

**From:** Neufeld, Laura R GCPE:EX [mailto:Laura.R.Neufeld@gov.bc.ca]  
**Sent:** Wednesday, August 28, 2013 3:13 PM  
**To:** Henry, Bonnie; Eric.Young@gov.bc.ca  
**Cc:** perry.kendall@gov.bc.ca; Kennedy, Theresa; Dabrowski, Alex; Rorison, Trish GCPE:EX; Shannon.Hagerman@gov.bc.ca  
**Subject:** Draft KMs on CanLyme

Hi there,

I've also pulled together these high level KMs so that we have them for reference in the future... can you just have a look and ensure you are ok with these?

Thx!

Laura << File: km\_CCDP\_CanLyme withdrawal of support\_draft\_Aug28.docx >>

## **Key Messages – Complex Chronic Disease Program – CanLyme Withdrawal of Support**

Aug 28, 2013

- It is unfortunate that the Canadian Lyme Disease Foundation has withdrawn their support and participation in PHSA's Complex Chronic Disease Program (CCDP).
- This Program is new – it opened through the Provincial Health Services Authority in March 2013 – and is working diligently to get up and running at full capacity.
- Since it opened, more than 550 patients have been referred to the clinic.
- As part of the development of this new program, PHSA is committed to working with stakeholders – including patient groups – to ensure that the program continues to develop so that it meets the needs of patients.

### **Additional background:**

- CanLyme has expressed concerns that the clinic is committed to treating each patient individually – and is not willing to offer blanket one-size-fits-all therapy to patients. However, to do so would be irresponsible.
- The CCDP assists people with undiagnosed chronic diseases such as fibromyalgia, myalgic encephalomyelitis/chronic fatigue syndrome and tick borne illnesses, such as Lyme disease.
- In addition to providing treatment and care, the program also includes a strong research component. The CCDP will support clinicians and researchers in their pursuit of causes, diagnosis and potential treatments for these types of chronic conditions.
- The CCDP offers an integrative care approach. Each patient in the program will receive a comprehensive medical assessment and will be able to access other health care services including specialty medicine, nursing, social work, physiotherapy, and naturopathy.

Q&A

**Lyme disease and Complex Chronic Disease Program**

**Q: Why are you not currently treating all patients with Lyme disease with long-term antibiotics?**

A: Lyme disease is treated on clinical grounds and if needed patients will be treated with long term antibiotics; this is reviewed on a case by case basis according to the IDSA guidelines which were adopted by Infectious Diseases specialists in Canada.

According to research published by the BC Centre for Disease Control in the BCMJ in March 2011, BC physicians feel they are generally aware of acute Lyme disease symptoms and are prepared to treat it on suspicion of infection. As part of BC's guidelines for physicians re antibiotics, long term antibiotic use is prescribed for cases of acute neurological Lyme disease e.g. acute Lyme meningitis or radiculopathy or late Lyme arthritis. IDSA Guidelines state: "There is no convincing biologic evidence for the existence of symptomatic chronic *B. burgdorferi* infection among patients after receipt of recommended treatment regimes for Lyme disease".

**Q: Some Lyme advocates would say that they are being discriminated against because doctors will not automatically treat them with long term antibiotics when there have been reports that have been reported ad hoc as having excellent results for disease patients?**

A: In British Columbia we are able to prescribe long term antibiotics but each patient must be assessed individually. At this point in time there has not been any research and/or clinical trials conducted on the safety and efficacy of long term antibiotic use in the "chronic" or "post-treatment" Lyme population. It is for this reason that the current IDSA treatment guidelines here in BC (and across Canada) do not include this type of therapeutic approach.

This is the type of research that must be conducted first before long term use of antibiotics can be incorporated in updated treatment guidelines.

**Q: How many people do you know and or anticipate have Lyme disease in BC?**

A: Lyme disease is a reportable disease. I would have to defer to the BC Centre for Disease Control for those numbers.

**Q: Why does there seem to be so much disagreement with some members of the Lyme community and the medical community regarding diagnosis and treatment?**

A: You are correct; in fact internationally we see that there is considerable debate and disagreement between the medical and patient communities surrounding the diagnosis and treatment of chronic complex illnesses. This is a result of the wide discrepancies in diagnosing and treating "Chronic Lyme disease" using different clinical Lyme treatment guidelines available in the world e.g. ILADS. It is very difficult to diagnose patients with Lyme disease, particularly when patients test negative for Lyme disease using the available tests for Lyme diseases which currently have a sensitivity rate of less than 50%.

Therefore, there are patients whose Lyme disease was not diagnosed or treated appropriately, who went on to have real, chronic complications. There are also a number of patients suffering with chronic symptoms that testing cannot confirm as being caused by Lyme disease.

