



The Solve ME/CFS CHRONICLE

FALL 2018

Ramsay Research Reaches New Heights

More proposals received than ever before; funding given to exciting avenues of research

Solve ME/CFS Initiative (SMCI) announces four newly funded research projects, half of which are led by investigators new to the ME/CFS field. Four important areas will be explored, including immunology, whole genome sequencing, neuroinflammation, and metabolism response.

2018 Class



Dr. Jonas Blomberg
Biomarkers of mitochondrial functioning and signaling in ME/CFS



Dr. Liz Worthey
Whole genome sequencing and analysis of ME/CFS



Dr. Theoharis Theoharides
Extracellular vesicles from ME/CFS patients and their effect on human mast cells and microglia mediators secretion



Dr. Vince Lombardi
Characterization of Janus kinase (JAK) activation profiles in ME/CFS subgroups

SMCI's Ramsay Research Award Program is a foundational mechanism to expand the number of researchers working in ME/CFS. It has four main objectives: 1) generate pilot data for larger grant applications; 2) produce findings that will increase our knowledge; 3) bring new researchers to the field of ME/CFS; and 4) increase collaboration among researchers.

Quick Facts about 2018 Ramsay Award Program

- We received double the number of requests for funding in 2018, indicating researcher interest in ME/CFS is growing.
- 50% of teams that applied for funds came from researchers **new to the ME/CFS field**.
- 70% of the proposals that advanced to our peer-review panel came from US-based teams. These projects may grow into applications to the National Institutes of Health (NIH).
- Two applications included collaborations with previous Ramsay awardees, growing our SMCI research family.
- Two individuals with ME/CFS served on the Ramsay 2018 Peer Review Panel, bringing the patient community into the SMCI research process.

It is clear from the volume and quality of proposals received in 2018 that the pool of researchers eager to work in ME/CFS is growing. In 2019 and beyond, our goal is to significantly expand the Ramsay program; not only funding more proposals but proactively reaching out to researchers in related fields and encouraging them to join the ME/CFS community.



Contribute to SMCI today and help us realize the full potential of the Ramsay Program!

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



SMCI Director of Advocacy and Community Relations Emily Taylor and Director of Research Programs Allison Ramiller at Genetic Alliance's "People Driven" conference

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

- Three SMCI-funded researchers presented at the Second Annual Community Symposium on the Molecular Basis of ME/CFS at Stanford University, SMCI-directed Projects partner, Dr. Maureen Hanson (Cornell University, SMCI Research Advisory Council (RAC) member), and two Ramsay Award Program Researchers, Dr. Jarred Younger (University of Alabama at Birmingham, Ramsay 2016) and Dr. Jonas Bergquist (Uppsala University, Ramsay 2017).
- SMCI's Chief Scientific Officer, Dr. Sadie Whittaker, attended the Centers for Disease Control and Prevention (CDC) Roundtable on Medical Education and ME/CFS in Atlanta, GA.
- Columbia University Mailman School of Public Health's Center for Infection & Immunity was funded by SMCI to complete a study aiming to build on recent metabolomics analysis. We provided \$50,000 to continue this comprehensive deep-dive, uncovering evidence for a biomarker signature for ME/CFS. Research results are anticipated in late 2019.
- SMCI funded an extension of the 2016 Ramsay Class project led by Dr. Geraldine (Jo) Cambridge (University College London). To build on promising results that have been accepted for publication in *Frontiers in Immunology*.
- Dr. Lubov Nathanson, funded by SMCI's Ramsay program, is leading a project to look at epigenetic changes in specific immune cell subtypes.
- SMCI RAC member Dr. Jose Montoya (Stanford University) presented at the medical education conference "Management of ME/CFS: Adult & Paediatric - 'First Do No Harm'" in the UK.
- 2017 Ramsay Awardee Dr. Jonas Blomberg's hypothesis that genetics and a leaky gut triggered by an infection results in an autoimmune cause of ME/CFS was featured in an article by Cort Johnson.
- As part of his Ramsay 2016 project, Dr. Bhupesh Prusty (University of Würzburg) published a novel experimental system to study mitochondrial alterations in a host cell that could be the result of HHV-6 reactivation. Read more on page 10.

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

- The NIH (National Institutes of Health) recently formed The ME/CFS Working Group of the NINDS (National Institute of Neurological Disorders and Stroke) Advisory Council. Carol Head, SMCI President and CEO, will also be a member.

- The 13th Invest in ME Research International ME Conference (IIMEC13) took place in London. Carol Head, SMCI President and CEO, addressed delegates from twenty different countries at the event's opening dinner. The theme for the 2018 IIMEC was "Working Together."
- The ME/CFS Blog, hosted by the Jackson Laboratories (JAX) features an interview with Chief Scientific Officer, Dr. Sadie Whittaker.
- Lynn Fuentes interviewed our President, Carol Head, as part of a series called the Koan of Illness.
- Our President and CEO Carol Head sent a rebuttal to a negative depiction of the #ME/CFS community in *Forbes*.
- SMCI's RAC member Dr. Susan Levine was featured in an episode of ME/CFS Alert.
- As part of SMCI's 2018 webinar series, Dr. Leonard Jason (DePaul University) provided an overview of the multi-year effort to develop a patient symptom questionnaire for ME and CFS.
- Special Needs Advocate Lisette Duarte presented SMCI webinars aimed at assisting parents of children with ME/CFS with school systems and accommodations.
- Derya Unatmaz of Jackson Laboratory presented an SMCI webinar on the "Crossroad of the Immune Response and the Microbiome: Impact on ME/CFS."
- In an "Insider Sources" article, SMCI was named as instrumental in generating more interest of ME/CFS in the medical research community, with NIH, and the public.

