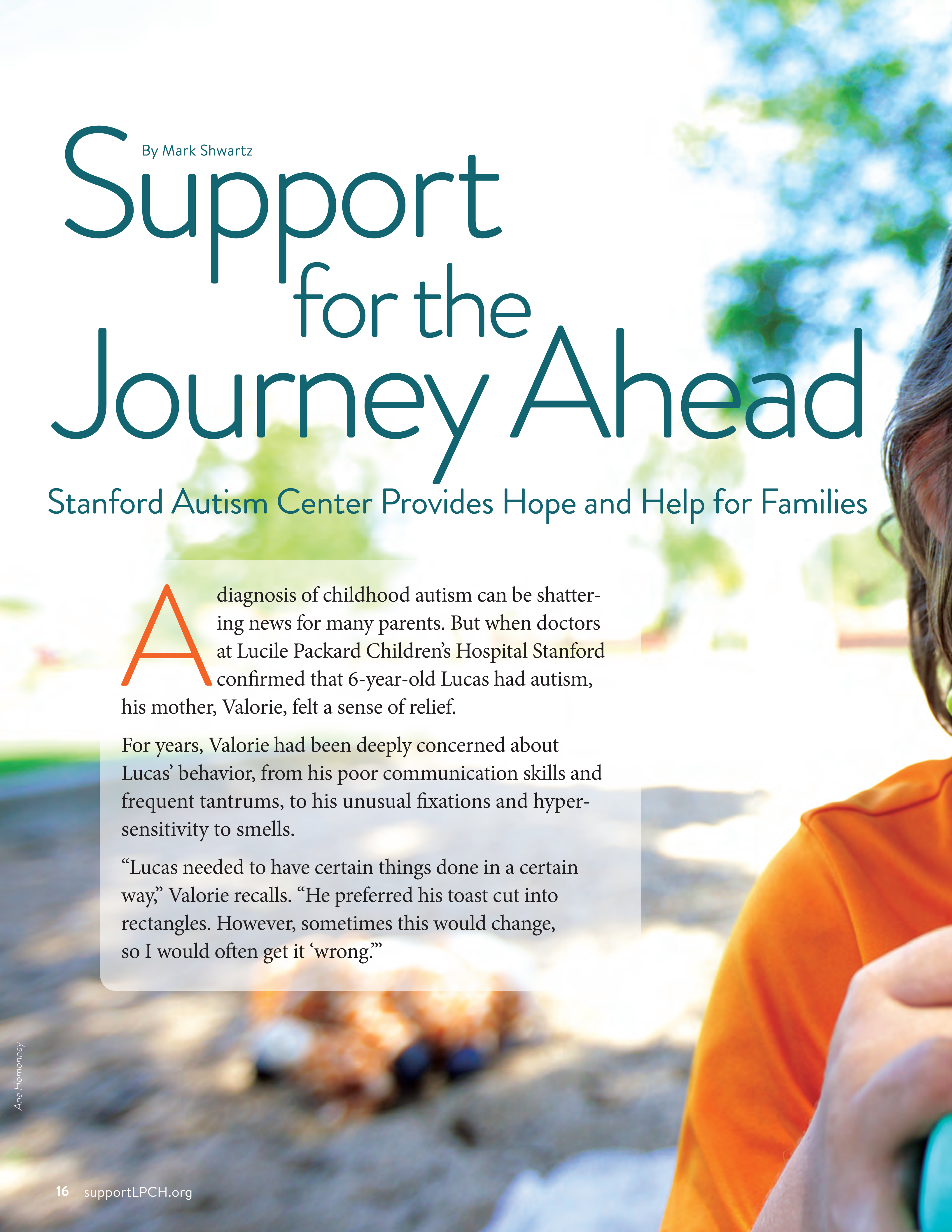
Ana Homonnay

By Mark Shwartz

Support for the Journey Ahead

Stanford Autism Center Provides Hope and Help for Families

A diagnosis of childhood autism can be shattering news for many parents. But when doctors at Lucile Packard Children’s Hospital Stanford confirmed that 6-year-old Lucas had autism, his mother, Valorie, felt a sense of relief.

