



The Solve ME/CFS CHRONICLE

FALL 2016

Combining ME/CFS Research and Philanthropy in New Ways

Launching the Cathleen J. Gleeson PhD Fund

Cathleen first met Dr. David Maughan in 1985 while completing the third year of her PhD degree in counseling psychology. Nine months later, Cathleen and her children, ages 8 and 12, flew out to Vermont, where she and David married the following year.

Always full of energy, Cathleen worked for the University of Vermont in three capacities: she taught several courses as a medical school professor, was the associate dean in admissions at the University of Vermont Medical School, and practiced therapy one day a week. In her leisure time, she enjoyed traveling the world with her new husband, David.

But in December 1999, things changed for Cathleen. It's a story we hear all too frequently. Shortly before Christmas vacation, Cathleen hugged a medical student whose mother had just died—only later to find out the young woman had an active case of



Cathleen J. Gleeson, PhD

mono. Reinfected with mono, Cathleen also picked up a flu virus from her sister and developed bronchitis. Two weeks later, Cathleen became very sick and collapsed in her husband's arms—she felt like she was dying.

Experiencing severe neurological symptoms, fatigue, and muscle pain, Cathleen had to stop working for a couple of months, hoping she would improve. She returned to her administrative and teaching responsibilities and resumed seeing patients as a therapist, although she worked shorter hours. Eventually she had to give up the teaching and therapy to focus only on her administrative

work, but after three years she had a major relapse that left her so sick she had to take a six-month medical leave. Near the end of the leave, Cathleen realized she was still too sick to return to work. Cathleen has never recovered her previous health,

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Give the Gift of Research
and Advocacy

A Letter from Our President



Carol Head, President



Dear Friends,

The graphic above sits directly in my line of sight every day; it's a relentless reminder of why we do the work we do.

This graphic is a collection of screenshots from a huge advertisement that's running high above Times Square in New York City. Painful as it is for all of us who know the devastation of this disease, our organization is showing this ad to millions of people so that they might grasp the seriousness of the disease commonly referred to by the awful, trivializing name "chronic fatigue syndrome."

While we don't usually do ME/CFS public awareness work, a generous donor provided almost all the funds for this one, powerful ad, which is running for three months. We hope it will begin to make a small dent in the public consciousness about our long-neglected disease.

All of us who have suffered with this disease, or have witnessed the suffering of those with ME/CFS, know the pain it brings—not simply the pain of the disease itself, but the pain of lives diminished, dreams put on hold, and barely veiled disdain from those who question whether we are really sick. For me, and for so many patients with whom I speak, over time it also brings humility—a deep reckoning as we come to understand our lives as we must live them. And from that deep reckoning grows a hardened resolve.

For me, it is a strong, steady, steely knowledge that the egregious underfunding of our federal government, the failure of the medical community to grasp the reality of this disease, and the insensitivity to our suffering is **wrong**. Deeply wrong. It is a wrong that must, and will be, made right—with highly credible medical research and the relentless pushing of our federal government to give ME/CFS patients the funding and respect they deserve.

The Solve ME/CFS Initiative is in this for as long as it takes.

In the long, painful history of our neglected disease, 2016 has been an extraordinary year. Here are a few of our organization's successes:

SOLVE ME/CFS INITIATIVE PROFESSIONAL STAFF



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*Vice President for Research
and Scientific Programs*



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*Administrative and
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Erin Davie
*Biobank and Patient
Registry Coordinator*



Lauren G.
Development Administrator

- We're now funding many small research studies that bring new researchers into ME/CFS.
- We're expanding our ME/CFS biobank and constructing a new patient registry as a tool for all ME/CFS researchers.
- We're participating in important discussions at the Centers for Disease Control and Prevention (CDC) regarding medical education and disease definition.
- We've spoken at the extraordinary #MillionsMissing Days of Action, organized by our comrade-in-arms sister organization, #MEAAction.
- We're demanding that the Chronic Fatigue Syndrome Advisory Committee (CFSAC) step up and do its job.
- We've succeeded, with others, in getting CDC funds reinstated in the federal budget.
- We're meeting with a very senior official at the Department of Health and Human Services, who oversees both the National Institutes of Health (NIH) and the CDC, for substantive, candid discussions.
- We're advising/consulting with scientists at the NIH regarding their intramural study.
- We've developed strong partnerships with preeminent research universities and Metabolon, an industry leader in metabolomics.
- We're collaborating with our new Research Advisory Council, which includes ME/CFS luminaries Dr. Anthony Kamaroff, Dr. Jose Montoya, Dr. Cindy Bateman, Dr. Andy Kogelnick, and Dr. Peter Rowe, among others, to outline the path forward for research.

