

State of Idaho
DEPARTMENT OF INSURANCE

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DEAN L. CAMERON
Director

March 6, 2025

The Honorable Chris Mathias, Representative, Idaho District 19
The Honorable John Vander Woude, Chair, Idaho House Health & Welfare Committee
The Honorable Julie VanOrden, Chair, Idaho Senate Health & Welfare Committee
The Honorable Brad Little, Governor, State of Idaho

Subject: HCR027 PANDAS and PANS Findings Report

Dear Representative Mathias and Members of the Idaho Legislature,

The Idaho Department of Insurance (Department) hereby submits findings in accordance with House Concurrent Resolution No. 27 (HCR027) concerning the coverage of, and cost related to, treatment for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS), as directed by the Second Regular Session of the Sixty-seventh Legislature. This report is being delivered to the First Regular Session of the Sixty-eighth Legislature as required by HCR027. The findings show a snapshot of an evolving diagnosis and the current availability of coverage for treatment options to Idahoans. We appreciate the opportunity to review this issue.

The Department was directed to take specific action to understand issues regarding the availability and coverage of treatments, for Idaho children diagnosed with PANDAS/PANS. In the report the Department outlines both the availability of treatment and barriers to coverage for treatment for PANDAS and PANS. HCR027 highlighted concerns related to coverage of Intravenous Immunoglobulin (IVIG) treatment for children with PANDAS and PANS. This report shows which health insurance companies cover IVIG treatment for Idaho children and outlines the barriers that consumers face in seeking insurance coverage for the treatment. The Department also provides information on concerns insurance companies have in covering IVIG treatment related to a PANDAS/PANS diagnosis.

The Department worked closely with health insurance companies serving Idaho residents to gather information and address the concerns outlined in HCR027. **The findings reflect only the carriers' insurance plans and do not account for the coverage of self-funded plans, which are plans typically provided by large employers.** Idaho-specific coverage requirements do not apply to Idaho residents covered by self-funded employer health plans as those plans operate under a different framework.

Some key takeaways from the report are as follows:

- All the major health carriers provide coverage for the initial recommended treatments of PANDAS/PANS. These include NSAIDs, antibiotics, steroids, and SSRIs as well as therapy.
- The Department found that four of the major health carriers in Idaho cover IVIG treatment for PANDAS/PANS. This coverage would be dependent on medical necessity requirements being met, and prior approval from the carrier.
- While there are treatment protocols that have been recommended by organizations focused on PANDAS and PANS, there is still debate about the efficacy of these protocols for diagnoses and treatment, as well as the need to consider and weigh potential risks related to those treatments.
- The lack of consensus on treatment can create issues for carriers in developing medical policies that meet the needs of consumers.

Given the concerns related to coverage of IVIG treatment for PANDAS/PANS, we'd like to recommend that constituents with this diagnosis seek assistance by contacting the Department if they are receiving denials. Department staff can assist Idahoans with understanding the carriers' appeals process and the Departments' independent external review program, which assigns an independent review organization to review the medical records and other relevant material to determine if the insurance company made the correct coverage decision.

Thank you for your attention to this issue and your concern for the citizens of Idaho. The Department of Insurance is available to provide further information or clarification as needed.

Sincerely,



Dean L. Cameron
Director

Idaho Department of Insurance

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Legislative Request

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) involve a misdirected autoimmune process that affects or weakens the blood-brain barrier in children, afflicting children with symptoms such as changes in personality, tics, intense fear or anxiety, depression, severely restricted food intake, and more.¹

While there are proposed standards of care for the treatment of PANDAS or PANS, some health insurance carriers have not adopted medical policies that include all of the requested treatments. Consequently, some parents have had difficulty securing doctor-recommended treatments for their children, in particular Intravenous Immunoglobulin (IVIG), and have sought assistance from legislators. Following this outreach, the Second Regular Session of the Sixty-seventh Legislature passed House Concurrent Resolution No. 27, directing the Idaho Department of Insurance (Department) to take specific actions to understand the issues and report its findings to the First Regular Session of the Sixty-eighth Legislature.

