



# Solve ME/CFS Initiative

Leveraging patient-centered  
research to cure ME/CFS

The Solve ME/CFS Chronicle

Summer 2016

## The Solve ME/CFS Initiative Research Plan

### Why We Ask for Your Support and How We Use Your Funds

Like other private ME/CFS research organizations, we rely on the generosity of families who live with ME/CFS. We appreciate the sacrifices made by our donors, large and small, and are highly aware that we must use each precious dollar strategically and effectively—hence the need for a strong research plan and our desire to describe it here.

#### The overarching objectives of our research plan are quite specific:

1. Increase understanding of the molecular basis of ME/CFS, which is the path to a cure
2. Identify a reliable biomarker and, therefore, credible, widely accepted diagnostic testing for ME/CFS
3. Develop effective treatment(s) for ME/CFS patients

#### Within those three overarching objectives, we have established three key areas of focus:

**Bioenergetics**, the field of science that describes the underlying biochemical activities of energy production needed for all cognitive and physiological activities.

**Immunity and inflammation**, including immune-surveillance and immunosenescence biology, pathogen/host

interaction, autoimmunity, immunotherapy, and pathologies of chronic inflammation.

**Neuroendocrine biology**, including the critical pathway that controls stress response, known as the hypothalamic-pituitary-adrenal (HPA) axis.

#### So, what are our programs for accomplishing these research objectives?

Our research plan is comprised of four components, split into two key areas: **external researcher** support and our organization's own **original research**.

#### First, we support *external researchers* in two ways:

**The Ramsay Award Program.** A continuation of our organization's longstanding grants to university researchers, we plan to award these seed grants every year. These grants attract participation from a wide variety of researchers, accelerate discoveries, and reduce barriers for entry into the challenging yet rewarding field of ME/CFS research. We do this by enabling scientists to pursue research projects that may not be funded otherwise,

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# A Letter from Our President

## Just How Long Must We All Keep On Keepin' On?!



Carol Head  
*President*

Dear Friends,

It is extraordinarily fascinating, gratifying, and frustrating to lead an organization working to solve this despicable disease each of us knows all too well.

The last several months have been an *exhilarating* time of forward movement for the ME/CFS community. And at the same time, this work is arduous. As president, it's my honor to talk with many of you who have this disease. And while SMCI can never claim to represent all patients, we hear from so many. Below is a sampling of the letters and calls I've received recently:



*An angry donor asking, "Why are you wasting time talking with those people at Health and Human Services?! They're all crooks. They have failed to significantly fund our disease for decades; why waste your time?!"*

My response: **Because that's where the money is.** The National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC), both of which fall under the umbrella of the US Department of Health and Human Services (HHS), have been, by far, the primary drivers of the medical research that has solved hundreds of diseases and saved millions of lives. According to their mission, "The Department of **Health and Human Services** is the United States government's principal agency for protecting **health** and providing essential **human services** to Americans."

Clearly, in the case of ME/CFS, HHS has failed. But HHS staff comes and goes, especially with the imminent presidential transition. Our cause is righteous. And while we don't put all our eggs in one federal basket, we would be utterly remiss if we did not continue to pound on the door to exact justice for all those who suffer with

ME/CFS. We are beginning to see cracks in that HHS wall, and we will pry those cracks open.



*A donor who asked if we could use additional funding for research and how, exactly, we would use the money.*

My response: Oh my goodness, yes! We can expand our Ramsay Award Program, fund our bioenergetics program, build out our BioBank and Patient Registry more quickly, or fund a convening meeting of researchers to build an ME/CFS Vision Plan to methodically identify the most promising areas of research. I could go on, as the research needs are enormous.



*A patient angry about the name of our disease, who noted emphatically that it should simply be called, "Chronic Fatigue Syndrome Sucks!"*

My response: I agreed with the sentiment and talked through the many strong opinions regarding the disease name; it is indeed complex. And, as we know, there is no one entity that has the authority to name diseases. None of us has forgotten that a new name for this disease must and will emerge, as the offensive name "chronic fatigue syndrome" undermines the severity and debilitation of this serious disease.



*Desperate patients upset they cannot find a doctor, cannot obtain disability, have been dismissed as malingerers, have become impoverished by the disease, have lost friends skeptical of the disease, or fear their child or spouse will take his/her life*

My response: No organization, including ours, can respond to all of these needs except by continuing to fight on for desperately needed funding for this disease.

All of this is heartbreaking. And at the same time, I do firmly believe in Dr. Martin Luther King's words, "The arc of the moral universe is long, but it bends towards justice." We have already waited a long time. And yet, we must continue to both fund smart, meaningful **research** and engage in knowledgeable, aggressive **advocacy**. That's what we do at SMCI: research and advocacy.

**So, we must keep on keepin' on.** There is no alternative. With intelligence, guts, transparency, knowledge, and the certainty of the justice of our work, we keep on.

