

Company number: 04974832  
Charity number: 1102391 (England and Wales)  
Charity number: SC040607 (Scotland)

# Ataxia UK Annual Report & Financial Statement

**For the financial year 1<sup>st</sup> April 2023 – 31<sup>st</sup> March 2024**

**ATAXIA**

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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 (No. 04974832)

## Statement from Chair

**Our current Strategic Plan ([www.ataxia.org.uk/strategic-plan-22-25/](http://www.ataxia.org.uk/strategic-plan-22-25/)) aims for faster, accurate diagnosis of ataxia; improving access to specialist, integrated care (including mental health care), treatments and drugs for the ataxias; and to consistently maximise the impact of research activity leading to treatments and cures. Its final ambition is to enable people affected by ataxia to have greater access to services aimed at improving financial circumstances.**

Last year our Annual Report celebrated the approval in the USA of the first drug for Friedreichs ataxia, Skyclarys, which we hoped would be available quickly to people in the UK. Throughout 2023 and early 2024 we were in touch with Biogen, the pharmaceutical company which is bringing it market, encouraging them to submit Skyclarys to the UK regulators to be approved here, and made available through the NHS. We continue to work to ensure the drug becomes available to people with FA as soon as possible, hopefully joined by at least one more treatment for another ataxia. As trials of potential treatments for the ataxias multiply, we are preparing for a new era in the work of Ataxia UK: as a channel for patient voices into the many drug approval processes that we hope will follow. In the meanwhile, we have partnered with others to bringing a rare ataxia from the basic, discovery, research stage to the trial of a potential treatment in 5 years.

Likewise, our support services to people affected by the ataxias have entered a transformative phase following the obtaining of a 5-year grant from the National Lottery Community Fund to support the development of our Helpline and Advocacy services in England and employ our first Specialist Ataxia Nurse to work with people affected by ataxia in January 2025, which we believe will, among other benefits, give access to quicker diagnosis. In April 2023 our Scottish Advice Service opened in partnership with Parkhead CAB in Glasgow; followed by the launch of the Advocacy service. These services add to the considerable support provided by the Helpline through which the financial circumstances of many Friends have been improved with the assistance of Ataxia UK.

The support that Ataxia UK provides to people affected by ataxia is made possible through the generous donations and fundraising of Friends and supports and the grant giving of Trusts and foundations. The consistent financial support provided through the fundraising of our supporters, even at this difficult time, is always impressive. We are also grateful to the many committed volunteers who provide the governance of the charity as Trustees or Sub-Group members, and support our service delivery as Helpliners or as Co-ordinators of peer support groups. Many thanks to everyone who contributed to our work over the last year.

## Reference & Administration Details of the Charity, its Trustees & Advisors

The charity's registered address is 12 Broadbent Close, London, N6 5JW.  
The Trustees that served during 2023 - 2024 were:

### Honorary Officers

**William Littleboy, Co-Chair**

**Kathy Jones** Honorary Treasurer

### Trustees

Angela Hosie

Carol McCudden  
(*Re-elected 2023*)

Gemma Fish

Rachel Harrison

Robert Perkins  
(*Retired Aug 2023*)

Harriet Brown

Nathan Hall  
(*Joined Oct 2023*)

Olivia Wood  
(*Joined Dec 2023*)

Prof Barry Hunt  
(*Scientific Advisor to the Board*)

Susan Millman  
(*Company secretary and CEO*)

**Ataxia UK uses the following  
professional advisors:**

### Auditors

Goldwins Limited  
75 Maygrove Road  
West Hampstead  
London NW6 2EG

### Bankers

Barclays Bank PLC  
PO Box 96 82-84 High Street  
Epsom KT19 8BH

### HR Consultants

NEST  
Bentley House  
North Heath Lane  
Horsham  
West Sussex RH12 5QE

### Solicitors

Bates Wells & Braithwaite London  
LLP  
2-6 Cannon Street,  
London EC4M 6YH



## Structure, Governance & Management

**Ataxia UK is a company limited by guarantee, incorporated in England and Wales on 25 November 2003, a registered charity in England and Wales (number 1102391) and a charity registered in Scotland (number SC040607). It is governed by its Memorandum and Articles of Association, adopted on 25 November 2003.**

Ataxia UK is managed by a Board of Trustees, which sets strategies and policies. All of the Trustees have a connection to ataxia either through having a diagnosis themselves or having friends or family with the condition.

The Annual General Meeting of the charity took place on Sunday October 22nd 2023.

Under the articles of association of the charity, trustees are nominated for election by the Friends of the charity, comprising beneficiaries affected by ataxia and others interested in the welfare of those affected by ataxia. Prospective Trustees have an interview with current Trustees before standing for election to be nominated by Friends. Trustees may remain in post for four years and then re-stand for a second term.

New Trustees are invited to an induction session with the CEO and the Chair(s) of the Board of Trustees before their first Board Meeting. The meeting covers the Ataxia UK constitution, including the objects of the charity; the legal duties of trustees; our Code of Conduct and Conflicts of Interest policies; Ataxia UK's finances; the current strategic plan; aims and objectives, and the internal structure of the charity. New Trustees are provided with the Ataxia UK's Trustee Handbook, which also includes links to the most significant documents on the Charity Commission website.

Pay and remuneration is considered annually by a Remuneration Committee, comprising the Chair, Treasurer and one other Trustee. It meets during the budget setting process to review salaries and grading levels, London weighting, incremental payments and inflation rises. The Remuneration Committee is provided with comparative benchmark information relating to similar posts in corresponding organisations to assist with their decision. Ataxia UK is a Living Wage Employer.

## Public Benefit

**In compliance with the Charities Act 2011, Ataxia UK has adopted a *Statement of Public Benefit* as follows:**

“Ataxia UK is an inclusive organisation which promotes the wellbeing of all people affected by ataxia.

**We provide information and support services to people affected by ataxia** and specialist services for this medical condition, many of which are not available from the NHS or other statutory or voluntary sources.

**We work to end isolation and promote engagement** in social, educational and leisure activities for people affected by ataxia and their families.

**We educate the broad community and key subsections within it**, such as the medical and social services professions, about the effects of ataxia.

**We also fund vital research projects into potential treatments**, aiming to find a cure for ataxia. There is currently no specific government funding for ataxia research.”

## Statement of Equality, Diversity and Inclusion

**Ataxia UK has also adopted a *Statement of Equality, Diversity and Inclusion*:**

“Our vision at Ataxia UK is a world free of ataxia. Our mission is to find treatments and cures for the ataxias and to support everyone affected by ataxia. We will not achieve these aims alone; that's why we consider both those who work for Ataxia UK and Friends (members) we support who are affected, and partners with whom we collaborate, to be critical to our eventual success. Ataxia UK has always been committed to equality of opportunity to ensure all those who work for Ataxia UK, and those we represent, are treated equally, with dignity and respect. We ensure this by creating an environment in which individual differences, and the contributions of all, are recognised, valued, and enabled to enhance everything we do.

We seek to ensure that every Ataxia UK campaign, programme and event promotes the principles of equality and diversity, and actively encourages our supporters and partners to share our standards and ambitions of fairness and inclusion.

Our aim is to create an environment which is welcoming to all sections of society to enable our staff to be truly representative of our Friends and supporters. Additionally, for each employee to feel respected and able to give their best, regardless of their background and abilities. We encourage and expect the highest possible standards of work and conduct in everyone associated with Ataxia UK; and we recognise that this can only be achieved if the people that work at Ataxia UK feel valued and included.

One of our core values is to ensure that everything we do has the needs of people affected by ataxia at its centre. We recognise that our Friends and supporters are people with differing needs, situations, goals and lifestyles. This is why equality and diversity are fundamental to our vision. Removing the barriers that limit access for everyone requires embedding equality and diversity into everything we do. That way, everyone can be confident that Ataxia UK is diverse and inclusive.

We are led by people affected by ataxia and ensure that the majority of our Board of Trustees is drawn from the diverse community which is affected by the condition.”

The Trustees confirm that they comply with their duty to have regard to the guidance on public benefit published by the Charity Commission and the

Office of the Scottish Charity Regulator OSCR in exercising their powers and duties.

Ataxia UK operates throughout the United Kingdom of Great Britain and Northern Ireland through its network of Branches and Support Groups, which provide activities and support to Friends. The 2023 Annual National Conference was held in person.

We have continued to work in partnership with other organisations with shared interests, principally Genetic Alliance UK, The Neurological Alliance, the Association of Medical Research Charities (AMRC) and Euro-ataxia. Our Chief Executive is the Secretary of Euro-ataxia, a federation of 20 patient organisations from 16 different European countries.

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The **Scientific Advisory Committee (SAC)** is a sub-committee of the Board of Trustees and provides independent scientific advice to the Board of Trustees on:

- Research priorities for Ataxia UK
- Whether to fund specific research proposals
- The significance of research developments in related fields for ataxia and the development of novel research approaches
- The direction and scope of activity of Ataxia UK's Research staff
- The quality and progress of research projects funded by the charity
- The best practice to review grant proposals
- The most appropriate mechanisms for attracting high-quality research proposals
- Promoting research in the field of ataxia

**The SAC comprises the following independent scientific members:**

Dr Javier Alegre-Abarretegui, Dr Franziska Denk, Professor Helen Dawes, Dr Mark Pook, Professor Keith Morris, Dr Gita Ramdharry and Dr Sophie Rowlands. The committee also included the following lay members during the year: Yanita Oparlakova, Harriet Brown and Nathan Hall.

Professor Barry Hunt acted as the Ataxia UK's Board Scientific Advisor.

All members are unpaid volunteers.

## Employees

During 2022-23 the average number of full-time equivalent employees during the year was 18 (with all employees' time involved in providing either support to the governance of the Charity or our charitable activities).

From May 2023 our Finance Department has been supported by Fiona Bevan of Bevan Financial Management Ltd. We outsource IT support and HR advice functions.

## Volunteers

In addition to the volunteers who function as trustees, many other volunteers play an important part in supporting Ataxia UK. During 2022-23 we have employed a number of interns and offered opportunities to volunteers throughout the charity. They have provided invaluable assistance in our day-to-day work, contributing towards our projects, such as the *Ataxia Magazine*. We have continued to recruit more committed volunteers.

The current economic situation is hitting people with disabilities very hard. We are therefore especially grateful to those who have managed to raise funds for us, those who have donated to our appeals and regular givers, and the very generous support of people who have left bequests to Ataxia UK.

We are also grateful to the volunteers who assist us by serving on the Finance Sub-Committee, Scientific Advisory Committee, Medical Advisory Panel, Pharma Advisory Group, Fundraising and Services Services Advisory Groups. During the year five trained volunteers supported the Helpline service by answering phone and email enquiries.

The contribution of all of our volunteers to the work of Ataxia UK is much valued and appreciated.

## Risk Management

**As in previous years, the Board actively managed the risks to the charity, focusing on the most serious.** We maintain a register of risks and controls, and activities to mitigate risk throughout the year; a register the most significant risks and their mitigation will be enclosed following further internal review.

## Objectives & Activities

**Ataxia UK's charitable objectives are to 'relieve those persons affected by ataxia'.**

Many different kinds of ataxia have been identified, with varying causes and characteristics. Typically, they are slowly progressive conditions in which initial clumsiness and poor balance and co-ordination can lead to total physical disability. Other symptoms may include problems with speech, sight and hearing. There is currently no treatment for most ataxias, although good progress towards treatments is being made for some.

One of our primary objectives is to find the causes of, and suitable treatments and cures for the various forms of ataxia. We do this by promoting and facilitating research in the ataxias, as well as funding research projects. Research grants are made on the basis of proposals from qualified researchers which have been assessed by peer reviewers and evaluated by Ataxia UK's Scientific Advisory Committee. All projects, where appropriate, have approval from the Ethical Approval Committee local to the lead researcher.

People with ataxia want a quick diagnosis that's delivered in a supportive and sympathetic manner, with the choices of care explained and assistance in accessing them available, if required. They want information about their condition and medical care to enable the management of symptoms. Ataxia UK seeks to improve treatments and care by researching the experiences and requirements of people with ataxia and by developing replicable model solutions to the problems they experience. Our most significant work in this area is the development of Ataxia UK's accredited Specialist Ataxia Centres: specialist clinics within the NHS that aim to bring together in a 'one-stop shop' all the services needed by someone with ataxia, from diagnosis to the ongoing management of their condition.

In the absence of treatments and cures, Ataxia UK recognises the need to provide as many care and support services for people affected by ataxia as our resources will allow. These services comprise all other services for beneficiaries, including information and website services, such as our quarterly *Ataxia Magazine*, monthly eNewsletter, Helpline services, conferences and workshops on topics of interest, our network of Branches and Support Groups, and our InControl project that aims to combat loneliness and isolation within the ataxia community.

