

Hello,

My name is Ariel Carlson. I am 22 years old and have been dealing with Lyme disease most of my life. I would like to share my story for the Bill No. S0368. Living with Chronic Lyme disease has changed my life forever, and I would do anything it takes to help this become a more well known thing. People need to be aware and doctors need to help. People, including myself shouldn't have to live the way we do.

When I was in 7th grade was when I was first diagnosed with Lyme disease after I was bit by a tick on a camp hiking trip. I went to the doctors where I was given medicine for 4 weeks and was told that would be all I needed to do. A few years later, as a freshmen in high school, I started to become very ill; chest pains, trouble breathing, dizziness, heart palpitations, trouble concentrating, remembering things, constantly catching every cold/sickness that was going around, etc. I saw every doctor there was and did tests after tests, being told by every doctor that they could not find anything, that nothing was wrong with me, and that it was all in my head. I had to stop lacrosse, a sport I loved so much, because I was in to much pain. I couldn't live normal, 14 years old and every doctor telling me there was nothing they could do and that I was fine, when I knew I wasn't. I started to lose hope and become very depressed. Finally, after a year later, my mom came across chronic lyme disease, got me an appointment with Dr. Jones, and it was confirmed, I had chronic lyme disease. Though I was finally getting medicine and it was helping, I was still sick for my whole 4 years of high school. My junior year I had to be home schooled for 3 out of my 5 classes cause I had to miss so much school. I was not able to live like a normal teenager.

Though I know what I have, it's still hard. I have to see doctors that can't accept insurance and buy medicine that costs hundreds of dollars. I'm not suppose to eat sugar, I shouldn't drink or have caffeine. I'm tired all the time, but I can't sleep at night, I have short-term memory problems and other cognitive problems. I get sharp pains all over and all my joints and overall body hurt so much there are times I can barely walk or hold anything. The worst are the chest pains, sometimes so bad I feel like I'm having a heart attack. Since I have had it for so long I have learned to hide my pain and my problems from people very well. I don't like sharing it most of the time because people tend to have no idea what Chronic Lyme Disease, and when I tell them what I go through, they look at me crazy at times. People don't believe me when I tell them whats going on, or don't understand that sheer pain I'm in and think I'm faking it to get out of things.

From everything I have had to deal with, I have developed depression and anxiety. I blame myself for my parents financial problems cause of how much they had to spend on me, and now, at 22 I'm having to figure out ways of paying for it all myself. I tried to move to Florida to be able to live out on my own, and because of this disease I have to move back due to my relapse. There are no doctors down there to help me, and I afford to travel back and forth. There are periods of time when I feel better and then it just comes back, and worst then the time before. I start to lose hope at times that I may never live the life I work so hard to deserve.

I grew up faster than I wanted, and I even though I know how to deal with what I have, I still can't do things like go out long nights with my friends, or be as physically active as I would like.

I'm tired of living this life where people don't understand. I'm tired of people comparing my disease to something they have that they feel is worse cause they don't understand what I go through, or hearing people say I'm faking my problems. No one should have to deal with this. Thousands of people are effected by this disease, its time people start realizing this is a problem. This is only a brief summary of the life I live, but the reality is it's worse than I can put into words. Hearing other people's stories helps me at times because I know I'm not alone, but it still breaks my heart. How could so many people have this disease, be suffering as much as we are, and yet still we are "making it up". How can people not see there is a problem, and that it needs to be solved.

I wish I could be at this hearing and could be able to share my story in person but because I live in Florida currently I cant, but as soon as my mom told me about this, I felt I needed to share. I am proud of myself for how much I have dealt with and how much I have grown up, but this is not they way I wish I had. I am still young and I do not want to spend the rest of my life spending hundreds and thousands of dollars on doctors and medicine cause insurance doesn't want to help me. I want to be able to live my life and live with the disease, and not let it control my life. I want to live happy and pain free, and have hope again.

Please send me a confirmation that you have received my story.

Thank you,  
Ariel Carlson