



The Solve ME/CFS CHRONICLE

SPRING 2017

7 Research Lessons from the Lab Bench of Dr. Nahle

In his first State of the Union address, President George Washington encouraged funding for science.

Our nation's first president told the first Congress in 1790, just prior to the creation of the first federal budget *"...that there is nothing which can better deserve your patronage than the promotion of science and literature. Knowledge is in every country the surest basis of public happiness. In one in which the measures of government receive their impressions so immediately from the sense of the community as in ours it is proportionably essential."*

Such esteem and priority bestowed on knowledge, scientific knowledge especially, has always been a guiding principle in the United States and embraced by our founders. That conviction was given form in 1863 when the National Academy of Sciences was created during the presidency of Abraham Lincoln. President Lincoln was a patron of science and the first, and only, American president to have been granted a scientific patent for an invention. Many institutions, foundations and trusts spanning the fields of science and engineering later ensued and flourished, including those supported by philanthropy and patronized by individuals blessed with vision and abundance.

"Such esteem bestowed on scientific knowledge has always been a guiding principle in the United States..."

Perhaps, the spirit of scientific innovation was most clearly immortalized through the words and actions of President John F. Kennedy in 1962 while describing his ambitious plans to use science for space exploration, *"We choose to go to the Moon in this decade and do the other things, not because they are easy, but because they are hard; because that goal will serve to organize and measure the best of our energies and skills, because that challenge is one that we are willing to accept, one we are unwilling to postpone, and one we intend to win..."*.



Dr. Zaher Nahle, featured for his passion for science

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A Letter from Our President Carol Head



Carol Head, President and CEO

Dear Friends,

I'm often asked how SMCI can be a leading research organization when we are not affiliated with a medical research university. This question always surprises me. The most effective non-profit disease organizations are standalone non-profits that, like our organization, exist for only one reason: ***to serve patients suffering with a disease we care passionately about.***

Just look at Michael J. Fox Foundation for Parkinson's research, the ALS Association or Susan G. Komen Foundation for breast cancer research. Although our budget is miniscule in comparison, we share this approach: **none of these organizations is affiliated with a single university. Instead, we each fund and perform research using highly expert scientific knowledge of the disease, with funds flowing to the universities where the most creative, promising research is being done.** As our disease is especially complex and in the early stages of biological understanding, our organization has the flexibility to invest dollars where they are most needed. We are currently invested in ME/CFS research studies at 9 universities in 4 countries.

As we are not within a single academic institution, we are free to draw from the ME/CFS disease knowledge, creativity, and focus of our Chief Scientific Officer, Dr. Zaher Nahle. We strengthen our knowledge with input from our Research Advisory Council—a virtual “who’s who” of experts in the ME/CFS field—including Dr. Kamaroff of Harvard, Dr. Montoya of Stanford, Dr. Hanson of Cornell, Dr. Susan Levine, and Dr. Rowe of Johns Hopkins.

There are additional advantages as a disease-research organization unaffiliated with a single university. For instance, most universities take a significant percent of donations to cover overhead, which can be well over 60 percent. Also, we are free of the academic “publish or perish” motivation that can inhibit transparency, genuine partnership, and data sharing. As a non-profit, we retain leverage to negotiate low costs for much of our research work and, because we work with numerous academic institutions, we can facilitate and create collaboration between them.

Our organization is fundamentally structured so that our supporters' donations get much more “bang for the buck,” funding the most promising research, wherever it may be.

In addition to our research work, we also emphasize advocacy and it's an area we've recently strengthened. Why? Because it's imperative to keep the pressure on federal decision-makers to fund research, educate physicians,

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and fulfill other patient needs that **only** the federal government has the power to do.

Advocacy moves at a faster pace than medical research and is also much more visible. But, make no mistake: we are first, foremost and always a medical research organization and our spending budget reflects that unwavering commitment. **We know that the best way to serve patients is to solve this awful disease.**

We're grateful that you are part of our growing community of patients and their loved ones, now over 28,000 strong. We share our struggles and pull together as we work to restore the vibrancy and fullness of lives that are tragically diminished by ME/CFS.

And, as always, I see the photos below on the wall in front of me every day. I never forget whom we serve.

With great affection for all courageous ME/CFS patients,

Onward!



Carol Head
President and CEO
Solve ME/CFS Initiative



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7 Research Lessons from the Lab Bench of Dr. Nahle (cont'd)

That indomitable spirit that hinged on science in the pursuit of challenging endeavors put the first human on the face of the moon, saved millions of lives from deadly diseases, and prevented incalculable disasters around the world. Science has forever changed the way we live on this planet and altered the patterns in which we interact with one another. Every single day, the science of medicine in particular brings health and wellness to millions of its beneficiaries. Biomedical research brings hope to millions of others still awaiting a breakthrough to help them overcome an illness or improve the life of a loved one.

I underscore throughout our communications the value of science and highlight the severe knowledge gaps existing in our disease space. Many of our problems in ME/CFS (*some shown to the right*) would be reduced, even eliminated, with a better understanding of the scientific basis of ME/CFS.

In the last issue of *The Solve ME/CFS Chronicle* (Winter 2017), we highlighted some of our scientific work in the pipeline using a “dashboard” of current studies. We believe that these will fill gaps in knowledge and spark additional work by us and others (*see graphic on facing page*).

Nonetheless, we are assisting, even shaping, national initiatives in the disease space through fair and unbiased participation in projects

that will create value in pre-clinical, clinical and translational ME/CFS research. As we expand our work and grow further our scientific portfolio,

