Solve Spearheads Call for New NIH Office for Infection-Associated Chronic Illness Research (IACIR)

This year, Solve is beginning one of our most ambitious advocacy projects to date — one which could alter the research landscape for ME/CFS, Long Covid, and other infection-associated chronic illnesses for decades to come. We’re working with our champions in Congress to call for the creation of a new, dedicated office at the National Institutes of Health (NIH).

This office would be responsible for overseeing and coordinating research and development efforts into infection-associated chronic illnesses within the NIH, accelerating research into a multitude of related illnesses, including ME/CFS, Long Covid, fibromyalgia, multiple sclerosis, chronic lyme disease, and POTS, among others. Currently, these diseases are funded across multiple centers and institutes without any method of synergy or oversight to avoid duplication.

There is tremendous value in creating a centralized office to coordinate this research. The multi-systemic nature of infection-associated chronic illnesses requires that research stretch across multiple specialities, focusing not only on specific bodily systems, but the interactions between them.

An office will enable multi-disciplinary approaches and inter-agency collaboration while creating new opportunities for patient-engagement and stakeholder input. This office can oversee and integrate research.

Our decades of experience in the ME/CFS community have also led us to recommend that the office should be located in the Office of Research on Women’s Health (ORWH). It is a common feature of infection-associated chronic illnesses to disproportionately impact women — ME/CFS impacts women 3-4 times more often than men. Like many autoimmune diseases, the predominant impact on women is cited as a factor for underfunding, dismissal and stigma.

Infection-Associated Chronic Illnesses currently do not have a dedicated funding source within the NIH and do not have a dedicated institutional home. This structure creates barriers to the development of multi-systemic research collaboration and is slowing the rate of progress in these disease areas which predominantly impact underserved and vulnerable communities. Establishing a coordinating office is a critical first step to addressing those barriers and creating an entity dedicated to coordinating and synergizing multidisciplinary projects across multiple institutions.

“[This new office would be critical to avoid potentially redundant research and ensure related research is cross-pollinating among different centers at the NIH.]” — Emily Taylor, Solve VP of Advocacy & Engagement

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Advocates Ask Congress to CARE for Advocacy Week in Washington, DC

In April, Solve hosted our 7th annual Advocacy Week online and in Washington, DC – the first in-person gathering for the event since 2019.

Each year, Advocacy Week brings together community members and elected leaders, providing an opportunity to advocate at the highest levels for ME/CFS, Long Covid, and post-infection diseases. Our expert team hosts training sessions and manages all meeting requests, making it easier than ever to educate lawmakers about the issues that matter.

Senate Day on April 18 was a full-day Washington D.C. Capitol Hill experience bringing participants face-to-face directly with Members of Congress and their staff. Advocates also participated virtually, as our House Day on April 20 allowed for fully online Zoom meeting participation with Representatives and their staff.

This year, we asked Congress to CARE by rallying around the CARE for Long Covid Act in both chambers of Congress. This legislation seeks to increase research and expand resources for those struggling with Long Covid and related conditions, including ME/CFS and other infection-associated chronic illnesses. This year ME/CFS is specifically mentioned in the bill language as one of the key comorbidities which occurs alongside Long Covid.

We also hosted our hallmark Advocacy Week event: EmPOWER M.E. This event is one of our favorite ways to connect with our community after a long week of congressional meetings. This year, our Lived Experience Taskforce (LET) partners helped us choose our topic: Navigating the World with Energy Limiting Disabilities. This special event featured expert ME/CFS and Long Covid advocates Laura Casey, Ashanti Daniel, Jalyn Mercadel, Amy Mooney, Alison Sbrana, and Dr. Sharon Stevenson sharing tips for overcoming personal, professional, and medical challenges.

Visit the Solve website at SolveME.org for a full report on our 2023 Advocacy Week turnout and successes!
Ramsay Research Grant Program Updates
Empower Patients

Through our Research Grant Program, Solve M.E. invests in research studies in ME/CFS, Long Covid, and other post-infection diseases with a particular emphasis on engaging young investigators and propelling researcher interest in long-haul diseases—an area in which, historically, there has been a dearth of research funding opportunities.

Since 2016, Solve has funded 34 studies, and created a global network of nearly 100 investigators and researcher collaborators. Now, we’re making some exciting changes to this funding program.

