



COMMONWEALTH of VIRGINIA

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January 7, 2026

MEMORANDUM

TO: The Honorable Glenn Youngkin
Governor, Commonwealth of Virginia

The Honorable L. Louise Lucas
President Pro Tempore, Senate of Virginia

The Honorable Don Scott
Speaker of the House, Virginia House of Delegates

FROM: Karen Shelton, MD
State Health Commissioner, Virginia Department of Health

SUBJECT: 2025 Report on the Advisory Council on Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome

This report is submitted in compliance with the Code of Virginia § 32.1-73.10, which states:

The Advisory Council shall report to the Governor and the General Assembly, by December 1 of each year, on the Advisory Council's recommendations related to:

- 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.*

Should you have any questions or need additional information, please feel free to contact me at (804) 864-7002.

KS/KB
Enclosure

Pc: The Honorable Janet V. Kelly, Secretary of Health and Human Resources

REPORT ON THE PEDIATRIC
AUTOIMMUNE NEUROPSYCHIATRIC
DISORDERS ASSOCIATED WITH
STREPTOCOCCAL INFECTIONS AND
PEDIATRIC ACUTE-ONSET
NEUROPSYCHIATRIC SYNDROME
ADVISORY COUNCIL

REPORT TO THE GOVERNOR AND THE
GENERAL ASSEMBLY

2025



VIRGINIA DEPARTMENT OF HEALTH

PREFACE

The Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome Advisory Council (PANDAS/PANS Council) is tasked by the Code of Virginia (§§ 32.1-73.9 through 32.1-73.11) with advising the Commissioner of Health on research, diagnosis, treatment, and education relating to pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) and pediatric acute-onset neuropsychiatric syndrome (PANS). The Council is to provide a report to the Governor and the General Assembly each year by December 1 summarizing the activities and recommendations of the Council. The Virginia Department of Health (VDH) is tasked with providing staff support to the Council and assisted the Council with preparing this document, which serves as the Council's 2025 report.

COUNCIL MEMBERS

Legislative Members

Delegate Patrick Hope, Chair
Delegate Debra Gardner, Vice-Chair
Senator Barbara Favola
Delegate Irene Shin
Senator David Suetterlein
Delegate Kathy Tran

Non-Legislative Members

Vacant, immunologist treating PANDAS/PANS
Ann Flippin, representative of Autism advocacy group
Brian Gottstein, parent of a child with PANDAS/PANS
Dr. David Jaffe, provider specializing in field
Dr. Galam Khan, medical researcher specializing in field
Kristina Nunnally, representative from PANDAS/PANS advocacy group
Dr. Aradhana Sood, child psychiatrist treating PANDAS/PANS
Dr. Susan Swedo, medical researcher specializing in field
Terry Woody, representative of Virginia School Nurses' Association

Ex-Officio Member

Dr. Vanessa Walker Harris, Director, Office of Family Health Services, Virginia Department of Health – Designee of the Commissioner

Virginia Department of Health Staff Supporting the Council

Christen Crews, Birth Defects Surveillance Program and PANDAS/PANS Advisory Council Coordinator, Office of Family Health Services
Marcus Allen, Director, Children and Youth with Special Health Care Needs, Office of Family Health Services
Toni Hayes, Child Development Centers and Virginia Bleeding Disorders Program Coordinator, Office of Family Health Services

Jennifer Macdonald, Director, Division of Child and Family Health, Office of Family Health Services

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EXECUTIVE SUMMARY

The Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) Advisory Council (Council) is tasked by the Code of Virginia (§§ 32.1-73.9 through 32.1-73.11) to advise the Commissioner of Health on research, diagnosis, treatment, and education relating to PANDAS and PANS. The Council is required to report to the Governor and General Assembly each year by December 1st summarizing the activities and recommendations of the Council related to practice guidelines for the diagnosis and treatment of PANDAS and PANS; mechanisms to increase clinical awareness and education; outreach to educators and parents to increase awareness; and the development of a network of volunteer experts.

The Council held three public meetings from November 2024 through July 2025, for which the Virginia Department of Health (VDH) provided staff support. The Council also established three subcommittees. Each subcommittee met two times during this timeframe. Additional meetings are planned for both the Council and subcommittees before the end of the year. Recommendations from the Council are listed below.

