



## LDAO May Spring Meeting - Minutes:

### Publication Update:

- As noted in the last Lyme Alert the June edition of Reader's Digest is now at the newsstands and contains the article on Lyme disease. It is a very good article although it ends on a sour note, when the main patient in the article, after experiencing immense improvement after being prescribed antibiotics by Dr. Murakami, states she does not know if she ever had Lyme disease.
- Another publication, the May issue of "Better Farming" has an excellent article on Lyme disease. This is a very thorough piece on Lyme, touching on one patient's experience (which is still ongoing), the testing and treatment dilemma, the politics of Lyme and how it has become so polarized. Unfortunately this magazine is by subscription only. We had hoped to be allowed to install it on our website but that is not going to be possible. We do have a couple of copies of the magazine, but if you want to read the article it may be best to check with any farming friends you may have to see if they receive the magazine.
- The Chatelaine article is due out in the July or August so watch for it as well.

### Petition:

Bob Bailey the MPP for Sarnia - Lambton has initiated a petition regarding Lyme disease, which he will present to the Ontario Legislature.

The petition requests the Ontario Minister of Health to direct the Ontario Public Health system and OHIP to include all currently available and scientifically verified tests for Acute and Chronic Lyme diagnosis, to do everything necessary to create public awareness of Lyme disease in Ontario and to have internationally developed diagnostic and successful treatment protocols available to patients and physicians.

The petition can be printed off from his website which is [www.bobbaileympp.com](http://www.bobbaileympp.com) Please print some copies from the site; get as many signatures as you can and mail them to MPP Bailey. They must be returned to his office by October.

I know we have had a number of these petitions over the years and hopefully one of these will be the blow that finally breaks the rock and brings the opportunity of correct testing and treatment to Lyme patients.

## News From Manitoba

John Scott our research consultant passed on some news from Manitoba. He has been in contact with Elizabeth Wood of the Manitoba Lyme Disease Support Group and was told that Lyme patients in Manitoba can now get diagnosed and treated for Lyme based on clinical diagnosis. This is a very positive step, as it is something Lyme disease patients and advocates have been fighting for over many years. It allows for treatment without relying on the unreliable two-tier testing protocol followed in Canada. This is another step forward in our quest for adequate diagnosis and treatment for Lyme disease.

### Freedom of Information Required to Release Confidential BC Government Report

Brian Schmidt the senior Vice-President of the BC Provincial Health Service Authority was commissioned by the BC government to do a confidential report on the state of Lyme disease in British Columbia. This report was presented to the Deputy Minister of Health in May of 2010. It was only released to the public through a freedom of information request.

The report revealed that, the majority of GP's lack knowledge about Lyme Disease, testing is poor allowing progression to a chronic form of Lyme, chronic Lyme disease patients are not receiving adequate treatment, the true incidence of Lyme disease in BC is unknown and the current state of diagnostic methods for chronic Lyme is inadequate. Unfortunately this is exactly what Lyme disease patients and advocates have been saying about the state of Lyme disease in Ontario and in fact across Canada for years

The report recommends improved public and physician education about the disease, improved diagnosis and treatment of Acute and Chronic Lyme disease and better support and protection for doctors willing to treat patients in any phase of the illness using antibiotics and other therapies.

If you would like to read the full report, go to the CanLyme website [www.canlyme.com](http://www.canlyme.com) and click on the link "Read the Government Report."

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**PLEASE WRITE TO YOUR MP & MPP's**  
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### **Cycling for Lyme**

James Christie is recovering from a 21 year battle with Chronic Lyme Disease. On May 21, 2011 James started his Cycle For Lyme at Queens Park in Toronto. His plan is to cycle around the province of Ontario to raise Lyme disease awareness. He plans to cover 2000 kilometres in the next 30 days. He estimates the cost to complete the Cycle For Lyme will be \$16,000.00 to \$17000.00. James is looking for donations to help defray the costs of this venture. The LDAO Directors approved a donation of \$100.00 to James's Cycling For Lyme.