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

- The Department of Health and Human Services announced the dissolution of the Chronic Fatigue Syndrome Action Committee (CFSAC). SMCI launched a Call to Action, demanding congress to act to pass legislation to ensure ME/CFS is represented, **funded**.
- SMCI Announced Wednesday April 3, 2019 for the next ME/CFS Advocacy Week and DC Lobby Day.
- SMCI was the only ME/CFS representative at the Genetic Alliance conference in Washington, D.C.
- SMCI joined The American Heart Association and 190 other health and patient advocacy organizations to call for the restoration of funding to the Navigator health insurance outreach and enrollment program, helping those with disabilities access health insurance.
- The "Advocacy Corner" on the SMCI website was launched, featuring current actions, local campaigns, and tools to empower your story to make change. Check it out at: <https://solvecfs.org/advocacy/> ■

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



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Ramsay Research Reaches New Heights (cont'd)

NEW FOR 2018

The Ramsay Award Program has delivered great results through two cycles. To strengthen the Ramsay Awards, check out these new program components in 2018.

>GO FORTH AND REPLICATE!

To accelerate discovery, researchers from the 2018 Ramsay class must share both positive and negative results to allow other researchers to build on their findings.

>RESEARCHER ADVOCATES.

Because policymakers respond well to researchers, each project in the Ramsay 2018 class will complete a visibility or advocacy action.

>INCREASING COLLABORATION AND DATA SHARING.

When researchers work together, discovery can be accelerated. New mechanisms will facilitate collaboration and data sharing across all three classes of Ramsay investigators.

"Extracellular vesicles from ME/CFS Patients and their effect on human mast cells and microglia mediators secretion"

Prof. Theoharides' (Tufts University) project will focus on the hypothesis that mast cells and microglia provoke neuroinflammation in ME/CFS patients. Using an innovative approach of examining the contents of extracellular vesicles (membrane surrounded structures released from cells involved in signaling), this study has the potential to bring novel insight to a highly provoking area of research that has only been explored preliminarily.



We are very grateful and proud to receive this award from Solve ME/CFS Initiative. This is the first time that extracellular vesicles from ME/CFS patients and some of their key contents will be characterized and studied for their effect on human mast cells and microglia. We anticipate that our results will identify a potential new pathogenetic mechanism that could also be used to monitor disease activity and serve as target for the development of effective therapies for ME/CFS."

Theoharis Theoharides, MD, PhD
Tufts University



"Characterization of Janus kinase (JAK) activation profiles in ME/CFS subgroups"

Prof. Lombardi (University of Nevada, Reno), an established ME/CFS researcher, plans to expand on pilot findings of activation of janus kinase (JAK), a signaling pathway involved in cytokine activity, in ME/CFS patients. This investigative choice could lead directly to treatments that are already FDA-approved for other conditions, making this project highly significant to progression of the field with the potential for translational benefit to patients.



Although the etiology of ME/CFS is not known at this time and progress is slow, we can take advantage of some fairly common clinical observations to identify potential treatment strategies. In that many inflammatory cytokines operate through the activation of Janus kinases, drugs that inhibit these enzymes represent promising options to treat the inflammatory component of ME/CFS. Moreover, there are currently several such drugs either in clinical trials or approved for the treatment of other inflammatory diseases that may benefit these patients. We are honored and grateful to have received the SMCI Ramsay award to understand the Janus kinase activation profile of ME/ CFS. We would also like to express our unwavering commitment to helping those who suffer with this devastating disease."



Vincent Lombardi, PhD
University of Nevada, Reno

RAMSAY AWARD PROGRAM



Make sure to subscribe to the **Research 1st** e-newsletter for more exciting announcements about Ramsay 2018 projects

"Whole genome sequencing and analysis of ME/CFS"

Dr. Elizabeth (Liz) Worthey (HudsonAlpha Institute) is an experienced investigator newly applying her expertise to the ME/CFS field. Along with **Dr. Camille Birch**, her research associate, Dr. Worthey will run whole-genome sequencing (WGS) against network analysis algorithms to test the hypothesis that an intrinsic genetic defect (or defects) in one or more metabolic pathways is stimulated by an external stimulus. There is a dearth of prior studies of WGS in the ME/CFS population and this powerful approach has potential to offer insight into a heritable component of the disease.

“My lab focuses on performing analyses to help to understand the genetic underpinnings of both rare and more common complex human diseases. We have been working to push the boundaries of genomics and informatics capabilities in this area for more than a decade. We will bring our tools, our experience, and our enthusiasm and dedication and work with other researchers to help find much needed answers for ME/CFS patients, their families, and their physicians”



Liz Worthey, PhD
HudsonAlpha Institute



Camille Birch, PhD
HudsonAlpha Institute

"Biomarkers of mitochondrial dysfunction and signaling in ME/CFS"

Prof. Jonas Blomberg (Uppsala University, Sweden), also a member of the Ramsay 2017 class, is partnering with **Prof. Anders Rosén (Linköping University, Sweden)** to study mitochondrial dysfunction in a large cohort of ME/CFS patients and healthy controls. They will be focusing on identifying autoantibodies targeting proteins in the mitochondria, including pyruvate dehydrogenase (PDH), an enzyme complex that plays a key role in energy production.

“This study is a collaborative effort between our two labs to better understand the role of mitochondria in the development of ME/CFS. This pilot funding is furthering our work to investigate the hypothesis we published in *Frontiers in Immunology* - that an infection initiates an autoreactive process, impacting several processes, including brain and energy metabolism.”

