



Solve ME/CFS Initiative

presents

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

Saturday, October 14 | Washington, DC



“Of the many mysterious illnesses that science has yet to unravel, ME/CFS has proven to be one of the most challenging.”

—Francis S. Collins, M.D., Ph.D., Director,
National Institutes of Health, 2015

Making ME/CFS understood, diagnosable and treatable

TABLE OF CONTENTS

3

Welcome

4

Agenda

5

Speaker Bios

12

Participants and Observers

15

About SMCI

WELCOME!

THIS IS AN EXTRAORDINARY TIME in the history of ME/CFS and progress is occurring on several fronts. Notably, commitment from federal agencies is stronger than ever. The establishment of ME/CFS Collaborative Research Centers (CRCs) and the Data Management and Coordinating Center (DMCC), announced by the National Institutes of Health last month, is arguably one of the largest investments in ME/CFS research by the agency to date. Similarly, the updates on medical information and authoritative redefinition of the curricula on ME/CFS at the CDC carry equal significance in the fight for broader recognition and support of this disease. A national Common Data Elements (CDE) project was also launched this year to standardize study data and metrics in ME/CFS. This is all occurring in conjunction with myriad positive changes in the disease space over the last few years.

At SMCI, we seek to add value and bring tangible change to the disease space. Using a variety of tools at our disposal, we are filling knowledge gaps, investing in innovative ideas, partnering with patients for real solutions, facilitating meaningful collaborations among stakeholders, creating reliable health record systems for patients, leading conferences and think tanks, advancing medical education, advocating for equitable research funding, and working constructively with medical agencies and government organizations towards solving ME/CFS. Our work is stronger alongside the commendable activities and efforts undertaken by other ME/CFS organizations and grass root movements.

Many transformative events took place at SMCI recently and we invite you to remain connected with us and find more about them. We also recognize that solutions to this debilitating disease will come from multidisciplinary efforts that are achieved through durable and meaningful partnerships. So, over the course of the day, you will hear from and interact with key opinion leaders – with cross sectional affiliations in academia, biotech, government, research, and clinical settings—who bring a wealth of experience and determination to the most pressing issues in ME/CFS.

It is our hope that such an assembly would spark additional collaborations. The driving force of this forum is to be disruptive to the status quo, incorporate novel perspectives into the field, and fuel cross-pollination. From the wide-ranging topics discussed, including basic science, clinical trials, biotechnology, epidemiology, medical education, policies, patient registries and electronic health record systems as well as ways to drive forward the ME/CFS agenda, we are confident that you will have a productive and memorable day.

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

Thank you for joining us.



Carol Head
President & CEO



Zaher Nahle
Chief Scientific Officer & Vice President for Research

AGENDA

7:30–8:30 AM	Registration and Breakfast	<i>McLean Room</i>
8:30–9:00 AM	Speaker Photos and Meet & Greet	<i>McLean Room</i>
9:00–9:15 AM	Opening Remarks from Zaher Nahle & Carol Head SMCI	
9:15–9:40 AM	Vicky Whittemore NIH	
9:40–10:05 AM	Ian Lipkin Columbia University	
10:05–10:30 AM	Rick Williams & Becky McNeil RTI International	
<i>15-minute break</i>		<i>Herndon Falls/ Church Room</i>
10:45–11:10 AM	Zaher Nahle SMCI	
11:10–11:35 AM	Maureen Hanson Cornell University	
11:35–12:00 PM	Ralph Garippa MSKCC	
12:00–12:25 PM	Ken Blount Rebiotix	
12:30–1:30 PM	Lunch	<i>McLean Room</i>
1:30–1:55 PM	Elizabeth Unger CDC	
1:55–2:20 PM	Dan Peterson Sierra Internal Medicine	
2:20–2:45 PM	Nancy Klimas Nova Southeastern University	
2:45–3:10 PM	Derya Unutmaz The Jackson Laboratory for Genomic Medicine	
<i>15-minute break</i>		<i>Herndon Falls/ Church Room</i>
3:25–3:50 PM	Peter Rowe Johns Hopkins	
3:50–4:15 PM	Lucinda Bateman Bateman Horne Center	
4:15–4:40 PM	Susan Levine Levine Clinic NYC	
4:40–5:05 PM	Charles Lapp Hunter-Hopkins Center	
5:05–6:00 PM	Open discussion	
7:00–9:00 PM	Dinner	<i>McLean Room</i>

