ATAXIA UK

England & Wales · Charity number 1102391

Details

Status	Registered
Legal form	Charitable company
Company number	04974832
Registered	2004-02-27
Register	View on the Charity Commission register

Contact

Address	12 Broadbent Close London N6 5JW
Phone	02075821444
Email	office@ataxia.org.uk
Website	www.ataxia.org.uk

Activities

Objects: TO RELIEVE THOSE PERSON AFFECTED BY ATAXIA

Activities: Ataxia UK supports people affected by ataxia by;funding medical and other research and thereafter disseminating results, providing information on ataxia to people with ataxia and also medical and social care professionals, distribution of welfare grants, campaigning for improvement in treatment and services, facilitating self-help groups and piloting new service delivery models

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities

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Geography

- **Area of benefit:** NATIONAL
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£1,783,693	£1,796,854	£514,455	19
2024-03-31	£1,813,777	£1,325,472	£527,616	20
2023-03-31	£1,450,152	£1,283,318	£39,311	18
2022-03-31	£1,574,508	£1,340,687	£-127,523	19
2021-03-31	£1,905,504	£3,006,956	£-361,344	18

Trustees

Name	Role	Appointed
Angela June Hosie		2021-11-26
David Ernest Martin		2024-10-26
Dr Harriet Judith Clare Brown		2022-09-23
Katharine Rudkin		2025-11-21
Katherine Anne Jones		2018-11-25
Nathan Hall		2023-10-22
Olivia Wood		2023-12-01
Rachel Anne Harrison		2021-11-26
Steve Reid		2025-05-21

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ATAXIA UK

England & Wales - Charity number 1102391

Accounts



ATAXIA UK

MYLES, AGED 7, HAS CEREBELLAR ATAXIA

ANNUAL REPORT AND FINANCIAL STATEMENT

2024 - 2025

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

ATAXIA

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OUR YEAR IN REVIEW 2024-25

During 2024-25 we made significant progress in developing our services to meet the needs of the ataxia community. We employed Ataxia UK's first Specialist Ataxia Nurse, who is expanding our support service across the NHS South West region, helping people to navigate the NHS and access the best possible care. Demand for our Helpline and Advocacy Services continues to grow, and we are proud to have supported more people than ever before, across a wider range of issues.

A particular highlight of the year was meeting supporters face to face at our three roadshows, held in the capitals of the devolved nations. The warm feedback we received at these events, both about the events themselves and the wider work of Ataxia UK, was hugely encouraging.

Our other major focus during the year was to support the progress of the first drug, omaveloxolone, towards approval for the treatment of Friedreich's ataxia through the UK regulatory system. The welcome news that the drug was granted a licence for sale in England and Wales came in April 2025. However, we were disappointed to learn that the drug has been withdrawn from the NICE evaluation process, resulting in further delays to its availability. This decision sets our agenda for the year ahead. Working in the rare conditions field, we know we are not alone in pressing for NICE to amend its processes to better reflect the needs of rare diseases, particularly those with no approved treatments, and we continue to collaborate with others to achieve this aim.

In a challenging economic environment Ataxia UK remained financially resilient thanks to the generosity of our supporters. Legacy income grew significantly, while our successful hosting of the International Congress for Ataxia Research generated sufficient in registrations and sponsorships to create a small surplus. We also strengthened our unrestricted funds and maintained healthy cash reserves, enabling us to continue investing in vital research and services for the ataxia community.

Looking ahead, we will continue to strengthen our staff team so that we can deliver on our ambitions and respond to the ever-increasing demands for Ataxia UK's support in accessing treatment and care, as well as in advancing drug development. We are working closely with neurologists at two hospitals in England with a view to opening Accredited Ataxia Centres in the next 12 months. In parallel, we are developing our new Strategic Plan for 2026 to 2029, in which the establishment of Accredited Ataxia Centres across the devolved nations will be a priority.

Finally, we extend our heartfelt thanks to everyone who supports Ataxia UK through fundraising, donating or volunteering. We could achieve nothing without you. We are proud to be a charity governed by people directly affected by ataxia.

Sincerely,

William Littleboy
Chair

Sue Millman
Chief Executive





REFERENCE AND ADMINISTRATION DETAILS



Trustees & Advisors

The charity's registered address is 12 Broadbent Close, London, N6 5JW.

The Trustees that served during 2024 – 2025 were:

Honorary Officers
William Littleboy, Chair
Kathy Jones, Honorary Treasurer

Trustees
Angela Hosie
Carol McCudden
Gemma Fish (Retired on 25 Oct 2024)
Rachel Harrison
Harriet Brown
Nathan Hall
Olivia Wood
David Martin (Joined on 25 October 2024)
Prof Barry Hunt (Scientific Advisor to the Board)
Susan Millman (Company Secretary and CEO)

Ataxia UK uses the following professional advisors:

Auditors
Goldwins Limited
75 Maygrove Road
West Hampstead
London NW6 2EG

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

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

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

Structure, Governance & Management

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

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

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

Public Benefit

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

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

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

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

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

We also fund vital research projects into potential treatments, aiming to find treatments and cures for ataxias. 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.

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 Ramdharmy, and
Dr Sophie Rowlands.

The committee also included the following lay members during the year:
Yanita Oparlakova,
Harriet Brown,
and Nathan Hall.

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

All members are unpaid volunteers.

Employees

During 2024–25 the average number of full-time equivalent employees during the year was 19 (with all employees' time involved in providing either support to the governance of the Charity or our charitable activities).

Volunteers

In addition to the volunteers who function as trustees, many other volunteers play an important part in supporting Ataxia UK. During 2024–25 we have employed several paid interns and offered opportunities to volunteers throughout the charity. They have provided invaluable assistance in our day-to-day work, contributing towards our projects, such as the Ataxia Magazine. We have continued to recruit more committed volunteers.

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

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

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

Risk Management

As in previous years, the Board actively managed the risks to the charity, focusing on the most serious.

We maintain a register of risks and controls and activities to mitigate risk throughout the year; a register of the most significant risks and their mitigation will be enclosed following further internal review.

Objectives & Activities

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

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

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

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

Raising awareness of ataxia is a fundamental desire of people with ataxia. Ataxia UK is focussing its efforts on improving understanding of the condition in the NHS, where diagnosis and treatment are often delayed, and also in the social care sector, where an understanding of the condition could significantly improve the situation of people affected by ataxia.

Our Strategic Plan

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

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

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

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

- Establish a peripatetic Specialist Ataxia Nursing Service to accompany patients to appointments and support them in managing all aspects of their care.
- Continue to develop the Helpline and Advocacy Service and improve the support information held on the website.
- Revise the Medical Guidelines for the Treatment of the Ataxias and publish the 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.

SERVICES



Highlights

Ataxia UK's Services team helps ensure that no one faces ataxia alone. This year we continued to connect with and support people across the UK through our Helpline and Advocacy services, peer support groups, online events, and in-person community activities.

We introduced a new one-day format for our information seminar All About Ataxia, expanded our All About AtaxiaPLUS programme, and held Roadshows in all the devolved nations. As a result, many people attended an Ataxia UK event for the first time.
We also hosted a successful Wellbeing Week and delivered more than 30 virtual sessions across the year.

Support Groups remained active, providing spaces online and across the UK for people affected by ataxia to connect, share experiences, and reduce isolation by meeting virtually or face to face.

We welcomed 744 new Friends this year

We worked with 83 volunteers who played a key role across our services, supporting the Helpline and clinics, running groups, and leading sessions online and in person.

We also began to review how we evaluate our services to better understand our impact and improve delivery. While some areas, such as website updates and feedback collection, still need work, we made significant progress against our aims and will continue building on this in 2025-26.

We continue to provide free, wallet-sized ID cards to help people explain their symptoms if challenged in public, with around 18 requests received each month.

Community Connections

We continued to bring people together through support groups, events, and virtual sessions. A total of 182 support group meetings were held across the UK (102 in person and 80 online), with 1,554 attendees overall. Ataxia UK staff joined a number of sessions to share updates and advice.

We delivered Roadshows in Cardiff, Belfast, and Edinburgh. These events were tailored to each location and included input from clinicians and peer speakers. Around 120 people attended, many for their first Ataxia UK event. The Roadshows helped reduce geographic and financial barriers and supported local connections. A further 139 people joined us online in October for our Annual Virtual Conference.

The information seminar All About Ataxia ran three times in its new one-day format, reaching 79 people (up from 63 last year). Average attendance rose to 27, and feedback remains positive.

We delivered five All About AtaxiaPLUS sessions on topics including gadgets and adaptations, mental health, and exercise. These sessions had 219 registrations and 125 attendees, with all participants receiving follow-up materials.

Across the year we hosted more than 30 virtual activities. Wellbeing Week in February 2025 was a highlight, attracting 197 participants.



Cardiff Roadshow – April 2024

Helpline and Advocacy

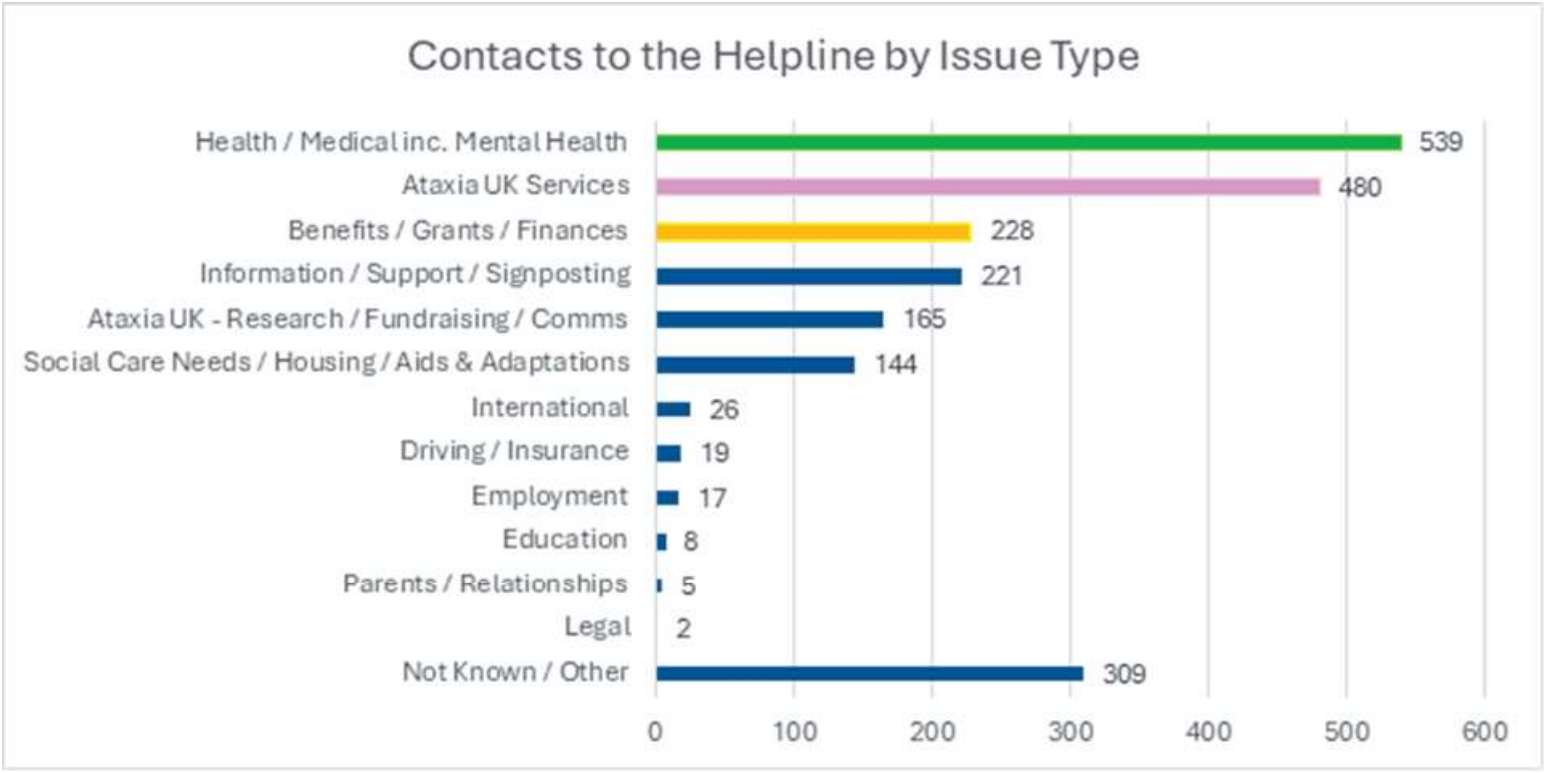
The Helpline responded to 1,596 contacts from 1,138 individuals, covering 2,164 issues. People contacted us for information, advice and emotional support on a range of topics including diagnosis, care, symptoms, access to services, benefits, grants, employment and more. We introduced a feedback survey in April 2024. Feedback was overwhelmingly positive:

- 89% said the Helpline was "very helpful"
- 93% said the information met their needs
- 96% would recommend the Helpline to others in the ataxia community

> ***"Very helpful, informative and friendly, with practical advice and quick follow-up."***
>
> ***"Jessica was helpful, professional and did what she said she would."***

The Advocacy Service supports people to understand their rights, have their voices heard, and access the services and support they are entitled to. This year we supported 109 individuals and helped secure £11,450 in grant funding and £66,266 in welfare benefits.

In addition, we advised on a wide range of issues including NHS access, social care, education, housing, employment, cost of living, driving, holidays, pensions and insurance.



The Gift of Speech

We continued to deliver the Gift of Speech programme, which includes our online speech therapy course and access to voice banking via SpeakUnique for people with ataxia experiencing communication difficulties.

Speech Therapy

Our intensive online course includes four one-to-one sessions with a speech and language therapist, followed by four weeks of daily group practice in a small group of six participants.

Five online speech therapy groups were delivered during the year, supporting 31 people. Two participants did not complete the full programme. Demand for the service remains high, and a waiting list of 19 people is in place.

Voice Banking

Voice banking involves recording your own voice so that if a person needs to use a communication device in the future, their synthetic voice will sound like them. Ataxia UK funded 49 synthetic voices during the year. A total of 233 people with ataxia have now registered with SpeakUnique, and 156 have banked their voices so that their synthetic voice is ready to download when they need it. Applications now require diagnosis confirmation and clinical sign-off, with the Helpline managing this process and following up where needed.

"It has been a life-changing experience not being able to speak as I developed what is thought to be SCA 27B — rare, like me!

I'll be able to talk again, and argue with David—which I'd given up on because it was just too much effort."

Looking Ahead

- We will prioritise improving the information available on our website, making it easier to access and more useful for the ataxia community.

- We want to secure funding to continue our Gift of Speech project so more people can benefit in the future.

"Thank you, thank you, I cannot thank you enough. Not only have you helped me with my speech but the experience as a whole has made such a difference.

We developed our own little support group and shared things that no one else would understand, and that meant such a lot to us all, I think. Thanks again for all your help.

As I said before, without Ataxia UK I do not know what I would have done."
Jenny T

- We plan to expand access to our Helpline and Advocacy Service by increasing capacity, extending hours and supporting more people with a wider range of issues.

- We aim to continue delivering high-quality online and in-person events, and to increase the reach and accessibility of these sessions.

- We will continue developing an evaluation approach to help us measure the impact of our work.

- We will review our conferences and in-person events and develop a strategy to deliver future events in the most effective and accessible ways for the ataxia community.

HEALTHCARE


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Highlights

Specialist Nurse

Thanks to partial funding from the National Lottery Community Fund, Ataxia UK is delighted to have appointed a Specialist Ataxia Nurse to work in the South West region of England, an area where patients do not have easy access to established Ataxia Centres. This new role will support people with ataxia, their families and carers to access timely, appropriate specialist care and treatment.

A Steering Group supported the development of the service from July 2024. Recruitment was completed in autumn, and Camilla Notley joined the team in January 2025. Her induction was delivered in collaboration with all three Ataxia Centres. The service officially launched in Exeter in May 2025 and is now accepting referrals via the Helpline.

Camilla Notley, our Specialist Ataxia Nurse has been working closely with the Ataxia Centres in London, Oxford and Sheffield, and has already begun building relationships with local neurologists and healthcare services in the region to support her work.



Ataxia Centres

Ataxia UK-accredited Specialist Ataxia Centres are centres of excellence, where people with ataxia receive the best quality of care from experts and a coordinated service combining diagnosis, treatment, support and research. There are currently accredited centres for adults and children with ataxia in London, Sheffield and Oxford.

Ataxia UK has been part of a research project led by Prof Giunti of the London Ataxia Centre evaluating Specialist Ataxia Centres, as part of a larger European Brain Council project. It involved surveying people with ataxia in the UK, Germany and Italy, and the results highlight the value of specialist centres in addressing the challenges for people living with ataxia. Patients attending Specialist Ataxia Centres felt the care they received was better than those in non-specialist settings, with no significant difference in cost.

During the year two papers were published in peer-reviewed medical journals, increasing the reach of our results and policy recommendations.

Supporting healthcare professionals

We continued our support of healthcare professionals involved in treating people with ataxia. We are working on updating our Medical Guidelines, written by healthcare professionals for healthcare professionals, which were last published in 2016. This update is being carried out by a range of contributors, with support and review from our Guidelines Development Group, which includes ataxia specialists and people affected by ataxia.

We kept the healthcare professionals on our registry updated on events, news, funding and training opportunities with our quarterly newsletter. We also used the newsletter to update healthcare professionals on the status of ataxia treatments in development, which is becoming increasingly important as more ataxia drugs enter late-stage clinical trials.



Ataxia Centre of Excellence - Sheffield Children's NHS Foundation Trust

In collaboration with our Medical Advisory Panel (MAP), we continued the Ataxia Grand Round programme. These closed sessions involve a case presentation from a neurologist, which is then discussed with ataxia specialists.

This enables neurologists from outside of the MAP to obtain invaluable expert advice from ataxia specialists on diagnosis and symptom management. Feedback from those involved has been very positive.

Positive changes in healthcare policy

Despite our limited resources, Ataxia UK's CEO Sue Millman has always endeavoured to ensure that we play an active role in the umbrella organisations which marshal the resources of the charity sector to advocate for changes to policies in health and care that would benefit people affected by ataxia. Sue is currently Vice-Chair of Genetic Alliance UK, an alliance of over 200 charities and support groups working together to improve the lives of people in the UK with genetic, rare and undiagnosed conditions, and plays an active part in its activities and campaigns.

In addition, Sue is a patient advocacy group member of the Department of Health/NHS Rare Diseases Framework Stakeholder Group, which is invited to comment on various elements of the Rare Disease Framework and Plan.



Looking Ahead

Specialist Nurse

- Our Specialist Ataxia Nurse will begin seeing patients (Already started from May 2025)
- The role supports people with ataxia, their families and carers to access specialist care.
- We aim to build NHS links in the South West and grow an ataxia clinic from the neurology hub in Bristol.
- Longer term, we hope to expand the model to other regions to improve access across the UK.

Access to treatments

Ataxia UK will continue in our efforts to influence the UK regulatory and reimbursement systems to improve early access to medications and more appropriate reimbursement processes for rare conditions and suitable prescribing. We will continue to engage with relevant stakeholders, while keeping the ataxia community informed and involved, to push for access to omaveloxolone for people with Friedreich's ataxia in the UK.

There are two more drugs in the pipeline for FA and SCAs that are being assessed by regulators in the US and EU, and we will advocate strongly for access in the UK for these and others as they become available.

Ataxia Centres

To expand upon our work with the Ataxia UK-accredited Ataxia Centres, we plan to accredit at least one more centre in 2025/26, giving easier access to a specialist ataxia centre in the East of England. As the number of centres grows, the need for monitoring becomes greater and we plan to establish annual monitoring of the Ataxia UK-accredited centres.

Our work with the Accredited Centres is likely to become more important as more ataxia drugs reach late-stage trials and enter the regulatory process. In order to seek specialist input on access and distribution of medications in the future, we plan to establish an Ataxia Centres Panel, providing a forum for discussion with neurologists running the ataxia centres.

RESEARCH



Highlights

November 2024 saw the International Congress for Ataxia Research (ICAR) come to London. ICAR was organised by Ataxia UK, along with the National Ataxia Foundation (NAF), the Friedreich's Ataxia Research Alliance (FARA) and the Ataxia Global Initiative (AGI). This was the biggest ICAR yet, with 600 in-person attendees and 50 online participants from 32 countries, including researchers, clinicians, representatives from the pharmaceutical industry and patient organisations. The congress brought together researchers from the ataxia field to share knowledge through talks, workshops, debates and poster presentations.

91% of attendees made new contacts at ICAR

In 2024-25 Ataxia UK awarded six grants to a range of projects, from supporting carers to developing antisense oligonucleotides for SCA3. Our 2025 impact report showed that over the last 10 years, for every £1 invested in research, £5 in further funding was secured by researchers for ataxia research.

We continue to engage people with ataxia in research. We provided feedback on surveys designed to gather information from people with ataxia, including an FA Burden of Illness study and a survey on attitudes to gene therapy for ataxia.

We publicised opportunities for people with ataxia to be involved in studies, and met with pharmaceutical companies and researchers to provide a patient perspective on their research programmes.

10 years of Ataxia UK funded research produced 58 journal articles

Engagement in research

Having a database of people with ataxia puts Ataxia UK in a unique position to support projects via the recruitment of participants. During the year, we publicised a number of studies for people with ataxia to be involved in research. This includes clinical studies, such as the SCA3 ESMI natural history study, as well as opportunities to complete surveys or take part in interview studies, such as the FA Burden of Illness survey.

These studies provide critical information to advance clinical trials for the ataxias and to help in the stages following successful trials where medications are assessed by regulators and those making decisions on access to medicines within the NHS.

Ataxia UK has an internal Ethics Review Committee, who provide feedback on surveys and patient facing information. They also make decisions on whether studies should be prioritised for the community. This Committee is made up of people that have ataxia or their family members. During this year, they reviewed six studies. This included patient information for a planned clinical trial, and surveys designed to gather information from people with ataxia.



Funded research

In 2024/25 Ataxia UK awarded six project grants and two travel awards. Including these projects, there are currently 25 projects being managed (including seven from the DRPLA programme). Applications for our grants programme are reviewed by the Scientific Advisory Committee, which provides independent advice to the Board of Trustees.

Title	Grant amount (£)
Towards a pharmacological model of Autosomal Recessive spastic Ataxia of Charlevoix-Saguenay (ARSACS)	5,000
Restoring NKX6-2 function by protein complementation: a proof-of-concept	5,000
A feasibility study of Remote Patient-Reported Outcome measures in Mitochondrial diseases and Spinocerebellar ataxias (R-PROMS)	4,998
Refinement of allele-specific antisense oligonucleotides for spinocerebellar ataxia type 3	28,775
Supporting a genome-wide associational study of genetic modifiers of age at onset in spinocerebellar ataxia 27B	30,000
DRPLA research (University of Girona grant)	7,781
Travel award	1,369
FA nicotinamide trial (Imperial College) - cancelled pre 2021 project	(15,000)
Total	**67,923**

Every year, we ask our funded researchers to report on the outcomes of their Ataxia UK-funded research. Our data collection from March 2025 showed that over the last 10 years, Ataxia UK-funded research has resulted in 72 collaborations in 14 different countries. Collaboration is extremely important in rare disease research.



Engagement activities and collaborations – Ataxia UK-funded research

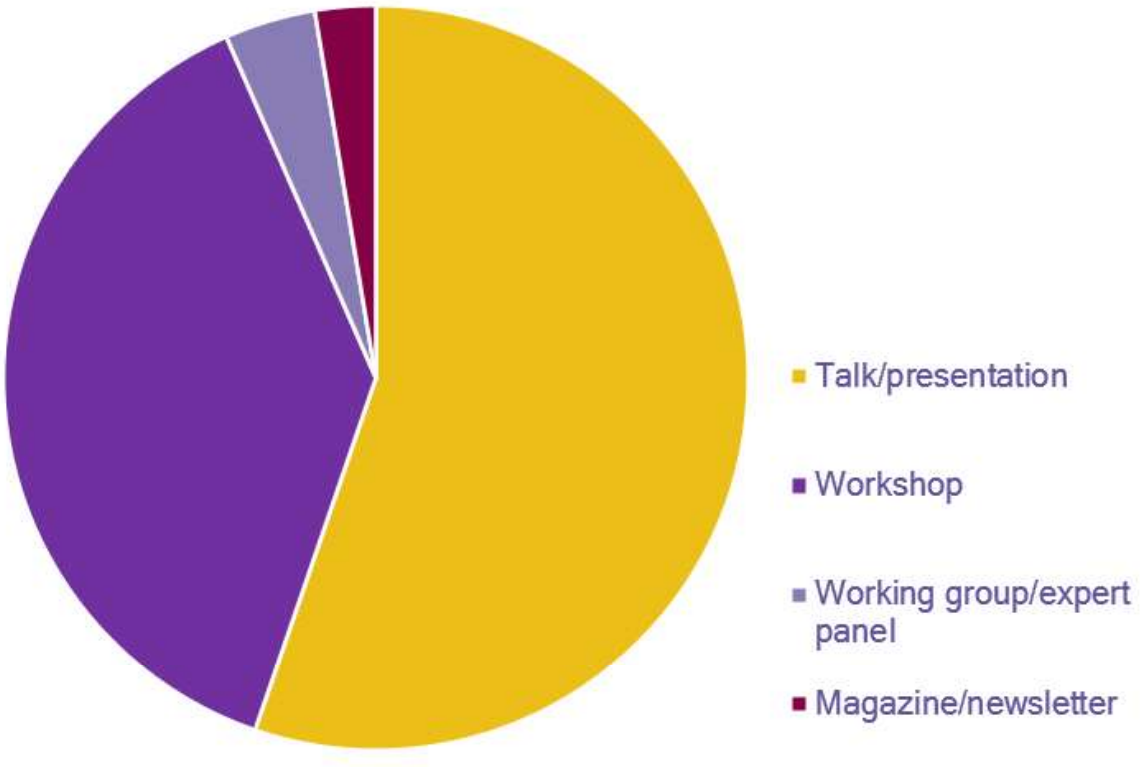
Researchers also reported 76 engagement activities over the last 10 years, demonstrating engagement with patient groups, researchers, clinicians, students and the general public. Engagements such as these help to increase awareness of ataxia research and foster idea-sharing amongst the community and beyond. The pie chart above shows the nature of the 76 reported engagement activities.

56% of Ataxia UK funded projects secured further funding for research

Promoting research and collaboration

Ataxia UK continues to work with pharmaceutical companies to support their ataxia programmes. For example, this year we worked with Biohaven Pharmaceuticals on their Burden of Illness study, focused on a number of types of SCA. The results of this study were presented by Biohaven at international conferences, with Ataxia UK's Director of Research named as an author on the conference abstracts.

To aid us in our work with pharmaceutical companies, we continue to meet with our Pharma Strategy Advisory Group. Topics discussed this year included the drug regulatory process and early access programmes available in the UK.



Types of engagement activities by Ataxia UK-funded researchers (past 10 years)

For rare conditions such as ataxia, international collaboration is key. To this end, we represented people with ataxia on a number of global ataxia projects, either through our work with Euro-ataxia or as Ataxia UK. The Ataxia Global Initiative (AGI) is a trial readiness initiative, aiming to increase the success of clinical research for the ataxias. Ataxia UK continues to have a role in the AGI, with Julie Greenfield representing patients on the steering committee, and Silvia Prades Abadias taking over in November 2024.

