

DSG Receives \$50,000 From Lucille and Bruce Lambert Foundation

The DSG received another amazing \$50,000 grant from the Lucille and Bruce Lambert Charitable Foundation for 2012. The foundation has contributed to DSG the last three years and this donation is being made in honor of the Lambert's great grandson Trenton who has Down syndrome.

Trenton's family has benefited greatly from DSG programs and services so they have offered us this amazing gift to advance our mission. We look forward to launching new programs with the funding and are so grateful to this generous family for supporting our work.



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Take Flight Conference January 28, 2012

Don't miss DSG's Annual Education Conference on January 28th from 8:00am-4:30pm at the Sheraton Crown Center. The goal of the conference is to provide all attendees with practical information and tools to help individuals with Down syndrome become successful in inclusive settings in the community and to enhance all attendees knowledge of Down syndrome and available local resources. **Registration packets will be in your mailbox soon or visit kcdsg.org for more information.**

The conference will start with coffee and conversation to those that want to come a little early and share resources, ask questions, catch up with old friends and meet new people. Attendees can select from a variety of sessions that help you address current issues or plan ahead for the future. Those encouraged to attend are: parents, grandparents, other family members, medical professionals, educators, therapists, service providers and direct care staff. There are registration scholarships available to those requesting assistance to attend the conference. There will also be CEU certification available to those who need it.

Break Out Session Topics Will Include:

- ... Play Your Way to Better Language
- ... Nutrition and Feeding Related Concerns for People with Down Syndrome
- ... What's All the Fuss About Working Memory ? Activities and Classroom Support to Enhance Learning.
- ... Creating Whole Lives and Accessing Resources in Ways that Promote Inclusive, Self-Determined Lives
- ... Disability Entrepreneurs: Using Your Imagination to Create a Brighter Future for Your Child with Down Syndrome
- ... Advocacy through Storytelling: Uniting the Unique Voices of Advocates to Influence Legislators and Professionals
- ... Sibling Q & A Panel
- ... Living a Successful Adult Life
- ... Enhancing Literacy Skills for Children with Down Syndrome
- ... Ain't Misbehavin'-Strategies for curbing problem behaviors
- ... Down Syndrome and Alzheimer's Disease
- ... Technology Through the Looking Glass- iPads and more!

COME ON DOWN TO

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



RSVP TO INFO@KCDSG.ORG

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

Ryan Prothe turned 12 years old on October 9th. It has been an exciting 12 years to say the least. When any child is born, we often think about what they will do when they grow up and what their interests will be. Well, the answers to those questions of what Ryan will do when he grows up are still a few years away. However, I can tell you where he is at this stage of his life as we approach the teen years.

Ryan is a movie watching, horseback riding, band loving, trombone playing, baseball hitting and catching, music listening, flag football touchdown scoring, acting silly, brother fighting, sister teasing, refrigerator sneaking (did someone eat the leftover pizza?), skit performing 6th grader. How can anyone be so busy?

Sometimes it takes a real effort on the part of mom and dad to get Ryan to all of his activities along with the activities of his younger siblings. However, we realize that there are many benefits to Ryan's activities whether it is social interaction, exercise, or gaining responsibility.

Ryan started therapeutic horseback riding four years ago having never been or near a horse. Through weekly riding lessons, Ryan gained lots of responsibility including getting out his own helmet and putting the pad, saddle, and reins on the horse. It has also been great physical therapy as some of those straps are hard to buckle.

Ryan now rides the horse with no one holding the lead rope and no one walking along side of the horse. Ryan has to be in charge and communicate with his horse through words and use of the reins or he doesn't get to where he wants to go. It has been exciting to see the growth Ryan has shown with this program. He was even nominated as a candidate for Rider of the Year at the ranch!

Ryan also loves his sports. His favorites are baseball in the summer time and flag football in the fall and spring. The smile on his face after sliding into home plate is priceless. After his football games, you can ask him how many touchdowns he scored and you always



"After his football games, you can ask him how many touchdowns he scored and you always get the same answer: One Hundred!!"

get the same answer: One Hundred!!!

School is going great even with a move to a Gardner school district this year. Ryan has not missed a beat. He is making new friends, loves lunch, and always want to know "do I really have to come in from recess?"

At home, life is full of typical sibling arguments and teasing and the he or she started it game. However, when Ryan, Emma, and Owen get everything worked out, they make a great team and it is fun to watch how much fun they can have together. It seems like Ryan's time at home is spent either watching a movie, listening to music, or trying to sneak a snack. I am not sure how many times a person can watch the same movie over and over but Ryan may set the record.

Ryan's first 12 years have been very exciting and it will be fun to see Ryan continue to grow into his teenage years. But not too fast, as the years are flying by faster than I would like.

