

CONNECTIONS



Building a network for individuals with Down syndrome, their families, and the professionals who serve them.

Volume 16 Number 4

WWW.KCDSG.ORG

July/August 2009

DSG BABY BOOM!

The DSG staff are on the go trying to keep up with the recent baby boom we are experiencing! In the last 9 weeks we have welcomed 19 new babies with Down syndrome to the DSG. Their families were all provided hospital visits, new parent baskets, Family & Friends Packets to educate those in their circle of support and matched with experienced parents for additional mentoring and support.

Our recent new parent support breakfast welcomed 15 new families with our youngest attendees being just three weeks old! If you are interested in helping DSG welcome new families adjusting to the diagnosis we encourage you to attend our upcoming parent to parent training to learn more.

Parent to Parent Training

Saturday, July 25, 2009

9:00 AM-11:00 AM

DSG Center

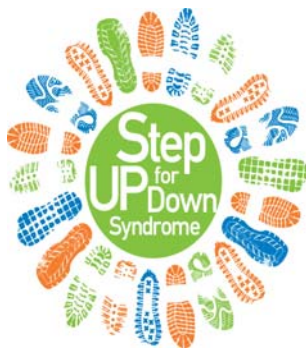
Childcare and dinner provided

RSVP required by July 20th

info@kcdsg.org or 913-384-4848

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Are You Ready to Step UP For Down Syndrome?

We are taking a step in a new direction this year! Mark your calendars now for the Step UP for Down Syndrome Walk which will take place on Saturday, October 24, 2009 at Arrowhead Stadium. Every step you take can and will make a difference in the life of someone with Down syndrome.

There are over 250 Down syndrome awareness walks held world wide each year. Kansas City is home to one of the largest celebrations in the world. We welcomed over 7,000 walkers and 300 teams last year. Raising over \$450,000 to support people with Down syndrome was an amazing accomplishment. We need your help to make that goal again. Besides creating greater awareness of Down syndrome, a majority of DSG's programs are funded through proceeds raised at the walk. That's why it is **VITALLY IMPORTANT** that you Step UP and make a team!



WALK DEADLINES YOU NEED TO KNOW ABOUT

August 31, 2009

Team Captain Commitment Forms Due– if you opt not to use the online registration system.

September 25, 2009

Team Name on T-Shirt Deadline– **SHOW YOUR PRIDE!** General event shirts provided to anyone who registers beyond this date.

October 17, 2009

T-shirt Pick Up Day and Fundraising Prize Deadline- Avoid long lines at registration!

October 22, 2009

Online registration closes at 5:00 PM

Register and start your team today!
www.stepupfordownsyndromekc.org



D.A.D.S. Family Fishing Fun

810ZONE

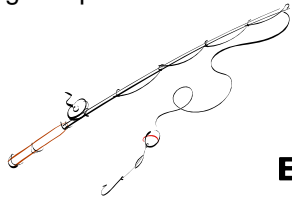
 Sunday, July 19, 2009
4:30pm to sundown
James A Reed Memorial
Wildlife Area
at Praire Hollow Lake

Thursday, August 20, 2009
6:30 PM-??
810 Zone
4900 W. 119th Street
Leawood, KS

What to expect for the day!

- Concrete walkway, great for first time fishers 
- Fishing license required for those over 15 years old.
- If you are planning to only help your little one with fishing you don't need a license
- DADS will provide hamburgers and hot dogs 
- Come join us as we enjoy food, fellowship and fishing!

Directions: At 50 Hwy and Ranson Rd, follow Ranson Rd south, past Browning Rd, and turn left into the area where Prairie Hollow Lake is located. Do not use main park entrance to get to pond.



RSVP to Kevin Hight
913.940.8377
info@dadskc.org
By Thursday, July 16th

Dads come out to meet other new dads who have joined our group and catch up with old friends! We will meet at 6:30 at the 810 Zone (at Town Center Plaza, 119th and Roe). DADS will cover \$5 towards your dinner. Contact Kevin Hight at 913.940.8377 or Robert Merritt at 816.419.9206 or you can always email us at info@dadskc.org Grab another DAD and bring them with you! Hope to see you there!



Our mission is to assist and support, through fellowship and action, the fathers and families of individuals with Down syndrome.

Download Now!



iPrompts™
www.handholdadaptive.com

 **HandHold Adaptive™**
Mobile Technology for the Differently Enabled

Now available for the iPhone and iPod Touch, **iPrompts™** is a customizable prompting tool for use with individuals that may benefit from having structure and visual aids throughout the day. The application is designed especially for parents, special educators and therapists to use with developmentally challenged and language-impaired individuals, like people with Autism, Down syndrome, Fragile X syndrome, and apraxia of speech. iPrompts™ also benefits kids who just need more structure, including kids with Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD), and even typical, pre-verbal toddlers!

The application provides several useful prompting tools to help individuals transition from one activity to the next, understand upcoming events, make choices, and focus on the task at hand. Visit the website today to watch a video tutorial!

* **PICTURE SCHEDULES:** Allows caregivers to create sequences of pictures, guiding those they care for through activities of any sort. Captions can be edited for each image, allowing users to create SOCIAL STORIES. Caregivers can also create simple FIRST THIS, THEN THAT picture prompts using only two images. Choose from hundreds of stock photos and illustrations provided by **iPrompts™**, or take pictures "on the fly" using the iPhone's built-in camera.

* **VISUAL COUNTDOWN TIMER:** Displays an image of the caregiver's choice along with a graphical countdown timer (set to any duration). Useful for demonstrating how much time is left before the next pictured activity begins.

* **CHOICE PROMPTS:** Lets caregivers select any two images which may be offered as a choice, empowering those who cannot vocalize their preferences. When rotated horizontally, the Choice Prompt and Picture Schedule features enlarge and orient images for display to individuals needing visual support.

* **IMAGE LIBRARY:** Includes hundreds of useful illustrations and digital pictures across numerous categories. Additional categories and pictures can be created and supplied by users.

