



Alliance to Solve PANS & Immune-Related Encephalopathies

SHARING YOUR PANS/PANDAS STORY WITH STATE LEGISLATORS

Highlighting the real impact of inaction on families

Your personal story is one of the most valuable things you can share with a legislator. While facts and policy details explain the issue, your experience demonstrates its real impact on your state's children and families. **You do not need to share your child's entire medical history. In most cases, it is best not to.**

Most conversations with legislators or their staff are brief, and written messages should be concise. Present your story as a highlight reel, focusing on key details that show the impact of delayed recognition, difficulty accessing care, treatment delays or denials, or lack of insurance coverage for necessary care.

The goal is to connect your family's experience to the larger issue: **There is a cost when your state's children with PANS/PANDAS are not recognized, appropriately treated, and able to access care.**

A SIMPLE WAY TO TELL YOUR STORY

1. Introduce yourself and your child

Keep this introduction brief. You do not need to list everything your child enjoyed or accomplished. One or two details are enough to show that a significant change occurred. For example:

"My name is [NAME], and I live in [CITY] in Representative/Senator [NAME]'s district. My child developed PANS/PANDAS when they were [AGE]. Before becoming ill, they were [one or two brief details that help show their previous level of functioning]."

2. Describe what changed

Select the symptoms or changes that had the greatest impact. You do not need to list every symptom your child experienced. Focus on details that help someone unfamiliar with PANS/PANDAS understand **how dramatically your child's functioning changed**. You might mention:

- sudden or newly worsening OCD or severe anxiety;
- restricted eating or difficulty drinking;
- tics or other motor changes;
- cognitive decline or difficulty thinking, concentrating, or completing schoolwork;
- severe emotional lability, aggression, or regression;
- sleep disruption;
- loss of independence;
- inability to attend school;
- inability to participate in activities your child previously enjoyed;
- a significant change in your child's ability to function at home, school, or in the community.

3. Explain the cost of inaction for your family

This section is the core of your story.

Ask yourself:

What happened because PANS/PANDAS was not recognized quickly, knowledgeable care was difficult to find, treatment was delayed, or insurance would not cover the care my child needed? Select the areas that are relevant to your family.

Delayed diagnosis or lack of provider education

Did your family:

- visit multiple doctors before anyone recognized PANS/PANDAS?
- spend months or years searching for an explanation?
- receive diagnoses or treatment that addressed symptoms without evaluating the underlying medical condition?
- encounter providers who had never heard of PANS/PANDAS?
- have to educate your own medical professionals about the condition?
- travel long distances or out of state to find a knowledgeable clinician?
- struggle to find a provider who accepted insurance?
- finally receive a diagnosis but still have difficulty finding someone prepared to treat your child?

Quantify your experience if possible.

Instead of: “We saw a lot of doctors.”

Consider: “We saw nine medical and mental health professionals over two years before someone recognized PANS.”

Delayed or denied treatment

If treatment was effective, mention this. Legislators should understand both the consequences of inadequate care and the improvements possible with appropriate treatment. Did your child:

- become progressively more impaired while waiting for appropriate treatment?
- require more intensive treatment because care was delayed?
- lose skills, independence, or important developmental time?
- experience repeated flares without adequate treatment?
- have treatment recommended but be unable to access it?
- have treatment delayed or denied by insurance?
- improve after finally receiving appropriate medical treatment?

Emergency, hospital, or crisis care

Did delayed or inadequate treatment lead to:

- emergency department visits?
- psychiatric hospitalization?
- medical hospitalization?
- residential treatment?
- repeated crisis evaluations?
- law enforcement involvement?
- other high-level services that might have been reduced or avoided with earlier recognition and treatment?



These experiences show legislators that when appropriate treatment is delayed, the cost shifts to other parts of the health care or public system.

School and educational impact

Specific numbers can be impactful. For example: “My child missed more than 70 school days that year.” or “A child who had always attended our neighborhood school eventually required an out-of-district special education placement.”

Did your child:

- begin missing significant amounts of school?
- require a 504 Plan or IEP?
- receive homebound instruction?
- require tutoring or additional school services?
- require an out-of-district or therapeutic placement?
- lose previously acquired academic skills?
- leave school entirely for a period of time?
- need substantially more educational support because of their illness?

