

A passion to treat autism

FOR TWO PROFESSIONALS WHO CARE FOR YOUNG PEOPLE WITH DEVELOPMENTAL DISORDERS, THE INSPIRATION TO SERVE WAS BORN AT HOME

THE WORD AUTISM DESCRIBES A SPECTRUM of conditions usually diagnosed in early childhood and marked by difficulties in communication and social interaction and sometimes by repetitive behaviors. It is treated today by specialists in the Developmental and Behavioral Pediatrics Division of The Children's Hospital at Saint Peter's University Hospital. And for two of that program's leaders, the cause is personal as well as professional: Developmental pediatrician Barbie Zimmerman-Bier, M.D., the director, and Genevieve Kumapley, a doctor of pharmacology and oncology pharmacist, both have sons who were born with autism.

Despite extensive professional training, neither had known much about the condition beforehand. But they set out to learn as much as they could to assist their children. Today, they put their knowledge to work helping other families cope with autism and similar disorders.

The Saint Peter's program treats a broad range of children, adolescents and young adults with an array of learning, behavioral and neurodevelopmental disorders (see "What's Treated, What's Provided," on page 36). It also collaborates with other specialty programs within The Children's Hospital, including speech and language, genetics, nutrition, occupational therapy, audiology, high-risk neonatal follow-up, adolescent medicine and family support clinics.

This multidisciplinary approach provides patients and their families with access to a broad range of professionals and medical disciplines, including pediatric neurologists, sleep specialists, pediatric gastrointestinal doctors, speech-language and occupational therapists, physical therapists, geneticists, child psychologists and nursing and family support coordinators. The program is also affiliated with the New Jersey Institute for Disabilities in Edison, Rutgers University's Graduate School of Applied and Professional Psychology and its Douglass Developmental Disabilities Center in New Brunswick.

Dr. Zimmerman-Bier might never have chosen this field had not Sam, the oldest of her four children, been born with autism in 1990. Though she was a practicing pediatrician in New York City, she says, "we learned very little about developmental pediatrics in medical school." She went for additional training, enrolling in a two-year developmental pediatrics program at New York Medical College. "This didn't exist as a specialty when I was in medical school," she says.

She and her husband, Steven Bier, M.D, a radiologist, moved to New Jersey in 2001 when she took a job at the University of Medicine and Dentistry of New Jersey. "I had come to realize that caring for Sam would be a long haul," she says. "We needed a lot of family support. Everyone had to understand Sam's needs and be involved with him more than with kids without developmental issues—and if something happened to us, we wanted to know that someone could take care of him. Family is also important to provide you with breaks."

In 2008 she was approached by Saint Peter's to expand its developmental pediatrics services. She started work in January 2009—"the same day President Obama started his job, but he got more fanfare than I did," she jokes. "I liked that it was a community hospital with ties to local pediatricians, and also an academic center with its relationship with Drexel University College of Medicine in Philadelphia. Because we interact with primary care doctors and work with researchers looking for new treatments, it made what I do a lot easier. And it's a nice group of people here."

One of the people she met was Kumapley. She and her husband, Robert, a civil engineer, have three children. When their middle child, Nicholas, 9, was diagnosed with autism, she was even more mystified by the disorder than Dr. Zimmerman-Bier was. "I had no clue—I didn't even know what autism was," she says. "It was never even discussed in my schooling. As a health professional and an



Barbie Zimmerman-Bier, M.D., right, chief of developmental pediatrics at The Children's Hospital at Saint Peter's University Hospital in New Brunswick, works with Nicholas Kumapley, a child who has autism, as his aunt, Bernadette Forson, looks on.

engineer, my husband and I knew nothing. And we were frustrated by the lack of resources and information out there. I could imagine someone not in a medical profession being even more clueless.”

So they started a charity and parent support group called My Goal. That's an acronym for “My Gateway to Overcoming Autism in Life.” Her group is now affiliated with the Saint Peter's program. “I work in Dr. Zimmerman-Bier's clinic as a parent advocate,” she says. “When she tells me she has a patient whose family needs information, I'm there.”

That information covers every aspect of behavioral and developmental needs. “We explain available therapies, dietary concerns, school-related services and resources that they usually don't even know are available,” she says. She also talks about other health problems that often occur in these children, something she had to learn firsthand. “When we learned Nicholas had a behavioral problem, we didn't realize such a problem could be ac-

What is autism?

