

My name is Kathy Rogers and I moved to Colchester, CT from New Jersey in April of 2007. Our property consists of two acres of land, open lawn surrounded by woods, which is very typical of most of the area. Having come down with Lyme Disease about 10 years ago in New Jersey and being successfully treated by a wonderful Lyme Literate doctor, I am very aware, as well as careful, concerning methods to discourage ticks on our property, as well as on my person. We keep our grass mowed, have our property sprayed regularly, we keep shrubbery trimmed, leaf litter down, avoid bird feeders to discourage mice.....all the recommended methods are followed. Our dog is treated with a topical anti-tick and flea oil and she is not allowed to run in the woods. We also avoid walking in the woods, sticking to the open trails, while wearing proper clothing and spraying ourselves with insect repellent.

This actually doesn't sound like the optimal summer fun does it. And I state that as a fact, not a question. But I have found that you **don't** want to contract Lyme Disease in the state of Connecticut!! And I tell you all of this because, in spite of all our precautions, I did come down with Lyme Disease in Oct. 2010 and I am now in a wheelchair struggling to regain my life! And I found that finding a doctor to treat, much less understand Lyme Disease is almost impossible in this area.

After suffering persistent arthritic like pains in my knees, I went to to my primary doctor who wouldn't consider Lyme because I didn't have a rash. (I didn't have a rash when I had it in New Jersey either. Not everybody does!) Fast forward to the time I finally ended up being taken to Hartford Hospital as all the feeling and sensation suddenly left my lower body from the pelvis down and I was left unable to walk. It was as if I was given a spinal block! I was in Hartford Hospital for a month as they tested me for everything known to mankind, except for Lyme Disease, which my husband and I begged them to do. That's what we felt very strongly had caused this. They consistently refused to do this. I was eventually diagnosed with Cauda Equina Syndrome, caused by "a virus of unknown origin" that hit the lower spine. They told me that while the virus had not permanently damaged the spine, it had caused all the nerves to go dormant and I would have to wait and see if the nerves would ever regenerate, a process that could take two years or more. I had gone quite suddenly from a vital, active person to one who is dependent and has to use a wheelchair. I struggle everyday with physical therapists, learning to walk again and going through the pain of regenerating nerves. It's not easy.

But why is my story important? It's important because when I was in the hospital undergoing one test after another, I had the strong feeling that we were dealing with Lyme Disease. Even as I begged them to just test for it, they held fast to their belief that it wasn't Lyme, even as every other test for other diseases came back negative. They couldn't figure out what I had and they still didn't want to consider Lyme Disease! The doctors obviously had little knowledge or experience as to what Lyme Disease could do. My husband and I finally forced the issue and they took the standard Lyme test, as well as a spinal tap, which they told me both came back negative. I had to take their word for it at that point, but I had my misgivings, because I was very well aware of the unreliability of the standard Lyme tests. As they continued to test me for other diseases that continued to come back negative, I insisted that they send a sample of my blood to IGenex Laboratories, in Palo Alto, California, the premiere Lyme testing facility in the country. They do nothing but study and test for Lyme disease and

Lyme co-infections and diseases. My neurologist was very much against this, but my husband and I insisted and we paid for it.

Unfortunately, when the test came back, my neurologist didn't know how to read and interpret the results and told me that the test had come back negative. When the test was sent away, I had told him that IGenex had doctors on staff to help doctors unfamiliar with these tests, to interpret the results, but he told me that he didn't need any help interpreting a test. At the time, I did take his word for it that the test had come back negative. I was just too sick at that point.

After a month in Hartford Hospital, I went to two rehab hospitals, before I was finally home again after three months. Nobody could tell me what I had, just the same vague diagnosis, a virus of unknown origin had entered the spine. But after being home a couple of months, I finally decided to call IGenex Lab myself and speak to a doctor there. I just had an uneasy feeling that my doctor misread the test results. I spoke to one of the doctors on staff there, who looked up my records and immediately said, "Of course you have Lyme Disease. It's right here in the test. I would advise you to find yourself a Lyme/Literate doctor and get yourself treated." I was shocked! I told him my story and asked him if my current condition could be the result of Lyme Disease and he said most definitely. It was very difficult to find a doctor who treated Lyme Disease and that also dealt with my insurance, but I'm sure you know that's another problem with the whole Lyme disease situation! But I was successful in finding one, who when she looked at my test results from IGenex, said "Of course you have Lyme Disease!" I thus began a lengthy treatment for Lyme, after which I was retested and finally tested a true negative.

I decided to tell my story because I am so aware of how important it is to push for accurate and reliable testing for Lyme Disease. The tests that are currently being run by the majority of doctors are woefully inaccurate and unreliable. This is the state where Lyme Disease got its start and it's incredible that most doctors in this state have very little practical knowledge on how to recognize it, must less test for it. Something needs to be done before we have a state full of citizens in wheelchairs, wondering just how they got there, with their doctors wringing their hands in confusion, ignorance, I don't know what.

I would suggest that if a task force is established to study Lyme Disease testing, which I hope that it will be, that one of the first things on the agenda should be to talk to a representative of IGenex Laboratories in California. I know they travel out to Connecticut for seminars and things. Please talk to them and find out what needs to be done to properly test for Lyme Disease and Lyme Disease co-infections. People have to be aware. And doctors have to step up.

Meanwhile, my nerves continue to regenerate, slowly and painfully. I continue to learn to walk again. I'm determined to do it and recover fully. But I will never put myself at the mercy of unknowing doctors and inaccurate testing ever again. Thank you for reading this and considering what I have to say.

This is a very important issue!