



## **ENMC collaborative workshops - toolkit for persons directly involved with a neuromuscular disorder**

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This toolkit provides an overview of the ENMC workshops, the processes relevant for the conduct of the workshop and reporting of the workshop outcomes. It describes what is being expected from you as a patient representative, how you can prepare at and make arrangements for the workshop.

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## **ENMC PatientPlus toolkit –** *persons directly involved with NM disorder*

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**Office of the ENMC in Baarn, The Netherlands**

*(Situated in the building of the Dutch patient organisation “Spierziekten Nederland”)*



**ENMC strategic workshop June 2012 (Musholm, DK) –Start of the Patient Participation Program**

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Patient participation in the 236<sup>th</sup> ENMC workshop in Amsterdam (June 2018) on  
“Bone protective Therapy in Duchenne muscular dystrophy:  
Determining the feasibility and standards of clinical trials”

## 1. Introduction

*The mission of the ENMC is to encourage and facilitate communication and collaboration in the field of neuromuscular research with the aim of improving diagnosis and prognosis, finding effective treatments and optimizing standards of care to improve the quality of life for affected people and their families.*

This mission of the ENMC is accomplished through the organisation of workshops (approximately 8-10 per year) which represent our core activity. The workshops usually take place in a conference hotel in the Netherlands from Friday afternoon to Sunday lunch time. Around 20 scientists, clinicians and patients representatives attend our workshops. The aim is to share new ideas and the latest research advances followed by a discussion on work in progress, prioritising the research agenda and make agreements on the next steps. A lay summary is written and translated in different languages to inform the lay public on the workshop progress. A full report of the workshop is subsequently published in the scientific journal “Neuromuscular Disorders”.

The workshops are aimed to be interdisciplinary to encourage a lively debate between the different experts working in clinical and basic research and the people who are affected with a neuromuscular disorder, being pre-eminently the ‘day to day experts’. All participants have an active role to achieve the deliverables of the workshop. The aim is to establish a long-lasting collaboration between basic scientists, clinicians and patient representatives resulting in improvements in diagnosis, development of treatments and the definition of care pathways for all neuromuscular disorders.

## 2. Why a patient toolkit?

At the time the ENMC was founded in 1991, the main aim of the workshops was to define diagnostic criteria and accelerate the pace of research in understanding the underlying genetic and molecular mechanisms of muscle and nerve wasting. Recently this strategic focus slightly changed with the addition of care workshops - discussing practical aspects of everyday patient care, e.g. the role of exercise training and management of pain and fatigue. To stimulate patient participation in the workshops, ENMC toolkits were developed; one for the **scientists organising the workshop** and one for **patient representatives attending the workshops**. The patient toolkit described in this document provides you with information and guidance and to give you advice on what to expect and how to prepare when planning to take part.

## 3. Why is participation by you, your relatives and patient advocates in ENMC workshops so important?

- The ENMC was originally founded by individuals directly or indirectly affected by a neuromuscular condition.
- It is a core value of the ENMC that the voice of individuals directly or indirectly affected by a neuromuscular condition is heard at the ENMC workshop to ensure the research and the topics discussed have the utmost relevance for patients.
- By being present at workshops, individuals affected by a neuromuscular condition, their families and advocates raise awareness among scientists and researchers of



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matters that are important in daily life. It raises issues that otherwise might be overlooked.

#### **4. What can you, your relatives and patient advocates contribute to workshops?**

- As an individual directly affected by a neuromuscular condition or as a partner or parent from someone with a neuromuscular condition you will be able to bring expertise to the meeting that clinicians, researchers and care professionals will not have. For example, you will be able to ask questions that clinicians and/or researchers may not consider in their daily routine.
- From a survey conducted in 2012, we learnt that participants of ENMC workshops do value the participation and input from patients and others directly or indirectly affected by a neuromuscular condition.
- You will also be able to raise awareness of what it means to live with the disease from day to day.
- Your participation will ensure that the focus of the research will remain relevant for the needs of affected individuals.
- Your participation will enhance the dialogue between researchers, clinicians and care professionals and their patients and will build a vital bridge between research and daily living with the condition.



