

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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A Better Night's Sleep: In this edition, we share information from professionals in California about recognizing signs of sleep problems and encouraging healthy sleep habits that will help the whole family.

As adults we can truly appreciate the importance of a good night's sleep. We are also able to recognize how a bad night's sleep can affect us; maybe we are grumpy with our family, have a hard time concentrating at work or forget important things on our to-do list. Getting a good night's sleep is just as crucial for children with and without disabilities. Dana Won, M.D., a pediatrician specializing in Autism Spectrum Disorders (ASDs) at Kaiser Permanente in Northern California, puts it simply, "As a family unit, to have all the members sleeping well is just really, really important."

While it might not be easy for a child to express how sleep influences their day, parents and professionals notice a big difference. "If a child doesn't sleep well even for one night you can tell the next day; their behaviors are different, usually worse, and they will not be as alert for learning. If this goes on for many days or even a lifetime, you can see how a child's behavioral problems will appear worse," states Dr. Won. Sleeping well is fundamental for both typically-developing children and for children who have an ASD or other developmental disability. It is not uncommon for children to have some sleeping issues; however, parents of children with ASDs do tend to report more sleep issues. Here are a few common sleep issues:

- Problems falling asleep at bedtime (taking longer than 30 minutes to fall asleep)
- Waking up often in the middle of the night (for a drink or to play)
- Refusing to fall asleep alone

These types of sleep problems can often be improved by promoting healthy sleep habits at home. It is important to remember that these are only general guidelines; healthy sleep behaviors can look a bit different for everyone.

Good sleep habits for children, especially children with developmental disabilities, begin with structure; "structure is the name of the game for the entire day including at bedtime," says Dr. Won. Here are some of the key healthy sleep habits that Dr. Won suggests:

- **Keep bedtime and wake-up time consistent 7 days a week.**
- **Make a bedtime routine and stick with it.** Your bedtime routine should always be done in the same order and as much as possible should be done in the child's bedroom. Sometimes using a picture schedule can be helpful.
- **Limit 'screen time' before bedtime.** Children should not be watching TV, using the computer, playing video games, etc. in the hours before bedtime. The shining light can make the brain think it is day time.
- **Create a comfortable sleep environment.** Pay attention to noise levels, temperature and the amount of light in your child's bedroom.
- **Be careful about possible stimulants.** Every child reacts differently to food and medicine. Caffeine in foods like chocolate, tea, and soda can affect a child's ability to fall asleep. Some medicines can also affect sleep too. Check with your pediatrician about possible side effects.
- **Get your kids active.** Physical activity during the day is a great way to prepare your kids for a good night's sleep.

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- **Time naps carefully.** Make sure naps aren't too close to bedtime.
- **Keep medical problems well-controlled.** Medical issues like coughing from asthma, itchy skin from eczema or a chronically stuffy nose can interfere with your child's sleep. Work with your pediatrician to treat and manage these conditions.
- **Let kids fall asleep alone.** It's normal for kids and adults to wake up briefly during the night. If your child is used to falling asleep alone they will be able to fall back to sleep by themselves more easily in the middle of the night.

Sometimes sleep problems can be a sign of a condition that requires medical attention. If your child has the following symptoms while sleeping: loud snoring, gasping for breath, or being extremely restless, for example, you may want to contact your pediatrician.

Getting a good night's sleep is very important for everyone in the family. Encouraging these healthy habits and setting a consistent structure around your child's day will help your child get the "really good deep, restorative sleep" that children need, says Dr. Won. For more information about healthy sleep habits, please visit:

<http://www.autismspeaks.org/family-services/tool-kits>

SHARING OUR WORK

Recent Publications

One way researchers share their work is through publishing scientific papers. Scientists write many different papers based on the information collected from a single study. Usually the first paper published about a study is called the 'methods paper'. This paper describes what scientists are hoping to learn and how scientists conducted the study. This paper helps other scientists evaluate the quality of study and shows how to repeat the study so other scientists can test the results.

In March 2012, SEED published our first paper, the methods paper. This was a very exciting first step towards sharing our results with other scientists and the public. Some topics for future papers include describing medical issues, developmental skills, genes and demographic factors. Expect to see more papers published in the next year.

