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# A Report to the Joint Standing Committee on Health Coverage, Insurance and Financial Services of the 129th Maine Legislature

Review and Evaluation of LD 1138, 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

**January 2020**  
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Janet T. Mills  
Governor

STATE OF MAINE  
DEPARTMENT OF PROFESSIONAL  
AND FINANCIAL REGULATION  
BUREAU OF INSURANCE  
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Eric A. Cioppa  
Superintendent

December 23, 2019

Senator Heather B. Sanborn, Chair  
Representative Denise A. Tepler, Chair  
Joint Standing Committee on Health Coverage, Insurance and Financial Services  
100 State House Station  
Augusta, ME 04333

*Re: Review and Evaluation of LD 1138, 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*

Dear Senator Sanborn, Representative Tepler, and members of the Committee:

Please accept this Review and Evaluation of LD 1138 from the Bureau of Insurance. As directed by the Health Coverage, Insurance and Financial Services Joint Standing Committee, the Bureau prepared the review and evaluation of LD 1138 pursuant to Title 24-A Maine Revised Statutes Annotated, Section 2752.

My staff and I would be pleased to answer any questions you may have regarding this report.

Sincerely,

Eric A. Cioppa  
Superintendent of Insurance



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Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric  
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## I. Executive Summary

The Joint Standing Committee on Health Coverage, Insurance and Financial Services (Committee) of the 129th Maine Legislature directed the Bureau of Insurance (Bureau) to review LD 1138, An Act to Ensure Health Insurance Coverage for Treatment for Childhood Postinfectious Neuroimmune Disorders Including 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 is a collaborative effort of the actuarial consulting firm, NovaRest, Inc. and the Bureau. NovaRest, Inc. has been assisting the Bureau review and evaluate proposed mandated benefits in Maine since 2003.

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 childhood postinfectious neuroimmune disorders including PANDAS and PANS. Treatments must include, but are not limited to long-term antibiotics, intravenous immunoglobulin (IVIG) therapy, steroids, plasmapheresis, and psychopharmacological interventions. The treatments authorized are described as the standard of care (Guidelines) in the 2017 Journal of Child and Adolescent Psychopharmacology, Volume 27, Number 7 (Journal). Coverage may not be excluded due to the diagnosis of autoimmune encephalopathy or autoimmune encephalitis.

It should be noted that there is some controversy about the diagnosis and treatment of PANDAS/PANS.<sup>1</sup> The American Academy of Pediatrics, for instance, does not recognize a relationship between PANDAS and group A Streptococcus.<sup>2</sup> 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 order to develop the cost estimate of implementing the mandate, we performed a survey of the largest carriers in Maine to determine the level of coverage already available and other critical information. We also note that the difference in cost between the markets is slight, so our cost estimate applies to the individual, small group, and large group markets. Some of the treatments are already covered by carriers, and therefore we believe the marginal cost of adding coverage is between \$58,000 and \$567,000 for the combined markets. This amounts to between \$0.02 and \$0.16 on a per member per month (PMPM) basis which is less than 0.03% as a percent of

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<sup>1</sup> 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.

<sup>2</sup> Ibid.

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premium. On a gross basis<sup>3</sup> we estimate the cost to be between \$105,000 and \$1,013,000 based on the prevalence and the treatment options pursued. This amounts to between \$0.03 to \$0.29 on a PMPM basis and less than 0.05% on a percent of premium basis. We had to make several assumptions to develop our cost estimate, which will be described in the following sections.

We interviewed Dr. Susan Swedo (Physician) with the PANDAS Physicians Network, who has made significant contributions in PANDAS/PANS research. We also received public comments for the bill including an advocate report for LD 1138. Both have informed our estimates.

## II. Background

PANDAS is a relatively new diagnosis, first described in a 1998 article<sup>4</sup> 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.<sup>5</sup> PANDAS is considered a subset of a larger syndrome, PANS<sup>6</sup>, which unlike PANDAS does not require a known trigger.<sup>7</sup>

### Causes

While a PANDAS diagnosis requires an association with a GAS infection, the causes of PANS are unknown and are currently under investigation, although studies have shown an association with infections<sup>8</sup> and an inciting GAS infection is found in as many as 40-77% of cases of PANS.<sup>9</sup>

The proposed bill concerns cases of both PANDAS and PANS that are incited by an infection.

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<sup>3</sup> 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.

<sup>4</sup> 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.

<sup>5</sup> Ibid.

<sup>6</sup> 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.

<sup>7</sup> 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.

<sup>8</sup> 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. Volume 27, Number 7, 2017. Mary Ann Liebert, Inc. Pp. 660-666.

<sup>9</sup> 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.

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Symptoms and Diagnosis

PANS and PANDAS have similar symptoms and they are generally treated as a single syndrome with the primary difference being that PANDAS requires strep infection.<sup>10</sup>

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.<sup>11</sup>

Common symptoms for PANDAS/PANS include:<sup>12</sup>

- 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 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.<sup>13</sup>

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<sup>10</sup> 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.

<sup>11</sup> 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.

<sup>12</sup> 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.

<sup>13</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures.