Happy Birthday Ryan,

Love, Dad

**Submitted By, Carey Prothe
Proud Dad to Ryan**

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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.

Lets Get Real About Down Syndrome—Dr. Brian Skotko

In mere months, pregnant American women might be able to learn if their fetuses have Down syndrome with a simple blood test. The test will be perfectly safe, eliminating the small, but real, chance of miscarriage that comes with our current diagnostic options. If these tests do become a routine part of obstetric care, thousands of expectant parents will be receiving a phone call from their healthcare provider each year with this message: you fetus has Down syndrome.

That will be a panicked moment, according to the women studied in previous research. But, what should healthcare professionals say about Down syndrome? What does it really mean to have Down syndrome? Six years ago, Sue Levine, Dr. Rick Goldstein, and I set out to find the answer to that question. Rather than let *Rahm Emmanuel* or *GQ Magazine* have the final word on what life is like with Down syndrome, we spoke to the people who truly understand.

We mailed surveys to families around the country, and 3,150 mothers, fathers, brothers, sisters and people with Down syndrome responded. Here is just a sample of what we found.

... **99% of people with Down syndrome said they were happy with their lives**

... **97% of people with Down syndrome liked who they are**

... **99% of parents said they love their child with Down syndrome**

... **5% of parents felt embarrassed by their child**

... **97% of brothers/sisters ages 9-11, said they love their sibling**



Prenatal decisions about Down syndrome present profound and deeply personal challenges to expectant parents. But for the first time, data about real families is available and can be considered by couples when they receive the diagnosis.

Our study may be complete, but my colleagues and I want to know more. What has been your experience with people who have Down syndrome? Do these statistics resonate with you? Send your comments, pictures, and videos to <http://childrenshospitalblog.org/let's-get-real-about-down-syndrome/>.

*All of the surveys' results have just been published in the *American Journal of Medical Genetics*.

**** Editors Note: DSG works closely with medical professionals and prenatally diagnosed couples to ensure accurate up to date information on Down syndrome is shared as options are being considered.**

DSG's Annual Report Wins Non-Profit Communication Award

Sponsored by Nonprofit Connect, the Philly Awards recognize the hard work and creativity of nonprofit staff and the professionals who help them achieve their missions in 12 categories of print, online and digital media. The award for Second Place in the Annual Report under 1 million division went to our 2010 Annual Report! This is DSG's fourth time winning a Philly award for our Annual Report.

Nonprofit Connect strives to model best practices as part of its mission to link the nonprofit community to education, resources and networking. For modeling the best in nonprofit communications, you can't beat the Philly Awards.

A special thank you to Terry Lee and the DSG Staff for their tireless effort on continuing to make our Annual Report a winning success!

***Plans are underway for our 2011 Annual Report. Please send photos or quotes to info@kcdsg.org by January 15th for consideration!**

The cover of the DSG Annual Report 2010. At the top, the word "SEE" is in small letters, followed by "ABILITIES." in large, bold, blue letters. Below this is a photograph of a man with short blonde hair, smiling, holding a young child with blonde hair and Down syndrome. The child is also smiling. The photo is framed with a blue border. Below the photo, the words "T·H·I·N·K" are written in a spaced-out font, followed by "POSSIBILITIES!" in large, bold, blue letters. At the bottom left is the DSG logo (Down Syndrome Guild of Greater Kansas City) and at the bottom right is the text "ANNUAL REPORT 2010".

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

Contact group leader, Yinka Perry, at dsg.aafriends@gmail.com for information about upcoming events. We look forward to seeing you at African American FRIENDS events in 2012.

CONECTANDO AMIGOS LATINOS

Yadira es la preparación de información de la reunión para los próximos meses. Hasta entonces por favor póngase en contacto con Yadira en yadis7@yahoo.com o llame 913-261-9546. Esperamos verte en nuestros eventos en el 2012!

FACES of Olathe

Calling all Olathe families! DSG is seeking new leadership for an Olathe Community Group! Please contact our office at info@kcdsg.org or 913-384-4848 if you are interested in leading or co-leading an Olathe based group.

DSG will provide administrative and funding support to the group and assist the leader in reaching out to families and serving them.

Dotte FRIENDS

It is time for Dotte Friends to get together for our annual bowling on Saturday, January 21st at 10 a.m. THIS YEAR WE ARE CHANGING THE LOCATION to Park Lane Bowling at 7701 Renner Road in Shawnee. Dotte Friends will pay for two games per person. Bring the family for some fun.

In February, we will have MOM'S NIGHT OUT at Olive Garden Italian Restaurant at 10760 Parallel Pkwy in Kansas City (by the Legends). Let's meet at 6 p.m. Dotte Friends will pay \$10 towards each mom's dinner.

