

**DPH PANDAS/PANS Advisory Council**

**July 12, 2023**

**4:00 – 6:00 PM**

***Please stand by. The meeting will begin shortly.***

**Agenda**

* Welcome: Roll Call & Vote to Approve 5/10/2023 Minutes
* Announcements: General & Housekeeping
* Discussion: Annual Report
* Discussion: Guest Speakers
* Wrap Up: Next Steps
* Next Meeting: Wednesday, September 13, 2023, 4-6PM
* Vote: Adjourn

**Opening Roll Call & Vote**

* Attendance **roll call**
* **Vote** to approve Meeting Minutes (May 10, 2023)

**Statutory Authority**

**Section 26 of Chapter 260 of the Acts of 2020**, or the Health Care Omnibus bill establishes a special advisory council, chaired by the Commissioner of the Department of Public Health, or his designee, to advise the commissioner on research, diagnosis, treatment and education relating to pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections and pediatric acute neuropsychiatric syndrome (PANDAS/PANS).

**Aim statement**

The DPH PANDAS/PANS Advisory Council aims to **advise the DPH Commissioner on research, diagnosis, treatment, and education** relating to pediatric autoimmune neuropsychiatric discovered associated with streptococcal infections and pediatric acute neuropsychiatric syndrome (**PANDAS/PANS**).

The Advisory Council will **issue a report to the general court annually with recommendations**

concerning:

* **Practice guidelines for the diagnosis and treatment** of the disorder and syndrome;
* Development of **screening protocols**;
* **Mechanisms to increase clinical awareness and education** regarding the disorder and syndrome among physicians, including pediatricians, school-based health centers and providers of mental health services;
* **Outreach to educators and parents to increase awareness** of the disorder and syndrome; and
* **Development of a network of volunteer experts** on the diagnosis and treatment of the disorder and syndrome. (From Section 26 of Chapter 260 of the Acts of 2020).

# PANDAS/PANS Awareness Day in October

* *Please contact* [*Madelyn.M.Goskoski@mass.gov*](mailto:Elaine.Gabovitch@mass.gov) *to add any other Advisory Council updates, announcements to future agendas.*

**General Announcements**

JV/SG

**Discussion: Annual Report - Process**

## Process

* + Today
    - Review priorities and recommendations
    - Identify one or two guest speakers (TBD) for 9/13 and standard questions
  + Report follow-up: DPH team will format report for flow and consistency
    - Maddy will send **final draft to AC by August 11th**
    - Council send any **edits to Maddy by August 25th**
    - Maddy will send **final report to AC for review by September 6th**
  + September 13 meeting
    - Vote on each priority and recommendation
    - Engage guest speaker(s)
    - Determine future guest speakers

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**Discussion: Annual Report - Legislation**

## Consider current bills to be listed as recommendations

* S1266 & H1975: Study of Pediatric Adolescent Psychiatric Settings (DMH & DESE)
* H3920: Screening in Medical/Clinical Settings (DPH)

***Decide whether to include in report recommendations after we review all drafted/proposed priorities & rec’s***

JV/SG

**Discussion: Annual Report - Recommendations**

## Review recommendation matrix

1. Review for appropriate recommendations
2. Eliminate duplication
3. Organize based on priority

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**Draft Priorities**

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| **#** | **Domain** | **Priority** |
| 1 | Research | Improve understanding of the prevalence of PANS/PANDAS within the Commonwealth of Massachusetts |
| 2 | Diagnosis | Decrease delays in the diagnosis of Pediatric Acute Onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) in Massachusetts. |
| 3 | Diagnosis | Report on missed diagnoses |
| 4 | Diagnosis | Determine the working diagnostic criteria for PANS and PANDAS to be used in MA |
| 5 | Treatment | Assess and evaluate the current treatment of PANS/PANDAS in the Commonwealth of Massachusetts. |
| 6 | Treatment | Review provider compliance with current insurance laws. |
| 7 | Education | Use mechanisms to increase clinical awareness and education regarding the disorder and syndrome among physicians, including pediatricians, school-based health centers and providers of mental health services. |
| 8 | Education | Conduct outreach to educators and parents to increase awareness of the disorder and syndrome |