Each night when my head hits the pillow, as I mentally scroll through the many small successes and challenges of a workday at breakneck pace, I pause to bring my head and my heart back to all the patients and families who suffer. I pause to remember the faces, desperate letters, and wrenching phone calls. And it gives me courage, once again, to get up the next day and continue the fight. **We are bending that arc toward justice.**

Onward,

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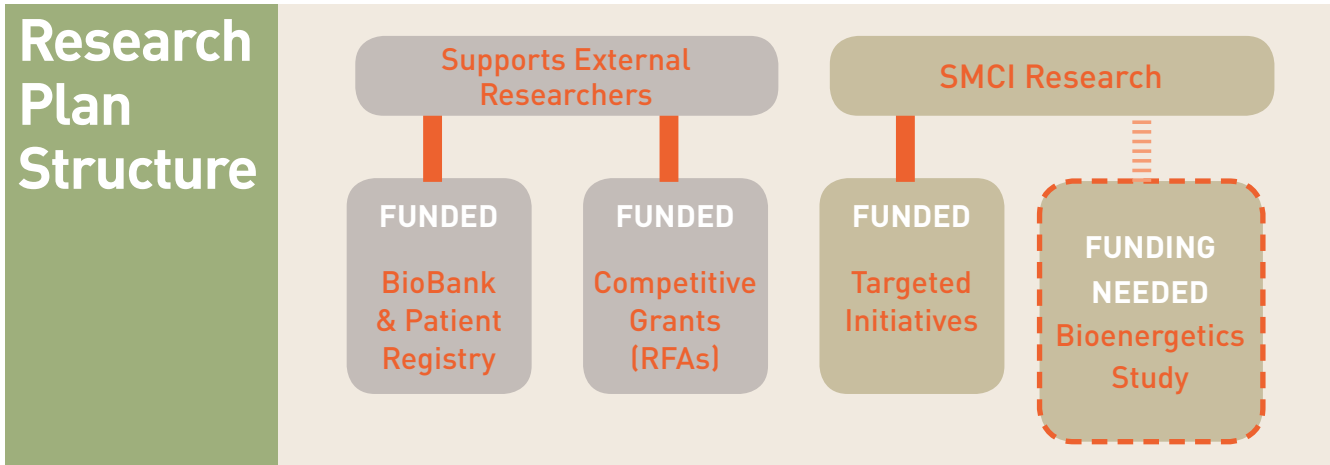
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Thank You for Funding the Fight

## The Solve ME/CFS Initiative Research Plan (continued from Page 1)



given the continued very low level of NIH funding for ME/CFS research. These grants also enable researchers to accumulate data to compete for larger federal grants requiring preliminary data or proof-of-concept investigations. We'll announce those who will be funded this year in the fall, once our rigorous peer review process has been completed.

**Our Solve ME/CFS Biobank and Patient Registry.** Our Biobank and Patient Registry is a repository of physical samples from patients to support the work of qualified researchers and accelerate discovery. This important aspect of the services we provide also links patients with researchers and facilitates the use of human samples for ME/CFS research.

**Second, a new aspect of our research program is conducting our own *original research*. This original research program also includes two components:**

**Targeted Initiatives.** These relatively modest studies dig into specific ME/CFS questions. Generally, they're quite focused and can be conducted relatively quickly, lasting

less than a year. Often, these initiatives take advantage of technological advances in science, allowing us to conduct studies that could not previously have been completed affordably. These projects are typically high risk/high reward and likely to generate information useful to the broader medical and scientific ME/CFS community. Results of these initiatives will be shared with the community to spark further studies.

We are currently embarking on targeted initiatives through three partnerships:

- **Metabalon** – We are under contract for high-tech analysis at a significantly reduced rate to explore metabolic changes in ME/CFS patients and determine patterns reflective of disease onset and progression
- **Memorial Sloan Kettering** – We have an agreement for lab access and genomic testing, where we will use the most current tools and technology to explore functional genomics
- **Washington University in St. Louis** – We have entered into a wet lab partnership to explore immunological and immunosenescence aspects of ME/CFS and the molecular basis of energy defects

**Bioenergetics Study.** As it is widely recognized that unexplained energy depletion is the signal characteristic of ME/CFS, our new study focuses directly on that attribute. This multi-million dollar, multi-year study is not yet funded, and we're actively seeking funds so that this innovative study can move forward. An umbrella project comprised of several individually ambitious studies, our Bioenergetics Study includes both hypothesis-generating and hypothesis-driven investigations and is designed to provide cumulative knowledge and fresh insights into the mechanism of bioenergetic defects in ME/CFS patients.

