

# Celebrating Milestones



**ANNUAL  
REPORT  
2009**

# Leadership Message

**T**wenty-five years ago, the Down Syndrome Guild of Greater Kansas City (DSG) was formed. From the beginning, DSG has provided practical resources for people with Down syndrome, as well as compassionate support for parents and siblings. DSG has been instrumental in pushing myths and stereotypes aside by providing educational and social opportunities for our members, and by celebrating their achievements and milestones.

**In the last quarter century, things have changed dramatically for people with Down syndrome:**

- They are rarely, if ever, institutionalized.
- They are achieving at levels never before thought possible.
- They are included more fully in their schools and communities.
- Their average life span has almost doubled, due to amazing medical advancements and community inclusion.
- They are attending college, getting married, driving cars, and living independent or semi-independent lives.

**Our outreach efforts have grown steadily through the years**, and our programs and staff have expanded to advance our mission of making the world a better place for people with Down syndrome. In our efforts to achieve excellence, we continually reinvent ourselves to remain responsive to the needs of individuals with Down syndrome, parents, family members, educators, therapists, medical professionals, and the community at large. DSG is proud to be part of advancing the Down syndrome movement both locally and nationally.



**Bridget Murphy**  
Board President



**Amy Allison**  
Executive Director

*"We have been proud to work with DSG on a variety of projects including brand, Web site and annual report development. DSG and the member families are an inspiration to us in our work. Thanks DSG and congratulations on 25 years!"*

–Jason Inskeep, Adsoka, a marketing agency in Minneapolis.



Amy Allison received Ingram's 40 Under Forty Award for 2009.

# DSG Historical Timeline

**1984: DSG forms:** A group of parents hosted the first Down Syndrome Guild meeting. Early activities included an infant-action program for new parents; a summer picnic; quarterly meetings with speakers; and socials for parents.

**1986: Articles of Incorporation and Bylaws are established.**

**1987: 501(c)(3) Status is received.**

**1989: Down Syndrome Clinic at Children's Mercy Hospital is established.**

**1992: First Downs for Down Syndrome is formed.**

**1995: Management staff is secured:** DSG contracted with Association Managers to provide office space, clerical and administrative support, and executive directorship.

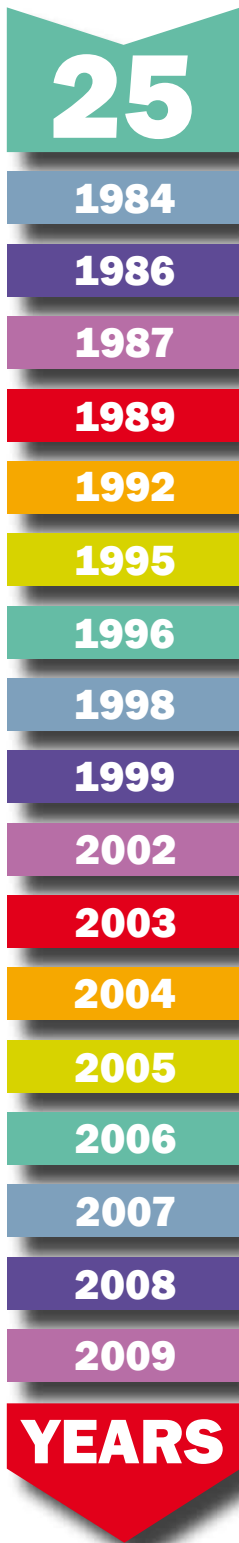
**1996: DSG hosts the first walk which raises \$8,000.**

**1998: Teen Grant is received:** Through the generosity of the Ewing Kauffman fund, DSG established a program for teens, and hired a part-time program director to help with age-appropriate activities for teens and young adults.

**1999: Adult Program is established:** DSG began offering social and educational programs for adults with Down syndrome.

**2002: DSG hires first full time paid Executive Director:** The relationship with Association Managers was dissolved, and DSG hired its first full-time paid Executive Director.