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| **Domain** | **Priority #1** | **Recommendations #1-3** | **Timeline** |
| Research | Improve understanding of the prevalence of PANS/PANDAS within the Commonwealth of Massachusetts | DPH will **estimate the prevalence** of PANS & PANDAS using data from MassHealth and insurance providers. Further, DPH will work with other agencies to see if they will **publish their study methodology** which may be implemented and replicated by other state health agencies around the country in order to expand and verify the results from this proposal. | Short or medium |
| The Department of Public Health/School Health Unit will **require school nurses to report data annually** on the prevalence of PANS/PANDAS. | Medium |
| State Legislators will establish a law to have the Department of Mental Health, in conjunction with the Department of Elementary & Secondary Education to **conduct a study of pediatric and adolescent psychiatric hospital settings and therapeutic day schools** to determine if any children within those settings have root causes in missed neuroimmune issues or PANDAS or PANS. | Short or  Medium |

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| **Domain** | **Priority #2** | **Recommendations #4-6** | **Timeline** |
| Diagnosis | Decrease delays in the diagnosis of Pediatric Acute Onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) in  Massachusetts. | Many patients and families in Massachusetts report that physicians do not consider a PANS/PANDAS diagnosis with initial presenting symptoms and patients and **families report long delays in accessing care with providers familiar with the diagnosis and treatment of neuroimmune disorders**. It is imperative that a broad range of Massachusetts physicians, including but not limited to pediatricians, developmental and behavioral pediatricians, family practice physicians, psychiatrists, neurologists, infectious disease specialists, rheumatologists, and allied providers become familiar with the diagnostic criteria and early immune modulating treatment options for PANS/PANDAS in order to improve timely diagnosis and access to care. (move to background/intro) | ? |
| State Legislators will **establish a law to screen for PANS/PANDAS at annual well visits** starting at the age of 3 as well as when a child or young adult has shifted in their mental status & seeks medical care. (rework wording and vote) | Short |
| Consider l**aboratory evaluation to screen for infectious triggers** and/or other disorders associated with neuropsychiatric symptoms, such as autoimmune, immune, or metabolic disorders (ex. immunodeficiencies, Systemic Lupus Erythematosus and other rheumatologic disorders, Thyroid disorders, Celiac  disease, Wilson’s disease, Nutritional deficiencies, Rheumatic fever.) (consider for education domain) | Short or Medium |

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| **Domain** | **Priority #3** | **Recommendation #7** | **Timeline** |
| Diagnosis | Report on missed diagnoses | DPH or DMH will **create a reporting mechanism for families and providers to report missed diagnosis** of PANS/PANDAS in the Commonwealth. This data will be used to better measure the prevalence of PANS/PANDAS in the state. | ? |

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| **Domain** | **Priority #4** | **Recommendations #8-11** | **Timeline** |
| Diagnosis | Improve the working diagnostic criteria for PANS and PANDAS  (reword to be broader and not MA specific, perhaps talk to consortium) | Consider creating a simplified and more inclusive set of **working diagnostic criteria for PANS**. Consider subsuming the PANDAS definition under the wider umbrella of PANS. | Long |
| Elaborate specific **diagnostic considerations to provide a framework** for physicians to diagnose and treat PANS/PANDAS. | Long |
| Once an improved working diagnostic criteria is created, the MA DPH will **develop a monitoring system to collect epidemiologic data** based on the working criteria, to assess the incidence and prevalence of PANS. | Long |
| MA DPH will review the epidemiologic data in MA and **compare with data from other state-level and national researchers**. Such comparison would enable review and possible revision of the diagnostic criteria for PANS. | Medium |

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| **Domain** | **Priority #5** | **Recommendation #12** | **Timeline** |
| Treatment | Assess and evaluate current diagnosis and/or treatment of PANS/PANDAS in the Commonwealth of Massachusetts. | The Division of Insurance will **survey current treatment providers** and hospitals in the Commonwealth to **determine who is providing PANS/PANDAS diagnosis and/or treatment** and what treatment they provide. When completed, provide the data to the council. | Short |

