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





Welcome

In each issue of The Developing Mind, experts at Children's Hospital Los Angeles respond to 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.

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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 Focus: The Importance of Early Intervention

Margarita (Rita) Gevondyan is a member of the Children's Hospital Los Angeles Autism Parent Advisory Committee. She has two sons, Greg, 5 and Alex, 3. Rita is an attorney and has also worked as a registered nurse. She became involved with the advisory committee as a way to help educate the community and care providers, and to share her inspiring story with other parents.

How did you first learn that your child has an autism spectrum disorder?

When Alex was a little over a year old, I noticed that he was not hitting the typical social and language milestones. He did not talk, point or clap and had very little engagement with us. Alex was first given his diagnosis of autism spectrum disorder (ASD) at the Boone Fetter Clinic at 16 months old ... I was told that he was the youngest patient ever given the diagnosis. A month later, he was given the same diagnosis at a regional center.

What was it like when you first learned about your child's autism diagnosis?

In a way, I had already known that Alex was on the spectrum but officially hearing it was devastating. I cried for hours every day

and spent every free moment searching for ways to help Alex. I withdrew from friends and family. And every moment I was with Alex, I was trying to engage him and pull him into our world. It was very tough on our family, especially my son, Greg, who was only 3 years old at the time. He did not understand why his brother did not walk or want to play with him when other boys Alex's age did. Shortly after I got over the initial shock of Alex's diagnosis, I was determined to help Alex any way I could ... I was obsessed, a woman with a mission. Alex started receiving early intervention therapies including floortime-based therapy, speech and language therapy and occupational therapy for approximately 15 hours a week.

These early intervention therapies really helped Alex engage with us and he began to communicate. In addition, I started searching and implementing "biomedical" alternative therapies, which I thought were extremely helpful—especially given the fact that Alex had gastrointestinal issues which are very common with kids on the spectrum. We had some great results with the biomedical therapies and also some not-so-great results.

Slowly, with everything we were doing, Alex started to do better. He was initially diagnosed with ASD in September 2009.



Aaron Tanner, SLP, with Greg, Alex and Margarita Gevondyan.



Margarita and her son, Alex.

And one year later, in October 2010, Alex was officially "undiagnosed." Alex no longer tests on the spectrum though he still shows some minor residual signs of ASD. Alex's journey has been a rollercoaster for our family but his progress has been a prayer answered. He started a typical preschool just a month ago and is doing fine. He is one of his teacher's favorite students. Alex is a perfect example of the possible outcomes with early, early intervention.

Why did you get involved with the parent advisory committee?

I really enjoy being part of the advisory committee. I got involved with this group in order to help educate the community and other parents of the importance of early intervention. In addition, I was hoping to provide traditional medical practitioners with information and insight into a parent's view of alternative therapies. I want parents to know not to lose hope ... though not every child is the same, there are always things you can do to help.

"When Alex was a little over a year old, I noticed that he was not hitting the typical social and language milestones."

Communication is Key: An interview with Aaron Tanner, SLP



"Communication is key for children with autism spectrum disorders, " says Aaron Tanner, SLP.

Aaron Tanner is a speech and language pathologist at Children's Hospital Los Angeles. Below, he discusses the importance of communication for children with autism.

Why is communication important for children with autism spectrum disorders?

A common challenge for children with autism spectrum disorders (ASD) is the inability to communicate to other people about what they are thinking and feeling. Autism can sometimes affect a child's motor planning, so he or she may have physical difficulties speaking or gesturing. More often, the social aspects of communication, or social language, present the most significant challenge for children of any age with autism. For example, following the rules of a schoolyard game, or understanding another student's joke, can be especially difficult for a child with autism.

How can parents know if their child's communication is developing normally?

As a child grows, there are several key developmental milestones that parents should look for. Children usually say their first words by 10-12 months of age. At around 18 months, children begin combining words to make short phrases, like "mama go." One very important milestone is the use of eye contact, which typically develops around 8 weeks of age. Eye contact is a baby's way of saying, "Hey, I know who you are." This is essential, because it shows social awareness and indicates that the baby's neurological growth and ability to communicate are developing normally.

