



Annual Report & Financial Statements
Year Ending 31 March 2019

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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Chairman's Statement

Ataxia is estimated to affect over 10,000 people in the United Kingdom. Yet, there is no treatment or cure for the condition. Ataxia UK is working very hard to change that. Families affected by ataxia must adjust to drastic changes in lifestyle and physical ability. This progressively debilitating condition causes decline in a person's ability to walk, talk, coordinate movement, swallow and use fine motor skills. Ataxia UK provides support to the ataxia community and in the coming year, we hope to strengthen our services for those who need them most.

I am proud that Ataxia UK works closely with the world's leading ataxia organisations, researchers, scientists, health professionals and pharmaceutical companies: promoting the exchange of ideas and innovation in its mission to find treatments and cures. We are on the steering committee of the SCA (spinocerebellar ataxia) Global Project and the ARCA Global (recessive ataxias) Project, as well as partners with FARA (Friedreich's Ataxia Research Alliance) in the United States in an exciting step forward: launching the Friedreich's Ataxia Global Patient Registry in 2020. In July 2018, we launched our new Research Strategy that keeps us focused on how we will develop our work in the coming years.

During the year we have prioritised the development of services for children with ataxia, with plans to open at least one Children's Specialist Ataxia Centre. Several paediatric consultants are assisting us, and we intend to open a Centre during 2019-20. £25,000 was raised by our supporters through 'The Big Give' Christmas Appeal in December 2018, which will provide the 'seed funding' to these NHS services.

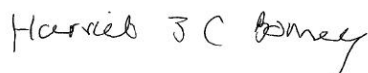
In 2018, we incorporated a new Fundraising Strategy that aims to maximise our income potential in the coming years. I want to especially thank our inspiring and hardworking fundraising supporters and volunteers, without whom we would not exist and whose dedication is both humbling and exciting.

Awareness of ataxia remains too low and so changing this is important for the charity. In 2018, with the support of global media agency TBWA, celebrities and Friends of Ataxia UK, we mounted a social media campaign entitled 'Fractured Lives.' This was very successful and I would like to thank everyone who took part.

In the summer we also held a very well attended conference in Stirling, Scotland, and our Annual Conference was held in the East Midlands. It is always good to see so many from the ataxia community come together at these occasions each year.

It's wonderful to see what can happen when our supporters help support the ataxia community. I am delighted to look back at what we've achieved together and reflect on what we can achieve as, together, we move closer to making our vision for a world free from the devastating effects of ataxia a reality. Together, we'll continue to be there for people with ataxia, offering friendship and support when it's needed most. Together, we will find treatments and cures for this rare condition. Together, we will beat ataxia.

To our donors, volunteers, supporters, researchers and clinicians, patrons, trustees, ambassadors and staff: thank you. Thank you for giving hope to the ataxia community and taking action towards finding a cure.



Dr Harriet Bonney, Chairman of the Board of Trustees for Ataxia UK

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 2018-19 are:

Honorary Officers

Dr Harriet Bonney, Chairman (Elected as Chairman 14 October 2012)

Howard Marshall, Vice Chairman (Retired as Vice-Chairman 24 November 2018)

Richard Brown, Vice Chairman (Elected as Vice-Chairman 24 November 2018)

Russell Brown, Honorary Treasurer (Retired as Honorary Treasurer 24 November 2018)

Kathy Jones, Honorary Treasurer (Elected as Honorary Treasurer 24 November 2018)

Trustees

John Abbott

Kathy Jones (Co-opted 24 November 2018)

Dr Harriet Bonney

Grace Kay (Retired 7 October 2018)

Russell Brown

Dr Anthony Kaye

Andrew Downie

William Littleboy (Co-opted 24 November 2018)

Graham Fryatt (resigned 7 October 2018)

Philip Griffiths

Alison Love

Prof Barry Hunt

Howard Marshall

Richard Brown

Robert Perkins (Elected 7 October 2018)

Susan Millman is the company secretary and CEO.

Ataxia UK uses the following professional advisors:

Auditors

Mazars LLP
Times House, Throwley Way
Sutton, SM1 4JQ

HR Consultants

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

Bankers

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

Solicitors

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

Structure, Governance & Management

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

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

Under the articles of association of the charity, trustees are nominated for election by the Friends of the charity, comprising of 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 receive briefing upon joining the Board. An induction day was introduced in 2009.

The Annual General Meeting of the charity took place on 7 October 2018.

New trustees are invited to an induction session with the CEO and the Chairman 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 of the Chair, Treasurer, and one other committee member, and meets during the budget setting process to review salary grading levels, London weighting, increment payments and inflation rises. The remuneration committee is provided with comparative benchmark information relating 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 2018 Regional Conference was held in Stirling, Scotland, and the Annual National Conference in the East Midlands.

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 19 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 Peter Maycox
Dr Patrick Lewis
Dr Claire Kelly
Dr Marija Sajic

Professor Zofia Chrzanowska-Lightowlers
Dr Franziska Denk
Dr Michele Lufino

During this year Dr Monica Busse-Morris and Dr Patrick Harrison stood down from the committee and we are extremely grateful for their support over the years.

The committee included the following lay members during the year:
Rosemary Homayoun, John Abbott and Pit Rink.

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

Employees

During 2018-2019 the average number of full time equivalent employees during the year was 13 (with all employee time involved in providing either support to the governance of the Charity or support services to charitable activities). IT support and HR 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 2018-2019 we have used a number of interns and volunteers at our central office. They have provided invaluable assistance in our day-to-

day work, contributing towards our projects, such as the *Ataxia Magazine*, as well as assisting with manning our Helpline and training as Ataxia Ambassadors to raise awareness of ataxia.

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. You can read about them below.

Additionally, the Ataxia UK accredited Specialist Ataxia Centre in London has been attended by volunteers throughout the year. Their role is to provide emotional and practical support to people with ataxia and their families visiting the centres. 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.

Risk Management

As in previous years, we actively managed the risks to the charity, focusing on the most serious. We have maintained a register of our controls and activities to mitigate risk throughout the year. The most serious risks we face are:

- Loss of key skills from the Board – after six years' service on the Board, last year our Treasurer Russell Brown indicated his intention to resign when a replacement could be found. We have been fortunate in identifying a replacement Treasurer, Kathy Jones, who was co-opted onto the Board in November 2018.
- Absence of funds to invest in research – this is being addressed by the implementation of our Fundraising Strategy which seeks to double our income in the next five years and will increase the resources available for fundraising.
- Prolonged absence/loss of key staff – we insure against the prolonged absence of the CEO.

Objectives & Activities

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

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

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

People with ataxia want a quick diagnosis that's delivered in a supportive and sympathetic manner, with the choices of care explained and assistance in accessing them available, if required. They want information about their condition and medical care to enable the management of symptoms. Ataxia UK seeks to improve treatments and care by researching the experiences and requirements of people with ataxia and by developing replicable model solutions to the problems they experience. Our most significant work in this area is the development of Ataxia UK's accredited Specialist Ataxia Centres: specialist clinics within the NHS which 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*, Helpline services, conferences and workshops on topics of interest, and our network of Branches and Support Groups.

Raising awareness of ataxia is fundamental to supporting people with ataxia in every way. An understanding of the condition is wanting 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 what we are trying to achieve, the more likely they are to donate to the charity. More can be read about our raising awareness events below.

Our Strategic Plan 2017-2020 has four major ambitions:

- **By 2020 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; Raising Awareness, and Fundraising.