Requests of the Department of Insurance under HCR027

- 1) Work with industry leaders in the insurance industry to determine how to make IVIG treatment available to all children who are insured.
- 2) Determine the cost of including IVIG treatment in private **insurance plans**.
- 3) Determine the cost to the Idaho General Fund to add this benefit to plans.
- 4) Report the findings to the First Regular Session of the Sixty-eighth Legislature.

Background

What are PANDAS and PANS

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) refers to the sudden onset of obsessive-compulsive symptoms or eating restrictions. While PANS does not require a known trigger, it is believed to be initiated by infections, metabolic disturbances, and other inflammatory reactions.²

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) is a subset of PANS and has five distinct diagnostic criteria: abrupt obsessive-compulsive disorder (OCD) or dramatic, disabling tics; a relapsing-remitting, episodic symptom course; young age at onset (average of 6-7 years); presence of neurologic abnormalities; and temporal association between symptom onset and Group A Streptococcal (GAS) infection.³

¹ <https://legislature.idaho.gov/sessioninfo/2024/legislation/hcr027/>

² <https://www.stanfordchildrens.org/en/services/pans-pandas/what-are-pans-pandas.html>

³ <https://www.pandasppn.org/what-are-pans-pandas/>

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How Common is PANDAS/PANS

Currently, there are no specific medical billing codes for PANDAS/PANS in the International Classification of Diseases, 10th Revision (ICD-10). The 2025 ICD-10-CM (International Classification of Diseases, Tenth Revision, Clinical Modification) effective October 1, 2024, added PANDAS to diagnosis code D89.89,⁴ “Other specified disorders involving the immune mechanism, not elsewhere classified.” D89.89 can now be used as a diagnoses code for PANDAS⁵. PANS does not currently have an ICD-10 code. Of note, ICD-11 will have specific codes for PANDAS and PANS, 8E4A.0 and 8A05.10, respectively. However, the United States has not yet adopted this standard, and there is no clear indication as to when that will take place. As a result, it is difficult to determine from current medical claims the exact number of children affected by PANDAS/PANS. Estimates vary significantly, with a parental support group, PANDAS Network, suggesting that 1 in 200 children in the U.S. are affected,⁶ while a 2023 report from the National Library of Medicine estimates the prevalence at 1 in 11,765 children.⁷

Treatment

Currently there are no FDA approved treatments for PANDAS/PANS. However, the PANDAS Physicians Network (PPN) has produced treatment protocols for its members and interested physicians. The PPN describes itself as an organization that is dedicated to helping medical professionals better understand PANDAS and PANS through real-time information and networking. It provides recommended treatment guidelines based on the severity of the case and treatment is divided into three categories: mild, moderate, and severe. According to PPN, the following are currently used to treat cases of PANDAS/PANS:

- 1) Nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen, naproxen sodium, and celecoxib, are used to reduce inflammation. Inflammation in the brain may be tied to some of the symptoms of PANDAS/PANS.
- 2) Antibiotics, such as penicillin, amoxicillin, and Augmentin, are used to fight infections that are thought to be tied to the onset of PANS.
- 3) Steroids, such as prednisone, show some evidence of providing benefits, especially in children with Sydenham chorea.⁸ However, steroids should be used with caution, as they can sometimes lead to worsening symptoms.⁹
- 4) Selective Serotonin Reuptake Inhibitors (SSRIs), such as fluoxetine, fluvoxamine, sertraline, and paroxetine, are used to treat anxiety symptoms.

