

Lyme WNY asked Lyme Warriors to share their feelings or thoughts regarding Lyme, these are their words...

"I don't share my struggle with Lyme with most family and friends. It's tiring to have to defend myself or feel I'm not believed. I'm not having particular symptoms because "I'm getting old" or starting menopause. I don't forget things "because everyone forgets things". I forget things because Lyme has affected my brain and cognitive skills. Please don't minimize my disease. It hurts me. Instead educate yourself before deciding that you know what my problems are or the solutions to them. Our just tell me you love me and support me no matter what."

"It feels like monsters have taken over and are shutting down your brain and body, cell by cell."

"Invisible illness doesn't always show people how you feel, sometimes you need to tell people how you feel".

"Helpless, burdensome, isolated from being house ridden, extremely forgetful, hopeless dismissed, insane, liar disabled, hopeless, poor, pitied, misunderstood, exhausted."

"Like my muscle spasms will never end and I may be wheelchair or walker bound forever. Like a 100 year old disabled person stuck in my 30s"

"I had breast cancer at 40, a stroke at 47 (caused from Lyme and TBD), nothing could prepare you for the dark journey of battling Lyme and Tick Borne Disease."

"It feels like I am underwater. Always struggling to reach the surface but never making it there. Frequently it feels as though I am being pushed deeper and deeper into the water and there seems to be no way out."

"Feels like my bones are breaking on the inside. I hate being stuck home with a picc line in my arm. I don't ever feel like myself anymore."

"IMAGINE YOUR WORST HANGOVER, PLUS JOINT PAIN, FOR YEARS."

“Lyme disease will humble you. The suffering can be immense and the lack of knowledge is frightening but I'm grateful that there is now a strong Lyme community in WNY where we support and advocate for each other.”

“People keep saying stay strong and hang in there. Sometimes you don't know how strong you can be, with the amount of pain it can cause. But having a great support system helps, a lot! It's not an easy disease to cure and it takes a lot of time and patience.”

“Living with a set of miserable symptoms is difficult enough. What makes matters worse is family and friends don't understand because we don't look sick. Some of the medical community doesn't believe in chronic Lyme disease even though they believe in other illnesses that fit the exact same symptoms and have no test”

“You really learn who your friends are even a few years after you and your daughter are diagnosed! It's all about how you "don't look sick"!

“It has taken away being 14, 15, and 16. I don't want to be defined by it. But it controls my body. The stress of school sometimes throws me under the bus no matter how hard I try to rise above it. I do daily injections I have for over 15 months.... and they hurt. I take 34 pills a day. And while I'm better than a year ago, I miss my health. A lot.”

“It robs you of your mind, the pain in my ribs, my back, my eyeballs ... no pain meds helped. We tried everything. I didn't want to live. It has taken away my sophomore year of school and most of this one, too. I can't work out or play sports with my friends because every time I try, I end up in unbearable pain and that leads to other things... constant nausea, excruciating light sensitivity... I don't wish this on anybody. And more than anything I wish someone would've told me that Lyme existed and how to prevent getting it. I have good days. But it's not the life anyone wants.”

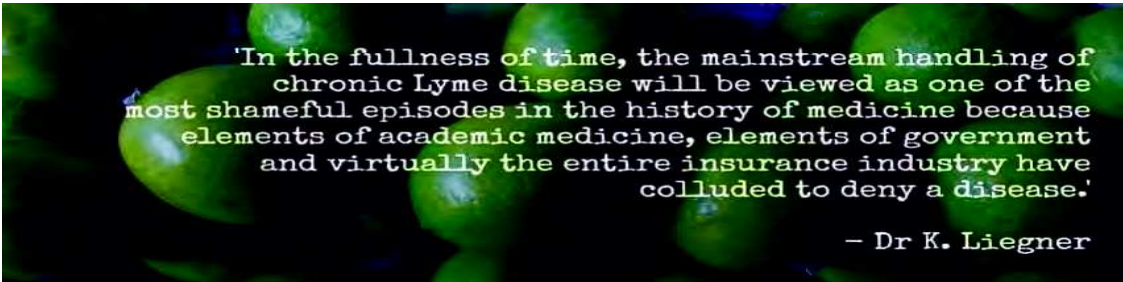
“You often hear “What, you are still on meds? You look good. Must be the Weather. You travel where? You didn't beat that yet? “

“Lyme disease is a crippling, debilitating and very painful disease that is grossly misunderstood and misdiagnosed often! It knocks you off your feet for years if not treated properly immediately! You feel alone when you have it and increasingly become angry because doctors don't know how to help you nor believe you! A horrible disease!”

"Lyme Disease is like drowning in an ocean. Every time you think you've survived the worst of it, another wave clobbers you and sends you under water. You find yourself disoriented; Everything is hazy. You're no longer sure which way is up to the surface. I used to think that Lyme Disease wasn't so bad, and that maybe it would just go away on its own. In actuality, if Lyme is left untreated, it can rob you of life and happiness. You'll find yourself in a downward spiral, never able to break away from the nightmare that has become your reality."

"I was eight years old when I got sick. 74 blood tests, MRI's, EMG's, skin testing, neurology, nephrology, general surgery, Urology, endocrinology, neuromuscular. All these well educated people, reviewing my symptoms, reviewing my tests results. Do you know that out of all that testing, only five things came back positive? Lyme IGM +23KD +41KD, Elevated Sed Rate, Immunofixation Urine, white matter lesions on brain, + skin testing for non-length dependent small fiber neuropathy. Hmmmm...a positive Lyme titer per CDC guidelines, and other tests showing signs of inflammation in my body. Do you know what I was told? " you have fibromyalgia " "You feel this way because you work nights" "You feel this way because you're overweight, you need to diet and exercise"(My BMI is 25) "Lyme tests are always a false positive" "You didn't have a bulls eye, you don't have Lyme" I now have an 11 year old daughter and when asked how Lyme affected our lives....she said....it took my mom and turned her into a sick person who can't do a lot of stuff with our family. Lyme disease is real. My doctors don't believe it. I do, my family does. We are living it."

"Lyme and Babesia destroyed every ounce of my being. For a minute, I lost faith that I would continue to live while the disease process brought me to my knees. I'm no longer the person that I used to be and I suspect that will never change, but I'm looking forward to putting the pieces back together and I thank God for allowing me to live."



'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 government and virtually the entire insurance industry have colluded to deny a disease.'

– Dr K. Liegner