

THE

DSG News

PEOPLE WITH DOWN SYNDROME - VALUED AND INCLUDED

May 2007

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 Coming events

Adult Issues Meeting

Services (or the lack thereof) for people with Down syndrome

Thursday, May 10, 2007

6:00 pm – light snacks will be provided

6:30 pm – 8:00 pm – meeting

Down Syndrome Guild

701 N. Central Expressway, Bldg. 5- I
Richardson, TX 75080

214-267-1374 (map available at
www.downsyndromedallas.org)

Frequently, DSG members call our office to ask how to get “services” for their child (school age and adults) with Down syndrome. Seems like a simple question! However, the answer is very complicated. It depends on the child’s age, the family’s income level, what kind of services, public or private service providers, availability of funding for existing programs, waiting lists for some programs, rules and regulations that constantly change, etc., etc., etc.

We have asked one of the most knowledgeable people we know to meet with us to help us learn more about services for children and adults with Down syndrome. Drew Dixon, Director of Intervention Services for the ARC of Dallas, is also a DSG Board member and THE most respected advocate in

our community. Drew will also address questions about the recent cuts in funding for services from Dallas MetroCare.

For additional information, contact Minnie Blackwell by email at minnieblackwell@tx.rr.com or by phone at 972-239-8771.

Meeting For Parents of Babies and Young Children

Parent Infant Coffee
Sunday, May 20, 2007

3:00 pm to 5:00 pm
St. Luke's Episcopal Church
5923 Royal Lane
Dallas, TX 75230

The next Parent/Infant get-together will be Sunday, May, 20, 2007. These informal meetings provide information and support for families, especially those with newborn or young children. Families who have children with Down syndrome of all ages are welcome.

St. Luke's is located just east of the Dallas Tollway on Royal Lane at Jamestown Road. Parking is in the back. Contact Becky Slakman at the DSG office at 214-267-1374 or dsged@sbcglobal.net for more information.

DSG Receives Grant to Fund Newsletter

DSG members, Mary Claire and Charles Phipps, through the Charles H. Phipps Family Foundation have awarded funds to underwrite our monthly newsletter for twelve months, including new software, new computer, printing, postage and staff time. We are very grateful for their support, generosity and friendship!

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New DSG Program to Honor Loved Ones

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

A donation of \$21 or more in multiples of 21 (\$42, \$63, \$84, \$105, \$2100, etc) allows the DSG to carry out its mission of providing accurate and current information, resources and support for people with Down syndrome, their families and the community.

A gift to DSG 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.

For questions or credit card Club 21 "membership," please contact Becky Slakman at the DSG office at 214-267-1374 or dsged@sbcglobal.net or mail checks to the office with the appropriate information.

Thank you to this month's Club 21 donors listed to the right of the page.

Executive Director's Message

By Becky Slakman

Everyone has inside of him a piece of good news. The good news is that you don't know how great you can be! How much you can love! What you can accomplish! And what your potential is! —Anne Frank

Let me begin this message by letting you know that I not only have good news, I have great news. In the short time that I have been the Executive Director of the Down Syndrome Guild (DSG), I have seen an extremely dedicated and passionate group of men and women give their hearts and their time to this organization. Many of your board members are in the DSG office or working from home several times a week ensuring that the DSG is providing the most relevant information and programming to you, our members. In the coming weeks and months, you will continue to see the great things that we have the potential to accomplish as we work together. You are reading this new and improved newsletter either by hard copy or on our frequently updated website. In addition to our

already fantastic programs, IEP clinics, Buddy Walk, Golf Tournament, Picnic, Parent-Infant Coffees, Teen Dances, Fall Conference and Mom's Escape, our future includes: Parent and Child Classes, partnership with a local Health and Fitness Club, Public School Outreach, and increased young adult programs. I urge you to participate in the opportunities available to you.

You recently received your membership and annual appeal letters. Thank you to those of you who have already returned your forms. If you have not done so already, please take a minute to update the information on your form and return it to our office. Our continued growth and strength is dependent on your continued membership participation and generosity.

In closing, I will paraphrase the words of the late Anne Frank, the DSG will continue to do what we love, celebrate our accomplishments and together we will reach our potential.

