



The Solve ME/CFS CHRONICLE

SUMMER 2018

Meet Dr. Sadie Whittaker, Chief Scientific Officer

I AM SO PLEASED to write to you in this issue of *The Chronicle*. I joined Solve ME/CFS Initiative (SMCI) as the Chief Scientific Officer because I am motivated to do whatever I can to help people who are struggling with grievous illness. While new to this disease, I have spent many years working in the fields of biotech, clinical development, healthcare advocacy and policy, and public health strategy.

I am excited by the prospect of serving the ME/CFS community. I know my skills and experience can be applied to drive towards the goal of making ME/CFS widely understood, diagnosable and treatable.

My first few months with SMCI have been a whirlwind of mapping the ME/CFS research landscape, meeting key people, and evaluating how we can be most impactful. There has been progress in the scientific and clinical understanding of ME/CFS and I look forward to building out more opportunities to raise awareness, bolster advocacy, shape policy, and communicate more widely about this disease and the devastating impact it has on families. **We're looking at how we can leverage our resources to drive discovery faster.**

Our programmatic work and investments in science and discovery will always be influenced by three major priority areas—**collaboration, putting patients at the center**, and **increasing awareness**. I'm delighted to report out on some initial steps we've taken to fulfill these core pillars:

1. FOSTERING COLLABORATION. How can SMCI connect key stakeholders, including patients and caregivers, academia, healthcare providers, pharma and biotech, and government agencies to work collaboratively, across institutions and disciplines, to power faster results?



Dr. Sadie Whittaker, Chief Scientific Officer

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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 Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) widely **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 welcomed Dr. Sadie Whittaker as our new Chief Scientific Officer.
- SMCI closed Request for Applications for the 2018 Ramsay Award Program on June 30. Applications undergo a rigorous peer-review process. Each grant award ranges between \$35,000 and \$55,000 for a one-year period, with the possibility of renewal for projects yielding promising results.
- Ramsay Awardees were prominently featured in journal publications. Dr. Carmen Scheibenbogen and her research group published in the prestigious *PLoS ONE* journal an examination of a potential autoimmune treatment in ME/CFS. Also, Dr. Jonas Blomberg wrote a highly-recognized conceptual review on ME/CFS as an infection-elicited autoimmune disease in *Frontiers in Immunology*.
- SMCI published a three-part series Community Guide for the upcoming National ME/CFS Patient Registry on the Platform for Engaging Everyone Responsibly (P.E.E.R.) system.
- Preliminary results from the 2016 cohort of the Ramsay Award program were announced. All four teams have manuscripts submitted for publication with results from their research studies.
- The First Canadian Collaborative Team Conference for ME/CFS Research was held in Montreal, Quebec and included presentations from eight members of the SMCI research family, including a discussion with CEO Carol Head.
- SMCI's MeetME Travel Award program supported Katya Lavine (Stanford ME/CFS Initiative researcher) and Fane Mensah (PhD candidate at University College London, Ramsay 2016 Team 2 member) for travel to ME/CFS research conferences and to enable scientific collaboration.



Katya Lavine at the London "Thinking the Future" conference for young ME/CFS researchers

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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 broadly.

- SMCI's popular webinar series continued with "Hot Areas in ME/CFS Research 2018" presented by Dr. Anthony Komaroff of Harvard University.
- SMCI President and CEO, Carol Head, was the dinner speaker at the pre-conference dinner of the 13th Annual Invest in ME Research conference in London.
- NIH announced an unprecedented ME/CFS research conference in partnership with SMCI scheduled for April 4 & 5, 2019 at the NIH campus in Bethesda, MD.
- As part of ME/CFS Advocacy Week, SMCI hosted a screening of the award-winning ME/CFS documentary *Unrest* in Washington, DC.

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 funding for all qualified researchers.

