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ANNUAL REPORT AND FINANCIAL STATEMENT

2024 - 2025

ATAXIA

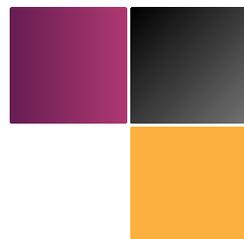
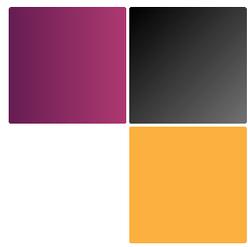


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OUR YEAR IN REVIEW 2024-25

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 However, we were disappointed to learn that the drug has been withdrawn from the NICE evaluation process, resulting in further delays to its availability.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

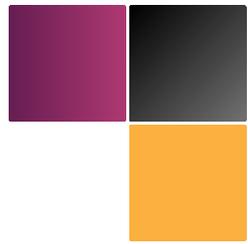
Sue Millman
Chief Executive



REFERENCE AND ADMINISTRATION DETAILS



ATAAXIA



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

HR Consultants

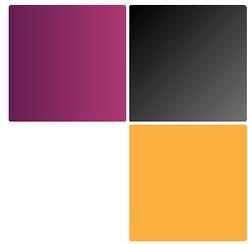
NEST
Bentley House
North Heath Lane
Horsham
West Sussex RH12 5QE

Bankers

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

Solicitors

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



Structure, Governance & Management

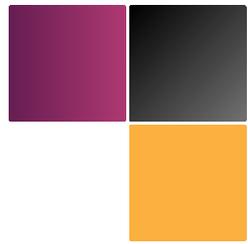
Ataxia UK is a company limited by guarantee, incorporated in England and Wales on 25 November 2003, a registered charity in England and Wales (number 1102391) and a charity registered in Scotland (number SC040607). It is governed by its Memorandum and Articles of Association, adopted on 25 November 2003.

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:

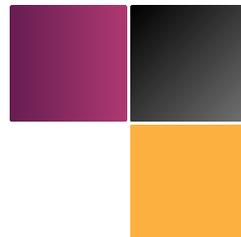
“Ataxia UK is an inclusive organisation which promotes the wellbeing of all people affected by ataxia.

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:

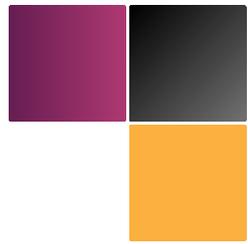
Yanita Oparlakova,

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.

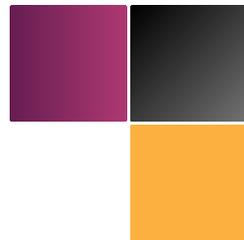
We are also grateful to the volunteers who assist us by serving on the Finance Sub-Committee, Research Ethics Committee, Scientific Advisory Committee, Medical Advisory Panel, Pharma Advisory Group, and Fundraising and Services Advisory Groups. During the year five trained volunteers supported the Helpline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

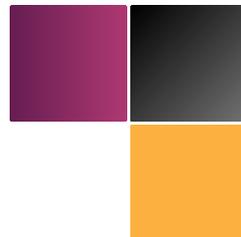
Ataxia UK's charitable objectives are to 'relieve those persons affected by ataxia'. Many kinds of ataxias have been identified, with varying causes and characteristics. Typically, they are slowly progressive conditions in which initial clumsiness and poor balance and co-ordination can lead to total 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

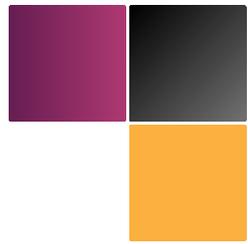
Our Strategic Plan 2022–25 takes into account the impact of the changes brought about in many areas of life by the Covid–19 pandemic which arrived towards the end of 2019–20, and the current economic climate which is affecting disabled people more than the general public and exacerbating the serious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

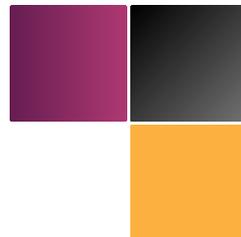
Support Groups remained active, providing spaces online and across the UK for people affected by ataxia to connect, share experiences, and reduce isolation by meeting virtually or face to face.

We 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 welcomed
744 new Friends
this year**

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.

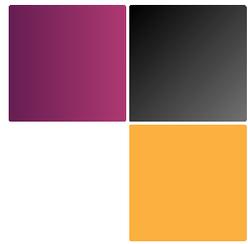
We delivered Roadshows in Cardiff, Belfast, and Edinburgh. These events were tailored to each location and included input from clinicians and peer speakers. Around 120 people attended, many for their first Ataxia UK event. The Roadshows helped reduce geographic and financial barriers and supported local 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.





