



# The Solve ME/CFS CHRONICLE

SPRING 2019

## CEO Carol Head's Journey: Looking Back, Moving Forward

*After nearly six years as President and CEO of the Solve ME/CFS Initiative (SMCI), Carol Head will step down from her leadership role, citing the gradual deterioration of her health due to ME/CFS. As the SMCI board of directors works with a national search firm to find her replacement, Carol reflects on her time as President and shares her thoughts on what the future may hold for SMCI and for people with ME/CFS.*

In 2013, when I was offered the opportunity to take on this position, I understood the suffering and difficulties with the disease itself, so I jumped at the chance to work toward treatment and cure. There were so many challenges regarding ME/CFS: genuine medical/physiological complexity, the politics of overcoming utterly deficient funding, our culture's wrongheaded perception of the disease, the dearth of physician care, the psychological burden of not being believed to be sick, the lack of insurance reimbursement that bankrupts families. I could go on.

Those reading this know these profound difficulties and how they are intertwined. So, I had to think strategically about how to attack each one separately, how they interrelate, and then prioritize which ones to go after. And, oh yes, while also raising the dollars to do so.

And there were some early administrative steps I felt were important to take. We changed the organization's name, moved the office from a smaller town in the Southeast to a metropolitan center in the West, and brought all the staff together under one roof. We engaged in a consistently pro-active manner with *everyone* in the community.

As any CEO must, I spent a significant percent of my time fundraising. I'm grateful to those families who have given so generously to this cause. I have witnessed truly sacrificial giving. And this is true not only for families of substantial means, and also those who must stretch to give what they can

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# SMCI THIS QUARTER: A Summary of Our Work in Research, Advocacy and Beyond

**RESEARCH:** Engaging the entire ME/CFS community and accelerating the discovery of safe and effective treatments.

SMCI's President and CEO Carol Head joined the new NIH NANS Work Group, serving as a voice and "seat at the table" for the ME/CFS community.

The SMCI 2018 Science and Discovery Webinar series closed out the year with a talk from Chief Scientific Officer Sadie Whittaker (PhD) on building a community resource through the You + M.E. Registry and a presentation by Ramsay Award Program awardee Jarred Younger (PhD) on results from his Ramsay pilot study into neuroimaging brain inflammation in ME/CFS.

SMCI introduced a new interactive graphic platform created in partnership with Rochelle Joslyn (PhD) that will serve as a data hub of research highlights for the ME/CFS community. (See page 5.)

## SOLVE ME/CFS INITIATIVE PROFESSIONAL STAFF

Carol Head  
President and CEO

Sadie Whittaker, PhD  
Chief Scientific Officer

Emily Taylor  
Director of Advocacy and  
Community Relations

Maryellen Gleason  
Interim Director of Development

Allison Ramiller, MPH  
Director of Research Programs

Deborah Saady  
Accounting and Operations Manager

Karman Kregloe  
Communications and Media  
Relations Manager

Angie Browne  
Development Coordinator

Shawna Woolridge  
Communications and  
Media Relations Coordinator

SMCI launched its new Ramsay Award Program microsite which features information on 16 studies and their impact over three cycles of the program.

Dr. Younger published his Ramsay pilot findings of neuroinflammation markers using brain imaging techniques in *Brain Imaging and Behavior* and submitted an application to the National Institutes of Health to run a confirmatory study in a larger cohort.

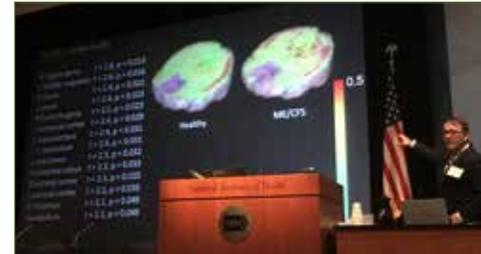
SMCI funded three new researchers from the

Ramsay Program 2018 Application Cycle: Dr. Li (PhD) from the Univ. of Vermont will examine

endogenous retroviruses and their expression in ME/CFS; Dr. Trivedi from Nova Southeastern Univ. will investigate neuromolecular changes using reprogrammed neurons; and Hector Bonilla (MD) from Stanford University will assess a genetic risk factor and association with herpes virus infection. The three new studies bring the total number of 2018 studies to seven.

