TREAT-NMD Neuromuscular Network

Spring 2009 · Introduction Newsletter for Central and Eastern Europe

Welcome to this special newsletter of TREAT-NMD. This edition is an introduction for patient organisations and patient groups in Central and Eastern Europe. Some of you know TREAT-NMD already and some of you do not know us yet.

TREAT-NMD is a network for people with neuromuscular diseases and professionals working in the field. It aims to advance diagnosis and care and develop new treatments for the benefit of patients and families, working closely with scientists, healthcare professionals, the pharmaceutical industry and patient groups around the world. TREAT-NMD is working with patients, patients organisations, physicians, researchers and industry. These projects are important tools to accelerate treatment for neuromuscular diseases. We need your support to help make these projects work and so reach our joint goal. You can actively participate and tell your physicians and researchers about us and our projects.

Newsletter contents

Become a Member of TREAT-NMD

If you are interested in becoming a member of the TREAT-NMD Network please visit our web site to download our membership charter. An application form is also available for download. The web link to our Members' section is: http://www.treat-nmd.eu/research/get-involved/. We look forward to welcoming new members!

About this newsletter

This is a special edition newsletter sent to all patient organisations and patient groups in Central and Eastern Europe. Earlier editions of the regular newsletter can be found online at our web site. If you would like to subscribe directly, please visit our website at www.treat-nmd.eu/ where you will find a subscription link at the bottom of the homepage. You can also use the same link if you no longer wish to receive this newsletter – just select the unsubscribe button.

Working with us

TREAT-NMD aims to be an inclusive rather than an exclusive network, and you do not have to be based in Europe or be a partner to be involved. International collaboration with experts from all over the world is already taking place, and new links are being developed.

If you are involved in any of TREAT-NMD's areas of interest and have something you'd like to say or a suggestion of where we could work together, we encourage you to get in touch by writing to us at info@treat-nmd.eu. The coordination team in Newcastle will be happy to put you in touch with the person most relevant to your particular interest.

Introduction

I would like to start this newsletter by introducing myself. My name is Maryze Schoneveld van der Linde and I have replaced Peter Streng as the European Neuromuscular Centre (ENMC) project manager for TREAT-NMD as of February 1st 2009. I have been closely involved in the process to get treatment for Pompe disease, a rare neuromuscular disorder. I look forward to working together with you all to encourage new treatments for those people with neuromuscular diseases who don't have treatment yet.

You can read more information about me, my experience and expertise at: http://www.enmc.org/people/?mid=57&id=16&people=7

We would like to inform you about TREAT-NMD and its important activities, meetings, publications and guidelines that can be of benefit for you and your organisation. We also need your support and feed-back on the work we are doing at TREAT-NMD. We aim to work with you and your feedback would be very valuable on the following questions related to the information addressed in this letter:

- What do you like or dislike in the current standards of care guidelines?
- Do you think the standards of care guidelines on Duchenne Muscular Dystrophy and Spinal Muscular Atrophy can be implemented in your country?
- Please can you tell us what kind of support you might need to implement these standards of care guidelines?
- What hurdles would you see to implement the Standards of Care in your country?

If you do have questions or suggestions, you can contact me at my email address: schoneveldvanderlinde@enmc.org

Membership of the TREAT-NMD Neuromuscular Network

The TREAT-NMD network has 22 partners covering 11 European countries. Those partners have committed themselves to perform specific tasks within the network. We fully recognize however that there are many other organisations, institutions, companies and individuals who are doing much valuable work in the neuromuscular field and might benefit from closer links with TREAT-NMD. To enable organisations and individuals to become involved in TREAT-NMD, one can become a member of TREAT-NMD. If you would like to become a member you must be willing to adhere to our 'Members' Charter'. You can read this Charter at: http://www.treat-nmd.eu/userfiles/file/general/TREAT-NMD_Members_Charter.pdf. Members benefit from closer ties with the network and to promote the tools and resources the network is creating worldwide, and we are working together with our members to help implement the network's goals, from improved patient care to specialist scientific training worldwide.

You can find the membership application form at:

http://www.treat-nmd.eu/userfiles/file/general/TREAT-NMD_Membership_Application_Form.doc

Please send your completed application form by email to Stephen Lynn, TREAT-NMD Network Manager at the following email addresses: Stephen.lynn@treat-nmd.eu or Stephen.lynn@ncl.ac.uk

Training and Education

One of the important aims of the TREAT-NMD Network is to spread knowledge on neuromuscular diseases worldwide. By offering training to young investigators and physicians they become more knowledgeable in the field and more willing to pursue a career in neuromuscular science and medicine.

