



# Solve ME/CFS Initiative

Leveraging patient-centered  
research to cure ME/CFS

The SolveCFS Chronicle

Fall 2015

## An ME Love Story

By Jeryldine Saville

**When Walter Irvine met Chardale Dotson at a 12-step meeting in 1996, she had just experienced the onset of symptoms that would later be diagnosed as Myalgic Encephalomyelitis.**

Char, as Walt calls her, had been working as an administrative assistant in the Boulder District of the U.S. Forest Service, when she came down with the same flu that hit everyone in her office. Like the rest of her coworkers, Char was out sick for roughly two weeks. Unlike the others, however, when she returned to work, she still hadn't bounced back. Her symptoms became so severe that she was forced to put self-preservation above all other roles—employee, daughter, and even mother.



Chardale Dotson and Walter Irvine a few weeks before their wedding in 2002.

She left her three children with her ex-husband in Denver and traveled to the mountains of Monroe, Utah, where she spent a year and a half in a trailer sleeping and doing virtually nothing else. She had her dog as a companion, and her mother would come to spend time with her when Char was at her worst, helping her get showered and cook her food.

As painful—and shameful—as the time was for Char and her children, it was exactly what she needed. Thanks in part to the extraordinary amount of rest, as well as some natural medicine she received from a holistic practitioner, she went into remission and was able to return to work for the Six County Association of Governments and get an apartment in Richfield, Utah. She was feeling good when she received a call from Walt, who had happened across her name in his address book and wanted to check in to see how her recovery was going.

Walt was living in Greeley, Colo., at the time, and the two began a phone

*Continued on Page 12*

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# A Defining Moment for ME/CFS Organizations

**There comes a point in many ME/CFS patients' lives when they realize they can no longer function without working interdependently with others. For many—including myself, a high-achieving, hard-driving career woman who never let a road bump slow me down—this was a humbling experience.**



**Carol Head**  
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To realize that you simply can no longer produce at the level at which you have been—whether it's working a professional job, raising a family, or simply cooking a meal or taking a shower—is devastating. And then, perhaps, you realize that the process is easier and the outcome is better when you are working side by side with someone who shares your goals.

I believe we have finally reached that point in the ME/CFS community.

As many of you are aware, the organizations that have been formed over the decades to raise awareness, increase research funding and lend support to the millions of ME/CFS patients suffering throughout the world have not always worked in concert. While all groups were well-intentioned and earnest, the differences in approach and execution sometimes created divides. The upshot was a fractured advocate and research community that lacked synergy and the influence and power that comes from working together.

This year has been a watershed in the history of ME/CFS. We have seen the Institute of Medicine and the Pathways to Prevention reports validate the serious physiological underpinnings of this

disease. We have seen media reports about our disease in the most respected national news outlets. And yet, our community's reward for this wonderful support at the highest levels of government and media? The proposed reduction of the already grossly inadequate \$5.4 million in ME/CFS CDC funding to \$0, which would mean that a monumental CDC multi-site ME/CFS study will not be able to be completed.

This appalling effort, which at press time is still being debated in the Senate Appropriations Committee, was the moment that galvanized our community. The moment when phones were picked up, emails were sent, meetings were convened and differences were set aside. This elimination of funding was the rallying point that all of us could get behind.

And as inhumane and insulting as the proposed deletion of CDC funding was to all of us who have suffered from this disease, it also was a great gift. Because now, we are working together. We are sharing ideas, leveraging resources and implementing tactics as a single dynamic and powerful community. The community we were intended to be all along. Onward! ■

# ME/CFS By the Numbers



- 84% to 91% of ME/CFS patients are not yet diagnosed
- Burden of \$17-24 Billion per year on the U.S. economy
- At least 25% of ME/CFS patients are house- or bed-bound at some point in their lives
- Only \$5 Million in funding for ME/CFS from NIH in 2014

