

The Developing Mind

Quarterly Newsletter from Childrens Hospital Los Angeles



in this issue

Trust Your Instincts

Research Highlight

Autism Warm Phone Line

What is a Developmental-Behavioral Pediatrician?

Support Groups

Calendar



ChildrensHospitalLosAngeles
International Leader in Pediatrics

INTRODUCING "THE DEVELOPING MIND"

Thank you for your interest in this inaugural 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 will provide up-to-date information about child development and behavior from the experts at Childrens Hospital Los Angeles. We hope that this issue and future issues of The Developing Mind will be useful to you and your family. For more information about the Boone Fetter Clinic, call 323.361.6102.

TRUST YOUR INSTINCTS

DOES YOUR CHILD HAVE AN AUTISM SPECTRUM DISORDER?

BY LARRY YIN, MD

From my years of medical practice, I have learned that parents are often the first to notice unusual behaviors in their child or to recognize that their child is not reaching important developmental milestones. I have also learned that a lot of parents have valid concerns which are repeatedly dismissed by their children's doctors. My advice to all parents is this:

- **Trust your instincts.**

No one knows your child better than you.

- Provide clear and specific examples of your concerns to your child's doctor.
- Videotape your child's behavior to demonstrate your concerns to your doctor.
- Ask a teacher or another family member to observe your child and write down their impressions.
- The more information you can provide and the more proactive you are, the more your child will benefit.
- If your concerns continue to be dismissed, consider getting another opinion.

Continued on page 2

TRUST YOUR INSTINCTS...

continued from cover



In the United States, one in 150 children is diagnosed on the autism spectrum each year. As researchers and clinicians, there is a great deal that we still don't know about autism. However, we do know that children who receive intervention early in their development respond better and show greater improvement. There are certain important developmental delays that should raise a red flag for parents including:

- No smiling by six months of age
- No facial expressions or back-and-forth sharing of sounds by nine months of age
- No babbling by 12 months of age
- No gesturing by 12 months of age
- No words by 16 months of age
- No two-word phrases by 24 months of age
- Loss of speech or babbling at any age

If any of these “warning signs” are present, further diagnostic evaluation is needed. I cannot stress enough how important the quality and thoroughness of this evaluation is to your child. You should receive an evaluation report which can be used by your child’s school and care providers to create individualized educational and care plans.

Parents often become paralyzed after receiving their child’s diagnosis. I always tell parents that you have to take it day-by-day rather than worrying too much about the future. Keep engaged with your child and focus on family activities or you’ll miss out on the great accomplishments your child is making right now.

Dr. Larry Yin is the medical director of the Boone Fetter Clinic at Childrens Hospital Los Angeles and assistant professor of clinical pediatrics at the Keck School of Medicine of the University of Southern California.

2009 walk now for autism

Raise money and awareness for Autism. Walk Now for Autism is a family-friendly event so bring the whole family along. There are activities for the children, resources for families, light refreshments and entertainment.

Contact: Autism Speaks for more information

Central Valley
Saturday, October 17, 2009 at Modesto Junior College

Orange County
Saturday, November 14, 2009 at Angel Stadium of Anaheim.

AUTISM WARM PHONE LINE

INTERVIEW WITH KATHRYN SMITH, RN MN

This year, the Boone Fetter Clinic received funding from the William Randolph Hearst Foundation to support an Autism Warm Phone Line. The Warm Line is staffed by Kathryn Smith, RN MN, the nurse care manager of the Boone Fetter Clinic who has more than 30 years of experience in the field of developmental disabilities. Kathi answers all calls made to the Autism Warm Phone Line, within two business days.

Maggie: What is the Autism Warm Phone Line?

Kathi: The Warm Line is a service available to the public to answer questions about autism spectrum, other neurodevelopmental and behavioral disorders. Through the Warm Line, I can inform callers about local resources and services for families with special needs. I make service referrals, listen and respond to parent concerns, and answer general questions about a child's healthy development.



Maggie: What kinds of questions do you answer on the Warm Line?

Kathi: I primarily get calls from parents, looking for a comprehensive and definitive diagnosis, as well as providers and advocates who are seeking information on the expert services available at Childrens Hospital Los Angeles.

Maggie: So a parent should call the Warm Line to make an appointment at the Boone Fetter Clinic?

