

TESTIMONY of
PAMELA S. ANDREWS
1187 Kestrel Way
Salisbury, Maryland 21804
To the
HEALTH & GOVERNMENTAL AFFAIRS COMMITTEE
MARCH 12, 2023

FAV - TESTIMONY IN FAVOR OF HOUSE BILL 1351
Health Insurance - Lyme Disease and Related
Tick-Borne Illnesses - Long Term Antibiotic Treatment

To the Honorable Delegates of the Committee:

In 2003, I became a founding member of the Lyme Disease Association of Delmarva, Inc. (LDAD), a non-profit organization whose primary purposes are education, and advocacy for patients of tick-borne illnesses. I have been president of LDAD for most of its twenty years. I did not willingly come to advocacy for Lyme disease patients. My inspiration for forming this organization was my youngest daughter, who is disabled with chronic Lyme disease, and has suffered permanent organ damage because she went nine years undiagnosed and untreated for Lyme disease.

At age 18, my daughter was a healthy, happy teenager who had lots of energy and several hobbies: modelling, karate, music and dancing to name a few. During that summer, in 1991, she went to Assateague Island then became very sick -- an event that changed her life forever.

I have gifted each of you with my recently published novel, ***LYME WARS - A Love Story***. As a novel, the story of the lives of Francesca and David is mostly fictitious. However, a few events portrayed in this book are drawn from real life. (I have used fiction to more globally portray truth.) Thus, a documentation of my daughter's descent into the world of tick-borne diseases is described on pages 168 - 170 (Chapter 17 - *Gathering the Storm*) which is, for the most part, a word for word letter I sent to her primary care physician who insisted she wasn't really sick.

This information is illustrative of the stories of perhaps thousands of patients I have met during the couple decades the LDAD has hosted monthly meetings for the general public. Representation of the stories of actual Lyme disease patients may be found in ***LYME WARS*** pages 193 - 195 (Chapter 20 - *Institute of Medicine*) which is a literal account of my testimony before the Institute of Medicine in 2010.

An understanding of situations which patients of Lyme disease often face is documented in ***LYME WARS*** on pages 198 - 204 (Chapter 21 - *The Pediatricians' Office*). Readers of this chapter have told me they are appalled by this portrayal. I agree. However, this account was told to me from an actual event of a young Lyme patient whom I know.

The sense of loss and hopelessness that many patients with chronic tick-borne diseases experience is depicted on pages 306 - 309 (Chapter 35 - *Echoes*).

My testimony before you this year is not my first time giving information to the State of Maryland Legislature. I also served on a Lyme disease working group for the State of Maryland. I have testified on Lyme disease and other tick-borne pathogens in the early 2000's, in 2010, in 2021 and in 2023. I have given testimony in Maryland, Delaware and Washington, DC. And our concerns and petitions are essentially the same:

1. Educate the medical community on diagnosis and treatment of tick-borne diseases and on the chronic state of those diseases.
2. Protect the right of medical professionals trained in proper diagnosis and treatment of tick-borne diseases to be permitted to use long-term antibiotics.
3. Stipulate that medical insurance companies shall provide coverage for the diagnosis and treatment of tick-borne diseases, including their chronic states.
4. Protect the rights of physicians trained in the diagnosis and treatment of tick-borne diseases to use up-to-date treatment protocols as supported by research, without censure or loss of their medical licenses by medical boards.
5. Due to the lack of accurate testing methods, advise the public that negative test results do not mean Lyme disease is not present. (Absence of evidence is not evidence of absence.)

When my daughter contracted tick-borne diseases, she was 18 years old and I was in my 40's. She got a diagnosis of Lyme disease when she was 27 years old; I was 56 years old. I have been her sole caretaker. Tick Borne Diseases (TBDs) have dominated our lives and our finances for thirty-three years. We have spent several thousand dollars out-of-pocket, each of those years, in our search for lives free of tick-borne pathogens. Our situation is not unique. There is a growing number of Maryland citizens with chronic TBDs. Today, my daughter is 51 years old; I am 80 years old. Our question is -- Do we care that untold and growing numbers of Maryland residents are being exposed to tick-borne diseases every year?

To quote a recent article by LymeDisease.Org, "The CDC released a surveillance report in February 2024, showing reported cases of Lyme disease rose from an average of about 37,000 from 2017-2019 -- to 62,000 in 2022."

The salient point in the LYME WARS is the denial by some that chronic Lyme disease exists. As the number of patients with chronic tick-borne infections grows, year after year, it is crucial that our residents have the protections set forth in HB1351. Those of us who have had TBDs for years, despite aggressive treatment, know with our own bodies that Lyme spirochetes are very invasive and survive many rounds of treatment. Maryland residents deserve to be treated by physicians who are properly trained in diagnosis and treatment of tick-borne diseases, and that those

physician not be sanctioned by medical boards for offering effective treatment to their patients. Maryland residents deserve coverage by medical insurance so their family finances are not decimated by medical bills.

Respectfully submitted,

Pamela S. Andrews, president
Lyme Disease Association of Delmarva