

ENMC INTERNATIONAL WORKSHOPS ON NEUROMUSCULAR DISEASES

GRANT APPLICATIONS, LOGISTICS, DELIVERABLES AND REPORTING 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 these aims, the ENMC sponsors grants to cover the costs of workshops on NMD and helps to organise and host the workshops.

Workshop proposals should be based on well focused topics relevant within the neuromuscular field. The chairperson of such a workshop is responsible for the scientific aspects of the programme and the composition of the inviting participants' list. Scientists who participate in ENMC international workshops will normally have published relevant papers in international peer reviewed journals. All workshops are held in The Netherlands and take place during the weekend to allow full participation by invitees and reduction of flight and accommodation costs.

Patients, representatives from patient organisations, basic scientists and clinical researchers in their early career as well as participants from the industry might be invited to the workshop as well. Invitation and funding of these participants will be discussed on a case by case basis with the ENMC office.

GRANT APPLICATION DOCUMENT

A request for a grant to organise an ENMC workshop should clearly indicate and contain the following four elements (as provided in the template for the workshop application):

1. Background and aims of the workshop

Concise and clear background information on the proposed topic / area of research should be provided (max. 1000 words) and this should quickly lead to the problem statement to be discussed at the workshop. Then the aims of the workshop for which support is requested should be stated, as well as the expected results (deliverables) of the workshop. Applicants need to review whether all deliverables are realistic and achievable. The workshop deliverables need to be focused and concrete. The lay and full reports are not workshop deliverables, but grant obligations. Therefore, they should not be listed as workshop deliverables. In addition, applicants should state what is needed for a successful follow up and implementation of the deliverables in the field. This may be a description or a plan of finding resources to follow up on the workshop deliverables. Within five years after the workshop, organisers will be asked about the impact of their workshop for the neuromuscular research and patient community. Furthermore, the neuromuscular aspects of the work should be emphasized and a few

pertinent references should be included. Applicants are asked to state if their application is merely:

1. Basic research
2. Clinical
3. Translational
4. Or a combination of the three themes

It is not necessary to add all themes to the workshop, i.e. organisers are not obliged to include clinical presentations in basic workshops and vice versa, to “fill up” the three days’ programme (contact the office for directions for alternative schedules at enmc@enmc.org). This procedure may increase the focus in the workshop and may have consequences for the list of participants. And, in the end for successfully achieving the primary workshop goal(s) and deliverables.

The applicants should be aware of and acknowledge the existence of international initiatives or networks, connected to the topic of the workshop. If applicable, it should be argued in the application why representatives from these known initiatives/networks are invited or not. If the application is made by a consortium, the previous activities of the consortium as well as the updated list of members of the consortium should be included. There is a prerequisite for applicants to provide a link to either the submitted or the published full report of previous ENMC workshop(s) from the same consortium to the ENMC together with their application.

Applicants should state what other grant applications have been made for the proposed workshop and follow up activities if any, and also list any relevant grant-supported work currently being carried out by the applicant (maximum ½ page).

2. An outline of the programme as described in the workshop application template

ENMC workshops normally follow a three days’ programme, starting with lunch on Fridays and ending at noon on Sundays. However, alternative time tables are allowed; such as one and one-and-a-half day ENMC workshops. In this case, other timetables, venues and maximum number of participants should be taken into account (see below).

The timetable of a three days’ workshop is as follows:

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

The first session on Friday is preceded with lunch from 12.00 hrs.

The first session is normally used to introduce the aims of the workshop and to set the scene for further detailed discussions. It is important to keep these presentations short, avoid repetition of presenting published data and move quickly to the problem(s) statement and discussions.

The second session usually deals with workshop aims in more depth (i.e. scientific matters, protocol definition, disease management), and requires a lot of discussion time. The last session on Sunday mainly concerns conclusions, establishing a Consortium for ongoing collaborative research, future activities and eventual funding strategy. Also, the workshop participants aim to produce an agreed upon English lay summary for publication on the ENMC website. To safeguard that the lay report reaches patients worldwide, organisers will appoint participants to translate the English lay report in their local language. Together with the ENMC, participants will ensure lay report dissemination via local patient associations and other related NMD organisations. Workshop participants also agree on a planning of writing the full report of the meeting to be submitted to Neuromuscular Disorders within 6 months' time after the workshop.

The guidelines of a one-and-a-half day workshop is as follows:

The timetable:

Friday 12.00 - 18.00 hrs

Saturday 09.00 - 15.00 hrs

People fly in on Friday morning and depart on Saturday afternoon.

Maximum number of participants is 15.

Workshops lasting for more than one day hence which include at least one overnight stay, will be organised at the Courtyard Marriott in Hoofddorp, The Netherlands.