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Treatment

The series of articles in the 2017 Journal of Child and Adolescent Psychopharmacology, Volume 27, Number 7 (Journal) discusses treatment guidelines (Guidelines) for PANDAS/PANS. These Guidelines represented consensus among Consortium members, and include:<sup>14</sup>

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

*Antibiotics & Nonsteroidal Anti-Inflammatory Drugs (NSAIDs)*

According to the Guidelines, 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.<sup>15</sup> Antibiotic and immune-based treatments can reduce or eliminate symptoms.<sup>16</sup> We interviewed Dr. Susan Swedo (Physician) who has made significant contributions to the PANDAS/PANS research. She indicated all PANDAS/PANS patients with moderate to severe symptoms should receive at least one-month of antibiotics. Some children may require antibiotics as prophylactic agents, although this number is relatively small compared to the total number who have PANDAS/PANS.

The Guidelines also mentioned the use of nonsteroidal anti-inflammatory drugs (NSAIDs), but it was not entirely clear when these medications would be prescribed. The Physician indicated NSAIDs can be effective, particularly for mild to moderately ill children and are inexpensive. Anecdotally, The Physician indicated 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 require more intensive treatments such as steroids, intravenous immunoglobulin (IVIG) therapy, or plasmapheresis.

The Physician stated that early recognition and treatment for PANDAS/PANS is critical. Patients

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<sup>14</sup> 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.

<sup>15</sup> 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.

<sup>16</sup> 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.



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diagnosed early can be treated with lower-cost, and widely available medications such as antibiotics and NSAIDs (such as ibuprofen). While treatment options can still be effective when delayed, the symptoms may worsen, leading to the need for more intensive treatments, including IVIG, plasmapheresis, steroid blasts, and rituximab. Rarely are NSAIDs and antibiotics alone effective when a child has been sick for several months.

The Physician also confirmed that all PANDAS/PANS patients should receive at least one-month of antibiotics. Some patients may require antibiotics as prophylactic agents (long-term antibiotics), although this number is relatively small compared to the total number of children who have PANDAS/PANS.

There is some controversy about the diagnosis and treatment of PANDAS/PANS.<sup>17</sup> The American Academy of Pediatrics, for instance, does not recognize a relationship between PANDAS and group A Streptococcus.<sup>18</sup> 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].”

*Psychiatric/Behavioral Interventions*

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.<sup>19</sup> 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 Physician confirmed that her group would try to refer to a therapist as soon as possible because it can be difficult to find a group that has availability. Also, a therapist can help the family with techniques that can prevent worsening symptoms. The Physician did acknowledge that some practitioners prefer to wait to see how the patient responds to antibiotics and NSAIDs during the acute phase of the illness, before recommending CBT and SSRIs.

There is evidence that psychological, behavioral, and psychopharmacologic interventions can

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<sup>17</sup> 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.

<sup>18</sup> Ibid.

<sup>19</sup> 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.

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provide symptom improvement and improve functioning.<sup>20</sup> Psychiatric and behavioral symptoms of PANDAS/PANS have been shown to respond to medications used for the same symptoms caused by other diseases.<sup>21</sup> Symptoms may differ between patients, so therapies must be individualized.<sup>22</sup> Although the majority of children under treatment will show overall improvement over time, relapses may occur after long periods of remission.<sup>23</sup>

*Anti-Inflammatory and Immune Modulating Treatments*

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.<sup>24</sup> 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 the Physician, steroids were not included in the original studies for PANDAS/PANS but have subsequently 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.<sup>25</sup> 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 (TPE), also known as plasmapheresis, in combination with IVIG, corticosteroids, and/or rituximab has been shown to produce the greatest symptom improvement.<sup>26</sup> It is very rare that a child would require this level of treatment. Anecdotally, the Physician indicated that fewer than 1,000 children in the world need plasmapheresis to treat PANDAS/PANS, meaning it is possible Maine would not

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<sup>20</sup> 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.

<sup>21</sup> Ibid.

<sup>22</sup> Ibid.

<sup>23</sup> 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.

<sup>24</sup> Ibid.

<sup>25</sup> 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.

<sup>26</sup> 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.

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have a child with PANDAS/PANS who would need this procedure. The Physician indicated 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. Rituximab similarly should only be administered by a rheumatologist or someone who has extensive experience using it for other diseases. The Physician indicated that due to the length of time needed to see results from rituximab in a patient with PANDAS/PANS, support in the medical community has waned recently and, if used, it would likely only be provided in combination with plasmapheresis or for steroid-dependent patients.

The Physician said that even if 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 at the time of the initial diagnosis.

***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 health benefits (EHBs) package and, if so, the estimated costs to the State to defray the costs of including the coverage in qualified health plans.

We received responses from the following carriers:

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

All carriers except UHC believe the bill would expand coverage beyond the EHBs. The ultimate determination of whether this is an additional benefit would be made by the U.S. Department of Health and Human Services (HHS).

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### 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.*

PANDAS/PANS are relatively new diagnoses and the true prevalence 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 1 in 1,000 to 1 in 200 for PANDAS/PANS.<sup>27</sup> The bill specifies post-infectious cases of PANDAS/PANS. Retrospective studies indicate 40%-77% of PANDAS/PANS studies are associated with infection.<sup>28</sup> Based on the covered lives in the 2018 National Association of Insurance Commissioners (NAIC) Supplemental Health Care Exhibit (SHCE), we assume this will affect between 21 and 206 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.<sup>29</sup>

The Physician indicated that there is a lack of trained Cognitive Behavior Therapy (CBT) professionals available, although the number is growing. The CBT professionals would need to know how to perform exposure and response prevention (ERP). 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 eight such cross-trained therapists available in Maine.<sup>30</sup>

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<sup>27</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures.