RECOMMENDATIONS

The Council developed the following recommendations based on public comments, presentations, and discussions from its meetings this year, as follows:

1. VDH should explore a partnership with a community organization or an academic institution to conduct a project that would assess the baseline knowledge of health care providers for the pediatric population (pediatricians, urgent care providers, emergency department providers, and current PANDAS/PANS providers). The goal would be to identify gaps in provider knowledge of PANDAS/PANS, as well as any gaps in screening and treatment standards for PANDAS/PANS.
2. Pilot a Center of Excellence for treating PANDAS/PANS and autoimmune encephalopathy (AE). This multi-disciplinary clinic, similar to the successful model of the VDH Pediatric Comprehensive Sickle Cell Centers, would provide access to multiple specialists, such as psychiatrists, immunologists, occupational therapists (OT), physical therapists (PT), and social workers, who work together to develop a comprehensive treatment plan for those with PANDAS/PANS. The Center of Excellence could serve as a model for expansion throughout the Commonwealth of Virginia.
3. The Department of Health Professions (DHP) could investigate continuing education (CEU/CME) training on PANDAS/PANS as part of licensure requirements for specific providers interacting with the pediatric population. These may include DHP-licensed physicians, physician assistants, and/or nurse practitioners.
4. It is recommended that VDH increase public communications about PANDAS/PANS. This could include developing and deploying an initial public awareness campaign about PANDAS/PANS to target multiple stakeholders including

providers, schools, and families. This could also include VDH enhancing the existing VDH PANDAS/PANS website to include improved accessibility and expanding to provide focused content, education, and resources relevant to different stakeholders (i.e. providers, schools, families).

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INTRODUCTION

REPORT MANDATE

The Code of Virginia § 32.1-73.9, promulgated by Chapter 466 of the 2017 Acts of the General Assembly, directs the Virginia Department of Health (VDH) to support the Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome Advisory Council (Council). The Code mandates that the Council advise the Commissioner of Health on research, diagnosis, treatment, and education relating to pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) and pediatric acute-onset neuropsychiatric syndrome (PANS). Pursuant to the Code of Virginia § 32.1-73.10, the Council is required to report to the Governor and General Assembly each year by December 1st summarizing the activities and recommendations of the Council.

COUNCIL ACTIVITIES

The Council reconvened on November 22, 2024 for the first time since October 2021. Since that time, the Council has adopted bylaws and an electronic meetings policy; elected a Chair and Vice-Chair; received presentations, held discussions, and invited public comments to learn more about the needs and challenges faced by individuals, families, and providers around PANDAS/PANS in Virginia; and established three subcommittees to focus on Council priorities. The PANDAS/PANS Advisory Council met three times and provided public comment periods at each meeting. Each of the three subcommittees met two times and provided public comment periods at each meeting. VDH staff provided support at each meeting.

A summary of this year's meetings is as follows:

NOVEMBER 22, 2024 COUNCIL MEETING

The Council reconvened on November 22, 2024. The meeting was held in-person at the Virginia Hospital and Healthcare Association (VHHA). The Council achieved a quorum, conducted introductions, and voted to adopt revised bylaws and an electronic meeting policy (EMP). The Council elected Delegate Hope as Chair and Delegate Gardner as Vice-Chair. VDH staff provided a historical overview of the Council and facilitated a discussion of Council goals, objectives, and priorities. Delegate Hope provided updates on the current legislative landscape of PANDAS/PANS in Virginia. A presenter from the Bureau of Insurance (BOI) reviewed their current study of PANDAS/PANS insurance coverage in Virginia, as mandated by the 2023 General Assembly Session. The Council discussed priorities and established three subcommittees (Provision of Care, Education, and Communication) to focus on potential action items. Two individuals provided public comments.

