

THE DSG News

PEOPLE WITH DOWN SYNDROME - VALUED AND INCLUDED

October 2008

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

Down Syndrome Guild Buddy Walk 2008



following events throughout the year:

- New Parent Meetings
- Kindergarten Round-up
- 2008 Fall Conference
- IEP Clinics
- Options for Adults
- Social Events for All Ages
- Parents & Schools in Partnership
- Art Therapy

The Buddy Walk is a festive way to build awareness for all

Be sure to share the fun with your family and friends by forming a team for this year's Buddy Walk by going to www.downsyndromedallas.org and downloading the team forms. Start organizing your team now to start raising money and promoting our goals of awareness, acceptance, and inclusion of people with Down syndrome!

For team development hints and how to register, go to our website at www.downsyndromedallas.org or contact Becky Slakman by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.

We look forward to celebrating with you on Sunday, November 9th!

Sunday, November 9, 2008
Flag Pole Hill near White
Rock Lake

8700 E. Northwest Highway
Dallas, TX 75238

Activities begin at 11:00 am

Walk begins at 1:00 pm

Please join us on Sunday,
November 9th for the 2008
Buddy Walk at Flag Pole Hill.

We're pleased to partner with Park Place Volvo to host Dallas' biggest community awareness event in support of families who have a child with Down syndrome. Your participation enables the Down Syndrome Guild of Dallas to support the programs that serve over 1100 families in North Texas. Your time and contribution at the Buddy Walk allows us to host the



people with Down syndrome. We need your help to support local programs, national research, education, and advocacy efforts. Needless to say, it promotes a cause that is important to all of us. Encourage your friends and family to join us for a day that includes the Flag Pole Hill Walk, food, fun, petting zoo, and music.

Inside This Issue:

- Texas Ranks 50th in Services for People with Developmental Disabilities.....2
- President's Message2
- Dad's Group Happy Hour2
- First Downs for Down Syndrome3
- Helpful Hint3
- Wrightslaw3
- A New Step in My Journey4
- Adult Halloween Party4
- Parting is Not Always Sweet Sorrow5
- Allowing Room for Growth Expands a Student's Career Options.....5-6
- New Research Grant to Study Environmental and Sleep Factors in Individuals with Down Syndrome6
- Who You Gonna Call?6
- The R-Word Isn't Just Hurtful, It's Hate Speech7
- In the DSG Library7
- DSG Calendar of Events8

Texas Ranks 50th in Services for People with Developmental Disabilities

Every year United Cerebral Palsy, a national non-profit organization, publishes a report about how well states serve people with developmental disabilities. In the most recent report, all 50 states and the District of Columbia have been ranked, based on a variety of key measures connected to Medicaid funding. Texas is number 50, next to last place!

Along with the statistics, the report offers guidance on tactics and policy procedures to help advocacy organizations, self-advocates, families, service providers, policymakers, and others take up the fight to improve circumstances in their own states.

To view the complete report, entitled *The Case for Inclusion*, go to www.ucp.org/Medicaid.

President's Message By Kelly Drablos

At this time of the year many of us are catching our breath after the “back to school” rush. Our new school year routines are becoming somewhat familiar. Family members are settling into patterns of work and play particular to this year. Temperatures outside are moderating. High school football dominates Friday nights in north Texas, the Dallas Cowboys are media darlings, and the State Fair is well underway.

This is the time to establish good relationships with new teachers and other professionals working with your child with Down syndrome. The dust has settled a bit and there is an opportunity to prevent problems that may arise over time. At our DSG kindergarten round-up in late July, we provided parents with a number of suggestions for a successful school year, including those I am listing below that were related to establishing relationships with professionals at your child's school:

1. Communicate effectively (calmly and clearly with prior preparation and notes if you need them)
2. Be a collaborator, (not a dictator nor an observer, but an active

considerate participant)

3. Provide support to your child's teacher without overwhelming or micromanaging (you are the parent, REMEMBER)
4. Give the teachers tools to know WHAT WORKS with your child and give them the opportunity to get to know your child (don't be shy)
5. Practice respect (give it, expect it)
6. Always be willing to “begin again” (you will get it right with persistence and good will)
7. Presume competence (everyone's competence)

Your child will experience difficulties at some point in the year. All children do. If you have effective relationships with your child's teachers, you have a means of working through these difficulties before they become serious problems.