Misinformation and antagonism

Lack of critical mass of researchers

Insignificant funding for research

Several diagnostic criteria

Elusive etiology

Lack of FDA approved drugs

Absent Pharma investment

Insurance and ICD coding debacles

Hard career path for researchers

No feasible biomarkers

Poor grasp of natural history

Minimal patient support

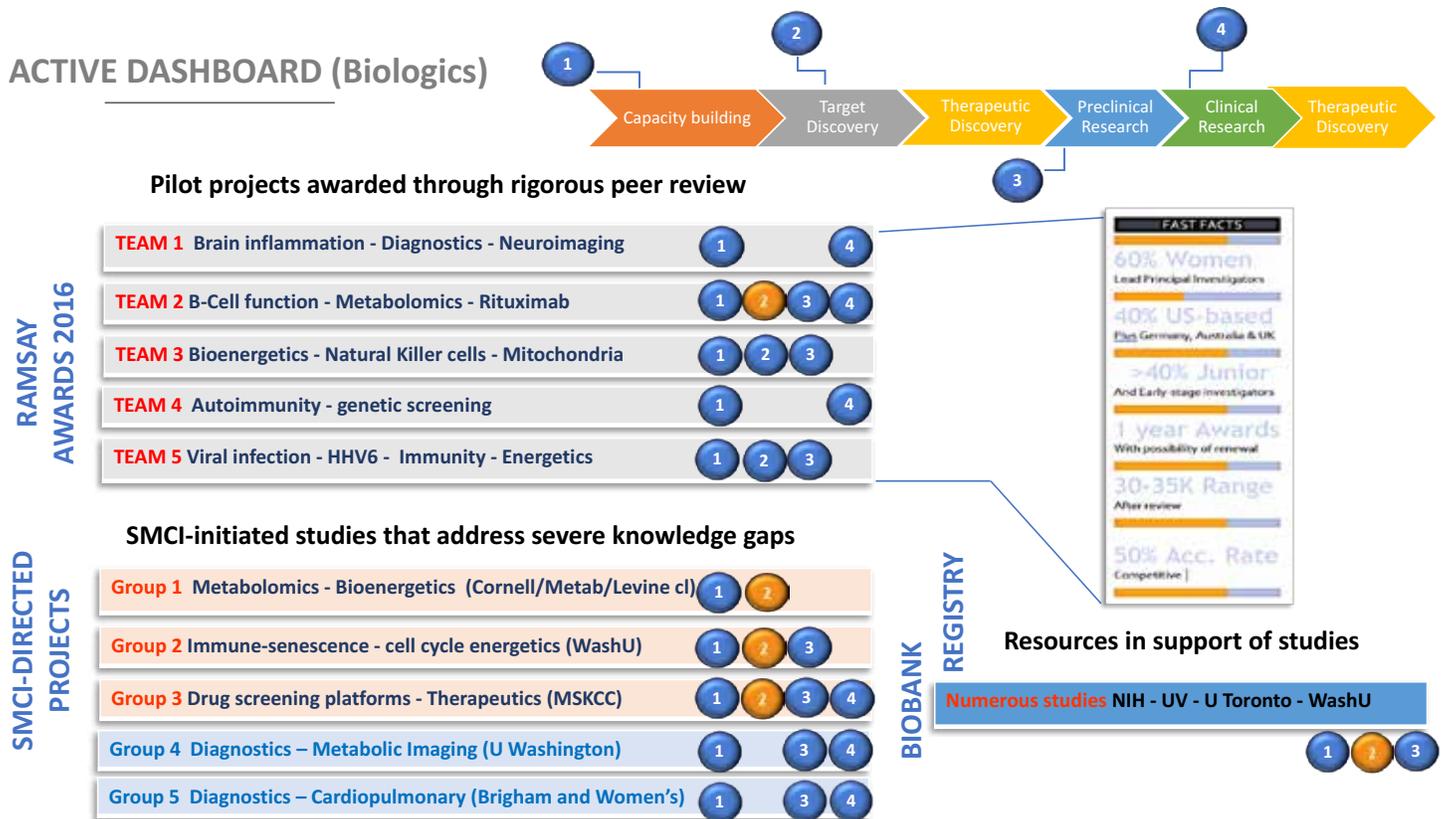
I wish to share a few thoughts about my own experience at the scientific laboratory bench and some lessons I picked up along the way:

1. Not every finding is a breakthrough: It is human to be excited about a scientific result but objectivity is at the core of scientific endeavors. Preliminary results, even publishable ones, should not be exaggerated (nor minimized either). Using the right tone when sharing data, especially in public, is more beneficial in the long run. It is what differentiates an article in a scientific journal from a sensational

column in a gossip magazine at the checkout isle. Scientific findings must be qualified up-front with all study assumptions, limitations and caveats.

- 2. Perseverance is essential:** Not every apple that falls from a tree can trigger a light bulb and inspire a new theory. And while some can be as perceptive a Newton himself, most of us regular folks encounter achievements as a result of sustained and laborious work day in and day out, a process that is often mired in many failures and setbacks. The discipline of seeing things to completion in experimental sciences – and not giving up – when things get rough is an invaluable characteristic.
- 3. Flexibility can save your life:** It is counterproductive to be ardently dogmatic in experimental sciences, or in any of the sciences for that matter. The very best researchers I know keep an open mind and are often persuadable. They revise, evolve, and update their hypotheses constantly and are fearlessly adaptable. They are curious to learn from others and will accept criticism from reviewers or even from detractors. Inflexibility is the Achilles’ heel of the discovery process.
- 4. Context is the crucial factor:** What works in animal models or cell culture systems may not work in humans and vice versa. Scientific context is supremely important. As such, extrapolating

ACTIVE DASHBOARD (Biologics)



findings from one context to the other without proof can be misleading, even reckless. Space and time are always crucial elements too. I always ask myself the three basic W's "what", "when", or "where" anytime I find myself reading an article or examining a study.

- Intellectual diversity is critical:** The cross-pollination of ideas and the diversity of thoughts and opinions can be the best thing that happens to a scientific enterprise. Collaboration with interdisciplinary teams will add considerable insights and enable scientists to explore new avenues.
- The system is not perfect:** The scientific system in its current state is far from perfect. It is credit-based and not merit-

value-based. This is a nuanced and complicated topic that requires a deeper analysis. Suffice it to say that understanding the shortcomings of the system is important. A quick example that comes to mind is our attitude towards negative results. Little exposure is given to those findings although they can help us avoid unnecessary repetitions, saving us time and money.

- There is no substitute for quality:** This is self-evident. Cutting corners is not only improper but can be unethical. Reproducibility of the data—under the exact same experimental or clinical conditions—is a requisite marker of quality.

All of these principles certainly apply to the field of ME/CFS research. Because our scientific research resources are so scarce at SMCI, as they are everywhere in the ME/CFS research field, none of us has time or money to waste by deviating from these truths about the research process.

