

# Sue Faber, RN, BScN Guest Blog – Lyme & Pregnancy

May Awareness LDA Guest Blogger



Sue Faber is a Registered Nurse (BScN) and Co-founder and President of LymeHope, a not-for-profit organization in Canada. Sue's specific area of expertise and research is in the compilation and analysis of the literature that exists on maternal-fetal transmission of Lyme and congenital Lyme

borreliosis; amplifying, supporting and powering urgent research initiatives to investigate this alternate mode of transmission with the ultimate goal of opening new doors to ensure that children and families affected are able to access appropriate care, treatment, and support.

In 2018, Sue co-authored a nursing resolution for the Registered Nurses Association of Ontario – based on the needs and voiced concerns of Canadians with Lyme disease coast to coast. ‘Patient First Treatment for Ontarians with Lyme Disease’– which was passed at the annual 2018 AGM in Toronto. Sue was awarded the RNAO HUB Fellowship award in 2019. Sue is honored to be an advisor to the newly formed advocacy group Mothers Against Lyme and has spoken at various conferences on maternal-fetal transmission of Lyme including ILADS (2019), LymeMIND (2019, 2020), NE Ohio Lyme Symposium, Lyme WNY Symposium and Target Lyme (Ontario). Sue is honored to collaborate with colleagues from McMaster Midwifery Research Centre in new ground-breaking research on Lyme and Pregnancy.

Sue is firmly committed to transparent and collaborative partnerships with governments, academia, research institutions, healthcare colleagues, and industry stakeholders, to collectively identify challenges, knowledge gaps, and fresh opportunities, to examine and develop transformative health policy, best practice guidelines, and research priorities, which are anchored in patient voice, values, and priorities.

## **Lyme and Pregnancy: A Hopeful and Tangible Path Forward**

**My History** I’ll never forget the day at the end of January 2017 that I received an official letter from my local public health department. The letter was in response to my requests for a meeting with senior management, to alert them to

positive test results for Lyme disease for both myself and one of my daughters and to discuss my concerns that I may have transmitted this infection to her in-utero. A year earlier I had tested two-tier positive for a European strain of Lyme in Canada – after years of complex multi-system medical symptoms which were fully investigated by multiple medical specialists, without any definitive answers. I had no recall of a tick bite or an erythema migrans rash and thus tickborne disease had never been considered as a differential diagnosis by my medical team. As a trained ER nurse, I knew nothing about Lyme disease.

It was a stroke of luck that my primary doctor decided to test me for Lyme after every other possible diagnosis had been ruled out. The test was positive. My eventual diagnosis of late-stage disseminated Lyme disease by a Canadian infectious disease physician was initially a relief as I now had a name to my illness and what I thought would be a defined path to recovery and healing. Little did I know that this diagnosis would be the start of a journey into advocacy – one which I have likened to climbing up a steep mountain – without a map or guide – trusting and hoping that one day, I'd make it to the top.

As a Registered Nurse I am extensively trained in evidence-based practice and problem-based learning which has put me in good stead after receiving my Lyme disease diagnosis. I started delving into the published literature on Lyme disease and soon discovered the multi-system complexities of Lyme disease with some researchers identifying striking similarities to syphilis. [i] [ii] Soon thereafter, I discovered the first published case report that Lyme disease could be transmitted from a mother to her baby in-utero in a paper titled 'Maternal-fetal transmission of the Lyme disease spirochete, *Borrelia burgdorferi*'. [iii] My heart started to race, I was nauseated and tears started to fall down my cheeks – could this mean that my precious daughters were also

impacted? Like most other aspects of Lyme, I would soon learn that the issue of maternal-fetal transmission was very controversial.

The onset of my symptoms was gradual and predated all of my pregnancies including one first trimester pregnancy loss. All my daughters had struggled with varying complex medical issues from birth which included jaundice, severe colic, high fevers, myocarditis, atypical seizures, severe OCD, night terrors, anxiety, joint pain, learning difficulties, abdominal pain, strange rashes, speech delay, severe headaches, frequent pneumonia and double vision. Each child had different clinical manifestations with one common theme – there were no definitive answers as to why. Could tickborne infection transmitted in-utero be contributing to their illnesses?

My infectious disease physician who was treating me at the time never mentioned that Lyme could be transmitted in pregnancy. Later after I asked, they acknowledged that yes, there were case reports. One of my daughters also tested two-tier positive in Canada for a European strain of Lyme disease – except unlike me who had lived in Asia and travelled throughout Europe where European strains of Lyme are predominant, she hadn't. We both had positive tests for a European strain of Lyme disease and this was why I had asked for a meeting with my local public health unit. I was hoping they would be interested in investigating the possibility of maternal-fetal transmission.

