



# Solve ME/CFS Initiative

Leveraging patient-centered research to cure ME/CFS

The SolveCFS Chronicle

Spring 2016

## Solve ME/CFS Initiative Launches New In-House Research Program

### Bioenergetics Study Will Serve as Cornerstone

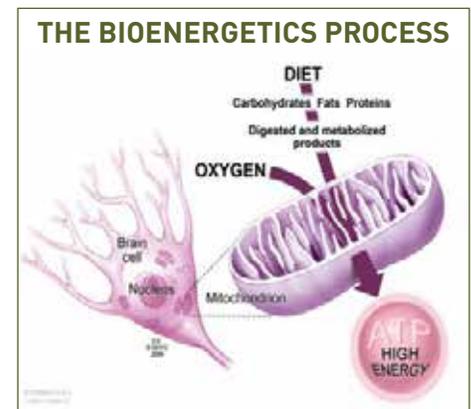
The Solve ME/CFS Initiative is launching its first in-house research program, the cornerstone of which will be our new Bioenergetics Research Study. The new in-house research effort will be in addition to the support we have given to researchers outside our organization for many years. SMCI also is expanding our support of external investigators, as detailed in the new research grants award program story on Page 7.

Bioenergetics is the field of science that describes the underlying biochemical activities of energy production needed for all cognitive and physiological activities. And as it is widely recognized that unexplained energy depletion is the signal characteristic of ME/CFS, our new study focuses directly on that attribute.

Many complex and interconnected regulatory systems at the cellular level—but also across the whole organism—are known to modulate the bioenergetics process. And it is the proper functioning of these components as a synergistic, working unit that ensures a healthy capacity across our organs and tissues, including

muscle and the brain. This is also what enables us to perform essential and nonessential functions, either voluntary ones like writing or dancing, or involuntary ones, such as maintaining our heart rate or dilation of our pupils.

As such, the integrity of the bioenergetics process is indispensable to the functioning of virtually all of our systems, from immune health to normal cardiovascular function. ME/CFS may well be a metabolic disease of dysfunctional bioenergetics, given that it is a systemic disease of physiological and biochemical abnormalities. These abnormalities are manifested by physical and mental fatigue, dysautonomia, visual disturbance, gastric dysmotility,



abdominal pain, muscle wasting, peripheral neuropathy, tachycardia, dizziness, seasickness, nausea, severe headaches along with clinical manifestations, such as post-exertional malaise (PEM) and orthostatic intolerance (OI).

The complexity of the bioenergetics machinery is underscored by the fact that different tissues and organs have demonstrably different bioenergetics demands and, therefore, there is no one-size-fits-all application when studying or examining this complex process. Skeletal, muscle and fat cells, in

*Continued on Page 8*

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# A Letter from President Carol Head

As we enjoy this refreshing spring weather, I think of so many in our ME/CFS community who cannot leave their beds or homes to feel the soft, warm breezes on their skin and the sun on their faces. Like so many caregivers and advocates, once we are deeply attuned to the life-diminishing effects of ME/CFS, life's simple pleasures take on a duality...we are so delighted to enjoy them and yet highly conscious of those who cannot.

So, I am especially pleased by the work of our small but mighty team here at the Solve ME/CFS Initiative. You will read more about our work in this issue of the *Chronicle*. Here are the highlights...

First, we have greatly expanded the focus of our research program, which for many years has supported outside researchers through our SolveCFS BioBank™ and the granting of research awards to highly qualified ME/CFS investigators. But the most significant structural change to our research program is that we are now conducting our own research via our new Targeted Research Initiatives and our new Bioenergetics Research Study—a comprehensive, multiyear, multimillion dollar study to dig deep into this specific area of dysfunction in ME/CFS.

Secondly, we are doubling down on our advocacy work and are now actively collaborating with others in this area, where there is simply so much work to be done with the NIH, CDC and Congress.

And I want to make a personal comment on advocacy, as I am the lead face for advocacy at our organization. One of my deeply held personal values is that ALL people must be treated respectfully. And in my experience, I have found that respectful, highly knowledgeable, forceful advocacy language that expresses the desperate needs of our community is the most effective.

**But please do not mistake my professional, respectful demeanor for anything less than a cover for my righteous indignation and outrage at the inhumanity of our community's treatment.**

The plight of ME/CFS patients is dire. The dearth of federal funding, and therefore of research, is egregious. This is a MORAL issue. The fire in my belly translates to passionate, respectful words. But that fire is burning.

Onward!




Carol Head  
President

# NIH Provides Details on New Intramural Study

The National Institutes of Health announcement that it would conduct an intramural study on its campus in Bethesda, Md., has been welcome news for many reasons:

- It marks the first serious attempt on the part of the NIH to take proactive steps and invest in a research study with full responsibility for its design and outcomes.
- It indicates that the pressure from the community—including our own organization—is able to effect change, even incrementally, at government agencies. The Institute of Medicine report, as well as the Pathways to Prevention Workshop report, both contributed to influencing attitudes at the NIH.
- It ushers additional studies through expansions of the current one or independent new programs, pointing toward a long-term NIH investment. The sentiment that this is just the beginning of a larger effort was stated numerous times by Dr. Walter Koroshetz, the director of the National Institute of Neurological Disorders and Stroke, who is heading the Trans-NIH Working Group for ME/CFS, and by Dr. Avindra Nath, the Principal Investigator of the new intramural study.
- The study's hypothesis, according to Dr Nath, is that *post-infectious ME/CFS is triggered by a viral illness that results in immune-mediated brain dysfunction.*



Dr. Walter Koroshetz, Director of NINDS and Trans-NIH Working Group Chair

The recent announcement of the study, however, did not occur without glitches. The clinical protocol itself appeared problematic since the patient recruitment process and the adopted clinical criteria stipulated for inclusion gave the impression that the Fukuda/Reeves criteria would be the one adopted in this study. This criteria is outdated and does not capture key features of the disease, like post-exertional malaise (PEM). The information on the study design was later updated to clarify that the Canadian Consensus Criteria (CCC) will be used, which is appropriate for this rigorous study.

