

Misdiagnosed bipolar: One girl's struggle through psych wards before Stanford doctors make bold diagnosis and treatment

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SAN JOSE — One day, Tessa Gallo was a typical sixth-grader, performing in school plays, running on the track team, goofing around with her two sisters and giggling with girlfriends at sleepovers.

The next, said her mother, Teresa, “She was psychotic and mentally retarded.”

In bizarre and frightening scenes, Tessa acted as frantic as a caged animal, darting out of the family car into traffic, jumping fences and hiding in neighbors’ bushes. At times she seemed catatonic, with food falling out of her mouth because she somehow couldn’t swallow. She repeated the same few sentences over and over, worried about her braces, wanting to go home.

And finally, she said nothing at all. For nine months, Tessa stopped talking. Not a word.

Doctors diagnosed her with bipolar disorder, prescribed psychiatric drugs that didn’t work and sent the San Jose family on a nightmarish odyssey through psych wards, group homes and isolation rooms.

Then, suddenly, more than 10 months into the Gallos’ terrifying ordeal, a pair of Stanford University doctors told the family that Tessa wasn’t bipolar at all. She was probably suffering from a tragically misdiagnosed condition that mimics mental illness in a way doctors are only starting to understand.

“I’ve seen cases like this before,” Dr. Jennifer Frankovich of Lucile Packard Children’s Hospital told the Gallos. “I think I can bring her back.”

Controversial diagnosis

What Frankovich, a pediatric rheumatologist, and Dr. Kiki Chang, a child psychiatrist, concluded was that Tessa likely had an infection or other trigger that caused her immune system to mistakenly attack her brain, dramatically changing Tessa’s behavior overnight. It’s a condition called PANS — pediatric acute-onset neuropsychiatric syndrome — that in some cases, if caught early enough, could be cured by commonly used antibiotics. Without early treatment, they say, children can suffer needlessly.

It would take a mother’s stubborn devotion and the conviction of two doctors willing to stake their reputation on a controversial treatment to bring Tessa back from the brink. At the same time, they believe cases like Tessa’s could help unlock the mysteries of the brain and reveal how something as common as an infection could be behind a growing number of psychological disorders.

PANS is so new and so misunderstood, that there are no reliable estimates of how many children are affected. A national PANS parent support group believes the number nationwide could be more than 150,000, or about a quarter of the children who have obsessive compulsive disorder or other tics.

But skeptics within the medical community question whether PANS even exists. At a symposium in Burlingame on Saturday, Teresa Gallo and Frankovich will try to dispel the lingering controversy that has thwarted efforts to legitimize the diagnosis, fund research and spread the word about possible treatments.

"To know how many patients are in mental institutions that have treatable diseases," Frankovich said, "we can't even wrap our head around this."

'You need to come home'

At the Gallo home in the east San Jose foothills, Teresa Gallo dumps out a shopping bag filled with half-empty bottles of Tessa's psychiatric drugs. Nothing worked. Not the Ativan or Lexipro for her anxiety. Not the Haldol to calm her and curb her aggression. Not the Ambien to help her sleep. They just made Tessa more manic. Her bright blue eyes turned dull and vacant.

Before Tessa's illness, life was good for the Gallo family: Teresa worked as a Weight Watchers leader, her husband as an engineer, their three daughters attended Catholic school. They loved to entertain in their backyard and keep up with Tessa's Girl Scouts and track meets. The household was happy and bustling.

That changed on July 8, 2011. The couple was on a vacation in New Orleans when Teresa received a call from her mother, who was watching the girls in San Jose.

"Tessa's not sleeping. She's not eating. She seems obsessed about her teeth," her mother, Kathy Downing, said. "You need to come home."

They took Tessa, who was 13, to the emergency room, where doctors asked whether Tessa had suffered something traumatic. Nothing, Teresa said. Tessa was given anti-anxiety medication and told to go home.

Day by day, Tessa's behavior grew worse. Riddled with obsessive behaviors, she wiped her hand across her face repeatedly. The teenager who was once so concerned with her hair and hygiene wouldn't bathe. When Teresa put Tessa in the shower and shampoo in her hand, Tessa would drop her arm to her side, the shampoo running down her leg. She cried nonstop. She started to hit her mother and family members until they were bruised. Teresa lay in bed with her all night, trying to calm her and make sure she didn't run out of the house. They were lucky to sleep two hours.

