



Solve ME/CFS Initiative

Leveraging patient-centered research to cure ME/CFS

The SolveCFS Chronicle

Winter 2015

Significant Breakthrough for ME/CFS at the NIH

On Oct. 29, the National Institutes of Health announced that it is taking several major steps to advance research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. NIH is launching a research project at the NIH Clinical Center to intensely study individuals with ME/CFS and will also be funding external research on the disease to a degree that will be “substantially greater” than our disease has received in the past, according to NIH Director Dr. Francis S. Collins.



Additionally, NIH announced that the leadership role for ME/CFS research, which was assigned to the Office of Research on Women’s Health, has now been assigned to the National Institute of Neurological Disorders and Stroke (NINDS). NINDS will lead a multi-institute ME/CFS research effort and a re-invigorated Trans-NIH ME/CFS Research Working Group. This move marks a very positive elevation of the status of our disease within NIH. NINDS Director Dr. Walter Koroshetz will chair the Working Group, along with Vicky Holets Whittemore, PhD, the NIH representative to the U.S. Department of Health and Human Services’ Chronic Fatigue Syndrome Advisory Committee (CFSAC),

on which Solve ME/CFS Initiative President Carol Head serves.

After the announcement, we followed up with Vicky Whittemore on a number of questions raised by this exciting news, which has brought renewed hope, and cautious optimism, to our community.

Q: What would you attribute as the most significant catalyst for these changes?

A: The release of the Institute of Medicine report and the NIH Pathways to Prevention conference and report on ME/CFS came together to elevate the discussion about ME/CFS at NIH.

Q: What does NIH hope to achieve with the changes?

A: The NIH hopes to stimulate and support meritorious research on ME/



Vicky Whittemore, PhD, explains the new direction taken by the NIH.

CFS that will lead to an understanding of the pathophysiology (causes) of ME/CFS, to the development of effective treatments and eventually to identify ways in which ME/CFS can be prevented. The Trans-NIH Working Group will initially be guided by the IOM and P2P reports in their discussions about potential new initiatives and research priorities, as well as input from the community.

Q: Our understanding is that these changes have come from the top down—Dr. Collins himself. Is that true?

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The Solve ME/CFS Initiative Board of Directors

Each Board member has a personal connection to the disease.

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A Letter from President Carol Head



Carol Head
President

Dear Friends,

Like many with ME/CFS, I am a determined optimist. When I was debilitated by this dread disease some 30 years ago, I clung to the hope that some treatment would improve my ill health, that some doctor somewhere would understand my symptoms, that I would somehow be able to resume my life someday.

This optimism has remained with me throughout these last 30 years, and particularly the last two years in my role as President of the Solve ME/CFS Initiative. And yet as we began 2015, even I did not anticipate the watershed changes that would take place in the course of just 12 months.

- A landmark Institute of Medicine report in February that would unequivocally establish both the physiological nature of the disease and the dramatic need for more research funding.
- An NIH Pathways to Prevention report in June that echoed the IOM findings and “dignified ME/CFS and those affected, while providing expert guidance to the NIH and the broader research community.”
- A slew of reports in respected mainstream media outlets that finally paid attention and gave credence to the gravity of the disease.
- And in October, an announcement by the NIH that ME/CFS will be given new leadership in the National Institute of Neurological Disorders and Stroke, be part of a new internal NIH ME/CFS research study and be given substantially greater funding for external research on the disease.

All told, 2015 will go down as arguably the pivotal year in our long, painful history of ME/CFS. We at the Solve ME/CFS Initiative are left a bit breathless by this winning chain of events—partly still in disbelief that we, in tandem with other advocates, were able to finally break through to real change at the national level after decades of effort. And also breathless because we feel that, although we just completed a marathon, the race is just now beginning.

While we have much work to accomplish in 2016, we will close out this year with a grateful heart for the many good things that the past year brought to all of us who have waited so long. We will continue to drive this new promise of 2015 home to fruition—to make ME/CFS understood, diagnosable and treatable.

Onward!

D.C. Advocacy Update

On Oct. 5, Solve ME/CFS Initiative President Carol Head and Board members Diane Bean and Christine Williams met with majority and minority staff members of the Subcommittee on Labor, HHS and Education of the Senate Appropriations Committee following their Board meeting in the Washington, D.C., area. Williams is a patient who worked for the federal government in health policy before retiring due to her illness and lives in Bethesda, Md. Bean, whose daughter is a patient, worked for the State Department and also lives in Bethesda.

