



THE DSG NEWS

Down Syndrome Guild of Dallas

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

downsyndromedallas.org

September 2006



DSG Calendar

SEPTEMBER


- September 11**
Board Meeting
- September 17**
Mom's Night Out
- September 21**
Adult Issues Meeting
- October 10**
Golf Classic
- November 11**
Fall Educational Conference
- November 12**
Buddy Walk

Other Events of Interest

September 22, 2006
 "Teaching Math" Author to Speak,
 Ft. Worth, TX

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**Keep Current!
Check**
www.downsyndromedallas.ORG
 for the most up to date
 activity info and to read the
 DSG newsletter online.

Se Necesitan Traductores

Se necesitan personas que puedan traducir artículos para este folleto. El motivo que no hay muchos artículos traducidos es por la falta de voluntarios. Si usted desea hacerse voluntario para que la comunidad de habla hispana este mas informada llame por favor a Patty Erbert al 972-412-3796. ¡Gracias!

- Submitted by Patty Erbert ☺



DSG Board Meeting

Monday, September 11, 2006
7:00 pm

701 North Central Expressway
Bldg 5-I
Richardson, TX 75080

All members are welcome to attend the regular meeting of the DSG board at the DSG office. Directions: From Dallas, take I-75 north and exit Arapaho – exit #25. Go left/west under I-75, then go left/south on the frontage road (or take U-turn lane). Turn right/west into the first driveway after Belle Grove. Look for a sign that says “701 N. Central Expressway.” Go to the end of the driveway and it’s the last building on the left, across from the bank.

-Submitted by Elizabeth Longworth ☺



Mom’s Night Out

Sunday, September 17, 2006

3:00 pm -5:00 pm

Premier Wines
4709 West Parker Road,
Suite #420, Plano, TX

Attention all moms needing a break - you are invited to Mom’s Night Out! If you haven’t made it out yet (and also if you have), please try to attend this month’s wine tasting event - and bring any other female member of your child’s family. This is also a great chance for grandmothers and aunts to network.

The wine tasting is free but attendees purchase appetizer platters. The cost should be \$25 or less per person. This outing requires at least 25 people, which would be more than we have had at any MNO. So, please invite your friends, sisters, mothers (in-law), anyone that might enjoy participating. **RSVP** to Maureen Tignor at 972-691-2458 or motig62@comcast.net as soon as possible so we can determine whether we are going to meet this minimum.

-Submitted by Maureen Tignor ☺

Escape para las mamás



Domingo, 17 de Sept., 2006

3:00 pm -5:00 pm

Premier Wines
4709 West Parker Road,
Suite #420, Plano, TX

Atención a todas las mamás que quieran salir a divertirse. Están invitadas a la Noche de Escape con otras mamás. Si usted nunca ha asistido, por favor trate de atender a uno o más de los siguientes eventos, y no deje de invitar a miembros de la familia de su niño. Para mujeres solamente. Esta es una buena oportunidad para las abuelas y tías que quieran mantenerse en contacto con otras familias las cuales tienen niños con el Síndrome de Down.

Nos reuniremos en el Premier Wines en Plano, para probar diferentes clases de vinos. Este evento es organizado profesionalmente. Las pruebas son gratis con la compra de un plato de aperitivos. El costo debe ser alrededor de \$25.00 o menos. Necesitamos al menos un grupo 25 personas. Así que invite a sus amigas, hermanas, madres, suegras o cualquier mujer que disfrutaría participar, y por favor llame a Maureen Tignor al 972-691-2458 o al correo electrónico motig62@comcast.net tan pronto sea posible para así determinar si van a asistir las personas suficientes para llevar a cabo este plan.

-Submitido por Maureen Tignor.

¡Gracias! ☺



Adult Issues Committee Meeting

Thursday, September 21, 2006

Down Syndrome Guild Office

701 N. Central Expwy., Building 5-I

6:00 pm – Socialize

6:30 to 8:30 pm – Program

Wills, Trusts and Guardianship

Attorney Rick O’Connor will give a short presentation about what families need to know in order to plan for their child’s future. The program will highlight issues facing families whose child with Down syndrome is 18 years or older. However, families of younger children are also welcome to attend.

Even those who have had a will since their child with Down syndrome was young need to review and reevaluate decisions as the child gets older. How should your estate (even if your assets are limited to a life insurance benefit) be divided among your children? Is the sibling of the child with Down syndrome the best person to administer the Special Needs Trust? Should that sibling also be the guardian? Rick will give us the benefit of his expertise and will answer our questions.

Please RSVP to Minnie Blackwell at 972-239-8771 or minnieblackwell@comcast.net.

DSG Newsletter Available Electronically

Save the DSG money, save yourself some time and save a tree! The Down Syndrome Guild newsletter is available on our website — generally before the 1st of every month. Now members have the option to completely forgo the paper copy of the newsletter. You can receive a notice via the Yahoo Group when the newsletter is available on the website. Members can “opt out of paper” at any time – just contact minnieblackwell@comcast.net.



DSG’s 2006-07 Membership Directory

A new DSG membership directory will be sent ONLY to parents/family members who paid their membership dues – and parents who have a baby with Down syndrome younger than 1 year as of May 31, 2006. New directories will be mailed in early September.

IT’S NOT TOO LATE. If you want a directory, renew your membership by emailing Minnie Blackwell at minnieblackwell@comcast.net or call her at 972-239-8771.



Pearls for Prevention

Medical Procedures:
Part 3

The Video Fluoroscopic Swallow Study

By Joanna Spahis, RN, CNS, APNG
Clinical Nurse Specialist,
Down Syndrome Clinic
Children’s Medical Center, Dallas

This procedure is commonly used to make sure an infant or young child with Down syndrome is swallowing properly and that no food or liquid is going into his or her lungs (aspiration.) Children with Down syndrome have an increased risk of swallowing disorders (dysphagia) due to low muscle tone, tongue thrust, and poorly coordinated suck/swallow reflexes.

Q: What is a video fluoroscopic swallow study (VFSS)?

A: It is a test that measures how well the swallowing mechanism works, using video x-rays. It is also known as a “modified barium swallow.”

Q: How is the procedure done?

A: A small amount of barium is mixed with the child’s formula or food in different amounts and different consisten-

cies and is fed to the child. Typically, thin liquid, thick liquid (nectar,) puree, and crushed solids are used. The images of the child are observed and recorded while swallowing to see if any food or liquid is being aspirated, and if so, under what circumstances.

