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A Report to the Joint Standing Committee on Health Coverage, Insurance and Financial Services of the 131st Maine Legislature

Review and Evaluation of LD 663, An Act to Require Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome

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Contents

I. Executive Summary

The Joint Standing Committee on Health Coverage, Insurance and Financial Services (Committee) of the 131st Maine Legislature directed the Bureau of Insurance (Bureau) to review LD 663, An Act to Require Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). The review was conducted as required by Title 24-A, Section 2752. This document and review are a collaborative effort of NovaRest, Inc. and the Bureau.

The bill requires all health insurance policies, contracts, and certificates executed, delivered, issued for delivery, continued or renewed in Maine to provide coverage for treatment of pediatric postinfectious neuroimmune disorders including PANDAS and PANS. Treatments must include, but are not limited to long-term antibiotics, intravenous immunoglobulin therapy, steroids, plasmapheresis, and psychopharmacological interventions. Coverage may not be excluded due to the diagnosis of autoimmune encephalopathy or autoimmune encephalitis.

The 129th Legislature considered a similar bill, LD 1138, and directed the Bureau of Insurance to conduct a mandate study on this topic.[1] The Committee reviewed the Bureau's mandate study and voted the bill unanimous Ought Not To Pass.

There are not significant differences in the language of LD 1138 and LD 663. LD 663 requires coverage for treatment of pediatric postinfectious neuroimmune disorders as opposed to childhood postinfectious neuroimmune disorders in LD 1138, which did not meaningfully change our understanding of the bill requirements. Additionally, we noticed in the Summary section, LD 663 does not specify any guidelines for treatments, while the previous bill, LD 1138, specifies that the treatments authorized are described as the standard of care in the 2017 Journal of Child and Adolescent Psychopharmacology, Volume 27, Number 7 ("the guidelines").

We did not perform any additional interviews for LD 663. Instead, we relied upon information provided in an interview for LD 1138 with Dr. Susan Swedo with the PANDAS Physicians Network, who has made significant contributions to PANDAS/PANS research. We also relied on public comments and an advocate report submitted for LD 1138. There were far fewer comments for LD 663, although we believe many of the comments for LD 1138 are applicable to LD 663 as well.

There is controversy about the cause of the PANDAS/PANS and how to treat it. The American Academy of Pediatrics Red Book doesn't recognize a relationship between PANDAS/PANS and group A Streptococcus (GAS).[2] Information regarding antibiotic therapy is conflicting. More studies may be needed for physicians to establish the effectiveness of some treatments.

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[1] A summary of the bill and public hearing testimony can be found here: http://www.mainelegislature.org/legis/bills/display_ps.asp?LD=1138&snum=129. This bill is regularly referenced throughout this report.

[2] https://publications.aap.org/aapnews/news/12434/PANDAS-PANS-treatments-awareness-evolve-but-some?autologincheck=redirected.

This mandate may step outside the role of insurance in that it requires carriers to reimburse providers for treatments such as plasmapheresis and intravenous immunoglobulin (IVIG), which the 2018 American Academy of Pediatrics Red Book and carrier responses contend have not been shown to be medically necessary or to improve symptoms.

We had to make several assumptions to develop our cost estimate, which will be described in the following sections.

In order to develop our cost estimate, we conducted a survey of the largest carriers in Maine to determine the level of coverage already available and other critical information. The difference in cost between the markets is slight, so the cost estimate applies to the individual, small group, and large group markets. Some of the treatments are already covered by carriers, and therefore the marginal cost of adding coverage is between $20,000 and $505,000 annually depending on the market. This amounts to between $0.03 and $0.25 on a per member per month (PMPM) basis which is less than 0.05% as a percent of premium. On a gross basis[3] we estimate the cost to be between $30,000 and $790,000 based on the prevalence and the treatment options pursued. This amounts to between $0.04 to $0.37 on a PMPM basis and less than 0.08% on a percent of premium basis. Our assumptions are explained in the following sections.

States are required to pay for ("defray") the costs of all health insurance benefit mandates that are included in individual Qualified Health Plans (QHPs), unless the mandate was in effect prior to December 31, 2011 and part of the state's defined essential benefit package (EHB). The state must pay to defray the cost of the mandate's premium impact on those individual exchange/QHP plans. Defrayal only represents the impact of a mandate on Maine's individual exchange plans and does not consider the mandate's impact on the small or large group market.

The Affordable Care Act (ACA) describes a broad set of benefits that must be included in a state's EHB package.[4] Federal regulators consider state mandated health benefits that were in effect prior to December 31, 2011 part of a state's EHB. Generally, mandates adopted by a state after December 31, 2011 are subject to defrayal. The ACA permits certain narrow exceptions to the defrayal requirements for mandates that are: an expansion of an existing mandate, required by federal law, a cost-sharing requirement, or a provider mandate.

Maine determined its current EHB benchmark plan based on guidance from the Federal Department of Health and Human Services (HHS). Maine chose the small group Anthem PPO Off Exchange Blue Choice, $2,500 Deductible as its benchmark plan.

Bureau staff met with Centers for Medicare & Medicaid Services (CMS) in November 2023 and they confirmed that Maine could be responsible to defray the total cost of specific mandated

[3] The gross basis includes the total cost of the treatments required by the mandate. Some of these treatments, such as antibiotics and psychological interventions are already covered.

[4] The 10 categories of benefits in an EHB package are: 1) ambulatory patient services, 2) emergency services, 3) hospitalization, 4) maternity and newborn care, 5) mental health and substance use disorder services, 6) prescription drugs, 7) rehabilitative and habilitative services and devices, 8) lab services, 9) preventive and wellness services and chronic disease management, and 10) pediatric services, including oral and vision care.

PANDAS/PANS treatments. We estimate the cost of total PANDAS/PANS treatment to be $0.04 - $0.40 PMPM. With an anticipated 63,388 QHP on-exchange members in Maine, we estimate a total defrayal cost to Maine of $30,000 to $300,000 for plan year 2025.

CMS recently proposed that any mandated benefits included in a state's benchmark plan as of 2025 would not require defrayal.[5] If finalized, we believe Maine could be required to defray only the cost of long-term antibiotics, IVIG, and plasmapheresis as a new benefit not currently in the EHBs for QHP on-exchange members. We estimate the cost of long-term antibiotics, IVIG, and plasmapheresis to be $0.03 - $0.25 PMPM and the total estimated defrayal cost to Maine of $20,000 to $200,000 for plan year 2024.

States also have the opportunity to redesign their EHBs for 2027 to include new benefits under CMS guidelines. However, it is important to note that the redesign process is complicated and any new EHB benchmark plan must meet typicality, generosity and other requirements. It could mean that a redesigned benchmark plan would need to eliminate some existing EHB benefits to achieve the generosity test.

This is not a legal interpretation, nor should it be considered legal advice.

II. Background

Our understanding is that treatment and guidelines regarding PANDAS/PANS have not changed significantly from our prior analysis for LD 1138, submitted in January 2020. Therefore, much of this section has not changed from our prior analysis.

PANDAS is a relatively new diagnosis which was first described in a 1998 article.[6] PANDAS is described as an abrupt development or worsening of neuropsychiatric abnormalities such as obsessive-compulsive disorder (OCD) or tic disorders incited by a group A Streptococcus (GAS) infection.[7] PANDAS is considered a subset of a larger syndrome, PANS[8] which does not require a known trigger.[9]

The causes of PANDAS/PANS are unknown and are currently under investigation, although studies have shown an association with infections[10] and an inciting GAS infection is found in as

[5] Notice of Benefit and Payment Parameters (NBPP) for 2025 https://www.cms.gov/newsroom/fact-sheets/hhs-notice-benefit-and-payment-parameters-2025-proposed-rule
[6] Chelsea Melerine, BSN, AND Linda M. Ledet, DNS, APRN, PMHCNS-BC. "PANDAS: What Nurses Need to Know." August 2019. Nursing2019.com. Copyright © 2019 Wolters Kluwer Health, Inc.
[7] Ibid.
[8] Cooperstock, MD, MPH et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III – Treatment and Prevention of Infections. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 594-606.
[9] Chelsea Melerine, BSN, AND Linda M. Ledet, DNS, APRN, PMHCNS-BC. "PANDAS: What Nurses Need to Know." August 2019. Nursing2019.com. Copyright © 2019 Wolters Kluwer Health, Inc.
[10] Mahony, BA et al. Palatal Petechiae in the Absence of Group A Streptococcus in Pediatric Patients with Acute-Onset Neuropsychiatric Deterioration: A Cohort Study. Journal of Child and Adolescent Psychopharmacology.

many as 40-77% of cases of PANS.[11] The proposed bill concerns cases of both PANDAS and PANS that are incited by an infection. PANS and PANDAS have similar symptoms and the guidelines treat them as a single syndrome with the primary difference being that PANDAS requires strep infection.[12]

PANDAS/PANS is a diagnosis of exclusion, meaning the diagnosis of PANDAS/PANS should be made when symptoms are not better explained by other neurological or medical disorders.[13] Common symptoms for PANDAS/PANS include:[14]

- Obsessive-compulsive symptoms
- Restricted eating behaviors
- Anxiety
- Emotional lability or depression
- Irritability/oppositionality/aggression
- Behavior regression
- Deterioration in school performance
- Sensory or motor abnormalities
- Somatic symptoms

Severe PANDAS/PANS symptoms could result in a child being unwilling to leave the house or refusing to eat due to fear of contamination. Testimony on the previous bill LD 1138 from an advocate cited numbers where 79% of PANDAS/PANS children have OCD that interferes with their ability to function in at least one area, 66% have debilitating anxiety and 59% suffer extreme sensory sensitivity.[15]

There is evidence that psychological, behavioral, and psychopharmacologic interventions can provide symptom improvement and improve functioning.[16] Symptoms of PANDAS/PANS have been shown to respond to the same medications of non-PANDAS/PANS cases.[17] Symptoms may differ between patients, so therapies may be individualized.[18] Although the majority of children

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Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 660-666.

[11] Cooperstock, MD, MPH et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III – Treatment and Prevention of Infections. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 594-606.

[12] Thienemann, MD et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part I—Psychiatric and Behavioral Interventions. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 566-573.

[13] Swedo MD et al. Overview of Treatment of Pediatric Acute-Onset Neuropsychiatric Syndrome. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 562-565.

[14] Frankovich, MD, MS et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 574–593.

[15] Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures

[16] Thienemann, MD et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part I—Psychiatric and Behavioral Interventions. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 566-573.

[17] Ibid.

[18] Ibid.

under treatment will show overall improvement over time, relapses may occur after long periods of remission.[19]

Dr. Susan Swedo stated that early recognition and treatment for PANDAS/PANS is critical and widely available through medications, including antibiotics and NSAIDs (such as ibuprofen). While treatment options can still be effective when delayed, the symptoms may worsen over time leading to the need for more intensive and expensive treatments, instead of less intensive, lower-cost, and widely available medications such as antibiotics and NSAIDs (such as ibuprofen). The more intensive treatments may include Intravenous Immunoglobulins therapy (IVIG), plasmapheresis, steroid blasts, and rituximab.

