

Key Findings

Analysis of California Assembly Bill 907 Coverage for PANDAS and PANS

Summary to the 2023–2024 California State Legislature, April 20, 2023



AT A GLANCE

The version of California Assembly Bill 907 analyzed by CHBRP would require health plans regulated by the Department of Managed Health Care (DMHC) and health policies regulated by the California Department of Insurance (CDI) to provide coverage for the prophylaxis, diagnosis, and treatment of Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS).

In 2024, 100% of the 22.8 million Californians enrolled in state-regulated health insurance would have insurance subject to AB 907.

Benefit Coverage: At baseline, 100% of enrollees with health insurance subject to AB 907 have coverage that includes diagnostic tests recommended by various guidelines related to PANDAS/PANS and would continue to have 100% coverage postmandate. At baseline, 100% of enrollees with health insurance subject to AB 907 would have coverage for antibiotics, oral prescription immunomodulatory medications, and behavioral therapies and medications for managing neuropsychiatric symptoms, consistent with recommendations for treatment of PANDAS/PANS under existing clinical guidelines, and 0% have coverage for intravenous immunomodulating therapies, including plasma exchange and intravenous immunoglobulin (IVIG) therapy; postmandate 100% would have coverage for the aforementioned treatments. AB 907 would not be likely to exceed essential health benefits (EHBs).

Medical Effectiveness: CHBRP found *insufficient evidence* that the treatments recommended by clinical guidelines were effective at reducing or eliminating prominent symptoms of pediatric patients with PANDAS/PANS, with the exception of antibiotics and IVIG; the evidence of the effectiveness of these two treatments for eliminating or reducing symptoms was *inconclusive*.

Cost and Health Impacts¹: In 2024, AB 907 would result in approximately an additional \$2.99 million (or 0.002%) in annual expenditures due to an estimated additional 90 enrollees utilizing IVIG, 0 additional enrollees utilizing plasma exchange, and an additional 22 enrollees utilizing other intravenous immunomodulating therapy (i.e., rituximab), as treatment for PANDAS/PANS.

The public health impact of AB 907 is unknown due to insufficient and inconclusive evidence regarding the effectiveness of treatments for PANDAS/PANS.

CONTEXT

PANDAS/PANS are terms used to describe a subset of children with symptoms that include a sudden onset of obsessive-compulsive disorder (OCD) and/or tic disorders co-occurring with a collection of neuropsychiatric symptoms usually following an infection.² Children may also become moody or irritable, or experience anxiety attacks, separation anxiety, rage, fatigue, phobias, insomnia, joint or muscle pain, or eating disorders.

PANDAS, currently classified as a subset of PANS, is hypothesized by some to be triggered by an autoimmune response to Group A Streptococcal bacteria (which cause strep throat or soft tissue infections). PANS is hypothesized to be triggered by causes other than Group A *Streptococcus* infection. Much remains unknown about PANDAS and PANS, and controversy remains regarding whether PANDAS differs enough from OCD/tic disorder and other neuropsychiatric disorders to warrant a different diagnostic category.

PANDAS/PANS has been primarily described in children between the ages of 3 and 12 years; however, the exact prevalence and age distribution of PANDAS/PANS is unknown. People over the age of 17 may also present with symptoms similar to those of PANDAS and PANS or have an initial diagnosis of either syndrome at a pediatric age that continues into adulthood. Because OCD is a required symptom for the diagnosis of

¹ Similar cost and health impacts could be expected for the following year, though possible changes in medical science

and other aspects of health make stability of impacts less certain as time goes by.

² Refer to CHBRP's full report for citations and references.

PANDAS and PANS, it is thought their prevalence can be estimated as a subset of the prevalence of pediatric OCD. Epidemiological research estimates that 0.5% to 5% of children in the United States are affected by OCD. One study estimates that 5% of children with OCD may meet the criteria for PANS/PANDAS.

CHBRP identified 3 clinical practice guidelines that meet AB 907’s criteria for diagnosing and treating patients with PANDAS/PANS, on which it based this analysis.