**2003: DSG creates Community Support Group plan** to meet the needs of growing membership in a large geographic area.



**2004: DSG Celebrates 20 years of service.**

**2005: DSG launches the Parents and Schools Partnership Program:** 45 school districts appointed Down Syndrome Specialists to serve as liaisons between DSG and school districts.

**2006: DSG Executive Director receives NDSC Meritorious Service Award,** and DSG staff grows to one full-time ED and two part-time employees.

**2007: DSG hosts two National Conferences, and is awarded National Parent Group of the Year.** DSG expands to three full-time staff members. DSG hosted the inaugural Affiliates in Action (AIA) Down Syndrome Leadership Conference in February. In addition, DSG hosted 1,800 attendees from around the world for the 35th Annual National Down Syndrome Congress Convention held August 3-5th. DSG was named the National Parent Group of the Year at the convention.

**2008: Down Syndrome Guild Center expands, and Kansas City hosts the largest Down Syndrome Walk in the nation:** The DSG office expanded to 4,000 square feet and welcomed the FDFDS staff. Over 7,000 people attended the walk which raised over \$450,000.

**2009: DSG hosts Down Syndrome Affiliates in Action Advocacy Day on Capitol Hill and launches Smart Start, STARS Program, and Dress Down Kits:** 300 Affiliate leaders from 38 states and 85 organizations joined DSG on Capitol Hill to advance policy priorities. Smart Start prepares students and parents for kindergarten success, and Special Teens Achieving Real Success (STARS) focuses on teaching teens with Down syndrome social, life, and pre-vocational skills. Dress Down for Down Syndrome Kits bring awareness and much-needed funds to DSG through casual days at local companies and schools.

DSG is grateful to the many individuals, families, and organizations who have contributed to our success.

# Public Awareness

**T**he DSG's Parent to Parent Program continues to be a hallmark offering of the DSG. In 2009, we provided consultation and support to 52 new families which received welcome baskets and visits from experienced parents in the hospital. "Family and Friends" packets were added to assist parents in sharing information about Down syndrome and DSG.

**Seventy-three families benefited from DSG's Hospital Meal Voucher Program**, which includes a hospital visit and monetary assistance to help offset costs related to hospital stays.

**DSG's Book Bundle Program exceeded this year's expectations** when 150 bundles sold out, and we still had more orders to fill! The addition of a DVD to the bundle was very popular. Over 900 books and videos were disseminated through the program, with 12 libraries and 68 schools receiving current and accurate information on Down syndrome.



**Changing Lives presentations were offered to medical professionals** on how to properly support families when giving a diagnosis of Down syndrome. In 2009, DSG facilitated ten Changing Lives presentations at six area hospitals. Physicians received gold-standard materials with research-based tips on appropriate diagnosis and support techniques.



*"DSG gave a great presentation. I enjoyed the personal stories and feel better prepared to meet my patients' needs moving forward."*

–Local Physician



**DSG's 2008 Believing in Achieving Annual Report was a KC Philly Award winner** for excellence in non-profit communications. Judges indicated the report was moving, informative, and contained critical information to help readers understand and connect with our mission. DSG extends our thanks to everyone who made this award-winning report possible.

**Connections newsletter continues to be a cover-to-cover reader for our members**, reaching over 2800 households. *Connections* is loaded with inspirational stories, medical and research updates, event information, community group listings, and helpful resources. We are thrilled to launch a fresh new look for *Connections* in 2010.

**DSG E-Blasts were implemented in the fall of 2009.** These bi-monthly E-mail updates contain important information about Down syndrome, links to our online publications, legislative alerts, research opportunities and updates, success stories, and information on how our members can get involved and support DSG.

**Peer Presentation Training was offered** to help our members learn effective strategies for sharing information about the similarities with and differences



between children with Down syndrome and their peers. DSG facilitated over 30 Peer Presentations in 20 schools during 2009.

