

Annual Report 2022-2023



Solve M.E.

Letter from the President

Two and a half years ago, Solve set out on a strategy to link ME/CFS with the emerging condition of Long Covid. While the initial scientific connections between these conditions were largely circumstantial, the past year has brought compelling evidence of shared biological roots among ME/CFS, Long Covid, dysautonomia, mast cell activation syndrome (MCAS), and other related conditions.



In response, Solve has broadened its mission, now encompassing a wider range of “infection-associated diseases,” particularly in our advocacy efforts and legislative initiatives.

Under this expanded mission, we are growing our research grant program to advance studies that pave the way for clinical trials. We’re also organizing conferences that bring together key players from the biotechnology and pharmaceutical industries, researchers, and the FDA to drive forward research and development. Additionally, we’ve launched new patient engagement initiatives to train advocates who can actively participate in and support research, ensuring that our research and programs are informed by the very communities they aim to serve.

At every opportunity, we are highlighting the connections between ME/CFS and Long Covid to both national and international audiences. By forming new alliances with other patient communities and advocacy organizations, we are enhancing our collective strength and influence.

The increased focus on Long Covid presents a once-in-a-lifetime opportunity to make significant strides in understanding and treating associated conditions like ME/CFS. We’re harnessing this momentum to push for more government funding and action, engage the pharmaceutical industry in the pursuit of solutions, increase equitable patient engagement, and amplify the voices of patient communities.

None of this would be possible without your steadfast support. Thank you for your continued investment of time, resources, and trust in our mission as we move forward on this hopeful path.

Oved Amitay

Oved Amitay
President and CEO
Solve M.E

New Ramsay Grant Researchers Push the Envelope with Innovative ME/CFS and Long Covid Studies



Deborah Duricka, PhD

Effect of Stellate Ganglion Block on ME/CFS Symptoms and Plasma Metabolites



Rob Wüst, PhD

Micro-clots, Skeletal Muscle Pain and Post-Exertional Malaise in Patients with Long Covid: from Pathophysiology to Treatment



Avik Roy, PhD

Targeting ATG13 in an Animal Model for ME/CFS



Dana Yelin, MD MPH

Enhanced External Counterpulsation (EECP), Non-invasive Approach to Treat Long Covid Fatigue



Katharine Seton, PhD

Immunosenescence, Premature Aging of the Immune System in ME/CFS and the Response to Fecal Microbe Transplantation



Solve M.E. ADVOCACY WEEK

April 17-22, 2023

222 Congressional Meetings

354 Attendees

47 States & D.C. Represented

95% Meetings Confirmed

13 member-level meetings

47 Senate meetings

175 House meetings

141 Democrat offices

80 Republican offices

1 Independent office

Fiscal Year in Review



August 2022

Solve M.E. launched the first of its kind national TV and Radio Public Service Announcement (PSA) campaign about Long Covid entitled “How Long?” The goal of this campaign is to broaden awareness of Long Covid, ME/CFS and other post-infection diseases, create empathy for those who suffer its devastating impact, and highlight the need for research to better understand it in order to adequately help patients. The campaign features :60, :30 and :15 TV and Radio ads in English and in Spanish. The videos garnered over 40,000 views across our YouTube, Instagram, Facebook, and Twitter channels.

As part of our August 8th Severe ME Awareness Day campaign, Solve collaborated with disability and LGBTQ advocate Jessica Kellgren-Fozard to create an informational video about severe ME/CFS. In addition to charismatically and accurately characterizing the disease, Jessica also shared the video to her YouTube channel with nearly 1 million subscribers.

September 2022

Solve M.E. Vice President of Advocacy and Engagement Emily Taylor recently attended the #MillionsMissing protest in Washington D.C. to highlight the fact that millions are being disabled from post-viral disease, including Long Covid & ME/CFS. Following her participation in the Millions Missing civil disobedience action on Monday, Emily returned to Capitol Hill to discuss current and future legislative solutions with key congressional champions, including Senator Markey and Representatives Bergman, Beyer, McGovern, and Swalwell.

