

## Ataxia UK's Research Strategy

### Research aims and objectives

Ataxia UK is the leading UK charity working with and for people with ataxia. The charity's overall objectives are to:

- stop the symptoms of ataxia starting or progressing
- repair the damage to the nerve and muscle cells
- help people to live with ataxia in the meantime

Ataxia UK is in the unique position of being the main UK support organisation for people with ataxia, as well as being a medical research charity that funds research. Ataxia UK aims to help the research effort in the following ways:

- provision of grants for research
- recruitment of participants in research projects
- research dissemination via a quarterly magazine and website
- organisation of research conferences and workshops

### Research funding

Ataxia UK will only consider funding research into conditions in which ataxia is the principle symptom, and in which the ataxia is likely to be progressive. This includes conditions such as Friedreich's ataxia, the spinocerebellar ataxias and other cerebellar ataxias (including idiopathic ones). It does not include conditions such as multiple sclerosis, ataxic cerebral palsy, or other conditions in which ataxic symptoms are present as the result of another underlying condition. Ataxia UK also does not fund research into ataxia telangiectasia, as there is an established UK charity that supports this form of ataxia (the AT Society). Research into ataxia due to traumas such as stroke, head injury and due to toxicity (e.g. from alcohol) are not normally considered for funding, unless they are likely to be of benefit to other ataxias.

All research funded by Ataxia UK must be demonstrated to be of actual or potential benefit to people with ataxia. Ataxia UK therefore provides funding for innovative and relevant projects that fit into an explicit therapeutic strategy. This does not exclude the advancement of scientific knowledge, however a potential eventual outcome for people with ataxia must be clearly linked.

Funds can be available for research into all aspects of ataxia, and particular areas of importance and priority are advised by Ataxia UK's Scientific Advisory Committee. These will include, as well as scientific and medical research, research into supportive treatments, such as physiotherapy, speech and occupational therapy.

Funds will be allocated in order to secure a portfolio of research activity that takes into account the range of ataxias among Ataxia UK's Friends database and the frequency of particular symptoms they experience.

There should be a balance of:

- basic and applied research

- long and short-term projects
- projects that are speculative and ones with clear potential benefits
- research that could benefit people of different ages

### **Research priorities**

Ataxia UK will give priority to projects with one or more of the following characteristics, namely that they:

- investigate the therapeutic effects of treatments with potential benefits to people with ataxia (including supportive strategies e.g. physiotherapy, speech and language therapy etc.)
- are of direct benefit to human ataxic conditions
- are based on reports from people with ataxia about their own experiences of the disorder
- are unlikely to be supported by mainstream funders for reasons other than quality
- foster collaboration and exchange of information between research groups and/or individuals

Ataxia UK is keen to encourage new researchers into the ataxia research area and therefore welcomes applications from such researchers, as well as from established ataxia researchers. Applications for PhD studentships are particularly welcome, as a means of involving young new researchers into ataxia research.

Ataxia UK is also keen to promote research that is collaborative in nature and which promotes exchange of information between different research groups. From time to time the Trustees of Ataxia UK on the advice of its Scientific Advisory Committee will review priorities for funding.

### **Research proposals**

Ataxia UK will consider a variety of proposals, including:

- projects
- PhD studentships
- research fellowships (contact Ataxia UK for further details)
- travel awards for researchers or students presenting at conferences
- satellite meetings at major Symposia of other organisations dealing with related disorders as a way of raising awareness and enhancing collaboration with researchers in these disciplines
- equipment to be used for ataxia research (by researchers not already in receipt of a grant from Ataxia UK)

Proposals will be accepted from:

- academic institutions
- private sector research companies
- suitably qualified individuals
- collaborative groups formed from a combination of the above

Because Ataxia UK is a small charity with limited resources

- grants will normally last for one to three years

- long-term research projects (ie: more than three years) are not normally supported
- it prefers to fund a variety of relatively short projects to the point where grant-holders can realistically seek funds from elsewhere; although it may consider continuation funding
- it will try to complement the funding of other grant-awarding bodies in order to create centres of excellence which will make a major impact on a range of ataxias

Ataxia UK normally will only accept proposals in which the principal applicant is based in the UK or in a European country that is part of Euroataxia (see <http://www.euro-ataxia.org/>). However, Ataxia UK would be willing to consider applications with immediate potential benefit to people with ataxia from researchers based elsewhere.

Funding opportunities will be advertised on the Ataxia UK and other websites. Relevant forms and conditions will be available electronically.

### **Selection process**

Applicants are encouraged to contact the office to discuss their applications with the Research Projects Manager before submitting a preliminary proposal.