<sup>28</sup> 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.

<sup>29</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures.

<sup>30</sup> International OCD Foundation. <https://kids.iocdf.org>.

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There are likely other qualified therapists available, but it appears there are limited qualified professionals available who are trained in both CBT and ERP.

IVIG does not appear to be widely available. Advocate input for LD 1138 indicates “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.” The Physician indicated IVIG is in shortage and doctors are looking for alternatives, such as steroids, which have shown positive results.

Additionally, advocates said there are no practitioners in Maine known to administer plasmapheresis or rituximab for PANDAS/PANS patients. The Physician indicated that for severe cases, use of plasmapheresis and rituximab would need to be done at a multi-disciplinary clinic. Georgetown University in D.C. is one such hospital but has limited availability.

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

Currently, normal durations of antibiotics, corticosteroids, and psychopharmacological interventions are covered by all carriers. Long-term antibiotics are rarely covered. Intravenous IVIG and plasmapheresis are not typically covered for PANDAS/PANS patients as they are considered experimental. We note psychological therapy was not discussed by the carriers. However, we assume it would also be covered as an EHB.<sup>31</sup> Additionally, rituximab was also not discussed by any of the carrier responses and based on our discussion with the Physician, we believe it is rarely prescribed.

<b>Covered?</b>	<b>Aetna</b>	<b>Anthem</b>	<b>CHO</b>	<b>HPHC</b>	<b>UHC</b>
Short-term antibiotics	Yes	Yes	Yes	Yes	Yes
Short-term steroids	Yes	Yes	No (Investigational)	Not specified	Yes
Psychopharmacological	Yes	Yes	Yes	Yes	Yes
Long-term antibiotics	Yes	No	No (Investigational)	No	Yes
IVIG	No (experimental for PANDAS/PANS)	No	No (Investigational)	No (lack of evidence; recommendations by some authorities not to cover outside of a clinical trial)	Yes
Plasmapheresis	No (experimental for PANDAS/PANS)	Yes	No (Investigational)	Not routinely covered	Yes

<sup>31</sup> “Mental Health & Substance Abuse Coverage” <https://www.healthcare.gov/coverage/mental-health-substance-abuse-coverage/>. Accessed September 3, 2019.

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*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.<sup>32</sup> Nearly a third of parents report either slowing or stopping therapy due to out-of-pocket expenses and 22% report they never started therapy because they could not afford it.<sup>33</sup>

Long-term antibiotics are covered by two of five carriers in the market. Steroids are covered by at least three of five carriers but IVIG is only covered by one carrier. 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.<sup>34</sup> The carriers did not indicate if rituximab is covered. Two carriers indicate plasmapheresis is covered, while one indicates it is not routinely covered. However, as noted above, it does not appear there are any practitioners in Maine who would provide either plasmapheresis or rituximab for PANDAS/PANS.<sup>35</sup>

*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 annual out-of-pocket costs for a single child. One person testified to nearly \$40,000 in out-of-pocket costs.<sup>36</sup>

*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, in opposition, and one letter from the Bureau providing information. Supporting testimony was provided by at least 19 providers.<sup>37</sup>

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<sup>32</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures

<sup>33</sup> Ibid.

<sup>34</sup> Ibid.

<sup>35</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures

<sup>36</sup> Ibid.

<sup>37</sup> "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?id=1138&PID=1456&snum=129&sec3#](http://www.mainelegislature.org/legis/bills/display_ps.asp?id=1138&PID=1456&snum=129&sec3#).

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The Physician and advocate input emphasized the importance of early recognition. The Physician 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. The Physician also stated that moderate to severe symptoms can require a parent to quit his or 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.

We found that five other states have passed legislation requiring coverage of treatment for PANDAS/PANS and forty states have passed legislation regarding PANDAS/PANS awareness.

*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 legislation 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.

Additionally, there is currently difficulty in diagnosing PANDAS/PANS as it is a diagnosis of exclusion, meaning eliminating other possibilities. In fact, HPHC noted that there is currently no diagnosis code for either PANDAS or PANS. Advocates and the Physician that we interviewed emphasized the importance of recognition and education.

*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 need as evidenced by the experience in other states.*

Five states – New Hampshire, Illinois, Arkansas, Minnesota, and Delaware – have passed legislation requiring insurance coverage of PANDAS.<sup>38</sup> Massachusetts is also currently considering a bill.<sup>39</sup> Additionally, there are almost 40 states that recognize PANDAS/PANS

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<sup>38</sup> PANDAS PANS Awareness Day. PANDAS Network. <http://pandasnetwork.org/legislation/>. Accessed August 27, 2019.

<sup>39</sup> “An Act relative to insurance coverage for PANDAS/PANS.” The 191st General Court of the Commonwealth of Massachusetts. <https://malegislature.gov/Bills/191/S613/BillHistory>. Accessed August 27, 2019.



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awareness day.<sup>40</sup> The Physician 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.

**Aetna:**

"As an alternative to the mandate, we would suggest the funding of high-quality research studies in order to establish the effectiveness and safety of treatments for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections."

**Community Health Options:**

"We suggest following current evidence-based guidelines/protocols for treatment."

**HPHC:**

"What is most needed for the effective treatment of this disease is ongoing research into its etiology and well-designed studies looking at the effectiveness of treatment interventions."

