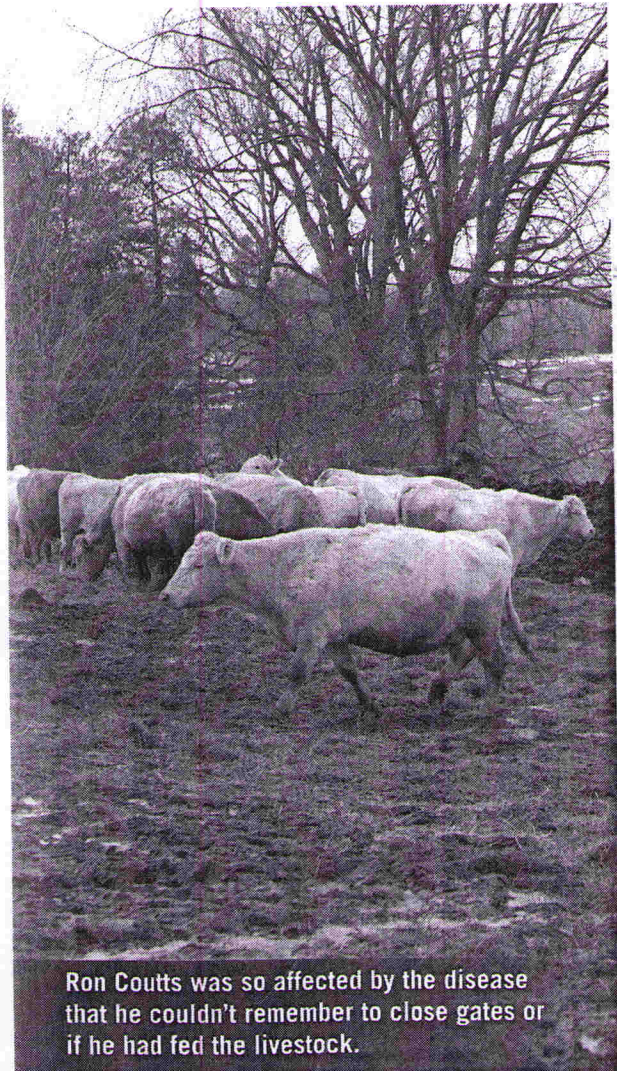


LYME DISEASE:

The painful *and* h

Some farm victims are finding that it takes years to diagnose and that the medical community is not unanimous about how to treat it. But when it strikes and treatment is delayed, the results can be catastrophic



Ron Coutts was so affected by the disease that he couldn't remember to close gates or if he had fed the livestock.

Ron Coutts smiles modestly into the camera during a television interview about his family's maple syrup and beef farm near Perth in Lanark County. The curved peak of his ball cap rides low, just shy of the seemingly hardy farmer's eyes. He's talking about making maple syrup: He and his wife Diana tap 6,000 maples and sell the syrup along with freezer beef and many other products from local farmers at their on-farm store. It's April 2008.

A year after this video was recorded, Ron became so sick he was barely able to leave his bed. Twelve months after that, his doctor advised him to put his affairs in order.

It all started, Ron says, in August 2004 with what he thought was a sudden allergic reaction after bale-wrapping some barley, oats and peas. The emergency room doctor at the Perth and Smith Falls District Hospital diagnosed cellulitis, a skin infection caused by bacteria.

Ron recovered but, two months later, he experienced flu-like symptoms, cold in his extremities, numbness and an odd tingling. Over the next six years, health problems persisted. Chest pains. Tingling. A Parkinson's-like tremor. Short-term memory loss so acute that he'd ask Diana the same question eight times in a row or he'd forget to shut the gates or if he'd fed the cows.



hard-to-diagnose infection

Ron and Diana Coutts, Lanark County.
"There were nights I'd sit up at the table
and cry in pain," says Ron.



It took all of his willpower to get out of bed to do the chores. "There were nights I'd sit up at the table and cry in pain," he says.

He landed in intensive care in June 2010 with severe chest pains. Doctors tested for lupus, multiple sclerosis and other conditions. Everything came up negative. He was referred to an Ottawa specialist who diagnosed fibromyalgia.

Yet Ron and Diana wondered if it could be Lyme disease. Earlier tests had produced negative results but, on the advice of a customer they knew who was dealing with chronic Lyme, they sent fresh samples to a private laboratory in California. The results were positive. He obtained a referral to an infectious disease specialist in Toronto who started him on daily doses of three different antibiotics. The treatment was not covered by OHIP and his medication, plus other health supplements, cost \$700 a month.