You can find out more about James Christie at his website [www.livingthelymelife.com](http://www.livingthelymelife.com)

To learn more about James' Cycle For Lyme visit his blog site - <http://cycleforlyme.blogspot.com/> where you will be able to read his daily journal of his endeavour to raise Lyme disease awareness. For example here is an excerpt of his final day on July 9th: "The final day! In 32 days on the road, I cycled 30 days. In those 30 days, I cycled a total of 1,828.8 kilometers for an average of 61 kilometers per day. Along the way I met a lot of people who knew a lot about Lyme. Along the way, I spoke in several school to students who unfortunately knew very little about a disease that if misdiagnosed for as few as 4 months, can cause the debilitating, and in Canada, the medically untreatable disease known as Chronic Lyme Disease."

### **A Lyme Disease Survival Guide: Pests, Protection, Politics**

The highlight of the meeting was a power point presentation by Rob Manten entitled A Lyme Disease Survival Guide: Pests, Protection, Politics. Rob has given this presentation to various groups on a number of occasions and it is an excellent presentation for those just learning about Lyme, to those who are familiar with Lyme and the problems that can occur from this disease.

As the title suggests the presentation is broken into 3 sections. The first "Pests" deals with the tick, the bite of which can cause Lyme disease. Namely the Western Blacklegged tick and the Lone Star tick also spread the disease. This section also touched on the history of Lyme and co-infections and a look at the bacteria which causes Lyme disease, "Borrelia burgdorferi."

Under "Protection" avoiding tick habitat, tick checks after possible exposure and use of Deet were noted. Methods of removing an attached tick were reviewed, as well as a review of symptoms, the two-tier testing protocol and the rising number of Lyme cases in the USA and Canada.

Under "Politics" Rob covered the IDSA Guidelines, the Connecticut Attorney General's investigation, legislation to protect doctors treating Lyme which is becoming more prevalent in some USA states ( but not yet in Canada), harassing of Lyme literate doctors in Canada, advocacy groups that have sprung up, media coverage, books and films.

This was a very thorough presentation and was well received by those in attendance. We thank Rob for not only doing the presentation, but also for putting this power point presentation together.

### **This completes the minutes of the Spring Meeting**

#### **Recap on tick removal**

If you do not have a copy of the LDAO brochure to refer to then please visit the web site at [www.lymeontario.org](http://www.lymeontario.org)

There you will find excellent instructions on removing a tick, how to store the tick, how to make notes of the bite and where to submit the tick for testing.

You may also find information on some new techniques being used by visiting [www.canlyme.com](http://www.canlyme.com) and performing a "Canlyme search" for "tick removal".

Using Tweezers for the removal of nymph ticks poses more difficulty in ensuring the mouthpart is fully removed and that the body of the tick is not damaged; therefore tools like "Pro-Tick Remedy", "Ticked Off" and the "O Tom Tick Twister" are recommended by researchers - <http://www.biosci.ohio-state.edu/~acarolog/needham/tickgone.htm>

#### **Flagging For Ticks**

John Scott the Scientific Researcher of the LDAO prepared a presentation of proper flagging methods last fall 2010. There have been enquiries as to how to go about doing this. For anyone interested in a copy of the flagging instructions in PDF form via email, please contact the LDAO

The Public Health Departments have made it very clear that they will not accept ticks unless they have been found on a person.

#### **ILADS Conference October 28th - 30th 2011**

For anyone interested in volunteering at the ILADS conference, please contact Lisa Torrey, President - National Tick-Borne Disease Advocates at [klcst@msn.com](mailto:klcst@msn.com)

It works like this....for each day of attendance you volunteer to work 3-4 hour block of time, per day. In return your registration fee is waived. Volunteers work at the registration table checking people in and giving out packets; putting packets together; signing people in for CME credits; secure the computers and projectors; and sell ILADS items. Most of this is done sitting down.

As we get closer to the conference, volunteers can review the agenda and fill out an information form as to which part of the day they want to see presentations, and which part of the day they will work their block of 3-4 hours.

