

Connecticut PANDAS/PANS Advisory Council
Meeting Minutes

October 11, 2013



Council Members Present: Christian Andresen, Dr. Robert Baltimore, Dr. Denis Boubolis, Alma Hernandez, Lynn Johnson, Rep. Susan Johnson, Dr. James Leckman, Dr. Lisa Karabelnik, Shannon Knall, Vicky Kobliner, Dr. Nancy Ohara,

Council Members by Phone: Dr. Susan Swedo, Cathy Witkos

Other Meeting Participants: Paula Penna, Tai Spargo, Rep. Prasad Srinivasan

Next meeting: Friday, November 8, 2013 10am - 12pm

Call to order: Rep. Susan Johnson called the meeting to order at 1:20pm.

Welcome and Introductions:

Representative Johnson welcomed the group and members present introduced themselves.

Review and Approval of Prior Meeting Minutes:

Rep. Johnson called for introductions of the council members and an acceptance of the previous meeting minutes. Dr. Baltimore recommended approval of the minutes and it was seconded by Dr. Boubolis and Shannon Knall. The minutes were approved.

Nominations and Vote for Chair:

Dr. Baltimore nominated Chris Andresen for council chairperson. Lynn Johnson nominated Dr. Boubolis. The final vote was Chris – 5, Dr. Boubolis – 3. Chris Andresen is the council chair.

Development of Report due in January:

Chris discussed the report that is due by January 1st. The council needs to develop recommendations about PANDAS/PANS to present to the public health committee. This council is an ongoing committee, and needs to identify short term goals. There was discussion about an assessment of providers for knowledge about PANDAS/PANS. Dr. Leckman suggested that partnering with other people who have registries for children with PANDAS might be helpful. Vicky Kobliner suggested awareness and education as a key goal, as many school personnel and even providers are not familiar with PANDAS. There was discussion regarding strep tests if a child presents with sudden onset OCD, and whether or not a negative strep test rules out strep. Lynn Johnson was concerned about the lack of providers who treat PANDAS, and whether providers who do are

protected legally and insurance reimbursement issues. Vicky Kobliner desires more data on PANDAS/PANS, and perhaps the council could identify funding or opportunities to collect data. Chris pointed out that as an agency, the Department of Public Health does not tell providers how to medically treat patients. Additionally, Dr. Leckman said that without consensus on what PANDAS is and how to treat it, it will be hard to provide education to providers/schools. Dr. Boubolis raised the issue of developing PANDAS practice parameters. However, the group felt that the Council is not the appropriate venue to develop practice parameters.

The group voted to narrow its focus on short term goals to: awareness and education, and data/assessment. Chris will reach out to members for subgroups conference to develop discussion points for the next full Council members on each topic.

Advisory Council meeting schedule through end of year:

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

Meeting was adjourned.

Video of meeting available at: <http://ct-n.com/ondemand.asp?ID=9499>