Jonas Blomberg, PhD, MD
Uppsala University



Anders Rosén, MD, PhD
Linköping University

2016 Ramsay Investigators Are Impacting the ME/CFS Research Landscape

(note: funds were distributed in 2016 and as projects generally last a full year, we are now seeing results)

1) BHUPESH PRUSTY, PHD, (Julius Maximilian University of Wurzburg, Germany, molecular virology) and his team published “HHV-6 encoded small non-coding RNAs define an intermediate and early stage in viral reactivation” in *Genomic Medicine* as part of his Ramsay project. The paper discusses HHV-6 small non-coding RNAs and their importance in **viral reactivation leading to mitochondrial alteration**—a mechanism he hypothesizes could be at play in ME/CFS. The second manuscript, with results particular to ME/CFS samples, is being prepared for submission. >>> The availability of Ramsay funding helped bring Dr. Prusty into the field of ME/CFS. Read more about his work on page 10.

Project 1



2) JO CAMBRIDGE, PHD, (University College London, England, metabolomics) Fane Mensah, and Chris Armstrong’s project, authored a manuscript titled “CD24 expression and B cell maturation shows a novel link with energy metabolism: potential implications for patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome”, has been accepted for publication in *Frontiers in Immunology*. The team has investigated how **metabolic activities in B cells, a type of white blood cell, might differ in individuals with ME/CFS as compared to healthy controls**. They established an experimental setting to follow up on **their novel finding of increased CD24**, a cell surface molecule on B cells in the immune system, in patients with ME/CFS.

Project 2



They have also used their pilot data to design a research project to apply the experimental method from their 2016 project to an expanded pool of samples, supported with extension funding from Ramsay.

3) JARRED YOUNGER, PHD (University of Alabama at Birmingham, USA, neuroinflammation) reported preliminary findings from his Ramsay study during a presentation titled “How Brain Inflammation Causes ME/CFS” at the Stanford Symposium in September 2018. The study outcome offers hope that this **strong evidence of neuroinflammation in ME/CFS could be validated through an expansion of this work—with a biomarker and neuroinflammatory treatment targets not far behind**.

Project 3



A manuscript detailing his team’s use of a neuroimaging technique to assess inflammation in the brains of individuals with ME/CFS has been

submitted for publication. Dr. Younger also **submitted a large R01 grant proposal** to the NIH that could enable an expansion of this important work.

IN HIS RECENT ARTICLE, “A Grant Generation Machine: The SMCI’s 2016 Ramsay Award Winners Score,” ME/CFS blogger Cort Johnson recently wrote of Dr. Younger’s NIH grant application, “The NIH wants to redo the grant application and add something to the study (a PET scan group). Yes, the NIH is actually asking Younger to ask for more money...It’s hard to believe Younger won’t get that grant award, and when he does, it will constitute a massive return on investment for the SMCI and the ME/CFS community. SMCI put in about \$50K and the ME/CFS community will get out something like \$3,000,000...Maybe there is a solution for the low researcher [NIH] grant application rate in ME/CFS—help fund the SMCI’s Ramsay Awards.”

- 4) CARMEN SCHEIBENBOGEN, MD, (Charité—Universitätsmedizin Berlin, Germany, immunology) found evidence for a promising autoimmune genetic signature in her Ramsay 2016 study of ME/CFS patients selected for infectious onset and elevated levels of specific antibodies.

Dr. Scheibenbogen aims to do a confirmatory study in a larger cohort before publishing. She is also working on another Ramsay-supported project, funded in 2017, to examine metabolic and functional changes of specific immune cell types—T cells and monocytes.

Project 4

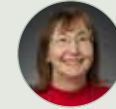


Research for the Ramsay Researchers Class of 2017 is in process; we expect results early next year. ■

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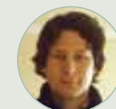
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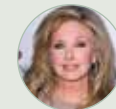


