

ATAxia

Annual Report & Financial Statements Year Ending: 1st April 2015 to 31st March 2016

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

2015 marked 50 years of Ataxia UK. To celebrate, we were delighted to be able to host a series of conferences across all the countries of the UK as well as our Annual Conference at Stansted. To round up the year we held our 50th Anniversary Ball at the Park Lane Hotel, which was attended by 300 guests and served as a wonderful opportunity to exhibit our work and raise much needed awareness in the process.

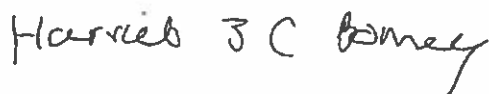
The year brought further developments in the field of research, fuelled by Ataxia UK's direct investment in research and our ongoing efforts to foster collaboration within the scientific community. We have continued to work closely with pharmaceutical giants, Pfizer, as part of our drug development project which was launched last year. During this year the charity has been working in partnership with Takeda, who are now investing in ataxia research and are in the process of testing the effect of a drug that, although not a cure, could relieve some symptoms in a range of ataxias.

The extensive network of Branches and support groups continue to be the lifeblood of the charity at a local level. Throughout the year staff and trustees were able to visit 50% of all Branches and Groups, engagement which we hope to continue in the forthcoming 12 months.

The year saw us adding to our information and promotional resources which now means that we have an extensive range of exceptional materials and films to accompany our new website which was launched in March 2015. The success of our venture to support young adults with the ataxia 16-30 Project has also highlighted there is now, more than ever, a need for support services and communication tools which can easily be accessed by people across the board.

In a difficult financial climate, fundraising has been particularly challenging. As a result we have taken measures to reduce our costs by relocating the office and regrettably having to make several redundancies. To supplement the staff team we have also started to employ paid interns. We are currently developing our new Strategic Plan which, together with the economies we have made, will give Ataxia UK a renewed sense of direction and strength, which will allow us to grow and achieve further success next year.

Finally, I would like to thank our staff, volunteers, trustees, members, donors and all those who have supported our work in a countless number of ways over the year in making life better for people affected by ataxia.



Harriet Bonney,
Chairman of Ataxia UK Trustees

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 2015-2016 are:

Honorary Officers

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

Howard Marshall, Vice Chairman (Elected as Vice-Chairman 30th November 2013)

Russell Brown, Honorary Treasurer (Elected as Honorary Treasurer October 2015).

Trustees

John Abbott

Prof Barry Hunt

Dr Harriet Bonney

Grace Kay

Richard Brown

Alison Love

Russell Brown

Howard Marshall

Andrew Downie

Peter Reeves

Gemma Fish

Philip Griffiths (appointed 4th October 2015)

Ann Truscott

The company secretary and CEO is Susan Millman, Ataxia UK.

Ataxia UK uses the following professional advisors:

Auditors

Mazars LLP

Times House, Throwley Way
Sutton, SM1 4JQ

Solicitors

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

Bankers

Barclays Bank PLC

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

HR Consultants

HR Services Partnership

Bentley House
North Heath Lane
Horsham
West Sussex RH12 5QE

Structure, Governance & Management

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

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

Under the articles of association of the Charity, trustees are nominated for election by the Friends of the Charity, comprising beneficiaries affected by ataxia and others interested in the welfare of those affected by ataxia. Each year one quarter of the trustees retire but are eligible to stand again if they so wish. In addition, the trustees may co-opt up to three additional trustees. New Trustees receive briefing upon joining the Board. An induction day was introduced in 2009.

The Annual General Meeting of the Charity took place on 4 October 2015.

New Trustees are invited to an induction session with the CEO and/or 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; the internal structure of the charity. New Trustees are provided with Ataxia UK's Trustee Handbook which includes links to the most significant documents on the Charity Commission website.

The pay and remuneration of the key managers of Ataxia UK is considered annually by a remuneration committee comprising the Chair, Treasurer, and one other committee member which 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 OSCR in exercising their powers and duties.

Ataxia UK operates throughout the United Kingdom and Northern Ireland, through its network of branches and support Groups which provide activities and support to Friends. The 2015 Regional Conferences were held in Cardiff, Belfast and Glasgow, and the National Conference at Stansted.

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 15 different European countries.

The **Scientific Advisory Committee (SAC)** meets three times per year. It 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

Professor Zofia Chrzanowska-Lightowlers

Dr Monica Busse-Morris

Dr Patrick Lewis

Dr Hélène Plun-Favreau

Dr Irina Udalova

Dr Claire Kelly

We are extremely grateful for their support over the years.

The Committee includes four lay members:

Rosemary Homayoun, John Abbott, Pitt Rink, John Dobson

Dr Gavin Kilpatrick, Professor Graham McClelland and lay member **Nigel Kilvington** resigned during this period.

Professor Barry Hunt attends as Trustee Scientific Advisor.

All members are unpaid volunteers.

Employees

During 2015-2016 the average number of full time equivalent employees during the year was 10 (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 2015-2016 we have used a number of interns and volunteers at our central office. They have provided invaluable assistance in our day to day work and taken responsibility for projects which would not have otherwise come

to fruition. Our Branches and Support Groups are all run by volunteers, many of whom have ataxia themselves. The Ataxia UK accredited Specialist Ataxia Centres in London and Newcastle and the ataxia clinic in Oxford are attended by volunteers whose role is to provide emotional and practical support to people with ataxia and their families visiting the clinics. We are also grateful to the volunteers who assist our Research Department by serving on the Scientific Advisory Committee and Medical Advisory Panel. Loyal and committed volunteer fundraisers run events both large and small to provide Ataxia UK with essential funds. 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 are:

- loss of income – we have sought to mitigate this risk through diversifying and increasing our fundraising efforts, and ensuring effective control of expenditure.
- loss of key staff – relevant staff and the Board of Trustees are kept informed of plans, and actions taken; significant functions are monitored through supervision structures and reports to relevant meetings.
- loss or corruption of key information – we ensure that information is retained systematically on robust systems.

Objectives & Activities

Ataxia UK's charitable objects are to 'relieve those persons affected by ataxia'. Many different kinds of ataxia have been identified, with varying causes and characteristics. They are, typically, 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 or 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 vision is to find a cure for ataxia, trustees recognise that in the more immediate term, those affected by ataxia need a variety of support, and this informs our activities.