The changes this year are two-fold: more patient engagement earlier on in the application process and continued throughout the grant; and greater researcher engagement across all supported studies.

Now, submissions will be accepted on a rolling basis starting later this summer, allowing researchers to engage with Solve and apply for funding throughout the year. We are also beginning to offer researchers feedback earlier on in the grant application process. By requiring a Letter of Intent (LOI), this preliminary step in the application process helps ensure that Solve and researchers are aligned before the work of writing and reviewing full proposals begins.

If the LOI is accepted, Solve will connect the researcher with a patient advocate from our Lived Experience Taskforce (LET) or Solve-backed patient advocates, and provide tailored one-on-one support to help the researcher improve their grant application. If the LOI is not accepted, the researcher will receive feedback on how to improve their application.

Solve is committed to helping researchers be more successful so that they will have opportunities to receive more follow-on funding, and we’re partnering with patient experts to make that happen.

Solve has invested over $1.5 million in research grants, which in turn helped researchers receive over $11 million in additional research funding—that’s a 10X return on the investment! With our expanded submission period and patient-informed process, we’re expecting to make an even greater impact.

This year, Solve is accepting applications for Lab-based Research Grants, supporting studies that will process and analyze biological samples. These grants range from $35,000 to $55,000 for a 1-year period, with the possibility of renewal for projects yielding promising results. Collaborative proposals (involving two or more research groups) and studies that examine the similarities and differences between ME/CFS and Long Covid will be prioritized for funding.

Stay tuned for more information about when our application period opens this summer and what we’ll be looking for.

If you’re a researcher with questions about Solve’s research grant program, please contact research@solveme.org.

Solve-funded Grantee Strengthens Connection Between ME/CFS and Long Covid Exercise Intolerance

Solve M.E. funded Dr. David M. Systrom at Brigham and Women’s Hospital in 2017 to study exercise intolerance in ME/CFS. Six years later, his findings have redefined our understanding of the exertion problems faced by people with ME/CFS and related conditions like Long Covid. The first-ever trial to directly test a promising treatment called Mestinon is also underway.

Dr. Systrom has long been at the forefront of using exercise testing for diagnostic and research applications. His clinic at Brigham and Women’s Hospital (BWH) uses invasive cardiopulmonary exercise testing (iCPET) to study patients with unexplained shortness of breath (dyspnea) or inability to exercise. The iCPET collects traditional CPET information plus a more comprehensive evaluation of breathing, heart function, and gas exchange at rest and while on an upright bike.

A new research paper* in Chest from Dr. Systrom and colleagues details evidence from hundreds of exercise tests that suggests similar processes are producing ME/CFS and Long Covid symptoms; specifically dysregulated blood flow, hyperventilation, mitochondrial dysfunction, and small fiber neuropathy (damaged nerve fibers). The findings are similar to connective tissue diseases, POTS, and Long Covid studies that have uncovered patterns of disrupted blood flow and oxygen delivery problems in patients.

These research efforts have opened up new, impactful ways to understand ME/CFS and related illnesses, implicating pathways that may be meaningful targets for treatments. In fact, the iCPET findings have already led to treatment trials of a drug called Mestinon, which might improve blood flow back to the heart, breathing, and oxygen uptake in the muscles.

Oved Amitay joins the NIH ME/CFS Research Roadmap Working Group

In 2019, the National Institutes of Health (NIH) National Advisory Neurological Disorders and Stroke (NANOS) Council Working Group for ME/CFS presented the Report of the NINDS Council Working Group for ME/CFS Research. Solve leadership and Research Advisory Council (RAC) members were part of the Working Group, and the delivery of the report they created was expected to be a sea change in how ME/CFS is addressed within NIH.

In 2022, as part of the strategic planning process outlined in the report, NINDS announced the development of a Research Roadmap for ME/CFS, which will identify research priorities to move the field toward translational studies and clinical trials.

Solve President and CEO Oved Amitay will join the Research Roadmap Working Group, which includes ME/CFS basic and clinical experts from the research community, leaders of ME/CFS non-profit advocacy and research organizations, as well as people who are living with ME/CFS, have a family history of ME/CFS, are caregivers/care partners of people living with ME/CFS, and/or identify as ME/CFS patient advocates.

