

CPMS-based care pathways

Activities report & how to participate

CPMS-based care pathways in ERN-RND

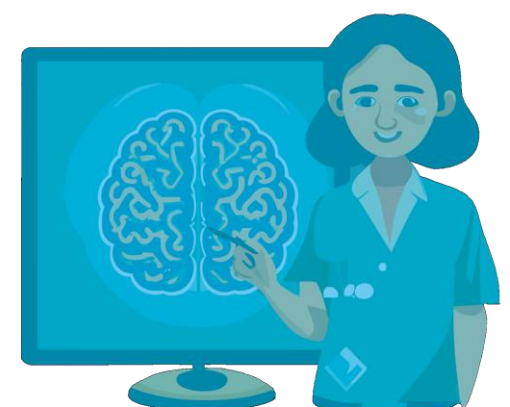
Disease Group specific consultations & best practice
Cases with focus on diagnosis or disease management, clustered by the 6 ERN-RND disease groups:

- Ataxia & HSP
- Atypical Parkinsonian syndromes (MSA, PSP, genetic Parkinson's disease)
- Chorea & Huntington's disease
- Dystonia, NBIA, Paroxysmal Disorders

Cases are discussed in "Case Discussion *jour fixe*" four times per year per group.

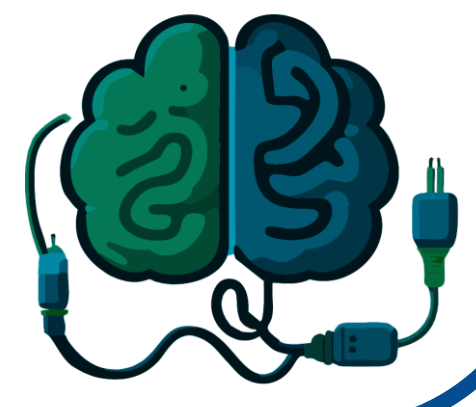


Neuroradiology advice panels
Standard pathway for receiving a (diagnostic) second opinion by neuroradiology experts on imaging findings of patients with rare neurological disease beyond & across Disease Groups.



Lead: Lübeck, DE

DBS for Dystonia
Homogenization of a highly specialised, invasive treatment: multidisciplinary board offering advice for European physicians for dystonia cases pre and post Deep Brain Stimulation.



Lead: Würzburg, DE

MLD Treatment Eligibility Panel
Not all MLD patients benefit from gene therapy or stem cell transplantation. In collaboration with MLDi, a consensus-based treatment recommendation is provided by this multidisciplinary expert panel.



Lead: Amsterdam, NL

Krabbe Treatment Eligibility Panel
High-risk, low evidence: European physicians may consult this panel for advice if or when to offer stem cell transplantation for their patient with Krabbe disease.



Lead: Tübingen, DE

How to use these ERN-RND cross-border healthcare services?

Contact ERN-RND CPMS helpdesk, who will support you in using CPMS & schedule a discussion with the respective expert panel: cpms-helpdesk_ern-rnd@med.uni-tuebingen.de

Usage of CPMS (2.0)

In the period Oct 2024 – Oct 2025...



86
clinicians newly signed up for CPMS (2.0)



74
RND Patients were enrolled in the system & discussed with ERN-RND experts



21,250 €
were distributed across 26 centers, reimbursing discussions of the last two years. In total, 85 patient discussions were reimbursed with 250€ each.

Case Discussions in the last year

37 meetings were conducted in order to discuss 82 patients in the period Oct 2024 – Sept 2025.

Care pathway...	#meetings	#cases	Average #participants
Neuroradiology Advice Panel	3	6	12
MLD Treatment Eligibility Panel	15	33	13
Krabbe Treatment Eligibility Panel	4	6	11
DBS for Dystonia	2	4	22
Disease Group specific <i>jour fixes</i>			
Ataxia & HSP	3	9	17
Atypical Parkinsonian Syndromes	3	6	12
Chorea & Huntington's disease	4	7	17
Dystonia, NBIA, Parox. Disorders	2	2	21
Frontotemporal Dementia	2	4	12
Leukoencephalopathies	2	5	13