

SEED Study to Explore Early Development

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This is a semi-annual newsletter of the Centers for Disease Control and Prevention-funded Study to Explore Early Development (SEED). The purpose of this newsletter is to inform the public of the study's progress.

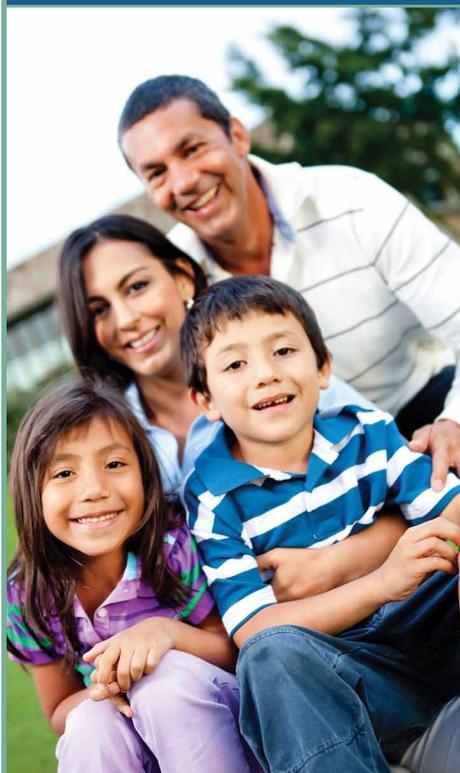
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Emergency Preparedness: In this edition, we share one family's story and offer some tips on emergency preparedness for families with children.

Taking care of your family includes being ready for emergencies. Parents can make sure family members know what to do to get ready for disasters, and what to do when they happen.

Lauren and Stephanie's Story

Lauren was with her daughter, Stephanie, in the intensive care unit at a local hospital when Hurricane Sandy hit. Stephanie has autism and recently underwent a kidney transplant, which requires her to have refrigerated medicine and to be in a climate-controlled environment at all times. When they returned home, there was no electricity or heat, and the family soon realized that they would need a generator to help care for Stephanie's medical needs. "We first thought of a generator before her kidney transplant, but it took being without electricity to realize we really needed it," says Lauren. These are familiar challenges faced by many families during storms and other emergencies.

Fortunately, the local fire department stepped in to store Stephanie's medicine and offered to find her a cool, dry place to stay. Items such as coolers and ice packs can help keep medications cool for a short time, if you do not have electricity.

Now Lauren keeps a "go" bag in case of emergencies, which can easily be carried in a car, in case she is away from home during an emergency. Lauren keeps essential items in her "go" bag so that she can have everything ready in case she needs to leave quickly. A "go" bag might include:

- Personal items (toothbrush, soap, and other items used daily)
- Diapering supplies
- Medications used daily
- A list of daily medications and their dosage
- Medical records
- Cold packs

Packing emergency supplies and information in an emergency kit can make it easier to prepare and respond during a disaster, especially if you have a child with special health care needs.

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It is important for families to keep medical supplies available and packed in multiple places in case of an emergency because **“you don’t have time to pack when it happens,”** says Lauren.

Children with Special Healthcare Needs in Emergencies

Children with special healthcare needs may be more vulnerable during an emergency. They may have difficulty moving from one location to another, have urgent or persistent medical needs, difficulty communicating, or have trouble with transitioning to different situations. A disaster can present all these difficulties at once. Knowing what to do can help keep your family calm and safe.

Please visit the following sites for more resources:

- <http://www.cdc.gov/ncbddd/disabilityandhealth/emergencypreparedness.html>
- <http://emergency.cdc.gov/children/families.asp>
- Disability.gov
- <http://ready.gov/kids>



HIGHLIGHTS OF SEED PROGRESS



SEED 2 is growing!

The SEED 2 sites started inviting families to take part in the study in the summer of 2012. So far, 1,668 families have enrolled. Increasing the number of families enrolled in SEED allows us to get an even better picture of what puts children at risk for developing an autism spectrum disorder. Thank you SEED families!

Watch for our next newsletter to see how SEED grows or visit www.cdc.gov/seed to see all the editions of the SEED newsletter.

SEED 1 2,700 families SEED 2 1,668 families



The graphic shows SEED 2 progress as of January, 2014.



A Father’s Perspective

Dr. Robert A. Naseef Ph.D. is a psychologist in Philadelphia, PA and is the author of a book called ***Autism in the Family: Caring and Coping Together***. Dr. Naseef shared with us some thoughts about how he learned to accept his own son’s diagnosis of autism and intellectual disability.

“I thought I could never accept my baby’s autism. After 29 years there are times when I still wonder who my son might have been, and who might I have been as well. Sometimes it seems like only yesterday when I held Tariq for the first time. My heart pounded with excitement as I held his soft body next to my heart and our eyes met. Instantly he made me a father with visions of playing baseball and building model airplanes together and having a warm, close relationship. How could it be that he would grow to adulthood and not read or write or speak?