For years, Valorie had been deeply concerned about Lucas’ behavior, from his poor communication skills and frequent tantrums, to his unusual fixations and hypersensitivity to smells.

“Lucas needed to have certain things done in a certain way,” Valorie recalls. “He preferred his toast cut into rectangles. However, sometimes this would change, so I would often get it ‘wrong.’”

Lucas rarely made eye contact with people, had serious speech problems, and even had difficulty holding a pencil. At age 4, he underwent a series of psychological tests that suggested he had an autism spectrum disorder. After two years of inconclusive results, Lucas' pediatrician referred him to Lucile Packard Children's Hospital Stanford for an evaluation.

It didn't take long for Stanford pediatrician Brian Tang, MD, and clinical psychologist Barbara Bentley, PsyD, MS Ed, to diagnose Lucas.

"They could see right away that he was on the autism spectrum," Valorie says. "For me and Lucas' father, the diagnosis was a huge relief. It finally gave us a direction to go in to give our son the help he needs."

For Valorie and other parents of newly diagnosed children, the roadmap for treatment is far from simple.

"When you see a doctor for high cholesterol, you get one drug and you're told to follow a diet," says Antonio Hardan, MD, director of the Autism and Developmental Disabilities Clinic. "But when you have a child diagnosed with autism, you may need to work with 10 different services, including occupational therapy, speech therapy, child psychiatry, developmental pediatrics, neurology, and medical genetics."

Over the last few years, the Stanford Autism Center has become a campus-wide effort to coordinate and facilitate clinical activities, research investigations, and supportive services for patients and families facing autism. "Our goal is to have all these services accessible to our patients and available in a coordinated way to their families," Hardan adds.


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■ Antonio Hardan, MD

Helping a Growing Community

Despite better coordination of services, a dramatic rise in children diagnosed with autism has made it increasingly difficult for families to get the help they need in a timely manner.

"The large number of new patients is overwhelming our clinical services," says Hardan, who is also a professor of psychiatry and behavioral sciences at Stanford. He points to recent statistics showing that about 1 in 68 American children — including 1 in 42 boys — has been identified with autism spectrum disorder.

"We get families coming in from throughout California, but we don't have enough staff or resources here to support all of them," adds psychologist Jennifer Phillips, PhD, co-director of the Autism and Developmental Disabilities Clinic. "Sometimes we have to tell parents that it will be a year before we can see their child."

Even children diagnosed with autism have a long wait for follow-up services and treatments. To address that challenge, our hospital and the Children's Health Council — with support from generous donors — recently established the Early Support

Program for Autism, or ESPA, to provide support services to parents at no cost following a diagnosis.

"The idea for ESPA came when we realized that it takes several weeks for kids newly diagnosed to get into treatment," Hardan explains. "During that time, the parents are dealing with a lot of emotions. We felt something should be done for them while they wait to connect with the right providers."

Valorie agrees. "We felt overwhelmed at first," she says. "Fortunately, Dr. Tang referred us to ESPA right away. The support they've given us has been amazing."

About 175 families have received services from ESPA since the program began in July 2013. The clinical care coordinator, Christina Ardel, is usually the first contact from ESPA who provides information about resources to families. She also refers them to the parent coach and trainer, Gina Baldi, who became the main contact for Valorie.

"Gina makes everything so much easier," Valorie says, "like scheduling evening appointments for me, which I really appreciate. She's helped me deal with the school district and my insurance company, and she's given me all kinds of useful advice, like where to find online chat rooms with local parents. Just today, she sent an email with helpful apps for my phone."

Valorie has also enrolled in several ESPA-run classes designed to help parents handle the lifelong challenges of autism. "I would never have been able to participate in ESPA if the services weren't available for free," she adds.

Less than a year after he was diagnosed at our hospital, Lucas is showing signs of improvement. His tantrums are more under control, and he has learned to hold a pencil and draw. He's even engaged other kids in conversation. "As a parent I can't express how much I appreciate everything ESPA and Packard Children's have done," Valorie says. "Even a little progress is good, and thanks to early intervention, his prognosis is likely to improve."

