



# Annual Report & Financial Statements

For the Year: 1 April 2021 to 31 March 2022

Ataxia UK 12 Broadbent Close London N6 5JW



# Contents

Statement from Chair	3
Reference & Administration Details of the Charity, its Trustees & Advisors	4
Structure, Governance & Management	5
Objectives & Activities	9
Strategic Plan	10
Achievements & Performance, and Aims for 2021-22	12
Financial Review	33
Statement of Trustees' Responsibilities	36
Independent Auditor's Report to the Trustees & Members of Ataxia UK	37
Statement of Financial Activities (SOFA)	40
Balance Sheet	42
Cash Flow Statement	43
Notes to the Financial Statements	44

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



# Introduction from the Chair

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

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

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

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

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

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

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



**William Littleboy,**  
Chair of Trustees

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

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

The trustees that served during 2021-2022 were:

### Honorary Officers

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

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

**Kathy Jones, Honorary Treasurer**

### Trustees

**Angela Hosie** (joined Nov 2021)

**Andrew Downie** (retired Nov 2021)

**Prof Barry Hunt** (retired Nov 2021)

**Carol McCudden**

**Gemma Fish**

**Philip Griffiths**

**Rachel Harrison** (joined Nov 2021)

**Robert Perkins**

**Terence McCaw** (retired Jul 2021)

**Prof Barry Hunt** is Scientific Advisor to the Board

**Susan Millman** is the company secretary and CEO.

### Ataxia UK uses the following professional advisors:

#### Auditors

Goldwins Limited  
75 Maygrove Road  
West Hampstead  
London NW6 2EG

#### Bankers

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

#### HR Consultants

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

#### Solicitors

Bates Wells  
10 Queen Street Place  
London EC4R 1BE

# Structure, Governance & Management

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

Ataxia UK is managed by a Board of Trustees, which sets strategies and policies. An Executive Committee, comprising the Honorary Officers, the Trustee Scientific Advisor and one other trustee (one of whom must have ataxia), conducts business as required between meetings of the full Board of Trustees. The trustees include people with ataxia, friends/family of people with ataxia and others with relevant experience and expertise.

The Annual General Meeting of the charity took place on 26 November 2021.

Under the articles of association of the charity, trustees are nominated for election by the Friends of the charity, comprising beneficiaries affected by ataxia and others interested in the welfare of those affected by ataxia. Each year one quarter of the trustees retire but are eligible to stand again if they so wish. In addition, the trustees may co-opt up to three additional trustees.

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

The pay and remuneration of the key managers of Ataxia UK is considered annually by a Remuneration Committee, comprising the Co-Chairs and one other committee member, and meets during the budget setting process to review salary grading levels, London weighting, increment payments and inflation rises. The Remuneration Committee is provided with comparative benchmark information relating to similar posts in corresponding organisations to assist with their decision.

## Public Benefit

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



Ataxia UK is an inclusive organisation which promotes the wellbeing of all people affected by ataxia. We provide information to people affected by ataxia at the early stages of diagnosis and specialist services for this medical condition, many of which are not available from the NHS or other statutory or voluntary sources.

We work to end isolation and promote engagement in social, educational and leisure activities for people affected by ataxia and their families. We educate the broad community and key subsections within it, such as the medical and social services professions, about the effects of ataxia.

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

## Statement of Equality, Diversity and Inclusion

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



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

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

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

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

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

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

Ataxia UK operates throughout the United Kingdom of Great Britain and Northern Ireland through its network of Branches and Support Groups, which provide activities and support to Friends. The 2020 Regional Conference was cancelled due to Covid-19 restrictions, and the Annual National Conference was held virtually.

We have continued to work in partnership with other organisations with shared interests, principally Genetic Alliance UK, The Neurological Alliance, the Association of Medical Research Charities (AMRC) and Euro-ataxia. Our Chief Executive is the Secretary of Euro-ataxia, a federation of 20 patient organisations from 15 different European countries.

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

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

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

**Dr Franziska Denk, Dr Claire Kelly, Dr Marija Sajic, Dr Mark Pook, Professor Keith Morris and Dr Gita Ramdharry.**

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

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

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

**Professor Barry Hunt** Ataxia UK Board Scientific Advisor.

All members are unpaid volunteers.



## Employees

During 2021-22 the average number of full-time equivalent employees during the year was 19 (with all employees' time involved in providing either support to the governance of the Charity or our charitable activities). IT support and HR advice functions are outsourced. We are currently working on a Data Officer; this role will include data protection & GDPR work.

## Volunteers

In addition to the volunteers who function as trustees, many other volunteers play an important part in supporting Ataxia UK. During 2020-21 we have employed a number of interns and offered opportunities to volunteers throughout the charity. They have provided invaluable assistance in our day-to-day work, contributing towards our projects, such as the Ataxia Magazine. Our InControl Project has seen the launch of more roles for volunteers, see p.29.

The pandemic has cancelled many events that our Friends and supporters might have participated in. We are therefore especially grateful to those who have managed to raise funds for us, those who have donated to our appeals and regular givers, and the very generous support of people who have left bequests to Ataxia UK.

We are also grateful to the volunteers who assist us by serving on the Finance Sub-Committee, Scientific Advisory Committee, Medical Advisory Panel, Pharma Advisory Group, Fundraising and InControl Steering Group. During the year five trained volunteers supported the Helpline staff by answering phone and email enquiries. The contribution of all of our volunteers to the work of Ataxia UK is much valued and appreciated.

## Risk Management

As in previous years, the Board actively managed the risks to the charity, focusing on the most serious. We maintain a register of risks and controls, and activities to mitigate risk throughout the year; in 2021-22 the register remained significantly influenced by the impact of the Covid-19 pandemic. At the beginning of the year the most significant risks and their mitigation were:

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



## Objectives & Activities

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

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

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

People with ataxia want a quick diagnosis that's delivered in a supportive and sympathetic manner, with the choices of care explained and assistance in accessing them available, if required. They want information about their

condition and medical care to enable the management of symptoms. Ataxia UK seeks to improve treatments and care by researching the experiences and requirements of people with ataxia and by developing replicable model solutions to the problems they experience. Our most significant work in this area is the development of Ataxia UK's accredited Specialist Ataxia Centres: specialist clinics within the NHS that aim to bring together in a 'one-stop shop' all the services needed by someone with ataxia, from diagnosis to the ongoing management of their condition.

