

# Collaborating for research and healthcare and healthcare

# Ataxia UK

#### What is ataxia?

The ataxias are a group of rare progressive neurological conditions. The majority have no cure or disease modifying treatments. As such, the ataxias represent an untapped need in medical research.

#### Who are we?

Ataxia UK is the charity supporting people with ataxia in the UK, by providing support and information services and promoting research. We fund first-class medical research around the world.

# Share your research at our conferences

Ataxia UK organises research conferences in partnership with other ataxia charities. The International Congress for Ataxia Research takes place every two years, and represents a fantastic opportunity to share research, and network with ataxia researchers from around the world.

For more information visit: www.ataxia.org.uk/ataxiaresearch/research-conferences/

# Sign up to receive our newsletter

Stay up to date with the latest ataxia research, information and resources by receiving our quarterly e-newsletter for researchers or healthcare professionals. Visit our website to sign up.

### TALK TO US

If you would like to know more please contact Ataxia UK's Head of Research, Dr Julie Greenfield

T: +44 20 7582 1444, E: jgreenfield@ataxia.org.uk, or visit: www.ataxia.org.uk

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 (4974832).

# What can we offer you?



# UK patient registry facilitating patient engagement and recruitment to studies

Ataxia UK has a registry of around 3,500 patients with a number of different types of ataxia. We regularly use this reach to publicise and help recruit for research studies.



#### Ataxia UK Medical Guidelines

Our *Medical Guidelines* were created by ataxia specialists and respond to patient needs. They were published in the Orphanet Journal of Rare Diseases, and their value affirmed by the European Reference Network for Rare Neurological disorders (ERN-RD).



## An experienced collaborative partner

Ataxia UK works closely with many other charities, pharma companies and researchers worldwide. Partnerships include jointly-funded projects, coordination of information exchange and new initiatives to drive research forward.



### **European network of patient groups**

Ataxia UK is an active member of Euro-ataxia, the umbrella organisation of ataxia patient groups, which provides a direct link to other patient groups across Europe. Visit www.euroataxia.org.



### An established research-funding body

We fund a range of high quality novel research projects into various aspects of the ataxias, from basic science to applied research, including pilot trials of therapeutic interventions.