There are four major strands to Ataxia UK's activities:

Funding and support of research towards finding treatments and a cure

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

Improvements in treatments and care

People with ataxia want a quick diagnosis delivered in a supportive and sympathetic manner, with the choices of care pathways explained to them, and assistance in accessing them 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 Centres.

Accredited Ataxia Centres are specialist clinics within NHS Trust Hospitals which bring together in a one-stop shop all the services needed by someone with ataxia from diagnosis to ongoing management of their condition.

Care and Support Services for people affected by ataxia

Care and support services comprise all other services for beneficiaries which include information and website services including our quarterly 'Ataxia Magazine', Helpline services, conferences and workshops on topics of interest and our network of Branches and Support Groups.

Raising Awareness

Ensuring that people are aware of ataxia is fundamental to all of our work. Changing public perception as well as increasing understanding of medical and healthcare professionals is also key to ensuring quicker diagnosis and better access to treatment and the services available to people with ataxia. This is inherently tied into fundraising. The more aware people are of what we are trying to achieve, the more likely they are to donate to the Charity.

Achievements & Performance

Funding and support of research towards finding treatments and a cure

Increase funding available for research

Ataxia UK's research staff have been active in fundraising for research as well as seeking ways to spend most effectively on Ataxia UK-funded research projects. This has been achieved in a number of ways:

- a) Encouraging and supporting researchers in successfully seeking funding from their own institutions to part-fund projects funded by Ataxia UK.
- b) Building and maintaining relationships with ataxia charities worldwide; encouraging them to co-fund research projects with Ataxia UK, and keeping them informed throughout the projects with regular progress reports. Our ongoing relationship with Ataxia Ireland has led them to contribute to two further research projects in 2015-16.
- c) Engaging with pharmaceutical companies which has resulted in closer relationships with Takeda Cambridge's employees selecting us as their Charity of the Year for a second year and donations totalling £10k, while Takeda is sponsoring a leaflet on research. (See below)
- d) A new partnership with Findacure charity, to develop a social impact model to fund research trials in rare diseases including ataxia.
- e) On behalf of Euro-ataxia supporting researchers in successfully gaining funds for two ataxia projects from the European Commission: one on the recessive ataxias (other than FA) and one on SCA3. Both have the involvement Dr Paola Giunti at the London Ataxia Centre and are large project grants with 6-8 partner Groups.

Secure a further research partnership with a pharmaceutical company

Ataxia UK has continued to build relationships with pharmaceutical companies which we hope will result in partnerships to develop treatments for the ataxias. During the year Ataxia UK has been working with Takeda, who are investing in ataxia research and are in the process of testing the effect of a drug that, although not a cure, could relieve ataxia symptoms in a range of ataxias. We are in touch with their scientific and clinical teams and working with them to support their research efforts. The Senior Medical Director working on this programme attended the annual Euro-ataxia meeting and gave a presentation on Takeda's programme. Takeda has generously agreed to produce and print a research leaflet to be used at events to inform about Ataxia UK's activities in research and explain the progress which has been made.

Co-ordinate the Euro-ataxia collaboration with FA natural history database

Ataxia UK has played a leading role in coordinating a Euro-ataxia collaboration to help fund the FA European database and natural history study. A total of six ataxia charities from different countries (members of Euro-ataxia) have come together to fund this important project that provides crucial information and infrastructure to run successful trials to test treatments in FA.

Secure sponsorship for the production of a quarterly Research Briefing

The newly created monthly e-newsletter now includes research briefings, and a new section of the website dedicated to research news has been created. This was a result of direct sponsorship for a quarterly briefing not being secured.

Work on structures to translate promising research findings to clinical practice

This has been postponed to 2017-18.

Review and re-launch Ataxia UK's Research Strategy

This has been delayed to 2016-17 as it will form part of the new Strategic Plan to be commenced in April 2017

Other research activities:

Ataxia UK funded research

During the year Ataxia UK awarded six new grants, plus one small grant under £5K (see Appendix). This included two grants as part of the Pfizer partnership project. We held three full meetings of the Scientific Advisory Committee where funding recommendations were made and continued to manage 12 research projects that were in progress during the period. This involves providing support to researchers where needed, evaluating annual reports, and monitoring finances.

As a member of the Association of Medical Research Charities Ataxia UK is required to maintain certain standards regarding our practice in awarding research grants. This year all charities were audited and Ataxia UK passed this audit successfully.

Data on research outcomes of projects we have funded over the last few years has been collected (using the Researchfish portal). The data showed some positive outcomes for our research, including promising results in further funding achieved by the researchers. During this period, the funding investment from Ataxia UK was £2,084,929 (including co-funders) or £1,595,101 (Ataxia UK portion). The amount of further funding raised during the grant period that went to ataxia research is £3,040,090.

Last year we reported the results of a pilot trial of nicotinamide in 10 people with FA that gave sufficient encouragement to pursue this line of research in a larger placebo-controlled trial. Ataxia UK has been exploring a new way to try and fund this trial involving a partnership with the charity Findacure.

Euro-ataxia and International Initiatives

Over the year Ataxia UK has produced a new website for Euro-ataxia (www.euroataxia.org). This gives us a presence in Europe, and has already resulted in some new contacts. Ataxia UK also organized the annual Euro-ataxia meeting, attended by around 30 people, including five academic researchers, two representatives from pharma and representatives from seventeen ataxia patients groups.

We have continued working closely with the American charity FARA on a number of projects. Our CEO also attended the National Ataxia Foundation conference ensuring our relationship NAF has also continued to flourish.

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:

- Genomics England study
- Developing new tools for measuring how nerves are affected in Friedreich's ataxia (Newcastle)
- Retinal changes in people with ARSACS (London)
- Natural history study in Friedreich's ataxia (London)

Dissemination of research

Information on relevant research developments is disseminated via the Ataxia magazine and research news pages. We also have a registry of over 500 researchers with an interest in ataxia to whom our regular e-newsletters are distributed containing information on events/conferences, funding opportunities and other ataxia related information.

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

Ataxia UK research staff have attended numerous meetings and conferences at which we were invited to give presentations or to have a display; raising the profile of ataxia and Ataxia UK, and providing opportunities to establish new collaborations and encourage ataxia research. This has resulted in new contacts with pharmaceutical companies and a partnership with Findacure. Our existing partnership with Pfizer (see below) facilitated several of these opportunities.

