



The Solve ME/CFS CHRONICLE

FALL 2017

A Significant Step Forward at the NIH: SMCI Honored to Partner on Three NIH-funded Centers

In late September, the National Institutes of Health (NIH) announced the outcome of the long-awaited ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) competitive consortium grants.

This marks an unprecedented and tangible commitment to the disease. The NIH selected four recipient teams; one Data Management Coordination Center (DMCC) and three Collaborative Research Centers (CRCs). Together, the projects will be funded at over \$7 million for fiscal year 2017, with support from multiple NIH Institutes and Centers that are part of the Trans-NIH ME/CFS Working Group. NIH's National Institute of Allergy and Infectious Diseases (NIAID) and National Institute of Neurological Disorders and Stroke (NINDS) will manage the funded centers.

What does this mean for ME/CFS research progress?

This is the first time ever that the NIH has established three five-year research centers for chronic fatigue syndrome and the first ever data coordinating center established to connect the three projects. This means that for the next five years, individual research work at prestigious universities will be done in those centers, with their activi-

>> to page 4



INSIDE

- 2 SMCI This Quarter: A Summary of Our Work
- 6 Letter from Zaher Nahle, PhD, MPA
- 8 Preview of the New SMCI National ME/CFS Patient Registry
- 10 Discovery Forum 2017: A New Era in ME/CFS Research
- 12 Building the Future of ME/CFS Research: The Ramsay Award Program
- 15 Solve ME/CFS Initiative Launches Two New Research Programs
- 16 "O Canada!" New Prevalence Data on ME/CFS
- 17 Moving Forward Together: Building ME/CFS Advocacy Partnerships
- 20 Patient Voices
- 21 SMCI Answers Reader Questions
- 22 Time to Make a Gift This Year is Running Out
- 23 Reflections from Our President Carol Head

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 your SMCI team in action and our relentless efforts to make **ME/CFS understood, diagnosable, and treatable.**

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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 announced the final stages of constructing a new state-of-the-art patient registry platform, which is a key component of the NIH supported Data Management Coordinating Center
- SMCI launched a partnership with the prestigious Memorial Sloan Kettering Cancer Center (MSKCC) in NY to investigate the biology of ME/CFS
- SMCI announced a partnership and ME/CFS Research Fund at Brigham and Women's Hospital (BWH) in Boston, MA
- Dr. Carmen Scheibenbogen, of SMCI-funded Ramsay Award project Team 4, published her work on ME/CFS in the *Journal of Translational Medicine*
- Dr. Maureen Hanson of SMCI's Research Advisory Council presented her recent work, including data derived from an SMCI funded partnership, at the Simmaron Research Institute's (SRI) Patient Day and Research Update in Incline Village, NV
- Four SMCI research partners and grant recipients presented at the Symposium on the Molecular Basis of ME/CFS at Stanford University

INFLUENCE and EDUCATION work in recent months

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

- SMCI brought awareness to the national day of recognition for Severe ME/CFS patients on August 8th with an online campaign
- SMCI joined forces with the *Time for Unrest* impact campaign, launched in September, to promote Jennifer Brea's ME/CFS documentary, *Unrest*. SMCI participated in and co-hosted five *Unrest* showings and events across the country
- SMCI facilitated a partnership with *Ms.* magazine which will feature a story on ME/CFS in its December issue, reaching hundreds of thousands of readers who are new to the disease
- SMCI President Carol Head appeared on the nationally syndicated PBS show "The White House Chronicle," and facilitated the first of two episodes dedicated exclusively to ME/CFS. With Llewellyn King, we seek to increase understanding to the disease among the general public



SMCI President Carol Head on-set for the filming of the recent nationally aired "White House Chronicle" episode on PBS, with the program's host Llewellyn King.

INFLUENCE and EDUCATION work in recent months (cont'd)

- SMCI national tour makes its first stop in Minnesota with receptions hosted by SMCI Board members Steve Curry and Sue Perpich
- SMCI President Carol Head was nominated for a WEGO Health Award as a Patient and Community Leader

ADVOCACY work in recent months

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

- Following SMCI's August action alert and advocacy from other ME/CFS organizations, the Senate Appropriations Committee recommended restoring ME/CFS funding. This restoration includes committee recommendations that were proposed by SMCI, #MEAction, and other advocates during the May ME/CFS Advocacy Week
- The National Organization for Women (N.O.W.) joins the advocacy fight for ME/CFS with a letter from president, Toni Van Pelt to NIH Director Francis Collins
- Congresswoman Zoe Lofgren led her colleagues, Representatives Anna Eshoo and Doris Matsui, in a letter encouraging restoration of ME/CFS funding in the Senate
- SMCI teamed up with Courtney and Bob Miller, Anita Patton and people with ME/CFS across Nevada to bring the first ME/CFS state delegation letter to NIH Director Francis Collins from the state of Nevada. 100% of the Nevada Congressional delegation signed the letter ■

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



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>> from page 1

A Significant Step Forward at the NIH: SMCI Honored to Partner on Three NIH-funded Centers (cont'd)

ties and discoveries **coordinated into a single repository of information.**

It also means regular coordination/collaboration meetings among the three teams and regular reporting to the public. While still funded at a very low level compared to other diseases, this represents a significant step forward. We hope that the dollars allocated to these four entities will increase each year.

“The NIH consortium grants are a much anticipated commitment of federal funds to solve this devastating disease. We hope and trust these consortia, along with the NIH intramural study, represent the dawn of a desperately needed, rapid expansion of the Federal commitment to ME/CFS.” --Carol Head, SMCI President

The Data Management Coordination Center (DMCC) will serve as the information hub to centralize, share, and standardize data from the ME/CFS Collaborative Research Centers. This will foster collaboration among the CRCs and the wider research community.

Dr. Rick Williams of **RTI International** will lead the DMCC in partnership with Dr. Peter Rowe of **Johns Hopkins School of Medicine** and Dr. Zaher Nahle, Chief Scientific Officer & VP for Research at the **Solve ME/CFS Initiative (SMCI)**. RTI International is an independent nonprofit research institute dedicated to improving the human condition and is a world leader in medical data aggregation and analytics. RTI International had no previous involvement with ME/CFS before Dr. Nahle reached out to invite them to submit for the ME/CFS grant. RTI International will provide modern analytics and data processing systems while concurrently propelling efforts to centralize and standardize the data from the CRC research teams.



Dr. Zaher Nahle and Carol Head with NIH Director Dr. Francis Collins following a meeting to urge changes and improvement in ME/CFS research funding (NYC, 2016)

Big data analysis is a key focus at SMCI and we are engaged heavily in the development of Electronic Health Record systems, which is why the Data Management Coordinating Center is an excellent fit for the Solve ME/CFS Initiative. The DMCC team (RTI, Peter Rowe, and Zaher Nahle) comprises statisticians, an epidemiologist, information technology professionals, clinicians, and scientists committed to ME/CFS.

The three research teams chosen by the NIH to lead the Collaborative Research Centers (CRCs) represent a wide range of expertise from prestigious institutions.