The meeting was held to underscore the need to preserve and augment funding for ME/CFS research and to determine how best to influence the Appropriations process for the next budget cycle.

The staff members offered a detailed description of the Appropriations process and the key timeframes in which patients and advocacy organizations should make their voices heard. While the Solve ME/CFS Initiative is first and foremost a research organization, we conduct advocacy to advance research funding for the disease and will be active in the next Appropriations cycle, which will begin in early 2016.

While in the Senate offices, the Solve ME/CFS Initiative group also met with the health staffers for Sen. Orrin Hatch (R-UT) and Sen. Michael Bennet (D-CO) to convey the severity of the disease and the urgency for more federal research funding.

Prior to the in-person meetings, Solve ME/CFS Initiative staff and Board members held phone calls with Sen. Al Franken (D-Minn.), as well as health policy staff members from the offices of Sen. Tammy Baldwin (D-Wisc.), Sen. Mark Kirk (R-Ill.) and Sen. Dick Durbin (D-Ill.).

We will continue to keep our community updated on our advocacy work to increase research funding for ME/CFS.

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Carol Head during the Solve ME/CFS Initiative's recent trip to Capitol Hill.

Significant Breakthrough for ME/CFS at the NIH (continued from Page 1)

A: Dr. Collins discussed these changes with the Institute Directors and has been encouraging and very supportive of the changes that have been made.

Q: What is the significance of the Trans-NIH Working Group?

A: The fact that the root cause and the driving pathobiology behind ME/CFS are unknown argues persuasively for a trans-NIH approach to research on this disease. The Trans-NIH Working Group on ME/CFS will engage multiple Institutes and Centers at NIH to support research on ME/CFS. NINDS will take the initial lead in chairing and staffing the Trans-NIH Working Group, but all of the relevant Institutes, Offices and Centers will continue to be involved and participate in supporting research.

Q: How will ME/CFS be factored into NIH's five-year strategic plan?

A: In order to advance its mission and fulfill a request from Congress, NIH is developing a five-year NIH-wide Strategic Plan to outline a vision for biomedical research that will pursue fundamental knowledge about the nature and behavior of living systems and apply that knowledge to extend healthy life and reduce illness and disability. NIH senior leadership and staff from all 27 Institutes, Centers and Offices (ICOs), with input from the Advisory Committee to the Director of NIH, have developed a framework for the Strategic Plan. As the

number of disorders in the NIH portfolio is extensive, the strategic plan could not address specific diseases but lays out the general framework for research at NIH. You can see more about the framework at: www.nih.gov/about-nih/nih-strategic-plan. We expect that the process will include discussion about research priority areas whether or not they are housed in a specific institute.

Q: Will there be money allocated specifically to ME/CFS?

A: NIH does not allocate funds for research on specific diseases except as is legislated by Congress (i.e., for HIV/AIDS, Alzheimer's disease and Autism).

Q: While we know that NINDS will be taking the lead, will the National Institutes of Allergy and Infectious Diseases (NIAID) also play a major role?

A: As noted, the ME/CFS Trans-NIH Working Group will coordinate research at NIH. Yes, NIAID will continue to play a critical role in ME/CFS research since the disorder commonly occurs following



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

an infectious illness and there are interesting data that suggest that abnormalities in the immune system play a role.

Q: What is the nature and composition of the reinvigorated Trans-NIH Working Group?

A: The Trans-NIH ME/CFS Working Group will be made up of representatives from 23 Institutes, Offices or Centers at the NIH. You can visit the NIH website to view the interests and activities that take place in each of these Institutes, Centers and Offices at: www.nih.gov.

Q: Our understanding is that leadership of the Trans-NIH Working Group for ME/CFS will rotate among institutes. Is this correct? If so, for how long will each institute chair the working group before the chair rotates? Will Dr. Koroshetz or yourself be chairing the working group?

A: The details for rotation of the leadership of the Trans-NIH Working Group have not been determined. Initially, Dr. Koroshetz will be chairing the Working Group with my assistance.

Q: Regarding the new ME/CFS clinical trial at the NIH, the understanding is that it is focused on the immunity aspect of the disease. Why was that the only focus chosen and/or is that part of a multi-step plan? Will this be expanded, for instance, by studying other fields implicated in ME/CFS or developing similar clinical trial protocols?

