



# The Solve ME/CFS CHRONICLE

SPRING 2018

## All in the Family: Is ME/CFS Inherited?

The quest to understand genetics and inherited traits is possibly one of the oldest and most exciting scientific endeavors. It is also a subject within ME/CFS that remains poorly understood.

Since people with ME/CFS can be found within the same family more often than random association would dictate, is there a possible genetic component to ME/CFS?

We've long understood that physical characteristics are inherited and that these same genes also contribute to our overall health and wellness. This includes the development and progression of various diseases. Today, we know that genetic mutations can cause complex diseases, from diabetes to cancer, and that genetic 'predisposition' can be a risk factor that shapes our health.

Our understanding of genetics has grown substantially. We can now read, map, interpret, and modify the building blocks that make up our DNA. Scientific advances now allow us to identify genetic irregularities quickly and for a reasonable

cost. A task that was science fiction just a few short years ago. In the near future, gene editing will allow us to correct 'faulty' genes associated with a range of human genetic disorders.

When discussing a complex disease like ME/CFS, particularly a sensitive topic like inherited traits, it helps to be mindful of at least three broad categories: classical genetics, epigenetics, and pathogenic-host interactions.

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# SMCI This Quarter: A Summary of Our Work

In this recurring section of *The Solve ME/CFS Chronicle*, SMCI summarizes the highlights of our work. Every quarter you see our SMCI team in action and our relentless efforts to make ME/CFS **understood, diagnosable, and treatable.**

## RESEARCH work in recent months

*SMCI seeks to engage the entire ME/CFS community in research and works to accelerate the discovery of safe and effective treatments.*

- SMCI held its second annual Discovery Forum, “a new era in ME/CFS research,” which brought together leaders from academia, government agencies, private clinics, and biotech and research institutions to discuss developments in ME/CFS research.
- SMCI announced the recipients of its 2017 Ramsay Program Awards which are funding **five** ME/CFS research proposals spanning **six** countries. The teams are exploring diverse promising areas including immunity, metabolomics, epigenetics, and the gut microbiome.
- SMCI announced the departure of Dr. Zaher Nahle. An international search is underway for new talent to fill the position of Vice President for Research and Scientific Programs.
- SMCI announced that the Request for Applications for the 2018 Ramsay Award Program cycle to open in May.

## INFLUENCE and EDUCATION work in recent months

*SMCI is a go-to source of trusted, up-to-date medical information, current research, and policy work on ME/CFS and seeks to disseminate this information effectively.*

- SMCI, an official partner with the impact team for the film *Unrest*, helped launch 10 days of house parties in conjunction with the film to raise awareness and education for ME/CFS.
- SMCI partnered with the widely-circulated women’s magazine *Ms.* and connected them with renowned author Julie Rehmeyer to produce an impactful piece on ME/CFS. The story “Pain and Prejudice”, which focuses on the struggle that women face in receiving a diagnosis for ME/CFS, was published in the Winter 2018 edition of the magazine.
- SMCI announced the kick-off of their 2018 Webinar series. The first installment, “Hot Areas in ME/CFS Research: 2018”, will be held in May.
- SMCI Scientific Administrator Allison Ramiller participated in a panel discussion on ME/CFS at the University Of California Berkeley School Of Public Health.
- SMCI launched a new video log series, “Fighting for ME with Carol Head,” in which President and CEO Carol Head shares her views on current issues in the ME/CFS space.

## SOLVE ME/CFS INITIATIVE PROFESSIONAL STAFF

Carol Head  
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Carolyn Mayo  
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Allison Ramiller  
Scientific Administrator

Diana Kerubo Sagini  
Development Coordinator

Karina Belyavskiy  
Controller / Human Resources /  
Administration

Sarah Jones  
Communication and Engagement  
Coordinator

*Each board member is a patient or has a family member affected by this disease.*



*Berkley School of Health Panel Discussion on ME/CFS including (left to right) David Tuller, Dr. Lily Chu, Dr. Ron Davis, Allison Ramiller (SMCI), and Dr. Jose Montoya (SMCI Research Advisory Council)*

## ADVOCACY work in recent months

*Through government advocacy, SMCI strives to enhance programs that serve patients and researchers and fights for an aggressive expansion of research funding.*

- Following a meeting with SMCI and in partnership with #MEAction, Congresswomen Ana Eshoo and Zoe Lofgren rallied 10% of the U.S. House of Representatives in a letter and appropriations request for ME/CFS.
- SMCI staff and board members stormed Congress to advocate for funding for ME/CFS from the Congressionally Directed Medical Research Programs.
- SMCI participated in the Chronic Fatigue Syndrome Advisory Committee (CFSAC) biannual meeting.
- SMCI joined Californian advocates in a Sacramento meeting with the California Department of Public Health to discuss improving California's response to ME/CFS
- SMCI solidified our continued partnership with the National Organization for Women, meeting in Washington DC. NOW has published newsletter pieces regarding ME/CFS.
- SMCI signed a joint letter and authored a supporting letter for Dr. Lily Chu's ICD-10 proposal, "Proposal for modifications to ICD-10-CM for Chronic Fatigue Syndrome, Myalgic Encephalomyelitis, and Post-viral fatigue syndrome," to the ICD-10 Coordination and Maintenance Committee. ■



*SMCI staff Emily Taylor and SMCI board member Rick Sprout visiting Capitol Hill to advocate for ME/CFS research funding*



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## All in the Family: Is ME/CFS Inherited? (cont'd)

**CLASSICAL GENETICS** is the study of genetics that hinges on how different genetic traits are passed down from parents to their offspring. Our genes contain instructions for the building and functioning of our body. The collection of genes known as the genome is grouped into structures called chromosomes. Most humans have 23 pairs of chromosomes and half of the genes are maternally or paternally derived. This is in addition to another set of genetic material in the mitochondria (known as the mitochondrial genome) that is inherited only from the mother. Variations in traits commonly seen in the population, such as hair color, arise from random mutations in the DNA code (polymorphisms). Other mutations, most often those that are rare, can be less benign and cause diseases. In ME/CFS, we have yet to identify a mutation in our genome of mitochondrial DNA that is responsible for the disease—like other definitive mutations that cause diseases such as cancer. However, a lack of evidence does not mean we can say it does not exist. It is worth noting, sequencing of the mitochondrial DNA in ME/CFS patients by a number of research teams has not revealed any characterized mutations that are associated with a metabolic disorder. However, they have shown some associated variations that did not rise to the level of significance.