Like children on the autism spectrum – who are on a range from severe to mild – parents’ reactions vary. Through my severely affected son, I have learned that regardless of a child’s ability, the experience of parenting a child on the spectrum can be a journey in which we become wiser, more compassionate, and more loving.

Parents need support and good services, to come to terms with what is possible and what is not for their child. I could not have ever found peace without support. My wife Cindy, Tariq’s step mom, weathered the storms of his autism with me and never wavered in her love. She helped me grasp the diagnosis I was trying desperately to deny.

On the path to acceptance, I have learned many things that have helped me. My son taught me the meaning

What is Autism Spectrum Disorder (ASD)?

ASD is a group of conditions that can cause significant social, communication, and behavioral challenges. ASD can range from very mild to severe. People with ASD share some similar symptoms, such as problems with social interaction. However, there are differences in when the symptoms start, how severe they are, and the exact nature of the symptoms. – CDC *For more about ASD, visit www.cdc.gov/autism*

of unconditional love—to honor his sacred right to be loved for who he is, not what he has achieved lately, how he looks or how much money he will earn. I learned the lesson that hard work isn’t everything. That grief comes and goes. That anxiety and sadness come and go. That it takes time to heal a broken heart. That happiness and meaning can abound with acceptance. We don’t have to push away our painful thoughts and uncomfortable feelings. I learned that acceptance does not mean giving up but rather learning to live with our mental and physical challenges.

I have come to know that Tariq’s life does make a difference in the world. He is still my little boy. He still puts his head on my shoulder, and I have never stopped wanting to hear the sound of his voice. Yet I love him no less because of that and perhaps more in ways I could have never imagined. He has brought many kind people into my life and helped me to understand myself and others. He made me a better father and a better man. His greatest gift to me is a glimpse into the human heart where it is not who you know or what you know or what you have—but who you are. My son has only ever spoken aloud to me once in a while—in my dreams; but this is how his autism has spoken to me every day.”

Highlights of North Carolina SEED II Progress

314 of 1,668 (or about 19 %) of the total number of families enrolled in SEED II have come from North Carolina.

We have invited 3,065 families, 314 enrolled, and approximately 177 have finished their participation. Most families are still working through the study steps. Our North Carolina families have been so wonderful to support our research and we are so thankful for them!

Enrolled Families	314
Maternal Interview done	257
Medical Records Releases (# of families)	177
Questionnaire Packets	242
Developmental Test done	177
Saliva samples (# of families)	173
Blood samples (# of families)	158

** as of Dec 17, 2013*



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Control and Prevention**
National Center on Birth Defects
and Developmental Disabilities

CADDRE
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SITE SNAPSHOT: MARYLAND



M. Daniele Fallin, PhD, is both the director of the Wendy Klag Center for Autism & Developmental Disabilities and the Maryland Principal Investigator for SEED.

In the state of Maryland, both Johns Hopkins University and Kennedy Krieger Institute work together on SEED to invite families to participate, conduct visits, and collect data.

The Johns Hopkins University Bloomberg School of Public Health recently hosted the inaugural symposium for the Wendy Klag Center for Autism and Developmental Disabilities in Baltimore, Maryland. This new center will unify and expand work on autism spectrum disorder (ASD) at

Johns Hopkins University, in hopes of informing practice and policy that will make a difference in the lives of children, adults, and their families.

Researchers from California, Pennsylvania, Georgia, and Maryland, including California SEED Principal Investigator Lisa Croen, PhD, and Maryland SEED co-investigator Rebecca Landa, PhD, CCC-SLP, presented a wide variety of talks about ASD at the event.

Also at the event, Bloomberg's Dean Michael J. Klag presented the Dean's Medal to Autism Speaks co-founders Suzanne and Bob Wright, for their global leadership in autism research and advocacy. The new center is named in honor of Dean Klag's late wife, who was the devoted mother of three children, one of whom has ASD. Maryland's SEED principal investigator, M. Daniele Fallin, PhD, directs the new Wendy Klag Center.

To view talks presented at the event, visit www.jhsph.edu/wkc/symposium

- Lisa Croen, PhD, of Kaiser Permanente in California: *The Epidemiology of Autism: Genetic and Environmental Interplay*
- Jennifer Mulle, PhD, of Emory University: *The Gut Microbiome and Autism Risk*
- David Mandell, PhD, of the University of Pennsylvania: *Building a System of Care for People with Autism*
- Maureen Black, PhD, of the University of Maryland: *Global Focus on Developmental Disabilities*
- Rebecca Landa, PhD, CCC-SLP, of Kennedy Krieger Institute in Maryland: *The Emergence of Autism: The First Three Years*