Mystery illness is just one fight for woman

Finding treatment has been a struggle for family

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Kara Chytka lives in constant pain. She takes 500 milligrams of morphine a day. She cannot walk or move her arms. Her speech is jumbled. She had a feeding tube implanted because she had difficulty swallowing. Her husband, Chris, quit his job to care for Kara, who requires 24-hour attention, and their four children.

It is unclear what is plaguing Kara, of Aumsville. A hematologist in San Francisco diagnosed her as having Lyme disease. Three neurologists from Oregon have said she has amyotrophic lateral sclerosis, also known as ALS or Lou Gehrig's disease. Kara, 27, and her family have no doubt that what is afflicting her is Lyme disease.

Kara's affliction highlights the controversy about how doctors diagnose and treat Lyme disease, the nation's most common insect-spread illness.

"Lyme-literate" doctors say Lyme disease is more prevalent than people realize. They also say long-term antibiotics treatment is needed to care for patients in some cases -- a practice others disagree with.

Doctors say most patients fully recover from Lyme disease after receiving the standard two to four weeks of antibiotic treatment. Also, they say, treating Lyme disease patients with long-term antibiotics has not been clinically proved effective and can be dangerous.

Doctors agree on the need for more research and clinical studies, especially into chronic Lyme disease, which some doctors call post-Lyme disease syndrome.

In 2004, the Centers for Disease Control and Prevention received 19,804 reports of Lyme disease, down from 21,273 in 2003. Oregon logged 11 cases in 2004, according to the CDC.

Pat Smith, the president of the Lyme Disease Association, a national advocacy group for Lyme disease sufferers, said there probably are 200,000 new cases nationwide each year. Many of these patients are not getting treatment, she said.

Lyme disease spreads to humans via bites from infected blacklegged ticks. Kara said she doesn't recall being bitten. And she never had the trademark "bulls-eye rash," which gradually expands to as much as 12 inches across and occurs in 70 percent to 80 percent of patients infected with Lyme, the CDC says.

Chris, 32, and Kara suspect that a tick bit her when she was younger. Kara said she had seizures from ages 7 to 15. She had problems with balance growing up. Her knees, hips and ankles throbbed with pain by the time she was 18.

In 2002, her speech and coordination deteriorated. She had blurred vision and saw spots. And she often felt like she was in a daze.

Diagnosis of ALS

That year, a neurologist diagnosed her as having ALS. Chris and Kara said the neurologist told them that 90 percent of people with ALS die in two to three years. Two other neurologists concurred with the diagnosis.

Kara said she never thought she had ALS. She researched her symptoms on the Internet, finding stories of people diagnosed with ALS who later were diagnosed with Lyme disease. She made plans to get tested for Lyme disease.

Diagnosis debate

The debate in the medical community about Lyme disease starts with diagnosis.

The two-tiered blood test that the CDC recommends for Lyme disease has been criticized because it can miss some patients who have the disease, Smith said. Because of this, some patients are not being properly treated.

The Lyme Disease Association is pushing the CDC to change its recommendations to a more liberal method that would not miss as many patients. Some doctors say that raises the possibility of falsely diagnosing Lyme, which also could delay proper treatment.

The CDC says there are misperceptions about the accuracy of the tests. The tests can detect Lyme infection 85 percent to 95 percent of the time in patients who have been infected for several weeks, said Hannah Gould, an epidemic intelligence service officer with the CDC.

In 2003, Chris and Kara went to Dr. Raphael Stricker, a hematologist in San Francisco. Stricker is the president of the International Lyme and Associated Diseases Society, a group of doctors who use more-liberal testing and treatment guidelines for the disease.

Chris and Kara said Stricker used a variety of blood tests to check for Lyme disease. He performed only the second of the two-tiered test recommended by the CDC. Kara tested positive. Stricker said Kara has a rare motor neurological form of the disease, which is nearly identical to ALS in its symptoms.

He prescribed intravenously administered antibiotics for Kara. When she returned to Oregon, her primary-care physician, Elizabeth Blount, put Kara on the antibiotics that Stricker recommended.

The Infectious Disease Society of America's guidelines for treating Lyme disease call for two to four weeks of antibiotics treatment. Only rare cases require more than four weeks of treatment, the guidelines state.

Treatment risks

There are numerous risks of long-term antibiotic treatment, said Dr. John Townes, an associate professor of infectious disease with Oregon Health & Science University. Bacterial infection, fungal infection, colitis, allergic reactions and other conditions are all possible effects of long-term antibiotic use.

"It is very risky," Stricker said. "Everything in medicine has risks. Leaving chronic Lyme disease untreated has even greater risks."

Kara said she feels she has no choice. While on the antibiotics, she was was strong enough to use a walker. Her speech was slurred, and she still had some pain. But she said she thought she was getting better.

After about a year of antibiotics treatment, her primary-care physician, Blount, met with an ethics committee at Silverton Hospital to discuss Kara's condition. Blount decided to take Kara off the antibiotic treatment, citing the risks.

"She continued to get worse" and didn't respond to treatment, Blount said.

Blount said she thinks Kara has ALS. She said that Kara perhaps had Lyme disease and it triggered a neurological response that might have caused her to develop ALS.

Still a mystery

Some doctors say chronic Lyme disease will remain a mystery until more scientific studies are done.

"Eventually, we can understand that better. Maybe the organism is hanging around still. Maybe not," Barbour said. "These people are suffering from something."

In the past two years, Kara has lost nearly all motor control over her arms and legs. Her speech is difficult to understand. Chris translates most of her words for others. She chews a bit better now but still receives much of her nutrition through her feeding tube.

Chris and Kara are looking for a doctor in Oregon who will put her back on antibiotics. They have discussed moving to California to get treatment from Stricker.

If they move to California, they will lose the support provided by their families and their church, Bethel Baptist Church in Aumsville. Chris said they cannot afford California's cost of living or moving there.

Meanwhile, their bills have been piling up. The Oregon Health Plan pays Chris a small stipend to take care of Kara. And she gets Supplemental Security Income payments. But Kara's health-care costs suck up most of their income, they say, making it difficult to travel to find a physician to put Kara back on antibiotics. Until then, they have to wait.

"I'm not going to give up," Kara said. "I'm not going to stop fighting."
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