- Rare disease conference, Oxford – May 2015 (Invited speaker)
- Findacure drug repurposing in rare disease networking event, Cambridge-Aug 2015
- Labour party conference breakfast roundtable meeting, Brighton - Sep 2015 (Invited to present Ataxia UK case study)
- World Orphan Drug Conference, Brussels – November 2015 (Ataxia UK display)
- Pfizer European Rare Disease Day, London - Jan 2016
- Findacure: Drug Repurposing in Rare Diseases, London (Invited talk)
- Orphan drugs and rare disease global congress, London – March 2016
- Genetic Disorders conference March 2016 (Invited speaker)

Improvements in treatments and care

Launch the 3rd edition of the 'Medical Guidelines for the Treatment of Ataxia'

The extensive revision of the Medical Guidelines has caused various delays but will be completed during 2017. It has been a huge project involving numerous experts in many different medical specialties relating to ataxia. Once launched, the 3rd Edition of the Medical Guidelines will provide a comprehensive guide to all aspects of diagnosing and managing ataxias.

Research patient experience in the four home countries of the UK to ascertain the treatment and care received by patients with ataxia from the NHS

We surveyed Friends in Wales, Northern Ireland and Scotland regarding their experiences of diagnosis and care in the NHS. We were not surprised to find very unsatisfactory delays in diagnosis and a general dissatisfaction with the care being received, although encouragingly a number of Friends reported that they were satisfied with the treatment and care they are getting.

Develop 'virtual Ataxia Centre'; obtain funds to launch 'virtual Ataxia Centre'

For several years we have been exploring the possibility of establishing 'satellite' Ataxia Clinics to enable ataxia patients to access specialist ataxia neurologists from Specialist Ataxia Centres without having to make long journeys. We envisage these would use telecare video links to allow remote consultation by the neurologist, supported by a specialist ataxia nurse based in the locality. We have been actively investigating the possibility of providing this type of facility in Northern Ireland where the Northern Ireland Rare Disease Partnership is in support of this sort of development. We were also hoping to assist in the development of a similar satellite service in Devon and Cornwall. In 2014 we were the grateful beneficiaries of nearly £20,000 from the Charitable Appeal of the Mayor of Exeter, Rachel Lyons and have sought additional funds to enable the introduction of this service. Unfortunately in the absence of funding we have put these ideas on hold and with members from the South West will be looking at other ways of deploying the funds raised by the Mayor of Exeter.

Host seminars for clinicians and therapists in Belfast and London

This project has been postponed due to delays in processing the funding in the Northern Irish Government for a seminar in Belfast and staff time constraints; however we hope that at least one of these seminars will go ahead in 2016-17.

Other Work to Improve Treatments and Care:

Accredited Ataxia Centres

The three Accredited Ataxia Centres in Sheffield, London and Newcastle have continued to thrive with increased caseload of ataxia patients and positive feedback. In addition, there is an Oxford Ataxia clinic.

Volunteers with personal experience of ataxia are supporting clinics in London, Newcastle and Oxford.

Medical Advisory Panel

A constructive discussion was held with five neurologists, one lay member and Ataxia UK representatives who attended the Medical Advisory Panel's annual meeting. It was a useful opportunity for each to share information on ongoing research and other activities. Presentations were given by Prof Hadjivassiliou, who spoke about his work in immune mediated ataxias and Dr Giunti who spoke about the natural history studies she is doing in FA and some SCAs and work on the development of a diagnostic tool in ARSACS. The Panel was asked for advice on Findacure's new model for funding trials and a cost of illness study in FA that is needed for this project.

Supporting charities in lobbying for improvements in care and research

We are members of a number of organisations, such as Genetic Alliance UK, Rare Disease UK, the Association of Medical Research Charities and the Neurological Alliance and we continue to support these organisations in the excellent work they do.

Responses to NHS Consultations/ request for expert advice

In partnership with Genetic Alliance UK we provided support in updating literature on the Genetics Home Reference (GHR), an information resource developed and maintained by the National Library of Medicine. The Research Manager was invited to be a consumer reviewer for a Cochrane Review on treatment of swallowing problems in people with hereditary ataxias.

Ataxia UK continues to be an active member of the Neurological Alliance and Sue Millman, our CEO, re-joined the Board in November 2015.

NHS England Public and Patient Voice Assurance Group for Specialised Commissioning

The CEO has continued in membership of this group which has monthly meetings often attended by very senior members of NHS England. It has participated in the development of a number of consultation processes during the last year including that for the review of the Clinical Reference Groups for Specialised Commissioning; and assured a number of other consultation processes.

Care and Support Services for people affected by ataxia

All About Ataxia seminars

All About Ataxia seminars are designed for anyone looking to understand more about the ataxia condition. This is provided in a format that is easy to understand with plenty of opportunities to ask questions and share personal experiences. All About Ataxia sessions were held at the three regional conferences and the annual conference. An additional All About ataxia day was held in Sheffield on 5th November 2015. Consultant Neurologist Prof. Marios Hadjivassiliou was also in attendance on the day. As well as providing answers to common medical and clinical questions, we hope that having brought people together who may never have attended an Ataxia UK event (or perhaps never even met someone with ataxia) they may wish to join an existing branch or support group or set up a new one.

Develop Ataxia 16 – 30 project

The annual conference also saw the inaugural Ataxia: 16-30 Chill Out, which was deemed a success by those in attendance. Several new young people joined the group and were also introduced to the work of Ataxia UK. We conducted filming across the day and carried out several interview-style films which have successfully been cut and edited. The films can be found on the 16-30 website and promote the project as well as sharing advice and tips for managing ataxia. This 16-30 Project has been made possible due to the funding from Comic Relief.

Develop website for the use of Branches and Support Groups

In order to manage the extensive network of Branch and Support Groups we have developed a microsite detailing all of the Groups, details of their primary contacts and a calendar of their forthcoming meet-ups and events.

Increase Branches and Support Groups

The UK – wide network of Branches and support Groups continue to develop. In the past 12 months, groups have been founded in Aberdeen, Chester, Crewe, Dudley, Gravesend, Lincolnshire, Liverpool, Redditch and Southampton. Additionally, the Nottingham and Wimbledon groups have been relaunched.

