

The Developing Mind

Quarterly Newsletter from Childrens Hospital Los Angeles



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A MESSAGE FROM KATHI

Thank you for your interest in this third issue of The Developing Mind, a newsletter brought to you by Childrens Hospital Los Angeles. We know that it is sometimes difficult to find a trustworthy source for answers to complex questions about your child's health and development. In this newsletter, published every three months, we provide up-to-date information from the experts at Childrens Hospital Los Angeles. In the current issue, we talk with Dr. Sally Ward and Dr. Iris Perez about sleep hygiene for children with autism, provide information about Regional Centers and the Early Start Program, and highlight some April autism events taking place in the area. We hope that this and future issues of The Developing Mind will be useful to you and your family. For more information about the clinic, please call 323.361.6102.



KATHI SMITH, RN, MN

SLEEP HYGIENE FOR CHILDREN WITH AUTISM

AN INTERVIEW WITH DR. SALLY WARD AND DR. IRIS PEREZ

Are sleep problems common in children with autism?

Yes, in general, children with autism have more sleep-related problems than typically developing children. Many parents of children on the autism spectrum report sleep problems, such as resistance to going to sleep at night, waking up often or sleepwalking during the night, and being groggy in the morning. The research shows that between 44% and 83% of school-age children with autism spectrum disorders (ASDs) have trouble sleeping, compared to about 25% of typically developing children.

What are the different types of sleep problems that they can have?

There are many types of sleep problems, as well as other issues that can disturb sleep. Some children have trouble falling asleep at night, but sleep soundly once they fall asleep. Others may fall asleep without any difficulty, but wake often during the night and can't get restful sleep. Not getting enough sleep can affect a child's health, mood and behavior. This can be stressful for parents, so it is important to find solutions that work for the family.

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SLEEP HYGIENE FOR CHILDREN WITH AUTISM

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Are the sleep problems of children with autism different than those of other kids?

The issues aren't really different, it's just that kids with ASDs have them more often. Depending on the individual child, this may be due to behavioral issues related to autism which can disrupt getting to sleep, or could be the result of differences in the parts of the brain that control sleeping patterns.

What are common behavioral issues?

The most common problem is simply refusing to go to sleep at night. Instead, they want to play, watch TV, hear another story, or anything other than going to bed! Some children may need to be rocked, patted or have someone lying next to them before falling asleep. Others may wake up easily during the night or want to sleep somewhere else other than in bed. It is difficult for the family, because everyone wakes up tired from not sleeping well. Parents are tempted to let their children nap during the day, but this only contributes to more problems at night.

The most important thing to do is to develop a consistent routine around sleep, and maintain what we call good sleep hygiene. Sleep hygiene is all about keeping a daily routine and providing an environment that promotes sleep. For example, the bed should be used only for sleeping; avoid watching TV or having snacks in bed. Consider taking the TV and other electronics out of the bedroom. A calm, supporting and consistent bedtime routine allows a child to wind down and be ready for sleep. Also, there should be a consistent wake-up time every day, and limited naps for older children.

What should a normal night's sleep be like?

It depends on the age. For a toddler, a normal night's sleep should be about 12-13 hours, with 1 to 2 daytime naps. At this age they are transitioning from crib to bed, so some behavioral issues may arise related to changing the sleep environment.

During childhood, between 9-11 hours is normal and napping is rare. At this time, the sleep pattern becomes more stable and consistent from night to night. For children with autism, early childhood is a crucial time to develop a consistent sleep routine and support good sleep hygiene habits. That means a regular bedtime, no distractions from sleep like TV or computer, and the child should sleep in his or her own bed.

What types of treatments are available for kids with autism who have sleep problems?

If you have a child with an autism spectrum disorder who has trouble getting a good night's sleep, there are both behavioral and medical treatments available. Your child can see a sleep specialist to determine the underlying reasons for sleep problems. A common medication used for sleep disorders is melatonin, which can help to establish a healthy

sleep rhythm. Make sure you discuss medications with your pediatrician or sleep specialist BEFORE trying them with your child.