- **DR. IAN LIPKIN** of **Columbia University** and his team, which includes **SMCI** (Dr. Nahle), is comprised of key collaborators from academia and government agencies. This CRC will study the *molecular footprints of potential bacterial, fungal, and viral triggers of ME/CFS*. It will track these triggers along with their corresponding immune responses, including autoantibodies. The team will also investigate *metabolites and gene expression following physical activity, data mining for insights into clinical features, comorbidities, and sub-types and refined laboratory analyses to enhance care*. Scientists will also work with the ME/CFS community to develop a mobile app to track symptoms in response to stressors and interventions. The app, which will be called “my ME/CFS,” will aggregate data to yield insights into triggers that initiate or exacerbate disease, including links between infection and disease in particular subsets of patients.
- **DR. MAUREEN HANSON**—a longtime **SMCI** collaborator (also a member of the SMCI Research Advisory Council)—and her colleagues at **Cornell University** will lead the Cornell ME/CFS Collaborative Research Center. This center also features a collaboration with **SMCI** (Nahle,

previously at Cornell University) and will target three main projects:

- One project will use advanced imaging techniques to *compare markers of neuroinflammation and oxidative stress* in the brains of individuals with the ME/CFS compared to healthy controls. Particularly, they will look for markers that indicate whether neuroinflammation and oxidative stress are linked to the disease.
 - A second study will seek to uncover the possible role of *extracellular vesicles—membrane-surrounded structures that contain proteins, lipids, hormones, and RNAs—and inflammatory signaling in ME/CFS*.
 - The third project will focus on *gene regulatory changes* in the immune system through the sequencing of RNAs in individual white blood cells from ME/CFS patients and controls.
- **DR. DERYA UNUTMAZ** and his team at the **Jackson Laboratory for Genomic Medicine (JAX)** plan to develop a robust and highly detailed collection of clinical and biological ME/CFS patient data that can be analyzed using novel computational technologies—such as machine learning approaches. Dr. Unutmaz and his colleagues hope to *track down the immune, metabolic, and microbiome disruptions* that potentially lead to the disease.

We are pleased that these new NIH grants have been approved. At the same time, it is regrettable that other

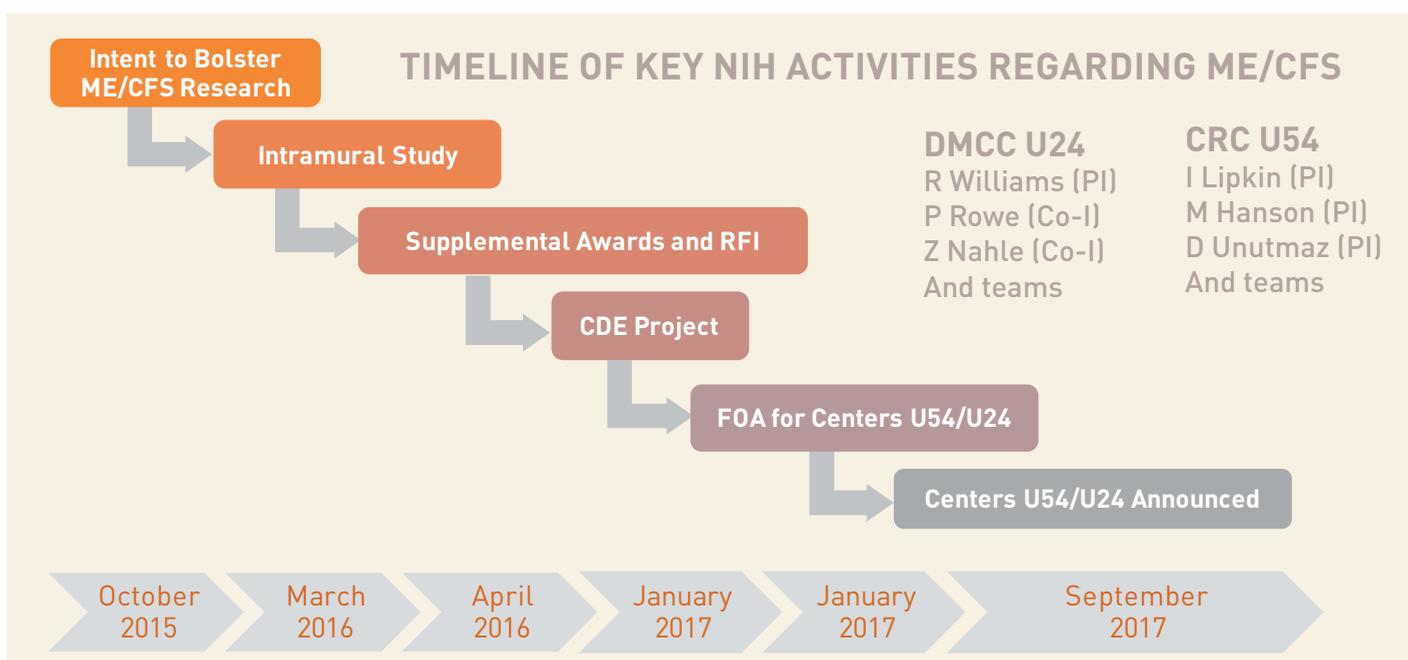
worthy grant applications were not selected. Clearly, more NIH funding is needed so that more ME/CFS applications can be funded.

How does this fit with other recent ME/CFS activities at the NIH?

After the funding announcement was released in January, the ME/CFS community waited anxiously to hear the results for this new era of ME/CFS research. The September announcement followed a progression from the NIH:

- A strong, public intent to increase support for ME/CFS by NIH Director Dr. Francis Collins in late 2015
- The launch of the NIH intramural study on ME/CFS in March 2016 (This important study is ongoing)
- The rollout of supplemental awards for existing grants (i.e. NIH-funded researchers from any field could receive funds to add ME/CFS to their ongoing studies)
- The solicitation of the Request for Information (RFI) to generate input from the scientific and patient community regarding ME/CFS in May 2016
- The Common Data Element (CDE) project, in partnership with the Centers for Disease Control and Prevention (CDC), which helps synchronize the research from many institutions and allows for much-needed collaboration and comparison among studies

>> to page 14



A Letter from Zaher Nahle, PhD, MPA

Dear Friends,

We Are Changing the Status Quo!

This is an extraordinary time in the history of ME/CFS and changes are happening on so many fronts.

AT THE NIH: Following a series of steps (highlighted in our cover story, “A Significant Step Forward at the NIH,” on page 1), the National Institutes of Health (NIH) announced the outcome of its consortium grant competition and named the awardees who will create the new ME/CFS Collaborative Research Centers (CRCs) and the Data Management and Coordinating Center (DMCC). These centers are arguably the largest commitments by the agency to invest in ME/CFS research to date.

This year, we’ve had the privilege of participating in several different applications organized by a diverse group of teams. We pride ourselves on being a trusted scientific partner, credible resource for everyone, and creating value in our ME/CFS community. Without bias or prejudice, our policy is to assist in every way we can for the cause, not for credit. We are especially thrilled to be partners on the NIH Data Management Coordinating Center (DMCC).

During this undertaking, we have worked diligently to shape up the DMCC team and attract new talent to the field of ME/CFS. It is a key milestone to become part of the federal effort to strengthen the research infrastructure for the field of ME/CFS over the next five years. Despite the limited funds allocated to this NIH consortium, it nonetheless comes with ambitious expectations and responsibilities which we take very seriously.

