

THE

DSG News

PEOPLE WITH DOWN SYNDROME – VALUED AND INCLUDED

July 2010

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 Annual Conference *Learning Together – Focusing on Possibilities*

Saturday, October 23, 2010
Crowne Plaza Suites – Dallas
7800 Alpha Road
Dallas, TX 75249
9:00 a.m. – 4:30 p.m.
\$40 registration fee

This year's conference will interest a diverse group of attendees. Family members who have a child of any age with developmental disabilities, educators and professionals will benefit. Confirmed speakers and topics to date include:

Nicolas Martin, M.A. will be a keynote speaker and present three breakout sessions on the topic of Advocacy in the IEP environment
~ It's About the Kids – Preventing Conflicts in special Education covers the formal and informal indicators of conflict, state and national statistics and trends, and how to know how our own schools or districts are doing in this important area. Specific recommendations for building strong and effective teams are also presented
~Strengthening Relationships When Children Have Special Needs presents an overview of the ten challenges commonly associated with raising a child with a disability along with specific recommendations for addressing them

~ Feeling Better When We Feel Bad provides the skills so very necessary for managing such challenging emotions as fear, grief, anger, and many more. This experiential workshop provides a variety of specific and proven techniques that can be of great practical value in many aspects of everyday life

Regan Roth Fitzgerald M.Ed., BCBA will present three breakout sessions:
~ Increasing language to decrease problem behaviors -This session will be an overview of functional communication training. Functional communication training teaches individuals how to use communication to replace problem behaviors currently being maintained by fulfillment of those needs
~Structure and schedules - Attendees will learn how structure and schedules are important in the lives and educational environment of a special needs child and will be given examples of implementation
~Positive Reinforcement - Attendees will be learning how positive reinforcement can be used to increase, change, and teach new behaviors, as well as maintain behaviors already in the repertoire. The importance of positive reinforcement and the nitty- gritty of reinforcement will be explored

Dr. Millie Gore is a Hardin Distinguished Professor of Special Education at Midwestern State University. She is the author of several books for parents and teachers including [Inclusion Strategies for Secondary Classrooms: Keys for Struggling Learners.](#)

~ Parents: Supporting Your Child's School Success
~Including All Students in Grades 6-12: Strategies to Increase Learning through Reading
~Including All Students in Writing: Writing in the Content Areas
Jo Ann Simons MSW, author of [The Down Syndrome Transition Handbook](#) is on the board of NDSS and has served as a board member and consultant for Special Olympics. She will present three sessions:
~What should school High School IEP's and Transition goals look like?
~Transition---Having a Vision
~It's a Brand New World (Titled after a chapter in her book)

For More Information

Please visit our website at
www.DownSyndromeDallas.org
for complete speaker bios.

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.*

In memory of Myrna Baines

Linda Sain
Marcia Coursey

In honor of the wedding of Kristi & Aaron Kelly

Leslie Wilson

In honor of Angela O'Brien's birthday

Stacey Kirkwood
Allison Gannon

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.

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

Meet the New Board Members

The DSG is proud to introduce the newest members of the board of directors.

Wes Chaar is beginning his first year on the Down Syndrome Guild board and is a professional in the Airlines and Travel industry space. He lives in the Dallas area with his wife and four children. Wes' children attend school in the Coppell Independent School District. Most of his non-work time is spent with his children. He is also an avid swimmer and walker/hiker.

Debbie Clark is a Licensed Clinical Social Worker and a Licensed Marriage and Family Therapist. She has 35 years of experience working with families of children with special needs. She has been a social worker at the Down Syndrome Clinic since its inception in 1993. In addition to working at Children's Medical Center, she has a counseling practice in North Dallas. She spends her free time at the movies and planning her next trip. She has a daughter, Allison, who will be a freshman at the University of Southern California studying Film and Television Production.

Francesca Jones, also beginning her first term on the Down Syndrome Guild board, is an adjunct professor of Special Education at SMU. Although her specialty was behavior, her current research focus has been on teaching reading to students with cognitive disabilities. Francesca is married to Scott Jones and has two preschool-aged daughters. She also has a seventeen year old sister with Down syndrome.