Achievements & Performance

Research aims for 2018-19

- Maximise impact of research activities
- Launch a new Research Strategy
- Develop and implement enhanced pharmaceutical strategy
- Address some of the symptoms experienced by people with ataxia highlighted in the strategic review (by developing collaborations with other medical charities)

Maximise impact of research activities

One way to maximise the impact of research activities is to help researchers to secure large grants, allowing them to continue research projects that have previously been supported by Ataxia UK. To this end, Ataxia UK has been supporting UK researchers in seeking a grant to fund the UK arm of the large multicentre nicotinamide trial in Friedreich's ataxia (FA), as other European sites are in receipt of EU funding via a scheme for which the UK is not eligible. This is a large grant and took a long time to obtain. It is hoped that patient recruitment for this trial will start in the autumn. Ataxia UK will have a large role in this, as a large number of participants are needed. Ataxia UK Trustee Prof Barry Hunt is on the Steering Committee.

Another way that Ataxia UK is maximising the impact of research is their involvement in global research initiatives, a few of which have been developed this year. Ataxia UK is heavily involved in all of the following initiatives.

SCA Global project: This project is led by a neurologist in Bonn, Germany. It aims to create a global registry of patients with dominantly inherited ataxias (SCA: spinocerebellar ataxia and DRPLA: dentatorubral-pallidoluysian atrophy). Ataxia experts from around the world will collect standardised clinical information on ataxia patients, resulting in a large cohort of patients from hospitals around the world who could be involved in future trials. This is particularly important for some of the rarer ataxias, where there may be only a handful of people in each country. Ataxia UK's Head of Research Dr Julie Greenfield was invited to be one of two patient group representatives on the Steering Committee. One of the first tasks was to organise the first SCA Global conference, which took place in Las Vegas in March. It was a huge success, with a large number of researchers attending and becoming engaged in the initiative. There was also interest from pharmaceutical companies, who see the value of this worldwide collaboration.

ARCA Global project: This is a similar initiative to SCA Global, but covers the recessively inherited ataxias. It has been launched by an ataxia specialist in Tübingen, Germany. Dr Julie Greenfield was invited to be the patient representative on this committee and the venture was officially launched at the SCA Global conference in Las Vegas.

FA Global Patient Registry: Ataxia UK trustees have agreed to partner with FARA-US to lead this new project. We hope it will be launched during the year. The project involves people with Friedreich's ataxia adding their information on an online registry, and should be a powerful resource for trials.

Having such global initiatives collectively covering all the inherited ataxias is incredibly helpful in preparing clinical trials, thus allowing us to maximise the impact of translational or clinical research.

Launch a new Research Strategy

The new Research Strategy was successfully launched at a Scientific Seminar event on 4 July 2018. Dr Mark Pook gave an update on FA research and Prof Barry Hunt, Ataxia UK Trustee, gave an update on Ataxia UK's research achievements. The Research Strategy has been disseminated via the website and at numerous conferences and events throughout the year.

Develop and implement enhanced pharma strategy

Ataxia UK held two meetings of the Pharma Strategy Group in June and December and mostly discussed the FA Global Registry governance. We also produced a new leaflet aimed at companies to be distributed at meetings etc. It is on our Partners section of our website and was included in the Friends' e-newsletter.

Recognising the importance of working with pharmaceutical and biotech companies, Ataxia UK has been working more at enhancing partnerships with pharma, which has involved us influencing and supporting their work on ataxia and resulted in grants and sponsorships, demonstrating the importance of our work.

This year we have been working with Biomarin, a company with an interest in FA. We gave a presentation at their London office, and two representatives from Biomarin attended the Euro-ataxia annual meeting we organised in Frankfurt in November (as well as providing sponsorship).

A new contact was made with Minoryx, a company just starting trials in FA in a number of European countries (not the UK). We have also continued to work with Pfizer on a funded FA research project. In addition, we helped another pharmaceutical company distribute a survey to people with Friedreich's ataxia, asking about preferences for different medicine formulations.

At the SCA Global conference in Las Vegas, there was an opportunity to meet many people face-to-face. There has also been a great involvement of Ataxia UK with Takeda due to the 'Value of Treatment' project (see 'Improvements in Treatment and Care').

A representative from Reata gave a presentation at the Euro-ataxia meeting in November. She was very responsive to the discussion on involving patients and patient groups in research, and was keen to involve Ataxia UK and Euro-ataxia as the programme develops, particularly in talking to regulators. In addition to Takeda, Reata has also awarded a grant to the 'Value of Treatment' project. We have also continued to work with Intrabio and are talking on a regular basis.

Address some of the symptoms experienced by people with ataxia highlighted in the strategic review

Ataxia UK has begun to address this via the research project 'Physical activities in rare neurological conditions collaboration' (PARC). The researchers involved succeeded in getting a one-year programme development grant from the National Institute for Health Research (NIHR) for a pilot study on physical activities in rare neurological conditions. The first meeting took place in October 2018 in London and was followed by one in February in Cardiff. Both meetings were attended by Dr Julie Greenfield. A survey is being developed to get the views of people with ataxia and the other rare neurological conditions on physical activities, so we can understand what people's interests are and what barriers there may be to their being physically active etc. This will be followed by a larger programme grant to develop the project further.

PARC aims to develop new ways for people living with rare conditions to be as physically active as they can and want to be. The plan is to build on a recent study which developed the supported “self- management” of physical activity for people with Huntington’s disease. In that study, people gained confidence about doing more physical activity and overcame barriers to build activity into their everyday lives. A group of clinicians, people living with rare neurological conditions and five charities supporting people with a group of rare neurological conditions will develop a new intervention and training package for health-care staff to support people with rare conditions to be more physically active.

The ataxias are one of the conditions included in this project. If the pilot works well and we are successful in getting the larger grant, this project could create a useful tool that helps people with ataxia be more physically active.

Other research activities

Ataxia UK funded research

During the year Ataxia UK awarded six new grants (three of which were from our small grants scheme of under £5,000) towards a variety of topics and types of ataxia. We held three meetings with the Scientific Advisory Committee, at which funding recommendations were made and the management of 20 ongoing research projects continued. This involved providing support to researchers where needed, evaluating annual reports and monitoring finances. A decision was made to decrease the size of grants made (from a maximum of £60-70,000 to £25-30,000), apart from in exceptional circumstances. This is more realistic in Ataxia UK’s current situation; with more financial and human resources, we could make greater and faster progress toward achieving some of these aims.

Analysis of research outcomes of Ataxia UK funded research

The impact of the research we fund has been evaluated again this year using the Researchfish online portal, and we are pleased to report very positive findings. We have now completed our fifth round of annual data collection, which shows interesting outcomes. For every £1 invested by Ataxia UK, a further £3 has been invested in ataxia research. This is encouraging, as it means the research we fund is recognised to be of a high quality and is attracting funding from other sources.

Supporting European research networks

Ataxia UK’s Head of Research Dr Julie Greenfield has continued to work as the patient group representative on the Steering Committee of the European network on SCA3 (ESMI project): attending regular teleconferences; giving a talk at the annual meeting on the Azores on the role of patient groups in research and the impact of ataxia on patients; being interviewed by the local TV and radio station. Meanwhile, Ataxia UK Trustee Prof Barry Hunt is a member of the Steering Committee of the Friedreich’s ataxia network (EFACTS project) and has attended some meetings. On behalf of Euro-ataxia, a new grant was awarded to this project (with contributions from Ataxia UK, the French charity AFAF (L’Association Française de l’Ataxie de Friedreich) and the Italian charity AISA (L’Associazione Italiana per la lotta alle Sindromi Atassiche)).

