2022 - 2023
Annual Report & Financial Statement

For the Year: 1st April 2022 – 31st March 2023

Ataxia UK, 12 Broadbent Close
London, N6 5JW

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

The year concluded with the approval by the FDA (in the USA) of Skyclarys, the first drug licensed for the treatment of Friedreich's ataxia. It was the very best news for the ataxia community and Ataxia UK. However, the celebrations in the UK cannot yet be wholehearted as we've yet to see an application for approval in the UK. Hopefully this is only a matter of time. Moreover, the pace of ataxia research is speeding up with a number of trials underway or pending, in various ataxias so we hope there may be other good news to report in the coming year. We know it's hard to be patient when it feels treatments are around the corner, but we hope that patience will be rewarded before too long. In the meanwhile Ataxia UK will do everything it can to support the approval of Skyclarys and any other prospective treatments for the ataxias.

In November, we were delighted to see the strides being made in research which were showcased at the International Congress for Ataxia Research in Dallas on which we were delighted to collaborate with the US National Ataxia Foundation and FARA. The conference had the greatest attendance ever, of any scientific conference exclusively devoted to the study of the ataxias which shows the increasing interest in this research area.
Ataxia UK's services have continued to develop and improve. In particular, Helpline and Advocacy benefitted from increased focus and the welcome support of a number of volunteers. At this time of financial crisis, it's imperative that we do all we can to support the community to deal with the financial and practical challenges which arise from an ataxia diagnosis. We are optimistic that we will see our work complimented by an Ataxia UK Specialist Ataxia Nurse during the coming year.

We regretfully cancelled our in-person conference in October 2022, but are excited to be holding our first face-to-face conference since 2019 on 20th/21st October at the Radisson Blu East Midlands. We appreciate that whilst many are looking forward to meeting others, some people are unable to travel and value the virtual encounters we are able to provide. As such, we are committed to maintaining our online services and will be providing a virtual version of conference for those who are unable to attend.

Our work is only possible with the generous support of the ataxia community which provides us with committed volunteers who help in the running of the charity – fulfilling roles as Board members and supporting our service delivery. The consistent financial support provided through the fundraising of our supporters, even at this difficult time, is always impressive. 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 2021-2022 were:

Honorary Officers

William Littleboy, Chair (Elected as Chair 6 October 2019)
Kathy Jones Honorary Treasurer

Trustees

Angela Hosie

Carol McCudden

Gemma Fish

Philip Griffiths
(Retired Oct 2022)

Rachel Harrison

Robert Perkins

Harriet Brown
(Joined Oct 22)

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

HR Services Partnership
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. An Executive Committee, compromising the Honorary Officers, the Trustee Scientific Advisor and one other trustee (one of whom must have ataxia), conducts business as required between meetings of the full Board of Trustees. The trustees include people with ataxia, friends/family of people with ataxia and others with relevant experience and expertise.

The Annual General Meeting of the charity took place on Friday 23rd September 2022.

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 Ataxia UK is considered annually by a Remuneration Committee, comprising the Chair, Treasurer and one other committee member, and meets during the budget setting process to review salary grading levels, London weighting, increment 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.

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 these 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 and promote research activities, 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 2022 Annual National Conference was held virtually.

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.

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-Abarrategui, 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 Bonney and Nathan Hall.

During this year Dr Claire Kelly, Dr Marija Sajic and lay member Alick Varma stood down from the committee and we are extremely grateful for their service on this committee. 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). IT support and HR advice functions are outsourced.

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*. Our InControl Project has continued to recruit more 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 InControl Steering Group.

During the year five trained volunteers supported the Helpline staff 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; in 2022-23 the register remained significantly influenced by the impact of the Covid-19 pandemic and was also affected by the prospect of an economic recession.

At the end of the year the most significant risks and their mitigation were:

Risk	**Mitigation/result**
Failure to recruit/retain competent staff	Ensure terms & conditions and financial remuneration are the best that we can afford. Where possible employ a paid Intern and give commitment to making post permanent if necessary standard reached
Long term risk of running reserves lower than Reserve Policy	Implement High Net Worth and Pharmaceuticals elements of the Fundraising Strategy
Absence of sufficient funds to implement research strategy in full.	Implement High Net Worth and Pharmaceuticals elements of the Fundraising Strategy
Failure to win National Lottery Community Fund bid	This was obtained in June 2023.
Procedural and systems documentation gaps/failure	Review policies and procedures.

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.

The trustees are clear that ataxia does not just affect the person with the disorder, but also his/her carer, and other members of the family. Ataxia UK regards all three groups as affected by ataxia and aims to help them all. Whilst the long-term vision is to find a cure for ataxia, trustees recognise that those affected by ataxia need a variety of support right now, and this informs our activities.

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 that 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 to. An understanding of the condition in the NHS, where diagnosis and treatment are often delayed, but also in the social care sector, where an understanding of the condition could significantly improve the situation for 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 4th 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.

Research

Research aims for 2022-2023

- Host the International Congress of Ataxia research in Dallas, USA

- Promote further involvement of people affected by ataxia in research process and activities

- Oversee recruitment and protocol compliance of the DRPLA Natural History and Biomarkers Study.

- Continue building the DRPLA research programme and disseminate the CureDRPLA Global Patient Registry

Host the International Congress of Ataxia Research (ICAR) in Dallas, USA

ICAR 2022 took place in November 2022 and was jointly organised by three ataxia charities: Ataxia UK, National Ataxia Foundation and Friedreich's ataxia Research Alliance. It was a very successful event with 420 delegates, an increase from the last research conference we held in 2019. Feedback was very positive with overall conference rating of 4.5 out of 5 stars. In addition, 92% of respondents to the feedback survey thought the conference was extremely useful of very useful for advancing their work and the Panel discussion with people with ataxia was very well rated, highlighting the recognition of the involvement of people with ataxia in all aspects of our work.

There was a strong focus on engagement of early career researchers, with bursaries provided and a programme of activities including mentoring and career discussions. To encourage participation from the UK Ataxia UK also provided nine travel bursaries from different research groups in the UK.

A very high representation from pharma companies and high levels of sponsorships also demonstrated the importance of such events to these stakeholders.

There was an extensive programme of research talks and poster sessions to maximise the exposure of many aspects of ataxia research. We also had an Ataxia UK stall with leaflets about us aimed at researchers and industry, plus forms or QR codes to encourage signing up to our registries. Dr Silvia Prades (Research Manager at Ataxia UK) presented a poster on the DRPLA patient registry and Ataxia UK staff were also named on five other posters of talks, included one Ataxia UK produced on the results of the Covid survey. Ataxia UK representatives were proactive in networking with delegates and various follow-up actions arose from this event to take research forwards.

After ICAR at the same venue the annual conference of Ataxia Global Initiative took place. This maximised the opportunities for researchers to attend both events. This event was an opportunity to focus on clinical research and talks focused on ‘trial readiness’.

