

Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee, my name is Deb Dirocco. I am a parent and support SB 37.

I can't even begin to explain how hard a road this has been for my son. He was finally diagnosed in 2015 with PANDAS/PANS at age 17. His doctor has confirmed he has had this since he was likely 2 years old. From age 1 1/2 he has had strep, ear infections, some OCD. At least 7 years ago I approached my pediatrician and begged her check to see if this was PANDAS since I felt he had many of the symptoms. She assured me that since he didn't have positive strep cultures, which was not what was going on in his case. Throughout his life he has suffers anxiety, phobias, skin picking, depression, strep symptoms (mostly without positive cultures), tics, movement disorders, had missed nearly 30 days of school several times during 3-5 grades, deteriorating. Handwriting. At age 5 he saw a pediatric neurologist because his father who is from Bulgaria and does not understand American medicine insisted he must be retarded or something severely wrong with him due to the tics and because he wouldn't control his bowels. Upon completion of the testing the neurologist said he had tics (Tourette's syndrome) and would either outgrow it by age 18 or not and there was nothing to do for it except perhaps give him medication given to kids with ADD although the doctor felt it would likely do nothing to stop the tics.

My son has spent the last 13 years being scolded by his father for the tics he is unable to control and mostly unaware of. As of 2016 his father and I have been divorced for 16 1/2 years. I was remarried when Nik was 3 1/2 and thankfully my husband is able to provide a loving home as well as medical insurance got Nikolas since his own father has failed to. Nik has been under the care of social workers, psychologists, psychiatrists, pediatricians, and neurologists since he was 5.

Knowledge is power and while I can't even begin to comprehend all that is going on in his body I know there are wonderful doctors who do understand this and know how to treat it. I do understand that time is of the essence especially for my son. Since this is a pediatric disease I have read there are some young adults that went undiagnosed and have no recourse in being treated and will live with the devastating lasting effects of this auto immune disease without having an ability to recover from it. When I finally filled out the paperwork for Dr. Nancy O'Hara regarding PANDAS/PANS I couldn't believe all of the boxes I had to check off and explain about his challenges throughout his 17 years. This is a smart loving boy with four siblings in our home and one in his fathers who had thoughts of suicide 2 years ago because he couldn't handle what was happening in his body any longer. Thank God he told me about it and is still here today. The psychiatrist, the hospital and the social workers have told me that since he didn't have a plan for his suicide, he most likely wasn't intending to harm himself. Well, any of you who have children just think about that for a moment... He probably wasn't going to go through with it... Is that ok with you? Can you imagine your child saying that to you? I will ever un hear the words as long as I live "mom I've been thinking of killing myself because I just can't go on like this anymore." (How many kids have gone through with it because if PANDAS/ PANS?)

I am terrified to be outside of a few mile radius of him. He has constant panic attacks at school and will either text me from the bathroom or the nurse's office. Mostly due to oral presentations at this point but sometimes it's just from situations that occur and he cannot stop himself from a trigger that will affect him. I have learned at least to work with people who have knowledge PANDAS and it's effects instead of taking him to psychologists who think it's OK to charge \$200 for 45 minutes to tell him he needs to stand up for himself and get over it. I can't imagine the help I can offer my son if insurance would cover the treatment of PANDAS/PANS. I have struggled financially for years but have found a way to get him treated recently once we have had some answers about this disease. He is now 18 years old and while most of his peers are deciding where they will go to college next fall he is still taking months of antibiotics for strep infections because anytime anyone is sick around him he gets reinfected. To date Nikolas has not decided what he feels he is capable of doing next year. He wants to continue his education and likely become a sports trainer at a high school or a physical therapist. His doctor has informed us that due to his PANDAS going off to a college campus maybe so overwhelming and difficult for him to handle him that he should consider only local schools where he could commute to. He is terrified to drive and despite his father's extreme dislike of this decision Nicholas has realized he is incapable of driving at this time since he lacks the reaction time necessary to drive safely. He is a talented and dedicated athlete who has just completed his senior year of football (he played tackle football for the last 7 years), plays Rec basketball currently and suffers from

terrible anxiety takes and social insecurities. He gets through every day but how much better could his quality of life be if I could offer him every treatment available for his condition. I don't know and may never know what Nik's perfect day symptom free day would be like since it hasn't happened since before he was 2 years old. I am his biggest cheerleader however I don't have the financial ability to give him everything available since it must come out of pocket and be reimbursed. At this point we have had to discontinue the cognitive behavioral therapy and could not begin the Neurofeedback therapy that might help him due to financial strain.

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