

# Charter of the TREAT-NMD Membership Alliance

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## Document History

Charter document first drafted in August 2011. Charter reviewed and approved by TREAT-NMD partners, Task Force and Scientific Advisory Committee (STAC) members in December 2011.

Revised charter reviewed by TREAT-NMD Membership Alliance Executive Committee in March 2012. Charter revised to incorporate membership information, Charter approved by the TREAT-NMD Alliance Executive Committee in August 2012.

Charter amended and approved by the Executive Committee on 2<sup>nd</sup> October 2014.

Charter amended to reflect majority vote by Executive Committee to allow Executive Committee members to be employees of a pharmaceutical company or a not-for-profit venture philanthropy pharmaceutical company. Those members would be precluded from holding (Vice-) Chair positions on the Executive Committee. Charter approved by the Executive Committee [HM2] [T3] on 25<sup>th</sup> January 2016.

Charter revised to separate membership information and clarify term of EC positions. Approved by EC November 2017.

Charter amended as in need of updating and to include reference to TEC, TREAT-NMD Services Ltd & Alliance Ltd, plus other minor amends. Charter approved by the EC on 15<sup>th</sup> April 2020

## Background

Members of the Executive Committee were elected for an initial term of 3 years. The Executive Committee is supported by a Secretariat.

Since its launch in January 2007 the network's focus has been on the development of tools that industry, clinicians and scientists need to bring novel therapeutic approaches through preclinical development and into the clinic, and on establishing best-practice care for rare neuromuscular disease patients worldwide.

TREAT-NMD received EU funding in 2007. The initial network encompassed over 350 researchers and clinicians in 22 European organisations, and the network expanded to include a large number of collaborators not only across Europe, but around the world.

In 2010, the major outcome from a Public Consultation was the endorsement that TREAT-NMD should continue to deliver and develop its platform of tools and resources for the neuromuscular field. This includes:

- helping industry and researchers identify the centres that have capacity and experience to conduct trials via the **care and trial site registry** (CTSR)
- utilising our federated international **patient registry network** to coordinate **global feasibility enquiries** to assist with clinical trial planning, answering research questions, or other activities such as assessing standards of diagnosis and care
- utilising our federated international **patient registry network** to also identify patients to **recruit into clinical trials**, in accordance with study inclusion criteria
- providing access to **biobanks** containing patient samples,
- providing advice (and consensus) on appropriate **standard operating procedures** and **animal models**
- facilitating the selection of appropriate validated **outcome measures**
- offer guidance on overall development programmes via **TREAT-NMD Advisory Committee for Therapeutics** (TACT)
- facilitating the development, updating, translation and dissemination of lay versions of the **standards of care (family guides)** and monitor implementation of **standards of care**
- organising and hosting **international meetings and conferences** to update and educate the field on key issues
- working towards the discovery of **biomarkers**
- engaging with the **regulatory authorities**, representing the neuromuscular field on key issues
- debating **social and ethical issues** of importance to the field
- offering guidance and approval of training and education programmes via the **TREAT-NMD Education Committee (TEC)**

In June 2019 the TREAT-NMD Executive Committee approved the proposal for the incorporation of a TREAT-NMD corporate and legal entity, to fulfil the commercial, legal (and secretariat) functions of the TREAT-NMD Membership Alliance.

Two companies were incorporated in the UK in July/Aug 2019; TREAT-NMD Alliance Ltd (a 'not for profit' company limited by guarantee) and TREAT-NMD Services Ltd (the commercial 'Enterprise' – a wholly owned subsidiary of the Alliance Ltd). Both companies are legally independent of the TREAT-NMD Membership Alliance and have their own Articles of Association, with 3 Directors who are on the Executive Committee of the TREAT-NMD Membership Alliance. They govern the businesses and report to the TREAT-NMD Executive Committee. The function of these two organisations is to service the commercial and legal requirements of TREAT-NMD, provide Secretariat support and help the TREAT-NMD Membership Alliance to fulfil its strategic objectives.

Work will be done in 2020 to review the structure and relationship between the original TREAT-NMD Membership Alliance and the new TREAT-NMD Alliance Ltd, with a view to

integrating the two into one, in a way that is advantageous to all stakeholders and in keeping with the ethos of TREAT-NMD.