Another study glitch was the selection of the control group—an extremely important aspect of study design—since it included patients with functional movement

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# Solve ME/CFS Initiative Announces New Research Advisory Council

The Solve ME/CFS Initiative is proud to announce its new Research Advisory Council (RAC). The recruitment of new members took place over the last several months based on our organization's current and projected needs; additional members will be recruited in a subsequent phase. Most of the members, who will serve two-year, renewable terms, were recruited based on their clinical or scientific expertise in fields associated with ME/CFS biology. This includes—but is not limited to—the areas of clinical investigation, cellular bioenergetics, neuroendocrine physiology, molecular genetics, neurology, microbiology, biotechnology, immunity and inflammation, as well as specialty areas associated with ME/CFS diagnostic criteria like orthostatic intolerance or post-exertional malaise.

Other RAC members were selected for their background and knowledge in a regulated industry or for specialized technical skills, including drug development, clinical trial design, bioinformatics, medical informatics, bioethics, patient services or healthcare policy analysis, with the intent to support and enhance the capacity of our organization's programming.

The recruitment of this council with science, medicine and biotechnology experts signals a new phase of collaboration at the Solve ME/CFS Initiative. Now more than ever, all hands are needed on deck as we tackle this insidious disease.

The scope of the RAC is broad by design. Members will provide strategic advice and may participate in assessing academic research activities, such as evaluating research proposals submitted to or by the organization. In addition,

members of the RAC may participate in other scholarly activities, such as serving as presenters in the Solve ME/CFS Initiative webinar series, assisting in raising public awareness about the disease or authoring professional opinion pieces.

RAC members will enrich all research initiatives and will have input on a variety of professional engagements on topics such as study design, grant evaluation, peer review, advocacy for research funding, strategic partnerships with academic centers or pharma, data privacy and security and medical ethics and education.

**The recruitment of this council with science, medicine and biotechnology experts signals a new phase of collaboration at the Solve ME/CFS Initiative.**

This distinguished assembly of medical practitioners, basic science and technology experts is a critical component of the Solve ME/CFS Initiative. It will shape how our organization positions, improves and articulates the merit of our scientific activities. This council also reflects our organization's commitment to inclusivity and partnerships with different influencers in the ME/CFS field.

"We underscore transparency and collaboration in all our functions," said Dr. Zaher Nahle, Vice President for Research and Scientific Programs, who recruited the new RAC members and is responsible for management of the council, along with President Carol Head. "All RAC members are volunteers who donate their time to public service and are committed to making ME/CFS understood, diagnosable and treatable."

At right is a roster of the newly recruited RAC members. ■

# Solve ME/CFS Initiative Research Advisory Council


**Tarek Absi, MD**

*Assistant Professor, Department of Cardiac Surgery, Vanderbilt University Medical Center  
Staff Surgeon, Cardiac Surgery, Nashville Veterans Administration Hospital  
Nashville, Tenn.*


**Daan Archer, MBA, MSc**

*Vice President for Technology & Strategy, Context Labs  
Visiting Researcher, Massachusetts Institute of Technology Media Lab  
Cambridge, Mass.*


**Nathalie Bloch, MD, MPA**

*Primary Care Physician and Internist at Mount Auburn Teaching Hospital, a Harvard Medical School Affiliate  
Cambridge, Mass.*


**Anthony Komaroff, MD**

*Simcox-Clifford-Higby Professor of Medicine at Harvard Medical School  
Senior Physician at Brigham and Women's Hospital  
Boston, Mass.*


**Susan Levine, MD**

*Chair, U.S. Department of Health and Human Services Chronic Fatigue Syndrome Advisory Committee  
Founder, Medical Office of Susan M. Levine, M.D.  
New York, N.Y.*


**Jose Montoya, MD**

*Professor of Medicine, Division of Infectious Diseases, at Stanford University Medical Center  
Head of the Stanford Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Initiative  
Stanford, Calif.*


**Peter Rowe, MD**

*Director of the Chronic Fatigue Clinic at Johns Hopkins Children's Center  
Professor of Pediatrics, Johns Hopkins Children's Center  
Baltimore, Md.*


**Michel Silvestri, PhD**

*Head of Clinical Laboratory, Gotland Region, Sweden  
Visby, Sweden*


**Sheila Stewart, PhD**

*Associate Professor of Cell Biology and Physiology at Washington University School of Medicine  
St. Louis, Mo.*

## Ad Hoc Members


**Cindy Bateman, MD**

*Founder and Chief Medical Officer of Bateman Horne Center  
Salt Lake City, Utah*


**Morgan Fairchild**

*Former ME/CFS Patient, Actress and Activist  
Los Angeles, Calif.*


**Andreas Kogelnik, PhD, MD**

*Founder and Medical Director, Open Medicine Institute  
Mountain View, Calif.*


**Zeina Nahleh, MD**

*Chief, Division of Hematology/Oncology at Texas Tech University Health Sciences Center (TTUHSC) Paul L. Foster School of Medicine  
Professor of Medicine and Biomedical Sciences, TTUHSC Paul L. Foster School of Medicine  
El Paso, Texas*


**John Nicols, MBA**

*President and CEO, Codexis Inc.  
Vice Chair, Solve ME/CFS Initiative Board of Directors  
Cupertino, Calif.*

## NIH Provides Details on New Intramural Study (continued from Page 3)

disorder, which has psychological aspects associated with it. The movement disorder group has been dropped from consideration based on the most recent statements by NIH officials.

The other control group of post-Lyme disease patients who no longer have fatigue remains part of the study.

Finally, there has been significant concern regarding previous statements made by key members of the study team, who attributed ME/CFS and Fibromyalgia to psychosomatic factors; this remains a source of concern in the community. In conversations with NIH



Dr. Avindra Nath, Principal Investigator of NIH's new in-house study on ME/CFS

officials, the Solve ME/CFS Initiative has been vocal about our own concerns regarding staffing of the study. "What we need is a steadfast commitment in both resources and researchers to uncover the systemic dysfunction



of this disease without prior baggage, bias or dogma," Dr. Zaher Nahle, Vice President for Research and Scientific Programs, said.

It's important to recognize that many new findings will inevitably result from the NIH work, and missteps should not dampen enthusiasm for the study, which is focused on the *immunological* aspect of ME/CFS.

The study includes three phases. In Phase I, researchers will conduct experiments—like neuro-imaging and metabolic chamber experiments—on recruited patients, in real time. They will also acquire materials—like spinal fluid and blood—from these patients to be tested later in the laboratory.

Phase I will also include:

1. Neurological assessment and whole body monitoring of patients' physiological indicators, including a large battery of tests, like neuroimaging techniques, heart rate monitoring and autonomic system function analysis before and after exercise using neurological diagnostic techniques.

