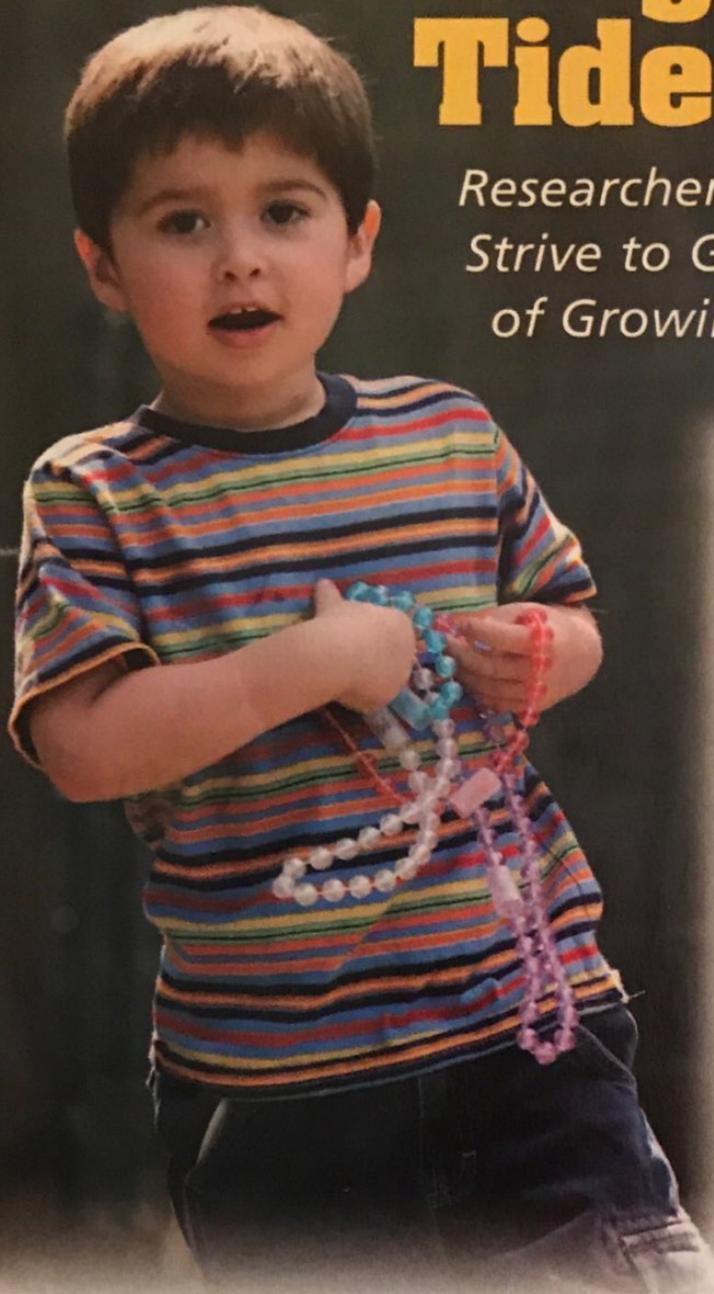


# Stemming the Tide of Autism

*Researchers Throughout South Texas Strive to Gain Better Understanding of Growing Neurological Disorder*



**By Laurie A. Kaiser**

Hope Cueva knows myriad ideas and emotions are buried inside her 4-year-old daughter, Kaitlyn. The San Antonio mother desperately wants to pull them out.

Until Kaitlyn's autism diagnosis one year ago, 36-year-old Cueva says of her then non-verbal daughter, "I just thought she was a late bloomer."

Still, other behaviors Kaitlyn exhibited caused Cueva to suspect something was wrong. When upset, Kaitlyn would bang her head on the floor and was obsessed with lining up objects.

At the time, Cueva, who suffers from bipolar disorder, says she wasn't familiar with autism. When the doctors delivered the news, Cueva says, "I cried my brains out ... Being told my daughter is 21 months behind breaks my heart."

