

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

The **Dentatorubral-pallidoluysian atrophy Natural History and Biomarkers Study (DRPLA NHBS)** is an international collaborative effort. This research project was developed and will be led by two patient associations: CureDRPLA and Ataxia UK. This research 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 as well as participants without DRPLA, so that we can compare how individuals with DRPLA differ from those without.

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. Each consultation may occur over two days. Neurologists will collect the following information:

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

What are the benefits of participating?

This research study is aimed at improving our understanding of DRPLA thereby enabling better planning of therapeutic trials, which may lead to better treatments.

If you are eligible to participate, you may receive up to \$300 for participating in the study for the duration of three years.

University of North Carolina (UNC) Study Site Information

To participate in the study at UNC, please contact:

Yulissa Gonzalez

Clinical Research Coordinator, UNC Department of Neurology

Phone: + 1 (919) 843-3516 / Email: yulissa_gonzalez@neurology.unc.edu

For general questions about your rights as a research participant at UNC, please contact:

The Institutional Review Board at ((919) 966-3113 and reference the study IRB# 21-1334

For more information about the study and how to contact other study sites please reach out to the DRPLA NHBS Coordinator:

Silvia Prades, Ataxia UK & CureDRPLA

Phone: +44 (0) 207 091 1591 / Email: spradesabadias@ataxia.org.uk