### **Babesiosis: Illness ticks spread on the rise**

Recently Dr. Gary Wormser (!) was on CBS stating- 1 in 20 people infected with Babesiosis die - <http://www.cbsnews.com/video/watch/?id=7371721n>

### **Finally! A link to CanLyme**

It was so nice to see a Canadian Government web site directing people to the Canadian Lyme Disease Foundation for more information. Thank you Nova Scotia! We hope this sets precedence for other Provinces and Territories.

<http://gov.ns.ca/lae/healthandsafety/deertick.asp>

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 \*\*\*PHAC was contacted regarding Wainfleet Bog not being listed as an "endemic area" - Robbin Lindsay replied "Thank you, we attempt to keep the site as up to date as possible, but it is a challenge."\*\*\*

### **"Lyme disease: a tick-transmitted bacterial disease of growing importance in Canada"**

(From the National Collaborating Centre for Infectious Diseases - full PDF can be downloaded here:

[http://www.nccid.ca/files/Issue\\_17\\_-\\_Lyme\\_EN.pdf](http://www.nccid.ca/files/Issue_17_-_Lyme_EN.pdf) )

We are pleased to present this special issue of the Purple Paper on Lyme Disease by Dr. Harvey Artsob. Dr. Artsob is the former Director of the Zoonotic Diseases and Special Pathogens program at the National Microbiology Laboratory (NML) of the Public Health Agency of Canada in Winnipeg. In this issue, Dr. Artsob discussed the history and future of Lyme disease in Canada, and his experience with the zoonotic disease in his career at the NML.

#### **Key Points**

- Lyme disease is a multi system disease that can be contracted in any Canadian province.
- Lyme disease is spreading in Canada and that spread can be expected to continue in the coming years.
- Studies to date have identified high risk endemic areas for Lyme disease within limited areas of Nova Scotia, New Brunswick, Quebec, Ontario, Manitoba and British Columbia.
- Current diagnostic tests are effective for detecting cases of disseminated, but not early, Lyme disease. Therefore, clinical cases of early Lyme disease are not well documented in Canada.
- Controversies exist over clinical and diagnostic aspects of Lyme disease but the 2006 guidelines published by the Infectious Disease Society of America have been strongly endorsed by an independent review panel.
- Research leading to improved diagnostics and to address medically unexplained symptoms is highly desirable.

\*\*\*This article clearly shows the stronghold the IDSA has over Canadian research and although it is nice to see that Lyme disease is finally being acknowledged in Canada, we are a long way from finding resolve to the controversies as Dr. Artsob's comments demonstrate.

### **Ontario Work for MPP Lyme Petition Support**

(An update on the petition mentioned on page 1)

Many Lyme patients and advocates have been supporting the petition in various ways; printing off copies and collecting signatures, making presentations to Regions/Counties as "delegates" to make a plea for support, e-mailing the petition to MPP's, Municipalities, Health Networks and Hospitals, Unions, the CPSO etc. There are efforts being made to get the petition on the Association of Municipalities of Ontario (AMO) agenda in August.

Media has given the subject of Lyme more press due to the efforts; responses to their articles are encouraged. The MOHLTC and various Public Health Departments have been sending out form letters in response to the media, MPP's and Municipalities

Despite their efforts to dissuade people, there has proven to be great support of this initiative. So far, Huron County, Perth, Middleton, Lambton, Oxford, Chatham Kent, Uxbridge, Pickering, Red Lake, Smooth Rock Falls, Quinte West, Georgian Bluffs, Huron Kinloss, Mulmur, Chatsworth, Parry Sound, North Kawartha, Loyalist Township, Archipelago, Peterborough, Wainfleet, North Stormont, Magnetawan, Odessa and Town of East Gwillumbury - Port Colborne has made it available to the Public in the City Hall and Library. MPP support thus far - John R. O'Toole, Steve Clark, Frank Klees, and we hope that this will finally create a big step in the direction of change for Lyme patients in Ontario.

