

Ataxia UK

**FINANCIAL STATEMENTS
and
TRUSTEES' ANNUAL REPORT**

Period 1 April 2010 to 31 March 2011

**Charity Registration Registered in England & Wales
(No 1102391) and Scotland (No SC040607)
Company Number 4974832**

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Chairman's Statement

2010/2011 has proved to be much more positive than I had anticipated thanks to the great family that is Ataxia UK, both friends and staff, with everyone working hard to keep the work of the charity on track.

Our membership has continued to increase, in particular in response to specific outreach efforts. Supporting people with ataxia continues to be one of our main priorities and to this end the Advocacy Service has grown with demonstrable efficiency. This service is an extension of the Helpline which continues its excellent efforts to respond to the specific needs of people affected by ataxia.

Our 2010 regional conference in Durham was a "bigger and better event" than we had previously achieved and proved to be most enjoyable as well as useful to attendees.

International collaboration in the funding of research, with no less than 8 different ataxia charities, has allowed for exciting research work to continue in a number of different directions.

The opportunities for scientific research are many and varied; we are fortunate to have research of superb quality to support. Looking back over the past 5 years the research potential has grown out of all recognition. Exciting days, but a long journey that we must all travel together if we are to achieve our aim of a world free of ataxia.

Elizabeth (Liz) Harrison
Chairman

Reference and Administrative Details of the Charity, its Trustees and Advisers

The charity's sole address is Lincoln House, Kennington Park, 1-3 Brixton Road London SW9 6DE. The trustees (who are also directors for the purposes of this report) who served during the year 2010/11 are:

Hon Officers:

Dr Elizabeth (Liz) Harrison	Chairman
Peter Taylor	Vice Chairman (Retired 10 October 2010)
Simon Bonney	Vice Chairman (Elected as Vice Chairman 22 January 2011)
Chris Bunton	Hon Treasurer

Trustees:

Dr Harriet Bonney	
Valerie Charbit	(Retired 10 October 2010)
Alison Gregg	
Marta Hancock	
Professor Barry Hunt	Chair of Research and Scientific Advisory Committee
Howard Marshall	
Elizabeth (Pit) Rink	(Retired 10 October 2010)
Darran Winfield-Stanesby	
Alan Thomas	
Martin McCudden	(Elected 10 October 2010)
Simon Bonney	(Elected 10 October 2010)
Peter Reeves	(Co-opted 10 October 2010)

Company Secretary is Susan Millman, Chief Executive, Ataxia UK.
Ataxia UK uses the following professional and other advisers:

Bankers:

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

Auditors:

Kingston Smith LLP
Devonshire House
60 Goswell Road
London EC1M 7AD

Investment managers:

Barclays Private Bank
1 Churchill Place
London E14 5HP

Solicitors:

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

HR Services:

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

Accountancy (to 30 Sept 2010):

The Kings Mill Partnership
75 Park Lane
Croydon
Surrey CR9 1XS

Structure, Governance and 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 Chairman of the Scientific Advisory Committee and two other trustees conduct business as required between meetings of the full Board of Trustees. The Trustees include people with ataxia, friends or 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 third of the trustees retire but are eligible to stand again if they so wish. In addition, the trustees may co-opt up to two 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 10 October 2010.

In compliance with the Charities Act 2006, 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 2010 Regional Conference was held in Durham, and the National Conference in Stansted.

This was the last year of our 3 year Strategic Plan; thus we spent time reflecting on the successes that we have achieved in implementing it, and developing a new plan for the coming 3 years to ensure that Ataxia UK continues on a firm basis: facilitating the research the search for a cure requires, and the immediate services needed by people living with ataxia.

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; and Vice-Chair of the Neurological Alliance.

The Scientific Advisory Committee meets three times per year. It provides independent scientific advice to the Board of Trustees on:

- The relevance of the Charity's research priorities
- The use of funds for supporting research related activities
- 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 of research activity sponsored by the Charity
- The nature and significance of scientific advice from independent reviewers
- The best practice to review grant proposals
- How to attract high quality research proposals
- Promoting research in the field of ataxia

Professor Barry Hunt is Chairman of the Scientific Advisory Committee (SAC). It comprises, as professional members, Dr Michael Barnes, Professor Patrick Chinnery, Dr Gavin Kilpatrick, Professor Bob Lightowlers and Professor Graham McClelland, Anne Rosser; and lay members Nigel Kilvington, Paul Stone and Katie Howie-Neaum. All members of the SAC are unpaid volunteers.

During 2010 Ataxia UK employed 13 members of staff (11 full-time equivalents). IT support and HR functions are outsourced. Accounting was brought back in house during the year upon the appointment of a Finance Manager, and the communications function was restructured to ensure an increased focus on awareness and income generation.

Volunteers: In addition to the volunteers who function as Trustees, many other volunteers play an important part in helping Ataxia UK to function. During 2010 we have started to use interns and volunteers at our central office. They have provided invaluable support to 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 Centre at the National Hospital for Neurology and Neurosurgery in London is attended by volunteers whose role is to provide emotional and practical support to people with ataxia and their families visiting the Centre. We are also grateful to the volunteers who assist our Research Department and serve 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.

Branch Network: In addition to the central functions and services, Ataxia UK supports branch and support groups which operate throughout the UK providing invaluable local support to people affected by ataxia. On 31st March 2011 the number of branches had risen to 21 and the number of support groups to 28, with three branches and 2 support groups being added during the year. Branches are formally affiliated to Ataxia UK, adopting our rules, and fundraising under the banner of Ataxia UK. Support groups are less formal, and over time may develop into branches.

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 and 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 three major strands to Ataxia UK's activities:

- ***Funding 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.

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.

- ***The Development of Ataxia Centres to improve 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 prevent deterioration and 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.

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.

Grants to Ataxia Centres are made following a visit to the applicant medical centre, by at least two members of the Ataxia Centres Committee which comprised Prof Barry Hunt, Dr Elizabeth Harrison, Dr Julie Greenfield (Research Projects Manager) and Susan Millman (CEO). This is followed by the submission of an application form detailing how the Centre will meet Ataxia UK's criteria, which is also assessed by the Ataxia Centres Committee which makes a recommendation to the Trustees.

- ***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 magazine 'The Ataxian', advocacy and helpline services, conferences and workshops on topics of interest and our network of branches and support groups. The raising of awareness of ataxia has been incorporated as a defined work strand in our new Strategic Plan.

Achievements and Performance

The last two years have been very difficult for charities, with many suffering income falls that threaten their existence. Despite this environment, we have returned to growth in 2010/11, although we are not yet back to our peak revenue levels of earlier years. In this harsh economic climate we were able to maintain and improve our services to Friends. Although the amount we were able to commit to research (£251k) was less than the exceptionally high levels of recent years, the funding partnerships we have developed have provided an additional £102k for new research projects. Economies in expenditure on all other areas of

spending mean that costs have been reduced whilst services have been maintained.

