

6/20/24 Detroit News (Detroit, Mich.) (No Page)  
2024 WLNR 9711051

Detroit News, The (Detroit, MI)  
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June 20, 2024

'A totally new kid': Parents push for coverage of controversial IV treatment for brain condition  
Legislation in the Michigan House would require insurers to cover the  
treatment for children who suffer from a brain condition believed to be cause...

Karen Bouffard

Legislation in the Michigan House would require insurers to cover the treatment for children who suffer from a brain condition believed to be caused by infections.

Nine-year-old Jack Stackpoole, who was diagnosed with autism at age 3, developed a host of new symptoms — severe tics, an aversion to eating and picking at himself until he bled — after getting sick with COVID in January 2021.

The Grosse Pointe Park child was diagnosed with a brain condition known as PANS, Pediatric Acute-onset Neuropsychiatric Syndrome. A monthly treatment with an antibody cocktail known as intravenous immunoglobulin (IVIG) brought immediate and life-altering relief, according to his mother, Michelle Hooks Stackpoole.

"We noticed immediately the tics and picking went away. He was making better eye contact," said Michelle Stackpoole of the treatment. "He seemed happier; he was trying new foods. Everything we had been struggling with improved."

But after 18 months, the family's health insurer, Blue Cross Blue Shield of Michigan, withdrew authorization. The reason was the lack of clinical evidence that the treatment works.

"IVIG is covered for certain conditions, but it is not covered for PANS or PANDAS, and the reason for that is ... it's not supported by clinical data at this time," said Dr. Kristyn Gregory, medical director at Blue Cross Blue Shield of Michigan.

Since the treatments were discontinued, "there have been multiple signs of regression," Stackpoole said. "He is struggling with eating and will only eat a few foods. ... His eye contact has decreased.

"In February, he developed a new tic."

Dozens of Michigan children like Jack who suffer from PANS and a similar condition, PANDAS — Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infection — have been denied the IV treatments that parents and doctors said give them relief from tics, obsessive-compulsive behaviors and other disturbing psychiatric and neurological symptoms.

Legislation recently introduced in the Michigan House would require health insurers to provide such children with coverage for IVIG — which one doctor said costs up to \$30,000 per infusion. The treatments involve infusions of extra antibodies to fight infection that people can't produce on their own.

The treatments have sometimes brought dramatic relief to kids diagnosed with PANS/PANDAS.

The conditions can occur following an infection caused by any kind of bacteria or virus, said Dr. Jules Constantinou, a pediatric neurologist with Henry Ford Health who is treating about 40 such patients with the infusions.

The treatments often require hospitalization for multiple days but sometimes can be delivered at home.

Constantinou said diagnoses of PANS or PANS/PANDAS are controversial; some pediatric neurologists don't recognize that they exist. Yet at least 11 states — including Illinois and Indiana — require that insurers cover treatment, including with IVIG.

The controversy arises in part from the lack of a definitive test to confirm the diagnosis, Constantinou said. It's largely a clinical diagnosis based on the child's symptoms and medical history.

The PANDAS Network, a national organization that advocates for children with the condition, estimates that it affects 1 in 200 children in the United States, though the network's website noted "the true lifetime prevalence of PANDAS/PANS is not known."

Tests might not reveal evidence of a previous viral or bacterial infection. And though doctors and parents attest to the effectiveness of IVIG treatments, little research has been done to provide evidence that it works.

Children with PANS or PANS/PANDAS can exhibit behaviors that mimic psychiatric conditions such as Tourette syndrome or obsessive-compulsive disorder, so insurers instead might support talk therapy or other psychiatric treatment.

After Jack's IVIG treatments were discontinued, the Blues required that the child have an MRI and a lumbar puncture as part of the reauthorization process. The parents, including dad Brian Stackpoole, initially balked at the procedures but relented out of desperation to get Jack's IVIG treatments approved.

The cost of IVIG runs from about \$20,000 to \$30,000 per infusion, depending on where it's administered, according to Constantinou. The most expensive would be an in-hospital infusion. The low end would be at home or at an infusion center, though he noted there are very few pediatric infusion centers.

