

Connecticut PANDAS/PANS Advisory Council
Meeting Minutes

December 13, 2013



Council Members Present: Christian Andresen, Dr. Robert Baltimore, Alma Hernandez, Dr. James Leckman, Dr. Lisa Karabelnik, Shannon Knall, Suzanne Levasseur, Dr. Tom Moorcroft, Dr. Nancy Ohara

Council Members by Phone: Dr. Susan Swedo, Cathy Witkos, Dr. Denis Boubolis, Lynn Johnson

Other Meeting Participants: Dr. Madeleine Cunningham, Sally Young, Joanne Sloan, Paula Penna, Lisa Williams, Renee Brian, Katie Zigman, Joan Maculla, Jim Carson

Council Members Absent: Denise Sheltz, Maria Synodi, Rep. Susan Johnson, Vicky Kobliner

Next meeting: To be determined

Call to order: Chris called the meeting to order at 10:05am.

Welcome and Introductions:

Chris welcomed the group and members and other people present introduced themselves.

Review and Approval of Prior Meeting Minutes:

Prior meeting minutes were reviewed by the members. Dr. Karabelnik recommended approval of the minutes and it was seconded by Shannon Knall. The minutes were approved.

PANDAS/PANS updates

Chris Andresen announced that a representative from the professional organization of school psychologists has been identified and will join the group in 2014. Chris also mentioned that he has a meeting with representatives from the Office of the Health Care Advocate (regarding non-Advisory Council issues) who are also involved in some of the children's mental health initiatives happening in the state and will broach the topic of PANDAS/PANS.

Paula Penna provided a brief update from the Northeast PANDAS meeting held in Providence in November. There is work being done on a national registry of PANDAS cases, possibly led by David Brick out of New York. Additionally, presenters talked about the importance of teachers being involved in PANDAS/PANS education because handwriting changes can be noticeable.

Dr. Karabelnik mentioned that this month's issue of the Journal of the American Academy of Child and Adolescent Psychiatry has an article about practice parameters for tic disorders in children and adolescents that includes some information about PANDAS/PANS. *(link to mentioned article: http://www.aacap.org/App_Themes/AACAP/Docs/practice_parameters/tic_disorders.pdf)*

Review of recommendations approved in November

Lynn Johnson suggested adding a recommendation for legal protection for physicians who treat PANDAS, similar to legislation for chronic Lyme disease. Drs Baltimore, Swedo, and O'Hara disagreed with Lynn since there is no need for physicians treating PANDAS to go outside the scope of normal practice and that there is no evidence that these physicians need additional legal protection.

(There were audio problems with the conference call. Members calling in were asked to disconnect while a new phone was installed and to call back. The new phone fixed the problems. Dr. Swedo and Cathy Witkos re-joined the meeting by phone. Dr. Bouboulis and Lynn Johnson did not rejoin the remainder of the meeting.)

Dr. Karabelnik moved to approve the recommendations as they stand and to table the additional protections of physicians, which was seconded by Shannon Knall. After further discussion, Dr. Karabelnik withdrew her motion.

Alma Hernandez moved to amend the current approved recommendations to add to #1 that the educational day is an "annual day" and to add "naturopaths" to the list of practitioners on #4. Dr. Moorcroft amended Alma's motion to add that DPH will review and approve any educational materials. It was seconded by Dr. Leckman. The vote was one opposed, no abstentions, and all others present supported. The motion passed.

Alma made another motion to create and fund within DPH a program to address autoimmune conditions including PANDAS. It was seconded by Shannon Knall. After discussion, the vote tallies were 2 in favor and 8 opposed. The motion did not pass.

Dr. Baltimore moved to create a full time position at DPH to implement the recommendations of the PANDAS Advisory Council. It was seconded by Dr. Leckman. All were in favor, no opposed, no abstained. The motion passed.

Dr. Moorcroft moved to add a recommendation to raise the awareness of and promote the use of established PANDAS registries. It was seconded by Dr. Leckman. All were in favor, no opposed, no abstained. The motion passed.

Dr. Swedo moved to add a recommendation that DPH receive reports of new onset behavioral problems that meet the criteria for PANDAS/PANS as well as rheumatic

fever. Dr. Lynn Sosa, deputy state epidemiologist at DPH, explained that rheumatic fever was on the list of reportable conditions but is being removed for 2014 because there have been no reports in at least 10 years. After council discussion, Dr. Swedo amended her motion to recommend that a system of reporting of acute onset behavioral changes, especially those associated with PANDAS/PANS, should be developed by the state of Connecticut and physicians should be informed, educated, and encouraged to report. Due to complexities involved with physician reporting and the capacity of DPH to follow up on these cases, Dr. Swedo later withdrew her recommendation.

Dr. O'Hara moved to amend the draft list of recommendations with today's approved recommendations and to email it to council members for approval. Dr. Karabelnik seconded it. All were in favor, no opposed, no abstained. The motion passed.

Advisory Council meeting schedule through end of year:

Chris will send a meeting survey to schedule the next meeting in January.

Meeting was adjourned.