

DSG Receives \$53,000 Donation

DSG received an AMAZING \$53,000 donation from the Bratton/Mitchem families in July in honor of Stephen Bratton whose family became involved shortly after his birth. Stephen's proud grandpa sent an email challenge to family/friends asking them to donate to the DSG and he offered to match every donation.



They came through with \$26,000 in donations and Stephen Mitchem matched every penny. As if that was not enough, the family also hosted a Car Show which raised \$1,000 which they also donated. This is the largest single donation in the history of the DSG and we are so honored.

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October is Down Syndrome Awareness Month

October is National Down Syndrome Awareness Month. This is the perfect chance for you to take a few moments and educate others on what Down syndrome is and how loving someone with Down syndrome has impacted your life. The DSG hopes you will consider some of the following activities when you are thinking about celebrating Down Syndrome Awareness Month.

- ... Write a letter to a local newspaper about what you have learned from people with Down syndrome.
- ... Take photos of your loved one with Down syndrome and send them to the DSG for use in our promotional materials.
- ... Host a presentation on Down syndrome at your school, church or civic organization.
- ... Encourage your school to start a circle of friends program that invites typical peers to form a support network for students with Down syndrome or other disabilities.
- ... Order a DSG Book Bundle and present it as a gift to your local school, library or hospital. Watch your mailboxes in late August for order forms.
- ... Encourage your employer to sponsor a Dress Down for Down Syndrome day and donate the proceeds to DSG. Contact DSG to request a Dress Down kit which contains everything your employer, group, or organization needs to host a Dress Down day!
- ... Thank your teachers for all that they do to help your loved one and give them a Down Syndrome Awareness Packet. Call the DSG if you need ideas of what to put in the packet.
- ... Ask a local business to donate a portion of the proceeds of their sales to the DSG during a day or weekend of sales in October to promote awareness.
- ... Thank your physician for their support and provide a copy of the Down Syndrome Health Care Guidelines. These can be uploaded at the DSG website or you can call the DSG Center and we will mail you a set.
- ... Ask your local library to put out a Down Syndrome Awareness Month display of books. Contact the DSG for a letter and materials with suggested book list for the library to display. We can also give you some book marks for the display.
- ... Contact the DSG to request complimentary copies of bumper stickers, book marks and posters to help promote Down Syndrome Awareness Month in your community.
- ... Ask your mayor to proclaim October Down Syndrome Awareness Month. We can provide you a sample proclamation!

Email info@kcdsg.org to request DSG materials to help with any of the above suggestions. Go forth and create awareness!!!!

DSG Mission:

The Down Syndrome Guild of Greater Kansas City is a 501 c 3 nonprofit organization whose mission is to provide support and resources for individuals with Down syndrome and their families.

DSG seeks to provide the entire community with information and education to broaden awareness and foster positive attitudes regarding people with Down syndrome.

Dad's CORNER

I can still clearly remember the evening of April 28, 1994 when Caleb was born. This was our first child and the anticipation and excitement was very great. I had no reason to expect anything else except a perfectly healthy baby. After Caleb was born and we were told he probably had Down Syndrome I remember thinking this couldn't possibly be true.

I kept looking at this precious little boy and thinking the Doctor's didn't know what they were talking about. I didn't think that he looked any different then any of the other babies in the maternity ward. Obviously what they said was true though.

Looking back on the past seventeen plus years I realize just how blessed myself and our entire family is because of Caleb. There are probably many dads that wish their seventeen year old was as excited to see them everyday as Caleb is to see me when I get home from work. No matter what the day was like just seeing his smiling face and being greeted with a big hug as I come in the door everyday will make you forget all of your cares.

Caleb is a junior at Shawnee Mission North this year. He has been attending school with the same group of kids since Kindergarten. This will be his second year of helping to manage the football team and boys basketball team. He proudly wears his school jacket with his varsity letter that he earned last year. He has also attended the last two homecoming dances with a different date each time.



"Looking back on the past seventeen plus years I realize just how blessed myself and our entire family is because of Caleb."

Seeing him at school fitting in with all of the other students is such a great sight. I am amazed at the number of students, parents, and school staff from the principal to the custodians that know Caleb by name. You can see how much they all enjoy him by the way their faces light up. Caleb also enjoys bowling and swimming with Special Olympics. Whether he finishes first or last he has the same amount of fun and is always cheering on his friends.

The thing that Caleb loves more than anything is the praise and worship at Church every week. There is always someone that comes up to us at Church and says what enjoyment they get from seeing him sing and dance. You almost have to drag him out of Church at the end of the service because he is never ready to leave.

My wife Jenni and I have two other children Noah 14 and Brooke 4 who think the world of Caleb. To them he is just their big brother. Thanks to Caleb we have met and become friends with so many people that otherwise we probably never would have known. I look forward to the upcoming years and what lies ahead for my remarkable son Caleb.

Submitted By, Gerald Willis
Proud DAD to Caleb



Editor's Note: Caleb is an active participant in the DSG Special Teens Achieving Real Success (STARS) Program. We so enjoy having him be a part of our activities and he has made great friends through STARS. If your teen with DS is between 12-18 years of age please contact our office to learn more about this program and how they can become involved.

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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.

Disclaimer: The information provided is done so through a variety of sources including names provided by members of DSG, 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.

Step Up for Down Syndrome Walk

Did you know that Kansas City is home to one of the largest Down syndrome awareness walks in the world? With over 7,000 attendees and \$400,000 raised last year, we are going to need your help to raise the bar even higher! Our goal is to have 10,000 attendees this year. That means we need you to invite even more friends, family members and co-workers to join the celebration. We have 125 registered teams already but hope to have 300+ join us at the walk.