*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 according to the Guidelines laid out in the Journal, and coverage required by LD 1138 is not inconsistent with the role of insurance to provide medically necessary services for a condition. However, as noted above, the 2018 American Academy of Pediatrics Redbook discourages "antimicrobial treatment or prophylaxis, IVIG, or

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<sup>40</sup> PANDAS PANS Awareness Day. PANDAS Network. <http://pandasnetwork.org/legislation/>. Accessed August 27, 2019.



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plasmapheresis for children with symptoms suggestive of [PANDAS/PANS],” hence this mandate may step outside the role of insurance by requiring carriers to reimburse providers for treatments which 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 social stigma attached to receiving treatment as most will be treated with common medications or treatments.

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

**Aetna:**

“These coverages are not part of the state’s current EHB package and therefore require additional coverage.”

**Anthem:**

“The expansion of coverage for long-term antibiotic therapy and intravenous immunoglobulin therapy under the bill as drafted would exceed the current scope of essential health benefits.”

**CHO:**

“Yes, this mandate requires coverage beyond the EHBs.”

**HPHC:**

“While health plans may cover some services or treatments required by this state mandate, many of the treatments required would be considered investigational and/or experimental for individuals diagnosed with PANDAS/PANS. No state health plan provides coverage for experimental/investigational treatments. Similarly, without corresponding diagnosis codes, no health plan provides coverage for the diagnosis of PANDAS/ PANS.”

**UHC:**

“We don’t believe this mandate will require coverage beyond the EHBs.”

*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.*

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As premiums increase due to mandated benefits, some employers choose to self-insure in order to have more control over the benefits that they provide to employees and control the cost of health insurance premiums. Since this mandate will have a minimal impact on premiums it is unlikely this will cause any shifting to self-insurance.

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

Anthem indicated a cost estimate of \$0.38 PMPM to cover the treatments listed under this proposed mandate for the State Employee Health Plan. 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, they have assumed a one-month period of treatment for long-term use of antibiotic therapy but as noted above, prophylactic use of antibiotics could continue for 5-10 years or more. For all other treatments, they used experience from their own block of business to determine the average duration of treatments. They noted that the cost estimates above may be inadequate should members receive treatments for longer than the durations assumed.

In developing the costs, they assumed that one in 200 children may have PANDAS/PANS. Of those diagnosed with PANDAS/PANS. They 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.

## **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 professionals trained in both CBT and ERP, according to the Physician, and an increase in demand could theoretically increase prices, although the number of CBT professionals has been increasing, so the supply of

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professionals could keep up with the demand. If the number of professionals did not increase, the cost may increase as demand exceeds the supply.

IVIG appears to be primarily administered in hospitals with only one person in the state providing care in the office or home care setting. Expanding coverage could increase the demand for this service in the office or home care settings, where it has a significantly lower cost.<sup>41</sup>

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.*

The proposed coverage would increase the use of long-term antibiotics which would be used to manage symptoms in a relatively small number of PANDAS/PANS patients according to the Physician. The use of long-term antibiotics may also decrease the number of children who would need to pursue more intensive procedures such as IVIG. The proposed coverage would also likely increase the appropriate use of IVIG and in rare cases, plasmapheresis, as currently it is not generally covered.

The Physician 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. According to the Physician, 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 plasmapheresis, although the Physician indicated a child would most likely be referred to a multi-disciplinary clinic for this treatment, with physicians who better understand PANDAS/PANS and 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 the amount of inappropriate treatment.

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<sup>41</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures.

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Additionally, some providers have been advocating for long-term low-dosage IVIG or steroids, which are costly and do not appear to be medically appropriate. The proposed coverage does not appear to prevent insurance carriers from refusing these treatments as they are not indicated in the guidelines.

**Anthem:**

“Long-term use of antibiotic therapy to treat continued symptoms associated with PANDAS/PANS is not consistent with evidence based medicine or generally accepted standards of care. In fact, 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.”

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

We do not believe the mandated treatment replaces other treatments. However, early treatment using antibiotics and NSAIDs 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.*

There is no language in the bill that prohibits 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.<sup>42</sup>

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<sup>42</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures.

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It is not unreasonable to believe covering this service will 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.

According to the Physician, there is a lack of trained CBT professionals with ERP training. The International OCD foundation offers trainings and currently lists eight such trained professionals in Maine.<sup>43</sup> 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.*

**Aetna:**

“Since pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections is not a reportable condition and does not have a clinical diagnosis or common diagnosis protocol within the medical community, it is not possible to provide accurate cost implications. Our ability to estimate premium impact is hampered by specific diagnosis and protocol codes, and our estimate of an increase of up to a tenth of a percent of the current premium levels applicable to both small and large group, represents an approach on how to start parsing data to arrive at a more defensible premium estimate.”

**Anthem:**

“The table below provides cost estimates for requiring coverage for the treatments listed under this proposed mandate.”

Individual	\$0.33
Small Group	\$0.38
Large Group	\$0.41

“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,

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<sup>43</sup> International OCD Foundation. <https://kids.iocdf.org/>.

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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.<sup>44</sup> 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.”

**HPHC:**

“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.”

**UHC:**

“There is no additional cost.”

**Other States:**

Five states have passed an insurance bill: New Hampshire, Illinois, Arkansas, Minnesota, and Delaware.<sup>45</sup> 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.<sup>46</sup>

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<sup>44</sup> <http://pandasnetwork.org/statistics>.

