

Would you like to participate in an ENMC workshop?

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

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A special thanks to all our members and other supporters

ENMC Full and Associated Members:



Thanks to the continuous support of our members and sponsors we are able to facilitate and organise on average 10 workshops per year. A successful format to connect researchers, clinicians and patients and thereby facilitating collaborations in neuromuscular research.

ENMC Company Forum Members:



And many workshop-specific supporters: www.enmc.org

patients



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

Connecting People

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What is the ENMC?

The mission of the ENMC is to connect healthcare professionals worldwide in order to advance progress in the diagnosis, treatment and care of people with a neuromuscular condition.

How do we achieve this?

ENMC organises workshops upon application by researchers and healthcare professionals who are experts in the field of rare neuromuscular disorders. Workshops take place over the 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 During a workshop, participants share their experiences, show unpublished data, discuss research gaps and plan future collaborations to find methods for establishing the right diagnoses and to develop successful treatments.

Mrs. Sarah Foye and Mrs Alison Rockett Frase
both joined the 219th ENMC workshop on Titinopathies.

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

Workshop experiences from patient representatives

"It really felt that all participants were equal in the workshop, whether you were patient, caregiver, clinician or researcher!"



Mrs. Mireille Hek, who joined the 237th ENMC workshop on GNE myopathy is eager to find more persons affected by this ultra-rare condition.

How does ENMC facilitate your contribution?

- The ENMC will reimburse your travel costs.
- The ENMC workshops always take place in a hotel that has adapted rooms for individuals with a neuromuscular condition.
- The ENMC provides a wheelchair accessible meeting venue and special taxi transportation, if needed.
- The ENMC office provides a patient toolkit for your further preparation.
- We take care that every workshop participant is being heard.

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 daily confronted with a neuromuscular disease 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.