- SMCI's ME/CFS Advocacy Day on May 15, 2018 included 102 people with ME/CFS and their loved ones and 122 meetings with congressional offices—the largest ME/CFS Capitol Hill Day to date.
- US Senator Ed Markey introduced Senate Resolution 508; a tri-partisan Senate Resolution to raise awareness and encourage more immediate government response for ME/CFS as part of ME/CFS Advocacy Day on May 15.
- Also, as part of ME/CFS Advocacy Day in May, Congressman Paul Gosar and Congressman Dwight Evans submitted a request for a hearing on ME/CFS to examine the ME/CFS clinical care crisis.
- Dr. Sadie Whittaker, Chief Scientific Officer for the Solve ME/CFS Initiative, joined more than 90 international clinicians and researchers in a second open letter to *The Lancet*, calling for an independent re-analysis of the PACE trial.
- SMCI participated in the Chronic Fatigue Syndrome Advisory Committee (CFSAC) biannual meeting.
- SMCI Ramsay Awardees Fane Mensah and Chris Armstrong met with members of the Australian Parliament to encourage further action and funding for ME/CFS research.
- Working with other advocates, SMCI helped facilitate written questions about ME/CFS to be submitted to Dr. Francis Collins as part of his testimony before US House Appropriations Subcommittee. ■



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



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Meet Dr. Sadie Whittaker, Chief Scientific Officer (cont'd)

KEY PRIORITIES



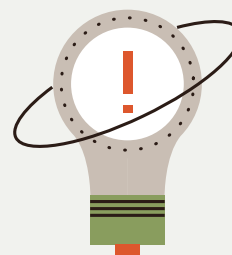
FOSTERING COLLABORATION

Activate a diverse network of stakeholders to collaborate and more rapidly advance discovery



ELEVATING PATIENT EXPERTISE & PERSPECTIVE

Meaningfully integrate those who know most about this disease—patients—into everything we're doing



DRIVING AWARENESS

Maximally leverage what we do in research to raise awareness of ME/CFS, particularly among healthcare providers and the broader public

Actions taken so far:

- Along with SMCI's President, Carol Head, I attended the 8th Biomedical Research into ME Colloquium in London. It was a meaningful opportunity to strengthen our network and lay the groundwork for future partnerships.
- We began outreach to existing biobanks and data repositories with the goal of forming a partnership to establish a robust, centralized data repository. This is a global disease, so we should work toward a global biobank and registry that serves the needs of patients and is readily available for use in quality research, anywhere.

2. ELEVATING PATIENT EXPERTISE & PERSPECTIVE. How can SMCI incorporate patient knowledge into our strategic thinking and funding decisions?

Actions taken so far:

- Individuals with ME/CFS served on the review panel for the 2018 Ramsay Award Program cycle. The Ramsay Awards promote original research through seed grants and introducing patient participation in the review process was a seminal moment in the growth of the program.
- ME/CFS patients and caregivers are a prominent part of an advisory body for the development process of the new patient Registry. Robust patient involvement will ensure the data capture is conducted in a way that addresses their needs.

3. DRIVING AWARENESS. What are the ways we can strategically communicate research findings to drive awareness within the ME/CFS community and more broadly?

Actions taken so far:

- Teams from the inaugural class of Ramsay grantees, funded at the end of 2016, have reported results. We communicated these preliminary findings in a series of articles in our monthly e-newsletter *Research1st* and through our YouTube channel. All the investigators are submitting manuscripts for publication and have indicated they will use the study data to apply for larger grants to continue their work (read more in “First Look: Research Results from 2016 Ramsay Awardee Program”, on page 8).
- SMCI’s 2018 webinar series kicked off with a comprehensive update on key areas of research by Dr. Anthony L. Komaroff. The webinar audience drove the discussion in a Q&A follow-up featured in the June edition of *Research1st*.
- We launched a reader poll in *Research1st* to get input on the types of stories that matter to you—from in-depth coverage of ongoing research, like the interview with Dr. David Systrom in this issue (read more in “Dr. David Systrom Breathing New Life into Research: A Report from the Patient-Scientist Partnership Program”, on page 6), to updates on action at the federal level, like the NIH ME/CFS Conference announcement (see below)—and how we can further improve our coverage of research developments.