Studies on the potential underlying genetic implications in ME/CFS have shown that both household contact

and genetic relationship are risk factors. This doesn't mean that either one is necessarily a cause. A 2005 study by Underhill & Gorman found about 20% of patients with sporadic ME/CFS reported having a family member with ME/CFS. In 18.3% of these patients, the affected relatives were genetically related and 70% of the genetically related family members were not living with the patient. Much more work is needed to better understand these reports, including larger groups and more robust methodologies.

**EPIGENETICS** is a research field that looks at changes in gene function and expression that are regulated by external factors. These changes do not involve alterations to the DNA sequence itself. For instance, DNA methylation—which entails the addition of a methyl group to DNA and often turns a gene to the “off” position—is widely recognized as one epigenetic mechanism of biological importance. DNA methylation relates to numerous cellular processes, and abnormal patterns of methylation have been linked to many disorders. In ME/CFS, there is growing evidence that epigenetic patterns are very different between patients and matched healthy controls, indicating that gene function and expression have been altered by some external factor in ME/CFS patients.

### **PATHOGENIC-HOST INTERACTIONS**

The interplay between humans and microbes and consequence for our health has historically been a major driver of medicine and research—and this now extends to the level of our DNA. Genetic variations play a large role in immunology and have been associated with susceptibility to various disease states. This variability is thought to be the results of long-term interactions between hosts and pathogens. In many cases, pathogens hijack our cellular machinery for their own survival. These pathogens can alter a range of critical functions, including immunity, metabolic regulation, and neurological function. Numerous viral and bacterial factors are associated with ME/CFS and could be triggers—especially for individuals with genetic predispositions.

There are indications that differential gene expression could underlie ME/CFS, which would explain some of the clustering patterns we see in families. But, much more research needs to be done. Efforts are currently underway to lay the foundation for stronger research. The development of integrative databases, like the upcoming SMCI Registry & BioBank, will allow for the collection of a much wider range of data—including genetic datasets. The Common Data Elements project, a national effort to develop standards for data elements and standardize relevant health information in ME/CFS, will strengthen comparative analysis.

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# SMCI Welcomes Two New Members to Its Board of Directors

We are pleased to introduce our newest board members: Barbara Lubash and Andrea Bankoski.

**Barbara Lubash** is a Director and Advisor for corporate and non-profit boards. She serves on boards of Advanced ICU Care and RedBrick Health. She is an Advisor to Clariful, Inc. and a member of Partners HealthCare Innovation Advisory Board.



In her prior careers as an executive and later as a venture capitalist, Barbara led and advised innovative healthcare and service organizations. She was

Co-founder and Managing Director of Versant Ventures and before that a Venture Partner at Crosspoint Ventures. Prior corporate boards include CodeRyte (natural language processing), Cogent Healthcare, Concerto HealthCare, Titan Health, and Vantage Oncology. She was Board Chair of the California HealthCare Foundation where she earlier led the development of the Foundation's PRI Impact Investment strategy (Innovation Fund). She was a senior executive at PacifiCare (health plan), and PHCS (a PPO), and held management roles at Hewlett Packard and the Harvard Community Health Plan (now Harvard Pilgrim).

She received a BS from Tufts University and a Master's in Health Policy and Management from Harvard University. She completed Board of Directors training at Stanford Directors College.

Barbara has close family members and friends struggling daily with the challenges of ME/CFS.

**Andrea Bankoski** has worked in public health leadership and clinical research for the past 17 years. She currently serves as the Assistant Data Manager at the Carolina Population Center at the University of North Carolina at Chapel Hill, where she manages the data for the National Longitudinal Study of Adolescent to Adult Health. Before her role at UNC, Andrea was the Chief Data Officer at the Maryland Department of Health. Andrea is also a person with ME/CFS. She earned her Bachelor of Arts, *cum laude*, from the Pennsylvania State University, a Graduate Certificate in Biostatistics from George Mason University, and a Master of Public Health in Epidemiology from George Mason University. ■



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## All in the Family: Is ME/CFS Inherited? (cont'd)

In short, the data and understanding of ME/CFS we have at this time does not exclude the possibility of a genetic contribution to the cause of

ME/CFS, but doesn't prove it either. There still hasn't been enough research to know for sure. ■

# What's in a Definition? Finding A Common Language for ME/CFS

Clinicians and researchers face huge challenges in distinguishing between ME/CFS cases and related conditions. As a multisystem disease without a known cause, ME/CFS can vary among patients. There is still no single official test or definitive definition to diagnose ME/CFS. Instead, it is diagnosed based by ruling out other fatigue-related health conditions, evaluating a patient's medical history, and using various overlapping case definitions that emphasize different aspects of symptom clusters.

Because ME/CFS is so complex, patients often wait years for a proper diagnosis. The different case definitions used to diagnose ME/CFS patients can also result in inconsistent selection of patients for research. This can sometimes result in unclear study results.

ME/CFS needs a common language, defined data standards, and improved coordination to allow researchers to compare studies and increase the effectiveness of clinical research. Fortunately, actions are currently underway to address this need internationally. Here we highlight two of those efforts, one in the United States and one in Europe.

## NINDS Common Data Elements

The Common Data Elements (CDE) project is a collaboration between National Institutes of Health (NIH) and Centers for Disease Control (CDC). Through this project, community members and disease organizations like the Solve ME/CFS Initiative (SMCI), are making a national effort to standardize and define the collection and sharing of health information in ME/CFS. Consistent data elements that overlap across study types will increase accuracy and allow for stronger comparison and analysis of ME/CFS and other diseases.

The CDEs will also make health information more easily accessible electronically. A problem with of electronic health records (EHR) in the broader healthcare delivery system is the lack of compatibility between networks of health systems. The CDEs will help the ME/CFS research field improve data and ensure that it can be communicated more universally.

There are other important national developments that the CDEs will factor prominently into—and strengthen. CDEs will be incorporated into the newly formed NIH Data Management & Coordinating Center (DMCC). The DMCC will serve as the organizing data hub for the ME/CFS Collaborative Research Centers funded by the NIH. SMCI is a co-investigator of the DMCC and will soon launch a national Registry, through the PEER platform, managed by Genetic Alliance, which will be designed to incorporate electronic health records and CDEs. This puts it in a prime position to be integrated into the DMCC and other efforts.