SPEAKER BIOS



LUCINDA BATEMAN, MD

Founder & Chief Medical Officer, Bateman Horne Center, SMCI RAC Member (*Ad hoc*)

@LBatemanMD

Dr. Lucinda Bateman has evaluated and followed more than 3,000 patients with chronic fatigue conditions since she started the Fatigue Consultation Clinic in 2000. The clinic was recently merged with the non-profit OFFER (The Organization for Fatigue and Fibromyalgia Education and Research) to form the Bateman Horne Center. Dr. Bateman has lectured extensively on issues relating to chronic fatigue syndrome and fibromyalgia. She has served on the boards of the Easter Seals of Utah, the International Association of Chronic Fatigue Syndrome (IACFS/ME) and the CFIDS Association of America, now known as SMCI. Throughout her career, Dr. Bateman's interest has become more focused on the diagnosis and management of unexplained chronic fatigue, ME/CFS and FM, inspired by the silent suffering of her sister, Shauna Bateman Horne. Prior to that, she started a small private group practice in 1991 and practiced General Internal Medicine until 2000. In 2000, she was one of three Utah internists chosen by her peers in *Top Doctors*, a national publication.

Dr. Bateman completed her BS and MS at Brigham Young University (BYU), attended the Johns Hopkins School of Medicine, returned to the University of Utah for Internal Medicine residency, and became certified by the American Board of Internal Medicine in 1991.



KEN BLOUNT, PhD

Head of External Research, Rebiotix

@rebiotix

Dr. Ken Blount is a seasoned director of collaborative research programs in biotech, pharma, clinical, and academic research settings, and his scientific expertise includes microbiome and small-molecule drug development, translational medical oncology, and RNA-targeting therapeutics. Dr. Blount is the Head of External Research at Rebiotix, where he is cultivating a portfolio of novel microbiome therapeutic programs. Prior to joining Rebiotix, Dr. Blount coordinated translational urologic oncology research for the Yale Cancer Center. Previously, he was a cofounder and the Director of Biology at BioRelix, a venture-backed Connecticut biotech that developed new antibiotics to target structured bacterial messenger RNAs. At BioRelix, Dr. Blount led a combined force of internal scientists and external resources that delivered development candidates for treating *Clostridium difficile* infections.

Dr. Blount received his undergraduate degree in biochemistry from the University of Arkansas and earned a PhD in biochemistry from the University of Colorado Boulder, after which he completed an NIH post-doctoral fellowship at the University of California San Diego.

SPEAKER BIOS



RALPH GARIPPA, PhD

Director, RNAi and Gene Editing (CRISPR-Cas9) Core Facility, Memorial Sloan Kettering Cancer Center

Dr. Ralph J. Garippa is the Director of the RNAi and Gene Editing (CRISPR-Cas9) Core Facility at MSKCC. His group develops protocols in the design and execution of gain- and loss-of-function shRNA screens, provides consultation in the areas of sh- and sgRNA library design, vector construction, CRISPR-Cas9 knockout protocols, and data analysis. Additionally, the group utilizes high speed automated fluorescent (high content microscopy and high throughput screening (HTS)). He is the former Head of Cell-Based High Throughput Screening (HTS) and Microscopic Imaging-based High Content Screening (HCS) at Hoffmann-La Roche's Nutley, NJ facility from 1998-2008. His previous academic partners included Harvard University, Massachusetts General Hospital, and The Hebrew University in Jerusalem, Israel. He was also involved with the NIH's MLPCN and MLSCN small molecule chemical probe screening effort since its inception.

