



The Solve CHRONICLE

Solve welcomes new President and CEO Kristin Jacobson!

FALL 2023

Solve Together: Transforming Your Data into Clinical Breakthroughs

Our new patient-centered data platform, Solve Together, is here!

Solve Together brings extensive advantages to the patient community and researchers. For decades, Solve has been committed to advancing research into infection-associated and fatigue-related illnesses, and empowering patients to participate in that work. This new platform builds on those efforts and allows users to track symptoms and connect with researchers, among other benefits.

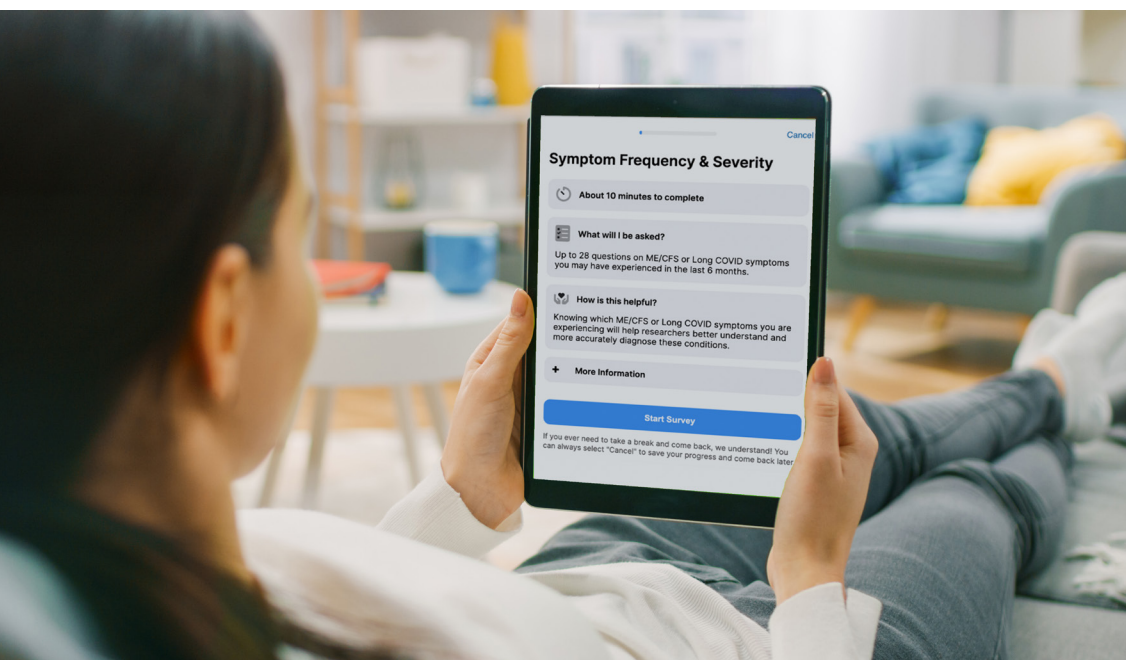
Solve Together was built with the needs of individuals with ME/CFS and Long Covid in mind. Fully accessible by smartphone, the platform allows participants to connect wearables (Fitbit, Apple Watch, and others), download reports for doctor visits, link electronic health records, and expend less time and energy on participation through short, infrequent surveys and passive data collection.

GET INVOLVED TODAY!

Any adult in the U.S. can join Solve Together, whether they have ME/CFS, Long Covid, other post-viral fatigue-related illnesses, or none of these conditions (serving as "Control" participants). Joining is free, voluntary, and participants can opt out anytime.

By joining Solve Together today, you can help accelerate progress toward precise diagnostics, treatments, and one day, a cure for ME/CFS, Long Covid, and other infection-associated chronic diseases.

Visit solveveme.org/solve-together to learn more.



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SOLVE TOGETHER GOALS

Solve envisions a world free of ME/CFS, Long Covid and other infection-associated chronic diseases. That's why we've created Solve Together, a data collection platform that serves as a catalyst for clinical researchers to access patients, controls, and contextual data in real-time for research that drives better diagnostics and therapeutics.



PATIENT-CENTERED

Support personal tracking of symptoms and experiences for individual care management.



INTEGRATION

Create a comprehensive, integrated research database with the goal of finding treatments and cures.