## Subgroups formed to work on the CDEs

- Baseline/Covariate Information
- Fatigue
- Post-Exertional Malaise (PEM)
- Sleep
- Pain
- Neurologic/Cognitive/Central Nervous System Imaging
- Autonomic
- Neuroendocrine
- Immune
- Quality of Life/Functional Status/ Cardiopulmonary Exertion Testing/Activity
- Biomarkers

## European Network on ME/CFS (EUROMENE)

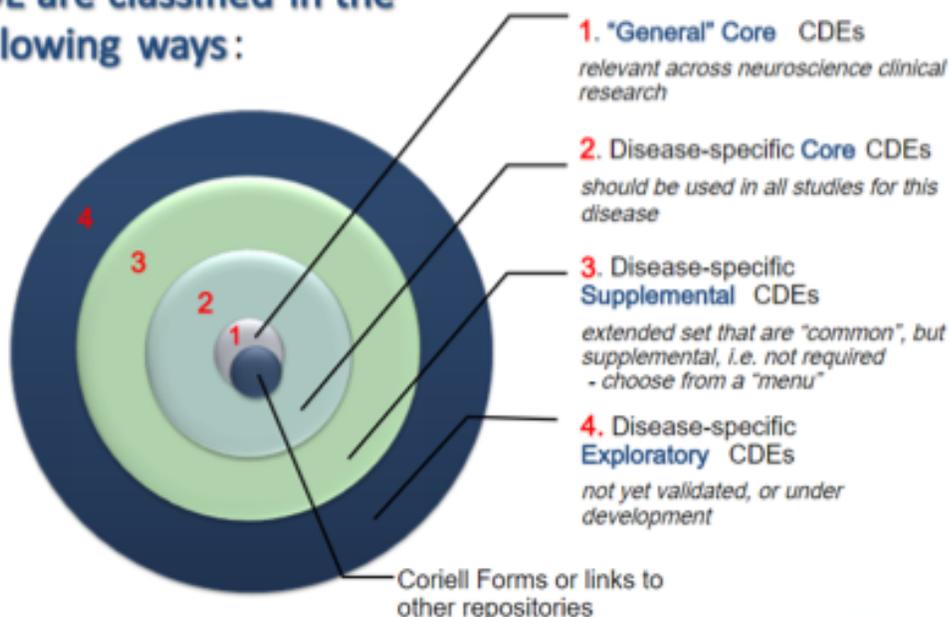
The European Network on ME/CFS (EUROMENE) was developed by the European Cooperation in Science & Technology. It works to enhance collaboration, develop common standards, and harness the power of data to aid the development of ME/CFS research strategies in Europe. The group is motivated to foster a network that will promote uniformity and improved diagnostic criteria for this disease. They aim to develop a data sharing system and use big data approaches in their research.

In a 2017 review published by the group on its Biomarker Landscape project, SCMI Ramsay Research award grantee Dr. Carmen Scheibenbogen and her co-authors highlight the need to better define patient subtypes. The dissimilarity among individuals with ME/CFS is considered a major obstacle to more refined study design and, ultimately, identifying the underlying pathobiology. Improved data collection efforts and

increased coordination by the European Network are important milestones to more understanding and progress for patients.

Common language standards will enable us to more reliably compare studies and improve clinical trial design. It will also help refine an accurate clinical definition and define a natural history of the disease. This opens the door for researchers to set and follow universal standards in discussing ME/CFS across the globe. We are seeing the beginning of a broad and collaborative research network that has the potential to bring together a comprehensive and integrated approach to data collection, management, and its use in research. ■

### CDE are classified in the following ways:



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES National Institutes of Health National Institute of Neurological Disorders and Stroke Project Overview

# PEM: It's Time to Retire the Term

## by Pete Hanauer




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A guest editorial by ME/CFS advocate Pete Hanauer. Mr. Hanauer was a law book editor for 35 years, after which he joined the staff at Americans for Nonsmokers' Rights, an organization he co-founded in 1976. He worked there for 16 years, analyzing thousands of tobacco control laws for a national database, until his chronic fatigue forced him to retire last summer. He lives in Berkeley, CA.

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**FOR MANY YEARS**, people who suffered the pain and disruption to their lives caused by ME/CFS also suffered the indignity of being thought, even by many doctors, to have a mental disorder or worse yet, to be malingerers. Fortunately, the medical community is now nearly unanimous in realizing that ME/CFS is very much a physical disease, with very severe consequences.

And yet, a remnant of the past remains in the terms still used to describe the primary symptom of the disease, namely the sheer exhaustion experienced by patients following even slight physical or mental exertion. The term, Post Exertional Malaise, or PEM, not only fails to accurately describe what happens to patients, but actually reinforces the idea that they have a mental or psychological condition.

According to Merriam Webster, there are two definitions of the word "malaise":

1. An indefinite feeling of debility or lack of health often indicative of or accompanying the onset of an illness
2. A vague sense of mental or moral ill-being

The first definition describes a "feeling" accompanying the onset of a disease—not the effect of the disease. The second relates totally to a mental condition. Moreover, a list of synonyms for the word "malaise" includes "unhappiness, uneasiness, unease, discomfort, melancholy, depression, despondency, dejection, angst, ennui; lassitude, listlessness, languor, weariness; indisposition, ailment, infirmity, illness, sickness, disease," all but the last few of which are mental or psychological conditions. In short, the term currently used to describe the principal symptom of ME/CFS strongly points to a mental or psychological illness rather than a physical one.

It is long past time to retire the term PEM and replace it with something that accurately reflects what happens to ME/CFS patients after physical or mental exertion and that respects their dignity. We suggest the term Post Exertional Disability, or PED. When patients must sit down or lie down after the slightest exertion, or are confined to bed or home, because they lack the energy to perform even routine tasks, they are, in a very real sense, disabled. ■

# Dr. Maureen Hanson: From Plant Biology to ME/CFS Champion

**DR. MAUREEN HANSON** is the Liberty Hyde Bailey Professor in the Department of Molecular Biology & Genetics at Cornell University and a member of the Solve ME/CFS Initiative (SMCI) Research Advisory Council (RAC). Notably, she is directing a National Institutes of Health (NIH) funded myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) Collaborative Research Center recently established at Cornell following a competitive grant process. Over the next five years, the Center will work on three primary research projects and work cooperatively with a network of three other ME/CFS centers. We recently sat down to speak with Dr. Hanson about her work.

