News release: Tackling Canada's Hidden Pandemic

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A group of early-career researchers at Queen's University have launched the MyLyme project (www.mylyme.ca), using the lived experience of patients to understand the link between tick bites and disease.

By the time May rolls around, Canadians are sick of being cooped up indoors. COVID-19 has made people even more eager than usual to get out and enjoy the spring sunshine. Unfortunately, we share our forests and hiking trails with ticks.

Many people bitten by ticks develop symptoms characteristic of Lyme Disease, including a red rash, fever, and headaches. Thanks to recent advances in health care, a lot of these cases are identified early and treated effectively with antibiotics. Unfortunately, for thousands more the story isn't as simple and they're left with serious, long-term symptoms, like severe pain and stiffness, tiredness, memory problems, and even the inability to move part of their face. Too many of these patients feel like their family, friends, and even physicians, don't believe them or understand what they're going through because we don't know exactly how or why they develop these chronic, treatment-resistant symptoms..

With funding from the Social Science and Humanities Research Council (SSHRC) and a Wicked Ideas Grant from Queen's University, scientists from the Departments of Anesthesiology & Perioperative Medicine, Biology, Biomedical & Molecular Sciences, and Psychology are working together to better understand Lyme Disease and to have the voices of those affected by Lyme Disease heard.

Their project kicks off with an online survey where patient reports are gathered and will be used to guide field work and laboratory-based models aimed at understanding how symptoms develop and why different people experience unique patterns of symptoms. Anyone who has Lyme Disease is asked to participate by going to www.MyLyme.ca to fill out this short survey.

"We've made a lot of progress in understanding Lyme disease" says Dr. Tim Salomons, one of the researchers on the project "but there's still way too many people with Lyme Disease symptoms who are being left behind".

The MyLyme project will be guided by these peoples' lived experience.

Links: mylyme.ca

Twitter: @ColauttiLab @head like egg @Queensu; @QueensuMedia

Media contact:
Dr. Tim Salomons
Assistant Professor, Queen's University
tim.salomons@queesu.ca