According to members of the Canadian Lyme Disease Foundation, or CanLyme, and its affiliate, the Lyme Disease Association of Ontario, Ron's experience has become typical for

possibly hundreds of Canadians. They claim that Lyme disease is far more pervasive than public health statistics indicate, physicians are slow to diagnose it and people are ending up gravely ill. The organizations want changes in approaches to diagnosis and treatment of Lyme disease.

Public health officials counter that the current diagnosis method and treatment is effective and people should look both ways before turning to extreme or questionable remedies.

Testing contentious

Lyme disease is named after the Connecticut town where it was first identified in the 1970s and is caused by a form of bacteria sometimes found in small mammals and birds. Ticks feeding on infected animals, often early in their life cycle, transfer the bacteria as they mature and feed from larger animals, such as dogs and deer as well as people.

The bacteria is found in ticks in Europe as well as North America, but Canadian public health officials say only the blacklegged tick, or deer tick, carries the bacteria in Ontario. And not all deer

ticks will carry it, they stress – only ticks that are in areas within Ontario where the bacteria might be regularly found in smaller animals or that have been transported by birds migrating from endemic areas farther south.

Right from the outset, controversy has plagued the disease's diagnosis and treatment. Ian Barker, a retired professor of wildlife diseases at the University of Guelph Ontario Veterinary College, calls it "the most political disease in North America."



Health officials say only the blacklegged tick carries the disease in Ontario.

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Barker discovered infected ticks in Canada in 1986.

One major area of contention is the two-phased testing used to confirm diagnosis. The U.S. Centers for Disease Control and Prevention (CDC) endorses the approach, as do Canadian public health authorities. Lyme activists, however, contend that the approach is seriously flawed.

Janet Sperling, a CanLyme board member and an entomologist, says that the ELISA (enzyme-linked immunoassay) blood test that's used first to screen patients can produce false negatives. The test screens for antibodies to the bacteria. It takes time for the body to produce these and they may not be present in blood if the test is adminis-

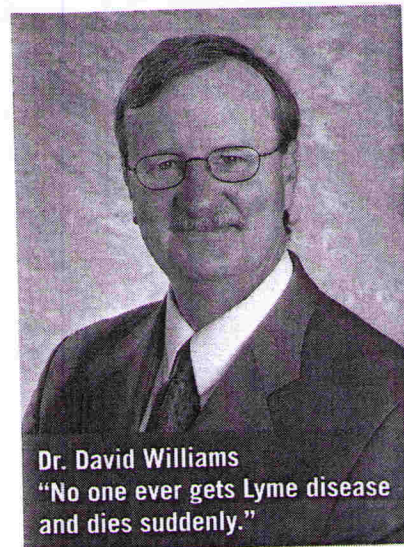
tered shortly after infection, she says. Without a positive test, doctors won't order the more accurate test, a Western Blot, to confirm the infection.

There are problems with the Western Blot, too. Sperling says the interpretive guidelines vary widely and those used in Canadian public health laboratories are not as accurate as those adopted by facilities like the private U.S. lab Ron Coutts sent his samples to.

Last February's revelation that the national public health agency's microbiology laboratory in Winnipeg had obtained false-negative results from its Western Blot test creates more uncertainty. There were 24 false-negatives over the course of nearly a year. That's

the equivalent of about a sixth of the cases diagnosed in Canada annually. The health agency blames a shift to an automated approach that created problems with how the test was being performed and with equipment. The lab is fixing the equipment and is continuing the manual test alongside the automated one for six months. (Ontario does its own testing).

Doctors depend on the tests to diagnose Lyme, says Sperling. So if the tests produce a negative result, people end up being shunted from one specialist to another, and from one diagnosis to another because Lyme mimics the symptoms of other conditions ranging from fibromyalgia and depression to Alzheimer's. And they get sicker.



Dr. David Williams
"No one ever gets Lyme disease and dies suddenly."

Photo: ONTARIO MINISTRY OF HEALTH

CanLyme wants the ELISA preliminary screening test eliminated, Sperling writes in a March 18 email. But most of all, the organization "would like to see clinical diagnosis using the professional judgment of the family doctor," rather than tests. "When the patient gets passed from specialist to specialist, the family doctor comes to the conclusion that this very sick person isn't fitting into any one 'box' and should be allowed a trial of treatment, provided all other treatable options have been eliminated."

Dr. David Williams, Ontario's deputy chief medical officer of health says doctors are treating before they receive test results even if they don't see a "bull's eye" rash (one of the early symptoms that appears in up to about 80 per cent of infections) but still suspect exposure to infected ticks.