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

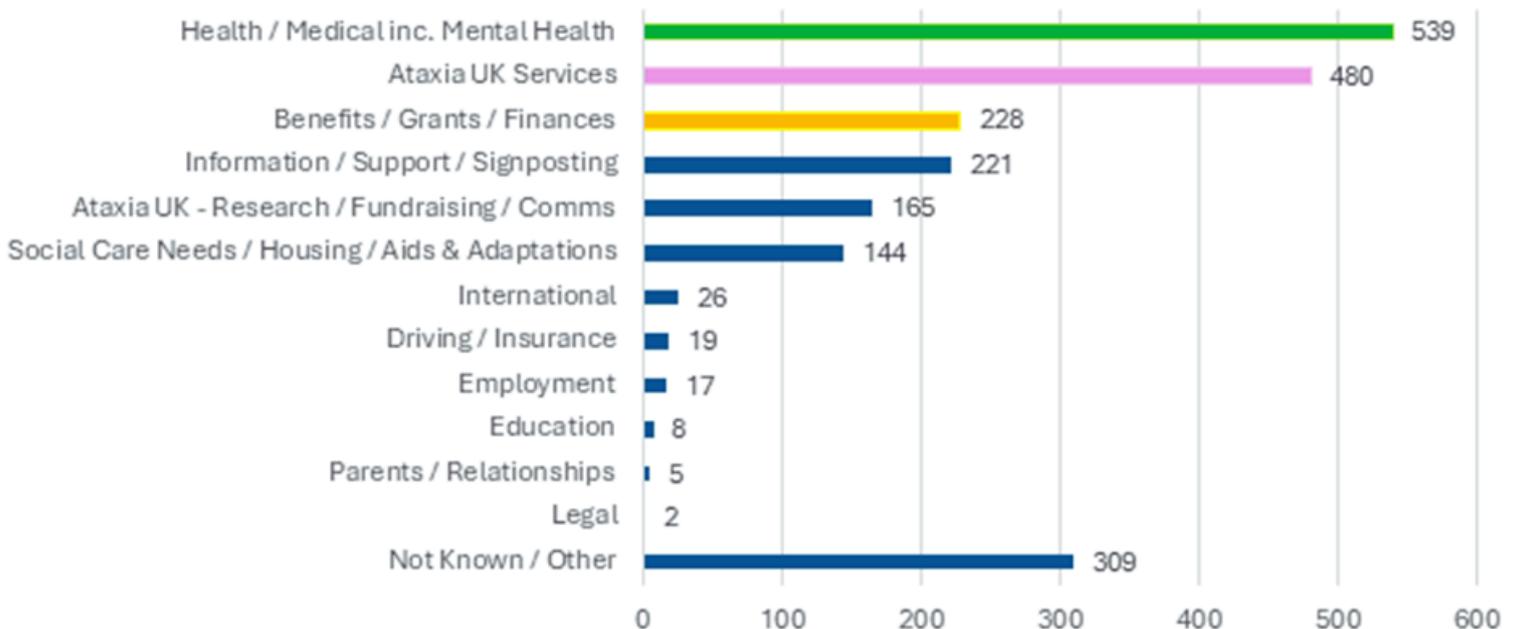
“Very helpful, informative and friendly, with practical advice and quick follow-up.”

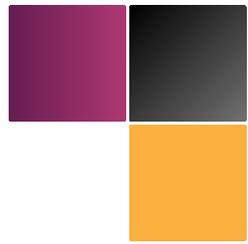
“Jessica was helpful, professional and did what she said she would.”

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.

Contacts to the Helpline by Issue Type





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.

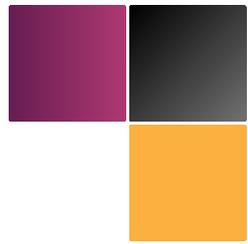
Five online speech therapy groups were delivered during the year, supporting 31 people. Two participants did not complete the full programme. Demand for the service remains high, and a waiting list of 19 people is in place.

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***

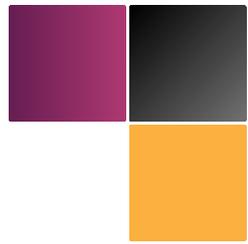
- We plan to expand access to our Helpline and Advocacy Service by increasing capacity, extending hours and supporting more people with a wider range of issues.
- We aim to continue delivering high-quality online and in-person events, and to increase the reach and accessibility of these sessions.
- We 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



happen. I knew that
had a good job and
support. So I knew
a very loving and ha
up to be exceptiona

So Isabella was bo



Highlights

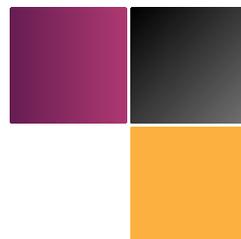
Specialist Nurse

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.





