

To the sponsors of bill HB24-1382 and members of congress,

I'm a resident of Colorado, with both a grandson and neighbor suffering from Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS).

My grandson was an honor student headed for an Ivy League college, until stricken with PANS/PANDAS. Unfortunately, because of its effects, he was mentally and physically unable to function well enough to continue high school.

Fortunately he is an Illinois resident; since Illinois mandates insurance that covers necessary treatments for PANS/PANDAS.

Because of that insurance and the treatment it afforded, my grandson is now physically, mentally and financially able to attend college, while still having regular treatments for the effects of PANS/PANDAS.

He has been selected as an intern at the National Institute of Health and will be studying medical research at a renowned medical school.

None of this would be possible without mandated insurance coverage.

The children of Colorado need the opportunity to treat and survive the effects of PANS/PANDAS, as children other states.

For our children's sake, please pass House Bill 24-1382.

Jennifer Frankovich, MD MS  
700 Welch Rd Suite 301  
Palo Alto, CA 94304

April 30, 2024

To: Colorado General Assembly  
Re: **HB24-1382** Insurance Coverage Pediatric Neuropsychiatric Syndrome

To Whom It May Concern:

I am writing to urge support of **Colorado Assembly Bill HB24-1382** advocating for health benefit and service coverage for the treatment of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) and pediatric acute-onset neuropsychiatric syndrome (PANS). I strongly believe that this bill proposal, which deals directly with the support and recognition of Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS), are vital steps forward in the provision of health care for the individuals affected by these conditions.

PANS/PANDAS is an abrupt-onset psychiatric disorder currently recognized, by our center and a number of other academic pediatric centers affiliated with Universities. Based on 4 imaging studies indicating pathology in the Basal Ganglia and 3 polysomnogram studies indicating movements during REM sleep—this is definitive evidence that this is an organic illness. Based on the acuity of onset, it is most probably post-infectious. Additionally, the basic science findings and clinical studies indicating a high rate of co-morbid arthritis and other autoimmune diseases all point towards this being an inflammatory disorder which involves the basal ganglia.

The first PANS Consortium meeting was held at Stanford in May 2013 where researchers and physicians from seven Academic Medical Centers met to outline the diagnostic workup of PANS. Since this meeting, expert opinion on treatment has been published, which outlines a three pronged treatment approach: clearance of current infection (if present), anti-inflammatories, and standard of care for the psychiatric symptoms (CBT, ERP, Tic reversal therapy, and psychotropics if needed).

Carrying out trials on a rare, abrupt onset disease affecting children is orders of magnitude more challenging than for common illnesses like atherosclerosis or cancer. There is little interest from government agencies to fund costly trials for these complex disorders. In the field of pediatric rheumatology, we treat a large number of autoimmune and autoinflammatory illnesses based on only indirect evidence of underlying mechanisms and past clinical experience. Most of these diseases are managed with immunomodulation --- and as a result, the morbidity and mortality of pediatric rheumatologic diseases have dramatically improved over the decades. The hospitalization rates for conditions like pediatric vasculitis, lupus, and systemic arthritis has plummeted. Like PANS/PANDAS, rheumatologic diseases are difficult to study in trials due to insufficient numbers, high cost of trials, and vast heterogeneity of disease. Pediatric rheumatologic diseases are now being treated according to Consensus Guidelines, and the different protocols are subsequently compared.

Despite the challenges, we have a large multi-site treatment study in progress and several additional trials planned for the future. However, these trials will take many years to enroll and then publish. In the meantime, children will incur irreversible brain injury, loss of school days, and miss opportunities for normal childhood

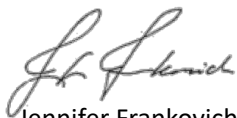
development. So, while we are awaiting more data, these children should be allowed to be treated with IVIG and other standard of care approaches used for other post-infectious inflammatory conditions (especially if guided by an academic center), based on the multiple smaller studies already published in peer-reviewed scientific literature.