Desired outcomes for the bioenergetics study include

- Understanding the pathophysiology of bioenergetics in ME/CFS
- Identification of specific biomarkers for diagnosis
- Testing therapeutic interventions that will lead to therapy

### **In summary, SMCI's research plan is unique and comprehensive:**

A complex and poorly understood disease like ME/CFS calls for an agile, unbiased, and creative scientific approach. We use innovative models of public/private partnerships throughout our work that fall outside of the traditional, sometimes bureaucratic academic system. Our non-profit, non-university-based organization occupies a unique space that gives us the privilege to do a number of things—like facilitate the research of others, invest in in-house scientific research, provide services to investigators through our biobank, disseminate medical education information through free webinars and other communication channels, and much more.

SMCI is uniquely qualified to manage this research plan for several reasons:

- Our organization has the clout to create the **national network** of partnerships necessary for a project of this scope
- Our patient-centered approach allows us to **openly share results** without externally imposed restrictions, such as those occurring at universities
- We occupy a unique space in the ME/CFS community with **strong ties to patients**, advocates, and researchers
- Dr. Nahle is a **published expert** in the field of bioenergetics and brings credibility to those whom we approach; we benefit from his findings and data generated previously in his laboratory while studying cancer and diabetes
- We have a deep-seated **sense of urgency**, as patient interests guide our work
- We are **solely committed** to solving ME/CFS—not other related diseases

Our interface with the scientific and research communities is comprehensive. We are leveraging relationships to gain access to university laboratories without the burden of excessive overhead, benefiting from cutting-edge technology at a fraction of the standard cost, and collaborating easily with ME/CFS thought leaders, as well as those in other relevant disciplines.

We welcome comments about our research program. We're proud to engage in creative approaches to squeeze value out of every research dollar we can muster. Working with others in this field, we continue to chip away at the awful mystery of ME/CFS and look forward to the day when treatments, and potentially even cures, will give back the full joy of living to all who now suffer.

# A Letter from Zaher Nahle, PhD, MPA

## Vice President for Research and Scientific Programs

Dear Friends,

Like many of you, I followed the Olympic Games—an event that brings the whole world together every two years to celebrate human endurance, both physical and mental. This year, I could not help but wonder if members of our community might have been competing in the Olympics had it not been for a sneaky, debilitating disease called ME/CFS.

Prior to their afflictions, many ME/CFS patients were first-class athletes in college or driven, high-charging individuals across all sectors of society. This begs the following question: is there a biological link between being a “go getter” and ME/CFS? We don’t know the answer to that, for this not-too-far-fetched hypothesis has not been thoroughly examined beyond anecdotal reporting.

To that end, there are many examples in physiology and medicine illustrating how certain overt patterns of biological input can influence, positively or negatively, the functional status of the whole organism. In other words, it is now well recognized—aside from genetic predispositions, risk factors, and trait determinants—that the properties of cells, organs, and tissues can be fundamentally altered, or even reprogrammed, in response to exaggerated biochemical or electrochemical pressure.

An example is the response seen in pancreatic beta cells tasked with sensing low insulin levels and increasing the production of this all-too-vital hormone as needed. These pancreatic beta cells fail, wither, and actually die in the presence of excessive levels of insulin stimulation, as the adaptive balancing mechanism is lost, leading to harmful results.



Dr. Zaher Nahle, VP for  
Research & Scientific Programs

Another example is that of adult neurons—historically thought of as the least malleable of cells. Now we know these dynamic structures can be modulated considerably in what is becoming the fascinating field of **neuroplasticity**. Related to that are the two phenomena of long-term potentiation (LTP) and long-term depression (LTD). **These phenomena represent a marked change in the functional properties or capacity of neurons dictated by a pattern of activities around them.** The altered state of LTP and LTD has been connected to serious diseases like Alzheimer’s, dementia, and neurodegeneration.

In short, we don’t yet know if ME/CFS can be scientifically associated with an exaggerated history in athleticism or intense cognitive engagement. Thousands of patients must be examined methodically to understand the natural history of the disease, and we’re not aware of any current work in that field. In that regard, the registry we’re currently building will become useful in providing clues to these

kinds of questions. We DO know that a number of serious physiological changes underscore the disease, including immunological, metabolic, neurological, and energy system defects, among others. Unfortunately, we simply don’t yet have a large enough group of patients with sufficient life experience detail to draw any conclusions.

Research is the only way to unlock the mysteries of a complex disease like ME/CFS. In our previous *Chronicle*, we highlighted the bioenergetics aspect of ME/CFS. In this *Chronicle* issue, we summarize the organization’s work on many scientific fronts, including new initiatives and programs. We hope you’ll take a look.

Best,

A handwritten signature in black ink, appearing to be 'Zaher Nahle'.

