



Kansas State Employee Health Plan (SEHP)

HB 2110 Review

PANS/PANDAS Diagnosis and Treatment Coverage

House Committee on Insurance and Pension Report

November 2021 / Gina Sander and Patrick Klein

Agenda

PANS and PANDAS Defined

Estimated Cost – SEHP Population Calculation

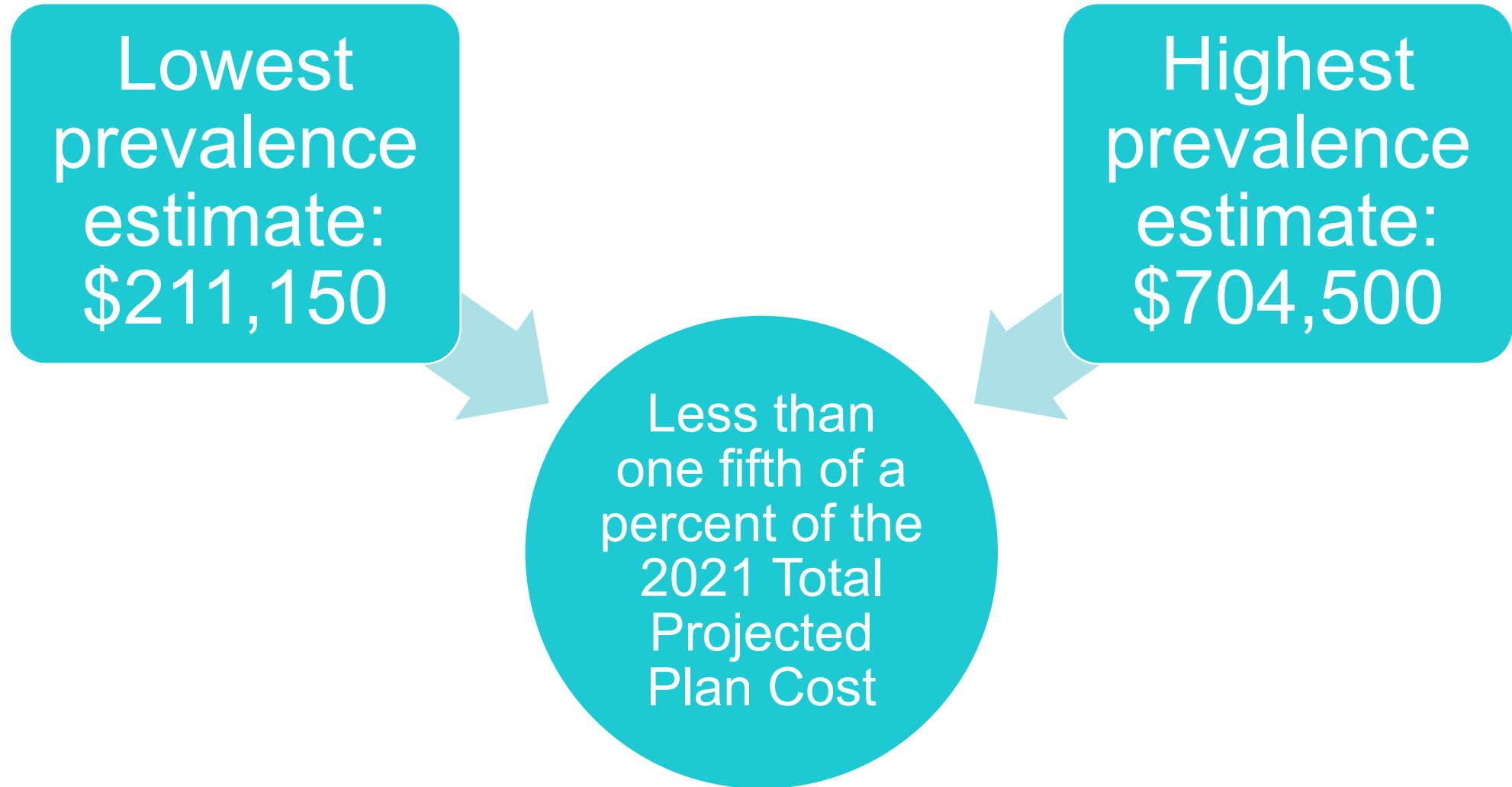
Social Impact

Financial Impact

PANS and PANDAS Defined

- **Pediatric Acute-onset Neuropsychiatric Syndrome (PANS)** is a clinical condition defined by the sudden encephalitic-like onset of obsessive-compulsive symptoms (OCD) and/or severe eating restrictions and at least two concurrent cognitive, behavioral, or neurological symptoms. PANS can be triggered by infections, metabolic disturbances, and other inflammatory reactions. It is easiest to understand PANS as an umbrella term for many triggers that create inflammation in the brain, leading to behavioral changes. PANS is a medical disorder with both physical and psychiatric presentations.^{13, 14}
- **Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS)** has five distinct criteria for diagnosis, including abrupt “overnight” OCD or dramatic, disabling tics; a relapsing-remitting, episodic symptom course; young age at onset (average of 6–7 years); presence of neurologic abnormalities; and temporal association between symptom onset and Group A strep (GAS) infection. The five criteria are usually accompanied by similar comorbid symptoms as found in PANS.¹³

