

# L'ERN EURO-NMD : CHANGEMENT DE COORDINATION ET PROJETS FUTURS

TERESINHA EVANGELISTA

COORDINATRICE DE EURO-NMD



**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

- 🌐 **Network**  
Neuromuscular  
Diseases (ERN EURO-NMD)
- **Coordinator**  
The Newcastle upon Tyne  
Hospitals NHS Foundation  
Trust — United Kingdom

# QU'EST-CE QU'UN ERN?

- Un réseau de prestataires de soins / centres de santé fournissant des soins hautement spécialisés, dans le but d'améliorer l'accès au diagnostic, au traitement et aux soins des patients à travers l'Europe "



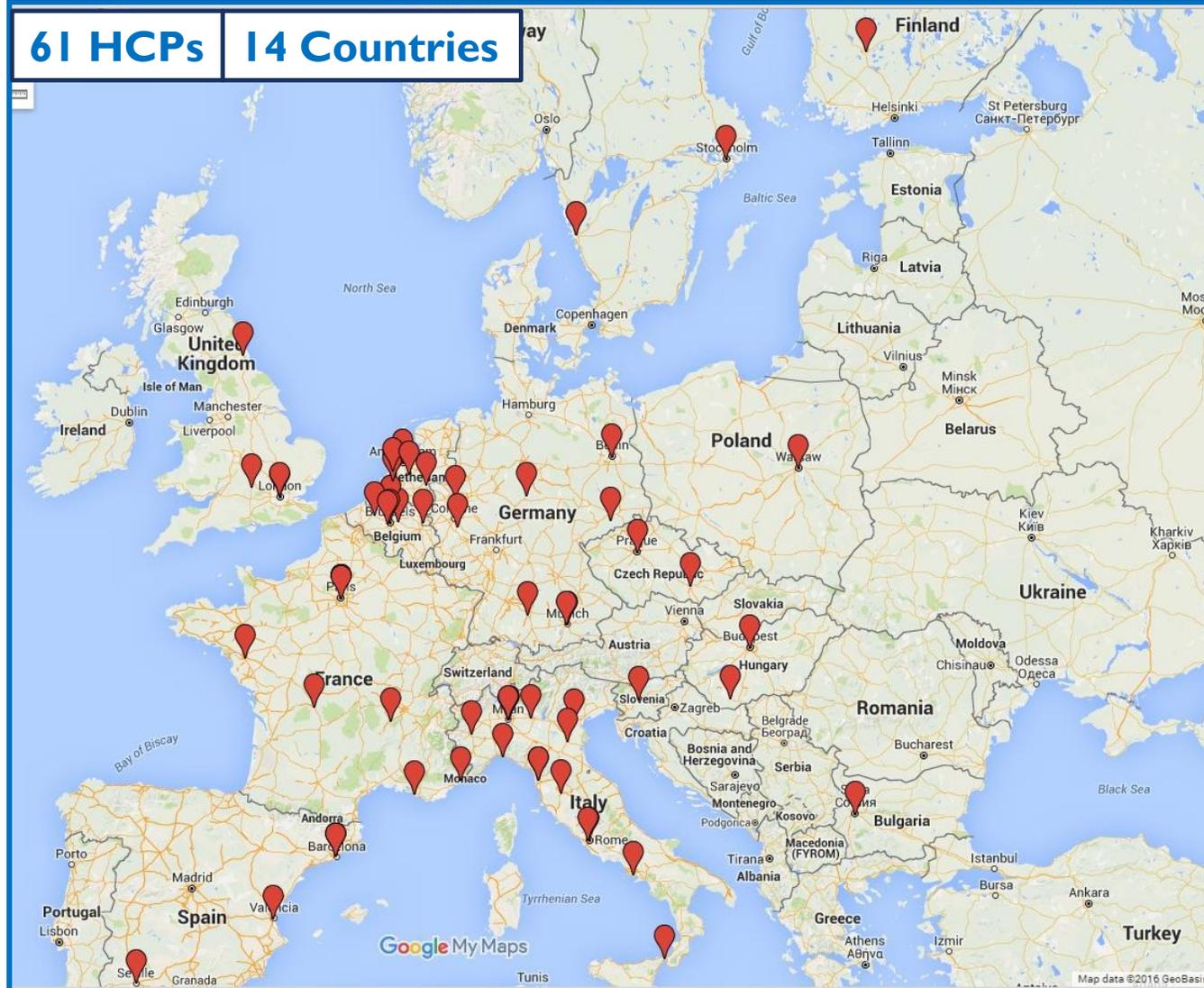


## European Reference Network

for rare or low prevalence complex diseases

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

**Coordinator**  
The Newcastle upon Tyne Hospitals NHS Foundation Trust — United Kingdom



**15 Italy**

**8 France**

**8 Germany**

**5 Spain**

**5 Belgium**

**5 