President's Letter

Dear Members,

"Let's hope for the best." We have heard this phrase from physicians, therapists and educators when embarking upon an evaluation for our child with Down syndrome. For many of us, best went out the window when the doctor walked through the door with the diagnosis.

With fifteen new babies born with Down syndrome in the past seven weeks, new parents all over the Kansas City area are grappling with hope and quickly redefining best. At the Murphy household hope has been replaced with success and the ever changing best with remarkable.

We are drawing closer to the end of our journey as parents of a child with Down syndrome and are about to embrace our new roles as persons who support a young adult with Down syndrome. A trip down memory lane is in order. New parents are welcome to enjoy.

A preschooler who is seemingly without language skills can still talk the rest of his bus mates into handing over their work so it can be thrown out the window. Failing to provide the sign language for, "I'm mad at you, Mom" will not prevent your child from making up his own sign.

Not every body of water is a bathtub, but every body of water must be experienced.

Halloween costumes are not just for Halloween, they are for any occasion no matter how formal. Heroes come in all shapes and colors. Markers can be used to change skin color to insure authenticity.

Docile and loving does not extend to siblings.

Christmas gifts are the best ever every year. Cards that are so full of over-the-top sentiments one can't believe anyone would buy them, find their way into your Mother's Day. Father's Day ends each year with two guys and a horror movie.

Planning for birthday parties begins the day after the previous birthday party. Counting money is exceptionally difficult. Understanding the value of a gift card is not.

Movie theaters are places where the most challenging behaviors melt away along with the butter on the popcorn. Movie trivia expertise does not necessarily insure full-time employment opportunities.

Professional wrestling is real.

Success and remarkable are always open to interpretation.

Bridget Murphy
DSG Board President

Frito Lay Supports DSG

DSG formed a wonderful partnership with Frito Lay in 2008. Frito Lay has been fantastic to provide yummy snacks and volunteer support for DSG events since our partnership formed.

Mark Hobson, of Frito Lay, states "the KC Zone Team realizes how important it is to support local community and charity events. We not only expect to lead our industry in savory snacks, but also lead in supporting the needs of their community as well. The KC Zone team learned about the annual walk from one of their recent new hires. In an effort to get to know new hire Mark Lietzow, it was discovered that his son had Down syndrome and they wanted to provide support."

The KC team contacted the DSG for more information. They teamed up with the Executive Director, Amy Allison, and invited her to a zone meeting in order to learn more about Down syndrome, the DSG and how they could get involved. In addition to donating 8500 bags of chips the team also signed up to participate in the walk at Arrowhead and assembled a team of volunteers to provide clean up support."

As if that was not enough, the KC Zone Frito Lay team decided to host a Trivia Night fundraiser for the DSG. In just four short weeks the event was put together and over 100 Frito Lay staff and friends gathered at PowerPlay in Shawnee. The evening was fantastic fun raising \$2,800 for the DSG.

When you are headed to the grocery store please make sure Frito Lay products are right at the top of your list to put in the cart!



KC Zone Frito Lay Staff
Amish Patel (L) and
Mark Hobson (R)
present DSG Executive
Director, Amy Allison, with a
\$2,800 check from the
Frito Lay Trivia Night.

African American Friends

Saturday, July 25th, from 1pm to 4pm. Meeting then *Swimming*, Cleaver Family YMCA, 7000 Troost Avenue. New Parents come out and meet teens and young adults with Down syndrome. Lifeguards on duty. Picnic Lunch will be served! RSVP by JULY 20th by contacting Petrice Welch at 816.531.7265 or via email at chelwelch@yahoo.com.

B.E.S.T. Network

Bring you 6-12 yr. old over to our studio, 8100 W 116th St, OP, KS. **EVERY Saturday**, from 10 –11:30am. We teach simple dance numbers, sign language to music, special activities, introduce them to a microphone, and encourage each individual to express themselves artistically, RSVP to Marlene, 913.663.9936

Dads Appreciating Down Syndrome

Sunday, July 19th at 4:30pm, DADS Annual Family Fishing outing at James A Reed Memorial Wildlife Area at Prairie Hollow Lake, located off 50 HWY and Ranson Rd. Bring the entire family to enjoy hamburger and hot dogs and an afternoon of fishing fun. If you're only planning to help your little one with fishing, you don't need a fishing license but if you will for those over the age of 15. Please remember not to use the main park entrance. Enter the James A Reed Memorial Park off Ranson Rd at the Prairie Hollow Lake entrance. RSVP by July 16th.

Thursday, August 20th at 6:30pm, Meet us at 810 Zone, 4800 W 119th St in Leawood, Ks. Dads will get together for food, fun, and fellowship. RSVP by August 18th.

To RSVP contact Kevin Hight by calling 913.940.8377 or Robert Merritt, 816.419.9206 via email at info@dadskc.org. Visit the DADS website at www.dadskc.org. Got a Facebook page? Search: D.A.D.S of Kansas City to join our group!

Dotte Friends

Saturday, July 18th at 11am Dotte Friends invite you to a picnic. We will have it at Leslie Kamai's house at 3548 N. 115th St. in Kansas City KS (Piper area). We will supply grilled hot dogs and hamburgers, drinks, and chips. You may bring a side item of your choice (fruit, side dish or dessert). Bring your lawn chairs and/or blanket to sit on.

Please RSVP by July 15th to Becky Mesler at 913-788-9013 or 913-940-8512 or Leslie Kamai (for directions) at 816-665-0171.

Down Syndrome Group of the Ozarks

Second Monday of each month, meetings are held from 6:30-8:30 PM at High Street Baptist Church. Childcare provided with RSVP and a small donation. Call 417.885-9905 or visit www.ozarksdsg.org for more information.

Eastland FRIENDS

Saturday, July 11th, 11am to 2pm. Bring the entire family out for Eastland Friends Annual Family Picnic. Hamburger, hot dogs, chips and drinks will be provided. Meet us at Burrus Old Mill Park, located at 112 NW Wood Chapel Rd, Blue Springs, Mo 64015. Must RSVP by July 9th. Please remember that when you RSVP, food is purchase for you and your family. We know things come up but if you RSVP please try your best to make it to the events. Thank you for your support.