Kevin Smith, another first year board member is an assistant controller at DG Fast Channel, Inc. He and his wife Liesl have three children; Madeline (12), Jacob (9) and Molly (14 months). Jacob has Down syndrome and attends Hyer Elementary. His family enjoys camping, swimming, playing in the front yard, traveling and reading. He attended Texas A&M and is a CPA. Kevin will

be a welcomed addition to the Down Syndrome Guild finance committee.

Cindy Taylor is new to the board but has been a long time member of the Down Syndrome Guild. She and her husband, Mike, have been married for 27 years and have been involved with the DSG since their daughter Mollie (age 24) was very young. Their son Kyle graduated last month from the University of Texas at Austin. The entire family is very active in Special Olympics. Many years ago Cindy served on both the DSG Parent to Parent committee and she used to type the DSG newsletter. Cindy is employed with American Greetings as a merchandiser.

Paul Wachsmann is beginning his first year on the Board. Paul graduated from the Notre Dame School of Dallas in 2001. Currently Paul participates in the Down Syndrome Guild's Volunteer Intern Program processing many of the mailings you receive in your homes. In the past Paul has volunteered at Scottish Rite Hospital and Target Stores. Paul has 2 sisters and 3 brothers and is a fabulous uncle to eight nieces and nephews. Paul is an award winning -medalist for swimming in Special Olympics. His hobbies include crossword puzzles and working on the computer.

Kari Zerbe is beginning her first year as a Board Member. She was born and raised in the Dallas area but left to attend college at Virginia Tech and returned to Texas for her Masters at UT. Kari and her husband recently welcomed their first child, Evelyn Ann Zerbe. Kari is currently the Educational Coordinator at The Rise School of Dallas, where she formerly held a classroom teaching position at the school. She lives an active life and enjoys distance running, traveling and being outdoors. Kari is looking forward to serving on the board and carrying out the mission of the Guild.

Executive Director's Message

By Becky Slakman

Your child will be better prepared to tackle the bumps on the road of life if he has been given the gift of guided independence. ~ Jacquie McTaggart

I hope you are enjoying your summer. Independence as a theme for my article always comes to mind for July. As we celebrate our country's birthday, you can give your child, no matter what age he or she is, the gift of independence. As parents we all try to raise our children to become independent. Often, to save time, we tend to do things for our children and teens because it is easier. By doing tasks that they are capable of for them, we are not doing them any favors in the long run. Children are capable of doing "chores" at a very young age. Every year you can increase his or her responsibilities. By taking these early steps, you are increasing your family member's independence.

The Down Syndrome Guild is beginning our "fundraising season". You can now begin forming your golf foursome and planning for your Buddy Walk team. Sponsorship information for both can be found on our website www.downsyndromedallas.org.

I am sad to let you know that Jessica McCartney, our administrative professional for the last year will be leaving at the end of July. Jessica will be attending New York University in the fall pursuing a Masters of Arts in Performing Arts Administration. I know you join me in wishing Jessica good wishes and great success.

In closing, try to stay cool this summer and remember to celebrate every step toward independence.

What's Your Slant 45?

The Super Bowl is coming and the Down Syndrome Guild of Dallas



self-advocates age 13-18 have found a SUPER way to get involved! We have joined SLANT 45, to become CHAMPIONS of community service!

SLANT 45 is a free youth education program developed for children. Designed and managed by creative-learning nonprofit Big Thought in partnership with the North Texas Super Bowl XLV Host Committee, SLANT 45 aims to become one of the biggest communitywide service-learning programs for children in America! The goal is to recruit 20,000 kids from more than 100 North Texas cities to generate 45,000 hours of community service.

Teams of kids will work with coaches Cara Prentice (DSG Program Specialist) and Becky Igo (DSG parent volunteer) to create a project that will benefit our community.

SLANT 45's key components include a reflective collage, a special touring art exhibition, and a January 2011 celebration event at Cowboys Stadium in Arlington. Even more exciting is that DSG has been selected as one of the groups to follow for the full length feature documentary being filmed by director Mark Birnbaum. Stay tuned for more details as our project moves along!

To learn more, visit www.slant45.org.

Next Chapter Book Club for Self Advocates

The Down Syndrome Guild is currently making preparations to start the Next Chapter Book Club. The NCBC is a program of The Ohio State University Nisonger Center, a research and training center on developmental disabilities. The program was founded in 2002 and has grown from two groups in Columbus, Ohio, to over 100 groups in the United States, Canada and Germany, and continues to grow. The DSG is excited to be one of the newest groups to join this program.