A NEW WAY TO HONOR LOVED ONES

Club 21

To: Sara Pfeffer

In appreciation of your assistance with the membership renewal mailing

From: Minnie Blackwell, DSG Membership Chair

To: Helaine Slakman

In appreciation of your assistance with the membership renewal mailing

From: Minnie Blackwell, DSG Membership Chair

To: Elizabeth Longworth

Happy Birthday

From: Becky Slakman

Nominations & Applications Due

Outstanding Educator of the Year Award Nominations

Each year the Down Syndrome Guild recognizes individuals and/or teams working with students with Down syndrome in an inclusive educational setting, public or private. Experience, education, professional 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-teachers and others of all grade levels.

Any DSG member family may nominate their favorite educator by going to the DSG website and downloading the nomination form. Deadline for the submission of the nomination is **June 15, 2007**. Nominees will be recognized at the DSG Fall Conference on September 29, 2007.

Members may also contact Becky Slakman at the DSG office at 214-267-1374 or dsged@sbcglobal.net and request that a form be sent out.

2008 Calendar Applications

It's time to start planning for the 2008 DSG calendar. Each year our calendar sales represent a significant share of the DSG fundraising efforts, but more important the calendar allows the faces of our beautiful children to be out in the community year-round. If you are interested in applying for the possibility of having your child's picture in the calendar, go to our website and find the application and requirements. If you do not have web access, call the DSG office (214-267-1374) and ask for the information and a form to be mailed to you. Give the information requested and send it to the DSG office no later than **May 20, 2007**.

It's Down Syndrome Guild Membership Renewal Time

In early April, everyone in the DSG's database receives a membership renewal form and the Annual Appeal letter. Take time to review the information on the renewal form, make corrections and return the form to the DSG office. In addition to your dues, please consider making a donation of ANY amount to the Annual Appeal. Your generosity will allow the DSG to continue to provide services and programs to enhance the lives of our families.

The membership form (in English and Spanish) can also be found on the DSG website:

www.downsyndromedallas.org. To be included in the new membership directory, you must return your membership form by **Thursday, May 31, 2007**. If you have questions about membership, contact Minnie Blackwell at 972-239-8771 or minnieblackwell@tx.rr.com.

If for financial reasons you are not able to pay the \$25 dues this year, there is an option for a free membership – but you must fill out and return a membership form.

In the Down Syndrome Guild Library

What Did You Say?
- Written by Libby Kumin,
PhD, CCC-SLP

What Did You Say? is an informative film by one of the most respected speech-language pathologists in the field. It looks at the importance of speech intelligibility (clear speech) specifically for people with Down syndrome (DS). This DVD will benefit families or professionals assisting people of any age with DS. Dr. Kumin explains many factors which underlie speech intelligibility problems and assisting parents and therapists pinpoint specific problem areas. There is an

additional section which explains how to build intelligibility goals into an Individual Education Plan (IEP).

A bonus on the DVD back cover is a picture of two of our local self-advocates.

Members may contact Becky Slakman at the DSG office at 214-267-1374 or dsged@sbcglobal.net to have this DVD mailed to your home on loan. You also may drop by and see the many valuable resources available in the DSG library at our office from 8:00 am to 5:00 pm, Monday through Friday.



I Advocate, Therefore I Am

By Terri Harmon, Boca Raton, FL

“We must strive for all children to reach their fullest potential, regardless of what that might be.”

Our sweet old dog, Alice, loved going out in the backyard to bark. So, it was very appropriate when we came across a cartoon showing a dog with the caption, “I woof, therefore I am.” From Alice’s perspective, I guess it is a dog’s way of saying, “What else would you expect me to do?”

And, so it was that one day, as I was driving away from an IEP meeting, “I advocate, therefore I am,” popped into my head. It made me think, “What else would anyone expect me to do?” As parents of children with Down syndrome, advocacy is simply a part of our being.

Many parents find out the importance of advocacy early. For some, it is in the hospital at the time of their newborn’s diagnosis, or it may begin when dealing with health issues that must be addressed before a family even begins to consider what it means to have DS. Others will discover how important advocacy is during early intervention. And, as our children begin school, we find out that we need advocacy skills to ensure they obtain the Free and Appropriate Public Education in the Least Restrictive Environment that they are entitled to because of the Individuals with Disabilities Education Act (IDEA).

As our children get older, we are very tired. School is over and we are hoping for relief from all this advocacy stuff. Instead, we are shocked to find that we need a new set of advocacy skills to manipulate the adult service system to get basic things that our young adults and

adults need to be part of their community, including health care. But, because we are parents of children and adults with DS, we must continue. “I advocate, therefore I am.”

