

THE DSG News

PEOPLE WITH DOWN SYNDROME - VALUED AND INCLUDED

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

August 2008

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

2008 Herb's Paint and Body/Down Syndrome Guild of Dallas Golf Classic



Tuesday, September 16, 2008
Canyon Creek Country Club
625 W. Lookout Drive
Richardson, TX 75080
\$175 entry fee

Once again we are partnering to raise funds that will allow the Down Syndrome Guild of Dallas to carry out its mission of providing accurate and current information, resources, and support for people with Down syndrome, their families, and the community. The DSG will receive all proceeds of the tournament. We are pleased to announce that Joe Trahan of WFAA will once again be the honorary chair of the golf tournament. This will be a tournament you will not want to miss!

Herb's Paint & Body is a family of auto repair businesses founded in 1956. Herb Walne started his business with a Humble Gas Station located in Northeast Dallas. Herb soon added a full-service paint and body shop that has become an icon in and around the Dallas area. Today, customer service is still their number one concern as well as giving back to the community. Currently, there are six full-service Herb's Paint & Body shops in the Dallas metro area.

There are many sponsorship opportunities available for the tournament. Honor your child by becoming a hole sponsor for only \$200. If you or your company is interested in a sponsorship packet, please contact Becky Slakman at (214) 267-1374 or dsged@sbcglobal.net.

Not a golfer - not a problem. Stephanie Crow, 2008 Golf Tournament Chair, and her committee also have many ways for you to volunteer and be a part of the day. Please contact Teresa Sims-Ramirez at teresa.sims-ramirez@bankofamerica.com if you are able to volunteer.

The DSG will provide lunch and dinner, and there will be a silent auction with items for everyone. We hope to see you there!

Annual Appeal Donors

Many thanks to these additional families who have chosen to support the Down Syndrome Guild of Dallas through its annual appeal *as of June 30, 2008*. New programs and better services will be available to you the members because of their generosity.

*Alverta & Boyce Collins
Mayela & Alfredo Coronado
Udene & Doug Fortney
Elaine & Paul Gattenby
Cinde & Jeff Rawn
Denise & Billy Shelton
Georgia & Doug Smith
Tamara & Robbie White
Golder Wilson, MD*

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Dad's Group Happy Hour

Wednesday, August 20, 2008

6:30 pm - 8:30 pm

The Londoner Restaurant

14930 Midway Road

Addison, TX 75001

(972) 458-2444

The Co-chairs of the Down Syndrome Guild's Dads' Group, Chris McKee and Doug Dureau, want you to join them for a drink and conversation. Feel free to invite other dads who might enjoy attending.

RSVP to Becky Slakman at dsged@sbcglobal.net or at (214) 267-1374. Even if you are not able to join this time, but would like to be added to the list to receive information for future events, let Becky know.

It's Party Time

Friday, August 22, 2008

7:00 pm - 10:00 pm

Christ Church Plano

4550 Legacy Drive

Plano, TX 75024

The Down Syndrome Guild of Dallas is hosting a get-together for adults with Down syndrome ages 19 and older. Join us for a few hours of fun with your friends - games, snacks, and movies!

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

Message from the DSG President By Kelly Drablos

At our June meeting, the Board of Directors of the DSG adopted a resolution supporting a petition prepared by *Community Now! Community Now!* is a statewide non-profit organization committed to promoting inclusive communities for people with disabilities. The petition will be presented to the 81st Texas Legislative Session attendees and calls for a number of specific actions including the long overdue full funding of the waiting list for Medicaid waiver programs.

Jeffrey Garrison-Tate, the president of *Community Now!*, will be a presenter at our annual Fall Conference on September 27, 2008. I urge you to take some time to think about the importance of inclusive communities keeping in mind all those we love with Down syndrome. The model of institutionalization has been disfavored for decades and yet many citizens of Texas remain in state schools, often in violation of their own desires to live in community settings.

Reflecting on these issues has

brought to mind for me images of brave people choosing to do the right thing even in the face of resistance:

(1) The mother of a young man with no speech vowing to be a voice for the voiceless

(2) The brother of a young girl with disabilities challenging his high school aged peers to abandon the use of the word "retarded" because the label is demeaning and hateful

(3) A lawyer friend of mine with post-polio syndrome confronting the founder of Southwest Airlines regarding dismissive and embarrassing treatment of people with disabilities seated in exit rows on airplanes.

My time spent with advocates for people with disabilities and differences has enriched my life and caused me to realize that the most typical of people are capable of pursuing justice. We each have a unique and eloquent voice to contribute to the process which will result someday in "people with Down syndrome, valued and included." Do not underestimate your own ability to be a difference maker.

