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Dear Sir, Madam,

The ENMC had a really exiting start of the year with 4 interesting workshops on Biomarkers in DMD, Inflammatory Myopathies, Adults with DMD and Respiratory Insufficiency in MD. All workshops were attended by a broad representation of scientist and clinicians as well as patients and/or patient representatives. The strategic focus of the ENMC was and is to include the patients voice in the workshops. We are happy to see that the dialogue between scientists and patients is lively and extremely informing for both groups.

Annual report 2013

The financial results and the activities in 2013 were approved during the Executive committee meeting held in May 2014.

News from the ENMC office team

We are happy to introduce our new Research Manager, dr. Alexandra Breukel. Alexandra holds a PhD in neuroscience and has worked in the pharmaceutical industry for the past 20 years. She has made contributions to the clinical development and marketing of medicines in the disease area of psychiatry and oncology.

We also introduce our new Research Director, Prof. Dr. George Padberg. George studied medicine at Leiden University and received his PhD with a thesis on facioscapulohumeral muscular dystrophy (FSHD). In 1993, he was appointed professor and head of the Department of Neurology at the Radboud UMC in Nijmegen. Last year, he retired from this position.

Furthermore, three new members for the Research Committee have been elected in May 2014; Prof. G. Comi (Italy), Prof. M. Ruegg (Switzerland) and Dr. P. Laforet (France).

New developments

Young Scientist Programme

In order to enable young scientists to get a chance to experience ENMC workshops, we have developed a program which allows "scientists of tomorrow" to attend ENMC workshops. This programme is funded by Genzyme. Candidates can apply and complete relevant forms which will be published on our website shortly.



Patient- and workshop organisers toolkits

The participation of persons directly involved with a neuromuscular disorder in ENMC workshops has always been extremely important and relevant. To facilitate this process for the participating patient representatives, we are currently finalizing a patient toolkit. This toolkit provides an overview of the ENMC workshop, the processes relevant for the conduct of the workshop and reporting of the workshop outcomes. It describes what is being expected from a patient representative, how one can prepare and make arrangements for the workshop.

REPORT OF A PATIENT EXPERIENCE IN AN ENMC WORKSHOP



“It was exciting to be part of the ENMC conference!”

Peter Mikkelsen, a 33-year old patient with Duchenne Muscular Dystrophy visited the 206th European Neuromuscular Centre (ENMC) workshop on: “Care for a novel group of patients: Adults with DMD”. Scope of the problem and need for care recommendations”. The Netherlands, 23-25 May 2014. For an overview of the full interview, please click [here](#).

In order to facilitate a successful workshop application procedure, we are also finalizing a toolkit for applicants and organisers. This toolkit will be officially launched in the coming months.



ENMC workshop application review rounds

During the first review round for workshop applications in 2014, a total of 5 applications were reviewed. Two applications were awarded. Further details on the upcoming workshops can be found here: <http://www.enmc.org/workshops/upcoming-workshops/>

The next call for ENMC workshop applications is now open and the deadline is September 15, 2014.

Memberships & Funding

We are very grateful for the generous support from our members from Denmark, Finland, France, Germany, Italy, Netherlands, Switzerland and the United Kingdom.



Deutsche Gesellschaft für Muskelkranke e.V. DGM



Finnish Neuromuscular Association

Next to this, we would like to acknowledge the support of Genzyme Europe BV (The Netherlands), GlaxoSmithKline Rare Diseases (UK), and many workshop-specific sponsors.





Workshop-specific co-funding was obtained by:

- The Dutch ZonMw Foundation
- The European Science Foundation
- The American Parent Project Muscular Dystrophy
- The American Myotonic Dystrophy Foundation

We are very grateful to these organisations for their continuous support which enables ENMC to conduct its activities.

Thank you for your interest in us by reading this newsletter. Please do not hesitate to contact us directly (+31-35 54 80 481 or enmc@enmc.org) should you wish to discuss a workshop, support of our organisation, or any other business.

With kind regards,

On behalf of ENMC,

Dr. Marita Pohlschmidt
Chair Executive Committee ENMC