

Adam Silverstein



My name is Adam Silverstein. I'm 30 years old, living in the Phoenix-metropolitan area. I'm an accountant by trade and a runner at heart. And I have myasthenia gravis.

My story begins on Tuesday, July 3, 2012. My partner and I had just returned from a

vacation in Québec where I had completed my third half marathon. While I'd been running for a few years, I'd only recently gotten into racing. I wasn't fast and I wasn't competitive in my races; I ran to prove to myself what I could accomplish and because I simply enjoyed doing it. I found myself back at my local gym after work, on a new treadmill the gym had installed while I was out of town. I'd typically run between 3 and 6 miles, up to 7 or 8 times a week, with an occasional 12 mile run thrown in if I was feeling particularly ambitious.

Time spent running was very therapeutic for me. It was almost meditative. It was my "me" time, when I could simply get lost in my thoughts or people watch and just enjoy what I was doing. I looked up at some point during that run to focus my attention on one of the TVs broadcasting one of the cable news channels. But as I tried to watch the TV, I suddenly found my eyes couldn't focus on it. "It must be this new treadmill," I thought to myself, conjuring up some excuse that it must be how my feet are striking the belt and that it would go away once I got accustomed to the new machine. I finished up my run and headed home.

Unfortunately, as the week progressed, I would find my eyes getting blurry in places other than the gym. By early the next week, after dealing with unexplained blurriness off and on for nearly a week, I decided it was time to make an appointment with an eye doctor. I was the only person left in my family who wasn't wearing prescription glasses, so I figured my time had finally come. The first available appointment would be the following Monday, which worked out perfectly, since I would be participating in my third long-distance relay event near Seattle that weekend. I certainly wouldn't miss out on a race simply because I had some blurry vision!

I completed over 24 miles during that race. It was the longest I had ever run in 24 hours and I did most of it with intermittent blurry vision. I returned from the

race on Sunday and found myself at the eye doctor by Monday afternoon. The doctor examined me and, much to my surprise, found nothing wrong with my vision, despite my complaints of blurred vision. She suggested I visit my primary care physician.

I quickly made an appointment with my primary care and was seen before the end of the week. I described my symptoms and told her about my trip to the eye doctor. She immediately zeroed in on a disorder that she couldn't quite remember the name of and couldn't quite pronounce. After several minutes of research, she stumbled on what she was looking for: Myasthenia Gravis.

The next day, I called up the neurologist she had referred me to and set up an appointment for August 29th. While I waited for my appointment, my symptoms got progressively worse. My eyes began to droop. I struggled to eat because my jaw was so weak. I could barely hold my head up at times and couldn't make it through a day at work because of extreme fatigues and weakness. As much as I wanted to, running was just about the last thing from my mind and I questioned whether I would ever be able to run again.

August 29th finally arrived and my neurologist swiftly diagnosed me with myasthenia gravis after an extensive physical examination. He sent me for bloodwork to confirm the diagnosis, but wrote me a prescription for Mestinon, referred me for a CAT scan to check for a thymoma and sent in a prescription for IVIg. Like any good runner, I asked him, "When can I run again?" He looked at me as if I'd asked for his first-born child and responded with a short, "You won't." I laughed at him.

I started taking Mestinon that night and by the next day, I had a significant change. Even people at work remarked at the difference. Meanwhile, my bloodwork came back and confirmed my diagnosis while my CAT scan would reveal a thymoma. I would get my first IVIg dose in the middle of September and truly felt like I was on the road to a quick recovery.

By early October, while I still had room for improvement, I was feeling much stronger. I signed up for a trail relay that month and soon followed it up with my fourth half marathon on my 28th birthday in November. The very next weekend, I completed my fifth relay event and a few short weeks later, my fifth half marathon.

In February 2013, I had my VATS thymectomy. I opted to have it done at the Mayo Clinic in Rochester, MN. After spending a week there the previous December, being extensively evaluated by another neurologist and a cardiothoracic surgeon, we scheduled the surgery in late February. Before leaving the hospital, I asked my surgeon, "When can I run again?" In sharp contrast to my first neurologist visit, he looked at me, smiled, and said, "As a runner, I trust you to listen to your body and know when you're ready." Six days after my surgery, I was back to running. It was an excruciatingly slow run, but I was running. Unfortunately, that high would last only a few weeks and I would soon find my health faltering once again.