Friday, August 14th, 5 to 7pm, Back to school swim party! Grab your suit, sunscreen and towel and join us at Summit Waves, 120 SW Blue Parkway, Lee's Summit, MO. Enjoy the water slides, action river and tons of water play. Your admission WILL BE covered for persons with Down syndrome and their immediate family. At this time you can bring food in or purchase food at the concessions. Cant wait to see you there!

To RSVP to each event or for questions, contact Jenni Bryan at 816.347.0994 or via email kjmmmbryan@yhaoo.com.

FACES of Olathe

Events details are in the making and were not available at the time of printing. For more information on FACES of Olathe please contact Debbie Horn at 913-768-6717 or email at Debbie@horns4.com.

FRIENDS of Joplin

Saturday, July 11th at 10:30am, we will be having guest speaker Sarah Royer from the Community Support Services of Jasper County to tell us more about their program. We will be meeting at Frisco Church, 908 W Daughtery in Webb City.

Saturday, August 8th at 6:30pm we will be meeting at the Sonic Drive In Playground at 720 Maiden Lane in Joplin. Come and enjoy a frozen treat and let the kids play. Friends of Joplin will provide a gift card for each family for to by a frozen treat of their choice.

For question, directions, and to RSVP please contact Alicia Hammer, 417.499.3606 or via email at alihammer@sbcglobal.net.

Johnson County FRIENDS

Wednesday, July 22nd at 6:30pm, Mom's night out at Garozzo's, at 135th and Mur-Len, 13505 S Mur-Len. JoCo friends will cover \$5 toward each mom's meal. Have dad watch the kiddo's for needed time off!

Monday, August 24th at 6:30, join us at the DSG office. More details will be coming watch your mailbox and email!

To RSVP or for questions please contact Debbie Yost, deb.opks@gmail.com or at 913.814.9739

Lawrence/Topeka Friends

Event details were not available at the time of printing. Watch your mailbox and email inbox for information on upcoming event for this group. Please contact Anne Martinez via email, Richard-anne@sbcglobal.net or at 785.354.8243 for questions or to be added to the Lawrence/ Topeka distribution list.

Northland Buddies

Sunday, July 19th, at 1:45pm, Come join us for our third annual Tiffany Springs Aquatic Center (9400 Congress Avenue Kansas City, MO 64153) outing!! We will meet at the entrance to the water park. You can swim until the park closes at 8 PM. Bring your swim suits, towels and sunscreen. The park provides lifejackets if you need/want them! There's lots of fun things to do at the water park including the slides, kid's fun play area, spray ground, competition pool (50 meters), high diving boards, low diving boards and vortex.

If you want to join the fun, you must RSVP by July 16 in order to get free admission for your entire family!

Friday, August 7th, 7:05pm, Take me out to the ball game! We plan to watch the T-Bones play on August 7th! Come to the CommunityAmerica ballpark (1800 Village West Parkway Kansas City, KS 66111) and join in the fun! Game starts at 7:05 and the T-Bones are playing the Rail Cats. RSVP is REQUIRED by July 23 in order to get free admission for your entire family.

For both events contact Kris Plubell at 816-792-4671 or via e-mail at kdkb@plubells.com to RSVP!

Rural Missouri Friends

Event Details are in the making and not available at the time of printing. Please contact Kathy McCurry if you would like to know more about Rural Missouri Friends or for questions via phone: 660.258.7204 or via email kmccurry@shighway.com

St. Joseph Community Group

Saturday, July 25, 9 am Plan to join us for a breakfast provided by the ladies of Grace Evangelical Church. Libby Jordan, occupational therapist, will present information on developing handwriting skills in children following the breakfast. Church volunteers will be available to watch the children during the 40 minute presentation. The church is located at 5103 S 50th Street, Saint Joseph. For directions and to RSVP, contact Stephanie by July 15th.

Saturday, August 15, 11 am Plan to join us for a swimming party at Noyes Aquatic Center at corner of 28th Street/Noyes Boulevard and Messanie Streets in Saint Joseph. The group will provide the entry fees to the park.

For more information or to RSVP, contact Stephanie Mefford, 816-364-0003 or by e-mail mef4ds@stjoelive.com.

Teen Club

Terrific, Enthusiastic, Educational, Necessary

Creative, Loveable, Useful, Blessed

Teen Club is still waiting for YOU to join us in our fun and fellowship. Anyone from the ages 13 and up to adults are welcome to join us for Art Expression, Field Trips, cooking, and crazy fun! Our meetings are usually on the **4th Saturday of each month from 10 am to 2pm** at the Timothy Lutheran Church in Blue Springs, MO, 425 NW RD Mize Rd. It will be noted if meeting are held otherwise.

To find out more about Teen CLUB Please contact Diane Chrisman at 816.229.2034 or dianesingsfor-joy@comcast.net.

Vision Con Esperanza

Thursday, July 30rd, 6:30 to 8:30pm, Parent Support Group meetings

Thursday, August 27th, 6:30 to 8:30pm Parent Support Group meetings

Every Tuesday: Social Skills Development Group from 3:00 to 4:30pm and Independent Living skills training from 4:30 to 6pm All meetings held at Mattie Rhodes, 148 Topping Ave, KCMO. For question or RSVP please contact Luis Cordova at 816.241.3780.

DSG Community groups

The DSG proudly provides administrative support and funding to the advertised community groups to help meet our members needs in their immediate communities. DSG members are encouraged to attend group meetings in their area but may also choose to attend other groups if the topic matter/event interests them.

Duodenal Atresia and Down Syndrome

What is Duodenal Atresia?

Duodenal Atresia means the duodenum (first part of the small intestine just beyond the stomach) is closed off rather than being a tube. This stops food and fluid passing from the stomach to the intestines.

How is it diagnosed?