Patient participation in the 237<sup>th</sup> ENMC workshop in Amsterdam (September 2018) on “GNE myopathy”

**5. What can you expect if you have been invited to participate?**

- You will receive information about the workshop and the program from the ENMC office.
- You will be asked to make your own travel arrangements for your journey to and from the meeting venue (which usually is in the vicinity of Amsterdam Airport, Netherlands). The staff at the ENMC office will assist you in planning your journey and for taking care of special requirements that you and/or your accompanying person may need.
- The ENMC workshops typically start around 2 pm on a Friday afternoon and will last until 1 pm on Sunday (including lunch). Workshop participants are asked to take part in the entire workshop; the return flight should therefore preferably be scheduled not before 4 pm on Sunday.  
However, if you feel that you will not be able to take part for the whole length of the workshop please let the staff in the ENMC office know so that it can be considered in the programme, where appropriate.
- During the workshop a large amount of potentially new information will be shared among the participants. Not all the information will be equally relevant and/or understandable to all participants – please feel free to skip certain lectures or discussions if you feel that you cannot contribute or if you feel exhausted.
- You will be reimbursed for your travel. The costs for the hotel, meeting and meals are directly covered by the ENMC and if required, you can bring a carer. Costs of your carer(s) will also be reimbursed by the ENMC. We will reserve a seat in the meeting room for one carer.
- The hotel is located in the center of the Netherlands, it is easy accessible, has a large parking area and has fully adapted rooms. Please inform the ENMC office of any special requirements for transport to and from the meeting venue, and also let ENMC know if you have particular dietary requirements and/or other services you need during the meeting.
- You will spend a weekend of hard work together with leading researchers and clinicians in the area of your condition to discuss topics in an interdisciplinary and open way.
- You will hear the views of the scientists and clinicians on the workshop topic and you are encouraged to directly interact with them and share your experiences and views as somebody directly affected by the condition.
- The ENMC has made participation of individuals directly or indirectly affected by a neuromuscular condition mandatory. Your participation is very important as a source of information for the scientific community and it is crucial that your “voice” will be heard.
- By participating and communicating your views to the other participants you are able to influence the direction of the research.

**6. How can you prepare?**

- You will receive comprehensive information about the workshop in a timely manner including background information on all participants.
- Consult one of the workshop organisers (directly or via the ENMC office) in case you have any questions that require clarification prior to the workshop.
- If you are representing a patient organisation or patient advocacy group liaise with them about the items that should be discussed and/or clarified during the workshop
- Visit the ENMC website about how the ENMC is organised so you have a general

idea about the topics being discussed.

- You will be contacted by the ENMC office way in advance to explain the rationale of the meeting, your role and to exchange logistical preparations needed for you to join the workshop.

#### **7. What happens at the start of the workshop?**

- An ENMC representative will give a short introduction about the ENMC and will provide practical guidance during the workshop. The participants of the workshop will then introduce themselves and one of the organisers of the workshop will formally start the meeting.
- Because unpublished scientific data may be shared amongst participants, all attendees will be asked to sign a confidentiality agreement before the start of the meeting.
- Furthermore, all attendees will need to sign for the use of their personal data by the ENMC office, in line with the GDPR law effective as of 25 May 2018.

#### **8. What expenses will be covered?**

- Please make your travel bookings as early as possible so that you benefit from the cheapest possible air or train fare.
- Airline or train tickets will be reimbursed up to € 300,-.  
There might be special circumstances that require an airfare of more than € 300,- for example transfer of wheelchairs, picking up services or use of special equipment during the flight. However, this will need to be approved by the ENMC office before booking otherwise the amount exceeding € 300,- might not be reimbursed.
- Please note that travel costs in the country of origin (taxi, car, train, parking) are **NOT** covered.
- The ENMC will arrange and cover special transport from Schiphol airport to and from the meeting venue.
- Should you travel to the workshop venue by car you can claim € 0.29 per kilometer.

#### **9. How accessible are ENMC workshops?**

- The ENMC workshops always take place in a hotel that is adapted for individuals with a neuromuscular condition and will be able to consider any special requirements you might have.
- The ENMC office will work with you beforehand to arrange as much as possible.

#### **10. What happens after the workshop?**

- At the end of the workshop the participants will draft an outline of the lay summary report ('lay statement') of the workshop. This workshop summary (approximately 1 page) will be completed and posted on the ENMC website within one week after the workshop has taken place.
- The lay report will be prepared with input of you as the patient representative who followed the presentations and discussions of the workshop. You should ensure that you have appropriate time to review the lay summary and provide any feedback,



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comments or amendments you would like to see adapted.

- Subsequently, this lay report will also be distributed through the ENMC network and placed on the ENMC website. Additionally, the organisers will ask some workshop participants to translate the lay report for further dissemination at the local level.
- The scientific workshop report will then be written by the workshop organisers and this report should also be reviewed and approved by all participants of the workshop.
- After publication of the workshop report in the peer reviewed journal “Neuromuscular Disorders” (usually 6-12 months after the workshop date), the ENMC office will disseminate the report through its network and will make it accessible through the ENMC website.



The participants of the 235<sup>th</sup> ENMC workshop in Milan (January 2018) about “The role of neuromuscular patients in Shared Decision Making”