



Annual Report & Financial Statements  
Year Ending: 31 March 2021

Ataxia UK  
12 Broadbent Close  
London  
N6 5JW

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

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## Introduction from Co-Chairs

Looking back on what has been very challenging year for the charity sector as a whole, Ataxia UK has shown great resilience getting through a pandemic looking after our staff and our Friends.

At the start of this financial year, we were very concerned about our ability to generate income through fundraising. We re-forecast our budget to account for the difficult times ahead. After your fantastic response to our emergency appeal, we re-forecast again.

Our highly skilled and regarded research team has focused on smaller and rarer ataxias. This work will contribute to the greater understanding of all the ataxias, but more significantly, the funding we received for this work has significantly contributed to our financial stability this year. In the New Year, we supported Friedreich's Ataxia Research Alliance (FARA) push to bring a promising treatment for Friedreich's ataxia to the market in the US. We are monitoring the situation very closely with a view to bringing this treatment to the UK.

Our Chief Executive has done a wonderful job keeping our staff together as they got used to remote working, paying careful attention to the mental health consequences we have all been feeling as we stayed at home. Although only meeting virtually throughout this year, we have refocused our Board. Making it leaner and better equipped to deal with challenges, while ensuring that people with ataxia continue to be at the very heart of everything Ataxia UK does.

Our managers and staff have risen to the of challenge of meeting our strategic aim of ensuring our Friends feel "supported and in control" through the Global Pandemic. We provided template letters for Friends who were having difficulties getting their vulnerability status confirmed. We provided a number of webinars about Covid-19 with expert clinicians so you could ask questions. With the support of the National Lottery, our InControl" project adapted and took many of our activities online. By the end of the financial year, we had provided activities and support to many, tackling loneliness and swelling our ranks with wonderful volunteers.

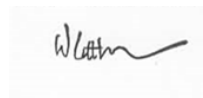
We welcomed around 180 guests to our virtual Annual Conference in October as we set out to inform, challenge and support you. It was our first major online event, but we still offered our usual varied array of speakers and wide range of workshops. The feedback from this event was excellent.

As you can see in our figures, Ataxia UK ended the financial year in a much better position than expected. We know that is down to our excellent staff and your generous support. We continue to face significant challenges from Brexit and as Ataxia UK seeks to reposition itself following the pandemic. We have learned a lot about ourselves and you, our Friends, and will use this and your feedback to build a strategic plan to continue driving us forwards over the next three years.

Thank you for your support.



**Richard Brown MBE, Co-Chair**



**William Littleboy, Co-Chair**

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

The charity's registered address is 12 Broadbent Close, London, N6 5JW. The trustees that served during 2020-2021 are:

### Honorary Officers

**Richard Brown, Co-Chair** (Elected as Co-Chair 6 October 2019)

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

**Kathy Jones, Honorary Treasurer**

### Trustees

**John Abbott** (Retired 27 November 2020)

**Richard Brown MBE**

**Andrew Downie**

**Kathy Jones**

**Prof Barry Hunt**

**Dr Anthony Kaye** (Retired 27 November 2020)

**Philip Griffiths**

**Robert Perkins**

**Alison Love** (Retired 7 July 2020)

**William Littleboy**

**Carol McCudden**

**Terence McCaw**

**Gemma Fish**

**Colleen Starkey** (Retired 7 July 2020)

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

### Ataxia UK uses the following professional advisors:

#### Auditors

Mazars LLP  
6 Sutton Plaza  
Sutton Court Road  
Sutton, Surrey, SM1 4FS

#### Bankers

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

#### HR Consultants

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

#### Solicitors

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

## Structure, Governance & Management

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

Ataxia UK is managed by a Board of Trustees, which sets strategies and policies. An Executive Committee, 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 27 November 2020.

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

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

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

### Public Benefit

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

*“Ataxia UK is an inclusive organisation which promotes the wellbeing of all people affected by ataxia. We provide information to people affected by ataxia at the early stages of diagnosis and specialist services for this medical condition, many of which are not available from the NHS or other statutory or voluntary sources. We work to end isolation and promote engagement in social, educational and leisure activities for people affected by ataxia and their families. We educate the broad community and key subsections within it, such as the medical and social services professions, about the effects of ataxia. We also fund vital research projects into potential treatments, aiming to find a cure for ataxia. There is currently no specific government funding for ataxia research.”*

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

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

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

The **Scientific Advisory Committee (SAC)** meets three times per year. It is a sub-committee of the Board of Trustees and provides independent scientific advice to the Board of Trustees on:

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

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

**Dr Franziska Denk**  
**Dr Claire Kelly**  
**Dr Marija Sajic**

**Dr Mark Pook**  
**Professor Keith Morris**  
**Dr Gita Ramdharry**

The committee included the following lay members during the year:  
**Rosemary Hodayoun, Harriet Bonney and Nathan Hall.**

During this year **Dr Michele Lufino** stood down from the committee and we are extremely grateful for his service on this committee.

**Professor Barry Hunt** attends as Trustee Scientific Advisor. All members are unpaid volunteers.

## **Employees**

During 2020/21 the average number of full-time equivalent employees during the year was 17.8 (with all employees' time involved in providing either support to the governance of the Charity or our charitable activities). IT support and HR advice functions are outsourced.

## Volunteers

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

Loyal and committed volunteer fundraisers run events both large and small to provide Ataxia UK with essential funds. Our Branches and Support Groups are all run by volunteers, many of whom have ataxia themselves.

We are also grateful to the volunteers who assist our Research department by serving on the Scientific Advisory Committee, Medical Advisory Panel and Pharma Advisory Group. The contribution of all of our volunteers to the work of Ataxia UK is much valued and appreciated.

We have three regular, trained, volunteers supporting our Helpline staff with phone and email enquiries.

## Risk Management

As in previous years, we actively managed the risks to the charity, focusing on the most serious. We maintain a register of our controls and activities to mitigate risk throughout the year; in 2020-21 the risk register was significantly influenced by the impact of the Covid-19 pandemic. The most serious risks we faced during 2020-21 were:

- Loss of fundraising through cessation of face-to-face fundraising activities and a reduction of donations – this has been mitigated through a redrafting of the budget for 2020-21 and by replacing physical activities with virtual events.
- Collapse of the remote IT infrastructure which enables remote working by all staff – this was addressed during the year by moving almost all processes to cloud based systems.

## Objectives & Activities

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

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

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

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

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

Raising awareness of ataxia is fundamental to supporting people with ataxia in every way. An understanding of the condition is needed in the medical sector, where diagnosis and treatment is often delayed, but also in the public, where misunderstandings of ataxic symptoms cause many difficulties for people with ataxia. An increase in awareness also often leads to an increase in fundraising. The more aware people are of our aims, the more likely they are to donate to the charity. More can be read about our raising awareness events on p.23.



## **Our Strategic Plan 2017-2020**

There remained much work to be done to benefit people affected by ataxia under the themes of the Strategic Plan 2017-2020. In 2020 we elected to extend it to 2022 whilst keeping the projects to which we are committed undertaken under review to take into account the impact of the changes brought about in many areas of life by the Covid pandemic which arrived towards the end of 2019-20.

### **It contains four major ambitions:**

- By 2022 we want people affected by ataxia to be able to say: “I feel supported and in control”
- To have increased our funded research activity
- To consistently maximise the impact of research activity
- To have fostered best practise in treatment & care

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

However, the changes in our work and environment during the Covid-19 pandemic and the opportunities which now present themselves mean that we are now developing a new Strategic Plan to take effect from April 2022.

## **Achievements, Performance & Aims**

### **Research**

#### **Research aims for 2020-21**

- Increase enrolment to FA Global Patient Registry.
- Build on DRPLA programme to coordinate research in the field.
- Plan next International Ataxia Research Conference.

#### **Increase enrolment to the Friedreich's ataxia global registry**

Ataxia UK and Friedreich's Ataxia Research Association USA (FARA) facilitate the FA Global Registry. We participate in governance, and recruitment of participants. 362 were registered during the year bringing total registrants to over 1,000 people.

#### **Build on DRPLA programme to coordinate research in the field**

Ataxia UK is collaborating with the US Foundation, CureDRPLA, to advance research in Dentatorubral-pallidoluysian atrophy (DRPLA), a rare form of inherited ataxia. Using a staff member funded by CureDRPLA, we also coordinate the DRPLA Natural History and Biomarkers Study (DRPLA NHBS) with study sites in the United Kingdom, the United States and Japan. We have been involved in protocol development, designing and building the electronic database, and creating a governance structure. Ataxia UK is also managing the CureDRPLA contracts and grant awards to Universities involved in the natural history study; and together we have established the CureDRPLA Global Patient Registry to gather patient reported data. We believe the networking and expertise being gained by Ataxia UK working on this DRPLA Research programme will be invaluable in helping us advance research towards treatments and cures in other ataxias.

#### **Plan the next International Ataxia Research Conference**

Ataxia UK is partnering with the US ataxia charities, Friedreich's ataxia research alliance and National Ataxia Foundation USA (NAF), to hold the International Congress for Ataxia Research (ICAR) in March 2022 in Orlando, USA. It will combine the best of the host organisations' popular research meetings, including previous International Ataxia Research Conferences (co-hosted by Ataxia UK, FARA, GoFAR,) and NAF's Ataxia Investigators Meeting.