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

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

## Our Strategic Plan

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

Strategic Plan 2017-22 contained four major ambitions:.



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



To have increased our funded research activity



To consistently maximise the impact of research activity



To have fostered best practise in treatment & care

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

Strategic Plan 2022-25 contains these new ambitions:



**Improve access to specialist, integrated care (including mental health care), treatments and drugs for the ataxias**



**Faster, accurate diagnosis**



**Consistently maximise the impact of research activity leading to treatments and cures**



**Enable greater access to services aimed at improving wellbeing and financial circumstances**

Our new Strategic Plan 2022-25 takes into account the impact of the changes brought about in many areas of life by the Covid-19 pandemic which arrived towards the end of 2019-20, and the coming financial pressures which will exacerbate the existing poverty of a small but significant number of people affected by ataxia.

Some of the most significant actions we will take over the next three years to meet these objectives are:

- Establish a peripatetic Specialist Ataxia Nursing Service to accompany patients to appointments and support them in managing all aspects of their care.

- Continue to develop the Helpline and Advocacy Service and improve the support information held on the website.
- Revise the Medical Guidelines for the Treatment of the Ataxias and publish the 4th Edition.
- Increase the patient representation work we undertake in research projects.
- Increase the number of Accredited Ataxia Centres in the NHS to at least six.
- Support the drugs approval process in the UK.
- Utilise the All About Ataxia seminar model to develop other online information seminars.

## FY21-22 Key Highlights

We have awarded:

**10** grants

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

We have supported the recruitment of participants for:

**9** **7**

research projects

surveys

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

Over the 10 years our funded research has produced:

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

**44** new research tools developed.

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

**£4.90**

in further funding used specifically for ataxia research.

Secured a grant of

**£104K**

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

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

The London Ataxia centre now runs

**4** ataxia clinics a week

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

The Helpline continues to support the ataxia community, with

**1237**

contacts during 2021-22.

Sponsored the

**Sheffield Ataxia Centre Study Day**

which provided training about ataxia to 180 healthcare professionals.

## Speech Therapy Project

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

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

## Research

### Research aims for 2021-22

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



### Host the 2022 International Congress for Ataxia Research

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

### Start clinical research programme in DRPLA

Ataxia UK has been collaborating with the US Foundation CureDRPLA, to advance research in Dentatorubral-pallidoluysian atrophy (DRPLA), a rare form of inherited ataxia. CureDRPLA provide funds to employ a Senior Research Manager to support the Head of Research in leading the DRPLA Research Programme. The expertise we are gaining will help us advance research in other ataxias.

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

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

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

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

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

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

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

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

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

Ataxia UK is a partner in the 'Critical Path to Therapeutics for the Ataxias' Consortium hosted by the US not-for-profit organization Critical Path Institute. This Global Consortium aims to bring together experts from across different fields of ataxia research, patient groups and pharma companies to create regulatory tools and strategies to catalyse the development of approved medicines for the ataxias. A crucial aspect of the Consortium is that it includes experts from regulatory bodies such as the US Food and Drugs Administration (FDA) in its discussions. It is funded by pharma companies who see the value of collaboration in increasing the efficiency and effectiveness of medical product development.

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

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

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

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



## Other Research Activities

### Ataxia UK Research Grants Programme

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

### Ataxia UK Grants

#### 1. Dr Marcus Grobe-Einsler and Prof Thomas

**Klockgether** (German Center for Neurodegenerative Diseases, Bonn, Germany) 'Assessment of ataxia severity under real-life conditions with SARAhome: A multicenter study in spinocerebellar ataxia type 3 (SCA3)' – \$80,000 (co-funded with National Ataxia Foundation).

**2. Dr Alexandra Silva** (Instituto de Investigação e Inovação em Saúde – i3S, Portugal) 'NanoSCA3: Development of brain-targeted nanobodies for application in spinocerebellar ataxia type 3 therapy' – £30,000 (co-funded with Plataforma R+SCAs, AISA, ACAH, Swedish SCA-network).

**3. Dr Barbara Borroni** (University of Brescia, Italy) 'Motor and cognitive outcomes of non-invasive transcranial alternate current stimulation by entrainment of cerebellar oscillation' – £5,000.

**4. Prof Richard Festenstein** (Imperial College London, UK) 'Generation and characterization of a cardiomyocyte model for Friedreich's ataxia to reveal the molecular mechanism of heart failure in patients' – £5,000.

**5. Dr Saul Herranz-Martin** (Centro de Biología Molecular Severo Ochoa, Madrid, Spain) 'Analysis of the mitochondrial dysfunction in FXN deficient neurones to generate a drug screening test' – £4,750.

**6. Prof Paola Giunti** (University College London, UK) 'Brain pathology in an A1FM1 mutation causing Cowchock syndrome' – £5,000.

**7. Dr Yi Shiao Ng** (Newcastle University, UK) 'Balance and gait abnormalities in adult patients with mitochondrial disease and spinocerebellar ataxia type 6' – £4,928.

**8. Prof Anja Lowit** (Strathclyde University, UK) 'A feasibility study of LSVT Artic to improve speech performance in people with progressive ataxia' – £2,862.

### DRPLA Grants

#### (in partnership with CureDRPLA)

**1. Dr Yael Shiloh Malawsky** (University of North Carolina at Chapel Hill, USA) 'DRPLA Natural History and Biomarkers Study (DRPLA NHBS)' – £131,448.69.

**2. Dr Giovanni Stevanin** (Institut du Cerveau et de la Moelle épinière (ICM), France) 'Preclinical development of an amelioration therapy for Dentatorubro-Pallidoluysian Atrophy – Funding Extension' – €50,100.