One solution to this disagreement is to be able to research and develop diagnostic capabilities through better tests. This in turn should assist and increase our knowledge in the diagnosis and treatment of this disease.

**Q: To date, what percentage of patients have you seen at the clinic who have presented with symptoms or confirmed Lyme disease?**

A: We are at the early days of the clinic opening and at this point in time we are seeing approximately 30% of patients who appear to have Lyme disease.



**From:** Money, Deborah  
**To:** Morshed, Muhammad  
**Subject:** RE: Lyme disease research  
**Date:** Tuesday, January 28, 2014 10:25:39 AM

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Hi Morshed,  
Since I e-mailed you it has become politically even more complicated. If you are able to convince Alison, with Miguel's assistance to proceed with a small appropriate study of diagnostics that would be great and there might be funding available. Cheers, Deb

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**From:** Morshed, Muhammad  
**Sent:** January 28, 2014 9:56 AM  
**To:** Money, Deborah  
**Subject:** RE: Lyme disease research

Hello Deborah:

My apology for delayed response. I had a meeting scheduled with Alison but delayed again due to our mutual availability. I thought I will write you after discussing with her and see if she has any funding available for some diagnostic related research. There are some opportunities e.g. we can evaluate C6 peptide assay which might give better sensitivity as first tier a screening assay in low endemic population like ours. We have already established/validated PCR test but the issue with Lyme spirochete is that they are not found in blood like other bacterial or viral agents. Borrelia burgdorferi is very transient in blood and they like to settle in tissues more. Getting tissue sample is also difficult. Often we receive tissue sample on those patient are serologically negative and does not make much sense to do PCR on those.

I will update you again after discussing with Alison and Miguel (Locum physician there).

Thank you

Regards,

Morshed

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**From:** Money, Deborah  
**Sent:** January 20, 2014 1:27 PM  
**To:** Morshed, Muhammad  
**Subject:** Lyme disease research

Hi Muhammad,  
I have been drawn into conversations here at BC Women's on Lyme disease research in our Chronic complex Diseases clinic. I am not sure what interface you have had with Dr. Alison Bested but wondered if you see any new opportunities for new diagnostics, evaluations of serology, new PCR based tools???? I am searching for opportunities to assist with this clinic's research program. Thanks for your thoughts.  
Cheers, Deb

**From:** Davies, Cheryl  
**To:** Kennedy, Theresa  
**Cc:** Bested, Alison  
**Subject:** RE: Urgent: additional info on CCDP clinic  
**Date:** Tuesday, March 04, 2014 5:16:29 PM

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*Clinic Functioning:* as the MoH is aware, the clinic has only been in operation for less than a year and we continue to look for efficiencies to see increased numbers of patients within existing resources. There remains a lengthy wait list for patients (over 800 patients on the waitlist).

*Patient Outcomes:* We assume you are referring to clinical outcomes? The program has only been in operation less than an year and is based on symptom management of complex diseases. Clinical outcomes are individualized to patients but include a range of measures including sleep, pain, fatigue, depression, myalgias and cognitive problems, etc. We look for improvements in better functioning, quality of life, etc. A patient database (5 year demographic study) has been initiated (97% consent rate from patients to participate) to capture the patient functionality for the first visit. We would need additional clerical and research support to enhance our ability to follow these patients over time and track their outcomes overall. We have patient satisfaction surveys that we have implemented which to date, reflect positively on the clinic service and with which we have made some improvements within our limited capacity.

*Testing:* Firstly, are we talking about Lyme testing? If so, patients have access to the standard testing available in BC; there continue to be limitations because the tests (Elisa) for Lyme Disease are insufficient; newer tests are not available in BC.

*Long-Term Antibiotics:* Firstly, we are in a consultative/educative model of care and therefore do not plan to see patients on a long-term basis, which would be required to manage the use of long-term antibiotic therapy. Nevertheless, we would be adhering to the clinical guidelines re: long-term antibiotic therapy for Lyme Disease, which continues to be a point of contention for some of the Lyme constituents.

We are leaving work now so hopefully this will suffice.  
Cheryl

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**From:** Kennedy, Theresa  
**Sent:** Tuesday, March 04, 2014 4:21 PM  
**To:** Davies, Cheryl  
**Subject:** Re: Urgent: additional info on CCDP clinic

That would be helpful. This is policy and would be unaware. This is happening along the way and we have asked for single channel and coordinated requests but it falls on deaf ears.

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**From:** Davies, Cheryl  
**Sent:** Tuesday, March 04, 2014 04:17 PM  
**To:** Kennedy, Theresa  
**Subject:** RE: Urgent: additional info on CCDP clinic

Hi Theresa,