<sup>45</sup> PANDAS PANS Awareness Day. PANDAS Network. <http://pandasnetwork.org/legislation/>. Accessed August 27, 2019.

<sup>46</sup> 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 August 27, 2019.

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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.<sup>47</sup> 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 carriers that we surveyed did not provide a cost estimate and the other states that have this mandate were not able to perform cost estimates due to a lack of prevalence data. Based on the information provided, with the caveat stated above, we developed the cost following cost estimate.

Treatment	Cost Per Session	Number of Sessions Annually	% Who Receive Treatment
Short-term antibiotics (0-4 wks)	\$16.94 <sup>48,49</sup>	1 month	100% (per guidelines) <sup>50</sup>
Long-term antibiotics	\$16.94	11 additional months	30% <sup>51</sup>
Psychological/Behavioral	\$100-\$200 <sup>52</sup>	Wkly (52) or Biwkly (26)	100% (per guidelines) <sup>53</sup>
IVIG	\$6,000-\$25,000 <sup>54</sup>	1-3 <sup>55</sup> (assumed 2)	10%-20%
Plasmapheresis	\$17,580 <sup>56</sup>	1-2	1%-5%
Rituximab	\$5,000 <sup>57</sup>	Given in combination with plasmapheresis	Given in combination with plasmapheresis

<sup>47</sup> 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 August 26, 2019.

<sup>48</sup> "Amoxil." GoodRx. <https://www.goodrx.com/amoxil> Accessed 10/16/2019.

<sup>49</sup> Providers may prescribe several different types of antibiotics, but the provider we interviewed mentioned amoxicillin.

<sup>50</sup> 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.

<sup>51</sup> The provider we interviewed indicated the number of children requiring antibiotics as prophylactic agents is relatively small compared to the number who have PANS so we assume 30% would require long-term antibiotics.

<sup>52</sup> "How Much Does Therapy Cost?" <https://www.goodtherapy.org/blog/faq/how-much-does-therapy-cost>. Accessed September 3, 2019.

<sup>53</sup> 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.

<sup>54</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures.

<sup>55</sup> 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.

<sup>56</sup> "Mandated Benefit Review of House Bill 984: An Act Relative to Insurance Coverage for PANDAS/PANS." Center for Health Information and Analysis. May 2015.

<sup>57</sup> "Cost of Medications Used in Neuroimmune Conditions." The Foundation for Children With Neuroimmune Disorders. <https://www.neuroimmune.org/cost-of-medication.html> Accessed 10/16/2019.

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There is little information on the prevalence of PANDAS/PANS due to it being a relatively new diagnosis and misdiagnosis. An advocate report provided a range of 1 in 1,000 to 1 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 1138 refers to “pediatric” and so we have focused our analysis on children under 18 years old.

The number of covered lives in Maine in 2018 (285,611) comes from the 2018 Supplemental Health Care Exhibit (SHCE). The percentage of persons under 18 in Maine (18.7%) was from the United States Census Bureau.<sup>58</sup>

LD 1138 applies to instances of PANDAS/PANS associated with infection. The estimates of PANDAS/PANS associated with infection are between 40% and 77%.<sup>59</sup> Using these assumptions, we estimate between 21 to 206 Maine covered children who would be diagnosed with PANDAS/PANS associated with an infection each year.

The Summary to LD 1138 states that the treatments authorized (Guidelines) are described in a series of articles in the 2017 Journal of Child and Adolescent Psychopharmacology (Journal). Our understanding of these articles is that these treatment options include:<sup>60</sup>

- 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 has 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.

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<sup>58</sup> QuickFacts: Maine. United States Census Bureau.

<https://www.census.gov/quickfacts/fact/table/ME,US/PST045218>. Accessed August 26, 2019.

<sup>59</sup> 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.

<sup>60</sup> 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.



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The treatment Guidelines indicate that an initial course of antibiotics<sup>61</sup> and psychological interventions<sup>62</sup> 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, the Physician indicated amoxicillin, and cephalosporin antibiotics may be prescribed and, based on the response of the patient, a provider may switch between the antibiotics. Azithromycin was also discussed in the Guidelines, however the Physician indicated some areas of the country have too much resistant strep to use it routinely. We assume 100% of newly diagnosed PANDAS/PANS patients would receive at 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 the Physician. We estimate a monthly cost of \$17.<sup>63</sup> This is currently covered by all carriers.

The Physician indicated that for PANDAS patients or for PANS patients with moderate to severe symptoms, antibiotics should be prescribed for at least a year. The number who would require long-term antibiotics is relatively small compared to the overall number of patients with PANS. 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 30% 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.

The Physician also indicated NSAIDs (such as ibuprofen) may be utilized as they are also less expensive, are effective, and are 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

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<sup>61</sup> 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.

<sup>62</sup> 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.

<sup>63</sup> “Amoxil.” GoodRx. <https://www.goodrx.com/amoxil> Accessed 10/16/2019.

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pharmacological treatments, or both. The Guidelines reference a 2006 study<sup>64</sup> where all children were prescribed fourteen 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 fourteen sessions to be consistent with the 2006 study. Sources indicate the cost of therapy typically ranges between \$100 and \$200,<sup>65</sup> so we have estimated \$150 per session. CBT is generally covered.

