

**DRPLA Centers of Excellence**

# Overview and Accreditation Benefits

CureDRPLA is a non-profit foundation dedicated to Dentatorubral-pallidoluysian atrophy (DRPLA), an ultra-rare form of ataxia. The mission of CureDRPLA is to connect families, physicians and scientific investigators to further DRPLA research and work toward a treatment for DRPLA.

DRPLA is a complex and heterogeneous condition that can impact many aspects of everyday life. As a result, individuals affected and their families require access to specialized care to gain a better understanding of this condition and find the best way to manage it while a treatment becomes available. To address this need, CureDRPLA has launched this initiative to award an accreditation of “DRPLA Centers of Excellence” to neurologists with experience in DRPLA care who commit to supporting the work of our organization.

In addition to providing expert clinical care and identifying the various needs of those diagnosed with DRPLA, these Centers must maintain an ongoing interest in research into DRPLA. With this initiative, we aim to help families more easily identify clinical experts in DRPLA for their healthcare needs.

The DRPLA Centers of Excellence will receive the following **benefits**:

* Join a network of DRPLA experts to provide support and guidance to individuals with DRPLA. This offers opportunities for collaboration to enhance clinical care and research efforts.
* Featured on the CureDRPLA and Ataxia UK websites as a recognized DRPLA Center of Excellence.
* Receive an award certificate that can be displayed in the clinic for awareness).
* Authorization to use this designation in both internal and external communications and applications. Receive updates on research and clinical projects, funding opportunities, events and other relevant information.

To become a DRPLA Center of Excellence, the clinician(s) applying must fulfill the criteria described below.

For any questions or queries please contact us (silvia.prades@curedrpla.org).

# Criteria for DRPLA Center of Excellence Accreditation

**Clinical Care**

* Each Center must have at least one neurologist with experience in DRPLA and specialized training in movement disorders, ataxia, neurogenetics or epilepsy. In this context ‘experience in DRPLA’ is defined by having seen at least four individuals with a DRPLA diagnosis throughout their professional career.
* Currently provide clinical care for at least two individuals with DRPLA annually.
* Provide information about DRPLA and refer patients and families to CureDRPLA for additional information on research and peer support.
* Offer referrals to other specialist clinical services to support all aspects of DRPLA (e.g., physiotherapists, genetic counselling and testing, family planning and reproductive health, physical and occupational therapy, speech therapy, social services, etc.).
* Follow-up visits are offered at least once a year.
* Evidence of a system for providing both medical information and support/advice for people with DRPLA and their caregivers between clinic visits.

**Community Involvement and Outreach**

* Engage in educational and outreach events for individuals with DRPLA, caregivers and families (e.g., participate in meetings or content for social media).
* Encourage participation in research studies and clinical trials. Willingness to attend meetings with representatives of CureDRPLA to learn more about the foundation’s projects and funding opportunities.

**Research Experience and Interest**

* Involvement of clinician(s) with a track record of research on DRPLA and other relevant conditions or who can provide evidence that they keep updated on recent developments in DRPLA research.
* Willingness to inform their patients of opportunities to participate in research projects that have been ethically approved.

# Accreditation Process

**Application overview**

Neurologist(s) seeking a DRPLA Center of Excellence accreditation must fill in the application form as described below and submit it to silvia.prades@curedrpla.org.

We accept applications all year round and it is open to applicants from all countries. If approved, the accredited centers will maintain this designation for three years (see requirements in the next section) from the date of approval. To renew the accreditation, they will be required to resubmit a proposal for review.

**Review of applications**

Applications will be reviewed by representatives of CureDRPLA and Ataxia UK (partner organization), individuals with DRPLA or other ataxias and caregivers. All applications will be reviewed for their own merits, and the quality of the overall application and the services provided will be considered against the accreditation criteria to ensure they are met.

Applicants not selected for designation can request feedback to explore if there are ways to strengthen future applications.

**Requirements post-approval**

If an application is approved, the accredited center will maintain this designation for three years. The sites must meet the following requirements to maintain this accreditation:

* Cases Followed – Annual Update: report the number of individuals with DRPLA followed annually (e.g., 2 people with DRPLA from the same family seen in 2023). This will help us understand the number of active cases followed in each center.
* Participation in research – Annual Update: report if their patients have participated in any research projects.
* Provide current contact information for all communications.

# Application for a DRPLA Center of Excellence Accreditation

Please fill in the following sections by typing directly into this word document. The application should be no more than 5 pages.

1. **Applicant(s) name and contact details**: we accept up to three applicants per site. Please provide updated contact details for all communications with CureDRPLA. *Please note this information will also be published on the CureDRPLA website (if we cannot display some of the details provided below, let us know).*

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| --- | --- | --- | --- |
|  | **Applicant 1** | **Co-applicant 2** | **Co-applicant 3** |
| **Full name** |  |  |  |
| **Affiliation** |  |  |  |
| **Job title** |  |  |  |
| **Location** |  |  |  |
| **Email address** |  |  |  |
| **Phone number** |  |  |  |

1. **Expertise in DRPLA**: each center must have at least one neurologist with experience in DRPLA and specialized training in movement disorders, ataxia, neurogenetics or epilepsy. In this context ‘experience in DRPLA’ is defined by having seen at least four individuals with a DRPLA diagnosis throughout his/her professional career. Describe for each applicant.
2. **DRPLA population served**: please provide the number of individuals with DRPLA each applicant is currently following. Provide any relevant details on the diversity of the patients served (e.g. from different families, whether they are adults or children). Providean estimated number of hours spent per month (or year) on DRPLA-specific matters.
3. **Clinical services**: list relevant clinical and professional services provided to patients through designated staff or through referrals within your institution or external health care providers. Briefly described how the referral system works in your clinic.
4. **Community involvement and outreach**: briefly describe any previous engagement in activities relating to DRPLA support, education, or outreach. Explain how you plan to support these activities in the future.
5. **Research experience and interest**: briefly describe any research activities that are relevant to DRPLA. Include any involvement in previous and/or active research projects relevant to the field. Explain how you plan to keep updated on recent developments in DRPLA research.