

My name is Mary Jean Hughes and I live in Sharpsburg, Maryland. I am testifying in support of HB1319.

I suffer from chronic Lyme disease, which some health professionals still deny exists in spite of numerous peer reviewed studies and evidence that the spirochete that causes Lyme can persist in the body for many years after the initial infection. My diagnosis came when I already had late-stage Lyme and the disease was widely disseminated and established. While I have permanent damage to my joints and lingering neurological symptoms, long-term antibiotic therapy saved my life.

I had three rounds of IV antibiotic cocktails, each lasting over a year. After the first two rounds I stayed relatively stable for a couple of months before I quickly regressed off of antibiotic therapy. The third time was the charm (so far) and I am maintaining with oral doxycycline, among other things.

I count myself fortunate that my insurance covered the cost of these treatments, which ran into the tens of thousands of dollars. Over the years I have talked with many people who were denied the same treatments and whose health deteriorated to the point where they were permanently bedridden and unable to work, as I had been temporarily.

The public misinformation surrounding Lyme and other tick-borne diseases is staggering. I know of no other disease that has been so politicized so that there are two competing standards of care – one which recognizes the persistence of the bacterial infection and one that denies it in spite of evidence to the contrary. When I got cancer, the contrast between how I was treated by both the medical community and ordinary people was stark. As a Lyme patient, I was disbelieved, dismissed, patronized, offered antidepressants and otherwise written off or ridiculed for over 10 years as the disease gained the upper hand. As a cancer patient I was offered appropriate treatment, empathy and a multitude of support services.

It is worth mentioning here that Lyme disease is often misdiagnosed, which contributes to the problem of chronic disease. If the “classic” bulls-eye rash is evident your chances of getting appropriate early antibiotic treatment are good. Absent that, doctors are reluctant to make a clinical diagnosis and instead will look for anything but Lyme. (“I really don’t want to go down that Lyme road” was the nurse practitioner’s response when my sister asked for my niece to be tested.) I live in a rural area and have had many tick bites over the years, but this was never taken into consideration when assessing my symptoms. My husband and daughter both had the bulls-eye rash; both were treated immediately and seemingly have had no further problems. My son was not so lucky, nor was my niece – both of them required long-term antibiotic IV therapy because of the delay in diagnosis.

Thank you for the opportunity to speak on this important issue. I urge you to support HB1319, which offers hope of some quality of life to people who are suffering needlessly from Lyme and other tick-borne diseases.