Support of researchers in recruitment of participants to studies

Having a database of people with ataxia puts Ataxia UK in a unique position to support research via the recruitment of volunteers to participate. During the year we have supported the following projects:

- Testing the effect of the drug Omaveloxolone in Friedreich’s ataxia (Reata pharmaceuticals trial in London)
- Testing the effect of the drug 'granulocyte colony stimulating factor' in FA (trial in Bristol)

- Effectiveness of a speech therapy technique called LSVT in improving communication in people with Friedreich's ataxia (around the UK)
- 100,000 Genome project (around the UK)
- Natural history study in Friedreich's ataxia (London UCL/UCLH)
- Natural history study in SCA3 (London UCL/UCLH)
- Natural history study of SCA1, SCA2, SCA6 and SCA7 (UCL/UCLH)

Raising awareness of ataxia research within the rare disease field and networking opportunities

Ataxia UK research staff have attended and given presentations at meetings and conferences, whilst ensuring costs are kept to a minimum with free passes and travel reimbursements. This has been very useful in raising the profile of ataxia and Ataxia UK, creating opportunities to establish new partnerships and encouraging further research in ataxia. As many pharmaceutical company representatives are present at these meetings, we have also been able to forge new collaborations and enhance current ones; global collaborations are important in striving to push research forwards. A list of events attended is shown below.

World Orphan drug conference, Washington, US

Awarded a free travel pass, Dr Julie Vallortigara represented Ataxia UK at the World Orphan Drug Congress in Washington DC. This was a two-day conference that had an interesting and diverse programme focusing on rare diseases and orphan drugs. Our attendance allowed us to establish new contacts.

Biomarin Staff Team Meeting, London

Ataxia UK's Head of Research Dr Julie Greenfield and Trustee Richard Brown, who has ataxia, gave a presentation and Q&A session to staff at the pharmaceutical company Biomarin's European Office in April 2018.

SCA3 European natural history project annual meeting, Azores

In May 2018, Dr Julie Greenfield attended the annual conference of this project and gave a presentation. Being on the Steering Committee of this project the costs were partly covered.

SCA global conference and National ataxia foundation patient conference, Las Vegas

Dr Julie Greenfield was invited and received funding to attend the SCA Global conference in March 2019 (see above). She also attended part of the National Ataxia Foundation (NAF) patient conference that took place at the same venue. She was additionally invited by FARA-US to attend a half-day meeting on the use of brain imaging in FA as biomarkers for trials.

Partnerships with ataxia charities worldwide

For a year we have been working with the Ataxia Telangiectasia (AT) Society, the UK charity supporting people affected by AT (the only form of progressive ataxia that is not within Ataxia UK's remit). We are contracted to provide a research support service one day a week. Dr Julie Greenfield also worked with the company Intrabio and attended a meeting at the European Medicine Agency, where their drug was granted orphan drug status for AT. This partnership has strengthened the link between the two UK ataxia charities, and we feel has worked well for both charities.

We have continued to work with other ataxia charities worldwide and during the year, three ataxia charities joined us in co-funding research projects. Ataxia UK has also been working more closely with the US charity NAF (National Ataxia Foundation), due to both our involvement in SCA Global and ARCA Global initiatives.

International Ataxia Research Conference 2019

Ataxia UK has been planning the next International Ataxia Research Conference (IARC) in collaboration with three other ataxia charities: FARA-US, FARA-Aus and GoFAR. This will be held in Washington, US in November and follows the success of the first two IARCs: 2015, Windsor, UK and 2017 Pisa, Italy.

Grants agreed in 2018-19

a) Prof Pandolfo on behalf of the European Friedreich's Ataxia Research Consortium (EFACTS), Ataxia UK contributed £25,000 to this European network project on natural history of FA. This was awarded via Euro-ataxia and two other charities contributed (AFAF and AISA).

Funded: £25,000

b) Dr Clevio Nobrega (University of Algarve, Portugal), 'Neuroprotective therapeutic approach for spinocerebellar ataxia type 2: pharmacological targeting of AMPK'

Funded: £10,500 for year 2 of the project

c) Dr Lorenzo Cingolani (Fondazione Istituto Italiano di Tecnologia, Genova, Italy), 'Regulation of alternative splicing of voltage-gated Ca²⁺ channels by CRISPR/Cas9-mediated genome editing as potential genetic therapy for episodic ataxia type 2'

Funded: £5,000

d) Dr Filip Lim (Madrid University, Spain), 'A New FA animal model for validating HSV-1 FXN gene therapy in Dorsal Root Ganglia'

Funded: £30,000 for year one. A grant for the same amount for year 2 would be subject to a satisfactory progress report.

e) Dr Christopher Carroll (St George's, University of London), 'Targeting metabolic remodelling as a therapeutic strategy for cardiomyopathy in Friedreich's ataxia'

Funded: £5,000 (half co-funded with FARA as used funds from screening of Ataxia film)

f) Dr Graca (Institute of molecular and cell biology, Porto, Portugal), 'Modelling SCA11 in cultured cells using CRISPR/Cas9'

Funded: £5,000

h) A conference sponsorship award was provided for the first SCA Global conference

Funded: \$2,500

The following two projects had been awarded last year on condition that the researchers succeeding in getting other funds, which they now have.

1) Prof Festenstein (Imperial College, London), Contribution to the 'Trial testing the effect of nicotinamide in Friedreich's ataxia.'

Funded: £15,000

2) Dr Gromak (University of Oxford), 'Molecular mechanisms of R-loop mediated frataxin gene silencing'

Funded: £35,000

Research aims for 2019-20

- Engage people with ataxia in the design of clinical trials
- Work with partners in establishing the three global initiatives in the inherited ataxias
- Host International Ataxia Research Conference
- Assist in recruitment to new clinical trials
- Enhance research dissemination to engage people with ataxia
- Work with Euro-ataxia on highlighting the importance of patient engagement in research

Improvements in treatments and care

Treatments and care aims for 2018-19

- Publish information on ataxia in a medical journal
- Investigate developing a new Specialist Ataxia Centre
- Investigate what people with ataxia need to improve their mental wellbeing
- *Investigate the hospital inpatient experiences of people with ataxia – deferred to 2020/21*
- Get the 'Value of Treatment' project approved, funded and started
- *Review Ataxia Centres has been deferred to 2019-20*

Publish information on ataxia in a medical journal

In November we were pleased to hear that the European Network for Rare Neurological Diseases had affirmed of value the Ataxia UK *Medical Guidelines*. This shows the recognition of European specialists of our guidelines, which were produced by UK specialists only.

Ataxia UK has been working with ataxia specialist clinicians Prof Paola Giunti and Dr Rajith de Silva in writing two papers about the diagnosis and management of the ataxias for publication in medical journals. We are delighted that both papers have been accepted for publication. The first is a summary of the Ataxia UK Medical Guidelines in the *Orphanet Journal of Rare Diseases*, and is useful in increasing the reach and spreading the word further amongst healthcare worldwide. The second, published in the journal *Practical Neurology*, is aimed specifically at neurologists and should provide useful insight into the diagnosis and management of adults with ataxia.

Takeda has also been working on a literature review project that focuses on FA, and in particular, on looking at a 'burden of illness' (looking at costs and impact of condition). Dr Julie Greenfield was invited to be an expert advisor on this project, together with Prof Paola Giunti. The review has now been completed and we are exploring presenting it as a poster at conferences, and working on a publication.

Investigate developing a new Specialist Ataxia Centre

The establishment of a Specialist Ataxia Centre for children is being supported, with the ultimate aim of it being an Ataxia UK accredited centre. We were delighted that over £25,000 was raised by our supporters through The Big Give in December 2018 which will be used to provide 'seed funding' to these NHS services. Work towards their establishment has taken place during the year and we hope for a launch in 2019-20.

Investigate what people with ataxia need to improve their mental wellbeing

Much of the year was spent developing an application for funds to the National Lottery Community Fund to reduce loneliness and improve mental wellbeing. This application has now been submitted and we await the result. If it is successful, we will be embarking on a significant project which will find out about people's mental wellbeing and offer them opportunities to engage with others through volunteering – a proven strategy to improving mental health.