Solve CFS BioBank and Patient Registry Update



In the last few months, our Solve CFS BioBank and Patient Registry has supported work on original ME/CFS research projects at the University of Vermont, the University of Nevada and, now, laboratories at the National Institutes of Health. By providing these readily-available blood samples, investigators are able to move forward in their work, saving months or years in their research efforts. We have built this capability as a

service to qualified ME/CFS researchers across the country and around the world.

Our Solve CFS BioBank and Patient Registry continues to grow with a current collection of approximately 9,600 samples that are professionally stored, de-identified and catalogued. This includes Peripheral Blood Mononuclear Cells (PBMCs), blood serum and blood-derived dry pellets; the rest of our registry is made up of consented patients ready to provide samples for research purposes when contacted.

Researchers interested in acquiring samples should contact Dr. Zaher Nahle, Vice President for Research and Scientific Programs, at znahle@solvecfs.org.

Patients and healthy controls seeking more information or to enroll in the BioBank and Patient Registry should go to SolveCFS.org/biobank. ■

ATTRIBUTES OF BIOBANK SAMPLES			
	Facility 1	Facility 2	On-demand, consented participants*
Female	167 / 74%	79 / 76%	799 / 75%
Male	58 / 26%	24 / 24%	257 / 25%
Total	225	103	1,056
Age Range	16 to 80 yrs	18 to 64 yrs	15 to 90 yrs
Avg. Age	55	38	67
*patients (~80%) & controls (~20%) not included in other facilities			

Significant Breakthrough for ME/CFS at the NIH (continued from Page 4)

A: The study participants will be those that are within five years of the onset of ME/CFS following an infectious illness. It was decided to focus on this population as a way to reduce the heterogeneity between the individuals in the study. The protocol will include many studies to determine changes in the immune system, as well as other systems. Other details about the number of patients and duration of the study will be announced as soon as they become available.

Q: What will be the process for patient recruitment and involvement for this trial?

A: As with other studies conducted

in the NIH Clinical Center, the study participants will be recruited through the website www.clinicaltrials.gov and through the NIH Clinical Center Patient Recruitment and Public Liaison Office.

Q: What is the post-trial process and how will the NIH follow up on these sorts of trials from precedence?

A: The study results will be reported both through the website www.clinicaltrials.gov as well as published in scientific journals. Follow-up studies and/or clinical trials of treatment will depend on the results of the study.

Q: Is there coordination with other international counterparts on this issue?

A: It will be important going forward to expand our communication with international counterparts so that common protocols can be launched in larger numbers of individuals with ME/CFS worldwide.

Q: Are there any details on an upcoming RFA (Request for Applications) for ME/CFS? What might the timeframe be and how much money might be attached to them?

A: No, there are no details at this time. The Trans-NIH Working Group will discuss future initiatives at an upcoming meeting. ■

Overcoming the Challenges of a Complex Disease

By Zaher Nahle, PhD, MPA, Vice President for Research and Scientific Programs

Within the spectrum of human diseases, ME/CFS is “one of the most challenging.” That is how the Director of the National Institutes of Health, Dr. Francis S. Collins, described this disease in a recent press release. Collins, as the head of a \$31 billion research operation investigating hundreds of complex diseases, has a unique perspective on medical challenges worldwide, which makes his description of ME/CFS especially telling.

So why is this disease so challenging? The answer is manifold.

1. The biological pathways involved in the disease are themselves very complex to investigate since by all indications they affect systems that are pleiotropic by nature; that is, they affect multiple interwoven systems and targets. Take cortisol, for instance, which is a critical steroid hormone regulator within neuroendocrine signaling. But at the same time, cortisol regulates critical components of cellular energy production—known as bioenergetics—and influences essential regulators of inflammatory cytokines as well. So one singular factor, which is reduced in most ME/CFS patients, controls functions and systems that are intertwined, complex and interconnected. When it goes awry, the consequences become multifactorial.
2. Solving medical mysteries, particularly stubborn ones, has been throughout history inversely proportional to investment in clinical investigations and basic research. Many precedents from polio, to HIV, to prion disease have taught us this repeatedly. It is, therefore, consequential that the meager spending on ME/CFS to date continues to sustain, if not fuel, the challenging nature of this disease.
3. There is no national strategy for attracting talented researchers to study ME/CFS. Such a strategy would facilitate entry of scientists into this stimulating area of research through, for instance: funding clinical and research mentorship programs in ME/CFS; establishing permanent federal grant opportunities targeted to ME/CFS; and defining the illness as one of the “most challenging” diseases in medical school curricula across the country.
4. A failure of the established psychiatric medical associations to take a clear and courageous stand on the etiology of ME/CFS as a physiological—not psychological—disease is also part of the challenge.
5. The reluctance of most pharmaceutical companies to invest in the ME/CFS field absent defined biomarkers. This eliminates the bulk of the financial and technological contributions from the private sector.