Promote further involvement of people affected by ataxia in research processes and activities

Ataxia UK has been working on producing a new Research Strategy (last update was in 2018) which will be published shortly. Input from people with ataxia has been an integral part of the review process, together with the involvement of Ataxia UK’s Scientific Advisory Committee. Patient engagement in research continues to play an ever-increasing role in all aspects of Ataxia UK’s work.

A Special Interest Group on Friedreich’s ataxia was created during the year to specifically support Ataxia UK in working towards getting access in the UK to the first drug that gained approval in FA adults in the US in February 2023. This group includes people with direct experience of FA (having the condition or being parents of people with FA). See further information below.

Ataxia UK has supported a number of pharma companies gain experience and understanding of the impact of ataxia from families via interviews, surveys and patient panels. Incorporating experience of people with ataxia is an integral part of the drug development and approval process and as more companies are reaching later stages of development there is a greater need for Ataxia UK's involvement in facilitating this process. It is important to share this information and we are pleased some of this data was presented at the International Congress for Ataxia Research in 2022 and other studies are being prepared for publication.

Continue building the DRPLA research programme and disseminate the CureDRPLA Global Patient Registry

Ataxia UK has been collaborating with CureDRPLA, a US foundation, since 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.

The CureDRPLA Global Patient Registry is an online questionnaire to collect health information from individuals with DRPLA that was launched in 2021. Following promotion activities this Registry now has 38 participants from eight different countries. Initial key findings from the patient registry were presented by the DRPLA Manager at the International Congress of Ataxia Research (ICAR) in November 2022. During the year we have been engaging pharmaceutical companies to pursue DRPLA research and this conference was a great opportunity to meet with some of those companies and foster new collaborations.

We continue with outreach activities via social media channels to keep the DRPLA community engaged and we organised a meet up for families affected by DRPLA who are based in Wales. Even though all of the families live nearby, they had not met before – this was probably the largest in-person gathering of DRPLA families to date.

In May CureDRPLA hosted the first-ever conference on DRPLA research in Boston (USA). We had over 30 attendees, including scientists, medical professionals and representatives from pharmaceutical companies. This conference created a strong sense of community and it was very helpful to share knowledge across different projects and explore therapeutic options for DRPLA. We are currently planning to host another conference in the autumn of 2023.

Oversee recruitment and protocol compliance of the DRPLA Natural History and Biomarkers Study

Ataxia UK and CureDRPLA are coordinating the DRPLA Natural History and Biomarkers Study. This is a global study with sites in the UK and the USA, which are currently recruiting participants.

Due to the high prevalence of DRPLA in Japan there are plans to open study sites in Japan and we have partnered with a Japanese academic organisation (TRI) to facilitate study start-up in Japan. We have supported all the sites in getting ethical approval to conduct this study, have disseminated the information broadly to facilitate the recruitment of participants and hold bimonthly meetings to ensure the project runs smoothly.

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 Andreia Teixeira-Castro** *(University of Minho, Portugal)* ‘Testing the multimodal anti-depressant vortioxetine as a therapeutic strategy to mitigate SCA3’ – *£30,000*.

2. **Dr Karen Anthony** *(University of Northampton, UK)* ‘Evaluation of RNA trans-splicing as a therapeutic strategy for spinocerebellar ataxia type 1’ – *£30,901*.

3. **Dr Francesca Salvatori** *(University of Ferrara, Italy)* ‘Personalised gene editing approach for the treatment of Spinocerebellar Ataxia Type 1 (SCA1)’ – *£5,000*.

4. **Prof Marios Hadjivassiliou** *(Sheffield Teaching Hospitals NHS Trust, UK)* ‘Improving the diagnosis and management of gluten ataxia’ - £157,158 (co-funded with Coeliac UK, the Sheffield Hospital Charity and the Greaves and Withey Foundation). Ataxia UK’s contribution is *£38,000*.

5. **Dr Roderick Maas** *(Radboud University Medical Center, The Netherlands)* ‘Looking beyond the central nervous system in SCA3: nerve and muscle ultrasound as potential imaging markers to quantify and monitor peripheral nervous system degeneration’ – *£29,980.54*.

DRPLA Grants (in partnership with CureDRPLA)

1. **Prof Paola Giunti** *(University College London, UK)* ‘Determine mitochondrial metabolism in DRPLA: a possible novel therapeutic approach’ – *£25,000*.

2. **Prof Paola Giunti** (*University College London, UK)* ‘Validating the therapeutic effect of VO659, a CAG repeat-targeting antisense oligonucleotide, on mitochondrial physiology in cellular models of DRPLA’ – £26,934.55.

Travel awards and sponsorships

1. Ataxia UK provided a travel award of *£1,500* to **Dr Pellerin** (UCL) to attend the American Academy of Neurology Annual meeting in March and give an oral presentation on ataxia research.

2. Ataxia UK provided a sponsorship of *£433* towards the **CAG triplet** disease disorders meeting at the Gordon Research Conference.

3. As part of the International **Congress for Ataxia Research** Ataxia UK also provided nine bursaries of *£750* each to UK researchers to help them attend the event and encourage participation from the UK.

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 £5.19 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 **43 new research tools**.

Medical Research Charities Covid Support Fund

For the second 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 *£178,794* 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.

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. We have also provided introductions to ataxia experts in a range of areas, promoted trials in the UK, and 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.

On 28th February 2023, the company Reata pharmaceuticals announced the exciting news that Omaveloxolone (now known as SKYCLARYS) was approved for the treatment of Friedreich's ataxia (FA) in over 16s in the United States. As the first drug approved to treat FA, this is a huge step for the entire community. However, it is now a priority for Ataxia UK that people with FA in the UK get access to the drug. We are doing everything we can to support and encourage Reata Pharmaceuticals to seek approval for SKYCLARYS in the UK. To drive forward the approval process in the UK, we have set up an FA Special Interest Group, which includes clinical experts, Ataxia UK staff, and parents of children with FA. The group is meeting regularly and developing an action plan. This work will continue in 2023-24. 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.

Pharma Strategy Advisory Committee

The Pharma Strategy Advisory Committee met in December 2022 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. The Committee also advised us on showcasing our work on patient engagement.

During the year Ataxia UK's Head of Research co-authored a paper with other medical research charities, all members of the Pistoia Alliance, that was published in the journal 'Pharmaceutical medicine'. This was an opportunity to highlight Ataxia UK and the work we do with pharmaceutical companies, emphasising the important role research-active patient groups play.

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. Not all applications have been successful but during the year one new project did get funding and Ataxia UK's Head of research is one of the Euro-ataxia representatives.

Newly funded project

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

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 form 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 two members of the Ataxia UK research team Dr Julie Greenfield and Dr Ruby Wallis representing Euro-ataxia. Ruby also participated and presented at the annual meeting of this project, held in Berlin. An active Patient Organisation Group is leading a Work package to create Patient Reported Outcome Measures, by creating surveys and distributing among the patient groups, to be used in this study and for future trials.

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. Ataxia UK Research Manager, Dr Emily Cutting, is a Euro-ataxia representative on this project. There have been a number of research dissemination activities and plans to organise a webinar. We are also working on gaining an understanding of people's understanding and expectations from gene therapies for the ataxias.

