LOUISIANA DEPARTMENT OF INSURANCE
JAMES J. DONELON
COMMISSIONER

January 31, 2023

The Honorable Kirk Talbot, Chairman
Senate Committee on Insurance
Baton Rouge, La. 70802
talbotk@legis.la.gov
Sent via email

The Honorable Mike Huval
House Committee on Insurance
Baton Rouge, La. 70802
huvalm@legis.la.gov
Sent via email

Louisiana State House of Representatives
C/O The Honorable Dustin Miller
Baton Rouge, La. 70802
millerd@legis.la.gov
Sent via email

RE: Report of Study Findings as Requested by House Concurrent Resolution 89 of the 2022 Regular Legislative Session

Dear Representative Miller and Chairmen Talbot and Huval,

The Louisiana Legislature requested that the Louisiana Department of Insurance (LDI) study and report on the status of health insurance coverage for Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS); Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS); and associated diagnoses of autoimmune encephalitis (AE) in House Concurrent Resolution 89 of the 2022 Regular Legislative Session. LDI surveyed publicly available research digests, other departments of insurance, and carriers.

LDI found that Louisiana, like most states, does not currently require commercial health insurance policies to cover treatment of PANS or PANDAS. Since 2019, seven states – Arkansas, Delaware, Illinois, Indiana, Maryland, Minnesota, and New Hampshire – have enacted laws requiring commercial health insurance policies to cover treatment of PANS or PANDAs. Three of these states included language in their enacting legislation to address the federal requirement to defray the cost of this mandate for plans sold on-Exchange in the individual market.

I. Background

PANS refers to a syndrome with child-age onset comprising three clinical criteria:
1) Abrupt onset of obsessive compulsive disorder (OCD) or eating restrictions;
2) Concurrent presence of additional neuropsychiatric symptoms, with similarly severare and acute onset), from at least two of the following seven categories:
    a. Anxiety
    b. Emotional lability and/or depression
    c. Irritability, aggression, and/or severely oppositional behaviors
    d. Behavioral (developmental) regression

e. Deterioration in school performance (related to attention-deficit/hyperactivity disorder(ADHD)-like symptoms, memory deficits, cognitive changes
f. Sensory or motor abnormalities
g. Somatic signs and symptoms, including sleep disturbances, enuresis, or urinary frequency;

3) Symptoms are not better explained by a known neurologic or medical disorder, such as [Sydenham chorea].[1]

PANDAS refers to a subgroup of OCD patients whose symptom onset was associated with streptococcal infections. Children with PANS[2] often exhibit extreme compulsions and behavioral manifestations. PANS is a "diagnosis of exclusion," arrived upon only after evaluating and ruling out other known psychiatric disorders with overlapping symptoms.[3] Symptoms of PANS overlap with other psychiatric disorders, such as OCD, Tourette's syndrome, ADHD, depression, and bipolar disorder, but PANS differs from these disorders in that its presentation of symptoms is both acute and simultaneous. PANS symptoms may also include visual and auditory hallucinations, raising the potential for incorrect diagnosis of schizophrenia, bipolar disorder, and lupus cerebritis.[4]

Scholarly reports estimating the incidence and prevalence of PANS were not available, although prevalence estimates from advocacy groups range from 0.5%-2% of children. Recommended treatment involves removing the source of inflammation with antimicrobial treatment, treating disturbances of the immune system with immunomodulatory treatment, and treating the symptoms of PANS with psychoactive medications, psychotherapies, and supportive interventions.[5] One increasingly common treatment for moderate to severe cases of PANS is intravenous administration of immunoglobulins (IVIG).[6] IVIG has on-label FDA approval for the treatment of Kawasaki disease, idiopathic thrombocytopenic purpura (ITP), and other immune-mediated diseases of childhood. It is considered experimental for the treatment of PANS. IVIG is not effective for treatment of Tourette's or classic OCD.[7]

II. Coverage of PANS/PANDAS treatment

Commercial insurance is generally required to provide coverage for mental health services at parity with the coverage provided for behavioral health services. Such coverage is provided for established treatments of disease. Because recognition of PANS as a separate syndrome is relatively recent and clinical study of treatment are still ongoing, most treatments beyond those

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[1] Chang K, et al. Clinical evaluation of youth with pediatric acute-onset neuropsychiatric syndrome (PANS): recommendations from the 2013 PANS Consensus Conference. *J Child Adolescent Psychopharmacology* 2015. 25(1):3-13.

[2] Note: unless otherwise specified, we will refer to both PANDAS and PANS collectively as "PANS" for the remainder of this report.

[3] *Id.*

[4] *Id.*

[5] Swedo, SE., Frankovich, J, and Murphy, TK. Overview of Treatment of Pediatric Acute-Onset Neuropsychiatric Syndrome. Journal of Child and Adolescent Psychopharmacology. Volume: 27 Issue 7, September 2017, 27(7): 562-565.