### **Other Research Activities**

#### **Ataxia UK research grant programme**

Five grants were awarded via our standard research programme. Five grants were awarded as part of the DRPLA (restricted) research programme and two new grants for spastic ataxia type 8 were funded by the DVS Foundation.

1. **Dr D'Autreax** (CNRS-CEA-Université Paris-Saclay, France) 'Development of a selective high throughput screening assay for the discovery of compounds replacing frataxin in FA' - £26,000.

2. **Dr Rufini**, Fratagene Therapeutics (University of Rome) – Etravirine as a potential therapeutic for Friedreich ataxia - £20,000.
3. **Prof Horvath (Cambridge, UK)** ‘PROSPAX: an integrated multimodal progression chart in spastic ataxias’ - £5,000.
4. **Year 2 Dr Filip Lim’s project** (University of Madrid, Spain) ‘Generating new Friedreich’s Ataxia animal models for validating HSV-1 FXN gene therapy in Dorsal Root Ganglia Dr Lim’ - £30,000 (50% from Kennedy Award Scheme).
5. **Prof Lowit** – A joint model of online Speech and language therapy intervention and peer support to enhance communication effectiveness and participation in people with progressive ataxia - £5,977.

### **DRPLA Grants (in partnership with CureDRPLA)**

1. **Prof Paola Giunti** (University College London, UK) ‘Comprehensive Biomarker Characterisation in Dentatorubral-Pallidoluysian Atrophy: £1,034M.
2. **Prof Henry Houlden** (University College London, UK) ‘Biomarkers, Somatic Instability and creating a DRPLA cell line resource’ - £492K.
3. **Prof Louise Corben** (Genetic Health Research & Murdoch Children's Research Institute, Australia) ‘Investigating the use of the Ataxia Instrumented Measure – Spoon in measuring upper limb function in DRPLA’ - £71K.
4. **Dr Heather Lau** (NYU Grossman School of Medicine, USA) ‘The DRPLA Natural History and Biomarker Study’ - £126K.
5. **Prof Adam Vogel** (Redenlab & The University of Melbourne, Australia) ‘Redenlab Scope of Work for the DRPLA Natural History Study (Speech and Dysphagia)’ - £51K.

### **Spastic ataxia type 8 grants (in partnership with DVS Foundation)**

1. **Dr Chelban and Prof Holden** (UCL Institute of Neurology, London) - NKX6-2 Related Spastic Ataxia and Leukodystrophy: Natural history, biomarkers and the potential of gene transfer method. - £69,988.
2. **Dr Tremblay** (Laval University, Canada) - Development of a PRIME editing therapy for Ataxia-8 due to the c.121 A to T point mutation - £34,600.

Our research programme currently comprises 19 projects. We provide support to researchers where needed, evaluating annual reports and monitoring finances.

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

We annually evaluate the impact of our funded research. The last 10 years’ data shows that every £1 invested by Ataxia UK, produces nearly 6-fold in further funding for ataxia research. In addition, nearly 100 research papers have been published in scientific/medical journals; with 42 new research tools developed over the 10 years.

Ataxia UK featured as a case study in The Association of Medical Research Charities (AMRC) report: 'Without Charities' - produced in anticipation of the Comprehensive Spending Review, to demonstrate the value of medical research charities' contribution to the UK's position as a world leader in medical research.

### **Association of Medical Research Charities (AMRC) Audit Review**

Every 2-3 years the AMRC audits its members' procedures for evaluating and funding research. Ataxia UK passed the 2020 audit with minor changes in our processes suggested. Head of Research, Dr Julie Greenfield was a member of the AMRC Auditors Team, reviewing submissions made by AMRC member charities.

### **Ataxia UK's involvement in Multi-Centre European Research Projects**

Ataxia UK partners with researchers in a number of projects to provide a patient view. Frequently this is through representing Euro-ataxia (the European federation of 22 patient groups). It is indicative of the value placed on Ataxia UK's expertise that we are invited to collaborate in these multi-million pound projects.

1. **European spinocerebellar ataxia type 3/Machado Joseph disease Initiative (ESMI)** - Dr Julie Greenfield is the patient group representative on the Steering Committee representing Ataxia UK and Euro-ataxia.
2. **Friedreich's Ataxia Consortium for Translational Research (EFACTS)** - Ataxia UK Trustee Prof. Barry Hunt is a member of the Steering Committee.
3. **PROSPAX study** – New EU funded project 'PROgression chart of SPastic ataXias' - Ataxia UK represents Euro-ataxia, (with German charity DHAG). The study will examine the progression of spastic ataxias.
4. **SCAIFIELD project** – New EU JPND project 'Spinocerebellar ataxia advanced imaging with ultra-high field MRI'. Patient input and support.
5. **PhaseAGE** – Ataxia UK's Head of Research joined the Scientific Steering Committee of this new EU funded project, which is a capacity building, training Consortium, with research projects on the formation of 'aggregates' by the phenomenon of phase separation (e.g. as when oil and water separate) in ageing and neurodegenerative conditions including SCA3.

### **Ataxia Global Initiative**

In 2020 SCA Global and ARCA Global merged, becoming The Ataxia Global Initiative. SCA Global focused on dominantly inherited ataxias (e.g. SCAs) and ARCA Global on recessively inherited ataxias (e.g. ARSACS/AOA). Dr Greenfield is a Steering Committee Member and co-chairs the Policy & Patient Engagement Group.

### **Critical Path to Therapeutics for the Ataxias Consortium**

Ataxia UK has participated in the formation of a Consortium for the ataxias. The Consortium is a public-private partnership between the Critical Path Institute, ataxia researchers, pharma companies, Ataxia Global Initiative, Ataxia UK and NAF. It intends to create regulatory tools and strategies that will catalyse the development of

approved medicines for the ataxias. A crucial aspect of the Consortium is to include experts from the regulatory bodies such as the US Food and Drugs Agency (FDA) in the discussions. Ataxia UK has signed an Advisory Agreement with them.

### **Approval of Omaveloxolone by the FDA (USA)**

In January 2021 we supported a campaign to press Reata to submit a New Drug Application on an urgent basis; and the FDA to consider approval of an NDA for Omaveloxolone. The petition gained 74,000 signatures (50% from outside USA) and seems to have precipitated further conversations between Reata and the FDA.

### **Spastic ataxia type 8 ((SPAX8) research programme**

Two grants were awarded to research the rare form of ataxia, (SPAX8) using genetic therapy approaches, A family donated the funds via the DVS Foundation.

### **AT Society Research Services**

Ataxia UK has continued to provide a research support service to the Ataxia Telangiectasia (AT) Society, the UK charity supporting people affected by AT.

### **Working with Pharmaceutical Companies and industry**

Ataxia UK values its collaborative relationships with pharmaceutical companies and is encouraged by their increased interest in the ataxias and the trials being planned.

- **Intrabio:** collaboration resulting in [scientific publication](#) describing a novel design for the trial that is of relevance to ultra-rare conditions.
- **Healix:** 'Rare Treatment Accelerator Therapy Development Collaboration' to re-purpose existing approved drug therapies for rare diseases, using artificial intelligence, drug discovery, and development expertise to advance FA research. This approach to drug discovery in FA offers a replicable model and we are already involved in efforts to establish similar approaches in other ataxias.

### **Pharma Strategy Advisory Committee**

The Pharma Strategy meeting in May 2020 discussed working with regulators in the drug approval process to engage and inject patient perspectives. We obtained a meeting with the UK Medicines and Healthcare Regulatory Agency (MHRA). This has led to Ataxia UK former Chairman and Volunteer, Dr Harriet Bonney, joining the MHRA patient group consultative forum as an Ataxia UK representative.

### **Recruitment of Participants to Research Studies**

Our database of people with ataxia enables Ataxia UK to recruit volunteers to participate in research projects. The following projects have been supported:

- ARSACS Optical Coherence Tomography (OCT) study (London UCL/UCLH)
- Tracking the natural progression of spastic ataxias to prepare treatment trials (University of Cambridge)
- Natural history studies in Friedreich's ataxia; SCA3; SCA1, SCA2, SCA6 and SCA7 (All London UCL/UCLH)
- Recording speech samples to improve voice recognition software for people with speech that is difficult to understand (Google AI)
- Online group and peer support speech therapy study for people with progressive ataxia (University of Strathclyde)

- Friedreich's Ataxia Global Patient Registry
- CureDRPLA Global Patient Registry.

We have also been involved in recruitment for the following surveys:

- Superficial Siderosis survey – a rare form of ataxia (London UCL)
- Childhood Neurological Conditions survey (British Paediatric Neurology Association)
- Covid-19 and ataxia survey (Ataxia UK)
- Symptoms of ataxia and hereditary spastic paraplegia survey (PROgression chart of SPAsitic ataXias project)
- Investigating the impact of COVID-19 on caregivers and patients survey (Queen's University Belfast/University of Aberdeen)
- Patient experience survey (Genetic Alliance).

### Raising Awareness of Ataxia Research

Ataxia UK research staff have attended meetings and conferences during the year.

