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February 23, 2021

The Honorable Rachel Prusak Chair, House Committee on Health Care
900 Court St. NE
Salem OR 97301

RE: Opposition to House Bill 2390

Dear Chair Prusak and members of the House Committee on Health Care,

Thank you for the opportunity to express my concerns about HB 2390. Kaiser Permanente exists to provide high-quality, affordable health care services and to improve the health of our members and the communities we serve. In my practice I treat children with the symptoms associated with PANS/PANDAS and am awaiting the results of treatment trials. I have concerns about HB 2390 because PANS/PANDAS are very difficult conditions to diagnose and there is no consensus that the treatments currently available are safe and effective for our patients.

The diagnostic criteria for (Pediatric Autoimmune Neuropsychiatric Disorder associated with Streptococcal Infection) PANDAS were laid out clearly in 1998, but they relied on the fact that there was a biomarker (lab evidence) for group A beta-hemolytic streptococcal infection (GABHS) infection. It became clear that many children had evidence of prior strep infection, regardless of whether they had any symptoms of PANDAS. To meet the criterion for a relapsing-remitting disorder with worsening of symptoms associated with recurrent strep infections, repeat labs would have been required, as a single point in time wouldn't have been sufficient. With the introduction of PANS (Pediatric Autoimmune Neuropsychiatric Syndromes), which did not claim association of symptoms with a particular infectious agent, this criterion was removed and a purely clinical diagnosis could be made.

In a 2015 study by an infectious disease expert who received referrals for evaluation of PANS patients, 76% of the referred children did not actually meet criteria for the disorder (Helm and Blackwood 2015). This parallels our experience in pediatric neurology clinic, where we see many patients with chronic symptoms which do not meet criteria for either PANDAS or PANS, but who are referred with concern for these disorders. There are children whose symptoms do meet criteria, but many more who do not. However, once the diagnosis is made, it is often difficult to explain why it is not the correct one. If the diagnosis is made by physicians or other practitioners who are less familiar with the nuances of these diagnoses, the diagnosis is easily given inappropriately, as many of the symptoms (tics, OCD, anxiety, irritability, decreasing school performance) are unfortunately common.

A working hypothesis is that PANDAS/PANS symptoms are related to antibodies generated in response to GABHS in PANDAS or to an as yet undefined infectious agent in PANS. These antibodies are thought to cross-react with some unidentified neuronal cells, which results in cellular dysfunction and neurological symptoms. Based on this, several treatments have been proposed, and in some cases, tested. These have included antibiotics, IVIg, and plasmapheresis as medical treatment as well as cognitive behavioral therapies and psychoactive medications.

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As antibiotics are given for streptococcal infection to minimize the likelihood of long-term consequences, this treatment has been less controversial, although a small number of clinical trials for treatment of PANDAS with antibiotics have shown no or modest effects on neuropsychiatric symptoms.

Two small, randomized, double blinded trials of treatment with IVIg have been reported. In one, there was reported improvement in 9 patients with PANDAS compared to a placebo group. However, after one month of treatment all patients were moved to open label use of IVIg, so no conclusion about long term effects could be drawn. In a second study, there was no improvement with IVIg in the treatment vs the control group. However, after patients moved to open label treatment with IVIg they did report improvement. There are additional survey studies and case reports of use, but it is not possible to draw conclusions because of the nature of these studies.

Plasma exchange was studied in 10 children with PANDAS on open label. This study reported significant improvement in the plasma exchange group, but as the trial was not blinded (due to the nature of the treatment, no sham plasma exchange was done) no clear conclusion can be made. There have also been survey studies and case reports of plasma exchange, with mixed results.

It is important to note that there are randomized and controlled trials which demonstrate the effectiveness of behavioral interventions and psychiatric medications for the symptoms of PANS and PANDAS. Appropriately randomized and blinded trials of immunomodulation are appropriate, and they may yield support for this type of treatment. However, these data are yet to be collected and obviously the fact that such a trial is planned should not be taken as support for the efficacy of the proposed treatment. There is no consensus with regard to appropriate, effective treatment with immunomodulation for children with these diagnoses. Of course, the results of the trials planned will be of real interest.

We need to focus on education to help us make accurate diagnoses for patients with PANDAS/PANS and other neuropsychiatric disorders, and we await results of treatment trials.

For these reasons, Kaiser Permanente respectfully opposes HB 2390.

Sincerely,

Sarah Copeland, MD, PhD
Pediatric Neurology

References

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS): Experience at a Tertiary Referral Center (2015). Helm, C and Blackwood, A. Tremor and other Hyperkinetic Movement Disorders, 5, p 270.
Treatment of PANDAS and PANS: a systematic review (2018). Sigra, S, Hesselmarck, E and Bejerota, S. Neuroscience and Biobehavioral Reviews, 86, pp 51-65.

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A Pediatric Neurology Perspective on Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infection and Pediatric Acute-Onset Neuropsychiatric Syndrome (2018). Gilbert, D, Mink, J, and Singer, H. Journal of Pediatrics, 199, 243-251.

Therapeutic plasma exchange and intravenous immunoglobulin for obsessive-compulsive disorder and tic disorders in childhood (1999). Perlmutter, S, Leitman, S, Garvey, M, Hamburger, S, Feldman, E and Leonard, H. The Lancet, 354, 1153-58.

Therapeutic Plasma Apheresis as a Treatment for 35 Severely Ill Children and Adolescents with Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (2015). Latimer ME, Nathan L'Etoile N, Seidlitz J and Swedo S. Journal of Child and Adolescent Psychopharmacology, 25 (1) 70-75.

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