# Research Study Conclusions in Brief

## Neuromuscular Strain in ME/CFS

A new study, partially funded by SMCI and published by **Dr. Peter Rowe** of Johns Hopkins and colleagues in the journal *PLoS One*, supports previous observations by the group that **increased mechanical sensitivity may be a contributor to the onset of ME/CFS symptoms.**

The results showed that, compared to individuals with ME/CFS in the sham strain group, **those with ME/CFS in the true strain group reported significantly increased body pain and concentration difficulties as well as increased composite symptom scores during the maneuver.**

“Healthcare practitioners should think long and hard about the practical implication of this study before recommending therapies involving neuromuscular strain like graded exercise therapy (GET) to their patients,” said Dr. Nahle,

vice president for research and scientific programs at SMCI. “This work makes it clear that such strain does increase symptom intensity in chronic fatigue syndrome.”

**Dr. Rowe** is a member of the SMCI Research Advisory Council and a professor of pediatrics at the Johns Hopkins Children’s Center in Baltimore, MD. To read the *PLoS One* study in its entirety, visit <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0159386>.

*SOURCE: Rowe PC, Fontaine KR, Lauver M, Jasion SE, Marden CL, Moni M, Thompson CB, Violand RL. Neuromuscular Strain Increases Symptom Intensity in Chronic Fatigue Syndrome. PLoS One. 2016 Jul 18;11(7). DOI: 10.1371/journal.pone.0159386.*

## Gut Microbiome and ME/CFS

Recent work from the **Dr. Maureen Hanson** group at Cornell University addressing the potential contribution of gut microbiome to the pathophysiology of ME/CFS was published in the journal *Microbiome*. In the study, researchers collaborating with **Dr. Susan Levine**, an ME/CFS doctor in New York City (and member of the SMCI Research Advisory Council), **correctly diagnosed myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in 83 percent of patients through stool samples and blood work.**

The study found that bacteria diversity was greatly reduced and there were fewer bacterial species known to be anti-inflammatory in ME/CFS

patients compared to healthy people. Researchers also discovered specific markers in ME/CFS patients of inflammation in the blood coming from gut bacteria that could be triggering an immune response, possibly worsening symptoms. In the future, the research team plans to look for evidence of viruses and fungi in the gut to determine how these microbes may contribute to the illness.

Importantly, such work stimulates all of us to investigate the mechanisms behind this anomalous bacterial presence in the blood (e.g., translocation mechanism, leaky gut) that could contribute to the disease. Notably, studies have previously implicated bacteria

such as chlamydia pneumonia in the pathophysiology of ME/CFS.

**Dr. Hanson** led a Solve ME/CFS Initiative (SMCI) webinar on her research on September 1 that is available to view on demand through our website at [solvecfs.org/2016-webinar-series](http://solvecfs.org/2016-webinar-series).

*SOURCE: Ludovic Giloteaux, Julia K. Goodrich, William A. Walters, Susan M. Levine, Ruth E. Ley, Maureen R. Hanson. Reduced diversity and altered composition of the gut microbiome in individuals with myalgic encephalomyelitis/chronic fatigue syndrome. Microbiome, 2016; 4 (1). DOI: 10.1186/s40168-016-0171-4*

# SMCI Research Roundup

A wide range of activities on the scientific and research fronts have been underway recently at SMCI. Here are some developments you may have missed:

## Creation of a new seed grant program, the Ramsay Awards

Review is underway for submissions to the recently established Ramsay Award Program. This competitive seed grant program is open to scientists and researchers at any career stage interested in studying ME/CFS. The program's main objectives are to invest in original ideas that could clarify the onset, progression, root causes, and natural history of ME/CFS; create open environments to attract, support, and retain scientific talent in the ME/CFS community; help awardees generate data to compete for long-term ME/CFS federal funding; and facilitate collaboration among dedicated researchers through the sharing of resources.



**meetME Travel Awards**

## Launch of the SMCI meetME Travel Award Program

The meetME Travel Award Program was created to aid collaboration and cross-pollination among professionals committed to solving ME/CFS by paying the travel expenses of junior scientists and underrepresented groups for ME/CFS-focused meetings and conferences around the world.



## Inclusion in the White Label Project funded by the Robert Wood Johnson Foundation

SMCI was one of only six disease-related organizations selected earlier this year to receive an award from the Robert Wood Johnson Foundation White Label Project. The competitive grant program, managed by Genetic Alliance (GA), gives SMCI the ability to use GA's Platform for Engaging Everyone Responsibly (PEER) to conduct our participant-centric research. The PEER network enables SMCI to launch a national, state-of-the-art patient registry for ME/CFS; includes built-in options for data sharing and collaboration among patients, researchers, and other disease organizations; and brings us one step closer to realizing the Chronic Fatigue Syndrome Advisory Committee's recommendation to establish a national patient registry.

## Formation of a new Research Advisory Council (RAC)

Announced in June 2016, the Research Advisory Council (RAC), comprised of medical practitioners as well as science and technology experts, was recruited based on SMCI's current and projected needs. A critical component of SMCI, RAC members will have input in a variety of matters such as study design, peer review, advocacy for research funding, strategic partnerships with academic centers or pharma, and more.