The SMCI family was out in full force at the NIH Young Investigators and Accelerating Research on ME/CFS conferences:

- Young investigators Christina Mueller, Irene Tsilionis (PhD), Camille Birch (PhD), and Dawei Li (PhD) presented data from Ramsay-supported research at the Thinking the Future conference and poster session for young investigators
- SMCI's CSO Dr. Whittaker moderated the microbiome/virome panel at the Accelerating Research conference and served on the "Next Steps" wrap-up panel with Joe Breen (PhD), Vicky Whittemore (PhD), Maureen Hanson (PhD), and Jose Montoya (Stanford)
- Dr. Bhupesh Prusty presented his working model of viral (HHV-6) contribution to altered mitochondria functioning in ME/CFS and Dr. Younger presented evidence for neuroinflammation in ME/CFS from their respective Ramsay-supported projects (*photo above*)
- SMCI Research Advisory Council (RAC) members Anthony Komaroff (PhD), Lucinda Bateman (MD), Susan M. Levine (MD), Jose Montoya (MD), Peter Rowe (MD) presented at various points during the conference
- SMCI provided partial support through a MeetME travel award for recent PhD graduate Dr. Daniel Vipond to present at the Young Investigators conference.



## ADVOCACY: Bringing government support, funding, and public awareness to ME

As a part of the advocacy webinar series, SMCI co-hosted "Best Practices for a Successful Advocacy Meeting" in a two-part online training series with #MEAction.

SMCI and #MEAction teamed up for the 3rd Annual Advocacy Day in Washington DC, which included a full day of advocacy training in Bethesda, Maryland which was livestreamed for online viewers. Over 200 members of the ME community requested 234 meetings with members of congress, and over 2,000 online actions were taken to call for congressional action.



SMCI hosted the first EmPOWER ME Roundtable, moderated by Board Certified Patient Advocate Sharon Stevenson DVM,

PhD, and featuring Ramsay Award researcher Dr. Camille Birch and former State Senator and current Maryland Department of Aging Secretary Rona Kramer (who recently joined the SMCI board of directors). Over 100 people attended, with over 300 registered online viewers.

Emily Taylor of SMCI and Beth Mazur of #MEAction presented at the NIH's ME/CFS Special Interest Group on "Advocacy and Digital Mobilization for ME/CFS."

Emily Taylor attended a patient-focused drug development meeting hosted by the Food and Drug Administration (FDA) and other drug development stakeholders working on mitochondrial diseases.

## INFLUENCE & EDUCATION: Providing trusted, up-to-date medical information, current research, & policy work on ME/CFS

SMCI sent a rebuttal to the University Times that falsely labeled ME/CFS as a "psychosomatic disorder" and engaged the community response urging retraction of the article.

SMCI collaborated with the Research Center at Columbia University to help survey the ME/CFS community in order to further develop a mobile symptom tracking app.

SMCI collaborated with the Genetic Alliance on their simple survey to help understand the ME/CFS community knowledge of family health history and genetic testing. SMCI collaboration with the NIH created the MECFSnet: Myalgic Encephalomyeli-

tis/Chronic Fatigue Syndrome Research Network in which the Data center will utilize SMCI's You + M.E. Registry.



SMCI issued corrections to an INSIDER article that conflated differences between chronic fatigue and Chronic Fatigue Syndrome.

SMCI funded Travel Awards for "Thinking the Future: A Workshop for Young/Early Career ME/CFS Investigators" at the NIH clinical center, Bethesda, MD. ■

## SOLVE ME/CFS INITIATIVE BOARD OF DIRECTORS

*Each board member has ME or has a family member affected by this disease*



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## Carol Head's SMCI Journey (cont'd)

with smaller gifts. I hope all of them understand my deep gratitude for their generosity. To this day, I cannot imagine a higher return on investment for *any* charity than giving to support groundbreaking, high-quality work that aims to alleviate the severe suffering of millions.



*Carol Head and CSO Dr. Sadie Whittaker in London for the Invest in ME Research International ME Conference*

I'm proud of all we've accomplished here in my time as president, especially:

1. SMCI has now funded a total of 16 Ramsay Grants, which are moving forward our understanding of this disease across many scientific disciplines
2. SMCI is building the sophisticated, large (both deep and wide) registry for all those with ME. *This is a foundational tool that has been missing in our field.* We're creating the Registry and biobank for use by all.
3. Three annual Capitol Hill Advocacy Days and the focused impact they have at the federal level—among them, retaining CDC funds for ME year after year.
4. The advocacy work that is not visible, including the emphatic conversations that we have with federal officials whose trust we have gained. As in any arena, much important work happens behind the scenes.
5. And that we've provided solace and hope to the many who struggle with ME. I trust that you all know that you are not struggling alone. And that a team of committed, aggressive, kind individuals are on the job. There are now nine staff at SMCI and this describes every single one of us. We fight for those who cannot. We are fierce in our drive to bring healing.