I want to give you hope and encouragement as the parent of a 19-year-old who graduated this past year from high school. We certainly all can be thankful that it is 2007 and not 1970. But, I would be remiss if I did not tell you that truly being a part of the community is not an easy task and it comes with many, “If I’d only known” thoughts. The good news is that people with DS are truly life long learners.

There are families who advocated, despite the system, for an outcome that would prepare their young adult for life in the community. Unfortunately, community services remain inadequate to support adults with cognitive disabilities so that they are successful and can truly access all that life has to offer.

Other young people essentially spent their school years being babysat by teachers who didn’t believe their students could learn and who have yet to understand that our young adults do and must have a place in the community for the sake of their own mental health. For parents, this realization hits too late and students exit school ill-prepared for jobs in competitive employment; to ride even special transportation; or because of socially inappropriate behavior, able to access integrated recreation. Only parents and advocacy can change this.

We must strive for all children to reach their fullest potential, regardless of what that might be. Setting goals and planning to attain them must begin when our children are born and continue throughout their lifetime.

Let the advocacy continue.

Terri Harmon is executive director of the Gold Coast DS Organization. This article first appeared in their newsletter, Gold Coast News, and was reprinted in the National Down Syndrome Congress’ newsletter, Down Syndrome News.

Interested in joining the Advocacy Committee? Contact Becky Slakman at dsged@sbcglobal.net or 214-267-1374 for more information.

Inclusion Helps: tools for teachers

Creating a Supportive Atmosphere in Your Classroom

Create a classroom that fosters kindness, consideration, empathy, concern and care for others. You can support this kind of atmosphere by following these practices:

- Hold class meetings in which students can express themselves and their perceptions of how things are going
- Use cooperative learning - emphasizing how students are interdependent to produce results
- Plan ahead to make sure all students are included in free-time activities
- Teach social skills such as how to communicate clearly, resolve conflicts and solve problems
- Help your students understand that everyone learns in their own way and everyone needs help with specific subject areas. Point out that this does not mean a person is weak or not smart, but rather just needs help

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Celebrate the experiences and differences that each child brings to the classroom. You can do this in a variety of ways:

- Model acceptance of diverse abilities, backgrounds and behaviors
- Be careful to include all students in class activities
- Establish buddy and peer-tutoring programs

One caution: Be aware of how often you ask or expect students who are not disabled to assume helping roles. True friendships are more likely to grow when children cooperate and interact often and of their own choosing.

Be sure to allow your student with Down syndrome to make mistakes and accept constructive criticism from peers. This allows your student the opportunity to receive peer feedback and learn from mistakes.

Thank you to the Down Syndrome Guild of Greater Kansas City for these inclusion hints.

May Mom's Escape

Every month the DSG moms get together for fun and fellowship. The moms who attend have children with Down syndrome from newborns to over 30 years old. There is no agenda for these gatherings, so the discussion goes wherever someone leads – the conversation is always interesting and lively. It is an evening of good food, good beverages and an opportunity to make good friends. The date and location change every month – so check the DSG website or contact Becky Slakman at the DSG office at 214-267-1374 or dsged@sbcglobal.net.

Taking Care of Your Marriage

By Debbie Clark, LC, LMFT

There is an old saying, “The best thing a father can do for his children is to love their mother.”

This saying highlights the importance of the relationship between parents. The marital relationship is essential to the well-being of the whole family. Without it, the entire family system is in jeopardy. In fact, the most important bond in the family is between the parents. If it is nurtured, it will exist before the children are born and endure after they have left home for independent lives. A happy, healthy marriage provides a secure, stable base of growth for children especially when one family member has Down syndrome.

But this relationship, as in any relationship, requires attention and care to survive. Most people do not plan the breakdown of communication and intimacy in their marriage. It occurs through neglect. The following are some suggestions for taking care of your marriage:

- Work together as a team, remembering that your spouse is your ally or your friend, rather than your enemy or “the problem”
- Negotiate and compromise with your spouse for time to be a couple and time to be alone. Try to arrange for each person to have some of their needs met
- Plan some activities without your children where you can relate to each other as adults. Spend quality time together during naptime or after bedtime, rather than paying bills or doing housework
- Create time for romance. Meet your mate for an intimate lunch date. Utilize

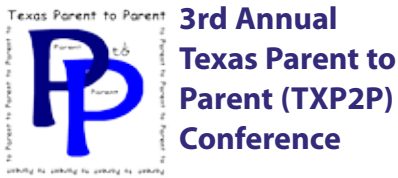
a babysitter and plan for a “mental health day” away from work together. Discover hotel specials for overnight vacations

- Lower your housekeeping standards. Consider hiring household help if your budget allows. Utilize take-out, home delivery and frozen foods. Conserve your time and energy for the relationships in your family

“**T**he marital relationship is essential to the well-being of the whole family. Without it, the entire family system is in jeopardy.”