The Netherlands**

**4 UK**

**2 Czech Republic**

**2 Hungary**

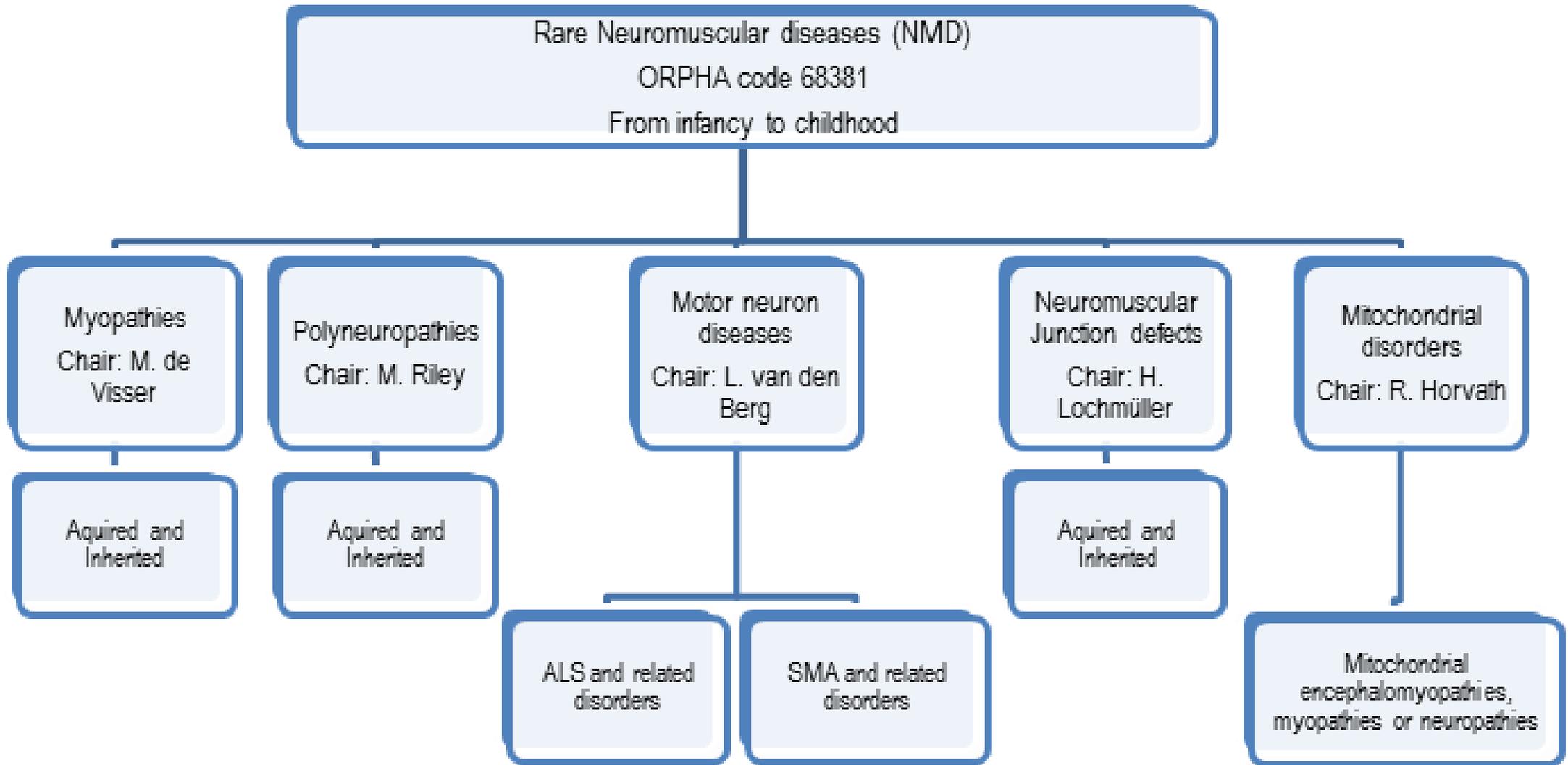
**2 Sweden**

**1 Poland**

**1 Bulgaria**

**1 Finland**

**1 Slovenia**

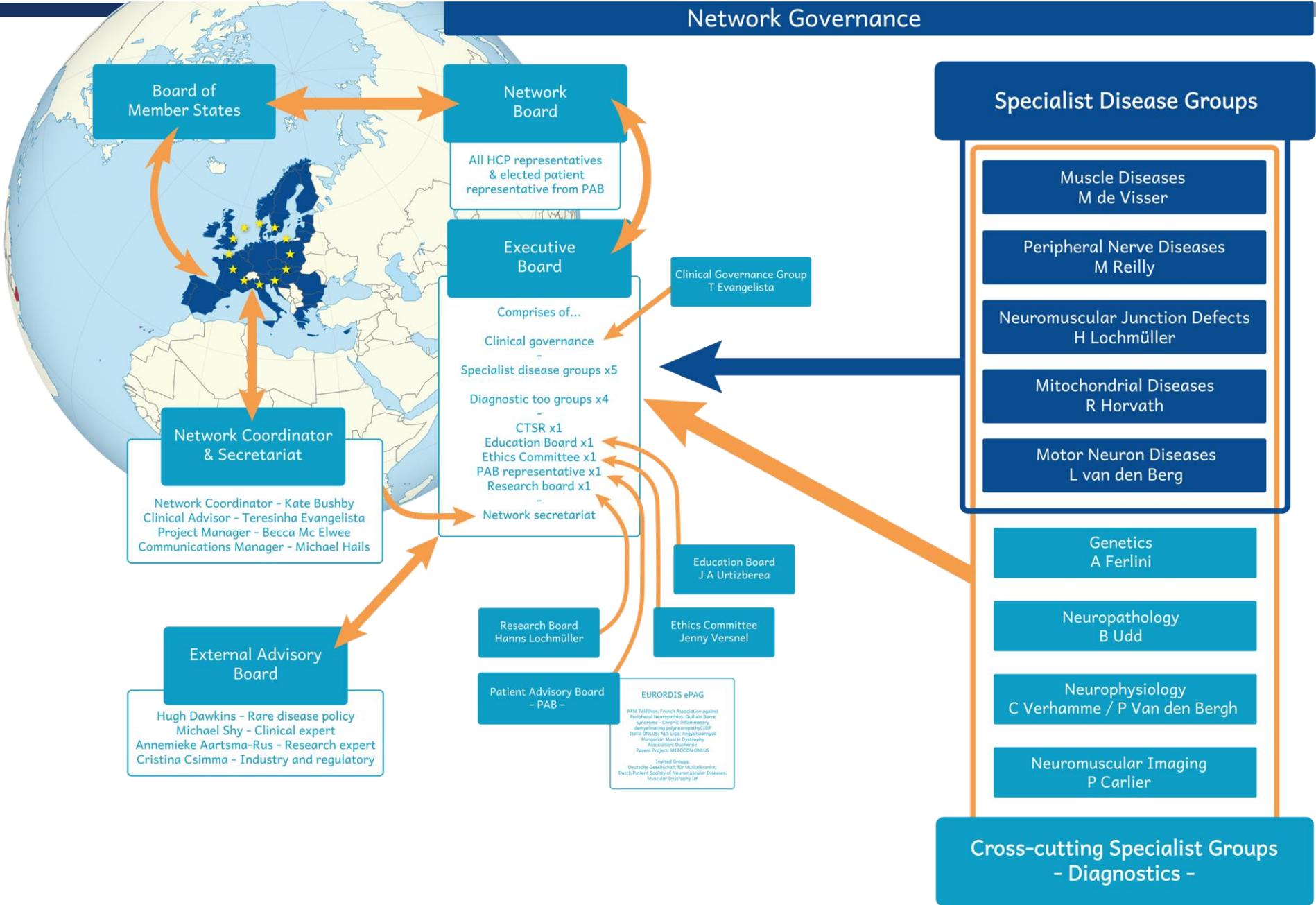


## NETWORK APPLICATION FORM

**8c. Please list the estimated activity for the main thematic or sub thematic areas of expertise covered by the Network. Specify the minimum number of patients to be diagnosed and treated per year**

