TESTIMONY of
PAMELA S. ANDREWS, president
LYME DISEASE ASSOCIATION OF DELMARVA, INC.
1187 Kestrel Way
Salisbury, Maryland 21804
To the
HEALTH & GOVERNMENTAL AFFAIRS COMMITTEE
MARCH 9, 2023
HOUSE of DELEGATES, MARYLAND LEGISLATURE

TESTIMONY IN FAVOR OF
HOUSE BILL 1199

To the Honorable Delegates of the Committee:

I have been a resident of the State of Maryland for about seven decades, where I live near my daughters and grandchildren. In 2003, I became a founding member of the Lyme Disease Association of Delmarva, Inc. (LDAD - formerly known as Lyme Disease Association of the Eastern Shore of Maryland), a non-profit organization whose primary purposes are education and advocacy for patients of tick-borne illnesses.

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. She went for nine years undiagnosed and untreated for Lyme disease, and was critically ill when she was finally diagnosed with Lyme disease in 2000. My goal in helping to form the LDAD was to ensure that other Marylanders do not suffer a fate like my daughter. She has spent many years of her life in bed, too sick to leave the house; too sick to work; too sick to complete college. She was seen by twelve doctors and three medical institutions before finally being diagnosed and treated for tick-borne diseases by a physician who was willing to explore the possibility of Lyme disease.

For the past twenty years, the LDAD has been holding monthly meetings for Lyme disease patients and the general public. (Monthly meeting were interrupted after the Covid-19 pandemic caused restrictions on public meetings.) Sadly, since our inception in 2003, the environment for getting correct diagnosis and adequate treatment for Lyme disease ,has not improved nearly as much as it should have. Indeed, misdiagnoses and inadequate treatments are too often the experience of our Lyme disease patients, and they pay for it with lives lived in pain, careers interrupted, and life-savings spent on medical bills because health insurance companies refuse to pay for appropriate diagnostic tests and adequate treatment.

In addition to my daughter having Lyme disease, I discovered I also have tick-borne diseases. I can personally relate that my family has likely spent a hundred thousand dollars on testing, treatments and bills from medical professionals, when my insurance company refused to pay for medical necessities to regain health. I am not a wealthy woman, so having such a large sum of money taken from my net worth has compromised our family finances.

Perhaps the greatest challenge faced by Lyme disease patients is to find doctors who are knowledgeable in tick-borne illnesses, and who are willing to treat Lyme disease patients in an environment politically charged and punitive to medical professionals who specialize in treating patients with tick-borne diseases. It is our opinion that this environment is largely caused by the actions of the Infectious Disease Society of America (IDSA), their very restrictive Treatment Guidelines, and their refusal to recognize Chronic Lyme Disease. The IDSA, over the past three decades, has refused to consider a vast number of research projects done throughout the nation which prove denials regarding chronic Lyme disease are wrong.

Some in the medical community label our doctors “quacks” or “charlatans” in order to delegitimize our progress, protect the status quo, and protect their established systems and financial interests. But we will not remain silent while the lives of our children and neighbors are ruined. *Lives lost to Lyme disease* do not always refer to deaths. The destruction of productive lives in our nation caused by tick-borne diseases is not overstated.

During my work with the LDAD I have met with thousands of Marylanders with Lyme disease, and I have a detailed understanding of the issues they have dealt with in trying to find medical help. And every year, thousands more Lyme disease patients join the ranks of patients chronically ill. Patients sometimes must choose between unnecessary suffering or depleting their resources because insurance companies refuse to pay for health care related to Lyme disease. Many are forced to forego needed treatment. Our stories do not need to be sensationalized -- but they must be told, and we shall do that. In the words of one of a highly respected Lyme doctor:

“In the fullness of time, the mainstream handling of Chronic Lyme Disease will be viewed as one of the most shameful episodes in the history of medicine, because elements of academic medicine, elements of the government and virtually the entire insurance industry have colluded to deny a disease.” -- Dr. Kenneth Liegner

In closing, please be assured that the LDAD has been acting aggressively to help remedy the plight of Lyme disease patients in Maryland. Our organization has sponsored several annual medical conferences, offering CME credits to medical professionals, with presentations by many of the nations most reputable experts on tick-borne diseases. We are in favor of House Bill 1199 which provides for Health Insurance coverage for Long-Term Antibiotic Treatment of tick-borne diseases

I welcome any questions regarding my work and experiences advocating for patients with tick-borne diseases.

Respectfully submitted,

Pamela S. Andrews

Pamela S. Andrews, president
Lyme Disease Association of Delmarva, Inc.
PamelaAndrews01@comcast.net