Research: Finding treatments and a cure

Aims for 2010/11 were

- Foster further research funding collaboration with international ataxia charities
- Launch a Research Fellowship in collaboration with the Association of British Neurologists
- Develop further patient involvement in our research strategy
- Commence the research study to establish prevalence of ataxia in children
- Increase the number of people with ataxia available to participate in drug trials
- Support the EC funded research consortium for translational research in Friedreichs Ataxia (EFACTS)

We have made substantial advances in all six aims.

1) Collaboration with international ataxia charities

We have continued to develop closer relations with ataxia charities in other countries and established new partners. This has resulted in joint funding of research projects with 8 organisations worldwide during the year (see funded research). These partnerships allow smaller organisations to participate in funding ataxia research which would not have the resources to administer and monitor grants, foster international collaboration between the larger international charities, and minimise the possibility of scientific projects being unnecessarily duplicated. In turn, they allow us to extend the reach of the research that we can commission.

Our closest international alliance is with FASI, the Irish patients' organisation which utilises Ataxia UK's rigorous process of peer review and selection of research projects to make decisions on projects to jointly fund with us. We have also jointly organised the annual euro-ATAXIA conference and AGM with them and share information and relevant services. FASI has welcomed, free of charge, Ataxia UK Friends from Northern Ireland onto their annual holiday.

Closer links have been developed with other charities who are members of euro-ATAXIA and regularly share information on research.

We have continued our partnership in the Stem Cell Task Force with FARA US; FARA Australasia, Go-FAR, and FASI. This group facilitates the collaboration between the funders and the leading researchers contributing to work in stem cells.

2) Association of British Neurologists Fellowship scheme

Ataxia UK has joined with other neurological charities in the clinical training research fellowship scheme run by the ABN. Applications are invited from trainee neurologists to apply for a three year fellowship to do a research project on ataxia

that if successful would be funded partly by Ataxia UK and partly by other funders who are part of the scheme. Unfortunately it was not possible to appoint an Ataxia Fellow in 2010 but two applications were received in 2011 and are being evaluated.

3) Patient involvement in research strategy

We have recruited and engaged more Friends in Ataxia UK's research process via a research workshop at the Annual Conference and the *Ataxian* magazine. A number of people have shown a keen interest in being involved so we have created a group of Friends who will be consulted from time to time on research issues or when other organisations are seeking patient opinions or involvement in research questions. The group has already been consulted for their views on physiotherapy research priorities as part of a consultation by the Chartered Society of Physiotherapists.

4) Prevalence study in children

The research study to establish prevalence of ataxia in children via the British Paediatric Neurology Surveillance Unit has started and we expect to have data next year.

5) Increase the number of people with ataxia available to participate in drug trials.

We established new contacts with over 500 people with ataxia and gained 274 new Friends with ataxia.

6) Support the EC funded research consortium for translational research in Friedreichs Ataxia (EFACTS)

We have helped in the recruitment of people with FA to take part in this European Union funded project and have assisted in the dissemination of information on the project at the euro-ATAXIA conference.

A. Research projects awarded

Ataxia UK has awarded grants for a number of research projects over the last year. Funding was approved for the five large projects and four small grants (see page 11-14 for details). During the year we also continued managing 21 research projects in progress. This involved providing support to researchers where needed, evaluating annual reports, and monitoring finances. Over the last few years we have encouraged young researchers to get involved in ataxia research by prioritising PhD studentship grants. In 2010 we awarded our first Ataxia UK fellowship grant, with the aim of encouraging scientists early in their career to remain within ataxia research.

The Scientific Advisory Committee has met three times during the year to evaluate new grants and in addition 2 teleconference meetings have been held to evaluate annual progress reports. Ataxia UK's research staff also arrange meetings with the

researchers in order to have closer contact, provide support where needed, identify any problems that might arise and advise on funding applications.

Research projects awarded funding during 2010/11

Trustees funded 5 research projects and 4 smaller grants.

Projects awarded funding during the year:

1. 'Antisense oligonucleotide mediated skipping of the CAG containing exon as a therapeutic approach for ataxias caused by a polyglutamine expansion'

Dr van Roon-Mom (Leiden University, Netherlands)

The Dutch ataxia Group ADCA-VN contributed some funds to this project.

Summary

This project aims to test a genetic therapeutic approach known as exon skipping in SCA3, SCA7, SCA17 and DRPLA patient cells. These types of cerebellar ataxias are all caused by expansions of certain parts of their gene (known as CAG expansions) that lead to the production of toxic protein. The exon skipping technique would eliminate the part of the gene that produces the toxic protein thus producing non-toxic normal protein. This technique has been shown by these researchers, working in collaboration with a small biotech company, to work in Duchenne Muscular Dystrophy (a neurological condition also caused by CAG expansions) in a proof-of principle human trial, with an advanced phase I/II clinical trial ongoing.

2. 'An investigation to determine the efficacy and safety of lentivirus mediated frataxin gene delivery for the correction of Friedreich's ataxia'

Dr Mark Pook and Dr Michael Themis (Brunel University, West London)

This project is jointly funded with FARA-US and FARA-Australasia.

Summary

FA is caused by a defect in the frataxin gene that results in the reduction of the frataxin protein. This project explores the potential to treat FA by frataxin gene therapy, where extra frataxin genes are artificially introduced into the body with the help of viral vectors to supplement the defective gene, thereby increasing the frataxin protein levels in the cells. Before human gene therapy clinical trials can be considered for FA, preclinical studies in mice are necessary to determine the best system that will result in the safest delivery of the frataxin gene to the appropriate affected tissues, resulting in a permanent increase in frataxin protein. This project will explore the safety and efficacy of introducing the frataxin gene into cultured FA cells and mice by means of a viral delivery system. In addition, any potential benefits of increased frataxin levels on FA-like symptoms in the mice will be assessed. The results obtained will provide very valuable information when considering future gene therapy clinical trials.

3. 'Development of second generation histone deacetylase inhibitors as therapeutics for Friedreich's ataxia'

Dr Elisabetta Soragni, Scripps Research Institute, US

Funding: This project was jointly funded by Ataxia UK and GoFAR.

Summary

Friedreich's ataxia is caused by very low levels of the essential protein frataxin. This defect is due to the expansion of a simple repetitive DNA sequence (GAA) in the frataxin gene, which causes the gene to be silenced, or switched off, due to specific modifications of proteins that bind DNA (histones). The researchers have shown that this can be reversed by the use of small molecules that inhibit the enzymes responsible for such modifications, and this restores frataxin gene expression. These molecules suffer from two important limitations; 1) a limited capacity to penetrate the brain and 2) production in the stomach of a secondary product that is inactive. The aim of this study is to develop new small molecules designed on the backbone of their current molecules, which have improved pharmacological properties. They will characterize these molecules and test their efficacy in restoring frataxin expression on neuronal cells that they derive from stem-like cells obtained in their laboratory from patient skin cells.