The guidelines of a one-day workshop is as follows:

The timetable:

Friday 12.00 - 18.00 hrs

Maximum number of participants is 10.

People fly in on Friday morning (Schiphol airport, Amsterdam) and depart on Friday late afternoon.

Location of a one day workshop: World Trade Centre at Schiphol airport, Amsterdam, The Netherlands.

3. Proposed participants

Proposed participants should be listed along with their place of work (affiliation), discipline and email address. The applicant should give a brief indication as to why each proposed participant is relevant to the programme of the workshop. The profile of the participants should be tailored to the type of workshop (basic / general / clinical research / care management and education).

Organisers are expected to contact all suggested participants *before* the submission of an application to the ENMC. The invitees will be asked to contribute to a potential

workshop and whether they are available for a future workshop date. In the application the organisers should indicate who is available e.g. with a special symbol like : *.

Should the workshop chairperson wish to replace any declined or cancelled invitations, these replacements should be proposed on a reserve list, included in the application. Participants invited to the workshop are expected to join the workshop for its full duration. Should participants not be able to join for the full weekend, they will be suggested to be replaced by one of the reserve participants.

European Privacy Data Protection Law

To be compliant with the European privacy data law^{1,2}, it is necessary that all candidate participants are aware **-and they should give permission to-** that their personal data are being stored on the ENMC registry “Perfect View” and that they become a member of the ENMC network. During your first contact with the potential workshop participants, to ask them about their interest and availability for an upcoming ENMC workshop, please ask them for permission to save their personal data on the ENMC registry and report this back to the ENMC in an e-mail.

1) <https://ec.europa.eu/info/strategy/justice-and-fundamental-rights/data-protection>

2) <https://www.autoriteitpersoonsgegevens.nl/nl/onderwerpen/avg-nieuwe-europese-privacywetgeving/algemene-informatie-avg>

The ENMC aims to use these personal data: 1) for inviting and communicating with the participants during the preparatory and follow up activities of the workshop; 2) for sharing with all the workshop participants with the aim to facilitate future collaborations; 3) for inviting them for future ENMC workshops and 4) for receiving e-newsletters from the ENMC as a member of the ENMC network.

If they do not agree that their personal information is saved in the ENMC registry and used for these purposes, please ask them to contact the ENMC office at enmc@enmc.org to discuss other means of communication. They can always unsubscribe from the ENMC newsletter list via the online system.

For more information about the rights of persons described in this European privacy data protection law, please refer to the ENMC website.

The personal data that the ENMC is saving on the ENMC registry Perfect View are:

- Name and surname
- E-mail
- Institute/organisation
- Institute/organisation address
- Telephone number(s)
- Country
- Salutation
- Discipline in research (basic, clinical, translational)

The **number of organisers** is confined to a maximum of 4. The number of participants is confined to a maximum of 20 participants, excluding representatives from the patient community, pharmaceutical companies and early-career programme. Only one participant per institute will receive a travel refund. One local colleague of the chairperson will receive a travel refund. It is recommended that every workshop also includes at least one invitee new to the ENMC workshops.

While setting up the list of participants, please be aware that the ENMC grant covers the costs of travel up to a max. of € 300,- and all accommodation expenses for participants from ENMC member countries only: i.e. Austria, Denmark, Finland, France, Germany, Italy, Switzerland, The Netherlands and the United Kingdom. Claim forms have to be submitted to the ENMC office **as soon as possible** but no later than one year after the workshop date. Workshops are administratively closed one year after the workshop date, after which reimbursements can no longer be executed.

For participants from non-ENMC member countries, ENMC will cover accommodation expenses **but not their travel (flight) costs**. If co-funding is required to cover the flights for participants from non-ENMC member countries, organisers should indicate in their proposal which organisations are committed to help support the travel costs and are obliged to keep the ENMC office informed about the co-funding.

The ENMC aims for a **geographically balanced** and a multidisciplinary group of participants, thus ENMC strongly recommends to see this reflected in the organisers' application and workshop participants list. This will ensure a broad consensus resulting from the workshop and wider implementation of the deliverables at the local level. After all, workshop participants will become ambassadors and committed to follow up activities after the workshop has taken place. In case it is not possible to invite participants from a broad spectrum of countries, institutes and specialisms, applicants are asked to provide arguments in the application why this cannot be done.

Participation of **patient representatives** in the workshop is highly encouraged. This is preferably a person directly suffering from the neuromuscular condition which is the topic of discussion at the workshop. It can also be a parent, a partner, a clinician or caregiver and/or members of patient advocacy organisations. In case a patient organisation is co-sponsoring the workshop, only one representative of this organisation may be added to the original list of participants.

