



Two Sensational Days with Dr. Winnie Dunn

10th International Symposium &
Pre-Conference Institute
March 4, 5 & 6, 2010
Denver, Colorado

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Sensations

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Dear Sensational SPDF Friend:

Never doubt that a few, thoughtful, committed citizens can change the world: Indeed, it is the only thing that ever has.

-Margaret Mead

Changing the world is what we are doing; it's what you are doing. We are a small group, but our numbers are growing every day. There are now more than 15,000 individuals receiving this newsletter alone. This year, we held more SPD awareness events across the globe than we did in the last five years combined. Our final application for diagnostic recognition of Sensory Processing Disorder were submitted for the 2012 revision of the Diagnostic and Statistical Manual (DSM-V), and we're holding our breath for word on a decision. And news about SPD was routinely published around the globe. [Our voices](#) are being heard, and it is because of you. 2009 was just another great beginning for this thoughtful, committed group, and 2010 promises to be even better.

For my introduction to this issue of Sensations, I want to focus on some of those great individuals and groups out there who are helping to promote our cause. I would encourage you to take a look at their efforts and give them a shout out.

Throughout 2009, our Parent Connection hosts, resources, and all of our dedicated volunteers were more active than ever before. There is no real way for me to truly express my gratitude to this group. Did you know that we now have over 70 Parent Connection groups in the United States and around the globe? You can find out more about our Parent Connection groups by following this [this link](#).

The staff at the Foundation has to be thanked a million times over. This has been a hard year for everyone financially, including the Foundation. Our team members have shown their incredible dedication by taking a 20% pay cut in order to help keep our mission on track.

The staff at the STAR Center has been a big help this year. They are right next door to the Foundation and are always there to lend a hand when we try to climb a hill that is just too big to climb alone.

Carrie Fannin has been helping the SPD cause for years now as host of SPD Washington and in countless other ways. If you aren't familiar with her social network, [Sensory Planet](#), I encourage you to check it out. It is a great place to meet other sensational families and share experiences and support with one another. Carrie will also be helping the Foundation with our 11th International Symposium during the fall of 2010 in Seattle.

The organizers of our first-time-ever worldwide Sensory Showtimes turned out to be an amazing group of advocates and fundraisers. Their success couldn't have come at a more crucial time.

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They staged more than 75 Showtime events around the globe this October. Erik Linthorst was also a big help with Sensory Showtime. He donated all the "[Autistic Like: Graham's Story](#)" movies for our Showtime events, and he personally attended at least two events!

The Foundation Board has been working overtime this year to ensure that we are moving in the right direction-financially and organizationally. Marla, Katy, Greg, Bill, Ryan, Carol, Rob, Ed, and Steve have been tremendous support for the Foundation and the SPD cause in 2009.

Parent and previous board member Jen Brout put on the Sensations to Emotion conference and a dynamite concert in New York City. She is absolutely amazing, and so was the conference. A super volunteer, Abby Eurich, started the Foundation's Facebook Cause page. It now has more than 4500 members. [Check it out!](#) Kim Lesserman, another parent, is equally amazing. Kim and her family matched every donation to SPDF made for a week in October. OT Beth Osten filled in at our national conference with only two days' notice. What a great friend and great speaker Beth is.

Our long-term supporters Laura and Jim Heneghen and the Wallace Research Foundation have put a great deal into the Foundation. We wouldn't be able to conduct our research, educate or advocate about SPD if it weren't for their support.

Finally, and most of all, I want to thank you and all those whose good works I missed in this letter! The SPD Foundation is here because of your interest, dedication, volunteerism, and support. We couldn't do what we do without you.

2009 isn't quite behind us yet, and we could really use some help getting ready for 2010. You might have noticed a thermometer at the beginning of this letter. This is the amount of money we need to raise by the end of the year through individual donations. This will help us recoup some of the funds we spent this past year on the DSM effort. It will also ensure that the Foundation enters 2010 on solid ground. If you can help in any way, [please do so today](#). Every little bit helps. In fact, if all 15,000 people who receive this newsletter contributed \$10 each, we would smash our goal with ease.

And please, don't forget there are other ways you can help the Foundation besides donating. To the left of this letter, you should see links to all of our affiliates. Every time you make a purchase at one of these merchants using the links provided in this email or through our website, we receive a percentage of your purchase. Or shop for sensory products in our [e-Store](#), where our generous partner FlagHouse donates a portion of every sale back to us. Buy from our [Business Members!](#) The dues they pay help sustain us, and your support makes their support worthwhile. You can also volunteer with the Foundation. Our sensational parent and volunteer coordinator JoEllen Nikkel is full of ideas. You can write her at JoEllen@SPDFoundation.net. And of course, you help every day when you spread the word about Sensory Processing Disorder. You know our motto: bringing hope and help to sensational families everywhere.