### **Legislative Actions in USA Amp Up**

There have been several Legislative initiatives launched in the USA over the last year - perhaps these are initiatives that should be started here in Canada? The following are just a few of the initiatives taking place or passed:

"Senator Blumenthal announced that he plans to continue his Lyme disease advocacy in the Senate with a bill aimed at promoting better diagnosis, reporting and research on the disease, which he said is widely underreported. The bill would also include funding for research into chronic Lyme disease, a condition that mainstream physicians say does not exist. Blumenthal described the bill as taking an "open-minded and open-ended approach," without prejudice toward any kind of treatment. But he left little question about his views on the controversial aspects of Lyme. He touted his past work fighting insurance companies and some medical professionals over the existence of chronic Lyme." (From CT Mirror - Arielle Levin Becker)

"Congressman Chris Smith, is the sponsor of the measure, H.R. 2557, which would support federal efforts concerning Lyme and other tick-borne diseases through the establishment of a Tick-Borne Diseases Advisory Committee. Smith co-chairs the House Lyme Disease Caucus, along with Frank Wolf (R-VA) and Tim Holden (D-PA), who are both cosponsors of the bill." (From Jackson, NJ Online)

"U.S. Senator Chuck Schumer, D-N.Y., visited Madison County Thursday to push for legislation on Lyme disease, a growing concern with close significance to him." (From Oneida Dispatch - Caitlin Traynor)

" State Sen. Chris Harris blames Lyme disease, left undiagnosed for 2½ years in the mid-1990s, for a heart attack and bone damage that left him with two titanium shoulders and a severely broken foot put back together with steel plates and screws.... Harris, R-Arlington, poured his experience into a bill that originally sought to force the Texas Medical Board and Texas Board of Nursing to recognize as valid the long-term use of antibiotics — sometimes lasting years — recommended in the treat-until-recovery approach of the International Lyme and Associated Diseases Society. That bill, opposed by the medical establishment, was dead on arrival. But a compromise recently reached with the Texas Medical Association has revived the bill, which along with an identical measure by Rep. Todd Hunter, R-Corpus Christi, received back-to-back committee hearings Tuesday and Wednesday. Harris and Hunter presented committee members with bills, unopposed by interest groups, that focus on training doctors to recognize Lyme disease and help set up a limited defense for physicians accused of overusing antibiotics to treat the malady. Now it's a race to passage with less than five weeks remaining in the session. House and Senate committees, however, have yet to vote on either bill.

" State Rep. David Linsky, D-Natick, chairman of the House Committee on Post Audit and Oversight - Linsky, who didn't want to go into his son's medical history, said nearly everyone seems to have a friend or relative afflicted by the illness..." "But it's flying under the radar," he said in a phone interview. The bill he filed late last month, now known as House docket No. 01956, bears similarities to earlier proposals. Like a bill filed by former state Rep. Jennifer M. Callahan, D-Worcester, in 2007, it would create a Lyme Disease Research Institute at the University of Massachusetts Medical School in Worcester. And like other earlier proposals backed by Cape legislators, it also would create a special commission to study the incidence and impact of Lyme and other tick-borne diseases in the state, including educating the medical community about the latest research. The difference this time is the stature of the legislator filing the bill. Linsky "is well-regarded by the leadership," said state Rep. Sarah Peake, D-Provincetown, who signed onto

his bill along with representatives Cleon Turner, D-Dennis, and Timothy Madden, D-Nantucket." (From Cape Cod Times - Cynthia McCormick)

### **Alzheimer's Disease - A Neurospirochetosis**

We are all very familiar with Dr. Allan MacDonald's research of spirochetes and the brain (Film Under Our Skin) The following is an abstract of an article covering the association between spirochetes and Alzheimer's disease. The entire PDF is available at: <http://www.jneuroinflammation.com/content/pdf/1742-2094-8-90.pdf>

"It is established that chronic spirochetal infection can cause slowly progressive dementia, brain atrophy and amyloid deposition in late neurosyphilis. Recently it has been suggested that various types of spirochetes, in an analogous way to *Treponema pallidum*, could cause dementia and may be involved in the pathogenesis of Alzheimer's disease (AD).