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. The investigators of both FACOMS and EFACTS see the need to combine efforts into a single global consortium with a unified natural history and clinical research infrastructure. The 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 Research Manager Dr Emily Cutting 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, as well as taking part in a session on career development. A face-to-face meeting is planned during the year to support patient organisations in building capacity and Ataxia UK will be actively involved in this activity.

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. A paper has been published in the medical journal *Cerebellum* explaining about AGI, and other consensus papers will follow with guidance and recommendations on data collection in the ataxias in a range of topics covered by the working groups (clinical assessments, brain scanning, biofluid sample collection, digital biomarkers).

A successful annual conference took place in November 2022, alongside the International Congress for Ataxia research (ICAR 2022). A number of other important initiatives have taken place. For example, the AGI program aims to develop a generally accepted ataxia rating scale that can be used in upcoming clinical trials and to this end a first AGI Consensus Conference took place in Bonn in January; Julie Greenfield attended as a patient representative.
AGI membership (academics and representatives from patient groups and pharma) has reached over 250 and there are 20 partner organisations.
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.

One mutation one medicine (1M1M) project

1M1M is a project set up by researchers in Germany and the Netherlands to develop antisense oligonucleotides as treatments for very rare genetic neurological conditions, where there may be only one or very few individuals worldwide with a particular gene mutation.

At the moment, the only ataxias being considered are Ataxia telangiectasia and Ataxia UK's Head of Research, Julie Greenfield was invited to be part of the Treatment Advisory Board, as part of the collaborative work with the AT Society.

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. Changes have been made to the Scientific Advisory Board following advice from the AMRC in the charity audit exercise. In addition, a new Biomarkers in AT Working Group was established to progress this area of research.

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 the 7 research projects and an additional 9 surveys/interview-based studies.

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 2023 - 2024

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

Care and Support Services for People Affected by Ataxia

Care and support aims for 2022-23

- Establish the Ataxia UK Helpline as the go-to place for people affected by ataxia in all aspects of their lives

- The Advocacy service will impact positively on the lives of people affected by ataxia by supporting access to rights and services

- Increase engagement with the ataxia community by enhancing service and information provision

- Secure funding to ensure the continuation of InControl, Information, Helpline and Advocacy Services

- Use the All About Ataxia model to bring the ataxia community together and provide information on other issues faced by people affected by the condition.

In May 2022, Ataxia UK welcomed a new specialist Helpline & Advocacy Officer to support both the Helpline Team and the wider ataxia community. As a result, we have observed a rise in contacts across all support topics, indicating the valuable contribution of this role. To ensure the sustainability of our services provision, we have submitted applications for grant funding, including to the National Lottery Community Fund. These efforts are aimed at securing the necessary resources to continue offering essential support to those affected by ataxia in the future.

Work is under way on developing the All About Ataxia+ series and we continue to work with the ataxia community on developing, delivering and monitoring services.

The Services Team

The InControl project, funded by the National Lottery Community Fund, which commenced in October 2019, reached its conclusion in October 2022. As a result of this project, the staff working on InControl have now been integrated with the Helpline and Advocacy Service to form the Ataxia UK Services Team. The team and our dedicated volunteers provide information, advice and support to those affected by ataxia.

The Services Subgroup

The Services Subgroup to the board meets 4-5 times per year and provides strategic and critical oversight of services activity. The group is chaired by a person with ataxia and comprises Ataxia UK staff, the Chief Executive, Head of Services and Advocacy & Community Services Officer and 4 other representatives from the ataxia community.

Virtual Activities (not including Conference)

We hosted a diverse range of 54 virtual activities, which have been attended by more than 540 participants. Activities include monthly wellbeing sessions, Occupational Therapy activities, Wellbeing Week, Volunteers Week, and various information sessions. We have continued to develop activities in a virtual format, ensuring that individuals affected by ataxia can continue to access important 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 aim to give 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. Hosted quarterly we have delivered All About Ataxia to 70 people.

All About Ataxia+

We are working on the development of our latest initiative, All About Ataxia+. Our objective is to deliver a series of seminars that focus on addressing specific issues faced by individuals in the ataxia community. The seminars will be structured in a similar format to our highly successful All About Ataxia series, which features informative videos and facilitated discussion groups.

We are excited to be taking this new initiative forward and anticipate that it will provide valuable insights and support to those impacted by ataxia. This program will be an essential resource for individuals seeking to deepen their understanding of the challenges associated with ataxia and to gain practical strategies for enhancing their quality of life.

Branch and Support Groups

We have a network of 44 branches and support groups across the UK, which are established and operated by our dedicated volunteers. These groups provide essential support and information for people affected by ataxia, and serve as a place for members to connect, have fun, and share experiences.

We have been delighted to welcome new groups to our network, including our Virtual Support Group, which has proven to be a valuable addition. Our groups have held more than 118 meetings, which have been attended by at least 792 individuals. Our network of branches and support groups plays a critical role in supporting and empowering the ataxia community.

Volunteering

We welcomed 8 new volunteers to the team In recognition of their invaluable contributions, we celebrated our volunteers during Volunteers Week in June. As part of the celebrations, we organized various activities and sent handwritten thank-you cards to our volunteers to express our gratitude for their dedication and hard work.

During the summer months, Genetic Alliance hosted two volunteer focus groups, aimed at learning from our volunteers about their experiences of volunteering with Ataxia UK. The insights gained from these focus groups, combined with feedback from our 2022 wellbeing survey, will be used to develop strategies to better engage volunteers from the ataxia community going forward.

We recognize the tremendous impact that our volunteers have on the ataxia community. We are grateful for their time, expertise, and unwavering commitment to supporting those affected by ataxia.

Wellbeing Survey

We launched our 2022 Wellbeing Survey, aimed at assessing the impact of COVID-19, volunteering, and Ataxia UK services on the ataxia community. We are pleased to report that we received an **impressive response, with more than 300 individuals participating** in the survey. This feedback will be instrumental in shaping our future strategies and ensuring that we continue to provide relevant and effective support to those affected by ataxia.

Ataxia Connect

We rebranded and relaunched Ataxia Connect, our befriending service aimed at reducing feelings of loneliness and isolation among individuals in the ataxia community. Ataxia Connect matches people with lived experience of ataxia with others who are seeking a listening ear and understanding of the condition. We are proud to report that the service has worked with 17 dedicated volunteers and 20 service users throughout the year. The impact of the service has been profound, helping to foster meaningful connections and enhance the wellbeing of those affected by ataxia.

Diverse Placements

Ataxia UK hosted two diverse placements for four MSc Occupational Therapy students from the University of Brighton. Throughout their placement, the students had the opportunity to gain valuable insights into ataxia and the ataxia community, which will undoubtedly prove beneficial as they prepare to graduate in 2023. They received support from a consultant Occupational Therapist, who is a member of the Ataxia UK board of trustees and has ataxia themselves.

