

# The Developing Mind

Quarterly Newsletter from Childrens Hospital Los Angeles



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**ChildrensHospitalLosAngeles**  
International Leader in Pediatrics

## 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 this issue, occupational therapist Dr. Shelby Surfes talks about the value of play, and provides some fun and beneficial activities you can do this summer with your children. In addition, we spoke with Moore Rhys from the Human Subjects Protection Program about what it means for a family to participate in research. 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

## HAVE A SENSORY SUMMER:

BY SHELBY SURFAS, OTD, OTR/L-DOCTOR OF OCCUPATIONAL THERAPY

## GET OUT AND PLAY!!

It's summer time, and for children with autism or other neurodevelopmental disorders, it's a great time to have new and engaging experiences, and build new cognitive, physical and interpersonal skills. Just by doing what kids do best, PLAYING!

If your child has ever been to an occupational therapist (please see the January 2010 issue of this newsletter for more information on occupational therapy), you may have noticed that the therapists often utilize play as a means to engage in therapeutic activities with your children. For instance, what may look like a fun game of climbing up a rock wall, the therapist knows to be beneficial to your child's proximal stability, motor planning, and sensory processing.

However, did you realize that play, in and of itself, is a critical element to your child's growth and development? This is not simply because 'playing is what children do', but rather, playing is an occupation which allows us to connect to other people, and to our own bodies, on a basic level. Although playing is not typically the goal of treatment, it challenges and develops a

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# HAVE A SENSORY SUMMER

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child's ideation, creativity and communication skills, so it is often incorporated into treatment.

Play is similar to life in that it is innately desired, fluid and most memorable when unpredictable, novel and shared with others. The next time you have an opportunity to have fun and play with your child, remember that the combination of play and the sensory experience work together to help children develop a better understanding of themselves and their relationship with the world around them.

**Here are some summer activities to try with your kids at home, at the beach or anywhere you can have fun!**

**Disappearing Pictures:** You will need a large piece of butcher paper (3'x5'), some chalk or washable markers, and a few mini squirt bottles filled with water. Tape the paper onto an outdoor wall at or above your child's eye level, and help them draw and color a favorite object or character up high to promote upper arm strength needed for more precise fine motor activities. When done drawing, encourage your child to squeeze the squirt bottles with their index and middle fingers, squirting water onto the drawing. Watch the pictures disappear while your child's hand muscles are strengthened and developed!

**Bubbles:** Many children (and adults) will smile at the site of bubbles. Have fun blowing bubbles and, to promote body awareness and motor planning, be creative and use feet, elbows, and even noses to pop the bubbles, rather than popping them with hands. Have your child practice blowing slowly to produce a large bubble, or fast to create lots of little bubbles. This will incorporate the concept of grading as well as oral motor control needed for speech development.

**Water Table Magic:** Kids love to play in water, but you don't need a pool to enjoy this fun summer activity. Make a water table by placing a large shallow bin on top of a child-sized table. Fill with water, add soap to make bubbles and even add sand, rice, or noodles for a different tactile experience. Pouring is a wonderful skill to practice with your child, make sure to have different sized cups and containers and even some funnels to increase their strength and coordination.

**It's Raining, It's Pouring:** Doing "practical" activities with your children, such as watering flowers, is an excellent way to promote purposeful play. Get a child-sized watering can and ask your child to help you water the flowers outside your house. Talk about how the flowers will grow big and strong with lots of water. Just like the water table, emphasize pouring carefully. You can expand on this activity by planting a lima bean in a cup of dirt and watching it grow! It will take about one week to sprout.

**Metamorphosis:** If your kids are into bugs, buy a butterfly kit and watch caterpillars turn into beautiful butterflies. You can buy the kit at a kids' store and send away for the caterpillars. The whole process takes about a month and

**Shelby Surfas, OTD, OTR/L, Doctor of Occupational Therapy** provides the OT component of an interdisciplinary team at the Boone Fetter Clinic. She has co-authored a documentary on the life of Sensory Integration pioneer Dr. A. Jean Ayres; consulted with major toy industry manufacturers, developed the Kid Scouts community participation program, and has taught Development in the Department of Occupational Science and Occupational Therapy at the University of Southern California.



then you can let the butterflies free outside. Make sure to read books (such as *The Very Hungry Caterpillar* by Eric Carle) with clear visuals about the process, while simultaneously increasing your child's sequencing abilities.

