At 15, Mary Ellen Denman has the same concerns as most other teenagers. She strives to do well in school and make friends, and she dreams of the future. Her parents describe her as tenacious and a hard worker. And, like all parents, they rejoice in her every achievement.
Those achievements are particularly momentous because Mary Ellen is constantly overcoming challenges associated with autism, a neurological disorder being diagnosed in more children each year.

“She was diagnosed with Asperger’s syndrome at age 5,” explained her father, Jack Denman. “For us the struggle was not the actual diagnosis, but finding a treatment that met her needs. As parents you’ll do whatever it takes to help your child. Throughout the years we’ve gone down quite a few rabbit holes looking for the best combination of treatments.”

Dr. Catherine Karni, associate professor of psychiatry at The University of Texas Southwestern Medical Center and

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Jack Denman
Four differences between an autistic and a normal mind during various tasks. From upper left, clockwise with the autistic brain on the left in each pair: attention task (subjects matched by accuracy), attention task (subjects matched by difficulty), sensory task and motor task.

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Dr. Catherine Karni and Mary Ellen Denman meet prior to one of their regularly scheduled sessions.

Recent data from the Centers for Disease Control and Prevention estimate that about 1 in 150 U.S. children has autism. Although the symptoms of the disease can be treated in many cases, there is no known cure, and the condition can cause tremendous strain on families.

Dr. Karni, medical director of the Crystal Charity Ball Autism Program, said the disorder covers a wide span of conditions and symptoms, from severe mental debility to mild social impairment. It wasn’t until 1980 that autism became an official clinical diagnosis and was recognized as being different from childhood schizophrenia or mental retardation.

Today, standard guidelines exist to help identify autism spectrum disorders in children younger than 2. Patients often display a
distinctive pattern of symptoms rather than just one. The main characteristics are impaired social interaction and communication, restricted interests and repetitive behavior. Parents are usually the first to notice the unusual behaviors and report them to the child's pediatrician.

“A pediatrician will document the developmental history while physically examining the child,” Dr. Karni said. “If the parents’ concerns are warranted, the pediatrician will refer the child to specialists for further evaluation. Autism cannot be diagnosed with a simple test. Having a team of specialists conduct specific assessments means there is a better chance for children to be diagnosed correctly and for the right treatments to be enacted immediately. Many parents take their child to a pediatrician because the child is not talking. But there are many possibilities for this behavior. Autism is only one.”

UT Southwestern faculty currently oversee medically related therapeutic services for children with autism spectrum disorders in many clinics at Children’s, including psychiatry, psychology, neurology, neuropsychology, sleep disorders, gastroenterology, speech and language therapy, physical therapy and occupational therapy.

Patients typically are examined by a psychologist, psychiatrist and speech therapist. After a comprehensive evaluation, families are counseled by the team about available treatment options. Medication can improve attention and reduce agitation and aggression, and special schooling can help the patient function better. Some autistic people may excel at mental tasks such as counting, measuring, art, music and memory.

“Mary Ellen is very capably minded, and she possesses some marvelous cognitive abilities,” said her mother, Patti Denman. “Her mind just cannot filter an abundance of stimuli. Asperger’s affects her attention span and causes a sort of chronic frustration, leading to mood swings. After Dr. Karni prescribed the right medication and therapy combination, we saw an immediate difference. She could filter stimuli so much better and not be overwhelmed.”

Dr. Lark Huang-Storms, program director of the Crystal Charity Ball Autism Program, says the project is in its infant stages. A key component is the creation of a centralized referral service for families, physicians and community-service providers. The project includes specialized case managers who will assist families in coordination of referrals and care, ongoing assessments for autistic children as they age, and an online database of resources. She also hopes to add family education and an on-site resource library.

“With the sheer number of autistic children, there are simply not enough existing resources,” said Dr. Huang-Storms, who is also a postdoctoral fellow of outpatient services at the Center for Pediatric Psychiatry at Children’s. “That’s a concern we hear from Crystal Charity Ball support will help families with autistic children get the best information and care in Dallas, according to Dr. Graham Emslie.

Drs. Debra Caudy and Clay Heighten, with their son, Jon, established Benefiting Research for Autism Investigators Now at Southwestern (BRAINS).
parents over and over again. And places that do offer services have extremely long waiting lists. Our vision is for parents to call just one phone number to gain access to not only state-of-the-art diagnostic services, but also an array of treatment options for their child.”

As part of the Crystal Charity Ball Autism Program, UT Southwestern faculty members work with Callier Center clinicians to diagnose and treat patients. The Callier Center currently has four classroom programs providing intensive therapies aimed at improving the communication and language skills of autistic children.

“We’re trying to establish a seamless procedure when children are diagnosed,” said Suzanne Bonifert, head of speech-language pathology at the Callier Center. “We’re developing a program for the summer that will enroll young children who have been diagnosed with autism at UT Southwestern and Children’s for a trial period of six weeks. During that time we’ll try different therapeutic techniques to help their communication and play skills. We also plan for there to be some parent training and to help parents establish goals for their child.”

### Symphony Director Supports Autism Research

Music therapy has been very effective for some autistic children. Dallas Symphony Orchestra Music Director Jaap van Zweden, and his wife Aaltje, have four children, one of whom is autistic. Before moving to the United States, they formed a non-profit foundation, which provides music therapy to autistic children in their homes.

