

Parting Thoughts from our President Carol Head

Dear Friends,

I spend virtually all my energy thinking about the awful, misunderstood disease that we know all too well. This intense focus is, indeed, my job, but more importantly my deeply felt passion.

I remember all too well my own anger, frustration and sense of injustice from those years when I lived in constant pain. I felt that my life as I had wanted it to be was over. I'm aware that I somehow got lucky and dodged a bullet with my significant (though far from complete) recovery. But those memories of despair run deep.

I often force myself to sit back and ask myself how our grand struggle against this disease that we each experience alone, but also collectively, is going. In other words: are we on the path toward genuine reason for hope in solving this disease?

First, I think about the areas in which *real frustration* continues:

- There are a smattering of studies with interesting findings, but they are limited—and there is no research funding for replicating them, so that they can be acted upon to move forward toward treatments.
- The vast majority of doctors still have no capability—and many have no interest—to treat the hundreds of thousands of people with ME/CFS who show up in their offices expecting medical care.
- There are no FDA-approved therapies or drugs.
- And while there are exceptions, many families and friends are still bewildered by our illness and fall short in their care and compassion for their loved ones. That can be deeply painful.

Then, I focus on the areas in which *genuine progress* is being made. And there are many. Here are just a few:

- Although there are not nearly enough studies, and those that exist are small, more and more are being done around the world. There is a slowly evolving therapy of the disease, with an increased focus on specific

areas of dysfunction. While there have been no breakthroughs, there is real movement. Let me repeat that: There is real movement.

- The NIH has begun a comprehensive, deep, rigorous study of this disease. Reports from participating patients are quite positive about the NIH's sensitivity and commitment.
- The NIH will soon announce the first-ever funding of two or three new research centers for ME/CFS.
- The CDC has updated its website so that doctors, patients or loved ones who go there seeking understanding will find much improved information.
- A rigorous, comprehensive new guide for the treatment of children and adolescents with ME/CFS has been written.
- The powerful documentary film about ME called "Unrest" recently premiered in the United States. Conservative estimates are that at least a million people will see it in the coming year and gain a deeply felt, new understanding of the severity of this disease.

So, yes, I am more hopeful with each passing month. We are all in this together. Those of us at SMCI continue to give it all we've got. We are obsessed and find deep gratification in working on behalf of those of you who are so burdened by this disease.

I wish you more good days than bad. I wish you peace as we move together along this too-long road to toward understanding this disease. And I wish *hope* to all, that one day you will be restored to the life you were born to lead.

Onward!



Carol Head
President and CEO, Solve ME/CFS Initiative



Carol Head, CEO and President