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1/21/15

To: Massachusetts Senate Joint Committee for Financial Services  
Re: Massachusetts Bill H.984: An act relative to insurance coverage for PANDAS/PANS

Dear Financial Services Committee,

We are writing this letter today in support for the Massachusetts Bill H.984: An act relative to insurance coverage for PANDAS/PANS. As you may know, Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) are two disabling psychiatric syndromes which affect children, often during the school-age years. The symptoms of these disorders typically involve significant obsessive-compulsive symptoms, motor and vocal tics, and occasionally, severe anorexia. Both of these disorders are thought to arise from an abnormal immune response to common infections, such as Group A Streptococcal infections (commonly referred to as “strep throat”). While these disorders are not universally recognized by the medical community, acceptance and recognition of these conditions has grown significantly in the last decade, and currently over 100 articles have been published in the scientific and medical literature describing these conditions.

To advance both our understanding of these disorders, as well as their identification and treatment, a consortium of academic clinics from around the country was organized in 2013. 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. While we are collaboratively working towards developing standardized treatment algorithms for these disorders, there is universal agreement among the consortium that these disorders arise from an abnormal immune response following infections, and thus treatment of these disorders may require medications which address these underlying immune abnormalities.

These immune-modulating therapies include, but are not limited to, a treatment known as Intravenous Immunoglobulin (IVIG). The efficacy of IVIG in treating the symptoms of PANDAS and PANS has been documented through a research study conducted at the National Institute of Mental Health, case reports, and the collected clinical experiences of the providers in the aforementioned academic consortium. The treatment of children with these conditions often includes multiple approaches; these vary from behavioral therapies to medications, though there are times when the use of IVIG is necessary due to either a lack of effect of these therapies, or the severity of a child’s symptoms. It is often difficult for patients to receive insurance coverage for IVIG due to its expense, and the consideration by many insurance companies that this represents an

experimental treatment for this disorder. This lack of insurance coverage for IVIG often leads to parents either forgoing this treatment due to expense, or paying out-of-pocket for IVIG at considerable cost.

PANDAS has yet to receive a specific International Classification of Diseases (ICD) code, and no epidemiological studies have been conducted to estimate the prevalence of PANS or PANDAS in the general population; we anticipate these will both be corrected with time and additional research. Despite this, our collective clinical experience and research suggests that IVIG is effective in treating the disabling symptoms of both PANS and PANDAS. We write this letter urging the Joint Committee for Financial Services to support Massachusetts Bill H.984, and 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, and please contact Dr. Kyle Williams with any questions pertaining to this letter.

Sincerely,



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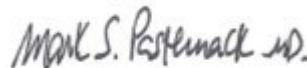
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