Q: What kind of information does the VFSS provide?

A: The VFSS can tell if the child with Down syndrome has a weak or abnormal swallowing mechanism so that the method of feeding the child can be changed. By using different consistencies of foods, the therapist can see which kind is best tolerated by the child with the lowest risk of aspiration.

Q: Who performs the procedure?

A: It is generally performed by a radiologist and a speech pathologist.

Q: What are some signs that my child has a swallowing disorder?

A: If your infant or child is constantly congested, if the congestion gets worse after feedings, if he or she has frequent lung infections or pneumonia, if he or she often gags, coughs, or chokes on food or liquid, he or she may have a swallowing disorder. Also, if your child repeatedly spikes an unexplained temperature (not associated with any illness or infection), he or she may be a 'silent' aspirator. If any of these occur, you should speak to your primary care practitioner about scheduling a swallow study.

Q: What are some treatments available if my child has a swallowing disorder?

A: To correct aspiration, the speech pathologist may recommend thickening liquids using a substance such as "Thick-It," "Thicken Up," or "Simply Thick." Other treatments include changing the child's feeding position, slowing the rate of feeding, using special equipment such as a Fast Flow nipple, and regular oral-motor therapy (exercises done by a speech therapist) to help strengthen the muscles of the mouth. In

severe cases when the child continues to have problems, a gastrostomy tube may need to be placed directly into the stomach to bypass the usual feeding by mouth. This is usually used temporarily until the child grows older and the muscles of the mouth get stronger.

Q: How often should the VFSS be repeated?

A: If the first VFSS shows abnormal swallowing or aspiration, it should be repeated every 4-6 months while modifications are being made, until normal swallowing function is demonstrated. ↻



Perlas para la Prevención

Procedimientos Médicos: Parte 3

Examen de Tragar a través del Video Fluoroscópico (VFSS)

Por Joanna Spahis, Enfermera Registrada especialista.

Clínica del Síndrome de Down, Hospital de Niños, Dalllas

Este procedimiento es comúnmente usado para estar seguro que su bebé o niño pequeño con SD (Síndrome de Down) este tragando apropiadamente y que los alimentos o líquidos, no estén dirigiéndose a los pulmones (aspiración). Ellos tienen un riesgo más alto teniendo problemas con tragar (disfagia) debido al tono bajo de músculos, a que mantienen la lengüita fuera y la pobre coordinación de mamar y tragar.

¿Que es un examen video fluoroscópico para tragar?

Es un examen en el que se observa como el niño traga y si el mecanismo de los músculos encargados de tragar trabajan como deben, estos son observados con las radiografías video. También se conoce como "Trago Modificado de Bario."

¿Como el procedimiento es hecho?

Una cantidad pequeña de bario se mezcla con la formula o el alimento del

niño en diversas cantidades y diversas consistencias y se alimenta al niño. Típicamente se utiliza el liquido fino, (néctar) liquido grueso (puré) y los sólidos machacados. Las imágenes del niño se observan y se registran mientras el traga, para considerar si se esta aspirando algún alimento o liquido, y si es así, bajo que circunstancias.

¿Que clase de información el VFSS (siglas usadas en ingles para el examen) proporciona?

El VFSS puede decir si el niño con SD tiene un mecanismo débil o anormal para tragar para así, el método de alimentación del niño sea cambiado si es necesario. Usando diferentes consistencias de alimentos, la terapeuta puede ver que clase es mejor tolerado por el niño y cual tenga el mas bajo riesgo de aspiración.

¿Quien hace el examen?

Es generalmente hecho por un radiólogo y una terapeuta de lenguaje.

¿Cuales pueden ser los síntomas que mi niño mostraría si tiene problemas para tragar?

Si su bebe o niño es constantemente congestionado, si la congestión es peor después que usted lo alimenta, si tienen frecuentes infecciones en los pulmones o neumonías, si frecuentemente , se amordazan, tosen o estrangulan en su alimento o liquido, estas pueden ser indicaciones de problemas en tragar. También, si su niño repetidamente le dan inexplicables altas temperaturas no asociadas con cualquier enfermedad o infección, el o ella podría ser un aspirador silencioso. Si cualquiera de estos ocurre, Usted debe hablar con su medico para que su niño pueda tener un estudio de tragar (VFSS)

¿Cuales son algunos de los tratamientos disponibles si en caso mi niño tiene problemas al tragar?

Para corregir la aspiración, la terapeuta de lenguaje puede recomendar espesar el liquido usando una sustancia tal como: "Thick-It", Thicken Up" o

"Simply Thick". Otros tratamientos incluyen el cambiar la posición de como se alimenta el niño, alimentándolo mas despacio, usando equipo especial como un biberón rápido de flujo, o terapia regular de oral-motor (ejercicios hechos por un terapeuta de lenguaje) para ayudar a hacer mas fuertes los músculos de la boca. En casos severos, cuando el niño continua teniendo problemas, un tubo para alimentar al niño (gastrostomy) puede ser colocado directamente al estomago para puentear la alimentación generalmente vía oral. Esto se utiliza generalmente temporalmente hasta que el niño crezca más y que los músculos de la boca sean más fuertes.

¿Que tan a menudo el VFSS debe ser repetido?

Si el primer VFSS demuestra que el niño traga anormal, debe ser repetido cada 4 a 6 meses mientras que se están haciendo las modificaciones, hasta que se demuestre la función de tragar es normal. ↻



DSG Fall Conference 2006

Sat. Nov. 11, 2006, 9:00 am - 4:00 pm
Fogelson Forum Auditorium
Presbyterian Hospital of Dallas
8200 Walnut Hill Ln. (E. of Central Expwy.)
Dallas, TX

**Dr. Rich Villa presents –
Exchanging Dissonance for Harmony:
Creative Responses for Students Experiencing Behavioral and Emotional Challenges**

Participants explore the relationships between theories of motivation, communication, and student behavior. They learn to distinguish between punishment and discipline, and examine assumptions underlying discipline systems. The workshop highlights a constellation of supports and services for meeting the needs of learners who experience behavioral and emotional challenges.

DSG Fall Conference 2006 Registration Form

Name _____

Organization _____

Address _____

City _____ State _____ Zip _____

Telephone (day) _____ (evening) _____

Email address: _____

I am: (Circle one) Parent Professional/Therapist Educator

I will need a Confidential Scholarship (Parents only)

I will need a Conference Attendance Certificate Y N

Includes Continental Breakfast, Lunch, Refreshments, Handouts and Free Parking.