I want to add “Do enjoy the fun parts” to the list. It really does go so fast! Share your pictures of your children in their Halloween costumes with us. We will see you all at the Buddy Walk next month on November 9th at Flagpole Hill.

Dad's Group Happy Hour

October 15, 2008
6:30 pm to 8:30 pm
The Londoner
14930 Midway Road
Addison, TX 75001
Phone: (972) 458-2444

Join Co-Chairs Chris McKee and Doug Dureau for drinks and conversation. Feel free to invite other

Down Syndrome Guild dads who might enjoy attending. Not able to join this time, but would like to be added to the list to receive information for future events, let us know that as well.

RSVP to Becky Slakman by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.

First Downs for Down Syndrome



DSG families participated in the halftime show at the Plano East High School football game on Friday, September 5, 2008, as part of the Plano East Golden Girls fundraiser benefiting the Down Syndrome Guild of Dallas.

Wrightslaw

Parents can never have too much current information. Wrightslaw has been a steady stream of good dependable information for families AND teachers on how to do education right! This last summer they offered to all who signed up free “Summer School for IEPs.” Below is a sample “lesson” sent by e-mail. For more excellent information and resources go to their website at www.wrightslaw.com.

IF Goals are Not Measurable, the IEP Does Not Pass Muster

IEP goals **cannot** be broad statements about what a child will accomplish in a year.

Assignment # 6: Writing SMART Goals

1. Write down several statements about what you want your child to know and be able to do.
2. Revise these statements into goals that are Specific, Measurable, use Action words, are Realistic, and Time-limited.
3. Break down each goal into a few measurable short-term steps. Describe what the child will know or be able to do. Focus on behavior that you can count or observe.

How will you know if your child is achieving these goals? Your child's progress should be assessed objectively and often. If your goals are measurable, you will be able to observe the child's behavior.

Helpful Hint

Many Down Syndrome Guild families are receiving services from a program called Home and Community-based Services (HCS). The state agency which oversees this program is called Texas Department of Aging and Disability Services (DADS). If you have a question about the services being provided, a complaint about your specific provider or any other issue, there is a resource many families have told us is helpful:

DADS

Office of Consumer Rights

Carolyn Fleming

1-800-458-9858

If you are not familiar with the HCS program and want more information, the DSG has several articles that we can send to you.

Contact Becky Slakman by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.

A New Step in My Journey By Renee Schultz

Maybe I'd become complacent or hopeless. Maybe I was just plain old worn out. Sometime in the last few years, I'd lost the buoyancy that kept my going for 24 years. Frankly, my husband and I were ready for a sabbatical after our son's heart surgery almost three years ago, the endless advocacy to have our son's needs met, and the challenges of having Ian move into a group home a little over a year ago. Friends, farther down the road than us, admitted that they too had a period when they'd simply needed a break. So, I cut myself some slack and allowed time off from the endless pursuit of an answer to Ian's complex behavioral issues. Well, not a total break. We continued attending team meetings as Ian's behavior continued plummeting. We reconnected him with a previous therapist, who had been more helpful than anyone acknowledging that Ian had complex psychiatric needs as well as cognitive and physical challenges. We attempted to let go a bit more as others helped in the care of our son.

So you might ask, why did we attend the NDSC Convention in Boston? I heard from a friend that this year's convention was going to be just a few hours from our home; and coupled with the hope that Ian might benefit from being around other young adults with Down syndrome, I signed us up. I'd stopped my NDSC membership years ago, in part because I was simply tired of all those cherry success stories. Despite high expectations, big dreams and the help of numerous professionals, my son, Ian, seemed to be heading down a dark slippery slope.

