



ERN EURO-NMD Membership Guide

Dear members of ERN EURO-NMD,
 Thank you for your interest in joining us. With this guide, we would like to warmly welcome you aboard our network of 82 healthcare providers across 25 European countries. We aim to ensure your smooth and seamless integration into the EURO-NMD community.

Most importantly, we extend our deepest gratitude for sharing your expertise with us. Your contribution is invaluable to the success of our mission, and we truly appreciate your commitment to advancing healthcare within our network. Together, we can achieve remarkable outcomes.

Shorten Time to Diagnosis & Make the Knowledge Travel, not the Patient.

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A few words about the ERN EURO-NMD

ERN EURO-NMD is a patient centered network which meets the needs of patients with rare neuromuscular disorders, both diagnosed and undiagnosed, of genetic and non-genetic origin. We cover five disease groups:

1. Muscle diseases (Orphacode: 98472)
2. Motoneuron diseases (Orphacode: 98503)
3. Mitochondrial diseases (Orphacode: 68380)
4. Neuromuscular Junction disorders (Orphacode: 98491)
5. Peripheral nerve disorders (Orphacode: 98496)

We provide an infrastructure for diagnosis, highly specialized multidisciplinary healthcare, evidence-based management and collection of secure patient data. Our members share best practices, and aim to appraise, produce and disseminate high quality, evidence-based Expert Consensus statements to improve and optimize patient care in a coordinated manner.

We facilitate training and capacity building in the field and are involved in active and collaborative research aimed towards the development of diagnostic tests and future therapies, notably through our involvement in the European Rare Diseases Research Alliance (ERDERA, follow-up project of the Joint Plan on Rare Diseases (EJP-RD)). We aim to use innovative e-health approaches to facilitate access to diagnosis for patients, especially those from EU member states in which diagnostic services are less well developed, and to provide Learning/e-Training opportunities to young specialists in our field. All activities of EURO-NMD include patients and their families as equal partners.

What is expected from you in this stage?

1. Please carefully read the following sections of this guide.
2. Please make sure that you express your interest in joining at least one work group (WG) in ERN EURO-NMD. You may do so by directly contacting the Coordination Contact specified in the WG table (page 6).
3. The CPMS 2.0 (Clinical Patient Management System) is a crucial tool for the functioning of ERNs. Please send us the contact of the person(s) that will be in charge of the management of the CPMS 2.0 in your HCP. If you do not have an EU login yet, please [create your EU-login](#). You will soon be contacted by the coordination team to arrange a specific training on CPMS 2.0 for you. One of the compliance rules for EURO-NMD is to actively participate to the clinical case discussion in the CPMS 2.0.
4. Please [register your center in the CTSR \(Clinical Trial Site Registry\)](#).
5. Please update [your hospital's information](#) and [your team member's profiles](#) (add or update an individual's information) in our website. The website has space to bring your publications, your training activities to a broader audience. Please use it!
6. Please establish a list of all your team members. Use this list to escalate all information that you will receive from us, on bursaries, funding opportunities, and for survey requests. This list will be very helpful for you to gather the requested monitoring data (see point 7).
7. When publishing, you and your team should acknowledge EURO-NMD: "One/Several of the authors is/are (a) member(s) of ERN Euro-NMD". Think of [entering your publications to our website](#)!

8. Being an official member of ERN EURO-NMD, you will participate in the Continuous Monitoring of the ERNs, a very important exercise for ensuring the continuity of ERNs in general. All the actors (European Member States Healthcare authorities, ERNs and the European Commission) have identified the need to establish a solid and valid continuous monitoring and assessment system of the ERNs to allow a closer follow up of the activities performed by the networks. This system should help to build a quality improvement system, to define appropriate outcomes of the ERNs, to identify areas of success and potential pitfalls and to demonstrate the value of the ERNs, ultimately learning from the experience. There are a number of indicators for which you will need to provide data (annually). The coordination team will contact you with explanations and a table that you will need to fill. Concretely, some of the indicators are:

- ✓ Total number of new patients referred to your hospital with the diagnosis of a disease condition that falls within the scope of the ERN
- ✓ Number of educational webinars/videos aimed at healthcare professionals delivered by the coordination or HCPs members of the ERN
- ✓ Number of formal educational activities (i.e. those accruing higher educational credits) aimed at healthcare professionals organized by the ERN
- ✓ Number of Clinical Trials or Observational prospective studies (with >1 Member State and Health Care Provider within the ERN)
- ✓ Number of accepted peer-reviewed publications in scientific journals regarding disease-groups within the ERN and which acknowledge the ERN
- ✓ Number of congresses/ conferences/meetings at which the ERN activities and results were presented

At this stage, we would recommend establishing contact with the persons in your HCP administration that can help with the collection of such data (number of new patients, for example).

