

THE

DSG News

PEOPLE WITH DOWN SYNDROME - VALUED AND INCLUDED

June 2009

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

From the DSG President *By Kelly Drablos*

As I begin the second year of my two-year term as President of the DSG, I welcome our seven new board members, Carla Austin, Lynn Campbell, Stephanie Crow, Jane Friou, Jim Gulley, Jennifer Hood, and Ross Redden, recently elected to our Board at our Annual Picnic and Membership Meeting on May 3, 2009. I also applaud the work and dedication of our three out-going members, Mike Arbour, Teresa Ramirez, and Marianna Sokolich. It has been a pleasure to work with Mike, Theresa, and Marianna, and I am very excited about Carla, Lynn, Stephanie, Jane, Jim, Jennifer, and Ross joining our Board of Directors.

Our DSG strategic planning and board development processes have resulted in some new initiatives for this coming year. Specifically, we have chosen to advocate for, publicize, and call attention to the benefits of life-long literacy for people with Down syndrome. We are convinced that the vast majority of people with Down syndrome can read well enough to impact their lives in very positive ways. We want to urge parents and

educators to remain resolved to pursue fluency in reading for their students and children with Down syndrome even when the students in question seem to be very reluctant and delayed readers. We believe children with Down syndrome who are taught to read often make huge strides in their spoken language after learning to read. We believe people with Down syndrome can and do make real academic progress into their twenties. We believe the skill of reading is a life skill far more important than any number of other skills taught in life skills curriculums. We believe friendships are easier to cultivate and maintain for people with Down syndrome who can read and have developed communication skills. We know people with Down syndrome who can read well will be easier to employ than those who cannot.

Please help us in this initiative. Read the article on page 4 titled "Reading, Writing, and Literacy for Children and Adults with Severe Disabilities." We live in the information age. People with Down syndrome can participate to an extent that would surprise and amaze many if they can read.

In Memory of Norman A. Williams

We grieve with Down Syndrome Guild member, Nakia Goodson, on the April third death of her son Norman A. Williams who had Down syndrome. Nakia said, "Norman was two years-old, and just a ray of sunshine."

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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 W. N. "Buck"
Saigling.*

From: Betty Brame, Robert & Charlene Chronister, Pat & Harold Copher, Carla Enna, Vicki & Mark Haseloff, The Lending Partners, Ltd, Charlotte McElligott, Pat Myrick, Barbara Paxton, Lutetia & Jack Raley, Suzanne Taylor, and J.E. & E.J. Uselton

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.

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

Upcoming Events

Dad's Group Happy Hour

Wednesday, June 17, 2009

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 dads who might enjoy attending. RSVP to Becky Slakman at (214) 267-1374 or e-mail 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.

Spa Saturday for Ladies

For adults with Down syndrome

Saturday, June 20, 2009

10:00 am - 1:00 pm

Murphy, Texas

(Address and directions will be given with your reservation)

It's time to be pampered! Join Mary Kay Sales Director, Joan Daniels, and her team of experts for a fun filled, relaxing afternoon of beauty and make-up. Joan is a skin care solutions and

glamour techniques expert, who trained with International Make-Up Artist, Robert Jones. The ladies will enjoy a spa hand and lip treatment with paraffin wax, spa foot treatment, and lotions. They will also be pampered with a facial and glamour make over. Space is limited so make your reservation now. RSVP to Becky Slakman by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.

Dual Diagnosis – Down syndrome and Autism

Saturday, June 27, 2009

10:00 am - 12:00 pm

Down Syndrome Guild Office

701 N. Central Expwy., Ste. 5-1

Richardson, TX 75080

This meeting is open to anyone interested in—for whatever reason—the dual diagnosis of Down syndrome and Autism. We will share information on behaviors, therapies, diet, medications, doctors, and schools.

If you have any concerns about your child's development or behaviors, please join us for this meeting. RSVP to Becky Slakman at (214) 267-1374 or e-mail dsged@sbcglobal.net.

Thank You Translators

For the past many, many months volunteers have been faithfully translating *The DSG News* for the DSG members who prefer reading in Spanish. They are Myrna Castillo, Roberto Gonzalez, and Ayako Chan. One of the volunteers, Myrna Castillo, is "retiring" from translating. Of all the volunteers she has been serving

us the longest. Thank you Myrna for you many hours of work! Although sad to see Myrna go, we are happy to announce new volunteers joining the translators, a husband/wife team, Monica Anderson and Gabriel Orozco. Welcome Monica and Gabriel. Thanks to all of you for your selfless and dedicated work.

Is Your Child on THE List?