During their placement, the students participated in a wide range of activities. They provided information to the ataxia community about Occupational Therapy and its potential to assist individuals with ataxia in carrying out the activities they want and need to do. They also organised therapeutic sessions focused on art therapy, mindfulness, and movement, as well as 1-2-1 Occupational Therapy, all delivered remotely. Through these placements, we are committed to promoting the importance of Occupational Therapy in the management of ataxia, as well as supporting the development of future professionals in this field.

Scottish Advice Service

We are pleased to announce that Ataxia UK has collaborated with Parkhead CAB in Glasgow on a two-year project aimed at offering specialised advice to the ataxia community in Scotland. This initiative has been made possible through funding from CAB in Scotland and Hugh Fraser. In February of this year, Parkhead recruited a Rare Conditions Adviser who will be responsible for spearheading this project. The adviser will work closely with the Ataxia UK Services Team and the ataxia community itself. The project is set to commence in April 2023, and we look forward to seeing the positive impact it will have on the ataxia community in Scotland.

Helpline & Advocacy Service

Helpline

Our Helpline received a total of 1,258 contacts from individuals seeking support and guidance. These contacts pertained to a diverse range of issues, with at least **950 individuals benefitting** from the assistance provided.

In total, **1,557 issues were addressed**, including but not limited to, welfare benefits, social care, housing, and aids and adaptations. Through the Helpline, we remain committed to offering vital support to those affected by ataxia, as well as their families and carers.

Issue type	Number of people supported
Health inc. referral, diagnosis & access to services	**431**
Access to Ataxia UK services	**404**
Support & information	**237**
Welfare benefits, grants & finances	**175**
Social care inc. housing, aids & adaptations	**110**
Research & fundraising	**63**
Education & employment	**27**
Insurance & travel	**23**
Not recorded	**70**

Advocacy Service

Our Advocacy Officer provided 1-2-1 advocacy support to 51 people on a range of topics including those mentioned above and we have supported the ataxia community to secure *£31,307* in grants and unclaimed benefits.

Membership

We welcomed 575 new Friends of Ataxia UK in 2022 - 2023.

Care & Support Aims for 2023 – 2024

- 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.
- Continue to provide opportunities for volunteering and engagement to the ataxia community.
- Enhance provision for carers in the ataxia community by providing virtual activities specifically addressing the needs of carers and supporting the development of carers support group/s.
- Develop All About Ataxia+ to deliver a range of seminars using the All About Ataxia model.

Improvements in Treatments & Care

Treatment & Care aims for 2022 – 2023

- Publish Ataxia Medical Guidelines
- Launch Paediatric Ataxia Centre in London
- Accredit further Ataxia Centres
- Launch 'The Gift of Speech' project –online speech therapy courses and Voice Banking
- Develop an Ataxia Specialist Nurse Project

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, we anticipate that the publication of the new Guidelines will take place before the end of the coming year.

Launch a Paediatric Ataxia Centre in London

An Ataxia UK accredited paediatric ataxia clinic has been launched at the London Ataxia Centre. The Paediatric Ataxia Clinic brings a new service to the 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 (who also leads the Adult Ataxia Centre), 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 and accepts referals for children aged 8-18. Ataxia UK has provided part-funding for the Ataxia Specialist nurse to support the Clinic.

Accredit further Ataxia Centres

During the year Ataxia UK accredited a Specialist Ataxia Centre in Oxford, at the John Radcliffe Hospital. All Ataxia UK-accredited Specialist Ataxia Centres are centres of excellence, where people with ataxia receive the best quality of care from ataxia experts. The Oxford Ataxia Centre offers a specialised service for adults and children with ataxia and has two adult neurologists (Dr Tofaris and Dr Rinaldi), a clinical geneticist (Prof Nemeth) and a paediatric neurologist (Dr Smith).

There are now three Ataxia UK accredited Ataxia Centres in the UK supporting adults and children with ataxia. These are based in London, Sheffield and Oxford.

Launch 'The Gift of Speech' project – online speech therapy courses and Voicebanking

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.

35 Friends of Ataxia UK have undertaken the course and there are a further 41 people on the waiting list.

We are proud to report that 62% of participants experienced improved communication as a result of the course, with over half (54%) doing more talking and feeling more confident speaking to people outside of their immediate social circle. Additionally, speech therapy course alumni have formed a group which meets monthly.

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 June 2022 we have funded 10 people with ataxia to download their personalised voice. In addition to this, 81 people with Ataxia have registered with SpeakUnique and of those 37 people have completed the voice banking process and created a voice.

Develop an Ataxia Specialist Nurse Project

Regrettably, our funding application to the Scottish National Lottery for the launch of our Specialist Nurse pilot in Scotland was unsuccessful. However, we have submitted an application to the English National Lottery Community Fund for a project that includes the introduction of a peripatetic specialist nurse service in the Southwest region.

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.

Other Activities Supporting Improvements in Treatments & Care

Clinical Care Pathways in England published

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. When Ataxia UK was notified that a pathway was going to be created for people with movement disorders in England, we successfully lobbied for a pathway specifically for people with ataxia to be included.

The Ataxia Health Care Pathway, developed by ataxia specialists and Ataxia UK, shows the ideal route to care within the NHS 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 (NNAG).

Medical Advisory Panel meetings

Ataxia UK's Medical Advisory Panel met twice during the year (May 2022 and January 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.
In January a discussion was held about the potential approval of the first drug for FA, Reata pharmaceuticals' drug omaveloxolone. It was agreed the Committee would meet again after the decision from the FDA and this meeting is scheduled. Ataxia UK has in the meantime been consulting with Ataxia UK Medical Advisors who joined the FA Special Interest Group (see above).

The creation of a new service provided by Ataxia UK was discussed called 'Virtual Grand rounds'. This would involve clinicians presenting difficult ataxia cases for advice from a group of ataxia experts. Advice could be sought on both diagnosis and management issues. This service was suggested by a member of the Committee, and it was agreed this could be a valuable new service to improve the care of people with ataxia in the UK. Planning is underway and we are aiming to pilot this in the coming year. Another topic of discussion was a concern around payments of the costs involved in brain donations. Ataxia UK will investigate this further.

Value of treatment project evaluating 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 run by the Prof Giunti at the London Ataxia Centre and it has involved surveying people with ataxia in the UK, Germany and Italy assessing the value of Ataxia Centres. The results of this project highlight the value of coordinated care and specialist centres to address the challenges for people living with ataxia.

Based on these results, the ataxia case study working group together with the European Brain Council made a number of recommendations designed to increase access to, and raise awareness of, Specialist Ataxia Centres, as well as improving education on management of the ataxias amongst primary care settings. Three papers have been written with the results of this project and these have submitted to medical journals.

The first paper focuses on the differences to the care that people with ataxia may receive in the different settings, the second focuses on the differences in costs and the third is a paper focusing on recommended patient pathways for Europe. In addition, results were presented at the International Congree for Ataxia Research in 2022.

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 must first be reviewed by the Ethics Review Committee. This Committee comprises five members, who either have ataxia or are family members of people affected by ataxia. The Ethics Review Committee met seven times throughout the year.