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.<sup>66</sup> The Physician estimated that PANDAS/PANS cohort would use less SSRIs than those with OCD. Therefore, we assume the lower end of the range or about 40% of patients would receive SSRIs with a monthly cost of about \$10<sup>67</sup> (for sertraline or fluoxetine as stated in the Guidelines). SSRI are typically covered.

The Physician indicated that experts estimate more than 80% of PANDAS/PANS cases are treated with antibiotics and NSAIDs.<sup>68</sup> She also indicated that steroids were being used either with or instead of IVIG and plasmapheresis in some circumstances. Therefore, we assume 20% of patients will receive short-term steroids, as the Physician 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.<sup>69</sup> Prednisone is a commonly prescribed corticosteroid at a price of \$11 for 5 tablets.<sup>70</sup> Short-term steroids are currently covered.

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<sup>64</sup> Storch EA, Murphy TK, Geffken GR, Mann G, Adkins J, Merlo LJ, Duke D, Munson M, Swaine Z, Goodman WK: Cognitive behavioral therapy for PANDAS-related obsessive-compulsive disorder: Findings from a preliminary waitlist controlled open trial. *Journal of the American Academy of Child and Adolescent Psychiatry* 45:1171–1178, 2006.

<sup>65</sup> “How Much Does Therapy Cost.” Good Therapy. <https://www.goodtherapy.org/blog/faq/how-much-does-therapy-cost>. Accessed August 27, 2019.

<sup>66</sup> “Treating obsessive-compulsive disorder.” Harvard Health Publishing. <https://www.health.harvard.edu/mind-and-mood/treating-obsessive-compulsive-disorder>. Accessed 10/16/2019.

<sup>67</sup> SSRIs. GoodRx. <https://www.goodrx.com/ssris>. Accessed 10/16/2019.

<sup>68</sup> Although not directly confirmed, we assume most of these patients would also be receiving psychological interventions.

<sup>69</sup> 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.

<sup>70</sup> Prednisone. GoodRx. [https://www.goodrx.com/prednisone?label\\_override=prednisone&form=tablet&dosage=50mg&quantity=5](https://www.goodrx.com/prednisone?label_override=prednisone&form=tablet&dosage=50mg&quantity=5) Accessed 10/16/2019.

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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.<sup>71</sup> According to the Guidelines IVIG should be given over a two-day period and patients usually require 1-3 courses.<sup>72</sup> 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.<sup>73</sup> 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, as the Physician indicated it is possible that a patient can have a flare-up within a year that can require another IVIG treatment course. 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 dose IVIG therapy in one day in an office setting costs \$6,000, or \$12,000 if administered over two days, or \$25,000 for a one-day course in the hospital. 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 \$12,000 per IVIG course is not an unreasonable estimate. IVIG is currently not covered by most carriers.

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.<sup>74</sup> We assume 1% will receive treatment and will also rely on the Massachusetts cost of \$17,580, as currently there are no known practitioners providing this treatment to children in Maine.<sup>75</sup> Rituximab is in the same category as plasmapheresis and if prescribed would likely be in combination with plasmapheresis. We

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<sup>71</sup> Mandated Benefit Review of House Bill 984: An Act Relative to Insurance Coverage For PANDAS/PANS. Center for Health Information and Analysis. May 2015.

<sup>72</sup> 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.

<sup>73</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures.

<sup>74</sup> Mandated Benefit Review of House Bill 984: An Act Relative to Insurance Coverage For PANDAS/PANS. Center for Health Information and Analysis. May 2015.

<sup>75</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures.

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assume \$5,000 for 500mg.<sup>76</sup> We have assumed one treatment as the Physician indicated it is unlikely a flare-up would cause a child to receive plasmapheresis more than once.

Using these assumptions, we estimate a \$0.03 to \$0.29 PMPM impact on premiums on a gross basis for the treatment of PANDAS/PANS. However, we have assumed short-term antibiotics, CBT, short-term steroids and SSRIs are currently covered by carriers in Maine, resulting in an estimate of \$0.02 to \$0.16 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, “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.”

The Physician 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.

*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

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<sup>76</sup> “Cost of Medications Used in Neuroimmune Conditions.” The Foundation for Children With Neuroimmune Disorders. <https://www.neuroimmune.org/cost-of-medication.html> Accessed 10/16/2019.

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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, there should be no 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.<sup>77</sup> The Physician indicated that amoxicillin and cephalosporin antibiotics are also effective, especially considering some areas of the country have too much resistant strep to use azithromycin routinely. Other articles show support for NSAIDs<sup>78</sup> and corticosteroids,<sup>79</sup> although both indicate that further placebo-controlled studies are warranted.

There have been several studies which have shown the therapeutic benefits of TPE (plasmapheresis) and IVIG. One double-blind placebo-controlled study showed IVIG and TPE were both effective in reducing obsessive compulsive symptoms, although it was noted that non-

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<sup>77</sup> 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.

<sup>78</sup> 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.

<sup>79</sup> Ibid.

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PANDAS OCD and tic disorders failed to show benefits from TPE and IVIG.<sup>80</sup> A more recent double-blind study was not able to show that the IVIG cohort decreased OCD severity more than the placebo with statistical significance.<sup>81</sup>

As noted above, the American Academy of Pediatrics does not recognize a relationship between PANDAS and group A Streptococcus<sup>82</sup> and in the Summary of Major Changes in its 2018 Redbook states that “language has been strengthened discouraging antimicrobial treatment or prophylaxis, IVIG, or plasmapheresis for children with symptoms suggestive of [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 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.”<sup>83</sup>

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<sup>80</sup> 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.