I could go on. We fight. We fight. We fight.

I'm proud of our work on behalf of those who suffer, like those in the heart-breaking pictures featured. And we need your support, too. SMCI is the first and only ME/CFS charity to earn the highest possible distinction (a 4-star rating) from Charity Navigator, America's largest independent charity evaluator. **And we are the only ME/CFS charity that both does medical research and advocates on behalf of patients.**

We have so much more we must do in 2017! If you are able, we hope that you'll support our resolve with your dollars. With your generous support, we will prevail over this insidious disease.

Onward!



Carol

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



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Combining ME/CFS Research and Philanthropy

which has been devastating for her; she's lost her health, her rewarding career, and much of her personal identity.

Cathleen was formally diagnosed with ME/CFS in 2000. Fortunately for her, with only a few exceptions, she has not had the misfortune of dealing with doctors who didn't believe she was sick or denied her condition, as so many other ME/CFS patients do. While all of Cathleen's symptoms have remained over the years (extreme fatigue, neurological deficiencies, muscle pain, and brain fog), some have lessened over time. She credits occasional relief to medication she's found to work for her (antivirals, sleeping aids, and marijuana tincture and salve) as well as weekly cranial sacral treatments, acupuncture, and counselling. She sleeps 10–11 hours every night.

“I had always thought it was something she could push through.”

When David must go on work trips, it's Cathleen's sister Colleen who flies out from Washington state to stay with and assist her.

These days, Cathleen's weeks are focused on her medical appointments and—if it's a good week—perhaps a social activity or two (like going to lunch or seeing her grandchildren).



The rest of her days, Cathleen lies on a recliner in the living room, reading. At times, just visiting on the phone for too long brings her to the point of absolute exhaustion. Once an avid traveler, Cathleen now takes just one trip with David each year, returning to their condo in Seattle to be with family. She flies out, spends a few months there, then returns back to Vermont (giving her ample recovery time between travel days).

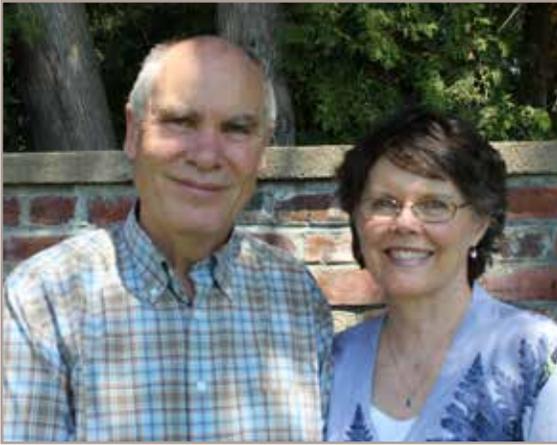
When asked what she would say to a patient recently diagnosed with ME/CFS, Cathleen recommended quitting work—or cutting back seriously—and resting a lot (if it were a financial possibility) while pursuing treatments to help with the disease. Unfortunately, not all patients have this option.

Cathleen's husband, Dr. David Maughan, a professor of molecular physiology at the University of Vermont, had spent his life's work

replicating and studying human muscle diseases in mice and flies. After retiring in 2010, he switched his focus to Cathleen's disease. As he read more about ME/CFS, he gained a better understanding of Cathleen's health challenges. As for what he originally thought of Cathleen's illness, David admits, “I had always thought it was something she could push through.” Like many family members of ME/CFS patients, David started out in a state of denial—something made all the more common by patients not looking sick. Recalls Cathleen, “When people told me I looked good, I thought I'd rather have a big, huge scar across my face and actually be well—and productive again.”

After doing research online, David and his collaborators at the University of Vermont began a research study looking at the immunological basis of ME/CFS. Partly funded by the New Jersey ME/CFS Association,

Inc., David's blood analysis study received a significant assist by way of Solve ME/CFS Initiative's bio-bank, which supplied the necessary plasma samples for the study. David, a productive and widely respected researcher, says collaborating with Solve ME/CFS Initiative Vice President for Research and Scientific Programs Dr. Zaher Nahle was a "transformative experience," given Dr. Nahle's charisma, knowledge, and desire to accomplish meaningful work in the world of ME/CFS. As was previously reported in our e-mail newsletter, David presented the results of this study at the IACFSME conference in late October.