The Step Up Walk is your chance to celebrate your loved one with DS while promoting greater awareness and raising funds for the critical programs and services the DSG offers to its members. It's an important opportunity for you to invite everyone you know to celebrate life with Down syndrome and learn more about DSG's important programs and services.



We invite you to walk with us and celebrate life with Down syndrome on Saturday, October 29th at Arrowhead Stadium. Participants are encouraged to register their family or team online and make walk fundraising pages featuring their personal experiences with Down syndrome and how their lives have been enriched. **Visit www.stepupfordownsyndromekc.org to register today.**



DSG Welcomes Morgan Moravec as Assistant Director

We are pleased to welcome Morgan back to the DSG! Morgan was previously our Administrative Assistant handling daily administrative tasks, volunteer coordinating and assisting with the programs and services that the Guild provides. Morgan left DSG in 2009 to work for the Leukemia and Lymphoma Society. She recently re-joined the staff as our Assistant Director. Morgan will be working with our community groups, facilitating awareness and educational presentations, assisting with program development, marketing, and providing oversight for DSG programs/services.

"I am thrilled to be back at DSG as the Assistant Director! I have a true passion for mission of DSG and I am grateful to have the opportunity to work with members again. Thank you for allowing me to be a part of the DSG family!"



Morgan Moravec pictured left with Amy Allison and Leslie Hernandez Brown. If you look closely you can read the shirts which say DIVA for DS Awareness!

Employment Survey for Adults with Down Syndrome

There is currently no information available on employment and unemployment status for adults with Down syndrome. There is also no information describing where people work and the kinds of jobs they do. We all need that information in order to document the current situation and advocate for job training programs, funding, and more variety and choices in jobs.

The purpose of this survey is to begin to collect that information. So, it is

important for you to fill out and return this survey whether you are working in paid or volunteer jobs, not currently working, or are in a training program to prepare you for jobs. The survey is designed for parents/caregivers and their adult children with Down syndrome, ages 18-50 years old.

Please share this link on your social networking sites or email it to your friends. The survey will be online from July 20 –December 31, 2011. Every-

one's response is important. Together we can make a difference!

This is the link for my survey: <https://www.surveymonkey.com/s/RK5SWWS>

Libby Kumin, Ph.D., CCC-SLP
Loyola University Dept. of Speech-Language Pathology/Audiology

4501 North Charles Street,
Baltimore, MD 21210

DSG COMMUNITY *Groups*

The DSG proudly serves a large geographic area and therefore provides administrative support and funding to the advertised community groups to help meet our members needs in their immediate communities. Please feel free to attend any event listed on these pages, even if its outside your area. 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. Please contact us at info@kcdsg.org if you would like to suggest a new group

African American Friends

We happy to announce Yinka Perry as the NEW leader for African American Friends. Yinka is preparing meeting information for the coming months. Until then please feel free to contact Yinka at dsg.aafriends@gmail.com. We look forward to seeing you at African American FRIENDS events in 2011.

B.E.S.T. Network

Every Thursday from 6:30 to 8:30pm, join us for Dance classes— From Hip Hop to Ballroom, Drama, Sign Language to Music and other Activities. All levels of talent welcomed, beginner, intermediate, and challenge. Call for fee prices.

1st and 3rd Saturdays of the month, from 3:30 to 6:00pm, Starring ME! Entertainment Club! Friends, Fun, and Food! We will enjoy Karaoke, Music Videos, Group and Line Dances. Entrance fee \$7 or \$10 for entrance fee and dinner.

All Meetings held at Bishop Miege North Campus, 4901 Reinhardt Dr., Roeland Park, Ks. We are in the 2nd building in the multi-purpose room, just north of the High School, through the north doors. To RSVP or questions, please contact Marlene, 913.663.9936 or email at bestnetarts@earthlink.net

CONECTANDO AMIGOS LATINOS

Viernes, 23 de septiembre 18:00-20:00, se reúnen en la oficina del DSG, 10.200 W 75th St Ste. 281 de Shawnee Mission, Ks. Hemos invitado a un orador invitado Dailin Rodríguez. Ella nos habla a través de algunos de los desafíos que enfrentamos son padres de niños con necesidades especiales. Por favor confirmar su asistencia a Yadira Muguria, yadis7@yahoo.com o 913.261.9546. Plan para crear un equipo de caminar a su ser querido con síndrome de Down, inscribir a su equipo y unirse a nosotros en el paso adelante para el Síndrome de Down Caminar, en Ocotober 29 en el Estadio Arrowhead. Llegamos al sitio web y registro de su equipo, pregunte a su familia y amigos a unirse a su equipo. www.stepupfordownsyndromekc.org.

Dotte FRIENDS

Plan to join your DSG family at upcoming event in September, Red Barn Farm in Weston, Mo on Sunday, September 11th.

Don't forget to make your team for the Step Up for Down Syndrome Walk on October 29th. Come celebrate life with Down syndrome with your family and friends. Visit stepupfordownsyndromekc.org today!

We looking for more families to join Dotte! Contact Becky Messler at abecky529@aol.com for information.

Eastland FRIENDS

Monday, September 12th, 6:30pm Mom;s Monday! Meet us at Winterset Park Community Center, 2505 SW Wintercreek Drive in Lees Summit, MO. Join us for good food and conversation. Please bring a snack to share and a drink for yourself. See you there! No need to RSVP to this event.

