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ACTING COMMISSIONER

**Massachusetts
Department of Public Health
PANDAS/PANS Advisory Council**

**Annual Report
Fiscal Year 2022**



Legislative Mandate

M.G.L. c. 111: An Act Promoting a Resilient Health Care System That Puts Patients First

Section 242. *(a) There shall be an advisory council on pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections and pediatric acute neuropsychiatric syndrome within the department, which shall advise the commissioner on research, diagnosis, treatment and education relating to the disorder and syndrome, hereinafter referred to as PANDAS/PANS.*

(b) The council shall consist of the commissioner, or a designee, who shall be an ex-officio, nonvoting member and the following members appointed by the commissioner: 1 physician specializing in infectious diseases, licensed and practicing in the commonwealth with experience treating persons with PANDAS/PANS and the use of intravenous immunoglobulin; 1 pediatrician licensed and practicing in the commonwealth who has experience treating persons with PANDAS/PANS; 1 child psychiatric practitioner with experience treating persons with PANDAS/PANS; 2 health care providers licensed and practicing in the commonwealth who have experience in treating persons with PANDAS/PANS; 1 medical researcher with experience conducting research concerning PANDAS/PANS, obsessive-compulsive disorder, tic disorder and other neuro-inflammatory disorders; 1 representative of a non-profit PANDAS/PANS advocacy organization in the commonwealth; 1 representative of a professional organization in the commonwealth for school nurses; 2 parents with a child who has been diagnosed with PANDAS/PANS; 1 social worker licensed and practicing in the commonwealth who has experience working with persons and families impacted by PANDAS/PANS; 1 special education administrator who has experience working with persons and families impacted by PANDAS/PANS; and 3 additional persons. Each member of the council shall serve for a term of 3 years and shall serve without receiving compensation. Any member of the advisory council appointed by the commissioner may be a member of the general court. The advisory council shall meet upon the call of the chair or upon the request of a majority of council members.

(c) The advisory council shall issue a report to the general court annually with recommendations concerning: (i) practice guidelines for the diagnosis and treatment of the disorder and syndrome; (ii) development of screening protocols; (iii) 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; (iv) outreach to educators and parents to increase awareness of the disorder and syndrome; and (v) development of a network of volunteer experts on the diagnosis and treatment of the disorder and syndrome.

(d) The advisory council may request from all state agencies such information and assistance as the council may require.

(e) The advisory council may accept and solicit funds, including any gifts, donations, grants or bequests or any federal funds, for any of the purposes of this section. Such funds shall be deposited in a separate account with the state treasurer, be received by the treasurer on behalf of the commonwealth and be expended by the advisory council in accordance with the law.

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Executive Office of Health and Human Services
Department of Public Health
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July 13, 2022

Steven T. James
House Clerk
State House Room 145
Boston, MA 02133

Michael D. Hurley
Senate Clerk
State House Room 335
Boston, MA 02133

Dear Mr. James and Mr. Hurley,

Pursuant to M.G.L. c. 111, s. 242, "An Act Promoting a Resilient Health Care Systems that Puts Patients First", please find enclosed a report from the Department of Public Health entitled, *The Massachusetts PANDAS/PANS Advisory Council FY2022 Annual Report*.

Sincerely,

Margret R. Cooke
Commissioner
Department of Public Health

Cc: Representative Josh Cutler (Legislative Commission Co-Chair)
Senator Name (Legislative Commission Co-Chair)

Executive Summary

Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS) are a set of disorders characterized by sudden onset of neuropsychiatric symptoms in children following an infection. Children with PANDAS/PANS experience an unimaginable and dramatic deterioration in areas of functioning including cognitive, motor, sensory, executive, social and emotional. PANDAS/PANS has a deep and profound impact on the lives of children with these conditions and their families, causing emotional, physical, and financial devastation.