Dr. David Maughan and Dr. Cathleen Gleeson

Like the Solve ME/CFS Initiative, David firmly believes in patient-centered research. Says David, "As a systems biologist, I know you've got to really bring everybody to the table—especially the patients. They are key to finding a cure for this disease; you get so much out of talking to them."

David's long research career in muscle physiology has brought him into contact with diverse fields of knowledge and techniques that he is able to bring into this new area of research. Most recently, the technique of magnetic resonance spectroscopy is a promising new method of studying fundamental abnormalities of energy replenishment, which could underlie many ME/CFS disabilities. This line of investigation is being pursued jointly at the University of Washington.

Cathleen's son Alex, now a successful business man in Seattle, decided to donate funds to the Solve ME/CFS Initiative in his mother's honor through the private family KOVO Foundation (a foundation that blends the last names of both Alex and his wife). These contributions seeded the Cathleen J. Gleeson PhD Fund, a fund at SMCI that will be dedicated solely to scientific research and discovery.

When asked what it means to her to have an ME/CFS research fund in her honor, Cathleen said, "I'm so proud of my son. He's always been supportive of me while I was sick. For him to fund this project, as well as others of David's, means the world. He's so respectful of David's intelligence and wants to help him do the work that in turn may help me and the millions in the world suffering from this disease."

"When people told me I looked good, I thought I'd rather have a big, huge scar across my face and actually be well—and productive again."

Dr. Nahle, who orchestrated the establishment of the research fund as a new model of collaborative space by working with Cathleen, Alex, and David, stated, "These types of partnerships bypass bureaucracies and put the power directly into the hands of patients and their families as close partners in research and key drivers of progress. That is a core belief of ours, and we are just delighted to launch the Cathleen J. Gleeson PhD Fund toward creating value and contributing to scientific research in our disease space." Dr. Nahle added, "Cathleen and David are not only friends of the organization and great human beings but also a model for resilience and determination in their support of one another and the inspiration they imbibe us with every day. We are just glad to be part of their life." ■

If you would like to inquire about contributing to the Cathleen J. Gleeson PhD Fund or set up a fund through the Solve ME/CFS Initiative for your loved one, please contact Karen Petersen at KPetersen@SolveCFS.org.

New Project Launched through Our Targeted Initiative Research Program

SMCI recently launched a new partnership as a component of our targeted initiative program, within our *Pathways and Biomarkers Discovery Track*.

The project consists of original research in the areas of bioenergetics, metabolomics, and lipidomics using high-throughput technology. Importantly, this new SMCI research project relies on blood from well-qualified patients from The Levine Clinic; it also builds on recent discoveries in gut microbiome from Dr. Maureen Hanson's lab, which uses these same patients.

As always, we partner with experts. In this instance, we have brought together the following group: Dr. Hanson, a professor of molecular biology and genetics at Cornell University; Dr. Levine, a member of SMCI's Research Advisory Council and the chair of the Department of Health and Human Services Chronic Fatigue Syndrome Advisory Committee; and Metabolon, an industry leader in the discovery of biomarkers through the use of metabolomics (a "high-throughput technology" and powerful scientific approach for the discovery and development of drugs and for early disease diagnosis).

Possible Outcomes

Findings from this new study have the potential to be quite significant and may lead to

- Expanding gut microbiome findings and providing additional context and clarity
- Identifying specific biological signatures from well-characterized patients
- Developing mechanistic insight into comorbidities 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 us 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 the next quarter, with results requiring additional mechanistic investigation to establish findings as reproducible and validated targets.

Dr. Zaher Nahle, SMCI's vice president for research and scientific programs, stated, "We could not be more excited about our partnership with Dr. Hanson, Dr. Levine, and Metabolon. We look forward to analyzing the metabolome of both early- and late-stage ME/CFS patients and their controls using Metabolon's multi-plex platforms. It is our hope that this study will reveal signatures and identifiers pointing toward **biomarkers** as well as a **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."