Raising awareness of ataxia is a fundamental desire of people with ataxia. Ataxia UK is focussing its efforts on improving the understanding of the condition in the NHS, where diagnosis and treatment are often delayed, and



also in the social care sector, where an understanding of the condition could significantly improve the situation of people affected by ataxia.

## Our Strategic Plan

### Ataxia UK's Strategic Plan for 2022-25 contains these ambitions:

- Improve access to specialist, integrated care (including mental health care), treatments and drugs for the ataxias
- Faster, accurate diagnosis
- Consistently maximise the impact of research activity leading to treatments and cures
- Enable greater access to services aimed at improving wellbeing and financial circumstances

Our Strategic Plan 2022-25 takes into account the impact of the changes brought about in many areas of life by the Covid-19 pandemic which arrived towards the end of 2019-20, and the current economic climate which is affecting disabled people more than the general public and exacerbating the serious poverty of a small but significant number of people affected by ataxia.

### Some of the most significant actions we are taking to meet these objectives are:

- Establish a peripatetic Specialist Ataxia Nursing Service to accompany patients to appointments and support them in managing all aspects of their care.
- Continue to develop the Helpline and Advocacy Service and improve the support information held on the website.
- Revise the Medical Guidelines for the Treatment of the Ataxias and publish the 4<sup>th</sup> Edition.
- Increase the patient representation work we undertake in research projects.
- Increase the number of Accredited Ataxia Centres in the NHS to at least six.
- Support the drugs approval process in the UK.
- Utilise the All About Ataxia seminar model to develop other online information seminars.

## **Achievements & Performance, Aims for 2024 – 2025**

### **Research**

#### **Research aims for 2023 – 2024**

- Facilitate networking amongst UK Ataxia Researchers
- Press for swift approvals for ataxia treatments in the UK
- Publication and dissemination of DRPLA research
- Plan next International Congress of Ataxia Research in London in Autumn 2024

#### **Facilitate networking amongst UK based ataxia researchers**

Ataxia UK hosted its first networking event for UK-based researchers in September 2023. This was an in-person event in London, with almost 50 attendees, including researchers, clinicians, Ataxia UK representatives and two people living with ataxia. We invited participants to present their research on a range of ataxias, share information, resources and expertise to foster collaboration. The event also featured a Q&A session with people who live with ataxia, on the value of patient engagement in ataxia research.

There was also an interesting discussion session at the end where we gathered ideas from the delegates on future events and activities Ataxia UK could do to facilitate research. We are exploring the possibility of setting up network for physios and one for junior researchers. It was a very successful networking event, and we received very positive feedback.

#### **Press for swift approvals for ataxia treatments in the UK**

Towards the end of last year, we had the exciting news that the first drug was approved for people aged 16 and above with Friedreich's ataxia in the US. This was followed by approval by the EU in February 2024. The drug, Skyclarys (also known as Omaveloxolone), has been shown to slow the progression of the condition in trials, and being the first approved drug to treat FA it is a huge step forward.

Following Brexit, the UK is no longer aligned with the EU drug regulatory framework, so Ataxia UK has been actively encouraging approval of the drug in the UK. First, we worked with Reata pharmaceuticals, who developed Skyclarys, and then following the acquisition of Reata by Biogen in September



2023 we have been supporting and encouraging Biogen to seek UK approval, and we are hopeful this will happen soon. Ataxia UK has also written to the Secretary of State for Health to request support in getting Skyclarys made available to UK patients sooner.

To drive forward the approval process in the UK, we set up an FA Special Interest Group, which includes clinical experts, Ataxia UK staff, and parents of children with FA. During the year we also engaged with consultants Realise Advocacy, who specialise in advising charities in this area. Together we drafted an Action plan and did an evidence review to identify any gaps in the information that will help with the drug approval and in the evaluation by the bodies that make recommendation on funding drugs on the national health service in the UK: NICE and Scottish Medicine Consortium. This is important so Ataxia UK can be prepared and get actively involved. Indeed, Ataxia UK and people with FA can play a critical role in this process to get Skyclarys to people with FA in the UK as soon as possible. We will do our utmost to ensure that the voices of people affected by FA are heard by the regulators, and as such Ataxia UK has been preparing to engage in the processes at every opportunity.

Ataxia UK also continues to work with other companies with FA programmes, as it is important to note that the currently approved drug is not a cure, and it is likely that a combination of different treatments will be needed in FA. In addition, the knowledge gained will have an impact when other drugs go through the same process for other ataxias. Indeed, for SCA3 we have already worked, via Euro-ataxia, in providing information on the condition for a drug that has been going through the EMA approval system.

### **Publication and dissemination of DRPLA research**

We continue to update our community on the progress of the DRPLA research programme through social media and newsletters. Additionally, this year, we published three articles in scientific journals to increase visibility of our work and share our findings with the scientific and medical community.

One article highlights the strides we have made in understanding DRPLA and our dedication to fostering a strong, united community of medical professionals, researchers and families. It also describes the resources scientists have developed to advance research on DRPLA and test potential treatments.

Our Research Manager collaborated with neurologists to publish a review of current knowledge about DRPLA and providing recommendations for the best clinical care for people with DRPLA.

CureDRPLA commissioned a company to interview people with DRPLA and their caregivers to better understand the impact of DRPLA, symptom

progression and their preferences for future clinical trials. The main findings from these interviews have been published in a scientific journal.

### **Plan next International Congress of Ataxia Research in London in Autumn 2024**

Plans are progressing well for the next International congress for ataxia research, which will be held in London. Ataxia UK is again working jointly with the two US ataxia charities NAF and FARA; and we are joined by the Ataxia Global Initiative. We are pleased to be working together on what promises to be a great opportunity for networking and learning the latest on ataxia research with experts from around the world.

The Scientific Steering Committee is working on an interesting scientific programme and there will also be input from a Trainee organising Committee who will organise specific activities to engage more junior researchers.

## **Other Research Activities**

### **Ataxia UK Research Grants Programme**

During the year Ataxia UK awarded seven grants, five via our standard research programme, and two under the DRPLA programme. Including these projects there are currently 23 projects being managed. In addition, we gave travel awards and a conference sponsorship.

### **Ataxia UK Grants**

- 1. Dr Abeti and Prof Giunti (UCL, UK)** - 'Exploring novel iron-mediated mechanisms to prevent cellular death in Friedreich's ataxia' - £5,000
- 2. Dr Anjoumani-Virmouni (Brunel University)** - 'Effect of targeting sphingolipid-metabolising enzymes in iPSC derived sensory neurones obtained from FRDA patients' - £4,955
- 3. Dr Hauser (DZNE, Germany)** - 'Identification of disease-associated single nucleotide polymorphisms in ataxin-3'-£4,470
- 4. Dr Hubener-Schmid (University of Tübingen, Germany)** - 'Development and Validation of SIMOA-based total and mutant Ataxin-2 Immunoassay for biomarker studies in SCA2 and SCA3' - £30,000
- 5. Dr Matassa University of Naples, Italy)** - 'Evaluating ribosome collisions on CAG expansions proteostasis and translational stress responses in Spinocerebellar Ataxia type 3' - £3,000

6. **Prof Clayton (Great Ormond Street Institute of Child Health, UK)** - Novel biomarkers of oxidative stress in Friedreich's ataxia' - £4,800
7. **Prof Tremblay (Universite' Laval, Canada)** Novel biomarkers of oxidative stress in Friedreich's ataxia' - £8,036
8. **Realise Advocacy consultancy** -'Preparing for the health technology assessment process in FA' - £5,800

### DRPLA Grants (in partnership with CureDRPLA)

1. **Dr Shiloh-Malawsky (University of North Carolina, US)** - Extension project "DRPLA Natural History and Biomarkers Study - £34,609.84.

### Analysis of research outcomes of Ataxia UK funded research

**The impact of the research we fund is evaluated every year using the Researchfish online portal with very positive findings.**

The last 10 years' data shows that every £1 invested in research by Ataxia UK, raises an extra £4.39 in further funding used specifically for ataxia research. This illustrates the high quality of our funded research.

Over the 10 years our funded research has produced 83 papers published in scientific/medical journals and the development of 42 new research tools.

### Medical Research Charities Covid Support Fund

For the third year running Ataxia UK secured a grant from the UK Government Covid Medical Research Charities Support Fund to support research we had funded during the year involving early career researchers in the UK. The grant of £218,585 is extremely welcome and will allow further funding of ataxia research. Being a member of the Association of Medical Research Charities (AMRC), and thus following good practice in the grant programme, meant Ataxia UK was an eligible organisation for this scheme.

### Update on DRPLA Research Programme

Ataxia UK has been collaborating with CureDRPLA, a US-based foundation, since March 2020 to advance research in Dentatorubral-pallidoluysian atrophy (DRPLA), a rare form of inherited ataxia.

CureDRPLA provides funds to employ a Research Manager within Ataxia UK to support the Head of Research in leading the DRPLA Research Programme. The expertise we are gaining will help us advance research in other ataxias.

Ataxia UK and CureDRPLA are coordinating the DRPLA Natural History and Biomarkers study, which is recruiting participants in the UK, US and other countries to understand how this condition progresses over time and collect clinical information that will inform future clinical trial designs. Several participants have completed the first study visit and a few have completed the year 1 follow-up visit.

We also coordinate the CureDRPLA Global Patient Registry, an online collection of questionnaires to better characterise DRPLA. The registry currently holds data on 49 people with DRPLA from 10 different countries. In 2024, we aim to analyse the data from this registry to gain insights into DRPLA symptoms and progressions. We have succeeded in attracting an MSc placement student who can support our DRPLA Research Manager in analysing the registry information and publishing the findings in a scientific journal.

In October 2023, CureDRPLA hosted the second DRPLA research conference in Boston (US) with 26 attendees. Including researchers from academic institutions in the US, UK, Italy and Japan attended the conference, along with representatives from three pharmaceutical companies. CureDRPLA is planning to host another conference in the autumn of 2024.

**An important milestone** has been reached in the DRPLA Research Programme as an experimental treatment has started in the US for a person with DRPLA. This is taking place via the n-LoReM Foundation who charitably provides experimental treatments to treat people with rare diseases that affect very people in the US. While there is a clear regulatory path to run such trials in the US, similar opportunities are being explored in other countries like the UK. It is possible that more people with DRPLA in the US and other countries might be eligible for this experimental treatment as well.

Ataxia UK and CureDRPLA have announced this to their communities, and we are supporting UK-based families with DRPLA in exploring if this could be possible for them. We also attended the Patient Colloquium n-LoReM organised in October 2023 to better understand their mission and who might be eligible for treatment, as their work could also be relevant to other ultra-rare genetic ataxias.

## Working with Pharmaceutical Companies in driving research forwards towards treatments for the ataxias

**Ataxia UK continues to work with pharma companies who have ataxia programmes, supporting them in advancing their research.**

A number of companies are getting closer to the drug approval stage and are thus needing to collect health-related quality of life data to support them in seeking approval. Ataxia UK has worked with these companies to facilitate this process. Some of this data has been presented at research conferences and we welcome this sharing of data.

We have also provided introductions to ataxia experts in a range of areas, provided information on the research landscape, and explained the opportunities available in developing treatments for the ataxias to companies considering drug development programmes in the ataxia field. We encourage companies to run clinical trials in the UK and we are pleased that during the year a trial testing the promising ‘antisense oligonucleotide’ therapy is taking place in people with SCA1 and SCA3 at the London ataxia Centre.

Ataxia UK also supported companies in ataxia awareness raising activities.

As more promising treatments are being developed for the ataxias, we are getting to the stage that companies are submitting drugs for approval via the regulators. Ataxia UK has been actively supporting this process. The pharmaceutical company Biohaven have submitted the drug Troriluzole for evaluation by the EU regulator, the European Medicine Agency, as a potential treatment for people with SCA3. As part of Ataxia UK’s work with Euro-ataxia we provided a comprehensive submission to the EMA, highlighting the impact SCA3 has on families, the urgent need for a treatment, and urging flexibility due to it being a rare disease with no treatments. We plan to engage with UK drug regulators and decision-makers as needed.

### Pharma Strategy Advisory Committee

The Pharma Strategy Advisory Committee met three times during the year and provided useful advice to Ataxia UK on collaboration with pharmaceutical and biotech companies, maximising our impact, and ways we can support drug development process. Due to the drug approval of the first drug for FA in Feb 2023 the Committee focused on advising Ataxia UK on the work the charity can do in this stage of the drug development process.



## **Multi-Centre European and International Research Projects**

Ataxia UK research staff are often invited to be partners in European and international research projects, to provide patient organisation involvement and expertise and to assist in providing the perspective of people with ataxia. Often this involves grant applications to EU or other funding schemes for research projects, and the invitations are either directly to Ataxia UK or to be representatives of Euro-ataxia (the federation of ataxia charities in Europe).

