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# Caregiver Experience in PANS/PANDAS

## Fear

- Parents Fear - Behaviors can be scary and dangerous
- Parents Fear - Symptoms coming back (PTSD)
- Parents Fear - How devastating symptoms are, how incapacitated their child is
- Patients Fear - Symptoms coming back (PTSD)
- Patients Fear - Losing the ability to function, think clearly, read and write
- Patients Fear - Losing friends and not being able to attend school, extra-curricular activities, social events.
- Patients Fear – Certain medical interventions

## Frustration

- By the lack of knowledge about PANS/PANDAS
- Lack of receiving an accurate and timely diagnosis
- Due to being blamed for the child's behavior
- Lack of compassion
- Lack of resources and insurance-based coverage in most states
- By the limited pool of providers who are well versed in PANS/PANDAS

## Not Being Heard

- Dismisses caregiver and patient input; do not believe what they experience
- Healthcare community too often dismissive, misdiagnoses, patronizing
- The emergency room is often ineffective
- Too often not provided appropriate treatment, sent to psychiatric wards where patients were heavily sedated and provided treatments that were ineffective or harmful
- Relieved when practitioners listen and are not quick to judge

Source: Implications for Advanced Practice Nurses When Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections (PANDAS) Is Suspected: A Qualitative Study McClelland, Molly, PhD, RN et al. Jnl Ped Health Care, 2015 Sep-Oct;29(5):442-52 doi:10.1016/j.pedhc.2015.03.005.