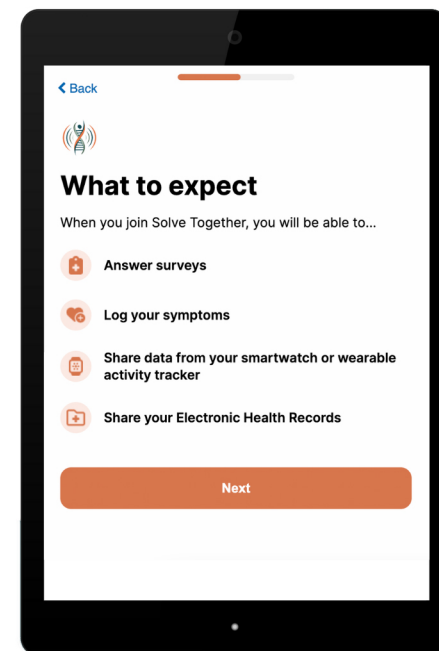


RESEARCH-DRIVEN

Help recruit for clinical studies.

We are in the midst of a patient-driven research revolution, and people with lived experience are actively partnering with scientists to design and conduct studies that address the issues that matter most.

The best way to initiate your Solve Together journey is to complete the Baseline and One-time Surveys, allowing your data to become a catalyst for research.



A HISTORY OF PATIENT-CENTERED RESEARCH AT SOLVE

2010 **SolveCFS Biobank**

Hundreds of participants contributed data and blood samples for research. Users made it possible to support a range of studies, produce 14 scientific publications, and bring new researchers into the field. Samples from the Biobank are still being used in research.

2020 **You + ME Registry**

Solve launched the You + ME Registry as an online observational clinical study. The platform was informed by patient, caregiver, and researcher perspectives, and data collected offered critical insights. It features standardized patient-reported outcome tools, a symptom-tracking app and free-form input.

2023 **Solve Together**

With growing needs and an expanded mission, Solve set out to create an integrated dataset (e.g. EMR, wearables, etc.) as a way to ensure the platform continued to deliver on the You + ME promise. By partnering with CareEvolution, an organization that specializes in collecting patient data, Solve launched the next phase of data collection and clinical research partnership.

FEATURES OF SOLVE TOGETHER

TRACK YOUR SYMPTOMS

Using the Symptom Log makes it easy to track daily symptoms and treatments. The Symptom Log was specifically designed by an ME/CFS patient to be as easy to use as possible.

CONNECT WEARABLE DEVICES

Passive data collection via linked wearable activity trackers that collect data without the burden of data entry.

LINK ELECTRONIC HEALTH RECORDS

Setting up a one-time connection to a wearable device or health records takes just a few minutes and allows participants to continue to contribute valuable data with no extra effort. Users can access lab results, medications, procedures, and other health history information once shared with Solve Together.

DOWNLOAD REPORTS TO SHARE WITH PROVIDERS

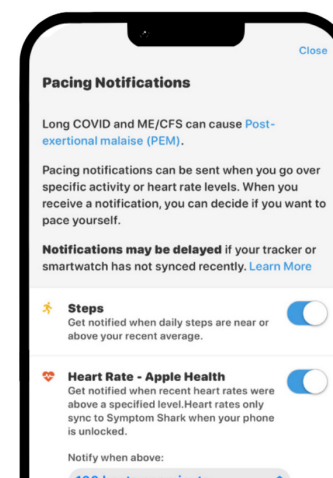
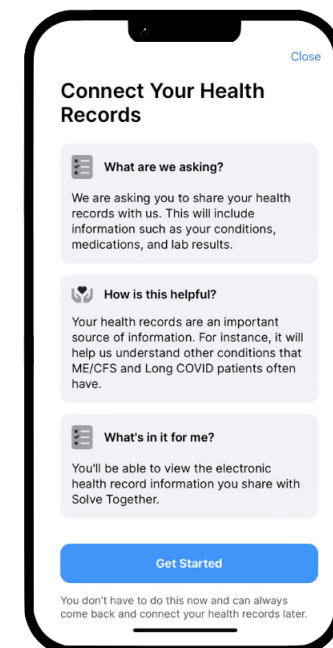
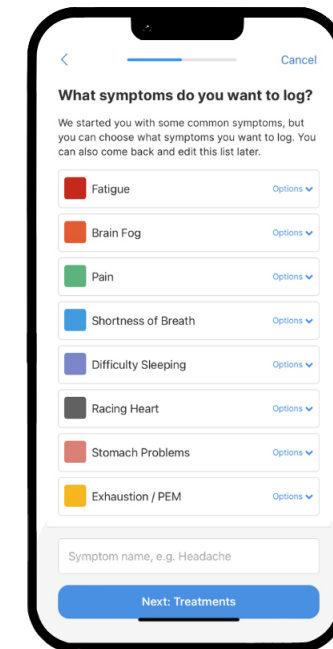
With Solve Together, it's easy to quickly download reports of centralized data to share with a doctor or caregiver, and viewing data from a wearable device alongside symptoms will help identify patterns and triggers that would otherwise be difficult to spot.