Rare or Complex Disease(s), Condition(s) or Highly Specialised Intervention(s)	Measure					
	Estimated Total Number of Patients (Visited, Treated, or Followed per Year for the Network)		Estimated Total Number of New Patients per Year for the Network		Estimated Total Number of Procedure per Year for the Network	
	Adults	Paediatric* Range:17	Adults	Paediatric* Range:17	Adults	Paediatric* Range:17
1. All Neuromuscular diseases	77243	26129	15449	5226		
2. Rare Muscle diseases	27136	9045	5427	1809		
3. Rare Peripheral nerve diseases	16030	5344	3206	1069		
4. Rare Neuromuscular Junction defects	7471	2490	1494	498		
5. Rare Motor neuron diseases	10002	3334	2001	667		
6. Rare Mitochondrial encephalomyopathies	4052	1351	810	270		
7. Neuromuscular biopsies (muscle, nerve, skin)					8785	2928
8. Neurophysiology					59598	19866
9. MRI applied to NMD					4583	1527
10. Autonomous nerve system tests					4494	n.a.
11. Genetic testing					37734	12578

# Network Governance





**European Reference Network**  
for rare or low prevalence complex diseases

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

# EURO-NMD

Building bridges and breaking barriers in rare neuromuscular diseases

[About EURO-NMD & ERNs](#)

[Patient engagement](#)

[Educational resources](#)

[Guidelines & protocols](#)

[Research & clinical trials](#)

[2018 Annual meeting](#)



## Clinical patient management system

The clinical patient management system or CPMS as it is often referred to will be critical to patient care, diagnosis and treatment as well as future clinical research.

This is a huge undertaking and there is no such multinational clinical system currently in existence. We will keep you informed via our various communications channels as to its development, progression and major updates as the system evolves to meet the needs of its users.

Initially the focus will on diagnosis and treatment for patients by providing tools for collaboration, virtual consultations.