**Dress Down for Down Syndrome Day Kits were launched** in the fall of 2009 to celebrate DSG's 25th Anniversary and Down Syndrome Awareness Month. Kits contained marketing fliers, participant stickers, collection envelopes, and DSG information packets to share when hosting an event. Over \$5,000 was raised through Dress Down Days in support of our mission.



*"We want to thank the DSG so much for coming to our daughter's school and giving such a wonderful peer presentation. The presentation comes at the perfect time (pre-middle school), and we had 5 parents tell us that the letter you sent home with the kids had so much information. Education does diminish fear. We appreciate the DSG for making our lives much easier with all the support, fun activities and camaraderie you offer. DSG is such a wonderful support system."*

—DSG Parent

The presentations, publications, and programs provided by DSG are designed to inform, educate, raise awareness, and improve the quality of life for individuals with Down syndrome.

# Public Education

**The DSG Believing in Achieving Conference welcomed over 250 participants** who were delighted to hear from self-advocates, parents, authors, and national experts on inclusion, creating friendships, prenatal testing, support for fathers, and techniques for teaching reading and math to students with Down syndrome.

**The Parents and Schools in Partnership Program continued to grow** with three new school districts appointing Down Syndrome Specialists who work collaboratively with DSG to insure students and educators have the resources they need to succeed. With 48 school districts participating, educators are better prepared to meet the needs of their students through directed training and individualized consultation offered by DSG. This program has been replicated by ten other Down syndrome organizations across the country.

**DSG's award-winning Inclusion Solutions newsletter provides educators and therapists with practical tips and strategies** to successfully educate and include students with Down syndrome. Over 1,200 recipients receive this quarterly publication.



In 2010, DSG will move to an eco-friendly electronic version of the newsletter so recipients will be able to access information easily from their computers at any time.

**DSG facilitated seven Practical Solutions for Educating Students with Down Syndrome seminars** in Kansas City. Sessions were filled with parents and professionals, the majority rating it as one of the best seminars they have ever attended. Down syndrome organizations in other states contracted with DSG to provide the seminar in their area. Over 5,000 parents and educators have now attended this cutting-edge presentation, which challenges seminar attendees to open lines of communication, while reducing the frequency of prompts and supports, to students with Down syndrome.

**DSG offered three Practical Solutions for Challenging Behaviors seminars**, where 250 educators learned strategies for reducing behaviors and increasing compliance with structured activities or routines.



*“DSG’s parent panel has proven to be a highlight session of my education classes at the University of Kansas each semester. My students, who are preservice teachers, have the rare opportunity to develop a deeper appreciation for the joys and struggles these families encounter while raising a child with a disability. Students routinely comment positively about the experience, always citing this opportunity as enlightening and enriching, leaving them feeling more fully prepared to teach students with DS and collaborate with their families in the future.”* –Juliet Hart Ph.D., Assistant Professor, Special Education Arizona State University



**DSG receives numerous calls each year from parents and educators** seeking advice and guidance on IEP or behavioral issues. In 2009, DSG worked collaboratively with 75 families and schools to provide consultation to reach satisfying outcomes and enhance home/school communications and relationships.

**DSG launched DS 101 for Paraprofessionals in 2009.** These 3-hour sessions cover medical, social, communication, and developmental needs of students with Down syndrome. The role of paraprofessionals is discussed, along with curriculum adaptations and the unique learning needs of students with Down syndrome.



**The Smart Start Pre-K Program was launched in 2009** in an effort to alleviate parent anxiety about sending a child with Down syndrome to kindergarten. Smart Start is a series of four 2-hour training sessions that address various issues such as parent and child readiness, placements, IQ testing and assessments, behavior support, and creating opportunities for friendships. Parents who complete the program receive a gift card to purchase school supplies.

**DSG coordinated six Parent Panels for students at local universities** specializing in education, physical therapy, and occupational therapy. Two-hour panel presentations focused on sharing a parent perspective, and best practices for working with individuals who have Down syndrome.