2. Immune system and microbiome analyses, including a thorough analysis of the immune system and inflammatory marker status, as well as sequencing of elements of the immune system (e.g., T-cells) for abnormalities, in addition to microbiome analysis to detect possible alterations. Metabolomics analysis also will be performed.
3. Energy assessment and evaluation with exercise using a variety of metabolic measurements, including metabolic chambers and exercise physiology techniques.
4. Cell culture analysis and experiments using patient stem cells to create a laboratory-based model for experimentation and analysis.

This Phase I study will be followed by Phase II, a long-term follow up and validation period of Phase I results, and Phase III, which will explore potential treatment with immunomodulatory drugs. Our organization will continue to be directly engaged with the NIH management staff of this new study.

To learn more about the study, go to:

[mecfs.ctss.nih.gov](http://mecfs.ctss.nih.gov) ■

# Solve ME/CFS Initiative Announces New Research Grants Program

The Solve ME/CFS Initiative is launching the Ramsay award program, a research grants competition open to basic scientists and clinical researchers interested in studying ME/CFS. The award is named after myalgic encephalomyelitis pioneer Dr. A. Melvin Ramsay, who was the recognized authority in ME from 1955 until his death in 1990, and whose sound descriptions of the disease have stood the test of time.

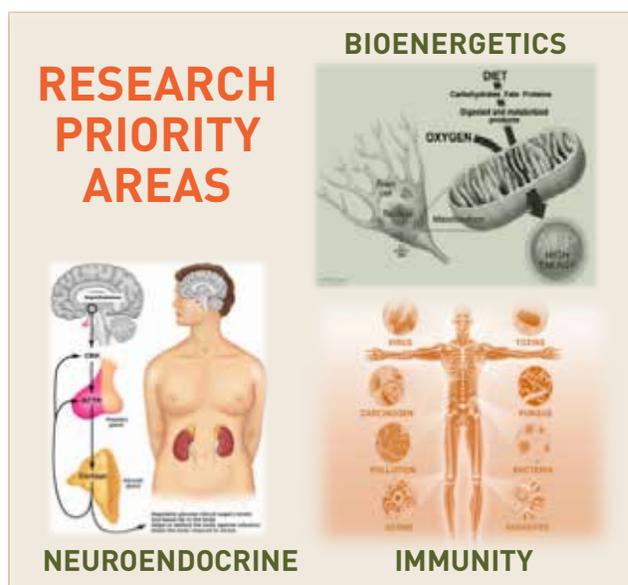
Our organization's previous grant program had a three-year cycle; our current plans are to make grant awards annually. Individual awards are expected to range between \$35,000 and \$55,000 made for a one-year period, with the possibility of renewals to projects yielding promising results. Submitted proposals will undergo a rigorous, peer-review process to select the most meritorious applications.

"The program is part of our organization's overall research strategy to encourage participatory investigations, accelerate new discoveries and reduce barriers for entry into the challenging yet rewarding field of ME/CFS," said Dr. Zaher Nahle, Vice President for Research and Scientific Programs.

The Ramsay program has three main objectives:

- **INVEST** in original ideas that will clarify the nature, progression and root causes of the disease.
- **CREATE** environments through these pilot grants to help awardees generate preliminary data and compete for long-term federal grants with the hope of retaining those researchers in the ME/CFS field.
- **FACILITATE** collaboration and cross-pollination among individuals committed to solving this challenging medical issue through our organization's network and its activities.

This year, we are especially encouraging proposals addressing the molecular basis (etiologies) of the disease—particularly those within our organization's three research priority areas as defined here.



## Bioenergetics

Bioenergetics projects will investigate the fundamental process of generating energy for physical and cognitive functions. This broad area of investigation extends to the fields of the cellular adaptation to metabolic and genetic stress conditions, mitochondrial dysfunction, energy systems (aerobic and anaerobic), cellular signaling of fuel uptake and processing, tissue oxygen delivery, REDOX biology, biochemical and free radicals toxicity and other processes affecting energy storage and utilization, including nutrient/gene interaction regulating of energy production.

## Neuroendocrine Biology

Neuroendocrine biology includes the critical pathway that controls stress response known as the HPA axis

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# SMCI Launches New In-House Research Program

## (continued from Page 1)

particular, regulate a significant portion of our resting metabolic rate and are crucial in adjusting our overall energy expenditure. The role and function of the bioenergetics process is highly context-dependent.

Yet, a characteristic feature of an effective cellular bioenergetics system, regardless of tissue specificity, lies in the *flexible and adaptive nature* of that energy-producing operation. This process is critical in helping to navigate routine metabolic pressure conditions by regulating the appropriate response and adjusting the production, rationing,

storage and use of energy accordingly. Real-time signals and inputs triggered by sensing of: the intracellular demand for energy; the abundance or lack thereof of nutrient resources; and the electrochemical status of the intracellular environment, such as acidity, pathogen invasion or damage to the genome, all inform this adaptive bioenergetics process and protect the organism's survival by regulating energy levels.

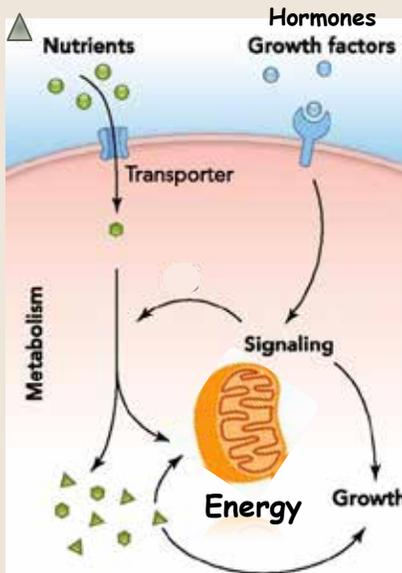
The process of bioenergetics also relies on the crosstalk between localized cellular contexts and larger units

that modulate the energy supporting machinery. For instance, organs like the liver, where production of glucose for use as fuel occurs, are key to maintaining the appropriate energy by controlling the supply and demand of fuel macromolecules. Once the adaptability and flexibility in the bioenergetics machinery are lost—either as a result of defects in nutrient and oxygen-sensing mechanisms or ATP productive capacity—dire consequences ensue like those contributing to cardiac ischemia, diabetic heart failure or those we see in ME/CFS.