Dr. Zaher Nahle, PhD, MPA

As we pursue our research and scientific programs and move forward with optimism in this climate of change at the national level, we are mitigating these challenges in several ways.

First, **we continue to put resources into projects that lower the research barriers for new, as well as established, investigators studying ME/CFS.** This enables scientists to acquire preliminary data and target larger funding opportunities, especially federal grants. We promote this function in at least two ways.

- One, we strive to supply any investigator who wants to study ME/CFS the research materials they need, using our Solve CFS BioBank and Patient Registry resources.
- And two, we fund meritorious grants through a competitive peer-review process to identify innovative technologies, concepts and biomarkers. Thus far, this has proven to be a durable partnership with our patient, researcher and donor communities and an important component of our overall mission.

Second, **we engage with government leaders, particularly those responsible for decision making in research and investigating diseases.** By cultivating these relationships, we can assure that the needs of research and researchers are articulated firmly and professionally. This research approach is driven by two fundamental beliefs:

- one, that it is the responsibility of the government to find cures for up to 2.5 million ME/CFS patients and not the other way around; and
- two, that major discoveries will not happen without significant funding from the federal government as we recently communicated in a meeting with NIH officials. These efforts, which we consider essential to our core mission, establish a healthy partnership with national and public health organizations while simultaneously maintaining the pressure aimed at finding real solutions to our disease.

Thirdly, **we maintain vigilance against misleading information and poorly designed studies** and disseminate information to refute suspect science.

Fourth, **through outreach to the pharmaceutical industry, we cultivate opportunities to help identify biomarkers.** We are currently expanding these efforts and are growing our partnerships, including sponsoring and collaborating on clinical trials with leaders in the field.

Fifth, and final, **we have developed an investigation framework that focuses on original research in three areas of promise in the ME/CFS field:**

Bioenergetics: Bioenergetics is the fundamental process of generating energy for physical and cognitive use. This broad area includes, but is not limited to: the cellular adaptation to metabolic and genetic stress conditions; mitochondrial dysfunction; cellular signaling and biochemical processes; as well as the interface between hormone functions involved in energy storage and utilization and nutrient/gene interaction regulating energy production.

Neuroendocrine Biology: One of the most critical pathways that controls stress response is what is referred to as the Hypothalamic-Pituitary-Adrenal axis, or HPA axis. Cortisol is just one player in this axis. There is great potential to learn from a wealth of knowledge already acquired from fields like obesity and diabetes, where this pathway is also involved.

Inflammation/Immunity: The area of Inflammation and immunity holds promise as well, for many reasons. This is among the most studied area of investigation within the ME/CFS field and the focus of a clinical trial recently established at the NIH. The promise this holds is across many fields, such as: pathogen host interaction, autoimmunity, immunotherapy, and the broad role of functions of inflammation in ME/CFS.

To achieve our research goals, the Solve ME/CFS Initiative will leverage our key assets, which include; a Research Advisory Council made up of highly respected experts drawn from diverse fields; our well-established Solve CFS BioBank and Patient Registry; an international network of researchers; a deeply committed board, each of whom has a personal connection to the disease; and our track record of successful seed grant funding.

Through our research activities, the Solve ME/CFS Initiative is remedying many key challenges confronting this community. We work to add value in our research endeavors by pursuing the most innovative applications and ideas in the ME/CFS field. ■

Updates on Solve ME/CFS Initiative-Funded Research

Dr. Dane Cook's PEM Research

Dr. Dane Cook, Co-Director of the Exercise Psychology Laboratory at the University of Wisconsin-Madison and Director of the Marsh Center for Research in Exercise and Movement, continues work on the research study on post-exertional malaise (PEM) that he launched thanks to the award he received from the Solve ME/CFS Initiative in 2012.

Generally speaking, PEM has been described as a debilitating exacerbation of the entire constellation of ME/CFS symptoms. Both 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.

Previous work by Dr. Cook (Meyer et al., 2013—funded by the Solve ME/CFS Initiative) demonstrated increased gene expression for several receptors, including adrenergic and cortisol, following maximal exercise in ME/CFS patients compared with controls. In a most recent SMCI-funded study, 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,



Dr. Dane Cook continues to investigate post-exertional malaise at the University of Wisconsin-Madison.

