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DOWN SYNDROME CLINIC EVERY FRIDAY
AT CHILDREN'S MEDICAL CENTER.
CALL (214) 456-2357

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DOWN SYNDROME GUILD OF DALLAS

This month on the DSG Calendar, Zoe and Kyla Postert show us how to share.



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

September

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

September 4

Showing of Movie *Praying with Lior*

September 8

Board Meeting

September 10

Mommy and Me Class Begins

September 16

Golf Tournament

September 18

Adult Options Meeting

September 21

Rally at the Denton State School

September 27

Fall Education Conference

November 9

Buddy Walk

THE DSG News

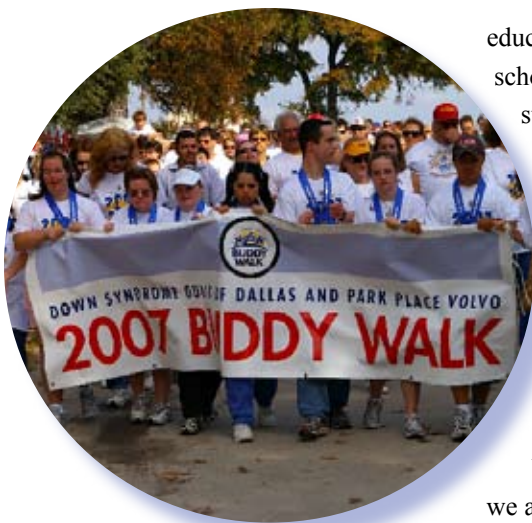
PEOPLE WITH DOWN SYNDROME – VALUED AND INCLUDED

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

September 2008

Affiliate of the National
Down Syndrome Congress
and the National Down
Syndrome Society

Buddy Walk 2008 Coming Very Soon



Sunday, November 9
Flag Pole Hill at
White Rock Lake
8700 E. Northwest Hwy.
Dallas, TX 75238

Activities begin at 11:00 am
Walk begins at 1:00 pm

The Down Syndrome Guild's biggest fundraising event of the year, the Buddy Walk, is only 2 months away! We are pleased to be partnering with Park Place Volvo again this year to bring you a fun-filled day including bounce houses, obstacle courses, slides, music, a petting zoo, food, and most of all friends - old and new.

Buddy Walk Challenge

The Buddy Walk raises funds to support the programs of the Down Syndrome Guild of Dallas, including

educational seminars for the families of school age children, parent to parent support, options for adults, and social events for all ages. Our goal this year is to double the donations and sponsorships we had last year. We need your help. So the *Buddy Walk Committee* is challenging each of you to double the funds you and/or your team raised last year!

Ready to start your team?

Whether you are a pro or a first timer, we are ready to help you! When you are ready to form a team for this year's Buddy Walk – and once again this year there will be prizes for the teams that raise the most money – you can go to the Down Syndrome Guild of Dallas website, www.downsyndromedallas.org and download team forms and return them to the office. It's never too early to get your team together and start raising money and promoting our goals of awareness, acceptance, and inclusion of people with Down syndrome!

We are still looking for corporate sponsorships - if you, your company, or anyone you know is interested in sponsoring the Buddy Walk, please Becky Slakman 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!

Simple Steps for Making a Buddy Walk Donation Online

1. Go to our website at www.downsyndromedallas.org.
2. Click on “*Donate Now*” in the top right corner.
3. Complete the contact information.
4. Scroll down to gift information.
5. Drop down to ***Buddy Walk***.
6. Write the name of team donating for in the “*comment box*.”

Inside This Issue:

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Tips for Building a Buddy Walk Team

Get everyone involved:

1. Family
2. School
3. Neighborhood
4. Business
5. Community

Tips for Raising Money for Your Team

- Day 1: Start by sponsoring your self for **\$25**.
- Day 2: Ask three family members to sponsor you for **\$25**.
- Day 3: Ask five friends to sponsor you for **\$20**.
- Day 4: Ask five co-workers to sponsor you for **\$10**.
- Day 5: Ask five neighbors to sponsor you for **\$10**.
- Day 6: Ask five people from your church/temple/mosque to sponsor you for **\$10**.
- Day 7: E-mail 15 people and ask for a **\$20** donation.
- Day 8: Ask five businesses you patronize for **\$25**.
- Day 9: Ask your company for a matching donation.