With the advances being made in diagnosis and treatment, however, parents such as Cueva can take heart. Hundreds of San Antonio area children such as Kaitlyn are making baby steps and big strides toward independence with the help of teachers, development psychologists, occupational therapists and others committed to diagnosing and treating autism. In fact, some view San Antonio and Texas as leaders in the research, diagnosis and treatment of autism, especially with regard to an innovative diagnostic treatment that's beginning to take off nationwide.

Like many parents, however, Cueva didn't entirely cede to doctors her role in helping Kaitlyn. The determined mom perused the Internet and read books late into the night to understand the neurological disorder, which is thought to affect as many as 1 in 166 children and interferes with communication skills, social skills and reasoning.

Kaitlyn, an affectionate, inquisitive child who is shy around strangers, seems like a typical 4-year-old in many ways. She loves to play outdoors and to dance. She likes to watch *Dora the Explorer* and TV commercials. However, she also has strong mood swings and is prone to tantrums. Doctors have prescribed for her the same medication her mother takes to treat her manic-depression.

"My life is Kaitlyn," says Cueva, who is single and has no other children. "I don't do things without her ... and it's hard. It limits what I am able to do." Yet, she adds, she "feels blessed" to have the little girl.

Cueva says she is fortunate, too, for the help she has received from Kaitlyn's elementary school and Any Baby Can, a non-profit organization that assists families of children with disabilities, among other services. Also, speech and occupational therapists, paid for by Medicaid, work with Kaitlyn in her home twice a week. The once silent girl has mastered about 120 words, which Cueva calls "tremendous progress." She hopes to see her daughter make the jump from short requests, like "Give me cookie," to conversational sentences.

Marci Taylor, director of Treehouse Pediatric Center, a private occupational therapy facility and school that specializes in autism treatment, says she sees "amazing progress" on a daily basis. She refers to an 8-year-old who started with no language skills but can now string two and three words

# Autism Awareness Walk

together and another child who once gravitated toward isolated activities and now prefers to be around people.

Taylor's experience expands beyond her facility, which employs applied behavioral analysis with a focus on applied verbal behavior. She also is working on a parent and physician education project with the Village of Hope, a clinic that is part of the University of Texas Health Science Center at San Antonio, one of a growing number of collaborations taking place in South Texas.

From a teleconferenced diagnostic clinic to a study looking at autism's relationship with genes and the environment, regional autism experts are working together to unravel the mysteries of the disorder that one parent compared to a kidnapper.

Alonzo Andrews, director of San Antonio's Autism Treatment Center (ATC), spearheaded a "virtual clinic" that links specialists in the San Antonio-Austin region with physicians studying autism in the Rio Grande Valley. As part of a state-funded partnership among the University of Texas Pan-American, the University of Texas in Austin and Texas State University, clinicians film young children who exhibit symptoms of autism. During the diagnostic sessions, developmental pediatricians, psychologists and graduate students observe the children via teleconferencing equipment and make observations in real time.

"It's really something to have a lot of professionals watching a child at once," Andrews says. "One could be focusing on speech, another on tics, another on compulsive behavior."

They also study food sensitivities, medical history and demographics, among other factors, and provide tracking and follow-up.

Years ago, there wasn't much interest in this type of diagnostic treatment, says Andrews, who has worked at ATC for 20 years. Now, it's gaining momentum throughout the country. Assistant U.S. Surgeon General Jose Cordero, M.D., called the virtual clinic a "model" for autism diagnosis. Reflecting on a visit to San Antonio in January for an autism conference, Cordero says, "San Antonio, and Texas in general, are ahead of other places. The spirit of collaboration coming from all sectors is very clear."

Andrews says that he sees professionals across the board realizing the complexity of autism and that, in general, "there is greater awareness of this disorder that has reached some kind of epidemic proportions."

Indeed, ATC, which provides diagnostic treatment, residential care for children and adults and a school, can't keep up with the demand for services. To help stem the tide, Andrews is opening an outpatient diagnostic clinic, located near the Autism Center on the Northeast Side, this spring. Designed to serve several populations, including clients on Medicaid, the clinic will offer diagnosis, speech and occupa-

Lace up your sneakers and help families of children with autism by participating in the Autism Awareness Walk April 8 at Kennedy Park, 3101 Roselawn.

