

THE

DSG News

PEOPLE WITH DOWN SYNDROME – VALUED AND INCLUDED

July 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

Announcing the Down Syndrome Guild's Annual Conference... **LEARNING TOGETHER – FOCUSING ON POSSIBILITIES**

The 2008 Down Syndrome Guild of Dallas Fall Education Conference

Saturday, September 27, 2008
Crowne Plaza Suites Hotel - Dallas
7800 Alpha Road
Dallas, TX 75240
9:00 am to 4:00 pm

Updates will follow in next month's issue of *The DSG News* and on the website. Registration forms will soon be available on the website or call the DSG office to have a form sent to you.

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.

Inside This Issue:

- Club 21 2
- Executive Director's Message 2
- Options for Adults Committee Meeting 3
- Kindergarten Round-Up 3
- UHCF Grants Can Help..... 3
- What's New on Our Website 3
- Lesson learned: Don't Turn Your Back on Your Kid 4
- Down Syndrome Caucus Launched 5
- Mark Your Calendar 6
- In the Down Syndrome Guild Library 6
- Annual Appeal Donors 6
- Down Syndrome Guild Photos 7
- DSG Calendar of Events..... 8

GREAT WAY TO HONOR LOVED ONES

Club 21
is a Down Syndrome
Guild program to honor a loved
one: matching the numeral of
the important chromosome that
affects our children.

To: Michele Gooch

In memory of Betty James
Hamra.

From: The Candalino Family

A gift to the Down Syndrome Guild to honor loved ones is a tangible way to recognize their lives, celebrate birthdays, anniversaries, graduations, new homes, or any number of occasions. A gift in memory of a friend or relative is a thoughtful and caring way to express sympathy while sharing concern for an important cause. Upon receiving a memorial or an honorarium gift, the DSG will notify the family or individual of your thoughtfulness and send you, the donor, a letter of receipt.

Interested in making a *Club 21* donation? Contact Becky Slakman by e-mail at dsged@sbcglobal.net or by phone at (214) 267-1374.

Executive Director's Message *By Becky Slakman*

W *The best way to predict your future is to help create it!"*

- Abraham Lincoln

The Down Syndrome Guild of Dallas provides accurate and current information, resources, and support for people with Down syndrome, their families, and the community. We continue to strive to be the "go to" organization for accurate, up-to date information and support. Please know how valuable your input is to enable us to achieve this goal. I want to thank those of you who took the time to complete our recent "*Voice of Our Membership*" Survey. We asked the questions, and your answers were very insightful. When asked what program or service do you find most beneficial, 71% of you who responded let us know that the Newsletter is the most important resource for you, followed by the website. It is our goal to continue to use these two venues to keep you aware of current information, resources, and programs. In the coming months you will discover that what you are asking for is what we will deliver. Congratulations to *Anita Lau* who won the drawing for the Ipod Nano for completing the survey.

Below is a sampling of the survey results:

Your top priorities:

- Information related to education and the IEP process
- Medical information
- Information related to social security and waiver programs
- Social events for all ages
- Political updates
- Parent-to-parent support for infants through adults

What does the Down Syndrome Guild of Dallas do well?

- Parent-to-parent support
- Newsletter
- Social events
- Information for the parents of newborns
- Getting information to families
- Education seminars

What could the Down Syndrome Guild of Dallas do better?

- Add more teen programming
- Move programs/meetings to other areas of the Metroplex
- Have more adult programs
- Help families with older children through the transition process: school, employment, housing
- Have more education training programs
- Provide schools and educators with current information
- Push for inclusive opportunities
- Educate healthcare professionals

Although the survey is complete, if you think of something you would like to see the Down Syndrome Guild offer or something that we should improve upon, please drop us an e-mail or call. Remember, we are here to help! If you would like to serve on a committee, please let us know that also. We need to work together to continue to improve.

Later this month, Kelly Drablos, our DSG President and I will be attending the National Down Syndrome Congress annual convention in Boston. We look forward to networking with other Down syndrome affiliate organizations and learning what is going on in other communities - bringing ideas and resources back to our community.

Happy July 4th! Stay Safe!