Tessa barely ate. She became dehydrated. Her lips cracked and bled.

So desperate after one month, Teresa begged the staff at Valley Medical Center in San Jose to admit her daughter. They were reluctant, saying all they had was an 8-by-8 windowless room. But they could keep her briefly, monitored and safe. It took five large male attendants to restrain the flailing, angry, wisp of a girl.

"Stay back, stay back!" one of them yelled as they carried the kicking and screaming child away.

Teresa crumbled to the floor. "It was the first and only time in my life I just dropped," Teresa said, "the vision of her being taken away like that and hoping it was the right decision."

'Just wanted my sister'

Across the Bay Area, four psychiatrists diagnosed Tessa with bipolar disorder and one suggested it might be schizophrenia. There were months at psychiatric wards and tortured stops at group homes, from Concord to San Mateo to Fremont. There were long stretches at home, locked with a caregiver in the family room so Tessa wouldn't escape. They shut off the water because Tessa was drinking obsessively. She even drank liquid soap and a bottle of nail polish remover.

Friends and neighbors carpooled her sisters, Briana and Julia, to their activities and brought over dinner casseroles to help the family cope.

"When someone is basically gone, it's hard to be positive," the youngest, Briana, said. "I just wanted my sister, to see her and have her back once again."

It's been so hard, Teresa's husband doesn't like talking about it and asked that his name not be included. Every Sunday, St. John Vianney parish would say Mass in Tessa's name. And every time, Teresa would break down in tears and run outside, sit on the steps and cry.

Finally, 10 months after Tessa's first episode and six months after Teresa first sought him out, Chang's office called. The noted pediatric bipolar expert could see Tessa. Heavily sedated, she curled up on the exam room floor and drooled.

Teresa explained how her daughter had changed overnight, how nothing helped, how hopeless they felt. Chang listened closely, studied Tessa, then told them something shocking.

"This is not bipolar," Chang said. "This is an autoimmune disease, and I'm so sorry it took me this long to see you."

First PANS clinic

He made her an appointment with Frankovich, the rheumatologist with whom he was working to help diagnose and treat PANS cases. When Tessa met Frankovich for the first time, she socked her in the arm.

It was 2012 and Chang and Frankovich were preparing to open the world's first PANS clinic, but the hospital provided only enough funding to operate a half day a week out of a room in the rheumatology department. Soon, there were 60 patients and a five-month waiting list. The two doctors, plus their mostly-volunteer staff, began working nights and weekends answering desperate calls from parents and pleading with insurance companies to fund novel treatments.

Since her medical school days at the University of Nevada in the 1990s, Frankovich had a hunch that a biological trigger could be underlying some psychiatric diseases. Once during her rotation through the psych ward back then, a boy who had the flu suddenly turned psychotic.

"I remember being on the ward and telling these families there's nothing we can do. Your child has a mental illness and has to go to the mental ward," Frankovich said in a recent interview. "It never felt right to me, but I had to say it because that was what I was trained to say."

But there had to be a connection, she thought.

About the same time, at the National Institute of Mental Health outside Washington, D.C., Dr. Susan Swedo was grappling with the same phenomenon. While many children exhibited signs of extreme anxiety and obsessive compulsive disorder, the ones who were particularly puzzling had symptoms that appeared almost overnight, within 24 to 48 hours. Parents described their children as acting like they were "possessed."

Swedo linked the sudden onset of these OCD symptoms to the strep infection and in 1998 coined the term PANDAS — pediatric autoimmune neuropsychiatric disorders associated with strep. But some children had all the signs of PANDAS without the strep infection, and in 2010 she broadened the diagnosis to include the possibility of other infections triggering psychosis, calling it PANS.

Critics, including some noted neurology experts, have long disputed the connection between strep and mental illness, and say the broader PANS diagnosis is no more than a hypothesis. "No one has established that it's true," said Dr. Roger Kurlan, a New Jersey neurologist specializing in Tourette syndrome. "No one has established what the infection is that brings it out or which antibodies bring it out."

In the meantime, the mainstream medical community remains largely unaware of PANS or reluctant to diagnose and treat it, waiting for the research to catch up and the controversy to quell.