There is so much good work occurring now: in medical research, training clinicians, federal advocacy, state advocacy, nascent clinical trials, and changing public perception. This was generally not true even three years ago. But we are all pushing a boulder uphill. Everyone in this field is exhausted by this work, both those with ME and those without. Everyone I know who works for any of the ME/CFS organizations is extraordinarily smart, hardworking, and dedicated. Most importantly, we are all driven.

So, while I am stepping down from a specific role, this is not goodbye. I am transitioning to an active volunteer role, and I will sit on the SMCI board of directors and continue to find ways to work for justice and healing for all who struggle daily with this disease. There are some intractable problems in our world; ME/CFS is not one of them. This disease can and will be understood, diagnosable and treatable. That's SMCI's mission...and mine as well. Onward! ■



*Carol Head presented at the NIH Collaborative Research Center meeting at the Jackson Lab*

# ME/CFS Research: The First Quarter of 2019 in Review

## A guide to promising new discoveries

By Rochelle Joslyn, PhD | Edited by Allison Ramiller, MPH

2019 is off to a strong start for ME/CFS research! From the search for sensitive and specific biomarkers in neuroimaging and CPET testing, to the use of next generation (RNA) sequencing in transcriptomic analyses of peripheral blood, findings from the first quarter of the year reflect engagement of transformative new technologies in deciphering biological evidence of disease. Major emphasis on the patient experience is also apparent in targeted characterizations of patient encounters with the health care system and foundational work to develop disease-specific methods to capture the experience of PEM. A spate of epidemiologic analyses describes the variable landscape of ME/CFS around the world.

Just 3 months in, this year is shaping up to be one of our best yet in revealing the breadth of what it means to live with ME/CFS, unraveling the biologic mystery driving disease, and moving closer to achieving the range of scientific and clinical tools necessary to initiate clinical trials.

Check out the interactive version of this wheel on our website at <https://solvecfs.org/me-cfs-research-the-first-quarter-of-2019-in-review/>. We'll be bringing you research updates via this hub quarterly in 2019.



### EPIDEMIOLOGY

**MONTOYA, ET AL.** corroborated previous findings of ME/CFS disease onset and course in a US cohort of 150 Fukuda-defined ME/CFS patients and added new understanding of longitudinal changes in symptoms. The authors found infection, stress and toxin exposure to be most common onset-related events, and that over 6 months elapsed before developing the full suite of ME/CFS symptoms in 38% of patients. Almost half of patients could not engage in activity or work, most described a fluctuating course of illness (with only 4% reporting steady improvement), and fatigue did not correlate with illness duration or

### SOLVE ME/CFS INITIATIVE RESEARCH ADVISORY COUNCIL



Anthony Komaroff, MD  
Harvard Medical School



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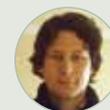
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John Nicols, MBA  
Codexis, Inc.



## ME/CFS RESEARCH: The First Quarter of 2019 in Review (cont'd)

age. Hormonal events exacerbated women's symptoms and 97% of patients had at least one comorbid condition.

An analysis of insurance records by **VALDEZ, ET AL.** revealed a prevalence of ME or CFS diagnosis of 0.5-1% (1.7-3.38 million in the US) and an estimated prevalence of 0.86% (2.8 million in the US) for ME. Though an elevated risk of diagnosis among females was observed, 35-40% of diagnosed patients are male. Healthcare costs due to ME or CFS were found to be 50% higher than

set following infectious illness with most receiving a diagnosis over one year after symptom onset.

**ROWE** found through long term follow-up of 784 pediatric ME/CFS patients in Australia that 35% recovered at 5 years and 68% at 10 years post diagnosis, with 5% remaining very unwell and 20% significantly unwell, but failed to identify predictors for recovery.

**SLOMKO, ET AL.** characterized the prevalence and symptomatic experience of Fukuda-defined ME/CFS patients in Poland.

### METABOLIC

**VENTER, ET AL.** examined the frequency of rare mitochondrial DNA (mtDNA) mutations (variants) predicted to be mildly deleterious in 261 Fukuda-defined moderately-severely affected patients from the UK and South Africa. Contrary to expectations, the authors found a lower frequency of these variants in ME/CFS patients than in healthy controls, also noting no difference in variant frequency between moderately and severely affected patients.

**TOMAS, ET AL.** assessed mitochondrial respiratory function in peripheral blood and muscle cells from 6 Fukuda-defined CFS patients and healthy controls, noting no differences between groups. The results suggest that mechanisms upstream of the mitochondrial respiratory chain may be responsible for metabolic impairment in ME/CFS.