There is no specific diagnostic test to confirm a diagnosis for PANDAS or PANS, and other conditions may present with similar symptoms, making it a difficult to reliably diagnose and study PANDAS/PANS. Clinicians use a differential diagnostic process that includes collecting a patient’s medical history, conducting a physical exam, and may include diagnostic tests to rule out other conditions with similar symptoms. Additional tests may include testing for Group A *Streptococcus*, or *Mycoplasma pneumoniae* – infections that may be associated with PANDAS or PANS.

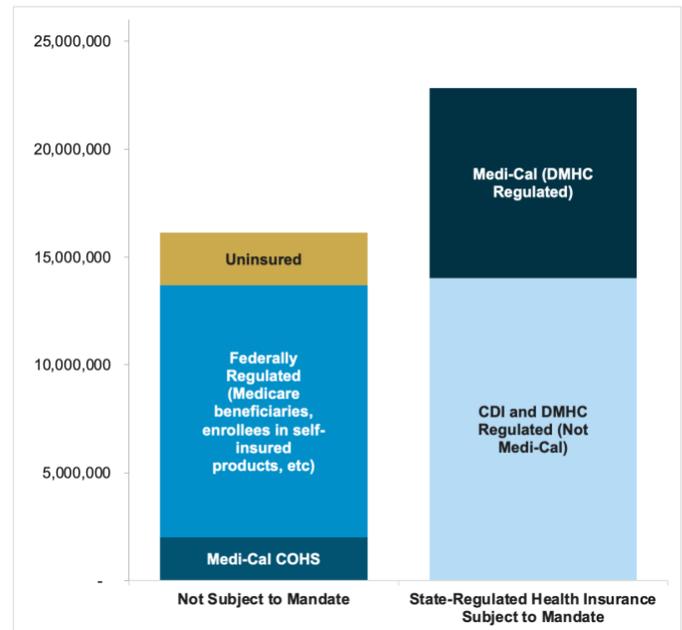
Per existing clinical guidelines, treatment options for PANDAS/PANS depend on the physical and/or neuropsychiatric symptoms experienced by the patient. The guidelines include treatments with: antibiotics; nonsteroidal anti-inflammatory drugs (NSAIDs); corticosteroids; cognitive behavioral therapy (CBT); psychotropics; intravenous immunoglobulin (IVIG); other immune-modulators (rituximab, mycophenolate mofetil); therapeutic plasma exchange; and vitamin D.

BILL SUMMARY

AB 907, as amended on March 16, 2023, would require Department of Managed Health Care (DMHC)-regulated health plans and California Department of Insurance (CDI)-regulated health policies to provide coverage for the prophylaxis, diagnosis, and treatment of PANDAS and PANS. Covered treatments must include antibiotics, medications and behavioral therapies to manage neuropsychiatric symptoms, immunomodulating medicines, plasma exchange, and intravenous immunoglobulin therapy. The bill also requires coverage to abide by several terms and conditions, including: 1) a prohibition on limitations to coverage for immunomodulating therapies for PANDAS/PANS in a manner inconsistent with clinical practice guidelines and evidence-based standards for diagnosis and treatment of PANDAS/PANS; and 2) a prohibition on a mandate for step therapy to treat only neuropsychiatric symptoms prior to authorization of coverage for immunomodulating therapies.

Figure A notes how many Californians have health insurance that would be subject to AB 907.

Figure A. Health Insurance in CA and AB 907



Source: California Health Benefits Review Program, 2023.

Key: CDI = California Department of Insurance; COHS = County Organized Health System; DMHC = Department of Managed Health Care.

IMPACTS

Medical Effectiveness

CHBRP analyzed the strength of evidence for the effectiveness of antibiotics, psychotropic medications, cognitive behavioral therapy, plasma exchange, IVIG and other immunomodulating medications addressed by AB 907, specifically, for children affected by PANDAS/PANS.

