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DSG LAYOUT EDITOR: JENNIFER FORD

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AT CHILDREN'S MEDICAL CENTER.

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DOWN SYNDROME GUILD OF DALLAS

*This month on the DSG calendar Ryan is ready to do summer things.*



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](mailto: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

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

**May 3**  
Annual Family Picnic & Membership Meeting

**May 17**  
New Parent Get-Together

**May 20**  
Dads' Group Happy Hour

**May 21**  
Microboard Information Meeting

**May 23**  
Medical Issues Conference

**June 30**  
Deadline for Outstanding Educator of the Year Nominations

## Medical Issues Conference featuring nationally-renowned speaker

The Down Syndrome Guild's Options for Adults Committee is pleased to

invite you to attend a conference featuring the nationally-renowned Dr. George Capone, Director of the Down Syndrome Clinic at the Kennedy-Krieger Institute at Johns Hopkins Hospital in Baltimore, MD. See [www.kennedykrieger.org](http://www.kennedykrieger.org) and click on "clinical programs." He is also an attending physician on the Neurobehavior Unit at the Institute and currently serves on the Board of the National Down Syndrome Congress.

Dr. Capone will give a short presentation about issues that many of our families have encountered as their children grow into young adults – followed by time for questions and answers.

At this conference, the DSG will also introduce Dr. Joseph Maher, who is board certified in medical genetics

and internal medicine. Dr. Maher sees patients with Down syndrome in the

Adult Genetics Clinic at the Aston Center in the UT Southwestern Medical Center (UTSW) complex on Harry Hines Boulevard in Dallas. Stacy Miller Utay, who worked for many years at the DS Clinic at Children's Medical Center Dallas, is the genetics counselor in the UTSW Adult Genetics Clinic. As the number of patients grows, Dr. Maher will be able to add the staff required to replicate the

Adult Down Syndrome Clinic model used in other major cities.

*There is no fee to attend this conference but an RSVP is required. Contact Becky Slakman, Executive Director of the DSG, by e-mail at [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net) or by phone at (214) 267-1374.*

To defray the cost of bringing Dr. Capone to Dallas, sponsorships of \$25 or more would be greatly appreciated. Please send your check to the Down Syndrome Guild of Dallas, 701 North Central Expwy., Bldg. 5-I, Richardson, TX 75080.

### Medical Issues Affecting Adults and Adolescents with Down Syndrome

*George Capone, MD  
Director, Down Syndrome Clinic at  
the Kennedy-Krieger Institute*

**Saturday, May 23, 2009**

**9:00 am - 11:00 am (coffee served  
beginning at 8:30 am – presentation  
begins promptly at 9:00 am)**

*Reading & Radio Resource office  
2007 Randall Street,  
Dallas, TX 75201  
([www.readingresource.org](http://www.readingresource.org))*

## Save the Date - Fall Education Conference 2009

*Learning Together - Focusing  
on Possibilities*

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

The Down Syndrome Guild's annual conference is always very well-received by parents, teachers, administrators, para-professionals, as well as self-advocates. Updates about this year's topics and presenters will follow in next month's issue of *The DSG News*.

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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 honor of their upcoming  
wedding.*

From: Shauna Roth &  
Ryan Milstein

*In memory of Susie Dietsche.*

From: Andromeda Soccer Club  
(1997 Girls White Team), Brad  
& Becky Ellerman, Krzysztof &  
Ewa Sobieski, Keven & Lisa  
Scott, Walter & Marla Daniels,  
Kenneth & Rhonda Hanks, Jean  
Boyea, Heather Martinez, and  
B. & J. Sexton

*In memory of W. N. "Buck"  
Saigling.*

From: Misty Mayfield-Ranschaert,  
Kristina Haeussler, the Turbyfill  
Family, Danny & Lana Mayfield,  
Rick Barrett, Margaret Cregg &  
Family, Paul Seaback, Chris &  
Susan Burgess, J. G. & Sharon  
Lewis, John & Cindy Wisdom,  
Susie Belote, Mr. & Mrs. Carrol  
Kennemer, Mr. & Mrs. Pete  
Moon, Mr. & Mrs. Jim White,  
Jesse & Betty Jane Covey, Mike  
& Angela O'Brien, Margaret  
McMahan, Tom Castleberry,  
Gary & Jane Strawn, Lynn &  
Barbara Bennie, Kheang, Brooke,  
& Madelynn Eung, and Plano East  
Social Studies Department