The series of articles in the 2017 Journal of Child and Adolescent Psychopharmacology, Volume 27, Number 7 discuss treatment guidelines for PANDAS/PANS. These guidelines resulted from consensus among PANS/PANDAS Research Consortium members, and include:[20]

- Psychoactive medications, psychotherapies, and supporting interventions to provide symptomatic relief
- Antibiotics to eliminate the source of neuroinflammation
- Anti-inflammatory and immune modulating therapies to treat disturbances of the immune system

A course of anti-streptococcal treatment is proposed for all new diagnosed PANDAS/PANS cases, and all patients with PANDAS/PANS should be closely monitored for other intercurrent infections.[21] Antibiotic and immune-based treatments can reduce or eliminate symptoms.[22] Specifically, the Journal of Child and Adolescent Psychopharmacology noted that the antibiotic azithromycin may be helpful in treating PANDAS/PANS and was well tolerated over a period of weeks.[23]

The guidelines also mentioned the use of nonsteroidal anti-inflammatory drugs (NSAIDs), but it was not entirely clear when these medications would be prescribed. Dr. Swedo indicated anecdotally that after conferring with colleagues at major clinics, more than 80% of PANDAS/PANS cases are currently being managed with antibiotics and NSAIDs, and do not

[19] Cooperstock, MD, MPH et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III – Treatment and Prevention of Infections. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 594-606.
[20] Swedo, MD, et al. Overview of Treatment of Pediatric Acute-Onset Neuropsychiatric Syndrome. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 562-565.
[21] Cooperstock, MD, MPH et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III – Treatment and Prevention of Infections. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 594-606.
[22] Thienemann, MD et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part I—Psychiatric and Behavioral Interventions. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 566-573.
[23] Murphy, MD, MS et al. A Double-Blind Randomized Placebo-Controlled Pilot Study of Azithromycin in Youth with Acute-Onset Obsessive-Compulsive Disorder. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 640-651.

require more intensive treatments such as steroids, Intravenous Immune Globulin (IVIG), or plasmapheresis.

According to the guidelines, psychiatric and behavioral interventions should begin when PANDAS/PANS is identified, as tangible benefits are found after 12-16 sessions of therapy.[24] The intervention method used is typically cognitive behavioral therapy (CBT). The Journal also notes that psychotropic medications such as selective serotonin reuptake inhibitors (SSRIs) may be prescribed although benefits may not be seen for 8-12 weeks after finding the optimum dosage level.

The Journal articles indicate immune treatments should only be used in cases where there is clear evidence of neuroinflammation or postinfectious autoimmunity as the underlying cause for PANDAS/PANS symptoms.[25] For mild symptoms, the guidelines indicate 'a tincture of time,' i.e. allowing the body to heal on its own, combined with cognitive behavioral therapy and other supportive therapies, may be sufficient. For moderate to severe symptoms, IVIG and/or corticosteroids are typically used. According to Dr. Susan Swedo, steroids were not included in the original studies for PANDAS/PANS but have been shown to be effective. In fact, one recent study showed high dosage steroids for a few days and tapering for about a month has had the effect of prolonging time between flare-ups and also shortening flare-up duration.[26] The physician indicated IVIG is effective in treating PANDAS/PANS symptoms although it is believed fewer children need IVIG than previously thought due to the effectiveness of antibiotics, NSAIDs, and steroids. When required, IVIG would be given with corticosteroids.

For children with extreme or life-threatening symptoms Therapeutic Plasma Exchange (also known as plasmapheresis) alone or in combination with IVIG, corticosteroids, and/or rituximab may produce the greatest symptom improvement.[27] It is very rare that a child would require this level of treatment. Anecdotally, Dr. Susan Swedo indicated that fewer than 1,000 children in the world need plasmapheresis annually, meaning it is possible Maine would not have a child who would need this procedure. A child at this level of symptoms would need to receive treatment at a multi-disciplinary clinic. Plasmapheresis is an invasive and potentially risky procedure and requires significant training to be applied appropriately and would likely require at least one week of hospitalization in the intensive care unit. Similarly, Rituximab should only be administered by a rheumatologist or someone who has extensive experience using it for other diseases. According to Dr. Susan Swedo, due to the length of time needed to see results from Rituximab in a patient with PANDAS/PANS, support in the medical community as a treatment

[24] Swedo MD et al. Overview of Treatment of Pediatric Acute-Onset Neuropsychiatric Syndrome. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 562-565.
[25] Ibid.
[26] Brown, BA et al. Pediatric Acute-Onset Neuropsychiatric Syndrome Response to Oral Corticosteroid Bursts: An Observational Study of Patients in an Academic Community-Based PANS Clinic. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 629-639.
[27] Frankovich, MD, MS et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 574–593.

for PANDAS/PANS has waned, and if used it would likely only be provided in combination with plasmapheresis or for steroid-dependent patients.

Dr. Susan Swedo said that even after treatments return patients to baseline or to a manageable level, flare-ups occur in a majority of children and that the treatment for flare-ups is typically the same as the initial treatment. Flare-ups could happen very soon after initial treatment or much later, although early recognition and treatment of flare-ups can lower their intensity and duration, similar to early recognition and treatment of the initial diagnosis. It is possible that a patient may have a flare-up (due to an additional trigger) that requires another IVIG treatment course, but rarely is plasmapheresis received more than one time.

There is controversy about the diagnosis and treatment of PANDAS/PANS.[28] The American Academy of Pediatrics, for instance, does not recognize a relationship between PANDAS and group A Streptococcus.[29] Notably, the Summary of Major Changes in the 2018 American Academy of Pediatrics Redbook states that "language has been strengthened discouraging antimicrobial treatment or prophylaxis, IVIG, or plasmapheresis for children with symptoms suggestive of [PANDAS/PANS]."

In addition to the statutory criteria, the Committee also asked that the review provide an analysis of:

- Whether the bill expands coverage beyond the State's essential benefits package and, if so, the estimated costs to the State to defray the costs of including the coverage in qualified health plans.

The bill expands coverage beyond the State's essential benefits package due to the inclusion of plasmapheresis which is not discussed as covered in the EHB Benchmark Plan Certificate of Coverage.[30] Treatment using steroids and antibiotics are covered under the current EHB Benchmark Plan. Additionally, one immunoglobulin class drug is included under the current EHB Benchmark Plan Summary posted on the CMS website, [31] although per carrier responses it does not appear to be used for PANDAS/PANS.

Current CMS requirements would cause an EHB to lose EHB status if it is included in a new state mandate, meaning Maine could be responsible to defray the total cost of PANDAS/PANS treatments. We estimate the cost of total PANDAS/PANS treatment to be $0.04 - $0.40 PMPM. With an anticipated 63,388 QHP on-exchange members in Maine,[32] we estimate a total defrayal cost to Maine of $30,000 to $300,000.

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[28] Jessica Pupillo. PANDAS/PANS treatments, awareness evolve, but some experts skeptical. AAP News & Journals. March 28, 2017. https://www.aappublications.org/news/2017/03/28/Pandas032817 Accessed August 13, 2019.
[29] Ibid.
[30] https://www.cms.gov/marketplace/resources/data/essential-health-benefits#Maine
[31] https://www.cms.gov/marketplace/resources/data/essential-health-benefits#Maine
[32] https://www.maine.gov/dhhs/blog/covermegov-concludes-second-open-enrollment-period-maines-state-based-health-insurance-marketplace-2023-01-20

CMS recently proposed that any mandated benefits included in a state's benchmark plan as of 2025 would not require defrayal.[33] If finalized, we believe Maine could be required to defray only the cost of long-term antibiotics, IVIG, and plasmapheresis for QHP on-exchange members. We estimate the cost of long-term antibiotics, IVIG, and plasmapheresis to be $0.03 - $0.25 PMPM and the total estimated defrayal cost to Maine of $20,000 to $200,000 for plan year 2024.

States also have the opportunity to redesign their EHBs for 2027 to include new benefits under CMS guidelines. However, it is important to note that the redesign process is complicated and any new EHB benchmark plan must meet typicality, generosity and other requirements. It could mean that a redesigned benchmark plan would need to eliminate some existing EHB benefits to achieve the generosity test.

We received responses from the following carriers:

- Aetna
- Anthem Blue Cross and Blue Shield (Anthem)
- Cigna
- Community Health Options (CHO)
- Harvard Pilgrim (HPHC)
- Taro Health
- United Health Care (UHC)

All carriers except UHC believe the bill would expand coverage beyond the EHBs.

III. Social Impact

A. Social Impact of Mandating the Benefit

1. The extent to which the treatment or service is utilized by a significant portion of the population.

The true prevalence of PANDAS/PANS in Maine is unknown. As a diagnosis of exclusion and with many symptom categories, it is difficult for children to be accurately diagnosed and to receive appropriate treatment early. According to the New England PANS/PANDAS Association (NEPANS), nationally 33% of children see more than five doctors before being correctly diagnosed.

Advocates quote a range of prevalence from one in 1,000 to one in 200 for PANDAS/PANS. [34] The bill specifies post-infectious cases of PANDAS/PANS. Retrospective studies indicate 40%-77% of PANDAS/PANS studies are associated with infection.[35] Based on the covered lives in

[33] Notice of Benefit and Payment Parameters (NBPP) for 2025 https://www.cms.gov/newsroom/fact-sheets/hhs-notice-benefit-and-payment-parameters-2025-proposed-rule
[34] Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures
[35] Cooperstock, MD, MPH et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part

the 2022 National Association Insurance Commissioners (NAIC) Supplemental Health Care Exhibit (SHCE), we assume this condition will affect between 21 and 198 children in Maine each year.

2. The extent to which the service or treatment is available to the population.

Antibiotics, NSAIDs, SSRIs, and corticosteroids are widely available. However, advocates in support for LD 1138 stated there is a lack of PANDAS/PANS literate health care professionals, which often delays treatment for children and a lack of PANDAS/PANS specialists, which leads to lack of disease acknowledgment and treatment.[36] We assume this is still true for LD 663, and an updated search actually showed fewer providers in Maine.

Dr. Susan Swedo indicated that there is a lack of trained Cognitive Behavior Therapy (CBT) professionals available, although the number is growing. The CBT professionals need to perform exposure and response prevention (ERP), although if they are trained for adults, their training should enable them to work with children as well. Currently, according to the International OCD Foundation there are no therapists available in Maine.[37] Other qualified therapists may be available, but with limited in training in CBT and ERP.

IVIG does not appear to be widely available. Advocate input for LD 1138 indicated "there is one known health care providers [sic] in Maine who will administer IVIG to children with PANDAS/PANS in an office or home care setting." Dr. Susan Swedo indicated IVIG is in shortage and doctors are looking for alternatives such as steroids which have shown positive results. We assume this is still true for LD 663.

Additionally, advocates for LD 1138 said there are no practitioners in Maine known to administer plasmapheresis or rituximab for PANDAS/PANS patients. Dr. Susan Swedo indicated that patients with severe cases would need to be at a multi-disciplinary clinic for plasmapheresis and rituximab treatment. Georgetown University Hospital is one such facility but has limited availability. The PANDAS Physicians Network is working on adding more trained groups. We assume this is still true for LD 663.

