



Photo by Lily Nawara



Wendy Nawara struggled to have her children diagnosed with PANDAS/PANS, eventually leading her to found PANDAS/PANS Advocacy and Support (www.pas.care), a group of parents committed to changing the landscape for PANDAS/PANS families.

WENDY NAWARA was no stranger to medical adversities faced by young children. The Chicago native spent the better part of her childhood at Children's Memorial Hospital with a younger brother who had Lowe syndrome, a rare X-linked genetic disorder. Wendy grew up with a desire to assist children with special needs, eventually earning both a bachelor of science degree in elementary education and a master's in social work. But it wasn't until her own children were diagnosed with pediatric autoimmune neuropsychiatric disorder associated with streptococcus/pediatric acute-onset neuropsychiatric syndrome (PANDAS/PANS) and comorbid immune deficiencies that Wendy discovered her true mission and calling.

PROFILE: Wendy Nawara, MSW

By Trudie Mitschang

Trudie: All three of your children were diagnosed with PANDAS/PANS. What advice do you offer parents of children with chronic illness and immune deficiencies?

Wendy: Parenting children with chronic illness that includes immune dysfunction is not easy, but it is possible. Anything is possible. Do your research and understand your child's illness so that you know how to best advocate for him. Don't fear advocating for your child, even though it is intimidating at times. If something is not right, speak up. Be diplomatic about this, but know you are a partner to your physician. You are the expert on your child.

Trudie: What were the greatest challenges you faced early on?

Wendy: My greatest challenges were the same as those faced by most PANDAS/PANS parents: simply being heard by the people who were in the position to best help us. Initially, that was our pediatrician's office and our school. A 15-minute visit with a doctor does not do parents justice when trying to explain how different their child has become, especially when doctors don't know how to help. I was traumatized by what was happening to my younger son, but had already learned from the experience with my older child that any behavioral changes would be quickly misconstrued as a parenting issue and not as a potentially physical illness that needed a closer

look. (Wendy's younger son was first to be officially diagnosed; her older son started displaying symptoms at age 2, but wasn't diagnosed until age 15.) I've also had a doctor remark that we were a complicated family, but that he couldn't, or wouldn't, help us.

Trudie: What prompted you to start a Facebook support group in 2011?

Wendy: By the time the Facebook group started, I had already spent a few years working with national groups and gaining my own support from friends I was making nationally, and even internationally. But I always felt like something was missing. Having children with chronic illness removes you from what you thought were your support systems. The ability to identify with the people who you felt were your friends is drastically changed for a variety of reasons. I just really wanted to be able to know the people who were becoming my friends and be able to meet them in person. I had been rejuvenated after conferences by being with people who understood how difficult navigating PANDAS/PANS could be. After a call from a parent in my state looking for local help and wanting to help others, we decided that we should start a local Facebook group and try to put people in the same room once in a while. Being a social worker was a natural step for me. But for the longest time, I felt alone in this. That call was

what I needed to move from just letting PANDAS/PANS happen to my family to really considering taking action.

Trudie: Tell us about PANDAS/PANS Advocacy and Support (PAS).

Wendy: PAS is a group of parents who are all committed to changing the landscape for PANDAS/PANS families everywhere. We are all volunteers. Our formal mission statement: PANDAS/PANS Advocacy and Support strives to build public awareness of PANDAS/PANS, and to provide support for families dealing with the medical, educational, social, emotional and financial hardships of this disorder. Our purpose is to raise funds to alleviate a portion of the financial burden encountered by families when treating their children, while also increasing the knowledge amongst medical providers, educators and legislators at the local, state and national levels.

Trudie: How has your nonprofit evolved since its inception?

Wendy: We started out with support group meetings and by providing informal 24/7 support in a private Facebook group. But, very quickly, we knew that further action would be needed to make real change. How many times can you hear that parents went to their doctor for help and had their concerns dismissed? We knew awareness and education needed to be broadened to include all physicians, as well as schools and therapists. And other parents, too! Our first try at increasing awareness and understanding was through requesting a proclamation for an awareness day in Illinois. We were successful and held an awareness day activity locally where we educated as many passersby as we could. We felt so empowered to take further action, and the very next awareness day, we began to talk seriously about meeting a dire need in the community at large.

We knew that science might take years to catch up with treating physicians, and we knew that insurance coverage for a disorder and syndrome that insurers were waiting for science to elucidate might take even longer; but in the meantime, children and families were suffering greatly without adequate diagnosis and treatment. We decided to provide grants to families so they could get what they needed for their children to get better.

Trudie: What are some of the key initiatives you are working on now?

Wendy: We are continuously working on providing support and mentorship through our local group, as well as financial support through our grants nationally. We are also focused on increasing the understanding of PANDAS/PANS by hosting educational meetings, grand rounds for physicians and exhibiting at conferences. We collaborate with groups of parents all over the country to work on advocacy. And, lastly, we are working on finding a way for families to get the standard treatments for PANDAS/PANS covered by insurance.

Trudie: How did your work as a social worker prepare you for your role today?

Wendy: I have a unique perspective on what it takes to be in a family with someone who has many different medical needs, having grown up as the sibling of a brother with disabilities. I watched my parents fight to have my brother's needs met, and my mother was a founding member of an international association. That is what drove my interest in social work from a very young age. Before I had my own children, I practiced in a school for children with disabilities. I did assessments, family counseling and worked on an early childhood diagnostic team. So when my own children began to have their own

unique medical needs, I had already witnessed firsthand how to navigate this type of challenge.

Trudie: How did starting the group help you personally?

Wendy: The group and the organization have given me a sense of purpose and saved me from some dark moments when I thought things might not ever change for my kids. Additionally, this life experience has taught me to trust my gut instincts about my children's health. I have learned that parents need to be both dedicated researchers and fierce advocates for their children.

Trudie: What are your goals for the future?

Wendy: I view them not as my goals, but simply as goals for the entire community. To know that doctors are all aware of what PANDAS/PANS is and know what to do to help their patients. To see children with PANDAS/PANS get recognized and treated expediently. To have insurance companies understand that a bacterial or viral illness that impacts both the physical and mental health of children is worth treating, because they do not need to become a drain on the system later.

Trudie: How are your children today?

Wendy: They are doing very well. Our oldest son is in college and loves it. Our middle son is a senior in high school and is preparing to go off to college in the fall. Our youngest, a daughter, still has some health concerns and receives intravenous immune globulin therapy for autoimmune issues when they flare up.

Trudie: What are you most thankful for?

Wendy: My ever-patient husband, Tom, and my three strong, resilient kids. ■

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