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

## Executive Director's Message By Becky Slakman

The Down Syndrome Guild of Dallas' Board of Directors recently held their annual planning session. At that meeting, we celebrated the successes of this year, evaluated what can be improved, and began to plan for 2009-2010. Goals established by the DSG Board include: ongoing parent to parent support; ensure the website and newsletter have up to date information and resources for our families; and strengthen our relationship with area school districts. It was determined that in addition to all the current initiatives, there are three new initiatives for the coming fiscal year, which begins on June 1, 2009. We will organize support and programs for grandparents and siblings and, as an organization, we will focus on lifelong literacy. I hope you will participate in the programs we offer.

As this newsletter goes to press, we are finalizing details to host "**Lose the Training Wheels,**" which is a week-long bicycle camp designed for children with disabilities and operated by professionals who travel across the country. The program will be in Dallas on Monday, August 3, 2009, through Friday, August 7, 2009. Anyone with Down syndrome who is 10 years or older may attend a daily 1 and ½ hour session to be held at Jesuit College Preparatory School. (*We are very grateful for all of the support the DSG continues to receive from the Jesuit Community!*) If you are interested in your family member attending, offering financial sponsorship of a camper or volunteering for the week, please contact me at the DSG office.

Are you looking for a way to honor all the women in your family on Mother's Day? Or possibly thanking

your child's education team with an end of the year gift? Why not consider making a donation in their honor to the Down Syndrome Guild of Dallas? We will notify the recipient of your generosity. You can call our office at (214) 267-1374, mail in your request, or make an online donation. Look how easy it is:

- go to our website at [www.downsyndromedallas.org](http://www.downsyndromedallas.org)
- click on "donate now" button in the top right corner
- complete contact information
- click on gift information
- click tribute/memorial
- complete payment information
- in the comment section, write recipient's name, address, and the reason for the donation

In closing, I would like to wish all the moms a very happy Mother's Day! Also, I hope the last month of school goes smoothly for your students.

## Dad's Group Happy Hour

**W**ednesday, May 20, 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 [dsged@sbcglobal.net](mailto: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.

## Microboard Information Meeting – Create Your Own Nonprofit and be a Medicaid Waiver Provider

**T**hursday, May 21, 2009  
7:00 pm - 9:00 pm  
First Community Bank  
of Richardson  
429 Belle Grove  
Richardson, TX 75080

Jennifer Mathews from the Arc of Texas, in conjunction with the Texas Microboard Collaboration, will present information regarding the process for forming a microboard for your family member with Down syndrome. The greatest benefit of a microboard is that the individual with a disability has control over his or her own life with supports from a nonprofit organization run by those who know and care about them most.

### **What is a Microboard?**

A microboard is formed when a small group of committed family and friends join together with a person with a disability to create a nonprofit organization. This group develops a person-centered plan called a PATH (Planning Alternative Tomorrows with Hope) to address the individual's support needs. This PATH-the goals and dreams of the person with a disability-becomes the microboard's mission. The microboard concept originated in Canada with the Vela Microboard Association. Tennessee is successfully operating over 170 microboards, and 13 other states are in various stages of implementing microboards.

### **How does a Microboard support a person's dreams?**

- Builds bridges that allow individuals to participate in and contribute to their communities.
- Provides social opportunities.

- Allows individuals to determine and carry out their own dreams.
- Manages services such as home supervision, transportation, medical care and job searches.
- As a Medicaid Waiver Program provider that serves an individual, you gain control over financial decisions.

To learn more about the Texas Microboard Collaboration, a program that supports the creation of a nonprofit to support one individual with a disability. More information about this program can be found at: <http://www.thearcoftexas.org/programs/reallife.asp>

RSVP to Becky Slakman at (214) 267-1374 or [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net).

## Automatic Translation Now Available on our Website

**W**e have added a new tool to our website called Babel Fish. Babel Fish is a web-based application on Yahoo that translates web pages from one language into another. To do this on our website, look for the Yahoo Babel Fish logo with the little yellow fish on the upper right hand corner of any page of our website. Click the language you want on the drop down menu. In just a few seconds you will see the screen change in the language you selected. If you want to go back to English, click on the Babel Fish link at the top of the page. It is that easy!

