



# Solve ME/CFS Initiative



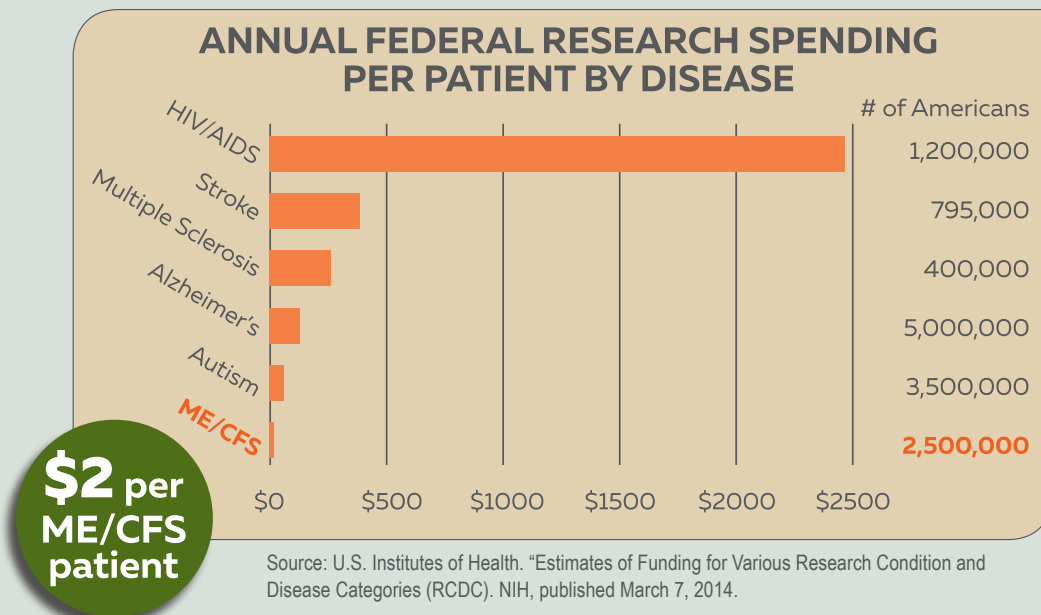
**The most prevalent, serious disease  
you've never heard of.**



**Annual Report  
2015**

**"Of the many mysterious illnesses that science has yet to unravel, ME/CFS has proven to be one of the most challenging."**

*—Francis S. Collins, M.D., Ph.D.,  
Director, National Institutes of Health, 2015*



# Building for the Future

Dear Friends,

I'm proud of the work our organization accomplished in 2015. And at the same time, I am chagrined by the slow pace of progress towards solving this disease that causes pain and anguish for so many. There remains so much to be done!

When I think of the **glass half full** at the end of 2015, I am proud that our organization played an important role. Here are just some highlights of Solve ME/CFS Initiative's accomplishments in 2015:

- We brought on board a powerhouse Vice President for Research and Scientific Programs, in **Dr. Zaher Nahle**. Dr. Nahle brought both his deep scientific knowledge as a PhD in physiology and biophysics, but also a public policy orientation with his MPA from Harvard's Kennedy School. And, most importantly, a grinding desire to join us in solving one of the critical medical problems of our time.
- We shone a bright light on the seminal Institute of Medicine (IOM) report that clearly described ME/CFS as a physical disease and called on the federal government to increase its commitment. Our March 2015 **briefing on Capitol Hill**, with both Dr. Ellen Clayton, who chaired the IOM report committee and activist and ME/CFS patient Morgan Fairchild, brought

critical attention to the IOM's findings and recommendations.

- We continued our **webinar series**, creating a forum for the best thinkers in ME/CFS research to be accessible to patients: Dr. Peter Rowe, Dr. Lily Chu, Dr. Cindy Bateman, Dr. Alan Light and Dr. Dane Cook.
- I was honored to bring the voice of patients and science to the **CFSAC** meetings, speaking forcefully for change. And when the federal responses to the CFSAC recommendations were inadequate, SMCI published a "report card" shining a light on the federal deficiencies.
- Dr. Nahle and I met with **senior level staff of the NIH** to urge more NIH commitment, more quickly.
- After meeting with the **senate appropriations committee**, we successfully beat back the zeroing out of all federal funding for the five year CDC study.