"It doesn't really matter if it's \$20,000 or \$30,000 because it's totally out of reach for most families," Constantinou said.

#### **Why mandate is opposed**

The two-page House Bill 5773, introduced recently by Rep. Kelly Breen, D-Novi, along with 24 Democratic co-sponsors, would require health insurers to provide treatment for children diagnosed with PANS or PANS/PANDAS, including IVIG.

Breen said she learned about PANS and PANS/PANDAS from a friend whose child was diagnosed with the condition and experienced "10 years of hell" as a result.

Breen said she's been working with the Blues on the issue. But while Michigan's largest health insurer has provided coverage in some of the individual cases Breen has brought to its attention, the company opposes a mandate.

The Blues' Gregory said the insurer has a responsibility to ensure that the treatments it pays for are evidence-based and clinically supported. That's not the case yet with IVIG for this condition.

And she said there are a variety of treatments that are covered for PANS/PANDAS, such as psychotherapy.

Asked why some families are asked to get their children an MRI or a lumbar puncture, Gregory said: "It's a diagnosis of exclusion, so in order to make that diagnosis, we have to overturn every stone."

In a follow-up email from Blue Cross Blue Shield of Michigan, the company said it covers IVIG therapy for confirmed cases of autoimmune encephalitis, a condition in which the body's immune system attacks the brain and causes inflammation. It does not cover the therapy for PANS/PANDA "as it is not an evidence-based, peer-reviewed treatment for the conditions that is supported by clinical data," the insurer said.

"We empathize with families whose children are suffering with the conditions related to PANDAS/PANS. We regularly review these coverage requirements to ensure treatment is supported through clinical evidence, data and proven outcomes. The research is not there yet when it comes to IVIG treatment for PANDAS/PANS.

"For members with PANDAS/PANS, we cover other types of treatment, including psychotherapies (particularly cognitive behavioral therapy), supportive interventions, antimicrobial interventions, and immunomodulatory and/or anti-inflammatory therapies."

The Economic Alliance for Michigan — a nonprofit representing companies and labor unions — and the Michigan Chamber of Commerce usually oppose insurance mandates because, they argue, the requirements drive up health care costs.

The economic alliance has not had time to analyze Breen's bill. But the alliance has a blanket policy of opposing insurance mandates "because of the extremely high cost of health care," said Bret Jackson, president and CEO of the Novi-based alliance that aims to maintain Michigan's competitiveness for attracting new companies and talent.

While many such insurance mandates are well-intentioned, they drive up the cost of health care and leave companies and union members with little flexibility to choose what medical conditions and benefits they want covered under their health plans for a reasonable cost, Jackson said.

"If we mandate the coverage of all conditions for everybody," he said, "then we won't be able to afford health care for everybody."

The chamber has a similar stance even though it hasn't adopted an official position on Breen's bill.

"We typically oppose one-size-fits-all health insurance mandates," said Wendy Block, the chamber's senior vice president of business advocacy. "We believe coverage decisions should be made in the workplace between employers and employees and unions where there is one. Mandating coverage of certain conditions and procedures adds to the cost of health insurance and makes it more unaffordable for small businesses.

"Ultimately, health insurance mandates do not benefit Michiganders if they do not have health insurance because their employers cannot afford coverage."

#### **Another child's family finds progress**

Constantinou said all parents, regardless of their health insurer, struggle to obtain or hold on to coverage for PANS/PANDAS treatment with IVIG.

"It's many insurance companies," Constantinou said. "It's always a struggle obtaining insurance company approvals; sometimes it's approved, and then it's denied. Very often."

That's what happened in the case of Dylan Cromie, now 14, who came down with PANS/PANDAS after a bout of walking pneumonia in 2017, when he was 7 years old.

"He got better, but we saw all kinds of changes and behaviors we'd never seen before," said Vanessa Cromie, Dylan's mother, of Rochester Hills. "He all of a sudden had verbal tics, would just yell out words all of a sudden, make facial grimaces at inappropriate times. There was bedwetting, severe OCD (obsessive compulsive disorder) ... separation anxiety. He didn't want to go to school."