⁴ <https://icdlist.com/icd-10/D89.89>

⁵ <https://icd10cmttool.cdc.gov/?fy=FY2021&query=PANDAS>

⁶ <https://pandasnetwork.org/get-involved/statistics/>

⁷ <https://pmc.ncbi.nlm.nih.gov/articles/PMC10551157/>

⁸ <https://www.pandasppn.org/steroids/>

⁹ <https://pandasnetwork.org/new-research-identifies-key-differences-between-sydenham-chorea-and-pandas/>

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- 5) Cognitive Behavioral Therapy (CBT) with Exposure and Response Prevention (ERP) involves working with a CBT professional to give the child and parent tools to manage the child's OCD. These treatments help both the child and parent understand what is happening and equip the parent to act as a "home therapist" to help the child work through these new behaviors.
- 6) Plasmapheresis involves using two venous catheters: one to draw blood out and into a plasmapheresis machine, and the other to return the blood to the child. The machine processes the blood, separating its elements and removing the plasma. The removed plasma is replaced with albumin, and then the blood is returned to the child. This treatment is believed to help remove the antibodies thought to be causing the condition.
- 7) Intravenous Immunoglobulin (IVIG) involves infusing a patient with antibodies derived from the blood of healthy donors. Similar to plasmapheresis, IVIG aims to add healthy antibodies to counteract those believed to be causing the condition.

The following are PPN's recommended treatment plans for the first visit, depending on the severity of the symptoms.¹⁰

For mild cases (symptoms are significant and cause disruptions at home and/or school, occupying a few hours a day):

- 1) Perform a comprehensive laboratory and clinical evaluation.
- 2) Look for infections (Throat swab/culture child and family members for strep, check for exposure to Group A Streptococcus through close contacts, inquire about perianal redness or itching which may indicate perianal strep, and check for mycoplasma or other infections, e.g., yeast).
- 3) While waiting for lab results:
 - a) Prescribe 14 days of antibiotics (penicillin/amoxicillin, azithromycin, cefdinir, Augmentin, or others).
 - b) Consider a 5-7 day course of NSAIDs at an immunomodulatory dose for 24-hour coverage.
 - c) Ensure the family has access to CBT with ERP and parent support.
- 4) Schedule a follow-up appointment.

For moderate cases (symptoms are distressing and interfere with daily activities, occupying 50%-70% of waking hours):

- 1) Perform comprehensive laboratory and clinical evaluation.
- 2) Look for infections (throat swab/culture child and family members for strep, check for exposure to GAS through close contacts, inquire about perianal redness or itching which may indicate perianal strep, and check for mycoplasma or other infections, e.g., yeast).
- 3) Perform additional laboratory testing to rule out other conditions and guide treatment.
- 4) While waiting for lab results:
- 5) Prescribe antibiotics (Penicillin/amoxicillin, azithromycin, cefdinir, Augmentin, or others). Consider an initial 3-4 week course.
- 6) Prescribe a steroid burst or a 5-7 day course of NSAIDs at an immunomodulatory dose.

¹⁰ <https://www.pandasppn.org/flowchart/>

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- a) Ensure the family has access to CBT/ERP. If the child is not able to engage in CBT/ERP due to the severity of symptoms, learning parent management techniques may be beneficial for the family.
- b) Consider a referral to a psychiatrist to help with symptom management.
- 7) Schedule a follow-up appointment.

For severe or extreme cases (symptoms are incapacitating, life-threatening, or occupy 71%-100% of waking hours):

- 1) Perform comprehensive laboratory and clinical evaluation.
- 2) Look for infections (Throat swab/culture child and family members for strep, check for exposure to Group A Streptococcus through close contacts, inquire about perianal redness or itching which may indicate perianal strep, and check for mycoplasma or other infections, e.g., yeast).
 - a) Order additional laboratory testing to rule out other conditions and guide treatment.
 - b) For patients experiencing ARFID (Avoidant/Restrictive Food Intake Disorder), evaluate to determine if hospitalization is needed due to dramatic weight loss or if intravenous hydration is required.
- 3) Prescribe a steroid burst or a 5-7 course of NSAIDs at an immunomodulatory dose.
- 4) Begin scheduling for IVIG (1.5-2g/kg over 2 days).
- 5) Prescribe antibiotics (Penicillin/amoxicillin, azithromycin, cefdinir, Augmentin, or others). Consider an initial 3-4 week course.
- 6) Consider a referral to a psychiatrist to help with symptom management.
- 7) Schedule telephone check-in and schedule a follow-up visit.