4) 'Functional investigation of GAA-mediated mechanisms of repression at the FRDA locus and identification of novel candidate factors involved in frataxin pathways.'

Dr Michele Lufino (University of Oxford)

This project was jointly funded with FARA-US, FARA-Aus, BabelFamily and AISA.

Summary

This project aims firstly to understand the mechanism by which the gene expansion in the frataxin gene affects its function and its localization within the nucleus. Secondly, the project seeks to identify new candidate genes involved in interacting with frataxin that are likely to be implicated in the cellular function of frataxin thus giving more information on the role of frataxin. Both of these make use of technological advances to lead to the eventual objective of identifying new targets for therapeutic strategies.

5) 'Pharmacodynamic studies of a histone deacetylase inhibitor in Friedreich's ataxia'

Professor Festenstein, Imperial College, London

This project is jointly funded with ACHAF, FASI and AISA.

Summary

This project aims to find out whether we can switch on the gene which is largely inactive in Friedreich's ataxia (FA), potentially providing a radical new therapy. The researchers have previously shown that an HDAC inhibitor drug can switch on this gene in cells from patients in the laboratory and can also increase levels of the frataxin protein that is deficient in people with FA.

In this first pilot trial a small number of people with FA will be given oral doses of an HDAC inhibitor. The trial will involve gradually increasing the dose given to patients until they observe an increase in frataxin levels or until we reach the safety limit. This will be done over a period of a few days for each participant. If successful, further trials will be needed to test whether this drug has an effect on the progression or severity of the condition.

Withdrawal of research grant

In addition, one grant made in prior years (Longitudinal analysis of Friedreich's ataxia) was withdrawn, because the researchers had been unable to start the project and a similar study had been started elsewhere, and another grant (Development of improved genetic testing) was reduced because equipment required could be funded from other sources.

Small grants

The following small awards were made to researchers to assist in attending research conferences and to sponsor ataxia conferences.

1) Two conference travel awards to help with dissemination of ataxia research were awarded. One supported a neurology student to attend the American Academy of Neurology conference to present research on spinocerebellar ataxia (contribution of £500) and the other was a travel award for an ataxia researcher to present research and information from Ataxia UK Guidelines at the World Congress of Physiotherapy (contribution £510).

2) Sponsorship of frataxin section of International conference on Iron-Sulphur protein biogenesis in Cambridge (contribution of £1,000).

3) Sponsorship of 4th International Friedreich's ataxia conference organised by FARA-US (contribution of £3,000 towards expense of UK researchers).

Dissemination of information to people with ataxia

We have continued to write regular articles in the *Ataxian* on research and provide updates at Regional and Annual Conferences and through our website. In addition we have supported other ataxia charities in dissemination eg: we are supplying an article for the newsletter of the Italian ataxia charity AISA.

Ataxia conferences and meetings

We believe that enabling researchers to attend conferences and putting on scientific conferences ourselves makes a significant contribution to the effectiveness of worldwide research into ataxia.

Ataxia UK financially supported, and was represented at, the successful 4th International FA conference in France, attended by over 200 delegates, which presented a unique opportunity to meet world experts on FA and be kept updated on latest developments. The annual *euro-ATAXIA* conference (which we hosted with FASI) was held at the same venue and time as the FA conference to facilitate

the exchange of information and save on travel costs. We also attended the Stem Cell Task force meeting, which brings together scientists working on stem cell and cell model research and patient support groups worldwide to identify gaps in research and potential support needed. This has resulted in the improved liaison with the ataxia charities, it has raised Ataxia UK's profile and has ensured our voice and that of people with ataxia in the UK to be heard in the establishment of new initiatives.

Support of research studies – recruitment of participants

Ataxia UK is playing an increasingly major role in the recruitment of participants with ataxia to research studies. Having a large database of people with ataxia puts us in a unique position to support research in this way and to be able to offer the opportunity to our Friends to take part, which is something we are often asked about. We are being approached by an increasing number of researchers (beyond those funded directly by us) for our support in this, suggesting awareness of Ataxia UK has risen over the last few years.

Projects supported with participants during the year:

- a) EC funded European Friedreich's ataxia consortium for translational research (EFACTS) – a natural history study (London Ataxia Centre) –anticipated as an aim for the year
- b) Speech impairment in ataxia project (DeMontford University, Leicester)
- c) Occupational therapy project – experiences of occupational therapists in ataxia (Brunel University, London)
- d) Two ataxia physiotherapy projects (University of Salford)

In addition we have provided support to a project run by the Society of Chartered Physiotherapists on the prioritization of research studies in physiotherapy by taking part and facilitating the involvement of patients in the process.

Ataxia Centres - Improving treatment and care

Our aims for 2010/11 were to:

- 1) Establish two accredited Ataxia Centres (Newcastle and Belfast)
- 2) Coordinate a campaign for an Ataxia Centre in Belfast
- 3) Investigate alternative ways of funding further Ataxia Centres
- 4) Submit a bid to the NHS National Commissioning Group for the funding of genetic testing of rarer forms of ataxia at four Ataxia Centres

1) Newcastle Ataxia Centre

We have moved forwards towards the establishment of an Ataxia Centre in Newcastle. A funding award for an Ataxia Nurse will soon be made.

2) Belfast Ataxia Centre

We continue to be hopeful that we can persuade the NHS in Northern Ireland to open an Ataxia Centre in Belfast, and have been actively looking for solutions with the Friends in Northern Ireland who have been assisting in lobbying for the centre.

3) Investigate alternative ways of funding further Ataxia Centres
In view of the state of flux in the NHS due to the reforms proposed by the government, we have been unable to pursue this objective during the year.

4) National Commissioning Group (NCG) bid
Ataxia UK partnered the four Ataxia UK accredited Ataxia Centres and the applicant Ataxia Centre in Newcastle, in the submission of a funding application to the National Commissioning Group to establish specialist facilities in the NHS for rare ataxias. The application passed the preliminary stage but was unfortunately not ultimately successful. We understand that the number of patients anticipated to be seen was too high. All partners were very disappointed with the outcome as it would have been a major improvement to the service for people with undiagnosed and rarer ataxias. We are considering with our partners, the possibility of a further bid for more targeted services at the earliest opportunity.

Existing Ataxia Centres

Oxford Ataxia Centre

This Centre was officially launched in December 2009, with funding from Ataxia UK and DENDRON Thames Valley for an Ataxia Specialist Nurse but due to staffing difficulties an appointment is yet to be made. We anticipate an Ataxia Nurse will be appointed in 2011, again jointly with Dendron, for two years.

