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HEALTH

Bellingham woman fights pulmonary fibrosis
Lung disease is a little known but deadly killer



NIKI DESAUTELS THE BELLINGHAM HERALD

Kristie McClellan, 57, waits outside her husband's office at Hardware Sales, their family-owned hardware store in Bellingham. McClellan was recently diagnosed with idiopathic pulmonary fibrosis, a disease that is turning her lungs into scar tissue and robbing her of her ability to breath, little by little.

MICHELLE THERIAULT
THE BELLINGHAM HERALD

Kristie McClellan has a disease that claims 40,000 lives every year — the same number as breast cancer.

But you've probably never heard of it.

In July, doctors told the 57-year-old Bellingham woman that she had idiopathic pulmonary fibrosis. They meant that her lungs were turning into scar tissue, and it would eventually

kill her. She and husband Jerry McClellan were bewildered by the diagnosis. "We'd never heard of it before," she says.

They weren't alone. They started asking everyone in their circle of friends, acquaintances and customers at their Bellingham business, Hardware Sales, about the disease.

Did they know anyone who had it? Had they ever heard of it?

They got sympathetic, blank looks in return.

Wracked with fear and sorrow, Jerry placed a classified ad in the newspaper, an open plea for people to start a support group with him. He got a single response, from a woman whose husband had died of the disease 2½ months after being diagnosed.

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LEARN MORE ABOUT PULMONARY FIBROSIS

The Coalition for Pulmonary Fibrosis:
<http://www.coalitionforpf.org/>

Pulmonary Fibrosis Foundation:
<http://www.pulmonaryfibrosis.org/>

To contact Jerry and Kristie McClellan: 966-3655 or jerry@hardwaresales.net

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They felt alone with their death sentence.

"Am I the only person out there? There have to be other people, if it's as common as they say," Jerry says.

"Confusing disease"

Idiopathic pulmonary fibrosis is an unexplained hardening of the air sacs in the lungs into scar tissue. This prevents the lungs from getting oxygen into the blood stream and makes breathing difficult until, eventually, it becomes impossible.

The Chicago-based Pulmonary Fibrosis Foundation says that at least 200,000 Americans have the disease; 40,000 die each year. Two-thirds die in five years. There are more than 200 interstitial lung disorders, which cause damage and swelling in the tissue between air sacs in the lungs.

Some cases of pulmonary fibrosis can be linked to exposure to occupational hazards like asbestos or metal dust. But the cause of other cases, like Kristie's, are a mystery.

It's believed that the condition, often misdiagnosed as emphysema, asthma or pneumonia, is largely unknown to those who don't suffer from it.

Abigail McGlothlen, communications director for the foundation, says that it's a messy, confusing disease that affects mostly middle-aged and older people.

"There's such limited understanding of the disease," she says. "Research is still going on to determine the definite causes, and they haven't really determined any effective treatments that seem to work."

Because the disease is easily misdiagnosed and poorly understood, support for sufferers tends to fall under a larger umbrella of lung diseases.

Loving help

The McClellans have been arm-in-arm since they were teens. Jerry, who has been running his family business Hardware Sales in Bellingham for more than 25 years, met Kristie first while they were students at Bellingham High School.

He can't imagine the golden years of his life without his wife of 38 years.

"This is like a bad dream," he says. "It's this horrible new thing we've never heard of before."

So it's natural that Jerry has gone, as his wife describes it, "overboard" in his efforts to battle her disease.

He's got a spreadsheet on his computer of all of her treatments: visits to a naturopath, a machine called the "Energetic Fitness System" that she swears clears her lungs, and vitamin supplements. He even called Evel Knievel, who suffers from the same disease. He got to Knievel's daughter, who couldn't tell him much.

He installed new furnace filters. He gave away his beloved parrot. He told the preeminent pulmonary fibrosis specialist in Seattle that he'd camp out in his RV in the parking lot for weeks for a chance to get off the six-month wait list for an appointment. "There is nothing I won't do to keep her on this Earth," he says.

Kristie has wracked her brain to pinpoint what could have gotten into her lungs: the kerosene they'd heat the rec room with? The dust at Hardware Sales? She'd smoked for years, but plenty of people who'd never lit a cigarette had the disease as well, doctors told her. (She quit smoking after her diagnosis.)

Doing all they can

So far, the disease is subtle. When she vacuums, she loses her breath.

"It feels," she says, "like a frog in your throat."

She can't walk stairs like she used to. She gets sweaty and loses her breath quickly with a bit of exertion.

The McClellans are focused on creating a support group for sufferers to connect with others who share their questions and fears. And Jerry is on a mission to tell the world about the disease.

He recently bought 200 IPF wristbands that he's set by the cash register at Hardware Sales. Funds raised will go to the foundation for research.

"I need help," he says.

For now, all Kristie can do is wait, hope and enjoy her life.

She still can baby-sit her 4-year-old granddaughter Brooklyn and take RV trips to the ocean or Palm Springs, Calif., one of her favorite places. Two different doctors told Kristie she wouldn't live long enough to see Brooklyn's eighth birthday. One told her to begin reading a book called "Death and Dying." Another told her that if she had anything she wanted to do, she should do it in the next year.

Kristie is unconvinced.

In a year, she hopes she can write a letter to the doctors who told her she'd be dead, just to prove they were wrong.

"I'm just going to be around," she says. "I'm not going nowhere."

She doesn't take the simple act of breathing for granted anymore. Now she savors the sweet air.

But she has begun writing a daily journal about her hardening lungs.

Eventually she says, her husband can give it to the Pulmonary Fibrosis Foundation in Chicago, so someone else won't feel so alone.

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