

Dear Lyme WNY Supporters,

I wanted to thank each and every one of you for attending this walk today, in support of "**Stomping Out Lyme**". The cause that is so near and dear to our hearts.

Our journey with Lyme disease began on August 26, 2013 when we received a phone call from the nurse at my husband's doctor, and she said, "your husband has tested positive for Lyme disease". My response was quick. "What do we do now? Who will help him?" Her response was just as quick, "Nobody"silence.

I remember this phone call as if it happened a moment ago. A part of us was so relieved because we had an answer, no more tests, no more scans, no more bloodwork, no more confusion, no more unknown, but in reality, our journey with Lyme and its co-infections had just begun. We went through a very difficult time trying to find doctors, in the Buffalo area, that would help us. Luckily, we found a local doctor who provided initial treatments. We soon learned that once Lyme becomes chronic it is often ignored and you are lost. In time, this doctor told us that his knowledge regarding long term treatment for this disease was limited. With this, we continued our mission, a mission to get my husband the healthcare, medication and treatment he needed and deserved. I scoured the internet for information, made phone calls, and cried. We were desperate for help. Our lives were turned upside down. Through these efforts, we learned that Lyme was not as uncommon as we thought. I began to meet people who also had Lyme who didn't go for just weeks undiagnosed, they went for 3-months undiagnosed, for 3-years undiagnosed, for 30-years undiagnosed. Not only undiagnosed or misdiagnosed, these people, who are around you today, also had to fight, fight for treatment, fight for help and fight to survive. Through our persistent search, and meeting others, we were fortunate to be referred to a doctor in Pennsylvania, who was a Lyme Literate Doctor, who has since provided my husband the treatment he needed and has now, for the past 3.7 years.

In April of 2016, during a quick stop at a local store we ran into another Lyme patient, Stephanie Szymanski who related her own personal story. This is when my husband and I decided this was not right. We decided then and there that we needed a collective voice and mutual support, and Lyme WNY began. Our group quickly formed, starting out with just a hand full of people and now, over the past several months, many dozens of Lymies also desperate for help and support have joined our group

Lyme and its co-infections are difficult to treat and they are not curable. Many of the Lymies you see here today travel across state, and out of state, to get the treatment that they need and deserve. Unfortunately, insurance does not typically cover long term Lyme treatment and many of the Lymies have payed thousands and thousands of dollars to get proper care, treatment and medicine. Your time, money and dedication to this cause is going to help many get the proper treatment they deserve. In addition, our mission is also to continue to educate others on the prevention of Lyme, what to do if you get Lyme, and to change local laws to ensure that patients are treated and covered here in Buffalo, NY. We will continue to support one another with our monthly meetings.

I only wish that nurse I spoke to on the phone exactly 3 years and 7 months ago could see us now. We do have somebody, we have each other, and we have you. **WE ARE NO LONGER IN SILENCE.**

Thank you for your support

NOW LETS STOMP OUT LYME!



Rebecca Roll

Founder of LYME WNY