1. **FindaCure meeting – September 2020** Research Manager Emily Cutting gave a talk at a Findacure webinar on building successful collaborations.
2. **Externally-Led Patient-Focused Drug Development Meeting on Ataxia - NAF and CureDRPLA meeting to inform the FDA of the impact of SCAs and DRPLA.**
3. **World Orphan Drug Congress – 2 to 5 of November 2020**
4. **Exclusive industry Round Table – Ataxia Global (Feb 2021)** - Organised by NAF for pharma companies that are part of their Pharma Consortium.
5. **BIA-AMRC Roundtable Feb 2021**  
A collaborative event between the BIA (UK Bioindustry Association) and the AMRC. This included presentations from charities and companies.
6. **NAF's Exclusive DDC Industry Roundtable April 2021**  
Lessons learned from Friedreich's ataxia Trials.
7. **World Orphan Drug Congress USA 2021 April 2021**  
The Head of Research and DRPLA Research Officer attended this virtual event.

### Research aims for 2021-2022

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

## Improvements in treatments and care

### Treatment and care aims for 2020-21

- Explore the development of a second Paediatric Ataxia Centre.
- Produce policy recommendations based on the results of the 'Value of Treatment' research project and assess their implications for current Ataxia Centres.
- Become engaged with the UK Medicines and Healthcare products Regulatory Agency (MHRA).
- Explore the development of an NHS care pathway for ataxias.

### Explore the development of a second Paediatric Ataxia Centre

There have been discussions during the year with Prof Giunti at the London Ataxia Centre for adults regarding the development of a Paediatric Ataxia Centre in London. We are delighted that Ataxia UK has been able to provide funding towards a part-time Specialist Ataxia Nurse for the Centre which is also being supported by a private donor. We are optimistic that with sufficient demand for the service, the Trust will look favourably on meeting the cost of this clinic in the future. Plans are underway to establish the Centre and we hope it will open during 2021-22.

### Produce policy recommendations based on the results of the 'Value of Treatment' research project and assess their implications for current Ataxia Centres

Ataxia UK worked with Prof Giunti (Head of London Ataxia Centre) in presenting a project on ataxia to the European Brain Council (EBC), which was approved as one of three rare diseases to be included in the 'Value of Treatment' project. The project is supported by funding from pharma companies, Takeda and Reata Pharmaceuticals. It broadly analyses adult patient diagnosis and care pathways in Specialist Ataxia Centres and general non-specialist settings, and will also explore the health economic effects of both settings.

A survey was designed and disseminated in the UK. Following analysis of the results a few modifications were made, and two new surveys were designed in German and Italian. The German survey has been receiving responses and the Italian one will be disseminated during 2021-22. Dissemination is being done via our collaboration with the patient groups in these countries who are members of Euro-ataxia. Data from all countries will be analysed and published next year. This will form the basis of policy recommendations regarding specialist centres on rare diseases that will be presented to the European Parliament.

### Become engaged with the UK Medicines and Healthcare products Regulatory Agency (MHRA)

As we get closer to the possibility of treatments being proposed to regulators for approval, it is important for Ataxia UK to become more engaged with medicine regulators such as the UK MHRA. Towards the start of the year a meeting was held with the MHRA and Ataxia UK Head of Research to discuss engagement with Ataxia UK and this led to Ataxia UK Friend and Volunteer, Dr Harriet Bonney, joining the MHRA Patient Group Consultative Forum as an Ataxia UK representative.

During the year Dr Bonney took part in numerous briefings and discussion meetings on a range of topics such as Covid-19 vaccines, Brexit transition and shaping the future of medical device approval. There were also preliminary discussions on the Innovative Licensing and Access Pathway. This builds on the existing Early Access to Medicines Scheme, which gives patients with life-threatening or seriously debilitating conditions access to medicines that do not yet have a marketing authorisation when there is a clear unmet medical need. Its goal is to deliver efficient and timely development of medicines and earlier patient access. Dr Bonney has now also joined the Patient Reference Group for the Innovative Licensing and Access Pathway and will be able to continue to provide input from the perspective of people with ataxia.

These developing links with the MHRA will place Ataxia UK in a better position to understand the processes of medicine approval and equip us with the necessary skills to represent patients' interests and campaign for drug approvals when the time comes. Ataxia UK will also increase the engagement with medicine regulators in the coming year due to the participation in 'Critical Path to Therapeutics for the Ataxias Consortium' (see Research section).

### **Explore the development of an NHS care pathway for ataxias**

Ataxia UK has continued to inject our views via the Neurological Alliance (England) into the NHS Care Pathways work being undertaken by the NHSE National Neurology Advisory Group (NNAG) and it is expected that draft pathways for a number of neurological conditions, one of which will cover the ataxias will be published in early summer 2021-22 for consultation with stakeholders including patient groups.

## **Other ongoing activities**

### **Medical Advisory Panel meetings**

Ataxia UK's Medical Advisory Panel comprises ataxia specialist clinicians and ataxia nurses, who provide advice to the charity on areas of interest in medical issues and healthcare. During the year two virtual meetings were held. Advice was sought on Covid-19 vaccinations for different types of ataxia and the creation of the Covid-19 survey was discussed (see below). Two new individuals joined the panel, a neurologist from Glasgow and a speech and language therapist. Ataxia clinic updates and new research publications from members were highlighted and discussed thus contributing to sharing knowledge and expertise on ataxia.

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

Three virtual seminars and Q&A sessions were held in March 2020, April 2020 and July 2020 with the team of the London Ataxia Centre (Prof Giunti and the Ataxia nurse Suzanne Booth) to provide information on Covid-19, on shielding, going to school, and numerous other practical issues. There was much demand for advice, and these were well attended events. The same team gave a similar seminar on vaccinations and priority groups in response to many enquires via social media and the Helpline. We were grateful to the staff of the London Ataxia Centre for their help in assisting people with ataxia.



The Ataxia UK website carried information on Covid-19 and when the vaccine became available, a template letter to facilitate access to it for people with ataxia was made available. This approach was used successfully by a number of people who managed to bring forward their vaccination.

## **Collecting data on impact of Covid-19**

### **Ataxia UK survey**

Following discussion at the last Medical Advisory Panel meeting we are working with ataxia neurologists Rajith de Silva and Paola Giunti in designing a survey to understand the impact of Covid-19 on people with ataxia of the effect of short- and long-term symptoms. This was reviewed by Ataxia UK's internal Ethics Committee and then distributed widely to Friends of Ataxia UK (between October 2020 and March 2021). Results are currently being analysed and will be submitted for publication.

### **IMPaCCt study**

Researchers at Queen's University Belfast and the University of Aberdeen have been doing a study to investigate the impact of Covid-19 on people with rare diseases and cancer in terms of healthcare service provision. Ataxia UK disseminated this survey to people with ataxia to get their perspective.

### **Formation of new Ataxia UK Ethics Review Committee**

When researchers contact Ataxia UK to publicise a research study to participants our procedure has always been to ensure that they have obtained ethical approval from a University or NHS Research Ethics Committee. However, there are instances where it may not be necessary for this to happen, but an internal ethics review will suffice. This may be the case, for example, when Ataxia UK wishes to do a survey of people with ataxia.

To this end, it was agreed that Ataxia UK should formalise the process of ethical review of any surveys and a procedure has been set up, together with the creation of an Ethics Review Committee. During the year the committee has reviewed seven surveys (two from Ataxia UK and five external ones).

### **Raising awareness and understanding of ataxia amongst healthcare professionals**

We continue to reach out to healthcare professionals with an interest in ataxia via our e-newsletters sent to our registry three times a year. Recent clinical papers on the ataxias are publicised, as well as information on events and funding opportunities.

Ataxia UK had awarded a grant to the Sheffield Ataxia Centre in order for them to run an ataxia training event. This event was postponed due to Covid-19, but they now have a new date for 2021 as a virtual event.

## **Ataxia UK accredited Ataxia Centres**

### **1. Sheffield Children Centre**

We now have the first Accredited Ataxia Centre for children, and this is based in Sheffield. There is a dedicated specialist ataxia paediatric neurologist running the

service and an Ataxia nurse. A formal opening had been scheduled for March 2020 however unfortunately this did not happen due to Covid-19. The Centre is progressing well and is receiving many referrals.

## **2. Adult Ataxia Centre – Sheffield:**

The team at the Accredited Ataxia Centre consists of two neurologists (Prof Hadjivassiliou and Dr Shanmugarajah) and two Ataxia Nurses, thus is a large concentration of expertise. In addition, they have close links with the paediatric ataxia clinic now run by Santosh Mordekar. Prof Hadjivassiliou continues to publish extensively on ataxia research, in particular autoimmune ataxias.

## **3. London adult Ataxia Centre**

Prof Giunti continues to run busy ataxia clinics and has the support of a full-time Ataxia Nurse, providing much needed assistance to the expanding clinic. She also has a second neurologist which has increased the capacity and enabled the team to see more ataxia patients. Prof Giunti continues to be involved in numerous research projects including trials. Her site is the only UK site for European natural history projects on the SCAs and FA and is also the site for the Reata trial in FA. During the year she was awarded a grant from Ataxia UK to be the main site of the DRPLA natural history study.

Due to Covid-19 all London Ataxia clinic appointments were changed to phone clinics with Prof Paola Giunti and the Ataxia Nurse Suzanne Booth. Ataxia UK has disseminated a feedback form to patients of the phone clinic to monitor and improve the service; 45 responses have been received. Overall, the satisfaction was high, with the average score being 8 out of a maximum score of 10. Unsurprisingly, the most common advantage (selected by 84% of respondents) was the lack of travel and waiting time. The most common disadvantage (selected by 60% of respondents) was the lack of a physical examination with specific comments being made about a lack of visual cues such as body language hindering communication. Most respondents (74%) said that they would have preferred a face-to-face appointment.