SET PACING NOTIFICATIONS

Solve Together is unique in its recognition of post-exertional malaise (PEM) and its ability to signpost fatigue and issue pacing notifications. Because we know how valuable and finite energy is, our surveys are labeled with their level of effort so users know what to expect and can track their symptoms at their own personal pace.

CONNECT TO CLINICAL TRIALS

One of the defining features of Solve Together is the ease with which users can be connected to specific clinical studies. Participants will be the first to know about new clinical recruitment opportunities, better positioning Solve Together users to be recruited early for these studies.



Anthony Komaroff, MD
*Simcox-Clifford-Higby
Professor of Medicine,
Harvard Medical School*

Susan Levine, MD
*Founder, Medical Office of
Susan M. Levine*

Maureen Hanson, PhD
*Liberty Hyde Bailey Professor,
Cornell University*

Peter Rowe, MD
*Professor of Pediatrics,
Johns Hopkins University School
of Medicine*

Lucinda Bateman, MD
*Founder & Chief Medical
Officer, Bateman Horne Center*

Rochelle Joslyn, PhD
*Immunologist, Independent
Consultant*

Sheila Stewart, PhD
*Associate Professor, Washington
University School of Medicine*

Daan Archer, MBA, MSc
Technology Entrepreneur

John Nicols, MBA
*Biotechnology Industry Advisor
CEO, Codexis Inc. ('12-'22)*

Morgan Fairchild
Actress and Activist

Ex Officio Members

Oved Amitay
*President & CEO,
Solve M.E.*

Building Solve Together with Lived Experience: Partnering with Amber Harrison and Chris Nowak

Chris Nowak, Solve Together's Platform Architect, and Amber Harrison, Lived Experience Consultant and Symptom Log Designer, are a husband-wife duo who laid the groundwork for our new patient-centered data platform.

Amber's health journey will be all too familiar to many individuals with ME/CFS and Long Covid. Though she first became ill with ME/CFS in 2017, it took four years to finally get an official diagnosis. Even when she did, Amber found the important process of tracking her symptoms to be overwhelming – particularly when preparing her hand-written symptom logs for doctor appointments.

In partnership with her husband, Chris, the duo set out to co-create a symptom-tracking app to ease the burden. Chris is a platform architect with CareEvolution, an organization with expertise in collecting a wide variety of patient data.

Together they created a symptom tracking app – which now powers Solve Together's symptom tracker. This app was designed to give users the ability to gather and organize their health data to better advocate for themselves in a care setting. Because of his experience with creating CareEvolution platforms used for conducting clinical research, clinical trials, and other health projects, Chris knew the app could also be useful for researchers studying complex conditions such as ME/CFS, because it enables users to capture information about a broad array of symptoms.

CareEvolution's mission is to accelerate research to a broad audience quickly, using technology as a bridge to communities otherwise hard to reach or too sick to participate. They are the architects of MyDataHelps, the platform underpinning the National Institutes of Health (NIH) All of Us study and the mobile platform for their RECOVER study of Long Covid. In partnering with CareEvolution, we will not only launch the next phase of Solve's data collection and clinical research partnership, but also increase representation in research from individuals in our community with severe symptoms, which often prevent their participation.

As a member of the chronically ill community, I am particularly invested in the understanding and care for those of us with ME/CFS. We face denial, dismissal and devastating loss...I designed it based on what my needs are (tracking multiple chronic illnesses) and what my chronically ill friends said they needed. I am grateful to Solve M.E. for sharing this symptom tracking system in Solve Together! I'm proud to contribute to ME/CFS research and to the incredible ME/CFS community.

