ENMC Impact Report 2020

Our year in highlights

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Contents

1 Message from Dr Arpad von Moers, Chair of the Executive Committee

What a year!

Of course, ENMC activities have been considerably affected by the Covid-19 pandemic.

The worldwide lockdown including travel restrictions and banning of face to face meetings impacted our core business. The team in Baarn, in close cooperation with the numerous workshop leaders, did a great job by reorganising the workshops completely. Technical requirements have been established to perform online and hybrid workshop formats. We anticipate this will be an ongoing process in 2021.

Nevertheless, seminal developments have been advanced. The Mid-Career Mentoring Programme was finalised and announced to the neuromuscular community in December 2020. This is an important contribution to motivate and educate clinicians and researchers as leading persons in the neuromuscular field.

Also, we are pleased to welcome Franziska Ott and Esther Smit as junior Operational Managers within the team in Baarn.

I would like to thank all the people who are dedicated to the ENMC, the team in Baarn as well as as the members of the Research Committee and Executive Committee, workshop organisers, researchers and clinicians, and of course patients and patient organisations, who are the basis for all of the work of the ENMC.

The successful performance under the challenging situations of 2020 allows me to be optimistic for 2021. The ENMC will continue as an important and visible partner in the neuromuscular field promoting patient involvement, collaboration, research and advanced training.

Dr Arpad von Moers,
Chair of the Executive Committee

Dr Arpad von Moers here with two brothers with dystrophinopathy (intermediate type Duchenne/ Becker). The picture was taken in February 2021 and published here with permission from the parents of the boys.

Dr Arpad von Moers is a member of the Executive Committee of the ENMC as representative of the "Deutsche Gesellschaft für Muskelkranke" (DGM) and has been now Chair of the board for two years.
Dr von Moers is pediatrician and serves as medical director of DRK Kliniken Berlin, Germany. He is head of the Department of Pediatric and Adolescent Medicine since 2005.
Dr von Moers is co-director of the nationwide child abuse and neglect helpline for medical professionals and he is head of the Berliner Transitions Program, a nationwide transition platform.

2 The mission of the ENMC

More than 27 years ago, a group of scientists and clinicians, together with parents of children affected by neuromuscular conditions, launched the European Neuromuscular Centre (ENMC). They had in mind the ultimate goal to improve diagnosis, accelerate the search for effective treatments and improve the quality of life of people with neuromuscular conditions. To achieve this goal, it was, and still is, of utmost importance that experts in this field of (ultra) rare disorders share their knowledge and experience and collaborate in research worldwide.

The ENMC encourages and facilitates this collaborative aim through the organisation of small interactive workshops for multidisciplinary groups of researchers, clinicians and persons affected by a neuromuscular condition, a unique concept in the scientific community.

ENMC Mission Statement

The mission of 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 optimising standards of care to improve the quality of life of people affected by neuromuscular disorders.

"Connecting people"

3 The ENMC workshops in 2020

Due to Covid-19, ENMC was forced to postpone seven out of eight workshops planned in 2020. Only one meeting, the 252nd ENMC workshop on mouthpiece ventilation in neuromuscular patients, could still take place on-site over the weekend of 6-8 March 2020. This was done in an hybrid-setting; 13 participants of the 22 invitees were able to travel to The Netherlands. For those who were restricted in travelling, Skype facilities were arranged so that they could contribute to the meeting with presentations and discussions online.

Seven face-to-face workshops were postponed to 2021 and workshop organisers were offered additional virtual meetings in the meantime to support preparatory discussions in the consortia during 2020. This new format of the workshops was well-received by the ENMC workshop organisers, who emphasised the importance "to keep the momentum" and to foster consortia-bonding. They appreciated the opportunity to start preparatory work with all participants involved in one to four separate online sessions, which will enhance the efficiency at the face-to-face consensus-building meetings.

Virtual meetings will not become the future standard format of an ENMC workshop. ENMC and 89% of surveyed workshop participants prefer the face-to-face setting, because it provides the best atmosphere to make connection, to "see and hear" each other, to raise problems and create solutions together while socializing during breaks and enjoying dinner together. However, we will learn from this experience and evaluate how we can make optimal use of online and hybrid formats in the future ENMC workshops.

In 2020, eleven workshop applications were submitted to the ENMC. Of these, five were selected for financing by the ENMC and are planned to take place in 2021 and 2022.

3.1 Summary of ENMC workshops held in 2020

In 2020, one of the eight planned workshops took place in the Marriott hotel, Hoofddorp, The Netherlands. Three further workshops, 253, 258 and 259, were held virtually in the autumn of 2020 and will be followed by a face to face meeting in 2021 or 2022. The organisers of the remaining four workshops (254-257) either started virtually in 2021 or fully postponed their workshops to a face-to-face meeting in 2021 or 2022.

The workshops are listed in the table on page 8.

ENMC workshops in 2020

Workshop no./date and format	Topic	Workshop leaders
Workshop no. 252 6-8 March 2020 (face-to-face)	Developing best practice guidelines for management of mouthpiece ventilation in neuromuscular disorders	Dr M.Toussaint, Dr M. Chatwin, Prof. J. Gonzales, Prof. M. Gonçalves
Workshop no. 253 30-31 October 2020 (virtual) 19-20 February 2021 (virtual) Every two months e-meetings are planned in April, June, August and October 2021 10-12 December 2021 (face-to-face)	Striated muscle laminopathies; natural history and clinical trial readiness	Dr G. Bonne, Dr L. Maggi, Prof. S. Quijano-Roy, Dr C. Bönnemann
Workshop no. 258 16 October 2020 (virtual) 4 December 2020 (virtual) 1-3 April 2022 (face-to-face)	Genetic epidemiology and clinical trial readiness in encephalomyopathy of Leigh syndrome	Prof. E. Bertini, Prof. S. Rahman, Dr M. Schiff, Prof. B. Cohen
Workshop no. 259 11 December 2020 (virtual) 28-29 May 2021 (virtual)	Anaesthetic management in neuro-muscular disorders	Dr N. Voermans, Dr M. Snoeck, Prof. H. Jungbluth, Prof. S. Riazi

Note: The workshop number (no.) is given once an application is officially approved and hence dates can be reserved. It does not always precisely reflect the timing of the execution of the workshop. Workshops 254-257 will take place in 2021 and are therefore not listed here.

252nd ENMC international workshop: Developing best practice guidelines for management of mouthpiece ventilation in neuromuscular disorders

Twenty-two participants with full representation of the multidisciplinary ventilation team and one patient affected by Duchenne muscular dystrophy (DMD) representing two patient advisory groups, attended this important ENMC workshop on mouthpiece ventilation (MPV). Participants came from Norway, Belgium, Italy, UK, France, Switzerland, Portugal, The Netherlands, Spain, USA and Canada to discuss the practical use of mouthpiece ventilation in comparison with other, sometimes more invasive, techniques such as nasal mask support or tracheostomy.

Background

Respiratory insufficiency and pneumonia are primary causes of mortality and comorbidity in many neuromuscular disorders (NMDs). Studies show that mechanical ventilation improves symptoms, gas exchange, quality of life and survival in NMDs.
In order to have up-to-date information on current worldwide practice of the use of MPV, a pre-workshop survey was sent to individuals working with NMDs. The survey gathered information around which countries, regions and type of hospitals utilise

Participants of the 252nd ENMC international workshop on "Developing best practice guidelines for management of mouthpiece ventilation in neuromuscular disorders".

MPV already frequently. Furthermore it addressed questions like:

- what is the preferred mode of utilisation?
- how is re-imbursement arranged locally?
- what barriers to MPV are perceived by the patients and their carers?
- what barriers to MPV are perceived by health care professionals?