London Ataxia Centre – patient feedback

The London Ataxia Centre has been accredited for over five years. Patient numbers have greatly increased, illustrating the demand for the service. Patient feedback, which has been collected since the Centre was established, has been excellent. Ataxia UK volunteers provide support and information to patients with ataxia after their clinic appointment, and they collect the patient feedback forms. Collated data shows that 95% report being satisfied with the clinic, and importantly 89% say that this is an improvement from the service they received previously.

Additional activities:

Medical Advisory Panel and other experts

We are grateful for the continued support of clinicians who serve on our Medical Advisory panel to improve services for people with ataxia. The panel meets annually to advise Ataxia UK and share information on latest developments in clinical research and clinical experiences. The panel is also consulted by Ataxia UK's Research Team on a number of specific medical queries raised by people with ataxia.

We are also grateful to the clinicians who attend the Doctors' Question and Answer sessions at our conferences.

Medical registry

We have continued to recruit healthcare professionals to our medical registry, thus allowing us to disseminate information on ataxia to more interested parties. Newsletters have been sent three times a year with information on ataxia

conferences, developments such as the Medical Guidelines, research studies and requests for people to take part in research.

Care and Support Services for Friends and their Families

Our aims for 2010/11 were to:

Care and Support Services for Friends and their Families

- Hold a training event for medical professionals
- Publish further articles to inform medical professionals about ataxia
- Explore ways to help people with ataxia as they move towards the end of life
- Investigate the benefits of an Ataxia UK Social Care registry.
- Investigate ways of lobbying to include ataxia in medical training to increase clinicians' understanding of ataxia so that they are able to help patients more.
- Continue to develop the Branch & Support Group Network (target 24 Branches and 30 Support Groups)
- Refocus the Welfare Grants programme in line with available resources
- Raise the profile of International Ataxia Awareness Day through increased events and press coverage
- Increase the membership of Ataxia UK by 10%

Ataxia training event for medical professionals

During the year, in partnership with Genetic Alliance UK and the Sheffield Ataxia Centre, we laid plans for an ataxia training event in Sheffield to be held in May 2011. Ataxia UK also supported a training event on ataxia held in Plymouth for physiotherapists and occupational therapists organized by one of our funded researchers. We publicised the event amongst healthcare professionals and had an Ataxia UK information stand.

Publications for medical professionals

We have produced an updated summary of the Ataxia Guidelines aimed at General Practitioners and encouraged distribution by people with ataxia to their own doctors. Nurses have been targeted in a publication in the Nursing Standard about ataxia and Ataxia Centres.

Development of Branch & Support Group Network

Our target for the year was to increase 24 Branches and 30 Support Groups from 18 Branches and 26 Support Groups. We achieved 21 branches and 28 support groups, with a number of requests to assist in establishing new groups still pending and showing no sign of diminishing. We held our fifth Branch Officers' Conference in April 2010 to encourage and support this group of volunteers by enabling them to meet together and share experiences.

Refocus the Welfare Grants programme in line with available resources

Our limited resources mean that we have felt compelled to reduce the funds available for Welfare Grants in favour of funding the Helpline and Advocacy projects. (see below). However we made available £5,000 in welfare funds towards the purchase of wheelchairs of which £2,601 was committed.

Raise the profile of International Ataxia Awareness Day through increased events and press coverage

The number of Branches and Support Groups holding Wheely Wobbly Walks to publicise International Awareness Day is steadily increasing as are the funds generated through this activity. Press coverage generated around International Awareness Day was less in 2010 than 2009, however we conducted a successful local awareness campaign in Newcastle using posters in city centre locations. This will be repeated in Leicester in 2011.

Increase the membership of Ataxia UK by 10%

We increased the number of Friends of Ataxia UK by over 500. This represented an increase of 13.5%. We are continuing to focus on increasing membership during the coming year.

The following aims were postponed to 2012/13

- Investigate the benefits of an Ataxia UK Social Care registry
- Explore ways to help people with ataxia as they move towards the end of life
- Undertake the work required to enable full Telephone Helpline Association accreditation
- Investigate ways of lobbying to include ataxia in medical training to increase clinician's understanding of ataxia so that they are able to help patients more.

Additional achievements:

Helpline & Advocacy Service - A wide range of issues were addressed including: access to care and support services, benefits, housing issues, financial/insurance concerns, aids and adaptations and employment issues. The Helpline saw an increase in demand from 3151 enquiries in 2009/10 to 3655 enquiries in 2010/11. By the year end as a result of the work the Advocacy Service has done since its inception, people with ataxia were in receipt of over £26,000 in increased benefits which will recur annually, and £314K has been received in one off payments.

Adaptations to Homes Project - We have been pleased to receive a substantial legacy from Catherine Cornberg, a long standing Friend of Ataxia UK, which she specified should be used to assist people with ataxia with mobility issues in their homes. We are working with Dr Juliette Truman and Dr Lesley Collier, Researchers in Occupational Therapy at Southampton University, with a view to commissioning them to undertake research into the specific needs of people with ataxia for aids and adaptations. Once we are aware of the needs we shall design a project to assist people using the money left by Catherine Cornberg, which is in the Adaptation of Homes Fund. We are very sensitive to the fact that adaptation of homes is often paid for by the state. We do not wish to use this generous bequest to substitute for state expenditure and will be careful to ensure that this programme, which is a new activity for us, avoids this pitfall. We anticipate the fund will be disbursed over a number of years.

Conferences and Events - Our national conference in Stansted in October 2010 was a great success and was attended by 200 Friends and supporters. Our Regional Conference was held in Durham and attracted 60 Friends many of whom had never been to an Ataxia UK event before.

Healthcare services in Greater Manchester - In 2008/9, Ataxia UK collaborated with a team of researchers and clinicians to obtain a grant from the NHS National Institute for Health Research to employ a researcher at the University of Manchester to evaluate services for people with ataxia in the Greater Manchester area. We have continued to support the work of this project by promoting opportunities to Friends in the area to participate by contributing their experiences. During the year two papers have been published in medical/sociological journals on diagnosis and experiences of healthcare services in people with ataxia in the Manchester area.

Facilitating networks of expertise project - Ataxia UK was one of the 9 charities chosen to be part of this project run by the Genetic Alliance UK with a grant from the Department of Health. We supported the project in identifying people with ataxia and healthcare professionals to participate, and have advised on the overall strategy of the project. Ataxia UK already has a network of expertise in its Medical Advisory Panel, which is active in supporting the charity. One of the concerns identified in the research was the lack of awareness and understanding of ataxia amongst healthcare professionals, and plans have been made to organise an initial ataxia training day in 2011 in partnership with Ataxia UK and the Sheffield Ataxia Centre.

Consultations and invitations to events - We have been invited as patient representatives to a number of other meetings, allowing us to put forward the views of people with ataxia. As Vice-Chair of the Neurological Alliance the Chief Executive has represented the Neurological Alliance at private meetings with Government Ministers and on the Richmond Group (a coalition of 10 major health charities) regarding the impending changes to the NHS.