If you have any questions out Eastland Friends or upcoming events please contact Kim Knipp, kknipp@kc.rr.com or Lindsay Tharpe, mamalins@yahoo.com

Eastland FRIENDS (con't)

EASTLAND friends will cover the cost of admission for members and their family. Concessions will not be covered by EASTLAND friends, but are available at the park. No need to RSVP, just identify yourself and your family as members of EASTLAND friends at the gate! For more information about Eastland Friends Kim Knipp at kknipp@kc.rr.com or Lindsay Tharpe, mamalins@hotmail.com.

FACES of Olathe

Calling all Olathe families! Join us! For detail about this group and Information on upcoming events, please contact Debbie Horn via email Debbie@horns4.com or at 913.768.6717.

FRIENDS of Joplin

Saturday, October 1 at 6pm. Its time for our Annual Fall Harvest Celebration at the Hammer's Home, 5728 Highway C, Joplin, MO. Please bring a side dish or dessert to share with your Joplin Friends. Don't forget your chairs to enjoy a bonfire, wiener roast, smore's and more! So we can plan for enough food for everyone, RSVP's must be received by September 28 Contact Alicia Hammer alihammer@sbcglobal.net or via phone (417)499-4614.

Johnson County FRIENDS

We hope everyone enjoyed their time at Deanna Rose Farmstead and had the opportunity to meet your new Johnson County FRIENDS group leaders, Jill Boster 913.219.0416 and India Hight, 913.709.2976. To be added to our email distribution list please contact: dsgjocofriends@gmail.com We hope to see many families out at Red Barn Farm on September 11th. Make sure and create your team for the Step Up for Down Syndrome Walk on October 29th.

Lawrence Topeka Friends

Watch out for details about our Annual Zoo event. Date and time to be announced. For information about Lawrence Topeka Friends or questions regarding upcoming events contact Anne at richard-anne@sbcglobal.net or by calling 785-354-8243.

Northland Buddies

We are taking a couple months off and Northland Buddies encourages everyone to attend upcoming DSG event. September 11th, DSG Annual Red Barn Farm in Weston, MO. A full day of family fun and treats! DSG will take your RSVP by calling 913.384.4848 or via email at info@kcdsg.org. Northland Buddies hopes to see all Buddies at the 2011 Step Up for Down Syndrome Walk, Saturday, October 29th. Register your team TODAY!



Do you enjoy the social fun and meetings your Community Group provides in your area? These activities are possible because of the funding raised for the Annual Step Up for Down Syndrome Walk. Create a walk team to help continued funding for our Community Groups!

Register your team today!
stepupfordownsyndromekc.org

Rural Missouri FRIENDS

For information about our group please contact Kathy McCurry 660.258.7204 or email kmccurry@highway.com. The new building is done so look forward to an event coming soon.

St. Joseph Comm. Group

Plan to attend DSG sponsored events during the months of September and October. Join us at the 2011 Step Up for Down Syndrome Walk. Come celebrate life with Down syndrome on October 29th at Arrowhead Stadium. If you would like more information about St. Joseph Community Group or would like to be added the email distribution list, please contact Renee Sherman. Her contact information is grover_rar@hotmail.com, or 816-232-7238 or via Facebook.

Sibling Support Group

Thursday, September 8th, 7 to 8:30pm. At the DSG office, 10200 W 75th St., Ste. 281 in Shawnee Mission, KS. If you are caring for an adult brother or sister who has Down syndrome, then this group is for you! Don't miss your chance to meet other siblings who are or will be primary care givers. Contact Sarah Jurcyk, 913.677.1213 or sjurcyk@kc.rr.com. You are welcomed to bring your sibling with Down syndrome to any upcoming meeting.

Teen Club

TEEN CLUB, terrific, enthusiastic, energetic, necessary, creative, lively, unique and blessed, is making some changes to their schedule. We will still meet once a month, on a 4th Thursday or Friday evening or possibly an occasional Sunday afternoon. We look forward to seeing new faces for each event.

We will usually meet at Timothy Lutheran Church, 425 NW R.D. Mize Road, Blue Springs, MO, unless otherwise noted in our monthly plans. Lots of fun activities are coming your way, so contact Diane at 816-229-2034, or dianesingsforjoy@comcast.net, to get on our email list.

RECENT Events



Books for All Features Books About Down Syndrome

When DSG parent Bonnie Reber and partner Stacey Adams saw a need for published, accessible and inclusive books for children with disabilities; they made the decision to make a difference. Books for All was organized with one primary intention, to make books available in a variety of formats to meet the needs of children with varied disabilities. Their purpose quickly grew to include public education and awareness about this timely issue and the importance of availability of published materials for ALL children at ALL levels of learning.

Adams, a former art and special education teacher, and Reber, a former elementary teacher and parent of a daughter with Down Syndrome, have shared similar experiences when it comes to presenting quality, independent reading materials to this often overlooked population. "Literacy is more important than ever in today's society, and when opportunities for growth and independence are limited for young learners who need individualized materials, windows to learning soon close," states Adams. Reber agrees, "We want what every parent and educator wants, an opportunity for each child to pursue and enjoy independent reading."

Unfortunately for many children who face physical, medical, and cognitive challenges, traditionally bound and formatted books such as those found in abundance on the shelves of libraries and bookstores just don't work. Adams says, "Bonnie and I are working together to create and promote books presented in language which is clear, concise and for the broadest possible audience. To be accessible, materials should be presented in a clear way with high contrast between text and background. It is even more effective when text is separated from illustrations utilizing simple fonts."