Sponsored by Any Baby Can and area businesses, the 1-mile walk begins at 9 a.m., with registration at 8:30 a.m. at Kennedy Community Center. Participants also can register in advance. Cost is \$15 for individuals and \$30 for families of up to four. For additional children, the fee is \$5; all registrations include a T-shirt. Proceeds will help families pay for access to autism/Asperger's support and education. For more information, call 227-0170.

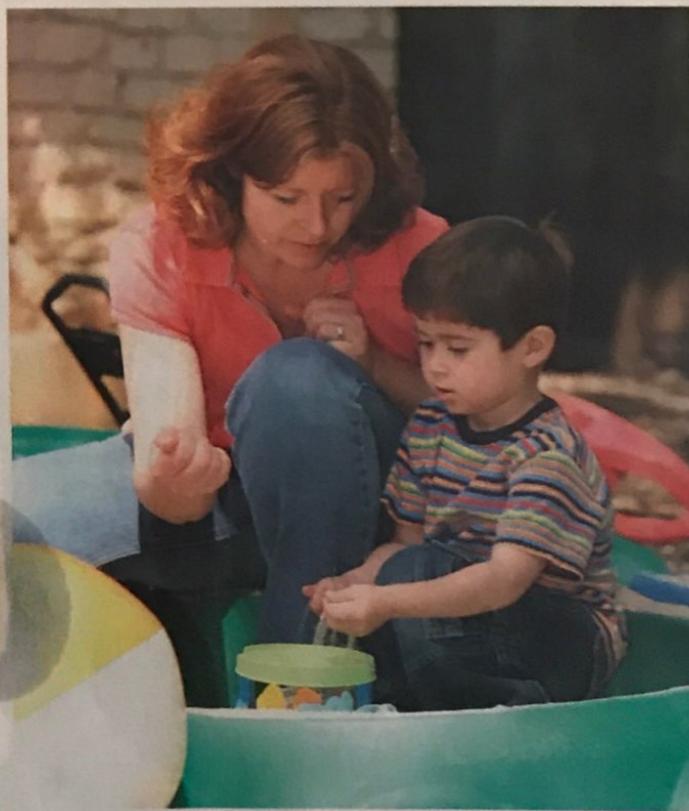
tional therapy and give families an action plan if their child fits inside the spectrum of autism disorder.

## Factors Tied to Autism

Although theories abound as to what causes autism and why it's growing at such a fast pace, scientists have yet to reach a consensus.

Taylor says environmental factors are to blame, but that autism affects children who are genetically predisposed. Claudia Miller, M.D., professor of occupational and environmental medicine at UT Health Science Center, also believes environmental factors play a role. While lead already has been tied to autism, the role of mercury is still being studied.

"It hasn't been established (as a cause) to everyone's satisfaction," Miller says. "We do know that heavy metals affect



**Theresa Diaz, shown playing with her 4-year-old son, Merced, has a multitude of ideas for helping children with autism and their families connect to local resources and services. In October Diaz became co-president of the Autism Society of Greater San Antonio.** PHOTO BY

MOVING PICTURES/KELLEY RAMOTOWSKI

the central nervous system," she adds.

The variable in the equation, however, is the child's genetic susceptibility to the disorder. "It could start at any point during pregnancy or in infancy when the brain is still growing," Miller says. "Some people shrug off environmental toxins and others can't. This is an area where much more research is needed."

Like with other disorders that emerge quickly and somewhat mysteriously, people desperate for help experiment with treatments before the scientific data is complete, Miller adds. "It's frustrating because the research always lags behind patient needs."

New findings could be on the horizon, however. Miller and her Health Science Center colleagues, in conjunction with researchers at the Health Science Center in Harlingen and UT Pan American, are planning to launch a regional study to investigate the environmental susceptibility of genes in children with autism compared with a control group.

"We want to look at food, environmental exposures and see if it's something that can be controlled," Miller says. "We want to determine which exposures may initiate autism or result in worsening of symptoms."

Because the study is focused on genetics and the environment the researchers hope to go into homes where the mothers of autistic children lived while pregnant in order to

estimate exposures, during early development.

