

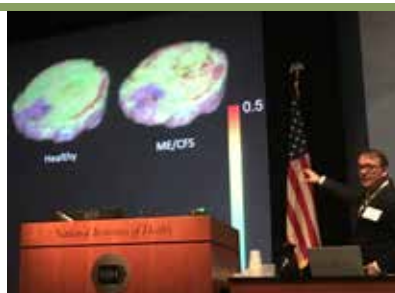


# Annual Report Fiscal Year 2018-2019



## Solve ME/CFS Initiative

Leading the Fight  
to cure ME/CFS



# Building Momentum for Our Next Chapter

Dear Friends,

This past year has been packed with exciting new developments that extend the reach of Solve M.E., driving progress in our fight against ME/CFS. 2019 marked some organizational changes, as our longtime CEO Carol Head transitioned onto the Solve M.E. Board and the search to find her successor was launched. Building on her legacy, below are just a few of the notable happenings from this fiscal year:

- › A major goal of our Ramsay Grant Program is to build an ME/CFS researcher workforce. This year's Ramsay Research Grant class was the largest we've funded to date, and it's clear that researcher interest in ME/CFS is growing. Not only did we receive double the number of requests for funding in 2018, half of the research teams that applied for funds came from researchers new to the ME/CFS field. The Solve M.E. Ramsay Grant Program provides funding to generate pilot data, bridging a gap in the research pipeline from innovative research ideas to larger grant dollars. We're thrilled that Dr. Jarred Younger from the University of Alabama, Birmingham recently secured a \$2.9 million multi-year R01 grant from the National Institutes of Health (NIH) to examine brain inflammation in ME/CFS based on promising findings from his [Ramsay pilot study](#).
- › In April 2019, we co-hosted our biggest ME/CFS Advocacy Week ever in Washington, DC. Our Lobby Day event drew over 240 registered ME/CFS advocates to attend 185 meetings with members of Congress and their staff. The week also included our first EmPOWER M.E. roundtable, dedicated to empowering patients and caregivers in the medical and advocacy environments, and giving our community tools to share our stories with impact. The event was livestreamed for viewers across the U.S. and will be available on DVD.

› Notably, the first-ever National Institutes of Health (NIH) conference devoted to ME/CFS took place in Bethesda, Maryland during 2019 Advocacy Week. Solve M.E. co-sponsored the conference, "[Accelerating Research on ME/CFS](#)," and a number of studies presented there were made possible by Solve M.E. Ramsay Grant Program funding and Solve M.E. sponsorship.

› Thanks in part to the groundwork laid by our 2019 Advocacy Day efforts, the U.S. Senate unanimously adopted S. Res 225: Supporting the goals of International Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Awareness Day and ME/CFS was added to the Peer-Reviewed Medical Research Program, opening \$350 million in new funding for applications from ME/CFS researchers. Both can be counted as huge, unprecedented victories for the ME/CFS community.

We close this fiscal year with the launch of our global [You + M.E. Registry and Biobank](#) on the near horizon. We believe this has the potential to be the single most important driver of progress in this disease. The more data we have on the most number of individuals affected by this disease, the greater our ability to identify disease subtypes, causes, and potential treatments. Stay tuned for our official launch in Spring 2020!

As the number of ME/CFS researchers and research opportunities grows and potential sources of federal funding increase, we're hopeful and excited about what the future holds for our fight against this terrible disease. Together, we will prevail.

Onward!



*Maryellen Gleason*  
Maryellen Gleason  
Interim President & CEO



*Sadie Whittaker*  
Sadie Whittaker  
Chief Scientific Officer



*Emily Taylor*  
Emily Taylor  
Director of Advocacy & Community Relations

**Solve M.E. is the only organization working holistically to solve this whole-body problem, advancing research, advocacy and disease education through programs that build fundamental capacity for ME/CFS.**

**CREATING** an ME/CFS research workforce through our Ramsay Grant program, designed to attract researchers, ensure they stay engaged, and facilitate them getting large NIH grants



- 16** original research projects funded
- 11** early-career researchers have gotten involved
- 34** Investigators and research Collaborators
- \$2.9M** awarded to Dr Jarred Younger by NIH, based on data generated through a Ramsay grant
- 4** experienced researchers have newly applied their expertise to ME/CFS

**PARTNERING** with federal and state government officials, medical and industry leaders, and scientific pioneers to ensure there are policies, funding and action to defeat ME/CFS

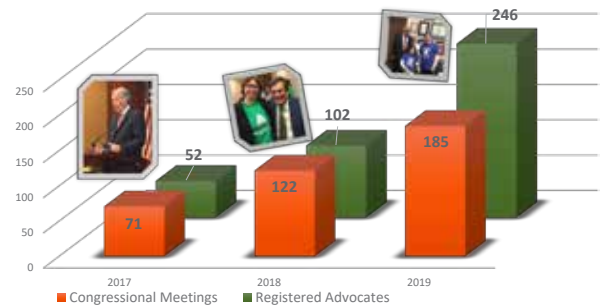


**CREATING** a Global Registry and Biobank that will serve as a resource for the entire ME/CFS community, allowing identification of subtypes and treatments