Thank you all and here's to a fantastic and equally amazing new year!

Lucy

Dr. Lucy

P.S. As you probably noticed, this installment of Sensations is a bit shorter than usual. As a cost-saving measure, we are currently revamping our newsletter process and distribution method. We should be back to normal newsletter production by next quarter.



Ask Dr. Lucy

**Lucy Jane Miller, PhD,
OTR
Founder and Executive
Director**

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Some fellow moms and I went to see the film “Autistic-Like: Graham’s Story” in October at a Sensory Showtime near our home last month. Two of my friends have kids with autism as well as Sensory Processing Disorder. They were startled that the movie talks about people using an autism diagnosis to get funding for services even if their child is only “autistic-like.” Why is this necessary, and what do you think of it?

Until we know the genetics of the many so-called mental health disorders, only conditions that have a genetic or blood test (e.g., Down Syndrome, Fragile X Syndrome) can be given a diagnosis that is “proven.” So we are left with an imperfect system of educated diagnoses based on training in discerning clusters of behavioral symptoms. The fact that some conditions, including Sensory Processing Disorder, are not currently listed in diagnostic manuals like the Diagnostic and Statistical Manual (DSM) and the International Classification of Diseases (ICD) intensifies the problem because it leaves health care providers without published standards with which to reliably diagnose these syndromes.

I personally believe that parents have the responsibility and deserve the right to choose what they want to do for the benefit of their children, including the choice of accepting an imperfect diagnosis in order to get needed services versus refusing to have their child mislabeled whatever the cost. But there is no one-size-fits-all answer. The family with excellent health coverage may feel more freedom to reject an imperfect diagnosis than a family whose only chance of getting help for their child is by accepting a diagnosis they know isn’t quite right. Parents advocating for their children typically are doing the best they can, and that’s what matters the most.

Whatever choice a family makes and whatever the reasons for making that choice, what is essential in every situation is to honor the family at the center of this dilemma and to reinforce the relationship between the child, the parents, and the other family members the way the Linthorsts do in “Autistic-Like.” Ultimately, quality of life matters - not the diagnostic label, not the name for the treatment. What’s important is whatever helps children participate in daily routines and be included in school and community activities, regardless of the challenges they face.

Research Update

**Sarah A. Schoen, PhD,
OTR
Research Director**

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Chicago Conference Sensory Processing Disorder Foundation goes to the Midwest

The 9th International SPD Foundation Symposium in Chicago was a huge success, attended by more than 250 people from across disciplines and around the world. Beyond the information-packed program, highlights included presentation of the Sensory Processing Disorder Lifetime Award to Antje Price, OT/FAOTA, for her significant lifetime contributions to research and education in sensory integration/Sensory Processing Disorder and a Sensory Showtime screening of the moving documentary film, “Autistic-Like: Graham’s Story.”

The three-day program kicked off October 8 with the Pre-Conference Institute on standardized scales and qualitative methods of assessment. In one of the four sessions, Antje Price described new insights from the motor accuracy scale within the Sensory Integration and Praxis Test (SIPT). An occupational therapist with more than 60 years of experience, Antje highlighted differences in performance based on a distinction she made between children with dyspraxia (difficulty carrying out the skilled motor act in the correct sequence) and children with dysmetria (inability to stop movements at desired points during the task). Children with dysmetria tended to overshoot the line and use too much force while those with dyspraxia had difficulty with the planning and sequencing of the actions. Antje’s results suggested that children with dyspraxia have the poorest accuracy scores and tend to perform the task way too fast.

During the two days that followed, a dozen scientists, therapists, and authors delivered presentations sharing the latest in research and intervention to the participants. Lucy Jane Miller, PhD, OTR, founder and executive director of the Foundation, provided a compelling overview of research related to the validity of Sensory Processing Disorder as a distinct diagnosis in one of four keynote addresses.

