



THE VOICE WITHIN

awakening to autism

BY LYNN MACHON

Twenty years ago, relatively little was known about the autism spectrum disorders that today affect one in 110 children born in the United States. Certainly, autism treatment options were rarely discussed and the possibility of an eventual cure for the lifelong disorder wasn't even on the scientific horizon.

But over the past two decades, greater awareness and a demand for answers from both impacted families and the medical community have led to groundbreaking

research and exciting advancements in autism diagnosis and treatment.


Each day, innovations bring scientists closer toward finding a cure that will help lead millions of children out from the shadows of autism. Remarkably, much of the success is due to the dedication of world-renowned researchers, clinicians and neurologists right here in the greater Sacramento area.

defining autism

Once thought of as a psychiatric condi-

tion, autism is now understood to be a complex neurodevelopmental disorder caused by abnormal structure or function of the brain.

An estimated 1.5 million American families have children affected by an autism spectrum disorder. Research shows boys are four times more likely than girls to develop autism, with an estimated one in 70 boys being diagnosed. Yet for some reason autism symptoms in girls tend to be more severe than in boys – a trend researchers strive to explain.



U.C. Davis MIND Institute

including now six-year-old Amanda—see her dad's perspective on page 18.

recognizing the signs

Symptoms of autism typically are first detected in early toddler years when parents notice their child not reaching normal developmental milestones. But experts say signs of autism can be identified in children as early as 10 months old.

The Centers for Disease Control (CDC) lists several traits and behavior indicators a young child with autism might display:

- Not responding to their name by 12 months.
- Not pointing at objects to show interest (pointing at an airplane flying over) by 14 months.
- Not playing "pretend" games (pretending to "feed" a doll) by 18 months.
- Avoiding eye contact and wanting to be alone.
- Having trouble understanding other people's feelings or talking about their own feelings.
- Having delayed speech and language skills.
- Repeating words or phrases over and over (echolalia).
- Giving unrelated answers to questions.
- Getting upset by minor changes.
- Having obsessive interests.
- Flapping their hands, rocking their body or spinning in circles.
- Having unusual reactions to the way things sound, smell, taste, look or feel.

Since early detection increases a child's positive outcome, the American Academy of Pediatrics encourages two developmental screenings before the age of two, the first as early as 12 months. Where autism is suspected, clinical assessments, observations and parent questionnaires can help ensure an accurate diagnosis along with appropriate interventions and support for families. Agencies such as Alta California Regional Center in Sacramento, along with a variety of local resources and support groups (see list on page 18), can

help families find the support services and care providers they need.

groundbreaking research

In the race to discover ways to prevent and cure autism, researchers must first identify risk factors that increase a child's likelihood of developing the disorder.

Our very own U.C. Davis MIND (Medical Investigation of Neurodevelopmental Disorders) Institute, founded in 1998 in Sacramento, is at the global forefront of that autism research. "The MIND Institute is a unique multidisciplinary collaboration," explains Phyllis Brown, senior public information officer with the U.C. Davis Health System. "The Institute has more than 200 international researchers from a variety of different fields – including psychiatry and psychology, neurology and neuroimaging, and genetics – all working together with families to discover treatments and cures for autism spectrum disorders and other neurodevelopmental disorders." Of the 136 clinical studies that have been completed at the MIND Institute, Brown says that 71 have been on autism.

With autism believed to be caused by a combination of both genetic and environmental factors, studies like the MIND Institute's Childhood Autism Risks from Genetics and the Environment (CHARGE) are helping to reveal specific triggers. Brown reports that two recent MIND Institute studies examined the connection between autism and pregnancy factors. The first study found that women who didn't take prenatal vitamins early in their pregnancies were at higher risk for having a child with autism. The second suggested that babies conceived in winter months have a significantly higher rate of autism than those in summer months.

Along with determining causes, researchers are working to better define autism and explain why symptoms of the disorder differ so greatly in individuals. Toward that goal, one of the MIND Institute's landmark projects is the Autism Phenome Project, a multi-year study launched in 2006 to explore the differ-

Autism primarily impacts a child's verbal and nonverbal communication skills, social interactions and behavior, and the disorder's associated features and symptoms can range from mild to severe in any child. Children who are severely impaired have difficulty communicating and completing daily tasks and may require assistance through adulthood.