What services are available for children with communication challenges?

For any child, communicating with family, care providers, teachers and peers is important for healthy development. At Children's Hospital Los Angeles, speech and language pathologists (SLP) help children and young adults with autism to overcome communication challenges. By engaging with children early, we can lay a strong foundation for language development and help children gain the social skills needed to communicate effectively and maintain healthy relationships.

How else do speech and language pathologists help?

Speech and language pathologists also play a vital role in the assessment of children who are thought to have autism or other neurodevelopmental disorders. During a team evaluation in the Boone Fetter Clinic, we will assess the strengths and weaknesses of a child's ability to use and understand language. We also look at non-verbal communication, use of social language and the child's ability to play, interact and socialize. This information helps the evaluation team create an accurate diagnosis and a therapeutic plan of care that is tailored to the child's needs.

With a unique understanding of what a child needs to be successful in a social

learning environment, SLPs are also able to help families find the right educational program for their child, as well as access services within the community. Communication is key for children with autism spectrum disorders, and the specialists at Children's Hospital work hard to help children overcome communication challenges and engage in healthy social relationships.

Glossary

Communication

Expression of thoughts and ideas through speech, signals, writing or behavior.

Developmental milestones

A child's traits and abilities that generally occur at specific ages. Doctors and parents use milestones to track a child's developmental progress. For example, head raising, crawling, walking and speech.

Evaluation

Assessment of a patient in order to form a diagnosis and plan of treatment.

Motor planning

The ability to plan and carry out new tasks. Children with motor planning difficulties can have problems organizing their thoughts and using language to express themselves.

Neurological growth

Development of the brain, spine and nervous system.

Social language

Verbal and nonverbal communication in face-to-face interactions. For example, conversation, eye contact, facial expressions.

Speech and language pathologist

Health professional trained to evaluate and treat people who have voice, speech, hearing, swallowing or language disorders that affect their ability to communicate.

Autism Treatment Network Center of Clinical Excellence – Update

As an Autism Treatment Network Center of Excellence, we're focused on being a local and national leader in the treatment and care of children with autism spectrum disorders (ASD). As a part of this effort, we are engaging with local care providers and health care leaders to help ensure that all children with ASD in Los Angeles have access to high quality care.

We've established an Autism Community Advisory Board, which includes local care providers, advocates, parents and others interested in better understanding the needs of children with ASD and their families. This advisory board will serve as



The Autism Treatment Network Center of Clinical Excellence at Children's Hospital continues to expand and develop.



Community Provider Workshops provide up-to-date information.

our interface with the autism community in Southern California. The board will help us to understand the needs and concerns of community members so that our work is focused on the most important issues; help us know the best ways to disseminate evidence-based practices to parents and community providers and identify opportunities for partnerships and collaborations on new projects and research studies.

In addition, we are hosting Community Provider Workshops with general pediatricians, family practitioners and community providers in the diverse communities of Los Angeles. These workshops are focused on providing up-to-date information about screening, diagnosis, current research and community resources, promoting the early identification of children who may have an ASD diagnosis and referral for evaluation and services, and raising awareness of medical conditions related to ASD and different management options.

The Autism Treatment Network Center of Clinical Excellence at Children's Hospital Los Angeles continues to grow and develop. Our community advisory board will ensure that our work focuses on what is most important: improving the lives of children with autism and their families.



We are focused on being a local and national leader in the treatment and care of children with autism spectrum disorders (ASD).

Autism Research at Children's Hospital Los Angeles

Research is key to improving the health and well-being of children with developmental concerns. Patients and families often participate in research as a way to learn about their diagnosis and treatment options and to help build understanding of the conditions that affect them. A research registry is a confidential and convenient way for families to connect with researchers and help to mobilize studies quickly. Autism research studies at Children's Hospital Los Angeles are focused on understanding these complex disorders, improving care and outcomes, and creating new tools to improve the lives of children and their families.

To learn more about autism research at Children's Hospital Los Angeles and how to participate, call our research manager, Marcia Higareda, at 323-361-8444.



Patients and families often participate in research to learn about their diagnosis and treatment options.