A second aim is to stimulate an integrated and multidisciplinary approach of physicians and researchers in the development of new diagnosis and treatment options leading to more optimal care for patients.

The tool to stimulate this is by exchange programs and training courses. The European Neuromuscular Centre (ENMC), being not a training facility itself, will facilitate the training and exchange within the network. The program has already awarded grants for young scientists and physicians from CEE countries for various training activities and exchange visits. A patient organisation often does know the physicians and researchers in their country who are involved in neuromuscular diseases. Therefore it's important for you to know about these training opportunities for your physicians and researchers and inform them about it.

Some examples of training grants for physicians and researchers

To encourage physicians and researchers to get training and education in neuromuscular diseases in other centres, grants can be given for several workshops, training sessions, conferences or Summer schools. This mobility plan to spread and increase the knowledge on neuromuscular diseases has showed to be effective. To give you an idea what this plan means the following example can be given:

An example of how exchange in knowledge and mobility to other centres across Europe can look like on a map.

A Polish clinician was looking for a training stay to learn more about Electromyography (EMG). Unfortunately we were not able to find a suitable training site, but this physician did receive a grant to attend the Association Française contre les Myopathies (AFM) summer school in Paris. A Moldavian physician applied for a training stay in Istanbul with a focus on paediatric neuromuscular diseases, especially electroneuromyography (ENMG). This technique is not yet available in Moldavia and the physician would like to set it up in Macedonia. A scientist from Italy has applied for a training stay in The Netherlands to learn more about the exon skipping technique. A Hungarian scientist travelled to Barcelona for training in DNA sequencing to diagnose SMA patients.

Conferences, Summer schools & Workshops

At present TREAT-NMD has 3 grant opportunities available for various courses, workshops and summer schools. These include:

Update in Neuromuscular Disorders, June 1-3, 2009, London, United Kingdom

This course, now in its second year, is the result of the merging of two popular yearly courses with an established international reputation: the "Hammersmith Hospital update" on the latest research and clinical management advances related to childhood neuromuscular disorders, and the "Institute of Neurology neuromuscular short course", a stimulating update on adult inherited and acquired neuromuscular disorders. For additional information, please visit: http://www.cnmd.ac.uk/index_courses

Please visit the TREAT-NMD website for a broader overview of all meetings that are being organised in the neuromuscular field that might be of interest to you and/or your organisation.

International workshop: clinical trials in Neuromuscular Diseases, June 4-6 2009, Freiburg, Germany.

One of the most common reasons for failed trials is poor protocol design. As neuromuscular disorders are very rare, clinical trials have to be multi-centre or even multinational to include enough patients. Therefore the aim of this workshop is to improve the efficiency of clinical trials in neuromuscular diseases. The workshop is aimed at physicians specialising in neuromuscular diseases who are already involved in clinical trial work. Please download the workshop flyer with specific information at: http://www.treat-nmd.eu/userfiles/file/general/CTCC_workshop_June09.pdf

The 12th Annual Summer School of Myology, 17 - 26 June 2009 at the Institut de Mylogie, Hôpital de la Salpétrière, Paris, France.

Every year the Institute of Myology offers the possibility to get trained in Myology in a 10-day course. The content of the Summer School is similar to that of the University Diploma by Paris-6 and Aix-Marseilles Universities all year long. A certificate of attendance will be given upon completion of the Summer School. Aspects of Myology will be addressed during the course, from basic science to cutting-edge therapies, clinical and muscle diseases are taught. All lectures and interactive workshops will be done in English. Please look for information at: http://www.institut-myologie.org/anglais/ewb_pages/e/ens_ecole_ete_objectifs.php

PhD Opportunities - Max F. Perutz Laboratories Vienna

One of the training opportunities is provided by the Max F. Perutz Laboratories. They are home to a strong group of scientists whose common long-term research goal is to investigate and understand signal transduction mechanisms in a variety of cell-based and organismal systems. The PhD program Molecular mechanisms of Cell Signaling, funded by the Austrian Science Fund (FWF), offers structured, state-of-the-art training in signal transduction and competitive PhD projects that combine biochemistry, molecular biology, cell biology, and genetics to study cell signalling in different model organisms. The curriculum will have a minimum duration of 3 years, an extension is possible. The students will obtain a PhD Degree conferred by the University of Vienna or by the Medical University of Vienna, depending on the affiliation of the Supervisor, and /or based on the topic of the Thesis. Deadline for receipt of completed applications is 15 May 2009. Please look for information at: http://www.phd-cellular-signaling.at/

