“If it wasn’t for research, I would not be here today. We, however, need more research done.”
I was diagnosed with pulmonary arterial hypertension in February 1995. It was not an easy journey to diagnosis. I started getting ill at the age of 34. At first, my monthly cycle stopped, and then the fluid started coming on in my lower extremities and abdomen. I went to the emergency room. The doctor said I looked pregnant put a Doppler radar on my belly. He told me that the fast heartbeat was a baby. I was the mother of two boys—I did not feel pregnant. But he insisted and sent me home. After two-and-a-half months, I went back to the ER because I couldn't walk up a flight of stairs without sitting down a couple of times. I insisted they do blood work to prove I wasn't pregnant, and they finally agreed with me.

After four more months of painful testing, I was given an appointment with the medical specialties doctor. He sat me down and told me the outcome: I had PAH, a poor prognosis with maybe three years to live “if I was lucky.” The pressure in my lungs was around 130 millimeters.

In August 1995, I started taking Flolan and Lasix with Potassium Chloride, which was the only medication available to me at that time. I was so sick by then that I was living in a hospital bed in my living room and using a wheelchair. I stopped walking due to skeletal pain from the medication. I was unaware I could be seen by a pain management team.

Two years went by until I finally spoke up to my doctor. He prescribed a cocktail of medication to relieve most of the pain, and I started physical therapy. After a couple of years, I started feeling better and getting out of the house. My pressure was down to 38 mm. By this time more medications were available to PAH patients. He

PULMONARY HYPERTENSION

Pulmonary hypertension (PH) is high blood pressure in the arteries going to the lung. If it persists or becomes very high, the right ventricle of the heart, which supplies blood to the pulmonary arteries, is unable to pump effectively, and the person experiences symptoms that include shortness of breath, loss of energy, and edema, which is a sign of right heart failure.

- PH is a general term that means that the blood pressure on the right side of your heart is too high, but does not explain why it is high. Causes include chronic lung disease (e.g., chronic obstructive pulmonary disease, interstitial lung disease, etc.), heart disease, and blood clots in the lung.
- Pulmonary arterial hypertension (PAH), is a specific type of PH that occurs when the blood vessels in the lung are directly diseased and become thick and narrow.

Learn more:
wanted to start titrating the Flolan down and put me on Tracleer. It went smooth and
I transitioned with no problems.

I then went into a double-blind study for Tyvaso. It was FDA approved and
added to my medication list, along with Adcirca. My pressures are maintaining at 45
millimeters, and I’m very active. I even started a support group in my area, and I am a
peer network mentor. If it wasn’t for research, I would not be here today. We, however,
need more research done.

Too many patients are losing their lives to PAH. It has to stop. We need more
options! Please help us fight for our lives and the possibility of a cure.

*Tina Silks was a patient speaker at the ATS 2012 International Conference in San Francisco.*