Duodenal Atresia can sometimes be discovered during pregnancy as it often shows up on ultrasound scans. Some babies with this condition are born prematurely. Many babies appear well at birth but when they start to feed, they are sick and their vomit is green. An X-ray can confirm this diagnosis.

Duodenal Atresia is a rare condition and occurs in about one in 10,000 births. It can be associated with other problems, so the doctors will examine your child closely to check if this is the case. One third of all children with Duodenal Atresia have Down syndrome.

How is it treated?

Duodenal Atresia is repaired in an operation under general anaesthetic which lasts around 90 minutes.

Are there any alternatives?

No. Duodenal Atresia requires treatment to allow your baby to feed.

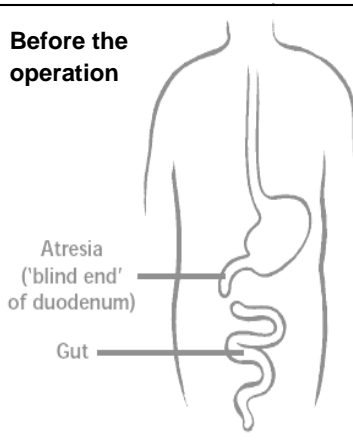
What happens before the operation?

To begin with, your child will be nursed in an incubator and will have a naso-gastric (NG) tube passed through his/her nose into the stomach. This will drain the contents of the stomach and stop your child feeling and being sick. It also releases any excess air from the stomach which could make your child uncomfortable. He/she will also have an intravenous infusion of fluids and medicines.

The surgeon will explain about the operations in more detail, discuss any worries you may have and ask you to sign a consent form giving permission for your child to have the operation. An anaesthetist will also visit you to explain about the anaesthetic.

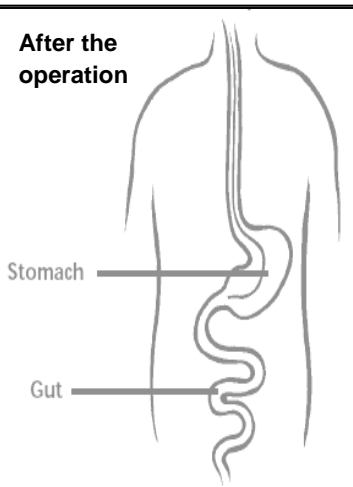
What does the operation involve?

The surgeon will cut the blind end of the Duodenum and connect it to the rest of the intestine. This provides a clear passage for food and fluid to travel from your child's stomach to his intestine.



You should check with your physician if your baby:

- Vomits frequently when feeding
- Has a swollen stomach
- Vomits green liquid
- Is not gaining weight



What happens afterward?

Your baby will come back to the room to recover, and you will be able to visit as soon as her or she is settled back in the incubator. For a while after the operation, your baby will need help with breathing so will be connected to a ventilator. All babies are closely monitored after the operation, and so your baby will be connected to monitors to check his/her breathing, heart rate, and oxygen levels. Your baby will also be given pain relief through the IV.

While your child's intestines recover and start to work, he/she will be fed through a tube into his/her veins. This will gradually be replaced by breast or bottled milk, given through the NG tube when your child is able to tolerate this. As your baby recovers, you will be able to feed him from the breast or bottle. Over time, the drips and monitors will be removed.

The nurses will encourage you to look after your baby as much as you feel able to during the recovery. This can be daunting, especially while your baby is connected to drips and monitors, but it will become easier with time.

You will be able to go home once your baby is feeding properly and gaining weight. Follow up visits with your pediatrician or a GI specialist will be scheduled to monitor your baby in the coming weeks.

What is the outlook for children with Duodenal Atresia?

If the Duodenal Atresia occurs on its own with no other associated problems, the outlook is good with the majority of children growing up to live normal lives, working and raising a family. The outlook for children with Duodenal Atresia varies depending on how severe the other problems are.

Some children who have had Duodenal Atresia develop a problem with gastro-esophageal reflux when they are older. This is where the contents of their stomach flow back up the esophagus (gullet) causing pain and irritation. Your child's primary care physician can provide support if this issue arises.

****Be sure to check with your child's primary care physician before pursuing any type of treatment.****

What if Your Child Goes Missing?

A child goes missing every 40 seconds in the United States, which means your child has a 1 in 42 chance of going missing. There are organizations that provide quick-response services to local police stations for free. Many of our own police departments are not taking advantage of these free services.

A Child is Missing (ACIM) is a Fort Lauderdale-based non-profit organization. It was created in 1997 for locating missing children, the disabled and elderly during the crucial first hours of disappearance. ACIM uses a rapid-response neighborhood alert program utilizing high-tech telephony systems. There are currently 13 counties in Kansas and 2 in Missouri that use this specific service or a similar one:

Prairie Village	Westwood	Kansas City, KS
Ottawa	Merriam	Park Ranger in KS
Johnson	Mission	Pleasant Valley
Lenexa	Leavenworth	Grandview
Leawood	Bonner Springs	Overland Park

DSG encourages you to contact your local police department if they are not using the system and advocate for this free service that could benefit your family. For more information on **ACIM** or how to advocate for this free service in your area, please visit www.achildmissing.org.

It's too late to coordinate a plan of action once your child, teen or adult with Down syndrome goes missing. Having an emergency response plan in place at home, school or while traveling is the best way to keep your loved one with Down syndrome safe. Join DSG to learn how to set up an emergency search plan BEFORE your loved one goes missing.

Emergency Response Plan Training

Tuesday, July 7, 2009

6:30 PM-8:00 PM

DSG Center

Childcare and dinner provided

RSVP required by July 5th

info@kcdsg.org or 913-384-4848



Beyond the Evening Star Theater
"Where every star shines bright!"