Estimated Cost of Coverage – Minimal Impact



Estimated Cost – SEHP Population Calculation

Estimated Costs per PANS and PANDAS Treatment		
Treatment Type	Avg Costs per Treatment	Severity Mix (est)
Mild: High-dose antibiotics to clear/prevent Group A Strep (GAS)	\$5,000	50%
Moderate: Antibiotics & IVIg treatment	\$16,972	45%
Severe: Antibiotics & IVIg treatment & Therapy	\$33,944	5%
Weighted Avg of Treatment Costs (listed above)		\$11,835

Assumes one treatment per year

Estimated Cost of Providing PANS and PANDAS Coverage					
Prevalence Percentage*	Enrollment Ages 3 to 14**	Prevalence Count	Avg Cost of Treatment	Estimated Annual Treatment Costs	Percentage of Total 2021 Projected Plan Cost
0.50% (1 in 200 rate)	11,904	60 (11,904*0.50%)	\$11,835	\$704,500	0.19%
0.15%	11,904	18 (11,904*0.15%)	\$11,835	\$211,150	0.06%

*1 in 200 rate is an estimated “lifetime prevalence”; utilization in any one year can be lower

**Eligibility: as of July 2021 Cerner eligibility data for Kansas State Employee Health Plan (“SEHP”)

Social Impact

A. The extent to which the treatment or service is generally utilized by a significant portion of the population

- **SEHP Population:**

- Research assumption of 1 in 200 children is affected with PANS/PANDAS
- 11,904 children between 3 to 14 years are currently enrolled
- Est 60 children between 3 to 14 years in SEHP population would be affected
- Est increased to 87 if the age range is expanded to 17 years

- **National Level:**

- Approximately 74.1 million children in the U.S. are 17 years of age or younger in 2021 (U.S. Census Bureau)
- Based on 0.50% (1 in 200) prevalence rate, an estimated 370,689 children could potentially be affected by PANS/PANDAS
- Projected to increase 2.4% by 2031 and by an additional 1.7% by 2041

National Statistics

PANS/PANDAS Prevalence

- Age at Onset: 11% at 1 to 3 years; 69% at 4 to 9 years; 19% at 10 to 13 years; and 1% at 14+ years ⁵
- Primary Symptoms: 37% with OCD; 14% with TICS; and 49% with BOTH
- PANS/PANDAS population overview: ⁵
 - Young age at onset: 6.5, +/- 2 years for Tics; and 7.4, +/- 2 years for OCD
 - In general, the ratio for boys to girls is 2.6:1 ; below age 8 years, the ratio of boys to girls is 4.7:1
- Approximately 500,000 children are diagnosed with OCD in the U.S. ⁵
- Approximately 138,000 children are diagnosed with Tourette Syndrome in the U.S. ⁵
- 1.5 million+ children were diagnosed with serious anxiety/phobia/OCD/bipolar in a given year (1994-2011)

Additional Statistics

- 10% of all pediatric hospitalizations are attributed to mental health conditions.¹¹
- An estimated 20% of children and adolescents in the U.S. meet diagnostic criteria for a mental health disorder.¹¹
- The CDC reports that attention deficit hyperactivity disorder (ADHD), behavior problems, and depression were the most commonly diagnosed mental disorders in children.¹⁰



B. The extent to which such insurance coverage is already generally available

**Traditional
Insurance
&
Medicaid**

**Covers treatment
for various behavior
and tic disorders
that are tied to more
prevalent
diagnoses**

**Same
Treatment
for PANS
and
PANDAS**

**Considered to be
experimental and
often not covered
by insurance**

Legislation

Illinois was first state to pass legislation requiring coverage of treatment for PANS/PANDAS in 2017.

Delaware, Indiana, Maryland, Minnesota, and New Hampshire later followed with Massachusetts being the most recent, having a January 1, 2022 effective date.