The Massachusetts Department of Public Health (DPH) PANDAS/PANS Advisory Council was created following the enactment of legislation in M.G.L. c. 111, s. 242 [“An Act Promoting a Resilient Health Care Systems that Puts Patients First”](#) or the “Health Care Omnibus” bill signed into law in January of 2021. The Council is charged with advising the DPH Commissioner and General Court on diagnosis, treatment, research, and education relating to PANDAS/PANS. Specifically, the Council is to compose an annual report with recommendations concerning: ¹

- 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
- Development of a network of volunteer experts on the diagnosis and treatment of the disorder and syndrome

Following the signing of the legislation, Elaine Gabovitch, DPH Director of the Division for Children and Youth with Special Health Needs was appointed as the DPH Commissioner’s Designee to chair the PANDAS/PANS Advisory Council. Ms. Gabovitch worked to research PANDAS/PANS, appoint a Council, and schedule their first meeting. The DPH PANDAS/PANS Advisory Council met for the first time on September 29th, 2021 and met an additional five times through May 2022. During this time, the Council detailed their collaborative approach, created a work plan, and named their short- and long-term goals. Additionally, the Council voted to create work groups in accordance with Open Meeting Law to allow for small subsets of the Council to focus their research on one of the four domains laid out in the legislation: diagnosis, treatment, research, or education.

¹ Acts of 2020, Mass Acts Chapter 260 § 26. (2021). <https://malegislature.gov/Laws/SessionLaws/Acts/2020/Chapter260>

This annual report for the period of September 2021 through May 2022 serves to report on the process of the Council and their preliminary work, with formal research findings and recommendations to be shared in successive annual reports to follow. The next annual report for the fiscal year of 2023 will share the Council's research and recommendations on the topics of diagnosis, treatment, research, and education.

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Background

What are PANS and PANDAS?

Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS) are disorders that are not currently widely understood and can have devastating impacts on affected children and their families.

PANS is a disorder characterized by a sudden onset of neuropsychiatric symptoms, including obsessive-compulsive symptoms or eating restrictions, and deterioration in at least two of seven other categories:²

1. Anxiety
2. Emotional lability and/or depression
3. Irritability, aggression and/or severe oppositional behaviors
4. Behavioral (developmental) regression
5. Sudden deterioration in school performance
6. Motor or sensory abnormalities
7. Somatic signs and symptoms (including sleep disturbances, enuresis, or urinary frequency)

PANDAS is a subgroup of symptoms within the PANS diagnosis that presents similarly to PANS with neurological abnormalities, acute onset of obsessive-compulsive disorder (OCD) and or tics, but specifically is a relapsing and remitting disorder, that first presents between three years of age and puberty and is associated with a Group A Streptococcal infection. PANS and PANDAS have been categorized into three severity levels: mild, moderate, and severe.³

The physical and behavioral changes in impacted individuals range from mild to severe, relapsing and remitting, and long term, resulting in serious, life-threatening conditions. Children with PANDAS/PANS experience a dramatic deterioration in one or more areas of functioning including cognitive, motor, sensory, executive, social and emotional. The acute neuroinflammation can result in loss of motor skills, tics, memory deficits, ADHD symptoms, sleep difficulties, and incontinence. Additionally, children's ability to function in school can be hindered by deterioration in memory, executive function, reading skills, math skills, and the ability to write or hold a pencil. The social and emotional changes can be devastating, causing intrusive thoughts, OCD, sudden and severe separation anxiety, rage, and physical aggression. It is not uncommon for children with PANDAS/PANS to experience life-threatening symptoms such as severe eating disorders, self-harming behaviors, and suicidality.

² PANDAS Physicians Network. (2022). *What is PANS/PANDAS?* PANDAS Physicians Network. <https://www.pandasppn.org/pandas/>

³ PANDAS Physicians Network. (2022). *What is PANS/PANDAS?* PANDAS Physicians Network. <https://www.pandasppn.org/pandas/>

The most common age of onset for PANDAS/PANS is between four and nine years old, accounting for 69 percent of cases.⁴ The exact prevalence of PANDAS/PANS is unknown but there are estimates that PANDAS/PANS may affect as many as one in 200 children in the United States.⁵

Massachusetts DPH PANDAS/PANS Advisory Council

The Department of Public Health (DPH) PANDAS/PANS Advisory Council was created in 2021 following the enactment of legislation in M.G.L. c. 111, s. 242, [“An Act Promoting a Resilient Health Care Systems that Puts Patients First”](#) or the “Health Care Omnibus” bill. This bill was signed into law in January of 2021 and established the PANDAS/PANS Advisory Council as a permanent entity consisting of 15 members.⁶

In the legislation, the Council is charged with advising the DPH Commissioner and General Court on diagnosis, treatment, research, and education relating to PANDAS/PANS. Specifically, the Council is to compose an annual report with recommendations concerning:⁷

- 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
- Development of a network of volunteer experts on the diagnosis and treatment of the disorder and syndrome

Additionally, the Council:⁸

- May request from all state agencies such information and assistance as the council may require
- May accept and solicit funds, including gifts, donations, grants or bequests or any federal funds

Refer to [Legislative Mandate](#) for complete details.