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.

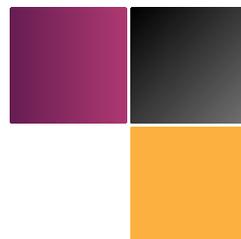
This enables neurologists from outside of the MAP to obtain invaluable expert advice from ataxia specialists on diagnosis and symptom management. Feedback from those involved has been very positive.

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 omeveloxolone 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.

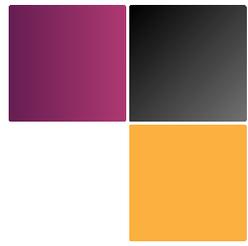
Ataxia Centres

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

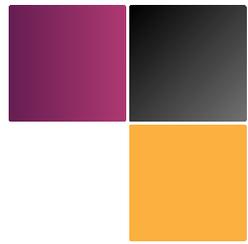
In 2024-25 Ataxia UK awarded six grants to a range of projects, from supporting carers to developing antisense oligonucleotides for SCA3.

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.



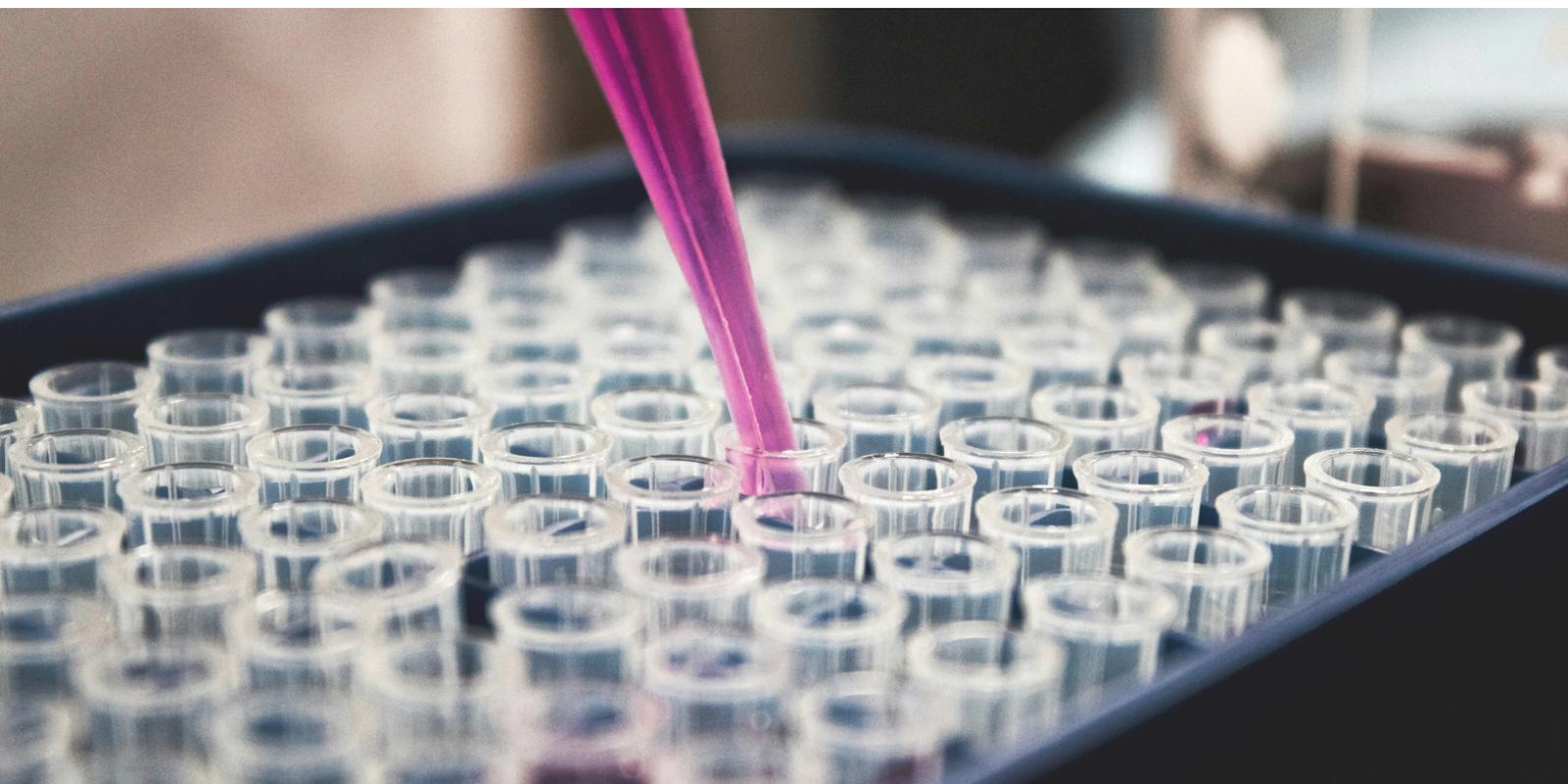


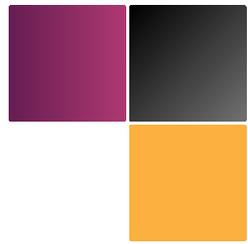
Funded research

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

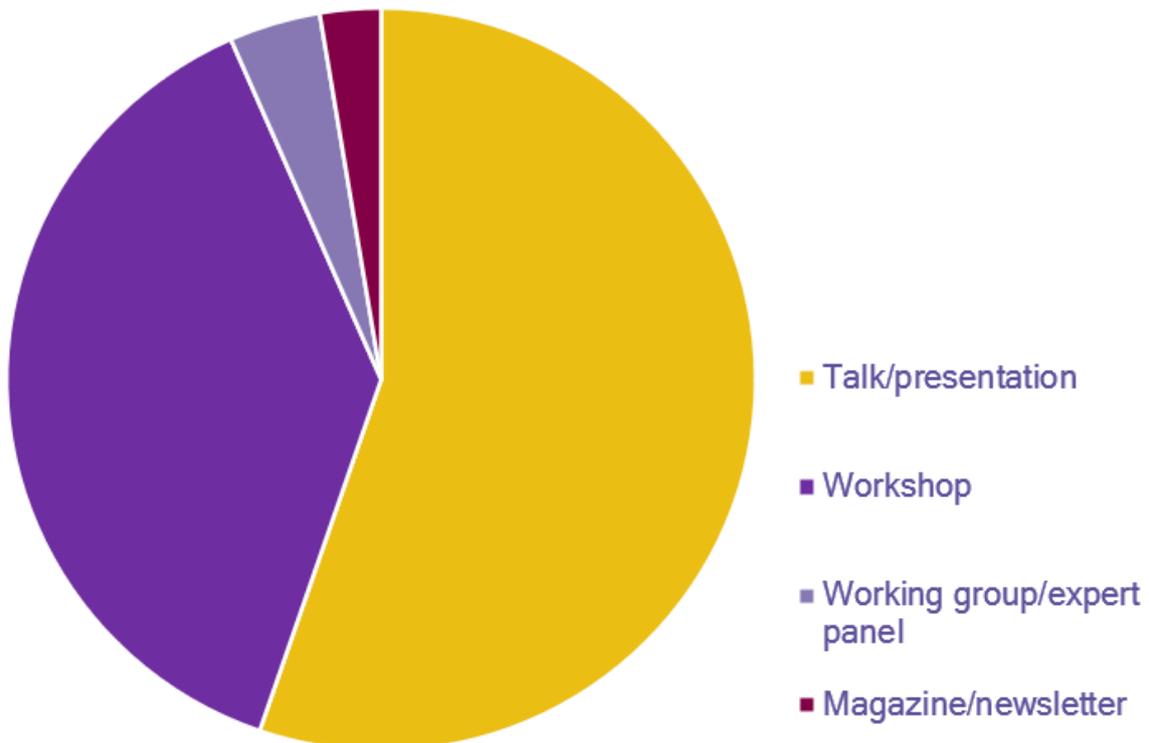
Researchers also reported 76 engagement activities over the last 10 years, demonstrating engagement with patient groups, researchers, clinicians, students and the general public. Engagements such as these help to increase awareness of ataxia research and foster idea-sharing amongst the community and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

Promoting research and collaboration

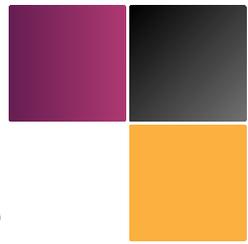
Ataxia UK continues to work with pharmaceutical companies to support their ataxia programmes. For example, this year we worked with Biohaven Pharmaceuticals on their Burden of Illness study, focused on a number of types of SCA. The results of this study were presented by Biohaven at international conferences,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

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

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)



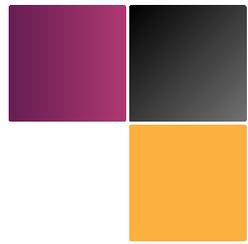
For rare conditions such as ataxia, international collaboration is key. To this end, we represented people with ataxia on a number of global ataxia projects, either through our work with Euro-ataxia or as Ataxia UK. The Ataxia Global Initiative (AGI) is a trial readiness initiative, aiming to increase 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.