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

The impact of the research we fund is evaluated every year using the Researchfish online portal with very positive findings. The last 10 years' data shows that every £1 invested in research by Ataxia UK, raises an extra £4.90 in further funding used specifically for ataxia research. This illustrates the high quality of our funded research. Over the 10 years our funded research has produced 87 papers published in scientific/medical journals and the development of 44 new research tools.

## Medical Research Charities Covid Support Fund

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

## Multi-Centre European Research Projects

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

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

The ESMI consortium has successfully established the largest cohort of systematically characterised patients with SCA3 worldwide. The consortium is also playing an important role in the development of biomarkers. This is an extremely useful resource for running trials in Europe. This project has been recruiting participants since 2017 and Dr Julie Greenfield has continued to participate in the Steering Committee as a Euro-ataxia representative. Since the EU JPND funding ended the Consortium has been in discussions with pharma companies who may support the continuation of the funding and during the year a partnership with the company Servier laboratories has been announced.

## Progression chart of spastic ataxias (PROSPAX) project

The PROSPAX project, launched in June 2020, is a collaborative effort between neurologists across Europe, plus Canada. The project aims to study the progression of spastic ataxias over time, from the clinical to the molecular level, including brain imaging, markers of progression and animal models. The project focuses mostly on ARSACS and SPG7, but will establish a more general research framework applicable to other spastic ataxias over time. Euro-ataxia is involved in the project as an active partner representing European ataxia patients, and is being supported by two members of the Ataxia UK research team Dr Julie Greenfield and Dr Ruby Wallis representing Euro-ataxia. An active Patient Organisation Group is leading a Work package to create Patient Reported Outcome Measures, by creating surveys and distributing among the patient groups, to be used in this study and for future trials.

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

This study, originally funded by the European Commission, gathers vital information about the progression of Friedreich's ataxia (FA) to generate a large FA patient database, alongside an integrated clinical and natural history database; this will be linked to a biological samples repository. It also aims to define a panel of clinical assessment tools for use in future trials. Data from this study has resulted in useful publications and is being used to plan clinical trials. Prof Barry Hunt of Ataxia UK is one of two Euro-ataxia representatives on the Steering Committee.

## Cerebellum and Emotional Networks (CEN)

During the year the Marie Skłodowska-Curie Innovative Training Network was funded by the European Research Council. To investigate the brain circuits that underlie emotional behaviour, the project will create a Virtual Institute of seven European universities and seven industry/charity partners, including Euro-ataxia. The training network is focusing on the role of the cerebellum, a previously overlooked part of the brain, and its involvement in the control of emotions. The knowledge gained will inform the development of new therapeutic strategies for individuals suffering from emotional disorders. Ataxia UK's Research Manager Dr Emily Cutting is the Euro-ataxia representative.

## TREAT-ARCA

This project, started in June 2020, focuses on recessive ataxias and in particular ARSACS and ARCA2 (also called COQ8A). It aims to design a toolbox of paradigmatic treatments for a targeted molecular medicine approach to autosomal recessive ataxias; including gene therapy in animal model systems of ARSACS and ARCA2. It also aims to develop biomarkers. Dr Emily Cutting is a Euro-ataxia representative on this project.

## Ataxia Global Initiative (AGI)

The Ataxia Global Initiative is a worldwide research network with the goal of facilitating the clinical development of therapies for ataxias. Dr Julie Greenfield continues to be a Steering Committee Member and co-chairs the Policy and Patient Engagement Working Group, tasked with setting all the policies for the initiative. These are shortly to be published and aim to help with harmonisation of data collection in ataxias trials. Membership of academics and representatives from patient groups and pharma has reached over 200 and there are currently 20 global collaborative research projects, endorsed by the AGI Steering Committee.

## AT Society

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

## Working with Pharmaceutical Companies and Industry

Ataxia UK continues to work with pharma companies who have ataxia programmes, supporting them in advancing their research. We have provided introductions to ataxia experts in a range of areas, promoted trials in the UK, and given input on trial design. We provided information on the research landscape, and explained the opportunities available in developing treatments for the ataxias to companies considering drug development programmes in the ataxia field.

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

### Pharma Strategy Advisory Committee

The Pharma Strategy Advisory Committee met in January and provided useful advice to Ataxia UK on collaboration with pharmaceutical and biotech companies, maximising our impact, and ways we can support drug development process.

### Recruitment of Participants to Research Studies

Having a database of people with ataxia puts Ataxia UK in a unique position to support research via the recruitment of participating volunteers. During the year we have supported nine research projects and seven surveys.

### Friedreich's ataxia Global Registry

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

### Raising Awareness of Ataxia Research

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

### Rare Champions of Hope Award

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

### Research aims for 2022-23

- Host the International Ataxia Research Congress in Dallas, USA and the Ataxia Global Initiative conference.
- Promote further involvement of people affected by ataxia in research process and activities.
- Oversee recruitment and protocol compliance of the DRPLA Natural History and Biomarkers Study.
- Continue building the DRPLA research programme and disseminate the CureDRPLA Global Patient Registry.



## Improvements in treatments and care

### Treatment and care aims for 2021-22

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



### Review and update Medical Guidelines on ataxia

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

### Launch a second Paediatric Ataxia Centre

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

### Establish additional Ataxia UK accredited ataxia clinics

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

### Pilot the use of peripatetic Specialist Ataxia Nurse

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

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

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

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

## Other activities supporting improvements in treatments and care

### Development of Clinical care pathways in the NHS in England

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

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

### Value of treatment project evaluating Ataxia Centres

Ataxia UK is a partner in this European Brain Council project, that focuses on evaluating coordinated care in three rare neurological diseases. The ataxia study is run by Prof Giunti at the London Ataxia Centre. The data collection has now ended, and the results of surveys carried out in people with ataxia in the UK, Germany and Italy assessing the value of Ataxia Centres is being prepared for submission to a medical journal.

