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NEW ENGLAND PANS/PANDAS ASSOCIATION

December 2014

New England PANS/PANDAS Association

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PANDAS Awareness Video



Thank you to everyone who participated in or PANDAS Awareness day Campaign! We were thrilled to see so

Happy New Year!

NE PANS/PANDAS Association wants to thank all of its supporters in making 2014 a success. We continually strive to fulfill our mission of raising awareness, supporting the medical community so they can help our children further, and to assist families in getting the care and support they need. We thank all the doctors that spoke at our events this year; we could not help our community, spread awareness or help families find medical care without you. We thank all those that attended our events, contributed to our Facebook community, shared opportunities to help and spread awareness. We thank our sponsors that have helped us put on the events throughout the year. And last but not least we thank all of the families in our community who we are here to try and help along this difficult path to heal our kids. We wish you all a healthy and happy 2015!

Health and Healing,

many of you follow through and share the amazing video that Adam and Robin McCune produced of their sons journey living with PANDAS. All of us were so excited to see how many people shared this and know that through our efforts we educated thousands that formerly knew nothing of this illness. A big shout out to Adam and Robin for allowing us to share their story on PANDAS awareness day. Thank also, a big thank you to anyone that donated to [PANDAS Network](#) that day.

[You Are Not Alone: A PANDAS Story](#)

"Our boy, our fighter was stricken with a series of strange ailments around age three. After nearly four years, we finally found relief for our him. Though he isn't cured, his good days far outnumber the bad ones. For each child there should be eternal hope."

Contact Us

NE PANS/PANDAS Assoc
PO Box 1315
Duxbury, MA 02231

Website

[NE PANS/PANDAS Assoc.](#)

Email

info@nepandasparents.com

About NE PANS/PANDAS Association

New England PANS/PANDAS Association Board
Robin Ahlgren, Michelle Britt-Thompson, Peter Capraro, Margaret S.Chapman, Michelle Danubio, Melissa Glynn-Hyman, Lisa Grisolia, Lisa Hart, Emily Klein, Elizabeth LaForest, Tiffani Maxwell, Kim Panton, Gabriella True, Jennifer Vitelli, Jennifer Whelan

Dr. O'Hara Expands Practice to Massachusetts

Seeing Established Patients

Dr. Nancy O'Hara is excited to share with NE PANS/PANDAS Association that she will now be available to see established patients at the Hope Clinic located at 21 Main Street, North Reading, Massachusetts. The dates and times Dr. O'Hara will be available at the Hope Clinic will vary from month to month.



New Patients must first be seen at Dr. O'Hara's office in Connecticut located at Center for Integrative Health, LLC, 3 Hollyhock Lane, Wilton, CT.

To make an appointment at either location please call the Integrative Health Office in Connecticut, at 203.834.2813. For more information on Dr. O'Hara's practice, please visit: www.ihealthnow.org

New Hampshire Conference

Post Conference News

The NH PANDAS event was held on Saturday, October 11th, 2014 at the SERESC Conference Center in Bedford. Peggy Chapman, Dr. Paul Hardy, Dr. Georgie Thomson and Dr. Rosario Trifiletti were the speakers at the event, as well as a young man who had been diagnosed with PANDAS as a child. Josh and his mother spoke about his story of recovery and the attendees had a chance to speak with Josh and ask questions after his story. The last hour of the conference was reserved for questions from the audience for the main speakers.

Approximately 75 people attended the event with most of them originating from New Hampshire, Massachusetts and Connecticut. One family arrived from Canada that morning to attend and one person came from Maryland. We were thrilled to have several nurses, a pediatrician and two naturopaths attend the conference!

One of the members of the committee was able to stream the event live, and although we had not advertised that fact before the event, there were almost 400 live views prior to the end of the conference.

Videos of Lectures and Q&A Panel

Links from the videos can now be viewed at [New Hampshire Conference Event Page](#)

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, Michelle Britt-Thompson, Peter Capraro, Margaret S.Chapman, Michelle Danubio, Melissa Glynn-Hyman, Lisa Grisolia, Lisa Hart, Emily Klein, Elizabeth LaForest, Tiffani Maxwell, Kim Panton, Gabriella True, Jennifer Vitelli, Jennifer Whelan

**Join Our
Mailing List**



Connecticut Conference

Post Conference News



The NE PANS/PANDAS Association, Connecticut Chapter Education Conference held on November 15, 2014 at Norwalk Community College in Norwalk, CT was a great success. We are so grateful for the edifying lectures by Denis A. Bouboulis, M.D., Judith G. Leventhal, PhD., Nancy O'Hara, M.D., and Rosario Trifiletti, M.D., Ph.D.. Each lecture provided unique, essential components of the various avenues in which to help heal children with PANS/PANDAS. The videos of three of the lectures and the Q&A are available on the NE PANS/PANDAS website.

Roughly 220 people registered and there were close to 200 in attendance. Among the attendees were parents, doctors, lawyers, advocates, teachers, nurses, naturopaths, pediatricians, psychologists and many more.

We also want to thank our Sponsors who not only provided financial support but also helped round out the information presented in the lectures (Superior Biologics, Moleculera Labs, Courtague Life Sciences, Biome Restoration, Organic 3, Advocate with Faith, and Brain Balance).

Connecticut Chapter Members:

Renee Bryan, Jim Carson, Lisa Killion, Joan McCullough, Paula Penna, Gabriella True, Lisa Williams, Katie Zigmond

Videos of Lectures and Q&A Panel:

Links from the videos can now be viewed at:
[Connecticut Conference Event Page](#)

PANS Consensus Paper

The Journal of Child & Adolescent Psychopharmacology

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.



The Journal of Child and Adolescent Psychopharmacology has released an online copy of [Clinical Evaluation of Youth with Pediatric Acute Onset Neuropsychiatric Syndrome \(PANS\): Recommendations from the 2013 PANS Consensus Conference](#).

Authors:

Chang K, Frankovich J, Cooperstock M, Cunningham M, Latimer ME, Murphy TK, Pasternack M, Thienemann M, Williams K, Walter J, Swedo SE.

Abstract

Abstract On May 23 and 24, 2013, the First PANS Consensus Conference was convened at Stanford University, calling together a geographically diverse group of clinicians and researchers from complementary fields of pediatrics: General and developmental pediatrics, infectious diseases, immunology, rheumatology, neurology, and child psychiatry. Participants were academicians with clinical and research interests in pediatric autoimmune neuropsychiatric disorder associated with streptococcus (PANDAS) in youth, and the larger category of pediatric acute-onset neuropsychiatric syndrome (PANS). The goals were to clarify the diagnostic boundaries of PANS, to develop systematic strategies for evaluation of suspected PANS cases, and to set forth the most urgently needed studies in this field. Presented here is a consensus statement proposing recommendations for the diagnostic evaluation of youth presenting with PANS.

To view the abstract and to access the online pdf, please visit

<http://online.liebertpub.com/doi/abs/10.1089/cap.2014.0084>.

A hard copy will be available for purchase in January or February 2015.

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