SMCI's research program, using the expertise of our Research Advisory Council, supporting the work and collaborating with ten research teams in four countries, demonstrates our commitment to genuine, collaborative scientific progress. For the many ME/CFS patients who struggle with this awful disease, the stakes are very high. We use the principles above to move forward with rigor, passion and speed—given the limited resources at our disposal. ■

A Letter from Zaher Nahle, PhD, MPA

Dear Friends,

April 22nd was an important day for two glorious reasons. On the one hand, it commemorated the all-too-important Earth Day. On the other hand, it was the day in which hundreds of thousands of people marched for science in the United States and around the world. Crowds massed that Saturday to support evidence-based investigations and the scientific pursuit of knowledge in all its forms, especially biomedical research.

I was itching to be in the crowd that day. Yet, I spent that whole weekend glued to my office chair writing away. I was completely dedicated to my contributions to no less than seven diverse grant applications to the National Institutes of Health (NIH) in response to their recent solicitation for the ME/CFS consortiums. The deadline of these grant applications was fast approaching and hundreds of pieces needed to be assembled and coordinated with different groups before May 2nd, the due date set forth for this long awaited NIH solicitation.

The privilege of participating in so many different applications organized by many teams who reached out to the Solve ME/CFS Initiative (SMCI) for partnership and collaboration was truly humbling. Our participation was requested on both Collaborative Research Center (CRC) and Data Management and Coordinating Center (DMCC) proposals. From the beginning, we strived to make SMCI a trusted scientific partner and a credible resource for everyone creating value in our disease space. Without bias or prejudice, our policy is to assist in every way for the benefit of our cause and not for credit.

Judging by the information I have so far, I expect the response to these “centers” grants to be extraordinary in count and quantity. Notably, I suspect that our field will be infused with new blood as well. In the last three weeks alone, I have coordinated, supported, and collaborated through strategy sessions with more than dozen world-class experts in epidemiology, biostatistics, clinical care, and management. All of these



Zaher Nahle, Chief Scientific Officer and Vice President for Research

exceptional specialists are applying their talent for the **first time** to the ME/CFS field. This in and of itself is a heartening fact.

So, in spite of the current climate of proposed federal budget cuts and uncertainty, I am encouraged by what I am witnessing in the days leading to this important milestone for the field of ME/CFS research. As always, we are standing by to assist the scientific community as they consolidate their ideas and streamline their research studies through the federal funding process. We look forward to the commencement of the review process this month. A date that will coincide with the launch of our own open grant competition, the Ramsay Awards. These seed grants in basic, preclinical, clinical and epidemiology research will continue to nurture and expand research into ME/CFS.

We wish all applicants the best of luck.

A handwritten signature in black ink, appearing to be 'Zaher Nahle'.

Sincerely,

Zaher Nahle, PhD, MPA
Chief Scientific Officer and Vice President for Research

SMCI-Directed Research Study Explores Immuno-Senescence

Another SMCI-Directed Research Study is being conducted in partnership with Dr. Sheila Stewart of Washington University in St. Louis and in collaboration with Dr. Masashi Narita of the Narita Group at Cambridge University in England. This study explores immuno-senescence and cell-cycle analysis in the pathophysiology (or functional changes that accompany a particular syndrome or disease) of ME/CFS.

As described by Dr. Stewart, recent work has shown patients with ME/CFS to have **alterations in immune cells** as well as in the p38 Map Kinase (p38MPAK), a key pathway critical for proper cell function.

Whether these observations are related to the symptoms associated with, is the cause of, or simply has a correlation to ME/CFS remains to be understood.

Immuno-senescence refers to the interplay between aspects of **immunity**, either localized or systemic, and those of **senescence** cells. Senescence, from Latin, means “to grow old” and refers to the biological process of aging. In other words, it refers to cells that have stopped duplicating or dividing earlier than is healthy for their age.

Factors known to trigger premature senescence include:

- Oxidative stress (stress caused by improper metabolic processing)
- Telomere dysfunction (telomeres act as a type of endcap for DNA, and their dysfunction contributes to diseases like cancer)

- DNA mutations/damage (which can be caused by irradiation and many other factors)
- Oncogenic pressure (improper functioning of cancer-causing genes)

Intriguingly, p38MAPK activation is an important component in the alteration of a tissue’s extracellular matrix (ECM), the function of local immune cells, and the growth and spread of tumor cells. Given the role senescence cells play in these different disease settings, it is possible that their activation contributes to symptoms in ME/CFS patients.

Results from this study have the potential to be quite significant and may include:

- Expanding the role of cellular senescence in ME/CFS and providing additional context and clarity
- Identifying specific biological signatures from well-characterized patients
- Developing mechanistic insight into comorbidities (other conditions) associated with ME/CFS
- Uncovering potential new biomarkers that could help with rapid and effective diagnosis

- Comprehending signaling pathway interactions involved in the disease
- Supporting existing projects and hypotheses by our research organization and others as well as generating new hypotheses
- Classifying patients based on molecular alterations
- Developing precision medicine profiles, categories, and subcategories in ME/CFS with additional patients

We expect that the initial phase of this new project will be completed in 2017, with results requiring additional investigation.

Dr. Zaher Nahle, SMCI’s chief scientific officer and vice president for research, stated, “This is an important investigation addressing an area of biology in ME/CFS that is still ill defined. And we could not be more excited about our partnership with Drs. Stewart and Narita, who are leading pioneers in this field. It is our hope that this study will reveal signatures and identifiers pointing toward **biomarkers** and also the **molecular basis** for the disease and its subgroups. The results from this study will help us to hone or validate our hypotheses. And, what’s more, we will be able to seek new partnerships and assist the work of others by publishing these results alongside our collaborators.” ■

Two SMCI-Funded Studies Published

The Solve ME/CFS Initiative facilitates all aspects and development phases of the research field in ME/CFS, including funding key studies which will contribute to the field. It is so rewarding to share with you the results of two of those investments published earlier this year.

“Neural consequences of post-exertion malaise”

The Solve ME/CFS Initiative is proud to support the research of Dr. Dane Cook, Co-Director of the Exercise Psychology Laboratory and Director of the Marsh Center for Research in Exercise and Movement at the University of Wisconsin-Madison, as he continues his work on post-exertional malaise (PEM) that was launched with the help of a Solve ME/CFS Initiative award. PEM has been described as a debilitating exacerbation of the entire constellation of ME/CFS symptoms following even mild physical or mental exertion. PEM is the “hallmark” symptom of ME/CFS. Clinical descriptions and results from research strongly suggest that PEM affects multiple physiological systems, consistent with the evidence that ME/CFS is a chronic multi-system disease.