Texas and Arkansas passed legislation forming an advisory team/council to provide guidance on protocols for research, diagnosis, and treatment.¹²

Proposed Legislation

The following states have proposed legislation to cover PANS/PANDAS treatment and are either pending or have not yet made it successfully through the process:

Iowa, Maine, New York, Oregon, Ohio, Rhode Island, and West Virginia.¹²

Billing Code Issues

Currently, there is no specific ICD-10 diagnosis code for PANS or PANDAS.

D89.89 code is a valid billable ICD-10 diagnosis code for *Other specified disorders involving the immune mechanism, not elsewhere classified*, **but based on information from the state of Illinois, causes issues with insurance codes not recognizing the disorders as PANDAS.**¹²

ICD-11 Codes

Effective January 2022, the ICD-11 diagnosis codes will include the PANDA-specific code 8E4A.0 *Paraneoplastic or autoimmune disorders of the central nervous system, brain or spinal cord*.

Also included will be ICD-11 diagnosis code 8A05.10 *Infectious or post-infectious tics*.

C. If coverage is not generally available, the extent to which the lack of coverage results in persons being unable to obtain necessary health care treatment

- **Lack of awareness, misunderstanding, and misdiagnosing PANS/PANDAS can have detrimental and long-term consequences on both the physical and mental condition.**
 - Early detection may prevent up to 25-30 percent of childhood mental illnesses¹³
- **As illness progresses, what may have been treated in 1-2 sessions of PANS/PANDA treatments may now require hospitalization and/or residential care. An unpublished survey by Moleculera Labs in 2018 revealed:**
 - On average, patients saw up to 12 medical providers and an approximate 3-year delay in receiving a diagnosis of PANS/PANDAS
 - At least 20% of patients with PANS/PANDAS experience delay 12+ months before receiving appropriate treatment even after being diagnosed
- **Aside from not receiving proper treatment when needed, the long-term effects may extend into adulthood negatively impacting performance in school, on the job, and in relationships.**

D. If the coverage is not generally available, the extent to which the lack of coverage results in unreasonable financial hardship on those persons needing treatment

- There are many articles describing the hardships faced by families trying to find the care needed for their child, and having to pay for coverage out of their own pockets.
 - Average costs range from \$5,000 to \$33,944, with one family reaching \$100,000 in out-of-pocket costs.
 - The majority of families faced having to establish ‘GoFundMe’ accounts, request loans from parents (grandparents) and other relatives, refinance their home, sell a vehicle or furniture, or quit their jobs as they could not afford a caretaker.^{15, 16, & 17}
- Per PANDAS advocate, Wendy Nawara:
 - *“PANDAS treatment attacks the things that need to be attacked as opposed to attacking a portion of the child's brain. Yes, it is extremely expensive. Like you said, up to \$15,000. It is dose-based on the weight of the child. So honestly, the longer we wait to treat these kids, they grow bigger and the more expensive that treatment becomes. And if a doctor has inadvertently missed it, or if an insurance company puts roadblocks up in front of a family for a year at a time — what could have been solved with perhaps a \$5,000 treatment becomes that \$15,000 treatment.”¹⁸*

E. The level of public demand for the treatment or service

- The House Committee on Health and Human Services Report dated January 2021 heard testimony for the demand of the treatment from the following:
 - Six parents and private citizens that provided testimony on symptoms
 - One psychiatrist
 - One rheumatologist
 - One immunologist
- PANS/PANDAS Annual October 9th Awareness Day Proclamations/Resolutions:⁵
 - Over half the states in the U.S. have in place
 - Approximately 10 states with requests filed
 - This is in addition to the nine states with PANS/PANDAS-related legislation and the seven with pending/attempted legislation, mentioned before

F. The level of public demand for individual or group insurance coverage of the treatment or service

Treatments associated with PANS/PANDAS are often considered to be experimental and are not covered by insurance. In recent years, as awareness of the condition has grown, several states have moved toward passing legislation related to PANS and PANDAS.

G. The level of interest of collective bargaining organizations in negotiating privately for inclusion of this coverage in group contracts

There were no findings specific to collective bargaining activity for PANS and PANDAS treatment.

