

Dear Chairman Prusak and Health Care Committee members,

I am writing with a plea for your support of HB 2390. I ask that you consider the following arguments, laid out in sections for easy review. My key points are:

- 1) Multiple insurers in Oregon, and across the United States, recognize the efficacy of IVIG treatment for PANDAS patients, and have repeatedly covered these treatments.
- 2) IVIG has been covered for our daughter and others by multiple insurers because they consider IVIG to be proven and effective.
- 3) All Oregon families deserve equal care, which is not currently available.
- 4) HB 2390 makes no change to the rights or ability of insurers to challenge a prescribed course of care. As with any prescription or medical treatment, insurance providers are able to review, consult, deny, or process appeals for IVIG treatments they might question.

1 – INSURERS ALREADY RECOGNIZE IVIG AS A VALID AND EFFECTIVE TREATMENT FOR PEDIATRIC AUTOIMMUNE DISORDERS, INCLUDING PANS AND PANDAS CASES

The first and most crucial point I want to make is that insurers in Oregon and across the country already recognize the efficacy of IVIG treatment for cases of autoimmune encephalitis and related neurological complications following strep, lyme, and other infections.

I can refer to decades of research and case studies from the National Institutes of Mental Health research, professional pediatric organizations, infectious disease and immunology specialists, but the most important fact when considering whether insurance companies should cover these treatments is that *they already do*.

Many of the same insurers who resist legislation such as HB 2390 have repeatedly recognized and approved IVIG treatment for these cases. Any assertion that IVIG treatment shouldn't be considered or covered for these cases flatly contradicts precedent.

So if insurers do indeed consider and sometimes cover it, why is coverage for PANDAS IVIG treatment still so rare? Because without a public mandate, insurers create their own criteria for review and approval. This puts the burden on families to not just appeal an insurer's denial, but to have them consider it in the first place.

As a result, care often comes only when a child has suffered so much that care becomes an unquestionable emergency. And even in those cases, approval can require a lengthy fight and repeated appeals by families, all while families are in the midst of crisis and faced with a massive financial burden.

In some cases, prior IVIG treatment must be proven to have *already* been effective for that particular child. Such chicken-or-egg requirements mean that no amount of medical review will lead to approval unless treatment has already been provided *and* has shown irrefutable results.

That is exactly what we experienced when our daughter required medical care.

2 — OUR STORY AND THE PRE-APPROVAL CHICKEN/EGG

Our daughter suffered an acute onset of neurological symptoms following a strep infection. I will spare you the details out of respect for her privacy and your time, but she suffered for years from some of the worst symptoms of PANDAS and autoimmune encephalitis.

Our daughter was diagnosed with PANDAS by a pediatrician who specializes in autoimmune disorders. She clearly met NIH / NIMH criteria for a diagnosis, and responded well to anti-inflammatories and antibiotics. Unfortunately, her overall condition persisted and symptoms became more severe.

IVIG treatment was prescribed, but approval to go through a lengthy review and appeal process. With no mandate for coverage, we had to read every detail of our insurer's approval criteria, and lobby them just to consider the diagnosis itself. At one point I was informally advised that slightly different terminology for the same condition could lead to easier approval, and we should ask our doctor to change the official diagnosis.

Meanwhile, our daughter's physical and psychological health deteriorated to such a point that she needed emergency care. ER doctors reviewed her history, observed her condition, and immediately admitted her for IVIG treatment.

Our insurer at the time had a policy that coverage for IVIG treatment in cases of pediatric autoimmune encephalitis would be covered if it had been previously shown to work in the same patient — the same chicken-or-egg criteria I refer to above. Many insurers across the country have similar policies where they are allowed to.

This meant that a pediatrician specializing in autoimmune disorders struggled to have treatment even considered until a crisis led us to the ER, where doctors rushed to arrange IVIG treatment. Treatment was unquestionably effective, and two different insurers approved future IVIG treatments based on its effectiveness.

So, again, as you consider this legislation, please keep in mind one simple fact:
IVIG has been covered for our daughter by multiple insurers because they consider it effective.

We will never know how much physical and psychological damage might have been prevented if our daughter had received IVIG care earlier. We will never know if that first approval might have eventually come without emergency intervention. What we do know is that unnecessary delays put her life at risk.

3 — FINANCIAL BURDEN AND INEQUALITY

So long as insurers are allowed to deny this coverage as a matter of policy, and to treat each of these cases as if it is the first they have ever seen, only the most privileged children will get the care that all children deserve.

We have been very fortunate. Our daughter received the prescribed treatments she needed, and each time we have been prepared to pay out-of-pocket if necessary.

Additionally, our daughter has two parents to care for her, and I work for myself. We have been able to spend hours on the phone with insurers and doctors. We have been able to stay up poring over medical studies, policy details, and legal histories.

It sounds like a burden, but it is a luxury most Oregon families cannot afford.

When you talk with parents who are doing this while at the same time caring for children tormented by debilitating symptoms, they will tell you what a costly, exhausting, and scary process it is. Parents of these children share stories about the hours of research and endless phone calls to convince insurance providers to just consider their child's case.

You will also hear many of them talk about their budgets. Parents discuss selling their cars or their homes, they talk about hard money loans and raising money online. Because families caring for a desperately suffering child will do whatever it takes to get prescribed treatments, even when paying out-of-pocket means paying a multiple of what an insurance company would pay for the same treatment.

And while children wait months or years to receive prescribed IVIG treatment, the odds of long term harm growing over time. Without effective treatment, families face the much greater cost of long term care, and possibly residency in a healthcare facility.

It is worth noting that the State of Oregon also faces these costs. Children who are not able to receive effective treatment will often require additional services in schools and social services, and are more likely to depend on the state for ongoing care as adults.

4 – INSURERS ARE STILL FULLY PROTECTED FROM COVERING QUESTIONABLE PRESCRIPTIONS OR UNVALIDATED TREATMENT

HB 2390 does not declare IVIG to be a miracle cure, nor recommend it in any way.

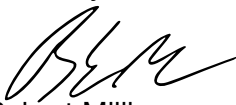
HB 2390 makes no change to the rights or ability of insurers to challenge a prescribed course of care. As with any prescription or medical treatment, insurance providers are able to review, consult, deny, or process appeals for IVIG treatments they might question.

What HB 2390 does do is provide access to timely treatment for thousands of children when IVIG is prescribed. HB 2390 prevents the sort of preemptive refusals and loopholes that contradict insurers' own established precedents.

HB 2390 levels the playing field, so that care and cases are reviewed equally, without unnecessary expenses and lengthy appeals that only the most privileged can afford.

Please vote in favor of fair and equal coverage for all children in Oregon. Please vote in favor of HB 2390.

Sincerely,



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