

Rhode Island Office of the Health Insurance Commissioner's Report

*Pursuant to Rhode Island General
Laws §§ 27-18-90, 27-19-82, 27-
20-78, and 27-41-95*

December 26, 2024

*This report presents the legislatively
mandated cost-benefit analysis of requiring
PANDAS/PANS treatment coverage
completed by the Office of the Health
Insurance Commissioner*



STATE OF RHODE ISLAND

Office of The Health Insurance Commissioner

Department of Business Regulation

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Table of Contents

EXECUTIVE SUMMARY	3
INTRODUCTION	4
BACKGROUND.....	5
OHIC Statutory and Regulatory Authority	5
COST-BENEFIT ANALYSIS	6
Limitations	7
Aggregate Claims Data and Other Information Collected from Health Insurance Carriers	8
Aetna.....	10
Blue Cross Blue Shield Of Rhode Island.....	10
Cigna.....	10
Neighborhood Health Plan of Rhode Island.....	10
Point32Health.....	11
UnitedHealthCare.....	11
PANDAS/PANS Coverage and Cost in Other States.....	12
Conclusion	12
APPENDIX	13
Coverage Policies	13
Aetna.....	13
Blue Cross Blue Shield of Rhode Island	13
Cigna.....	13
Neighborhood Health.....	13
Point32Health	13
UnitedHealthCare.....	14

EXECUTIVE SUMMARY

This report is in response to R.I.G.L. § [27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#). The report provides a cost-benefit analysis of the PANDAS/PANS treatment coverage required under these laws. This cost-benefit analysis was conducted to the best of OHIC's ability based on the information and data available. The report also identifies what PANDAS/PANS is, how it is treated, and its estimated prevalence.

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) are rare clinical diagnoses. According to the PANDAS Networks, approximately 1 in 200 children in the United States has PANDAS/PANS; however, the true lifetime prevalence is unknown.¹ The age of onset can range from three to twelve years of age, with reactions after age twelve categorized as rare.² The disorder can result from a Group A Streptococcal bacterial infection, commonly known as strep throat. Following a strep infection, children may develop physical, neurological, and psychological symptoms interfering with daily lives.³ Signs and symptoms of the diagnoses can range from tics, disturbances in sleep, OCD-like symptoms, and restrictive eating or food avoidance.

Although there are no definitive tests associated with either diagnoses, treatments can include antibiotics such as Penicillin, Augmentin (Amoxicillin/Clavulanate Blend), Cephalosporins (Cephalexin, Cefdinir) and Azithromycin; Prophylactic antibiotics, Nonsteroidal anti-inflammatory drugs (NSAIDs), Intravenous Immunoglobulin (IVIG), and Plasmapheresis.⁴ The course of treatment can vary based on the symptoms and may include multiple of the above-mentioned interventions.

[House Bill 7503 Substitute B as amended](#) (H7503Baa) and [Senate Bill 2203 Substitute B as amended](#) (S2203Baa) were signed into law by Governor Daniel J. McKee on June 30, 2022. Rhode Island General Laws (R.I.G.L.) § [27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#) require health insurance carriers to provide coverage for the treatment PANDAS/PANS. Coverage for PANDAS/PANS treatment must include, but not be limited to, the use of intravenous immunoglobulin therapy. The legislation also requires that health insurance carriers provide data related to PANDAS/PANS claims to the Office of the Health Insurance Commissioner (OHIC). It further requires that OHIC "report to the General Assembly a cost-benefit analysis of the implementation of the benefit coverage" required by the statute by January 1, 2025. The legislation states that "the intent of this cost-benefit analysis is to determine if adding the benefit coverage provided in this section produces a net savings to health insurance carriers and to policy holders." It does not require an assessment of broader impacts to social welfare that may accrue from this coverage mandate. Such impacts may include, but are not limited to, improved outcomes for effected children over the life course, resource savings for effected families, or broader impacts on public health. The legislation contains a sunset provision, repealing the required coverage of treatment for PANDAS/PANS diagnoses effective December 31, 2025.

In August 2024, pursuant to R.I.G.L. § [27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#), OHIC requested data from the Rhode Island health insurance carriers that are required to provide PANDAS/PANS treatment coverage as of January 1, 2023. These insurers include Aetna, Blue Cross Blue Shield of Rhode Island, Cigna, Neighborhood Health Plan of Rhode Island, Point32Health, and United Healthcare. OHIC requested that the carriers provide data from January 2018 through September 2024. The data request included the total number of claims by month, and the total cost associated with those claims, for autoimmune encephalitis, PANDAS, PANS, and intravenous immunoglobulin therapy (IVIG).

¹ PANDAS Network (2024). [PANDAS/PANS Prevalence](#)

² National Library of Medicine (2024). [Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections \(PANDAS\)](#).

³ PANDAS Network. (2024). [What Is PANDAS? The Latest Research and Treatment Options](#)

⁴ National Library of Medicine (2024). [Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections \(PANDAS\)](#).

