

THE DSG News

PEOPLE WITH DOWN SYNDROME – VALUED AND INCLUDED

March 2007

Affiliate of the National
Down Syndrome Congress
and the National Down
Syndrome Society

A P U B L I C A T I O N O F T H E D O W N S Y N D R O M E G U I L D O F D A L L A S

What's New On the Web

Go to downsyndromedallas.org to find more information. Some items are too long to go in the newsletter, but you can find them on our website. Items added this month are:

- ◆ **New Parent Information Pages**
- ◆ **Snackin' With Santa Update** - Thanks to donors and fantastic pictures
- ◆ **Shining Starts Classes Resume** - New information! – Creative movement classes for kids with special needs at Chamberlain Ballet in Plano.
- ◆ **Panel Calls For Big Changes In Medicaid** - A federal advisory panel recommends sweeping changes to rein in costs, including greater use of managed care for the sickest Medicaid recipients.
- ◆ **State Settles With Advocacy Group** - State settles with advocacy group on services for people with disabilities. State officials to ask lawmakers for money to reduce waiting lists for programs that provide at-home services.
- ◆ **Special Ed. Official Leads Data Collection Push** - States will have to report more information for their students with disabilities than ever before under previous incarnations of the law.
- ◆ **Announcing the SibKids and SibNet Listservs** - Information about listservs just for siblings of people with disabilities
- ◆ **"What's Lost In Prenatal Testing"** - *Washington Post* article
- ◆ **Disability Coalition 2007 Legislative Goals** - Learn what a national disability coalition recommends to congress

Coming events

Last IEP Clinic in the 2007 Series

March 17, 2007

10:00am – noon

Region 10 Education Service Center
904 Abrams Road in Richardson

Lynn Campbell, a private speech pathologist with extensive experience working with children and adults who have Down syndrome, will speak on the topic: "Reading, a Major Key to Lifelong Learning."

SPACE IS LIMITED

Please RSVP to kelly@thompson-realty.com or call Kelly Drablos at 972-562-8997 to confirm your reservation.

Barnes and Noble Event

Barnes and Noble book stores across the country is honoring and recognizing Down syndrome in the next few weeks. Steve Riggio, President of Barnes and Noble has a daughter with Down syndrome.

The Barnes and Noble on Northwest Highway at Central Expressway, across from NorthPark is having two events. One story time on Wednesday, February 21 at 10:30 A.M. will have appropriate pre-school stories read about people and issues related to Down syndrome. On Saturday, March 10 at 10:30 A.M. there will be another story time, this one featuring five local young adults with Down syndrome reading to young children. Please mark your calendars and come to these

story times and show support for Down syndrome. Bring your young children to be read to by our young adults! See the DSG website for more details.

Teen Dance – Kick Up Your Heels at the Spring Carnival!

Friday, March 2, 2007

7:00 – 10:00pm

Cistercian Prep School
One Cistercian Road
Irving, TX 75039

It's time for the annual Spring Carnival Dance hosted by the students at Cistercian Prep School for the DSG's teens and young adults. If your child is 13 years old or older, this is a great opportunity to mix and mingle in a safe – yet inclusive environment. The boys from Cistercian, with the assistance of the girls from Ursuline Academy and The Hockaday School, make sure that everyone has a dance partner!

For more information and to RSVP, contact Joan Pruitt at truthnlove9@yahoo.com or 817-481-2147.

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In Perspective: A look at the world around us *Joy Dwyer*

“So, Mr. and Mrs. Dwyer, now that you’ve just delivered a baby with special-needs, what are you going to do next?”
“We’re going to Disney World!”

With the Super Bowl and its infamous commercials just a few weeks behind us, I am reminded of one of the most widely used ad campaigns which highlights the upcoming – and apparently much anticipated – trip to Disney World. You know the one – the winning team puts a camera in front of one of its players and asks: “You’ve just won the Super Bowl ... what are you going to do next?” Then, the scripted answer of going to Disney World is produced, like it’s even better than winning the mother of all football games.

A keen marketing ploy to be sure, but I, too, can now attest to the magic of the Magic Kingdom.

No, we didn’t take our son with Down syndrome, Alan, there right after he was born 10 years ago, but we did go just last November, with Alan and his two older brothers, Sean, 16, and Ryan, 13.