**Beach Time:** Bury small toys in the sand and encourage your children to find the buried treasure! Squatting while digging will improve balance and leg muscle strength. Watch to see if your child is using his/her vision, or sense of touch to locate the objects. Typically a child will rely on their vision, so try to use some dry sand to make it easier to search. You can also practice scooping with small shovels and other beach tools to encourage motor planning. To expand further on this activity, have the kids clean each toy after digging it up by dunking it in a bucket of water.

**Beach Time Part 2:** Utilize the oceans waves and practice jumping skills with your little ones. Stand at the water's edge and jump over the water each time a wave washes up the shoreline. To increase body awareness, play the bury game. If they are comfortable with it, you can bury their feet and legs with sand, and allow him/her to bury you too!

**Cool Summer:** Try "licking" popsicles with your child. Encourage your child to "stick-out" his/her tongue and then "lick" the popsicle to encourage motor planning and tongue protrusion. Also, try placing the popsicle on different parts of their lips and encourage them to "catch" the popsicle. The cold and tart flavors of the popsicle can help stimulate the tongue and other oral structures such as the lips. These exercises also help to increase tongue control and improve oral sensory awareness.

**Blowing Exercises:** Try blowing pinwheels, whistles, horns, bubbles, flower petals, or leaves with your child. Blowing exercises are a great way to improve your child's respiratory control which is important for speech production.

*The goal of these games is exploration and shared social engagement. The activities will be most therapeutic when the child is motivated and having fun. Always make sure your child is feeling comfortable and enjoying the activity. If not, find another activity that is fun for them and also a little challenging.*

# PARTICIPATING IN RESEARCH: WHAT DO PARENTS NEED TO KNOW?

At Childrens Hospital Los Angeles, there are a number of research studies taking place related to autism and other neurodevelopmental disorders. Some of these studies invite children and families to participate by providing information, answering questions, or doing an activity.

For families, deciding whether or not to participate in research is an important decision. On one hand, taking part in research is an opportunity to learn more about a child's unique condition and needs. On the other, it is not always clear what happens in research or if it could really help, so some parents might hesitate to get involved.

Moore Rhys is a representative of Children Hospital Los Angeles' Human Subjects Protection Program. The main focus of her work is making sure that research studies are doing everything they can to minimize risk to participants and protecting patients' privacy. Through her efforts, if a parent decides to participate in a research study at Childrens Hospital Los Angeles, they can be confident that their child's safety and privacy will be protected.

We talked to Moore about what parents should know about participating in research.

## **To begin, what is research all about?**

Research is a carefully planned test to answer a certain question. Medical research (also called 'clinical research') is meant to answer important questions about health, medicine or diseases. A researcher might be testing an idea about what causes a disease, or testing a new treatment to see what is most effective.

## **Why is research with children needed?**

Research with children is needed because children are different than adults. To really understand the diseases and disorders that affect children, research involves both children and their families.

## **Moore Rhys, C.I.P., IRB Administrator, Human Subjects Protection Program**

*provides analysis of research protocols for the Committee on Clinical Investigations. Before joining the human subjects protection program, Moore worked as a research coordinator for 15 years; her work has included clinical drug trials, basic epidemiology, and testing social/behavioral interventions. She, along with the HSPP team, is happy to talk with families participating in or considering participating in research at CHLA.*



## **Why should a family participate in research?**

Participating in research, even if your child is generally healthy, may lead to new and important knowledge that could benefit other children in the future. Depending on the research, you could also learn a lot about your child's unique condition and how it affects them. Of course, not every research study is right for every patient, so there is usually a process to determine if a child is a good match for a given study.

