

Patient Perspective: From the Dunk to the Dark

By Herb Malcomson

The title conjures up images of a Tim's coffee and chocolate donut, but it is the other dunk. For those unfamiliar, a basketball dunk is when you elevate the ball above the 10 foot rim and slam it in with much bravado. There begins my story as a young man, with a tremendous confidence in my muscles' ability to be challenged and grow to achieve new heights. The opposite bookend to the dunk is sporadic inclusion body myositis (sIBM). Falls have me now largely committed to a rollator, with the imminent wheelchair beckoning with the call of, "Don't be stupid". Let's go there for a moment, to see what stupid (or vanity) looks like.

On occasion I walk unassisted, while the "silent chair" whispers of the many falls, with injuries from pride to the more serious bone breaks requiring surgeries. Trivial injuries like scrapes and bruises aren't an issue, given the rough and tumble of sports. A broken hand surgery, five others for fractured patellae, and a complete knee rebuild where a collapsed leg chose a non-linear plane of flexion, were more difficult. One's vanity rationalizes away the 'on your back in bed' rehab that contributes to further atrophy, but "hey, a guy needs to pee, right!"

The "chair" continues, "What about the concussions?" it cries. "I've had them before and recovered", one says. It continues, "Remember the GP saying that concussions are cumulative, and how the last one caused you to completely lose consciousness?"

Therein lies the temptation of the darkness, as you reply, "Yeah well, this isn't much quality of life anyway!"

My sIBM journey started innocently with a ring finger that wouldn't fully extend in 2006. I avoided the proposed ulnar nerve entrapment surgery that year. As the disease progressed unbeknownst, unexpected falls happened. A winery bicycle tour, where I couldn't pedal up a modest slope, raised red flags. That same day in the bathtub, I noticed the Iliotibial band more pronounced on my left leg (Yup, Bachelor of Science in Kinesiology from the University of Waterloo). A return visit to my GP in 2007 produced a referral to a neurologist who, after a muscle biopsy, confirmed sIBM in 2008. He was surprised when I expressed relief, but I now had something tangible to tackle, and the mystery was over.

I was fortunate then to stay active with 5-6 gym workouts per week, minor athletics, and full-time work. In 2012 at a neurological follow-up, the specialist was surprised at my mobility. He had predicted 5-10 years to a "chair". He encouraged me to try for a clinical trial. My



Herb and his amazing caregiver.

employer supported this, and in May 2013 I began that chapter. I flew to Ohio for testing where a promising trial was underway, and then connected with other trial sites, but was not accepted into any. I suspected my passport flag was a factor, but I cannot confirm that.

I found a local myositis group who were very helpful. I left their initial meeting happy that I hadn't been prescribed methotrexate, or steroids like prednisone, which have no disease impact but have many serious side effects.

I learned there was no Canadian myositis patient organization, and heard that the US group (*TMA.org*) grew significantly via a \$2M grant from a Canadian! I heard too that various Canadian rheumatologists felt a similar body would be highly useful, so with several others we started Myositis/Myosite Canada. We achieved many objectives, including charitable status, robust governance, and we raised about \$60K. After three years, I stepped down as Canadian President but continue to run their research grant program and southern Alberta support group, which is curiously the largest in Canada.

I was fortunate to have a quick eighteen-month path to diagnosis (versus an average of 59 months in the US) and doubly fortunate to not have been subjected to steroid therapy.

So, what of the mentioned "Dark"? I can still walk in year 18 post diagnosis, but learning to dance in the rain is hard when your experience is that it may soon stop. Idiopathic inflammatory myopathies don't stop and, like a thief, visit each night to collect. Learning to let sadness wash in and then assisting it to wash out like the tide is my secret sauce to shun the dark.

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