

2017 Report to the Governor and General Assembly

Virginia Department of Health Report on the Pediatric Autoimmune
Neuropsychiatric Disorders Associated with Streptococcal Infections and
Pediatric Acute-onset Neuropsychiatric Syndrome Advisory Council

Executive Summary

The Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) advisory council is established in the Code of Virginia [§32.1-73.9] to advise the Commissioner of Health on research, diagnosis, treatment and education relating to PANDAS and PANS. The advisory council is required to report to the Governor and General Assembly by December 1st of each year recommendations related to the following:

1. Practice guidelines for the diagnosis and treatment of PANDAS and PANS
2. Mechanisms to increase clinical awareness and education
3. Outreach to educators and parents to increase awareness
4. Development of a network of volunteer experts

Council members have been appointed as outlined in the law. One advisory council meeting was held and efforts are underway to develop the three-year work plan to accomplish the goals of the council. This document summarizes the advisory council's activities for 2017.

What are PANDAS and PANS?

PANDAS is an abbreviation for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections. The term was first used in 1998 to describe a subset of children and adolescents who have obsessive compulsive disorder (OCD) and/or tic disorders, and in whom symptoms worsen following strep infections such as strep throat or scarlet fever.¹ The PANDAS subgroup is part of a larger cohort of children whose symptom onset is unusually abrupt and dramatic, or Pediatric Acute-onset Neuropsychiatric Syndrome (PANS).² PANS is defined by three clinical criteria:

1) Abrupt onset of OCD or eating restrictions.

2) Concomitant onset of at least two of seven of the following: anxiety (particularly separation anxiety); emotional lability and/or depression; irritability, aggression and/or oppositional behaviors; deterioration in school performance; motor or sensory abnormalities; and somatic signs and symptoms (particularly sleep disturbances, enuresis and urinary urgency or frequency).

3) The acute-onset symptoms are not better explained by another neurologic or medical disorder.

Symptoms of PANS may result from a variety of causes, including post-infectious autoimmunity (e.g. PANDAS) and other autoimmune processes, as well as a diverse array of disorders causing neuroimmune activation.³

Background

The PANDAS and PANS advisory council was established during the 2017 General Assembly session as a result of HB2404. The purpose of the advisory council is to make

recommendations to the health commissioner on research, diagnosis, treatment and education relating to PANDAS and PANS.

The membership of the council must comply with the specifics set out in the Code of Virginia, Chapter 2 of Title 32.1, Article 16, sections 32.1-73.9, 32.1-73.10, and 32.1-73.11. The advisory council consists of fifteen members and one ex-officio member. The advisory council also consists of both legislative and non-legislative members. The six legislative members includes four members from the House of Delegates and two members from the Senate. Nine non-legislative members are citizens of the Commonwealth and include individual representatives from the following medical or healthcare specialty fields: one licensed health care provider with expertise in treating PANDAS/PANS; one pediatrician with experience treating PANDAS/PANS; one child psychiatrist with experience treating PANDAS/PANS; one immunologist with experience treating PANDAS/PANS; one medical researcher with experience conducting research concerning PANDAS/PANS, obsessive compulsive disorder, tic disorder, and other neurological disorders; one representative of a professional organization for school nurses; one representative of an advocacy and support group for individuals affected by PANDAS/PANS; one representative of an advocacy and support group for individuals affected by autism; and one parent of a child who has been diagnosed with PANDAS/PANS. The Commissioner of Health or his/her designee serves as ex officio without voting privileges. Staff to the advisory council is provided by the Virginia Department of Health.

The advisory council must prepare and submit an annual report to the Governor and General Assembly by December 1st of each year until HB2404 sunsets in 2020. The council will report on recommendations related to:

- Practice guidelines for diagnosis and treatment of PANDAS and PANS;

- Mechanisms to increase awareness and education regarding PANDAS and PANS among physicians, including pediatricians, school-based health centers and providers of mental health services;
- Outreach to educators and parents to increase awareness of PANDAS and PANS; and
- Development of a network of volunteer experts on the diagnosis and treatment of PANDAS and PANS to assist in the delivery of education and outreach.