**European Reference Networks**  
Clinical Patient Management System



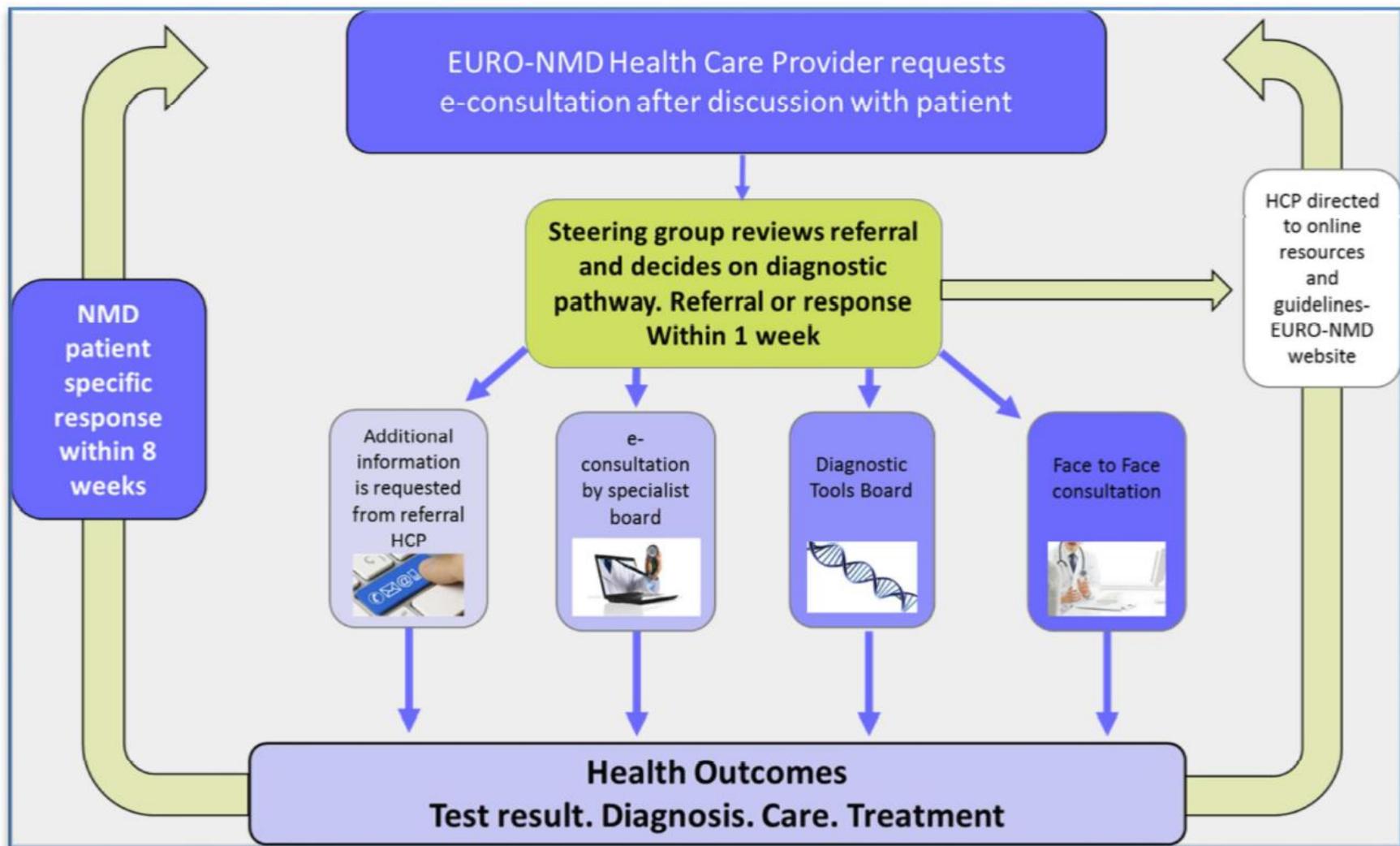
[Overview](#)

### [Link to the CPMS](#)

*(Please note that access to this system is available only for members of our ERN)*