Dr. Garippa holds a PhD in Pharmacology from Columbia University in New York City (where he studied GLUT4 translocation in the laboratories of Drs. Fred Maxfield and Tim McGraw) and a BA degree in Biology from Fairleigh Dickinson University in New Jersey (where he studied developmental biology in the axolotl *Ambystoma mexicanum* with Dr. Gervasia Schreckenbergl).



MAUREEN HANSON, PhD

Founder & Director, Center for Energating Neuroimmune Disease Cornell University, SMCIRAC Member

Dr. Maureen R. Hanson is the Liberty Hyde Bailey Professor in the Department of Molecular Biology & Genetics at Cornell University. Dr. Hanson previously served on the faculty of the Biology Department at the University of Virginia, following the completion of an NIH post-doctoral fellowship at Harvard. She moved to Cornell as Associate Professor and was promoted to Professor in 1991. She is presently a member of the graduate fields of Genetics and Development, Plant Biology, and Biochemistry, Molecular, and Cell Biology. Dr. Hanson has two different research programs; one in plant biology on the genome-containing organelles of plants, chloroplasts and mitochondria, and a second focus on the pathophysiology of ME/CFS. These programmatic concentrations are related through their dependence on modern methods for examining genome sequences and gene expression.

Dr. Hanson received a BS degree at Duke University and a PhD in Cell and Developmental Biology from Harvard University.

SPEAKER BIOS



NANCY KLIMAS, MD

**Director, Institute for Neuro Immune Medicine,
Nova Southeastern University**

Dr. Nancy Klimas is a Professor of Medicine at Nova Southeastern University, Professor and Chair of the Department of Clinical Immunology, and Scientific Director of the Institute for Neuro Immune Medicine. Dr. Klimas has more than 30 years of professional experience and has achieved international recognition for her research and clinical efforts in multi-symptom disorders, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Gulf War Illness (GWI), Fibromyalgia, and other Neuro Immune Disorders. She is immediate past president of the International Association for CFS and ME (IACFS/ME), a professional organization of clinicians and investigators, and is also a member of the VA Research Advisory Committee for GWI, the NIH P2P CFS Committee, and the Institute of Medicine ME/CFS Review Panel. Dr. Klimas has advised three Secretaries of Health and Human Services, including Kathleen Sebelius, during her repeated service on the Health and Human Services CFS Advisory Committee. Dr. Klimas has been featured on "Good Morning America," in *USA Today* and the *New York Times*.



CHARLES LAPP, MD

Founder, Hunter-Hopkins Center

Dr. Charles Lapp has maintained a private practice of medicine and pediatrics since 1978. Dr. Lapp began collaborating with Dr. Paul Cheney in 1987, and after acting as Medical Director of the Cheney Clinic in Charlotte, opened a Charlotte office for general medical consultations, with special interests in Chronic Fatigue Syndrome, Fibromyalgia, and related conditions in 1995. He is a diplomate of the American Board of Internal Medicine as well as the American Board of Pediatrics; he is a Fellow of the American Academy of Pediatrics, the American Academy of Family Physicians, and the American Academy of Disability Evaluating Physicians. Dr. Lapp served 3 years on the CFS Advisory Committee, is a member of the American Association for CFS and the American Fibromyalgia Syndrome Association, advisor to ProHealth Incorporated.

Dr. Lapp earned his MD degree from Albany Medical College, NY, and completed residencies in both internal (adult) medicine and pediatrics at the University of North Carolina at Chapel Hill.

SPEAKER BIOS



SUSAN LEVINE, MD

Founder, Levine Clinic NYC; SMCI RAC Member

Dr. Susan M. Levine first became intrigued by CFS patients during a fellowship period working with Dr. Charlotte Cunningham-Rundles, one of the co-authors of the original case definition of CFS/ME. Dr. Levine examined natural killer cell function and abnormalities in catecholamine response in these patients and then opened a private practice to provide medical support to a growing CFS population in the New York and New Jersey area. Over the last two decades, she has collaborated with other clinicians and researchers, co-authored “A Manual for Physicians,” a primer for internists about the care of CFS patients, and is currently serving on the Federal Advisory Committee for CFS. She remains committed to seeking better treatments for CFS/ME patients and to collaborating with like-minded scientists to gain a better understanding of this illness. Dr. Levine is Chairperson of the Federal Advisory Committee (CFSAC). She is also involved in several NIH funded clinical trials with Drs. Lipkin and Hornig at Columbia’s Mailman School of Public Health and with Dr. Maureen Hanson at Cornell University and served as a reviewer for the IOM report on ME/CFS.

