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New support group is connecting Wyoming people affected by a rare disorder

By KRISTY GRAY
Star-Tribune staff writer



It's not like cancer.

Yes, it drains a patient's energy and robs him of his quality of life. It is expensive to treat. Like cancer, it has no cure and needs money for research.

Yes, it can be fatal.

But it's not like cancer.

Cancer people have heard of. Cancer has support groups and places to go to for information, advice and comfort.

Pulmonary Hypertension doesn't even sound that serious. People hear it and think blood pressure, something that can be controlled by medication.

But this 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.

Cricket Mitchell was alone in her doctor's office when she heard the diagnosis. She'd felt out of breath doing the most mundane of activities: running into the grocery store for a quick errand, climbing a flight of stairs. At first, she had chalked it up to being a little out of shape. But she was only 33 at the time, so she went to ask her doctor.

"He came back and told me that I had this very rare disease and that unfortunately, I could die from it. It was scary. I was in the doctor's office by myself and I was devastated," said Mitchell of Riverton, now 44.

This year, she and another Riverton woman, Nancy Stearns, started a support group to help patients and caregivers deal with an illness most people haven't heard of and few, if any, Wyoming doctors specialize in.

The Wyoming Pulmonary Hypertension Support Group held its first face-to-face meeting in June. The pair had spent much of the spring travelling to health fairs across the state passing out information and reaching out to people with the disease.

"Because it's such a rare disease and it's so isolating and limiting, we knew that we needed support. And because we knew that, we knew that others needed it as well," Stearns said.

Mitchell's story began like the stories of many other PH patients: She couldn't breath doing the most menial of tasks. She was diagnosed with primary PH in 1997, meaning hers wasn't a complication of another condition.

She went on oxygen full time. When her condition didn't improve, Mitchell's doctor wanted her to start a medication called Flolan, which is still undergoing FDA approval. But she felt like a guinea pig and didn't want to live with side effects that sounded worse than the condition. She decided to put it off as long as she could.

In 2002, her doctor told her it wasn't working. She was a walking time bomb. Her heart had enlarged so much that it was practically encased inside her rib cage. If it were to rupture, there'd be no bringing her back.

In the kindest words he could manage, her doctor told Mitchell that if she were his wife or his daughter, he'd tell her to go on the medication.

Now, Mitchell mixes the Flolan every morning. It is continuously administered through a heart catheter. At 44, she breaths through oxygen tubes day and night.

Her doctor, a specialist in Denver, asked if she wanted to talk to any of his other PH patients to find out more. But she pictured people in their 50s and 60s and couldn't relate to them, so she declined.

"I thought, 'They don't know what I'm going through.' I felt like they weren't in my age group so I would just deal with this by myself."

Across town, another Riverton woman was facing her own diagnosis. Stearns was an English teacher at Riverton High School. Just walking to the office to get her messages left her winded and out of breath. She couldn't remember how to spell words at the chalk board and couldn't lead a classroom discussion without the most detailed of outlines.

She was diagnosed with secondary PH caused by her severe sleep apnea. Her specialist, also based in Denver, put her on oxygen. She wore the tank all day and all night.

Faced with the possibility of going on Flolan, Stearns called Mitchell asking for advice. The two became friends.

And then they got to thinking: Wouldn't it be nice to have a group closer than those in Salt Lake and Denver where they could talk about mixing medications, living with oxygen, heart catheters and pumps? They had found each other, there had to be others in Wyoming.

So they formed their own group. At the June meeting, people from across the state shared their stories, their tears and their triumphs.

"It's not a visible disease unless someone is on oxygen. We all have to drive considerable distances to treat this. We just felt the need to connect," Stearns said.

"It was an emotional meeting. Everyone sharing their frustrations, not just the patients but also the caregivers. We were really quite charged up after the June meeting.

"One of our major goals of the group is to educate. Not just the patients, but the public and the doctors."

Though her PH is being managed, learning about the disease has become a passion for Stearns. She

figures it's the teacher in her, the need to learn about it and pass on what she's learned to patients, doctors and the public.

Lora Knight, 51, of Green River, said the support group has been invaluable.

"Especially in Wyoming, we're just not a very populated state," she said. "It's just knowing you're not battling a disease by yourself. We don't necessarily like talk to each other every day, but it's knowing that they are there if you need them."

Knight has been married for 31 years and has three daughters and six grandchildren. She was diagnosed eight years ago, her PH developing from an autoimmune disease called scleroderma. By the time her doctors found it, they figured she was within two years of dying, she said.

Her best weapon against the disease is her positive attitude, as cliché as that might sound. That last time she went to see her specialist in Salt Lake City, he exclaimed: Eight years! Can you believe it? Isn't that great!

Now, she wears a pump that administers her medicine, Remodulin, continuously into her arm. Her grandchildren now know to look for the pump so they climb into Grandma's other arm. She's worn her oxygen tubes so long that she feels weird without them.

The first year on her medication, it cost \$24,000 a month and she has long since hit the \$1 million mark for her care. But now, major medical coverage pays much of the cost.

Knight looks forward to seeing her doctor for another eight years, even it means travelling to Salt Lake City every three to six months.

And she looks forward to more meetings of the support group, though Wyoming weather and distance will keep face-to-face meetings to just a few a year.

"It's like a family kind of feeling. They're like the extended relatives you see once a year at holidays," Knight said.

"But I wish those holidays came around more often."

Pulmonary Hypertension

* **What it is:** Continuous high blood pressure in the pulmonary artery in the lungs, resulting in an enlarged heart, which can also lose its ability to pump. It can affect people of all age levels and ethnic backgrounds.

* **Symptoms:** Because its early symptoms are similar to those of other conditions, PH is often not diagnosed until the disease is quite advanced. Symptoms include chest pain, breathlessness, low energy, dizziness and fainting, swollen ankles and legs, bluish lips and skin.

* **Treatments:** Until 1990, there were no accepted treatments for PH. Because there are no known PH specialists in Wyoming, patients often have to travel out of state. Some Wyoming doctors have expressed interest in specializing in the disease and some Billings, Mont., doctors have come to the Cody area to see patients, said Nancy Stearns, cofounder of the Wyoming Pulmonary Hypertension Support Group.

Many treatments are expensive and highly invasive, requiring the use of a pump that continuously administers medicine into the heart by an indwelling catheter. Other treatments include heart and lung transplants, supplemental oxygen and medication.

* **Prognosis:** The length of survival seems to be improving with some patients able to manage the disease for 15 to 20 years or longer. With continuing research, specialists hope patients will survive

even longer and a cure may someday be found.

*** Information:** Contact the Pulmonary Hypertension Association, 800-748-7274, www.phassociation.org, pha@phassociation.org.

-- Source: Pulmonary Hypertension Association

The support group

The Wyoming Pulmonary Hypertension Support Group was founded in April by Nancy Sterns and Cricket Mitchell, both of Riverton.

The pair wanted to give a voice to other patients with PH and be a source of information and support to caregivers and patients who have few outreach options in Wyoming. The pair went to health fairs across the state handing out information and looking for PH patients.

The group had its first face-to-face meeting in June with about a dozen patients and caregivers. They had a second meeting in September.

Sterns and Mitchell hope to host a meeting twice a year. They also put out a newsletter and are networking with PH patients and caregivers from around Wyoming through e-mail and phone calls.

To learn more, contact Nancy Sterns at 1206 Timber Lane, Riverton, WY 82501, 307-856-6976 or at pinnut3200@yahoo.com. Visit the Web site at <http://tinyrul.com/ywb6e3>.