Wow, you raised **\$775** plus a company match!

Executive Director's Message By Becky Slakman

I recently returned from the 36th Annual National Down Syndrome Congress Convention in Boston.

The quality of information was unbelievable. World renowned professionals were sharing their knowledge and the sessions were very informative.

In attendance were over 2700 parents, educators, and professionals. There was a young adult tract that had over 275 attendees from all over the United States and Latin America. Many of these individuals are attending college, gainfully employed, and living independently. I attended several sessions on inclusive education. The most powerful session I attended was titled ***"Inclusion Does Work! Inspiration and Information to Counter the "Push-back" against Inclusive Education"*** presented by Cheryl M. Jorgensen, Ph.D., Assistant Research Professor and Project Director, Institute on Disability, University of New Hampshire. Her theme for parents is the importance of literacy and that all children with Down syndrome MUST learn to read as soon as they are able. Dr. Jorgensen stated, *"In grades Kindergarten through 3 we learn to read, grades 4 throughout our life, we read to learn."* How true is that statement!

Another fact repeated throughout the weekend was *"the key to a child or young adult being included in education and community is knowledgeable and well informed parents."* If you haven't been to the NDSC convention in a while or have never been, I suggest that you consider attending. For those of you who like to plan ahead next year's convention is July 31 – August 2, 2009 in Sacramento, California.

The Down Syndrome Guild of Dallas has many opportunities for you to increase your knowledge locally - enabling you to advocate for your children from infancy through adulthood. I look forward to seeing you at our Fall Conference *"Learning Together – Focusing on Possibilities."* Maureen Tignor, Kelly Kile and their committee have worked very hard to bring you presenters whose topics will guide you from infancy through options for adults. Don't forget to invite your child's teachers.

Stay tuned for more information on our winter IEP workshops. Carrie Park has lined up a great series that will kick off in 2009. January's topic is *Inclusion: From Law to Implementation*, March will be *Developing and Understanding Behavior Intervention Plans (BIPS)*, and we will conclude our series in April with *Facilitating Friendships and Ways to Include Friendships in Your Child's IEP*. Kathi Hutchins, Sherri Munn and their committee have recently completed a Resource Guide for families of adults with Down syndrome. They also continue to offer quarterly informational programs on a variety of topics particularly for the parents of adults. Please plan to attend as many of these seminars as you can.

I will close with a quote that I recently saw. Believe it or not, it is an Adidas print ad:

"Impossible is just a big word thrown around by small individuals who find it easier to live in the world they've been given than to explore the power they have to change it. Impossible is not a fact. It's an opinion. Impossible is not a declaration. It's a dare. Impossible is potential. Impossible is temporary. Impossible is nothing."

Change Won't Happen Without YOU!

Have you heard about the 10 year waiting list for people with Down syndrome and other developmental disabilities to receive the services they need in the communities where they live? Have you read the series of articles in the *Dallas Morning News* about the abuse of residents at the Denton State School? Now YOU have an opportunity to change this critical situation.

Under the leadership of Community Now!, the Down Syndrome Guild of Dallas along with several Metroplex area disability and civil rights organizations have collaborated to plan a Rally and Press Conference in front of Denton State School. The purpose of this effort is to generate media coverage to convince voters and their elected state representatives to:

- *End the violence and neglect at the Denton State School*
- *Provide funding for any resident of a Texas State School who wants to move out*

- *Develop a plan to consolidate unnecessary state school facilities as the institutional population decreases*
- *Redirect the funding to community-based services and programs*

All DSG families and their children of any age are urged to join this important event – the bigger the crowd the more impact this rally will have! Let us know if you are interested in participating with us.

