

**Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS)  
and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) Advisory Council Meeting**  
Friday, November 22, 2024  
10:00 AM – 2:00 PM

**Meeting Location**  
Virginia Hospital & Healthcare Association  
Washington and Jefferson Meeting Rooms  
4200 Innslake Dr, Glen Allen, VA 23060

**Virtual Access Link for Public:**  
[https://www.zoomgov.com/webinar/register/WN\\_bRPvcY5HTsKIOKU5DsaWQA](https://www.zoomgov.com/webinar/register/WN_bRPvcY5HTsKIOKU5DsaWQA)  
*Meeting attendance required prior registration.*

**Draft Meeting Minutes**

Council Member Attendance	Voting Record			
	Y=Yes, N=No, A=Abstain, M1= Motion, M2= Second			
<b>Bold</b> = Present <i>Italicized</i> = Absent	Bylaws	Electronic Meeting Policy	Chair Delegate Hope	Vice-Chair Delegate Gardner
<b>Voting Members</b>				
<u>Legislative</u>				
<i>Senator Barbara Favola</i>				
Delegate Debra Gardner	Y	Y	M1	A
Delegate Patrick Hope	M1	M1	A	M2
Delegate Irene Shin – <i>arrived at 11:05</i>			Y	Y
<i>Senator David Suetterlein</i>				
Delegate Kathy Tran	M2	M2	M2	M1
<u>Non-Legislative</u>				
Ann Flippin	Y	Y	Y	Y
Brian Gottstein	Y	Y	Y	Y
Dr. David Jaffe	Y	Y	Y	Y
Dr. Galam Khan	Y	Y	Y	Y
Kristina Nunnally	Y	Y	Y	Y
Dr. Aradhana Sood	Y	Y	Y	Y
Dr. Susan Swedo	Y	Y	Y	Y
Terry Woody	Y	Y	Y	Y
<b>Ex Officio Members</b>				
Dr. Vanessa Walker-Harris (VDH)				
<b>Vacant Seat</b>				
<i>Immunologist</i>				

**Virginia Department of Health (VDH) Staff Attending:** Christen Crews, Jennifer Macdonald, Rebecca Edelstein, Marcus Allen, Toni Hayes, Beatrice Lele

### **Council Business**

- Call Meeting to Order – Christen Crews called meeting to order and reviewed housekeeping items for in-person attendees and review of open public meeting for Council.
- Introductions and Roll Call – Christen Crews took roll call and requested that Council members introduce themselves with a brief overview of experience and how it could benefit the Council.
- VDH staff and public attendees also introduced themselves.
- Review Agenda – Christen Crews provided an overview of the agenda and no edits were proposed by the Council.

### **Council Operations**

- Review Bylaws- The previous Council Bylaws adopted 9/2017 were disseminated electronically prior to the meeting for Council members to review with proposed amendments. Council members were advised to send all communication for the Council through Christen Crews to disseminate to the Council to be in compliance with FOIA's public meeting policy. The process of transparent roll-call voting and recording requirements was explained to the Council. A quorum of 9 will be required for all meetings to do Council business, and a simple majority of voting members will pass a motion. The Bylaws were adopted with amendments as presented (11- Y, 0 – N, 0– A).
  - The Council did not have any questions or concerns regarding in the proposed amendments.
  - David Jaffee requested that we follow up with the group to provide who fits into which seat; VDH staff clarified this determination is made by the Governor's office, and we will circulate this list after the meeting.
  - Delegate Gardner inquired about the electronic meetings policy and whether it had been adopted; VDH staff clarified there have been changes to FOIA regarding this policy and the Council must therefore vote to adopt them.
  - Delegate Hope moved to adopt the bylaws, Delegate Tran seconded the motion
  - The Council voted to adopt the bylaws
- Review Electronic Meetings Policy – The Electronic Meetings Policy draft for the Council was disseminated electronically prior to the meeting for Council members to review. The Policy was explained by Christen Crews with specifics to the Virginia Freedom of Information Act (FOIA) Council and recent legislative changes for remote participation and the requirement to adopt annually. The Electronic Meeting Policy was adopted as amended. (11- Y, 0 – N, 0 – A).
  - VDH staff offered one edit to the Electronic Meeting Policy to say that 50% of the meetings could be held electronically (previously said 25%).
  - Council members had some follow up questions about: (1) Whether individuals participating remotely for personal reasons specifically would counts towards quorum and can vote; (2) Whether House members have different rules for participation and have to meet in person always; (3) Whether if three Delegates are in a House meeting discussing PANDAS/PANS legislation, if this would count as a public meeting of the Council; VDH will follow up with the Council members to confirm answers to these questions
    - Becca Edelstein, OFHS Policy Analyst, confirmed during the meeting that VDH staff confirmed during the meeting that individuals participating remotely for personal reasons specifically would counts towards quorum and can vote if there is a physical quorum.
  - Delegate Hope moved to adopt, Delegate Tran seconded
  - The Council voted to adopt the Electronic Meeting Policy as amended
- Council Chair- Per the Council Bylaws, a chairman and vice chairman shall be selected annually from its legislative membership. Delegate Hope was nominated for Chair and confirmed (11- Y, 0 – N, 1 – A) and Delegate Gardner was nominated for Vice Chairman and confirmed (11- Y, 0 – N, 01– A).
  - VDH staff introduced the requirements for voting for Chair/Vice Chair; noted that both legislative members present and those not present could be considered.
  - In response to a question from the Council, VDH staff confirmed that the Chair and Vice Chair could be from the same chamber, there is no Code requirement that says otherwise.
  - Delegate Gardner motioned for Delegate Hope to be Chair, Delegate Tran seconded