**Permanent debilitating neuropsychiatric sequelae occur when PANS/PANDAs go untreated.** At Stanford, we have studied 400 patients with PANS, and it is clear that in many cases, untreated flares result in a worsened baseline and many patients become disabled by permanent neuropsychiatric symptoms. **Your state of Colorado could significantly reduce the burden of these chronic psychiatric sequelae by increasing coverage for both medical and psychiatric therapies including but not limited to IVIG.**

I fully support **HB24-1382** that seeks to mandate coverage to large group policies and contracts issued or renewed in this state on or after January 1, 2025 as well as individual and small group policies and contracts issued on or after January 1, 2026 so all individual and group health benefit plans will be required to provide health insurance coverage for pediatric acute-onset neuropsychiatric syndrome (PANS) and includes pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections (PANDAS) treatment which may include antibiotics, medication and psychological and behavioral therapies to manage neuropsychiatric symptoms, immunomodulating medicines, plasma exchange, and intravenous immunoglobulin therapy if certain conditions are met. This inclusion will not only alleviate some of the financial burdens the afflicted individuals and their families bear, but also create a remarkable precedent for the 38 other states still lacking protection, by officially recognizing PANDAS/PANS as medical conditions deserving of standardized healthcare coverage.

Thank you for your dedication to public health, and for considering my letter of support for this critical piece of legislation.

Sincerely,



Jennifer Frankovich, MD MS  
Clinical Professor of Pediatrics- Rheumatology  
Stanford University  
Director, Stanford Immune Behavioral Health Clinic and Research Program  
<https://med.stanford.edu/pans.html>

*\*this letter of support is of my own personal opinion and does not reflect support from Stanford Medicine or Stanford University*

Senate Health & Human Services

05/02/2024 01:30 PM

HB24-1382 Ins Coverage Pediatric Neuropsychiatric Syndrome

Typed Text of Testimony Submitted

Name, Position, Representing	Typed Text of Testimony
Alyssa Oland For The Colorado Psychological Association	<p>My name is Alyssa Oland and I am a licensed pediatric psychologist in Colorado and the president of the Colorado Psychological Association. Thank you for allowing me to testify today in support of HB 1382 on behalf of the Colorado Psychological Association. I have worked with pediatric clients who have been diagnosed with PANDAS after a strep infection. PANDAS can affect mental health in profound ways, such as causing increased anxiety, depression, and symptoms similar to obsessive compulsive disorder. This can be very detrimental to a child's social, academic, emotional, and behavioral functioning. This can also be very disruptive for family members and parents, as the mental health symptoms can be acute and severe, and sometimes involve safety concerns such as risk of harm to self or others. It is important for children to be able to access care for PANDAS, without a lack of insurance coverage creating obstacles to care or undue financial burden. Insurance coverage for PANDAS would enable affected children to access care, reducing missed days of work by parents, and improving the quality of life of affected children and their parents.</p>
Sarah Lemley For Northwest PANDAS/PANS Network	<p>Colorado General Assembly Capitol Office 200 E Colfax Denver, CO 8023-1716 Re: Support HB24-1382, Coverage for PANDAS and PANS Dear Esteemed Members of the Colorado General Assembly, My name is Sarah Signe Lemley and I am the Executive Director and Co-Founder of the Northwest PANDAS/PANS Network, a 501c3 nonprofit serving Oregon, Washington and Idaho. More importantly, I am the mother of a child who had PANDAS. PANDAS and PANS are post-infectious neuroinflammatory disorders affecting 1 in 200 children. An affected child generally has an abrupt onset of obsessive-compulsive disorder (OCD), restricted eating, tics or other abnormal movements, anxiety, personality changes, decline in math and handwriting abilities, sensory sensitivities, rage, suicidal ideation and more. HB24-1382 will ensure access to medical care that is required for children with PANDAS/PANS. The State of Oregon has APPROVED and now provides IVIG treatment coverage for</p>