The patient's voice was well covered at this important meeting by Mr Johann Chaulet, who is affected by DMD and is dependent upon 24/7 MPV. Mr Chaulet was accompanied by his personal assistant Mr Jeremy Guene.

Outcome

Based on the survey and the experience of the delegates, it was concluded that MPV is currently underutilised. The attending experts discussed barriers and limitations to the provision of MPV including lack of understanding around the equipment required and the ventilation modes and settings. There are differences between countries regarding provision of MPV and its funding. Several benchmark studies were described relating to state of the art knowledge of technical issues, physiological aspects and ventilator alarms. The workshop participants expressed their expectations that industry should further develop dedicated portable devices, modes and equipment for MPV.

Lively discussions followed the topics on the physiology of MPV and on how to initiate and monitor MPV. These sessions were based on the available evidence, clinical experience and expertise. The participants and MPV users were in agreement that MPV offers several advantages, for example facilitating speaking, eating, swallowing and coughing. MPV has a huge impact on quality of life as it allows mobility and decreases social isolation, since there is no mask on the face as a barrier to social inclusion. However, issues of safety and caregiver training were highlighted and recommendations and teaching tools were devised to support this. In further discussions, both the cost and the benefit of the MPV technique were explored.

During the workshop, treatment protocols and algorithms were prepared to provide practical recommendations and detailed information about the MPV technique. The participants answered the key questions about when to start, what ventilator, what mode, what mouthpiece, what monitoring, and what follow up is required for individuals using MPV.

The full scientific report of this workshop is published in Neuromuscular Disorders: **June 2020** Volume 30, Issue 9, Pages 772–781.

253rd ENMC international workshop: Striated Muscle Laminopathies; natural history and clinical trial readiness

This summary covers the work done in the two virtual meetings in October 2020. The workshop will be followed up by two additional virtual meetings in February 2021 and one face-to-face consensus meeting in December 2021.

The first virtual meetings were held on 30 and 31 October 2020. This event gathered 30 healthcare providers and researchers from Argentina, Germany, France, Italy, The Netherlands, Poland, Spain, the UK and USA, as well as patients and patient representatives from four advocacy associations (Cure-CMD, Fundación Andrès Marcio Niños Contra las laminopatía (FAM), Muscular Dystrophy UK (MDUK) and Associazione Italiana Distrofia Muscolare di Emery Dreifuss Onlus (AIMED)).

Background

Striated muscle laminopathies (SMLs) are rare and heterogeneous muscle diseases due to mutations in the *LMNA* gene and affecting both pediatric and adult subjects, sometimes causing severe motor disability. Although there is an increasing interest in these diseases since the identification of the first *LMNA* gene mutation by Gisèle Bonne and her group in 1999, and some experimental drugs seem to be promising for the near future, to date there is no effective treatment for SMLs.

There are no sensitive and clinically meaningful outcome measures to evaluate patients affected by *LMNA*-related myopathies to underpin possible future clinical trials and the natural history of these diseases is still unclear. In addition, SMLs are characterised by high clinical variability, even within the same family, making it challenging to establish genotype-phenotype correlations and hampering prognostic speculations on the basis of molecular data. Therefore, biochemical, molecular and imaging biomarkers have been proposed as possible alternative outcome measures, considering they may show earlier response to treatment and provide very objective data. In the context of a multidisciplinary approach to muscle diseases, ancillary tools to assess swallowing and pulmonary respiration which can be affected by muscle weakness, should also be taken into account among outcome measures in order to facilitate patient management. Hence, a multidisciplinary approach to the identification of outcome measures in SMLs is strongly suggested, including clinical and basic research *LMNA*-experts. For these reasons, the organisers applied for an ENMC workshop to bring these experts together in one room to exchange new data and insights and seek opportunities for future collaboration.

Main objectives

The main objectives of this workshop were: to increase knowledge in striated muscle laminopathies, to improve SMLs diagnosis, clinical management and follow-up; to facilitate the identification of biomarkers; and to move forward in possible therapeutic strategies.

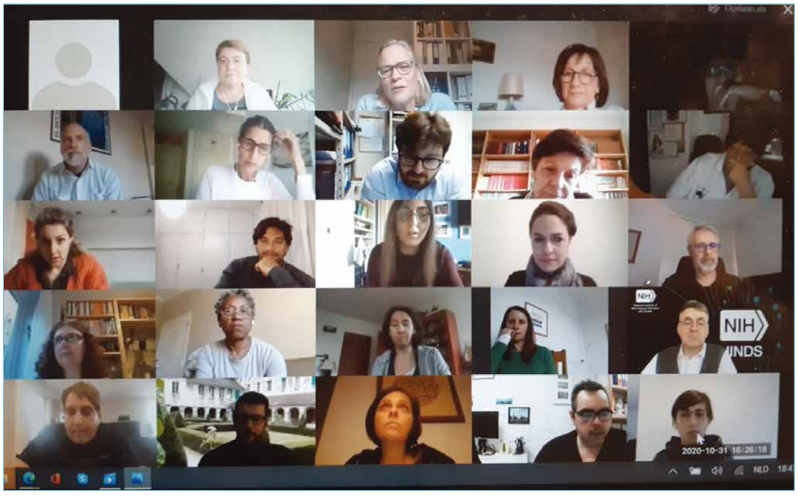
During the first afternoon, participants worked in separate working groups. In each group, patients, families and advocacy group representatives had a time-slot to express their challenges, needs and expectations. Clinicians and basic researchers shared their research data, identified gaps in the knowledge on laminopathies and discussed how they can intensify the international collaborations to improve the impact for patients affected by laminopathies.

After these brainstorming sessions, all working groups reconvened in a single virtual room and group leaders presented the most important data and results, which allowed to update the-state-of-the-art knowledge on laminopathies. The second afternoon session was used to structure and discuss all presented data.

Although it was the first time ever that an ENMC workshop was organised fully online, participants found it a successful experience; it allowed experts in clinical and basic research, and patient representatives to review updated data, interact in real-time, identify research priorities and face future perspectives. Afterwards, Dr Gisèle Bonne commented about the virtual meetings:

Dr Gisèle Bonne:

"These virtual meetings have been an excellent opportunity to update and deepen our knowledge of the natural history of laminopathies, promoting the international research and collaborative studies to better characterise and follow our patients."

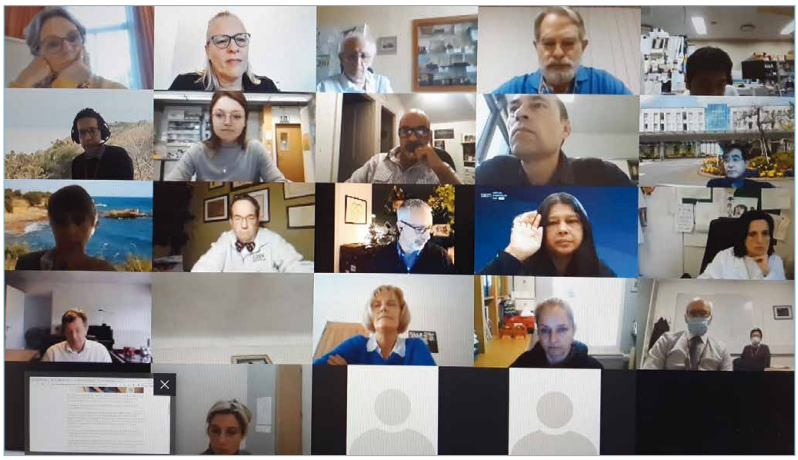


Patient representatives, clinicians and basic scientists participating in the 253rd ENMC virtual meeting discuss the natural history and clinical trial readiness in striated muscle laminopathies.