## \$'s Spent Per Patient | 2014 NIH FUNDING



**ME/CFS RANKS 232 OUT OF THE 242  
NIH SPENDING CATEGORIES**

## In this issue

Page 1

An ME Love Story

Page 2

From our President  
Board of Directors and Professional Staff

Page 4

A Conversation with Dr. Zaher Nahle,  
Vice President of Research and Scientific  
Programs

Page 8

SolveCFS BioBank™ Gets Retooled and  
Renamed

Page 10

SMCI Adds New Board Members

Page 15

The Defeat ME/CFS Research Plan



# A Conversation with Dr. Zaher Nahle

## Vice President for Research and Scientific Programs

Zaher Nahle, PhD, MPA, became Vice President for Research and Scientific Programs at the Solve ME/CFS Initiative in June. In this Q&A, Dr. Nahle provides his thoughts on how he will approach the exciting undertaking of leading SMCI's research program during a period with great momentum.

**Q: What drew you to this position?**

A: I wanted to work for a mission-driven national organization in the field of health sciences that is making a difference. That was the general framework and my mindset initially. What made this position my top choice over all others is the nature of the illness itself. It is so challenging: a disease with difficult diagnosis, unknown etiologies and no cures. That either makes people run to the door or be mesmerized by it out of sheer scientific curiosity. It is a multifactorial disease where immune, endocrine, nervous and skeletal systems, to name a few, are contributing one way or another, and to someone with a PhD in Physiology and Biophysics, that is a goldmine of intellectual stimulation.

But what clinched it for me was the type of colleagues I get to work with, who are both professional and compassionate. I met with President Carol Head and several board members during the interview process, and I felt that we shared the same vision. They are



Dr. Nahle has a PhD in Physiology and Biophysics from Cold Spring Harbor Laboratory and Stony Brook University and a Master in Public Administration from Harvard University's John F. Kennedy School of Government.

Dr. Nahle also completed post-doctoral fellowships at Harvard and Stony Brook. He has a history of securing prestigious funding in healthcare and patient-oriented research and has generated \$7.4 million in total research funding through direct competitions and philanthropic solicitations.

all either themselves patients or have a spouse or child afflicted with this disease, so I recognized that this is a serious organization with invested and committed leadership. These are the types of folks I like to be associated with in creating value and investing my time and effort at this stage of my life.

**Q: What are your early impressions of the community?**

A: My impression is that this is a wonderful community that has been disenfranchised for far too long. I am still learning and developing relationships, and my hands are extended to everyone who wants to collaborate and join forces or just offer tips, advice or simply talk.

I had an opportunity recently to meet with patients for I wanted my first engagement at the Solve ME/CFS Initiative to be unfiltered and right at the source: face to face with patients and their families. That was truly a powerful experience that shaped my thinking and cemented my commitment to this plight.

**Q: You have had training and degrees from the most prestigious institutions like Harvard and Cold Spring Harbor Laboratory, publications in *Nature* and many high-profile awards. How will your background help you in your position at the Solve ME/CFS Initiative?**

A. First of all, BEWARE of entitlement! Many mistake the fact that they went to a good school or trained in prestigious

environments as an inevitability for their success in life and sufficient preparation. That is a trap.

I am pleased that I was competitive in awards and admissions and have been in places where folks before me went on to do good things in life. But that is precisely why I take this responsibility very seriously.

On the practical side, the networks of connections to established institutions, mentors, alumni platforms and resources is helpful, and we have started tapping into that already to give more visibility to this disease and describe our work in these circles.

While I have been in the United States since 1998, I came from a humble background in Lebanon, and my parents are hardworking schoolteachers, so that keeps me honest, too. Teachers usually ask you what are you doing now and next, not what you did before!

**Q: What will be your approach to tackling this mysterious and insidious disease?**

**A:** A collaborative approach, first and foremost. This is not one of those individual activities or solitary exercises. We must come at this from different angles but share ideas and expertise and be methodical and adaptive about it—not wedded to one rigid belief or concept. I appreciate individual

passion about one particular hypothesis because, after all, curiosity and drive is a great motivator, but at the same time sharing ideas and creating an intellectual space for an open exchange and dialogue is what makes us hone our skills and better our thinking. That is my vision for the Solve ME/CFS Initiative research program.