Now, I thought the magic would begin with the boys’ first plane ride. And I must admit that the three boys all did remarkably well (no need for the Dramamine I packed or the little bags for stomach upsets in the front pocket of the seats). But, magic? No, not really. Everyone was plugged into his iPod, talk was at a minimum, and while I got some unexpected and most welcomed rest before the frenzied activities began, it wasn’t what I would label “magical.”

The next opportunity for magic to show itself was upon entering the Magic Kingdom – all the characters, the rides, the food ... well, I don’t know about you, but traveling with teenagers can quickly redefine what true magic is. Oh, the older boys had a good time, but let’s face it: When Mickey tries to put a hug on a 16-year-old boy, it just doesn’t go over well. I now understand why that Tigger character may be facing assault charges.

But, I digress.

All in all, a great time was had by all the Dwyers – the rides, parades and the fireworks elicited the proper oohs and ahhs. Still, I wanted more. I wanted the magic they promised. WHERE WAS THE MAGIC?!

Then, it happened ... in one of the most unexpected of places.

We had gone into the largest Disney store in the world – to the horror and dismay of me and my husband, Brad. We needed to find a hooded coat for Ryan (yes, the temperature “magically” dropped to all-time lows during our trip, and we had to buy coats to survive). As a result, we were forced into this den of Disney paraphernalia, the likes and quantities of which we had never seen. Kids and parents were everywhere; walking space was at a minimum, and prices were not. Pandemonium does not even describe it. My eyes were crossing in front of me, as we staggered from one rack to another, looking for the Goofy “hoodie” that Ryan coveted. I kept a firm clutch on Alan, lest he be swept away in the Disney tidal wave of shoppers.

We actually were moving at a pretty good clip, until Alan began to pull

against me – against the wave of screaming kids begging for one more toy added to their parents’ growing Visa bill. I tried to pull him back in line with us, but he was determined.

“Look, Mom, look!” He was yelling for me to come and see.

I tried to reason with him; we would be going against the stream. Not a pretty place to be in this mega Disney place. Finally, he wore me down. I gave Brad the “I’ll-be-back-in-a-minute-with-some-expensive-toy” sign, and turned to follow Alan’s lead. We walked past row after row of brightly colored toys – Alan never even looked. Finally, he stopped and pointed. Up.

There, on the ceiling, were lifelike replicas of Peter Pan and Wendy – flying high above the craziness below. Serene. Peaceful. MAGICAL.

Alan’s eyes were filled with wonder, and all he wanted to do was stand and gaze. He didn’t want to buy, touch or beg for toys. He wanted to look upon the true magic of the Magic Kingdom. Tears sprang to my eyes. This wonderful little boy saw what others didn’t – I can honestly say I didn’t see anyone else looking up in that store. It felt like a secret between me and my littlest guy. The one who understands more than most of us ever will.

I learned a lesson that day – magic is what you make it. It can’t be manufactured in stores or even theme parks – it comes from the heart. One small boy looking up taught me that. And while we didn’t make our trip to Disney World just after having Alan in February 1997, I can say with certainty that our magical adventure began then and there.

Inclusion Solutions

These ideas from the Down Syndrome Guild of Kansas City are specifically to pass on to educators who are already doing amazing things!

Tips for Dealing With Challenging Behaviors

- State expectations clearly in terms the student can understand.
- Catch the student being good. Look for opportunities to define what to do rather than what not to do.
- Offer praise when the student exhibits desirable behavior.
- Describe the alternative. Name the behavior you wish to see less of and describe the alternate behavior you wish to see more of. This should be stated in 10 seconds or less.
- Present limited reasonable choices. Encourage the student to learn more about how to make a good decision and how to accept consequences.
- Wait for a neutral time. Discuss things that went wrong at a good time rather than in the middle of the behavior.

Curriculum Adaptation Tips

- Try to plan one academic activity a day which the student can participate in easily.
- Give directions in a mode other than solely auditory.
- Rewrite directions at a more appropriate reading level.
- Tape record directions or have peers deliver directions.
- Allow the student to dictate responses.
- Provide a sample of desired finished product before beginning an activity.

Two versions of the DSG News

The DSG News staff is happy to announce that there are now two versions of the publication, one in English and one in Spanish. This is thanks to our hard working volunteer translators Myrna Castillo and Patricia Erbert. We are so appreciative of their dedication as well as their language skills! If you are receiving this publication in one language and would prefer it in the other, please contact Minnie Blackwell at minnieblackwell@tx.rr.com, or call the

The Down Syndrome Guild needs YOU!!