\$50.00 for General Admission. With current Down Syndrome Guild Membership the cost is \$40.00 per person or \$70.00 for married couples.

Please mail registration form with check. Make checks payable to DSG of Dallas and mail to: Katy Arbour, 18015 Windtop Lane, Dallas, Texas 75287.

Registration Deadline is November 6th. A late fee of \$10 will be charged for any reservations received after the 6th. For questions call: 972-930-0117 or 214-267-1374.

What do people say about Dr. Richard A. Villa?

“Richard Villa is a spell-binding speaker who brings out all the issues of inclusion sharply with humour and in a way that is immediately practical. We learnt so much from him...”

Professor Tim Brighouse, Education Czar London, England

“I was afraid of inclusion - and very hesitant to be open about it. Rich’s delivery, material, and examples helped me relax and look forward to enjoy!”

Donna Monas, General Education Teacher

“I should have brought a team from my high school! There was a ton of beneficial information”

Wendy Van Batavia, EDD/SLD Teacher

“Thank you for practical, useful seminar. I’ve some great ideas I’m eager to use and share!”

Linda Butler, Resource Teacher

“Exactly what I was looking for! Validated my belief in inclusion and gave me many new strategies and ideas!”

Karen Reed, General Education Teacher ☺



Volunteers Needed for Parent to Parent Committee

The Parent to Parent Committee is in need of volunteers who are willing to reach out to the parents of newborns with Down syndrome in the DFW area. We are also in desperate need of bilingual or Spanish speaking volunteers who can provide support and information to families who speak ONLY Spanish. If you are interested in serving the DSG in this capacity, please contact Merit Dureau at 214-351-4497 or Dureau@swbell.net.

-Submitted by Merit Dureau ☺



Necesitamos Voluntarios para el Comité de Padres a Padres

El Comité de Padres a Padres esta en la necesidad de voluntarios para que ayuden a los padres de bebés recién nacidos con Síndrome de Down en el área de Dallas. También necesitamos desesperadamente personas bilingües o personas que hablen español para padres que hablan solo español. Si usted esta interesado en servir con este comité, por favor comuníquese con Merit Dureau al 214-351 4497 o al correo electrónico Dureau@swbell.net

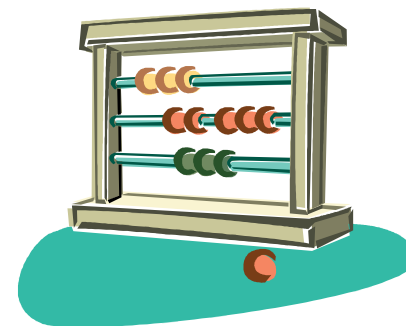
-Elaborado por Merit Dureau ☺

“Teaching Math” Author to Speak

Friday, September 22, 2006
8:30 am -3:30 pm
Texas Christian University
2913 W. Lowden St.
Fort Worth, TX 76129

The Down Syndrome Partnership of Tarrant County, Green Oaks School, and Kinderfrogs School at Texas Christian University present an important conference with DeAnna Horstmeier, author of Teaching Math to People with Down Syndrome and Other Hands-On Learners. This math program has been used successfully with preschoolers, children and adults with Down syndrome, as well as those with Autism Spectrum Disorder and other cognitive disabilities. Covered skills include: number sense, recognizing and writing numerals, time, calculator skills, counting, measurements, addition, place value, shapes, subtraction, and money. The program also includes more advanced math skills needed for independent living.

There is no charge for parents of children with special needs and a \$10 fee for those requiring Continuing Education Credits. For additional information, contact the Down Syndrome Partnership of Tarrant County at 817-421-1812. ☺



2006 Buddy Walk



Sunday, Nov. 12, 2006
11:00 am – 3:00 pm
Walk starts at 1:00 pm
Flag Pole Hill
Northwest Highway at
Buckner Blvd.
Dallas, TX

One of the DS Guild's biggest fundraising events of the year, the Buddy Walk is our annual walk in support of Down syndrome and specifically your family member with Down syndrome. The 2006 Buddy Walk will be at an exciting, new and larger location – Flag Pole Hill near White Rock Lake in Dallas. Mark your calendars, and tell all your “buddies” to be there!

We are still looking for **corporate sponsorships** -- if you, your company, or anyone you know is interested in sponsoring the Buddy Walk, please contact Anna Cardenas at 214-824-3937 or annacardenas@sbcglobal.net for a sponsor packet. There are several sponsorship levels from which to choose – and one is right for you!

The new and improved Buddy Walk Teams!!!

Camaraderie, Fundraising, Teamwork, Prizes & more! Want to be a Buddy Walk Team Captain? Get your teams ready! Contact Maureen Tignor at 972-691-2458 or motig62@comcast.net for more information or for a team registration form. You can also obtain the team registration form and other useful forms and information on the DSG website, www.downsyndromedallas.org.

Buddy Walk Team Benefits

This is still plenty of time to register your Buddy Walk team. Teams consist

of 3 or more persons (of any age) who pre-register, raise money and walk together at the Buddy Walk. Whether your goal is to raise \$100, \$1000 or \$10,000, there are many benefits to forming a team.

First of all, there will be no individual fundraising prizes this year. All incentives will be earned by teams. You and your team can earn team posters, water bottles, visors and more. We will make sure that our teams stand out and are recognized and rewarded for their fundraising efforts.

While you still must raise an average of \$25 per team member for each person to earn a t-shirt, teams will have the opportunity to turn in their donations and pick up their t-shirts PRIOR TO the Buddy Walk...this means no standing in long registration lines on the day of the event.

All team forms can be found at the DSG website (www.downsyndromedallas.org), or you may contact Maureen Tignor at motig62@comcast.net or 972-691-2458.

So, avoid the long lines, and reap the rewards of participating as a team....
REGISTER NOW!!!!

Tips for Building a Team

Start with people that are closest to you:

1. Family Members
2. Friends
3. Neighbors
4. Business Associates
5. Others in the community (your hairdresser, doctor, etc)

Buddy Walk Challenge

The Buddy Walk raises funds to support the programs of the DSG, including meetings for the parents of newborns,

educational seminars for the families of school age children, and social events for teens and young adults.

Our goal this year is to double the donations and sponsorships we had last year. But 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!

Tips for Raising Money for the Buddy Walk:

- Day 1: Start by sponsoring yourself 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!

Look for more ideas on the DSG website, www.downsyndromedallas.org.



