

# STUDY TO EXPLORE EARLY DEVELOPMENT

# SEED



Center for Autism and Developmental Disabilities Research and Epidemiology

CADDRE

*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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## WELCOME to the second edition of the SEED Newsletter!

**SEED – (the Study to Explore Early Development)** is going very well. We have over 2000 families who have agreed to be a part of the study so far.

In this second edition of the newsletter, we will talk about what to look for in how your child develops. Of course, we will also give you more information on SEED!

Here we go...

## Child Development

Growth is physical (weight gain and getting taller), but it is also how a child learns, how they play, how they talk and how they get along with other people. Every child develops at their own rate.

**BUT**, there are clues to what you can expect to see at different ages (See Box on page 2). Your child may develop in a different way. Ask your primary doctor or nurse practitioner what you should expect.

The earlier that you can do something about a delay or change in your child's development, the better. Treatment(s) should be started as early as possible to help your child develop the best he/she can. There are no blood tests to tell you if your child's development is right for his/her age. You and your primary health care provider should work together to watch how your child develops. If you think there is a problem with how your child is developing, **DO NOT WAIT**, talk about it, and ask questions. If there is a problem, it is very important to get your child help as soon as possible. A developmental delay (development that is slow) might make it harder for your child to learn when they start school. Recent surveys have found that in the United States, many (13%) of children have developmental delay or behavioral problems (<http://www.cdc.gov/ncbddd/dd/ddsurv.htm>).

- Visit the Centers for Disease Control and Prevention (CDC) website

for links to information on child development and early actions at [www.cdc.gov/actearly](http://www.cdc.gov/actearly).

- Learn more about developmental disabilities at <http://www.cdc.gov/ncbddd/dd/default.htm>.

Your child's physical growth, emotional development and social relationships are all part of child development.

Eating the right foods, getting enough exercise, rest and sleep each day are very important for your child's health and development. Don't forget to laugh, play, read and sing with your child. Giving your child a safe home and taking the time to talk, watch TV, play and listen to music with him/her can make a big difference in how he/she grows and develops.

Another part of your child's development is their safety. Protecting your child is a part of being a parent. No parent wants to see their child harmed for any reason. Burns, falls and motor vehicle injuries, are some of the most common reasons for a child's injury or death in the United States.

- Learn more on what you can do to help protect your child, talk with your primary healthcare provider and visit <http://www.cdc.gov/safechild/> for more information.

You are part of keeping your child safe.

*(See table on page 2)*

<p><b>By the end of 7 months, many children are able to:</b></p> <ul style="list-style-type: none"> <li>• turn head when name is called</li> <li>• smile back at another person</li> <li>• respond to sound with sounds</li> <li>• enjoy social play (such as peek-a-boo)</li> </ul>	<p><b>By the end of 11/2 years (18 months), many children are able to:</b></p> <ul style="list-style-type: none"> <li>• do simple pretend play ("talk" on a toy phone)</li> <li>• point to interesting objects</li> <li>• look at object when you point at it and tell them to "look!"*</li> <li>• use several single words unprompted</li> </ul>	<p><b>By the end of 3 years (36 months), many children are able to:</b></p> <ul style="list-style-type: none"> <li>• show affection for playmates</li> <li>• use 4- to 5-word sentences</li> <li>• imitate adults and playmates (run when other children run)</li> <li>• play make-believe with dolls, animals, and people ("feed" a teddy bear)</li> </ul>
<p><b>By the end of 1 year (12 months), many children are able to:</b></p> <ul style="list-style-type: none"> <li>• use simple gestures (waving "bye-bye")</li> <li>• make sounds such as "ma" and "da"</li> <li>• imitate actions in their play (clap when you clap)</li> <li>• respond when told "no"</li> </ul>	<p><b>By the end of 2 years (24 months), many children are able to:</b></p> <ul style="list-style-type: none"> <li>• use 2- to 4-word phrases</li> <li>• follow simple instructions</li> <li>• become more interested in other children</li> <li>• point to object or picture when named</li> </ul>	<p><b>By the end of 4 years (48 months), many children are able to:</b></p> <ul style="list-style-type: none"> <li>• use 5- to 6-word sentences</li> <li>• follow 3-step commands ("Get dressed. Comb your hair, and wash your face.")</li> <li>• cooperate with other children</li> </ul>

## SEED Questions and Answers

### 1) How long is SEED? How long will my family be involved?

How long you are in SEED depends on how fast you go through each step. It usually takes 1 – 2 weeks to fill out all the forms and do the telephone interviews. After the forms are done, you will be scheduled for a clinic visit. After the clinic visit you will be asked to fill in the diet and stool diaries. Most families finish everything in about 10 hours over 2 months.

### 2) Do I have to send stool back to the study group?

No. The diet record and stool diary are filled in by you. We want you to write down everything your child eats for 3 days. We want you to look each time

*your child has a stool and write down what it looks like. You only need to send in what you write down on the form we give you.*

### 3) What if I don't remember my child's early development?

Answer each question as best you can with as much as you can remember. Your baby book (if you used one) might help you remember. Don't worry if you don't remember every date and every medicine. Any information is a big help.