- Delegate Tran motioned for Delegate Gardner for Vice Chair, and Delegate Hope seconded

### **Historical Council Overview, Christen Crews, Virginia Department of Health**

- Christen Crews, VDH, presented a historical overview of the Council.
- Establishment of council Code of Virginia reference §32.1-73.9 through 32.1-73.11. Council now sunsets July 1, 2028
- Council has 15 voting members with composition defined by §32.1-73.9, including four members from the House of Delegates, two members from the Senate), one ex-officio member, and none non-legislative members. The nine non-legislative members are citizens of the Commonwealth and include individual representatives from medical and healthcare specialty fields, as well as parents and advocates of children with PANDAS/PANS, specified in the Code. The Commissioner of Health or his/her designee serves as ex-officio without voting privileges. VDH provides staff support for the Council.
- Council Tasks : advises 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.
- The report timeline was reviewed with tentative dates including initial draft prepared by VDH staff (July 1<sup>st</sup>), Council review (August 1<sup>st</sup>), Final Draft (September 1<sup>st</sup>) with published on LIS by December 1<sup>st</sup>. The different levels of review was discussed and leadership oversight.
- An overview of the report submitted for 2024 was provided to the Council. This report did not receive any Council edits as the Council was in the process of being reconvened.
  - Overview of PANDAS/PANS
  - Summary previous Council activities
  - Status update
  - Plans to reconvene the Council
- Historical activities of the Council were shared with accomplishments, outcomes, and outstanding tasks.
  - Development of subcommittees for three key focus areas
    - Practice guidelines for diagnosis and treatment
    - Mechanisms to increase clinical awareness
    - Outreach to educators and parents
  - Subcommittees developed draft resources for stakeholders including PANDAS/PANS diagnosis and treatment algorithm for providers; parent education and guidance documents; and informational resource document for school educators
  - Council previously engaged external stakeholders to inform the work of the Council and obtained feedback on the documents developed and the Council priorities from Code.
  - The Council’s previous recommendation on the establishment of a Center of Excellence in Virginia to treat PANDAS/PANS and autoimmune encephalopathy (AE) was discussed. This Center would conduct basic, clinical, and translational research for PANDAS/PANS and autoimmune encephalopathy (AE); provide assessment and treatment for patients, children and adults, with a diagnosis of PANDAS/PANS and AE; and establish a network of community providers to provide support and education for local delivery of care including the use of all available modalities such as telemedicine.
  - The Council also previously discussed dissemination of the documents developed, a potential webinar, and challenges with insurance coverage as a barrier to assessment and treatment.

### **Current Legislative Landscape of PANDAS/PANS in Virginia, Delegate Hope, Virginia House of Delegates**

- Advisory Council was established in 2017, now sunsets 2028.
- There was confusion during pandemic whether there was an ability to extend advisory councils, commissions, boards to continue during this time when there was a sunset clause (senate approved, house could not vote).