	<p>PANDAS/PANS. This decision was made after a 14-month review process for the inclusion of coverage for Medicaid recipients. Shortly thereafter, Senate Bill 628 was passed which mandates private and commercial insurers provide the same coverage. This bill received unanimous and bi-partisan support in both the House and Senate floor votes.</p> <p>Most PANDAS/PANS families cannot afford to pay privately for the care and treatments that are so often denied by insurers. Instead, they are forced to watch their child be crippled by psychiatric distress, losing parts of their childhood they will never get back. No parent should face such a tragedy that is preventable when access to treatment is available.</p> <p>Those who require IVIG are the sickest, most debilitated children. They are being withheld medically necessary treatment. Their health is being put at risk the longer they go without medical care and this increases the risk of serious neurological and psychological harm, long-term disability and suicide. Their suffering is being allowed to continue unnecessarily. In order to ensure every child in Colorado has access to the medical care they require, passage of this bill is necessary.</p> <p>Sincerely,                  Sarah Lemley, MPA; HA                  Executive Director                  Northwest PANDAS/PANS Network (NWPPN)</p>
<p>Tambre Rasmussen                  For                  themself</p>	<p>Tambre Rasmussen                  1183 Hummingbird Cir.                  Longmont, CO 80501</p> <p>4/30/2024</p> <p>I write to share my family’s experience with the illness PANDAS and in support of HB24-1382, insurance coverage for IVIG treatments for PANS/PANDAS. At age 12 in 2014 my older child developed PANDAS. It was a sudden onset like turning on a light switch very scary neurological and psychiatric symptoms including vocal and motor tics, hallucinations, urinary incontinence, dilated pupils, suicidal thoughts, severe anxiety and OCD.</p> <p>With many exhausting sleepless nights of searching the internet, and then finding a doctor who could help us my child was diagnosed in the spring of 2016. Treatment included tonsillectomy to eradicate streptococcus A, counseling, psych meds, antibiotics, but the real game</p>

	<p>changer was high dose IVIG infusions. These were administered by a home health nurse in our house. The first time was a five day infusion followed by six months of two day infusions. The infusions were primarily covered by our insurance at the time which was Anthem Blue Cross. My child needed another round of infusions again at age 15 as she had a flareup of symptoms after another infectious exposure. This consisted of six months of two day IVIG infusions. It was covered by Medicaid. Without these infusions I am certain I would have lost my child due to suicide. This treatment should be covered by insurance for everyone. It is hard enough to endure this terrible illness. It can be incredibly difficult to obtain a diagnosis. Parents shouldn't also have to fight with insurance companies to get treatment.</p> <p>My child is now 20 and preparing to go to college in the fall. I am incredibly thankful that their life got a second chance thanks to IVIG.</p> <p>Thank you for your time, Tambre Rasmussen</p>
<p>Cierra Case For themselves</p>	<p>My name is Cierra Case. I am 17 years old. I have been a first hand witness to the effects of PANDAS my whole life. My brother struggled with PANDAS for over a decade. When we were little we loved playing and laughing together but he and I grew apart as he got older and as his symptoms got worse. For a long time, I went to bed every night hearing yelling and arguing. I feared he was going to hurt himself, me or our parents, and a few times he did. I had an unnerving feeling knowing that there was always the possibility of having to call 911 if he had a flare. It took a tremendous toll on his life and wellbeing as well as impacted everyone around him. Our family felt like it was being torn apart. This made it so hard for me to have a good connection with my brother and I feared we never would. However, after years of being held hostage by this disease, my mom discovered IVIG. My brother started getting the infusions. His old sweet self started to show again and I could see the light come back in his eyes. Our relationship started to mend and now we are closer than I ever imagined. He is my absolute best friend and I am so grateful that with IVIG we were able to bring him back. Please vote for this bill. Thank you very much.</p>
<p>Robin Cullen For themselves</p>	<p>I am a special education teacher that worked with a student with PANDAS for 2 years during his 7th and 8th grade years. He was often angry and would spend a 45 minute class period focusing on one assignment and not being able to make progress because of brain fog and the inability to focus. As my time working with him progressed his OCD increased and he was not able to walk through a doorway without completing a ritual. He would often be 10 minutes late because he would stop at each entrance way. In the middle of his 8th grade school year the parents began using IVIG. After these procedures he would come back to school and be more focused and happy during the school day. The biggest change that I saw was that his OCD was not apparent and he was able to make it to class on time. He was able to get work in and feel success at school again. Talking to parents there is also a huge</p>

	change at home with less anger and more stamina after having a long day at school.
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# moleculera labs

April 30, 2024

Health and Human Services Committee  
Colorado General Assembly  
200 E Colfax Avenue  
Denver, CO 80203