Texas Medicaid waiver programs are available for children and adults with disabilities. The waivers allow the states to offer Medicaid funded services in the community, rather than institutions. These waivers do not look at the parent's income but are based on the applicant's income and resources. Call NOW to place your child on the "interest list." Eligibility will be determined when they get to the top of the list, which may take years.

For additional information about the following programs, visit the website for the Texas Department of Aging and Disability Services (DADS) at www.dads.state.tx.us. To put your family member's name on the "interest list" call DADS at 1-877-438-5658.

Home and Community Services (HCS) Respite services, nursing, OT, PT, speech, dental services, foster parenting, psychology and social work services, case management services, supported home living offered to persons with mental retardation [sic] living at home, on their own, with foster parents, or in a residence with

no more than four individuals who receive services.

Medically Dependent Children Program (MDCP) Respite services, home modifications, and adaptive aids for medically involved children to be able to live at home.

Community-Based Alternatives (CBA) CBA provides home and community-based services to the aged and adults with disabilities. CBA provides many services, similar to those in HCS and CLASS. If a young adult is nearing 21, you should place his or her name on the interest list for this program.

Community Living Assistance and Support Services (CLASS) For persons with a disability other than mental retardation [sic] occurring before age 22, that affects ability to function in daily life. These services offer an alternative to placement in a facility.

In Home and Family Support (IHFS) A small annual grant for Texans with disabilities that live in the community to assist them with payment of disability related expenses.

Charles H. Phipps Family Foundation Honors Us Again!

The Board and staff of the Down Syndrome Guild of Dallas offer a very enthusiastic thank you to the *Charles H. Phipps Family Foundation!* They are not only funding another year this publication, *The DSG News*, they are continuing

to fund the new program, *Parents and Schools in Partnership*. Mary Claire and Charles Phipps have been members, as well as benefactors, of the Down Syndrome Guild for many years. Thank you Phipps family!

2009-10 Board of Directors Announced

The membership of the Down Syndrome Guild of Dallas elected the following Officers and Directors at the Picnic and Annual Meeting on May 3, 2009:

President: Kelly Drablos

Vice President: Terri McKinney

Treasurer: Scot O'Brien

Secretary: Tamara White

Member at Large: Angela O'Brien
(Appointed by the President)

1st term complete and elected for a second 3 year term:

Scot O'Brien

Jessica Smith

Elected for first 3 year term:

Carla Austin

Lynn Campbell

Stephanie Crow

Jane Friou

Jim Gulley

Jennifer Hood

Ross Redden

Board members continuing current terms:

Gail Brookshire

Doug Dureau

Anita Ford

Chris McKee

Ian Rawn

Luke Strawn

The following have completed 2 terms and rotated off the Board:

Mike Arbour

Teresa Sims-Ramirez

Marianna Sokolich

Reading, Writing, and Literacy for Children and Adults with Severe Disabilities

Can children with severe disabilities learn to read or write?

Answer: Recent federal legislative efforts have focused on mandates in education that include reading development and achievement for all school age children. These programs include all children: children with and children without disabilities.

Literacy opens a critical path to the acquisition of, and access to, many forms of knowledge and experience within our contemporary society. From early school experiences through adult employment, literacy skills are needed to maximize one's functional participation. Education, self-determination, employment, quality of life, and enjoyment as a fully participating member of society all may hinge on an individual's ability to read and/or to write.

Many educational methods and materials may be employed to develop and enhance literacy. Far too often, an emphasis on daily living and/or vocational skills has excluded the incorporation of literacy instruction. In general, research has demonstrated that neither IQ, nor perceptual motor skills predict reading success; it is a child's knowledge of letters and phonemic awareness that evidences a strong relationship. How is that knowledge gained?

Children must be given opportunities to learn about print. Reading is not a single skill; rather it is composed of a smoothly integrated system of skills coupled with a backdrop of world

knowledge and experience. Reading is about extracting meaning. For young children, immersion in, and attention to, examples of the use of print—on cereal boxes, on signs, in books and magazines and games, and on television programs

From The DSG News Editor:

The DSG Board has chosen reading as the topic of the year to emphasize in 2009-10 because reading skills affect so many aspects of our children's lives - no matter what their ages. Beginning this month, The DSG News will offer articles about the subject of reading in each publication. The surrounding article is from an organization called The National Joint Committee for the Communication Needs of Persons with Severe Disabilities. Although the use of the term "severe" is unfortunate, clinical, and antiquated, we are publishing the article because of its excellent general content as well as its intrinsic value.

—Nancy Davenport

like Sesame Street—are everywhere.

Children with severe disabilities must have access to the full complement of literacy experiences in order to support the development of reading and writing skills. These skills may range from experiences that foster emergent literacy to those that support fluent sophisticated writing skills.

