

Karen Erickson

ALPHA-1 ANTITRYPSIN DEFICIENCY



My 2000 diagnosis with Alpha-1 antitrypsin deficiency was delivered with a prognosis of living for two years.

I stayed active and fit for my journey with AATD and to prevent the surgical intervention for as long as possible. I was confident I would slide into transplant in the nick of time. That all changed one day late in 2012.

As I took then-foster dog, Sasha, out to train, I readied myself with my portable oxygen. Upon my first breath of a new tank, I felt an indescribable pain throughout my body.

I thought I would succumb to the incident. I remember smiling, and I was at peace at that moment. The foster pup greeted me with her wet nose, and I knew I had to get up, if only to get her inside. I took a couple of steps and realized I would not make it far without more oxygen. I hoped to find another source of O₂ but was unsuccessful, so I resorted to a second breath from the same system. Almost everything is blank after that, but I do have some recollection of a 911 call.

Karen Erickson was a patient speaker at the ATS 2018 International Conference in San Diego, California.

Alpha-1 Antitrypsin Deficiency

Alpha-1 antitrypsin deficiency is an inherited form of emphysema. People with the condition, also known as AAT Deficiency or alpha-one antitrypsin deficiency, do not have enough of a protein called alpha-1 antitrypsin (AAT) in their blood. This protein is made in the liver, and it protects the lungs so they can work normally. Without enough AAT, the lungs can become damaged by chemical enzymes in the tissue that cause emphysema. Alpha-one antitrypsin deficiency also can also cause liver damage. Alpha-one antitrypsin deficiency testing is recommended for certain groups of people, including those who have:

- Family history of alpha-one antitrypsin deficiency.
- Early-onset emphysema (less than 45 years old).
- Emphysema without an obvious risk factor such as smoking or occupational exposure to a substance known to cause the disease.
- Emphysema that is worse at the bottom of the lungs.
- Difficult to control asthma.
- Recurrent pneumonia or bronchitis.
- Unexplained liver disease.
- Patients diagnosed with COPD should consult with their health care provider to see if they would benefit from being tested for alpha-one antitrypsin deficiency.

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I was unresponsive upon my arrival at the emergency department, with present and worsening respiratory distress and seizures. Multiple emergency interventions were required to prevent further deterioration. Labs and radiologic evaluation followed. Indication of both renal and hepatic insufficiency were noted. I took my history of shattering prognoses, added a little extra fight, and I was able to make it home.

I worked on regaining my strength and some much needed weight. It was evident that I had a tough journey to travel to be healthy enough for transplant. By my next visit, three months later, my lung function had not recovered at all but I had added some fitness and weight to my body. Five days later, I was called for a double lung transplant.

I just celebrated my fifth anniversary, and I am pleased to say that Sasha has been by my side through all of it. ■

*Learn more: ATS Patient Education Series
What is Alpha-1 Antitrypsin Deficiency? New York, NY. www.thoracic.org/patients/patient-resources/resources/alpha-1-antitrypsin.pdf*