Buddy Walk 2006



Domingo, Nov. 12, 2006
Flag Pole Hill
Northwest Highway
at Buckner Blvd.
Dallas, TX

Uno de los eventos para recaudación de fondos más grandes del año del DS Guild, la Caminata de Amigos o Buddy Walk es nuestra caminata anual en apoyo al Síndrome de Down y específicamente a nuestros hijos con síndrome de Down. La **Buddy Walk 2006** se llevará a cabo en una excitante, nueva y más grande instalación – Flag Pole Hill cerca de White Rock Lake en Dallas. Mark your calendars, and tell all your “buddies” to be there!

Aún estamos buscando **patrocinios corporativos** – si usted, su empresa, o alguien que conoce está interesado en patrocinar la Buddy Walk, por favor contacte a Anna Cardenas al 214-824-3937 o annacardenas@sbcglobal.net para obtener el paquete de patrocinador. Existen varios niveles de patrocinio de entre los cuales escoger – y uno es el correcto para usted!

Los nuevos y mejorados Equipos Buddy Walk!!!

Camaradería, Recolección de Fondos, Trabajo en Equipo, Premios y Más! ¿Quieres ser un Capitán del Equipo de Buddy Walk? ¡Ten a tus equipos listos! Contacta a Maureen Tignor al 972-691-2458 o motig62@comcast.net para más información o para obtener una forma de registro para equipo. También puedes obtener la forma de registro y otros útiles formatos e información en el sitio de internet del DSG, www.downsyndromedallas.org.

Beneficios del Equipo Buddy Walk Team

Todavía hay tiempo suficiente para registrar a tu equipo Buddy Walk. Los

equipos consisten de 3 o más personas (de cualquier edad) que se inscriben con anticipación, recaudan dinero y caminan juntos en la Buddy Walk. Ya sea que tu meta sea recaudar \$100, \$1000 o \$10.000, hay muchos beneficios al formar un equipo.

Ante todo, este año no habrá premios individuales por la recaudación de fondos. Todos los incentivos serán ganados por los equipos. Tú y tu equipo pueden ganar carteles de equipo, botellas para agua, las viseras y más. Nosotros nos aseguraremos que nuestros equipos se destaquen y sean reconocidos y recompensados por sus esfuerzos de recaudación de fondos.

Aunque todavía tengas que recolectar un promedio de \$25 por miembro del equipo para que cada persona pueda ganar una playera, los equipos tendrán la oportunidad de entregar sus donativos y recoger sus camisetas ANTES DE la Buddy Walk. ... esto significa el no hacer largas filas para registrarse el día del evento.

Se pueden encontrar todas las formas de equipos en el sitio web de DSG (www.downsyndromedallas.org), o usted puede contactar a Maureen Tignor en motig62@comcast.net.

¡¡¡¡ Así es que evita las largas filas, y obtén las recompensas de participar como un equipo.REGISTRATE AHORA!!!!

Consejos para Construir un Equipo

Empieza con personas que son más cercanas a tí:

1. Los miembros de la familia
2. Los amigos
3. Los vecinos
4. Los socios de empresas
5. Los demás dentro de la comunidad (tu peluquero, el médico, etc)

Desafío Buddy Walk

La Buddy Walk recolecta fondos para sostener los programas del DSG, incluyendo reuniones para los padres de recién nacidos, seminarios educativos para las familias de niños en edad escolar, y para acontecimientos sociales para jóvenes y adultos jóvenes.

Nuestra meta este año es duplicar los donativos y los patrocinios que obtuvimos el año pasado. Pero necesitamos tu ayuda. ¡Así que el Comité de Buddy Walk desafía a cada uno de ustedes a duplicar los fondos que tú y tus compañeros hayan recaudado el año pasado!

Consejos para Recaudar Dinero para la Buddy Walk:

- Día 1: Empieza patrocinándote a ti mismo con \$25
- Día 2: Pide a tres miembros de la familia que te patrocinen con \$25
- Día 3: Pide a cinco amigos que te patrocinen con \$20
- Día 4: Pide a cinco colegas que te patrocinen con \$10
- Día 5: Pide a cinco vecinos que te patrocinen con \$10
- Día 6: Pide a cinco personas de tu iglesia/el templo/mezquita que te patrocinen con \$10
- Día 7: Manda un correo electrónico a 15 personas y pide un donativo de \$20
- Día 8: Pide a cinco negocios que te patrocinen con \$25
- Día 9: Pide a tu empresa que te patrocine con un donativo igual
- ¡Wow, recaudaste \$775 más una iguala de la empresa!

Busca más ideas en el sitio de internet del DSG, www.downsyndromedallas.org.

Buddy Walk Raffle

The Buddy Walk Raffle is a way to participate even if you cannot attend. It is also a great way to involve family and friends who cannot attend – especially those who live out of town!

RAFFLE ITEMS

- Balloon Ride for two from Balloon Trek
- Two autographed Dallas Cowboy footballs
- Jewelry
- Fossil Gift Box
- Gift Certificate to Crescent Designs
- Hand Carved Walking stick and corresponding DMN article about the artist
- Beaded Plant Hanger
- ...and more!!

Raffle Instructions:

- 1) Print or copy ticket(s).
- 2) Sell as many as you like!
- 3) Buyer keeps dated portion of ticket.
- 4) Fill out buyer's information on each RAFFLE TICKET portion, and return with payment via mail to:

**Down Syndrome Guild of Dallas
701 N. Central Expressway
Building 5-I
Dallas, TX 75080**

Payment must be by check or money order ONLY. Please do not send cash.

For questions or to donate items for the raffle, call Michele Watson Gullely at 214-357-2125. **All tickets must be received by October 30, 2006 in order to be entered for this raffle.** After that date, raffle tickets will be sold only at the Buddy Walk on Sunday, November 12, 2005.

Please be creative in your efforts to raise money to support the Buddy Walk and the DSG!

-Submitted by Anna Cardenas ☺

Rifa Buddy Walk

La Buddy Walk es una manera de participar aunque no puedas asistir, y también implica a familiares y amigos dentro y fuera de la ciudad que no pueden asistir.

ARTÍCULOS PARA RIFA

- Paseo en Globo para dos en Balloon Trek
- Dos balones autografiados de los Dallas Cowboys
- Joyería
- Caja de Regalo Fossil
- Certificado de Regalo de Crescent Designs
- Bastón para caminar Tallado a Mano y el correspondiente artículo DMN sobre el artista
- Macetero Colgante con cuentas
- ...y más!!

