

# Why Is Funding ME/CFS Research So Difficult?



Carol Head, President and CEO

Dear Friends,

It's a fresh new year...and once again we look forward to building on 2016's successes as we continue the too-long battle for treatments and a cure for patients with ME/CFS.

As we look to 2017, some of our 2016 work will certainly move forward. We know that the five Ramsay Award Program research projects (discussed in this issue's cover story) will proceed, and we know that our SMCI-Directed Research Studies (detailed on pages 6-7) will yield meaningful results. We will continue our research webinar series, just as we will continue to partner with other research and advocacy organizations.

And at the same time, as we look forward, some matters seem quite uncertain. With the federal administration transition, will National Institutes of Health (NIH) funds be expanded or cut? Will the next director of the Department of Health and Human Services (HHS) continue to support the Chronic Fatigue Syndrome Advisory Committee (CFSAC)? Will the Trans-NIH Working Group continue to build on its progress? Will the Centers for Disease Control and Prevention (CDC) continue its multi-site clinical assessment?

Certainly, come what may, we will continue our relentless, thoughtful, assertive work in both research and advocacy.

**On a different note**, I'm often asked why we, as a private medical research non-profit, repeatedly ask patients and their loved ones for financial donations to support our work. When other disease organizations like ours (e.g., Michael J. Fox Foundation for Parkinson's Research, Susan G. Komen, and the American Heart Association) obtain funds from a wide variety of sources, why don't we?

Certainly, this is top of mind for us! It is painful to ask for funding from those who suffer with this disease and often have extremely limited resources. So let me provide our perspective on this core funding problem our disease faces.

First, by far the primary source of funds for medical research in general is the federal government. Our efforts to obtain those funds for ME/CFS are years long and relentless. It is a long haul, and we have described this at length.

Second, there are unique attributes of our disease that make fundraising, both from individuals and private foundations (e.g. Gates, Ford, and Kaiser), quite difficult:

- **There's a stigma.** Most people simply still do not believe this disease is "real." We can report that our organization has received very few gifts from individuals who have not seen this disease up close and personal. For people who do

## SOLVE ME/CFS INITIATIVE PROFESSIONAL STAFF



Carol Head  
President and CEO



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



Karen Petersen  
Director of Development



Emily Taylor  
Advocacy and  
Engagement Manager



Jennifer Arganbright  
Communications and  
Media Relations Manager



Linda Leigh  
Accounting, HR, and  
Administration Manager



Mamie-Louise Anderson  
Administrative and  
Development Coordinator



Erin Davie  
Biobank and Patient  
Registry Coordinator



Diana Sagini  
Development Coordinator

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



Vicki Boies, PsyD  
Chair  
Chicago, IL



John Nicols  
Vice Chair  
Cupertino, CA



Beth Garfield, Esq.  
Treasurer  
Los Angeles, CA



Aaron Paas  
Secretary  
New York, NY



Michael Atherton  
Arlington, VA



Brett Balzer  
Chicago, IL



Diane Bean, Esq.  
Bethesda, MD



Mary Dimmock  
Waterford, CT



Fred Friedberg, PhD  
Stony Brook, NY



Carol Head  
Los Angeles, CA



Sue Perpich  
Minneapolis, MN



Rick Sprout  
Washington, DC



Christine Williams, M.Ed.  
Chevy Chase, MD

not live with this disease, if the donation choice is between this “weird disease,” which they may not even believe in, or, say, Lupus or MS or cancer—which people know are awful and real—where would you give your dollars?

- **There is little sense of urgency.** This disease has been around for a long time. And it’s not generally fatal (we know the disease can be fatal, but most don’t). As we sometimes say, “ME/CFS is a life sentence, not a death sentence.” Just think of the difference with AIDS in the 1990s, when people were suddenly dying quickly and in significant numbers.
- **The disease is complicated and poorly understood.** Where to start to do research? It can feel overwhelming for potential funders.
- **There is a tendency to give again where individuals and foundations have given before.** So it is a tough bootstrap effort to solicit *initial* gifts.

The other significant source of funds for other diseases is the pharmaceutical industry. Drug companies, as private, for-profit organizations, are responsible primarily to their shareholders. They generally invest in new drugs for diseases when there is a clear “target” for the drug.

With so very little understood about the underlying causes and attributes of ME/CFS, we are years away from a time when pharmaceutical companies are likely to step up. Of course, that time will come. The good news/bad news is that there are a lot of ME/CFS patients. So, at some point, this disease will become an attractive market for pharmaceutical companies—it just hasn’t yet.

Lastly, for individuals, the longstanding tradition of run/walks and other participatory events is difficult when folks don’t really believe in the disease. There doesn’t yet exist a critical mass of people who will put themselves out for this strange, misunderstood disease. The stigma is real. When someone says, “I’m going out to walk for breast cancer on Saturday!” there is much affirmation. Imagine someone saying, “I’m going out to walk for ME/CFS on Saturday!” to blank stares and perhaps even scoffing.

So where does that leave us regarding fundraising to fight for this disease? It’s adding insult to injury that ME/CFS patients carry the additional burden of funding research into this disease. We know that someday this will change. But until it does, please know that we must continue to ask...and we are deeply grateful for every gift. We know that every gift is given with passion and fervent hope. Our responsibility to use each dollar *effectively* lies heavy on my heart.

I end this letter with deep gratitude to the patients whom we serve. We stand when you cannot. We invest in research when you cannot. We advocate when you cannot. We fight when you cannot. Onward into 2017!

Carol