






The Late-Onset Neuromuscular Disease Consortium (LONDC) is in the midst of its first project, the **Common Experience Research and Awareness Campaign**. The goal of this project is to speed time to diagnosis for people with late-onset neuromuscular diseases (LONDCs) through earlier referrals to the right specialists.

## Project Plan for Phase 1

 <b>Preparation</b>	<ul style="list-style-type: none"> <li>• Hold informational interviews with LOND community to review and align on Phase 1 plan</li> </ul>
 <b>Research</b>	<ul style="list-style-type: none"> <li>• Interview patients to capture symptom presentation and language</li> <li>• Survey physicians to identify barriers to specialist referrals</li> <li>• Analyze and combine results for consensus building</li> </ul>
 <b>Consensus Building</b>	<ul style="list-style-type: none"> <li>• Review information and gain consensus on common symptoms and physician-focused tool with KOLs, patients, and other stakeholders through a series of meetings</li> </ul>
 <b>White Paper</b>	<ul style="list-style-type: none"> <li>• Develop a manuscript to present findings, including physician-focused tool to better recognize LONDCs or when to refer a patient with a potential LOND to a neuromuscular specialist</li> </ul>
 <b>Mnemonic</b>	<ul style="list-style-type: none"> <li>• Create a consumer-focused mnemonic to help people identify symptoms and empower them to request a referral</li> </ul>

## 2025 Project Focus

The first phase of the project is designed to culminate in a peer-reviewed publication and tools that will be the foundation of an awareness and education campaign. In 2025, the LONDC is focused on refining and securing consensus on the symptom-based decision-making tool with clinicians and community leaders and developing the white paper.

The LONDC relies on sponsorships and grants to continue advancing this important work and to ensure a sustainable future for the consortium.

Contact us at [LONDC@neuromuscularfoundation.org](mailto:LONDC@neuromuscularfoundation.org) to learn how **your organization can take part in collaborative efforts** to address the unmet needs of individuals affected by LONDCs.