I’m feeling galvanized by this start. I look forward to seeing the science evolve and to contributing to this wave of progress on behalf of those with ME/CFS and their families.

Until next time, my friends!



Sadie Whittaker, PhD
Chief Scientific Officer

BREAKING NEWS

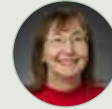
NIH Announces New, First Ever ME/CFS Research Conference in Partnership with SMCI

IN MAY, DR. VICKY WHITEMORE, NIH Program Director with responsibility for the Trans NIH ME/CFS Working Group, announced there will be a two-day NIH conference dedicated to ME/CFS research and developed in partnership with the Solve ME/CFS Initiative (SMCI). The conference will be held on the NIH campus and is scheduled to include a component for patients and a workshop for Young Investigators of ME/CFS. SMCI is proud to partner on this unprecedented conference and will report more details as the event takes shape. ■

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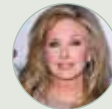


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Dr. David Systrom Breathing New Life into Research: A Report from the Patient-Scientist Partnership Program

At the 5th International ME/CFS Conference organized by Invest in ME in 2010, Dr. Paul Cheney said, “the whole idea that you can take a disease like [ME/CFS] and exercise your way to health is foolishness, it’s insane.”

Dr. Cheney, a physician at the center of the 1984 outbreak in Incline Village, was strongly repudiating the practice of graded exercise therapy (GET), an incremental increase in physical activity, as a means of “curing” a psychological and physical deconditioning cause of ME/CFS. GET as an effective treatment has now been debunked and the evidence strongly supports a pathological disease process, not deconditioning, as a cause.

And “post exertional malaise”, a worsening of symptoms after mental or physical exertion that can last more than 24 hours, has become recognized as a unique characteristic of ME/CFS.

With that understanding, exercise has reemerged in the ME/CFS field in an exciting way—an increasing number of determined patients are climbing on stationary bikes to see if the targeted use of an exercise protocol in research studies might,

in fact, hold the key to understanding the physiological and molecular basis of ME/CFS.

Dr. David M. Systrom, a physician trained in pulmonology who directs a dyspnea (shortness of breath) clinic at Brigham & Women’s Hospital in Boston, is at the forefront of using exercise for diagnostic and research applications. The reference to dyspnea belies the full range of exercise intolerant patients referred from clinicians stumped by unexplained, persistent symptoms. According to Dr. Systrom, the clinic evaluates “patients with fatigue and lightheadedness, [including individuals] labeled with ME/CFS, fibromyalgia (FM), and postural orthostatic tachycardia syndrome (POTS)” in addition to those with dyspnea resulting from heart and lung disease. The team of expert clinicians and exercise physiologists now sees about 1,000 new patients each year.

Dr. Systrom and his colleagues use a powerful approach to diagnose and research exercise intolerance: invasive cardiopulmonary exercise testing (iCPET) (see the inset for more information). This testing has uncovered a pattern of vascular dysregulation (abnormal blood flow) during upright exercise in patients



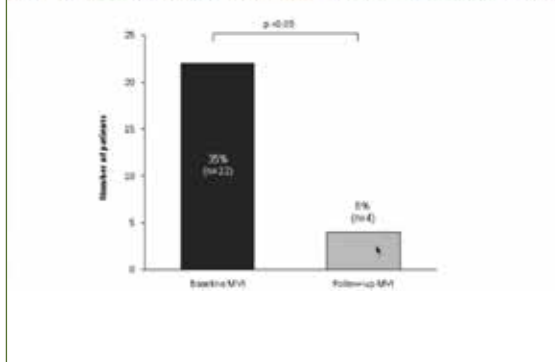
Dr. David Systrom (second from right) conducting an invasive cardiopulmonary exercise test in collaboration with his team at the Brigham & Women’s Hospital Dyspnea Clinic. Photo from the September 2017 Volume of *Pulmonary Circulation*, courtesy of the Pulmonary Vascular Research Institute.

with ME/CFS and related conditions, such as POTS and FM. Dr. Systrom and his team have observed evidence of preload failure, or low filling pressures of blood in the heart chambers due to insufficient constriction of veins and reduced return of blood to the right side of the heart. There are also indications of insufficient uptake of oxygen in the skeletal muscle cells, which could be the result of circulatory problems or mitochondrial dysfunction. These results have compelled Dr. Systrom to expand his research into ME/CFS.