Get the 'Value of Treatment' project approved, funded and started

Ataxia UK worked with Prof Giunti in presenting a project on ataxia to the European Brain Council (EBC), which was approved of as one of three rare diseases to be included in the 'Value of Treatment' project. The project broadly will analyse adult patient diagnosis and care pathways in the Specialist Ataxia Centres and general non-specialist settings, and will also explore the health economic effects of both settings.

During the year, working with Prof Giunti, we were able to secure funding from Takeda and Reata; this was essential for the project to go ahead. We then employed the healthcare company Costello Medical to work on producing a survey to be distributed to Friends of Ataxia UK (Costello has previously worked with us on a pro-bono project). The survey closed with over 300 completed surveys returned from UK patients with ataxia, and the data is currently being analysed.

As this is a European project, the EBC require similar data to be collected from at least two other European countries and that work is in progress. When Dr Julie Greenfield presented this project at the Euro-ataxia annual meeting in November, there was interest to do such a survey in Germany and Italy.

Investigate the hospital inpatient experiences of people with ataxia

This aim ties in with the 'Value of Treatment' project described above. Some of the information we hope to gain from the project is the hospital inpatient experiences of people with ataxia.

We feel that the 'Value of Treatment' project is an excellent opportunity to raise awareness of the ataxias at a high European level, as a good example for rare diseases in general. It should also provide useful information towards comparing the Ataxia Specialist Centres and how their healthcare services differ from other healthcare settings.

Other Work to Improve Treatments and Care

Specialist Ataxia Centres

This year unfortunately saw the closure of the Accredited Specialist Ataxia Centre in Newcastle. This is because the neurologist running the service, Prof Rita Horvath, has left Newcastle and moved to Cambridge.

The team at the Accredited Specialist Ataxia Centre in Sheffield 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 on the autoimmune ataxias.

Prof Giunti continues to run busy ataxia clinics in London with a full-time ataxia nurse, who provides much needed support to the expanding clinic. She also has the support of a second neurologist, thus increasing capacity and enabling the team to see more ataxia patients. She 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.

We run a volunteer scheme of Ataxia UK representatives at the London Centre, whereby people with personal experience of ataxia are available on clinic days to talk to patients. A meeting of the London Specialist Ataxia Centre Ataxia UK volunteer reps was held in October. It was an opportunity for all the volunteers to meet, share best practice and discuss with Dr Julie Greenfield any issues. We now have six volunteers and we were pleased that all were able to attend the meeting.

Ataxia UK's Medical Advisory Panel

The annual meeting of the Medical Advisory Panel took place in March and we were pleased to welcome two ataxia nurses as new members. The annual meeting was a useful opportunity for each to share information on ongoing ataxia research and other activities.

Recent research that could have implications for the care of people with ataxia were also discussed, as well as issues regarding the poor access to certain medications for episodic ataxia.

Medical Registry

We continue to reach out to healthcare professionals with an interest in ataxia via our e-newsletters, which are sent to our registry three times a year.

Euro-ataxia

Euro-ataxia is the federation of 19 ataxia patient groups in Europe, of which Ataxia UK is one. The annual Euro-ataxia conference took place in Frankfurt in November. A total of 20 Euro-ataxia representatives from 14 different groups attended (including two new members): a strong level of participation. A one-day research programme was organised by Dr Julie Greenfield. We managed to collaborate with EFACTS project coordinators to hold the annual EFACTS meeting at the same venue the day after Euro-ataxia. We also liaised with the European Reference Network for Rare Neurological Diseases and succeeded in having their meeting at the same venue the day before Euro-ataxia.

One advantage of collaborating with EFACTS was that ten EFACTS researchers additionally attended the Euro-ataxia conference, alongside invited researchers. This, together with representatives from two pharmaceutical companies (Biomarin and Reata) made a very diverse group that encouraged interesting discussions. For example, a discussion session focused on the role of patient groups and patients in research, and as a result a Patient Charter is now being prepared.

As Ataxia UK is the largest member organisation of Euro-ataxia, we take responsibility for much of its activities, including adding information on the website and disseminating information via social media.

Communication about science research

At the Ataxia UK Annual Conference we had a stall from Costello Medical Consulting, the healthcare company working with us on the 'Value of Treatment' project. They were conducting research on communication with people with rare diseases, and asked us to include the views of people with ataxia. A total of 35 people completed their online survey and the results will be presented at a healthcare conference with a poster entitled 'How do Patients and Caregivers Access Scientific Literature'. Dr Julie Greenfield is an author on the poster due to her contribution to creating the survey and ongoing support of the project. Results were shared with Ataxia UK Friends.

Supporting charities in lobbying for improvements in care and research

We are members of a number of 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, our CEO, is also a Trustee of Genetic Alliance UK, increasing our engagement with this organisation. Genetic Alliance UK 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.

Ataxia UK continues to be an active member of the Neurological Alliance and Sue Millman remains a member of the Board of Trustees. 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, for whom Alison Love (Ataxia UK Trustee) is a Trustee and actively engaged in their work. Carol McCudden, an Ataxia UK Ambassador, represents us on the Board of the Welsh Neurological Alliance and attends many NHS meetings representing patients in Wales.

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

a) Rare Disease Advisory Group (RDAG)

Sue Millman is a member of the NHS England Rare Disease Advisory Group (RDAG) which meets four times per 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.

b) Specialised Commissioning Patient and Public Voice Assurance Group (PPVAG)

Sue Millman also belongs to the PPVAG as a representative of RDAG. It has monthly meetings that are often attended by senior members of NHS England. 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 2019-20

- Launch of an Ataxia UK accredited Paediatric Ataxia Centre
- Obtain, disseminate and act upon results from the 'Value of Treatment' project
- Review the Specialist Ataxia Centres
- Evaluate the mental wellbeing of the ataxia community as part of our combating loneliness and isolation project

Care and Support Services for people affected by ataxia

Care and support aims for 2018-19

- Create four new Branches/Support Groups
- Increase support to Branches and Support Groups through volunteers providing help and guidance at a local level
- Develop Ataxia 16–30's Project and the Ataxia Ambassadors Project
- Initiate work with children with ataxia and their parents
- Initiate work with parents who have ataxia and young children

Create four new Branches/Support Groups

Ataxia UK has increased the number of Branches and Support Groups to 49 across the UK, with six new groups created over the financial year and five more planned for 2019-20. The groups continue to play a crucial part in enabling Ataxia UK to provide support at a local level, and we continue to receive positive feedback from group members stating that they find the support from these groups helps to ease isolation and provides great friendship.

Increase support to Branches and Support Groups through volunteers providing help and guidance at a local level

Many of the Branches and Support Groups also fundraise by taking part in community and sports events, and most also organise social outings which are well received by members. Ataxia UK continue to seek co-ordinators for more groups so that we can have complete coverage across the UK with more people able to access a Support Group within an hour's travel.

Develop Ataxia 16-30's Project and the Ataxia Ambassadors Project

The Ataxia Ambassadors Project trains up people affected by ataxia to share their stories. This raises awareness of the condition across the country, and empowers people to talk about ataxia with confidence. Additionally, the project helps to reduce isolation for people with ataxia, as proven by our ambassador-led event: the Naidex disability exhibition (April 2018 and March 2019), where our ambassadors forged strong friendships with one another. Over 60 individuals from the ataxia community have signed up to take part since June 2018, and more than four different types of ambassador roles have been created and applied for.