CureDRPLA partnership

It has been five years since Ataxia UK established a partnership with CureDRPLA to advance research towards treatments for DRPLA, a rare form of ataxia. The CureDRPLA Global Patient Registry has become instrumental in better understanding the prevalence of DRPLA and how this condition presents over time. To date there are 61 participants in the registry.

One aspect of this collaboration has allowed Ataxia UK and CureDRPLA to be involved with the n-Lorem Foundation. This year we are excited to share that the n-Lorem Foundation has developed an experimental treatment that is available for people with DRPLA living in the United States. While this experimental treatment is not yet available elsewhere, potential pathways are being explored to bring it to the UK.



Looking Ahead

The next year holds many exciting opportunities for further international collaboration. In October 2025 Ataxia UK will co-host a small, invitation-only conference designed to allow engagement between patient groups, drug regulators, clinicians and researchers. The aim of this conference is to improve trial design, increase the chances that ataxia treatments are successful at the regulatory stage, and ensure medicines are licensed for use in people with ataxia and ultimately funded by the NHS.

Following this conference, Euro-Ataxia, with the support of Ataxia UK, will host the Global Patient Advocacy Group meeting.

We will continue our work to ensure the patient voice is included at all levels of research. We will be collecting data from people with genetic ataxia on their attitudes towards gene therapy, as part of the international TREAT-ARCA project, on which we represent people.



FUNDRAISING & COMMUNICATIONS



Highlights

2024/25 again proved to be a challenging economic environment for the charity, however, we continue to be very grateful for the consistent support and generosity of our supporters. The charity continues to ensure that our income is used in the most effective way to meet our strategic goals.

The total income raised in FY24/25 was £1,784,000 of which £960,000 was restricted income and £824,000 was unrestricted income with an overall decrease year on year of 2%. There was a considerable increase in unrestricted income overall this year, made possible due to the timing of some very generous legacy gifts. After a disappointing year for legacy gifts in the previous financial year 2023-24, this was a significant rebound, surpassing the stretch target for the year and coming in at £230,000 just over £80,000 up on the original budget. Total income from Events & Community fundraising for the year 2024-25 was £236,257, slightly down on budget; nonetheless, income from our events and community work achieved over 92% of the budget for the year, which is a strong achievement given staffing issues across the year resulted in long-term capacity constraints within the function.

£1,784,000 total income raised in 2024-25

The fundraising landscape remains challenging. Investments into the Fundraising and Communications teams in late 2024 and a renewed focus on unrestricted income will ensure we are best placed to navigate towards sustained growth in future years.



Events & Community Highlights

The London Marathon

We had 9 amazing supporters (4 ballot/own places), including Ben Spencer, our first ever wheelchair participant in the run. Together **our London Marathon team raised an amazing £44,856 including Gift Aid.** This was our best performance to date. The fundraising total amount reflects several large donations including some match funding.

The London Landmarks Half Marathon

We had 16 runners this year, all in charity places as we didn't receive any places through the ballot this year. The fundraising reached £16,600 including Gift Aid which was a modest performance compared to previous years.

Ataxia UK Skydiving Action Day

This was our first Action Day since 2017. Our target was 10 jumpers for the first date and we ended up with 11. Five had to be rescheduled to May due to bad weather but the others completed their jump on 29 March. The combined fundraising was £12,641 including Gift Aid.

Great North Run

We had 16 runners (4 ballot/own places) completing the run this year raising £12,282 including Gift Aid. This was the best performance and the biggest team we have ever had at the run!

The Big Ataxia Cake Bake

We had nine participants this year raising a total of £3,415 (up from £1,512 last year).
We are giving this event a lot more proactive marketing support to get wider reach in the coming year.

Legacies

FY24/25 was a good year for legacy gifts and Ataxia UK's most successful since FY21/22. After a disappointing legacy total in FY23/24, it is good to see the difference legacy gifts can make to the charity. However, it is significant that a large majority of legacy income this year was received as a single gift, which accounted for 77% of total legacy income.

It is always hard to predict legacy income, but the impact of one or two gifts can be transformative. Supporters typically do not indicate how much they intend to leave in their will, and often do not tell us at all. This can mean a wonderful surprise when the gift comes in. Towards the end of FY24/25 we upskilled our Junior Individual Giving Manager, following their work on legacies in this period, and they transitioned to Individual Giving & Legacy Manager. With this shift there was more focus on managing legacies and better stewarding our legacy pledgers.

We need to continue to steward legacy pledgers to ensure they maintain their intention of leaving a legacy, but we also need to continue to invest in our legacy work, as the difference between a good and bad year with legacies can have a significant impact on total fundraising income for the charity.

Big Give

The 2024 Big Give Christmas Challenge, From Lab to Treatment: Your Gift Their Future, sought to raise unrestricted funds to help navigate the next steps of drug development. This contrasted with the last few Big Give campaigns, where the focus was on services.

The success of the campaign in 2024 reflects the importance the ataxia community places on supporting drug development and research more broadly. While the official online campaign total reads £50,773, once we factor in Gift Aid and offline donations our total announced to the community was £57,500, which surpassed our budget for the year. We would like to thank everyone who supported the Big Give Christmas Challenge in 2024.



Communications Overview

This year has been a transition phase for our communications team and strategy. Staff turnover and a period of vacancies towards the end of the year required cross-organisation support in order to maintain our core communications outputs. The magazine and monthly e-news continued to be delivered quarterly and monthly, respectively, to a high standard.

The information for patients, carers and other stakeholders on our website and contained in our information packs has been identified as a priority output of the organisation. A new Communications team has been recruited to focus on revitalising our information offer, alongside growing brand visibility and engagement.



Looking Ahead

Fundraising

Our new Director of Fundraising & Communications joined in the final quarter of FY24/25 and has been building a new-look Fundraising & Communications department designed to deliver sustainable growth, with a major focus on increasing our unrestricted income. In late 2025 we will launch a new Philanthropy function at Ataxia UK, which will, for the first time, provide dedicated resource for our work with High Net Worth Individuals (HNWI), strengthening our ability to identify, cultivate and steward major donors. This will form part of our new multi-year fundraising strategy to develop a focused pipeline of major and regular (multi-year) donors, alongside continuing to recruit legacy pledgers from HNWI communities. Additionally, investments made into the fundraising team in FY24/25, specifically to support the development of Corporate Partnerships, Individual Giving, Legacy and Events & Community work, will continue to support stronger budgeting and pipeline delivery in the years to come.

Communications

The Communications team will work with the Director F&C to increase the visibility of, and engagement with, our brand and cause. In addition to developing new strategies and a refreshed 'tone of voice' for social media, our focus will be on the following priority areas:

Information

The availability of clear information and guidance for patients, medical professionals and other stakeholders is of paramount importance to the charity's mission. The infrastructure we use, such as our website, to communicate or provide this information requires refreshing. This work will be conducted alongside a review of our brand and branded assets to ensure they are engaging and accessible.

Policy & Advocacy Work

A key part of our relationship with the community is our role in providing the 'patient voice' and community advocacy. As the development of treatments continues, we need to meet expectations by working with press, policymakers and other stakeholders to highlight issues of policy and process which affect our patients.

Accessibility

As a disability charity, it is vital that our communications materials and assets, including our website and printed materials, are fully accessible. A project to review this will be conducted in two phases. First, as part of our Information project, any new or refreshed webpages or materials will be designed with accessibility as the guiding principle. Second, following completion of the information project, the review will focus on developing an organisation-wide Accessibility Guide, to provide guidance on accessible communications across the organisation, such as emails, messaging, AI chat functions and more.

FINANCIAL REVIEW



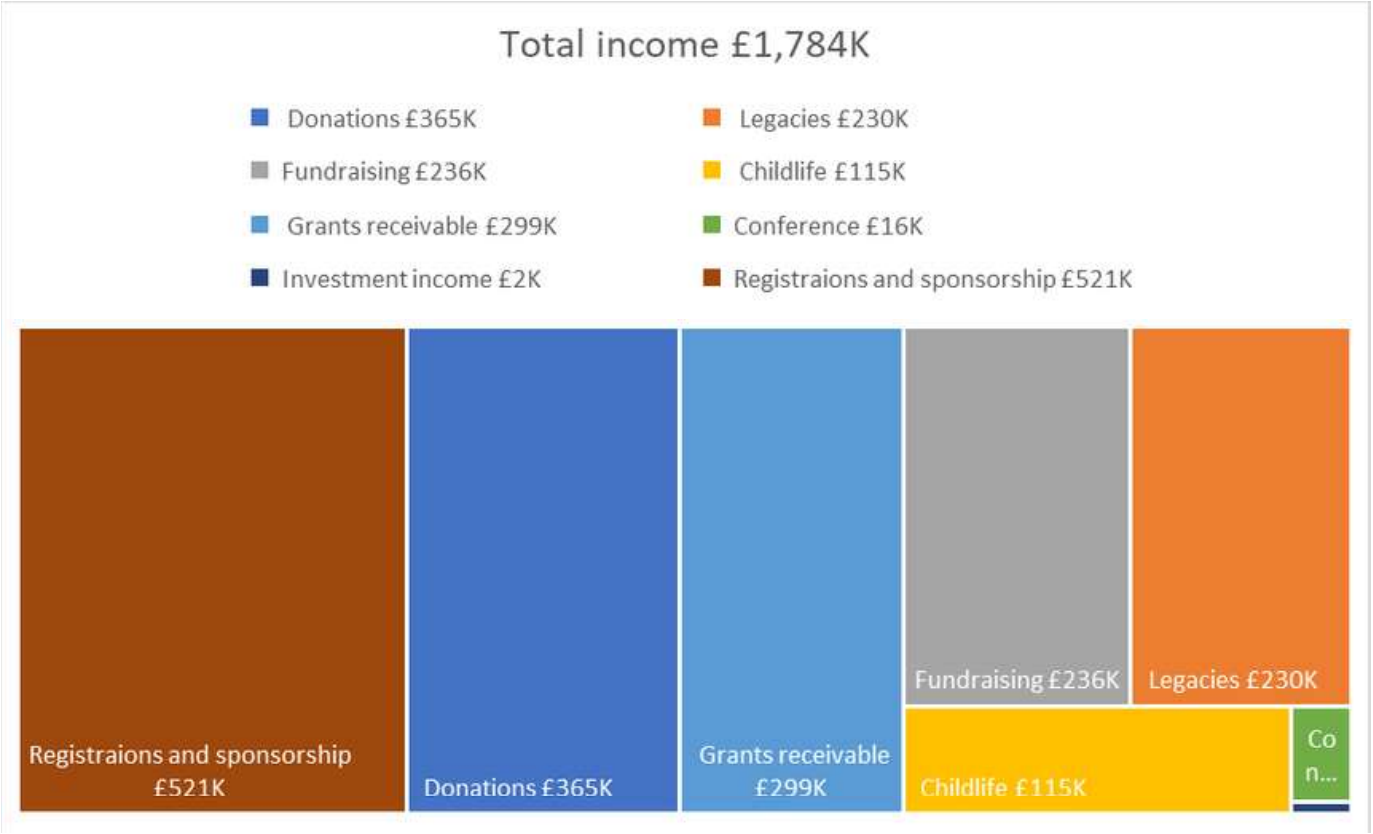
Overview

2024-25 again proved to be a challenging economic environment for the charity, however, we continue to be very grateful for the continued support and generosity of our supporters. The charity continues 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 decrease in Ataxia UK's funds, as a result of a -£13K deficit in the year (2023-24: £488K). The charity has therefore moved from a net asset position of £528K in the 2023-24 financial year to £514K in 2024-25.

We remain with a net liabilities position for restricted funds on the balance sheet, which has increased from -£16K to -£109K. A three year expenditure commitment was made for the DRPLA and NKX6-2 projects in 2020-21, whilst the funding is only received gradually over the same period resulting in net liabilities for the duration of the projects. The projects have progressed slightly slower than originally planned, hence the funding being pushed out for more than the 3 years originally agreed, but the projects are progressing well.

Unrestricted funds have increased to £623K (2024: £543K) which is excellent. Further details of this are given later in this review as are details of reserves. We continue to maintain a healthy cash flow and have cash at bank and in hand of £1.7 million.

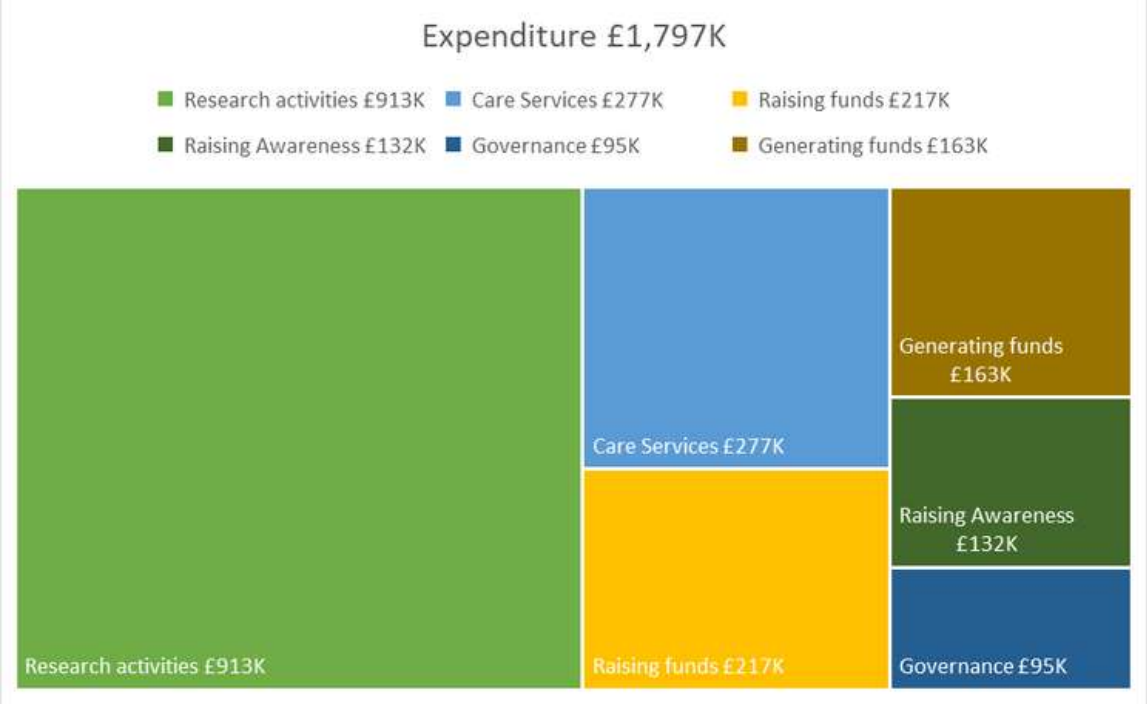


Review of Income

Total income for 2024-25 was £1,784K (2023-24: £1,814K) a decrease of 2% however the source of the income was very different to the previous year reflecting the fluctuating, and therefore challenging, nature of charity income streams. We were delighted to see legacy income increase to £230K for the year (2023-24: £32K), an increase of 619%. Our ten year annual average is considered to be £150K which is almost met over the two years. Childlife income increased by 15% to £115k (2024: £100K) and conference income increased to £16K, (2023-24: £14K) an increase of 14%. £521K was also received for Registrations and sponsorship of the International congress of ataxia research (ICAR) which was very successful and hosted by Ataxia UK and partners in November 2024 (see Research section).

In contrast, donation income was much lower than the previous year, £365K (2023-24: £830K) a decrease of 56%. Income from fundraising activities also decreased to £236K (2023-24: £286K) a decrease of 17%. There were fewer cycling and trekking activities during the year which reduced the income. Grants receivable decreased to £299K (2023-24: £554K), a 46% decrease reflecting the greater demand for, and therefore competitive nature of grant funding.

Review of expenditure



Total expenditure for 2024/25 was £1,797K (2023-24: £1,325K) an increase of 36%.Spending on research activities increased to £913K (2023-24: £382K), however, about 50% of research expenditure is due to the ICAR conference. There was a 14% increase in spend on care services to £277K (2023-24: £243K). Cost of raising awareness decreased from the previous year to £132K (2023-24: £193K) a decrease of 32%. Expenditure on raising funds also decreased by 33% to £217K (2023-24: £271K), whilst on generating funds there was a 9% increase to £163K (2023-24: £150K).

Staff costs and professional fees contribute to these increases as changes were made to the team structure over the year. Governance costs increased by 10% to £95K (2023/24: £86K).

Reserves levels at year end

	2025 (£K)	2024 (£K)
General funds	335	465
Designated funds	288	79
Total unrestricted funds	623	543
Total restricted funds	(109)	(16)
Total funds held	514	528

The charity saw a slight decrease in reserve levels ending the year on £514K (31 March 2024: £528K), due to the total net decrease in funds of -£13K in the year.

Restricted funds were -£109K (2023-24: -£16K), (detailed in Note 22) with deficit positions remaining for DRPLA and NKX6-2 along with the Prospax project and Research service contracts which were due to timing of payments over the year end. A milestone payment of £178K from DRPLA that was expected before the year end was received shortly after the year end.

Designated Funds totalled £288K (2023-24: £79K) representing funds held at branches (£10K) and other designated funds (£278k) as detailed under Note 21.
The fund for the Research conference (ICAR) is no longer required as that has taken place and resulted in a small surplus. The parental fund remains in place. A premises fund has been added in the light of a potential office relocation. The £198K designation for Service development is to cover the increase in services and development of additional ataxia centres around the country.

General reserves of the charity as at 31 March 2025 were £335K (31 March 2024: £465K) a 28% decrease due to the increase in designated funds. 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 was updated in 2024 to reflect the fact that operating costs are impacted by one off incidents such as ICAR. The policy is therefore to hold unrestricted, undesignated reserves equal to a minimum of 3 months operating costs adjusted for out-of-pocket costs covered by research and services restricted income. For 2024/25 the required reserve amounts to £327K and is therefore covered by unrestricted funds.

Going Concern

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



ATAXIA UK – STATEMENT OF TRUSTEES RESPONSIBILITIES



Statement 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.
- Prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity 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, the 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

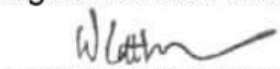
Insofar as the Trustees are aware:

- 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 have taken 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 trustees on 9th October 2025 and

signed on their behalf by;



William Littleboy, Chair



Kathy Jones – Treasurer

Independent Auditor's Report to the Trustees of Ataxia UK

Opinion

We have audited the financial statements of Ataxia UK for the year ended 31 March 2025 which comprise the Statement of Financial Activities, Balance Sheet and notes to the financial statements, including a summary of significant accounting policies.
In our opinion the financial statements:

- Give a true and fair view of the state of the charitable company's affairs as at 31 March 2025 and of its incoming resources and application of resources 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 Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, and the Charities Accounts (Scotland) Regulations 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 section of our report. We are independent of the charitable company 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 at least twelve months from when the financial statements are authorised for issue.

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

Other information

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

Matters on which we are required to report by exception

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

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- Adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- The financial statements are not in agreement with the accounting records and returns; or
- Certain disclosures of Trustees' remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit; or
- The Trustees were not entitled to take advantage of the small companies exemption.

Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, 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 the Trustees 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 charitable company'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 charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's 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 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.
    - 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

4 December 2025

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 2025

	Notes	Unrestricted funds	Restricted funds	Total funds *2025*	Total funds *2024*
		£	£	£	£
Income					
Donations and legacies	3	*556,687*	*38,174*	**594,861**	*859,346*
Other trading activities	4	*226,554*	*9,138*	**235,692**	*285,854*
Charitable activities	5	*38,602*	*912,656*	**951,258**	*668,577*
Investments	6	*1,882*	*-*	**1,882**	*-*
Total income		*823,725*	*959,968*	***1,783,693***	*1,813,777*
Expenditure on:					
Raising funds	7	*(217,421)*	*-*	***(217,421)***	*(271,119)*
Charitable activities	8	*(524,138)*	*(1,055,295)*	***(1,579,433)***	*(1,054,353)*
Total expenditure		*(741,559)*	*(1,055,295)*	***(1,796,854)***	*(1,325,472)*
Net losses on investments		-	-	-	-
Net income/(expenditure)		*82,166*	*(95,327)*	***(13,161)***	*488,305*
Transfer from Unrestricted to Restricted		*(2,286)*	2,286	-	-
Net movement in funds		*79,880*	*(93,041)*	***(13,161)***	*488,305*
Total funds brought forward		*543,290*	*(15,674)*	***527,616***	*39,311*
Total funds carried forward		***623,170***	***(108,715)***	***514,455***	*527,616*

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

All recognised gains and losses are included in the SOFA.

The accompanying pages form part of these financial statements.

ATAXIA UK

DETAILED COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

(incorporating the income and expenditure account)

(incorporating the results of the Charity's branches)

for the year ended 31st March 2024

	Notes	Unrestricted funds	Restricted funds	Prior year Total funds *2024*
		£	£	£
Income				
Donations and legacies	3	*308,728*	*550,618*	*859,346*
Other trading activities	4	*275,182*	*10,672*	*285,854*
Charitable activities	5	*14,545*	*654,032*	*668,577*
Investments	6	-	-	-
Total income		*598,455*	*1,215,322*	*1,813,777*
Expenditure on:				
Raising funds	7	*(271,119)*	-	*(271,119)*
Charitable activities	8	*(509,372)*	*(544,981)*	*(1,054,353)*
Total expenditure		*(780,491)*	*(544,981)*	*(1,325,472)*
Net losses on investments		-	-	-
Net income/(expenditure)		*(182,036)*	*670,341*	*488,305*
Transfer from Unrestricted to Restricted		(871)	871	-
Net movement in funds		*(182,907)*	*671,212*	*488,305*
Total funds brought forward		*726,197*	*(686,886)*	*39,311*
Total funds carried forward		*543,290*	*(15,674)*	*527,616*

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

All recognised gains and losses are included in the SOFA.

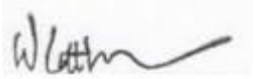
The accompanying pages form part of these financial statements.

ATAXIA UK
BALANCE SHEET
As at 31st March 2025

	Notes	*2025* £	£	*2024* £	£
Fixed assets					
Tangible assets	14	**12,182**		13,723	
			12,182		13,723
Current assets					
Debtors	15	**435,141**		358,520	
Cash at bank and in hand	16	**1,686,350**		1,875,365	
		2,121,491		2,233,885	
Creditors: amounts falling due within one year	17	**(1,131,513)**		(1,123,662)	
Net current assets			**989,978**		1,110,223
Total net assets less current liabilities			**1,002,160**		1,123,946
Creditors: amounts falling due after more than one year	18		**(487,705)**		(596,330)
Total net assets/(liabilities)	19		**514,455**		527,616
Accumulated funds					
Unrestricted funds					
General funds	20		**334,653**		464,563
Designated funds	21		**288,517**		78,727
			623,170		543,290
Restricted funds	22		**(108,715)**		(15,674)
Total funds			**514,455**		527,616

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 21st November 2025 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 2025

	2025	2024
	£	£
Cash generated from operating activities:		
Net cash provided by operating activities	**(183,576)**	294,384
Cash flows from investing activities:		
Dividends and interest from investments	**1,882**	-
Purchase of property, plant and equipment net of sales	**(7,321)**	(8,251)
Net cash provided/(used in) by investing activities	**(5,439)**	(8,251)
Net increase in cash:	**(189,015)**	286,133
Cash at bank and in hand less overdrafts at the beginning of the year	**1,875,365**	1,589,232
Change in cash and cash equivalents	**(189,015)**	286,133
Cash at bank and in hand less overdrafts at the end of the year	**1,686,350**	1,875,365

Reconciliation of net income to net cash flow from operating activities

	2025	2024
	£	£
Net (expenditure)/income	**(13,161)**	488,305
Adjustments for:		
Depreciation charges	**8,862**	10,890
Dividends and interest from investments	**(1,882)**	-
(Increase)/Decrease in debtors	**(76,621)**	6,521
Increase/(Decrease) in creditors	**(100,774)**	(211,332)
Net cash provided by operating activities	**(183,576)**	294,384

Analysis of cash at bank and in hand less overdrafts

	2025	2024
	£	£
Cash at bank and in hand	**1,686,350**	1,875,365
	1,686,350	1,875,365

ATAXIA UK
NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2025

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 2024/25 financial year, we had a net deficit in total funds. The balance sheet shows a net asset position. The DRPLA and NKX6-2 grants were agreed in 2020/21 with the funding received over 3 years. Covid delayed the start of the projects and means the research should be completed and all funds received by 2026. See note 22 (note I DRPLA and note ii NKX6-2) below for further details. The cost of living crisis has had an impact on donations and could continue to have an impact on the 2025/26 financial year. We continue to take steps to ensure the continued viability of the charity. The cashflow is reviewed regularly to ensure that unrestricted cash is going to be adequate at all times, but in the current year, legacy giving is surpassing expectations. The Finance Committee meet regularly to monitor the situation and the fundraising department are continuing to pursue other ways to raise funds to safeguard income. To aid robust forecasting, a budget and associated cash flow have been drawn up for 2025-2027. The Trustees feel there are adequate resources to continue operating for the foreseeable future. The Trustees feel that there are no material uncertainties about the charitable company's ability to continue as a going concern. Accordingly, we continue to adopt the going concern basis in preparing this annual report and financial statements.

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

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

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

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

Principal Accounting Policies (continued)

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

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

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

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

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

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

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

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

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

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

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

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

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

Note 3 Donations and Legacies Income

	2025	2024
	£	£
Donations	**364,721**	827,551
Legacies	**230,140**	31,795
	594,861	859,346

Note 4 Other Trading Activities

	2025	2024
	£	£
Fundraising activities	**235,692**	285,854
	235,692	285,854

Note 5 Charitable Activities Income

	2025	2024
	£	£
Childlife	**115,000**	100,000
Annual conference	**16,444**	14,156
Grants receivable	**298,698**	554,421
Registrations and sponsorship	**521,116**	-
	951,258	668,577

Note 6 Investment Income

	2025	2024
	£	£
Interest	**1,882**	-
	1,882	-

Note 7 Raising Funds Expenditure

	2025	2024
	£	£
Costs of generating funds	**217,421**	271,119
	217,421	271,119

Note 8 Charitable Activities Expenditure

	Direct Costs	Grants	Support Costs	2025 Total	2024 Total
	£	£	£	£	£
Research activities	737,524	67,923	107,288	**912,735**	472,326
Adjustment of committed costs**	-	-	-	**-**	(90,414)
Care services	213,885	9,845	53,230	**276,960**	243,334
Total	951,409	77,768	160,518	**1,189,695**	625,246
Generating funds	-	-	163,107	**163,107**	150,021
Raising awareness	95,472	-	36,398	**131,870**	193,148
Governance	-	-	94,761	**94,761**	85,938
Total charitable activities	**1,046,881**	**77,768**	**454,784**	**1,579,433**	1,054,353

** The reduction in grant was notified in January 2023. As a result, the related committed funds were reduced in FY 23/24 since the full grant amount had already been included in committed funds in the previous year when it was initially approved.

