



March 5, 2019

Dear Chair Salinas and Members of the House Health Care Committee,

Thank you for the opportunity to provide testimony on House Bill 2511. I had the opportunity to listen to the first hearing for this bill and want to acknowledge the heartfelt testimonies from families and share my appreciation for their willingness to share their stories. As a pediatrician and parent, I have deep empathy for what they have had to face when navigating the health system for their children.

I am here to respond to several questions that the committee asked of the Oregon Health Authority.

First, we were asked to provide clarity on coverage of services under the Oregon Health Plan for children with a clinical diagnosis connected to PANDAS/PANS.

Historically, the legislature has delegated decisions about coverage prioritization for specific conditions and treatments to the Health Evidence Review Committee (HERC). The HERC has not yet completed a formal evidence review of PANDAS/PANS and their treatments. Researchers and clinicians who specialize in PANDAS/PANS have recommended a range of treatments including psychotherapy, psychiatric medications, antibiotics, intravenous immunoglobulin (IVIG) and therapeutic apheresis. Some of these treatments do have risks associated with them and may be recommended only for a subset of patients with PANDAS/PANS, particularly IVIG and therapeutic apheresis. In addition, the research on these conditions and consensus on their treatments continue to evolve.

While PANDAS/PANS has not been explicitly reviewed by the HERC to date, coverage for PANDAS/PANS does currently exist under the Oregon Health Plan. As you know, the Prioritized List is made up of pairs of conditions and their treatments, represented by ICD-10 codes and procedure codes, for example. However, there is no specific ICD-10 code representing PANDAS/PANS, and coverage is likely determined through use of a generic diagnosis code, specifically "D89.89 Other specified disorders involving the immune mechanism, not elsewhere classified". This diagnosis code appears in the funded region of the Prioritized List along with the procedure codes for IVIG and therapeutic apheresis. It is important to note that the decision to give a high priority to this diagnosis code and set of treatments was made before PANDAS was added to the coding manual under this diagnosis code. Despite placement in the funded region of the Prioritized List, these treatments could still be denied for PANDAS/PANS during prior authorization, if reviewers find that there is insufficient evidence of effectiveness for some treatments for certain individuals.

HERC is responsible for making difficult decisions and responding to changing knowledge and accepted practice around effective health care services. HERC can review these conditions, hear testimony from stakeholders, and make a decision about prioritizing these treatments by verbal request without legislative requirements.

Second, OHA was asked to provide information on the prevalence rate of children in the Oregon Health Plan who have PANDAS/PANS.

Unfortunately, due to the lack of specific diagnosis coding for PANDAS/PANS, it's impossible for health plans to know how many Oregon patients are diagnosed with these conditions. Furthermore, estimates of prevalence in the literature vary widely, due to evolving diagnostic criteria for these conditions. Some researchers in the field say these conditions may affect as many as 1 in 100 children. Other estimates say that the conditions are much rarer.

Finally, OHA was asked to identify which states are covering services for these diagnoses. We are aware that, in 2017, the state of Illinois passed a mandate for coverage of IVIG for PANDAS/PANS patients in the individual and group commercial health insurance markets. Other states are considering similar legislation, and it is possible that treatments for PANDAS/PANS are being covered by states without statutory action.

Thank you for the opportunity to testify on this important topic. I am happy to answer any questions you may have.

Sincerely,

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