III – Treatment and Prevention of Infections. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 594-606.

[36] Advocate Inputs for LD 1138 Mandated health legislation procedures

[37] International OCD Foundation. Search for PANDAS/PANS Specialty in Maine. https://kids.iocdf.org/. 9.21.2023

3. The extent to which insurance coverage for this treatment is already available.

Currently, while not directly confirmed by all carriers, normal durations of antibiotics, corticosteroids, psychological therapy and psychopharmacological interventions are covered by all carriers for PANDAS/PANS.[38, 39] Long-term antibiotics are covered for PANDAS/PANS by two of the seven carriers. Intravenous IVIG was not indicated as covered for PANDAS/PANS by any carriers and plasmapheresis was only indicated as covered for PANDAS/PANS by one of the seven carriers. Some carriers indicated only what was not covered, but did not indicate what was covered.

Covered?	Aetna	Anthem	Cigna	CHO	HPHC	Taro	UHC
Short-term antibiotics	Not specified	Yes	Not specified	Yes	Yes	Yes	Not specified
Short-term steroids	Not specified	Yes	Not specified	Yes	Not specified	Yes	Not specified
Psychopharm-acological	Not specified	Yes	Not specified	Yes	Yes	Yes	Not specified
Psychological Therapy	Not specified	Not specified	Not specified	Yes	Yes	Yes	Not specified
Long-term antibiotics	Not specified	No	Yes (For other conditions)	Yes (As appropriate for patient)	No	No	Not specified
IVIG	No	No	No (Investigational)	No (Investigational)	No (due to a lack of clinical evidentiary support)	No (Investigational)	Not specified
Plasmapheresis	Not specified	Yes	No (Investigational)	No (Investigational)	Not routinely covered	No (Investigational)	Not specified

4. If coverage is not generally available, the extent to which the lack of coverage results in a person being unable to obtain the necessary health care treatment.

According to advocates in support of LD 1138, 65% report that barriers from insurance companies and/or out-of-pocket expenses slowed their child's diagnosis and treatment.[40] Nearly a third of parents report either slowing or stopping therapy due to out-of-pocket expenses and

[38] Based on our understanding of the EHB Benchmark Plan Certificate of Coverage.
[39] "Mental Health & Substance Abuse Coverage" https://www.healthcare.gov/coverage/mental-health-substance-abuse-coverage/. Accessed September 3, 2019.
[40] Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures

22% report they never started therapy because they could not afford it.[41] We assume this is still true for LD 663.

Long-term antibiotics are covered by at least two of seven carriers in the market. Dr. Susan Swedo indicated all cases on PANDAS and moderate to severe cases of PANS should receive at least one-month of antibiotics per treatment guidelines published in the Journal of Child & Adolescent Psychopharmacology, Sep 2017. For children with mild symptoms, re-exposure to the strep virus may trigger a flare-up if long-term antibiotics are not provided.

For children with moderate to extreme symptoms, long-term antibiotics may be prescribed to manage symptoms. If long-term antibiotics are not provided, children may face more flare-ups or will have worsening symptoms. However, we note carriers referenced the U.S. Centers for Disease Control and Prevention, the National Institute of Health, the National Institute of Allergy and Infectious Disease, and the Infectious Diseases Society of America which do not recommend long-term antibiotics due to potential harmful effects.

For children with moderate-to-severe PANDAS/PANS symptoms, the guidelines indicate steroids and/or IVIG therapy is the most effective. Steroids are covered by at least three of seven carriers for PANDAS/PANS but IVIG was not specified as covered for PANDAS/PANS by any carriers. Additionally, there are very few providers who administer IVIG in an office or home setting. Instead, children would have to receive IVIG at a hospital at a significantly higher price.[42]

For children with extreme or life-threatening symptoms, or when IVIG and steroids have not improved symptoms, plasmapheresis and/or rituximab is likely to be prescribed. The carriers did not indicate if rituximab is covered. One carrier indicated plasmapheresis is covered, while one indicates it is not routinely covered. However, it does not appear there are any practitioners in Maine who would provide either plasmapheresis or rituximab for PANDAS/PANS.[43]

5. If coverage is not generally available, the extent to which the lack of coverage involves unreasonable financial hardship.

According to advocates in support of LD 1138, families estimate $10,000 - $25,000 in out-of-pocket costs annually for a single child. One person testified to nearly $40,000 in out-of-pocket costs.[44] Testimony for LD 1138 was done in 2019, so we expect these costs have further increased for LD 663. From carrier responses it appears families could receive coverage for mental health and short-term antibiotics with a PANDAS diagnosis, but would need to pay out of pocket for long-term antibiotics, IVIG and plasmapheresis because carriers consider these treatments experimental.

[41] Ibid.
[42] Ibid.
[43] Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures
[44] Ibid.

6. The level of public demand and the level of demand from providers for this treatment or service.

The Joint Standing Committee on Health Coverage, Insurance and Financial Services received 27 public hearing testimony items regarding LD 1138, with 25 letters in support of the legislation and 1 letter in opposition. Supporting testimony was provided by at least 19 providers.[45]

The Joint Standing Committee on Health Coverage, Insurance and Financial Services received 3 public hearing testimony items regarding LD 663, with 0 letters in support of the legislation, Healthcare Purchaser Alliance testified neither for nor against and 1 letter in opposition from the Maine Association of Health Plans. No providers provided supporting testimony. [46]

Dr. Susan Swedo, along with advocate input, emphasized the importance of early recognition. Dr. Swedo indicated early recognition and treatment is effective and can prevent many children from having worsening symptoms which would require more intensive and more expensive treatments. Worsening symptoms can strain family and community resources. Advocates indicate moderate to severe symptoms can require a parent to quit their job to provide 24/7 assistance to a child with PANDAS/PANS. Additionally, it strains school resources if they have to issue a home tutor when a child cannot leave their home due to PANDAS/PANS symptoms.

7. The level of public demand and the level of demand from the providers for individual or group coverage of this treatment.

Much of the testimony in support of earlier LD 1138 reflected the cost to the family for treatment. The advocate input also indicated that many families were not able to pursue treatment due to cost. We assume this is still true for LD 663.

8. The level of interest in and the extent to which collective bargaining organizations are negotiating privately for the inclusion of this coverage by group plans.

No information is available.

9. The likelihood of meeting a consumer's need as evidenced by experience in other states.

Nine states have passed legislation requiring insurance coverage of PANDAS, which include Arkansas, Delaware, Illinois, Indiana, Maryland, Massachusetts, Minnesota, New Hampshire,

[45] "An Act To Ensure Health Insurance Coverage for Treatment for Childhood Postinfectious Neuroimmune Disorders Including Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome." Public Hearing. Accessed 10/10/2019. http://www.mainelegislature.org/legis/bills/display_ps.asp?ld=1138&PID=1456&snum=129&sec3#

[46] "An Act to Require Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome." Public Hearing. Accessed 9/21/2023. https://legislature.maine.gov/legis/bills/display_ps.asp?LD=663&snum=131#

and Oregon.[47] Dr. Susan Swedo indicated that both the Arizona and Virginia Departments of Health have been doing a lot of educational work with physicians and schools to raise awareness.

10. The relevant findings of the state health planning agency or the appropriate health system agency relating to the social impact of the mandated benefit.

State agencies did not provide findings pertaining to the proposed legislation.

11. The alternatives to meeting the identified need.

The following are the relevant portions of the responses from commercial insurance carriers to the Bureau's request for information. We are not opining on the validity of the following assumptions or conclusions, but rather are repeating them as provided. Only carriers who were able to provide a discussion of alternatives are included.

Anthem:

"The bill, as currently worded, is very broad in nature and would expand the services covered for the treatment of PANDAS/PANS.

As noted above, long-term use of antibiotic therapy to treat continued symptoms of PANDAS/PANS is not consistent with evidence-based medicine or generally accepted standards of care. Prolonged exposure to antibiotic treatment can actually be harmful to members and has been expressly rejected as an appropriate treatment by the U.S. Centers for Disease Control and Prevention, the National Institute of Health, the National Institute of Allergy and Infectious Disease, and the Infectious Diseases Society of America.

Given that the proposal is very broad in nature, requires coverage for certain treatments that are not medically supported, and would increase costs for consumers, Anthem suggests that the bill should not be enacted."

Cigna:

"Cigna recommends supporting sufficiently powered randomized controlled trials to definitively establish the efficacy or lack thereof of IVIG therapy for PANDAS and PANS."

Community Health Options:

"We would suggest no mandate for IVIG coverage, but a recommendation that it could be rarely covered with appropriate criteria for beginning the medicine and for continuing it (for improvement)."

[47] PANDAS Network. http://pandasnetwork.org/legislation/. Accessed September 5, 2023.

12. Whether the benefit is a medical or a broader social need and whether it is inconsistent with the role of insurance and the concept of managed care.

The benefit is a medical need and coverage required by LD 663 is not inconsistent with the role of insurance to provide medically necessary services for a condition. However, this mandate may step outside the role of insurance in that it requires carriers to reimburse providers for treatments such as plasmapheresis and IVIG, which the 2018 American Academy of Pediatrics Redbook and carrier responses contend have not been shown to be medically necessary or to improve symptoms.

13. The impact of any social stigma attached to the benefit upon the market.

The actual symptoms of PANDAS/PANS affect a child's ability to function in various areas and may prohibit the child from participating in school or even leaving the house. However, there is unlikely to be a social stigma attached to receiving treatment as most cases will be treated with common medications or treatments.

14. The impact of this benefit upon the other benefits currently offered.

For several carriers, LD 663 would expand the use of antibiotics to include long-term use, and would expand IVIG to be used for PANDAS/PANS. If these treatments are effective, there is potential for less intensive behavioral health services as an alternative.

15. The impact of the benefit as it relates to employers shifting to self-insurance and the extent to which the benefit is currently being offered by employers with self-insured plans.

As premiums increase, employers look for ways to have more control over the benefits they provide to employees and to control the costs. While this mandate, considered individually, is expected to have a minimal impact on premiums, it does add to the cumulative impact of mandates on overall rates. Many employers have the option of moving to self-insurance, and the cumulative impact of mandates is likely a consideration for employers when considering moving out of the fully-insured market or when shifting a higher cost-sharing responsibility to their covered employees.

16. The impact of making the benefit applicable to the state employee health insurance program.

Anthem indicated a cost estimate of $0.60 PMPM to cover the treatments listed under this proposed mandate for the State Employee Health Plan.

IV. Financial Impact

B. Financial Impact of Mandating Benefits

1. The extent to which the proposed insurance coverage would increase or decrease the cost of the service or treatment over the next five years.

Antibiotics, NSAIDs, steroids, and SSRIs are commonly used for many conditions. It is unlikely that the cost of these would be impacted. There is a lack of trained CBT professionals according to Dr. Susan Swedo, and an increase in demand could theoretically increase prices. Currently, according to the International OCD Foundation there are no therapists available in Maine.[48] Other qualified therapists may be available, but with limited training in CBT and ERP. If the number of professionals does not increase, the cost may increase as demand exceeds supply. We cannot anticipate the increase in professionals or the potential impact on cost for CBT professionals.

