

## Scott's Story

About 15 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 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.

This past fall, a friend of mine (CSM alum John Porcari who grew up in Rochester but moved out of state for career) who had rekindled his long-lost interest in cycling, said "we should take a week next summer and ride the canal path across the state". Realizing that with disease progression as constant concern, such extensive ride could potentially be my last big ride across the state. All the more reason for me to do it. While I knew I could do it, I wasn't sure John could accomplish the task. But since he did finish one 50-mile ride last fall successfully, and agreed to train over the winter, it was a *game-on* situation! He quickly reasoned that we needed a cover story to justify our time away from home/work, especially for other riders we hoped to recruit. Then he said, "let's do it for the kids", we'd ride to raise money for CSM campership fund. Then all that was left was for the planning of the mission, which is my specialty, drafted over the winter. With the plan created and the assistance of the CSM Alumni Association and John Quinlivan, Executive Director at CSM, the campaign is now moving forward!