In a recent SMCI-funded study from Dr. Cook, brain imaging was incorporated to examine the neural consequences of PEM. Participants were asked to perform 30 minutes of exercise on a bicycle at 70% of their estimated peak heart rate. Prior to and 24 hours post-exercise, detailed symptom data were gathered, blood samples collected, and participants

performed both non-fatiguing and fatiguing cognitive tasks while collecting functional brain data. Preliminary results from the ongoing studies suggest that, consistent with previous studies, submaximal exercise results in large increases in a host of symptoms, such as fatigue, pain and difficulty with attention. Moreover, this data suggest that cognitive performance worsens 24 hours post-exercise and the worsening is accompanied by increased brain activity compared with controls. This study was able to “provide objective evidence of the detrimental neurophysiological effects of post-exertion malaise.” Studies like this one will help to define the neural behavioral components of PEM to improve future research and diagnosis.

Continuing work is now concentrated on determining whether changes in brain function are related to peripheral markers of PEM, that is, upregulated gene expression. This work is evolving into a promising collaboration among Dr. Cook at the University of Wisconsin-Madison, Dr. Alan Light at the University of Utah and Dr. Gordon Broderick at



Dr. Dane Cook, Marsh Center for Research in Exercise and Movement at the University of Wisconsin-Madison

Nova Southeastern University—all previous recipients of Solve ME/CFS Initiative research funding and support. This new, multi-center collaboration incorporates gene expression data, neuroimaging data, as well as additional physiological systems to determine the interactions among them in the pathophysiology of PEM. SMCI is so pleased to see the early results of our research investment in this publication.

Epigenetic function study in ME/CFS

The Solve ME/CFS Initiative has been supporting the work of Dr. Patrick McGowan at the University of Toronto in the area of epigenetic regulation for a number of years. Epigenetics is the research field that studies changes in the regulation of genes that are influenced by non-genetic or external factors, such as chemical imbalance, nutrition, and the environment.

We reported earlier on results from these investigations, indicating that a number of epigenetic markers are associated with the response to glucocorticoids and certain ME/CFS symptoms. Now, the study is published under the title of “Epigenetic modifications and glucocorticoid sensitivity in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)” in the medical journal *BMC Medical Genomics*.

Building on previous work regarding DNA mechanisms (called methylation) that control gene expression, this study detected 12,608 sites with measurably different methylation processes between ME/CFS patients and healthy controls. Some of these differences were related to quality of life scores. One area specifically (called glucocorticoid sensitivity) “may be important as biomarkers for future clinical testing,” according to the publication.

The researchers write, “Modifications to epigenetic loci associated with differences in glucocorticoid sensitivity may be important as biomarkers for future clinical testing. Overall, these findings align with recent ME/CFS work that point towards impairment in cellular energy production in this

patient population.” This early work may pave the way to a deeper understanding to the potential genetic and cellular level dysfunction which leads to ME/CFS.”

For a previous study by this group on the subject, also primarily funded by SMCI, please see “DNA Methylation Modifications Associated with Chronic Fatigue Syndrome,” Published in August 11, 2014 as well as two studies from the Centers for Disease Control and Prevention (CDC) by Falkenberg VR et al, “Acute psychosocial stress-mediated changes in the expression and methylation of perforin in chronic fatigue syndrome” (*Genet Epigenet.* 2013 Jan 28;5:1-9) and “Functional genomics of serotonin receptor 2A (HTR2A): interaction of polymorphism, methylation, expression and disease association” (*Neuromolecular Med.* 2011 Mar;13(1):66-76.) ■



Dr. Patrick McGowan, University of Toronto Scarborough

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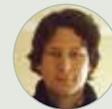
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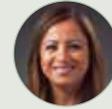
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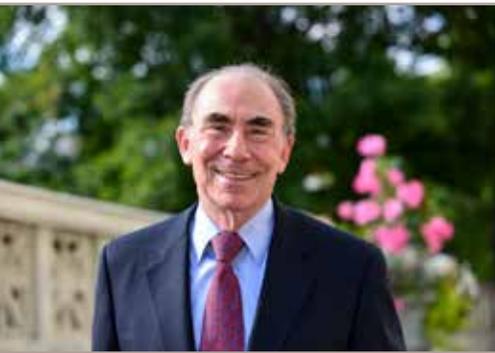
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Dr. Komaroff—A Leader in Medicine and ME/CFS Research

DR. ANTHONY KOMAROFF is a talented physician who has accomplished numerous feats that justify his title of Simcox–Clifford–Higby Distinguished Professor of Medicine, Harvard Medical School; Senior Physician, Brigham & Women’s Hospital. We are fortunate to have Dr. Komaroff on our Research Advisory Council at the Solve ME/CFS Initiative, driving our work into groundbreaking research. We had the chance to speak with him recently to delve into his motivations and aspirations, as well as his prognosis for the future of ME/CFS.



It was in the mid 1970’s that ME/CFS peaked Dr. Komaroff’s interest. Still an unknown disease at the time, ME/CFS was staring him in the face when a patient with a presumed “persistent case of Mononucleosis” had come to see him.

“In my clinical experience, I had seen plenty of cases of mono and every one had gotten back to full health, but this was very odd and I wanted to study it.”

Finding it hard to study something with no history and with no previously documented cases, he tabled his investigation until a few years later when he was again confronted with this mystery as several patients came into his practice with similarly unusual illnesses. They surely didn’t have mono and this unknown type of illness that continued for months and months compelled Dr. Komaroff to take action. “There’s definitely something here, it’s not in any of the textbooks and I want to study it,” Dr. Komaroff reflected. At the same time, people at the NIH and doctors from Atlanta and Denver were also noticing cases like this. “We found each other, we began talking and sharing notes, and finding that our experiences were very similar. And that’s when I said, ‘ok, I am going to devote time to this’ not only as a clinician and as a doctor, but also as an investigator.”

