



CURE
DRPLA

Dentatorubral-pallidoluysian atrophy (DRPLA), is a progressive brain disorder that causes involuntary movements, mental and emotional problems, and a decline in thinking ability. The average age of onset of DRPLA is 30 years, but this condition can appear anytime from infancy to adulthood.

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CureDRPLA is a US based non-profit founded by Paul and Andrea Compton. Paul and Andrea have a son that was diagnosed with DRPLA in August 2018.

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Visit our website

[HTTPS://CUREDRLA.ORG/EN/](https://curedrpla.org/en/)

OUR MISSION

The mission of CureDRPLA is to connect families, physicians and scientists to further DRPLA research and work towards a treatment for DRPLA.



CureDRPLA Global Patient Registry

The objective is to establish a database of patient-reported data over time.

Collect information on demographics, specifics of diagnosis, medical history, participation in research, mobility, quality of life, health economics and care needs.

Available in English, French, Italian, Japanese, Korean and Portuguese. Open to all DRPLA patients and families regardless of country of residence.

Information collected will be used for research purposes, such as learning more about DRPLA, symptoms that matter to patients, facilitate participation in trials.

Filled in by individuals with DRPLA or caregivers. All is done online, it only takes ~20 minutes to complete it.

Reviewed and approved by an ethics committee (WCG IRB).



FIND OUT MORE & JOIN

<https://curedrpla.org/en/global-patient-registry/>

DRPLA

Natural History & Biomarkers Study

International collaborative project, led by CureDRPLA & Ataxia UK

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.

Participants will be asked to complete a study visit **once a year for 3 years**.

Overview of information collected:

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

STUDY SITES

United Kingdom (London), United States (New York, North Carolina) & Japan. Participants from anywhere in the world could also be recruited.

Contact us and we will connect you with the relevant study site.

OUR RESEARCH

CureDRPLA is funding research in hopes of rapidly developing novel therapeutics for DRPLA. Our primary motivation is time, and we are working strategically with both academic and commercial partners to advance DRPLA treatments to the clinic as quickly as possible.


Information on our currently funded projects is available on our website.

CureDRPLA has partnered with Ataxia UK, the leading charity in the UK for people affected by any ataxia, to further its efforts.



CONTACT US !

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