H. The impact of indirect costs, which are costs other than premiums and administrative costs, on the question of the costs and benefits of coverage

- Indirect costs include:
 - Excessive travel
 - Unnecessary medical bills
 - Anxiety due to the many physician visits, diagnostic testing, medications, etc., as a result of misdiagnosis
- Many parents have had to borrow money from relatives, quit their jobs to care for their children, and homeschool their children
- Children suffer unnecessarily from misdiagnoses, diagnostic testing, ineffective medication, social stigma, etc.
- The associated stress and anxiety results manifest in additional physical and mental health issues.¹⁵

Additional commentary relative to PANS/PANDAS:

- “A disease that manifests as psychiatric symptoms but doesn’t respond to psychiatric medications” ¹⁵
- “Tests (ex. brain MRI) kept coming back normal. Neurologists referred him to psychiatrists. Psychiatrists referred him back to neurologists. Pediatricians recommended therapists. Therapists suggested psychologists.” ¹⁶



Financial Impact

A. The extent to which insurance coverage of the kind proposed would increase or decrease the cost of the treatment or service

Recommended treatment for PANS/PANDAS includes a combination of:

- Antibiotics
- IVIg
- Possible therapy

Appropriate combination of medication and number of treatments depends on the severity of the condition

Cost estimates:

- According to severity of condition range from \$5,000 to just under \$34,000 per treatment
- Weighted average per-treatment cost approximately \$12,000, as most cases fall into the mild to moderate level of severity

These treatments are:

- Currently available
- Frequently utilized to treat other autoimmune, immune-deficient, and chronic inflammation conditions
- Covered by insurance for those other types of conditions.

Extending insurance coverage for treatment of PANS/PANDAS:

- Is unlikely to impact the actual billed cost of the treatment
- However, it would have a significantly positive impact on the affordability of treatment and quality of life for the families impacted

B. The extent to which the proposed coverage might increase the use of the treatment or service

- Providing coverage for treatment of a condition that was previously not covered will certainly increase the use of the treatment.
- The incidence of PANS/PANDAS is fairly low, impacting approximately 1 in 200 children between the ages of 3 and 14 years. However, early diagnosis and treatment is ideal, and will greatly reduce the incidence of chronic and more costly conditions likely to have occurred with longer term misdiagnoses and mistreatment.
- PANDAS Diagnostic Flowchart and Treatment Guidelines
<https://www.pandasppn.org/flowchart/>

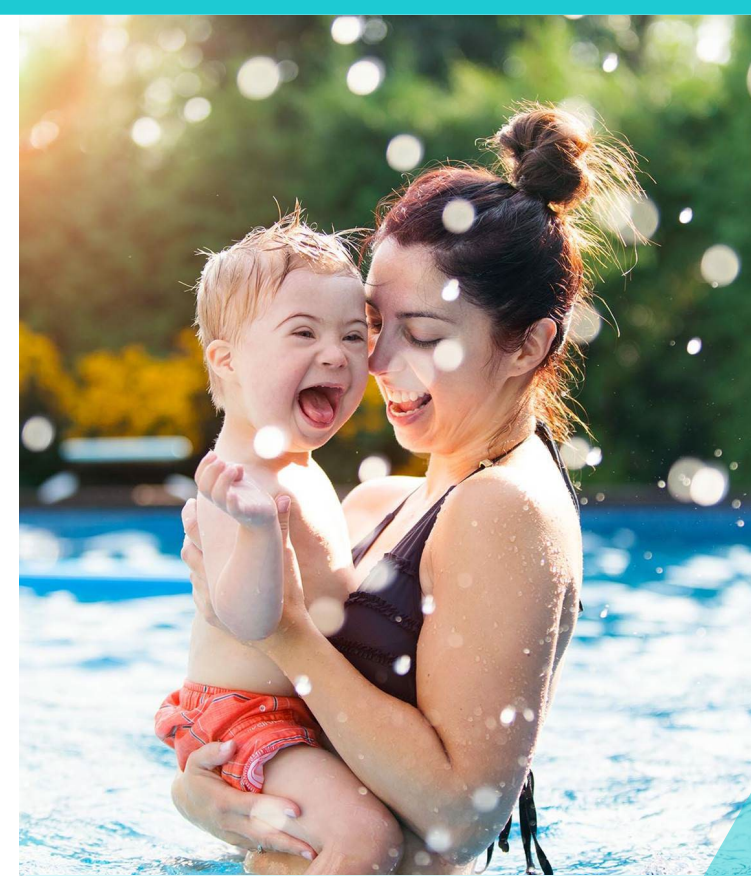


C. The extent to which the mandated treatment or service might serve as an alternative for more expensive treatment or service

- Early diagnosis and treatment with the longstanding protocol of antibiotics and IVIg, is preferable and much less costly in the long run.
- Appropriate and timely treatment will greatly reduce the incidence of chronic and more costly conditions likely to have occurred with longer term misdiagnoses and mistreatment.
- Segal estimates 60 children may be impacted by PANS/PANDAS. If all PANS/PANDAS cases fell into the Mild category, treatment costs would be approximately \$718,320 less costly than if all had fallen into the Moderate category, and \$1,736,640 less costly than if all had fallen into the Severe category.

