American Neuromuscular Foundation

LONDC

Late-Onset Neuromuscular Disease Consortium

LONDC Progress Report

Year End 2025

American Neuromuscular FOUNDATION®

INTRODUCTION

The Late-Onset Neuromuscular Disease Consortium (LONDC) has made remarkable strides and continues its mission to unite the community and foster collaboration that enhances care, education, and quality of life for individuals affected by late-onset neuromuscular diseases (LONDs). In 2025, we advanced our first project to its launch phase while strengthening partnerships and expanding our reach.

Purpose of the LONDC

The LONDC is dedicated to addressing the unique needs of individuals living with neuromuscular conditions that typically manifest in adulthood. We support multiple conditions in this category and aim to improve outcomes through shared knowledge, advocacy, and coordinated action.

STEERING COMMITTEE

Our Steering Committee is comprised of representatives from leading advocacy organizations that serve individuals impacted by neuromuscular conditions. We are deeply grateful for their guidance, commitment, and expertise. Current member organizations include:

The ALS Association

GBS | CIDP Foundation International

Hereditary Neuropathy Foundation

Kennedy's Disease Association

The Lambert-Eaton LEMS Family Association

Myasthenia Gravis Association

Myositis Support & Understanding

Neuromuscular Disease Foundation

Pompe Alliance

REDUCING DELAYS TO DIAGNOSIS – CLINICAL AND CONSUMER TOOLS POISED FOR LAUNCH

The LONDC inaugural project is ambitious. We hypothesized that by analyzing commonalities in early signs and symptoms across LONDs we could:

1. Identify a set of signals that would be highly indicative of an LOND.
2. Create tools for clinicians and patients that would aid in earlier detection and streamline the referral to neuromuscular specialists.

Phase 1, which focused on the research and tool development, is nearing completion, and the Phase 2 effort to launch and distribute these materials will kick off in early 2026.

2025 ACHIEVEMENTS

Consensus on Clinical Tool Supporting Recognition & Referral of LONDs

We completed primary research with physicians and patient communities in 2024 and leveraged this to develop a draft clinical tool. We then collaborated with neuromuscular key opinion leaders to refine the tool's framework, content, usability, and design. Upon developing a full draft, we took the tool to a broader group of physicians to secure additional feedback and refine further through a virtual consensus process.

Consensus Process

We recruited a virtual panel of 32 US-based neuromuscular specialists from both neurology and physical medicine rehabilitation, of which 27 panelists completed the consensus process*. The panel balanced years of clinical experience, gender, and other demographics.

The process used a modified Delphi methodology via multiple rounds of an anonymous online survey. The survey presented a version of the tool and secured self-reported level of agreement and qualitative input on whether the tool:

- Provides clinically meaningful information that will improve the ability of primary care physicians (PCPs) and advanced practice providers (APPs) to identify individuals with LONDs.
- Increases the likelihood of timely referrals of individuals suspected of having a LOND, from PCPs, APPs, and community-based neurologists to neuromuscular specialists.
- Improves the completeness and accuracy of referrals from PCPs, APPs, and community-based neuromuscular specialists of patients suspected of having LONDs.
- Practically and realistically can be embedded into primary care and neurology practice workflows to accomplish the stated goal of early identification of patients with LONDs.

We refined the tool based on recommendations and concerns gathered via each consensus round. We also conducted live review meetings with neuromuscular specialists and held a two-hour focus group with five advanced practice providers to ensure clarity, usability, and workflow integration of the tool.

After two rounds, we achieved over 80% consensus agreement across the four dimensions of the tool's content and utility, and an overall agreement average of 95%. Agreement was defined as a rating of 6 or 7 on a 1-7 scale (1=strongly disagree and 7= strongly agree).

Foundational research completed in 2024:

- More than 60 US-based interviews with patients across 14 LONDs to capture first-hand experience with early signs and symptoms.
- Insights from 120 clinician surveys (40 advanced practice, 40 primary care, and 40 community-based neurologists) to identify diagnostic challenges and referral barriers.
- Synthesis of key opinion leader clinical observations and literature, to form a symptom catalogue.