The NCBC model promotes social connectedness, literacy learning, and community inclusion. The premise is simple. A group of 5 to 8 people with intellectual disabilities and a wide range of reading skills gather with two volunteer facilitators in a local bookstore or café to read aloud and discuss a book for one hour a week. Just like members of any other book club, NCBC members choose the book they want to read and how they would like to structure their club. Members will learn a lot and make new friends all while having fun.

If you are age 19 or older and are interested in finding out more information, or becoming a part of the NCBC, please email Cara Prentice at cprentice.dsg@verizon.net. We hope to begin meeting in the fall.

All levels of readers (and non-readers) are welcome. The materials will be adapted, and facilitators are trained to make sure everyone is able to participate.

Summer Vacation: Time for Fun and Time to Plan *by Kathie Snow*

A hhhh, summertime—vacations, swimming, camping, family time, lazy days, and more. Make this your family’s best summer ever, and at the same time, lay the groundwork for a successful school year when September rolls around.

If your child is included in typical, inclusive community activities this summer, not only will she have a wonderful time and make new friends, she’ll also demonstrate that she can be included in “regular” activities. This can be a very important piece of “evidence” at her next IEP meeting! And while your child is having fun, you’ll be creating new friends who can be valuable allies in your efforts to ensure your child is in an inclusive classroom at school!

You may be thinking, “My child can’t participate in ‘normal’ activities—there’s no way all this will work for us.” But your child can be successful in inclusive community activities! Read on—

Begin by checking out all the organized activities in your community that your child might enjoy, such as YMCA or Park and Recreation classes/sports; library/museum classes; and Scouts, Campfire, 4-H, etc. Look for activities that will enable your child to be with similar-aged children without disabilities who may be classmates during the next school year.

In addition, put your thinking cap on and consider what activities you could orchestrate: a neighborhood play date every Friday, a field trip to community activities (zoo, park, etc.) once a week, or anything else that will enable you and your child to make new connections in inclusive settings.

As you check out organized activities, learn as much as you can about them ahead of time: ask other parents; observe the activity, if that’s possible; and/or call the sponsor and ask lots of questions (but don’t mention your child’s disability at this point).

While you’re doing this “reconnaissance,” think about what your child will need to be successful: physical or environmental modifications, assistive technology devices, support from other children or an adult leader, and so forth. Your child doesn’t need a one-to-one aide; that person will get in the way of your child making real connections. Instead, teach your child how to ask for help from whoever is closest—another child or the adult leader or volunteer. (My articles, “Ask and You Shall Receive” and “When Less is More” might be helpful.)

Next, talk to your child and enthusiastically share what you’ve learned! Describe the activities, share your ideas about supports and modifications he might need, get his input, listen to his concerns, and let him make the final decision about which activities he might want to try. It might even be possible for your child and another family member to participate together. When my then nine-year-old son, Benjamin, took karate classes, his dad took the class with him! This class was for all ages, and my husband knew to “back off” and allow Benjamin to make friends, instead of sticking to him like glue!

Next, enroll your child and don’t say one word about his disability at that time. At enrollment time, try to learn more about the activity, the other participants, and so forth, and then

modify, as necessary, your ideas about supports, accommodations, etc. A few days before the activity starts, call the leader and, in a positive, helpful manner, describe what your child will need and describe how it can be done. You do not need to disclose your child’s diagnosis (that can be scary for some people to hear)—you only need to share what your child needs!

Say something like, “Since my son uses a wheelchair, he’ll need some assistance with…” or “My daughter will do best if she has a couple of peer helpers.” Don’t ask permission for these things and don’t whine or get angry! Simply state what your child will need and describe how to provide it. If you tell people what your child needs, without describing how to provide the help, they may not know what to do and failure is likely. And, of course, do all this with excitement, good manners, kindness, and patience, developing allies in the process! If the leader of the activity demonstrates any concerns or resistance, stay positive and ask, “What will it take for you to feel more comfortable,” and assure the person that this will be a successful adventure if the lines of communication remain open!

You may not think you know what supports and accommodations your child needs, but you really do—you’re an expert on your child! Sit and ponder, talk with others, brainstorm with family members, and ask your child. Your first ideas may not be perfect, and that’s OK. After the activity begins, you and your child, along with the activity leader, might need to fine-tune things. And this is great—everyone can learn together!