Dr. Mary L. Schneider, professor and director of the occupational therapy program at the University of Wisconsin-Madison, addressed the conference on neurobiological correlates of SPD in a primate model including habituation, sensitization, and dopamine function. Dr. Schneider is a research associate at the Harlow Primate Laboratory where she conducts studies

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investigating the underlying neural mechanisms associated with fetal alcohol exposure, prenatal stress and sensory processing disorder. Her research strives to understand some of the most important questions we have about SPD:

1. What are some of the physiological underpinnings? What brain regions or neurotransmitter systems are associated with particular patterns of Sensory Processing Disorder?
2. Do genetic factors explain some variance in sensory processing? What is the role of environmental factors? How do genetic and environmental factors interact to contribute to outcomes?
3. What about the role of stress? Could stress be a factor even before birth when neurons are migrating and proliferating?
4. What is the role of alcohol and other drugs during the prenatal period on Postnatal Expression Sensory Processing Disorder?

Dr. Schneider's findings suggest that atypical sensory processing behaviors can be identified in rhesus monkeys and that the subtype they manifest depends in part upon the timing of pre-natal events in genetically vulnerable offspring. Her research found an association between neurotransmitter function and atypical sensory behaviors. Specifically, post-natal lead exposure and pre-natal stress were related to sensory over-responsivity. She has concluded that atypical sensory processing appears to be influenced by both genetic and environmental factors.

Dr. H. Hill Goldsmith, professor of psychology at University of Wisconsin-Madison, presented a genetic epidemiological perspective on the question, "Are sensory processing symptoms distinct from other childhood behavioral challenges?" Goldsmith founded the University of Wisconsin Waisman Twin Center, where he conducts research in socio-emotional development from infancy to middle school years in twins. Currently, there are multiple ongoing studies at the Twin Center, three of which include Sensory Processing Disorder. Each of his studies strives to uncover the links among various socio-emotional characteristics including personality and characteristics in other domains such as vulnerability to psychopathology and patterns in physiological activation. Because his studies examine twins, they elucidate both the genetic and environmental influences on various aspects of development.

Of particular interest over the past decade has been the study of genetic influences on sensory over-responsivity using twin methodology. The two studies Dr. Goldsmith presented focused on tactile and auditory over-responsiveness in toddlers and first graders. His results suggest that tactile symptoms tend to be stable from toddlerhood to school age, indicating that children who had more symptoms at a younger age also tended to have elevated levels at the older age. Furthermore, in the first-grade sample, 44% of the children who screened positive for tactile and auditory over-responsivity did not have any other clinical diagnosis. He reported high correlations between mother and child sensory symptoms as well as support for the heritability of both auditory and tactile over-responsivity.

Beth Osten, MS, OTR/L and owner/director of Beth Osten and Associates - Pediatric Therapy Services, presented on assessment of emotional development. Beth is a member of the advisory board and on the DIR Institute faculty for the Interdisciplinary Council on Developmental and Learning Disorders. Her presentation emphasized the relationship among sensory processing capacities and emotional development, highlighting how affect can be used to impact a child's ability to make meaning of sensation. She described how parenting patterns can impact the child's sensory and regulatory profile as well as how to determine a child's functional emotional developmental level in designing appropriate treatments.

The 10th International Symposium of the Sensory Processing Disorder Foundation and Pre-Conference Institute will be held March 4-6 in Denver, Colorado. The conference will feature two days in which Dr. Winnie Dunn will talk about "Living Sensationally at Home, School, and in the Community." For details and registration, click [here](#).

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STARLights

Electronic Toys for the Holiday Season

As the holidays approach, one of the most common questions we receive as therapists at STAR is regarding the appropriateness of electronic gifts for children. This is the age of video games, but it is often difficult to discern what is appropriate for each child and the boundaries to be set

Lynn Witzen
Clinical Supervisor at
STAR Center

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with use of the games.

There is a great diversity of games as well as systems available. In addition, there are some interesting new electronic products to support skills such as pre-reading. We make our recommendations based on the age of the child, skill level and ability to engage with the games. We select games to focus on some of the areas of challenge for the child such as motor planning, coordination or use of controlled eye movements. The games can often be so motivating for a child that he/she will work to develop the needed skills to master the games. Obviously it doesn't substitute for therapeutic intervention, but it does supplement the development of some of the skills we work on in the therapy setting.

We do recommend games that facilitate children moving rather than sitting and interacting with games on a screen. Fisher Price recently introduced two games that plug into a television and provide this type of activity for children from developmental ages of three to six years old. The Smart Fit Park includes a number of fun learning based games that also incorporate skills such as hopping, skipping and jumping. In addition, there is a Smart Sports Plug & Play that includes challenges such as baseball, tennis and golf. The pack has a small baseball bat, tennis racket and golf club that are used during each of the games. It is similar to Wii Sports, but presents this at a level that is appropriate for a very young child.

