



South Shore Community Partners in Prevention

South Shore Community Partners in Prevention (CHNA 23)

Wednesday, February 9, 2022

8:55 A.M. to 10:15 A.M.

Zoom Meeting

Minutes

In attendance: Vicky Butler, Program Director for Plymouth County Outreach and Steering Committee member; Kevin Burrill, United Way BSU Social Work Intern; Katelyn McSweeney, High Point Prevention, Plymouth Area Prevention Collaborative; Cristina Wilson, Plymouth YMCA; Dora Teague, South Shore Community Action Council; Sam Correia, Duxbury Free Library, Maureen Doherty, BID Plymouth; Lisa Grisolia New England PANS/PANDAS Association; Malissa Kenney, Healthy Plymouth, Inc.; Alex Newcomb, Community Services Manager at the Duxbury Senior Center; Sheila Flaherty - NAMI Plymouth Area; Amy Sylvia South Shore Resource and Advocacy Center; Maureen King, DDS SE Learning & Development; Susan West BID-Plymouth Family Ed; Jen Cantwell, Plymouth County District Attorney's Office; Siobhan McKay - Area Nurse for the Plymouth Department of Developmental Services; Michelle Cardoso (BMCHP) Consumer Engagement Representative; Kim Scotland, United Way of Greater Plymouth County/ SSCPP; Michael Jackman, SSCPP Chair, Congressman Keating's Office; Jennifer McCormick Vitelli, PANDAS/PANS; Laura Carroll, Abigail Foley, Gosnold; Amanda Crowley; Jennifer Edwards and Meclina Priestley, Co-Founders Community Art Collaborative; Grace Zhao; Jennifer Hoadley, Alzheimer's Association; Melissa Thompson; Nicholas Mott; and Sheila Flaherty, NAMI

Mike kicked off meeting at 8:56am. All encouraged to introduce themselves in the chat.

SSCPP will be hosting its annual **Health Literacy Awards on June 8th**. Nomination forms have been sent out and are also posted on the SSCPP [website](#). Encouraged all to check out the form. The deadline to send in nominations is April 29th.

SSCPP will be hosting a reschedule of the BID Plymouth Listening Session with JSI on February 17th at 9:00AM. We will send around a reminder.

Major Topic: PANDAS/PANS: What You Need to Know

Presenters: Jennifer M. Vitelli, MBA, PANDAS/PANS Advocate; Margaret Chapman, PMHCNS-BC, PANDAS/PANS Provider; Lisa Grisolia, President of New England PANS/PANDAS Association; Cathy Witkos, Founder, The JBC PANS & PANDAS Foundation

- Mike shared that one of SSCPP's goals is awareness and health literacy. He introduced Jennifer Vitelli.
- Jennifer shared about PANS "Pediatric Acute-onset Neuropsychiatric Syndrome and PANDAS "Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections"

- Jennifer's story began in the fall of 2011. Her son Gino (and several other of her children) developed the condition. She shared [Gino's testimonial and a video with more info on PANS/PANDAS](#).
- Jennifer introduced Peggy Chapman, a PANDAS/PANS provider. Peggy has a private practice in Hingham and treated her first PANDAS case in 1999. She shared an overview.
- PANS and PANDAS is a condition in which a subset of children and adolescents experience an inflammation of the brain resulting in an onset of neuropsychiatric symptoms. The symptoms occur following exposure to an immune trigger such as Group A Streptococcus. COVID has also been found to be a contributing factor to PANS/PANDAS symptoms.
- Shared a diagram of brain. The body has an infection, creates antibodies, and they get misdirected to the basal ganglia because they have a structure like strep and so the body issues an autoimmune reaction and self- attacks.
- Average age of diagnosis is 10-13. Symptoms can vary. About 71% of families have autoimmune issue history. Adults can have PANDAS also.
- Diagnosis criteria – sudden onset of obsessive compulsive behaviors or a severely restricted food intake. Needs to be accompanied by two of the following other issues as well: anxiety and depression, motor abnormalities, deterioration in school performance, somatic signs, behavioral regression, and sensory amplification.
- Showed a diagram of the limbic system. Each person's basal ganglia reacts differently. Hand writing can change as well as academic function. Major impact on school work is common.
- The antibodies attack healthy tissue causing injury and psychiatric symptoms. In PANS, it comes on acutely and suddenly. Jen shared it would be very interesting as her children would have only psych symptoms but come back with an infection. Could have strep without knowing it. Do not have to have illness, just exposure.
- Shared treatment approach below.

