



# ANNUAL REPORT

Solve ME/CFS Initiative

# 2014

**ESTIMATED  
20 MILLION  
AFFECTED  
WORLDWIDE**

**UP TO  
2.5 MILLION  
AFFECTED  
NATIONWIDE**

**UP TO 91%  
OF PATIENTS  
NOT YET  
DIAGNOSED**

# what a difference a year makes



*Carol Head, President*

Shortly before the 2013 Annual Report was published, I had just joined the organization as President. Since that time, we have adopted a new name—the Solve ME/CFS Initiative—to better reflect our global, purpose-driven mission. In addition, we moved the organization’s headquarters from North Carolina to California to have ready access to a vibrant biomedical research community.

And while these were the most sweeping changes, we also implemented a number of narrower, though equally salient, organizational improvements.

**We reengineered** our Solve CFS BioBank so that it has a streamlined, scalable infrastructure to best handle procurement, management, tracking and the processing procedures for patients’ blood and tissue samples.

**We strengthened** our Board of Directors to expand our visibility and presence across the spectrum of industries and communities necessary to attract philanthropic investment in research initiatives.

**We improved** our competitive position for research funding as an organization that can manage multi-institutional collaborations that tap world-class resources in both academia and industry.

**We developed** new approaches to sustainable fundraising that move beyond “grass roots” support to increased philanthropic investments and competitive awards from public and private sources.

And while our organization implemented a significant number of changes in 2014, one thing remains the same: **our heartfelt gratitude for your support as we work steadfastly to make ME/CFS understood, diagnosable and treatable.**

Onward!

# on my desk I have the pictures of three ME/CFS patients I've never met

I look at them in the morning when I come in and again at night on the way out. They serve as a daily reminder that those who suffer in silence from this disease have real faces, names and families.

After less than two months at the Solve ME/CFS Initiative, I feel truly fortunate to have joined this community. My excitement to work on such a complex disease is increasing daily, and I find myself coming to the office with a bigger skip in my step thanks to the indomitable spirit of our patient community and the laser-like focus and dedication of my colleagues. My zest for the challenge at hand is also fueled by the unwavering commitment I see from researchers across the world—despite their paucity and lack of funding—to this righteous cause.

Like many researchers in this field, I was drawn to it first by sheer curiosity. But more important, I felt that my interdisciplinary training could add value in practical and tangible ways scientifically, as well as in matters



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

of public policy. My experience at the laboratory bench informs my approach to research, which is adaptive, methodical and thorough—the outcome of rigorous training and inspiring mentors at Cold Spring Harbor Laboratory and Stony Brook. My education in policy and management at the Harvard Kennedy School of Government has also proved particularly valuable in this post-Institute of Medicine report era. To effect change globally, we must devise clever and feasible policies, appreciate the rules of regulated industries and build consensus—regardless of personal differences or agendas—particularly in creative fields like scientific research.

While I am new to the field of ME/CFS, I am not a newcomer to the plight of the physically disabled as my association with the disability agenda is visceral and deep. It started in graduate school when I co-founded a trans-Atlantic organization, Ibrak Partners, with a classmate stricken by polio. Because of this endeavor, I know that the fight for recognition and cures for devastating non-communicable diseases like ME/CFS is not an easy one. **Yet, it is winnable.** Yes, there is a huge deficit in resources, but there is no shortage of talent or commitment to defeat this dread disease. Our visionary President Carol Head, a patient herself, reminded me recently of one of my favorite quotes from President John F. Kennedy: “We choose to go to the moon in this decade and do the other things, not because they are easy, but because they are hard.” So it is with solving ME/CFS.

So please continue to follow and support our growth and development. Together, we will succeed!

# 2014: the year in review

## JANUARY

Dr. Peter Rowe, Director of the Chronic Fatigue Clinic at Johns Hopkins Children's Hospital, completed a research study *funded by our organization* that looked at whether neuromuscular strain increases the cardinal symptoms of CFS, contributes to post-exertional malaise and increases central sensitization.

2014 was a transformative year for our organization, as we continued to make strides to Solve ME/CFS. Throughout the year, we held Research Roundtables in six cities—Los Angeles, Denver, Chicago, Washington, San Francisco and New York—to meet directly with patients and answer their questions about ME/CFS research. We also hosted seven webinars on ME/CFS research, featuring a range of investigators and clinicians, including Dr. Cindy Bateman, Dr. Dane Cook, Dr. Patrick McGowan, Dr. Peter Rowe and Dr. Derya Unutmaz.

Here's a look at our highlights, month by month.

## FEBRUARY

Dr. Marvin Medow, Professor of Pediatrics-Physiology and Associate Director of the Center for Hypotension at New York Medical College, completed a research study *funded by our organization* that investigated whether reduced cerebral blood flow is the cause of impaired cognition.