Additional treatment statistics

- The National Institute of Mental Health (NIMH) estimates 25-30 percent of childhood mental illness may be preventable through appropriate treatment of PANS and PANDAS.
- “Several case studies into IVIg have confirmed IVIg’s efficacy one year following treatment. A 2018 longitudinal study had a follow-up time of up to 4.8 years, and 88% did not experience “clinically significant obsessive-compulsive symptoms” within the follow-up time.”⁹
- “For many patients, one course of IVIg is enough to reduce symptoms and even reverse PANDAS.”⁸
- The data reported suggest that early and aggressive treatment of infection may decrease both the likelihood of residual symptoms and the likelihood of recurrence, potentially preventing the high levels of functional impairment seen particularly in the postpubertal years. Having increased vigilance for new infections and exposure to group A Streptococcal infections (GAS) is likely also helpful to minimize the impact of recurrence of PANS symptoms.”¹⁰



D. The extent to which insurance coverage of the health care service or provider can be reasonably expected to increase or decrease the insurance premium and administrative expenses of policyholders; and the impact of this coverage on the total cost of health care

The impact to claims cost and administrative expenses is expected to be minimal. The estimated annual cost range for PANS/PANDAS treatment is \$211,150 to \$704,500, or 0.06% to 0.19% of total plan costs, based on the lowest and highest prevalence estimates.

Sources

Sources

1. Neuroimmune Foundation, Interview with Dr. Susan Swedo: <https://neuroimmune.org/susan-swedo-pandas-interview/>
2. Swedo et al (1998) PANDAS: Clinical Description of the First 50 Cases; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4340334/>
3. International Classification of Diseases 11th Revision: <https://icd.who.int/en>
4. National Institute of Mental Health: <https://www.nimh.nih.gov/health/publications/pandas>
5. PANDAS Network: <https://pandasnetwork.org/get-involved/statistics/> & <https://pandasnetwork.org/get-involved/awareness-day/>
6. Anxiety Canada: <https://www.anxietycanada.com/disorders/introduction-on-pandas-and-pans/>
7. Reuters: <https://www.reuters.com/article/us-illinois-insurance/illinois-law-requires-coverage-of-pediatric-autoimmune-disorders-idUSKBN1A32B7>
8. The Center for Fully Functional Health, IVIg for PANDAS: Costs, What to Expect, Side Effects & More: <https://fullyfunctional.com/2020/04/08/intravenous-immunoglobulin-treatment-for-pandas/>
9. National Library of Medicine, National Center for Biotechnology Information: <https://pubmed.ncbi.nlm.nih.gov/29119300/>
10. Illinois PANS/PANDAS Advisory Council, 2020 Report: <https://dph.illinois.gov/content/dam/soi/en/web/idph/files/publications/pandas-pans-advisory-council-2020-report.pdf>
11. Bardach NS, et al. Common and Costly Hospitalizations for Pediatric Mental Health Disorders. *Pediatrics*. 2014 Apr; 133(4): 602–609.
12. ASPIRE Legislative Resources page: <https://aspire.care/resources/legislative-resources/>
13. PANDAS Physicians Network: <https://www.pandasppn.org/what-are-pans-pandas/>
14. ASPIRE Definition page: <https://aspire.care/what-is-pans/definition/>
15. "My daughter was gone.' A Dalton girl lost years to a rare illness. Inside her mom's fight for answers", *The Berkshire Eagle*, By Francesca Paris, 4-Jul-2021 https://www.berkshireeagle.com/news/local/my-daughter-was-gone-a-dalton-girl-lost-years-to-a-rare-illness-inside-her/article_a73b37ea-d948-11eb-b494-b34db81d4a3b.html
16. "A Boy, His Brain, and a Decades-Long Medical Controversy", WIRED > BACKCHANNEL by SEEMA YASMIN, 03.25.2021 10:59 AM (<https://www.wired.com/story/a-boy-his-brain-and-a-decades-long-medical-controversy/>)
17. "We're fighting for our kids': Catonsville mother works to expand insurance coverage for pediatric neurological disease", CATONSVILLE TIMES, By CODY BOTELER, FEB 25, 2019 AT 5:00 AM <https://www.baltimoresun.com/maryland/baltimore-county/ph-ca-at-pandas-bill-0227-story.html>
18. "Families Of Children With PANDAS Disorder Still Struggling To Get Insurance Coverage", npr Illinois 91.9 UIS, By Daisy Contreras, Published April 18, 2019 at 4:16 PM CDT <https://www.nprillinois.org/health-harvest/2019-04-18/families-of-children-with-pandas-disorder-still-struggling-to-get-insurance-coverage>