

Paula Jackson Jones
Field Hearing Testimony – Orono, Maine
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Chairman Collins,

Thank you for holding this hearing and for inviting me to testify today. My name is Paula Jackson Jones, and I am here to share my story and my life's work. This has been a 10-year crusade for me, with the first 5 years fighting for my life and the latter fighting on behalf of others.

I was bit by a tick in October of 2009 while outside doing fall clean up with my husband. At the end of the day, while cleaning up, I discovered a tick embedded in my side. We removed it, flushed it and never gave it another thought. Not even when I became systematic 10 days later. For the next 2 years, I was misdiagnosed by 23 doctors and specialist with everything from panic attacks to respiratory infections, chronic fatigue to fibromyalgia. When a scan revealed lesions on my brain and my neurological symptoms intensified, I was tested and diagnosed with MS. When my symptoms became even more severe and I was not responding to treatment, I was re-evaluated and my diagnosis changed to Parkinson's. When I got lost driving, my doctor revoked my license and when I began to have trouble swallowing and the use of my arms and legs was a daily challenged, my medical providers wanted me tested for ALS. I knew that was a death sentence for me and it was at this point I knew that I needed to fight and advocate for myself.

Thanks to a family member who kept pressing me to be checked for Lyme disease, even though I had 4 negative tests, I demanded to see a provider who knew about Lyme. My primary doctor refused to give me a referral because that was not what they thought I had. However, the intern gave me a scrap of paper with the name of someone he knew who saw Lyme patients and that doctor, a Maine doctor, number 24, saved my life.

In April 2011, after clinical examination, additional bloodwork and tests, I was diagnosed with late stage neurological Lyme, Babesia, Bartonella, Rocky Mtn Spotted Fever and Erlichiosis. That medical provider, who knew more about Lyme and tick-borne disease, not only saved my life but gave my life back to me.

When a cancer doctor thinks outside the box and heals their patient, they are deemed a hero. When a Lyme provider does it, they are brought up under medical scrutiny and disciplined beyond belief.

The Infectious Diseases Society of America (IDSA), the governing body that exists and controls all things to do with disease wrote in their guidelines a foot note that reads as follows:

“These guidelines were developed and issued on behalf of the Infectious Diseases Society of America.

It is important to realize that guidelines cannot always account for individual variation among patients. They are not intended to supplant physician judgment with respect to particular patients or special clinical situations. The Infectious Diseases Society of America considers adherence to these guidelines to be voluntary, with the ultimate determination regarding their application to be made by the physician in the light of each patient's individual circumstances.”

My treatment was not conventional or mainstream but it was effective. It was tailored to my infections and to how I was responding. Thankfully, my medical provider had a vast amount of resources to turn to when treatment options failed. And in April 2014, I went into remission. Today, I remain in full

remission going on 5 and a half years. Although faced with a mountain of medical bills not covered by insurance to the tune of \$250,000, I am thankful every day for my health. Others have not been so fortunate. Misdiagnosis leads to a life riddled with pain, robbed of joy, floundering from lack of support and struggling just to be heard and validated and that's if the disease doesn't take your life in the process.

In April of 2014, after going into remission I wanted to make a difference where I lived. I wanted to help raise awareness about the risk of tick-borne disease and educate people on how to protect themselves. But more importantly, I wanted to make their search for resources not only easier to find but accessible and affordable. I co-founded and became President of Midcoast Lyme Disease Support & Education (MLDSE). We are a charitable nonprofit 501c3 organization that travels statewide, hosting year round free educational and prevention talks and events. We advocate for change at state and federal levels and provide support to those in Maine afflicted by tick-borne disease by connecting them to medical providers, educational and financial assistance programs. We are the Maine partner of the national Lyme Disease Association, members of Maine's CDC Vector-borne Work Group and active in Maine's Lyme legislation. We are members of the worldwide Ad-Hoc Patient-Physician Coalition consisting of 67 organizations from 6 countries who are concerned that the proposed Lyme disease guidelines of the Infectious Diseases Society of America (IDSA), American Academy of Neurology (AAN), and American College of Rheumatology (ACR) will further restrict access to care and harm patients by leaving them undiagnosed and undertreated. The coalition consists of over 35 patient groups, (including LymeDisease.org, the National Lyme Disease Association, Bay Area Lyme Foundation among others) and the International Lyme and Associated Diseases Society, which represents clinicians who treat Lyme disease nationwide.

In 2018, I served as the co-chair to the Federal Health & Human Services Tick-borne Disease Working Group's Access to Care Services and Patient Support subcommittee. Our role was to identify gaps and barriers that patients faced in accessing proper diagnosis and treatment. That information went into a report presented to the federal TBDWG, who compiled all subcommittee reports into a report to Congress. I was honored to have been selected for that role as it defines who I am these days, sitting in the trenches alongside patients and their families and connecting them with whatever services they need as they journey back towards health and wellness. I am not a victim but a survivor and one who advocates for those who cannot advocate for themselves. A fulltime job for and one that I do year round and on a voluntary basis without pay.

Lyme and tick-borne disease is not a cookie cutter disease and yet, the cookie cutter approach has failed time and time again.

It has been acknowledged at a federal level that current Lyme Disease testing is, at best, 25-40% reliable. It is less accurate in acute cases because providers test too soon, and patients may not have produced antibodies. Also, more physician education is needed to determine just what test is warranted. In an April 1, 2018, National Institute of Health article "Advances in Serodiagnostic Testing for Lyme Disease Are at Hand" it was concluded that "for the past 2 decades, the concept of a 2-tiered strategy aimed at high sensitivity and specificity has been widely used, but the current approach is insensitive during the first weeks of Lyme disease, and Western blotting can be complex to perform and interpret."

Then, in a July 25, 2018 National Institute of Health article "Tick-borne Diseases Are Likely To Increase", there were several points mentioned that caught my eye:

- The incidence of tick-borne infections in the United States has risen significantly within the past decade.

- It is imperative, therefore, that public health officials and scientists build a robust understanding of pathogenesis, design improved diagnostics, and develop preventive vaccines.
- Tickborne virus infections are also increasing and could cause serious illness and death.
- The public health burden of tickborne disease is considerably underreported, according to the authors. According to the authors, this is due in part to the limitations of current tickborne disease surveillance, as well as current diagnostics, which may be imprecise in some cases and are unable to recognize new tickborne pathogens as they emerge.

It was suggested:

- By focusing research on the epidemiology of tickborne diseases, improving diagnostics, finding new treatments and developing preventive vaccines, public health officials and researchers may be able to stem the growing threat these diseases pose.

So faulty tests are identified and the need for more physician education is imperative to curtailing this growing epidemic. This is where passing the TICK Act Bill into law will provide a lifeline not only to patients but to medical providers. With funding available for research and education, we can get medical providers on the same page not only with better diagnostic tools but better, more effective treatment options for their patients.

[See Appendix A: The Ad Hoc Patient and Physician Coalition Comments of the IDSA Proposed Lyme Guidelines]

Link to Article 1 [Read the full article here: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6019075/>]

Link to article 2 [Read the article in full here: https://www.niaid.nih.gov/news-events/tickborne-diseases-are-likely-increase-say-niaid-officials?fbclid=IwAR3spS7ypl7xgr6l1YLSVH_XDJZoXsfOaAceDVh72myTxhM-boQhxJVrSp0]