

CELEBRATE SOCIAL & FAMILY DANCE

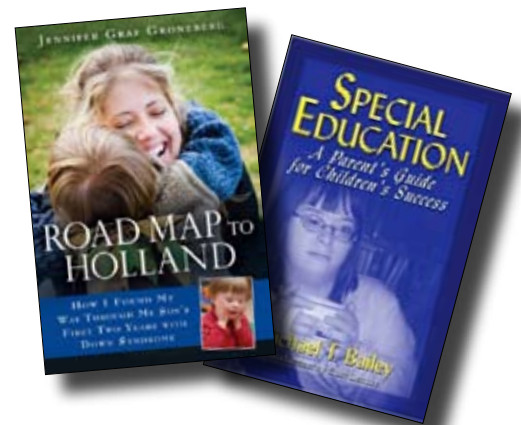
Whether you are making it to the Pathfinders Conference or not, be sure to join us for the Celebrate Social & Family Dance from 6:30 - 9:30 p.m. on Thursday, April 16, following the opening day of the Pathfinder's Conference. The event is FREE and set to celebrate individuals with special health care needs, Down syndrome and their families. Authors Michael Bailey and Jennifer Graf-Groneberg will be joining us for the evening.

You bring the family and we'll bring the music, snack and the fun will show up all on its own. Sponsored by: Designer Genes, Family Voices of North Dakota and The Arc of Bismarck.

DOWN SYNDROME SPEAKERS FEATURED AT PATHFINDER'S EVENT

Two prominent authors connected to Down syndrome will be featured at the Pathfinder's annual Parent Involvement Conference on April 16-17, at the Doublewood Inn in Bismarck. Michael Bailey and his daughter Eleanor will open the 2009 conference by offering practical tips and useful advice on ways to help the student's voice be heard in the IEP meeting. Bailey is the author of *Special Education, A Parent's Guide to Children's Success*. His daughter, Eleanor, who has Down syndrome, is co-presenting with him.

Jennifer Graf-Groneberg, author of *Road Map to Holland*, will share her journey to acceptance and success in parenting a child with Down syndrome as well as discussing how to become an advocate for your child through writing.



You can find more information on the conference at www.pathfinder-nd.org. Parent scholarships for the registration fee are available. It's an amazing opportunity for our Down syndrome community – come out and support it. Designer Genes will be exhibiting at the event and co-sponsoring the Celebrate Social taking place April 16 – more information on the social is provided to the left and in the flyer included with the newsletter.

ASSISTIVE TECHNOLOGY EXPO APR. 30

Sometimes the solution you need is as simple as an assistive technology device to get you there. If you're looking for solutions, don't miss the 6th Annual Assistive Technology Expo taking place April 30th from 8 - 6 p.m. at the Fargo Ramada Plaza Suites. This event offers demonstrations on all types of assistive technology devices and services for people of any age and ability to help them live, learn, work, and play.

For more information, call 1-877-760-2939 or visit www.atexpo.org.

DON'T BE AFRAID TO QUESTIONS

BY ROXANE ROMANICK, DESIGNER GENES PRESIDENT

What do you do when you're unhappy with services and supports? What do you do about questions you have about what should be happening in early intervention, special education, or other services that you or your child receives? Do you find yourself not returning phone calls from professionals or canceling appointments? Are you confused about who is who, and who is supposed to do what? Do you find yourself saying something like: "well, it's a *free* program, so can I really complain?"

First steps first. Find someone that you can talk to or discuss the questions that you have. No matter which way we look at it, we are our child's one and only true advocate. Questioning whether services are being delivered in a way they are supposed to be—or in such a way that works for your family—is what you're supposed to do. The truth of the matter is there is probably new information out there for you to discover. Sometimes it's hard to ask the person that you're working directly with, so find someone else.



Because your child was found eligible for early intervention or special education services, you have many rights that are afforded to you by the federal Individuals with Disabilities Education Act (IDEA) and other state regulations. Don't throw that away—use it to make the services and supports work for your child and family.

You do have several team members that you can always talk with—your DD

Case Manager, your Early Interventionist, your special education staff, school principal, other consultants (or therapists) on your team—but if this doesn't work for you, here's a couple of other suggestions:

- 1) If your child is in Early Intervention, talk with the Experienced Parent Specialist in your region.
- 2) Contact Family Voices of North Dakota at 701-493-2634, visit them at www.fvnd.org.
- 3) Another agency that is actually paid by the federal government to answer these questions is Pathfinders Parent Center in Minot—call them at 1-800- 245-5840 or visit them at www.pathfinders-nd.org.
- 4) Call another Designer Genes contact you've made. Sometimes comparing notes, frustrations and successes is just what you need.