We are building **the most comprehensive research program** in the ME/CFS field. We were proud that our 2014 status garnered the highest **4-star rating from Charity Navigator**, the gold standard for non-profit integrity.

And, on most days I continue to see the **glass as half empty**. There is so much more that must be done to



*Carol Head, President and CEO*

bring relief for the pain and suffering of so many with ME/CFS. We have a long way to go to achieve an appropriate level of federal research funding. To change the public's perception of this disease. To educate medical professionals. And, simply, to find biomarkers, treatments, and a cure. Our mission "to make ME/CFS understood, diagnosable, and treatable" is far from being realized.

I'm proud of our role in this fight to solve ME/CFS...and know how much further we must go.

Onward!

A handwritten signature in black ink that reads "Carol Head".

*Carol Head  
President and CEO*

# Building for Research

Dear Friends,

This year brought significant changes to the world of ME/CFS, from the landmark Institute of Medicine (IOM) report to the announcement by National Institutes of Health (NIH) Director Francis Collins of the NIH's intent to bolster ME/CFS research through tangible and forthcoming actions.

This year also brought internal changes to our organization leading to extraordinary growth and new collaborations. I am so very pleased to have joined the work of this organization and to lead its research program assertively and creatively. Numerous innovative programs are being designed with special emphasis on rigor, quality, and durable partnerships with stakeholders and the greater community.

For instance, a new Research Advisory Council (RAC) of world-class leaders has been assembled to provide greater depth and value to our scientific programming. By welcoming a diversity of thought and cultivating expert opinions to address a complex medical problem, we benefit from the collective wisdom and the institutional memory of the whole group. This also keeps us honest to our mission—working on behalf of all patients. Our RAC experts include leaders in the field like Anthony Komaroff, MD (Harvard), Susan Levine, MD (CFSAC, Levine Clinic), Jose Montoya, MD (Stanford), Peter Rowe, MD (Hopkins), Cindy Bateman, MD (Bateman Horne Center), Andreas Kogelnik, PhD, MD (OMI) as well as a number of other science leaders and technology experts.

Also in the planning is a world-class national registry for ME/CFS, a grand project that will facilitate information sharing among organizations and boost the understanding to the natural history of the disease. Understanding the natural history of a disease is crucial for improving study design, clinical trials and tailored therapeutic interventions.

We are also gearing up to launch a new seed grants program that will engender international submissions with high-quality, innovative proposals. That is in addition to a travel award program for young investigators to attend ME/CFS conferences and build scientific networks. We also invigorated our medical webinar series to become the “go to” source for trusted, up-to-date medical information in the field. And our plan to participate in and contribute to scientific conferences and meetings has also been retooled: we are taking the lead in creating permissive environments for cross-pollination of ideas and the exchange of tools and information through established platforms and assemblies. We are working toward partnerships with leading medical centers, industry leaders and prestigious laboratories to conduct targeted, disruptive investigations that will change the status quo and bring different perspective to the field of ME/CFS in the areas of bioenergetics, neuroendocrine biology and immunity, among others. Finally, we continue to debunk and expose misleading information through opinion pieces that will help shape the accurate narrative of our disease and filter out the fad and the fallacies.

While we remain cognizant of the stubborn challenges confronting the community, we are determined to build on that momentum into the future.

Yours,



Zaher Nahle, PhD, MPA  
Vice President for Research and Scientific Programs



Zaher Nahle, PhD, MPA  
Vice President for Research  
and Scientific Programs

# Thank You

We thank our donors—thousands of patients, family members and friends—for their generous support of SMCI in 2015. Each gift helped to make our work possible, funding researchers and fostering innovation, collaboration and discovery.