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### Bioenergetics Project Scope

An umbrella project composed of several individually ambitious studies, including both hypothesis-generating and hypothesis-driven investigations. Designed to provide cumulative knowledge and fresh insights into the mechanism of bioenergetics defects in ME/CFS patients using a progressive research process with each step building upon the next.



### Areas of Focus

1. Nutrient sensing and signaling
2. Energy production
3. Hormonal regulation

### Desired Outcomes

- Understanding the pathophysiology of bioenergetics in ME/CFS patients
- Identification of specific biomarkers for diagnosis
- Testing therapeutic interventions that will lead to therapy

### Rationale for Research Emphasis

- Problems with energy/fatigue is one primary ME/CFS symptom, cited nearly universally. ME/CFS is always a dysfunction of bioenergetics.
- An under-researched area for ME/CFS and dearth of published work
- Most basic element at the source of ME/CFS dysfunction
- Effective treatments that alter the bioenergetics system have proven successful in other diseases and may also for ME/CFS
- Expertise and successful track record in Bioenergetics of our Vice President for Research and Scientific Programs
- Synergistic, yet little overlap, with other current, large studies

# Solve ME/CFS Initiative Research Program Overview

The Solve ME/CFS Initiative research program has four distinct components, each designed with a specific purpose and all intersecting to add value and advance the field of ME/CFS through biomedical research.

## BioBank and Patient Registry



Our Solve CFS BioBank and Patient Registry™ holds a repository of physical samples from ME/CFS patients that supports the work of qualified researchers to accelerate discovery.

This is an important aspect of services that our organization provides to researchers. It also represents our efforts to link patients directly to researchers and facilitate the use of human materials in the process of investigating ME/CFS.

Recently, we have streamlined the BioBank application process for researchers and simplified the process for patients to register by adding electronic consent forms. Current BioBank researchers include: Dr. Jay Chung of the National Institutes of Health; Dr. David Maughan and Dr. Mercedes Rincon of the University of Vermont; Dr. Isabel Silvestre and Dr. Dorothy Hudig from the University of Nevada; Dr. Patrick McGowan of the University of Toronto; and many other researchers who benefited from this service (See Page 10).

## Seed Grants that Fund Original Research



This grants program (featured on Page 7) funds promising researchers investigating ME/CFS and also draws new researchers to the field.

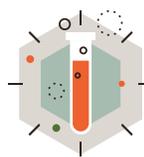
This is a continuation of our organization's long-standing grants to university researchers. We are changing our plan to award seed grants every year, rather than every three years. These seed grants reflect our desire to attract participation from a wide variety of researchers, accelerate new discoveries and reduce barriers for entry into the challenging, yet rewarding, field of ME/CFS.

These pilot grants are important because they enable scientists to pursue research projects that would otherwise not

be funded, given the continued very low level of NIH funding for ME/CFS research. They will also enable researchers to accumulate data, so they can compete for larger federal grants that require preliminary data or proof-of-concept investigations.

This program is designed to facilitate collaboration and cross-pollination among individuals committed to solving this challenging research issue.

## Targeted Initiatives Program



Initiated this year, this program leverages in-house expertise to help close the knowledge gaps in our organization's three research priority areas: bioenergetics, neuroendocrine biology and immune dysfunction. We conduct these targeted initiatives through projects initiated at our organization, either independently or in collaboration with researchers, vendors or medical centers. These projects are typically high risk/high reward and likely to generate information useful to the broader medical and scientific ME/CFS community. Results of these initiatives will be shared with the community to spark further studies.

Currently, we have several targeted initiatives in the areas of metabolomics, functional genomics and RNA interference, as well as patient registry platforms being developed with commercial entities like Metabolon, research centers like Memorial Sloan Kettering Cancer Center and large organizations like Genetic Alliance.

## Bioenergetics Research Plan

The Bioenergetics Research Study is the cornerstone of our research program. See detailed story on Page 1.

All of these scientific and research activities are bolstered by consultations, advice and recommendations from our Research Advisory Council (RAC), comprised of leading ME/CFS experts and professionals (See Page 5). ■

# BioBank and Patient Registry Research Update



The Solve CFS BioBank and Patient Registry™, which our organization built and supports as a service to the ME/CFS research community, aims to reduce barriers to ME/CFS research by providing samples to qualified researchers and to support new researchers. Currently, we are supporting projects spanning the areas of autoimmunity, metabolism, genomics and mitochondrial myopathies.

## Autoimmunity

*Study: Autoantibody detection study by Dr. Mercedes Rincon, Dr. David Maughan and team at the University of Vermont, supported by a grant from the New Jersey Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Association*

The premise of the study is that some system protein in ME/CFS patients becomes abnormally citrullinated in response to a viral infection, or some other foreign agent and that the immune system—recognizing the citrullinated protein(s) as a foreign object—will generate an antibody (an “autoanti-

body”). The autoantibody will attack the modified protein, which results in compromised protein function and tissue



inflammation. No previous studies have reported the presence of an anti-citrullinated protein antibody (ACPA) in ME/CFS. This hypothesis—that plasma from blood drawn from ME/CFS patients contains an ACPA that is not present in healthy subjects—is tested through samples provided through the Solve CFS BioBank and Patient Registry™.

The research team reported the following promising results:

- Plasma samples from seven of 25 ME/CFS subjects tested positive for anti-CCP antibody, while plasma samples from only two of 25 control subjects tested positive for anti-CCP antibody.
- Of the 25 ME/CFS samples, two tested positive for IgG1-anti-CCP antibody, four for IgG4-anti-CCP antibody and one for both.

- Of the 25 control samples, two tested positive for IgG4-anti-CCP, but none for IgG1-anti-CCP. It is possible that the two subjects who tested positive had Rheumatoid Arthritis when this antibody is present.

Based on these findings, the Solve ME/CFS Initiative and the research team are collaborating further to expand the number of samples, assess reproducibility and validate these promising results through a larger analysis.

## Biomarkers

*Study: Dr. Jay Chung, Group Leader and Senior Investigator at the Laboratory of Obesity and Aging at the National Institutes of Health*



Chung will use blood specimens from our BioBank and Patient Registry of ME/CFS patients and matched controls to test the metabolic biomarkers he is researching. Dr. Chung was recently named an Associate Investigator on the new National Institutes of Health intramural study on ME/CFS, which is led by Principal Investigator Dr. Avindra Nath.

