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# NEW ENGLAND PANS/PANDAS ASSOCIATION

January 27, 2014

## New England PANS/PANDAS Association

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[info@nepandasparents.com](mailto:info@nepandasparents.com)



**BROWN**  
Alpert Medical School

**SAVE THE DATE!**

**PANS, PANDAS, and Acute-Onset Neuropsychiatric Syndrome**

*Clinician Only Continuing Medical Education Track: March 14, 2015 - 8:00AM-4:30PM*

*Parent Update Track: March 15, 2015 - 8:00AM-12:00PM*

Providence, RI



Image courtesy of Stuart Miles at FreeDigitalPhotos.net

Warren Alpert Medical School of Brown University  
CME Conferences on PANS, PANDAS, Acute-Onset  
Neuropsychiatric Syndromes - Clinician Track

### Physician & Healthcare Provider CME Track

**March 14, 2015**

**7:00-4:30 - Registration to Close**

#### Program Description:

There is increasing evidence for the role of infectious as a trigger for illness e.g. helicobacter pylori and ulcers. Since the late 1980's, researchers have identified infectious triggers they believe lead to rapid onset cases of OCD and tic disorders-now a widely accepted consensus. Through his Director's Post in August 2010, the Director of the National Institutes of

## Join Our Mailing List



Mental Health, Thomas Insel, MD supported these concepts in "Microbes and Mental Illness" (<http://www.nimh.nih.gov/about/director/index-ocd.shtml>). He also pointed to the history and added research in a 2012 post "From Paresis to PANDAS and PANS". These neuropsychiatric disorders have been widely under-recognized. The role of this conference is to increase provider awareness, understanding and recognition of appropriate cases"

## 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

### **Speakers:**

Michael Cooperstock, MD  
 Madeleine Cunningham, PhD  
 Jenny Frankovich, MD  
 Christine J. Harling-Berg, PhD  
 Mady Hornig, MD  
 Louise S. Kiessling, MD, FAAP  
 Paul Knopf, PhD  
 James Leckman, MD  
 Tanya Murphy, MD  
 Susan E. Swedo, MD  
 Kyle Williams, MD  
 Xiangping Zhou, MD

### **Topics Will Include:**

- Is PANS Controversial?
- How to Recognize PANS
- Anti-neuronal Antibodies and Animal Models
- Clinical Laboratory and Physical Findings
- T-Cells and IVIG
- Chemokines and Cytokines
- Blood/Brain Barrier
- Diagnostic Dilemma
- Psychiatric Management
- Role of Antibiotics
- Immune Modulatory Treatment
- Co-morbid Abnormalities: EEG and Polysomnographic

### **Target Audience:**

~Physicians~Physician Assistants~Psychologists~Nurse Practitioners~Social Workers~Researchers Specializing in pediatrics, psychiatry, immunology, infectious diseases, neurobiology, neurology, and family medicine

### **Educational Objectives:**

At the conclusion of this activity, participants should be able to:

1. Analyze the evidence for and against the diagnostic entities of Pediatric Autoimmune Neuropsychiatric Syndrome (PANS), Pediatric Autoimmune Neuropsychiatric Disorder Associated with the Streptococcus (PANDAS) and Acute-Onset Neuropsychiatric Disorders.
2. Identify the symptoms associated with PANS, PANDAS and Acute-Onset Neuropsychiatric Disorders.
3. Identify the laboratory measures that are consistent with these diagnoses.
4. Discuss the basic science evidence for these diagnoses as distinct

## 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**

entities.

5. Describe the various treatment modalities and their appropriateness for the individual patient.

### Clinician Conference Flier:

[http://nepandasparents.com/images/Brown\\_Clinician\\_Flier.pdf](http://nepandasparents.com/images/Brown_Clinician_Flier.pdf)

### Clinician Conference Program/Schedule:

[http://nepandasparents.com/images/Brown\\_Clinician\\_Program.pdf](http://nepandasparents.com/images/Brown_Clinician_Program.pdf)

### Register Online for Clinician CME Track:

[https://apps.biomed.brown.edu/cme\\_registration/product\\_info.php?products\\_id=235](https://apps.biomed.brown.edu/cme_registration/product_info.php?products_id=235)

### Registration Fees:

\$155.00 Physicians

\$95.00 Other Healthcare Providers & Interested Community Members

### For More Information:

Contact the Brown CME Office

Ph: 401-863-3337

Email: [CME@Brown.edu](mailto:CME@Brown.edu)

### Brown Alpert Medical School-Office of CME

<https://brown.edu/academics/medical/education/other-programs/continuing-medical-education/live-conferences>

### Cancellation Policy:

Cancellations/substitutions must be made in writing to the Brown CME Office at least two weeks prior to the conference, no later than February 27, 2015. A \$50.00 administrative fee will be charged for all refunds (no refunds for "no shows"). There will be no additional charge for substitutions. This conference is subject to change or cancellation.

