The Down Syndrome Guild of Kansas City is privileged to support individuals with Down syndrome and their family through the years — from those first tender moments in the hospital to the first day on the job. We aim to be a valued partner that provides resources, programs, and assistance along every step of the journey, and we recognize that individuals and families have different needs and interests at different stages.

Our programs and resources reflect the growth and development throughout the life of a person with Down syndrome. We send baskets with resources and gifts to new and expectant parents and then host parties and events for young children. When those children move on to school, we offer training and resources for families and professionals to establish a foundation for a successful school experience. During these formative years, we understand that parents and siblings also need guidance, so we offer workshops, outings, and conferences to meet their unique needs. Then, when those children reach adolescence and become adults, we host events and job training for them to be successful, independent, and socially active members of their community.

We also understand there we have many partners in the community who need direction and training to help individuals with Down syndrome reach their full potential. This is why DSG also provide resources, information, and training to medical providers, educators, and employers, through medical outreach programs, the Parents and Schools in Partnership program, and employee referrals. We strive to build communities of acceptance and inclusion that embrace people with Down syndrome through peer presentations, community events, and our film “Just Like You.” We are thrilled that this film, developed in partnership with Just Like You films, has ignited a nationwide effort to promote awareness and acceptance while encouraging friendships and understanding.

People with Down syndrome are living longer, healthier, richer, and more meaningful lives than ever before. This is because families and communities are embracing individuals with Down syndrome and working together every step of the way to ensure individuals achieve their goals and enjoy all the opportunities available. The board, staff and volunteers at the DSG enjoy providing guidance and resources to help individuals with Down syndrome thrive and share their unique talents and gifts with the world.

Because of your advocacy and generous contributions, DSG is able to build a foundation that lasts a lifetime. However, there is still more to be done. Our goals in the next year are to build more employment services for adults with Down syndrome so that young adults have a bright horizon ahead of them. We want to spread the “Just Like You” message far and wide, and we will build sustainable training programs for educators facing increasingly limited budgets.

Please join us in celebrating the milestones we have accomplished with your support during 2012 and help us continue to build a network that strengthens our members through the years.

Joe Roos
BOARD PRESIDENT

Amy Allison
EXECUTIVE DIRECTOR
WE WRAP OUR ARMS AROUND NEW AND EXPECTANT PARENTS when their emotions are raw and tender after receiving a diagnosis. Then we help them understand what life is like for people living with Down syndrome and introduce them to other families who can join them on their journey. We also invite expectant parents to join our extended DSG family throughout their pregnancy by attending support breakfasts and by matching grandparents and siblings with others who can understand their unique perspectives.

DSG partners with 22 area hospitals to provide the most current information, research, and training for medical providers. Our goal is to share the best practices for delivering a diagnosis of Down syndrome so that expectant parents receive the most informative and compassionate care available during those critical moments after receiving the news.

“When our doctor confirmed the diagnosis of Down syndrome at 14 weeks into our pregnancy, we felt like our world was crashing in around us. We had so many fears and questions, and DSG was there for us every step of the way. We visited with parents and their children and gained a better perspective on the realities of life with Down syndrome which helped us prepare for and celebrate our daughter’s birth.”

DSG provides copies of Understanding a Down Syndrome Diagnosis, the gold standard, medically-approved booklet, to parents and medical professionals.

“CHANGING LIVES”

PRENATAL DIAGNOSIS

“PRESENTATIONS for local hospitals”

EXPECTANT PARENT PACKETS

“delivered to new parents”
WE CRADLE SWEET NEWBORN BABIES IN OUR ARMS AND TELL their parents that their lives will be different than they planned but wonderful in the most unexpected ways. We celebrate their new arrival with a basket of resources and baby gifts. Then, we introduce them to other parents to make sure they have all the information they need for a bright start.

“&quot;We will never forget the basket DSG brought to the hospital. It was filled with information, support and hope that made it possible for us to dream a new dream for our daughter. That 30 minute visit and special delivery changed our perspective and made us realize we had a wonderful support network ready and willing to help us advocate for our daughter.”

“We have checked out many items and found them all to be very helpful.”