PLEASE RSVP to both events to Becky Melsler @ abecky529@kc.rr.com or 913-788-9013 or 913-940-8512.

We are always looking for new families to join Dotte Friends!

Eastland FRIENDS

Join the Eastland Friends on **Tuesday, January 24th** at 6:00pm at **Waldo Pizza** (1543 Douglas St, Lee's Summit) to Celebrate the New Year! Eastland Friends will provide pizza and soft drinks to families who RSVP by January 15th to eastland-friends@gmail.com

Mom's Monday! Meet us **Monday, February 20th** at 7:00pm for a snack or cup of coffee at **Panera Bread** ~ 1686 Northwest Chipman Road, Lee's Summit

We are updating our contact list. To be added, please contact: eastland-friends@gmail.com

A special Thank you to Kim Knipp for her support as a community group leader. Christa Merritt will now be taking over Kim's responsibilities for Eastland Friends as a co-leader with Lindsay Tharpe.

Rural Missouri FRIENDS

We thank Kathy for her support as a community group leader! Moving forward this group will be under new leadership, For information about our group please contact info@kcdsg.org.

FRIENDS of Joplin

On January 2, 2012 at 10 am Joplin Friends will meet at the House of Bounce on N. Main in Joplin. Each child will have to pay \$2 towards their admission and Friends of Joplin will pay the rest.

In February, we will have a Movie and Game Night for teens and adults with Down syndrome. on February 4, 2012 from 6-8 pm at Impact Life Church (709 Virginia in Joplin). Please bring a snack to share!

Please RSVP to Alicia Hammer (417)499-4614 or alihammer@sbcglobal.net

Johnson County FRIENDS

Watch for details about upcoming Meetings ! To be added to the JOCO friends Email list please contact Jill or India via email at dsgjocofriends@gmail.com .

We look forward to a wonderful 2012 with all of our FRIENDS!

Lawrence Topeka Friends

Watch out for details about our New Year Meetings our annual sing-along/book fest is coming up, watch your mail for an invite. For information about Lawrence Topeka Friends or questions regarding upcoming events contact Anne at richard-anne@sbcglobal.net or by calling 785-354-8243.

St. Joseph Comm. Group

Thursday, January 19 at 6:30 we will meet at UCP, Sally Crumb, M.S. Ed Autism and Behavior Consultant will speak with our group.

Sunday, February 5 from 2-4pm at UCP we will host our own Chili Tasting Challenge. Bring a winning crock pot of chili . Chili chosen will be served at St. Joseph DS booth (decorated with fabulous faces of our children) at The 25th Annual UCP Chili Challenge March 4.

Contact Renee Sherman at grover_rar@hotmail.com /816-232-7238 or Stephanie Anderson slander-son@hotmail.com /816-387-8770 for more information.

Northland Buddies

4th annual GAME NIGHT on Saturday, January 28th from 7 – 9 PM at North Cross United Methodist Church (1321 NE Vivion Rd. Kansas City, MO). We will be meeting in the Youth Room of the church and enter via the side door by the playground on the right side of the church. Bring your favorite board game and a dessert to share with all your friends and join us for a fun time!! RSVP by e-mailing Kris Plubell at kdkb@plubells.com or calling her at 816-792-4671.

MOMS NIGHT OUT on Friday, February 24 at 6:30 at Golden Corral (8329 N. Church Kansas City, MO 64158). NLB's will contribute \$5.00 towards your meal and we will have our very own private room so we can chat and fellowship at our leisure! Please plan to attend without your children and catch up with all your fellow Moms!! Please RSVP by e-mailing Kris Plubell at kdkb@plubells.com or calling her at 816-792-4671.

****VERY IMPORTANT!!!!**** If you haven't already done so, you need to sign up with google.com so that you can receive e-mails from Kris. Her server will no longer allow mass e-mails!

You can join by going to: <https://groups.google.com/group/northland-buddies-kc>

Sibling Support Group

SAGA meetings will be held the second Thursday every other month at the DSG offices from 6:15 p.m. until 7:30 p.m. The dates are as follows:

January 12th, March 8th, May 10th

July 12th* social meeting held at a restaurant, Sept 13th, Nov 8th

Don't miss your chance to meet other siblings who are or will be primary care givers.

Contact group leader Sarah Jurcyk at 913.677.1213 or via email at sjurcyk@kc.rr.com. You are welcomed to bring your sibling with Down syndrome to any upcoming meeting.

DADS

Thursday January 19th 2012 @ 6:30 – 9:30 DADS @ Sadlers Indoor Racing
325 N Mur-Len, Olathe, KS 66062.
Racing and Pizza Provided By DADS and the DSG of Greater Kansas City. Please RSVP to info@dadskc.org

Thursday February 16th 2012 @ 6:30-9:30 DADS @ the Down Syndrome Guild of Greater Kansas City office

Guest Speakers Jason Cannon and Justin Heigle are fellow members of DADS KC parenting two children with Down syndrome who also have experience adopting a child with DS. Please join us for discussion and fellowship.

