are so generously collecting donations for Ataxia UK instead of birthday presents. Such a thoughtful idea and we are very grateful. Congratulations to **Lynn Thomas** ⁹ who turned 100 years old and had a big party to celebrate, collecting over £500 in donations. **Derrick Knowles** kindly raised £110 in birthday donations. **Peter Smeaton** has also fundraised for us for his 80th birthday! There have been lots of you who have set up birthday fundraisers for us on Facebook, including: **Amanda Groombridge, Steve Ashton, Abi Starkey, Kate Tolson, Ashley Reeves, Caroline Lyons** and **Sherena Harper** - Happy Birthday to you all and thank you for thinking of Ataxia UK.



Thank you to all of our runners, including **Colin Byer** ⁶, who took on the **Brighton Marathon** in support of his dad, raising an incredible £1,500, and **Louis Parker** and **Dean Lupin** ⁷, who completed the Southampton Marathon and raised a brilliant £1,600. **Cheryl Heath and her team** ¹⁰ at **Archbishop Sentamu Academy** did the **Hull 10K** and smashed their sponsorship target, raising a fab £436!

Thank you to **Patricia Castledine, Mel Priest** and the **Dudley Support Group** who completed the **Great Midlands Fun Run** together. They all sported their Ataxia UK t-shirts and made a huge impact with 25 of them taking part. Together they raised over £1,500! Some of them will also be taking part in the **Gauntlet Games** later this year; thank you all for the fantastic result.

Thank you to **Lucy Davies** and **Kez Cracknell** ¹¹ who raised £750 by successfully finishing the **Sprint Triathlon**, consisting of a 750m open water swim, a 20km cycle and a 5km run at **Hampton Court**. Lucy's grandparents, who are part of our **North West London Support Group**, are very proud of them, as are we. Despite the triathlon not being easy, their families were there cheering them on to keep their spirits up! Well done everyone; fantastic effort!

Congratulations to **Georgia Thomas** ⁵ on completing her first ever half marathon for Ataxia UK! She recently took part in the **Swansea Half** and raised a fabulous £710. Thanks to **Gareth Coombs**, too, who also took part and raised £320!

Harvey Smith, Rachel and **Lexi Gatt** ¹⁴ tackled a **Tough Mudder** challenge in support of Ataxia UK, as Harvey's mum has ataxia. It was cold, wet and tiring but they did it. They smashed their target, too, with £1,672! Also taking part in a Tough Mudder challenge were **Melissa, Michaela, Maddie, Ella, Gwin, Olivia** and **Caroline** ¹³, who raised a fantastic £3,237. The team decided to take part as someone very dear to them, **Tallulah**, was diagnosed with a rare type of ataxia. Tallulah is also fundraising for Ataxia UK and has raised over £9,000 for research. You can catch team '**Ataxic Fantastic**' at their Tough Mudder challenge below.

And last but not least, our thanks go to **Harry** and **Zac** ¹², who ran around **Leeds Rhinos** rugby pitch in June to collect donations in support of Harry's cousin **Izzy** ¹², who has FA. The boys did an incredible job and managed to raise £1,410 for Ataxia UK!



Adapting to life



We asked Matthew Law what advice he'd give his younger self. Here, Matt reflects on his life at different times and how his attitude to living independently with ataxia has changed.



Above:
Matt with his friend
and PA, Paul

Below:
Matt at Wimbledon

Adapting to a life with ataxia is, for me, more about adapting mentally than it is adapting physically. Everyone can see the adaptations you have made physically, for example using crutches to walk or using a wheelchair, using a kettle tipper to make your tea, eating only with a fork and not a knife (you need one hand to balance yourself), and getting in and out of the bath (not that anybody saw me, but you know what I mean). In fact, now that I think about it, there is virtually nothing that I do now which is done in the same way as when I was growing up.

That I cannot even remember most of them highlights the fact that these changes have all been made consciously and with no one else's advice. When something became difficult, I just changed the way I did it. It was easier for me that way I guess.

However, looking back now I can clearly see that if I had made these changes earlier on, when these problems first arose, then my life could have been far easier from a younger age. This doesn't mean that at a younger age I would have been any

happier a person but my life certainly would have been easier.

I began using a wheelchair at around the age of 24. This was a good eight years after I noticed problems occurring with my walking. I could have spent much of my younger years without having the constant fear of falling on my mind. That would have enabled me to have far more room in my mind for my studies.

I stopped driving a car at the age of 46 but was beginning to feel a bit unsafe at about the age of 42. Maybe I was just lucky but if I'd had a serious accident between the ages of 42 and 46, then I would have only had myself to blame.

When messing up a transfer from my wheelchair to another place (sofa, toilet, or bed), I spent at least three years becoming physically exhausted and emotionally upset trying to climb back into my wheelchair before having a lifeline button installed. Of course, it is still very frustrating to want to get on with your day, having to lay on the floor waiting for the paramedics to come and pick you up, but I now suffer no exhaustion, no upset, just press my lifeline button and wait.