Overall, the evidence is insufficient or inconclusive that any of these treatments are effective at reducing prominent symptoms, such as OCD symptoms, tics, or eating restrictions, for pediatric patients with PANDAS/PANS.

The body of research on PANDAS and PANS is small (number of studies and sample sizes of available studies) compared with many other diseases and conditions. Additional studies involving controlled clinical trials, larger sample sizes, and clear eligibility criteria are necessary to determine which treatments are effective for children with PANDAS/PANS.

More specifically, CHBRP found *insufficient evidence*³ on the effectiveness of CBT, psychotropics, NSAIDs, corticosteroids, plasma exchange, rituximab, mycophenolate mofetil, and vitamin D in reducing or eliminating the prominent symptoms associated with PANDAS/PANS.

CHBRP found *inconclusive evidence*⁴ on the effectiveness of antibiotics and IVIG in reducing or eliminating the prominent symptoms associated with PANDAS/PANS.

Each of the medications reviewed for this analysis is associated with a variety of side effects and harms. See Table 3 of the full report for more details.

Benefit Coverage, Utilization, and Cost

Benefit Coverage

At baseline, 100% of enrollees with health insurance that would be subject to AB 907 have coverage that includes diagnostic tests associated with PANDAS/PANS recommended by various guidelines for diagnosing PANDAS/PANS.

At baseline, 100% of enrollees with health insurance that would be subject to AB 907 have coverage that includes some, but not all, treatments for PANDAS/PANS. Coverage by type of treatment varies substantially. CHBRP found that 100% of enrollees have health insurance that includes antibiotics commonly used for PANDAS/PANS and some oral prescription immunomodulatory medications including steroids and nonsteroidal anti-inflammatory medications (NSAIDs). Similarly, 100% of enrollees have health insurance that includes coverage for psychotropics used for treatment of neuropsychiatric symptoms of PANDAS/PANS, including selective serotonin receptor inhibitors (SSRIs), benzodiazepines, and antipsychotics. One hundred percent of enrollees also have health insurance that includes coverage of behavioral health therapies used for treatment of neuropsychiatric symptoms of PANDAS/PANS, including cognitive behavioral therapy (CBT). CHBRP finds that 0% of enrollees have coverage for intravenous immunomodulating therapies, including plasma exchange, B-cell modulators (rituximab), and intravenous immunoglobulin (IVIG) therapy.

Postmandate, 100% of enrollees with health insurance subject to AB 907 would have coverage for all diagnostic tests and treatments included under the bill.

Utilization

CHBRP estimates that at baseline, 15,410 enrollees use diagnostic tests for PANDAS/PANS. These include various blood tests, throat cultures, and nose swabs. CHBRP estimates that for every 23 children tested for PANDAS/PANS using these diagnostic tests, 1 child is diagnosed with PANDAS/PANS and 22 children are not given this diagnosis. Given that 100% of enrollees already have baseline coverage, CHBRP estimates no changes in utilization for these diagnostic tests.

At baseline, CHBRP estimates that 670 enrollees have a PANDAS/PANS diagnosis. Among these enrollees, average annual utilization of oral prescription medications used for the treatment and management of neuropsychiatric symptoms (including medications such as antibiotics, steroids, NSAIDs, and psychotropics) is 17.8 prescriptions, each with a 30-day supply. At baseline, annual utilization of CBT is 20 visits per year. Given that 100% of enrollees already have baseline coverage for these medications and behavioral health therapies such as CBT, CHBRP estimated no changes in utilization of these specific medications and CBT services postmandate.

CHBRP estimates that IVIG, rituximab, and plasma exchange have extremely limited use at baseline. CHBRP estimates that average annual utilization of IVIG among all enrollees with PANDAS/PANS would increase to 0.7 infusion therapy sessions per year. This results in an estimated 90 enrollees with moderate or severe PANDAS/PANS utilizing IVIG at least once per year, with greater expected utilization among those with severe PANDAS/PANS. CHBRP estimates that average annual utilization of rituximab would increase to 0.1 infusion therapy sessions. This results in an estimated 22 enrollees with severe PANDAS/PANS utilizing an estimated average of 3 rituximab infusions per year. CHBRP estimated no change in the use of plasma exchange services given their low availability and the lack of evidence of their effectiveness in PANDAS/PANS.