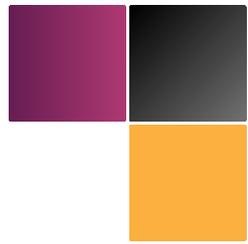
Following this conference, Euro-Ataxia, with the support of Ataxia UK, will host the Global Patient Advocacy Group meeting.

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

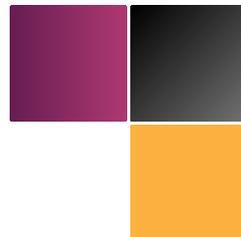
2024/25 again proved to be a challenging economic environment for the charity, however, we continue to be very grateful for the consistent support and generosity of our supporters. The charity continues to ensure that our income is used in the most effective way to meet our strategic goals.

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.

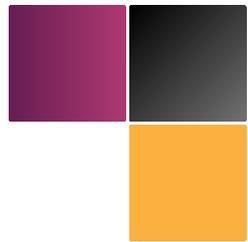
We need to continue to steward legacy pledgers to ensure they maintain their intention of leaving a legacy, but we also need to continue to invest in our legacy work, as the difference between a good and bad year with legacies can have a significant impact on total fundraising income for the charity.

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

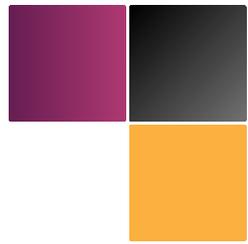
A key part of our relationship with the community is our role in providing the 'patient voice' and community advocacy. As the development of treatments continues, we need to meet expectations by working with press, policymakers and other stakeholders to highlight issues of policy and process which affect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