Instrucciones para la Rifa:

- 1) Imprime o copie los boletos.
- 2) Vende tantos como quieres!
- 3) El comprador mantiene la porción del boleto con la fecha.
- 4) Llena la información del comprador en cada porción del BOLETO DE RIFA, y envíalo por correo a:


**Down Syndrome Guild of Dallas
701 N. Central Expressway
Building 5-I
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El pago debe hacerse con cheque o giro postal SOLO. Por favor no mande dinero en efectivo.


Para preguntas o para donar artículos para la rifa, llama a Michele Watson Gullely al 214-357-2125. **Todos los boletos deben ser recibidos a más tardar el 30 de octubre de 2006 en orden para participar en esta rifa.** Después que esa fecha, los boletos para la rifa se venderán sólo en la Buddy Walk el domingo, 12 de noviembre de 2005.


Por favor sé creativo en tus esfuerzos para recaudar fondos para apoyar la Buddy Walk y al DSG!


-Remitido por Anna Cardenas ☺


 2006 BUDDY WALK RAFFLE \$5.00 Hosted by \$5.00 The Down Syndrome Guild of Dallas	Raffle Ticket Receipt Date: _____
	2006 Buddy Walk Sunday, Nov. 12, 2006 11:00 am - 3:00 pm Walk starts at 1:00 pm Flag Pole Hill Northwest Highway at Buckner Blvd. Dallas, TX \$5.00
Name: _____	
Address: _____	
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	2006 Buddy Walk Domingo, Nov. 12, 2006 11:00 am - 3:00 pm Caminata comienza a 1:00 pm Flag Pole Hill Northwest Highway at Buckner Blvd. Dallas, TX \$5.00
Nombre: _____	
Domicilio: _____	
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Nombre: _____	
Domicilio: _____	
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Tuesday, October 10, 2006
 The Tribute Golf Course
 1000 Boyd Road
 The Colony, TX
www.thetributegolfinks.com

Get ready for the DSG's Golf Classic!
 A 'hit' with golfers and non-golfers alike, this event provides major funding for the programs and services of the Down Syndrome Guild of Dallas.

Volunteers Needed

For Volunteer Opportunities please call Teresa Sims-Ramirez at 972-252-1512 or email her at TeseRamirez@aol.com. No golf skills required, just your time.

Golf Classic Corporate Sponsor Opportunities

Diamond - \$10,000

12 Golf spots / 24 dinners
 Company name on corporate board
 Listing on tournament banner
 Company logo or name in tournament entry brochure
 Sign at driving range or practice green
 Recognition at Awards Dinner
 Full page ad in tournament program
 Hole recognition sign
 Company logo on all promotional material

Platinum - \$5,000

8 Golf spots / 16 dinners
 Company name on corporate board
 Listing on tournament banner
 Company logo or name in tournament entry brochure
 Recognition at Awards Dinner
 Hole recognition sign
 1/2 page ad in tournament program

We welcome sponsors at any time before the tournament. However, inclusion in the tournament program cannot be assured for donations made after September 1, 2006.

Please invoice OR enclose a check made out to DSG or AMEX, VISA, MC (circle one)

Card number: _____ Expiration Date: _____

Company Name: _____

Contact Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Telephone Number: _____

MAIL or FAX to:

Down Syndrome Guild Golf Classic, c/o Down Syndrome Guild of Dallas
 1244 Jeanette Way, Carrollton, TX 75006
 Phone: 972-242-3664, FAX: 972-446-0438 Attn: Carole George

Golf Classic Underwriting Opportunities

Shirts — \$5,000

Underwriting the player and volunteer shirts will give your organization the opportunity to make everyone look good on the course, while placing your logo on the sleeves of 200 energetic and visible people. The high-quality shirts provided to each player and volunteer will be worn again and again, linking your name with the event throughout the year. You receive four golf spots, a half-page ad in the program, listing on the corporate board and eight dinner tickets.

Forecaddie — \$3,600

Be recognized by every foursome! Each group will have a forecaddie to assist in shot selection and efficient play. Caddies will wear tournament bibs with your company logo on the front and back. You receive two golf spots and four dinner tickets. Deadline for sponsorship is August 15, 2006.

Dinner — \$3,500

After play, everyone will be looking forward to dinner and the Awards Reception. Underwrite this event and your company name/logo will be displayed throughout the reception area and listed in the tournament program as the Dinner Sponsor. You receive two golf spots and four dinner tickets.

Lunch — \$2,000

Prior to play, everyone will be counting on a tasty box lunch. Underwrite this event and your company name/logo will be displayed throughout the area and listed in the tournament program as the Lunch Sponsor. Four dinner tickets will also be provided.

Logo Golf Balls — \$1,000

Tournament participants will receive a sleeve of golf balls with the tournament logo and your company name or logo imprinted. Every time the golfer uses the balls, whether at the tournament or later, they will be reminded of your business. Two dinner tickets will also be provided.

Postage — \$500

Tournament brochures will be distributed to over 800 homes and businesses throughout Dallas and its surrounding suburbs. Your company will be acknowledged as the underwriter of postage. You will also receive two dinner tickets.

We welcome sponsors at any time before the tournament. However, inclusion in the tournament program cannot be assured for donations made after September 1, 2006.

Please invoice OR enclose a check made out to DSG or AMEX, VISA, MC (circle one)

Card number: _____ Expiration Date: _____

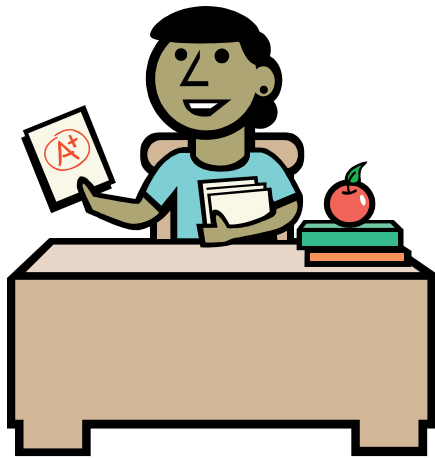
Company Name: _____

Contact Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Telephone Number: _____



Perspectives in Parenting – Opening lines of chatter yield results

By Nancy Lambert Davenport

“How was your day, Sweetie?” most mothers ask as their child gets in the car after school.

“Okay,” is inevitably the answer.

Why do we even bother to ask?

We want to know more, but we don't want to interrogate. We wish we could just call up the teacher every day and ask how things went. Everyone gets a little frustrated with communication between parent and school, but it can get particularly frustrating when the student has disabilities which involve language.

