

## List of reference centers

A reference center is composed of a multidisciplinary team of medical and para medical experts in the neuromuscular field. The centers are there to organize the **multidisciplinary consultations** coordinated with the physicians and paramedical staff treating them. In Belgium, there are 9 Reference Centers recognized by the NIHDI.

- **CHR de la Citadelle**  
Boulevard du 12ème de Ligne 1, 4000 Liège  
04 225 6982 - [bnmdr@chrcitadelle.be](mailto:bnmdr@chrcitadelle.be)
- **Cliniques Universitaires Saint-Luc**  
AV. Hippocrate 10, 1200 Bruxelles  
02 764 1311 - [bnmdr@uclouvain.be](mailto:bnmdr@uclouvain.be)
- **ULB Hôpital Erasme**  
Route de Lennik 808, 1070 Bruxelles  
02 555 8125 - [bnmdr@erasme.ulb.ac.be](mailto:bnmdr@erasme.ulb.ac.be)
- **ULB - HUDERF - UKZKF**  
Av. Jean-Joseph Crocq 15, 1020 Bruxelles  
02 477 3311 - [bnmdr@huderf.be](mailto:bnmdr@huderf.be)
- **UZ Antwerpen**  
Wilrijkstraat 10, 2650 Edegem  
03 821 4508 - [bnmdr@uza.be](mailto:bnmdr@uza.be)
- **UZ Brussel – Site UZBrussel**  
Laarbeeklaan 101, 1090 Brussel  
02 477 8816 - [bnmdr@uzbrussel.be](mailto:bnmdr@uzbrussel.be)
- **UZ Brussel – Site Inkendaal**  
Inkendaalstraat 1, 1602 Vlezenbeek  
02 531 5250 - [bnmdr@inkendaal.be](mailto:bnmdr@inkendaal.be)
- **UZ Gent**  
De Pintelaan 185, 9000 Gent  
09 240 3887 - [bnmdr@uzgent.be](mailto:bnmdr@uzgent.be)
- **UZ Leuven**  
Herestraat 49, 3000 Leuven  
016 34 35 08 - [bnmdr@uzleuven.be](mailto:bnmdr@uzleuven.be)

## Additional information

### CONTACT DETAILS OF PATIENT ORGANIZATIONS

**ABMM asbl**  
Association Belge  
contre les Maladies Neuromusculaires  
Rue Achille Chavée 52/02, 7100 La Louvière  
Tél./fax : 064/450.524 - 0495/439.800  
[secretariat@abmm.be](mailto:secretariat@abmm.be)



**ALS Liga België vzw - Amyotrofe Lateraal Sclerose**  
Campus Sint Rafaël, Blok H, 4de verdieping  
Kapucijnenvoer 33 B/1, 3000 Leuven  
Tel/fax: 016/23.95.82 - 016/29.98.65  
[info@alsliga.be](mailto:info@alsliga.be) – [www.alsliga.be](http://www.alsliga.be)



**Nema vzw**  
Vlaamse Vereniging  
Neuromusculaire Aandoeningen  
Haarbendenstraat 55/1, 3500 Hasselt  
Tel./fax. : 011/72.31.87  
[secretariaat@nema.be](mailto:secretariaat@nema.be)



## Contact the BNMDR

Project manager at the Scientific Institute  
of Public Health

[www.bnmdr.be](http://www.bnmdr.be)  
[BNMDR@wiv-isp.be](mailto:BNMDR@wiv-isp.be)



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## Belgian Neuro Muscular Disease Registry

### INFORMATION BROCHURE FOR PATIENTS



Neuromuscular diseases are rare diseases,  
on average touching more than  
250,000 people in Europe.

Together we can make a difference. Join the Registry!





# The Registry, cooperative work amongst us

## What is the Neuromuscular Disease Registry ?

### BNMDR

The Belgian Neuromuscular Disease Registry, also known as BNMDR, is a collaborative work between the NIHDI, the reference neuromuscular disease centers and the Scientific Institute of Public Health (WIV-ISP). It has been operating since 2008.

It gathers relevant medical data from patients having been diagnosed with neuromuscular diseases. The information is collected annually from **WILLING** patients. It is stored **SECURELY** and remains **ANONYMOUS**.

#### The aim of the registry is:

- Epidemiologically study neuromuscular diseases;
- Facilitate clinical research;
- Inform public authorities of the importance of improving health care services for patients with these diseases.

A new module has been added for patients having Spinal Muscular Atrophy (SMA) or Duchenne Muscular Dystrophy (DMD)



[www.treat-nmd.eu](http://www.treat-nmd.eu)

BNMDR collects data for the European network, TREAT-NMD, which recruits patients for clinical trials.

**Put your trust in us and sign the consent form so that research can move forward**

## What do I need to do to sign up?

If you are willing, sign up at one of the 9 Reference Centers where you can be treated for neuromuscular diseases (locations detailed overleaf).

## Why is my inscription important for the Registry?

- If researchers are looking for candidates for clinical trials, you could be contacted by your Reference Center.
- You might not personally benefit from the registry, but there will be long-term benefits from your participation which would greatly assist the progress of research in understanding and managing these rare diseases.