<sup>81</sup> *Ibid.*

<sup>82</sup> *Ibid.*

<sup>83</sup> Advocate Inputs for LD 1138: 2752 Mandated health legislation procedures.

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The Physician indicated severe symptoms including anxiety, depression, anorexia complications, and even suicide could occur if left untreated.

*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 an 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.*

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 impacted 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 2019

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*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 July 1, 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 were reported slightly higher than the historical range in 2017 as 4.6% and dropped slightly in 2018 to 4.4%. Mental health claims are expected to stay close to the range.

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 2.3% in 2017 after meeting pent-up demand of 9.4% in 2015. In 2018, claims increased slightly to 3.5% but still within a stabilized range.



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♦ ***Substance Abuse*** (Enacted 1983)

Maine's mandate only applied to group coverage. Effective October 1, 2003, substance abuse was added to the list of mental health conditions for which parity is required. Effective on January 1, 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 decreased from 1.7% in 2017 to 1.4% in 2018 of the total group health claims. The decrease is believed to be random variation in an expected increasing trend a result of the changing demographic of group coverage as more contracts are being transferred to individual coverage. Individual substance abuse health claims decreased from 2.5% in 2016 to 1.9% in 2017 and 1.0% in 2018. As expected, substance abuse claims have leveled out as pent-up demand is met and carriers manage utilization.

♦ ***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 2018, was 0.80% of total health claims. Prior to 2014, the level has typically been lower for individual than for group. Individual claims at 0.61% have for the first time in the last few years dropped back below group claims at 0.88% in 2018. Although it is likely that some of these costs would have been covered even in the absence of a mandate, we have no basis for estimating how much. We have included the entire amount, thereby overstating the impact of the mandate to some extent.

♦ ***Screening Mammography*** (Enacted 1990)

This mandate requires that benefits be provided for screening mammography. We estimate the current 2018 levels of 0.67% for group and 1.18% 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.

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♦ ***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. HMOs would typically cover these costs and, for non-HMO plans, the relatively small cost of this test would not in itself satisfy the deductible, so there would be no cost unless other services were also received. 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 (PCP). To the extent the 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%.

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♦ ***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. Group claims in 2017 were 1.47% compared to individual claims at 1.36% with the combined impact remaining level with past years at 1.4%.

♦ ***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.

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♦ ***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.

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♦ ***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 is 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.

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♦ ***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.

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**COST OF EXISTING MANDATED HEALTH INSURANCE BENEFITS**

<b>Year Enacted</b>	<b>Benefit</b>	<b>Type of Contract Affected</b>	<b>Est. Maximum Cost as % of Premium</b>
1975	Must include benefits for <b>dentists'</b> 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 <b>alcoholism and drug dependency</b> .	Groups	1.41%
		Individual	1.03%
1975 1983 1995 2003	Benefits must be included for <b>Mental Health Services</b> , including psychologists and social workers.	Groups	4.44%
		Individual	3.45%
1986 1994 1995 1997	Benefits must be included for the services of <b>chiropractors</b> to the extent that the same services would be covered by a physician. Benefits must be included for therapeutic, adjustive and manipulative services.	Group	0.88%
		Individual	0.61%
1990 1997	Benefits must be made available for screening <b>mammography</b> .	Group	0.67%
		Individual	1.18%
1995	Must provide coverage for <b>reconstruction of both breasts</b> to produce symmetrical appearance according to patient and physician wishes.	All Contracts	0.02%
1995	Must provide coverage for <b>metabolic formula</b> 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 <b>maternity (length of stay)</b> 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 <b>diabetes</b> and approved self-management and education training.	All Contracts	0.20%
1996	Benefits must be provided for <b>screening Pap tests</b> .	All	0.01%
1996	Benefits must be provided for <b>annual gynecological exam</b> without prior approval of primary care physician.	Group managed care	0.10%
1997	Benefits provided for <b>breast cancer treatment</b> for a medically appropriate period of time determined by the physician in consultation with the patient.	All Contracts	1.69%
1998	Coverage required for <b>off-label use of prescription drugs</b> for treatment of cancer, HIV, or AIDS.	All Contracts	0.30%
1998	Coverage required for <b>prostate cancer screening</b> .	All Contracts	0.07%

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1999	Coverage of nurse <b>practitioners and nurse midwives</b> and allows nurse practitioners to serve as primary care providers.	All Managed Care Contracts	0.16%
1999	Prescription drug must include <b>contraceptives</b> .	All Contracts	0.80%
1999	Coverage for <b>registered nurse first assistants</b> .	All Contracts	0
2000	Access to <b>clinical trials</b> .	All Contracts	0.19%
2000	Access to <b>prescription drugs</b> .	All Managed Care Contracts	0
2001	Coverage of <b>hospice care services</b> for terminally ill.	All Contracts	0
2001	Access to <b>eye care</b> .	Plans with participating eye care professionals	0.04%
2001	Coverage of <b>anesthesia</b> and facility charges for certain <b>dental</b> procedures.	All Contracts	0.05%
2003	Coverage for <b>prosthetic devices</b> 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 <b>infant formulas</b>	All Contracts	0.1%
2008	Coverage for <b>colorectal cancer screening</b>	All Contracts	0
2009	Coverage for <b>independent dental hygienist</b>	All Contracts	0
2010	Coverage for <b>autism spectrum</b>	All Contracts	0.3%
2010	Coverage for <b>children's early intervention services</b>	All Contracts	0.05%
2014	Coverage for <b>chemotherapy oral medications</b>	All Contracts	0
2014	Coverage for <b>human leukocyte antigen testing</b>	All Contracts	0
2014	Coverage for <b>dental hygienist</b>	All Contracts	0
2015	Coverage for <b>abuse-deterrent opioid analgesic medications</b>	All Contracts	0
2018	Coverage for <b>naturopath</b>	All Contracts	0
2018	Coverage for <b>preventive services</b>	All Contracts	0
2019	Coverage for <b>adult hearing aids</b>	<b>All Contracts</b>	<b>0.20%</b>
2019	Coverage for <b>abortion services</b>	<b>Individual</b>	<b>0.14%</b>
		<b>Group</b>	<b>0.19%</b>
	<b>Total cost for groups larger than 20:</b>		<b>10.63%</b>
	<b>Total cost for groups of 20 or fewer:</b>		<b>10.68%</b>
	<b>Total cost for individual contracts:</b>		<b>9.33%</b>