Dr. Levine graduated from Albert Einstein School of Medicine in 1981 and completed a residency in Internal Medicine at Montefiore Hospital in the Bronx followed by two fellowships in Infectious Diseases and Allergy and Immunology at Memorial Sloan Kettering Cancer Center and Mt. Sinai Hospital.



IAN LIPKIN, MD

John Snow Professor, Epidemiology; Director, Center for Infection & Immunity, Columbia University

Dr. Ian Lipkin has over 30 years of experience in diagnostics, microbial discovery and outbreak response, has mentored and trained more than 35 students and post-doctoral fellows and leads a team of over 65 investigators, post-doctoral fellows, and research and support staff in New York City and another 150 across the world. In the 1980s, Dr. Lipkin identified AIDS-associated immunological abnormalities and inflammatory neuropathy, which he showed could be treated with plasmapheresis, and demonstrated that early life exposure to viral infections affects neurotransmitter function. He was the first to use purely molecular methods to identify an infectious agent, and pioneered the use of high throughput sequencing in pathogen discovery. He and his team implicated West Nile virus as the cause of the encephalitis epidemic in New York in 1999 and have discovered or characterized more than 1,000 infectious agents. Dr. Lipkin assisted the World Health Organization and China during the 2003 SARS outbreak, Saudi Arabia in addressing the challenge of Middle East Respiratory Syndrome, and the Indian government on the current unexplained encephalitis outbreak in Uttar Pradesh. He also directs large programs focused on autism and chronic fatigue syndrome wherein gene-environment interactions, such as infection and intoxication, are postulated to cause disease. Dr. Lipkin has been featured in several publications and was the chief scientific consultant for the Soderbergh film “Contagion.”

SPEAKER BIOS



BECKY MCNEIL, PhD

Research Statistician, RTI International

Dr. Becky McNeil (Durham, NC) was born in Michigan, and has lived since the early '90s in various locations in the Carolinas, Georgia, and Florida. She holds a PhD in biostatistics from the Medical University of South Carolina, with cross-training in epidemiology and bioinformatics, and completed her undergraduate studies in math and biology at Western Carolina University in the beautiful mountains of Cullowhee, NC. Becky is a lead biostatistician in the Center for Clinical Research Network Coordination at RTI International, where she works with a mix of observational and interventional projects. Prior to joining RTI, she worked with the Department of Veterans Affairs (Durham, NC) and the Mayo Clinic (Jacksonville, FL). Her research interests include methods for multivariate and longitudinal data, and methods for improving the quality and reproducibility of scientific research.

Beyond work, she is married, loves animals, and is an avid gardener with a preference for native plants and open-pollinated/heirloom varieties that are well-adapted to the Southern and mid-Atlantic climate. Her indoor recreational activities most often include cooking and learning selected fiber arts, such as crocheting and loom weaving.



DAN PETERSON, MD

President, Sierra Internal Medicine at Incline Village

Dr. Daniel Peterson is president of Sierra Internal Medicine of Incline Village, established in 1981. Dr. Peterson was a treating physician at Incline Village during an outbreak of CFS that began in 1984 in the Lake Tahoe region. In 1995, Dr. Peterson and other investigators began a 10-year follow-up study on patients seen during the outbreak. The study results were published in 2001 by the *Journal of Chronic Fatigue Syndrome*. Dr. Peterson founded Simmaron Research Inc. in April 2011 to fund and conduct pilot studies in collaboration with others to further advance the discovery of diagnostic markers and potential treatment options for CFS patients. He was also part of the founding board and is a past-president of the International Association for CFS/ME, a professional organization advocating for the interests of CFS researchers and clinicians worldwide. Dr. Peterson received the Rudy Perpich award in 2003, was honored with the Nelson Gantz Outstanding Award from IACFS/ME in 2007, and was commended by the Assembly and Senate of the State of Nevada for his work and dedication to persons with CFS in 1999.