The full scientific report of this workshop will be published in Neuromuscular Disorders after the face-to-face meeting has taken place in **December 2021**.

258th ENMC international workshop: Genetic epidemiology and clinical trial readiness in encephalomyopathy of Leigh syndrome spectrum

In total, 25 participants from Czech Republic, France, Germany, Italy, The Netherlands, UK, Australia, Japan and the USA gathered in two virtual meetings on 16 October and 4 December 2020. Participants included clinicians, scientists, two industrial collaborators, representatives of patient organisations and one patient affected by Leigh syndrome. The final meeting of this ENMC workshop is planned as a face-to-face/hybrid meeting in 2022.



Patient representatives, clinicians and basic scientists participating in the 258th ENMC online meeting discuss genetic epidemiology and clinical trial readiness in encephalomyopathy of Leigh syndrome spectrum.

Background

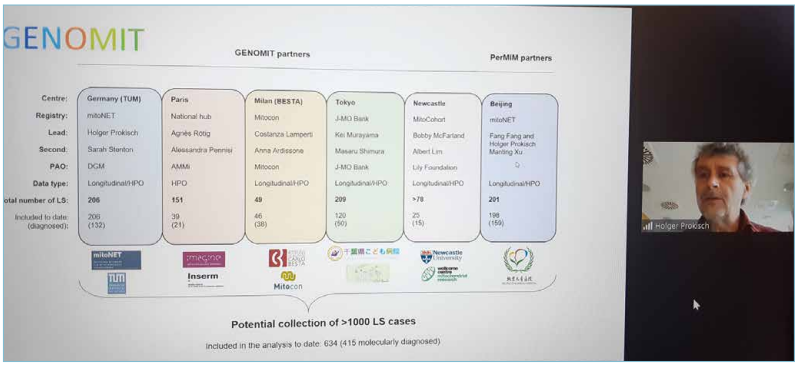
Leigh syndrome, also known as a "subacute necrotising encephalomyopathy", is a genetically heterogeneous disease that primarily affects the central nervous system. Necrosis means death of cells through disease, especially in a localised area of a tissue or organ. Originally described in 1951, this syndrome is characterised by focal and bilaterally symmetrical, necrotic lesions involving a few specific areas in the brain: the thalamus, brainstem, and posterior columns of the spinal cord. Leigh syndrome typically affects children; adult onset is rare.
Leigh syndrome is a severe and progressive disorder with a defect in the energy batteries of the muscle cells (called mitochondria).

Objective

During this virtual ENMC workshop, international expert members of the Leigh syndrome consortium met with the following main objectives: to increase knowledge of the natural history of Leigh syndrome; to improve its diagnosis; to collect information on the genetic epidemiology of the syndrome; to facilitate the identification of biomarkers; and to move forward with possible therapeutic strategies.

The first afternoon session was dedicated to addressing several issues concerning the diagnosis and the clinical and genetic landscape of Leigh syndrome.

Based on a recent publication, the importance of developing biomarkers in order to set outcome measures for future trials was raised. The genetic and clinical spectrum of patients with Leigh syndrome in the USA was presented, together with the Leigh Syndrome Roadmap Project that aims to improve diagnosis and the impact on the lives of patients.
One of the organisers, Prof. Shamima Rahman (UK), talked about the importance of an appropriate Leigh syndrome definition and the need for a differentia-



Dr Holger Prokisch presenting the GENOMIT initiative during both virtual meetings on Leigh syndrome.

tion in the Leigh syndrome spectrum disorders. She mentioned the *ClinGen* international gene curation process, a project involving 30 experts from all over the world, dedicated to define the Leigh syndrome-associated genes and the level of evidence for their association with Leigh syndrome disorders. Furthermore, data from different local registries of mitochondrial patients, including Leigh syndrome, and the Genomit project were shown to the workshop participants.

After these brainstorming sessions, major issues were discussed regarding definition of the Leigh syndrome spectrum, outcome measures, importance of metabolomics (which is the large-scale study of small molecules, commonly known as metabolites, within cells, biofluids, tissues or organisms), and proper functional scales to be used in clinical trials.

In the second afternoon session, other experts presented genetic data from their local Leigh syndrome patient databases: France, Australia, Japan, Czech Republic, and Dr Holger Prokisch showed data from the Genomit registry (Germany, Paris, Milan, Tokyo, Beijng and Newcastle).

This virtual meeting was an excellent opportunity to update and deepen the current knowledge of the genetic cause (aetiology) and natural history of Leigh syndrome, promoting international research and collaborative studies to better characterise and follow the patients affected by Leigh syndrome.

The full scientific report of this workshop will be published in Neuromuscular Disorders after the face-to-face meeting has taken place in **2022**.

Ms Faye Wylie, who is affected by Leigh syndrome, attended the meeting both on October 16 and December 4, 2020. Faye wants to share her voice, and was very pleased to be able to attend this ENMC workshop from her home. In the following link you can read more about Faye and the activities she employs for patients like her:
https://acecentre.org.uk/news/finding-my-voice-to-make-a-difference/

259th ENMC international workshop: Anaesthesia and neuromuscular disorders

The first virtual conference on December 11 gathered 26 participants from Belgium, Denmark, Germany, France, The Netherlands, Spain, Sweden, Switzerland, Brazil, Canada and USA. Participants were medical doctors and/or researchers in the field of (paediatric) neurology, genetics and anaesthesia.

Background
Currently, the European Malignant Hyperthermia Group (EMHG) is preparing guidelines on anaesthesia in myopathic patients using a Delphi process. These guidelines are mainly written for the anaesthesiologists, whereas the ENMC workshop aimed to produce anaesthesia recommendations for neuromuscular neurologists and geneticists. The anaesthetic management of patients and peri-operative complications reported in medical literature was reviewed in the first session. The next part of the meeting was performed in two virtual rooms with the audience split in two groups.

Objectives
Main objectives were to increase and share knowledge on the anaesthetic management of patients with neuromuscular disorders (NMDs) and provide a consensus statement and a practical peri-operative risk tool for neuromuscular disorders and anaesthesia. In the first parallel session, the anaesthetic management of myotonic dystrophy, muscular dystrophies (e.g. Duchenne-, Becker-, limb girdle- muscular dystrophy and facioscapulohumeral dystrophy), acquired and congenital neuromuscular junction disorders (e.g. myasthenia gravis) was presented.

The second parallel session covered the anaesthetic management of mitochondrial and metabolic myopathies, channelopathies such as periodic paralysis and congenital myopathies.

During the final plenary session of this meeting, a framework of the risk assessment tool was presented by Dr Nicol Voermans and Dr Marc Snoeck.
All presenters were asked to complete this tool for the specific neuromuscular disorders.
Prof. Heinz Jungbluth ended the meeting by giving a preview on the second meeting in May 2021.
He presented four cases of patients with various neuromuscular disorders and mutations in the RYR1 gene. These mutations are associated with malignant hyperthermia, a life threatening anaesthesia complication. The difficulties with the RYR1 variants identified during diagnostic investigations in the neuromuscular clinic were presented. This topic will be addressed at the next meeting in 2021.

The full scientific report of this workshop will be published in Neuromuscular Disorder after the follow-up meeting in **2021**.

Dr Nicol Voermans:

"This virtual meeting has been a great opportunity to exchange knowledge about the anaesthetic management of patients with various neuromuscular disorders. The advantage of splitting a workshop in two separate meetings is that knowledge can be digested and participants can work on the practical risk assessment tool for anaesthesia and neuromuscular disorders in advance of the face-to-face meeting."