Host conferences for Friends in Wales, Scotland, Northern Ireland and England

To celebrate the fiftieth anniversary of Ataxia UK we hosted a series of national conferences in Cardiff, Belfast and Glasgow, alongside the *All About Ataxia* days in each city. We were delighted with the attendance and were able to provide an overview of the past 50 years as well as research updates and the future plans of the charity.

Friends Survey

We have formulated a survey for Ataxia UK to be distributed next year. The survey will provide us with what Friends deem important to them in terms their ataxia and the direction in which the charity should be moving and how our resources are spent.

Grants

In addition to the Jerry Farr Travel Fellowship, Cornberg Grant and Headley Trust, we now facilitate the distribution of two other grants. The Mark Dower Trust offers an annual grant of up to £3,000. The aim is to support young people with ataxia by enabling them to pursue skills, hobbies or further educational opportunities and hence allow them to maximise their independence. The fifth grant Friends can access is from the Florence Nightingale Aid in Sickness Trust, which provides funding towards medical equipment for children and adults of all ages.

Raising Awareness

Conclude development of Ataxia UK Website

The updated Ataxia UK website was launched in mid-March 2015 and has been developed over the year based on user feedback and their suggested improvements. The bookings for all our conferences in 2015 and the 50th Anniversary Ball were successfully managed through the website. Fundraising through the website has also increased throughout the year as donors have steadily switched from the traditional platforms, such as *JustGiving* and *Virgin Money Giving*, and moved across to the new website which unlike the other platforms makes no charges for handling a donation.

Awareness film

Millie Mae Ormsby first appeared in our 2020 Vision campaign in 2012. We revisited her this year to make a new film records the progress in her condition since the initial film. A short version of the film was shown at the 50th Anniversary Ball and we are currently finalising a longer version, which will accompany a press release to local and national news agencies. This film is to be used as a fundraising tool when applying for grants as well as being showcased at the 2016 conferences. We have also begun filming a series of short films that highlight the importance of Ataxia UK's work. This work is the result of a grant from the James Tudor Trust.

TBWA Partnership

We continue to work with the renowned creative agency, TBWA as part of our marketing programme. We now have a clearly defined brand that not only embodies the condition that we are fighting to cure, but in a crowded market of thousands of charities, is visually striking and different. We also have at our disposal a portfolio of images, posters and films that have been crafted by leading designers working at the very top of their field.

Ataxia Magazine

It is a year since we rebranded the Ataxia Magazine which has been warmly received by supporters for its increased visual appeal and variety of content. We aim to include a variety of information including research, fundraising updates and first-hand accounts from people with ataxia. We now distribute over 4000 hard copies or digital versions, and we know the readership is considerably greater than this.

Produce Ataxia UK '50 Years Review'

As 2015 marked 50 years of Ataxia UK we created a 50th Review to accompany the Christmas appeal. This reflective booklet, utilised archive and current information, graphics and images, was completed and distributed in early December. Feedback was overwhelmingly positive with several people contacting the office directly to compliment us.

Ataxia Newsletter

By popular request, and as a result of our successful Branch & support group monthly e-newsletter we have changed it into a monthly Ataxia UK e-newsletter to update all Friends who wish to receive it between our quarterly magazines.

Rare Disease Day

As part of International Rare Disease Day, Pfizer Pharmaceuticals asked all its partner charities to exhibit their work at their UK head office. It was a great opportunity to chat with industry professionals and educate them on the complexities of the ataxia conditions.

Social Media

Our social media following continued to grow throughout the year. In the past 12 months we have gained 1,038 new Facebook followers and 766 new followers on Twitter. We enjoyed excellent levels of engagement around Ataxia Awareness Day, with our primary Facebook post being shared 818 times, resulting in over 70,000 people being reached. We have also created a charity LinkedIn page, as well as an Instagram account which has 82 followers.

Plans for Future Periods: Aims for 2016-2017

Funding and support of research towards finding treatments and a cure

Aims for 2016-17

- Organise International ataxia research conference for 2017
- Review messages for new Research strategy
- Analyse research outcomes of Ataxia UK funded research
- Engage and provide support to three large European research projects on Friedreich's ataxia and the cerebellar ataxias
- Support European Friedreich's ataxia research network in securing further funds for the FA database and natural history project
- Explore creation of a global patient registry for research
- Support Findacure in developing a social impact model to fund drug repurposing trials in rare diseases, and if successful plan an ataxia trial using nicotinamide.
- Work on translating promising research findings to clinical practice
- Develop new ways of engaging with pharmaceutical companies to further ataxia research

Improvements in treatments and care

Aims for 2016-17

- Launch the third edition of the 'Medical Guidelines for the management of the ataxias'.
- Disseminate the Ataxia Guidelines widely
- Host seminars for clinicians and therapists on ataxia
- Seek funding to develop 'Virtual Ataxia Centre'
- Explore creation of a further Specialist Ataxia Centre

Care and Support Services for people affected by ataxia

Aims for 2016-17

- Continue with All About Ataxia Seminars
- Create four new Branches/support groups
- Increase support to Branches and support groups through volunteers providing help and guidance at a local level
- Continue and develop the monthly newsletter
- Continue to develop Ataxia 16 -30 Project
- Initiate work with children (and their parents)

Raising Awareness

Aims for 2016-17

- Aim to build relationships with schools in the area close to our office as well as the community
- Update and modify the website content accordingly
- Continue the TBWA partnership
- Continue to create more engaging video content

Grants Agreed

1) Dr Mark Baker (University of Newcastle) 'Developing a new neuronal biomarker in FA'

Extension grant jointly funded with FARA-US (£3,100 each).

Funding: £6,200

2) Dr Sarah Doss (Charité - University Medicine Berlin) 'Investigating cerebellar glutathione in SCA14'

Funding: £11,600 over one year. The German ataxia charity DHAG also contributed additional funds to this project.

3) Prof Massimo Pandolfo (Universite' Libre de Bruxelles) 'European Friedreich's ataxia database and natural history study'

Funding: Ataxia UK contributed £40,000 for one year to this project to be used in multiple sites that are part of this project including one site in the UK.

4) Dr Michele Lufino (Oxford University) 'Pfizer partnership FA drug development project'

Funding: £79,020 over 2 years.