When: *Sunday, September 21st at 2:00 pm*

Where: *Entry Gate of the Denton State School*

Details: *Contact Becky Slakman at (214) 267-1374 or dsged@sbcglobal.net*

For additional information about Community Now! visit their website at www.CommunityNowFreedom.com. To learn more about the violence at the Denton State School, read the July 31, 2008 *Dallas Observer* article entitled, "The Caretaker" by Jesse Hyde at www.dallasobserver.com.

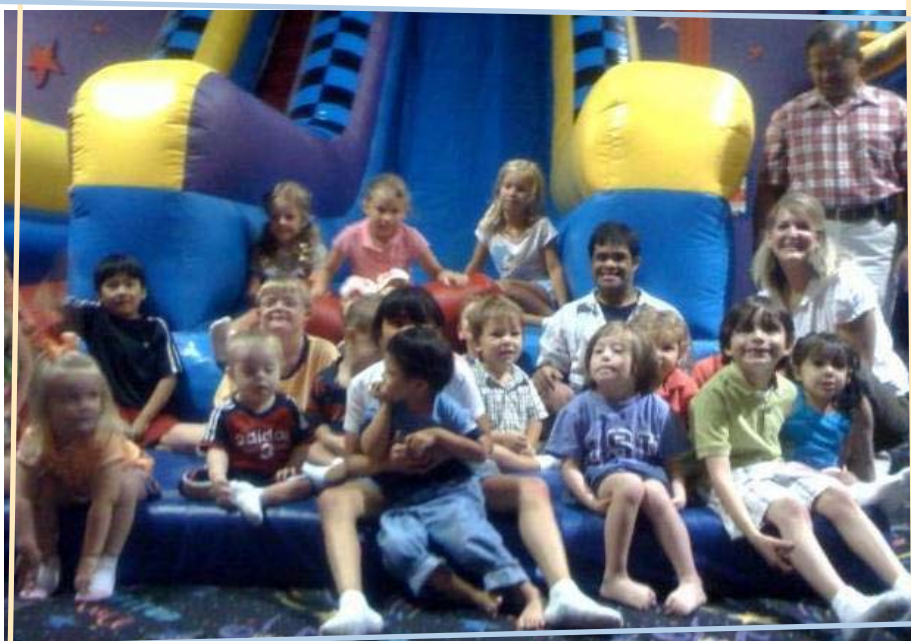
“When we heard that our son had Down syndrome, it took our breath away. Since then, our experience has been breath taking.” - from a parent at the July 2008 NDSC Convention

2008 Herb's Paint and Body/Down Syndrome Guild Golf Classic

Tuesday, September 16
Canyon Creek Country Club

625 W. Lookout Drive
Richardson, TX 75080
\$175 entry fee

To join us to play golf or to be a sponsorship, contact the DSG office as soon as possible. If you are not a golfer come anyway at 6:00 pm to the dinner and silent auction for \$25. There are always many valuable items going for bargain prices. We hope to see you there! Contact us at the DSG office to participate in any way at (214) 267-1374 or dsged@sbcglobal.net.



These kids had a fun-filled day with dad at the Dad's Group outing on Sunday, June 22, 2008, at Pump It Up in Plano.

GREAT WAY TO HONOR LOVED ONES

Club 21

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

To: Austin Davenport
Happy Belated Birthday.
From: Marilyn Elliott

To: Karen & Paul Lowe
In Memory of Betty Otis.
From: Helen & Wayne Sorenson

To: The Lowe Family
In Memory of Betty Otis.
From: Helen & Wayne Sorenson

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

“If you haven't met someone with Down syndrome, you don't know who you are missing.” - from a professional at the July 2008 NDSC Convention

In the Community

Pfamily Arts

Shining Stars---An Inclusive program September through December, Saturday at 9:00 am or Monday at 4:00 pm

PFAMILY ARTS is pleased to announce a new FREE offering for children and adults with disabilities. This program will have volunteer students without disabilities participating along side their peers with disabilities. Shining Stars goal is to develop self confidence, physical coordination, social awareness, and self esteem through creative drama and movement all based in music through the wonderful world of Music Theater. This class provides a wonderful opportunity for your shining star to open up and express themselves in a positive nurturing environment and to experience the thrill that only the stage can provide. We know what it's like to take our kids from therapy to therapy, so we decided to make Shining Stars FREE as you already pay enough. All instructors have Masters Degrees in Fine Arts or Music or have significant professional performing credits. (The lead instructor and founder of PFAMILY ARTS is a DSG member and father of Mr. November in the 2008 DSG Calendar.)