PANS/PANDAS Treatment 3-pronged approach

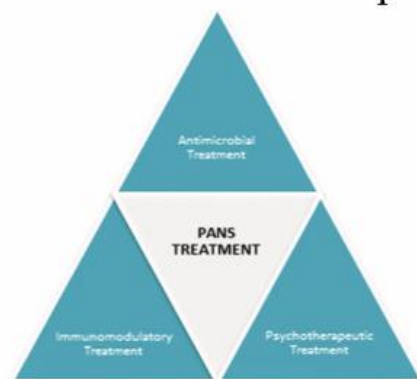


FIG. 1. The PANS treatment triangle. PANS, pediatric acute-onset neuropsychiatric syndrome. Color images available online at www.liebertpub.com/cap

PANS is a broad spectrum of neuropsychiatric conditions with various etiologies. Treatment is based on three complementary modes of intervention:

- 1. Treating the symptoms with psychoactive medications, psychotherapies (particularly cognitive behavioral therapy), and supportive interventions (including school)
- 2. Removing the source of the inflammation with antimicrobial interventions
- 3. Treating disturbances of the immune system with immunomodulatory and/or anti-inflammatory therapies

- Many do not recognize this disorder and it is a misunderstood issue commonly. Discussed family burdens. Not uncommon to have more than one child with the condition.
- Shared about the [New England PANS/PANDAS Association](#). 10 years ago there were no resources and so they founded NEPANS with six local moms and a medical advisor. NEPANS hosted a 2 day medical conference with over 400 attendees.
- Lisa spoke next. She has 2 children diagnoses with PANDAS and is the President of NEPANS. Her kids are adults now. Her child was 7 when she first had symptoms. Started a support group.
- NEPANS supports the community and medical community. Host conferences and events and much more. Support cause for insurance coverage with this illness.
- Cathy was unable to join live so Jennifer shared a bit about her role. Cathy is a founding member of NEPANS and the Founder and President of [JBC PANS/PANDAS Foundation](#) located in Scituate. Their mission is to offer hope and support to children with PANS/PANDAS and raise awareness. Help with navigation, educating schools, community, insurance, etc. Also provide grants for family to help with financial burden. Meet weekly with parents and would welcome partnerships in Plymouth County.
- Jennifer shared the group has done a lot of work within the state of MA. After working tirelessly to advocate and on Jan 1, 2021 Governor Baker signed into law an insurance mandate covering PANS/PANDAS! Also established a permanent PANDAS/PANS advisory council. Meet every month and folks can find info about the group on DPH.
- If anyone would like more information from NEPANS www.nepans.org, contact nepans@yahoo.com. Opened for Q &A.

Mini Grant Outcomes Report: Community Art Collaborative

Jennifer Edwards and Meclina Priestley, Co-Founders

- Jenn shared about the art collaborative and their work having conversations in our community when we have all been separated in a pandemic. Are hosting the culmination of the series this March.
- Vision is to engage with artists, communities, educational and faith-based organizations to contribute to public works of art through the contribution of small piece of art into a larger work of art, bringing communities together around a central idea.
- All of their work is based on honeycomb art pieces that anyone can contribute to. Objective of the SSCPP grant is “art for all.” Wanted to create a project to re-create sense of community during the pandemic. Felt the honeycomb was the right metaphor for this. Creating collaborative public art is a great way to look at how we can use art as a vehicle for connection.
- First project was at BID Plymouth. Also did a project with Healthy Plymouth at nine gardens with Plymouth Schools. Created the illuminating stories series as well as a 3D workshop with Herring Pond Wampanoag Tribe at Pilgrim Hall.
- Want to partner with organizations on upcoming projects. Shared about the “In This Together” Series which includes 15 original poems. Long term home for this will be at Stephens Field Walking Path and are hosting an unveiling on March 31st at 4:00pm. Will share flyer with SSCPP.

Opened for announcements. Mike shared SSCPP is planning a movie club with the Plymouth Library from Kanopy. Hope to share more details on this soon.

Kim encouraged all to “like” SSCPP on Facebook and to share posts to be included in the SSCPP Health Literacy highlight social media series. www.facebook.com/chna23