He graduated from the University of Rochester School of Medicine, Rochester, NY in 1976 and was an intern and resident at the University of Utah Medical Center from 1976 to 1979. In 1979, he became a diplomat of the American Board of Internal Medicine.

SPEAKER BIOS



PETER ROWE, MD

**Director, Children's Center Chronic Fatigue Clinic,
Johns Hopkins; SMCI RAC Member**

Dr. Peter Rowe is a professor of pediatrics at the Johns Hopkins University School of Medicine. He is the inaugural Sunshine Natural Wellbeing Foundation Professor of Chronic Fatigue and Related Disorders and serves as the director of the chronic fatigue clinic at Johns Hopkins Children's Center. His areas of clinical expertise include chronic fatigue syndrome, fibromyalgia and orthostatic intolerance. Dr. Rowe was the first to describe the relationship between chronic fatigue syndrome (CFS) and treatable orthostatic intolerance syndromes, as well as the association between Ehlers-Danlos syndrome and CFS. He is a member of the American Pediatric Society, the Society for Pediatric Research, the Canadian Pediatric Society, the American Academy of Pediatrics and the Academic Pediatric Association.

After receiving his undergraduate degree from the University of Toronto, Dr. Rowe earned his medical degree at McMaster University Medical School in Ontario. He completed his residency in pediatrics at Johns Hopkins and performed his fellowship with the Robert Wood Johnson General Pediatric Academic Development Program.



ELIZABETH UNGER, MD, PhD

**Chief, Chronic Viral Disease Branch, Centers for
Disease Control and Prevention**

Dr. Elizabeth Unger is the Chief of the Chronic Viral Diseases Branch (CVDB) in the Division of High-Consequence Pathogens and Pathology (DHCPP), National Center for Emerging and Zoonotic Infectious Diseases (NCEZID), Centers for Disease Control and Prevention (CDC). Dr. Unger is responsible for guiding research and public health studies encompassing molecular pathology and epidemiology of human papillomavirus-associated diseases and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). As part of her CDC tenure, Dr. Unger has served as a consultant on human papillomavirus issues for the World Health Organization and the Federal Drug Administration (FDA) and as a consultant on ME/CFS to FDA and NIH.

Dr. Unger received her undergraduate degree in Chemistry at Lebanon Valley College, Annville, PA and her PhD and MD from the University of Chicago. She completed her residency and fellowship in anatomic pathology at the University of Chicago and Pennsylvania State University Hershey Medical Center. During this time, Dr. Unger developed a practical method of colorimetric in situ hybridization. This work led to interest in tissue localization of HPV and ultimately to her initial appointment to CDC in 1997 to pursue molecular pathology of HPV and CFS.

SPEAKER BIOS



DERYA UNUTMAZ, MD

**Professor, The Jackson Laboratory for Genomic
Medicine**

@Derya_

Dr. Derya Unutmaz has been Professor at Jackson Laboratory for Genomic Medicine, in Farmington, CT, and affiliated Professor at UConn School of Medicine since 2015. In 2006, he began at NYU School of Medicine as a tenured Professor of Microbiology, Medicine and Pathology. Previously, he was an assistant professor at Vanderbilt University, where he received tenure. He is the Immunology section editor of *PLoS One* journal, serving in that capacity since its inception, and has published more than 100 original papers, including in *Nature* and *Science*. His lab developed various genetic methods and assays to interrogate human T cells derived from healthy and patient subjects. These approaches led to discoveries on disruptions in human T cell subsets in disease states, such as HIV infection. In recent years, he has shifted his focus to understand disruption of immune regulation during a variety of chronic diseases, including cancer, chronic fatigue syndrome, and aging.