Limitations to the cost-benefit analysis of the mandated coverage of PANDAS/PANS treatment include, but are not limited to, the unavailability of accurate billing and diagnosis codes associated with a PANDAS/PANS diagnosis. R.I.G.L. § [27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#) state that:

For billing and diagnosis purposes, PANDAS and PANS shall be coded as autoimmune encephalitis until the American Medical Association and the Centers for Medicare & Medicaid Services create and assign a specific code for PANDAS and PANS. Thereafter, PANDAS and PANS may be coded as autoimmune encephalitis, PANDAS, or PANS.

Since the passage of the PANDAS/PANS treatment coverage requirement in 2022, the American Medical Association and the Centers for Medicare & Medicaid Services has not created and assigned a specific code for PANDAS and PANS. Even if a specific code had been created, current law permits health insurance carriers to code PANDAS and PANS claims as autoimmune encephalitis, PANDAS, or PANS. This causes a lack of specificity in the claims data that OHIC collected from health insurance providers.

PANDAS/PANS is a rare disease. Given the rarity of this clinical diagnosis, combined with the limitations to coding described in this report, it is difficult to infer trends from claims counts and claims expenditures. Year to year changes may be driven by random variation due to small numbers. With these limitations stated, OHIC provides in this report the aggregate claims data and other information collected from health insurance carriers. Additionally, this report includes a review of PANDAS/PANS coverage and costs in other states.

Based on the information and data available, OHIC does not have evidence to support that PANDAS/PANS treatment coverage mandate would produce a net savings to health insurance carriers or to policy holders. However, using the information and data that OHIC has collected from health insurance carriers and from other states, OHIC has determined that it is likely that PANDAS/PANS treatment coverage has only a minimal effect on health insurance premiums.

INTRODUCTION

This report is in response to R.I.G.L. § [27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#). The report provides a cost-benefit analysis of the PANDAS/PANS treatment coverage required under these laws. This cost-benefit analysis was conducted to the best of OHIC's ability based on the information and data available. The report also identifies what PANDAS/PANS is, how it is treated, and its estimated prevalence.

[House Bill 7503 Substitute B as amended](#) (H7503Baa) and [Senate Bill 2203 Substitute B as amended](#) (S2203Baa) were signed into law by Governor Daniel J. McKee on June 30, 2022. Rhode Island General Laws (R.I.G.L.) § [27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#) require health insurance carriers to provide coverage for the treatment of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) and pediatric acute onset neuropsychiatric syndrome (PANS). Coverage for PANDAS/PANS treatment must include, but not be limited to, the use of intravenous immunoglobulin therapy. The legislation also requires that health insurance carriers provide data related to PANDAS/PANS claims to the Office of the Health Insurance Commissioner (OHIC). It further requires that OHIC "report to the General Assembly a cost-benefit analysis of the implementation of the benefit coverage" required by the statute by January 1, 2025. The legislation states that "the intent of this cost-benefit analysis is to determine if adding the benefit coverage provided in this section produces a net savings to health insurance carriers and to policy holders." It does not require an assessment of broader impacts to social welfare that may accrue from this coverage mandate. Such impacts may include, but are not limited to, improved outcomes for effected children over the life course, resource savings for effected families, or broader impacts on public health. The legislation contains a sunset provision, repealing the required coverage of treatment for PANDAS/PANS diagnoses effective December 31, 2025.

BACKGROUND

PANDAS/PANS Prevalence and Treatment

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) are rare clinical diagnoses. According to the PANDAS Networks, approximately 1 in 200 children in the United States has PANDAS/PANS; however, the true lifetime prevalence is unknown.⁵ The age of onset can range from three to twelve years of age, with reactions after age twelve categorized as rare.⁶ The disorder can result from a Group A Streptococcal bacterial infection, commonly known as strep throat. Following a strep infection, children may develop physical, neurological, and psychological symptoms interfering with daily lives.⁷ Signs and symptoms of the diagnoses can range from tics, disturbances in sleep, OCD-like symptoms, and restrictive eating or food avoidance.

Although there are no definitive tests associated with either diagnosis, treatments can include antibiotics such as Penicillin, Augmentin (Amoxicillin/Clavulanate Blend), Cephalosporins (Cephalexin, Cefdinir) and Azithromycin; Prophylactic antibiotics, Nonsteroidal anti-inflammatory drugs (NSAIDs), Intravenous Immunoglobulin (IVIG), and Plasmapheresis.⁸ The course of treatment can vary based on the symptoms and may include multiple of the above-mentioned interventions. In mild cases, antibiotics and NSAIDs are typically prescribed. In moderate cases, antibiotics and NSAIDs are prescribed for longer courses. IVIG therapy may be used if improvement is not observed with the initial course of antibiotics and NSAIDs. In severe cases, children may be prescribed antibiotics and NSAIDs in addition to IVIG therapy.⁹

OHIC Statutory and Regulatory Authority

Created in 2004, OHIC is Rhode Island's commercial health insurance policy reform and regulatory enforcement agency. OHIC seeks to improve health care access, affordability, and quality. The office does so as it: (1) guards the solvency of health insurers; (2) protects the interests of consumers; (3) encourage fair treatment of health care providers; (4) encourage policies and developments that improve the quality and efficiency of health care service delivery and outcomes; and (5) view the health care system as a comprehensive entity and encourage and direct insurers toward policies that advance the welfare of the public through overall efficiency, improved health care quality, and appropriate access.¹⁰

Under Rhode Island law, OHIC conducts oversight and certifies all benefit determination and utilization review agents for fully insured health insurance companies pursuant to OHIC regulation 230-RICR-20-30-14 and R.I.G.L § 27-18.9-3 to ensure consumer protections are in place.