He credits a \$280,000 provincial public education campaign launched last year for helping to raise awareness in both doctors and the general public about the importance of early treatment. The initiative included developing a website and printed materials about

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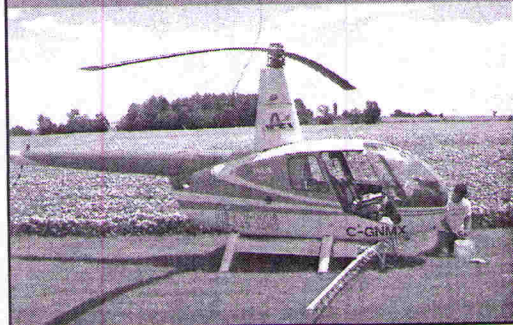
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Lyme disease. As well, local health units have begun organizing information sessions for doctors.

He acknowledges the ELISA test may not detect antibodies in the early days of the disease and there's still a lot of science that needs to be developed. But two-phase testing is the best approach available at the moment for confirming the disease. "In the push to try and answer everybody's questions before the science exists, there may be some people that will suffer from either being missed or they might be over treated or incorrectly treated," he notes.

Disagreements about treatment
Nicholas Ogden, director of the zoonotics division of the national agency, points out that the alternative Western Blot test the U.S. private lab used to diagnose Ron Coutts and many others doesn't follow the CDC recommendations. It might pick up more people who

are truly positive, but the risk for false positives also rises. "And then they will go on to get treatment for something that they haven't got and possibly not treat them for something they do have."

Disputes about diagnosis are minor compared to the dissension on how to treat chronic Lyme disease.

Conventional medicine argues the condition is a lingering autoimmune response (where the body's immune system attacks itself) triggered by infection and is unresponsive to antibiotics. Treatment follows CDC guidelines, which call for a "few weeks" of oral or intravenous antibiotic treatment for the disease itself, depending on its severity, and a second four-week course of therapy for those with recurrent symptoms.

"Longer courses of antibiotic treatment are not beneficial," the Center states. "Longer courses of antibiotics have been linked to serious complica-

tions, including death."

Activists, on the other hand, argue that chronic Lyme is a biological infection that can survive the CDC-recommended antibiotic treatment. Consequently, they would like to see the Canadian health system embrace the treatment guidelines developed by the International Lyme and Associated Diseases Society (ILADS), which call for longer-term use of antibiotics to treat more persistent cases and repeated applications if symptoms recur. "Nine months is a pretty standard amount," Sperling says.

In the United States, the conflict between patient activists and the medical establishment about chronic Lyme became so acute that some authorities began revoking doctors' licenses if they employed long-term antibiotic therapy.

In 2006, the attorney general in Connecticut launched an antitrust

Lion's share of cases in Ontario

Lyme disease only affects dogs and people. In the United States, human cases now number in the thousands,

Figure 1: Summary of Lyme Disease cases reported in Ontario 2005-2009

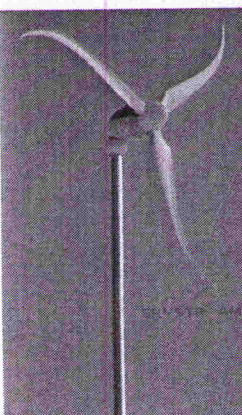
Year	Total number of reported cases	Number of cases reporting travel outside of Ontario	% of cases reporting travel outside of Ontario
2005	43	11	26%
2006	48	26	54%
2007	69	31	45%
2008	108	36	33%
2009	79	33	42%

Source: Ontario Ministry of Health and Long Term Care

annually. Canadian public health officials say the number of cases reported here (it has been a reportable disease since last year) has grown to about 150 a year, with the lion's share in Ontario. (See Figure 1.)

Farmers' risk of exposure depends on the type of farming and activity as well as their geographic location. There's little chance of getting bitten riding on a tractor. Chances increase working in a woodlot.

Caught early, it's easily treated. But, undetected it will trigger reactions in some people that result in joint, heart and nervous system problems. "Nobody ever gets Lyme disease and dies suddenly," says Dr. David Williams, Ontario's deputy chief medical officer of health. But evidence shows people with ongoing severe Lyme disease can become chronically debilitated. BF



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investigation into the Infectious Disease Society of America to explore allegations of conflict of interest in its Lyme disease expert panel. The Society's treatment recommendations inform the CDC's recommendations.