⁴ PANDAS Network. (2022). *Statistics*. PANDAS Network. <https://pandasnetwork.org/get-involved/statistics/>

⁵ PANDAS Network. (2022). *Statistics*. PANDAS Network. <https://pandasnetwork.org/get-involved/statistics/>

⁶ Acts of 2020, Mass Acts Chapter 260 § 26. (2021). <https://malegislature.gov/Laws/SessionLaws/Acts/2020/Chapter260>

⁷ Acts of 2020, Mass Acts Chapter 260 § 26. (2021). <https://malegislature.gov/Laws/SessionLaws/Acts/2020/Chapter260>

⁸ Acts of 2020, Mass Acts Chapter 260 § 26. (2021). <https://malegislature.gov/Laws/SessionLaws/Acts/2020/Chapter260>

Members

The Advisory Council consists of 15 members, each to serve on the Council for three years without compensation. Elaine Gabovitch, the Director of the DPH Division for Children and Youth with Special Health Needs (DCYSHN) within the Bureau of Family Health and Nutrition (BFHN) is the DPH Commissioner’s Designee and serves as the ex-officio Chair to oversees Council activities.

The 15 members and chair are listed below:

State Ex-officio Member	Affiliation	Council Seat
Elaine Gabovitch, MPA	Commissioner’s Designee, Director of Division for Children & Youth with Special Health Needs, Massachusetts Department of Public Health	Chair
Council Member	Affiliation	Council Seat
Margaret Chapman, MSN, PNMHCNS	Bridge Consultants	Child psychiatric practitioner
Karen Colwell	Massachusetts Coalition for PANDAS/PANS Legislation	Appointed council member
Sylvia Fogel, MD	Mass General Hospital Lurie Center for Autism	Appointed council member
John Gaitanis, MD	Tufts Medical Center	Health care provider/medical specialist
Sheilah Gauch, LICSW, MEd PANDAS/PANS Advisory Council Co-Facilitator	Dearborn Academy Massachusetts Coalition for PANDAS/PANS Legislation Bridge Consultants	Special Educator Administrator
Melissa Glynn-Hyman, LICSW	Private Practice New England PANS/PANDAS Association	Licensed social worker
Lisa Grisolia	New England PANS/PANDAS Association	Representative of a Massachusetts non-profit PANDAS/PANS Advocacy Organization

Kathleen Maher, MS-PhCNS, RN	Massachusetts School Nurse Organization	Representative of a professional organization in this State for school nurses
Melissa McCormack, MD, PhD	Wholistic Pediatricians Bridge Consultants	Pediatrician
Mark Pasternack, MD	Massachusetts General Hospital for Children	Physician specializing in infectious diseases
Michelle Pinto, MSN, RN, CNE	University of Massachusetts-Dartmouth Massachusetts Coalition for PANDAS/PANS Legislation	Parent of a child with PANDAS/PANS
Blake Poggi, MA, CCC-SLP	Mending Minds Foundation for the Diagnosis and Treatment of Post-infectious Neuroimmune Disorders	Appointed council member
Jennifer M. Vitelli, MBA PANDAS/PANS Advisory Council Co-Facilitator	JBC PANS & PANDAS Foundation Massachusetts Coalition for PANDAS/PANS Legislation	Parent of a child with PANDAS/PANS
Kyle Williams, MD, PhD	Massachusetts General Hospital MGH Lurie Center for Autism	Medical researcher
Yujuan (Julia) Zhang, MD	Tufts Medical Center	Health care provider/medical specialist

Overview of Council Activities

Preliminary Advisory Council Work

Following the enactment in January 2021 of “An Act Promoting a Resilient Health Care Systems that Puts Patients First”, the Department of Public Health (DPH) Division for Children and Youth with Special Health Needs (DCYSHN) within the Bureau of Family Health and Nutrition (BFHN) was contacted to take the lead on facilitating the formation of the DPH PANDAS/PANS Advisory

Council (for more information about the legislative history of the PANDAS/PANS insurance mandate and advisory council, please see Appendix A).

The DCYSHN Director, Elaine Gabovitch, was designated by then-DPH Commissioner Monica Bharel to represent her as Chair and ex-officio, nonvoting member of the Council. Ms. Gabovitch researched the background behind the bill and between March and May 2021 conducted key informant interviews of parent advocates and professionals closely associated with the legislation to learn more. She then determined the timeline and process to appoint the Council members during the summer of 2021 and scheduled their inaugural meeting by early fall 2021.

