

Connecticut PANDAS/PANS Advisory Council
Meeting Minutes

November 8, 2013



Council Members Present: Christian Andresen, Alma Hernandez, Dr. James Leckman, Dr. Susan Swedo, Shannon Knall, Cathy Witkos, Dr. Tom Moorcroft

Council Members on Phone: Vicky Kobliner, Dr. Robert Baltimore, Dr. Nancy Ohara

Other participants: Tai Spargo, Dr. Bob Bransfield, Rep. Srinivasan, Renee Bryan, Sally Young

Council Members Not Present: Dr. Denis Bouboulis, Lynn Johnson, Rep. Susan Johnson, Dr. Lisa Karabelnik, Suzanne Levasseur, Denise Sheltz

Next meeting: Friday, December 13, 2013 10am - 12pm

Call to order: Chris called the meeting to order at 10:07am.

Approval of minutes:

Chris called for introductions of the council members and an acceptance of the previous meeting minutes. Dr. Leckman recommended approval of the minutes and it was seconded by Dr. Moorcroft. The minutes were approved.

Conference calls subgroup discussions:

The first subgroup was about data and assessment. The only council participants on the call were Chris and Dr. Baltimore. They briefly discussed the possibility of promoting PANDAS/PANS awareness in the broader context of autoimmune diseases since there are many autoimmune conditions that are misdiagnosed.

The second subgroup was about education and awareness. The council participants were Chris, Dr. Leckman, Alma Hernandez, Sue Levasseur, and Dr. Karabelnik. Chris brought up the idea of autoimmune diseases that was discussed on the first call. Dr. Leckman agreed that it was a good idea to talk about PANDAS/PANS within the context of autoimmune diseases. Providers might respond better to discussions about PANDAS/PANS in the context of autoimmune diseases as a whole. The group discussed the controversy about PANDAS/PANS, other neuropsychiatric illnesses in children, involving the neurologic community in discussions, and the anti-NMDA receptor in addition to PANDAS/PANS. It was decided that before educational outreach could be completed, there need to assess knowledge, awareness, and perception of PANDAS in the community. There was also discussion a PANDAS registry, which Dr. Leckman says has been started in New York.

The council discussed these two calls and their findings. Dr. Swedo mentioned that at a recent meeting she attended, the bottom line with diagnosing PANDAS/PANS is acute

onset OCD. Chris said that building partnerships with other committees and groups is important, especially with children's mental health groups that are forming in this state. The group discussed facing the controversy of PANDAS head on in any surveys or assessments, what groups should be assessed, and whether education should be part of the assessment.

Council recommendations:

The council came up with four recommendations, after discussion. Each was voted on and approved.

1. The Public Health Committee in relationship with the Education and Children Committees, along with other relevant legislative committees, hosts a day to educate the community on PANDAS/PANS which involves all stakeholders from education, medical communities and parents.
 - a. All voted in favor of this recommendation.
2. Develop an outreach program specific to school nurses to increase PANDAS/PANS awareness, and present this product to the Connecticut Association of School Nurses and the State Department of Education.
 - a. All voted in favor except for Dr. Baltimore, who abstained because it was difficult to hear the discussion on the phone.
3. Develop programs for school mental health professionals and educators to increase PANDAS/PANS awareness.
 - a. All voted in favor except for Dr. Baltimore, who abstained because it was difficult to hear the discussion on the phone.
4. Conduct an assessment that includes an educational component which will include practitioners that interact with children (i.e. pediatricians, family practitioners, mental health professionals, neurologists, and school nurses, immunologists, allergists, infectious disease doctors, and emergency room physicians).
 - a. All voted in favor of this recommendation.

Next meeting:

The next meeting will be either the first or second week of December, and an email will be sent out to council members for scheduling.

Meeting was adjourned.