This project, in preparation since early 2016, is one of three targeted research initiatives we have begun this year. Our intent is to accelerate the research process, capitalizing on unexpected opportunities, discoveries, and premises in real time. We'll describe our other tar-

geted initiatives in more detail in future issues of *The Solve ME/CFS Chronicle*. They include

- **Immunosenescence and cell-cycle analysis** in the pathophysiology (the functional changes that accompany a particular syndrome or disease) of ME/CFS. Partners in this targeted initiative include Dr. Masashi Narita of the Narita Group at **Cambridge University** and Dr. Sheila Stewart of **Washington University in St. Louis**.
- **Functional genomics** studies aiming to uncover potential drug screening targets in ME/CFS. Partners in this targeted initiative include Dr. Ralf Garippa, Dr. Scott Lowe, and Dr. Myles Fennell from the **Memorial Sloan Kettering Cancer Center**.

Creative Partnerships

We're proud of this innovative, disruptive approach to medical research. Many have asked how our organization, without "wet lab" facilities or a single university affiliation, can do original ME/CFS research. We do that research by first identifying, in an unbiased manner and without any pressure or political consideration, the knowledge gaps in research, then partnering with the best experts in their respective fields who also share our vision and sense of urgency (in this case, an experienced clinician, an esteemed scientist at Cornell University, and private firm Metabolon). By pulling together a single research project that embodies the specific resources

required to perform that research work, we are focused on a specific issue.

It is VERY important to recognize that by organizing rigorous research without traditional academic constraints, we can do our work at a significantly lower cost. We avoid university overhead costs that can, and often do, consume up to 80% of the cost of research. In other words, we more than DOUBLE the "bang for our research buck." While it takes more creativity and negotiating skills, we put together project plans with the best people. We are nimble. And we do research at a significantly lower cost.

It's also worth noting that all of these efforts are supported by the national ME/CFS patient registry we are building in order to help clarify the natural history of the disease. Using state-of-the-art technology platforms, our patient registry will facilitate interactions between organizations, researchers, and patient groups. Partners on our patient registry include the Robert Wood Johnson Foundation and Genetic alliance, alongside many ME/CFS clinics and centers in the U.S. and around the world.

We firmly believe that this creative approach to rigorous research, outside the often sluggish and expensive culture of academia, is the way of the future for science. We are proud to be leading the way in this creative, uncompromising manner. ■

Our Research Advisory Council at Work



RAC meeting participants, pictured left to right: SMCI President Carol Head; Michel Silvestri, PhD, Sweden; Vicky Whittemore, PhD, NIH (guest); Sheila Stewart, PhD, WashU; Natalie Block, MD, MPA, Mount Auburn; Anthony Komaroff, MD, Harvard; SMCI Vice President for Research and Scientific Programs Zaher Nahle, PhD, MPA; Jose Montoya, MD, Stanford; Cindy Bateman, MD, Bateman Horne Center; Sue Levine, MD, CFSAC; Peter Rowe, MD, Johns Hopkins Medical Center; not pictured: Andy Kogelnik, MD, PhD, Open Medicine Institute.

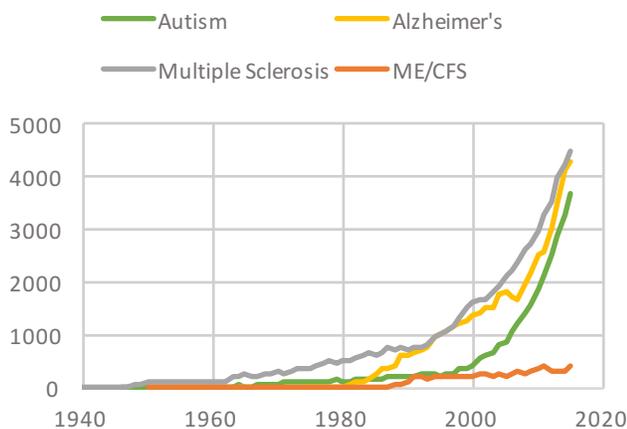
A Letter from Zaher Nahle, PhD, MPA

Dear Friends,

We often talk about severe gaps in knowledge when referring to ME/CFS. We advocate for more research across all scientific fronts, from basic to translational to clinical research. We also condemn, alongside the Institute of Medicine and all responsible observers, the lack of understanding about our disease—the shortage of information on its causes, molecular basis, and clinical definition. Even Director Collins of the National Institutes of Health underscored the deficit when it comes to our disease when he stated, “Of the many mysterious illnesses that science has to yet unravel, ME/CFS has proven to be one of the most challenging.”