When should I start reading to my child?

Answer: It is never too soon nor is your child too young to begin learning about print.

Marilyn Adams (1994), author of

Beginning to Read, describes how she read to her son since the time he was 6 weeks old. Daily reading, especially when the child is engaged at a level that is slightly above his or her expected level of performance is essential to offering wide experience with print. Playing word games, using magnetic letters, identifying letters and words in different environments are other ways in which to make children aware of the links between oral and written language. For children with significant disabilities, the development of reading skills sometimes can be neglected since parents and professionals may believe that other types of language skills should be in place before teaching the child about print.

What are signs of "emergent literacy" in a child with severe disabilities?

Answer: Emergent literacy is made up of several behaviors that range from the child knowing a few letters of the alphabet to recognizing some icons or signs or identifying his or her own name in print. The child also may be able to match words with pictures or with objects. Interest in looking at books or magazines can denote a child's growing awareness of print. Following and comprehending a story are illustrations of a child's developing interest in print as well.

Just like the typically developing child, the child with disabilities may not know that the letters of the alphabet represent sounds in speech.

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Comprehension of spoken language will set the stage for reading comprehension. Children's vocabularies expand when adults and others read to them.

What strategies can I use to teach reading and writing to an individual with severe disabilities?

Answer: Effective instruction must provide a match between an individual's profile of skills, (strengths and weaknesses in spoken and written language) and the instructional content. Careful and specific analyses of the tasks and skills needed in the development of reading are required. Children, for example, who can decode, but have difficulty with comprehending text, would have instruction tailored to their need. Innovative applications of software have been developed for instruction in both reading and writing. They include interactive books in different media. All function to increase individuals' experience with print. Families, teachers, and other professionals must collaborate to identify and design instructional plans that allow children to progress in their school's literacy curricula.

Language and literacy instruction is not and should not be limited to elementary school age children. The fundamental skills should be integrated into the curriculum across all ages and in all contexts and activities.

Reprinted with permission from Communication services and supports for individuals with severe disabilities: FAQs by the National Joint Committee for the Communication Needs of Persons with Severe Disabilities. Available from www.asha.org/njc.

Learning Together – Focusing on Possibilities Fall Education Conference

Saturday, October 10, 2009
9:00 am - 4:30 pm
Registration begins at 8:00 am
Crowne Plaza Suites - Dallas
7800 Alpha Road
Dallas, TX 75240

Parents, family members, self advocates, service providers, educators, para-professionals, and school administration are all encouraged to attend. This year's conference is sure to include something for everyone with two keynote speakers and a variety of session topics.

Keynote speakers

Susan Fitzell:

- *Paraprofessional/Teacher Collaboration*

- *Special Needs – How Do We Make It Work In The Classroom*

Craig Blackburn:

- *Visions, Dreams & Goals*

Additional Speakers

Leslie Walker-Hirsch:

- *Six Key Components for Meaningful Sexuality Education*
- *Living Independently: Understanding Social Boundaries*

Jan Deaton:

- *Visualizing for Comprehension*
- *Recipe for Success: Accommodations & Modifications for the Elementary Classroom*

Regan Roth Fitzgerald:

- *Behavior Intervention Plans (BIP), Data Collection & Techniques*

Outstanding Educator of the Year Award - Nominations Due

Each year the Down Syndrome Guild of Dallas recognizes individuals and/or teams working with students with Down syndrome in an inclusive educational setting, public or private. Experience, education, and community involvement, as well as teaching philosophy are all criteria that the *Award Committee* will consider. Past winners have included teachers, transition specialists, speech therapists, para-professionals, and others working at all grade levels.

Any Down Syndrome Guild of Dallas member may nominate

their favorite educator by going to www.downsyndromedallas.org and downloading the nomination form.

Deadline for nominations is June 30, 2009. Nominees will be recognized at the Down Syndrome Guild of Dallas, *Learning Together, Focusing on Possibilities* Fall Education Conference on Saturday, October 10, 2009.

Members may also contact Executive Director, Becky Slakman at the Down Syndrome Guild of Dallas office at (214) 267-1374 or dsged@sbcglobal.net and request that a form be sent to you.

Did You Miss the DSG Membership Renewal Deadline?

June 1, 2009, is the first day of the new membership year for the Down Syndrome Guild. If we don't receive your membership form by June 10, 2009, – you will be listed as “inactive” and you will not receive the July edition of *The DSG News*. Membership entitles you to the monthly newsletter, notification about free events and services, and registration discount for the Fall Education Conference. In addition, the number of families who are members of the DSG is an important statistic when making requests to foundations for grant funds.

