

DSG Donates \$5,000 to NDSS National Policy Center Efforts

DSG believes individuals with Down syndrome need strong representation in Washington DC. The NDSS National Policy Center provides year round advocacy on Capitol Hill to insure legislators are knowledgeable about current issues facing people with Down syndrome, their families and the professionals who support them. DSG was pleased to present a \$5,000 donation to Jo Ann Simons, NDSS Board Chair, at the Forecasting the Future Conference.



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Celebrate World Down Syndrome Day on 3/21

World Down Syndrome Day was established to focus attention on the value and potential of children, teens and adults born with the chromosomal anomaly also known as Trisomy 21. March 21st has been designated by Down Syndrome International as the day to bring awareness to individuals affected by the condition. This is a wonderful opportunity for DSG members to educate family and friends and to celebrate and thank those individuals who support their loved one with Down syndrome. Please consider one of the following suggestions as you consider your World Down Syndrome Day celebrations:

- ... **Dress Down for Down Syndrome Day:** Host a casual day at your school, work or civic group. Ask for a small donation and provide DSG materials to those who participate so they will be educated. Request a kit from DSG to help you host a successful day.
- ... **Peer Presentation:** Provide a 15-20 minute overview of Down syndrome to students in your child's grade level. DSG has kits and presentation materials to help you!
- ... **Nominate an individual or organization for a DSG Excellence Award:** DSG wants to celebrate the champions in greater KC who are supporting our members. Complete the nomination form on page 10 of this newsletter and remit it by March 10th. DSG will spend World Down Syndrome Day driving around and surprising people with awards!
- ... **Send a thank you note and update about your loved one to your physician:** Contact your pediatrician, OB/GYN, therapists and send a thank you note with an updated picture and story about your loved one's progress and achievements.



DOLLS & DESSERTS FOR DOWN SYNDROME

A FUNDRAISER FOR



ADMIT ONE!



Join us for a wonderful Mother & Daughter event

Sunday April 3, 2011 6-9pm

American Girl Doll Store
Oak Park Mall
11327 W 95th Street
Overland Park, KS

Mothers and daughters will enjoy delicious desserts from:

- 3 Women and an Oven
- BabyCakes
- Cupcake A La Mode
- Natasha's Mulberry & Mott
- Smallcakes

Bring your American Girl doll and get her hair styled. Decorate your own dress cookie and enter to win a weekend package at the Crowne Plaza Hotel.

Contact stoll@fdfds.org to order tickets for \$25 per person.

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.

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Olathe, Kansas

Tom Wagstaff
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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.

Dad's CORNER

On March 20th, 2008 God blessed our family with a beautiful daughter Sophia. Sophia made a grand entrance coming into the world looking like a boxer on the losing side of a long hard match. My wife and I only got to see Sophia for a brief moment before she was whisked off to the neonatal intensive-care unit.

No, it can't be...there must be a mistake...this can't be happening to us...what are we going to do??? These were some of the many thoughts running through my head when the news was given to us that Sophia had Down syndrome. It was a very surreal moment. Neither my wife nor I knew anything about Down syndrome and I could only think about how our lives were going to be very different from what we had dreamed. I remember family and friends telling us, "God wouldn't have given you this beautiful child if you couldn't handle it".

I am a little embarrassed to admit this but at that time I wasn't as sure about myself as family and friends were. I had doubts about being able to rise up to the challenges we were going to face of raising a child with special needs. I was relieved to find out later that the emotions I had were normal for parents of children with Down syndrome. And, within a short period of having Sophia in our lives the doubts began to vanish by an overwhelming realization of how my family and I are so blessed to have Sophia just as she is.

Sophia has had multiple eye muscle surgeries to correct strabismus and cataract removal in both eyes. Before Sophia, I never imagined an eight week old child requiring contacts or what it would be like to have to put them in her small delicate eyes. When Sophia was younger it was a one parent operation. As she grew and got stronger it became a two parent operation. One of us holds her down and the other opens Sophia's eye with one hand and gently places the contact in with the other hand. Now my wife and I are old pros at it, an acquired skill not appreciated by Sophia.

Everyday we give Sophia thyroid medicine. The easiest way to get her to take it is enlisting the assistance of her older brother, Taylor. If he is clapping and cheering, Sophia will eat just about anything. At times I wonder what we would do without his help. Sophia absolutely adores her big brother. When he isn't home, she walks around the house calling his name and is determined she is going to find him.