The Working Group will also make a presentation at the NIH ME/CFS research conference to be held in person (and virtually) at NIH in Bethesda, MD, December 12-13, 2023. Stay tuned for more details on Working Group activities and the December NIH conference!
Solve Awarded Nearly $250k from Chan Zuckerberg Initiative to Fund Bold New Patient Leadership Program

The Chan Zuckerberg Initiative (CZI) awarded Solve M.E. a significant grant in support of our Long Covid Patient Leader Advancement Network (LC-PLAN), a groundbreaking program designed to bridge the gap between Long Covid research and patient needs.

With $247,500 in funding from CZI, Solve 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 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.

“The 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 and the recent Health+ Long Covid report, patient contributions have been vital. Thanks to CZI, Solve’s LC-PLAN program will empower patients to be full partners in these efforts and other Long Covid research opportunities.”

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 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.

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. Upon completion, the LC-PLAN Training Program itself will be made available to Long Covid patients, non-profit organizations and researchers.

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.

The COC is Formed

In January, we invited 11 highly qualified individuals to form the Curriculum Oversight Committee (COC) for the LC-PLAN. This committee is developing and refining the training curriculum over the upcoming calendar year. Together, they will help design a 10-12 module program to train and empower the LC-PLAN participants. Each module may include short prep “homework,” such as online video training or reading materials, a one-hour virtual instructor-led discussion workshop, and a 15-25 multiple choice assessment.

We’ll also run a mini pilot program to “test out” the structure, content, and delivery of the LC-PLAN modules. The pilot program is expected to launch in July of this year. Using feedback from the pilot cohort, the COC will further improve and refine the curriculum.

The first official full LC-PLAN cohort will launch in January, 2024.

Centering Patient Voices: The Lived Experience Task Force (LET)

Building on our commitment to centering the crucial voices from our community in the leadership and decision-making at Solve, this year we transformed our Community Advisory Council (2019-2022) into the Lived Experience Task Force (LET).

The Lived Experience Task Force (LET) serves as a leadership partner with Solve. This partnership is based on the principles of meaningful community engagement where equity is our goal and expectation. LET partners — many from historically under-engaged communities — are improving our ability to deliver responsive services, programming, training, and technical assistance to organizations and other partners affected by ME/CFS, Long Covid and other associated conditions.

In forming LET, we actively sought community partners who are:

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

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.

Heartfelt thanks to the Community Advisory Council (CAC), a previous iteration of LET, for providing guidance and recommendations on numerous Solve programs throughout the years.

**OUR NEW LET MEMBERS**

- Tracy Conrad
- Kelly Ruta
- Janice Frisch
- Kate Sanchez
- Benjamin Ho
- Lala Shanks
- Soh-Yeon Lee
- Jessica Turner
- Jailyn Mercadel
- Christina Yesenofski
- Hollis Mickey
- Ursula Wilkerson

www.SolveME.org
Funding Affordable and Accessible Care: The TREAT Long Covid Act

On May 11, as the Biden administration ended the Public Health Emergency for COVID-19, Congresswoman Ayanna Pressley (MA-07), alongside Representatives Don Beyer (VA-08) and Lisa Blunt Rochester (D-DE), reintroduced the Targeting Resources for Equitable Access to Treatment for Long COVID (TREAT Long COVID) Act.

The TREAT Long COVID Act is much needed legislation that will direct the Department of Health and Human Services (HHS) to provide dedicated grant resources for the expansion of Long Covid Clinics. In partnership with community advocates, the bill text was adjusted to prioritize grant funding for entities who engage with Long Covid patient organizations.

Pressley’s office notes, “People battling Long Covid require and deserve accessible and affordable medical care and treatment. Currently, there is no federal program focused on expanding treatment options for this growing population. The absence of specialized support contributes to patients experiencing greater physical and mental anguish, disruption in employment and education, and reduced quality of life.”

The bill requires that the Secretary of HHS report to Congress on the activities of the grantees, and that those reports include recommendations for expanding coverage for clinical care for Long Covid and its associated conditions (such as ME/CFS).

Solve supports the bill, and VP of Advocacy Emily Taylor noted, “We’re pleased that the TREAT Long Covid Act will deliver desperately needed resources for Long Covid care, and will prioritize funding those providers who are committed to health equity.”