	2025	2024
	£	£
Total support costs		
Staff costs	**226,160**	250,218
Office costs	**219,765**	188,280
Depreciation	**8,862**	10,890
	454,787	449,388

Note 9 : Research Grants

	2025	2024
	£	£
Research grants made in year comprise		
Development of a PRIME editing therapy for Ataxia-8 due to the c.121 A to T point mutation'	-	*8,036*
Z-University of North Carolina at Chapel Hill - new award Dr Malawsky	-	*34,610*
'Development and Validation of SIMOA-based total and mutant Ataxin-2 Immunoassay for biomarker studies in SCA2 and SCA3'	-	*30,000*
Z-Institut du Cerveau et de laMoelle épinière-ICM	-	*691*
Novel biomarkers of oxidative stress in Friedreich's ataxia	-	*4,800*
Identification of disease-associated single nucleotide polymorphisms in ataxin-3	-	*4,470*
Evaluating ribosome collisions on CAG expansions proteostasis and translational stress responses in Spinocerebellar Ataxia type 3	-	*3,000*
Consultancy support with respect to preparing for Health Technology Assessment	-	*5,800*
Effect of targeting sphingolipid- metabolising enzymes in iPSC-derived sensory neurons obtained from FRDA patients	-	*4,954*
Exploring novel iron-mediated mechanisms to prevent cellular death in Friedreich's Ataxia	-	*5,000*
Z-University of Tübingen (Germany) -)- Refinement of allele-specific antisense oligonucleotides for spinocerebellar ataxia type 3 (SCA3)	***28,775***	-
Z - University Miami - Supporting a genome-wide association study of genetic modifiers of age at onset in spinocerebellar ataxia	***30,000***	-
Z Institut D'assistacencia Sanataria Salt (Girona) – DRPLA research	***7,781***	-
Z-Algarve Biomedical Center Research Institute - grant to attend and present a poster at the Cell Death Gordon Research Conference 2024	***1,369***	-
Z-Universidade de Lisboa - Grant application entitled 'Towards a pharmacological model of Autosomal Recessive Spastic Ataxia of Charlevoix-Saguenay (ARSACS)'	***5,000***	-
Z-Universidade de Lisboa - Restoring NKX6-2 function by protein complementation: a proof-of-concept	***5,000***	-
Z-Newcastle University, Dr Ng - A feasibility study of Remote Patient-Reported Outcome measures in Mitochondrial disease and Spinocerebellar ataxias (R-PROMS)	***4,998***	-
Z-Festenstein - Imperial - Cancelled pre 2021 project	***(15,000)***	-
	67,923	101,361

Note 10 : Staff Costs

	2025	2024
	£	£
Staff costs comprised:		
Salaries	**768,424**	758,818
Social security contributions	**75,466**	74,813
Pensions	**36,928**	38,269
Redundancy and termination costs	**-**	-
	880,818	871,900

The average number of employees during the year was 19 (2024: 20) with all employee time involved in providing either support to the governance of the charity or support services to charitable activities.

The senior management team consists of the Chief Executive, Chief Operating Officer and the Directors of Services, Research, Fundraising and Communications.The total employee benefits of the senior management team were £268,586 (2024: £294,585).

The following number of staff members received emoluments in the year:	2025	2024
£80,000 - £90,000	1	1

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

Note 11 : Pension Schemes

All permanent members of staff were eligible to receive payment of 5% of their salary paid into a stakeholder personal plan. The pension premiums payable during the year were £36,928 (2024: £38,317). There was a outstanding balance of £4.710 (2024: £5,090) at the year end.

Note 12 : Trustees

Certain trustees carry out duties that would otherwise be undertaken by paid staff. They receive no remuneration but, along with the other trustees, may claim reimbursement of out of pocket expenses. During the year, total trustee expenses £3,830 for attending the board meetings were incurred. 2 trustees (2024: 1) reimbursed expenses totalling £511 (2024: £81).

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

	2025	2024
	£	£
Auditor's remuneration and account preparation excluding VAT	**7,500**	7,500
Depreciation	**8,862**	10,890
Operating lease costs	**-**	1,000

Note 14 : Tangible Fixed Assets

	Building Works	Other Assets	Total
	£	£	£
COST			
As at 1st April 2024	5,333	52,535	**57,868**
Additions	-	7,321	**7,321**
Disposals	-	-	**-**
As at 31 March 2025	5,333	59,856	**65,189**
DEPRECIATION			
As at 1st April 2024	5,191	38,954	**44,145**
Charge for year	142	8,720	**8,862**
Disposals	-	-	**-**
As at 31 March 2025	5,333	47,674	**53,007**
NET BOOK VALUE			
As at 31 March 2025	**-**	**12,182**	**12,182**
As at 1st April 2024	142	13,581	13,723

Included within the net book value of the 'Other Assets' is an amount of £Nil (£1,000 in 2024) relating to items acquired on Finance Lease/Hire purchase.

Note 15 : Debtors Under 1 Year

	2025	2024
	£	£
Income tax recoverable	**51,465**	51,464
Other debtors	**351,310**	268,633
Prepayments	**32,366**	38,423
	435,141	358,520

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

	2025	2024
	£	£
Other creditors	**27,874**	11,361
PAYE/NI	**50,714**	60,775
Deferred income	**214,962**	85,886
Accruals	**27,066**	30,043
Research grants	**810,897**	935,597
	1,131,513	1,123,662

Note 18 : Creditors: Amounts falling due after one year

	2025	2024
	£	£
Research grants	**487,705**	596,330
	487,705	596,330

Note 19 : Analysis of net assets between funds

	Restricted Funds	Designated Funds	General Funds	Total 2025	Total 2024
	£	£	£	£	£
Fixed assets	632	-	11,550	**12,182**	13,723
Debtors	-	-	435,141	**435,141**	358,520
Cash at bank and in hand	1,189,255	288,517	208,578	**1,686,350**	1,875,365
Creditors	(1,298,602)	-	(320,616)	**(1,619,218)**	(1,719,992)
	(108,715)	**288,517**	**334,653**	**514,455**	527,616

Note 20 : Unrestricted Funds

	General Funds	Designated Funds	Total
	£	£	£
Balance as at 1 April 2024	464,563	78,727	**543,290**
Net increase/(decrease) in funds during the year	78,090	1,790	**79,880**
Transfers	(208,000)	208,000	**-**
Balance as at 31 March 2025	**334,653**	**288,517**	**623,170**

Note 21 : Designated Funds

	Opening Balance	Net Movement	Transfers	Closing Balance
	£	£	£	£
Funds held in branches	8,727	1,790	-	**10,517**
Premises Fund	-	-	40,000	**40,000**
Parental	40,000	-	-	**40,000**
Service development	-	-	198,000	**198,000**
Research conference fund	30,000	-	(30,000)	**-**
	78,727	**1,790**	**208,000**	**288,517**

a) Funds held in branches: Funds held by the branches and not available for normal activities of central office.
b) Parental: Funds being held to cover potential periods of maternity leave.
c) Premises: Funds held to cover the costs associated with a potential office relocation.
d) Service development: Funds held to cover the increased provision of services and the development of additional ataxia centres.

Note 22 : Restricted Funds

	At 1 April 2024	Income	Expenditure	Transfers	At 31 March 2025
	£	£	£	£	£
General Research	303,515	25,074	(105,460)	15,000	**238,129**
Friedreich's ataxia research	11,841	7,988	(24,903)	32,973	**27,899**
Cerebellar ataxia research	1,091	7,719	(11,057)	9,421	**7,174**
Gene therapy survey project	-	7,000	(1,400)	-	**5,600**
Young Person's projects	7,959	-	-	-	**7,959**
Jerry Farr travel fund	671	-	-	-	**671**
Welfare - The Gift of Speech	8,677	97	(10,536)	1,762	**-**
Nicotinomide	24	-	-	-	**24**
Scottish Project	-	10,000	(6,500)		**3,500**
Helpline	4,152	-	-	-	**4,152**
Misc Grants	450	8,624	(8,239)	-	**835**
Childlife	-	115,000	(57,606)	(57,394)	**-**
Awareness	4,171	-	-	-	**4,171**
Kennedy Award	9,198	-	-	-	**9,198**
Research Stem Cell FA	78	-	-	(78)	**-**
Mark Dower Trust	224	2,000	(2,826)	602	**-**
Spinocerebellar Ataxia Research Project	4,912	-	-	-	**4,912**
DRPLA Research	(478,581)	7,878	(7,781)	-	**(478,484)**
The National Lottery Community Fund – RC England Wide	71,912	81,367	(142,412)	-	**10,867**
DRPLA Department	15,876	179,202	(172,842)	-	**22,236**
Scotland	800	-	-	-	**800**
NKX6-2	(23,391)	-	(1,639)	-	**(25,030)**
AOA2	7,009	858	(123)	-	**7,744**
Prospax Project	(440)	4,611	(5,456)	-	**(1,285)**
Research Service Contracts	-	3,902	(14,707)	-	**(10,805)**
Research SCA6	573	-	-	-	**573**
Research SCA3	62	-	-	-	**62**
Research ICAR Conference	27,565	498,016	(481,808)	-	**43,773**
Misc AAA++	5,978	632	-	-	**6,610**
	(15,674)	**959,968**	**(1,055,295)**	**2,286**	**(108,715)**

Purpose of restricted funds

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

Purpose of restricted funds (continued)

m) Exeter: Funds to be expended in the Exeter area.
n) Awareness: Funds provided to raise awareness of Ataxia.
o) Kennedy Award: A fund set up to assist researchers studying Friedreich's ataxia with attending scientific conferences and other small research studies.

p) 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.

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

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

s) In Control Project: Funds provided by the Lottery to promote volunteers and provide support to the ataxian

t) The National Lottery Community Fund – RC England Wide : Grant to develop services for people affected by ataxia

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

v) Scotland: Funds to be expended in Scotland.
w) NKX6-2: Funds provided by donors specifically for research into NKX6-2**.** See note 2 below.
x) AOA2: Funds provided by donors specifically for research into ataxia with oculomotor apraxia type 2.
y) Prospax Project: Funds provided by donors specifically for research into spastic ataxias.
z) Research Service Contracts: Funds provided for projects undertaken by the research department.
aa) SCA6: Funds provided by donors specifically for research into Spinocerebellar ataxia type 6 .
ab) SCA3: Funds provided by donors specifically for research into Spinocerebellar ataxia type 3.
ac) ICAR Conference: Funds provided towards costs of International Congress for Ataxia Research 2024 being held in London, UK.

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

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

During the 2023-4 financial year income of £513k was received and the grants awarded reduced by net £53k because of a reduction in the scope of work.

During the 2024 **–** 5 financial year income was £7878. It is anticipated that the project will be completed by March 2027.

Note ii: Two NKX6-2 research grants of £105k were agreed 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 signed agreements in place with both the funder and the recipients of the research grants outlining the payment structure ensuring these future commitments will be met.

During the 2023-4 year income was received of £23k and £8k of grants awarded by the charity.

Nil income was received during the 2024-5 financial year. It is anticipated that this project will complete during the 2024-5 year.

Note 23 : Capital Commitments

There are no capital commitments at 31 March 2025 (2024: Nil)

Note 24 : Lease Commitments

At 31 March 2025 the charity had future minimum lease payments under non-cancellable operating leases as follows:

	2025		2024	
	Land & buildings £	Other £	Land & buildings £	Other £
Payments due:				
Within one year	-	1,861	-	1,608
Within two to five years	-	5,195	-	-
	-	**7,056**	-	1,608

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.

Thank You to Our Supporters

Ataxia UK extends heartfelt thanks to all the individuals, community groups, schools, companies, and organisations who have supported us during 2024–25.

Our Supporters 2024–25

Porthmadog Golf Club, AJ Case Management, XN Leisure Systems Ltd, MD Law (Yorkshire) LLP, Will Street, Porthmadog – Sandra Creamer, MidexPro – Avebury Computing, Shaw Heath Bees FC, RBC GAM UK, State Street Bank, Crosshill Social Club, Gala Bowling Club, St Edward's Church, Stanstead Abbotts Village Club, All Hallows Church, Centura Golf Society, Rhiwbina Trefoil Guild, St Mary's Methodist Church Bright Hour, Waverley School, Woodhouse Community Music Groups, The Lodge of Harmony and Progress, SQS Ltd via Martin Jones, Harris Academy, North Cornwall Whist Holiday Group, Harrogate Spa Town Ukes, Brandhall Community Choir, Dalton District Girlguiding, Richmond Amateur Dramatic Society, Poeton Industries, St Mary's Methodist Church, Reddam House School.

Collaborations/Partners

Parkhead CAB in Glasgow. Cure DRPLA

ICAR 2024 Sponsors

Ataxia UK also warmly thanks all sponsors of the International Congress for Ataxia Research (ICAR 2024) for their invaluable support and partnership in driving progress for the ataxia community worldwide.

Biogen, Biohaven, Larimar Therapeutics, PTC Therapeutics, Lexeo Therapeutics, Amgen, Quince Therapeutics, Stealth BioTherapeutics, Solaxa, Fannin, Alexion, Design Therapeutics, Astellas, Insmed, Friedreich's Ataxia Research Alliance Ireland (FARA), Association Française de l'Ataxie de Friedreich (AFAF).

We'd like to thank the following Individuals and Trusts and Foundations

National Lottery Community Fund, Ernest Hecht Charitable Foundation, Foundation Rumsey-Cartier, Keith Miller, The Hospital Saturday Fund, James Rapson and the Bishops Cannings Cricket Club, The Big Give Trust, Citizens Advice Scotland Development Fund.

Our Ataxia Angel in this financial year is Neil Dennehy

Our 2024 Big Give Pledgers

Peter Reeves, Andrew Downie, Harriet Brown, Colin Wise, Nicholas Luff, John Chapman

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Ataxia UK is a Charity registered in Scotland (SC040607) & England & Wales (1102391); & Limited Company (4974832)

ATAXIA UK

England & Wales - Charity number 1102391

Accounts

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

Ataxia UK Annual Report & Financial Statement

For the financial year 1st April 2023 – 31st March 2024

ATAXIA

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Ataxia UK works across the whole of the UK and is a charity registered in Scotland (No. SC040607) and in England and Wales (No. 1102391) and a company limited by guarantee (No. 04974832)

Statement from Chair

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

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

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

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

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

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

Honorary Officers

William Littleboy, Co-Chair
Kathy Jones Honorary Treasurer

Trustees

Angela Hosie

Carol McCudden
(Re-elected 2023)

Gemma Fish

Rachel Harrison

Robert Perkins
(Retired Aug 2023)

Harriet Brown

Nathan Hall
(Joined Oct 2023)

Olivia Wood
(Joined Dec 2023)

Prof Barry Hunt
(Scientific Advisor to the Board)

Susan Millman
(Company secretary and CEO)

Ataxia UK uses the following professional advisors:

Auditors

Goldwins Limited
75 Maygrove Road
West Hampstead
London NW6 2EG

Bankers

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

HR Consultants

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

Solicitors

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

Structure, Governance & Management

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

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

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

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

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

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

Public Benefit

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

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

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

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

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

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

Statement of Equality, Diversity and Inclusion

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

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

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

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

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

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

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

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

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

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

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

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

The SAC comprises the following independent scientific members:

Dr Javier Alegre-Abarretegui, Dr Franziska Denk, Professor Helen Dawes, Dr Mark Pook, Professor Keith Morris, Dr Gita Ramdharry and Dr Sophie Rowlands. The committee also included the following lay members during the year: Yanita Oparlakova, Harriet Brown and Nathan Hall.
Professor Barry Hunt acted as the Ataxia UK's Board Scientific Advisor.

All members are unpaid volunteers.

Employees

During 2022-23 the average number of full-time equivalent employees during the year was 18 (with all employees' time involved in providing either support to the governance of the Charity or our charitable activities).
From May 2023 our Finance Department has been supported by Fiona Bevan of Bevan Financial Management Ltd. We outsource IT support and HR advice functions.

Volunteers

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

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

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

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

Risk Management

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

Objectives & Activities

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

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

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

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

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

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

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

Our Strategic Plan

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

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

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

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

- Establish a peripatetic Specialist Ataxia Nursing Service to accompany patients to appointments and support them in managing all aspects of their care.
- Continue to develop the Helpline and Advocacy Service and improve the support information held on the website.
- Revise the Medical Guidelines for the Treatment of the Ataxias and publish the 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.

Achievements & Performance, Aims for 2024 – 2025

Research

Research aims for 2023 – 2024

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

Facilitate networking amongst UK based ataxia researchers

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

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

Press for swift approvals for ataxia treatments in the UK

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

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

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

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

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

Publication and dissemination of DRPLA research

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

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

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

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

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

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

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

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

Other Research Activities

Ataxia UK Research Grants Programme

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

Ataxia UK Grants

1. **Dr Abeti and Prof Giunti (UCL, UK)** - 'Exploring novel iron-mediated mechanisms to prevent cellular death in Friedreich's ataxia' - £5,000

2. **Dr Anjoumani-Virmouni (Brunel University)** - 'Effect of targeting sphingolipid-metabolising enzymes in iPSC derived sensory neurones obtained from FRDA patients' - £4,955

3. **Dr Hauser (DZNE, Germany)** - 'Identification of disease-associated single nucleotide polymorphisms in ataxin-3'-£4,470

4. **Dr Hubener-Schmid (University of Tubingen, Germany)** - 'Development and Validation of SIMOA-based total and mutant Ataxin-2 Immunoassay for biomarker studies in SCA2 and SCA3' - £30,000

5. **Dr Matassa University of Naples, Italy)** - 'Evaluating ribosome collisions on CAG expansions proteostasis and translational stress responses in Spinocerebellar Ataxia type 3' - £3,000

6. **Prof Clayton (Great Ormond Street Institute of Child Health, UK)** - Novel biomarkers of oxidative stress in Friedreich's ataxia' - £4,800

7. **Prof Tremblay (Universite' Laval, Canada)** Novel biomarkers of oxidative stress in Friedreich's ataxia' - £8,036

8. **Realise Advocacy consultancy** -'Preparing for the health technology assessment process in FA' - £5,800

DRPLA Grants (in partnership with CureDRPLA)

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

Analysis of research outcomes of Ataxia UK funded research

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

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

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

Medical Research Charities Covid Support Fund

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

Update on DRPLA Research Programme

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

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

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

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

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

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

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

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

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

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

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

Ataxia UK also supported companies in ataxia awareness raising activities.

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

Pharma Strategy Advisory Committee

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

Multi-Centre European and International Research Projects

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

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

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

Accelerating and expanding the drug repurposing pipeline for rare neurological, neurometabolic and neuromuscular disorders by exploiting SIMilarities in clinical and molecular PATHology (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 Ataxia UK. A representative of the Ataxia UK Research team attended the annual meeting of this project, held in Turkey, and we have continued to produce blogs and disseminated communications to the community.

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

TREAT-ARCA Project

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

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

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

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

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

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

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

FA Global Clinical Consortium

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

Cerebellum and Emotional Networks (CEN)

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

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

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

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

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

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

Ataxia Global Initiative (AGI)

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

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

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

AT Society Collaboration

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

Recruitment of Participants to Research Studies

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

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

Raising Awareness of Ataxia Research

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

Ataxia UK's Research Aims for 2024 - 2025

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

Care and Support Services for People Affected by Ataxia

Care and support aims for 2023-24

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

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

Services Overview

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

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

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

Community Activities

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

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

All About Ataxia

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

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

All About AtaxiaPLUS

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

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

Wellbeing Week

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

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

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

Volunteers' Week

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

Branch and Support Groups

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

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

Volunteering

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

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

Diverse Placements

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

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

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

Scottish Advice Service

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

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

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

Helpline & Advocacy Service

Helpline

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

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

Advocacy Service

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

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

Membership

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

Care & Support aims for 2024 - 2025

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

Improvements in Treatments & Care

Treatment & Care aims for 2023-24

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

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

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

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

Hold Euro-ataxia annual conference in Greece

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

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

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

Interviews were also conducted with patient group representatives, researchers and clinicians to get their perspective on important issues facing the ataxia community.
We were successful in getting a grant from the European Union's Horizon 2020 research and innovation programme (under the EJP RDCOFUND-EJP N° 825575), and sponsorship from pharmaceutical companies, meaning we could offer participants contributions to the cost of attending.

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

Publish Ataxia Medical Guidelines

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

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

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

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

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

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

Speech Therapy

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

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

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

Voice Banking

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

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

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

Other Activities Supporting Improvements in Treatments & Care

Medical Advisory Panel meetings

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

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

Value of Treatment Project - evaluating the work of Ataxia Centres

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

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

Ataxia UK Ethics Review Committee

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

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

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

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

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

Consultations for changes in healthcare services

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

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

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

Ataxia UK accredited Ataxia Centres

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

Sheffield Adult Ataxia Centre – Royal Hallamshire Hospital Sheffield

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

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

Ataxia Children's Centre at Sheffield Children's Hospital

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

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

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

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

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

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

London Paediatric Ataxia Centre

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

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

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

Oxford Ataxia Centre at John Radcliffe Hospital

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

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

Euro-ataxia

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

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

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

Lobbying for improvements in care and research

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

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

Treatments & Care Aims for 2024 - 2025

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

Fundraising

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

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

Maintain income, seeking modest growth where possible.

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

Continual revision and improvement of our thanking process.

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

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

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

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

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

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

Our Approach to Fundraising

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

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

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

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

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

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

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

Our Supporters

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

Highlights

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

Communications

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

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

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

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

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

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

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

Complete and launch our first full length ataxia documentary

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

Continue improving our core services / information dissemination

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

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

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

Financial Review

For the year ending 31 March 2024

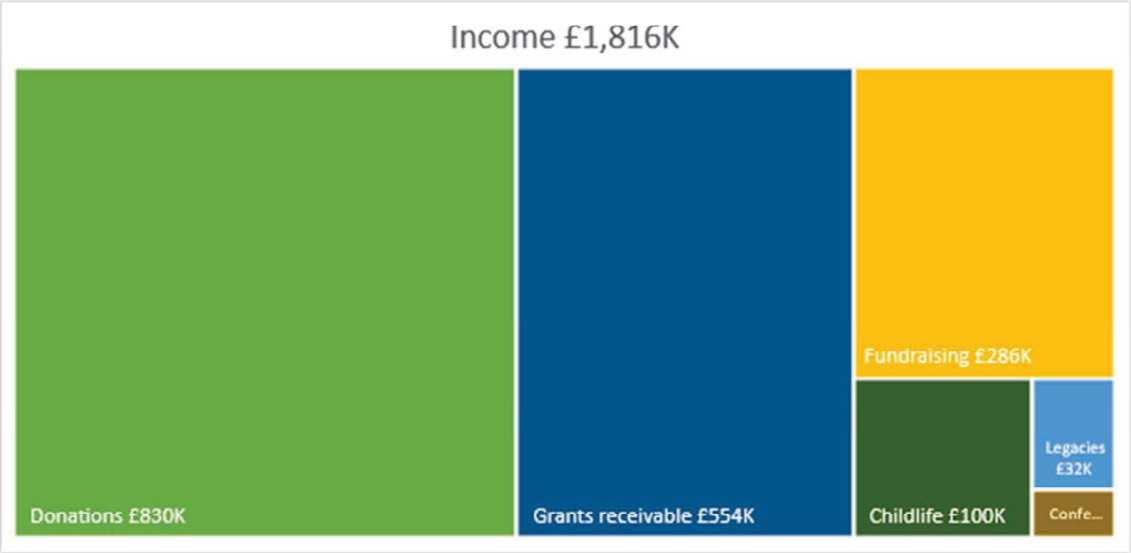
Overview

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

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

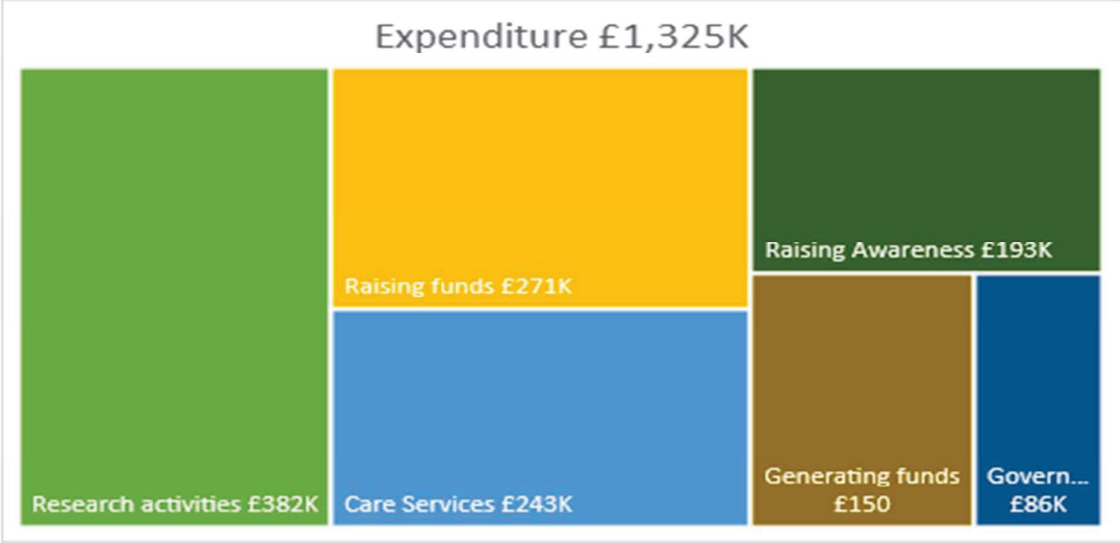
The deficit in restricted funds, of which DRPLA and NKX6-2 funds are part, have decreased over the year to (£16K) (2023: (£687K)). General unrestricted funds have unfortunately decreased to £543K (2023: £726K) due to the costs of running the charity increasing at a greater rate than the income. Further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

Review of income



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

Review of expenditure



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

Reserves levels at year end

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

The charity saw an increase in reserve levels ending the year on £528K (31 March 2023: (£39K)), due to the total net income of £488k generated in the year.
Restricted funds were (£16K) (2022/23: (£687K)), (detailed in Note 22) with their still being deficit positions for DRPLA and NKX6-2. These deficit positions have very much decreased in the year.
Designated Funds totalled £79K (2022/23: £343K) representing funds held at branches (8.7K) and other designated funds (£70k) as detailed under Note 21.
The trustees have released 5 designated funds during the year and decreased one. These were unrestricted funds which were set aside by trustees for a future purpose but were felt to no longer be needed. A parental fund and Research conference fund remain; the conference fund relates to the ICAR conference to be held in November 2024.

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

GOING CONCERN

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

Statements of Trustees' responsibilities

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

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

In preparing the accounts, the Trustees are required to:

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

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

Statement as to disclosure to our auditors

Insofar as the trustees are aware:

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

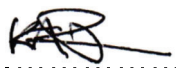
In preparing this report, the trustees have taken advantage of the small companies exemptions provided by section 415A of the Companies Act 2006.

Approved by the trustees on 9th October 2024 and

signed on their behalf by;



William Littleboy, Chair



Kathy Jones – Treasurer

Independent auditor's report to the members of Ataxia UK

Opinion

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

In our opinion, the financial statements:

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

Basis for opinion

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

Conclusions relating to going concern

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

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

Independent auditor's report to the members of Ataxia UK

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

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

Other information

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

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

We have nothing to report in this regard.

Opinion on other matters prescribed by the Companies Act 2006

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

- the information given in the trustees' report (incorporating the directors' report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and

- the trustees' report (incorporating the directors' report) has been prepared in accordance with applicable legal requirements.