We use the Wii at STAR as one of our activities and often recommend it for use at home. There are many skills that can be developed depending on the use of the Wii and choice of games. Again, as with the Fisher Price game, we recommend interactive games that involve movement whenever possible. The Wii comes with a game pack of sports such as baseball, bowling, boxing and tennis. This is a good beginning and can be played by one to four players depending on the game chosen. We have games at STAR that are chosen because of the skills most of our children need to develop. For instance, Outdoor Challenge by Bandai Namco Games works on gross motor skills such as running, jumping, balance and timing. It is a fun game, so the fun is a motivator for our children to develop higher-level skills in some challenging areas.

Wii offers similar games, but for players of different ages. The popular Dance Dance Revolution began as a game for teens, but there are now specific versions for younger players who do not have the skills the teen version demands. Dance Dance Revolution Disney High School Musical 3: Senior Year is designed for "tweens" and Dance Dance Revolution Disney Grooves is for the six to nine year olds. Each game provides age appropriate motor skill challenges as well as lots of fun!

We also have Wario Smooth Moves which incorporates motor planning into a mini-game format. The mini-game format means that the games are limited in duration, each section of the game requiring less than one to three minutes. We find this is helpful so our children don't become hyper focused and "zone out" when playing games. The challenges change quickly and are highly engaging. They involve changing the position of the controller quickly, motor planning challenges, visual targeting, and precise timing to complete games along with quick thinking to move from one challenge to another.

Our boys who are 8 and above particularly enjoy playing Ninja Reflex which is a martial arts-based game. As the challenges of motor planning, reaction times, and balance are met, the player "earns" an advanced belt indicating levels of achievement. It is fun, engaging and helps to reinforce many skills we address during our therapy sessions.

The Wii balance board provides even more challenge as it incorporates balance and weight shifting as well as skills utilized in other games. Mountain Sports by Activision is for younger players from 6 and up and includes winter-based activities such as snowboarding and skiing. Shaun White Snowboarding Road Trip by UBI Soft is designed for players 10 years and older and incorporates skill challenges as players face the slopes in different virtual locations.

Although there are specific games mentioned above, the selection and use of games for individual children varies. The recommended age range may be too high level for children with developmental challenges, so lower level games may provide success and fun for them. Parents need to determine time limits for game play prior to introducing gaming systems and make these clear to the players. Some games with multiple levels that are played while children are sitting can be mesmerizing and difficult to stop. The games provide great lessons in turn taking, socializing with others, and physical skill development. The strong positive experience with Wii

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 SPD Foundation.**

can also provide a potential behavioral reinforcement. For instance, a child may have an entitlement to a certain amount of time on Wii, but earn additional time through positive behaviors at home or school.

There are also benefits to utilizing hand held electronic games in moderation. For instance, many of our younger children from the age of three or four enjoy playing the Leapster Learning Game System. It helps to develop pre-academic skills through fun games. Children from the age of six enjoy using the Nintendo DS system. Again, as noted with the Wii, games that are short in duration tend to work the best for our children. There are many puzzle type games available as well as strictly "fun" games. Reviews of the games and appropriate player ages are available on Amazon, Toys R Us and similar websites. Parents report that these portable game systems can be lifesavers for children while traveling or having to wait in places like restaurants.

Finally, Leap Frog just introduced a touch reading system called "Tag." The original Leap Frog Leap Pad was a rather cumbersome notebook type device in which a special book was placed and the pen attached to the Leap Pad was utilized to read the story. The Tag system is far more portable to use, as it is a scanning pen that reads to the child as it is moved across the printed page. This is not a substitute for someone engaging and reading to the child, but does offer the opportunity to work on tracking, listening and reading skills more independently. This system is designed for children from four to eight years of age and there are presently more than 30 books and games available. The book subjects and titles are familiar to children in this age range and include topics from pirates and princesses to Miss Spider and Kung Fu Panda. The Tag system just received the Toy of the Year Award for 2009. There is a younger version for children from two to four years of age. The books are age appropriate in topics, print size and ease of scanning. The scanner device is sized for smaller hands and easier to grasp and move.

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When deciding on electronic gifts, there is no absolute right or wrong choice as long as developmental age and abilities as well as purpose of use of games are considered. Most of the systems reviewed have potential to expand and grow with the child, so boredom due to repetition should be minimal. These games provide exciting options that enable children to have fun while learning and developing skills. However, keep in mind that the electronic games or activities fulfill only one part of a child's overall play needs.