But how do we measure knowledge in one field or another? And what does that knowledge gap look like when we quantify it? Let me illustrate this with a very simple comparative analysis.

Number of Peer-Reviewed Research Publications by Disease, 1940 to Present



On the graph above, you see a representation of the number of research publications per year for different diseases. This is depicted on the vertical line and plotted as a function of time on the horizontal line (in years). Peer-reviewed publications like these are considered evidence-based findings. They are typically a metric of the health of the body of research focus, reflecting

new research findings and advances in a field. They also reflect the size of the human capital—the effort of researchers and research institutions—involved. As such, and using visuals, we can track the activities and patterns of original information out there.

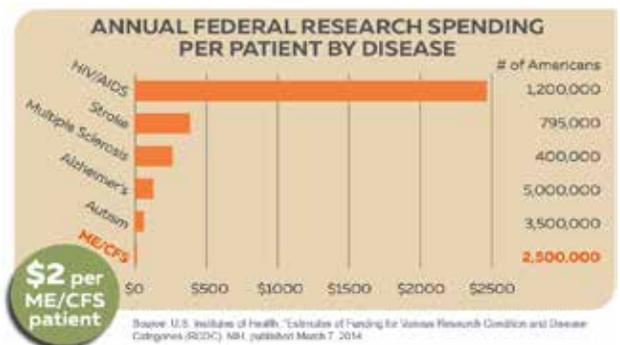


We can see the sharp rise in scientific papers on Autism since the late 90s, the spike in Alzheimer's research in the 80s, and the steady rise in Multiple Sclerosis studies since the 60s. For all of these terrible diseases, we can also deduce from the size and shape of these graphs the continuous growth of information published. Sadly for ME/CFS, its graph is an uneventful, nearly flat line. And **that** represents our knowledge gap in ME/CFS.

As we'd expect, the knowledge gap correlates with the amount of spending per disease (see graphic below). Knowledge in biomedical sciences is a direct function of spending on medical research. That is why we advocate for, facilitate, and invest in medical research.

There is no substitute for filling the knowledge gap as we work toward making ME/CFS understood, diagnosable, and treatable. Here at the Solve ME/CFS Initiative, we press forward.

Best, Zaher



The No Spin Zone

We debunk common misperceptions about ME/CFS with data, facts, and science



Among the many challenges patients face on a daily basis are spins and misperceptions in disease science reporting. Some are harmless, simply reflecting a lack in public awareness, yet others are malicious and seek to dismiss and weaken the pathophysiology (the functional changes that accompany a particular syndrome or disease) behind ME/CFS.

Regardless of the motivation, these are some of the most common—and perhaps most hurtful—misperceptions we hear about ME/CFS; today we will debunk several of these with data, facts, and science.

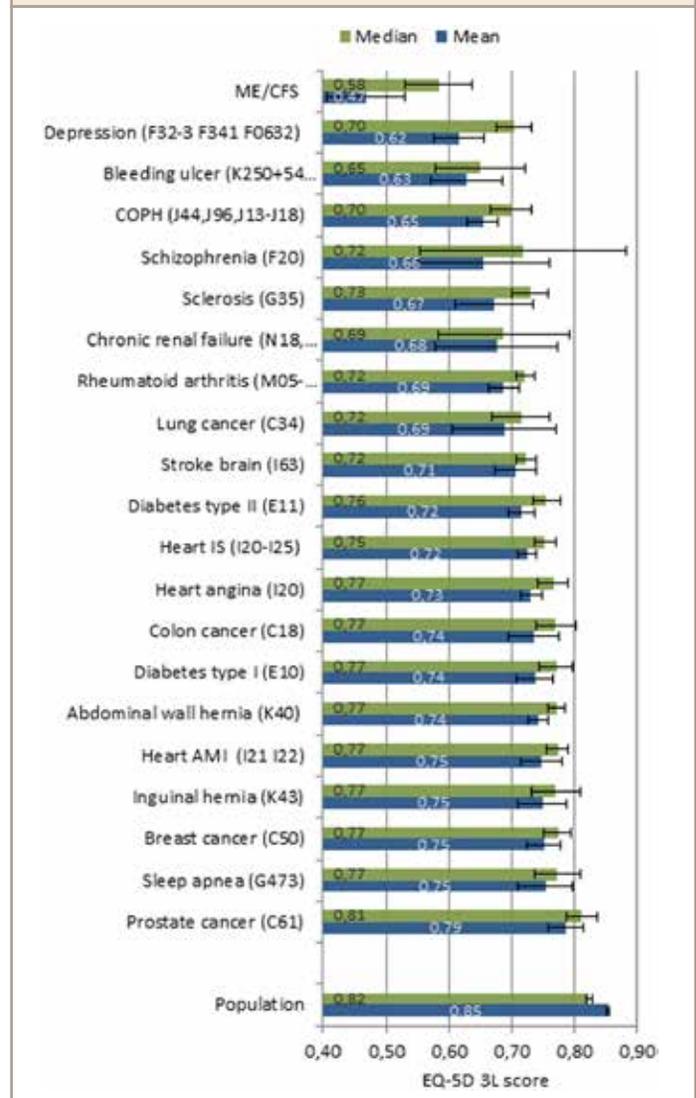
ME/CFS Spin 1: I'm tired too!