The Public Education Committee is key to the ongoing efforts to educate the community and advance the mission of DSG.

# Community Groups

**I**n an effort to better serve our 1,100 member-families, DSG funds and provides administrative support to 14 community groups throughout the Greater Kansas City area. During 2009, community groups hosted over 200 meetings, which included speakers on topics from estate planning or behavior modification; visiting a newly developed Community Center; and simply enjoying each other's company for a game night.

**Community group participants often become go-to resources** and "extended family" members. Groups are led by dedicated volunteer DSG members who coordinate events. A variety of communication vehicles have made it easier to reach out to new members and share breaking news on topics related to Down syndrome. It is vital to our members to connect with others who share the same concerns and live in the same community.

*Being a Community Group through the DSG allows us to reach out to a previously under-served community without re-inventing the wheel. We can focus on making connections and not worry about the lack of resources –Petrice Welch, African American Friends Group Leader*



## **DSG Community Groups:**

- African American FRIENDS
- DADS
- B.E.S.T. Network
- Dotte Friends
- Eastland FRIENDS
- FACES of Olathe
- Friends of Joplin
- Johnson County FRIENDS
- Lawrence/Topeka Friends
- Northland Buddies
- Rural Missouri Friends
- St. Joseph Community Group
- Teen Club
- Visions Con Esperanza

# Social

**The DSG hosts several All-Guild Social Activities each year** which provide members the opportunity to connect, support one another, laugh together, and share dreams about their loved ones with Down syndrome. Our Easter Eggstravaganza, Family Carnival, Red Barn Farm Family Day, and Annual Holiday Party are premier social events that welcomed over 1,800 attendees in 2009.

**These activities are free to members and their immediate families**, made possible through our partnership with local vendors, support from local high school service projects, and other community outreach programs.

**DSG hosts seasonal dances for teens and adults** during the year, most notably a Sweetheart Dance, Halloween Boo Bash, and Holiday Party. Each of these special evenings is filled with food, fun, and friends. DSG's An Evening Under the Stars Prom welcomed over 450 individuals with various disabilities, including Down syndrome, Autism, Spina Bifida, Cerebral Palsy, and Traumatic Brain Injury.

**Additionally, the DSG hosts age-specific activities**, as well as parents' nights out so parents can enjoy a date night or respite from caregiving. If you haven't experienced a DSG social event, plan to do so this year. We promise it will be unforgettable!



*"It is wonderful to live in an area where we have access to DSG programs and support. Our group provides a setting for families to gather and learn best practices for our child with Down syndrome. We network and share local resources, and have great gatherings full of fun and friends. This gives parents a chance to compare notes and share strategies. Individuals with Down syndrome and their siblings socialize, exercise, laugh, and make fond memories. We are fortunate to have these opportunities."  
-Anne Martinez, Lawrence/  
Topeka Friends Group Leader*

DSG hosts social events so children, teens, and adults with Down syndrome and their families can get together to socialize, share resources, and make lasting connections.

**Social**

# Advocacy

**T**he DSG feels strongly that policies and laws which positively impact people with Down syndrome should be a top priority. DSG was proud to coordinate a national Down Syndrome Advocacy Day on the Hill in February of 2009. Over 300 affiliate leaders from 85 organizations in 38 states joined us in Washington, D.C., to bring an organized message to legislators. Our legislative priorities included:

- Funding for the **Kennedy-Brownback Prenatally and Postnatally Diagnosed Conditions Awareness Act**.
- Support for the **ABLE Act**, which will allow parents and individuals with Down syndrome to save funds while remaining eligible for government entitlement programs.
- Encouraging legislators to join the **Congressional Down Syndrome Caucus** to advocate for the needs of people with Down syndrome.

After an inspirational breakfast reception with keynotes by Cathy McMorris Rodgers (mother to a son with DS and head of the DS Caucus) and Patrick Kennedy, affiliate leaders held over 200 meetings on Capitol Hill. **Self-advocates with Down syndrome played a pivotal role** as they shared their story and impressed upon legislators the importance of policies that promote research, independence, and education.