- HB514 in 2023 GA was passed to continue AC
- HB513 in 2023 GA proposed that DMAS payments/reimbursements for medical assistance for diagnosis of PANS/PANDAS
  - Was tabled. General Assembly recommended this bill to go to the Health Insurance Reform Commission and was asked to expedite recommendation analysis. Delegate Hope has met with JLARC and Bureau of Insurance.
- Delegate Hope pre-filed a bill for the upcoming GA session, similar to HB513 last year
- Council members made suggestions for legislative and other interventions:
  - Establishing a clear protocol for diagnosis of PANDAS/PANS
  - Increasing preventative and early interventions and discussing how those interventions might help reduce costs/societal cost of PANDAS/PANS
  - Having Virginia be a leader in bringing together providers across disciplines to share best practices and experiences with PANDAS/PANS
  - Having a specific diagnosis code for PANS/PANDAS – currently there are not specific codes, and immunologists will not use neurology code and vice versa
  - Increasing awareness of PANDAS/PANS among providers and where they can send patients who are diagnosed with PANDAS/PANS for treatment that is covered by insurance
  - Ensuring earlier diagnosis and treatment – the earlier the diagnosis and earlier the treatment is instituted properly, the better the outcomes
  - Improving education for parents and providers how to work with parents that this diagnosis is not a deadly disease – PANDAS/PANS diagnosis is inducing panic among patients when they receive this diagnosis

#### **Public Comment Period**

- Juan Garcia Gomez: nursing student would like a copy of the resource documents. Christen will send follow-up documents
- Teresa Champion: Previous member of the Advisory Council. Thank you for being here, appreciates the Council's efforts.

#### **Break**

#### **Presentation, Virginia Bureau of Insurance, Bradley Marsh**

- Provided an overview of the BOI, its roles, and what responsibilities it has related to legislative proposals to mandate coverage of health insurance benefits or providers
  - Only fully insured plans are subject to regulation by BOI; represents coverage of about 20% of Virginia population
  - Health insurance mandate is defined in Section 38.2-3406.1
- Provided an overview of the Health Insurance Reform Commission (HIRC) and what its role is
  - Tasked with assessing legislatively proposed mandates that are referred by the chairs of committees having jurisdiction over those bills
  - Letter is then sent to BOI – and BOI begins their assessment
- Shared that BOI is responsible for doing an assessment for HIRC, and then HIRC ultimately makes a decision about next steps (e.g., considering as part of essential health benefit (EHB) benchmark plan review; jointly assessing for the social and financial impact by BOI and the Joint Legislative Audit and Review Commission (JLARC), other.)
- Reviewed what an EHB benchmark plan is –
  - A minimum standard on which all new individual and small group plans are modeled
  - ACA has required that states have this plan and there are some benefits included in this plan that are required by the ACA, categorized by type
- Reviewed what health benefits are mandated by Virginia
  - Do not need a legislative mandate for a benefit to include this in the EHB benchmark plan
  - States can also mandate benefits “in addition to EHBs” but then the state has to make payments to defray the cost

- Grandfathering clause of January 1, 2012, for benefits not included in EHB benchmark plan is considered to be “in-addition” and the state pays the carriers for mandates
  - Changing benchmark plan to include additional benefits prevents need for state to defray costs, 5-year plan review established by Chapter 698 of the 2023 Acts of Assembly to ensure periodic review.
  - Stakeholder workgroup established and reports to HIRC by March 2025
  - HIRC will consider recommendations to identify benefit changes for EHB benchmark
- Current review will be reported to HIRC in 2025
  - If HIRC recommends Virginia apply for a new EHB benchmark plan, legislation must be enacted to direct BOI to select a new benchmark plan that includes specific benefit changes
- Provided an EHB benchmark review timeline
- Stated that EHB benchmark is a “Step 1” assessment; there is an option for a “Step 2” analysis by BOI and JLARC, which is more comprehensive assessment
- Clarified that Step 2 assessments consider current coverage in Virginia, expected impacts, and expected additional costs to the state.
  - Expedited Step Two review requested for PANDAS/PANS coverage as outcome of HB513 (2024), BOI prioritizes the review for the insurance mandate coverage
  - Shared that the review has found the following of note:
    - No Current Procedural Terminology (CPT) codes for PANDAS/PANS
    - Some carriers cover all named treatments as medically necessary, and other carriers some named treatments to be experimental
    - Coverage not included in current EHB and would cause the Commonwealth to incur costs
- Clarified that BOI uses a range of numbers due to actual prevalence of PANDAS/PANS unknown due to inaccurate coding or provider not aware
- Council members asked clarifying questions about:
  - What kinds of plans BOI regulates
  - Who regulates cost-sharing
  - What JLARC is looking at versus what BOI is looking at in terms of impact/cost estimates
  - Which entity is looking at costs to insurance over time essentially
  - How information is gathered when providers are not using ICD-10 code to associate with a PANDAS/PANS diagnosis
  - How to send data or other information regarding PANDAS/PANS
  - Whether BOI has any control over what treatments that carriers classify as “experimental”
  - How does BOI look at cost of treatment based on contracts with pharmacy and cost benefit analysis of treatment
  - What components should be factored in by Council for specific ask to have insurance coverage
  - If BOI/JLARC look at findings from other states during their analysis
- Stated that data can be sent to [hiredata@scc.virginia.gov](mailto:hiredata@scc.virginia.gov) , and PANDAS/PANS coverage is still under review
- Dr. Swedo shared recent consortium clarified that 1 in 20,000 needs IVIG- less than 10%
- Kristina Nunnally shared that California performed a study on the cost of inaction of a PANDAS/PANS diagnosis with regards to psychiatric infrastructure
- Shared have to review caps on charges for carriers and members when factoring defrayal costs
- Shared that the advocacy and information provided for the current PANDAS/PANS has been substantial
- BOI focuses on cost to carrier/member for cost-benefit analysis, where JLARC cost-benefit analysis is expanded to socio-economical and other infrastructure impacts
- Clarified that contractor reviews literature and outcomes from other states with mandates and summarizes, but focus is on Virginia carriers
- JLARC will present findings at next HIRC meeting on 12/9, open to the public and there will be a public comment period
  - Christen will send out Town Hall info for HIRC 12/9