## **What is involved in participating in research?**

This depends on the particular study. Some studies will simply ask for permission to access your child's medical history record. Other studies may invite you to come into a clinic for one or more visits to do an activity. Studies that involve DNA and genetics may ask to collect a blood sample as well. Usually, agreeing to participate is not a significant time commitment.

## **Are there risks involved in participating in research?**

There are always some uncertainties when it comes to research. For example, if a researcher is testing a new therapy, there is some chance that the therapy will not be

## LAS MADRINAS RESEARCH HIGHLIGHT

### **Introducing the Boone Fetter Clinic Patient Registry**

The Boone Fetter Clinic Patient Registry maintains a confidential registry of families and individuals who are interested in being notified about research on autism and other neurodevelopmental disorders. Research studies at the Boone Fetter Clinic may focus on different topics including genetic factors, gene/environment interaction, diagnosis and development of the disorder, and treatment and therapeutic options.

#### **If you decide to join the registry:**

- We will collect information about your family and your child.
- You will receive calls when there are new research studies that you or your child may be eligible for.
- We will call you two times each year to make sure your contact information is up-to-date.

Keep in mind that enrolling in our registry does not obligate you or your family to participate in any project. Your participation is completely voluntary and you may withdraw from the registry at any time.

**If you would like to learn more about the Boone Fetter Clinic Patient Registry, please contact Maggie Memmott at: [mmemmott@chla.usc.edu](mailto:mmemmott@chla.usc.edu) or 323.361.7504**

# PARTICIPATING IN RESEARCH

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effective. However, research that takes place at an institution such as Childrens Hospital Los Angeles is always carefully planned and monitored to minimize any risk to the participant. The Human Subjects Protection Program will only approve research that has sufficient plans in place to ensure the participants' privacy and minimize risks to research subjects.

## What is "informed consent"?

Informed consent is the parents' opportunity to learn about the nature and purpose of the study and decide whether or not to participate. Parents can ask questions or address any concerns they have, so that they can make a fully informed decision.

## What is a research registry?

A research registry is a list of families who want to learn about future opportunities to participate in research. When a new study is started, a researcher can use the registry to find eligible families and let them know about the opportunity. If you join a research registry, expect to be contacted periodically with information about new research studies.

## Is there pay for participating in research?

Sometimes, there is pay or compensation for your time and effort involved in a study. If there is compensation, you will learn about this during the informed consent process.

## Is participation required?

No. Deciding whether or not to participate is a personal decision. If you are asked by your doctor or staff, you can decide to not be a part of a study and your decision will have no impact on your relationship with the clinical team.

## How can parents learn more?

If you have any questions about your rights as a research subject, you can contact the Human Subjects Protection Program at 323.361.2265; you also have the opportunity to attend a meeting where research projects at Childrens Hospital Los Angeles are being reviewed for human subjects protection issues.

If you have specific questions about autism research or the Boone Fetter Clinic Patient Registry, you can call the Boone Fetter Clinic's Warm Phone Line at 323.361.6102.

## calendar

**July 17, 10:00 a.m.**

Sensory Friendly Films - *Despicable Me*  
Visit [www.autism-society.org](http://www.autism-society.org) for more info.

**July 25, August 21, September 25**

Family Fun Festivals & 20th Anniversary Gala  
Center for Autism and Related Disorders  
Visit [www.centerforautism.com](http://www.centerforautism.com) for more info.

**August 13-14, 8:30 a.m. - 5:00 p.m.**

5th Annual Pasadena-Anaheim Autism/  
Asperger's Conference  
Pasadena Convention Center  
480.831.2047 [autismconferences@gmail.com](mailto:autismconferences@gmail.com)

**August 17-22**

FACT Family Presents: Summer Courage Camp  
in Malibu. Contact [Ashley@factfamily.org](mailto:Ashley@factfamily.org) or visit  
[www.factfamily.org](http://www.factfamily.org)

## Boone Fetter Clinic

Boone Fetter Clinic: Diagnostic, Clinical & Research  
Center for Autism, other Neurodevelopmental &  
Behavioral Disorders

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



**ChildrensHospitalLosAngeles**

*International Leader in Pediatrics*

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## 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.