Also of note, for mild cases, PPN does not recommend IVIG in subsequent visits; for moderate cases, PPN recommends IVIG if symptoms continue after the second follow-up visit; and for severe cases, PPN recommends scheduling IVIG on the first visit.

Important Considerations Regarding Coverage of Health Plan Benefits

Health insurance carriers offer two primary types of major medical health plans: **insurance plans** and **self-funded plans**. **Insurance plans**, also known as **fully-insured plans**, are subject to a state's insurance laws, including coverage mandates and consumer protections. These plans require the insurance company to assume the financial risk for the policyholders' medical expenses. As such, they must adhere to state regulations that require specific benefits, coverage limits, and standards of care.

In contrast, **self-funded plans**, typically offered by large employers, operate under a different framework. These plans are governed by the Employee Retirement Income Security Act of 1974 (ERISA), which exempts them from state insurance laws regarding benefits and coverages. Instead, the employer assumes the financial risk and decides what benefits and coverages to offer, as well as any limitations or exclusions. As a result, Idaho-specific coverage requirements do not apply to Idaho residents covered by **self-funded employer health plans**.

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Medical necessity is a key contractual standard for insurance coverage of healthcare services. It is demonstrated when specific criteria outlined in the carrier’s medical policy are met. These criteria typically include considerations of clinical effectiveness, evidence-based practices, and the appropriateness of the treatment for the patient’s condition. The aim is to ensure that the services provided are necessary for the diagnosis or treatment of an illness, injury, condition, or its symptoms and are in accordance with the generally accepted standards of medical practice. The criteria to determine medical necessity may vary from one carrier to another. This variability means that two patients with similar medical conditions might receive different coverage decisions based on their respective insurance carriers' criteria.

Findings

As directed by the legislature through HCR027, the Department has surveyed health insurance carriers serving Idaho residents to gather information to report. The findings in this report reflect only the carriers’ **insurance plans** and do not account for the coverage of **self-funded plans**. The health insurance carriers surveyed include¹¹:

- Aetna Life Insurance Company (Aetna)
- Blue Cross of Idaho Health Service, Inc. (BCI)
- Cigna Health and Life Insurance Company (Cigna)
- Montana Health Cooperative (MHC)
- Moda Health Plan, Inc. (Moda)
- Molina Healthcare of Utah, Inc. (Molina)
- PacificSource Health Plans (PacificSource)
- Regence BlueShield of Idaho, Inc. (Regence)
- Select Health, Inc. (Select Health)
- St. Luke’s Health Plan, Inc. (St. Luke’s)
- United HealthCare Insurance Company (UHC)
- WMI Mutual Insurance Company (WMI)

While HCR027 focused on IVIG treatment and its associated costs, the Department also worked with health insurance carriers to examine the coverage of the suite of treatments for PANDAS/PANS. The aim was to understand where consumers might encounter challenges in accessing the prescribed care.

The Department reached out to carriers on three occasions to request information about the treatment of PANDAS/PANS and how they are addressing this need. After each request, the Department worked individually with carriers to clarify what information was being requested.

The treatments examined by the Department included:

¹¹ The names used are those the companies are licensed under with the Idaho Department of Insurance.

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- NSAIDs, Antibiotics, Steroids, and SSRIs
- Therapy
- Plasmapheresis
- IVIG

Carrier Coverage of PANDAS/PANS Treatments

The following chart is a visual representation of the coverage reported by each carrier. The findings reflect only the carriers' **insurance plans** and do not account for the coverage of **self-funded plans**. The colors in the table below correspond to a carrier's representation of their coverage:

- Green: Treatment is covered when medical necessity is demonstrated, without prior authorization or other utilization management steps.
- Yellow-green: Treatment is covered if medical necessity is demonstrated, and prior authorization is required.
- Red: Treatment is not covered.