October 2022

Solve’s Ramsay Grant Program Class of 2022 was announced and included the following projects:

- **Deborah Duricka, PhD** Effect of Stellate Ganglion Block on ME/CFS Symptoms and Plasma Metabolites
- **Avik Roy, PhD** Targeting Atg13 in an Animal Model for ME/CFS
- **Katharine Seton, PhD** Immunosenescence, Premature Aging of the Immune System in ME/CFS and the Response to Fecal Microbe Transplantation
- **Rob Wüst, PhD** Micro-clots, Skeletal Muscle Pain and Post-Exertional Malaise in Patients with Long Covid: from Pathophysiology to Treatment
- **Dana Yelin, MD MPH** Enhanced External Counterpulsation (EECP), Non-invasive Approach to Treat Long Covid Fatigue

Thanks to joint efforts of Solve and several other organizations, doctors will now be able to add a unique diagnostic code (G93.32) for ME/CFS into patient medical records. As of October 2022, Americans diagnosed with ME/CFS, including any new cases following COVID, will no longer be invisible.

As part of Solve’s “How Long?” PSA and awareness campaign launched in August, Solve organized a satellite media tour with 27 different TV and radio stations broadcasting to local audiences all over the United States. The day-long event included Interviews with medical expert and Solve Research Advisory Council member Dr. Peter Rowe and Solve board member and ME/CFS and Long Covid patient advocate Cynthia Adinig, which

received over 400 national airings and reached an estimated audience of 7 million (TV, radio, online).

November 2022

The Patient-Led Research Collaborative (PLRC) announced \$4.8 million in biomedical research awards for Long Covid and associated conditions. Seven of the awardees received early funding from Solve’s Ramsay Research Grant program, evidence that the Ramsay Grant program continues to fulfill its main objectives: to provide seed funding for innovative projects that will generate data to facilitate applications for larger grants, attract researchers to the field of ME/CFS and Long Covid and ensure they stay engaged, and add to the cumulative, scientific knowledge.

December 2022

The Milken Institute hosted their annual Future of Health Summit. Solve CEO & President Oved Amitay and Solve Board Member Cynthia Adinig joined other leaders in a panel on Thursday titled, “Is Long COVID the Next Public Health Emergency?” The three-day summit centered around the profound influence of the pandemic, which has informed our health systems, public policy, scientific discovery, communication, and more. It connected the Milken Institute’s community of changemakers to advance biomedical research, health equity, and food access to healthy longevity, mental health, and technological innovation.

The Chan Zuckerberg Initiative (CZI) awarded Solve M.E. a significant grant in support of our Long Covid Patient Lead-

er 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 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.

January 2023

Building on our commitment to centering the crucial voices from our community in the leadership and decision-making at Solve M.E., transformed our Community Advisory Council (2019 – 2022) into our new Lived Experienced Task Force (LET). LET's partnership with Solve will improve 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.

February 2023

Solve M.E. and The Biotechnology Innovation Organization (BIO) hosted a three-hour virtual event "Long Covid: What Will It Take to Accelerate Therapeutic Progress?" to convene stakeholders and advance research and development to diagnose and treat Long Covid, ME/CFS, and other post-infection diseases. The event included remarks by Long Covid patient and US Senator Tim Kaine, Admiral of the U.S. Public Health Service and U.S. Department of Health and Human Services,

Rachel L. Levine, M.D., as well as disease experts Akiko Iwasaki, PhD, Sterling Professor of Immunobiology (Microbial Diseases), Yale School of Medicine, David Putrino, PhD, Associate Professor, Rehabilitation and Human, Katie Bach, MBA, Nonresident Senior Fellow, Brookings Institution, among others.

March 2023

Kevin Timms, PhD, joined Solve's Ramsay Grant Program. His project, "Enriching the You + ME Registry: Exploring Access-to-care and Other Real World Data," focuses on patient data collected in Solve's You + ME Registry. It aims to enrich registry data with external geographic, socioeconomic, and other nonclinical variables to offer researchers a tool for hypothesis testing of how certain social circumstances affect ME/CFS and Long Covid patient outcomes.

April 2023

Solve hosted a hybrid in-person and virtual Advocacy Week in Washington, DC. 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.

In preparation for the FDA's virtual public meeting on Patient-Focused Drug Development (PFDD) for Long Covid, Solve hosted a free educational webinar featuring FDA experts who gave our community of patients and patient representatives tips on making an impact at the meeting and fully leveraging this unique opportunity to share experiences with important decision-makers.

May 2023

Solve M.E. and the Long Covid Alliance (co-founded by Solve) secured a \$77,000 CDC Foundation Grant to form a new infection-associated chronic conditions patient advocacy coalition (IACC PAC). The effort seeks to strengthen cross-sector partnerships among disease groups, to identify common objectives and actionable steps for this community.