Status Report on PANDAS/PANS Advisory Council Activities

Appointments to establish the PANDAS/PANS advisory council began in spring 2017. In April 2017, two legislative members from the Senate were appointed to the advisory council, and four legislative members were appointed from the House of Delegates in late July 2017. On August 4, 2017, Governor McAuliffe issued the formal announcement of the nine non-legislative member appointments. The PANDAS/PANS advisory council is comprised of the following members:

Legislative Members

Senator George Barker
Delegate Richard Bell
Delegate Eileen Filler-Corn
Delegate Gordon Hesel
Delegate Roxann Robinson
Senator David Suetterlein

Non-Legislative Members

Ms. Teresa Champion, Autism Support Group
Ms. Jessica Gavin, PANDAS Research & Advocacy Initiative
Dr. David Jaffe, Children's Hospital of Richmond at VCU
Ms. Stefanie Levensalor, Parent Advocate
Ms. Stacey Link, Virginia Association of School Nurses
Dr. Melissa Nelson, Pediatric Associates of Richmond
Dr. Bela Sood, Children's Hospital of Richmond at VCU
Dr. Susan Swedo, National Institute of Mental Health
Dr. Wei Zhao, Children's Hospital of Richmond at VCU

New treatment guidelines for PANS were released in July 2017, and VDH included related links to articles published in the Journal of Child and Adolescent Psychopharmacology on the agency's PANDAS web page. VDH staff coordinated and facilitated the first PANDAS/PANS advisory council meeting, which was held on September 26, 2017. Staff developed and distributed draft documents to include bylaws, a preliminary year one work plan and a list of pre-identified resources to council members in advance of the meeting.

Thirteen advisory council members and three VDH staff were in attendance for the September meeting. The purpose of the meeting was to formally introduce council members; establish council governance; provide an overview of PANDAS/PANS; and begin development of a three-year work plan. The following is a summary list of key points discussed at the first meeting of the advisory council:

- Election of the Chair and Vice Chair
- Review and approval of Council bylaws as amended (Appendix A)
- Overview of PANDAS/PANS from both clinical and advocacy perspectives
- Review and discussion of preliminary outline for year one work plan
- Discussion and planning for November 2017 meeting
- Discussion of December 1st status report

Full meeting details are included in the September 2017 meeting minutes (Appendix B).

Summary and Future Plans

The council will continue to develop the three-year work plan to include a realistic timeline for conducting activities toward developing recommendations on research, diagnosis, treatment and education relating to PANDAS and PANS. The next advisory council meeting is scheduled for Monday, November 27, 2017. (See Appendix C for the November meeting agenda.) Given the timing of the meeting and the status report due date, a summary of the

meeting and the approved minutes will be included in the December 2018 report to the Governor and General Assembly.

References

¹Swedo SE, et al. Pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections: clinical description of the first 50 cases. *Am J Psychiatry* 1998. 155(2):264-71.

²Swedo S, Leckman J, Rose N. From research subgroup to clinical syndrome: modifying the PANDAS criteria to describe PANS (Pediatric Acute-onset Neuropsychiatric Syndrome). *Pediatr Therapeut* 2012. 2:113. doi: 10.4172/2161-0665.1000113

³Chang K, et al. Clinical evaluation of youth with pediatric acute-onset neuropsychiatric syndrome (PANS): recommendations from the 2013 PANS Consensus Conference. *J Child Adolescent Psychopharmacology* 2015. 25(1):3-13.

Appendix A: PANDAS/PANS Advisory Council Bylaws

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) Advisory Council Bylaws

I. Purpose

The Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) advisory council was established during the 2017 General Assembly session as a result of HB2404 (Attached). The purpose of the advisory council is to make recommendations to the health commissioner on research, diagnosis, treatment and education relating to PANDAS and PANS.

II. Council Composition

The membership of the council must comply with the specifics set out in the Code of Virginia, Chapter 2 of Title 32.1, Article 16, sections 32.1-73.9, 32.1-73.10, and 32.1-73.11. The advisory council will consist of fifteen members and one ex-officio member. The advisory council will consist of both legislative and non-legislative members. Six legislative members will include four members from the House of Delegates and two members from the Senate. Nine non-legislative members shall be citizens of the Commonwealth and will include individual representation from the following medical or healthcare specialty fields:

- one licensed health care provider with expertise in treating PANDAS/PANS;
- one pediatrician with experience treating PANDAS/PANS;
- one child psychiatrist with experience treating PANDAS/PANS;
- one immunologist with experience treating PANDAS/PANS;
- one medical researcher with experience conducting research concerning PANDAS/PANS, obsessive compulsive disorder, tic disorder, and other neurological disorders;
- one representative of a professional organization for school nurses;
- one representative of an advocacy and support group for individuals affected by PANDAS/PANS;
- one representative of an advocacy and support group for individuals affected by autism; and
- one parent of a child who has been diagnosed with PANDAS/PANS.