Ataxia clinic volunteers have not been able to attend the clinic and we are trying to set up a system for them to provide support virtually.

## **Euro-ataxia**

Euro-ataxia is the federation of ataxia charities across Europe, with 22 member groups. Ataxia UK's CEO is the Secretary General and Ataxia UK's Head of Research is the Research Advisor.

Regular Board meetings have been held during the year and an online AGM and meeting of members was held in December 2020. Ataxia UK's Head of Research gave a research update of all the European projects Euro-ataxia is involved in plus new Ataxia Global initiatives.

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

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

We are members of a number of sector organisations, including Genetic Alliance UK/Rare Disease UK, the Association of Medical Research charities and Neurological Alliance and we support these organisations in the work they do. Sue Millman, CEO of Ataxia UK, is also a Trustee of Genetic Alliance UK and the Neurological Alliance to increase our engagement with these organisations.

The Genetic Alliance is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. It seeks to raise awareness of genetic conditions and improve the quality of services and information available to patients and families. It actively campaigns on issues of policy and practice to influence governments, policy makers, industry and care providers such as the National Health Service. It also coordinates Rare Disease UK (RDUK) which is the national campaign for people with rare diseases and all who support them. RDUK is working with health departments across the UK to implement the UK Strategy for Rare Diseases to ensure that patients and families living with rare conditions have equitable access to high quality services, treatment and support.

The Neurological Alliance is the only collective voice for over 80 organisations working together to make life better for millions of people in England with a neurological condition. We are also members of Scottish Neurological Alliance (the CEO joins their policy meetings) and Trustee, Carol McCudden, is on the Board of Trustees of the Wales Neurological Alliance, playing an active role in the activities of the organisation.

## **Working with government bodies and the National Health Service to influence healthcare policies of relevance to people with ataxia**

### **Covid-19**

Many people affected by ataxia were concerned at the lack of priority given to people with ataxia during the Covid-19 pandemic in being assessed as Extremely Clinically Vulnerable (ECV) thereby being advised to shield, and subsequently entitled to be in Category 4 for the vaccine. It was clear when the 'shielding letters' were originally issued, that whether people with an ataxia received a letter was very hit and miss. Very soon it was apparent that it was common across a number of neurological and rare diseases. Ataxia UK was active in support of the efforts of Rare Disease UK/Genetic Alliance UK and the Neurological Alliance who made strong representations via various routes for the situation to be rectified; we received a sympathetic reception but no positive result.

It's clear that in some areas the problem has been rectified locally for some conditions – but it was not consistent. In a Neurological Alliance survey answered by 1,672 people, 49% reported difficulty with shielding notification. In this situation we decided that Ataxia UK should support people by advising them to approach their GP to explain why their status should be changed (see above). The Association of British Neurologists then issued more specific guidance on the priority groups for vaccination for people with neurological conditions, including the ataxias. This, and the progress in rolling out the vaccine seems to have dissipated the problem.

### **Rare Disease Advisory Group (RDAG)**

Our CEO Sue Millman has been a member of the NHS England Rare Disease Advisory Group for the last four years but reached the end of her term towards the end of the year. RDAG makes recommendations to NHS England and the devolved administrations of NHS Scotland, NHS Wales and NHS Northern Ireland on developing and implementing the strategy for rare diseases and the commissioning of highly specialised services.

### **Patient and Public Voice Assurance Group (PPVAG)**

Sue Millman has also served on the PPVAG as a representative of RDAG, but this appointment has also expired. The Patient and Public Voice Assurance Group (PPVAG) works to offer strategic assurance to NHS England that effective mechanisms are in place to fully involve patients and the wider public in the development of the national specialised services portfolio. The UK Rare disease strategy implementation plan was a topic discussed this year and we were able to influence some key decisions.

### **Treatment and care aims for 2021-2022**

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

# Care and Support Services for people affected by ataxia

## Care and support service aims for 2020-21

- Develop services to meet the needs of people affected by ataxia during the Covid-19 pandemic.
- Establish the services of the InControl Project.
- Conduct a Mental Wellbeing Survey of Friends and produce a report.
- Conclude research into the financial circumstances of Friends and issue a report.
- Construct a Service Delivery Development Strategy taking account the conclusions of the two reports above.

## InControl Project

InControl is a three-year funded project from the National Lottery Community Fund. The main objectives of the project are to decrease feelings of social isolation and increase feelings of mental wellbeing for the ataxia community. This is delivered through the development of new services and volunteering opportunities for the ataxia community. Due to Covid-19 restrictions we have adapted the project to be delivered virtually, which has been welcomed by the ataxia community.

### 1. **All About Ataxia**

Quarterly two-day learning workshop for people who have recently received a diagnosis of ataxia. This is supported by volunteers, who facilitate discussion with participants. This can also be useful for people who have had their diagnosis for a longer time but are keen to find out more about ataxia.

### 2. **Branch and Support Groups**

Operating through Zoom, our volunteers have offered 59 meetings since October 2020.

### 3. **Friends Connect**

A virtual Befriending service, which has 12 ongoing relationships between volunteer and Beneficiaries.

### 4. **Media Ambassadors**

Media ambassador volunteers create blogs/vlogs/articles that highlight their experience of living with ataxia.

### 5. **Speech Therapy**

We are working with Dr Anja Lowit from Strathclyde University to run virtual speech therapy groups. This is for adults with mild/moderate speech issues, and the groups are part of a trial to establish whether the peer support methodology is beneficial. The first cohort of participants began in early March 2021.

### 6. **Volunteer Recruitment**

We have recruited an additional 40 volunteers as part of InControl through 20/21. This is supported through regular messaging on social media and in Ataxia UK magazine. Our onboarding resources and templates are produced

in line with best practice standards in volunteering.

## **7. Virtual Activities**

Our virtual activity program was launched in April 2020. We have provided games/discussion groups/exercise classes and Music groups. Through 20/21 we delivered 61 sessions, with a total of 848 participants attending.

## **Helpline**

The Helpline continues to be busy with both calls and emails. The total number of contacts to the Helpline during 2020-2021 was 1,441, including enquires by email and phone. The topics covered were very wide-ranging, with most people calling about questions on Ataxia UK and what we can offer; queries on medical issues and asking about referrals to Ataxia clinics or specific information on diagnosis, and welfare benefits were common topics. Many people were contacting Ataxia UK to get general support to live with their condition. During the year many enquiries came regarding Covid-19 and a new section of the website was created specifically in response to this demand, in addition to organising four information webinars with the London Ataxia Centre clinical team.

Many people come to Ataxia UK for help with accessing benefits or appealing decisions. Ataxia UK has continued to provide them with letters of support, explaining about ataxia and the impact it has, with some success.

Template letters were provided on the website to assist people in being placed in the correct Covid-19 vaccination priority group. This information was distributed widely to Friends and we were pleased to get some positive feedback as to the success of these letters in their requests for moving up the priority list.

During the year we were pleased to welcome 520 new people who joined Ataxia UK as Friends.

## **Other work on Care and Support Services**

### **Grants**

Ataxia UK acts as a third party for four Charitable Trusts, supporting people with ataxia to apply for grants towards mobility aids, adaptations to the home and other supportive equipment. During the year, grants have been awarded by the Headley Trust, the Florence Nightingale Aid in Sickness Trust and The Barchester Charitable Foundation. As a result of our efforts, £12,410 has been raised for people with ataxia, mostly towards purchasing wheelchairs and adaptations to wheelchairs.

Ataxia UK works alongside the Mark Dower Trust which offers a grant up to £3,000 per year to be split among awardees aged between 16-30. The aim is to help promote and encourage independence. Ataxia UK publicises the trust through social media, our e-newsletter, website and the Ataxia Magazine. Throughout FY20-21, seven people applied for the grant and have been each awarded a grant.

We are grateful to those whose generosity has made these grants possible and for enabling Ataxia UK to help support, enrich and ease the lives of people with ataxia.

### **Care and support aims for 2021-22**

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

## **Raising Awareness**

### **Awareness aims for 2020-21**

- Investigate and implement new strategies to increase the awareness of Ataxia UK in the ataxia community and encourage the sign up of new Friends.
- Consider the feasibility of campaigning and lobbying for the ataxia community.
- Continue to grow our social media audiences and increase engagement rate.
- Explore the use of paid advertising to reach targeted audiences for both awareness and fundraising.
- Review database requirements in light of expected growth, recommend and implement new solutions as required.

Due to the onset of the pandemic at the start of the financial year, we had to adjust our priorities and re-prioritise activities and resources in order to respond to the ever-changing landscape we found ourselves in.

### **Investigate and implement new strategies to increase the awareness of Ataxia UK in the ataxia community and encourage the sign up of new friends**

One of the core new approaches to raising awareness of Ataxia UK within the ataxia community this financial year has been securing the Google Grant. The Google Grant means we have access up to \$10,000 per month in search adverts shown on Google.com. Between November 2020 and March 2021, we had 5.27k impressions and 903 clicks through to the website. We hope to build on this in the coming months and better utilise this resource for awareness, new Friends and fundraising, where possible.

### **Consider the feasibility of campaigning and lobbying for the ataxia community**

The disruption of the last year caused a delay in this work which has now been merged into our Strategic Planning process.