Independent auditor's report to the members of Ataxia UK

Matters on which we are required to report by exception

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

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

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

Responsibilities of the trustees

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

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

Our responsibilities for the audit of the financial statements

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

Independent auditor's report to the members of Ataxia UK

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

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

Capability of the audit in detecting irregularities

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

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

Independent auditor's report to the members of Ataxia UK

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

A further description of our responsibilities is available on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. 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

10 October 2024

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

ATAXIA UK

STATEMENT OF FINANCIAL ACTIVITIES

(incorporating the income and expenditure account)

(incorporating the results of the Charity's branches)

for the year ended 31st March 2024

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

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

All recognised gains and losses are included in the SOFA.

The accompanying pages form part of these financial statements.

ATAXIA UK

DETAILED COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

(incorporating the income and expenditure account)

(incorporating the results of the Charity's branches)

for the year ended 31st March 2023

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

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

All recognised gains and losses are included in the SOFA.

The accompanying pages form part of these financial statements.

ATAXIA UK

BALANCE SHEET

As at 31st March 2024

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

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

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

William Littleboy, Chair

Kathy Jones - Treasurer

The accompanying pages form part of these financial statements.

Charity Number: 1102391 Company Number : 04974832

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

	2024	2023
	£	£
Cash generated from operating activities:		
Net cash provided by operating activities	**294,384**	(168,296)
Cash flows from investing activities:		
Dividends and interest from investments	**-**	1,464
Purchase of property, plant and equipment net of sales	**(8,251)**	(4,611)
Proceeds from sale of investments	**-**	-
Net cash provided/(used in) by investing activities	**(8,251)**	(3,147)
Net increase in cash:	**286,133**	(171,443)
Cash at bank and in hand less overdrafts at the beginning of the year	**1,589,232**	1,760,675
Change in cash and cash equivalents	**286,133**	(171,443)
Cash at bank and in hand less overdrafts at the end of the year	**1,875,365**	1,589,232

Reconciliation of net income to net cash flow from operating activities

	2024	2023
	£	£
Net (expenditure)/income	**488,305**	166,834
Adjustments for:		
Depreciation charges	**10,890**	9,873
Net losses on investments	**-**	-
Dividends and interest from investments	**-**	(1,464)
(Increase)/Decrease in stocks	**-**	-
(Increase)/Decrease in debtors	**6,521**	(92,264)
Increase/(Decrease) in creditors	**(211,332)**	(251,275)
Net cash provided by operating activities	**294,384**	(168,296)

Analysis of cash at bank and in hand less overdrafts

	2024	2023
	£	£
Cash at bank and in hand	**1,875,365**	1,589,232
	1,875,365	1,589,232

1. Charity Information

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

2. Principal Accounting Policies

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

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

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

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

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

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

Principal Accounting Policies (continued)

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

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

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

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

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

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

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

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

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

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

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

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

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

Note 3 Donations and Legacies Income

	2024	2023
	£	£
Donations	**827,551**	743,120
Legacies	**31,795**	218,100
	859,346	961,220

Note 4 Other Trading Activities

	2024	2023
	£	£
Fundraising activities	**285,854**	242,021
	285,854	242,021

Note 5 Charitable Activities Income

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

Note 6 Investment Income

	2024	2023
	£	£
Interest	**-**	1,464
	-	1,464

Note 7 Raising Funds Expenditure

	2024	2023
	£	£
Costs of generating funds	**271,119**	203,099
	271,119	203,099

Note 8 Charitable Activities Expenditure

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

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

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

Note 9 : Research Grants

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

Note 10 : Staff Costs

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

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

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

The following number of staff members received emoluments in the year:	2024	2023
£80,000 - £90,000	1	1

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

Note 11 : Pension Schemes

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

Note 12 : Trustees

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

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

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

Note 14 : Tangible Fixed Assets

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

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

Note 15 : Debtors Under 1 Year

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

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

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

Note 18 : Creditors: Amounts falling due after one year

	2024	2023
	£	£
Research grants	**596,330**	963,756
Misc creditors	**-**	1,000
	596,330	964,756

Note 19 : Analysis of net assets between funds

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

Note 20 : Unrestricted Funds

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

Note 21 : Designated Funds

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

a) Funds held in branches: Funds held by the branches and not available for normal activities of central office.
b) Parental: Funds being held to cover potential periods of maternity leave.
c) Research conference fund: Funds being held to cover costs, if required, of ICAR conference in November 2024.

Note 22 : Restricted Funds

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

Purpose of restricted funds

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

Purpose of restricted funds (continued)

m) Exeter: Funds to be expended in the Exeter area.
n) Awareness: Funds provided to raise awareness of Ataxia.
o) Kennedy Award: A fund set up to assist researchers studying Friedreich's ataxia with attending scientific conferences and other small research studies.

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

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

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

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

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

u) Ataxia Centres: Funds to assist with the set-up of additional ataxia centres/virtual centre.
v) DRPLA Department: Funds provided by donors specifically for staff to support DRPLA research.

w) Scotland: Funds to be expended in Scotland.
x) NKX6-2: Funds provided by donors specifically for research into NKX6-2. See note 2 below.
y) AOA2: Funds provided by donors specifically for research into ataxia with oculomotor apraxia type 2.
z) Prospax Project: Funds provided by donors specifically for research into spastic ataxias.
aa) Research Service Contracts: Funds provided for projects undertaken by the research department.
ab) SCA6: Funds provided by donors specifically for research into Spinocerebellar ataxia type 6 .
ac) SCA3: Funds provided by donors specifically for research into Spinocerebellar ataxia type 3.
ad) ICAR 2024 Conference: Funds provided towards costs of International Congress for Ataxia Research 2024 being held in London, UK.
ae) Misc AAA++: Funds provided by donors specifically for expansion of the All About Ataxia offerings.

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

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

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

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

Note 23 : Capital Commitments

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

Note 24 : Lease Commitments

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

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

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.

ATAXIA UK

England & Wales - Charity number 1102391

Accounts

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

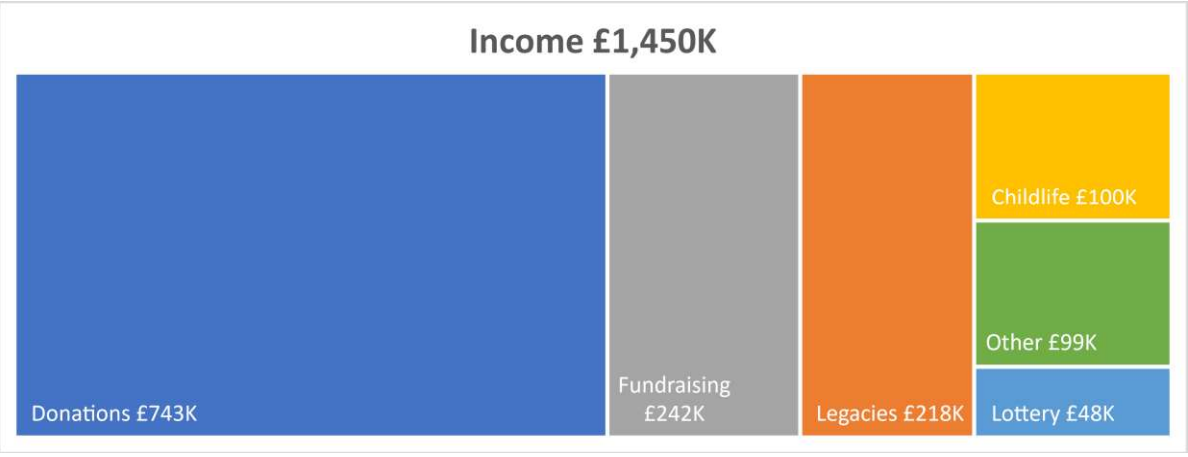
Overview

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.

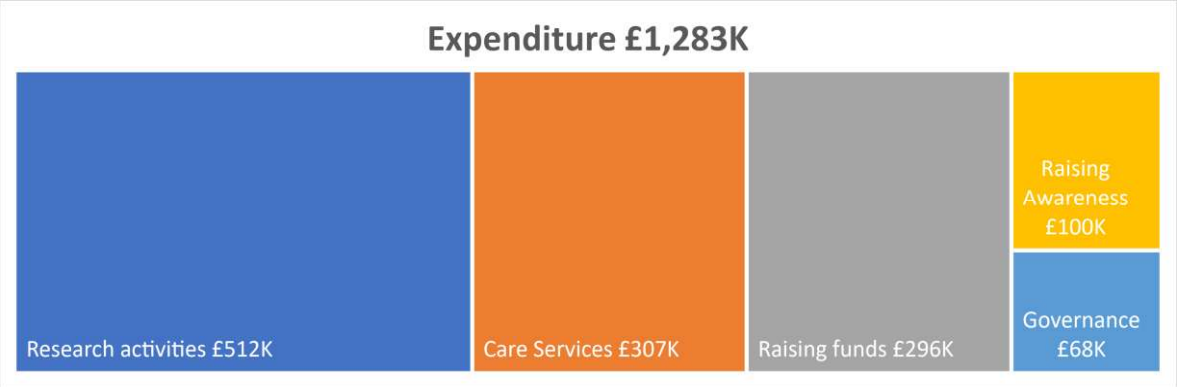
Review of income



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

Ataxia UK
Notes to the financial statements
for the year ending 31 March 2023

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.

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.

ATAXIA UK

England & Wales - Charity number 1102391

Accounts

Annual Report & Financial Statements

For the Year: 1 April 2021 to 31 March 2022

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 (04974832)

Introduction from the Chair

Ataxia UK had a very successful year in 2021-22, despite the continuing impacts of the Covid-19 pandemic on our ability to host face-to-face events and facilitate fundraising. Many supporters with mobility difficulties, who could not attend in-person events, have welcomed the advent of our online activities which have enabled their participation which otherwise would not be possible. As we re-introduce face-to-face events, we will ensure that we continue to provide them online. In this respect the pandemic has helped us understand better the ways we can improve the accessibility of our activities.

In the face of the financial pressures facing so many people, which are often more extreme for people with disabilities, we are pleased that we had already made plans to increase our advice and information service to . Our advice services have been going through a number of changes; Sheila Benneyworth, our committed Helpline Officer of 17 years, took her well-deserved retirement and an Advocacy service was introduced to provide increased support for difficult problems. We are grateful to the many volunteers who support the service.

Research into the ataxias continues apace; there has never been so many research projects and trials for the ataxias. We are encouraged that Reata, the developers of the first drug for Friedreich's ataxia, Omaveloxolone, are planning to submit an application for market authorisation in Europe during 2022 and we will encourage them to do so in the UK. Ataxia UK's reputation and influence in the field of ataxia research is extending through our increasing participation in the steering committees of global research projects as patient advocates.

Our DRLPA project which commenced with basic research and has progressed to more complex levels has enabled us to gain new skills and experience which will translate into other work. We were disappointed at the postponement of the International Congress for Ataxia Research which was due to be in March 2022 but pleased that it has been rescheduled to November 2022.

The Board has spent time this year considering a major refresh of our strategy and has received much valuable input from members concerning what matters most to them. We are close to finalising this refresh which will be published shortly and is more about changes in emphasis given changes in the world than significant changes in direction. The headlines are included in the report to follow.

Our financial situation has improved during the year, primarily due to the generosity of Friends and supporters who have left us numerous bequests and the loyalty of donors and fundraisers during the pandemic. The fundraising environment remains very challenging for charities such as ours, and I commend the Board for their consistent prudence in coming through these difficult times.

We know that challenges lie ahead, due to the worsening economic situation, but we have confidence that we have a Board of Trustees, a staff team, and committed supporters who will enable us to further develop our support to people affected by ataxia and ultimately ensure that treatments and cures are found.



William Littleboy,
Chair of Trustees

Reference & Administration Details of the Charity, and 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

Richard Brown, MBE, Co-Chair
(Elected as Co-Chair 6 October 2019, retired Nov 2021)

William Littleboy, Co-Chair
(Elected as Co-Chair 6 October 2019,
Chair from November 2021)

Kathy Jones, Honorary Treasurer

Trustees

Angela Hosie (joined Nov 2021)

Andrew Downie (retired Nov 2021)

Prof Barry Hunt (retired Nov 2021)

Carol McCudden

Gemma Fish

Philip Griffiths

Rachel Harrison (joined Nov 2021)

Robert Perkins

Terence McCaw (retired Jul 2021)

Prof Barry Hunt is Scientific Advisor to the Board

Susan Millman is the company secretary and CEO.

Ataxia UK uses the following professional advisors:

Auditors
Goldwins Limited
75 Maygrove Road
West Hampstead
London NW6 2EG

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

HR Consultants
HR Services Partnership
Bentley House
North Heath Lane
Horsham
West Sussex RH12 5QE

Solicitors
Bates Wells
10 Queen Street Place
London EC4R 1BE

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 26 November 2021.

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. Each year one quarter of the trustees retire but are eligible to stand again if they so wish. In addition, the trustees may co-opt up to three additional trustees.

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 includes links to the most significant documents on the Charity Commission website.

The pay and remuneration of the key managers of Ataxia UK is considered annually by a Remuneration Committee, comprising the Co-Chairs 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 to people affected by ataxia at the early stages of diagnosis and specialist services for this medical condition, many of which are not available from the NHS or other statutory or voluntary sources.
>
> We work to end isolation and promote engagement in social, educational and leisure activities for people affected by ataxia and their families. We educate the broad community and key subsections within it, such as the medical and social services professions, about the effects of ataxia.
>
> We also fund vital research projects into potential treatments, aiming to find a cure for ataxia. There is currently no specific government funding for ataxia research."

Statement of Equality, Diversity and Inclusion

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

"

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

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

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

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

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

The Trustees confirm that they comply with their duty to have regard to the guidance on public benefit published by the Charity Commission and the Office of the Scottish Charity Regulator OSCR in exercising their powers and duties.

Ataxia UK operates throughout the United Kingdom of Great Britain and Northern Ireland through its network of Branches and Support Groups, which provide activities and support to Friends. The 2020 Regional Conference was cancelled due to Covid-19 restrictions, and the 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 15 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 Franziska Denk, **Dr Claire Kelly**, **Dr Marija Sajic**, **Dr Mark Pook**, **Professor Keith Morris** and **Dr Gita Ramdharry**.

The committee also included the following lay members during the year:

Yanita Oparlakova, **Alick Varma**, **Harriet Bonney** and **Nathan Hall**.

During this year lay member **Rosemary Homayoun** stood down from the committee and we are extremely grateful for her service on this committee.

Professor Barry Hunt Ataxia UK Board Scientific Advisor.

All members are unpaid volunteers.

Employees

During 2021-22 the average number of full-time equivalent employees during the year was 19 (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. We are currently working on a Data Officer; this role will include data protection & GDPR work.

Volunteers

In addition to the volunteers who function as trustees, many other volunteers play an important part in supporting Ataxia UK. During 2020-21 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 seen the launch of more roles for volunteers, see p.29.

The pandemic has cancelled many events that our Friends and supporters might have participated in. 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 2021-22 the register remained significantly influenced by the impact of the Covid-19 pandemic. At the beginning of the year the most significant risks and their mitigation were:

Risk	Mitigation/result
Impact of lockdown and isolation on beneficiaries	We provided online activities, online speech therapy and pilates, and increased advocacy and advice services.
Over-reliance on a single funding source.	Funding diversified and risk resolved by year end.
Face–to–face fundraising and community fundraising will be affected by the pandemic.	Although fundraising has not returned to pre-pandemic levels, it exceeded our (reduced) budgeted figure.
Inadequate funds to invest in research.	This was mitigated by the grant from the Covid-19 Support Fund (see detail in Research section).

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 into 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 E-newsletter, 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 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

There remained much work to be done to benefit people affected by ataxia under the themes of the Strategic Plan 2017-2020 and in 2020 we elected to extend it to 2022 whilst retaining the projects to which we are committed.

Strategic Plan 2017-22 contained four major ambitions:.



By 2022 we want people affected by ataxia to be able to say: **"I feel supported and in control"**



To have increased our **funded research activity**



To consistently **maximise the impact** of research activity



To have **fostered best practise** in treatment & care

The work we have done during the year has been designed to contribute to these aims. This can be read about below under the headings of Research; Improving Treatment & Care; Services; and Raising Awareness; with Fundraising, and Communications supporting these activities.

Strategic Plan 2022-25 contains these new 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 new 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 coming financial pressures which will exacerbate the existing poverty of a small but significant number of people affected by ataxia.

Some of the most significant actions we will take over the next three years 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.

FY21-22 Key Highlights

We have awarded:

10 grants

Including this 10 there are currently **26 projects being managed**.

We have supported the recruitment of participants for:

9 research projects

7 surveys

We are closely following the work of Reata pharmaceuticals as **they seek approval for their drug Omaveloxolone, which would be the first drug for Friedreich's ataxia.** During the year they submitted a new drug application to the US FDA. We await the decision & will do all we can to support early approval in the UK.

Over the **10 years** our funded research has produced:

87 **papers published** in scientific/medical journals

44 new **research tools** developed.

The last **10 years' data** shows that **every £1 invested** in research by Ataxia UK, raises an **extra**

£4.90

in further funding used **specifically for ataxia research.**

Secured a grant of

£104K

from the **UK Government Covid Medical Research Charities Support Fund** allowing further funding of ataxia research.

Plans are underway to set up a **Paediatric Ataxia Centre** in London in collaboration with the **Adult Ataxia Centre.**

The London Ataxia centre now runs

4 ataxia clinics a week

with the support of a **full-time Ataxia Nurse**, providing much needed assistance to the expanding clinic.

The **Helpline** continues to support the ataxia community, with

1237

contacts during 2021-22.

Sponsored the

Sheffield Ataxia Centre Study Day

which provided training about ataxia to **180 healthcare professionals.**

Speech Therapy Project

Pilot groups trialling the peer support method in **June 2021** proved effective and the **service continues to develop.**

The **Advocacy Service** is already providing **1-2-1 support** to people in the ataxia community with a range of issues. Successful outcomes include **improvements in financial circumstances, faster diagnosis** and access to **specialist neurology**, access to **appropriate housing**, and **support in school for children** affected by ataxia.

Research

Research aims for 2021-22

- Host the 2022 International Congress for Ataxia Research.
- Start clinical research programme in DRPLA.
- Gather and publicise information on the perspective of people with ataxia on research trials.
- Further the involvement with Global Initiatives to help the future approval of medicines for the ataxias.
- In collaboration with other patient groups, support the approval and distribution of treatments for the ataxias in the UK and across the world.
- Evaluate the research priorities of Ataxia UK and incorporate into the forthcoming Strategic Plan.



Host the 2022 International Congress for Ataxia Research

The International Congress for Ataxia Research, jointly organized by Ataxia UK, and the US charities National Ataxia Foundation and Friedreich's Ataxia Research Alliance (FARA) was due to be held in March 2022. As a result of the Covid-19 pandemic situation the difficult decision was made to postpone it to ensure a face-to-face meeting could be held. It will now be held in November 2022 in Dallas, USA.

Start clinical research programme in DRPLA

Ataxia UK has been collaborating with the US Foundation CureDRPLA, to advance research in Dentatorubral-pallidoluysian atrophy (DRPLA), a rare form of inherited ataxia. CureDRPLA provide funds to employ a Senior Research Manager 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.

We coordinate the DRPLA Natural History and Biomarkers Study (DRPLA NHBS) with study sites in the United Kingdom, the United States and Japan. Ataxia UK has supported the sites in preparing the study documents for submission for ethical approval. The US site started recruiting participants in April 2022 and will be followed by the other sites during 2022-23. Ataxia UK and CureDRPLA have partnered with a Japanese academic organisation (TRI) to facilitate study start-up at the Japanese sites. Ataxia UK is also managing the contracts and grant awards to the Universities involved in the natural history study, funded by CureDRPLA.

Ataxia UK and CureDRPLA are facilitating the CureDRPLA Global Patient Registry, which was launched in English in February 2021 to gather patient-reported data. In November 2022, we launched the registry in Japanese, Korean, French, Italian, and Portuguese. To date, the CureDRPLA Global Patient Registry has 23 participants from six different countries.

CureDRPLA commissioned a company called Casimir to conduct research interviews with six DRPLA carers and three people with DRPLA to understand symptoms, natural history, impact on daily activities and quality of life, and understand the outcomes that are important and relevant to patients and their families. Ataxia UK provided feedback on the interview guides and will provide pre-publication feedback on the manuscript.

CureDRPLA and Ataxia UK are preparing the first in-person DRPLA meeting in Boston in May 2022 which will be attended by representatives of CureDRPLA, Ataxia UK, researchers funded by CureDRPLA/Ataxia UK, and representatives from contract research organisations and pharmaceutical companies. The meeting aims to facilitate building the DRPLA patient community; share knowledge across the research projects and encourage pharmaceutical companies to advance their DRPLA programmes.

Gather and publicise information on the perspective of people with ataxia on research trials

Ataxia UK ensures the views of people affected by ataxia are considered in research activities. To this end we collaborated with researchers at the London Ataxia Centre (UCL/UCLH), Children's Hospital of Philadelphia and FARA US to gather information on the perspective of people with ataxia on trials. The object was to understand the motivations and barriers to participation in clinical trials to improve recruitment, participation, and experience for people with ataxia.

Ataxia UK and FARA surveyed their members, asking questions on personal motivation, drug therapy, trial design, and on the most important symptoms people with ataxia wish to be addressed by a potential treatment. 342 people responded, and interesting data was gathered. Results were published in the medical journal 'Orphanet Journal of Rare Diseases' in January 2022 and publicised in the ataxia community, and among researchers and pharma companies planning ataxia trials.

During the year we also worked with an academic researcher and member of our Medical Advisory Panel, to publish data from an Ataxia UK 2016 survey on the impact of ataxia on patients. This has been published in the online open access journal AMRC Open Research Platform. Despite the age of the data, there has been much interest from pharma companies in this type of information and a peer reviewed formal publication will give the data a wider reach. As we get closer to drug approvals and decisions on funding of new drugs it is important to collect information about the impact of ataxia to provide as evidence. We have also supported pharma companies in collecting similar information from people with ataxia.

Further the involvement with Global Initiatives to help the future approval of medicines for the ataxias

Ataxia UK is a partner in 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. It is funded by pharma companies who see the value of collaboration in increasing the efficiency and effectiveness of medical product development.

In collaboration with other patient groups, support the approval and distribution of treatments for the ataxias in the UK and across the world.

Currently the drug closest to approval is a drug being developed for FA by Reata pharmaceuticals. Ataxia UK is following the work of Reata pharmaceuticals closely as they try to get approval for their drug Omaveloxolone, which would be the first drug for Friedreich's ataxia. We invited a representative of Reata to the Euro-ataxia research conference we organised in June followed by a discussion. There is of course much interest in the FA community in this potential drug.

Evaluate the research priorities of Ataxia UK and incorporate into the forthcoming Strategic Plan.

The Research Strategy was produced in June 2018, and needs updating to form an element of the organisation's Strategic Plan. During the year the Research Strategy was reviewed by the Scientific Advisory Committee (SAC). During 2022-3 a meeting will be held to get the input of people affected by ataxia. Patient engagement in research is playing an ever-increasing role in all aspects of Ataxia UK's work. During the year there has been an improvement in the engagement of the lay members in SAC meetings due to the introduction of pre-meeting with research staff to improve the understanding of the research being evaluated and maximise their opportunities for input. We plan to launch the new Research Strategy during 2022-3.

Other Research Activities

Ataxia UK Research Grants Programme

During the year Ataxia UK awarded 10 grants, eight via our standard research programme, and two under the DRPLA programme. Including these projects there are currently 26 projects being managed.

Ataxia UK Grants

1. **Dr Marcus Grobe-Einsler and Prof Thomas Klockgether** (German Center for Neurodegenerative Diseases, Bonn, Germany) 'Assessment of ataxia severity under real-life conditions with SARAhome: A multicenter study in spinocerebellar ataxia type 3 (SCA3)' – $80,000 (co-funded with National Ataxia Foundation).
2. **Dr Alexandra Silva** (Instituto de Invesigacão e Inovacão em Saúde – i3S, Portugal) 'NanoSCA3: Development of brain-targeted nanobodies for application in spinocerebellar ataxia type 3 therapy' – £30,000 (co-funded with Plataforma R+SCAs, AISA, ACAH, Swedish SCA-network).
3. **Dr Barbara Borroni** (University of Brescia, Italy) 'Motor and cognitive outcomes of non-invasive transcranial alternate current stimulation by entrainment of cerebellar oscillation' – £5,000.
4. **Prof Richard Festenstein** (Imperial College London, UK) 'Generation and characterization of a cardiomyocyte model for Friedreich's ataxia to reveal the molecular mechanism of heart failure in patients' – £5,000.
5. **Dr Saul Herranz-Martin** (Centro de Biología Molecular Severo Ochoa, Madrid, Spain) 'Analysis of the mitochondrial dysfunction in FXN deficient neurones to generate a drug screening test' – £4,750.
6. **Prof Paola Giunti** (University College London, UK) 'Brain pathology in an AIFM1 mutation causing Cowchock syndrome' – £5,000.
7. **Dr Yi Shiau Ng** (Newcastle University, UK) 'Balance and gait abnormalities in adult patients with mitochondrial disease and spinocerebellar ataxia type 6' – £4,928.
8. **Prof Anja Lowit** (Strathclyde University, UK) 'A feasibility study of LSVT Artic to improve speech performance in people with progressive ataxia' – £2,862.

DRPLA Grants (in partnership with CureDRPLA)

1. **Dr Yael Shiloh Malawsky** (University of North Carolina at Chapel Hill, USA) 'DRPLA Natural History and Biomarkers Study (DRPLA NHBS)' – £131,448.69.
2. **Dr Giovanni Stevanin** (Institut du Cerveau et de la Moelle épinière (ICM), France) 'Preclinical development of an amelioration therapy for Dentatorubro-Pallidoluysian Atrophy – Funding Extension' – €50,100.

Analysis of research outcomes of Ataxia UK funded research

The impact of the research we fund is evaluated every year using the Researchfish online portal with very positive findings. The last 10 years' data shows that every £1 invested in research by Ataxia UK, raises an extra £4.90 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 87 papers published in scientific/medical journals and the development of 44 new research tools.

Medical Research Charities Covid Support Fund

Ataxia UK secured a grant of £104,000 from the UK Government Covid Medical Research Charities Support Fund. This will allow further funding of ataxia research. The fund was the result of campaigning by the Association of Medical Research Charities (AMRC), of which Ataxia UK is a member.

Multi-Centre European Research Projects

A new call for research proposals was launched by the EU under the Horizon Europe Programme entitled 'Developing new effective therapies for rare diseases'. The involvement of patient groups was a requirement for all applicants. Ataxia UK agreed to be a partner in two Research Consortia, and Euro-ataxia agreed to be a partner on three projects, on whose behalf Ataxia UK would carry out most of the work. The projects cover a wide range of ataxias and Ataxia UK has been involved in the project development. The results of the preliminary stage will be known in May 2022. It is encouraging to see the importance given to the participation of patient groups in research projects and for the recognition Ataxia UK and Euro-ataxia are getting within the field. Ataxia UK also continues to be involved in a number of European Research Consortia as partners to ataxia researchers. In many cases this involvement is by being a Euro-ataxia representative. It is important that Ataxia UK is supporting their projects and providing expertise and patient input.

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. This project has been recruiting participants since 2017 and 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 been in discussions with pharma companies who may support the continuation of the funding and during the year a partnership with the company Servier laboratories has been announced.

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. 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.

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

This study, originally funded by the European Commission, gathers vital information about the progression of Friedreich's ataxia (FA) to generate a large FA patient database, alongside an integrated clinical and natural history database; this will 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 being used to plan clinical trials. Prof Barry Hunt of Ataxia UK is one of two Euro-ataxia representatives on the Steering Committee.