I have great compassion for all of us—particularly parents with infants

and young children—who need to have a hopeful vision for our sons' and daughters' lives. I was no different when my son was a baby and we pursued every possible avenue to help him. What parents don't want the best for their children? When Ian was young, I was fighting the outdated idea that children with DS were *trainable*, at best. We fought hard to make sure our son would learn to read and that he'd be given the opportunity to be included with the other students in our small school community, in Boy Scouts, and other recreational activities. And we succeeded! But when Ian became a young adult, the problem behaviors that had been a struggle when he was younger escalated. New symptoms appeared. It seemed impossible that we'd ever unravel the complexity of Ian's issues.

At the convention, my husband and I were quick to attend the sharing meeting entitled, *Complex Needs, Mothers and Fathers*. Suddenly we realized that we weren't, in fact, alone. We came to recognize that despite the splash of success stories, many parents feel shame and isolation because our sons and daughters aren't what I've come to refer to as the *Super Stars of the Down syndrome World*. In fact, there may be far more of us than I ever imagined struggling to unravel the challenging mysteries associated with our children.

I have to admit I was dubious that I'd get much from attending the NDSC Convention, except for the job of helping my son be a bit more accepting of his disability (he'd still much prefer not to have DS). But, here it is barely two weeks later and I am writing to say thank you to all the hardworking people who have given so much of themselves to

make the NDSC happen and to support the ongoing research that ultimately will better the lives of people with DS, and no doubt, their families. Since the convention, we have already discovered our son has celiac disease. Although we'd resisted acknowledging that he probably also has sleep apnea, we've signed him up for a sleep study. We've come to understand that the mental health issues of adults with DS are far more multi-layered than we'd known. (In one study, 21 of 22 had sleep apnea.) We don't have all the answers in addressing our son's complex needs, but learning from other parents and professionals has given me a boost to once again rally to meet both my son's needs as well as my own. For that, I say a big Thank You.

Renee Schultz is a parent and a writer from Westhampton MA. This article was first published in the Down Syndrome News 2008 Convention Issue of the National Down Syndrome Congress.

Adult Halloween Party

Adults age 19 and above
Friday, October 17, 2008
7:00 pm to 10:00 pm

The Warren Center
320 Custer Road
Richardson, TX 75080

Come dressed in your favorite costume or as yourself. There will be music, games and healthy snacks.

RSVP to Becky Slakman by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.

Parting is Not Always Sweet Sorrow *By Debbie Clark*

Young children frequently have difficulty leaving an enjoyable activity without protest. I often say the difference in a three year old and a four year old is that a three year old will kick and scream, while a four year old will perhaps cry quietly and ask when they can come again. The difference is related to cognitive ability and the maturity to understand that events can and do happen again. Expectations for children with Down syndrome should be based on their developmental age rather than their chronological age.

With the inherent issues noted above, here are some guidelines to begin to teach children to cope with leaving:

- Rehearse the event, i.e. “We are going to Grandma’s house. We will have lunch and play. Then Mommy will say it’s time to go home, and we will get in the car and come home.”
- Give child a five minute warning. Use a timer if possible.
- Calmly, but firmly tell the child it is time to go.
- If the child is upset, tell him/her that you understand it hard to leave when you are having fun, but that it is time to go.
- If the child falls down on the floor, tell your child that they can choose to walk or you can carry them.
- At all times, remain calm and neutral using a level voice. When

dealing with a child who is having trouble maintaining control, it is essential that the parent set the tone for the interaction. Remember, this is a learning situation, and it may take more repetition than the average child, for your child with Down syndrome to learn how to leave a social situation gracefully.

- Try to maintain a sense of humor and realize that your child is probably not the only child having a hard time learning to leave.

