

**MINUTES OF THE
PANDAS / PANS Advisory Council Meeting**
Illinois Department of Public Health

Wednesday, June 1, 2016 12:00 – 2:00 p.m.

LOCATION:

Director's Office Conference Room – 35th Floor, 69 West Washington, Chicago
Director's Office Conference Room – 535 West Jefferson – 5th Floor, Springfield

I. Meeting Call to Order

Meeting was called to order at approximately 12:10 by Dr. Natalie Drummond.
Council members present:

Dr. Natalie Drummond	Michelle Gentry-Wiseman, Assistant Director IDPH
Wendy Nawra	Laura Vaught, IDPH
Tiffany Tummaro	Representative Conroy's Chief of Staff
Dr. Pam Campbell	Senator Cullerton's Staff
Kara (by telephone)	
Jessica Gerdes, ISBE (by telephone)	

II. Review and approval of minutes

Minutes from the March 2016 meeting were reviewed and approved without change from the draft. Motion was made by Wendy Nawra and seconded by Tiffany Tummaro.

III. Review and Discussion of Adoption of Consensus Document from 2013 Stanford Consensus Conference on PANS/PANDAS Diagnosis.

The group discussed the consensus document along with the need for potential changes or if the Council would be adopting the statement as written.

Dr. Drummond commented that the document was a thorough discussion related to diagnosis and was theoretically complete but difficult to transfer to the real world and use with a child presenting with symptoms.

It was recommended that information related to treatment needs to be included along with the adoption of the diagnosis statement.

Other information, available on the PPN website, has complete and detailed information in a flowchart type of form that would be useful as a resource for physicians.

Dr. Drummond volunteered to work with Dr. Sharon to develop a flow chart document based on the PPN information related to treatment. The document will be distributed to all Council members.

The providers that would be targeted to receive this type of information would include family medicine physicians, primary care physicians, pediatricians, child psychiatry and child psychology.

IV. Review and Discussion of DRAFT tab on PANDAS for IDPH webpage

The group reviewed a draft of webpage content developed by the Department. Dr. Drummond suggested that information related to diagnostics – a copy of the diagnostic flow chart or, at least a link should be included on the site. Additionally, recommendations were made to add a section related to schools and emergency IEP's, along with a list of concrete accommodations that can/should be made at schools when they have a child with PANDAS/PANS. Michelle suggested that they would make some additions and changes to the draft document for review.

Wendy N. asked how long it would be to get the information up on the website. Michelle relayed to the process to get it up on the website would not be lengthy once there was a “final” document. It would need to be reviewed by legal and publications staff but, that would not be a significant time period.

V. Review of compilation list of associations for schools/medical community

The list was reviewed by the group. Suggestions for additions included the following organizations:

National Association of Social Workers, Illinois Chapter
PTA Association
Occupational Therapy Association
Speech Pathology Association
Illinois Council of Child and Adolescent Psychiatry
Associations representing providers who are immunologists and rheumatologists
Infectious Disease Society of America
Illinois Federation of Teachers
Illinois Education Association

This listing is of organizations or associations that would be targeted for information and education related to PANDAS/PANS by the Council.

VI. Next Steps

- a. Development of draft of initial report to legislature
- b. Investigations/research to be done on issues related to insurance coverage.

Two items discussed:

- 1) development of a draft for the initial report of the Council to the legislature and

Ms. Gentry-Wiseman relayed that the report does not have a prescribed structure but, can be structured as the committee wishes. There generally is an introductory page or letter, copy of the legislative language, discussion of meetings, discussion of process, timelines or next steps, etc. Wendy volunteered to develop a DRAFT report outline for the first report to the legislature. Tiffany agreed to assist with the draft.

- 2) the need for inquiry related to insurance coverage and PANDAS/PANS.

According to Council members Nawra and Dr. Drummond, the goal of the legislation related to insurance coverage is to have a full range of options that are covered by insurance related to PANDAS/PANS. A standard of care already exists with the treatment information provided by the PPN and other documentation supplied by the NIH. Based on previous court cases, Ms. Nawra suggested that the insurance companies be made aware of the existing standard and therefore a time period would be initiated when some action would need to be taken. Wendy will provide a draft copy of a letter that can be sent to the insurance companies.

VII. Announcements

- a. Next meeting will be held Wednesday, July 27th. Other meetings are outlined in the agenda and will be held in September, and December of this year.

A request was made by Dr. Drummond and Ms. Nawra to research whether or not the West Chicago Office of the Department was equipped to handle video conferencing. The drive downtown to the Chicago office for the vast majority of attendees in Chicago requires several hours on both ends of the trip. Ms. Gentry-Wiseman will be looking into reserving a spot at West Chicago for the July meeting and for meetings in the future.

A reminder was made related to the July Meeting of the International OCD conference in the Chicago area. Dr. Swedo will be presenting Grand Rounds at the University of Chicago during the conference.