

## GOVERNANCE

The EURO-NMD Registry is a patient registry for all rare, paediatric and adult, neuromuscular diseases. It is a pan-European, collaborative effort led by EURO-NMD, an ERN for the thematic grouping of rare neuromuscular diseases, to build the first unified NMD Registry in the EU.

The purpose of the EURO-NMD Registry is to improve the quality of care and outcomes for NMD patients across Europe, while providing sufficient data to launch research and clinical trials, inform policy and regulatory decisions.

The Registry received funding from the 3rd EU Health Programme and was jointly developed by a consortium of organisations: · Assistance Publique–Hôpitaux de Paris (AP-HP), · University Medical Centre Freiburg (UKLFR), · Radboud University Medical Center (Radboudumc), · World Duchenne Organization (UPPMD), · Duchenne Data Foundation (DDF), · Institute of Myology (AIM), · French Muscular Dystrophy Association (AFM-Téléthon).

The Coordinating Centre of the ERN EURO-NMD (AP-HP) is the owner of the EURO-NMD Registry. The University Medical Centre Freiburg (UKLFR) is responsible for hosting the Registry server and database.

The EURO-NMD Registry governance structure comprises the following bodies:

The **EURO-NMD Coordinator**, who acts as the Registry lead on behalf of the Network and provides oversight to the Registry's operations.

The **Steering Committee (SC)**, constituted by the EURO-NMD Coordinator and members of the EURO-NMD Registry Consortium, is the Registry's main governing and decision-making body. It provides strategic direction and ensures that agreed policies and procedures are followed. The SC works closely with EURO-NMD Executive Committee, where each thematic Work Group of the Network is represented.

Chaired by the EURO-NMD Coordinator, the SC takes its decisions on the basis of consensus, if not by absolute majority. The SC follows the operational procedures defined in the EURO-NMD Registry Consortium Agreement. The composition of the SC will be reviewed periodically and its appointed representatives updated as required.

The **Management Team**, under the guidance of the EURO-NMD Registry SC, is responsible for the daily management and the day-to-day operations of the Registry. This group is composed of members



*This document is part of the project 'EURO-NMD Registry' co-financed by the European Commission under the Third Health Program (grant agreement 101055286). The EURO-NMD Registry has also received funding for 5 months from the EU4health program (grant agreement 101085084) and will continue to be funded for the 2023-2027 period under the call EU4H-2023-ERN-IBA.*



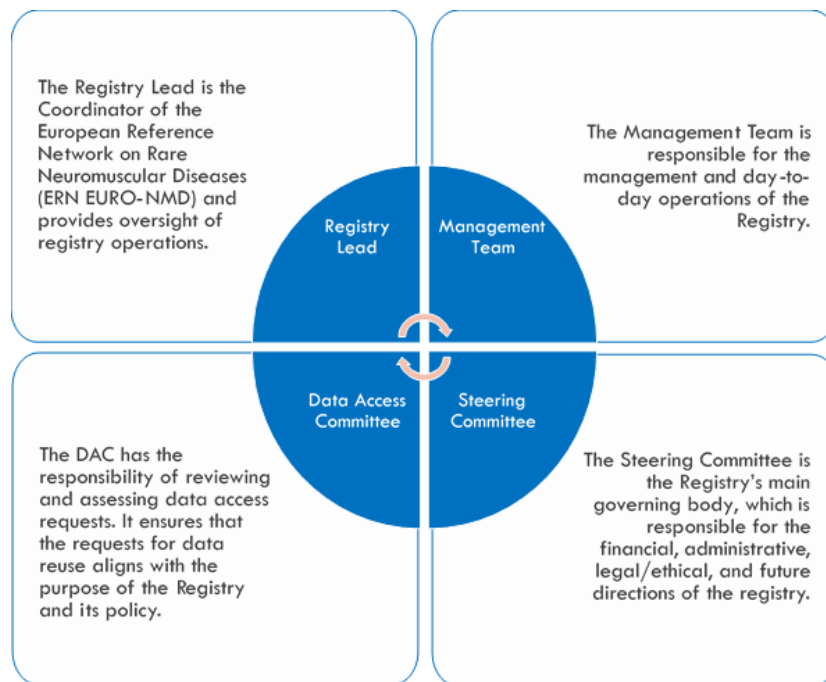
## EURO-NMD Registry Hub

European Reference Network  
for neuromuscular diseases

of the ERN EURO-NMD coordination office based in Paris, who are responsible for the overall management of the Registry, and the operational management team based in Freiburg, composed of IT experts and data managers, with overall responsibility for data operations and maintenance of the data entry system.

Additionally, a **Data Access Committee (DAC)** has been established to review and assess data access requests submitted by third parties in accordance with the EURO-NMD Registry Data Access Policy.

In the event that the Registry or the Network are discontinued for any reason, the Steering Committee shall determine whether the data shall be destroyed, returned to the HCPs they originate from or other options to maintain the data for research in accordance with applicable privacy law.



**Governing Structure of the EURO-NMD Registry**



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