Further information regarding the TREAT-NMD Membership Alliance can be found on the website at [www.treat-nmd.org](http://www.treat-nmd.org)

## Article I – Organisation and Affiliation

- 1.1 This organisation is known as the TREAT-NMD Membership Alliance [*The Alliance*]. It is an independent, non-profit consortium of interested parties. The aim is to work together and provide a platform of tools and resources, that will support therapy delivery and accelerate translational research, to advance diagnosis, care and treatment for those living with rare neuromuscular disorders around the world, using the most efficient and effective means possible.
- 1.2 TREAT-NMD Services Ltd is the Commercial ‘Enterprise’ [*The Enterprise*] and is a wholly owned subsidiary of TREAT-NMD Alliance Ltd, which is affiliated to the TREAT-NMD Membership Alliance and manages its legal and commercial affairs.
- 1.3 The views of the TREAT-NMD Membership Alliance do not necessarily represent the views of the institutions and organisations with which members are affiliated

## Article II – Membership

- 2.1 Members of the TREAT-NMD Membership Alliance agree to sign a membership form and agree to work with the Alliance to further advance the aims and objectives of the Alliance
- 2.2 To apply for membership a completed membership form should be signed and submitted to the Secretariat of the TREAT-NMD Membership Alliance. Membership forms will be approved by the Executive Committee.
- 2.3 On becoming a member, members will receive a membership certificate and will be listed as a member on the TREAT-NMD website (name and location), unless requested otherwise. Members representing organisations may be required to provide their logo for the TREAT-NMD website.
- 2.4 An *Individual Member* of the TREAT-NMD Membership Alliance is defined as one person, either a patient, patient representative or an academic for example.

Individual members are entitled to:

- Discount on TREAT-NMD conference registration fees
- 20% discount to the Journal of Neuromuscular Diseases individual yearly subscription and 10% discount to Open Access fee for papers being submitted
- Opportunity to nominate yourself or nominate a TREAT-NMD member to fill a vacancy on the Executive Committee
- Vote on a number of TREAT-NMD matters [note: Individual Industry members, i.e. those who work for pharma companies, will not receive a right to vote on TREAT-NMD matters]

2.5 An *Organisation Member* of the TREAT-NMD Membership Alliance is defined as a business, patient organisation, pharmaceutical company or government body.

Organisation members are entitled to:

- Appear on the TREAT-NMD website to show they are affiliated with TREAT-NMD
- 20% discount to the Journal of Neuromuscular Diseases individual yearly subscription and 10% discount to Open Access fee for papers being submitted

2.6 Members should be aware that membership of TREAT-NMD does not afford or entitle the member (individual or organisation) to any of the following:

- To use of the TREAT-NMD name or logo as a mark of endorsement, affiliation or collaboration without the express permission of the TREAT-NMD Secretariat and Executive Committee.
- To approach companies or any other body to request funding for a project, under the auspices of TREAT-NMD, without the express permission of the TREAT-NMD Secretariat and Executive Committee.
- To complete work in the name of TREAT-NMD. If you, or your organisation, wishes to collaborate with TREAT-NMD, you should contact the TREAT-NMD Secretariat and/or approval of the Executive Committee.
- To any endorsement your organisation, event or conference etc. A request should be submitted to the TREAT-NMD Secretariat if you wish to have TREAT-NMD endorsement of an educational course, conference etc.
- To any guarantee of receipt of any training or educational courses within or outside of those organised by TREAT-NMD, which are open to all eligible delegates regardless of a TREAT-NMD membership.
- To receipt of any information regarding therapies, research etc. that would not ordinarily be made available to the public.

2.7 Members who wish to terminate their membership should contact the Secretariat of the TREAT-NMD Membership Alliance in writing by emailing [info@treat-nmd.org](mailto:info@treat-nmd.org) at any time. Membership will cease after 30 days from receiving the termination

request and the members' information will be removed from the web site within this period.