If you haven't returned a membership form, please do so as soon as possible! Forms are available on our website at www.downsyndromedallas.org or call the office at (214) 267-1374.

If payment of the \$25 membership dues is a problem for your family this year, fill out and return a membership form – check the appropriate box to receive a scholarship membership. Additional questions about membership issues should be discussed with the Down Syndrome Guild's Executive Director, Becky Slakman at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.

What are Natural Supports? By Dee Blose

Natural supports refer to the support and assistance that naturally flows from the associations and relationships typically developed in natural environments such as the family, school, work, and community. These relationships and the support and assistance they offer, maintain and enhance the quality and security of life for people with disabilities.

A natural support is something that you or your family can access for fun, for encouragement, or for assistance because it has already been established through natural relationships or typical routines. This support is available, regardless of any "disability" issue, just like it is available to others! Everyone has interdependent relationships in life. Natural supports are already there!

Why would I want to access natural supports?

Using natural supports promote feelings of belonging and participation in LIFE! They draw on people's natural inclination to care for others and form relationships that last. They do NOT contribute to artificial relationships, but rather people are together because they desire to be together. They have longer staying power! Developing and using natural supports makes more sense for your long-term sanity! They are not dependent upon "funding" or "eligibility." They do depend upon YOU though and your persistence to find them and make them fit into your life.

Natural Supports can be a who
---friends, family, neighbors, acquaintances, co-workers, volunteers, peers, community group members, church members.

Natural Supports can be a what
---family events, holiday celebrations, community events, community group activities, recreation activities, churches, community locations, volunteer experiences, social events, school time activities.

Tips for accessing natural supports:

Don't limit your options to specialized programs. Explore a variety of resources and programs in your community. Options need not be limited to specialized or segregated programs for individuals with disabilities. While participation in special programs is at times beneficial, regular programs offer a wider range of opportunities and are offered at more locations.

Move toward inclusion.

If special programs are chosen, consider transitioning at some point into a program of similar nature where skills can be carried over. For example, participation in Special Olympics swim training can lead to taking a swim class at the local community center. Tell others WHY this is important for your child. Remind others that your child wants to participate in his community just like all of his friends and other children. Let them know how important this is for his self-confidence and self-esteem.

Resistance to participation.

Sometimes others don't understand why you would want to participate and will direct you to programs with special supports. You will have to invest the time necessary to explain why it is so important to your child and family.. Ask the question, "What will it take?" You may have to assist with

continued on following page

"modifications," give suggestions, or even be willing to model assisting your child to participate.

Fight the isolation.

Too many families become isolated when they have a child with a disability. It is a progression in our culture that you must FIGHT! You are not doing your child any favors to isolate him. While you may feel that it is a temporary solution due to overwhelming environments, you CANNOT make isolation your long-term solution. That is no solution and will only create new problems.

Think long-term.

What you do everyday is your child's "program." LIFE is your program! Get out, get about, and get on with your

life! Don't let today's problems keep you and your children from experiencing life and all it holds. Make sure you have developed a set of supporters that care about your child like you do, so that he will have lots of opportunities in the future.

Be patient.

None of this happens overnight. You will have setbacks. Some people will never understand, don't let them get you down. Keep your eye on the goal. Cut yourself a break now and then. But..... Don't give up! Think of the long-term benefits for your child to have the opportunity to participate and for your family to HAVE A LIFE!

Local Band Member in NYC Parade



▲ Yousef Mallalah, son of DSG members Bader and Phyllis Mallalah, proudly carried the Stars and Stripes in the New York City St. Patrick's Day Parade.

In the Community

Arc L.I.F.E.

Vist www.arcdallas.org to learn about the many summer activities offered by the Arc of Dallas.

Food is an Art - Meal Preparation with Kathy

(Designed for young adults with developmental disabilities)

Tuesdays, June 16 –

July 21, 2009

1:00 pm - 4:00 pm

Richland College

12800 Abrams Road

Dallas, TX, 75243

Part 1 of this course (1:00 - 2:30 pm) is basic meal preparation demonstrations with student participation and Part 2 (2:30 - 4:00 pm) students use a digital camera and graphic arts to explore "food is art" and design a cookbook. Tuition is \$175.00. For more information contact Richland College at www.richlandcollege.edu.

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DOWN SYNDROME GUILD OF DALLAS

This month on the DSG calendar Payton, Kallen, Avery, Jordan, and Audry finally have time to play.



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

June

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

June 1

Deadline for DSG Membership Renewal for 2009-10

June 17

Dads' Group Happy Hour

June 27

Dual Diagnosis Group Meeting

June 30

Deadline for Outstanding Educator of the Year Nominations