SEED Meets Fertile Ground

WELCOME to the first edition of the Study to Explore Early Development (SEED) newsletter! This semiannual newsletter will provide up-to-date information on SEED for the benefit of people enrolled in SEED and those who have an interest in the study.

SEED is a multisite study being conducted by the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network set up and funded by the Centers for Disease Control and Prevention.

The CADDRE Network is made up of six study sites, a central laboratory, and a data coordinating center. The six CADDRE study sites are located in California, Colorado, Georgia, Maryland, North Carolina, and Pennsylvania. The CADDRE data coordinating center is in Michigan (see map).

SEED is the largest study to date of risk factors for autism spectrum disorders (ASDs) and other developmental disabilities. SEED will give researchers a better idea about the many things that increase the chances a child will have autism or other developmental problems.

CADDRE began inviting families to participate in SEED in winter 2008. Staff at the CADDRE sites are working with partners in their respective communities to invite families to participate in SEED. Altogether about 2,700 children and their parents will be invited to take part in the study.

SEED will comprise children 2 through 5 years of age with ASDs, with other developmental disabilities, and with typical development. To take part, children will have to have been born and still be living in a CADDRE community.

Taking Root: The Science of SEED

What is SEED studying?
SEED is studying 3 areas:

Area 1: Physical and behavioral features of young children, such as how they behave and interact with others.

Area 2: Health-related conditions among young children, such as medical problems, sleep patterns, and diet.

Area 3: Risk factors for autism and other developmental problems, such as genes, family history, and experiences during pregnancy or early life.

What information is SEED collecting?
Parents are being asked to do the following:

- Complete questionnaires and interviews about their child’s development and the family’s medical history.
- Bring their child to a clinic for developmental testing and a brief physical examination.
- Give small samples of blood, hair, and cheek cells.
- Give permission to review the medical records of the mothers and children.
1. Should parents discuss their child’s developmental test results with their primary care provider? If parents have questions or concerns about their child’s development they should talk with their child’s health care provider or teacher, or both.

2. How is the information used? All of the information collected will be used to see if something happens more or less often among the different groups of children enrolled in the study. SEED investigators are using a kind of math called "statistics" to make these comparisons. Then, they will publish papers to let the general public know of their findings.

3. When people read about SEED, will they be able to find individual information? No, the study investigators are not looking at any one person’s information, only at groups. So, study results will not be reported in a way that lets readers identify any one person. Also, study records that show names or other identifiers will be secured at the study location. Each SEED site has signed a certificate of confidentiality to add an extra level of protection for participants.

4. Are there parent support groups or advocacy groups for children with developmental disabilities or autism? Local SEED staff may be contacted for a list of community partners who might be able to provide advice or services.

Highlights of SEED Progress

Since SEED started in winter 2008 about 1,350 families have agreed to participate. To reach the final goal of 2,700 families, SEED will continue to enroll families for about another 18 months to 2 years.

SEED staff work closely with families to complete each step of the study. The adjacent tables show how much progress the SEED families have made at each step so far. Each step is important because it adds more information for each area that SEED is studying. The more information SEED gets at each step, the more clues there will be about the many things that increase the chances a child will have autism or other developmental disabilities.

Data Collections Corner: The Caregiver Interview

Participating in the caregiver interview is one of the early steps that families take in SEED. The interview is an important way to find out if experiences of the mother during pregnancy or of the child around the time of birth or in early life could lead to autism or other developmental problems. During the interview, questions will be asked about the mother’s pregnancy history, family background, and lifestyle, as well as health conditions she and the child might have had and medications and treatments they might have received. Questions also will be asked about the birth father’s background, his health, and some medications he might have taken during and around the time of the pregnancy.

The interview takes about one and a half hours to complete and usually is given over the telephone using a computer-assisted telephone interview (CATI) set-up. If the primary caregiver is not the birth mother, the caregiver will be asked about his or her own background, health conditions of the child and medications and treatments the child has received.

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<thead>
<tr>
<th>Enrolled Families</th>
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<td>Caregiver Interviews Done</td>
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<tr>
<td>Cheek Cell Samples</td>
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<tr>
<td>Questionnaire Packet 1</td>
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<td>Developmental Tests Done</td>
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<tr>
<td>Blood Samples</td>
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<td>Hair Samples</td>
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<tr>
<td>Diet Diary</td>
<td>393</td>
</tr>
<tr>
<td>Stool Diary</td>
<td>392</td>
</tr>
</tbody>
</table>

*As of June 1, 2009
Joanna Jaeger, an advocate and mother of a 17 year-old son explains the value of research:

“The reality is parents end up being experts, in a way the researchers don’t ever really have an opportunity to be. At least we are experts on our own child. By participating in the study or being a part of the advisory board we can bring our expertise to the process as well. There’s no doubt that with the numbers we’re seeing and the crisis level we are at, that these kinds of multi-layered studies will give insight and understanding and hopefully some direction on how to proceed. I would love to know that we can start the work of preventing autism, but we don’t yet know what’s causing it.”

