

Annual Report Fiscal Year 2017-2018



Solve ME/CFS Initiative

Leading the Fight
to cure ME/CFS



Renewed Hope for the Future

Dear Friends,

In the last year we've seen real progress in the battle against ME/CFS; I'm proud that SMCI has played a leading role in many promising new developments. Some of those include:

- › Funding five proposals from six countries with our 2017 Ramsay Program Awards, and accepting new applications from the upcoming 2018 Ramsay Class
- › Hosting the largest ME/CFS Advocacy Day ever in Washington, D.C. and co-hosting a Congressional briefing, in the Capitol, on ME/CFS with Senator Ed Markey
- › Gathering preeminent leaders from research centers, federal health agencies, ME/CFS clinics, and the biopharmaceutical industry in Washington DC to participate in *SMCI's Second Annual Discovery Forum*
- › Launching a new ME/CFS research program with Dr. David Systrom at Brigham and Women's Hospital
- › Expanding a substantive biotech research partnership with Metabolon, conducted at Cornell
- › Issuing an action alert to restore federal Centers for Disease Control ME/CFS funding, with over 1,850 messages sent to Congress by advocates

And I'm delighted to welcome Dr. Sadie Whittaker as our new Chief Scientific Officer. Her innovative approach has brought new life to our research program. Her vision for our research program includes expanding the ME/CFS Registry/Biobank, funding more Ramsay grants, and collaborating with more researchers and industry players. She joins our staff of smart, creative, and dedicated people who, along with our volunteer board and Research Advisory Council, make SMCI a powerful force in the ME/CFS community.

I look forward to what the year ahead holds for all of us at SMCI, and for the communities we serve. Our generous donors, many of whom are ME/CFS patients, have provided great inspiration and fuel for our work. With them, we are a tenacious, passionate and caring community capable of toppling all obstacles to solving this terrible disease.

Onward together!



Carol Head
President and CEO
Solve ME/CFS Initiative



Carol Head, President and CEO

Fiscal Year 2017/2018* in Review

RESEARCH TO UNDERSTAND THE FUNDAMENTALS REGARDING ME/CFS

SMCI and partners initiated a new ME/CFS Research Fund at Brigham and Women's Hospital (BWH) in Boston, MA supporting the continuation of Dr. David Systrom's ME/CFS research.

At the Simmaron Research Institute (SRI) annual Patient Day and Research Update in Nevada, Dr. Maureen Hanson of SMCI's Research Advisory Council presented a summary of her recent work including data from the partnership with SMCI and data obtained from an NIH R21 grant.

SMCI launched a new partnership with Memorial Sloan Kettering Cancer Center (MSKCC) to investigate the biology of ME/CFS and explore investigation strategies using advanced technologies.

SMCI president Carol Head attended the Chronic Fatigue Syndrome Research Center Community symposium organized by the OMF/Stanford Genome Center. Other attendees included Ramsay '16 awardees Dr. Jarred Younger, Christopher Armstrong and RAC members Dr. Maureen Hanson (also a Ramsay '16 awardee) and Dr. Cindy Bateman.

The National Institutes of Health (NIH) recently committed a grant package totaling \$35 million over five years to support three ME/CFS Collaborative Research Centers (CRCs) and one Data Management & Coordinating Center (DMCC) in the United States. SMCI is a key collaborator in the CRC network.

SMCI held its second annual Discovery Forum, bringing together leaders from academia, government agencies, private clinics, and biotech and research institutions to discuss developments in ME/CFS research.

Dr. Maureen Hanson, a longtime SMCI collaborator and Research Advisory Council member, and her colleagues at Cornell University hosted a kickoff meeting of the Cornell ME/CFS Collaborative Research Center.

The Bateman Horne Center in Salt Lake City, Utah hosted a gathering of expert ME/CFS clinicians, including Center Director, Dr. Cindy Bateman (SMCI Research Advisory Council ad hoc member) and Dr. Sue Levine (Levine Clinic NYC, SMCI RAC member).

ADVOCACY TO OBTAIN ADDITIONAL FEDERAL SUPPORT FOR ME/CFS

SMCI's ME/CFS Advocacy Day on May 15, 2018 included 102 people with ME/CFS and their loved ones and 122 meetings with congressional offices—the largest ME/CFS Capitol Hill Day to date.