—Amber Harrison

Amber and Chris aren't just the masterminds behind the Solve Together symptom-tracking app, they are also participants in Solve Together. We hope you and your loved ones will join Amber, Chris and the growing Solve Together community by signing up today at solveME.org/solve-together!



Lived Experience Taskforce Offers Insights On New Data Platform

Solve's Lived Experience Taskforce (LET) dove right in this year by offering critical feedback into the development of Solve's programs and initiatives – including Solve Together. Centering the voices of our community members was critical to the development of the new data platform.

LET members serve as leadership partners and offer a deep understanding of both the lived experience of these diseases and the needs of our community. Many are from historically under-engaged communities, and they champion our collaboration with community members affected by ME/CFS, Long Covid and other associated conditions.

Before we launched Solve Together to our broader community, several LET partners tested the new platform to ensure it was user-friendly, responsive to their needs, and added value to our community. Below you'll find feedback from two LET partners who engaged in early testing of the platform.

Tina Yesenofski

My lived experience was most valuable in how I was able to provide feedback from the perspective of someone with "brain fog."



It's simple things like labels and a focus on clarity and simplicity that really help those of us with cognitive deficits.

The app is easy to use, and colorful, which makes it even a little fun to use – and let's be honest, those with chronic illness and disabilities can really appreciate a fun moment of reprieve!

I find the ability in the app to link my health records with just a few clicks absolutely phenomenal. Linking data allows researchers greater access to larger data sets, enabling research that could eventually lead to advanced pathology understanding and actual treatments for ME/CFS and Long Covid.

Hollis Mickey

For me, the fundamental reason to have any app is to see trends over time so that I can adapt behavior (treatments, activity levels, triggering events).



Solve Together (ST) is superior in its ability to easily determine what to track and in what way (number of symptoms, kinds of treatments, how/if to scale). It also has an easy interface (in terms of visual design and data entry) and can hold more information than most other apps, for example the intersection of wearable devices, and health-care records alongside daily symptom logs.

ST offers comprehensive reports which are personally useful and serve as meaningful careteam reference. The reports can be generated in a variety of different manners, and as a visual thinker the pie charts with colors are different and more helpful than other kinds of data I've seen in the past.

Solve's New Chief Scientific Officer Addresses the Community

We're pleased to share that H. Timothy Hsiao, Ph.D. recently joined us as Chief Scientific Officer, Head of Research Strategy and Alliances. He addresses the community in the letter below.

Dear Solve M.E. Community,

With sincere gratitude, I am excited for this privilege to stand, walk, and run with you in the journey of medical research to understand and fight against the mystery and toll of ME/CFS and Long Covid. *I believe that research is a powerful tool that can not only enrich the collective knowledge of humankind but also, more importantly, bring hope to patients, families, and all of us who care about one another's well-being.*



mechanisms among infection-associated chronic conditions (IACCs) such as ME/CFS, Long Covid, Lyme Disease, and Multiple Sclerosis. This realization among the scientific communities opens the door for comparative research to expedite the necessary discoveries for better diagnosis, treatment, and care for ME/CFS and Long Covid patients.

We aim to forge new relationships, such as those with the for-profit sector (bio-tech, pharmaceutical, and/or health tech

companies), to bring in new capabilities that can empower the research and development (R&D) of ME/CFS and Long Covid diagnostics and interventions. To accelerate R&D, we will proactively leverage Solve Together's capability in data collection, research planning, and patient engagement, as well as our content expertise and convening power to not only promote more clinical studies but also expedite the critical steps of initiation, recruitment, and analysis for human-subject research that target ME/CFS, Long Covid, or other IACCs.

Each of you in the Solve community plays a critical role in our collaborative endeavor to realize Solve's mission: "Make ME/CFS, Long Covid and other post-infection diseases widely understood, diagnosable, and treatable." Solve's research team is committed to working with all of you and across the biomedical research ecosystem to make breakthroughs possible.