Currently, IVIG appears to be primarily administered in hospitals with only one available office or home care setting in Maine. Expanding coverage could increase the demand for this service in the office or home care settings, where it has a significantly lower cost.[49]

None of the carriers were able to identify any potential lowering of costs.

2. The extent to which the proposed coverage might increase the appropriate or inappropriate use of the treatment or service over the next five years.

Many treatments including short-term antibiotics, CBT, short-term steroids and SSRIs are currently covered by carriers in Maine and should not change due to the proposed mandated coverage.

The proposed coverage would increase the use of long-term antibiotics used to manage symptoms of PANDAS/PANS. The proposed coverage would also likely increase the use of IVIG and in rare cases, plasmapheresis, as currently it is not generally covered. However, there is disagreement in the provider community about the efficacy of these treatments.

Dr. Susan Swedo indicated that PANDAS/PANS is a clinical diagnosis made on the basis of history, and that laboratory tests are confirmatory but are not diagnostic. Therefore, it is possible children may receive an incorrect PANDAS/PANS diagnosis and pursue inappropriate treatments. This is also the concern of the American Academy of Pediatrics. Dr. Susan Swedo believes more recognition and understanding among physicians would limit inappropriate treatments.

The proposed mandate for coverage may increase the use of IVIG when it is unnecessary, because coverage would be required. The mandate may also inappropriately increase the use of

[48] International OCD Foundation. Search for PANDAS/PANS Specialty in Maine. https://kids.iocdf.org/. 9.21.2023
[49] Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures

plasmapheresis, although a child would most likely be referred to a multi-disciplinary clinic for this treatment, with physicians who would be unlikely to prescribe plasmapheresis or rituximab if it were unnecessary. The proposed coverage does not prohibit cost sharing and medical management methods which would limit inappropriate treatment.

3. The extent to which the mandated treatment or service might serve as an alternative for more expensive or less expensive treatment or service.

The mandated treatment does not replace other treatments. However, early treatment using antibiotics and NSAIDs, which are already typically covered, could prevent more expensive treatments such as IVIG and plasmapheresis in some cases.

4. The methods that will be instituted to manage the utilization and costs of the proposed mandate.

The language in the bill does not prohibit medical management. Carriers will be able to limit services to those that they determine to be medically necessary. If treatment is not effective, medical management could discontinue coverage of the treatment.

5. The extent to which insurance coverage may affect the number and types of providers over the next five years.

Per New England PANS PANDAS Association (NEPANS) and caregiver/provider advocates, there is one known health care provider in Maine who will administer IVIG to children with PANDAS/PANS in an office or home care setting. There are no known practitioners in the state who prescribe either plasma exchange or rituximab to patients for treatment of PANDAS/PANS.[50] This was provided for LD 1138, and we assume this is still true for LD 663.

Covering this service could increase the number of providers who will provide IVIG or plasmapheresis for PANDAS/PANS. However, because the American Academy of Pediatrics Redbook discourages the use of these treatments in such cases, providers may wait until more evidence is discovered.

Dr. Susan Swedo indicated there is a lack of trained CBT professionals, especially with exposure and response prevention (ERP) training. The International OCD foundation offers trainings and currently lists eight such trained professionals in Maine.[51] More awareness for PANDAS/PANS could increase the number of CBT professionals trained in ERP.

6. The extent to which the insurance coverage of the health care service or providers may be reasonably expected to increase or decrease the insurance premium or administrative expenses of policyholders.

The table below summarizes the carrier input and is followed by the carrier specific language.

[50] Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures
[51] International OCD Foundation. https://kids.iocdf.org/

Carrier	Estimated Premium Impact PMPM
Aetna	$0.04 to $0.12 PMPM
Anthem	$0.46 to $0.51 PMPM
Cigna	Small but not insignificant
Community Health Options	$0.06 to $0.47 PMPM[52]
HPHC	$0.03 to $0.05 PMPM
Taro Health	$0.10 to $0.40 PMPM
UnitedHealthcare	Not specified

Aetna:

"We estimate the mandate would have a $0.04 to $0.12 PMPM increase to premium (same across all lines of business). No impact on administrative or indirect costs."

Anthem:

"Assuming full coverage with $0 cost share:

Individual	$0.46
Small Group	$0.51
Large Group	$0.49

Previously (for LD 1138):

"The proposed mandate does not establish a limit or duration for the treatments listed. Costs would vary greatly, depending on the length of treatment. As a proxy, we have assumed a one-month period of treatment for long-term use of antibiotic therapy, but we would note that prophylactic use of antibiotics could continue for 5-10 years or more. For all other treatments, we used experience from our own block of business to determine the average duration of treatments. Please note that the cost estimates above may be inadequate should members receive treatments for longer than the durations assumed.

"In developing the costs, we assumed that 1 in 200 children may have PANDAS/PANS.[53] Of those diagnosed with PANDAS/PANS, we assumed approximately 75% would receive treatment through long-term antibiotic therapy, 7% through IVIG therapy, 3% through a combination of IVIG therapy and long-term antibiotic therapy, 1% through plasmapheresis, and the remaining 14% would seek an alternative treatment or no treatment at all. To the extent that a greater percentage of IVIG therapy treatments were rendered, the costs described above would be greater."

[52] Community Health Options provided a total cost. We calculated the PMPM by dividing by a 80% loss ratio and dividing by the 349,740 member months, which are the combined indv, sg, and lg member months reported in the 2022 SHCE.

[53] http://pandasnetwork.org/statistics/

Cigna:

"Leveraging analysis from other states that required coverage of PANDAS Cigna anticipates this legislation would have a small, yet not immaterial impact."

Community Health Options:

"Our response remains consistent with the previous PANDAS inquiry.

Range of IVIG therapy (depending on place of service): IVIG cost. Assume a child weight of 100lb (45.5kg). According to the following study J Child Adolesc Psychopharmacol. 2018 Mar;28(2):92-103. doi: 10.1089/cap.2017.0101. Epub 2017 Aug 23, (https://www.ncbi.nlm.nih.gov/pubmed/28832181) a dose of 0.8g/kg was originally used (73 J-code units)

After further review of the article, the dosage range was 0.8g/kg to 1.1g/kg. An updated dollar value was calculated based on 1.0g/kg (91 J-code units) along with unit pricing as of July 2023, which calculated a range of $4,500 (lowest cost provider) to $33,000 (highest cost facilities) per infusion. The study also indicated that the infusion was given every 2-5 weeks (but did not indicate for how long). Assuming there were 4 infusions over a period of 6 months, that would be a minimum range of costs from $18,000 to $132,000."

Harvard (HPHC):

"Under the mandate, the additional coverage of intravenous immune globulin is estimated to be an additional $0.03-$0.05 PMPM. There is no real change in our responses based on the previous report. Long term antibiotic use may have other adverse effects on children."

Previously (for LD 1138):

"HPHC has determined the cost implications to be less than 0.1%. We are estimating it to be essentially very small across all segments, and it would be misleading to even state that we could estimate statistically significant differences by group size. The cost is considered to be very low largely because accurate prevalence rates cannot be accurately determined. The illness is diagnosed by ruling out other disease states and not in a straight-forward way. Furthermore, there is no diagnosis code for either condition and multiple sources show widely varying prevalence rates. Finally, members with this condition likely have some access to other treatment options, partially offsetting any increase in cost."

Taro Health:

"Given the unknown amount of PANDAS patients we would see in our membership pool, we believe the cost of the additional services and benefits would be between $0.10 and $0.40 on a PMPM basis."

United Healthcare (UHC):

"We expect very little additional cost if the mandate is covered. However, due to the size of our block, one claim could increase costs significantly."

Other States:

Nine states have passed a PANDAS/PANS insurance bill: Arkansas, Delaware, Illinois, Indiana, Maryland, Minnesota, New Hampshire, and Oregon.[54] We were not able to find a cost estimate for most of these states. Delaware's fiscal note assumed one round of IVIG therapy for each eligible member to a total estimated cost of $100,000. For 18,000 members, this amounts to about $0.46 PMPM. Illinois noted that an accurate cost cannot be completed as the number of cases was not provided.[55]

Minnesota Statute § 62A.3097, which became law in 2019, requires all health plans to provide coverage for treatment associated with PANDAS/PANS. Treatments that must be covered include antibiotics, medication and behavioral therapies to manage neuropsychiatric symptoms, plasma exchange, and immunoglobulin. Minnesota determined the new requirements of the law constituted a new benefit mandate as defined under the Affordable Care Act (ACA). Section 1311(d)(3) and must have associated costs defrayed by the State. Reimbursements began with plan year 2022 and expected to be paid in 2023.

We did find some cost analyses provided by Connecticut and Massachusetts. Massachusetts performed an analysis in 2015 and estimated an average annual increase over five years to the typical member's monthly health insurance premiums of between $0.003 (0.001%) and $0.039 (0.008%) per year.[56] Connecticut performed an analysis in 2014 and estimated a $0.013 PMPM impact on group policies and $0.014 PMPM impact on individual policies.

Our Estimate

In performing the cost estimate, we note that there is not a significant amount of data on the prevalence of PANDAS/PANS or the treatments that the families pursue. In fact, two of the seven carriers that we surveyed did not provide a cost estimate and other states were not able to perform cost estimates due to a lack of prevalence data.

[54] PANDAS Network. http://pandasnetwork.org/legislation/. Accessed September 6, 2023.
[55] Bill Status of HB2721. Illinois General Assembly. http://www.ilga.gov/legislation/BillStatus.asp?DocTypeID=HB&DocNum=2721&GAID=14&SessionID=91&LegID=104021. Accessed September 6, 2023.
[56] Mandated benefit review of House bill 984 : an act relative to insurance coverage for PANDAS/PANS. May 2015. https://archives.lib.state.ma.us/handle/2452/265203. Accessed September 6, 2023.

Treatment	Cost Per Session	Number of Sessions Annually	% Who Receive Treatment
Short-term antibiotics (0-4 weeks)	$14[57,58]	1 month	100% (per guidelines) [59]
Long-term antibiotics	$14	11 months (addition to 1 month everybody would receive)	70%[60]
Psychological and Behavioral Interventions	$125-$250[61]	Weekly (52) or Biweekly (26)	100% (per guidelines) [62]
IVIG	$7,400-$31,000[63]	1-3[64] (assumed 2)	10%-20%
Plasmapheresis	$21,800[65]	1-2	1%-5%
Rituximab	$6,200[66]	Given in combination with plasmapheresis	Given in combination with plasmapheresis

There is little information on the prevalence of PANDAS/PANS due to it being a relatively new diagnosis and due to misdiagnosis. An advocate report provided a range of one in 1,000 to one in 200, which appears to be consistent with other sources we have seen. The prevalence data was applied to the covered lives under 18. Although we have seen sources that indicate PANDAS/PANS can affect people of all ages, LD 663 refers to "pediatric" and so we have focused our analysis on covered lives under 18 years old.

