



Via Email

Deputy Administrator and Director Peter Nelson
Center for Consumer Information and Insurance Oversight
Centers for Medicare and Medicaid Services
Department of Health and Human Services
Baltimore, Maryland 21244

February 27, 2025

Re: Coverage of Pediatric acute-onset neuropsychiatric syndrome (PANS) & Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS)

Dear Director Nelson,

In 2024, the General Assembly legislature passed House Bill (HB) 24-1382, which requires carriers to cover pediatric acute-onset neuropsychiatric syndrome. The required coverage would include the prophylaxis, diagnosis, and treatment of Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS).

The legislation requires the Division of Insurance ("Division") to determine whether this benefit would be subject to state defrayal and submit its determination to the Department of Health & Human Services ("HHS"). For the reasons set forth below, the Division has determined that the requirement in HB24-1382 is not a new mandate requiring state defrayal under the Affordable Care Act. Further, as required by HB24-1382, the Division requests that HHS confirm the Division's determination within sixty (60) days after receiving this submission.

HB24-1382 requires the coverage for PANS/PANDAS to "adhere to the treatment recommendations developed by a consortium of medical professionals"¹ and may include: (i) antibiotics; (ii) medication and psychological and behavioral therapies to manage neuropsychiatric symptoms; (iii) immunomodulating medicines; (iv) plasma exchange; and (v) intravenous immunoglobulin therapy.

In the Notice of Benefit and Payment Parameters for 2025, HHS finalized an amendment to 45 C.F.R. § 155.170(a)(2), which states that "a benefit covered in the State's EHB-benchmark plan is considered an EHB." Further, the released guidance states that "benefits covered in a State's

¹ HB24-1382, Insurance Coverage Pediatric Neuropsychiatric Syndrome, available at: <https://leg.colorado.gov/bills/hb24-1382>.

EHB benchmark plan will not be considered in addition to EHB, even if they had been required by State action taking place after December 31, 2011.”² Additionally, HHS stated “under this policy, there would be no obligation for the State to defray the cost of a State mandate enacted after December 31, 2011, that requires coverage of a benefit if that benefit is included in the State’s EHB-benchmark plan.”³

In December 2023, the Division provided a coverage survey of individual, small group, and large group carriers in Colorado with plans regulated by the Division to determine the current coverage of PANS/PANDAS treatment. Carriers identified prescription drug treatments and behavioral health therapy for treatment of PANS/PANDAS were already covered.⁴ The carriers also reported that in some instances, treatment of severe cases, which might require Intravenous Immunoglobulin (IVIG) and plasma exchange, were outside of the scope of coverage.

PANS/PANDAS is a rare disease that usually occurs in children ages 3-12 years. A recent article published by the National Library of Medicine estimates that 1 in 11,765 children are diagnosed with the disease.⁵ Acute episodes of the disease can be treated effectively with antibiotics.⁶ A patient with neuropsychiatric symptoms may require additional medications and behavioral therapies. Only in the most severe cases is plasma exchange or IVIG required to treat the disease.⁷ Additionally, a 2016 study found “prompt diagnosis and expeditious treatment...can alter the course of the disease in the long term.”⁸ Early treatment not only decreased the likelihood of recurrence of the disease, but also reduced the number of residual symptoms.⁹ Since many cases are treated with antibiotics and given the small number of children infected with the disease each year, the number of patients requiring advanced treatment such as plasma exchange or IVIG is very low. Additionally, the effectiveness of treatment and importance of early detection for long term improved health and reduced need for additional health care expenses also demonstrate the need for coverage of this treatment. As a result, because the benefits are largely already covered and the legislature passed a requirement for coverage, there is no obligation for the state to defray the costs.

² Patient Protection and Affordable Care Act, HHS Notice of Benefit and Payment Parameters for 2025; Updating Section 1332 Waiver Public Notice Procedures; Medicaid, Consumer Operated and Oriented Plan (CO-OP) Program’ and Basic Health Program, 89 Fed. Reg. 26218-01, 26225 (April 15, 2024).

³ *Id.*

⁴ PANS/PANDAS Coverage Analysis, Prepared for the Colorado Division of Insurance, March 13, 2024, Milliman Report, available at:

<https://drive.google.com/file/d/1Ke7z2aFB0LXKHjrwBk4EJPhJvyl0oaZU/view>.

⁵ Estimate of the Incidence of PANDAS and PANS in 3 primary care populations, September 21, 2023, available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10551157/>.

⁶ National Institute of Mental Health, PANDAS - Questions and Answers, available at: <https://www.nimh.nih.gov/health/publications/pandas>.

⁷ *Id.*

⁸ Illinois PANDAS/PANS Advisory Council, 2019 Report, available at:

<https://dph.illinois.gov/content/dam/soi/en/web/idph/files/publications/pandas-pans-advisory-council-2019-report.pdf>.

⁹ *Id.*

For these reasons, HB24-1382 does not create a new state mandate requiring defrayal of additional premium costs.

Please let us know if you have any questions or would like to discuss this matter further with the Division.

Sincerely,

A handwritten signature in black ink, appearing to be 'KH' followed by a stylized flourish.

Kate Harris
Chief Deputy Commissioner
Colorado Division of Insurance