For more information contact Pfamily Arts at (972) 379-1234. They are located in Plano at Lakeside Market, 4017 Preston Road #544.

Brown Bag Lunch Series

They're back! The Arc of Dallas and Advocacy, Inc. are teaming up again this fall to offer the popular "Brown Bag Education Power Lunches." These sessions are 45 minutes of slam-bam-just-the-facts-no-fluff information on how to get your child the best education possible. Each session tackles a different education topic.

The workshops are held on the first Friday of the month starting at noon and

conducted by Advocacy Inc.'s Elise Mitchell.

Friday, October 3, 2008
Basics of a good ARD meeting

Friday, November 7, 2008
Successful IEP's

Friday, December 5, 2008
Discipline issues

The "Brown Bags" will all be at The Arc of Dallas, 12700 Hillcrest, Suite 200, Dallas, TX 75230. Please make your reservation for the free workshops at info@arcdallas.org with "Brown Bag" in the subject line or call (214) 634-9810. We need an accurate count to prepare handouts.

Adventure Series

For families living in McKinney, the Arc of Dallas has created a new afterschool program for students with developmental disabilities. There is an "Adventure Club for Teens!" just for students 13 to 21 and an "Adventure Club for Kids!" designed for students 5 to 12. The clubs operate from 3:00 pm to 6:30 pm on days when school is in session. McKinney school buses will provide transportation from the students' schools to the clubs' site at Slaughter Elementary School.

Also joining the "Adventure" series is the new "Adventure Nights!" Each month parents of children ages 5 to 21 can have a night of adventures all to themselves knowing that their loved ones are in good hands. Thanks to Northhaven United Methodist Church (in north Dallas between Forest and Royal on Preston Road) for helping make this special needs childcare program a reality.

For information on the new *Adventure!* programs, contact April Allen at (214) 634.9810 or aalenn@arcdallas.org.

Award Winning Documentary Film

Praying with Lior
 Thursday, September 4, 2008
 7:00 pm Angelika Theater
 at Mockingbird Station
 5321 E. Mockingbird Ln., Ste. 230
 Dallas, TX 75206

In cooperation with the Jewish Community Center, 3starscinema, and the Special Needs Initiative of the Jewish Federation of Greater Dallas, the Down Syndrome Guild of Dallas is proud to co-sponsor the Dallas premier of *Praying with Lior*. This multiple award winning documentary is currently being screened all over

the United States.

Lior Liebling has Down syndrome and has spent his entire life praying. Some call him a “spiritual genius,” others a vessel of unfulfilled wishes. Lior, whose name means “my light,” shares part of his life with film viewers as he prepares for his Bar Mitzvah. Ilana Trachtman, the film’s director, will be available to address the audience after the screening.

Tickets \$9 must be purchased in advance by ordering through www.3StarsCinema.org.

Don't Forget to Register for the DSG 2008 Fall Education Conference

Learning Together –
 Focusing on Possibilities
 Saturday, September 27, 2008
 9:00 am - 4:00 pm
 Crowne Plaza Suites Hotel - Dallas
 7800 Alpha Road
 Dallas, TX 75240

Parents and educators will come together for a day of learning how to increase student achievement including:

- Concrete strategies that support students in inclusive classrooms
- How to build collaborative relationships between families and educators
- What is possible for the student as s/he leaves the school system

Join the Down Syndrome Guild for the 2008 Fall Education Conference and experience first class presenters and hands-on sessions full of information you can take back to your home and

classroom immediately. There will be plenty of opportunities to network with fellow conference participants and to shop our resource fair for products, services, and information that will help parents and educators support your children both at school and at home.

