

Spotlight On Patients

The community of patients with alpha-1 antitrypsin deficiency or alpha-1 is, without question, the most amazing group of people I have ever met. My story is very similar to most other patients who have been diagnosed, so I will try to do them justice by walking you through the long and twisted path of my own experience.

When I was diagnosed with alpha-1 seven years ago at the age of 35, I was scared. I finished the usual panel of tests when a physician's assistant pulled me aside and asked me if she could draw blood to rule out a rare genetic disease. We drew the blood and I went off to work. And she called me the same day and told me that it was urgent that I come in the next day to discuss the test results.

The conversation went something like this: "You have a genetic disease called alpha-1-antitrypsin deficiency. Your body is basically eating your own lungs. There is no cure for the condition. With treatment though, you will be able to continue for a few years. I am going to give you a number to a pulmonologist so you can discuss your options. Can I answer any questions for you?" I replied: "Nope, I'm good." Wow, what a lie that was. I was scared as hell.

I was once a competitive athlete and Pilates instructor. Now I can barely make it through a spin class on six liters of oxygen per minute or even a simple walk through the park. Although I was oxygen-free four years ago, I now have nights where I am awakened in a paralyzed state and am, by the grace of God, able to make it to my concentrator to turn up the oxygen in hopes of living.

I give myself shots for osteoporosis everyday because my BMD is so low due to prednisone. I have a constant fear of how many flights of stairs separate me from my next meeting. I have wet myself in some of the most beautiful places in the world because my tolerance for altitude is unpredictable and continues to worsen. Each night, I go to bed with a text message ready to send my family and friends that says: "I love you and enjoyed the journey," in case I am unable to make it to my concentrator when I wake up. I field questions from my young niece about whether or not I am going to die.

I was always very driven and sought knowledge about everything. Alpha-1, well this was different. I didn't want to know. While everything had always been science-based for me in the past, I really just let the doctors handle this one. My denial had kicked in.

Then, one day, everything changed. Two months after I was diagnosed, I was in Ireland on an ex-pat work assignment. I continued my monthly infusion of Prolastin over there and had them done at local hospitals. No one ever even asked about my medicine or what my condition was, although they did have a concern when I told them I wasn't Roman Catholic. Their biggest issue, initially, was how they would possibly administer my last rites if something went wrong. I was fine with that, as I didn't want to talk about alpha. I just wanted to infuse and get out. Then months later, at a hospital in Loughlins town, some questions came up.

Karen Erickson



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I mentioned alpha-1 and the place blew up. There were a number of doctors onsite that actively researched the disease. Of course, they had never seen my medicine before, so my infusion became quite an event. Their interest was infectious and really sparked mine.

When I returned to the U.S., I hit the ground running. I met up with Dr. McKenna from Cedar's Sinai Medical Center and discussed lung volume reduction surgery. I became a patient at UCLA and armed myself with a long list of questions to have answered (sorry Dr. Ross). I attended alpha-1 education days and met people who are my mentors and heroes today. Then, while at an international conference on alpha-1—which took place in Ireland ironically—I met a transplant patient who had started Team Alpha-1—a group of patients, family members and friends who do athletic activities to spread awareness of and raise money for alpha-1. Her drive was amazing...is amazing. I was pumped. That was something I could do...that I would love to do.

The timing was off, but I continued to stay in the best shape possible so that I was ready to be an active part of Team Alpha-1 when the time was right. I was lifting weights, spinning and doing both Pilates and cross-training classes like crazy. Before I was able to get an event going, a terrible bout with Staphylococcal pneumonia dropped me to crazy levels of pulmonary function. I was prescribed O₂ for sleep and to use during workouts. Initially, that stopped me dead in my tracks. Wow, that was not sexy. I asked myself, "is this really my life?"

It took me a few months of being doubled over in the back of the room at the gym, but with the support of my friends, I finally put that nasal cannula in. I was

back on board and have been moving ever since. Today, I continue to seek out information about what I can do and learn about any limits that my doctors feel are needed. I stay up-to-date on the research out there. I am compliant with my meds and take every chance possible to meet as many patients as I can.

I am as grateful now as I was scared when I was first diagnosed. I did get an event going for Team Alpha by starting a partnership with the American Lung Association—and bringing a team of riders and supporters out for their bike ride. For the last four years, we have been the top fundraising team. We have had the sincere honor of providing awareness of alpha-1 all over the rolling hills of California.

I also serve as president of a disability awareness diversity group called ABLE, which deals with access for all disabled individuals and teaches them the leadership and business skills needed to overcome challenges. Earlier this year, I was elected to the Alpha-1 Association's Board of Directors.

This is all par for the course for alpha-1 patients, who struggle through every day. That said, this group of individuals takes those challenges and turns them into opportunities—opportunities that lead us toward a common mission of finding a cure for this disease and then to getting it to every patient out there who needs it.

This disease is tragic and it is going to be challenging, but I don't think I really lived until I started to die. Until I saw a patient strap on an oxygen tank and ride seven miles in as many hours to spread awareness of alpha-1 and hope for our mission. Until I was proud enough to let a friend put his arm on my back to help me keep pedaling on my bike. ■

2009 ATS PAR EVENTS CALENDAR

DATE	MEETING	CONTACT
August 1-2	Children's Interstitial Lung Disease Foundation— ChILD Conference 2009 , Denver, CO	Greg Porta dporta@cinci.rr.com
August 1-3	Respiratory Health Association of Metropolitan Chicago— CowaLUNGa Bike Tour , Gurnee, IL	Niki Bartosiak nbartosiak@lungchicago.org
August 2	National Lung Cancer Partnership— Free to Breathe® 5K Run/Walk and 1.5 Mile Walk , Los Angeles, CA	Regina Vidaver Regina@national-lungcancerpartnership.org
August 15	TS Alliance of the Upper Midwest— Tournament for TSC Champions , St. Paul, MN	Neil Gibbons gib2514@aol.com
August 29	National Lung Cancer Partnership— Free to Breathe® Rumble Run 5K Run/Walk and Motorcycle Rally , Toledo, OH	Regina Vidaver Regina@national-lungcancerpartnership.org