Second, I am a strong believer that for this disease, I am not interested in conducting science just for the sake of science. Everything we do and focus on must be translational—applicable to treatment modalities—and have potential for therapeutic manipulations. Our scientific research will be focused in three main areas of investigation: bioenergetic dysfunction, neuroendocrine malfunction and immunity/inflammation

pathologies. Each of these broad categories carries promise and hope toward understanding the disease and finding treatments and cures.

The third point I will stress is the emphasis on quality and integrity. I will never forget the advice a very famous scientist whom I idealized gave me at my PhD graduation party at Cold Spring Harbor Laboratory. He said two things, while motioning the V sign with his fingers: 1. “Garbage in, garbage out”—so, focus on quality; and 2. “Fast is slow, and slow is fast”—as in, don’t cut corners. I have been heeding that advice ever since.

Finally, our methodologies have to be innovative in looking at this disease; we must use modern and complementary approaches. For example, we need to



## A Conversation with Dr. Zaher Nahle (continued from Page 5)

generate hypotheses in unbiased ways, such as employing high-throughput methodologies and large-scale screens. We also must have an equal focus on testing and validating these hypotheses in our particular contexts in vivo, not in theory, via hardcore mechanistic investigations of the basic sciences. This is what leads to understanding signaling pathways and the cellular hardwiring of pathophysiology and then targeted therapy.

I have to also say that it is truly difficult to be in the shoes of ME/CFS researchers given the lack of funding. Working to increase funding is also part of my approach.

**Q: How is your experience in public policy and public administration relevant in the scientific field of biomedical research and for this role specifically?**

A: For us to effect change at a larger scale, we must devise clever and feasible policies, understand how regulated industries really work, and build consensus, regardless of personal differences or agendas, particularly in creative fields like research. My education at Harvard added modern techniques in dispute resolution, organizational behavior, public-private partnership, policy analysis and national campaign design, as well as negotiation and persuasion to all my technical and scientific training.

This background is useful as we expand our research programs and retool our Solve CFS BioBank and Patient Registry, which is a public resource designed solely for the benefit of our researcher and patient communities.

**Q: What do you think will be your greatest challenge?**

A: This community has been dealing with challenges for decades. I wrote a blog post not too long ago about the challenge of funding, especially in light of the recently proposed CDC cuts. It is truly a barrier. Even with the best intentions and the greatest minds, without funds, little can be achieved in biomedical research, at least not at the pace that is commensurate with the gravity

of the situation, considering up to 2.5 million are affected by this in the United States alone.

There are many other barriers including the entry of new investigators into this field, the lack of incentives, such as research dollars, and the paucity of comprehensive and large patient registries that could inform the community about demographics, natural history, disparities, quality of care, etc., that influence the prognosis for ME/CFS.

We are doing all we can at the Solve ME/CFS Initiative to fill that research gap and drive collaborations that foster promising discoveries. That said, we insist on a clear, tractable and transparent federal funding agenda for ME/



Dr. Nahle with former classmate and riding buddy, Mark Asuncion, U.S. Navy Captain, in Harvard Square



**“It is the responsibility of the government to investigate cures for diseases afflicting millions of its citizens, not the other way round.”**

CFS as the most effective path toward a cure. It is the responsibility of the government to investigate cures for diseases afflicting millions of its citizens, not the other way round.

The other challenge that I see is man-made and not policy related. Every now and then we have a “genius” poking their head in and lecturing us about somatization or regurgitating the fallacies of those two psychiatrists back in the 1970s who refused to accept this disease as a real physiological disease and even tried to change the name of Myalgic Encephalomyelitis to Encephalomyelitis Nervosa; because it affected mostly women, they felt it must be hysteria. So, really, we are combating sexism camouflaged with junk science and fueled by ignorance. These human barriers to progress bother me.

