

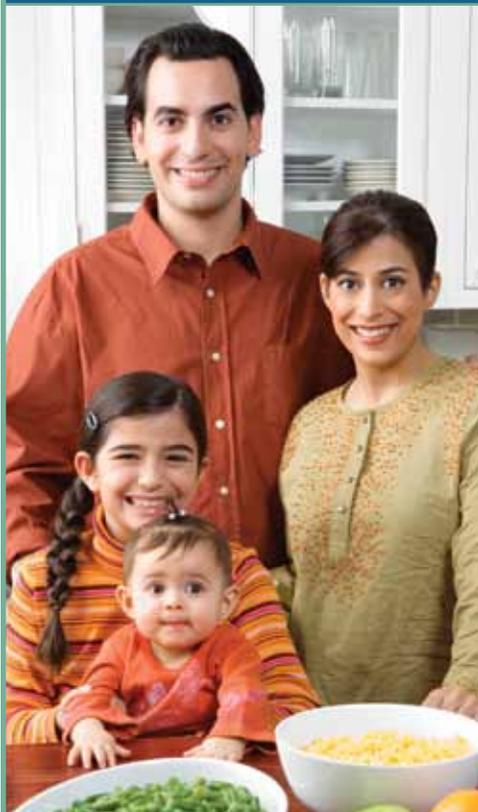
# SEED Study to Explore Early Development

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*This is a semi-annual newsletter of the CDC-funded Study to Explore Early Development. The purpose of this newsletter is to inform the public of the study's progress.*

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In this edition, we share the knowledge of one of the professionals in Maryland on issues important to new parents or parents with young children!

### **ASK THE EXPERT: Early Detection of Autism Spectrum Disorders**

By Rebecca Landa, PhD, CCC-SLP, Director of the Center for Autism and Related Disorders at the Kennedy Krieger Institute and Co-PI of the Maryland SEED Study

When a child's developmental delay is not apparent at birth, parents often search their memories for the earliest signs that something was not right. The idea of 'early detection' is not new, but recent research with infants and toddlers has shed light on particular signs of autism and milder social and communication delays. For one- and two-year-olds, these signs include things like:

- not responding to his or her name
- having poor eye contact with others
- rarely smiling back at someone who smiles at the child
- rarely trying to talk with others
- language delay
- lack of response to direction
- doing something over and over (repetitive play)
- strange movements (like turning the hand in circles).

When several signs are present at the same time, or if there is any loss of skills, a child should see a doctor who specializes in child development, such as a developmental pediatrician.

Early detection of autism is very important because it helps a child to receive early intervention services, such as speech therapy. Research has shown that most children with autism do not show much improvement in social development on their own during the second year of life. This means that children with autism need extra help to learn the skills that will open the doors to more successful social interaction and communication. The type of experiences that children receive in well-designed early intervention will have a great impact on how they make sense of the world around them. This is helpful to the developing brain. It is important for children with autism to have every opportunity to understand and enjoy social opportunities, and to interact as much as possible with loved ones.

At the Center for Autism and Related Disorders (CARD) at the Kennedy Krieger Institute (KKI), early intervention research is being done to better understand how to help the development of very young toddlers who are showing social and communication delays (even if they don't have a diagnosis of autism). Research is being done in parent training, parent education, and direct intervention with the children. In the parent training sessions, parents are coached in ways to help their child interact, communicate, and play with others. In the parent education classes, parents learn about child development and ways to enrich children's development, as well as share their experiences and wisdom with each other. In the direct child-intervention sessions, children are taught to share and play with other children, and to grow in their communication skills.

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Our hope is that, in the near future, most children with autism will be identified well before their third birthday. We also hope to learn how best to improve the course of development for young children with autism, and to give them a brighter future!

For more information, the Centers for Disease Control and Prevention has put together a website and free materials on what to look for in your child's development and what to do if you think there may be a problem: <http://www.cdc.gov/ncbddd/actearly/>

## SUMMER TIME HIGHLIGHTS: TRAVELING

Michelle Landrum is the mother of two sons, one who is on the ASD spectrum. Michelle, who works with SEED researchers at the Maryland site, offers these mom-tested sanity savers for traveling by plane, but will work for train or car travel too!