And so, he did. “Over the last 35 years that I’ve been studying ME/CFS and taking care of patients with this disease, we’ve moved from utter and total ignorance and widespread disbelief, even in the validity of the illness, to a situation where we now know an awful lot about what is going on in the body of people with this illness.” Dr. Komaroff was a supporter of SMCI back in its infancy in 1987, “I’ve been close to the organization since its inception. I’m a big supporter of foundations that focus on an important problem, generate interest in it, generate political action, and raise money to both do research and to educate the public.”

Recently, when given a mild break from his hectic professional life, he jumped at the opportunity to join the SMCI Research Advisory Council (RAC) where he provides his expertise on which projects our organization should pursue to defeat this disease. In conjunction with our esteemed council members, he works to “identify important areas that need more attention and identify people with the skills to pursue those important questions. This helps the staff of this organization so we can focus our extremely limited resources on what appears to be the greatest opportunity to the scientific board.” Dr. Komaroff also understands the importance of prominent distinguished individuals, such as himself, joining organizations like SMCI. Their presence pushes this horrible disease, affecting millions, into the public’s consciousness and into the federal budget. “Members of the RAC, including myself, bring credibility. We are a reason for other people, who are very good scientists but who know nothing about the illness, to say, ‘hmm, I’m going to listen to this, maybe there’s something I need to know, something I can contribute to solving the problem.’”

How has the ME/CFS space evolved? More importantly, what does the future hold? Dr. Komaroff delivered a very positive prognosis. “To me there’s been enormous progress, but as is true with most diseases, we know a lot about what’s going wrong with the body, but we don’t have a perfect understanding of *why*. But we’ve made a

What's in a Brain?

From our partners at the Brain Donor Project and in partnership with the National Institutes of Health

Many patients are interested in helping future generations know more about treating and/or preventing Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). If you are among them, here's something you may want to consider: making arrangements **now** to donate your brain when you die.



There is an urgent need for brain donation for a variety of neurological disorders, including ME/CFS. Breakthroughs in neuroscience require this precious resource, for which there simply is no substitute. And, there are many imaging studies that indicate that the brains of ME/CFS patients have unique characteristics which warrant further study and understanding.

The Brain Donor Project (www.braindonorproject.org) is an innovative not-for-profit that was developed

to make high quality, well-characterized brain tissue available for neurological researchers. Their focus is on raising awareness of the critical need for this precious tissue and on simplifying the process for brain donation upon death. The Solve ME/CFS Initiative is so proud to partner with The Brain Donor Project in this effort. Since the NIH has identified a need for the brains of patients who've suffered with ME/CFS to further their research goals, we're anxious to help potential donors understand what's at stake and potentially recruit additional donations for ME/CFS research.

More has been learned about the human brain in the last 20 years than in all of recorded history, but there is so much yet to discover, especially when it comes to a highly perplexing disorder like ME/CFS. You may not be aware that

- Signing up to be an organ donor does **not** mean your brain is included. Separate arrangements need to be made for brain donation.
- Donating your body for anatomical study does **not** mean your brain will be used for neurological research. Again, separate arrangements are needed.
- People who have not been diagnosed with ME/CFS can help, too. Control brains are just as valuable.

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Dr. Komaroff—A Leader in Medicine and ME/CFS Research (cont'd)

lot of progress. If I had to bet, I would say that within 10-15 years there will be some treatments that are highly effective, if not curative. And we will understand even better than we do today what's going wrong in the body and *why* it's going wrong."

SMCI feels confident working with highly talented and determined individuals, like Dr. Komaroff, that we can reach our goals together of a solution to ME/CFS. **"There are a number of different groups that focus on ME/CFS and, over the years since the early 1990s, I believe that the Solve ME/CFS Initiative has been the most effective in all areas; in supporting research, in educating elected and federal officials, and raising**

funding for this illness. No other organization in the country has been as effective as this one."

Up next for Dr. Komaroff, The Precision Medicine World Conference on May 24, where he will be a featured speaker in a panel led by SMCI Chief Scientific Officer Dr. Zaher Nahle. This conference is a major forum for the exchange of information in health care and biotechnology. Dr. Komaroff explains, "We have an opportunity to interest an enormous amount of really talented people who might see something in this illness that attracts them and makes them believe they can apply their talent to solving it." ■

2017: The Advocacy Road So Far...

In the last issue of the Chronicle, the article “SMCI Continues Its Work to Drive Federal Action for ME/CFS” outlined a clear plan of action for our advocacy work in 2017. We are pleased to report we have met those goals and beyond in March, April, and May.

MARCH: WEATHERING THE STORMS OF WASHINGTON, DC AS SMCI MEETS WITH 30 SENATORS AND OFFICES TO FIGHT FOR RESEARCH AND PATIENTS

Beginning in January, our team began crafting our strategic approach to the Congressional appropriations process for fiscal year 2018, which begins October 1, 2017. The big-picture goal of these actions is to be proactive in the budget conversation and avoid the reactive scramble to preserve funding experienced in previous years.

BACKGROUND: The funding process is an annual event. Congress is tasked with producing a budget resolution and 12 appropriations bills for each federal fiscal year. The process generally begins in February with the formal submission of the President’s budget request. Congress initially responds to the request with a budget resolution which establishes the total level of discretionary funding (known inside the beltway as the “302a allocation”). Through March and April, Congress responds in the form of hearings and markups of those 12 appropriations bills which divide up the 302a allocation and set policy targets in the process through committee reports that accompany each of the 12 appropriations bills.

The SMCI strategic planning process identified three key targets for the “appropriations push” during our March visits:

1. A request to include more assertive instructions to key federal agencies regarding ME/CFS in the fiscal year 2018 appropriations committee report
2. A request for additional funds in the CDC Chronic Fatigue Syndrome program, specifically to fund medical education and epidemiological research, and
3. Identify a potential well-placed Senate champion who would help return ME/CFS into the eligible peer-reviewed medical research program under the Congressionally Directed Medical Research Program (a potential new source of federal funds for ME/CFS, outside of NIH).

To accomplish these goals, SMCI developed a target list of 50 Members of Congress, Congressional Committees, and federal agencies. SMCI was successful at securing meetings with 30 of the 50 targets from March 14 through March 16, 2017 with the assistance of local constituent patient advocates.

IN MARCH, SMCI MET WITH...