The Council held their first meeting on September 29, 2021 and met an additional five times through May 2022. Each meeting was announced and open to the public to attend and in accordance with [Chapter 22 of the Acts of 2022](#) regarding Massachusetts COVID-19 provisions to Open Meeting Law, all meetings were held online. Over the course of their six meetings, the Council set up their collaborative approach as they prepared to research the four domains in the legislation. During this period, they created a work plan to detail their aim and goals, define their scope and establish their work process.

Aim Statement

The DPH PANDAS/PANS Advisory Council aims to advise the DPH Commissioner and General Court on diagnosis, treatment, research, and education relating to PANDAS/PANS.

PANDAS/PANS can impact all facets of life including mental health, special health needs and education. The disorder can be devastating for the entire family, especially when mismanaged or delayed, potentially leading to chronic illness. Because of this, individuals with PANDAS/PANS and their families in the state of Massachusetts need a better-informed, more effective system of care to provide sound diagnoses and appropriate treatment grounded in evidence-based research. Through an annual report, the Council will advise the DPH Commissioner and General Court, and educate and inform MA legislature, healthcare providers, mental health providers, pharmaceutical companies, judicial systems, insurers, schools (including school nurses), after-school programs and extracurricular activities (including sports), state agencies, advocates, and researchers.

Work Groups

In order to allow for more in-depth analysis and research into each of the four domains laid out in the legislation, the Council decided at the March 9th, 2022 meeting to form work groups. In accordance with Open Meeting Law, this allows for subsets of the Council to meet outside of the bimonthly meetings to discuss and work on materials. Each work group will focus specifically on one of the four domains: diagnosis, treatment, research, or education. The work groups hold independent public meetings to work on materials and discuss their domain and

then request to present their progress at a full Council meeting as they see fit. Each work group consists of four Council members, one of which serves both as a facilitator of the work group and an active, voting member. The Council members selected a work group based on their interests and expertise.

The work groups and facilitators are listed below:

Work Group	Members
Diagnosis	Sylvia Fogel (Facilitator) Melissa McCormack John Gaitanis Julia Zhang
Education	Lisa Grisolia (Facilitator) Karen Colwell Kate Maher Michelle Pinto
Research	Mark Pasternack (Facilitator) Blake Poggi Jennifer Vitelli Kyle Williams
Treatment	Melissa Glynn-Hyman (Facilitator) Peggy Chapman Sheilah Gauch Melissa McCormack

Work Plan and Work Done

Preliminary work from the DPH PANDAS/PANS Advisory Council included establishing roles based on the skills and expertise of the various Council members, learning about Open Meeting Law, setting up clear Council rules of engagement, drafting a work plan, and performing an environmental scan. The work plan details the goals and scope of the Council, including the aim statement, why statement, target audience, and approach, as well as provides workflow guidelines and phases. An abbreviated environmental scan was performed by Jennifer Vitelli and Sheilah Gauch prior to the establishment of the Council to obtain baseline information about diagnosis, treatment, research and education. This scan was distributed to the work groups to serve as foundational data for their consideration. The Council also wrote and sent a letter to the DPH Commissioner advising her about their concerns regarding the Tufts Children’s Hospital closure in Boston and its impact on the two legislative domains of diagnosis and treatment of the PANDAS/PANS community.

PANDAS/PANS Advisory Council Letter to the DPH Commissioner
re: The Effect of the Tufts Children's Hospital on their Community

Tufts Children's Hospital in Boston has been a central site for diagnosis and treatment of children with PANDAS/PANS. After over a century, the hospital decided to close its pediatric inpatient unit in July of 2022 to provide additional services to adult patients. This left the PANDAS/PANS community and members of the Advisory Council concerned about continuity of care. Tufts announced that 41 inpatient beds would be transferred to Boston's Children's Hospital effective July 1, 2022. Tufts served a significant portion of the PANDAS/PANS patients in Massachusetts and was the only pediatric hospital that readily provided necessary Intravenous immune globulin (IVIG) blood infusions as treatment for these disorders.

