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NEW ENGLAND PANS/PANDAS ASSOCIATION

January 23, 2014

New England PANS/PANDAS Association

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Attention: Doctors and Connecticut Residents!

CT RESIDENTS & ANY DOCTORS PLEASE WRITE TESTIMONY IN SUPPORT OF SB 15 TO MANDATE INSURANCE TREATMENT IN CONNECTICUT

The Conn. Insurance and Real Estate Committee, led by CT State Senator Joe Crisco, has introduced a bill to require health insurance coverage for PANDAS in CT. *The public hearing is January 27, 2015 at 1:00.* If you plan on attending, please note that this is the 5th out of 6th bill on the agenda so we don't know at this time what time testimony will start for this bill. *Testimony is due by Monday, January 26 before 12:00pm.*

It is important that people submit individual testimony on this bill. Your testimony will help inform legislators and become public record that can be referenced for future use. In your testimony, it would be helpful if you explained what the impact is on your child or your patient and what problems result if they do not have proper insurance coverage for PANDAS. If you have submitted testimony for a previous similar bill, please submit testimony again. It is essential to submit your testimony to the Insurance and Real Estate Committee as well as to your Legislators.

About NE PANS/PANDAS Association

The New England

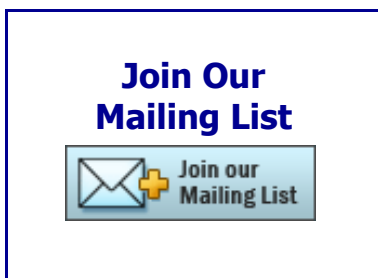
PANS/PANDAS Association is a group of parent volunteers from various states across the New England focused on raising awareness of Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS), also known as Pediatric Acute-onset Neuropsychiatric Syndrome (P.A.N.S.).

Our mission is simple:

- * To raise awareness of PANS/PANDAS in our community and beyond
- * To support the medical community in their mission to heal our children suffering from PANS/PANDAS
- * To look for ways to expand the medical care available
- * To create opportunities to assist families searching for solutions

Board Members:

Robin Ahlgren, Peter Capraro, Margaret Chapman, Michele Danubio, Melissa Glynn-Hyman, Lisa Grisolia, Lisa Hart, Emily Klein, Tiffany Maxwell, Kim Panton, Beata Takahashi, Laura Tedeschi, Gabriella True, Jennifer Vitelli, Jennifer Whelan



What is PANS/PANDAS?

Please note that in the past, the health plans, insurance associations and the business trade groups and their lobbyists routinely submit testimony against ALL insurance mandates that may raise premiums so we need to get our message in front of them. It is uncertain if this bill will pass, as there is an associated cost that is difficult to determine due to not knowing how many individuals in Connecticut have PANDAS, a number from which actuaries set their rates.

Please submit your testimony by Monday, January 26 before 12:00pm. The NE PANS/PANDAS, CT Chapter will be collecting testimony and forwarding to the Insurance & Real Estate Committee as a whole.

Submit Testimony by Monday, January 26, 2015 by 12:00pm

NE PANS/PANDAS, CT Chapter (will make copies & forward to Insurance & Real Estate Comm.):
ctpandas@gmail.com

Find your Legislators:

<http://www.cga.ct.gov/asp/menu/cgafindleg.asp>

Public Hearing Date:

January 27, 215 at 1:00pm, Room 2D, Legislative Office Building
 Directions: <http://cga.ct.gov/html/citizen/DrivingDirections.pdf>

Questions Regarding SB 15:

Jim Carson, CT. State Legislature & Parent
jim.carson@cga.ct.gov

Bill Status Link:

http://www.cga.ct.gov/asp/CGABillStatus/cqabillstatus.asp?selBillType=Bill&bill_num=SB15

Committee Bill:

<http://www.cga.ct.gov/2015/TOB/S/2015SB-00015-R01-SB.htm>

Example of How to Format Your Testimony

CT General Assembly
 Insurance & Real Estate Committee Public Hearing

Testimony in **Support of SB 15, AAC Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections.**

By **YOUR NAME HERE**
 Submitted **DATE**, 2015

Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee. My name is **(YOUR NAME HERE)**, I am a **(YOUR CONNECTION TO THIS ISSUE, PROFESSIONAL DEGREES, RESEARCH, etc.)**

P.A.N.D.A.S (*Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections*) and **P.A.N.S.** (*Pediatric Acute-onset Neuropsychiatric Syndrome*) are terms used to describe a subset of children and adolescents who experience an encephalitic-like onset of neuropsychiatric symptoms following an infection such as Strep, Pneumonia, and Mononucleosis.

In simple terms, antibodies created to fight the infection become misdirected and attack a small area of the brain known as the basal ganglia. This autoimmune reaction results in an acute onset of neuropsychiatric symptoms that can include: separation anxiety, OCD, tics, age regression, sleep difficulties, personality changes, urinary frequency, irritability, rage, sensory sensitivities, deterioration in learning abilities and anorexia.

in support of SB 15.

(PLEASE EXPLAIN THE IMPACT/PROBLEM OF NOT HAVING HEALTH INSURANCE COVERAGE FOR PANDAS.)

(PLEASE EXPLAIN HOW INSURANCE COVERAGE WOULD BE BENEFICIAL.)

(YOU CAN ADD ANY ADDITIONAL SUGGESTIONS TO EXPAND ON THIS BILL.)

Conference Videos

Videos from Past Conferences



New Hampshire Education Conference - October 2014

Videos Available: Peggy Chapman, Dr. Trifiletti, Dr. Thompson, Dr. Hardy, A Story of Recovery, Q&A Panel

<http://nepandasparents.com/events/2014fallnhevent.html>

Connecticut Chapter Education Conference - November 2014

Videos Available: Dr. O'Hara, Dr. Leventhal, Dr. Trifiletti, Q&A Panel

<http://nepandasparents.com/events/2014fallctevent.html>

Doctor Breakfast with National Specialists - April 2014

Videos Available: Dr. Swedo, Dr. Latimer, Dr. Cunningham, Dr. O'Hara, Dr. Pasternak

<http://nepandasparents.com/videos/2014drbreakfastvideo.html>

Parents Q&A - April 2014

Videos Available: Dr. Cunningham, Dr. Nancy O'Hara, Specialists from Coram CVS Specialty Infusion Services

<http://nepandasparents.com/videos/2014parentsqavideos.html>

Rhode Island Education Conference - November 2013

Videos Available: Dr. Swedo, Dr. Latimer, Dr. Trifiletti, Dr. Bock, Dr. Walter, Peggy Chapman, Dr. Hubbuch, Dr. Micco

<http://nepandasparents.com/videos/2013conferencevideos.html>

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