Debbie Clark, LCSW, LMFT, is the social worker on the team at the Down Syndrome Clinic at Children’s Medical Center Dallas and a regular contributor to The DSG News.

Allowing Room for Growth Expands a Student’s Career Options *By Nancy Davenport*

I have some doubts about the trend in public education toward early career selection. It is hard to beat a classic education for keeping all the options open. Too many kids who seem destined for mediocrity at one stage of their lives, take a 180 degree turn when they meet walls or encounter people of influence. If those students had their career options set in concrete by limiting their education, it would be a great loss.

In the case of students with disabilities, it is no different. Too often people have such low expectations because of a label, that the student’s educational placement becomes a self-fulfilling prophecy: expect a kid to be unemployable and by golly he or she will be.

Parents don’t have to accept other people’s expectations for their

children. If they want their children to be employable, they don’t have to wait for others to make it happen. They can draw up plans and lay the ground work themselves.

When the children are in elementary school, parents can:

- Talk about and point out different people doing various jobs in the community
- Be sure children do jobs at home with a positive approach and in a timely manner
- Help students see beyond job gender stereotypes
- Introduce young people to a broad selection of sports and activities in which they can feel successful and comfortable while trying new things and meetings new people
- Accept all possible job choices when discussing “What I will be

when I grow up.”

- Encourage reading material and videos that show a broad spectrum of work and social settings
- Help children to understand the importance of school as it relates to occupations and daily living

Then when kids reach junior high age, parents can:

- Help set up volunteer work for students
- Talk about their own work and how it meets their needs
- Discuss your student’s skills, abilities and interests as they might relate to work
- Help build financial understanding that money must come in to be able to do and have certain things

(continued on page 6)

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When students reach high school parents can:

- Begin the process of helping teens link present choices with the future
- Take students to visit places of work that might be of interest to THEM (not necessarily the parents)
- Encourage them to have a part time job
- Help students understand that social skills are just as important as job skills
- Give them economic obligations, so they can learn independence in that area
- Point out often how capable they are in many ways

Parents must not wait for the public education process to do everything, especially career development, because it won't happen. They must continue the parenting process into this area until the job is done.

Thank you to Down's Update and AIM HIGH! News and Notes of Albany, New York for some material in this article.

Nancy Davenport is editor of The DSG News and the parent of Austin who has DS. Contact her at nancdave@swbell.net or through the DSG office.

New Research Grant to Study Environmental and Sleep Factors in Individuals with Down Syndrome

The Down Syndrome Research and Treatment Foundation (DSRTF) has announced the award and funding for a new Innovation Research Grant. The long-term goal of the researchers is to uncover the factors that lead to variation in the cognitive characteristics (phenotype) of Down syndrome. In examining the factors relating to variation in cognitive function, they focus on the function of three specific brain regions, the hippocampus, prefrontal cortex, and cerebellum. They believe these brain systems are central to the cognitive difficulties experienced by those with Down syndrome because they are critical to everyday tasks such as attention, decision-making, and memory. Through neuropsychological methods they will be measuring learning and behavior in a trial group of individuals with Down syndrome ages 4 to 18. They initially intend to focus on genetic and environmental factors influencing the variability in cognitive outcomes as

well as, the impact of sleep problems on cognitive outcome. Identifying the factors influencing the variability in cognitive outcomes may be central to developing successful treatments for cognitive difficulties in individuals with Down syndrome.

DSRTF has become the largest non-governmental funding source for Down syndrome biomedical research. Since its founding in 2004, DSRTF has generated more than \$4 million to fund and support major new results-driven research programs. This has led to 'unprecedented' progress in identifying new potential therapeutic/drug targets to improve cognition in individuals with Down syndrome.

To learn more about DSRTF, the research the Foundation supports and to make a donation, please visit <http://www.dsrtf.org/>. Also go to the Down Syndrome Guild website at www.downsyndromedallas.org for the unedited article on this subject.

Who You Gonna Call?

