# A special thanks to all our members and supporters

Thanks to the continuous support of the nine European patient organisations and ENMC members, the ENMC is able to facilitate and organise on average eight workshops per year. With the support of additional partner organisations and of the ENMC Company Forum we can facilitate the attendance of young scientists and patient representatives and occasionally also reimburse travel costs of participants from non-ENMC-member countries.

ENMC full and associated member countries Denmark, Finland, France, Germany, Italy, the Netherlands, Switzerland, the United Kingdom.

Partner organisations CureCMD, CureSMA, Duchenne Parents Project, Euromac, A Foundation Building Strength for Nemaline Myopathy, Joshua Frase Foundation, Kennedy's Disease Association, LGMD-2i Fund, MDA USA, Myositis UK, The Myositis Association, Myotonic Dystrophy Foundation, Myotubular Trust, Parent Project Muscular Dystrophy, RYR-1 Foundation, SMA Europe, SMA Foundation, SMA support UK, Team Titin and many others.

ENMC full and associated members:

Company Forum:





vormgeving: Vormgevers Arnhem



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#### THE ENMC:

Connecting health care professionals and patients worldwide in order to advance progress in the diagnosis, treatment and care of people with a rare neuromuscular condition.



#### How?

The ENMC organises workshops upon application by researchers and health care professionals who are experts in the field of rare neuromuscular disorders. Workshops take place over a weekend in the vicinity of Amsterdam Schiphol airport. During a workshop, participants share their experience, show unpublished data, discuss research gaps and plan future collaborations to develop standards of care, launch disease registries, improve outcome measures and advance research.

Topics in 25 years of ENMC workshops	%
Clinical trial readiness and outcome measures	45
Reaching consensus on treatment guidelines	10
Registries or clinical databases	5
Care management	
Basic research/diagnosis	25

#### From bench ...



### ... to bedside!



## The ENMC Company Forum

The "ENMC Company Forum" supports the general ENMC activities and extra programs like the *Young Scientist Program* and the *Patient Participation Program*.

The first young scientist who participated in a workshop through the Young Scientist Program was *Benjamin Gallais (PhD)*, a clinical psychologist from Canada who attended the 207<sup>th</sup> ENMC workshop on respiratory insufficiency in NMD.

Benjamin Gallais:

"I really appreciate that ENMC gives the opportunity to young scientists to share one's views and research with key experts in the field. I thank ENMC and the Company Forum for giving me this privilege!"

## Sponsoring the ENMC

ENMC's core activities are supported by its member organisations. Individual workshops are sometimes supported by disease-specific patient organisations. However, in this time of rapid medical progress, the ENMC can only face the increasing demand for international workshops with the additional sponsoring of the ENMC Company Forum and Partner organisations.

Contributions of the different sponsoring organisations to the ENMC activities

All current ENMC sponsoring organisations are acknowledged on the next page.



What does a Company For membership entail?	um	Value for your company
• Contribution: At least 3-years € 5.000 to € 20.000 per year		<ul> <li>A transparent contribution to the global development of treatments for people with a neuromuscular disease.</li> </ul>
<ul> <li>Conditions: The contribution support all ENMC workshops year, regardless of the disease This yearly contribution and r adheres to international rules and sponsorships.</li> </ul>	throughout the e-specific topic. membership	Disclosure of membership in all ENMC publications, workshops and communications.

## Would you like to join us?

Contact us at: +31 35 5480482 or enmc@enmc.org