Kim Voss, a mother in Tulsa, Oklahoma came up with some methods to help open that communication and keep it open. She points out that home-to-school-to-home communication systems only work if they meet the needs of people on both ends of the lines of communication.

They are also more likely to be used if

they are quick, understandable and easy, she said, in the article that appeared in the March/April 2000 edition of Disability Solutions. The most important part of setting up this system is to get everyone together who is in the communication loop. Decide at that time whether the system should be a check list, fill in the blank, or a narrative.

In other words will there be a standard list of accomplishments or needs to check off, will everyone jot a quick note concerning predetermined subjects, or will parents and teachers just write a note?

At this first get-together everyone needs to decide on some parameters:

- When there is a student with a disability involved, ask what part the student will play in the communication if any. Get that commitment up front.
- Ask who will contribute information--teacher, therapist, etc. and one or both parents.
- Decide how often everyone should write.
- Find out what people want to know--daily behavior, homework, activities, etc. Try to keep it simple, so that the maximum information can be communicated in the minimum amount of time.
- Ask what form this communication will take---a notebook with long narratives, some bound together forms to fill in the blank, multiple copies of a list in a three-ring binder to check off accomplishments, or even electronically through email.

If relationships are strained between home and school, keep in mind that long narratives are probably less constructive than the other methods.

An example of a fill-in-the-blank list might contain:

- *Today Chuck enjoyed:*
- *In class we worked on:*
- *Today Chuck's buddy in class was:*
- *Today Chuck was feeling:*
- *Today Chuck needs to work on at home:*
- *Comments from the teacher:*
- *Return comments from home:*

For kids with disabilities, it is a good idea to put the method of communication in the student's Individual Education Plan (IEP). Otherwise there is no way to insist that the communication continue if it breaks down.

Voss points out that this tool turns into more than a communication device when used well. It is also a teaching tool.

Students learn about the calendar, learn to plan ahead, and have a bouncing off point to tell family about their day.

If the student is involved in the delivery of the information to and from home, he or she has some responsibility to enjoy.

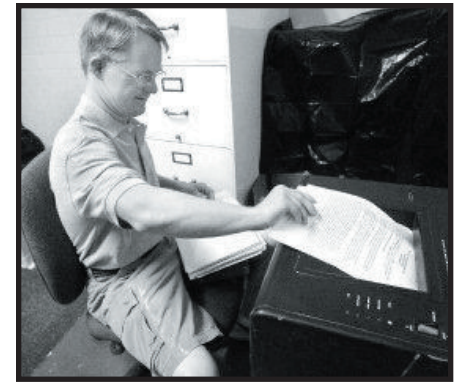
This certainly may help parents get out of that terrible pattern of knowing so little of what is going on at school and will help teachers get that support from home they want so much.

Thank you to Kim Voss and her article “How Was Your Day? Designing Home-to-School Communication for Your Child” in the publication “Disability Solutions” Volume 4 Issue 2, March/April 2000.

Contact Nancy at nancdave@swbell.net.

Man With Disability Is Sure He Can Cut It In Business

By Terry Lee Goodrich,
Ft. Worth Star-Telegram Staff Writer



STAR-TELEGRAM/EMILY HUGHES

Chad Turner shreds clients' documents recently at his shredding business, Chad's Chopp'N Company, in Euless.

In his younger days, Chad Turner used to sit in his bedroom and pretend that it was his office. But these days, Turner is a company president with a real office.

Turner, 25, who has Down syndrome, in mid-May started Chad's Chopp'N Company -- a Euless commercial paper-shredding business -- and is fervently marketing and networking to build a business that will help recycling efforts.

“I love to shred,” he said.

Most people born with Down syndrome, a congenital condition, have limited cognitive ability, as Turner does. But the Bedford resident also has determination, family support and a boost from area business executives willing to give him a chance. Plus he has a spiffy green shirt with a logo he chose and business cards touting him as “Your Safe, Secure, Experienced Shredder.”

Turner, a 2001 graduate of L.D. Bell High School in Hurst, completed the Transitional Skills Program at Tarrant County College's Northeast Campus, in Hurst, in fall 2003. Then it was on to earn an office skills certificate last July at Eastern New Mexico University in Roswell, where he was enrolled in the Special Services Occupational Training Program.

In Roswell, he shredded papers for the Hispanic Chamber of Commerce and took a liking to the work.

"One thing they taught Chad and others in the program at Roswell is that they have limitations and have to accept them but that they also have lots of choices and opportunities," said Larry Turner, Chad Turner's father and sales manager of the shredding company.

In April, uncle Steve Brodie of Pottsboro gave Chad Turner a heavy-duty paper shredder for his business, which began in the family garage.

Chad Turner went to the Service Corps of Retired Executives, laid out his business plan and sought advice for marketing and running the business.

Chad Turner and his father brainstormed to come up with a company name, adding an extra p to chop to make it more memorable. Chad Turner selected the logo -- a hatchet and greenery -- to signify chopping up paper and convey the notion of "green," as in recycling. He is seeking a recycling company to buy his shredded paper.

Chad Turner has made a presentation to the Hurst-Eules-Bedford Chamber of Commerce to drum up business; he hands out business cards at every chance, including to his dentist and speech therapist. His target market is businesses within a 10-mile radius of

his office, on Clinic Drive. Some clients drop off paper; for others, his father takes him to pick up documents.

"I review all our accounts payable and receivable with him, and I have invoices for his signature," Larry Turner said.

The business is still in the red, but Chad Turner pays himself a small salary and commission. He is saving diligently to get a larger shredder that will cost more than \$4,000, his father said.

"And sometimes, I save some of my money for our church," Chad Turner said.

His clients include Dr. Cody Mihills of Southlake, a family physician who is impressed by Turner's initiative.

"He spoke to our office manager and set it up very confidently and independently," Mihills said.

"He's joyful and fun to be around."

Another fan is Connie Ogden, president of the Liberty Tax Service franchise in Bedford, who hired him to work for her during the height of income tax season this year. He donned an Uncle Sam costume and waved at passers-by to promote the tax business.

"I worked for Uncle Sam," Chad Turner said with a laugh.

Ogden said he did a good job and was enthusiastic.

Chad Turner's schedule is jam-packed. He works a second job at Cinemark Tinseltown Grapevine theater, where he ushers and cleans.

He also takes a self-defense class and sees a speech therapist.

"And I have a girlfriend," Turner said, his face lighting up.