AT THE CDC: Updates to the myalgic encephalomyelitis chronic fatigue syndrome (ME/CFS) information page on the Centers for Disease Control and Prevention (CDC) website were made recently. The most noticeable change is the removal of the cognitive behavioral therapy (CBT) and graded exercise therapy (GET) as recommended treatments for ME/CFS. This is a key first step in improving general knowledge about ME/CFS and removing noxious and dated inaccuracies. This change is consistent with recent steps taken by government agencies regarding ME/CFS as a result of intense pressure from patients, experts, and stakeholders. This area has been a longstanding point of contention between the CDC and the patient community. There is still much work to be done to improve the CDC site, but this is a positive forward step.



Zaher Nahle, Chief Scientific Officer and Vice President for Research

AT SMCI: Many transformative events have taken place since the last issue of the *Chronicle*! This is a short breakdown of our recent progress in the fight against ME/CFS:

- We held our annual Discovery Forum in Washington DC. This annual forum, now in its second year, brings together leaders from across industry, academia, federal agencies, and biotech companies, to tackle the most pressing issues that confront ME/CFS today. (Read more in “Discovery Forum 2017: A New Era in ME/CFS Research” on page 10)
- The results of our Ramsay 2017 cycle awards in basic, clinical, translational, and epidemiology research are announced in this issue. We received exciting proposals which were submitted by talented individuals in several critical areas of investigation (Read more in “Building the Future of ME/CFS Research: The Ramsay Award Program” on page 12).
- SMCI launched two new science and discovery programs dedicated to ME/CFS at prestigious organizations: **Memorial Sloan Kettering Cancer Center (MSKCC)** in New York City and **Brigham and Women’s Hospital (BWH)** in Boston. This effort to establish meaningful and diverse ME/CFS projects at leading research centers is part of our strategic plan. (Read more in “Solve ME/CFS Initiative Launches Two New Research Programs” on page 15)
- Our modern ME/CFS patient registry is taking shape and is expected to be launched in the coming months (Read more in “Preview of the New SMCI National ME/CFS Patient Registry” on page 8)

These developments stand alongside a series of commendable activities and efforts at other ME/CFS organizations and grassroots movements. Using different instruments and tools at our disposal, we strive to fill knowledge gaps, invest in innovative ideas, partner with patients for solutions, facilitate meaningful collaborations among stakeholders, create reliable health record systems for patients, lead conferences and think tanks, advance medical education, advocate for equitable funding, and work constructively with medical agencies and government organizations towards solving ME/CFS.

Once again, this is an extraordinary time in the history of our disease. All hands on deck are needed now more than ever to change the status quo and effect real change!



Zaher Nahle, PhD, MPA
Chief Scientific Officer and Vice President for Research
Solve ME/CFS Initiative

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Preview of the New SMCI National ME/CFS Patient Registry

The Solve ME/CFS Initiative (SMCI) is in the final stages of constructing a new state-of-the-art patient registry platform.

Last year, we took the initiative to create a new and better patient registry in order to facilitate research and address a key barrier to defining the natural history of myalgic encephalomyelitis, commonly referred to as chronic fatigue syndrome (ME/CFS). SMCI will use this new technology to enhance our ability to collaborate and exchange data with various organizations and groups. The new patient registry contributes to the overarching goal of harnessing robust, patient-driven data. The development of this tool is vital to furthering the scientific understanding of ME/CFS and producing tangible benefits for the ME/CFS community. Virtually all other diseases have a centralized registry; SMCI is pleased to fill this void for ME/CFS.

This registry is also important in light of the NIH ME/CFS collaborative **Data Management Coordinating Center (DMCC)** expected to launch in early 2018. SMCI's registry will work in conjunction with the NIH **Collaborative Research Centers (CRCs)** to form a comprehensive and integrated approach to data collection, management, and its use in research.

A REGISTRY is an organized system (database) that collects and stores uniform, detailed data and information to evaluate populations defined by a specific disease, condition, or exposure. Individuals voluntarily provide information about themselves to these registries. Registries support research, including understanding the natural history of a disease.

This platform features all the benefits of modern registry design, such as a collaborative network and patient-centered functionality to give individuals the power over their own health information. The registry will enable a range of functionality for researchers and patients including:

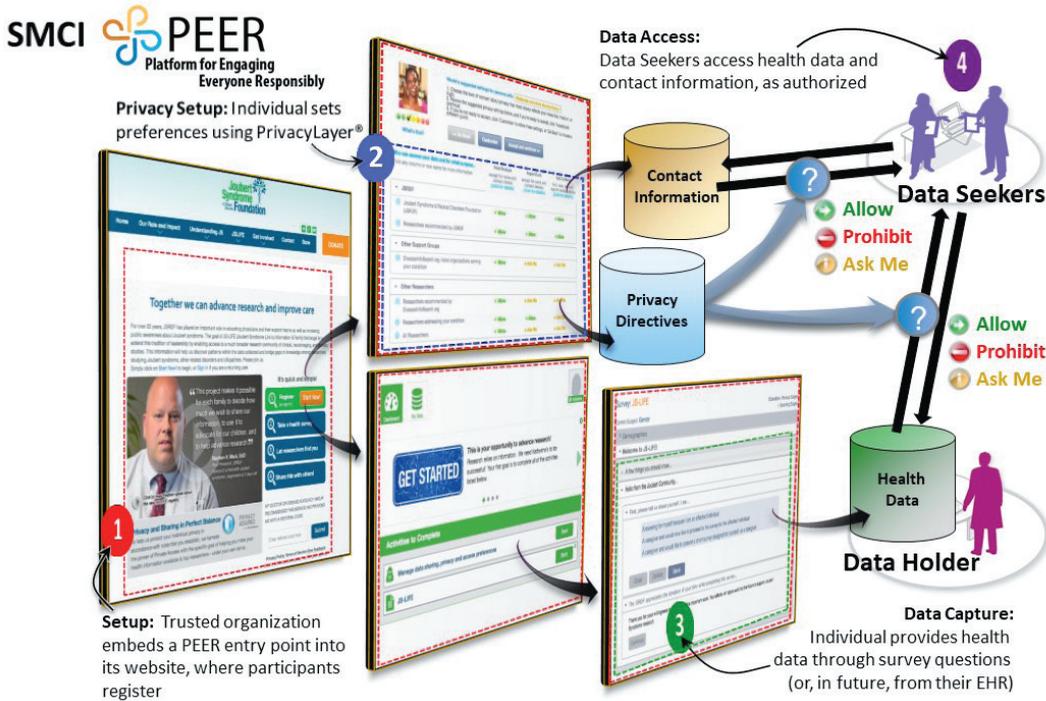
- Performing multiple types of studies and providing information to help design clinical trials
- Sharing information with organizations and researchers for educational and research purposes



Dr. Nahle unveiling plans for the ME/CFS Registry at the prestigious Precision Medicine World Conference (PMWC), Silicon Valley 2017.

- Collecting demographic, genetic, social sciences, health disparity, comorbidity and treatment outcome data
- Conducting relevant and targeted surveys
- Creating an information hub that will benefit the ME/CFS community as a whole
- An easy to follow animated and step-by-step tutorial
- Simple and short surveys that participants can complete at their own pace over the course of a year
- Individual respondents will be able to make decisions about who will have access to the information they share through easy to use privacy settings
- Active alerts will signal both researchers and patients if a person or study matches their needs in a specific clinical trial

SMCI's Platform for Engaging Everyone Responsibly (PEER) registry is equipped to incorporate **Electronic Health Records** and creates more comprehensive patient history over time. Additionally, the **Common Data Elements (CDE)** project, a joint project between the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC), will standardize and define relevant health information about ME/CFS. Using the CDE in SMCI's new registry will allow for precise and consistent patient information to be analyzed by ME/CFS experts.