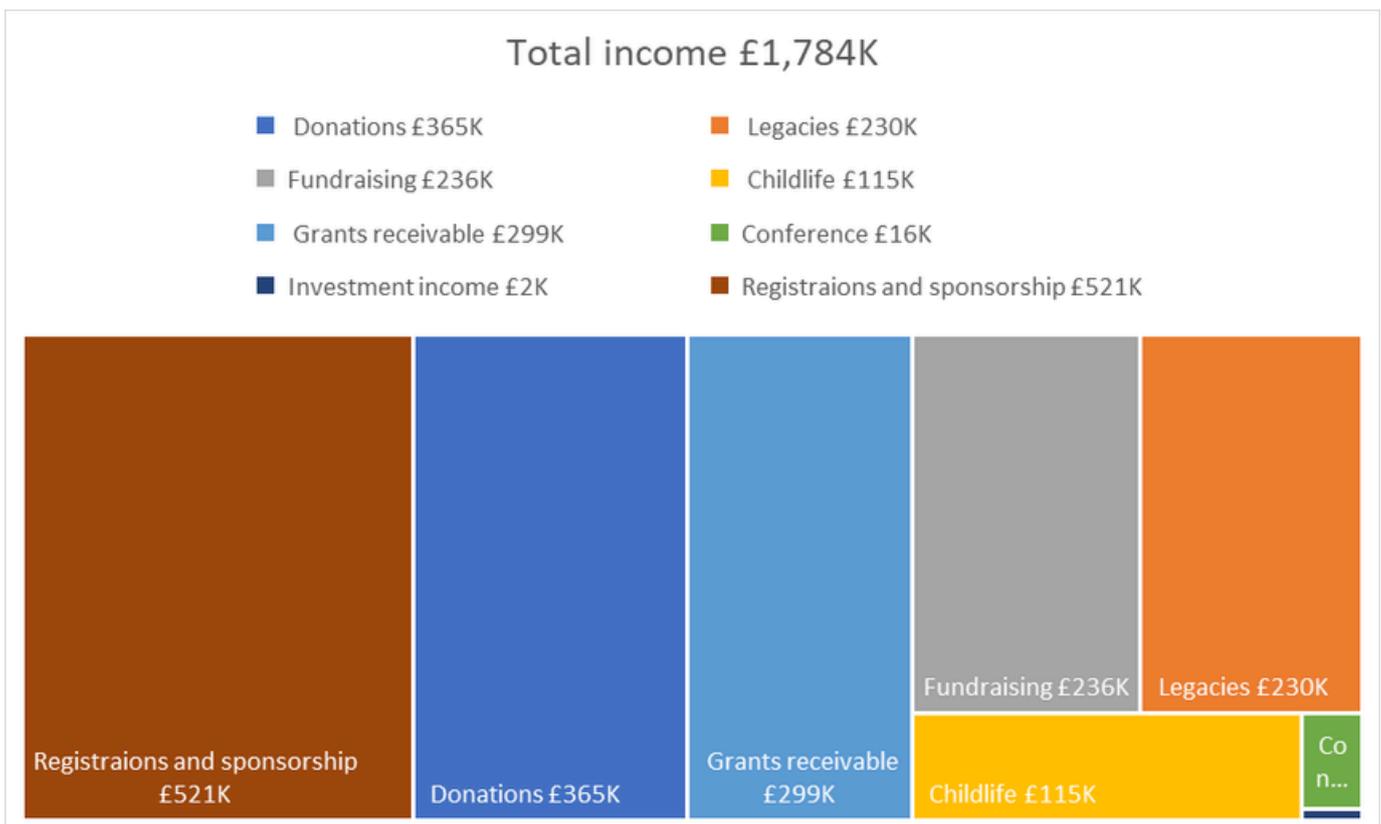
Overview

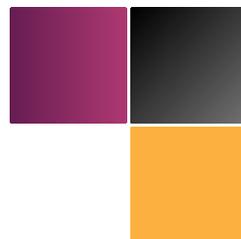
2024-25 again proved to be a challenging economic environment for the charity, however, we continue to be very grateful for the continued support and generosity of our supporters. The charity continues to ensure that our income is used in the most effective way to meet our strategic goals.

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.



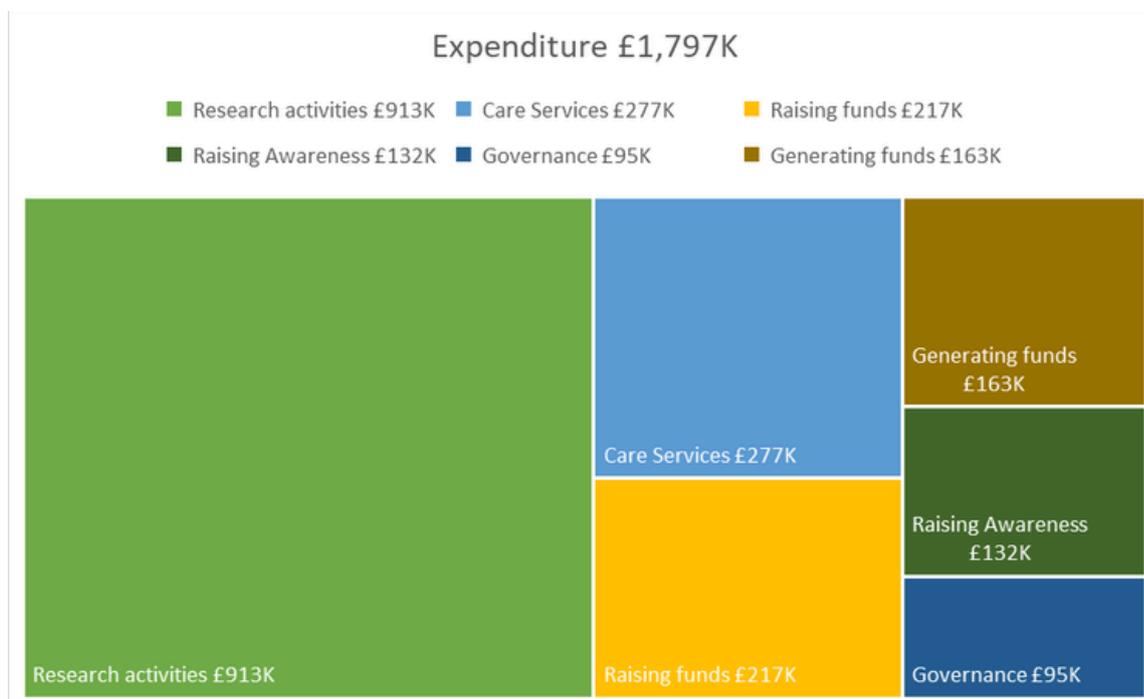


Review of Income

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

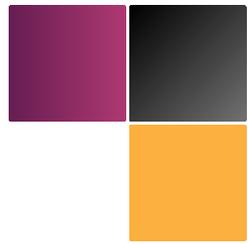
	2025 (£K)	2024 (£K)
General funds	335	465
Designated funds	288	79
Total unrestricted funds	623	543
Total restricted funds	(109)	(16)
Total funds held	514	528

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.

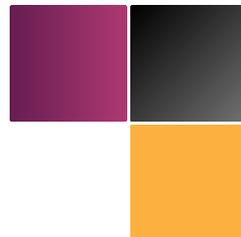
Going Concern

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:

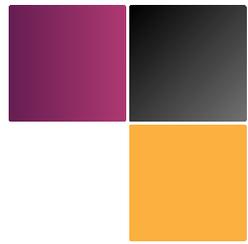
- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles in the Charities SORP.
- Make judgements and estimates that are reasonable and prudent.
- Prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity 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.