"Sophia brings incredible people into our lives. DSG has been amazing for our family!"

By the time Sophia was six months old she had seen more doctors than I have my entire life. Keeping track of all the resources, doctors, appointments, treatments, events, etc. is in itself a challenge. Fortunately I have an amazing wife, Heather and she diligently put together a binder to keep track of everything going on. It's no doubt our daughter is achieving the things she is because of the tremendous time and effort my wife has put into her therapy and playtime.

Sophia brings incredible people into our lives. DSG has been amazing for my family. They called us at the hospital and offered us support right away. They provide resources, a path of action, hope, encouragement and friendship. Over the past few years we have made many new friends through DSG. It is fantastic to talk with other parents going through the same challenges of raising a child with Down syndrome.

We love attending DSG events throughout the year and supporting fundraisers organized by First Downs for Down syndrome, especially the "Step Up Walk". I have been active with Dad's Appreciating Down syndrome (D.A.D.S.) group meetings and have established great new friendships from it. If you are a new Dad or have not been to a D.A.D.S. meeting, you should definitely come check it out.

Nothing in life is more enjoyable and rewarding than seeing your child accomplish a goal or developmental milestone. I can't wait to see what Sophia will accomplish in her lifetime!

Submitted By: James Sanders

President's Letter

Dear Members:

I write this as I sit on a plane traveling home from Washington D.C. and a day of advocating for my kid and yours on Capitol Hill. Your support allows for a team from Kansas City to travel to D.C. once a year for a national day of legislative advocacy.

Our team included Lee Jones. Lee is an adult with Down syndrome who holds a college degree, driver's license, the keys to his own condo and a brochure outlining his public speaking services. Lee is also a lot of fun as a traveling companion. It was an honor to watch him represent everything that is good about having Down syndrome.

I couldn't help but wonder what my 19-year-old Jack Murphy would have said to the congressmen and senators if he were given the chance. Here are a few scenarios that come to mind.

"I am visiting you today because I want to live on my own. Your federally funded housing lacks hot tubs and man caves. Could you look into that for me?"

"Last week I went to the ATM machine to withdraw some money. The screen said that there was not enough money in the account. I am quite sure my disability caused this so could you look into sponsoring a No Zero Balance bill? If out of control spending is good enough for Uncle Sam, it's good enough for me."

"Parental rights are a problem. Could you eliminate those? I have the right to life, liberty and the pursuit of happiness."

"My shoe size is 7.5. There are very few places one can buy 7.5 size shoes. Men's socks fit shoe sizes 8 to 12. A referendum requiring the Big and Tall shops to recognize me as a consumer would be helpful."



Your fantastic fundraising efforts allow DSG to send representatives to Washington DC once a year to advocate for our 1100 members.

"I attend a state university. Surely there are federal matching funds for state universities. Could you put the squeeze on mine to start classes after 10:00 am? It is a metabolism issue."

"Currently, on-line dating services are not regulated. Privacy on those sites can be compromised. I know because I never told my parents about mine and they still shut it down."

"Well Senator, it's been a pleasure. Let me know if you are in town. I might consider making an appearance or giving you my endorsement."

The journey continues.

Bridget Murphy

DSG Attends NDSS Buddy Walk on Washington to Advocate for 1100 Members

DSG's Executive Director, Board President and a self advocate attended the NDSS Walk on Washington on February 8th. We visited with seven legislators and requested their support in the following areas:

- ... Joining the Congressional Down Syndrome Caucus
- ... Supporting the Achieving a Better Life Experience Bill when it is reintroduced during this session of Congress
- ... Asking the National Institutes of Health to improve research funding for Down syndrome

Please watch for DSG action alerts regarding policy initiatives that require your support. We need you to contact your legislators to insure a bright future for people with Down syndrome!



DSG met with Senators McCaskill, Blunt, Roberts and Moran. We also met with Representatives Jenkins, Carnahan and Graves

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.

DSG members are encouraged to attend group meetings in their area but may also choose to attend other groups if the topic matter/event interests them. Please contact us at info@kcdsg.org if you would like to suggest a new group

African American Friends

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

B.E.S.T. Network

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

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

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

CONECTANDO AMIGOS LATINOS

Estamos muy contentos de anunciar un nuevo grupo latino, "Conectando Amigos Latinos", para nuestras familias que hablan español. La reunión será **el Viernes 25 de Marzo de 6:00 pm a 8:00 pm** y se llevará a cabo en la Oficina de DSG, 10200 W 75th St, suite 281 en Shawnee Mission, Kansas. Hemos invitado a un psicólogo que dará consejos sobre como lidiar con los días buenos y malos cuando se está al cuidado de un niño con Síndrome de Down. Esperamos contar con su presencia.