Certain types of health insurance fall under OHIC's regulatory jurisdiction, while other types of health insurance do not. The following is a breakdown of the different types of health insurance broken out by whether OHIC has regulatory authority:

OHIC has regulatory authority over:

- **Individual market health insurance plans** for people who are not connected to employer-based coverage. These plans are purchased by individuals or families through Rhode Island's state-based exchange, HealthSourceRI, or directly from an insurance company in Rhode Island.¹¹

⁵ PANDAS Network (2024). [PANDAS/PANS Prevalence](#)

⁶ National Library of Medicine (2024). [Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections \(PANDAS\)](#).

⁷ PANDAS Network. (2024). [What Is PANDAS? The Latest Research and Treatment Options](#)

⁸ National Library of Medicine (2024). [Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections \(PANDAS\)](#).

⁹ Pandas Physician Network (2020). [PANS/PANDAS Diagnostic Flowchart and Treatment Guidelines](#).

¹⁰ See Rhode Island General Laws § 42-14.5-2

¹¹ See Rhode Island General Laws § 27-18.5-2 for the full definition.

- **Large group market health insurance plans** for people who obtain health insurance for themselves and their dependents through a group plan maintained by a large employer in Rhode Island, which is generally defined as an employer with at least 51 employees.¹²
- **Small employer health insurance plans** for people who obtain health insurance for themselves and their dependents through a plan maintained by a small employer in Rhode Island, which is generally defined as an employer with no more than 50 eligible employees.¹³
- **Medicare supplement insurance policies** for people who are eligible for Medicare to use as a supplement to reimbursements under Medicare for hospital, medical, or surgical expenses.¹⁴
- **Other fully insured policies** such as dental, student health plans, stop loss policies, and other limited benefit plans.

OHIC does not have regulatory authority over:

- **Self-funded plans, or self-insured plan, received through an employer** (e.g., health insurance plans offered by Brown University to its employees.) These plans are usually offered by large companies where the employer collects premium contributions from employees and takes on the responsibility of paying employees' and dependents' medical claims. Employers can contract for insurance services with a third-party administrator, or insurance services can be self-administered.¹⁵ These plans fall under the jurisdiction of the federal government.
- **Self-funded, non-federal government plans** (e.g., state of Rhode Island employee health insurance plans or health insurance offered through a municipal employer.) These plans also fall under the jurisdiction of the federal government.
- **Medicare plans** including Medicare Advantage plans (e.g., United Senior of Blue Chip for Medicare.) Medicare is a federal health insurance program for individuals who are 65 and older and certain younger individuals with disabilities.¹⁶
- **Medicaid plans** including managed Medicaid products provided by Neighborhood Health Plan of Rhode Island, United Healthcare, or Tufts Health Plan. Medicaid is a government assistance plan for individuals and families who have low incomes or a qualifying disability.¹⁷ These plans fall under the jurisdiction of the Rhode Island Executive Office of Health and Human Services.
- **Out-of-state health insurance plans** these plans are regulated by the state of origin of the federal government, depending on the type of plan.
- **All other types of insurance** (e.g., life insurance, auto insurance, or long-term disability insurance.) These plans are regulated by the Rhode Island Department of Business Regulation.

R.I.G.L. § [27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#), require coverage for treatment of PANDAS/PANS within Rhode Island individual market health insurance plans, large group market health insurance plans, small employer health insurance plans, and other fully insured policies. As described above, Rhode Island law does not have authority over self-funded plans, Medicare plans, or out-of-state health insurance plans. Self-funded employer plans may voluntarily choose to align benefits with state coverage mandates, but they are not required to do so by law.

COST-BENEFIT ANALYSIS

In August 2024, pursuant to R.I.G.L. § [27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#), OHIC requested data from the Rhode Island health insurance carriers that are required to provide PANDAS/PANS treatment coverage as of January 1, 2023. These insurers include Aetna, Blue Cross Blue Shield of Rhode Island, Cigna, Neighborhood Health Plan of Rhode Island, Point32Health, and United Healthcare. OHIC requested that the carriers provide data from January 2018 through September 2024. The data request included the

¹² See Rhode Island General Laws [§ 27-18.6-2 for the full definition.](#)

¹³ See Rhode Island General Laws [§ 27-50-3 for the full definition.](#)

¹⁴ See Rhode Island General Laws [§ 27-18.2-1 for the full definition.](#)

¹⁵ <https://www.healthcare.gov/glossary/self-insured-plan/>

¹⁶ <https://www.healthcare.gov/glossary/medicare/>

¹⁷ <https://www.healthcare.gov/medicaid-chip/>

total number of claims by month, and the total cost associated with those claims, for autoimmune encephalitis, PANDAS, PANS, and intravenous immunoglobulin therapy (IVIG). OHIC instructed carriers to only include IVIG claims that are associated with autoimmune encephalitis, PANDAS, or PANS. This is because IVIG can be used to treat other conditions that are unrelated to PANDAS/PANS.