This is arguably the most common response when an ME/CFS patient reveals his or her diagnosis, with “you look normal” coming in a close second.

Applicable to a wide range of health conditions and treatments, EQ-5D-3L HRQoL utility scores are a standardized measure of health. Remarkably, a study published just last year found this measure to be lowest, and thus quality of life to be the poorest, among ME/CFS patients when compared to those of patients with other devastating diseases, such as stroke, diabetes, and cancer*. The chart at right illustrates these test scores.

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Rigorous Analysis Shows ME/CFS Patient Quality of Life Scores Lowest among Surveyed Patient Groups



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No Spin Zone

ME/CFS Spin 2: This is caused by depression or anxiety!

Here we have another popular spin. Depression and anxiety are the most common emotional **responses** to most medical illnesses; it makes sense for many ME/CFS patients to suffer from these conditions as well, as a result of their physical disease. That said, if there is any disease screaming to us that it is **not** caused by anxiety or depression, it has now been rigorously demonstrated that it would be ME/CFS. The table below includes just some of the conflicting biomarkers illustrating this point.

DEPRESSION/ANXIETY CHARACTERISTICS	VS	ME/CFS CHARACTERISTICS
Hypercortisolism (too much cortisol)		Hypocortisolism (too little cortisol)
Enlarged adrenal glands		Reduced adrenal glands
Reduced serotonin levels		Abnormal increase in serotonin levels
Unable to feel pleasure, lack of motivation		Lack of energy—not a lack of motivation
Exercise improves patients with depression		Exercise causes malaise/crash, worsening the condition

ME/CFS Spin 3: Your blood tests came back normal!

The above is a phrase our patients hear all too often. For a minute this spin may seem plausible, as it is often expressed by a healthcare professional who has examined you. But ME/CFS has unknown causes and biomarkers, and there are thousands of factors that have not yet been tested, such as metabolites, proteins, enzymes, hormones, waste products, toxins, pathogens, oxygen, CO₂, heavy metals, gas exchanges and other blood parameters, or metrics and hemodynamic function in the many blood cell types across all blood compartments and compositions. A more accurate result would be, “the few things that we measured using routine tests of your blood came back normal.” Sophisticated, high-tech analysis is revealing that very little is “normal” about the blood of ME/CFS patients.

Specifically, below are just a handful examples in the last year or so indicating radical differences between blood from ME/CFS patients and controls.

- Using nuclear magnetic resonance: **metabolic signature** (2015 Metabolomics, Armstrong et al.)
- Using mass spectrometry: **metabolic signature** (2016 PNAS, Naviaux et al.)
- Using high-tech sequencing: **abnormal pathogenic features** (2016 Microbiome, Giotoux et al.)
- Using immune profiling: **distinct signatures** (2015 Science Adv., Hornig et al.)
- Using microRNA and proteomics: **distinct signatures** (2016 PlosOne, Petty et al and 2016 Transl Psychiatry, 2016 Ciregia et al.)