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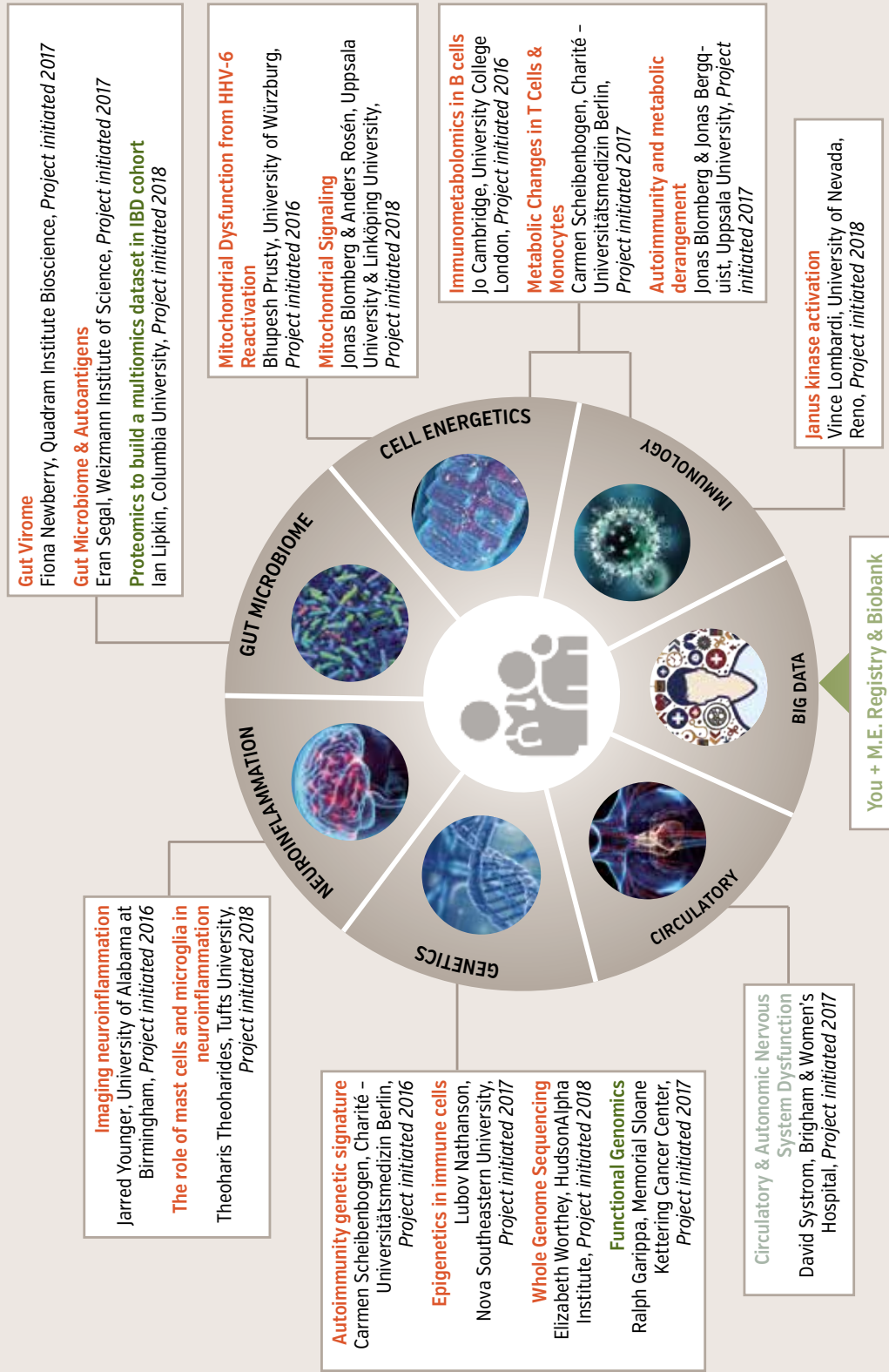
Andreas Kogelnik, MD, PhD
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SMCI's Research Portfolio is Expansive

KEY: **Ramsay Award Program** **SMCI-Directed Project** **Patient-Initiated Project**





Your support drives innovation

You + M.E.

Registry & Biobank

In 2010, Solve ME/CFS Initiative (SMCI) launched the SolveCFS Biobank to connect researchers with well-characterized patient samples and clinical data.

Since its inception, SMCI has pioneered this approach to strengthening the infrastructure for ME/CFS research and grown a repository of biological samples and data from individuals with ME/CFS and healthy individuals (controls).

The Biobank has supported a range of studies, enabled patient participation, brought new researchers into the field, and contributed to the cumulative understanding of the disease.

It's now time to go further. SMCI is implementing a redesign of our current process and building a new patient registry that will be linked with our existing biobank: You + M.E. We are designing the You + M.E. Registry with five broad goals in mind:

You + M.E.

1

DATA COLLECTION IS EASY

Integrate app for ongoing data collection of common core symptoms
At home blood sample collection for severe patients



2

GLOBAL, CENTRALIZED, AND STANDARDIZED

Integrate siloed data repositories
Promote the use of common data elements
Establish standard procedures for sample collection



3

DATA IS ACCESSIBLE

Easy for investigators to understand available data
Process to access samples is nimble
Ensures samples are only used for quality research



4

PATIENTS MEANINGFULLY INTEGRATED

Data collected is important to patients
Data capture process is easy and takes advantage of digital health
Data is used in research meaningful to patients



5

LEVERAGE TO BUILD DISEASE AWARENESS

Use the Registry to increase disease awareness, particularly targeting healthcare providers



Will you be one of the thousands of patients who will contribute their data to the You + M.E. registry? Help us understand more about this disease by re-registering. Check our website for more information.

Ramsay Program Inspires 2016 Ramsay Investigator Dr. Bhupesh Prusty to Deepen His Engagement in ME/CFS

BHUPESH PRUSTY, PHD, a molecular virologist at University of Würzburg, Germany, designed his Ramsay 2016 project to explore the hypothesis that **deficient energy production observed in ME/CFS may be related to a host-pathogen interaction**. He focused on HHV-6, a human herpes virus that has been implicated in chronic conditions.

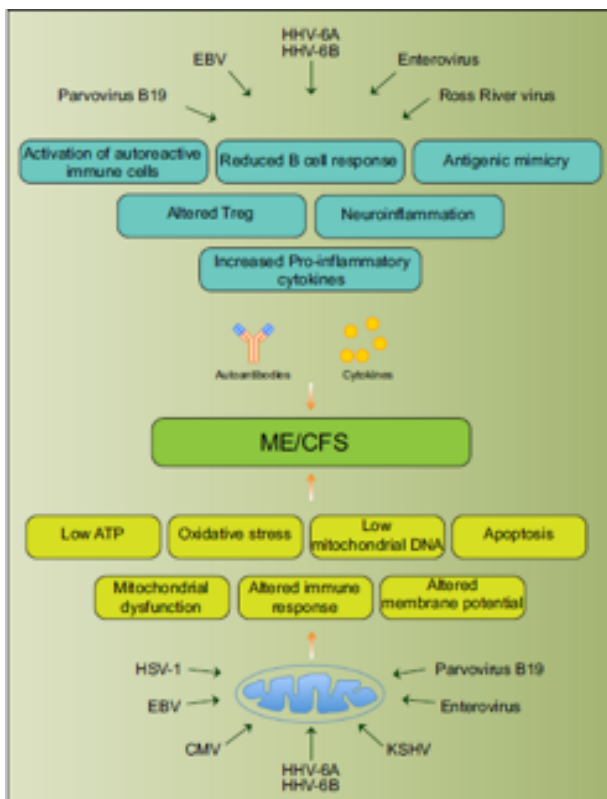
The preliminary manuscript from his Ramsay-funded work, titled "HHV-6 encoded small non-coding RNAs de-