APRIL 25, 2025 COUNCIL MEETING

The April 25, 2025 PANDAS/PANS Advisory Council meeting was held virtually. The Council achieved a quorum, conducted introductions, and voted to approve prior meeting minutes. During this meeting, the Council received presentations from Brian Gottstein (Council Member, parent of a child with PANDAS/PANS), Delegate Hope (Chair, PANDAS/PANS

Advisory Council), Rhonda Newsome (Department of Medical Services, DMAS), and Christen Crews (VDH). Brian Gottstein shared his personal experience with the family perspective and diagnostic odyssey for diagnosis and treatment challenges for his daughter. Delegate Hope provided updates on legislation that was enacted during the 2025 General Assembly session directing DMAS to amend coverage for screening and treatment of PANDAS/PANS effective July 1, 2025 (<https://lis.virginia.gov/bill-details/20251/HB1641>). Rhonda Newsome presented an overview of DMAS and its responsibilities related to legislative mandates for coverage of health insurance benefits and providers. The Council members discussed how it is important to familiarize providers with the syndromes/conditions for PANDAS/PANS, including diagnosis codes. The Council also discussed how additional education of providers and parents about PANDAS/PANS is needed. Christen Crews reviewed operational updates for the Council including procedures for convening subcommittee meetings and Council's contribution to the mandated annual report through recommendations. No individuals provided public comment.

JUNE 2, 2025 SUBCOMMITTEE MEETING: PROVISION OF CARE

The June 2, 2025 Provision of Care Subcommittee Meeting was held virtually. The Subcommittee achieved a quorum, selected a Chair (Kristina Nunnally), and reviewed the electronic meeting policy (EMP). Delegate Hope (Chair, PANDAS/PANS Advisory Council) discussed the charge of the subcommittee, how the subcommittee will report findings to the full Council, and that the goal of the meeting was to develop a workplan to guide subcommittee activities. Open discussion of subcommittee members focused on how to treat individuals as early as possible and the concept of a multidisciplinary Center of Excellence. The main problem the subcommittee identified was that children in the Commonwealth of Virginia lack access to high quality in-state care for PANDAS/PANS. The majority of the subcommittee meeting was used to develop the first draft of a subcommittee workplan. The workplan identified several goals and objectives related to the developing Specialty Care (a Center of Excellence) for those diagnosed with PANDAS/PANS, improving knowledge of PANDAS/PANS cases and providers in Virginia, and developing recommendations for best practices/standards of care for PANDAS/PANS ([Appendix C](#)). No individuals provided public comment.

JUNE 6, 2025 SUBCOMMITTEE MEETING: EDUCATION

The June 6, 2025 Education Subcommittee Meeting was held virtually. The Subcommittee achieved a quorum, selected Co-Chairs (Kristina Nunnally and Dr. Galam Khan), and reviewed the electronic meeting policy (EMP). Delegate Hope (Chair, PANDAS/PANS Advisory Council) discussed the charge of the subcommittee, how the subcommittee will report findings to the full Council, and that the goal of the meeting was to develop a workplan to guide subcommittee activities. Open discussion of subcommittee members focused on previous educational resources developed by the Council, dissemination to providers/families, and potential needs for updates. The main problem identified was that PANDAS/PANS is not adequately diagnosed and treated because community members, clinicians, and decisionmakers are not educated and aware of PANDAS/PANS diagnosis, treatment guidelines, and available resources. The majority of the subcommittee meeting was used to develop the first draft of the workplan. The workplan identified several goals and objectives related to increasing PANDAS/PANS awareness among target audiences, including parents and clinicians; increasing knowledge of providers and families regarding mandated insurance coverage updates for PANDAS/PANS testing and

treatment; and reviewing existing Council resources on PANDAS/PANS education for updates ([Appendix C](#)). No individuals provided public comment.

JUNE 9, 2025 SUBCOMMITTEE MEETING: COMMUNICATION

The June 9, 2025 Communication Subcommittee Meeting was held virtually. The Subcommittee achieved a quorum, selected a Chair (Brian Gottstein), and reviewed the electronic meeting policy (EMP). Delegate Hope (Chair, PANDAS/PANS Advisory Council) discussed the charge of the subcommittee, how the subcommittee will report findings to the full Council, and that the goal of the meeting was to develop a workplan to guide subcommittee activities. Open discussion of subcommittee members focused on previous Council activities around communication and for this subcommittee to support the other two subcommittees for dissemination of education and training resources. The main problem identified was lack of knowledge of PANDAS/PANS, awareness and access to resources, and misdiagnosis leading to delay in treatment, affecting families and the medical community in the Commonwealth of Virginia. The majority of the subcommittee meeting was used to develop the first draft of the workplan. The workplan identified several goals and objectives identified with supporting action items such as utilize existing relationships and avenues of health promotion for increasing awareness of PANDAS/PANS; supporting PANDAS/PANS Advisory Council and Subcommittees with communication outreach; and designing new materials and formats of education material and resources of PANDAS/PANS ([Appendix C](#)). No individuals provided public comment.