We have also collaborated with Genetic Alliance UK in providing responses to consultations on topics of relevance to people with ataxia, such as the EU Directive on in vitro diagnostic medical devices and a submission to the HFEA on pre-implantation genetic diagnosis in a type of ataxia.

Financial Review

Total revenue for 2010/11 was £1,096K, up 21.5% on 2009/10 revenue of £902K. After the setback that we, in common with many charities, experienced during the world financial crisis and its immediate aftermath, our key income sources have returned to growth. However, we operate in the environment of a UK economy that is recovering only very slowly from the recession, and in that context fundraising remains difficult.

Legacies generated £307K this year (£181K in 2009/10). Of this total, £258K represented a legacy from Mrs Catherine Cornberg for the adaptation of homes of people with ataxia to aid their daily living. This activity is a new one for us and we are currently planning how best to use this very generous bequest in a manner that supplements rather than substitutes for the role of local authorities. This fund will be disbursed over a number of years.

Fundraising and donations, which have always been the core of our income, increased to £527K this year (£428K in 2009/10), illustrating the loyalty and commitment of our supporters. However, progress in gaining trust income was more difficult to achieve since so many trusts rely on investment income to fund their grants.

Against this backdrop, we continued to concentrate on maintaining our essential services and keeping a firm grip on costs, while not adding any major new initiatives.

Spending on research was £251K (£706K in 2009/10). The unusually high spending in 2009/10 was because we were still finalising research projects initiated in earlier years, for which money had been put aside in Designated Funds. The research pipeline continues to be exciting and the trustees have approved several additional projects that are being developed in 2011/12.

Care services expenditure – helping people with ataxia live with the condition – was £417K, up slightly on 2009/10. The continued demand seen for support in daily living underlines the difficulty people with ataxia experience in these recessionary times.

Ataxia centre spending was £46K in 2010/11 (£103K in 2009/10). During the year we continued to support and develop our three existing centres and have been making substantial progress in finalising the opening of the fourth centre in Newcastle.

The year showed a net surplus of £178K. Of that, restricted funds showed a surplus of £213K, including a surplus of £219K in the adaptation of homes fund, where we are currently designing the programme. Unrestricted funds shows a net outflow of £35K, which represents spending of commitments (primarily research) made from prior years' surpluses, which had been agreed and provided for through Designated Funds. General funds not allocated to specific projects at the end of the year amounted to £36K.

The trustees believe the charity has weathered the recession and our task now is to rebuild income to the levels we experienced prior to the financial crisis.

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.

Designated Funds and Reserves – Policy and Application

It is Ataxia UK's policy to establish designated funds to cover known and contingent commitments such as approved research programmes, lease commitments and provisions for responding to adverse events. The charity's reserves are included within those designated funds, specifically in the provisions for adverse events (the Operational fund) and the provision for lease commitments. Consequently, the full amount shown as General Funds is available for the trustees to apply to new spending initiatives.

The specific components of Designated Funds are as follows:

1. **Research grants and new projects.** It is the policy of the trustees only to make grants, whether for research or other purposes, from funds that are currently available at the time the grant is considered. Research programmes and ataxia centre programmes typically last one to three years. Where grants are negotiated and confirmed as commitments within the financial year, the full amount is charged to the SOFA and the undisbursed element recorded within creditors. To the extent they are not so confirmed, e.g. because the charity is still developing the project, a provision for the full approved amount is established within designated funds, except to the extent the project is externally funded.

This designated fund includes research grants, grants to ataxia centres and other major expenditure projects committed but not completed. The amounts included for each project are the trustees' best estimates of the likely cost of each specific project. These commitments will usually be disbursed over one to five years.

2. **Operational Fund.** This fund is designed to provide against any setbacks that the charity might encounter, either in its affairs or in the investment markets, to the extent that the charity is exposed to those markets. It is established at a level considered adequate to reflect the cost of reorganising or curtailing activities if that were to become necessary and to cover any possible losses in the investment markets.

3. **Others.** Separate funds have been established that reflect the investment in fixed assets, lease commitments fund and balances held in branches that are not available for normal activities of the central office.

Ataxia UK does not aim to retain significant free reserves in excess of those prudential reserves held in the Operational Fund and lease commitments. However, it will not commit income to new projects until that income has been received regardless of when the funds for the spending project will flow out. The trustees will retain a relatively small level of reserves to allow the Charity to grasp

opportunities at short notice but would normally expect to commit most of each year's free reserves within a short time of those surpluses being determined.

It is our policy to review the levels of these reserves annually.

Total funds of the charity on 31 March 2011 were £1,116K (£938K in 2009/10). Restricted Funds of £240K (detailed in Note 19) represented the Adaptation of homes fund – still in the development stage – and the Jerry Farr travel fund, both of which will be disbursed over a number of years.

Designated Funds of £839K compared with £879K in 2009/10 and are detailed in Note 18. Of this total, £468K is the Research Grants and New Projects Fund. This fund consists of a number of individually costed specific projects (primarily research) that the trustees are developing but had not yet been advanced to unconditional grant letters at the end of the year.

The Operational Fund has increased to £195K from £191K. Each year the Board conducts a full review of all reserves in light of the risks to which it is exposed and the likely management responses to possible adverse events. This review is conducted against the backdrop of the charity's risk management programme and follows an established methodology. On the basis of this review the trustees decided to increase the Operational Fund to £195K, which reflected the current scale of the charity. The Contractual Lease Commitments Fund is unchanged at £129K. The Fixed Asset Fund stands at £9K and the Funds in Branches stands at £38K.

Free reserves of the charity as at 31 March 2011 were £36K, slightly higher than the level of £31K in 2010. Since the amounts that the trustees consider should be held as reserves are retained in the appropriate Designated Fund, as discussed above, there is no need to retain separate reserves in General Funds. The trustees' policy is under normal circumstances to allocate surpluses to specific spending projects within a relatively short time of those surpluses being determined, holding a small balance to take advantage of unexpected opportunities. This level of reserves reflects that policy.

Plans for Future Periods

Our Strategic Plan (2011-14) focuses on four main strands of Ataxia UK activity and places emphasis on ensuring the ongoing viability of Ataxia UK.