For information on these courses, workshops and other events and meetings that can be of interest for your physicians and researchers, please look at: http://www.treat-nmd.eu/patients/events/events/

If you do like to get more information you can contact Katelijne Senden at the European Neuromuscular Centre (ENMC) . Her email address is: senden@enmc.org

TREAT-NMD / NIH International Conference, 17 – 19 November 2009, Brussels, Belgium

We would like to invite you to register for the TREAT-NMD / NIH international conference on '*Bringing down the Barriers - Translational Medicine in Inherited Neuromuscular Diseases'.*

TREAT-NMD is planning its first international conference in collaboration with the National Institute of Health in the USA. The aim of the meeting is to share progress in the area of translational medicine in inherited neuromuscular diseases and set the future collaborative agenda. This conference will build on achievements of the NIH and TREAT-NMD. It will be a highly interactive meeting with a strong focus on the key issues surrounding "trial readiness" in the neuromuscular field. The conference will be held at the Crowne Plaza Hotel in Brussels City Centre in Belgium. Please look for more information at: http://www.treat-nmdconference2009.eu/

EAMDA 39th Annual General Meeting, 17 – 20 September 2009, Belgrade, Serbia

The European Alliance of Neuromuscular Disorders Associations (EAMDA) is the European umbrella of patient organisations for neuromuscular diseases. Every year a conference and annual meeting is being held in one of EAMDA's member countries. This year Serbia will host the meeting. You can find information at: http://www.eamda.net/belgrade.html

EURORDIS Summer School for Patient Advocates: Training in clinical trials & drug development, 14 – 18 June 2009, Barcelona, Spain

Many patient advocates who are members of EURORDIS are involved in the EU decision making process in the EU regulatory agency, the EMEA, as members of scientific committees and working parties. This summer school provides a unique opportunity for patient advocates to meet and interact for the first time with each other, regulators, academic partners and industry and to learn from each other's experience. The 4 day programme covers aspects of clinical trials and drug development, as well as steps involved in the regulatory process in Europe. More information on this summer school can be found at: http://www.eurordis.org/article.php3?id_article=1702

If you do like to get more information you can contact Katelijne Senden at the European Neuromuscular Centre (ENMC) . Her email address is: senden@enmc.org

Care and Trials Site Registry

As neuromuscular diseases (NMD) are very rare, clinical trials must recruit patients at multiple centres so as to achieve large enough sample sizes and have sufficient statistical power to address important clinical questions. The Care and Trials Site Registry was set up by the TREAT-NMD Clinical Trials Coordination Centre with the aim of helping investigators and the pharmaceutical industry to find adequate trial sites when they are planning a multi-centre clinical trial in NMD. The TREAT-NMD Care and Trials Site Registry contains information about personnel, facilities and patient population in hospitals that are interested in participating in clinical trials in neuromuscular diseases.

To detect contact addresses, members of the TREAT-NMD network in different countries were asked to identify potential investigators and hospitals which could take part in clinical trials in neuromuscular diseases. Many of the patient organisations in the Central and Eastern European countries did so already, but some countries are still lacking. From the physician names and addresses we received, physicians were contacted and informed about the background and the objective of the Care and Trials Site Registry and were encouraged to register if they were interested. On a regular basis (at least annually) investigators will be reminded to update the information on their centre. The information is collected via the online feasibility questionnaire and flows directly into the database so that the database is continuously up-to-date. Data are kept in confidence and committed only for the purpose of clinical trials and only with the consent of the investigator for each individual query.

If you know an institution in your country that would be interested in hosting potential future clinical trials for NMDs or has a population of neuromuscular patients that would benefit from TREAT-NMD's care standards information, please look at: http://www.treat-nmd.eu/patients/clinical-trials/care-and-trial-site-registry/

It's in all our benefit to find as many investigators and hospitals as possible to participate in this project.

TREAT-NMD global patient registries - A unified global source of information about neuromuscular patients

Scientific advances over recent years have lead to substantial changes in the treatment of many neuromuscular diseases. New therapeutic strategies are being developed and, for some of these treatments, plans for large studies involving patients from more than one country are already in place.