June 2023

Solve Research Grant winner Armin Alae-dini (Professor of Medicine at Columbia University & New York Medical College) leveraged \$47,000 in seed funding from Solve into over \$275,000 in NIH follow-on funding to make important discoveries regarding the link between gastrointestinal, immunologic, and metabolic dysfunction in ME/CFS. In June, the results of this groundbreaking work were published in the prestigious Science Direct.

Independent Auditor's Report

To the Board of Directors, Solve ME/CFS Initiative,
Glendale, California

Report on the Audit of the Financial Statements

Opinion

We have audited the accompanying financial statements of Solve ME/CFS Initiative (a nonprofit organization), which comprise the statement of financial position as of June 30, 2023, and the related statements of activities, functional expenses, and cash flows for the year then ended, and the related notes to the financial statements.

In our opinion, the financial statements present fairly, in all material respects, the financial position of Solve ME/CFS Initiative as of June 30, 2023, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of Solve ME/CFS Initiative and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audit. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about Solve ME/CFS Initiative's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

Auditor's Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with generally accepted auditing standards will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial likelihood that, individually or in aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with generally accepted auditing standards, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the

purpose of expressing an opinion on the effectiveness of Solve ME/CFS Initiative's internal control. Accordingly, no such opinion is expressed.

- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about Solve ME/CFS Initiative's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control related matters that we identified during the audit.

Report on Summarized Comparative Information

We have previously audited Solve ME/CFS Initiative's June 30, 2022 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated March 22, 2024. In our opinion, the summarized comparative information presented herein as of and for the year ended June 30, 2022, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Lewis Sharpstone & Co.

Lewis Sharpstone & Co.
5850 Canoga Avenue, Suite 400
Woodland Hills, California 91367
September 27, 2024



The first You + ME Registry peer-reviewed paper was published in the August 2022 edition of the *Journal of Medical Internet Research*.



In August, Solve M.E. launched the first of its kind national TV and radio Public Service Announcement campaign about Long Covid, entitled "How Long?"



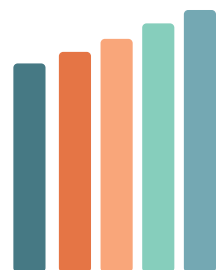
In October, Solve conducted a satellite media tour to raise awareness about Long Covid, ME/CFS and other post-infection diseases. Dr. Peter Rowe and patient advocate Cynthia Adinig were hosts.

Statement of Financial Position

June 30, 2023

(With Comparative Totals as of June 30, 2022)

ASSETS	2023	2022
Cash and cash equivalents	\$ 222,501	\$ 3,663,853
Investments	1,567,345	35,897
Contributions and grants receivable	326,648	194,184
Prepaid expenses and other assets	71,582	50,420
Total Assets	\$ 2,188,076	\$ 3,944,354
LIABILITIES AND NET ASSETS		
LIABILITIES		
Accounts payable and accrued expenses	\$ 527,903	\$ 473,438
Total Liabilities	527,903	473,438
NET ASSETS		
Without donor restrictions	1,322,430	3,362,611
With donor restrictions	337,743	108,305
Total Net Assets	1,660,173	3,470,916
Total Liabilities and Net Assets	\$ 2,188,076	\$ 3,944,354



Statement of Activities

Year Ended June 30, 2023

(With Comparative Totals for the Year Ended June 30, 2022)

	2023			2022
	Without Donor Restrictions	With Donor Restrictions	Total	Total
REVENUES AND SUPPORT				
Contributions and grants	\$ 1,125,846	\$ 863,051	\$ 1,988,897	\$ 5,474,111
In-kind contributions	174,087	-	174,087	212,690
Investment income	54,014	937	54,951	221
Net assets released from restrictions	634,550	(634,550)	-	-
Total Revenues and Support	1,988,497	229,438	2,217,935	5,687,022
EXPENSES				
Program services				
Research	1,262,558	-	1,262,558	1,788,823
Advocacy and communication	1,641,341	-	1,641,341	1,109,023
Total program services	2,903,899	-	2,903,899	2,897,846
Management and general	459,919	-	459,919	479,704
Fundraising	664,860	-	664,860	304,735
Total Expenses	4,028,678	-	4,028,678	3,682,285
CHANGE IN NET ASSETS	(2,040,181)	229,438	(1,810,743)	2,004,737
NET ASSETS, Beginning of Year	3,362,611	108,305	3,470,916	1,466,179
NET ASSETS, End of Year	\$ 1,322,430	\$ 337,743	\$ 1,660,173	\$ 3,470,916

Expanding Solve's Mission: Long Covid and Post-Infection Diseases

This year, Solve formally expanded our organizational mission to include Long Covid and other post-infection diseases.