Speaker bios and session descriptions, along with registration information can be found on the DSG website. Space is limited, so register now. For additional information, contact Becky Slakman by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.

Note: The DSG has a small block of rooms reserved for attendees who wish to stay overnight before the conference. Call (972) 233-7600 to make your reservation. Reference code DDS to receive a special \$89 rate.

Best Buddies - Meeting and Sign-up

Thursday, September 18
 6:00 pm - social time
 6:30 pm - program
 The Warren Center
 320 Custer Road
 Richardson, TX 75080

The Down Syndrome Guild is excited to again partner with the Southern Methodist University chapter of the Best Buddies program for our member families with young adults - ages 19 and up. Sylvia White, Program manager for Best Buddies in our Texas area, will be our guest. She will answer questions about how the program operates, how to initiate communication with your buddy, and how we can make our chapter successful, fun and meaningful for everyone!

Parents and self-advocates are invited to attend this important meeting to fully understand the Best Buddies program and the time commitment required before signing up. Please plan to attend this important meeting. This will also give you the opportunity to get your paperwork in promptly! RSVP to Becky Slakman by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.

Growing Up With Grace *By Mackenzie Kile, daughter of Kelly and Bruce Kile*

From the moment the twins were born, I recall feeling as if nothing was amiss—well except for the fact that the princess of the house had just been de-throned. As I sulked on the way to the hospital in my papa’s white truck which I had named Tommy, I wondered how different life was going to be now—a brother and a sister—Tad and Grace. That was quite a bit to comprehend. The twins didn’t start off well in my book, may I just say—just born and already starting their sibling duties of “ruining my life.”

After the twins came home, there were always a lot of people at our house helping my mom with the twins. I tried to get their attention by dancing, singing a song, or doing anything interesting. Of course I resented them for booting me from my throne and taking a lot of the attention off me, but I was enamored with being an “older” sibling, most of the time at least. That doesn’t mean I didn’t try to take the focus off them and back onto me though. God knows I did that every single day. It’s funny to go back and watch old family videos of Tad and Grace’s first birthday, and my dad is filming them playing with their cake. Of course you could hear me in the background hollering at him to watch me because I had a new trick.

As Gracie got older, she got sassier and meaner just as normal siblings do. I remember one time in particular she was bothering me while I was listening to music. So of course I turned it up as

loud as it would go and made her listen to it. After I finished I asked her how she liked it, and she didn’t answer. So I asked her again. No answer.

I thought to myself, “Oh crap, what if I caused her to go deaf. Not only does she have Down syndrome but now she is deaf. I am going to get in so much trouble.”

As I worried to myself, a whiny voice broke through the thick silence.

“I am ignoring you, because you are rude,” and she just marched out as sassily as she could manage.

Looking back on that it makes me laugh. It never really hit me until the fall after I turned sixteen. We were at the playground, and I was watching Grace entertain herself. Then some more kids came to the playground. I just sat there and watched her interact with those kids, and got really sad. It’s not like they were being mean, they were just shooting each other looks. You know what I’m talking about—THE look. I don’t know how else to describe it. All of a sudden a tidal wave of sixteen years of sadness washed over me. I can’t count the number of times I’ve buried myself in my bed and cried because I was so afraid and upset about what Grace has in store for this life. I guess that’s why I decided to write this, not only is it good for me, but if anyone else ever reads it then they can understand that they are not the only one feeling this way.

Then we have the other days, when Grace and I can play for hours, and talk

about hot boys and kissing them and girly things like that. It’s those times that make the screaming fests worth it. As I look back at all I’ve written it seems to paint this morbid and dark picture. And you know what maybe it is. I don’t really know, but our lives have been so enriched and blessed by Grace, it’s unbelievable. Even if I’m mad at her and don’t want to admit it, I still understand that.

