

Solve M.E. Awarded Grant From Chan Zuckerberg Initiative to Support Patient Engagement in Long Covid Research

New program will address disease disparities and bridge the gap between Long Covid research and patient needs

LOS ANGELES, CA – Today, [Solve M.E.](#) announced it is the recipient of significant grant funding from the [Chan Zuckerberg Initiative \(CZI\)](#). With the \$247,500 in funding, Solve M.E. will develop a groundbreaking program that will train a network of patient leaders, scientists and other stakeholders with diverse backgrounds to enhance patient engagement in Long Covid research. These trained patient representatives will ultimately create a targeted research agenda, a network of empowered patient-advocates and a guide to working with Long Covid patients for researchers. These critical tools will provide urgently needed guidance on achieving patient-centered research in the Long Covid field, as well as help to empower communities in other related fields.

More than 20 million Americans who had COVID-19 continue to suffer health impacts long after the expected recovery period.¹ These lingering symptoms, which are referred to as Long Covid or post-acute sequelae of COVID-19 (PASC), could result in a lifetime disability. Additionally, COVID-19 can trigger myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Cases of ME/CFS are expected to increase from 2.5 million to an estimated 9 million because of the pandemic.²

"For more than three decades, Solve M.E. has provided critical support to thousands of ME/CFS patients who are suffering from a misunderstood illness," said Tania Simoncelli, Vice President for Science in Society at CZI. "As such, they were among the first to recognize that a significant subset of COVID-19 survivors exhibited ME/CFS symptoms, as well as the critical importance of advancing a patient-centric Long Covid research agenda. We are thrilled to support the program, which will catalyze research by building the capacity of Long Covid patient leaders to partner with researchers and amplify their work."

"Long Covid presents a potentially mass-disabling event and must be an urgent focus of the continued pandemic response," said Oved Amitay, President and CEO of Solve M.E. "Research is critically needed to better understand Long Covid and to rapidly develop treatments. All the while, it remains essential to integrate the experience of Long Covid patients into research. Without addressing barriers to participation, patient engagement efforts will fail to represent the underserved populations who were disproportionately impacted by the pandemic. Thanks to the support of CZI, we can mobilize a new generation of patient advocates with the knowledge and support to make a difference."

Through the CZI grant funding, Solve M.E. will create a replicable model designed to engage Long Covid patients in present and future research, which will include a custom curriculum. Patients who complete this curriculum will become part of the Long Covid Patient Leader Advancement Network (LC-PLAN), a group of patients and caregivers who are fully trained for patient advisory research roles. These individuals will convene with leading scientists and researchers to develop much-needed tools, including a research agenda, a core set of patient-reported outcomes and patient-preferred practices.

¹ https://solvecfs.org/wp-content/uploads/2022/04/Long_Covid_Impact_Paper.pdf

² <https://www.tandfonline.com/doi/abs/10.1080/21641846.2022.2062169?journalCode=rftg20>

These materials will be invaluable guides to establish patient-driven input at the outset of research related to Long Covid, when crucial decisions that determine outcomes are being made. Additionally, the LC-PLAN Training Program itself will be made available to Long Covid patients, non-profit organizations and researchers when completed.

“Patients hold the key to transforming Long Covid research and care, so it’s essential to maintain the trust and inclusion of the patient community,” said Emily Taylor, Vice President of Advocacy and Engagement at Solve M.E. “Patient engagement in research is emerging as a priority of the Biden Administration. In key publications, like the [National Research Action Plan on Long Covid](#)³ and the recent [Health+ Long Covid report](#)⁴, patient contributions have been vital. Thanks to CZI, the new Solve M.E. LC-PLAN program will empower patients to be full partners in these efforts and other Long Covid research opportunities.”

One of the most important tools of patient engagement in research is including patients at key agenda setting meetings. Patient Focused Drug Development (PFDD) meetings, like those hosted by the Food and Drug Administration (FDA) and other key stakeholders, provide an opportunity to hear directly from patients, their families, caregivers and patient advocates about the symptoms that matter most to them, the impact the disease has on daily life and experiences with currently available treatments. One of the goals of the LC-PLAN Training Program is to prepare patients to participate in such meetings and similar opportunities to elevate the voice of the patient community in drug development.

Visit solvelongcovid.org to learn more about the work of Solve M.E. to solve Long Covid and associated conditions, as well as participating in research and joining in advocacy and awareness efforts.

About Solve ME/CFS Initiative (Solve M.E.)

The Solve ME/CFS Initiative (Solve M.E.) is a non-profit organization that serves as a catalyst for critical research into diagnostics, treatments, and cures for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long Covid and other post-infection diseases. Our work with the scientific, medical and pharmaceutical communities, advocacy with government agencies and alliances with patient groups around the world is laying the foundation for breakthroughs that can improve the lives of millions who suffer from various “long haul” diseases.

About the Chan Zuckerberg Initiative

The Chan Zuckerberg Initiative was founded in 2015 to help solve some of society’s toughest challenges — from eradicating disease and improving education, to addressing the needs of our local communities. Our mission is to build a more inclusive, just, and healthy future for everyone. For more information, please visit chanzuckerberg.com.

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³ <https://www.covid.gov/assets/files/National-Research-Action-Plan-on-Long-COVID-08012022.pdf>

⁴ <https://www.hhs.gov/sites/default/files/healthplus-long-covid-report.pdf>