Now, when you hear someone use these common ME/CFS spins, you’ll be armed with the knowledge necessary to better educate him or her. We offer this as a scientifically rigorous, practical tool for use by every ME/CFS patient. ■

*Source: Falk Hvidberg M, Brinth LS, Olesen AV, Petersen KD, Ehlers L (2015) The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). PLoS ONE 10(7): e0132421

The Mighty Fifty-Five: Congress Takes A Stand for ME

Advocates obtain the bipartisan support of 55 members of Congress for strengthened ME/CFS research

This summer, the Solve ME/CFS Initiative teamed with a nationwide coalition of myalgic encephalomyelitis (ME) advocates with the goal of making members of Congress take notice of ME, more commonly known as chronic fatigue syndrome (CFS).

Months of perseverance paid off when advocates secured the support of U.S. Representatives Zoe Lofgren and Anna Eshoo of California, who committed to lead the charge by authoring a letter to the director of the National Institutes of Health (NIH), Dr. Francis Collins.

The letter demanded Director Collins 1) strengthen the NIH's efforts in ME/CFS biomedical research, 2) consider the input from the recent ME/CFS Request for Information (RFI) in a timely manner, and 3) provide regular updates to Congress on the NIH's plans for ME/CFS research for fiscal years 2016, 2017, and 2018.

Given only ten working days to approach over 435 members of Congress, patients and caregivers around the country went to work with thousands of calls and emails. When the letter was released on September 9, an impressive bipartisan 55 members of Congress had signed on to lend their voices in support of those with ME/CFS.

We extend a heartfelt thank you to the mighty fifty-five members of Congress listed at right. If your representative is listed, we hope you'll reach out to thank him or her too. To view the complete letter, or get help thanking your member of Congress, email Emily Taylor at ETaylor@SolveCFS.org. ■



- | | |
|------------------------------------|---|
| Rep. Zoe Lofgren (D, CA-19) | Rep. Barbara Lee (D, CA-13) |
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| Rep. Vern Buchanan (R, FL-16) | Rep. David B. McKinley (R, WV-01) |
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| Rep. Steve Cohen (D, TN-09) | Rep. Patrick Meehan (R, PA-07) |
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| Rep. Peter T. King (R, NY-02) | |
| Rep. Steve Knight (R, CA-25) | |

#MillionsMissing: The Biggest Action in ME/CFS History

Thousands worldwide join international Day of Action, urge public health officials to ramp up funding for ME/CFS research, clinical trials, and education

On Tuesday, September 27, the ME/CFS community gathered for the second #MillionsMissing Day of Action. Organized by #MEAction, protests and gatherings took place in 25 cities across the globe (as well as online) to call attention to the disease and make patient voices heard. #MEAction is an international network of patients empowering each other to fight for health equality for myalgic encephalomyelitis (ME), commonly known as chronic fatigue syndrome (CFS).

The Solve ME/CFS Initiative was a proud supporter of these events. President Carol Head and Board Chair Vicki Boies spoke at the Chicago action, and Advocacy and Engagement Manager Emily Taylor addressed patients and advocates at the San Francisco action. You can view pictures and live videos from these actions on the Solve ME/CFS Initiative Facebook page at www.facebook.com/SolveMECFSInitiative.

Said SMCI President Carol Head, “While it is wonderful to be here today with so many of us who care deeply about this disease, we shouldn’t have to be here at all. Our federal government must do

the right thing and step up its support by funding research into this serious disease as it has for so many other diseases.”

Speaking in San Francisco to over 100 patients, Advocacy and Engagement Manager Emily Taylor called upon the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) to fund ME/CFS research at \$250 million annually. “We are fighting today because for 30 years the government has ignored and underfunded this disease. \$2 per patient is an insult when 75% of patients are unable to work. And millions are missing from society and even from their own lives... We are not invisible. We will not ‘wait our turn.’ We are fed up with the excuses, and we are going to fight!”

These public actions, in coordinated combination with SMCI’s advocacy work in Washington DC conducted “sitting across the table” from senior officials from the Department of Health and Human Services, NIH, and CDC, create an effective “outside and inside” advocacy strategy. ■



Carol Head speaking at the Chicago #MillionsMissing action (above) and Emily Taylor representing SMCI in San Francisco (below).



PATIENT VOICES

In this recurring section of *The Solve ME/CFS Chronicle*, SMCI will feature the creativity and talent of the ME/CFS community. Every quarter you can find the art, writing, and other creations of ME/CFS patients here. To submit an item to Patient Voices, please email Emily Taylor at ETaylor@SolveCFS.org.