BBQ provided By DADS and the DSG of KC RSVP to info@dadskc.org.

RECENT Events



A special Thank You to our 2010-2011 community group leaders for their continued support to DSG. Without them DSG would not be able to reach outlying areas and provide support to those that are not able to always make it in to a DSG event.

We look forward to working with all DSG Community Groups in 2012.

DSG Member, Daniel Camacho, Receives Eagle Scout

On Dec. 27, 2010, Daniel earned the rank of Eagle Scout with his Boy Scout troop, just like his 3 brothers before him. His Eagle Scout Court of Honor was held on November 26, 2011 in Lenexa, Kansas. Representatives from the Marine Corps League, the Lenexa VFW Post, and the US Marine Corps attended and presented Daniel with Certificates of Recognition.

Daniel received letters of congratulation from over 25 dignitaries nation-wide including the President of the U.S. and the Governor of the State of Kansas. On Tuesday, December 6, 2011, the Mayor and City Council of the City of Lenexa presented Daniel with a Certificate of Recognition at a ceremony held at the Lenexa City Hall.

It took Daniel almost 9 consecutive years to attain this goal vice the normal 4 to 6 years for other Scouts. Along the way he earned 37 merit badges, became a Brotherhood Member in the Order of the Arrow, and became a "hard-way" Warrior in the Tribe of Mic-O-Say, an honorary Boy Scout camping society founded by H. Roe Bartle in 1929. Only 2 to 4% of all scouts nation-wide ever attain the rank of Eagle Scout.

Daniel's Eagle Scout project consisted of designing and building two large stand-alone shelving units in a storage room located to the left side of the Holy Trinity Church's altar in Lenexa, Kansas. The large shelves are used to organize, store, and protect a large number of sacramental items used for church services. This project served to directly benefit Daniel's church and community.

Daniel has been accepted by Eastern New Mexico University in Roswell, New Mexico, starting in August 2012, to participate in a program that the University has for individuals with disabilities. He will be living on campus in a dormitory, taking care of himself entirely (with some assistance), attend classes, and be involved in a practicum (work) three times a week. His aspiration is to become a certified child care attendant and work in the child care field with pre-school children.



Isabel Is My Friend

Isabel is my friend. She likes to play with me. She likes me to push her on the swing. She likes hanging out with me. Isabel likes to hug me. Isabel has Down syndrome, she has something in her body that means she cannot run very fast or talk that good sometimes.

Being friends with Isabel is fun because she is my best friend...actually Isabel calls it BFFF. I just hug her when she says it like that. I first met Isabel in first grade, I felt good about her. I have spent the night with Isabel two times. Once we went swimming. Isabel is really good at swimming, it really surprised me! Seeing her swim makes me feel good about her. It makes me proud for her.

Our class had to choose three people who are responsible and those people are called lunch-

room monitors. The monitors work in the lunchroom everyday looking for people who are being respectful, responsible and being a learner.

The monitors then give students stickers, slicky lizards or silly bands. Isabel was chosen to be a lunchroom monitor. She was so excited. She is doing a really good job. The principal had me help her the first week to train her, now Isabel does it herself.

Sometimes I feel surprised about people with disabilities because even though they have disabilities in their body they do things really good. Isabel inspires me how she does things. I am glad she is my friend.



Lose the Training Wheels Bike Camp



Lose the Training Wheels Program Returns to Overland Park for its 5th Annual Event!

To teach children with disabilities how to ride a conventional bike without training wheels

The Overland Park Camp

40 children and adults with disabilities have the opportunity to participate in the 5th Annual Lose the Training Wheels program in Overland Park from March 12 – 16, 2012 at Johnson County Community College gymnasium; 12345 College Blvd; Overland Park, KS.

Each participant will be instructed for approximately 75 minutes each day for 5 days.

Cost for each participant is \$150. (Note: this cost covers only a portion of the total camp costs; the majority of this camp is funded by our generous sponsors)

Applications are available by e-mailing Dave Krug at dkrug@jccc.edu.

Qualified participants are accepted on a first come, first served basis.

For applications and details, e-mail Dave at the above e-mail address.



About the Program

Lose the Training Wheels uses adapted equipment and specialized teaching methods to help people with disabilities discover how to ride a conventional two wheeled bike. Our program is based on over 20 years of university level research by Dr. Richard Klein and his wife Marjorie. With a proper environment and training with adapted bikes, people with disabilities discover how to ride a conventional bike within a 5-day period. For more information about Lose the Training Wheels, visit

www.losethetrainingwheels.org.