Numerous studies of young patients with autism have already confirmed the value of early childhood interventions. One method widely used at Stanford is pivotal response training, a technique that teaches parents creative ways to build a child's language and social skills at home.

"In pivotal response training, the parent learns how to set up behavioral expectations naturally," Phillips says. "Instead of letting the child take a snack from the

Endowed Directorship Named for Feinstein

Carl Feinstein, MD, professor emeritus of psychiatry and behavioral sciences at the Stanford University School of Medicine, was the first holder of the Endowed Directorship of Child and Adolescent Psychiatry at Lucile Packard Children's Hospital. Last summer, he stepped down from the position, which will now be named in his honor.

Feinstein has devoted his career to the mental health needs of children with medical illness, including improving the scientific understanding and treatment of autism spectrum disorders and neurodevelopmental disorders. Over the past 15 years, he has overseen the creation of the Stanford Autism Center at Lucile Packard Children's Hospital and helped launch Stanford's annual Autism Spectrum Disorders Update.

The success of the Stanford Autism Center has been made possible largely by the support of generous donors including the Eucalyptus Foundation, the Taube Foundation, and the Koret Foundation.

In admiration of Feinstein's legacy and instrumental role in advancing treatment for children and adolescents with mental and developmental disorders, anonymous donors stepped forward to endow the directorship and requested that it be named in Feinstein's honor. The Carl Feinstein Directorship of Child and Adolescent Psychiatry at Lucile Packard Children's Hospital Stanford will ensure ongoing support for the hospital's research and patient care in the area of childhood mental health.

"While providing expert evidence-based care is my primary objective, every patient is different and the care I provide is as personalized as possible," Feinstein says. As director of child psychiatry, he championed the practice of psychotherapy for children and adolescents and has been particularly active in training the next generation of child psychiatrists in psychotherapy.

Feinstein continues to lead the Stanford Autism Center. His research has contributed to a better understanding of the clinical features of autism, particularly the social deficits that are its defining feature.

cupboard, he's taught to ask for what he wants and to make eye contact when he asks for it. By using a kid's natural motivation for things they want, you can get them to socialize more and to use more language."

Phillips and Hardan, in collaboration with their colleague Grace Gengoux, PhD, are now leading a clinical trial to evaluate what happens when parents of children age 5 and under with autism use the pivotal response technique in their home for six months in combination with in-home therapy provided by a trained clinician. "Based on our earlier research, we expect promising results with the 'higher dose' of six months compared to the standard regimen of three months," Hardan says.

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>
> ▪ Carl Feinstein, MD

He and his Stanford colleagues, including Karen Parker, PhD, assistant professor (research) of psychiatry, are also conducting placebo-controlled clinical trials to determine if children ages 6 to 12 with autism respond to treatments of oxytocin or vasopressin — two hormones that play an important role in social recognition and bonding.

The majority of participants in these and other clinical trials are drawn from a large pool of children, adolescents, and young adults who visit the Stanford Autism Center, which receives more than 3,500 patient visits each year. Lucas is one of many patients whose parents have agreed to participate in this research.

Preparing for Adulthood

For TJ and Cheryl Scimone, innovative research offers the most promising pathway to a successful treatment for their son, Alex. Diagnosed with autism at age 3, Alex is now 15 years old, stands 6'2" tall, and weighs 190 pounds.

"I play a lot of games and I draw cartoons," he says quietly. "When I grow up, I want to either build an arcade or work at my father's company."

Despite his seemingly calm demeanor, Alex is prone to sudden outbursts of violence. "He's huge, and if he has a meltdown, it can be pretty scary," says Cheryl.

As Alex approached adolescence, he became increasingly aggressive. "He was very explosive. The smallest thing would set him off," Cheryl says.

"A toothpaste cap not put on properly or the wrong facial expression could cause a debilitating tantrum that would last the whole day," TJ recalls.

