

SOLVE M.E. LONG COVID PATIENT LEADERSHIP ADVANCEMENT NETWORK (LC-PLAN)

Background

Recent data shows that nearly one in five (19%) of adults in the United States that reported having COVID-19 are currently experiencing symptoms of long COVID (LC). Overall, 1 in 13 (7.5%) of the adult US population have LC symptoms, which are defined as new or worsening symptoms lasting three or more months after first contracting the virus. This presents the potential for a mass-disabling event and must be a central feature of the continued pandemic response. While patient-centered research has been at the forefront of research into the causes and potential therapeutic interventions of LC, there remains an urgent need to develop a robust engagement approach that allows for the integration of lived experience in all phases of the research process.

Purpose

To address this need, with the support of the Chan-Zuckerberg Initiative, Solve M.E. will form the Long COVID Patient Leader Advancement Network (LC-PLAN). This groundbreaking program invests in the development of LC community leaders by creating a patient-focused training program designed to prepare a network of patients and caregivers for advisory research roles and enhance patient engagement in LC research. The LC-PLAN leadership committee of patients and experts will develop, monitor and make recommendations for the improvement and refinement of the training program. The program will ultimately create a network of empowered patient-advocates, a targeted research agenda, and a researcher guide for working with LC patients. These critical tools will provide urgently needed guidance on achieving patient-centered research in the Long Covid research realm.

Goals

- Develop a LC patient-centered, open source training program
- Train 135 participants through the program
- Maintain a network and connect graduates with advisory opportunities
- Develop and disseminate patient-preferred resources and materials for integration into the LC research agenda

JANUARY - JUNE 2023

- Establish project leadership committee of patients and experts
- Develop a 8-10 module training curriculum
- Create a facilitator quick reference guide for each module
- Complete a 2-week pilot training session

JULY 2023 - JUNE 2024

- Collect feedback and finalize training materials
- Make training materials publicly available
- Recruit and train 3 cohorts through 14-week program
- Host a graduation event

JUNE 2024 ONWARD

- Maintain a network of graduates
- Identify opportunities for community representation
- Connect graduates to key scientific and government conferences
- Facilitate a convening of graduates and experts to create a:
 - Targeted Long COVID research agenda
 - Core set of patient-reported outcomes
 - Researcher guide for working with Long COVID patients



Solve M.E.