The four meeting organisers are displayed on the top of the picture. They were assisted by the two Early-Career researchers at the bottom of the picture, who were selected for an ENMC award to attend the meeting and present their research and clinical work during the workshop. For information on the Early-Career Programme: www.enmc.org.

3.2 Participants at ENMC workshops in 2020

The ENMC strives for diversity in its workshop participants, to ensure that consensus can be reached at the meetings by having all relevant decision-makers around the table.

For each workshop that took place in 2020, the numbers of different stakeholders are shown in the table below.

The number of workshop participants and the different stakeholders attending each workshop in 2020

No	Workshop Title	Total number of participants	Clinicians	Basic researchers	Patients	Patient represen-tatives	Pharma represen-tatives	Early-Career researchers
252	Mouthpiece ventilation in neuromuscular disorders	**22**	16	1	1	2	0	2
253	Striated muscle laminopathies	**34**	18	7	0	7	1	1
258	Leigh syndrome spectrum	**25**	15	4	1	2	2	1
259	Anaesthetic management in neuromuscular disorders	**26**	15	8	0	1	0	2
Average of 4 workshops (n)		**27**	**16**	**5**	**0,5**	**3**	**0,8**	**1,5**
%		100%	60%	19%	2%	11%	3%	6%
Total of 4 workshops (n)		**107**	**64**	**20**	**2**	**12**	**3**	**6**

Each workshop had on average 60% clinicians and 19% basic researchers, showing that the latter group was less represented in the four (predominantly clinically oriented) workshops held in 2020. Together, clinicians and basic researchers formed the majority of the participants (79%). A primary aim of ENMC workshops is to connect basic researchers with clinicians to overcome the bridge between the lab and the clinic and bring the fundamental science closer to the clinic and vice versa.

Through the ENMC *Patient Participation Programme* we try to ensure that at least 10% of the participants of each workshop are persons affected by a neuromuscular condition, parents or advocates of these patients and/or representatives from a disease-specific patient or funding organisation. On average 2% of participants were patients and 11% were patient representatives at the ENMC workshops in 2020, which shows that we reached our goal to have the patient's voice well-represented (13% of participants) this year.

In addition, either one or two Early-Career researchers attended an ENMC workshop this year; one of ENMC's main aims is to increase the presence of young scientists in established neuromuscular networks via the ENMC Early-Career Programme see: *Introduction – ENMC: **https://www.enmc.org/early-career-programme/introduction/***
In two workshops, where it was relevant, we also had representatives from pharmaceutical companies.

New numbers to be proud of in 2020

Patients and patient representatives
This year we welcomed 2 persons affected by a neuromuscular condition and 12 patient representatives (parents, representatives of patient associations, patient advocates) to our workshops. They all gave a presentation, asked questions and intermingled in the discussions, which was very helpful for the researchers and clinicians in the workshops to learn the patients' real needs and interests.

Researchers
Despite the Covid-19 pandemic, we held 4 workshops in 2020 with the attendance of 20 basic researchers and 64 clinicians, respectively 19% and 60% of the total participants. We are very proud of our Early-Career Programme which made it possible for 6 young researchers to attend the ENMC workshops and pave their way to enter into the neuromuscular network.

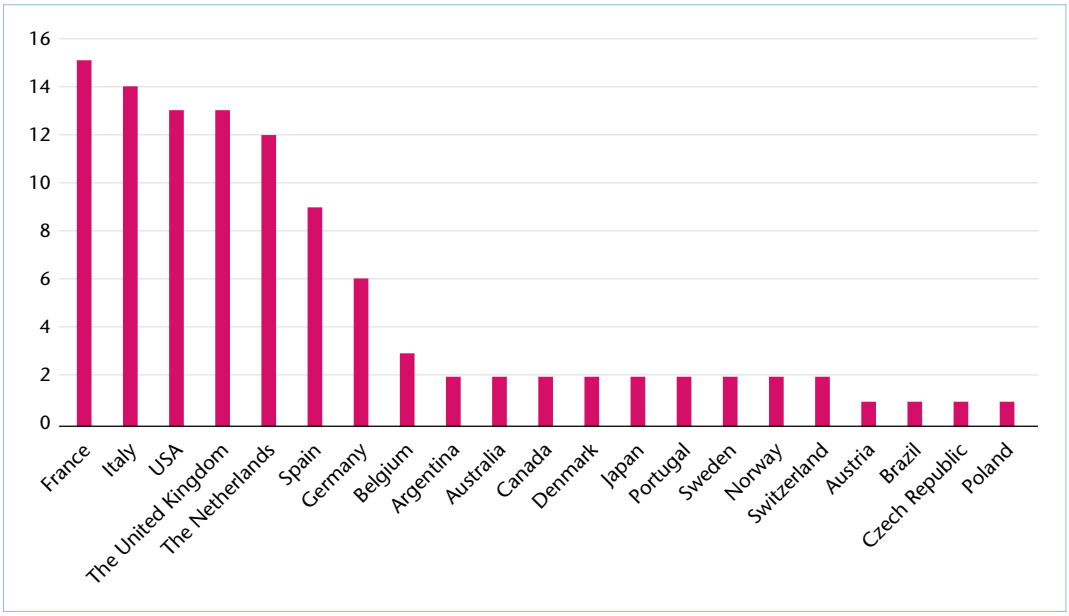
Sponsors
In 2020, the ENMC was sponsored by eight full members and two associated members. One company, Philips, co-sponsored the ventilation workshop (252) and eight pharmaceutical companies supported us by their membership in the ENMC Company Forum. We are very thankful for the support from all these parties and acknowledge them with gratitude.

3.3 Countries represented in ENMC workshops in 2020

One of the key criteria for workshop approval by the ENMC is the geographical balance of the participants. The ENMC thinks that a wide coverage of countries in the workshops is important, to make sure that consensus is reached at ENMC workshops.

This will help to start international research collaborations, ensure the standardisation of healthcare provision for people affected by a neuromuscular condition, and improve the quality of diagnosis and treatment for patients worldwide. In 2020, many countries from all over the world were represented at the ENMC workshops (see diagram below), with a predominance of several ENMC member countries (France, Italy, The Netherlands, the United Kingdom and Germany) and non-member countries like the USA and Spain. We hope that the numbers of participants will be more balanced across the countries once all workshops, originally planned in 2020, have taken place.

Total numbers of participants per country in ENMC workshops 2020



The countries/states with the highest number of workshop participants were from Europe and USA.

4 Creating global awareness about ENMC workshops

4.1 Publication and dissemination of workshop outcomes

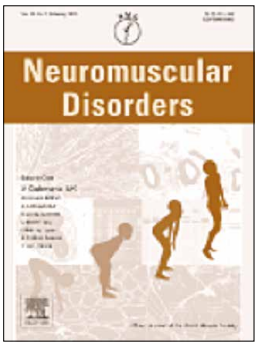
Patients and families

Informing patients and their families about the achievements of ENMC workshops is a key priority of the ENMC. This is done by the workshop lay report, which is written by workshop participants and published on the ENMC website within two weeks after the workshop. Nowadays, all lay reports are translated into many different languages other than English, which increases the accessibility of these reports for people worldwide. The ten European patient member organisations and other co-sponsors help to disseminate these translated lay reports via their local patient networks and the ENMC creates awareness on social media (Twittername: _ENMC; LinkedIn: ENMC group) during the workshops and whenever lay reports are published on its website.

The ENMC maintains an online archive of all workshops organised since 2000, which provides access for the general public to the lay reports produced after each ENMC workshop:

https://www.enmc.org/reports/scientific-publications/

Research community



Researchers, clinicians and healthcare providers who are active in the research field of rare neuromuscular disorders need to be able to read about the scientific results of ENMC workshops in the literature. Therefore, it is mandatory that workshop organisers submit a full workshop report to *Neuromuscular Disorders* within 6 months after the workshop.