During the March 9, 2022 Advisory Council meeting, the Chair explained to the Council that addressing the Tufts closure broadly is outside of the Council's scope per the Statute, but it would be appropriate to address as individual citizens or on behalf of members' independent organizations. Members were encouraged to participate in the DPH Essential Services Closure Process led by the Bureau of Healthcare Safety and Quality (BHCSQ). However, because the Council is set up to advise the DPH Commissioner on matters that impact diagnosis, treatment, research, and education, it would be appropriate for the Council to brief the DPH Commissioner on how Tufts Children's Hospital's closure would impact both diagnosis and treatment. On March 25th, 2022, the Council wrote a letter to the DPH Commissioner to advise her of their concerns and the potential effects the Tufts Children's Hospital closure would have on both diagnosis and treatment for the PANDAS/PANS community.

See [Appendix A](#) for the letter to the DPH Commissioner.

Meeting Summaries

The Advisory Council met monthly from September through November 2021, and then moved to a bi-monthly meeting schedule from January through May 2022 for a total of six meetings. Each meeting was open to the public to attend. The meeting summaries are as follows:

September 29th, 2021:

The first meeting consisted of determining meeting logistics and providing informational reviews of Open Meeting Law and Conflicts of Interest. This information was presented by the BFHN legal counsel Sophia Apostola. The legislation, Statutory Authority, and Statutory Requirements were shared by the Chair, along with Council expectations and next steps.

October 25th, 2021:

During the October meeting, the Council agreed upon the best time for the group to hold bi-monthly meetings. The remainder of the time was spent in an introductory exchange among

the Council members to explain what brought them to the Council, what expertise they could contribute, and the goals they hope to achieve.

November 29th, 2021:

BFHN legal counsel Sophia Apostola was invited back to the November meeting to give a more in-depth presentation about Open Meeting Law and to field any questions the Council may have. The Council then started to draft the work plan, by first developing and approving the Council's aim statement.

Error! Reference source not found. January 12th, 2022:

At the January meeting, the Chair shared information with the Council about the [DPH COVID Community Impact Survey \(CCIS\)](#) as a valuable source of data that might be useful for their research. She also shared information about her meeting with the Executive Director of the Massachusetts Autism Commission to learn about their use of work groups in keeping with Open Meeting Law. The Chair pointed out how both recourses may provide valuable information for this PANDAS/PANS Advisory Council. The Council then edited their work plan and discussed and voted on work groups. They lastly discussed a timeline moving forward and next steps.

Error! Reference source not found. March 9th, 2022:

At the March meeting, the Council reviewed, edited, and voted to approve a letter that was later sent to the DPH Commissioner regarding concerns that the impending closure of Tufts Children's Hospital in Boston might have on the PANDAS/PANS community's access to appropriate diagnosis and treatment. The Chair explained appropriate protocol to submit comments as individual citizens to the DPH Essential Services Closure Process led by the Bureau of Healthcare Safety and Quality (BHCSQ). The Council also continued to edit the work plan and finalized decisions on work groups and their work processes.

May 11th, 2022:

During the May meeting, each work group presented their progress and process following their first public work group meetings. The work groups discussed their plans for an environmental scan, goals for the future, and division of roles. The work groups then took comments and questions from the Council. Following work group discussions, the report writer, Amy Benison, discussed progress on the annual report and received feedback and edits from the Council.

Refer to the mass.gov website for full meeting minutes.

Work Groups' Preliminary Research

Prior to the Statute for the creation of the Council, two Council members performed an initial literature search to obtain baseline information about the four domains of diagnosis, treatment, research, and education. With this baseline information each work group met to discuss their plans for research and the process to do so. Over the next year, each work group will build upon this foundation for future research and recommendations to the DPH Commissioner and the General Court, which will be detailed in subsequent annual reports.

The following provides background about each work groups initial public meeting and their plans moving forward.

Diagnosis

The diagnosis work group seeks to clarify the definition of PANDAS/PANS with a goal of early and accurate diagnosis. Recognizing that neuroinflammatory disorders are broad in their clinical presentation and that no single test exists to confirm the disorder, the preference is to maintain a broad definition so that uncommon symptom complexes are not overlooked. The emphasis is towards defining PANDAS/PANS as clinical entities, based on clinical features rather than any single laboratory study. The core clinical features involve an acute or subacute onset of new or worsening neuropsychiatric symptoms, which respond sub-optimally to traditional medication management. To maintain a broad working definition, the work group will not divide specific neuropsychiatric symptoms as “major” or “minor,” but will instead include the common and uncommon manifestations as a single entity. Likewise, confirmatory studies will be acknowledged, but no single imaging or laboratory evaluation will be required since the emphasis is towards presenting PANDAS/PANS as a clinical diagnosis. To provide diagnostic criteria based on the most up to date research, members of the work group are examining literature on the evolving definitions of PANDAS/PANS over time, the full spectrum of presenting symptoms, emerging evidence of the immune systems influence on the brain, and recent findings regarding neuropsychiatric symptoms following COVID-19 infections. Those findings will be incorporated into the final definitions and recommendations of the diagnosis work group.

