

**THE ENMC GRANT APPLICATION TEMPLATE NEEDS TO BE FILLED IN ACCORDING TO THESE GUIDELINES**

## INTRODUCTION

The European Neuromuscular Centre (ENMC) aims to encourage and facilitate collaborative research within the field of neuromuscular diseases (NMD). In order to foster this, the ENMC financially covers the costs of workshops on NMD topics and organises and hosts the workshops.

Workshop proposals should be based on well focused topics relevant within the neuromuscular field. The chairperson of a workshop is responsible for the scientific aspects of the programme and the composition of the inviting participants' list. This list should be according to ENMC's requirement to balance the specialisms, countries and different perspectives in the meeting. All workshops are held in The Netherlands and take place during the weekend to allow full participation by invitees.

Within five years after the workshop, organisers will be asked about the impact of their workshop for the neuromuscular research and patient community.

## 1. Workshop formats

### Regular, 3 days' workshop

Friday	14.00 - 18.00 hrs
Saturday	09.00 - 18.00 hrs
Sunday	09.00 - 12.00 hrs

Number of participants is 20-25.

Location: Courtyard Marriott Hotel in Hoofddorp, The Netherlands, nearby Schiphol Airport.

Alternative timetables are allowed (see below). This should be discussed with the ENMC office before submission.

### 1 1/2-day workshop:

Friday	12.00 - 18.00 hrs
Saturday	09.00 - 15.00 hrs

Number of participants is 15-20

Location: Courtyard Marriott in Hoofddorp, The Netherlands.

### 1 day workshop:

Friday	12.00 - 18.00 hrs
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Number of participants is 10-15.

Location: World Trade Centre at Schiphol airport, Amsterdam, The Netherlands (no hotel facilities).

## 2. Participants

### General

Participants are expected to join the workshop for its full duration. Organisers may propose a reserve list.

It is recommended that every workshop also includes at least one invitee and preferably one organizer, both new to the ENMC workshops.

Avoid more than one participant from the same institution, unless there is a rationale for that.

### Agreements

To enable sharing of unpublished data and create a safe discussion environment, the ENMC confidentiality agreement will be sent before the start of the meeting and needs to be signed by all participants. If one is cannot sign off, he/she cannot attend the meeting.

In compliance with the *European privacy data law*<sup>1,2</sup>, all candidate participants are aware - and they should give permission to- that their personal data are being stored on the ENMC registry "Tribe" and that they become a member of the ENMC network. If participants do not agree that their personal information is saved in the ENMC registry and used for these purposes, the ENMC office should be contacted at [enmc@enmc.org](mailto:enmc@enmc.org) to discuss other means of communication. For more information about the rights of persons described in this European privacy data protection law, please refer to the ENMC website.

### Participation of Industry, Patients, Early Career researchers

Industry representatives can be invited, if there is a rationale for this. They are included in the max number of participants. The ENMC requires that if industry is invited, at least two companies must be represented. Travel and accommodation costs of industry representatives are covered fully by their companies.

The participation of one and preferably more **patient representatives is mandatory**. This is preferably a person directly suffering from the neuromuscular condition which is the topic of discussion at the workshop. The role and contribution of the patient representative(s) to the workshop and possible involvement in writing the lay report should be clearly stated in the application. In case no patient representative is included in the participants list, please justify this with a rational. Please contact the ENMC office if you need assistance with finding an applicable patient (representative/advocate). In case a patient organisation is co-sponsoring the workshop, one representative of this organisation may be added to the list of participants. See toolkits on the website. Patients, patients' representatives are not included in the max number of participants.

The participation of at least two **Early-Career** researchers, clinicians or paramedics is **required**. The ENMC's Early-Career programme is available to support this participation. Early careers are supposed to actively help in preparing the lay summary, co-writing the full workshop report and may be added as co-authors next to the organisers if their contribution was evident. See application form on the website. Early Career researchers are not included in the max number of participants.

