

THE

DSG News

PEOPLE WITH DOWN SYNDROME - VALUED AND INCLUDED

April 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

DSG Annual Spring picnic

Sunday, April 29, 2007
1:00 pm to 5:00 pm
lunch will be served

from 1:30 pm to 3:00 pm

Park Lane Ranch (NEW LOCATION!)

8787 Park Lane in Dallas

www.parklaneranch.com

(located just west of Abrams Road on the north side of Park Lane)

The DSG picnic is one of our most popular events! You will have the opportunity to visit with friends, old and new. At this year's event there will be new



Photo courtesy of Park Lane Ranch

activities – miniature golf, mini arcade, Bingo, arts and crafts, petting barnyard, basketball hoop shot and batting cages – fun for every member of the family. This event is free for member families, but we need reservations – include the number of adults and children who will be attending. You may renew your DSG membership at the picnic – dues for 2007-08 are \$25/ family.

Please make your reservation by e-mailing dsged@sbcglobal.net or by calling 214-267-1374 no later than Wednesday, April 18, 2007.

Young Adult Bingo & Pizza Night

Saturday, April 14, 2007
4:00 pm to 7:00 pm
at the office of the
Down Syndrome Guild of Dallas
701 N. Central Expressway Suite 5-I
Richardson, TX 75080

Come join other DSG Young Adults (ages 18+) as we play all types of Bingo – Regular, Blackout, Texas T, 4 corners.

Pizza will be served.

There is no cost for this program – just bring a \$5 unisex prize

RSVP is a must to Becky Slakman at 214-267-1374 or dsged@sbcglobal.net.

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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 214-267-1374 or dsged@sbcglobal.net. Hope to see you this month!

From the Board President

By Elizabeth Longworth

With April being National Volunteer Month, I want to thank everyone who volunteers their time to the DSG. Our success depends upon us working as a team which we have proven time and again. Thanks to our many volunteers, we have wonderful programs such as IEP Clinics, a new DSG Newsletter, an updated website, Mom's Night Out, Parent-Infant Coffees, Fall Conference, Spring Picnic, DSG calendar, teen dances, young adult outings, adult issues support group, DS Clinic and much more. Our amazing volunteers also made our 2006 Buddy Walk, Golf Tournament and Fashion Show great events. We truly owe our volunteers a debt of gratitude!

The change from an all-volunteer organization to having paid staff is a very exciting time for the DSG! Our volunteers have worked hard to attain

this vision, and it's wonderful to see it realized. I hope you will drop by the office and meet Becky Slakman, our Executive Director, and Jennifer Miller, our Administrative Professional. They have great spirit, energy, skills and commitment to the success of the DSG.

Continuing on with the spirit of volunteers, I recently had the pleasure of attending the annual *Inclusion Works!* Conference in Austin. It was insightful, educational and inspiring. *Inclusion Works!* is not only about inclusive education, but about adults with developmental disabilities living, working and playing in the community with their family members and non-disabled friends. The professionals that spoke at the conference are truly dedicated to making the world a better place for all people with disabilities. I really encourage you to attend this wonderful conference next February.

I'll leave you with one of my favorite quotes by Margaret Mead - "*Never believe that a few caring people can't change the world. For, indeed, that's all who ever have*".

I hope to see you all at the Spring Picnic!

DSG Wish List

Maybe you can help! The DSG is always in need of small and large donated items. Check this space each month to see if you have a gently used or brand new item on the list that you would like to donate. This month's needs are:

- New or gently used toys (must be able to be sterilized) to have at the office for children to play with when they are there
- Laser color printer
- Blank CD-R's
- CD holders
- Ink cartridges for HP 5610xi Officejet Printer

Club 21 Program

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

What's New On Our Website

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

- ◆ **It's Time to Renew Your DSG Membership!**
- ◆ **NDSC and NDSS' Responses to Prenatal Testing for Down syndrome**
- ◆ **George Will's Newsweek Response to Prenatal Testing for Down syndrome**
- ◆ **Have Opinions About People with Disabilities Changed Over 45 Years?**
- ◆ **Stanford Research Drug Findings**

www.downsyndromedallas.org

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 example, the Jones' want to celebrate that their child just began walking. They send a check for \$84 with the information they want to celebrate. The *DSG News* lists under *Club 21* a statement that says: "Jim and Joan Jones – to honor their daughter Jennifer's first steps." *continued on next page*

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Or if Jim and Joan had their 50th wedding anniversary, their good friends John and Mary Smith could honor them with a donation to *Club 21*. John and Mary might send a check to DSG for the amount of \$42. Along with the check, they would provide Jim and Joan's full name and address, as well as their own. DSG would send a letter to Jim and Joan telling them that John and Mary sent a donation honoring their anniversary. DSG would also send a thank you/receipt to Jim and Joan. We in turn would list under *Club 21* – "John and Mary Smith – honoring the 50th anniversary of Jim and Joan Jones."