While everyone is entitled to her or his opinion, they are hurtful to the morale of the community and also disturbing

in the sphere of public opinion. They provide a counter-narrative to progress and the advancement of science and muddy the water.

I do not include in this group healthcare professionals who are not informed; it is important that they be educated on recent progress, case definitions and new advances in basic and medical research.

**Q: How has your transition to your new role in Los Angeles been?**

A: I feel that everything I have done so far has prepared me, one way or another, for this transition: scientific training, public policy and administration credentials and, recently, work on the disability agenda. I have been deeply involved for the last few years with the plight of the physically disabled and



Dr. Nahle, with Mukhtar Ogle, Co-Founder of Ibrak Disability Empowerment

have co-founded an organization—Ibrak Partners that operates primarily in Africa—with a classmate at Harvard stricken by polio.

I worked with various stakeholders and national and international councils and organizations to drive forward the disability agenda and provide services to the most vulnerable populations, especially children with physical disabilities. So that helped me understand at least the struggles for recognition, research and medical care in diseases seriously affecting function and mobility like ME/CFS.

I live and work less than 10 miles from downtown LA and have been trying to find an hour to go there since I joined the organization, but I still have never been. That gives you an idea of the intensity at our organization, but that is the good kind of busy. I work with an exceptional team at the Solve ME/CFS Initiative, who have made my transition as smooth as possible.

I am liking the weather in Southern California and appreciating the fact that I can enjoy every day without much planning or time constraints. I enjoy riding my motorcycle and am looking forward to some trips up and down the California coast. ■

# SolveCFS BioBank™ Gets Retooled and Renamed



The Solve CFS BioBank™ has been renamed the Solve CFS BioBank and Patient Registry to reflect its scope as an even broader, more accessible and robust resource for patient-centered research. Since its creation, the BioBank, which is made possible thanks to the participation of patient volunteers who donate their blood and tissue samples and share their disease experiences to advance knowledge in this field, has proven itself as a credible and reliable tool for researchers.

The newly retooled Solve CFS BioBank and Patient Registry features revised and simplified content and a streamlined interface, both in print and online, which makes it easier for researchers and participants to navigate. Many of these changes are based on feedback from the patient community. In addition to continuing to serve as a data mining and sample collection tool that captures participants' ME/CFS experience at the time of enrollment, the Solve CFS BioBank and Patient Registry will also begin to collect longitudinal data on individual subjects at multiple points in time.

The collection of longitudinal data will enable BioBank administrators to engage with participants on a more regular basis. The BioBank will also capture more specific information at the time of enrollment. Participants with ME/CFS have now been broken down into more appropriate categories, such as "ME/CFS patient diagnosed by a physician," "Patient not yet diagnosed" or "Patient in recovery/remission."

These and other improvements will not only enable researchers to narrow in on the types of samples they need, but also allow patients to report their experience with greater precision initially and over time, which can be valuable for studies aimed at understanding the course of the disease, health care disparities, effectiveness, cost, safety, treatment paradigms, disease pattern or other factors that could influence prognosis in ME/CFS patients.

## Key Features

- The availability of clinical information and accessible samples reduces barriers and costs of doing research to investigators.
- Strict safeguards are used to assure the confidentiality and integrity of clinical information and samples.
- Privacy is ensured by assigning unique hash codes to participants so that data and samples are tractable across multiple studies; this also eliminates duplication or redundancy.
- An on-demand system is used to maximize efficiency so that consented patients are only contacted when a suitable study with matching specifications materialize.



Here's a look at key changes by category.

## Patients

The Solve ME/CFS Initiative continues to collaborate with ME/CFS clinics to facilitate the procurement of research materials from our large base of consented volunteers during routine and scheduled visits. Additionally, patients—especially those with limited access to these clinics—will now have access to more than 1,700 specialized collection sites for professional medical handling and processing throughout the United States. The graphic at right—also available at [solvecfs.org/biobank](http://solvecfs.org/biobank)—shows how easy it is for patients to locate a site near them. The new process not only minimizes the travel needed on the part of our community, but also maintains consistent processing of acquired samples from all consented patients.

