



ALPHA-1 PATIENT

Lynn Lothian

SHARES HER ADVOCACY STORY



Lynn Lothian and family

IN THE LATE 1980s, Lynn Lothian started having trouble breathing. She was told she had COPD—chronic obstructive pulmonary disease—and was advised to quit smoking, which she did in 1990. But, her health never improved. Lynn continued to suffer from frequent colds and bronchitis.

In 1999, Lynn learned that she needed spinal surgery and was required to see a pulmonologist to evaluate her COPD and assess her treatment and health prior to the surgery. However, the specialist took a look at her age—she was 42 at the time—and symptoms and quickly concluded that she had alpha-1 antitrypsin deficiency. Lynn's augmentation therapy infusions began in March of 2000 and she receives a 15 to 20 minute infusion at home once a week, administered by a nurse.

In addition to receiving regular infusions and being treated with oxygen, Lynn also uses a portable nebulizer, frequently uses inhaled drugs including albuterol, fluticasone and tiotropium depending on her symptoms.

Today, Lynn's lung function is merely 22 percent, however, she continues to work as an administrative assistant for Northrop Grumman in Arlington, Virginia, a company she has been with for 21 years. Lynn praises her employer for working with her as she manages her alpha-1.

Understanding Her Therapy and Thanking Donors

Several years ago, Lynn was able to visit a fractionation facility with other plasma protein therapy users and met donors at a plasma collection center—ironically the same center where her son was once a donor. “It was nice to sit down and meet with donors, to say ‘thank you for saving my life,’” Lynn said. She describes the full day as a wonderful experience.

Advocating for Other Alphas

About four years ago, Lynn attended an advocacy day on Capitol Hill, teaming up with an alpha-1 patient who was liver-affected. Lynn describes the experience as an awakening for both patients, who have different symptoms and treatments as a result of the disease. On that first advocacy day, Lynn explains that her partner did most of the talking. However, this spring Lynn attended PPTA's annual Capitol Hill Fly-In and had the chance to share her story first hand. “I wasn't expecting to lobby—I thought I would be listening more than speaking,” she said. “Going to the offices was very different for me. I was actually speaking with health delegates. Being able to tell my story and talk to them about what it's like to breathe, or rather, not breathe. Some of the staff looked at me like, ‘you have to be kidding,’” Lynn said.

“Telling my story over and over again, sometimes it made me feel, ‘gosh, I'm really sick.’ But I look at it like some others are so much sicker. It makes me feel good that I can advocate for the community, especially those who can't, and I would truly like to do it again.”

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