

A MATTER OF PERSPECTIVE: REBECCA'S JOURNEY HOME FROM PANDAS

By Jeffrey Symes
One Sky

Jacky Sullivan could only watch through the window in a locked door as her teenaged daughter, Becky, was led away until she disappeared down a long corridor. It was a point that had been reached after much hardship and pain, but before anyone realized that Becky's violent attacks against herself and against her mother were cries that needed medical attention, not psychiatric treatment.

The Sullivan family had arrived in the spotless, institutional halls after Jacky and her husband, Ron, endured the sight of their daughter's self-abuse and the marks and cuts of her self-inflicted wounds, after the attacks on Jacky, after the 911 calls, and when there were no other options left. Then-13 years old, Becky was admitted to a secure inpatient treatment program at Hampstead Hospital, a private psychiatric hospital in Hampstead, N.H.

Becky, who is non-verbal and diagnosed on the autism spectrum, was going to take part in Hampstead's program of intensive stabilization for children and adolescents with extremely challenging psychiatric and behavior disorders. It meant she would be in a residential facility, away from family for the first time, away from home where she lived and learned in her homeschool program. "I had no idea what it meant," Sullivan recalls of the day Becky was first admitted to residential treatment. "And then when it dawned on me I was a basket case. They gave me a cot and I didn't leave for two days."

It was the beginning of a long journey Becky and her parents and younger sister, Niki, would have to endure before she could truly return home again. Jacky describes it simply as "to hell and back." For five months, including the holiday season, Becky



JACKY SULLIVAN, LEFT, AND HER TEENAGED DAUGHTER, BECKY, TRIED A VARIETY OF PSYCHIATRIC TREATMENTS FOR BECKY'S BEHAVIOR CHANGES BEFORE GETTING A DIAGNOSIS OF PEDIATRIC ACUTE-ONSET NEUROPSYCHIATRIC SYNDROME (PANDAS), WHICH INSTEAD REQUIRED MEDICAL TREATMENT WITH ANTIBIOTICS.

remained at Hampstead. At the end of it, she moved on to Crotched Mountain School where she would live for the next seven years with visits home every other weekend and holidays.

When Becky was 3 years old, clinicians in the family's native upstate New York region advised Jacky and Ron to institutionalize her because, as they were told, she would never learn to speak or do anything meaningful in her life. It seemed like those dark forecasts were coming true and it would get even darker. By age 15, Becky's self-abuse and aggression had intensified to such an extreme that she needed two adults with her 24/7 to keep her safe. Within a year, she underwent an induced coma twice at Dartmouth Hitchcock Medical Center because she wasn't eating or drinking, and dehydration was leading to kidney failure. When she was awake, she was manic, screaming day and night and not sleeping for several nights.



BECKY SULLIVAN

Doctors at Dartmouth finally landed on a medical diagnosis: Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). More specifically, when doctors discovered a strep infection it was recognized as a subset of PANS known as Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS). According to the website pandasnetwork.org, symptoms can include "abrupt, dramatic onset of OCD or severely restricted food intake ... anxiety ... irritability, aggression and/or severely oppositional behaviors ..."

It's hard to square Sullivan's memories of her daughter during those dark times with the picture of Becky today, smiling, quietly working on her art. It was a shift in behavior that had happened almost overnight. "She was fine one day and suddenly she was ripping herself apart," Sullivan recalls. "It didn't make sense."

Strangely, a swab for strep had turned up negative and doctors only discovered the infection when they did a biopsy of Becky's tonsils. Once the clinical diagnosis was made, Becky's recovery seemed almost as fast as the onset of the severe symptoms. Sullivan said it took about 72 hours on antibiotics and Becky was "calm, quiet, and playing games on her iPad." She has been on antibiotics for the past five years. Last year, she had her tonsils removed.

Today, Becky lives at home with her parents in her own space in the house that includes her own

kitchen and bathroom. She spends as much time with her younger sister as she can when Niki is home visiting from college. And Jacky runs the self-directed program through One Sky Services to provide the staffing support that Becky needs to stay as active as she does.

For the past two years, Becky has been volunteering with a church in Exeter and a thrift store in Durham. They are waiting to hear if she has landed another volunteer position with "End 68 hours of Hunger." Becky likes to stay active these days. In the meantime, she also has bowling, regular walks, yoga, and her art to keep her busy. She sold two original multimedia pieces at the Kingston Fair.

It's been nearly three years now since Becky moved back home and Sullivan isn't looking back. "It's been amazing," she says. "She's back home and part of the family. It was definitely the right decision, no doubt."

"This whole journey has taught me that nothing lasts forever. So in the deepest, darkest, saddest moments, you just have to keep walking. Because those moments don't last either. There's a plan greater than us. And it's just holding onto that idea."



Incorporated in 1983, One Sky Community Services has been dedicated to providing a comprehensive array of services, supports and programs to individuals and families with intellectual and developmental disabilities, as well as acquired brain disorders. A private 5013C nonprofit organization, it is the designated area agency serving the following communities: Brentwood, Deerfield, East Kingston, Epping, Exeter, Fremont, Greenland, Hampton, Hampton Falls, Kensington, Kingston, New Castle, Newfields, Newington, Newmarket, North Hampton, Northwood, Nottingham, Portsmouth, Raymond, Rye, Seabrook, South Hampton and Stratham. One Sky works with nearly 1,200 individuals and families on a yearly basis.