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Meltdowns and  
Autism, Page 3



## Welcome

It is sometimes difficult to find a trustworthy source for answers to complex questions about your child's health and development, so we provide this newsletter to bring you up-to-date information from specialists and researchers at Children's Hospital Los Angeles, a proud member of the Autism Speaks Autism Treatment Network. For more information about the Boone Fetter 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 at 323.361.6102, email [BooneFetterClinic@chla.usc.edu](mailto:BooneFetterClinic@chla.usc.edu) or visit [CHLA.org/AUTISM](http://CHLA.org/AUTISM).

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Members of the Autism Parent Advisory Board: Sonia Guzman-Gonzalez (left), Margaret Billard, Kameena Ballard, Jess Block-Nerren and Kymberly Mariajimeñez

The Autism Parent Advisory Board at Children’s Hospital Los Angeles is a dynamic and active group of parents who give generously of their time to help ensure that we provide care and services that are relevant and responsive to the diverse needs of families of children with autism spectrum disorder (ASD).

Several of the board members have received care at Children’s Hospital Los Angeles and are able to provide insight and input regarding our services, policies and procedures, and help educate our providers and clinical staff. They also help develop new articles for The Developing Mind newsletter, and make sure that it stays relevant to the needs of families.

This partnership is helping to improve the quality of care and resources we provide to families, as well as contributing to efforts through the Autism Speaks Autism Treatment Network to improve the lives of all children and families affected by ASD.

A few of the parents shared their reasons for joining the Autism Parent Advisory Board:

### Jezreel Tavie:

*“Nothing we do in life is more important than the effect it has on a child—specifically those with special needs. As both a parent of an ASD child and a member of the Autism Parent Advisory Board, I’ve dedicated my life’s work to not only successfully guiding my child on this autism journey, but also assisting and supporting parents like myself who are on a personal journey as well.”*

### Margaret Billard:

*“I wanted to be part of the group because I, like the other members, am a parent to an autistic child. My child, however, is 25 years old. I didn’t have the luxury of the many accommodations that the parents of younger children now have, and I know what it is to advocate for your child where there are few guidelines. My hope is to encourage these parents, to help guide them to the proper agencies or groups that can assist them, and to help with the academics who interact with our parents’ group in creating accessible, accurate literature for these parents.”*

### Judy Bishop:

*“Parenting special needs children is a unique challenge. It can be extremely difficult, but the rewards are amazing. My mission is to not only guide my children and help them to be the best people they can be as they travel down their individual paths, but to also support others around me who are just starting on their ASD journey.”*

### Kimberly Mariajimeñez:

*“We are a voice for our children. As an ASD child’s mother, I can understand the obstacles and hardships that may come with raising autistic children; more importantly, though, I understand the extreme measures of love and selflessness that your child will show you. Being an Autism Parent Advisory Board member, I have the privilege of helping ASD children and their families who do not have the opportunity of voicing their opinions. The efforts and dedication of the Autism Parent Advisory Board will leave a legacy of care, hope and love for the special needs children of the future.”*

To support autism research and programs at CHLA, visit [support.CHLA.org/pages/autism](http://support.CHLA.org/pages/autism)

All parents know about the trials of dealing with a child’s occasional temper tantrums. For some parents of children with autism, however, handling temper tantrums and enduring behavioral meltdowns can be an almost daily challenge.

### Tantrum triggers

Tantrums are a way for children to let out pent-up frustration, and to let others know they are upset. Tantrums can be triggered when the child is hungry or tired, or has become upset by a change in routine. The child may also have become overstimulated by the surrounding environment. A tantrum turns into a meltdown when the child loses control of his or her emotions and behaviors. The triggers are different for each child, so it is important to learn what sets off your child’s tantrums.

### Tantrums and autism spectrum disorders

Children with autism are often more sensitive to their environment and can become overstimulated very quickly. A trip to the shopping mall may be fun for a typically developing child, but for a child with autism, the sights and sounds can lead to an overwhelming experience. This overstimulation can cause stress and put the child on edge. Also, children with autism usually have some challenges communicating and processing spoken information. This can make it difficult for



them to let their parents know what they are feeling, or inhibit their ability to take directions or instructions from a parent. Autism can also affect the ability to regulate one’s emotions, which means that children with autism can go from content to upset very quickly. These combined factors make kids with autism particularly susceptible to tantrums, and cause their tantrums to escalate more quickly into meltdowns.