[57] "Amoxil." GoodRx. https://www.goodrx.com/amoxil Accessed 9/6/2023.
[58] Providers may prescribe several different types of antibiotics, but Dr. Susan Swedo mentioned amoxicillin.
[59] Cooperstock, MD, MPH et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III – Treatment and Prevention of Infections. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 594-606.
[60] Dr. Susan Swedo estimated 30-40% of PANDAS/PANS cases as mild. These cases would not likely require long-term antibiotics, so we assume 70% would require long-term antibiotics.
[61] "How Much Does Therapy Cost?" https://www.goodtherapy.org/blog/faq/how-much-does-therapy-cost. Accessed September 3, 2019. Cost Trended by 5.5% annually from 2019 to 2023.
[62] Thienemann, MD et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part I—Psychiatric and Behavioral Interventions. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 566-573.
[63] Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures. Cost Trended by 5.5% annually from 2019 to 2023.
[64] Frankovich, MD, MS et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 574–593.
[65] "Mandated Benefit Review of House Bill 984: An Act Relative to Insurance Coverage for PANDAS/PANS." Center for Health Information and Analysis. May 2015. Cost Trended by 5.5% annually from 2019 to 2023.
[66] Ibid.

The number of insured lives in Maine in 2022 (286,883) comes from the 2022 Supplemental Health Care Exhibit (SHCE). The percentage of persons under 18 in Maine (17.9%) was from the United States Census Bureau.[67]

LD 663 applies to instances of PANDAS/PANS associated with infection. The estimates of PANDAS/PANS associated with infection are between 40% and 77%.[68] Using these assumptions, we estimate between 21 to 198 Maine covered children who would be diagnosed with PANDAS/PANS associated with an infection each year.

The Summary to the previous bill, LD 1138, states that the treatments authorized are described in a series of articles in the 2017 Journal of Child and Adolescent Psychopharmacology. Our understanding of these articles is that these treatment options include those listed below:[69] We used the same understanding in pricing LD 663, which does not include a reference to the journal but the benefits described are substantially similar.

- Psychoactive medications, psychotherapies, and supporting interventions to provide symptomatic relief.
- Antibiotics to eliminate the source of neuroinflammation.
- Anti-inflammatory and immune modulating therapies to treat disturbances of the immune system.

PANDAS/PANS have a wide range of symptoms and severities, meaning that treatment plans should be personalized to the patient. Our estimate relies on the primary courses of action described in the guidelines, although each child will have different needs.

The treatment guidelines indicate that an initial course of antibiotics[70] and psychological interventions[71] is proposed for all newly diagnosed cases of PANDAS/PANS. Thus, we assume that 100% of cases would pursue these treatment options.

For antibiotic treatment, we assumed amoxicillin and cephalosporin antibiotics may be prescribed, and based on the response of the patient a provider may switch between the antibiotics. We assume 100% of newly diagnosed PANDAS/PANS patients would receive at

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[67] QuickFacts: Maine. United States Census Bureau. https://www.census.gov/quickfacts/fact/table/ME,US/PST045218. Accessed September 6, 2023.
[68] Cooperstock, MD, MPH et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III – Treatment and Prevention of Infections. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 594-606.
[69] Swedo, MD, et al. Overview of Treatment of Pediatric Acute-Onset Neuropsychiatric Syndrome. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 562-565.
[70] Thienemann, MD et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part I—Psychiatric and Behavioral Interventions. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 566-573.
[71] Cooperstock, MD, MPH et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III – Treatment and Prevention of Infections. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 594-606.

least 30 days of antibiotics, consistent with the guidelines. We have assumed the patient would be prescribed amoxicillin, as it is cheap, widely available, and effective according to Dr. Susan Swedo. We estimate a monthly cost of $14.[72] We believe this is currently covered by all carriers.

We assumed that for PANDAS patients, or for PANS patients with moderate to severe symptoms, antibiotics would be prescribed for at least a year. We do not have accurate prevalence data for PANDAS as opposed to PANS or the percent of PANS cases that are moderate to severe, but based on our research we estimate about 70% of cases would require at least a year of antibiotics, which we also assumed would be amoxicillin. Long-term antibiotics are not consistently covered in the market for PANDAS/PANS.

Dr. Susan Swedo suggested that every patient should receive at least a trial of NSAIDs (such as ibuprofen) as they are also less expensive, effective, and widely available. She said that some experts indicate that at least 80% of PANDAS/PANS cases would be managed with antibiotics and NSAIDs. We have not included NSAIDs in our cost estimate as they are widely available over the counter, oftentimes at a lower cost than an insurance copay.

Psychological interventions should also be pursued with all new cases according to the guidelines. Primarily we would expect these interventions to include either behavioral or pharmacological treatments, or both. The guidelines reference a 2006 study[73] where all children were prescribed 14 90-minute cognitive behavior therapy (CBT) sessions over three weeks. We assume that 100% of newly diagnosed PANDAS/PANS patients would receive CBT sessions. While we have not found definitive support for the number of sessions needed, we used 14 sessions consistent with the 2006 study. Sources indicate the cost of therapy typically ranges between $100 to 200,[74] which we trended at 5.5%[75] annually from 2019 to 2023 to an approximate range of $125 to $250. We used the midpoint of $186 per session. CBT appears to be generally currently covered for PANDAS/PANS.

We are unclear how often SSRIs would be prescribed to PANDAS/PANS patients, although Harvard Health indicates that 40% to 60% of patients with OCD would receive at least a partial reduction in symptoms with SSRIs.[76] Dr. Susan Swedo indicated that she would guess the PANDAS/PANS cohort would use fewer SSRIs than those with non-PANDAS OCD. We assume the lower end of the range or about 40% of patients would receive SSRIs with a monthly cost of about $10[77] (for sertraline or fluoxetine as stated in the guidelines). SSRI appears to be generally covered services for PANDAS/PANS.

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[72] "Amoxil." GoodRx. https://www.goodrx.com/amoxil Accessed 9/6/2023.
[73] Storch EA, Murphy TK, Geffken GR, Mann G, Adkins J, Merlo LJ, Duke D, Munson M, Swaine Z, Goodman WK: Cognitivebehavioral therapy for PANDAS-related obsessive-compulsive disorder: Findings from a preliminary waitlist controlled open trial. J Am Acad Child Adolesc Psychiatry 45:1171–1178, 2006.
[74] "How Much Does Therapy Cost." Good Therapy. https://www.goodtherapy.org/blog/faq/how-much-does-therapy-cost . Accessed September 6, 2023.
[75] Based on an analysis of National Health Expenditure data from 2019 to 2023.
[76] "Treating obsessive-compulsive disorder." Harvard Health Publishing. https://www.health.harvard.edu/mind-and-mood/treating-obsessive-compulsive-disorder. Accessed 9/6/2023.
[77] SSRIs. GoodRx. https://www.goodrx.com/ssris. Accessed 9/6/2023.

We assume more than 80% of PANDAS/PANS cases are treated with antibiotics and NSAIDs.[78] We assume 20% of patients will receive short-term steroids, as Dr. Susan Swedo indicated long-term low-dose steroid or IVIG is not advisable. The steroids may be oral or administered via IV and the guidelines recommend 1-2 mg/kg/day for 5 days for moderate to severe flare-ups.[79] Prednisone is a commonly prescribed corticosteroid at a price of $19 for 5 tablets.[80] Short-term steroids appear to be generally covered services for PANDAS/PANS.

The combination of CBT, SSRI, and antibiotics is a sufficient treatment plan for most children diagnosed with PANDAS/PANS, although some with more severe symptoms will require more intensive treatment. According to the guidelines, the next treatment option is IVIG. We were unable to find published studies on the percentage of patients who would receive IVIG, but a mandated benefit review in Massachusetts referred to an interview with an expert who indicated that approximately 10% would receive this treatment, which we believe is not unreasonable and was used for the prior analysis of LD 1138.[81] For LD 663 we increased our estimate to 15% considering an additional efficacy study displayed on the PANDAS Network website supporting IVIG.[82] According to the guidelines IVIG should be given over a two-day period and patients usually require 1-3 courses.[83] An advocate report further supported this assumption by indicating if there was no improvement from 3 courses of IVIG over 4 weeks, it would not be used further.[84] We assume 2 courses on average. This includes an average 1.5 for initial treatment and another average 0.5 treatments for flare-ups within a year. Flare-up treatment would start with antibiotics and NSAIDs again and would not directly pursue IVIG immediately. We estimate one-third (1/3) of patients who receive IVIG would receive another average 1.5 courses of IVIG within a year due to a flare-up within a year, which equals an average 0.5 treatment as discussed above. The advocate report also stated that a two IVIG therapy in an office setting costs $6,000 or $12,000 for a two-day course of administration or $25,000 for a one-day course in the hospital. We trended these costs at 5.5% annually from 2019 to 2023, to a cost range of $7,400 to $31,000 We assume patients will typically pursue treatment in an office setting, and while we assume not all patients will pursue a two-day treatment, we believe $15,000 per IVIG course is

[78] Although not directly confirmed, we assume most of these patients would also be receiving psychological interventions.
[79] Frankovich, MD, MS et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 574–593.
[80] Prednisone. GoodRx. https://www.goodrx.com/prednisone?label_override=prednisone&form=tablet&dosage=50mg&quantity=5 Accessed 9/6/2023.
[81] MANDATED BENEFIT REVIEW OF HOUSE BILL 984: AN ACT RELATIVE TO INSURANCE COVERAGE FOR PANDAS/PANS. CENTER FOR HEALTH INFORMATION AND ANALYSIS. May 2015.
[82] Melamed I, Kobayashi RH, O'Connor M, Kobayashi AL, Schechterman A, Heffron M, Canterberry S, Miranda H, Rashid N. Evaluation of Intravenous Immunoglobulin in Pediatric Acute-Onset Neuropsychiatric Syndrome. J Child Adolesc Psychopharmacol. 2021 Mar;31(2):118-128. doi: 10.1089/cap.2020.0100. Epub 2021 Feb 18. PMID: 33601937; PMCID: PMC7984935.
[83] Frankovich, MD, MS et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 574–593.
[84] Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures

not an unreasonable estimate. IVIG is currently not covered by most carriers for PANDAS/PANS.

In some severe or life-threatening cases, plasmapheresis may be recommended. Similar to IVIG, we are not aware of published studies on how many children will receive plasmapheresis. The Massachusetts mandated benefit review assumed from 0.3 to 1.0 percent of children will receive this treatment, which we believe is not unreasonable.[85] We assume 1% will receive treatment and will also rely on the Massachusetts cost (trended at 5.5% annually from 2019 to 2023) of $22,000 as currently there are no known practitioners providing this treatment to children in Maine.[86] Rituximab is in the same category as plasmapheresis and if prescribed would likely be in combination with plasmapheresis. We assume $6,200 for 500mg.[87] We have assumed one treatment as Dr. Susan Swedo indicated it is unlikely a child would receive plasmapheresis more than once.

Using these assumptions, we estimate a $0.04 to $0.40 PMPM impact on premiums on a gross basis for the treatment of PANDAS/PANS. However, as we assumed short-term antibiotics, CBT, short-term steroids and SSRIs are currently covered by carriers in Maine, we estimate a $0.03 to $0.25 PMPM impact to premiums due to the mandate.