### Remote workshop participation

One of the unique qualities of ENMC workshops is personal interaction between the participants, during the workshop itself but certainly also during coffee breaks, lunches and dinners. However, sometimes there are pressing reasons why a participant cannot attend in person. In order to facilitate bringing in the indispensable ideas and visions of the people online into the meeting, the ENMC can call in a professional audiovisual company. If participants have valid reasons not to come in person, this must be discussed with the ENMC office director. If remote access is granted, remote attendees should adhere to following guidelines:

- attend the full duration of the workshop (if intercontinental timelapses allow)
- keep their camera's on during their presence
- present (if applicable) their talk (of lecture) from their own laptops
- are expected to actively contribute to the discussions

### 3. Funding policy

The ENMC grant covers accommodation expenses (hotel, meals, venue costs) for all participants with exception of industry representatives.

Travel costs up to a max. of € 300,- are covered by the Global Travel Fund (GTF) for participants, patients and their caregivers are reimbursed by ENMC up to a maximum of euro 300 (European continent) or euro 1.000,- (other continents).

All Early Careers are reimbursed by ENMC up to a maximum of euro 300,- (European continent) or euro 1.000,- (other continents)

Claim forms with the original travel documents have to be submitted to the ENMC office within 2 months after the workshop. If not received within 2 months, ENMC office assumes reimbursement is not required. Travel reimbursements to the organisers will be done *after* submission of the full report to Neuromuscular Disorders and not later than one year after publication.

Travel costs for all participants are covered by GTF but additional co-funding of the GTF is needed. Organisers should propose co-funding in the application and keep the ENMC office informed about and work together on the co-funding.

### 4. Submission and deadlines

#### Submission

The application should be sent to the ENMC office using the following e-mail address: [enmc@enmc.org](mailto:enmc@enmc.org). The ENMC office will confirm receipt of the application. If you do not receive such a confirmation, please contact the ENMC office.

#### Preview

If you wish an eligibility check by the ENMC office, please submit at least two weeks before the official submission deadline of 1 March or 1 September.

#### Review

Applications will be reviewed by the Research Committee twice a year (usually in April and in October). Incomplete applications will not be processed. Applications submitted after the deadline will not be included in the review round.

#### Feedback

The final decision will be communicated by 3 months after the submission deadline. The ENMC office, Research Director and Research Committee (RC) members are available for applicants to discuss the contents of the applications and suggestions made by the RC.

If the application is selected and/or minor comments from the RC have been adopted in the programme and participation's list, a workshop date will be assigned and the ENMC will take over all relevant financial and organisational matters. A dedicated ENMC workshop coordinator will be assigned, who will work closely with the organisers, invitees, Early Careers and patient representatives to prepare for and be the host at the meeting.

If the application is not selected, the organisers will be invited to re-apply with a revised version in the following review round, taking into consideration the suggestions from the RC. An application can be resubmitted only once.

### 5. Workshop logistics

The ENMC office sends an official invitation mail, together with the programme, to each participant of the selected workshops and informs on organisational matters (hotel, transfer, etc.)

Participants book their own travels to the workshop location.

In case the workshop programme needs to be adjusted, the final programme is due at the latest two weeks before the workshop.

## 6. Mandatory reports

**Lay summary** for dissemination on the website of the ENMC and to its partner patient organisations and Company Forum, co-written with or at least reviewed by the patient (and/or patient representative/advocate) to guarantee their input in the document. This lay summary should be provided to the ENMC office within two weeks following the workshop. Participants are asked to help with translations of the lay report in several languages for a broad dissemination to patients and their families.

**Full report**, should be submitted to Neuromuscular Disorders within 6 months following the workshop.

In agreement with Neuromuscular Disorders, the traditional four authors of the ENMC workshop report can now be extended with maximally two extra names of those Early-Careers who are proactive and efficient contributors to both the workshop and the writing of the full report.

(see separate writing reports guidelines on the ENMC website).