Current technology provides a variety of accessible formats that, in the past, were out of reach to many. Audio, and e-Book downloads are available for many titles, but the next step is to make that technology available to everyone independent of financial resources. Lastly, education must follow that makes this technology user-friendly to each child with a disability and those that support them. "This is where our charitable foundation makes a difference. Our hope is to raise the funds needed to produce these materials, provide opportunities for education, and make accessible books available at little or no cost to children who need that extra support," concludes Reber.



I Am Grace—Grace is like you, but she is different too. She has Down syndrome. Spend time with Grace as she shares her world and teaches that all friendships are unique, rich and meaningful.

Smiles for Grace— Grace loves to smile, and she knows a healthy smile is important. She takes care of her teeth by brushing them every day. Another way she takes care of her teeth is regular visits to the dentist. Join Grace on a visit to her dentist's office as she shares her experience step by step and teaches us about this important part of a healthy life.

Both books conclude with an informational section which parents and teachers can use for further topic discussion with their children/students. The combination of simple sentence structure, high frequency words, and an engaging plot promotes literacy and a love of reading while introducing social awareness.

**Pre-order these books online
for \$10 each by visiting
www.booksforallonline.com**

Subscribe to DSG E-blasts



Are you currently receiving DSG E-blasts? We send out at least two blasts each month which are full of information on current research, medical issues, education resources, upcoming events and more. Visit the DSG website at www.kdcsg.org and scroll to the E-blast sign up link. Enter your name and email address to receive future blasts.

How Technology Can Stop Elopement

If you have ever experienced losing your child you understand the initial panic and fear that grips you as you try to be rational and think what to do first. Whether they become separated from you in a public place or leave home without your knowledge it is always an unsettling time.

Everyone struggles with trying to watch their child and juggle other activities each day. For a parent of a child with Down syndrome, wandering off from home is one of the most trying of times, especially since we may not learn of their departure until sometime later. And we all know time is not on our side when our child leaves the house without our knowledge.

Parents have devised many ways to keep their child from leaving the home or to be aware of their activities. However, we have busy lives with other children to care for, activities around the home and even home based jobs. Wouldn't it be nice to know that if your child were to leave the home you will be immediately notified whether you were on another floor of the house or even outside in the yard?

Home For Life Solutions, located in Lee's Summit, MO offers technology solutions that will monitor your child's activities and help avoid the elopement concerns. The way it works is, when your child opens a door that is monitored you will be notified immediately, giving you the ability to intercept them before they have the opportunity to get lost. You will

have peace of mind knowing that if your child were to elope they will only have a few seconds' head start rather than the minutes or hours.

Unlike traditional home monitoring companies, Home For Life Solutions do not require outside monitoring or call center notification. The solutions will be private to each home and all notification calls will be directed to designated family care givers. This solution is portable, allowing you to take the monitoring solution to grandparents, hotels or a vacation home. Another advantage is cost. There are no monthly monitoring fees and the upfront cost to acquire the solution is much less than traditional products.

Home For Life Solutions will partner with the Down Syndrome Affiliates in Action to test this solution in five homes this year and plan to have the results by the end of the year.

To learn more about Home For Life Solutions their web site is www.homeforlifesolutions.com, or contact Gary Hostin at 816-581-5121 or gghostin@homeforlifesolutions.com. They also have a demo center at their offices located on the John Knox Village campus in Lee's Summit, MO, that will give you the opportunity to see and experience all of their solutions. If you have concerns about seizures, incontinence, falls, medicine management or wander management for older individuals or other home safety issues Home For Life Solutions may have an answer. Call Gary to schedule a visit.



At the heart of Home For Life Solutions products is the Caresse+ base unit, a personal emergency response system (PERS) – a system that will either audibly or silently monitor the daily actions and environment of individuals. It can be used to assist older adults or anyone with a need for additional safety and security, by bridging them to a full range of integrated products without invading their privacy. Visit www.homeforlifesolutions.com for more great technology!

COME TO THE FIRST EVER

A fun night is planned
Just for kids ages 8-12
that have a sibling with
Down syndrome!



RSVP TO INFO@KCDSEG.ORG

Seven Back to School Tips for Students with Disabilities

1. Build Alliances

The old saying, “There is strength in numbers,” is still true today. If challenges arise during the school year, it is helpful to know you have others you can turn to. Now is the time to nurture alliances with teachers, support staff, parents, students and others who impact you and your child. Call or send a thank you note to those who provided “bright spots” during the previous year. Mention how you appreciated their involvement and how you look forward to their future support. Contact others you would like to include among your supporters in the coming year and let them know the important impact they can have in your lives. Be sure to offer your support to others in return.

2. Review Your Child’s IEP

Many times Individual Education Programs (IEP’s) are written in the spring. Your child’s new teacher this fall may have no idea which learning goals are priorities for the coming year. Before school starts, read through the IEP to refresh your own memory. Talk over the learning goals with your child, especially those old enough to advocate for themselves. Then make sure each classroom teacher working with your child has a copy and understands the IEP’s intent. An IEP’s strength lies in the parents’ and teachers’ understanding of it and active participation in implementing it.

3. Create a “What Works” Portfolio

All parents should consider creating a “What Works” portfolio. It can be used to smooth your child’s transition each new school year. The portfolio should contain positive descriptions of your child. Include a profile describing your child’s strengths, interests, favorite activities, and learning priorities for the year. Include tips about physical assistance or communication with your child if these are needs. Describe behavioral supports that work or ways to structure situations to avoid behavior challenges. Make a list of tasks, roles, and responsibilities for a teacher’s assistant, if applicable. Describe classroom arrangements that help support your child (i.e., seating and positioning needs, noise-level tolerance, climate comfort levels, etc.). Include samples of your child’s work and describe any accommodations or modifications that were made to the original assignment. Share the names of students who are friends with your child and give tips on facilitating connections with other students. Finally, include a photo or brief video showing your child participating with other students and being supported successfully in the classroom.