Aims for 2011/12

Finding treatments and a cure

- Catalogue and evaluate the outcomes of research projects funded by Ataxia UK
- Review the Research Strategy
- Maintain & develop funding partnerships with international ataxia charities and seek new partners

- Produce an information leaflet explaining what is involved when participating in a research project, aimed at managing patient expectations
- Plan for a scientific research conference and *euro-ATAXIA* conference in autumn 2012
- Establish a registry of researchers and evaluate the need for a regular newsletter.
- Undertake fundraising from trusts for research projects

Improving treatments and care

Ataxia Centres

- Analyse outcomes of the North West England 'Care of ataxia patients' study and respond accordingly
- Establish volunteer support schemes at Oxford and Newcastle Ataxia Centres

Other activities

- Produce updated Ataxia Medical Guidelines
- Expand medical professionals registry & collect feedback on the newsletter
- Hold an ataxia training event for medical professionals
- Explore ways in which to help people with ataxia towards the end of their lives
- Respond to the results of the childhood prevalence study by producing a work programme to meet identified needs.
- Contribute to consultations regarding the future of the NHS and social care on behalf of people affected by ataxia
- Explore models for including ataxia in medical training (eg: seminar for trainee neurologists, promoting the involvement of people with ataxia as case studies)
- Investigate the benefits of an Ataxia UK Social Care registry

Services to Friends and people affected by Ataxia

- Undertake the work required to enable full Telephone Helpline Association accreditation
- Implement a Helpline and Advocacy Satisfaction project
- Review the process for welfare grants in view of the low take up of grant applications since implementing the new process
- Implement a process for administering welfare grants for Northern Ireland
- Increase branches and support groups by 5% each

Raising Awareness

- Investigate the viability of paid support from PR agency to increase awareness and understanding amongst medical professionals
- Obtain Department of Health Information Standard accreditation
- Increase press coverage
- Produce a DVD to inform young people about ataxia
- Maximise the benefit of our Radio 4 Appeal going out in October 2011
- Increase membership of Ataxia UK by 10%

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 required 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 incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the trustees are required to:

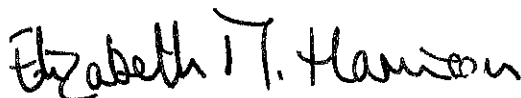
- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in 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 16 July 2011 and signed on their behalf by:



Elizabeth Harrison, Chairman



Chris Bunton, Treasurer

Date: 25 August 2011

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

We have audited the financial statements of Ataxia UK for the year ended 31 March 2011 which comprise the Statement of Financial Activities (the Summary Income and Expenditure Account), the Balance Sheet, 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).

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charitable company's trustees, as a body, in accordance with section 44 (1)(c) of the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken for no purpose other than to draw to the attention of the charitable company's trustees and members those matters which we are required to include in an auditor's report addressed to them. To the fullest extent permitted by law, we do not accept or assume responsibility to any party other than the charitable company and the charitable company's trustees and members as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of trustees and auditors

As explained more fully in the Trustees' Responsibilities Statement, 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.

We have been appointed auditors under section 44 (1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report to you in accordance with those Acts.

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 Ethical Standards for Auditors.

Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition we read all the financial and non-financial information in the Trustees Annual Report to identify material inconsistencies with the audited financial

statements. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

Opinion on the financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2011 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended; and
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 And regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

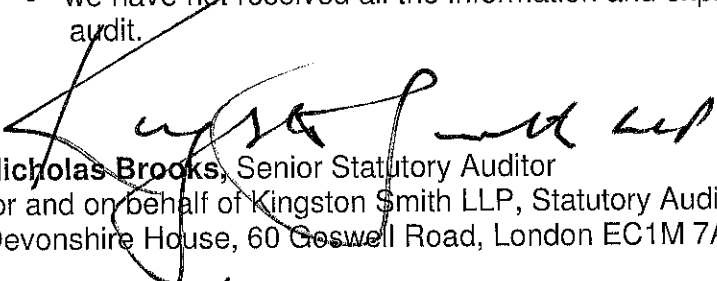
Opinion on other matters prescribed by the Companies Act

In our opinion the information given in the Trustees' Annual Report for the financial year 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 and the Charities Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- the charitable company has not kept proper and adequate accounting records 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' remunerations specified by law are not made; or
- we have not received all the information and explanations we require for our audit.


Nicholas Brooks, Senior Statutory Auditor
for and on behalf of Kingston Smith LLP, Statutory Auditor
Devonshire House, 60 Goswell Road, London EC1M 7AD

Date:1/9/11.....

Kingston Smith LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006

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 2011

	Notes	Unrestricted funds £	Restricted funds £	Total £	2010 Total £
Incoming resources					
Incoming resources from generated funds					
Voluntary Income	2	399,909	563,563	963,472	770,811
Activities for generating funds		72,155	12,884	85,039	79,565
Investment income	3	30,891	2,156	33,047	40,548
Incoming resources from charitable activities		14,258	-	14,258	11,086
Total Incoming resources		517,213	578,603	1,095,816	902,010
Resources expended					
Costs of generating funds					
Costs of generating voluntary income		59,891	67,000	126,891	182,745
Fundraising trading: cost of goods sold and other costs		16,436	18,387	34,823	35,384
Investment management costs		1,765	1,975	3,740	3,250
Charitable activities					
Research activities		53,507	197,747	251,254	706,101
Ataxia centres		38,653	7,500	46,153	102,974
Care services		346,394	70,328	416,722	393,844
Governance costs					
		43,749	2,500	46,249	39,463
Total resources expended	4	560,395	365,437	925,832	1,463,761
Net (expenditure)/income		(43,182)	213,166	169,984	(561,751)
Other recognised gains/losses					
Gains/(losses) on investments					
Unrealised gains on investments		10,324	-	10,324	13,348
Realised (losses) / gains on sale of investments		(2,138)	-	(2,138)	12,777
Net movement in funds		(34,996)	213,166	178,170	(535,626)
Total funds brought forward		910,620	27,194	937,814	1,473,440
Total funds carried forward		875,624	240,360	1,115,984	937,814

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 2011

		2011		2010	
	Notes	£	£	£	£
Fixed assets					
Tangible fixed assets	10	7,423		9,729	
Investments	11	523,683		574,477	
			531,106		584,206
Current assets					
Debtors	12	136,085		252,178	
Cash at bank and in hand	13	1,682,189		1,679,086	
		1,818,274		1,931,264	
Creditors: amounts falling due within one year	14	(988,234)		(1,114,961)	
			830,040		816,303
Net current assets			830,040		816,303
Total net assets less current liabilities			1,361,146		1,400,509
Creditors : amounts falling due after one year	15		(245,162)		(462,695)
Total assets	16		1,115,984		937,814
Accumulated funds					
Unrestricted funds					
General funds	17		36,331		31,345
Designated funds	18		839,293		879,275
			875,624		910,620
Restricted funds	19		240,360		27,194
Total funds			1,115,984		937,814

The financial statements were approved by the Trustees on

16 July 2011

and signed on their behalf by

Elizabeth H. Harrison

Elizabeth Harrison - Chairman

Chris Bunton

Chris Bunton - Treasurer

The accompanying pages form part of these financial statements.

