

April 14, 2019

HB 2511:PANDAS/PANS Health Care Access and Awareness

Dear Oregon Legislature,

I am a physician who is also the parent of a child with PANDAS. I am writing in support of HB 2511 which requires health benefit plans, health care service contracts, and medical assistance coverage of PANDAS/PANS. It also requires the Oregon Health Authority to conduct an education and outreach campaign in collaboration with an advisory council. Increased awareness of and coverage for treatment of PANS/PANDAS is certainly needed. As a family physician with medical education and extensive resources, it took nine months to diagnose my daughter with PANDAS, despite her classic presentation. She was evaluated by four physicians and I spoke to numerous other medical colleagues. We also sought diagnostic evaluations from providers not covered by our insurance benefits, including a naturopathic physician, an acupuncturist, and an out of network psychiatrist. Finally her psychologist reached out in desperation to her listserv trying to find some guidance. Once the suggestion of PANDAS was made, we were able to quickly initiate appropriate treatment, resulting in my daughter's excellent response and recovery. However, she and my family suffered for nine unnecessary months due to lack of awareness. We are grateful to have had the resources, but this is not the case for most families.

Increased PANDAS education is needed to be able to quickly make this diagnosis. Also health benefit coverage is needed. In my daughter's case, only continued antibiotics with inexpensive penicillin is needed, however a vast majority of children with PANDAS require IVIG and/ or plasmapheresis for definitive care and recovery. These treatments are expensive and frequently not covered by insurance. Children forgo treatment while parents often must leave their employment to care for children who are severely debilitated. The economic loss both personally and as a society can be devastating.

Vast resources are wasted as children with PANS/PANDAS are inappropriately treated with psychiatric medications while a phantom mental illness is chased, when in reality following the treatment guidelines, which includes use of immunomodulatory IVIG and sometimes plasmapheresis, can result in cure. Money is saved and young lives are improved when the correct treatment is given. Children treated properly for PANS/PANDAS can recover, succeed in school, and become contributing members of society. In our country, where the numbers of children on psychiatric drugs and disability rolls continue to climb, it is more important than ever to identify treatable root causes. A suffering child does not have to be labeled mentally ill and potentially never become gainfully employed. By appropriately assisting families and ensuring that the necessary treatments are covered, the symptoms of debilitating anxiety and OCD can be cured. However, this treatment cannot and does not happen unless PANS/PANDAS is widely recognized and covered by health care benefits. This bill will improve and even save lives for Oregon's youth. Please give HR 2511 your supportive vote.

Respectfully,

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