The involvement of patient groups in projects is becoming increasingly important to the success of projects. During the year we have been involved in supporting researchers submit new grant applications and hopefully some will get funded.

These are the projects we have participated in over the year:

### **Accelerating and expanding the drug repurposing pipeline for rare neurological, neurometabolic and neuromuscular disorders by exploiting SIMilarities in clinical and molecular PATHology (SIMPATRIC)**

Euro-ataxia is a partner in this project that focuses on nine different rare conditions, including Spinocerebellar ataxia type 3. It aims to find and test the effect of drugs that are already available to patients for other conditions (repurposed drugs). It received funding from the European Commission Horizon Europe programme. Ataxia UK's Head of Research is a Euro-ataxia representative on this project.

### **European SCA3/Machado Joseph disease initiative (ESMI)**

The ESMI consortium has successfully established the largest cohort of systematically characterised patients with SCA3 worldwide.

The consortium is also playing an important role in the development of biomarkers. This is an extremely useful resource for running trials in Europe. A number of important publications have arisen from this project. This project has been recruiting participants since 2017 and Ataxia UK's Head of Research, Dr Julie Greenfield, has continued to participate in the Steering Committee as a Euro-ataxia representative. Since the EU JPND funding ended the Consortium has secured funding from pharma companies to continue the project.

## Progression chart of spastic ataxias (PROSPAX) project

**The PROSPAX project, launched in June 2020, is a collaborative effort between neurologists across Europe, plus Canada.**

The project aims to study the progression of spastic ataxias over time, from the clinical to the molecular level, including brain imaging, markers of progression and animal models. The project focuses mostly on ARSACS and SPG7, but will establish a more general research framework applicable to other spastic ataxias over time. Euro-ataxia is involved in the project as an active partner representing European ataxia patients, and is being supported by Ataxia UK. A representative of the Ataxia UK Research team attended the annual meeting of this project, held in Turkey, and we have continued to produce blogs and disseminated communications to the community.

An active Patient Organisation Group is leading a Work package to create Patient Reported Outcome Measures, by creating and distributing surveys and gathering the views of people with ataxia on the impact of their condition on different aspects of their lives. The results of these surveys are being written up for publication in a scientific journal.

## TREAT-ARCA Project

This project, started in June 2020, focuses on recessive ataxias and in particular ARSACS and ARCA2 (also called COQ8A). It aims to design a toolbox of treatments for these ataxias; including gene therapy in animal model systems of ARSACS and ARCA2.

There have been a number of research dissemination activities and in September we organised a well-attended webinar on gene therapy. We are also working on gaining an understanding of people's understanding and expectations from gene therapies for the ataxias. This will be done via a multi-national survey to people with inherited ataxias. A Research team working on this has been set up including researchers and patient groups and Ataxia UK is leading this project.

It is particularly important to gather the views of people with ataxia, as research is advancing at both preclinical and clinical stages for the ataxias, with the first trials already taking place in people with FA.

## The European Friedreich's ataxia Consortium for Translational Studies (EFACTS)

This is a study originally funded by the European Commission and that is gathering vital information about the progression of Friedreich's ataxia (FA). The purpose is to generate a large FA patient database, alongside an

integrated clinical and natural history database; this is be linked to a biological samples repository. It also aims to define a panel of clinical assessment tools for use in future trials.

Data from this study has resulted in useful publications and is also being used to plan clinical trials. Ataxia UK have supported the project over the years. There are two Euro-ataxia representatives on the Steering Committee for this project, one being from Ataxia UK (Prof Barry Hunt).

### **FA Global Clinical Consortium**

During the year efforts have progressed in combining the efforts of EFACTS with the other well established natural history study in Friedreich ataxia, FACOMS (includes people from US, Canada, Australia, New Zealand and India). These studies have been conducted in parallel with many similarities in protocol design, objectives and study conduct. A new FA Global Clinical Consortium and a harmonized global study protocol has now been established. Ataxia UK has a patient group representative (Prof Barry Hunt) on this Consortium.

### **Cerebellum and Emotional Networks (CEN)**

This is a training network funded by the EU (Marie Skłodowska-Curie Innovative Training Network) that investigates the brain circuits that underlie emotional behaviour. The training network is focusing on the role of the cerebellum, a previously overlooked part of the brain, and its involvement in the control of emotions. The knowledge gained will inform the development of new therapeutic strategies for individuals suffering from emotional disorders. Ataxia UK's Head of Research is the Euro-ataxia representative.

### **PhaseAGE project ('Phase Transitions in Aging and Age-related Diseases')**

This project is a capacity building, training Consortium funded by the EU, and lead by a researcher in Portugal. It includes research projects on the formation of 'aggregates' by a phenomenon of phase separation (e.g. as when oil and water separate) in neurodegenerative conditions and in ageing. In particular, they are focusing on SCA3, hence Ataxia UK's involvement.

Ataxia UK's Head of Research is on the Scientific Steering Committee and has been involved in the evaluation of the progress of this training project, A face-to-face meeting was held in September in Portugal to support patient organisations in building capacity and Ataxia UK was actively involved in this event, with both the Head of Research and Head of Services participating and



giving presentations on ‘Involving patients and patient groups in research’ and ‘Engaging your community’.

The talks were followed by small group discussions and an art exhibition, showcasing photographs and stories from people with the conditions and artistic images of the proteins involved in the conditions.

### Ataxia Global Initiative (AGI)

The Ataxia Global Initiative is a worldwide research network with the goal of facilitating the clinical development of therapies for ataxias. Dr Julie Greenfield (Ataxia UK’s Head of Research) continues to be a Steering Committee Member and co-chairs the Policy and Patient Engagement Working Group, tasked with setting all the policies for the initiative. During the year there have been meetings to encourage further participation of patients group representatives in activities of AGI.

During the year eight papers were published in a special series of the medical journal *Cerebellum*. These are consensus papers with expert guidance and recommendations in a range of topics covered by the working groups (clinical assessments, brain scanning, biofluid sample collection, digital biomarkers, assessments using smartphones, speech assessments, oculomotor assessments and data sharing and analysis in next-generation sequencing to help diagnosis).

AGI works closely with the ‘Critical Path to Therapeutics for the Ataxias’ Consortium hosted by the US not-for-profit organization Critical Path Institute. This Global Consortium aims to bring together experts from across different fields of ataxia research, patient groups and pharma companies to create regulatory tools and strategies to catalyse the development of approved medicines for the ataxias. A crucial aspect of the Consortium is that it includes experts from regulatory bodies such as the US Food and Drugs Administration (FDA) in its discussions. Ataxia UK is a partner of this initiative and attends regular meetings.

### AT Society Collaboration

Ataxia UK has continued to provide a research support service to the Ataxia Telangiectasia (AT) Society, supporting people affected by AT. During the year we supported them in their research grant programme, and other research activities. A new Biomarkers in AT Working Group was established by the AT Society to progress this area of research and a review paper has been drafted for publication. In addition, work is underway to organise an AT clinical research meeting in 2025.

## Recruitment of Participants to Research Studies

Having a database of people with ataxia puts Ataxia UK in a unique position to support research via the recruitment of participating volunteers. During the year we have supported 23 studies find participants.

This includes studies understanding balance and gait, speech difficulties and a clinical trial testing a medication. Ataxia UK also supported a researcher run two workshops on working with patient samples in neuroscience. Ataxia UK has an internal Ethics Review Committee who provides input on studies involving people with ataxia, as needed.

## Raising Awareness of Ataxia Research

Ataxia UK research staff have attended meetings and conferences throughout the year. This has been very useful in raising the profile of ataxia and Ataxia UK, creating opportunities to establish new partnerships and encouraging further research in ataxia.

## Ataxia UK's Research Aims for 2024 - 2025

- Host the International congress for ataxia research in London
- Work with pharmaceutical company to accelerate access of Skyclarys to UK patients
- Actively engage with pharmaceutical companies who have drugs close to approval
- Gather the views of people with ataxia on gene therapies

## Care and Support Services for People Affected by Ataxia

### Care and support aims for 2023-24

- Secure funding to sustain and enhance the complete range of Ataxia UK Services
- Provide another Occupational Therapy placement for the University of Brighton
- Expand the Helpline and Advocacy Service further
- Collaborate with Rare Minds to launch a dedicated Ataxia UK counselling service.

- Pilot an Ataxia UK Specialist Nurse in the Southwest region to offer specialised care and resources to that community.

## Services Overview

In July 2023, Ataxia UK achieved a significant milestone by securing five years of funding from the National Lottery Community Fund in England. This funding serves as a vital support for the expansion of our Helpline and Advocacy Service. On the second year of this project, we are proud to announce the appointment of a Specialist Nurse. This role will facilitate the coordination of specialist services for people within the ataxia community, particularly focusing on the southwest region of England, where access to specialised neurology services for ataxia patients is limited.

Additionally, the funding has enabled us to appoint a second part-time staff member to enhance the Helpline and Advocacy Service, allowing us to reach and assist more individuals affected by ataxia. Furthermore, we have successfully secured additional funding to fulfil the match-funding requirement of the Lottery Project and to support various other essential services.

Ataxia UK had the privilege of hosting its third Occupational Therapy placement, welcoming students from the University of Brighton, furthering our commitment to education and collaboration within the community.

## Community Activities

We hosted a diverse range of 45 virtual activities, drawing in over 761 participants, a notable increase from the 540 participants in 2022-2023. These activities included monthly wellbeing sessions, Occupational Therapy activities, and noteworthy events such as Wellbeing Week, Volunteers Week, and various information sessions. With the exception of one in-person event in October 2023 we have continued to develop activities in a virtual format, ensuring the ataxia community can continue to access key services and support.

These activities have proven to be an effective means of enhancing the wellbeing of participants and fostering a sense of community for people affected by ataxia.

## All About Ataxia

All About Ataxia seminars provide people who have a relatively recent diagnosis information about ataxia, although we know that people who have been diagnosed much longer have also found them useful.

The sessions were conducted three times this year, a decrease from quarterly in the previous year, although the total number of attendees increased with 82 participants in 2023-24, up from 70 in 2022-23. Sign-ups per session were higher, notably boosted by the in-person All About Ataxia event held before the National Conference in October, which attracted 37 attendees.

### **All About AtaxiaPLUS**

All About Ataxia PLUS is a series of information seminars developed by the ataxia community and Ataxia UK, and is aimed at bringing people in the ataxia community together to share information and learn from each other.

Each All About Ataxia PLUS session delivers information on a particular subject which is important and helpful for people with ataxia and their friends, families, and carers. Three sessions of All About AtaxiaPLUS were delivered, focusing on practical tips and tools for individuals with ataxia. The initial session, All About AtaxiaPLUS Life Hacks, was attended by 23 participants and garnered positive feedback. Building on its success, the session evolved into All About AtaxiaPLUS Gadgets, Aids & Adaptations, delivered during Wellbeing Week to 48 participants, receiving highly positive feedback once more. A session titled All About AtaxiaPLUS Your Mental Health was collaboratively developed with Rareminds, reaching 23 attendees.

### **Wellbeing Week**

Hosted in January 2023 Wellbeing Week was a series of free virtual workshops designed to increase emotional and physical wellbeing with the ataxia community. Attendance was high and feedback overwhelming positive with many attendees asking for more of the same.

The sessions included topics such as Managing Symptoms, Exercise, Speech Therapy, Gadgets Aids & Adaptations, and Mindfulness. A total of 343 individuals registered for these sessions, with 255 attendees participating.

Following each session, all registrants were sent a follow-up email containing access to watch the session again, presentation slides or handouts, a feedback survey link, and responses to any questions posed during the session, as applicable.

### **Volunteers' Week**

To celebrate Volunteers' Week, we expressed our gratitude to all our volunteers by sending hand-written thank you cards and hosting a special volunteers week quiz.

## Branch and Support Groups

Ataxia UK's Support Groups and Branches are vital hubs of support and activity, all powered by the dedication of Ataxia UK volunteers. These groups provide invaluable spaces for sharing support, information, and camaraderie, hosting a total of 186 meetings with more than 1135 attendees. Support Groups, totalling 36 across the UK, offer members the opportunity to connect, share experiences, and unwind.

Our 5 Branches serve as local arms of the charity, each with a Chair and Treasurer, actively support group meetings and activities throughout the year. In addition to geographical Support Groups and Branches, we also have 5 non-geographical support groups, catering to specific needs within our community. These include the Virtual Support Group, designed for remote connection, the 16-30s Group for younger members, and specialised groups such as the Episodic Ataxia Group. Recently introduced are the Carers and the Autoimmune & Gluten Ataxia Support Groups, both established within the last year, enriching our support network, and meeting the diverse needs of those affected by ataxia.