- 2.8 Members will have access to reports, including financial reports, newsletters, work plans and updates on activities.
- 2.9 Members must not, whether knowingly or negligently, act in a way which could bring the Alliance into disrepute or lead to a possible loss of public confidence.
- 2.10 If a member is found to have brought, or could possibly bring, the Alliance into disrepute then the member will be contacted by the Chair of the Executive Committee in writing to request an explanation of the reasons for their actions and how this can be resolved. The member will be given a period of 30 days to resolve the issue(s) or explain why they feel they have not contravened the obligations in Article 2.6. If the member does not comply then they will be asked to remove the TREAT-NMD logo and any other association from any publishable materials, i.e., websites, newsletters etc., and their membership will be terminated forthwith following a two-thirds vote of the Executive Committee members.
- 2.11 Members will not claim to be a member of the Alliance without first having signed the membership form referred to in Article 2.2.
- 2.12 Members must comply with all relevant known national and international data protection, privacy and ethical laws and guidelines.
- 2.13 Members should note that membership of the Alliance is distinct and should not be confused with, TGDOC Affiliation (the latter has its own charter for members)

## **Article III – Membership Meetings**

- 3.1 Membership meeting: The date of the membership meeting will be set by the Executive Committee who will also set the time and the place. The frequency of this will not be pre-determined and will likely take place at the TREAT-NMD Conference. This will be announced at least six months in advance.
- 3.2 Special meetings: Special meetings (either in person or virtual) may be called by the Executive Committee.
- 3.3 Notice of meeting agendas and supporting documents for each meeting will be given to each member, by (electronic) mail, not less than fourteen (14) days before the meeting, where applicable.

## **Article IV – Executive Committee**

- 4.1 The Executive Committee is responsible for providing overall policy and strategic direction to the TREAT-NMD Membership Alliance, oversees activities and progress, and delegates responsibility for day-to-day operations to the representatives of the various Activity Groups. The Executive Committee will also act as advisors to the Directors of the two incorporated TREAT-NMD not for profit organisations; TREAT-NMD Alliance Ltd & TREAT-NMD Services Ltd.
- 4.2 The Executive Committee will have no more than 13 and not fewer than 8 members. The Executive Committee receives no compensation other than reasonable expenses. Members of the Executive Committee are elected as private individuals and not representatives of their home institution or organisation.
- 4.3 At least 2 of the Executive Committee Members must be Directors of the TREAT-NMD Companies (TREAT-NMD Services & Alliance Ltd). Rules on conflict of interest within this Charter (see 4.5) and the company's Articles of Association, must be applied/adhered to.
- 4.4 Only individual members of the TREAT-NMD Membership Alliance can be elected into the Executive Committee and up to four of the Executive Committee will be elected from individuals nominated by patient organisation or advocacy groups. The remaining Executive Committee membership will be composed of academic members of the TREAT-NMD Membership Alliance. An 'Academic' representative is defined as follows:
- A person who has an academic post in a relevant discipline
  - A person who has substantial experience in the neuromuscular field
  - A person who can represent TREAT-NMD at scientific based NMD/rare disease conferences

A 'Patient' representative is defined as:

- A person who is actively involved in the activities of a neuromuscular disease patient organisation or,
- A neuromuscular disease patient

Individuals nominated to be elected into the Executive Committee may be employees of a pharmaceutical company or a not-for-profit venture philanthropy pharmaceutical company, but are precluded from holding (Vice)/Chair positions on the Executive Committee.

- 4.5 All Executive Committee Members must sign a Confidentiality Disclosure Agreement (for a term of five years) and annually complete a 'Conflict/Declaration of Interest' form. If any Executive Committee Member is found to have shared confidential information with a third party, or has an interest which conflicts with the ethos, mission or work of TREAT-NMD, their case will be taken to the Executive Committee

for review and consideration as to whether the Executive Committee Member should be removed from the Committee.