The Committee reviewed seven 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 around 300 people on the Registry four times a year. In addition, this group was also sent communications about the International Congress for Ataxia Research.

Ataxia UK accredited Ataxia Centres

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 during the year by Ataxia UK, Coeliac UK and other funders (see above) to improve diagnosis and management of gluten ataxia, an area of expertise of this Centre.

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. During the year there has been a change in the nurse at the Sheffield Paediatric Centre.

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 has been involved in the Reata Pharmaceuticals drug trial that has lead to the first drug to be approved in FA (currently only in the US).

The Centre is also supported by Ataxia UK clinic volunteers. Since the pandemic the support has changed from face-to-face to phone and online support.

New Ataxia Centres

As detailed above during the year a paediatric Ataxia Centre has been accredited in London and an Adult and paediatric Centre was accredited in Oxford.

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.

A Euro-ataxia AGM and annual meeting was held virtually in June 2022. This was attended by 16 of the 20 Member groups. A new Trustee was appointed from the Greek FA Association and all other Trustees stayed on the Board. Ataxia UK's Head of Research gave a research update on all the projects Euro-ataxia is a partner in.

Ataxia UK is working closely with the Hellenic Friedreich's ataxia association in organising a face-to-face Euro-ataxia annual meeting and conference in May 2023. This will be the first in-person event since 2019, and is proving to be a popular event.

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 applications has succeeded in getting funding and Euro-ataxia is a partner (see above).

Supporting charities in 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 2023 – 2024

- 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.

Fundraising

Our strategic fundraising priorities for the financial year 2022 – 2023 were:

- Recruit New Regular Givers
- Maintain Income
- Plug Skills Gaps
- Supporter Journey
- Content
- Consent

Recruit New Regular Givers

Due to a decline in overall income and the challenging economic environment, we decide to implement cost-saving measures. As a result, we temporarily paused our investment in recruiting regular givers, which led to a net saving of £25k for the year.

Maintaining Income

Overall fundraising income is 10% lower than the previous financial year. The primary contributors to this is a 48% decline in donation from major donors and a 15.5% decline on legacy donations. Both of these income streams are traditionally “boom or bust” for Ataxia UK and fluctuations, positive or negative, tend to be significant. Income in Individual Giving is down 1% which considering the wider economic environment is acceptable. Income from Events and Community Fundraising grew by 3% on the previous financial years performance and is an encouraging step forward in getting back to pre-pandemic levels.

Throughout the financial year, the fundraising environment continued to challenge as we moved out of the worse of the Covid-19 pandemic and into a cost-of-living crisis.

This has been reflected in our income figures and whilst there are some areas of improvement, overall fundraising income is down 10% on the previous year.

Plugging Skills Gaps

Through the appointment of some key personnel, we have managed to plug our primary skill gaps in Digital Media, Facebook Advertising and Website management and are now working on a programme of continual improvements.

Supporter Journey

We have started to work on the user experience with a particular focus on the digital journey and supporter stewardship.

Content

We have made a number of improvements to our fundraising and marketing communications including the introduction and implementation of a new case for support and beginning the recording of content for a new documentary.

Consent

Being able to communicate with supporters in the ways they want to hear from hear from us is essential. We have explored new ways to keep our supporters updated including specialist topic newsletters and improving the ease of sign up.

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;
- Seeking grants from 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 didn't receive any complaints relating to our fundraising.

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

- Garfield Weston supported us with an unrestricted gift

Our strategic Fundraising priorities for the financial year 2023 – 2024 are:

- 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.

Communications

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

- Improve our email marketing
- Create a Website strategy
- Content, including new videos

The Communications Team continued to support the ataxia community in 2022 – 2023 by providing key information at vital points throughout supporters' journeys. We focused on improving our email communications, and the number of subscribers grew by 13%.

We also implemented a new visual identity, which helped double our click rates.

We made significant improvements to the website, including improving the loading speed, implementing a new visual identity, and introducing a new, more user-friendly page design. We also made a number of other improvements to the user experience.

As reported in the fundraising section, we increased our focus on the production of content, including making a start on our first documentary! This will focus on the ataxic journey of one of our supporters Ben and document his life with ataxia as well as his awareness-raising effort to highlight accessibility on the London Underground network by travelling to every single one of the 272 tube stations. His effort has also been picked up by a number of media outlets including the ITV News, BBC London and Euronews, which brought a lot of attention for the charity and the condition.

Our strategic communications priorities for financial year 2023 – 2024 are:

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

- Complete and premiere our first full length ataxia documentary

- Continue improving our core services / information dissemination

Financial Review
For the year ending 31 March 2023

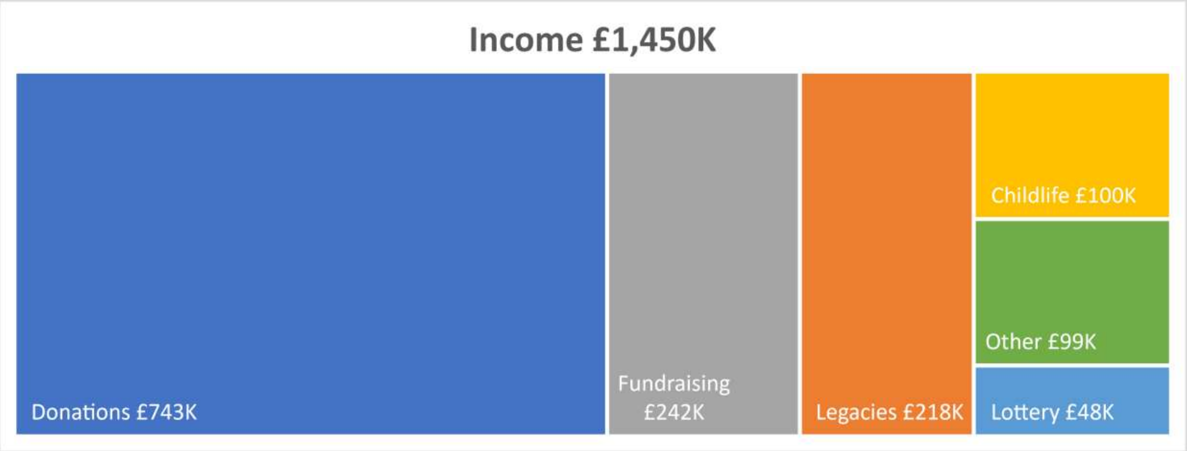
Overview

In what has continued to be a challenging environment due to the ongoing impact of the current economic climate, we are filled with gratitude for the continued support and generosity of our supporters. The charity has successfully navigated the year and 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 £167K surplus in the year (2021/22: £234K). The charity has moved from a net liability position of (£128K) in the 2021/22 financial year to a net asset position of £39K in the current year. A net liabilities 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 has been pushed out by a further year but the situation will be resolved over the next 2 years as year 1 funding has already been received.