Additionally, OHIC requested supplemental information from insurance carriers including:

- Carriers' coverage policies related to PANDAS/PANS,
- Whether adding the new benefit coverage required by law produced a net savings to health insurance carriers and to policy holders,
- An estimated, or actual, per member per month cost or savings associated with the new coverage required by this law, and
- Any additional information that would be helpful for OHIC to take into consideration when conducting the cost-benefit analysis required by law.

Limitations

Limitations to the cost-benefit analysis of the mandated coverage of PANDAS/PANS treatment include, but are not limited to, the unavailability of accurate billing and diagnosis codes associated with a PANDAS/PANS diagnosis. R.I.G.L. § [27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#) state that:

For billing and diagnosis purposes, PANDAS and PANS shall be coded as autoimmune encephalitis until the American Medical Association and the Centers for Medicare & Medicaid Services create and assign a specific code for PANDAS and PANS. Thereafter, PANDAS and PANS may be coded as autoimmune encephalitis, PANDAS, or PANS.

Since the passage of the PANDAS/PANS treatment coverage requirement in 2022, the American Medical Association and the Centers for Medicare & Medicaid Services has not created and assigned a specific code for PANDAS and PANS. Even if a specific code had been created, current law permits health insurance carriers to code PANDAS and PANS claims as autoimmune encephalitis, PANDAS, or PANS. This causes a lack of specificity in the claims data that OHIC collected from health insurance providers.

Aligning with the limitations identified above, Blue Cross Blue Shield of Rhode Island's (BCBSRI) data submission to OHIC included the following notes:

- Currently, there are no diagnoses codes to identify PANDAS or PANS, so BCBSRI is following a similar law in Oregon¹⁸ that references diagnosis codes D89.89 "Other specified disorders involving the immune mechanism, not elsewhere classified" for PANDAS and D89.9 "Disorder involving the immune mechanism, unspecified" for PANS.
- BCBSRI is using diagnosis code G04.81 as mentioned in the legislation as autoimmune encephalitis. BCBSRI has defined intravenous immunoglobulin therapy IVIG as CPT codes between 90281-90399, starting with J15, or J1459, J2788 and has included those claims in their respective diagnosis categories as well as separately per the updated guidance.
- The assumption that the D89.89 and D89.9 codes represent the PANDAS and PANS conditions is likely causing claims to be included that are not truly PANDAS and PANS due to their broad definition. We noticed members under the age of 2 and over the age of 50 in our data that indicate we likely have too broad of a definition.
- In the occasional case that a claim has more than one of the 3 diagnoses anywhere on the claim, we've assigned one diagnosis based on Primary, Secondary, Tertiary hierarchy and sequence number within each. For example, if a claim has a primary diagnosis of G04.81 and a secondary diagnosis of D89.89, we assign the claim as G04.81.

¹⁸ https://www.oregon.gov/oha/HPA/DSI-HERC/EvidenceBasedReports/Prioritization-Changes_PANDAS-PANS.pdf