JULY 18, 2025 SUBCOMMITTEE MEETINGS

On July 18, 2025, concurrent subcommittee meetings were held in-person at the VHHA prior to the afternoon full Council meeting.

The Provision of Care Subcommittee meeting achieved a quorum and voted to approve prior meeting minutes. The subcommittee discussed establishing an outreach program to assess knowledge gaps for diagnosing and treatment in current providers and establishment of a pilot project of a Center of Excellence. The members proposed to start with a list of known providers and expand with additional data gleaned from the All Payors Claims Database (APCD). The subcommittee members also discussed the previous proposal to establish a pilot Center of Excellence. This Center would provide a multi-disciplinary clinic and treatment, similar to the successful model of the Pediatric Sickle Cell Centers, to provide a clinic day with all provider specialties such as psychiatrists, social worker(s), OT/PT, etc. The Chair, Kristina Nunnally, discussed two bills currently moving through Massachusetts for PANDAS/PANS and shared with the legislative members. The subcommittee members identified recommendations to report to the full Council on findings of the subcommittee. No individuals provided public comment.

The Education Subcommittee meeting did not achieve a quorum and was unable to approve previous meeting minutes. The members discussed different formats of continuing medical education (CME) and continuing education units (CEU) credits, with the limitations of the Council to create without funding or authority. Dr. Galam Khan (Co-Chair, Education Subcommittee), explored potential partnerships with other education institutions and suggested collaboration with the Communication subcommittee for promotion and awareness. Dr. David

Jaffe provided updates on feedback from the PPN (PANDAS/PANS Physician Network) on the Council's current educational resources. The subcommittee members voiced concerns of misdiagnosis and potential impact on future careers (i.e. military, police officer, government jobs). Formal recommendations were unable to be developed to report to the full Council due to a lack of quorum. No individuals provided public comment.

The Communication Subcommittee meeting achieved a quorum and voted to approve prior meeting minutes. The members reviewed the draft logos for branding the Council prepared by the VDH OFHS Communication team. The majority of the meeting focused on member discussion of potential recommendations to the full Council and actionable steps to promote awareness of PANDAS/PANS in Virginia. The subcommittee members discussed the importance of promoting awareness by having families share personal stories with legislative members and the Governor. The subcommittee members voiced that the Council submit a request for a Proclamation of PANDAS/PANS Day for October 9th, 2025 and work on an awareness campaign using social media. The members agreed that the PANDAS/PANS website, located under VDH Epidemiology, should be updated to a more accessible location and be segmented to focus on different audiences (i.e. school, providers, families). The Chair, Brian Gottstein, reported the findings of the subcommittee to the full Council for the annual report. No individuals provided public comment.

JULY 18, 2025 COUNCIL MEETING

The July 18, 2025 Council meeting was held in-person at the VHHA after the subcommittee meetings. The Council achieved a quorum, conducted introductions, and voted to approve the prior meeting minutes. During this meeting, the three Chairs of the subcommittees reported to the full Council updates on the subcommittees including identified problems, objectives, points of discussion, and needs for collaboration from the other subcommittees. The Provision of Care Subcommittee Chair, Kristina Nunnally, shared the recommendations of establishing an outreach program to survey providers to identify knowledge gaps and piloting a Center of Excellence model for PANDAS/PANS. The Communication Subcommittee Chair, Brian Gottstein, shared the draft logos for the Council to receive additional feedback and the recommendations to the Council for promoting PANDAS/PANS awareness with request for Governor's Proclamation, family stories, social media, and communication campaigns; and update the existing VDH PANDAS/PANS website to expand focus on different audiences or stakeholders. Dr. Galam Khan, Co-Chair of the Education Committee, shared discussion items from the subcommittee; however, he was unable to provide formal recommendations to the Council due to not having a quorum. The Council drafted recommendations for the Education subcommittee including recommending mandating CEU/CME training on PANDAS/PANS for providers interacting with the pediatric population. Delegate Hope, Chair, reviewed the recommendations presented for each subcommittee domain and consensus voting approved including them in the annual report. Christen Crews, VDH Staff, reviewed the mandate for the submission of the annual report on Council activities and that a draft report will be disseminated to the Council members for feedback. No individuals provided public comment.