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 rationale. Please contact the ENMC office if you need assistance with finding an applicable patient (representative/advocate). Participating patients/representatives/advocates are NOT included in the maximum number of 20 participants.

Candidacy of at least two but preferably three early-career researchers to attend the ENMC workshop is highly encouraged. A grant programme to support young scientists/clinicians or health care providers is available to facilitate their education, networking and obtaining state-of-the-art scientific information through active participation in ENMC workshops. These candidates can be PhD-students or researchers in their first post-doc position. Participating early-career researchers can be added on top of the number of 20 participants. Please find more information about this Early-Career programme on the ENMC website.

Researchers and/or clinicians from **industry** can also be invited to participate in the workshop. If industry is represented, there should be at least two different companies invited by the organisers. All costs for these participants will be covered by the companies themselves. Representatives from industry are included in the maximum number of participants of 20.

4. A brief CV of the applicant(s) (1-2 pages)

The CV's are stored during the application process on the ENMC server, and will only be used for dissemination to the Research Committee to support them in judging the workshop application, if needed. Once the application has been selected, the CV's will be deleted from the ENMC server. By sending their CV's to the ENMC, organisers give their consent of distributing the CV's to the Research Committee members and storing the CV's for a limited time on the ENMC server.

SUBMITTING THE APPLICATION, DEADLINES FOR REVIEW ROUNDS

Preview

- The application should be sent to the ENMC office using the following e-mail address: enmc@enmc.org.
- The ENMC office will confirm receipt of your application. If you do not receive such a confirmation, please contact the ENMC office at +31-35 5480481 or +31-6-20428770 to check the proper arrival of all required documents.
- The ENMC office and Research Director will subsequently run an eligibility check versus the ENMC application guidelines and, if relevant, provide the organisers with suitable input.
- This preview can only be done if applications have been received at least two weeks before the official submission deadline of March 1 or September 1.

Review

Workshop applications can be submitted on an ongoing basis. However, incoming applications will be reviewed by the Research Committee twice a year (usually in April and in October). For each of these review rounds, the submission deadlines will be made available to applicants and on the ENMC website. In general, the deadlines for the above mentioned review rounds are March 1 and September 1. Incomplete applications will not be processed. Applications submitted after the deadline will not be included in the review round. A workshop application can be submitted and reviewed two times at the most.

Feedback

The Research Director will convey the Research Committee's conclusions and recommendations to the applicant after a final decision on the application has been made by the ENMC Executive Committee. This typically will be done 10 weeks 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. Please contact the office at enmc@enmc.org or +31-35 5480481 or +31-6-20428770 for further directions.

If the application is selected, a workshop date and other details will be agreed with the ENMC office, who also will take care of relevant financial and organizational matters as described in the workshop logistics section (below).

If the application is not selected, the organisers will be invited to re-apply with a revised version taking into consideration the suggestions from the RC. As mentioned above, an application can be submitted maximally two times.

WORKSHOP LOGISTICS

Upon approval of the workshop application by the Research Committee, and the processing of the RC recommendations in a final application, the workshop organiser(s) will be

contacted by the ENMC office for the final version of the list of participants (including address, telephone, e-mail) and the final programme. The ENMC office will then send an official invitation mail to each participant, which contains information on organisational matters (hotel, transfer, etc.) together with the provisional programme.

The ENMC office arranges accommodation, meals and the meeting room in a hotel nearby Schiphol. All participants are expected to book their own travels.

The workshop chairperson is expected to provide the ENMC office with a final programme two weeks before the workshop in order to prepare the conference folders and for publication on the ENMC website and social media.

Upon arrival in the hotel, participants will receive a conference folder containing organisational information (welcoming letter, programme, participants list, travel expenses claim form if applicable, information on meals and meeting room, etc.).

MANDATORY REPORTS (see separate guidelines on the ENMC website)

The production of a lay- and a full report is obligatory and should not be included in the deliverables of a workshop.

1. For each workshop a summary paragraph (lay statement) for dissemination on the website of the ENMC and its member patient organisations is expected to be produced in close co-operation with the workshop participants. The lay report will be co-written or at least reviewed by the patient (and/or patient representative/advocate) for their input. This lay statement should be provided to the ENMC office within two weeks following the workshop. It is encouraged that this lay report is translated in several languages for local dissemination to patients and their families.
2. Next to this, the full report on the workshop is expected within 24 weeks following the workshop. Travel reimbursements to the organisers will be done *after* submission of the full report to Neuromuscular Disorders and not later than one year after the workshop date. Please refer to the separate section describing the report guidelines.