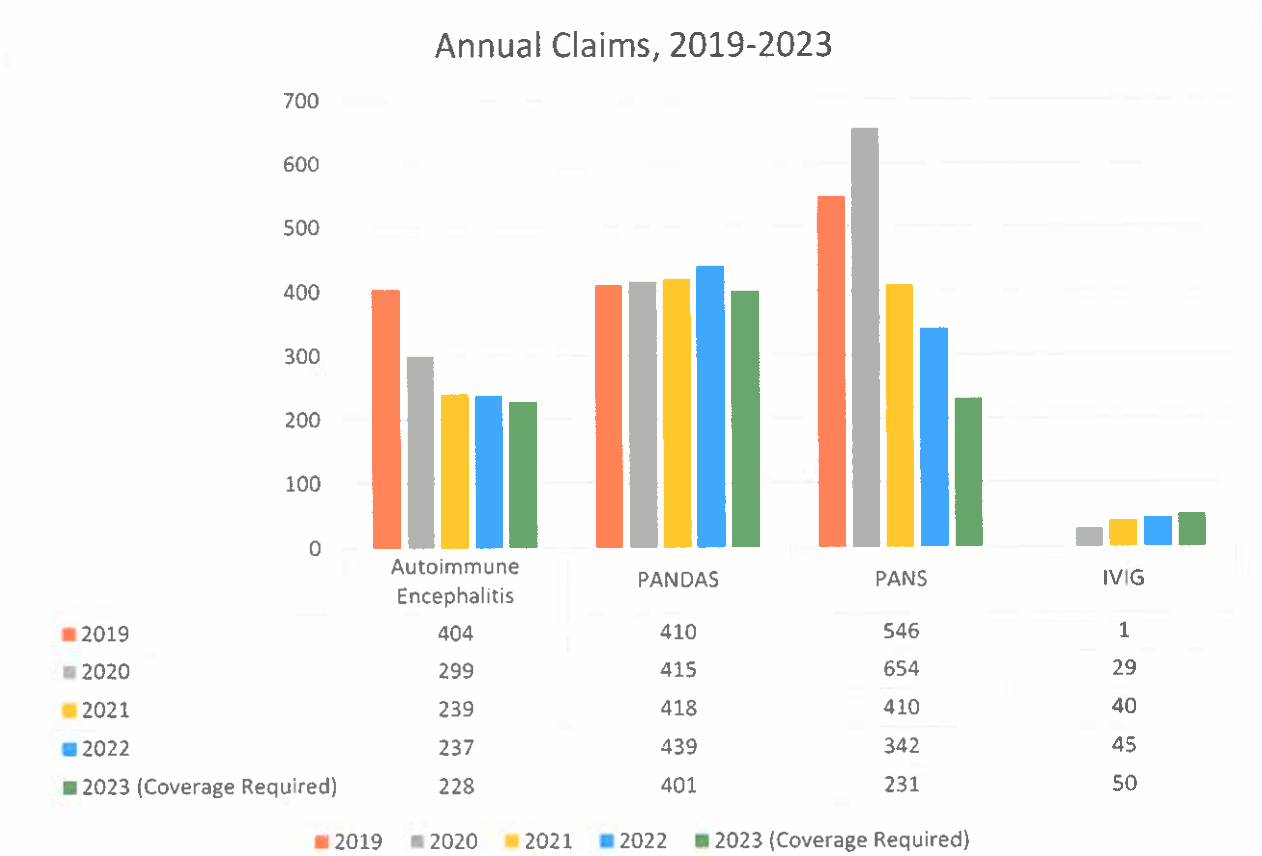
BCBSRI's data notes provide helpful context to the data collection limitations that OHIC encountered when conducting the cost-benefit analysis required by law.

Aggregate Claims Data and Other Information Collected from Health Insurance Carriers

PANDAS/PANS is a rare disease. Given the rarity of this clinical diagnosis, combined with the limitations to coding described above, it will be hard to infer trends from claims counts and claims expenditures. Year to year changes may be driven by random variation due to small numbers. With these limitations stated, OHIC provides the following summary of the data.

The following graph, and corresponding table, depicts the total annual number of claims received for each claim type (Autoimmune Encephalitis, PANDAS, PANS, and IVIG) inclusive of all insurers. There is a decrease in claims for Autoimmune Encephalitis, PANDAS, and PANS after the PANDAS/PANS mandate had been implemented, and there was a slight increase in claims for IVIG therapy from 2022 (pre-mandate) to 2023 (post-mandate).

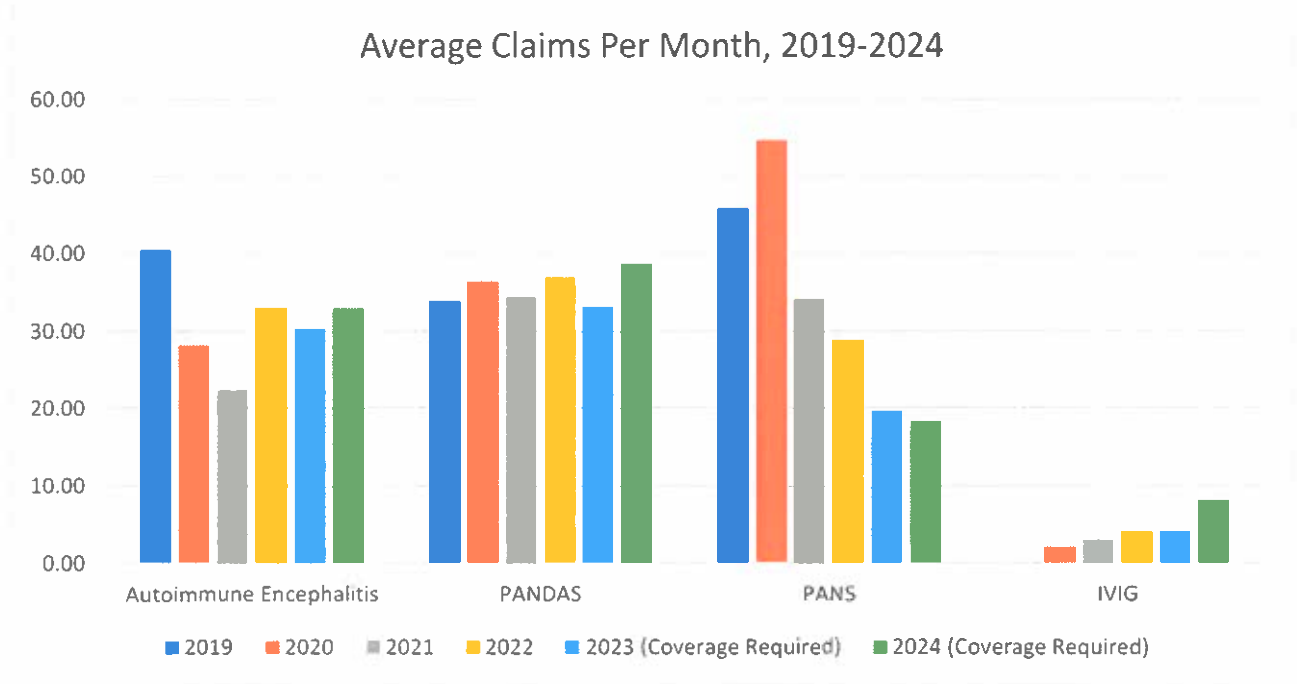
FIGURE 1.