Treatment

At their inaugural meeting, the treatment work group discussed their short-term goals of identifying the current baseline for treatment of PANDAS/PANS and the long-term goal of identifying gaps in the treatment. Members discussed the scope and breadth of treatment and how best to break this down for the baseline data. There was discussion and acknowledgement about how complicated treatment can be at times. The work group also discussed the importance of understanding what the infectious trigger is, in order to best treat it. Various other areas that require treatment when a child is impacted by PANDAS/PANS will be reviewed going forward, including the immune system, gastrointestinal (GI) system, allergies, food etc. The work group will therefore investigate data in these areas and ensure that the baseline study is expanded to include them. There was further discussion around the need for mental health treatment for these illnesses and the concern that there is a lack of related research. The work group agreed that they would look carefully at the totality of mental health research and these illnesses (i.e., psychotropic medication, CBT treatments, other limbic retraining supports), while acknowledging the gap in research.

Research

The research work group outlined at their first meeting their short-term goals of classifying and understanding existing PANDAS/PANS research with a long-term goal of identifying research areas that will be important for future investigation. The members focused on the processes that will be utilized in the course of the group's work and discussed classifying existing research efforts into three major domains: basic science, translational research, and clinical trials. Reported studies can be readily classified in this manner which will provide a framework for further investigation and research planning.

The domains are classified as follows:

- Basic Science:
 - Laboratory-based investigations that address disease mechanism, particularly autoimmunity
 - Animal studies
 - Genetic studies that investigate possible heritable markers which convey an increased risk of PANDAS/PANS
- Translation Research:
 - Investigations of epidemiology of PANDAS/PANS and possible triggers of the syndromes
 - Imaging studies including quantitative volumetric analysis of brain structures and investigation of the blood-brain barrier in children with PANDAS/PANS
 - Clinical investigations that develop and validate symptom scores and other clinical features of these illnesses
- Clinical Trials:
 - Therapeutic trials of IVIG, steroid therapy, nonsteroidal anti-inflammatory therapy, therapeutic and prophylactic antibiotic therapies, and others

The workgroup members will work individually and in groups to build a database and populate the framework categories with relevant publications. The Research Workgroup used [ASPIRE Foundation](#)'s annotated [PANDAS/PANS Research Toolkit](#) as their starting point, and at their second meeting (July 2022), expanded the inventory considerably using PubMed searches and adding studies known to workgroup members. The workgroup is in the process of reviewing other external databases to identify recent and non-duplicate entries.

Education

The education work group has started to gather preliminary sources to best inform their priority audiences about PANDAS/PAN: families, healthcare providers in both inpatient and outpatient settings, staff in school settings, and social services. At their first work group meeting, the members discussed that two starting goals are to conduct a baseline environmental study, followed by a gap analysis of education topics. Some of their initial work included discussing the scope and breadth of educational topics, how best to organize the

environmental study and create a comprehensive outline of educational service locations and recipients. After brainstorming a variety of resources, the work group divided the work of the baseline study with each group member investigating resources available in a particular service location. The group collected and organized tools and resources to target the following audiences and settings: families, healthcare providers in both inpatient and outpatient settings, staff in school settings, social services, and the justice systems. The work group has already started a detailed outline of available educational resources including journal articles, online resources, books, documentaries, webinars, conference recordings, support groups, social media groups, blog posts, and podcasts. They will continue to work to compile more resources and determine how to best educate their audiences.

Conclusion

PANDAS/PANS has a deep and profound impact on the lives of children with these conditions and their families, causing emotional, physical, and financial devastation. Countless children with PANDAS/PANS are sub-optimally treated exclusively for mental illness with a focus on symptom management. In fact, many have a neuroimmune illness that when identified and treated is critical to their recovery.

Establishment of this Advisory Council is an important acknowledgment of the many children and families who have lost their childhood, quality of life, family unit and unintentionally lost their lives to these disorders. An Advisory Council at the highest level of state government gives hope for a real and substantial shift in Massachusetts, not only in PANDAS/PANS diagnosis and treatment, but also in the way pediatric and psychiatric illnesses are approached. It may establish mental health parity for this devastating disease that tragically is non-existent today.