### Conference Location:

The Providence Marriott 1 Orms Street, Providence, RI 02903 401-272-2400 | [www.marriottprovidence.com/](http://www.marriottprovidence.com/)

### Hotel Accommodations:

Make hotel reservations at The Providence Marriott Hotel with our room block rate of \$115.00/night plus taxes, available Friday and Saturday night. Deadline for booking is February 20, 2015.

### New England PANDAS/PANS Assoc. Conference Page:

<http://nepandasparents.com/currentevents/browncliniciantrack.html>

Warren Alpert Medical School of Brown University  
Conferences on PANS, PANDAS, Acute-Onset  
Neuropsychiatric Syndromes - Parent Track

## Mailing List



## 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.

## Parent Update Track

**March 15, 2015**

**7:30-12:00** - Registration/Breakfast to Close

### Program Description:

On March 15th, expert faculty from the March 14th PANS, PANDAS, and Acute-Onset Neuropsychiatric Syndromes Warren Alpert Medical School of Brown University CME Conference will be hosting this parents meeting. The goal of this event is to provide information on neuropsychiatric disorders. New research results, potential therapies and treatment recommendations will be discussed. Diagnosis, assessment, and co-morbid conditions will also be reviewed. An extensive question and answer panel session will round out the program.

### Expert Faculty:

Michael Cooperstock, MD MPH  
 Madeleine W. Cunningham, PhD  
 Jenny Frankovich Sargent, MD, MS  
 Christine J. Harling-Berg, PhD  
 Mady Hornig, MA, MD  
 Louise S. Kiessling, MD, FAAP  
 Tanya K. Murphy, MD, MS  
 Susan E. Swedo, MD  
 Kyle A. Williams, MD  
 Xiangping Zhou, MD

### Parent Update Conference Flier:

[http://nepandasparents.com/images/Brown\\_Parents\\_Flier.pdf](http://nepandasparents.com/images/Brown_Parents_Flier.pdf)

### Register Online for Parent Update

[https://apps.biomed.brown.edu/cme\\_registration/product\\_info.php?products\\_id=236](https://apps.biomed.brown.edu/cme_registration/product_info.php?products_id=236)

### Registration Fees

\$50.00 One Family Member Individual  
 \$25.00 Additional Family Members

### Cancellation Policy:

Cancellations/substitutions must be made in writing to the Brown CME Office at least two weeks prior to the conference, no later than February 27, 2015. A \$15.00 administrative fee will be charged for all refunds (no refunds for "no shows"). There will be no additional charge for substitutions. This conference is subject to change or cancellation.

### Conference Location:

The Providence Marriott 1 Orms Street, Providence, RI 02903 401-272-2400 | [www.marriottprovidence.com/](http://www.marriottprovidence.com/)

### Hotel Accommodations:

Make hotel reservations at The Providence Marriott Hotel with our room block rate of \$115.00/night plus taxes, available Friday and Saturday night. Deadline for booking is February 20, 2015.

**NE PANDAS/PANS Assoc Conference Page:**<http://nepandasparents.com/currentevents/brownparenttrack.html>**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**

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*

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 DiDomenico (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 \_\_\_\_\_

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.



**Attention: Doctors and Connecticut Residents!**

**SNOW DAY HEARING DELAY**  
**HEARING DATE WILL BE RE-SET.**  
**PLEASE EMAIL TESTIMONY IN BY**  
**THURSDAY, JANUARY 29TH BY 12:00pm**  
**[ctpandaspan@gmail.com](mailto:ctpandaspan@gmail.com)**

**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.):

[ctpandasparents@gmail.com](mailto:ctpandasparents@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](mailto:jim.carson@cga.ct.gov)

**Bill Status Link:**

[http://www.cga.ct.gov/asp/CGABillStatus/cgabillstatus.asp?selBillType=Bill&bill\\_num=SB15](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.)**

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