The Commissioner of Health or his designee shall serve ex officio without voting privileges.

III. Council Chair

Members of the advisory council will select a chairman and a vice chairman annually from its legislative membership.

IV. Duties

Every council member shall participate in council activities to ensure completion of a report to the Governor and the General Assembly, by December 1 of each year, on the advisory council's recommendations related to the following:

1. Practice guidelines for the diagnosis and treatment of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome;

2. Mechanisms to increase clinical awareness and education regarding pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome among physicians, including pediatricians, school-based health centers, and providers of mental health services;
3. Outreach to educators and parents to increase awareness of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome; and
4. Development of a network of volunteer experts on the diagnosis and treatment of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome to assist in the delivery of education and outreach.

V. Membership Appointments, Terms, Vacancies and Compensation

Appointments. The four members of the House of Delegates are to be appointed by the Speaker of the House of Delegates in accordance with the principles of proportional representation contained in the Rules of the House of Delegates. The two members of the Senate to be appointed by the Senate Committee on Rules. The non-legislative citizen members to be appointed by the Governor.

Terms and Vacancies. Legislative members and the ex officio member of the advisory council shall serve terms coincident with their terms of office. The ex officio member shall serve for the duration of their term in office. Appointments to fill vacancies, other than by expiration of a term, shall be for the unexpired terms. Vacancies shall be filled in the same manner as the original appointments. All members may be reappointed for a maximum of two consecutive two year terms.

Compensation. Legislative members of the Advisory Council shall receive such compensation as provided in § 30-19.12. Non-legislative members shall serve without compensation or reimbursement.

VI. Council Staff

Staff to the advisory council shall be provided by the Department of Health. All agencies of the Commonwealth shall provide assistance to the advisory council, upon request.

VII. Advisory Council Meetings

The advisory council shall meet at such times as may be called by the chairman or a majority of the advisory council. A majority of the members shall constitute a quorum. Notice of the council meetings will be sent to council members in advance and will be published on the Virginia Regulatory Town Hall web site not less than three days before the meeting date. Such notice will state the time and place of the meeting.

Each meeting shall consist of a public comment period not to exceed twenty (20) minutes with a maximum of three minutes per speaker. Council reserves the right to alter the time limitations set forth above without notice and to ensure that comments presented at the meeting conform to these bylaws.

VIII. Amendments

These bylaws may be amended or repealed by the advisory council, pursuant to a vote by a majority of the members present at any regular meeting at which a quorum is present.

Appendix B: PANDAS/PANS Advisory Council Meeting Minutes

PANDAS/PANS Advisory Council Meeting

Libbie Mill Library – Large Meeting Room
Tuesday, September 26, 2017
1:00 p.m. – 4:00 p.m.

Meeting Minutes

Legislative Members Present: Del. Richard Bell, Del. Eileen Filler-Corn, Del. Roxann Robinson, Senator David Suetterlein

Non-Legislative Members Present: Ms. Teresa Champion, Ms. Jessica Gavin, Dr. David Jaffe, Ms. Stefanie Levensalor, Ms. Stacey Link, Dr. Melissa Nelson, Dr. Bela Sood, Dr. Susan Swedo, Dr. Wei Zhao

VDH Staff Present: Ms. Robin Buskey, Mr. Joe Hilbert, Dr. Vanessa Walker Harris

Welcome and Introductions

Dr. Vanessa Walker Harris, Director of the Virginia Department of Health's (VDH) Office of Family Health Services (OFHS), called the meeting to order. She introduced herself and stated that she will serve as designated staff to the PANDAS/PANS Advisory Council. She welcomed all council members and asked that all council members introduce themselves by name and organization. Dr. Walker Harris then acknowledged the presence of VDH staff: Joe Hilbert, Director of Governmental and Regulatory Affairs, and Robin Buskey, OFHS Grant Consultant.

Agenda Overview and Review of HB 2404 Requirements

Dr. Vanessa Walker Harris provided a review of the meeting purpose to include:

- formal introduction of council members;
- establish council governance;
- provide an overview of PANDAS/PANS from both clinical and advocacy perspectives; and
- begin development of a three-year work plan.

Dr. Walker Harris then provided an overview of the meeting agenda in its entirety before reviewing specified sections of HB 2404. Dr. Walker Harris read sections C, D, E and the report requirements. Council members were advised to read along from the materials provided in the meeting packets, as well as on the overhead screen.