Options for Adults Committee Meeting

Thursday, July 24, 2008

6:00 pm – socialize and snacks

6:30 pm to 8:00 pm – program

First Community Bank - Conference Room
429 Belle Grove

Richardson, TX 75080

Across the parking lot from the DSG office

Last fall the Down Syndrome Guild Board established a new committee – Options for Adults, which is chaired by Kathi Hutchins and Sherri Munn. Please join us to learn more about all the projects being undertaken by the Options for Adults Committee. The presentation will be very brief – leaving ample time for discussion, suggestions, and questions about whatever topic is important to you.

For many years Minnie Blackwell has chaired a support group, which we call the Adult Issues Committee, for the families of children who are no longer receiving school services. The purpose of Minnie's group has been to provide a forum for discussion and to present speakers on a variety of topics that are of interest to those families. Also, for many years Teresa Ramirez has taken the lead to plan social activities for the adults. These efforts will continue – and we

thank Minnie and Teresa for their on-going commitment.

The Options for Adults Committee will more broadly address the complex challenges faced by our adults with Down syndrome and their families. The committee is currently developing a resource guide that will be completed in the fall and is continuing to network with Richland Community College in an effort to offer more classes of interest to adults with Down syndrome.

The other new offering is an opportunity to meet one-on-one with our contract consultant, Yvonne Davis, to discuss how to best navigate the myriad of state, federal, and local agencies that provide funding and/or services for adults with Down syndrome. This program is available at no fee (maximum of four hours of the consultant's time) to any DSG member family whose child is no longer receiving school services.

We look forward to your attendance and participation in the discussion on July 24th.

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

UHCF Grants Can Help

The United Healthcare Children's Foundation has announced that new grants are available to help children who need critical health care treatment, services, or equipment not covered or not fully covered by their parents' health benefit plans.

UHCCF provides grants to families to help pay for child health care services such as speech therapy, physical therapy, occupational therapy sessions, prescriptions, and medical equipment such as wheelchairs, orthotics, and eyeglasses.

Parents and legal guardians may apply for grants of up to \$5,000 each for child medical services and equipment by completing an online application at the UHCCF website:

http://www.uhc.com/about_us/community_connection/unitedhealthcare/childrens_foundation.htm

To be eligible for grants, children must be 16 years of age or younger. Families must meet economic guidelines, reside in the United States, and be covered by a commercial health benefit plan.

Kindergarten Round-Up

Saturday, July 26, 2008

10:00 am to 12:00 pm

First Community Bank –
Conference Room

429 Belle Grove

Richardson, TX 75080

Across the parking lot from the DSG office

Parents of children ages 4 to 6 years old are invited to attend this new program. A panel of professionals and parents will facilitate a discussion offering important "how to" information regarding the school processes, procedures, and rights for your child. Come ready to ask lots of questions, and we will give you lots of answers.

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

What's New on Our Website

Updates are made weekly to the DSG website. Visit often to get the latest news and information.

- ◆ **2008 Buddy Walk Team Information**
- ◆ **2008 Fall Conference - Learning Together - Focusing on Possibilities**
- ◆ **2008 Educator of the Year Nomination Forms**
- ◆ **Texas Advocates Conference (August 8-10)**

Lesson learned: Don't Turn Your Back on Your Kid *By Nancy Davenport*

Maybe it's the open windows during the lovely weather this week that reminded me of this experience. Perhaps it's the cleaning and organizing I do at this time of year, that I mentally relived one of my son, Austin's, most infamous exploits.

He was about five years old. He had gone through some hair-raising episodes of walking out of the house without our knowing it when we thought he was asleep in bed. I understand this is a chronic problem of young children with Down syndrome. Every parent has a story.

As a result of our own personal experiences, we put a deadbolt on the outside of his bedroom door, so we could sleep at night. We had already tried fancy locks on the front door but our family was undependable about leaving it secure. I know it may sound abusive to lock the bedroom door, but we were desperate.

That day the weather was beautiful. I convinced Austin that it would be a wonderful time to clean and organize his closet. That is always a fun thing to do because children find toys they have not seen in months and see them as almost new. Austin was no exception. Together we pulled toys off the shelves, dusted them, and put them back. We threw things out, sat and re-read long lost books, and generally had a wonderful time.

Austin gradually lost interest though, and began wandering and checking on his sister who was in our basement watching TV (We were living in Lubbock at the time.) I could tell he was becoming irritated by my inordinate attention to the details of organizing his closet, but I was determined to finish what I had started.

He wandered out of the room again and I paid no attention—until I heard the quiet click of the latch on his bedroom door and then a firm smack of the deadbolt going into its place.