NEW PARENT BASKETS

51
DELIVERED

LENDING LIBRARY

300+  
100+

MATERIALS AND GROWING

QUARTERLY SUPPORT BREAKFASTS

80
FAMILIES SERVED
WE HOLD THE HANDS OF KINDERGARTENERS AND PRESCHOOLERS AS THEY HEAD TO THEIR FIRST DAY OF SCHOOL. WE DO THIS BY GIVING THEIR PARENTS THE SKILLS AND INFORMATION THEY NEED TO HELP THEIR CHILDREN SUCCEED IN SCHOOL. WE ALSO TRAIN SCHOOL DISTRICT STAFF ON THE UNIQUE LEARNING PROFILE OF STUDENTS WITH DOWN SYNDROME AND OFFER SUGGESTIONS ON HOW TO INCLUDE, EDUCATE, AND ENJOY THEIR STUDENTS.

DSG FACILITATES PARENT-TO-PARENT MATCHES WITHIN SCHOOL DISTRICTS SO THEY CAN SHARE THEIR EXPERIENCES AND DRAW STRENGTH FROM EACH OTHER.

“We were very anxious about sending our son to Kindergarten. When the Smart Start program was announced it was like an answer to our prayers. We learned valuable tips and information that helped us focus on the skills we needed to be good advocates and the skills our son needed to succeed in the classroom.”
We encourage school-age children to become independent while creating an atmosphere of acceptance to help them thrive. We provide training and tips to teachers, administrators, peers, and friends to make sure they understand how to include children with Down syndrome while promoting tolerance, acceptance and friendship. We also send out Inclusion Solutions e-blasts full of tips and strategies for adapting curriculum, dealing with behavior, creating effective IEP goals and highlighting success stories.

**Parents and Schools in Partnership**

“DSG offers so many wonderful resources to educators and professionals through the Parents and Schools in Partnership Program. We have had peer presentations in our classrooms, sent our teachers and paras to training, and borrowed items from the lending library. We enjoy working in collaboration with DSG to bring about positive outcomes.”

**Inclusion Solutions**

We also decorate cookies, exchange cards, and get our fingers sticky with glue alongside children at the Valentine’s Party, the Spring Craft Night, and the Spook-tacular Party. These are the precious moments when parents and kids play together and make new friends who uniquely understand what it means to navigate an IEP meeting or multi-task at occupational therapy.

**Parties**

“My friend has Down syndrome, but I never really knew what that meant until the DSG came into our classroom and gave a peer presentation. The hands on activities we did helped me understand why some things are hard for my friend and why she leaves the classroom to get extra help. Kids also learned what things they have in common with students with Down syndrome which was important too.”

**Classroom Peer Presentations**

“25 peer presentations”

**Children attended events**

“70 children attended events”

**Parents and Schools in Partnership**

“450 newsletter recipients”

**Inclusion Solutions**

“25 peer presentations”
We pin boutonnieres and corsages on guests and dance the electric slide with teens and adults with disabilities enjoying their first or twentieth dance. We also coordinate service projects, tour potential employment sites, go bowling and watch movies with teens who become lifelong friends.

**DSG PROM**

“Our daughter and her boyfriend talk about and look forward to the DSG Prom all year long. They plan matching outfits, practice dancing, and talk about special requests they will make to the DJ when they arrive. When the invitation comes in the mail, the date is immediately reserved, and the countdown starts. It’s the best night of the year for them. Thanks DSG!”

**ADULT ACTIVITIES QUARTERLY**

The DSG hosts adult activities each quarter to ensure adults with Down syndrome and their friends have opportunities to meet new people, cultivate romances, and build rich and meaningful social networks at activities like the DSG Prom, the Spring Fling, and the Holiday dance.

**S.T.A.R.S. PROGRAM**

 SPECIAL TEENS ACHIEVING REAL SUCCESS

“The teen years are challenging for all kids and parents. A teen with Down syndrome is no different. Our son looks forward to attending STARS every week. He likes catching up with his friends, hanging out, and participating in the service projects. It’s been wonderful to see so much growth in his social skills and willingness to try new things since he started attending the STARS program.”

**REFERRALS TO ADULT SERVICE PROVIDERS**

DSG works with self-advocates and parents to address issues such as guardianship, special needs trusts and medical issues. We help our members identify post-secondary programs, housing options, employment opportunities and community activities which will ensure a rich adult life.
$500,000 raised at the largest grossing Down syndrome awareness walk in the world.

STEP UP WALK
www.stepupfordownsindromekc.org

“The Step Up for Down Syndrome Walk is an awesome day for families to come together and celebrate their loved one with Down syndrome. It’s wonderful to see thousands of people walking and raising awareness. Our family is always overwhelmed with the turnout from our family, neighbors, co-workers, and our church. We look forward to the walk year-round and love the spirit of camaraderie and solidarity we feel at the event.”

