

Having trouble viewing this email? [Click here](#)

NEW ENGLAND PANS/PANDAS ASSOCIATION

January 25, 2014

New England PANS/PANDAS Association

In This Issue

[~Att: MA Residents](#)

[~Att: Doctors & CT Residents](#)



Follow Us On Facebook



Attention: Massachusetts Residents!

MA RESIDENTS

Docket Number HD 343:

An Act Relative to Insurance Coverage for PANDAS/PANS.

PLEASE CONTACT LEGISLATORS TO

MANDATE INSURANCE TREATMENT IN MASSACHUSETTS

Contact Us

NE PANS/PANDAS Assoc

PO Box 1315
Duxbury, MA 02231

Website

[NE PANS/PANDAS Assoc.](#)

Email

info@nepandasparents.com

We hope to re-file our insurance-related bill **Docket Number HD 343: An act relative to insurance coverage for PANDAS/PANS.** Due to the success of our bill during the previous legislative session, we are guaranteed a CHIA (Center for Health Information Analysis) review. This is a HUGE hurdle for any insurance mandate.

The deadline for co-sponsoring Representative John Scibak's legislation is this Friday, January 30th, so we have less than one week to get this done!

As of right now, we have the following co-sponsors:

- Rep. Josh Cutler*
- Rep. Carolyn Dykema*
- Rep. Angelo Puppolo*
- Rep. Peter Kocot*
- Rep. James Dwyer*

Join Our Mailing List



Conference Videos



CT Conference - 11/14

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

NH Conference - 10/14

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

Doctor Breakfast - 4/14

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

Parents Q&A - 4/14

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

RI Conference - 11/13

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

Last session, we had 17 co-sponsors so we still have a long way to go. The following are co-sponsors from the last Legislative Session who have, not yet, signed on for co-sponsorship. Please contact them and urge them to sign on again. Anyone can contact these legislators, but the message is particularly strong if you are a constituent.

Rep. Tom Calter (12th Plymouth-Kingston, Plymouth, Plympton, Duxbury, Halifax, and Middleborough)

Rep. James Cantwell (4th Plymouth-Marshfield and Scituate)

Rep. James Murphy (4th Norfolk-Hingham and Weymouth)

Rep. Ellen Story (3rd Hampshire-Amherst, Granby, and Pelham)

Rep. Walter Timilty (7th Norfolk-Milton and Randolph)

Rep. John Lawn (10th Middlesex-Newton, Waltham, and Watertown)

Rep. Marjorie Decker (25th Middlesex-(Cambridge)

Sen. Karen Spilka (2nd Middlesex and Norfolk-Ashland, Framingham, Holliston, Hopkinton, Natick, Franklin, and Medway)

Sen. Sal DiDominico (Middlesex and Suffolk-(Cambridge, Everett, Boston, and Chelsea)

Sen. Stan Rosenberg (Hampshire, Franklin, and Worcester Counties)

We've also lost three co-sponsors due to changes in the Legislature. Please call to urge their successors to also sign on to the bill:

Rep. John Keenan (7th Essex-Salem) replaced by Rep. Paul Tucker

Rep. Steve Walsh (11th Essex-Lynn and Nahant) replaced by Rep. Brendan Crighton

Rep. Rhonda Nyman (5th Plymouth-Hanover, Norwell, and Rockland) replaced by Rep. David DeCoste

The following is a link to names, email addresses, and phone numbers for members of the Massachusetts Legislature. Please feel free to call the above legislators to thank them for their support, but more importantly make sure you call the other representatives that have not yet signed onto the bill. While we have been told that there is no direct correlation between co-sponsor numbers and the final disposition of a bill, every additional legislator that signs on is one more informed politician that will help us to build the momentum to put the control of our children's medical treatments back in the hands of our dedicated PANDAS/PANS doctors and out of the reach of insurance companies.

Find Your Legislators:

<https://malegislature.gov/People/Search>

Example of How to Format Your MA Testimony

If you are interested in having your friends, family, or colleagues write a quick email to their local representative, feel free to use/tweak the following template letter. However, we have found that a phone call is a much more powerful tool. Ask to speak to the Legislative Director or the staffer that handles health-care related issues.

Dear Representative _____

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

**Join Our
Mailing List**

Representative John Scibak of the Second Hampshire District has filed the following bill for the upcoming legislative session. This bill addresses insurance coverage for children affected by PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcus infections) and PANS (Pediatric Acute-Onset Neuropsychiatric Syndrome).

Docket Number: HD 343: An Act relative to insurance coverage for PANDAS/PANS

I would greatly appreciate your co-sponsorship of this important bill. By co-sponsoring this bill you will help children and their families struggling with this disorder by providing them with the opportunity to pursue the therapeutic recommendations of their doctors. Currently, many of these children are denied access to IVIg (Intravenous Immune Globulin) and other therapies by insurance companies more concerned with bottom-line profits than providing doctor recommended therapies. Sadly, this creates a situation in which families are forced to choose between their children's health and financial ruin.

According to the National Institutes for Mental Health

"PANDAS, is an abbreviation for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections. The term is used to describe a subset of children and adolescents who have Obsessive Compulsive Disorder (OCD) and/or tic disorders, and in whom symptoms worsen following strep infections such as "Strep throat" and Scarlet Fever."

Recent research at NIMH has led to an expansion of the original PANDAS criteria and the subsequent use of the term PANS:

"PANS is a newer term used to describe the larger class of acute-onset OCD cases. PANS stands for Pediatric Acute-onset Neuropsychiatric Syndrome and includes all cases of abrupt onset OCD, not just those associated with streptococcal infections. "

If you would like more information regarding these disorders, please visit the National Institute for Mental Health's (NIMH) website at

<http://intramural.nimh.nih.gov/pdn/web.htm>

Thank you for supporting this important piece of legislation.





What is PANS/PANDAS?

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.

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.

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.):
ctpandaspan@gmail.com

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

Public Hearing Date:

January 27, 2015 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/cgabillstatus.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 CT 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.)** 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.)

Forward this email

This email was sent to kim@rockpaperscissors.com by kim@nepandasparents.com | [Update Profile/Email Address](#) | Rapid removal with [SafeUnsubscribe™](#) | [Privacy Policy](#).



NE PANS/PANDAS Association | 45 Depot Street | Duxbury | MA | 02332