4. Request a Meeting

Call your child’s teacher and request a meeting to share insights and information about your child. This is your chance to begin

developing a positive relationship with your child’s teacher and to establish yourself as an active team member in your child’s education. This is a great time to review your child’s IEP and “What Works” portfolio. Most teachers will appreciate your involvement and the knowledge you can share about how your child learns best. Consider this initial meeting as a “marketing” opportunity for your child. End the meeting with plans for ongoing communication with the teacher. Will you make contact daily, weekly, or only “as needed?” Will you communicate using notes, telephone, email, or in person? Establishing this routine reinforces your involvement.

5. Visit the Classroom

Making a presentation to your child’s classmates can be a great way to begin developing positive connections between other students and your child. Be sure to present your child as the “star” of the presentation. Consider starting with a story that is fun, educational, and sparks discussion. There are many books that speak about differences or disability in a positive way. Some examples for elementary-age children include *A Bad Case of Stripes*, *Different Just Like Me*, and *Special People, Special Ways*. Explain how your family views your child’s disability and what makes your child unique. Answer their questions honestly and address any fears. (Can he play with me? Will I hurt her? How do I talk to him? etc.) Kids are natural helpers so let them know what they can do to be a friend and support to your child. Finally, remind them that we are all more alike than different.

6. Stay Involved

After laying the groundwork, you can help ensure your child’s success by being involved at school throughout the year. Consider joining the PTA or Building Accountability Committee, volunteering in the classroom, helping in the lunchroom or library, or assisting with special events. The more active you are, the more impact you can have on your child’s school, the people who work there, and the education your child is receiving.

7. Continue Your Own Education

Because you are your child’s most important ally, it is essential that you develop the skills to help your child create a rich and meaningful life. Maybe you would like to learn more about your child’s developmental and educational needs, how to write and implement a good IEP, or how to advocate for your child. Families Together, Inc. in KS and MPACT in MO offer a variety of resources to assist parents to increase their knowledge and skill. Visit www.familiestogetherinc.org or mpactpti.org for more information.

Adapted from “Back to School: Getting Off to a Good Start”, PEAK Parent Center

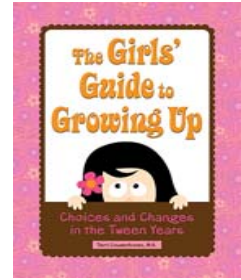
The Girls Guide to Growing Up

Here's a book just for girls beginning a new phase of their lives! This appealing and easy-to-follow guide for girls with intellectual disabilities is an introduction to the physical and emotional changes they'll encounter during puberty. Written on a third-grade reading level for preteens or young teenaged girls to read by themselves or with a parent, it's filled with age-appropriate facts, realistic illustrations and photos, icons, and a Q&A.

The Girls' Guide to Growing Up advises girls about their changing bodies, privacy issues, and how to feel their best, including:

- ... What is puberty?
- ... Body changes (height & shape, breasts & bras, body hair, skin & blemishes, body odor)
- ... Emotional changes (moodiness & handling your feelings, sexual feelings & what to do about them, flirting do's & don'ts)
- ... Periods (what to expect, using a pad)
- ... Hygiene (keeping face & body clean, showering, using deodorant)
- ... Privacy, safety & social appropriateness (private parts, rules for who can touch you & when, rules for touching others, what to do if you feel unsafe)

The Girls' Guide to Growing Up is written by an experienced sex educator who specializes in working with people with intellectual disabilities and who is also the author of the popular **Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality**. Parents, physicians, schools, and support groups will want to share this encouraging book with girls to help answer their questions about puberty and reassure them it's all part of growing up.



Order a copy today at:
www.woodbinehouse.com

DSG Member Attends World Special Olympics Games in Greece

DSG member Chris Ringot was the only athlete with Down syndrome on Team Missouri for the World Games and he did an incredible job! This was a life-changing experience for all of our athletes as we spent 18 days travelling together. We encountered so many new experiences and people along the way, and all of our athletes handled it with ease. Chris made a ton of new friends and represented Missouri well. His coaches told us many times how impressed they were by his swimming, and also with how well he got along with teammates and everyone he met.



DSG member Chris Ringot pictured with his teammates in Greece at the World Special Olympics Games.

Chris was surprised to return home to KC and find people at the airport waiting to meet and cheer for the team. "I saw my family there. When we got home there were balloons and flowers and cinnamon rolls waiting for me. Yum. There's no place like home. It was a once in a lifetime experience for me. When I see the pictures I can't believe I really was there. It was the best time of my life. People stop me all the time and ask how it was and I can't describe it. It was like living a dream."

Memorial Donations

DSG is always saddened to hear of the loss of a loved one who is a member or relative of a member. We are honored when a family thinks of us during a difficult time and requests donations be made to the DSG in behalf of their loved one who has passed.



DSG received many wonderful donations in loving memory of Ryan Beavers. We extend our sincere sympathy to his family on their loss.

