

ERN on neuromuscular diseases (ERN EURO-NMD)

Neuromuscular diseases (NMDs) occur from early childhood to late adulthood and are characterised by muscle weakness and wasting. They may also be associated with other symptoms including fatigue, pain, numbness, blindness, swallowing difficulties, breathing difficulties and heart disease. Most NMDs are progressive and debilitating, with reduced lifespan and quality of life.

There are significant gaps and disparities in access to diagnostics and treatment across Europe. Major challenges in improving outcomes include the delay in referral from primary care to a specialist centre and managing the transition from paediatric to adult services.

EURO-NMD unites Europe's leading experts to provide patients with access to specialist care through virtual and in-person consultations. The network aims to reduce time to diagnosis, improve diagnostic yield and increase access to appropriate care pathways.

In the first half of 2021, a total of 12,882 new patients consulted EURO-NMD partners, and partners participated in 258 clinical trials. Since 2018 the number of new patients consulting network partners has risen by 37.5 percent and the participation of EURO-NMD partners in clinical trials has increased by 63 percent.

In addition, the network continuously develops new guidelines and provides healthcare professionals and patients with disease-specific best practice information. The knowledge generated and curated by the network is widely available online and through publicly-available webinars, as well as via eHealth tools such as CPMS discussions. A Moodle-based learning management system (LMS) is currently under construction.

Building on a strong legacy of cooperation, the network continues to foster collaborations with the potential to drive research and therapy development to address unmet patient needs. Promoting transnational data sharing through ethically robust, high quality registries and research data platforms is also a priority.

NETWORK COORDINATOR

Dr. Teresinha Evangelista
Sorbonne University - Pitié
Salpêtrière Hospital - Assistance
Public Hopitaux de Paris, France