The process also enables us to reach as many patients as possible, including those located outside major metropolitan areas. As we retool and improve our plans, we're focused on being able to reach the severely ill, house-bound or bedridden patients, who are particularly isolated with no ability for regular clinic visits, let alone participation in demanding research activities. Through mobile clinics and targeted at-home phlebotomy services, participation by our severely ill patients can be made possible.

Our intent is to give a voice and representation to the most vulnerable patients and establish a more comprehensive database for specialized projects studying this patient population. As new methodologies in data acquisition, tracking, processing and collection evolve, we will revise and update our processes accordingly. Patients and healthy controls—who are particularly needed—that have questions about the Solve CFS BioBank and Patient Registry should contact Veena Manohar at [vmanohar@solvecfs.org](mailto:vmanohar@solvecfs.org).

## Researchers

We have put new policies into place to make it easier for investigators to acquire research materials from the Solve CFS BioBank and Patient Registry. The graphic on Page 14 outlines the key steps in the application process. Applications



## Patient Enrollment Process

To view the graphic online, go to [solvecfs.org/biobank](http://solvecfs.org/biobank).

To enroll in the  
SolveCFS BioBank  
and Patient Registry,  
go to  
[solvecfs.org/biobank](http://solvecfs.org/biobank)

*continued on Page 14*

# SMCI Adds New Board Members

The Solve ME/CFS Initiative has added three new members to its Board of Directors: John Nicols, Sue Perpich and Susan Vitka. In keeping with our organization's commitment to represent the patient community as passionately and accurately as possible, all three new Board members have a personal connection to the disease.



**John Nicols** currently serves as President and CEO of Codexis Inc., a leading San Francisco Bay Area biotechnology company that engineers and markets proprietary proteins for the world's pharmaceutical industry. John started as CEO of Codexis in June of 2012 and also serves on the publicly listed company's board of directors.

Prior to Codexis, John held roles of increasing responsibility over a 22-year career at Albemarle Corporation, a globally leading specialty chemical company headquartered in Baton Rouge, La. Before leaving Albemarle, John was responsible for the corporation's strategic development department as well as the company's flagship \$1+ billion global catalyst business. During his tenure at Albemarle, John and his family resided for three years in Tokyo.

A native of New York City, John earned an MBA from the Sloan School of Management, and a Bachelor of Science in Chemical Engineering from the NYU Polytechnic University. John has served on numerous trade association boards during his extensive career, including currently serving on the board of directors of BayBio, the premier biotechnology industry association in the San Francisco Bay Area.

John is married with two children and four grandchildren. His wife, Marcie, has suffered for over 20 years with Myalgic Encephalomyelitis (ME/CFS) and Fibromyalgia.



**Sue Perpich** has built a career of successfully bringing people together around a common goal at the top levels of business, industry and government. She has represented diverse industries in the areas of business development and high-level sales, where she has been successful in negotiating within various sectors such as government and multinational business. She currently serves as a Senior Advisor for Eastbridge Strategies in London. Sue previously held senior positions at a range of national and multinational firms, including: Al Khaymah Establishment U.S.A., an international company that forges joint ventures between U.S. and Saudi Arabian companies; The Livingston Group,

a Washington, D.C., based lobbying and government relations firm; and Drexel Burnham Lambert, a Wall Street investment banking firm.

Sue earned a bachelor's degree in Business Administration & Management from the University of St. Thomas in Saint Paul, Minn., and an MBA from Fordham University in New York.

Sue's father, the influential and beloved late Gov. Rudy Perpich (D-MN), began public awareness and fundraising efforts on behalf of his son and Sue's brother, Rudy, who has been debilitated by ME/CFS since graduating from Stanford Law School over 30 years ago. In recognition of Gov. Perpich's distinguished service to the IACFS/ME, the Board of Directors established a Senior Lectureship Award in his memory. The award is presented to a distinguished CFS/FM scientist, physician or healthcare worker every two years at the IACFS/ME conferences.