5) Dr Paola Giunti (UCL Institute of Neurology) 'Pfizer partnership FA drug development project'

Funding: £12,500 over one year. Ataxia Ireland co-funded this project contributing £2,840 of this grant.

6) Dr Manolis Fanto (King's College, London) 'Understanding cell toxicity in DRPLA and other SCAs'

Funding: £14,000

7) Drs Mark Pook and Michael Themis 'Gene therapy in FA'

Funding: Small grant application of £5,000. This includes co-funding from Ataxia Ireland of £2,840.

In addition to the above grants we are also administering a grant to Dr Paola Giunti (UCL, Institute of Neurology) on behalf of two ataxia charities based outside the UK: GoFAR and FARA-US. This grant is for **£77,586**.

Financial Review

Overview

Fundraising conditions within the UK continue to be enormously challenging for charities of our size. One of the strengths of Ataxia UK has however always been its resilience and ability to rely on a core group of regular donors. At the same time, because of the challenges of the existing economic environment, the charity has seen a reduction in reserves over a period of time.

Part of this reduction in reserves was planned as it related to awards in the year from the unspent amount of restricted legacies or donations from previous financial periods (for example Cornberg and Jerry Farr Travel fund). In addition, we have drawn down on surpluses from previous financial periods which were restricted to specific research (particularly Friedreich's Ataxia research), as we balance our core services within treatment and care with the maintenance of a level of funding into important research programmes.

During the 2015/16 financial year, we saw a £137k reduction in restricted reserves as a result of this utilisation of prior year surpluses and unspent amounts. Unrestricted funds decreased by £112k which, while disappointing was managed in the knowledge that we would make changes to our cost base in line with the pattern of income reduction over time. We have taken steps to address this by moving to a new property, thereby significantly reducing our fixed establishment costs and have restructured the charity to reduce headcount, while still maintaining core services.

These changes have been made in order to arrest the gradual erosion of unrestricted funds by ensuring that we have a cost base which better mirrors our recent income generation.

Review of Income

Total revenue for 2015/16 was £1,041k, a decrease of 20% on the previous year (2014/15: £1,305k). The reduction in income is largely as a result of an absence of research conference income which contributed £241k in 2014/15. Excluding this amount, the results are comparable.

Of our major components of income, voluntary income excluding legacies at £585k fell by 19% (2014/15: £726k). This is primarily as a result of the biennial Big Bad Bike Ride event not occurring in the 2015/16 financial year (£140k of income generated in 2014/15).

Grant income increased by 30% in the year to £171k as a result of growth in our success in attracting funding from trusts and foundations, as well as our ability to secure co-funding for our research projects.

Review of Expenditure

Our spending on research was £246k, an increase of 33% on the previous year (2014/15: £185k). This increased level of investment in research projects is predominantly due to our success in bringing in co-funders for our research programmes, (such as GoFAR/FARA). We continue to explore ways to stretch our ability to fund exciting new

research by attracting joint financing of those projects. Care services expenditure (helping people affected by ataxia live with the condition) increased by 8% to £250k (2014/15: £231k). This expenditure level reflects our commitment to support those people who are living with ataxia, many of whom are facing severe financial challenges. Ataxia Centre spending was consistent with the previous financial year at £29k (2014/15: £31K).

Investment policy and performance

Our investments are, in all cases, held in the form of publicly quoted bonds and cash. The portfolio is managed by investment managers whose performance is reviewed regularly against agreed benchmarks for the return on the portfolio. 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.

Reserve levels at year end

Total funds of the charity on 31 March 2016 were £453k (31 March 2015: £702K).

Restricted Funds were £174k, (detailed in Note 24), primarily comprising the Cornberg Adaptation of Homes fund which will be disbursed over a number of years. The trustees have also allocated a small element of reserves to take advantage of research opportunities at short notice (£31k).

Designated Funds totalled £16k representing funds held at branches (31 March 2015: £55k) and are detailed in Note 23.

General reserves of the charity as at 31 March 2016 were £264k (31 March 2015: £337k). 'Free reserves' of the charity are calculated as unrestricted funds less the net book value of tangible fixed assets. 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. As at 31 March 2016, free reserves totalled £179k, equating to three months' operating expenditure (31 March 2015: Five months), a level that the trustees consider to be adequate.

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 of the 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

Approved by the trustees on 21st December 2016

Harriet J C Bonney



Harriet Bonney
Chair of Trustees

Russell Brown
Treasurer

Independent Auditor's Report to the Trustees & Members of Ataxia UK

We have audited the financial statements of Ataxia UK for the year ended 31 March 2016 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

Respective responsibilities of trustees and auditors

As explained more fully in the Trustees' Responsibilities Statement set out on page 21, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's (APB's) Ethical Standards for Auditors. 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.

Scope of the audit of the financial statements

A description of the scope of an audit of financial statements is provided on the Financial Reporting Council's web-site at www.frc.org.uk/auditscopeukprivate.

Opinion on the financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 March 2016 and of its income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Opinion on the other matter prescribed by the Companies Act 2006

In our opinion the information given in the Trustees' Annual Report for the financial period for which the financial statements are prepared is consistent with the financial statements.

Matters on which we are required to report by exception

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

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

.....*N J Wakefield*.....

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: *21st December 2016*

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 2016

		Unrestricted funds	Restricted funds	Total 2016	Total 2015
	Notes	£	£	£	£
Income					
Donations and Legacies	3	667,739	65,245	732,984	782,750
Charitable activities	4	60,435	235,016	295,451	507,946
Investments	5	12,631	0	12,631	13,938
Total Income		<u>740,805</u>	<u>300,261</u>	<u>1,041,066</u>	<u>1,304,634</u>
Expenditure on:					
Raising Funds	6	(241,942)	0	(241,942)	(163,338)
Charitable Activities	7	(566,258)	(473,192)	(1,039,450)	(1,179,854)
Total Expenditure		<u>(808,200)</u>	<u>(473,192)</u>	<u>(1,281,392)</u>	<u>(1,343,192)</u>
Net (Expenditure)		(67,395)	(172,931)	(240,326)	(38,558)
Net (Losses) on Investments		(8,588)		(8,588)	(9,615)
Net movement in Funds		(75,983)	(172,931)	(248,914)	(48,173)
Transfer from Unrestricted to Restricted		(36,088)	36,088	0	0
Total Funds brought forward		391,770	310,530	702,300	750,473
Total Funds Carried Forward		<u>279,699</u>	<u>173,687</u>	<u>453,386</u>	<u>702,300</u>

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

All recognised gains and losses are included in the SOFA.