Yet it's important to note that many children on the spectrum are able to overcome developmental challenges, often uniquely inspiring those around them,

ent subgroups of autism and how the causes and treatment for each may differ. Heralded as the largest and most comprehensive assessment of children with autism to date, the study currently has 350 children enrolled and will eventually include biomedical and behavioral data from 1,800 children.

new interventions and treatments

Thankfully, this greater understanding of autism has brought about innovative strategies that reduce the learning challenges and behavioral and social obstacles faced by children on the autism spectrum. Today's interventions focus on therapeutic interaction through behavior management, occupational, speech-language and physical therapies that help minimize autism symptoms and maximize a child's learning and communication potential.

Therapeutic horseback riding, at places like UCP Saddle Pals in Orangetown and Ride and Shine at the Grace Foundation in El Dorado Hills, is producing exciting outcomes in children with autism. Similarly, music therapy like that offered through McConnell Music Therapy in Auburn or Carly Litvik Music Therapy in Citrus Heights, and integrated playgroup therapy such as at Folsom's Montessori Autism Programs and Services are helping local kids reconnect with their world. Additionally, many families have found that following diets that are gluten- and casein-free and/or that include specific vitamins and supplements dramatically improve symptoms of autism. One recent study even found that pet cats in some way provide unique benefits to autism patients, a theory currently being explored at the MIND Institute.

On the medical treatment front, doctors have found that certain medications help in controlling or reducing autism-related symptoms such as gastrointestinal issues, epilepsy and sleep disorders. Our region's Sutter Autism Treatment Center and Sutter Transition for Autism and Neurodevelopmental Disorders

Clinic (STAND) is one of only a few clinical treatment facilities in California. Sutter's Director of Pediatric Neurology, Dr. Michael G. Chez, is beloved by local families for his successful medical and non-medical treatment outcomes in autism patients. Dr. Chez recently published a book, *Autism and Its Medical Management: A Guide for Parents and Professionals* that details his accomplishments and related research.

educating special learners

The growing prevalence of young learners with autism throughout our school system has educators scrambling to develop a new lesson plan. As a result, school districts throughout greater Sacramento now offer classes specifically designed for children on the autism spectrum. Most local campuses also host teacher in-service days and workshops to help staff stay current on the latest techniques for identifying and educating students on the spectrum.

While most children with autism are successfully mainstreamed in the public school system, others need a little extra support. Specialized schools in the area such as Sacramento's Therapeutic Pathways help uniquely prepare and nurture young children prior to elementary school. Other schools like Land Park Academy provide customized education for children with neurodevelopmental disorders from kindergarten all the way through high school. •

RESOURCES AND SUPPORT GROUPS

- Alta California Regional Center**
altaregional.org
- American Academy of Pediatrics**
healthychildren.org
- A Touch of Understanding**
touchofunderstanding.org
- Autism and Its Medical Management: A Guide for Parents and Professionals** by Dr. Michael Chez, Sutter Health Pediatric Neurologist
- Autism Institute**
autisminstitute.com
- Autism Society of America**
autism-society.org
- Autism Speaks**
autismspeaks.org
- Capitol Autism Services**
capitolautismservices.com
- Center for Learning and Autism Support Services**
autismsupportservices.com
- Centers for Disease Control and Prevention (CDC)**
cdc.gov
- Families for Early Autism Treatment**
feat.org
- First Signs**
firstsigns.org
- National Institute of Child Health and Human Development**
nichd.nih.gov
- Special Learning, Inc.**
special-learning.com
- Sutter Autism Medical Treatment Center**
checksutterfirst.org
- U.C. Davis MIND Institute**
mindinstitute.org

A PARENT'S PERSPECTIVE

When my daughter was diagnosed with autism at age two, I wanted to find a way to connect with her. At first it was through animal sounds, and her favorite was the turkey so I spent a good amount of time gobbling to her. In exchange, what I got was laughter and lots of it. What autism demands of you, other than patience, is the ability to laugh. A sense of humor is key. Surround your child with laughter and you will see



the difference, even on days when your laughs are in short supply. Now that my daughter is older, I don't ever want to forget to laugh and to have fun with the unique qualities she

brings to the world. I embrace and encourage her differences. She has taught me several valuable lessons about life, and I'm better for it.

—Justin Buettner, Folsom resident and father of now six-year-old Amanda