This Council has spent the past year on crucial tasks to create a work plan and outline goals for the future. Over the next year, the Council and work groups will strive to collect research and make evidence-based recommendations that improve the quality of care and quality of life for children and their families living with PANDAS/PANS. To institute tangible change, it needs to start at the top of the state and this PANDAS/PANS Advisory Council will be that catalyst.

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Appendix

Appendix A: Legislative History of PANDAS/PANS: Insurance Mandate and Advisory Council

In 2013, Heather and Jacob Masenior, PANDAS parent advocates, came together with their Massachusetts state legislator, Representative John Scibak to file the first PANDAS/PANS insurance mandate bill (H.984) in the United States. The legislation was co-sponsored by a coalition of 18 House and Senate lawmakers, including Rep. Josh Cutler, who would later play a major role in the passage of the legislation. Although the bill was not passed during that initial legislative session, it led to two important developments. The first being the establishment of an annual PANDAS/PANS Awareness Day on October 9 (Chapter 175 of the Acts of 2014) and the second being the commissioning of a report by the Center for Health Information and Analysis (CHIA) to evaluate the potential fiscal impact of the insurance mandate. This [CHIA report](#) was ultimately published in 2015 and would later be used by seven other states to pass their own PANDAS/PANS insurance mandates into law.

The PANDAS/PANS insurance mandate bill was refiled for the 2015-2016 legislative sessions and again for the 2017-2018 legislative sessions but did not pass the committee stage in either session. Upon Representative Scibak's retirement in 2019, Representative Paul Brodeur (H.920), Sen. Jason Lewis (S.613), Rep. Cutler (H.947) and Rep. Carmen Gentile (H.990) all filed versions of the PANDAS/PANS bill for the 191st General Court of the Commonwealth of Massachusetts legislative term (2019-2020). Each of these legislators had constituents impacted by PANDAS/PANS. This time, another group of parents from the Massachusetts Coalition for PANDAS/PANS Legislation led by Sheilah Gauch and Jennifer Vitelli, met with state legislators to advocate for the passage of the bill. For most of 2019, Representative Brodeur and Senator Lewis were the lead bill sponsors for each branch. In November 2019, Representative Cutler took over as the lead House sponsor.

In March of 2020, the bill, now Rep. Cutler's (H.947), was sent to the Joint Committee on Health Care Financing and later was accompanied by Sen. Lewis (S.613). Two weeks later, the COVID-19 pandemic hit, which slowed the legislative process down as the Legislature and the Administration focused on handling new challenges. The bills remained under review in the Health Care Financing Committee and were extended until June 19, 2020. With strong advocacy from the PANDAS/PANS community, the bill was successfully moved to the Senate Ways & Means Committee.

While the insurance mandate process was unfolding, Ms. Gauch and Ms. Vitelli discussed at length with legislators the possibility of establishing a permanent PANDAS/PANS Advisory Council in addition to the existing insurance coverage bill. It was proposed that establishing an advisory council at the highest level of state government would mean a real and substantial shift in Massachusetts not only in PANDAS/PANS diagnosis and treatment but also in the way pediatric and psychiatric illnesses are approached.

In July of 2020, the House took up an omnibus health care bill, known as “An Act Putting Patients First,” which had previously passed in the Senate. During the floor debate, Rep. Cutler filed an amendment to this bill to establish a PANDAS/PANS Advisory Council. The Cutler amendment was adopted and was included in the broader bill that was passed by the House.

A Conference Committee was then appointed by the House and Senate to reconcile the difference between the two health care bills and the Conference Committee continued their review and negotiations for much of the fall. Throughout this process, Ms. Gauch and Ms. Vitelli continued their advocacy with the help of key medical experts led by Dr. Mark Pasternack, Mass General's Unit Chief of Pediatric Infectious Diseases. The goal was to ensure that the Conference Committee kept the PANDAS/PANS Advisory Council component in the final version of the omnibus health care bill, while continuing to advocate for the separate insurance coverage mandate bill that was pending in the Senate.

Finally, on December 22, 2020, the Conference Committee released its final report on the omnibus health care bill. The Conference Committee’s final bill included both the PANDAS/PANS Advisory Council and the health insurance coverage mandate. On December 23, 2020, the bill was enacted on a unanimous vote in both the House and the Senate and was then sent to the Governor’s desk. On January 1, 2021, Governor Baker signed into law the healthcare bill, now known as “An Act Promoting a Resilient Health Care Systems that Puts Patients First.” The new law (Chapter 260 of the Acts of 2020) established the insurance mandate for PANDAS/PANS medical coverage and established the permanent Department of Public Health PANDAS/PANS Advisory Council.