H. Timothy Hsiao, Ph.D.
Chief Scientific Officer, Head of Research Strategy and Alliances

Before joining Solve, I spent more than twenty years either carrying out research projects or managing research programs and funding. As a believer in the power of collaboration, I dedicated my time to crafting partnerships with industry, government, and other research foundations to advance medicine together when I led a department of scientific affairs in the non-profit sector. During my tenure at the National Institutes of Health, I managed a multi-million-dollar portfolio of federal research investments, as well as coordinated clinical and translational research with a large consortium of academic medical centers across our country. Building on my experience, I especially hope to increase the awareness of ME/CFS among researchers, promote collaborative research, and secure more funding for tangible ME/CFS research studies.

As the longest-serving U.S. non-profit organization that advocates for and supports ME/CFS patients, Solve has laid a solid foundation in the preceding decades to nurture an environment that is much more conducive for scientific breakthroughs in ME/CFS. From this solid foundation we are witnessing the growing recognition of the similarity and possibly shared

Solve Patient Leadership Program Pilot is Underway

Last year, we shared the exciting news that 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.

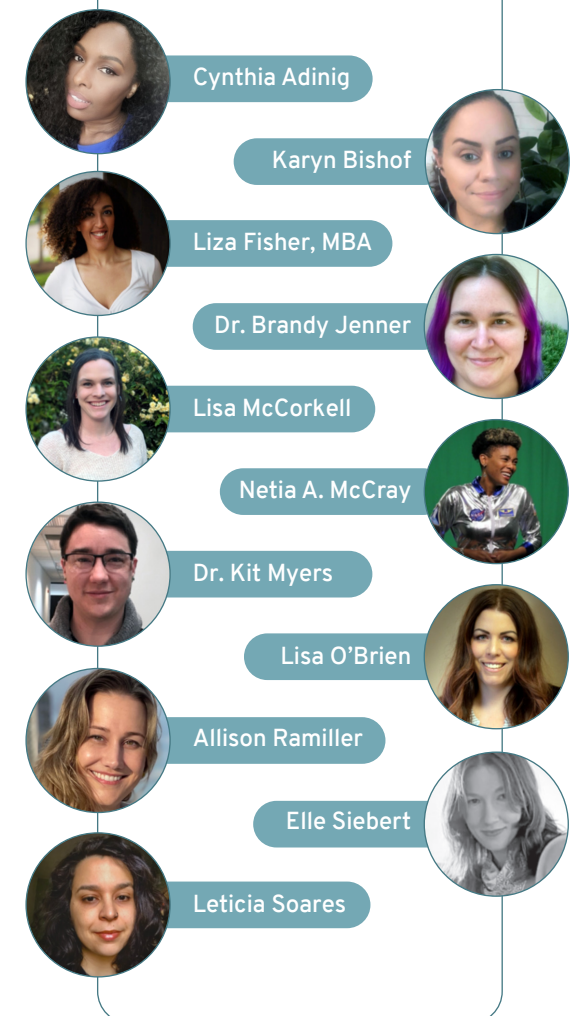
The LC-PLAN is designed to train a network of patient leaders, scientists and other stakeholders with diverse backgrounds to enhance patient engagement in Long Covid research – creating a targeted research agenda, forming a network of empowered patient advocates, and providing a blueprint for other organizations and researchers to do the same. With these tools, patients can also participate meaningfully in meetings and conversations about drug development.

We need to get organized as a community to effectively advocate for ourselves and each other, and for the funding that is needed for research, education, care and treatment. To become an effective community, we first need to have a shared understanding of what we're all going through, a shared vocabulary, and a shared vision for what can be done about it.

—David Heeger, PhD, LC-PLAN Pilot Participant, *Julius Silver Professor of Psychology and Neural Science, New York University*

Over the past year, we formed a Curriculum Oversight Committee (COC) with 11 highly qualified individuals to develop and refine the training curriculum. Their dedication produced 10 modules to train and empower LC-PLAN participants, and we're excited to begin running a pilot program to assess the structure, content, and delivery of the LC-PLAN modules.

- The 10 modules are divided between two track focuses: Research and Advocacy
- Each week explores a different module, with themes ranging from "Self-advocacy and Self-care" to "Ethical Participation in Research"
- Participants will learn basics on how to self-advocate, both personally in the doctor's office and publicly at the state and national level
- Research fundamentals, like how a research study works and how patients can (and should!) be involved, will be reviewed
- Each weekly module will be led by a subject matter expert, and participants will have the opportunity to engage and ask questions during live Zoom sessions or throughout the week via email
- Participants will graduate prepared to participate in research studies and with the tools to advocate for themselves and others in various settings



In November, we'll share details about an upcoming webinar designed to provide additional information about joining our LC-PLAN. The first official full LC-PLAN cohort will launch in January, 2024.

