



February 1, 2015

To: **Insurance and Real Estate Committee**

Re: Connecticut Bill S.B. No. 15 (COMM) AN ACT REQUIRING HEALTH INSURANCE COVERAGE FOR PEDIATRIC AUTOIMMUNE NEUROPSYCHIATRIC DISORDER ASSOCIATED WITH STREPTOCOCCAL INFECTIONS.

Dear members of the Insurance and Real Estate Committee,

I am writing this letter today in support for the Connecticut Bill S.B. No. 15 (COMM) AN ACT REQUIRING HEALTH INSURANCE COVERAGE FOR PEDIATRIC AUTOIMMUNE NEUROPSYCHIATRIC DISORDER ASSOCIATED WITH STREPTOCOCCAL INFECTIONS. As you may already know, Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) are two disabling psychiatric syndromes which affect young children, typically in the elementary school-age years. The symptoms of these disorders typically involve significant obsessive-compulsive symptoms, motor and vocal tics, and occasionally, severe Avoidant and Restrictive Food Intake. A subset of these cases are thought to arise from an abnormal immune response to common infections, such as Group A Streptococcus (commonly referred to as "strep throat"). While these disorders still 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. Other post-infectious autoimmune conditions associated with Group A Streptococcus, including Sydenham's chorea are more widely accepted by the medical community.

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 the University of California at Irvine, Georgetown University, Harvard University, 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, as well as here at Yale University. While we are collaboratively working towards developing standardized assessment and treatment algorithms for these disorders, there is universal agreement among the consortium that some cases may require medications which address these underlying immune abnormalities.

These immune-modulating therapies include treatment with plasmapheresis and/or treatment with Intravenous Immunoglobulin (IVIG). The efficacy of these treatments in treating e symptoms of PANDAS and PANS has been documented

through a research study conducted at the National Institute of Mental Health, case reports, as well as the collected clinical experiences of the providers in the

aforementioned academic consortium. While the treatment of children with these conditions often includes multiple approaches which include behavioral therapies and medications, there are times when the use of plasmapheresis or IVIG is necessary due to either a lack of effect of these therapies, or the severity of a child's symptoms. Unfortunately, it is often difficult to patients to receive insurance coverage for either plasmapheresis or IVIG due to its expense and the consideration by many insurance companies that these are "experimental" treatments. This lack of insurance coverage often leads to parents either forgoing this treatment due to expense, or paying out-of-pocket at considerable cost.

Neither PANS nor PANDAS have yet to receive a specific International Classification of Diseases (ICD) code, and no epidemiological studies have been conducted which estimate the prevalence of PANS or PANDAS in the general population; we anticipate these will both be corrected with time and additional research.

We write this letter urging the Insurance and Real Estate Committee to support Connecticut Bill S.B. No. 15 (COMM) AN ACT REQUIRING HEALTH INSURANCE COVERAGE FOR PEDIATRIC AUTOIMMUNE NEUROPSYCHIATRIC DISORDER ASSOCIATED WITH STREPTOCOCCAL INFECTIONS to mandate insurance coverage for plasmapheresis and/or 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 me with any questions pertaining to this letter.

With best regards,



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