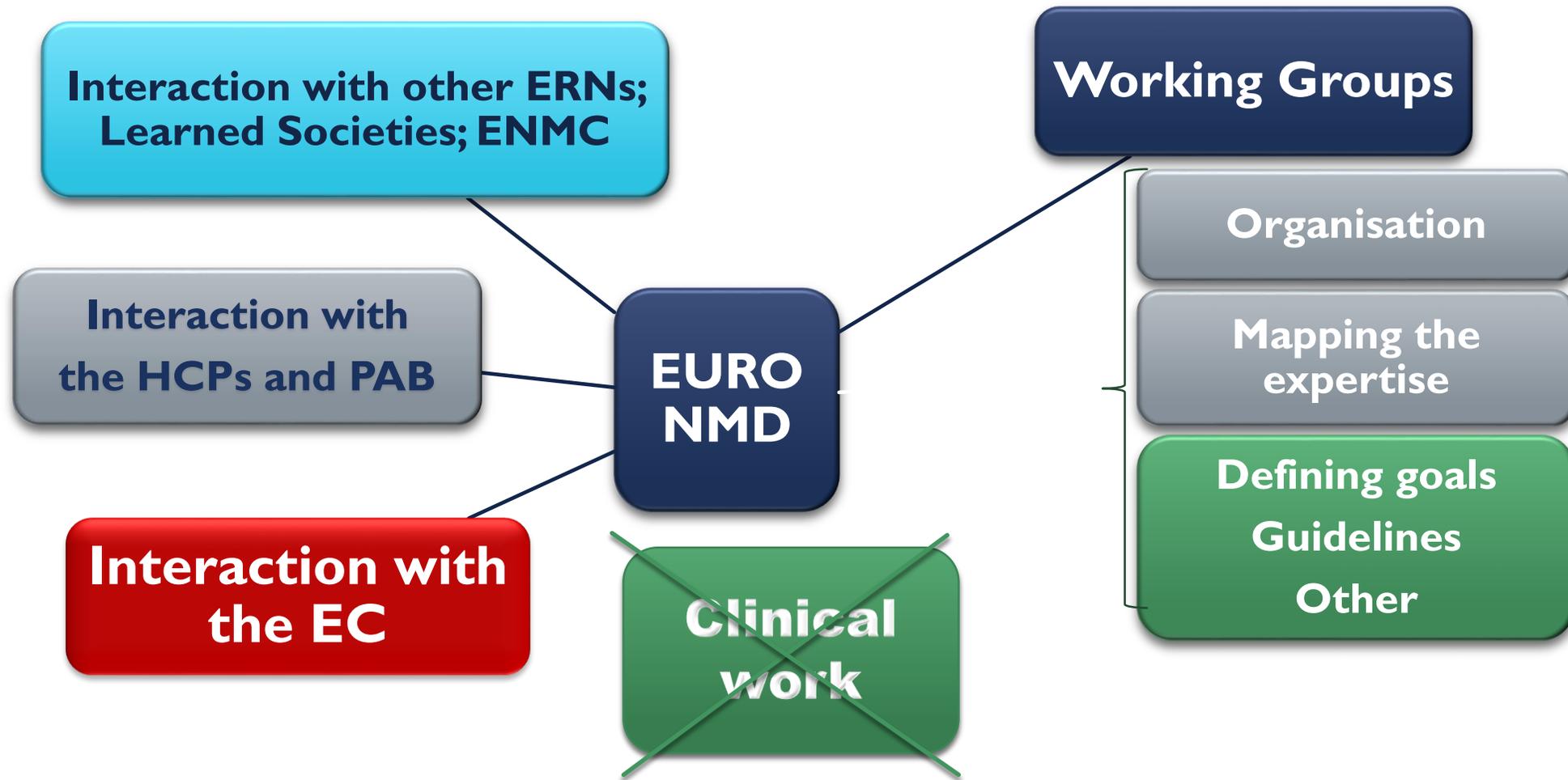
## Diagram 1 - Care Pathways



# 1<sup>ST</sup> YEAR GOALS

- i. To establish a functional Europe-wide network
- ii. To collate and review existing information on NMDs
- iii. To provide a map of expertise across Europe and define pathways for clinicians and patients to access the centres of excellence;

These primary goals were **for most achieved**



# EURO-NMD – Year One achievements

The screenshot shows the EURO-NMD website with the following elements:

- Header:** European Reference Network logo and tagline "Building bridges and breaking barriers in rare neuromuscular diseases".
- Main Content:** A large banner for "Share4Rare" with the text "Share4Rare – the project to develop a new collective awareness platform for social innovation launches!". Below it, a smaller text block states: "Based on a socially innovative approach, and building on citizen science and collective intelligence, the Share4Rare Project will engage and connect all relevant stakeholders towards improving quality ...".
- Upcoming events:** A list of events including:
  - International Congress of Research on Rare Diseases – RE(ACT) Congress 2018 (7 March 2018)
  - MDA Clinical Conference 2018 (11 March 2018)
  - British Peripheral Nerve Society meeting 2018 (16 March 2018)
  - Genomics of Rare Diseases (26 March 2018)
  - Translational Science of Rare Diseases – From Rare to Care III (11 April 2018)
- ER background:** A graphic showing "5 000–8 000 RARE DISEASES", "300 RARE DISEASES WITH NO TREATMENT", and "30 MILLION PEOPLE IN EUROPE".
- Recent activities:** A link to "RARE DISEASE DAY" with a colorful logo.
- Our platforms:** A button labeled "Our platforms".

First Conference Nov 17 –Freiburg  
2<sup>nd</sup> Nov 2018 -Prague

secretariat did not reach full capacity until October 2017

The screenshot shows the newsletter content with the following elements:

- Header:** "Newsletter - October 2017".
- Section: Board Members**

The Board of the ERN was established in accordance with the procedure stipulated by the Commission Delegated Decision. It includes one representative from each healthcare provider (full member) of EURO-NMD and one patient representative elected by the Patient Advisory Board. Katie Busby, Coordinator of the ERN chairs the Board.