The accompanying pages form part of these financial statements.

ATAXIA UK

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 2016

	Unrestricted funds	Restricted funds	Total 2015
	£	£	£
Income			
Donations and Legacies	556,094	226,656	782,750
Charitable activities	291,851	216,095	507,946
Investments	13,938	0	13,938
Total Income	<u>861,883</u>	<u>442,751</u>	<u>1,304,634</u>
Expenditure on:			
Raising Funds	(161,738)	(1,600)	(163,338)
Charitable Activities	(768,591)	(411,263)	(1,179,854)
Other			
Total Expenditure	<u>(930,329)</u>	<u>(412,863)</u>	<u>(1,343,192)</u>
Net (Expenditure) Income	(68,446)	29,888	(38,558)
Net (Losses) on Investments	(9,615)		(9,615)
Net movement in Funds	(78,061)	29,888	(48,173)
Transfer from Unrestricted to Restricted	(11,097)	11,097	0
Total Funds brought forward	480,928	269,545	750,473
Total Funds Carried Forward	<u>391,770</u>	<u>310,530</u>	<u>702,300</u>

The SOFA has been prepared on the basis that all operations are continuing.
 All recognised gains and losses are included in the SOFA.
 The accompanying pages form part of these financial statements.

ATAXIA UK
BALANCE SHEET
As at 31st March 2016

		2016		2015	
	Notes	£	£	£	£
Fixed assets					
Tangible Assets	13	42,040		12,573	
Intangible Assets	14	42,529		49,354	
Investments	15	<u>509,080</u>		<u>580,779</u>	
			593,649		642,706
Current assets					
Stock	16	0		6,501	
Debtors	17	184,001		210,056	
Cash at bank and in hand	18	<u>112,400</u>		<u>318,178</u>	
		296,401		534,735	
Creditors: amounts falling due within one year	19	<u>(406,571)</u>		<u>(443,859)</u>	
Net current (liabilities) assets			<u>(110,170)</u>		<u>90,876</u>
Total net assets less current liabilities			483,479		733,582
Creditors: amounts falling due after more than one year	20	<u>(30,093)</u>		<u>(31,282)</u>	
Total Net Assets	21		<u>453,386</u>		<u>702,300</u>
Accumulated funds					
Unrestricted funds					
General funds	22		263,866		336,872
Designated funds	23		<u>15,833</u>		<u>54,898</u>
			279,699		391,770
Restricted funds	24		<u>173,687</u>		<u>310,530</u>
Total funds			<u>453,386</u>		<u>702,300</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 21st December 2016 and signed on their behalf by

Harriet J C Bonney

.....

Harriet Bonney - Chairman

Russell Brown

.....

Russell Brown - Treasurer

The accompanying pages form part of these financial statements.

Charity Number: 1102391

Company Number : 04974832

ATAXIA UK
Statement of Cashflow
As at 31st March 2016

	2016	2015
	£	£
Cash generated from operating activities:		
Net cash provided by (used in) operating activities	(239,572)	(250,206)

Cash flows from investing activities:		
Dividends, interest and rents from investments	12,631	13,938
Purchase of property, plant and equipment	(41,948)	(15,550)
Proceeds from sale of investments	133,295	139,662
Purchase of investments	(70,184)	(137,658)
	33,794	392
	(205,778)	(249,814)

Net increase/(decrease) in cash:		
Cash at bank and in hand less overdrafts at the beginning of the year	318,178	567,992
Change in cash and cash equivalents	(205,778)	(249,814)
Cash at bank and in hand less overdrafts at the end of the year	112,400	318,178

Reconciliation of net income/expenditure to net cash flow from operating activities	2016	2015
	£	£
Net income/(expenditure)	(248,914)	(48,173)
Adjustments for:		
Depreciation charges	19,306	6,355
Net (gains)/losses on investments	8,588	9,615
Dividends and interest from investments	(12,631)	(13,938)
(Increase)/decrease in stocks	6,501	(6,501)
(Increase)/decrease in debtors	26,055	(101,102)
Increase/(decrease) in creditors	(38,477)	(96,462)
Net cash provided by (used in) operating activities	(239,572)	(250,206)

Analysis of cash at bank and in hand less overdrafts	2016	2015
	£	£
Cash at bank and in hand	112,400	318,178
	112,400	318,178

ATAXIA UK
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 2015/16 financial year, we had a decrease in our net movement in funds. We have addressed this decrease through changes to our cost base in line with the pattern of income reduction over time. Through monitoring of the 2017 budget and with balanced budgets planned for the next two years 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. **Reconciliation with previous Generally Accepted Accounting Practice:** In preparing the accounts, the trustees have considered whether in applying the accounting policies required by FRS 102 and the Charities SORP FRS 102 the restatement of comparative items was required. At the date of transition (1st April 2014) in applying the requirement to recognise liabilities arising from employee entitlement to paid annual leave. The initial liability recognised at the date of transition was for the holiday entitlement carried forward and for the entitlement arising in the year which was due but not taken. The initial liability was for £5,988. No other restatements were required. In accordance with the requirements of FRS102 a reconciliation of opening balances is provided.
- d. **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.
- e. **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.
- f. **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.
- g. **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.

- h. **Income Recognition:** Income is recognised on an accrual basis, with the exception of donations and fundraising receipts, which are on a cash basis. Deferred income represents grants received for future years and is released to income in the period for which it has been received. All income previously deferred has been released during the current year.
- i. **Legacy Recognition:** In accordance with SORP 2015, legacies are recognised when they are certain and measurable.
- j. **Income tax recoverable:** Income tax recoverable has been added to the relevant income source to which it applied.
- k. **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.
- l. **Unrestricted funds:** Unrestricted funds are funds that can be used in accordance with the charitable objects at the discretion of the Trustees.
- m. **Designated funds:** Designated funds represent amounts put aside by the trustees as outlined in Note 23.
- n. **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.
- o. **Branches:** The accounts of the Charity's branches have been consolidated into these accounts.
- p. **Operating Lease Rentals:** Rentals applicable to operating leases are charged to the Statement of Financial Activities as they become due.
- q. **Contractual Lease Commitments:** Formal and unconditional commitments to research expenditure and other grants at the balance sheet date are included within creditors, in accordance with SORP 2015. 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.
- r. **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.
- s. **Taxation:** As a registered charity, the Charity is exempt from taxation under section 505 (1) of the Income & Corporation Taxes Act 1988.
- t. **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.
- u. **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 provided.