Performing Arts for All People of All Abilities

Summer Classes and Activities 2009

Combined B.E.S.T. Troupe and B.F.'s on Campus May 28 - July 30
Ages 13+
Session lasts 10 weeks
Day and time: Thursday 6:30 - 8:00
Membership fee for Summer Session \$150

B.E.S.T. Performing Arts Camp July 20 thru July 24
Ages 13+
One week day camp
Days and times: Monday thru Friday 10:00-3:00
Membership fee for camp \$150

Introductory to Acting Class July 29 - Sept. 2
Ages 13+
6 week class
Day and time: Wednesday 6:30 - 8:15
Membership fee for class \$100

Arts Activity Days
Ages 13+
June 9 - August 13 (No class on July 2, 21, 23)
Tuesdays and Thursdays 12-4
Cost \$40 per day
All materials included
Have fun creating a variety of visual arts projects, learning new songs, and simple dance steps

Beyond the Evening Star Theater
Once Upon A Dream Studio
8100 W. 116th St.
Overland Park, KS 66210
913 663-9936
bestnetarts@earthlink.net
www.thebestnetwork.org



DSG received a limited number of free tickets to some great shows at Starlight Theatre this summer. Call DSG at 913-384-4848 to receive up to 4 tickets for your family to one show!



Saturday
July 4th
8:30 PM



Wednesday
July 15th
8:30 PM



Sunday
August 2nd
8:00 PM



Thursday
August 13th
8:00 PM



Sunday
September 13th
8:00 PM

Learn more about these great shows at www.kcstarlight.com

Seclusion Rooms

The use of seclusion rooms can be a divisive issue. It is important to understand what a seclusion room is. According to the Children's Health Act of 2000, a seclusion room is "any behavior control technique involving locked isolation." This is different from time-out techniques that are defined as removing a child from a desired activity (reinforcing stimuli) when they engage in unwanted behavior. Time-out typically will include some kind of criterion for the child to return to regular activities. The idea is the child has to show appropriate behavior in order to engage in desirable activities.

Seclusion rooms can be used in similar ways, but typically they are employed to protect other children or the classroom from an aggressive child. Whether or not a seclusion room is used as a form of protection or a behavior control technique, a child is locked in a room by themselves against their will. It may be a place where the child can calm down, but normally the child does not go there willingly.

The biggest risk to a child who is put in isolation is the possibility of injury. Despite most seclusion rooms being vacant, it is still possible for an unsupervised child to injure themselves. If a child is capable of doing bodily harm to their person it is imperative that the child should not be placed in a seclusion room without an adult present.

Some children can do harm to themselves regardless of whether the room is padded and empty. A child should never be locked in a seclusion room and if a seclusion room is going to be used it should be for a very short time-period.



Does your school have a Seclusion Room?



If so, be sure to ask when and how it is used.



If any child's school and parents are considering a seclusion room the following issues should be considered and discussed in an IEP team meeting **PRIOR** to a seclusion room being utilized:

- **Environment** – where is the room, what is in the room, and what is the size of the room?
- **Procedures** – what behavior would lead to use of the seclusion room, how will the child be placed in the room, will the room be locked, how long will the child be placed in the room, and will the child be required to demonstrate appropriate behavior to be released?
- **Supervision** – will the child be in a room by themselves, will there be a staff member in the room with the child, and will the child be visually supervised?
- **Definitions** – what is meant by time-out, seclusion room, seclusion, cool down, etc.?

It is important to understand that children engage in behavior that works for them. Instead of placing a child in a seclusion room as a form of behavior management, it is important to find out why the child is engaging in the behavior that is unacceptable.

The child can then be taught to obtain what they need with appropriate behavior. It is difficult, if not nearly impossible, to teach a child appropriate behavior when they are isolated in a room.

Submitted by, Brian Cowley

The Down Syndrome Guild of Greater Kansas City DOES NOT support the use of seclusion rooms. If seclusion rooms are being utilized we believe the following tenants are necessary to protect students, parents, educators, and school districts.

- Parents and school district personnel should discuss seclusion rooms and their usage at IEP team meetings PRIOR to their use. All other forms of behavior modification should be considered at this time.
- All school district personnel should be fully trained on the appropriate use of seclusion rooms. Ongoing training will be necessary as new research on seclusion rooms continues to emerge.
- Parents should always be notified if a seclusion room is used as a behavioral modification technique for their child.
- Data should be taken any time a seclusion room is used. Data should be reviewed regularly so the IEP team can discern if the use of a seclusion room is effective or appropriate.

Ready-to-use *See and Learn Language and Reading* kits are now available to order online from Down Syndrome Education International.

Effective support for early language development

The *See and Learn Language and Reading* programme provides instructions, materials and checklists to help families effectively support their child's early language development.

Step-by-step activities

The first three steps in the programme teach early vocabulary using carefully structured activities. The activities present visual language teaching techniques using clear pictures and written words. These evidence-based techniques help children with Down syndrome to learn language more successfully.

Evidence-based visual teaching methods

The activities in the *See and Learn Language and Reading* programme are based on research showing significant benefits from visual approaches and the use of early reading to teach language. Early language and reading activities can improve spoken speech and language, memory, literacy, wider cognitive development and later academic achievement. They have been developed by expert professionals with many years of experience teaching young children with Down syndrome.

Freely available online

Down Syndrome Education International's *See and Learn* programmes are freely available online at www.see-and-learn.org.