Sue continues her father's good work on behalf of her brother and all of those who suffer from this disease.

**Susan Vitka** brings over 30 years of experience advising clients ranging from startups to Fortune 100 companies on complex financial and competitive matters. Susan was a principal at Charles River Associates; prior to that, she held senior positions at Putnam, Hayes & Bartlett and The Brattle Group. She maintains an independent advisory practice and is an active early stage investor.

Susan has served on numerous boards in the U.S. and abroad, including Women for Women International, Women for Women International UK (as chair), Physicians for Human Rights, and Nest (as founding chair). She currently serves on the Advisory Board of the Carr Center for Human Rights Policy at the Harvard Kennedy School of Government, the President's Board of The Physicians Committee for Responsible Medicine, and is Vice Chair of the board of The Environmental Film Festival in Washington, D.C.

A lifelong student, Susan received her undergraduate degree from Mount Holyoke College, did her graduate work in Economics at The London School of Economics and Harvard University, and has done additional graduate work in public health, immunology and nutrition. ■





# An ME Love Story

(continued from Page 1)

friendship that lasted for three months. They would call each other at 9:01 each night—right after the long-distance cell phone minutes became free—and talk for hours, sometimes watching basketball games together. Char had been a standout player on her college team at the University of Wyoming.

Walt, who was working as a computer programmer at the time, suggested they get together in person. Char was nervous to see him after so many years since she had put on 80 pounds from her illness and was wondering if he would still find her attractive. She put her pride aside, and the two reconnected in September 2001. “We had our first face-to-face in nearly six years, and it was like magic,” Walt recalls.

***His favorite thing to say to her was: “I’d swim the ocean for you.”***

A few months later, Walt had planned a casino and golf trip in Mesquite, Nev., over Christmas and asked Char if she wanted to go with him. She said yes, and they headed out on the freeway. As they were traveling along Interstate 70, Walt said, “Hey, do you want to get married?” A surprised Char said, “Uh, sure!” They stopped in St. George, Utah, to pick up the rings and tied the knot in a civil ceremony at the Las Vegas Courthouse just before midnight on Dec. 26, 2002.

Walt was devoted to his wife and “lived every day to help her fill her bucket

list.” He took her on a cruise to Mexico, where she swam with the dolphins, and took her whale watching in San Diego. He surprised her with tickets to concerts by all of her favorite musicians—Brooks & Dunn, Tim McGraw, Celine Dion. His favorite thing to say to her was: “I’d swim the ocean for you.”

And then something unexpected happened: Walt got sick, too.

He had just been under an extreme amount of stress, having abruptly lost his high-paying contractor job and had to move to Oregon on short notice for new employment. He had been pursuing a graduate degree and was completing his coursework just prior to the move, including giving a paper and a presentation the evening before. His normally good health also had some hiccups as he had been involved in a small RV accident and had surgery on his neck to remove two bone spurs. He went to see a doctor who told him that if he didn’t shed some stress from his life soon, his coping mechanism would be broken.

“My immune system was shut down from all the trauma,” Walt said. And yet, “Neither one of us realized I had ME. I never suspected that I had it. I thought it was just the neck surgery that was taking forever to heal.”



Char was the one who first noticed the changes. Whereas Walt used to bounce out of bed in the morning, he was sleeping in, and Char would have to wake him so that he wouldn't be late for work. "She could tell that I was going downhill," Walt said.

It wasn't until 2012, when Char was diagnosed with ME during an appointment with a doctor in Orlando, that the doctor also began to ask Walt about his health. He ended up being diagnosed, too, and his last day of employment was Dec. 22, 2012.

The inability to work was devastating for Walt. Even more upsetting was that he could no longer take care of his wife. "It was very hard on our marriage—my being sick and her being sick," he says. "I felt very angry that I couldn't be her caregiver anymore. I felt that I failed. Until I got sick, she was the princess."