I froze waiting for the sound of the bolt to unlock.

With careful restraint I said, "Austin, unlock the door."

Silence.

I repeated my request, each time getting louder.

Finally I heard, "Okay, Mom," followed by a charming but maybe slightly diabolical giggle.

I could hear the rattle and pushing on the other side of the door as he tried to unlock it. Nothing happened. He became a little frantic I could tell, as did I. I tried pushing against the door as he tugged at the bolt. I tried pulling. Nothing worked. Then I began yelling for him to just unlock the door only to get a plaintive, "Okay Mom, I try."

I began screaming for my daughter to come. Of course she could not hear me. Our basement served also as a tornado shelter so was a huge concrete box—completely sound proof. I screamed anyway. It made me feel better.

I tried to calm down and told Austin to go get Liz. There was another patient, "Okay, Mom." While I waited I sat with my head in my hands leaning against the door.

Austin didn't come back, and I knew what happened. He couldn't communicate to Liz what had happened, then immediately forgot about me. They were probably happily cuddling together watching TV.

There was only one option left, so I removed the screen and climbed out the window. The drop was about six feet, but I was desperate. I broke a nail, scratched myself on a bush, and twisted my ankle, but I made it. I limped around to the front door and leaned on the door bell.

No one came. Of course. No one can hear the doorbell in the basement. I rang it some more anyway. After venting my frustration on the door bell, I hobbled down the street trying neighbors' houses. The only person I found at home was the very elderly mother of a friend. She wasn't quite sure who I was so hesitated to let me in to use the phone, especially after I babbled an explanation about why I needed it.

I guess she felt sorry for me, because she finally let me in. I made my call where I got a cheery hello from Liz. Happily, as a young teenager, Liz seldom allowed the phone out of earshot. I snarled at her to unlock the front door and gave my explanation why. Her laughter was echoed by the little old lady's who finally figured it all out.

My only lift from the whole experience was that the neighbor thanked me for giving her something to tell her friends. I said, "You're welcome," and limped home.

I still enjoy my summer cleaning but as a result of this experience, do it with a little caution—watching my back so to speak.

Nancy Davenport is editor of The DSG News. She can be reached at nancdave@swbell.net.

Down Syndrome Caucus Launched

In a press release from Washington, DC, Congressman Pete Sessions (R-Dallas) announced the creation of the Congressional Down Syndrome Caucus with co-chairs Congressman Patrick Kennedy (D-MA), Congresswoman Cathy McMorris Rodgers (R-WA) and Congresswoman Eleanor Holmes Norton (D-DC).

Congressman Sessions stated:

As the father of a young man with Down syndrome, I have learned firsthand the endearing and valuable contributions that individuals with Down syndrome bring to their families and communities. I am always inspired by their dedication and enthusiasm for life, and I have made disability advocacy and research among my top priorities in Congress. I am pleased that the Congressional Down Syndrome Caucus will champion their continued development through increased education opportunities, employment and savings options, and research to improve quality of life.

The Congressional Down Syndrome Caucus is designed to educate Members of Congress and their staff about Down syndrome and to promote public policies that would enhance the quality of life for individuals with Down syndrome, including through the following goals:

- To raise expectations and improve outcomes in education
- To remove barriers to economic opportunity in employment and in programs that promote savings and investment
- To promote and fund research that accelerates the development of

effective treatments and therapies

- To promote inclusiveness for people with Down syndrome
- To help provide family support services and a community of care model
- To protect the rights of those with Down syndrome and make sure those rights are being enforced

The Caucus will also promote the translation of Down syndrome research into effective new treatment through interdisciplinary cooperation among NIH Institutes, the FDA, the CDC, and privately funded scientists and clinicians. Research support will also focus on broadening the understanding of related secondary disorders that affect significant numbers of individuals without Down syndrome, including Alzheimer's disease, atherosclerosis, and developmentally-associated cognitive impairment.

Congressman Patrick Kennedy said:

We live in a nation that believes in providing all children with an equal chance to achieve, that every child deserves an equal chance to succeed. Early identification leading to early intervention with behavioral services provides the best outcomes for kids. We especially want to see young adults with Down syndrome be able to make the transition to young adulthood with integrated supports to protect their best potential and highest aspirations.

Congresswoman Cathy McMorris Rodgers said:

It's important for parents with a developmentally disabled child to know that they are not alone. There are

tremendous resources, support, and early intervention available to families. As a mother of a child with Down syndrome, those resources and support have been invaluable. I look forward to helping other parents make sure their children with Down syndrome reach their full potential.