Senator Martin Heinrich (NM)
 Senator Ed Markey (MA)
 Senator Elizabeth Warren (MA)
 The Office of Senate President Pro Tempore Orrin Hatch (UT)
 The Office of Senator Patty Murray (WA)
 The Office of Senator Bill Cassidy (LA)
 The Office of Senator Diane Feinstein (CA)
 The Office of Senator Mark Warner (VA)
 The Office of Senator Roy Blunt (MO)
 The Office of Senator Richard Burr (NC)
 The Office of Senator Tammy Baldwin (WI)
 The Office of Senator Lamar Alexander (TN)
 The Office of Senator Kirsten Gillibrand (NY)
 The Office of Senator Catherine Cortez Masto (NV)
 The Office of Senator Richard Durbin (IL)
 The Office of Senator Al Franken (MN)
 The Office of Senator Chris Van Hollen (MD)
 The Office of Senator Kamala Harris (CA)
 The Senate Committee on Health, Education, Labor, and Pensions (HELP)
 The Senate Committee on Appropriations
 The Senate Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and related agencies
 The Office of Congresswoman Zoe Lofgren (CA)
 The Office of Congresswoman Lucille Roybal-Allard (CA)
 The Office of Congresswoman Barbara Lee (CA)
 The office of Congresswoman Karen Bass (CA)
 The Office of Congressman Ted Lieu (CA)
 The House Committee on Appropriations
 The Health and Human Services Office of Women’s Health
 The designated federal officer for CFSAC
 The National Institutes of Health
 The Research!America Alliance

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Senator Martin Heinrich (NM) and SMCI Advocacy and Engagement Manager Emily Taylor

The meetings yielded positive results and our follow-up continues to secure our target objectives. As the appropriations process continues, our work will follow, ensuring that our key targets are included and carried in each part of the appropriations cycle until finalized in the Fiscal Year 2018 budget on October 1st, 2017.

MARCH AND APRIL: ADVOCACY IN ACTION AT THE NIH—DR. COLLINS STAYS ON AND MEETS WITH ME/CFS PATIENT

At the Genetic Alliance Conference this year, Dr. Zaher Nahle, Chief Scientific Officer and Vice President for Research, met with Dr. Francis Collins who announced at the conference that he has been officially invited by the new administration to continue as the Director of the NIH. SMCI is pleased about the continued leadership of Director Collins who has publicly pushed for an increased commitment to ME/CFS research with mixed results.

Director Collins and the chair of the Trans-NIH ME/CFS Working Group, Dr. Walter Koroshetz, jointly published a blog on the NIH website called “Moving Toward Answers in ME/CFS.” Given the recent presidential budget proposal to cut NIH funding, we are heartened by the signal in support of ME/CFS by these two NIH leaders.

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What’s in a Brain? (cont’d)

- Brain donation is not disfiguring—an open casket is still an option.
- There’s no additional cost to the family for brain donation.
- Arrangements must be made in advance of the time of death.

This is certainly a sensitive decision, and yet our organization has been asked about it many times. If you are interested in learning more about brain donation, starting the process is easy. Just go to braindonorproject.org to get answers to your questions about brain donation. If you’re ready to sign up, click on the “Sign Up” button at the top right, and complete the online form. You’ll be asked for contact information

and whether you’ve been diagnosed with a neurologic condition. If you are acting on behalf of a loved one with ME/CFS, it’s important to know that this must be done prior to the patient passing away.

Please indicate your diagnosis of ME/CFS when you sign up. Your medical records will later be used to verify.

Once you submit the form, you’ll hear from one of the brain banks within the NeuroBioBank of the National Institutes of Health (NIH) within ten business days. Consent and release forms will be delivered to you, along with instructions for your family. When that time comes,

your body will be transported to a medical or mortuary location (at no cost to your family) for the brain to be retrieved and shipped. Time is of the essence at this point, so making arrangements to register in advance helps ensure that all of these arrangements can be accomplished as quickly as possible and the body is then released for whatever funeral arrangements will take place.

If you are interested in making this precious gift, visit braindonorproject.org and start the process. Thank you for considering this invaluable gift as a way to advance science and understanding of ME/CFS. ■

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2017: The Advocacy Road So Far... (cont'd)

Just prior to writing this blog, Director Collins heard from two powerful advocates face to face which likely influenced his decision to write such a powerful public statement.

Those two advocates, Kat Fox and her husband, John, had the unique opportunity to sit down with the four biggest decision makers regarding ME/CFS at the NIH including Dr. Vicky Whittemore, Dr. Walter Koroshetz, Dr. Avi Nath, and Director Collins himself. Knowing this was a significant opportunity, Kat and John spent weeks preparing, using resources and information provided by the Solve ME/CFS Initiative and others in the advocacy community. With poise and armed with knowledge, Kat told the story of her journey with ME/CFS backed by strong research, genuine passion, and substantial understanding about the complexities of this disease. We applaud Kat and John for their dedication, perseverance, and top-notch advocacy work.

MAY: BUILDING COMMUNITY: ME/CFS ADVOCACY WEEK 2017

SMCI has partnered with #MEAction for ME/CFS Advocacy week in May 2017. This monumental advocacy effort included actions for every patient energy level and ability to join, from a social media post to a Washington, DC face-to-face with Congressional leaders. The goal of our efforts is to educate, empower, and deliver our message to Congress to take action on ME/CFS now!

The first training for local district advocates was held on April 19 and focused on setting up and preparing for local meetings with their Members of Congress. The next webinar training on May 3 covered everything volunteer advocates needed to know about how to conduct a local district meeting. The ME/CFS Advocacy week team provided talking points and insider tips for each patient to have a strong congressional meeting. Both webinars featured our own Director of Advocacy and Public Relations Emily Taylor and the Congressional Chair of #MEAction, Gail Cooper.

The Capitol Hill Storm Day took place on Wednesday May 17th organized by SMCI with our partners at #MEAction. Our ME/CFS Week Advocacy team, including SMCI president Carol Head and #MEAction co-founder Jennifer Brea, traveled to DC with 55 advocates representing 24 states, territories and districts to conduct over 85 meetings throughout the day with congressional offices. Additionally, SMCI and #MEAction sponsored a Capitol Hill briefing for congressional members and staff on May 18 featuring a clip from UNREST, Jennifer Brea's award-winning documentary recently showcased at Sundance. To further educate members of congress and their staff about this disease, Dr. Zaher Nahle presented about the ways federal action can bolster ME/CFS research, along with SMCI president Carol Head discussing policy.