As clear as those first six months of my story are to me, much of 2013 and early 2014 remains a blur. I was in a constant battle with my health, struggling to stay working and, at times, feeling like I was straining just to live. I could hardly eat and found my weight plummet from a healthy 190 to a thin and frail 150. I was barely able to talk most of the time, my speech mostly unintelligible whenever I would try. I wore an eye patch almost constantly and battled crippling hand cramps and weakness that made it near impossible to type or hold things. Life was a struggle, beyond anything I thought I would possibly deal with at my age.

I fought hard to maintain my ability to run even through all those months and I often paid for it. I completed a relay event near Toronto, but almost had to bow out the morning it started because I didn't even have the strength to swallow my pills. I literally sucked on my pills and finally got to a point where I felt safe enough to complete the race. I walked a local half marathon but it took me nearly four hours, when before I could finish in closer to two and a half hours. I had all but lost my ability to actually run, settling for walking the races I felt I could do. But I never lost hope.

In mid-March 2014, I finally hit rock bottom. I'd just returned from walking a half marathon in Grand Junction, Colorado. I picked up a cold somewhere along the way, most likely on the return flight, and it took me down. Luckily, I already had an appointment scheduled with my neurologist that week. By the time I got to see him, I barely had the strength to walk. My breathing was just beginning to get labored. And yet I sat on the exam table, as calm as could be. He looked me in the eye, or I presume he did, considering I couldn't see straight, and said to me, "I would be putting you in the hospital right now, but I've never seen someone as bad as you are, as calm as you are."

In that moment, he finally understood me. While myasthenia gravis had all but ravaged my physical strength, he realized I had mental strength that, he admitted, he had never seen before in his patients. He immediately put me on IV Solu-Medrol. I'd resisted steroids in the past. I'd flat out refused to take prednisone when he tried to put me on it. But just as he finally understood me, I understood that I needed more than the current status quo.

At first, the Solu-Medrol did more harm than good. I went from barely being able to walk to not being able to stand up on my own. I had to be lifted from wherever I sat and placed on my feet. And even then, I could barely make it across my own house before I felt like I was going to collapse. I suffered for nearly a week and my mental strength was beginning to crack. The realization that my running may, in fact, be over, was almost more than I could bear. It was the biggest hope I had held onto all this time and I could see it slipping away. How could I run a half marathon when I couldn't even get myself up off the toilet?

And then, seemingly overnight, it happened. It was the first week of April. I had strength I hadn't felt in months. I vividly remember savoring every bit of the most delicious steak I had ever eaten. I remember taking off my eye patch to drive for the first time in over a year. I no longer struggled to eat or see or drink or stand or talk or breathe.

By the end of the month, I found myself in Oklahoma City, running my 10th half marathon. And I was actually running! It was a slow run, but a run nonetheless. I completed that race with a huge smile plastered across my face. And I finished it in less than 3 hours.

I began scheduling more and more and more races. I had my 10th and 11th relays that May and June. I finished my 11th half marathon that July. I conquered my 12th and 13th relays that September and quickly followed it up with two more half marathons and another relay.

Today, my health isn't perfect, but I hardly have anything to complain about. I was forced to trade my IVIg for Imuran because of my insurance company. I still get occasional weakness in my jaw in the evening. And I stumbled a bit during one of my relay events when I lost my Mestinon. But I'm stronger today than I have been in years.

I can proudly say that I've now completed 21 half marathons, 19 relays and one marathon. I currently have an additional three half marathons scheduled in the next two months and three more relays between February and October, with up to four more I'm thinking of adding before the end of the year.

As trite as it might be, I no longer take my health for granted. I live every day knowing that my symptoms could come back tomorrow. But I also live every day with positivity and the knowledge that I have the strength to get through any challenge I face. I run not only because I want to, but because I can. Wherever you are in your battle with MG, no matter the struggles you've encountered or the ones you will endure, keep positive. MG may take your physical strength, but it will only take your mental strength if you let it.