The results of this project highlight the value of coordinated care and specialist centres to address the challenges for people living with ataxia. Based on these results, the ataxia case study working group together with the European Brain Council made a number of recommendations designed to increase access to, and raise awareness of, Specialist Ataxia Centres, as well as improving education on management of the ataxias amongst primary care settings. The results of

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

### Medical Advisory Panel meetings

Ataxia UK's Medical Advisory Panel met during the year and provided advice to Ataxia UK on a number of important topics such as the revision of the Ataxia Medical Guidelines and advice to people with ataxia on the Covid-19 treatments. The meetings are also an opportunity for Ataxia UK to provide an update on the latest activities and for the group to be kept updated on research developments they are each involved in.

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

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

### Ataxia UK Ethics Review Committee

Surveys that are distributed to Friends of Ataxia UK or shared on our social media channels must first be reviewed by the Ethics Review Committee. This Committee comprises five members, who either have ataxia or are family members of people affected by ataxia. The Ethics Review Committee met four times throughout the year, to review two Ataxia UK surveys and six external surveys.



## Raising awareness and understanding of ataxia amongst healthcare professionals

### Healthcare professionals' registry

We continue to reach out to healthcare professionals with an interest in ataxia via our e-newsletters sent to 300+ people on the Registry, three times a year.

### Sheffield Ataxia Centre Study Day

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

## Ataxia UK accredited Ataxia Centres

### Ataxia Children's Centre – Sheffield Children's Hospital

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

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

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

### London Adult Ataxia Centre

The London Ataxia Centre, led by Prof Giunti, now runs four ataxia clinics a week, with the support of a full-time Ataxia Nurse, providing much needed assistance to the expanding clinic. There is also a multidisciplinary clinic, where patients see the neurologist along with other healthcare professionals, such as speech and language therapists and physiotherapists. In January 2022 a vestibular clinic was also established to run on the same day as an ataxia clinic, and neuro-ophthalmology and neuro-urology clinics, providing even more integrated care.

Prof Giunti continues to be involved in numerous research projects including trials. Her research laboratory studies a wide range of ataxias and is the only UK site for European natural history projects on the SCAs and FA.



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

## Euro-ataxia

Euro-ataxia is the federation of ataxia charities across Europe, with 20 member groups from 15 countries.

Ataxia UK's CEO is the Secretary General and Ataxia UK's Head of Research is the Research Advisor.

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

Various letters of support for new research projects have been written to support ataxia researchers get funding from the EU and other funders. Euro-ataxia offers to provide the patient perspective and input to funded ataxia projects where needed.



## Supporting charities in lobbying for improvements in care and research

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

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

## Treatment and care aims for 2022-2023

- Publish Ataxia Medical Guidelines.
- Launch Paediatric Ataxia Centre in London.
- Accredite further Ataxia Centres.
- Launch ‘The Gift of Speech’ project – online speech therapy courses and Voicebanking.
- Develop an Ataxia Specialist Nurse Project.



## Care and Support Services for people affected by ataxia

### Care and support aims for 2021-22

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



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

### Services

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

### InControl

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

### Virtual Activities

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

## Branch and Support Groups

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

## Volunteer Recruitment

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

## Friends Connect

The virtual befriending service has 14 pairs who meet weekly.

## Speech Therapy Project

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

## Voice Banking

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

## Helpline and Advocacy Service

### Helpline

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

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

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

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

### Advocacy Service

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

### Membership

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

## Care and support aims for 2022-23

- Establish the Ataxia UK Helpline as the go-to place for people affected by ataxia in all aspects of their lives.
- The Advocacy service will impact positively on the lives of people affected by ataxia by supporting access to rights and services.
- Increase engagement with the ataxia community by enhancing service and information provision.
- Secure funding to ensure continuation of InControl, Information, Helpline and Advocacy Services.
- Use the All About Ataxia model to bringing the ataxia community together and provide information on other issues faced by people affected by the condition.
- Launch 'The Gift of Speech' project – online speech therapy courses and Voicebanking.



## Communications

### Communications aims for 2021-22

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

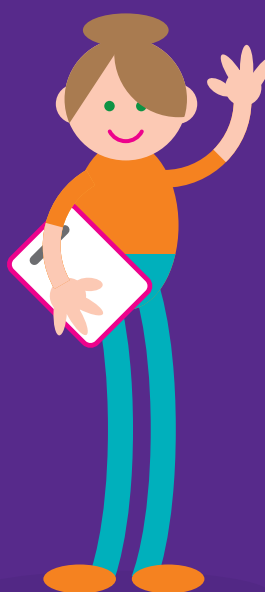
Throughout 2021-22 the communications team continued to support the ataxia community by providing key information at vital points throughout supporters' journeys. One of the most important milestones in someone's journey with ataxia is diagnosis. Sadly, too often diagnosis of ataxia can take a long time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

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

### Communications aims for 2022-23

Our strategic priorities for financial year 2022-23 are:

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



## Fundraising

### Fundraising aims for 2021-22

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



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

Ataxia UK has an in-house fundraising team undertaking a range of activities including: direct marketing; events and community fundraising; legacy fundraising; seeking grants from trusts and foundations; and major donor fundraising. We did not work with any professional external fundraisers or commercial participators this financial year. Supporters do fundraise on our behalf and are given support throughout their event by our dedicated Events and Community fundraisers. Ataxia UK is registered with the Fundraising Regulator, and we are committed to following the Regulator's Code of Practice and Fundraising Promise which set the standards for fundraising behaviours in our interactions with the public and our supporters. We have a Vulnerable Persons Fundraising Policy which sets out how we identify such potential vulnerability and how we aim to respond in such circumstances.

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

## Review the existing Fundraising Strategy

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

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

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

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

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

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

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

## Begin work on charity wide supporter journey

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

## Fundraising aims for 2022-23

Our strategic priorities for financial year 2022-23 are:

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





# Financial Review

For the year ending 31 March 2022

## Overview

In what has continued to be a challenging environment due to the ongoing impact of the Covid-19 pandemic and difficult economic times, we are filled with gratitude for the continued support and generosity of our supporters. The charity has successfully navigated the year and will continue to ensure that our income is used in the most effective way to meet our strategic goals.