Ryan was born in June of 1989. He was a wonderful baby boy who was loved by so many. He loved sports from a very young age. He could not pass by any ball without wanting to play with it. He grew up playing baseball, soccer, football and basketball. He attended Good Shepherd Catholic Grade School. He graduated from Bishop Miege High School in 2007. He played varsity soccer and tennis. The most wonderful aspect of Ryan was his personality. He loved people!! He always brightened everyone's day. Ryan's younger sister Katie, who has Down Syndrome, loved it when he was around because he would play with her and make her laugh. They brightened each other's days. He was a wonderful son and brother! He will be dearly missed by all his family and friends.

Marry & Mark, Molly & Katie Sasenick

Larry & Missy, Cameron & Brandon Beavers

Joplin Tornado Claims Lives of Three Men With DS

My brother, Tripp Miller, passed away at the young age of 49 early Monday morning, May 23, 2011, after sustaining severe injuries in the Joplin tornado. Tripp resided in a group home along with two of his life-long friends, Mark Farmer and Rick Fox who also had Down syndrome. All three died when the tornado leveled their house, which was across the street from the destroyed Joplin High School.

Tripp was the son of Patricia Gray Miller and Ray Donald Miller, Jr. of Joplin and was born in 1961. He was affectionately called Tripp because he was the "triple," or third, Ray Donald Miller of the family. The doctor didn't tell my parents that Tripp had Down Syndrome until he was 3 months old and they encouraged Mom and Dad to institutionalize him stating that he would probably never be able to function in society. My parents decided to raise Tripp at home with the rest of us. They opted to treat him just like the rest of us as they believed if he was treated special, then he would expect to be treated special and they didn't want him to become that type of person. They wanted Tripp to be the self-sufficient, loving person that he turned out to be.

Having Tripp as a brother was probably different than most people's sister/brother relationships in that he was forever my childlike brother as far as his mental age, but his wisdom and the simple but profound way of looking at things blew right past my abilities as an adult in those areas. When someone was upset, his most common saying of "I do want you happy" was a testament to his character and all that needed to be said to make you feel better.

Tripp attended school at the Cerebral Palsy Clinic. My parents were instrumental in forming a state school for the handicapped in Joplin and Tripp graduated from Collegeview State School in 1982. Tripp worked at the Sheltered Workshop in Carthage for two years and then at Joplin Workshop, Inc. where he was employed the last 27 years. He volunteered for Meals on Wheels and was a lifelong member of the First Presbyterian Church in Joplin where he attended regularly his God's Fellowship Sunday School class. Tripp loved living with his childhood friends, Rick and Mark, bowling with friends, attending 1st Presbyterian Church; traveling to see his siblings, going to Mizzou football games with family where he was a very proud member of the University of Missouri Alumni Association, and rooting, as a life-long fan, for the St. Louis Cardinals.

Tripp loved sports and was an enthusiastic fan of local high school teams, particularly the Parkwood Bears and Joplin Eagles. He participated in Special Olympics since his school days and was honored to carry the Olympic torch a few years ago when the SO was hosted by Joplin. He excelled at bowling, swimming and basketball. He won his last of many gold medals at the State Special Olympics in the fall of 2010 by bowling the best game of his life.

Tripp had a very happy, full life with his family as he grew up with his four siblings, attended all of their school events and was their biggest supporter. He truly was the center of all the kids' lives. Tripp, who was given the title "No. 1 Uncle" by his five nieces and four nephews, was family-oriented, and was



Tripp Miller (pictured center) with his friends Mark Farmer and Rick Fox. All three men lost their lives in the Joplin tornado. DSG extends sincere condolences to their families.

set to so excited to be a groomsman in his nephew's wedding on July 30, 2011.

On May 22, 2011, Tripp was found by our sister, Mary, about 45 minutes after the tornado struck sitting on the foundation floor of what was left of his house. A Joplin resident unknown to our family stopped to help. He went with Mary to where Tripp was sitting, picked him up in his arms and carried him to his Jeep. Mary told Tripp she was with him and that this man was taking him to the hospital. Tripp's whispered to him, "Oh, thank you." Even at the end he used what little strength he had to thank someone that was being kind to him. Many people risked their lives to come to Tripp, Mark and Rick's aide as the streets were blocked with downed live electrical lines and trees, large debris falling from the trees that were left standing and mangled cars.

At the hospital Tripp stopped breathing, but was revived in the ER and then sent immediately to surgery where they removed his spleen and one kidney to hopefully stop the bleeding. Two nurses worked non-stop all through the night to bring his body temperature up to normal and pump new blood into him to replace the blood he was losing. He fought the good fight just as he always did with the life God gave him. I am so proud to call him my brother and so thankful that I was his sister.

Tripp was our son, our brother, our uncle, our friend, our angel. He taught us the lesson of kindness, unconditional love, humility and never to complain no matter how tough things got. He taught us the richness of enjoying others. He touched the lives of so many people, and we were all better people having him in our life. His family will miss him terribly every moment of every day.

Submitted By: Mindy Crowe



2011-2012 School Year

*Utilizing Technology for Learners
With Down Syndrome*

*Enhancing Speech/Communication
for students with Down Syndrome*

Down Syndrome 101 for Educators

*Practical Solutions for Educating
Students With Down Syndrome*

DSG is committed to providing parents and educators the best tools and resources to support students with Down syndrome.



DSG offers a several FREE seminars throughout the school year which highlight best practices and available resources. Share this informational flier with anyone who would benefit from attending a DSG seminar. We welcome your feedback on additional training topics or needs.



"Thank you DSG for hosting these wonderful seminars. I always come away with great information and new strategies I can use in my classroom."

"I wish I had this training 20 years ago when I started working with students who have Down syndrome."

"I am excited to go back to school and share the information I learned with my team!"