Dr. Chung’s primary research interest is in understanding how aging decreases our ability to burn calories and generate energy. Dr. Chung’s lab also works to understand the key molecular mechanisms that underlie the benefits of caloric restriction in order to develop therapies that mimic these effects and protect against metabolic diseases.

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# SMCI Receives Award from Robert Wood Johnson Program



Robert Wood Johnson Foundation

The Solve ME/CFS Initiative has received an award through the Robert Wood Johnson Foundation White Label PEER (Platform for Engaging Everyone Responsibly) program.

The competitive grants program is managed by Genetic Alliance, which represents 10,000 organizations, 1,200 of which are disease organizations. Sharon Terry is Genetic Alliance President and CEO and a visionary behind PEER and the RWJF White Label project.

The Solve ME/CFS Initiative was one of only six disease-related organizations to be selected to participate in the

program and utilize PEER to engage our community in participant-centric research.

Our organization will use the award to boost our Solve CFS BioBank and Patient Registry™, which has received growing interest from patients and researchers alike in the past year (See related content at left). Specifically, we will undertake a much-needed expansion of the BioBank and Registry, which will enable us to: collect more comprehensive and useful data on patients and their experience with ME/CFS; inform study design; and support clinical, translational and epidemiological studies. ■

## Genomics

Methylation studies by Dr. Patrick McGowan, University of Toronto

*Study: Epigenome alterations of glucocorticoid signaling pathway in CFS*

Dr. Patrick McGowan has completed data collection and quality control on all of the subjects from the research funded by the Falk Medical Research Trust. The total subject numbers analyzed are: 61 ME/CFS patients (46 female, 15 male) and 48 healthy controls (36 female, 12 male). Dr. McGowan experienced no difficulties capturing T-cells for epigenetic studies by cell sorting techniques. He also experienced no issues with the quality control for both epigenetic and genetic microarrays. He has identified 157 differently methylated regions between ME/CFS and control females thus far.



Next, Dr. McGowan's lab will implement a multi-stage analysis to identify how many of the epigenetic differences can be accounted for by genotype. Plans are also in place to

examine the relationship between the observed epigenetic signaling identified experimentally and symptom severity by linear regression and statistical validation methodologies.

We expect to announce the findings of Dr. McGowan's work in the late spring.

## Other Studies Using Solve CFS BioBank Samples



University of Nevada, Reno

Through our BioBank and Patient Registry, the Solve ME/CFS Initiative will be providing research materials to projects led by Dr. Dorothy Hudig and Dr. Isabel Silvestre at the University of Nevada in the areas of immunity, cellular toxicity and mitochondrial myopathies in ME/CFS. One line of investigation being explored is the genetic familial links and their effects on T-cell function in ME/CFS. The research is funded by an NIH exploratory grant for which Dr. Hudig is the senior investigator. ■

# Solve ME/CFS Initiative Meets with NIH, Congress

**As part of the Solve ME/CFS Initiative's expanding role in the advocacy arena, President Carol Head traveled to Washington, D.C., March 7 for a series of meetings with staff from the National Institutes of Health and congressional offices.**

Head kicked off the trip with a meeting at NIH on March 8. She was accompanied by fellow advocate Mary Dimmock, mother of an ME/CFS patient and author of "Thirty Years of Disdain: How HHS and a Group of Psychiatrists Buried Myalgic Encephalomyelitis." The two met with Walter Koroshetz, Director of the National Institutes of Neurological Disorders and Stroke, Vicky Holets Whittemore, NIH Program Director and Coordinator of the Trans-NIH ME/CFS Working Group, and Marian Emr, Communications Director for NINDS.

The remainder of the trip focused on visits with congressional offices, particularly those of Senators who serve both on the Health, Education, Labor & Pensions Committee, as well as on the Appropriations Committee. At every visit, the group made specific requests regarding additional federal funding for ME/CFS, supported by copies of last year's Institute of Medicine report.

On March 9, Head and Solve ME/CFS Initiative Board member Chris Williams



The Solve ME/CFS Initiative visited congressional offices in March as part of our organization's expanded advocacy efforts.

met with staff at the offices of Rep. Van Hollen (D-MD). Williams, herself a patient, is a constituent of Van Hollen's. Head and Williams were accompanied by two patient constituents, Loetta Vann and Greg Burge, who testified to their personal struggle with ME/CFS.

Later that afternoon, Head and Williams met with Stephen Steigleder, the House minority staff member who handles spending for NIH. They conveyed the urgent need for dramatically more research funding. Head and Williams then met with Health Legislative staff at the office of Sen. Patty Murray (D-WA), ranking member of the Senate Committee on Health, Education, Labor & Pensions. Head

was joined by phone in the meeting with Sen. Murray's constituent and ME/CFS patient Elaine Boel. Head provided background on the disease, while Boel conveyed her personal account of the serious impact the disease has on her life.

On March 9, Head held meetings with the staff members of five Senators, including:

- Sen. Mark Kirk (R-IL), a member of both the Senate Appropriations Committee and the Health, Education, Labor & Pensions Committee. She was joined by phone by Solve ME/CFS Initiative Board chair Vicki Boies, who is a constituent of Sen. Kirk's.

- Sen. Bill Cassidy, MD (R-LA), a member of both the Senate Appropriations Committee and the Health, Education, Labor & Pensions Committee. Head was joined by phone by Sen. Cassidy's constituent and ME/CFS patient Matt Wray and advocate Mary Dimmock.
- Sen. Tammy Baldwin (D-WI), a member of both the Senate Appropriations Committee and the Health, Education, Labor & Pensions Committee. Head was joined by phone by Pat Fero, Sen. Baldwin's constituent and president of the Wisconsin ME/CFS Association, and advocate Mary Dimmock.
- Sen. Elizabeth Warren (D-MA), a member of the Health, Education, Labor & Pensions Committee. Charmian Proskauer, Sen. Warren's constituent and President of the Massachusetts CFIDS/ME & FM

Association, led the meeting, which also included Sen. Warren's constituent Leah Williams and Sen. Alexander's constituent Ashley Hultman.

- Sen. Lamar Alexander (R-TN), a member of the Senate Appropriations Committee and Chairman of the Health, Education, Labor & Pensions Committee. Head was joined in person for the meeting by Sen. Alexander's constituent and ME/CFS patient Ashley Hultman, Charmian Proskauer, Leah Williams, whose daughter and son both have ME/CFS, and advocate Mary Dimmock.

