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TOP STORY

Region 12 youth mental health symposium covers psychiatric conditions linked to infections

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I tould have started with a tick bite, Lyme disease and migraines in fifth grade, but Kara Chasteen on Thursday told a group of school counselors from McLennan County and surrounding counties she knew for sure something was the matter with one of her young family members when he began to experience diminished appetite, compulsive behaviors and lost his ability to do complex math as he prepared for his sophomore year of high school.

The Burnet High School student had excelled in middle school, qualifying for an engineering academy in high school that he had to bow out of because his math skills diminished as he experienced the other changes in spring and summer 2015, Chasteen told educators gathered for a recent Teen Suicide Prevention Symposium at Education Service Center Region 12 in Waco.

Chasteen said her young family member continued to be heavily involved in agricultural competitions, and his condition flared up after cleaning out a moldy barn, when he did not eat for three days during an FFA trip that spring.

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"We found him walking around in the pasture holding a cat, even though the cat had scratched him," Chasteen said. "It was four days of hell, followed by 10 weeks with no appetite, but we finally found a doctor who knew what PANS and PANDAS were and who would treat him. ... Then it was three solid years of medicine and treatment, but he really began to recover in his senior year of high school."

Pediatric acute-onset neuropsychiatric syndrome, PANS, and pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections, PANDAS, have been estimated to affect about 11,000 children each year in Texas. The syndromes, linked to infections that do not typically cause long-term complications, were among several topics covered at the Region 12 symposium.

Chasteen and other parents made many phone calls during the state's 2019 legislative session to support a bill from Rep. Terry Wilson, R-Marble Falls, to create the Texas Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council.



Chasteen
Education Service Center Region 12, provided

"The council made big difference for parents and kids who have been trying for years to resolve behavioral issues," said Jeff Frazier, Wilson's chief of staff.

The council is made up of physicians, psychiatrists, parents and other experts, Frazier said. It created a legislative report for the Texas Health and Human Services Commission that explains PANS and PANDAS. It also makes annual reports that provide recommendations for diagnosing and treating the conditions, and informs the medical community and school districts of PANS and PANDAS.

"Correct diagnosis and treatment is night and day," Frazier said.

Starting work with a mental health therapist and getting a team of clinicians together can help with treatment, said Kiley Magerkurth, Wilson's legislative director. Getting a school counselor, a school nurse and teachers on board with the parents can help the child find success in school.

Chasteen said her family member is now 24, working at a job in computers and studying for a second degree.

His high school counselor, Deana Thomas, also spoke to the symposium in Waco about what she saw and how she assisted him.

"When he came back to school, he was experiencing a great deal of anxiety," Thomas said. "Also sometimes he would have sensory overload from what he saw and heard and smelled."

Some days success for him was just getting to school, Thomas said. Some days it was going to class.

Thomas

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Thomas also said many people affected by PANS or PANDAS may consider self-harm.

PANS and PANDAS are caused by an autoimmune response in the brain when

pathogens cross the blood-brain barrier to enter the brain, Austin child psychiatrist Dr. Qazi Javed said. The syndromes are linked to issues that arise in the basal ganglia region of the brain.

"The problem is not so much the pathogen infecting the basal ganglia region of the brain, it is more the autoimmune response within the brain to the pathogens," Javed said.

The basal ganglia are several linked structures that control motor function and sensory understanding, and problems in that part of the brain can present as obsessive-compulsive disorder, mood disorders, hallucination or tics and uncontrolled movements, he said.

"Parents and teachers do not need to fear that every sore throat will lead to OCD and severe anxiety," Javed said. "But if they see unexplained changes in behavior or academic performance, it may not be just a discipline issue. Something more may be going on. They should be open to understand and treat the root cause. This is the path to healing."

PANDAS was initially discovered in the 1980s as investigators at the National Institutes of Mental Health observed a group of children with obsessive-compulsive disorder who had an unusually abrupt onset of post-infection psychiatric symptoms, according to a Texas Health and Human Services Commission report.

The infections identified included streptococcus, Mycoplasma pneumoniae and varicella, or chickenpox, among others.

Diagnosing PANS or PANDAS is not like diagnosing COVID-19 or the flu, where a blood test identifies a virus or the antibodies left as the body fights the virus, Burnet physician Dr. Amy Offutt said. It requires identifying a number of symptoms and understanding the medical history, environment and life of the patient.

It can be compared to diagnosing depression, Javed said.

For PANS or PANDAS the patient will present with intense anxiety that manifests as OCD or severely reduced appetite and suddenly becoming a very picky eater, Javed said. But each person expresses obsessions, compulsions and anxiety based on life experience.

Teachers in public schools may see a different presentation form a child who has been bullied by other students than from a student who has difficulties in the home, Javed said.

"Also, about 20% of kids who have it (PANS or PANDAS), may experience hallucinations," Javed said. "Those who are intensely Christian may hear the voice of Jesus. Those who are less religious and love sports may hear the voice of a major NBA star."

Other symptoms include separation anxiety; irritability and oppositional behavior; involuntary tics, facial movements and other involuntary body movements; insomnia; bed wetting; sensory overload; or anxiety induced by a smell or a texture, Offutt said.

PANDAS and PANS are often misdiagnosed as autism or other mental health conditions, Thomas said.

Some drugs for depression and anxiety may be helpful in controlling some of the anxiety-related symptoms, Javed said. Some drugs for epilepsy may be helpful in controlling the involuntary movements.

Chasteen and Thomas both said putting someone with PANS or PANDAS in an inpatient psychiatric hospital on major psychoactive medications, would not lead to healing.

"It will take a team to manage this condition and find healing," Javed said.

"Antibiotics to treat the pathogen may help, but not always. A rheumatologist or an

immunologist or allergist may be helpful in taming the immune response."

And having parents, school counselors and teachers on board will also help a child find success, Thomas said.

By Christopher De Los Santos