"My family and I are passionate about improving treatment and supporting research for autism," van Zweden said. “We have been working since 2000 through our Dutch foundation, Stichting Papageno, to bring music therapy into the homes of autistic children. We have been very impressed with the programs of UT Southwestern and look forward to working closely with the UT Southwestern team in the future.”

Jaap van Zweden’s passion for music led him and his wife to establish a foundation that supports music therapy for children with autism.
At the UT Dallas’ Center for BrainHealth, autistic adolescents will have an opportunity to participate in a new brain therapy program to develop social coping skills. Using the latest computer technology, clinicians will teach patients the basic building blocks of face perception and body language to help them function in a social context, such as a job interview. The Denmans hope to enroll Mary Ellen in the curriculum this summer.

“We hope the Crystal Charity Ball Autism Program will serve as a link between the extensive research occurring at UT Southwestern and patients with autism who might benefit from cutting-edge studies,” said Dr. Emslie, holder of the Charles E. and Sarah M. Seay Chair in Child Psychiatry.

Researchers at UT Southwestern also hope that breakthroughs in genetics and neurobiology will one day lead to dramatic improvements in the diagnosis and treatment of autism. Currently five new genetic mouse models of autism are being studied to understand brain dysfunction and develop new treatments.

In 2006 Dr. Luis Parada, chairman of developmental biology and director of the Kent Waldrep Center for Basic Research on Nerve Growth and Regeneration, discovered that deleting the gene Pten in certain parts of mice’s brains created animals that displayed deficits in social interactions similar to those seen in humans with autism disorders.

Dr. Parada, who holds the Diana K. and Richard C. Strauss Distinguished Chair in Developmental Biology and the Southwestern Ball Distinguished Chair in Nerve Regeneration Research, said mice are social animals and good models for autism research. The altered mice’s brains were noticeably different in the areas where the gene was deleted. The nerve cells were thicker than normal and had a higher-than-normal number of connections to other nerve cells. Dr. Parada suspects this may explain the sensory overload people with autism are believed to experience.

Dr. Lisa Monteggia, assistant professor of psychiatry, is studying how a gene called MeCP2 mediates autistic-like behavior in mice. Mutations in MeCP2, which result in loss of function of the gene, occur in a developmental disorder called Rett syndrome, a human disease that shares many clinical features with autism.

In collaboration with Dr. Ege Kavalali, Dr. Monteggia has found that an imbalance between excitatory and inhibitory nerve connections may be important in autistic behavior.

Dr. Craig Powell, assistant professor of neurology and psychiatry, has developed yet another mouse model of autism, which has proved to be responsive to experimental medications. The combination of work by Powell, Monteggia, Kavalali, Parada and their colleagues has made UT Southwestern one of the world’s leading centers in the genetics of autism.

In addition to the Crystal Charity Ball, funding for autism research has come from Drs. Debra Caudy and Clay Heighten. The couple’s son, Jon, is autistic, and they created the nonprofit organization Benefiting Research for Autism Investigators Now at Southwestern (BRAINS) in his honor. Its mission is to raise funds for autism research at UT Southwestern.

“We feel UT Southwestern has the talents and capability of making a meaningful contribution to understanding autism,” Dr. Caudy said. “This type of research is essential if autistic
children hope to have a better future than they currently face.”

In 2006 Drs. Caudy and Heighten pledged $750,000 to UT Southwestern to initiate the Endowed Scholars Program in Autism Spectrum Disorders, which is designed to provide start-up research support for four years to bright early-career researchers investigating the causes, diagnosis and treatment of the neurological disorder. Peter and Joanna Townsend, who have two autistic grandsons, Nick and Pete, also pledged $1 million for the autism program to create the Peter and Joanna Townsend Family Distinguished Chair in Research on Autism Spectrum Disorders.

“With the sheer number of autistic children, there are simply not enough existing resources.”  

Dr. Lark Huang-Storms

“One of the most important reasons we decided to invest in autism research at UT Southwestern is the long-standing tradition the school has of integrating different disciplines,” Mr. Townsend said. “Only by bringing together the knowledge of these different disciplines will we get a better understanding of autism and its possible cures.”

UT Southwestern and UT Dallas plan to spread the word about the Crystal Charity Ball Autism Program to area physicians, especially pediatricians, and to local families that have or suspect they have an autistic child.

“There are still many aspects of this disorder that we do not understand,” Dr. Huang-Storms said. “One thing we do know is autistic kids are not all the same. One child with autism is so different from another; no one can say one medication works for every child or one therapy works for every child. The trick is to find the right combination of interventions.”

Jack and Patti Denman said they are thrilled that more treatments have emerged for their daughter. Although acknowledging that their family’s journey with the disorder has been bumpy, they quickly point out that she is teaching them amazing things each day.

“Jack and I feel it is a privilege to be her parents,” Mrs. Denman said. “We think about a passage in the Old Testament, ‘I am fearfully and wonderfully made.’ She is just that, and we’re inspired by her persistence in seeking to overcome the challenges with which she struggles. She is developing into a precious young woman, and we’re really proud of her.”

Joanna and Peter Townsend, pictured with daughter, Pamela Mandt, and grandsons, (left) Pete and Nick Mandt, pledged $1 million for autism research.