The next full Council meeting is scheduled for November 7, 2025 and the findings will be reported in next year's report. The subcommittees will meet prior to the full Council meeting and continue efforts on action items to report at the full Council meeting.

REPORT OUTLINE

This report provides an overview of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) and pediatric acute-onset neuropsychiatric syndrome (PANS) and the establishment of the Council. It also highlights previous Council activities, provides a status update on the Council, and summarizes recommendations from the Council.

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CLINICAL OVERVIEW OF PANDAS/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 (Swedo et al., 1998). 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)(Swedo et al., 2012). 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); and*
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 (Change et al., 2015). The incidence and prevalence of PANDAS/PANS are unknown. A conservative estimate of the prevalence of PANDAS/PANS in the United States is 1 in 200 children. In Virginia, a comprehensive system of care that fully meets the needs of families of individuals with a diagnosis of PANDAS/PANS is lacking. As a result, clinical providers may need additional education and training on how to diagnose and treat PANDAS/PANS. While a variety of treatment options are available to address the range and severity of PANDAS/PANS symptoms, the lack of health insurance coverage for treatment presents a barrier. Additionally, the absence of standardized use of current procedural terminology (CPT) codes among providers when billing for insurance reimbursement for treatment of PANDAS/PANS symptoms can cause barriers to receiving care.

HISTORY OF THE PANDAS/PANS ADVISORY COUNCIL

During the 2017 Virginia General Assembly Session, Chapter 466 of the 2017 Acts of the General Assembly amended the Code of Virginia by adding §§ 32.1-73.9 through 32.1-73.11 to establish the Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome Advisory Council. The Council is tasked with reporting annually by December 1 to the General Assembly on Council activities; 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.

The Council membership is comprised of fifteen members, including legislative representatives (four members from the House of Delegates and two members from the Senate), and one ex-officio member. 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 activities since 2017 can be summarized as follows:

- In 2017, Council meetings were initiated, and two meetings convened with the majority of members in attendance. The activities of the Council included the adoption of Council governance documents, education to the Council of PANDAS/PANS, and review of the first-year work plan for the Council. The Council established three subcommittees to further expand work on key focus areas. The three subcommittees include practice guidelines for diagnosis and treatment; mechanisms to increase clinical awareness; and outreach to educators and parents.
- In 2018, the Council convened joint subcommittee meetings to develop draft resources for various stakeholders. These resources included a PANDAS/PANS diagnosis and treatment algorithm for providers; parent education and guidance documents; and an informational resource document for school educators. The Council engaged external stakeholders to inform the work of the Council and obtained feedback on the following points related to PANDAS/PANS recommendations: diagnosis and treatment guidelines currently used; mechanisms for disseminating resources in practice/clinic settings; recommended tools and resources that will provide the greatest reach to increase awareness and education; evidence-based practices for educators and parent; and structuring a network of volunteer experts.
- In 2019, the Council finalized revisions to the draft resources including an evaluation and treatment algorithm for clinicians; an informational handout for parents; an informational handout for school systems; and a frequently asked questions (FAQs) resource. The Council discussed strategies to increase awareness and education of clinicians, parents, and educators. Barriers with insurance coverage was also discussed as a barrier to assessment and treatment about PANDAS/PANS. The Council convened a forum of experts for discussion of the proposed recommendation to establish a center of excellence in Virginia to treat PANDAS/PANS and autoimmune encephalopathy (AE). Example centers of excellence models were reviewed, included a proposed hybrid model developed for the Children's Hospital at VCU. The Council agreed to include in the annual report to the General Assembly the recommendation to establish a center of excellence in Virginia. 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.