Above: Allison Ramiller, SMCI's new Scientific Administrator, is assisting in the implementation of the SMCI PEER Patient Registry.

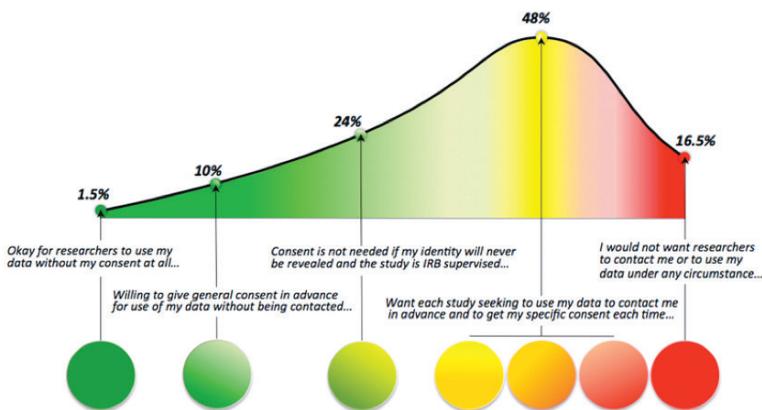
Left: A summary of the various interfaces including a map of the key registry components.

So, why is a registry so important to the progress of research?

In 2015, the Chronic Fatigue Syndrome Advisory Committee (CFSAC), which advises the federal government on ME/CFS, wrote “consistent with CFSAC’s recommendation to standardize assessment methods and measures, CFSAC recommends development and on-going use of a patient registry...in order to reduce one obstacle to ME/CFS research.” Despite this recommendation, no action has been taken by any federal agencies to initiate a ME/CFS patient registry.

Registries can exist within a research network to provide a shared infrastructure and standardized data collection. This can potentially extend intersectional benefits across disease populations based on generalizability of the data. Given the many factors of the ME/CFS illness (for example, symptom overlap, such as pain and fatigue that are evident across many diseases like diabetes and cancer) and comorbidities with other diseases (e.g. POTS, fibromyalgia), participation in a broad and collaborative research network will be invaluable.

Public Views of Privacy and Health Research



>> to page 16

SMCI’s intent is to provide high quality data to a much broader research community studying ME/CFS. Strong data collection and data sharing by the SMCI national ME/CFS PEER registry will further our understanding of ME/CFS and possibly impart benefits to other disease populations as well. Researchers may uncover patterns within the data which lead us to more efficient, accessible, and better healthcare for individuals with ME/CFS. The registry seeks to identify new subtypes of ME/CFS, develop new treatments, and provide key data to researchers.

Left: A graphic illustrating Public Views of Privacy and Health Research. This is the approach used by the SMCI PEER Registry. Courtesy of Genetic Alliance, based on data from a 2009 study commissioned by Institute of Medicine.

Discovery Forum 2017: A New Era in ME/CFS Research

On Saturday, October 14, the Solve ME/CFS Initiative (SMCI) held its annual Discovery Forum in Washington, DC, bringing together an auspicious group of research and thought leaders.

The forum was a unique opportunity to assemble ME/CFS leaders in academia, government agencies, private clinics, biotech, and research institutions. The participants tackled pressing issues in the ME/CFS field and discussed current and future research tracks and collaborations. The goal was to break new ground in ME/CFS by bringing new perspectives and partnerships together.

We are proud that, in SMCI's growing role as a research hub AND a convener of key players in the ME/CFS field, we succeeded in gathering this pre-eminent group to work together towards our common goals.

Internationally, there are efforts to improve data collection, enhance research funding and quality, and foster networks of groups engaged in both clinical and basic research. In fact, as reported in our cover story, ("A Significant Step Forward at the NIH" on page 1), there have been significant developments at the fed-

eral level in the United States. These steps include the NIH grants to fund three ME/CFS Collaborative Centers for Research and a Data Management Coordinating Center. This undertaking is occurring alongside the diligent work of dedicated ME/CFS researchers and clinicians, as well as new researchers seeking to apply their expertise to the field.

The convening participants at *Discovery Forum 2017* were an impressive representation of the dynamic changes in ME/CFS research. The forum was a powerful indicator that we are building a strong foundation for high-quality biomedical research and future clinical outcomes for those with ME/CFS.

Throughout the session, productive exchanges took place between presenters and SMCI Research Advisory Council (RAC) members, including Drs. Bateman, Silvestri, Levine, and Rowe, as well as members of the SMCI board of directors, who joined the meeting. As all SMCI board members are patients or family members of patients, their interest is intense and personal. The day was full of insights, debates, data, and plans for future research.

We look forward to reporting out details of the *Discovery Forum* in a future issue. Make sure to visit the Solve ME/CFS Initiative YouTube channel (www.youtube.com/solvecfs) to view highlights from *Discovery Forum 2017*. ■

Discovery Forum 2017 featured presentations from (in order of appearance):

- **Dr. Zaher Nahle**
SMCI Chief Scientific Officer and VP for Research
- **Carol Head**
SMCI President
- **John Nicols**
CEO Codexis and SMCI Board Chair
- **Dr. Ian Lipkin**
Columbia University
- **Dr. Vicky Whittemore**
National Institutes of Health
- **Drs. Rick Williams and Becky McNeil**
RTI International
- **Dr. Maureen Hanson**
Cornell University
- **Dr. Ralph Garippa**
Memorial Sloane Kettering Cancer Center
- **Dr. Ken Blount**
Rebiotix
- **Dr. Beth Unger**
Centers for Disease Control and Prevention
- **Dr. Dan Peterson**
Sierra Internal Medicine
- **Dr. Nancy Klimas**
Nova Southeastern University
- **Dr. Derya Unutmaz**
The Jackson Laboratory for Genomic Medicine
- **Dr. Peter Rowe**
John Hopkins Medicine
- **Dr. Lucinda Bateman**
Bateman Horne Center
- **Dr. Susan Levine**
Levine Clinic NYC
- **Dr. Charles Lapp**
Hunter-Hopkins Center

DISCOVERY FORUM 2017: A New Era in ME/CFS Research

Saturday, October 14 | Washington, DC

This annual forum, now in its second year, brings together leaders from across industry, academia, federal agencies, and biotech companies to tackle the most pressing issues confronting ME/CFS today, including basic, clinical, translational and epidemiology research; policy design;

outcome research; patient care; and electronic health record systems design. SMCI's goal in convening such an assembly is to create exemplary environments for collaborations and actionable plans towards solving this debilitating disease.