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| **Domain** | **Priority #6** | **Recommendation #13** | **Timeline** |
| Treatment | Review insurers compliance with current PANS/PANDAS insurance coverage laws | The Division of Insurance will **provide a report with data regarding any compliance concerns** related to the current law to the DPH PANS/PANDAS Advisory Council. | Short |

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| **Domain** | **Priority #7** | **Recommendations #14-15** | **Timeline** |
| Education | Use mechanisms to increase clinical awareness and education regarding the disorder and syndrome among health care  providers including physicians, pediatricians, school-based  health centers and providers of mental health services. | Legislature will appropriate **funding for training and mentorship programs**  to ensure cross-discipline ability to provide effective treatment. (DPH) | Short or Medium |
| [MH w/ DPH and MCAAP] will conduct a **survey with pediatric primary care providers** that will include questions regarding **whether providers are considering a diagnosis of PANS/PANDAS** when a child presents with symptoms. The survey will **assess provider awareness** of the PANS/PANDAS ICD-10 code, symptomatology, clinical diagnosis guidelines, awareness and access to treatment guidelines, and provider understanding of insurance, billing, and Massachusetts legislation. Finally, the survey will **assess whether providers have accessed or can access the resources** available on the major non-profit sites, and whether providers are printing any materials for parents/families. | Short or Medium |

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| **Domain** | **Priority #8** | **Recommendations #16-20** | **Timeline** |
| Education | Conduct outreach to educators and parents to increase awareness of the disorder and syndrome | [WHO] will conduct a **survey of school nurses** at public schools in Massachusetts to assess s**chool nurse awareness** of PANS/PANDAS, as well as whether they have accessed or can access the resources available online. | Short |
| The Department of Public Health **create a PANS/PANDAS informational web page**  accessible through a PANS/PANDAS search on the mass.gov DPH website. | Short |
| The Department of Public Health will **publish or release a guidance memorandum(?) informing the public, schools, and social service agencies about the availability of resources** once a DPH PANS/PANDAS homepage is created. This central location should include links to the major non-profit organizations’ web pages where links to resources already exist. | Short |
| Due to the unique role of school nurses in the identification, referral, and care coordination of children with PANS/PANDAS, the Department of Public Health will **make an announcement (?) of the availability of the PANS/PANDAS resources and webinars for school nurses**. Additionally, the Department of Public Health will recommend that school nurses be educated to include PANS/PANDAS using the ICD-10 code for diagnosis in the school health record: PANDAS D89.89; PANS D89.9 to facilitate tracking and reporting on prevalence. | Short |
| The Department of Elementary and Secondary Education (DESE) will r**equire school districts to offer professional development to all school staff** related to PANS/PANDAS. | Medium |

**Discussion: Guest Speakers**

### Who do we want to invite for the first meeting?

* + DPH and DOI?

### Which questions will we ask?

* + Provide brief agency description
  + Overview of program and services
  + Data, stats and incidence related to PANDAS/PANS
  + Eligibility
  + Case management and training
  + Recent family support efforts
  + Funding
  + Gaps and challenges
  + Future goals and initiatives

**Next Steps**

# Fourth meeting of 2023

* + **Wednesday, September 13, 2023, 4-6 PM**

#### Future meetings via WebEx Events

* + - If you need help, please email Maddy Goskoski at [madelyn.m.goskoski@mass.gov](mailto:madelyn.m.goskoski@mass.gov) in advance who will find assistance.

# Next steps:

* + Maddy will send **final draft by August 11th**
    - P/P Council members send **edits to Maddy by August 25th**
  + Maddy will send **final report to review and vote on by September 6th**

#### Email [madelyn.m.goskoski@mass.gov](mailto:madelyn.m.goskoski@mass.gov) to get on the September agenda

* + Anything else?

EG

**Motion to Adjourn**

Thank You!