CONNECTIONS NEWSLETTER

We share the DSG Connections Newsletter with members, educators, medical providers, and area service providers six times per year. Our goal is to keep parents and professionals up-to-date on the latest information about Down syndrome, including medical issues, research, upcoming events, seminars, workshops, and conferences. The newsletter is distributed to over 3300 recipients in 28 states and 4 countries.
WE INVITE SIBLINGS 8-18 YEARS OF AGE TO FUN EVENTS where they can meet other siblings. We listen to any frustrations or challenges and give them advice when they lean in to tell us that they don’t understand why their sibling has easier chores or why kids at school just don’t understand why the r-word is hurtful. We share coping strategies and encourage siblings to talk openly with their parents about their needs.

“Our son has three older siblings who love him and spoil him. That being said, the siblings definitely experience unique challenges their friends don’t have to face because their brother has Down syndrome. We were so excited when DSG started hosting Siblings Night Out as it gives our kids a chance to meet other siblings, talk about anything they are frustrated about, and learn how to advocate for their brother and themselves.”

SIBLINGS NIGHT OUT

40 siblings at 4 events
COMMUNITY

We invite community members to volunteer and share their passion and talents with us. This provides them a glimpse of the true reality of life with Down syndrome. Volunteers assist with childcare during trainings, dancing the night away with guests at the DSG Prom, helping kids collect eggs at the Easter Eggstravaganza, assisting teens as they perform a service project, or just hanging out with adults enjoying a dinner and movie. We change perspectives profoundly by helping volunteers understand that life with Down syndrome is both ordinary and remarkably fulfilling.

“I have volunteered for many organizations in my adult life. None of them compare to the DSG! I so enjoy working with people with Down syndrome — whether it be in the childcare room, at the Step Up Walk, dancing the night away at the prom, or at a STARS event. DSG’s volunteer program is very well organized, and expectations are made clear. There is always a meaningful job to do when I arrive, and I know I am touching lives, so volunteering is a joy.”

1,000 volunteers provided 7500+ hours of service

www.kcdsg.org/volunteer1.php
“Our Community Group has become our extended family. We now have a network of people we can contact if we have questions or need a referral for a doctor or specialist. It’s comforting to know we have a group of parents who get it that we can talk to about any challenges we are facing or brag to about our son’s latest accomplishment.”

“My daughter spent a lot of time at Children’s Mercy Hospital this year for various issues. The visits and meal voucher checks from DSG helped lift our spirits and cover some of the costs related to being in the hospital. The third time we were in we didn’t even call DSG. Someone else must have notified them and they just showed up to support our family without us even asking.”

“DSG events provide a great opportunity to meet other parents and exchange information and resources while having a great time. Every detail is planned carefully so families can enjoy one another’s company while meeting up with old friends or making new ones.”

“My wife and I have a great relationship, but we never pass up the chance to attend DSG’s Mind Your Marriage Retreat. We enjoy meeting other couples, the activities which remind us to focus on one another, and the fabulous overnight stay at the hotel. It’s great to know that DSG really cares about our whole family and knows we will be better parents if we get away for some respite!”
JUST LIKE YOU FILM

JUST LIKE YOU — DOWN SYNDROME explores the challenges and dreams of three teens with Down syndrome — Elyssa, Rachel, and Sam — and their friends. The film shares the importance of inclusion, friendship, and thoughtful language. Parents, educators, peers, and advocates are sharing the film in schools, churches, and recreational centers across the country. The video, created in partnership between DSG and Just Like You, has ignited a nationwide movement to break down myths and promote acceptance and inclusion.

“This is the best advocacy tool I have seen to date to help explain Down syndrome. The film addresses some of the medical, physical, and academic challenges kids with Down syndrome face but also highlights similarities to typical peers. Every school should show this film to help promote tolerance, acceptance and friendships.”

justlikeyou-downsyndrome.org

400 DVDs to schools, organizations and families

56,000 VIEWS in 3 months

23 states with screenings at schools

56,000 views in 3 months
FIRST DOWNS FOR DOWN SYNDROME


THE 2ND ANNUAL DOLLS & DESSERTS FOR DOWN SYNDROME is a unique mom and daughter event held Sunday September 9, 2012 at the American Girl Doll Store at Oak Park Mall. The sweet event featured desserts from five KC sweet spots: Cupcake A La Mode, Krispy Kreme, Smallcakes, Three Girls Cupcakes & Three Women & an Oven. Girls and their moms decorated their own sugar cookie and sampled desserts while their doll got her hair styled in the doll salon. The event raised over $4,100.