The Balance Sheet and Statement of Financial Activities shows a significant improvement in Ataxia UK's funds, as a result of a £234K surplus in the year (2020/21: (£1,103K)). A net liabilities position still exists on the balance sheet due to the 3 years expenditure commitment being made for the DRPLA and NKX6-2 projects last year, whilst the funding will be received gradually over the 3 year period of the projects. The net liabilities position on the balance sheet has decreased to (£128K) from (£361K) in the prior year. The projects had a delayed start so the funding has been pushed out a year but the situation will be resolved over the next 2 years as year 1 funding has already been received.

The deficit in restricted funds, of which DRPLA and NKX6-2 funds are part, have also decreased over the year to (£851K) (2021: (£960K)). Once the outstanding restricted funds are removed the net total is £243K (2021: £134K). General unrestricted funds have however increased to £724K (2021: £599K). Further details of reserves are given later in this review. We continue to maintain a healthy cash flow and have cash at bank and in hand of £1.8 million.

## Review of income

Income £1,575K		
Donations £858K	Legacies £258K	Lottery £89K
	Fundraising £240K	Childlife £80K
		Other £50K

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

## Review of expenditure

Expenditure £1,341K		
Research Activities £501K	Care Services £331K	Raising Funds £340K
	Raising Awareness £105K	Governance £64K

Our spending on research activities decreased to £501K (2020/21: £2,227K), a decrease of 77.5%. This significant decrease is due to a reduction in research grants being made in the year, £249K versus £1,989K in 2020/21, a decrease of 87% on prior year. The two DRPLA grants amounting to £175K account for the majority of the research grants made during the year. The detailed breakdown of the research grants made can be found in note 9. There was a 15% increase in spend on care services to £331K (2020/21: £288K). Cost of raising awareness decreased slightly from the previous year to £105K (2020/21: £109K). Expenditure on raising funds increased slightly to £340K (2020/21: £324K). Governance costs increased by 8% to £64K (2020/21 £59K) due to the survey and research into Situations of People with Ataxia and we would not expect governance costs to increase otherwise. We have cut some governance costs by implementing a new accounting system and appointing new auditors. There was no research conference held in the year due to Covid restrictions.

## Investment policy and performance

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

## Reserves levels at year end

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

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

Restricted funds were (£851K) (2020/21: (£960K)), (detailed in Note 24) with their still being deficit positions for DRPLA and NKX6-2. These deficit positions have not decreased in the year due to a delay in the start of the research projects so year 2 and year 3 payments have been pushed out by a year. Ataxia UK has signed agreements in place outlining the payment structure ensuring these future commitments will be met.

Designated Funds totalled £154K (2020/21: £8K) representing funds held at branches (£8K) and other designated funds (£146k) as detailed under Note 23. The trustees have set up four designated funds during

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

- Funds held in branches, £8K: Funds held by the branches and not available for normal activities of central office.
- Coeliac UK Joint Project, £30K: Funds designated to fund a Coeliac gluten ataxia research project.
- In Control Project, £71K: Funds designated to cover the costs of the In Control project to 31 March 2023 should sufficient lottery funding not be received.
- Premises Fund, £35K: Funds are being set aside to build a reserve to cover costs of moving and setting up new premises in case we need to move at the end of our 3-year term.
- Research Conference Fund, £10K: Funds being held to cover costs of the 2022 ICAR conference.

General reserves of the charity as at 31 March 2022 were £570K (31 March 2021: £590K) a 3% decrease. The trustees consider that it is both prudent and appropriate as part of their risk management policy to maintain a minimum level of contingency within free reserves to provide against any unforeseen changes in income and/or expenditure. The reserves policy continues to be that holding unrestricted free reserves equal to a minimum of 3 months operating costs (presently £70K per month, 2020/21: £64K per month) was an acceptable level to hold. This reflects a balance between being prudent and allowing the charity to direct as much resource as possible into research and care activities. 'Free reserves' of the charity are calculated as unrestricted funds less the net book value of tangible fixed assets, £22K (2020/21: £30K). As at 31 March 2022, free reserves totalled £548K (2020/21: £560K) equating to 7.83 months operating costs (2020/21: 8.73 months) and is therefore in excess of the reserves policy.

## Covid-19/going concern

With the ongoing impact of the Covid-19 pandemic during the last year, the importance of having adequate reserves, as detailed above, continued to be a priority. Covid-19 has had, and continues to have, an impact on how we raise funds but due to the generous support of the ataxia community it hasn't had a significant impact on our results to 31 March 2022. Due to the current challenging economic conditions as a result of the pandemic plus other world events, we will maintain the close scrutiny of the management accounts and cashflow and take whatever steps necessary to ensure the continued viability of the charity.

## Statement of Trustees' Responsibilities

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

Company law requires Trustees to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charitable company, and income and expenditure, of the charitable company for that period. In preparing these financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained on the financial statements;
- Prepare the financial statements on the going concern basis, unless it is inappropriate to presume that the charitable company will continue in business.

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

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

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

### Brexit

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

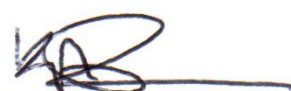
### Covid-19

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

Approved by the trustees on 28 July 2022



**William Littleboy, Chair**



**Kathy Jones, Treasurer**

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

## Opinion

We have audited the financial statements of Ataxia UK for the year ended 31 March 2022 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and notes to the financial statements including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

### In our opinion, the financial statements:

- give a true and fair view of the state of the Charity's affairs as at 31 March 2022 and of its income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice;
- have been prepared in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and with the requirements of the Companies Act 2006.

## Basis for opinion

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

responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

## Conclusions relating to going concern

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

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

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

## Other information

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

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material

inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

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

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

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

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

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

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

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

### Responsibilities of the trustees

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

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

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

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

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



## Capability of the audit in detecting irregularities

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

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

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

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

## Use of our report

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

*Anthony Epton*

**Anthony Epton**  
**(Senior Statutory Auditor)**  
3 August 2022

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

## Statement Of Financial Activities

(incorporating the income and expenditure account)

(incorporating the results of the Charity's branches)

For the year ended 31st March 2022

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

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

All recognised gains and losses are included in the SOFA.