The state ended the investigation in 2008 after the society agreed to submit its guidelines for independent review. The guidelines were upheld. In the meantime, however, Connecticut passed a law that protected doctors from reprisal for using long-term antibiotic treatment for the disease. Similar laws have been introduced in Rhode Island, California and Massachusetts.

Canadian Lyme activists allege the College of Physicians and Surgeons of Ontario, like some U.S. medical authorities, is using its disciplinary powers to pressure physicians to stick with the CDC-recommended treatment. But

Kathryn Clarke, the College's senior communications co-ordinator, says no doctors have been disciplined for their treatment or diagnosis of Lyme disease.

Tardy diagnosis

Rossana Magnotta, a member of CanLyme's board, and a recipient of this year's Farm Credit Canada Rosemary Davis award, found out the hard way how difficult it was to convince Ontario doctors to consider Lyme disease as the cause of her late husband's illness.

Magnotta believes her husband Gabe contracted the disease in 2002 or 2003 while game bird hunting. "It was four and a half years before he got diagnosed," she says.

The Magnottas founded Magnotta Wineries, a Vaughan winery with stores in southern Ontario and vineyards near Beamsville and in Chile. (Rossana is a

microbiologist who once worked at Humber River Regional Hospital.)

She says doctors discounted her suspicions that her husband had a bacterial infection despite her medical experience. "I was just always shut down by the doctors that I went to see," she says. "They kept on pushing him into different fields. I saw neurologists. I saw every field, rheumatologists, allergists – all kinds of people."

Like Ron Coutts, Gabe tested negative several times on the ELISA screening test, so the couple decided to send a sample for testing to the United States. The test results came back positive.



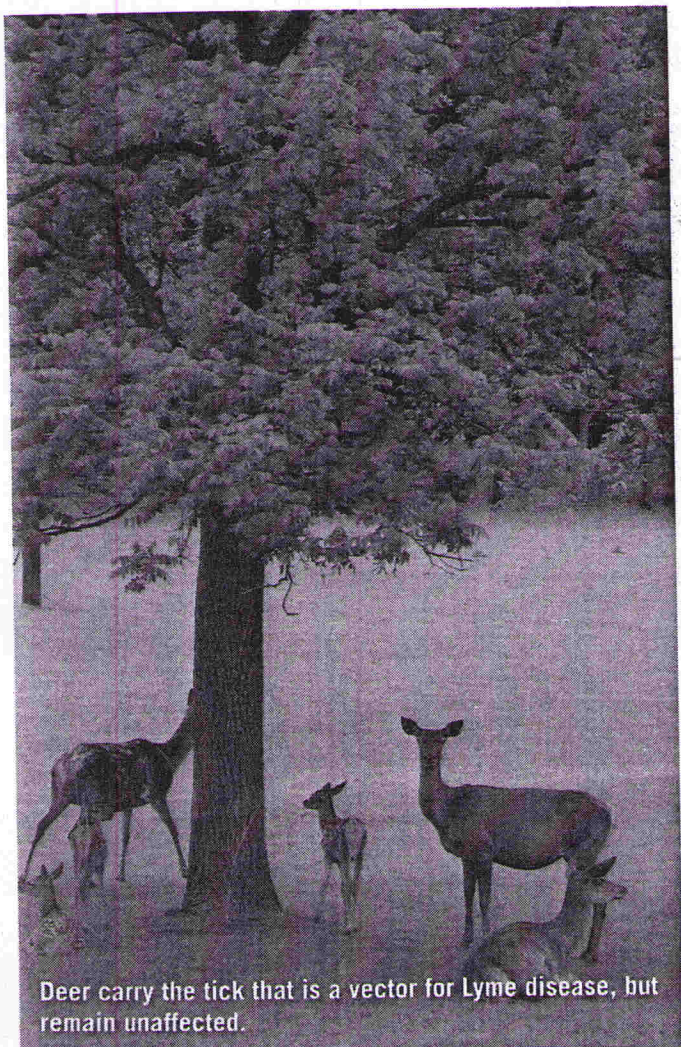
Rossana Magnotta: "Our government is making decisions on how you're going to get treated and whether you are going to get treated."

They sought treatment first in the United States and subsequently in Germany. He was cleared of the disease in August 2009, but died of a heart attack five months later. "He obviously had some side effects from all the aggressive treatment we had to use over five years," Rossana says. Gabe was 60.

Rossana blames her husband's death on the length of time it took to obtain treatment. She's critical of the inflexible approach to treatment under Canada's publicly funded health care system. Americans are free to choose which approach they want. "Our government is making decisions on how you're going to get treated and whether you're going to get treated."