Massachusetts is the first state in the country to pass both the insurance mandate and advisory council together.



The Commonwealth of Massachusetts
Executive Office of Health and Human Services
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March 9, 2022

Commissioner Margret R. Cooke
Massachusetts Department of Public Health
250 Washington Street
Boston, MA 02108

Dear Commissioner Cooke:

As the newly established DPH PANDAS/PANS Advisory Council charged with advising you on research, diagnosis, treatment, and education relating to Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections and Pediatric Acute Neuropsychiatric Syndrome (PANDAS/PANS), we are bringing to your attention an area of concern related to diagnosis and treatment for PANDAS/PANS families in Massachusetts regarding the impending closure of Tufts Children's Hospital (TCH).

What are PANDAS and PANS?

- Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) are neuroimmune disorders believed to result from a misguided immune response, which attacks the brain following streptococcal or other common bacterial or viral infections.
- PANDAS and PANS frequently begin with dramatic deterioration in one or more areas of functioning including cognitive, motor, sensory, executive, social, and emotional.
- Children abruptly develop neuroinflammatory symptoms such as regression, loss of motor control, tics, memory deficits, ADHD, sleep difficulties, and incontinence. In school, cognitive skills deteriorate and they struggle to read, perform basic math functions, and hold a pencil. Children often have extended absences, particularly when they are undiagnosed, causing caregivers to leave or lose their jobs.
- There is often an alarming change in mood and personality. Children have intrusive thoughts, obsessions, and compulsions, and experience severe separation anxiety or rage behaviors including physical aggression. Many have life-threatening symptoms including severe anorexia, self-harm, and suicidal ideation. Many have tragically lost their lives.

Appendix B: Letter to DPH Commissioner

- These conditions are devastating to children and costly to their families, school systems, medical providers, and insurers. The burden grows as diagnosis and treatment are delayed, untreated neuroinflammation worsens, and the illness becomes chronic.

Identification and Treatment of PANDAS/PANS

- In 2017, the PANS Research Consortium immunomodulatory task force (PRC-ITF) published comprehensive guidelines for diagnosis and treatment of PANS/PANDAS. The consortium was composed of immunologists, rheumatologists, neurologists, infectious disease experts, general pediatricians, psychiatrists, nurse practitioners, and basic science experts in neuroimmunology.
- The guidelines outline [three modes](#): treating the symptoms, removing the source of the inflammation, and treating disturbances of the immune system. Treatment includes [psychiatric and behavioral interventions](#), [anti-inflammatory and immunomodulatory therapies](#), and [treatment of infections](#) (please see embedded links).

The closing of Tufts Children's Hospital (TCH) will have a significant impact on the ability of PANDAS/PANS children and families in the Commonwealth to access **diagnosis and treatment** of these conditions. Given the acute timeline, we feel it is imperative you know that TCH is one of the two hospitals that currently prescribe immune therapy for PANDAS/PANS in accordance with the [Massachusetts treatment mandate](#). A substantial fraction of all of the children with P/P in MA are treated at TCH. TCH is the only pediatric hospital that has a readily available pediatric-staffed outpatient infusion center to treat these children. This infusion center currently provides a level of safety and emergency response for many of the most acute, children with ASD, and younger patients including hospitalists, child-life specialists, and PICU staff. It was brought to our attention that BCH is not following current consortium guidelines summarized above and has no treating physicians in Boston as reported to the Department of Insurance by Massachusetts insurers.

As an Advisory Council, we will conduct an environmental scan in 2022 to gather data on the current state of **diagnosis, treatment, research, and education** for these disorders. As part of our assessment, we will request diagnosis and treatment guideline policies from all Massachusetts hospitals. As private citizens, we will submit our written and oral comments to the DPH Bureau of Healthcare Safety and Quality under their Essential Services Closure Process to guide the transfer of care of these patients from TCH to BCH. This advisory memo serves to anticipate the deficit of evidence-based treatment for individuals with PANDAS/PANS and their families in Massachusetts as the result of the closure of TCH.

Respectfully submitted,

Members of the DPH PANDAS/PANS Advisory Council
(With the exception of Dr. Yujuan Zhang and Dr. John Gaitanis of Tufts Children's Hospital)

Att. (1): DPH PANDAS/PANS Advisory Council Member List