“We are describing the prevalence of small fiber polyneuropathy in ME/CFS.”

In 2017, a visionary individual with ME/CFS funded Dr. Systrom's work through Solve ME/CFS Initiative's (SMCI) "patient-scientist" program, a funding mechanism designed to facilitate patient-driven research. In his current study, Dr. Systrom has been working to establish whether small fiber neuropathy (SFN), which has been described in FM by his collaborator at Mass General Hospital, Dr. Anne Oaklander, might play a role in ME/CFS. SFN refers to damaged nerve fibers in the peripheral nervous system; producing a range of symptoms. Notably, these nerve fibers are important in the functioning of the autonomic nervous system, which could underlie the vascular dysregulation observed in patients. Dr. Systrom has report-

Figure 1. Frequency of patients with MVI >1 among preload patients (n=62)



ed out preliminary data that similar numbers of ME/CFS patients with preload failure also have SFN.

Dr. Systrom is also focused on validating the therapeutic use of pyridostigmine, a parasympathetic drug that targets preload failure, through a random clinical trial. In his practice, pyridostigmine has made a meaningful difference to the vast majority of patients with

Graph from a 2016 paper by Oliveria, R.K. et al. showing an index score of exercise intolerance in patients before and after pyridostigmine treatment presented by Dr. Systrom during a Dysautonomia International Webinar (Jan. 2018). Dr. Systrom is launching a double-blind placebo-controlled study to further validate the use of this drug.

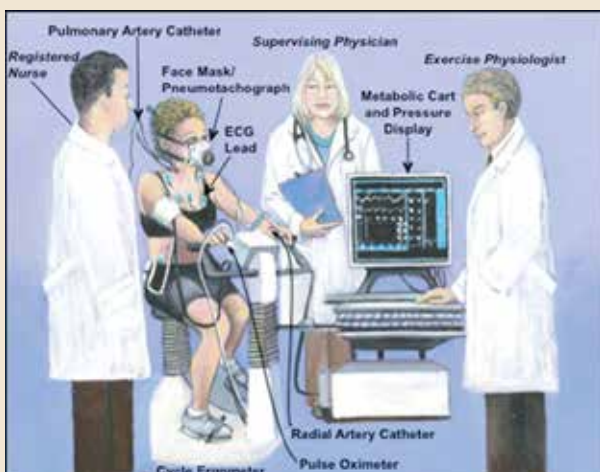
preload failure. Moving forward, Dr. Systrom would like to see more work to define "plasma metabolomic/proteomic/transcriptomic signatures during exercise" to predict treatment response. Both researchers and patients seem primed to meet that goal. There have been an increasing number of studies incorporating an exercise protocol and both the Cornell and Columbia Collaborative Research Centers funded by the National Institutes of Health are including exercise tests as a component of their research projects. ■

What is the difference between non-invasive CPET and invasive CPET?

Non-invasive, or conventional, cardiopulmonary exercise testing (CPET) provides a readout of the integrative exercise responses involving multiple systems, including cardiovascular, pulmonary, musculoskeletal, and cellular oxidative systems. Ventilation (respiratory gas exchange) and cardiac output are monitored during an incremental cycling protocol that entails a gradual increase in work load (pedal resistance). Compared with traditional exercise tests this provides a much more detailed level of insight, but Dr. Systrom qualifies

its usefulness by saying "non-invasive CPET is a reasonable screening test, but it lacks specificity...[for example] decreased aerobic capacity and ventilatory inefficiency are common to a variety of conditions heart failure, pulmonary hypertension, dysautonomia and mitochondrial myopathy."