The deficit in restricted funds, of which DRPLA and NKX6-2 funds are part, have also decreased over the year to (£687K) (2022: (£851K)). Once the outstanding restricted funds are removed the net total is £424K (2022: £243K). General unrestricted funds have increased to £726K (2022: £724K). Further details of reserves are given later in this review. We continue to maintain a healthy cash flow and have cash at bank and in hand of £1.6 million.

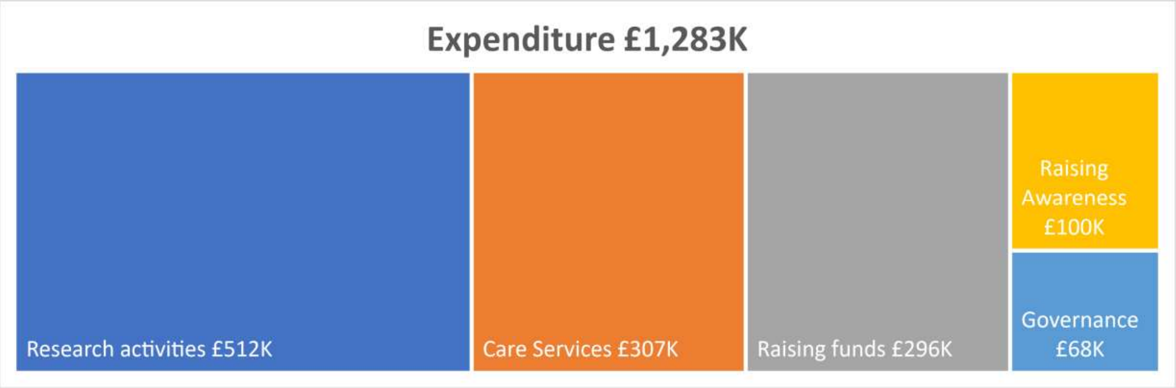
Review of income



Total income for 2022/23 was £1,450K (2021/22: £1,575K) a decrease of 7.9%. Donation income was lower than the previous year, £743K (2021/22: £858K) a decrease of 13.4%. Legacy income has decreased to £218K for the year (2021/22:

£258K), a decrease of 15.5%. We remain very grateful to the Friends and supporters who remember us in this way. Income from fundraising activities increased to £242K (2021/22: £240K) an increase of 1%. The decrease in donations is a reflection of the current economic situation where supporters don't have as much money to give as in the past. Childlife income increased to £100k (2022: £80K) an increase of 25%. The lottery grant for the In Control project came to an end in September and as result the funding decreased from £89k in 2021/22 to £48k in the current year. Other income is made up of conference income of £20K, the ICAR 24 conference income of £49k, research contract income £18k, welfare grants of £4K, goods & services provided for free 6.3K and interest income £1.5K.

Review of expenditure



Total expenditure for 2022/23 was £1,283K (2021/22: £1,341K) a decrease of 4.3%. Spending on research activities increased slightly to £512K (2021/22: £501K), an increase of 2.2%. There was a reduction in research grants being made in the year, £188K versus £249K in 2021/22, a decrease of 24.5% on prior year. DRPLA grants amounted to £52K which was 27.6% of the research grants made during the year. The detailed breakdown of the research grants made can be found in note 9. There was a 7.3% decrease in spend on care services to £307K (2021/22: £331K). Cost of raising awareness decreased slightly (4.8%) from the previous year to £100K (2021/22: £105K). Expenditure on raising funds decreased slightly to £296K (2021/22: £340K). Governance costs increased by 6.3% to £68K (2021/22 £64K) due to inflation.

Reserves levels at year end

	2023(£K)	2022(£K)
General funds	383	570
Designated funds	343	154
Total unrestricted funds	727	724
Restricted research funds	(844)	(951)
Restricted services funds	157	99
Total restricted funds	(687)	(852)
Total funds held	40	(128)

The charity saw an increase in reserve levels ending the year on £39K (31 March 2022: (£128K)), due to the total net income of £167k generated in the year.

Restricted funds were (£687K) (2021/22: (£852K)), (detailed in Note 22) with their still being deficit positions for DRPLA and NKX6-2. These deficit positions have not decreased in the year due to a delay in the start of the research projects so year 2 and year 3 payments have been pushed out by a year. Ataxia UK has signed agreements in place outlining the payment structure ensuring these future commitments will be met.

Designated Funds totalled £343K (2021/22: £154K) representing funds held at branches (£8K) and other designated funds (£335k) as detailed under Note 21. The trustees have released 3 designated funds during the year. These were unrestricted funds which were set aside by trustees for a future purpose. The designated funds released in the year were:

- Coeliac Research Project, £30K: A research grant of £38k was made during the year of which £30k was funded from this designated fund.
- In Control Project, £71K: Funds designated to cover the costs of the In Control project to 31 March 2023 which were used to meet these costs as the Lottery bid outcome is due in May 2023.

- Research Conference Fund, £10K: These funds were held to cover costs of the 2022 ICAR conference and were not needed so released back into unrestricted reserves.

And also included in other designated funds are premises fund, £50K: Funds are being set aside to build a reserve to cover costs of moving and setting up new premises in case we need to move at the end of our 3-year term.

General reserves of the charity as at 31 March 2023 were £384K (31 March 2022: £570K) a 33% decrease. 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 continues to be that holding unrestricted free reserves equal to 3 to 6 months operating costs (presently £72K per month, 2021/22: £70K per month) and given the current challenging economic environment Ataxia is leaning towards 5 months to ensure the ongoing stability of the charity. This reflects a balance between being prudent and allowing the charity to direct as much resource as possible into research and care activities. 'Free reserves' of the charity are calculated as general funds less the net book value of tangible fixed assets, £16K (2021/22: £22K). As at 31 March 2023, free reserves totalled £367K (2021/22: £548K) equating to 5 months operating costs (2021/22: 7.83 months) and is therefore within the reserves policy.

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. Due to the current challenging economic conditions as a result of world events, 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 26/07/2023 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 2023 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 2023 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, 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.

Independent auditor's report to the members of Ataxia UK

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.

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.

Independent auditor's report to the members of Ataxia UK

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 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.

Independent auditor's report to the members of Ataxia UK

- 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.

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. 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.