Best Buddies - Coming Again this Fall



The Down Syndrome Guild is excited to again partner with the Southern Methodist University chapter of the Best Buddies program for our member families with young adults - ages 19 and up. Best Buddies, a non-profit organization, links college students with our young adults who have Down syndrome in mutually enriching one-to-one friendships.

See www.bestbuddies.org.

In early fall, an e-mail will be sent with further information, as well as, all the paperwork that will need to be filled out. (Yes, you have to fill out paperwork even if you have participated in Best Buddies before.) Thank you to Sherri Munn, Co-chair of the *Options for Adults Committee*, who will be coordinating this effort for the DSG. For additional information, please contact Becky Slakman by phones at (214) 267-1374 or dsged@sbcglobal.net.

2008 Buddy Walk – Start Planning Now

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

8700 E. Northwest Hwy.
Dallas, TX 75238

Activities begin at 11:00 am
Walk begins at 1:00 pm

Mark your calendar for the Down Syndrome Guild's 2008 Buddy Walk. We are 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. The Buddy Walk is an incredible day of celebration with family and friends to raise awareness, raise funds, and raise the hope of a better world for all people with Down syndrome.

Buddy Walk Challenge

The Buddy Walk helps us raise funds to support the programs of the Down Syndrome Guild of Dallas. This includes educational seminars for the families of school age children, parent to parent support, options for adults, as well as social events for all ages. Our goal this year is to double the donations and sponsorships we had last year. We need your help!! So the *Buddy Walk Committee* is challenging each of you to double the funds you and/or your team raised last year!

It's easy to form a Buddy Walk team by going to downsyndromedallas.org and downloading the team forms. Once again this year there will be prizes for the teams that raise the most money. Start organizing your team now to start raising money and promoting our goals of awareness, acceptance, and inclusion of people with Down syndrome!



Tips for Building a Team

Start with people that are closest to you:

1. Family Members
2. Friends
3. Neighbors
4. Business Associates
5. Others in the community (your hairdresser, doctor, etc)

Corporate sponsorships are also an important part of our effort. If you, your company, or anyone you know is interested in sponsoring the Buddy Walk, please contact the DSG at (214) 267-1374 or dsged@sbcglobal.net for a sponsorship packet. Sponsors will be featured in all publications and on the official Buddy Walk t-shirts. There are several sponsorship levels from which to choose – and one is right for you!

Plan now to join us for a fun filled day that includes bounce houses, obstacle courses, slides, music, a petting zoo, food, and most of all friends - old and new. Watch the newsletter in the coming months for more details and easy ways to raise money to support the Buddy Walk and the Down Syndrome Guild of Dallas.

Tips for Raising Money for the Buddy Walk

- Day 1: Start by sponsoring your self for **\$25**.
- Day 2: Ask three family members to sponsor you for **\$25**.
- Day 3: Ask five friends to sponsor you for **\$20**.
- Day 4: Ask five co-workers to sponsor you for **\$10**.
- Day 5: Ask five neighbors to sponsor you for **\$10**.
- Day 6: Ask five people from your church/temple/mosque to sponsor you for **\$10**.
- Day 7: E-mail 15 people and ask for a **\$20** donation.
- Day 8: Ask five businesses you patronize for **\$25**.
- Day 9: Ask your company for a matching donation.

Wow, you raised **\$775** plus a company match!

New Easy Steps for Donating Online!

1. Go to our website at downsyndromedallas.org.
2. Click on "Donate Now" in the top right corner.
3. Complete the contact information.
4. Scroll down to gift information.
5. Drop down to Buddy Walk.
6. Write the name of team donating for in the "comment box."

10 Tips for a Successful School Year By Pat Howey, Advocate

Question: *Help! School is starting. I want to make sure I have done my homework so this year is better than last year.*

Answer: You need to view your role as your child's "case manager." (Learn more about "The Parent as Project Manager" in Chapter 3 of *Wrightslaw: From Emotions to Advocacy*).

You need to be watchful, even when things appear to be going well.

Here are ten tips to help you get off to a good start at the beginning of the new school year.

1. Help your child deal with transitions.

Is your child making the transition from preschool to kindergarten, from elementary to middle school, or from middle school to high school? Plan to take your child to visit the new school or classroom before the first day of school.

2. Reread your child's IEP.

Do you understand what the school agreed to provide? Do your child's teachers understand what they are to provide?