The invasive CPET (iCPET), takes the determination of functional capacity and impairment a step further with the insertion of pulmonary artery and radial artery catheters before exercise. The catheters measure blood flow and filling pressures of the heart, oxygen content and other factors, allowing for a more detailed and simultaneous assessment of cardiovascular, respiratory, and metabolic function during exercise. The iCPET broadly expands the range of data acquired during exercise and it has emerged as the preferred diagnostic strategy for patients with an uncertain mechanism of dyspnea.



A graphic representation of an invasive CPET. Maximal volume of oxygen consumption (VO₂), peak cardiac output (CO), and premature ventricular contraction are statistically different in patients with preload failure. Retrieved from: Maron B.A., Cockrill B.A., Waxman A.B., Systrom D.M. The Invasive Cardiopulmonary Exercise Test. *Circulation*. 2013;127:1157-1164



First Look: Research Results from 2016 Ramsay Award Program

IN 2016, SOLVE ME/CFS INITIATIVE launched the first cycle of the Ramsay Award Program. The Ramsay Award Program is one part of the Solve ME/CFS Initiative's overall research strategy. The program is designed to encourage participatory investigations, accelerate new discoveries, and reduce barriers for entry into the challenging yet rewarding field of ME/CFS. The Ramsay Awards are foundational to SMCI's commitment to

RAMSAY AWARD PROGRAM



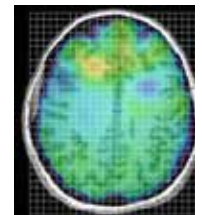
Seed Funding for Promising Ideas

"This pilot study would not have been conducted without the Ramsay award. The importance of these awards is that they fund early ideas that have the potential to change science and medicine."

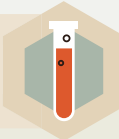
—Jarred Younger, PhD
University of Alabama at Birmingham



- Dr. Younger tested the hypothesis that ME/CFS fatigue is due to inflammation in the brain
- Using a non-invasive imaging technique, his team found that several markers of neuroinflammation are elevated in the brains of individuals with ME/CFS
- He used the data in a large grant application to continue the work



RAMSAY AWARD PROGRAM



Fostering International Collaboration

"Due to the Ramsay award, I think we have managed to send out a statement of how two young researchers thousands of miles apart can collaborate on an ME/CFS project. We have set an example which hopefully many will follow."

—Fane Mensah
University College London



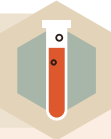
- Dr. Geraldine Cambridge and PhD candidate Fane Mensah at University College London designed a study in partnership with Dr. Chris Armstrong at the University of Melbourne in Australia
- The study focus was on how metabolic activities in B cells, a type of white blood cell, might differ in individuals with ME/CFS
- The group established an experimental setting to build on this work

explore worthy research avenues and provide seed dollars so that researchers can go on to obtain funds for larger studies in their areas of expertise.

Because the underlying biological cause of the disease is not yet known, SMCI invests in a diverse set of disciplines to find answers for ME/CFS.

We are pleased to announce the first group of research teams funded by the Ramsay Awards are beginning to report results. We look forward to providing a full report following the publication of the study outcomes in the coming months. ■

RAMSAY AWARD PROGRAM



Translating Findings into Understanding

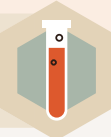
“This is a disease which is unique in a negative way, it is so frequent and severe, and we have so little knowledge—and no satisfactory treatment for our patients.”

—Carmen Scheibenbogen, MD
Charité-Universitätsmedizin Berlin



- Dr. Scheibenbogen has been working to better understand immune system dysfunction in ME/CFS through two Ramsay-funded projects
- In her 2016 study, the research team found evidence for a genetic autoimmune signature.
- They aim to do a confirmatory study in a larger cohort

RAMSAY AWARD PROGRAM



Bringing New Researchers into the Field

“The Ramsay Award was very timely help for us to take our work one step ahead. We [plan] to publish our work soon and this should help gather momentum in the scientific community, and open funding opportunities for this research topic.”