## MARCH

Our organization attended the 11th Biennial Conference of the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis in San Francisco. We hosted a roundtable discussion among leaders from various ME/CFS organizations involved in advocating for better clinical care, increased funding, improved public awareness and research progress.

## APRIL

Our organization began a months-long cooperative effort with other ME/CFS advocacy and research organizations to inform federal officials about the Institute of Medicine's work on ME/CFS and the NIH Pathways to Prevention program on ME/CFS.

## MAY

On May 12, our organization submitted a thorough review of the FDA Draft Guidance for Industry concerning ME/CFS. The document offered industry input on trial design and duration, potential efficacy endpoints, the need for patient-reported outcomes and safety considerations. The guidance focused on specific drug development and trial design issues that are unique to the study of ME/CFS and how effective treatments can be developed for the disease.

## JUNE

Our organization participated in the Chronic Fatigue Syndrome Advisory Committee meeting in Washington, D.C., to outline the strategies for our Solve CFS BioBank and Patient Registry.

## OCTOBER

We convened our Research Advisory Board and Governance Board for a joint discussion of new research strategies.

## NOVEMBER

The Solve ME/CFS Initiative was awarded a \$500,000 grant from the Dr. Ralph and Marian Falk Medical Research Trust to further explore epigenetic changes in ME/CFS patients versus controls. The competition for the Falk Grant was open to any U.S.-based research team; almost 250 proposals were received. Our organization was one of only a handful of projects to receive the award.

The Solve ME/CFS Initiative was awarded an Innovator Presentation slot at Partnering for Cures 2014, a FasterCures conference that was held in New York City.

## JULY

The first ME/CFS epigenetic study was conducted with samples from the Solve CFS BioBank and Patient Registry. The research was led by Dr. Patrick McGowan, with assistance from Wilfred de Vega, a PhD candidate at the University of Toronto. The paper, "DNA Methylation Modifications Associated with Chronic Fatigue Syndrome," was published in the open access and highly regarded journal *PLOS ONE*.

## AUGUST

We worked with Dr. Steve Elledge, Professor of Genetics at Harvard Medical School, and Dr. Lenny Jason, Director of the Center for Community Research at DePaul University, to interpret antibody profiling data. Elledge analyzed Solve CFS BioBank and Patient Registry samples with a new technology he developed at Harvard.

As part of our efforts to educate healthcare professionals on ME/CFS, we communicated with Medscape to receive the statistics on the 2008 Medscape course sponsored by the Solve ME/CFS Initiative. We subsequently shared this data with the Agency for Healthcare Research and Quality's Evidence-Based Center and the Institute of Medicine ME/CFS Committee.

## DECEMBER

The Solve ME/CFS Initiative provided updated research results to the National Institutes of Health's P2P meeting in Washington, D.C.

## SEPTEMBER

The Solve ME/CFS Initiative participated in a meeting in Palo Alto, Calif., to explore opportunities with two other research organizations that conduct ME/CFS research: the Chronic Fatigue Initiative in New York and the Open Medicine Institute in Palo Alto.

To sign up for our publications, go to [solvecfs.org/newsletters](http://solvecfs.org/newsletters).

To sign up for our blog, go to [solvecfs.org/blog](http://solvecfs.org/blog).

As we look back on 2014, we hold dear the support of and faith shown by you, our donors. Virtually all of the research progress that the Solve ME/CFS Initiative has funded has been made possible by individuals giving selflessly to invest in a brighter future for all those impacted by this insidious disease.

Thousands of individuals—patients, family members and friends—invested in our dream of a world free of ME/CFS. Whether you gave \$1 or \$100,000, you made a valuable contribution to our efforts to make ME/CFS understood, diagnosable and treatable. We stand united with patient families who understand the devastation of this disease and know that together we are making a difference.

To support  
the Solve ME/CFS  
Initiative's research  
efforts, go to  
[solvecfs.org/  
donate](http://solvecfs.org/donate).

thanks to  
our donors

## McDermott Will & Emery

The Solve ME/CFS Initiative extends our sincere thanks to the international law firm McDermott, Will & Emery, which has provided our organization with legal services pro bono. As a nonprofit with limited resources, MWE's contribution is invaluable in helping us to make well-informed decisions that impact the health of our organization and the work we are doing on behalf of the ME/CFS community.

# independent auditor's report

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

We have audited the accompanying financial statements of Solve ME/CFS Initiative (the "Organization"), which comprise the statement of financial position as of December 31, 2014, 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 audits 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 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 Organization'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 Organization'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, 2014, and the changes in net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.**

## Other Matter

The financial statements of the Organization for the year ended December 31, 2013, were audited by another auditor who expressed an unmodified opinion on those statements on March 10, 2014.