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

### SENATE

HEATHER B. SANBORN, DISTRICT 28, CHAIR  
GEOFFREY M. GRATWICK, DISTRICT 9  
ROBERT A. FOLEY, DISTRICT 34

COLLEEN MCCARTHY REID, LEGISLATIVE ANALYST  
VERONICA SNOW, COMMITTEE CLERK



### HOUSE

DENISE A. TEPLER, TOPSHAM, CHAIR  
MICHAEL F. BRENNAN, PORTLAND  
ANNE MARIE MASTRACCIO, SANFORD  
HEIDI E. BROOKS, LEWISTON  
GINA M. MELARAGNO, AUBURN  
VICTORIA FOLEY, BIDEFORD  
DWAYNE W. PRESCOTT, WATERBURY  
MARK JOHN BLIER, BUXTON  
JOSHUA MORRIS, TURNER  
GREGORY LEWIS SWALLOW, HOULTON

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

June 19, 2019

Eric A. Cioppa  
Superintendent  
Bureau of Insurance  
34 State House Station  
Augusta, Maine 04333

Dear Superintendent Cioppa:

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 1138, 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.**

A copy of the bill is enclosed. Please prepare the evaluation using the guidelines set out in Title 24-A § 2752. In addition, we ask that the Bureau 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.

Please submit the report to the committee no later than January 1, 2020 so the committee can take final action on LD 1138 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,

Handwritten signature of Heather B. Sanborn.

Sen. Heather B. Sanborn  
Senate Chair

Handwritten signature of Denise A. Tepler.

Rep. Denise A. Tepler  
House Chair

Enclosure: LD 1138

cc: Marti Hooper, Bureau of Insurance  
Rep. Donna Bailey

*LD 1138, 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*

## Appendix C: LD 1138

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

2        **Sec. 1. 24-A MRSA §4320-L** is enacted to read:

3        **§4320-L. Coverage for treatment of childhood postinfectious neuroimmune**  
4        **disorders including pediatric autoimmune neuropsychiatric disorders**  
5        **associated with streptococcal infections and pediatric acute-onset**  
6        **neuropsychiatric syndrome**

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

15       **2. Application.** The requirements of this section apply to all policies, contracts and  
16       certificates executed, delivered, issued for delivery, continued or renewed in this State.  
17       For purposes of this section, all contracts are deemed to be renewed no later than the next  
18       yearly anniversary of the contract date.

19       **Sec. 2. Application.** The requirements of this Act apply to all policies, contracts  
20       and certificates executed, delivered, issued for delivery, continued or renewed in this  
21       State on or after January 1, 2020. For purposes of this Act all contracts are deemed to be  
22       renewed no later than the next yearly anniversary of the contract date.

### 23       **SUMMARY**

24       This bill requires health insurance coverage for treatment of childhood postinfectious  
25       neuroimmune disorders, a group of medical conditions that includes autoinflammatory  
26       encephalopathic conditions including pediatric autoimmune neuropsychiatric disorders  
27       associated with streptococcal infections and pediatric acute-onset neuropsychiatric  
28       syndrome. The treatments authorized include certain treatments described as the standard  
29       of care in a series of articles in the 2017 Journal of Child and Adolescent  
30       Psychopharmacology, Volume 27, Number 7. The requirements apply to all individual  
31       and group policies and contracts issued or renewed on or after January 1, 2020.

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## 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.<sup>84</sup>

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.<sup>85</sup>

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.<sup>86</sup>

Intravenous Immunoglobulin Therapy - This therapy can help people with weakened immune systems or other diseases fight off infections.<sup>87</sup>

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.<sup>88</sup>

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.<sup>89</sup>

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<sup>84</sup> <https://praikids.org/what-is-pandas/>

<sup>85</sup> <https://www.nimh.nih.gov/health/publications/pandas/index.shtml>

<sup>86</sup> <https://www.nimh.nih.gov/research/research-conducted-at-nimh/research-areas/clinics-and-labs/sbp/information-about-PANDAS/PANS-pandas.shtml>

<sup>87</sup> <https://www.webmd.com/a-to-z-guides/immunoglobulin-therapy#1>

<sup>88</sup> <https://www.healthline.com/health/plasmapheresis>

<sup>89</sup> <https://rarediseases.info.nih.gov/diseases/11979/autoimmune-encephalitis>

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## 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