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Raising red flag over Lyme

Eagle Lake resident warns public to take disease seriously

BY **TIM ROWLAND**

◀ 460

◀ 1

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Photo provided

Todd Condon didn't get a diagnosis of Lyme until it was too late.

TICONDEROGA | Todd Condon creates art on his iPad, not necessarily because he prefers to, but because the joints in his fingers have seized up to the point that he cannot grip brushes and pens. He still has good days, which to him means getting to the grocery store and back without incident, or being relatively free of painful

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Condon contracted Lyme disease three years ago, and the illness has become chronic largely, he says, because of a lengthy delay in its diagnosis. Doctors wrote off his condition to joint maladies or fibromyalgia and balked at his repeated requests for advanced blood work.

His joints and head throbbed, he was tired all the time, and he lost coordination and was easily confused.

"Everybody who knew me said, 'What's wrong with this guy?'" Condon said. "The scary thing was, I didn't know myself."

'WHAT DO YOU DO NOW?'

For 25 years, Condon, of Eagle Lake, had worked for International Paper in Ticonderoga, but the disease eventually overcame his ability to do the job he loved. By this time he knew what was dogging him, having finally been availed of a specialist who performed the blood work Condon had wanted two years before.

The results were sobering. Not only did he have Lyme, he tested positive as well for West Nile disease and Bartonella, co-infections likely spread by the same tick.

Had Condon gotten the blood tests when he wanted, things might have been different. But now the condition had worked its way into his nervous system and advanced to the point that treatment was far less effective.

Physicians poured on the antibiotics, six months' worth of pills taken twice daily and, when that didn't work, prescribed a half-hour a day's worth of intravenous drugs for a month. That didn't work either.

"If the antibiotic isn't doing anything, what do you do now?" he said.

RAISING AWARENESS

Condon says he still has hope, if not relief. His other goal is to raise awareness of Lyme and help people who are in chronic pain, no matter what the cause. To that end he has started a Chronic Pain and Illness Support Group that meets at the Ticonderoga Hospital on the second Sunday of every month at 7 p.m.

"All are welcome to attend," he said. "It's a place where people can share their stories and feel they have a caring and supportive environment."

Meanwhile, he sifts through medical and social-media sites hoping to find evidence of a cure.

SEVERE SPIKE

Lyme was relatively unknown in the Adirondacks, until climate change expanded the range of the deer tick that carries it. According to research by Lee Ann Sporn, a professor at Paul Smith's College, Essex County saw a severe spike in Lyme disease beginning in 2012.

But scientists and physicians have been dismayed this year that the New York Senate has to date failed to provide for a continuance of the funding that has paid for baseline research — an indication that Lyme is still not garnering the attention it should.

In a statement sent to the Senate in support of funding, Dr. Russ Hartung, emergency physician at Champlain Valley Physicians Hospital in Plattsburgh, said research into tick populations and infection rates provide critical guidance to the medical community.

He also said the seriousness of the illness is still understated.

"The general public may not realize that Lyme causes more than just achy joints and a rash," he wrote. "It can cause critical illness like cardiac disease and meningitis, and the other tick-borne pathogens can be even worse."

According to Sporn's research, "it's a coin flip" as to whether a tick is a carrier or not, so it's best to assume that any tick bite is cause for concern. Checking for ticks after being out in the bush is critical, since if the tick is pulled off within 24 hours, the disease, studies indicate, probably has not had time to be transmitted. Tick bites are also more dangerous in July and August than in the spring and fall.

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Condon believes Lyme is still going undiagnosed and that too many in the medical and insurance industries still treat it as a phantom disease. It can be hard to find doctors that have a good, up-to-date understanding of Lyme, he said.

"I don't think it's gotten the proper attention," he said. "If you don't catch it quickly, you can get in trouble."


Lyme is also insidious because it can come with co-infections and can show up differently in different people. Someone might be infected, but show no symptoms. And when they do show, those symptoms can vary radically, making diagnosis more difficult.

"You have to be your own advocate," Condon said. "Find a doctor who is Lyme literate."

Patients need to be careful too that the physician's care will be covered by insurance, since companies sometimes balk at paying for Lyme treatments.

Condon said he's a walking exhibit of the need for early treatment.

"It's been three years of hell," he said. "It feels like my joints are being torn apart on the inside. Things that people take for granted become a struggle. I just hope the word spreads far enough that people know what to do, and that no one else gets to this point."

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