



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 peer-reviewed publication and two specific tools that will be the foundation of an awareness and education campaign: 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 mnemonic to help a person identify symptoms and know when to ask for a referral.

Project Plan for Phase 1 (~18 months)

1. Preparation*

- Host webinars with LOND community to review plan
- Source publication list for literature review from KOLs

2. Literature Review

- Conduct literature review, extract a symptom catalog for each disease state, and analyze common symptoms across all

3. Patient Interviews

- Conduct interviews to capture patient language and presentation of common symptoms
- Field survey to physicians
- Combine all feedback for consensus process

4. Consensus Building

- Review information and gain consensus with KOLs and patients through a series of meetings and workshops

5. Publication

- Develop a manuscript to present findings and secure publication in a peer-reviewed journal

6. Mnemonic

- Create a consumer-focused mnemonic that will serve as the foundation for the forthcoming education and awareness campaign

*The LONDC is in the **Preparation** portion of the project

[Contact us](#) to learn how **your organization can take part in collaborative efforts** to address the unmet needs of individuals affected by late-onset neuromuscular diseases.

londc.neuromuscularfoundation.org