Vanessa Wallace, mother of four children on the autism spectrum and a SEED Study participant talked about the benefits to parents of participating in the SEED study.

“There is a lot of misinformation out there because there’s so much we don’t know about autism. Being part of this study will help you sort out fact from fiction. It will help you know who your child is and what makes him tick – which makes you a better parent. It was important to my husband and me going into it, the backing this study has -- the governmental involvement. It will have an impact on policy decisions related to autism and developmental disorders. That was something we were impressed by -- that this will have a national impact and positive effect on people with disabilities.”

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From our new Outreach Coordinator...

The staff is grateful to dedicated Community Advisory Board members who help to conduct ongoing outreach activities at local conferences and community events including in the Latino/ Spanish speaking community. This year, we have participated in conferences in Palo Alto, San Francisco, Santa Clara, and Hayward and in a Walk Now for Autism event. We’ve provided materials within the parent support networks of Marin, Santa Clara, Santa Cruz and Sonoma counties. I look forward to hearing your ideas about ways to increase awareness of autism research among the general public, within the medical community, with service providers and educators. Please be in contact with us: autism.research@kp.org. – Joanne Ruby

From our Community Advisory Board members...

Our Community Advisory Board (CAB) is a key component of the SEED Study in California. Our members include parents with a child affected by autism or developmental delay, clinicians and community providers. Aside from their readiness to represent SEED at community events and meetings, most importantly, they provide advice on recruiting and working with families, ensuring a positive experience and increasing retention of participants. Three parent members shared their perspectives about their participation on the CAB with our new Outreach Coordinator.

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Jane Schoenfeld, a writer and mother of a 22 year-old daughter joined the CAB to make a meaningful contribution.

“Research studies can help answer many of the questions you have now and make life easier for you and for parents whose children are diagnosed in the future. That’s why we need people to participate in this study. My daughter was 9 when we learned about the tuberous sclerosis and the autism spectrum diagnosis came only in bits and pieces. This study could help provide pediatricians and child care providers with better tools for identifying developmental delays early on and for directing parents to intervention services.”
The Centers for Disease Control and Prevention (CDC) is a part of the U.S. Department of Health and Human Services. CDC is the primary government agency that carries out and supports public health activities in the United States.

At CDC, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to prevent, monitor the occurrence, and find the causes of birth defects and developmental disabilities as well as finds ways to help all children reach their full potential by promoting health and well-being across their lifespan. To do this, NCBDDD uses a public health approach with three important parts: surveillance or monitoring, research, and prevention (see Figure).

Developmental Disability surveillance. Information from public health surveillance can be used:
1. To find out about the characteristics of people who have a particular health condition.
2. To find out how often a health condition occurs in a community and if that changes over time.
3. To understand better the differences in health among different racial, ethnic, and socioeconomic groups.

Metropolitan Atlanta Developmental Disabilities Surveillance Monitoring Program (MADDSP)
Today, MADDSP monitors the prevalence of five developmental disabilities (cerebral palsy, hearing loss, vision loss, intellectual disability, and autism) among 8-year-old children living in the Atlanta area.

To better understand the occurrence of developmental disabilities in the United States, CDC started the Autism and Developmental Disabilities Monitoring (ADDM) Network in 2000 using the MADDSP model. The ADDM Network monitors the prevalence of autism at 11 sites in the U.S. A group of these ADDM sites monitor cerebral palsy and/or intellectual disability in addition to autism.

Developmental Disabilities Research
Research is the next step following surveillance. For instance, MADDSP and ADDM can help find groups of children who are at high risk for having developmental disabilities. With this information, researchers can do studies to find specific risk factors that might increase the chances a child will have a developmental disability.

Study to Explore Early Development (SEED)
SEED is NCBDDD’s main research study of autism and other developmental disabilities. Findings from research studies such as SEED can help shape public health action.

Prevention of Developmental Disabilities
NCBDDD’s “Learn the Signs. Act Early” campaign is an example of a public health prevention activity for developmental disabilities. This campaign focuses on educating parents, health care providers, and educators about the early warning signs of a developmental delay, because this could be a sign of a developmental problem, even autism.