## Volunteering

Ataxia UK is deeply grateful for the invaluable contributions of our dedicated volunteers, totalling 89 individuals, many of whom perform multiple roles, including 6 new recruits. Our volunteers are the backbone of the organisation, actively supporting various facets of our work. They play pivotal roles in on the Helpline, by responding to queries, providing support and processing new Friend applications, and ensure the smooth operation of our branches and support groups.

Additionally, they contribute to the development and delivery of virtual activities, participate in clinics at specialist ataxia centres, and tirelessly fundraise to sustain our mission. Moreover, many volunteers serve on committees and advisory groups, lending their expertise and passion to further our cause. Ataxia UK recognises and appreciates the indispensable role of our volunteers, without whom our work would not be possible.

## Diverse Placements

We facilitated a diverse placement opportunity by hosting two occupational therapy students from the University of Brighton. Throughout their placement, they actively engaged with our community, participating in various support group meetings to offer insights into occupational therapy. Additionally, they conducted an Occupational Therapy drop-in clinic and led a session highlighting how occupational therapy can assist carers. Furthermore, they



worked one-to-one with members of the ataxia community, gaining valuable firsthand experience of the challenges faced by those affected by the condition and deepening their understanding of living with a rare progressive neurological condition.

Throughout their placement, the students were supported by the Ataxia UK services team and received long-arm supervision from a consultant occupational therapist, who is also a member of the board of trustees and themselves a person living with ataxia, further enriching their learning experience.

### **Scottish Advice Service**

Ataxia UK's Rare Conditions Advice Pilot, in collaboration with Parkhead CAB in Glasgow, aims to pioneer and evaluate tailored advisory services for individuals with ataxia in Scotland. Through robust evidence gathering, the project seeks to influence social policy and support frameworks for other rare conditions, extending beyond ataxia. In its first year, the project recruited and trained a Rare Conditions Adviser, promoted the service through various channels, and facilitated collaboration between Ataxia UK and CAB staff.

The project's initial findings reveal the complexity of client cases, with an average of 18 issues per person, significantly higher than standard advice services. Challenges include cross-border referrals due to the absence of a Specialist Ataxia Centre in Scotland. However, the project has increased awareness and capability among frontline advisers, improved communication strategies, and enhanced service delivery channels.

Partnering has facilitated knowledge exchange, proving valuable amid Scottish benefit devolution. Plans for the second year involve continued support for the ataxia community, sharing project learnings, and undergoing rigorous external evaluation.

## **Helpline & Advocacy Service**

### **Helpline**

Ataxia UK's Helpline received a total of 1,350 contacts, providing support to 996 individuals across a range of concerns, covering 1,645 distinct issues. These included the provision of information about ataxia, health needs, therapies, referrals, and diagnosis. Furthermore, our assistance extended to addressing social care requirements, such as housing, aids, and adaptations, as well as navigating welfare benefits, grants, and financial matters.

During this period, we welcomed 4 new volunteers to join our Helpline Team, bolstering our capacity to provide support. Regrettably, we also bid farewell to two volunteers who contributed significantly to our efforts.

### **Advocacy Service**

Due to increased staff hours, over the past year Ataxia UK's Advocacy Service has been hard at work, handling 118 cases and providing vital support to 94 people in our community. The support covers a range of issues as stated above with particular focus on benefits (31 cases), navigating the NHS (33 cases) and grant applications (28 cases).

In addition to achieving outcomes like access to specialist health services, appropriate adapted housing and adequate care and support, the service has secured £14,877 in grant funding for specialist equipment and services and £19,403 in unclaimed welfare benefits.

### **Membership**

We welcomed 696 new Friends of Ataxia UK in 2023-24, that is up from 575 last year.

## **Care & Support aims for 2024 - 2025**

- Review content and format of All About Ataxia seminar to encourage attendance
- Connect with the ataxia community by attending Ataxia UK Branch & Support Group meetings both online and in-person
- Roadshows to devolved nations
- Enhance volunteer support by providing supervision by Rareminds for Helpline Team
- Develop and deliver more All About AtaxiaPLUS sessions
- Update website information
- Introduce evaluation strategy for services
- Extend Helpline opening hours
- Increase the number of people supported by the Helpline and Advocacy Service

## Improvements in Treatments & Care

### Treatment & Care aims for 2023-24

- Develop 'Virtual Grand rounds' for expert advice on ataxia patients' diagnosis and management
- Hold Euro-ataxia annual conference in Greece
- Publish Ataxia Medical Guidelines
- Pilot an Ataxia UK Specialist Nurse in the Southwest region to offer specialised care and resources to that community
- Expand the Speech Therapy Service to support those Friends who are waiting for or unable to access the course.

### Develop 'Virtual Grand rounds' for expert advice on ataxia patients' diagnosis and management

Following advice from Ataxia UK's Medical Advisory Panel (MAP) during the year we launched 'Virtual Ataxia Grand Rounds'. A successful pilot was held during the year, involving two difficult ataxia cases being presented by clinicians to a group of four expert ataxia clinicians, plus Ataxia UK Research staff, who discussed the cases.

Following positive feedback, a second grand round was held, and this time the event was publicised to UK clinicians who are on the Ataxia UK registry of healthcare professionals with an interest in ataxia to submit cases. This is a new useful service that Ataxia UK can provide in order to assist clinicians in cases that require expert input in diagnosis and management of cases with ataxia. We plan to run more Grand rounds over the coming year.

### Hold Euro-ataxia annual conference in Greece

Euro-ataxia, of which Ataxia UK is an active member, is the federation of over 20 European ataxia patient organisations. Each year, Euro-ataxia organises a conference to enable patient groups across Europe to network and hear updates on research for the ataxias. The 2023 Euro-ataxia research conference was held in Greece, in May. More than 50 participants attended physically, including patient organisation representatives, people with ataxia, researchers, clinicians and pharmaceutical company representatives, as well as more than 20 who followed the event online. The event was organised by the Greek patient group (HEFAA) and Euro-ataxia, with support from Ataxia UK.



The research conference was very successful with a range of interesting research talks, a panel discussion with people with ataxia, updates from pharma companies.

The presentations covered a wide range of topics, including gene discovery, improvements in diagnosis, emerging and existing therapeutics, natural history studies, and biomarkers of ataxia. Flash talks from four early career scientists were included to promote their research findings. Engaging junior scientists in a patient-centred research event such as this is beneficial in broadening their perspectives on the needs of people with ataxia, highlighting the importance of their research and encouraging them to continue their careers in ataxia research.

Interviews were also conducted with patient group representatives, researchers and clinicians to get their perspective on important issues facing the ataxia community.

We were successful in getting a grant from the European Union's Horizon 2020 research and innovation programme (under the EJP RDCOFUND-EJP N° 825575), and sponsorship from pharmaceutical companies, meaning we could offer participants contributions to the cost of attending.

The first day was dedicated to the research conference and the second day was for Euro-ataxia members only. The main topic of conversation was the progress made in individual countries on access to Skyclarys the first approved drug for FA (see above) and member groups were able to share what is happening in the different countries.

### **Publish Ataxia Medical Guidelines**

Progress is being made in updating the Ataxia Medical Guidelines to help health professionals diagnose and manage people with ataxia. Specialist contributors for all sections have been identified and many sections have been updated. The Guideline Development Group has been reviewing the sections throughout the year. As this is a very long document, there have been delays and we were not able to publish them during the year.

### **Pilot an Ataxia UK Specialist Nurse in the Southwest region to offer specialised care and resources to that community**

Funding secured in 2023-24 from the National Lottery Community Fund will enable Ataxia UK to appoint a Specialist Nurse in the Southwest region. The Nurse will be appointed in early 2025. Funding secured in 2023-24 from the National Lottery Community Fund will enable Ataxia UK to appoint a Specialist Nurse in the Southwest region. The Nurse will be appointed in early 2025. This region lacks access to ataxia specialist services, as the specialist centres in London, Oxford, and Sheffield are quite far away. The introduction of a

specialist nurse will significantly improve access to appropriate, coordinated, and specialist care for people with ataxia in the Southwest.

### **Expand the Speech Therapy Service to support those Friends who are waiting for or unable to access the course**

The Gift of Speech project seeks to address the speech difficulties faced by people with ataxia. We offer an online speech therapy course aimed at slowing the progression of ataxia speech symptoms. Additionally, we fund voice banking services that facilitate the development of a customised synthetic voice to be used with a communication aid in the event that speech becomes incomprehensible due to ataxia symptoms.

#### **Speech Therapy**

Our Speech Therapy program consists of a 6-week course that begins with four individual sessions with our Speech and Language Therapist. During these initial sessions, participants receive personalised guidance to identify and work on areas for speech improvement. Following this, participants join a small group of 5-6 individuals for daily sessions over the next 4 weeks. There are five group sessions each week, one of which is led by the Speech and Language Therapist.

60 Friends of Ataxia UK have undertaken the course and there are a further 38 people on the waiting list. We are excited to have recruited a second speech and language therapist to help us deliver the course more regularly.

To accommodate those on the waiting list and for individuals in our community who may be unable to commit to a six-week intensive course, Ataxia UK delivered two standalone speech therapy sessions.

#### **Voice Banking**

We now offer funding for people with ataxia to bank their voice with SpeakUnique. Voice Banking involves recording an individual's natural voice, to be used to create a personalised synthetic voice. This means people can retain their identity and communicate in a voice that sounds like their own, even when natural speech is not possible.

Voice Banking is designed to be inclusive, ensuring that everyone has access to a personalised synthetic voice, even if their natural voice is already unintelligible. Voice Design uses various voice characteristics, such as age, gender, and regional accent, to create a unique and tailored voice. Additionally, individuals have the option to use old recordings or donor voices to create their synthetic voice.

Since we launched in 2022, we have funded 38 people with ataxia to download their personalised voice. In addition to this, 163 people with Ataxia have registered with SpeakUnique and of those 81 people have completed the voice banking process and created a voice.

## Other Activities Supporting Improvements in Treatments & Care

### Medical Advisory Panel meetings

Ataxia UK's Medical Advisory Panel met twice during the year (June and November 2023) and provided advice to Ataxia UK on a number of important topics. The meetings are also an opportunity for Ataxia UK to provide an update on the latest activities and for the group to be kept updated on research developments they are each involved in.

A main topic of discussion was the approval of the first drug for adults with FA and its implications for UK patients (see research section). Other discussions focused on progress with the Virtual grand rounds, results of a treatment trial for SCA27B, and issues around lack of funding for Brain banks.

### Value of Treatment Project - evaluating the work of Ataxia Centres

Ataxia UK is a partner in this European Brain Council project, that focuses on evaluating coordinated care in three rare neurological diseases. The ataxia study is being conducted Prof Giunti at the London Ataxia Centre. It has involved surveying people with ataxia in the UK, Germany and Italy to assess the value of Ataxia Centres. The results of this project highlight the value of coordinated care and specialist centres in addressing the challenges for people living with ataxia. Patients attending Specialist Ataxia Centres felt the care they received was better than those in non-specialist settings. There was no significant difference in the cost of the two different settings.

Over the year two papers based on this research have been accepted for publication in peer-reviewed medical journals. The first focuses on the differences to the care that people with ataxia may receive in the different settings and the second paper focuses on the differences in costs. A third paper has been submitted to a journal presenting more detailed information on the UK setting. Prof Giunti was also invited by the European Brain Council to present the data at an event in Brussels on Rare disease day (29<sup>th</sup> Feb), thus increasing awareness further.

## Ataxia UK Ethics Review Committee

Research studies, such as surveys, that are distributed to Friends of Ataxia UK or shared on our social media channels are first reviewed by the Ethics Review Committee. This Committee comprises five members, who either have ataxia or are family members of people affected by ataxia. During the year the Committee reviewed six surveys and interview-based studies, information leaflets to be provided to participants of an upcoming trial and a research workshop.

## Raising awareness and understanding of ataxia amongst healthcare professionals - Healthcare professionals' registry

We continue to reach out to healthcare professionals with an interest in ataxia via our e-newsletters sent to 545 people on the Registry four times a year. In particular we publicised the publication of the Optimal Clinical Pathway for adults with movement disorders in England.

The optimal clinical pathway sets out what good treatment, care and support looks like for people with neurological conditions, from those experiencing the first symptoms, to those that have lived with such conditions for a long time. Following lobbying by Ataxia UK this pathway includes an Ataxia Health Care Pathway, developed by ataxia specialists and Ataxia UK.

This shows the ideal route to care within the NHS in England for people with ataxia, and emphasises the important role of the specialist ataxia centres. This is part of a suite of optimal neuroscience clinical pathways that have been developed by the neurological community, with the support of NHS England and the National Neurosciences Advisory Group.