## ...What I Know Now!

*I would have known early on that I was my child's best advocate. Others can provide information and support, but I am the one that knows her intimately and will be with her through life. Everyone else can come and go. The best information I received was from experts who have experience in the field of disability – parents. Experts and experience take on a whole new meaning when you talk with those who live with the day-to-day dealings of life.*

*I would have known that disability is a natural condition of the human experience not special.*

*Special is just another term used to justify separate, segregated services and supports.*

*I would have focused on my child's strengths, nurtured and encouraged them. It is through these strengths that we are best able to support her needs.*

If you have a quote you would like to share, please send it to: [arcnetc@att.net](mailto:arcnetc@att.net). Information based on life experiences is priceless when shared with others.

- With permission from the Arc of Northeast Tarrant County

## If I Knew Then...

**A** compilation of quotes from parents who when asked the question “If you knew then what you know now, what would you share with others?”

They offered the following:

*I would take the “experts” advice with a grain of salt, hold on to the dreams for my son, and do whatever it takes to ensure my son and my family enjoyed a normal, happy life. As it turned out, I learned to do these things pretty quickly, but it took a 180 degree shift in my perspectives and my actions to make it happen! Today, he’s a successful college student and lives the life of his dreams!*

*I would follow my motherly instincts and not let the professionals challenge or change my thoughts and opinions about my son or our goal. I would have known that a person’s biggest barriers to success are not because of their disability but instead, because of human and attitudinal barriers.*

- *Children had the opportunity to create beautiful things at the DSG art class in March.*
- *The young adults partied hard at Amazing Jakes in March with a group on Spring Break from Northwestern College in Iowa.*

## Calling All Members

**E**veryone knows what wonderful programs the Down Syndrome Guild has to offer, from arts & crafts to hip-hop class; from cooking class, to service projects. But how do these programs happen? They happen in large part because of you, the member. Many of our programs and activities are led by members or family and friends of members who have an interest, talent, or hobby that they are willing to share. In January, member, Jennifer Hood, taught a cooking class to our adult self advocates. In February, Board President Kelly Drablos’ daughter, Katie, and her team of friends from the SMU School of Dance taught a hip-hop class. And in March, the Girl Scout troop of Mike and Katy Arbour’s daughter, led our 8-16 year olds in an arts & crafts class. Our success depends on your commitment.

So what do you have to offer - a talent, hobby, or skill? Do you know someone who would like to teach a

painting class or lead a discussion? Do you like computers or enjoy dancing? A successful activity depends on the participants having fun, not the perfection of a particular outcome. It is not necessary to be great at something, if you are willing to step out and share your experience with our enthusiastic self advocates. If you are the parent of a child with Down syndrome, consider spending time with our young adults. If your child is grown, take a look back by spending time with the kids. There is no right or wrong way to help, just join us for some fun. Won’t you offer your time and talents? This is a wonderful way to get to know others, have fun, share your experience, or see the bright future ahead. To volunteer, or if you would like to help but are not sure how, please call Becky Slakman at (214) 267-1374 or e-mail [dsged@sbcgloabl.net](mailto:dsged@sbcgloabl.net).

## Spring Break Activities



## Annual Family Picnic and Membership Meeting

**S**unday, May 3, 2009  
 1:00 pm - 5:00 pm  
 (lunch will be served from  
 1:30 pm - 3:00 pm)  
 Park Lane Ranch  
 8787 Park Lane  
 Dallas, TX 75231

[www.parklaneranch.com](http://www.parklaneranch.com)

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

The Down Syndrome Guild 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 many activities - miniature golf, mini arcade, Bingo, arts and crafts, petting barnyard, basketball hoop shot, and batting cages - fun for

every member of the family. All the activities and a buffet lunch are free for member families. You may renew your DSG membership at the picnic. Dues for 2009-2010 are \$25/family.

This gathering also serves as the Down Syndrome Guild's annual meeting, at which the members vote for the organization's new Board members and the Executive Committee for 2009-2010.