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 work, 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. Work is concentrated now 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 Nova Southeastern University—all previous recipients of Solve ME/CFS Initiative research funds. 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. ■

On Nov. 19, Dr. Cook presented “Deciphering Post-Exertion Malaise: The Intersection of Biology and Behavior,” as part of the Solve ME/CFS Initiative’s 2015 Webinar Series.

To view the webinar recording, go to our YouTube channel:

youtube.com/SolveCFS.

Update on Biovista Project

The Solve ME/CFS Initiative continues to work with Biovista, a biotech firm with expertise in repurposing old drugs for new uses, on the drug combination of predicted targets for ME/CFS. We anticipate being able to share the results with the community in early 2016.

In 2012, the Solve ME/CFS Initiative contracted with Biovista to take advantage of the company's unique computational platform and expertise to identify drug repurposing opportunities for the treatment of ME/CFS. These compounds were reviewed for a range of ME/CFS symptoms, including cognitive impairment and unrefreshing sleep.

Drugs antagonizing the effects of serotonin—which is elevated in ME/CFS—have been particularly examined using the company's proprietary algorithms for their



potential benefit in ME/CFS. Profiles of all approved drugs exhibiting such behavior were then matched against the symptoms, comorbidities and known elements of ME/CFS pathophysiology.

A specific drug combination with the potential to offer benefits to ME/CFS patients, including the improvement of the frequently comorbid sleep difficulties, depression and pain, was finally detected and characterized. We will keep our community updated as we finalize these important results.

Dr. McGowan's Epigenetic Research

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 now, first through a seed grant in 2012 and then through a 2014 grant from the Falk Foundation. Epigenetics is the research field that studies changes in the regulation of



Dr. Patrick McGowan is analyzing genetic alterations in patients.

genes that are influenced by non-genetic or external factors, such as chemical imbalance, nutrition and the environment. The Solve ME/CFS Initiative-funded studies detected pronounced differences in epigenetics in several biological pathways.

Blood from approximately 100 patients and healthy control counterparts has been collected, processed and shipped to Dr. McGowan's laboratory. Work is currently underway to analyze the epigenome—all of the epigenetic alterations across the whole genome—in the study participants. The work is being done in collaboration with the Bateman Horne Clinic in Salt Lake City, Utah. The Bateman Horne Clinic recruited patients and provided demographic and health questionnaire data, along with results from a physical examination, to annotate

blood samples that will be used in the epigenetic research as well as stored in a biorepository for future research.

Early results from these investigations indicate that a number of epigenetic markers are associated with the response to glucocorticoids and certain ME/CFS symptoms. The epigenetic marks also appear to be distinct in immune cells from ME/CFS sufferers that show a robust response to the glucocorticoids.

Although these results are preliminary, they suggest that epigenetic markers may one day be helpful in classifying subtypes of the disease. The team is currently examining the relationship between genetic differences and epigenetic marks to discover the role of environmental and other non-genetic factors in ME/CFS symptoms.

Give a Gift of Research for ME/CFS Patients

Support the Solve ME/CFS Initiative Research Program

Ask any ME/CFS patient, and they will tell you why we need medical research.

“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 weary 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 lives might not be so limited.

The Solve ME/CFS Initiative is pleased by the National Institutes of Health’s newly announced focus on ME/CFS research. We are hopeful for meaningful progress and much larger, appropriate funding levels for our disease. We also realize the necessity of maintaining—and even increasing—the intensity of our research work to ensure that there are sufficient researchers doing “proof of concept” studies which we fund. Our seed grant studies improve the chances of investigators securing NIH funding for larger, more comprehensive studies that will move the ME/CFS science forward.

Looking for a way to support our work? The Solve ME/CFS Initiative Giving Guide provides several examples of ways your donation contributes to the realization of our plans. Every gift matters and brings us closer to achieving our goal of making ME/CFS understood, diagnosable and treatable. ■

To make a gift, go to solvecfs.org/donate.
Thank you for supporting our research work
with your tax-deductible gift.