Note: Though OHIC requested data from January 2018 through September 2024, not all health insurance carriers were able to provide data for that entire time period. As a result, 2018 data and 2024 data were omitted from Figure 1.

The following graph depicts the average number of claims per month for each claim type (Autoimmune Encephalitis, PANDAS, PANS, and IVIG). 2024 data is limited to 6 months of data, January through June, while years 2019 through 2023 include data for all 12-months of each year.

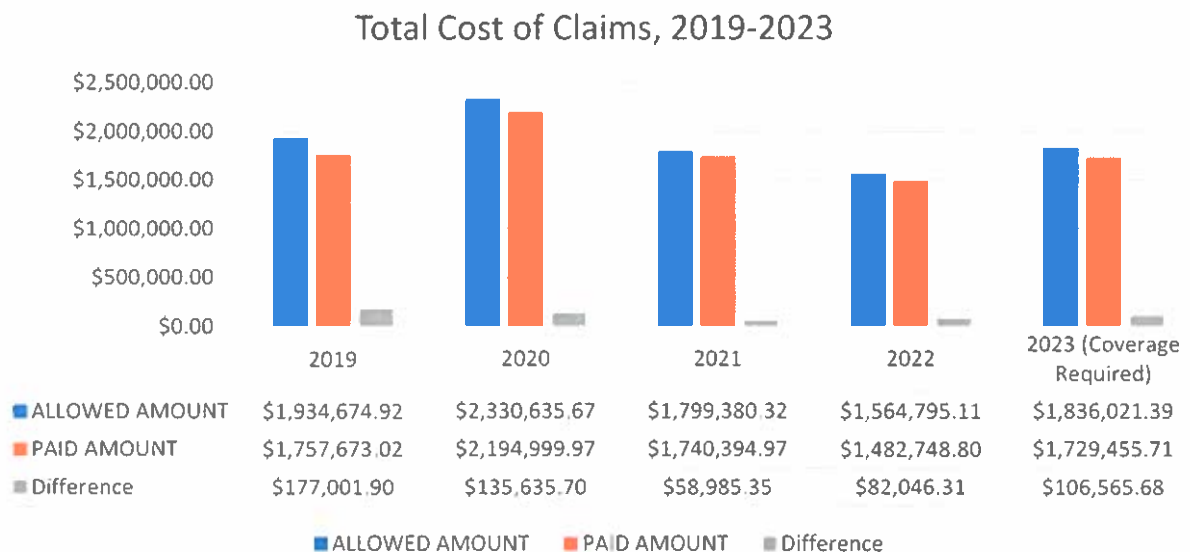
FIGURE 2.



Note: Though OHIC requested data from calendar year 2018, not all health insurance carriers were able to provide data for that time period. As a result, 2018 data was omitted from Figure 2. Additionally, 2024 includes average claims for the months January to June.

The following graph, and corresponding table, shows the total allowed amount and the total paid amount for all of the claim types combined (Autoimmune Encephalitis, PANDAS, PANS, and IVIG), for all insurers from 2019-2023. The allowed amount is the amount the health insurance carrier paid a provider, plus any member cost sharing (coinsurance, copay, deductible) for a claim. The paid amount is the amount that only the health insurance carrier paid the provider. The difference between the allowed amount and the paid amount is the amount that the health insurance subscriber paid.

FIGURE 3.



Note: Though OHIC requested data from January 2018 through September 2024, not all health insurance carriers were able to provide data for that entire time period. As a result, 2018 data and 2024 data were omitted from Figure 3.

As discussed above, in accordance with current law, OHIC asked health insurance carriers whether adding the new benefit coverage required by law produced a net savings to health insurance carriers and to policy holders. Additionally, OHIC asked carriers for an estimated, or actual, per member per month cost or savings associated with the PANDAS/PANS treatment coverage requirement. The following are the responses provided by the health insurance carriers. Additionally, the applicable PANDAS/PANS coverage policies can be found in the [Appendix](#) of this report.

Aetna

In response to OHIC's request for an estimated, or actual, per member per month cost or savings associated with the coverage required by R.I.G.L. § [27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#), Aetna stated, "due to the lack of membership for RI contracted plans, we do not have any claims information to share."

Blue Cross Blue Shield Of Rhode Island

Blue Cross Blue Shield of Rhode Island (BCBSRI) stated that, "the data and coding assumptions/restrictions make an estimate of the costs or savings of this coverage difficult to determine." Details about such coding assumption and restrictions can be found in the "limitations" subsection of this report.

