

Liesl's Story



Liesl Wilke

I first heard the term Chronic Lyme in 2010. I had just seen my first Lyme specialist after spending several years gracing the halls of practitioners too numerous to count, from psychiatrists to allergists to orthodontists. I saw sleep specialists. I saw ENTs. I took up

yoga and pilates, gave up dairy, alcohol and sugar. I gave myself shots of B-12, tried IVs of vitamin C and glutathione, the newest antiviral drugs, a wealth of mood enhancers, all the usual antibiotics for the sinus infections I'd contract regularly, then antifungals to correct the balance I'd just undone. I tried all these things because I was desperate. I had lost the ability to live a full life, plagued by exhaustion, pain and loss of brain function (I couldn't concentrate, retrieve short-term memories, put together sentences without great effort). I had bizarre drops in blood pressure, dizziness, depression, nightmares, fevers, joint pain. All of it coming and going, moving and changing, but never, alas, relenting.

So when I was told I had Lyme Disease, I was actually thrilled. Now I knew! I wasn't crazy. I had something treatable. It might take years, I was told, but I would get better. It's been almost four years now, and I am not better. I'm not worse. I'm not dead. But I'm not ready to give in either. So, what's to be done? What do I not know? The answer to both is the same: A great deal.

I appreciate that my current doctor can acknowledge that we just don't know exactly what's wrong with me. We're working with inadequate testing and a complicated set of symptoms. On this, everyone seems to agree. But why do some of us have these lingering problems years after infection? Are we still infected? Is there an autoimmune syndrome at work that's not fully charted? Is it worth taking years of antibiotics when we don't know if they will help?

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I heard about ISB through a Lyme doctor in Seattle who was frustrated with medicine's inability to answer these questions and prodded me to go and see what systems biology was all about. I remember leaving after my first tour of the ISB facilities and feeling profoundly hopeful and inspired. Here was an entirely new way of looking at disease. Was it possible to cut through the political stalemate in the medical community about late-stage or chronic Lyme? Even better, to simply ignore it and apply new technology to the problem, changing the entire conversation? I called my husband and told him to set aside some time. He had to hear what ISB was doing. And once he did, we both knew that if we could get ISB interested in Lyme, big things would happen. And it's interesting – I don't have any idea whether or not the work ISB will do around Lyme will benefit my medical condition in any way, and I don't care. I want the information, the knowledge, the looking forward. We humans

are host to and sometimes opponents of a multitude of organisms. The idea that we will collectively learn better how the systems of our bodies work, in disease and in the absence of disease, is enticing, and that of actually lessening the suffering of the people we care about no less than thrilling. I don't like to whine more than necessary,

but in this case it's important to share that my life has been crippled by this disease. I was an active mother, a writer, an artist, and now I'm frequently bed-ridden and have narrowed the scope of my life sometimes with grace and patience, but more often with frustration and sadness. And I'm not alone. Not a week goes by that I don't hear about someone who's very ill with something that might be Lyme and can't seem to get better. None of these people want to give up, and neither do I.

So, here's to ISB and to the future. May we learn, flourish and celebrate the best science has to offer. There's a great void of knowledge in the world of Lyme. I believe that only the biggest, most elegant computational science can fill it, and ISB is uniquely positioned to do just that.