When a child is able to master riding a bicycle – and without those dreaded training wheels – the benefits become instantly evident. The child smiles, and the child desires to get onto the bike to ride around. Some of the longer term benefits include peer inclusion, success at an age appropriate activity, improved exercise opportunities, increased stamina, increased cognitive stimulation and decision making, and even the ability for the family to participate in a fun activity as a family group

Left: Our adapted bikes allow participants to graduate from a stable bike to an unstable bike gradually at their own pace. Over 80% of participants can ride a two wheel bike within 5 days.

For more information, an application to participate or to volunteer, contact Dave Krug by e-mailing him at dkrug@jccc.edu

Q & A on Podiatry and Down Syndrome

Mark Birmingham, DPM, The North Shore Podiatry Group

I often laugh to myself when I think how my daughter has such flat feet. She has a double-whammy: ligamentous laxity, a ubiquitous characteristic of Down syndrome (Ds), and a father with flatfeet. Make that a triple-whammy; I'm also a podiatrist

I'd like to offer a specialist's experience and answer some commonly asked questions regarding the foot and ankle that may affect those with Ds. Most questions will address the pediatric population, but I will also touch on adults with Ds and what long-term foot and ankle issues may occur.

What types of foot/ankle issues are more common with individuals with Ds?

By far, the most common issue that parents/guardians are concerned with is their child's flat feet. The term 'flat feet' actually encompasses many different issues. Due to the ligamentous laxity associated with Ds, these different issues present themselves earlier than they usually present in their typically developing peers.

Foot and leg fatigue is very common. When muscles and tendons are over-stressed attempting to keep an arch or ankle upright, they become tired, achy and painful. Children with Ds will often communicate this by wanting to sit after walking any increased distance or during increased activity. Of course, this can also be seen as an exercise of autonomy, depending on the developmental age of the individual.

Areas of redness or sores on the inside or outside of the foot/ankle can also be seen. This again is due to the added pressure against an ill-supporting shoe or sandal or even prolonged times of being barefoot.

Without the proper support, these issues can develop into bunion deformities, foot/ankle arthritis as well as problems with tendons of the foot/ankle.

Why are they more prevalent?

I briefly mentioned ligamentous laxity in a previous paragraph. Ligaments attach bones to bones. As there are 26 bones in the foot alone, there are many times more ligaments that have the job of keeping all these bones together. Any amount of weakness to these ligaments can affect the structure of the foot/ankle. Low muscle tone (hypotonia) does play a role in the foot and ankle, but should not be confused with the child's muscle strength. As any person caring for a child with Ds can tell you, our children are not weak!

This analogy has always struck with me: when a house is built on a compromised foundation, the structures above it will, at some point, be affected.

At what age do they first appear?

Typically developing children that start with lowered arches/flatfeet will usually 'grow out' of their flatfeet by four to six years of age, if they will indeed develop a normal arch. Children with Ds will usually show the signs of severely pronated feet (flattened arches) upon beginning to 'cruise' after starting to bear-weight on their feet. This typically continues into their first steps of walking. Fatigue, aching and pain may shortly follow this. I have seen permanent changes in the structure of the feet of kids with DS as early as four to five years of age.

Can they delay walking?

Although I am far from the expert on gross motor development for children with Ds, the general answer is, yes. The lower extremity is a very complex structure consisting of not only the foot and ankle, but also the knee, hip and lower back. All these areas have to be properly evaluated and addressed to optimize walking for our children.

Is therapy helpful?

Without question, physical therapy is essential to the early development of children with Ds in regard to weight-bearing and gait. Much like mathematics, I believe that physical therapy starts with the basics of locomotion and then builds on itself to reach much more complex goals. The foot, ankle and lower extremity are no exception.

Are orthotics needed for most issues?

Orthotics are custom-made devices that are placed within the shoes to maintain, increase or create support of the foot and ankle. I believe that preventative medicine is key for the youngest of our children with Ds. Giving the support needed in the foot and ankle can not only prevent foot and ankle issues, but can also affect the function and well-being of the knee, hip and lower-back. Remember the foundation of the house? This plays a huge factor for our adolescent and adult loved-ones with Ds.

Multiple professionals can create an orthotic device. I have seen excellent devices made by podiatrists, orthotist/pedorthotists as well as physical therapists.

Conservative care of the foot and ankle for individuals with Ds is extremely successful. This is often accomplished by proper shoe gear selection, physical therapy, a correct diagnosis as well as proper assistive devices (i.e., foot and/or ankle orthoses). As I always attempt the most conservative options first, these too can fail and/or not be sufficient for the symptoms experienced. If this occurs, we rely on surgical intervention that not only relieves symptoms, but can improve the way of life for many individuals.

Originally published in the November 2011 Newsletter for the National Association for Down Syndrome.

