SOLVE M.E. LIVED EXPERIENCE TASKFORCE

The Lived Experience Taskforce (LET) will serve as leadership partners with Solve M.E. This partnership will be based on the principles of meaningful community engagement where equity is our goal and expectation. LET partners — many from historically under-engaged communities — will improve our ability to deliver responsive services, programming, training and technical assistance to organizations and other partners affected by ME/CFS and Long Covid. LET partners will be equitably compensated for their time and lived experience expertise.





Purpose

Lived experience helps to develop a deeper understanding of the conditions affecting certain populations, the solutions that are most appropriate for those impacted by the issue, and the potential harmful unintended consequences of the current and past actions taken by the existing system on the people it aims to serve. Solve intends to involve LET partners throughout the entire decision-making process, including at the conceptualization, implementation, and evaluation levels to the fullest extent possible.

Shared Leadership

- The lived experience expertise of our community partners will be held in the highest regard, respected and considered equally with technical expertise from our research partners.
- We will recognize and examine disparities in power that exist among our organization, technical experts and individuals with lived experience.
- We will work collaboratively to share power by ensuring individuals with lived experience not only have a seat at the table but also can meaningfully contribute to decision-making throughout the full lifecycle of our programs.
- We work to proactively ensure historically excluded populations can meaningfully participate in opportunities to lend lived experience expertise to Solve M.E.
- We will ensure thoughtful, intentional, and inclusive engagement with lived experience task force partners.
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 BY ME AND LONG
 COVID **POSITIONS OR ACTIONS FOR** SOLVE INCLUSIVE OF TIMELINES FOR **ACTION ADVISING ON** DISSEMINATION OF CULTURALLY APPROPRIATE **IDENTIFYING VOLUNTEERS INFORMATION** /STAFF TO TO PRIORITY FILL SPECIFIC ORGANIZATIONS **NEEDS** AND PEOPLE AFFECTED Solve M.E. LIVED EXPERIENCE TASK FORCE **PROVIDING IMPROVEMENTS** RECOMMEND **FOR EXISTING ATIONS FOR SOLVE NEW SOLVE PROGRAMS PROGRAMS GRANT REVIEW** RECOMMENDATIONS **FOR FUNDING BY** SOLVE

• We will allocate resources to equitably compensate people with lived experience commensurate with their role in the engagement.

Targeted Recruitment

We are actively seeking community partners who are:

- Partners affected by myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS); these partners can be patients or caregivers
- Partners affected by Long Covid and associated conditions; these partners can be patients or caregivers
- Partners from communities that have been historically economically and/or socially marginalized and are currently affected by ME/CFS or Long Covid