Following Naidex, our ambassadors had this to say:

- "Becoming an Ambassador has improved my making eye contact with people and talking about ataxia... a month ago, I couldn't have believed I'd do this." – Aila
- "Speaking to doctors about my condition made me feel equal to them; I wasn't just another body in a wheelchair." – Ashley
- "I've enjoyed it so much. I could talk to strangers about ataxia in my sleep, now." – Dan
- "It's been unbelievable; I've met so many great people and made them ataxia aware! It's done wonders for my confidence." – Gemma

Due to capacity restraints this financial year, the Ataxia 16-30's Project has not been substantially developed. However, we held a very successful 16-30's conference at the Annual Conference in October 2018 that focused on mental wellbeing. With two members having expressed suicidal feelings or contemplated the act itself over the year, we listened to our group's needs and invited a therapist specialising in mental wellbeing for people with rare diseases and genetic conditions. She highlighted the various services that are available for when these mental health struggles occur.

Initiate work with children with ataxia and their parents and initiate work with parents who have ataxia and young children

A lack of financial and human resources have impeded our ability to make significant progress in some of these aims; however, much time has been invested in assembling an application to the National Lottery Community Fund, which was submitted a few weeks after the year end. We are optimistic that this will succeed and provide the opportunity to commence this work more fully.

Other work on Care and Support Services for people affected by ataxia

Grants

Ataxia UK acts as a third party for four charitable Trusts, helping people with ataxia to apply for grants towards purchasing 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, The Barchester Charitable Foundation and the Mark Dower Trust. As a result of our efforts, more than £12,500 has been raised for people with ataxia, mostly towards purchasing and installing aids and adaptations in their homes.

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

Helpline

The Helpline continues to be busy with both calls and emails. The total number of contacts to the Helpline during 2018-19 (1st April-31 March) was 1,695. This is an increase from last year (1,423), but consistent with previous years. The majority were emails (1,139) and phone calls (448). The topics covered were very wide-ranging, with most people calling about questions on Ataxia UK and what we can offer; requesting publications; issuing queries on medical issues, and welfare benefits were common topics.

With the many cuts to welfare benefits for disabled people, many people are coming to Ataxia UK for help when they are having problems with accessing benefits or having to appeal decisions. Ataxia UK has continued to provide letters of support in these cases, explaining about ataxia and the impact it has, with some success to date.

Care and support aims for 2019-20

- Further develop the Ataxia Ambassadors Project
- Develop volunteering across Ataxia UK to expand our services, with the aim of decreasing isolation in the ataxia community among volunteer participants and beneficiaries of the charity
- Continue to seek co-ordinators for more Branches and Support Groups
- Services to be improved/developed
 - Helpline
 - Online services
 - Ambassadors Project
 - Branches and Support Groups

Raising Awareness

Awareness aims for 2018-19

- Continue to build and improve our digitalised campaigns
- Continue to raise awareness in selected locations and schools
- Improve and implement social media strategy to grow our audience and increase engagement
- Launch 'Fractured Lives' campaign with TBWA

Continue to build and improve our digital campaigns

2018-19 has been our strongest year yet for digital campaigning. Comparing our social media campaign for Rare Disease Day 2017 against the same campaign in 2018, we saw an increase in engagement of over 40%, demonstrating our improved approach to social media over the year. We also made great progress in using digital campaigning to access new audiences on International Ataxia Awareness Day with our 'Fractured Lives' campaign in September (see below).

Continue to raise awareness in selected locations and schools

The Fundraising and Communications departments have collaborated to improve awareness and fundraising activities in schools this year, including three visits to primary schools made by our team. We have also collaborated on improving our Schools Pack, which offers materials for fundraising and awareness within schools, including videos and case studies that teachers can share with their pupils to enhance understanding. We have heard a number of stories in which children with ataxia's lives have improved after sharing about their condition with their peers.

One pupil who gave a school assembly on ataxia, and said: "It's so frustrating that not enough people know about ataxia, which has led to bullying. My attitude has always been that 'I don't want your sympathy, just treat me the way I am'. As soon as I did that assembly, the bullying stopped. It's been amazing how the whole school have been fine with it."

Improve and implement social media strategy to grow our audience and increase engagement

Our social media presence has continued to grow after we implemented two social media strategy reviews, one in early 2018 and another in January 2019. We have monitored our performance over different channels, types of content and techniques in order to continuously improve our audience engagement. Over the last financial year we have seen an 11% growth of our Facebook audience, demonstrating our success.

Launch 'Fractured Lives' campaign with TBWA

Through our 'Fractured Lives' awareness campaign on International Ataxia Awareness Day in September 2018, we aimed to raise awareness of ataxia among new audiences. We enlisted celebrities to participate, enabling us to reach their own, larger audiences, and liaised with design agency TBWA to create shareable social media materials to allow members of the public to take part. More than 900 individuals who were not commissioned directly by us took part in this campaign, as monitored on Twibbon (a social media campaigning platform); additionally, our Google Analytics showed a 359% increase of visitors to our website on the day of the campaign – 89% of whom were first time visitors.

Through the help of TBWA, we were able to share professional, emotive and effective campaign materials, including ad hoc images made especially for our celebrities. Social media analyses showed that our reach and levels of engagement dramatically increased during the campaign: 176% increase in Facebook engagement; 140% increase of page

followers; 134% increase of reach during the week, compared to the week before. On the day of the campaign, we also saw just fewer than 10,000 impressions on Twitter: more than quadruple our average daily performance.

Awareness aims for 2019-20

- Test segmenting audiences and raising awareness among a specific audience with specific purposes and messages
- Investigate using social media to recruit Friends and improve membership rates
- Further develop branding and implement across organisation
- Create a Case for Support document

Fundraising

Fundraising aims for 2018-19

- Continue to improve the fundraising experience to build long-term, rewarding relationships with our Friends and supporters by enhancing the donor journey
- Maximise the return on our fundraising activities
- Develop new, innovative fundraising options that recognise the different ways people choose to support us
- Continue to develop our relationships with Trusts, Foundations and corporate businesses
- Ensure that all GDPR policies and procedures are fully operational.

Overall, 2018-2019 has been a good year for Fundraising, with an increased income of 18% compared to budget. A significant contributor to this success was the over performance of legacy income compared to budget, which was £200,000 higher than expected. Excluding legacies, individual giving is down £75,000 compared to budget, with the biggest deficit coming from general donations. However, participation and income from challenge events and community fundraising is up £18,000 compared to budget, and this continues to be an area of growth.

Improve the fundraising experience to build long-term, rewarding relationships with our Friends and supporters by enhancing the donor journey

This is an ongoing objective and in FY18-19 we have focused on improving how we steward our supporters. There has been marked improvement following the implementation of a Supporter Schedule, which we continue to improve. The Supporter Schedule helps to ensure that we are keeping in regular contact with supporters throughout their fundraising journeys and beyond, building stronger, longer-term relationships. We have also reviewed our thank-you communications across the board and have made initial amends to wording. This is such an important area that we will continue to review and seek to improve these communications.

One fundraiser in particular this year, Richard Bradford, has dedicated great effort and time in fundraising towards Ataxia UK activities with our support. Richard and his team raised £23,318 (including Gift Aid) towards part funding a research project with FARA, at the University of Bristol, studying stem cell mobilising drug as a potential treatment for FA (Granulocyte colony stimulating factor or GCSF). A collection of our other supporters raised the remaining funds to hit the £29,000 required. Richard undertook a number of challenges, including organising 18 cyclists to cover 250 miles on bikes and 3000ft on foot up Mount Snowdon in his 3 Day EPIC. Richard is now planning more events for 2019-20 and continuing to seek to fund much needed research into FA. He has future events planned for 2019-20.

Maximise the return on our fundraising activities

Maximising ROI is a key focus of the team's daily life. Some of the ways we looked to improve ROI in 2018-19 include undertaking repairs to our database and cleaning our data analysis and segmentation, allowing us to more efficiently target our fundraising communications.