7. The impact of indirect costs, which are costs other than premiums and administrative costs, on the question of the cost and benefits of coverage.

There should not be any additional cost effect beyond benefit and administrative costs.

8. The impact on the total cost of health care, including potential benefits and savings to insurers and employers because the proposed mandated treatment or service prevents disease or illness or leads to the early detection and treatment of disease or illness that is less costly than treatment or service for later stages of a disease or illness.

Advocates stated in support of LD 1138, "When diagnosed early and treated appropriately, PANDAS/PANS patients have an excellent outcome. However, the tremendous burden placed both on families and our state/local resources caused by protracted diagnosis and untreated/under-treated PANDAS/PANS is considerable and preventable."

Dr. Susan Swedo echoed this statement by saying this could become a chronic unrelenting form of OCD, anxiety disorder, depression, mental/physical disorder, etc. which has a tremendous cost to families. Additionally, in a severe case a parent may have to quit his or her job to become a full-time caretaker. Schools would also bear the cost of sending home tutors for children who will not leave the house or cannot perform in school.

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[85] MANDATED BENEFIT REVIEW OF HOUSE BILL 984: AN ACT RELATIVE TO INSURANCE COVERAGE FOR PANDAS/PANS. CENTER FOR HEALTH INFORMATION AND ANALYSIS. May 2015.
[86] Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures
[87] "Rituxan Prices, Coupons & Savings Tips - Webmdrx." WebMD, WebMD, rx.webmd.com/drug-prices/rituxan#:~:text=8-,Rituximab%20is%20used%20to%20treat%20certain%20types%20of%20cancer%20(such,%2F50ml%20each%2C%20is%20%2420%2C973.10. Accessed 6 Sept. 2023. Trended at 5.5% annually from 2019 to 2023

The carrier responses and one public testimony noted there is disagreement among the provider communities of the efficacy of the more intensive and expensive treatments including long-term antibiotics use, IVIG, and plasmapheresis.

9. The effects of mandating the benefit on the cost of health care, particularly the premium and administrative expenses and indirect costs, to employers and employees, including the financial impact on small employers, medium-sized employers and large employers.

There is a concern that the broad language of the bill will lead to more inappropriate diagnosis and use of health care services such as long-term antibiotics or IVIG when unnecessary, which would have the effect of increasing premiums. However, as discussed above, the bill does not prohibit medical management and carriers will be able to limit services to those that they determine to be medically necessary.

10. The effect of the proposed mandates on cost-shifting between private and public payers of health care coverage and on the overall cost of the health care delivery system in this State.

These additional services are not currently covered by MaineCare or other public payers. Therefore, we do not anticipate any cost-shifting.

V. Medical Efficacy

C. The Medical Efficacy of Mandating the Benefit

1. The contribution of the benefit to the quality of patient care and the health status of the population, including any research demonstrating the medical efficacy of the treatment or service compared to the alternative of not providing the treatment or service.

A double-blind placebo-controlled study shows that the antibiotic azithromycin is helpful in treating the PANDAS/PANS diagnosis particularly in those with elevated levels of OCD and tic symptoms.[88] Other articles show support for NSAIDs[89] and corticosteroids,[90] although both indicate that further placebo-controlled studies are warranted.

There have been several studies which showed the therapeutic benefits of TPE (plasmapheresis)

[88] Murphy, MD, MS et al. A Double-Blind Randomized Placebo-Controlled Pilot Study of Azithromycin in Youth with Acute-Onset Obsessive-Compulsive Disorder. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 640-651.
[89] Brown, BA et al. Effect of Early and Prophylactic Nonsteroidal Anti-Inflammatory Drugs on Flare Duration in Pediatric Acute-Onset Neuropsychiatric Syndrome: An Observational Study of Patients Followed by an Academic Community-Based Pediatric Acute-Onset Neuropsychiatric Syndrome Clinic. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 619-628.
[90] Ibid.

and IVIG. One double-blind placebo-controlled study showed IVIG and TPE were both effective in reducing obsessive compulsive symptoms in PANDAS/PANS cases, although it was noted that non-PANDAS OCD and tic disorders failed to show benefits from TPE and IVIG.[91] An additional small sample study demonstrated IVIG treatment of PANDAS/PANS successfully ameliorated psychological symptoms and dysfunction.[92]

Most carrier responses indicate IVIG and plasmapheresis are considered investigational as treatments for PANDAS/PANS.

2. If the legislation seeks to mandate coverage of an additional class of practitioners:

a. The results of any professionally acceptable research demonstrating the medical results achieved by the additional class of practitioners relative to those already covered; and
b. The methods of the appropriate professional organization that assure clinical proficiency.

The bill does not mandate coverage of an additional class of practitioners.

VI. Balancing the Effects

D. The Effects of Balancing the Social, Economic, and Medical Efficacy Considerations

1. The extent to which the need for coverage outweighs the cost of mandating the benefit for all policyholders.

Advocates for LD 1138 indicated that patients who do not receive treatment have a "poor quality of life, are generally unable to function in school and social settings, have school regression and antisocial behaviors."[93] Dr. Susan Swedo indicated severe symptoms including anxiety, depression, anorexia complications, and even suicide could occur if left untreated.

We believe the most common treatments such as steroids, SSRI, short-term antibiotics, and CRT are already being covered for PANDAS/PANS. There is disagreement in the provider communities regarding the efficacy of the more intensive and expensive treatments such as long-term antibiotics, IVIG, and plasmapheresis which would be required by LD 663.

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[91] Frankovich, MD, MS et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies. Journal of Child and Adolescent Psychopharmacology. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 574–593.
[92] Melamed I, Kobayashi RH, O'Connor M, Kobayashi AL, Schechterman A, Heffron M, Canterberry S, Miranda H, Rashid N. Evaluation of Intravenous Immunoglobulin in Pediatric Acute-Onset Neuropsychiatric Syndrome. J Child Adolesc Psychopharmacol. 2021 Mar;31(2):118-128. doi: 10.1089/cap.2020.0100. Epub 2021 Feb 18. PMID: 33601937; PMCID: PMC7984935.
[93] Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures

2. The extent to which the problem of coverage can be resolved by mandating the availability of coverage as an option for policyholders.

It is likely that only those who would benefit from the services would purchase the coverage. This would result in alternative coverage that would cost more than the additional cost of services because of the administrative charges that would be added to benefit costs. This cost would be reduced if the option were only available when the coverage was initially purchased, but it would then be less effective because many individuals would not anticipate needing the coverage and, therefore, would not purchase it. In addition, separate riders for ACA plans are prohibited.

3. The cumulative impact of mandating this benefit in combination with existing mandates on costs and availability of coverage.

	Min	**Max**
Total cost for groups larger than 20:	10.41%	10.45%
Total cost for groups of 20 or fewer:	10.46%	10.51%
Total cost for individual contracts:	10.49%	10.54%

The estimated cost of current Maine mandates is detailed in Appendix A. For most of these mandates, our estimate is based on the net impact on premiums as estimated at the time the mandate was enacted. Four of the mandates – mental health, substance abuse, chiropractic, and screening mammograms – require carriers to report annually the number of claims paid for these benefits and the estimates are based on that data.

The true cost for the Maine mandates is affected by the fact that:

1. Some services would be provided and reimbursed in the absence of a mandate.
2. Certain services or providers will reduce claims in other areas.
3. Some mandates are required by Federal law.

VII. Appendices

Appendix A: Cumulative Impact of Mandates

Bureau of Insurance

Cumulative Impact of Mandates in Maine

Report for the Year 2023

This report provides data for medical insurance coverage of mandates as required by 24-A M.R.S.A. §2752 and compiled by the Bureau of Insurance. While some data was provided through annual mandate reports by insurers, other figures were estimated as a part of the proposed mandates study. The following provides a brief description of each state mandate and the estimated claim cost as a percentage of premium. Many of these mandates are now required by the federal Affordable Care Act (ACA). In addition, the ACA requires benefits covered by the benchmark plan which includes all state mandates to be covered by all individual and small group plans effective January 1, 2014. A summary chart is provided at the end of this report.

- ***Mental Health*** (Enacted 1983)

Mental health parity for group plans in Maine became effective in 1996 and was expanded in 2003. The percentage of mental health group claims paid has been tracked since 1984 and has historically been between 3% - 4% of total group health claims. Claims jumped sharply in 2020 by 1.3% to 5.2% for groups after steadily declining by a half point per year for the previous 3 years. For 2022, group claims were 4.11% of total medical claims.

Maine mental health parity was only a mandated offer for individual plans until it was included in the essential health benefits for ACA (Affordable Care Act) individual and small group plans beginning 2014. The Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) amended the PHS Act, ERISA, and the Code to provide increased parity between mental health and substance use disorder benefits and medical/surgical benefits and extended parity to all individual plans. As expected, mental health claims have stabilized back to a lower level of 2.5% in 2017 after meeting pent-up demand of 9.4% in 2015. For 2022, individual claims are 3.07% of total medical claims.

- ***Substance Abuse*** (Enacted 1983)

Maine's mandate initially only applied to group coverage. Effective in 2003, substance abuse was added to the list of mental health conditions for which parity is required. Effective in 2014 the federal Affordable Care Act requires substance abuse treatment benefits for individual and small group plans as part of the essential health benefits. The percentage of claims paid for group plans has been tracked since 1984. Substance abuse claims paid have remained flat at 1% average for the past 3 years of the total group health claims. Individual substance abuse health claims have also remained flat at 1% for the past 3 years. As expected, substance abuse claims have leveled out as pent-up demand is met and carriers manage utilization. For 2022, group claims for substance abuse were reported as 1.10% and individual claims 0.77% of total medical claims.

- ***Chiropractic*** (Enacted 1986)

This mandate requires coverage for the services of chiropractors to the extent that the same services would be covered if performed by a physician. Using annual experience reports from the carriers, the percentage of claims paid has been tracked since 1986 and, in 2022, was 0.52% of total health claims. Individual claims at 0.32% (group at 0.58%) in 2022 have continued a trend of lower than group claims since 2017 when they were equivalent.

- ***Screening Mammography*** (Enacted 1990)

This mandate requires that benefits be provided for screening mammography at no cost to the insured. We estimate the current 2022 levels of 0.66% for group and 1.2% for individual going forward. Coverage is required by ACA for preventive services.

- ***Dentists*** (Enacted 1975)

This mandate requires coverage for dentists' services to the extent that the same services would be covered if performed by a physician. A 1992 study done by Milliman and Robertson for the Mandated Benefits Advisory Commission estimated that these claims represent 0.5% of total health claims and that the actual impact on premiums is "slight." It is unlikely that this coverage would be excluded in the absence of a mandate. We include 0.1% as an estimate.

- ***Breast Reconstruction*** (Enacted 1998)

This mandate requires coverage for reconstruction of both breasts to produce a symmetrical appearance after a mastectomy. At the time this mandate was being considered in 1995, one carrier estimated the cost at $0.20 per month per individual. We do not have a more recent estimate. We include 0.02% in our estimate of the maximum cumulative impact of mandates.