A brief awakening

Tessa's is an extreme case and Frankovich is the first to admit there's a lot she and Chang don't understand. But when she began treating Tessa with the same autoimmune and anti-inflammatory therapies she used on her lupus patients — whose immune systems become hyperactive and attack healthy tissues — Tessa started getting better.

"Nothing worked for 10 months in the psych wards," Frankovich said of Tessa, "but after three days of an infusion of steroids, it was a pretty dramatic improvement that was sustained."

At home in the Gallo house, Tessa was coming back to life. She could write and draw again. Her OCD symptoms calmed. And finally, after several months of silence, Tessa spoke.

"I'm hungry," she said next to a fountain outside Lucile Packard hospital. "I want to go home."

In her euphoria, Teresa called her family and summoned Frankovich, who came running from a nearby building and shared in the tears.

"I love you," Tessa told her mom, as the two tightly hugged.

But as surprising as it started, Tessa's ability to speak lasted only two hours.

"My husband missed it. My parents missed it," Teresa said. "It was heartbreaking and she didn't speak for another five or six months."

More heartbreak followed. Tessa regressed further, as doctors tried to wean her from steroids. For the first time, she started hearing voices.

Frankovich knew she needed more aggressive measures to bring Tessa back. In December 2012, after much debate within Stanford itself, agreement was reached to conduct a three-day treatment called plasmapheresis that would run Tessa's blood through a machine to clean out toxic antibodies, followed by a powerful immune-suppressing drug called Rituximab.

The goal was stop her immune system from attacking her brain, but suppressing the immune system leaves the body vulnerable to fatal infection, Frankovich said. "We can't justify using this medicine unless all the doctors involved say there's no hope for the child."

Bold treatment

By that point, Tessa was in such a bad mental state she was living in a group home with five autistic boys and teens. When the Gallos brought Tessa in for the procedure, she was kicking and screaming. Teresa needed to hold her down while doctors strapped Tessa to the table.

"This was literally what we thought was Tessa's last hope," Teresa said. She prayed it would work.

The early signs of success were subtle. That first night, Tessa slept until morning for the first time in months. By February 2013, she was talking again, and singing. In June, she moved back home.

"Watching Tessa come out of this was like watching a child come out of a coma," Teresa said.

The once shy girl became an outgoing jokester.

The illness robbed Tessa of more than two years of schooling, but she remembered all her times tables. She attends a special education class at Mount Pleasant High School. She still gets mild cases of OCD, but they're manageable. Her family is vigilant about infections and wears medical masks at the first sign of sniffles. She had another flare in December, but more immunosuppressants brought her about 80 to 90 percent back. She is still a Girl Scout, plays softball on Sundays and joins a hip hop class on Wednesdays. A boy from her class invited her to the school prom. She plans to wear a light blue dress.

"I feel good," said Tessa, now 16, who explains that when she "lost her voice" she was "just tired. All I could do is hear what people were saying, but I couldn't talk back to them."

These days, Tessa hugs her mother a lot. "She's a loving person," Tessa said, "that I will love forever."

From dark to light

Frankovich and Chang believe their continued work with patients like Tessa will provide answers to the skeptics and build a body of research to help more suffering children get their lives back. But funding is needed for the kinds of scientific breakthroughs and clinical trials to better understand the connections between the psychological and the physical, to find the underlying causes of PANS and to prove their treatment is working. The road ahead is daunting.

"I have had lots of sleepless nights," Frankovich said. "But I have to tell you, every time Tessa comes to clinic, I feel somewhat validated that I'm doing the right thing."

When Tessa visited the clinic this month, she showed Frankovich and Chang two pictures she painted. One was almost totally black, created during one of her tortured, manic flares. The other, painted in February, was a bright green and blue heart with splashes of yellow and orange.

Chang asked about the dark one, how Tessa felt when she painted it. But Tessa avoided the question.

Then he pointed to the painted heart. "How were you feeling when you did this one?"

"I was feeling happy," Tessa said, happy like the song that sticks in her head.

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FIND OUT MORE ABOUT PANS

To attend PANS Symposium: Saturday, April 26, at Embassy Suites, Burlingame, or go to www.pandasnetwork.org

To learn more about it: PANS Question and Answer: <http://healthier.stanfordchildrens.org/q-sudden-symptoms-first-sign-pans-pandas> or call 650-497-9063.

To donate to the PANS Clinic: <http://give.supportlpch.org/goto/PANSclinic>