Walt dealt with his inadequacies the only way he knew how: He started pushing Char away. "It's very hard emotionally to be a positive and upbeat person if you don't have anything you have faith in," he explains. "When I lost my faith, I lost Char."

Walt says that Char was unfailingly loving and forgiving during this two-year period, but that ultimately, the emotional distance between them was too much for her to take. "I was the



only thread of life that she was holding on to," he says. "Losing the marriage was the thing that pushed her over the edge."

She overdosed herself with insulin on Feb. 22 of this year. She was 54.

Her tombstone reads: "I told you I was sick. Taken by Myalgic Encephalomyelitis." The epitaph was one of Char's requests to Walt a year ago when she was having an especially difficult time with her illness.

Walt still blames himself for her loss and is seeing a therapist to deal with the grief. He's comforted by the fact that he can continue to help Char fulfill her wish of telling her story and having it make an impact on the officials who are in charge of funding research for the disease and the health care providers who are uneducated or outright dismissive of ME patients.

"She still fought every day to get a cure for me," he says. "She said, 'Walt, don't take no for an answer. You have a chance of being cured.' She was one of the most selfless people that I've ever known. She was always trying to help people achieve their greater good. That was her purpose."

Walt is still grieving the loss of his own purpose, with his career and his marriage now both over. "What can I do?" he asks. "The God of my understanding is gone." ■

**Walt asks that anyone who would like to honor Char's life make a gift to the Solve ME/CFS Initiative to help fund ME/CFS research.**

**To do so, go to [solvecfs.org/donate](https://solvecfs.org/donate) or call 704-364-0016.**

## SolveCFS BioBank™ (continued from Page 9)

will be evaluated by a research panel for both their scientific merit as well as the availability of samples of consented volunteers, based on the requests specified by researchers. Following the evaluation, investigators will be notified immediately, and samples will be earmarked for their projects, pending completion of required protocols if applicable.

This rapid review process, which should take only two weeks, will further fuel the surge in investigators who request samples from the Solve CFS BioBank and Patient Registry. Researchers who have questions about the application process or who want to relay specific requests, such as specialized research studies or studies with more demanding designs, should contact Dr. Zaher Nahle, Vice President for Research and Scientific Programs, at [znahle@solvecfs.org](mailto:znahle@solvecfs.org).

