

Public Health Committee: H.B. 6200

We would like to share with you a story about our now seventeen-year-old daughter. She became ill at the end of her 3rd grade school year. Tests were done and even though everything came back negative, we were told that she had mono, as that blood work shows many false negatives. She was 8 years old. *Now we know that Lyme blood work also shows many false negatives.* Over the next few years she became ill, mainly in the winter and had multiple testing done. In September of 6th grade she again became very ill and has never recovered. She has been on home tutoring since that time. This is a child who is an A student and loves learning. *She has missed out on her entire childhood.*

We finally had a Doctor draw the western blot blood work, which we had asked other doctors to do, at the beginning of 8th grade and this *came back positive.* *However, five long years had passed with Lyme damaging her autonomic nervous system. She had developed Dysautonomia, which has caused her to become basically homebound. In her case, she has postural orthostatic tachycardia syndrome, her heart rate increases dramatically every time she is in an upright position for any length of time. The Dysautonomia specialist we saw in Ohio said this was caused by Lyme Disease.* She has had severe headaches for 6 years, every waking moment. Her gastrointestinal system is involved and she has joint pain.

We are currently fighting our insurance company for a second round of IV antibiotics as the first round really gave our daughter some relief. However, after stopping them she slowly declined and her head hurts more than ever, she is having difficulty with reading and comprehension again and is experiencing ataxia. Her Lyme doctor and her cardiologist have written letters supporting the need for IV antibiotics again, but our appeal has just been denied.

We understand that Lyme is a very controversial issue in the medical field, but our daughter has been suffering the consequences of their in fighting. We applaud the legislators who are taking action to protect and assist Lyme Disease patients.

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