ENMC-workshop derived publications are cited 24% more than average (100%). In bibliometric terms this means that they have a "high impact" in the research field.

4.2 International conferences in 2020

ENMC representatives have attended the following international virtual congresses:

- International Congress of the World Muscle Society (WMS), October 2020
- European Conference on Rare Diseases (ECRD), May 2020
- The International Congress on Neuromuscular Diseases (ICNMD), September 2020

5 New programmes developed in 2020

Every year, the ENMC discusses its strategy during the biannual Research and Executive Committee meetings to adhere to the current needs of the neuromuscular community. One of these needs is to bridge between the new and established generation of leaders within the neuromuscular research field.

One of the key pillars of the ENMC is to help early career researchers connect with established scientists and clinicians in the neuromuscular field and to give them a chance to obtain state-of-the-art knowledge on research topics. We are very proud of the Early-Career Programme, which allows predominantly PhD students, post-docs and young medical doctors to participate in ENMC workshops [1] of their choice where they listen, present their research, discuss and report on the workshop outcomes.

From a survey that we undertook in 2020 it became clear that this Early-Career Programme helped the young researchers to expand their network, to start new research collaborations and to find new internships and/or positions. While most were genuinely and intrinsically interested in the field of neuromuscular disorders (NMD), results of the survey stressed the importance of creating more career opportunities and positions with good tenure-track perspectives to encourage the most promising people to stay in the NMD field. Close interaction with inspiring NMD leaders also emerged as an aspiration and important motivational drive.

From interviews held among senior leaders in the field, we have learned that there is a need to support and prepare talented people for leadership, thereby promoting innovation and progress of future neuromuscular research. However, it appears that there is currently no such specific leadership programme within the NMD field for strongly motivated scientists and clinicians, who already have a proven track record in neuromuscular science. Empowering these "mid-career" professionals would help them to stay committed to the field and prepare them for independent leadership, most importantly increasing their chances of reaching high positions where they have the possibility to open up tenure-track perspectives for the next generations. Therefore, the ENMC decided to develop a new and ambitious Mid-Career Mentoring Programme to foster the needs of the next generation of independent researchers and leaders in the neuromuscular field.

Early-Career Workshop Programme

Mid-Career Mentoring Programme

5.1 The ENMC Mid-Career Mentoring Programme

This programme has been developed for people who wish to seek mentoring in order to become independent researchers and/or potential future leaders in the NMD field. These individuals will be at the stage in their careers where they are developing their own research plans and have a proven track record in the neuromuscular field. They have established research teams and collaborative networks.

Dr Ana Ferreiro, Research Director of the ENMC:

"The neuromuscular research field has quickly evolved and expanded due to impressive progress in the last decade. To support and accelerate this progress, future leaders will need to be able to effectively communicate with funders, media, industry, patient advocacy organisations, health care professionals and administrative offices. It is also important to have leaders who embrace working in team-science and promote a healthy research environment."

Goal of the Mentoring Programme

The goal of the new ENMC Mid-Career Mentoring Programme is to facilitate the emergence and support of the next generation of specialists and potential research leaders in the NMD field. We aim at providing opportunities to help them develop their full potential, in order to accelerate progress and innovation in NMD research [2,3].

Since innovation often arises from different perspectives, visions and voices working together, ENMC will strive for a balance in diversity of mentors and mentee candidates.

Short summary of the Mentoring Programme

- One mentee has 1-to-1 contact with two mentors, albeit in separate sessions, who have different and complementary backgrounds (i.e. academia vs business).
- Mentors and mentees are matched according to the type of skills that the mentee seeks to develop or improve. It is not a training programme to develop scientific or clinical skills.
- Mentors and mentees meet 3-4 times per year by video call, phone, online and/or if possible face-to-face. The programme may last for 3-4 years.
- ENMC may help mentees to have access to leadership skill training opportunities that are available on the internet.
- Through its patient associations, ENMC may invite mentees to join one or two national patient days during his/her mentorship, taking place in the country of residence. Talking to, and being around, people affected by a neuromuscular condition is important for mentees to be able to understand the patient's (and families') perspective and implement patient engagement in their work.

Call for Ambassadors

ENMC asks you to help create awareness about this important Mid-Career Mentoring Programme within your own local and international networks. Perhaps you are interested in becoming a mentor yourself or you may be or know a suitable mentee candidate for this programme. Please, feel free to contact us at enmc@enmc.org for any questions or materials to share. The submission deadline for applying as mentee is 1 July each year. The guidelines and the mentee and mentor forms can be found on the ENMC website: **www.enmc.org**

References

1 *Breukel et al. "The impact of European Neuromuscular Centre (ENMC) workshops on the neuromuscular field; 25 years on …" published in: Neuromuscular Disorders Vol 29, Issue 4, P330-340, April 01, 2019. https://www.nmd-journal.com/article/S0960-8966(18)31374-9/fulltext*

2 *The Australian Academy of Sciences EMCR (early-mid career researcher) Forum: https://www.science.org.au/supporting-science/early-and-mid-career-researchers-0/about-emcr-forum and the Australian Academy of Health and Medical Sciences: https://aahms.org/mentorship-program/*

3 *Clance and Imes (Fall 1978). "The Impostor Phenomenon in High Achieving Women: Dynamics and Therapeutic Intervention"(PDF). Psychotherapy: Theory, Research & Practice. 15 (3): 241–247. doi:10.1037/h0086006. https://psycnet.apa.org/doi/10.1037/h0086006*

6 Resources and financial management in 2020

Financial summary 2020

Annual accounts for the year 2020 were compiled in accordance with Guideline C1 for the reporting of small-sized non-profit organisations as published by the Dutch Accounting Standards Board. The financial accounts are drawn up in Euros.

In the summary table below, the overall income and expenses over the year 2020 are shown in comparison with the figures for the previous financial year 2019.

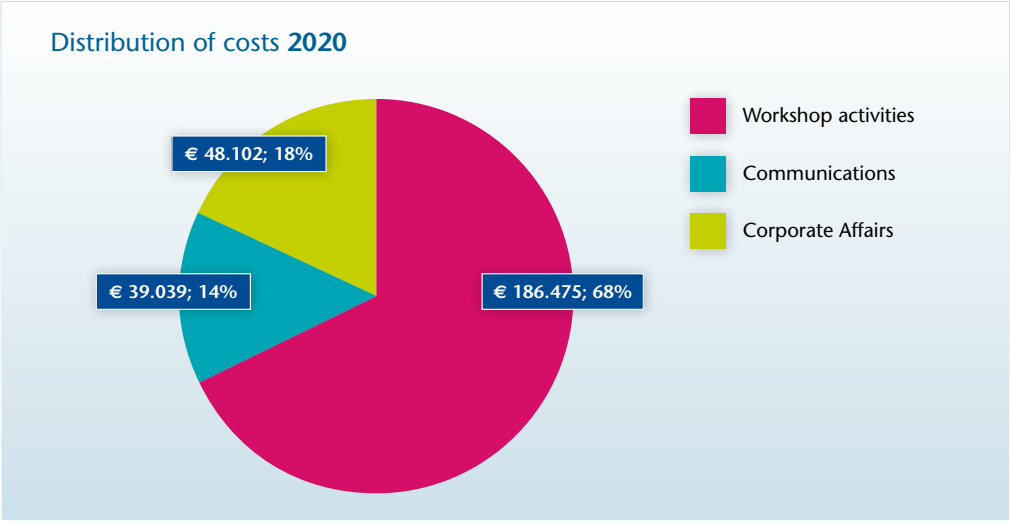
Statement of income and expenses for the year 2020 in Euros (€)		
	2020	2019
INCOME		
Member contributions	231.000	210.000
Associated member contributions	10.000	10.000
Company Forum contributions	75.791	91.151
Other contributions	1.000	22.165
Total income	**317.791**	**333.316**
EXPENSES		
Personnel expenses	156.237	144.090
Rental expenses	11.326	11.421
Activity (workshop) expenses	68.059	115.233
Organisational expenses	37.996	44.365
Total operating expenses	**273.618**	**315.109**
Operating result		18.207
Interest income	– 106	117
Net result	**44.067**	**18.324**
APPROPRIATION OF RESULTS		
Development reserve	80.000	
Development reserve withdrawal*	– 3.652	
Other free reserves	– 32.281	55.312
CASH AT BANKS ON 31 DECEMBER	**573.745**	**477.725**