For advocates and patients who were unable to travel, multiple local, phone-based, and social media actions are scheduled to ensure everyone's voice is heard. We targeted an additional 50 advocates to participate in a local district meeting with their congressional office. Also planned were social media campaigns in conjunction with May 12th, International ME/CFS Awareness Day. And, for the day of the Capitol Storm, patient advocates joined by phone in coordinated call-in efforts. ■

KEY DATES OF ME/CFS ADVOCACY

April 19	District Meetings Webinar Training
May 3	Conducting Congressional Meetings
May 8-11	Local Actions and District Meetings
May 11	CA State Senate Resolution Vote (<i>tentative</i>)
May 12	Int'l ME/CFS Awareness Day & Social Media Storm
May 16	Washington DC Advocate Training
May 17	Washington DC Capitol Hill Storm
May 18	Senator Markey Sponsored ME/CFS Briefing
June 2	Sacramento ME/CFS Awareness & Resolution Rally

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.

This quarter we feature community builder and ME/CFS patient DJ Gilbert. Over the past nine years, ME/CFS has taken DJ on a journey littered with trials and tribulations. DJ likened his experience to a hot air balloon ride.



“You begin to see things from a grander perspective. The green pastures become more vibrant. Your worries begin to fade, because from this view, it’s only you.”

As DJ gained experience living with ME/CFS, he progressively gained a broader understanding of how to live his life to the fullest. DJ feels that ME/CFS has taught him how to appreciate the little things in life that he missed before.

DJ decided to give back to others with ME/CFS when a friend pulled him into a new project: *The Spoonie Planner*. The spoonie concept is that one begins each day with a number of spoons and must decide how to “spend” those spoons for that day. It means making conscious choices, e.g. get the dishes done or let them sit while enjoying playing the piano. *The Spoonie Planner* is a calendar/planner created for the chronic illness community as a whole.

Aside from the all-encompassing “Spoonie” message, there were no labels. “And with no labels attached, I was ecstatic to help introduce it to the ME/CFS community,” DJ reports.



The Spoonie Planner is much more than a calendar. It’s a tool designed to teach people with chronic illness how to live their lives to the fullest through a system of allocation. For DJ, *The Spoonie Planner* communicates a subtle message; “just because our batteries may never reach 100% charged (or even 10% for that matter), it doesn’t mean we can’t find a way to make the most of the little energy that we do have.”

Thanks DJ for dedicating your time and energy to helping others with ME/CFS and other chronic diseases. ■

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

SMCI in Conference: Past and Upcoming ME/CFS Presentations to Research Leaders

As part of the Solve ME/CFS Initiative's reinvigorated outreach and education efforts in the research space, the leadership of SMCI has hit the road this year presenting, speaking, and educating the leaders of the international research community about ME/CFS. In this article, we feature five major ME/CFS presentations and meetings conducted by SMCI in just under five months. SMCI is working to make ME/CFS a key issue for scientists and researchers around the world.

SMCI Chairs Panel Dedicated to ME/CFS at Precision Medicine World Conference, Silicon Valley

One of the goals of the Solve ME/CFS Initiative is to entice new researchers to study ME/CFS. To work toward this goal, SMCI brought the plight of ME/CFS onto the world stage late in January at the 2017 Precision Medicine World Conference (PMWC) in Mountain View, CA. SMCI presented an hour-long session on ME/CFS. The session's title, "ME/CFS: The Mysterious Illness Science Has Yet to Unravel," is a nod to National Institutes of Health Director Dr. Francis Collins and his statement, "Of the many mysterious human illnesses that science has yet to unravel, ME/CFS has proven to be one of the most challenging." Presenting at PMWC was an investment in the ecosystem of ME/CFS, as we were able to educate the heavy hitters in medical research in order to actively draw new scientists into the field.

Dr. Zaher Nahle chaired this exclusive session addressing a range of pressing issues in ME/CFS. Panelists included Carol Head (SMCI) and Dr. Andy Kogelnik (OMI).

PMWC is the leading forum for personalized medicine with over 8,500 attendees, mostly the who's who in the biotech industry and academic research. This year's program included many prominent figures including Dr. Keith Yamamoto (UCSF). For most attendees, we believe this was their first exposure to ME/CFS.



Carol Head, Andreas Kogelnik and Zaher Nahle at PMWC 2017.

Dr. Zaher Nahle Meets with Nutrition and Senescence Experts at Washington University

On February 27, Dr. Zaher Nahle traveled to Washington University in St Louis for a series of meetings with key researchers and collaborators in the ME/CFS research field. Dr. Nahle met with:

- **LUIGI FONTANA, MD, PHD**, an internationally known human systems biologist and leader in the field of nutrition and healthy longevity in humans. Their meeting addressed the most recent advances in the ME/CFS research field, including SMCI's project designed to understand nutrient sensing mechanisms and the role of nutrition and food in the context of disease prognosis.
- **SHEILA STEWART, PHD**, Professor, SMCI research advisory council member and research collaborator, met with Dr. Nahle to discuss and evaluate joint projects on immune-senescence as part of SMCI-Directed Research Program. See our article in this issue "SMCI-Directed Research Study Explores Immuno-senescence" to learn more about Dr. Stewart's work with our team.

30th Anniversary Genetic Alliance: The Official Alliance of Genetic Testing and Molecular Biomarkers #CoCreateHealth

Just two weeks later, Dr. Nahle hit the road again, this time to Bethesda, Maryland for the 30th Anniversary Genetic Alliance Conference. He spent his time at the conference raising awareness about our disease and sharing the plight of ME/CFS with this international assembly of stakeholders and influencers in science, policy, and medicine. Through a new partnership with the Alliance, the Solve ME/CFS Initiative was able to make ME/CFS part of the meeting agenda this year and focus a bright spotlight on a global platform. The conference was also an opportunity to meet briefly with NIH director Dr. Francis Collins who was also in attendance.



One of the keynote speakers captured the ME/CFS research experience in one sentence. “One size does not fit all...One medicine certainly does not fit all,” observed Adolph Falcón during his presentation *Blinded by Stereotypes: Focused on the Individual*. Our new partnership with the Genetic Alliance will help others in the international science community find the fit for ME/CFS research.