—Bhupesh Prusty, PhD
Julius-Maximilians-Universität Würzburg



- Dr. Prusty applied his expertise in molecular virology to explore the hypothesis that there is a pathogenic connection to mitochondrial dysfunction in ME/CFS
- The preliminary results indicate that HHV-6 activation can lead to changes to mitochondrial structure and function

May ME/CFS Advocacy Week Brings Awareness and Action to Congress

This May, SMCI led the largest Capitol Hill action to date, more than doubling last year's ME/CFS Advocacy Day. Senator Markey (MA) introduced an ME/CFS Senate Resolution and momentum is building for a US House of Representatives hearing request.

After over 300 #MillionsMissing actions worldwide, the Solve ME/CFS Initiative (SMCI) brought together 102 people with ME/CFS, their loved ones and advocates to a call for action on Capitol Hill. In conjunction with local efforts across the country, SMCI called for action and funding for ME/CFS research.

Together, we accomplished:

- 122 meetings with congressional offices
- 16 meetings face-to-face with Members of Congress
- The bi-partisan introduction of a Senate Resolution for ME/CFS; S. Res 508, called "Supporting the goals of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome International Awareness Day"
- A bi-partisan request was submitted for a hearing on ME/CFS in the US House of Representatives
- Over 95 states and districts were represented among the many Congressional visits
- 102 ME/CFS advocates stormed Capitol Hill.

Actress Amy Carlson (of the TV series *Blue Bloods*) and Congressman Gus Bilirakis of Florida joined ME/CFS advocates during a Capitol Hill reception, concluding the second annual ME/CFS Advocacy Day. It was humbling to see so many people with ME/CFS consciously use up their limited energy to help fight for our cause.

In conjunction with the event, Senator Ed Markey of Massachusetts introduced a bipartisan Senate resolution (S. Res 508) to raise awareness and encourage more immediate government response for ME/CFS. The resolution is co-sponsored by Senator Angus King (I) of Maine, Senator Susan Collins (R), Senator Dianne Feinstein (D) of California, and Senator Chris Van Hollen (D) of Maryland. This Senate resolution is the result of a collaborative partnership between Solve ME/CFS Initiative, #MEAction and the Massachusetts CFIDS/ME & FM Association.



SMCI Director of Advocacy and Communications Emily Taylor, Amy Carlson of Blue Bloods and SMCI President and CEO Carol Head

"ME/CFS has been in the shadows for too long," said Senator Markey. "Our resolution is just one step to help shine light on this condition and what we can collectively do to help improve the quality of life of those impacted."

SMCI also announced that Congressman Paul Gosar (R) of Arizona and Congressman Dwight Evans (D) of Pennsylvania have submitted a request for a hearing on ME/CFS. The request calls for the Energy and Commerce Subcommittee on Health to hold a hearing to examine the ME/CFS clinical care crisis and review federal agency efforts to combat this urgent health need. ■

“Too many have already died. Too many are turning to suicide, feeling there is no way out of their nightmare. Too many suffer in silence with little hope. It’s time to change this,” stated Carol Head, President and CEO of the Solve ME/CFS Initiative and person with ME/CFS.



SMCI President and CEO Carol Head with representatives from Massachusetts ME/CFS & FM Association



SMCI Director of Advocacy and Engagement Emily Taylor and Congressman Gus Bilirakis



Congressman Jim McGovern invited ME/CFS Advocates into his Capitol Hill Office



Congressman Jamie Raskin met with ME/CFS advocates, patients and constituents from his district



Congressman Tom Emmer welcomed SMCI on the big screen



Senator Todd Young invited ME/CFS advocates to a select coffee conversation in the Russell Senate Office Building

PATIENT VOICES

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

The Sabbath

By Jenny Little Dow

I take to my bed for what feels
like the millionth time,
to rest this splintered shell.

To once again reconcile
my type "A" personality,
with my body,
hovering near the farthest reaches of the alphabet.

Reaching for the remote,
I look for low level diversion.
The TV blinks on,
tuning into the signal from
last night's programming.

PBS and the muted grays and browns
of hard seaside rocks,
and their soft nubbly
frosting of resting seals.