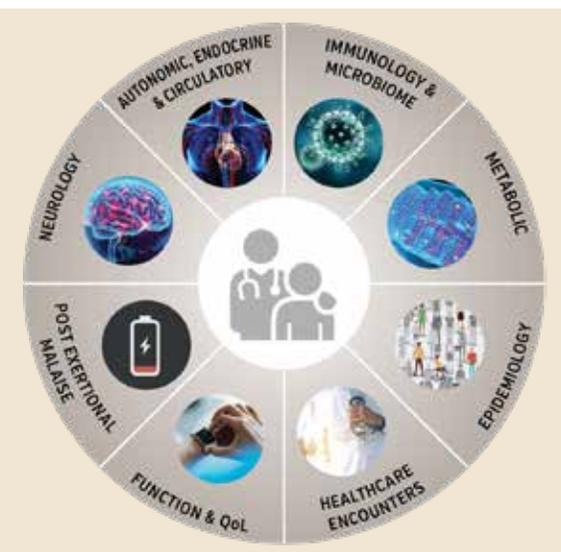
**POLLI, ET AL.** explored the relationship between oxidative stress (a buildup of metabolic toxins) and pain in female ME/CFS patients relative to inactive healthy controls. Oxidative stress correlated with reported pain in patients but not controls both before and after exercise, but not with heart rate variability.

Building upon prior studies which documented that the thresholds of exertion at which ME/CFS patients enter anaerobic metabolism are lower than healthy controls, **NELSON, ET AL.** sought to determine objective cutoff values which distinguish patients from controls, potentially for use as a biomarker. The authors found a significantly decreased work rate (energy output) of up to 9.8% on day 2 in patients versus controls, and no association among other measures.

### HEALTH CARE ENCOUNTERS

**MCMANIMEN, ET AL.** performed a qualitative assessment of patients' negative experiences with health care professionals, revealing an impact of perceived physician attitudes on patient wellbeing and describing strategies for supportive clinical care of ME/CFS patients.

An analysis of ME/CFS patient experiences with hospital emergency departments by **TIMBOL, ET AL.** found that a majority of patients had visited an ER, often due to orthostatic intolerance, but encounters were unfavorable and patients were often dismissed by staff who lacked



those of lupus or ME, and 3-4 times higher than the general population.

**KNIGHT, ET AL.** assessed the incidence of pediatric CFS diagnoses in Australia, identifying a rate of 0.00025% in young children and 0.0013%-0.0055% among adolescents. The authors also noted geographical differences in incidence, a majority of female and Caucasian cases, and commonly a gradual on-

knowledge of the disease. 41% of patients reported avoiding an ER visit because they anticipated care would be ineffective and dismissive.

## IMMUNOLOGY

**JEFFREY, ET AL.** analyzed gene expression data from 33 Fukuda-defined ME/CFS patients and healthy controls to identify functional pathways that might be drug-targetable, implicating immunosuppressants as candidate treatments. The researchers found evidence of immune dysregulation (namely B and T cell receptors, TNF $\alpha$ , and TGF- $\beta$ ), metabolic dysfunction, and cardiovascular factors, each which strongly correlated with clinical measures of fatigue.

**ESPINOZA, ET AL.** measured decreased frequency and amounts of a cell surface molecule, CD57, on T cells in ME/CFS patients versus healthy controls, indicating these cells are less mature, less potent in their activity, and have more proliferative capacity.

**SWEETMAN, ET AL.** measured gene expression by RNA sequencing in peripheral blood from 10 CCC-defined ME/CFS patients and healthy controls, revealing significant differences in inflammatory, metabolic and cellular stress related genes.

**ALMENAR-PEREZ, ET AL.** performed a meta-analysis of existing gene expression data from immune cells of ME/CFS patients to identify associations with expression of noncoding DNA sequences (called transposons) which activate innate immune sensors of infection in the absence of a pathogenic infection.

## PEM

In response to the need identified in NIH's 2018 **COMMON DATA ELEMENTS (CDES)** initiative for an instrument to accurately assess post-exertional malaise (PEM), **HOLTZMAN, ET AL.** undertook an online survey of over 1,500 patients to identify key elements of the PEM experience. The authors found that many aspects of PEM are not captured in existing measures, indicating the need for development of new instrumentation.

**BOUQUET, ET AL.** measured host and viral gene expression changes by RNA sequencing in patient and healthy control blood following 2-day CPET testing. While, as with previous studies, the majority of patients displayed diminished oxygen consumption on day 2, only 6 genes were differentially expressed in patients versus controls and no significant gene expression changes were observed pre- versus post-exercise in patients. Additionally, viral gene expression did not correlate with PEM.