At home, having a consistent bedtime ritual and the same sleep and wake-up times every day will go a long way to helping your child and your family get a good night's sleep. Good sleep hygiene is also important during the day. Make sure that your child gets out in the sunlight every day for some exercise.

tips for good sleep hygiene

At bedtime:

- ✓ Sleep in a dark, cool and quiet room
- ✓ A comfortable bed, used only for sleep
- ✓ Practice a routine bedtime ritual
- ✓ Limit the use of TV, computers or games before bedtime
- ✓ No snacks or drinks at bedtime
- ✓ No vigorous exercise 1-2 hours before bedtime
- ✓ No mentally-stimulating activity before bedtime
- ✓ Dim the lights in the evening and before bedtime

During the day:

- ✓ No caffeine, such as soda or coffee
- ✓ Limit "catch up" sleep on weekends to two hours in the morning
- ✓ Age-appropriate naps only
- ✓ Exposure to sunlight for at least 30 minutes, preferably in the morning
- ✓ Exercise regularly during the day
- ✓ Use techniques throughout the day to relieve stress and worry

Dr. Sally Ward, MD, is Division Head of Pediatric Pulmonology and Director of the Childrens Hospital Los Angeles Sleep Laboratory, and Associate Professor of Pediatrics at the Keck School of Medicine of USC. She is board-certified in Pediatrics, Pediatric Pulmonology and Sleep Medicine. She conducts research on sleep-related breathing disorders.

Dr. Iris Perez, MD, is an Assistant Professor of Clinical Pediatrics at the Keck School of Medicine of USC. She is board-certified in Pediatrics, Pediatric Pulmonology and Sleep Medicine. Her areas of interest include sleep-related breathing disorders and hypoventilation syndromes.

APRIL IS AUTISM AWARENESS MONTH!!

April 1, 10:00 a.m. - 11:30 a.m.

Understanding Regional Center Services.
Family Focus Resource & Empowerment Center.
Contact 661.250.3943 or family.focus.scv@csun.edu

April 3, 9:00 a.m. - 3:00 p.m.

Autism Awareness Walk - Antelope Valley.
Clear Channel Stadium, Lancaster. Contact
661.225.9598 or visit www.cesausa.org

April 10, 10:00 a.m.

Sensory-friendly showing of the movie *How to Train Your Dragon*. AMC Theaters in Orange, Covina, Torrance, Ontario, Anaheim and Woodland Hills.

April 13, 10:00 a.m. - 12:00 p.m.

Preparing for Your Child's IEP.
Family Focus Resource & Empowerment Center.
Contact 661.250.3943 or family.focus.scv@csun.edu

April 17, 8:00 a.m. - 3:00 p.m.

Tools for Transformation Conference.
FREE! Sponsored by The Special Needs Network.
Junior Blind of America, Los Angeles. Contact
213.389.7100 or info@specialneedsnetwork.org

April 19, 6:00 p.m. - 8:00 p.m.

Summer Activities Fair.
Bridgeport Elementary, Santa Clarita. Contact
661.250.3943 or family.focus.scv@csun.edu

April 24, 10:00 a.m.

2010 Los Angeles Walk Now for Autism Speaks.
The Rose Bowl, Pasadena. Visit
www.walknowforautismspeaks.org

April 25, 10:00 a.m. - 6:00 p.m.

Kids Are 1st Safety Festival
Brentwood. Contact info.kidsare1st@gmail.com

April 28, 12:30 p.m. - 6:00 p.m.

Teaching Interactions: A Conversational Approach to Intervention.
At Autism Partnership, Seal Beach. Contact
800.816.9293 or www.autismpartnership.com

April 30 - May 1:

Plan & Prepare: Transition to Adulthood Conference.
Los Angeles Valley College. Contact 562.804.5556 or
visit www.asa-la.org

May 1, 9:00 a.m. - 5:00 p.m.