Earlier in the afternoon, Head, Proskauer, Williams and Dimmock met with two additional Appropriations staff members:

- Laura Friedel, Senate Majority, who handles NIH; and
- Lisa Bernhardt, Senate Minority, who handles CDC.

The Solve ME/CFS Initiative plans to make additional trips to Washington, D.C., later this year to further our connections with those who can be influential in generating more funds for ME/CFS. Keeping the ME/CFS issue in front of Congress members and NIH officials will serve as a reminder and a reinforcement of the devastation of this disease and the desperation of patients.

While all staffers listened attentively and clearly understood the history of underfunding for ME/CFS, the Appropriations staff members said that it will be difficult to be successful with new funding requests, particularly during an election year. Advocacy with Congress is a long road, and our organization's efforts on this trip and others this year will set the stage for 2017—with a new president and a new Congress. ■

## SMCI Launches New In-House Research Program (continued from Page 8)

It follows, then, that the integrity of the bioenergetics process is fundamental in human health and disease, especially the flexibility and adaptability in utilizing fuel accordingly. **We believe there is a significant likelihood that ME/CFS—as a cardinal metabolic disease for which the root causes lie in a severe bioenergetics defect—is caused, at least in part, by a**

**metabolic inflexibility in the bioenergetics machinery.** As little research has been conducted directly on this issue, we believe we can contribute significantly to the field by exploring it.

This new multi-year study is a deep dive into the cause of bioenergetics deregulation in ME/CFS patients. With this study, we seek to discover ME/CFS biomarkers, treatments and,

ultimately, a cure. We will begin raising funds to support this study later this spring.

In addition to the cornerstone Bioenergetics Research Study, SMCI will conduct additional in-house research through our Targeted Initiatives Program, which is detailed on Page 9. ■

# Solve ME/CFS Initiative Updates Its Report Card on Revised CFSAC Responses

As part of its role in providing advice and recommendations to the Secretary of Health and Human Services (HHS) on issues related to ME/CFS, the Chronic Fatigue Syndrome Advisory Committee—of which the Solve ME/CFS Initiative is a member—presented 18 recommendations to the Secretary of the HHS in August 2015. The HHS released its responses to the CFSAC recommendations in October. In most instances, the agency responses were inadequate and not in line with the urgency of our disease documented in last year’s Institute of Medicine and Pathways to Prevention reports, which unequivocally called for federal agency focus on ME/CFS.

The Solve ME/CFS Initiative issued a report card the day after the initial responses were published to document

our dissatisfaction with them. In late March, the National Institutes of Health published revised responses; our organization has updated our report card based on these revised responses. Because other HHS agencies have not updated their responses that commentary is not included in this report card.

We offer this assessment to continue a constructive, problem-solving dialogue regarding how our federal government can effect these recommendations and live into the IOM’s and P2P’s mandates. The 18 recommendations will be discussed further at the next CFSAC meeting, which is scheduled for May 17-18. To view the HHS responses, go to: [hhs.gov/advcomcfs/recommendations](https://hhs.gov/advcomcfs/recommendations).

PART/ RECOMMENDATION #	RECOMMENDATION TOPIC	OUR GRADE	RATIONALE FOR SOLVE ME/CFS INITIATIVE GRADE
Part I, Recommendation #1	Standardize Assessment Methods and Measures re: Patient Registry	<b>Update Grade from a C to a C+</b>	It is good news for ME/CFS researchers that the National Institutes of Health will drive forward with both Common Data Elements and Data Coordinating Centers, although the timetable for implementation remains unclear. These two new NIH-driven structures, in conjunction with the previously noted requirement that all NIH researchers commit to a data-sharing plan, are commendable. (Note: It is unclear what specifically a “data sharing plan” means, given that university-based researchers almost always withhold their data as they are highly motivated to publish in order to advance their careers. Additional clarification is requested of NIH regarding the requirements and penalties regarding “data sharing.”) Further, it appears that the creation and management of the ME/CFS Registry will be accomplished by private institutions, not public. The Solve ME/CFS Initiative plans to build such a registry.
Part II, Recommendation #1	Prioritize Development of Biomarkers and Objective Diagnostic Tests	<b>Update Grade from a D- to a C-</b>	The most promising aspect of the updated NIH response is its seeming commitment for the Trans-NIH ME/CFS Working Group to issue new RFAs. This is eagerly awaited by patients and researchers alike and will be the clearest, most meaningful signal that the NIH is living into the spirit of the Institute of Medicine report. While we eagerly await those RFAs, we note that there is as of yet no plan to include patient-experts in a meaningful way in the creation of the “comprehensive research strategy for ME/CFS.”

