

FTR

Dear Senator Crisco, Representative Megna and honorable members of the Insurance & Real Estate Committee,

My name is Lynn Haber; I am a mother of a young man with PANDAS in support of SB 37.

My name is Lynn Haber, and my husband Sam and I have lived in Connecticut for 20 years and in Trumbull since 2001, when our older son Gary turned five and was ready to start kindergarten. In March of 2013, Sam and I testified in support of a PANDAS bill while our son, Gary, was residing at the state psychiatric hospital for children. PANDAS was winning; it had taken away his childhood and his normal life and he was struggling with not just severe OCD, tics, and chronic insomnia, but persistent auditory hallucinations and delusions that interfered with his functioning throughout each day and night of his life. Since then his functioning has improved in some small ways, and he is currently residing in a private, integrative group home facility in New Jersey. My husband and I continue to advocate for him in every way possible and will never stop fighting to get him well. We have been through a journey that can't be described adequately in words. Along the way, we have met many other PANDAS families who are struggling, and I have learned that sharing our story openly is the best way to help other families, especially those who have the opportunity for early treatments that could make all the difference and spare them from the long-term impairments that might follow if this is addressed as a typical psychiatric disorder rather than as the infection-triggered autoimmune illness that it is.

Gary was once a high-achieving student who won writing awards, had many friends and numerous creative and academic interests. He had a zest for life and a thirst for knowledge; knew the alphabet at 18 months, comprehended fourth grade level multiplication as a first grader, became an avid reader, and was considered a role model by his teachers. His second grade teacher began the parent-teacher conference with, "Your son is a joy to have as a student. I wish I had 25 Garys in my class!" These kinds of comments were typical of every conference throughout Gary's years in elementary school.

All of this changed when Gary contracted a strep throat during the winter of his fifth grade year. Within a couple of weeks, he was complaining of curse words and other thoughts that were stuck in his head. We brought Gary to an OCD therapist, who believed he could have PANDAS, but told us if this were the case the OCD would get better with time. But several months after the strep, two vaccines that were given during his 11-year-old checkup exacerbated his OCD and caused new and debilitating symptoms. Gary would become unresponsive and stare blankly into space for minutes at a time. In addition to these "trances," Gary developed severe motor tics, hyperactivity, and insomnia, and he was unable to have normal conversations with people. We began our long medical journey, going from doctor to doctor, getting numerous tests and trying to figure out what was wrong. One neurologist prescribed SSRI medication which ended up exacerbating Gary's symptoms and causing impulsive, reckless behavior. We later found out that in cases of PANDAS, SSRIs don't address the underlying causes and often make matters much worse. Multiple doctors and psychiatric hospitalizations followed. We consulted with leading Tourettes and PANDAS expert, Dr. James Leckman, and his Yale team, and Gary was admitted to Yale for extensive testing. Dr. Leckman referred us to a doctor at Children's Hospital of Philadelphia, who did plasmapheresis, which began the healing process. Over the next two years, we saw neurologists, psychiatrists, immunologists, integrative doctors as well as Lyme doctors since he had tested positive for Lyme, and these doctors believed that Lyme, in addition to strep, was an infectious trigger contributing to his psychiatric symptoms. There were numerous medical interventions and alternative treatments, and we saw great improvements over time. Shortly after he finished his plasmapheresis treatments in the summer of 2008, he started seventh grade and was able to attend school for a full day instead of just a few hours. He made attempts to do homework, and some of his creative interests started to come back. Slowly we began to see glimpses of the boy we knew, and with intensive tutoring, he was able to have his BarMitzvah at the end of seventh grade. It was a wonderful day and it felt like a victory over the PANDAS. Over the next year, we saw more improvements, which were the result of additional medical interventions including IVIG treatments. When Gary graduated from 8th grade he was the recipient of the Rotary Club Award for Extraordinary Progress. That year he developed a website for kids to

educate them about PANDAS, and he also wrote a personal essay about his struggles, which he titled "I've Come a Long Way." He was about 80% better. But we didn't know at that time what a long way he would fall. In the summer following his eighth grade graduation, Gary fractured his arm at camp and this triggered a major setback with his PANDAS. Symptoms continued to worsen after a growth spurt. By the spring of 2011 Gary began to suffer from delusions and in spite of many types of interventions including PANDAS and Lyme treatments and the addition of antipsychotic medication, Gary's mental state deteriorated. By the time he entered tenth grade, he was hearing voices. He became a danger to himself, and we hospitalized him at St. Raphael in New Haven. Psychiatrists there began to try higher doses of antipsychotics but nothing helped. His case was accepted for voluntary services with DCF; he received Medicaid and was transferred to the state psychiatric hospital for children. He was completely disabled with auditory hallucinations and was unable to function outside of a hospital. He would spend his days pacing and talking to himself. He could not read, write, draw, play games, do school work, or engage in normal conversations. He was on Clozaril, which is considered the gold standard antipsychotic medication for schizophrenia, but it was not helping with his very severe OCD, delusions, and hallucinations. The psychiatrists at the state hospital lacked training and experience with PANDAS and disagreed with our outside doctors who felt that the autoimmune origin and component of Gary's illness was very real. They refused to consider the kinds of treatments that our PANDAS practitioners outside of the hospital were recommending, treatments that had been helpful to Gary in the past. We were stuck and did not know what to do. Gary was not stable enough to live outside of the hospital, and the doctors treating him at the hospital refused to consider treatments that might have helped him reach that level of stability. Eventually, when Gary was close to adulthood, he participated in a study at the National Institute of Mental Health and became more stable. His creative ability, his reading, and his interest in cartooning and photography started to return. He was a long way from where he needed to be but he was stable. Several months after Gary's 18th birthday, we were able to carry out our plan to move him to the integrative group home in New Jersey, where he is today. He is finally in a residence where his doctors acknowledge the PANDAS and are willing to think out of the box and address this as the complex

autoimmune medical illness that it is. Gary has been at this facility for a year and is making some progress. We continue to try new interventions, and some of these interventions appear to be making a difference. We know we have a long road ahead of us, but we remain hopeful that with the right kind of treatments Gary will heal. We will never give up on our son and will continue to advocate for him, just as you would do for your child.

For a moment please imagine yourselves in our place as parents. What would you do if a simple bacterial infection set off an antibody reaction that acted like an assault weapon on your child's brain, taking away his or her ability to function in a normal way? What would you want from your child's doctors, your insurance companies, and your state legislators?

Many people say PANDAS and PANS are controversial disorders. But those of us who have lived it know too well that this illness is real. We mourn the child we had before it struck; we want others to imagine being in our shoes for a day, even a minute so they can understand. When we talk about PANS and PANDAS, we need to take the word "controversy" out of our vocabulary and replace it with language that is helpful and that will facilitate the opportunity for healing. Words that come to mind are "belief", "understanding", "legitimacy", and "support". One of the best ways to support our families is to require insurance companies to pay for treatments that will enable those suffering from this disorder to live the normal lives that they deserve. We hope you will help us reach that goal.

Lynn Haber
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