**SUPPORTING** individuals with ME/CFS and their caregivers through education and outreach

**Our ME/CFS Advocacy Day Impact**



# 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, 2019, 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.

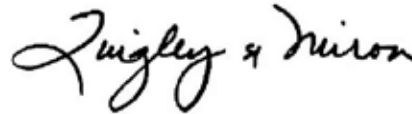
An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or 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, 2019, 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, 2019

# Solve ME/CFS Initiative Statement of Financial Position

June 30, 2019

## ASSETS

Cash	\$ 1,241,783
Investments	22,584
Contracts Receivable	125,421
Other Receivable	14,617
Prepaid expenses and other assets	28,532
Property and equipment, net	1,486

<b>Total Assets</b>	<b>\$ 1,434,405</b>
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## LIABILITIES AND NET ASSETS

### LIABILITIES

Accounts payable	\$ 69,815
Accrued liabilities	15,515

<b>Total Liabilities</b>	<b>\$ 85,330</b>
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### NET ASSETS

Without donor restrictions	\$ 1,193,424
With donor restrictions	155,651

<b>Total Net Assets</b>	<b>1,349,075</b>
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<b>Total Liabilities and Net Assets</b>	<b>\$ 1,434,405</b>
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# Solve ME/CFS Initiative Statement of Activities

## Year Ended June 30, 2019

OPERATING ACTIVITIES	Without Donor Restrictions	With Donor Restrictions	Total
<b>Support and Revenues</b>			
Contributions and grants	\$ 2,243,525	\$ 351,183	\$ 2,594,708
Interest and other income	1,620	-	1,620
In-kind contributions	66,511	-	66,511
<b>Total Support and Revenues Before Reclassifications</b>	<b>2,311,656</b>	<b>351,183</b>	<b>2,662,839</b>
Reclassifications			
Net assets released from restrictions	263,189	[263,189]	
<b>Total Support and Revenue After Reclassifications</b>	<b>2,574,845</b>	<b>87,994</b>	<b>2,662,839</b>
<b>Expenses</b>			
Program services			
Research	852,262	-	852,262
Advocacy and communication	689,088	-	689,088
<b>Total Program Services</b>	<b>1,541,350</b>	<b>-</b>	<b>1,541,350</b>
Supporting Services			
Management and general	149,842	-	149,842
Fundraising and development	296,808	-	296,808
<b>Total Supporting Services</b>	<b>446,650</b>	<b>-</b>	<b>446,650</b>
<b>Total Expenses</b>	<b>1,988,000</b>	<b>-</b>	<b>1,988,000</b>
<b>Change in Net Assets from Operating Activities</b>	<b>586,845</b>	<b>87,994</b>	<b>674,839</b>
<b>Nonoperating Activities</b>			
Investment return, net	-	800	800
Loss on disposal of equipment	[834]	-	[834]
<b>Total Nonoperating Activities</b>	<b>[834]</b>	<b>800</b>	<b>[34]</b>
<b>Change in Net Assets</b>	<b>586,011</b>	<b>88,794</b>	<b>674,805</b>
<b>NET ASSETS</b> at Beginning of Year	607,413	66,857	674,270
<b>NET ASSETS</b> at End of Year	<b>\$ 1,193,424</b>	<b>\$ 155,651</b>	<b>\$ 1,349,075</b>



# Solve ME/CFS Initiative

## Board of Directors\*

All Board Members are ME/CFS patients or caregivers.



**John Nicols, Eng.**  
Atherton, CA  
*Chair*



**Bill Hassler, Esq.**  
Washington, DC



**Vicki Boies, PsyD**  
Chicago, IL  
*Vice Chair*



**Carol Head**  
Los Angeles, CA



**Beth Garfield, Esq.**  
Los Angeles, CA  
*Secretary*



**Rona Kramer**  
Olney, MD



**Mike Atherton**  
Arlington, VA  
*Treasurer*



**Barbara Lubash**  
Corona del Mar, CA



**Andrea Bankoski**  
Chapel Hill, NC



**Rick Sprout**  
Washington, DC



**Diane Bean, Esq.**  
Bethesda, MD



**Janice Stanton**  
Harrison, NY



**Maryellen Gleason**  
Los Angeles, CA



**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

### **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, MA

### **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 Energizing Neuroimmune Disease (CEND), Liberty Hyde Bailey Professor in the Department of Molecular Biology & Genetics, Cornell University

### **Tarek Absi, MD**

Assistant Professor, Department of Cardiac Surgery, Vanderbilt University Medical Center Staff Surgeon, Cardiac Surgery, Nashville Veterans Administration Hospital

### **Michel Silvestri, PhD**

Head of Clinical Laboratory, Gotland Region, Sweden, Visby, Sweden

### **Rochelle Josylyn, PhD**

Immunologist, ME/CFS expert, independent consultant, advocate, Seattle, WA

## 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*

**Maryellen Gleason, MBA**

*Interim President & CEO*

**Sadie Whittaker, PhD**

*Chief Scientific Officer*

**Allison Ramiller, MPH**

*Director of Research Programs*

**Emily Taylor**

*Director of Advocacy &  
Community Relations*

**Jody Short**

*Director of Development*

**Karman Kregloe**

*Communications & Media  
Relations Manager*

**Shawna Woolridge**

*Communications & Media  
Relations Coordinator*

**Deborah Saady**

*Accounting & Operations  
Manager*

**Angie Brown**

*Development Coordinator*

**Jessie Brown-Clark**

*Administrative Coordinator*

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