Now, Rossana is fundraising to establish a centre for research on Lyme and other vector-borne zoonotic diseases in Canada. "We definitely need a centre like this in this country," she says. "But we're far from announcing something."

Robert Leadlay, a beekeeper in London, says he also encountered resistance from Ontario's medical system while being treated for the chronic Lyme disease he contracted in 1995. When he was finally diagnosed in 2007, his doctor prescribed intravenous antibiotics to be delivered by a peripherally inserted central catheter (PICC). The catheter was inserted in a hospital in Toronto; the line ran into his right



Deer carry the tick that is a vector for Lyme disease, but remain unaffected.



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bicep and through a vein to his heart. Robert and his wife Tammy were in the process of moving to London from Grimsby, so when an infection developed from the PICC a few months later, he went into the London Health Sciences' emergency department.

"When they saw the PICC, they assumed that it was for chemotherapy and I got treated very well," he says. "Then when the doctor came in, the doctor asked what chemotherapy agent I was on." When Robert told him it was for antibiotics to treat Lyme disease, "you could just see the look on his face and he just turned and walked away." He was released without treatment; the infection went away once his course of antibiotics resumed.

Robert says that, on another occasion when he approached the hospital to get his line replaced, he was told that it could not handle the procedure because he and his doctor were out of the hospital's health region and the department that dealt with these was already juggling a large caseload.

Patricia White (not her real name) says the same hospital used that reason in 2009 for refusing to adjust a PICC for her father, a southwestern Ontario farmer being treated for chronic Lyme. A retest showed that he had recovered enough to end the intravenous antibiotic therapy.

Patricia's father was diagnosed with Lyme in 2005, a year after she was diagnosed with the disease. Confirmatory tests came from a private lab in the United States, but Patricia says she eventually tested positive under Ontario's testing protocols, too.

Patricia lives with her parents on their mixed organic farm a few miles from Lake Erie and operates an unrelated business. She is concerned that she could lose clients if it becomes known she has the disease. Her father, now in his 80s, farms soybeans and spelt. They also raise some organic chickens and turkeys.

Patricia thinks she was bitten while walking in the long grass in the family farm's back fields and her father was often bitten by ticks while cutting wood at the back of their farm. She says the London-based orthopedic surgeon who

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had scheduled two knee replacement operations for her father prescribed his controversial antibiotic treatment. London Health Sciences had inserted the PICC line and he was provided with home care.

When hospital staff said they would not replace the line, "I think even the (orthopedic) surgeon was shocked," says Patricia. Several other hospitals in the province also rejected their request, she says.

Bärbel Hatje, a London Health Sciences spokesperson, says she could not comment without more details about the patients. "In general, we don't have boundaries for medical treatment," she says, adding that the hospital would not adjust PICC lines if there were an active infection.

Canadian exposure increasing

While there are disputes about diagnosis and treatment, there are also differences as the actual incidence of Lyme disease. About 150 people a year now come down with the disease in Canada, according to public health officials, but Lyme activists put the figure at between 1,000 and 3,000.

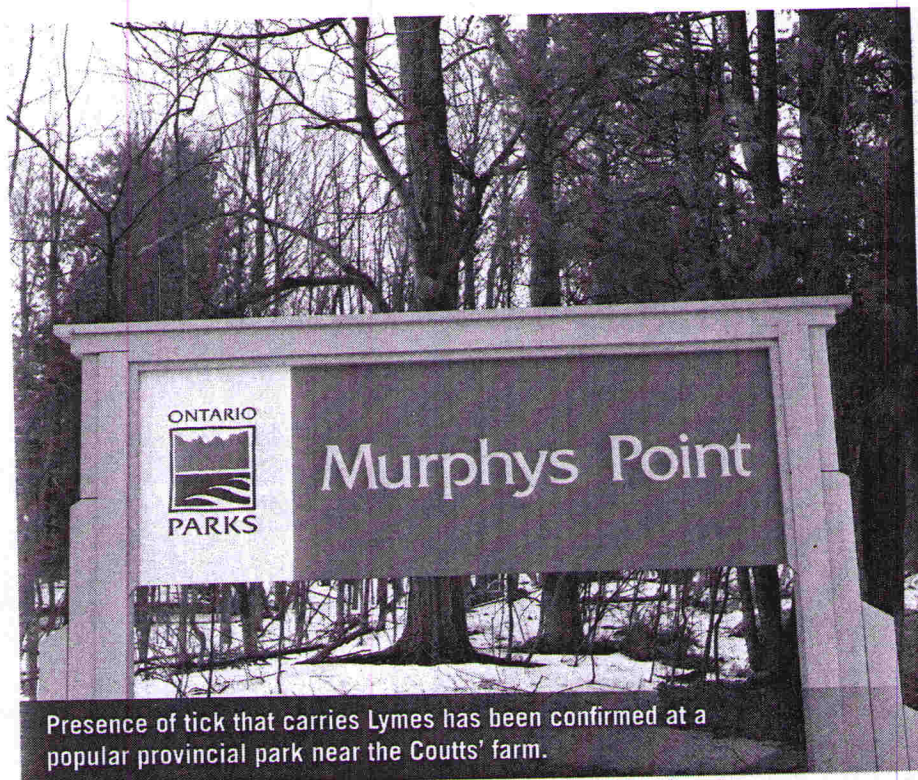
Both camps do agree, however, on one point: the risk of exposure is growing in Canada. The geographic area where the bacteria-infected tick can be found has expanded exponentially since Barker first confirmed the infection in mice and ticks in the Long Point Wildlife Area on Lake Erie south of Tillsonburg. Endemic infected populations of ticks now occupy a number of areas along Lake Ontario, Lake Erie and the St. Lawrence River.