Don't hesitate to call your state senator or representative about issues that pertain to children with disabilities. The next session of the Texas Legislature will begin in January 2009. Now is a good time to call your state senator or representative at his/her office in your community – before they convene in Austin!

Hints:

- Have one issue per call
- Be sure the issue is something over which they have a controlling vote
- Be specific
- Be clear

You can find your state senator or representative at: www.house.state.tx.us.

The R-Word Isn't Just Hurtful, It's Hate Speech

What is hate speech?

Hate speech occurs when a majority group freely makes jokes about a minority group including negative stereotypes and negative images, not just language. It is commonly seen as harmless by the majority, but it sets the stage for more severe outlets for prejudice, harm, and abuse.

People with developmental and intellectual disabilities are at greater risk of violence

1 in 3 children with disabilities are victims of some form of abuse, sexual abuse, or neglect. (Sullivan & Knutson, 2000).

Individuals with developmental disabilities are 4 to 10 times more likely to be victims of a crime than people without disabilities (Sobsey, et al., 1995).

Children with developmental disabilities are at twice the risk of physical and sexual abuse compared to children without disabilities (Crosse et. al., 1993).

People with developmental and intellectual disabilities are often disenfranchised from justice

Many people with intellectual disabilities are not able to articulate the abuse they've sustained.

Many victims with intellectual disabilities are not perceived as credible witnesses.

Abuse often occurs as part of name-calling, bullying, hazing, or other targeted attacks based on disability status. THIS IS A HATE CRIME.

Ending the use of the R-word is more than a "politically correct" notion

Retard and *retarded* are derogatory and dehumanizing terms – on par with the N-word when used to describe African Americans, and various hateful terms used to describe members of the Jewish, gay and lesbian, and other minority communities.

Self-advocates with intellectual disability have clearly stated that negative language leads to harmful action, discrimination, abuse, negative stereotypes, disenfranchisement, and violence.

Shouldn't people with intellectual disabilities just lighten up? It's a joke!

NO! People with intellectual disabilities have a history of institutionalization, genocide, forced sterilization, segregation, and being regarded as less than human.

More than any other group, they experience record unemployment, significant physical, mental, and sexual abuse, and limited rights.

This discrimination and victimization continues, in large part, due to antiquated, discriminatory portrayals in the media and pervasive prejudice.

What's funny about that?

Written and distributed by the Arc of the United States in response to the movie Tropic Thunder.

In the DSG Library

Down Syndrome—*Issues and Information*
by Sue Buckley, Gilliam Bird, and Ben Sacks

This set of publications provides comprehensive information and practical advice about the range of development, health and social issues related to Down syndrome in a concise and very readable format. The DSG purchased them recently at the National Down Syndrome Congress convention. Publication topics purchased and now available in the library are:

- *An overview of the development of teenagers with Down syndrome (11-16 years)*
- *Motor development for individuals with Down syndrome—an overview*
- *Reading and writing for individuals with Down syndrome—an overview*
- *Speech and language development for children with Down syndrome (5-11 years)*
- *Number skills for children with Down syndrome (5-11 years)*

To borrow a book from the DSG library, contact Becky Slakman at (214) 267-1374 or dsged@sbcglobal.net to arrange a time to come by the office or ask that a book be mailed to you.

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AT CHILDREN'S MEDICAL CENTER.
CALL (214) 456-2357

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This month on the DSG Calendar, Sophie and Morgan know what's good for them.



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ARE YOU MOVING? DON'T FORGET TO PROVIDE US WITH YOUR CHANGE OF ADDRESS BY CALLING THE OFFICE OR BY E-MAIL AT DALLASDSG@SBCGLOBAL.NET.

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Down Syndrome Guild Calendar of Events

October
Mom's Escape - *Visit the website for details about the October outing.*

October 13
Board Meeting

October 15
DAD's Group

October 17
Young Adult Halloween Party

November 9
Buddy Walk