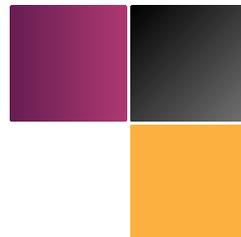
In preparing this report, the Trustees have taken advantage of the small companies exemptions provided by Section 415A of the Companies Act 2006.

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

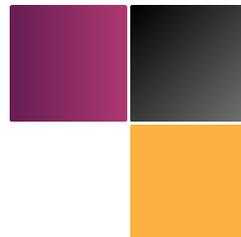
We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities section of our report. We are independent of the charitable company in accordance with 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.

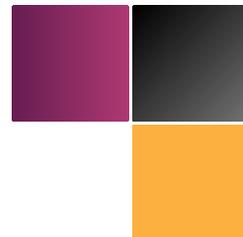
We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- 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 (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

		Unrestricted funds	Restricted funds	Total funds 2025	Total funds 2024
	Notes	£	£	£	£
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		<u>823,725</u>	<u>959,968</u>	<u>1,783,693</u>	<u>1,813,777</u>
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		<u>(741,559)</u>	<u>(1,055,295)</u>	<u>(1,796,854)</u>	<u>(1,325,472)</u>
Net losses on investments		-	-	-	-
Net income/(expenditure)		<u>82,166</u>	<u>(95,327)</u>	<u>(13,161)</u>	<u>488,305</u>
Transfer from Unrestricted to Restricted		(2,364)	2,364	-	-
Net movement in funds		<u>79,802</u>	<u>(92,963)</u>	<u>(13,161)</u>	<u>488,305</u>
Total funds brought forward		543,290	(15,674)	527,616	39,311
Total funds carried forward		<u>623,092</u>	<u>(108,637)</u>	<u>514,455</u>	<u>527,616</u>

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

		Unrestricted funds	Restricted funds	Prior year Total funds 2024
	Notes	£	£	£
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		<u>598,455</u>	<u>1,215,322</u>	<u>1,813,777</u>
Expenditure on:				
Raising funds	7	(271,119)	-	(271,119)
Charitable activities	8	(509,372)	(544,981)	(1,054,353)
Total expenditure		<u>(780,491)</u>	<u>(544,981)</u>	<u>(1,325,472)</u>
Net losses on investments		-	-	-
Net income/(expenditure)		<u>(182,036)</u>	<u>670,341</u>	<u>488,305</u>
Transfer from Unrestricted to Restricted		(871)	871	-
Net movement in funds		<u>(182,907)</u>	<u>671,212</u>	<u>488,305</u>
Total funds brought forward		<u>726,197</u>	<u>(686,886)</u>	<u>39,311</u>
Total funds carried forward		<u>543,290</u>	<u>(15,674)</u>	<u>527,616</u>

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

		2025		2024	
	Notes	£	£	£	£
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	
		<u>2,121,491</u>		<u>2,233,885</u>	
Creditors: amounts falling due within one year	17	<u>(1,131,513)</u>		<u>(1,123,662)</u>	
Net current assets			<u>989,978</u>		<u>1,110,223</u>
Total net assets less current liabilities			<u>1,002,160</u>		<u>1,123,946</u>
Creditors: amounts falling due after more than one year	18		<u>(487,705)</u>		<u>(596,330)</u>
Total net assets/(liabilities)	19		<u>514,455</u>		<u>527,616</u>
Accumulated funds					
Unrestricted funds					
General funds	20		334,575		464,563
Designated funds	21		288,517		78,727
			<u>623,092</u>		<u>543,290</u>
Restricted funds	22		<u>(108,637)</u>		<u>(15,674)</u>
Total funds			<u>514,455</u>		<u>527,616</u>

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 on2025 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	<u>(183,576)</u>	<u>294,384</u>
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	<u>(5,439)</u>	<u>(8,251)</u>
Net increase in cash:	<u>(189,015)</u>	<u>286,133</u>
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	<u>1,686,350</u>	<u>1,875,365</u>
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	<u>(183,576)</u>	<u>294,384</u>
Analysis of cash at bank and in hand less overdrafts		
	2025	2024
	£	£
Cash at bank and in hand	1,686,350	1,875,365
	<u>1,686,350</u>	<u>1,875,365</u>

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.