- 4.6 Elected Executive Committee members will be allocated a specific responsibility, (upon agreement with and at the discretion of the Chair) and will be expected to fulfil that obligation, in order to ensure that the Executive Committee as a whole fulfil the executive and strategic requirements of the TREAT-NMD Membership Alliance
- 4.7 The Executive Committee will meet at least annually, either in person or virtually, at an agreed upon time and place, in order to hold an Annual General Meeting.
- 4.8 Election of new Executive Committee members or re-election of current Executive Committee members to a second term will occur as the first item of business at the Annual General Meeting.
- 4.9 When a vacancy on the Executive Committee exists, Executive Committee members will be elected by a ranked vote of the current TREAT-NMD Membership Alliance members. Nominations for new members will be sought from current TREAT-NMD Alliance members only and must be received by the Secretariat two weeks in advance of an Executive Committee meeting. All nominations will then be sent out to the individual TREAT-NMD Alliance members to be voted upon and results announced at the next Executive Committee meeting. Only individual members (not organisations) are eligible to vote (excluding those employed by Pharmaceutical companies – see 2.4)). A separate ballot will be held for the patient organisation candidates and the academic candidates, as required. These vacancies will be filled only to the end of the particular Executive Committee member's term, or sooner in the event of a formal resignation or formal removal of and Executive Committee member
- 4.10 All Executive Committee members will serve 3 year terms, but are eligible for re-election at the end of their term (excluding Chair and Vice chair positions who are not eligible for re-election). An existing Committee Member can nominate themselves for re-election, if they wish to do so.
- 4.11 Executive Committee Members may step down sooner than the agreed term, if they wish, by tendering their resignation to the Secretariat, who will bring it to the attention of the Exec Chair/other Executive Committee members
- 4.12 A quorum must be attended by at least two thirds of the Executive Committee members before business can be transacted or motions made or passed.
- 4.13 An Executive Committee meeting requires that each Executive Committee member have written notice of the agenda at least one week in advance.
- 4.14 There will be two officers of the Executive Committee consisting of a Chair and Vice-Chair. Their appointment will be via nominations from within the Executive

Committee which will be collated, then Executive Committee members will vote anonymously, with the nominee who receives the majority of votes being appointed for each role. When only one candidate is nominated, the Executive Committee members will still vote, with the member appointed when receiving the majority of the votes.

[Note: The Chair of TGDOC and the TEC will also have voting rights equal to that of individual Executive Committee members]

Their duties are as follows:

- 4.14.1 The Chair will convene regularly scheduled Executive Committee meetings, will preside or arrange for the Vice-Chair or other members of the Executive Committee to preside at each meeting.
- 4.14.2 The Chair will serve a minimum 1 year term of office. This term can be extended for up to an additional 2 years by a two-thirds vote of the Executive Committee members, at the Annual General Meeting each year, (or sooner through the calling of an Extraordinary General Meeting, if required).
- 4.14.3 The Vice-Chair will serve a minimum 1 year term of office. This term can be extended for up to an additional 2 years by a two-thirds vote of the Executive Committee members, at the Annual General Meeting each year, (or sooner through the calling of an Extraordinary General Meeting, if required).

Unless the current Chair is re-elected for an additional 1 year term of office as described in article 4.13.2, the Vice-Chair will assume the role of Chair, and a new Vice-Chair will be sought from existing Executive Committee members. Nominations will be collated, then Executive Committee members will vote anonymously, with the majority of votes determining who will be appointed. This voting process will also apply, even if only one person is nominated.

- 4.14.4 Where possible, the Past Chair will remain until the Chair steps down. The Past Chair will provide a supporting role to the Chair/Vice-Chair and provide continuity to the Committee.
- 4.15 Resignation from the Executive Committee must be in writing and received by the Secretariat.
- 4.16 An Executive Committee member will be removed from the Executive Committee if they attend less than 33% of the regular Executive Committee meetings/or following an appeal, where a three-quarter vote of the remaining Executive Committee recommends removal.

- 4.17 An Executive Committee member may be removed for other reasons by a three-fourths vote of the remaining Executive Committee members following an appeal. All appeals must be submitted to the Chair of the Executive Committee on request.

## **Article V – Secretariat to the Executive Committee**

- 5.1 The Secretariat to the Executive Committee will be provided by Newcastle University, until such a time as these positions are transferred to the newly formed 'Commercial Enterprise' (TREAT-NMD Services Ltd) who will then take over the administrative and financial responsibility for this role.
- 5.2 The Chair of the Executive Committee will be provided administrative support to ensure efficient communication between the Chair, other members of the Executive Committee, the membership and the Secretariat.
- 5.3 The Secretariat will also be responsible for planning and delivering all meetings (virtual and in person) of the Executive Committee, as well as any other meetings deemed necessary by the Executive Committee.
- 5.4 The Secretariat will provide all supporting documentation and information to the Executive Committee at their regular meetings.
- 5.5 The Secretariat will be responsible for keeping records of Executive Committee actions, including overseeing the taking of minutes at all Executive Committee meetings, sending out meeting announcements, distributing copies of minutes and the agenda to the Executive Committee and members, and assuring that records are maintained.
- 5.6 The Secretariat will provide an ongoing advisory role to the Executive Committee and members, as well as administrative support, communications support (website, newsletter), and project management support where required and is dependent on sufficient funding available to support these roles.
- 5.7 The Secretariat is responsible for supporting the activities of the Executive Committee, coordinating the implementation of the strategic priorities, fiscal procedures, support the development of donations/fundraising and grant plans and providing annual activity and financial reports to the TREAT-NMD Membership Alliance members. The Executive Committee must approve the annual reports.
- 5.8 The Secretariat will also provide an annual office report to the Executive Committee, showing income, expenditures, justifications, and pending income, as well as describing the activities and financial status of the Secretariat. This report will be submitted by the Secretariat until such time as it is replaced with or incorporated into the annual report from the 'Commercial Enterprise' (TREAT-NMD Services Ltd)

