

Submitter: Steve Schubert

On Behalf Of:

Committee: House Committee On Behavioral Health and Health Care

Measure: SB628

Our son was struck with PANDAS six years ago when he was in 4th grade. We are registered voters in Oregon and ask you to please pass Senate Bill 628. There are two reasons this bill is so important:

1. The Health of the Kids: Children who can get IVIG shortly after diagnosis have much better health outcomes and faster roads to recovery. Like the vast majority of PANDAS kids, our son was a totally healthy boy in school until one day his world was turned upside down when strep got into his brain. The symptoms are very severe when strep hits a child's brain. There are both high immediate health risks to kids whose brains are inflamed with PANDAS as well as longer term impacts if they don't get proper treatment. Our son was not able to get treated with IVIG in 2017 due to the restrictive approval process. While he has made a lot of improvement, six years later he still suffers from symptoms which early access to IVIG would have addressed.

2. Economics: PANDAS treated with less than the standard of care leaves the brain too inflamed for too long and the immune system suppressed. This ends up costing insurance companies and the families so much more over time. In our case, we've now spent around \$50,000 to treat our son and that doesn't take into account lost wages from reduced work time. This bill will allow all families to afford the proper early onset treatment and reduce the costs for treatment for their children due to much more rapid recovery.

I ask you to please pass this bill. I can't imagine a more logical bill given the severity of the health issue for the kids who are hit by it and the cost reduction over time for the health care system. We know five other families whose kids have PANDAS. This is a much more common disorder than most people realize.

I'm 54 and have never written submitted testimony for a bill, but can tell you from experience that the harmful impact on kids and their families is immeasurable from PANDAS which doesn't get treated with today's standard of care.

Thank you so much for your consideration,
Steve Schubert