SOLVE'S IMPACT BY THE NUMBERS



34

ORIGINAL RESEARCH PROJECTS
FUNDED BY RAMSAY GRANTS

\$1.25BN

SECURED FOR
LONG COVID
RESEARCH &
CLINICAL TRIALS



1,000,000



DATA POINTS
COLLECTED BY
YOU + ME
REGISTRY

SOLVE MEETINGS
WITH CONGRESS

1,168



22

SCIENTIFIC
PAPERS
PUBLISHED
TO DATE



\$100M

SECURED FOR
POST-VIRAL
DIAGNOSTICS
AT NIH



1



CARES FOR LONG COVID BILL
INTRODUCED IN CONGRESS



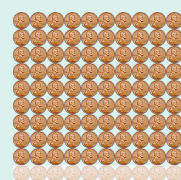
VIEWS OF
RECORDED
CONTENT

11,500



\$1M RAMSAY GRANTS HELPED
RESEARCHERS SECURE \$8M+
ADDITIONAL FUNDING

FOUR STAR CHARITY NAVIGATOR RATING



90

CENTS

OF EVERY \$1 DONATED
SUPPORTS OUR CAUSE

2,000+

ORGANIZATIONS &
INDIVIDUALS RECRUITED TO
#STOPTHELONGHAUL



29,081

ELECTRONIC MESSAGES SENT
DURING ADVOCACY WEEKS

20



FREE WEBINARS & EVENTS



6

INTERNATIONAL COLLABORATIONS
ENABLED BY RAMSAY GRANTS



15

PATIENT TRAVEL AWARDS
FOR ADVOCACY WEEK 2023

At Solve, we know that at the heart of everything we do are the donors who drive our work and who make breakthroughs possible. Without your support, none of our work in research, advocacy, patient empowerment, and community engagement would be possible.

For everything you do for our organization and the communities we serve, thank you!

Thank you
for making breakthroughs possible



OUR COMMUNITY OF SUPPORTERS

The list below is a small representation of the enormous community of supporters driving our work at Solve. These donors, many of whom are patients or loved ones, often have a long history of generously contributing to our mission and all gave exceptional gifts over the last year.

Anonymous

Andrew Ansorge & Laura Koopman

Susan & Stephen Baird

Brett & Tess Balzer

Vicki Beltz & Grant Hodgson

Melissa Boyer

Dr. Jeffrey C. Blum

Dr. Diane ("Dinah") Davidson

Mary Eldredge

Ilise Friedman

Carolyn & Milton Frye

Lynn & Jose Fuentes

Steven Furst

Gary & Julie

Ellen Geis & Andy Freeman

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Kathleen Gustafson

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Pam Shriver

Matthew Simon

Anna Sofranko

Nathan Dominic Spencer

Dr. Jeffrey Toback

Lisa & Lindsay Walsh

Nora Whiteman & Tom Rush

Chris Williams

Mary Clare VanderSchaaf

Village Rising

OUR BOARD OF DIRECTORS

Solve's Board of Directors is extraordinary in many ways. Their passion comes from deeply personal experiences with infection-associated chronic conditions and their commitment to finding treatments and cures is unwavering. Their steadfast support, ranging from the contributions of their expertise and time to financial investments in our mission, cannot be understated. We are honored to recognize their contributions here.

Cynthia Adinig

Michael & Christine Atherton

Joseph Barrera

Kenya Beckmann

Bill & Vicki Boies

Stewart Gittelman

William Hassler & Mary Gay Sprague

Carol Head

Hunter Howard

Kristin Jacobson

Gurdial & Manjeet Kalsi

Rona Kramer

Barbara Lubash & Paul Moses

John & Marcie Nicols

Fern & Louis Oppenheim

Amrit Shahzad

Barbara & Rick Sprout

Janice Stanton

Solve has the utmost respect for our donors' privacy and does not run the name of any donor without their explicit consent. If at any time you decide you do not want your name listed, or if you notice an error, please contact Elissa Regan at 303-503-0253 or eregan@solvecfs.org so that we may correct our records.