fine an intermediate and early stage in viral reactivation," was published in *Genomic Medicine* in September 2018. The paper outlines a mechanism that accounts for how, even with a low number of copies of the virus in the blood, HHV-6-infected cells might still impact energy production in adjacent or distant cells through factors secreted in the blood plasma. The unique stage of viral activation identified by Dr. Prusty and his co-authors has the potential to serve as a biomarker for ME/CFS.



Dr. Bhupesh Prusty (center) and colleagues

and molecular mechanisms, including altered immune cells, changes in mitochondria, and autoimmunity in the development of ME/CFS. Advances in understanding the behavior of various pathogens **caused the review authors to cast doubts over the validity of several past findings**. However, the authors conclude there is evidence for a role of viral infection in at least a subgroup of ME/CFS patients. They recommend future strategies to improve studies through subtyping the patient population, standardization, the use of disease controls, and longitudinal data collection.



A figure showing a number of viral pathogens linked to ME/CFS and mechanisms in the body potentially altered by these pathogens that might contribute to ME/CFS development. (Rasa et al. *J Translational Med* (2018) 16:268. <https://doi.org/10.1186/s12967-018-1644-y>)

As part of his 2016 study, Dr. Prusty applied this experimental method to ME/CFS patient samples. In October, a second manuscript with that data was being prepared for publication. Pilot data from the project has the potential to secure larger grant funding.

Dr. Prusty is an inspiring example of a researcher **new to ME/CFS** who is staying engaged in the field. In addition to contributing to ME/CFS research literature through his Ramsay project, he also co-wrote an extensive review on chronic viral infection in ME/CFS in the October 2018 edition of *Translational Medicine*, on behalf of the European Consortium (EUROMENE) on ME/CFS. Dr. Prusty's review surveyed studies on the potential role of various viruses

In collaboration with Prof. Carmen Scheibenbogen, another SMCI Ramsay-supported researcher, and other members of the EUROMENE Biomarkers Working Group, Dr. Prusty hopes that this review article **"will help researchers plan future studies on finding viral etiology behind ME/CFS."** SMCI is thrilled that Dr. Prusty has expanded his influence in the ME/CFS field and added his voice to a powerful collective calling for improved study methods and collaboration. ■

Mission NOT Accomplished: Fighting For a Voice for ME/CFS

On September 6, the Secretary of Health and Human Services disbanded the federal Chronic Fatigue Syndrome Advisory Committee (CFSAC). Solve ME/CFS Initiative mobilizes the call to Congress to restore ME/CFS representation.



CFSAC had all the pieces of the puzzle to make a significant difference for ME/CFS

Without any prior notice to committee members or the public, the Department of Health and Human Services (HHS) announced that the charter for the Chronic Fatigue Syndrome Advisory Committee (CFSAC) was allowed to expire. In a prepared statement, the agency claimed:

"The committee and ex-officio members ably fulfilled the duties in the charter, which included informing the public and health care professionals about the illness, and insuring that input from patients and caregivers was incorporated into Departmental research now being conducted by NIH and CDC."

In other words, "Mission Accomplished. Nothing more to see here – go home."

And, in a collective voice, the ME community said "Not on our watch!"

SMCI responded immediately – mobilizing a congressional action that same week – calling on Congress to immediately "work with ME/CFS organizations, experts, and community representatives to create and pass legislation creating a new federal ME/CFS advisory committee and programs." An unprecedented 7,905 messages were sent to Congress, more than any other online action to date.

And, Congress responded!

Two informal coalitions in the House and the Senate both responded promptly to the public outcry. In the Senate, six congressional offices worked collectively to make inquiries of the HHS about the nature and cause of the committee's termination. In the House, ME/CFS champion Rep. Ana Eshoo's office became the point of contact for strategic conversations about a collective response. SMCI Director of Advocacy and Community Engagement Emily Taylor has been actively collaborating with Congressional staff and other advocacy organizations and ME advocates to ensure that people with ME/CFS are represented in their own Federal government.

SMCI's Director of Advocacy and Community Relations said,

"I believe this is an opportunity in disguise. For the past two years, we've been urging Congress to use their statutory authority to help people with ME/CFS. And, now they are finally paying attention. Because of our previous work on Capitol Hill, we have opened the door for conversations about ME legislative programs and solutions. It's up to us to capitalize on this moment and our voices matter now more than ever. I expect big things from the 116th Congress."

Formed in 2002, CFSAC was the ONLY federal entity focused entirely on ME/CFS. It included many relevant federal agencies, including NIH (National Institutes of Health), CDC (Centers for Disease Control and Prevention), the VA (Veteran's Administration) and the SSA (Social Security Administration).

If you would like to take action as part of SMCI's advocacy effort, visit our online "Advocacy Corner" at <https://solvecfs.org/advocacy/> ■

ME/CFS Federal Funding Escapes the Hatchet for Another Year

On September 28, the President signed into law a Federal Budget compromise for Fiscal Year 2019 including continued funding for the Chronic Fatigue Syndrome program at the Centers for Disease Control (CDC). This is a victory for ME/CFS advocacy.