The accompanying pages form part of these financial statements.



## Statement Of Financial Activities

(incorporating the income and expenditure account)

(incorporating the results of the Charity's branches)

**For the year ended 31st March 2021**

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

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

All recognised gains and losses are included in the SOFA.

The accompanying pages form part of these financial statements.

## Balance Sheet

As at 31st March 2022

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

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

The financial statements were approved by the Trustees on 28 July 2022 and signed on their behalf by:



William Littleboy, Chair



Kathy Jones, Treasurer

The accompanying pages form part of these financial statements.

**Charity Number:**

1102391

**Company Number:**

04974832

## Statement of Cash Flows

For the year ended 31 March 2022

	2022 £	2021 £
<b>Cash generated from operating activities:</b>		
<b>Net cash provided by operating activities</b>	144,012	879,388
<b>Cash flows from investing activities:</b>		
Dividends and interest from investments	1	1,505
Purchase of property, plant and equipment net of sales	(810)	(2,797)
Proceeds from sale of investments	-	160,475
<b>Net cash provided/(used in) by investing activities</b>	(809)	159,183
<b>Net increase in cash:</b>	143,203	1,038,571
Cash at bank and in hand less overdrafts at the beginning of the year	1,617,472	578,901
Change in cash and cash equivalents	143,203	1,038,571
Cash at bank and in hand less overdrafts at the end of the year	1,760,675	1,617,472
<b>Reconciliation of net income to net cash flow from operating activities</b>	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Net (expenditure)/income	233,821	(1,102,528)
Adjustments for:		
Depreciation charges	9,132	8,457
Net losses on investments	-	1,076
Dividends and interest from investments	(1)	(1,505)
(Increase)/Decrease in stocks	6,218	(63)
Decrease in debtors	(60,683)	104,340
Increase in creditors	(44,475)	1,869,611
<b>Net cash provided by operating activities</b>	144,012	879,388
<b>Analysis of cash at bank and in hand less overdrafts</b>	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Cash at bank and in hand	1,760,675	1,617,472
	1,760,675	1,617,472

## Notes

### To the financial statements for the year ended 31 March 2022

#### 1. Charity Information

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

#### 2. Principal Accounting Policies

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

**b. Going Concern:** During the 2021/22 financial year, we had a net positive movement in both unrestricted and restricted funds. The charity continues to show a net liabilities position on the balance sheet. This is the result of two DRPLA research grants and one NKX6-2 research grant being made in 2020/21 but the funding being received over the 3 years of the grant. All three grants have been delayed in starting due to Covid. As a result, the year 2 & year 3 funding has been delayed as well. See note 24 (note i DRPLA and

note ii NKX6-2) below for further details. Covid-19 has continued to impact how we raise funds but due to the generous support of the ataxia community it hasn't had a significant impact on our results to 31 March 2022. The cost of living crisis could have an impact on the 2022/23 financial year. We continue to take steps to ensure the continued viability of the charity. The cashflow was reviewed regularly to ensure that actual unrestricted cash was going to be adequate at all times. The Finance Committee meet regularly to monitor the situation and the fundraising department are continuing to pursue other ways to raise funds to safeguard income. A budget and associated cash flow have been drawn up for the next financial year 2022/23 to maintain robust future forecasting. We continued to have the office closed for most of 2021/22 with only a minimal number of staff going into the office. Our systems have allowed remote working with minimal disruption. The Trustees feel there are adequate resources to continue operating for the foreseeable future. The Trustees feel that there are no material uncertainties about the charitable company's ability to continue as a going concern. Accordingly, we continue to adopt the going concern basis in preparing this annual report and financial statements.

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

# Notes

## To the financial statements for the year ended 31 March 2022

- d. Tangible Fixed Assets:** Tangible fixed assets costing more than £1,000 are capitalised and depreciated over their anticipated useful life. Office equipment is depreciated at the rate of 25% per annum on a straight-line basis.
- e. Intangible Fixed Assets:** Intangible fixed assets costing more than £500 are capitalised and amortised at the rate of 25% per annum on a straight-line basis.
- f. Investments:** Investments are shown at market value and represent funds not immediately required for charitable expenditure and can be realised at short notice for such expenditure should such funds be required. Gains and losses on investments are shown in the Statement of Financial Activities. Realised gains and losses on investments are calculated as all the differences between sales proceeds and opening market value, or value at purchase date if later. Unrealised gains and losses are calculated as the difference between the market value at the year end and the opening market value, or value at purchase date if later.
- g. Income Recognition:** Income is recognised on an accrual basis, with the exception of donations and some fundraising receipts, which are on a cash basis. Deferred income represents fundraising income received for future events and is released to income in the period in which the event takes place. All income previously deferred has been released during the current year.
- h. Legacy Recognition:** In accordance with SORP (FRS 102), legacies are recognised when they are probable and measurable.
- i. Income tax recoverable:** Income tax recoverable has been added to the relevant income source to which it applied.
- j. Apportionment of Staff Costs and Overheads:** Staff costs and related office overheads have been apportioned between direct charitable expenditure, fundraising, raising awareness and governance according to the time spent by staff on each of these activities. The costs of raising awareness of the issues surrounding ataxia have been separately identified to reflect the increasing importance of this activity.
- k. Unrestricted funds:** Unrestricted funds are funds that can be used in accordance with the charitable objects at the discretion of the trustees.
- l. Designated funds:** Designated funds represent amounts held by Ataxia branches and some unrestricted funds which have been set aside by trustees for an essential spend or future purpose. See note 23 for further details.
- m. Restricted funds:** Restricted funds represent funds donated and raised by supporters of the Charity, which have been given for particular research or care services projects, together with grants received in respect of specific projects. The movements on the restricted reserves during the year are shown in note 24.
- n. Branches:** The accounts of the Charity's branches have been consolidated into these accounts.
- o. Operating Lease Rentals:** Rentals applicable to operating leases are charged to the Statement of Financial Activities as they become due.
- p. Contractual Commitments:** Formal and unconditional commitments to research expenditure and other grants at the balance sheet date are included within creditors, in accordance with SORP (FRS 102). Commitments to such projects that have been agreed by the trustees but have not yet been confirmed to the recipient, and therefore do not yet represent contractual commitments, are shown as designated funds,

## Notes

### To the financial statements for the year ended 31 March 2022

except a) to the extent that equivalent reserves are maintained in restricted funds and b) to the extent that they are funded by commitments from other bodies.