## NEUROLOGY

**MUELLER, ET AL.** performed whole-brain magnetic resonance spectroscopy (MRS) on 15 female ME/CFS patients and healthy controls. Quantification of metabolites linked to inflammation revealed significant differences between patients and controls in several regions, many of which correlated with reported fatigue. Additionally, patient brain (but not body) temperature was elevated in several regions.

**ROBINSON, ET AL.** assessed cognitive performance in Fukuda-defined CFS patients with and without comorbid

depression, identifying poor processing speed which correlated with heart rate variability and is not due to depression.

## FUNCTION & QOL

**ROMA, ET AL.** found that 55 Fukuda-defined adolescents scored significantly worse by all measures in quality of life (QoL) and function than their healthy counterparts and those with other chronic diseases (asthma, diabetes mellitus, epilepsy, eosinophilic gastroenteritis, and cystic fibrosis). 85% of patients also met IOM criteria and these patients had lower QoL scores than Fukuda-only patients. The authors noted that PEM frequency, more so than cognitive impairment, associated with the severity of diminished QoL and that orthostatic intolerance was present in 96% of patients.

## AUTONOMIC, ENDOCRINE & CIRCULATORY

**CLARK, ET AL.** logged measurements of autonomic nervous system (ANS) output in 42 Fukuda-defined patients and 9 controls during active standing and supine rest periods. Using a network analysis approach, the researchers found that patient autonomic function networks were less well-connected overall, with notable differences in systolic blood pressure and heart rate. The researchers also completed a more comprehensive network analysis in a total of 15 patients, finding evidence for a shift in homeostasis of the ANS, immune system and hypothalamic-pituitary-adrenal axis regulatory systems. ■

# We Fight for You in the Halls of Power

## SMCI Champions Increased Federal Funding for ME/CFS

Solve ME/CFS Initiative (SMCI), in collaboration with ME organizations and advocates across the country, guided simultaneous budget efforts to secure additional ME/CFS federal funding over multiple years.

Despite the dismal storms in February, fortunes for ME/CFS on Capitol were looking up this winter. SMCI's Director of Advocacy, Emily Taylor, braved the snow and the rain over two visits to Washington DC in October 2018 and February 2019 in preparation for the turbulent appropriations season in March and April.



After 36 meetings and a dozen requests, ME/CFS Champions Congressmembers Zoe Lofgren and Anna Eshoo led two appropriations request letters in the House drawing 45 cosigners. Senator Markey matched their action, writing letters to the Senate appropriations Subcommittees of Defense and Labor, Health and Human Services, Education, and Related Agencies. Both actions were collaborative efforts with #MEAction and Massachusetts ME/CFS & FM Association.

The letters to the House and Senate Defense subcommittees requested that ME/CFS be once again added as an "eligible research topic area" as directed by Congress. This committee report language would enable ME/CFS researchers to apply for grants in the Peer-Reviewed Medical Research Program (PRMRP).

In a bold move forward, 44 members of the House joined together in requesting a \$4.5 million sustained funding increase for ME/CFS programs at the Centers for Disease Control. This increase is a total of \$9.9 million in annual funding for the CDC program.

The increase will be utilized for:

1. National Epidemiological Study, a 3-4 year project
2. Improved dissemination of appropriate and updated medical education
3. Creating a Project ECHO (Extension for Community Healthcare Outcomes) tele-mentoring medical education program
4. Accelerating results of the Multiple Clinical-site Assessment of ME/CFS study

To learn more about this advocacy action or to read the congressional letters, visit the Solve ME/CFS Initiative Advocacy Corner at: [www.solvecfs.org/advocacy/](http://www.solvecfs.org/advocacy/) ■

## ME/CFS Advocacy Week in Washington DC Hosts 9 SMCI Events

During ME/CFS Advocacy Week April 1–7, SMCI led nationwide action to raise awareness, advocate for increased federal funding, and tell the stories of people with ME.

By fax and by phone, from social media to local congressional district offices, ME advocates came together to contact their representatives. The keystone April 3rd event on Capitol Hill drew over 200 registered ME/CFS advocates to attend 234 requested meetings (23 of them member-level) with members of Congress and their staff.

SMCI presented, partnered, and hosted NINE different ME/CFS events as part of ME/CFS Advocacy Week in

Washington, DC. The events of ME/CFS Advocacy Week, including the SMCI Board Meeting and several research conferences, are part of a robust joint research and advocacy strategy to call for increased investment, action, and collaboration to improve the lives of people with ME.