Election of Chair and Vice Chair

Delegate Richard Bell made a motion to elect Delegate Eileen Filer-Corn as Chair of the PANDAS/PANS Advisory Council. The motion was seconded. Delegate Eileen Filler-Corn was elected as Chair by unanimous vote.

Delegate Eileen Filler-Corn moved to elect Senator David Suetterlein as Vice Chair of the PANDAS/PANS Advisory Council. The motion was seconded. Senator David Suetterlein was elected as Vice Chair by unanimous vote.

Review of Draft Council Bylaws

Dr. Walker Harris asked council members if there were any questions or concerns regarding the draft PANDAS/PANS Advisory Council By-laws that were distributed to members for review prior to the meeting. A question was raised regarding the requirement for council members to attend *all* council meetings; a council member wanted to know if participation could be done via teleconference. Joe Hilbert responded that the ability to attend meetings electronically is governed by FOIA. Under current statute, there are provisions for two tracks:

1. A member can meet electronically by phone from a location that is accessible to the public. A quorum must be present in one place. The member who is meeting remotely by phone is not counted in the quorum. The meeting notice will have to indicate who is calling in and the location from where they are calling.
2. A member can participate from a location that is not open to the public. The public body must develop a written policy that governs such meetings. Each member can participate remotely in this manner for no more than two meetings each year.

In response to various inquiries, Joe Hilbert also provided the following points:

- The PANDAS/PANS advisory council meeting will not always be held at the Libbie Mill Library location; Ms. Stefanie Levensalor offered her company's facilities as an option.
- A council member who participates via an electronic format will not be counted in the quorum.
- With regard to communication among council members between meetings, per FOIA, if three or more members are engaged in a phone call or another format of communication, that is considered a meeting. Members were advised not to "Reply All" when communicating via email. All communication should be sent through Dr. Vanessa Walker Harris.
- In response to the inquiry about forming subcommittees, Mr. Hilbert advised that this is possible as long as public notice is provided in advance. Ms. Champion indicated that she would like to reserve the right to hold subcommittee meetings.
- In response to Del. Filler-Corn's inquiry regarding the requirement to call a meeting ahead of sending out information to council members, Mr. Hilbert advised council members to send information through Dr. Vanessa Walker Harris.
- In response to Dr. Sood's inquiry that all information will be centralized in one place, Mr. Hilbert advised that is seen as part of VDH's role to the council.
- In response to Dr. Sood's inquiry, Mr. Hilbert confirmed that a quorum is met when eight members of the 15-member advisory council is present.
- Mr. Hilbert advised that he will request a copy of the written policy regarding conducting remote meetings that was recently developed by the Commission on Healthy Youth. Once obtained, the policy can be reviewed and potentially adopted for use by the PANDAS/PANS advisory council.

Senator Suetterlein made a motion to strike the commitment requirement to attend all Council meetings contained in Section IV. The Council unanimously approved the motion. Senator Suetterlein also suggested deleting the second line in Section V regarding term appointments for legislative members.

Delegate Bell made a motion to accept the PANDAS/PANS Advisory Council Bylaws as amended. The motion was unanimously approved.

PANDAS/PANS Presentations

Delegate Filler-Corn provided introductory remarks prior to Dr. Susan Swedo's presentation, *Recognition, Diagnosis and Treatment of PANDAS*, to the council. Dr. Swedo is a principal investigator for the National Institute on Mental Health and was one of the first researchers to discover the PANDAS disorder in the 1990s. Following Dr. Swedo's presentation, the council engaged in a question and answer session.

Delegate Filler-Corn acknowledged that no members of the general public were in attendance at the meeting. She suggested a revision to the agenda to include only one break since the designated public comment period would not be utilized. Council members recessed for a fifteen-minute break before resuming presentations.

Delegate Filler-Corn introduced Ms. Jan Kirby as the second presenter at the meeting. Ms. Kirby works as a patient advocate at the Children's Hospital of Richmond at VCU. She provided an informal presentation to the council, offering an advocacy perspective on the challenges and hurdles faced by children with the PANDAS and PANS disorder. Following Ms. Kirby's presentation, the council engaged in discussion regarding current PANDAS/PANS treatment options, treatment costs, current and past studies and PANDAS/PANS activity in other states.

Review of Draft Work Plan

Delegate Filler-Corn directed everyone to the draft preliminary outline contained in the meeting packets and provided on the screen. The document was provided to council members for review in advance of the meeting. Dr. Walker Harris provided a brief review of the document and asked council members to provide feedback on the draft preliminary outline, which includes council activities through December 2018.