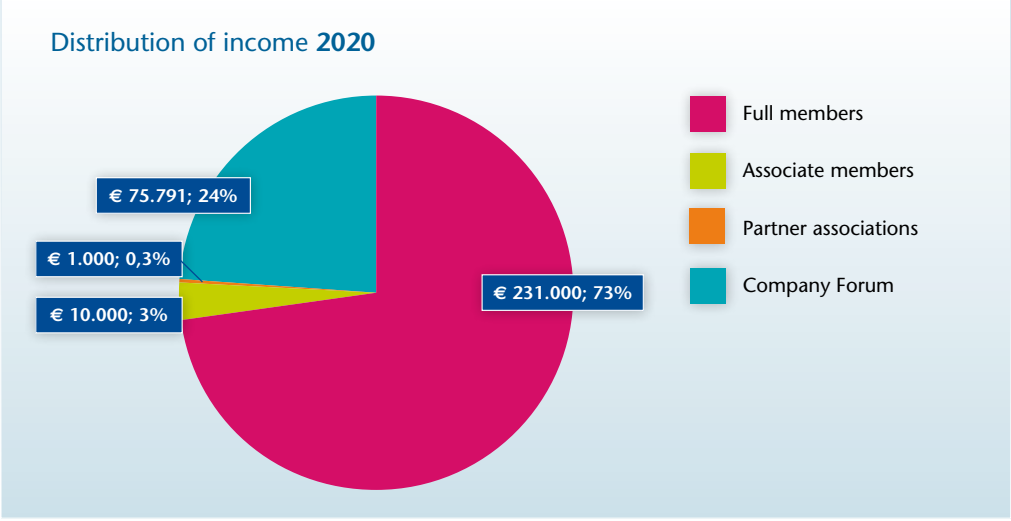
**Note: Withdrawal means that these costs were made in 2020 and could be taken from this provision.*

The distribution of income from the different ENMC supporters and the distribution of costs over the key accounts: workshop activities, corporate affairs and communications, are provided in the two diagrams below. Outside the ENMC administration, three organisations (Association Belge contre les Maladies neuro-Musculaires (ABMM), Parent Project Muscular Dystrophy (PPMD), ResMed and BREAS International) supported the flights of three participants in the 252nd ENMC workshop. They originated from non-ENMC countries, namely, Belgium, Spain and Norway.

Opinion of the auditors

The independent accountants have verified and approved the annual accounts. For a full PDF version of the annual accounts report of 2020, please visit the ENMC website: https://www.enmc.org/about-us/annual-report/





7 Governance in 2020

The European Neuromuscular Centre was founded as a non-profit organisation on 24 November 1992 under Dutch law. The foundation is supported by financial contributions of ten European patient organisations for neuromuscular disorders and many other related organisations. The statutory location is in Baarn, The Netherlands, in the building of the Dutch Neuromuscular Diseases Patient Association.

7.1 The ENMC Executive Committee

The ENMC is governed by an Executive Committee consisting of representatives of ENMC member organisations.

Composition of the ENMC Executive Committee on 31 December 2020
Dr K. Adcock (United Kingdom)
Dr A. Ambrosini (Italy)
Dr S. van den Berge (The Netherlands)
Dr I. Meijer (The Netherlands)
Dr A. Méjat (vice-Chair, France)
Dr A. von Moers (Chair, Germany)
Dr J. Rahbek (Denmark)
Dr R. Willmann (Switzerland)

7.2 The ENMC Research Committee

The ENMC Research Committee is responsible for reviewing the scientific content and quality of the workshop applications and advises the Executive Committee on awarding the grants for ENMC workshops.

Composition of the ENMC Research Committee on 31 December 2020
Dr A. Buj Bello (France)
Dr A. Ferreiro (Chair, France)
Prof. Dr N. Goemans (Belgium)
Prof. Dr E. Gomes (Portugal)
Prof. Dr H. Jungbluth (United Kingdom)
Prof. Dr C. Kornblum (Germany)
Dr M. Olivé (Spain)
Prof. Dr T. Sejersen (Sweden)
Prof. Dr W. Stenzel (Germany)
Prof. Dr V. Timmerman (Belgium)
Dr N. Voermans (The Netherlands)

7.3 The ENMC Office

The office takes care of the daily business of the ENMC.

ENMC Office staff on 31 December 2020
Dr A. Breukel (Managing Director)
Ms A. Zittersteijn (Operational Manager)
Ms F. Ott (jr Operational Manager)
Mrs E. Smit-Branderhorst (jr Operational Manager)
Dr A. Ferreiro (Research Director)
Mrs C. van Santen (Workshop Assistant)

Welcome to the new members of the Research Committee

Prof. Edgar Gomes is professor at the Faculty of Medicine of the University of Lisbon and group leader at the Instituto de Medicina Molecular (iMM), Lisbon, Portugal. He is a biochemist by training and performed his PhD on cell biology in Coimbra, Portugal. Thereafter, he did his post-doc at the University of Columbia, NY, USA. In 2007, at the Institute of Myology, Paris, France, Edgar set up his own research group and became a Director of Research. Since 2014, he has headed a lab at iMM, where they are interested in how the cell architecture of skeletal muscle cells works, for instance in centronuclear myopathies. Recently he became a Professor of Histology and Developmental Biology at the Faculty of Medicine, where he works closely with Hospital Santa Maria, the main hospital in Lisbon, at the edge of diagnostics and therapeutics.

Dr Ana Buj Bello is research director at INSERM and head of the Gene-based Therapies for Congenital Myopathies team at Genethon, France. She received her degree in Medicine and Surgery from the University of Lleida, Spain, and a PhD in Neurosciences from the University of St Andrews, United Kingdom. She also obtained a diploma in Myology from the University of Pierre et Marie Curie, France. After a post-doctorate at the Institut de Génétique et Biologie Moléculaire et Cellulaire (IGBMC), she joined the INSERM in 2004 and has worked at Genethon since 2009. Her research activities focus on developing adeno-associated virus (AAV)-based gene therapies for neuromuscular disorders, in particular congenital myopathies, with a major interest in clinical translation. Her pioneering work on gene replacement therapy for myotubular myopathy has led to the initiation of a clinical trial in patients. She is member of the The Myotubular and Centronuclear Myopathy Patient Registry Steering Committee.

Prof. Dr Cornelia Kornblum works at the Department of Neurology, University Hospital of Bonn, Germany. She heads the Section of Neuromuscular Disorders established in 2018 that includes a specialised clinical trial unit for adult patients and a Neuromuscular Laboratory, located within the Department of Neurology. Cornelia received her MD from the University Medical School of Bonn in 1999 and specialised in neurology in 2003. Thereafter, she worked as a postdoctoral fellow at the Department of Epileptology and the Life & Brain Center in Bonn, studying mitochondrial genetics. Since 2006, she has been a Senior Neurologist and Head of the Neuromuscular Group of the University Hospital of Bonn. Cornelia was appointed Associate Professor of Neurology in 2014. Her main clinical interests include metabolic myopathies, mitochondrial disorders and myotonic dystrophies. Currently her research focuses on the clinical, genetic, myopathological and brain imaging characterisation of hereditary multisystemic neuromuscular diseases affecting the central nervous system.