The DSG Nominating Committee is soliciting committee volunteers for the new term, which begins on June 1, 2007. We are hoping to find people who are willing to commit their time and energy to one or more of the DSG's programs, services or projects. Committee members have the opportunity to make new friends, learn more about Down syndrome, and contribute to the good work done by the DSG. Please go to www.downsyndromedallas.org and click on the link to see the list of committees. Fill out the form and return it – NO LATER THAN MARCH 30, 2007! If you have questions, contact minnieblackwell@tx.rr.com or 972-239-8771.

DSG office. ALSO - if you would like to "opt out" of the paper newsletter, please let Minnie know, and you will receive an email when each month's newsletter is posted on the website.

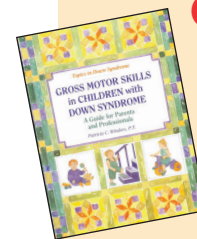
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MARCH FOR RESPECT
Thousands of people . . .
Making a difference . . .
Giving back to the community . . .

**The walk is one mile.
 The possibilities are endless...**

SATURDAY, MARCH 31, 2007
 Activities begin at 9 a.m.
 March begins at 11 a.m.

REGISTER TODAY, IT'S FREE!!!
 Teresa Sims-Ramirez at 972-252-1512 or
teseramirez@aol.com

Event Web site:
<http://www.marchforrespect.org/>



Calling all Parents!!!

PAT WINDERS, PT

Come learn about

GROSS MOTOR SKILLS *for children with Down syndrome*

SATURDAY, APRIL 28
 9:00 am to 12:00 pm at The RISE School
 5923 Royal Lane, Dallas, TX 75230

**COST: \$10 PER INDIVIDUAL
 OR COUPLE**

FREE CHILD CARE IS PROVIDED
but you must pre-register by April 20th.
Questions? Call Angela O'Brien
at 214-546-0507.



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BUILDING 5-I
RICHARDSON, TX 75080
Return service requested

214-267-1374
En Español 972-248-6845
www.downsyndromedallas.org

EXECUTIVE DIRECTOR: BECKY SLAKMAN
PRESIDENT: ELIZABETH LONGWORTH
DSG NEWS EDITOR: NANCY DAVENPORT

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DSG Calendar - March 2007

March 2

Teen Dance at Cistercian Prep School

March 10

Barnes and Noble reading by self-advocates

March 12

Board Meeting

March 17

IEP Clinic—Reading, a major key to lifelong learning

March 31

March for Respect—join the DSG team

March Moms' Escape—Check the website for date and location

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From the Executive Director

I am Becky Slakman and am very happy to be the new Executive Director of the Down Syndrome Guild. I look forward to a long, rewarding partnership with all of you involved at the DSG. Everyone I have met has been very welcoming. Please continue to take advantage of all of the wonderful opportunities and valuable resources that the DSG offers--upcoming IEP Clinics, Parent to Parent gatherings, picnics, teen dances, adult

issues, Moms' Escape, lending library, Golf Tournament, Buddy Walk, as well as the informative monthly newsletter. I also encourage you to let us know what additional services you would like to see. I can be reached at 214-267-1374 or dsged@sbcglobal.net.

A little bit about me. I am a native Dallasite. I have worked for non-profit agencies in Dallas since 1981. My husband, Norman, is a CPA in private practice. I have 2 children, Brian, age 18

and Elyssa, age 16.

We have a new administrative assistant in the DSG office. Her name is Jennifer Miller. She is from Shreveport, LA and has several years of experience in the area of non-profit.

Become involved! Be ambassadors for the DSG. As our mission states, *we will provide accurate and current information, resources, and support for people with Down syndrome, their families, and the community.*

MISSION STATEMENT: THE DOWN SYNDROME GUILD OF DALLAS PROVIDES ACCURATE AND CURRENT INFORMATION, RESOURCES, AND SUPPORT FOR PEOPLE WITH DOWN SYNDROME, THEIR FAMILIES, AND THE COMMUNITY.

ARE YOU MOVING? DON'T FORGET TO PROVIDE US WITH YOUR CHANGE OF ADDRESS BY CALLING THE OFFICE OR BY EMAIL AT MINNIEBLACKWELL@TX.RR.NET.