ATAXIA UK
NOTES TO THE FINANCIAL STATEMENTS 31 MARCH 2025

Principal Accounting Policies (continued)

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

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

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

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

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

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

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

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

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

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

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

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

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

ATAXIA UK
NOTES TO THE FINANCIAL STATEMENTS CONTINUED

Note 3 Donations and Legacies Income

	2025	2024
	£	£
Donations	364,721	827,551
Legacies	230,140	31,795
	<u>594,861</u>	<u>859,346</u>

Note 4 Other Trading Activities

	2025	2024
	£	£
Fundraising activities	235,692	285,854
	<u>235,692</u>	<u>285,854</u>

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	-
	<u>951,258</u>	<u>668,577</u>

Note 6 Investment Income

	2025	2024
	£	£
Interest	1,882	-
	<u>1,882</u>	<u>-</u>

Note 7 Raising Funds Expenditure

	2025	2024
	£	£
Costs of generating funds	217,421	271,119
	<u>217,421</u>	<u>271,119</u>

Note 8 Charitable Activities Expenditure

	Direct Costs £	Grants £	Support Costs £	2025 Total £	2024 Total £
Research activities	735,885	69,562	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	<u>949,770</u>	<u>79,407</u>	<u>160,518</u>	<u>1,189,695</u>	<u>625,246</u>
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	<u>1,045,242</u>	<u>79,407</u>	<u>454,784</u>	<u>1,579,433</u>	<u>1,054,353</u>

** 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.

ATAXIA UK
NOTES TO THE FINANCIAL STATEMENTS CONTINUED

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

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 la Moelle épinière-ICM	-	691
Novel biomarkers of oxidative stress in Friedreich's ataxia	-	4,800
Identification of disease-associated single nucleotide polymorphisms in ataxin-3	-	4,470
Evaluating ribosome collisions on CAG expansions proteostasis and translational stress responses in Spinocerebellar Ataxia type 3	-	3,000
Consultancy support with respect to preparing for Health Technology Assessment	-	5,800
Effect of targeting sphingolipid- metabolising enzymes in iPSC-derived sensory neurons obtained from FRDA patients	-	4,954
Exploring novel iron-mediated mechanisms to prevent cellular death in Friedreich's Ataxia	-	5,000
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'assistencia 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)	-
	<u>67,923</u>	<u>101,361</u>

ATAXIA UK
NOTES TO THE FINANCIAL STATEMENTS CONTINUED

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

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 an 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

ATAXIA UK
NOTES TO THE FINANCIAL STATEMENTS CONTINUED

	£	£	£
COST			
As at 1st April 2024	5,333	52,535	57,868
Additions	-	7,321	7,321
Disposals	-	-	-
As at 31 March 2025	<u>5,333</u>	<u>59,856</u>	<u>65,189</u>
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	<u>5,333</u>	<u>47,674</u>	<u>53,007</u>
NET BOOK VALUE			
As at 31 March 2025	<u>-</u>	<u>12,182</u>	<u>12,182</u>
As at 1st April 2024	<u>142</u>	<u>13,581</u>	<u>13,723</u>

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
	<u>435,141</u>	<u>358,520</u>

Note 16 : Cash at bank and in hand

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

Note 17 : Creditors: amounts falling due within one year

	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
	<u>1,131,513</u>	<u>1,123,662</u>

ATAXIA UK
NOTES TO THE FINANCIAL STATEMENTS CONTINUED

Note 18 : Creditors: Amounts falling due after one year

	2025	2024
	£	£
Research grants	487,705	596,330
	<u>487,705</u>	<u>596,330</u>

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	1,189,333	288,517	208,500	1,686,350	1,875,365
Creditors	(1,298,602)	-	(320,616)	(1,619,218)	(1,719,992)
	<u>(108,637)</u>	<u>288,517</u>	<u>334,575</u>	<u>514,455</u>	<u>527,616</u>

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	78,012	1,790	79,802
Transfers	(208,000)	208,000	-
Balance as at 31 March 2025	<u>334,575</u>	<u>288,517</u>	<u>623,092</u>

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)	-
	<u>78,727</u>	<u>1,790</u>	<u>208,000</u>	<u>288,517</u>

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.

ATAXIA UK
NOTES TO THE FINANCIAL STATEMENTS CONTINUED

te 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	-
Nicotinamide	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) **Nicotinamide ataxia research:** Funds provided by donors specifically for research on Nicotinamide.
- 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.

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NOTES TO THE FINANCIAL STATEMENTS CONTINUED

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.

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NOTES TO THE FINANCIAL STATEMENTS CONTINUED

Note 23 : Capital Commitments

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

Note 24 : Lease Commitments

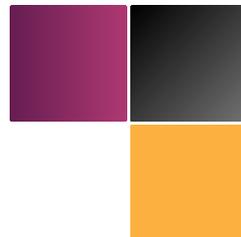
At 31 March 2025 the charity had future minimum lease payments under non-cancellable operating leases as follows:

	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 Abbots 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, Insmmed, 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



+44 020 7582 1444



www.ataxia.org.uk



communications@ataxia.org.uk



**Ataxia UK, 12 Broadbent Close, London,
N6 5JW**