DSG Mom Finds Inspiration In Her Son

Each year around October Lorrie Newman and her family would typically fundraise for the annual Step Up for Down Syndrome walk. This year Lorrie decided to go above and beyond and take on a personal challenge and she decided to run the Kansas City Marathon on October 15th! Lorrie committed to running 26.2 miles for her son, Keith as she sees the challenges, he faces each and every day of his life, and she thought he served as the perfect inspiration to run the marathon.

Lorrie sees firsthand how a person who is physically and cognitively delayed tries to get by in a world that isn't always very accommodating and accepting. Her son Keith's determination, perseverance, and appreciation of the "little" things made her realize the marathon was a great idea and she wanted to support the DSG as it's a cause close to her heart.

Lorrie sent out letters to solicit donations to support DSG while she trained for the marathon, she also promised that she would cross the finish line, and she did! Lorrie ended up raising an amazing \$3,800 for DSG while accomplishing a personal goal through a wonderful inspiration, Keith. We applaud you, Lorrie and thank you for the dedication that you have shown not only to your son, Keith, but to all individuals with Down syndrome!

A note from Lorrie: Many have asked if I would do it again, if I've got the bug. At the finish line, I would have said, "Absolutely no way would I ever do that again." However, now I say, "Never say never!" As I tell my children, if you don't set goals how can you reach them!

****Contact info@kcdsg.org or 913-384-4848 if you are interested in running the 2012 KC Marathon and raising funds for the DSG.***



Lorrie crossing the KC Marathon finish line!



Lorrie posing with her children after finishing the race.

Follow DSG on Twitter and Facebook

Are you currently following DSG on Facebook and Twitter? We post great resources, event updates, free giveaways, success stories, current research and legislative updates several times each week! Visit facebook and find the DSG page under Down Syndrome Guild of Greater Kansas City and on Twitter @dsgkc. Social networking is a great place to connect with other families!



If you ever need a resource for your own child or family, please contact us at info@kcdsg.org with the question and we would be happy to post it on our facebook page. We are finding that we can get great resources for our families quickly via social networking!



DSG invites you to Tri-21!

Want to make a difference and help DSG touch more lives? Please consider making an annual, bi-annual, quarterly or monthly \$21 donation to support our vital programs and services.

Click the DONATE NOW button
www.kcdsg.org



Prenatal Down Syndrome Test Launched in Twenty Cities

A new test was launched in November which can detect Down syndrome in a fetus using a sample of the mother's blood, potentially reducing the need for riskier invasive tests while also stirring ethical concerns.

Researchers say the new tests may not be reliable enough yet to replace amniocentesis or chorionic villus sampling, two invasive techniques that carry a slight risk of inducing a miscarriage. But they may lower the numbers of women who undergo those tests but then learn their fetus is typical.

The first new test, which analyzes fetal DNA in the mother's blood, began being offered in 20 major cities in October by Sequenom, a biotechnology company in San Diego whose previous work on a Down syndrome test had been marred by a scandal over manipulating data that resulted in the firings of top officials.

The results of a study published online Monday by the journal *Genetics in Medicine* showed that Sequenom's new test picked up 98.6 percent of Down syndrome cases. The false-positive rate — when the test incorrectly said that a baby would have Down syndrome — was 0.2 percent.

"It's better than anything by far that we've ever seen in testing for Down syndrome noninvasively," said Jacob A. Canick, a professor of pathology at Brown University and the senior author of the study.

The test can be used as early as 10 weeks into a pregnancy, though half of the samples tested in the study were from the second trimester, meaning 15 weeks or more.

Another company, Verinata Health, has said it would introduce a similar test in early 2012. Gene Security Network hopes to have a test ready later in 2012.

Sequenom's test, called MaterniT21, would be ordered by doctors, not directly by consumers. All samples will be sent to Sequenom's laboratory for analysis. The test is expected to cost about \$1,900, about as much as amniocentesis.

The company said that privately insured women would have to pay \$235 out of pocket, with the company assuming the risk of getting insurers to pay the rest. It is not clear how willing insurers will be to cover this test.

Sequenom's test has not been approved by the Food and Drug Administration. The agency has typically not regulated tests that are offered by a single laboratory, although it has said it might start doing so.

"The number of American women who will have to grapple with this information prenatally will substantially increase," said Dr. Brian G. Skotko of the Down syndrome program at Children's Hospital Boston. His sister has Down syndrome, he said, and he pointed out that these tests could encourage more people to end their pregnancies, causing a decline in the numbers of people with the condition and lead to diminished support for them.

DSG Is Committed to Supporting Prenatal Diagnosed Couples

DSG anticipates a shift in our service delivery soon. Rather than meeting with parents who were surprised by a diagnosis in the delivery room, we will be meeting with couples in the early stages of their pregnancies who are looking for support and resources. We anticipate many of these couples becoming involved with DSG throughout the remainder of their pregnancies and we are confident our members will welcome them with open arms.