Cerebellum and Emotional Networks (CEN)

During the year the Marie Skłodowska-Curie Innovative Training Network was funded by the European Research Council. To investigate the brain circuits that underlie emotional behaviour, the project will create a Virtual Institute of seven European universities and seven industry/charity partners, including Euro-ataxia. 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.

TREAT-ARCA

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 paradigmatic treatments for a targeted molecular medicine approach to autosomal recessive ataxias; including gene therapy in animal model systems of ARSACS and ARCA2. It also aims to develop biomarkers. Dr Emily Cutting is a Euro-ataxia representative on this project.

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 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. These are shortly to be published and aim to help with harmonisation of data collection in ataxias trials. Membership of academics and representatives from patient groups and pharma has reached over 200 and there are currently 20 global collaborative research projects, endorsed by the AGI Steering Committee.

AT Society

Ataxia UK has continued to provide a research support service to the Ataxia Telangiectasia (AT) Society, supporting people affected by AT. During the year in addition to supporting their research grant programme and dissemination activities, we organised a joint webinar on Ataxia with oculomotor apraxia types 1 and 2 (AOA1 and AOA2). The webinar featured a research update by Ataxia UK staff followed by Q&A and discussion. The event resulted in a support group being formed for families affected by AOA2, and we are exploring ways of creating one for AOA1.

Working with Pharmaceutical Companies and Industry

Ataxia UK continues to work with pharma companies who have ataxia programmes, supporting them in advancing their research. We have provided introductions to ataxia experts in a range of areas, promoted trials in the UK, and given input on trial design. We 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.

In particular, we have been following the work of Reata pharmaceuticals as they seek approval for their drug Omaveloxolone, which would be the first drug for Friedreich's ataxia. During the year they submitted a new drug application to the US FDA. We await the decision and will do all we can support early approval in the UK.

Pharma Strategy Advisory Committee

The Pharma Strategy Advisory Committee met in January 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.

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 nine research projects and seven surveys.

Friedreich's ataxia Global Registry

Ataxia UK and FARA are the lead organisations facilitating the FA Global Registry. Ataxia UK has helped recruit participants by ensuring every new Friend of Ataxia UK affected by FA is given an information flyer about the registry and a webinar we produced explaining how to register is on the Ataxia UK website. There has been a substantial increase in participants in the last year from around 1,000 to around 1,400.

Raising Awareness of Ataxia Research

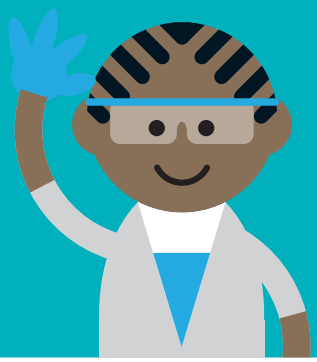
Ataxia UK research staff have attended meetings and conferences throughout the year. This has been very useful in raising the profile of ataxia and Ataxia UK, creating opportunities to establish new partnerships and encouraging further research in ataxia.

Rare Champions of Hope Award

Each year, Global Genes, a leading global rare disease patient advocacy organisation, invites nominations of exceptional people for their RARE Champions of Hope Awards. We are delighted that Head of Research, Dr Julie Greenfield, selected as the winner of the in the 2021 Champion of Hope in the Science and Technology category. The Award was accompanied by a $1000 donation from Global Genes.

Research aims for 2022-23

- Host the International Ataxia Research Congress in Dallas, USA and the Ataxia Global Initiative conference.
- 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.



Improvements in treatments and care

Treatment and care aims for 2021-22

- Review and update Medical Guidelines for the Treatment of the Ataxias.
- Launch a second Paediatric Ataxia Centre.
- Establish additional ataxia clinics with expert neurologists.
- Pilot the use of a peripatetic Specialist Ataxia Nurse.
- Further our engagement with medicine regulators to facilitate the approval of treatments for the ataxias when they become available.



Review and update Medical Guidelines on ataxia

A Guideline development Group has been assembled to oversee the review of the Medical Guidelines and a procedure for updating the Guidelines has been agreed. During the year we aim to produce updated Guidelines.

Launch a second Paediatric Ataxia Centre

Plans are underway to set up a Paediatric Ataxia Centre in London in collaboration with the Adult Ataxia Centre. Ataxia UK has allocated funding for this, in order to employ a part-time ataxia specialist nurse to support ataxia families. There have been delays in the launch, but progress has been made.

Establish additional Ataxia UK accredited ataxia clinics

Due to the Covid-19 pandemic and pressures on the NHS this has been delayed. We are making progress with discussions with one clinic and hope for it to be launched during the year.

Pilot the use of peripatetic Specialist Ataxia Nurse

Plans have been drawn up and funding is being sought for an ataxia specialist nurse in Scotland.

Further our engagement with medicines regulators to facilitate the approval of treatments for the ataxias when they become available

Ataxia UK research staff have attended training sessions and webinars to gain a better understanding of the UK medicine regulatory system and subsequent health technology assessment and funding of drugs within the NHS. This is becoming increasingly important, as more therapies are going through clinical trials in the ataxias.

During the year Ataxia UK responded to a consultation on the creation of a new fund called the Innovative Medicine Fund. This new Fund would aim to provide early access to medicines to patients, which is based on the already established Cancer Fund. This is a system whereby after drugs are approved by the regulator, if there is a need to collect more data prior to recommendation for funding by NICE they could be selected to be made available to patients via the Innovative Medicine Fund. Ataxia UK attended discussion meetings with Genetic Alliance UK and provided a response supporting this new Fund but suggested some changes to reflect the needs of people with a rare condition such as the ataxias.

Other activities supporting improvements in treatments and care

Development of Clinical care pathways in the NHS in England

Ataxia UK responded to a consultation on a draft Movement Disorders clinical care pathway, highlighting the need for more specific information for the ataxias and other rare neurological conditions. As a result of this, a decision was made to include an Appendix specifically on Ataxia, and Ataxia UK were given the responsibility of drafting this.

Ataxia UK's CEO and Head of Research worked with the lead neurologists at the London and Sheffield Ataxia Centres and an Ataxia UK Friend with expertise in NHS Specialised Commissioning to produce the Clinical Care pathway Appendix on Ataxias. This was well received, and we await the publication of the Movement Disorders Pathway with this Ataxia Appendix.

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 Prof Giunti at the London Ataxia Centre. The data collection has now ended, and the results of surveys carried out in people with ataxia in the UK, Germany and Italy assessing the value of Ataxia Centres is being prepared for submission to a medical journal.

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. The results of the Value of treatment project will be used to make policy recommendations which we hope will improve the healthcare of people with ataxia.

Medical Advisory Panel meetings

Ataxia UK's Medical Advisory Panel met during the year and provided advice to Ataxia UK on a number of important topics such as the revision of the Ataxia Medical Guidelines and advice to people with ataxia on the Covid-19 treatments. 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.

Providing information and advice to people with ataxia during the Covid-19 pandemic

People with ataxia have continued to need support during the year on issues relating to Covid-19. Ataxia UK has responded to this by updating the Ataxia UK website with the latest information on vaccines, treatments and developments of relevance to people with ataxia. Last year a survey was written and sent to Ataxia UK Friends to ascertain the impact of Covid-19 on their ataxia. In collaboration with some members of the Medical Advisory Panel the results were analysed and submitted for publication during the year.

Ataxia UK Ethics Review Committee

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 four times throughout the year, to review two Ataxia UK surveys and six external surveys.

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 300+ people on the Registry, three times a year.

Sheffield Ataxia Centre Study Day

This event, which had been postponed due to the pandemic, was held in November 2021 as a virtual event. It was hosted and run by the Ataxia Centre with the aim of providing training about ataxia to healthcare professionals. Ataxia UK sponsored the event and provided logistical support. The event was successful and had a high attendance, with 180 delegates.

Ataxia UK accredited Ataxia Centres

Ataxia Children's Centre – 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.

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 above, which facilitates the transition between children's and adult services. Prof Hadjivassiliou continues to publish extensively on ataxia research, in particular autoimmune ataxias.

London Adult Ataxia Centre

The London Ataxia Centre, led by Prof Giunti, now runs four ataxia clinics a week, with the support of a full-time Ataxia Nurse, providing much needed assistance to the expanding clinic. 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 January 2022 a vestibular clinic was also established to run on the same day as an ataxia 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.

During the year we have been able to reinstate the support of the Ataxia UK clinic volunteers, which was suspended during the pandemic. New procedures have been put in place and the volunteers are providing support by either email, phone or videocall. This service has always been highly appreciated by patients at the clinic.

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.

We were pleased to be able to arrange a virtual conference for Euro-ataxia this year. The first day was a research conference, which consisted of eight presentations and Q&A. We invited academic researchers running large European projects in which Euro-ataxia is represented on a range of ataxias, and four pharma companies working on FA and SCAs. The event was attended by eleven out of the twenty Euro-ataxia charities, plus two other non-member charities plus some Friends of Ataxia UK. It was a very interesting diverse conference with a good level of discussion.

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.



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 has launched the follow up initiative to the Rare Disease Strategy: The UK Rare Diseases Framework in early 2021. Sue Millman secured a place on the UK Rare Diseases Forum to representing the Neurological Alliance (England) and has attended numerous meetings during the year regarding the Rare Disease Framework. 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.

Treatment and 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 Voicebanking.
- Develop an Ataxia Specialist Nurse Project.



Care and Support Services for people affected by ataxia

Care and support aims for 2021-22

- Establish face-to-face elements for InControl services when permitted.
- Undertake the Interest in Volunteering (IIV) accreditation to ensure best practice in our InControl volunteering project.
- Develop and implement our Diversity Strategy as it relates to services.
- Support the engagement of Friends in the development of our new Strategic Plan.
- Develop and implement an improvement plan for our Helpline, Advocacy and Information services.



The pandemic and its aftermath have prevented face-to-face events though activities continue online. Work on the Investors in Volunteers accreditation has been put on hold as other activities take priority. We are now working with Breaking Down Barriers to develop and implement our diversity strategy in relation to services.

Services

During the year we created the role of Head of Services to take a strategic and operational lead in service development and delivery.

InControl

InControl is a three-year project funded by the National Lottery Community Fund. The project aims to decrease feelings of social isolation and increase mental wellbeing within the ataxia community. This is achieved through the development and delivery of services, including volunteering opportunities, by and for the ataxia community. Covid restrictions and a reluctance to meet face-to-face have kept activities largely virtual.

Virtual Activities

Weekly virtual activities have been phased out in favour of less frequent, information and support-focussed sessions such as Pilates (monthly), Wellbeing Week (bi-annually), and All About Ataxia (quarterly) which are popular with the ataxia community.

Branch and Support Groups

Our volunteers have offered 118 meetings from April 2021 to March 2022. As restrictions lifted in 2022 some groups are phasing in a hybrid of Zoom and face-to-face meetings depending on what is required locally.

Volunteer Recruitment

We have 96 volunteers in total of which 21 were recruited 2022-23. More than half of our volunteers perform more than one role.

Friends Connect

The virtual befriending service has 14 pairs who meet weekly.

Speech Therapy Project

Pilot groups trialling the peer support method in June 2021 proved effective and the service continues to develop. Starting May 2022 sessions will be rolled out to the waiting list of 59 people with our own speech therapist. In the meantime, Prof Anja Lowit is conducting additional research to hone the method going forward.

Voice Banking

A funding partnership is being developed with SpeakUnique. Friends will be able to bank their voice now and choose between three synthetic voice options depending on the level of deterioration of their natural voice when it is recorded.

Helpline and Advocacy Service

Helpline

The Helpline continues to support the ataxia community, with 1,237 contacts during 2021-22, mostly via email and phone. Just under half of enquiries received related to ataxia and Ataxia UK with an increasing number of contacts about welfare benefits, social care needs and housing. Initial support is required around understanding ataxia and the treatments and therapies available; further contacts occur as ataxia symptoms progress and additional support is required.

A review of the Helpline was undertaken during the summer of 2021 and recommendations made to enhance the service to offer more holistic support to the ataxia community.

Follow-up contacts with enquirers ensure additional support can be provided when required, including referral on to other services when appropriate.

Dedicated Helpline and Advocacy Officer recruited to work alongside Helpline volunteers and deliver 1-2-1 advocacy.

Advocacy Service

The Advocacy Service is already providing 1-2-1 support to people in the ataxia community with a range of issues. Successful outcomes include: improvements in financial circumstances; faster diagnosis and access to specialist neurology; access to appropriate housing; and support in school for children affected by ataxia. The advocacy service continues to sponsor applications to grant funds.

Membership

We welcomed 612 new Friends of Ataxia UK in 2021-22.

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 continuation of InControl, Information, Helpline and Advocacy Services.
- Use the All About Ataxia model to bringing the ataxia community together and provide information on other issues faced by people affected by the condition.
- Launch 'The Gift of Speech' project – online speech therapy courses and Voicebanking.



Communications

Communications aims for 2021-22

We are re-examining our aims for awareness raising in the future and are intending to focus on raising awareness in tandem with the aims of our workplans in other areas rather than running 'independent' awareness campaigns. In particular we wish to harness our communications work in support of lobbying campaigns undertaken in support of Friend's aspirations

Throughout 2021-22 the communications team continued to support the ataxia community by providing key information at vital points throughout supporters' journeys. One of the most important milestones in someone's journey with ataxia is diagnosis. Sadly, too often diagnosis of ataxia can take a long time due to the rare nature of the condition. For the 2021 International Ataxia Awareness Day we ran a campaign called, "Two steps towards Speedier Ataxia Diagnosis". The aim of which was to encourage supporters to undertake a sponsored walk whereby they would take the Ataxia UK Medical Guidelines to their GP to help raise awareness of ataxia amongst medical professionals.

The campaign was promoted on social media and reached 22,226 people on Facebook alone.

Communications aims for 2022-23

Our strategic priorities for financial year 2022-23 are:

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



Fundraising

Fundraising aims for 2021-22

- Review the existing Fundraising Strategy.
- Continue to adapt our fundraising approach to changing and challenging external environment and maintain income.
- Continue to increase the number of people who give to Ataxia UK regularly.
- Begin work on charity wide supporter journey.



Financial Year 2021-22 has been another challenging year to fundraise in and whilst income is yet to return to pre-pandemic levels, we are seeing some recovery.

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; and major donor fundraising. We did not work with any professional external fundraisers or commercial participators this financial year. Supporters do fundraise on our behalf and are given support throughout their event by our dedicated Events and Community fundraisers. Ataxia UK is registered with the Fundraising Regulator, and we are committed to following the Regulator's Code of Practice and Fundraising Promise which set the standards for fundraising behaviours in our interactions with the public and our supporters. We have a Vulnerable Persons Fundraising Policy which sets out how we identify such potential vulnerability and how we aim to respond in such circumstances.

In this financial year we received six complaints relating to our fundraising. We respond to each individual who registers a complaint and work with them as much as possible to come to a satisfactory conclusion. As of a result of these complaints we have reviewed existing processes, taken action where needed and continue to improve what we do in order to provide the best supporter experience we can.

Review the existing Fundraising Strategy

A review of the existing Fundraising Strategy was presented to the board May 2021.

Broadly, the review concluded that given the turbulent and unpredictable nature of the fundraising environment we find ourselves in that we adjust our strategy and focus on:

- Maintaining income during the economic downturn
- Seeking modest growth where possible in core income streams such as IG and E&C Including a focus on "intangible" activities which drive income but which is very difficult to quantify the £ benefit such as perfecting the thanking process
- Focus on income streams which are more "robust" during economic downturns
- Refocusing objectives onto core metrics which ensure long term income
- Plugging skill gaps
- Charity wide supporter journey
- Funding research
- Establish an "Income Generation Working Group"

Continue to adapt our fundraising approach to changing and challenging external environment and maintain income

Throughout the year we constantly reviewed our activity looking for opportunities and working with the ever-changing Covid landscape. One such change was deciding to hold our Ataxia Classic cycle ride virtually instead of physically this year.

Continue to increase the number of people who give to Ataxia UK regularly

Whilst only a small increase, the number of people giving a regular gift to Ataxia UK increased 2% compared to the previous financial year.

Begin work on charity wide supporter journey

Due to changes in team structures and a challenging recruitment environment, this work has been postponed until key vacancies can be filled.

Fundraising aims for 2022-23

Our strategic priorities for financial year 2022-23 are:

- Recruit 216 new regular givers
- Maintaining income
- Plugging Skills gaps
  - Facebook advertising
  - Digital Media
- Mentoring and networking
- Marketing
- Supporter Journey
- Case for support
- Consent.



Financial Review

For the year ending 31 March 2022

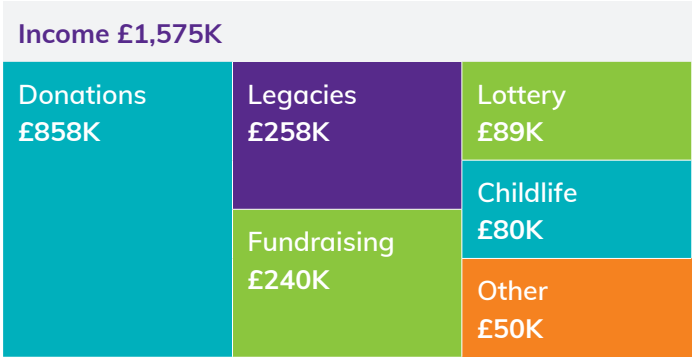
Overview

In what has continued to be a challenging environment due to the ongoing impact of the Covid-19 pandemic and difficult economic times, 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 £234K surplus in the year (2020/21: (£1,103K). A net liabilities position still exists on the balance sheet due to the 3 years expenditure commitment being made for the DRPLA and NKX6-2 projects last year, whilst the funding will be received gradually over the 3 year period of the projects. The net liabilities position on the balance sheet has decreased to (£128K) from (£361K) in the prior year. The projects had a delayed start so the funding has been pushed out a year but the situation will be resolved over the next 2 years as year 1 funding has already been received.

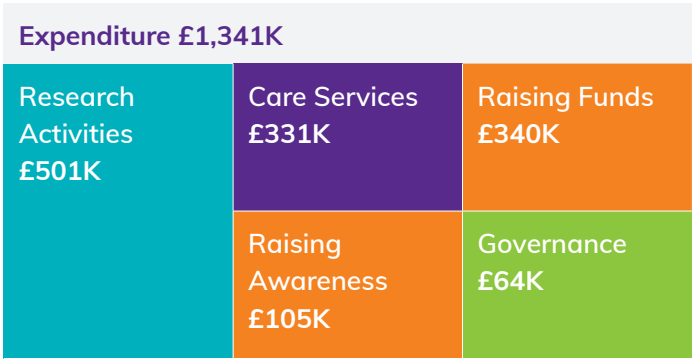
The deficit in restricted funds, of which DRPLA and NKX6-2 funds are part, have also decreased over the year to (£851K) (2021: (£960K)). Once the outstanding restricted funds are removed the net total is £243K (2021: £134K). General unrestricted funds have however increased to £724K (2021: £599K). Further 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 £1.8 million.

Review of income



Total income for 2021/22 was £1,575K (2020/21: £1,906K) a decrease of 17%. Donation income was substantially lower than the previous year, £858K (2020/21: £1,278K) a decrease of 33%. Legacy income has significantly increased to £258K for the year (2020/21: £189K), an increase of 37%. We remain very grateful to the Friends and supporters who remember us in this way. Income from fundraising activities increased to £240K (2020/21: £227K) an increase of 6%. The decrease in donations and increase in fundraising income reflects a change in activity as more fundraising has taken place in the year as we came out of Covid-19 restrictions. Childlife income increased to £80k (2021: £63K) an increase of 27%. Grants received decreased from £147K to £136K. The grants received income is made up of lottery funding of the In Control project (£89k), co-funding (£31k), plus other welfare grants (£16k).

Review of expenditure



Our spending on research activities decreased to £501K (2020/21: £2,227K), a decrease of 77.5%. This significant decrease is due to a reduction in research grants being made in the year, £249K versus £1,989K in 2020/21, a decrease of 87% on prior year. The two DRPLA grants amounting to £175K account for the majority 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 15% increase in spend on care services to £331K (2020/21: £288K). Cost of raising awareness decreased slightly from the previous year to £105K (2020/21: £109K). Expenditure on raising funds increased slightly to £340K (2020/21: £324K). Governance costs increased by 8% to £64K (2020/21 £59K) due to the survey and research into Situations of People with Ataxia and we would not expect governance costs to increase otherwise. We have cut some governance costs by implementing a new accounting system and appointing new auditors. There was no research conference held in the year due to Covid restrictions.

Investment policy and performance

Our investments are, in all cases, held in the form of publicly quoted bonds and cash. There are no restrictions on the Charity's power to invest and the trustees have not adopted an ethical investment policy. Cash balances not immediately required are kept in interest bearing accounts with banks that are subject to strict credit criteria. All investments matured during the prior year and with the current very low interest rates have not, as yet, been re-invested.

Reserves levels at year end

	2022 (£K)	2021 (£K)
General funds	570	590
Designated funds	154	8
Total unrestricted funds	724	598
Restricted research funds	(951)	(1,065)
Restricted services funds	99	105
Total restricted funds	(852)	(960)
Total funds held	(128)	(362)

The charity saw an increase in reserve levels ending the year on (£128K) (31 March 2021: (£361K)), due to the total net income of £234k generated in the year.

Restricted funds were (£851K) (2020/21: (£960K)), (detailed in Note 24) 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 £154K (2020/21: £8K) representing funds held at branches (£8K) and other designated funds (£146k) as detailed under Note 23. The trustees have set up four designated funds during

the year in addition to the funds held at branches. These are unrestricted funds which have been set aside by trustees for an essential spend or future purpose. The designated funds are:

- Funds held in branches, £8K: Funds held by the branches and not available for normal activities of central office.
- Coeliac UK Joint Project, £30K: Funds designated to fund a Coeliac gluten ataxia research project.
- In Control Project, £71K: Funds designated to cover the costs of the In Control project to 31 March 2023 should sufficient lottery funding not be received.
- Premises Fund, £35K: 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.
- Research Conference Fund, £10K: Funds being held to cover costs of the 2022 ICAR conference.

General reserves of the charity as at 31 March 2022 were £570K (31 March 2021: £590K) a 3% 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 a minimum of 3 months operating costs (presently £70K per month, 2020/21: £64K per month) was an acceptable level to hold. 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 unrestricted funds less the net book value of tangible fixed assets, £22K (2020/21: £30K). As at 31 March 2022, free reserves totalled £548K (2020/21: £560K) equating to 7.83 months operating costs (2020/21: 8.73 months) and is therefore in excess of the reserves policy.

Covid-19/going concern

With the ongoing impact of the Covid-19 pandemic during the last year, the importance of having adequate reserves, as detailed above, continued to be a priority. Covid-19 has had, and continues to have, an impact on how we raise funds but due to the generous support of the ataxia community it hasn't had a significant impact on our results to 31 March 2022. Due to the current challenging economic conditions as a result of the pandemic plus other 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.

Statement of Trustees' Responsibilities

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

Company law requires Trustees to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charitable company, and income and expenditure, of the charitable company for that period. In preparing these financial statements, 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;
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained on the financial statements;
- Prepare the financial statements on the going concern basis, unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements 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. In so far as the trustees are aware:

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

Brexit

The trustees are continuing to assess the impact on the charity of the United Kingdom's decision to leave the EU. They are not expecting this to have a significant impact on the charity.

Covid-19

The trustees continue to assess and monitor the impact of the pandemic and the consequences for Ataxia UK. In the short term we are striving to preserve sources of funding, whilst continuing to provide the support required by our community.

Approved by the trustees on 28 July 2022



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 2022 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 2022 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.

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.

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.
- 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

Anthony Epton
(Senior Statutory Auditor)
3 August 2022

for and on behalf of
Goldwins Limited
Statutory Auditor
Chartered Accountants
75 Maygrove Road
West Hampstead
London NW6 2EG

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

		Unrestricted funds	Restricted funds	**Total funds 2022**	Total funds 2021
	Notes	**£**	**£**	**£**	**£**
Income					
Donations and legacies	3	590,170	526,258	**1,116,427**	1,467,220
Other trading activities	4	221,390	18,572	**239,962**	226,588
Charitable activities	5	8,510	209,607	**218,117**	210,191
Investments	6	1	-	**1**	1,505
Total income		820,071	754,437	**1,574,508**	1,905,504
Expenditure on:					
Raising funds	7	(228,420)	(6,608)	**(235,028)**	(234,302)
Charitable activities	8	(466,381)	(639,278)	**(1,105,659)**	(2,772,654)
Total expenditure		(694,801)	(645,886)	**(1,340,687)**	(3,006,956)
Net losses on investments		-	-	**-**	(1,076)
Net income/(expenditure)		**125,270**	**108,551**	**233,821**	**(1,102,528)**
Transfer from Unrestricted to Restricted		-	-	**-**	-
Net movement in funds		125,270	108,551	**233,821**	(1,102,528)
Total funds brought forward		598,643	(959,987)	**(361,344)**	741,184
Total funds carried forward		723,913	(851,436)	**(127,523)**	(361,344)

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.

Statement Of Financial Activities

(incorporating the income and expenditure account)

(incorporating the results of the Charity's branches)

For the year ended 31st March 2021

	Unrestricted funds	Restricted funds	**Total funds 2021**
	£	**£**	**£**
Income			
Donations and legacies	599,322	867,898	**1,467,220**
Other trading activities	222,340	4,248	**226,588**
Charitable activities	8,888	201,303	**210,191**
Investments	1,505	-	**1,505**
Total income	832,055	1,073,449	**1,905,504**
Expenditure on:			
Raising funds	(233,384)	(918)	**(234,302)**
Charitable activities	(399,810)	(2,372,844)	**(2,772,654)**
Total expenditure	(633,194)	(2,373,762)	**(3,006,956)**
Net losses on investments	(1,076)	-	**(1,076)**
Net income/(expenditure)	**197,785**	**(1,300,313)**	**(1,102,528)**
Transfer from Unrestricted to Restricted	(18,646)	18,646	**-**
Net movement in funds	179,139	(1,281,667)	**(1,102,528)**
Total funds brought forward	419,504	321,680	**741,184**
Total funds carried forward	598,643	(959,987)	**(361,344)**

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.