Charity Number: 1102391
Company Number : 4974832

ATAXIA UK

Notes to the Financial Statements at 31st March 2011

1 Principal accounting policies

- a) The financial statements have been prepared under the historical cost convention, subject to the revaluation of investments which are stated at market value at the balance sheet date, and in accordance with the Statement of Recommended Practice "Reporting and Accounting for Charities" 2005 (SORP 2005) and have been prepared in accordance with Companies Act 2006 and Charities Act 1993. The Charity is exempt from preparing a cash flow statement.
- b) 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.
- c) 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.
- d) 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 incoming resources in the period for which it has been received. All income previously deferred has been released during the current year.
- e) In accordance with SORP 2005, legacies are recognised when they are certain and measurable.
- f) Income tax recoverable has been added to the relevant income source to which it applied.
- g) Staff costs and related office overheads have been apportioned between direct charitable expenditure, fundraising and publicity and governance according to the time spent by staff on each of these activities.
- h) Unrestricted funds are funds that can be used in accordance with the charitable objects at the discretion of the Trustees.
- i) Designated funds represent amounts put aside by the trustees as outlined in Note 18.
- j) 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 19.
- k) The accounts of the Charity's branches have been consolidated into these accounts.
- l) Rentals applicable to operating leases are charged to the Statement of Financial Activities as they become due.
- m) Formal and unconditional commitments to research expenditure and other grants at the balance sheet date are included within creditors, in accordance with SORP 2005. 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 17 and 18.
- n) 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.
- o) As a registered charity, the Charity is exempt from taxation under section 505 (1) of the Income & Corporation Taxes Act 1988.
- p) Governance costs include audit, legal and professional fees and the apportionment of staff costs, and office overheads costs according to the amount staff time spent on this activity.

ATAXIA UK

Notes to the Financial Statements at 31st March 2011 (continued)

	2011 £	2010 £
2 Voluntary Income		
Donations and covenants	165,166	161,773
Legacies	307,098	181,386
Fundraising	361,808	266,102
Childlife - (see note 9)	125,000	137,500
Other grants receivable	4,400	24,050
	<u>963,472</u>	<u>770,811</u>

3 Investment Income		
Income on investment portfolio	17,081	16,946
Interest	15,966	23,602
	<u>33,047</u>	<u>40,548</u>

				2011 Total	2010
	Direct Costs	Grants	Support Costs		
Research activities	1,012	134,416	115,826	251,254	706,102
Ataxia centres	671	-	45,482	46,153	102,974
Care services	<u>70,751</u>	<u>19,046</u>	<u>326,925</u>	<u>416,722</u>	<u>393,844</u>
Total charitable activities	72,434	153,462	488,233	714,129	1,202,920
Generating funds	73,278	-	92,176	165,454	221,378
Governance	-	-	46,249	46,249	39,463
Total	<u>145,712</u>	<u>153,462</u>	<u>626,658</u>	<u>925,832</u>	<u>1,463,761</u>

Included under care services are 5 grants (2010 - 23) given to individuals during the year of £9,046 (2010 - £23,190) and a grant of £10,000 to the Friedrich's Ataxia Society Ireland (FASI) to facilitate holidays for people with ataxia.

Support costs that cannot be directly allocated to a particular resources expended heading are allocated according to staff time spent on the relevant activity.

Total Support Costs		
Staff costs	421,709	423,110
Office costs	197,786	194,467
Depreciation	5,847	7,868
Annual Report	1,317	4,098
	<u>626,659</u>	<u>629,543</u>

ATAXIA UK

Notes to the Financial Statements at 31st March 2011 (continued)

5 Research and Medical Grants	2011 £	2010 £
Research grants made in the year comprise:		
<i>Leiden University, Netherlands:</i> Testing a novel genetic therapeutic approach in cerebellar ataxia	44,570	-
<i>Brunel University:</i> Exploring the potential to treat Friedreich's ataxia by frataxin gene therapy	50,730	-
<i>Oxford University:</i> Understanding the mechanism whereby gene expansion affects the frataxin function	49,598	-
<i>Imperial College, London:</i> Clinical trial of HDAC inhibitor	29,555	-
<i>Imperial College London:</i> Grant to purchase frataxin dipstick reader	-	5,327
<i>Sheffield Children's Hospital:</i> Paediatric prevalence study	-	10,660
<i>Institute of Neurology, London:</i> Study of balance disruption	-	24,484
<i>University of Tuebingen, Germany:</i> Investigation of ataxin transport mechanisms in SCA3	-	119,060
<i>University of Rome Tor Vergata:</i> Investigation of frataxin degradation in Friedreich's ataxia	-	69,660
<i>St Bartholomew Hospital:</i> Investigation into the properties and potential role of cerebellar stem cells	-	79,480
<i>San Raffaele Institute, Milan:</i> Investigation into replacement of damaged cells in the cerebellum.	-	156,000
<i>Hôpital Robert Debré, Paris:</i> Investigation into the mechanism of oxidative stress in Friedreich's ataxia	-	17,573
<i>Scripps Institute USA:</i> Examining the dosing and timing of HDAC inhibitors to treat Friedreich's ataxia	24,870	15,002
<i>Royal Free Hospital:</i> Longitudinal analysis of Friedreich's ataxia	(43,012)	43,012
<i>Oxford University:</i> development of improved genetic testing for cerebellar ataxias	(14,834)	-
<i>Oxford University:</i> RNAi therapy in SCA7	-	64,423
<i>Other Grants:</i>	3,500	1,000
Medical grants made in the year comprise:		
<i>John Radcliffe Hospital Oxford:</i> Grant towards ataxia centre	-	36,098
<i>Sheffield Hallamshire Hospital:</i> Grant towards ataxia centre	-	18,783
Under spend on grants awarded in prior years	(10,561)	(7,254)
	<u>134,416</u>	<u>653,308</u>

Included above is the withdrawal of a grant to the Royal Free Hospital, because the project was not started, and the reduction of a grant to Oxford University when the scope was reduced.

ATAXIA UK

Notes to the Financial Statements at 31st March 2011 (continued)

10 Tangible fixed assets

	Office equipment £	Total £
COST		
As at 1st April 2010	51,147	51,147
Additions	3,540	3,540
Disposals	(11,119)	(11,119)
As at 31st March 2011	<u>43,568</u>	<u>43,568</u>
DEPRECIATION		
As at 1st April 2010	41,418	41,418
Charge for the year	5,846	5,846
Disposals	(11,119)	(11,119)
As at 31st March 2011	<u>36,145</u>	<u>36,145</u>
NET BOOK VALUE		
As at 31st March 2011	<u>7,423</u>	<u>7,423</u>
As at 1st April 2010	<u>9,729</u>	<u>9,729</u>

11 Investments

	2011 £	2010 £
Market value at 1 April 2010	574,477	564,299
Acquisitions	-	507,931
Disposals	(58,980)	(523,878)
Total gains arising on revaluation	8,186	26,125
Market value at 31st March 2011	<u>523,683</u>	<u>574,477</u>
Cost of investments	493,782	553,768
Realised (losses) / gains	(2,138)	12,777
Unrealised gains	32,039	7,932
	<u>523,683</u>	<u>574,477</u>