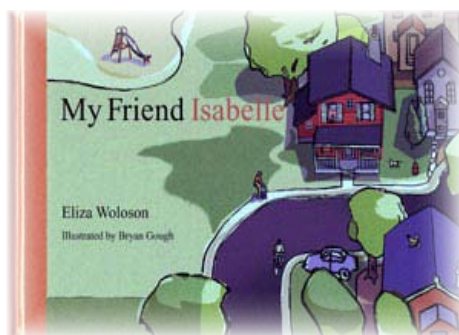
For questions or credit card *Club 21* "membership," please contact Becky Slakman at the DSG office at 214-267-1374 or dsged@sbcglobal.net or mail checks to the office with the appropriate information.

2008 Calendar Applications Needed Now

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 at 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 Tuesday, May 15, 2007.

In Our Library



The Down Syndrome Guild has an extensive library with up to date material on Down syndrome and related topics. In addition, we have many children's books at various reading levels that relate to Down syndrome. Material may be checked out by phoning the office and asking that a book be mailed to you, or you may come in Monday through Friday 8:00 am to 5:00 pm and look for something yourself.

One of the books in our collection, *My Friend Isabelle*, is labeled as appropriate for ages 2 to 6. It is new to our library and was recently donated by Barnes and Noble on Northwest Highway in Dallas.

My Friend Isabelle is written by Eliza Woloson and illustrated by Bryan Gough. Isabelle and Charlie are friends. They both like to draw, dance, read, and play at the park. They both like Cheerios, but like most friends they are also different from each other. Isabelle has Down syndrome. Charles does not. This book encourages us to think about why friendships are special and how our differences can make the world more interesting.

It's 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 renewal form (in English and Spanish) can also be found on the DSG website at www.downsyndromedallas.org. To be included in the new membership directory, you must return your membership form by May 31, 2007. If you have questions about membership, contact Minnie Blackwell at minnieblackwell@tx.rr.com or 972-239-8771.

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.

Cervical Spine Instability in Down Syndrome

By Joanna Spahis, RN, CNS, APNG

Down Syndrome Clinic, Children's Medical Center Dallas

Individuals with Down syndrome (DS) generally have more flexible joints and ligaments than other individuals, due to the hypotonia associated with this condition. This may include the ligaments that support the spinal cord, and can cause the person with DS to be at greater risk for spinal cord injury. It is estimated that approximately 10-15% of people with DS have this condition, called either “atlanto-axial instability” (AAI) or “atlanto-occipital instability” (AOI), but that only about 2% actually have symptoms related to spinal cord compression. Cervical spine instability is especially important to consider in the case of injury to the head/neck area or when the individual with DS needs to have any procedure where the neck is extended back or forward beyond the normal range of motion.

Q: How is screening for cervical spine instability done?

A: Screening for this condition is done by means of a series of radiographs (X-rays) of the upper (cervical) spine in neutral, flexion and extension positions sometime after age 3 years. Then very small measurements are made between the occiput (base of the skull) and first cervical vertebrae and between the first and second cervical vertebrae in the above positions. A space of over 5 mm is considered significant. If there is too much space between the occiput and first vertebrae, it is called “atlanto-occipital” or “craniovertebral” instability. If there is too much space between the first and second cervical vertebra, it is called “atlanto-axial” instability.

Q: What is recommended if a person has cervical spine instability?

A: Individuals who are found to have AAI or AOI are advised not to participate in certain physical activities, including gymnastics, horseback riding, diving, trampoline and competitive contact sports that might put them at risk of head or neck injury. Children with instability are usually checked again a year or two later to see if anything has changed. If the ligament laxity (looseness) is severe or does not improve after several years, surgery may be performed to stabilize the spine, but this is not common. The recommendations for screening and for restriction of some activities continue to be controversial.

Q: Why is the screening and management of cervical spine instability so controversial?

A: The radiographs are often difficult to obtain, due to unwillingness of the child with DS to cooperate. They may not be read by qualified pediatric radiologists, which could lead to missed cases. The measurements are made in millimeters and can possibly change over time (becoming better or worse). More accurate tests for this condition include fluoroscopy, CT scan or MRI, but these are quite expensive. It is also not known for certain if cervical spine instability without symptoms will later show symptoms. Some doctors feel it is too extreme to restrict people with DS from certain sports if they have no neurologic symptoms, no matter what the results show.