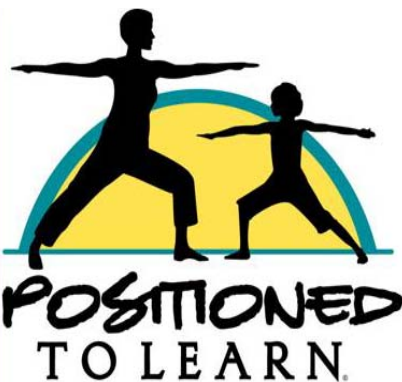
Convenient, ready-to-use kits

Ready-to-use *See and Learn* kits offer the convenience of premade guides, checklists, picture and word cards, reading books and other teaching materials in a plastic storage box. The resources are printed in full, high quality colour, with materials printed on card and cut ready for use straight out of the box. Three kits are available:

See and Learn First Word Pictures - the first step in the *See and Learn Language and Reading* programme teaches the first 60 words using pictures and matching and selecting activities

See and Learn First Written Words - the second step in the *See and Learn Language and Reading* programme uses reading as a support to language development introducing 16 written words and 34 two key word phrases

See and Learn More Word Pictures - the second step in the *See and Learn Language and Reading* programme teaches a further 55 words using pictures and matching and selecting activities



Yoga for Students with Unique Needs

Monday & Wednesday

Class Times: 1:15 or 2:00

Class Dates: July 13, 15, 20, 22, 27, and 29

Church of the Resurrection

East Building Room 215

13720 Roe Avenue

For further information or to reserve a spot contact:
Barb Kolom at 913-339-6109 or bkolom@everestkc.net

TEEN SIBLINGS AND DOWN SYNDROME

Growing up with a brother or sister with Down syndrome can be fun, but sometimes you might find it difficult. Remember that all siblings feel this way about each other sometimes. You may feel lots of different emotions about your sibling with Down syndrome. You may feel: happy, sad, annoyed, embarrassed, jealous, guilty, proud, or protective over them. Occasionally, you may find that you worry about your sibling. Sometimes it helps to tell someone how you are feeling. Other siblings, parents and even your sibling with Down syndrome may have felt the same way too. As a sibling, you may already be aware the people react in different ways to your brother or sister. Sometimes your sibling may be treated in a way that makes you feel embarrassed or angry. Try some of the strategies and tips listed below to help you through your emotions.

NEED TO LET OFF SOME STEAM?

- Go for a run or walk or catch the latest movie with your friends.
- Write down everything you are feeling in words or draw a picture of how you feel. You may want to keep a journal and share your thoughts with some one or throw them away when you feel better.
- Write down all the positive things that people have said about your brother or sister with Down syndrome.
- Find a sibling support group in your area or visit on an online site for siblings.

HOW TO DEAL WITH OTHER PEOPLE'S ATTITUDES

- Try to educate people about Down syndrome.
- Try not to become defensive, though it isn't always easy.
- Try to control your own anger. Remember, there attitude is likely due to ignorance, it's not personal.
- Try to remember your own attitudes and actions. Maybe you had some of the same thoughts before you had a sibling with Down syndrome.

ENJOYING YOUR RELATIONSHIP WITH YOUR SIBLING WHO HAS DOWN SYNDROME

- Don't feel guilty if you need some space! You are also an individual with your own needs.
- Stop being hard on yourself, you can't be perfect all the time, even it feels as though you have to be.
- Accept your sibling for who he/she is.
- Talk about your feelings with others.
- Try doing lots of fun things with your sibling
- Remember that all siblings argue at some point, whether they have Down syndrome or not.
- Talk to someone who might understand how you are feeling
- Tell your parents and other family members what you are comfortable helping out with and what you think your sibling should be doing independently or with other family members help.
- Remember that your sibling is very similar to you in many ways but may require additional support or time to do the same things you do.

Even the closest brothers and sisters don't always get along or understand each other. Add a disability like Down syndrome to the mix, and that sibling relationship gets even more complicated, especially for teenagers.

FASTEN YOUR SEATBELT is the first book written exclusively for teens with a brother or sister with Down syndrome. In an easy-to-read, question & answer format, it tackles a broad range of their most common issues and concerns. Nearly 100 questions--all posed by teen siblings--are grouped into the following categories:

- Facts and stats about Down syndrome
- How people with Down syndrome learn
- Handling parent and family conflicts
- Dealing with your sibling's frustrating behaviors
- Managing uncomfortable situations
- Sorting out your feelings
- Becoming an advocate
- What the future holds for you and your sibling
- Finding local and national resources



FASTEN YOUR SEATBELT IS ONE OF THE TITLES IN DSG'S DOWN SYNDROME AWARENESS BOOK BUNDLES THIS YEAR.

WATCH FOR YOUR ORDER FORM!

Thoughtful, knowledgeable answers are provided by Brian Skotko, the brother of a young woman with Down syndrome, and Sue Levine, a social worker focused on sibling issues for the past 30 years. **FASTEN YOUR SEATBELT** gives teens the green light to explore their own feelings and questions about their sibling with Down syndrome and how their relationship may change in the future.

Seven Tips for Partnering with Your Child's School During the Transition Years

Before you realize it, your child is a teenager. When he was young, he was eager for you to admire his finger painting, attend school events, and help out with math circle. Now school notices are lost in the backpack, and the answer to "How was your day at school?" is a mutter. Your child is learning to be independent, yes, but does this mean that you have a lesser role to play? No! In fact, during the Transition years of 14 - 22, the partnerships you foster with your child's school can be key to his success as an adult.

Contrary to what you might think, research clearly shows that parents - not peers - still exert the biggest influence on teenagers. Teens whose parents are involved at school, check homework, and know their children's friends have more positive post-high school outcomes than teens whose parents do not. **How can you stay involved during the middle and high school years? Here are seven tips:**

1. Most importantly, get to know your child's teachers, and make sure they know you and your child. Middle and high school teachers are committed to helping kids - yet they are exceptionally busy people, often with large numbers of students. At the beginning of the year, make a pleasant phone call or send a cheerful e-mail introducing yourself as Sarah's Mom, expressing your interest in partnering, and asking how you can be most helpful.



http://fcsn.org/publications_resources/newsline/nlv2_8n4.pdf, A number of websites with Transition resources are listed.

5. During the Transition years, it's important for you, your child, and the school to begin partnering together so that your child will develop the skills necessary for a successful adulthood. Before the IEP meeting, talk with your child about his vision for the future. What kind of job would he like to have? Where would he like to live? What are his hobbies, talents, interests? What are his needs? What skills will he need to develop to achieve his vision? At the IEP meeting, use this information to guide the Team's discussion. From age 14 onward, your child must be invited to attend IEP meetings so both you and your child will be able to provide key input into the process. Once the discussion is concluded, goals should be transferred from the Transition Planning Form to the IEP.