COHORT 1



Ian Lipkin, MD
John Snow Professor Epidemiology
Director, Center for Infection &
Immunity, Columbia, New York, NY



Vicky Whittemore, PhD
Program Director, National Institute
of Neurological Disorders and Stroke,
NIH, Bethesda, MD



Rick Williams, PhD
Principal Investigator for Medical
& Public Health Research, RTI
International, Durham, NC



Becky McNeil, PhD
Research Statistician, RTI
International, Durham, NC

COHORT 2

Zaher Nahle, PhD, MPA
Chief Scientific Officer and Vice President
for Research, Solve ME/CFS Initiative, Los
Angeles, CA

Maureen Hanson, PhD
Founder & Director, Center for Enervating
Neuroimmune Disease, Cornell University,
SMCI RAC Member, Ithaca, NY

Ralph Garippa, PhD
Director, RNAi and Gene Editing Core
Facility, Memorial Sloan Kettering Cancer
Center, New York, NY

Ken Blount, PhD
Head of External Research,
Rebiotix, New York, NY



COHORT 3

Nancy Klimas, MD
Director, Institute for Neuro Immune
Medicine, Nova Southeastern
University, Fort Lauderdale, FL



Dan Peterson, MD
President, Sierra Internal Medicine,
Incline Village, NV



Elizabeth Unger, MD, PhD
Chief, Chronic Viral Disease Branch,
CDC, Atlanta, GA



Derya Unutmaz, MD
Professor, The Jackson Laboratory for
Genomic Medicine, Farmington, CT

COHORT 4

Peter Rowe, MD
Director, Children's Center Chronic
Fatigue Clinic, Johns Hopkins
SMCI RAC Member, Baltimore, MD

Lucinda Bateman, MD
Founder & Chief Medical Officer,
Bateman Horne Center, SMCI RAC
Member (Ad hoc), Salt Lake City, UT

Susan Levine, MD
Founder, Medical Office of
Susan M. Levine, SMCI RAC Member,
New York, NY

Charles Lapp, MD
Founder, Hunter-Hopkins Center,
Charlotte, NC



Building the Future of ME/CFS Research: The Ramsay Award Program

The Ramsay Award grant program, now in its second year, has developed into a robust component of the Solve ME/CFS Initiative's strategic approach to research. The program funds methodical scientific inquiry from committed researchers, addressing crucial gaps in the understanding of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). The Ramsay program, named for pioneering advocate Dr. A. Melvin Ramsay, is a competitive, open process for scientists and researchers at any career stage interested in studying ME/CFS. Each grant application undergoes a rigorous peer review process in two independent stages:

PHASE ONE matches each applicant with a reviewer counterpart from the applicant pool with specialized expertise on the proposed research (i.e., each applicant reviewed a grant from the pool).

PHASE TWO consists of external reviews with individuals knowledgeable regarding the specific research area, usually from our Research Advisory Council; some reviewers were assigned two applications.

The reviewers evaluate the proposals based on their potential significance for the ME/CFS field, caliber of the investigative team, level of innovation, and feasibility of the study aims and methods.

The Ramsay Award Program Has Three Objectives:

INVEST in original ideas that could clarify the onset, progression, root causes, and natural history of ME/CFS.

CREATE permissive environments to attract, support, and retain talent in the ME/CFS community and help awardees generate relevant data to compete for long-term federal funding.

FACILITATE collaboration among dedicated researchers through the sharing of resources, access to additional programming and SMCI's network.

Update on Ramsay Award Cycle 2016

The inaugural set of Ramsay awardees were announced in 2016 and began working on their research projects in early 2017. The five Ramsay 2016 research teams are currently conducting research in a variety of promising tracks, including:

- Neuroinflammation (inflammation of brain tissue)
- Bioenergetics, or the study of energy transformations in cells
- Alterations in mitochondrial energy production and impacts on the immune system
- Natural killer (NK) cells, which launch attacks against infections, and immune dysfunction
- Genetic and cellular traits that underlie autoimmunity
- An infection-induced mechanism for development of ME/CFS

Mid-stream updates from the primary investigators for these projects demonstrate the value of the Ramsay grant seed funding for the ME/CFS research landscape.



Announcement of New Ramsay 2017 Awardees

We are thrilled to support the work of these talented scientists from around the world through the 2017 Ramsay Award Program. Five teams have been selected to begin work in 2018. All five teams are committed to ME/CFS research through the exploration of diverse promising areas, including:

- the link between infection and cellular metabolism
- changes in DNA structure and immune dysfunction
- composition of the gut microbiome
- altered metabolism in immunity cells
- the interplay of the microbiome and immune system

With this second group of Ramsay Awardees, SMCI is now supporting 10 projects in 7 countries, in addition to SMCI's own research projects.

While we were disappointed that our limited funds were unable to support additional Ramsay applicants, we congratulate all our 2017 Ramsay Award program awardees! ■

Meet the 2017 Ramsay Award Research Teams



Team 1: SWEDEN

Biomarkers for Initiation (Infection) and Metabolic Derangement in ME/CFS

Jonas Blomberg, Jonas Berquist
Uppsala University Hospital
 Carl Gerhard Gottfries
Gottfries Clinic AB



Team 2: US & SPAIN

Effect of ME/CFS on epigenetic regulation in specific immune cell types

Lubov Nathanson, Vladimir Beljanski,
 Malavv Suchin Trivedi
Nova Southeastern University
 Elisa Oltra
Universidad Catolica de Valencia



Team 3: UNITED KINGDOM

Investigating alterations in the intestinal virome in CFS/ME

Fiona Newberry, Simon Carding
Qudram Institute Bioscience
 Tom Wileman
University of East Anglia



Team 4: GERMANY

Immunometabolism of T cells and monocytes in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Carmen Scheibenbogen,
 Franziska Sotzny
Charité Universitätsmedizin Berlin



Team 5: ISRAEL

Deciphering antibody reactivities against autoantigens and the microbiome in ME/CFS

Eran Segal
Weizmann Institute of Science

>> from page 5

A Significant Step Forward at the NIH: SMCI Honored to Partner on Three NIH-funded Centers (cont'd)

SMCI has actively contributed to these efforts by using pointed conversations with NIH officials, taskforces, and direct participation in grant proposals.

The response to the January NIH grant solicitations was strong and attracted high caliber applicants. Ten proposals were submitted spanning expertise in immunity, inflammation, neuroendocrine biology, bioenergetics, epidemiology, biostatistics, clinical care, and clinical management—some of whom were applying their talent for the first time in the ME/CFS field.

SMCI was honored participate in seven of the ten proposals. We work to serve as a credible scientific partner and a trusted resource for **everyone** who is creating value in our disease space. We seek to remain the trusted neutral in our work. SMCI will also continue to maintain

and pursue collaborations with the groups whose proposals were not funded.

“We are thrilled to be part of that effort in what is a landmark turning point development for our disease,” said Dr. Nahle, Chief Scientific officer and VP for Research, the creator of these strategic partnerships.

As partners of the Data Management Coordinating Center, SMCI is committed to advancing the field through big data analysis and electronic health record systems. For the past nine months, we have been preparing the **new national SMCI ME/CFS patient registry**, which is crucial to understanding this disease. (See “Preview of the New National ME/CFS Patient Registry” on page 8). This is a key part of SMCI’s contribution to the DMCC effort and gives the project a significant head start. ■

RECENT CDC EFFORTS ON ME/CFS

It is important to note, in addition to these changes lead by the NIH, updates to the ME/CFS information page on the Centers for Disease Control and Prevention (CDC) website were also made recently. This welcome development was key first step forward in refining the narrative about ME/CFS and purging the disease space from dated inaccuracies—including cognitive behavioral therapy (CBT) and graded exercise therapy (GET).