Develop new, innovative fundraising options that recognise the different ways people choose to support us

One of the developing areas we have invested time and energy into is Facebook. In 2018-19 we developed internal processes for managing Facebook fundraisers and had 113 set up Facebook Fundraisers, raising over £25,000. This seems particularly popular with younger fundraisers and Friends, and is a promising avenue for future growth.

Continue to develop our relationships with Trusts, Foundations and corporate businesses

We have been working hard to grow our corporate and community/sports club partnerships, by creating a new area on the website and a better 'offer', which is resulting in an increase in support and closer relationships being built. In 2018-19 we continued to develop our relations with Trusts and Foundations, and we hope to see an impact on our income from this source in 2019-20. Our relationship with media agency TBWA has continued to flourish and we thank them for their considerable in-kind contribution to our awareness campaigns.

Ensure that all GDPR policies and procedures are fully operational

We worked with outside experts on GDPR to produce our policies and procedures, which are now in place. Staff were briefed on these and a training day was held.

Additional Fundraising activities

As part of our Fundraising Strategy, we have continued to cultivate our relationships with long standing major donors and potential new ones. We held a Scientific Seminar in 2018 to launch the new Research Strategy, inviting donors to share our vision and see for themselves the ataxia research advances made globally. This successful event will be repeated in 2019. We are delighted by the prospect that two of our major supporters are holding important fundraising dinners in 2019 and others are organising events which promise to give a major boost to our research income in 2019/20.

Fundraising aims for 2019-20

- Recruit more regular givers
- Review our Friendship model
- Plan and develop a bespoke Ataxia UK challenge event
- Expand support and increase income from trusts, corporates and foundations.

Financial review – to March 2019

Overview

Net income for the year is £1.4K, which is an excellent result in comparison to a £13.5K deficit in 2017/18. This is mainly due to legacy income being higher than average as detailed below. The main focus for the charity during the year was to support the new fundraising strategy and this is reflected in increased expenditure.

Restricted funds have decreased over the year from £111K in 2018 to £102K in 2019, whilst general unrestricted funds have increased from £388K in 2018 to £398K in 2019. Further details of reserves are given later in this review.

Review of income

Total income for 2018/19 was £1,011K an increase of 22% on the previous year (2017/18 £832K). There are number of factors that contributed to this increase. Legacy income was much higher than the previous year at £307K for the year (2017/18: £85K), an increase of 260%. We are very grateful to the Friends and supporters who remember us in this way. Donation income was slightly higher than the previous year at £315K (2017/18: £309K) an increase of 2%. Income from fundraising activities dropped to £284K (2017/18: £319K) a decrease of 11%. The contribution from Childlife remained at the same level as in 2017/18, £52K.

Review of expenditure

Our spending on research activities increased to £242K (2017/18: £186K), an increase of 30%. Included within this were research grants of £132K (2017/18: £84K), an increase of 57% on prior year. This year there was very little additional investment in Ataxia centres, however restricted funds of £21K were received for the proposed London and Sheffield Paediatric centres. Cost of raising awareness increased slightly from the previous year at £179K (2017/18: £165K). This was due to the generous contribution in kind received from TBWA for our Fractured Lives campaign. Expenditure on raising funds increased by 43% from £141k (2017/18) to £204k in the current year. This increased expenditure is expected to produce increased income in the coming years.

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.

Reserves levels at year end

Total funds of the charity on 31 March 2019 were very similar to the previous year at £511K (31 March 2018: £510K).

Restricted funds were £102K (2017/18: £111K), (detailed in Note 24) with the largest amounts being the Kennedy award, £34K, London and Sheffield Paediatric Centres, £21K, Stem Cell Research, £18K and Young Persons projects, £11K.

Designated Funds totalled £11K (2017/18: £10K) representing funds held at branches and are detailed under Note 23.

General reserves of the charity as at 31 March 2019 were £398K (31 March 2018: £388K) The trustees consider that it is both prudent and appropriate as part of their risk management policy to maintain a minimum level of contingency within free reserves to provide against any unforeseen changes in income and/or expenditure. The reserves policy was reviewed during the year and it was decided that holding unrestricted free reserves equal to a minimum of 3 months operating costs (presently £52K per month, 2017/18: £42K 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, £16K (2017/18: £24K). As at 31 March 2019, free reserves totalled £381K (2017/18: £354K) equating to 7.3 months operating costs (2017/18: £350K, 8.3 months). Although this exceeds the reserves policy, it has been built up to support the investment in the fundraising strategy.

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:

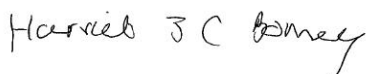
- There is no relevant audit information of which the charitable company's auditor is unaware; and
- The trustees have taken all steps that they ought to have taken, to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

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.

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

Approved by the trustees on



Dr Harriet Bonney
Chairman of Trustees



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 2019 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 2019 and of its income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice;
- have been prepared in accordance with the requirements of the 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.

The impact of uncertainties due to Britain exiting the European Union on our audit

The Trustees' view on the impact of Brexit is disclosed on page 28.

The terms on which the United Kingdom may withdraw from the European Union are not clear, and it is therefore not currently possible to evaluate all the potential implications to the charity's trade, customers, suppliers and the wider economy.

We considered the impact of Brexit on the charity as part of our audit procedures, applying a standard firm wide approach in response to the uncertainty associated with the charity's future prospects and performance.

However, no audit should be expected to predict the unknowable factors or all possible implications for the charity and this is particularly the case in relation to Brexit.

Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charity's ability to continue to adopt the

- going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

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

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

We have nothing to report in this regard.

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 for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- 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 Trustees' Report.

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

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specific 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 statement of trustees' responsibilities set out on page 28, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the 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 these financial statements.

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

Use of the audit report

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

Nicola Wakefield

(Senior Statutory Auditor)

for and on behalf of Mazars LLP

Chartered Accountants and Statutory Auditor

Times House, Throwley Way, Sutton, Surrey, SM1 4JQ.

Date:

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 2019

	Notes	Unrestricted funds £	Restricted funds £	Total 2019 £	Total 2018 £
Income					
Donations and legacies	3	803,499	102,024	905,523	712,385
Charitable activities	4	14,821	86,438	101,259	112,333
Investments	5	4,619	0	4,619	7,228
Total income		822,939	188,462	1,011,401	831,946
Expenditure on:					
Raising funds	6	(201,913)	(1,871)	(203,784)	(141,305)
Charitable activities	7	(539,233)	(264,776)	(804,009)	(695,531)
Total expenditure		(741,146)	(266,647)	(1,007,793)	(836,836)
Net gains/(losses) on investments		(2,243)	0	(2,243)	(8,601)
Net income/(expenditure)		79,550	(78,185)	1,365	(13,491)
Transfer from Unrestricted to Restricted		(68,303)	68,303	0	0
Net movement in funds		11,247	(9,882)	1,365	(13,491)
Total funds brought forward		398,247	111,435	509,682	523,173
Total funds carried forward		409,494	101,553	511,047	509,682

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 (Continued)

(incorporating the income and expenditure account)

(incorporating the results of the Charity's branches)

for the year ended 31st March 2018

	Unrestricted funds	Restricted funds	Total 2018
	£	£	£
Income			
Donations and legacies	588,685	123,700	712,385
Charitable activities	14,311	98,022	112,333
Investments	7,228	0	7,228
Total income	610,224	221,722	831,946
Expenditure on:			
Raising funds	(115,334)	(25,971)	(141,305)
Charitable activities	(447,544)	(247,987)	(695,531)
Total expenditure	(562,878)	(273,958)	(836,836)
Net gains/(losses) on investments	(8,601)	0	(8,601)
Net income/(expenditure)	38,745	(52,236)	(13,491)
Net movement in funds	(23,033)	23,033	0
Transfer from unrestricted to restricted	15,712	(29,203)	(13,491)
Total funds brought forward	382,535	140,638	523,173
Total funds carried forward	398,247	111,435	509,682