He met her in Roswell, and she lives

in Fairview. The two talk often on the phone and went to a Dallas Mavericks game together.

"She's the best," Chad Turner said.

He recently moved out of his parents' home in Bedford into a condominium in a complex operated by North Texas Special Needs Assistance Partners (SNAP) in Grapevine. And he is about to move from a tiny space in an office complex owned by the SNAP board chairman to a renovated larger space in the same building.

Chad Turner's mother, Marlene Turner, treasurer of North Texas SNAP, said she is delighted to see her son moving toward independence.

"I'm just really proud of him," she said. "He's had a lot of accomplishments in the past several years, but this one is the top of the list. It's beautiful to see the community support, and I'm sure he feels proud of himself. You can tell by his smile."

Chad Turner is particularly proud of the "destruction certificates" he gives to customers certifying that he has destroyed their documents and thanking them for the opportunity to serve them.

"It's going good," he said.

- Submitted by Elizabeth Longworth. The girl friend mentioned in the article is Alana Drablos, a member of the DSG. © 2006, Ft. Worth Star Telegram. The story is available online for a limited time at <http://www.dfw.com/mld/dfw/news/15056548.htm>. Reach Terry Lee Goodrich at 817-685-3812 or tgoodrich@star-telegram.com.



Diagnosis of Autism in Children With Down Syndrome

Synopsis

As many as ten percent of persons with Down syndrome may also be diagnosed from autism. Exact data is difficult to obtain. Many cases go undiagnosed, or are diagnosed at a later age. Many diagnosticians are unaware that the two conditions may exist or are reluctant to apply the second diagnosis. Autism diagnosis is much more complicated than Down syndrome; there is no blood test, genetic marker, facial features, or other characteristics that apply to all autistic persons. The diagnosis is subjective, depending on meeting observations of certain behaviors. Diagnosis and treatment of autism is much more critical than for Down syndrome. Without early detection and intervention the life of a person with autism may be much more limited than that of a person with Down syndrome and often results in children with autism living in a residential school rather than at home because of inability of the parents and the school system to cope with the child's behaviors.

Symptoms of autism in Down syndrome

The key area affected developmentally in a child with Down syndrome is the cognitive area, the development of thinking, reasoning, and understanding. Delays are expected in this area. Another area of development is the social and emotional development.

These areas develop more normally in a child with Down syndrome but not in a child with autism. Coleman and Rogers (1992) give the following account of the expected social and emotional development in a child with Down syndrome.

Most babies with Down syndrome show the least delay in social and emotional development, smiling when talked to at 2 months (range 1.5-4 months), smiling spontaneously at 3 months (range 2-6 months, and recognizing parents at 3.5 months (range 3-6 months); each of these milestones show only a 1-month delay on average. Although some studies suggest that the intensity of affective responses such as smiling and laughing may be slightly less than that shown by typical babies, parents respond warmly to the onset of smiling and eye contact. Babies with Down syndrome begin to enjoy pat-a-cake and peek-a-boo games at about 11 months (range 9-16 months), which is about 3 months later than typical babies. Studies in the second year of life show the babies to be skilled in social communication even using social skills to attempt to distract an adult from a task the baby does not want to attempt. Babies with Down syndrome typically are warm, cuddly, and usually responsive to physical contact, unlike babies with some other types of disabilities such as autism.

This normal emotional responsiveness continues into adult life, and as studies of teenagers have shown, it develops into proper empathy, making the person with Down syndrome a sensitive and socially aware person to live with.

So the key areas to watch for in a child with Down syndrome suspected

of having a complicating behavior disorder such as autism are in the social and emotional areas. Some professionals will argue that social and emotional development can be expected to be affected by delays in cognitive development and it is not evidence of a separate disorder. This is where the subjective nature of autism diagnosis comes in. It's a matter of degree.

Some key behaviors that may point to the possibility of autism in a child with Down syndrome are:

1. Extreme Autistic Aloneness - The child does not relate to people normally and seems to prefer to be left alone. The child seems to consider other persons as objects, not people. He will not join in group play with other children. Unlike children with Down syndrome, who are usually very lovable and huggable, the child with autism does not want to be held.

2. Anxiously obsessive desire for the preservation of sameness - Any differences in daily routines can cause a large upset.

3. Lack of eye contact – People with autism typically do not make eye contact but will look away or “right through” other people.

4. Shows repetitive, “Stereotypical” movement, like sitting for long periods of time with an object in his hand and just waving it back and forth looking at it.

A checklist of autistic behaviors is presented in Figure 1. Some of these characteristics are normal, up to a point, in a child with Down syndrome -- complicating the diagnosis of autism in those children.

Individuals with autism usually exhibit at least half of the traits listed below. These symptoms can range from mild to severe and vary in intensity from symptom to symptom. In addition, the behavior usually occurs across many different situations and is consistently inappropriate for their age.



Figure 1. Checklist of autistic behaviors

Adapted from the original by Professor Rendle-Short, Brisbane Children's Hospital, University of Queensland, Australia.

Autism and PDD - Definitions

The official term for autism, as defined by the American Psychiatric Association in their DSM-IV, is Pervasive Developmental Disorders (PDD). The Pervasive Developmental Disorders is a class of five diagnosable disorders including Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Aspergers's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. Sometimes the term autism is used to describe the Autistic Disorder and sometimes it is used to describe all five PDD's. There are also other related diseases that together are called the autistic spectrum disorders. For purposes of this article I assume autism to include all five PDD's.

Diagnosis of Autism in Down Syndrome - DSM-IV Checklist

Autism is diagnosed by evaluating the behavior of the patient. There are sixteen descriptive symptoms to look at. If an appropriate combination of eight are displayed, a diagnosis of autism is reached. These symptoms are grouped into four general areas; Severely Impaired Social Interactions, Severely Impaired Communications and Imagination, Extremely Limited Interests and Activities, and First Observed in Infancy or Early Childhood. In some cases, as in Down syndrome, cognitive delay may mask the autism and a diagnosis may come later or not at all.

When diagnosing autism in a person with Down syndrome, the diagnostician must examine each criteria in terms of whether it is a normal trait for the person with Down syndrome and, if it is a normal trait, is it more severe than normally found in a person with Down syndrome.

Issues in diagnosing autism in persons with Down syndrome

There are a number of reasons why there are not very many reported cases of autism in persons with Down syndrome.