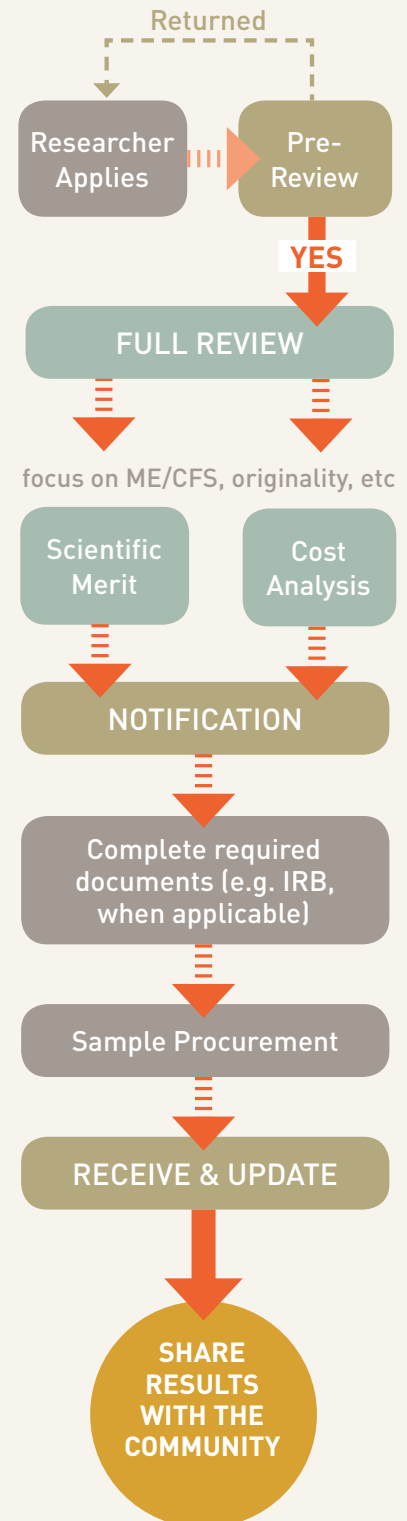
### In-House Studies

In addition to providing samples to investigators, we have expanded the scope of the Solve CFS BioBank and Patient Registry to include future mining and analyzing longitudinal, cross-sectional and demographic data in-house at the Solve ME/CFS Initiative. We're placing special emphasis on the quality and method in which such comprehensive data is acquired since this will determine the usability of the registry in making recommendations and generalizable conclusions.

We anticipate that the data collection will inform decision-makers, stakeholders and the patient community through evidence-based analysis. This could also provide statistical data that will prove helpful to investigators as they develop new research projects or expand existing ones. Other plans for sharing resources and collaboration with the Solve CFS BioBank and Patient Registry are in development and will be shared with our community as they materialize.

"It is an exciting time of growth and innovation in the investigation of ME/CFS," says Veena Manohar, BioBank and Patient Registry Coordinator. "The SMCI BioBank and Patient Registry is positioning itself to be an even more valuable tool for researchers who are working to find solutions to this confounding and persistent disease that is still so poorly understood." ■

## Researcher Enrollment Process







## Research to Improve the Lives of Millions

# The Defeat ME/CFS Research Plan

Devastating the lives of as many as 2.5 million Americans, ME/CFS is the most understudied, underfunded and underestimated disease facing us today. Under the direction of our newly appointed Vice President for Research and Scientific Programs, Dr. Zaher Nahle, the Defeat ME/CFS Research Plan is an ambitious strategy to transform ME/CFS from a medically unexplained syndrome to a diagnosable and treatable disease.

Our plan begins with the creation of a comprehensive “big data” database of medical and scientific information, alongside molecular investigations to which we will apply bioinformatics for systematic integration and analysis. We will actively expand our already well-established SolveCFS BioBank and Patient Registry by engaging a community of thousands to participate in research and contribute their disease experience information and biological samples. Working with preeminent scientists and using proven technology, we will generate molecular data about how genes, viral exposure, immune response and other factors contribute to ME/CFS and its subtypes.

### DEFEAT ME/CFS PLAN OUTCOMES

- 1** Define ME/CFS subtypes to provide patients with deeper insights into their own experience and effective, targeted treatments.
- 2** Foster understanding and acceptance among medical professionals, researchers and the greater public of the legitimacy of ME/CFS.
- 3** Create an enduring Information Commons, a knowledge network and ongoing tool for qualified researchers who have an interest in contributing to the ME/CFS field.
- 4** Develop committed partnerships with patients and pharmaceutical companies for clinical trials for diagnostic and drug development.
- 5** Build an infrastructure to drive objective diagnosis and targeted treatments as part of the FDA approval process.

*continued on Page 16*

## The Defeat ME/CFS Research Plan (continued from Page 15)

“ *We believe the best way to understand ME/CFS and provide patients with the answers they deserve is to provide direct evidence that comes from the combination of thousands of engaged patients and the highest quality research data.* ”

— Carol Head, President,  
Solve ME/CFS Initiative

As all patients with ME/CFS know, this is an extremely complex disease that is poorly understood by medical science. To date, much of the research conducted has been small scale and targeted to singular aspects of the disease. The Defeat ME/CFS Research Plan is a comprehensive plan to master the complexity of this illness and render meaningful results, bringing us closer to a cure.

There is no doubt this research is necessary. It is also clear that this important undertaking is an expensive proposition. Until ME/CFS receives substantial research funding from our federal government, we must rely on the continued generous support of patients, family members and friends. ■

To support our work,  
you can make a secure  
online donation at  
**DefeatMECFS.org**

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