

## TESTIMONY IN FAVOR OF HOUSE BILL 1268

To the Honorable Delegates of the Committee:

My name is Heather Liberati. I am the mother of a daughter who lives just a few minutes from here, going to Crofton High School and the Center of Applied Technology South nearby in Edgewater, graduating in May! I am the mother of a 17 year old daughter with now chronic Lyme disease that she's been fighting since October of 2021.

Growing up, we were taught that if you were bit by a tick, you'd get a bullseye rash and need to get tested for Lyme. No one ever said what could happen and it seemed like it could just be treated easily. That could be the case if caught and treated with a full antibiotic course immediately. With tick-borne illness on the rise and many emerging vector-borne diseases becoming a rising threat, this legislation is pivotal in the State of Maryland and along the Northeast coast, although Lyme is everywhere. According to the CDC, tick-borne disease has more than doubled in the last 13 years. That's only the reported cases. Since it is such a controversial disease for some reason, many cases go unreported because they aren't the certain bands that the CDC deems relevant, which unfortunately, does not cover most of the Lyme bands.

When detected in its early stage, Lyme disease is treatable with an appropriate course of antibiotic therapy. The Lyme bacteria is very slow growing, and its life cycle is approximately 28 days. If undetected and untreated, the bacteria replicate, and the disease progresses into its late stages, becoming persistent and chronic. Treatment for chronic Lyme disease is prolonged and complex. One antibiotic for a short duration may not be enough to kill the bacteria. In many cases, the conventional antibiotic course prescribed during the early stages of Lyme may effectively eliminate the acute infection. However, the challenge lies in the bacterium's ability to transform into dormant forms or hide in tissues, evading the immune system and traditional antibiotic treatments. This leads to the development of persistent or chronic Lyme Disease, where symptoms endure long after the standardly prescribed course of antibiotics.

Patients and healthcare providers alike must recognize that Lyme Disease is a complex, multi-faceted condition, and tailored treatment plans are crucial for addressing the chronic form Lyme disease. From the Global Lyme Alliance, Spirochetes are savvy. They spiral away from antibiotics, burrowing into bones, cells, joints, and nerves. They can even cross the blood-brain barrier, bringing Lyme disease into your central nervous system. They replicate and spread; all it takes is one dormant spirochete to start reproducing for a Lyme infection to flare up. This is why late-stage Lyme—which goes untreated for a long time and has spread around the body and into the central nervous system—is difficult to treat, if not virtually impossible to fully eradicate.

An appropriate length of antibiotics in the first 30 days is necessary to give people the absolute best chance at eradicating these diseases. If a physician prescribes the maximum number of days of antibiotics that the insurance allows, the bacteria can live past that treatment, and we are just setting that person up for treatment failure, and the victim is left to pay any further treatment out of pocket.

If one full course of antibiotics could prevent just one person from turning chronic, this bill is worth passing. If just one family would not have to go through what my daughter has been through, this would be a win. And if one family did not have to see the extreme financial hardship that this disease costs, after the months it can take to find a doctor who knows how to treat it, but isn't allowed to take insurance because the treatment for chronic Lyme is not approved by the CDC, then this is worth it. The cost of a full doxycycline treatment through insurance is pennies compared to the thousands of dollars and years to treat it once it's past the point of antibiotics. This doesn't even begin to tap into the mental anguish that goes along with this disease and the medical gaslighting.

My daughter is 17. She spent 9th grade in home and hospital after her pediatrician got her an emergency appointment at Arundel Lodge for a psych evaluation because she woke up one morning unable to walk. It took months and countless doctors in a medical area as this with University of MD, Hopkins and all of these specialty medical professionals to figure out and find a doctor that knew it was Lyme. In 10<sup>th</sup> grade, she was in and out with another tickborne disease, Babesia. Her Lyme resurfaced with two other strains in 11<sup>th</sup> grade (Lyme is never fully gone, it can only be sent into remission). Now she is in 12th grade, and while it is in remission, the Lyme has done so much damage, that her hormones make her inflame so bad once a month in the areas that the Lyme weakened, that she is unable to walk for a week a month. She misses school for a week or two at a time, because she is inflamed so bad that she cannot walk. She is a 17 year old with a walker. She is a 17 year old that can't hang out with friends because she is in excruciating pain. She is a 17 year old that is going to be a Lyme doctor so that she can help kids going through this.

A stat from that same doctors office that told her that she was just imagining this (Annapolis Pediatrics), says that 20-30% of deer ticks in Maryland transmit Lyme disease. The fact that this bill has been up multiple times and never been passed baffles me. Until you've lived through it, or had to carry your child who is the same height as you, because she cannot walk, to doctors appointment after doctors appointment looking for answers, just to be told that you're imagining it, then to finally find a doctor that knows what Lyme is and how to treat it, just to find out that it's all out of pocket. Then to know that it could have been covered, had doctors been more educated

and your kid could have never see the chronic conditions. You have no idea until your family has lived through it. I know I didn't.

Many in Maryland are suffering from tick-borne illnesses, as it is now to endemic stages. Those with state-regulated Insurance (or private pay) are, in most cases, only receiving 7-14 days of treatment. If they were undiagnosed for any length of time, like my daughter Brianna, treatment becomes much more complex. Many are losing their families, homes, businesses, and pensions trying to pay for continued treatment, and this legislation provides them with just the bare minimum but is a start. For my daughter, who is past the point of a round of antibiotics, I've spent over \$30K in treatments for the disease coupled with pain relief treatments to get her through this, since nothing regarding Lyme is covered by insurance, and there are only a handful of doctors in the DMV that know how to treat Lyme and its coinfections. Since Lyme did so much damage to her body, we have had to purchase equipment to help with the pain, totaling over \$25K. Knowing now that if she were treated properly at the beginning of this, it would have been in remission years ago.

On behalf of the Maryland Lyme Community, we just want to say thank you to Delegate Howard for seeing the great importance of this legislation. It is extremely important to catch this in its tracks before it becomes chronic and knowledge and insurance coverage are good first steps. Don't let anyone else's family go through the pain that my daughter lives with daily in her fight against Lyme.

In closing, we all know that long term antibiotics are by no means a solution on their own. Long term antibiotics could give doctors an opportunity to "pulse" antibiotics, or at least provide someone a fighting chance by lessening the bacterial "load" to help their immune system take on the Lyme bacteria. Anyone with Lyme, who has lived this story, knows that this is not enough alone, but we have to start somewhere. This is why we seek your favorable vote in support of this bill.

Don't let anyone else's family go through the physical pain and the mental trauma that my daughter lives with daily in her fight against Lyme Disease, and voting favorable to this bill is just one small step in the right direction.

Sincerely,

Heather Liberati