Your Stories

The Canadian PH community is made up of many exceptional individuals: patients, caregivers, healthcare providers, researchers, and supporters who individually and collectively refuse to give up in the face of the many challenges brought on by this disease. Every individual in our PHamily has a unique story to tell and can help make a difference in the lives of Canadians affected by PH. We are happy to feature the stories of exceptional PHighters whose unwavering commitment to the cause, unique journeys, or remarkable accomplishments deserve the spotlight.

My Experience Participanting in a Human Stem Cell Trial

Jo-Anne Mainwood is one of the few Canadian PH patients to be taking part in a unique clinical research trial studying the possibility of using human stem cells to treat PAH (see page 22). Jo-Anne quickly became a beloved member of the community after her PH diagnosis by starting a support group in Ottawa. Today, she is still living in Ottawa (ON) with her family, where she continues—through hard determination—to live life to the fullest.

Jo-Anne Mainwood pictured alongside her family.

My PH journey began like many others: I began to notice I felt "off". I would walk up a flight of stairs and need to catch my breath. Head fog would set in and I'd struggle with following group conversations—simply talking would make me out of breath! I felt like I wasn't being the parent I wanted to be to my two fantastic children, Graham and Kirsten. My incredible husband, Chris, took care of the household, never complaining when I couldn't get off the couch. At first, my family doctor diagnosed me as having depression and provided me with meds. Seeing as that did not solve the breathlessness, I was referred to a respirologist; that is when I first met Dr. Chandy. He listened to my concerns, ran tests, and diagnosed me with asthma. In spite of the puffers he prescribed, I continued to struggle with stairs and inclines. At my next appointment, I emphasized my breathing difficulties and how I felt achy and spacey. We made a plan involving a series of tests, and that's when a VQ scan raised the first of many red flags. The test showed what appeared to be blood clots in my lungs. I was immediately admitted to hospital and injected with blood thinners. After a week in hospital, a CT scan showed I didn't have blood clots after all. That's when they sent me for a right heart catheter and the results were in: I had Idiopathic Pulmonary Arterial Hypertension (IPAH).

By this time, the disease had stretched and reached into so many aspects of my life. I was emotionally and physically spent by 5pm on most days, working and living in a "breathing typical" world. And although I am eternally grateful for the amazing support of my family and medical team (Dr. Chandy and Advanced Practice Nurse Carolyn Doyle-Cox), I wanted to connect with others in the community. So I started an Ottawa support group. Due to balancing both family and work, I was incredibly grateful to Charlene and Teri for restarting the group after I needed to let it go.

Our first meeting featured a talk by Dr. Stewart, a stem cell expert. He spoke about the excellent results he was having injecting enhanced stem cells into the pulmonary arteries of mice with PH. His research (called SAPPHIRE) was very promising, and I was (of course) instantly interested in getting involved. The purpose of the study was to learn more about the long-term safety and effectiveness of "gene-enhanced" cell therapy for PAH. It investigates whether monocyte cells, enhanced with a small loop of DNA, will repair blood vessels by using a protein called human endothelial nitric oxide synthase (or eNOS). Participants in the study would receive either a placebo or the study product by intravenous injections. The enhanced injected cells travel to the smallest arteries of the lungs, which is the site of the vessel-damage that causes PAH to develop.

The criteria to be part of the study are pretty intense. Participants have to sign a consent form, which states the possible risks of the study (abnormal growth of cells, tumours, embolization, etc.). Despite the risks I didn't hesitate, I wanted a chance to beat this disease at all costs. I also had to go through numerous tests to make sure I was sick enough, but also well enough to participate. The VQ scan from eight years ago—the one that gave an initial