Take a journey through a summary of SMCI’s ME/CFS Advocacy Week on pages 10 & 11. Don’t forget to check out the videos and join the conversation using #CONGRESSFIGHT4ME and #REPMEINDC. ■



Group photo of ME/CFS Advocates before the Capitol Hill storm



Rep. Danny Davis (D-IL) meets with constituents on Advocacy Day

## ME/CFS Advocacy Day on Capitol Hill

The keystone event for the week, ME/CFS Advocacy Day 2019, was a joint partnership between Solve ME/CFS Initiative and #MEAction on April 2 & 3rd. The event kicked off with a live-streamed advocacy training that you can view on the Solve ME/CFS Initiative YouTube Channel ([www.YouTube.com/SolveCFS](http://www.YouTube.com/SolveCFS)) and a networking reception.

On April 3rd, over 200 people with myalgic encephalomyelitis (ME), caregivers and allies joined together to make our voices heard! Members of Congress were asked to 1) co-sponsor an ME/CFS resolution, 2) support the funding requests for ME/CFS (described on page 8), and to raise awareness on social media for people with ME/CFS for May 12, International ME/CFS Awareness Day.



At the end of the day, Congressman Jack Bergman and Amy Carlson of CBS’ Blue Bloods addressed the ME Community at the ME/CFS Champions Reception on Capitol Hill. ■



# We Fight for You in the Halls of Power (cont'd)

## The EmPOWER M.E. Roundtable and Live Webcast

SMCI hosted our first ever EmPOWER M.E. Roundtable on April 2, 2019 moderated by Board Certified Patient Advocate Sharon Stevenson, DVM PhD. This event was free for over 100 attendees and over 300 viewers registered to watch online.

The goal of EmPOWER M.E. RoundTable was to provide specific tools and guidance to help empower people with ME/CFS to feel more comfortable advocating and representing their needs. The EmPOWER M.E. Roundtable featured two workshop-style panels:



### Session 1

#### **"Empowerment in the Doctor's Office: Overcoming White Coat Syndrome"**

**Exercises and ideas for empowering your experience in the medical environment**

#### Panelists

Dr. Nancy Klimas: ME/CFS clinician and researcher, Director of the Institute for Neuro-Immune Medicine, Nova Southeastern University, Nova Southeastern University

Dr. Camille Birch: Ramsay Award Research Awardee and person with ME, Genome Analyst, HudsonAlpha Institute for Biotechnology

Eric Braun, PhD: Caregiver and ME Advocate



### Session 2

#### **"Advocacy: Your Story, Your Impact"**

**How telling your story can empower you and make change by combining advocacy and self-representation**

#### Panelists

Secretary Rona Kramer: Secretary, Maryland Department of Aging, Former State Senator, family member of person with ME

Emily Taylor: Director of Advocacy, Solve ME/CFS Initiative, and caregiver of person with ME

## “Accelerating Research on ME/CFS” NIH Conference

Concurrent with ME/CFS Advocacy Week, the National Institutes of Health (NIH) hosted the “Accelerating Research on ME/CFS” conference at the NIH campus in Bethesda, MD. The Solve ME/CFS Initiative partnered on the event which included presentations from our Chief Scientific Officer, Sadie Whittaker, Ramsay Award Program researchers Dr. Jonas Bergquist, Dr. Bhupesh Prusty, Dr. Jarred Younger, and members of the SMCI Research Advisory Council.

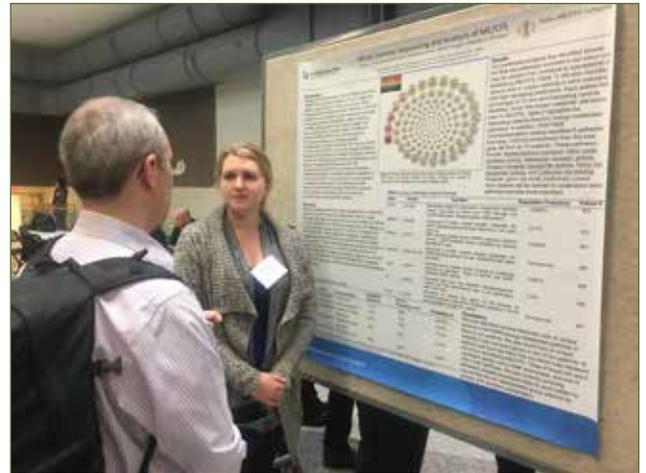


The conference also featured “Thinking the Future: A Workshop for Young/Early Career ME/CFS Investigators.” Read more about these events on page 2. ■