Q: What are some possible symptoms of spinal cord compression?

A: Any of the following signs/symptoms could mean that the spinal cord is being compressed or pinched and should be reported to a physician immediately: persistent head or neck pain, torticollis (twisting of neck to one side,) sudden weakness or paralysis of arms or legs, sudden difficulty or inability to swallow, change in the pattern of walking or refusal to walk, loss of bowel/bladder control. It should be noted that very young children and those who cannot communicate may not be able to talk about specific complaints such as those listed.

Q: What activities and procedures should be avoided if there is evidence of cervical spine instability?

A: The American Academy of Pediatrics Committee on Sports Medicine advises restriction from activities that could cause injury to the neck or spine, such as contact sports, gymnastics, trampolines, diving and horseback riding. There are also medical procedures that need to be modified if a person has cervical spine instability, such as neck manipulation during anesthesia, dental procedures and even the instillation of eye drops! In general, the neck should be protected and not extended backward or flexed forward beyond what is comfortable for the person to do himself.

Q: What else does research on this topic show?

A: There may be other ways to determine which individuals are at risk for spinal cord compression. Instead of

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measuring the distance between the cervical vertebrae, some radiologists feel that a more useful predictor of cord compression is to calculate the amount of space in the neural canal. It has also been suggested that physicians rely not only on radiographs, but on physical exam and neurologic symptoms as well.

“The Preventive Medical Checklist for Down Syndrome” currently recommends cervical spine screening at age 3 years. It is not done before this age because the cartilage in the spine has not fully changed to bone and results can be unreliable. Cervical spine radiographs are also required before children with DS begin to participate in Special Olympics.

Actual findings from over 600 children seen in the DS Clinic at Children’s Medical Center of Dallas who have been screened show that about half who show c-spine instability on their first screening for this problem are negative when screened a year or more later. New research may indeed change the recommendations now in place for detecting cervical spine instability.

Translators Wanted

The Down Syndrome Guild is looking for a translation service or individual professional English to Spanish translators. If you have had personal experience with any individual or group with whom you have been pleased, contact the DSG office with your reference by calling Becky Slakman at 214-267-1374 or via e-mail at dsged@sbcglobal.net.

Where There's a Will There's a Way *By Nancy Davenport*

One of the perks of writing a newspaper column is that I meet interesting people whom I might not ordinarily have the opportunity to meet. When my son was in high school, Diane called long distance often. We both had teens with disabilities, so we not only hashed out problems of kids with disabilities, but we also tried to keep from going nuts because they were teens.

With one call, I learned that Diane’s daughter, Emily (both names have been changed), had begun stealing. Twice she had taken wallets of girls—once at school and one in her home—and secreted them away in her dresser. Each time, Diane discovered the stolen items when she was putting away the laundry in her daughter’s room. Neither time did Emily spend any of the money that was in the wallet.

Diane had two concerns. First, of course, was how to get her daughter to stop wanting to steal; and second, she was terrified about the consequences that could rain upon Emily if the school authorities found out about the theft at school. Her school’s principal was not sold on educating a student with disabilities along side typical students and would have loved to have an excuse to kick her out.

It is interesting that when Diane returned the wallet to the mother of its owner, that mother mentioned the same potential danger of Emily getting removed from school. The mother said she so valued the experience for her daughter to be around Emily that she would simply report that the wallet turned up and to call off the search. She knew that Emily was not a thief and that something else was going on in her head.

So what was going on in her head? Diane’s daughter has trouble communicating verbally, so it was difficult to sit down and hash it out in discussion. In our phone conversation we discussed several possibilities.

Diane’s household would be considered well-to-do, so desire for more money was not the root. Desiring attention was possibly the answer since the wallets were so easily found. Vicarious enjoyment while pretending to be the owner of those wallets was another thought. Emily possibly found it appealing to pretend that all those pictures in those wallets were her friends.

Those trails of thought ended up naturally in a conversation about low self-esteem—a plague to many teenaged girls.

To start with, Diane said she would try to help her daughter have more friends at school beginning with someone with whom she could eat lunch.

Second, Diane concluded that her project for a while would be to find something great upon which to have Emily build her self-esteem. Diane concluded that she needed to find something her daughter already does well and help her be “the best.” Experts say everyone needs to have something they do exceptionally well, so when their ego is attacked in academics or athletics or social situations or in some other area, they know they still are a great stamp collector or bowler or artist.