In 2022, a different version of the TREAT Long Covid Act was introduced in both the House (HR 7482) and the Senate (S 4015), but failed to advance.

The TREAT Long Covid Act:
- Authorizes HHS to award grants up to $2,000,000 to health care providers, including community health centers
- Grants funding for the creation and expansion of multidisciplinary Long Covid clinics to address the physical and mental health needs of patients
- Prioritizes funding for health providers that plan to engage Long Covid patient organizations, medically underserved populations, and populations disproportionately impacted by COVID-19
- Ensures that treatment is not denied based on insurance coverage, date of method of diagnosis, preexisting conditions, or previous hospitalization
- Encourages ongoing medical training for physicians in Long Covid Clinics and other health care workers serving patients
- Requires grantees to submit an annual report on its activities that includes evaluations from patients
- Authorizes HHS to award grants to other health care providers, including community health centers
- Ensures that treatment is not denied based on insurance coverage, date of method of diagnosis, preexisting conditions, or previous hospitalization
- Encourages ongoing medical training for physicians in Long Covid Clinics and other health care workers serving patients
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- Requires grantees to submit an annual report on its activities that includes evaluations from patients

Solve Conference Invites Biotech to Join In Fighting Post-Infection Disease

In February, Solve M.E. and The Biotechnology Innovation Organization (BIO) co-hosted “Long Covid: What Will It Take to Accelerate Therapeutic Progress?” convening stakeholders to advance research and development to diagnose and treat Long Covid, ME/CFS, and other post-infection diseases.

By increasing awareness among drug developers to the unmet needs of our communities, we hope to inspire these industry players to study these diseases and create therapeutic breakthroughs.

“Our belief is that there is a lot of knowledge that has been gained over the years that could really help unlock the current topic of Long Covid — and the other way around: The renewed interest because of Long Covid could really potentially help these people who had these diseases prior to COVID,” noted Solve President Oved Amitay.

Perspectives from government, academic, and industry researchers, patient groups, funding sources, and policymakers were represented, with presentations by Akiko Iwasaki, PhD (Yale School of Medicine), Walter Koroshetz, MD (Director, National Institute of Neurological Disorders and Stroke-NINDS), Margaret Kozelj, MD, SVP (Axcella Therapeutics), Bruce Patterson, MD (IncellDx), Amy Proal, PhD (PolyBio), and David Puttnoc, PhD (Icahn School of Medicine at Mount Sinai).

“It was a most interesting webinar – the first in a series of programs from Solve M.E. and BIO – on how to best advance the Long Covid treatments,” Journalist Cort Johnson.

“Solve’s reach and its ability to bring in a diverse array of experts in different fields was amply demonstrated.”

Events like this can help to engage drug developers and evaluate how their platforms and approaches could be deployed in this direction.

Honoring the Work of Dr. Peter Rowe

Solve M.E. recently honored Dr. Peter Rowe for his work as a medical provider, researcher, educator, and advocate for health equity.

Dr. Rowe is a Professor of Pediatrics at the Johns Hopkins University School of Medicine and Director of the Chronic Fatigue Clinic at the Johns Hopkins Children’s Center. His clinical and research work has focused on Chronic Fatigue Syndrome and more recently on Long Covid.

Solve acknowledged with gratitude Rowe’s unwavering support of our community and his outstanding contributions as a physician and scholar. Solve Board Member Vicki Boies, whose family members have been treated by Dr. Rowe for many years, presented the award and recalled his decades-long promise to “never give up” in his pursuit of treatments and cures. “Dr. Rowe has a wonderful ability to let patients know he understands how sick they are, how much they’ve suffered, how much they’ve lost, and yet because of his expertise, knowledge, and especially his great sense of humor, he also makes them feel hopeful and cared for.” She also quoted a young family member with ME/CFS who simply stated, “Dr. Rowe saved my life.”

Thank you, Dr. Rowe, for the care and consideration given to our community in your many years of medical practice. We’re grateful for your contributions!