At right: Dr. Whittaker introduces a clinician panel discussion with SMCI RAC members Tony Komaroff (moderator), Dr. Lucinda Bateman, Dr. Susan Levine, Dr. Jose Montoya, Dr. Peter Rowe, and expert clinician Dr. Dan Peterson at the NIH conference

## NIH ME/CFS Special Interest Group Presentation

Emily Taylor of SMCI and Beth Mazur of #MEAction presented at the NIH’s ME/CFS Special Interest Group on “Advocacy and Digital Mobilization for ME/CFS.” This presentation at the NIH campus enabled candid and collaborative conversations about improving the relationship between the ME community, ME/CFS Stakeholders and the NIH. ■



## Energy in Action: Patient-Focused Drug Development Meeting



There is evidence to suggest that ME/CFS patients suffer from dysfunctional production of energy in mitochondria, the “power houses” of the cell. On March 29, the Food and Drug Administration (FDA) and other drug development stakeholders

working on mitochondrial diseases hosted a Patient-Focused Drug Development Meeting and Emily Taylor joined to represent people with ME and SMCI research initiatives. Four of SMCI’s science and discovery programs are investigating mitochondria and ME/CFS. ■



Right middle: Ramsay Award Program researcher Camille Birch (PhD) at the NIH Poster Session. Right lower: Carol Head, Allison Ramiller & Ramsay Award Program researcher Dr. Bhupesh Prusty at Day 1 of the NIH “Accelerating Research on ME/CFS” Conference

# PATIENT VOICES

Every quarter, *The Solve ME/CFS Chronicle* features the creativity and talent of the ME/CFS community. In this edition, we feature the art of Jenni White of Kansas. Jenni lives with her husband, three children, and with ME symptoms for the past 16 years. Creating art about her experience with ME has given her an outlet to describe the impact of the disease on her life. Learn more at [www.jenniwhite.com](http://www.jenniwhite.com).



Artwork titles, L to R, top: *Resolve*; *What Remains*; *The Two M.E.s - The Two Me's*; Bottom: *Displaced*; *Head to Hart*; *Imprisoned*

# SMCI Answers Reader Questions

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

**Q:** *I feel frustrated with my representative. I have contacted his office in the past to sign on to Solve ME/CFS Initiative actions, but he doesn't take action. Today, I emailed the letter with a personal note and called his office. I didn't feel like the person who answered really cared. It felt like she just wanted to get me off the phone. What should I do?*

**A:** Thank you so much for raising your voice to support our advocacy actions! Advocacy can often feel frustrating, especially when you don't seem to be making an impact. But you are not alone! It's our collective voices, supporting one another and working together that make the biggest impact. Also, building a strong and responsive relationship with a Congressional office is hard work. It takes time, constant touch-points, and is often a group effort. Two ways you can make a big difference is to 1) Identify the right person and 2) build a relationship.

Members of Congress get thousands of calls about hundreds of issues. The person who answered the phone was probably very overwhelmed with other callers waiting. How can you make your request stand out amongst so many others?

I encourage you to keep calling, if your health allows. Even just once or twice every two months can make a big impact. When you call, ask to speak to the "Health legislative staffer" about an important upcoming issue. Ask for the staffer's name and contact information. Make sure you speak to that individual when you make your requests. When you send an e-alert, take the extra time and send a copy directly to the staffer's e-mail. And, don't forget to say you are contacting them as part of a national advocacy effort!

One great way to build a stronger relationship with a Congressional office is to meet (by phone or in person) with their staff, to help make a more personal connection. This connection applies both to you as an individual and to the issue of ME/CFS.

Another helpful resource might be our online training, "6 Ways to Maximize Your Congressional Advocacy," on the Solve ME/CFS Initiative YouTube channel. This training discusses these strategies and more to help you make the most impact in our fight against ME/CFS. Onward, together!

**Q:** *My friend said I need a health advocate to speak to doctors, Medicare, etc. on my behalf. I'm too sick like millions to educate and search. Cancer patients have this. Maybe some of our donations can go toward this. Organize and assist?*

**A:** We recognize that medical education and medical advocacy is an urgent and common patient need. To help fill that gap, we partnered with a Board Certified Patient Advocate to present the **#EmPOWERME** Roundtable on April 2nd that will train you with exactly those tools. You can watch online for free! Check out our website to view the event: <https://solvecfs.org/empower-m-e-livestream/> ■



# Your Support Makes an Impact!

## People like you make ME/CFS Advocacy Week Possible

Our Advocacy Week events in Washington are **crucial** to pushing the needle forward in both **research** and **advocacy**. The payoff is significant, and Advocacy Week requires costly investment.