Is your child's IEP SMART? (specific, measurable, action words, realistic, and time-specific)? (Review Chapter 12 about SMART IEPs from *Wrightslaw: From Emotions to Advocacy*).

3. Meet with your child's teacher(s) to discuss your child's special needs.

Take a picture of your child to the meeting. Teachers are more likely to take a personal interest in your child and remember your child's special needs if s/he has seen a picture of your child.

4. Take extra copies of your child's IEP to the meeting with the teacher(s).

Never assume that teachers have

had time to read your child's IEP before school begins. Teachers have many things to do as they prepare for the first day of school. The teacher may not understand how important the IEP is to your child's success. Leave a copy of your child's IEP with each teacher.

5. Make a list of important things about your child.

Make a list of the five most important things that the teacher(s) need to know about your child. Explain why these things are vital to your child's success. Leave a copy of the list with each teacher.

6. Prepare to deal with potential problems early.

If your child is in general education classes, prepare for the teacher(s) who wants to see how your child "gets along" before making any changes in the way they run their classrooms.

Teachers often take this position because they want to give their students a fresh start. You may need to explain why your child may fail unless the teacher understands his/her unique needs and provides the necessary services, accommodations, and supports.

7. Resolve old concerns and issues.

If you have concerns or issues that were not resolved during the last IEP meeting, request another IEP meeting immediately. Try to resolve these issues and concerns before your child begins to have problems this year.

8. Get a new assessment.

Consider getting your child's skills tested very early in the school year. Where are your child's skills on standardized educational achievement tests? Use these scores as baseline data. You can compare these scores with scores

obtained at the end of the year to measure your child's progress. (See Chapter 8, Your Child's Evaluations, in *Wrightslaw: From Emotions to Advocacy*).

9. Go to your school's Open House.

In addition to giving you another chance to meet with your child's teachers (and make a good impression), teachers often explain their classroom rules during Open House. When you attend, you have a chance to see if your child may have trouble understanding the teachers' rules. You will also be in a better position to explain these rules to your child.

10. Get a bound notebook.

Use the notebook as a "contact log" to send messages to the teachers. Write a sentence or two to the teacher(s) every day. Do not make your child the bearer of messages about problems at school. Make an extra copy of your log often in case the notebook is lost.

Have a great school year!

From the DSG News Editor:

This material by Pat Howey is from Wrightslaw, an organization whose mission is to provide parents, advocates, educators, and attorneys with accurate, up-to-date information about special education law and advocacy so they can be effective catalysts. The DSG recommends that you subscribe to their Special Ed Advocate e-newsletter. This informative material is designed to help parents throughout the year to be better advocates for their children in their schools. Right now the e-newsletter is running a "Summer School for Parents." To subscribe, email newsletter@wrightslaw.com and request subscription to the Special Ed Advocate e-newsletter.

The Concept of Preventive Management By Joanna Spahis

The Down Syndrome Clinic at Children's Medical Center Dallas uses a concept of care called "Preventive Management." Why is this important? Preventive management began as a formal concept in the 1990's with the development of checklists for the management of patients with specific conditions such as Down syndrome. Drs. W. Carl Cooley and Golder Wilson (former director of the DS clinic at Children's Medical Center Dallas) published a book in 2006, *Preventive Health Care for Children with Genetic Conditions*, in which they detail the ways that primary health care providers can help to prevent common health concerns before they occur or detect them at an early age. But what does this mean for parents who bring their children to the DS clinic?

Q: What is the purpose of preventive management?

A: Preventive management allows health care providers to supplement the initial diagnosis with a positive plan of action that can benefit patients and empower families. (Wilson, 1999.) This means that after a child is diagnosed with a disability, the health care provider has something encouraging to offer the family. It is a proactive, organized series of steps to evaluate the child's health and well-being at different ages throughout the life span.

Q: Why does the clinic recommend that I take my child to the eye specialist even though his vision seems normal?

A: The preventive management checklist for children with Down syndrome is based on the most common

medical concerns found in people with Down syndrome. Vision can be affected by various eye problems, including strabismus (crossing,) nystagmus (wiggling of the pupils,) cataracts, or blocked tear ducts. These complications can be successfully treated if found at an early age. Otherwise, loss of vision may be the result.

Q: Why do all babies with DS need to have an echocardiogram, even if my physician can't hear a heart murmur?

A: This is because 40-50% of all babies with DS are born with some type of heart condition. The preventive medical checklist recommends that ALL babies with DS be screened by an echocardiogram (ultrasound of the heart) at birth, so that no serious problems are missed. Some holes in the heart can be so large that they can't be heard using a stethoscope, and if surgery is not done at an early age, it may be too late when the heart defect is finally discovered.

