



Euro-ataxia Patient Charter: The role of patients and patient groups in clinical research

Euro-ataxia (the federation of ataxia charities in Europe) believes that all ataxia clinical studies should involve the input of people affected by ataxia (patients and their parents or carers) and patient group representatives. This Patient Charter outlines our vision for this, why it is important, and proposes how it should be implemented.

1. Patient engagement should take place from an early stage in designing clinical studies and maintained during all stages.
2. The involvement of patients, carers and patient groups in clinical research (including trials) is crucial to get the input of patients on:
 - a. what aspects of the condition matters most in the development of treatments (e.g. speech)
 - b. the research question asked
 - c. the relevance of clinical measures
 - d. the design of the study
 - e. defining acceptable burdens and ways to minimise these in the involvement in the study and for future treatments
 - f. ensuring correct information in an understandable language and format is provided to potential participants of studies
3. It is important for patients and patient groups to be engaged in continuing dialogue with researchers in order to gain understanding of research trials and other studies (e.g. exclusion/inclusion criteria, trial design) in order to maximise their input.
4. Clinical research studies should have a clear structure for patient engagement to ensure clarity on when and how patients will be consulted, for what specific purpose, and how their views will be used e.g. patient advisory group.
5. Patient groups have an important role in disseminating information about research studies (e.g. to help recruitment of participants and to inform people affected by ataxia about ongoing studies and their outcomes).
6. We propose that researchers engaged in an ataxia clinical study involving patients in Europe contact Euro-ataxia, who will assist in providing patient engagement. Where possible this will involve input from a patient group from the country in which the study is taking place and ensure diversity.

Date: May 2019

About Euro- ataxia

Euro-ataxia is the federation of ataxia patient groups in Europe, with currently 19 members. The aim of Euro-ataxia is for member groups to work together to help people with progressive ataxia lead their best life.

Objectives:

- To drive forward research and treatment of the ataxias.
- To encourage the free flow of information between members on the latest research.
- To foster and improve contacts between practitioners interested in the ataxias, and people with ataxia.
- To investigate social, political and cultural matters connected to the welfare of people with ataxia, and promoting and improving the exchange of this information.
- To promote co-operation on an international level between national ataxia organisations.
- To raise awareness of ataxia among clinicians, scientists and society.

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Euro-ataxia charity details:

UK Company limited by guarantee no: 08187765 UK Charity registered no: 1149330.

Background to the creation of this Patient Charter

At the Euro-ataxia meeting in Frankfurt on 9th November 2018 a workshop was held to discuss the role of patients and patient groups in research. This was attended by Euro-ataxia member groups, academic researchers specialising in ataxia and representatives from pharma companies. The questions addressed in the workshop were: *'What do you see is the role of patients and patient groups in clinical research?'* and *'What are the barriers for their involvement?'* The outcome of these discussions has led to the creation of this Patient Charter, approved by the Euro-ataxia Board.