

THE THREAT OFFICIALS DON'T WANT TO ACKNOWLEDGE

Lyme disease very real in Alberta

Re: "Teen's 'living death' was Lyme disease, family says: Province says no local case has ever been found, but parents insist lab's blood tests gave many false negatives," *The Journal*, April 4.

I'm extremely grateful to see a story of Lyme disease that was treated here in Edmonton.

I'm another Albertan who is not an official statistic. I remember an insect bite on my thigh last summer, but not a bulls-eye. It itched into the fall. I haven't been outside of Canada in 20 years. I tested negative at the provincial lab, but my result at the California lab showed three bands of tickborne infection.

My story began like Ed Sperling's. I had a raging sinus infection. It took three courses of antibiotics.

Then, I started waking up with delirious fevers and flu-like symptoms. They just never let up. My jaw seized shut.

One morning I couldn't walk. My legs were concrete slabs; my hips locked shut. I felt strong electrical shocks coursing through my muscles. The rheumatologist was stymied. I didn't have arthritis, lupus, ALS, fibromyalgia or MS.

I was at wit's end as my symptoms became bizarre. I made sandwiches butter-side-up. I began hallucinating. The sparrows flying past became out-of-control cars.

When I said "mashed potatoes," it came out "mash-atoes." I wrote sentences backwards. When I began slurring my words, my doctor referred me to a neurologist. While waiting, she prescribed antibiotics for a blotchy face rash. That cleared up, I stopped hallucinating, my hips unlocked.

I knew I had Lyme disease when I responded quickly to antibiotics. I found a specialist in B.C. who prescribed long-term antibiotics. I'm on my third month now and my walking is improving. I no longer babble gibberish and my energy is returning. It's been a rough year.

What would I be like without antibiotics today? I shudder to think.

Jan Melnyk, Edmonton

Local MDs skeptical

I, too, was diagnosed with Lyme Disease three years ago after many months of declining health, frustration and visits to a specialist who insisted there was nothing medically wrong with me.

After being tested for MS, lupus and a multitude of other diseases and many thousands of dollars spent on a diagnostic MRI and various other blood tests which came back negative, an Edmonton neurologist reluctantly agreed to giving me the only test Alberta physicians give for Lyme disease. I asked the doctor to test me for it and he stated "there is no need for that as we do not have infected ticks in Alberta." I told him I was not bitten in Alberta, but had received a bite while vacationing in the Maritimes.

This test came back with a false negative and he dismissed me, telling me to return in a year if I still had the symptoms.

My symptoms were worsening and new ones appeared weekly. I did some research on the Internet and kept coming back to Lyme disease.

I contacted a Dr. Ernie K. Murakami, a professor emeritus of bacteriology and immunology at UBC who treats patients with Lyme disease. He tested me right



PUBLIC HEALTH IMAGE LIBRARY OF THE CENTERS FOR DISEASE CONTROL
The blacklegged tick, *Ixodes scapularis*, which can carry Lyme disease, has been found on songbirds and dogs in northern Alberta.

away. The results were positive and I began a four-month course of strong antibiotics.

I am now cured of Lyme disease and feel great. I hate to think what would have happened had I not contacted Dr. Murakami.

I am fortunate to have a family physician who worked with us on the treatment and was very supportive. She admitted that she knew little about Lyme disease and it is not something that Alberta physicians are taught a lot about.

Dr. Murakami told me he had treated several patients who were bitten in Alberta. Alberta doctors should educate themselves on this disease. It will save thousands of health-care dollars and hopefully save someone's life.

Gayle Rettmer, Fort Saskatchewan

Alta. Health in denial

Our family read with interest the April 4 article on Lyme disease. Shockingly, it echoes a lot of what we went through with our son a decade earlier.

It is sad to see that Alberta Health is still in denial, claiming that the disease does not exist in this province.

Like the Sperlings, we watched our teenaged boy turned from vivid reader, grade A student, and competitive swimmer to a glassy-eyed, sad kid who was too fatigued to go to school. It happened in a matter of weeks after a family vacation in Waterton Park.

My wife, who grew up in Sweden where Lyme is well known and readily treated, quickly connected the holiday memory of itchy bite mark on our son's leg to his symptoms. Yet, just like the Sperlings, we were told by doctors that this was just our son's rebelliousness, that perhaps he doesn't like school and that we should give him antidepressants to make him happy again.

The test for Lyme that Alberta doctors use are not reliable. We travelled to California to have him tested. The results were positive for Lyme disease.

Upon our return to Edmonton, we were told Lyme-carrying ticks do not exist in Alberta. It took another year and many tests for various other possible causes, before we finally convinced a doctor to allow our son to have intravenous antibiotics for Lyme disease.

After a week, our son started to recover.

He lost four of his teenage years and his education was delayed by two years because of the lack of treatment. Happily, he is attending the third year of engineering at U of A.