ERN EURO-NMD main tools

Coordinating a European-wide network in growth is a challenging task, therefore please do follow us via the tools described in this section.

- EUROPA WEBSITE

Visit: https://ec.europa.eu/health/ern_en for general information on ERNs.

- ERN EURO-NMD WEBSITE

Visit our website: <https://ern-euro-nmd.eu/>

The website is the depository of all our activities; please make full use of it!

There you can find and review our webinars, make contact with your 81 fellow network members from 25 European countries, find out about their activities and the secretariat's activities. You can sign up to our newsletter, you will find the canvas on the bottom of our website pages.

- ERN EURO-NMD REGISTRY HUB WEBSITE

Visit our registry hub website: <https://registry.ern-euro-nmd.eu>

Here you can find all the updates on the EURO-NMD Registry hub project

- ECP (ERN Collaborative Platform)

Please visit: <https://webgate.ec.europa.eu/ern/>. You will need an EU login to first access the platform. Then, please request access to ERN EURO-NMD network.

- CPMS 2.0 (Clinical Patient Management System)

Please register to the CPMS 2.0 and encourage your team members to do the same for that follow the link: <https://cpms.ern-net.eu/login/> if you experience difficulties to get access to the CPMS please contact our CPMS 2.0 helpdesk at support@ern-euro-nmd.eu.

You can find detailed information on how to request an EU Login and how to gain access to the CPMS 2.0 following the link: [CPMS Getting Started](#).

Send to Antonio Atalaia, our Clinical Advisor (a.atalaia@ern-euro-nmd.eu) the Contact(s) for your HCP that will be responsible for the follow-up of the CPMS 2.0 activities (it can be a young member of your team or an administrative).

In a nutshell, the CPMS 2.0 aims at supporting ERNs in improving the diagnosis and treatment of rare or low prevalence complex diseases across national borders of Member States in Europe.

The CPMS 2.0 is a secure Software as a Service (SaaS) that enables health professionals to discuss patient's care using comprehensive data models. Health professionals can use the CPMS 2.0 to collaborate actively and share patient data safely within and across ERNs.

The CPMS 2.0 is supported by Virtual Communication Tools and DICOM viewers to facilitate the interaction between clinicians. Reporting tools are among the functionality of the system to seamlessly empower users to generate reports of interest for administrative and clinical purposes.

- ZOOM

Many ERN EURO-NMD meetings are organized via the Zoom platform. You do not need an account to log in, simply follow the links that the coordination team will provide.

- Twitter

Follow us on [@euro_nmd!](#)

- [ERN EURO-NMD YOUTUBE CHANNEL](#)

Here you can find all the EURO-NMD webinars, watch and like them, and start again! You will also find our educational videos.

Feel like you need a crash-course on ERNs and the EU? Please contact us and we will try to organize something!

The General Governance of ERN EURO-NMD

The coordination team (secretariat)

The coordination team are the people responsible for the day-to-day management of EURO-NMD, and is hosted by the *Assistance Publique Hôpitaux de Paris (AP-HP)* in the *Pitié Salpêtrière Hospital* in Paris, France:

1. **Coordinator:** Dr. Teresinha Evangelista
2. **Clinical advisor:** Dr. Antonio Atalaia, in charge of clinical guidelines, the registry hub, CPMS training, webinars, research activities

3. **Senior project manager:** Carla D'Angelo: Management of the team, in charge of the EURO-NMD registry hub, contractual aspects and grant management.
4. **Project managers:**
 - a. Heike Pascal: WGs management, in charge of budget, reporting, monitoring, training mobility, congresses.
 - b. Houda Ali: WGs management, reporting, summer schools, related projects (JARDIN, ERICA, ERDERA).
5. **Communication Officer:** Elisabeth Avidi Muelle, in charge of Euro-NMD's website, newsletter, social medias, webinars.