"He really wasn't having much quality of life with all of the screaming and hair-pulling," Cheryl adds. "We wound up at Stanford about four years ago because of the need for medication. I'm glad we found Dr. Hardan. I like the way he works with Alex. He's very friendly and calm."

Over the years, Hardan has prescribed different medications to help stabilize Alex's violent mood swings and to complement the behavioral interventions that are being implemented. "He's gotten better," TJ says. "It's still a challenge, but it's not as bad as it used to be."

What worries TJ most is what will happen when Alex becomes an adult, and his parents are no longer able to care for him. "What's the prognosis for Alex?" TJ wonders. "We don't know, but he'll need a lot of care for a very long time."

Having a large staff capable of helping patients like Alex transition to adult care is one of the many challenges facing the Stanford Autism Center, says Carl Feinstein, MD, professor emeritus of psychiatry and behavioral sciences.

"Right now, we're sort of a virtual autism center," Feinstein says. "We need a unified place where the clinicians are all together so parents can have one-stop shopping and coordinated care. We could triple the number of patients we see, but we've hit a wall because we don't have enough space to hire more clinicians. Silicon Valley leads the way in so many areas, but it hasn't fully awakened to how big a problem autism is. "

But some entrepreneurs are paying attention. In 2008, TJ Scimone founded a Silicon Valley company called Slice, which manufactures a range of ceramic-blade cutting tools designed to reduce injuries. Slice now donates 1 percent of its corporate sales to autism research programs, including Stanford, and encourages other corporations and individuals to donate as well.

Toni Gauthier

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▪ TJ Scimone, Alex’s father

Transformational Giving

Private philanthropic support has played an integral role in expanding clinical care and research efforts through the Stanford Autism Center. The Early Support Program for Autism (ESPA, see page 18) was established by a grant from the John and Marcia Goldman Foundation. Other generous donors including the Simons Foundation, Oxnard Foundation, and Nancy and Bruce Mosbacher have also made key investments that have significantly expanded our hospital's ability to care for and understand the needs of children with autism.

While much has been achieved, there are still many unmet needs as the number of children being diagnosed with autism continues to increase. Support for the following would ensure continued advances in care for future generations of children and families.

Endowed Chairs $4 million

An endowed chair, the highest honor that can be awarded to a faculty member, would enable our hospital and School of Medicine to recruit and retain leading physician-scientists who will teach and mentor the next generation of care providers.

Endowed Fellowships & Faculty Scholar Awards $2 million

Fellowships and faculty scholar awards provide advanced training and research support for talented young physicians poised to become the next generation of leaders.

Research Support

Expendable support for research personnel, equipment, and infrastructure will enable our faculty to make exciting breakthroughs to improve care for children with autism. Endowed research funds can be established with gifts of $100,000 or more.

For more information about giving opportunities, please call **(650) 498-7641** or email **leanne.newman@lpfch.org**.

"After meeting Dr. Hardan, we thought it would be a good idea to give the money directly to his department," TJ explains. "He's been doing this a long time. You can tell just by talking to him that he's passionate and cares so much."

For Hardan, it's the parents' commitment to their children that fuels his enthusiasm. "They do their best to make things better just so their kid can go to a baseball game or a movie," he says. "It's very humbling when you see what they do every day. It puts things in perspective."

In April, Slice co-sponsored Stanford's seventh annual Autism Spectrum Disorders Symposium, a day-long conference focusing on the latest research on brain imaging, oxytocin treatment, and related topics. About 300 parents, educators, and health care providers heard talks by Feinstein, Hardan, Phillips, and other autism experts from Stanford and elsewhere.

"The day may come when researchers finally figure out what causes autism spectrum disorders," says Cheryl Scimone. "We have quite a few friends whose children have autism, and everybody is just scratching their head, wondering why did this happen? We don't know yet. Maybe someday we'll have an answer."

Adds Hardan, "We want to have a great autism and developmental disabilities center at Stanford that will make us proud. We've made some progress, but we need more support and help to make it happen." ●

Toni Gauthier

Alex Scimone has made significant progress with our care.