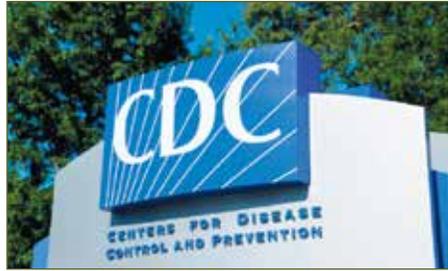
PART/ RECOMMENDATION #	RECOMMENDATION TOPIC	OUR GRADE	RATIONALE FOR SOLVE ME/CFS INITIATIVE GRADE
Part II, Recommendation #2	Address Gaps in Basic, Translational, Clinical and Epidemiological Research	<b>Update NIH Grade from a D to a D+</b>	We are heartened to know that the Trans-NIH ME/CFS Working Group and the Office of Disease Prevention and other federal agencies will meet to address gaps in ME/CFS research, as this is an appropriate response to the National Institutes of Health's Pathways to Prevention Workshop. Time will tell what measures and new research funds will result from this gathering. We encourage patient-experts be included in research.
Part II, Recommendation #3	Advance Treatments and Therapeutics	<b>Update Grade from a C+ to a B</b>	We are encouraged that the NIH has moved quickly to design the protocol and will begin enrolling patients this summer. We recognize that, for the NIH, this speed demonstrates serious commitment. And at the same time, concerns remain that: 1) the clinical study includes individuals without a clear recognition of the IOM's statement that this is a physical disease; and 2) the clinical study lacks the inclusion of patient-experts in the planning and processes.
Part II, Recommendation #4	Standardize Assessment Methods and Measures	<b>Update Grade from a D to a D+</b>	Although the NIH did not submit a formal updated response, we do note the NIH's clarification that the patient recruitment plan will adhere to the 2003 Canadian Consensus Criteria. This is an important step forward.
Part II, Recommendation #5	Assign the Disease to an Institute	<b>Keep Grade at an A-</b>	We continue to be pleased that the National Institute of Neurological Disorders and Stroke has taken on responsibility and management of ME/CFS until such time as there is a better understanding of the pathophysiology of the disease. While this lack of a permanent "home" within NIH makes many advocates uneasy, NIH's points regarding the strength of the revamped Trans-NIH Working group make sense.
Part II, Recommendation #7	Provide Research Funding Commensurate with the Burden of Disease	<b>Keep grade at an F</b>	The updated NIH response continues to perpetuate the status quo and fails to recognize the deep, longstanding chasm between appropriate funding—roughly \$250 million annually—and current funding—roughly \$25 million annually, plus the unknown, laudable expenditures on the new NIH ME/CFS clinical study. Significant progress cannot and will not be made until federal agencies recognize that their current funding approaches continue to leave this disease egregiously underfunded.
Part II, Recommendation #10	Provide Disease Guidance with the Criteria	<b>Keep grade at a C-</b>	As NIH did not provide an update, our previous commentary stands: The NIH's statements demonstrate no additional federal work on the issue of disease guidance, post-IOM report. We understand that primary responsibility for the specific recommendation lies outside of NIH's authority. Kudos to the International Association for CFS/ME (IACFS/ME) for creating a primer. The federal government has not enacted the CFSAC recommendation.
Part II, Recommendation #12	Promote Medical Education and Awareness	<b>Keep grade at a D+</b>	While we realize that this work is outside the direct purview of NIH, we recognize NIH's support for training of pre- and post-doctoral fellows and are heartened that the Trans-NIH ME/CFS Working Group is looking at strategies to increase interest in young investigators. At the same time, the grade remains at a D+—which may be too generous—as the education of medical practitioners is a step that can be taken NOW, without the benefit of further research. This education is urgent, as the majority of patients continue to receive no diagnosis and are frequently given information that is actively damaging to their fragile health. There is zero rationale for federal foot-dragging on the issue of medical education and awareness.

## Dr. Zaher Nahle Serves on CDC Workgroup

**Dr. Zaher Nahle, the Solve ME/CFS Initiative's Vice President for Research and Scientific Programs, is serving as a member of the Centers for Disease Control and Prevention's new Technical Development Workgroup (TDW) for ME/CFS. The CDC has formed the group to ensure that any educational materials on ME/CFS are evidence-based, understandable and useful to stakeholders.**

This new effort from the CDC is significant since the ME/CFS community has long been concerned that information on the CDC website is out of date, and in some cases, can be damaging to patients. The CDC site is a foundational source of information for many doctors who are not familiar with ME/CFS. By correcting information on the CDC site, we will help ensure that clinicians will receive accurate and

appropriate information regarding both the seriousness of the disease and how it should be treated.



Members of the TDW will assess and revise existing CDC educational materials and create new materials to incorporate the recommendations of last year's Institute of Medicine (IOM) report, "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness." The IOM report recommended changes in the diagnostic criteria and algorithms and dissemination of updated information to clinicians and others.

Dr. Nahle's work on the group, which includes medical professionals, patient advocates, researchers and patients, will take place over the course of the next 16 months. Dr. Beth Unger, chief of the CDC's Chronic Viral Diseases Branch, will chair the group. As the first step, group members are participating in one-hour calls with five to 10 of their fellow group members. The phone calls are in advance of a face-to-face meeting.

In its communication to members of the invitation-only group, the CDC said: "As part of this stakeholder dialogue, we want to assure that all voices are heard, that clinicians understand the concerns and difficulties that persons with ME/CFS face, and that patients understand how physicians and other health care professions use and disseminate educational materials about ME/CFS." ■

## Carol Head Joins CFSAC Subcommittee on Centers of Excellence

Solve ME/CFS Initiative President Carol Head serves on a subcommittee of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) that is adding depth to the CFSAC recommendation to establish ME/CFS Centers of Excellence. Centers of Excellence are not uncommon for other diseases; COEs are specialized facilities, generally spread among regions in the United States that focus on disease research and often include clinics. Both research centers

and additional clinical care centers are much needed for ME/CFS.

The CFSAC subcommittee is divided into two teams: one that will make the case to the federal government that such Centers of Excellence are needed. The second—on which Head serves—will look at how such Centers of Excellence would be structured and funded. ■

# JOIN THE FIGHT Against ME/CFS

## WHY WE FIGHT FOR UNDERSTANDING

"I am very angry that ME/CFS is not more recognized, and I'm embarrassed to tell people that I have it because I'm afraid of how they will react...If only people would understand and treat us the same as they would if we told them we had MS or Lupus, or any other recognized illness."—Lisa, patient

## WHY WE FIGHT FOR TREATMENTS

"My friends are fully engaged in active lives while I am on the sidelines feeling sick most of the time with swollen glands, headache, sore throat—it's like having the flu 24/7. I want some effective treatments in my lifetime."—Chris, patient

## WHY WE FIGHT FOR A CURE

"I often wish life would be over already, as it is so difficult. But I do have many friends and family who help to make it worth living day to day. Also, there is always hope that someday, someone will find a cure."—Connie, patient

Last year was a pivotal point in the battle against ME/CFS. Game-changing reports from the Institute of Medicine and the National Institutes of Health's Pathways to Prevention Workshop delivered long-awaited public credibility for our disease. The federal ME/CFS landscape has shifted, and there is newfound openness and awareness among key governmental agencies. This positive change has heightened the battle as we fight for scientific understanding, fight for treatments and fight for a cure.

The Solve ME/CFS Initiative has been fighting for patients of this insidious disease for many years, and we recognize that progress has been slow. Insufficient federal funding, the complexity of the disease and disbelief are all obstacles that have thwarted progress.

Building on 2015's momentum, we are increasing our efforts; we are fighting harder today than ever before. We are fighting relentlessly for patients like Lisa, Chris and Connie, who are quoted at left.

**We are fighting for YOU by:**

### Taking a Leadership Role with the NIH

We are working to increase medical research spending on ME/CFS at the National Institutes of Health (NIH). We've initiated discussions with NIH staff about the ME/CFS study protocol and research team composition to ensure that the NIH's work results in credible, replicable research that will move the science forward. We hold a seat on the Chronic Fatigue Syndrome Advisory Committee, which makes recommendations to the NIH regarding ME/CFS.