Now, onto the next phase: developing allies! Contrary to popular opinion, the

best people to assist parents in achieving school inclusion are not other parents of kids with disabilities or professional advocates. Bringing “big guns” to the IEP meeting can inflame an already heated situation. The best helpers are those who do not bring “special ed expertise” to the meeting—like the new friends you’ll be making over the summer—who can bring common sense and cool heads to IEP meetings.

Once your child is involved in inclusive summer activities, your job is to become friends with the other kids’ parents, the activity leaders, and/or volunteers. Reach out to them: invite their children over to play, offer to carpool, organize a pot luck supper after a big game, volunteer to help with the activity (but not as your child’s aide—help all the kids), or do whatever it takes to create and maintain new friendships.

As the relationships develop, brag about your child’s gifts (has a great memory, is happy, is trying really hard to talk, collects baseball cards, etc.). After you’ve detailed positive characteristics—and only then—share more about your child’s needs related to his disability, and do this in a way that generates a positive, respectful, and accurate portrayal of your child. Say, “My son needs behavior supports,” instead of, “He has behavior problems.” Say, “My daughter uses a communication device,” instead of, “My daughter is non-verbal.”

As you get to know these new friends, tell them you’d like your child to be included in a regular ed class in the neighborhood school with supports and accommodations. At the same time, do not tell all your war stories about educators you don’t like! You want to build bridges and create allies, and slamming others (even if they deserve it) doesn’t help! You can, however,

share general information about how schools have traditionally undereducated students with disabilities in segregated classrooms, and how harmful this practice has been (like contributing to the 75 percent unemployment rate of people with disabilities). Your new friends will see that since your child is experiencing success in typical summer activities with supports and/or accommodations, he could also be successful in a regular ed classroom with curriculum modifications, supports, and so forth.

As the lazy days of summer pass and your friendships deepen, ask your new allies for help with school inclusion. They may be able to recommend general ed teachers, get you connected to educators who can become allies, and/or use their influence on behalf of your child! They can attend the IEP meeting and provide “testimony” about your child’s inclusion in summer activities.

Resolve to enjoy every precious moment of summer vacation! Have fun as you get your child involved in inclusive community activities, make new friends, and begin a journey that can lead to inclusive education! With the appropriate supports, accommodations, assistive technology, and/or modifications, every child can be successful in inclusive settings—in the community and at school! Success in these settings will put your child on a path to success as an adult—in a job, at college, and for the rest of his life!

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Karaoke



Christie Davenport and Abby Munn belt out a song during Karaoke night at Dallas Karaoke.

Start Planning for the 2010 Buddy Walk

Sunday, November 7, 2010
Flag Pole Hill at White
Rock Lake

Activities begin at 11:00 am

Walk begins at 1:00 pm

Mark your calendar for the 2010 Buddy Walk® on Sunday, November 7th. 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.

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.

It's easy to form a Buddy Walk® team by going to the DSG website at www.downsyndromedallas.org and downloading team forms. Start organizing your team now to begin raising money and promoting our goals of awareness, acceptance and inclusion of people with Down syndrome!

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 us at (214) 267-1374 or dsged@sbcglobal.net for a sponsorship packet. There are several sponsorship levels from which to choose – and one is right for you!

Traveling this summer? Tips to make your life easier

Reprinted with permission from the National Down Syndrome Congress

Remember the days when your parents would just throw you and your siblings into the back of the station wagon and prayed you would sleep until your destination was reached? Well, a lot has changed since then!

Today, mounted DVD/Game players are an option in almost all new vehicles, making those long car rides much easier and more pleasant.

Traveling and vacationing with children with Down syndrome can still pose a few challenges, though. We hope these tips will help things go a little more smoothly for your family.

Plan your vacation with your child's limitations in mind. For instance, if your child cannot endure walking long distances and is too big (or unwilling) to ride in a stroller, then you probably shouldn't plan a walking tour of Washington, DC or a hike to the Grand Canyon. Maybe that's a trip best saved for next year or the one after that.

Does your child have sensory issues? One parent tells us about their first trip to Universal Studios. "It was a nightmare! Unlike Disney's Magic Kingdom there were not many rides that were without loud noises, dark environments, and unexpected sharp movement." Not all amusement parks are alike -- do some research to find the best fit for your child's age and stage.