Balance Sheet

As at 31st March 2022

	Notes	2022 £	2022 £	2021 £	2021 £
Fixed assets					
Tangible assets	14	21,624		29,946	
Investments	15	-		-	
			21,624		**29,946**
Current assets					
Stock	16	-		6,218	
Debtors	17	272,777		212,094	
Cash at bank and in hand	18	1,760,675		1,617,472	
		2,033,452		1,835,784	
Creditors: amounts falling due within one year	19	(836,495)		(993,083)	
Net current assets			**1,196,957**		**842,701**
Total net assets less current liabilities			**1,218,581**		**872,647**
Creditors: amounts falling due after more than one year	20		(1,346,104)		(1,233,991)
Total net (liabilities)	21		**(127,523)**		**(361,344)**
Accumulated funds					
Unrestricted funds					
General funds	22		569,800		590,306
Designated funds	23		154,113		8,337
			723,913		**598,643**
Restricted funds	24		**(851,436)**		**(959,987)**
Total funds			**(127,523)**		**(361,344)**

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 28 July 2022 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

Statement of Cash Flows

For the year ended 31 March 2022

	2022	2021
	£	£
Cash generated from operating activities:		
Net cash provided by operating activities	144,012	879,388
Cash flows from investing activities:		
Dividends and interest from investments	1	1,505
Purchase of property, plant and equipment net of sales	(810)	(2,797)
Proceeds from sale of investments	-	160,475
Net cash provided/(used in) by investing activities	(809)	159,183
Net increase in cash:	143,203	1,038,571
Cash at bank and in hand less overdrafts at the beginning of the year	1,617,472	578,901
Change in cash and cash equivalents	143,203	1,038,571
Cash at bank and in hand less overdrafts at the end of the year	1,760,675	1,617,472

Reconciliation of net income to net cash flow from operating activities	**2022**	**2021**
	£	£
Net (expenditure)/income	233,821	(1,102,528)
Adjustments for:		
Depreciation charges	9,132	8,457
Net losses on investments	-	1,076
Dividends and interest from investments	(1)	(1,505)
(Increase)/Decrease in stocks	6,218	(63)
Decrease in debtors	(60,683)	104,340
Increase in creditors	(44,475)	1,869,611
Net cash provided by operating activities	144,012	879,388

Analysis of cash at bank and in hand less overdrafts	**2022**	**2021**
	£	£
Cash at bank and in hand	1,760,675	1,617,472
	1,760,675	1,617,472

Notes

To the financial statements for the year ended 31 March 2022

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 2021/22 financial year, we had a net positive movement in both unrestricted and restricted funds. The charity continues to show a net liabilities position on the balance sheet. 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 24 (note i DRPLA and note ii NKX6-2) below for further details. Covid-19 has continued to impact how we raise funds but due to the generous support of the ataxia community it hasn't had a significant impact on our results to 31 March 2022.The cost of living crisis could have an impact on the 2022/23 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 2022/23 to maintain robust future forecasting. We continued to have the office closed for most of 2021/22 with only a minimal number of staff going into the office. Our systems have allowed remote working with minimal disruption. The Trustees feel there are adequate resources to continue operating for the foreseeable future. The Trustees feel that there are no material uncertainties about the charitable company's ability to continue as a going concern. Accordingly, we continue to adopt the going concern basis in preparing this annual report and financial statements.

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

Notes

To the financial statements for the year ended 31 March 2022

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 at the rate of 25% per annum 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. **Investments:** Investments are shown at market value and represent funds not immediately required for charitable expenditure and can be realised at short notice for such expenditure should such funds be required. Gains and losses on investments are shown in the Statement of Financial Activities. Realised gains and losses on investments are calculated as all the differences between sales proceeds and opening market value, or value at purchase date if later. Unrealised gains and losses are calculated as the difference between the market value at the year end and the opening market value, or value at purchase date if later.

g. **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.

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

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

j. **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.

k. **Unrestricted funds:** Unrestricted funds are funds that can be used in accordance with the charitable objects at the discretion of the trustees.

l. **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 23 for further details.

m. **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 24.

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

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

p. **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,

Notes

To the financial statements for the year ended 31 March 2022

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 22 and 23.

q. **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.

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

s. **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.

t. **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.

Notes

To the financial statements for the year ended 31 March 2022

3. Donations and Legacies Income

	2022	2021
	£	£
Donations	858,024	1,278,323
Legacies	258,403	188,897
	1,116,427	1,467,220

4. Other Trading Activities

	2022	2021
	£	£
Fundraising activities	239,962	226,588
	239,962	226,588

5. Charitable Activities Income

	2022	2021
	£	£
Childlife	80,000	62,500
Annual conference	2,327	909
Grants receivable	135,790	146,782
	218,117	210,191

6. Investment Income

	2022	2021
	£	£
Income on investment portfolio	-	114
Interest	1	1,391
	1	1,505

Notes

To the financial statements for the year ended 31 March 2022

7 Raising Funds Expenditure

	2022	2021
	£	£
Costs of generating funds	235,028	234,161
Investment managers fees	-	141
	235,028	234,302

8. Charitable Activities Expenditure

	Direct Costs	Grants	Support Costs	2022 Total	2021 Total
	£	£	£	£	£
Research activities	172,510	248,753	79,799	501,062	2,226,523
Ataxia centres	-	-	-	-	-
Care services	175,945	3,183	151,356	330,484	287,553
Total	348,455	251,936	231,155	831,546	2,514,076
Generating funds	-	-	104,785	104,785	90,212
Research conference	-	-	-	-	-
Raising awareness	32,253	-	72,950	105,203	109,173
Governance	-	-	64,125	64,125	59,193
Total charitable activities	380,708	251,936	473,015	1,105,659	2,772,654

	2022	2021
	£	£
Total support costs		
Staff costs	305,096	316,885
Office costs	158,787	124,159
Depreciation	9,132	8,457
	473,015	449,501

Notes

To the financial statements for the year ended 31 March 2022

9. Research Grants

	2022	2021
	£	£
Research grants made in year comprise		
Development of a selective high throughout screening assay for the discovery of compounds replacing frataxin in FA		26,000
Etravine as a potential therapeutic for Friedreich ataxia		20,000
PROSPAX: an integrated multimodal progression chart in spastic ataxias		5,000
An Online Knowledge Translation Platform for Ataxia Research: Responding to Community Feedback from Stakeholders		1,200
Investigating the use of the Ataxia Instrumented Measure – Spoon (AIM-S) in measuring upper limb function in Dentatorubral-pallidoluysian atrophy (DRPLA)		71,311
Comprehensive Biomarker Characterisation in Dentatorubral-Pallidoluysian Atrophy (CBC-DRPLA)		1,033,858
London Paediatric Centre		23,000
DNA repair pathways underlie common genetic mechanisms that modulate onset in spinocerebellar ataxias and other inherited ataxias		2,100
DRPLA: Biomarkers, Somatic Instability and creating a DRPLA cell line resource		492,318
Generating new Friedreich's Ataxia animal models for validating HSV-1 FXN gene therapy in Dorsal Root Ganglia'		30,000
SCA Global Flash Talk		352
'NKX6-2 Related Spastic Ataxia and Leukodystrophy: Natural history, biomarkers and the potential of gene transfer methods		69,988
'A joint model of online SLT intervention and peer support to enhance communication effectiveness and participation in people with progressive ataxia.'		5,977
The DRPLA Natural History and Biomarker Study'		126,084
Development of a PRIME editing therapy for Ataxia-8 due to the c.121 A to T point mutation		34,600
Scope of work for the DRPLA Natural History Study		51,131
ARCA Global Conference		380
University claimed less than amount of grant awarded		(3,858)
Assessment of ataxia severity under real-life conditions with SARAhome: A multicenter study in spinocerebellar ataxia type 3 (Sca3)	20,000	

Notes

To the financial statements for the year ended 31 March 2022

	2022 £	2021 £
Research grants made in year comprise		
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	
	248,753	1,989,441

Notes

To the financial statements for the year ended 31 March 2022

10. Staff Costs

	2022	2021
	£	£
Staff costs comprised:		
Salaries	664,733	651,929
Social security contributions	70,028	57,934
Pensions	34,104	30,021
Redundancy and termination costs	29,125	-
	797,990	739,884

The average number of employees during the year was 19 (2021: 18) with all employee time involved in providing either support to the governance of the charity or support services to charitable activities.

The senior management team consist of the Chief Executive and the heads of Development, Finance, Fundraising, Research and Services. The total employee benefits of the senior management team were £335,048 (2021: £291,107).

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

	2022	2021
£80,000 – £89,999	1	1

The pension contributions in respect of the above named individual in the year totalled £4,190 (2021: £3,700).

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

Notes

To the financial statements for the year ended 31 March 2022

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 £34,104 (2021: £30,021). There was no outstanding balance (2021: £0) at the year end.

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 (2021: 0) claimed expenses totalling £0 (2021: £0).

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

	2022 £	2021 £
Auditor's remuneration	9,980	15,545
Depreciation	9,132	8,457
Operating lease costs	1,000	1,000

Notes

To the financial statements for the year ended 31 March 2022

14. Tangible Fixed Assets

	Building Works	Other Assets	Total
	£	£	£
COST			
As at 1st April 2021	35,007	69,375	104,382
Additions	-	1,164	1,164
Disposals	(29,674)	(30,289)	(59,963)
As at 31 March 2022	5,333	40,250	45,583
DEPRECIATION			
As at 1st April 2021	31,839	42,597	74,436
Charge for year	1,067	8,065	9,132
Disposals	(28,681)	(30,928)	(59,609)
As at 31 March 2022	4,225	19,734	23,959
NET BOOK VALUE			
As at 31 March 2022	1,108	20,516	21,624
As at 1st April 2021	3,168	26,778	29,946

Included within the net book value of the 'Other Assets' is an amount of £3,000 (£4,000 in 2021) relating to items acquired on Finance Lease/Hire purchase.

15. Investments

	2022	2021
	£	£
Market value at 1 April	-	161,387
Disposals	-	(169,390)
Unrealised gain/(loss)	-	8,003
Market value at 31 March	-	-

Notes

To the financial statements for the year ended 31 March 2022

16. Stock

	2022	2021
	£	£
Stock for resale	-	6,218

17. Debtors Under 1 Year

	2022	2021
	£	£
Income tax recoverable	108,860	113,383
Other debtors	131,482	71,525
Prepayments	32,435	27,186
	272,777	212,094

18. Cash at bank and in hand

The Trustees maintain a policy that all cash balances are held in interest bearing accounts with the exception of a nominal daily float held on current account. Interest receivable is disclosed in note 6.

19. Creditors: amounts falling due within one year

	2022	2021
	£	£
Other creditors	25,764	9,919
PAYE/NI	19,639	16,252
Deferred income	13,086	10,185
Accruals	31,157	45,593
Research grants	746,849	911,134
	836,495	993,083

Notes

To the financial statements for the year ended 31 March 2022

20. Creditors: Amounts falling due after one year

	2022	2021
	£	£
Research grants	1,346,104	1,230,991
Misc creditors	-	3,000
	1,346,104	1,233,991

21. Analysis of net assets between funds

	Restricted Funds	Designated Funds	General Funds	Total 2022	Total 2021
	£	£	£	£	£
Fixed assets	-	-	21,624	21,624	29,946
Investments	-	-	-	-	-
Stock	-	-	-	-	6,218
Debtors	-	-	272,777	272,777	212,094
Cash at bank and in hand	1,241,516	154,113	365,046	1,760,675	1,617,472
Creditors	(2,092,952)	-	(89,647)	(2,182,599)	(2,227,074)
	(851,436)	154,113	569,800	(127,523)	(361,344)

22. Unrestricted Funds

	General Funds	Designated Funds	Total
	£	£	£
Balance as at 1 April 2021	590,306	8,337	598,643
Net increase/(decrease) in funds during the year	125,494	(224)	125,270
Transfers	(146,000)	146,000	-
Balance as at 31 March 2022	569,800	154,113	723,913

Notes

To the financial statements for the year ended 31 March 2022

23. Designated Funds

	Opening Balance £	Net Movement £	Transfers £	Closing Balance £
Funds held in branches	8,337	(224)	-	8,113
Coeliac UK Joint Project	-	-	30,000	30,000
In Control Project	-	-	71,000	71,000
Premises Fund	-	-	35,000	35,000
Research Conference Fund	-	-	10,000	10,000
	8,337	(224)	146,000	154,113

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

b. **Joint Research Project with Coeliac UK:** Funds designated to fund a gluten ataxia research project.

c. **In Control Project:** Funds designated to cover the In Control project to the 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 conference.

Notes

To the financial statements for the year ended 31 March 2022

24. Restricted Funds

	At 1 April 2021	Income	Expenditure	Transfers	At 31 March 2022
	£	£	£	£	£
General Research	-	178,525	82,585	-	95,941
Friedreich's ataxia research	(1)	64,953	51,794	-	13,158
Cerebellar ataxia research	87	2,627	525	-	2,189
Young Person's projects	7,959	-	-	-	7,959
Jerry Farr travel fund	671	-	-	-	671
Welfare	634	-	-	-	634
Welfare – The Gift of Speech	-	30,607	8,983	-	21,624
Goods and Services Received	-	6,610	6,610	-	-
Helpline	31,870	-	-	(31,870)	-
Misc Grants	450	-	-	-	450
Childlife	-	80,000	80,000	-	-
Exeter	582	-	-	-	582
Awareness	4,895	-	724	-	4,171
Kennedy Award	16,948	-	4,750	-	12,198
Research Stem Cell FA	-	97	19	-	78
Mark Dower Trust	1,326	3,625	3,183	-	1,768
Spinocerebellar Ataxia Research Project	-	2,076	415	-	1,661
DRPLA Research	(1,047,450)	174,713	174,713	-	(1,047,450)
In Control Project	4,784	89,671	116,855	31,870	9,470
Ataxia Centres	51,039	-	-	-	51,039
DRPLA Department	11,536	118,477	114,239	-	15,774
Scotland	800	-	-	-	800
NXK6-2	(46,782)	-	-	-	(46,782)
AOA2	665	2,456	491	-	2,629
	(959,987)	754,437	645,886	-	(851,436)

Notes

To the financial statements for the year ended 31 March 2022

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. **Goods and Services Received:** Goods and Services received free of charge in respect of Google ads.

i. **Helpline:** Funds to support the helpline.

j. **Miscellaneous Grants:** Funds provided for general grants.

k. **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.

l. **Exeter:** Funds to be expended in the Exeter area.

m. **Awareness:** Funds provided to raise awareness of Ataxia.

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

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

p. **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.

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

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

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

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

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

v. **Scotland:** Funds to be expended in Scotland.

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

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

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 £1.0m which equates to the year 2 & year 3 payments. Both projects have had a delayed start which has resulted in year 2 & year 3 payments being delayed. Ataxia has signed agreements in place outlining the payment structure ensuring these future commitments will be met.

Notes

To the financial statements for the year ended 31 March 2022

Note ii: Two NKX6-2 research grants of £105k were issued during the 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.

25. Capital Commitments

There are no capital commitments at 31 March 2022 (2021: Nil)

26. Lease Commitments

At 31 March 2022 the charity had future minimum lease payments under non-cancellable operating leases as follows:

	2022		2021	
	Land & buildings	Other	Land & buildings	Other
	£	£	£	£
Payments due:				
Within one year	50,604	1,608	49,604	1,608
Within two to five years	61,802	3,217	29,302	4,825
	112,406	4,825	78,906	6,433

Notes

To the financial statements for the year ended 31 March 2022

27. 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.

www.ataxia.org.uk

Ataxia UK 12 Broadbent Close London N6 5JW

ATAXIA

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 (04974832)

ATAXIA UK

England & Wales - Charity number 1102391

Accounts

Annual Report & Financial Statements

Year Ending: 31 March 2021

Ataxia UK
12 Broadbent Close
London
N6 5JW

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 (04974832)

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Introduction from Co-Chairs

Looking back on what has been very challenging year for the charity sector as a whole, Ataxia UK has shown great resilience getting through a pandemic looking after our staff and our Friends.

At the start of this financial year, we were very concerned about our ability to generate income through fundraising. We re-forecast our budget to account for the difficult times ahead. After your fantastic response to our emergency appeal, we re-forecast again.

Our highly skilled and regarded research team has focused on smaller and rarer ataxias. This work will contribute to the greater understanding of all the ataxias, but more significantly, the funding we received for this work has significantly contributed to our financial stability this year. In the New Year, we supported Friedreich's Ataxia Research Alliance (FARA) push to bring a promising treatment for Friedreich's ataxia to the market in the US. We are monitoring the situation very closely with a view to bringing this treatment to the UK.

Our Chief Executive has done a wonderful job keeping our staff together as they got used to remote working, paying careful attention to the mental health consequences we have all been feeling as we stayed at home. Although only meeting virtually throughout this year, we have refocused our Board. Making it leaner and better equipped to deal with challenges, while ensuring that people with ataxia continue to be at the very heart of everything Ataxia UK does.

Our managers and staff have risen to the of challenge of meeting our strategic aim of ensuring our Friends feel "supported and in control" through the Global Pandemic. We provided template letters for Friends who were having difficulties getting their vulnerability status confirmed. We provided a number of webinars about Covid-19 with expert clinicians so you could ask questions. With the support of the National Lottery, our InControl" project adapted and took many of our activities online. By the end of the financial year, we had provided activities and support to many, tackling loneliness and swelling our ranks with wonderful volunteers.

We welcomed around 180 guests to our virtual Annual Conference in October as we set out to inform, challenge and support you. It was our first major online event, but we still offered our usual varied array of speakers and wide range of workshops. The feedback from this event was excellent.

As you can see in our figures, Ataxia UK ended the financial year in a much better position than expected. We know that is down to our excellent staff and your generous support. We continue to face significant challenges from Brexit and as Ataxia UK seeks to reposition itself following the pandemic. We have learned a lot about ourselves and you, our Friends, and will use this and your feedback to build a strategic plan to continue driving us forwards over the next three years.

Thank you for your support.





Richard Brown MBE, Co-Chair **William Littleboy, Co-Chair**

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 2020-2021 are:

Honorary Officers

Richard Brown, Co-Chair (Elected as Co-Chair 6 October 2019)

William Littleboy, Co-Chair (Elected as Co-Chair 6 October 2019)

Kathy Jones, Honorary Treasurer

Trustees

John Abbott (Retired 27 November 2020)
Richard Brown MBE
Andrew Downie
Kathy Jones
Prof Barry Hunt
Dr Anthony Kaye (Retired 27 November 2020)
Philip Griffiths
Robert Perkins
Alison Love (Retired 7 July 2020)
William Littleboy
Carol McCudden
Terence McCaw
Gemma Fish
Colleen Starkey (Retired 7 July 2020)

Susan Millman is the company secretary and CEO.

Ataxia UK uses the following professional advisors:

Auditors
Mazars LLP
6 Sutton Plaza
Sutton Court Road
Sutton, Surrey, SM1 4FS

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 27 November 2020.

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. Each year one quarter of the trustees retire but are eligible to stand again if they so wish. In addition, the trustees may co-opt up to three additional trustees.

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 includes links to the most significant documents on the Charity Commission website.

The pay and remuneration of the key managers of Ataxia UK is considered annually by a Remuneration Committee, comprising the Co-Chairs 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 to people affected by ataxia at the early stages of diagnosis and specialist services for this medical condition, many of which are not available from the NHS or other statutory or voluntary sources. We work to end isolation and promote engagement in social, educational and leisure activities for people affected by ataxia and their families. We educate the broad community and key subsections within it, such as the medical and social services professions, about the effects of ataxia. We also fund vital research projects into potential treatments, aiming to find a cure for ataxia. There is currently no specific government funding for ataxia research."

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 2020 Regional Conference was cancelled due to Covid-19 restrictions, and the 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 and Euro-ataxia. Our Chief Executive is the Secretary of Euro-ataxia, a federation of patient organisations from 20 different European countries.

The **Scientific Advisory Committee (SAC)** meets three times per year. It 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 Franziska Denk
Dr Claire Kelly
Dr Marija Sajic
Dr Mark Pook
Professor Keith Morris
Dr Gita Ramdharry

The committee included the following lay members during the year:
Rosemary Homayoun, **Harriet Bonney** and **Nathan Hall**.

During this year **Dr Michele Lufino** stood down from the committee and we are extremely grateful for his service on this committee.

Professor Barry Hunt attends as Trustee Scientific Advisor. All members are unpaid volunteers.

Employees

During 2020/21 the average number of full-time equivalent employees during the year was 17.8 (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 2020-21 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 seen the launch of new roles for volunteers, see more on page 21.

Loyal and committed volunteer fundraisers run events both large and small to provide Ataxia UK with essential funds. Our Branches and Support Groups are all run by volunteers, many of whom have ataxia themselves.

We are also grateful to the volunteers who assist our Research department by serving on the Scientific Advisory Committee, Medical Advisory Panel and Pharma Advisory Group. The contribution of all of our volunteers to the work of Ataxia UK is much valued and appreciated.

We have three regular, trained, volunteers supporting our Helpline staff with phone and email enquiries.

Risk Management

As in previous years, we actively managed the risks to the charity, focusing on the most serious. We maintain a register of our controls and activities to mitigate risk throughout the year; in 2020-21 the risk register was significantly influenced by the impact of the Covid-19 pandemic. The most serious risks we faced during 2020-21 were:

- Loss of fundraising through cessation of face-to-face fundraising activities and a reduction of donations – this has been mitigated through a redrafting of the budget for 2020-21 and by replacing physical activities with virtual events.
- Collapse of the remote IT infrastructure which enables remote working by all staff – this was addressed during the year by moving almost all processes to cloud based systems.

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 this is 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 E-newsletter, 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 fundamental to supporting people with ataxia in every way. An understanding of the condition is needed in the medical sector, where diagnosis and treatment is often delayed, but also in the public, where misunderstandings of ataxic symptoms cause many difficulties for people with ataxia. An increase in awareness also often leads to an increase in fundraising. The more aware people are of our aims, the more likely they are to donate to the charity. More can be read about our raising awareness events on p.23.

Our Strategic Plan 2017-2020

There remained much work to be done to benefit people affected by ataxia under the themes of the Strategic Plan 2017-2020. In 2020 we elected to extend it to 2022 whilst keeping the projects to which we are committed undertaken under review to take into account the impact of the changes brought about in many areas of life by the Covid pandemic which arrived towards the end of 2019-20.

It contains four major ambitions:

- By 2022 we want people affected by ataxia to be able to say: “I feel supported and in control”
- To have increased our funded research activity
- To consistently maximise the impact of research activity
- To have fostered best practise in treatment & care

The work we have done during the year has been designed to contribute to these aims. This can be read about below under the headings of Research; Improving Treatment & Care; Services; and Raising Awareness; with Fundraising, and Communications supporting these activities.

However, the changes in our work and environment during the Covid-19 pandemic and the opportunities which now present themselves mean that we are now developing a new Strategic Plan to take effect from April 2022.

Achievements, Performance & Aims

Research

Research aims for 2020-21

- Increase enrolment to FA Global Patient Registry.
- Build on DRPLA programme to coordinate research in the field.
- Plan next International Ataxia Research Conference.

Increase enrolment to the Friedreich's ataxia global registry

Ataxia UK and Friedreich's Ataxia Research Association USA (FARA) facilitate the FA Global Registry. We participate in governance, and recruitment of participants. 362 were registered during the year bringing total registrants to over 1,000 people.

Build on DRPLA programme to coordinate research in the field

Ataxia UK is collaborating with the US Foundation, CureDRPLA, to advance research in Dentatorubral-pallidoluysian atrophy (DRPLA), a rare form of inherited ataxia. Using a staff member funded by CureDRPLA, we also coordinate the DRPLA Natural History and Biomarkers Study (DRPLA NHBS) with study sites in the United Kingdom, the United States and Japan. We have been involved in protocol development, designing and building the electronic database, and creating a governance structure. Ataxia UK is also managing the CureDRPLA contracts and grant awards to Universities involved in the natural history study; and together we have established the CureDRPLA Global Patient Registry to gather patient reported data. We believe the networking and expertise being gained by Ataxia UK working on this DRPLA Research programme will be invaluable in helping us advance research towards treatments and cures in other ataxias.

Plan the next International Ataxia Research Conference

Ataxia UK is partnering with the US ataxia charities, Friedreich's ataxia research alliance and National Ataxia Foundation USA (NAF), to hold the International Congress for Ataxia Research (ICAR) in March 2022 in Orlando, USA. It will combine the best of the host organisations' popular research meetings, including previous International Ataxia Research Conferences (co-hosted by Ataxia UK, FARA, GoFAR,) and NAF's Ataxia Investigators Meeting.

Other Research Activities

Ataxia UK research grant programme

Five grants were awarded via our standard research programme. Five grants were awarded as part of the DRPLA (restricted) research programme and two new grants for spastic ataxia type 8 were funded by the DVS Foundation.

1. **Dr D'Autreax** (CNRS-CEA-Université Paris-Saclay, France) 'Development of a selective high throughput screening assay for the discovery of compounds replacing frataxin in FA' - £26,000.

2. **Dr Rufini,** Fratagene Therapeutics (University of Rome) – Etravirine as a potential therapeutic for Friedreich ataxia - £20,000.

3. **Prof Horvath (Cambridge, UK**) 'PROSPAX: an integrated multimodal progression chart in spastic ataxias' - £5,000.

4. **Year 2 Dr Filip Lim's project** (University of Madrid, Spain) 'Generating new Friedreich's Ataxia animal models for validating HSV-1 FXN gene therapy in Dorsal Root Ganglia Dr Lim' - £30,000 (50% from Kennedy Award Scheme).

5. **Prof Lowit –** A joint model of online Speech and language therapy intervention and peer support to enhance communication effectiveness and participation in people with progressive ataxia - £5,977.

DRPLA Grants (in partnership with CureDRPLA)

1. **Prof Paola Giunti** (University College London, UK) 'Comprehensive Biomarker Characterisation in Dentatorubral-Pallidoluysian Atrophy: £1,034M.

2. **Prof Henry Houlden** (University College London, UK) 'Biomarkers, Somatic Instability and creating a DRPLA cell line resource' - £492K.

3. **Prof Louise Corben** (Genetic Health Research & Murdoch Children's Research Institute, Australia) 'Investigating the use of the Ataxia Instrumented Measure – Spoon in measuring upper limb function in DRPLA' - £71K.

4. **Dr Heather Lau** (NYU Grossman School of Medicine, USA) 'The DRPLA Natural History and Biomarker Study' - £126K.

5. **Prof Adam Vogel** (Redenlab &The University of Melbourne, Australia) 'Redenlab Scope of Work for the DRPLA Natural History Study (Speech and Dysphagia') - £51K.

Spastic ataxia type 8 grants (in partnership with DVS Foundation)

1. **Dr Chelban and Prof Holden** (UCL Institute of Neurology, London) - NKX6-2 Related Spastic Ataxia and Leukodystrophy: Natural history, biomarkers and the potential of gene transfer method. - £69,988.

2. **Dr Tremblay** (Laval University, Canada) - Development of a PRIME editing therapy for Ataxia-8 due to the c.121 A to T point mutation - £34,600.

Our research programme currently comprises 19 projects. We provide support to researchers where needed, evaluating annual reports and monitoring finances.

Analysis of research outcomes of Ataxia UK funded research

We annually evaluate the impact of our funded research. The last 10 years' data shows that every £1 invested by Ataxia UK, produces nearly 6-fold in further funding for ataxia research. In addition, nearly 100 research papers have been published in scientific/medical journals; with 42 new research tools developed over the 10 years.

Ataxia UK featured as a case study in The Association of Medical Research Charities (AMRC) report: 'Without Charities' - produced in anticipation of the Comprehensive Spending Review, to demonstrate the value of medical research charities' contribution to the UK's position as a world leader in medical research.

Association of Medical Research Charities (AMRC) Audit Review

Every 2-3 years the AMRC audits its members' procedures for evaluating and funding research. Ataxia UK passed the 2020 audit with minor changes in our processes suggested. Head of Research, Dr Julie Greenfield was a member of the AMRC Auditors Team, reviewing submissions made by AMRC member charities.

Ataxia UK's involvement in Multi-Centre European Research Projects

Ataxia UK partners with researchers in a number of projects to provide a patient view. Frequently this is through representing Euro-ataxia (the European federation of 22 patient groups). It is indicative of the value placed on Ataxia UK's expertise that we are invited to collaborate in these multi-million pound projects.

1. **European spinocerebellar ataxia type 3/Machado Joseph disease Initiative (ESMI)** - Dr Julie Greenfield is the patient group representative on the Steering Committee representing Ataxia UK and Euro-ataxia.