Dylan's parents, including his dad, Jim Cromie, spent three years taking him to various doctors and trying various treatments and therapies, none of which helped, his mother said. Then, in 2021, Dylan came down with another infection, which exacerbated his symptoms.

Dylan was overwhelmed with feelings of hopelessness.

"He had just turned 11," his mother recalled. "He said, 'I don't want to feel like this anymore.'"

"I started posting online, 'I need help with this,' and that's when people reached out about Dr. Constantinou."

By Nov. 1, 2021, Dylan had received his first IVIG treatment, which brought swift relief for his symptoms.

"By that fourth session, he was like a totally new kid," Vanessa Cromie said. "It was incredible. Everything was gone. We could start moving him off medication. He felt better, he felt more confident, school became easy.

"He wasn't struggling anymore, and we were so incredibly surprised and happy and elated that this was working."

Dylan continued monthly treatments for a while, and then the treatments were reduced to every two months. After about 16 months of treatment, Blue Cross Blue Shield of Michigan began denying coverage, though it was always approved on appeal, Vanessa Cromie said. However, treatment was denied completely from August 2023 until January of this year.

"What we noticed was all the symptoms started coming back," Vanessa Cromie said.

After initially hearing that coverage would be permanently denied, the Cromies were told Dylan could receive the treatments at home — but would first have to undergo a lumbar puncture.

"That was my Waterloo," Vanessa Cromie said. "This has been working for him for two years, and you're telling me now he needs an LP? Why would I torture my poor kid, who's been tortured for four years?"

After reaching out to a patient advocate at Blue Cross Blue Shield of Michigan, the insurer relented. Dylan was approved for six months of treatments starting in January and was just recently approved for another six months. Cromie said she thinks letters submitted to the insurer by two of Dylan's teachers, testifying to the improvements they'd observed following Dylan's IVIG treatments, might have supported Dylan's case.

"They said he's been a changed student since January. He can keep up in class," Cromie said of the teachers' letters. "I came with a load of data. So we got it (approval), but then I hear from other people (whose children) didn't get it."

Breen, the legislator, said she understands the need for second opinions.

"But when you have multiple physicians that recommend this particular treatment for a child, who is anybody else to say, 'No, that's not right?'" she said.

"You don't just jump to this treatment," Breen added, noting the medical odysseys families often go through before arriving at a PANS or PANS/PANDAS diagnosis and finding a treatment that works.

"It's incumbent upon us to get these children help," she said. "If treating physicians say this is the one thing that will help them, we need to do it."

This article originally appeared on The Detroit News: 'A totally new kid': Parents push for coverage of controversial IV treatment for brain condition

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Company: BLUE CROSS BLUE SHIELD OF MICHIGAN MUTUAL INSURANCE COMPANY; Michigan Chamber of Commerce; HENRY FORD HEALTH SYSTEM; Michigan House of Representatives

Industry: (Financial Services (1FI37); Health Insurance (1HE18); Healthcare (1HE06); Healthcare Practice Specialties (1HE49); Healthcare Services (1HE13); Insurance (1IN97); Pediatrics (1PE85); Psychiatric Disorders & Conditions (1PS79); Psychiatric Services (1PS61); Psychiatry (1PS63))

Region: (Americas (1AM92); Michigan (1MI45); North America (1NO39); U.S. Midwest Region (1MI19); USA (1US73))

Language: EN

Other Indexing: (PANDAS Network; Economic Alliance for Michigan; Blue Cross Blue Shield of Michigan; Michigan Chamber of Commerce; Henry Ford Health; Michigan House)

Keywords: (Coronavirus COVID-19,Blue Cross Blue Shield of Michigan,Wayne County, MI,Oakland County, MI,Article Plus,Tall Image Topper,Health Insurance,Drugs & Medications,Health Policy,Medical Literature & Resources,Medical Procedures,Vaccines & Immunizations,Neurological Conditions,Pediatrics,Health News,Mental Health,Covid-19)

Word Count: 1983

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