### 4) I like helping with studies like this, are there other studies I can help with?

The SEED researchers or study staff located the closest to you can help to answer this question.



## Data Collections Corner: Diet and Stool Diaries

The diet and stool records are an important part of SEED. We are going to use them to look at how children eat and what their bowel movements are like. This is one of the last steps in SEED, but it is really important.

### Food / Diet:

- We need you to write down what your child eats for 3 days.
- What do we need – as much as you can give!
- Remember the "visualize your portion size" from the clinic visit? Use that as a guide to write down the amounts of each food. Remember to put the time for each meal and each snack.
- Write as much as you can about what your child eats. Was the cereal Kellogg or Post? Was it a cup or a bowl? Did you use 2% milk or regular milk? Did you put ½ cup or a full of milk in the bowl?

### Bowel Movements: Poop– Who Knew!!!

- Yes, we want to know about your child's bowel movements.
- We need you to tell us about your child's bowel movements. The form we give you to fill in at the clinic visit will tell you exactly what to write down.
- For example we would like to know
  - How many per day?
  - What they look like
  - Large or medium?
  - What color was it?
  - Was it soft or hard?
- If you like, ask somebody else to help you explain and write down what the bowel movement looks like.

If you write the meals and the bowel movements down each day, it will not take a lot of time. There is a calendar in your packet, use it to help you remember when to start to keep track of food and bowel movements. Put it on the refrigerator or at your desk, this can be a reminder for you.

Remember, we want to know all the foods your child has eaten for 3 days, AND we want the bowel movements for 7 days.

Questions???? Call your SEED study office at **404.498.0058** and they will help you get this last part finished. THANKS.

# We're glad Georgia SEED is on your mind!

**Georgia SEED** enrolls families living in the 5-county Atlanta area (see map). So far, Georgia SEED has enrolled over 400 families into the study. GA SEED progress could not have been possible without the help from the GA SEED families! Nineteen percent of the total number of families enrolled in SEED have come from Georgia.

Enrolled Families	429
Caregiver Interviews Done	314
Cheek Cell Samples	240
Questionnaire Packets	284
Developmental Tests Done	261
Physical Exams Done	129
Blood Samples	124
Diet Diary	60
Stool Diary	61

## Meet some of the team members who make up Georgia SEED!!!



**Diana Schendel, PhD**  
*Lead Investigator*



**Laura Schieve, PhD**  
*Co-Investigator*



**Aimee Alexander, MS**  
*GA CADDRE  
Study Coordinator*



**Marques Harvey, MPH**  
*CADDRE  
Project Coordinator*



**Stuart Shapira, MD**  
*Clinician*



**Charmaine McKenzie**  
*Research Assistant*



**Subrina Parker**  
*Recruiter*



**Andy Autry, PhD**  
*Statistician*



**Shawanna Taylor, RN**  
*Nurse*



**Phyllis Cook-Stillwell**  
*Nurse*



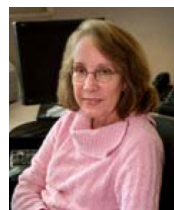
**Melody Stevens**  
*Community Liaison*



**Veronica Masters**  
*Recruiter*



**Shryl Epps, RN**  
*Interviewer*



**Nancy Hobson, PhD**  
*Clinician*



**Horace Thompson**  
*Data Manager*



**Julia Richardson, MPH**  
*Research Assistant*



**Karen Clay, RN**  
*Nurse*



**Lisa Wiggins, PhD**  
*Clinician*

# Site Snapshot: Pennsylvania

## Pennsylvania Center for Autism and Developmental Disabilities Research and Epidemiology (PA-CADDRE)

PA-CADDRE is a joint-effort of the University of Pennsylvania, School of Nursing and The Children's Hospital of Philadelphia. The Center for Autism Research (CAR) is where the coordination and support for autism research from each center comes together.

The goals of CAR research efforts are to:

- Understand why and how children with ASD are different from each other
- How is development different for children with ASD
- What developmental and treatment needs do these children have

The research at CAR includes:

- Epidemiology
- Genetics
- Health services
- Neurobiology
- Neuroscience
- Social work
- Radiology
- Psychiatry, psychology
- Nursing
- Neuropsychology

**Want to know more?** Visit the Pennsylvania CAR website at <http://stokes.chop.edu/programs/car/> or call the toll-free number: **1-866-570-6524**.

# Highlights of SEED Progress

SEED started in winter 2008.

**Our goal:** 2,700 families combined from all the SEED study sites. We now have over 2300 families enrolled.

SEED staff works closely with families on each step of the study. Every step is important. The tables below show our progress. The more information SEED gets the more we all learn about children with Autism Spectrum Disorder (ASD) and other developmental disabilities.

Enrolled Families	2,304
<b>Caregiver Interviews Done</b>	<b>1,711</b>
Cheek Cell Samples	1,565
<b>Questionnaire Packets</b>	<b>2,008</b>
Developmental Tests Done	1,365
<b>Physical Exams Done</b>	<b>1,186</b>
Blood Samples	1,094
<b>Diet Diary</b>	<b>752</b>
Stool Diary	754

\*As of February 1, 2010



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and Prevention (CDC)  
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