# Volunteers



**D**edicated volunteers provide vital support to the DSG. The volume of programs and services would not have been possible without the support of these wonderful individuals. In 2009, volunteers donated 12,000 hours of service to DSG. While researchers calculate volunteer service at a rate of \$20.25 an hour, the real value of our volunteers is priceless.

**DSG's Volunteer Voice newsletter is received by 1,300 recipients in the Kansas City area.** We receive requests for volunteer opportunities from individuals and groups interested in our mission. Volunteers not only give countless hours of service to support DSG, they also help foster positive attitudes in the community about individuals with Down syndrome. These volunteers serve as friends and role models leaving a lasting impression on the lives of DSG members.

**We would like to extend a special thank-you to our 2009 Volunteers of the Year, Fidencio and Linda Hernandez.** This dedicated couple's hard work and enthusiasm shined this year. They are always lending a hand, whether translating for conferences, cleaning the office, or helping out at social events. Their dedication to supporting individuals with Down syndrome is inspirational.

# STARS Program

**T**eens with Down syndrome face many of the same challenges as their peers.

They are dealing with socialization and inclusion issues, various physical and psychological changes, self-identity, and the realization that adulthood is right around the corner. Feedback from DSG parents indicates teens with Down syndrome need increased support and skill development to achieve their highest potential, particularly as they prepare for adulthood. The STARS program is meeting a significant need felt by teens and their families.

*"I love coming to STARS because I want to have many friends and do fun things together. Thank you for making STARS happen for me."*

–STARS Program Participant



## The STARS Program at a Glance:

**STARS Activities** – Teens gather for various activities and community outings twice each week during summer vacation. During the school year, teens enjoy a similar level of engagement and participation in at least six activities per month.

**STARS Camps** – The STARS program offers a camp during the winter holiday, spring breaks, and summer. Camps encourage fellowship during time away from school.

**Reading for Rewards** – The importance of literacy is undeniable. The Reading for Rewards program empowers teens to independently select books to read, which in turn results in a reward for the teen. The reward is a gift card of the teen's choosing. All teens who participate are registered to win a larger reward, such as an iPod, at the end of the semester.

**Rockhurst Bowling** – Rockhurst High School National Honor Society partners with DSG to offer monthly bowling to teens eligible for the STARS program. These bowling events offer peer role modeling, as each event is hosted by National Honor Society students from Rockhurst High School.



*"Our son is experiencing many activities that he hadn't been introduced to before the STARS program began. He is interacting with other teens with Down syndrome, and it is having a very positive effect on him. We're thrilled that he is having this opportunity, which would not have been possible without the STARS program."*

–DSG Parents

The Special Teens Achieving Real Success (STARS) Program was launched in June of 2009. STARS brings teens together on a regular basis through activities focused on social, life, and pre-vocational skill enhancement.

# Financial

**In 2009, DSG revenue was \$639,245.**

The 2009 revenue represents a 9% decrease from 2008 revenue of \$698,136. We received \$411,600 from First Downs for Down Syndrome from their fundraising events, compared to \$405,700 in 2008.

Expenditures in 2009 were \$627,688. Of this amount, **we are proud that only 14% 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. A breakdown of expenses is as follows:

Technology	2%
Community Support	5%
Administrative	14%
Social	20%
Public Awareness	22%
Public Education	37%



**The resulting net income enabled DSG to contribute \$22,671 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 \$129,600 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 for 2010.

The work of DSG would not be possible without the financial support of the individuals, companies, organizations, and groups who are willing and ready to turn ideas into action and support our mission. We greatly appreciate those who supported DSG in 2009.

# Looking Forward



Over the last 25 years, DSG has brought increased community awareness and acceptance of people living with Down syndrome. Much work remains to be done, however, and we remain committed to breaking down stereotypes, to increasing inclusion in schools and the community, and to celebrating the lives of people living with Down syndrome.