## **Continue to grow our social media audiences and increase engagement rate**

We are seeing continual growth among our digital communication channels. In the last year our e-newsletter subscribers have increased by 32%, we've had 9% growth in Facebook followers and likes, 7% growth in Twitter followers and 30% on Instagram. On HealthUnlocked we have a 13.26% reduction in active members but the platform is still frequently used by the ataxia community.

## **Explore the use of paid advertising to reach targeted audiences for both awareness and fundraising**

Throughout FY2020-21 we have run a number of campaigns on Facebook with multiple goals including the recruitment of new regular givers, promoting will writing guides and boosting multiple posts. We will continue to explore this channel.

## **Review database requirements in light of expected growth, recommend and implement new solutions as required**

This financial year we upgraded our on-site server hosted database to the latest cloud-based version. This upgrade provides new functionality to help improve our service delivery and fundraising.

## **Awareness aims for 2021-22**

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



## Fundraising

### Fundraising aims for 2020-21

- Continue to increase the number of people who give to Ataxia UK regularly.
- Plan and deliver the bespoke Ataxia UK Challenge Event – Ataxia Classic 2020.
- Continue to establish a proactive Major Donor strategy.
- Expand support and increase income from trusts, corporates and foundations.
- Review database requirements in light of expected growth, recommend and implement new solutions if required.

As with many charities, we had to review and adapt our existing plans to respond to the pandemic. We had expected a significant impact to our income across the board. Thanks to the generosity and support of the ataxia community along with some significant donations made to a specific research stream, the year ended very strongly, and Ataxia UK is in a good position to continue supporting those affected by ataxia through these historic times.

In this financial year we received two complaints relating to our fundraising, both specifically around the time it had taken to dispatch thank you letters. We have launched a review of our acknowledgement processes and will be working towards ensuring everyone is promptly thanked for their support.

Ataxia UK has an in-house fundraising team undertaking a range of activities including direct marketing, events and community fundraising, legacy fundraising, seeking grants from trusts and foundations, and major donor fundraising. We do not utilise any professional external fundraisers. Ataxia UK is registered with the Fundraising Regulator, and we are committed to following the Regulator's Code of Practice and Fundraising Promise which set the standards for fundraising behaviours in our interactions with the public and our supporters. We have a Vulnerable Persons Fundraising Policy which sets out how we identify such potential vulnerability and how we aim to respond in such circumstances.

### Increase regular giving

We recruited 79 new regular givers this financial year and whilst this is lower than the previous year, it still represents an increase on the recruitment before we implemented this strategy and is unsurprising given the disruption of the last year.

### Plan and execute the bespoke Ataxia UK Challenge Event – Ataxia Classic 2020

Despite much uncertainty, a scaled down, Covid safe version of the Ataxia Classic 2020 was held in September 2020 and was a fantastic success. We had a great response from those brave enough to take on the challenge of the 100km and 50km Yorkshire course and we will build on this success in FY21-22.

### Continue to establish a proactive Major Donor Strategy

Due to the need to move our database online we were not able to deploy resources in this area during the last year, however this work has now resumed.

## **Expand support and increase income from trusts, corporates and foundations**

Given the pressures on Trusts and Foundations funding in 2020/21 caused by the pandemic and their shift towards supporting front-line charities during the pandemic, we were not able to expand our income from this source of fundraising during the year. However, given the expected return to normality and our development of support projects for the ataxia community in the UK, we expect income from Trusts and Foundations to rise significantly in 2021/22.

We are very grateful to all the Trusts and Foundations, large and small, who continued to support us financially during 2020/21.

## **Review database requirements in light of expected growth, recommend and implement new solutions as necessary**

This financial year we upgraded our on-site server hosted database to the latest cloud-based version. This upgrade provides new functionality to help improve our service delivery and fundraising.

## **Fundraising aims for 2021-22**

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

## Financial review – to March 2021

### Overview

2020/21 was a very challenging year financially due to the Covid-19 pandemic, but one through which the charity has come through successfully.

The Balance Sheet and Statement of Financial Activities show a substantial drop in Ataxia UKs funds, however this is due to the 3 years expenditure commitment being made for the DRPLA and NKX6-2 projects, whilst the funding will be received gradually over the 3 year period of the projects. Hence the present net liabilities on the balance sheet, a situation which will be resolved over the 3 year period. This is also the reason behind the decrease in net income for the year to -£1,103K (2019/20: £230K).

Restricted funds, of which DRPLA and NKX6-2 funds are part, have also decreased over the year for the same reason to -£960K (2020: £322K). Once the outstanding restricted funds are removed the net total is £134K. General unrestricted funds have however increased to £599K (2020: £420K). This reflects the way the nature of giving has changed during the pandemic period; specific events tend to raise restricted funds and these were replaced with the emergency appeal which created unrestricted funds. Further details of reserves are given later in this review.

### Review of income

Total income for 2020/21 was £1,906K (2019/20: £1,389K) an increase of 37%. Donation income was substantially higher than the previous year, £1,278K (2019/20: £768K) an increase of 66%. Legacy income has also increased to £189K for the year (2019/20: £149K), an increase of 3%. We remain very grateful to the Friends and supporters who remember us in this way. Income from fundraising activities decreased to £227K (2019/20: £334K) a decrease of 32%. The increase in donations and decrease in fundraising income are due as previously mentioned to the change in activity due to the Covid-19 pandemic. Childlife income remained at £63K but grants received increased from £59K to £147K. The grants received income is made up of lottery funding of the In Control project (£122k), co-funding and furlough payments (£17k), plus other welfare grants (£8k).

### Review of expenditure

Our spending on research activities increased to £2,227K (2019/20: £304K), an increase of 633%. Included within this were research grants of £1,989K (2019/20: £174K), an increase of 1,043% on prior year. Five DRPLA grants amounting to £1,775K account for the majority of this along with £105K for the NKX6-2 project. There was no further investment in the Ataxia centres during the year, and a small increase on care services to £288K (2019/20: £249K). Cost of raising awareness decreased slightly from the previous year at £109K (2019/20: £134K). Expenditure on raising funds decreased by 15% to £234K (2019/20: £276K). Governance costs increased very slightly, and there was no research conference held.

### Investment policy and performance

Our investments are, in all cases, held in the form of publicly quoted bonds and cash. There are no restrictions on the Charity's power to invest and the trustees have not adopted an ethical investment policy. Cash balances not immediately required are kept in interest bearing accounts with banks that are subject to strict

credit criteria. All investments matured during the year and with the current very low interest rates have not, as yet, been re-invested.

### **Reserves levels at year end**

The charity saw a decrease in reserve levels ending the year on -£361K (31 March 2020: £741K), due to the large negative restricted funds balance created by the DRPLA and NKX6-2 agreements.

Restricted funds were -£960K (2019/20: £322K), (detailed in Note 23) with the largest amounts received being for DRPLA and NKX6-2, but with the associated larger expenditure commitment causing the current negative balance. Ataxia UK has signed agreements in place outlining the payment structure ensuring these future commitments will be met.

Designated Funds totalled £8K (2019/20: £12.5K) representing funds held at branches and are detailed under Note 22.

General reserves of the charity as at 31 March 2021 were £590K (31 March 2020: £407K) a 45% increase. The trustees consider that it is both prudent and appropriate as part of their risk management policy to maintain a minimum level of contingency within free reserves to provide against any unforeseen changes in income and/or expenditure. The reserves policy continues to be that holding unrestricted free reserves equal to a minimum of 3 months operating costs (presently £64K per month, 2019/20: £53K per month) was an acceptable level to hold. This reflects a balance between being prudent and allowing the charity to direct as much resource as possible into research and care activities. 'Free reserves' of the charity are calculated as unrestricted funds less the net book value of tangible fixed assets, £30K (2019/20: £36K). As at 31 March 2021, free reserves totalled £560K (2019/20: £371K) equating to 8.73 months operating costs (2019/20: 7 months) and is therefore in excess of the reserves policy.

### **COVID-19/GOING CONCERN**

With the impact of the Covid-19 pandemic during the last year, the importance of having adequate reserves, as detailed above, became immediately apparent. A revised Covid-19 budget was drawn up and management accounts and cashflow have been kept under close scrutiny to ensure the ongoing viability of the charity. Covid-19 has had, and continues to have, an impact on how we raise funds but due to the generous support of the ataxia community it hasn't had a significant impact on our results to 31 March 2021. Due to the ongoing uncertainties surrounding the pandemic we are aware that this could still have an impact on the 2021/22 financial year. We will maintain the close scrutiny of management accounts and cashflow and take whatever steps necessary to ensure the continued viability of the charity.

## Statement of Trustees' Responsibilities

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

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

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

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

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

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

### Brexit

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

Covid-19

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

Approved by the trustees on 11 October 2021



Richard Brown, Co-Chair



William Littleboy, Co-Chair



Kathy Jones - Treasurer

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

### Opinion

We have audited the financial statements of Ataxia UK (the 'charity') for the year ended 31 March 2021 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 March 2021 and of its income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

### Basis for opinion

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

### Conclusions relating to going concern

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

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

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

### Other information

The other information comprises the information included in the Trustees' Report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. Our opinion on the financial statements does not

cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

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

We have nothing to report in this regard.

### **Opinions on other matters prescribed by the Companies Act 2006**

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

- the information given in the Trustees' Report which includes the Directors' Report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Directors' Report included within the Trustees' Report has been prepared in accordance with applicable legal requirements.