***If you had a magic wand, what are the top three barriers you would remove first in order to accelerate the discovery process or improve the lives of patients?***

Despite recent increases in funds for ME/CFS at NIH, an important barrier is the relatively modest amount of NIH support devoted to grant proposals to study ME/CFS. The funding rates of investigator-initiated proposals at most NIH Institutes is less than 20%. If proposals to study HIV and AIDS had been this low during the AIDS epidemic, many more years would have been needed to develop life-saving drugs. We need the federal government, NIH, other government research agencies, and the general public to realize that there is a hidden disease raging that is taking away people's lives, even though most victims are not being buried in the ground. Requests For Applications (RFAs) for regular research grants are needed, with designated funding, so that a larger number of worthwhile proposals can be funded even if they don't rank



*Project Leads for the Cornell ME/CFS Collaborative Research Center at our "kickoff" meeting. Left to right: Dr. Dikoma Shungu (Radiology, Weill Cornell Medicine), Dr. Maureen Hanson (Molecular Biology and Genetics, Cornell University), Dr. Andrew Grimson (Molecular Biology and Genetics, Cornell University).*

## SOLVE ME/CFS INITIATIVE RESEARCH ADVISORY COUNCIL



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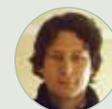
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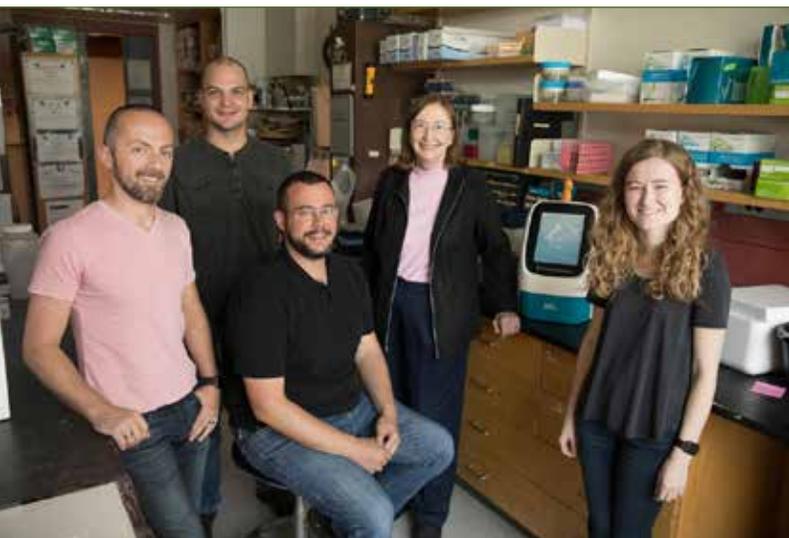
## Dr. Maureen Hanson: From Plant Biology to ME/CFS Champion (cont'd)

in the top 20% of all proposals submitted to NIH. A proposal that ranks in the top 25% is not a “bad” proposal that cannot accelerate the discovery process for this neglected disease. But without a targeted RFA with a designated funding level, such a proposal will be rejected.

Second, my wand would wave a readily performed diagnostic test into existence. If patients could arrive at their doctor’s office complaining of ME/CFS symptoms, and a simple blood or urine test could be ordered that would reveal whether or not the patient has ME/CFS, then no longer would patients be told they are lazy, have psychosomatic illness, and are not truly physically ill. Also, such a test would likely stimulate interest from the pharmaceutical industry in drug development. Once patients can be objectively measured, and the difference between an ill and a healthy

individual can be observed, drugs can be tested and the patients’ responses to the drug can be objectively measured to determine whether the drug induces a healthy profile.

Third, I would have the FDA approve a drug for the treatment of ME/CFS. The best candidate for such a drug is Ampligen, which is a miracle for those patients who respond, though only a subset does respond. The approval of a drug in the US that can restore some patients to health has great value symbolically. It will demonstrate to the medical profession and the general public that the disease can be treated and that more drugs that help additional subsets of patients can and should be developed. The drug industry will take notice. And at least some fortunate Ampligen responders will get their lives back.



The ME/CFS researchers in the Hanson lab. Left to right: Dr. Arnaud Germain, Mr. Adam O’Neal (graduate student), Dr. Ludovic Giloteaux, Dr. Maureen Hanson, Ms. Alexandra Mandarano (graduate student).

### **What policies can be advanced by advocates and government officials that will support progress in ME/CFS? What are some of the barriers/strategies to enacting these policies?**

Advocates need to pressure the federal government for additional support for ME/CFS for relevant agencies, including NIH, CDC, and in the Department of Defense. I would wager that a large number of service personnel have been disabled by ME/CFS. They need the same attention and research support given to their disease as has been provided to study Gulf War illness.

I have heard it said repeatedly at CFSAC [the Federal Chronic Fatigue Syndrome Advisory Committee] meetings by various governmental agency representatives that there are not enough researchers who are interested in ME/CFS, so no more funds for ME/CFS research grants should be allocated. I disagree. Researchers will come into the field once funds are available. How many individuals were studying retroviruses when HIV was initially discovered? The answer is very few. But funding for AIDS resulted in many researchers from other fields changing their research em-

phasis to work on HIV/AIDS. Because of the hypercompetitive nature of NIH grant funding these days, many new researchers would be attracted into the field were RFAs for ME/CFS proposals available.

***How could the NIH-sponsored center that you lead affect change and improve our understanding of ME/CFS?***

Our Center is focused on one of the most disabling symptoms of ME/CFS: post-exertional malaise (PEM). We want to understand why it occurs and we are using the phenomenon to probe what goes wrong in victim's bodies when it is happening. Our research projects will gather data about patients in their baseline state and after PEM has been induced. Learning what has changed at the molecular, biochemical, neurological, and physiological levels may reveal to us what fundamental disruptions are occurring in the disease. At Weill Cornell Medicine, Dr. Dikoma Shungu is leading a project to assess neuroinflammation and oxidative stress in the brain. At Cornell-Ithaca, I am supervising a project to examine the role of extracellular vesicles, signaling molecules, and metabolism. Functioning of the immune system will be studied through single-cell RNA sequencing in a project led by Dr. Andrew Grimson. All of these projects also have the potential to lead to diagnostic tests for the disease. Our website [www.neuroimmune.cornell.edu](http://www.neuroimmune.cornell.edu) provides more information about these projects and the collaborators and patient advocates who are associated with the Center.