### Preventing tantrums

The most important thing is to keep a consistent routine. Children on the spectrum rely on a consistent daily routine to provide structure, and can become easily upset if this routine is disrupted. For example, if your child is used to going straight home after school, a quick trip to the grocery store could be very upsetting. If you need to change the routine, let your child know beforehand that things will be different so he or she knows what to expect.

Also, try to identify what specific situations or events trigger tantrums with your child. You may notice that your child tends to have tantrums right after getting home from school. This may be his or her way of letting out all the anxiety and frustration that has built up over the day. If this is the case, you may want to have “quiet time” or a relaxing activity as soon as you get home to help your child release the anxiety in a healthier way. If you find your child

gets overwhelmed in public places, try to bring along a favorite toy or something that helps avert any stress.

Another important thing to consider is that children tend to pick up on their parents’ anxiety. That is, if their parents are feeling anxious, then they will react to that by taking on some of that anxiety themselves. It’s really important for parents to take care of themselves and manage their own stress level, so that it doesn’t feed into their child’s own anxiety.

Lastly, remember that a child is always learning. If a child is having a tantrum over a candy or toy that the parent is withholding, if the parent relents and gives up the desired item, then the child will learn that a tantrum is a great way to get what he or she wants. So a good way to prevent future tantrum episodes is to not give in to the current one. While assuring that the child is safe, let the tantrum run its course. The child will learn that tantrums don’t work.

### Tips:

- Keep a consistent routine.
- Prepare ahead of time.
- Manage your own stress level.
- Don’t give in to tantrums.
- Learn the triggers:
  - Feeling hungry
  - Change in routine
  - Overstimulation
  - Feeling tired
  - Stressful events

If you have any questions or need additional information or help managing your child’s tantrums and meltdowns, you can call our Autism Warm Phone Line at 323-361-6102.

## Research Highlight: Addressing Autism Disparities

In our previous newsletter, we discussed the topic of autism disparities and our current research into understanding the complex challenges that African-American and Latino families face getting a diagnosis, and then accessing related services for their children with autism.

In focus groups with parents, the research team from the Boone Fetter Clinic learned that families need:

- General knowledge and education on the warning signs for autism
- Assistance navigating complicated service systems
- Training in how to advocate for their children

The team is now focused on creating new resources for families to address these needs, in order to promote early diagnosis and access to services for Latino and African-American families in the Los Angeles area.

To begin, the team has adapted an educational curriculum called Developmental Milestones. Originally developed by the Organization for Autism Research, the curriculum has been adapted for Latino

families in Los Angeles, building a single educational program that integrates those three themes: knowledge about autism, advocacy training and assistance navigating the service system. The research team worked with parents, community organizations and promotores to ensure the curriculum is culturally appropriate and addresses the community's broad needs. Promotores are lay community health workers who are part of the community they serve. They receive training to educate, advocate and assist families in accessing health services. The researchers will test the new curriculum with Latino families in community settings, using the "promotor" model, which has proven effective in other areas, such as diabetes and obesity prevention and promotion of reproductive health.

The overall goal of this work is to reduce autism disparities by helping underserved families of children with autism to get a diagnosis earlier, and increase their access to intervention services, such as speech and occupational therapy. Based on what they learn from this program, the researchers will also adapt the program for African-

American families, using a similar model with community health workers.

This important work is being done in partnership with the Southern California Clinical and Translational Science Institute and the Autism Speaks Autism Treatment Network.

### Vaccines Do Not Cause Autism

Our team of experts in the Boone Fetter Clinic and across Children's Hospital Los Angeles agrees with this statement from Autism Speaks:

*Over the last two decades, extensive research has asked whether there is any link between childhood vaccinations and autism. The results of this research are clear—vaccines do not cause autism. We urge that all children be fully vaccinated.*

## Research Opportunity: Intervention for Sensory and Motor Delays

Experts at Children's Hospital Los Angeles are conducting a study to improve care for children with autism spectrum disorder (ASD) who have sensory and motor delays. Sensory and motor delays are common in children with ASD and can significantly impact their performance in everyday activities, including schoolwork, play with peers and participation in community events.

According to lead researcher Stefanie Bodison, OTD, OTR/L, "We want to better understand how the brain uses sensory and motor information, and if improvement can be made by a specific sensory-enriched occupational therapy intervention." The information learned through this study will help researchers develop and refine future interventions targeting the sensory and motor delays in children with ASD.

The study is currently enrolling boys with ASD 6 to 8 years of age. Eligible families will visit Children's Hospital Los Angeles three times and receive six months of free occupational therapy intervention at Pediatric Therapy Network in Torrance, California. For more information, contact our study coordinator at **323-361-7756** or email us at **brainstudy@chla.usc.edu**.