

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

Advisory Council

Friday, April 25, 2025

10:00 AM – 11:30 AM

Meeting Location

Virtual

Virtual Access Link:

https://www.zoomgov.com/webinar/register/WN_vUVOVhfdQK-w-lukxCG-pQ

Meeting attendance requires prior registration. Please register at link above.

Note: Council members have been pre-registered and should not register again.

Draft Meeting Minutes

Council Member Attendance	Voting Record Y=Yes, N=No, M1= Motion, M2= Second
<i>Italicized = Absent</i>	Meeting Minutes November 22, 2024
Voting Members	
<u>Legislative</u>	
Senator Barbara Favola	M1
Delegate Debra Gardner	Y
Delegate Patrick Hope	Y
Delegate Irene Shin	Y
Senator David Suetterlein	Y
Delegate Kathy Tran	M2
<u>Non-Legislative</u>	
Ann Flippin	Y
Brian Gottstein	Y
Dr. David Jaffe	Y
Dr. Galam Khan	Y
Kristina Nunnally	Y
<i>Dr. Aradhana Sood</i>	
Dr. Susan Swedo	Y
Terry Woody	Y
Ex Officio Members	
Jennifer Macdonald, <i>Proxy for Dr. Vanessa Walker-Harris (VDH)</i>	
Vacant Seat	
<i>Immunologist</i>	

Virginia Department of Health (VDH) Staff Attending: Christen Crews, Marcus Allen, Toni Hayes

Council Business

- Call Meeting to Order – Delegate Hope called meeting to order at 10:05 am.
- Introductions and Roll Call – Christen Crews took roll call and a quorum was confirmed.
- Review Agenda – Delegate Hope provided an overview of the agenda and no edits were proposed by the Council.
- Review and Approval of November 22, 2024 Meeting Minutes: The draft minutes were disseminated electronically for Council Members to review prior to the meeting. No edits were proposed. Senator

Favola motioned to adopt, Delegate Tran seconded. A consensus vote occurred and no objections were voiced by any present Council members to adopting the minutes as presented.

Public Comment Period

- There were no members of the public present requesting to make a public comment.

Family Perspective of PANDAS/PANS, Brian Gottstein, Council Member

- Brian Gottstein shared the story of his daughter and her diagnostic odyssey with PANDAS. She was in kindergarten and had been a healthy and joyful girl prior to the first day of symptoms presenting. After PANDAS/PANS was finally identified, the family was unable to find a provider and a specialist was found out of state. The costs of testing and treatment were not covered by insurance, and currently in thousands of debt. Mr. Gottstein stated that he joined this council to help those parents who deal with the issue of their children being misdiagnosed and not having resources or support available. The longer PANDAS/PANS goes undiagnosed, the greater the impact and cost for treatment. The medical community, schools, school nurses, and families need to be made aware of PANDAS/PANS, potential symptoms, and supports in place.
- Senator Favola- Raised the question to the Council if the practice of early detection has been identified within the state of Virginia.
- Brian Gottstein: Communications professional, committed to help getting education and resources out.
- Kristina Nunnally: There is no single test that can rule out PANDAS/PANS; there are screening tools available.
- Delegate Hope: Referenced the resources developed previously by the Council, subcommittees can be charged with reviewing and updating.

Legislative Updates, Delegate Hope, Virginia House of Delegates, Council Chair

- Delegate Hope: Introduced bill that was adopted to direct DMAS to amend coverage for screening and treatment of PANDAS/PANS, believes would go into effect on July 1st as there isn't another date in the bill. Fighting for many years. Unanimous vote in the General Assembly to move forward with passing the legislation.
- Dr. Jaffe: Important for individuals and not just specialists to know to begin treatment ASAP. The expensive treatment (IVIG) is not needed if detected early. Referenced resources the committee previously created for parents, providers, and schools developed by the committee. Encourage to begin treatment while waiting to see specialist.
- Dr. Swedo: Acknowledged that PANDAS/PANS has been recognized as a real entity, we can get the word out to pediatricians and using AAP/VDH. Goal is to have every child recognized within 1-2 days of onset.

