Volunteers needed to take part in an international natural history study of DRPLA

The **D**entato**r**ubral-**p**allido**l**uysian **a**trophy **N**atural **H**istory and **B**iomarkers **S**tudy (**DRPLA NHBS**) is an international collaborative effort. This research project was developed and is led by two patient associations: CureDRPLA and Ataxia UK. The study is funded by CureDRPLA.

What is the purpose of this research study?

- Characterize how subjects with DRPLA change over time (natural history).
- Identify genetic factors and biomarkers that could predict how the condition progresses.
- Provide information to support the design and conduct of clinical trials in the future.

Who can participate?

We are looking for participants of any age that carry the mutation that causes DRPLA. The study also recruits participants without DRPLA as controls, so that we are able to compare how individuals with DRPLA differ from those without. Therefore, we also invite unaffected individuals to participate.

What will happen to me if I take part?

If you participate, you will be asked to attend a consultation once a year for three years. Neurologists will collect the following information:

- Demographics, family and medical history, medications, comorbidities, activities of daily living and quality of life.
- Neurological and cognitive examination.
- Brain MRI and biosamples collection (optional).

What are the benefits of participating?

This study is aimed at improving our understanding of DRPLA. It will improve the information that we give out to patients in clinic regarding prognosis and quality of life, and will allow better planning of therapeutic trials, which may lead to better treatments.

If you are based in the UK and would like to participate or receive more information, please contact:

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Individuals in countries with no study sites might be able to participate in this study. If that is your case please contact:

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CURE DRPLA ATAXIA