2. **Friedreich's Ataxia Consortium for Translational Research (EFACTS)** - Ataxia UK Trustee Prof. Barry Hunt is a member of the Steering Committee.

3. **PROSPAX study –** New EU funded project 'PROgression chart of SPAstic ataXias' - Ataxia UK represents Euro-ataxia, (with German charity DHAG). The study will examine the progression of spastic ataxias.

4. **SCAIFIELD project –** New EU JPND project 'Spinocerebellar ataxia advanced imagining with ultra-high field MRI'. Patient input and support.

5. **PhaseAGE –** Ataxia UK's Head of Research joined the Scientific Steering Committee of this new EU funded project, which is a capacity building, training Consortium, with research projects on the formation of 'aggregates' by the phenomenon of phase separation (e.g. as when oil and water separate) in ageing and neurodegenerative conditions including SCA3.

Ataxia Global Initiative

In 2020 SCA Global and ARCA Global merged, becoming The Ataxia Global Initiative. SCA Global focused on dominantly inherited ataxias (e.g. SCAs) and ARCA Global on recessively inherited ataxias (e.g. ARSACS/AOA). Dr Greenfield is a Steering Committee Member and co-chairs the Policy & Patient Engagement Group.

Critical Path to Therapeutics for the Ataxias Consortium

Ataxia UK has participated in the formation of a Consortium for the ataxias. The Consortium is a public-private partnership between the Critical Path Institute, ataxia researchers, pharma companies, Ataxia Global Initiative, Ataxia UK and NAF. It intends to create regulatory tools and strategies that will catalyse the development of

approved medicines for the ataxias. A crucial aspect of the Consortium is to include experts from the regulatory bodies such as the US Food and Drugs Agency (FDA) in the discussions. Ataxia UK has signed an Advisory Agreement with them.

Approval of Omavoloxolone by the FDA (USA)

In January 2021 we supported a campaign to press Reata to submit a New Drug Application on an urgent basis; and the FDA to consider approval of an NDA for Omaveloxolone. The petition gained 74,000 signatures (50% from outside USA) and seems to have precipitated further conversations between Reata and the FDA.

Spastic ataxia type 8 ((SPAX8) research programme

Two grants were awarded to research the rare form of ataxia, (SPAX8) using genetic therapy approaches, A family donated the funds via the DVS Foundation.

AT Society Research Services

Ataxia UK has continued to provide a research support service to the Ataxia Telangiectasia (AT) Society, the UK charity supporting people affected by AT.

Working with Pharmaceutical Companies and industry

Ataxia UK values its collaborative relationships with pharmaceutical companies and is encouraged by their increased interest in the ataxias and the trials being planned.

- **Intrabio:** collaboration resulting in scientific publication describing a novel design for the trial that is of relevance to ultra-rare conditions.
- **Healx:** 'Rare Treatment Accelerator Therapy Development Collaboration' to re-purpose existing approved drug therapies for rare diseases, using artificial intelligence, drug discovery, and development expertise to advance FA research. This approach to drug discovery in FA offers a replicable model and we are already involved in efforts to establish similar approaches in other ataxias.

Pharma Strategy Advisory Committee

The Pharma Strategy meeting in May 2020 discussed working with regulators in the drug approval process to engage and inject patient perspectives. We obtained a meeting with the UK Medicines and Healthcare Regulatory Agency (MHRA). This has led to Ataxia UK former Chairman and Volunteer, Dr Harriet Bonney, joining the MHRA patient group consultative forum as an Ataxia UK representative.

Recruitment of Participants to Research Studies

Our database of people with ataxia enables Ataxia UK to recruit volunteers to participate in research projects. The following projects have been supported:

- ARSACS Optical Coherence Tomography (OCT) study (London UCL/UCLH)
- Tracking the natural progression of spastic ataxias to prepare treatment trials (University of Cambridge)
- Natural history studies in Friedreich's ataxia; SCA3; SCA1, SCA2, SCA6 and SCA7 (All London UCL/UCLH)
- Recording speech samples to improve voice recognition software for people with speech that is difficult to understand (Google AI)
- Online group and peer support speech therapy study for people with progressive ataxia (University of Strathclyde)

- Friedreich's Ataxia Global Patient Registry
- CureDRPLA Global Patient Registry.

We have also been involved in recruitment for the following surveys:

- Superficial Siderosis survey – a rare form of ataxia (London UCL)
- Childhood Neurological Conditions survey (British Paediatric Neurology Association)
- Covid-19 and ataxia survey (Ataxia UK)
- Symptoms of ataxia and hereditary spastic paraplegia survey (PROgression chart of SPAstic ataXias project)
- Investigating the impact of COVID-19 on caregivers and patients survey (Queen's University Belfast/University of Aberdeen)
- Patient experience survey (Genetic Alliance).

Raising Awareness of Ataxia Research

Ataxia UK research staff have attended meetings and conferences during the year.

1. **FindaCure meeting – September 2020** Research Manager Emily Cutting gave a talk at a Findacure webinar on building successful collaborations.

2. **Externally-Led Patient-Focused Drug Development Meeting on Ataxia** - NAF and CureDRPLA meeting to inform the FDA of the impact of SCAs and DRPLA.

3. **World Orphan Drug Congress – 2 to 5 of November 2020**

4. **Exclusive industry Round Table – Ataxia Global (Feb 2021)** - Organised by NAF for pharma companies that are part of their Pharma Consortium.

5. **BIA-AMRC Roundtable Feb 2021**
   A collaborative event between the BIA (UK Bioindustry Association) and the AMRC. This included presentations from charities and companies.

6. **NAF's Exclusive DDC Industry Roundtable April 2021**
   Lessons learned from Friedreich's ataxia Trials.

7. **World Orphan Drug Congress USA 2021 April 2021**
   The Head of Research and DRPLA Research Officer attended this virtual event.

Research aims for 2021-2022

- Host the 2022 International Congress for Ataxia Research.
- Start clinical research programme in DRPLA.
- Gather and disseminate information on perspectives of people with ataxia on research trials.
- Continue involvement with global initiatives to facilitate future approval of medicines for the ataxias.
- In collaboration with other patient groups, support the approval and distribution of treatments for the ataxias in the UK and across the world.
- Evaluate the research priorities of Ataxia UK and incorporate into the forthcoming Strategic Plan.

Improvements in treatments and care

Treatment and care aims for 2020-21

- Explore the development of a second Paediatric Ataxia Centre.
- Produce policy recommendations based on the results of the 'Value of Treatment' research project and assess their implications for current Ataxia Centres.
- Become engaged with the UK Medicines and Healthcare products Regulatory Agency (MHRA).
- Explore the development of an NHS care pathway for ataxias.

Explore the development of a second Paediatric Ataxia Centre

There have been discussions during the year with Prof Giunti at the London Ataxia Centre for adults regarding the development of a Paediatric Ataxia Centre in London. We are delighted that Ataxia UK has been able to provide funding towards a part-time Specialist Ataxia Nurse for the Centre which is also being supported by a private donor. We are optimistic that with sufficient demand for the service, the Trust will look favourably on meeting the cost of this clinic in the future. Plans are underway to establish the Centre and we hope it will open during 2021-22.

Produce policy recommendations based on the results of the 'Value of Treatment' research project and assess their implications for current Ataxia Centres

Ataxia UK worked with Prof Giunti (Head of London Ataxia Centre) in presenting a project on ataxia to the European Brain Council (EBC), which was approved as one of three rare diseases to be included in the 'Value of Treatment' project. The project is supported by funding from pharma companies, Takeda and Reata Pharmaceuticals. It broadly analyses adult patient diagnosis and care pathways in Specialist Ataxia Centres and general non-specialist settings, and will also explore the health economic effects of both settings.

A survey was designed and disseminated in the UK. Following analysis of the results a few modifications were made, and two new surveys were designed in German and Italian. The German survey has been receiving responses and the Italian one will be disseminated during 2021-22. Dissemination is being done via our collaboration with the patient groups in these countries who are members of Euro-ataxia. Data from all countries will be analysed and published next year. This will form the basis of policy recommendations regarding specialist centres on rare diseases that will be presented to the European Parliament.

Become engaged with the UK Medicines and Healthcare products Regulatory Agency (MHRA)

As we get closer to the possibility of treatments being proposed to regulators for approval, it is important for Ataxia UK to become more engaged with medicine regulators such as the UK MHRA. Towards the start of the year a meeting was held with the MHRA and Ataxia UK Head of Research to discuss engagement with Ataxia UK and this led to Ataxia UK Friend and Volunteer, Dr Harriet Bonney, joining the MHRA Patient Group Consultative Forum as an Ataxia UK representative.

During the year Dr Bonney took part in numerous briefings and discussion meetings on a range of topics such as Covid-19 vaccines, Brexit transition and shaping the future of medical device approval. There were also preliminary discussions on the Innovative Licensing and Access Pathway. This builds on the existing Early Access to Medicines Scheme, which gives patients with life-threatening or seriously debilitating conditions access to medicines that do not yet have a marketing authorisation when there is a clear unmet medical need. Its goal is to deliver efficient and timely development of medicines and earlier patient access. Dr Bonney has now also joined the Patient Reference Group for the Innovative Licensing and Access Pathway and will be able to continue to provide input from the perspective of people with ataxia.

These developing links with the MHRA will place Ataxia UK in a better position to understand the processes of medicine approval and equip us with the necessary skills to represent patients' interests and campaign for drug approvals when the time comes. Ataxia UK will also increase the engagement with medicine regulators in the coming year due to the participation in 'Critical Path to Therapeutics for the Ataxias Consortium' (see Research section).

Explore the development of an NHS care pathway for ataxias

Ataxia UK has continued to inject our views via the Neurological Alliance (England) into the NHS Care Pathways work being undertaken by the NHSE National Neurology Advisory Group (NNAG) and it is expected that draft pathways for a number of neurological conditions, one of which will cover the ataxias will be published in early summer 2021-22 for consultation with stakeholders including patient groups.

Other ongoing activities

Medical Advisory Panel meetings

Ataxia UK's Medical Advisory Panel comprises ataxia specialist clinicians and ataxia nurses, who provide advice to the charity on areas of interest in medical issues and healthcare. During the year two virtual meetings were held. Advice was sought on Covid-19 vaccinations for different types of ataxia and the creation of the Covid-19 survey was discussed (see below). Two new individuals joined the panel, a neurologist from Glasgow and a speech and language therapist. Ataxia clinic updates and new research publications from members were highlighted and discussed thus contributing to sharing knowledge and expertise on ataxia.

Providing information and advice to people with ataxia during the Covid-19 pandemic

Three virtual seminars and Q&A sessions were held in March 2020, April 2020 and July 2020 with the team of the London Ataxia Centre (Prof Giunti and the Ataxia nurse Suzanne Booth) to provide information on Covid-19, on shielding, going to school, and numerous other practical issues. There was much demand for advice, and these were well attended events. The same team gave a similar seminar on vaccinations and priority groups in response to many enquires via social media and the Helpline. We were grateful to the staff of the London Ataxia Centre for their help in assisting people with ataxia.

The Ataxia UK website carried information on Covid-19 and when the vaccine became available, a template letter to facilitate access to it for people with ataxia was made available. This approach was used successfully by a number of people who managed to bring forward their vaccination.

Collecting data on impact of Covid-19

Ataxia UK survey

Following discussion at the last Medical Advisory Panel meeting we are working with ataxia neurologists Rajith de Silva and Paola Giunti in designing a survey to understand the impact of Covid-19 on people with ataxia of the effect of short- and long-term symptoms. This was reviewed by Ataxia UK's internal Ethics Committee and then distributed widely to Friends of Ataxia UK (between October 2020 and March 2021). Results are currently being analysed and will be submitted for publication.

IMPaCCt study

Researchers at Queen's University Belfast and the University of Aberdeen have been doing a study to investigate the impact of Covid-19 on people with rare diseases and cancer in terms of healthcare service provision. Ataxia UK disseminated this survey to people with ataxia to get their perspective.

Formation of new Ataxia UK Ethics Review Committee

When researchers contact Ataxia UK to publicise a research study to participants our procedure has always been to ensure that they have obtained ethical approval from a University or NHS Research Ethics Committee. However, there are instances where it may not be necessary for this to happen, but an internal ethics review will suffice. This may be the case, for example, when Ataxia UK wishes to do a survey of people with ataxia.

To this end, it was agreed that Ataxia UK should formalise the process of ethical review of any surveys and a procedure has been set up, together with the creation of an Ethics Review Committee. During the year the committee has reviewed seven surveys (two from Ataxia UK and five external ones).

Raising awareness and understanding of ataxia amongst healthcare professionals

We continue to reach out to healthcare professionals with an interest in ataxia via our e-newsletters sent to our registry three times a year. Recent clinical papers on the ataxias are publicised, as well as information on events and funding opportunities.

Ataxia UK had awarded a grant to the Sheffield Ataxia Centre in order for them to run an ataxia training event. This event was postponed due to Covid-19, but they now have a new date for 2021 as a virtual event.

Ataxia UK accredited Ataxia Centres

1. **Sheffield Children Centre**

We now have the first Accredited Ataxia Centre for children, and this is based in Sheffield. There is a dedicated specialist ataxia paediatric neurologist running the

service and an Ataxia nurse. A formal opening had been scheduled for March 2020 however unfortunately this did not happen due to Covid-19. The Centre is progressing well and is receiving many referrals.

2. Adult Ataxia Centre – 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 paediatric ataxia clinic now run by Santosh Mordekar. Prof Hadjivassiliou continues to publish extensively on ataxia research, in particular autoimmune ataxias.

3. London adult Ataxia Centre

Prof Giunti continues to run busy ataxia clinics and has the support of a full-time Ataxia Nurse, providing much needed assistance to the expanding clinic. She also has a second neurologist which has increased the capacity and enabled the team to see more ataxia patients. Prof Giunti continues to be involved in numerous research projects including trials. Her site is the only UK site for European natural history projects on the SCAs and FA and is also the site for the Reata trial in FA. During the year she was awarded a grant from Ataxia UK to be the main site of the DRPLA natural history study.

Due to Covid-19 all London Ataxia clinic appointments were changed to phone clinics with Prof Paola Giunti and the Ataxia Nurse Suzanne Booth. Ataxia UK has disseminated a feedback form to patients of the phone clinic to monitor and improve the service; 45 responses have been received. Overall, the satisfaction was high, with the average score being 8 out of a maximum score of 10. Unsurprisingly, the most common advantage (selected by 84% of respondents) was the lack of travel and waiting time. The most common disadvantage (selected by 60% of respondents) was the lack of a physical examination with specific comments being made about a lack of visual cues such as body language hindering communication. Most respondents (74%) said that they would have preferred a face-to-face appointment.

Ataxia clinic volunteers have not been able to attend the clinic and we are trying to set up a system for them to provide support virtually.

Euro-ataxia

Euro-ataxia is the federation of ataxia charities across Europe, with 22 member groups. Ataxia UK's CEO is the Secretary General and Ataxia UK's Head of Research is the Research Advisor.

Regular Board meetings have been held during the year and an online AGM and meeting of members was held in December 2020. Ataxia UK's Head of Research gave a research update of all the European projects Euro-ataxia is involved in plus new Ataxia Global initiatives.

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.

Supporting charities in lobbying for improvements in care and research

We are members of a number of sector organisations, including Genetic Alliance UK/Rare Disease UK, the Association of Medical Research charities and Neurological Alliance and we support these organisations in the work they do. Sue Millman, CEO of Ataxia UK, is also a Trustee of Genetic Alliance UK and the Neurological Alliance to increase our engagement with these organisations.

The Genetic Alliance is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. It seeks to raise awareness of genetic conditions and improve the quality of services and information available to patients and families. It actively campaigns on issues of policy and practice to influence governments, policy makers, industry and care providers such as the National Health Service. It also coordinates Rare Disease UK (RDUK) which is the national campaign for people with rare diseases and all who support them. RDUK is working with health departments across the UK to implement the UK Strategy for Rare Diseases to ensure that patients and families living with rare conditions have equitable access to high quality services, treatment and support.

The Neurological Alliance is the only collective voice for over 80 organisations working together to make life better for millions of people in England with a neurological condition. We are also members of Scottish Neurological Alliance (the CEO joins their policy meetings) and Trustee, Carol McCudden, is on the Board of Trustees of the Wales Neurological Alliance, playing an active role in the activities of the organisation.

Working with government bodies and the National Health Service to influence healthcare policies of relevance to people with ataxia

Covid-19

Many people affected by ataxia were concerned at the lack of priority given to people with ataxia during the Covid-19 pandemic in being assessed as Extremely Clinically Vulnerable (ECV) thereby being advised to shield, and subsequently entitled to be in Category 4 for the vaccine. It was clear when the ‘shielding letters’ were originally issued, that whether people with an ataxia received a letter was very hit and miss. Very soon it was apparent that it was common across a number of neurological and rare diseases. Ataxia UK was active in support of the efforts of Rare Disease UK/Genetic Alliance UK and the Neurological Alliance who made strong representations via various routes for the situation to be rectified; we received a sympathetic reception but no positive result.

It's clear that in some areas the problem has been rectified locally for some conditions – but it was not consistent. In a Neurological Alliance survey answered by 1,672 people, 49% reported difficulty with shielding notification. In this situation we decided that Ataxia UK should support people by advising them to approach their GP to explain why their status should be changed (see above). The Association of British Neurologists then issued more specific guidance on the priority groups for vaccination for people with neurological conditions, including the ataxias. This, and the progress in rolling out the vaccine seems to have dissipated the problem.

Rare Disease Advisory Group (RDAG)

Our CEO Sue Millman has been a member of the NHS England Rare Disease Advisory Group for the last four years but reached the end of her term towards the end of the year. RDAG makes recommendations to NHS England and the devolved administrations of NHS Scotland, NHS Wales and NHS Northern Ireland on developing and implementing the strategy for rare diseases and the commissioning of highly specialised services.

Patient and Public Voice Assurance Group (PPVAG)

Sue Millman has also served on the PPVAG as a representative of RDAG, but this appointment has also expired. The Patient and Public Voice Assurance Group (PPV AG) works to offer strategic assurance to NHS England that effective mechanisms are in place to fully involve patients and the wider public in the development of the national specialised services portfolio. The UK Rare disease strategy implementation plan was a topic discussed this year and we were able to influence some key decisions.

Treatment and care aims for 2021-2022

- Review and update Medical Guidelines on ataxia.
- Launch a second Paediatric Ataxia Centre.
- Establish additional ataxia clinics with expert neurologists.
- Pilot the use of a peripatetic Specialist Ataxia Nurse.
- Further our engagement with medicine regulators to facilitate the approval of treatments for the ataxias when they become available.

Care and Support Services for people affected by ataxia

Care and support service aims for 2020-21

- Develop services to meet the needs of people affected by ataxia during the Covid-19 pandemic.
- Establish the services of the InControl Project.
- Conduct a Mental Wellbeing Survey of Friends and produce a report.
- Conclude research into the financial circumstances of Friends and issue a report.
- Construct a Service Delivery Development Strategy taking account the conclusions of the two reports above.

InControl Project

InControl is a three-year funded project from the National Lottery Community Fund. The main objectives of the project are to decrease feelings of social isolation and increase feelings of mental wellbeing for the ataxia community. This is delivered through the development of new services and volunteering opportunities for the ataxia community. Due to Covid-19 restrictions we have adapted the project to be delivered virtually, which has been welcomed by the ataxia community.

1. **All About Ataxia**
   Quarterly two-day learning workshop for people who have recently received a diagnosis of ataxia. This is supported by volunteers, who facilitate discussion with participants. This can also be useful for people who have had their diagnosis for a longer time but are keen to find out more about ataxia.

2. **Branch and Support Groups**
   Operating through Zoom, our volunteers have offered 59 meetings since October 2020.

3. **Friends Connect**
   A virtual Befriending service, which has 12 ongoing relationships between volunteer and Beneficiaries.

4. **Media Ambassadors**
   Media ambassador volunteers create blogs/vlogs/articles that highlight their experience of living with ataxia.

5. **Speech Therapy**
   We are working with Dr Anja Lowit from Strathclyde University to run virtual speech therapy groups. This is for adults with mild/moderate speech issues, and the groups are part of a trial to establish whether the peer support methodology is beneficial. The first cohort of participants began in early March 2021.

6. **Volunteer Recruitment**
   We have recruited an additional 40 volunteers as part of InControl through 20/21.This is supported through regular messaging on social media and in Ataxia UK magazine. Our onboarding resources and templates are produced

in line with best practice standards in volunteering.

7. **Virtual Activities**
   Our virtual activity program was launched in April 2020. We have provided games/discussion groups/exercise classes and Music groups. Through 20/21 we delivered 61 sessions, with a total of 848 participants attending.

Helpline

The Helpline continues to be busy with both calls and emails. The total number of contacts to the Helpline during 2020-2021 was 1,441, including enquires by email and phone. The topics covered were very wide-ranging, with most people calling about questions on Ataxia UK and what we can offer; queries on medical issues and asking about referrals to Ataxia clinics or specific information on diagnosis, and welfare benefits were common topics. Many people were contacting Ataxia UK to get general support to live with their condition. During the year many enquiries came regarding Covid-19 and a new section of the website was created specifically in response to this demand, in addition to organising four information webinars with the London Ataxia Centre clinical team.

Many people come to Ataxia UK for help with accessing benefits or appealing decisions. Ataxia UK has continued to provide them with letters of support, explaining about ataxia and the impact it has, with some success.

Template letters were provided on the website to assist people in being placed in the correct Covid-19 vaccination priority group. This information was distributed widely to Friends and we were pleased to get some positive feedback as to the success of these letters in their requests for moving up the priority list.

During the year we were pleased to welcome 520 new people who joined Ataxia UK as Friends.

Other work on Care and Support Services

Grants

Ataxia UK acts as a third party for four Charitable Trusts, supporting people with ataxia to apply for grants towards mobility aids, adaptations to the home and other supportive equipment. During the year, grants have been awarded by the Headley Trust, the Florence Nightingale Aid in Sickness Trust and The Barchester Charitable Foundation. As a result of our efforts, £12,410 has been raised for people with ataxia, mostly towards purchasing wheelchairs and adaptations to wheelchairs.

Ataxia UK works alongside the Mark Dower Trust which offers a grant up to £3,000 per year to be split among awardees aged between 16-30. The aim is to help promote and encourage independence. Ataxia UK publicises the trust through social media, our e-newsletter, website and the Ataxia Magazine. Throughout FY20-21, seven people applied for the grant and have been each awarded a grant.

We are grateful to those whose generosity has made these grants possible and for enabling Ataxia UK to help support, enrich and ease the lives of people with ataxia.

Care and support aims for 2021-22

- Establish face to face elements for InControl services when permitted.
- Undertake the Interest in Volunteering (IIV) accreditation to ensure best practice in our InControl volunteering project.
- Develop and implement our Diversity Strategy as it relates to services.
- Support the engagement of Friends in the development of our new Strategic Plan.
- Develop and implement an improvement plan for our Helpline, Advocacy and Information services.

Raising Awareness

Awareness aims for 2020-21

- Investigate and implement new strategies to increase the awareness of Ataxia UK in the ataxia community and encourage the sign up of new Friends.
- Consider the feasibility of campaigning and lobbying for the ataxia community.
- Continue to grow our social media audiences and increase engagement rate.
- Explore the use of paid advertising to reach targeted audiences for both awareness and fundraising.
- Review database requirements in light of expected growth, recommend and implement new solutions as required.

Due to the onset of the pandemic at the start of the financial year, we had to adjust our priorities and re-prioritise activities and resources in order to respond to the ever-changing landscape we found ourselves in.

Investigate and implement new strategies to increase the awareness of Ataxia UK in the ataxia community and encourage the sign up of new friends

One of the core new approaches to raising awareness of Ataxia UK within the ataxia community this financial year has been securing the Google Grant. The Google Grant means we have access up to $10,000 per month in search adverts shown on Google.com. Between November 2020 and March 2021, we had 5.27k impressions and 903 clicks through to the website. We hope to build on this in the coming months and better utilise this resource for awareness, new Friends and fundraising, where possible.

Consider the feasibility of campaigning and lobbying for the ataxia community

The disruption of the last year caused a delay in this work which has now been merged into our Strategic Planning process.

Continue to grow our social media audiences and increase engagement rate

We are seeing continual growth among our digital communication channels. In the last year our e-newsletter subscribers have increased by 32%, we've had 9% growth in Facebook followers and likes, 7% growth in Twitter followers and 30% on Instagram. On HealthUnlocked we have a 13.26% reduction in active members but the platform is still frequently used by the ataxia community.

Explore the use of paid advertising to reach targeted audiences for both awareness and fundraising

Throughout FY2020-21 we have run a number of campaigns on Facebook with multiple goals including the recruitment of new regular givers, promoting will writing guides and boosting multiple posts. We will continue to explore this channel.

Review database requirements in light of expected growth, recommend and implement new solutions as required

This financial year we upgraded our on-site server hosted database to the latest cloud-based version. This upgrade provides new functionality to help improve our service delivery and fundraising.

Awareness aims for 2021-22

We are re-examining our aims for awareness raising in the future and are intending to focus on raising awareness in tandem with the aims of our workplans in other areas rather than running 'independent' awareness campaigns. In particular we wish to harness our communications work in support of lobbying campaigns undertaken in support of Friend's aspirations.

Fundraising

Fundraising aims for 2020-21

- Continue to increase the number of people who give to Ataxia UK regularly.
- Plan and deliver the bespoke Ataxia UK Challenge Event – Ataxia Classic 2020.
- Continue to establish a proactive Major Donor strategy.
- Expand support and increase income from trusts, corporates and foundations.
- Review database requirements in light of expected growth, recommend and implement new solutions if required.

As with many charities, we had to review and adapt our existing plans to respond to the pandemic. We had expected a significant impact to our income across the board. Thanks to the generosity and support of the ataxia community along with some significant donations made to a specific research stream, the year ended very strongly, and Ataxia UK is in a good position to continue supporting those affected by ataxia through these historic times.

In this financial year we received two complaints relating to our fundraising, both specifically around the time it had taken to dispatch thank you letters. We have launched a review of our acknowledgement processes and will be working towards ensuring everyone is promptly thanked for their support.

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, and major donor fundraising. We do not utilise any professional external 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.

Increase regular giving

We recruited 79 new regular givers this financial year and whilst this is lower than the previous year, it still represents an increase on the recruitment before we implemented this strategy and is unsurprising given the disruption of the last year.

Plan and execute the bespoke Ataxia UK Challenge Event – Ataxia Classic 2020

Despite much uncertainty, a scaled down, Covid safe version of the Ataxia Classic 2020 was held in September 2020 and was a fantastic success. We had a great response from those brave enough to take on the challenge of the 100km and 50km Yorkshire course and we will build on this success in FY21-22.

Continue to establish a proactive Major Donor Strategy

Due to the need to move our database online we were not able to deploy resources in this area during the last year, however this work has now resumed.

Expand support and increase income from trusts, corporates and foundations

Given the pressures on Trusts and Foundations funding in 2020/21 caused by the pandemic and their shift towards supporting front-line charities during the pandemic, we were not able to expand our income from this source of fundraising during the year. However, given the expected return to normality and our development of support projects for the ataxia community in the UK, we expect income from Trusts and Foundations to rise significantly in 2021/22.

We are very grateful to all the Trusts and Foundations, large and small, who continued to support us financially during 2020/21.

