

# Clinical Urgency in Treating PANS/PANDAS

## Urgent Need for Early Diagnosis and Treatment

Delayed PANS/PANDAS diagnosis, often taking three years and consultations with many providers, risks permanent neurological damage and developmental disruption, highlighting the critical need for timely, aggressive intervention to improve outcomes.

## Tragic Impact of Misdiagnosis

Missed diagnoses result in inappropriate psychiatric treatments, worsening suffering, and, in some tragic cases, suicides, despite PANS/PANDAS being treatable with early intervention.

**PANS/PANDAS often goes undiagnosed due to limited awareness, delaying treatment and prolonging suffering. Families typically endure a three-year diagnostic journey, consulting many doctors, which risks permanent neurological damage, developmental disruption, and profound family distress. Misdiagnoses lead to harmful psychiatric treatments or costly institutionalization, with some patients, overwhelmed by untreated symptoms, tragically resorting to death by suicide. Early antibiotic treatment targeting inciting infections can significantly reduce symptoms and recurrence, yet resources remain scarce, especially for adults with persistent or adult-onset cases. There is an urgent need for increased awareness and access to insurance based care. We must ensure prompt, effective care to avert devastating outcomes.**

- PANS/PANDAS is treatable. Early identification and appropriate treatment improve the odds of a successful outcome. Research suggests that early and aggressive treatment of the inciting infection with antibiotics decreases the likelihood of residual symptoms and recurrence.
- Parents currently see an average of 8 doctors and spend three years seeking a correct diagnosis due to a lack of awareness and education.
- If left untreated, possible permanent neurological damage, years of developmental disruption, life-long struggle to the patient, and devastation to their families cannot be ignored. Thus, early identification is paramount.
- Missed PANS/PANDAS diagnoses have resulted in patients being placed on unnecessary psychiatric medications or in more restrictive costly psychiatric facilities, causing more harm than healing. According to the NIMH, a timely diagnosis and appropriate treatment may prevent as much as 25% of all pediatric mental illnesses.
- Multiple deaths of PANS/PANDAS patients have resulted in death by suicide, for a treatable illness to accelerate to this tragic outcome is alarming.

