“People who looked in worse shape than me would zoom up a flight of stairs with no problem. When I would try to keep up, I’d feel like I was ready to faint.”
Although I was diagnosed with idiopathic pulmonary arterial hypertension in 2013, I believe that I have had the condition for a while. The first episode was in 2008. I went to the emergency room because I couldn’t breathe and my ankles were swollen. I was diagnosed with “systemic” high blood pressure and prescribed diuretics to reduce the swelling. I started a low sodium diet and experienced shortness of breath and water retention if I binged on salty foods.

I was 26 years old and looked healthy, but I couldn’t run, use an elliptical machine, or dance for more than a minute without feeling like I was going to pass out. People who looked in worse shape than me would zoom up a flight of stairs with no problem. When I would try to keep up, I’d feel like I was ready to faint.

By 2012, my fatigue had increased. I would sleep on weekends for 16 hours straight and I would still feel exhausted. My primary care physician diagnosed me with a single episode of major depression and prescribed anti-depressants.

By the next year, my symptoms worsened. The water retention became more frequent, and the shortness of breath became more evident when I retained water. On July 23, 2013, after a weekend of very poor eating decisions, my body decided it had had enough. My face was swollen, my abdomen felt full, and I was retaining fluid in both my legs. I couldn’t even walk 10 to 15 feet without running out of breath. I went to urgent care, and the doctor heard a heart-murmur and told me that I needed to go to the emergency room so that they could rule out pulmonary hypertension. He was the first doctor who told me that it wasn’t normal for a 30 year old to have ankle swelling and shortness of breath.

Michelle Figueras
I was transferred to University of California, Irvine Health, which performed my right heart catheterization and confirmed the diagnosis on July 23, 2014.

By searching the hashtags “pulmonary hypertension” on Facebook and Instagram, I found a local PH support group in Long Beach. I attended a meeting, and they urged me to look at the Pulmonary Hypertension Association website to find a specialist. Many recommended Ronald Oudiz, MD, at Harbor UCLA Medical Center.

During a PH support group meeting, speaker Joy Beckman, a pulmonary hypertension nurse who worked with Dr. Oudiz, discussed clinical trials. Since my insurance was such a pain to go through, I knew the only way I’d get treatment from him was through a clinical trial.

I qualified for AMBITION, a clinical trial for two drugs for that I was already prescribed to take after being discharged—Ambrisentan (Letaris) and Tadalafil (Adcirca)—which meant the risk of participating in the trial was non-existent. The study is meant to test the efficacy of single drug therapy versus combination drug therapy. I felt safe knowing that I would at least be getting some treatment.

Since being in the trial and being better educated about my condition, my quality of life has improved 100 percent. I can walk up two flights of stairs, do some moderate cardio exercise, and walk slight inclines without feeling short of breath. My water retention is under control and I understand my body a lot better.

The study is in its final phase, and I am curious to learn the results. It makes me feel good to know that I helped contribute to how PH will be treated in the future.

*Michelle Figueras was a patient speaker at the ATS 2014 International Conference in San Diego.*