Dr. Nahle reviewing recommended changes to the CDC website during a meeting with Dr. Elizabeth Unger and team at the CDC (Atlanta, 2016)

Promoting the use of CBT and GET has been a longstanding point of contention between the CDC and the patient community. The CDC website change is in line with recent steps taken by government agencies regarding ME/CFS. This is the result of intense pressure from patients, stakeholders, and SMCI. We are proud to have worked diligently with others to affect these changes through continuous advocacy and engagement with federal officials. Our work is far from over, but this is an important step forward.

Solve ME/CFS Initiative Launches Two New Research Programs

Solve ME/CFS Initiative's comprehensive science and research strategy spans every phase of the discovery process. Our goal is to advance innovative research and identify the underlying causes of ME/CFS, develop safe and effective treatments, and find a cure. To that end, we are pleased to share two new research partnerships which launched this quarter.

Dr. David Systrom and Exercise Testing at Brigham and Women's Hospital

SMCI and our partners are initiating a new ME/CFS Research Fund at **Brigham and Women's Hospital (BWH)** in Boston, MA. The establishment of this fund supports the continuation of Dr. David Systrom's ME/CFS research.

Dr. Systrom is a pulmonologist, with a state-of-the-art clinical cardiopulmonary lab (specializing in the function of the heart and lungs). Doctors treating patients with ME/CFS sought out Dr. Systrom for invasive cardiopulmonary exercise tests (iC-PET's) which highlight biological functions in people with exercise intolerance. His work has resulted in one of those most extensive databases of biological functions during exercise in ME/CFS.

SMCI is working with Dr. Systrom to create a program using iCPET to sample and measure blood from multiple parts of the body at varying points of exercise. *This research and data will hopefully uncover the molecular basis of exercise intolerance in people with ME/CFS for the first time.*

This program is made possible with a generous donation from a visionary person with ME/CFS, who wishes to remain anonymous, through our recently established 'patient-scientist' program. The 'patient-scientist program' is designed to facilitate patient participation in research through partnerships between patients, SMCI, and selected medical programs.

When completed, this work will further our understanding of **the autonomic, peripheral neuropathy, and cardiovascular** features of ME/CFS. In other words, this research focuses on the involuntary nervous system, nerve pain in the hands and feet, and the heart and blood vessels.

SMCI and Dr. Systrom are committed to reporting on progress of this project to the community as new data becomes available.



Dr. Ralph Garippa Drug Screening, Genetics, and Treatment Targets at Memorial Sloan Kettering Cancer Center

SMCI launched a new partnership with the prestigious **Memorial Sloan Kettering Cancer Center (MSKCC)** in New York City. The collaboration between the MSKCC scientist team and SMCI will investigate the biology of ME/CFS with Dr. Ralph Garippa, an expert in drug screening analysis and target validation. Dr. Garippa is the Director of the Gene Editing & Screening (GES) Core Facility at the Sloan Kettering Institute (SKI) and the MSKCC.



The work at MSKCC will focus on improvements to patient care, broadly involving **drug screening** and **functional genomics** (gene and protein function). *These studies will use ME/CFS patient samples to examine potential treatment targets, possibly uncover biomarkers, and generate information about the molecular basis of ME/CFS.* Using ME/CFS immune cells specifically, we hope this work will identify targets for future myalgic encephalomyelitis/chronic fatigue syndrome treatments. Our objective is also to isolate, evaluate, and validate potential biomarkers for ME/CFS using large-scale genetic screening and big data. ■

“O, Canada!” New Prevalence Data on ME/CFS: How many people have ME/CFS?

IN MARCH 2017, STATISTICS CANADA released results from the 2016 Canadian Community Health Survey (CCHS). The CCHS relies on a large sample size of Canadian respondents and collects information on various markers of health and health care utilization, increasing the power of its design to provide reliable estimates every two years.

Statistics Canada included a data instrument on “chronic fatigue syndrome,” (also known as myalgic encephalomyelitis or ME/CFS), in the surveys from 2014 and 2016. The survey contained a stipulation that an individual should mark “yes” if they have experienced symptoms for six months or more **and** received a diagnosis from a health professional. The 2016 data found that 560,000 Canadians (1.6% of the Canadian population) indicated they have ME/CFS, a roughly 37% increase over the number that confirmed an ME/CFS diagnosis in 2014.

If that same 1.6% were applied to the US population, it would mean that close to 5.2 million Americans have the disease. This is a drastic increase from the current estimate of between 836,000 to 2.5 million people published in a 2015 Institute of Medicine report. However, it is difficult to extrapolate the proportion of Canadian sufferers reflected in the CCHS to the American population due to the lack of uniform diagnostic criteria for ME/CFS and differences in healthcare access between the two countries. Although we can’t derive a definitive prevalence of ME/CFS in the US from the Canadian results, this discrepancy further validates the need for both a clear definition of the disease and a new US study to determine how many Americans have ME/CFS. ■



>> from page 9

Preview of the New SMCI National ME/CFS Patient Registry (cont'd)

“We believe that the research network will allow us reciprocal benefit with participating research groups and position SMCI as a key source of information to other disease organizations, government agencies, and the public,” said **Dr. Zaher Nahle, Chief Scientific Officer and Vice President for Research.** **“Creating a modern platform with collaborative features supported by an initial award from the Robert Wood Johnson Foundation is a key development that will assist patients, researchers, organizations, and policy makers.”**

This project was made possible by a grant from the Robert Wood Johnson Foundation White Label PEER project, an innovative, patient-centered research network. This competitive grant program is managed by Genetic Alliance, a leading advocacy organization committed to transforming health through genetics, promoting novel partnerships, and improving access to information to enable translational research. We are grateful for all of this support as it further establishes our commitment to connecting patients with researchers and expediting the discovery process for ME/CFS. ■

Moving Forward Together: Building ME/CFS Advocacy Partnerships

Early in August, the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies approved a preliminary budget proposal which once again eliminated funding for ME/CFS for Fiscal Year 2018.

Like last year, the community immediately mobilized. Solve ME/CFS Initiative (SMCI) led an online action alert calling on individuals to contact their member of congress to restore the lost funding in the Senate version of the budget.

Using the SMCI technology, **over 2,100 messages** from people with ME/CFS and their loved ones were sent to Congress. The fight for funding resulted in exciting new allies including the National Organization for Women (N.O.W.). With a combined effort from SMCI, N.O.W., ME/CFS clinical care specialists, Congresswomen Zoe Lofgren, Ana Eshoo, and Doris Matsui, and hundreds of individuals across the country, **the funding for ME/CFS was restored** in the Senate version of the federal budget. At the time this article was written, the congressional budget reconciliation process was underway and looking favorable to *again* safeguard \$5.4 million for ME/CFS in the Fiscal year 2018 budget. Though, our best information from friends on the hill indicates we will see a continuing resolution budget at Fiscal Year 2016 funding levels including a continued \$5.4 million for the chronic fatigue syndrome program.

Just one day later, the entire state of Nevada became the first state ever to unify its congressional delegation for ME/CFS. 100% of Nevada’s senators and representatives sent a letter to Dr. Francis Collins, Director of the National Institutes of Health (NIH), urging him to “strengthen and accelerate” NIH’s work on ME/CFS.