Ms. Teresa Champion proposed that the council develop/state the end goals then work backwards to fill in what needs to be done to reach those goals.

Del. Filler-Corn indicated that the preliminary outline was a good starting place and proposed that the council could flesh it out in the current meeting or work individually and send comments later. In response to Dr. Sood's inquiry about the purpose of the council's makeup, Del. Filler-Corn reviewed the four areas included in the outline on which the council is to provide recommendations.

Council members discussed various ideas and possible actions that should take place. Mr. Hilbert reminded the council of HB 2404's three-year sunset. He reminded members that the Council has three years to accomplish the goal of providing recommendations in the four areas. For the report that is due December 1, 2017, Mr. Hilbert indicated that there are no set requirements for what has to be included in the report. He suggested that the council could build upon the preliminary outline by thinking about which groups to include/invite to present at future meetings.

Dr. Vanessa Walker Harris followed up with suggestions that the December 1st report will serve as a status report and include the following:

- Requirements of the bill
- First meeting minutes as approved by the Council
- Final work plan for the first year based on revisions to preliminary outline

Delegate Robinson suggested that the report also include progress that has been made in the last three months and what has been done prior to the first meeting to lay the groundwork.

Next Steps

Ms. Jessica Gavin indicated that she would like to have workgroups within the Council. She offered to present the Arizona council format to the PANDAS/PANS advisory council as a starting point for moving forward. Dr. Wei Zhao acknowledged that Ms. Gavin's organization has already done a great deal of work in this effort and that the work of the council should begin there. Delegate Filler-Corn shared comments in agreement with Dr. Zhao, acknowledging and thanking Ms. Gavin for the work that has already been done. She suggested that all council members look at Ms. Gavin's information.

Dr. Zhao inquired if it would be appropriate for the advisory council to develop a wish list for the Governor (i.e., mandating that insurance companies include coverage for treatment of PANDAS/PANS). Mr. Hilbert replied that the PANDAS/PANS advisory council is advisory to the State Health Commissioner; the report is to the Governor and General Assembly. Mr. Hilbert also said that there is time for the advisory council to figure out the right questions and right groups to include, and how the council will use that information in the report.

Future Meeting Dates:

Dr. Walker Harris reviewed the proposed future meeting dates as indicated in the preliminary outline – Nov 2017; April 2018; June 2018; Sep 2018; and Nov 2018. Council members held a general discussion about possible meeting dates in October and November. It was decided that Robin Buskey would send out a Doodle poll to members with possible November meeting dates.

Dr. Walker Harris provided a summary agenda for the November meeting to include the following:

- Ms. Gavin's presentation of the Arizona council format
- Review and comment of the draft report due December 1, 2017
- Review of written policy regarding remote meetings

Dr. Walker Harris advised that the meeting minutes and draft report will be sent out to council members for review in advance of the November meeting. VDH staff will write the draft minutes and report.

Dr. Swedo said she would provide a copy of the PowerPoint slide presentation (version without video footage) to VDH staff for dissemination to the advisory council.

Adjournment

Delegate Filler-Corn provided closing remarks and thanked council members for their time and participation. The meeting was adjourned at 3:56 p.m.

Appendix C: PANDAS/PANS Advisory Council Meeting Agenda

PANDAS/PANS Advisory Council
Virginia Department of Health
Monday, November 27, 2017
1:00 – 4:00 p.m.

Libbie Mill Library – First Floor Meeting Room
2100 Libbie Lake East Street
Henrico, VA 23230

AGENDA

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| I. | Call to Order | Delegate Eileen Filler-Corn
<i>Chair</i> |
| II. | Welcoming Remarks and Agenda Overview | Dr. Vanessa Walker Harris
<i>Office Director, VDH</i> |
| III. | Review and Approval of September Meeting Minutes | Council Members |
| IV. | Presentation of Arizona Advisory Council Format | Ms. Jessica Gavin
<i>Council Member</i> |
| V. | Review and Comment on the Draft December Report | Council Members |
| BREAK | | |
| VI. | Revisions to First Year Work Plan <ul style="list-style-type: none">• Identification of organizations to invite to future meetings | Council Members |
| VII. | Review of Remote Meeting Policy | Council Members |
| VIII. | Public Comment Period | |
| IX. | Revisit Proposed Future Meeting Dates - April 2018; June 2018; Sep 2018; Nov 2018 | |
| X. | Next Steps | |
| XI. | Adjournment | |