Barker, who is closely involved in provincial efforts to survey the infection in ticks and wildlife populations, says the chances are high that there are other endemic populations in the mixed woodlands of southern Ontario, particularly in the more heavily forested areas of eastern Ontario. (In fact, infected

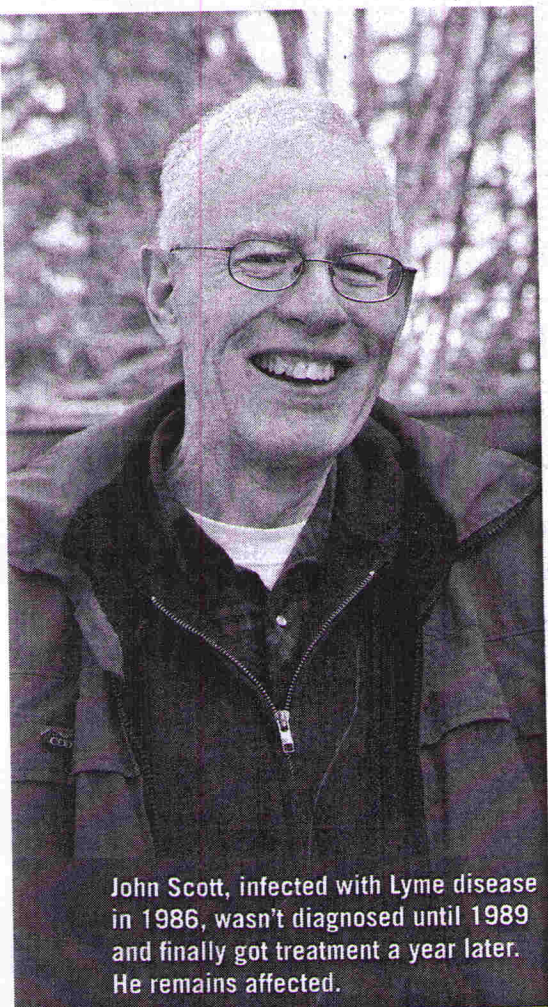
How do I avoid picking up ticks?

- Wear light-coloured clothing, long pants, a long-sleeved shirt, closed footwear and socks.
- Tuck your pants into your socks.
- Use a tick repellent that has DEET.
- Put tick and flea collars on your pets and check them for ticks periodically.
- If you frequent the areas where blacklegged ticks are established, examine yourself thoroughly for ticks every day. Pay special attention to areas such as groin, scalp and armpits. Use a mirror to check the back of your body or have someone else check it.

From the Ontario Ministry of Health and Long Term Care
Lyme disease website –
www.health.gov.on.ca/en/public/publications/disease/lyme.aspx



Presence of tick that carries Lyme's has been confirmed at a popular provincial park near the Coutts' farm.



John Scott, infected with Lyme disease in 1986, wasn't diagnosed until 1989 and finally got treatment a year later. He remains affected.

populations are now found at Murphy's Point Provincial Park near the Coutts' farm and park staff is considering posting permanent signage this year).

As well, research shows migrating birds carry ticks to other parts of the province. Although environmental conditions prevent establishment of a permanent population, "there's always some risk of being exposed to a potentially infected" deer tick, Barker says.