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 2019

		<i>2019</i>		<i>2018</i>	
	Notes	£	£	£	£
Fixed assets					
Tangible assets	13	16,064		23,885	
Intangible assets	14	1,500		14,300	
Investments	15	<u>182,720</u>		<u>255,020</u>	
			200,284		293,205
Current assets					
Stock	16	6,407		4,442	
Debtors	17	364,934		144,468	
Cash at bank and in hand	18	<u>238,379</u>		<u>311,252</u>	
		609,720		460,162	
Creditors: amounts falling due within one year	19	<u>(256,768)</u>		<u>(181,167)</u>	
Net current assets/(liabilities)			<u>352,952</u>		<u>278,995</u>
Total net assets less current liabilities			553,236		572,200
Creditors: amounts falling due after more than one year	20		<u>(42,189)</u>		<u>(62,518)</u>
Total net assets	21		<u>511,047</u>		<u>509,682</u>
Accumulated funds					
Unrestricted funds					
General funds	22		398,440		388,091
Designated funds	23		<u>11,054</u>		<u>10,156</u>
			409,494		398,247
Restricted funds	24		<u>101,553</u>		<u>111,435</u>
Total funds			<u>511,047</u>		<u>509,682</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 28 August 2019 and signed on their behalf by:

Harriet J C Bonney

Harriet Bonney - Chairman

Kathy Jones

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 2019

	2019	2018
	£	£
Cash generated from operating activities:		
Net cash (used in)/provided by operating activities	(143,373)	28,281
Cash flows from investing activities:		
Dividends and interest from investments	4,619	7,228
Purchase of property, plant and equipment	(4,175)	(5,010)
Proceeds from sale of investments	70,056	100,131
Purchase of investments	-	-
Net cash provided by investing activities	70,500	102,349
Net increase in cash:	(72,873)	130,630
Cash at bank and in hand less overdrafts at the beginning of the year	311,252	180,622
Change in cash and cash equivalents	(72,873)	130,630
Cash at bank and in hand less overdrafts at the end of the year	238,379	311,252
Reconciliation of net income/(expenditure) to net cash flow from operating activities		
	2019	2018
	£	£
Net income/(expenditure)	1,365	(13,491)
Adjustments for:		
Depreciation charges	24,796	26,097
Net losses on investments	2,243	8,601
Dividends and interest from investments	(4,619)	(7,228)
(Increase) in stocks	(1,965)	(843)
(Increase)/Decrease in debtors	(220,466)	47,342
Increase/(Decrease) in creditors	55,272	(32,197)
Net cash (used in)/provided by operating activities	(143,373)	28,281
Analysis of cash at bank and in hand less overdrafts		
	2019	2018
	£	£
Cash at bank and in hand	238,379	311,252
	238,379	311,252

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).

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.

b. Going Concern:

During the 2018/19 financial year, we had an increase in our net movement in funds. We continue to monitor our budget closely. The Trustees are investing in a fundraising initiative, which will initially need to be covered by reserves. 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.

NOTES TO THE FINANCIAL STATEMENTS

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 24.

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

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

p. Contractual Commitments: Formal and unconditional commitments to research expenditure and other grants at the balance sheet date are included within creditors, in accordance with SORP (FRS 102). Commitments to such projects that have been agreed by the Trustees but have not yet been confirmed to the recipient, and therefore do not yet represent contractual commitments, are shown as designated funds, except a) to the extent that equivalent reserves are maintained in restricted funds and b) to the extent that they are funded by commitments from other bodies. The movements on general funds and designated funds are shown in notes 22 and 23.

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

r. Taxation: As a registered charity, the Charity is exempt from taxation under section 505 (I) of the Income & Corporation Taxes Act 1988.

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

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

Note 3 Donations and Legacies Income

	2019	2018
	£	£
Donations	315,070	309,090
Legacies	306,502	84,794
Fundraising activities	283,951	318,501
	<u>905,523</u>	<u>712,385</u>

Note 4 Charitable Activities Income

	2019	2018
	£	£
Childlife	51,500	51,500
Annual conference	13,320	12,764
Grants receivable	36,439	48,069
	<u>101,259</u>	<u>112,333</u>

Note 5 Investment Income

	2019	2018
	£	£
Income on investment portfolio	3,039	7,217
Interest	1,580	11
	<u>4,619</u>	<u>7,228</u>

Note 6 Raising Funds Expenditure

	2019	2018
	£	£
Costs of generating funds	203,416	140,573
Investment managers fees	368	732
	<u>203,784</u>	<u>141,305</u>

Note 7 Charitable Activities Expenditure

	Direct Costs £	Grants £	Support Costs £	2019 Total £	2018 Total £
Research activities	53,096	132,435	56,593	242,124	185,626
Ataxia centres	-	439	-	439	33,265
Care services	81,234	7,299	141,019	229,552	163,671
Total	<u>134,330</u>	<u>140,173</u>	<u>197,612</u>	<u>472,115</u>	<u>382,562</u>
Generating funds	-	-	98,602	98,602	88,624
Research conference	2,294	-	-	2,294	23,613
Raising awareness	101,572	-	76,950	178,522	165,277
Governance	-	-	52,476	52,476	35,455
Total charitable activities	<u>238,196</u>	<u>140,173</u>	<u>425,640</u>	<u>804,009</u>	<u>695,531</u>

	2019	2018
	£	£
Total support costs		
Staff costs	309,698	258,443
Office costs	91,146	65,289
Depreciation	24,796	26,097
	<u>425,640</u>	<u>349,829</u>

Note 8 : Research Grants

	2019	2018
	£	£
Research grants made in year comprise		
Studying G-CSF as a potential treatment for Friedreich's Ataxia'		58,061
Neuroprotective therapeutic approach for Spinocerebellar Ataxia type 2: pharmacological'		9,500
RNA-FISH evaluation of the FXN gene transcription: focus on cell-to-cell and cell cycle modulation, and the role in origin and evolution of the Friedreich's ataxia GAA-repeat mutation'		4,800
Novel pharmacological approach to treat Episodic ataxia type 1		5,000
Discrimination of wild type and mutant ATXN3 mRNA levels by qPCR:protocol design & implementation		5,000
Research Conference 2017 Poster Award		878
Sponsorship of the Society of the study of cerebellum & ataxias conference 2019		500
The UK arm of a multi-centre study of the efficacy and safety of nicotinamide in patients with Friedreich's ataxia (NICOFA).	15,000	
Molecular mechanisms of R-loop mediated frataxin gene silencing	35,000	
EFACTS Project	25,000	
Generating new Friedreich's Ataxia animal models for validating HSV-1 FXN gene therapy in Dorsal Root Ganglia'	30,000	
Regulation of alternative splicing of voltage-gated Ca ²⁺ channels by CRISPR/Cas9-mediated genome editing as potential genetic therapy for episodic ataxia type 2	5,000	
Dr Carroll grant - Metabolic Remodelling	5,000	
Sponsorship of SCA Global Conference (\$2,500)	1,935	
Modelling SCA11 in cultured cells using CRISPR/Cas9	5,000	
Neuroprotective therapeutic approach for Spinocerebellar Ataxia type 2: pharmacological targeting of AMPK	10,500	
	<u>132,435</u>	<u>83,739</u>

Note 9 : Staff Costs

	2019	2018
	£	£
Staff costs comprised:		
Salaries	457,221	367,674
Social security contributions	42,821	32,408
Pensions	20,973	16,125
	<u>521,015</u>	<u>416,207</u>

The average number of employees during the year was 15 (2018: 10) 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 £243,418 (2018: £212,925).