- 5.9 The financial records of the TREAT-NMD Alliance are public information and will be made available to the membership, Executive Committee members and the public.

## **Article VI – Subcommittees and Advisory Boards**

- 6.1 The Executive Committee may create Subcommittees and Advisory Boards as needed, such as fundraising, membership, conference, etc.
- 6.2 The Executive Committee Chair appoints all Subcommittee and Advisory Board chairs upon agreement by the Executive Committee. All Subcommittees and Advisory Boards will report to the Executive Committee.
- 6.3 Advisory Boards will be required to report and provide recommendations to the Executive Committee based on the remit of the advisory board as defined by the Executive Committee.

These bodies include, but are not limited to:

### **6.4 TREAT-NMD Global Databases Oversight Committee (TGDOC)**

- 6.4.1 The TREAT-NMD Global Databases Oversight Committee (TGDOC) is the governing structure of the TREAT-NMD global databases on behalf of associated national and international TREAT-NMD registries according to the registry charter.
- 6.4.2 The TGDOC has a current Chair, Chair-elect and past Chair; with the Chair being elected bi-annually (as per TGDOC charter). Industry shall not be directly represented in the committee.
- 6.4.3 The current Chair of TGDOC will also have voting rights equal to that of individual Executive Committee members, for voting on Executive Committee matters.
- 6.4.4 The TREAT-NMD Global Registries are federated networks of local and national patient registries collecting data on patients with relevant neuromuscular diseases. Member registries collect a minimum standard core dataset, and can provide anonymised data to a single global database in the event of a global registry enquiry.
- 6.4.5 The TREAT-NMD Global Registries are governed by the TREAT-NMD Global Database Oversight Committee (TGDOC), which is a sub-committee of the TREAT-NMD Executive Committee and is chaired by a troika (consisting of the past chair, current chair and chair elect).

- 6.4.6 Disease-specific subgroups will support the TGDOC Chairs. Subgroup members will be invited from the appropriate disease-specific registries who comprise the wider TGDOC membership. Each subgroup should include a patient or patient representative, and will have one or two nominated lead members. Subgroup leads will join the TGDOC Chairs on their calls with the Secretariat on a quarterly basis, or as and when needed. Subgroup categories and membership will be reviewed and discussed if necessary at the annual TGDOC Registry Curators Meeting.
- 6.4.7 TGDOC membership is comprised of TREAT-NMD Registries and relevant members of the wider TREAT-NMD network (patient representatives, one Project Ethics Council representative, and the Care and Trial Site Registry) as detailed in this document.
- 6.4.8 All members of the TGDOC must have signed TREAT-NMD Confidentiality Disclosure Agreements and must update the disclosure statements on an annual basis. Members of the TGDOC will also be required to sign confidentiality agreements if a third party requests, them prior to having access to the inquiry of the third party.
- 6.4.9 The TGDOC Membership has its own TGDOC Charter. Please refer to this charter for specific details.

## **6.5 TREAT-NMD Advisory Committee for Therapeutics (TACT)**

- 6.5.1 The TREAT-NMD Advisory Committee for Therapeutics (TACT), is an expert multidisciplinary body that provides the neuromuscular community (clinicians, researchers, patient advocacy groups and industry) with independent and objective guidance on advancing new therapies (whether novel or repurposed) for neuromuscular diseases.
- 6.5.2 Its goal is to position the potential therapy along a realistic pathway to eventual clinical trial and registration by evaluating preclinical data as well as drug development considerations that are crucial for the conduct of studies that generate meaningful data.
- 6.5.3 The remit of the committee is to provide applicants with transparent and consistent guidance and advice, in an educational and directional context, on the readiness of drugs and/or therapeutic targets for trial. TACT advice will be helpful for preparing funding applications and investigational drug applications, while the publication of a non-confidential summary will ensure the TREAT-NMD Alliance and wider community receives expert feedback on the progress of the application.