2. By law, teachers are responsible for implementing your child's Individualized Education Program (IEP). Ease your child's transition to the new year by creating a "Sarah-at-a-Glance" one-page document, highlighting your child's learning strengths and needs, as well as necessary accommodations and modifications. Sitting down with your teen to draw this up together will help to develop her self-advocacy skills. Distribute this document to all your child's teachers and service providers. Your child's teachers will still need to read the entire IEP, but your one-pager will help the process along

Talk with your child about his/her vision for the future. Frame all IEP goals around your child's strengths and areas where he/she needs extra support.



6. Network with other parents in your local special education parent advisory council (PAC). Learn about your school district's services for students of Transition age, and volunteer to meet regularly with school officials as a PAC representative to discuss district Transition programming. According to state law, the PAC's role is to advise the school district "on matters that pertain to the education and safety of students with disabilities." By partnering with other parents and with your school, you can have a positive impact on both your own child's education and on the education of all students on IEPs.

3. According to the law, your child is entitled to receive progress reports as often as children who do not have IEPs. If you want more frequent updates, phone your child's teacher at regular intervals - perhaps once a week - and ask for a return phone call. Educators are usually good about returning calls, but they are busy people and appreciate reminders. If your child's school uses a Website to update parents on student progress and assignments, be sure to check it regularly. Talk to your child about his schoolwork, too. Even though he's older, he will be more successful if he knows you're still interested and involved.

Make a transition timeline so you know when tasks are supposed to be completed by and who is responsible for completing the tasks!

7. Make community connections. Get to know local business owners. Find out how people with disabilities can become involved in your community through recreation programs, volunteering, or jobs. Not only will you build future connections for your own child, you will also help to increase opportunities for other students when you share these resources with your school.

4. Learn about best practices in Transition by searching the Web, by reading, and by attending workshops. Share information and resources with your child (to help her become an effective self advocate) and with her teachers. Federation for Children with Special Needs' Spring 2008 issue of Newsline can be viewed online at our website at:



Written by Amanda Greenthe, Federation for Children with Special Needs www.fcsn.org

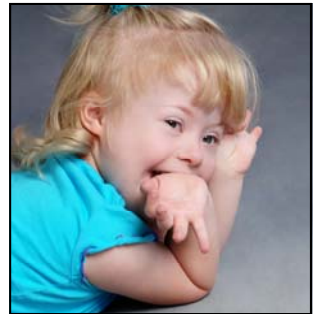


Improving Feeding Skills and Speech Clarity Using Oral-Motor Therapy

Oral Placement Therapy (OPT) for feeding and speech is a specialty within the field of speech therapy. A physical therapist works on muscle skill development to improve mobility and control for gross motor activities such as walking. An occupational therapist works on muscle skill development to improve mobility and control for fine motor activities such as hand to mouth control. A speech pathologist works on muscle skill development to improve mobility and control for fine motor activities such as feeding and speech clarity or articulation.

Beginning shortly after birth, OPT can be used to prevent certain characteristics generally associated with children and adults with the diagnosis of Down syndrome. Early intervention feeding therapy to address the position in which an infant should be held and the type of bottle used can maximize a child's potential for feeding skill development and eventual speech clarity. When this protocol is followed infants with the diagnosis of Down syndrome do not develop these preventable characteristics; tongue protrusion, open mouth posture, obligatory mouth breathing, and propensity for upper respiratory problems and conductive hear loss. For more information on the importance of early intervention feeding go to the TalkTools website at www.talktools.net to download the article entitled "The Oral-Motor Myths of Down Syndrome."

Even though these techniques have proven to be highly successful, many children with Down syndrome have not received OPT. Their speech therapy has been centered on the development of receptive and expressive language skills. Although language development is a primary concern, ignoring the importance of feeding skill development and oral motor control for speech clarity can result in significant communication deficits. When speech therapy only focuses on increasing word usage, the result is a gap between what the child is saying and what can be understood by the listener as the muscle skills needed to support speech clarity have never been targeted.



Oral Placement Therapy can be used with individuals of any age (birth to adult) to close the gap between what is said and what is understood. It ensures that what is said can be understood by everyone. In addition, other behaviors including drooling, teeth grinding, thumb sucking and pacifier usage can be remediated with Oral Placement Therapy.

Oral Placement therapy is used in conjunction with traditional speech therapy to improve speech clarity. It is a tactile teaching technique which uses therapy tools disguised as toys to improve compliance and is based upon a success model. Each activity is based on a hierarchy of skills working towards normal placement, movement and grading in the muscles of speech: abdomen, larynx, velum, jaw, lips and tongue. Once the appropriate placement is achieved the movement is transitioned into function for feeding and speech clarity. These techniques have been designed to maximize each child's speech clarity and are easily implemented by therapists and parents.


Written by Sara Rosenfeld-Johnson, MS, CC-SLP. She has 35 years of experience in speech therapy. She is a member of the National Down Syndrome Congress' Professional Advisory Committee (PAC) and a regular speaker at national Down syndrome and American Speech-Language-Hearing Association (ASHA) conferences. For more information, go to www.talktools.net


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DSG is now on facebook! Visit www.kcdsg.org and click the link to join our cause page on facebook. We will provide updates on upcoming DSG events, the latest research, success stories, medical issues, new programs and fundraisers. This is a great way for you to network with other DSG members too! Don't wait, join today.


National Down Syndrome Study Research Announcement

Kennedy Krieger Institute is inviting families of children with Down syndrome to participate in an NIH funded study to identify genetic and environmental factors that increase the chance of congenital heart defects. This study will help us understand why some children with Down syndrome have heart defects while others do not.

 **WHO:** We are planning to enroll 600 children born with DS and atrioventricular septal defect (AVSD), commonly called AV canal, and 600 children born with DS without any structural heart defect. The children must all be under the age of 18 years old. This is an expansion of previous studies started in 2001. If you have participated before, you will not need to enter this study again.