Table 1: Treatment Coverage by Carrier

| Carrier | NSAIDs, Antibiotics, Steroids, SSRIs | Therapy | Plasmapheresis | IVIG |
|---------------|--------------------------------------|---------|----------------|--------------|
| Aetna | Green | Green | Red | Red |
| BCI | Green | Green | Green | Red |
| Cigna | Green | Green | Red | Red |
| MHC | Green | Green | Green | Yellow-green |
| Moda | Green | Green | Red | Red |
| Molina | Green | Green | Red | Red |
| PacificSource | Green | Green | Yellow-green | Yellow-green |
| Regence | Green | Green | Green | Yellow-green |
| Select Health | Green | Green | Red | Red |
| St. Luke's | Green | Green | Green | Red |
| UHC | Green | Green | Yellow-green | Red |
| WMI Mutual | Green | Green | Green | Yellow-green |

Additional Details from Coverage Responses

NSAIDs, Antibiotics, Steroids, and SSRIs

All surveyed carriers indicated they provide access to prescription medications for treating PANDAS/PANS. While some higher-cost drugs may require prior authorization, most drugs in these classifications do not. Availability would be limited by the plan formulary, and prescriptions must comply with FDA labeling and maximum dosing limits.

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Therapy

All carriers represented that they provide access to therapy according to current published guidelines.

Plasmapheresis

Aetna, Cigna, Moda, Molina, and Select Health each indicated that plasmapheresis is not covered for PANDAS/PANS. PacificSource and UHC indicated it is covered only with prior authorization, and the remaining five indicated that it is covered without prior authorization.

IVIG

Based on the survey responses, IVIG treatment appears to be the most restricted. Aetna, BCI, Cigna, Moda, Molina, Select Health, St. Luke's, and UHC stated that this treatment would not be covered. MHC, PacificSource, Regence, and WMI Mutual indicated that prior authorization would be required.

BCI provided documentation with studies outlining the use of IVIG in patients with PANDAS/PANS, which designated the use of IVIG as "may provide benefit." PacificSource provided documentation that PANDAS/PANS is listed under their "Covered Uses" of IVIG treatment.

The Department also provided a sample IVIG treatment referral form and asked carriers to explain how the referral would be covered. Regence and WMI Mutual responded to the form, and both stated that there was not enough information on the form to provide feedback. The other carriers did not address the form in their responses.

The Department asked additional questions specifically regarding each carrier's coverage of IVIG treatment, including policy language support for their response and if IVIG is covered in other states. Several, but not all, carriers provided policy language specific to IVIG treatment. The following table summarizes those responses.

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Table 2: Coverage of IVIG by Carrier

| Carrier | Contract Language Provided | IVIG Provided in Idaho | IVIG Provided in Other States |
|---------------|----------------------------|------------------------|-------------------------------|
| Aetna | Yes | No | Yes |
| BCI | Yes | No | No |
| Cigna | No | No | If Required |
| MHC | Yes | Yes | Yes |
| Moda | Yes | No | If Required |
| Molina | No | No | If Required |
| PacificSource | Yes | Yes | Yes |
| Regence | Yes | Yes | Yes |
| Select Health | No | No | If Required |
| St. Luke's | No | No | If Required |
| UHC | Yes | No | If Required |
| WMI Mutual | Yes | Yes | Yes |

PacificSource provided prior authorization requirements for PANDAS/PANS coverage.

Select Health provided a copy of the formulary and a blank prior authorization form, no policy documents were provided.

UHC provided their medical policy on plasmapheresis, which they indicated was proprietary.

