Alison Christy
Pediatric Neurology
Providence Health & Services
9427 SW Barnes Road, Suite 395
Portland, OR 97225
(503)216-6050

To Whom It May Concern,

I am writing this letter today in support of HB 2510 and 2511, particularly to request insurance coverage for PANDAS/PANS. I am a board-certified pediatric neurologist with a PhD in immunology and a focus on pediatric neuroinflammatory disease.

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections (PANDAS) was initially described in 1994. School-aged children, generally prepubescent, presented with tics and obsessive-compulsive symptoms following a Group A streptococcal infection ("strep throat") and worsened when re-infected. Since that time, multiple studies have failed to reveal a clear biomarker of the disease: for instance, any particular antibody, inflammatory marker, or visible lesion on head imaging. Because of this, the disease has remained controversial, and it has been challenging to identify and study this population of children.

In 2013, a consortium of academic clinics from around the country was organized to better understand and study this illness. This consortium includes physicians and researchers from Columbia University, the University of California at Irvine, Georgetown University, Harvard University, the University of Illinois at Chicago, the University of Missouri, the University of Minnesota, the National Institute of Mental Health, the University of Oklahoma, the University of South Florida, Stanford University, and Yale University. Because many children present without a clear streptococcal infection, this group revised the criteria of PANDAS. The criteria now include sudden onset of obsessive compulsive symptoms and/or food restriction (severe anorexia), as well as other behavioral and somatic abnormalities. This disorder is now called Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS).

Both of these conditions are presumed, though not proven, to be caused by an abnormal inflammatory response to certain infections, including but not limited to streptococcal infections. In 2017, the PANS consortium published consensus guidelines for the medical community, recommending immunomodulatory therapies as treatment, including steroids, intravenous immunoglobulin (IVIG), antibiotics and non-steroidal anti-inflammatory medications (including ibuprofen and naproxen).

These disorders can be profoundly disabling for children, some of whom leave school due to anxiety and obsessive-compulsive symptoms, and their family members, who watch their child develop strange symptoms seemingly overnight. In addition, it is often

difficult for patients to receive insurance coverage for medications: particularly IVIG, due to its expense.

Many insurances deny coverage on the basis that IVIG represents an experimental treatment for this disorder. While it is true that we do not have evidence for this treatment based on randomized controlled trials, it is also true that many medications commonly used to treat patients have not been tested or do not show clear benefit in randomized controlled trials. I believe that insurance denial for IVIG in this disorder is unethical, as it penalizes families in distress for pursuing care recommended in published consensus guidelines endorsed by the National Institutes of Health.

I write this letter urging inclusion of insurance coverage for IVIG as one of an array of therapies for the treatment of PANS and PANDAS. Thank you for consideration of this request. I am happy to address any further questions regarding this letter.

Alison Christy, MD, PhD

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