Cigna

In response to OHIC's question about whether adding coverage for PANDAS/PANS treatment produced a net savings to health insurance carriers and to policy holders, Cigna replied, "with no claims for Rhode Island, a specific review to Rhode Island has not been completed. Nationally, we expect the overall impact to premiums to be very low." And in response to OHIC's request for an estimated, or actual, per member per month cost or savings associated with the new coverage required by law, Cigna stated that "based on a national study, we expect a premium impact of \$0.01-\$0.02 per member per month."

Neighborhood Health Plan of Rhode Island

In response to OHIC's question about whether adding coverage for PANDAS/PANS treatment produced a net savings to health insurance carriers and to policy holders, Neighborhood Health Plan replied, "Neighborhood covered intravenous immunoglobulin therapy as a benefit without consideration of diagnosis prior to this legislation. Commercial members that received this treatment prior to or after the passing of the legislation were responsible for their portion of the services based on their plan design. Neighborhood has not observed a cost savings due to the implementation of the legislation."

In response to OHIC's request for an estimated, or actual, per member per month cost or savings associated with the new coverage required by law, Neighborhood shared their annual per member per month (PMPM) cost "for intravenous immunoglobulin therapy when treated for diagnosis of PANDAS, PANS, or autoimmune encephalitis."

Year	PMPM
*2019	\$-
2020	\$0.13
2021	\$0.12
2022	\$0.13
2023	\$0.16

**“Neighborhood did not observe any claims for intravenous immunoglobulin therapy when treated for diagnosis of PANDAS, PANS, or autoimmune encephalitis in 2019.”*

Additionally, Neighborhood shared that they anticipate “that intravenous immunoglobulin therapy treatment associated with PANDAS or PANS will increase year over year due to the legislation creating awareness of the coverage of this treatment.”

Point32Health

In response to OHIC’s supplemental questions around costs or savings associated with the coverage required by R.I.G.L § [§ 27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#), Point32Health stated:

“We would note that it has been well acknowledged that state-mandated benefit coverage requirements increase the cost of health insurance. To comply with the Affordable Care Act (ACA), states are required to defray the costs of any new mandated benefits above the federal EHB benchmark, which includes the PANS/PANDAS mandate passed in Rhode Island.

We have not yet conducted an actuarial assessment of the additional costs from this new mandate. They would note, however, that the Massachusetts Center for Health Information and Analysis (CHIA) report did evaluate the additional costs of a similar mandate for plans there. CHIA’s report is available here: <https://www.chiamass.gov/assets/Uploads/mbr-h984-pandas.pdf>

As indicted in the linked report, CHIA performed an analysis, in consultation with Compass Health Analytics, to determine the financial impact and medical efficacy of a then-proposed bill that would require commercial health insurance plans to cover ‘treatment of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections [PANDAS] and pediatric acute-onset neuropsychiatric syndrome [PANS]. Said treatment shall include, but not be limited to, the use of Intravenous immunoglobulin (IVIG) therapy.’ Per the CHIA report, for a five-year estimated impact on the Massachusetts fully insured membership, CHIA and Compass Health Analytics found the average cost for this mandated benefit could be as high as \$1.1 million per year. It is important to note that the CHIA report was published in 2015, and health care costs have only grown exponentially in the years since.”

An excerpt from the CHIA report, referenced by Point32Health, puts CHIA’s cost estimate another way, “requiring coverage for this benefit by fully-insured health plans would result in 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.”¹⁹ With a population more than six-times higher than Rhode Island’s, Massachusetts’s market is considerably larger than Rhode Island’s.

UnitedHealthCare

In response to OHIC’s request for an estimated, or actual, per member per month cost or savings associated with the new coverage required by law, United said, “based on the information that United Healthcare has available, PANS/PANDAS costs approximately \$0.12 PMPM in fully insured. This is immaterial and therefore United Healthcare did not build any costs into our projections/rate filings.”

¹⁹ Center for Health Information and Analysis (2015). [Mandated Benefit Review of House Bill 984: An Act Relative to Insurance Coverage for PANDAS/PANS](#), page 2.

PANDAS/PANS Coverage and Cost in Other States

Several states including Delaware, Illinois, Indiana, Maryland, Minnesota, New Hampshire, and Oregon require health insurance carriers to cover the treatment of PANDAS and PANS including, but not limited to the use of intravenous immunoglobulin therapy.^{20,21}

In Maine, the legislature directed the Bureau of Insurance to review bill LD 663, An Act to Require Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS).²² The Maine bill required coverage of treatment for PANDAS and PANS and stated that treatments must include, but not be limited to, long-term antibiotics, intravenous immunoglobulin therapy, steroids, plasmapheresis, and psychopharmacological interventions.

As a part of its analysis, the Maine Bureau of Insurance explored whether the cost of mandating coverage for the treatment of PANDAS/PANS would include a state “defrayal” cost in accordance with the Affordable Care Act:²³

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

The Affordable Care Act (ACA) describes a broad set of benefits that must be included in a state’s EHB package. Federal regulators consider state mandated health benefits that were in effect prior to December 31, 2011, part of a state’s EHB. Generally, mandates adopted by a state after December 31, 2011, are subject to defrayal.”²⁴

In 2023, Centers for Medicare & Medicaid Services (CMS) confirmed that Maine could be responsible to defray the total cost of specific mandated PANDAS/PANS treatments. The Maine Bureau of Insurance estimated that the cost of PANDAS/PANS treatment would be \$0.04 - \$0.40 per member per month. The Bureau anticipated that there would be 63,388 QHP on-exchange members in Maine and estimated a total defrayal cost to the state of \$30,000 to \$300,000 for plan year 2025.

