

L'ERN neuromusculaire à Paris

T EVANGELISTA; JA URTIZBEREA; H PASCAL



61 HCPs 14 Countries

15 Italy
8 France



Assistance Public Hopitaux de
Paris
France



Centre Hospitalo-Universitaire
e – Assistance Publique
aux de Marseille

New Afilliated Partners from 9 EU Countries

2. Austria

1. Estonia

New Members - number ?

More than 10



CHU Lim
France



Hôpital Bicêtre
universitaires
France

1. Malta

2. Denmark

1. Croatia

1. Luxembourg



University Hospital of Saint-
Etienne
France



University Hospital Raymond-
Poincaré AHP
France

Expertise



**European
Reference
Network**

for rare or low prevalence
complex diseases



Network
Neuromuscular
Diseases (ERN EURO-NMD)

Specialist Disease Groups ORPHA 68381



Muscle



Peripheral Nerve



Neuromuscular Junction



Motor Neuron



Mitochondrial Diseases

Expertise



**European
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 **Network**
Neuromuscular
Diseases (ERN EURO-NMD)

Transversal Working Groups



Imaging



Neurophysiologie



Pathology



Genetics



Research



Education

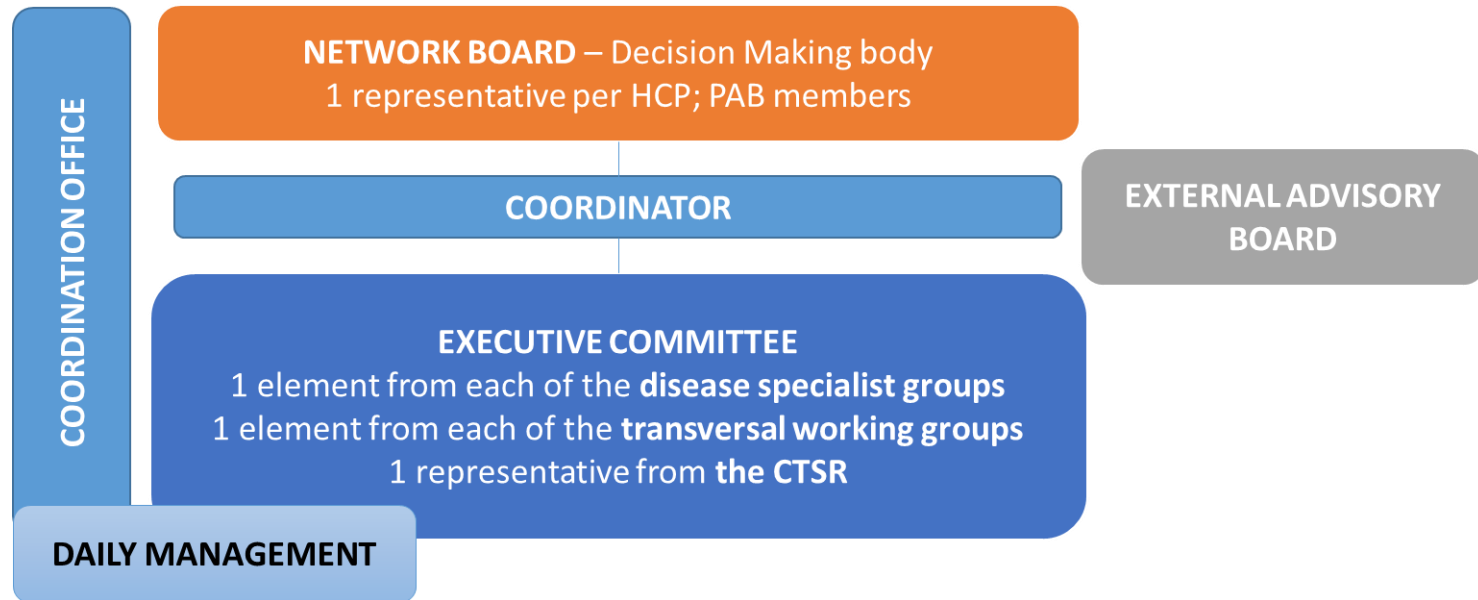


Ethics



PAB

Governance



**European
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Primary goals established in the ERN application

1. improve quality and equity of healthcare
2. enable the exchange of knowledge through teaching and training
3. facilitate translational research

- Focus on **strengthening the collaboration** amongst the 61 HCPs so that, when new members are proposed and endorsed, their integration is swift with minimum impact on the ERN's activities.



European
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Action Plan for the next 3 years

2019-2021

Main Objectives

- Education
- Clinical care
- Facilitate research

Education

ESTABLISH REGULAR THEMATIC WEBINARS

❖ Clinicians

❖ Patients

**There is a major role for
the French Centres**

Proposing themes / speakers

Diffusing the information

**Collaborate with FILNEMUS
in a shared program ?**

What are EURO-NMD webinars?