Viernes, 15 de abril, 6 pm a 8 pm, nuestro encuentro en la oficina del DSG. Hemos invitado a un representante de YMCA a unirse a nosotros para hablar sobre las actividades que se llevan a cabo para los niños con necesidades especiales. Hay bocadillos y refrescos serán proporcionados.

Dotte FRIENDS

Friday, March 4th from 6:30 to 8:30pm. Come join us for a family game night. Bring your favorite board games and snacks and come ready for some fun. We will meet at Down Syndrome Guild office at 10200 West 75th Suite 281 Shawnee Mission KS.

Mark your calendars for the Easter Extravaganza on Saturday, April 9th. We looking for more families to join Dotte! Contact Becky Messler for information and Please RSVP on both events, 913-788-9013 or 913-940-8512 or via email at abecky529@kc.rr.com.

Eastland FRIENDS

Monday, March 14th, 6:30pm to 9pm, MOMS MONDAY! Meet at 2505 SW Wintercreek Drive in Lee's Summit, MO. Bring a snack and/or drink to share. If you have a favorite party/board game bring it too!

Sunday, April 10th Swim Party at CoCo Key Water Resort at the Holiday Inn KC, 103 East 39th Street, KCMO. We have 20 ticket for KIDS to GIVE AWAY, DSG member and siblings only please! Parents can purchase tickets for themselves or family and friends for only \$10 each. This is a special reduced rate! YOU MUST

Eastland FRIENDS (con't)

Send your check or cash to DSG by April 1st. Children 2 and under are free into the Park. The Water Park is open from 10am-8pm, you may pick up your tickets before the event, in order that you can come at a time that works for your family. The tickets are for all day.

RSVP or questions contact Kim Knipp at kknipp@kc.rr.com or Lindsay Tharpe RSVP to Lindsay at mamalins@hotmail.com.

FACES of Olathe

Olathe FACES needs some NEW FACES to join! For detail about this group and Information on upcoming events, please contact Debbie Horn via email Debbie@horns4.com or at 913.768.6717.

FRIENDS of Joplin

Thursday, March 3rd at 6pm. Join us for Mom's Night Out at Red Onion in Joplin. Joplin FRIENDS will pay \$5 toward each Mom's dinner. RSVP by March 1st.

Saturday, April 2nd at 2:30pm. Mark the calendar for our Annual Easter Party at the Coate Family Home, 2120 N. Duquense, Joplin, Mo. Bring a dozen filled Easter egg per child and a snack or dessert to share. RSVP by March 31st. Contact Alicia for questions and RSVP's, alihammer@sbcglobal.net or via phone 417.499.4614.

Johnson County FRIENDS

Monday, March 21 at 6:30 pm. join us for a Ladies Night Out at Barley's Brewhaus, 16649 Midland Drive, Shawnee, KS. We have the loft area reserved so we can move around and chat easier. JoCo Friends will pay \$5 per each person's tab. Watch your email for an evite closer to the time of the event!

Thursday, April 14th at 6:30pm. We will start with dinner followed by our speaker at who will be announced at a later date. Watch your email for an evite closer to the event. Babysitters will be provided. RSVP to events or for questions email at debopks@gmail.com.

Lawrence Topeka Friends

Watch your mailbox or email for info on Oral Health: Birth to Adult, presented by Jackie Leakey from Oral Health Kansas. Date and time to be announced. More information contact Ann at richard-anne@sbcglobal.net or 785-354-8243.

Northland Buddies

Friday, March 18, from 6pm to 8pm. Join all your Northland Buddies for another fun night at our 3rd. Annual Fun Run Night, 1919 Industrial Dr. Liberty, MO. Fun Run has several inflatables, an Imagination Village to play in, a small arcade and a special place for our little buddies to play. There is also a snack bar for your convenience. Your child needs to bring a pair of socks to play in. If you plan to join the fun, please RSVP by March 16 have your child with Down syndrome and sibling covered!