***Why are you so dedicated to the MECFS population and what sparked your interest in this disease in the first place?***

I am very aware of the seriousness of the disease and how it affects patients' lives since my adult son has now been ill for 20 years and has missed many of the milestones of adolescence and young adulthood. Fortunately, he is not bedbound, though he is largely housebound and must spend much of the day horizontal. After he was diagnosed, I attended the IACFS [International Association for Chronic Fatigue Syndrome] meetings in 2004 and 2007, where I realized that very few molecular geneticists were studying the disease. All my previous scientific research had been in plant genetics and I had never previously studied human genes. But, to paraphrase Gertrude Stein: a gene is a gene is a gene. I knew that I could contribute to knowledge of ME/CFS and thus 10 years ago, I began seeking grant support to initiate biomedical projects.

***Where do you think the major finding will come from? Do you have a favorite theory?***

It is my theory that a single fundamental biological disruption underlies the disease, despite the differences seen between the symptom constellation in patients, the existence of subsets of treatment responders, and variation in the illness-inciting events that patients report. Real progress will be made in producing therapies once the identity of this damaging culprit is revealed. There may be existing, FDA-approved drugs that could benefit patients, if we understood the cause of the disease and therefore knew that the medications should be administered. Such existing drugs give the best chance to improve the lives of patients without long delay. ■

# Advocacy in Action: 44 Members of Congress Unite for ME/CFS Funding and SMCI Looks for New Opportunities for Federal Research Funding

In March 2018, members of the Solve ME/CFS Initiative (SMCI) staff and board of directors traveled to Washington, DC to meet with the offices of the Senate and U.S. House of Representatives Appropriations Committees about funding myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) research.

## Looking for Federal ME/CFS Research Support from New Federal Budget Sources

Since their inception in 1992, the Congressionally Directed Medical Research Programs (CDMRP) of the Department of Defense have overseen \$11.9 billion in scientific research. The Peer Reviewed Medical Research Program (PRMRP) is one of the most flexible and responsive of the programs, in which researchers may apply for financial support in one of 48 topic areas selected each year by members of Congress. These areas of eligible research are called "Congressionally Directed Topic Areas." One of the key intentions of the program is to "fill research gaps by funding high impact, high risk and high gain projects that other agencies may not venture to fund." ME/CFS is a perfect fit.

The complex physiology of ME/CFS and the underdeveloped state of

the scientific understanding of the disease have proved an obstacle for other federal agencies. ME/CFS is exactly the kind of research area that this program was designed to support. ME/CFS was an eligible topic area for potential research projects funded by the Peer Reviewed Medical Research Program (PRMRP) in 2011, but it was removed from the list of eligible research areas the following year. If SMCI is successful in returning ME/CFS to the program as a "Congressionally Directed Topic Area," ME/CFS researchers will be able to apply and compete for grants in a \$300 million program beginning fiscal year 2019.

## SMCI and #MEAction Lead Nationwide Advocacy Effort for Federal Guidance and Funding for ME/CFS

Solve ME/CFS Initiative and #MEAction jointly pursued a bi-partisan Congressional letter calling for funding and congressional guidance on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Responding to the call from advocates from all across the U.S., 44 members of congress jointly signed a letter to the U.S. House of Representatives Subcommittee on Labor, Health and Human Services and Education.

The letter, led by U.S. Representatives Zoe Lofgren and Anna Eshoo of California, requests continued funding for ME/CFS research and education programs at the Centers for Disease Control (CDC) and,



SMCI Board members Rick Sprout, Diane Bean, and Mike Atherton, celebrating in front of the U.S. Capitol. All have family members with ME/CFS.

- Encourages the CDC to complete the work of its multi-site clinical assessment of ME/CFS, to resolve ME/CFS case definition issues, and to better educate health care providers about the disease and its appropriate management;
- Recommends the National Institutes of Health (NIH) establish a strategic plan for research to ensure forward progress and to increase the amount and types of research funding and grants used in this effort;
- Urges the Office of the Secretary of Health and Human Services (HHS) to devise a multi-year strategic plan for addressing ME/CFS and fill the vacancies on the federal Chronic Fatigue Syndrome Advisory Committee (CFSAC).

## SMCI's 2nd Annual ME/CFS Advocacy Day: Bigger, Better, and Bolder

### #MakeMayMatter4ME

In 2017, the Solve ME/CFS Initiative partnered with #MEAction to launch the first ME/CFS Advocacy Day in Washington DC. 52 ME/CFS patients and advocates stormed Capitol Hill and to educate more than 80 members of Congress and their representatives about ME/CFS. These advocates shared personal stories, pictures, and experiences to call for Congress to take action on ME/CFS.

ME/CFS Advocacy Week also included nationwide call-in actions, online messaging tools, and Congressional briefing featuring parts of the film *Unrest* and the film's creator, Jennifer Brea. This was the first time the ME/CFS community coordinated such a strong singular action in the halls of Congress.

On Tuesday May 15th, SMCI will return to Capitol Hill for the 2nd Annual ME/CFS Advocacy Day. This event will bring people with ME/CFS, their loved ones, advocates, scientists, clinicians and caregivers from across the country together to call for more action and research funding, meet other advocates, and share their unique stories with members of congress—together in one voice.

This year, SMCI's ME/CFS Advocacy week is shaping up to be bigger, better, and bolder. It will feature four Capitol Hill events, a potential screening of *Unrest*, and solidarity with the #MillionsMissing action on Saturday, May 12th.

If you are interested in learning more about ME/CFS Advocacy Week activities, please visit the "Advocacy Corner" of the Solve ME/CFS Initiative website at [www.solvecfs.org](http://www.solvecfs.org). ■



## THANK YOU!

We extend a heartfelt thanks to the forty-four members of Congress listed here. If your representative is listed, we hope you'll reach out to thank him or her too. To view the complete letter or to get help thanking your member of Congress, email Emily Taylor at [etaylor@solvecfs.org](mailto:etaylor@solvecfs.org).