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SOLVE M.E. RESEARCH ADVISORY COUNCIL

Dr. Rowe (left) and Dr. Peter Rowe

Oved Amitay (left) and Dr. Peter Rowe

The Solve Chronicle

www.SolveME.org
Donor Spotlight: A Legacy for Generations to Come

Dr. Jeffrey was a practicing ENT surgeon when he developed ME/CFS in 1990. His story is like that of many others—after fighting through fatigue and brain fog for years, he was forced to give up his surgical practice.

Navigating the disease required him to base his entire life on his ongoing physical limitations. “Having reduced my professional and personal activities by more than 50%, I essentially met my illness half-way!” This positive attitude is reflected in the journey he embarked on over the last three decades, seizing the “opportunities of life” to live fully with his disease. This included obtaining an executive MBA, participating in a Big/Little Brother program, starting an at-home piano teaching business and amassing a significant travel photography collection.

Dr. Jeffrey has also been a long-time supporter of Solve M.E. Now, after nearly 30 years of donating to our organization, he has decided to name Solve as a beneficiary in his will.

“Leaving a bequest to Solve M.E. is a natural continuation of my ongoing support for the organization. It is important to me to participate in providing the funds necessary for an organization to function beyond my lifetime when I am deriving significant benefits during my lifetime.”

Dr. Jeffrey says that Solve and other patients in the community have been his primary resource for information about specialists knowledgeable about ME/CFS before the Internet; and that Solve continues to offer him ways to participate in advocacy and research efforts. He also shares that he is heartened to see that Solve has taken steps to align the ME/CFS and Long Covid communities, so that both can benefit from ongoing research and newly developed treatments. “I want to be part of this ongoing effort during my lifetime and as part of my legacy to future patients and their families.”

A heartfelt thank you to Dr. Jeffrey for his trust and support over the decades. We’re inspired by your dedication and honored to continue working on your behalf serving the millions of individuals with these devastating chronic conditions.

To learn more about planned giving or to let us know that you’ve named Solve in your will, email us at Development@SolveME.org or call us at the number listed below.

Make a gift today using the QR code, online at solveme.org/donate, or call our Development team at 704-364-0016 ext. 207. Thank you!

Seizing the Moment, Making a Difference

Two and a half years ago, Solve embarked on a strategy that connected ME/CFS with Long Covid, which was just emerging at that time as a clinical condition. While initially the scientific connection was primarily circumstantial, last year provided ample evidence pointing to the similar biological underpinnings of these conditions, as well others such as dysautonomia and mast cell activation syndrome (MCAS).

Solve formally expanded its mission and began to use a broader term, “infection associated diseases,” particularly in the advocacy space and legislative language.

Today, other parts of our ecosystem are finally catching up.

A major effort by the National Academies of Sciences and Medicine to define a research agenda in infection associated chronic illnesses and examine overlapping clinical and biological factors is underway, with a public workshop scheduled for June 29-30.

The report coming from this committee will be as important as the 2015 Institute of Medicine report that redefined ME/CFS, and is a critical element in our advocacy effort to get significant government funding (see more in the advocacy section). Dr. Peter Rowe, a member of our Research Advisory Council is a member of the committee, as is Dr. Amy Proal, a previous Ramsay research grant awardee.

On the patient community front, the CDC Foundation announced a new program focusing on creating partnerships to address chronic conditions caused by infections. The Initiated Chronic Conditions Understanding and Engagement (ICUE) project will fund patient organizations to develop collaborations, tools and strategies to address the concerns and challenges of people living with Long Covid, ME/CFS and similar infection-related long-term illnesses. The Long Covid Alliance, co-founded by Rowe, a member of our Research Advisory Council is a member of the committee, as is Dr. Amy Proal, a previous Ramsay research grant awardee.

Onward,

Oved Amitay
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Humans of Chronic Illness: HumansofChronicIllness.org
Solve Long Covid: SolveLongCovid.org

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SOLVE ME/CFS INITIATIVE (SOLVE M.E.) is 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 lays the foundation for breakthroughs that can improve the lives of millions who suffer from various “long haul” diseases.

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Our “How Long?” PSA campaign was designed to broaden awareness of Long Covid, ME/CFS, and other post-infection diseases; create empathy for those who suffer their devastating impact; and highlight the need for research to better understand them in order to adequately help patients. Find Long Covid resources and learn how you can get involved at SolveLongCovid.org.