Editor's Note: This piece is excerpted from Jeff's memoir, *The Fun Master*, which portrays his struggles with CMT and his journey as caregiver to a son in fragile health. The book will be published by SparkPress in 2021. Jeff wrote about his training routine in the Spring 2020 issue of *The CMTA Report.*

The Feet of Dorian Gray (An Excerpt)

BY JEFFREY SEITZER

I approached the waiting room of the CMT clinic at Wayne State University full of anticipation. In 30 plus years struggling with CMT, I had only met one person outside my family who had it. I imagined being greeted there by a throng of fellow CMT sufferers eager to share stories and exchange shoe tips. Alas, the waiting room was empty.

After a few minutes, I was led into an examination room, where I was joined by Dr. Michael Shy, who told me, "You have the strangest case of CMTX we have ever seen. In terms of your neural response, muscle mass, muscle tone, you appear to have a very mild case of Type 2. In a male, this is rather surprising. By age 60, men with CMTX typically require a cane or even AFOs to walk."

I explained about breaking out of the plastic leg braces in my twenties because my calf muscles had gotten so big from vigorous exercise.

"I can imagine," he said. "Your calves look great."

I raised my eyebrows, surprised anyone would say that about my calves. I asked him if he agreed with the neurologist who told me that in some cases people plateau at a level with limited decline, then experience a precipitous decline much later. "Am I merely waiting for the other foot to drop, so to speak?" I asked, secretly pleased with my play on words.

"I don't think so," he answered. "CMT is slowly progressive, so your condition will worsen. But you've established a certain trajectory. Your degeneration should continue along the line already established."

"Your case is interesting in another respect," he continued. "To understand how unusual it is, let me go over some of the most important aspects of your type of CMT."

I was looking at him while he spoke, but my mind was elsewhere. It was like a waking dream moving back in time. First, I was speaking with the neurologist at the University of Chicago, who said I might not even have CMT; then I was speaking with the mysterious stranger who told me about reconstructive foot surgery; followed by the 20-something shoe salesman who suggested I get plastic rather than metal braces. All of them gave a new direction to my life. Sensing that this moment was important as well, I worked hard to concentrate on what he was saying.

"Your case is better than most CMTX cases," I heard him say. "There is less atrophy. Why is unclear."

"That's a lot to take in," I said, glancing at my notes, which looked like an experimental poem. Content to let my wife Janet, family science officer, sort out the technical details, I focused on my new principal worry, the difference between my right and left sides. "If my left leg, the good leg, not the right, is the lead indicator of the degeneration produced by CMT, then I feel I'm in good shape. Is that your sense as well?"

"Perhaps," he said. "We will have to study your case more. It may not be possible to determine that conclusively. The fact that you've had encephalitis and CMTX, though, is highly interesting. Your form of CMT involves a protein, Connexin 32. It is a little different from other proteins affected by CMT in that it is located in both the central and peripheral nervous systems. It is in a little different location in each. But there is a possible connection with encephalitis. In a very small number of cases, some activity like high altitude

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Jeffrey Seitzer and son Ethan

INPUT ON CMT AWARENESS IN SCHOOLS SOUGHT

CMTA Advisory Board member and educator Sarah Kesty is seeking input from the community on how to encourage CMT awareness in schools.

Sarah entered a contest sponsored by Sarepta Therapeutics that asked educators to create lessons that build understanding of, and empathy for, rare diseases and those affected by them. The winning lessons will be posted on sharemylesson.com.

"Rare Lessons" is a program intended to promote the development and implementation of rare disease lessons in the K-12 classroom. According to the company, "We believe that rare disease education is an important component of disease awareness and diversity and inclusion within the classroom setting and that the study of rare diseases sets the foundation for enhanced education throughout students' academic lives."

Kesty said she was honored to participate in Rare Lessons, which fosters the empathy- and understanding-building she would like to see in all classrooms. Noting that her CMT was a particular challenge when she was younger, she said, "Lessons like these would have truly helped my classmates, teachers and me better understand the impact and nature of rare diseases."

Sarah talks with Emaya G. about the characters in Sarah's book, *Everyone Has Something.*

Sarah is seeking answers to the following questions from the community:

- What would you like other students to understand about CMT?
- What do school leaders need to know to improve your child's experience at school?
- What challenges do you face in sharing about CMT with others?

Drop Sarah an email at info@cmtausa.org and she'll address your concerns in an upcoming article. ☆

climbing or deep-sea diving can produce a metabolic shock, which, in turn, might cause a temporary central nervous system problem, in your case perhaps encephalitis, with some of the symptoms you've had."

I was stunned. "Whoa," I said. "What are the chances of that?"

"Not high. There might be 10 or 12 known cases of this happening."

I just shook my head in disbelief. After a pause, he asked, "Well, do you have any other questions?"

After a deep breath, I said, "A neurologist told me that alcohol damages the sheathing around nerve fibers, so I should give it up immediately. I drink a couple glasses of red wine every day," I added, knowing it was often more, rarely less. "One is for my heart health, and the other because I like it so much." The proportion was actually weighted decidedly toward the latter, but I figured he didn't need to know that. "Is it something I should cut out altogether?" I asked, bracing myself to receive the bad news.

"Whatever you are doing, keep it up. It's really working. In fact, you might want to share some of your experiences with the support group, particularly your approach to conditioning. They may benefit from it."

"I'll do that," I said, adding, "It might be a multivolume work."

I was positively giddy while I waited for the elevator. You'd think I'd just been told that with a simple change of diet or some easy to take medication, all my troubles would be over. I still had to contend with the residual effects of encephalitis and the slow, progressive decline of CMT. But I would not end up like my mother or my grandfather, who were both severely hobbled at a much younger age than I was then. I could manage my condition well without fear of complete incapacity. For the first time since my diagnosis at age 12, I felt truly lucky. ☆

Jeff teaches at Roosevelt University and has published recently in Adoptive Families Magazine, The Omaha World-Herald, Brevity Nonfiction Blog, Hippocampus, *and elsewhere.*