



European
Reference
Network

for rare or low prevalence
complex diseases

 Network

Neuromuscular
Diseases (ERN EURO-NMD)

The needs of the ERNs from the perspective of a Network coordinator

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EURO-NMD



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- “The long-term sustainability of ERNs requires **all MS to take ownership of the ERN model** at the highest political level and across different government portfolios. Adequate **funding, appropriate resources and long-term financial support** is required if ERNs are to function as permanent structures and ensure the continuity of their operations.”

From: “EURORDIS Recommendations on the Integration of European Reference Networks (ERNs) into National Health Systems; November 2018”

Cooperation with Member States /Integration in National Health Systems

- Raise awareness about the importance and potential of the ERNs
- Develop efficient communication platforms involving national healthcare officials, ERNs coordinators, and the European Commission
- Develop action plans with realistic time lines to integrate ERNs in National Health Systems

Reviewing of compensatory schemes

- **Novel rehimbursement schemes** for highly specialized therapeutic interventions in rare disease patients – there is a need to consider revisiting/revising the way Member States use the current reimbursement systems.
- **Compensation scheme for e-Medicine solutions** currently not covered by the CBHCD - these should be seen as highly specialized care that has to be reimbursed

The **CPMS** - an excellent tool that allows virtual expert advice by healthcare professionals.

The system needs:

promotion

dedicated staff (besides help desk)

financial compensation for the HCPs

Adequate funding

- To **develop a professional and dedicated support structure** - non clinical staff
- **Dedicated healthcare professionals** – that could, for instance, overview the usage of the CPMS
- **Educational activities** – to spread good practices across borders
- **Development of guidelines** - to implement patient-centric care pathways for better health care in currently disadvantaged populations.

European Quality Care Models

- To foster with integrated multidisciplinary teams across patient age groups.
- The implementation of specialised Integrated Care Centres with appropriate case managers.
- The Commission and Member States should undertake common efforts and commitments to bring these much needed structures to life.

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“EURO-NMD is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. The ERNs are **co-funded** by the European Union (Health Programme and CEF).

For more information about the ERNs and the EU health strategy, please visit ec.europa.eu/health/ern“