THE 9TH ANNUAL PRIVATE CELLAR WINE TASTING & AUCTION was very successful with over 430 guests and raising over $165,000 making this year’s wine event the most successful. Special guests included Kansas City Chiefs Offensive Lineman Ryan Lilja and Jon Asamoah and KC Lyric Soprano Heather Phillips. Guests enjoyed sipping and bidding on unique wines from Kansas City’s foremost collectors, while enjoying the spectacular view from the 24th floor of the law firm of Shook Hardy & Bacon L.L.P.

THE 16TH ANNUAL HUDDLE TIME SPORTS AUCTION was held on May 30 at Mestizo’s in Leawood. The event had over 250 attendees, bidding on unique sports memorabilia and vacation get-a-ways. Stephen St. John with Sports Radio 810 was the emcee, along with Ryan Lilja, Matt Cassel, Tony Moeaki, Eric Winston, Jon Asamoah and many other members of the Kansas City Chiefs football team! Guests enjoyed fabulous food, drinks and the opportunity to rub elbows with current Chiefs players. The event raised $40,500.

THE 10TH ANNUAL FIRST DOWNS GOLF CLASSIC hosted 34 teams in a 4 man shot-gun scramble tournament at the beautiful - Shoal Creek Golf Club. Golfers enjoyed lunch, hole contests, “fun” holes, an awards dinner and a great day of golf for a great cause! The event raised $37,000.

THE 17TH ANNUAL STEP UP FOR DOWN SYNDROME WALK & FESTIVAL was held on Saturday October 27 at Arrowhead Stadium. The Step Up Walk was a huge success with over 10,000 people in attendance, over 345 teams and not to mention, the event raised over $497,800! Walkers enjoyed food courtesy of KFC, friends, music from Radio Disney & the Swingsters, carnival games and festivities for every age group. Kansas City is very proud to be recognized as one of the largest walks in the Nation!

University of Kansas- Adult Down Syndrome Clinic, The Lee Ann Britain Infant Development Center, The Mission Project, and the Kansas City Down syndrome community.

On behalf of the First Downs for Down Syndrome Board of Directors, we would like to thank our sponsors for their support of our cause.

101 The Fox
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DST Systems
Glazer’s
JE Dunn Construction
KCTV5
KC Hops
KBP Foods/Kentucky Fried Chicken
Krispy Kreme Donuts
Major Brands
National Marketing Resources
Shook, Hardy & Bacon

Other 2012 fundraising activities by FDFDS include:

- 5th Annual Kentucky Derby Gala — in partnership with the Mission Project
- Football Academy Camp — in partnership with the Football & Cheerleading Club of JOCO
- First Downs High School Football Fundraiser

These are just a few of the exciting events that FDFDS sponsors to raise money for the Down syndrome community. If you would like to learn more about FDFDS, please contact Executive Director, Amy Stoll at 913-722-2499.
The work of DSG would not be possible without the financial support of the individuals, corporations, and groups who are willing and ready to turn ideas into action and support our mission. We greatly appreciate those who supported DSG in 2012.

In 2012 DSG revenue was $736,672. The 2012 revenue represents a 16% increase from 2011 revenue of $621,292. We received $490,280 from First Downs for Down Syndrome from their fundraising events, compared to $386,550 in 2011.

**WE THANK OUR MAJOR DONORS**

- Assurant
- JoAnn Butaud
- Bratton & Mitchem Families
- CVS/Caremark
- First Downs for Down Syndrome
- Lucille and Bruce Lambert Foundation
- Mechanical Contractors Association
- Dyan & Abel Mojica
- Bridget & John Murphy
- John Pascucci & Jacqueline Charitable Trust
- Platte County Board of Services for the Developmentally Disabled
- Silpada Foundation
- Variety Children's Charity
- Joan S. Weiner Foundation

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Within 2012 expenditures we are proud that only 15% was used for administrative purposes. As a result, more of our resources were available to directly support individuals with Down syndrome and their families, to provide information, and to educate the community about Down syndrome.

The resulting net income enabled DSG to contribute $34,205 to the endowment fund. Our goal is to contribute 5% of unrestricted revenue each year until the fund reaches an amount equal to one year’s operating expenses. Currently, DSG has approximately $255,450 in the endowment fund, which will be held to secure our future. In addition, the resulting net income allows us to carry forward resources to help in meeting and improving our programs in 2013.
The Down Syndrome Guild of Greater Kansas City is a nonprofit volunteer 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 individuals with Down syndrome.