Discount Registration for the World Vaccine Congress West Coast 2023

Solve is proud to be a supporting partner for the World Vaccine Congress West Coast 2023, November 27-30 in Santa Clara, CA. Solve CEO Oved Amitay will be a presenting panelist.

Solve community members can use the personalized registration link at solve.org/events and the code **SME25** to receive a 25% discount. Please feel free to share the registration link and discount code with friends and family interested in joining.

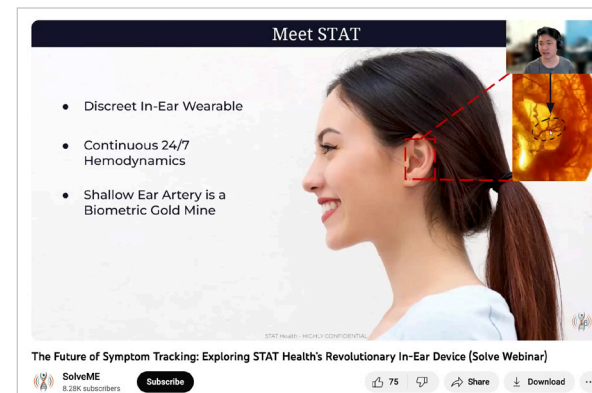
The event will connect key stakeholders in infectious disease vaccines, cancer immunotherapies and antiviral therapeutics from across the industry. From early development to commercialization, with a key focus on the methods and technology used to decode the immune system enabling us to develop more effective and targeted therapies for both ID and cancer, this is an event not to be missed.

WORLD VACCINE CONGRESS WEST COAST

Solve Summer Webinars

If you missed the following events this summer, all Solve webinars are recorded and made available on our YouTube channel at youtube.com/solve.

- **Webinar:** The Future of Symptom Tracking: Exploring STAT Health's Revolutionary In-Ear Device That Measures Blood Flow to Head
- **Meeting:** Caregiver Corner "Resilience Tools for Difficult Times" featuring Stephanie Harrison, The New Happy Founder
- **Meeting:** Advocacy Cafe Chat: The Appropriations Process
- **Webinar:** Stem Cell Therapy As a Potential Treatment for Long Covid

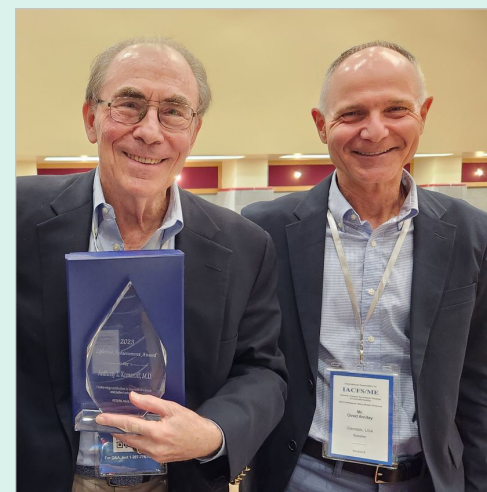


Solve Presents

During the recent 2023 IACFS/ME Conference, Solve M.E. was thrilled to join IACFS/ME in presenting Dr. Anthony Komaroff with a Lifetime Achievement Award, recognizing his outstanding contributions to biomedical science and patient advocacy. He's pictured here with Solve CEO Oved Amitay (right).

A longtime member of Solve's Research Advisory Council, Dr. Komaroff is a distinguished ME/CFS expert who has spent decades helping to define the disease, care for patients, and further public and scientific understanding.

Congratulations to Dr. Komaroff for this well-deserved recognition!



Dr. Anthony Komaroff and Oved Amitay

Dear Friends,

It has been an honor to serve you and our growing community as President and CEO of Solve M.E. On October 16, 2023 I stepped down from this role and would like to use this opportunity to share my thoughts with you, one last time.

So much has happened in the world since I made my commitment to join Solve in February of 2020. The global COVID-19 pandemic had tragic consequences, but also offered a silver lining: researchers and clinicians are now examining the common, overlapping clinical and biological factors of ME/CFS, Long Covid, POTS, Chronic Lyme and other associated conditions. We are working with our partners in this space to bring together this wider patient community, and I believe that Solve is now well positioned to provide leadership in the quest for better solutions to these growing unmet needs.