Solve ME/CFS Initiative

GIVING GUIDE

Gift ideas to support our research program

\$33

Store one BioBank sample for one month
maintains vital research resource

\$1,220

Sponsor one-day strategy session with NIH leaders
influences direction of federal research plan

\$55

Add new patient records to our Registry
important precursor to biomarker study that leads to credible diagnosis

\$5,530

Create one clinical study protocol
accelerates clinical trials for treatment and cure

\$262

Enroll a patient in the BioBank
enables more research studies

\$10,000

Fund one-tenth of a biomarker study
facilitates credible diagnosis

\$517

Enroll a bedridden patient in the BioBank
encourages inclusion of disenfranchised patients

\$25,500

Support one pilot study for proof of concept
leads to therapeutic treatment

Make your tax-deductible gift at SOLVECFS.ORG/DONATE

Humans of ME/CFS: We Want to Hear Your Story

The Solve ME/CFS Initiative has launched a campaign to help increase awareness of—and ultimately research funding for—ME/CFS. The campaign, “Humans of ME/CFS” is a takeoff of the popular “Humans of New York” photoblog and Facebook page and is housed on our website: HOMECEFS.SolveCFS.org.

On the website, we share the personal stories of ME/CFS sufferers so that those in charge of allocating research funds cannot deny the widespread devastation this disease has inflicted on so many for so long.

The site is intended to be a community-wide resource that patients, family members and advocates worldwide



can use as they seek to increase awareness and understanding of the disease among family, friends, co-workers, medical professionals, politicians and anyone else in their sphere of influence.

In just a short period of time, we have already received almost 100 entries from patients internationally.

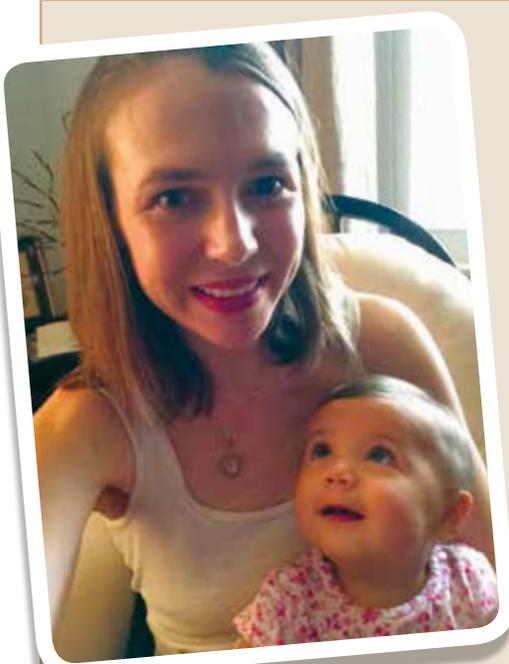
Given that there are up to 2.5 million ME/CFS patients in the United States and an estimated 20 million worldwide, we have no shortage of stories to tell as a community. We would love to include your journey with ME/CFS on the website. To share your own story or read those of others, go to: HOMECEFS.SolveCFS.org. ■

Lauren S.: My Humans of ME/CFS Story

I got mononucleosis when I was a freshman in college in 2003. My body was never the same after that. I noticed I had significantly less strength and stamina. Also, I seemed to get what felt like the flu for weeks at a time every year. I still managed to graduate and go on to spend five years as a high school history teacher.

In 2011, I was having a particularly stressful year. I had a very bad reaction to an antibiotic I took, and that's when things really fell apart with my health. Suddenly, everything I was eating was going straight through me, and I had unrelenting stomach pain. As I was going through all the testing with my gastroenterologist, I recall the “flu” hit me like a linebacker after a colonoscopy. I would use every ounce of strength to get up, get dressed and go into work. After my first class ended and my planning began, the room would spin, and

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Lauren S.: My Humans of ME/CFS Story (continued from Page 11)

I would be able to barely lift my head off my desk.

By January 2012, I knew I was doing my students and coworkers a disservice by attempting to hold onto my job—my teaching job that meant the world to me. The students deserved a teacher that could actually make it into class. I moved in with my wonderful boyfriend, now husband, as I could no longer live on my own.

I was diagnosed with fibromyalgia/CFS in early 2012. I was relieved to put a

name to the odd collection of mysterious symptoms I had experienced for the last 10 years. Yet leaving my career and still being virtually bedridden presented a whole new set of challenges. The debilitating fatigue was now on par with the confusion one would experience with a complete loss of independence and identity.

I did the dance of a million different doctors, specialists, Eastern medicine and found the only things that provided modest improvement were antiviral

medications, antidepressants and pacing myself. That and I have been blessed with an amazing support system. Many times, I wanted to give up and, every time I did, a family member or a friend would show up on my doorstep. Namely, my father in one of my most desperate times.

I have since married, and we have an incredibly happy, healthy seven-month-old little girl.

I am so grateful this disease is getting the recognition it deserves. ■

Stay in touch!

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