



The Late-Onset Neuromuscular Disease Consortium (LONDC) has begun 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 (LONDs) through earlier referrals to the right specialists.

The first phase of the project is designed to culminate in a white paper and two tools: a symptom-based decision-making tool for physicians to better recognize or identify when to refer a patient with a LOND to a neuromuscular specialist; and a consumer-focused tool to help a person identify key symptoms and empower them to request a referral.

Project Plan for Phase 1 (~18 months)

Preparation

- Hold informational interviews with LOND community to review and align on Phase 1 plan

Research

- Interview patients to capture symptom presentation and language
- Survey physicians to identify barriers to specialist referrals
- Analyze and combine results for consensus building

Consensus Building

- Review information and gain consensus on common symptoms with KOLs, patients, and other stakeholders through a series of meetings

White Paper

- Develop a manuscript to present findings, including physician-focused tool

Mnemonic

- Create the consumer-focused mnemonic

Contact us at LONDC@neuromuscularfoundation.org to learn how **your organization can take part in collaborative efforts** to address the unmet needs of individuals affected by LONDs.

londc.neuromuscularfoundation.org