- Educational webinars
- Monthly basis
- Designed for healthcare professionals

Webinar Structure

- Last approximately 45' followed by 15' Q&A
- Hosted on Zoom software which allows, polls and live chat

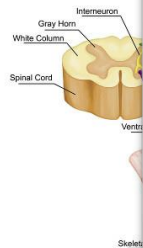
Done in cooperation with the ERN RND
Approved by the EAN

Education

Translation

- Translation with TFR

- ❖ 20
- ❖ A
- be



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Education

Other

- ❖ Endorse/produce guidelines; work being done with the EAN and hopefully with the EPNS
- ❖ Active participation and dissemination of the Paris Neuromuscular Summer School
- ❖ Organise 1 thematic workshop/year (Themes to be proposed by the Board)
- ❖ Fellowships

EDUCATION

Fellowships

RULES:

- Affiliated to one of the 61 HCP
- Young research/clinician (<40 years of age) working in the field of NMD
- The scientific meeting you choose is in the field of NMD
- Candidates from ITC countries and those who would present a poster or a talk at the meeting will be favoured
- Short CV, a letter of intention
- Assessment: by the **Exec. committee**
- Invitation to attend Euro-NMD's annual meeting and present an overview of the meeting attended

CARE

❖ Increase the use of the CPMS (e-Consultations)

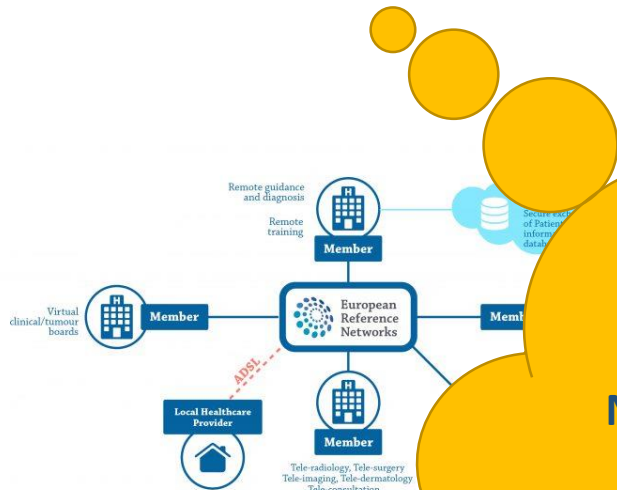
- Operational Helpdesk
- Develop and implement disease–specific datasets
- Implementation of a scan bank and a bank for pathology images (integrated with the CPMS)

❖ Work on guidelines and care pathways

- Each working group and the PAB to select themes and develop an action plan

❖ Work on information for patients

The Clinical Patient Management System (CPMS)



Interaction with the French Centres mostly has experts for the panels

Need to have an accurate knowledge of the expertise of the participants

Develop a CPMS training session in France under the umbrella of FILNEMUS (?)

<https://cpms.ern-net.eu/>

The Training Version of the CPMS

<https://cpms-training.ern-net.eu/login/>

Password: **cpmsern**

Live CPMS:

<https://cpms.ern-net.eu/login/>

You will need access to:

- EU Login/ECAS
- European Collaborative Platform
- SaaS

UserName	KnownAs	Country
euronmdcoord	euronmd coordinator	CZ
euronmddatabase	euronmd database	BG
euronmdguest	euronmd guest	BE
euronmdhpuser1	euronmdhpuser1 testuser	IT
euronmdhpuser2	euronmdhpuser2 testuser	HU
euronmdhpuser3	euronmdhpuser3 testuser	DE
euronmdhpuser4	euronmdhpuser4 testuser	FR
euronmdhpuser5	euronmdhpuser5 testuser	FI

Facilitate research

- ❖ Dissemination of news about ERN (newsletter, meetings, workshops, etc.)
- ❖ ERN Registry, a database of experts and projects
- ❖ Increase involvement of experts in ERN projects
- ❖ Collaboration with the European Commission (database)
- ❖ Support suggestions from the ERN Scientific Working Groups regarding collaborative projects

The ERN is a privileged tool to establish international networks and to facilitate additional funding

What direction would you like to see the ERN research activities go?

- Establish consortia and stimulate trans-national collaboration in research projects
- Clinical tool to help less privileged colleagues/patients; concentrate on helping with the CPMS
- Focused on the work within the working groups to try to get concrete projects – favouring collaborative groups of research
- Getting funding and support for projects; increase the awareness about funding opportunities
- Improve collection of NH on rare neuromuscular diseases towards trial readiness
- Develop meetings focused on selected topics , webinars

Facilitate research



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Fundings and Calls



The EJP RD will foster annual **Joint Transnational Calls (JTC)** for collaborative research projects resulting in funding encompassing various research fields of rare diseases in continuation of previous E-Rare calls.

The EJP RD will also fund the **Networking Support Scheme (NSS)** to encourage sharing of knowledge on rare diseases and/or rare cancers between healthcare professionals, researchers, and patient advocacy organizations.

Furthermore, the EJP RD will also fund the **Rare Diseases Research (RDR)** Challenges which is an innovative funding scheme to foster private-public partnerships and multi-stakeholder collaborations.