Instead, the letter I received back was disheartening and disconcerting. I was advised that despite having tested positive in Canada, using two-tier criteria, both our cases would not be counted in Canadian surveillance statistics because our symptoms were 'non-specific' and we didn't have a 'clear onset' or 'reliable travel history.' Furthermore I was informed that they had completed 'a significant amount of research and no scientific evidence to support congenital Lyme in the scientific literature was found.'

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**Starting a Non-Profit: LymeHope** By this time, I had read more primary research papers reporting transmission of Lyme from mother to baby in-utero [iv] [v] including a report issued by the World Health Organization[vi] and Health and Welfare Canada[vii] clearly documenting the risk of this alternate mode of transmission and possible adverse pregnancy outcomes. Shortly thereafter, myself and colleague Jennifer Kravis co-founded the Canadian not-for-profit organization LymeHope.[viii]

In February 2017, we started a ‘Ticking Lyme Bomb’ petition[ix] which now has over 86,600 signatures and over 17,000 personal comments from across Canada. We also arranged meetings with Federal politicians from all parties, organized a bi-partisan round-table in Ottawa on Lyme disease,[x] testified at a Parliamentary Health Committee hearing[xi] and met with senior executives, scientists and officials from the Public Health Agency of Canada and Health Canada. We were invited to meet with then Federal Minister of Health[xii] and then leader of the Conservative Party of Canada – each time drawing attention to the many complex, serious issues faced by Lyme sufferers across Canada including the documented risk of maternal-fetal transmission. Each meeting represented another step ‘up the mountain’ with goals of identifying and initiating meaningful, collaborative solutions including innovative research – anchored in meaningful patient engagement and triaged by patient priorities.

In 2018 I co-authored a resolution on Lyme disease which was passed by the Registered Nurses Association of Ontario (RNAO) membership titled: ‘Patient First Treatment for Ontarians with Lyme Disease.’ [xiii] This resolution highlights the multi-faceted issues faced by Canadian Lyme sufferers and the RNAO would later feature our resolution in an article[xiv] in their Registered Nurse Journal. I am so grateful for the ongoing support of the RNAO and especially the brilliant leadership of

Dr. Doris Grinspun who leads the organization. I'll never forget her addressing the RNAO membership at the 2018 Annual General Meeting in Toronto – this was the meeting in which our resolution was later being presented for vote. She shared in general terms that 'disruption' may be necessary when confronting obstacles which stand in the way of Canadians accessing appropriate health care. As she spoke, tears flowed down my cheeks as I recalled the numerous letters, petition comments, personal testimonies and cries for help from my fellow Canadians – adults[xv] and children[xvi] alike – struggling to access appropriate care[xvii] and treatment for Lyme disease within Canada.[xviii]

I personally didn't want to be labeled as a 'disruptor' but rather a bridge-builder and peace-maker. I so badly wanted meaningful, sustainable change for Canadians with Lyme disease. However, I have since learned that 'disruption' is sometimes necessary if it leads to re-calibration, innovation and opens new opportunities for critical thinking, trust-building, identifying strategic research initiatives and initiates forward momentum. Many issues around Lyme disease urgently need re-investigation including adequate testing, treatment and alternate modes of transmission. New research continues to emerge which challenges the status quo, such as the persistence of the Lyme spirochete despite antibiotic treatment.[xix] [xx] This is an issue which advocates, clinicians and scientists have identified for decades and is anchored in findings from hundreds of peer-reviewed papers.[xxi] What is most important is that new research on Lyme disease must be patient relevant. In a 2016 CMAJ editorial article by Kristen Patrick[xxii], she states, 'For patient-relevant research to be meaningful, patient and public engagement in research cannot comprise a token lay person on a research ethics review board. Patients and their caregivers must be involved in decision-making at all steps in the research process, from design, to choice of primary and secondary outcomes, through dissemination and implementation.'

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**National Media Coverage** In 2019, CTV National News[xxiii] highlighted our advocacy work regarding maternal-fetal transmission of Lyme disease and the importance of initiating new research collaborations on this important, under-studied issue. This national media coverage also highlighted a systematic review on gestational Lyme[xxiv] which had been authored by scientists from both the Public Health Agency of Canada and CDC. This review included a meta-analysis which identified a significant difference in the frequency of adverse outcomes between treated and untreated pregnancies affected by Lyme disease.

In 2020, an advocate shared with me a discovery that three Federal Canadian agencies including: Health Canada[xxv], Public Health Agency of Canada[xxvi] and Occupational Health and Safety Canada,[xxvii] had historically acknowledged the risk of adverse outcomes associated with Lyme and pregnancy and/or maternal fetal transmission of Lyme on their respective websites. In all three cases, over a period of several years, this precautionary guidance was subsequently removed. For years, we had been advocating for acknowledgement of these issues which had already been publicly communicated!