## Consultations for changes in healthcare services

**Response to consultation by HFEA (Human Fertilization and Embryology Authority) on use of PGT** Ataxia UK provided a response to a survey created by Genetic Alliance to be submitted to the Human Fertilization and Embryology Authority (HFEA) in helping them decide whether to license the reproductive technique, pre-implantation genetic testing (PGT), for couples with a chance of having a child with autosomal recessive spinocerebellar ataxia-17 (SCAR17).

The response included information on the impact of the condition and recommended that families are given the choice to use PGT and hence recommended a license be granted. Ataxia UK also publicised the consultation to people with ataxia so their input could be gathered. The HFEA approved the use of PGT for this condition. This is part of ongoing efforts by Ataxia UK to

respond to consultations when any couple seek a licence for a not-yet licensed form of inherited ataxia.

## **Ataxia UK accredited Ataxia Centres**

Ataxia UK-accredited Specialist Ataxia Centres are centres of excellence, where people with ataxia receive the best quality of care from ataxia experts and a coordinated service combining diagnosis, treatment, support and research. In order to receive accreditation Centres need to comply to criteria devised by Ataxia UK.

### **Sheffield Adult Ataxia Centre – Royal Hallamshire Hospital Sheffield**

The team at the Accredited Ataxia Centre consists of two neurologists (Prof Hadjivassiliou and Dr Shanmugarajah) and two Ataxia Nurses, thus is a large concentration of expertise. In addition, they have close links with the Children's Ataxia Centre below, which facilitates the transition between children's and adult services. Prof Hadjivassiliou continues to publish extensively on ataxia research, in particular autoimmune ataxias.

A grant was awarded last year by Ataxia UK, Coeliac UK and other funders to improve diagnosis and management of gluten ataxia, and this project is now underway. The Sheffield team are also organising an Ataxia Training Day for healthcare professionals in June 2024, and ataxia UK helped publicise the event.

### **Ataxia Children's Centre at Sheffield Children's Hospital**

The Sheffield Children's Centre, staffed by ataxia specialist paediatric neurologist, Dr Santosh Mordekar, supported by an Ataxia nurse, continues to receive referrals and see children with a range of ataxias.

### **London Adult Ataxia Centre – UCL/UCLH National Hospital for Neurology and Neurosurgery**

The London Ataxia Centre, led by Prof Giunti, now runs four ataxia clinics a week, with the support of a full-time Ataxia Nurse. There is also a multidisciplinary clinic, where patients see the neurologist along with other healthcare professionals, such as speech and language therapists and physiotherapists. In addition, there is a vestibular clinic and neuro-ophthalmology and neuro-urology clinics, providing even more integrated care.

Prof Giunti continues to be involved in numerous research projects including trials. Her research laboratory studies a wide range of ataxias and is the only



UK site for European natural history projects on the SCAs and FA. Importantly this Centre was involved in the drug trial that led to the first drug to be approved in FA, in addition to the laboratory studies that contributed data on the effectiveness of the drug. During the year a new treatment trial for SCA1 and SCA3 has started.

The Centre is also supported by Ataxia UK clinic volunteers. Since the pandemic the support had changed from face-to-face to phone and online support; but we are now planning for return to face-to-face support (in addition to phone support as needed).

### **London Paediatric Ataxia Centre**

The Paediatric Ataxia Clinic is an addition to the Adult London Ataxia Centre, at the National Hospital for Neurology and Neurosurgery (NHNN), enabling children with ataxia to receive care at this centre of excellence. The clinic team at the Paediatric Ataxia Clinic includes Professor Paola Giunti, Dr Shpresa Pula (consultant in Paediatric Neurology), and Katarina Manso (ataxia nurse).

The Paediatric Ataxia Clinic leads a large translational research programme, which aims to put research findings into practice. It's primarily focused on the genetic basis of ataxias, particularly Friedreich's ataxia. They recognise the importance of clinical registries and gathering natural history data, so that when therapeutic trials are offered, their service is "trial-ready".

Children referred to the Paediatric Ataxia Clinic will need to be monitored and supported by local healthcare professionals between visits.

### **Oxford Ataxia Centre at John Radcliffe Hospital**

The Adult and paediatric Centre was accredited in Oxford last year. The Oxford Ataxia Centre offers a specialised service for adults and children with a suspected or confirmed ataxia.

The service is provided by a multidisciplinary team including two adult neurologists (Dr Tofaris and Dr Rinaldo), a clinical geneticist (Prof Nemeth), and a paediatric neurologist (Dr Martin).

### **Euro-ataxia**

Euro-ataxia is the federation of ataxia charities across Europe, with 20 member groups from 15 countries. Ataxia UK's CEO is the Secretary General and Ataxia UK's Head of Research is the Research Advisor.

The Euro-ataxia annual conference was held in May (see above). A new member, FARA Ireland, joined Euro-ataxia during the year.

Various letters of support for new research projects have been written to support ataxia researchers get funding from the EU and other funders. Euro-ataxia offers to provide the patient perspective and input to funded ataxia projects where needed. During the year one such application has succeeded in getting funding, which led to the establishment of a Gene therapy Centre in Portugal.

### **Lobbying for improvements in care and research**

We are active members of a number of representative 'umbrella' organisations, including Genetic Alliance UK/Rare Disease UK, the Association of Medical Research Charities (AMRC) and the Neurological Alliances in England, Scotland and Wales. Sue Millman, CEO of Ataxia UK, is also a Trustee of Genetic Alliance UK. and Carol McCudden, is on the Board of Trustees of the Wales Neurological Alliance. All of these organisations seek to influence and improve investment, policy and practice in activities and services which influence the lives of people affected by ataxia, and we actively engage in their training, policy development, surveys and lobbying activities.

The Government launched the follow up initiative to the Rare Disease Strategy: The UK Rare Diseases Framework in early 2021. Sue Millman represents the Neurological Alliance (England) on the UK Rare Diseases Forum. The Forum enables engagement and collaboration between patient advocates, the UK Rare Disease Framework Board, the Delivery Group/ implementation boards for England and the devolved nations. The CEO has attended numerous meetings during the year regarding the Rare Disease Framework.

### **Treatments & Care Aims for 2024 - 2025**

- Pilot an Ataxia UK Specialist Nurse in the Southwest region to offer specialised care and resources to that community
- Hold Euro-ataxia conference in November in London

## Fundraising

### **Our strategic fundraising priorities for the financial year 2023 – 2024 were:**

- Maintain income, seeking modest growth where possible.
- Continual revision and improvement of our thanking process.
- Make improvements to our supporter journey – with a focus on improving digital usability, particularly on our website.
- Focus on fundraising streams which are traditionally more robust during times of economic difficulties - Trust and Foundations and Major Donor Fundraising.

#### **Maintain income, seeking modest growth where possible.**

FY23-24 was a mixed bag for income performance with growth in some channels and underperformance in others. The primary underperformers were in income streams we have less influence over such as legacies which ended the year 85% below budgeted expectations. The positives though were seeing growth in Individual Giving and our Events and Community Fundraising which grew year on year by 3% and 18% respectively.

#### **Continual revision and improvement of our thanking process.**

Throughout the year we continued our focus on ensuring we thank our supporters as best we can for their generosity and support. To this end we held our first ever thank-a-thon in September 2023 which involved all members of staff across all departments join in with phoning, emailing, and writing to our supporters to thank them for their support.

#### **Make improvements to our supporter journey – with a focus on improving digital usability, particularly on our website**

Work on improving our supporter continued this year and we've rolled out the new design to a lot of the new website sections, and booking interfaces. A comprehensive holistic redesign, with particular attention paid to the top two layers of the website will be carried out in the Autumn of 2024.



## **Focus on fundraising streams which are traditionally more robust during times of economic difficulties - Trust and Foundations and Major Donor Fundraising.**

Much of the previous financial year and along with the early part of FY23-24 was focused on producing our bid to the National Lottery Community Fund requesting support over 5 years to support and transform our service provision. I am very pleased to report that this application was successful in securing £499,251 over 5 years.

Throughout the rest of the year, we focused on producing applications to match fund this amount. We also continued to implement our Major Donor Fundraising Strategy and built plans for 2 new initiatives to support this area of work to be implemented in FY24-25.

## **Our Approach to Fundraising**

Ataxia UK has an in-house fundraising team undertaking a range of activities including:

- Direct marketing
- Events and community fundraising
- Legacy fundraising
- Trusts and Foundations
- Major donor fundraising

This financial year we worked with an agency – “The Fundraisers” - who helped us prepare Trust and Foundation bids throughout the year. All their work is monitored and reviewed by Ataxia UK before submission. We did not work with commercial participators this financial year.

Supporters fundraise on our behalf and are given support throughout their event by our dedicated Events and Community fundraisers.

Ataxia UK is registered with the Fundraising Regulator, and we are committed to following the Regulator’s Code of Practice and Fundraising Promise which set the standards for fundraising behaviours in our interactions with the public and our supporters.

We have a Vulnerable Persons Fundraising Policy which sets out how we identify such potential vulnerability and how we aim to respond in such circumstances. In this financial year we received complaints relating to our fundraising including, 2 complaints about the content of our appeals, 1 relating to a missing thank you, 1 relating to the lack of accessible challenge events, 1

about the conduct of a volunteer fundraiser and 1 in relation to figures used in our art exhibition.

## **Our Supporters**

The vision of a world without ataxia will only be realised through the support and generosity of the ataxia community. They help make everything in this report possible and we are incredibly grateful for their passion, commitment, and support.

## **Highlights**

- Secured the support of the National Lottery Community Fund over 5 years totalling £499,251
- James Rapson holding his bi-annual clay pigeon shoot raising over £24,000
- Our Big Give Pledgers, who make our largest appeal of the year possible
- The Rumsey-Cartier Foundation for their continued support

## **Communications**

**Our strategic Communications priorities for financial year 2022 – 2023 were:**

- Produce a new Marketing and Communications Strategy aligned with the holistic Strategic Plan
- Complete and our first full length ataxia documentary
- Continue improving our core services / information dissemination

### **Produce a new Marketing and Communications Strategy aligned with the holistic Strategic Plan**

In late 2022 and 2023, we've identified areas of communications, both internal and external, that required improvements to enable the sustainable growth of Ataxia UK's communications and to remain on-par with the advances expected to be made within the wider UK charity sector in the coming years.

In Q3, a new Communications & Marketing strategy was agreed by the board, setting out the goals for Ataxia UK's sustainable digital growth as well as a variety of improvements to traditional means of communications. The plan is spread across the years 2023-2026.

While the primary focus of this strategy is digital growth, it also encompasses traditional marketing and plans on how to streamline the flow of information and user journeys from traditional channels to digital channels and vice versa.

In addition to supporting the main charity objectives being at the heart of this strategy, it also pays particular focus to ensuring we move towards more inclusive, accessible, data and user insight-driven decision making.

### **Complete and launch our first full length ataxia documentary**

Filming and production of our first full length ataxia documentary continued in FY23-24 and will be launched in autumn 2024.

### **Continue improving our core services / information dissemination**

The communication team is a key component in ensuring the vital information and resources are made available to the community.

Some highlights of how they made this happen in FY23-24 are:

- Improving page load speeds on the website making the website more user friendly and improving their experience
- Simplified our online joining process meaning supporters are becoming friends of Ataxia UK in 5 mins as opposed to the 20mins it took previously
- Increased subscriptions to our monthly newsletter by over 15%

## Financial Review

### For the year ending 31 March 2024

#### Overview

2023/24 again proved to be a challenging economic environment for the charity, however, we continue to be very grateful for the continued support and generosity of our supporters. The charity will continue to ensure that our income is used in the most effective way to meet our strategic goals.

The Balance Sheet and Statement of Financial Activities shows a significant improvement in Ataxia UK's funds, as a result of a £488K surplus in the year (2022/23: £167K). The charity has improved from a net asset position of £39K in the 2022/23 financial year to a net asset position of £528K in the current year. A small net liability position still exists for the restricted funds on the balance sheet due to the 3 years expenditure commitment being made for the DRPLA and NKX6-2 projects in 2020/21, whilst the funding will be received gradually over the 3 year period of the projects. The projects had a delayed start so the funding was pushed out by a further year but the situation is now almost resolved and is the reason for the accounts showing such a good net asset position.

