

Pulmonary Hypertension: A Misleading Name

by Nancy Stearns, Group Leader

Pulmonary hypertension is a misleading name for a disease: It doesn't sound as serious as it is. People hear it and think blood pressure, something that can be controlled by medication. But pulmonary hypertension (PH) is different. PH is a rare lung disorder in which the blood pressure in the pulmonary arteries rises and can damage the heart. The heart can swell and lose the ability to pump blood through the body. Treatments for the condition are limited and expensive.

Cricket Mitchell from Riverton, WY, was alone in her doctor's office when she heard the diagnosis. At age 33, she was out of breath doing the most mundane of activities. Her doctor told her that she had a very rare disease and unfortunately, she could die from it. She had primary PH, meaning hers wasn't a complication of another condition.

She went on oxygen full time. Flolan, a new medication still undergoing Food and Drug Administration approval, was an option but Mitchell put off going on it as long as she could.

In 2002, her heart had enlarged and she had no choice but to go on the medication. Now every morning, at 44, Mitchell mixes the Flolan which is continuously administered through a heart catheter.

Nancy Stearns was a Language Arts teacher at Wind River High School in Pavillion, WY. Just walking to the office to get messages left her winded and out of breath. She struggled how to spell words at the board and couldn't lead a classroom discussion without the most detailed of outlines. Stearns was diagnosed with secondary PH caused by her severe sleep apnea. Her specialist prescribed supplemental liquid oxygen.

Mitchell and Stearns met and became friends. Eventually, they thought it would be nice to have a group where they could talk about mixing

medications, living with oxygen, heart catheters and pumps. Mitchell and Stearns started the Wyoming Pulmonary Hypertension Support Group in June 2007 with seven PH patients and five caregivers. Since that first meeting, the group has grown to nearly 30 patients. Mitchell and Stearns have traveled to health fairs and distributed informational packets to physicians and hospitals throughout the state. It is their goal to eliminate the loneliness and isolation of PH patients.

Lora Knight, 51, of Green River, WY, said the support group has been invaluable, "It's just knowing you're not battling a disease by yourself." She was diagnosed eight years ago, her PH developing from an autoimmune disease called scleroderma. Her best weapon against the disease is her positive attitude.

Knight wears a pump that administers her medicine, Remodulin, continuously into her arm. The drug cost \$24,000 a month. She's worn her oxygen so long that she feels weird without it.

Learn more about the Wyoming Pulmonary Hypertension Support Group and its newsletter and activities on its website, www.orgsites.com/wy/pulmonary-hypertension-support/index.html.

Learn more about pulmonary hypertension and the Pulmonary Hypertension Association at: www.phassociation.org.



The Pulmonary Hypertension Support Group poses during a recent meeting in Cheyenne, WY.