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

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

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

- adequate and proper accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

### **Responsibilities of Trustees**

As explained more fully in the trustees' responsibilities statement set out on page 29, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.



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

### **Auditor's responsibilities for the audit of the financial statements**

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

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. Based on our understanding of the charity and its activities, we identified that the principal risks of non-compliance with laws and regulations related to the Charities Act 2011, UK tax legislation, pensions legislation, employment regulation and health and safety regulation, anti-bribery, corruption and fraud, money laundering, non-compliance with implementation of government support schemes relating to COVID-19, and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements, such as the Companies Act 2006 and the Charities Statement of Recommended Practice.

We evaluated the trustees' and management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls) and determined that the principal risks were related to posting manual journal entries to manipulate financial performance, management bias through judgements and assumptions in significant accounting estimates, in particular in relation to use of restricted and endowment funds, and significant one-off or unusual transactions.

Our audit procedures were designed to respond to those identified risks, including non-compliance with laws and regulations (irregularities) and fraud that are material to the financial statements. Our audit procedures included but were not limited to:

- Discussing with the trustees and management their policies and procedures regarding compliance with laws and regulations;
- Communicating identified laws and regulations throughout our engagement team and remaining alert to any indications of non-compliance throughout our audit; and

- Considering the risk of acts by the charity which were contrary to applicable laws and regulations, including fraud.

Our audit procedures in relation to fraud included but were not limited to:

- Making enquiries of the trustees and management on whether they had knowledge of any actual, suspected or alleged fraud;
- Gaining an understanding of the internal controls established to mitigate risks related to fraud;
- Discussing amongst the engagement team the risks of fraud; and
- Addressing the risks of fraud through management override of controls by performing journal entry testing.

There are inherent limitations in the audit procedures described above and the primary responsibility for the prevention and detection of irregularities including fraud rests with management. As with any audit, there remained a risk of non-detection of irregularities, as these may involve collusion, forgery, intentional omissions, misrepresentations or the override of internal controls.

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

### **Use of the audit report**

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



Nicola Wakefield

(Senior Statutory Auditor)

for and on behalf of Mazars LLP

Chartered Accountants and Statutory Auditor

6 Sutton Plaza, Sutton Court Road, Sutton, Surrey, SM1 4FS

Date: 13 October 2021

## ATAXIA UK

### STATEMENT OF FINANCIAL ACTIVITIES (incorporating the income and expenditure account) (incorporating the results of the Charity's branches) for the year ended 31st March 2021

	Notes	Unrestricted funds £	Restricted funds £	Total 2021 £	Total 2020 £
<b>Income</b>					
Donations and legacies	3	821,662	872,146	1,693,808	1,251,385
Charitable activities	4	8,888	201,303	210,191	134,448
Investments	5	1,505	-	1,505	2,905
<b>Total income</b>		<b>832,055</b>	<b>1,073,449</b>	<b>1,905,504</b>	<b>1,388,738</b>
<b>Expenditure on:</b>					
Raising funds	6	(233,384)	(918)	(234,302)	(275,529)
Charitable activities	7	(399,810)	(2,372,844)	(2,772,654)	(881,415)
<b>Total expenditure</b>		<b>(633,194)</b>	<b>(2,373,762)</b>	<b>(3,006,956)</b>	<b>(1,156,944)</b>
Net losses on investments		(1,076)	-	(1,076)	(1,657)
Net income/(expenditure)		197,785	(1,300,313)	(1,102,528)	230,137
Transfer from Unrestricted to Restricted		(18,646)	18,646	-	-
Net movement in funds		179,139	(1,281,667)	(1,102,528)	230,137
Total funds brought forward		419,504	321,680	741,184	511,047
<b>Total funds carried forward</b>		<b>598,643</b>	<b>(959,987)</b>	<b>(361,344)</b>	<b>741,184</b>

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

All recognised gains and losses are included in the SOFA.

The accompanying pages form part of these financial statements.

## ATAXIA UK

### STATEMENT OF FINANCIAL ACTIVITIES

(incorporating the income and expenditure account)

(incorporating the results of the Charity's branches)

**for the year ended 31st March 2020**

	Unrestricted funds	Restricted funds	Total 2020
	£	£	£
<b>Income</b>			
Donations and legacies	748,628	502,757	1,251,385
Charitable activities	13,321	121,127	134,448
Investments	2,905	-	2,905
<b>Total income</b>	<b>764,854</b>	<b>623,884</b>	<b>1,388,738</b>
<b>Expenditure on:</b>			
Raising funds	(253,027)	(22,502)	(275,529)
Charitable activities	(459,547)	(421,868)	(881,415)
<b>Total expenditure</b>	<b>(712,574)</b>	<b>(444,370)</b>	<b>(1,156,944)</b>
Net losses on investments	(1,657)	-	(1,657)
Net income	50,623	179,514	230,137
Transfer from Unrestricted to Restricted	(40,613)	40,613	-
Net movement in funds	10,010	220,127	230,137
Total funds brought forward	409,494	101,553	511,047
<b>Total funds carried forward</b>	<b>419,504</b>	<b>321,680</b>	<b>741,184</b>

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

All recognised gains and losses are included in the SOFA.

The accompanying pages form part of these financial statements.

**ATAXIA UK**  
**BALANCE SHEET**  
**As at 31st March 2021**

		2021		2020	
	Notes	£	£	£	£
<b>Fixed assets</b>					
Tangible assets	13	29,946		35,770	
Investments	14	<u>-</u>		<u>161,387</u>	
			<b>29,946</b>		<b>197,157</b>
<b>Current assets</b>					
Stock	15	6,218		6,155	
Debtors	16	212,094		316,434	
Cash at bank and in hand	17	<u>1,617,472</u>		<u>578,901</u>	
		1,835,784		901,490	
Creditors: amounts falling due within one year	18	<u>(993,083)</u>		<u>(303,463)</u>	
<b>Net current assets</b>			<u><b>842,701</b></u>		<u><b>598,027</b></u>
<b>Total net assets less current liabilities</b>			<b>872,647</b>		<b>795,184</b>
Creditors: amounts falling due after more than one year	19	<u>(1,233,991)</u>		<u>(54,000)</u>	
<b>Total net (liabilities)/assets</b>	20		<u><b>(361,344)</b></u>		<u><b>741,184</b></u>
<b>Accumulated funds</b>					
Unrestricted funds					
General funds	21		590,306		406,974
Designated funds	22		<u>8,337</u>		<u>12,530</u>
			<b>598,643</b>		<b>419,504</b>
Restricted funds	23		<u>(959,987)</u>		<u>321,680</u>
<b>Total funds</b>			<u><b>(361,344)</b></u>		<u><b>741,184</b></u>

These accounts have been prepared in accordance with Section 398 of The Companies Act 2006 and Section 138 of The Charities Act 2011. These accounts are prepared in accordance with special provisions of part 15 of The Companies Act relating to small companies and constitute the annual accounts required by The Companies Act 2006.


The financial statements were approved by the Trustees on 11 October 2021 and signed on their behalf by:



Richard Brown, Co-Chair



William Littleboy, Co-Chair



Kathy Jones - Treasurer

The accompanying pages form part of these financial statements.

Charity Number: 1102391

Company Number : 04974832

**ATAXIA UK**  
**Statement of Cash Flows**  
**For the year ended 31 March 2021**

	2021	2020
	£	£
<b>Cash generated from operating activities:</b>		
<b>Net cash provided by operating activities</b>	879,388	351,026
<b>Cash flows from investing activities:</b>		
Dividends and interest from investments	1,505	2,905
Purchase of property, plant and equipment net of sales	(2,797)	(33,085)
Proceeds from sale of investments	160,475	19,676
<b>Net cash provided/(used in) by investing activities</b>	159,183	(10,504)
<b>Net increase in cash:</b>	1,038,571	340,522
Cash at bank and in hand less overdrafts at the beginning of the year	578,901	238,379
Change in cash and cash equivalents	1,038,571	340,522
Cash at bank and in hand less overdrafts at the end of the year	1,617,472	578,901
<b>Reconciliation of net income to net cash flow from operating activities</b>		
	2021	2020
	£	£
Net (expenditure)/income	(1,102,528)	230,137
Adjustments for:		
Depreciation charges	8,457	14,879
Net losses on investments	1,076	1,657
Dividends and interest from investments	(1,505)	(2,905)
(Increase)/Decrease in stocks	(63)	252
Decrease in debtors	104,340	48,500
Increase in creditors	1,869,611	58,506
<b>Net cash provided by operating activities</b>	879,388	351,026
<b>Analysis of cash at bank and in hand less overdrafts</b>		
	2021	2020
	£	£
Cash at bank and in hand	1,617,472	578,901
	1,617,472	578,901

# NOTES TO THE FINANCIAL STATEMENTS

## 1. Charity Information

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

## 2. Principal Accounting Policies

- a. **Basis of Preparation:** The financial statements have been prepared in accordance with the Statement of Recommended Practice (SORP) applicable to charities preparing their accounts in accordance with the Financial Reporting Standard (FRS) applicable in the UK and Republic of Ireland (FRS 102), the Charities SORP (FRS 102) the Financial Reporting Standard applicable in the UK and Republic of Ireland and the Companies Act 2006. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).
- b. **Going Concern:** During the 2020/21 financial year, we had a net positive movement in unrestricted funds and a net negative movement in restricted funds due to timing issues of funding for DRPLA and NKX6-2 research grants. This has resulted in a net liabilities position on the balance sheet. The funding for these will be received over the next 3 years with the initial payment already received, see note 23 (note i DRPLA and note ii NKX6-2) below for further details. Covid-19 has continued to impact how we raise funds but due to the generous support of the ataxia community it hasn't had a significant impact on our results to 31 March 2021. Due to the ongoing uncertainties surrounding the pandemic we are aware that this could still have an impact on the 2021/22 financial year. We continue to take steps to ensure the continued viability of the charity. The cashflow was reviewed regularly to ensure that actual unrestricted cash was going to be adequate at all times. The Finance Committee meet regularly to monitor the situation and the fundraising department are continuing to pursue other ways to raise funds through virtual events to safeguard income. A budget and associated cash flow have been drawn up for the next financial year 2021/22 to maintain robust future forecasting. We continued to have the office closed during 2020/21 with only a minimal number of staff going into the office. Our systems have allowed remote working with minimal disruption. The Trustees feel there are adequate resources to continue operating for the foreseeable future. The Trustees feel that there are no material uncertainties about the charitable company's ability to continue as a going concern. Accordingly, we continue to adopt the going concern basis in preparing this annual report and financial statements.