Soothing narration lulls
my empty but wired system.
My nerves signaling,
This will do.

Then a long shot of an Alaskan coast.
More brown and a solitary bear.
"Lingering oil from the Exxon Valdez can
still be found in the beaches."
Click.

I return to watching the wildlife in my room.
Two striped cats,
in grays, charcoal and golds,
grooming each other.

Each pass of their bristly tongues
on shiny coats,
quiets my soul.

Reminding me that is enough
to rest your head on another's warmth,
and sink into a soft blanket.

And today is that day
which even the non-faithful
of my cultural tribe
hold apart from other days.

This seventh day of rest,
which started with rain,
then flitted through sun,
and settled on milky bright shadows.

A day when the movement of wheels
rolling by my window,
is less.
And children's voices stilled.

Sinking into this
soft blanket feels easier.
Less fraught.
Less isolating.



SMCI Answers Reader Questions

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

Q: *A question for Dr Whittaker. Whether it's mitochondrial dysfunction, autonomic nervous system dysfunction or immune dysregulation, all the key features of ME/CFS involve the hypothalamus. Why aren't researchers looking into this more extensively?*

A: Thank you for starting a discussion on hypothalamic dysfunction. There has been some work to explore the influence of the HPA (hypothalamic-pituitary-adrenal) axis, a stress-response system, in ME/CFS. HPA dysregulation does appear to be associated with ME/CFS, but we don't have evidence of a causal role. However, there is interest in expanding knowledge in this area and developing treatments based on this target. For example, Dr. Nancy Klimas and her group at the Institute for Neuro Immune Medicine have put forward research suggesting a role for the HPA axis, HPG (hypothalamic-pituitary-gonadal) axis, and the immune system in perpetuating or regulating both Gulf War Illness (GWI) and ME/CFS. They are now exploring this model in a clinical trial.

Q: *From a participant in May's ME/CFS Advocacy Day. Two Questions: 1) We had followed up by email with all of the staff we met. Is there additional follow up that you recommend? 2) Are the dates for Advocacy Week/Day on the Hill for next May 2019 set?*

A: First, please let us say "Thank you!" for your energy and dedication for ME/CFS Advocacy Day. It was such a pleasure to work with you in Washington DC! Regarding follow-up, Congressional staff are often out of the office or taking vacations during the August recess while the "boss" spends that time in the home district. That would be a perfect time for a quick "check-in" with DC staff to keep them involved and to keep ME/CFS at the front of their minds.



If you connect with DC staff during the recess, keep pushing our requests and education efforts from May. You can find them outlined in the "ME/CFS Advocacy Week Local and Online Toolkit 2018" on the advocacy corner of our website – <https://solvecfs.org/patient-resources/advocacy/>. All the work we did in May and continue to do is building again with consistent advocacy in spring 2019.

As for next year's advocacy week, we can't say for certain until the new House/Senate calendar is released. We expect the majority party to issue the schedule in mid-January. That being said, we always try to target the best full working day as close to May 12th as we can manage. Keep an eye out for announcements and details in our e-newsletters, social media, and advocacy alert notices. ■

Your Support Drives Innovation

SMCI is committed to discovering treatments and a cure for ME/CFS and is dedicated to innovation in the field of ME/CFS research.

Two examples of our most innovative ME/CFS programs are the Ramsay Award Program and our new National ME/CFS Patient Registry.

Established in 2016, **The Ramsay Award Program** attracts new researchers to the field of ME/CFS and provides seed funding for pilot studies, which can be used to apply for larger grants. Our founding Class of 2016 Ramsay Award recipients have recently reported the results of their studies in neuroinflammation, immune cell changes, autoimmunity and mitochondrial function. You can get a first look at these results in this issue of *The Chronicle*. And importantly, all of these researchers are using their data for publication and to apply for larger grants!

The five 2017 Ramsay research teams are now conducting their work. And, applications for the 2018 Ramsay Awards were submitted on June 30. For the first time in 2018, we will incorporate individuals who have ME/CFS into our rigorous peer review process.