## DSG's strategic goals for the coming year include:

- enhancing teen programs
- exploring vocational programs
- expanding prenatal outreach
- increasing legislative advocacy

Our strength, as we look forward to these challenges, comes from the dedication, commitment, and professionalism of the people who make up the DSG. **Our membership staff and board share a common mission to support, encourage, and advocate for people with Down syndrome** so they can live fulfilling and productive lives. Community support is critical to our continued success! We invite you to join us on our quest to make the world a better place for people with Down syndrome.



## DSG Board Members:

**Kristin Bechtel**  
Kansas City, Missouri

**Jo Ann Butaud**  
Shawnee, Kansas

**Brian Cowley**  
Parkville, Missouri

**Toni Harrison**  
Kansas City, Missouri

**Terry Lee**  
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**Joe Roos**  
Kansas City, Missouri

**Scott Thompson**  
Leawood, Kansas

**Doug Wager**  
Kansas City, Missouri

**Tom Wagstaff**  
Mission Hills, Kansas

## DSG Staff: (left to right)

**Rose O'Dell** - Teen Program Coordinator

**Morgan Moravec** - Administrative Assistant

**Amy Allison** - Executive Director

**Leslie Hernandez-Brown** - Program Manager

DSG invites you to support our mission, programs, and services. We are enthusiastic about what the next twenty-five years will bring for our members.

**Looking  
Forward  
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# Fundraising



## **First Downs for Down Syndrome...**

Gaining Ground for a Winning Cause.

**First Downs for Down Syndrome (FDFDS) is a non-profit 501(c)3 organization that 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.

**The 6th Annual Private Cellar Wine Tasting & Auction**, proudly sponsored by M&I Wealth Management, was very successful with over 340 guests. Special guests included Master of Wine and Master Sommelier, Doug Frost, along with Kansas City Chiefs Representatives Dick Vermeil, Carl Peterson, and Eddie Kennison. 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 LLP. The event raised a total of \$89,470 for DSG.

**The 13th Annual Huddle Time Sports Auction** was held at Yia Yia's Euro Bistro, Hawthorne Plaza, Leawood. The event attracted over 135 attendees, who bid on unique sports memorabilia and vacation getaways. Stephen St. John with Sports Radio 810 was the emcee, along with members of the Kansas City Chiefs Offensive Line. Guests enjoyed fabulous food, drinks, and the opportunity to rub elbows with current Chiefs players. The event raised \$46,665 for DSG.

**The 7th Annual First Downs Golf Classic** hosted 36 teams in a four-man shot-gun scramble tournament at Hillcrest Country Club.



Golfers enjoyed contest holes, fun holes, and a great day of golf for a great cause. The event raised \$38,656 for DSG.

**The 14th Annual Step Up for Down Syndrome Walk & Festival** was held on Saturday, October 24, at Arrowhead Stadium. The Step Up Walk was an overwhelming success with over 6,000 people in attendance, and over 270 teams. Walkers enjoyed food, friends, music, carnival games, and festivities for every age group, and they had a chance to mingle with the Chiefs players. Kansas City is proud to host one of the largest walks in the nation. The event raised \$383,200 for DSG!

### **Other 2009 fundraising activities by FDFDS include:**

- First Downs High School Football Fundraiser
- Dress Down for Down Syndrome Fundraiser



## Fundraising

These are just a few of the exciting events that FDFDS Sponsors to raise money for the Down syndrome community.

**DFDSD Board of Directors:**

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**Kevin Walker, President**  
CBIZ

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*Vice President*  
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**John Melvin, Treasurer**  
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*Honorary Chairman*  
Kansas City Chiefs

**Brian Waters, Honorary Chairman**  
Kansas City Chiefs



**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.**

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- Digital Designs
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- Pepsi
- Sprint



If you would like to learn more about FDFDS, please contact Amy Stoll, Executive Director, at 913-722-2499.



**Fundraising**

# Mission

## **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.

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