### ■ **Know what to expect.**

Before and during a trip, speak calmly with your children about what to expect. I hold on-the-spot 'family meetings' to let my kids know 'here's what's coming next.' Short stories or photographs of the plane may help too.

### ■ **Try to keep yourself calm.**

If I'm anxious, my kids know it. Remember: Whatever you forgot to pack, you can probably buy during your trip.

### ■ **Be prepared.**

Book plane trips with enough time between connecting flights. Pack snacks, juice boxes, a soft blanket, favorite toys, plus some new toys that your child hasn't yet seen. Earphones or ear buds are great to plug into a handheld videogame, MP3 player loaded with an audio book, and the plane's audio system if you're flying. If your child has very sensitive hearing, consider bringing ear protection.

### ■ **Ask the Airline staff for help.**

If your child has special needs, let the airline know ahead of time. You may be able to do a test-run at the airport, or to be among the first passengers to board.

## DATA COLLECTIONS CORNER: QUESTIONNAIRES

The SEED study is like a three-legged stool, supported equally by biological sampling, clinical visits, and self-reported questionnaires. If a participating family does not complete all three parts, they topple into SEED's "Incomplete" category and cannot contribute fully to our research. You might think the questionnaires we send to families' homes would be the easiest step to complete. But, in fact, they are one of the top reasons families may not be included in SEED's final results.

If you have lost your questionnaire packets, no worries! Just call your SEED contact and they'll mail you another packet. The questionnaires – covering topics such as parents' medical and work history, the child's early development, bowel

function and sleep habits – give important information that can be joined with biological samples and clinical information to help understand the causes of autism. There are no right or wrong answers to these questionnaires. Maryland SEED Project Coordinator Jamie Dahm says, "The questionnaire packets are just as important to SEED goals as the clinic visit and the phone interviews. They give the researchers a lot of information about the different aspects of ASD and perhaps tie some health or behavioral characteristics with the genetic information. We value all information collected, and ask that all parents do their best to send SEED staff any questionnaire packets they may receive".

## HIGHLIGHTS OF SEED PROGRESS

### **SEED** started enrolling families in the winter of 2008.

*The table shows SEED progress as of June 22, 2011.*



Enrolled Families	3,748
Caregiver Interviews Done	3,021
Cheek Cell Samples	2,800
Questionnaire Packets	2,370

Developmental Tests Done	2,589
Physical Examinations Done	2,402
Blood Samples	2,217
Diet Diary	1,526
Stool Diary	1,525
Complete Families	1,908

## WHAT'S NEXT FOR SEED IN CALIFORNIA?

The first 5-year phase of the investigation, the largest study of its kind, is wrapping up in October and we are close to reaching our data collection goals for all study groups.

Over the next few years, data will be compiled and analyzed and a number of papers will be developed. You can expect to see publications on the following topics:

- Methods used in SEED I
- Socio-demographics: is there an association between advanced parental age and ASD
- Behavioral phenotype: general description of study population
- Hormones: is maternal history of infertility disorders and infertility treatment associated with ASD
- Immune function: are children w/ ASD more likely to have a family history or personal history of autoimmune disease than control children
- Gene-environment interactions: do exposures during pregnancy, including behaviors (smoking and alcohol use), infection, or medication use, interact with genes to increase risk for ASDs?

SEED Phase II will be launched in December, 2011. We look forward to enrolling a new birth cohort of children with ASD, children with other neurological impairments, and typically developing children – children born between July 2007 and June 2011. We will continue to recruit from Alameda and Santa Clara counties since the system is in place and staff is prepared to continue working with us.



Members of the SEED Community Advisory Board celebrated at the final meeting in March.

