



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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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."

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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.