



Winter, 2003-2004

# Sensations

A Newsletter for the Benefactors and Friends of the Foundation for Knowledge In Development

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### The Foundation for Knowledge In Development (KID Foundation)

serves children with sensory processing disorders by **INCREASING** public and professional awareness of the scope and severity of these disorders, by **PROVIDING** information and resources to families, educators, physicians, and other health care professionals, and by **SUPPORTING** advocacy for and research on dysfunction in sensory integration.

## OUR FIRST ISSUE!

A big welcoming hello to everyone! We proudly and enthusiastically unveil our inaugural issue of *Sensations*, the newsletter designed exclusively for the friends and benefactors of the KID Foundation.

The KID Foundation is dedicated to serving children with sensory processing disorders, specifically dysfunction in sensory integration (DSI), through education, advocacy and research. We are committed to sharing the progress and promise of research with the community and finding additional ways to better serve families living with DSI.

This newsletter is a celebration of that commitment to serve and a pledge to support the ongoing search for ways to meet the needs

of children with DSI and their families. Contained within its pages will be articles on the latest developments in sensory research conducted at the Sensory Processing Treatment And Research (STAR) Center, located at the Children's Hospital of Denver (which the KID Foundation helps support), a success story about a child with DSI, and upcoming events and workshops for those interested in learning more about sensory processing disorders.

We look forward to being your source of information on the latest developments and happenings in the field and welcome for review any ideas, articles or information you deem applicable for inclusion in the newsletter. ■

## A WORD FROM THE EXECUTIVE DIRECTOR

By Lucy Jane Miller, Ph.D., OTR

We are very excited about the initiation of our newsletter. It will enable us to better communicate with everyone and to keep you abreast on what is happening with our research, continuing education, parental support and advocacy efforts related to sensory processing disorders.

For this first edition, I want to let you know about some new and exciting developments.

### Current Research Activities

The goal of our research program, located at the Children's Hospital of Denver, is to define the underlying

neurological and physiological mechanisms of sensory processing disorders. To help to accomplish this goal, we developed a physiologic laboratory that looks like a pretend spaceship, where children's reactions to sensory stimuli are measured as they sit in a specialized chair.



(continued on page three)



## Parent's Corner: A Success Story

By Laurie Renke  
DSI Parent Connections  
National Coordinator

Picture the worst DSI CHILD you have ever seen at the dentist for a normal cleaning. Picture the looks from people in the waiting room. Looks from the staff. Looks from the so called child friendly dentist, and hygienist, etc. Hear the screams before they even touch him. Feel the sharp pinches, hits, etc. that this scared beautiful child is inflicting on you AND anyone who comes within reaching distance. Smell the HOSPITAL TYPE smell in the air. See the equipment; it looks like it is from outer space. Squint from the bright fluorescent lighting. Hear the drill or water bubbler making noise in the room you are trying to push, pry or drag the child into. Hear the cries from yet another happy child from another room. This effect is the most comforting of all to your child. NOT! Attempt to not lose your mind; attempt to NOT cry, but go ahead anyway. I mean the dream child is certainly not present and you have now undoubtedly become the worse parent on the face of the planet, a marshmallow who should start believing in THE WHIP! NOT!

After a decision that the teeth NEED to be cleaned, because GOD forbid a return trip for a filling! HORRORS! So either you decide to sit in the chair with the child on top of you, MY OPTION! or somehow hold the child down. Work begins. NOT soft, gentle, fun loving an adventure work, but in/out, hard finish the task work. "GOD, get me away from this child!", is almost heard coming out of the dentist's brain, and anyone in

the waiting room, so thrilled their child's appointment was at the same time as yours. The ripple effect is bound to continue until the afternoon office lunch break. Here is where all the employees who have survived your visit compare notes between your child and still yet a worse child who actually bites someone other than their own parent. The bottles of Excederin come pouring out of pocketbooks and briefcases and the staff breaths a sigh of relief. Perhaps their luck will not continue for the day and a DSI free afternoon will follow. You'll never know, because you are still under attack from the aftermath that will continue until bedtime or even the dreaded NEXT DAY effect.

If you are reading this as a JOKE, BACK UP! This is NO JOKE! This was Jake (4 years ago at age 4) If you think your child is worse, I might have some good arguments for you to read but no bother. Lets call it a draw. Sometimes we need to think our child has it the worst, to force us to push back and fight. That's what I did.

Now, fast forward 4 years! (During this time, we tore apart his diagnosis and forced everyone to look at the whole child, piece by piece. He has had therapy for 99% of that time. OT tops the list along with diet intervention, DSI goggles/behavior, modifying our lives for him, glasses,

parental support, education about school laws, etc.)

