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Published 6/10/09

Families React to ALS Cluster

Relatives Learn of Possible Algae Link

By Martin F. Downs
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Windsor -- For Tim Quinlan, 51, memories of summer days spent swimming in Windsor's town pond did not immediately come to mind when his brother, Todd, was diagnosed with Lou Gehrig's disease five years ago.

But those memories came flooding back yesterday, when he heard that a researcher at Dartmouth-Hitchcock Medical Center had identified a cluster of the disease near Kennedy Pond, also called Mill Pond, in Windsor.

Scientists suspect that a neurotoxin in a kind of algae commonly found in ponds and lakes could trigger the disease in some susceptible people. Using DHMC patient records, researchers there have mapped cases of Lou Gehrig's disease in Vermont, New Hampshire and Maine, and have located clusters of cases near Mascoma Lake and Kennedy Pond, among others.

Quinlan, who now lives in upstate New York, said that he and his brother, who turns 56 today, are intrigued by the possibility of a link between the disease and the pond where they swam as kids.

"This is all so new to us, and so spectacularly specific to us," he said in a telephone interview yesterday. "This is very interesting stuff."

Quinlan spoke his brother's behalf because the disease has impaired his ability to speak.

Lou Gehrig's disease is also known as amyotrophic lateral sclerosis, or ALS. It's a progressive and often fatal disease that attacks nerve cells in the brain and spinal cord, according to the ALS Association.

Dartmouth neurologist Elijah Stommel is working with a team of researchers at other institutions to determine if clusters of ALS around lakes and ponds are linked to blooms of blue-green algae, also called cyanobacteria, in the water. A toxin produced by cyanobacteria has been found in brain tissue of people with ALS and other degenerative neurological diseases. That has led scientists to question whether the toxin could trigger ALS in some people with an as-yet-unknown genetic trait.

Srommel has mapped three cases of ALS near Kennedy Pond in Windsor, and a cluster of nine cases near Mascoma Lake.

But mapping clusters is only a first step in the research that Stommel is pursuing, along with researchers at the University of New Hampshire, the Wyoming-based Institute for Ethnomedicine and the New Hampshire Department of Environmental Services.

“We have not found the actual toxin in the bodies of water,” Stommel said.

He said that the research team planned to take water samples from Kennedy Pond and Mascoma Lake this summer.

Stommel said that scientists were just beginning to study the potential link between ALS and cyanobacteria, and he stressed that exposure to cyanobacteria toxin hasn't been proven to cause the disease.

Nancy Danyew of Windsor said that she and her late husband, Ernest Danyew, lived for 22 years in a house on Cherry Street, overlooking Kennedy Pond. He was diagnosed with ALS in January of this year and died of the disease in March, at age 67.

Danyew said the doctors that diagnosed her husband attributed his ALS to having been in the Army.

“It has nothing to do with the pond down here,” Danyew said in a telephone interview yesterday.

She said her husband grew up in Windsor, and that he often fished and swam in the pond. But she said he also served in the Army in the early 1960s, as a military police officer stationed in Germany.

Danyew was treated at the Veteran's Administration Medical Center in White River Junction. The care he received was entirely paid for by the government, she said, because ALS is recognized as a disease related to military service.

According to the ALS Association, the Department of Veterans Affairs classified ALS as a “service-connected disease” in new regulations published last September: “This means that if a service member is diagnosed with ALS, his or her condition will be presumed to have occurred during or been aggravated by military service,” a document on the association Web site states.

Studies show that Americans who have been in the military are at greater risk for ALS, no matter when or where they served, or what branch of the military they were in, an ALS Association report says. The report cites a Harvard University School of Public Health study published in the journal *Neurology* in 2005, which found that men with any history of military service were 60 percent more likely to get ALS than men who had never been in the military.

Health and environmental officials in Vermont do not routinely test ponds and small lakes for cyanobacteria, according to Angela Shambaugh, an algae specialist with the Water Quality Division of the Department of Environmental Conservation, in Waterbury.

“We depend on the public to tell us that they have concern,” she said.

She said that the state only routinely monitors Lake Champlain water for cyanobacteria, in cooperation with the University of Vermont.

“Cyanobacteria are really a natural component of water anywhere,” Shambaugh said. “We do worry about that because there are some that are potentially toxic.”

According to the Centers for Disease Control and Prevention, cyanobacteria toxin in water can cause rashes, hives or blisters on people's skin. Swallowing water contaminated with the toxin can cause severe diarrhea and vomiting.

If there were a link between cyanobacteria and ALS, it might be that some people have a gene that makes them more likely to get the disease when exposed to cyanobacteria toxin over a long period of time, Stommel said.

Quinlan said that both he and his brother moved away from Windsor in the 1970s.

Considering how many unknowns there are, Stommel said he couldn't speculate on whether being exposed to the cyanobacteria toxin could lead to ALS decades later.

Quinlan said that he isn't worried that he might also get ALS, because the disease is relatively rare -- an estimated 5,600 people in the United States are diagnosed each year, according to the ALS Association -- and because no one else in his family has had it, besides his brother.

“It would still be very unlikely for it to happen to me, too,” he said.

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