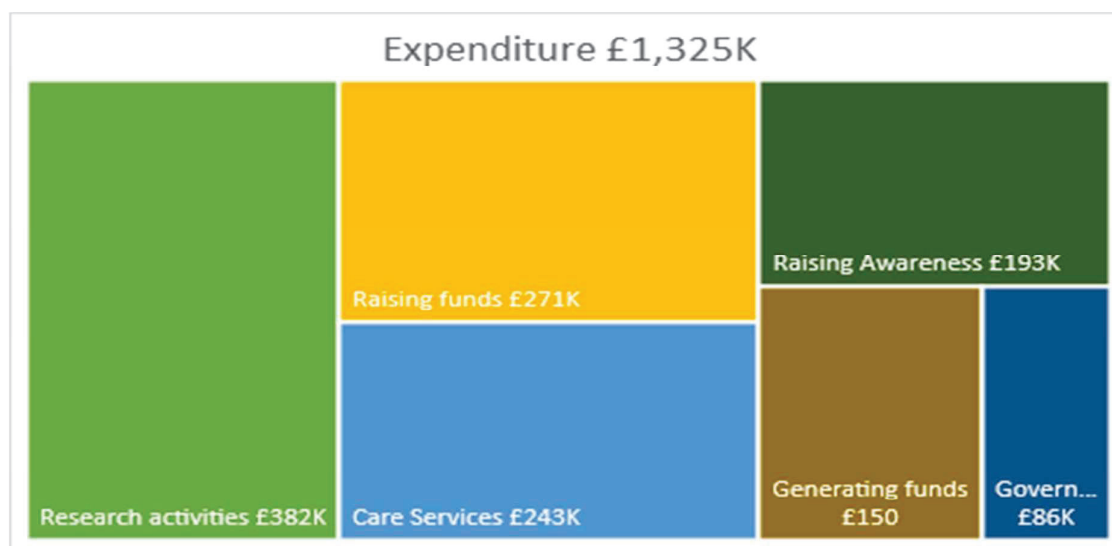
The deficit in restricted funds, of which DRPLA and NKX6-2 funds are part, have decreased over the year to (£16K) (2023: (£687K)). General unrestricted funds have unfortunately decreased to £543K (2023: £726K) due to the costs of running the charity increasing at a greater rate than the income. Further details of this are given later in this review as are details of reserves. We continue to maintain a healthy cash flow and have cash at bank and in hand of £1.9 million.

#### Review of income



Total income for 2023/24 was £1,814K (2022/23: £1,450K) an increase of 25%. Donation income was higher than the previous year, £830K (2022/23: £743K) an increase of 11.7%. Legacy income was exceptionally low and decreased to £32K for the year (2022/23: £218K), a decrease of 85%. We had a good pipeline of legacies about which we had been notified, but very little came to fruition during the year. Income from fundraising activities increased to £286K (2022/23: £242K) an increase of 18%. Childlife income remained at £100k (2023: £100K). Grants receivable increased to £554K (2022/23 £76K), a 629% increase which was due to income relating to the DRPLA and NXK6-2 projects above. Conference income dropped to £14K, (2022/23: £20K) a decrease of 30%.

## Review of expenditure



Total expenditure for 2023/24 was £1,325K (2022/23: £1,283K) an increase of 3.2%. Spending on research activities decreased to £382K (2022/23: £512K), a decrease of 25%. This was partly due to a reduction in research grants made during the year; £101K (2022/23: £188K), a decrease of 46%. The detailed breakdown of the research grants made can be found in note 9. There was a 21% decrease in spend on care services to £243K (2022/23: £307K). Cost of raising awareness increased greatly from the previous year to £193K (2022/23: £100K) an increase of 93%. This is largely related to the annual conference, Ataxian production, and an increase in salaries required due to the high cost of living. Expenditure on raising funds increased by 33% to £271K (2022/23: £203K), and on generating funds to £150K (2022/23: £93K) a 61% increase. Both were due to an increase in salaries because of the high cost of living and also trust fundraising. Governance costs increased by 26.5% to £86K (2022/23: £68K).

## Reserves levels at year end

	2024 (£K)	2023 (£K)
General funds	465	383
Designated funds	79	343
Total unrestricted funds	543	727
Total restricted funds	(16)	(687)
Total funds held	528	39

The charity saw an increase in reserve levels ending the year on £528K (31 March 2023: (£39K)), due to the total net income of £488k generated in the year.

Restricted funds were (£16K) (2022/23: (£687K)), (detailed in Note 22) with their still being deficit positions for DRPLA and NKX6-2. These deficit positions have very much decreased in the year.

Designated Funds totalled £79K (2022/23: £343K) representing funds held at branches (8.7K) and other designated funds (£70k) as detailed under Note 21.

The trustees have released 5 designated funds during the year and decreased one. These were unrestricted funds which were set aside by trustees for a future purpose but were felt to no longer be needed. A parental fund and Research conference fund remain; the conference fund relates to the ICAR conference to be held in November 2024.

General reserves of the charity as at 31 March 2024 were £465K (31 March 2023: £384K) a 21% increase. The trustees consider that it is both prudent and appropriate as part of their risk management policy to maintain a minimum level of contingency within free reserves to provide against any unforeseen changes in income and/or expenditure. The reserves policy has been updated slightly in 2024 to reflect the fact that operating costs are impacted by one off incidents such as ICAR. Therefore the new policy is to hold unrestricted, undesignated reserves equal to a minimum of 3 months operating costs adjusted for out-of-pocket costs covered by research and services restricted income. This figure amounted to £312,704 as of 31 March 2024, and the total of unrestricted, undesignated reserves was £468,053. This reflects a balance between being prudent and allowing the charity to direct as much resource as possible into research and care activities.

## GOING CONCERN

With the impact of the current economic climate on charity giving, the importance of having adequate reserves, as detailed above, continued to be a priority. We are blessed by the generous support of the ataxia community. We will maintain the close scrutiny of the management accounts and cashflow and take whatever steps necessary to ensure the continued viability of the charity.



## Statements of Trustees' responsibilities

The Trustees, who are also the directors of Ataxia UK for the purpose of company law, are responsible for preparing the Trustees' Report and the accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company Law requires the Trustees to prepare accounts for each financial year which give a true and fair view of the state of affairs of the charitable company and the incoming resources and application of resources, including the income and expenditure, of the charitable company for that year.

In preparing the accounts, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent; and
- prepare the accounts on the going concern basis unless it is inappropriate to presume that will continue in operation.

The Trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the accounts will comply with the Companies Act 2006, Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

## Statement as to disclosure to our auditors

Insofar as the trustees are aware:


- There is no relevant audit information of which the charitable company's auditors are unaware; and
- The trustees have taken all steps that they ought to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

In preparing this report, the trustees have taken advantage of the small companies exemptions provided by section 415A of the Companies Act 2006.

Approved by the trustees on 9th October 2024..... and

signed on their behalf by;

  
.....  
William Littleboy, Chair

  
.....  
Kathy Jones – Treasurer

## Independent auditor's report to the members of Ataxia UK

### Opinion

We have audited the financial statements of Ataxia UK for the year ended 31 March 2024 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and notes to the financial statements including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the Charity's affairs as at 31 March 2024 and of its income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice;
- have been prepared in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and with the requirements of the Companies Act 2006.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively,

## Independent auditor's report to the members of Ataxia UK

may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

### Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report (incorporating the directors' report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the trustees' report (incorporating the directors' report) has been prepared in accordance with applicable legal requirements.

## Independent auditor's report to the members of Ataxia UK

### Matters on which we are required to report by exception

In the light of the knowledge and understanding of the Charity and environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 or the Charity Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- sufficient accounting records have not been kept;
- the financial statements are not in agreement with the accounting records and returns; or
- we have not obtained all the information and explanations necessary for the purposes of our audit.

### Responsibilities of the trustees

As explained more fully in the trustees' responsibilities statement, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as they determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the Charity or to cease operations, or have no realistic alternative but to do so.

### Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could

## Independent auditor's report to the members of Ataxia UK

reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud are set out below.

### Capability of the audit in detecting irregularities

In identifying and assessing risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, our procedures included the following:

- We enquired of management, which included obtaining and reviewing supporting documentation, concerning the charity's policies and procedures relating to:
- Identifying, evaluating, and complying with laws and regulations and whether they were aware of any instances of non-compliance;
- Detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected, or alleged fraud;
- The internal controls established to mitigate risks related to fraud or non-compliance with laws and regulations.
- We inspected the minutes of meetings of those charged with governance.
- We obtained an understanding of the legal and regulatory framework that the charity operates in, focusing on those laws and regulations that had a material effect on the financial statements or that had a fundamental effect on the operations of the charity from our professional and sector experience.
- We reviewed the financial statement disclosures and tested these to supporting documentation to assess compliance with applicable laws and regulations.
- We performed analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud.
- In addressing the risk of fraud through management override of controls, we tested the appropriateness of journal entries and other adjustments, assessed whether the judgements made in making accounting estimates are indicative of a potential bias and tested significant transactions that are unusual or those outside the normal course of business.

## Independent auditor's report to the members of Ataxia UK

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities is available on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

### Use of our report

This report is made solely to the Charity's trustees, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and under Section 44(1) (c) of the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the Charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



10 October 2024

**Anthony Epton (Senior Statutory Auditor)**  
**for and on behalf of**  
**Goldwins Limited**  
**Statutory Auditor**  
**Chartered Accountants**  
**75 Maygrove Road**  
**West Hampstead**  
**London NW6 2EG**



# ATAXIA UK

## **STATEMENT OF FINANCIAL ACTIVITIES** (incorporating the income and expenditure account) (incorporating the results of the Charity's branches) **for the year ended 31st March 2024**

		<b>Unrestricted funds</b>	<b>Restricted funds</b>	<b>Total funds 2024</b>	<b>Total funds 2023</b>
	Notes	£	£	£	£
<b>Income</b>					
Donations and legacies	3	308,728	550,618	<b>859,346</b>	961,220
Other trading activities	4	275,182	10,672	<b>285,854</b>	242,021
Charitable activities	5	14,545	654,032	<b>668,577</b>	245,447
Investments	6	-	-	-	1,464
<b>Total income</b>		<b>598,455</b>	<b>1,215,322</b>	<b>1,813,777</b>	<b>1,450,152</b>
<b>Expenditure on:</b>					
Raising funds	7	(271,119)	-	<b>(271,119)</b>	(203,099)
Charitable activities	8	(509,372)	(544,981)	<b>(1,054,353)</b>	(1,080,219)
<b>Total expenditure</b>		<b>(780,491)</b>	<b>(544,981)</b>	<b>(1,325,472)</b>	<b>(1,283,318)</b>
Net losses on investments		-	-	-	-
Net income/(expenditure)		<b>(182,036)</b>	<b>670,341</b>	<b>488,305</b>	<b>166,834</b>
Transfer from Unrestricted to Restricted		(871)	871	-	-
Net movement in funds		<b>(182,907)</b>	<b>671,212</b>	<b>488,305</b>	<b>166,834</b>
Total funds brought forward		726,197	(686,886)	<b>39,311</b>	(127,523)
<b>Total funds carried forward</b>		<b>543,290</b>	<b>(15,674)</b>	<b>527,616</b>	<b>39,311</b>

The SOFA has been prepared on the basis that all operations are continuing.

All recognised gains and losses are included in the SOFA.

The accompanying pages form part of these financial statements.

# ATAxia UK

## DETAILED COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

(incorporating the income and expenditure account)

(incorporating the results of the Charity's branches)

for the year ended 31st March 2023

		Unrestricted funds	Restricted funds	Prior year Total funds 2023
	Notes	£	£	£
<b>Income</b>				
Donations and legacies	3	464,601	496,619	961,220
Other trading activities	4	222,065	19,956	242,021
Charitable activities	5	21,643	223,804	245,447
Investments	6	1,464	-	1,464
<b>Total income</b>		<b>709,773</b>	<b>740,379</b>	<b>1,450,152</b>
<b>Expenditure on:</b>				
Raising funds	7	(196,757)	(6,342)	(203,099)
Charitable activities	8	(482,193)	(598,026)	(1,080,219)
<b>Total expenditure</b>		<b>(678,950)</b>	<b>(604,368)</b>	<b>(1,283,318)</b>
Net losses on investments		-	-	-
Net income/(expenditure)		30,823	136,011	166,834
Transfer from Unrestricted to Restricted		(28,539)	28,539	-
Net movement in funds		2,284	164,550	166,834
Total funds brought forward		723,913	(851,436)	(127,523)
<b>Total funds carried forward</b>		<b>726,197</b>	<b>(686,886)</b>	<b>39,311</b>

The SOFA has been prepared on the basis that all operations are continuing.

All recognised gains and losses are included in the SOFA.

The accompanying pages form part of these financial statements.

**ATAXIA UK**  
**BALANCE SHEET**  
**As at 31st March 2024**

		<b>2024</b>		<b>2023</b>	
	Notes	£	£	£	£
<b>Fixed assets</b>					
Tangible assets	14	<b>13,723</b>		16,362	
			<b>13,723</b>		16,362
<b>Current assets</b>					
Debtors	15	<b>358,520</b>		365,041	
Cash at bank and in hand	16	<b>1,875,365</b>		1,589,232	
		<b>2,233,885</b>		1,954,273	
Creditors: amounts falling due within one year	17	<b>(1,123,662)</b>		(966,568)	
<b>Net current assets</b>			<b>1,110,223</b>		987,705
<b>Total net assets less current liabilities</b>			<b>1,123,946</b>		1,004,067
Creditors: amounts falling due after more than one year	18		<b>(596,330)</b>		(964,756)
<b>Total net assets/(liabilities)</b>	19		<b>527,616</b>		39,311
<b>Accumulated funds</b>					
Unrestricted funds					
General funds	20		<b>464,563</b>		383,508
Designated funds	21		<b>78,727</b>		342,689
			<b>543,290</b>		726,197
Restricted funds	22		<b>(15,674)</b>		(686,886)
<b>Total funds</b>			<b>527,616</b>		39,311

These accounts are prepared in accordance with special provisions of part 15 of The Companies Act relating to small companies and constitute the annual accounts required by The Companies Act 2006.