- c. **Childlife:** The Charity is a member of a consortium, with three other charities, called Childlife, through which the member charities are able to collectively raise funds for their respective causes through the operation of a combined payroll deduction scheme and donor development. In accordance with FRS 102 Childlife is not consolidated in the financial statements of Ataxia UK as Ataxia is not part of a group that is required to prepare consolidated financial statements. As a grant funder of Ataxia UK, Childlife is treated on the same basis as any other funder and trading transactions between Ataxia UK and Childlife are reflected as such in these financial statements.
- d. **Tangible Fixed Assets:** Tangible fixed assets costing more than £1,000 are capitalised and depreciated over their anticipated useful life. Office equipment is depreciated at the rate of 25% per annum on a straight-line basis.
- e. **Intangible Fixed Assets:** Intangible fixed assets costing more than £500 are capitalised and amortised at the rate of 25% per annum on a straight-line basis.
- f. **Investments:** Investments are shown at market value and represent funds not immediately required for charitable expenditure and can be realised at short notice for such expenditure should such funds be required. Gains and losses on investments are shown in the Statement of Financial Activities. Realised gains and losses on investments are calculated as all the differences between sales proceeds and opening market value, or value at purchase date if later. Unrealised gains and losses are calculated as the difference between the market value at the year end and the opening market value, or value at purchase date if later.
- g. **Income Recognition:** Income is recognised on an accrual basis, with the exception of donations and some fundraising receipts, which are on a cash basis. Deferred income represents fundraising income received for future events and is released to income in the period in which the event takes place. All income previously deferred has been released during the current year.
- h. **Legacy Recognition:** In accordance with SORP (FRS 102), legacies are recognised when they are probable and measurable.
- i. **Income tax recoverable:** Income tax recoverable has been added to the relevant income source to which it applied.
- j. **Apportionment of Staff Costs and Overheads:** Staff costs and related office overheads have been apportioned between direct charitable expenditure, fundraising, raising awareness and governance according to the time spent by staff on each of these activities. The costs of raising awareness of the issues surrounding ataxia have been separately identified to reflect the increasing importance of this activity.



- k. **Unrestricted funds:** Unrestricted funds are funds that can be used in accordance with the charitable objects at the discretion of the Trustees.
- l. **Designated funds:** Designated funds represent amounts held by Ataxia branches.
- m. **Restricted funds:** Restricted funds represent funds donated and raised by supporters of the Charity, which have been given for particular research or care services projects, together with grants received in respect of specific projects. The movements on the restricted reserves during the year are shown in note 23.
- n. **Branches:** The accounts of the Charity's branches have been consolidated into these accounts.
- o. **Operating Lease Rentals:** Rentals applicable to operating leases are charged to the Statement of Financial Activities as they become due.
- p. **Contractual Commitments:** Formal and unconditional commitments to research expenditure and other grants at the balance sheet date are included within creditors, in accordance with SORP (FRS 102). Commitments to such projects that have been agreed by the Trustees but have not yet been confirmed to the recipient, and therefore do not yet represent contractual commitments, are shown as designated funds, except a) to the extent that equivalent reserves are maintained in restricted funds and b) to the extent that they are funded by commitments from other bodies. The movements on general funds and designated funds are shown in notes 21 and 22.
- q. **Pensions:** The Charity contributes to certain employees' individual personal pension schemes, the assets of which are held separately from those of the Charity in a separately administered fund. Contributions to the scheme are charged to the Statement of Financial Activities as they fall due.
- r. **Taxation:** As a registered charity, the Charity is exempt from taxation under section 505 (1) of the Income & Corporation Taxes Act 1988.
- s. **Governance Costs:** Governance costs include audit, legal and professional fees and the apportionment of staff costs, and office overheads costs according to the amount of staff time spent on this activity.
- t. **Goods and Services in Kind:** Donated Services and equipment are included as income and related expenditure where the value to the charity can be reasonably quantified. The value of services provided by volunteers has not been included.

**Note 3 Donations and Legacies Income**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Donations	1,278,323	768,141
Legacies	188,897	149,460
Fundraising activities	226,588	333,784
	<u>1,693,808</u>	<u>1,251,385</u>

**Note 4 Charitable Activities Income**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Childlife	62,500	63,000
Annual conference	909	12,821
Grants receivable	146,782	58,627
	<u>210,191</u>	<u>134,448</u>

**Note 5 Investment Income**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Income on investment portfolio	114	2,891
Interest	1,391	14
	<u>1,505</u>	<u>2,905</u>

**Note 6 Raising Funds Expenditure**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Costs of generating funds	234,161	275,279
Investment managers fees	141	250
	<u>234,302</u>	<u>275,529</u>

**Note 7 Charitable Activities Expenditure**

	Direct Costs £	Grants £	Support Costs £	2021 Total £	2020 Total £
Research activities	139,163	1,989,441	97,919	2,226,523	303,700
Ataxia centres	-	0	-	0	435
Care services	153,077	6,410	128,066	287,553	249,241
<b>Total</b>	<b>292,240</b>	<b>1,995,851</b>	<b>225,985</b>	<b>2,514,076</b>	<b>553,376</b>
Generating funds	-	-	90,212	90,212	111,136
Research conference	-	-	-	0	29,133
Raising awareness	35,062	-	74,111	109,173	133,871
Governance	-	-	59,193	59,193	53,899
<b>Total charitable activities</b>	<b>327,302</b>	<b>1,995,851</b>	<b>449,501</b>	<b>2,772,654</b>	<b>881,415</b>

	2021 £	2020 £
Total support costs		
Staff costs	316,885	311,038
Office costs	124,159	100,955
Depreciation	8,457	14,879
	<u>449,501</u>	<u>426,872</u>

**Note 8 : Research Grants**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
<b>Research grants made in year comprise</b>		
Funding of an Ataxia Nurse for half a day a week to support the Ataxia clinic in Sheffield		10,000
Non-invasive transcranial cerebellar stimulation: double blind, randomised, sham-controlled study followed by an open label extension phase		25,000
Preclinical development of an amelioration therapy for Dentatorubro-Pallidolusian Atrophy		100,000
Preliminary investigation into impacts of normobaric hypoxia on neuromuscular and cardiac function in FA		5,000
Awarded various travel grants to researchers from the Kennedy Award		1,800
Investigating the role of bioactive sphingolipids in Friedreich's ataxia (FRDA)		26,471
Awarded various travel grants to researchers from the CA Fund		1,000
ARCA Global Conference		3,825
SCA Global Conference		2,000
University claimed less than amount of grant awarded		(1,073)
Development of a selective high throughout screening assay for the discovery of compounds replacing frataxin in FA.	26,000	
Etravine as a potential therapeutic for Friedreich ataxia	20,000	
PROSPAX: an integrated multimodal progression chart in spastic ataxias	5,000	
An Online Knowledge Translation Platform for Ataxia Research: Responding to Community Feedback from Stakeholders	1,200	
Investigating the use of the Ataxia Instrumented Measure – Spoon (AIM-S) in measuring upper limb function in Dentatorubral-pallidolusian atrophy (DRPLA).	71,311	
Comprehensive Biomarker Characterisation in Dentatorubral-Pallidolusian Atrophy (CBC-DRPLA)	1,033,858	
London Paediatric Centre	23,000	
DNA repair pathways underlie common genetic mechanisms that modulate onset in spinocerebellar ataxias and other inherited ataxias	2,100	
DRPLA: Biomarkers, Somatic Instability and creating a DRPLA cell line resource	492,318	
Dr Lim - Generating new Friedreich's Ataxia animal models for validating HSV-1 FXN gene therapy in Dorsal Root Ganglia'	30,000	
SCA Global Flash Talk	352	
'NKX6-2 Related Spastic Ataxia and Leukodystrophy: Natural history, biomarkers and the potential of gene transfer methods	69,988	
A joint model of online SLT intervention and peer support to enhance communication effectiveness and participation in people with progressive ataxia.'	5,977	
The DRPLA Natural History and Biomarker Study'	126,084	
Development of a PRIME editing therapy for Ataxia-8 due to the c.121 A to T point mutation (NKX6-2)	34,600	
Scope of work for the DRPLA Natural History Study	51,131	
ARCA Global Conference	380	
University claimed less than amount of grant awarded	(3,858)	
	<u>1,989,441</u>	<u>174,023</u>

**Note 9 : Staff Costs**

	<b>2021</b>	<b>2020</b>
	£	£
<b>Staff costs comprised:</b>		
Salaries	651,929	493,293
Social security contributions	57,934	47,170
Pensions	30,021	23,662
	<u>739,884</u>	<u>564,125</u>

The average number of employees during the year was 18 (2020: 14) with all employee time involved in providing either support to the governance of the charity or support services to charitable activities.