**We couldn't do our work without you.** At SMCI, we will not rest until ME/CFS is understood, diagnosable, and treatable. You have our heartfelt thanks.

McDermott  
Will & Emery

We'd also like to give a special deep thanks to the hardworking team at the national legal firm McDermott Will & Emery LLP and our generous board of directors.

# 2015 Year in Review

## JANUARY

President Carol Head participated in a working group convened by the Chronic Fatigue Syndrome Advisory Committee (CFSAC) to craft a response to the Pathway to Prevention draft report, honing and strengthening its recommendations. SMCI endorsed the CFSAC response in its feedback to the P2P report.

## FEBRUARY

With contributions from SMCI, the Institute of Medicine (IOM) released a comprehensive report which included a new diagnostic criteria, called for more research, and proposed new disease name for ME/CFS. The report, commissioned by multiple government agencies, legitimized decades of patient advocacy and will continue to have a profound impact in the public sphere.

## MARCH

On Mar 25, Solve ME/CFS Initiative hosted a briefing in Washington, DC to move the IOM report on ME/CFS/SEID into action. The briefing gathered congressional representatives, reporters, government officials, and researchers, and more than 300 people viewed the event through a live webcast. The landmark report was reviewed and Carol Head, SMCI president and CEO, made a strong and compelling call for more federal research funding.

## APRIL

Dr. Lucinda Bateman delivered a webinar discussing whether SEID diagnostic criteria will improve diagnosis and treatment.

## MAY

SMCI co-hosted a Research Roundtable May 2 with the Massachusetts CFIDS/ME & FM Association. International ME/CFS Awareness Day was on May 12 and SMCI created an Awareness Day webpage to help people find a way to participate.

The Solve ME/CFS Initiative was reappointed as one of the liaison organizations for the Chronic Fatigue Syndrome Advisory Committee (CFSAC) for the term May 2015 through May 2017.

Suzanne Vernon stepped down as SMCI's research director.

## JUNE

Dr. Zaher Nahle joined our organization as Vice President for Research and Scientific Programs.

Stephen J. Elledge from Harvard and his graduate student George Xu used samples from the SolveCFS BioBank, in addition to blood samples from around the world, to look for antibodies against more than 200 viruses. Their work was published June 5 by *Science*, one of the world's top scientific journals.

Earlier in the month, SMCI hosted a webinar with Dr. Lily Chu called, "Post-Exertional Malaise: History, Characteristics, and Evidence."

## JULY

Dr. Zaher Nahle traveled to Salt Lake City, Utah to meet with ME/CFS research colleagues and gain first-hand insights into the patient experience. Dr. Nahle began his trip at the Bateman Horne Clinic, where clinic founder Dr. Cindy Bateman hosted him for a three-day workshop focused on clinical management and research of ME/CFS patients. Dr. Nahle also met with patients and their families.

SMCI welcomed Dr. Peter Rowe, director of the Chronic Fatigue Clinic at Johns Hopkins Children's Center, for his webinar, "Inducing Post-Exertional Malaise in ME/CFS: A Look at the Research Evidence."

## AUGUST

The Solve ME/CFS BioBank was renamed the Solve CFS BioBank and Patient Registry to reflect its scope as an even more accessible and robust resource for patient-centered research and also began to collect longitudinal data on individual subjects at multiple points in time.

Carol Head returned to CFSAC to present the needs of ME/CFS research and patients.

SMCI welcomed new board members John Nicols, whose wife has suffered from ME/CFS for more than 20 years, and Sue Perpich, whose brother has suffered from ME/CFS for more than 30 years.

## SEPTEMBER

SMCI launched the “Humans of ME/CFS” campaign, inspired by the wildly popular “Humans of New York” photoblog.

We published a video interview with Stuart Murdoch (an ME/CFS patient), lead

singer of the band Belle and Sebastian, when he was in Los Angeles performing as part of a world tour.