[6] https://www.pandasppn.org/ivig/

[7] *Id.*

applied to classic OCD cases will be considered experimental/investigational and are often barred from coverage on that basis, or as a specific exception to coverage, or both. Unless coverage is expressly required under state law, coverage of experimental/investigational treatments by commercial insurance is at the discretion of the insurer. Coverage of such treatments is exceedingly rare outside of the Patient Protection and Affordable Care Act (ACA)'s requirement that insurers cover certain individuals' participation in clinical trials.

In the case of PANS, a number of states have enacted express coverage requirements, as summarized by the table below:

State and Statute	Summary	Notes
Arkansas Ark. Code Ann. §23-79-1905	Requires off-label coverage of IVIG to treat PANS	Sunsets 12/31/23 unless extended by the General Assembly
Delaware Del. Cod. Ann. tit. 18 §§3370B & 3571T	Health insurance must cover treatment of PANS, including IVIG	Automatic sunset if the federal government requires defrayal
Illinois 215 Ill. Comp. Stat. Ann. 5/356z.25	Health insurance must cover treatment of PANS, including IVIG	Automatic sunset if the federal government requires defrayal
Indiana Ind. Code. Ann. §§27-8-37 – 27-8-87-3	Health insurance must cover treatment of PANS, including IVIG	
Maryland Md. Code Ann. Ins. §15-855	Health insurance must cover medically necessary diagnosis, evaluation, and treatment of PANS, including IVIG	Amended by HB 820 (2022)
Minnesota Minn. Stat. Ann. §62A.3097	Health plans must cover treatment of PANS. Treatments must be recommended by the insured's licensed health care professional and include antibiotics, medication and behavioral therapies, plasma exchange, and IVIG.	Statute provides express requirement for the Minnesota Department of Insurance to make payments to insurers to reimburse them for the coverage required by the statute. Satisfies any potential federal defrayal requirement.
New Hampshire N.H. Rev. State. Ann. §417-E:1	Requires coverage of PANS at parity with physical illness.	

III. Defrayal

The ACA requires states to make payments to insurance carriers to defray the cost to qualified health plans (QHP, or "on-Exchange product") of any state benefit mandate enacted after December 31, 2011. For example, if the state were to pass a law requiring insurers to cover elective

cosmetic procedures, the ACA would require the carriers for all QHPs to estimate the cost that new benefit represents to each QHP they offer and bill the state for that cost. As long as the calculation is made in accordance with generally accepted actuarial principles and methodologies and was conducted by e member of the American Academy of Actuaries, the state is required to pay that amount to defray the cost of the new mandate to the QHP.[8] The intent of this requirement was to prevent states from taking advantage of the fact that QHP premiums are effectively "capped" at a fixed percentage of the insured's income, with the federal government paying for any remaining premium above the cap through advance premium tax credits (the ACA's "subsidy"). Under that structure, the state has essentially unbounded authority to add expensive benefit mandates, because the cost of those mandates would simply add to the excess premium above the cap and therefore be paid entirely by the federal government. The solution to this problem was the ACA's defrayal requirement – rather than allowing the states to "charge" the cost of benefit mandates to the federal government, the Act instead requires the states to cover those costs directly.

It is likely – although not certain – that the PANS statutes described in the table *would* trigger the ACA's defrayal provision. LDI is unaware of any previous case in which a law requiring existing coverage be expanded to include certain experimental/investigational treatments has been evaluated by HHS to determine whether defrayal is required. Still, the requirements of the PANS statutes is fairly similar to other past statutes for which HHS *did* require the state to make defrayal payments, so the expectation is that HHS would impose the same requirement here. This possibility, along with the slight uncertainty noted above, is the reason for the "automatic sunset" provisions noted in some state laws, as well as the payment provision in the Minnesota law. These two provisions – the automatic sunset and the payment provision – represent opposite mechanisms for dealing with the ACA's defrayal requirement. Minnesota addresses it by simply making defrayal payments from inception, avoiding any possibility that HHS will penalize the state for violating the ACA's defrayal provision. Delaware and Illinois, one the other hand, have chosen to simply sunset their PANS law immediately upon a determination by HHS that it would require defrayal.

IV. Conclusion

As discussed, above, the state can require coverage of common PANS diagnosis, evaluation, and treatment strategies through statutes mirroring those of other states. As with those states, it would need to decide how to approach the ACA's defrayal requirement, whether by including an automatic sunset, proactively paying the defrayal cost, or seeking direct HHS clarification of the defrayal status of a proposed bill.

The state should also consider the disparate impact of a state benefit mandate across Louisiana employers. State benefit mandates are not applicable to self-funded plans under federal ERISA preemption, which would exempt roughly three-fifths of privately insured lives from the statute. Any new premium impact of the bill would be borne solely by the remaining two-fifths of covered lives in the fully-insured market. This is a common consideration for any state insurance law, as small businesses, which are especially likely to operate in the fully-insured market, find

[8] 45 C.F.R. 155.170

that such costs deepen their competitive disadvantage relative to larger employers whose self-funded plans do not have to comply with state benefit mandates.

If you have questions or concerns, please contact me.

Sincerely,

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