I am encouraged by recent research and new insights that can get us closer to finding solutions. In my next chapter, I will remain committed to leveraging my experience to advance diagnostics and therapeutics in this field.

I am thankful to Solve's Board for their incredible support during my tenure, and wish Kristin Jacobson all the best as the new leader of Solve. I know that the organization is in the right hands!

Leading Solve on behalf of our community during this challenging time was a privilege that changed me forever.

I am indebted to the dedicated staff, Board and mostly to you, who make this work possible.

Please accept my deepest gratitude for your friendship and support.

With my heartfelt regards,

Oved Amitay

Oved



Dear Solve community,

It is with excitement and enthusiasm that I take the helm of Solve at such a critical inflection point for the organization and our disease category.

I'm privileged to have been a member of Solve's Board of Directors before I was selected as Solve's new President and CEO. I've witnessed this organization's dedication to you, our community, and feel much optimism as I'm charged with building on these efforts.

Solve has been a leader in the ME/CFS disease space for over three decades, and we're beginning to see the labor of this organization's efforts in advocacy, research, and awareness bear fruit. Our community has grown exponentially with the inclusion of Long Covid, Chronic Lyme, and other infection-associated chronic conditions wreaking havoc on patients' lives. So too has the need to better understand how to improve the lives of all individuals experiencing various manifestations of these devastating conditions. Our shared family of patients stands to win when we combine our voices and demand to be valued, cared for, recognized, and invested in.

I have spent my career bringing attention, focus, and health access to underserved patient populations. Health equity and health access are my guiding principles, and I have fought especially hard to reach marginalized communities, communities of color, and low-income communities.

We are poised to soon make incredible gains for our community, and I am deeply committed to improving quality of life and achieving symptom relief for all individuals suffering. Together, we can remove the invisibility and isolation of the patient experience and speak together in one united voice to catalyze change.

With hope,

Kristin

Kristin



Kristin Jacobson
President and CEO

Oved Amitay
Strategic Advisor

Afifah Ayub
Clinical Data Coordinator

Ilise Friedman
Associate Director, Donor Relations

Erin Gary
Organization Support Coordinator

H. Timothy Hsiao, Ph.D.
Chief Scientific Officer,
Head of Research Strategy and Alliances

Amanda Martin
Engagement Manager

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Vice President of Advocacy and Engagement

Ani Vahradyan
Social Media and Marketing Manager

Jason Van Over
Database Administrator

Monique Wike
Advocacy Manager

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Glendale, CA 91206

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Solve ME/CFS Initiative
350 N Glendale Avenue
Suite B #368
Glendale, CA 91206

Telephone: 704-364-0016

E-mail: SolveCFS@SolveCFS.org

Website: SolveME.org

Facebook: [facebook.com/
SolveMECFSInitiative](https://facebook.com/SolveMECFSInitiative)

Instagram: [Solve_CFS](https://www.instagram.com/Solve_CFS)

LinkedIn: [Solve ME/CFS Initiative](https://www.linkedin.com/company/Solve-ME-CFS-Initiative)

Twitter: [@PlzSolveCFS](https://twitter.com/PlzSolveCFS)

YouTube: youtube.com/SolveME

Solve M.E. Chronicle archive:
SolveME.org/news-and-insights

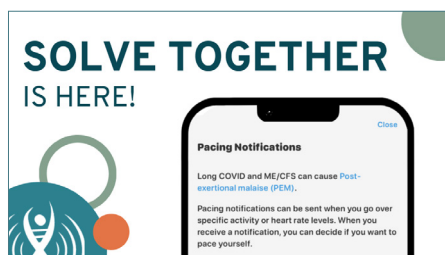
Humans of Chronic Illness:
HumansofChronicIllness.org

Solve Together:
SolveME.org/solve-together

SUPPORT SOLVE M.E.
SolveME.org/DONATE

FALL 2023

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 infection-associated chronic diseases. Our work lays the foundation for breakthroughs that can improve the lives of millions who suffer from various “long haul” diseases.



Solve Together is here! This patient-centered data platform brings extensive advantages to the ME/CFS and Long Covid patient communities and researchers. Fully accessible by smartphone, participants can track symptoms, connect wearables, download reports for doctor visits, link electronic health records, and more.

IN THIS ISSUE

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- An Interview with Solve Together Developers
- Community Letter from Chief Scientific Officer