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Prevalence of PANDAS/PANS in Carrier Data

As mentioned at the outset, there are currently no medical billing codes being used that are specific to PANDAS/PANS. The Department still requested that carriers provide the number of cases they were able to identify from their claims data over the last five years, from 2019 to 2023. The table below shows the data reported to the Department. While PANDAS is considered a subset of PANS, PANDAS cases are not included in the PANS case counts unless indicated. The findings reflect only the carriers' **insurance plans** and do not account for the coverage of **self-funded plans**.

Table 3: Identified Cases of PANDAS/PANS in Idaho from 2019 to 2023

| Carrier | PANDAS Idaho | PANS Idaho | Total 2023 Covered Idaho Lives |
|----------------|---------------------|-------------------|---------------------------------------|
| Aetna | 1 | 2 | 11,380 |
| BCI | 0 | 0 | 244,875 |
| Cigna | 1 | 1 | 5,986 |
| MHC | 0 | 0 | 11,092 |
| Moda | 1 | 0 | 5,134 |
| Molina | 0 | 0 | 1,267 |
| PacificSource | 0 | 0 | 36,262 |
| Regence | * | 2 | 116,676 |
| Select Health | 1 | 0 | 88,858 |
| St. Luke's | 0 | 0 | 4,496 |
| UHC | * | 0 | 12,238 |
| WMI Mutual | 0 | 0 | 34 |
| Total | 4 | 5 | 538,298 |

* Carrier indicated they cannot separate PANDAS and PANS; therefore, they provided a combined number.

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Insurance Claims Cost of Treatment Coverage

As part of the survey, the Department asked carriers to identify the financial impact of covering PANDAS/PANS. Of the twelve carriers surveyed, five responded with cost estimates. These costs ranged from \$0.01 to \$0.63 per member per month (PMPM). The findings reflect only the carriers' **insurance plans** and do not account for the coverage of **self-funded plans**.

Table 4: Claims Cost Estimates of PANDAS/PANS Treatment (PMPM unless otherwise noted)

| Carrier | Individual Market | Small Group | Large Group | Other Markets |
|---------------|-------------------|-----------------|-----------------|-----------------|
| Aetna | \$0.01 - \$0.12 | \$0.01 - \$0.12 | \$0.01 - \$0.12 | \$0.01 - \$0.12 |
| BCI | No Amount | No Amount | No Amount | No Amount |
| Cigna | NA | NA | \$0.01 - \$0.02 | NA |
| MHC | Unknown | Unknown | Unknown | Unknown |
| Moda | \$434.26 | \$428.06 | \$7.72 | NA |
| Molina | No Amount | NA | NA | NA |
| PacificSource | \$0.50 | \$0.63 | \$0.29 | \$0.13 |
| Regence | <\$0.10 | <\$0.10 | <\$0.10 | <\$0.10 |
| Select Health | No Amount | No Amount | No Amount | No Amount |
| St. Luke's | \$0.00 | \$0.00 | \$0.00 | \$0.00 |
| UHC | NA | \$0.20 | \$0.20 | NA |
| WMI Mutual | NA | Unknown | NA | NA |

BCI, Molina, and Select Health did not provide amounts, noting that they identified no members receiving treatment for PANDAS/PANS.

Cigna indicated that they used cost estimates from an actuarial consulting firm combined with their PANDAS/PANS exposure estimates in Idaho.

Moda did not provide a cost spread over all members, but rather a cost based on members receiving treatment for PANDAS/PANS, the cost of treatment, and the number of member months.

PacificSource provided a cost estimate based on covered cases in other states.

St. Luke's stated that since most medications for the treatment of PANDAS/PANS are tier 1, there would be no additional cost to members.

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Conclusions

HCR027 directed that the Department gather specific information related to PANDAS/PANS due to concerns that certain requested treatments may not be available or that there may be significant barriers to coverage. The Department presents the following findings, based on survey responses from carriers, for each item requested in HCR027. The findings reflect only the carriers' **insurance plans** and do not account for the coverage of **self-funded plans**.