- 6.5.4 TACT reviews also address issues of drug formulation, bioavailability and toxicology as well as possible regulatory requirements and marketing considerations.
- 6.5.5 TACT is also dedicated to providing information on rational and economical trial design. The ultimate goal of TACT is to help pave the pathway for successful drug registration by providing professional and independent advice.
- 6.5.6 The TACT committee convenes once every six months to consider selected applications. TACT will consider more than one drug at a time and therefore will have panels of experts, selected from the TACT members, reviewing the drugs concurrently, with the same chair and core committee for continuity.

## **6.6 TREAT-NMD Education Committee (TEC)**

- 6.6.1 TREAT-NMD recognised this need and created a range of masterclasses and a number of other education initiatives. The growing demand for these events led to the formation of the TREAT-NMD Education Committee (TEC). While the focus of TEC is on health care professionals, the Committee aspires to educate all stakeholders involved in the management and therapeutic development of NMD patients, including patients and families, industry colleagues and regulators.
- 6.6.2 Established in 2018, the TREAT-NMD Education Committee (TEC) is a board of experts (academics and patient representatives) who are affiliated with TREAT-NMD and have an interest in the education events and materials that TREAT-NMD produces. This group has overall responsibility for overseeing the quality, independence and appropriateness of all educational materials and activities created by, linked to or endorsed by TREAT-NMD.
- 6.6.3 The TEC provides endorsement for medical education in the form of meetings and events of the highest quality within the neuromuscular community, thus supporting the best and most up-to date patient care globally. In order to guarantee the endorsement of high-level education, the TEC will only endorse events if they meet our pre-determined criteria as laid out in the guidance form found on our website
- 6.6.4 The TEC has a Chair who is appointed by the core committee and serves a term of 2 years. The chair may be re-elected with no restriction on the term served.
- 6.6.5 The Chair of the TEC will also have voting rights equal to that of individual Executive Committee members, for voting on Executive Committee matters.

## 6.7 TREAT-NMD Project Ethics Committee (PEC)

- 6.7.1 The PEC is a high-level advisory group offering advice and guidance on the ethics and governance issues arising within TREAT-NMD
- 6.7.2 It will be the responsibility of the PEC to ensure that ethical practices are adhered to within TREAT-NMD Partners by monitoring the activities of the Governing Board who will have oversight of network activities.
- 6.7.3 Where appropriate the PEC, in conjunction with project partners, and any relevant external agencies will contribute to maintaining researchers' awareness of ethical issues.

## Article VII – TREAT-NMD Alliance Publication Policies and use of TREAT-NMD Logo

- 7.1 All publications involving work by members that was supported by the TREAT-NMD Membership Alliance (financially or in kind) should be acknowledged by the main author as described in article 7.2 of this charter and a copy of the publication should be forwarded to the Secretariat. Members are encouraged to use open source journals for publication whenever possible.
- 7.2 The TREAT-NMD Membership Alliance should be duly acknowledged in the acknowledgements section of the manuscript with the following text: “*This work has been supported by the TREAT-NMD Membership Alliance*”. If a journal policy complies and the Alliance contribution is deemed significant in accordance with publication good practice, it is recommended that the author line conclude with the statement “*in conjunction with the TREAT-NMD Membership Alliance*”\*. The asterisk (\*) refers to the TREAT-NMD web site address as a footnote on the first page of the manuscript ([www.treat-nmd.org](http://www.treat-nmd.org).)
- 7.3 Membership of TREAT-NMD does not automatically entitle the member (individual or organisation) to use the TREAT-NMD logo or state that TREAT-NMD endorses or is a partner with/to any individual or organisation.
- 7.4 Should any member wish to use the TREAT-NMD Logo, state in any promotional material/media that it is working in partnership, or wish to have themselves or any of their products or services endorsed, this can only be done through specific approval by the TREAT-NMD Executive Committee or associates sub groups.

In order to achieve approval, the member must submit a ‘specific request’ to TREAT-NMD detailing the type of request, the purpose of the request and how the relationship with TREAT-NMD will be promoted.