You are never going to be made to act on your questions or concerns—sometimes it just helps to “think out loud” with someone else. Don't sit there and wonder—ask!



HANDS-ON SIGNING HELP

Are you using sign language with your child but struggle to figure out from a book how a sign is made? A new web site makes it as easy as watching to figure out the most tricky hand motions: www.signingsavvy.com.

Simply type in the word you'd like to know a sign for and a helpful man pops up demonstrating the sign for you in live motion. Voila! It's like magic only you get to take the credit for being so smart to know where to get the information.





SIB SUPPORT WORKSHOP OPPORTUNITY

Red Door Pediatric Therapy in Bismarck is hosting sibling support workshops for brothers and sisters of kids with special needs. Sibshops are lively, pedal-to-the-metal celebrations of the many contributions made by brothers and sisters of kids with special needs. The sessions acknowledge that being the brother or sister of a person with special needs is for some a good thing, others a not-so good thing, and for many somewhere in between. They reflect a belief that brothers and sisters have much to offer one another—if they are given a chance. The Sibshop model intersperses information and discussion activities with new games, cooking activities, and special guests who may teach participants.

Sibshops seek to provide siblings with opportunities for peer support. Because Sibshops are designed (primarily) for school-age children, peer support is provided within a lively, recreational context that emphasizes a kids'-eye-view. Families do not have to be receiving services at Red Door Pediatric Therapy to attend. For more information and future Sibshops dates please contact Holly English at 222-3175 or visit www.siblingsupport.org. The cost of the program is \$20 per event.



Interested in stories from brothers and sisters who have a sibling with Down syndrome or special needs, check out:

- Band of Angels Brothers and Sisters Gallery www.bandofangels.com/Inspiration/BrothersAndSisters/
- Woodbine is putting out two new books about siblings: www.woodbinehouse.com

Fasten Your Seatbelt: A Crash Course on Down syndrome for Brothers and Sisters

Thicker Than Water: Essays by Adults Siblings of People with Disabilities

YOUTH WITH DEVELOPMENTAL DISABILITIES IN COLLEGE

Youth with intellectual disabilities have not had many chances to go to college. This is changing as individuals across the country begin to create opportunities for youth with developmental disabilities to reap the benefits of postsecondary education. Find out more about the possibilities at www.thinkcollege.net.

PROMOTING POSITIVE BEHAVIOR

Bismarck Public Schools HEART (Helping Educators – Autism Resource Team) will be presenting on how to promote positive behaviors in children with autism and other disabilities on Tuesday, April 21 from 6:30 - 8 p.m. at Hughes Educational Center (Board Rooms 1 and 2), 806 N. Washington Street in Bismarck. (Park in the west parking lot and come up the ramp, take a quick right and come in the double doors). Contact Shanna Crouse at 323-4009 for more information.

DESIGNER GENES MOVING FORWARD

Designer Genes is working hard to gain our non-profit status before the Buddy Walk coming up on September 26. We have officially incorporated and adopted by-laws which can be viewed at www.designergenesnd.com and elected an interim slate of officers to serve until we can elect one at our first membership meeting coming up this fall. Your current board members are:

- Roxane Romanick - President
- John Moririson - Secretary
- Heather Lundeen - Jason Yeager - Deb Clarys - Members-as-Large
- Sandra McMerty - Vice President;
- Marlene Zimmerman - Treasurer

Please feel free to contact any of them with questions you may have about Designer Genes or information you'd like the board to consider.



MARK YOUR CALENDARS

UPCOMING DESIGNER GENES DATES OF NOTE.

April 16 | Celebrate Social & Family Dance

6:30 -9:30 p.m., Bismarck Doublewood Inn

May 2 | Mother's Day Brunch

Faith Lutheran Church - Watch for your invitation soon.

June 2 | Designer Genes Board Meeting

6:30 p.m. - Place to be Determined

July 16 | Designer Genes Board Meeting

6:30 p.m. - Place to be Determined

August 13 | Designer Genes @ Urban Harvest

Bismarck - Downtown 4th Street between Boulevard & Thayer Ave

August 23 | Designer Genes Summer Picnic

September 26 | 6th Annual Buddy Walk

10 a.m. Registration - 11 a.m. Walk

Bismarck State Capitol Grounds



A · DOWN · SYNDROME · SUPPORT · NETWORK

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