

## **The European Reference Network (ERN) EURO-NMD is looking for a Project Officer (m / f)**

### **Organization:**

ERN EURO-NMD (European Reference Network for Rare Neuromuscular Diseases)

### **Location:**

Hôpital Pitié-Salpêtrière, Assistance Publique - Hôpitaux de Paris (AP-HP), Paris, France

### **ERN EURO-NMD**

European Reference Networks (ERNs) are networks involving centers of expertise and health care providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialized treatment, and a concentration of knowledge and resources. Established in 2017 and funded by the European Commission under the EU4Health programme, EURO-NMD is a European reference network for the thematic grouping of rare neuromuscular diseases (NMDs), a broad group of related disorders that represent a major cause of mortality and lifelong disability in children and adults.

The network brings together 82 highly specialized multidisciplinary healthcare providers (HCPs) from 25 European countries, as well as 23 patient organisations. It is structured around five disease groups, five cross-cutting diagnostic groups, working groups dedicated to research and education and a patient advisory board.

The ERN main areas of action are facilitating multidisciplinary virtual consultations using a dedicated IT platform known as CPMS, developing clinical guidelines and other clinical decision support tools, managing the EURO-NMD patient registry, and providing education and training initiatives. EURO-NMD is also a partner in other EU-funded projects, in particular the ERICA consortium, in which all 24 ERNs participate, the Joint Action JARDIN, and ERDERA

The coordination of EURO-NMD is based at the Pitié-Salpêtrière Hospital, Assistance Publique - Hôpitaux de Paris (AP-HP), Paris, France. Currently, the coordination of the ERN is ensured by the AP-HP and operated by a team of 6 people: The Network Coordinator, a Clinical Advisor, a Senior Project Manager, two Project Managers, and a Communication Officer.

### **Main objective**

The main aim of this post is to provide day-to-day administrative and organizational, support to the Network activities, related with the EURO-NMD Registry, under the supervision of the Clinical Advisor and the Senior Project Manager. This role will

involve liaising with the Network and registry partners and other stakeholders to facilitate the implementation of the registry and support the expansion of it.

Associated to the above mentioned main objective, this post is also aimed at supporting the CPMS helpdesk when needed; helping and eventually leading in the full organisation of the ERN and registry related meetings (annual meeting, board meetings, executive committee meetings) with the support of the other members of the coordination team.

## **Main tasks and responsibilities**

- **Registry Management:** Assist the Network Coordinator, Clinical Advisor, and Senior Project Manager in the management and maintenance of the EURO-NMD Registry, i.e. registry helpdesk, organization of meetings, support to partners in the functioning of the registry, liaise with the Communications Officer to promote the registry; be able to extract basic data from the registry to be available on the website and support the Clinical Advisor and the Senior Project Manager in their respective activities related to the registry;
- **CPMS Helpdesk:** Under the supervision of the Clinical Advisor and in coordination with the CPMS Work Package (WP) Leader, the person must possess in-depth knowledge of the functioning of the platform and be able to help users with difficulties regarding access. Responsibilities include monitoring the CPMS WP and maintaining constant contact with the leading team in Ferrara (Italy). An activity report of this WP should be presented to the coordination team every three months;
- **Project Coordination:** Assist with administrative and support tasks related to the registry, CPMS, and other future activities according to the work requirements (e.g., data management, documentation);
- **ERN project management:** Assist in the execution of specific project tasks as assigned by the Coordinator or Senior Project Manager, such as financial and technical reports;
- **Meeting Organization:** Assist in the planning and organization of ERN-related meetings, i.e. Board Meetings, Annual Meetings, Executive Committee Meetings and registry related meetings (e.g., scheduling meetings, preparing agendas, minutes, and follow-up actions points);
- **Event Support:** Provide organizational and logistical support for the Annual Meetings of the network (e.g., venue, travel arrangements, onsite support);
- **Communication:** Maintain effective communication with the Network partners and stakeholders. Respond to inquiries and provide necessary information. This implies a good knowledge of all the work streams of the ERN and the ability to interact with the other team members for updates;

- Ad Hoc Tasks: Undertake other tasks as appropriate to support the smooth functioning of the Network. Liaise with other projects in which the ERN is involved.

## Qualifications

- University degree (Bachelor's or equivalent)
- Previous experience with EU-funded projects or equivalent
- Familiarity with rare diseases, patient registries or databases is a plus
- Fluency in both French and English is essential.
- Good interpersonal skills, ability to work effectively in a multicultural environment.
- Responsive and adaptable to changing priorities and project needs.

## Job specifications:

- English environment (working language of the network)
- Requires travelling in the EU (occasionally)
- Remote work possible (2 days/week)

## Other:

- Fixed-term contractual position
- Working hours: 100%.
- Salary according to experience, diploma and APHP's salary grid.

## Application:

Please send your application (CV + cover letter) by e-mail to the following address:  
[c.dangelo@ern-euro-nmd.eu](mailto:c.dangelo@ern-euro-nmd.eu)

Desired starting date: 01/10/2024