The financial statements were approved by the Trustees on 9 October 2024 and signed on their behalf by:



William Littleboy, Chair



Kathy Jones - Treasurer

The accompanying pages form part of these financial statements.

Charity Number: 1102391

Company Number : 04974832

**ATAXIA UK**  
**Statement of Cash Flows**  
**For the year ended 31 March 2024**

	2024	2023
	£	£
<b>Cash generated from operating activities:</b>		
<b>Net cash provided by operating activities</b>	<b>294,384</b>	<b>(168,296)</b>
<b>Cash flows from investing activities:</b>		
Dividends and interest from investments	-	1,464
Purchase of property, plant and equipment net of sales	<b>(8,251)</b>	<b>(4,611)</b>
Proceeds from sale of investments	-	-
<b>Net cash provided/(used in) by investing activities</b>	<b>(8,251)</b>	<b>(3,147)</b>
<b>Net increase in cash:</b>	<b>286,133</b>	<b>(171,443)</b>
Cash at bank and in hand less overdrafts at the beginning of the year	<b>1,589,232</b>	1,760,675
Change in cash and cash equivalents	<b>286,133</b>	<b>(171,443)</b>
Cash at bank and in hand less overdrafts at the end of the year	<b>1,875,365</b>	<b>1,589,232</b>
<b>Reconciliation of net income to net cash flow from operating activities</b>		
	2024	2023
	£	£
Net (expenditure)/income	<b>488,305</b>	166,834
Adjustments for:		
Depreciation charges	<b>10,890</b>	9,873
Net losses on investments	-	-
Dividends and interest from investments	-	(1,464)
(Increase)/Decrease in stocks	-	-
(Increase)/Decrease in debtors	<b>6,521</b>	(92,264)
Increase/(Decrease) in creditors	<b>(211,332)</b>	<b>(251,275)</b>
<b>Net cash provided by operating activities</b>	<b>294,384</b>	<b>(168,296)</b>
<b>Analysis of cash at bank and in hand less overdrafts</b>		
	2024	2023
	£	£
Cash at bank and in hand	<b>1,875,365</b>	1,589,232
	<b>1,875,365</b>	<b>1,589,232</b>

## **1. Charity Information**

The Charity is a company limited by guarantee and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The company is registered in England and Wales (company registration number 4974832) with a registered office at 12 Broadbent Close, London, N6 5JW. It is also a registered charity in England and Wales (Registration number 1102391) and Scotland (Registration number Charity SCO40067). The charity meets the definition of a public benefit entity under FRS 102.

## **2. Principal Accounting Policies**

a. Basis of Preparation: The financial statements have been prepared in accordance with the Statement of Recommended Practice (SORP) applicable to charities preparing their accounts in accordance with the Financial Reporting Standard (FRS) applicable in the UK and Republic of Ireland (FRS 102), the Charities SORP (FRS 102) the Financial Reporting Standard applicable in the UK and Republic of Ireland and the Companies Act 2006. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b. Going Concern: During the 2023/24 financial year, we had a net positive movement in total funds. The balance sheet shows a net asset position. The DRPLA and NKX6-2 grants were agreed in 2020/21 with the funding received over 3 years. Covid delayed the start of the grants and means the funding has been spread over a longer period and should be completed by 2026. See note 22 (note i DRPLA and note ii NKX6-2) below for further details. The cost of living crisis has had an impact on donations and could continue to have an impact on the 2024/25 financial year. We continue to take steps to ensure the continued viability of the charity. The cashflow was reviewed regularly to ensure that actual unrestricted cash was going to be adequate at all times. The Finance Committee meet regularly to monitor the situation and the fundraising department are continuing to pursue other ways to raise funds to safeguard income. To aid robust forecasting, a budget and associated cash flow have been drawn up for 2024-2026. The Trustees feel there are adequate resources to continue operating for the foreseeable future. The Trustees feel that there are no material uncertainties about the charitable company's ability to continue as a going concern. Accordingly, we continue to adopt the going concern basis in preparing this annual report and financial statements.

c. Childlife: The Charity is a member of a consortium, with three other charities, called Childlife, through which the member charities are able to collectively raise funds for their respective causes through the operation of a combined payroll deduction scheme and donor development. In accordance with FRS 102 Childlife is not consolidated in the financial statements of Ataxia UK as Ataxia is not part of a group that is required to prepare consolidated financial statements. As a grant funder of Ataxia UK, Childlife is treated on the same basis as any other funder and trading transactions between Ataxia UK and Childlife are reflected as such in these financial statements.

d. Tangible Fixed Assets: Tangible fixed assets costing more than £1,000 are capitalised and depreciated over their anticipated useful life. Office equipment is depreciated over 3 years on a straight-line basis.

e. Intangible Fixed Assets: Intangible fixed assets costing more than £500 are capitalised and amortised at the rate of 25% per annum on a straight-line basis.

f. Income Recognition: Income is recognised on an accrual basis, with the exception of donations and some fundraising receipts, which are on a cash basis. Deferred income represents fundraising income received for future events and is released to income in the period in which the event takes place. All income previously deferred has been released during the current year.

**Principal Accounting Policies (continued)**

g. Legacy Recognition: In accordance with SORP (FRS 102), legacies are recognised when they are probable and measurable.

h. Income tax recoverable: Income tax recoverable has been added to the relevant income source to which it applied.

i. Apportionment of Staff Costs and Overheads: Staff costs and related office overheads have been apportioned between direct charitable expenditure, fundraising, raising awareness and governance according to the time spent by staff on each of these activities. The costs of raising awareness of the issues surrounding ataxia have been separately identified to reflect the increasing importance of this activity.

j. Unrestricted funds: Unrestricted funds are funds that can be used in accordance with the charitable objects at the discretion of the Trustees.

k. Designated funds: Designated funds represent amounts held by Ataxia branches and some unrestricted funds which have been set aside by trustees for an essential spend or future purpose. See note 21 for further details.

l. Restricted funds: Restricted funds represent funds donated and raised by supporters of the Charity, which have been given for particular research or care services projects, together with grants received in respect of specific projects. The movements on the restricted reserves during the year are shown in note 22.

m. Branches: The accounts of the Charity's branches have been consolidated into these accounts.

n. Operating Lease Rentals: Rentals applicable to operating leases are charged to the Statement of Financial Activities as they become due.

o. Contractual Commitments: Formal and unconditional commitments to research expenditure and other grants at the balance sheet date are included within creditors, in accordance with SORP (FRS 102). Commitments to such projects that have been agreed by the Trustees but have not yet been confirmed to the recipient, and therefore do not yet represent contractual commitments, are shown as designated funds, except a) to the extent that equivalent reserves are maintained in restricted funds and b) to the extent that they are funded by commitments from other bodies. The movements on general funds and designated funds are shown in notes 20 and 21.

p. Pensions: The Charity contributes to certain employees' individual personal pension schemes, the assets of which are held separately from those of the Charity in a separately administered fund. Contributions to the scheme are charged to the Statement of Financial Activities as they fall due.

q. Taxation: As a registered charity, the Charity is exempt from taxation under CTA 2010 section 478.479.

r. Governance Costs: Governance costs include audit, legal and professional fees and the apportionment of staff costs, and office overheads costs according to the amount of staff time spent on this activity.

s. Goods and Services in Kind: Donated Services and equipment are included as income and related expenditure where the value to the charity can be reasonably quantified. The value of services provided by volunteers has not been included.



**ATAXIA UK**  
**NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2024 CONTINUED**

**Note 3 Donations and Legacies Income**

	2024	2023
	£	£
Donations	827,551	743,120
Legacies	31,795	218,100
	<u>859,346</u>	<u>961,220</u>

**Note 4 Other Trading Activities**

	2024	2023
	£	£
Fundraising activities	285,854	242,021
	<u>285,854</u>	<u>242,021</u>

**Note 5 Charitable Activities Income**

	2024	2023
	£	£
Childlife	100,000	100,000
Annual conference	14,156	69,391
Grants receivable	554,421	76,056
	<u>668,577</u>	<u>245,447</u>

**Note 6 Investment Income**

	2024	2023
	£	£
Interest	-	1,464
	<u>-</u>	<u>1,464</u>

**Note 7 Raising Funds Expenditure**

	2024	2023
	£	£
Costs of generating funds	271,119	203,099
	<u>271,119</u>	<u>203,099</u>

**Note 8 Charitable Activities Expenditure**

	Direct Costs £	Grants £	Support Costs £	2024 Total £	2023 Total £
Research activities	260,764	101,361	110,201	472,326	511,885
Adjustment of committed costs**	-	(90,414)	-	(90,414)	-
Care services	170,279	9,862	63,193	243,334	307,840
Total	<u>431,043</u>	<u>20,809</u>	<u>173,394</u>	<u>625,246</u>	<u>819,725</u>
Generating funds	-	-	150,021	150,021	92,602
Raising awareness	153,113	-	40,035	193,148	100,018
Governance	-	-	85,938	85,938	67,874
Total charitable activities	<u>584,156</u>	<u>20,809</u>	<u>449,388</u>	<u>1,054,353</u>	<u>1,080,219</u>

\*\* The reduction in grant was notified in January 2023. As a result, the related committed funds were reduced during the year as the full amount of grant had already been taken into committed funds in prior year when it was approved.

**ATAXIA UK**  
**NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2024 CONTINUED**

	2024 £	2023 £
Total support costs		
Staff costs	250,218	339,985
Office costs	188,280	141,516
Depreciation	10,890	9,873
	<b>449,388</b>	<b>491,374</b>

**Note 9 : Research Grants**

	2024 £	2023 £
<b>Research grants made in year comprise</b>		
Development of a PRIME editing therapy for Ataxia-8 due to the c.121 A to T point mutation'	8,036	-
Z-University of North Carolina at Chapel Hill - new award Dr Malawsky	34,610	-
'Development and Validation of SIMOA-based total and mutant Ataxin-2 Immunoassay for biomarker studies in SCA2 and SCA3'	30,000	-
Z-Institut du Cerveau et de la Moelle épinière-ICM	691	-
Novel biomarkers of oxidative stress in Friedreich's ataxia	4,800	-
Identification of disease-associated single nucleotide polymorphisms in ataxin-3	4,470	-
Evaluating ribosome collisions on CAG expansions proteostasis and translational stress responses in Spinocerebellar Ataxia type 3	3,000	-
Consultancy support with respect to preparing for Health Technology Assessment	5,800	-
Effect of targeting sphingolipid- metabolising enzymes in iPSC-derived sensory neurons obtained from FRDA patients	4,954	-
Exploring novel iron-mediated mechanisms to prevent cellular death in Friedreich's Ataxia	5,000	-
Determine mitochondrial metabolism in DRPLA: a possible novel therapeutic approach	-	25,000
Testing the multimodal anti-depressant vortioxetine as a therapeutic strategy to mitigate SCA3	-	30,000
Evaluation of RNA trans-splicing as a therapeutic strategy for spinocerebellar ataxia type 1	-	30,901
Personalized gene editing approach for the treatment of Spinocerebellar Ataxia type 1 (SCA1)	-	5,000
\$500 Sponsorship of CAG Triplet Repeat Disorders Gordon Research Conf and Seminar	-	433
Validating the therapeutic effect, a CAG repeat-targeting antisense oligonucleotide, on mitochondrial physiology in cellular models of DRPLA	-	26,935
Improving the diagnosis and management of gluten ataxia	-	38,000
Dr David Pellerin travel grant award of £1500 to attend and present an oral presentation at the American Academy of Neurology 2023 Annual Meeting	-	1,500
Looking beyond the central nervous system in SCA3: nerve and muscle ultrasound as potential imaging markers to quantify and monitor peripheral nervous system degeneration.	-	29,980
	<b>101,361</b>	<b>187,749</b>

**ATAXIA UK**  
**NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2024 CONTINUED**

**Note 10 : Staff Costs**

	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
<b>Staff costs comprised:</b>		
Salaries	<b>758,818</b>	703,788
Social security contributions	<b>74,813</b>	67,548
Pensions	<b>38,269</b>	35,616
Redundancy and termination costs	-	-
	<b>871,900</b>	<b>806,952</b>

The average number of employees during the year was 20 (2023: 18) with all employee time involved in providing either support to the governance of the charity or support services to charitable activities.

