



# **LONDC Steering Committee Governance**

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## 1. Document Purpose

The purpose of this document is to outline and define the Late-Onset Neuromuscular Disease Consortium Steering Committee's (LONDC-SC) governance, structure, and operations.

## 2. LONDC-SC Considerations & Objectives

- Clearly defined governance is a key indicator of a well-functioning consortium
- LONDC-SC members will have different priorities and interests that will need to be reconciled
- The governance structure outlined in this document will be available for community feedback

The LONDC-SC will provide ongoing strategic direction to the Late-Onset Neuromuscular Disease Consortium (LONDC).

## 3. The role of the LONDC-SC

- Act as an advocate for the LONDC and its initiatives
- Provide input on project selection as well as strategic direction, goals, and scope
- Guide and oversee project execution, recommending adjustments as needed
- Support identification and selection of consultants or partners that may be required

## 4. Key Principles

The LONDC-SC is committed to the following principles to ensure a fair, equitable, and effective approach to scoping and execution of LONDC's work:

- Participation and representation of stakeholders to deliver effectively on the LONDC mission
- Transparency in decision-making and implementation
- Establish criteria for measuring/meeting milestones
- Establish a charter that outlines expectations for each project
- Consider the formation of one or more subcommittees as needed

## 5. Membership and Designation

The Committee shall consist of 10 core members. Members are determined by the American Neuromuscular Foundation (ANF) and must be knowledgeable in the field of neuromuscular conditions or related areas. Committee delegates commit to a 12-month term, which renews annually until the delegate or the ANF discontinue their participation in the Steering Committee, or the Steering Committee or the LONDC ceases to exist.

- **Committee Delegates:** Participating organizations will appoint a board member, staff member, or organization volunteer as a committee delegate. Committee delegates put forward by participating organizations will need to be approved by the ANF to become official LONDC-SC members.
- **Committee Facilitator:** Delegate from SmithSolve as contracted by the ANF to manage execution of LONDC projects and meetings and perform administrative functions. The Committee Facilitator will be a part of the LONDC-SC and will present recommendations to the ANF Board for approval.

Changes needed prior to the end of a 12-month term will be addressed by the Committee on an as-needed basis.

## 6. Frequency of Meetings

- LONDC-SC meetings shall be held approximately 2-4 times a year; 2-3 virtual and 1 hybrid (in-person/virtual) meeting at the annual AANEM meeting or at the spring Board Meeting
- Meetings shall be open to all LONDC-SC members
- Notice of all LONDC-SC meetings will be issued via email

## 7. ANF Board & Independent Experts

LONDC-SC membership will include leaders of advocacy organizations in the neuromuscular space and will include input from industry and medical advisors on an ad-hoc basis. All recommendations put forward by the LONDC-SC will need approval from the ANF Board.

A subcommittee(s) may be derived as needed to address specific issues or projects. Subcommittees may make preliminary recommendations to the LONDC-SC regarding specific issues for subsequent action by the full LONDC-SC.

## 8. Member Role and Expectations

- Commit to attending the majority of LONDC-SC meetings
- Review and provide timely feedback on materials and programs, as requested
- Actively and meaningfully engage in Consortium activities
- Offer skills, experience, and knowledge as needed to Consortium
- Contribute in a respectful and constructive manner
- Respect Consortium confidentiality without sacrificing transparency

## 9. Compensation

Participating organizations of the LONDC- SC members will be provided an honorarium to the organization in recognition of their time in the amount of \$2,000 per year.

## 10. Recordkeeping

Committee Facilitator will be responsible for:

- Recording the minutes of each meeting
- Managing the master set of minutes, agendas, and working papers

## 11. Intellectual Property & Confidentiality

The ANF shall own any and all intellectual property including copyright in any material created by members involved in the LONDC-SC. Participating organizations will have the ability to utilize material created by the LONDC with permission from the ANF and appropriate acknowledgment of the ANF.