- In 2020, the Council reviewed final revisions to the four resource documents previously developed. The Council recommended that VDH disseminate a PANDAS/PANS diagnosis and treatment algorithm to physicians and clinicians throughout the state. The Council developed a draft evaluation and treatment algorithm to address the two primary focus areas including practice guidelines for diagnosis and treatment and mechanisms to increase clinical awareness. The Council provided recommendations on potential dissemination of the resources to providers, parents, and educators once finalized.
- In 2021, the Council discussed disseminating the resources throughout the state and hosting an educational webinar for providers. The Bureau of Insurance (BOI) presented an overview of the insurance mandate process in Virginia. The Council drafted letters to accompany the dissemination of resources to the various stakeholders throughout the Commonwealth. Additional edits and resources were recommended to be added to the VDH PANDAS webpage. The webpage can be accessed at:
<https://www.vdh.virginia.gov/epidemiology/epidemiology-fact-sheets/pediatric-autoimmune-neuropsychiatric-disorders-associated-with-streptococcal-infections-pandas/>.
- In 2024, pursuant to § 32.1-73.11 and Chapter 391 of the 2024 Acts of Assembly, the Council, which was set to sunset July 1, 2022 and continued by the 2022 Appropriations Act, was continued to July 1, 2028. VDH staff reconvened the Council in November 2024.

Additional details on the Council's activities and accomplishments from 2017 to 2024 are outlined in previously published reports to the General Assembly and can be accessed on the Virginia Legislative Information System:

<https://rga.lis.virginia.gov/search/?query=pandas+pans>.

RECOMMENDATIONS

The Council developed the following recommendations based on public comments, presentations, and discussions from its meetings this year, as follows:

1. VDH should explore a partnership with a community organization or an academic institution to conduct a project that would assess the baseline knowledge of health care providers for the pediatric population (pediatricians, urgent care providers, emergency department providers, and current PANDAS/PANS providers). The goal would be to identify gaps in provider knowledge of PANDAS/PANS, as well as any gaps in screening and treatment standards for PANDAS/PANS.
2. Pilot a Center of Excellence for treating PANDAS/PANS and autoimmune encephalopathy (AE). This multi-disciplinary clinic, similar to the successful model of the VDH Pediatric Comprehensive Sickle Cell Centers, would provide access to multiple specialists, such as psychiatrists, immunologists, occupational therapists (OT), physical therapists (PT), social worker, who work together to develop a comprehensive treatment plan for those with PANDAS/PANS. The Center of Excellence could serve as a model for expansion throughout the Commonwealth of Virginia.
3. The Department of Health Professions (DHP) could investigate continuing education (CEU/CME) training on PANDAS/PANS as part of licensure requirements for specific providers interacting with the pediatric population. These may include DHP-licensed physicians, physician assistants, and/or nurse practitioners.
4. It is recommended that VDH increase public communications about PANDAS/PANS. This could include developing and deploying an initial public awareness campaign about PANDAS/PANS to target multiple stakeholders including providers, schools, and families. This could also include VDH enhancing the existing VDH PANDAS/PANS website to include improved accessibility and expanding to provide focused content, education, and resources relevant to different stakeholders (i.e. providers, schools, families).

REFERENCES

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APPENDIX A – AUTHORIZING CHAPTERS

CHAPTER 466 OF THE 2017 ACTS OF ASSEMBLY

Be it enacted by the General Assembly of Virginia:

1. That the Code of Virginia is amended by adding in Chapter 2 of Title 32.1 an article numbered 16, consisting of sections numbered [32.1-73.9](#), [32.1-73.10](#), and [32.1-73.11](#), as follows:

Article 16.

Advisory Council on Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome.

§ [32.1-73.9](#). Advisory Council on Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome; membership.

A. There is hereby created in the executive branch of state government the Advisory Council on Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome (the Advisory Council), for the purpose of advising the Commissioner of Health on research, diagnosis, treatment, and education relating to pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome.

B. The Advisory Council shall have a total membership of 15 members that shall consist of six legislative members, nine nonlegislative citizen members, and one ex officio member. Members shall be appointed as follows: four members of the House of Delegates 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; two members of the Senate to be appointed by the Senate Committee on Rules; and the following nine nonlegislative citizen members to be appointed by the Governor: one licensed health care provider who has expertise in treating persons with pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome and autism; one pediatrician who has experience treating persons with pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome; one child psychiatrist who has experience treating persons with pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome; one immunologist with experience in treating persons with pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome and the use of intravenous immunoglobulin; one medical researcher with experience conducting research concerning pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome, obsessive-compulsive disorder, tic disorder, and other neurological disorders; one representative of a professional organization for school nurses in the Commonwealth; one representative of an advocacy and support group for

individuals affected by pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome; one representative of an advocacy and support group for individuals affected by autism; and one parent of a child who has been diagnosed with pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome and autism. The Commissioner of Health or his designee shall serve ex officio without voting privileges. Nonlegislative members shall be citizens of the Commonwealth.