Insurance Coverage Updates, Rhonda Newsome, Department of Medical Services (DMAS)

- Rhonda Newsome, DMAS, provided an overview of the agency, its roles, and what responsibilities it has related to legislative mandates for coverage of health insurance benefits or providers. She stated that it will be important to familiarize providers with the syndromes/conditions for PANDAS/PANS; including diagnosis codes, and increase understanding by educating providers and parents. There is no diagnosis code for suspected PANDAS/PANS. Suggested to have PANDAS/PANS diagnosis so other providers can be aware.
- Provider bulletins will be disseminated by end of June to educate providers for what has changed with coverage and provide education.
- The Council will consider what other avenues and ways we can further inform the public (Communication subcommittee).
- Delegate Hope questioned when mandated coverage would go into effect, Rhonda Newsome confirmed July. He would like to request DMAS to participate on Education subcommittee, Will Frank (DMAS) said to include them on communication for future meetings.
- Senator Favola: Asked if promulgating regulations would go effect in July and fiscal support would start in January. If on July 1st a claim was received for PANDAS/PANS, confirmed with DMAS that the claim would be paid.

- Dr. Jaffe: Any provider seeing a patient with diagnoses of OCD, irritability, insomnia and then bill for management of disorders, any insurance company would cover claim even if provider is considering PANS. Do not have to be a psychiatrist to identify codes or bill for treatments.
- Kristina Nunnally: D89.89 is the most common code used for PANDAS/PANS and historically denied, questioned if that will that be used by DMAS for reimbursement. Rhonda Newsome said that D89.89 has usually been used as PANS, since PANDAS is a sub-disorder and very specific, it can be very confusing for practitioners as to what code to use. Providers can be overwhelmed by abrupt behavioral changes that result in a psychiatric treatment. Suggesting that if treating for 2-3 of the disorders associated with PANDAS/PANS, may be missing bigger picture- this will be included in the bulletin.

Council Operations, Christen Crews, Virginia Department of Health (VDH) Support Staff

- **Annual Report:** Christen Crews, VDH, presented on the annual report required of the Council. The Council is tasked to advise the “Commissioner of Health on research, diagnosis, treatment, and education relating to PANDAS/PANS” and mandated to submit a report to be published on the Legislative Information System (LIS) by December 1 each year. Does have to go through several phases of review.
- The report timeline was reviewed with tentative dates including initial draft prepared by VDH staff (July 1st), Council review (August 1st), Final Draft (September 1st) with published on LIS by December 1st. The different levels of review were discussed and leadership oversight.

Council Business

- Subcommittees
 - Establish lead to report out at council meeting.
 - Delegate Hope touched on the subcommittees being able to identify the charge/focus for that specific group. Brian Gottstein inquired on the formatting/logistics of subcommittees.
 - Christen Crews shared next steps including how/when subcommittees would meet (ideally after or before council meetings) as well as noted that the description of the subcommittees was used as a framework. She reviewed council rules centered around meetings, format, and remaining in compliance with the Virginia FOIA Council.
 - Senator Favola presented the potential for subcommittees to meet at 10am and the council meet at 11am.
 - Dr. Swedo inquired about her term end date (June 2025). She is interested in renewing and continuing to serve. Dr. Khan shared that he submitted paperwork to renew his term. Christen Crews will send information to gubernatorial appointees on process for renewal application.
 - Kristina Nunnally inquired on if we can add a subcommittee centered around focusing on legislation. Delegate Hope shared his thoughts that the legislators would carry this focus based on the recommendations that are shared out from the council and the work completed within the subcommittees.
- Open Discussion
- Next Meeting/Agenda items: July 18, 2025 at the Virginia Healthcare and Hospital Association in Glen Allen, Virginia. Christen Crews will finalize the times with the Chairs.
- Adjourn: The Council meeting was adjourned at 11:24am.