In 2023, the California Health Benefits Review Program (CHBRP) analyzed and issued a report on California Assembly Bill 907, which would require health plans to provide coverage for the prophylaxis, diagnosis, and treatment of PANDAS/PANS.²⁵ CHBRP estimated that premiums would increase by 0.001%, or \$0.01 per member per month.

Conclusion

R.I.G.L. § [§ 27-18-90](#), [27-19-82](#), [27-20-78](#), and [27-41-95](#) state that the intent of OHIC’s mandated cost-benefit analysis of the implementation of PANDAS/PANS mandated treatment coverage is “to determine if adding the benefit coverage provided in this section produces a net savings to health insurance carriers

²⁰ <https://pandasnetwork.org/get-involved/legislative-tools/>

²¹ <https://www.cga.ct.gov/2022/rpt/pdf/2022-R-0104.pdf>

²² Maine Department of Professional & Financial Regulation (2024). [A Report to the Joint Standing Committee on Health Coverage, Insurance and Financial Services of the 131st Main Legislature: Review and Evaluation of LD 663.](#)

²³ Maine’s report states that defrayal only represents the impact of a mandate on Maine’s individual exchange plans and does not consider the mandate’s impact on the small or large group market. It is Rhode Island’s belief that defrayal would include the small group market.

²⁴ Maine Department of Professional & Financial Regulation (2024). [A Report to the Joint Standing Committee on Health Coverage, Insurance and Financial Services of the 131st Main Legislature: Review and Evaluation of LD 663.](#) (page 4).

²⁵ California Health Benefits Review Program (2023). [Analysis of California Assembly Bill 907 Coverage for PANDAS and PANS: A Report to the 2023–2024 California State Legislature.](#)

and to policy holders.” OHIC does not have any evidence to support that PANDAS/PANS treatment coverage mandate would produce a net savings to health insurance carriers or to policy holders. However, using the information and data that OHIC has collected from health insurance carriers and from other sources, OHIC has determined that it is likely that PANDAS/PANS treatment coverage has only a minimal effect on health insurance premiums.

APPENDIX

Coverage Policies

A link to each insurers applicable coverage policy document is provided in the appendix.

National policies, including those of Aetna, Cigna, Point32Health and UnitedHealthCare do not provide language indicating PANDAS and PANS treatment coverage. However, the policies do address that state mandates may supersede that of the national coverage. Through OHIC's form review process, the office ensures compliance with state and federal laws, such as mandated benefits coverage. For individual and small group market plans, OHIC reviews benefit coverage documents that includes certificate of coverage and schedule of benefits.²⁶

Aetna

[Link to Coverage Policy²⁷](#)

Blue Cross Blue Shield of Rhode Island

[Link to Coverage Policy²⁸](#)

Cigna

[Link to Immune Globulin Coverage Policy²⁹](#)

[Link to Plasmapheresis Coverage Policy³⁰](#)

Neighborhood Health

[Link to Certificate of Coverage³¹](#)

Point32Health

[Link to Coverage Policy³²](#)

²⁶ Office of the Health Insurance Commissioner (2024). <https://ohic.ri.gov/rate-form-network-plan-and-benefit-determination-review/form-review>

²⁷ Aetna Coverage Policy (2024). https://www.aetna.com/cpb/medical/data/200_299/0206.html

²⁸ Blue Cross Blue Shield Coverage Policy (2023).

<https://www.bcbsri.com/providers/sites/providers/files/policies/2022/12/PANDAS%20and%20PANS%20Mandate.pdf>

²⁹ Cigna Immune Globulin Coverage Policy (2024).

https://static.cigna.com/assets/chcp/pdf/coveragePolicies/pharmacy/ph_5026_coveragepositioncriteria_immune_globulin_intraveno_us_iqiv.pdf

³⁰ Cigna Plasmapheresis Coverage Policy (2024).

https://static.cigna.com/assets/chcp/pdf/coveragePolicies/medical/mm_0153_coveragepositioncriteria_plasmapheresis.pdf

³¹ Neighborhood Health Certificate of Coverage (2023). https://www.nhpri.org/wp-content/uploads/2023/09/2024-COC-Neighborhood-PLUS_HSRI.pdf

³² Point32Health Coverage Policy (2024). <https://www.point32health.org/provider/wp-content/uploads/sites/2/2024/01/IVIG-SCIg-MNG-COM-QHP-RIT.pdf>

UnitedHealthCare

[Link to Coverage Policy](#)³³

³³ UnitedHealthCare Coverage Policy (2024). <https://www.uhcprovider.com/content/dam/provider/docs/public/policies/comm-medical-drug/immune-globulin-ivig-scig.pdf>