

Congressman Smith and Members of the Global Health & Human Rights Committee,

Thank you for the opportunity to testify on a problem I've seen blossom from a regional to international issue. 27 years ago I saw the devastation in my school district caused by an unknown disease affecting staff and students. To educate myself and fellow school board members, I had to contact a nearby naval base, although many of my enquiries were returned with, that's classified.

The past 20 years, I've traveled the country, 15 as president of the all-volunteer national non-profit Lyme Disease Association, listening to patients, scientists, doctors, and government officials. Through the perspective of Lyme, I've found some individuals charged with public welfare have lost their focus; instead of solving the problems of humanity, some have abrogated their responsibilities, affecting people worldwide.

Over time, I have heard Lyme called a housewife's disease, a Yuppie disease, hard to catch, easy to cure; heard patients referred to as hysterical, faking, crazy, paranoid, even antibiotic seeking; and heard Lyme advocates portrayed as crazed-know-nothings responsible for mass hysteria over Lyme. Many US Lyme organizations and others have been victimized in peer review by noted researchers who do not agree that Lyme doctors should be permitted to use clinical judgment in treating Lyme, attacking those who are working tirelessly to raise research and education funds for Lyme disease advocates and patients. Many patients confide to me they would rather have cancer.

CDC and NIH have awarded grants to many of the same people, some for studies that rely on the strict CDC surveillance criteria for inclusion, including the use of faulty tests. Thousands of patients have questioned this practice and ask for studies which can provide solutions to their dilemmas as chronic Lyme patients: My doctor won't treat me when I'm sick, No one believes my children and I are sick. A common refrain is, why isn't the government doing anything about Lyme?

NIH funded several treatment studies, and the broad brushed conclusions put a nail in the coffin of Lyme patients. One could possibly conclude from the studies that specific treatments used by study participants over the length of the study were not effective for the restrictive population chosen for research purposes. Instead, conclusions became "no long-term treatment is effective for anyone with Lyme." Many doctors in mainstream medicine who had treat to date, now turned a blind eye and deaf ear to patients with Lyme.

The CDC Lyme surveillance system is in shambles. CDC criteria have become stricter, reducing the patient pool for reported cases. Lyme surveillance is very labor intensive, including calling doctors to verify data. Human resources have been cut, forcing states to institute cost savings measures involving changing case reporting methods, affecting national and regional numbers.

Officials continue to declare there is "no Lyme in the South/Midwest." Reasons given for that stance range from: there are no deer ticks in the South; if there are deer ticks there, they are not infected with Lyme because there are no reservoir hosts in the South (those are small mammals that carry Lyme bacteria and transmit it to ticks who infect people); deer ticks in the South feed on lizards which do not transmit Lyme bacteria to ticks; deer ticks in the South behave differently; and deer ticks in the South do not bite people. Scientific studies do not support those conclusions, yet many physicians still refuse to diagnose and treat Lyme in the South, forcing patients to seek medical treatment in endemic areas of the country, adding to already overburdened medical practices.

Compounding the problem, the very strict Lyme definitions meant for surveillance only are abused by mainstream medicine, insurance companies, pharmacists, and even public officials who are charging moms with Munchausen's by Proxy and taking away their children. Their crime? Having a licensed doctor prescribe antibiotics for their children's Lyme.

On its website, CDC disclaims any responsibility, stating its criteria are for surveillance only. Its actions belie that position. CDC openly endorses the IDSA guidelines, featured on its website, guidelines written by researchers, not clinicians who care about patient outcomes. For example, IDSA guidelines recommend against any long term treatment with antibiotics, recommend against any alternatives, and recommend against supplements for Lyme patients. Patients have no treatment options open to them under these guidelines, even if they can find a doctor still willing to treat under the threat of license removal for exercising clinical judgment in treating Lyme.

The CDC surveillance criteria form the basis for the IDSA guidelines. Intertwined, inseparable, like strands of a rope, they form a noose around the neck of Lyme patients, sometimes leaving them die a very slow painful death without medical treatment. Even in death, there's no rest for Lyme victims and their families. A published study examined 114 death certificates listing Lyme as a cause, and the researchers concluded "most terminal events listed on death certificates for which Lyme was the underlying cause of death were inconsistent with the well characterized complications of Lyme disease," leaving only one death record standing as Lyme disease, a conclusion reached without even conducting medical chart reviews.

Researchers have concluded that Lyme causes more pain and suffering than osteoarthritis, myocardial infarction, and type II diabetes, but they still have not left patients any recourse, denying any clinical judgment in patients who otherwise have no treatment options. Since Lyme often affects more than one family member and those at the highest risk are the most defenseless, children ages 5-9, mothers often forgo their own treatment to save their children.

These same moms may find themselves accused of Munchausen's by Proxy, a controversial diagnosis which blames parents for making their own children sick. I've advocated for parents and children whose schools accuse them of faking illness, despite reputable research showing a drop in IQ of 22 points in children with Lyme, rectified by antibiotic treatment. I have mourned with those families whose children committed suicide after leaving notes which said no one believed them to be sick, and they could not bear the pain of the disease and of the rejection.

This hearing provides a public forum for Lyme issues to be discussed before an impartial audience with the ability to initiate and implement changes. Whatever our differing viewpoints today, we all came to testify and be part of the solution. I came today as a grandmother of 4, trying to protect my granddaughters and others against the agonies of Lyme experienced by 2 of my daughters.

Yet, as I look around the room, I notice the absence of key players in Lyme, CDC, NIH, IDSA, who were invited to be part of the solution and instead chose to remain part of the problem, at the least, abrogating their responsibilities, at the worst, violating a basic tenant of medicine, first do no harm. They need to be brought to the table with patients, advocates, and treating physicians who have heretofore been locked out of the process, so that patients who suffer from Lyme can find treatment and the millions of potential victims worldwide can be spared the medical and political debacle we call Lyme disease. Thank you.

Patricia V. Smith, President, LDA July 17, 2012