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

£60,000 - £69,999	1	1
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The pension contributions in respect of the above named individual in the year totalled £3,360 (2018: £3,360).

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 £20,973 (2018: £16,125). There was no outstanding balance (2018: £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, these comprised travelling, accommodation, postage and telephone costs. 12 trustees (2018: 12) claimed expenses totalling £8,787 (2018: £8,994).

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

	2019	2018
	£	£
Auditor's remuneration	7,077	6,922
Legal Fees	-	4,387
Payroll costs and accountancy services	1,153	1,800
Depreciation	24,796	26,097
Operating lease costs	1,114	3,156

Note 13 : Tangible Fixed Assets

	Building Works	Other Assets	Total
	£	£	£
COST			
As at 1st April 2018	32,337	31,988	64,325
Additions	-	4,175	4,175
As at 31 March 2019	<u>32,337</u>	<u>36,163</u>	<u>68,500</u>
DEPRECIATION			
As at 1st April 2018	14,454	25,986	40,440
Charge for year	7,879	4,117	11,996
As at 31 March 2019	<u>22,333</u>	<u>30,103</u>	<u>52,436</u>
NET BOOK VALUE			
As at 31 March 2019	<u>10,004</u>	<u>6,060</u>	<u>16,064</u>
As at 1st April 2018	<u>17,883</u>	<u>6,002</u>	<u>23,885</u>

Included within the net book value of the 'Other Assets' is an amount of £1,284 (£3,404 in 2018) relating to items acquired on Finance Lease/Hire purchase.

Note 14 : Intangible Fixed Assets

	Software £
COST	
As at 1st April 2018	82,226
Additions	-
As at 31 March 2019	<u>82,226</u>
DEPRECIATION	
As at 1st April 2018	67,926
Charge for year	<u>12,800</u>
As at 31 March 2019	<u>80,726</u>
NET BOOK VALUE	
As at 31 March 2019	<u>1,500</u>
As at 1st April 2018	<u>14,300</u>

Note 15 : Investments

	2019 £	2018 £
Market value at 1 April	255,020	363,752
Disposals	(77,452)	(103,111)
Unrealised gain/(loss)	5,152	(5,621)
Market value at 31 March	<u>182,720</u>	<u>255,020</u>
Cost of investments at 31 March	190,342	267,795
Total unrealised loss	<u>(7,622)</u>	<u>(12,775)</u>
Market value at 31 March	<u>182,720</u>	<u>255,020</u>
Investments consist of:		
1.25% UK Gilt Snr 22	-	15,032
1.75% UK Gilt Reg-S Snr 22	20,061	20,264
2% UK Gilt Snr-Reg	76,325	77,019
1.5% UK Gilt Snr-Reg-S	86,334	86,494
Non UK Investments		
Euro Inv Bank 4.75% 2018	-	56,211
	<u>182,720</u>	<u>255,020</u>

Note 16 : Stock

	2019 £	2018 £
Stock for resale	6,407	4,442

Note 17 : Debtors Under 1 Year

	2019 £	2018 £
Income tax recoverable	83,995	60,995
Other debtors	238,558	60,003
Prepayments	42,381	23,470
	<u>364,934</u>	<u>144,468</u>

Note 18 : Cash at bank and in hand

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

Note 19 : Creditors: amounts falling due within one year

	2019	2018
	£	£
Other creditors	28,720	20,901
PAYE/NI	12,411	9,130
Deferred income	33,021	12,406
Accruals	16,346	13,158
Research grants	166,270	125,572
	<u>256,768</u>	<u>181,167</u>

Note 20 : Creditors: Amounts falling due after one year

	2019	2018
	£	£
Research grants	40,000	58,060
Misc creditors	2,189	4,458
	<u>42,189</u>	<u>62,518</u>

Note 21 : Analysis of net assets between funds

	Restricted Funds £	Designated Funds £	General Funds £	Total 2019 £	Total 2018 £
Fixed assets	1,650	-	15,914	17,564	38,185
Investments	-	-	182,720	182,720	255,020
Stock	-	-	6,407	6,407	4,442
Debtors	-	-	364,934	364,934	144,468
Cash at bank and in hand	99,903	11,054	127,422	238,379	311,252
Creditors	-	-	(298,957)	(298,957)	(243,685)
	<u>101,553</u>	<u>11,054</u>	<u>398,440</u>	<u>511,047</u>	<u>509,682</u>

Note 22 : Unrestricted Funds

	General Funds	Designated Funds	Total
Balance as at 1 April 2018	388,091	10,156	398,247
Net increase in funds during the year	78,652	898	79,550
Transfers	(68,303)	-	(68,303)
Balance as at 31 March 2019	<u>398,440</u>	<u>11,054</u>	<u>409,494</u>

Note 23 : Designated Funds

	Opening Balance	Net Movement	Transfers	Closing Balance
Funds held in branches	10,156	898	-	11,054
	<u>10,156</u>	<u>898</u>	<u>-</u>	<u>11,054</u>

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

Note 24 : Restricted Funds

	At 1 April 2018	Income	Expenditure	Transfers	At 31 March 2019
	£	£	£	£	£
General Research	-	27,382	94,956	67,574	-
Friedreich's ataxia research	21,592	34,664	51,592	-	4,664
Cerebellar ataxia research	359	658	572	-	445
Young Person's projects	42,445	25	31,178	-	11,292
Jerry Farr travel fund	1,199	-	528	-	671
Welfare	518	5,625	5,624	-	519
Nicotinamide	20	-	-	-	20
Goods and Services Received	7,700	20,000	26,050	-	1,650
Helpline	136	-	-	-	136
Misc Grants	450	-	-	-	450
Childlife	-	50,000	50,000	-	-
Exeter	582	-	-	-	582
Awareness	503	-	-	-	503
Kennedy Award	33,748	-	-	-	33,748
Mark Dower Trust	2,183	3,185	1,147	-	4,221
Stem Cell Research	-	18,469	-	-	18,469
Episodic Ataxia Research Project	-	254	-	-	254
Spinocerebellar Ataxia Research Project	-	2,679	-	-	2,679
Metabolic Remodelling Ataxia Research Project	-	4,271	5,000	729	-
London Paediatric Centre	-	12,750	-	-	12,750
Sheffield Paediatric Centre	-	8,500	-	-	8,500
	111,435	188,462	266,647	68,303	101,553

- 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 for nicotinamide research.
- 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.
- 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 with travel and registration costs to scientific conferences.
- 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) **Stem Cell Research:** Funds for immobilising stem cells project
- q) **Episodic Ataxia Research Project:** Funds for episodic ataxia research project
- r) **Spinocerebellar Ataxia Research Project:** Funds for spinocerebellar ataxia research project
- s) **Metabolic Remodelling Ataxia Research Project:** Funds for metabolic remodelling in FA
- t) **London Paediatric Centre:** Funds to assist set-up of London paediatric centre
- u) **Sheffield Paediatric Centre:** Funds to assist set-up of Sheffield paediatric centre

Note 25 : Capital Commitments

There are no capital commitments at 31 March 2019 (2018: Nil)

Note 26 : Lease Commitments

At 31 March 2019 the charity had future minimum lease payments under non-cancellable operating leases as follows:

	2019		2018	
	Land & buildings	Other	Land & buildings	Other
Payments due:				
Within one year	31,200	1,336	31,200	1,336
Within two to five years	22,994	2,370	54,194	4,458
	<u>54,194</u>	<u>3,706</u>	<u>85,394</u>	<u>5,794</u>

Note 27 : Associated Organisations

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

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