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**20 Years of Research Has Not Overtuned Publish Risks Adverse Outcomes** As there has been no new research in over 20 years which has negated, questioned or overturned the published findings of earlier investigators, these precautionary statements should be clearly communicated. This is highlighted by the tenants of the Precautionary Principle and clearly communicated in a Health Canada Framework on Managing Health Risks which states: [xxviii] ‘A key feature of managing health risks is that decisions are often made in the presence of considerable scientific uncertainty. A precautionary approach to decision making emphasizes the need to take timely

and appropriately preventative action, even in the absence of a full scientific demonstration of cause and effect.’ Both the public and healthcare practitioners should be made aware of these documented risks of adverse pregnancy outcomes and of in-utero transmission of Lyme itself, even if considered rare. I have asked Canadian Public Health Agency officials for rationale as to why this guidance was removed and continue to await an evidence-based response.

I trust that the Public Health Agency of Canada and Health Canada will follow the CDC[xxix] and NIH[xxx] in updating their public guidance on Lyme and pregnancy to acknowledge that YES, Lyme can be transmitted in utero. With this simple, evidence-based acknowledgement as a starting point – new doors WILL open for urgent, multi-disciplinary research to better understand this alternate mode of transmission and open new avenues for families and children impacted to receive the medical care and support they need and deserve.

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**So where do we go from here?** There is action, HOPE and meaningful forward momentum! In Canada, a brand new research project on Lyme and Pregnancy was initiated in the fall of 2020 by McMaster University Midwifery Research Centre[xxxii] and remains open for participants from the US, Canada and globally, I am thankful to part of this research team. The Canadian Association of Schools of Nursing (CASN) has just released free, open access, online resources including online learning modules for nurses and other professionals working with clients, communities and populations facing climate-driven infectious diseases.[xxxiii] This innovative resource acknowledges both the risk of maternal-fetal transmission of Lyme disease and potential for adverse pregnancy outcomes and also includes a section titled: ‘Living with Climate-Driven Vector-Borne Disease’ which highlights patient advocacy efforts, patient stories and patient centered resources.[xxxiii] I am so proud that nurses are listening,



engaging and paving an inclusive way forward which respects, empowers and includes patients.

In the US, the Cohen Foundation[xxxiv] continues to lead with generous philanthropy for Lyme disease research, innovation and collaboration. For the last two years I have been honored to represent LymeHope as a panelist in the LymeMind Conference[xxxv], speaking directly to the issue of maternal-fetal transmission of Lyme[xxxvi] and alongside other experts, bringing this important, understudied alternate mode of transmission back into the forefront of academia and government. I recently spoke at a webinar hosted by Project Lyme and Mothers Against Lyme Disease [xxxvii] where I shared an overview of the literature on Lyme and Pregnancy[xxxviii] and also shared several research recommendations for a path forward.

The recent US HHS announcement of LymeX, in partnership with the Steven and Alexandra Cohen Foundation[xxxix] is an extraordinary step forward in bringing together diverse stakeholders including government, non-profits, academia, advocates, patients and industry to 'accelerate Lyme innovation.' A recent Notice of Special Interest by the NIH for improving outcomes for maternal health[xl] included 'development and validation of diagnostics for gestational Lyme disease, which can adversely impact maternal health and pregnancy outcomes.' All of these things are indicators of positive forward momentum and provide me with renewed Hope that new science, innovation and collaboration will lead the way and open new doors.

Four years after starting Lyme advocacy I believe that we are collectively reaching a Lyme tipping point and patients and advocates are being respected, welcomed and heard. I admit, there have been times I have been discouraged, exhausted, frustrated and even wanted to step away from leadership. I'm so thankful for many who encourage me to keep going. Advocacy in a field as contentious as Lyme disease can be a lonely,

misunderstood place. Pushing for change can be met with skepticism and silence. If we continue to take one step and another, anchored in evidence, leaning on scientific inquiry and partnered with respectful dialogue and meaningful collaboration – we will make it up to the top of the mountain.

I really look forward to the view from the top of the mountain and one day reaching the pinnacle and planting a flag which represents the hard work and dedication of advocates, patients, scientists, researchers, not-for-profits, clinicians and government officials – all determined to make a lasting difference on behalf of Lyme sufferers . For all the families impacted by Lyme disease and those concerned that in-utero transmission may be a factor in their child's illness – don't give up! I wish I could give you a big Mama-bear hug – we must keep speaking out and sharing our stories, concerns and ideas for solutions. Our collective voice is being heard and acknowledged and I truly believe that help is on the way.

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## Footnotes

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SueFaber\_Maternal-Fetal-Transmission-of-Lyme-Research-Gaps-and-Next-Steps\_April-29-2021\_Webinar.pdf

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