Zaher Nahle educates Genetic Alliance Conference attendees.

Bringing the ME/CFS Cause to the Upcoming International Meeting of PMWC 2017 at Duke University

In late May, Dr. Nahle will again take to the podium to chair the second dedicated ME/CFS panel discussion at a research conference this year. Dr. Nahle will be joined by Dr. Anthony Komaroff, professor and senior physician at Harvard Medical School, and John Nicols, President and CEO of a leading Silicon Valley biotech company, Codexis Inc. The conference features opening remarks from North Carolina Governor Roy Cooper, Chancellor and CEO A. Eugene Washington of Duke University, and a presentation from Dr. Francis Collins, Director of the National Institutes of Health.



Zaher Nahle advocates for ME/CFS.

Invest in ME International ME Conference 2017

The 12th Annual Invest in ME international research conference is a platform for the latest and most promising biomedical research into ME/CFS. Participants will include researchers, clinicians, doctors, nurses, occupational therapists, healthcare professionals, and patient groups from twenty countries around the world including our president, Carol Head and Chief Scientific Officer, Dr. Zaher Nahle. Our team will be participating in this year’s Biomedical Research Colloquium, “Mainstreaming ME Research” to discuss the data from our SMCI Directed Research programs and biobank projects. ■



SMCI Answers Reader Questions

In this section of the Solve ME/CFS Chronicle, SMCI addresses common questions we receive from those in the ME/CFS community.

Q: I have written to SMCI and explained in detail the ways I have changed my diet, my lifestyle and the nutrients I take. While I am not completely well, I have regained a near-normal lifestyle. When these kinds of cures are known to be effective, why don't you spread the word and tell everyone about them?

A: Over the years, we have gotten information from hundreds of patients explaining what has made them much better. The difficulty is there is little consistency between patients regarding what has improved their symptoms. This is a complex disease and clearly what works for one person may not work for another. So, touting “cures” as though they apply generally to all patients, is not something we feel is helpful.

Instead, our work is focused less on treating symptoms, but on understanding, at a deep molecular level, the underlying cause of the disease. Understanding the disease at a molecular level is not yet understood, although progress is being made. It's critical to moving the science forward in a significant way. It is also very difficult and requires rigorous, thoughtful, creative research. That is what we do at SMCI. Our primary focus is in solving the underlying causes of the disease so that treatments can be created that work for all.

Q: With documented vision problems in ME/CFS, I find it very challenging to read printed text. Could the font in your publication be changed to something easier to read?

A: We are very pleased to consider that! We think about the accessibility of our communications and publications and try to make our work as easy to access as possible. Comments from our community are helpful to improving the work we do. Please take a moment to review the sample fonts at right and visit us online to vote on your favorite. ■



Q: I have serious food and chemical sensitivity, and so do many others who suffer from ME/CFS. Why doesn't SMCI include food and chemical sensitivity in your clinical diagnostic criteria, when it seems so prevalent?

A: First, please understand that SMCI does not develop clinical diagnostic criteria. That is the work of the Institute of Medicine and other formal bodies who examine the ME/CFS research and listen to the experiences of expert clinicians. The challenge is to write a diagnostic criteria that is wide enough to include all ME/CFS patients, but narrow enough so that people without similar symptoms are not included. This is very difficult, given that many of the symptoms of ME/CFS are similar to those of other diseases. Currently, there are at least eight clinical diagnostic criteria; until one emerges and is used broadly by all physicians, it remains a work in progress. Once again, we see that nothing is simple or straightforward with this complex disease!

FONT 1:

The quick brown fox jumps over the lazy dog

FONT 2:

The quick brown fox jumps over the lazy dog

FONT 3:

The quick brown fox jumps over the lazy dog

Vote for your preferred font at:

www.solvecfs.org/survey

The End of Fiscal Year 2017 is Right Around the Corner, on June 30

In this issue of *The Solve ME/CFS Chronicle*, we updated you on some of the ME/CFS research that is being funded and generated by SMCI, the collaborations we are involved in, and our work on the advocacy front. There is still much more work to do in the fight against ME/CFS. We must continue funding researchers, fostering innovation, inciting collaboration, and fueling discovery. We need national recognition so we must also continue to support advocacy to create change at the federal level. At SMCI, we will not rest until ME/CFS is understood, diagnosable, and treatable.

“Our organization is fundamentally structured so that donations get much more ‘bang for the buck,’ funding the most promising research, wherever it may be.”

—Carol Head, SMCI President and CEO

The June 30 end of SMCI’s fiscal year is fast-approaching. We set an ambitious fundraising goal of \$1.7 million dollars to fund our research and advocacy work. So far, we’ve received \$1.53 million in gifts and pledges from 1,800 donors. We are 18% ahead of where we were at this time last year, but we still have a distance to go.

And, we cannot do this without you. Please consider a gift to SMCI before June 30. Every gift will help us move forward in our fight against ME/CFS.

Visit us at www.donate.solvecfs.org or use the envelope included inside your free issue of *The Solve ME/CFS Chronicle* to make your gift today. ■

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



Make your tax-deductible gift at
donate.SolveCFS.org

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SolveCFS.org/archive

Humans of ME/CFS:
HOMECFS.SolveCFS.org

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2017 Webinar Series to Date

What a start to the year for our webinar series.

A Clinical Approach to ME/CFS in Adolescent and Young Adults: A Practical Primer

On March 16 Dr. Peter Rowe, director of the Chronic Fatigue Clinic and professor of pediatrics at Johns Hopkins Children's Center in Baltimore, Maryland hosted this webinar that appealed to both those just learning about the disease as well as

those who have been investigating and/or dealing with ME/CFS and are looking for answers. Dr. Rowe delved into the clinical features and investigation of pediatric ME/CFS, which was a very unique field we were excited to learn about.

Power to the Patients!

On March 2 our very own Director of Advocacy and Public Relations, Emily Taylor, led this webinar educating us on how to maximize your advocacy impact for ME/CFS. She covered the best practices in general when approaching advocacy as well as SMCI's specific goals and methods. The heart of her presentation went over 6 ways you can maximize your congressional impact. She detailed step by step how to interact with legislators to ensure they hear your voice and convert



your concerns into tangible outcomes. To watch the webinars on our YouTube channel, go to: www.youtube.com/SolveCFS ■