When the Administration released its proposed budget for Fiscal Year 2019 back in February, the news was bad. Biomedical and scientific research programs were cut to the bone, key healthcare research agencies were eliminated, and the Chronic Fatigue Syndrome program at the CDC (the only direct appropriations item for ME/CFS in the federal budget) was gone entirely. The recommendation to eliminate the program came from leadership within CDC.

"These changes, if implemented, would be devastating for ME/CFS research, ME/CFS clinical care and education efforts, and biomedical research more broadly," wrote SMCI in a statement to Congressional leaders on February 15, 2018.

Throughout the year, Solve ME/CFS Initiative ensured that your voice was heard. Patients with ME/CFS and their loved ones used the SMCI Congressional Messaging tool to send over 6,000 messages to congress. SMCI facilitated over 200 meetings with members of congress calling for funding for ME/CFS.

As a result of this persistent and targeted advocacy, the initial federal budget eliminating ME/CFS was rejected. The recently passed Federal Budget compromise increases biomedical research funding and restores the Chronic Fatigue Syndrome program. Currently, the CDC Chronic Fatigue Syndrome program is working on:

- Medical Education initiatives
- Data Analysis for the Multi-Site Clinical Assessment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (MCAM)
- State tracking mechanism for ME/CFS
- Improving the identification of patients with ME/CFS

For next year's federal budget process, the Solve ME/CFS Initiative is already paving the way for requesting an increase in funding for these key programs at the CDC and additional support for a long overdue prevalence study of ME in the U.S. In order to accomplish this funding increase, our advocacy efforts will need swift and targeted action in February and March 2019. Keep an eye out for how you can make a difference in the new year. Stay connected with SMCI's advocacy at our new online "Advocacy Center" at:

<https://solvecfs.org/advocacy/> ■

FEDERAL RESEARCH BUDGET

AGENCY	FY18	PRESIDENT'S FY19 REQUEST	SMCI COALITION FY19 ASKS	FY19 HOUSE	FY19 SENATE	FY19 MINIBUS
NIH*	\$37.08 bn	\$33.89 bn	\$39.30 bn	\$38.30 bn	\$39.08 bn	\$39.08 bn
CDC*	\$8.30 bn	\$6.08 bn	\$8.45 bn	\$7.60 bn	\$7.87 bn	\$7.94 bn
FDA**	\$2.81 bn	\$3.26 bn	\$3.3 bn	\$3.11 bn	\$2.97 bn	CR
NSF*	\$7.77 bn	\$7.47 bn	\$8.45 bn	\$8.17 bn	\$8.10 bn	CR
AHRQ**	\$0.33 bn	\$0 bn	\$0.45 bn	\$0.334 bn	\$0.334 bn	\$0.338 bn

* indicates that program level is reported in this chart

** indicates that budget authority is reported in this chart

Move Over, May—April is the New 2019 Advocacy Week and DC Lobby Day

Joining side by side with the first ever National Institutes of Health (NIH) research conference for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), the 3rd Annual ME/CFS Advocacy Week and Lobby Day returns to Washington DC in April 2019.

The keystone event of ME/CFS Advocacy Week is Washington DC Lobby Day, a full-day Capitol Hill storm where hundreds of advocates meet face to face with members of congress and their staff. In 2019, that day will be Wednesday, April 3rd. ME/CFS Advocacy Week brings 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.

In 2017, the inaugural ME/CFS Advocacy Week and Lobby Day events totaled 71 congressional meetings and 1,161 online actions. In 2018, the largest ME/CFS congressional advocacy event to date brought over 100 ME/CFS advocates to Washington DC who conducted 122 congressional meetings and coincided with the introduction of an ME/CFS U.S. Senate Resolution.

"ME/CFS has been in the shadows for too long," said Senator Markey, the author of the Senate Resolution for chronic fatigue syndrome. "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."

Science and Advocacy Coincide

In 2019, the Solve ME/CFS Initiative expects the biggest turn out yet, adding leading researchers to the army of advocates storming the halls of Congress. Solve ME/CFS Initiative is linking the **3rd Annual ME/CFS Advocacy Week and Lobby Day on April 3** with the **National Institutes of Health conference "Accelerating Research on ME/CFS"** on April 4th and 5th 2019. SMCI is a partner with the NIH sponsoring this two day research conference. Researchers, clinicians, and scientists will also be key participants on Capitol Hill. You can register and get more information about ME/CFS Advocacy Week and Lobby Day at:

<https://solvecfs.org/advocacy/>

If you are interested in joining our team in Washington, DC on April 3rd, please contact: Emily Taylor, Director of Advocacy and Community Relations, at ETaylor@solvecfs.org or (704) 264-0016 x209. ■



Representing the Misrepresented: The Real Role of the Advocate

By Emily Taylor, Solve ME/CFS Initiative Director of Advocacy and Community Relations

Recently, a Netflix Docu-series called “Afflicted” misrepresented seven people with chronic illnesses and their families, including one person with ME/CFS. When a community like ours is faced with stigma and damaging storytelling, advocates play an especially important role in direct representation.

Prior to joining the Solve ME/CFS Initiative, I served as the Director of Policy and Advocacy for an award-winning autism organization. Like the ME/CFS community, the autism world struggles with misrepresentation. Often, we see children with autism portrayed as amazing savants with unusual gifts. Sometimes, a child who is severely impacted by autism will be depicted as violent and a terror to their own family. These children represent particular extremes of autism (and are often used as fundraising tools), but it’s not a fair representation of the “average” experience with autism. Highlighting the extreme experiences spreads fear and misunderstanding.

As an autism advocate, I often struggled against extreme representations and misrepresentations. Eventually, I learned one of the most important lessons of being an effective, professional advocate...