- Relax your career and work standards. It is difficult to maintain quality family relationships while living “life in the fast lane” from a career/work perspective. If possible, consider part-time or flex-time work options for the second salary in the family
 - Remember your courtship. Pay special attention to your spouse’s birthday and holidays. Give cards, notes or gifts for no particular reason. Celebrate the events of your relationship, such as your wedding anniversary, your first date or the date you became engaged
 - And last but not least, maintain a sense of humor. Seeing the lighter side can help you keep a healthy perspective and assist with problem-solving
- Debbie Clark is a member of the staff at the Down Syndrome Clinic at Children’s Medical Center in Dallas and works at Lakewood Therapy, Inc.*

In the Community & Around the Nation



Creating a Good Life for Your Child!

Omni Austin Hotel at SouthPark

Austin, TX

June 7, 8 and 9

Sessions available in English
and Spanish

Registration information and
conference schedule: www.txp2p.org
or 866-896-6001 (toll free)



35th Annual NDSC Convention

August 3-5, 2007
Kansas City, MO

Network and socialize with other families and attendees from sea to sea, and a few from around the world. Join over 2000 friendly faces traveling on a similar journey. The conference will feature a number of the most renowned speakers on Down syndrome and related topics, as well as the largest self-advocate program in the nation, planned and presented by individuals with Down syndrome - over 200 are expected to participate.

For more details and registration go to www.ndsccenter.org.

What's New On Our Website

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

- ◆ **Outstanding Educator Form Available**
- ◆ **HHS Approves Iowa as First to Add Home and Community-Based Services to Medicaid State Plan**
- ◆ **ARC of Texas Advisory on New State School in Texas**
- ◆ **PARTICIPANTS NEEDED: Families' Experience and Understanding of Down syndrome - Social Research Dissertation Study**

Social Skills Checklist: *What should I focus on for my child with DS?*

Body Language

Using good posture
Facing the person
Keeping a comfortable distance
Making eye contact

Classroom Skills

Listening to the teacher
Doing what the teacher asks
Doing their best work
Following class rules
Following the class schedule

Conversation Skills

Beginning and ending a conversation
Using a pleasant voice
Listening attentively
Taking turns talking
Asking and answering questions

Conflict Skills

Giving criticism
Coping with anger
Negotiating
Responding to teasing

7 0% of adults with Down syndrome are underemployed or unemployed. The #1 issue contributing to this is the inability to consistently exhibit many of the social skills identified in this article. Students with Down syndrome who exhibit these abilities are much more likely to succeed in school, the community and the workplace.

Participation Skills

Joining activities already in progress
Taking "no" for an answer
Following rules

Cooperation Skills

Asking for help
Accepting help
Showing respect
Following rules

Friendship Skills

Using polite words
Appropriate touching
Sharing
Apologizing

Time Management Skills

Following schedules
Using time wisely
Transitioning between activities smoothly
Finishing tasks

Thank you to Inclusion Solutions from the DSG of Kansas City for this article

Down Syndrome Guild Teen Dance hosted by Cisterian Prep School



These two photos certainly reveal that a great time was had by all at the DSG Teen Dance on March 2, 2007, hosted by Cistercian Prep School.



(Pictured above from L to R) Jessica Smith, Austin Davenport, and Cindy Johnson, three self-advocates, read children's books related to Down syndrome at a dedicated story time at the Barnes & Noble on Northwest Highway and Central Expressway on March 10, 2007. As you can see from the photo on the right, many families took part in the story time.

Barnes & Noble Recognizes People with Down syndrome at a Special Story Time



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En Español 972-248-6845

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

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Our calendar in May shows that Katie and Madison are ready for play.

May 2007 Down Syndrome Guild Calendar

May 10

Adult Issues Meeting

May 14

Board Meeting

May 20

Deadline to Apply to Have Your Child's Photo Featured in the 2008 DSG Calendar

May 20

Meeting of Parents of Babies & Young Children

May 31

Deadline to Return Your Membership Renewal Form

May

Mom's Escape - *Check the Website or Call the Office for Date and Time*

Calendars are still available for sale. Contact the DSG office to place an order.

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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 MINNIEBLACKWELL@TX.RR.COM.