Solve ME/CFS Initiative President Carol Head was quoted in a *MedPage Today* article, “Chronic Fatigue: A Call for Real Answers to a Real Disease.” The article followed her remarks at the Aug 18-19 CFSAC meeting in Washington, DC. In the article, Head addressed the pressing need for greater awareness and understanding of the disease among healthcare professionals.

## OCTOBER

Dr. Zaher Nahle participated in the inaugural conference of the Patient Centered Outcome Research Institute (PCORI).

SMCI President Carol Head and board members met with committee staff members of the Senate Appropriations Committee following their Board meeting in Washington, DC. SMCI board and staff also met with NIH officials regarding

ME/CFS research and how to increase NIH funding.

Dr. Alan Light, Professor of Anesthesiology and Neurobiology and Anatomy at the University of Utah, conducted an educational webinar on Oct 15.

SMCI provided research materials and samples to support two new ME/CFS research projects through our Solve CFS BioBank and Patient Registry.

President Carol Head was invited to join the Patient Advocacy Board of UCLA’s Clinical and Translational Science Institute.

## NOVEMBER

President Carol Head and Vice President for Research and Scientific Programs Dr. Zaher Nahle met with NIH leadership, agreeing to partner with NIH’s National Institute of Neurological Disorders and Stroke (NINDS), the new home of ME/CFS research within the NIH, to deliver guidance, recommend researchers, and provide patient input.

The Solve ME/CFS Initiative webinar series welcomed Dr. Dane Cook from the University of Wisconsin, Madison, who presented “Post-Exertion Malaise: The Intersection of Biology and Behavior.”

## DECEMBER

President Carol Head joined CFSAC subcommittee for exploring the framework and feasibility of establishing centers of excellence.

Dr. Zaher Nahle presented a webinar summarizing the research summarizing the field of ME/CFS research throughout the year. ■

# Independent Auditor's Report

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

We have audited the accompanying financial statements of Solve ME/CFS Initiative (the Organization), which comprises the statement of financial position as of December 31, 2015, 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.

## Auditors' 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 from 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 auditors' 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 the Organization as of December 31, 2015, and the results of its operations and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.**

## Other Matters

As described in Note 10 to the financial statements, cash and net assets as of December 31, 2014 were restated to correct errors resulting in an overstatement of unrestricted revenue for the year ended December 31, 2014.

The 2014 financial statements were audited by Stanislawski & Harrison, whose practice became part of CliftonLarsonAllen, LLP as of December 1, 2015, and whose report dated July 9, 2015, expressed an unmodified opinion on those statements.

*CliftonLarsonAllen LLP*

CliftonLarsonAllen LLP | Pasadena, California  
March 8, 2017

# Solve ME/CFS Initiative Statements of Financial Position

December 31, 2015 and 2014

<b>ASSETS</b>	<b>2015</b>	<b>2014</b>
Cash	\$ 936,975	\$ 1,529,345
Contributions receivable	23,897	124,901
Prepaid expenses and other assets	42,126	33,532
Property and equipment, net	7,123	10,229
<b>Total Assets</b>	<b>\$ 1,010,121</b>	<b>\$ 1,698,007</b>

<b>LIABILITIES AND NET ASSETS</b>		
Accounts payable and accrued expenses	\$ 36,125	\$ 43,694
Other liabilities	72,185	38,262
<b>Total Liabilities</b>	<b>\$ 108,310</b>	<b>\$ 81,956</b>

Commitments		
Unrestricted net assets	\$ 812,371	\$ 1,118,793
Temporarily restricted net assets	84,040	491,858
Permanently restricted net assets	5,400	5,400
<b>Total Net Assets</b>	<b>\$ 901,811</b>	<b>\$ 1,616,051</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 1,010,121</b>	<b>\$ 1,698,007</b>