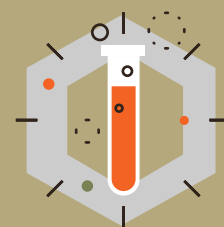
Donor support enables us to fund this important program—generating valuable research and bringing new researchers to the field.

Our new **National ME/CFS Patient Registry** will be the first registry of its kind for this disease. It will further our understanding of the natural history of ME/CFS, enable clinical trials, and enhance data sharing and collaboration among patients, researchers and other disease organizations. This robust data repository includes physical samples from patients to support the work of qualified researchers and accelerate discovery. **The registry will play a critical role in moving the needle forward in ME/CFS research, and it has been made possible thanks to the generosity of donors to SMCI.**

Every dollar we raise goes towards finding treatments and a cure for ME/CFS. **Your** support fuels our work and drives this innovation forward. Please help us to continue to fund our work toward a cure with a gift to SMCI using the enclosed envelope, or online at <https://solvecfs.org/donate>.

WE ARE ALL IN THIS TOGETHER. ■

RAMSAY AWARD PROGRAM



Investing in innovative ideas around the world.

NATIONAL ME/CFS PATIENT REGISTRY & BIOBANK



Creating data management platforms, patient registries & biobanking

Reflections from our President Carol Head



Carol Head, CEO and President

Dear friends,

So, how are you feeling, *today*?

I've learned to add the word "today" for all of us with ME/CFS, because we know the answer changes day-to-day with this unpredictable, dreadful disease. Today is likely different from yesterday. Some days getting out of bed is possible; other days it is not.

Today I'm feeling *hopeful*. My focus is single-minded, looking forward: *How can we accelerate bringing treatments and cures to those who struggle with this disease?* I've seen a marked uptick in the last year—in research, in government work, and in advocacy. I see increased cooperation among advocates, especially in the magnificent efforts in May with #MillionsMissing and the intense ME/CFS Advocacy Day in Washington, DC. I see more research being funded. I see more attention paid to ME/CFS in the media. I see the movement toward radical change in attitudes toward ME in the UK Parliament.

And I am especially heartened by SMCI's new, brilliant Chief Scientific Officer, Dr. Sadie Whittaker, and by the results from our Ramsay Research Awards.

I see that the slow, upward curve of progress is gaining accelerated height. And, I know that at some point progress will accelerate as the flywheel gains

speed. That's how progress happens: Periods with little movement (like the last several dire decades!), then an increase, and then, suddenly—significant change.



There truly are unsolvable problems in our world. ME/CFS is not one of them. Human beings have solved more difficult medical problems in the past. And, we will solve this one.

So, today I'm feeling hopeful.

Those of us who know the truth about ME know that we are in this fight for justice together. And, we will prevail in this fight. I have no doubt. So, I value my outrage of yesterday, which fuels my hope today, as I see real progress being made.

I celebrate so many who have gone before us in this fight, and the people who join us, every day. I am proud to be in this difficult, passionate, invigorating fight. It's an honor to serve with all of you—*today*, tomorrow, and every day until we find treatments and cures for ME/CFS.

Onward, with hope!

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SUMMER 2018

Solve ME/CFS Initiative (SMCI) is the leading disease organization solely dedicated to solving the devastating disease Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). SMCI is committed to making ME/CFS widely **understood, diagnosable, and treatable**. This issue of *The Chronicle* is a

free public service providing information and analysis for the ME/CFS community.

ME/CFS is a complex and debilitating multi-system, chronic disease with a serious impact on the quality of life of up to 2.5 million Americans. At this time, the cause of ME/CFS is not fully understood. There is no diagnostic test, no FDA-approved treatment, and patients often suffer for life.

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- Meet Dr. Sadie Whittaker, our new Chief Scientific Officer
- NIH Announces ME/CFS Research Conference with SMCI
- 102 ME/CFS Advocates Took Action on Capitol Hill
- A First Look at the 2016 Ramsay Research Award Program Results
- Dr. David Systrom Breathing New Life into Research: A Report from the Patient-Scientist Partnership Program



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