

On Campus

Rutgers program offers treatment and support to families struggling with Tourette Syndrome

By Carla Cantor



Credit: Courtesy of the Bellino family

Louis Bellino Jr., who has Tourette Syndrome, and his sister, Danielle, recently completed an intensive family therapeutic program at Rutgers. Louis learned social skills alongside other children with TS; Danielle participated in a sibling support group.

Louis Bellino was the happiest of babies. Bubbly and cuddly, he ate beautifully and took two naps a day. The first clue that all was not well came as he moved into the toddler years. "He couldn't tolerate discomfort," said his mother, Patti Bellino. "I had to pull the tags off all his clothing."

By the time he was 6, Louis's problems had become more severe. He threw tantrums, didn't play well with other children, blinked constantly, and made funny noises, like clearing his throat and grunting. Then came the diagnosis: Tourette Syndrome (TS), an inherited neurological disorder characterized by vocal and physical tics and often accompanied by co-occurring conditions, such as depression, obsessive compulsive disorder, or attention deficit disorder.

Devastated, Patti and her husband, Louis Sr., embarked on a journey that would take them from parochial and public schools to special education, and involve myriad physicians, therapists, hospitals, and medications. But even after getting Louis, now 10, into the right school program and on a stabilizing "cocktail of meds," the family still felt alone and isolated.

"I was looking for a therapeutic family experience that would address how our lives had changed," Patti Bellino said. "To have a child who is being tortured by his own body breaks your heart. I knew Louis's self-esteem had to be in the gutter, but didn't know how to help him. We needed more support."

The Bellinos found it this spring in a specialized treatment program offered at [Rutgers' Graduate School of Applied and Professional Psychology](#) (GSAPP), which provides a variety of psychological services to the public. The program, a partnership between GSAPP and the [Tourette Syndrome Association of New Jersey Inc.](#) (TSANJ), is the only stand-alone, [student-run clinic](#) for Tourette patients and their families in the nation.

The Rutgers clinic, a partnership between the Graduate School of Applied and Professional Psychology and the Tourette Syndrome Association of New Jersey Inc., is the only stand-alone, student-run treatment center for Tourette patients and their families in the nation.

“When I found out about the [Rutgers] program, it was like someone had told me it was going to be Christmas every day,” said Bellino, who traveled with her family from her home in Staten Island to Piscataway for 10 weeks of intensive group therapy sessions. The Rutgers-TSANJ Therapeutic Program offered the Bellinos a triple play: a social skills group for Louis and other children with TS, a parents’ support group, and sibling sessions for Louis’s 6-year-old sister, Danielle, all of which occurred simultaneously.

“We couldn’t wait to get into the car on Thursday nights,” Bellino said. “There were eight or nine families who understood and could be there for each other. We all embraced the program; the program embraced us.”

The Rutgers-TSANJ alliance began eight years ago when TSANJ director, Faith Rice, the mother of a son with TS who launched the Somerville-based association in 1994, approached Lewis Gantwerk, GSAPP’s executive director, with the idea of creating a therapeutic center to serve the needs of the more than 7,000 people in New Jersey believed to have full-blown TS. (One in 200 children and adults exhibit partial symptoms of the disorder.)

“Creating a TS specialty clinic was perfect for us,” Gantwerk said. “It allowed us to offer our graduate students hands-on experience and train a new generation of professionals in an area where treatment services are badly needed.” When the clinic opened its doors in 2000, there were few resources in New Jersey for patients and families with TS, Gantwerk said. “People had to travel outside the state – to New York or Philadelphia – and often would wait months to see a TS specialist.”

Lori Rockmore, the program’s clinical director, handles the daily operations of the clinic and directs a staff of therapists, all of whom are advanced doctoral students at GSAPP. Rockmore, a psychologist with expertise in child development, impulse control disorders, and social and emotional learning, said that in the early years of the clinic people shied away, perhaps reluctant to be treated by student-clinicians. But as the program’s reputation spread, the client base has grown steadily.

“Our TS clinic is inundated with requests for services,” Rockmore said. “We are now at a point where we have a waiting list of patients seeking treatment and students wanting to treat to them.” Families are referred to the program from TSANJ, the Rutgers community, and surrounding communities, schools, and human service agencies.

New Jersey’s TS efforts were given a boost in 2006 with a \$125,000 grant from Rutgers’ Academic Excellence Fund to expand the Rutgers-TSANJ program’s multidisciplinary scope and research focus. James Walkup, an associate professor of psychology at GSAPP, joined the team and has undertaken a research project that examines the issue of stigma associated with TS patients. The award also provides funding for GSAPP to study pioneering, computer-assisted neuro- and bio-feedback treatments that show promise in mitigating the tics and other symptoms associated with TS.

At about the same time, a new DNA sharing resource was formed – the nation’s first sharing repository of human tissue for Tourette Syndrome research – under the direction of Jay Tischfield, chair of Rutgers’ Department of Genetics and director of the Rutgers Cell and DNA Repository.

With the help of TSANJ, Tischfield’s team is collecting genetic samples from New Jersey TS patients and their families and offering researchers the opportunity to mine data that could lead to better treatments and a cure for the disorder.



Credit: Nick Romanenko
Some of those involved with Rutgers-TSANJ Therapeutic Program, left to right: Lori Rockmore, clinic director; Snigdha Rathor, doctoral student; Lew Gantwerk, executive director, GSAPP; Shawn Ewbank, doctoral student; and James Walkup, associate professor of clinical psychology.

“New Jersey is leading the nation in addressing the need for more treatment options and services for families with TS, and Rutgers plays an important part in that,” said TSANJ’s Rice.

The growing interest in TS research and treatment – and funding from the New Jersey Department of Health and Senior Services – prompted Rice to establish a new umbrella organization called The New Jersey Center for Tourette Syndrome and Associated Disorders. The center is a collaborative effort among the association, community practitioners, Rutgers, and the University of Medicine and Dentistry of New Jersey to provide diagnoses and treatment for children and adults with TS; training for medical and mental health professionals and educators; coordinated care for families; and research opportunities for scientists looking into causes, treatment, and cures.

All this is good news for people like Patti Bellino, who feels more hopeful today than she has in years. Inspired by Rice, she has begun to do advocacy work in her community on behalf of children with TS. “There are still days when I don’t want to pick my head off the pillow,” Bellino said. “But as Faith told me, ‘You have a choice: to let yourself be shattered by this disease, or to turn it into a positive and try to make a difference.’”

Most rewarding for Bellino is a new confidence and self-acceptance she sees in her son. She first noticed it in the car, on the way to one of the last sessions in Piscataway, when she glanced in the rearview mirror and saw Louis happily listening to his iPod. He was chilling with the music, obviously looking forward to his session.

“In that moment, I saw the child I knew nine years ago. There was that twinkle in his eye. He was there. Life will be hard for him, there is no question. But at least in that moment, I knew, he’d be okay.”

For more information about the program, visit the clinic's website, www.rutgerspsychservices.com, or call clinic supervisor Lori Rockmore at 732-445-6111. For more information about TS, visit the TSANJ website, www.tsanj.org, or call 908-575-7350.