"What is different about this study," Miller notes, "is that it's looking at the onset of autism and the impact of environmental factors, including foods ... It's setting the stage for new ways to prevent and treat autism, going well beyond behavioral interventions and drugs."

## Early Diagnosis Critical

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National studies indicate that catching and treating autism early can reduce the cost of treatment over a lifetime by two-thirds, says Lee Grossman, president and CEO of the Autism Society of America.

Most San Antonio autism experts say that early detection and treatment are the key to reducing symptoms that keep children locked in a private world. Children who come into Andrews' clinics, for instance,

are typically 2 to 3 years old and in a good stage for treatment. He wants to conduct diagnostic tests with even younger children. "Eventually, we'd like to bring in 12-month-olds," he says.

The Centers for Disease Control and Prevention (CDC) launched an early awareness campaign last year to educate physicians, childcare providers and parents about signs of autism. "Autism needs to be diagnosed early, before age 3, to provide the best opportunity for treatment," according to Cordero, who also serves as the director of the National Center on Birth Defects and Development Disabilities at the CDC.

Taylor agrees that reaching an autistic child early can garner amazing results. "If parents see something is wrong, that their child is not making connections, it's so important to get to him before the window closes and pull him out," Taylor says.

Often the window shuts around 24 months. "There are still opportunities later," she says, "but they are really easy to mold at this time."

While early intervention is the ideal, it doesn't always happen. Theresa Diaz, co-president of the Autism Society of Greater San Antonio, still hears from parents whose kids are just getting their diagnosis at 6 or older. It's challenging, Diaz says, in a town with more than 1 million people and only five or six development pediatricians. This shortage reflects a trend throughout the country, according to Grossman.

While development pediatricians certainly aren't the only ones able to make an autism diagnosis, hurried pediatricians who have a long list of patients to see may not pick up on the symptoms early. And some insurance plans require a referral before a child can see a specialist. "Once a doctor

*Continued on page 16*



**Kaitlyn Cueva, who was diagnosed a year ago with autism, loves to play outside, to dance and to watch television. With the help of therapists, she has learned 120 words, which her mother calls "tremendous progress."** PHOTO COURTESY OF HOPE CUEVA

## Autism Support Groups Offer Solace and Information

Elisa Carranza remembers exactly how she felt when her son Josiah's developmental delays were given the name autism. "I felt very alone," Carranza recalls.

She found solace and friendship through a support group sponsored by Any Baby Can, a non-profit organization that provides a range of services for families who have a child with disabilities or development delays.

"It was a lifesaver for me," Carranza says. "I just wanted to share with other parents what I was going through."

This was eight years ago when only a handful of parents constituted the group. Now, between 30 and 40 participants gather each month as part of Any Baby Can's parent education program, Reaching Families Facing Autism (RFFA).

As a young child Josiah didn't talk. Now, at 12, "he won't be quiet," Carranza says with a laugh. He has also progressed from looking at pictures to being able to read.

But even with a high-functioning child with autism disorder, there are challenges: outbursts, unpredictable behavior and a need for a strict adherence to routine.

"This is not an easy disability," she says. "When I see new kids come in, it breaks my heart."

Along with the opportunity to network with other parents, the RFFA

meetings include speakers who discuss everything from extended-school-year services to alternative therapies. In January, a second group formed for parents of children with Asperger's Syndrome, a higher functioning type of autism.

Shaun Ipock, the former president and now webmaster of the Autism Society of Greater San Antonio, travels from her home in Cibolo to attend RFFA meetings, as well as the Autism Society's monthly support group. Ipock, whose son, Dylan, 6, received an autism diagnosis more than three years ago, says she relishes the information she gets at the meetings.

Most months, about 70 people come to the Autism Society meetings.

"Our philosophy is not to tell anyone how to intervene with children or which therapy is best but to serve as a resource and support for people of all ages with autism," Autism Society President Theresa Diaz explains.

The society plans to offer a few social events for families this year, such as an Easter egg hunt and possibly a picnic in the summer.

Finding the support group at Any Baby Can, where she was referred after Dylan's diagnosis, was "the best thing I did," Ipock says. "It was better to get support and information than to crawl in a hole and cry."

— Laurie A. Kaiser

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