Register for one or more of these great seminars today! Email info@kcdsg.org or call 913-384-4848 to reserve your seat.

All sessions will be at:

Kauffman Foundation
Conference Center
4801 Rockhill Road
Kansas City, MO 64110

8:30-11:30 AM

Breakfast provided

**Practical Solutions for Educating
Students With Down Syndrome**
September 15, 2011 OR February 9, 2012
Kauffman Foundation Conference Center
8:30 AM-11:30 AM Breakfast Provided

Over 5,000 parents and educators have attended this seminar. Designed to help you understand how to successfully engage, instruct and enjoy your student with Down syndrome, the presenter will provide an overview of the specific learning needs characteristic of students with Down syndrome. Tips, strategies and solutions for pre-school through high school will be covered. Topics include:

- ... How to improve student communication
- ... How to move your student towards independence
- ... The right placement with the right schedule
- ... How to change behavior
- ... Simple approaches to adapting curriculum

**Enhancing Communication and Speech
in students with Down Syndrome**
October 13, 2011 OR April 12, 2012
Kauffman Foundation Conference Center
8:30 AM-11:30 AM Breakfast Provided

Students with Down syndrome have amazing receptive language. Expressive language can be quite lacking which leads to frustration, inappropriate behavior and more time out of the classroom if not addressed. Attendees will learn many practical exercises they can utilize to enhance speech and communication. Topics covered include:

- ... Speech techniques that work
- ... Ideal therapy goals and environment
- ... Group therapy/individual therapy benefits
- ... How to change behavior
- ... Simple approaches to adapting curriculum

**Utilizing Technology for Learners
Who Have Down Syndrome**
December 8, 2011 OR March 1, 2012
Kauffman Foundation Conference Center
8:30 AM-11:30 AM Breakfast Provided

Are you using technology to help your students with intellectual disabilities? If not, why? This presentation will highlight common challenges with implementing and accessing technology and important resources you can access to help your students. Topics covered include:

- ... Using technology for students transitioning from grade to grade or building to building
- ... Curriculum adaptations through technology use
- ... Progress monitoring using technology
- ... When to schedule an IT/AT evaluation
- ... What to do when you have invested time/money and the student is not interested in the technology

**Down Syndrome 101
for Educators**
November 3, 2011 OR January 12, 2012
Kauffman Foundation Conference Center
8:30 AM-11:30 AM Breakfast Provided

Are you an educator or paraprofessional working with a student who has Down syndrome currently? If so, do you understand the unique learning profile of your student and how you can most effectively include, educate and enjoy your student? DS 101 for Educators will cover the following topics:

- ... Common medical issues related to Down syndrome
- ... Communication issues and strategies for success
- ... How to improve social skills
- ... Processing time and memory issues
- ... Benefits of inclusive education
- ... Environmental issues which can hamper success
- ... Ways to adapt the curriculum

**REGISTER FOR ANY
OF THESE FREE
SEMINARS:
INFO@KCDSEG.ORG**

**QUESTIONS?
PLEASE CONTACT**



10200 West 75th Street
Suite 281

Shawnee Mission, KS 66204
www.kcdsg.org
info@kcdsg.org
913-384-4848

STARS Program Upcoming Events for September/October



The STARS program is for teens with Down syndrome who are 12-18 years old. Our focus is on social, prevocational and life skills which will help our teens prepare for adulthood, employment and independent lifestyles. Email leslie@kcdsg.org if you would like to be added to the STARS activity email list. Please visit www.kcdsg.org and click on 'Calendar' for complete details on upcoming STARS activities.

September Events

Sept 7: 6pm to 8pm, Bowling, AMF Northland Lanes - snack

Sept 10: 9am to 1pm, Shatto Milk tour - snack

Sept 14: 6pm to 8pm, Movie Night - snack

Sept 21: 6pm to 8pm, Yoga - snacks

Sept 23: 6pm to 9pm, Photo shoot, Crossroads Area- dinner

Sept 28: 6pm to 8pm, Karate - snacks

October Events

Oct 5: 6pm to 8pm, PowerPlay- snack

Oct 12: 6pm to 8pm, Hip Hop lesson- snack

Oct 19: 6pm to 8pm, Games 2 U - snack

Oct 21: 7pm to 9pm, Halloween Dance- snacks

Oct 29: 9am to 1pm, Step Up for Down Syndrome Walk

September						
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4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

October						
S	M	T	W	T	F	S
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29

Transportation Options

DSG is establishing increased transportation options for STARS activities. Our intent is to offer occasional pick up/drop off at locations throughout the metro for some activities. If you are interested in learning about transportation options for STARS activities, please visit www.kcdsg.org and click on 'Calendar'. Transportation information will be available by viewing details for STARS activities via weekly email reminders. If you have questions please email Leslie Hernandez Brown, leslie@kcdsg.org.

Quarterly Lunch with Friends

The STARS Program will now offer a quarterly "Lunch with Friends" on Saturdays at varying locations throughout the metro. These lunchtime opportunities are intended to reach outlying areas of the Kansas City metro, increase participation in the program and promote new friendships among those eligible for the STARS Program.

Contact

To RSVP for an upcoming STARS activity or for questions, please call 913.384.4848 or email leslie@kcdsg.org.

KFC Teams with First Downs for a BIG Fall Promotion!



KFC & FDFDS are gearing up for a big fall promotion! Rather than having just one day, KFC and FDFDS are planning to have many opportunities where anyone can visit their local KFC and receive a great deal on dinner, meet Chiefs players, KFC Wolf and Chiefs Cheerleaders, plus support Down syndrome!