Autism is a disorder that is usually first diagnosed in early childhood. The main signs and symptoms of autism involve communication, social interactions and repetitive behaviors.

Children with autism may have problems talking with you, or they may not look you in the eye when you talk to them. They may have to line up their pencils before they can pay attention, or they may say the same sentence again and again to calm themselves down. They may flap their arms to tell you they are happy, or they may hurt themselves to tell you they're not. Some people with autism never learn how to talk.

Because people with autism can have very different features or symptoms, health care providers think of autism as a “spectrum” disorder. Asperger's syndrome is a milder version of the disorder.

The cause of autism is not known. Autism lasts throughout a person's lifetime. There is no cure, but treatment can help. Treatments include behavior and communication therapies and medicines to control symptoms.

Source: National Institute of Child Health and Human Development

accompanied by other medical issues,” she says. “Often these kids don’t express themselves well—my son is completely nonverbal—so you don’t know what’s bothering them. My son would scream and cry all the time, and we thought it was behavioral. We didn’t know that these kids often have gastrointestinal issues. Nicholas had constipation and heartburn, which we didn’t know until we saw a GI doctor, because he couldn’t tell us he was in pain.”

My Goal has also received a grant to train one physician resident each year to better understand how to manage children with these disorders. This training is called “SMART,” an acronym for Specific Mentoring Autism Residency Training. Kumapley also does community outreach, going to disadvantaged areas to screen for symptoms of behavioral and developmental disorders and offering access to services and, for needy families, financial support.

Kumapley’s charity also sponsors monthly support groups, lecture series and family counseling and stress-management activities at Saint Peter’s. “I started this organization to provide support so marriages could stay together,” she says. “The stress level is so high for these families that the divorce rate is much higher than normal. We offer family counseling to find ways to minimize stress so families are better equipped to stay and work together.”

“Genevieve is a very inspiring person,” says Dr. Zimmerman-Bier.

The Developmental and Behavioral Pediatrics Division has teamed with Drexel to develop a number of studies to address the needs of children with autism and developmental disabilities. One study looks at the link between autism and pancreatic enzymes, which help with digestion and may play a role in the GI problems that occur with some types of autism. Another study, funded by the National Institutes of Health, is looking at genetic markers for certain behavioral disorders to help identify and treat them better.

And The Children’s Hospital at Saint Peter’s has joined a network of other healthcare institutions, including the Children’s Hospital of Philadelphia, the New Jersey Institute of Disabilities and the Rutgers University Genetics Department and Graduate School of Applied and Professional Psychology. This network provides even more clinicians, researchers, families, educators, students and advocacy agencies, all located within a 10-mile radius of each other in Middlesex County.

Kumapley and Dr. Zimmerman-Bier are gratified to be able to help others in situations in which they once

felt adrift. “I feel great comfort when I see others being comforted—that means the world to me,” says Kumapley.

Dr. Zimmerman-Bier feels the same way. “We’re a small program,” she says. “But we’re really having an impact.” ■

What’s treated, what’s provided

The Developmental and Behavioral Pediatrics Division at The Children’s Hospital at Saint Peter’s University Hospital treats children, adolescents and young adults with learning, behavioral and neurodevelopmental disabilities such as:

- autism spectrum disorders
- attention-deficit hyperactivity disorder (ADHD)
- language and communication impairments
- learning disabilities
- Tourette syndrome
- genetic syndromes
- sensory impairments
- fetal alcohol syndrome

All patients receive:

- complete developmental, behavioral, medical and treatment histories, with a focus on pressing family and patient concerns.
- standardized neurodevelopmental examination and baseline behavioral assessment.
- targeted referral and diagnostic testing, developmental surveillance, medical management and monitoring of progress.
- care coordination with primary care physicians, medical specialists and community providers.
- family support services, including a parent advocate group through an affiliation with Autism Family Services of New Jersey. The family support service helps families understand the recommendations for school services and provides information about community programs and case management services.

To find out more about autism and the Saint Peter’s Developmental and Behavioral Pediatrics programs, call 732-339-7045 or log onto:

- www.saintpetershcs.com/SPChildrensHospital/Developmental_Pediatrics
- www.MyGoalAutism.org