Welcome to the new staff members of the ENMC office

Ms Franziska Ott, junior Operational Manager

Franziska Ott holds a Bachelor of Engineering and worked in the Clothing Industry over the past 10 years. Franziska has developed performance sportswear for global brands and managed the whole product creation process.

As one of the two junior Operational Managers, Franziska organises workshops and takes care of all financial and HR administrative matters. She is also the contact person for the ENMC Executive Committee and the ENMC Early- and Mid-Career Programmes.

Mrs Esther Smit-Branderhorst, junior Operational Manager

Esther Smit studied French language and communications and has worked for several pharmaceutical companies in marketing communications and management support. She is also a passionate (freelance) photographer.

As one of the two junior Operational Managers, Esther organises workshops and she supports the Managing Director with public relations and communications. Esther is the contact person for the ENMC Research Committee and the ENMC Patient Participation Programme.

7.4 Ms Annelies Zittersteijn says goodbye after 16 years working for ENMC

Ms Annelies Zittersteijn began enjoying her well-deserved retirement in March 2021. Therefore, she is unfortunately saying goodbye to the ENMC, after more than 16 years....!

We are extremely grateful for all the work she has done for the ENMC with the passion she has had for so many years.

Annelies will be succeeded by two junior Operational Managers; Franziska Ott and Esther Smit, who are introduced here as well.

Annelies:

"I have enjoyed every minute of my working for the ENMC in the last 16 years. I have always been impressed by the enthusiasm and commitment of the workshop organisers, the participants and the ENMC Executive- and Research Committees. Your efforts have led and will lead to new discoveries, which is changing the landscape of available NMD therapies. Working with you was a great pleasure and I would like to thank you all for your great co-operation and kindness. I wish you all the best for the future and will, with pleasure, keep on following the developments of this fantastic foundation: the ENMC."

Going back to 2004 with Annelies Zittersteijn

When did you join the ENMC and can you describe in a few lines what the ENMC organisation looked like, do you have a few examples?

I joined the ENMC in August 2004 after my predecessor had left already. Two months later, the new Managing Director was hired, so we started as a new unexperienced but very enthusiastic team.

The submission of workshop applications was not yet structured into biannual review rounds; organisers could apply the whole year through, but the applications were only assessed once a year. Another important difference with how workshops are run now, is that the main topics of the workshops were on basic science; molecular research and identification of genes causing the neuromuscular diseases. Whereas nowadays the workshops are devoted to clinical trial and treatment readiness. And also a major difference is that fewer female experts were participating in ENMC workshops 15 years ago.

What are the most important developments within the ENMC over the years (strategically and/or operationally)? What role did you have in these changes?

There are several, but just to name a few:

- Without a doubt, the fact that in the last decade, we could support the development of therapies by organising workshops focussing on clinical trial readiness. Recently, we organised a workshop about new born screening, a very important and ethical topic addressed in the light of new therapies coming on the market. From the workshop it became clear that babies should be treated as soon as possible to avoid irreparable muscle damage, which will occur if treatment only starts when a child already shows symptoms.
- People affected by a neuromuscular condition became more and more involved in ENMC workshops. This frequently resulted in important contributions and initiatives. Nowadays, their presence is mandatory during a workshop.
  My responsibility was to personally inform the patients and patient representatives about the course of events during a workshop and to encourage them to let their voice be heard.
  I admire very much the power and resilience of patients who, often in a wheelchair, travelled from far to be present during an ENMC workshop and share their day-to-day life with the workshop participants. This frequently resulted in high quality input which led to new initiatives from our side such as the White paper on shared-decision making (see: *Papers on Patient Participation – ENMC*).
  This White paper and associated publications resulted from a special workshop held in Milan, Italy.
- The ENMC organisation became better structured and important new initiatives were established such as the ENMC Company Forum, a recurring five year impact analysis on the results of workshop outcomes, an annual Impact Report and the Early Career- and Mentoring Programmes.

"ENMC is a very professional and highly qualified organisation as well as a warm and confidential environment. ENMC connects people and that has been our mission for more than 27 years"

For these projects, I worked closely with the Managing Director who gave me a lot of responsibility and trust. This helped me to play my role supporting the ENMC both in organising the workshops and performing logistical operations as well as hosting the weekends together with other colleagues.

You have always done your job with full dedication. Where does your drive come from?

This comes from the people I worked with, the Executive- and Research Committees, workshop organisers and -participants; everyone is so dedicated and works so hard, that inspired and motivated me a lot. Being part of the ENMC and joining workshops with top specialists made me proud and gave me the feeling that my work matters. Time well spent!

What has been your biggest success? What are you most proud of?

I am very proud that the ENMC has existed for over 27 years now and still has a unique concept of hosting small, highly interactive workshops during which knowledge and experience is shared.
We connect people very successfully.
I am also proud that the workshop reports are very much cited. My personal biggest success is that people think of me as the 'the heart of the ENMC'.

"ENMC: a real step forward in connecting people world-wide to make progress in the treatment of patients with Neuromuscular Disorders."

Esther and Franziska will continue the work you have done. What message would you like to leave them with?

To play a role in a dynamic field and be surrounded by dedicated, very experienced and talented people, who are most of the time very busy. Making their stay enjoyable and worthwhile, that is a great thing to do.

Thank you very much, Annelies, for all you have done for the ENMC.
Wishing you all the best in the new, exciting phase of your life!

Ms Annelies Zittersteijn here organising one of the virtual meetings in 2020 in a special studio in Hilversum, The Netherlands. Due to the pandemic, many of the face-to-face workshops had to be cancelled. Instead, Annelies -together with the workshop organisers and team in Baarn- rearranged the infrastructure and set-up online Zoom meetings to keep the momentum for the workshop consortia and facilitated the ongoing exchange of state-of-the-art knowledge and scientific discussions.

8 A special thank-you to all our members and supporters

It is thanks to the continuous support of the ten European patient organisations that the ENMC is able to facilitate and organise, on average, eight workshops per year. With support from additional partner organisations, such as condition-specific associations and members of the ENMC Company Forum, we are also able to invite participants from non-ENMC countries and facilitate the attendance of early-career researchers, patients and patient representatives.

ENMC full and associated members

AFMTÉLÉTHON
INNOVER POUR GUERIR

Österreichische MuskelForschung

FONDAZIONE Telethon

Muscular Dystrophy UK
Fighting muscle-wasting conditions

SPIERZIEKTEN NEDERLAND

MUSKELSVINDFONDEN

fsrmm
fondation suisse de recherche sur les maladies musculaires
fondazione svizzera per la ricerca sulle malattie muscolari
schweiz. stiftung für die erforschung der muskelkrankheiten

Finnish Neuromuscular Disorders Association

Deutsche Gesellschaft für Muskelkranke e.V. DGM

PRINSES BEATRIX SPIERFONDS
KRACHTIG TEGEN SPIERZIEKTEN

Members of the Company Forum

NOVARTIS

SANOFI GENZYME

Biogen

Roche

Amicus Therapeutics

PerkinElmer
For the Better

LUPIN NEUROSCIENCES

IONIS

Workshop-specific sponsors

Parent Project Muscular Dystrophy
LEADING THE FIGHT TO END DUCHENNE

PHILIPS
RESPIRONICS

ABMM
Maladies neuromusculaires

BREAS

ResMed

9 Looking forward to 2021 and beyond

9.1 Workshops in 2021 and 2022

Twelve ENMC workshops in several separate (virtual and/or face-to-face) meetings are planned to take place in 2021 and 2022 (see table below). Despite the Covid-19 pandemic and the consequent travel and event restrictions, we are able to organise these workshops, albeit in separate settings and on different dates. We herewith would like to thank all organisers and participants for their flexibility in changing the dates in their calendars and for being cooperative and very active in the online meetings.