The most shocking fact is that some of doctors who were denying the treatment to our son in 1998 are the ones who gave the Sperlings the run around in 2005.

How many other kids are missing out on their education and life experience right now, and how many will still have to go through misdiagnoses or unwillingness to acknowledge that Lyme-carrying ticks are in Alberta?

We thank the Sperlings for going public with their story. Hopefully it will bring the Lyme disease diagnosis and treatment issues in Alberta to light, especially as hiking season is about to start again.

Inger and Waldemar Lysz, Edmonton

Difficult diagnosis

My teenage son also suffered from Lyme disease. He went to the brink of death and was brought back to the land of the living with antibiotics.

He was treated for an "illness of unknown origin," as his Alberta Lyme tests were negative. His illness was violent, with vomiting and diarrhea, coughing and pain.

He was suspected of having early onset Alzheimer's, Whipple's disease, MS and was even tested for Mediterranean familial disease.

We did not get him tested in the U.S., as we had a team of three doctors and a psychologist (at the end) who took control of his illness and helped him survive.

He did get other tests done in Canada but they were indicative of a past infection. Tests said he had a past infection of Bartonella henselae (cat scratch disease), Rocky Mountain spotted fever, and babesiosis (a malaria-like illness). But, past infections should not cause current problems.

After 10 months of antibiotics, my sports jock is back doing what 21-year-olds do. He suffered for 3½ years before we found help. He started this journey at 16. We found help through the Canadian Lyme Disease Foundation. If not for these people and the doctors who believed, I think my son would not have survived.

Thank goodness Alberta has so many wonderful doctors who know the difference between a psychiatric, "faked" illness and someone who is physically ill.

It sounds like a strange comment to make, but confusing Lyme with a mental disorder is common. My son's diagnosis just before Lyme was post-traumatic stress disorder. Our psychologist adamantly denied this could even remotely be the problem.

This spurred us on, with him supporting our family, to find a team who could help us.

Sherry Drew, Lethbridge

Ticks found in Alberta

The medical profession are certainly fearful of any Lyme disease in Alberta. This bacterial disease, which is recognized worldwide, is found across Canada.

As stated in the article, the young patient, Ed Sperling, was likely bitten in California where the western blacklegged tick, *Ixodes pacificus*, is infected with the Lyme disease bacterium, *Borrelia burgdorferi*. However, these ticks have been retrieved from wild-caught songbirds in Alberta during spring migration (Morshed et al. 2005). As well, the blacklegged tick, *Ixodes scapularis*, another vector of Lyme disease, has been reported in central and northern Alberta on songbirds (Scott et al. 2001, and Morshed et al. 2005).

Now, Lyme disease-infected blacklegged ticks have been reported on untravelled dogs in Alberta.

After ticks are released from birds, they molt to the next stage and attach to hosts including humans and domestic animals.

Furthermore, Canadian researchers have also cultured *Borrelia burgdorferi* from two additional species of ticks collected in Alberta (Banerjee et al. 1995, and Fernando et al. 2008).

In winter, ticks are comfortable under an insulating blanket of snow, and in summer they go down into the cool, moist leaf litter when temperatures rise above 25 C. Ticks have antifreeze-like compounds in their bodies, just like the spruce budworm overwintering in the buds of a spruce tree, and adjust easily to daily and seasonal thermal fluctuations and climate change.

Sperling and his parents are heroes for addressing Lyme disease in Alberta and for pushing for treatment for him. Not only are vectors of Lyme disease in the province, the Lyme bacterium has been identified in at least three species of ticks collected from domestic and wildlife hosts.

Clearly, the medical profession, including the infectious disease specialists who examined Sperling, must go back to the drawing board and address the presence of Lyme disease in Alberta. Lyme disease is a reality in the province.

John D. Scott, research consultant, Lyme Disease Association of Ontario, Fergus, Ont.

MORE LETTERS

To read more letters on Lyme disease, go to www.edmontonjournal.com and click on ONLINE EXTRAS

MAIL

U of A's 'exorbitant' outrage

Re: "U of A president leads nation in pay," *The Journal*, April 4.

If University of Alberta president Indira Samarasekera and the head of academic affairs were truly interested in the well-being of the students, they would not be increasing their salaries as tuition rises so vehemently.

I am not a fan of their pay, but they are symbols of a system that squeezes every last cent in order to run a business that the province has managed into believing is a public good.

These outrageous salaries at this institution have no national purpose as a cost-cutting measure.

This is truly disgusting and inexcusable. Stop it.

David S. Schwab

Motorcycles

Notwithstanding the fall, motorcycles are still a popular mode of transport.

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Let fans invest in new arena

THE PAPASCHASE LAND CLAIM

Top court rejects case on a technicality, but the band's claim is not without merit

LETTERS

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M.C. Edm.