Dr. Unutmaz received his MD from Marmara University Medical School, Istanbul, Turkey. He completed post-doctoral studies at Novartis, Switzerland and at NYU.



VICKY WHITTEMORE, PhD

**Program Director, National Institute of Neurological
Disorders & Stroke, National Institutes of Health**

Dr. Vicky Whittemore is a Program Director in the Synapses, Channels and Neural Circuits Cluster at the National Institutes of Health. Her portfolio includes grants that focus on understanding the underlying mechanisms of the epilepsies and Sudden Unexpected Death in Epilepsy (SUDEP). In addition, Dr. Whittemore works closely with Walter Koroshetz, MD (Director of NINDS) to coordinate the Trans-NIH ME/CFS Working Group. She is also the NIH representative to the HHS CFSAC. Dr. Whittemore was on the faculty of the University of Miami School of Medicine in The Miami Project to Cure Paralysis prior to working with several non-profit organizations including the Tuberos Sclerosis Alliance, Genetic Alliance, Citizens United for Research in Epilepsy (CURE), and the National Coalition for Health Professional Education in Genetics (NCHPEG). She also just completed a four-year term on the National Advisory Neurological Disorders and Stroke Council.

Dr. Whittemore received a PhD in anatomy from the University of Minnesota, followed by post-doctoral work at the University of California, Irvine, and a Fogarty Fellowship at the Karolinska Institute in Stockholm, Sweden.

SPEAKER BIOS



RICK L. WILLIAMS, PhD

Principal investigator for Medical & Public Health Research, RTI International

Dr. Rick L. Williams has more than 35 years of experience as a statistician working in public health-related research. He is actively involved in the development and application of analysis methods for correlated data and for sample survey data. Dr. Williams is skilled in the design of clinical trials, population surveys and observational studies. He routinely leads the statistical activities of large studies and often serves as the overall project director. Dr. Williams has authored many research proposals, study reports, presentations, and refereed articles in publications such as *Biometrics*, *American Journal of Epidemiology*, and the *Journal of the*

American Medical Association. He frequently conducts workshops and training classes on the use of statistical analysis methods for cluster-correlated, longitudinal, or repeated measures data such as generalized estimating equations (GEE) for marginal models, hierarchical linear and nonlinear mixed models, and multilevel models.

Dr. Williams received an MS in statistics from Iowa State University and PhD in Biostatistics, with a minor in Epidemiology, from the University of North Carolina at Chapel Hill.

PARTICIPANTS AND OBSERVERS

Michel Silvestri, PhD

Head of Clinical Laboratory,
Gotland Region
SMCI RAC Member



Miriam Tucker

Freelance Science Writer
Contributing Writer, Medscape

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Former Special Advisor on CFS, HHS
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SMCI Board Member



Mary Dimmock, MBA
Formerly with Pfizer
SMCI Board Member

SMCI STAFF



CAROL HEAD, MBA

President

Ms. Head leads the Solve ME/CFS Initiative with an unparalleled passion as a champion for this disease. Before assuming leadership of the Solve ME/CFS Initiative, Carol served as the CEO of two companies in the private sector and, prior to that, was the vice president of marketing for two internet-based companies. She founded a non-profit organization that empowers impoverished entrepreneurs in the developing world and has served on three boards for national organizations supporting human rights for women. Carol was recognized by *O, The Oprah Magazine* as a “2017 Health Hero.” Carol is a person with ME/CFS. She has 30 years of business leadership experience and an MBA from Stanford University.



ZAHER NAHLE, PhD, MPA

Chief Scientific Officer & Vice President for Research

Dr. Nahle, an award-winning scientist, oversees the research and scientific portfolio at SMCI that includes the peer-review grant program for external investigators, specialized biobanking and patient registry platforms as well as numerous medical education initiatives for patients and healthcare professionals. He also directs a specialized investment program with medical centers, government agencies and industry partners to spark innovation and accelerate the discovery process in the ME/CFS disease space. Dr. Nahle is a frequent speaker at international conferences and serves on specialized committees at federal agencies, including the NIH and the CDC. He earned a PhD in Physiology and Biophysics from Cold Spring Harbor Laboratory/Stony Brook and an MPA from Harvard University, where he also completed a fellowship in public policy and management at the John F. Kennedy School of Government.