Legislative members and the ex officio member of the Advisory Council shall serve terms coincident with their terms of office. Nonlegislative members shall be appointed for terms of two years. 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.

C. Legislative members of the Advisory Council shall receive such compensation as provided in § [30-19.12](#). Nonlegislative members shall serve without compensation or reimbursement.

D. The Advisory Council shall elect a chairman and a vice-chairman annually from among its legislative membership. A majority of the members shall constitute a quorum. The Advisory Council shall meet at such times as may be called by the chairman or a majority of the Advisory Council.

E. 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.

§ [32.1-73.10](#). Advisory Council; report.

The Advisory Council shall report to the Governor and the General Assembly, by December 1 of each year, on the Advisory Council's recommendations related to:

- 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.*

[32.1-73.11](#). *Sunset.*

This article shall expire on July 1, 2020.

CHAPTER 391 OF THE 2024 ACTS OF ASSEMBLY

Be it enacted by the General Assembly of Virginia:

1. That § [32.1-73.11](#) of the Code of Virginia is amended and reenacted as follows:

§ [32.1-73.11](#). (Continued pursuant to Acts 2022, Sp. Sess. I, c. 2, Item 299 D) Sunset.

This article shall expire on July 1, ~~2020~~ 2028.

APPENDIX B – ACRONYMS AND ABBREVIATIONS

AE - autoimmune encephalopathy

BOI - Bureau of Insurance

CPT – current procedural terminology

DHP – Department of Healthcare Professions

DMAS – Department of Medical Assistance Services

OCD – obsessive compulsive disorder

OFHS – Office of Family Health Services (VDH)

PANDAS – pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections

PANS – pediatric acute-onset neuropsychiatric syndrome

VDH – Virginia Department of Health

VHHA – Virginia Hospital and Healthcare Association

APPENDIX C- SUBCOMMITTEE WORKPLANS

Provision of Care Subcommittee Workplan

| Problem | Goal/Objective | Action Items | Supporting Action Items |
|---|--|--|--|
| Children in the Commonwealth of Virginia lack access to high quality in-state care of PANDAS/PANS | Train all pediatric primary care providers to recognize, evaluate, and initiate treatment of PANDAS/PANS | Recommend Department of Health to disseminate Council developed resources on PANDAS/PANS and follow-up survey | |
| | | Consider partnering with Virginia Chapter of AAP and other professional society chapters for dissemination (i.e. email blasts) | |
| | Train all urgent/crisis care providers to recognize, evaluate, and initiate treatment of PANDAS/PANS | Recommend Department of Health to disseminate Council developed resources on PANDAS/PANS and follow-up survey | |
| | | Consider partnering with Virginia Hospital and Healthcare Association (VHHA) and professional society chapters for dissemination (i.e. email blasts), lunch and learns, and members of the Advisory Council reaching out to their institutions | |
| | Specialty care (Center of Excellence) for those diagnosed with PANDAS/PANS | Determine best model for specialty care to modify, adopt, and implement in Virginia (i.e. Center of Excellence, training staff at different hospitals, refer to a clinic after ED visit) | |
| | | Ensure viability of fiscal support and sustainability of specialty care | Review NC and other models process of legislation/funding procurement |
| | Improve knowledge of PANDAS/PANS cases in the Commonwealth of Virginia | Review Virginia All-Payers Claim Database (APCD) for identifying providers treating for PANDAS/PANS | |
| | | Consider recommendation for PANDAS/PANS mandated reporting for Infectious Disease (ID) | |
| | Improve knowledge of PANDAS/PANS providers in the Commonwealth of Virginia | Review Virginia All-Payers Claim Database (APCD) for identifying providers treating for PANDAS/PANS | |
| | | Consider recommendation for provider directory of those qualified to diagnose/treat PANDAS/PANS | VDH Staff will follow-up with GRA and Office of Licensure |
| | Recommend best practices/standards of care for PANDAS/PANS (providers) | Evaluate existing standards of care for PANDAS/PANS in hospitals/Children hospitals for developing recommendation | |
| | | Consider legislation to mandate adopting standards of care for acute onset neuropsychiatric disorders | Task Council to develop standards of care as opposed to legislatively mandated workgroup |

