



The TREAT-NMD Members' Charter

On becoming a member of TREAT-NMD, members agree to abide by the following charter:

The Charter

1. About TREAT-NMD

1.1 TREAT-NMD exists to achieve the following main purposes:

- 1.1.1 To eliminate the fragmentation that currently exists in the neuromuscular field by harmonising research efforts across the community, from basic research to the development of new and cutting-edge therapies and treatments for patients, thereby advancing clinical trials for neuromuscular disease.
- 1.1.2 To inform and communicate network results and findings to the wider neuromuscular community, including patient organisations and industry.
- 1.1.3 To establish integrating activities that will address common problems, such as developing standards for diagnosis and care, harmonising international patient databases and biobanks and establishing a Clinical Trials Coordination Centre.
- 1.1.4 To train and educate scientists and clinicians with the aim of spreading excellence across the world.
- 1.1.5 To develop standardised protocols to assess the efficacy of novel therapies in the preclinical phase and establish the best animal models for the individual diseases; whilst evaluating outcome measures with the aim of standardising the best approach.
- 1.1.6 To draw up standardised procedures for the production of therapeutic agents and for their toxicology, quality and safety assessment.
- 1.1.7 To work with Industrial Partners to develop new and effective treatments for neuromuscular diseases.
- 1.1.8 Partners within TREAT-NMD are currently funded by FP6 and the Charter outlines the benefits and responsibilities of TREAT-NMD members under the current funding mechanism. As and when the legal status of TREAT-NMD is modified Members will be given the opportunity to sign a new Members' Charter agreement that will supersede this agreement, or terminate their membership. This new agreement may include a membership fee structure based on the nature of members and their organisation.
- 1.1.9 A "Partner" within TREAT-NMD is defined as an organisation or institution that has signed a contract with the EU, and received financial support, to undertake a specific task or workpackage and provide time-dependent deliverables to the Commission.

- 1.1.10 A “Member” within TREAT-NMD is defined as an organisation, institution or individual that agrees to sign this Charter and work with the Network to further advance the aims and objectives of the Network within their country of origin. The Member is not expected to sign the EU contract and will therefore, not receive financial support under the current EU contract.

2. Responsibilities of Members

- 2.1 Members must not, whether knowingly or negligently, act in a way which could discredit the TREAT-NMD Neuromuscular Network or lead to a possible loss of public confidence in it.
- 2.2 Members are strongly encouraged to promote TREAT-NMD actively in their country, such as the harmonisation of research approaches and dissemination of standards of care through utilisation of the communication strategy and infrastructure, e.g. TREAT-NMD web site, newsletter and acknowledgement of the network at meetings and conferences.
- 2.3 Members will be encouraged to endorse and use the outputs and resources of the network and agree to participate in group discussions regarding implementation with their national colleagues.
- 2.4 Members will be requested to submit data annually to the TREAT-NMD Coordination Office that provides information on their overall activities and contribution to the aims and goals of the network – this information will be circulated to the TREAT-NMD Governing Board. The data will be collected via a Members’ questionnaire circulated annually by the TREAT-NMD Coordination Office.
- 2.5 Members will not claim either to be a member of the TREAT-NMD Neuromuscular Network or to have used its resources or services without first adhering to this Charter.

3. Terms and Conditions of Web Site Use and Membership

- 3.1 As a member of TREAT-NMD you will agree to the following terms and conditions.
- 3.1.1 Once you have completed the application form and registered with the TREAT-NMD Coordination Office you will become a member of the TREAT-NMD Network and will receive a letter to confirm this.
- 3.1.2 Newcastle University currently owns all intellectual property rights on behalf of TREAT-NMD on the web site, such as copyright, design rights, and trademark on the TREAT-NMD logo and name, unless otherwise stated. You will be permitted to download copy or print any part of the web site, with the provision that it is solely for your own personal use and has no commercial bearing. The copyright to material published on this web site remains with the contributing authors and may not be reproduced without written consent of the author. To obtain permission, please contact the TREAT-NMD Coordination Office and specify the exact content you wish to reproduce and the intended purpose of use.
- 3.1.3 TREAT-NMD may terminate your membership of the network at any time by giving you 30 day’s written notice. Should you wish to terminate your membership please contact the TREAT-NMD Coordination Office.
- 3.1.4 TREAT-NMD cannot guarantee that the web site will be virus-free or run without interruptions beyond our control. We cannot guarantee the accuracy of the information.

- 3.1.5 We may introduce some periodic changes to the web site in order to improve our service to you. Should this happen, and our terms are modified, TREAT-NMD will assume your acceptance by your continued use of the web site and participation in network activities.
- 3.1.6 Members will receive access to all services outlined in the TREAT-NMD deliverable list*, except those restricted to Partners only, and the benefits therein. These services can be used internally within your own organisation or network, and externally when written permission has been obtained.
- 3.1.7 Any Member publications that result from involvement with TREAT-NMD must cite the network in the acknowledgements section and a copy of the final proof must be submitted to the TREAT-NMD Coordination Office.
- 3.1.8 Members may submit relevant questions to the network and will receive a considered and thorough response.
- 3.1.9 Members may cite their membership of TREAT-NMD in internal and external communications.
- 3.1.10 Members will be licensed to use the registered TREAT-NMD logo in their communication materials.

4. Governance

- 4.1 The TREAT-NMD Neuromuscular Network Governing Board is comprised of representatives from each of the 21 partner institutions, and meets approximately every six months.
- 4.2 The Governing Board is supported by four advisory councils: Science and Technological, Industrial Liaison, Intellectual Property Use and Dissemination, and Project Ethics.
- 4.3 Members may submit questions for suggested discussion by the Governing Board through the TREAT-NMD Coordination Office.

*Deliverable List for Members includes, but not limited to;

- Identify training opportunities in the network
- Issue calls for visiting scholars to partner institutions
- Ensure non-discrimination through gender, age, ethnicity or religion
- Reference document for evidence-based diagnosis of DMD
- Reference document for evidence-based diagnosis of SMA
- Ensure links with other resources available outside of TREAT-NMD
- Establishing a European patient registry for neuromuscular diseases
- Validation of animal models for pre-clinical studies
- Protocols and standard operating procedures for clinical studies
- Medical and ethical standards of care pertaining to clinical studies