John Scott, an agrologist who once worked for the Ontario Ministry of Agriculture, Food and Rural Affairs and has a Masters degree in environmental biology, is also looking into tick populations. His personal battle with Lyme disease since 1986 motivates him. He's exploring the possibility of different types of ticks carrying the infection to Canada on the wings of migrating birds. "There's one new species of tick which is a vector (an organism that can transmit an infectious agent from one being to another) of Lyme disease which we've found in Canada for the first time," he says.

Study results published by Ogden and other mainstream researchers in March in the American Society for Microbiology's journal, Applied and Environmental Microbiology, don't find

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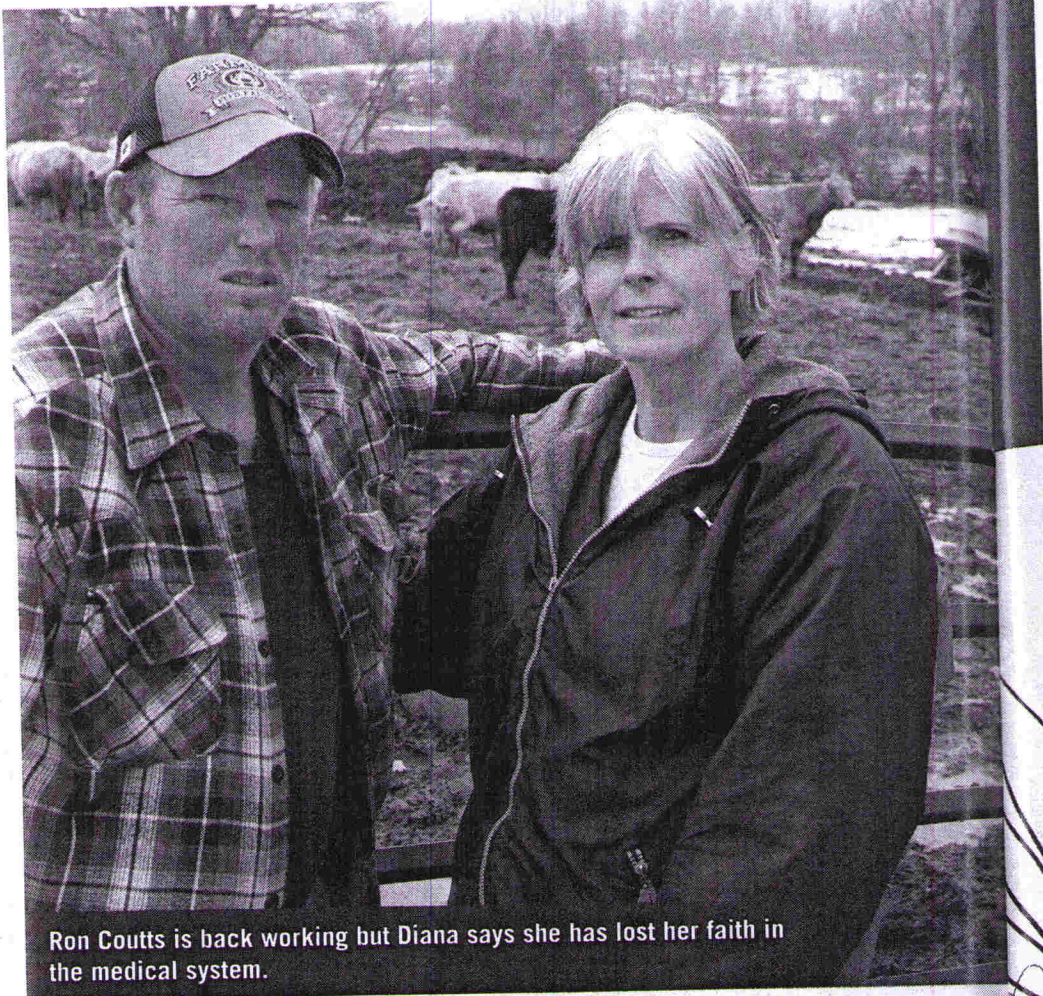
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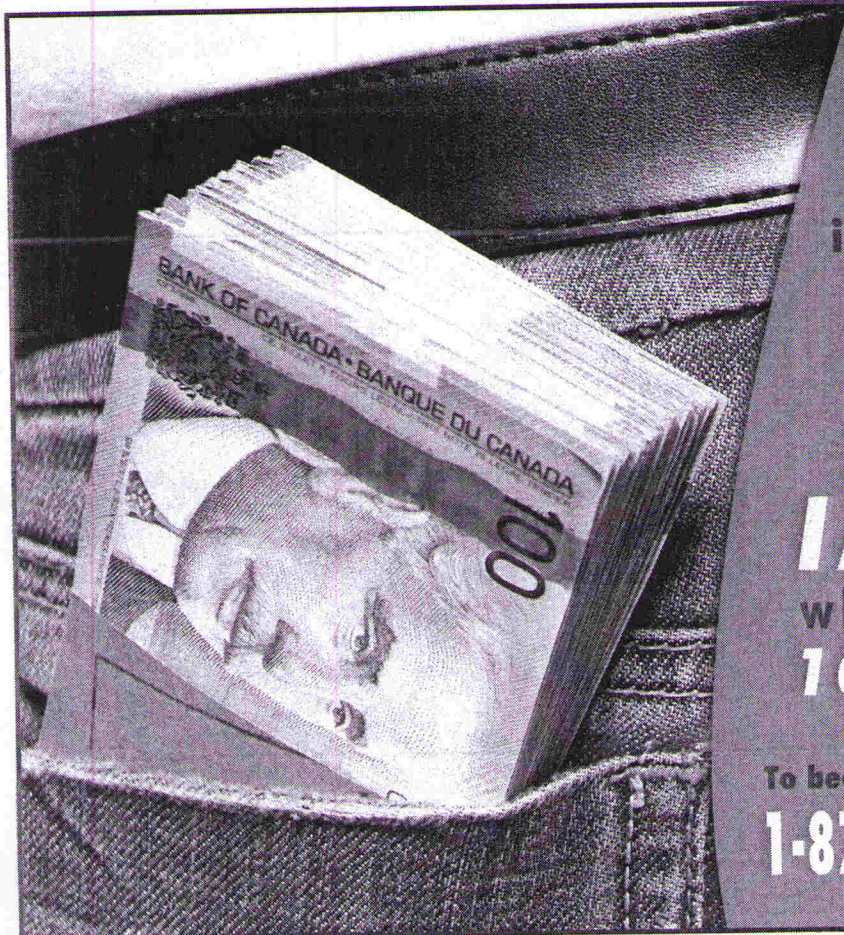
other ticks carrying the disease in Ontario. But they do conclude that ticks collected in Canada that were infected with the Lyme-causing bacteria were also infected with another type of bacteria at a ratio of one to 24. The study predicts the bacteria would appear at a higher rate in ticks in nature. The researchers also uncovered a new species of bacteria related to the Lyme-causing bacteria and documented 40 different types of the Lyme-causing bacteria, 16 of which were "entirely new."

