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:

Deutsche Gesellschaft für Muskelkranke e.V. DGM

Finnish Neuromuscular Disorders Association

Spierziekten Nederland

Telethon

AFM Téléthon

Muscular Dystrophy UK

Prinses Beatrix Spierfonds

fsrmm

Muskelsvindfonden

Company Forum:

IONIS

Amicus Therapeutics

genzyme A SANOFI COMPANY

santhera Pharmaceuticals

Sanquin Plasma Products

EUROPEAN NEURO MUSCULAR CENTRE

European Neuromuscular Centre (ENMC)
Lt. Gen. van Heutszlaan 6, 3743 JN Baarn, The Netherlands
+31 35 5480481 enmc@enmc.org www.enmc.org

Vormgeving: Vormgevers Arnhem

Connecting People

The voice of patients is essential in ENMC workshops: to share your daily experiences and explain to scientists and clinicians what priorities should be given to research!

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.

EUROPEAN NEURO MUSCULAR CENTRE

How?

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 During a workshop, participants share their experiences, show unpublished data, discuss research gaps and plan future collaborations to improve diagnosis procedures and to develop successful treatments.

What can a patient contribute?

The ENMC strongly encourages the participation of patients, relatives and/or advocates from patient organisations to represent the ***patient's voice***. Our experience shows that the perspective and the experience of people who are confronted with a neuromuscular disease every day is of extreme importance for researchers and health care professionals. It helps them in their efforts to improve care and diagnostic tools or in the planning of clinical trials and new disease registries.

Examples

> "To be present at an ENMC workshop as a patient makes the condition real, the patient gets a 'face'. Spending the weekend together, having dinner together shows how disabling my condition is for patients like me."

Nynke Koelma joined the 216th ENMC Workshop on FKRP muscular dystrophies.

> "The idea of having 20 of the world's best experts on my son's rare muscle disease in one room for a workshop was a dream coming true!"

Mrs Sarah Foye (left) of Team Titin and Mrs Alison Rockett Frase of the Joshua Frase Foundation, both mothers of children with a titinopathy, are thrilled with the outcomes of the 219th ENMC workshop on titinopathies (TTN).

Would you like to participate in an ENMC workshop?

- Check **www.enmc.org** for the topics of the upcoming workshops.
- Download the toolkit for patients to learn what you can expect from a workshop, how to prepare and what is expected of you.
- Contact the ENMC to become involved in your workshop of interest at **enmc@enmc.org** or **+31 35 5480481**.

ENMC provides wheelchair accessible meeting venues and taxi transportation. The ENMC ensures that the participant is heard at every workshop.