This quarter, we are featuring the beautiful quilts of Maryann Roylo of Cranberry Township, PA (pictured above). Maryann has struggled with ME/CFS since her mid-20s and began quilting 16 years ago, first making a millennial quote quilt for her mother. Often Maryann uses recycled clothing to create her masterpieces. Now at 71 years old, Maryann's illness has forced her to work exclusively from bed—but she still creates her quilts, collecting ideas, ordering fabrics, and sketching designs when she is too sick to sew.

Despite her illness, Maryann says, "I can still create beautiful quilts for loved ones, and that's an acceptable consolation." Maryann, we honor your spirit. ■



Give the Gift of Research and Advocacy



Ask any ME/CFS patient. He or she will tell you why we desperately need medical research to understand ME/CFS and why it's important to advocate for increased governmental research spending. Urging our federal government to fund this disease at appropriate levels is critically important.

"Everything about my illness is opposite of what doctors are trained to say and do to help me. Everything they tell me to try makes me sicker. I have become very wary of their ideas. This is why we need research."

—Melanie P.

"...after a full day at the office, I would collapse at home, sometimes just about managing to feed myself and do a few basic tasks. Other times I would just sleep until it was time to go to work again. I had no life."

—Katherine S.

"...no one really believes you're sick at all, and they think it's probably psychological or you're faking because you look normal." —Tom W.

So little is known about this disease that destroys the lives of up to 2.5 million Americans. Patients like Melanie, Katherine, and Tom are forced to eke out their best manageable existence, knowing that were their disease better understood, their quality of life could be significantly improved.

The Solve ME/CFS Initiative works in three ways to increase ME/CFS research:

- By facilitating the work of credible ME/CFS researchers through seed grants, bioank samples, and the creation of research webinars and meetings
- By investing in our own internally led research projects done in partnership with leading corporate and academic entities
- By meeting with key NIH and CDC officials to advocate for spending on ME/CFS medical research

Why so much effort? Because through credible, validated research, we can unravel the mystery of ME/CFS at the cellular level. This will

lead to an understanding of the disease's cause, biomarkers, and treatments—all of which will lead to a cure.

None of this work is possible without your donations. In the words of a generous and loyal donor from Minnesota, “We support you guys because you give us hope. We believe in you and the important work you are doing to solve this disease.”

Will you consider a tax-deductible gift to support our research and advocacy work? The Solve ME/CFS Initiative Giving Guide details numerous examples of ways your donation contributes to the realization of our plans. Whether you want to sponsor a month of biobank sample storage or fund a pilot research study, we have giving opportunities of all sizes to fit all budgets. Every gift matters and brings us closer to achieving our organization's mission: making ME/CFS understood, diagnosable, and treatable. ■

DONATE TODAY

Make your donation in one of three easy ways:

1

Go to SolveCFS.org/DONATE

2

Mail your gift using the enclosed envelope or send to
Solve ME/CFS Initiative
5455 Wilshire Blvd., Suite 806
Los Angeles, CA 90036

3

Call us at (704) 364-0016, ext. 201

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 targeted initiative

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

\$30,000

Sponsor one Ramsay Award Program grant

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



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

Solve ME/CFS Initiative
5455 Wilshire Blvd.
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Solve ME/CFS Initiative
5455 Wilshire Blvd., Suite 806
Los Angeles, CA 90036

Telephone: 704-364-0016

E-mail:
Communications@SolveCFS.org

Website: SolveCFS.org

Facebook: www.facebook.com/
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HOMECFS.SolveCFS.org

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SolveCFS.org/donate

ME/CFS in the Mainstream Media

Thanks to the #MillionsMissing Day of Action, ME/CFS saw heightened attention from the mainstream media last month. Here are some articles worth looking up online (use Google to search their titles) if you're eager to see how our disease is being covered outside of the ME/CFS community.

Domestic

- *The Huffington Post* | MillionsMissing: A Hidden Epidemic and a Day of Action
- *The Huffington Post* | Millions Are Missing: Will The World Finally Notice?
- *U.S. News and World Report* | Protesters Demand Increased Funding for ME/CFS Research

International

- *The Guardian* | ME affects four times as many women as men. Is that why we're still disbelieved?
- *The Oxford Times* | Rows of empty shoes outside the Radcliffe Camera, Oxford will represent Chronic Fatigue Syndrome sufferers at Millions Missing
- *The Times* | Exercise and therapy cure for ME is 'seriously flawed'