## Announcement of a robust educational webinar schedule for late 2016

SMCI's 2016 Webinar Series, moderated by Dr. Zaher Nahle and featuring thought leaders from academia as well as industry and government agencies, is offered free of charge on our website at [solvecfs.org/2016-webinar-series](http://solvecfs.org/2016-webinar-series).

With two webinars from September available on demand and three webinars scheduled between now and year-end, SMCI's 2016 Webinar Series is worth checking out.



## Advancement of the national ME/CFS agenda

Earlier this year, the Centers for Disease Control and Prevention (CDC) formed a Technical Development Workgroup (TDW) in response to concerns from the ME/CFS community that information on the CDC website is out of date and, in some cases, damaging to patients. SMCI's own Dr. Zaher Nahle is a member of this invitation-only workgroup consisting of medical professionals, patient advocates, researchers, and patients. Because the CDC website is a foundational source of information for many doctors who are not familiar with ME/CFS, we believe that by correcting the information found there we will help ensure clinicians receive accurate and appropriate information regarding the seriousness of ME/CFS and how it should be treated.

## Engagement with the scientific community at our Los Angeles office and around the world

In March, Dr. Nahle had meetings in New York to build collaboration regarding ME/CFS with researchers and clinicians like **Dr. Ian Lipkin** and **Dr. Mady Hornig** at Columbia University, ME/CFS expert and clinician **Dr. Sue Levine**, and **Dr. Scott Lowe** from the Memorial Sloan Kettering Cancer Center (MSKCC).

In May, Dr. Nahle met with collaborators at MSKCC to finalize a new functional genomics project. That month he also gave a presentation at the CDC on current ME/CFS affairs, as well as new research efforts underway at SMCI, before attending a number of meetings with event host **Dr. Elizabeth Unger** and other CDC scientists.

In June, SMCI staff was pleased to welcome Research Advisory Council member **Dr. Tarek Absi** to their Los Angeles headquarters to discuss a range of topics related to ME/CFS research and clinical manifestations.

## Participation in meetings and conferences on ME/CFS

Dr. Zaher Nahle will be lecturing on the most recent ME/CFS research advances at the CFS/ME Research Collaborative (CMRC) Annual Science Conference held September 28 – 29 in Newcastle upon Tyne, United Kingdom. Earlier this year, Dr. Nahle participated in the conference and associated colloquium (BRMEC6, Biomedical Research for ME Colloquium 6) held June 1-2 and organized in London by Invest in ME-Research, a UK-based charity.

# The Federal Government and ME/CFS: The Year in Review

The last several months have indeed been an exciting time of forward movement for the ME/CFS community, culminating in an August 2016 meeting between five ME/CFS advocates and the acting assistant secretary for health at the US Department of Health and Human Services (HHS)—second in command at the organization in control of a full quarter of the US discretionary budget.

With so many advocates working for decades to get DC to pay attention to our disease, how did we get here? Take a look at some of the community's recent efforts that helped get us to where we are today.

## The 2015 Briefing

In March 2015 on the heels of the groundbreaking report, “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness” by the Institute of Medicine (IOM), the Solve ME/CFS Initiative (SMCI) hosted an informational congressional briefing in Washington DC on both the IOM report and the devastation caused by this disease. While this report redefined the world of ME/CFS, no one in Washington was paying attention.

The briefing gathered congressional representatives, reporters, government officials, and researchers in addition to more than 300 live webcast viewers (to watch a recording of the briefing, go to <https://youtu.be/ZW2Tcsp75a0>).

## Forming an Advocacy Coalition

A few months later, after the August 2015 Chronic Fatigue Syndrome Advisory Committee (CFSAC) meeting, SMCI President Carol Head invited a number of members of the ME/CFS community, who had been conducting independent efforts at policy change, to meet together and discuss **potential collaboration**. This small step was the seed that grew into a nationwide working group, now led by long-time advocate Charmian Proskauer of the Massachusetts CFIDS/ME & FM Association.

The newly formed coalition rallied around a number of issues, including concerns about the intramural study from the National Institutes of Health (NIH), ME/CFS funding restoration by the Centers of Disease Control and Prevention (CDC), and congressional action.

Also that year, the netroots platform #MEAction was founded, and a powerhouse coalition was born. In December, this coalition made an impact by issuing a joint statement cosigned by 23 organizations and advocates. “To achieve these goals, we are going to need broad participation across the community,” the coalition wrote in its inaugural letter. To read the letter in its entirety, visit <http://bit.ly/2b21o2q>.

## The Congressional Visits

Last February, the newly formed advocacy coalition was put to the test when the administration submitted their FY

2017 budget proposal to Congress... with **zero** ME/CFS funding.

