

HOUSE BILL 292

INSURANCE: PEDIATRIC NEUROPSYCH DISORDERS

Bill Sponsor-Representative Julie Coulombe

WHAT IS PANDAS/PANS?

PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections) occurs when a streptococcal infection (strep throat) triggers a misdirected immune response and results in inflammation in a child's brain. As a result, the child quickly begins to exhibit life changing symptoms such as OCD, anxiety, tics, personality changes, decline in math and handwriting abilities, sensory sensitivities, restrictive eating, and more.

PANS ("Pediatric Acute-onset Neuropsychiatric Syndrome") is when an infectious trigger, environmental factors, and other possible triggers create a misdirected immune response which results in inflammation in a child's brain. In turn, the child quickly begins to exhibit life changing symptoms such as OCD, severe restrictive eating, anxiety, tics, personality changes, decline in math and handwriting abilities, sensory sensitivities, and more.

HOW MANY ALASKA CHILDREN HAVE PANDAS/PANS?

A conservative estimate is 1 in 200 children in the U.S. alone are affected by these disorders. However, the true lifetime prevalence of PANDAS/PANS is not known. The statistical relevance is equal to Pediatric Cancer, Pediatric Diabetes I and II., and ALS. In Alaska, that conservative estimate indicates that around 870 children and families are affected by these disorders.

WHY IS THERE IS A LACK OF AWARENESS ABOUT PANDAS/PANS?

Discovered in the early 90's, it was Dr. Sue Swedo at the National Institute of Mental Health who identified the correlation between strep infections and the abrupt onset of OCD similar to Sydenham chorea, the neurological form of rheumatic fever which also causes neuropsychiatric symptoms related to untreated strep infections. Peer reviewed diagnostic and treatment guidelines were first published in 2015 and 2017 in the Journal of Child & Adolescent Psychopharmacology. Historically, medical providers have not had an avenue to diagnose PANDAS due to a lack of a billing code. In October of 2020 a medical billing code was released for which PANDAS now falls under (ICD 10, 89.89).

HOW IS IT DIAGNOSED?

PANDAS/PANS is a clinical diagnosis based on medical history and physical examination, rather than laboratory testing. Laboratory findings can still be helpful in identifying infectious triggers and inflammatory markers but are not definitive to a diagnosis of P/P. Recent research from [Yale](#) and [Stanford](#) confirm the presence of a biomarker in these children. Further development of mainstream testing is needed.

CAN IT BE TREATED?

YES! Early treatment of PANDAS/PANS results in better outcomes and sometime complete recovery. Treatment guidelines are based on severity of symptoms defined as mild, moderate or severe/extreme. Treatments include antibiotics, anti-inflammatories, cognitive behavioral therapy, steroids, IVIG and/or plasmapheresis.

IS TREATMENT COVERED?

First line treatments such as antibiotics, anti-inflammatories, steroids and even tonsillectomies are typically covered by health insurance. IVIG is often denied because it is being used 'off label' with insurers claiming it is 'investigational' or 'experimental' despite decades of studies to the contrary and expert consortium consensus. It is important to note that 1 in 3 medications are used off label. When treatment is not covered by insurance, the cost for a family to pay privately is exorbitant with one treatment costing tens of thousands of dollars on the low end.

WHAT IS THE IMPACT ON PREMIUMS?

A [2015 Massachusetts benefit review](#) found that 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. Other states have concluded similar nominal premium impact.

WHAT IS IVIG?

IVIG is an intravenous pooled blood product comprised of immunoglobulins that is used in treating immune deficiencies, encephalitis, multisystem inflammatory syndrome in children caused by COVID and other medical conditions. IVIG is endorsed for treating PANDAS by a [consortium of physicians and researchers](#), as it is an autoimmune irregularity that causes encephalitic-like inflammation. This treatment has been shown to lessen symptom severity in children with tic disorders and OCD triggered by an infection. A 2020 [research study](#) published in the journal of Neurology found that "IVIG successfully ameliorated psychological symptoms and dysfunction, with sustained benefits for at [least 8 weeks, and up to 46 weeks](#), following the final infusion". A recent Phase 3 placebo controlled [IVIG trial sponsored by Octapharma](#) demonstrated a [statistically significant and clinically relevant improvement in their secondary benchmark](#), Clinical Global Impression (CGI). CGI assesses the overall impact of treatment on a child's life, including behavior, cognition and physical health.

DOES EVERY PANDAS/PANS CHILD REQUIRE IVIG?

NO! It's [estimated between 10% to 20% of children](#) with P/P require these interventions. Increased awareness will lead to more timely diagnosis and an expectation the percentages will decrease.

WHAT ARE THE ONGOING RISKS OF NOT TREATING PANDAS/PANS?

Undiagnosed and untreated children with PANDAS/PANS have demonstrated increased needs in the educational system, problems with the justice system, and frequent overuse of our emergency departments and crisis services. Long term those who go without proper diagnosis or treatment are at risk of suffering a lifetime of mental illness, brain injury or suicide. In addition, lifelong dependency on state services can be anticipated. Failure to address these preventable risks can impose a cost of life-long mental illness which is estimated to be \$1.85M per patient.

WHAT IS THE LEGISLATIVE PRECEDENT?

[15 other states](#) have already passed legislation requiring insurers to provide coverage for treatment, including IVIG. This includes Illinois, Delaware, Arkansas, Minnesota, New Hampshire, Massachusetts, Indiana, Maryland, Rhode Island, Oregon, Colorado, California, Virginia, Georgia and Tennessee. Several states have also been successful in advancing Medicaid coverage for some of the higher line treatments including Oregon and Washington. Oregon's Health Evidence Review Committee (HERC) spent 14 months examining the evidence and hearing from subject experts before ruling to provide coverage for IVIG.