In addition to building her friendships and self-esteem, Diane felt that no matter what the reason Emily had for stealing, she must endure some direct

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consequences for her actions. In the spirit of the punishment fitting the crime, Diane decided to “ground” Emily for two weeks from the use of two things which are precious to her—a beloved jacket and a pair of newly acquired running shoes. This way Emily could possibly feel the loss that the other girls had experienced at her hands.

Of course, there is never one clear answer anytime we parents come across a problem like this one. It’s not any more perplexing than working with an “A” student who cheats on a test or a talented athlete who enjoys putting others down.

We all keep trying solutions hoping one will hit the target. Knowing Emily now a few years later, it is clear these tactics were successful in helping her find her way.

H₂OPE Program

H₂OPE is a fun, community outreach aquatic fitness program for children with special needs. H₂OPE provides an alternative recreational activity to help meet physical, cognitive and psychosocial needs emphasizing fun, safety and non-competitive and successful experiences. This is a grant-funded program with **no cost to the caregiver**. Register online at differentstrokesswimschool.com. 2007 Classes begin in April and run through October. For more information please call Bev at 817-649-SWIM.

In the Community

The following workshops are being offered by the ARC of Dallas.

For additional information or to RSVP, contact April Allen at aallen@arcdallas.org or 214-634-9810 ext. 106.

Behavior Management

Speaker: Tammy Cline
Saturday, April 14, 2007
9:30 am to 11:30 am
Region 10 Education Service Center
Richardson, TX

Teaching Social Skills

Speaker: Courtney Boggs
Saturday, April 21, 2007
9:30 am to 11:30 am
Arc of Dallas
12700 Hillcrest, Suite 200
Dallas, TX

Supplemental Security Income

Speaker: Angie Hoquang
Saturday, April 28, 2007
9:00 am to noon
Greer Learning Center
510 Heard Street
McKinney, TX

Recruiting Adolescents for a Study of Brain Function in People with Down Syndrome

Greg Allen at UT Southwestern Medical Center is researching brain function of people with Down syndrome. Participants will undergo magnetic resonance imaging (MRI) of the brain at rest as well as while engaging in visual and motor tasks. The purpose of this research is to study how brain structure and function affect people with Down syndrome. We hope that this research will open the door for future studies examining the impact of clinical interventions on brain functioning and improved quality of life in people with

Down syndrome. If your child has Down syndrome, is 12–17 years old, right-handed, and interested in participating in this research, please contact us to see if your child is eligible. Participants will be compensated for their time.

Contact Information:

Kami Vinton
(Research Assistant to Greg Allen, Ph.D.)
UT Southwestern Medical Center
Department of Psychiatry
(214) 645-2767
Kami.Vinton@UTSouthwestern.edu

PAT WINDERS, PT GROSS MOTOR SKILLS for children with Down syndrome

Saturday, April 28, 2007
9:00 am to 1:00 pm
at The RISE School
Located in St. Luke’s Episcopal Church,
5923 Royal Lane, Dallas, TX 75230
FREE pre-registered child care
and refreshments
Cost: \$10 per individual or couple

Pat Winders, PT is a Senior Physical Therapist at the Down Syndrome Clinic at Kennedy Krieger Institute in Baltimore, MD. Since 1981, she has specialized in providing PT to children with Down syndrome, ages 0-5 and is the author of, *Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals*.

Fill out a registration form that you can find on the DSG website or call Angela at 214-546-0507. Registration form with payment must be received by April 20th.

RDC for Children Breaks Ground

Congratulations to Kay Hopper, Executive Director and the Board of RDC for Children on the groundbreaking for their new building in Richardson. This ECI group has worked tirelessly and waited long for this moment.

Down Syndrome Guild Photos



◀ The DSG's young adult Buddy Walk teams celebrate at Trail Dust Restaurant.

✔ The Rockin' Walkers team raised over \$10,000 and took the second place prize!



✔ There's no escaping it. These moms and others enjoyed themselves at Americas Latin Cuisine & Tapas on McKinney Avenue in Dallas February 21, 2007. Manager, Alfredo Medina, who has a sister with Down syndrome has as much fun as anyone.



▲ Many beautiful faces showed up at the Parent-Infant meeting February 18, 2007.



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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 little Miss April is ready for Spring.

April 2007 Down Syndrome Guild Calendar

April 9

-Board meeting at DSG office, *Open to members*

April 14

-Young Adult Bingo Night
-Behavior Management, Arc of Dallas

April 21

-Teaching Social Skills, Arc of Dallas

April 22

-Spring Picnic and Annual Meeting

April 28

-Supplemental Security Income, Arc of Dallas
-Pat Winders speaking at RISE School

April

-Mom's Escape, *Check website or call office for date and location*

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

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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 MINNIEBLACKWELL@TX.RR.NET.