It has only been within about the last year that I have accepted the fact that my balance is directly affecting my eating. I am unable to cut up my own food, not because I am too weak, but because I need one hand to balance myself even in the sitting position, and so cannot hold a knife as well as a fork. I now get my PAs or parents to cut up my dinners.

It all comes down to accepting help in the end and I suppose as I have gotten older, I have learnt that I have to accept help at times to stay independent and safe. There is also no harm in making things simple for yourself. I have a friend who has ataxia (she knows who she is) who feels that the more she keeps doing things, even when they become difficult, the more benefit she will get as her condition will not deteriorate as quickly. I can see where she is coming from and I guess an independent life with ataxia is all about balancing 'make your life simple' with 'keep doing things that you always have'. If you don't use it, you lose it.

Matthew Law
matthewlaw1968@yahoo.co.uk



Families together with Skoe

Skoe is a new company that provides equipment that makes it easier for parents with mobility requirements to get out and about with young children.

Their most recent product, the **Skoe Hitch**, is a device that attaches to mobility scooters and solves the problem of looking after young children safely while on a mobility scooter.



The company was set up by **Steven**, (left) a designer with over 15 years' experience in designing products for the disability market. He says: "Roughly five years ago, my wife **Kellie** (below left) was diagnosed with MS. We have young children, which made it difficult for Kellie to go shopping or on days out using her mobility scooter. Anyone who uses a mobility scooter while caring for children knows that kids often hang off the back of the scooter which can be quite dangerous and affects steering, stability and controls. I looked at a way my wife could still independently take our children out without the stress of trying to stop them running loose. I came up with a trailer for kids that attaches to my wife's scooter. It has had a huge impact on our family days out, holidays and everything in between. My wife feels like part of our family again and our kids love it. Our youngest sits in the seat and the oldest hops on and off as she pleases."



Kellie, who has MS says, "It makes me feel less disabled and gives me the freedom to go out on my own with the kids. I had to have someone else with me before we had the hitch but now I can take the kids out on my own. **When we're out, it feels more like we're a family group, all using the scooter, and not just me separate from the rest of the family.** Now we're all together on days out, and it's also a bit of fun."

The trailer attaches easily to most mobility scooters, is portable, lightweight, and folds easily for transportation. It comes in various colours and includes a lap belt for children. Skoe also provide **stylish crutch covers** called '**Skoe Wraps**'. The wraps are designed to allow users to customise their crutches to match their outfit. The covers are very easy to attach with hook and loop fastenings and they come in a variety of colours and styles. Meeting Kellie at **Naidex**, where Skoe were presenting their Skoe Wraps, she said that using mobility aids and equipment shouldn't affect how good you feel; why not match your equipment with your outfit?

Why not indeed? For more information, visit the Skoe website at www.skoe.co.uk or email them on info@skoe.co.uk

Ranking up the RADAR key



The **RADAR** key opens more than 9,000 accessible toilets in the UK and many people with ataxia already use one.

A new and improved RADAR key has now been launched that still provides people with the peace of mind of knowing that they have quick and easy access to accessible toilets. The new improved **RADAR NKS** key was recently launched at **Naidex**. The new key has a unique, raised edge handle which makes for an easier grip, and their new computer-controlled key cutting ensures that the keys are reliable and provide easy opening. They've also given the key a new, more fashionable, look than the previous model.

CHANGING PLACES APP

Radar has also just launched a **free app from their website service called 'Changing Places'** which allows users to easily find their nearest accessible bathroom. Both the website and the app are easy to use. They track your current location and automatically show you a selection of your nearest **Changing Places** toilets, then give you directions and tell you whether or not you'll need a key to access them. The company are also currently compiling a list of accessible toilets and will soon be launching another two new apps, improving their lists and locations of accessible toilets and public toilets. Anyone signed up to their current app or website will be notified as soon as these new apps are released.

*If you think the Radar key scheme could be useful for you and you want to know more, visit their website: www.loo.org or call them on: 01395 265 543. If you want to know more about the new **RADAR NKS** key please follow this link: www.radarkey.org You can find the **Changing Places** app on both the Apple and Android app stores by searching '**Changing Places Toilet Finder**.'*

Becoming an Ataxia Ambassador

Below:
Dan, one of
 our Ataxia
 Ambassadors

This year at our **Scottish Conference**, we met many wonderful delegates who gave talks, presentations, and told us about the fantastic work they do to raise the profile of ataxia.

Seeing the enormous number of likes, shares and re-tweets of the new **Emmerdale** character with ataxic cerebral palsy (p. 5); how well the **Derby**

Campaign went (p. 10) and the success of **Naidex** back in April, we're seeing a trend: sharing stories is a valid and beneficial way to spread awareness of ataxia and empower ourselves.

Any good journalist will tell you that stories are what change public ideas: people relate to people far more than statistics or infographics. That's why in 2019, we'll be launching our **Ataxia Ambassadors Project** across our whole community, welcoming people of any age, with any type of ataxia, from anywhere in Britain and Northern Ireland, to take part: to share stories.