RE: Support for HB24-1382, Insurance Coverage for Pediatric Neuropsychiatric Syndrome

Dear Health and Human Services Committee Members:

I am a medical research scientist with over 35 years of experience in the biotechnology industry. I am currently the CEO of a precision medicine company that was founded to help children and adults suffering from devastating but medically treatable neuropsychiatric conditions such as PANDAS/PANS. I have witnessed, over the past 13 years since starting Moleculera Labs, the pain, agony, hopelessness, and despair of parents and children who suffer from PANDAS/PANS. Since then, we have tested over 15,000 patients from over 50 different countries and prescribed by over 2,500 doctors for clinical laboratory testing of antineuronal antibodies in their blood, which have been known to trigger these symptoms. I have also witnessed remarkable recoveries of these patients when they have received the proper diagnosis and treatment, sometimes after suffering for more than a decade. With the proper testing and treatment, we find these antineuronal antibodies recede to normal levels, and it is accompanied by remarkable improvement in patient symptoms and return to everyday life.

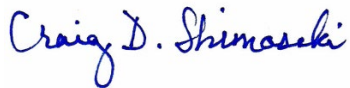
I strongly support HB24-1382. The impact of this condition is far-reaching. Not only do PANDAS/PANS impact these patients and families, but it also impacts the cost of healthcare, hospitalizations, and medications, and oftentimes, these patients spend time in and out of institutions. Support for this bill will reduce the overall burden of medical care for these patients, thus saving healthcare dollars in Colorado. It is estimated that 1 in 150 children suffer from these conditions, but of equal importance is that PANDAS/PANS is a medical model for other neuropsychiatric disorders in patients who are not responsive to typical psychotropic drugs.

On a daily basis, we hear from parents of children suffering from PANDAS/PANS and how they struggle to obtain the needed diagnosis and medical treatment that has proven to be effective in the recovery of these debilitating symptoms.

We wholeheartedly support HB24-1382 and medical insurance coverage for PANDAS and PANS. This would provide the medical support needed to bring hope and healing to these children and their families and reduce the overall burden of care and medical costs for these patients.

Thank you for your pioneering work in changing how medicine is practiced for the multitudes of suffering children and families with PANDAS/PANS in Colorado.

Most sincerely,



Craig Shimasaki, PhD, MBA  
President & CEO  
Moleculera Labs, Inc.



April 8, 2024

Members of the Health and Human Services Committee of the Colorado State Legislature:

Chair, Lindsey Daugherty [lindsey.daugherty.house@coleg.gov](mailto:lindsey.daugherty.house@coleg.gov)

Vice Chair, Mary Young [mary.young.house@coleg.gov](mailto:mary.young.house@coleg.gov)

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Rep. Ron Weinberg [ron.weinberg.house@coleg.gov](mailto:ron.weinberg.house@coleg.gov)

CC: Christine Case, Chair, Colorado PANS/PANDAS Coalition

RE: Support for HB24-1382, <https://leg.colorado.gov/bills/hb24-1382>

Dear colleagues,

On behalf of the families in Colorado whose children are battling Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) or Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS), we strongly recommend that the Colorado State Legislature pass bill HB24-1382. This bill has the potential to significantly improve the lives of children and families affected by PANS/PANDAS across Colorado by ensuring that insurance coverage is available for the comprehensive treatment for the children affected with PANS/PANDAS. For some children this will include treatment with Intravenous Immunoglobulin (IVIG).

For additional information concerning PANS and PANDAS as well as up to date articles, please download:

<https://undark.org/2024/04/03/pandas-infection-sparks-obsession/>;

<https://pubmed.ncbi.nlm.nih.gov/27663941/>; and

<https://pandasnetwork.org/?s=leckman>.

If you have any questions, please do not hesitate to contact us:

[james.leckman@yale.edu](mailto:james.leckman@yale.edu); [linda.mayes@yale.edu](mailto:linda.mayes@yale.edu)



Respectfully yours,

James F. Leckman, M.D., Ph.D.  
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Child, Adolescent, and Psychiatry,  
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Yale University

Linda Mayes, M.D.  
Arnold Gesell Professor  
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