The diversity reflected findings in the United States but indicates that local conditions will influence the bacteria to differentiate them from those found south of the border, the researchers write. Genetic diversity "could be clinically or diagnostically significant," and "infections in humans could be occurring in Canada for which we currently have no diagnostic methods."

Back at the Coutts' farm, Ron says he's on the road to recovery. In March, he was once again able to work the 12 to



Ron Coutts is back working but Diana says she has lost her faith in the medical system.



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14 hours a day that he normally put in before he got sick. But the fight to recover has taken its toll. The Parkinson's-like tremors remain.

Meanwhile, Diana struggles with how far to trust the health system. She advises everyone who comes into the store to check for ticks on themselves and their pets and send any found for testing either through their public health unit or family doctor. Yet she also questions the reliability of the testing process: "When you send it away in a bottle, how do you know you're getting the right diagnosis back?"

**"How do you know
you're getting
the right diagnosis back?"**

— DIANA COUTTS

And then there are the broken relationships. She recalls pleading with two local doctors, regular visitors to her store, for help when Ron was in hospital. "They don't come into the store anymore."

What do I do *if* I find an attached tick?

- Prompt removal of ticks from your skin will help prevent infection, since transmission of the Lyme disease agent usually requires the tick to be attached for more than 24 hours.
- Using fine-tipped tweezers, carefully grasp the tick as close to your skin as possible. Pull it straight out, gently but firmly.
- Don't squeeze it. Squeezing the tick can cause the Lyme disease agent to be accidentally introduced into your body. Don't put anything on the tick, or try to burn the tick off.
- After the tick has been removed, place it in a screw-top bottle (like a pill vial or film canister), and take it to your doctor or local health unit. They can send it to the Ontario Public Health Laboratory for identification.
- Remember where you most likely acquired the tick. It will help public health workers to identify areas of higher risk.
- Thoroughly cleanse the bite site with rubbing alcohol and/or soap and water.

From the Ontario Ministry of Health and Long Term Care Lyme disease website – www.health.gov.on.ca/en/public/publications/disease/lyme.aspx



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