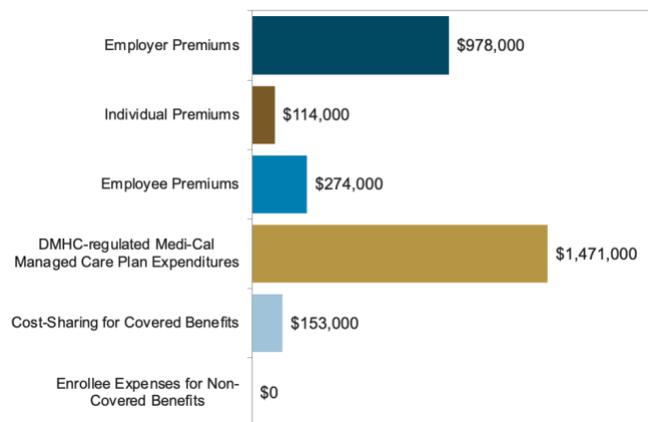
³ *Insufficient evidence* indicates that there is not enough evidence available to know whether or not a treatment is effective, either because there are too few studies of the treatment or because the available studies are not of high quality. It does not indicate that a treatment is not effective.

⁴ *Inconclusive evidence* indicates that although some studies included in the medical effectiveness review find that a treatment is effective, a similar number of studies of equal quality suggest the treatment is not effective.

Expenditures

AB 907 would increase total net annual expenditures by total net annual \$2,990,000 or total net annual 0.0020% for enrollees with DMHC-regulated plans (including DMHC-regulated Medi-Cal) and CDI-regulated policies.

Figure B. Expenditure Impacts of AB 907



Source: California Health Benefits Review Program, 2023.

Medi-Cal

For this analysis, CHBRP has included potential impacts on Medi-Cal beneficiaries. In addition to the expected increase of \$1.47 million in premiums CHBRP is estimating for the 8.8 million Medi-Cal beneficiaries enrolled in DMHC-regulated plans (a figure that represents a 0.005% increase in premiums), it seems reasonable to assume that a population proportional increase of \$370,000 would occur for the 2.0 million beneficiaries enrolled in county organized health systems (COHS) managed care.

CalPERS

For enrollees associated with CalPERS in DMHC-regulated plans, premiums would increase by 0.001% (\$0.01 per member per month, or \$83,000 total increase in expenditures).

Covered California – Individually Purchased

Premiums for enrollees in individual plans purchased through Covered California would increase by a total of \$69,000 in annual expenditures.

Number of Uninsured in California

Because the change in average premiums does not exceed 1% for any market segment, CHBRP would expect no measurable change in the number of uninsured persons due to the enactment of AB 907.

Public Health

In the first year postmandate, the public health impact of AB 907 is unknown due to insufficient and inconclusive evidence regarding the effectiveness of treatments for PANDAS/PANS. Please note that the absence of evidence is not “evidence of no effect.” It is possible that an impact – desirable or undesirable – could result, but current evidence is insufficient to inform an estimate.

Long-Term Impacts

Utilization of diagnostic tests and treatments for PANDAS/PANS is expected to be similar in the long term as utilization in the first 12 months postmandate. However, should evidence about the effectiveness of new diagnostic tests or treatments such as IVIG or rituximab become more conclusive, for example, via more evidence from larger randomized controlled clinical trials, more physicians may prescribe these treatments.

Cost impacts are expected to also be similar to those projected in the first 12 months postmandate.

Due to the dearth of research about PANDAS/PANS, CHBRP finds an unknown public health impact of AB 907 over the long term.

Essential Health Benefits and the Affordable Care Act

AB 907 would not require coverage for a new state benefit mandate that appears to exceed the definition of EHBs in California.