

Elyse Schwartz



by Lisa Levin Reichmann

Elyse Schwartz joined MCRRC three years ago after taking up running despite a diagnosis of Postural Orthostatic Tachycardia Syndrome (POTS), a neurological disorder caused by a malfunction of the autonomic nervous system and characterized by lightheadedness, chest pains, and shortness of breath that occur when standing up from a prone or sitting position. For individuals with POTS, simply standing upright can lead to heart rate of 170 bpm or more. Determined not to let her diagnosis slow her down, Elyse has participated in the Winter Half Marathon program since its inception and most recently ran the NYC Half Marathon in March of this year.

When did you start running?

I started running about four years ago as a challenge to myself. I always told myself that I couldn't run because I didn't have a runner's physique. One day at the gym, all the elliptical machines were taken and there was an open treadmill so I decided to see how long I could run. I told myself I would stay on the treadmill for ten minutes. Lo and behold I was on there for 30 minutes — needless to say, I was hooked!

When did you first experience symptoms of POTS? What were those symptoms?

I started experiencing symptoms as a teenager, which is the typical age of onset. I recall avoiding an after school aerobics class because I always felt like I was going to pass out and later realized this was because we were constantly changing positions in class and I was constantly near syncope (fainting). The symptomatology became far more acute when I was in my sophomore or junior year of college. I was fatigued, lightheaded, and unable to get up without feeling like I was going to pass out and my heart was always racing.

How long did it take to get diagnosed with POTS?

I was very fortunate that my diagnosis came fairly quickly. I was a college student in Boston and was referred to the head of the Autonomic Lab of one of the Harvard Hospitals. I had a Tilt Table Test and the diagnosis was confirmed. Often times, people go years without a definitive diagnosis because of the myriad symptoms that can be attributed to so many other disorders.

Do you still experience symptoms? If so, how do you manage them?

Oh yes, I experience symptoms on a daily basis, including lightheadedness and near syncope (fainting) when I stand up. My symptoms are always worse in the summer time, as my body does not tolerate heat well. When my symptoms get very bad, or occur more frequently, I increase my fluid/water and sodium intake. I also experience severe tachycardia (fast pulse) and take a beta blocker twice daily to manage this symptom. I have extreme heat intolerance, which is why I can only run outdoors in the winter time.



Photo: Jason Schwartz

How does your diagnosis affect your running?

I have to be super careful about hydration and be sure to replenish my electrolytes more frequently than other runners. Because POTS symptoms mimics dehydration and an increase in sweating (also a POTS symptom) causes me to lose liquids faster, I need to rehydrate more frequently and with larger amount of fluids. I tend to carry more (electrolyte enhanced) water when I run or do any physical exercise because of my propensity to dehydrate. On a typical day, a POTS patient needs to drink upwards of 4 liters a day and eat large amounts of sodium which helps retain the fluids in our system. I get in about 3 liters a day, more if

I'm working out. My biggest challenge on a long run is to remain hydrated — but not so much that I need to go to the bathroom constantly — though my pace group knows I never pass up an opportunity to use a porta-potty!

And vice versa, how does your running affect your symptoms?

Running has helped me stay conditioned and in shape. I find I have more energy the more I work out, although I have to be extraordinarily careful about remaining hydrated with any physical exercise I do.

Were your doctors supportive of your running goals?

My doctors have encouraged and supported my active lifestyle. I know my body well and am able to gauge how I'm feeling and what my body needs in order to remain healthy.

Have you found networks that you turn to for support and information? If so, what has been most useful about having those networks?

Because there is not a lot of awareness about POTS, or dysautonomic disorders in general, I only recently met others who suffer from this syndrome. I turned to online support, primarily informational pages on Facebook, to exchange ideas and learn things from others. For instance, I asked for suggestions of high sodium, low calorie snacks to eat to maintain my sodium intake and was able to ask others on a POTS Facebook page for recommendations. Also, I have found an enormous amount of information on DysautonomiaInternational.org. They have a great website that has a lot of information and does advocacy work on behalf of dysautonomia research. They recently held their first conference in DC, which was a great success.

What advice would you give runners (or aspiring runners) who are facing a chronic illness?

Listen to your body! I am constantly monitoring how I feel days before a run, during the run and afterwards to make sure I feel hydrated enough. All runners do this, but running with a chronic illness makes it all the more challenging — thus, all the more rewarding!