- 7.5 Each request received will be reviewed and a response made to the member making the request. Only upon receipt of formal approval can the member use the TREAT-NMD Logo, state any affiliation or partnership with TREAT-NMD or claim endorsement of any products or services.

## **Article VIII – Conflict of Interest Guidelines**

- 8.1 The TREAT-NMD Membership Alliance wishes to promote independence, objectivity and a fair balance of representation, in all its activities. As such, members of the TREAT-NMD Membership Alliance should maintain the highest personal and professional standards in conducting activities. TREAT-NMD Membership Alliance members have an obligation to act in the public interest and in the interests of the TREAT-NMD Membership Alliance, its stakeholders and the rare disease communities that it represents
- 8.2 Members of the Executive Committee, of the Secretariat and of Advisory Boards and Subcommittees (where applicable), are expected to disclose any potential Conflicts of Interest, such as their financial or in-kind relationships with their organisations, industry and any other groups or bodies that could represent a potential conflict of interest with TREAT-NMD and its associated activities. Full disclosure is expected even when it is not clear whether a relationship or affiliation constitutes a conflicting interest, so that the Executive Committee as a whole can decide.
- 8.3 The TREAT-NMD Membership Alliance recognises that these relationships do not necessarily imply bias or decrease the value of participation in professional activities.
- 8.4 Disclosure of these relationships is necessary for others to make an informed decision about the impact of the disclosed relationship.
- 8.5 All relationships over the previous three years (including future commitments which are foreseen over the coming year) must be disclosed.
- 8.6 Executive Committee members, Secretariat members, Advisory Board and Subcommittee members are required to undertake the following Disclosure Process:
- 8.6.1 The completion of a Declaration of Interests form as part of the application to their role within the TREAT-NMD Membership Alliance Committee/Boards etc. (or when a new version of the Disclosure of Interests form is released)
- 8.6.2 Renewal of their disclosures by completion of a Disclosure of Interests form, on an annual basis.

8.6.3 Informing the Executive Committee of any *New* potential conflicts of interest that may arise during these periods (above).

8.7 Any Declaration of Interests disclosed will be reviewed by the Executive Committee to ascertain the level of conflict and the impact this may have on the TREAT-NMD Membership Alliance and its associated activities. This review process will result in a voting poll amongst the Executive Committee whereby a quorum of at least three-fourths of the Executive Committee must vote and a two-thirds majority of the voting Executive Committee must agree on the outcome.

If the outcome determined is that the conflict of interest is sufficient enough to be detrimental to the TREAT-NMD Membership Alliance and its associated activities, then the individual involved will be asked to either cease the activities giving rise to the conflict of interest or withdraw from their role within TREAT-NMD Membership Alliance (Note: this will not preclude them from remaining as an individual member of TREAT-NMD)

8.8 Any form of appeal on the decision, must be put in writing to the Chair of the TREAT-NMD Membership Alliance, within 14 days of notification of the decision. The Chair will then review the appeal with the Executive Committee, who will again vote on the FINAL decision (utilising the same voting process as in 8.6)

## **Article IX – Date of Activation of Charter and Interim Officers**

9.1 When approved by at least two-thirds of the votes cast by the Executive Committee, this Charter will become active and adopted at the time of the business meeting. It will thereafter be displayed on the TREAT-NMD Website for members (and others) to view.

## **Article X – Amendment of Charter Statement**

10.1 This Charter may be amended when necessary by a two-thirds majority of the Executive Committee. A quorum of at least three-fourths is required. Proposed amendments must be submitted to the Secretariat to be sent out with regular Executive Committee announcements.

## **Article XI – Dissolution of the TREAT-NMD Membership Alliance**

- 11.1 The dissolution of the TREAT-NMD Membership Alliance will be decided by an affirmative vote by written ballot of three-fourths of votes of the members of the TREAT-NMD Membership Alliance. The procedure on dissolution will follow that outlined for proposing amendments in Article X (above).
- 11.2 If the TREAT-NMD Membership Alliance is wound up, all of the Alliance's assets which would otherwise be available to its members generally shall be transferred on its winding up either to another body with objects similar to that of the Alliance or to another body, the objects of which are the promotion of charity and anything incidental or conducive thereto (whether or not the body is a member of the Alliance).

This revised Charter was approved following a meeting and vote of the Executive Committee of the TREAT-NMD Membership Alliance on 15<sup>th</sup> April 2020