Several new therapeutic strategies for neuromuscular diseases target specific genetic defects. When a clinical trial is being planned, it is very important that patients suitable for that trial can be found and contacted quickly. The best way of ensuring this can happen is to make sure that patients' details are all collected together in a single database or "registry" that contains all the information that researchers will need, including each patient's particular genetic defect and other key information about their disease.

The TREAT-NMD network is creating this kind of registry in countries across Europe and is also linking with other national registry efforts worldwide. We focus on registries for DMD and SMA, but we welcome contact from people interested in setting up other registries. These national registries all feed into a single global registry which will combine the information from each of the national registries, and this will ensure that patients who register in their national registry can be contacted if their profile fits a clinical trial. In addition, these registries will help researchers to answer questions such as how common the individual diseases are across the world and will support other activities to improve patient care, such as the assessment of care standards in different countries. Pharmaceutical companies interested in locating patients for a clinical trial will be able to request information from the TREAT-NMD global registry. The patients' details are protected but companies with legitimate interests can speedily find the information they need. All of this will help ensure that promising new treatments can be brought to patients as quickly as possible.

If your organisation is interested to participate, please look for information at: http://www.treat-nmd.eu/patients/patient-registries/toolkit/ The registries pages contain a lot of information for patients, for pharmaceutical companies, for researchers and for people interested in setting up a registry where none yet exists. You can also contact Dr. Hanns Lochmuller at: hanns.lochmuller@ncl.ac.uk

Registration and systematic review of outcome measures for NMD

This part of the TREAT-NMD project aims to catalogue existing Outcome Measures (OM). Outcome measures are tools used to assess change in a patient over time. They measure change in a way that informs collaborative decisions about treatment. By cataloguing these outcome measures researchers can more easily find existing OMs and more rapidly assess what they do and how they are administered. The work package also seeks to provide information, or links to information, that will support informed choice of OMs for NMD trials or studies.

To achieve this, we have developed an on-line Registry of Outcome Measures (ROM) which will identify existing Outcome Measures and provide descriptive information about each, along with links to more detailed information and contact details. Supporting web pages will cover topics such as such as guidelines for conducting systematic reviews of OMs, advice on selecting an appropriate OM, notes on consistent application of OM for data comparison purposes, and other Frequently Asked Questions.

This will enable those planning NMD clinical trials and studies to make an informed choice of OMs appropriate for their study. It may also increase harmonisation in the selection of outcome measures for clinical trials. The Registry is available on-line at www.researchrom.com

If you need help finding an outcome measure or to use the Registry, please contact the Registry Co-ordinator Joanne Auld at her email address: Joanne.Auld@iop.kcl.ac.uk

Biobanks

The basic scientific research being carried out on neuromuscular diseases relies on the availability of high-quality biomaterials (DNA, cells and tissue), while clinical trials rely on the availability of suitable patient cohorts. For new treatments to make their way into clinical practice for patients affected with neuromuscular disorders across Europe, it is essential that access to biomaterials is facilitated. The improvement of supranational biobanks and the introduction of European patient databases for DMD, SMA and other neuromuscular diseases are therefore major goals of this integrating activity within TREAT-NMD.

Before new, innovative therapeutic strategies can be applied to patients, scientists have to perform numerous pre-clinical experiments, including tests on biomaterials, such as muscle cells. The idea of a supranational biobank is to provide a network of biobanking facilities that will encourage the storage of biomaterials for NMD patients and help scientists to obtain more easily the specific material they need for their experiments on neuromuscular diseases. Therefore, one goal of TREAT-NMD is to improve the availability and the exchange of biomaterial among scientists across Europe, in collaboration with the already existing EuroBioBank network. This unique network of twelve biobanks from seven EU countries stores and distributes quality DNA, cell and tissue samples for scientists conducting research on rare diseases, including neuromuscular disorders. Set up by two patient organisations, now partners of TREAT-NMD, Eurordis (European Organisation for Rare Diseases) and AFM (Association Française contre les Myopathies), it has been administratively coordinated by Eurordis (http://www.eurordis.org), Paris, France, since its creation in 2001. You can find more information on the Biobank website: http://www.eurobiobank.org/en/services/CatalogueHome.jsp.html. This information is available in German, English, Spanish, French, Italian, Slovenian and Hungarian. If you know scientists or researchers in your country who are interested in this biobank training sessions can be organised upon request.