Anthony Epton

28 July 2023

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 2023

	Notes	Unrestricted funds £	Restricted funds £	Total funds *2023* £	Total funds *2022* £
Income					
Donations and legacies	3	464,601	496,619	**961,220**	1,116,428
Other trading activities	4	222,065	19,956	**242,021**	239,962
Charitable activities	5	21,643	223,804	**245,447**	218,117
Investments	6	1,464	-	**1,464**	1
Total income		709,773	740,379	**1,450,152**	1,574,508
Expenditure on:					
Raising funds	7	(196,757)	(6,342)	**(203,099)**	(235,028)
Charitable activities	8	(482,193)	(598,026)	**(1,080,219)**	(1,105,659)
Total expenditure		(678,950)	(604,368)	**(1,283,318)**	(1,340,687)
Net losses on investments		-	-	**-**	-
Net income/(expenditure)		30,823	136,011	**166,834**	233,821
Transfer from Unrestricted to Restricted		(28,539)	28,539	**-**	-
Net movement in funds		2,284	164,550	**166,834**	233,821
Total funds brought forward		723,913	(851,436)	**(127,523)**	(361,344)
Total funds carried forward		726,197	(686,886)	**39,311**	(127,523)

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

STATEMENT OF FINANCIAL ACTIVITIES

(incorporating the income and expenditure account)
(incorporating the results of the Charity's branches)
for the year ended 31st March 2022

	Notes	Unrestricted funds £	Restricted funds £	Total funds 2022 £
Income				
Donations and legacies	3	590,170	526,258	1,116,428
Other trading activities	4	221,390	18,572	239,962
Charitable activities	5	8,510	209,607	218,117
Investments	6	1	-	1
Total income		820,071	754,437	1,574,508
Expenditure on:				
Raising funds	7	(228,420)	(6,608)	(235,028)
Charitable activities	8	(466,381)	(639,278)	(1,105,659)
Total expenditure		(694,801)	(645,886)	(1,340,687)
Net losses on investments		-	-	-
Net income/(expenditure)		125,270	108,551	233,821
Transfer from Unrestricted to Restricted		-	-	-
Net movement in funds		125,270	108,551	233,821
Total funds brought forward		598,643	(959,987)	(361,344)
Total funds carried forward		723,913	(851,436)	(127,523)

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 2023

	Notes	2023 £	2023 £	2022 £	2022 £
Fixed assets					
Tangible assets	14	16,362		21,624	
			16,362		21,624
Current assets					
Debtors	15	365,041		272,777	
Cash at bank and in hand	16	1,589,232		1,760,675	
		1,954,273		2,033,452	
Creditors: amounts falling due within one year	17	(966,568)		(836,495)	
Net current assets			987,705		1,196,957
Total net assets less current liabilities			1,004,067		1,218,581
Creditors: amounts falling due after more than one year	18		(964,756)		(1,346,104)
Total net assets/(liabilities)	19		39,311		(127,523)
Accumulated funds					
Unrestricted funds					
General funds	20		383,508		569,800
Designated funds	21		342,689		154,113
			726,197		723,913
Restricted funds	22		(686,886)		(851,436)
Total funds			39,311		(127,523)

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 26 July 2023 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 2023

	2023 £	2022 £
Cash generated from operating activities:		
Net cash provided by operating activities	(168,296)	144,012
Cash flows from investing activities:		
Dividends and interest from investments	1,464	1
Purchase of property, plant and equipment net of sales	(4,611)	(810)
Proceeds from sale of investments	-	-
Net cash provided/(used in) by investing activities	(3,147)	(809)
Net increase in cash:	(171,443)	143,203
Cash at bank and in hand less overdrafts at the beginning of the year	1,760,675	1,617,472
Change in cash and cash equivalents	(171,443)	143,203
Cash at bank and in hand less overdrafts at the end of the year	1,589,232	1,760,675

Reconciliation of net income to net cash flow from operating activities

	2023 £	2022 £
Net (expenditure)/ income	166,834	233,821
Adjustments for:		
Depreciation charges	9,873	9,132
Net losses on investments	-	-
Dividends and interest from investments	(1,464)	(1)
(Increase)/ Decrease in stocks	-	6,218
Decrease in debtors	(92,264)	(60,683)
Increase in creditors	(251,275)	(44,475)
Net cash provided by operating activities	(168,296)	144,012

Analysis of cash at bank and in hand less overdrafts

	2023 £	2022 £
Cash at bank and in hand	1,589,232	1,760,675
	1,589,232	1,760,675

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 2022/23 financial year, we had a net positive movement in both unrestricted and restricted funds. The balance sheet shows a small net asset position. This is the result of two DRPLA research grants and one NKX6-2 research grant being made in 2020/21 but the funding being received over the 3 years of the grant. All three grants have been delayed in starting due to Covid. As a result, the year 2 & year 3 funding has been delayed as well. 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 2023/24 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. A budget and associated cash flow have been drawn up for the next financial year 2023/24 to maintain robust future forecasting. 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.

Principal Accounting Policies (continued)

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.

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.

Principal Accounting Policies (continued)

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 2023 CONTINUED

Note 3 Donations and Legacies Income

	2023 £	2022 £
Donations	743,120	858,024
Legacies	218,100	258,403
	961,220	1,116,427

Note 4 Other Trading Activities

	2023 £	2022 £
Fundraising activities	242,021	239,962
	242,021	239,962

Note 5 Charitable Activities Income

	2023 £	2022 £
Childlife	100,000	80,000
Annual conference	69,391	2,327
Grants receivable	76,056	135,790
	245,447	218,117

Note 6 Investment Income

	2023 £	2022 £
Interest	1,464	1
	1,464	1

Note 7 Raising Funds Expenditure

	2023 £	2022 £
Costs of generating funds	203,099	235,028
	203,099	235,028

Note 8 Charitable Activities Expenditure

	Direct Costs £	Grants £	Support Costs £	2023 Total £	2022 Total £
Research activities	210,499	187,749	113,637	511,885	501,062
Care services	156,024	2,643	149,173	307,840	330,484
Total	366,523	190,392	262,810	819,725	831,546
Generating funds	-	-	92,602	92,602	104,785
Raising awareness	31,930	-	68,088	100,018	105,203
Governance	-	-	67,874	67,874	64,125
Total charitable activities	398,453	190,392	491,374	1,080,219	1,105,659

	2023 £	2022 £
Total support costs		
Staff costs	339,985	305,096
Office costs	141,516	158,787
Depreciation	9,873	9,132
	491,374	473,015

Note 9 : Research Grants

	2023 £	2022 £
Research grants made in year comprise		
Assessment of ataxia severity under real-life conditions with SARAhome: A multicenter study in spinocerebellar ataxia type 3 (Sca3)		20,000
Funding extension for the grant application entitled ‘Preclinical development of an amelioration therapy for Dentatorubro-Pallidoluysian Atrophy		43,264
DRPLA Natural History and Biomarkers Study (DRPLA NHBS)		131,449
Motor and cognitive outcomes of non-invasive transcranial alternate current stimulation by entrainment of cerebellar oscillations.		5,000
Sheffield Ataxia Study Day		700
Generation and characteization of a cardiomyocyte model for Friedreich’s ataxia to reveal the molecular mechanism of heart failure in patients		5,000
Analysis of the mitochondrial dysfunction in FXN deficient neurones to generate a drug screening test		4,750
Brain pathology in an AIFM1 mutation causing Cowchock syndrome		5,000
Balance and gait abnormalities in adult patients with mitochondrial disease and spinocerebellar ataxia type 6		4,928
A feasibility study of LSVT Artic to improve speech performance in people with progressive ataxia		2,862
NanoSCA: Development of brain-targeted nanoboides for application in spinocerebellar ataxia type 3 therapy		25,800
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	
	187,749	248,753

Note 10 : Staff Costs

	2023 £	2022 £
Staff costs comprised:		
Salaries	703,788	664,733
Social security contributions	67,548	70,028
Pensions	35,616	34,104
Redundancy and termination costs	-	29,125
	806,952	797,990

The average number of employees during the year was 18 (2022: 19) with all employee time involved in providing either support to the governance of the charity or support services to charitable activities.