The letter was led by Representative Mark Amodei from Reno. We are so pleased to have teamed up with Courtney and Bob Miller, Anita Patton, Annette Whittemore, and people with ME/CFS across Nevada to successfully launch the very first ME/CFS delegation letter in the state. Thank you to the many residents of Nevada who took action to make this possible.

Additionally, SMCI has facilitated an understanding with the widely-circulated women’s magazine *Ms.* and the renowned author Julie Rehmeyer. The collaboration will result in a feature story on ME/CFS (previously known as chronic fatigue syndrome) in the December issue of *Ms.* magazine which is circulated to over one hundred thousand print and online subscribers.

We hope to have many more collaborators and partners join our cause as we continue to build a broad coalition of support for ME/CFS.

>> to page 18



Longtime ME/CFS Advocate Courtney Miller and SMCI Director of Advocacy and Public Relations Emily Taylor hold a copy of the Nevada delegation letter to Director Collins.

Moving Forward Together: Building ME/CFS Advocacy Partnerships (cont'd)

Going National: SMCI featured on “The White House Chronicle”

A nationally televised program on ME/CFS aired on the show “The White House Chronicle,” with host Llewellyn King. The first of two half-hour programs featuring the work of the Solve ME/CFS Initiative includes heartrending interviews with the Camenzind family, whose son Tom is severely ill with ME/CFS, and powerful comments from SMCI President Carol Head.

The second episode was filmed at the National Institutes of Health (NIH) Bethesda campus to tackle the science and research future of ME/CFS. This feature included Dr. Walter Koroshetz, Director of the National Institute of Neurological Diseases and Stroke and chair of the Trans-NIH ME/CFS Working Group. Our own Chief Scientific Officer and Vice President for Research, Dr. Zaher Nahle, spent an hour with Dr. Koroshetz delving into the ME/CFS research field. This episode explored the current scientific understanding of ME/CFS, what research is currently underway, and what the scientific field can expect in the future.

Both programs are available for free online on Solve ME/CFS Initiative’s YouTube channel: SOLVECFS (www.youtube.com/solvecfs). Or check your local listings for air times of the “White House Chronicle” on PBS. You can also catch the program on Sirius XM’s POTUS channel.



Dr. Zaher Nahle, Chief Scientific Officer and Vice President for Research of SMCI interviews alongside Dr. Walter Koroshetz, Director of the National Institutes of Neurological Diseases and Stroke, for the second “White House Chronicle” feature on ME/CFS.

Activism vs Advocacy

Activism and advocacy are two sides of the same coin, working together to facilitate political and social change. Advocates are often activists, and vice versa, but advocacy and activism serve very different functions in accomplishing a common goal. SMCI often describes our strategic advocacy efforts, but does that make us activists?

Activism is action-oriented and values based. Activists take concentrated steps (like taking to the streets) to cause change. Activists are perceived as working outside of the system with guerrilla theatre, grassroots organizing, and direct action. Activists focus on a particular situation and fight to bring that issue to light and create change.

Advocacy is people-oriented and evidence based. Advocates act on behalf of others and represent their interests. Advocates provide guidance and advice, often operating within the system (holding a seat at the table) with decision makers. They serve to represent the interests,

concerns, and needs of a group of people. Advocates focus on the larger picture or systemic structure and their goal is long-term, sustainable improvements on behalf of the group they represent.

In the fight to solve ME/CFS, we need both activists and advocates. SMCI’s work with the federal government is entirely in the advocacy and advisory realm, while our organization simultaneously supports activism within the ME/CFS community. Yet, Solve ME/CFS Initiative is ultimately a **DISEASE** organization representing the interests and needs of people with ME/CFS and the researchers who work for them.

What makes SMCI’s actions unique is that we span the entirety of the policy spectrum on behalf of those with ME/CFS including organizing, advocacy, activism, and advising. Additionally, we focus beyond just the federal government, and bring our commitment to serve those with ME/CFS into **research, science, and policy** as well. ■



PATIENT VOICES

In this recurring section of *The Solve ME/CFS Chronicle*, SMCI features the creativity and talent of the ME/CFS community. In every issue you can find the art, writing, or other creations of ME/CFS patients here.

At age thirty, Jasmine Farrow felt lost. She had always gravitated towards the creative arts, but as life moved on, she no longer had any creative outlet.

Then, at thirty-two, she was struck down by ME/CFS.

Jasmine slept around 18 hours a day, most of the time in a kind of hypnagogic state where she would experience visual and auditory hallucinations. She suffered extreme sensitivity to light and had to stay shrouded by darkness. She was isolated. Even experts couldn't fully grasp how ME/CFS was affecting her.

As she lay in darkness, she imagined being outside. She visualized the North Norfolk landscape in the United Kingdom she loved as a child.

After two years, Jasmine finally regained enough strength to sit up in bed. Later, she had the strength to begin painting.

She found, through her illness, what had been missing. She found her creativity.

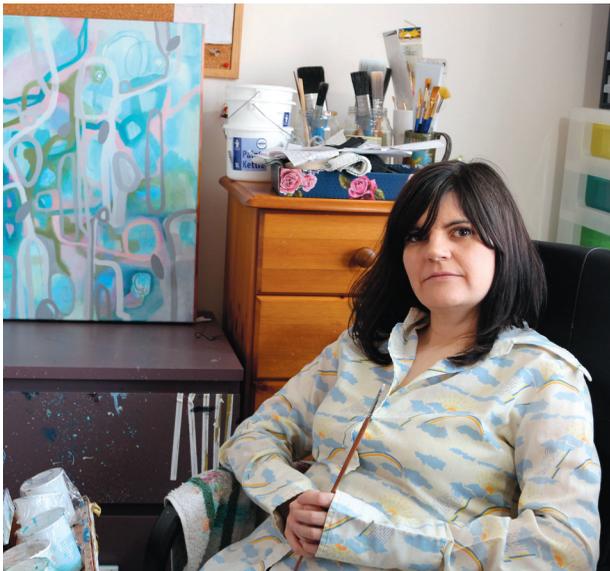
Now, at thirty-seven, Jasmine sometimes feels well enough to paint. She uses her work to express herself without the need to find words. Her brush strokes articulate her experience with ME/CFS, her abstract hallucinations, and the



memories that kept her going as she lay in darkness for days. She can even find the strength to get outside on her electric scooter to the nature she dreamed about for so long.

To see more of Jasmine's work, visit: www.jasminefarrowart.com. ■

To submit an item to Patient Voices, please email Emily Taylor at ETaylor@SolveCFS.org.



SMCI Answers Reader Questions

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

Q: While many people with myalgic encephalomyelitis (pwME) live with family, some do not have family and some would prefer to live alone due to noise issues or even family issues. The Disability Integration Act (DIA) will help make it possible for pwME and all with disabilities to have meaningful choices in living arrangements. Will you support the DIA?

A: The Solve ME/CFS Initiative is already a supporter of the Disability Integration Act (DIA) and has been a supporter since 2016. We are committed and heartily support this legislation together with over 600 other organizations (though, we are the only ME/CFS or chronic fatigue syndrome organization in the coalition). We analyzed the legislation closely and support it for three key reasons:

1. The DIA creates new federal definitions of “disability” for certain programs which are MUCH more favorable to people with ME/CFS.
2. The DIA ensures that public entities and insurance providers that provide long-term services cannot discriminate against people based on disability or illness when providing home or community-based services and support.
3. Public entities and insurance providers MUST inform their consumers of their right to receive services and support in their home or community over an institutional placement. The DIA is good policy and we are proud to support it.