**Panel assembled with 32 physicians, 30 completed round 1 review, and 27 completed round 2 review.*

Consumer LOND Awareness Campaign

In parallel with the efforts focused on the clinical tool, we developed early creative concepts for a public-facing awareness campaign. The campaign aims to educate consumers broadly on LOND symptoms and encourage self-advocacy and action. Campaign concepts were introduced at the 2025 LONDC Annual Meeting where clinicians and community members had the opportunity to evaluate their effectiveness and provide feedback for further refinement.

MAXIMIZING VISIBILITY AND UTILITY OF NEW RESOURCES

Communication Plan

We will launch both the clinical tool and consumer awareness campaign in 2026 via a dedicated website, making these resources and information about LONDs more widely available.

The effort will be supported by a robust, ongoing communications strategy. The goal is to educate, raise awareness, and promote the availability and use of these resources across the community and relevant stakeholders for years to come.

Pilot Program

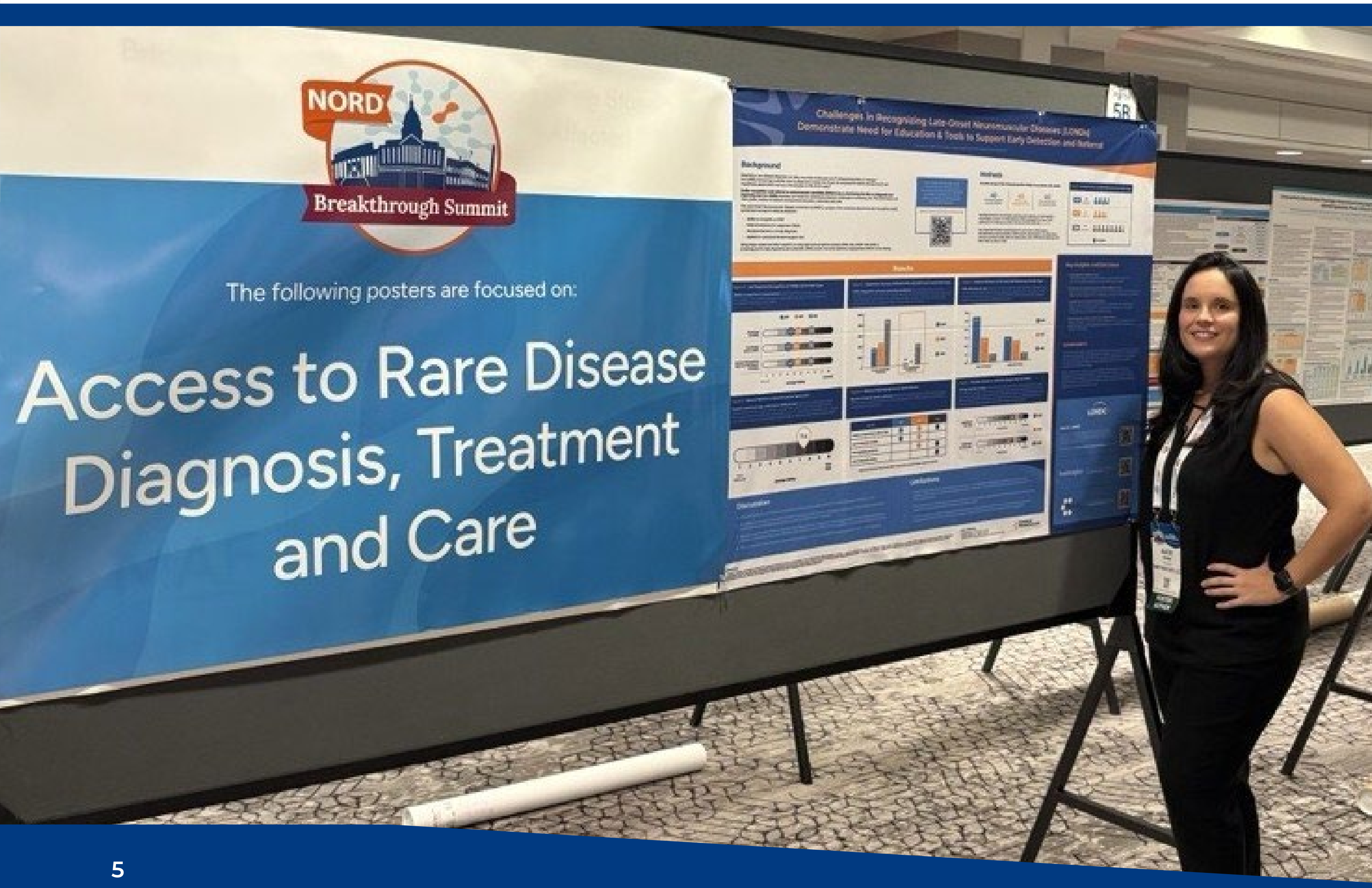
We are in the early stages of identifying partner clinicians and institutions interested in piloting the clinical tool in real-world practice settings. We will design a program for practices to distribute, train, and use the clinical tool, and gather feedback on its usability, effectiveness, and referral quality.

