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# NEW ENGLAND PANS/PANDAS ASSOCIATION

Testimony for SB 37

[www.nepans.org](http://www.nepans.org)

Testimony Submitted February 17, 2016

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

My name is Gabriella True; I am President of New England PANS/PANDAS Association, I sit on the CT PANDAS Advisory Council to the DPH, help run CT PANS PANDAS Partnership and am a mother of an eleven-year-old boy with PANDAS in support of SB 37.

Children and young adults with PANS/PANDAS are truly sick and urgently need insurance coverage. PANS/PANDAS, if untreated comprehensively and immediately, can lead to devastating and often permanent chronic illness that affects patients both physically and mentally. The longer patients with PANS/PANDAS are left untreated the more symptoms can exacerbate which only places greater and continuing strains on not only the insurance system but also the mental health system and the educational system. Many of the patients who were originally treated by the NIH are now 15 to 20 years old and are symptom free and healthy. There are some patients who no longer have symptoms but are on continued antibiotics to control flares from exposure to Group A strep. These children would have had much different lives if this devastating illness had not been treated correctly.

The National Institute of Mental Health (<http://www.nimh.nih.gov/health/publications/pandas/index.shtml>) and the PANDAS Physicians Network (<http://www.pandasppn.org>) have developed a standard of treatment options, which encompass a range of therapies and medications dependant upon the severity of PANDAS symptoms. These include IVIG, plasmapheresis, prophylactic antibiotics, cognitive behavior therapy (CBT), as well as a few other treatments. However, families are not able to consistently secure insurance coverage for these needed treatments. Thus, families have to carry a financial burden by paying out of pocket for doctor visits and often-expensive treatments or they face the staggering future of watching their child get worse and deteriorate before their eyes.

Last year I provided testimony in which I spoke in depth about my son's struggle with PANDAS and how the financial burden of paying for treatments has been acute and has put a strain on the entire family but the idea of not treating him, not helping him and watching his symptoms become so severe that I was afraid he would need to be institutionalized was suffocating. I want to be clear that I am far from the only parent who has had their life completely consumed with how to get treatment for their child. On a daily basis, I connect with countless families with children who are suffering from PANDAS. I wish I could have rallied every single one of them to write testimony and come speak at the public hearing. It would surely be staggering and sobering for you all to read and hear. Every one of them fears the future. Every one of them fears not being able to access proper health care. Every one of them is struggling. Every one of them desperately needs insurance coverage so the children don't suffer a lifelong debilitating illness.

Connecticut must support these sick kids now or everyone will face a bleak future. Myself, New England PANS PANDAS Association, The Connecticut PANS PANDAS Partnership and the families within the community truly appreciate Senator Crisco and Representative Megna along with members of the Insurance & Real Estate Committee for continuing to be a champion of the PANDAS community. We thank you for the time and effort you put into working towards a brighter future for children in Connecticut with PANDAS.

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There is a similar bill put forth by the Illinois General Assembly; I hope you will pass SB37 and ensure that Connecticut stays at the forefront of mandating insurance for those who so desperately need it so they will have a healthy and productive future.

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