

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.

CONGRESO FAMILIAR

One of the SEED study's greatest assets is our diversity. We have sites across the country and recruit families from many different backgrounds. In California and Colorado we also recruit families who are Spanish speaking.

Recently, the SEED study in California attended Congreso Familiar, an event held just for Spanish speaking families with children with disabilities. Families come from throughout California to attend this lively annual event. Experts give presentations on a variety of topics ranging from bullying to dental hygiene, all with a focus on people with disabilities. This year Dr. Lisa Croen, a SEED scientist in California, gave a presentation about the importance of the Latino community participating in autism research. The rate of ASD appears to be lower in the Latino community but researchers do not know why. The risk factors for ASD may be different for Latinos, or children may go undiagnosed because there are fewer resources available to Spanish speaking families. Scientists can only learn more if Latino families participate in ASD research.

The Congreso Familiar event is not just an opportunity to learn from experts. It is also a social event for families to



connect and have fun. This year the reception included a mariachi band as well as a resource fair for families. SEED had a booth at the resource fair and we got to talk with many enthusiastic families.

We love attending events like Congreso Familiar. If you have an event you think we should attend, please let us know!

MHRN AUTISM REGISTRY

At Kaiser Permanente's Autism Research Program (ARP) we work on a lot of different research studies at one time. In addition to SEED, the ARP is also part of the Mental Health Research Network (MHRN). The mission of the MHRN is to improve the management of mental health conditions by more closely connecting research, practice, and policy.

One project of the MHRN is an Autism Registry. This project is really exciting and our goal is to have 10,000 families take part across the county.

What is the MHRN Autism Registry?

- It is a project collecting information about children and teens with ASDs and the impact ASDs have on families
- It involves one web-based survey and the collection of saliva or blood samples from children with ASDs and their parents
- The study is being funded by the National Institute of Mental Health
- The study team includes Harvard Pilgrim Health Care in Boston and four Kaiser Permanente regions: Georgia, Northern California, Southern California and the Northwest.

What are goals of the Autism Registry?

- Understanding how ASD affects the whole family
- Studying the differences in the number of ASD diagnoses across the different regions
- Looking at other medical and psychiatric issues present in the ASD population
- Learning about services families use and which are most helpful
- Collecting bio-samples to look for genetic and environment factors of ASDs

For both the MHRN Autism Registry and SEED, families like yours are one of our most valuable resources. We couldn't do this work without you; thank you for your participation!

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.



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