### Sponsoring and Generating New Research

We are currently supporting four early stage pilot studies, as discussed elsewhere in this publication;

- A study with promising preliminary results for a potential ME/CFS biomarker;
- An autoimmune dysfunction study that has identified elevated levels of previously unknown antibodies in ME/CFS patients;
- A genetic analysis exploring the possible hereditary aspects of ME/CFS; and
- A study investigating the compromised immune system in ME/CFS patients.

*Continued on Page 18*

To support our efforts, go to [SolveCFS.org/donate](https://SolveCFS.org/donate)

# Register for Our 2016 Webinar Series

The Solve ME/CFS Initiative kicked off our 2016 webinar series March 17 with a presentation by Sue Levine, MD, founder of the Medical Office of Susan M. Levine, M.D. Dr. Levine addressed “The Future of ME/CFS.”

To view the webinar recording, visit our YouTube channel at:



[youtube.com/SolveCFS](https://youtube.com/SolveCFS).

Registration for the April, May and June webinars is available on our website

at [SolveCFS.org/webinar](http://SolveCFS.org/webinar). The free webinars will take place at 1 p.m. Eastern time.

On April 21, our webinar will feature **Avindra Nath, MD**, Clinical Director at the National Institutes of Health’s National Institute of Neurological Disorders and Stroke. Dr. Nath is Principal Investigator of NIH’s new intramural study on ME/CFS.

On May 19, we’ll feature **Jarred Younger, PhD**, Associate Professor

in the Departments of Psychology, Anesthesiology and Rheumatology in the University of Alabama at Birmingham. Dr. Younger established

*Continued on Page 20*



Jarred Younger, PhD, University of Alabama, presents a webinar May 19.

## Join the Fight Against ME/CFS (continued from Page 17)

We are pleased to announce in this issue the launch of our 2016 Request for Research Applications Competition that reflects the latest advances in ME/CFS science. Our goal is to fund three to four new research grants and draw investigators into the ME/CFS field.

Dr. Nahle, our Vice President for Research and Scientific Programs, has formed partnerships with Metabolon, a health technology leader, the Memorial Sloan Kettering Cancer Center and with Dr. Susan Levine’s ME/CFS clinic in New York to facilitate our own targeted research initiatives. These research studies are scheduled to commence in the late summer.

### Engaging & Informing the ME/CFS Community

*Research 1<sup>st</sup>*, our monthly electronic newsletter, and the *Chronicle*, this print publication, offered as a service at no charge, keep the ME/CFS community informed on research and other developments relevant to ME/CFS. “In the depths of my illness, the *Chronicle* was the only thing that kept me going.”—Penny R., patient

Our website, Humans of ME/CFS ([HOME.CFS.SolveCFS.org](http://HOME.CFS.SolveCFS.org)), gives voice to patients and their stories, helping to reduce the isolation felt by so many. Additionally, we initiated the US Action Working Group, a coalition of ME/CFS stakeholders formed to create a unified front for our community in advocacy efforts.

### Advancing the Discourse on ME/CFS

Dr. Nahle is a member of the Centers for Disease Control and Prevention’s Technical Development Workgroup on ME/CFS, and we are actively advocating with Congress members on behalf of ME/CFS patients. Dr. Nahle’s frequent opinion pieces in *Research 1<sup>st</sup>* and the *Chronicle* also help to guide the ME/CFS narrative.

**Will you join us in our fight?** Your donation today will continue our important work and bring hope to so many who suffer. Please use the enclosed envelope, or go online at [SolveCFS.org/donate](http://SolveCFS.org/donate) to make your tax-deductible donation. ■

## SMCI Announces New Research Grants Program (continued from Page 7)

(Hypothalamic-Pituitary-Adrenal axis). Cortisol is just one player in such axis. The potential to learn from the wealth of knowledge acquired in fields like obesity and diabetes, where this pathway is involved, is very promising.

### Immunity and Inflammation

Research in this area holds great promise and is considerable relative to other fields of research, yet many contradictory reports exist. The Solve ME/CFS Initiative is interested in studies addressing aspects of pathogen/host interaction, autoimmunity, immunotherapy and the pathologies of chronic inflammation in ME/CFS. Studies that will synergize, inform or complement existing efforts (e.g., the new intramural ME/CFS study at the National Institutes of Health) are of interest.

In addition, proposals incorporating the development of new therapeutic modalities or seeking the identification of reliable biomarkers in ME/CFS will also be considered favorably.

The Solve ME/CFS Initiative is especially interested in applications incorporating new technologies or interdisciplinary approaches to investigate the disease. Additional details on submission and eligibility will be made public to researchers through a Request for Applications (RFAs) in late spring 2016. The submission deadline is July 15, 2016, with an anticipated award notification date of Sept. 1, 2016. All pre- and post-award management of the program will be managed internally by our organization. Inquiries can be addressed to Dr. Zaher Nahle at [znahle@SolveCFS.org](mailto:znahle@SolveCFS.org).

This program comes at an opportune time given the recruitment of our new Research Advisory Council (See Page 4), which includes leading ME/CFS experts. These subject matter experts, along with Dr. Nahle, President Carol Head and qualified outside reviewers, will be conducting the review process. ■

**Our publications are offered FREE of charge to ALL in the ME/CFS community.**

**If you know of others who would find this printed *Chronicle* to be of interest, please ask them to sign up online at [SolveCFS.org/chronicle](http://SolveCFS.org/chronicle), call us at 704-364-0016, ext. 201, or email us at [SolveCFS@SolveCFS.org](mailto:SolveCFS@SolveCFS.org), and we will make sure they receive future issues.**

**To sign up for our free monthly newsletter *Research 1<sup>st</sup>*, go to [SolveCFS.org/research1st](http://SolveCFS.org/research1st), call us at 704-364-0016, ext. 201, or email us at [SolveCFS@SolveCFS.org](mailto:SolveCFS@SolveCFS.org).**

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## Register for Our 2016 Webinar Series (continued from Page 18)

the Neuroinflammation, Pain and Fatigue Laboratory at UAB, where he oversees the development of new diagnostic tests and treatments for chronic pain and fatigue disorders.

On June 16, we'll host **Jose Montoya, MD**, Professor of Medicine in the Division of Infectious Diseases at

Stanford University Medical Center. Dr. Montoya leads the Stanford Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Initiative.

Webinars for the second half of the year will be announced in the coming months. Check our website or social media pages, listed below, for updates. ■



### Stay in touch!

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