- Rep. Nanette Barragan (CA-44)
- Rep. Joyce Beatty (OH-03)
- Rep. Donald Beyer Jr. (VA-08)
- Rep. Suzanne Bonamici (OR-01)
- Rep. Vern Buchanan (FL-16)
- Rep. Michael Capuano (MA-07)
- Rep. André Carson (IN-07)
- Rep. Judy Chu (CA-27)
- Rep. Steve Cohen (TN-09)
- Rep. Bonnie Watson Coleman (NJ-12)
- Rep. Danny Davis (IL-07)
- Rep. Susan Davis (CA-53)
- Rep. Peter DeFazio (OR-04)
- Rep. Anna Eshoo (CA-18)
- Rep. Adriano Espaillat (NY-13)
- Rep. Zoe Lofgren (CA-19)
- Rep. James McGovern (MA-02)
- Rep. Jamie Raskin (MD-08)
- Rep. Eleanor Holmes Norton – (DC)
- Rep. Barbara Lee (CA-13)
- Rep. Jackie Speier (CA-14)
- Rep. Eric Swalwell (CA-15)
- Rep. John Lewis (GA-05)
- Rep. Peter Welch (VT)
- Rep. William Keating (MA-09)
- Rep. Ro Khanna (CA-17)
- Rep. Ann McLane Kuster (NH-02)
- Rep. Al Lawson (FL-05)
- Rep. Ted Lieu (CA-33)
- Rep. Daniel Lipinski (IL-03)
- Rep. Stephen Lynch (MA-08)
- Rep. Doris Matsui (CA-06)
- Rep. Seth Moulton (MA-06)
- Rep. Donald Norcross (NJ-01)
- Rep. Tom O'Hallern (AZ-01)
- Rep. Beto O'Rourke (TX-16)
- Rep. Scott Peters (CA-52)
- Rep. Lisa Blunt Rochester (DE)
- Rep. C.A. Dutch Ruppersberger (MD-02)
- Rep. Jacky Rosen (NV-03)
- Rep. Bobby Scott (VA-03)
- Rep. Krysten Sinema (AZ-09)
- Rep. Louise Slaughter (NY-25)
- Rep. Adam Smith (WA-09)

# #M.E. Too? Can the Women's Health Equity Movement Bring Attention to ME/CFS?

Gender disparities in medical research and healthcare are frequent talking points in American politics as movement for women's health equity has gained momentum. Given that about 80% of people with ME/CFS are women, can this growing pressure to address women's needs in the medical and healthcare space provide tangible benefits for all patients with ME/CFS?

Gender bias in the US health care system is well documented. There are countless examples of medical studies failing to include female study participants or treatment protocols excluding symptoms that affect women, with devastating results. A February 2018 study showed 53% of women who sought medical care for symptoms before suffering a heart attack were told by their doctors that their symptoms were not heart-related.

"I was patronized, dismissed, viewed as a drama queen and called an anxious female. Days later, I suffered a heart attack," shared Katherine Leon, a heart attack survivor.

According to a study from the American Autoimmune Related Diseases Association, 45% of patients report being labeled as "chronic complainers" or "hypochondriacs" in the earliest stages of their illnesses.

This experience is all-too-familiar for many people with ME/CFS who face similar dismissal, disbelief, and stigma in the health care setting. For people with ME/CFS, an estimat-

ed 84-91% of patients are undiagnosed or misdiagnosed and our community continues to fight the "psychosomatic" mislabeling.

As awareness of this documented gender disparity spreads and coalitions are formed to improve the experiences of female patients, ME/CFS is quickly developing into a case-study of sexism in medicine. In fact, the recently published book "Doing Harm" by Maya Dusenbery examines mountains of research and case studies to probe the depth and scope of the problem which has a profound effect on women's health. She dedicates an entire chapter to ME/CFS as a prime example of the trend.

This creates an opportunity for ME/CFS awareness and advocacy with new allies in a context that could yield some real improvement for all people with ME/CFS. Here's a few of the ways SMCI hopes that ME/CFS will benefit:

- **AWARENESS** Major women-centered news outlets have successfully integrated ME/CFS as a key

issue. Solve ME/CFS Initiative facilitated national media coverage from "Ms." Magazine, bringing the story of ME/CFS to new communities, unfamiliar with the disease. Additionally, strong women ME/CFS advocates are being featured in magazines like *Vogue*, *Marie Claire*, and other female-centered media outlets. SMCI believes increased awareness will bring increased acceptance and funding.

- **ADVOCACY** Women's groups are a major coalition and key voting bloc that can leverage major pressure and action. For example, Solve ME/CFS Initiative and other ME/CFS advocates worked with the National Organization for Women (NOW), an organization representing more than 500,000 members. As a result, NOW's president wrote a strong letter to the director of the National Institutes of Health (NIH) urging more investment in ME/CFS.
- **ALLIES** Bringing together strong allies and broad coalitions is a key for successful advocacy. Solve ME/CFS Initiative recently joined Hadassah's Coalition for Wom-

en’s Health Equity with 28 other national organizations including: Drexel University College of Medicine, American Heart Association, and the Nurse Practitioners in Women’s Health. Joining coalitions like this one opens up new partners to support SMCI’s advocacy work and new opportunities for collaboration with healthcare providers and medical education institutions. SMCI hopes to educate and collaborate with many coalition partners (like Drexel University College of Medicine) and that those efforts will translate into tangible improvements, like improved medical education.

“Failing to include women in health care research initiatives at the same rate as men makes women more susceptible to receiving wrong diagnoses, poor treatment or subpar care.”

—Congresswoman Ileana Ros-Lehtinen, FL-18 (R)

- **MEDICAL EDUCATION** Medical colleges and universities are facing increased pressure to address women’s health with more credibility and accuracy. This movement to re-evaluate what information is taught to future health care providers creates an opportunity to improve and update medical textbooks and university curricula with accurate information about ME/CFS. This is a significant priority for SMCI, recognizing that ME/CFS is only included in 1/3 of medical curricula and text books.

- **CLINICAL CARE** Physicians and healthcare providers are facing increased scrutiny for dismissing patients, particularly female patients. As the pressure to take patient-reported symptoms more seriously grows, we expect to see a corresponding improvement for ME/CFS patients. According to Professor Deb Colville in *The Conversation*, “Gendered medicine is not only about women. It is about identifying differences in clinical care and ensuring the best health care is provided for all.”

