



European
Reference
Networks



Euro-NMD bilan d'activités 2017

J. Andoni URTIZBEREA
L'ERN-messenger



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

2017 Meeting
29-30 november



over **900** healthcare units → **24** thematic networks

Frequently asked questions

Vytienis Andriukaitis, European Commissioner for Health and Food Safety, says the value of EU collaboration is

Upcoming events

-  **Action Duchenne International Conference 2017**
📅 10 November 2017
-  **Imaging in Neuromuscular Disease 2017**
📅 19 November 2017
-  **TREAT-NMD Conference**
📅 27 November 2017
-  **EURO-NMD Meeting 2017**
📅 29 November 2017



– consortiums

- APHP
 - Paris-Est, Canalopathies, et SLA
 - GNMH + CARAMMEL
- Nice
 - Muscle, SLA, mitochondries (CALISSON)
- Limoges-Tours
 - Muscle et SLA
- Marseille
 - Muscle, SLA
- Rhône-Alpes
 - Muscle, SLA

– CRM

- APHP : Bicêtre
- Nantes





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Healthcare Providers

Healthcare Provider Country:

- Belgium
- Bulgaria
- Czech Republic
- Finland
- France
- Germany
- Hungary
- Italy
- Netherlands
- Slovenia
- Spain
- Sweden
- UK

Specialised Groups:

- Muscle diseases
- Peripheral Nerve Disease
- Motor Neuron Disease
- Neuromuscular Junction Defects
- Mitochondrial Diseases

Cross Cutting Specialised Groups:

- Genetics
- Neuromuscular Imaging
- Neuromuscular Pathology
- Neurophysiology

Advisory Boards:

- Education
- Ethics
- Research

BOARD – (14 m)			
Bushby	Coordinator	Newcastle	UK
Evangelista	Project manager	Newcastle	UK
Lochmüller	Research	Newcastle	UK
Reilly	Neuropathies	Londres	UK
Horvath	Mitochondria	Newcastle	UK
Carlier	Imagerie	Paris	France
Urtizberrea	Education	Hendaye	France
Lamy	Ethics – e-PAG	Paris	France
Udd	Anatomo-pathologie	Tampere	Finlande
Van den Bergh (P)	Electrophysiology	Bruxelles	Belgique
Ferlini	Genetics	Ferrara	Italie
Kirschner		Freiburg	Allemagne
De Visser	Muscle	Amsterdam	Pays Bas
Van den Berg (L)	Motoneuron	Utrecht	Pays Bas

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Patient Advisory Board Members

François Lamy (AFM Téléthon, France)

Jean-Philippe Plançon (French Association against Peripheral Neuropathies: Guillain Barre syndrome-Chronic inflammatory demyelinating polyneuropathy, France)

Massimo Marra (CIDP Italia ONLUS, Italy)

Evy Reviere (ALS Liga Belgium)

Judit Varadine Csapo (Angyalszarnyak Hungarian Muscle Dystrophy Association)

Marisol Montolio (Duchenne Parent Project Spain)

Piero Santantonio (MITOCON ONLUS, Italy)

Other Patient Representatives:

Inge Schwersenz (DGM; Deutsche Gesellschaft für Muskelkranke; Germany)

Ria Broekgaarden (VSN; Dutch Patient Society of Neuromuscular Diseases)

Nick Bungay (Muscular Dystrophy UK)



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Activités 2017

- intronisation du réseau Euro-NMD (mars, Vilnius)
- mise en place du site internet Euro-NMD
 - base déclarative des 61 HCP
- mise en place des commissions spécialisées et boards
- Executive Committee (board) : réunion mensuelle TC
 - 14 membres dont 3 de Filnemus
 - P. Carlier, JA Urtizbera, F. Lamy
- accord-cadre EAN – Euro-NMD
- meeting Euro-NMD Freiburg 29 novembre 2017



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Prévisionnel 2018

- déploiement de la plate-forme de télémédecine
- Translational Summer School Euro-NM :
 - juillet 2018, Newcastle, 30 personnes
- autres activités de formation : notamment Imagerie
- partenariat sociétés savantes
 - EAN, EPNS, ESPRIM, autres
- partenariat programmes européens de recherche
 - type SOLVE-RD (errance diagnostique)
 - EJP (European Joint Program)
- 2^{ème} vague de labellisation de HCP



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Analyse critique

– Éléments positifs

- effet structurant, visibilité des MNM au niveau européen
- respect du calendrier, mise en place coordination
- partenariat sociétés savantes

– Éléments moins positifs

- flou persistant sur l'impact du Brexit
- retard plateforme de télémédecine
- sous-financement
- place/rôle des représentations de patients
- délimitation ligne de partage EURO-NMD / TREAT-NMD