Kathi: Yes. If they suspect that their child has autism or another neurodevelopmental disorder, a parent can call our offices and ask for an appropriate assessment. We also diagnose and care for children with attention-deficit/hyperactivity disorder, behavioral disorders, learning problems and developmental disabilities.

Maggie: What if a child has already been diagnosed with an ASD?

Kathi: I also help parents with referrals to community agencies, and help them to advocate for their child with their school district or with regional center staff and providers.

Maggie: Thank you for your time, Kathi. Is there anything else you want to tell us about the Boone Fetter Clinic?

Kathi: At the Boone Fetter Clinic we know that each child is unique, so our services are tailored to the specific needs of each child and family. Our goal is to provide families with clear information about their child's development and ensure their care is well connected and coordinated. It all starts with a call to the Autism Warm Phone Line, and continues as parents develop the skills they need to serve as an effective advocate for their child.

Call the Autism Warm Phone Line 323.361.6102

RESEARCH HIGHLIGHT

Thanks to the Las Madrinas Endowment for Autism Research, Intervention and Outcomes, Childrens Hospital Los Angeles has initiated a range of important studies. In each edition, we will provide a small profile on a study, share findings and discuss the implications of that research. Our goal is to work with other researchers, parents, advocacy groups and children to develop a stronger understanding of what causes autism spectrum disorders. In addition, we are committed to developing improved diagnostic and intervention services that support better care and support for the development of children with autism spectrum, other neurodevelopmental and behavioral disorders.

In this edition, we are excited to announce the Tummy Troubles study, a new project that is being initiated through collaboration with the Zilkha Neurogenetic Institute at USC and Vanderbilt University. Under the guidance of Dr. Pat Levitt, this research will investigate a possible genetic association between gastrointestinal dysfunction and autism spectrum disorders. This innovative study combines modern genetic research techniques with high-quality clinical assessments. "We hope that in the future the study results will help doctors make decisions on treatment that may improve the lives of children and adults with developmental delays and gastrointestinal problems," shared Dr. Levitt.

This research is supported by the National Institute of Child Health and Human Development.

For more information on research, contact Maggie Memmott at 323.361.7504.

WHAT IS A DEVELOPMENTAL-BEHAVIORAL PEDIATRICIAN?

A developmental-behavioral pediatrician is a doctor with the training necessary to better understand the needs of children with conditions such as autism, learning problems, attention-deficit disorder, and other neurodevelopmental or behavioral disorders.

When a family brings their child to meet with a developmental-behavioral pediatrician, the visit is usually very different than a visit to the child's regular doctor. Because parents are often the first to recognize that their child is failing to reach key developmental milestones, a developmental-behavioral pediatrician will listen closely to a parent's concerns about the child's development. During a visit which may last one to two hours, the doctor will conduct an in-depth physical health and behavioral assessment. The doctor may also perform standard behavior and learning tests to determine the nature of the child's condition.

Children with developmental or behavioral concerns often benefit from regular meetings with a developmental-behavioral pediatrician in addition to their primary doctor because the specialized evaluation can provide a uniquely broad view of the child's physical and mental development. To support each child in reaching his or her full potential, a developmental-behavioral pediatrician works closely with parents, primary caregivers, educators, and other medical specialists to develop a plan-of-care that meets the unique health and educational needs of each child.

SUPPORT GROUPS

Antelope Valley/ Friends of Autism

4th Thursday, 10-11 am
661.951.1271

Atwater Village/Fathers Support Network

2nd Monday, 7-9 pm
323.687.8903

South Bay/Harbor Regional Center

Last Thursday, 7-9 pm, 1st Tuesday,
6:30-8:30 pm, 4th Wednesday 6:30-8:30 pm
(Spanish)
562.595.9134

Los Angeles/Asperger's Support Group

2nd Wednesday, 7-9 pm
310.543.5064

Childrens Hospital Los Angeles

Padres Unidos Lanterman, Grupo en Español
2nd Tuesday, 7-9 pm
323.461.9307

Call Autism Warm Phone Line

323.361.6102

for additional listings

The Developing Mind Newsletter was made possible by a grant from the William Randolph Hearst Foundation.

Boone
Fetter
Clinic



ChildrensHospitalLosAngeles
International Leader in Pediatrics

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

To make an appointment:

Call 323.361.6102 and speak
to a nurse care manager.

www.childrenshospitala.org/boonefetterclinic