Reference
Networks

Facilitate research

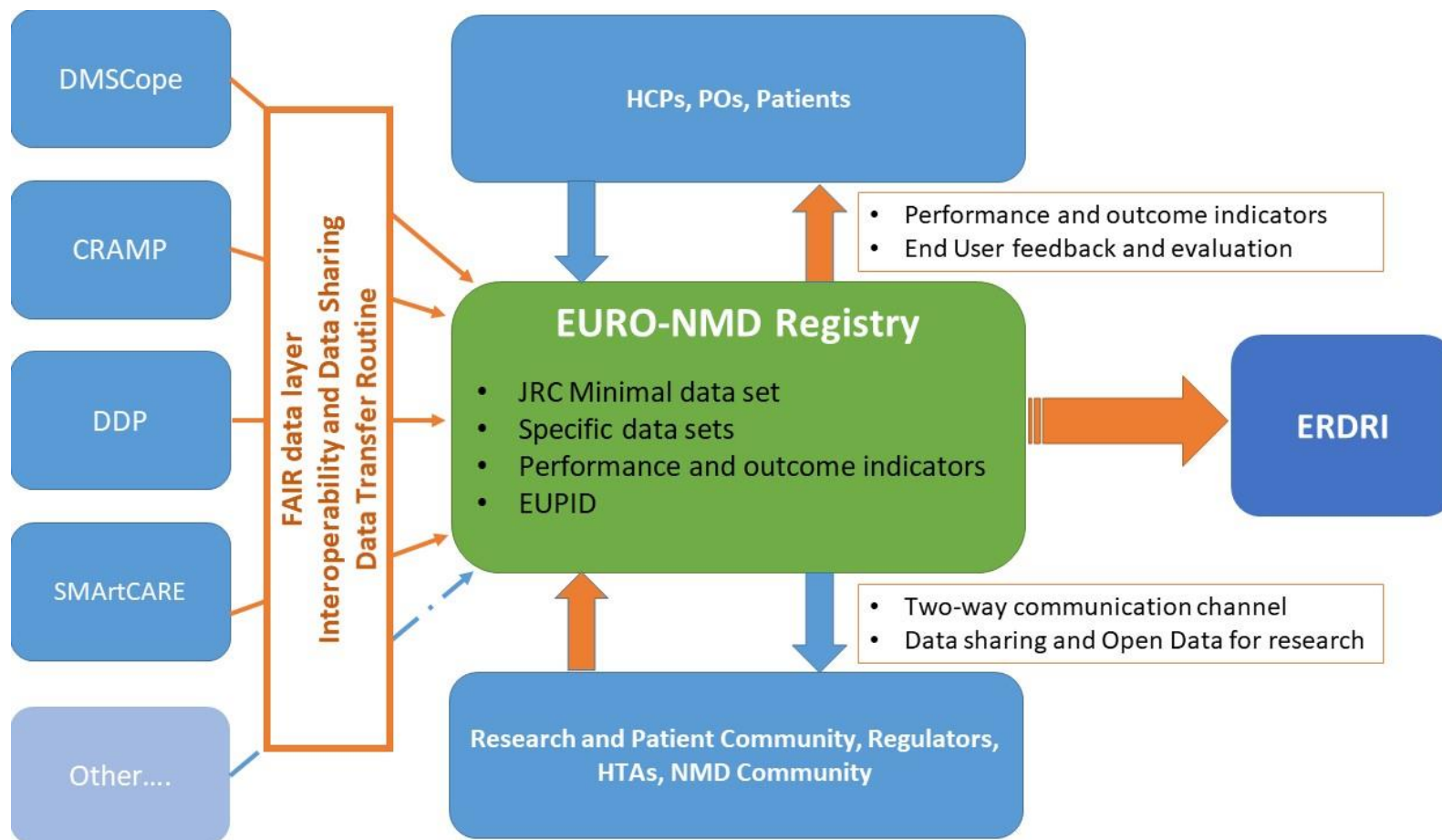


AIM

- (i) to solve large numbers of RD, for which a molecular cause is not known yet, by combined Omics approaches
- (i) to improve diagnostics of RD p... web"

**HCPs not yet involved
in SOLVE-RD may
become associated
partners and establish
an association
agreement with the
project coordinator**

Registries Call



EURO-NMD is a learning and evolving network

- ERN monitoring
- Survey for values and services the ERN can provide
- ERN registries
- NGS usage
- Neonatal screening
- Mapping of existing resources

Position statement papers on:

- Overprice of repurposed drugs (ex Mexiletine)
 - Neonatal screening
 - NGS for diagnostic testing

Your feed back is important

1. What services could/should the ERN provide to support you to provide care for patients?
2. What can the management team do to help improve de national status of your centre?
3. What other benefits can EURO-NMD create for you in your local hospital/ national health service?



For further details contact: info@ern-euro-nmd.eu

 [@euro_nmd](https://twitter.com/euro_nmd)

ern-euro-nmd.eu

CPMS help Desk: support@ern-euro-nmd.eu

“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”

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