The movements on general funds and designated funds are shown in notes 22 and 23.

- q. Pensions:** The Charity contributes to certain employees' individual personal pension schemes, the assets of which are held separately from those of the Charity in a separately administered fund. Contributions to the scheme are charged to the Statement of Financial Activities as they fall due.
- r. Taxation:** As a registered charity, the Charity is exempt from taxation under CTA 2010 section 478.479.
- s. Governance Costs:** Governance costs include audit, legal and professional fees and the apportionment of staff costs, and office overheads costs according to the amount of staff time spent on this activity.
- t. Goods and Services in Kind:** Donated Services and equipment are included as income and related expenditure where the value to the charity can be reasonably quantified. The value of services provided by volunteers has not been included.

## Notes

To the financial statements for the year ended 31 March 2022

### 3. Donations and Legacies Income

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

### 4. Other Trading Activities

	2022	2021
	£	£
Fundraising activities	239,962	226,588
	<u>239,962</u>	<u>226,588</u>

### 5. Charitable Activities Income

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

### 6. Investment Income

	2022	2021
	£	£
Income on investment portfolio	-	114
Interest	1	1,391
	<u>1</u>	<u>1,505</u>

## Notes

To the financial statements for the year ended 31 March 2022

### 7 Raising Funds Expenditure

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

### 8. Charitable Activities Expenditure

	Direct Costs £	Grants £	Support Costs £	2022 Total £	2021 Total £
Research activities	172,510	248,753	79,799	501,062	2,226,523
Ataxia centres	-	-	-	-	-
Care services	175,945	3,183	151,356	330,484	287,553
Total	<u>348,455</u>	<u>251,936</u>	<u>231,155</u>	<u>831,546</u>	<u>2,514,076</u>

Generating funds	-	-	104,785	104,785	90,212
Research conference	-	-	-	-	-
Raising awareness	32,253	-	72,950	105,203	109,173
Governance	-	-	64,125	64,125	59,193
Total charitable activities	<u>380,708</u>	<u>251,936</u>	<u>473,015</u>	<u>1,105,659</u>	<u>2,772,654</u>

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



## Notes

To the financial statements for the year ended 31 March 2022

### 9. Research Grants

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

## Notes

### To the financial statements for the year ended 31 March 2022

	2022	2021
	£	£
<b>Research grants made in year comprise</b>		
Funding extension for the grant application entitled 'Preclinical development of an amelioration therapy for Dentatorubro-Pallidoluysian Atrophy	43,264	
DRPLA Natural History and Biomarkers Study (DRPLA NHBS)	131,449	
Motor and cognitive outcomes of non-invasive transcranial alternate current stimulation by entrainment of cerebellar oscillations	5,000	
Sheffield Ataxia Study Day	700	
Generation and characterization of a cardiomyocyte model for Friedreich's ataxia to reveal the molecular mechanism of heart failure in patients	5,000	
Analysis of the mitochondrial dysfunction in FXN deficient neurones to generate a drug screening test	4,750	
Brain pathology in an AIFM1 mutation causing Cowchock syndrome	5,000	
Balance and gait abnormalities in adult patients with mitochondrial disease and spinocerebellar ataxia type 6	4,928	
A feasibility study of LSVT Artic to improve speech performance in people with progressive ataxia	2,862	
NanoSCA: Development of brain-targeted nanobodies for application in spinocerebellar ataxia type 3 therapy	25,800	
	<u>248,753</u>	<u>1,989,441</u>

## Notes

To the financial statements for the year ended 31 March 2022

### 10. Staff Costs

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

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

The senior management team consist of the Chief Executive and the heads of Development, Finance, Fundraising, Research and Services.

The total employee benefits of the senior management team were £335,048 (2021: £291,107).

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

	2022	2021
£80,000 – £89,999	1	1

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

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

## Notes

### To the financial statements for the year ended 31 March 2022

#### 11. Pension Schemes

All permanent members of staff were eligible to receive payment of 5% of their salary paid into a stakeholder personal plan. The pension premiums payable during the year were £34,104 (2021: £30,021). There was no outstanding balance (2021: £0) at the year end.

#### 12. Trustees

Certain trustees carry out duties that would otherwise be undertaken by paid staff. They receive no remuneration but, along with the other trustees, may claim reimbursement of out of pocket expenses. During the year, all board meetings were held remotely and as a result no trustee expenses were incurred. 0 trustees (2021: 0) claimed expenses totalling £0 (2021: £0).

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

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

## Notes

To the financial statements for the year ended 31 March 2022

### 14. Tangible Fixed Assets

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

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

### 15. Investments

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

## Notes

To the financial statements for the year ended 31 March 2022

### 16. Stock

	2022	2021
	£	£
Stock for resale	-	6,218

### 17. Debtors Under 1 Year

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

### 18. Cash at bank and in hand

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

Interest receivable is disclosed in note 6.