TACA's "Real Help Now" Medical Conference.
Orange County. Contact 949.640.4401 or register at
www.realhelpnowconference.org.

May 8, 12:00 p.m. - 3:00 p.m.

Foothill Autism Alliance Annual Picnic.
Lower Scholl Canyon Park, Glendale. RSVP by May
5th to rsvp@foothillautism.org or 818.66.AUTISM

May 15, 8:00 a.m. - 12:00 p.m.

KiDA Summit on Autism.
University of California Irvine's Bren Events Center.
Contact 949.222.2214 or register at www.kida.com

June 13, 11:00 a.m. - 3:00 p.m.

TACA's 6th Annual Family Picnic.
Hidden Valley Park, Irvine. Register at
www.talkaboutcuringautism.org.

LAS MADRINAS RESEARCH HIGHLIGHT

Twin-Twin Transfusion Syndrome Study

Twin-Twin Transfusion Syndrome (TTTS) is a condition that can result when two fetuses share the same placenta during gestation, and one fetus gets more blood supply than the other. This imbalance can lead to severe health complications and disabilities, such as cerebral palsy, as children grow older. A surgical treatment is available to restore the balance of blood flow to the twins, but little is known about the outcomes of the children who received this treatment.

This study will examine the developmental outcomes, including cognitive and social skills, of these children at 24 months of age. By understanding the risk factors involved, such as gestational age at treatment and birth weight, this study will help to improve treatment procedures and prevent disability in children with TTTS.

This project is a collaboration of the Developmental-Behavioral Pediatrics Program and the Institute for Maternal-Fetal Health. Funding from the Las Madrinan Endowment for Autism Research, Intervention and Outcomes allows Childrens Hospital Los Angeles to support important studies in the area of neurodevelopmental and behavioral disorders. For more information or to find out about participating in research at the Boone Fetter Clinic, contact Maggie Memmott, MPH, at 323.361.7504

KNOW YOUR REGIONAL CENTER

Regional Centers are nonprofit organizations that contract with the State of California to provide services and support for individuals with developmental disabilities and their families. There are 21 Regional Centers throughout California, including seven in Los Angeles County. Regional Centers provide a wide range of services, including assessment and diagnosis, counseling, individualized planning and service coordination, and children's programs such as the Early Start (early intervention) Program.

The Early Start Program is designed especially for children under age three who have or may develop developmental disabilities. An Individualized Family Service Plan details the services and support needed by a child in order to enhance his or her development, such as speech and language

services, occupational or physical therapy, and dental or medical services.

Services provided through the Regional Centers are free to families. Regional Centers do require the use of generic services first - your health insurance or school district services - before they provide additional services. Anyone can make a referral, including a parent, doctor or teacher. After receiving a referral, a service coordinator will help the family through a process to determine eligibility.

If you would like to know more about Early Start, or other services provided through California's regional centers, you can call 800.515.BABY or email earlystart@dds.ca.gov, or visit the Department of Developmental Services website at www.dds.ca.gov.



warm phone line

323.361.6102

Staffed by Kathi Smith, RN, MN, nurse care manager at the Boone Fetter Clinic, the warm line is available to the public to answer questions about autism spectrum and other neurodevelopmental and behavioral disorders.

Boone Fetter Clinic

Boone Fetter Clinic: Diagnostic, Clinical & Research Center for Autism, other Neurodevelopmental & Behavioral Disorders
CHLA-USC Institute for the Developing Mind
Childrens Hospital Los Angeles
1300 North Vermont Ave., Suite 905
Los Angeles, CA 90027

boonefetterclinic@chla.usc.edu

www.chla.org/boonefetterclinic

To make an appointment, call **323.361.6102** and speak to the nurse care manager.



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