For Primary muscle cell culture (University of Munich in Germany) you can contact Dr. Sarah Baumeister: mtcc@med.uni-muenchen.de
For DNA extraction techniques (Second University of Napoli in Italy) you can contact Prof. Luisa Politano: luisa.politano@unina2.it
For other information please contact: contact@eurobiobank.org

Guidelines

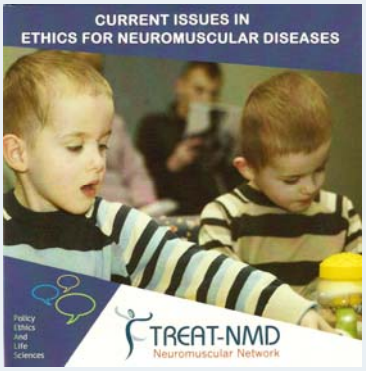
-Standards of care for neuromuscular diseases

TREAT-NMD is working with leading specialists worldwide to create international consensus on care and management for patients suffering from neuromuscular diseases. Receiving the best care can dramatically improve patients' quality of life and even prolong life expectancy. However, the relative rarity of the individual neuromuscular diseases means that until recently there has not been any consensus among doctors about how best to care for patients, and care standards differ not only from country to country but also even within individual countries. Not only does this impact on quality of life, it also makes clinical trials of promising new treatments much harder to carry out, because it is impossible to compare results from different centres if patients are cared for in different ways. You can find information on the standards of care on **SMA** and **Duchenne Muscular Dystrophy** on the TREAT-NMD website:

SMA Guidelines: http://www.treat-nmd.eu/patients/patient-care/sma/
DMD Guidelines: http://www.treat-nmd.eu/patients/patient-care/dmd/

- DVD - Current Issues In Ethics For Neuromuscular Diseases

Recently the Ethics working group of TREAT-NMD has made a DVD on ethical issues in neuromuscular diseases and clinical trials. This DVD is enclosed with this letter. Please let us know, if there is any feedback you would like to share with us on this DVD.



Successful first TREAT-NMD training course on Standards of Care in SMA and DMD

In February 2009, TREAT-NMD organised its first training course on Standards of Care in SMA and DMD in Budapest, Hungary. The aim of this kind of meeting is to offer various publics located in CEE countries the opportunity to join training courses given by specialists in SMA and / or DMD at a low cost. The audience (amongst others (paediatric) neurologists, geneticists, parents, patient organisations) during this first training course consisted of 43 trainees originating from 8 different CEE countries (Hungary, Romania, Serbia, Turkey, Macedonia, Croatia, Poland and Slovenia). The full article of the meeting can be found at http://www.treat-nmd.eu/healthcare/news/news/469/. A similar training course will be organized prior to the EAMDA Annual General meeting in September 2009. Further information on this training course will be published on the TREAT-NMD website in the near future. Please forward information on this training opportunity within your network.

Other publications of interest

- Scoliosis in Neuromuscular Disorders

Children with neuromuscular disorders with a progressive muscle weakness such as Duchenne Muscular Dystrophy and Spinal Muscular Atrophy frequently develop a progressive scoliosis. A severe scoliosis compromises respiratory function, makes sitting more difficult, and is perceived as unaesthetic. In order to optimize the treatment for neuromuscular scoliosis a Dutch guideline has been composed addressing conservative treatment, the preoperative, perioperative, and postoperative care of neuromuscular scoliosis. The guideline is based on scientific evidence and expert opinions. A high degree of consensus was reached about the management of patients with neuromuscular scoliosis. This was translated into a set of recommendations, which are now accepted as a general guideline in the Netherlands. This Dutch guideline has been published in *Scoliosis 2008, 3:14*. See for A Dutch Guideline for the Treatment of Neuromuscular Scoliosis: http://www.scoliosisjournal.com/content/3/1/14

- A Best Practice Guideline on: *'Wheelchair provision for children and adults with muscular dystrophy and other neuromuscular conditions'*. Topics in this essential guide include wheelchair considerations for different age groups, principles of seating, assessment guidelines, posture issues, specific features and functions and planning for different environments. To order a free copy of this publication from the Muscular Dystrophy Campaign in the UK you can call +44 20 7803 4800 or email to info@muscular-dystrophy.org