Consisting of representatives from 61 healthcare providers from across Europe the Board is the primary decision making body accountable for fostering collaboration; removing obstacles to the network successful functioning; and maintaining the focus of the network on the agreed scope, outcomes and benefits.
- Members listed:**
  - Adriano Chia (Azienda Ospedaliero Universitaria Città della Salute e della Scienza, Italy)
  - Alessandra Ferlini (University Hospital St. Anna)
  - Andrés Nascimento (Hospital San Juan de Deu Universidad de Spain)
  - Anna Kostera-Pruszczyk (SPCSK, Medical University of Warsaw, Poland)
  - Ans van den Ploeg (Erasmus MC University Medical Center, Netherlands)
  - Antonio Federico (Azienda Ospedaliera Universitaria Seneze, Italy)
- Section: EURO-NMD features in WMS 2017 poster highlights**

The EURO-NMD poster was chosen for the poster highlights session at the World Muscle Society conference in St Malo, France. Teresinha Evangelina, who focused on the structure, function and aims of EURO-NMD, said how significant they felt EURO-NMD is for the who neuromuscular community.

[find out more](#)

Subscribe to Newsletter

59 of 61 HCP fully engaged

CPMS Piloted and tested 1<sup>st</sup> patients ready to refer

The graphic features a network of icons connected by dotted lines, including a red heart with a white cross, a green asterisk, a blue microscope, and a blue pill. Below the icons, the text reads: "Working for patients with rare, low-prevalence and complex diseases" and "Share.Care.Cure.".

# EURO-NMD current work

## Prioritising PROMS:

- ALS
- SMA
- Myasthenia Gravis
- Peripheral Neuropathies and
- Myotonic Dystrophy



## Working on **new** guidelines :

- Guillain-Barre Syndrome
- Myositis
- GNE Myopathy
- Paediatric Myasthenia Gravis
- ALS



Planning the Summer School and 2019 training programme

Neuromuscular Translational Summer School

2-6 July 2018

EURO-NMD  
Neuromuscular Network

European Reference Network  
for rare or low prevalence complex diseases  
Network Neuromuscular Diseases (ERN EURO-NMD)



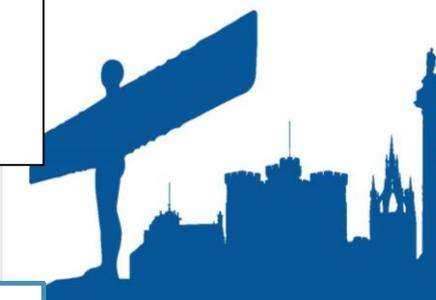
Starting Work on S4R and SOLVE RD

Solve RD

Receiving and managing the diagnosis and treatment of the first patients through CPMS

EJP –RD

Planning a COST Action on genetics



## SITUATION A PRÉSENT

- La **coordination** est encore à Newcastle
- Le Board de l'ERN a décidé de transférer la coordination à Paris (APHP / Institut de Myologie) en mars 2019 indépendamment du Brexit
- La **Commission Européenne** a demandé à tous les ERNs coordonnée du Royaume Uni de ne pas soumettre le projet pour la « Grant de Coordination » jusqu' à ce qu'il donne des nouvelles indications
- La subvention pour la deuxième année se termine fin Février 2019 – on commence à avoir des problèmes avec les personnes employées sur cette subvention

# PROBLÈMES

- Incertitude en regardent le future; «Timelines » imposée par la CE
- Changement de personnel de Newcastle à Paris; comment ça peut ce faire sans perturber les travaux?
- Utilisation du CPMS et les problèmes regardent la responsabilité civile des compte rendus écrits
- Comment incorporer des nouveaux membres et les « Affiliated Partners »?
- Intégration des ERNs dans le système national de santé des états membres
- Remboursement des actes médicaux pratiqués au sein de l'ERN

# LE FUTURE

## Lignes des actions principales

- EDUCATION
- E-Consultation
- Lignes directrices
- Forte participation dans des programmes européennes – ouvert a tout les HCPs
  
- Continuer l'interaction avec La Commission Européenne afin d'influencer les politiques concernant les ERNs
- Au niveaux Nationale avoir une action concertée avec FILNEMUS at FILSLAN
- Interaction avec EMA

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For further details contact: [info@ern-euro-nmd.eu](mailto:info@ern-euro-nmd.eu)

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

[ern-euro-nmd.eu](http://ern-euro-nmd.eu)

**CPMS help Desk: [support@ern-euro-nmd.eu](mailto: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](http://ec.europa.eu/health/ern)“