These special days will raise awareness and funds for First Downs for Down Syndrome. Each of the 53 KFC's in the Greater Kansas City area, along with stores in the Manhattan/Topeka, Kansas areas participating. Look for future emails and information on this very soon!

Step Up for Down Syndrome Walk Saturday October 29, 2011

We have many great, family fun activities planned— pony rides, inflatables, clowns, face painters and so much more! We look forward to seeing all of you on Saturday, October 29th. Please invite your family, friends, co-workers and neighbors to join your walk team to help promote awareness and raise funds. Please note EVERYONE who attends the walk must pay the registration fee if they are 3 or older.



The team fundraising deadline is quickly approaching!!! Please bring all of your monies (and pick up your team's shirts too) at our office on Saturday, October 22nd from 9am-1pm. Questions— please call Amy or Tiffany at the First Downs office at 913-722-2499.



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.



Area Corporate Sponsors also support First Downs for Down Syndrome. We thank them for make for their generosity. For information regarding events or other fundraisers, please 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



FDFDS Calendar of Events

Gaining Ground for a Winning Cause.....

15th Annual Huddle Time

**Date & Time: Wednesday
June 9, 2011**

**6:00-9:00 p.m. Roe
in Leawood**

Enjoy a great evening, support a fabulous cause and meet Chiefs players.



9th First Downs Golf Classic

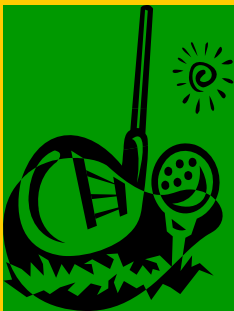
Monday July 18, 2011

Registration 10:00 a.m.

Shot gun start 11:00 a.m.

Shoal Creek Golf Course

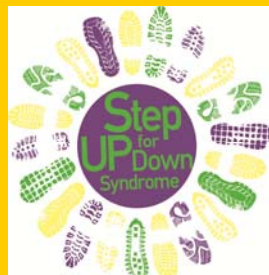
Take Monday off and enjoy playing golf with friends! All proceeds benefit First Downs for Down Syndrome.



16th Annual Step Up for Down Syndrome Walk & Family Festival

**Date & Time: Saturday
October 29, 2011**

Location: Arrowhead Stadium- Lot C



Thank You for Your Support of the 9th Annual First Downs Golf Classic!

The July 18 outing raised over \$40,000!

Golfers played the links at Shoal Creek Golf Course and enjoyed lunch, specialty drink holes, hole contests, dinner and so much more! Thank you for attending and for your continued support of FDFDS.

Pictured below: The NMR Golf Team- Scott Bland, Len Page, Phil Smith & Steve Thorne pose with Chiefs Cheerleaders

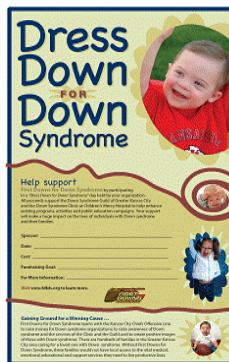


FIRST DOWNS FOR DOWN SYNDROME HIGH SCHOOL FUNDRAISER GEARING UP FOR THE 2011-2012 SEASON!

Blue Valley Northwest
Bonner Springs
Hardin Central
Raytown
Kearney
Leavenworth
Olathe East

Olathe Northwest
Pleasant Hill
Santa Fe
Shawnee Mission West
Smithville
St. Pius X
St. Thomas Aquinas

The above schools will participate in the joint fundraising efforts between high school football teams & FDFDS. The program is designed to create awareness and provide additional resources to benefit individuals with Down syndrome. while also raising money for the football teams. If your school is not on the list, we would like to get them involved. Please call the FDFDS office at 913-722-2499 for information.



Host a Dress Down for Down Syndrome Day at Your Office or School to Benefit FDFDS

Do you and your co-workers/friends like wearing jeans to work? Here is an easy way to be comfortable all day AND to also help those with Down syndrome. Help spread awareness and display the many gifts and talents of individuals with Down syndrome by hosting a Dress Down Day! Contact FDFDS at 913-722-2499 for more information .



10200 West 75th Street
 Suite 281
 Shawnee Mission, Kansas 66204
 913-384-4848
 info@kcdsg.org
 www.kcdsg.org

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**FOOD
 GAMES
 HAYRIDES**

**DSG FAMILY DAY AT THE
 WESTON RED BARN FARM**

**Sunday, September 11th
 1:00 PM — 4:00 PM
 16300 Wilkerson Road
 Weston, MO 64098**

Bring the whole family for a fun for all ages day on the farm. Visit the animals, enjoy a hayride, participate in family games and check out the pumpkin patch!

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

Join us for the DSG
 Parent and Extended Family
 Support Breakfast
 Saturday, September 17th
 DSG Office
 8:30 AM-9:00 AM
 First time attendee orientation
 9:00 AM-11:00 AM
 Breakfast and meeting

Parents of children between the ages of 0-2 are invited to join our new parent breakfast. Parents of children between the age of 3-5 who have Down syndrome are invited to join us for the toddler parent breakfast. Bring your extended family members too for a wonderful breakfast to connect with others learn about valuable resources and discuss any concerns you may have regarding your child.

Representatives of the DSG will be available to answer your questions and share the many benefits and resources DSG offers to members.

Please join us for a wonderful and enriching networking breakfast. Babysitting is provided for kids of all ages when you RSVP to the DSG office with number and ages of children attending.

RSVP by September 12th
 to info@kcdsg.org
 or via phone to 913-384-4848