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Oregon Council of Child and Adolescent Psychiatrists Statement on HB 2390

As Child & Adolescent Psychiatrists, we are experts in the assessment and treatment of Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). We have had robust discussion of HB 2390 and seek to provide our perspective. We hope that this letter provides context to many of the issues that this bill seeks to address and aids the legislature in their discussion of potential solutions. A summary of our key points followed by a detailed rationale follows:

Summary of Key Points

PANS is a complex, life-altering, and potentially life-threatening health condition which leaves families desperate for help.

- There is a preliminary but growing body of evidence to support the treatment of PANS with a variety of treatments, including intravenous immunoglobulin (IVIG).
- Due to multiple complex reasons, including the stigma associated with mental health disorders, there have been delays in the research of PANS. This sometimes leads insurers to cite lack of evidence to deny potentially life-altering treatment to those believed to suffer from PANS. This further perpetuates stigma and delays research.
- The assessment of PANS is complex, and its treatment carries risk. This syndrome should be diagnosed and managed by providers who have expertise with PANS and that are familiar with the national guidelines for management of this syndrome.

Rationale

Pediatric Acute-onset Neuropsychiatric Syndrome is the current diagnostic label for the abrupt development, often overnight, of severe symptoms of Obsessive-Compulsive Disorder (OCD) or food restrictions. Symptoms frequently include abnormal motor movements including tics, depression, irritability, and anxiety. These conditions represent an autoimmune reaction that follows infectious illnesses. The rapid onset distinguishes it from typical OCD, eating disorders, tics, and other mental health disorders. Typically developing children can become rapidly disabled by this condition requiring a nearly 24/7 focus on the child by their families – it is a truly devastating condition. Pediatric Acute Onset Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) is a disorder in the PANS family where Streptococcal Infections are associated with a fluctuating course of the illness.

PANS is a life-altering and at times, life-threatening health condition requiring interdisciplinary assessments by psychiatrists, neurologists, rheumatologists, and infectious disease experts. While researchers and clinicians at the National Institute of Health and prominent medical centers in the US continue to define the illness, examine the underlying

mechanisms, and explore potential treatments, we continue to be in an evolving period of discovery. While the evidence base continues to evolve, children and their families are desperate for help. Some argue that if this were to be an adult health condition, we might have made more effort and had more answers by now. Unfortunately, children and their families are met with skepticism and face stigma because we have not defined a biological marker for these conditions that is commercially available and definitive.

Members of OCCAP are often in the position of evaluating and treating children presenting with PANS. There is emerging evidence to support modifying the immune system to mitigate the severity of this illness.

Informed clinicians knowledgeable about evolving data and the risks and benefits of various therapies, including IVIG, should be allowed to prescribe and have these therapies funded, especially when following national guidelines.

We bear witness to the fear and ordeal of coping with this life-threatening and life-altering condition. We empathize with families having to choose financial ruin in order to follow a sound clinical recommendation for a potentially life-changing therapy under dire circumstances.

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