The senior management team consist of the Chief Executive and the heads of Finance, Fundraising, Research and Services. The total employee benefits of the senior management team were £294,585 (2023: £339,870).

The following number of staff members received emoluments in the year:

	<b>2024</b>	<b>2023</b>
£80,000 - £90,000	1	1

Ataxia UK operates a defined contribution pension scheme and the amounts above represent the charity's total contribution for the year.

**Note 11 : Pension Schemes**

All permanent members of staff were eligible to receive payment of 5% of their salary paid into a stakeholder personal plan. The pension premiums payable during the year were £38,317 (2023: £35,637). There was a outstanding balance of £5,090 (2023: £0) at the year end.

**Note 12 : Trustees**

Certain trustees carry out duties that would otherwise be undertaken by paid staff. They receive no remuneration but, along with the other trustees, may claim reimbursement of out of pocket expenses. During the year, total trustee expenses £203 for attending the board meetings were incurred. 1 trustee (2023: 0) reimbursed expenses totalling £81 (2023: £0).

**Note 13 : Net (expenditure)/income is stated after charging:**

	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
Auditor's remuneration and account preparation excluding VAT	<b>7,500</b>	6,660
Depreciation	<b>10,890</b>	9,873
Operating lease costs	<b>1,000</b>	1,000

**ATAXIA UK**  
**NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2024 CONTINUED**

**Note 14 : Tangible Fixed Assets**

	<b>Building Works</b>	<b>Other Assets</b>	<b>Total</b>
	<b>£</b>	<b>£</b>	<b>£</b>
<b>COST</b>			
As at 1st April 2023	5,333	44,284	<b>49,617</b>
Additions	-	8,251	<b>8,251</b>
Disposals	-	-	-
As at 31 March 2024	<u>5,333</u>	<u>52,535</u>	<u><b>57,868</b></u>
<b>DEPRECIATION</b>			
As at 1st April 2023	4,948	28,307	<b>33,255</b>
Charge for year	243	10,647	<b>10,890</b>
Disposals	-	-	-
As at 31 March 2024	<u>5,191</u>	<u>38,954</u>	<u><b>44,145</b></u>
<b>NET BOOK VALUE</b>			
As at 31 March 2024	<u><b>142</b></u>	<u><b>13,581</b></u>	<u><b>13,723</b></u>
As at 1st April 2023	<u>385</u>	<u>15,977</u>	<u>16,362</u>

Included within the net book value of the 'Other Assets' is an amount of £1,000 (£2,000 in 2023) relating to items acquired on Finance Lease/Hire purchase.

**Note 15 : Debtors Under 1 Year**

	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
Income tax recoverable	<b>51,464</b>	127,305
Other debtors	<b>268,633</b>	209,858
Prepayments	<b>38,423</b>	27,878
	<u><b>358,520</b></u>	<u>365,041</u>

**Note 16 : Cash at bank and in hand**

The Trustees maintain a policy that all cash balances are held with reputable financial institutions. Interest receivable is disclosed in note 6.

**Note 17 : Creditors: amounts falling due within one year**

	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
Other creditors	<b>11,361</b>	8,939
PAYE/NI	<b>60,775</b>	-
Deferred income	<b>85,886</b>	28,732
Accruals	<b>30,043</b>	25,188
Research grants	<b>935,597</b>	903,709
	<u><b>1,123,662</b></u>	<u>966,568</u>

**ATAXIA UK**  
**NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2024 CONTINUED**

**Note 18 : Creditors: Amounts falling due after one year**

	2024 £	2023 £
Research grants	596,330	963,756
Misc creditors	-	1,000
	<b>596,330</b>	<b>964,756</b>

**Note 19 : Analysis of net assets between funds**

	Restricted Funds £	Designated Funds £	General Funds £	Total 2024 £	Total 2023 £
Fixed assets	469	-	13,254	<b>13,723</b>	16,362
Debtors	-	-	358,520	<b>358,520</b>	365,041
Cash at bank and in hand	1,515,784	78,727	280,854	<b>1,875,365</b>	1,589,232
Creditors	(1,531,927)	-	(188,065)	<b>(1,719,992)</b>	(1,931,324)
	<b>(15,674)</b>	<b>78,727</b>	<b>464,563</b>	<b>527,616</b>	<b>39,311</b>

**Note 20 : Unrestricted Funds**

	General Funds £	Designated Funds £	Total £
Balance as at 1 April 2023	383,508	342,689	<b>726,197</b>
Net increase/(decrease) in funds during the year	(183,945)	1,038	<b>(182,907)</b>
Transfers	265,000	(265,000)	-
Balance as at 31 March 2024	<b>464,563</b>	<b>78,727</b>	<b>543,290</b>

**Note 21 : Designated Funds**

	Opening Balance £	Net Movement £	Transfers £	Closing Balance £
Funds held in branches	7,689	1,038	-	<b>8,727</b>
Premises Fund	50,000	-	(50,000)	-
Parental	50,000	-	(10,000)	<b>40,000</b>
Restructuring	30,000	-	(30,000)	-
Service development	150,000	-	(150,000)	-
Conference subsidy	5,000	-	(5,000)	-
Staff training	20,000	-	(20,000)	-
Research conference fund	30,000	-	-	<b>30,000</b>
	<b>342,689</b>	<b>1,038</b>	<b>(265,000)</b>	<b>78,727</b>

**a) Funds held in branches:** Funds held by the branches and not available for normal activities of central office.

**b) Parental:** Funds being held to cover potential periods of maternity leave.

**c) Research conference fund:** Funds being held to cover costs, if required, of ICAR conference in November 2024.

**ATAXIA UK**  
**NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2024 CONTINUED**

**Note 22 : Restricted Funds**

	At 1 April 2023	Income	Expenditure	Transfers	At 31 March 2024
	£	£	£	£	£
General Research	139,219	230,341	66,045	-	303,515
Friedreich's ataxia research	23,457	14,540	59,129	32,973	11,841
Cerebellar ataxia research	-	2,094	10,424	9,421	1,091
Young Person's projects	7,959	-	-	-	7,959
Jerry Farr travel fund	671	-	-	-	671
Welfare	1,069	12,389	9,238	(4,220)	-
Welfare - The Gift of Speech	18,372	-	9,695	-	8,677
Nicotinomide	24	-	-	-	24
Services roadshows	-	-	872	872	-
Helpline	62,862	14,351	77,862	4,801	4,152
Misc Grants	450	-	-	-	450
Childlife	-	100,000	57,606	(42,394)	-
Exeter	582	-	-	(582)	-
Awareness	4,171	-	-	-	4,171
Kennedy Award	9,198	-	-	-	9,198
Research Stem Cell FA	78	-	-	-	78
Mark Dower Trust	1,723	-	1,499	-	224
Spinocerebellar Ataxia Research Project	4,912	-	-	-	4,912
DRPLA Research	(1,047,450)	513,479	(55,390)	-	(478,581)
Lottery Project (previously Ataxia Centres)	51,039	121,652	100,779	-	71,912
DRPLA Department	12,128	161,425	157,677	-	15,876
Scotland	800	-	-	-	800
NXK6-2	(38,746)	23,391	8,036	-	(23,391)
AOA2	3,811	3,997	799	-	7,009
Prospax Project	(440)	4,611	4,611	-	(440)
Research Service Contracts	-	12,902	12,902	-	-
Research SCA6	500	73	-	-	573
Research SCA3	-	77	15	-	62
Research ICAR 2024 Conference	49,220	-	21,655	-	27,565
Misc AAA++	7,505	-	1,527	-	5,978
	<b>(686,886)</b>	<b>1,215,322</b>	<b>544,981</b>	<b>871</b>	<b>(15,674)</b>

**Purpose of restricted funds**

- a) General Research:** Funds provided for general research into ataxia.
- b) Friedreich's ataxia research:** Funds provided by donors specifically for research on Friedreich's ataxia.
- c) Cerebellar ataxia research:** Funds provided by donors specifically for research on cerebellar ataxia.
- d) Young Person's projects:** Funds provided by donors to develop materials to help young people after diagnosis.
- e) Jerry Farr travel fund:** Funds given by friends of Jerry Farr to help young people after diagnosis.
- f) Welfare:** Funds provided for welfare grants.
- g) Welfare - The Gift of Speech:** Funds provided for speech therapy grants and voicebanking.
- h) Nicotinomide ataxia research:** Funds provided by donors specifically for research on Nicotinomide.
- i) Goods and Services Received:** Goods and Services received free of charge in respect of Google ads.
- j) Helpline:** Funds to support the helpline.
- k) Miscellaneous Grants:** Funds provided for general grants.
- l) Childlife:** Funds given by Childlife to promote the relief of children who are in need. The auditors have agreed that the income received from Childlife has been spent in accordance with the terms of and conditions of the grant.



**Purpose of restricted funds (continued)**

**m) Exeter:** Funds to be expended in the Exeter area.

**n) Awareness:** Funds provided to raise awareness of Ataxia.

**o) Kennedy Award:** A fund set up to assist researchers studying Friedreich's ataxia with attending scientific conferences and other small research studies.

**p) Research Stem Cell FA:** Spinocerebellar Ataxia Research Project: Funds for spinocerebellar ataxia research project.

**q) Mark Dower Trust:** A fund set up to support young people in their quest for independent living through enabling them to develop skills, hobbies or interests.

**r) Spinocerebellar Ataxia Research Project:** Funds for spinocerebellar ataxia research project.

**s) DRPLA Research:** Funds provided by donors specifically for research on Dentatorubral-pallidoluysian atrophy. See note 1 below.

**t) In Control Project:** Funds provided by the Lottery to promote volunteers and provide support to the ataxian community.

**u) Ataxia Centres:** Funds to assist with the set-up of additional ataxia centres/virtual centre.

**v) DRPLA Department:** Funds provided by donors specifically for staff to support DRPLA research.

**w) Scotland:** Funds to be expended in Scotland.

**x) NKX6-2:** Funds provided by donors specifically for research into NKX6-2. See note 2 below.

**y) AOA2:** Funds provided by donors specifically for research into ataxia with oculomotor apraxia type 2.

**z) Prospax Project:** Funds provided by donors specifically for research into spastic ataxias.

**aa) Research Service Contracts:** Funds provided for projects undertaken by the research department.

**ab) SCA6:** Funds provided by donors specifically for research into Spinocerebellar ataxia type 6.

**ac) SCA3:** Funds provided by donors specifically for research into Spinocerebellar ataxia type 3.

**ad) ICAR 2024 Conference:** Funds provided towards costs of International Congress for Ataxia Research 2024 being held in London, UK.

**ae) Misc AAA++:** Funds provided by donors specifically for expansion of the All About Ataxia offerings.

Note i: DRPLA research grants of £1.8m were issued during the 2020/21 financial year with income being received of £0.8m. Two of the research grants are being funded over three years leaving a deficit of £1m which equates to the year 2 & year 3 payments. Both projects have had a delayed start which has resulted in year 2 & year 3 payments being delayed. Ataxia has signed agreements in place outlining the payment structure ensuring these future commitments will be met.

During the 2023-4 financial year income of £513k was received and the grants awarded reduced by net £53k because of a reduction in the scope of work. It is anticipated that the project will be completed by March 25.

Note ii: Two NKX6-2 research grants of £105k were issued during the 2020/21 financial year with income being received of £58k. One grant was fully funded, and the second grant will be funded over three years. The £58k deficit equates to year 2 and year 3 funding which is being held in an escrow account. The project has had a delayed start which has resulted in year 2 & year 3 payments being delayed. Ataxia has a signed agreement in place outlining the payment structure ensuring these future commitments will be met.

During the 2023-4 year income was received of £23k and £8k of grants awarded by the charity. It is anticipated that this project will complete during the 2024-5 year.

**ATAXIA UK**  
**NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2024 CONTINUED**

**Note 23 : Capital Commitments**

There are no capital commitments at 31 March 2024 (2023: Nil)

**Note 24 : Lease Commitments**

**At 31 March 2024 the charity had future minimum lease payments under non-cancellable operating leases as follows:**

	2024		2023	
	Land & buildings £	Other £	Land & buildings £	Other £
Payments due:				
Within one year	-	1,608	37,168	1,608
Within two to five years	-	-	-	1,608
	<b>-</b>	<b>1,608</b>	<b>37,168</b>	<b>3,216</b>

**Note 25 : Associated Organisations**

The charity is a member of a consortium, with three other charities, called Childlife, through which the member charities are able to collectively raise funds for their respective causes through the operation of combined payroll deduction scheme and donor development.

Childlife is a company limited by guarantee and registered in England and Wales - number 3696656 - and a registered charity - number 1080536. Each of the members of Childlife provide a guarantee limited to £1.