

Introductory Statement

Good morning – on behalf of all our patient advocates here we would like to express our appreciation for this opportunity. We hope this is the beginning of ongoing collaboration and partnership - so that together we can begin implementing real solutions to the Lyme crisis in Canada.

All of us are Lyme patients or parents of children with tick-borne diseases, and I along with others here, are both.

We all know that the issue of Tick-Borne disease in Canada is incredibly complex, and there are no quick fixes or magic bullets.

We want this meeting to be authentic and frank, and in that spirit, I can say that we all know this journey has been fraught with often intense conflict.

But we all know that addressing tick-borne disease is urgent, as the disease is spreading rapidly, only going to get worse, and poses a very serious risks, not only to the health and welfare of all Canadians, but also to the stability of our health care and disability systems and to our economy as a whole.

All of us here today are united in hope and belief that it truly is time to build bridges and it is critical that we look forward not backwards. It is also absolutely critical that we engage our physicians, they are confused, feel ill equipped to help patients and across Canada, patients are given conflicting advice. This is unacceptable and is leading to excruciating loss and suffering from those infected who are missed.

Canadians cannot afford to have progress impeded by egos, alternate agendas, bias, history, or conflict. The stakes are simply too high.

It is absolutely essential to fully engage all of our available resources and stakeholders in a meaningful and full partnership. All of us share a common goal – we must take immediate steps to prevent more Canadians, especially children, from being disabled by these hideous diseases. We also must find ways to provide help and hope to those

who are already suffering - many who have been suffering, marginalized and financially destroyed for decades.

Collectively, the advocates here today and the many who are not here but devote their lives to effecting change and providing support, bring a wealth of passion, knowledge, experience and expertise to the table. We also collectively bring the voices and experience of tens of thousands of Canadians spanning decades.

We want to help, we can help and we must participate in setting priorities and solutions to address the most critical needs efficiently and in a cost effective manner. We do not wish to be engaged in a process that is going to lead to nothing and take us nowhere.

Many of us attended the May 2016 Federal Lyme Conference and I would like to quote some of the things that Dr. Greg Taylor, the then Chief Public Health Officer, said in his closing remarks:

“And the hope that I have heard throughout, has just been incredible. People aren’t here to bitch and complain; people are here to make it better, and that’s great, and that’s where we are all on the same page. That hope and clearly that commitment and clearly the altruism because every comment I heard was about making it better for other people and making it better for other Canadians so we are on the same page for that one, because that’s our job too. “

He said:

“We must engage Canadians better and more. We must engage patients, better and more. “

He also said:

“Transparency, that’s key - absolutely key, and we will certainly do the best that we can to ensure that as we go forward, we are as transparent as possible. “

And his closing remarks were as follows:

It’s been a very moving experience for me personally and I do want to thank you all for sharing. There’s been some really amazing stories the

last few days, and you all took a lot of risk. I got to say that. A lot of risk – revealed yourself personally because you believe that together, we can work and be more effective. I'm there with you. I look forward to working with you in the future “

At that moment with Dr. Taylor finished that speech, hundreds of Conference participants, and thousands of Lyme patients across Canada had Hope.

Hope that over the decades as voices and suffering continues to go unrecognized, denied and ignored, was reignited.

It is not too strong a statement to say that the draft and now final Framework has been devastating to thousands of Canadians who feel betrayed and are in despair again.

We need to find a way to restore that hope and trust in our Government, and in you – our public health leaders and experts.

So here we are, ready to engage, ready to roll up our sleeves and partner with you. The time allotted to this meeting is not nearly enough to address all the issues but we hope we can set the stage and begin drawing the roadmap to success together.

We sincerely hope this is just the beginning of a true partnership, and that the best is still to come.

Thank you