- 'The Voice of 12,000 patients – Experiences and Expectations of Rare Disease Patients on Diagnosis and Care in Europe'. Rare diseases, to which also neuromuscular diseases often belong, are often chronic, progressive, degenerative, life-threatening and disabling diseases. Many rare disease patients are denied their right to the highest attainable standard of health and continue to advocate their need to overcome common obstacles. Through the publication of this book, *"The Voice of 12,000 Patients"*, the patient's perspective can go beyond patients' anecdotes and be additionally represented by the analysis of data collected through two surveys. These surveys investigated patients' experiences and expectations regarding access to diagnosis and to health services, for a variety of significantly relevant rare diseases across Europe. On the pages 131 – 134, you can read information on Duchenne Muscular Dystrophy. This book can be downloaded fully or by sections from the Eurordis website at: http://www.eurordis.org/article.php3?id_article=1960

- The EuroGen guide Project, a website on genetics and related issues

EuroGenGuide is a 3-year project funded by the European Commission for Life Sciences and Biotechnology, as part of the Sixth Framework Programme for Research and Technological Development, and co-ordinated from London by the Genetic Interest Group. It started in January 2007 and will last for 3 years. The aim of EuroGenGuide is to provide accurate, high-quality information on the Internet about genetic testing and research in Europe, for use by all to whom information about genetics is relevant. EuroGenGuide particularly wishes to be able to provide knowledge and information to those regions and countries in Europe where knowledge of genetics and available treatment is still limited. In raising public visibility and awareness of genetic research and what it may be able to achieve in future, EuroGenGuide hopes to be able to contribute to maintaining the pace of this research and thus ensure that an increasing number of people affected by genetic disease can get the help and treatment they need. The EuroGenGuide website contains information about genetic testing, counselling and research across Europe. The information is intended as a resource for both patients and their families, and health professionals alike. You might be concerned that you or a relative may be affected by a genetic condition, or your doctor may have asked you if you would be prepared to donate biological samples to a DNA bank for use in research. Alternatively you may be a doctor with a patient who might have a genetic condition and requires a test, or you might be a genetic researcher carrying out a study. In these situations EuroGenGuide can help. Within the website you will be able to find comprehensive information for patients and the public, and also guidelines for health professionals. You can find EuroGenGuide at the following websites: www.eurogenguide.eu and www.eurogenguide.org.uk

Participation of patient groups in reviewing updates and reviews

TREAT-NMD and the Cochrane Neuromuscular Disease Group

The Cochrane Neuromuscular Disease Group is a group that carries out systematic reviews of treatments for neuromuscular diseases. We have worked closely in the past with the ENMC and are also part of the TREAT-NMD network.

We try to obtain comments from patient groups on both protocols (methods and objectives for reviews) and on full systematic reviews to try to ensure that they are relevant and accessible to patients as far as possible.

We are looking for patient representatives in the muscle disease are and in particular the following conditions: Spinal Muscular Atrophy, Muscular Dystrophy and Myotonic Dystrophy.

For many areas of management in neuromuscular disease reviews of the evidence base are lacking. For establishment of standards of care and for planning future trials, such reviews of the evidence are crucial. The Cochrane Collaboration has developed technology for doing this and the Cochrane Neuromuscular Disease Group has responsibility for reviewing the evidence of effectiveness of treatments in trials of neuromuscular disease.

Each review is developed in the same way: publishing a review protocol in advance, outlining the methods and objectives for the review, a comprehensive search for both published and unpublished randomized controlled trials in all languages, assessment of the quality of relevant trials, and if possible combining the results from several studies in a meta-analysis, a single numerical estimate of the efficacy of a treatment. The review then draws conclusions about the effectiveness of a particular treatment based on the available evidence and makes recommendations for the design of future research. All protocols and reviews are rigorously peer reviewed, revised and edited before publication. Cochrane reviews, unlike reviews published in print journals, are revisited regularly and updated at least every two years if new data become available. Part of the peer review process involves obtaining comments from patient organisations to ensure that the reviews address concerns that are relevant to patients and are accessible. We would like to involve more patient groups in our work and would like to invite you to participate in the peer review of reviews and updates being prepared as part of the TREAT-NMD programme of work.

If interested, please contact Kate Jewitt, Review Group Co-ordinator, Cochrane Neuromuscular Disease Group, cochranenmd@ion.ucl.ac.uk
For more information about the group visit: www.neuromuscular.cochrane.org

Send us your news and views!

We strongly encourage everyone to become a member of TREAT-NMD and to send their own news and updates and we will be happy to include them in future editions of the newsletter. Please send your contributions to emma.heslop@treat-nmd.eu