One issue in the diagnostic criteria is the requirement for onset before age three. In the case of Down syndrome, the parents of a young child with Down syndrome and the professionals attending them are concerned with the Down syndrome itself with its possible complications of cardiac problems, leukemia, and other problems. Delays in development are expected. Given the expected delays in development, it simply does not occur to parents or professionals that autism may be present. The parents have probably never heard of autism and are completely unaware of symptoms. The same can be true for some of the professionals dealing with a child with Down syndrome. Only the most astute of diagnosticians is likely to recognize autism in a child with Down syndrome before age three. Only when the child becomes older, or if the parent persists, may it become clear that autism is present. But some diagnosticians will apply the three year rule and decline the autism diagnosis later on because the records do not show the presence of the symptoms before age three. The issue of early onset, then, becomes a major obstacle to the diagnosis.

Another issue is that persons with Down syndrome can exhibit a few of the DSM-IV criteria as a result of the Down syndrome. When looking for eight of sixteen specified criteria the diagnostician may be tempted to excuse those symptoms characteristic of Down


syndrome and not garner enough symptoms to give the autism diagnosis.

Some diagnosticians may not wish to burden the family with an additional label, i.e. autism. This denies the family the opportunity to join autism support groups and to seek out autism interventions. While the autism and Down syndrome treatment protocols overlap and have many similar characteristics, the autism treatments are much more intense. And treatment for autism is more critical in averting lifetime consequences.

I am in contact with a number of parents with children having the dual diagnosis of Down syndrome and autism. All have reported extreme difficulty in obtaining the dual diagnosis. They could not understand the failure of their children to develop socially and emotionally, with deficits beyond that normally found in a child with Down syndrome. They had to shop around and practically beg the professionals to tell them what was going on with their child. These are not cases of hypochondriac parents trying to pile up diagnoses but rather concerned parents who want to know what is going on with their child.

As mentioned earlier, diagnosis of autism is rather subjective to begin with, and gets even murkier in persons with Down syndrome and other known forms of cognitive delay. Finding clear and valid statistical data is very difficult due to the vagaries of autism diagnosis. Establishment of a clear scientific statistic is not the point. The point is that the two disorders do indeed co-concur, and in significant numbers. Since the stakes are much higher in autism as mentioned earlier, it is critical that autism be recognized when it is present in children with

Down syndrome so that appropriate treatment protocols can be pursued and the parents can look outside the Down syndrome community.

-Submitted by Patty Bates-Ballard.
© 1998 Glenn Vatter, a retired engineer whose son with Down syndrome, now 25, was diagnosed with autism when he was twelve then later withdrawn. This article was edited for length and for people first language. You can read the complete article, including DSM-IV for the Autistic Disorder with bullets after each criteria at <http://www.altonweb.com/cs/downsyndrome/index.htm?page=autism.html>. 



A Baby Is A Baby First

By Kate Sefton, Master Developmental Therapist

There is nothing quite like a baby... there's a lurch in the heart when we touch the beginning of a life in the small person of an infant. For some parents, the lurch is made more poignant, even painful, by their baby's diagnosis of Down syndrome.

Recently, I've had the great pleasure of holding a number of soft, beautiful babies who have Down syndrome. Their parents want to find out what it all means, what they can do, what to think about the future. The first professionals to talk to the parents of babies with Down syndrome tend to discuss the differences parents may see, difficulties babies will encounter. Armed with information about what milestones their child may not reach, what problems she may have, what services they should obtain to avoid potential problems, new parents want to help their babies as soon as possible. So they come to me (and to

numerous others) to get this help...to find therapy, activities, and solutions to problems that may or may not exist.

We just don't know, at an early age, in exactly which ways Down syndrome may affect a child. She may be really good at cognitive activities, but have significant delays in movement... thereby falling behind her peers in playground and paper-and-pencil activities. He may be fairly good at gross motor, excelling in sports. Ocular control may be an area of need, or may be perfect. Language may be good, or may need lots of work. However, one thing we know for certain... babies don't deal with these things no matter what their chromosomes look like. They lie down and expect to be carried, cuddled, talked to, fed and generally catered to. They learn they are lovable, cute, and the center of the universe. They begin to know who their family members are, and who is the soft touch in the house in the middle of the night.

If these adorable creations have Down syndrome they are at risk for certain physical and cognitive delays. It behooves parents to keep an eye open for problems that could arise. It's important that they know something about their child's diagnosis so that they can be alert and helpful. But my belief is that the most important things that parents of babies with Down syndrome can do are exactly those things that all parents do. You know: cuddle, feed, sing and love. Not the kind of things you need a Developmental Therapist for... or any other therapist, for that matter.

I want to be clear. Young children with Down syndrome often show delays that need to be addressed so that they can be happy with themselves and do their very best. There are concerns about early development in very young babies with Down syndrome. And doubtless, parents will find themselves

driving this child about for ear infections, speech therapy, developmental evaluations, etc. But the main advice I have for parents of new babies with Down syndrome boils down to this:

You have a beautiful new baby.

There will be some areas that need work, but what you have right now IS PRECIOUS AND PERFECTLY RIGHT.

-Submitted by Patty Bates-Ballard.
© 2006, Kate Sefton, Down Syndrome Connection of the Bay Area. Reprinted with permission. The article is located at <http://www.ndscenter.org/resources/package2.php>.



A Very Special Wedding

By Patty Bates-Ballard

Time Magazine's July 24, 2006 issue featured an article on the wedding of a young couple with Down syndrome. The article, by Claudia Wallis, follows Upstate New Yorkers Carolyn Bergeron, 29, and Sujeet Desai, 25, as they take their vows first at a Hindu ceremony and later at a Christian church. "There is news today," says the Rev. James Paulson. "Love," he says, can't be stopped by cultural differences or different faiths. "Love can't be stopped by Down syndrome." Carrie and Suj, as they're known, met at a National Down Syndrome Congress conference. He was shy and asked his mom what he should say to her. She had been longing to have a relationship after seeing her siblings get married. You can read the full story for a small fee at <http://www.time.com/time/magazine/article/0,9171,1214946,00.html>. See the beautiful wedding photos for no charge at http://www.time.com/time/photosays/2006/special_wedding/.

SAVE THE DATE!!!

March 12, 2007



Are you waiting for community services, therapy, attendant care, durable medical equipment or respite?

Are you struggling with transition from children's services to adult health care services?

Are transportation issues keeping your loved one with a disability from work, medical care or school?

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We are looking for:

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Contact Jeanine Pinner at jeanine@txp2p.org or 512-217-3558 to find out how to share your story!

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