Members described the positive nature of the SEED CAB as a vibrant group of individuals from diverse backgrounds who worked together to provide a community and parent perspective on conducting autism research. Members felt that the new CAB should work to maintain a dialogue with the SEED study participants and the community since it will take some time before findings are released.

Enrolled Families	652
Caregiver Interviews	446
Cheek Cell Sample	457
Questionnaire Packets	443
Developmental Testing	374
Physical Examinations	385
Blood Samples	320
Diet Diaries	245
Stool Diaries	243
Completed Families	309

### More from our California investigators:

Results of a study published last year in *PEDIATRICS* (Vol. 126 No. 4, October 2010, pp. 656-664) show that immunization with thimerosal-containing vaccines during pregnancy or in the first two years of life does not increase a child's risk of developing autism. The Centers for Disease Control and Prevention (CDC) and Kaiser Permanente Division of Research and two other managed care organizations conducted the study by reviewing the immunization histories of over 1000 children. Lisa Croen, PhD, co-PI explains that the study is important because some parents fear that vaccines, or that vaccines containing thimerosal, increase the risk of ASDs and consequently refrain from vaccinating their children. The study should help lessen parents' concerns about vaccinations. The article is: "**Prenatal and Infant Exposure to Thimerosal from Vaccines and Immunoglobulins and Risk of Autism**".

Another SEED investigator with the Center for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) at the California Department of Public Health, Gayle Windham, PhD, completed the **Study of Birth Prevalence of Autism Spectrum Disorders in the San Francisco Bay Area by Demographic Characteristics** published in the *Journal of Autism and Developmental Disabilities Online* in 2010. CADDRE received funding from CDC to conduct detailed monitoring (or counting) of autism in 6 counties of the San Francisco Bay Area for children born in 1994 or 1996. Working with the California Department of Developmental Services (DDS), the Kaiser Permanente Medical Care Program, and private medical care specialty providers, the study identified children with diagnoses or evaluations for ASD by age eight and then reviewed their medical records to determine final ASD case status according to our surveillance definition. The results of the California surveillance program indicate with very careful counting, about 1 in 200 children born in the San Francisco area in the mid-1990's were diagnosed with autism by age eight. It also found higher autism rates in boys and in children of older mothers, as well as lower rates in children of less educated fathers.

## SITE SNAPSHOT: MARYLAND

Johns Hopkins University (JHU) and Kennedy Krieger Institute work together on SEED to invite families to participate, conduct visits, and collect data (with help from the Maryland State Department of Education and Department of Vital Statistics!). Below is a snapshot of other projects that are ongoing at JHU and Kennedy Krieger.

**EARLI:** Directed in Maryland by Dr. Daniele Fallin of Johns Hopkins, the Early Autism Risk Longitudinal Investigation – or EARLI study – is a research study funded by the National Institutes of Health to look at possible genetic and environmental risk factors for autism that may occur in pregnancy or early life. There are EARLI study sites in northern California, Philadelphia, and Maryland. The study follows moms through pregnancy and their new babies until age 3. This is the first autism-focused pregnancy study of its kind. More information is available at [www.earlistudy.org](http://www.earlistudy.org), or on the Facebook page for the Early Autism Risk Longitudinal Investigation!

**ADDM:** Autism and Developmental Disabilities Monitoring Network (ADDM), led in Maryland by Dr. Li-Ching Lee of Johns Hopkins, has surveillance sites in a dozen states. Funded by the Centers for Disease Control and Prevention, ADDM looks to understand the rate of Autism Spectrum Disorders and whether they are more common among certain populations or particular areas of the nation.

**The Early Intervention Study:** Directed by Dr. Rebecca Landa at Kennedy Krieger, this study is looking in to how a group-based early intervention affects social development in toddlers with ASD.

**The Autism Treatment Network (ATN):** Directed by Dr. Landa and Dr. Stewart Mostofsky, this study, funded by Autism Speaks, is developing a comprehensive medical care model for children with ASD. The ATN has over 200 specialists from a wide variety of areas, from 17 leading children's hospitals and academic medical centers throughout the United States and Canada.



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