Although this event is free, you **must make a reservation** by e-mailing [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net) or by calling (214) 267-1374 *no later than Wednesday, April 29, 2009*. Include in your message the number of adults and children who will be attending.

## Quarterly Meeting for Families with Babies

**S**unday, May 17, 2009  
 3:00 pm - 5:00 pm  
**NEW LOCATION:** Aaron Family Jewish Community Center (The J)  
 7900 Northaven Road  
 Dallas, TX 75230-3392

We realize that with the birth of your child with Down syndrome you may have entered a whole new world - one that can be confusing and filled with deep feelings. Please join us for our New Parent Get Together! Come meet other parents, some new - some not so new! Get information, ask questions, and find out how the Down Syndrome Guild of Dallas can be a resource and support for you and your family. We look forward to meeting you and your whole family!

**Speaker:** Paula Tarver - Child Find Coordinator with ECI on the staff of Special Care and Career Services

**Topic:** Early Childhood Intervention (ECI); Everything You Wanted to Know (or just wondered about)

**NEW LOCATION:** As you walk in the front door of The J, you go straight ahead down the main hallway, and we will be in the first and second rooms on the right. The adults are in the Big D Room, and the siblings have their own play room right next door in the *Yad B'Yad Room*.

If you have any questions, please call the DSG office at (214) 267-1374.

## Outstanding Educator of the Year Award Nominations Due

**E**ach 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 member may nominate their favorite educator by going to our website at [www.downsyndromedallas.org](http://www.downsyndromedallas.org) and downloading the nomination form. **Deadline for nominations is June 30, 2009.** Nominees will be recognized at the DSG, *Learning Together, Focusing on Possibilities* Fall Conference on Saturday, October 10, 2009. Members may also contact Becky Slakman at the DSG office at (214) 267-1374 or [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net) and request that a form be sent to you.

## Washington D.C. Representation by the DSG

Three representatives of the Guild, Becky Slakman, Anita Ford and Lynn Favorite, recently attended the annual *Affiliates in Action* conference which, because it was held in Washington, D.C., primarily provided a focus on advocacy. More than 300 Down syndrome advocates from 35 states gathered at the U.S. Capitol and stated their mission to seek federal funds to help spread accurate information about prenatally diagnosed disabilities.

Those from the DSG met with staff from the offices of Senator John Cornyn, Congressman Joe Barton, and Congressman Ralph M. Hall and called on each of them to improve the quality and availability of information about Down syndrome. Specifically, funding was requested for the Kennedy/Brownback Bill and passage of the ABLÉ account.

Members of Congress are being urged to allocate \$25 million over five years to implement the *Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2009*, known as the Kennedy/Brownback Bill. On September 23, 2008, the Senate passed the bill, which was then passed by the House of Representatives. On October 8, 2008, President Bush signed the bill into law marking one of the most historic moments in the lives of families of children with Down syndrome.

The measure provides that families receiving a prenatal or postnatal diagnosis of Down syndrome will

be offered accurate and up-to-date information about the nature of the condition as well as be connected with support services. In addition, a registry of parents willing to adopt children with disabilities will be compiled and maintained.

The intent of the measure is to create a sensitive and coherent process for delivering factual information about a diagnosis of disability. Down syndrome advocates say medical professionals too often give prospective parents inaccurate and incomplete information or none at



▲ DSG members Anita Ford as well as DSG Executive Director, Becky Slakman, enjoyed visiting with Patrick Kennedy at the *Affiliates in Action* meeting.

all, leaving parents anxious and fueling irrational bias against people who have the condition.

Those attending the conference also pushed for a bill to encourage individuals with disabilities and their families to save, tax-free, for disability-related expenses. Called the *Achieving a Better Life Experience Act (ABLE)*, this legislation is intended to help people with all kinds of disabilities become more financially independent. It would allow them to save money without jeopardizing government disability benefits.

If this bill becomes law, it will allow an account to be held in the name of the individual with a disability. The accounts would be similar to college savings accounts, IRA's, and other instruments that let people put aside funds tax-free for education, medical needs, and retirement. Presently, people with disabilities may not use such accounts because to do so would jeopardize their federal disability benefits. ***This is important*** because currently \$2000 is the asset limit for individuals receiving benefits under

important federal programs such as Medicaid and SSI. Medicaid is the primary source of funding for long-term support services for adults with disabilities. The legislation's intent is to supplement rather than to replace benefits provided by other sources. In addition, money earned on the principal of the trust would not be taxable which means that it can grow tax free. The accounts have a contribution limit of \$500,000. These accounts will give

families another tool to use in estate planning along with other mechanisms such as a Special Needs Trust.