The community reacted immediately. SMCI President Carol Head and other advocates, including those from #MEAction and the coalition, flew to Washington DC to have urgent meetings across Capitol Hill. Eight different congressional offices were contacted, and a “Dear Colleague” letter was circulated in a crucial appeal to save the meager \$5.4 million currently allotted to ME/CFS at the CDC. **The efforts were successful**, as the Senate Appropriations Report reflected with strongly worded recommendations to both the NIH and the CDC.

But these successes were purely responsive. How could the ME/CFS community get attention **proactively**?



The #MillionsMissing DC protestors, led by #MEAction, among the empty shoes of hundreds of patients

## #MillionsMissing

All of these actions laid the groundwork for 12 separate #MillionsMissing protests on May 25, 2016, led by #MEAction. Carol Head delivered a powerful speech to the gathered patients, caregivers, and allies at the largest protest, held in San Francisco, CA, which can be viewed here: <https://youtu.be/Xo7L-dQv5eM>. #MEAction and the hundreds of patient activists made a statement that day that may have finally facilitated progress.



SMCI President Carol Head addresses the crowd at the #MillionsMissing action in San Francisco

## A Senior-Level Meeting at HHS

Following the May 25, 2016, protest actions, the work conducted by a nationwide group of advocates led by Mary Dimmock bore fruit: Jen Brea, Terri Wilder, Jennie Spotila, Mary Dimmock, and SMCI President Carol Head met with Dr. Karen DeSalvo, the acting

assistant secretary for health, marking the highest ranking meeting of patients and HHS officials in recent memory.

The meeting with Dr. DeSalvo, lasting a full hour, was positive and constructive. Dr. DeSalvo was very engaged and well prepared, leaving those participating with a sense of being heard.

The discussion called on HHS to dramatically step up its commitment to ME and focused on the need for fundamental change as well as the importance of including ME in the transition plan for the next administration to ensure that current efforts do not stall. Dr. DeSalvo agreed to a second meeting in October 2016 to continue forward movement.

Carol Head of SMCI said, "This meeting is a start. At long last, we are talking with the federal government at a level high enough to potentially bring about the massive increase in federal commitment to our disease that is warranted."

## The Future

With #MillionsMissing 2.0 on the horizon (demonstrations are scheduled on September 27), SMCI looks forward to making an impact in collaboration with #MEAction and advocates across the globe.

SMCI has also recently committed to new partnerships with **AllTrials**, an international initiative for scientific research transparency, and **Research!America**, the nation's largest not-for-profit public

education and advocacy alliance committed to making health research a higher national priority. In October, SMCI returns to Washington DC for additional actions and meetings.



SMCI President Carol Head at the main Washington DC Office of the US Department of Health and Human Services

## Getting Involved and Making Your Voice Heard

With two new staff members onboard, focusing on advocacy and communications, SMCI is poised to ramp up its influence. In the past year, SMCI, #MEAction, and advocates across the country have shown that every voice can make a difference.

No matter what your ability, education, or health, your story matters. Share your story online, and join the Humans of ME/CFS ([homecfs.solvecfs.org](http://homecfs.solvecfs.org)). Or, take your story to the next level. To become part of SMCI's advocacy and volunteer team, contact Emily Taylor ([etaylor@solvecfs.org](mailto:etaylor@solvecfs.org); 704-364-0016 ext. 209).

# SMCI Volunteers and the Silver Screen: Making a Difference

**Laura Furey has struggled with ME/CFS for six years.** Like many patients, Laura's ME/CFS started with a simple illness, and her condition slowly declined. At the age of 24, she was bedbound for eight months, unable to tolerate light or sound. Her weight dropped to a mere 80 pounds, and she was hospitalized. After her release, Laura was confined to a wheelchair for months.



ME/CFS patient and screening organizer Laura Furey

"When I was at my sickest, I swore—if I were ever to get better—I would give back," Laura recalls today. And she did. Earlier this year, Laura hosted one of the most successful screenings of *The Forgotten Plague* to date. Called a "must-see documentary" by the Huffington Post, *The Forgotten Plague* follows director Ryan Prior and his journey into myalgic encephalomyelitis as both a patient and a journalist.

Answering the call to action by SMCI, Laura brought together over 100 people for a screening of *The Forgotten Plague* in her hometown of Madison, Connecticut, to raise awareness, accept donations, and celebrate. With the help of her parents, Julie and Tom, she secured a commercial movie theater and solicited donations from

local businesses, generating a whopping \$4,800 for research and education efforts.

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**"When I was at my sickest, I swore—if I were ever to get better—I would give back."**

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Said Laura, "This screening was my way of giving back—by creating awareness for this disease and how much more is needed for progress to be made. I consider it a true gift that I was able to pull this event together."

## Are you interested in hosting a film screening?

Screenings range from small in-home gatherings to huge red carpet premieres. The goal of these screenings is to touch people—the number of people is up to you.