- ***Errors of Metabolism*** (Enacted 1995)

This mandate requires coverage for metabolic formula and prescribed modified low-protein food products. At the time this mandate was being considered in 1995, Blue Cross estimated the cost at $0.10 per month per individual. We do not have a more recent estimate. We include 0.01% in our estimate.

- ***Diabetic Supplies*** (Enacted 1996)

This mandate requires that benefits be provided for medically necessary diabetic supplies and equipment. Based on data collected in 2006, most carriers reported that there would be no cost increase or an insignificant cost increase because they already provide this coverage. Based on our report we estimate 0.2%.

- ***Minimum Maternity Stay*** (Enacted 1996)

This mandate requires that if a policy provides maternity benefits, the maternity (length of stay) and newborn care benefits must be provided in accordance with "Guidelines for Prenatal Care." Based on carrier responses indicating that they did not limit maternity stays below those recommended, we estimate no impact.

- ***Pap Smear Tests*** (Enacted 1996)

This mandate requires that benefits be provided for screening Pap smear tests. We estimate a negligible impact of 0.01%. Coverage is required by ACA for preventive services.

- ***Annual GYN Exam Without Referral*** (Enacted 1996)

This mandate only affects HMO plans and similar plans, and it requires the provision of benefits for annual gynecological exams without prior approval from a primary care physician. To the extent the Primary Care Physician (PCP) would, in absence of this law, have performed the exam personally rather than referring to an OB/GYN, the cost may be somewhat higher; therefore, we include 0.1%.

- ***Breast Cancer Length of Stay*** (Enacted 1997)

This mandate requires that benefits for breast cancer treatment be provided for a medically appropriate period of time as determined by the physician in consultation with the patient. Claims for breast cancer treatment in 2022 remain level with past years at 1.7% of total medical claims.

- ***Off-label Use Prescription Drugs*** (Enacted 1998)

This mandate requires coverage of off-label prescription drugs in the treatment of cancer, HIV, and AIDS. Our 1998 report stated a "high-end cost estimate" of about $1 per member per month (0.6% of premium) if it is assumed there is currently no coverage for off-label drugs. Because the HMOs claimed to already cover off-label drugs, in which case there would be no additional cost; and, providers testified that claims have been denied on this basis, we include half this amount, or 0.3%.

- ***Prostate Cancer*** (Enacted 1998)

This mandate requires prostate cancer screenings. Our report estimated additional claims cost would approximate $0.10 per member per month. With the inclusion of administrative expenses, we would expect a total cost of approximately $0.11 per member per month, or approximately 0.07% of total premiums. Coverage is required by ACA for preventive services.

- ***Nurse Practitioners and Certified Nurse Midwives*** (Enacted 1999)

This law mandates coverage for nurse practitioners and certified nurse midwives and allows nurse practitioners to serve as primary care providers. This mandate is estimated to increase premium by 0.16%.

- ***Coverage of Contraceptives*** (Enacted 1999)

This mandate requires health plans that cover prescription drugs to cover contraceptives. Our report estimated an increase of premium of 0.8%.

- ***Registered Nurse First Assistants*** (Enacted 1999)

This mandate requires health plans that cover surgical first assistants to cover registered nurse first assistants if an assisting physician would be covered. No material increase in premium is expected.

- ***Access to Clinical Trials*** (Enacted 2000)

This mandate requires that coverage be provided for an eligible enrollee to participate in approved clinical trials. Our report estimated a cost of 0.19% of premium.

- ***Access to Prescription Drugs*** (Enacted 2000)

This mandate only affects plans with closed formularies. Our report concluded that enrollment in such plans is minimal in Maine and therefore the mandate will have no material impact on premiums.

- ***Hospice Care*** (Enacted 2001)

No cost estimate was made for this mandate because the Legislature waived the requirement for a study. Because carriers generally covered hospice care prior to the mandate, we assume no additional cost.

- ***Access to Eye Care*** (Enacted 2001)

This mandate affects plans that use participating eye care professionals. Our report estimated a cost of 0.04% of premium.

- ***Dental Anesthesia*** (Enacted 2001)

This mandate requires coverage for general anesthesia and associated facility charges for dental procedures in a hospital for certain enrollees for whom general anesthesia is medically necessary. Our report estimated a cost of 0.05% of premium.

- ***Prosthetics*** (Enacted 2003)

This mandate requires coverage for prosthetic devices to replace an arm or leg. Our report estimated a cost of 0.03% of premium for groups over 20, and a cost of 0.08% of premium for small employer groups and individuals.

- ***LCPCs*** (Enacted 2003)

This mandate requires coverage of licensed clinical professional counselors. Our report on mental health parity indicated no measurable cost impact for coverage of LCPCs.

- ***Licensed Pastoral Counselors and Marriage & Family Therapists*** (Enacted 2005)

This mandate requires coverage of licensed pastoral counselors and marriage & family therapists. Our report indicated no measurable cost impact for this coverage.

- ***Hearing Aids*** (Enacted 2007 and revised 2019)

The prior mandate required coverage for a hearing aid for each ear every 36 months for children age 18 and under. The mandate was phased-in between 2008 and 2010, and our report estimated a cost of 0.1% of premium. For 1/2020 the hearing aid mandate was expanded to require adult hearing aids. Based on rate filings and a proposed mandate study we estimate 0.2% addition impact to rates to provide hearing aids to adults.

- ***Infant Formulas*** (Enacted 2008)

This mandate requires coverage for amino acid-based elemental infant formulas for children two years of age and under, regardless of delivery method. This mandate is effective January 2009,

and our report estimated a cost of 0.1% of premium.

- ***Colorectal Cancer Screening*** (Enacted 2008)

This mandate requires coverage for colorectal cancer screening. This mandate is effective January 2009. No carriers stated they denied coverage prior to this mandate; therefore, our report estimated no impact on premium. Coverage is required by ACA for preventive services.

- ***Independent Dental Hygienist*** (Enacted 2009)

This mandate requires individual dental insurance or health insurance that includes coverage for dental services to provide coverage for dental services performed by an independent practice dental hygienist. This mandate applies only to policies with dental coverage; therefore, there is no estimated impact on medical plan premiums.

- ***Autism Spectrum* Disorders** (Enacted 2010)

This mandate was effective January 2011 and required all contracts to provide coverage for the diagnosis and treatment of autism spectrum disorders for individuals five years of age or under. It was expanded to age 10 for January 2014 effective dates. A recent report estimated a cost of 0.3% of premium once the mandate is fully implemented if it included those under age 10. Based on that estimate and recently reported experience we are estimating this going forward.

- ***Children's Early Intervention Services*** (Enacted 2010)

This mandate requires all contracts to provide coverage for children's early intervention services from birth to 36 months for a child identified with a developmental disability or delay. This mandate was effective January 2011, and our report estimated a cost of 0.05% of premium.

- ***Chemotherapy Oral Medications*** (Enacted 2014)

Policies that provide chemotherapy treatment must provide coverage for prescribed orally administered anticancer medications equivalent to the coverage for IV or injected anticancer medication. No material increase in premium is expected.

- ***Bone Marrow Donor Testing*** (Enacted 2014)

Reimbursement for human leukocyte antigen testing to register as a bone marrow donor. Limited to $150 per lifetime. May not be applied to any deductible or other cost share. No material increase in premium is expected.

- ***Dental Hygienist*** (Enacted 2014)

Coverage for services provided by a dental hygiene therapist for policies with dental coverage. No material increase in premium is expected.

- ***Abuse-Deterrent Opioid Analgesic Drugs*** (Enacted 2015)

Coverage for abuse-deterrent opioid analgesic drugs on a basis not less favorable than that for opioid analgesic drugs that are not abuse-deterrent and are covered by the health plan. No material increase in premium is expected.

- ***Preventive Health Services*** (Enacted 2018)

Coverage for preventive health services including evidence-based items or services with a rating of A or B in the United States Preventive Services Task Force or equivalent, preventive care and screenings and immunizations supported by the federal DHHS. Currently covered and no material increase in premium is expected.

- ***Naturopathic Doctor*** (Enacted 2018)

Coverage for services provided by a naturopathic doctor when those services are covered when provided by any other health care provided and within the lawful scope of practice of the naturopathic doctor. No material increase in costs is expected and if the services are a substitute for medical doctor services, there may be a decrease in cost for some patients.

- ***Abortion Coverage*** (Enacted 2019)

This mandate requires that health insurance carriers who provide coverage for maternity services also provide coverage for abortion services except for employers granted a religious exclusion.

- ***Coverage for certified registered nurse anesthetists (CRNA)*** (Enacted 2021)

This mandate requires insurers, health maintenance organizations and nonprofit hospitals or medical service organizations to provide coverage for the services of certified registered nurse anesthetists provided to individuals.

- ***Coverage for certified midwives*** (Enacted 2021)

This mandate requires insurers, health maintenance organizations and nonprofit hospitals or medical service organizations to provide coverage under those contracts for services performed by a certified nurse midwife to a patient who is referred to the certified nurse midwife by a primary care provider when those services are within the lawful scope of practice of the certified nurse midwife.

- ***Coverage for HIV prevention drugs*** (Enacted Federal 2021)

This mandate requires health insurance carriers to provide coverage for an enrollee for HIV prevention drugs that have been determined to be medically necessary by a health care provider.

- ***Mental health parity for individuals 21 years of age or younger*** (Enacted 2022)

This mandate requires health insurance carriers to provide coverage for mental health services that use evidence-based practices and are determined to be medically necessary health care for individuals 21 years of age or younger. No material premium impact expected.

- ***Expanded coverage for contraceptives without cost-sharing*** (Enacted 2022)

This mandate requires health insurance carriers to provide coverage for all prescription contraceptives without cost-sharing.

- ***Expanded coverage for postpartum care*** (Enacted 2022)

Health insurance carriers must provide coverage to include recommendations in the "Optimizing Postpartum Care" opinion published May 2018 by the American College of Obstetricians and Gynecologists including pelvic floor surgery. Our report estimated a cost of 0.15% of premium.

- ***Fertility care*** (Enacted 2022)

This mandate effective 1/1/2024 requires health insurance carriers to provide coverage for fertility diagnostic care, fertility treatment if the enrollee is a fertility patient and for fertility preservation services. Our report along with limits in the proposed regulation estimated a cost of 0.56% of premium.

- ***Prosthetic needs of children for recreational purposes*** (Enacted 2022)

This mandate requires health insurance carriers to provide coverage for prosthetic devices of those under 18 years of age to meet the recreational needs of an enrollee in addition to their medical needs. No material premium impact expected. Our report estimated a cost of 0.01% of premium.

- ***Medically necessary dental procedures for cancer patients*** (Enacted 2022)

This mandate requires health insurance carriers to provide coverage for dental procedures that are medically necessary to reduce the risk of infection, eliminate infection, or to treat tooth loss or decay in an enrollee prior to beginning cancer treatment or that are the direct or indirect result of cancer treatment. Our report estimated a cost of 0.2% of premium.

- ***Donor breast milk for infants (***Enacted 2023)

This mandate requires health insurance carriers to provide coverage for donor breast milk for infants when medically necessary. No material increase in premium is expected.