- **RESEARCHERS AND SCIENTISTS** According to a study in *Nature Human Behavior Journal*, gender bias in medical research is less likely if there’s a woman on the team. As women become more active and prevalent in STEM fields, we can expect to see an increase in the serious consideration of ME/CFS. SMCI specifically encourages for diversity in our research programs. We walk the talk: 60% of our 10 Ramsay Awardees are women-led teams.

- **CLINICAL TRIALS** Responding to increased pressure, the NIH created guidelines and policies for including women in clinical trials and also requires animal and preclinical models to include both males and females. These changes were only implemented in 2014. According to the NIH, “failure to account for sex as a biological variable may undermine the rigor, transparency, and generalizability of research findings.” New policies and trial design that include both females and males at every step (even in animal modeling) improves the data and outcomes

that can lead to strong scientific progress for ME/CFS.

*Special thanks to ME/CFS advocate Bobbi Ausubel for her diligent research used in this article.*

**“PAIN AND PREJUDICE”**  
AN ME/CFS FEATURE  
IN MS. MAGAZINE

SMCI partnered with the widely-circled women’s magazine *Ms.* and connected with renowned author Julie Rehmeyer to produce an impactful piece on ME/CFS. The 6-page feature, “Pain and Prejudice,” features some of the women leading the fight in ME/CFS.

“Carol Head, president of the Solve ME/CFS Initiative, likens the situation to the way that autism was once blamed on cold, unloving mothers. ‘I think similarly in the future, people will be ashamed of the views they had of ME/CFS in 2017,’ she says. The dismissiveness arises partly, she says, because it is a genuinely complex illness that isn’t yet diagnosable with an objective test. But the stigma is also driven by the trivializing name—and the fact that it predominantly affects women. ‘We all live in this myth—it’s 2018, this can’t still be happening!’ Head says. ‘It’s clear to me that gendered bias occurs with this disease. This is one of the areas where women tend to be marginalized.’”

To read the full article, check out the January 2018 issue of *Ms. Magazine* or visit [www.msmagazine.com](http://www.msmagazine.com) for a blog from Carol in the health issue section.

# PATIENT VOICES

Every quarter, *The Solve ME/CFS Chronicle* features the creativity and talent of the ME/CFS community. In this edition, we are exploring the extraordinary poetry from members of our community.



## Hope

by *Chris Garcia*

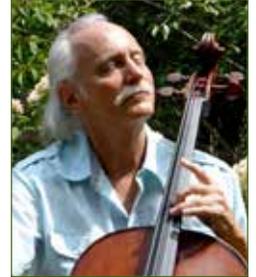
Remember, the buoyancy in life  
is found in our enchanted dreams,  
joyful wishes, and silent prayers.

All create infinite seas of  
luminous hope. Throughout life  
we float on hope.

## Safe Harbor Within

by *Ron Clearfield*

A safe harbor within resides,  
The precious gift of life inside.  
The great teachers all spoke of a place,  
Of shining light in our inner space.



The challenges we experience come and go,  
The ups and downs of life we well know,  
But within inside there dwells a safe place,  
Where all that we truly are is fully embraced.

The preciousness of life is beyond comprehension,  
Seeking beauty and fulfillment is our life's intention.  
Why waste existence feeling shame and sorrow,  
Breath in joy seizing today, not hoping for tomorrow.

We're living in a world of chaos and confusion,  
Misguided by leaders with selfish delusions,  
With fear and coercion they poison humanity and earth,  
Abusing human rights and this the planet of our hallowed birth.

We've come to this inn on our evolutionary path,  
To learn the true meaning of life's sacred math.  
Pheidius and Fibonacci discovered the ratio of gold,  
Discovering your relationship with the infinite is there to behold.

Life was meant to be enjoyed,  
Find that joy in every day.  
Know thyself, why anyone else?  
Follow your heart and you will never stray.

# SMCI Answers Reader Questions

SMCI addresses questions we receive from the ME/CFS community.

**Q:** *Is there any known connection between CFS/ME and "Common variable immune deficiency"? Any chance they could be one and the same entity, or can they be differentiated?*

**A:** Common Variable Immune Deficiency (CVID) is a heterogeneous immune deficiency syndrome and it does share some similarities with ME/CFS, including recurrent infections. It is one of many broadly defined diseases which may overlap with ME/CFS. CVID is also characterized by B-cell dysfunction and enlarged lymph nodes, which have been described in some ME/CFS patients. However, there is no conclusive evidence of a connection. While some ME/CFS patients exhibit signs of some kind of immune deficiency, others appear to have an overactive immune system. Defining changes in immune system functioning and possible subgroups continues to be a major focus of our research and will help to clarify any association between these two diseases. The new Common Data Elements Project of the NIH/CDC will be invaluable to providing this more comprehensive understanding.

**Q:** *Are you looking for research subjects?*

**A:** This is a question we receive so often, we've created a special email list for people interested in participating in research studies. Studies also need healthy controls—so, we encourage folks to share these opportunities with family and friends, even if they don't have ME/CFS. SMCI



also regularly shares study opportunity announcements from our research partners and collaborators on this mailing list and our social media accounts. If you are receiving SMCI e-mail updates and you are interested in participating in research efforts, be sure to "manage your subscriptions" and select to be a part of our **Volunteers and Research Studies** mailing list. Or, follow us on Facebook (Solve MECFS Initiative) and Twitter (@PlzSolveCFS) to receive updates on study opportunities. To sign up for SMCI email notifications, visit [www.solvecfs.org](http://www.solvecfs.org).

One of the key functions of the upcoming SMCI National ME/CFS Patient Registry will connect patients with study opportunities. Be sure to keep an eye on our newsletters for more information about the registry timeline and updates on how to participate. ■

## NEW SMCI WEBSITE LAUNCHED



In case you missed it:

SMCI recently launched an all new, redesigned website. The new website was designed with you in mind. We hope that you find it helpful and easier to navigate.

See what's new at [www.solvecfs.org](http://www.solvecfs.org). ■

# Your Support Fuels Our Efforts

In this issue of The Chronicle, you've seen the work we're doing to make ME/CFS **understood, diagnosable and treatable**. Your support fuels our efforts.