As Laura demonstrates, screenings are a great tool to raise awareness, recruit supporters, and raise money for ME/CFS research and advocacy. And SMCI can help you identify opportunities in your area. To learn more about hosting a screening, watch this three-minute video from Ryan Prior: <https://youtu.be/rZ-b1omWXH4>.

If you're interested in hosting a screening, please contact Emily Taylor, SMCI's advocacy and engagement

manager ([etaylor@solvecfs.org](mailto:etaylor@solvecfs.org); 704-364-0016, ext. 209) for assistance promoting your event. Or, you can contact *The Forgotten Plague* team directly at [info@forgottenplague.com](mailto:info@forgottenplague.com).

For larger screenings, you may find Tugg.com useful. They will handle all screening details, including securing a theatre, selling tickets, and promoting your event. Visit <https://www.tugg.com/titles/forgotten-plague> to get started today. Please choose Solve ME/CFS Initiative as your preferred organization to ensure the proceeds support our research and advocacy.

# Become Part of the SMCI Team—Learn How You Can Support Our Work

SMCI is looking for a few good women and men to make a difference in the ME/CFS community. Please check out the available volunteer positions below. This is a wonderful opportunity for patients—and especially friends and family of patients—to do meaningful work in the name of ME/CFS advocacy.

## Humans of ME/CFS Project Editors (3-7 hours per week)

Do you correct your friends' usage of "your" vs. "you're" on Facebook? If so, we need you! We are looking for a few good editors to review submissions and find the perfect words to promote awareness and understanding of ME/CFS. This is work you can do at home and only requires a computer, MS Word, email, and a good eye for grammar and written composition (see our Humans of ME/CFS webpage here: [homecfs.solvecfs.org](http://homecfs.solvecfs.org)).

## Regional Resource Researchers (time commitment varies and is flexible)

As patients know, there are remarkably few resources available for patients with ME/CFS—and our files regarding knowledgeable doctors and local support groups need an update. We are looking for regional volunteers willing to explore their local community for resources to share with other ME/CFS patients. This important work is done remotely, wherever you live, and at your own pace. Volunteers will be asked to create as comprehensive a list as possible of local organizations, doctors, services, and offices that may prove helpful to new patients.



## Film Screening Organizers (a one-time commitment of 10-15 hours)

As Laura Furey showed us (see story on page 12), film screenings that show the complexity and difficulty of ME/CFS can have a meaningful impact on your community. We want to get a screening of patient Ryan Prior's groundbreaking documentary *The Forgotten Plague* in every state across America. With several hours of your time and the participation of friends and family, you can host a successful screening too. The online [Tuggs.com](http://Tuggs.com) toolkit will give you everything you need, and SMCI will help you get the word out and support you in your work.

**If you're interested in one of the volunteer positions listed above, or have questions, please email Advocacy and Engagement Manager Emily Taylor ([etaylor@solvecfs.org](mailto:etaylor@solvecfs.org)) with your availability and contact information, making sure to list the position title that interests you in the subject line. Thank you for helping to give back to our ME/CFS community in this meaningful way.**

# Patient Voices

In this new, recurring section of the Chronicle, SMCI will feature the remarkable creativity and talent of ME/CFS patients through their art, writing, and other creations.

Here, we feature poems from a book of poetry by Vivian R. Treves. Vivian was first affected by ME/CFS in fall 1993 and still suffers from frequent relapses.



Vivian's poignant ME/CFS poetry collection *In The Shadow of the Eclipse* is available on Amazon at <https://smile.amazon.com/Shadow-Eclipse-Vivian-Treves/dp/059546369X/>.

To view a reading of "The Joys of Day" by the author, visit <https://youtu.be/JT-S7EMP36c>.

