



Northeast PANS/PANDAS Parents Association News To Use

Greetings

We have some exciting updates and urgent news to share in this issue.

We've added a program component to the April 6th event including talks about IVIG, the Cunningham Panel and Lyme. In addition, we need your help with the Massachusetts IVIG bill h.984. Please take the time to read through the entire newsletter. Thank you.

NE PANS/PANDAS
Parent Association
Founding Members,
*Kim Panton, Cathy
Witkos, Jennifer Vitelli,
Peggy Chapman, Lisa
Grisolia, Megan
Greenstein, Lisa Hart,
Tiffani Maxwell*

NORTHEAST
PANS/PANDAS
PARENT ASSOCIATION



**HELP SPREAD THE
WORD**

and Laurie Tedeschi



**West Coast
PANDAS/PANS
Symposium**
April 26, 2014 ~ California



**Registration
Now OPEN!
West Coast
PANDAS/PANS
Symposium**



PandasNetwork.org is hosting the West Coast PANS/PANDAS Symposium taking place April 26th at the Embassy Suites at SFO.

To learn more and register [CLICK HERE](#)

**Featured
Speakers:**

Dr. Susan Swedo
Chief Pediatrics and

**New program component
added to April 6th event**

To register [Click here](#)

Afternoon Program begin at 1pm

- **IVIG Infusion Overview** - presented by Heather Troiano RN, BSN and Susan Kondik RN, CRNI, Coram Specialty Infusion - Home vs. hospital infusion, working with insurance companies, and the difference between infusion products
- **Understanding the Cunningham Panel** - presented by Dr. Madeleine Cunningham, Moleculera Labs - Review of case studies and explanation of how to read it and what to do.
- **Lyme in PANDAS kids** - presented by Dr Nancy O'Hara, Center for Integrative Health - How to detect and treat Lyme in your child

***Q&A Panel Discussion
begins at 3pm
Featuring PANS/PANDAS
Specialists:***

Susan Swedo, M.D.

*Chief Pediatrics & Developmental
Neuroscience Branch at the NIMH*

Madeleine Cunningham, PhD;

*Co-Founder and Chief Scientific Officer,
Moleculera Labs*

Beth Latimer, M.D.

Pediatric, Adolescent and Adult Neurologist

Nancy O'Hara, M.D.

Pediatrician, Center for Integrative Health

Mark Pasternack, M.D.

*Unit Chief, Pediatric Infectious Disease at
Massachusetts General Hospital*

In addition, we have received multiple

Developmental
Neuroscience Branch at
the NIMH (National
Institute of Mental
Health)

**Dr. Jennifer
Frankovich**

Pediatric
Rheumatologist, Director
PANS Clinic, Lucile
Packard Children's
Hospital Stanford

**Dr. Melanie Burgos-
Alarcio**

Pediatric Neurologist,
Leading PANDAS/PANS
Physician

Dr. Eric Fier

Child, Adolescent and
Adult Psychiatry and
Leading PANDAS/PANS
Physician

Amy Joy Smith

Nurse Practitioner,
Integrative Medicine,
Director PANDAS/PANS
Program, Hill Park
Medical Center

Dr. Eric Fier

Child, Adolescent and
Adult Psychiatry, Leading
PANDAS/PANS
Physician

**Dr. Jamie Candelaria-
Greene**

Education Specialist,
Visiting Scholar, UC
Berkeley

**Dr. Margo
Thienemann**

Child & Adolescent
Psychiatrist

requests to provide free tickets to school
nurses and/or school
psychologists/teachers. Due to this request
we will allow 2 free tickets per school to be
used by a school nurse or educator. First
come first serve. They need to email us with
their request and it must be accompanied
with a letter from the school asking for these
tickets. They can email us at
info@nepandasparents.com

CHANGE
STARTS HERE.
CAN WE COUNT YOU IN?

**March 14th is the
deadline to help us with
the MA IVIG Bill H.984**

The hearing at the State House last Wednesday
went well, but our work still isn't done! We have
until Friday March 14 (less than one week) to
gather support and submit final testimony.
Everyone can contribute to this effort, whether you
are a Massachusetts resident or not. Help us to
build momentum for this precedent-setting bill.

PLEASE VISIT [THE NE PANS/PANDAS Website](#)
for specific details on how to help and review a
sample letter you can submit. Below is some basic
info but our website has all the details.

To keep up on new updates please visit the official
[Facebook Page](#)

We are up against a powerful lobby, but together
we can make this happen! We need to put out a
unified message of support for this bill.

Your letter of support or phone call should be
CONCISE and include the following message:

* Reference H.984: PANDAS/PANS legislation in
the subject line of the email.

Diana Pohlman
Executive Director,
PANDAS Network.org

Sarah Jane Alleman
PANDAS Mom,
Advocate, and Dedicated
Blogger

Personal Testimonials by
**Lance Smith, Vanessa
Vann**, and other
PANDAS/PANS children

Afternoon Sessions

In the afternoon,
attendants will have the
opportunity to attend
breakout sessions
focusing on their unique
needs.

For Parents - The
afternoon session for
parents and care givers
will feature "Survival
Tools" that focus on the
emotional and personal
effects of caring for a
child with PANDAS and
PANS; provide tools on
how to help a child
dealing with OCD and
currently experiencing an
exacerbation of
symptoms; and share
tools for advocacy.

For Educators -
Educators will have the
option to attend an
afternoon workshop that
is especially designed for
educators, school
psychologists,
administrators, and other
providers who serve
student communities. In

* Please support H.984: An act relative to insurance coverage for PANDAS/PANS. Support for this bill will enable our doctors to treat our children without fear of denial by insurers. Help our doctors treat our kids in the manner they see fit.

* It would also be helpful to include a BRIEF summary of your experience with this illness (impacts to child, family, and finances, as well as insurance company denials)

*To read a copy of the full bill please go to our face book page at:

<https://www.facebook.com/pages/PANDAS-PANS-Massachusetts/252559741557318>

**Review conference
videos on our new
YouTube Page...
*Dr. Sue Swedo summary now
available!***



We are working hard to get the conference videos available for review and appreciate your patience. Thank you Christine Mitsogiorgakis for all your hard work. She has finished Dr. Swedo's presentation and it is now available for viewing on our YouTube page. [TO VIEW DR. SWEDO'S VIDEO CLICK HERE](#)

In addition, we have made available a mother's story of her child's recovery. Thank you Malia Ott for allowing us to share your daughter's amazing journey to recovery! [TO SEE THIS MOM'S STORY CLICK HERE](#)

this seminar, Dr. Candelaria Greene will provide an overview of this often unrecognized autoimmune disorder, and describe its impact on behavior, attention, and cognitive skills. Attendees are then provided with specific recommendations for accommodations, assessments, compensatory strategies, and other supportive services. In order to maintain a smaller "class size", this breakout session is open only to those in school related fields.

For Providers -

Providers will have the option to attend a "training session" led by Dr. Susan Swedo, Chief Pediatrics and Developmental Neuroscience Branch at the NIMH, Practitioners will learn first-hand how to identify a PANDAS/PANS child and learn the possible forms of needed treatment. This is an amazing opportunity! In order to maintain a smaller "class size", this breakout session is open only to providers.





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