In addition to congressional outreach, the Caucus will work with national and local Down syndrome advocacy groups to develop leading-edge initiatives that support individuals with Down syndrome.

Sessions concluded:

I look forward to working with Congressional Down Syndrome Caucus members to raise awareness of Down syndrome issues, support research, and expand opportunities for Down syndrome population.

In the U.S., over 350,000 individuals have Down syndrome, which is a genetic condition that causes delays in physical and intellectual development. Individuals with Down syndrome have 47 chromosomes instead of the usual 46, and they are prone to health complications such as congenital heart defects, infection, respiratory, vision and hearing problems, and other medical conditions.

Mark Your Calendar

The Down Syndrome Guild of Dallas is pleased to announce its Fall 2008 events:

Tuesday, September 16

2nd Annual Herb's Paint & Body/
Down Syndrome Guild of Dallas
Golf Classic
Canyon Creek Country Club
625 West Lookout Drive
Richardson, TX 75080

Saturday, September 27

Fall Education Conference
New Location -
Crowne Plaza Suites Hotel - Dallas
7800 Alpha Road
Dallas, TX 75240

Sunday, November 9

8th Annual Buddy Walk
Flag Pole Hill
8700 E. Northwest Hwy.
Dallas, TX 75238

To find out more about these upcoming events and corporate sponsorship opportunities, please contact the DSG office by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.

In the Down Syndrome Guild Library



Steps to Independence
Teaching Everyday Skills to
Children with Special Needs
- Bruce L. Baker and Alan J. Brightman
This popular parenting book, now in

its fourth edition, will certainly make teaching independence easier for a parent of a child of any age. After all, isn't that the goal we have for all of our children? It begins with an easy-to-read overview of teaching methods, then it goes deeper with a step-by-step guide teaching seven types of skills from toilet training to self-care. It's laced with humor, charming illustration, and vignettes with which anyone can identify.

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.

Annual Appeal Donors

Many thanks to the following families who have chosen to support the Down Syndrome Guild of Dallas through its annual appeal. New programs and better services will be available to you, the members, because of their generosity. There is still time to be part of this DSG fundraising effort. Please send your checks to the DSG office or contribute online - noting in the comment box that it is for the Annual Appeal.

Perla & Cesar Acosta
Mike Andereck
Donna Brence & Bryan Mannion
Myrna & Virgil Castillo
Lea Cerqueira
Ayako & Jason Chan
Lynn & David Chase
Karen & David Deary
Helen Dobbs
Jerri Ann & Tim Drake
Kim & Randy Ford

Michele & Jim Gulley
Lois & Patrick Haynes
Beverly Hester
Becky & Dave Igo
Tricia Ikard
Brenda & Tim Judkins
Kathy & Terry Kwasniak
Aileen & Luis Lim
Elizabeth & Greg Longworth
Phyllis & Bader Malallah
Larane & Harry McKee
Doreen & Robert McKenzie
Terri McKinney
Laura Nell & Paul Morrow
Paula & Mark Null
Alix & John Perritt
Alicia & Mike Pitre
Teresa & Sam Ramirez
Nete & Pete Sessions
Pat Shoemaker
Linda & David Thiede
Kari & Bryan Urban
*as of May 31, 2008

Down Syndrome Guild Photos



Everyone had a great time at the Youth Bingo and Pizza Night on Saturday, May 17, 2008.

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

Disclaimer: The Down Syndrome Guild of Dallas (the DSG) assumes no specific or implied liability with respect to the interpretation, use, misuse or subsequent communication of editorial content or information contained in this publication. The opinions, beliefs and viewpoints expressed herein are those of the individual authors and contributors and do not necessarily represent those of the DSG, its directors, members or the editor of this publication. The content of all *The DSG News* is provided as a public service for informational purpose only and is not a substitute for medical or professional advice. *The DSG News* does not endorse any particular therapy, institution or professional system. The information herein is presented as is, without warranty of any kind express or implied. Submissions to *The DSG News* are edited to ensure usage of 'people first' language.

*This month on the DSG Calendar Cameron
Lanford celebrates freedom.*



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

July
Mom's Escape -
Check website for time and date

July 24
Options for Adults Committee Meeting

July 25
Last Art Therapy Class

July 26
Kindergarten Roundup