Two review rounds for workshop applications are scheduled in 2021: one in the spring and one in the autumn (submission deadline 1 September 2021).

The workshops that are selected at these review rounds will all be planned for 2022.

Preliminary ENMC programme 2021 and 2022

Workshop no. and date	Topic	Workshop leaders
Workshop no. 255 15-16 January 2021 (virtual) 15-16 October 2021 (face-to-face)	Muscle imaging in idiopathic inflammatory myopathies	Prof. M. de Visser, Prof. J. Vencovský, Prof. P. G. Carlier
Workshop no. 256 5-7 February 2021 (virtual) 8-10 October 2021 (face-to-face)	Myositis specific and associated autoantibodies	Dr Y. Allenbach, Prof. O. Benveniste, Dr J. Damoiseaux, Dr A. Mammen
Workshop no. 253 19-20 February 2021 (virtual) 4 bimonthly meetings on 16 April, 18 June, 3 September and 22 October 2021 10-12 December 2021 (face-to-face)	Striated muscle laminopathies; natural history and clinical trial readiness	Dr G. Bonne, Dr L. Maggi, Prof. S. Quijano-Roy, Dr C. Bönnemann
Workshop no. 261 19 March 2021 (virtual) 29-31 October 2021 (face-to-face)	Management of safety issues arising following AAV gene therapy	Prof. L. Servais, Prof. F. Muntoni, Dr C. Bönnemann
Workshop no. 259 28-29 May 2021 (virtual)	Anaesthetic management in neuro-muscular disorders	Prof. H. Jungbluth, Dr N. Voermans, Dr M. Snoeck, Prof. S. Riazi

Workshop no. and date	Topic	Workshop leaders
Workshop no. 263 25-26 June 2021 (virtual) 26-27 November 2021 (virtual) 13-15 May 2022 (face-to-face)	Focus on female carriers of dystrophinopathy: refining recommendations for prevention, diagnosis, surveillance and treatment	Prof. A. Ferlini, Dr J. Bourke, Dr R. Quinlivan, Dr A. Sarkozy
Workshop no. 258 9 July 2021 (virtual) 25-27 March 2022 (face-to-face)	Genetic epidemiology and clinical trial Readiness in encephalomyopathy of Leigh Syndrome spectrum	Prof. E. Bertini, Prof. S. Rahman, Prof. B. Cohen, Dr M. Schiff
Workshop no. 262 16 July 2021 (virtual) 17 December 2021 (virtual) 11-13 February 2022 (face-to-face)	Standards of Care for the Dysferlinopathies	Prof. V. Straub, Dr A. Mayhew, Dr T. Stojkovic, Dr L. Bello
Workshop no. 260 17-19 September 2021 (face-to-face)	Congenital myasthenic syndromes	Dr L. Maggi, Dr P. Rodriguez-Cruz, Dr D. Beeson, Prof. H. Lochmüller
Workshop no. 257 1-3 October 2021 (face-to-face)	The 3rd ENMC workshop on Dystroglycan and the Dystroglycanopathies	Prof. S. Winder, Prof. V. Straub, Prof. K. Campbell
Workshop no. 264 19-21 November 2021 (face-to-face)	Multi-system involvement in Spinal Muscular Atrophy	Dr G. Baranello, Prof. T. Gillingwater, Prof. K. Swoboda, Prof. R. Kothary
Workshop no. 254 28-30 January 2022 (face-to-face)	Formation of a European network to initiate a European data collection, along with development and sharing of treatment guidelines for adult SMA patients	Prof. P. Laforêt, Dr E. Pegoraro, Dr L van der Pol, Prof. M. Walter

9.2 CO_2 Foot print of the ENMC

ENMC brings on average 250-300 persons per year from all over the world to The Netherlands. This number mostly comprises participants of ENMC workshops, but also members of the Research and Executive Committees travel to attend the biannual ENMC board meetings.

Most people travel by aeroplane (70-80%), the rest travels by car and by train. Plane travel and car journeys are particularly impactful on the climate [1], hence we felt it is time to take our responsibility as an organisation and try to help reduce global warming, even if it is a small portion. The high level of CO_2 emissions are a cross-border problem and requires a European/international approach.

With the positive, virtual experiences ENMC gained over the last 12 months, new hybrid meeting and travel preferences were set-up to achieve this.

Hybrid Zoom-room

The ENMC is developing a hybrid Zoom-room, which allows people to stay at home but still attend an ENMC workshop together with persons who are able to travel to The Netherlands and who can attend the meeting in-person. This is particularly beneficial for workshop participants, who have to travel from far away (Australia, Japan, Canada, USA etc.) or who have other reasons (health, budget, personal) for not being able to travel. The new hybrid set-up guarantees a real life experience, making it possible to attend the workshop during the entire weekend. This indirectly has a positive effect on the climate, since less travel by plane is expected.

Travel by train

To further enable this vision, ENMC encourages that workshop participants and members of the ENMC Committees take the train instead of a plane when possible. This may e.g. be applicable for people who can reach the meeting destination near Amsterdam within a maximum of eight hours travel time.
We understand that people may require taking a plane because of personal, geographical or work-related reasons; train travel is not always convenient for everyone. Therefore, this train preference is not mandatory and ENMC is not withdrawing its reimbursement policy for plane or car travel. ENMC is willing to be flexible and offers extra hotel nights to overcome the long travel hours by train: **https://www.enmc.org/workshops/how-to-apply/step-2-application-guidelines/**

9.3 International conferences in 2021

ENMC representatives will attend the following international virtual congresses with an "e-booth":

- The International Congress on Neuromuscular Diseases (ICNMD), 21-22 & 28-29 May 2021.
- The Peripheral Nerve Society (PNS), 12-13 & 25-27 June 2021.
- International Congress of the World Muscle Society (WMS), 20-24 September, 2021.

[1] *Air travel burdens the environment 7 to 11 times as much as the same journey by train," explains Anne Kluivers of Environment Central. And especially on shorter distances, the plane is relatively polluting compared to the train or the car. The fact that the aircraft is so polluting is due, on the one hand, to the consumption of kerosene, but on the other hand to the height at which aircraft emit the harmful substances. "By burning kerosene, aircraft emit CO_2, contributing to global warming". It was calculated that 1,000 kg of CO_2 emissions is approximately released by 6,000 kilometres of driving a diesel car (with a consumption of 1 in 15), 71,000 kilometres by train (emissions per passenger) and 8 flights back and forth from Amsterdam to London (emissions per passenger).*

9.4 Budget for 2021

This table presents the budget forecast for 2021 established on 31 December 2020.

Budget 2021 in Euros (€)	Actuals 2020	Budget 2021
INCOME		
Member contributions	231.000	231.000
Associated member contributions	10.000	10.000
Company Forum contributions	75.791	65.000
Other contributions	1.000	10.000
Total income	**317.791**	**316.000**
EXPENSES		
Personnel expenses	156.237	155.000
Rental expenses	11.326	11.300
Activity expenses	68.059	140.000
Organisational expenses	37.996	47.000
Total operating expenses	**273.618**	**353.300**
Interest income	– 106	0
NET RESULT	**44.067**	**– 37.300**

Colophon

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