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Judicial Proceedings Committee

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## THE SENATE OF MARYLAND ANNAPOLIS, MARYLAND 21401

Testimony of Senator Charles E. Sydnor III
Re: SB 0475 Health Insurance –
Pediatric Autoimmune Neuropsychiatric Disorders
Before the Finance Committee
On February 26, 2020

Good afternoon Madam Chair Kelley and members of the Finance Committee,

Senate Bill 475 is being introduced to ensure that Medicaid and other insurers cover treatment for young children suffering from Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections, otherwise known as PANDAS. The disorder, which manifests itself rapidly and affects children as early as age 3, can result in extreme symptoms such as volatile mood changes, development of obsessive compulsive disorder, an inability to control movement, and changes in motor skills, among others. Not only does PANDAS impact the child's physical and mental well-being, it also has long-lasting academic, medical and social repercussions.

The good news is that there is a treatment for PANDAS that is proven to be highly effective. The bad news is that this treatment is prohibitively expensive and most health insurance companies currently do not cover it. Currently, parents must pay tens of thousands, and in some cases hundreds of thousands of dollars out of pocket to treat their child afflicted with the condition. For some parents in Maryland, upon learning that their child has the condition, they are forced to wait helplessly for months or even years before they can afford the treatment. Unfortunately, the more time that lapses between diagnosis and treatment, the less likely a child is able to successfully recover and the more likely it is that a child relapses and suffers further physical and/or mental harm. The pain of watching their child relapse has caused many families in Maryland to suffer additional trauma and financial hardship.

Since I announced my support for this legislation as a member of the House of Delegates, I have received numerous emails from constituents who have children, grandchildren, and great-grandchildren who suffer from this illness. I am introducing this bill to ensure that in the state of Maryland, no parent is forced to choose between getting treatment for their child and making ends meet. Senate Bill 475 mandates that insurers cover the cost to diagnose, evaluate, and treat PANDAS.

Support for Senate Bill 475 is critical if we are to ensure that families are not becoming impoverished in the process of paying for their child's medical treatment. A study of PANDAS families by one local group, Maryland PANDAS Support, found that over 60% of Maryland

residents were paying more than \$5,000 out of pocket to cover their child's treatment. In at least one case, a resident was forced to pay over \$70,000 out of pocket in 2018. By passing this bill, we can ensure that Maryland families are not being saddled with the physical, mental, and financial pain that results from not being able to provide effective, lifesaving treatment for children suffering from PANDAS. I urge the committee to vote in favor of SB 475.