Here, we review all data available in the literature on the detection of spirochetes in AD and critically analyze the association and causal relationship between spirochetes and AD following established criteria of Koch and Hill. The results show a statistically significant association between spirochetes and AD ( $P = 1.5 \times 10^{-17}$ ,  $OR = 20$ ,  $95\% \text{ CI} = 8-60$ ,  $N = 247$ ). When neutral techniques recognizing all types of spirochetes were used, or the highly prevalent periodontal pathogen *Treponemas* were analyzed, spirochetes were observed in the brain in more than 90% of AD cases. *Borrelia burgdorferi* was detected in the brain in 25.3% of AD cases analyzed and was 13 times more frequent in AD compared to controls. Periodontal pathogen *Treponemas* (*T. pectinovorum*, *T. amylovorum*, *T. lecithinolyticum*, *T. maltophilum*, *T. medium*, *T. socranskii*) and *Borrelia burgdorferi* were detected using species specific PCR and antibodies. Importantly, co-infection with several spirochetes occurs in AD. The pathological and biological hallmarks of AD were reproduced in vitro.

The analysis of reviewed data following Koch's and Hill's postulates shows a probable causal relationship between neurospirochetosis and AD. Persisting inflammation and amyloid deposition initiated and sustained by chronic spirochetal infection form together with the various hypotheses suggested to play a role in the pathogenesis of AD a comprehensive entity. As suggested by Hill, once the probability of a causal relationship is established prompt action is needed. Support and attention should be given to this field of AD research. Spirochetal infection occurs years or decades before the manifestation of dementia. As adequate antibiotic and anti-inflammatory therapies are available, as in syphilis, one might prevent and eradicate dementia."

(The article closes with the following paragraph)

The accumulated knowledge, the various views, and hypotheses proposed to explain the pathogenesis of

AD form together a comprehensive entity when observed in the light of a persisting chronic inflammation and amyloid deposition initiated and sustained by chronic spirochetal infection. As suggested by Hill, once the probability of a causal relationship is established prompt action is needed. Similarly to syphilis, one may prevent and eradicate dementia in AD. The impact on healthcare costs and on the suffering of the patients would be substantial."

### **Acorns good - Ticks Bad**

A recent article by Robert Miller of Newstimes.com titled "Acorns Good Ticks Bad" (<http://www.newstimes.com/news/article/EARTH-MATTERS-Robert-Miller-Acorns-good-ticks-1468279.php#ixzz1UMQ5gbS1>) prompted an informative response from our Scientific Researcher, John D. Scott. In the article, Richard Ostfeld, a disease ecologist at the Cary Institute of Ecosystems Studies in Millbrook, N.Y, stated that 2012 will be a banner year for blacklegged ticks due to the Fall of 2010 having the largest crop of Acorns they had seen in 20 years. Ostfeld's response to the bumper crop, " "We don't know why," he said. "It could have just been a random thing." John Scott's response to the article clarifies: "**Abundant acorns proliferate rodents and Lyme disease**"-The reason oaks produce an abundance of acorns in any given year is based on arid weather the previous year. When a summer is hot and dry, oak trees will initiate lots of flower buds in August. The following year, these buds will flower and, in turn, develop into a plentiful harvest of acorns. This natural phenomenon of plant physiology induces deciduous and coniferous trees to produce more seeds and fruit because of weather stress. Ultimately, mice and chipmunks have a larger cache of acorns to feed themselves and their offspring, and increase their numbers.

Blacklegged ticks proliferate on mice and chipmunks and, with high more hosts, will have a better chance to acquire Lyme disease spirochete, *Borrelia burgdorferi*. Since these mammalian hosts are competent reservoirs of *B. burgdorferi*, these ticks will have higher rates of infection. Songbirds will also disperse more Lyme-infected larvae and nymphs of the blacklegged ticks. People do not have to frequent an endemic area to contract Lyme disease.

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