She is a breed of her own—outgoing, warm, funny, sassy, sweet, smart, beautiful, and loving. She can walk into a room, and it automatically brightens. She’s not afraid to help comfort people if they need it, even if it is in her own special way. She is Grace in every sense of the word, and I am proud to say that she is my sister. I know that no matter what, she will always have me, and I will always have her, so everything will turn out okay. There is hope, I think. I’ll get back to you when I know for sure. All I know is that you have to keep on.

*From the DSG News editor:
Seventeen year old Mackenzie Kile is from Richardson TX. Unfortunately because of space in this issue, we had to edit out quite a bit of Mackenzie’s remarkable and unique perspective on life with a family member with Down syndrome. To read the complete unedited version, go to the DSG website at www.downsyndromedallas.org.*

Parents as Partners of the Health Care Team *By Joanna Spahis*

Parents play a crucial role in the quality of life of their children, especially those who have special health care needs. In addition to the universal needs of food and shelter, parents must be advocates for the best therapy, the best education, and the best medical care that is available to their child. They determine which health care providers the child sees and how often. They must give love as well as discipline in the right amounts at the right time to shape the child's behavior. Parents must plan ahead for their child's future, in terms of housing, guardianship, job training, and financial security. The following are suggestions for just one aspect of parenting - that of being a respected partner on their child's health care team.

Q: How do I find the best primary care doctor for my child?

A: Talk to other parents in your area who have children with Down syndrome or similar health issues. Ask your obstetrician/gynecologist who they recommend. Contact me at the Down Syndrome Clinic at (214) 456-2017. If you have a list of providers through your insurance company, have that handy for reference.

Once you find a doctor or nurse practitioner, talk to them by phone or in person. Ask them how many patients they have had with special needs, and if they feel comfortable taking care of children with DS. Mention if there was someone who referred you to them.

Don't be afraid to change health care providers if they seem uninterested, do not give your child adequate time or attention, do not listen to your concerns, or fail to provide referrals to recommended specialists. This will be

a valuable long term partnership so take your time finding the right person!

Q: What can I do to be better prepared for visits to my primary care doctor or to my child's specialists?

A: Be on time for your appointment, or call well ahead of time to cancel it. Write down your questions/concerns before the visit. Prepare a list of current medications your child is taking, including the doses and schedule, and any allergies to food or medication.

If your child is seeing a specialist, make sure your primary care doctor has sent a referral authorization if your insurance company requires one. Also check to make sure the specialist has the medical records, letters, or reports they need to understand your child's medical history or diagnosis.

At the end of the visit, ask the doctor or nurse to write down any recommendations for treatment or new medications. Request that copies of dictated letters be sent back to your referring doctor. If your child is young, be sure to bring enough formula, food, snacks, toys, and/or diapers to last several hours. (You may also want to pack a snack for yourself!)

Q: How can I communicate more effectively with the health care team?

A: Educate yourself about different medical issues that are commonly found in people with Down syndrome. Read books or articles from reputable sources like the National Down Syndrome Congress, the Down Syndrome Guild of Dallas (lending library,) Woodbine House publishing company, or the American Association on Intellectual and Developmental Disabilities. These organizations all have excellent web sites.

Learn the medical terminology for conditions that affect your child. Learn the possible side effects of your child's medications and report them if you notice anything unusual. If your child has a chronic health condition such as asthma, keep a log or diary to record changes in his/her health, what treatment or medicine was given, and whether or not it was effective.

When your provider recommends you see other specialists, follow through on their suggestions. Try to identify and report problems to your health care provider early, as children with DS may become ill more often or more quickly than other children.

Don't be afraid to page the provider on call after business hours or bring your child to the nearest emergency room if you are very worried about an illness. Most of all, don't be afraid to ask questions!

You can take active steps to become an effective partner of your child's health care team. The people you choose to care for your child depend on you to plan ahead, to be knowledgeable about your child's disability or illness, to communicate effectively, to ask questions, and to follow a plan of care that is agreed upon by all the members of the health care team. Through this partnership, your child will benefit from the highest level of health care available, and this will help improve his/her quality of life.

Joanna Spahis, RN, CNS, APNG is a Clinical Nurse Specialist for the Down Syndrome Clinic at Children's Medical Center Dallas.