Plan for downtime for your child to just "chill". Many of our kids get over-stimulated and tire more quickly than others. Set aside a portion of the day for a little quiet time. Even restaurants are jam-packed with loud music, eye-candy, and too much activity. Sometimes we all need a quiet place to chill for a little while.

Plan a portion of each day doing an activity that your child with Down syndrome prefers. Does he love to swim and hang out by the pool? Or maybe bowling, miniature golf, the zoo? To reduce meltdowns and bouts of

"inflexibility", give him something to look forward to.

Visiting family? Prepare your relatives for potential issues. If your child is a finicky eater, chances are she won't eat something she doesn't like, just because she's at Grandma's house. If you are visiting family or friends that aren't familiar with your child, help them get to know her in advance -- her likes, dislikes and favorite things.

It's hard, but keeping to any child's routine as much as possible will help a lot. Vacations are a fun time to explore and have new adventures, but the more our kids can count on the familiar, the less trouble you'll have.

Don't forget, if your child has special dietary needs, plan to bring along certain foods that you may not be able to find in other parts of the country.

And finally, use the internet to research your destination(s), and search for language about "visitors with special needs". You might find they already have some plans in place to make your visit better.

Dad's Group Happy Hour

Wednesday, July 21, 2010
6:30 pm - 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. RSVP to Becky Slakman at (214) 267-1374 or via e-mail at dsged@sbcglobal.net. Not able to join this time, but would like to be added to the list to receive information for future events? Let Becky know that as well.

2010 Herb's Paint and Body/Down Syndrome Guild Golf Classic

Tuesday, September 21, 2010
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-TV will 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. 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? Kari Hatfield, 2010 Golf Tournament Chair and her committee also have many ways for you to volunteer and be a part of the day.

Lunch and dinner will be provided. We hope to see you there!

****Returning this year!** Non-tournament participants will have the opportunity to purchase drawing tickets for great packages. Stay tuned for additional information.

Got Connections?

The 4th Annual Herb's Paint & Body/Down Syndrome Guild Golf Classic will be held Tuesday, September 21, 2010, at Canyon Creek Country Club in Richardson. The committee is actively seeking Corporate Sponsors as well as drawing prizes. If you know of anyone who would like to be a corporate sponsor or donate a drawing prize please contact the DSG office at 214-267-1374.

Drawing prizes wish list includes but is not limited to the following:

- Spa packages
- Sport tickets
- Airline tickets
- Jewelry
- Lasik surgery
- Teeth whitening
- Golf clubs
- 4 Seasons Stay and Play package
- Horseshoe Bay Golf package
- Hyatt Hill Country Stay & Play
- Great Wolf Lodge stay
- Gaylord Texan/Cowboys Golf Club package
- Gas gift card
- Department Store gift card
- Restaurant gift card
- Jim McLean Golf Academy package
- PGA Superstore gift card
- Autographed sports memorabilia
- Hotel packages

Greeting Card Making Party For adults with Down syndrome

Friday, July 9, 2010
7:00 pm-9:00 pm
The Down Syndrome
Guild of Dallas
1702 N. Collins Blvd. Suite 170
Richardson, TX 75080
(enter on the east side of the building)

The Down Syndrome Guild of Dallas is proud to be an organization that gives back to the community that helps support us. Young adults 19 and older are invited to join together as we make Halloween greeting cards to be donated to the Visiting Nurses Association Meals-on-Wheels and Hospice programs. We will enjoy music and plenty of fun while helping others in need. Won't you join us for this great cause? RSVP to Becky Slakman at 214-267-1374 or email dsged@sbcglobal.net

1702 N. COLLINS
SUITE 170
RICHARDSON, TX 75080

Return Service Requested

(214) 267-1374

www.downsyndromedallas.org

dsged@sbcglobal.net

EXECUTIVE DIRECTOR: BECKY SLAKMAN

PRESIDENT: TERRI MCKINNEY

LAYOUT EDITOR: JESSICA MCCARTNEY

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AT CHILDREN'S MEDICAL CENTER.

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DOWN SYNDROME GUILD OF DALLAS



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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

July 5-9
Lose the Training Wheels
Bike Camp

July 9
Greeting Card Making Party
For Adults

July 31
Sexuality Workshop

July 21
Dads' Group Happy Hour