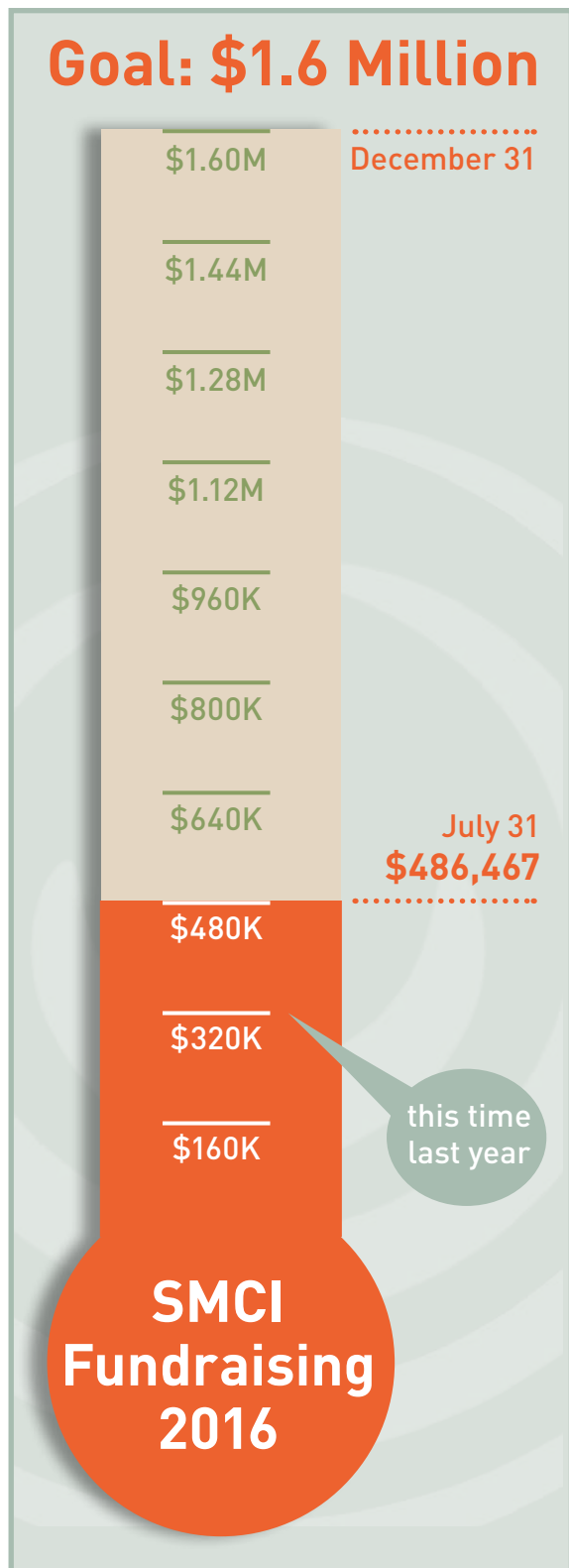
To submit an item to Patient Voices, please e-mail Emily Taylor at [etaylor@solvecfs.org](mailto:etaylor@solvecfs.org).

## The Joys of the Day

It is easier to be happy now  
 For the joys are little ones  
 Not having a headache  
 Or a muscle ache  
 Or forgetting something  
 Noticing that the sun is shining  
 Listening to hear birds singing  
 Sleeping the whole night fitfully  
 Having a friend call  
 Knowing that today  
 I am better than yesterday  
 These are the little joys.

Having CFS  
 Is like  
 Belonging to a club  
 You don't want to  
 Be a member of  
 The members themselves  
 Are wonderful  
 Kind. Generous. Empathetic.  
 They don't want to belong either  
 But it is nice  
 To find comfort in misery  
 And know we are not alone.

# THANK YOU for Funding the Fight



If you are reading *The Solve ME/CFS Chronicle*; our monthly email, *Research 1st*; and our weekly email, *SMCI This Week*, then you have a sense of how hard our organization is working on behalf of ME/CFS patients. We've made substantial progress in the first half of 2016, yet there is still so much more to be done.

We are so grateful for the nearly 1,700 gifts received from almost 1,000 donors so far this year—half of whom are new to us in 2016. Because of your generous support, we are tracking 52% ahead of last year's fundraising efforts to-date. So far, we have achieved 30% of our 2016 fundraising goal. And, yes, we understand that many ME/CFS patients have been impoverished by this awful disease and cannot donate. Regardless, we continue to work on your behalf.

***If you can, will you consider a gift to SMCI today to ensure that we sustain the fight for ME/CFS patients in the areas of both research and advocacy?***

## DONATE TODAY

Make your donation in one of three easy ways:

1  
Go to <http://solvecfs.org/DONATE/>

2  
Mail your gift using the enclosed envelope  
OR

send to Solve ME/CFS Initiative  
5455 Wilshire Blvd., Suite 806  
Los Angeles, CA 90036

3  
Call us at (704) 364-0016, ext. 201

***We are grateful for the financial support that powers our work!***

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## Solve ME/CFS Initiative

### **Our Vision:**

A world free of ME/CFS

### **Our Mission:**

Make ME/CFS understood, diagnosable, and treatable

We thank you for supporting our organization  
and being a part of what we do.

### **Stay in touch!**

Solve ME/CFS Initiative  
5455 Wilshire Blvd., Suite 806  
Los Angeles, CA 90036  
Telephone: 704-364-0016  
E-mail: [Communications@SolveCFS.org](mailto:Communications@SolveCFS.org)

**Website:** [SolveCFS.org](http://SolveCFS.org)  
**Facebook:** [www.facebook.com/SolveMECFSInitiative](http://www.facebook.com/SolveMECFSInitiative)  
**Instagram:** [solve\\_cfs](https://www.instagram.com/solve_cfs)  
**LinkedIn:** [Solve ME/CFS Initiative](https://www.linkedin.com/company/solve-me-cfs-initiative)  
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