Work with industry leaders in the insurance industry to determine how to make IVIG treatment available to all children who are insured.

Four of the twelve carriers stated they provide IVIG treatment for PANDAS/PANS. All four carriers require prior authorizations for coverage. Importantly, even without prior authorization requirements, a treatment must meet the carrier's medical policy criteria for medical necessity. If these criteria are not met, the claim could be denied.

Carriers that do not cover IVIG expressed concerns over the lack of robust clinical data to support its use for treating PANDAS/PANS. A lack of robust clinical data often leads to a treatment being deemed experimental or investigational. It is a lawful and common practice for health insurance policies to include language that excludes coverage of both experimental and investigational treatments.

Carriers who covered IVIG also communicated concerns related to the potential risks of the treatment compared to the clinical likelihood of efficacy. Side effects of IVIG treatment range from relatively mild (headache, vomiting, and arthralgia) to severe (allergic reaction, kidney failure, heart attack, stroke, and blood clots). These risks and lack of evidence supporting efficacy were cited as to why IVIG may require prior authorization and may not be approved for all cases. Carriers wanted emphasized that they recommend consumers to appeal IVIG coverage denials, as these appeals undergo a thorough review and may result in the initial denial being overturned.

*Determine the cost of including IVIG treatment in private **insurance plans**.*

The Department was asked to collect data to ascertain the financial impact on health insurance premiums to cover PANDAS/PANS. Carriers with experience in covering members with PANDAS/PANS reported a consensus that the cost would be \$0.63 PMPM or less.

Determine the cost to the Idaho General Fund to add this benefit to plans.

The Department only collected the cost impact to the General Fund of PANDAS/PANS coverage attributable to the state's employee health plan. There may be non-insurance impacts to the General Fund that are outside of the Department's scope, for example from Medicaid. The Department relied on the PMPM cost provided by Regence, the current insurer for the state's employee health plan, to estimate the current cost to the General Fund. With an estimated 62,000 covered employees and dependents, and a PMPM cost of \$0.10, the current cost impact to the General Fund is \$74,400 per year.

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Summary

The Department found that four of the major health carriers in Idaho cover IVIG treatment for PANDAS/PANS. The findings reflect only the carriers' **insurance plans** and do not account for the coverage of **self-funded plans**. All of those covering the treatment indicated that there would be prior authorization and medical necessity requirements that would need to be met before treatment would be covered. The carriers reported varying occurrence rates of PANDAS and PANS in Idaho. Similarly, the estimated cost to cover IVIG treatment in private **insurance plans** ranged from \$0.01 to \$0.63 PMPM, while the estimated cost to the Idaho General Fund to add this benefit would be approximately \$74,400 per year.

The Department found that IVIG treatment is covered differently between carriers. The reasons for this vary but include a lack of consistent diagnosis codes, a lack of large-scale studies to support IVIG treatment, and prior authorizations requesting specific medical criteria be met first. The difference in coverage for children with PANDAS/PANS can create uncertainty for those children and their families. While there are treatment protocols that have been recommended by organizations focused on PANDAS and PANS, there is still debate about the efficacy of these protocols for diagnoses and treatment, as well as the need to consider and weigh potential risks related to those treatments. The lack of consensus on treatment can create issues for carriers in developing medical policies that meet the needs of consumers.

The Department reviewed its records and as of December 7, 2024, had received no complaints related to claims denials of PANDAS or PANS treatment. The Department encourages consumers with PANDAS/PANS insurance coverage difficulties to reach out to the Department's Consumer Affairs section. Through the Consumer Affairs section, consumers can receive guidance, file complaints, and request external reviews of claims decisions. Before requesting an external review, consumers will need to utilize the appeals process with their insurance carrier. Consumer Affairs officers act as unbiased resources, helping consumers resolve disputes with insurance companies and agents. The Department's Consumer Affairs section can be reached by calling 208-334-4350.