3. Donations and Legacies Income

	2016	2015
	£	£
Donations	279,854	182,224
Legacies	148,030	56,463
Fundraising Activities	305,100	544,063
	<u>732,984</u>	<u>782,750</u>

4. Charitable Activities Income

	2016	2015
	£	£
Childlife	107,500	117,500
Annual Conference	16,500	17,866
Research Conference	0	240,682
Grants Receivable	171,451	131,898
	<u>295,451</u>	<u>507,946</u>

5. Investment Income

	2016	2015
	£	£
Income on investment portfolio	2,111	11,796
Interest	10,520	2,142
	<u>12,631</u>	<u>13,938</u>

6. Raising Funds Expenditure

	2016	2015 Restated
	£	£
Costs of Raising Funds	238,946	159,646
Investment Managers Fees	2,996	3,692
	<u>241,942</u>	<u>163,338</u>

7. Charitable Activities Expenditure

	Direct Costs	Grants	Support Costs	2016 Total	2015 Restated Total
	£	£	£	£	£
Research Activities	70,536	245,906	73,146	389,588	301,382
Ataxia Centres	-	28,835	-	28,835	31,204
Care Services	48,763	44,110	157,660	250,533	230,039
Total Charitable Activities	<u>119,299</u>	<u>318,851</u>	<u>230,806</u>	<u>668,956</u>	<u>562,625</u>
Raising Funds		-	125,077	125,077	118,708
Research Conference					251,419
Raising Awareness	66,872	-	102,954	169,826	173,215
Governance	25,762	-	49,829	75,591	73,887
Total	<u>211,933</u>	<u>318,851</u>	<u>508,666</u>	<u>1,039,450</u>	<u>1,179,854</u>

	2016	2015
	£	£
Total Support Costs		
Staff Costs	267,099	243,087
Office Costs	222,261	196,992
Depreciation	19,306	6,355
	<u>508,666</u>	<u>446,434</u>

8. Research Grants

	2016	2015
	£	£
Research Grants Made in year comprise		
<i>Small Molecule Neurotrophic Receptor Agonists as Potential Therapeutic Agents</i>		284
<i>Beta-band EMG-EMG coherence: a novel, painless and simple screening test for the onset of corticospinal tract disease/dorsal root ganglionopathy in Friedreich's ataxia'</i>		65,446
Gene Therapy of Friedreich's Ataxia: Generation of Herpesvirus FXN Vectors for use in humans		25,301
Investigating the mechanisms of long-range epigenetic gene regulation (LREGR) at the Friedreich's ataxia (FRDA) locus		66,438
Coenzyme Q10 a potential therapeutic target for ataxia: Evaluation of therapeutic strategies		37,710
Developing a new neuronal biomarker in FA	6,200	
Investigating cerebellar glutathione in SCA14	11,600	
Pfizer partnership – FA drug development project	12,500	
Pfizer partnership – FA drug development project	79,020	
Understanding cell toxicity in DRPLA and other SCAs	14,000	
Grant from GoFAR/FARA to Dr Giunti administered by Ataxia UK	77,586	
Small grant - gene therapy in FA	5,000	
European database and natural history study – EFACTS	40,000	
Medical Grants in year comprise		
Under spend in grants awarded in prior years		(10,386)
	<u>245,906</u>	<u>184,793</u>

9. Staff Costs

	2016	2015
	£	£
Staff costs comprised:		
Salaries	423,773	376,330
Social security contributions	38,302	32,007
Pensions	17,556	17,616
	<u>479,631</u>	<u>425,953</u>

The average number of full time equivalent employees during the year was 12 (2015: 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 heads of Fundraising, Research and Finance. The total employee benefits of the senior management team were £198,901 (2015: £187,908).

Staff costs includes £20,219 (2015 £0) of redundancy costs in respect of 3 (2015:0) employees.

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

£60,000 - £69,999

1

1

The pension contributions in respect of the above named individual in the year totalled £3,260 (2015: £3,260).

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

10. Expenditure

	2016	2015
	£	£
Expenditure includes:		
Auditors Remuneration	6,340	6,270
Payroll costs and accountancy services	2,145	1,733
Depreciation	19,306	6,355
Leases	7,566	

11. Related Party Transactions

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 and 7 Trustees (2015:16) claimed expenses totalling £9,755 (2015: £7,200). There were no other related party transactions that require disclosure.

12. 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 provides a guarantee limited to £1.

13. Tangible Fixed Assets

	Building Works £	Other Assets £	Total £
COST			
As at 1st April 2015	0	33,509	33,509
Additions	21,482	14,466	35,948
Disposals	0	(10,879)	(10,879)
As at 31 March 2016	<u>21,482</u>	<u>37,096</u>	<u>58,578</u>
DEPRECIATION			
As at 1st April 2015	0	20,936	20,936
Charge for year	0	6,481	6,481
Disposals	0	(10,879)	(10,879)
As at 31 March 2016	<u>0</u>	<u>16,538</u>	<u>16,538</u>
NET BOOK VALUE			
As at 31 March 2016	<u>21,482</u>	<u>20,558</u>	<u>42,040</u>
As at 1st April 2015	<u>0</u>	<u>12,573</u>	<u>12,573</u>

Included within the net book value of the 'Other Assets' is an amount of £13,755 (£4,700 in 2015) relating to items acquired on Finance Lease/Hire purchase.

