

Dear Grandparent, Friend, Family Member,

If you are reading this letter, it is because you are a valued member of our family, and we want you to know that we appreciate you.

I know it is not easy to watch from the outside as your child/grandchild/friend/student is struggling—or to hear that they are—but to not see the evidence of it.

What we need you to understand is that we are on a journey to uncover what hinders our child, and it's not easy or clear cut. Our child has a disorder called PANS/PANDAS.

Pediatric Acute-onset Neuropsychiatric Syndrome/Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANS/PANDAS) is considered an autoimmune condition. When our child's body has a virus, infection, or exposure to toxins, their immune system has a misguided attack on the basal ganglia (the main "motor circuit board") of their brain and nervous system. This can cause all sorts of symptoms, such as dysregulation, mood swings, irritability, depression symptoms, aggression, rage, Obsessive-Compulsive Disorder (OCD), Attention Deficit Hyperactivity Disorder (ADHD), restrictive eating, and more.

What makes it difficult is that there are days when our child may seem to be perfectly "fine." They may be calm, clear headed, kind, and artistic. This can change overnight if their immune systems are triggered, which can make them seem unruly, anxious, irritable, and angry. It is easy to think they just need more discipline, structure, or correction; but, it is not that simple. (If it were, we would get right on it; I assure you!) Their body and brain are sick and need healing to restore "order" to their mind.

We are working to bring about this healing, which may mean we try treatments that seem unfamiliar to you, or we try various diets to eliminate inflammatory foods. There may be candies and prepackaged foods that we choose to avoid, not because we want our child to miss out, but because we want them to be whole and mentally healthy.

We may implement new routines or guidelines to help our child thrive. We know this may feel uncomfortable at times, and we may seem preoccupied or overwhelmed while on this journey to healing. This is hard and we are doing our best.

We know you want to support us in meaningful ways, and we may not be able to ask for help or know what we need. Please remain hopeful and loving towards our child, do your best to respect any changes we are implementing, and ask gently before offering your insight.

We love you and are thankful to have your presence in our lives.

Sincerely,