

February 26, 2020

To: The Honorable Delores G. Kelley
Chair, Finance Committee

From: Stephen J. Weyler, University of Maryland Law School

Re: SB 475 Health Insurance – Pediatric Autoimmune Neuropsychiatric Disorder -
Coverage (**SUPPORT**)

Senate Bill 475

Senate Bill 475 requires the Maryland Medical Assistance Program, beginning on January 1, 2021, to provide services for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute Onset Neuropsychiatric Syndrome. The bill requires insurers, nonprofit health service plans, and health maintenance organizations that provide health insurance benefits to comprehensively cover all medically necessary diagnosis, evaluation and treatment of Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute Onset Neuropsychiatric Syndrome.

This bill is needed to allow children in Maryland the fighting chance to overcome these disorders, through necessary medical treatment. Although this is just the start for recognizing the disease and providing assistance to those affected by it, Senate Bill 475 is a tremendous step in the right direction.

I urge this Committee to report favorably on Senate Bill 475.

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) is a disease that affects nearly 1 in every 200 children.¹ PANDAS occurs when streptococcus bacteria triggers a misdirected immune response and results in inflammation on a child's brain.² According to the National Institute of Mental Health at the National Institutes of Health, PANDAS is caused by streptococcus bacteria that “survives in the human host by hiding from the immune system as long as possible.” Eventually, the strep bacteria are recognized as “foreign” to the body, and the child's immune system reacts to the molecules by producing

¹ PANDAS NETWORK, *What is PANDAS?*, <http://pandasnetwork.org/medical-information/> (last accessed Feb. 5, 2020).

² *Id.*

antibodies.³ In children with PANDAS, the antibodies “attack” the mimicked molecules in the child’s own tissues; the antibodies that react to both the molecules on strep bacteria and similar molecules found on other parts of the body are an example of “cross-reactive” antibodies. Research has shown that in children with PANDAS, the cross-reactive antibodies *target the brain*.⁴

The hallmark trait for PANDAS is sudden acute and debilitating onset of intense anxiety, and mood lability accompanied by Obsessive Compulsive like issues, and/or Tics in association with streptococcal-A infection that has occurred immediately prior to the symptoms.⁵ In some cases, there is a very abrupt onset or worsening of symptoms⁶—sometimes occurring overnight or within 2 to 3 days.⁷ Other symptoms associated with PANDAS are attention-deficit/hyperactivity disorder, separation anxiety, mood changes, trouble sleeping, bed-wetting, and a change in motor skills, such as handwriting and smiling (samples attached).⁸

All too often, children with PANDAS are misdiagnosed as having a psychiatric illness and are treated solely with psychotropic drugs to manage the symptoms.⁹ Unfortunately, for PANDAS patients, this does not address the root causes of the symptoms. Therefore, a necessary diagnosis is vital for proper treatment.

Early treatment is key to stopping the progression and long-term disability related to PANDAS. Early treatment options include the use of antibiotics like Penicillin, Augmentin and Cephalosporins, as well as prophylactic antibiotics.¹⁰ If caught and treated early enough, subsequent relapse or episodes are less likely and can even remit entirely.¹¹ In children with more severe forms of PANDAS, treatment options include strong forms of antibiotics, IV steroids for inflammation, a tonsillectomy, IVIG treatment and Rituxan.¹²

Unfortunately, treatment for PANDAS is extremely expensive, and many families must decide whether to pay out-of-pocket or forego treatment. Generally, insurance companies refuse to pay for such treatment options, as there is no mandate that insurance companies cover the cost of

³ National Institute of Mental Health, *PANDAS – Questions and Answers*, <https://www.nimh.nih.gov/health/publications/pandas/index.shtml> (last accessed Feb. 5, 2020).

⁴ *Id.*

⁵ PANDAS NETWORK, *PANDAS Criteria*, <http://pandasnetwork.org/medical-information/> (last accessed Feb. 5, 2020).

⁶ National Institute of Mental Health, *Signs and Symptoms: How is PANDAS diagnosed?*, <https://www.nimh.nih.gov/health/publications/pandas/index.shtml> (last accessed Feb. 5, 2020).

⁷ Stanford Children’s Health, Lucile Packard Children’s Hospital Stanford, *What are PANS and PANDAS?*, <https://www.stanfordchildrens.org/en/service/pans-pandas/what-are-pans-pandas> (last accessed Feb. 5, 2020).