14. In-tangible Fixed Assets

	Software £
COST	
As at 1st April 2015	76,226
Additions	<u>6,000</u>
As at 31 March 2016	<u>82,226</u>
DEPRECIATION	
As at 1st April 2015	26,872
Charge for year	<u>12,825</u>
As at 31 March 2016	<u>39,697</u>
NET BOOK VALUE	
As at 31 March 2016	<u>42,529</u>
As at 1st April 2015	<u>49,354</u>

15. Investments

	2016	2015
	£	£
Market Value at 1 April	580,779	592,398
Acquisitions	70,184	137,658
Disposals	(124,446)	(141,624)
Unrealised Gains	(17,437)	(7,653)
Market Value at 31 March	<u>509,080</u>	<u>580,779</u>
Cost of Investments at 31 March	495,548	549,809
Total Unrealised gains	<u>13,532</u>	<u>30,970</u>
Market Value at 31 March	<u>509,080</u>	<u>580,779</u>

UK Investments

Treasury UK Govt of 1.25% 2017	82,763	147,890
Treasury UK Govt of 2.5% 2016	128,126	130,719
GE Capital 4.125% 2017	41,674	42,915

Non UK Investments

Kreditanst FUR Wie 1% 2017	70,306	70,345
Nordrh-Westfalen 1.204% 2016	50,044	50,362
Euro Inv Bank 4.75% 2018	65,841	67,784
CSE D'Amort Dette 2.25% 2015		70,764
1.25% Municipality Finance plc Snr Reg-S	70,326	

16. Stock

	2016	2015
	£	£
Stock for ReSale	0	6,501

17. Debtors Under 1 Year

	2016	2015
	£	£
Income Tax Recoverable	48,687	30,159
Other Debtors	105,566	127,679
Prepayments	29,748	52,218
	<u>184,001</u>	<u>210,056</u>

18. Cash at Bank and in hand

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

19. Creditors: amounts falling due within one year

	2016 £	2015 £
Other Creditors	51,905	27,264
PAYE/NI	(166)	12,291
Deferred Income	7,941	14,995
Accruals	54,973	97,702
Research Grants	291,918	291,607
	<u>406,571</u>	<u>443,859</u>

20. Creditors: amounts falling due after one year

	2016 £	2015 £
Grants Payable	17,815	28,148
Misc Creditors	12,278	3,134
	<u>30,093</u>	<u>31,282</u>

21. Analysis of net assets between funds

	Restricted Funds £	Designated Funds £	General Funds £	Total 2016 £	Total 2015 £
Fixed Assets	-	-	84,569	84,569	61,927
Investments	77,120	-	431,960	509,080	580,779
Stock	-	-	-	-	6,501
Debtors	-	-	184,001	184,001	210,056
Cash at bank and in hand	96,567	15,833	-	112,400	318,178
Creditors	-	-	(436,664)	(436,664)	(475,141)
	<u>173,687</u>	<u>15,833</u>	<u>263,866</u>	<u>453,386</u>	<u>702,300</u>

22. Unrestricted Funds

	General Funds	Designated Funds	Total
Balance as at 1 April 2015	336,872	54,898	391,770
Net Decrease in funds during the year	(73,006)	(2,977)	(75,983)
Net transfers (see note 23)	0	(36,088)	(36,088)
Balance as at 31 March 2016	<u>263,866</u>	<u>15,833</u>	<u>279,699</u>

23. Designated Funds

	Opening Balance	Net Movement	Transfers	Closing Balance
Research Grants	36,088	-	(36,088)	-
Funds held in branches	18,810	(2,977)	-	15,833
	<u>54,898</u>	<u>(2,977)</u>	<u>(36,088)</u>	<u>15,833</u>

Designated Funds represent amounts put aside by the Trustees to meet approved grant and new project expenditure and contractual commitments at the balance sheet date. Designated funds comprise:

- Research grants:** To cover research programmes that the Trustees believe are promising avenues of research and appropriate research proposals in the process of development. These provisions are the Trustee's best estimate of the likely costs of specific projects and most are developed into unconditional grants within the year following the balance sheet date.
- Funds held in branches:** Funds held by the branches and not available for normal activities of central office.

24. Restricted Funds

	Opening Balance	Income	Expenditure	Transfer from Designated	Closing Balance
	£	£	£	£	£
General Research	-	33,852	2,606	-	31,246
Friedreich's ataxia research	100,694	101,683	218,146	15,769	-
Cerebellar ataxia research		4,835	25,154	20,319	-
Adaptation of homes	138,649	-	54,684	-	83,965
Young Person's projects	2,682	33,000	35,682	-	-
Jerry Farr travel fund	16,854	714	6,500	-	11,068
Welfare	1,644	165	1,809	-	-
Northern Ireland		450		-	450
Nicotinamide		20		-	20
Goods and Services Received	25,850	-	4,950	-	20,900
Helpline		164		-	164
Misc Grants		5,250	4,800	-	450
Childlife		107,500	107,500	-	-
Exeter	19,424	-	-	-	19,424
Awareness		6,628	6,628	-	-
Living with Ataxia videos		6,000		-	6,000
Others	4,733	-	4,733	-	-
	<u>310,530</u>	<u>300,261</u>	<u>473,192</u>	<u>36,088</u>	<u>173,687</u>

- 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. **Adaptation of home:** A legacy of Catherine Cornberg to provide adaptation of homes of people with ataxia to aid their daily living.
- e. **Childlife:** Funds given by Childlife to promote the relief of children who are in need. The auditors have agreed that the income received from Childlife has been spent in accordance with the terms of and conditions of the grant.
- f. **Young Persons projects:** Funds provided by donors to develop materials to help young people after diagnosis.
- g. **Jerry Farr travel fund:** Funds given by friends of Jerry Farr to help young people after diagnosis.
- h. **Welfare:** Funds provided for welfare grants.
- i. **Goods and Services Received:** Goods and Services received free of charge in respect of design and software services for Ataxia's website together with branding and design services.
- j. **Exeter:** Funds to be expended in the Exeter area.
- k. **Northern Ireland:** Funds to be expended in Northern Ireland.
- l. **Nicotinamide:** Funds for nicotinamide research.
- m. **Helpline:** Funds to support the helpline.
- n. **Living with Ataxia videos:** Funds to make videos for our website.

25. Capital Commitments

There are no capital commitments at 31 March 2016 (2015: Nil)

26. Lease Commitments

	2016		2015 (Restated)	
	Land & buildings	Other	Land & buildings	Other
Operating lease which are due:				
Within one year	31,200	2,536	64,205	3,133
Within two to five years	116,594	13,034	-	1,567
	<u>147,794</u>	<u>15,570</u>	<u>64,205</u>	<u>4,700</u>

27. Pension Schemes

All 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 £17,556 (2015: £17,616). £4,105 (2015: £939) was still outstanding at the year end.