 **WHAT:** Parents will be asked to complete a telephone interview (30-45 minutes) about their pregnancy and reproductive histories and maternal and family health related factors. Additionally, parents will be asked to donate a saliva sample for DNA analysis. Adolescents will be asked to donate a small blood sample (1.5-4 teaspoons), and younger children will be asked to donate a smaller blood sample (minimum 1/5 teaspoon) for DNA analysis

The blood samples can be drawn during a regular visit to one of the sites or by arrangement with your primary care physician. We will ask to obtain your child's medical records that relate to their diagnosis (such as a karyotype) and their heart status (such as an echocardiogram report). There are no direct medical benefits or significant risks for participating in this study.

 **WHERE:** This study is a collaborative effort between multiple sites, including Kennedy Krieger Institute and Johns Hopkins University, both in Baltimore, MD.

 **HOW:** If you are interested in participating or have questions, please contact us!

Charnan Koller, R.N., C.C.R.P.
Kennedy Krieger Institute
Research Coordinator
1-800-873-3377 ext. 9131
koller@kennedykrieger.org



DS HEART PROJECT
People with Down
syndrome helping to cure
congenital heart disease
in all people!

George Capone, MD
Kennedy Krieger Institute
Director Down Syndrome Clinic
Principal Investigator
RPN: 00-06-06-03



DSG Launches New Teen Program

My name is Rose O'Dell and I am thrilled to join the Down Syndrome Guild of Greater Kansas City! I feel fortunate to be given the opportunity to serve this organization and its families by joining the office as the new Teen Program Coordinator. In the past I have worked as a respite care provider, providing support to children and teens living with autism and Down syndrome. I later worked in the hospital setting, managing various administrative functions and personnel. My goals over time have changed and I was looking for a rewarding opportunity to and make a positive impact in the lives of others . I have

no doubt my experience at DSG will provide this! Our teen program, S.T.A.R.S. (Special Teens Achieving Real Success), will serve teens with Down syndrome between the ages of 12-17. We hope to provide fun and educational sessions focusing on the following domains: social networking, life skills and pre-vocational skills. Look for upcoming events to be mentioned in Connections, as well as other marketing materials in your mailboxes soon. As we roll out this program, we look forward to feedback from our teens and their parents. For questions about the S.T.A.R.S. program, please call our office at 913-384-4848.

**STARS activities will take place on Tuesdays and Fridays at the DSG Center
from 1:00-4:00 PM unless otherwise noted below.**

RSVP's are required so we can plan for volunteers and supplies.

July 3rd– DSG Center closed for the holiday

July 7th– Tour of Harley Davidson Plant

July 10th-Union Station Planetarium & Sheridans

July 14th—Interactive Reality Games

July 17th—Yoga & Yogurt

July 21st– Henna Body Art Tattoos

July 24th— Activity to be announced later

July 28th– Tye Dye Shirts & Pizza Party

July 31st– Paint/Glaze/Fire Ceramics Outing

August 4th-Games, Movie & Healthy Snacks

August 7th- Back to School Party & Dance

Step UP and register your team today!

www.stepupfordownsyndromekc.org

The 1st Annual Step UP for Down Syndrome Walk is just around the corner! Mark your calendars and start thinking about friends and family you want to invite to join your team to celebrate your loved one with Down syndrome. Visit the Step UP website today to register, add pictures, tell your story, send emails announcing the walk, and start promoting greater Down syndrome awareness.



Last year we had 300 teams at the walk. Our goal this year is 350 teams!



7,000 walkers and 400 volunteers joined us last year!



Show your team pride! Register early to make sure your team name is on your shirt!



KC Chiefs players will be waiting at the finish line to greet you and take pictures!



Will you be there to help us cross the finish line?

First Downs for Down Syndrome teams with the Kansas City Chiefs Offensive Line to raise money for the Down Syndrome Guild, the Down Syndrome Clinic at Children's Mercy Hospital and other Down syndrome organizations. A number of fundraising events are held each year to raise money and provide awareness of Down syndrome and the services of DSG and the Down Syndrome Clinic. Area Corporate Sponsors also support First Downs for Down Syndrome by donating money based on the number of first downs the Chiefs score in the season! We thank them for making a huge impact on our organization. For information regarding events or other fundraisers, contact Amy Stoll, Executive Director, at 913-722-2499 or email stoll@fdfds.org. You can also learn more by visiting our website at www.fdfds.org



DSG Mission Statement: The Down Syndrome Guild of Greater Kansas City is a non-profit 501 c 3 organization whose mission is to provide support and resources for individuals with Down syndrome and their families. The Guild seeks to provide the entire community with information and education to broaden awareness and foster positive attitudes regarding people with Down syndrome.

Disclaimer: The information provided is done so through a variety of sources including names provided by members of the Guild, networking, referrals by professionals, other agencies, mail advertisements, etc. DSG cannot attest to the quality or qualifications of the individuals or organizations described. We encourage you to be a wise consumer and ask questions in order to make your own independent evaluation of utilizing the services described. We share information about research projects but in doing so, it is not reflective of any type of endorsement.



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Calendar of Upcoming Events

Emergency Response Training
 Tuesday, July 7th
 6:30 PM-8:00 PM
 DSG Center

Coffee & Conversation
 Thursday, July 16th
 DSG Center
 9:30 AM-11:30 AM

Parent to Parent Training
 Saturday, July 25th
 DSG Center
 9:00 AM-11:00 AM

Coffee & Conversation
 Thursday, August 20th
 DSG Center
 9:30 AM-11:30 AM

Practical Solutions for Educating Students With DS
 Thursday, September 10th
 Kauffman Foundation Center
 8:30 AM-11:30 AM

Call 913-384-4848 or email info@kcdsg.org to RSVP

Down Syndrome Guild Board of Directors

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Connections is a bi-monthly publication of the Down Syndrome Guild of Greater Kansas City. Please contact the office at (913) 384-4848 if you have any questions about the contents of this newsletter or would like to contribute an article.

Board President: Bridget Murphy
Executive Director: Amy Allison