The senior management team consist of the Chief Executive and the heads of Development, Fundraising, Research and Finance. The total employee benefits of the senior management team were £291,107 (2020: £263,895).

The following number of staff members received emoluments in the year:	2021	2020
£70,000 - £79,999		1
£80,000 - £89,999	1	

The pension contributions in respect of the above named individual in the year totalled £3,700 (2020: £3,444).

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

**Note 10 : Pension Schemes**

All permanent members of staff were eligible to receive payment of 5% of their salary paid into a stakeholder personal plan. The pension premiums payable during the year were £30,021 (2020: £23,662). There was no outstanding balance (2020: £0) at the year end.

**Note 11 : Trustees**

Certain trustees carry out duties that would otherwise be undertaken by paid staff. They receive no remuneration but, along with the other trustees, may claim reimbursement of out of pocket expenses. During the year, all board meetings were held remotely and as a result no trustee expenses were incurred. 0 trustees (2020: 14) claimed expenses totalling £0 (2020: £7,714 ).

**Note 12 : Net (expenditure)/income is stated after charging:**

	<b>2021</b>	<b>2020</b>
	£	£
Auditor's remuneration	15,545	7,365
Legal Fees	3,061	-
Payroll costs and accountancy services	8,223	1,440
Depreciation	8,457	14,879
Operating lease costs	1,000	2,088

**Note 13 : Tangible Fixed Assets**

	Building Works £	Other Assets £	Total £
<b>COST</b>			
As at 1st April 2020	35,007	66,578	101,585
Additions	0	3,055	3,055
Disposals	0	(258)	(258)
As at 31 March 2021	<u>35,007</u>	<u>69,375</u>	<u>104,382</u>
<b>DEPRECIATION</b>			
As at 1st April 2020	30,481	35,334	65,815
Charge for year	1,358	7,099	8,457
Disposals	0	164	164
As at 31 March 2021	<u>31,839</u>	<u>42,597</u>	<u>74,436</u>
<b>NET BOOK VALUE</b>			
As at 31 March 2021	<u>3,168</u>	<u>26,778</u>	<u>29,946</u>
As at 1st April 2020	<u>4,526</u>	<u>31,244</u>	<u>35,770</u>

Included within the net book value of the 'Other Assets' is an amount of £4,000 (£5,960 in 2020) relating to items acquired on Finance Lease/Hire purchase.

**Note 14 : Investments**

	2021 £	2020 £
Market value at 1 April	161,387	182,720
Disposals	(169,390)	(20,952)
Unrealised gain/(loss)	<u>8,003</u>	<u>(381)</u>
Market value at 31 March	<u>-</u>	<u>161,387</u>
Cost of investments at 31 March	-	169,390
Total unrealised loss	<u>-</u>	<u>(8,003)</u>
Market value at 31 March	<u>-</u>	<u>161,387</u>
<b>Investments consist of:</b>		
2% UK Gilt Snr-Reg	-	75,438
1.5% UK Gilt Snr-Reg-S	-	85,949
	<u>-</u>	<u>161,387</u>

**Note 15 : Stock**

	<b>2021</b>	<b>2020</b>
	£	£
Stock for resale	6,218	6,155

**Note 16 : Debtors Under 1 Year**

	<b>2021</b>	<b>2020</b>
	£	£
Income tax recoverable	113,383	140,858
Other debtors	71,525	145,000
Prepayments	27,186	30,576
	<u>212,094</u>	<u>316,434</u>

**Note 17 : Cash at bank and in hand**

The Trustees maintain a policy that all cash balances are held in interest bearing accounts with the exception of a nominal daily float held on current account. Interest receivable is disclosed in note 5.

**Note 18 : Creditors: amounts falling due within one year**

	<b>2021</b>	<b>2020</b>
	£	£
Other creditors	9,919	41,315
PAYE/NI	16,252	14,320
Deferred income	10,185	18,006
Accruals	45,593	23,772
Research grants	911,134	206,050
	<u>993,083</u>	<u>303,463</u>

**Note 19 : Creditors: Amounts falling due after one year**

	<b>2021</b>	<b>2020</b>
	£	£
Research grants	1,230,991	50,000
Misc creditors	3,000	4,000
	<u>1,233,991</u>	<u>54,000</u>

**Note 20 : Analysis of net assets between funds**

	Restricted Funds £	Designated Funds £	General Funds £	Total 2021 £	Total 2020 £
Fixed assets	-	-	29,946	29,946	35,770
Investments	-	-	-	-	161,387
Stock	-	-	6,218	6,218	6,155
Debtors	-	-	212,094	212,094	316,434
Cash at bank and in hand	1,182,138	8,337	426,997	1,617,472	578,901
Creditors	(2,142,125)	-	(84,949)	(2,227,074)	(357,463)
	<u>(959,987)</u>	<u>8,337</u>	<u>590,306</u>	<u>(361,344)</u>	<u>741,184</u>

**Note 21 : Unrestricted Funds**

	General Funds	Designated Funds	Total
Balance as at 1 April 2020	406,974	12,530	419,504
Net increase/(decrease) in funds during the year	201,978	(4,193)	197,785
Transfers	(18,646)	-	(18,646)
Balance as at 31 March 2021	<u>590,306</u>	<u>8,337</u>	<u>598,643</u>

**Note 22 : Designated Funds**

	Opening Balance	Net Movement	Transfers	Closing Balance
Funds held in branches	12,530	(4,193)	-	8,337
	<u>12,530</u>	<u>(4,193)</u>	<u>-</u>	<u>8,337</u>

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



**Note 23 : Restricted Funds**

	At 1 April 2020	Income	Expenditure	Transfers	At 31 March 2021
	£	£	£	£	£
General Research	-	45,764	50,009	4,245	-
Friedreich's ataxia research	68,306	10,824	94,885	15,754	(1)
Cerebellar ataxia research	-	109	22	-	87
Young Person's projects	7,959	-	-	-	7,959
Jerry Farr travel fund	671	-	-	-	671
Welfare	634	3,000	3,000	-	634
Nicotinamide	-	1,181	236	(945)	-
Goods and Services Received	-	918	918	-	-
Helpline	-	70,200	38,330	-	31,870
Misc Grants	450	352	352	-	450
Childlife	-	62,500	62,500	-	-
Exeter	582	-	-	-	582
Awareness	7,049	-	2,154	-	4,895
Kennedy Award	31,948	-	15,000	-	16,948
Mark Dower Trust	1,241	3,495	3,410	-	1,326
Spinocerebellar Ataxia Research Project	-	1,096	220	(876)	(0)
London Pediatric Centre	15,000	-	15,000	-	-
DRPLA Research	-	727,252	1,774,703	-	(1,047,451)
In Control Project	16,590	87,706	99,512	-	4,784
Ataxia Centres	59,039	-	8,000	-	51,039
DRPLA Department	112,211	-	100,674	-	11,537
Scotland	-	1,000	200	-	800
NXK6-2	-	57,806	104,588	-	(46,782)
AOA2	-	245	49	469	665
	321,680	1,073,449	2,373,762	18,646	(959,987)

**a) General Research:** Funds provided for general research into ataxia.

**b) Friedreich's ataxia research:** Funds provided by donors specifically for research on Friedreich's ataxia

**c) Cerebellar ataxia research:** Funds provided by donors specifically for research on cerebellar ataxia

**d) Young Person's projects:** Funds provided by donors to develop materials to help young people after diagnosis.

**e) Jerry Farr travel fund:** Funds given by friends of Jerry Farr to help young people after diagnosis

**f) Welfare:** Funds provided for welfare grants.

**g) Nicotinamide:** Funds restricted to research trial of nicotinamide in Friedreich's ataxia.

**h) Goods and Services Received:** Goods and Services received free of charge in respect of design and software services for Ataxia's website.

**i) Helpline:** Funds to support the helpline.

**j) Miscellaneous Grants:** Funds provided for general grants.

**k) Childlife:** Funds given by Childlife to promote the relief of children who are in need. The auditors have agreed that the income received from Childlife has been spent in accordance with the terms of and conditions of the grant.

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

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

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

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

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

**q) London Paediatric Centre:** Funds to assist set-up of London paediatric centre

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

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

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

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

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

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

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

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

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

**Note 24 : Capital Commitments**

There are no capital commitments at 31 March 2021 (2020: Nil)

**Note 25 : Lease Commitments**

**At 31 March 2021 the charity had future minimum lease payments under non-cancellable operating leases as follows:**

	2021		2020	
	Land & buildings	Other	Land & buildings	Other
Payments due:				
Within one year	49,604	1,608	49,604	2,568
Within two to five years	29,302	4,825	78,906	6,433
	<u>78,906</u>	<u>6,433</u>	<u>128,510</u>	<u>9,001</u>

**Note 26 : Associated Organisations**

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

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