

SUMMER 2011

THE DEVELOPING MIND

The Boone Fetter Clinic: Diagnostic, Clinical & Research Center for Autism and other Neurodevelopmental & Behavioral Disorders



Kameena Ballard with her daughter, Keena, at the Boone Fetter Clinic at Children's Hospital Los Angeles

Welcome

In each issue of The Developing Mind, experts at Children's Hospital Los Angeles respond to issues and questions called in to the Autism Warm Line by parents and providers like you. Because it is sometimes difficult to find a trustworthy source for answers to complex questions about your child's health and development, we provide this newsletter to bring you up-to-date information from specialists and researchers at Children's Hospital. For more information about the clinic or if you have a question about your child's development, please call the Autism Warm Line at 323-361-6102.

In This Edition:

- 2 Parent Profile: Kameena Ballard
- 2 Children's Hospital Los Angeles has Joined the Autism Treatment Network
- 3 Research Highlight: Creating a Sensory-Smart Dental Office
- 4 Latest News and Events



To make an appointment, call the Autism Warm Line: 323.361.6102, email boonefetterclinic@chla.usc.edu or visit CHLA.org/BOONEFETTERCLINIC
1300 N. Vermont Ave., Ste. 905, Los Angeles, CA 90027

Parent Profile: Kameena Ballard

Kameena Ballard is a member of the Children's Hospital Los Angeles Autism Parent Advisory Committee.

Kameena Ballard wears many hats. She's an identical twin and an entertainer—as one half of the female singer/songwriter and recording duo “K-Divas.” Kameena is also an advocate for her 8-year-old daughter, Keena, who has autism.

As a single parent, Kameena is adamant about parent training and has encouraged her entire family to become Applied Behavioral Analysis-trained. She is also a member of the Community Emergency Response Team and actively involved at her daughter's school, The Help Group – Sherman Oaks.

Using Keena as motivation, Kameena and her family extend their reach for awareness, as participants in the “Autism in Urban Context” research project, through the University of Southern California's Division of Occupational Science and Occupational Therapy. The study is examining multi-ethnic African American children with ASD and how they receive diagnosis and treatment. Kameena also represents Children's Hospital on the Family Advisory Committee of the Autism Treatment Network.



Keena and Kameena Ballard

Children's Hospital Los Angeles has Joined the Autism Treatment Network

Children's Hospital Los Angeles recently joined the Autism Treatment Network (ATN) as a Center of Clinical Excellence. The ATN is supported by Autism Speaks, North America's largest autism science and advocacy organization. Children's Hospital Los Angeles is now the only ATN site in California.

The ATN is a clinical program that serves an important role in creating new and effective ways to meet the complex medical needs of children with an autism

spectrum disorder. As an ATN site, Children's Hospital joins a network of hospitals and doctors using a common approach to diagnose autism and treat associated medical conditions. The hospital also will be able to expand its innovative research programs, which engage patients in order to change the future for children with autism and their families.

“It is with great enthusiasm that we join the Autism Treatment Network,” says Michele

Kipke, PhD, vice chair of research in the Department of Pediatrics and director of the Boone Fetter Clinic. “Participation will allow us to engage in leading-edge research that seeks to promote both discovery and delivery of high-quality care to children with autism spectrum disorders and their families.”

Children's Hospital Los Angeles uses a family-centered care model for patient care. At the hospital's two autism clinics, the Boone Fetter Clinic and the University of Southern California (USC) University Center for Excellence in Developmental Disabilities, staff conduct interdisciplinary assessments while a nurse management team coordinates services throughout the hospital, making parents partners in the delivery of care. This is considered the gold-standard model of service and participation in the ATN is helping make the best even better.



Boone Fetter Clinic staff: Desiree Go, MA, OTR/L, SWC, (left), Director Michele D. Kipke, PhD, Kathi Smith, RN, DrPH, Cody Haight, Larry Yin, MD, Marcia Higareda and Sarah Mason

Research Highlight: Creating a Sensory-Smart Dental Office

Visiting the dentist for routine teeth cleaning can be difficult and stressful for children with autism spectrum disorders (ASD). This is due in part to sensory sensitivity to bright lights, loud noises, being touched by other people and the tastes and smells of toothpaste and other oral health products. This makes visiting the dentist a real challenge for families and can lead to poor oral health for some children.

A group of clinicians and researchers at Children's Hospital Los Angeles and the University of Southern California (USC) have teamed up on a research project to understand the experiences that children with ASD have with oral health care. They are developing an intervention to make teeth cleanings not only easier and less stressful for the child, but also more time-efficient, safer and less expensive. This team is led by Sharon Cermak, EdD, an occupational therapist with expertise in ASD and professor in the Division of

Occupational Science and Occupational Therapy at USC; Jose Polido, DDS, head of the Division of Dentistry at Children's Hospital and Marian Williams, PhD, a clinical psychologist at the USC University Center for Excellence in Developmental Disabilities with expertise in autism and anxiety.