### 19. Creditors: amounts falling due within one year

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

## Notes

To the financial statements for the year ended 31 March 2022

### 20. Creditors: Amounts falling due after one year

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

### 21. Analysis of net assets between funds

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

### 22. Unrestricted Funds

	General Funds £	Designated Funds £	Total £
Balance as at 1 April 2021	590,306	8,337	598,643
Net increase/(decrease) in funds during the year	125,494	(224)	125,270
Transfers	(146,000)	146,000	-
Balance as at 31 March 2022	<u>569,800</u>	<u>154,113</u>	<u>723,913</u>

## Notes

To the financial statements for the year ended 31 March 2022

### 23. Designated Funds

	Opening Balance £	Net Movement £	Transfers £	Closing Balance £
Funds held in branches	8,337	(224)	-	8,113
Coeliac UK Joint Project	-	-	30,000	30,000
In Control Project	-	-	71,000	71,000
Premises Fund	-	-	35,000	35,000
Research Conference Fund	-	-	10,000	10,000
	<u>8,337</u>	<u>(224)</u>	<u>146,000</u>	<u>154,113</u>

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

**b. Joint Research Project with Coeliac UK:** Funds designated to fund a gluten ataxia research project.

**c. In Control Project:** Funds designated to cover the In Control project to the 31 March 2023.

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

**e. Research Conference Fund:** Funds being held to cover costs of ICAR conference.



## Notes

To the financial statements for the year ended 31 March 2022

### 24. Restricted Funds

	At 1 April 2021 £	Income £	Expenditure £	Transfers £	At 31 March 2022 £
General Research	-	178,525	82,585	-	95,941
Friedreich's ataxia research	(1)	64,953	51,794	-	13,158
Cerebellar ataxia research	87	2,627	525	-	2,189
Young Person's projects	7,959	-	-	-	7,959
Jerry Farr travel fund	671	-	-	-	671
Welfare	634	-	-	-	634
Welfare – The Gift of Speech	-	30,607	8,983	-	21,624
Goods and Services Received	-	6,610	6,610	-	-
Helpline	31,870	-	-	(31,870)	-
Misc Grants	450	-	-	-	450
Childlife	-	80,000	80,000	-	-
Exeter	582	-	-	-	582
Awareness	4,895	-	724	-	4,171
Kennedy Award	16,948	-	4,750	-	12,198
Research Stem Cell FA	-	97	19	-	78
Mark Dower Trust	1,326	3,625	3,183	-	1,768
Spinocerebellar Ataxia Research Project	-	2,076	415	-	1,661
DRPLA Research	(1,047,450)	174,713	174,713	-	(1,047,450)
In Control Project	4,784	89,671	116,855	31,870	9,470
Ataxia Centres	51,039	-	-	-	51,039
DRPLA Department	11,536	118,477	114,239	-	15,774
Scotland	800	-	-	-	800
NXK6-2	(46,782)	-	-	-	(46,782)
AOA2	665	2,456	491	-	2,629
	(959,987)	754,437	645,886	-	(851,436)

## Notes

### To the financial statements for the year ended 31 March 2022

- a. **General Research:** Funds provided for general research into ataxia.
- b. **Friedreich's ataxia research:** Funds provided by donors specifically for research on friedreich's ataxia.
- c. **Cerebellar ataxia research:** Funds provided by donors specifically for research on cerebellar ataxia.
- d. **Young Person's projects:** Funds provided by donors to develop materials to help young people after diagnosis.
- e. **Jerry Farr travel fund:** Funds given by friends of Jerry Farr to help young people after diagnosis.
- f. **Welfare:** Funds provided for welfare grants.
- g. **Welfare:** Funds provided for speech therapy grants and voicebanking.
- h. **Goods and Services Received:** Goods and Services received free of charge in respect of Google ads.
- i. **Helpline:** Funds to support the helpline.
- j. **Miscellaneous Grants:** Funds provided for general grants.
- k. **Childlife:** Funds given by Childlife to promote the relief of children who are in need. The auditors have agreed that the income received from Childlife has been spent in accordance with the terms of and conditions of the grant.
- l. **Exeter:** Funds to be expended in the Exeter area.
- m. **Awareness:** Funds provided to raise awareness of Ataxia.
- n. **Kennedy Award:** A fund set up to assist researchers studying Friedreich's ataxia with attending scientific conferences and other small research studies.
- o. **Research Stem Cell FA:** Spinocerebellar Ataxia Research Project: Funds for spinocerebellar ataxia research project.
- p. **Mark Dower Trust:** A fund set up to support young people in their quest for independent living through enabling them to develop skills, hobbies or interests.
- q. **Spinocerebellar Ataxia Research Project:** Funds for spinocerebellar ataxia research project.
- r. **DRPLA Research:** Funds provided by donors specifically for research on Dentatorubral-pallidoluysian atrophy. See note i below.
- s. **In Control Project:** Funds provided by the Lottery to promote volunteers and provide support to the ataxian community.
- t. **Ataxia Centres:** Funds to assist with the set-up of additional ataxia centres/virtual centre.
- u. **DRPLA Department:** Funds provided by donors specifically for staff to support DRPLA research.
- v. **Scotland:** Funds to be expended in Scotland.
- w. **NKX6-2:** Funds provided by donors specifically for research into NKX6-2. See note ii below.
- x. **AOA2:** Funds provided by donors specifically for research into ataxia with oculomotor apraxia type 2.

**Note i:** DRPLA research grants of £1.8m were issued during the 2020/21 financial year with income being received of £0.8m. Two of the research grants are being funded over three years leaving a deficit of £1.0m which equates to the year 2 & year 3 payments. Both projects have had a delayed start which has resulted in year 2 & year 3 payments being delayed. Ataxia has signed agreements in place outlining the payment structure ensuring these future commitments will be met.

## Notes

### To the financial statements for the year ended 31 March 2022

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

## 25. Capital Commitments

There are no capital commitments  
at 31 March 2022 (2021: Nil)

## 26. Lease Commitments

At 31 March 2022 the charity had future minimum lease payments under non-cancellable operating leases as follows:

	2022		2021	
	Land & buildings	Other	Land & buildings	Other
	£	£	£	£
Payments due:				
Within one year	50,604	1,608	49,604	1,608
Within two to five years	61,802	3,217	29,302	4,825
	<u>112,406</u>	<u>4,825</u>	<u>78,906</u>	<u>6,433</u>

## Notes

To the financial statements for the year ended 31 March 2022

### 27. Associated Organisations

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

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



[www.ataxia.org.uk](http://www.ataxia.org.uk)

Ataxia UK 12 Broadbent Close London N6 5JW

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

**ATAXIA**