**Please consider making a gift to support our efforts to represent the needs of people with ME/CFS in the halls of power in Washington, DC.\***

Your gift today will help us cover the costs of:

- travel scholarships for patients
- advocating for federal funding for ME/CFS research
- printing of ME/CFS educational materials presented to Congress
- livestreaming events for those too ill to attend in-person
- congressional meeting scheduling
- wheelchair accessible buses
- the work of our staff, who travelled to DC and cheerfully worked long hours to assist patients and caregivers who are making their voices heard



**SMCI is passionate about securing a seat at the table for the ME/CFS community when powerful government officials and organizations make the decisions that impact our future.**

An envelope is included for your convenience, or you can give online at

**<https://solvecfs.org/donate>**.

## WE ARE ALL IN THIS TOGETHER!

*\*Gifts to SMCI are not restricted to individual programs.*

# Reflections from our President Carol Head

Dear friends,

As you read in our cover story in this issue of *The Chronicle*, I'll be stepping down from my role as President and CEO because of the deterioration of my health due to ME/CFS. Our board of directors are deep into the process now, working with a national search firm, to identify a powerful new leader. That individual will be someone who can work effectively across many constituencies, raise the dollars we need to leverage our capable staff, and drive all the work needed bring treatments and cure.

Certainly, we'll continue with Ramsay Grants to seed ME research as the most effect approach to drive toward larger NIH grants. We'll get our You + M.E. registry to the point that it jump-starts researchers across the globe, brings insights regarding subtypes, and provides longitudinal understanding of the progress of this disease.

We'll continue to convene researchers to drive collaboration. Build bigger and more powerful advocacy actions. Provide more information to more families about this disease. Support work to improve clinician treatments. Produce more accurate media stories about the disease. There is so much in the works here at SMCI, and I'll support those efforts by serving on the board and volunteering my time and experience. I recently spoke to the national magazine *Health*\* about living with ME/CFS, and I hope doing so will help raise the profile of the disease in mainstream media. I will continue to use my voice to encourage greater awareness of ME/CFS well after my tenure as president of SMCI has ended.

The work of garnering widespread attention for ME/CFS is considerable and costly. If we want to see our stories told in print and on television, we must relentlessly



Carol Head, CEO and President

beat down the doors of news outlets. With that media spotlight and subsequent public awareness, the burden of raising more funds for research, medical education, and patient services will become just a bit easier to bear. Your donation to SMCI gives us the bandwidth to correct misinformation and pitch accurate, compelling stories to

media outlets who can shine a light on this disease and our terribly underserved, often misrepresented, community. **Please consider making a gift today and help us tell your stories for a global audience.**

Meanwhile, as I transition to a volunteer position, without the daily tasks of managing an organization tackling a complex issue, my first priority is to regain my health, at least to the level when I started with the CFIDS Association of America (the original name of SMCI).

And, I must admit, now well into my 60's, having worked full time for 40+ years while managing this disease and raising two sons, I'd like to carve out a bit of time sitting in the sun and reading a book. That sounds awfully grand to me. And I will not take that for granted. I wish it for every one of you as well.

I look forward to seeing you at ME meetings in the future.

Onward, with real hope!

Carol Head  
President & CEO  
Solve ME/CFS Initiative



## WHAT NO ONE SEES

Millions of women who look perfectly healthy on the outside are grappling with chronic conditions that make "normal" life anything but. This is what it's really like to have an invisible illness. BY LORRAINE HANCOCK

*Health magazine article*

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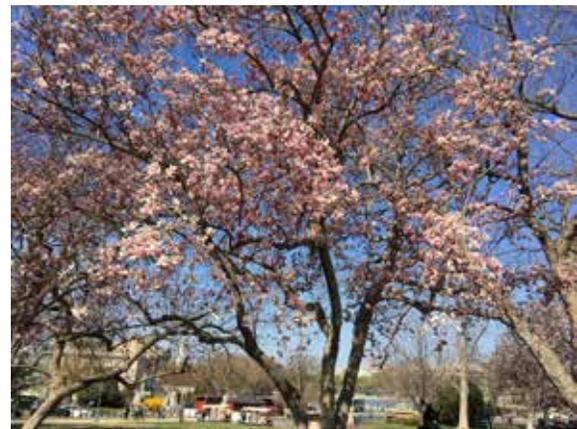
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## SPRING 2019

Solve ME/CFS Initiative (SMCI) is the leading disease organization solely dedicated to solving the devastating disease Myalgic Encephalomyelitis (ME). SMCI is unrelenting in our drive to make the disease widely understood, diagnosable and treatable. We build better lives for people with ME.



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