Today: Jake: Age 8. ORAL SURGEON, 8:00AM, 45 minutes away. NO FOOD, NO DRINK, NOT EVEN A SIP! Yes that reads correctly. 4 teeth need to be pulled for braces.

Can you even imagine what I thought as I saw the teeth growing in crooked? If your child is like above, or was, you understand. SHEAR FEAR! I do know about Jake's successes. He is doing great and is a new child, but still I FEAR!

Well, all that fear was for nothing; I asked if he was nervous,. He said "NO, let's just get it over with. Can I have bubble gum smells" Drive there, angel. Walking in, angel. Paperwork, angel. Name called, angel. In the chair, angel. I kissed him goodbye, to wait in other room. angel. Whole appointment, angel. Gauze in mouth, angel. Numb lips, top and bottom, angel. Ride home, angel. The doctor even commented that Jake is in the running for the BEST PATIENT he has ever had for 4 teeth removed at the same time! "Honest" he said.

AM I DREAMING? YES, I was dreaming of this day 4 long years ago, and it finally came true. IT CAN COME TRUE FOR YOU TOO! I will pray it does soon! ■

### DSI Parent Connections Meeting

Denver Chapter

Our Next Meeting:

Koebel Library  
5955 S. Holly St.  
Centennial, CO 80121

Time: 7:30 P.M.

Date: December 16, 2003

DSI Parent Connections is a grassroots organization created by and for parents to provide support, information, and understanding to anyone living with someone with Dysfunction in Sensory Integration (DSI). Support is provided through story sharing, informational exchanges, guest speakers and group discussions.

## DIRECTOR...

(Continued from page 1)

The Pferrele brothers of PlayAway, Inc. not only generously donated the lab chair for our use but also lab chairs for the three collaborative sites initiated through an NIH planning grant: the Pediatric Therapy Network and the University of Southern California, the Occupational Therapy Associates and Boston University, and Thomas Jefferson University in Philadelphia. *Thank you, PlayAway!*

**Sensory Research Planning Retreat II** We are receiving assistance with planning from the Coleman Institute for Cognitive Disabilities to again host a Sensory Research Planning Retreat funded by the Wallace Research Foundation on February 6-8, 2004. At the last retreat, 12 NIH funded researchers were here to discuss a

future agenda for research in sensory processing disorders. Three pilot projects were continued and five new initiatives were funded. This year, we plan to expand the group to about 20. The Retreat titled "The Neurobiology of Sensory Processing Disorders" will feature Michael First, Ph.D., Editor in Chief of the DSM-V as keynote speaker. His talk is entitled "Sensory Processing Disorders: A Possible Pathway to DSM-V." Bruce Pennington, Ph.D., Professor of Psychology at the University of Denver will speak on "Validating Complex Behavioral Disorders: Lessons from Dyslexia and ADHD".

### National DSI Resource Directory

The KID Foundation is particularly proud of and very pleased to announce that starting in early 2004, our SInetwork.org web site will include a National DSI Resource Directory. The DSI Directory will help parents find those providers who have identified



The Spaceship Lab Chair

themselves as having some expertise with assessments and/or providing services for children with DSI. The directory will include treatment centers, physicians, dentists, occupational, speech, and physical therapists, and community resources (gyms, camps, etc.) listed by city and state. Parents and professionals alike will be able to find resources quickly and easily in their local area by simply entering their city and state! If you are professional who treats children with DSI, visit [www.SInetwork.org](http://www.SInetwork.org) to register! ■

## Our Generous Donors

*Between August 1, 2003 and November 30, 2003, the KID Foundation received gifts from the following. Gifts of \$5000 or above are in bold.*

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*Thank you for your support.*

## Save the Date



Mark your  
calendars for the  
First Annual  
Sensational Golf  
Tournament to  
benefit the KID  
Foundation.

Monday, May 3, 2004  
Glenmoor Country Club  
Cherry Hills Village, Colorado

If you are interested in  
sponsorship, playing or volunteering,  
please call Fran Birx at  
303-794-1182.

## Volunteers Needed !

The KID Foundation is in need of a volunteer  
force to help with upcoming special events,  
general office tasks and  
miscellaneous projects.

If you are able to offer some  
of your time and talent,  
please contact Fran Birx  
at 303-794-1182.



**THANK YOU BECOMING A PART OF  
THE VOLUNTEER FORCE.**

## KID FOUNDATION STAFF

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*Serving children with DSI and bringing  
sense to their world*



**Sensations**  
News from the KID Foundation

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