Support and generosity from thousands of patients and their families just like you has enabled us to:

- Award 5 **new Ramsay Awards Program** research grants to scientists from around the world, to bring our total to 10 total Ramsay recipients. Preliminary research results from the 2016 Ramsay Award recipients are expected this year.
- Bring government, researchers, and patients together as part of the new **NIH-funded ME/CFS Consortium Centers**. SMCI is proud to be participating in three of the four grants awarded.
- Establish our new **National ME/CFS Patient Registry** to facilitate ME/CFS research and bring patients and researchers together.
- Execute the **largest ME/CFS Capitol Hill storm ever**, which included 81 congressional meetings with more than 50 advocates in a single day.
- Expand **SMCI-directed research studies** in key areas, including metabolomics, drug screening, and therapeutic exploration.

The end of our fiscal year is quickly approaching. We set an ambitious fundraising goal of \$2 million by June 30<sup>th</sup> to support our research and advocacy work. So far, we've received 3,319 gifts totaling more than \$1.4 million.

**Could your contribution be what leads to the next breakthrough in ME/CFS research?**



## Make a Gift by Check or Credit Card

Every gift to SMCI is meaningful and brings us one step closer to finding treatments for ME/CFS and a cure. You can give online at [www.solvecfs.org/donate](http://www.solvecfs.org/donate) or use the envelope enclosed in this issue.

## Give a Gift of Appreciated Securities

By donating appreciated securities to SMCI, you can avoid the capital gains tax you would have paid if you had sold the asset. If you have owned the securities for longer than one year, you will also receive an income tax charitable deduction for their full fair-market value. Please contact our Development Office at (704) 364-0016 for more information.

## Become a Sustaining Donor with a Monthly Gift

Monthly donations are a wonderful way to simplify your giving and maximize your support by setting up a monthly donation, online or using the enclosed envelope.

## Set Up A Personal Fundraising Page

Raise funds for SMCI by setting up a personal fundraising page using the Crowdrise website [www.crowdrise.com/SolveCFS#projects](http://www.crowdrise.com/SolveCFS#projects).

We've created a template that you can easily personalize with your own ME/CFS story. You can then invite friends and family to donate.

Every gift helps us move forward in our fight against ME/CFS. Thank you for **fueling our work.** ■

# Reflections from our President Carol Head



Carol Head, CEO and President

Dear friends,

*I am so grateful for you – and here's why!*

I want you to understand that you really are invaluable in finding treatments and a cure for ME/CFS. Without your financial support, none of what we do would be possible.

Like most national disease organizations (think Michael J. Fox for Parkinson's or the Alzheimer's Association), SMCI's programs fall into three areas: 1) Research, 2) Advocacy, and 3) Education.

**RESEARCH** – our most significant program:

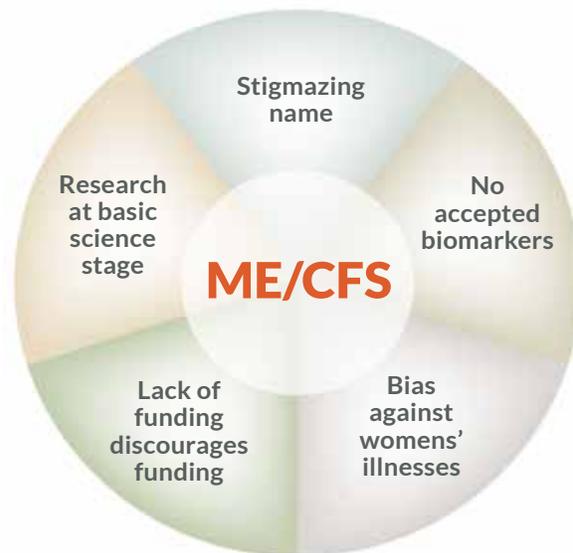
- Our annual **Ramsay Award Grants** support promising research across a variety of disciplines and recruit new researchers to the ME/CFS field. The Ramsay Awards also enable researchers to build preliminary data to gain funding from other institutions. SMCI is a leader in this important seed grant function.
- Our **PEER National Patient Registry**, a data infrastructure that brings together patients and qualified researchers to accelerate the discovery process.
- **SMCI Directed Research Projects** support specialized research projects (e.g. metabolomics work at Cornell). When we see a worthy project that needs funding, we consult with our Research Advisory Council and move forward to provide financial support, free of the limitations of academia.

**ADVOCACY:** We demand action on ME/CFS in Congress, the NIH, the CDC, and by supporting state initiatives. Tapping the government's funding and power is critically important to accelerating improvements for people with ME/CFS.

**EDUCATION:** Creating an informational webinar series and other materials that provide reliable information for patients, caregivers, researchers and health care providers.

In each of these program areas, our budgets are inadequate to satisfy the desperate need of so many with this terrible disease. I spend much of my time working to increase dollars to support our work, but raising funds for this disease not easy.

Why is it so difficult to raise funds outside our own ME/CFS community? ME/CFS hits a perfect storm of challenges.



Nearly all our financial support comes from you—**individuals who have seen the suffering caused by this disease up close and personal.**

In 2017, 1,309 of you came together to support our work with gifts large and small. We are deeply grateful. We could not continue our work without your generosity, your hope, your fortitude, and your determination.

Onward!! Together,

Carol Head  
President and CEO  
Solve ME/CFS Initiative

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SolveMECFSInitiative

**Instagram:** Solve\_CFS

**LinkedIn:** Solve ME/CFS Initiative

**Twitter:** @PlzSolveCFS

**YouTube:**  
www.youtube.com/SolveCFS

**Solve ME/CFS Chronicle archive:**  
SolveCFS.org/archive

**Humans of ME/CFS:**  
HOMEFCFS.SolveCFS.org

## SPRING 2018

Solve ME/CFS Initiative (SMCI) is the leading disease organization solely dedicated to solving the devastating disease Myalgic Encephalomyelitis (ME). SMCI is committed to making ME/CFS **understood, diagnosable, and treatable.**



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- Advocacy in Action: 44 Members of Congress Unite for ME/CFS Funding
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- #M.E. Too? Can the Women's Health Equity Movement Bring Attention to ME/CFS?
- Read the inspirational poetry penned by members of the ME/CFS community
- SMCI Welcomes Two New Members to Its Board of Directors

**TO SUPPORT SMCI**  
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