Please visit us at

<http://www.cdc.gov/ncbddd/features/SEED-March-2012.html>

if you would like to read more about our methods paper.

Recent Presentations:

In addition to publishing papers, SEED scientists also share their work at conferences. Researchers give formal presentations and display posters describing their work. One of the largest conferences we attend is called IMFAR, the International Meeting for Autism Research. This conference started in 2001 in order to give researchers studying ASDs a place to share their work with peers. Some of the presentations and posters from SEED scientists at IMFAR include:

- the behavioral and developmental profile of children with and without ASDs;
- the Gene-Environment Wide Interaction Study (GEWIS);
- how researchers are conducting SEED; and,
- information about general sociodemographics between families participating in SEED.

IMFAR is a wonderful opportunity to present our work and to collaborate with researchers from all over the world.

HIGHLIGHTS OF SEED PROGRESS



The graphic shows SEED 2 progress as of January, 2013.

NORTH CAROLINA SEED ONLINE

In an effort to reduce paper waste, North Carolina SEED will be moving to electronic distribution of SEED newsletters. This is the last paper version of the newsletter you will receive unless you contact our office to request a paper version. Beginning with the next newsletter edition (Summer 2013) we will send postcards or emails (if we have your email address) announcing the availability of the newsletter online and giving you information on how to access it. Future editions will only be posted to our website and we will announce their availability on our Facebook and Twitter accounts.

If you would like to keep up with study progress and announcements you can:

➤  Like us on Facebook <https://www.facebook.com/NCSEEDStudy>

➤ Follow us on  [@NC_SEED](https://twitter.com/NC_SEED)

➤ “Bookmark” or “Favorite”  our website www.NCSEED.org



- To view the newsletters on the website:
 - » Click Participant Log In (under the “Interest Form” button on the right side of the page)
 - » In the password box type **Balloons** (the password is case sensitive)
 - This takes you to the SEED II Participant Pages
 - » In the brown tool bar under the photo banner, click on SEED Newsletters
 - » Browse through all our past newsletter issues!

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- To email us:
 - » Use SEED NEWSLETTER in the Subject line
 - » In the body of the email
 - Include your full name
 - Your enrolled child’s first name and
 - Your email address
 - » This will help us link your email address to the right family. We will email future newsletters to you.



HIGHLIGHTS OF NORTH CAROLINA SEED II PROGRESS

83 of 560 (or 15.0%) of the total number of families enrolled in SEED II have come from North Carolina.

We have invited 626 families, 83 enrolled, and approximately 38 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	83
Maternal Interview done	65
Medical Records Releases (# of families)	41
Questionnaire Packets	55
Developmental Test done	38
Saliva samples (# of families)	36
Blood samples (# of families)	29

* as of January 31, 2013



**Centers for Disease
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National Center on Birth Defects
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Center for Autism and
Developmental Disabilities Research
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The University of North Carolina at Chapel Hill
Campus Box 8126
Chapel Hill, NC 27599-8126

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SITE SNAPSHOT: CALIFORNIA

California SEED is a team effort between Kaiser Permanente's Division of Research (KP DOR) and the California Department of Public Health.

This year marks the 50th anniversary of Kaiser Permanente's Division of Research. Although KP DOR is not widely known to the general public, it is considered one of the top health research organizations in the U.S. that is not part of a university. Currently, there are over 60 investigators and 600 staff working to better understand the causes of illness, factors related to good health and how to provide the best health care. Research topics range from autism and developmental disabilities to cancer and chronic diseases. Right now more than 350 research studies are happening at KP DOR and every year investigators publish about 250 research papers.

For the last 10 years KP DOR has had a dedicated team studying autism, the Autism Research Program (ARP). As you know from SEED, we work with researchers across the country. We share our findings to help keep doctors and families up to date with the latest research. Our work on autism covers a lot of different areas including causes of autism, autism in adults, and medical problems among people with autism. We are committed to learning more about autism and we are excited about what SEED will add to our current knowledge.

If you would like to learn more about our work at the Autism Research Program, please contact us at 866-279-0733 or visit us at www.autismresearch.kaiser.org.