DSG provides training and literature to local hospitals to ensure that the most up to date information is shared with families that have received a diagnosis of Down syndrome. DSG recently partnered with other DS Organizations in the US to exhibit at the American College of Obstetrics and Gynecology and Association of Women's Health, Obstetric and Neonatal Nurses conferences.

DSG matches expectant parents with couples who have also received a prenatal diagnosis and we will provide a complimentary copy of the Down Syndrome Pregnancy book to any couple looking for more information.

Please contact DSG at info@kcdsg.org or 913-384-4848 to request a packet of information you can share with your OB/GYN, geneticist or pediatrician.





**World
Down
Syndrome
Day**



DSG is celebrating World Down Syndrome Day on 3/21 by recognizing community members who provide dedicated and exemplary service to individuals with Down syndrome and their families. Do you know of an educator, physician, employer, therapist or other service provider that is going above and beyond? If so, we hope you will remit a nomination so DSG can recognize this person or organization. We have fun prizes planned and will be making special deliveries on 3/21 to celebrate our award winners. Please complete and remit your nomination by March 10, 2012 for consideration.

Commitment to Excellence Award Nomination

Name of Nominee:

Nominee's profession:

Nominee Address:

Nominee City, State, Zip:

Nominee Phone:

Nominee Email:

How long and in what capacity have you known the nominee?

How does the nominee exhibit excellence in serving/supporting people with Down syndrome and their families?

Has this nominee been recognized for their great work with people with Down syndrome in the past? If so, how?

Please share any additional information regarding your nominee that we should consider.



**Submit nominations to
the DSG by March 10, 2012:**

Down Syndrome Guild
10200 West 75th Street
Suite 281
Shawnee Mission, KS 66204
Fax: 913-384-4949
Email: info@kcdsg.org

Name of person nominating individual:

Address:

Phone:

Email:

DSG Member Crowned Homecoming King!

Senior Connor Bickle was announced as Homecoming king on Friday, Oct. 7 at the Homecoming game against Basehor-Linwood High School. Bickle describes his reaction to his win.

Why did you want to win Homecoming king?

I wanted to win Homecoming king because it would be awesome!

How did it feel to win?

Like a million bucks.

What was Homecoming week like for you?

Awesome, I was so excited to be nominated.

How did you find out you were nominated?

Well, I found out from all my friends and they said they would vote for me a thousand times so I would win.

How did your family react?

My mom was screaming a lot and I said "okay mom, why are you doing that?"

How have your friends reacted?

My friends were clapping and yelling "Connor, Connor" and my girlfriend Erica was excited too. She is really beautiful.

How did the other candidates react to you winning?

They were excited, but they were like, "Aw man Connor won," but I said "You'll get it next time."

Why do you think everyone voted for you for Homecoming king?

Because everybody likes me, and the girls think I'm cute.

What has home life been like since you were crowned Homecoming king?

I do this a lot to my mom, I say "Sorry mom I'm king so I do what I want," and she said "Connor this is my house so I'm king" and I was like, "No you're not, why don't you wear a crown?" then I said, "Oops, I love you."

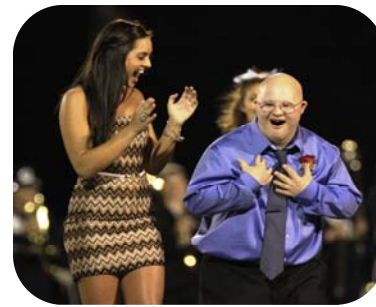
How will the win influence your senior year?

It's been the best year ever. It's been off the hook since I won.

What did you do right after your name was announced that you won?

I flexed and said, "yes!" and then I pointed to my girlfriend.

Reprinted from the Mill Valley High School Jagline Newsletter.



DSG Annual Report Call for Photos and Quotes

DSG is in the process of developing our 2011 Annual Report and we need your help! We are looking for great photos of your family that are taken at DSG events or other places. We need high quality images without a lot of clutter or background.

We are interested in people with Down syndrome of all ages and ethnicities. We are also in need of quotes about how DSG has helped you during the past year. Let us know which programs are making the most impact in your life.



We will share as many of the contributed images and quotes as possible in the annual report so that members, donors and the community at large will be inspired by people with Down syndrome and support the important work of the DSG.

Email photos or quotes to info@kcdsg.org by January 15th to be considered. Thank you for your assistance!

STARS Program Upcoming Events for January/February



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.