US Senator Ed Markey introduced Senate Resolution 508, a tri-partisan Senate Resolution to raise awareness and encourage more immediate government response for ME/CFS as part of ME/CFS Advocacy Day on May 15.

As part of ME/CFS Advocacy Day in May, Congressman Paul Gosar and Congressman Dwight Evans submitted a request for a hearing on ME/CFS to examine the ME/CFS clinical care crisis.

SMCI participated in the Chronic Fatigue Syndrome Advisory Committee (CFSAC) biannual meeting.

SMCI Ramsay Awardees Fane Mensah and Chris Armstrong met with members of the Australian Parliament to encourage further action and funding for ME/CFS research.

Working with other advocates, SMCI helped facilitate written questions about ME/CFS to be submitted to Dr. Francis Collins as part of his testimony before US House Appropriations Subcommittee.

GAINING PUBLIC AWARENESS AND COMMUNITY ENGAGEMENT

SMCI President Carol Head appeared on the nationally syndicated PBS show "The White House Chronicle," facilitating the first two episodes dedicated entirely to ME/CFS, and was also nominated for a WEGO Health Award as a Patient and Community Leader.

Dr. Sadie Whittaker, Chief Scientific Officer for the Solve ME/CFS Initiative, joined more than 90 international clinicians and researchers in a second open letter to *The Lancet*, calling for an independent re-analysis of the PACE trial.

SMCI President Carol Head was honored by *O, The Oprah Magazine* as a "2017 Health Hero," one of 14 "visionaries who are healing bodies, minds and communities."

SMCI's popular webinar series continued with "Hot Areas in ME/CFS Research 2018" presented by Dr. Anthony Komaroff of Harvard University.

SMCI President and CEO, Carol Head, was the dinner speaker at the 13th Annual Invest in ME Research conference in London.

NIH announced an unprecedented ME/CFS research conference in partnership with SMCI scheduled for April 4 & 5, 2019 at the NIH campus in Bethesda, MD.

As part of ME/CFS Advocacy Week, SMCI hosted a screening of the award-winning ME/CFS documentary *Unrest* in Washington, DC.

* 7/1/17 – 6/30/18

Independent Auditor's Report

Board of Directors
Solve ME/CFS Initiative
Los Angeles, California

We have audited the accompanying financial statements of Solve ME/CFS Initiative (SMCI), a nonprofit organization, which comprise the statement of financial position as of June 30, 2018, and the related statements of activities, functional expenses, and cash flows for the year then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes 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.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement.

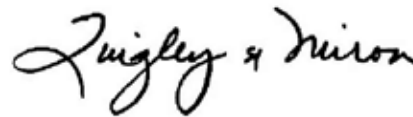
An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements 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 the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Solve ME/CFS Initiative as of June 30, 2018, and the changes in its net assets and cash flows for the year then ended, in accordance with accounting principles generally accepted in the United States of America.



Quigley & Miron
Los Angeles, California
November 2, 2018

Solve ME/CFS Initiative Statement of Financial Position

June 30, 2018

ASSETS

Cash	\$ 799,194
Investments	16,822
Prepaid expenses and other assets	17,182
Property and equipment, net	4,807
Total Assets	\$ 838,005

LIABILITIES AND NET ASSETS

LIABILITIES

Accounts payable	\$ 116,757
Accrued liabilities	46,978
Total Liabilities	\$ 163,735

NET ASSETS

Unrestricted	\$ 607,413
Temporarily restricted	60,857
Permanently restricted	6,000
Total Net Assets	674,270
Total Liabilities and Net Assets	\$ 838,005