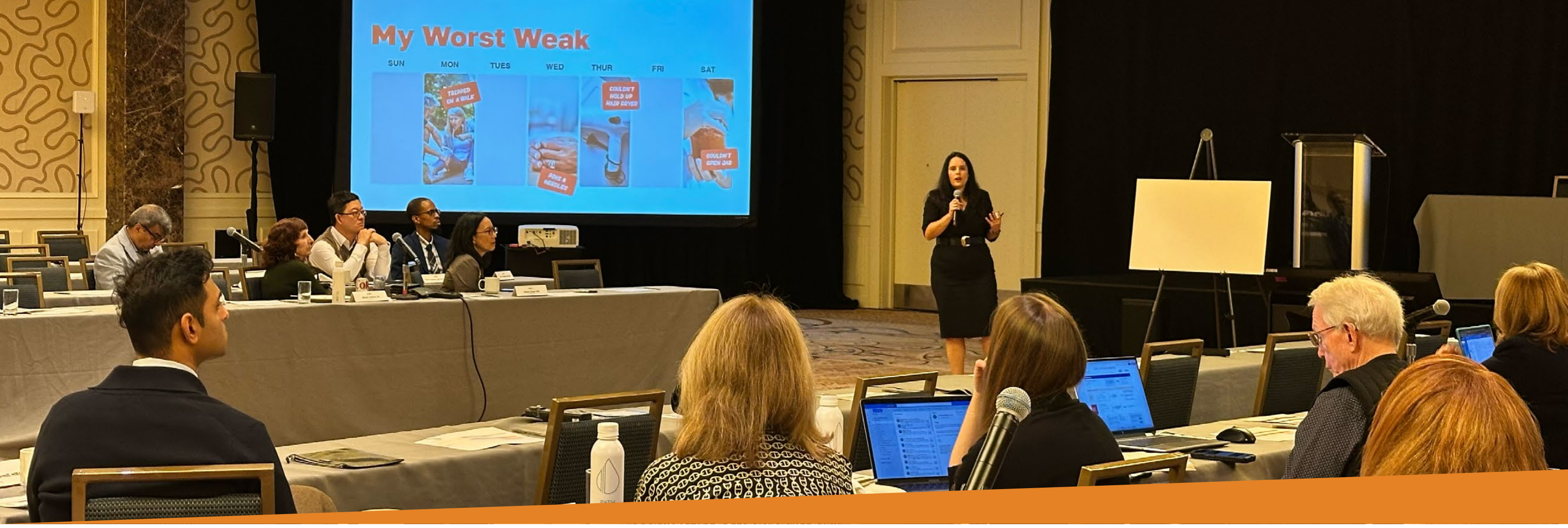
EMR Integration

We are sourcing case examples and exploring partnerships to lay the groundwork for a plan to integrate our findings and guidance into electronic medical records. We appreciate the importance of a tool that is integrated into practices' digital workflow, and are assessing the steps to make that happen as a future phase of the project.