January Events

Jan 11: 6pm to 8pm, Employment Tour, Sams - snacks

Jan 18: 6pm to 8pm, Yoga-snacks

Jan 25: 6pm to 8pm, Healthy Relationships-snack

January						
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	30	31				

February Events

Feb 1: : 6pm to 8pm, Power Play- snack

Feb 8: 6pm to 8pm, Community Service Project-snack

Feb 13: 7pm to 8:30pm, Sweetheart Dance, Shawnee Mission East

Feb 15: 6pm to 8pm, Bowling-snack

Feb 22: 6pm to 8pm, Cooking Class- dinner

Feb 29: 6pm to 8pm, Movie Night-snacks

February						
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.

Inclement Weather Policy

As we move through winter months, STARS activities will be cancelled on dates when the Shawnee Mission School District cancels school due to inclement weather. We reserve the right to cancel activities if SMSD has school but our staff feel the roads are unsafe

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.

KC Hopps, Ltd., raises over \$10,500 for First Downs!

KC Hopps, Ltd., chose First Downs for Down Syndrome as their charity during Down syndrome awareness month. In each of their restaurants & locations— which include— 75th Street Brewery, 810 Zone, Barley's, Blue Moose, O'Dowd's & the Alley, servers and greeters were committed to having their guests help those with Down syndrome. Each customer that dined at any of the KC Hopps restaurants were asked to give \$1.00 to FDFDS.

This awareness piece was such a success. The monies raised help over 1,200 + families, caring for a loved one with Down syndrome!

Thank you to the management, staff and the entire KC Hopps team for their support!



Check Presentation: Amy Stoll, FDFDS & Chris Sutton, KC Hopps, Ltd.

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.....

Fundraising Event Dates for 2012

9th Annual Private Cellar Wine Tasting & Auction

Date & Time: Thursday April 19, 2012, 6-9 pm

Shook Hardy & Bacon LLP

Join us for an evening of fun and great wine as we celebrate those with Down syndrome. Taste wines from around the world & the opportunity to bid on unique wines from KC's foremost private collectors.

5th Annual Run for the Roses Kentucky Derby Gala

In partnership with the Mission Project

Date & Time: Saturday May 5, 2012, 2:30-6:00pm

Kansas City Carriage Club

"The two most exciting minutes in sports," AKA "the run for the roses"

This event includes both silent & live auctions, "betting" on favorite horses, Derby fare, prizes for best-dressed individual & best hat. Plus other surprises!

10th Annual First Downs Golf Classic!

Date & Time: Monday July 16, 2012

Registration at 10am with a shotgun start at 11am

Shoal Creek Golf Club

Take Monday off and enjoy playing a full day of golf. Create a foursome with your fellow co-workers, your best clients and or your friends. Lunch, dinner, drink holes, holes contests and so much more... All proceeds benefit First Downs for Down Syndrome.

FIRST DOWNS High School Fundraiser!

Summer/Fall 2012

Get your local high school involved in the FDFDS **High School football fundraiser**. Players raise pledges based on the number of first downs a team scores in each game/season (or seek flat donations). Half the funds raised stay at the school to help the team and the other half go to FDFDS. We have all the materials available for you to share with your high school.

Thank You for Your Support of the KFC/FDFDS Days!



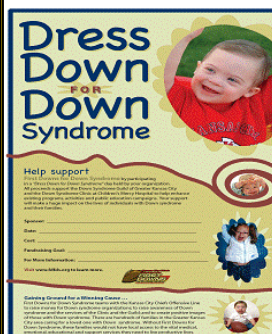
First Downs for Down Syndrome has teamed up with KFC for the past eight years. A special thanks to all area KFC locations and families who Dined Out for Down Syndrome!



Ryan Lilja, KC Chiefs and Kaden Mead

Congratulations to all the 2011, high school participants for their participation in the FIRST DOWNS high school program. Below are the participating schools:

- | | |
|------------------------------|----------------------|
| Blue Valley | Pleasant Hill |
| Bonner Springs | Raytown |
| Center | Santa Fe |
| Hardin Central | Shawnee Mission West |
| Kearney | Smithville |
| Leavenworth High School | St. Pius X |
| Olathe East High School | St. Thomas Aquinas |
| Olathe Northwest High School | Uniontown |



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! Call the FDFDS at 913-722-2499 office for details.



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

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Mind Your Marriage Retreat

Saturday, February 11, 2012
2:30 PM-5:30 PM

Crowne Plaza Hotel
1301 Wyandotte Street
Kansas City, MO

\$75 per couple

Wondering what to do for Valentine's Day this year? Book a sitter and join other couples who have children with Down syndrome for a fun interactive session which will explore creative ways to put the ZING back into your marriage.

Registration fee includes seminar, romantic overnight stay at the Crowne Plaza, parking and continental breakfast when you wake up refreshed on Sunday morning. Space is limited to the first 75 couples to RSVP to the DSG at 913-384-4848.

