Noël Holly

PULMONARY HYPERTENSION

"I went numb. I called my pastor's wife and said that I was diagnosed with a rare and deadly disease. Driving home, the tears started."

Prior to being diagnosed with Pulmonary Hypertension, I was someone who was relatively energetic. I was an office manager and executive assistant and was always on the go. I also stayed busy with gardening, teaching Sunday school, dancing, and keeping up my household.

I walked more to manage Type 2 diabetes, but I began to cough a lot. During a church retreat to the mountains in Idyllwild, I had a hard time breathing but chalked it up to being out of shape. Stairs became an issue for me, but I figured it was due to double pneumonia weakening my lungs years ago. It was a drier cough, and there were times when I was like a cat coughing up a fur ball.

Then came a morning when I got up for work but felt very weak. I thought I could go to the emergency room, get some oxygen, and go on to work. When I marched into the ER, I was given a bed, and they tested my oxygen saturation, which was in the low 80s. I was put onto oxygen, and they inserted an IV into my arm. I then underwent an MRI, CAT scan, and blood work.

The doctor informed me that I had massive blood clots in both lungs, and my initial response was, "Oh, get on with ya." I thought blood clots only happened to smokers, and I didn't smoke. I started to get rather indignant. But they insisted that I be admitted. Other tests followed, including a V/Q scan and ultrasound scan of my legs, and I had initially had a blood clot (deep vein thrombosis) in my leg that had travelled through the heart and into my lungs. It was a silent clot, as I never had redness, bruising, or pain.

I was given massive amounts of heparin and prescribed bed rest. After 10 days I was released. I continued to cough, and saw the doctor for follow up visits. As the year continued, the coughing worsened and it was still difficult to make it from my car to

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Because the different kinds of pulmonary hypertension are treated differently, it is important that your health care provider takes the time and orders the necessary tests to find out what kind of pulmonary hypertension you have. Tell your health care provider if you are having:

- Increased shortness of breath
- Dizziness
- Feeling like you might faint
- Fainting
- Chest pain
- Heart palpitations (feeling like your heart is racing or pounding)
- Increased swelling of your feet, legs or belly
- Your lips and/or fingers turn blue

Learn more: ATS Patient Information Series. "Pulmonary Arterial Hypertension" New York, NY: American Thoracic Society 2013. patients.thoracic.org

front door without collapsing, and all other normal functions were impossible.

An echocardiogram revealed that I had PH. My doctor said it was rare, incurable, and that the life expectancy is three years. The Echo showed that both the left and right side of my heart was enlarged. I said, "Well, that was good for the Grinch—isn't it good for me?" He sighed deeply, and referred me to a PH specialist at University of California, Los Angeles.

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The PH specialist said it was a result of blood clots called chronic thromboembolic pulmonary hypertension, and that they were inoperable because what was left of them had become too fibrous in both lobes.

I transferred to a PH specialist closer to me, and right heart catheterization determined that my mean pulmonary arterial pressure was 55—when the normal should be no higher than 25—and that I fall under Class IV New York Heart Association functional capacity. My doctor started me on Tracleer (bosentan), and it took some time, but I did notice that I could do more.

That first year after diagnosis was what I call "The year of frustration." Thankfully, I discovered the Pulmonary Hypertension Association, received their book Pulmonary Hypertension: A Patient's Survival Guide, and met other PH patients through a support group. I now participate in awareness and advocacy.

At first, the words "rare and fatal" were constantly flashing in front of me like a neon sign. But now they do not control me.

Noël Holly was a patient speaker at the ATS 2014 International Conference in San Diego.