To contact the coordination team in general, please write to:

coordination@ern-euro-nmd.eu

Individual contacts:

t.evangelista@ern-euro-nmd.eu

a.atalaia@ern-euro-nmd.eu

c.dangelo@ern-euro-nmd.eu

h.pascal@ern-euro-nmd.eu

h.ali@ern-euro-nmd.eu

e.avid-muelle@ern-euro-nmd.eu

Executive Committee (ExeC)

The Executive Committee is responsible for providing overall policy and strategic direction to the EURO-NMD network, oversees activities and progress, and delegates responsibility for day-to-day operations to the representatives of the various Activity Groups.:

- a. All the members of the Coordination Team;
- b. Chair and co-chair of all WGs;
- c. Chair and co-chair of the Patient Advisory board
- d. Representative of the CTSR (Clinical Trial Site Registry)

The Executive committee meets on-line on the 1st Monday of every month (except August), and holds 2 face-to-face meetings (before each Board meeting). The agenda and minutes are prepared by the secretariat.

Board of Network (BoN)

The Board of the Network (EURO-NMD) provides strategic direction and leadership to ensure that the goals of the network are achieved.

The Board of EURO-NMD is constituted by

1. 1 representative of every HCP (Healthcare Provider), that is a full member of the ERN (voting rights)
2. 1 representative from each of the affiliated partners/hubs (without voting rights)
3. All members of the Patient Advisory Board (voting rights)
4. The coordinator (voting rights)

When officially joining ERN EURO-NMD, your local representative will become member of the Board by default. In case of a vote, all representatives of full members and each of the representatives of the Patient Advisory Board have a vote.

Governance documents

In a near future you will receive the updated *EURO-NMD Network agreement*, the updated *Board terms of Reference* for your signature. All members have signed a Logo agreement, which entitles the member to use the ERN Euro-NMD logo for any correspondence.

ERN EURO-NMD Work Groups

Working Groups are very important entities in the work of ERN EURO-NMD. Each new HCP should contribute to at least one WG. You will find below the contact details of the ERN Euro-NMD work groups in order to help you choose in which one you or a member of your team would like to participate.

EURO-NMD's disease work groups	
Muscle diseases	Marianne de Visser, Amsterdam m.devisser@amsterdamumc.nl
Motor Neuron diseases	Jan Kirschner, Freiburg (SMA) janbernd.kirschner@uniklinik-freiburg.de Vincenzo Silani, Milano (ALS) vincenzo.silani@unimi.it
Mitochondrial diseases	Cornelia Kornblum, Bonn cornelia.kornblum@ukb.uni-bonn.de Michelangelo Mancuso, Pisa mancusomichelangelo@gmail.com
Neuromuscular Junction disorders	Hanns Lochmüller, Freiburg hanns.lochmuller@gmail.com Lorenzo Maggi, Milano lorenzo.maggi@istituto-besta.it
Peripheral Nerve disorders	Davide Pareyson, Milano Davide.Pareyson@istituto-besta.it
EURO-NMD's cross-cutting diagnostics work groups	
Imaging	Pierre Carlier, Paris pghrmgc@gmail.com
Genetics	Alessandra Ferlini, Ferrara fla@unife.it
Neuromuscular Pathology	Edoardo Malfatti, Paris edoardo.malfatti@aphp.fr
Physiology	Camiel Verhamme, Amsterdam c.verhamme@amsterdamumc.nl Peter van den Bergh, Brussels peter.vandenbergh@saintluc.uclouvain.be
Multidisciplinary Management & Care	Marianne Nordstrøm, Oslo mal@frambu.no

EURO-NMD's advisory boards	
Education board	Jean-Philippe Plançon, Paris jean-philippe.plancon@epodin.org Sabrina Sacconi, Nice SACCONI.S@chu-nice.fr Marianne de Visser, Amsterdam m.devisser@amsterdamumc.nl Kristl Claeys, Leuven Kristl.Claeys@uzleuven.be
Research board	Hanns Lochmüller, Freiburg hanns.lochmuller@gmail.com
Patient advisory board	François Lamy, Paris flamy@afm-telethon.fr

European Union's EU4Health Programme



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