

Submitter: Sara Zeman
On Behalf Of:
Committee: Senate Committee On Health Care
Measure: SB628

Dear Legislators & Staff,

I'm writing in support of Senate Bill 628, a bill to ensure health insurance parity for Oregon children with PANDAS/PANS who are covered under private, commercial, and employer-sponsored plans. As a retired health law attorney, as an Oregon resident and registered voter, and most importantly, as a parent of a child with PANS who is currently in IVIG treatment, I am keenly aware of how important this Bill is to the children whose lives depend on this treatment and their families, whose welfare and financial security depends on the coverage this Bill will ensure.

My whole family has endured unspeakable trauma living through my daughter's PANS, and the financial strain this disease has wrought on us has been immense. We watched my daughter transition--almost overnight--from a highly sociable, humorous, "life-of-the-party" teenager who was a Straight-A student, talented artist, cross country and soccer team member, and youth symphony musician, into a profoundly physically and psychologically ill child who could barely leave her dark room due to the physical pain and mental anguish of PANS. Multitudes of doctors were unable to understand what was happening to my child, which delayed appropriate treatment for years. So, when my child's current doctor finally prescribed IVIG last summer, we were desperate to start treatment as soon as possible. Unfortunately, though, my daughter's health insurance, through her father's employment as a tenured professor at Oregon State University, denied the authorization necessary to begin treatment. We thus inquired whether could we start her treatment as self-paying while we simultaneously pursued appeals with insurance. The infusion service informed us that the initial 6 months of my daughter's IVIG treatments would cost us approximatey \$120,000.00. I am astounded by that figure, and you should be too. Nonetheless, and despite not having this kind of money at our disposal, in order to ensure my daughter could start IVIG treatment as soon as possible, we committed to this debt. Frankly, I was ready to do anything, from begging online for donations, to losing our home, to declaring bankruptcy if necessary. No family of a PANS child should have to face such an egregiously insurmountable financial barrier to receiving IVIG treatment, especially considering all of the other delays and barriers to care with which we already contend for this horrific disease. I implore this Legislature to pass SB 628 to bring parity to families in Oregon who have commercial or employment-sponsored health insurance plans. It is imperative we do everything we can to help these children overcome this devastating illness. My daughter has a long way to go in her treatment and healing, because so

many doctors we sought help from did not know about PANS. But, we are hopeful, because her initial IVIG treatments brought some remarkable improvements (where so many other traditional mental health treatments failed).

Also, you should know that my daughter's secondary health insurance, through my federal retiree benefits, subsequently approved coverage of her initial IVIG treatments -- based on nationally recognized guidelines. That coverage was at an out of network rate. We are still not certain if (or how) we will be able to afford our share of the costs of IVIG treatments my daughter has already undergone. Further, my daughter will continue IVIG treatments this year, and continuing coverage is not guaranteed. Your passage of this Bill could mean the difference between financial stability or financial ruin for my family.

Passing this bill is the right thing to do for Oregonians.

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