- ***First dollar coverage for diagnostic breast exams*** (Enacted 2023)

Health insurance carriers are prohibited from imposing cost-sharing on diagnostic breast examinations, including mammography, MRI, or ultrasound. No material premium impact expected.

COST OF EXISTING MANDATED HEALTH INSURANCE BENEFITS

Year Enacted	Benefit	Type of Contract Affected	Est. Maximum Cost as % of Premium
1975	Must include benefits for **dentists'** services to the extent that the same services would be covered if performed by a physician.	All Contracts	0.10%
1983	Benefits must be included for treatment of **alcoholism and drug dependency**.	Groups	1.10%
		Individual	0.77%
1975 1983 1995 2003	Benefits must be included for **Mental Health Services**, including psychologists and social workers.	Groups	4.11%
		Individual	3.07%
1986 1994 1995 1997	Benefits must be included for the services of **chiropractors** to the extent that the same services would be covered by a physician. Benefits must be included for therapeutic, adjustive and manipulative services.	Group	0.58%
		Individual	0.32%
1990 1997	Benefits must be made available for screening **mammography**.	Group	0.66%
		Individual	1.20%
1995	Must provide coverage for **reconstruction of both breasts** to produce symmetrical appearance according to patient and physician wishes.	All Contracts	0.02%
1995	Must provide coverage for **metabolic formula** and up to $3,000 per year for prescribed modified low-protein food products.	All Contracts	0.01%
1996	If policies provide maternity benefits, the **maternity (length of stay)** and newborn care benefits must be provided in accordance with "Guidelines for Prenatal Care."	All Contracts	0
1996	Benefits must be provided for medically necessary equipment and supplies used to treat **diabetes** and approved self-management and education training.	All Contracts	0.20%
1996	Benefits must be provided for **screening Pap tests**.	All	0.01%
1996	Benefits must be provided for **annual gynecological exam** without prior approval of primary care physician.	Group managed care	0
1997	Benefits provided for **breast cancer treatment** for a medically appropriate period of time determined by the physician in consultation with the patient.	All Contracts	1.71%
1998	Coverage required for **off-label use of prescription drugs** for treatment of cancer, HIV, or AIDS.	All Contracts	0.30%
1998	Coverage required for **prostate cancer screening**.	All Contracts	0.07%
1999	Coverage of nurse **practitioners and nurse midwives** and allows nurse practitioners to serves as primary care providers.	All Managed Care Contracts	0
1999	Prescription drug must include **contraceptives**.	All Contracts	0.80%

1999	Coverage for **registered nurse first assistants**.	All Contracts	0
2000	Access to **clinical trials**.	All Contracts	0.19%
2000	Access to **prescription drugs**.	All Managed Care Contracts	0
2001	Coverage of **hospice care services** for terminally ill.	All Contracts	0
2001	Access to **eye care**.	Plans with participating eye care professionals	0
2001	Coverage of **anesthesia** and facility charges for certain **dental** procedures.	All Contracts	0.05%
2003	Coverage for **prosthetic devices** to replace an arm or leg	Groups >20	0.03%
		All other	0.08%
2003	Coverage of licensed clinical professional counselors	All Contracts	0
2005	Coverage of licensed pastoral counselors and marriage & family therapists	All Contracts	0
2007	Coverage of hearing aids for children	All Contracts	0.1%
2008	Coverage for amino acid-based elemental **infant formulas**	All Contracts	0.1%
2008	Coverage for **colorectal cancer screening**	All Contracts	0
2009	Coverage for **independent dental hygienist**	All Contracts	0
2010	Coverage for **autism spectrum**	All Contracts	0.3%
2010	Coverage for **children's early intervention services**	All Contracts	0.05%
2014	Coverage for **chemotherapy oral medications**	All Contracts	0
2014	Coverage for **human leukocyte antigen testing**	All Contracts	0
2014	Coverage for **dental hygienist**	All Contracts	0
2015	Coverage for **abuse-deterrent opioid analgesic medications**	All Contracts	0
2018	Coverage for **naturopath**	All Contracts	0
2018	Coverage for **preventive services**	All Contracts	0
2019	Coverage for **adult hearing aids**	All Contracts	0.20%
2019	Coverage for **abortion services**	Individual	0.14%
		Group	0.19%
2021	Coverage for **certified registered nurse anesthetists**	All Contracts	0
2021	Coverage for **certified midwives**	All Contracts	0
2021	Coverage for **HIV prevention drugs**	All Contracts	0
2022	Mental health parity for those 21 and younger	All Contracts	0
2022	Expanded coverage for contraceptives without cost-sharing	All Contracts	0
2022	Expanded coverage for postpartum care	All Contracts	0.15%
2022	Coverage for fertility care	All Contracts	0.56%
2022	Prosthetics for the recreational needs of children	All Contracts	0.01%
2022	Medically necessary dental procedures for cancer patients	All Contracts	0.02%
2023	Coverage for donor breast milk for infants	All Contracts	0
2023	First dollar coverage for diagnostic breast exams	All Contracts	0
	Total cost for groups larger than 20:		**10.41%**
	Total cost for groups of 20 or fewer:		**10.46%**
	Total cost for individual contracts:		**10.49%**

Appendix B: Letter from the Joint Standing Committee on Health Coverage, Insurance and Financial Services with Proposed Legislation

STATE OF MAINE
ONE HUNDRED AND THIRTY-FIRST LEGISLATURE
COMMITTEE ON HEALTH COVERAGE, INSURANCE AND FINANCIAL SERVICES

June 7, 2023

Timothy A. Schott
Acting Superintendent
Bureau of Insurance
34 State House Station
Augusta, Maine 04333

Dear Acting Superintendent Schott,

Title 24-A Maine Revised Statutes Annotated, Section 2752 requires the Joint Standing Committee on Health Coverage, Insurance and Financial Services to submit legislation proposing health insurance mandates to the Bureau of Insurance for review and evaluation if there is substantial support for the mandate among the committee after a public hearing on the proposed legislation. Pursuant to that statute, we request that the Bureau of Insurance prepare a review and evaluation of **LD 663, An Act to Require Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome.**

A copy of the bill is enclosed. As you know, the Bureau of Insurance previously reviewed a substantially similar proposal considered by the 129th Legislature, LD 1138. Please prepare an updated review of the proposed mandate for coverage of these conditions using the guidelines set out in Title 24-A § 2752. In addition, we ask that the Bureau provide an analysis of the extent to which the bill expands coverage beyond the State's essential benefits package and, if so, the estimated costs to the State to defray the costs of including the coverage in qualified health plans.

Please submit the report to the committee no later than January 15, 2024 so the committee can take final action on LD 663 before the end of the Second Regular Session. If you have any questions, please do not hesitate to contact us or our legislative analyst, Colleen McCarthy Reid.

Sincerely,

Sen. Donna A. Bailey
Senate Chair

Rep. Anne C. Perry
House Chair

Appendix C: LD 663

131st MAINE LEGISLATURE

FIRST REGULAR SESSION-2023

Legislative Document **No. 663**

H.P. 432 House of Representatives, February 16, 2023

An Act to Require Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome

Reference to the Committee on Health Coverage, Insurance and Financial Services suggested and ordered printed.

ROBERT B. HUNT
Clerk

Presented by Representative ROEDER of Bangor.
Cosponsored by Senator BALDACCI of Penobscot and
Representative: RANA of Bangor.

Be it enacted by the People of the State of Maine as follows:

Sec. 1. 24-A MRSA §4320-V is enacted to read:

§4320-V. Coverage for pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome

A carrier offering a health plan in this State shall provide coverage for treatment of pediatric postinfectious neuroimmune disorders including pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome. Treatments that must be covered include, but are not limited to, long-term antibiotics, intravenous immunoglobulin therapy, steroids, plasmapheresis and psychopharmacological interventions. Coverage may not be excluded due to the diagnosis of autoimmune encephalopathy or autoimmune encephalitis.

Sec. 2. Application. The requirements of this Act apply to all policies, contracts and certificates executed, delivered, issued for delivery, continued or renewed in this State on or after January 1, 2024. For purposes of this Act all contracts are deemed to be renewed no later than the next yearly anniversary of the contract date.

SUMMARY

This bill requires health insurance coverage for treatment of pediatric postinfectious neuroimmune disorders including pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome. The requirements apply to all individual and group policies and contracts issued or renewed on or after January 1, 2024.

Appendix D: Definitions

Neuroimmune Disorders - Neuroimmune disorders refer to a group of illnesses that are the result of acquired dysregulation of both the immune system and the nervous system, most often resulting in chronic illness and disability.[94]

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) - Obsessive-compulsive disorder (OCD), tic disorder, or both suddenly appear (or symptoms become worse) following a streptococcal (strep) infection, such as strep throat or scarlet fever.[95]

Pediatric Acute-onset Neuropsychiatric Syndrome – PANDAS/PANS is a newer term used to describe the larger class of acute-onset OCD cases. PANDAS/PANS stands for Pediatric Acute-onset Neuropsychiatric Syndrome and includes all cases of acute onset OCD, not just those associated with streptococcal infections.[96]

Intravenous Immunoglobulin Therapy - This therapy can help people with weakened immune systems or other diseases fight off infections.[97]

Plasmapheresis - Plasmapheresis is a process in which the liquid part of the blood, or plasma, is separated from the blood cells. Typically, the plasma is replaced with another solution such as saline or albumin, or the plasma is treated and then returned to your body.[98]

Psychopharmacological Interventions - Psychopharmacology is the study of the use of medications in treating mental disorders.

Autoimmune Encephalitis - refers to a group of conditions that occur when the body's immune system mistakenly attacks healthy brain cells, leading to inflammation of the brain.[99]

[94] https://praikids.org/what-is-pandas/
[95] https://www.nimh.nih.gov/health/publications/pandas/index.shtml
[96] https://www.nimh.nih.gov/research/research-conducted-at-nimh/research-areas/clinics-and-labs/sbp/information-about-PANDAS/PANS-pandas.shtml
[97] https://www.webmd.com/a-to-z-guides/immunoglobulin-therapy#1
[98] https://www.healthline.com/health/plasmapheresis
[99] https://rarediseases.info.nih.gov/diseases/11979/autoimmune-encephalitis

Appendix E: Acronyms and Initialisms

ACA	Affordable Care Act
CBT	Cognitive Behavior Therapy
CHO	Community Health Options
ERP	Exposure and Response Prevention
GAS	Group A Streptococcus
HPHC	Harvard Pilgrim
IVIG	Intravenous Immune Globulin
IVIG	Intravenous Immunoglobulins Therapy
MHPAEA	The Mental Health Parity and Addiction Equity Act of 2008
NAIC	National Association Insurance Commissioners
NEPANS	New England PANS/PANDAS Association
NSAIDs	Non-steroidal Anti-inflammatory Drugs
OCD	Obsessive-compulsive Disorder
PANDAS	Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections
PANS	Pediatric Acute-onset Neuropsychiatric Syndrome
PCP	Primary Care Physician
PMPM	Per member per month
SHCE	Supplemental Health Care Exhibit
UHC	United Health Care