Education Subcommittee Workplan

| Problem | Goal/Objective | Action Items | Supporting Action Items |
|--|---|--|---|
| PANDAS/PANS is not adequately diagnosed and treated because community members, clinicians, and decision makers are not educated and aware of PANDAS/PANS diagnosis, treatment guidelines, and available resources. | Increase PANDAS/PANS awareness among target audiences, including parents, clinicians (peds, fp, urgent care, EDs, etc), schools, etc | Review existing Council resources on PANDAS/PANS for potential edits Ask PANDAS/PANS Research Consortium (Stanford) for feedback on existing resources Incorporate feedback from Consortium Update existing resources Recommend to Communication subcommittee dissemination of updated resources Develop handout for PANDAS/PANS symptoms to look out for after a diagnosis of strep infection or when to return to provider (i.e. after visit summary) | Reach out to Consortium regarding timeline for updated guidelines |
| | Create content for education of stakeholders including school nurses, providers (Pediatricians, Child Psych, Urgent Care, Speciality Providers), Child Development Centers (CDC), etc. (i.e. webinars or trainings) | Review and consider using updated guidelines from PANDAS/PANS Research Consortium for content Consider recommending CME certification for webinars to the Commissioner of Health | |
| | Increase knowledge of providers and families regarding mandated insurance coverage updates for PANDAS/PANS testing and treatment | Network with local chapters and medical provider professional societies to offer education Contact DMAS, Virginia Association of Health Plans, Bureau of Insurance, and SCC on educational information that will be given to providers and/or families for insurance coverage on PANDAS/PANS | Collaborate with VMAP and DBHDS on PANDAS/PANS training Consider including resources such as PANDAS Physician Network has list of testing and initial labs |

Communication Subcommittee Workplan

| Problem | Goal/Objective | Action Items | Supporting Action Items |
|---|---|---|---|
| Lack of knowledge of PANDAS/PANS, awareness and access to resources, misdiagnosis leading to delay in treatment, affecting families and the medical community in the Commonwealth of Virginia | Utilize existing relationships and avenues of health promotion to increase awareness of PANDAS/PANS | Include links to PANDAS/PANS educational resources on existing avenues of health promotion to providers from VDH | |
| | | Collaborate with Virginia Association of School Nurses (VASN) to promote education of PANDAS/PANS | Explore opportunity to present or share resources at Fall Conference or Spring VDOE training |
| | | Partner with local chapters of medical organizations (VA AAP, school nurses, VMAP, ASCV, etc.) | Collect Virginia family stories affected by PANDAS/PANS (Virginia PANDAS/PANS Alliance) |
| | | | Explore webinars, "Lunch n Learns", Grand Rounds, other speaking opportunities |
| | | | Consider contributing to emails and quarterly publications |
| | Support Council and Subcommittees with Communication Outreach | Provide support to Council and other subcommittees with dissemination plans, design, wordsmith, appropriate language for audience, etc. | |
| | | | |
| | Design new materials and formats of education material and resources of PANDAS/PANS | | Pursue development of a specialized website for parents, providers, and advocates of Virginia resources |
| | | Develop brochures (providers and parents), videos, specialized website, clinic posters | Collaborate with other subcommittees on content for developing webinars, brochures, and posters for clinics |
| | | | Consider using volunteers or advocacy groups to create video resources |
| | Develop branding for PANDAS/PANS Council | | Create VDH Creative Communication Request for branding/logo of Council |
| | Raise awareness of PANDAS/PANS in Virginia | Promote October 9th as PANDAS/PANS awareness day | Collaborate with VDH Communication Team to share content from subcommittee for social media campaign |
| | | | LHD and Board of Supervisors |
| | | | Submit request to Governor to proclaim October 9th for PANDAS/PANS |
| | | | VDH Staff advised that Council members can only reach out to legislative members in individual capacity and not as representing the Council |
| | | | Speak with Lt. Governor's office regarding PANDAS/PANS |
| | | | Speak with Congresswoman Abigail Spanberger office |
| | | | Promote and share Council resources with legislative colleagues in Virginia |