Will you join us?

WHAT DO AMBASSADORS DO?

Ambassadors are welcome to do one, some or even all of the following!

- Blog and write, for their own blog/publications or ours
- Offer social media support for our campaigns, or create their own messages
- Write to local press to share their story
- Take part in AUK awareness campaigns
- Speak publicly and represent AUK at events
- Network and research organisations that could be of use to the ataxia community
- Attend fundraising events as support for participants, man merchandise stalls and hand out leaflets to raise awareness
- Visit local GPs to hand out leaflets, or the local hospital to assist with medical training
- Visit schools and present assemblies about ataxia, with the ready-made AUK presentation pack
- Feature in Ataxia UK videos for support, awareness or information
- Offer their skills to us: filming, photography, organisation skills, events planning, social media, editorial work, advice videos

HOW DO THEY DO IT?

In order to become an official ambassador, ambassadors must undergo training in some - or all! - of the following, depending on their interests, skills and time:

- Speaking to the press, radio and on TV with BBC's **Trevor Barnes**
- Blog/write for different purposes with **Steph** and the **Comms team**
- Train and trial in effective social media work
- Public speaking: writing a speech and how to present well

They will also receive updates from the charity through an **Ambassador newsletter**, highlighting opportunities to get involved that they can choose to take part in.

Ataxia Ambassadors work to take control over how their condition is perceived by the public, organisations or healthcare professionals who may not understand their symptoms. By doing so, they build their self-confidence, while gaining experience in volunteering, public speaking, networking, communications, representing an organisation, digital skills and market research - all of which look great on a CV for employment, studies, volunteering and other activities.

*If you are interested in taking part we'd love to hear from you; just get in touch with **Steph** at communications@ataxia.org.uk to outline your interest.*



Soaring high

Holly Almond was diagnosed with having Friedreich's ataxia at the age of thirteen. She tells us about her sister **Leanne's** skydive and shares her poem 'Phoenix Life'.

Ever since I was nine years old, I've loved writing poetry; my grandparents, **Valerie** and **Fred**, still have a framed poem that I wrote at nine! Growing up, I always excelled in English and dreamt of one day being an English teacher. Not long after I was diagnosed with ataxia however, I developed a virus. On getting better, I went to walk to school with my sister, Leanne, and literally forgot how to walk. I was only 13 and Leanne was 15, so we were unsurprisingly terrified as Leanne helped me get back home. I am close to my whole family, but this is why I often describe Leanne as my 'angel on earth'.

After that, I returned to school in a wheelchair. When I became confined to a wheelchair full time, life for me, my two sisters and mum and dad changed forever. Even so, I went on to do my English A Levels, despite my whole school life the majority of teachers saying: "a disabled person is suited to office work or no work at all." I gained a double C in my English A Levels and ended up passing an English degree, despite having a love life that rivaled a soap opera! Throughout the majority of my studies, I was in denial of the progressive nature of Friedreich's ataxia, though eventually I accepted that it would be incredibly hard to teach while having it. Nonetheless, my love of poetry has never stopped and you can read some at www.hollylousharmonies.blogspot.com

My family have always supported me in my hopes and dreams. In 2014 I made the decision to live independently, with the unconditional support of my family, especially Mum! They obviously worry but they support me in doing what feels right. In 2015 I had a near fatal accident on my hoist but thanks to the quick thinking of Leanne, she literally saved my life. After that, Leanne actually became my part-time carer, along with **Sarah McIntyre** and my Mum **Jane** who gives the majority of support. Leanne turns 30 this month and decided to do a skydive to raise money for Ataxia UK. She did the jump on 10 June at Hibaldstowe airfield **raising over £1,000**. She says she is 'absolutely overwhelmed' by the support of her sponsors, and I'm very proud of her!

Since my degree I've done various volunteer work including two placements that got rid of me because of my Dysphagia cough, a symptom of FA. I've been through extremely tough periods in my life and I've almost not survived, but I've never given up. I have passed further study and in September I'm beginning a volunteer role with my ex-tutor, the head of the English department at my local secondary school, **Michelle**. I'm so excited and I can't speak highly enough of her. Who knows what the future entails?

Below:
Holly and her
sister, **Leanne**

My following poem 'Phoenix Life' is to inspire other people with ataxia to soldier on no matter how hard it gets, because we are as powerful as the reincarnating Phoenix and everyone dies someday, but what doesn't kill you makes you stronger.



PHOENIX LIFE

*It tortures my withering soul
Never relenting
Trying hard to never let me go
Always presenting*

*But I will rise out of the flames
I will rise up out of this pain
Figure of enchantment I will be reborn
Holding onto beauty and never be torn*

*Trying best to keep my soul down
Resonating through every inch of my brow
Curdling my spirit
Trying to take me with it*

*But I will rise again from ash encased dreams
Fire of my soul repairing my seams
Sublime that lives forever
Flying light like a feather.*



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