Solve ME/CFS Initiative Statement of Activities

Year Ended June 30, 2018

	Unrestricted	Temporarily Unrestricted	Permanently Unrestricted	Total
SUPPORT AND REVENUES				
Contributions and grants	\$ 1,660,871	\$ 46,200	\$ 400	\$ 1,707,471
Interest and other income	5,828	-	-	5,828
Loss on investments	-	[3]	-	[3]
In-kind contributions—Note 9	26,397	-	-	26,397
Total Support and Revenues Before Reclassifications	1,693,096	46,197	400	1,739,693
Reclassifications				
Net assets released from restrictions	96,207	[96,207]		
Total Support and Revenue After Reclassifications	1,789,303	[50,010]	400	1,739,693
EXPENSES				
Program services	1,383,717	-	-	1,383,717
Management and general	169,719	-	-	169,719
Fundraising and development	269,235	-	-	269,235
Total Expenses	1,822,671	-	-	1,822,671*
CHANGE IN NET ASSETS	[33,368]	[50,010]	400	[82,978]
NET ASSETS at Beginning of Year	640,781	110,867	5,600	757,248
NET ASSETS at End of Year	\$ 607,413	\$ 60,857	\$ 6,000	\$ 674,270

*Note: Program expenses comprise 76% of total expenses.



Solve ME/CFS Initiative

Board of Directors*

All Board Members are ME/CFS patients or caregivers.



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Rick Sprout
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Janice Stanton
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Steve Curry
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Christine Williams, M.Ed.
Chevy Chase, MD

Research Advisory Council

Anthony Komaroff, MD

Simcox-Clifford-Higby Professor of Medicine at Harvard Medical School; Senior Physician at Brigham and Women's Hospital, Boston, MA

Sue Levine, MD

Former Chair, U.S. Department of Health and Human Services Chronic Fatigue Syndrome Advisory Committee; Founder, Medical Office of Susan M. Levine, M.D., New York, NY

José Montoya, MD

Professor of Medicine, Division of Infectious Diseases, at Stanford University Medical Center; Head of the Stanford ME/CFS Initiative, Stanford, CA

Sheila Stewart, PhD

Associate Professor of Cell Biology and Physiology at Washington University School of Medicine; Former Postdoctoral Fellow at University of California, Los Angeles; Former Postdoctoral Fellow, Whitehead Institute for Biomedical Research, Cambridge, M

Nathalie Bloch, MD, MPA

Director, Innovation Center, Sheba Medical Center, Israel

Daan Archer, MBA

Innovation & Product Lead, Founding Partner of a new tech decentralization company; Former Fulbright Scholar and MIT Sloan School of Management Fellow

Peter Rowe, MD

Director of the Chronic Fatigue Clinic at Johns Hopkins Children's Center Professor of Pediatrics, Johns Hopkins Children's Center, Baltimore, MD

Maureen Hanson, PhD

Founder and Director of the Center for Energating Neuroimmune Disease (CEND), Liberty Hyde Bailey Professor in the Department of Molecular Biology & Genetics, Cornell University

Tarek Absi, MD

Michel Silvestri, PhD

AD HOC MEMBERS

Cindy Bateman, MD

Founder & Chief Medical Officer of Bateman Horne Center, Salt Lake City, UT

Andy Kogelnik, MD, PhD

Founder & Medical Director, Open Medicine Institute, Mountain View, CA

John Nicols, Eng., MBA

President & CEO, Codexis Inc.; Vice-Chair, Solve ME/CFS Initiative Board of Directors, Atherton, CA

Morgan Fairchild

Actress; Medical Research Advocate; Former ME/CFS Patient, Los Angeles, CA



Solve ME/CFS Initiative

The Solve ME/CFS Initiative (SMCI) is a non-profit disease organization that works to accelerate the discovery of safe and effective treatments, strives for an aggressive expansion of funding for research that will lead to a cure and seeks to engage the entire ME/CFS community in research.

OUR VISION:

A WORLD FREE OF ME/CFS.

OUR MISSION:

**MAKE ME/CFS WIDELY UNDERSTOOD,
DIAGNOSABLE, AND TREATABLE**

What is ME/CFS? Myalgic encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) is a complex and debilitating chronic disease with a serious impact on quality of life. The disease affects up to 2.5 million Americans and an estimated 20 million people worldwide.

Professional Staff

Carol Head

President and CEO

Sadie Whittaker, PhD

Chief Scientific Officer

Emily Taylor

*Director of Advocacy and
Community Relations*

Carolyn Mayo

Director of Development

Allison Ramiller

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Karina Belyavskiy

*Accounting & Operations
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