Financial impact

You do not need to share exact dollar amounts unless you are comfortable. If you are, and the number clarifies the issue, include it. Did your family:

- pay for medical care out of pocket?
- pay privately because knowledgeable providers did not accept insurance?
- pay for medications, testing, travel, lodging, therapy, tutoring, advocates, or other services?
- drain savings?
- take on debt?
- refinance or sell assets?
- postpone other family expenses?
- forgo recommended treatment because you could not afford it?

Employment and caregiver impact

This is also part of the cost of untreated or inadequately treated illness.

Did a parent or caregiver:

- reduce work hours?
- repeatedly miss work?
- take unpaid leave?
- use FMLA?
- turn down a promotion or career opportunity?
- leave the workforce entirely?
- become a full-time caregiver because the child could no longer attend school or function independently?

Impact on the entire family

You do not need to describe every difficult experience. Select examples that best demonstrate the consequences of delayed recognition and limited access to treatment. You may briefly mention the effect on:

- siblings;
- marriages or partnerships;



- family finances;
- the ability to care for other children;
- social isolation;
- the family's ability to participate in ordinary activities;
- the emotional and physical demands of providing intensive care.

4. Connect your story to what your state can do

Do not conclude with only your family's experience. Clearly state what needs to change. Your state currently has opportunities to address two major barriers affecting families with PANS/PANDAS:

Provider Education

Your state needs more health care professionals who can recognize PANS/PANDAS, appropriately evaluate or refer patients, and provide knowledgeable treatment and ongoing care.

Insurance Coverage

Your state's families need appropriate access to medically necessary treatment for pediatric neuroinflammatory disorders, including PANS and PANDAS, without inappropriate insurance barriers delaying or preventing care.

[PANDAS AWARENESS TX: INSERT CURRENT BILL/LEGISLATIVE LANGUAGE AND LINKS]

Then, make your request clear: "Please support efforts to improve PANS/PANDAS provider education and access to medically necessary treatment in your state."

YOUR STORY IN 1 TO 2 MINUTES

A short conversation might sound something like this:

"My name is [NAME], and I live in [CITY]. My child developed PANS/PANDAS at age [AGE]. Before becoming ill, [ONE BRIEF DESCRIPTION OF PREVIOUS FUNCTIONING].

Within [TIME PERIOD], they developed [2 OR 3 MAJOR SYMPTOMS OR FUNCTIONAL CHANGES].

It took us [TIME] and [NUMBER, IF USEFUL] providers before PANS/PANDAS was recognized. During that time, [ONE OR TWO MAJOR CONSEQUENCES].

Because we could not access appropriate care, our family experienced [SCHOOL / HOSPITAL / FINANCIAL / EMPLOYMENT / OTHER IMPACT].

When my child finally received [APPROPRIATE CARE/TREATMENT, IF APPLICABLE], [BRIEF RESULT].

Our family's experience is why your state needs better provider education and access to medically necessary treatment for children with PANS/PANDAS and related neuroinflammatory disorders.

I am asking you to support [BILL / EDUCATION LANGUAGE / LEGISLATIVE EFFORT]."

FOR A SHORT LETTER OR EMAIL

Use the same basic structure:

Who you are

Your name, city, and connection to the district.

What happened

One or two sentences describing your child before PANS/PANDAS and the major change caused by the illness.

What the lack of recognition or access cost

Choose two or three strong examples.



What needs to change

Connect your experience to provider education, insurance coverage, or both.

Your request

Ask the legislator specifically to support your state's legislative effort.

An effective letter may be only a few paragraphs long.

REMEMBER

You do not need to share every detail for your story to be powerful.

You may feel you could write a book about your family's experience. Many families feel the same.

For legislative advocacy, brevity is often more effective.

Choose the details that answer:

What happened?

What did delayed recognition or lack of access cost my child and family?

What could your state do differently?

Remain respectful and focused, even if your family has faced significant challenges with the medical or insurance systems. You are not expected to be a medical or legislative expert; you are the expert on your family's experience.

If you are asked a question you cannot answer, it is appropriate to respond:

"I don't know, but I can have someone follow up with that information."

Additional ASPIRE Advocacy Resources

Legislative Talking/Writing Points and Examples

<https://aspire.care/blog/legislative-talking-writing-points/>

Legislative Talking Tips for PANS/PANDAS

<https://aspire.care/blog/legislative-talking-tips-for-pans-pandas/>

[STATE PANDAS AWARENESS: INSERT CONTACT INFORMATION AND STATE-SPECIFIC RESOURCES]