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Thank you for allowing me to comment on my experiences as the stepfather of a son with PANS and as a pediatrician committed to helping other families with children affected by PANS/PANDAS. I have lived it personally and treated the condition professionally.

I am also the father of child with Autism. In contrast to the gradual awakening that something is wrong with your child that precedes an Autism diagnosis, PANS/PANDAS often comes on like a thief in the night. That is, one moment your child is normal and the next is not; sometimes in a very scary, unrecognizable way. Anxious to the point of not allowing Mom out of sight. Stuck in patterns of behavior that cannot be controlled. Requiring family compliance with rigid routines or your child will fly into a vengeful rage. Withdrawn and troubled from thoughts too scary to describe or mention. Or such a profound loss of appetite that they do not eat enough to prevent severe weight loss and need to be tube-fed supplemental nutrition. I have witnessed these circumstances daily with my patients, as more than 50% of my patients have PANS/PANDAS and experienced the fear as a parent for my stepchild for what this diagnosis could mean for him.

With proper medical care there is hope, healing and a chance to put this illness in the rearview mirror. I have seen patients improve in days with antibiotics or with steroids. However, the true healing processes I have seen typically take much longer and can be interrupted by recurrence of symptoms known as "Flares." Flares for the child is a resurgence in symptoms, and for the family it is often a re-triggering of the panic and fear they have experienced with the cycle of symptoms previously. In fact, many of the family members of PANS/PANDAS patients have PTSD (Post-Traumatic Stress Disorder) due to the intensity of behaviors and symptoms of their loved one. Imagine this in more than one child in the family, which is not uncommon in my practice. The entire family is impacted by this disease, not just the afflicted individual.

I am thankful for the research and clinicians who have been helping to elucidate the causes and treatment of PANS/PANDAS. I have listed several useful references below. I have too many stories of illness to relate in a single letter, yet with the help of the experts referenced here we were able to publish a case report of a mutual patient with PANS. It was the clinical history that allowed us to recognize his mental illness (schizophrenia) was infectious and inflammatory. Ultimately this led to effective treatment and complete reversal of years of severe, psychotic behavior.

In my experience with hundreds of families, two impediments for receiving effective care exist. First, is the need for early recognition and diagnosis – a greater awareness by clinicians. Some patients have been ill for years prior to diagnosis, as their mental illness is thought to be primarily psychiatric, which in the case referenced above, it was not. The second obstacle is the difficulty of getting insurance coverage because treatment may include long term antibiotics, frequent office visits, counseling & behavioral therapy, and/or costly immunosuppressive therapies such as IVIG or B-Cell Depletion Agents. With better recognition and diagnosis, treatment would be implemented much earlier thus reducing the suffering of the patient and family, and likely lead to prompter remission. This also holds true in being able to access needed treatment, especially when primary and simpler options are not working.

Clinically and personally, this is where HB #488 could aide us in our desire to help patients, their families and my family.

Thank you Mr. Speaker and distinguished Representatives of the Ohio State House of Representative for your time in reading my letter and for considering this vital legislation to help a generation of young people get an accurate diagnosis, timely care and not add financial burden to families already carrying a heavy load.

Sincerely,

Allen T. Lewis, MD

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