Unrealised gains reported in the Statement of Financial Activities represent changes in market value since the previous balance sheet date. Unrealised gains shown above show the net movement since acquisition. All the above investments are listed on the UK recognised stock exchange. Investments comprising more than 5% of the total value of investments at 31st March 2011 are:

UK Investments

UK Treasury 4.25% stock: 2011	-	61,118
UK Treasury 2.5% indexed linked stock: 2016	73,550	69,840
UK Treasury 1.25% indexed linked stock: 2017	135,642	125,895

Non UK Investments

Kreditanstalt fuer Wiederaufbau 4.75% notes: 2012	61,075	62,378
European Investment Bank 4.5% notes: 2013	61,507	62,691
Kreditanstalt fuer Wiederaufbau 3.25% notes: 2014	97,722	97,871
European Investment Bank 3.375% notes: 2014	94,187	94,684

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Notes to the Financial Statements at 31st March 2011 (continued)

	2011	2010
	£	£
12 Debtors		
Income tax recoverable	25,400	27,500
Other debtors	99,725	193,793
Prepayments	10,960	30,885
	<u>136,085</u>	<u>252,178</u>

13 Cash at bank and in hand

The Trustees maintain a policy that all cash balances are held on interest bearing accounts, with the exception of a nominal daily float held on current account and in the petty cash. Interest receivable in the year is disclosed in note 3.

		2011	2010
		£	£
14 Creditors: amounts falling due within one year			
Other creditors		211,202	86,088
Deferred Income	1d	1,500	687
Taxes and NI		12,003	0
Accruals		52,407	42,535
Grants payable		711,122	985,651
		<u>988,234</u>	<u>1,114,961</u>
15 Creditors: amounts falling due after one year			
Grants payable		<u>245,162</u>	<u>462,695</u>

16 Analysis of net assets between funds

	Restricted funds	Designated funds	General funds	Total 2011	Total 2010
	£	£	£	£	£
Fixed assets	-	7,423	-	7,423	9,729
Investments	-	523,683	-	523,683	574,477
Debtors	-	13,376	122,709	136,085	252,178
Cash at bank and in hand	240,360	294,811	1,147,018	1,682,189	1,679,086
Creditors	-	-	(1,233,396)	(1,233,396)	(1,577,656)
	<u>240,360</u>	<u>839,293</u>	<u>36,331</u>	<u>1,115,984</u>	<u>937,814</u>

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Notes to the Financial Statements at 31st March 2011 (continued)

17 Unrestricted funds

	General funds	Designated funds	Total
	£	£	£
Balance at 1 April 2010	31,345	879,275	910,620
Net decrease in funds during the year	(34,996)	-	(34,996)
Net Transfers (see note 18)	39,982	(39,982)	-
	<u>36,331</u>	<u>839,293</u>	<u>875,624</u>
Balance at 31st March 2011	<u>36,331</u>	<u>839,293</u>	<u>875,624</u>

18 Designated funds

	Balance 1 April 2010	movement in year	Balance 31 March 2011
	£	£	£
Research grants and new projects	527,309	(59,429)	467,880
Operational fund	191,000	4,000	195,000
Contractual lease commitments	128,636	469	129,105
Fixed assets not readily realisable	10,479	(1,422)	9,057
Funds held in branches	21,851	16,400	38,251
	<u>879,275</u>	<u>(39,982)</u>	<u>839,293</u>
	<u>879,275</u>	<u>(39,982)</u>	<u>839,293</u>

Designated funds represent amounts put aside by the Trustees to meet approved grant and new project expenditure, contractual commitments at the balance sheet date and other amounts that the Trustees consider prudent to put aside in order for the Charity to secure its ability to continue its ongoing activities. Designated funds comprise:

- Research grants and new projects: the aggregate amounts of research and medical grants agreed by the Trustees for which contractual commitments were not yet in place on 31 March 2011, amounts to cover research programmes that the Trustees believe are promising avenues of research and are in the process of developing appropriate research proposals, and the expected costs of other projects agreed by the Trustees but not completed as of 31 March 2011. In each case, these provisions are the Trustees' best estimates of the likely costs of specific projects and most are developed into unconditional grants within the year following the balance sheet date.
- Operational fund: a contingency fund to allow the charity to curtail or wind up its activities if its future on its current scale could no longer be reasonably anticipated.
- Contractual lease commitments: a provision for the losses that might be incurred under the lease of the office premises if those premises were to be vacated.
- Fixed and other assets not readily realisable: the total value of fixed assets and long term debtors that are not available for normal activities.
- Funds held in branches: funds held by the branches and not available for normal activities of the central office.

The Operational fund and Contractual lease commitments fund together comprise the reserves the Trustees consider necessary to hold in case of adverse circumstances.

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Notes to the Financial Statements at 31st March 2011 (continued)

19 Restricted funds

	Opening Balance £	Incoming resources £	Outgoing resources £	Closing Balance £
General research	-	14,860	(14,860)	-
Friedreich's ataxia research	-	142,180	(142,180)	-
Cerebellar ataxia research	-	27,858	(27,858)	-
Adaptation of homes	-	260,384	(41,144)	219,240
Childlife	-	125,000	(125,000)	-
Jerry Farr travel fund	27,194	1,025	(7,099)	21,120
Welfare	-	5,296	(5,296)	-
Others	-	2,000	(2,000)	-
	<u>27,194</u>	<u>578,603</u>	<u>(365,437)</u>	<u>240,360</u>

Restricted funds comprise:

- General research: funds provided for general research into ataxia or to contribute towards particular such general research projects.
- Friedreich's ataxia research: funds provided by donors specifically for research on Friedreich's ataxia.
- Cerebellar ataxia research: funds provided by donors specifically for research on cerebellar ataxia.
- Adaptation of homes: legacy of Catherine Cornberg to provide adaptation of homes of people with ataxia to aid their daily living.
- 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 and conditions of the grant.
- Jerry Farr: funds given by friends and family of Jerry Farr to fund travel grants.
- Welfare: funds provided for welfare grants
- Others: various smaller grants and donations for specific projects conducted during the year.

20 Capital commitments

There are no capital commitments at 31 March 2011 (2010: nil).

21 Lease commitment

	2011		2010	
	Land and buildings £	Other £	Land and buildings £	Other £
Operating lease which expire:				
In less than one year	-	2,664	-	-
In the second to fifth year	-	5,387	62,867	6,931
After 5 years	64,205	-	-	952
	<u>64,205</u>	<u>8,051</u>	<u>62,867</u>	<u>7,883</u>

22 Pension scheme

All members of staff were eligible to receive payments of 5% of their salary paid into a stakeholder personal pension plan. The pension premiums payable during the year were £17,521 (2010: £14,043). £10,168 (2010: £5,368) was still outstanding at the year end.