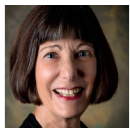
# Solve ME/CFS Initiative Statement of Activities

for the year ended December 31, 2015

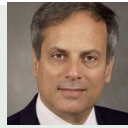
	Unrestricted	Temporarily Unrestricted	Permanently Unrestricted	Total
<b>SUPPORT AND REVENUES</b>				
Contributions and grants	\$ 1,185,842	\$ 50,112	-	\$ 1,235,954
Rental income	21,310	-	-	21,310
Interest and other	775	-	-	775
In-kind donations	254,162	-	-	254,162
Assets released from restrictions	423,820	(423,820)	-	-
<b>Total Support and Revenues</b>	<b>\$ 1,885,909</b>	<b>\$ (373,708)</b>	<b>-</b>	<b>\$ 1,512,201</b>
<b>EXPENSES</b>				
Program services	1,553,617	-	-	1,553,617
Management and general	274,768	-	-	274,768
Fundraising and development	363,946	-	-	343,946
<b>Total Expenses</b>	<b>\$ 2,192,331</b>	<b>-</b>	<b>-</b>	<b>\$ 2,192,331</b>
<b>LOSS ON CONTRIBUTIONS RECEIVABLE</b>	-	(34,110)	-	(34,110)
<b>CHANGE IN NET ASSETS</b>	(306,422)	(407,818)	-	(714,240)
<b>NET ASSETS</b> , Beginning of Year	1,118,793	491,858	5,400	1,616,051
<b>NET ASSETS</b> , End of Year	<b>\$ 812,371</b>	<b>\$ 84,040</b>	<b>\$ 5,400</b>	<b>\$ 901,811</b>

# Solve ME/CFS Initiative Board of Directors\*

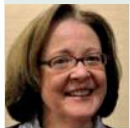
All members of the Solve ME/CFS Initiative Board of Directors have a personal relationship with the disease. They are either patients themselves or have a family member who suffers from it. This intimate connection furthers their commitment to making ME/CFS understood, diagnosable and treatable.



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



**Fred Friedberg, PhD**  
Stony Brook, NY



**Christine Williams, M.Ed.**  
Chevy Chase, MD  
*Vice Chair*



**Carol Spiciarich Mahoney**  
Fort Collins, CO



**Beth Garfield**  
Los Angeles, CA  
*Treasurer*



**John Nicols**  
Atherton, CA



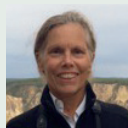
**Aaron Paas**  
New York, NY  
*Secretary*



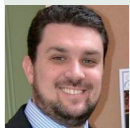
**Sue Perpich**  
Minneapolis, MN



**Mike Atherton**  
Arlington, VA



**Susan Vitka**  
Washington, DC



**Brett Balzer**  
Chicago, IL



**Carol Head**  
Los Angeles, CA



**Diane Bean**  
Bethesda, MD

\* at year end 2015

## Professional Staff\*

**Carol Head**  
*President and CEO*



**Zaher Nahle, PhD, MPA**  
*Vice President for  
Research & Scientific  
Programs*



**Mamie-Louise Anderson**  
*Administrative  
& Development Coordinator*



**Cheryl Belajonas**  
*Accounting, Human Resources  
& Administration Manager*



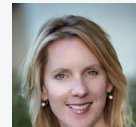
**Lauren Greene**  
*Development  
Administrative Assistant*



**Karen Petersen**  
*Director of Development*



**Jeryldine Saville**  
*Director of Communications  
& Engagement*



**Veena Manohar**  
*BioBank & Patient Registry  
Coordinator*





# Solve ME/CFS Initiative

The **Solve ME/CFS Initiative** (SMCI) was founded in 1987 and has established itself as the leading charitable organization dedicated to myalgic encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS).

**Our mission is to make ME/CFS understood, diagnosable, and treatable.** We do this by stimulating participatory, patient centered research aimed at the early detection, objective diagnosis and effective treatment of ME/CFS through expanded public, private and commercial investment.

**OUR VISION:** A WORLD FREE OF ME/CFS.

**OUR CORE VALUES:** TO LEAD WITH INTEGRITY, INNOVATION AND PURPOSE.

**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.



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