Testimony of Christopher Philbrook Before the Special Committee on Aging's Field Hearing Orono, Maine September 5, 2019

It's a small thing, but I didn't realize how important smiling was to my mental health until I couldn't do it anymore.

On a Saturday afternoon in 2007, I took a trip to Hogback Mountain in Virginia. Shortly after that trip, I woke up incapacitated. I could barely move a muscle. I thought I might have the flu, so I stayed in bed and did not think much of it at first. But I've always been healthy and quick to recover, so when my condition did not improve in a few days, I flew home to Maine to see my doctor.

One problem with Lyme disease is that the symptoms mimic so many other things, as I would soon discover.

When I got home, my 7th cranial nerve, which runs down the left side of the face, went into a state of trauma. In addition to the flu-like symptoms, I now also had Bell's palsy. I also couldn't eat or sleep for days, and was in a state of pain so debilitating that I went to emergency room and received a CAT scan. The scan showed nothing abnormal, so the doctor suggested I see a neurologist.

I also scheduled a dentist appointment to see if something was wrong with my teeth, because they hurt badly. The dentist took one look at me and said, "Bell's palsy can be the result of Lyme disease. Do you have a tick bite or bullseye rash?"

I didn't.

But I mentioned this to my neurologist, and he tested me for Lyme.

The test came back negative.

Shortly after that, the right side of my face went into paralysis. I now had Bell's palsy on both sides of my face, and the neurologist recommended an MRI.

That MRI showed what looked like a tumor either blocking or growing on my cavernous sinus, a nerve that runs from the brain to the face. We started talking about surgery and radiation.

Now I'm starting to worry.

Next, the neurologist recommended a spinal tap. If you've never had a spinal tap, consider yourself very lucky. It's awful.

The neurologist also ordered a second MRI, this time injecting a blue dye into my body so the tumor would show up in greater detail. He also ordered a chest x-ray because I was having trouble breathing.

The spinal tap showed Lyme in my spinal fluid, and the blue dye showed that the disease had attacked the nerves in my brain, causing extreme inflammation.

But, the good news? I didn't have a tumor.

I did, however, need to have a picc line installed immediately. For four weeks, the line delivered a strong dose of antibiotics from my bicep to my heart.

I was working on Senator Collins' staff at the time, and she watched my pain and suffering first hand. I still have daily notes from her checking in on me. One said, "you gave us quite a scare."

It was scary. And it remains scary to know that ticks carrying Lyme are a constant threat in my own backyard. With its proposed private-public partnerships including pest control, the TICK Act aims to alleviate that threat – a prospect that would relieve a lot of anxiety for anyone who has been through this disease.

I was lucky that my dentist spoke up, that I had a spinal tap (not a normal Lyme testing protocol), and that my Lyme disease was treated quickly, within the first month and a half. I'm happy to say that after my antibiotic treatment, I was cleared of the disease, although residual effects remain – mainly sleep disturbances and facial paralysis.

Others are not so lucky. When Lyme is not diagnosed quickly, co-infections can develop and the disease can become much more difficult to treat. This happens far too often, which is why the TICK Act's directive for improved diagnostic testing is so important.

For my ongoing symptoms, the most effective relief has come from food. After eight years without improvement, and having been told the only solution was plastic surgery, I started on a ketogenetic diet and intermittent fasting – something author Tim Ferriss said was the only thing that knocked out his Lyme disease. Within seven days, I felt movement in my face that I hadn't felt in years. Because ketosis is unrealistic for me to maintain long-term, I've fallen back on Tom Brady's eating and training regimen, the TB12 method. While this approach may not work for everyone, it has kept my symptoms at bay. The problem is, my story doesn't scale – I heard about this approach by chance on a podcast. Conversely, the TICK Act would create database where treatment approaches and outcomes could be shared immediately in the context where it matters most – the doctor's office.

Thank you, Senator Collins, for this opportunity and for your work on this public health threat. I hope the TICK Act, when enacted, gives people currently suffering with Lyme disease validation and hope that they can and will get better.