Emily Taylor, MA

Director of Advocacy & Public Relations



Carolyn Mayo

Director of Development



Allison Ramiller

Scientific Administrator



Mamie~Louise Anderson

Administrative & Development Coordinator



Diana Sagini

Development Coordinator

ABOUT SOLVE ME/CFS INITIATIVE

THE SOLVE ME/CFS INITIATIVE (SMCI) is the leading disease organization solely dedicated to solving ME/CFS. We are committed to making ME/CFS understood, diagnosable, and treatable. SMCI works to accelerate the discovery of safe and effective treatments, strives for an aggressive expansion of funding for research that will lead to a cure, and seeks to engage the entire ME/CFS community.

OUR WORK SMCI is a non-profit disease organization that works to accelerate the discovery of safe and effective treatments, strives for an aggressive expansion of funding for research that will lead to a cure and seeks to engage the entire ME/CFS community in research. Through scientific research and advocacy, SMCI serves patients and researchers alike, serving as an information center for the entire ME/CFS community, and enabling SMCI to make an even stronger case for federal government ME/CFS spending, by generating verifiable and large data sets with reliable metrics.

Filling Knowledge Gaps Through Original Research

SMCI designs and invests in innovative scientific studies to address severe knowledge gaps in ME/CFS. Priority areas include the fields of bioenergetics, neuroendocrine biology, and inflammation and immunity. Our partners in these pursuits are leading experts in the field of ME/CFS. SMCI has developed a portfolio of investments at some of the most prestigious medical centers and research laboratories in the United States and abroad.

Establishing a Patient Scientist Partnership Program for Diagnostic Testing and Clinical Applications This program facilitates patient participation in decision-making and defining research priorities.

Investing in Innovative Ideas Around the World: The Ramsay Awards This international program creates environments to attract, support and retain talent in the ME/CFS research community and helps awardees generate relevant data to compete for long-term federal funding, and facilitates collaboration and cross-pollination among researchers through the sharing of resources and access to additional programming and the organization's network.

Facilitating Connection and Partnerships: SMCI'S MeetME Travel Awards SMCI's MeetME Travel Awards fund junior scientists and researchers

from underrepresented groups to attend ME/CFS conferences and help build scientific networks by paying their travel expenses for ME/CFS-focused meetings. A goal of this program is to attract new researchers to the field.

Creating Reliable Electronic Record Systems, Data Management Platforms, Biobanking and Patient Registries Our new, state-of-the-art national registry for ME/CFS will enable clinical trials, further understanding of the natural history of this disease, and includes built-in options for data sharing and collaboration among patients, researchers, and other disease organizations. This also includes a repository of physical samples from patients to support the work of qualified researchers and accelerate discovery.

Driving Advocacy SMCI acts as an agent for change and unity in the ME/CFS community by focusing our efforts in advocating for policies, funding, and action. We meet with senior government officials, medical and industry leaders, and scientific pioneers; only a strong and multi-faceted coalition of stakeholders will effect change at the federal level. SMCI authors dozens of opinion and technical pieces addressing current ME/CFS affairs across the science, research, and policy landscapes. Also, we debunk fallacies and misinformation through our "No Spin Zone."



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 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 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 Enerivating 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 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



Solve ME/CFS Initiative

Leading the Fight
to cure ME/CFS

THANK YOU...

To all the colleagues who could not be with us due to travel,
scheduling, or space constraints,

To our partner in Genetic Alliance, Sharon Terry,

To the Robert Wood Johnson Foundation White Label PEER program,

To our collaborators at Metabolon and many other associates, and

To our many supporters and partners—there are simply too many to list.



Robert Wood Johnson Foundation

*This program is dedicated to all people with ME/CFS
worldwide and their families.*