RAISING AWARENESS AND BUILDING SUPPORT AMONG RARE NEUROMUSCULAR COMMUNITIES FOR THE LONDC

- **NORD Breakthrough Summit:**
  - Presented a poster in October at the NORD Breakthrough Summit: *Challenges in Recognizing Late-Onset Neuromuscular Diseases (LONDs) Demonstrate Need for Education & Tools to Support Early Detection and Referral.*
- **AANEM Annual Meeting:**
  - Shared an encore presentation of the NORD poster at the AANEM Annual Meeting to broaden awareness among neuromuscular specialists.
- **MDA Clinical & Scientific Conference:**
  - Secured an exhibit table at the upcoming MDA conference in March 2026, where we will debut the launch of the clinical tool and consumer campaign.





NEXT STEPS

As we reflect on the progress the LONDC made in 2025, we recognize that our work is only just beginning. The foundation we have built through research, tool development, and community engagement sets the stage for meaningful impact in the years ahead. Moving forward our priorities include:

- **Launching the clinical referral tool and consumer awareness campaign** with coordinated communications across healthcare providers, patient communities, and advocacy organizations.
- **Publishing a manuscript** on the LONDC's project and development of the clinical tool.
- **Piloting and refining the clinical tool** in real-world settings to optimize usability and effectiveness.
- **Expanding awareness and education around LONDs** through conferences, publications, and advocacy partnerships.
- **Strengthening partnerships and sponsorships** to sustain and grow our initiatives.
- **Identifying and prioritizing** future projects for the LONDC.

The LONDC remains committed to uniting stakeholders, driving innovation, and improving the lives of individuals affected by LONDs. With the collective strength of our Steering Committee, sponsors, partners, and community members, we are excited to continue to advance our work in 2026 and beyond.

LONDC 4TH ANNUAL MEETING

Held in San Francisco on October 28, 2025, ahead of the AANEM Annual Meeting, the LONDC's 4th Annual Meeting convened clinicians, patient communities, and industry representatives. Highlights included:

- Introduction of the clinical referral tool
- Feedback on consumer awareness campaign concepts
- Presentation of LONDC research findings in our first poster
- Updates from Steering Committee members on priority initiatives and upcoming projects

This annual gathering continues to be a cornerstone for collaboration and shared progress across the LOND community.

CONTRIBUTORS

The following individuals are a part of the LONDC Steering Committee:

- **Rich Brennan, MA,** *Vice President, Federal Affairs, The ALS Association*
- **Lisa Butler,** *President & CEO, GBS | CIDP Foundation International*
- **Allison Foss,** *Executive Director, Myasthenia Gravis Association*
- **Manuel Lubinus, PhD,** *Chief Science Officer, Myositis Support & Understanding*
- **Allison Moore,** *Founder, CEO, Hereditary Neuropathy Foundation*
- **Kristen Russell,** *Patient Representative and Volunteer, The Lambert-Eaton LEMS Family Association*
- **Heather Shorten, MSW, LSW,** *Founder and Executive Director, Pompe Alliance*
- **Terry Thompson,** *President, Kennedy's Disease Association*
- **Tara Voogel,** *Patient Advocate Program Manager & Blogger, Neuromuscular Disease Foundation*

The following physicians have actively contributed to the LONDC initiatives:

- **Anthony Chiodo, MD, MBA,** *University of Michigan Health (AANEM Historian)*
- **Raghav Govindarajan, MD,** *HSHS Elizabeth's Hospital*
- **Ali Habib, MD,** *University of California Irvine (UCI) Health*
- **Holli Horak, MD,** *University of Arizona*
- **Ileana Howard, MD,** *University of Washington School of Medicine*
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- **Dianna Quan, MD,** *UCHealth University of Colorado Hospital (AANEM Past President)*
- **Devon Rubin, MD,** *Mayo Clinic (AANEM Secretary/Treasurer)*

AANEM/ANF Representatives

- **Shirlyn Adkins, JD,** *Executive Director*
- **Rita Hawkins,** *Senior Development Manager*

Partners

- **Engage Health, Inc.**
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