



## Northeast PANS/PANDAS Parents Association News To Use

### Greetings

There's so much going on in the PANS/PANDAS world it's hard to know where to start. Please take the time to read through the entire newsletter. Our hard work will mean nothing without your help. Please support our efforts to help children and families affected with PANS/PANDAS. Thank you.

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

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

*now available!*

NORTHEAST  
PANS/PANDAS  
PARENT ASSOCIATION



**HELP SPREAD THE WORD  
TWO AMAZING EVENTS...  
APRIL 6th FOR PARENTS**



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](#)



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



## APRIL 6th FOR PARENTS APRIL 7th FOR DOCTORS

Wonder what changes Dr. Cunningham is making to the Cunningham panel?

Wonder what Dr. Swedo is researching and if there are any updates on her studies?

Wonder what protocols Dr. Latimer recommends to get rid of strep?

Wonder how Dr. Pasternack treats stubborn infections that traditional treatments can't fight?

Wonder how Dr. O'Hara heals through alternative therapies?

**April 6th is for parents, grandparents, school nurses, teachers and anyone interested in learning more about PANS/PANDAS.** The event is taking place at North Quincy High School. [CLICK HERE TO LEARN MORE AND REGISTER](#)

**April 7th is a breakfast meeting at the Quincy Marriott for the medical community to hear from experts.** If you are a doctor or member of the medical community, please join us for an informative breakfast with local and national PANS & PANDAS specialists discussing their treatment protocols, latest research findings, case studies and answering your questions. [CLICK HERE TO LEARN MORE AND REGISTER](#)

**If you are a parent, please promote this event and encourage your child/children's doctors to attend.**

To print out a flyer with the details [Click Here to go to our events page and find the PDF icon!](#)

### 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*

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

### **HIGHLIGHTS INCLUDE:**

-Spend a couple days with your biggest fans: EACH OTHER

-Afternoon breakout training sessions for Educators, and for Providers

- See website to download the INVITATIONS and send to your child's teachers / providers

-Special private time for parents to process, and to learn more about dealing with OCD flares and other PANDAS specific-issues

-Men's group luncheon - for men only, with Dr. Eric Fier

-Hear from PANDAS kids, their own stories in their own words

-Specific information about requesting educational support, IEP's and 504's

-Learn about successful Advocacy Efforts around the country and how we can use them to launch our own - use our collective pain as power to change the dialogue

-Oh, of course - come and learn about PANS/PANDAS from Sue Swedo and a few West Coast providers.

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

 Join Our Mailing List

 Like us on Facebook 

**Mark Pasternack, M.D.**  
*Unit Chief, Pediatric Infectious Disease at  
Massachusetts General Hospital*

**CHANGE**  
STARTS HERE.  
CAN WE COUNT YOU IN?

## **HELP US PASS MA LEGISLATION TO GET OUR CHILDREN THE HELP THEY NEED!**

Good news! Our Massachusetts PANDAS/PANS legislation has been scheduled for a hearing before the Joint Committee on Financial Services on Wednesday March 5 at 1 PM. As the date nears we will post frequent updates on our Facebook page so please follow us at <http://tinyurl.com/pandas-pans-massachusetts>

We hope to gain as much momentum as possible before the hearing so that our collective voice can be heard! We have only a few weeks to organize, but we are a smart, creative, and motivated group that is used to seemingly impossible odds. For our family, this legislation is about choice. We hope to put our children's care in the hands of our doctors and wrestle it away from the insurance companies. Our goal is to pass this landmark Massachusetts legislation and pave the way to help children across the country.

If you are a Massachusetts resident, here's what you can do...

1. Contact your local Legislators and let them know why you support H.984: An act relative to insurance coverage for PANDAS/PANS.
- Search for your Legislators by Town/City [BY CLICKING HERE](#)
1. Contact members of the Joint Committee on Financial Service. To find their info [CLICK HERE](#)
1. Contact members of the Legislative Leadership. To find their contact info [CLICK HERE](#)

If you live in Massachusetts or anyplace else, here's what you can do...

1. Tell us your PANDAS/PANS story.
  1. Let us know about onset of illness, financial and

emotional hardship, and treatment stories. Although we know it is difficult to limit your story, it would be best if your experiences were limited to one page in length. If you have before/after video that you'd be comfortable entering into testimony, please share it with us.



Email stories to: [pandaspanma@gmail.com](mailto:pandaspanma@gmail.com)

1. Help us to pack the house on March 5th!

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Thank you for helping us to help our kids!  
Heather Punska and Jacob Masenior

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