⁸ National Institute of Mental Health, *“Are there any other symptoms associated with PANDAS episodes?,”* <https://www.nimh.nih.gov/health/publications/pandas/index.shtml> (last accessed Feb. 5, 2020).

⁹ Moleculeralabs, *PANS AND PANDAS OVERVIEW: Children with PANS and PANDAS are often Misdiagnosed*, <https://www.moleculeralabs.com/pans-and-pandas-overview/> (last accessed Feb. 5, 2020).

¹⁰ PANDAS NETWORK, *Why Early Treatment Matters*, <http://pandasnetwork.org/treatment/> (last accessed Feb. 5, 2020).

¹¹ *Id.*

¹² Susan Swedo (NIMH), et al., *Table and Text Excerpt from: “Treatment of Pediatric Acute-onset Neuropsychiatric Syndrome (PANS),”* <https://www.pandasppn.org/wp-content/uploads/2017/05/PANS-Clinical-Care-Standards-for-Use-of-IVIG.pdf> (last accessed Feb. 5, 2020).

treating the disease.¹³ Currently, five states, including New Hampshire, Illinois, Arkansas, Minnesota, and Delaware have passed legislation requiring insurance coverage of PANDAS.¹⁴ Maryland must be next. With legislation in place that requires insurance and the Maryland Medical Assistance Program to cover treatment related to PANDAS, children will have a fighting chance to return to their normal lives. Without the required treatment, all too often, there are tragic early endings to the stories and lives of children with PANDAS disease.¹⁵

Senate Bill 475 is vital to the success of many Maryland children who are suffering from this awful disease. This bill will allow many who would otherwise not have the means to pay for needed therapy and treatment the ability to return to a normal life, just as my younger sister, Barbara Weyler was able to do after fighting PANDAS for over 2 years. This is the future that should be given to all children suffering from PANDAS – the chance to be the best versions of themselves. Senate Bill 475 would provide that necessary help.

For the reasons set forth, I urge this Committee to report favorably Senate Bill 475.

cc: Members of the Judiciary Committee

¹³ Cody Boteler, *'We're fighting for our kids': Catonsville mother works to expand insurance coverage for pediatric neurological disease,* Baltimore Sun (Feb. 25, 2019), <https://www.baltimoresun.com/maryland/baltimore-county/ph-ca-at-pandas-bill-0227-story.html>.

¹⁴ PANDAS NETWORK, *Legislative News*, <http://pandasnetwork.org/legislation/> (last accessed Feb. 5, 2020).

¹⁵ Anna Medaris Miller, *PANDAS: When a Simple Strep Throat Leads to Frightening Behavior*, US NEWS Health (July 26, 2018)(quoting Dr. Elizabeth Latimer who has two patients die by suicide), <https://health.usnews.com/health-care/patient-advice/articles/2018-07-26/pandas-when-a-simple-strep-throat-leads-to-frightening-behavior> (last accessed Feb. 5, 2020).

PRE-PANDAS WRITING SAMPLE (10 Years Old)

Student Self-evaluation Sheet

2015-2016 School year

Date 9/8/15

Name Barbie Weyler

As a Reader,

my strengths are I can read clearly and loudly.

my weaknesses are Drawing a conclusion in my head.

As a Writer,

my strengths are I am neat, and creative.

my weaknesses are sometimes I do not include enough details, and I could use better descriptive words.

As a Listener,

my strengths are Listening and Following directions.

my weaknesses are Fully understanding what I hear.

PANDAS WRITING SAMPLE

farther and I would get
so scared I can
only talk to Mommy
about it because no
one else gets and they
might get mad. I just
don't get why I have to
go to school cause it

People
say
I
don't
feel
-not
just
I
feel
sad
out
sometimes

Makes me see

I can't stop thinking about it
When Daddy's in Colorado he's
too far to help me. They boys
might get mad at me. I want
Mommy to stay home with me.
When I am with Mommy and
Daddy we are together in our
house or in a hotel room
for Steve and I always
want that.

I get scared. I am sad
that I scared. I don't
like being scared but
I am. I scared that
people will get mad at
me if I tell anyone

that I am sad.
Daddy is away I just

wanna stay home from
school but no one wants
me too I don't like
going to school but people

PRE-TREATMENT / DURING TREATMENT



POST TREATMENT