Review database requirements in light of expected growth, recommend and implement new solutions as necessary

This financial year we upgraded our on-site server hosted database to the latest cloud-based version. This upgrade provides new functionality to help improve our service delivery and fundraising.

Fundraising aims for 2021-22

- Review the existing Fundraising Strategy.
- Continue to adapt our fundraising approach to changing and challenging external environment and maintain income.
- Continue to increase the number of people who give to Ataxia UK regularly.
- Begin work on charity wide supporter journey.

Financial review – to March 2021

Overview

2020/21 was a very challenging year financially due to the Covid-19 pandemic, but one through which the charity has come through successfully.
The Balance Sheet and Statement of Financial Activities show a substantial drop in Ataxia UKs funds, however this is due to the 3 years expenditure commitment being made for the DRPLA and NKX6-2 projects, whilst the funding will be received gradually over the 3 year period of the projects. Hence the present net liabilities on the balance sheet, a situation which will be resolved over the 3 year period. This is also the reason behind the decrease in net income for the year to -£1,103K (2019/20: £230K).
Restricted funds, of which DRPLA and NKX6-2 funds are part, have also decreased over the year for the same reason to -£960K (2020: £322K). Once the outstanding restricted funds are removed the net total is £134K. General unrestricted funds have however increased to £599K (2020: £420K). This reflects the way the nature of giving has changed during the pandemic period; specific events tend to raise restricted funds and these were replaced with the emergency appeal which created unrestricted funds. Further details of reserves are given later in this review.

Review of income

Total income for 2020/21 was £1,906K (2019/20: £1,389K) an increase of 37%. Donation income was substantially higher than the previous year, £1,278K (2019/20: £768K) an increase of 66%. Legacy income has also increased to £189K for the year (2019/20: £149K), an increase of 3%. We remain very grateful to the Friends and supporters who remember us in this way. Income from fundraising activities decreased to £227K (2019/20: £334K) a decrease of 32%. The increase in donations and decrease in fundraising income are due as previously mentioned to the change in activity due to the Covid-19 pandemic. Childlife income remained at £63K but grants received increased from £59K to £147K. The grants received income is made up of lottery funding of the In Control project (£122k), co-funding and furlough payments (£17k), plus other welfare grants (£8k).

Review of expenditure

Our spending on research activities increased to £2,227K (2019/20: £304K), an increase of 633%. Included within this were research grants of £1,989K (2019/20: £174K), an increase of 1,043% on prior year. Five DRPLA grants amounting to £1,775K account for the majority of this along with £105K for the NKX6-2 project. There was no further investment in the Ataxia centres during the year, and a small increase on care services to £288K (2019/20: £249K). Cost of raising awareness decreased slightly from the previous year at £109K (2019/20: £134K). Expenditure on raising funds decreased by 15% to £234K (2019/20: £276K). Governance costs increased very slightly, and there was no research conference held.

Investment policy and performance

Our investments are, in all cases, held in the form of publicly quoted bonds and cash. There are no restrictions on the Charity's power to invest and the trustees have not adopted an ethical investment policy. Cash balances not immediately required are kept in interest bearing accounts with banks that are subject to strict

credit criteria. All investments matured during the year and with the current very low interest rates have not, as yet, been re-invested.

Reserves levels at year end

The charity saw a decrease in reserve levels ending the year on -£361K (31 March 2020: £741K), due to the large negative restricted funds balance created by the DRPLA and NKX6-2 agreements.
Restricted funds were -£960K (2019/20: £322K), (detailed in Note 23) with the largest amounts received being for DRPLA and NKX6-2, but with the associated larger expenditure commitment causing the current negative balance. Ataxia UK has signed agreements in place outlining the payment structure ensuring these future commitments will be met.
Designated Funds totalled £8K (2019/20: £12.5K) representing funds held at branches and are detailed under Note 22.
General reserves of the charity as at 31 March 2021 were £590K (31 March 2020: £407K) a 45% increase. The trustees consider that it is both prudent and appropriate as part of their risk management policy to maintain a minimum level of contingency within free reserves to provide against any unforeseen changes in income and/or expenditure. The reserves policy continues to be that holding unrestricted free reserves equal to a minimum of 3 months operating costs (presently £64K per month, 2019/20: £53K per month) was an acceptable level to hold. 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 unrestricted funds less the net book value of tangible fixed assets, £30K (2019/20: £36K). As at 31 March 2021, free reserves totalled £560K (2019/20: £371K) equating to 8.73 months operating costs (2019/20: 7 months) and is therefore in excess of the reserves policy.

COVID-19/GOING CONCERN

With the impact of the Covid-19 pandemic during the last year, the importance of having adequate reserves, as detailed above, became immediately apparent. A revised Covid-19 budget was drawn up and management accounts and cashflow have been kept under close scrutiny to ensure the ongoing viability of the charity. Covid-19 has had, and continues to have, an impact on how we raise funds but due to the generous support of the ataxia community it hasn't had a significant impact on our results to 31 March 2021. Due to the ongoing uncertainties surrounding the pandemic we are aware that this could still have an impact on the 2021/22 financial year. We will maintain the close scrutiny of management accounts and cashflow and take whatever steps necessary to ensure the continued viability of the charity.

Statement of Trustees' Responsibilities

The trustees (who are also directors of Ataxia UK for the purposes of company law) are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).
Company law requires Trustees to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charitable company, and income and expenditure, of the charitable company for that period. In preparing these financial statements, 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;
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained on the financial statements;
- Prepare the financial statements on the going concern basis, unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements 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. In so far as the trustees are aware:

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

Brexit

The trustees are continuing to assess the impact on the charity of the United Kingdom's decision to leave the EU. They are not expecting this to have a significant impact on the charity.

Covid-19
The trustees continue to assess and monitor the impact of the pandemic and the consequences for Ataxia UK. In the short term we are striving to preserve sources of funding, whilst continuing to provide the support required by our community.

Approved by the trustees on 11 October 2021



Richard Brown, Co-Chair



William Littleboy, Co-Chair



Kathy Jones - Treasurer

Independent auditor's report to the members of Ataxia UK

Opinion

We have audited the financial statements of Ataxia UK (the 'charity') for the year ended 31 March 2021 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 FRS 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 2021 and of its income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance 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 charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

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

Other information

The other information comprises the information included in the Trustees' Report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. 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 course of 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.

Opinions 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 which includes the Directors' Report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Directors' Report included within the Trustees' Report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception
In light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the Directors' Report included within the Trustees' Report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate and proper accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of Trustees
As explained more fully in the trustees' responsibilities statement set out on page 29, the trustees (who are also the directors of the charitable company for the purposes of company law) 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 the trustees 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.

Auditor's 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 the 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. Based on our understanding of the charity and its activities, we identified that the principal risks of non-compliance with laws and regulations related to the Charities Act 2011, UK tax legislation, pensions legislation, employment regulation and health and safety regulation, anti-bribery, corruption and fraud, money laundering, non-compliance with implementation of government support schemes relating to COVID-19, and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements, such as the Companies Act 2006 and the Charities Statement of Recommended Practice.

We evaluated the trustees' and management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls) and determined that the principal risks were related to posting manual journal entries to manipulate financial performance, management bias through judgements and assumptions in significant accounting estimates, in particular in relation to use of restricted and endowment funds, and significant one-off or unusual transactions.

Our audit procedures were designed to respond to those identified risks, including non-compliance with laws and regulations (irregularities) and fraud that are material to the financial statements. Our audit procedures included but were not limited to:

- Discussing with the trustees and management their policies and procedures regarding compliance with laws and regulations;
- Communicating identified laws and regulations throughout our engagement team and remaining alert to any indications of non-compliance throughout our audit; and

- Considering the risk of acts by the charity which were contrary to applicable laws and regulations, including fraud.

Our audit procedures in relation to fraud included but were not limited to:

- Making enquiries of the trustees and management on whether they had knowledge of any actual, suspected or alleged fraud;
- Gaining an understanding of the internal controls established to mitigate risks related to fraud;
- Discussing amongst the engagement team the risks of fraud; and
- Addressing the risks of fraud through management override of controls by performing journal entry testing.

There are inherent limitations in the audit procedures described above and the primary responsibility for the prevention and detection of irregularities including fraud rests with management. As with any audit, there remained a risk of non-detection of irregularities, as these may involve collusion, forgery, intentional omissions, misrepresentations or the override of internal controls.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of the audit report

This report is made solely to the charity's members as a body in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charity's members 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 and the charity's members as a body for our audit work, for this report, or for the opinions we have formed.

N J Wakefield

Nicola Wakefield

(Senior Statutory Auditor)

for and on behalf of Mazars LLP

Chartered Accountants and Statutory Auditor

6 Sutton Plaza, Sutton Court Road, Sutton, Surrey, SM1 4FS

Date: 13 October 2021

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 2021

	Notes	Unrestricted funds	Restricted funds	Total *2021*	Total *2020*
		£	**£**	**£**	**£**
Income					
Donations and legacies	3	*821,662*	*872,146*	*1,693,808*	*1,251,385*
Charitable activities	4	*8,888*	*201,303*	*210,191*	*134,448*
Investments	5	*1,505*	-	*1,505*	*2,905*
Total income		*832,055*	*1,073,449*	*1,905,504*	*1,388,738*
Expenditure on:					
Raising funds	6	*(233,384)*	*(918)*	*(234,302)*	*(275,529)*
Charitable activities	7	*(399,810)*	*(2,372,844)*	*(2,772,654)*	*(881,415)*
Total expenditure		*(633,194)*	*(2,373,762)*	*(3,006,956)*	*(1,156,944)*
Net losses on investments		*(1,076)*	-	*(1,076)*	*(1,657)*
Net income/(expenditure)		*197,785*	*(1,300,313)*	*(1,102,528)*	*230,137*
Transfer from Unrestricted to Restricted		*(18,646)*	*18,646*	-	-
Net movement in funds		*179,139*	*(1,281,667)*	*(1,102,528)*	*230,137*
Total funds brought forward		*419,504*	*321,680*	*741,184*	*511,047*
Total funds carried forward		*598,643*	*(959,987)*	*(361,344)*	*741,184*

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 2020

	Unrestricted funds	**Restricted funds**	**Total *2020***
	£	**£**	**£**
Income			
Donations and legacies	*748,628*	*502,757*	*1,251,385*
Charitable activities	*13,321*	*121,127*	*134,448*
Investments	*2,905*	-	*2,905*
Total income	*764,854*	*623,884*	*1,388,738*
Expenditure on:			
Raising funds	*(253,027)*	*(22,502)*	*(275,529)*
Charitable activities	*(459,547)*	*(421,868)*	*(881,415)*
Total expenditure	*(712,574)*	*(444,370)*	*(1,156,944)*
Net losses on investments	*(1,657)*	-	*(1,657)*
Net income	*50,623*	*179,514*	*230,137*
Transfer from Unrestricted to Restricted	*(40,613)*	*40,613*	-
Net movement in funds	*10,010*	*220,127*	*230,137*
Total funds brought forward	*409,494*	101,553	*511,047*
Total funds carried forward	*419,504*	*321,680*	*741,184*

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 2021

	Notes	*2021* £	£	*2020* £	£
Fixed assets					
Tangible assets	13	29,946		35,770	
Investments	14	-		161,387	
			29,946		**197,157**
Current assets					
Stock	15	6,218		6,155	
Debtors	16	212,094		316,434	
Cash at bank and in hand	17	1,617,472		578,901	
		1,835,784		901,490	
Creditors: amounts falling due within one year	18	(993,083)		(303,463)	
Net current assets			**842,701**		**598,027**
Total net assets less current liabilities			**872,647**		**795,184**
Creditors: amounts falling due after more than one year	19		(1,233,991)		(54,000)
Total net (liabilities)/assets	20		**(361,344)**		**741,184**
Accumulated funds					
Unrestricted funds					
General funds	21		590,306		406,974
Designated funds	22		8,337		12,530
			598,643		**419,504**
Restricted funds	23		(959,987)		321,680
Total funds			**(361,344)**		**741,184**

These accounts have been prepared in accordance with Section 398 of The Companies Act 2006 and Section 138 of The Charities Act 2011. 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 11 October 2021 and signed on their behalf by:





Richard Brown, Co-Chair William Littleboy, Co-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 2021

	2021	2020
	£	£
Cash generated from operating activities:		
Net cash provided by operating activities	879,388	351,026
Cash flows from investing activities:		
Dividends and interest from investments	1,505	2,905
Purchase of property, plant and equipment net of sales	(2,797)	(33,085)
Proceeds from sale of investments	160,475	19,676
Net cash provided/(used in) by investing activities	159,183	(10,504)
Net increase in cash:	1,038,571	340,522
Cash at bank and in hand less overdrafts at the beginning of the year	578,901	238,379
Change in cash and cash equivalents	1,038,571	340,522
Cash at bank and in hand less overdrafts at the end of the year	1,617,472	578,901

Reconciliation of net income to net cash flow from operating activities

	2021	2020
	£	£
Net (expenditure)/income	(1,102,528)	230,137
Adjustments for:		
Depreciation charges	8,457	14,879
Net losses on investments	1,076	1,657
Dividends and interest from investments	(1,505)	(2,905)
(Increase)/Decrease in stocks	(63)	252
Decrease in debtors	104,340	48,500
Increase in creditors	1,869,611	58,506
Net cash provided by operating activities	879,388	351,026

Analysis of cash at bank and in hand less overdrafts

	2021	2020
	£	£
Cash at bank and in hand	1,617,472	578,901
	1,617,472	578,901

NOTES TO THE FINANCIAL STATEMENTS

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 2020/21 financial year, we had a net positive movement in unrestricted funds and a net negative movement in restricted funds due to timing issues of funding for DRPLA and NKX6-2 research grants. This has resulted in a net liabilities position on the balance sheet. The funding for these will be received over the next 3 years with the initial payment already received, see note 23 (note i DRPLA and note ii NKX6-2) below for further details. Covid-19 has continued to impact how we raise funds but due to the generous support of the ataxia community it hasn't had a significant impact on our results to 31 March 2021. Due to the ongoing uncertainties surrounding the pandemic we are aware that this could still have an impact on the 2021/22 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 through virtual events to safeguard income. A budget and associated cash flow have been drawn up for the next financial year 2021/22 to maintain robust future forecasting. We continued to have the office closed during 2020/21 with only a minimal number of staff going into the office. Our systems have allowed remote working with minimal disruption. The Trustees feel there are adequate resources to continue operating for the foreseeable future. The Trustees feel that there are no material uncertainties about the charitable company's ability to continue as a going concern. Accordingly, we continue to adopt the going concern basis in preparing this annual report and financial statements.

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

d. **Tangible Fixed Assets:** Tangible fixed assets costing more than £1,000 are capitalised and depreciated over their anticipated useful life. Office equipment is depreciated at the rate of 25% per annum 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. **Investments:** Investments are shown at market value and represent funds not immediately required for charitable expenditure and can be realised at short notice for such expenditure should such funds be required. Gains and losses on investments are shown in the Statement of Financial Activities. Realised gains and losses on investments are calculated as all the differences between sales proceeds and opening market value, or value at purchase date if later. Unrealised gains and losses are calculated as the difference between the market value at the year end and the opening market value, or value at purchase date if later.

g. **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.

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

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

j. **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.

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

l. **Designated funds:** Designated funds represent amounts held by Ataxia branches.

m. **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 23.

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

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

p. **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 21 and 22.

q. **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.

r. **Taxation:** As a registered charity, the Charity is exempt from taxation under section 505 (I) of the Income & Corporation Taxes Act 1988.

s. **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.

t. **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.

Note 3 Donations and Legacies Income

	2021	2020
	£	£
Donations	1,278,323	768,141
Legacies	188,897	149,460
Fundraising activities	226,588	333,784
	1,693,808	1,251,385

Note 4 Charitable Activities Income

	2021	2020
	£	£
Childlife	62,500	63,000
Annual conference	909	12,821
Grants receivable	146,782	58,627
	210,191	134,448

Note 5 Investment Income

	2021	2020
	£	£
Income on investment portfolio	114	2,891
Interest	1,391	14
	1,505	2,905

Note 6 Raising Funds Expenditure

	2021	2020
	£	£
Costs of generating funds	234,161	275,279
Investment managers fees	141	250
	234,302	275,529

Note 7 Charitable Activities Expenditure

	Direct Costs	Grants	Support Costs	**2021** Total	**2020** Total
	£	**£**	**£**	**£**	**£**
Research activities	139,163	1,989,441	97,919	2,226,523	303,700
Ataxia centres	-	0	-	0	435
Care services	153,077	6,410	128,066	287,553	249,241
Total	292,240	1,995,851	225,985	2,514,076	553,376
Generating funds	-	-	90,212	90,212	111,136
Research conference	-	-	-	0	29,133
Raising awareness	35,062	-	74,111	109,173	133,871
Governance	-	-	59,193	59,193	53,899
Total charitable activities	327,302	1,995,851	449,501	2,772,654	881,415

	2021	**2020**
	£	**£**
Total support costs		
Staff costs	316,885	311,038
Office costs	124,159	100,955
Depreciation	8,457	14,879
	449,501	426,872

Note 8 : Research Grants

	2021 £	2020 £
Research grants made in year comprise		
Funding of an Ataxia Nurse for half a day a week to support the Ataxia clinic in Sheffield		*10,000*
Non-invasive transcranial cerebellar stimulation: double blind, randomised, sham-controlled study followed by an open label extension phase		*25,000*
Preclinical development of an amelioration therapy for Dentatorubro-Pallidoluysian Atrophy		*100,000*
Preliminary investigation into impacts of normobaric hypoxia on neuromuscular and cardiac function in FA		*5,000*
Awarded various travel grants to researchers from the Kennedy Award		*1,800*
Investigating the role of bioactive sphingolipids in Friedreich's ataxia (FRDA)		*26,471*
Awarded various travel grants to researchers from the CA Fund		*1,000*
ARCA Global Conference		*3,825*
SCA Global Conference		*2,000*
University claimed less than amount of grant awarded		*(1,073)*
Development of a selective high throughout screening assay for the discovery of compounds replacing frataxin in FA.	*26,000*	
Etravine as a potential therapeutic for Friedreich ataxia	*20,000*	
PROSPAX: an integrated multimodal progression chart in spastic ataxias	*5,000*	
An Online Knowledge Translation Platform for Ataxia Research: Responding to Community Feedback from Stakeholders	*1,200*	
Investigating the use of the Ataxia Instrumented Measure – Spoon (AIM-S) in measuring upper limb function in Dentatorubral-pallidoluysian atrophy (DRPLA).	*71,311*	
Comprehensive Biomarker Characterisation in Dentatorubral-Pallidoluysian Atrophy (CBC-DRPLA)	*1,033,858*	
London Paediatric Centre	*23,000*	
DNA repair pathways underlie common genetic mechanisms that modulate onset in spinocerebellar ataxias and other inherited ataxias	*2,100*	
DRPLA: Biomarkers, Somatic Instability and creating a DRPLA cell line resource	*492,318*	
Dr Lim - Generating new Friedreich's Ataxia animal models for validating HSV-1 FXN gene therapy in Dorsal Root Ganglia'	*30,000*	
SCA Global Flash Talk	*352*	
'NKX6-2 Related Spastic Ataxia and Leukodystrophy: Natural history, biomarkers and the potential of gene transfer methods	*69,988*	
A joint model of online SLT intervention and peer support to enhance communication effectiveness and participation in people with progressive ataxia.'	*5,977*	
The DRPLA Natural History and Biomarker Study'	*126,084*	
Development of a PRIME editing therapy for Ataxia-8 due to the c.121 A to T point mutation (NKX6-2)	*34,600*	
Scope of work for the DRPLA Natural History Study	*51,131*	
ARCA Global Conference	*380*	
University claimed less than amount of grant awarded	*(3,858)*	
	1,989,441	174,023

Note 9 : Staff Costs

	2021 £	2020 £
Staff costs comprised:		
Salaries	651,929	493,293
Social security contributions	57,934	47,170
Pensions	30,021	23,662
	739,884	564,125

The average number of employees during the year was 18 (2020: 14) with all employee time involved in providing either support to the governance of the charity or support services to charitable activities.

The senior management team consist of the Chief Executive and the heads of Development, Fundraising, Research and Finance. The total employee benefits of the senior management team were £291,107 (2020: £263,895).

The following number of staff members received emoluments in the year:	2021	2020
£70,000 - £79,999		1
£80,000 - £89,999	1	

The pension contributions in respect of the above named individual in the year totalled £3,700 (2020: £3,444).

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

Note 10 : 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 £30,021 (2020: £23,662). There was no outstanding balance (2020: £0) at the year end.

Note 11 : 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 (2020: 14) claimed expenses totalling £0 (2020: £7,714).

Note 12 : Net (expenditure)/income is stated after charging:

	2021 £	2020 £
Auditor's remuneration	15,545	7,365
Legal Fees	3,061	-
Payroll costs and accountancy services	8,223	1,440
Depreciation	8,457	14,879
Operating lease costs	1,000	2,088

Note 13 **: Tangible Fixed Assets**

	Building Works	Other Assets	Total
	£	£	£
COST			
As at 1st April 2020	35,007	66,578	101,585
Additions	0	3,055	3,055
Disposals	0	(258)	(258)
As at 31 March 2021	35,007	69,375	104,382
DEPRECIATION			
As at 1st April 2020	30,481	35,334	65,815
Charge for year	1,358	7,099	8,457
Disposals	0	164	164
As at 31 March 2021	31,839	42,597	74,436
NET BOOK VALUE			
As at 31 March 2021	3,168	26,778	29,946
As at 1st April 2020	4,526	31,244	35,770

Included within the net book value of the 'Other Assets' is an amount of £4,000 (£5,960 in 2020) relating to items acquired on Finance Lease/Hire purchase.

Note 14 **: Investments**

	2021	**2020**
	£	£
Market value at 1 April	161,387	182,720
Disposals	(169,390)	(20,952)
Unrealised gain/(loss)	8,003	(381)
Market value at 31 March	-	161,387
Cost of investments at 31 March	-	169,390
Total unrealised loss	-	(8,003)
Market value at 31 March	-	161,387
Investments consist of:		
2% UK Gilt Snr-Reg	-	75,438
1.5% UK Gilt Snr-Reg-S	-	85,949
	-	161,387

Note 15 : Stock

	2021 £	2020 £
Stock for resale	6,218	6,155

Note 16 : Debtors Under 1 Year

	2021 £	2020 £
Income tax recoverable	113,383	140,858
Other debtors	71,525	145,000
Prepayments	27,186	30,576
	212,094	316,434

Note 17 : Cash at bank and in hand

The Trustees maintain a policy that all cash balances are held in interest bearing accounts with the exception of a nominal daily float held on current account. Interest receivable is disclosed in note 5.

Note 18 : Creditors: amounts falling due within one year

	2021 £	2020 £
Other creditors	9,919	41,315
PAYE/NI	16,252	14,320
Deferred income	10,185	18,006
Accruals	45,593	23,772
Research grants	911,134	206,050
	993,083	303,463

Note 19 : Creditors: Amounts falling due after one year

	2021 £	2020 £
Research grants	1,230,991	50,000
Misc creditors	3,000	4,000
	1,233,991	54,000

Note 20 **: Analysis of net assets between funds**

	Restricted Funds £	Designated Funds £	General Funds £	Total **2021** £	Total **2020** £
Fixed assets	-	-	29,946	29,946	35,770
Investments	-	-	-	-	161,387
Stock	-	-	6,218	6,218	6,155
Debtors	-	-	212,094	212,094	316,434
Cash at bank and in hand	1,182,138	8,337	426,997	1,617,472	578,901
Creditors	(2,142,125)	-	(84,949)	(2,227,074)	(357,463)
	(959,987)	8,337	590,306	(361,344)	741,184

Note 21 **: Unrestricted Funds**

	General Funds	Designated Funds	Total
Balance as at 1 April 2020	406,974	12,530	419,504
Net increase/(decrease) in funds during the year	201,978	(4,193)	197,785
Transfers	(18,646)	-	(18,646)
Balance as at 31 March 2021	590,306	8,337	598,643

Note 22 **: Designated Funds**

	Opening Balance	Net Movement	Transfers	Closing Balance
Funds held in branches	12,530	(4,193)	-	8,337
	12,530	(4,193)	-	8,337

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

Note 23 **: Restricted Funds**

	At 1 April 2020	Income	Expenditure	Transfers	At 31 March 2021
	£	£	£	£	£
General Research	-	45,764	50,009	4,245	-
Friedreich's ataxia research	68,306	10,824	94,885	15,754	(1)
Cerebellar ataxia research	-	109	22	-	87
Young Person's projects	7,959	-	-	-	7,959
Jerry Farr travel fund	671	-	-	-	671
Welfare	634	3,000	3,000	-	634
Nicotinamide	-	1,181	236	(945)	-
Goods and Services Received	-	918	918	-	-
Helpline	-	70,200	38,330	-	31,870
Misc Grants	450	352	352	-	450
Childlife	-	62,500	62,500	-	-
Exeter	582	-	-	-	582
Awareness	7,049	-	2,154	-	4,895
Kennedy Award	31,948	-	15,000	-	16,948
Mark Dower Trust	1,241	3,495	3,410	-	1,326
Spinocerebellar Ataxia Research Project	-	1,096	220	(876)	(0)
London Pediatric Centre	15,000	-	15,000	-	-
DRPLA Research	-	727,252	1,774,703	-	(1,047,451)
In Control Project	16,590	87,706	99,512	-	4,784
Ataxia Centres	59,039	-	8,000	-	51,039
DRPLA Department	112,211	-	100,674	-	11,537
Scotland	-	1,000	200	-	800
NXK6-2	-	57,806	104,588	-	(46,782)
AOA2	-	245	49	469	665
	321,680	1,073,449	2,373,762	18,646	(959,987)

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) Nicotinamide: Funds restricted to research trial of nicotinamide in Friedreich's ataxia.

h) Goods and Services Received: Goods and Services received free of charge in respect of design and software services for Ataxia's website.

i) Helpline: Funds to support the helpline.

j) Miscellaneous Grants: Funds provided for general grants.

k) 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.

l) Exeter: Funds to be expended in the Exeter area.

m) Awareness: Funds provided to raise awareness of Ataxia.

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

o) 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.

p) Spinocerebellar Ataxia Research Project: Funds for spinocerebellar ataxia research project

q) London Paediatric Centre: Funds to assist set-up of London paediatric centre

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

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

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

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

v) Scotland: Funds to be expended in Scotland.

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

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

Note i: DRPLA research grants of £1.8m were issued during the year with income being received of £0.8m. Two of the research grants are being funded over three years leaving a deficit of £1.0m which equates to the year 2 & year 3 payments. Ataxia has signed agreements in place outlining the payment structure ensuring these future commitments will be met.

Note ii: Two NKX6-2 research grants of £105k were issued during the 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. Ataxia has a signed agreement in place outlining the payment structure ensuring these future commitments will be met.

Note 24 : Capital Commitments

There are no capital commitments at 31 March 2021 (2020: Nil)

Note 25 : Lease Commitments

At 31 March 2021 the charity had future minimum lease payments under non-cancellable operating leases as follows:

	2021		2020	
	Land & buildings	**Other**	**Land & buildings**	**Other**
Payments due:				
Within one year	49,604	1,608	49,604	2,568
Within two to five years	29,302	4,825	78,906	6,433
	78,906	6,433	128,510	9,001

Note 26 : 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.