There are two stages in the selection process. Initially applicants should submit a preliminary application. Forms are available from Ataxia UK's Research Projects Manager, or to download from the website. Preliminary applications will be reviewed by Ataxia UK's Scientific Advisory Committee, who will decide whether an application is within Ataxia UK's remit. If applications pass this initial selection process applicants are invited to submit a full application (see application form on Ataxia UK's website).

All full research proposals for projects and studentships will be reviewed by at least 2 peer reviewers, and assessed, with the reviews, by Ataxia UK's Scientific Advisory Committee.

The Committee will assess each project qualitatively according to

- quality
- cost
- novelty ( i.e. how similar it is to research done elsewhere)
- the fit of the project with Ataxia UK's strategy and priorities
- the time that will elapse until worthwhile results might be achieved
- how directly the project might benefit people affected by ataxia
- the number of people who might benefit.

The Scientific Advisory Committee will provide advice to the Trustees on whether specific research proposals should be funded, as well as advising on the merits of applications involving information exchange and dissemination (e.g. travel awards) and equipment grants without necessarily seeking peer reviews. The Trustees will make the final decisions, based on the Scientific Advisory Committee's advice and the funds available.

Ataxia UK may also commission a specific researcher or research group to investigate a topic of interest. These applications will also be peer reviewed and discussed by the Scientific Advisory Committee, who will advise the Trustees.

#### Role of Ataxia UK's Scientific Advisory Committee

This Committee will comprise independent experts from fields including Molecular Biology, Biochemistry, Clinical Pharmacology, Physiology, Neuroscience, Genetics and Neurology plus lay representatives. A list of the current Committee is found in Appendix A.

It has the following terms of reference:

To provide independent scientific advice to the Trustees of Ataxia UK on:

- research priorities for Ataxia UK
- whether to fund specific research proposals
- the most appropriate mechanisms for attracting high quality research proposals
- the use of funds for supporting research related activities
- the direction and scope of activity of the Ataxia UK Research staff.

Ataxia UK's Scientific Advisory Committee meets three times a year (generally in February, June and October), and applications are reviewed at each meeting.

#### Ataxia UK Research staff

Ataxia UK employs research staff who will manage the research grants programme, ensure that dissemination of information takes place and ensure appropriate interaction between Ataxia UK and its members, its funded researchers, project applicants and the scientific community.

#### **Information dissemination**

Information exchange is imperative for research progress. Funded researchers are expected to disseminate results through peer-reviewed high-impact journals. In addition, any research outcome or product (e.g. animal models) should be made freely available to other researchers.

Additionally, Ataxia UK will encourage information exchange by supporting national/international links, by for example, funding attendance at international meetings by Ataxia UK representatives and external ataxia researchers.

Information exchange and collaborations are also encouraged with researchers in other research areas in academia and industry (such as mitochondrial disorders, gene therapy, stem cell therapy and neural regeneration).

Reports of members based upon their personal experience of what happens or worsens their ataxia are also encouraged, as Ataxia UK believes that their analysis may contribute to the development of new lines of research.

### **Research appraisal**

Funded projects are appraised through the critical evaluation of annual reports and occasional site visits by the Research Projects Manager.

### **Appendix A: Members of Ataxia UK's Scientific Advisory Committee**

Chairman: Professor Barry Hunt, Faculty of Health and Human Sciences, University of Hertfordshire; Trustee of Ataxia UK

Scientific Members:

Dr Michael Barnes, Head of Molecular Genetic Informatics, GlaxoSmithKline Pharmaceuticals

Professor Patrick Chinnery, Department of Neurology, University of Newcastle

Dr Gavin Kilpatrick, Director of Drug Discovery, CeNeS Pharmaceuticals

Professor Bob Lightowlers, Department of Neurology, University of Newcastle

Professor Graham McClelland, Visiting Professor at the Universities of Surrey, and Ain Shams, Cairo.

Dr Irina Udalova, Kennedy Institute of Rheumatology

Ataxia UK representatives:

Dr Julie Greenfield, Ataxia UK's Research Projects Manager and Alison Stevenson, Ataxia UK's Research Officer

Lay members:

Katie Howie Neaum, Nigel Kilvington and Paul Stone.

*Lay members are Friends of Ataxia UK who either have ataxia themselves or are close to someone who has ataxia.*

For further information on Ataxia UK's Research strategy or any other aspects of research (such as applying for funding) please contact Ataxia UK's Research Projects Manager ([research@ataxia.org.uk](mailto:research@ataxia.org.uk)). More details can also be found on Ataxia UK's website: [www.ataxia.org.uk](http://www.ataxia.org.uk)

November 2008

Ataxia UK, Lincoln House, Kennington Park, 1 – 3 Brixton Road, London SW9 6DE. Tel: 0207 582 1444 [www.ataxia.org.uk](http://www.ataxia.org.uk)