So far, their research shows that parents report children with ASDs have a much harder time in the dental office compared to children with non-ASD disabilities and typically developing children. The research also shows that difficulties and negative experiences at the dentist reported by the parents (such as trouble during cleanings, uncooperative behaviors and needing to use restraints) may be related to children's sensory challenges.

In collaboration with investigators at Beit Issie Shapiro Center in Israel, the team has developed a program which will modify

the sights, sounds and the overall environment of the dental office so that it is more sensory-friendly. The next step in the research process is to test this program by comparing the behavior and level of anxiety of children in the adapted environment to that of children in a normal dental environment.

The team is currently seeking funding to support its research. Ultimately, they expect to find that the sensory-adapted environment is beneficial not only to children with ASD but also to typically developing children with anxiety or sensory sensitivities. The researchers hope the program will be successful in decreasing anxiety and negative behaviors as well as reducing the need for restraints or sedative medication. As a result, treatment will be safer, more efficient, faster and less costly, making access to care easier for all families, but especially those with children with ASDs.



Marian Williams, PhD, (left), Jose Polido, DDS, and Sharon Cermak, EdD

The team has developed a program which will modify the sights, sounds and the overall environment of the dental office so that it is more sensory-friendly.

Latest News and Events

Reporting Back on Autism Awareness Month

The Boone Fetter Clinic at Children's Hospital Los Angeles works to spread autism awareness, knowledge and resources through the greater Los Angeles community. April was Autism Awareness Month and the clinic celebrated with a range of exciting community events. Staff dressed up in blue, went outside and walked with families. They let their creativity shine through arts and crafts, and highlighted successes and shared in the scientific achievements of their peers in the growing field of autism research.

Fiesta Educativa

Fiesta Educativa's first Autism Research Conference in April 2011 brought information about the Boone Fetter Clinic and its research to the Los Angeles community of Latino parents raising children with autism. About 100 parents were in attendance. Phil Gorrindo of the Zilkha Neurogenetic Institute at the University of Southern California presented "Tummy Troubles," a research study at the Boone Fetter Clinic exploring a genetic link

between gastrointestinal issues and autism. The presentation's key point was that each child with autism is unique, and this uniqueness can help understand genetic risk and how autism develops biologically. Gorrindo also emphasized that children with autism need health care services tailored to their individual needs.

Though Autism Awareness Month has ended, the need for autism awareness has not. Thankfully, the resources, information and community support for autism are growing. The Boone Fetter Clinic is proud to be a part of this wonderful community as a resource and source of support.

Walk Now for Autism

Walk Now for Autism was the perfect opportunity to reach families of children with ASD in the community. The walk took place at the Rose Bowl in Pasadena on April 23, 2011. The Boone Fetter Clinic's booth was a great resource, stocked with clinical information and newsletters, as well as an arts and crafts station for children. The kids loved making bubble art with paper, straws and colored water in green, red, orange and blue.

Kameena Ballard, a member of the hospital's Autism Parent Advisory Committee, and her daughter, Keena, walked, along with clinicians and staff. "It was a pleasure being this year's Walk Team Captain," Kameena said after the event. "I gained so many valuable resources, and my daughter and I had a blast!"

Light It Up Blue!

The Boone Fetter Clinic kicked off Autism Awareness Month by participating in Light It Up Blue, an international event to show



Boone Fetter Clinic staff and friends at Walk Now for Autism.

support for the autism community by wearing blue. The Boone Fetter Clinic, in partnership with Autism Speaks, hosted an informational table in the front lobby of Children's Hospital Los Angeles. Greeting the staff, volunteers and patient families as they came through the main entrance, they were able to reach out to about 100 families and shared newsletters and information about clinical services. The kids and adults who came to the booth left with a blue puzzle-piece sticker (the emblem of Autism Speaks) to show their support of the autism community.

Turn on the Lights

At the exciting *Turn on the Lights! Walk for Kids*, in honor of Children's Hospital's new hospital building, the Marion and John E. Anderson Pavilion, the Boone Fetter Clinic proudly celebrated by hosting an informational table and kids' arts and crafts table before joining the Walk. Staff and clinicians were available to answer questions and connect with local clinicians outside of Children's Hospital Los Angeles, who were excited to meet the clinic's developmental-behavioral pediatrician, Douglas Vanderbilt, MD.



Marcia Higareda (left) and Flannery LaGrua at Fiesta Educativa.