Q: Why does my teenager need to have her thyroid checked every year?

A: Thyroid malfunction can occur in people with DS at any age, so the preventive medical checklist recommends a yearly thyroid screen (blood test) for everyone with DS. The early symptoms of hypothyroidism (not enough thyroid hormone) may not be noticed, and include fatigue, weight gain, intolerance to cold, dry skin, and constipation. A simple blood test can tell how much thyroid hormone the body is producing and can even predict future hypothyroidism by measuring how hard the body is working to make it. It is always preferable to detect a problem before symptoms are obvious.

Q: Are there also recommendations for social services like early intervention, vocational training, and estate planning?

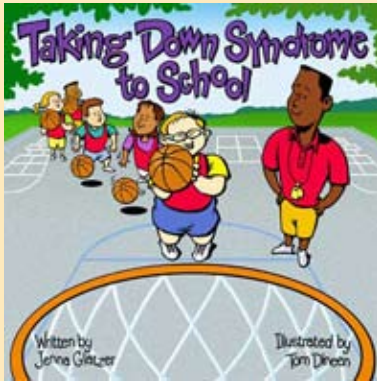
A: Yes, these are also important components of the preventive management concept. It is just as important to pay attention to issues such as therapy, job training, and planning for future financial security as it is to focus on the medical needs of the person with Down syndrome.

As you can see, the idea of preventive management using preventive health care guidelines (the preventive medical checklist) is a complete and comprehensive way to examine and address the many medical and psychosocial needs of people with Down syndrome at different ages throughout life. Down syndrome is a complex condition affecting nearly every aspect of life and health, and the concept of preventive care can provide an organized way to help improve the quality of life for these individuals. An online version of the Down Syndrome Health Care Guidelines may be found at www.ds-health.com.

Reference: *Preventive Health Care for Children with Genetic Conditions*, Wilson GN & Cooley WC: 2nd ed. Cambridge University Press, 2006.

Joanna Spahis, RN, CNS, APNG is a Clinical Nurse Specialist at the Down Syndrome Clinic at Children's Medical Center Dallas.

In the DSG Library...Taking Down Syndrome to School



Written by Jenna Glatzer
Illustrated by Tom Dineen

This book would be ideal to read to a class so they can learn about students with Down syndrome - how much they are just like everyone else, and how best to be their friends. At the end, there is a series of excellent leading questions designed to encourage discussion among young students. There is also a section called "10 Tips for Teachers" that might be helpful. The Down Syndrome Guild library has several copies of this book.

Down Syndrome Guild members can check this book out of the DSG library by either coming by the office during regular business hours, or if you like, we can mail any book in our library directly to you. Contact Becky Slakman by e-mail at dsged@sbcglobal.net or by phone at (214) 267-1374.

Learning Together - Focusing on Possibilities

The Down Syndrome Guild of Dallas
2008 Fall Education Conference
Saturday, September 27, 2008
Crowne Plaza Suites Hotel – Dallas
7800 Alpha Road
Dallas, TX 75240
9:00 am - 4:00 pm

This year's conference will interest a diverse group of attendees – parents with all ages of children with disabilities, educators, para-professionals, as well as self-advocates. For the first time, the Down Syndrome Guild will have three keynote speakers and a variety of session topics.

Karen Gaffney—Keynote Speaker

She is a self-advocate and frequent speaker at the National Down Syndrome Congress conventions. In addition to telling about her successful swim across Lake Tahoe, she will speak of her experience as a member of the first generation of adults with Down syndrome who have benefited from early intervention and inclusion. She will also tell about how she is now advocating for herself and others with developmental disabilities.

Michael Remus—Keynote Speaker

As a nationally-renowned consultant and author on inclusion, he will speak on behavior management and inclusive practices.

Jeff Garrison-Tate—Keynote Speaker

He is a Texas-based advocate who will provide participants with a broad overview of the *Community Paradigm*, which is based on the precept that ALL people should have every opportunity to be included in their communities.

Laura Buckner

This knowledgeable educator will share how to have positive collaboration between parents and educators and how to improve a child's quality of life through *Person Centered Planning*.

Lynn Campbell and Sidney Crim

These local speech and language pathologists, who have extensive experience working with children and adults with disabilities, will speak about writing composition as a means of enhancing effective communication.

Yvonne Davis

She is a consultant for the Down Syndrome Guild of Dallas. Her session will address transition issues at all age levels and the *Options for Adults* programs for adults with Down syndrome and their families.