Our Mission:

Make ME/CFS, Long Covid, and other post-infection diseases widely understood, diagnosable, and treatable.

The most prevalent Long Covid symptoms – crippling fatigue, post-exertional malaise (PEM) and cognitive dysfunction – mirror those of ME/CFS and both are post-infection diseases. We believe that learning more about Long Covid can deepen our understanding of ME/CFS, and that what we know about ME/CFS can shed light on Long Covid – and ultimately point to treatments and cures for both, as well as other “long haul” diseases that share their characteristics.

Solve M.E. embraces and supports many post-infection chronic disease communities, such as: ME/CFS, Long Covid, postural orthostatic tachycardia syndrome (POTS), other forms of dysautonomia, Ehlers-Danlos Syndrome (EDS), hypermobility spectrum disorder (HSD), and mast cell activation syndrome (MCAS). Solve has fought to increase federal funding dollars and research solutions that will make ME/CFS, Long Covid, and other post-infection diseases more diagnosable, better understood, and treatable.

While our mission statement is new, Solve M.E. has been a leader in the fight against post-infection diseases like Long Covid for nearly 40 years.

Based on decades of research and advocacy experience advancing the understanding of post-infection diseases, we were one of the first organizations to recognize the emerging threat of the long-term debilitating outcomes of the global COVID-19 pandemic.

As early as April 2020, we called on Congress to have immediate response measures, recommending budget appropriation to the National Institutes of Health (NIH)

for post-viral research. In December 2021, we launched our [Long Covid Initiative](#) to strengthen our response to this emerging crisis while ensuring that progress made will benefit everyone with a “long haul” disease.



We co-founded the [Long COVID Alliance](#) in February 2021, and expanded our advocacy efforts beyond ME/CFS to educate policymakers and accelerate research to address the emerging challenges facing those with ME/CFS, Long Covid and related “long haul” diseases.

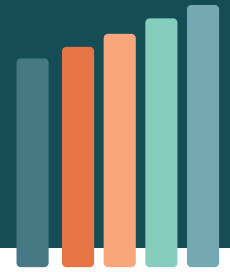


Solve M.E. also opened our You + ME Registry to include Long Covid and expanded our [Ramsay Research Grant program](#) to include the study of Long Covid. Both will help researchers track conditions similar to ME/CFS and other post-infectious diseases from onset, helping us to understand the effects of viral diseases on the immune system. We also produced a national Public Service Announcement (PSA) to raise awareness about Long Covid, published a white paper on the economic impact of Long Covid, and conducted multiple educational webinars designed to inform our community about the similarity of Long Covid to ME/CFS and other post-infection diseases.



The formal change to Solve's mission statement simply reflects our existing and ongoing commitment to make breakthroughs that can improve the lives of millions who suffer from ME/CFS, Long Covid and various “long haul” diseases.

Solve M.E. Team



Board of Directors

Each board member has a personal connection to infection-associated diseases. They either themselves live with these diseases, have a loved one who suffers, or care for people who are impacted.

Cynthia Adinig, Alexandria, VA
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Joseph Barerra, Newport, CA
Kenya Beckman, Los Angeles, CA
Victoria Boies, Chicago, IL
Stewart Gittelman, Lloyd Neck, NY
William Hassler, Esq., Washington, DC
Carol Head, Los Angeles, CA
Hunter Howard, Dallas, TX
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Barbara Lubash, Vice-Chair, Corona Del Mar, CA
John Nicols, Chair, Redwood City, CA
Fern Oppenheim, Scarsdale, NY
Amrit Shahzad, San Diego, CA
Rick Sprout, Secretary, Fairfax, VA
Janice Stanton, Harrison, NY
Karl Zeile, Westlake Village, CA

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Kate Mudie, Registry Research Manager
Leslie Phillips, You + ME Registry Lead
Emily Taylor, Vice President of Advocacy and Engagement
Ani Vahradyan, Social Media and Marketing Manager
Jason Van Over, Database Administrator
TaKeisha S. Walker, Chief Operating Officer

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School of Medicine

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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 Member:
Oved Amitay, President & CEO, Solve M.E.



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