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

- Deferred to next session due to time constraints of meeting from Council discussions

### **Council Business**

- Planning Discussion
  - The Council reviewed the authorization in Code for the Council priorities, including practice guidelines for the diagnosis and treatment of PANDAS/PANS; mechanisms to increase clinical awareness and education regarding PANDAS/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/PANS; and development of a network of volunteer experts on the diagnosis and treatment of PANDAS/PANS to assist in the delivery of education and outreach.
  - The Council identified the following current goals:
    - Standardized Education
    - Promote awareness of importance for insurance coverage (diagnosis and treatment)
    - Awareness campaign
  - The Council identified the following current priorities:
    - HIRC Meeting Outcome:
      - Favorable: focus on education, outreach, and awareness
      - Not favorable: Collect more data, also focus on education, outreach, and awareness
    - Establish 3 new subcommittees, will bring recommendations to Council and report out
      - Education
        - Target audiences include providers, schools, families, early childhood providers, urgent care, emergency department
        - Suggested handout for pediatricians to have in office (electronic through EMR)
        - Consider webinar with CME accreditation, attached case studies
        - Survey pediatricians re: knowledge of PANDAS/PANS
          - Consider REDCap survey
        - Webinar with CME attached case studies
      - Communication
        - Design Communication campaign
        - Review outstanding communication recommendations for dissemination including law enforcement
        - Utilize VDH resources such as clinician's letter and provider newsletter, partner with local health districts, promote PANDAS/PANS awareness day on October 9<sup>th</sup>
        - Dr. Vanessa Walker-Harris spoke to Health Department avenues of communicating information – healthcare newsletter, local health departments, partnerships such as MSV, etc. As of now, currently do not have funding to facilitate full communication campaign, but will request quote from VDH Communications for such campaigns (DOI, billboards, promotion of radio spots, websites, etc.)
  - Provision of Care (e.g. Center of Excellence)
    - Explore potential implementation and funding opportunities

- Center of Excellence (one example is of University of Arizona model – CHOR was recommended as pilot in the past, and recommendation was made to Governor for establishment of Center of Excellence in previous report)
  - PANDAS/PANS education as a professional license requirement- (Department of Health Professionals) or have them assist with increasing education
  - Survey of providers to know who has treated PANDAS/PANS – consider review All Claims Payor Database
- Discussion on how fast and when can Advisory Council take action without higher level approval
  - No-cost approach, in kind support, vs legislation/regulatory action
  - Some items can be done now and does not need necessarily need to move forward to
- Budget amendment considerations
- Next Meeting/Agenda items -
  - 3-4 meetings of full Advisory Council annually
    - Subcommittees to meet in-between Council meetings and report out
    - Next full meeting of Council likely to be in April
  - VDH will send out survey to council to determine which subgroup they would like to serve on and poll for next meeting
  - Request send emails to Christen Crews, VDH Staff, only to meet FOIA public meeting requirements
  - Next meeting agenda items:
    - Subcommittee Report Outs
    - Legislative updates
    - Mr. Brian Gottstein presentation
    - CME presentation/discussion with UVA CME office
    - Data
    - Guest Speakers/Other state experiences: California, VA AAP rep,
- Adjourn – at 2:05p