Mary Jane Williams

This session will address the how-to's and benefits of portfolio development for students with disabilities as well as how to write measurable goals and objectives.

There will be plenty of opportunities to network with fellow conference participants and to shop our resource fair for products and services that will help educators and parents support each other and children at school, at home, and in the community.

Registration forms will be mailed to all DSG members. For additional information, please contact Becky Slakman at (214) 267-1374 or dsged@sbcglobal.net.

Fall Classes for Adults with Down Syndrome

Richland College
12800 Abrams Road
Dallas, Texas 75243-2199
(972) 238-3750

The Down Syndrome Guild's *Options for Adults Committee* continues to network and coordinate with the Richland College and Department of Assistive and Rehabilitative Services (DARS). As a result of those efforts, we are pleased to announce the "employability" course offerings (listed below) for the Fall 08 semester. **Registration begins on August 6th but is not available through the Richland website.** For information about the classes and the registration process, families should **contact Melinda Weaver at Richland at (972) 238-3750.**

Option 1:

The Continuing Education Department of Richland College is offering several classes, which are designed to improve employment outcomes for people with disabilities. The following courses are currently listed in the schedule at a cost of \$150 per class. Students may enroll in one or more of these classes:

Community Safety for Positive Employment Outcomes

Tuesday 2:00 pm – 4:00 pm
9/9/08 through 11/25/08 or

Saturday 10:00 am – 12:00 pm
9/6/08 through 11/22/08

Employability Skills

Thursday 2:00 pm – 4:00 pm
9/11/08 through 12/4/08 or

Saturday 10:00 am – 12:00 pm
9/6/08 through 11/22/08

Computer Skills

Monday 2:00 pm – 4:00 pm
9/8/08 through 11/24/08

Option 2:

We are especially excited about the new **Employability Certification Program**, which is being introduced this fall – for the very first time – and is designed to give students with disabilities a more complete "college experience." This comprehensive certification program includes components covering employability skills, job search skills, workplace safety, basic computer skills and internship opportunities on the Richland Campus. Classes are expected to meet from approximately 9:00 am to 4:00 pm each weekday – and the program includes an unpaid internship on the campus. Tuition for the program is \$1,100 and requires \$150 in book costs.

The cost of both of these options may be paid by DARS if they are considered consistent with the student's Individual Plan for Employment. Families should discuss these vocational education opportunities with their DARS counselors as soon as possible to determine if DARS funding is available to them and what steps need to be taken prior to enrollment. These courses are also available on a private pay basis.

Transitioning from School to Work

August 9, 2008

9:00 am - 1:00 pm

Weatherford College

Mince Administration Building

225 College Park Drive

Weatherford, TX 76086

Weatherford ISD and Education Service Center Region XI are presenting a workshop for families of students who are planning the transition from school to adult life in the community—including work, residence, and recreation for persons with cognitive disabilities.

Joseph and Marilyn Henn will present their own personal testimony on effective transition strategies using "possibility thinking." Staff from Texas Health and Human Services Systems, Social Security Administration, U.S. Department of Housing and Urban Development, MHMR, ARC of Tarrant County, Easter Seals, and Texas Parent to Parent have been invited to participate.

There is no fee but registration is required. To register, visit the ESC Region XI Web site at www.esc11.net and click on "Workshops/Logins."

701 N. CENTRAL EXPRESSWAY
BUILDING 5-I
RICHARDSON, TX 75080

Return Service Requested

(214) 267-1374
En Español (972) 248-6845
www.downsyndromedallas.org
dsged@sbcglobal.net

EXECUTIVE DIRECTOR: BECKY SLAKMAN
PRESIDENT: KELLY DRABLOS
DSG LAYOUT EDITOR: JENNIFER FORD

DOWN SYNDROME CLINIC EVERY FRIDAY
AT CHILDREN'S MEDICAL CENTER.
CALL (214) 456-2357

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This month on the DSG Calendar Avery, Claire, and Maddie show they know how to enjoy the summer.



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 E-MAIL AT DALLASDSG@SBCGLOBAL.NET.

THE PUBLICATION OF *THE DSG NEWS* IS MADE POSSIBLE BY THE GENEROSITY OF THE CHARLES H. PHIPPS FAMILY FOUNDATION.

Down Syndrome Guild Calendar of Events

August
Mom's Escape - *There will be no get-together in August*

August 18
Board Meeting

August 20
Dad's Group Happy Hour

August 22
Party for Adults with Down syndrome

September 16
Herb's Paint & Body/Down Syndrome Guild of Dallas Golf Classic

September 27
Fall Conference