ATAXIA UK
NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2023 CONTINUED

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 £339,870 (2022: £335,048).

The following number of staff members received emoluments in the year:	2023	2022
£80,000 - £89,999		1
£90,000 - £99,999	1	

The pension contributions in respect of the above named individual in the year totalled £4,334 (2022: £4,190).

Ataxia UK operates a defined contribution pension scheme and the amounts above represent the charity’s total liability 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 £35,637 (2022: £34,104). There was no outstanding balance (2022: £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, all board meetings were held remotely and as a result no trustee expenses were incurred. 0 trustees (2022: 0) claimed expenses totalling £0 (2022: £0).

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

	2023	2022
	£	£
Auditor’s remuneration	6,660	9,980
Depreciation	9,873	9,132
Operating lease costs	1,000	1,000

Note 14 : Tangible Fixed Assets

	Building Works	Other Assets	Total
	£	£	£
COST			
As at 1st April 2022	5,333	40,250	45,583
Additions	-	5,098	5,098
Disposals	-	(1,064)	(1,064)
As at 31 March 2023	5,333	44,284	49,617
DEPRECIATION			
As at 1st April 2022	4,225	19,734	23,959
Charge for year	723	9,150	9,873
Disposals	-	(577)	(577)
As at 31 March 2023	4,948	28,307	33,255
NET BOOK VALUE			
As at 31 March 2023	385	15,977	16,362
As at 1st April 2022	1,108	20,516	21,624

Included within the net book value of the ’Other Assets’ is an amount of £2,000 (£3,000 in 2022) relating to items acquired on Finance Lease/Hire purchase.

Note 15 : Debtors Under 1 Year

	2023 £	2022 £
Income tax recoverable	127,305	108,860
Other debtors	209,858	131,482
Prepayments	27,878	32,435
	365,041	272,777

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

	2023 £	2022 £
Other creditors	8,939	25,764
PAYE/NI	-	19,639
Deferred income	28,732	13,086
Accruals	25,188	31,157
Research grants	903,709	746,849
	966,568	836,495

ATAXIA UK
NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2023 CONTINUED

Note 18 : Creditors: Amounts falling due after one year

	2023 £	2022 £
Research grants	963,756	1,346,104
Misc creditors	1,000	-
	964,756	1,346,104

Note 19 : Analysis of net assets between funds

	Restricted Funds £	Designated Funds £	General Funds £	Total 2023 £	Total 2022 £
Fixed assets	2,222	-	14,140	16,362	21,624
Debtors	-	-	365,041	365,041	272,777
Cash at bank and in hand	1,178,356	342,689	68,187	1,589,232	1,760,675
Creditors	(1,867,464)	-	(63,860)	(1,931,324)	(2,182,599)
	(686,886)	342,689	383,508	39,311	(127,523)

Note 20 : Unrestricted Funds

	General Funds	Designated Funds	Total
Balance as at 1 April 2022	569,800	154,113	723,913
Net increase/(decrease) in funds during the year	(297,292)	299,576	2,284
Transfers	111,000	(111,000)	-
Balance as at 31 March 2023	383,508	342,689	726,197

Note 21 : Designated Funds

	Opening Balance	Net Movement	Transfers	Closing Balance
Funds held in branches	8,113	(424)	-	7,689
Coeliac Research Project	30,000	-	(30,000)	-
In Control Project	71,000	-	(71,000)	-
Premises Fund	35,000	15,000	-	50,000
Parental	-	50,000	-	50,000
Restructuring	-	30,000	-	30,000
Service development	-	150,000	-	150,000
Conference subsidy	-	5,000	-	5,000
Staff training	-	20,000	-	20,000
ICA conferences 2023-24	-	30,000	-	30,000
Research Conference Fund	10,000	-	(10,000)	-
	154,113	299,576	(111,000)	342,689

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

b) Coeliac Research Project: Funds designated to fund a gluten ataxia research project in partnership with Coeliac UK which was funded during the year ending 31 March 2023.

c) In Control Project: Funds designated to cover the In Control project were used during the year ending 31 March 2023.

d) Premises Fund: Funds being set aside to cover costs of moving and setting up new premises

e) Research Conference Fund: Funds being held to cover costs of ICAR 2022 conference which were released to unrestricted funds as they were not required.

Note 22 : Restricted Funds

	At 1 April 2022	Income	Expenditure	Transfers	At 31 March 2023
	£	£	£	£	£
General Research	95,941	179,361	136,083	-	139,219
Friedreich's ataxia research	13,158	11,415	34,090	32,973	23,457
Cerebellar ataxia research	2,189	11,862	23,472	9,421	-
Young Person's projects	7,959	-	-	-	7,959
Jerry Farr travel fund	671	-	-	-	671
Welfare	634	960	525	-	1,069
Welfare - The Gift of Speech	21,624	527	3,779	-	18,372
Nicotinomide	-	30	6	-	24
Goods and Services Received	-	6,342	6,342	-	-
Helpline	-	93,887	31,026	-	62,862
Misc Grants	450	-	-	-	450
Childlife	-	100,000	57,606	(42,394)	-
Exeter	582	-	-	-	582
Awareness	4,171	-	-	-	4,171
Kennedy Award	12,198	-	3,000	-	9,198
Research Stem Cell FA	78	-	-	-	78
Mark Dower Trust	1,768	2,073	2,118	-	1,723
Spinocerebellar Ataxia Research Project	1,661	4,064	813	-	4,912
DRPLA Research	(1,047,450)	51,935	51,935	-	(1,047,450)
In Control Project	9,470	47,861	85,870	28,539	-
Ataxia Centres	51,039	-	-	-	51,039
DRPLA Department	15,774	142,631	146,277	-	12,128
Scotland	800	-	-	-	800
NXK6-2	(46,782)	8,036	-	-	(38,746)
AOA2	2,629	1,478	296	-	3,811
Prospax Project	-	4,611	5,051	-	(440)
Research Service Contracts	-	12,902	12,902	-	-
Research SCA6	-	625	125	-	500
Research SCA3	-	1,187	1,187	-	-
Research ICAR 2024 Conference	-	49,220	-	-	49,220
Misc AAA++	-	9,372	1,867	-	7,505
	(851,436)	740,379	604,368	28,539	(686,886)

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: 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.
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
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
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

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.

Note 23 : Capital Commitments

There are no capital commitments at 31 March 2023 (2022: Nil)

Note 24 : Lease Commitments

At 31 March 2023 the charity had future minimum lease payments under non-cancellable operating leases as follows:

	2023		2022	
	Land & buildings	Other	Land & buildings	Other
Payments due:				
Within one year	37,168	1,608	50,604	1,608
Within two to five years	47,501	1,608	61,802	3,217
	84,669	3,216	112,406	4,825

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.