Find the right audience and get out of the way!

I relearned this lesson before I started working at SMCI, when trying to be my mother’s advocate. Like many people with ME/CFS, my mother and I traveled to doctor after doctor seeking answers. After each failed visit, I would try a different approach. I thought if I could just find the “right” way to present my mother’s symptoms, then the doctors would finally listen and we would get some answers.

I gave my mom advice to try and “look sicker.” I looked online for “fancy” sounding terminology for her symptoms to make the doctors take notice. I thought that somehow the representation of my mother’s



Stock image

VS.



Real patient

illness was the problem and if I could find the “right” way to present the problem, the doctors would take my mother’s disease seriously.

Of course, none of those efforts made a difference because my “representation” of my mother wasn’t the problem. **The problem was the misunderstanding and stigma of the medical community.** Light bulb moment! I was using the wrong tool to solve the problem.

What I needed to do was find the right doctor, make sure that doctor was willing to listen with an open mind, and then step back and let my mom describe her own needs and symptoms, in her own words.

In short, I needed to find her the right audience and get out of the way.

Now, in the wake of “Afflicted”, I am again reminded why representation matters and the critical role that advocates play.



"Afflicted" is Netflix's recent "docu-series" about chronic illness—skirting the lines between documentary and reality TV. In fact, the show is listed on Netflix in both the "Reality TV" and "Biographical Documentary" genres. (That dual-definition should really should be downright impossible, right?) The producers follow seven people, including one young man with ME/CFS, as they desperately seek answers and treatment.

Immediately following the airing of the show, the show's unpaid participants expressed their collective outrage at how their lives were depicted. They bravely shared the REAL stories of their experience on set and gave example after example of how the producers of "Afflicted" had manipulated their words, images, and stories to present a false narrative of their lives. Even as a compassionate caregiver, well versed in chronic illness and actively working as an advocate for ME/CFS, I had still been fooled by the misrepresentation of the patients in "Afflicted."

The Real Role of the Patient Advocate

Often, professional advocates are taught to "represent those who are misrepresented." But, that's not the true calling of an advocate. You can never truly become someone else's voice. While advocates can articulate hardships, identify policy solutions, or relate a community's needs, an advocate cannot truly tell someone else's story unless they have lived it.

Our job as "professional advocates" is to **make sure that the right people are listening.** We pave the

way, we get people's attention, we lead the cheers, we stand shoulder to shoulder with our community, but when it comes time to telling the story, ***we get out of the way.*** People with ME/CFS can and must represent themselves.

That's why I take such pride in Lobby Day, Humans of ME/CFS, and the SMCI congressional messaging tool—they are effective mechanisms to easily connect people with ME/CFS to the right audiences. These projects are mechanisms of unadulterated self-representation.



SMCI Director of Advocacy and Community Relations
Emily Taylor with Congressman Gus Bilirakis at ME/CFS
Lobby Day 2018

Advocates simply pave the way so people can represent themselves.

As more healthy allies join the ME/CFS cause, we must remember how important representation is and why misrepresentation is so common. We cannot allow our spokespeople, reality TV producers, or even our loved ones to steal the real stories of those with ME/CFS. Our community must be its own voice. And, it is my honor to serve as your advocate—to ensure ***your*** voice is heard. ■

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 photography of Tammi Rhoney, who uses her talents in her own backyard.



“Photography is an excellent hobby for PWMs! It’s low energy with very little prep or cleanup and I am always awed by the beauty of creation!” – Tammi Rhoney



SMCI Answers Reader Questions

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



Q: *I took your questionnaire and it is very likely that I have ME/CFS. Even before I retired from the Air Force I was experiencing the symptoms from CFS. What research have you done to help Gulf War Vets to get the VA and the DoD to recognize CFS?*

A: The Department of Veterans Affairs (VA) has been one of our biggest challenges in advocacy. Several studies have shown that Gulf War Illness (GWI) and ME/CFS are connected. Veterans with GWI have been shown to be more likely to also exhibit ME/CFS. Clinically, the two conditions are so similar they can often be interchangeable. A leading researcher, Dr. Nancy Klimas of Nova Southeastern University, has studied both diseases extensively. You might find Dr. Nancy Klimas' comments on the comparisons between ME/CFS and GWI illness during our Discovery Forum last year helpful. You can see those videos on our YouTube channel at www.YouTube.com/SolveCFS.

Currently, the VA refers to ME/CFS and a collection of other illnesses as "chronic multi-symptom illnesses" or CMIs. Also in this category are Fibromyalgia, Functional gastrointestinal disorders, and other undiagnosed illnesses.

We are currently urging congress to improve funding and response from the DoD regarding ME/CFS research. However, since the Chronic Fatigue Syndrome Advisory Committee (CFSAC) has been disbanded, our advisory work with the VA must be conducted directly with that agency which has slowed progress considerably.

Q: *As the season approaches where doctors encourage patients to get the flu shot, is there any recommendation that the organization can make as to whether to take the shot or not?*

A: The science is still divided about the effects of the flu vaccine on people with ME/CFS. And we offer a reminder that we cannot give medical advice.

There is high diversity among ME/CFS patients in how each reacts to a wide variety of medical treatments, including vaccines. You should carefully consider your personal medical history and consult with your doctor before making the decision if the flu shot is right for you. We can provide some information that may help you and your doctor decide what is right for you:

In 2002, a paper called "Influenza vaccination: is it appropriate in chronic fatigue syndrome?" was published in American Journal of Respiratory and Critical Care Medicine reported that "clinical trials in CFS have yet to find that any type of immunization has produced a deleterious effect on symptoms or functioning... influenza immunization appears to provide protective antibody levels without worsening CFS symptoms or causing excessive adverse effects."