STANISLAWSKI & HARRISON

July 9, 2015



# Solve ME/CFS Initiative statements of financial position

december 31, 2014 and 2013

<b>ASSETS</b>	<b>2014</b>	<b>2013</b>
Cash	\$ 1,221,220	\$ 1,444,203
Contributions receivable	124,901	314,837
Prepaid expenses and other assets	33,532	33,977
Cash reserved for long-term purposes	356,926	-
Property and equipment, net	10,229	10,755
<b>Total Assets</b>	<b>\$ 1,746,808</b>	<b>\$ 1,803,772</b>

## **LIABILITIES AND NET ASSETS**

Accounts payable and accrued expenses	\$ 68,511	\$ 41,524
Capital lease payable	13,445	17,256
<b>Total Liabilities</b>	<b>\$ 81,956</b>	<b>\$ 58,780</b>

Commitments		
Unrestricted net assets	\$ 1,167,594	\$ 1,418,067
Temporarily restricted net assets	491,858	321,525
Permanently restricted net assets	5,400	5,400
<b>Total Net Assets</b>	<b>\$ 1,664,852</b>	<b>\$ 1,744,992</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 1,746,808</b>	<b>\$ 1,803,772</b>



# Solve ME/CFS Initiative statement of activities

for the year ended December 31, 2014  
with comparative totals for the year ended December 31, 2013

	Unrestricted	Temporarily Unrestricted	Permanently Unrestricted	Total	
				2014	2013
<b>SUPPORT AND REVENUES</b>					
Contributions and grants	\$ 671,431	\$ 644,079	-	\$ 1,315,510	\$ 2,155,405*
Research subcontracts	1,500	-	-	1,500	18,091
Rental income	3,875	-	-	3,875	-
Interest and other	631	-	-	631	2,432
In-kind donations	288,495	-	-	288,495	105,961
Assets released from restrictions	473,746	(473,746)	-	-	-
<b>Total Support and Revenues</b>	<b>\$ 1,439,678</b>	<b>\$ 170,333</b>	<b>-</b>	<b>\$ 1,610,011</b>	<b>\$ 2,281,889</b>
<b>EXPENSES</b>					
Program services					
Research	933,590	-	-	933,590	916,340
Engagement	334,511	-	-	334,511	248,936
Supporting services					
Management and general	175,474	-	-	175,474	68,768
Fundraising and development	246,576	-	-	246,576	236,808
<b>Total Expenses</b>	<b>\$ 1,690,151</b>	<b>-</b>	<b>-</b>	<b>\$ 1,690,151</b>	<b>\$ 1,470,852</b>
Loss on disposal of assets	-	-	-	-	1,968
Change in net assets	(250,473)	170,333	-	(80,140)	809,069
<b>NET ASSETS, Beginning of Year</b>	<b>1,418,067</b>	<b>321,525</b>	<b>5,400</b>	<b>1,744,992</b>	<b>935,923</b>
<b>NET ASSETS, End of Year</b>	<b>\$ 1,167,594</b>	<b>\$ 491,858</b>	<b>\$ 5,400</b>	<b>\$ 1,664,852</b>	<b>\$ 1,744,992</b>

\* includes a one-time, significant bequest

# 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, Ill.  
*Chair*



**Diane Bean**  
Bethesda, Md.



**Christine Williams, M.Ed.**  
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**Carol Spiciarich Mahoney**  
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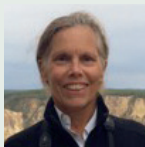
**Aaron Paas**  
New York, N.Y.  
*Secretary*



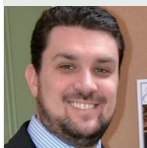
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**Mike Atherton**  
Arlington, Va.



**Susan Vitka**  
Washington, D.C.



**Brett Balzer**  
Chicago, Ill.



**Carol Head**  
Los Angeles, Calif.

## professional staff

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*President*



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



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



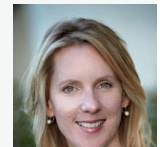
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*Accounting, Human Resources  
& Administration Manager*



**Karen Petersen**  
*Director of Development*



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



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





## Solve ME/CFS Initiative

Leveraging patient-centered  
research to cure ME/CFS

The **Solve ME/CFS Initiative** (SMCI) has been the leading organization focused on myalgic encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) since being founded in 1987.

SMCI envisions a world free of ME/CFS and works steadfastly to make this disease understood, diagnosable and treatable. SMCI seeks to actively engage the entire ME/CFS community in research, works to accelerate the discovery of safe and effective treatments, and strives for an aggressive expansion of funding towards a cure.

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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