Upon the death of the individual who is benefitted, the residue in the account may be claimed by the government to repay expenses the government has incurred supporting the individual.

***Please understand that upon the death of the individual who is benefitted, the residue in the account may be claimed by the government to repay expenses the government has incurred supporting the individual.***

## The Joy of Learning *By Sarah Bonilla*

**M**y daughter, Paloma, just started seventh grade at West Chicago Middle School. I felt like the last nine years, three years of school and kindergarten through sixth grade, we have located along on a wonderful inclusion bubble. She was fully included all those years and great effort was taken to ensure her success in the class.

Now we have entered into a new world. She was taken off the regular bus, which she was on for six years, and put on a “special ed” bus. Now we are told that the social studies and science classes she has been in for a few weeks are not appropriate for her. They cannot provide the necessary modifications to remain in those classes because of the large discrepancy between the course content and Paloma’s cognitive abilities.

They offered an alternative Life Skills class that will teach her things “more appropriate” such as measuring, reading a map and a bus schedule, and down the road, how to balance a check book.

I remind the school staff that Paloma is 12 years old and is driven around by her mother like ALL suburban kids, and as far as balancing a check book, does anyone even do that any-more?

The Life Skills class has value, but it is not a substitute for science and social studies. I told them I would like my daughter to be treated like the young person she is and be allowed to learn all the interesting things about our world that other seventh graders are allowed to learn, like the rainforest, the planets, and the weather, or different people and cultures around the world. Who is to assume this is not appropriate for my child to learn?

I am told I need to adjust my expectations.

I am fully aware that much of the course content may go over Paloma’s head. Nevertheless, I expect her to be in the class, with her peers, where she belongs.

They tell me the material in these classes is way too hard for her, and it is too costly and time consuming to modify the curriculum. I ponder the legality of what they are saying to me but keep that thought to myself.

The fact is that no one, not a teacher or even I, knows definitively what my child may learn from being in those classes. I know she does retain kernels of information. These kernels grow into stalks and bloom forth when you least expect it.

We are sitting on a bench at the park the same day as my meeting with the school. Paloma tells me in an excited voice about some project they did that day in science—something about soil and a seed and folding paper. With her limited communication skills, I have no idea what she is saying or what they actually did.

But that is irrelevant. She is excited.

My doubts about fighting to keep her in science lessen. The joy of learning is exciting! This is what school should be about. Does a teacher look out on their class of 30 and alter the curriculum according to the potential of every student? Do we not teach calculus to some kids because they may end up doing manual labor? Of course not. So what’s the point? Each “regular ed” kid is given equal opportunity to explore a range of intellectual endeavors, but people with cognitive disabilities are not. It is assumed that they do not share the same thrill of learning. It is assumed it is a waste of time because they are going to end up in a menial job.

Intellectual pursuits don’t necessarily

have anything to do with careers.

I have found in these last few weeks, much to my disappointment, that many well-meaning and likeable people in the special education system have a limited and rigid view of the potential of our kids and what the education system can offer them.

I know what a central joy in life learning can be. This is why we read novels and magazines and surf the web for hours. We go back to school mid-life. We take vacations to interesting places and listen to foreign language tapes in the car. We do this our whole lives, and how dull life would be if we didn’t.

Let’s not deny this joy to our own precious children.

*By Sarah Bonilla, Reprinted with thanks to NADS News, newsletter of the National Association for Down Syndrome.*

## Social Security's Economic Recovery One-Time Payments Information Page

**P**resident Obama recently signed the American Recovery and Reinvestment Act of 2009. This act provides for the one-time payment of \$250 to individuals who get Supplemental Security Income (SSI) or Social Security benefits.

We expect everyone who is entitled to a payment to receive it by late May 2009. The Social Security Administration is currently working on the details regarding how they will issue nearly 55 million one-time payments to SSI beneficiaries. **No action is required on your part.**