Two additional studies in 2012 found mixed results.

"The Effects of Influenza Vaccination on Immune Function in Patients with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis" published in the *International Journal of Clinical Medicine* reported "In this pilot study immunization with influenza vaccine is accompanied by a degree of immune dysregulation in CFS/ME patients compared with controls. While vaccination may protect CFS/ME patients against influenza, it has the ability to increase cytotoxic activity and pro-inflammatory reactions post vaccination."

"Humoral and cellular immune responses after influenza vaccination in patients with chronic fatigue syndrome" published in *BMC Immunology* found "Identical antibody titers were observed in CFS patients and healthy controls. Patients and controls demonstrated similar seroprotection rates against all three virus-strains of the influenza vaccine, both pre- and post-vaccination." ■

TIME IS RUNNING OUT to Support SMCI's Work This Year

How Your Donation Can Impact the SMCI Community

\$50,000

Build the
You + M.E.
Registry

\$25,000

Fund SMCI's
Lobby Day in
Washington,
D.C.

\$10,000

Fund the
creation of
an interactive
SMCI patient
support
website

\$5,000

Support
a Ramsay
researcher
campaign to
secure NIH
funding

\$2,500

Fund a SMCI
Capitol Hill
educational
briefing

\$1,000

Send a SMCI
researcher
to a nation-
al ME/CFS
conference

\$550

Send a SMCI
advocate to
meet with
members of
Congress in
Washington,
D.C.

\$250

Add 5 patients
records to the
You + M.E.
registry

Solve ME/CFS Initiative (SMCI) is the foundational organization dedicated to making ME/CFS widely understood, diagnosable and treatable. Your support fuels everything we do, including both research and effective federal advocacy.

Here's what sets SMCI apart:

- **We believe it is fundamentally important to improve the ME/CFS research ecosystem.** We designed our Ramsay Award Program to bring new researchers into the field and to make ME/CFS more attractive for institutional level funders. We're currently supporting studies in **metabolism, neuroendocrine biology, the gut microbiome, genetics** and **immunology**.
- We are also launching **You + M.E., a Patient Registry and Biobank for ME/CFS**. This new tool will create a rich data infrastructure that can be used by all researchers to accelerate discovery.
- **We believe that this disease will be solved through collaboration.** While many research organizations have single labs, SMCI works with labs

all over the world. We are the hub that connects many labs and scientists and we serve as a conduit so researchers can collaborate and synthesize their discoveries.

- **We know the power of advocacy.** SMCI acts as a change agent by advocating for policies, funding, and action at a national level. We meet with senior government officials, medical and industry leaders, and scientific pioneers to foster a strong and multi-faceted coalition of stakeholders.
- **We recognize the value of every dollar.** Because our organization is not housed within a university, our overhead costs are significantly lower. As a result, we spend 76% of our funds on research and advocacy.

We understand our role to be savvy stewards of your dollars. None of our work would be possible without your support. During this season of giving, please give a tax-deductible contribution to SMCI before December 31. Every gift—large and small—makes a difference, and brings us closer to treatments and a cure for ME/CFS. We passionately work toward that goal EVERY day. ■

Reflections from our President Carol Head

Dear friends,

What a fall this has been, with a stunning array of developments both positive and negative, for all who suffer with ME. Certainly, there have been more positive than negative developments!

In September, the abrupt termination of the federal Chronic Fatigue Initiative Syndrome Advisory Committee (CFSAC)—the ONLY federal organization focused on ME/CFS for over a decade—was a stunning blow. But if there is a silver lining, its elimination has served to boost to SMCI's congressional advocacy work. We're now actively talking with members of Congress on legislation to create a new committee focused on ME/CFS. If passed, a congressionally-mandated committee will have more authority and power than CFSAC. That would be a substantial silver lining.

On a positive note, the federal government has formed a new panel, the NIH National Institute of Neurological Diseases and Stroke (NINDS) Council Working Group for ME/CFS Research. This is not a replacement for CFSAC, as it is housed wholly within the NIH. This new Working Group will report to NINDS Council in September 2019, a long time off from the perspective of patients. But that timeframe is relatively fast from an NIH perspective. I'm very pleased to have a seat on this NIH panel.

This new group reports to the NINDS Advisory Council on how to advance ME/CFS research. This is a very broad mandate. Our specific charge is to "...provide scientific guidance to the NINDS Council on how best to advance research on ME/CFS at the National Institutes of Health (NIH)." My reaction to this charge is summarized as, "**More dollars! Faster!**" Moving beyond that fervent sense of urgency, my role is to bring substance regarding how to do that, pulling both from SMCI's deep research knowledge and advocacy expertise in how to get things done in the federal government. It's powerful for SMCI to have an active voice in this planning work.



Carol Head, CEO and President



AND ON A DIFFERENT NOTE, PLEASE JOIN US for yet another powerful day on Capitol Hill. Wednesday, April 3, 2019 will be SMCI's 3rd annual ME Advocacy Day. As in previous years, we will train you. We will support you. We will help you find a place to stay in D.C. We will provide all advocacy materials. And if you're not an experienced advocate, we will partner you with someone who is. You will feel our love.

And in return, you'll know you've made a difference for all who suffer with this disease. And you will feel energized by the company of all of us who understand your pain and despair. Please join us! You can register here, <https://solvecfs.org/advocacy/>

We are strong. And, together, we are gaining against this disease.

Onward, with hope!

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FALL 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.



Photo by Vlad Tchompalov on Unsplash

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