

## Scott's Story (1980-83 counselor alumni)

About 16 years ago, started noticing a slight neuromuscular type of symptom that was obviously not normal. Although I could still run the J.P. Morgan Chase Corporate Challenge (3.5 miles) in under 25 minutes, while zigzagging in heavy traffic, something was not right. The neurologist said the tests and scans were clear, so we would just have to just wait and see what develops. As symptoms gradually became more pronounced, a top neurologist finally diagnosed me with a rare neuromuscular condition 4 years later. It's an untreatable degenerative condition and the cause is unknown. Less than one-thousand people have it in the U.S. The disease involves loss of muscle strength and coordination and muscle cramping as the main symptoms.

The day I couldn't run anymore (legs too slow) while hanging onto treadmill handles (late 2015), I started shopping recumbent trikes, since my balance was not good enough for a bike (sold my bike a few years prior). So, in 2016 I started riding my new trike modest distances. Then in 2017, I started pushing the distances longer, with less fear of legs cramping and stranding me. In 2018 I rode across the state on the canal path, utilizing 3 separate weekends of 2 days, 2 days, and 3 days, most of the days during cool weather. One of those days was an 80-mile ride, which is my maximum range (I still can do), to avoid experiencing unreasonable leg cramps. Note that I maintain my strength as much as possible with weight machines workout every other day, along with recumbent trike riding long distance for aerobic fitness but using stationary indoor bike when there is snow cover outside. Resisting this disease is my focus every day, and exercise is the most important weapon to use against it. Isn't that true for most diseases? I only do what I have to do.

Fast forward to the summer of 2024: a small group of us, mostly CSM alumni, did the first CSM Alumni Erie Canal Ride For Camperships, riding across the state on 7 hot days, raising over \$16K for camperships. Note that as we approached Rome on Wednesday of that week, the sky darkened and I was notified that there were a few tornadoes on the ground behind us, including in Oswego County and Wayne County! We rode faster after that, under dark clouds. We ended up finishing the ride week successfully in Albany, after enduring a lot of beautiful scenery along the way, along with about 375 miles of great exercise!

While the 2025 canal ride is only for one day this summer, I say "let's do it for the kids"! Join us!