Q: I have had ME/CFS for over 30 years and been treated but without success. I am a member of the BioBank and would like to know how to become part of the new Registry.

A: We will be launching our new SMCI National ME/CFS Patient Registry in early 2018. If you are already in our SMCI Biobank, we will reach out to you directly to confirm your interest and provide updated information on how to transfer to the new Registry. For now, sit tight and you will hear from us. There will be a short “gap period” of transition as we move from the old system to the new system where we will be unable to accommodate new participants. When the new system is online, you’ll be the first to know. We are so grateful that you have offered up your experience for our biobank and upcoming registry. It is an incredibly meaningful way to bring benefit to the entire ME/CFS community. ■

Sneak Peek: New Look of the Solve ME/CFS Initiative



Solve ME/CFS Initiative

Leading the Fight
to cure ME/CFS

TO REFLECT THE NEW ERA of science and discovery, Solve ME/CFS Initiative is updating our icon to reflect our patient centered scientific and research focused programming. The new icon represents uplifting people with ME/CFS through science and discovery with our community at the center of our work. We’ve also implemented a new tagline “Leading the Fight to Cure ME/CFS.” But, our name and our mission—making ME/CFS understood, diagnosable, treatable—is unchanged. ■



Time to Make a Gift this Year is Running Out

ME/CFS is an urgent health crisis. Very little is known about this debilitating disease that affects up to 2.5 million Americans and 20 million people worldwide. There are no FDA-approved drugs or treatments. There is no cure. And the federal government only spends roughly \$5 per ME/CFS patient on research.

Solve ME/CFS Initiative GIVING GUIDE

Gift ideas to support our research and advocacy

\$50

Sponsor a congressional information kit

enables creation, printing, and distribution of one information packet

\$1,220

Enable advocacy travel to Washington, DC

sends one SMCI representative to advocate to Congress and other key federal agencies

\$100

Support webinar hosting

underwrites one quarter of the cost to host an SMCI webinar featuring ME/CFS thought leaders

\$3,500

Sponsor one meetME scientific travel grant

encourages participation of underrepresented groups in ME-related scientific meetings and helps to expand our research community

\$275

Enroll a patient in the biobank

supports the work of qualified researchers with biological samples

\$10,000

Fund phase I of an SMCI-directed research project

covers preliminary funding for original work studying relevant, current, and urgent ME/CFS topics

\$550

Add ten patient records to our new patient registry

creates a natural history of ME/CFS, an important precursor to biomarker studies that lead to credible diagnosis

\$35,000

Fund full SMCI-directed research project

sponsors a "proof of concept" pilot study necessary to precede large-scale studies

DONATE TODAY

Make your donation in one of three easy ways:

- 1 Go to SolveCFS.org/DONATE/
- 2 Mail your gift using the enclosed envelope to
Solve ME/CFS Initiative
5455 Wilshire Blvd., Suite 1903
Los Angeles, CA 90036
- 3 Call us at (704) 364-0016, ext. 201

"We need more doctors. We need more research. Too many of us are sick, dying, and merely existing. We need to find a cure or at the least a way to manage this disease. I am 43 years old. I should be enjoying my life. Instead I am imprisoned in a body that continually betrays me, doctors who don't understand this condition, little options for treatment and a life wasted..." —Kristina

"I started showing symptoms of ME/CFS around age 5 and I have never experienced a normal life. I struggled to finish high-school. Now, my symptoms are so severe I cannot complete college classes on-line." —Kelly

SOLVE ME/CFS INITIATIVE (SMCI) IS THE LEADING DISEASE ORGANIZATION DEDICATED EXCLUSIVELY TO DEFEATING ME/CFS. We are committed to making ME/CFS understood, diagnosable, and treatable. We work tirelessly to accelerate the discovery of safe and effective treatments, strive for an aggressive expansion of funding for research that will lead to a cure, and seek to engage the entire ME/CFS community. 2017 has been a pivotal year for SMCI:

- We have significantly expanded our comprehensive Science and Discovery work.
- We are building the first state-of-the-art ME/CFS patient registry.
- We have convened the top minds in clinical care, research and federal agencies to collaborate on key issues related to ME/CFS.
- And, we have advocated for an aggressive expansion of federal funding for ME/CFS research.

None of our work would be possible without your support. During this season of giving, please consider a tax-deductible gift to SMCI **BEFORE DECEMBER 31ST**. Even the smallest gift is meaningful, as it brings us closer to making ME/CFS **understood, diagnosable, and treatable.** ■

Reflections from our President Carol Head



Carol Head, CEO and President

Dear friends,

If you've read through this issue, I hope it's clear that the Solve ME/CFS Initiative is becoming the leading ME/CFS organization taking a comprehensive approach to solving this disease. We are moving forward on so many fronts.

Our work now includes:

- convening a prestigious group of ME/CFS researchers and clinicians at Discovery Forum 2017,
- funding 10 rigorous research studies in diverse areas of human biology,
- driving the movement to get more support from the federal government—including Congress, the NIH, and the CDC—and,
- building the long-needed ME/CFS patient registry for all ME/CFS research.

The fact that our organization was included on three of the four NIH grants (as described in our cover story "A Significant Step Forward at the NIH"), including the creation of the Data Management Coordinating Center, **substantiates SMCI's central role** in driving progress with this awful disease across all fronts.

As always, I am so grateful to hear from many patients and family members who express their gratitude for SMCI's rigorous work to fight for people with ME/CFS. And my answer is always:

Thank you.

We are honored to work on your behalf. You keep us going.

The truth is that to continue and increase our work, we must have the budget to support it. Please understand that when I ask you for financial support, I am asking because we cannot sustain our work without the generous support from people with ME/CFS and their families.

SMCI strives to do what other mainstream disease organizations do, but with a budget that is literally one percent of theirs. It is deeply gratifying to be included in the recent three NIH grants, but SMCI receives only a sliver of the dollars from those grants. Therefore, we need ongoing financial commitment from our generous community to bring those grants to fruition.

If you believe in SMCI's work, I ask for your support. By giving generously, you join hundreds of other patients and their loved ones who believe in SMCI's commitment, professionalism, and passion.

We truly cannot do it without you.

With sincere thanks and gratitude – and with hope as cures and treatments come closer into view.

Onward!

Carol Head
President and CEO
Solve ME/CFS Initiative

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SolveCFS.org/archive

Humans of ME/CFS:
HOMECFS.SolveCFS.org

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FALL 2017

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.**

IN THIS ISSUE

- A Significant Step Forward at the NIH: SMCI Honored to Partner on Three NIH-funded Centers
- Discovery Forum 2017: A New Era in ME/CFS Research
- A Preview of the New SMCI National ME/CFS Patient Registry
- Announcing the Ramsay Award Program 2017: Five more research programs funded by SMCI
- Activism vs Advocacy? What we do and why we do it.
- Meet Jasmine Farrow and her experience with ME/CFS using art
- SMCI launches two new research programs with prestigious partners