Saturday, April 16 from 10am to 1pm. It will be our First Annual Easter Party at North Cross United Methodist Church, 1321 NE Vivion Rd., KCMO. NLB and NorthCross guest will share an outdoor Easter Egg Hunt, weather permitting, snacks, games and crafts, and tons of fun! Please plan to bring 2 dozen filled Easter eggs to share and your own basket. RSVP by April 14. Kris Plubell at 816-792-4671 or kdkb@plubells.com for both events.

Rural Missouri FRIENDS

Sunday, March 6th 2pm-4pm. Gymnastics Studio of Y above Brookfield Physical Therapy on Main Street in Brookfield. Gymnastics and dance fun for our kids!!! Birthday treats to follow for Ms. Jael Head! For questions please contact Kathy McCurry, 660.258.7204 or email kmccurry@shighway.com

St. Joseph Community Group

Sunday, March 20th 2pm to 3pm. First Baptist Church, 500 E Pawnee St, Savannah, Mo. Mary Ringot, reading specialist and mother of a young adults with Down syndrome, presents information on promoting reading in children with Down syndrome. Feel free to bring your children, we will have some activities for them in another room.

Saturday, April 30th at 11:30pm. Join us for lunch at CiCi's Pizza, 2207 N Belt Hwy. The group will pay for the cost of lunch. RSVP to events with Stephanie, 816.364.0003 or mef4ds@stjoelive.com.

Sibling Support Group

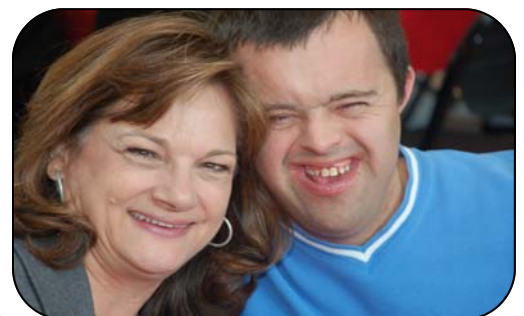
Thursday, March 10th, 7 to 8:30pm. At the DSG office, 10200 W 75th St., Ste. 281 in Shawnee Mission, KS. If you are caring for an adult brother or sister who has Down syndrome, then this group is for you! Don't miss your chance to meet other siblings who are or will be primary care givers. Contact Sarah Jurcyk, 913.677.1213 or sjurcyk@kc.rr.com. You are welcomed to bring your sibling with Down syndrome to any upcoming meeting.

Teen Club

TEEN CLUB is waiting for you! Anyone from the ages 13 and up to adults are welcomed to join us.

Typically events are held on the **4th Saturday of the month.** from 10am to 2pm, at Timothy Lutheran Church, 425 NW R.D. Mize Rd, Blue Springs, Mo. March will probably be an indoor carnival, along with cooking up some fun and tasty lunch. Contact Diane Schiefelbein, 816-229-2034 or email dianesingsforjoy@comcast.net for more information about detail of upcoming events Look for us on Facebook, search Teen club (for teens and adults with disabilities).

RECENT Events





MISSOURI GOVERNMENTAL
AFFAIRS COMMITTEE
NEEDS YOUR HELP!

WE NEED YOUR ASSISTANCE TO REACH
LEGISLATORS AND IMPACT POLICY

Who we are? A state-wide committee of people concerned about policies and legislation that impact our loved ones with Down syndrome.

What we do? Our mission is to empower individuals with Down syndrome, their families and the professionals who support them, by identifying relevant issues, gathering support and educating legislatures, Civic leaders and agencies in their communities to achieve positive change.

When we meet? We meet via teleconference one hour each month.

Where we focus? Our current priorities include:

- *Getting more Missouri Congressional Reps to join the Down Syndrome Caucus*
- *Monitoring Parental Involvement in IDEA*
- *Medicaid/Adult services wait list*

Please join our committee!

KANSAS CITY CONTACT:
chelwelch@yahoo.com

SPRINGFIELD CONTACT:
karleent7@gmail.com

ST. LOUIS CONTACT:
dschuchi@dsagsl.org

DSG Member Stars in Paul Messner Production

Our family has always enjoyed Paul Messner Puppets productions. We have included The Nativity as part of our holiday season Christmas celebration. It's a magical experience and some performances take place in the dark.

Calum has been so mesmerized by the story and its telling, that for two years he persisted in wanting to be the donkey. We have the DVD of The Nativity, which Calum has watched so many times—always insisting that he **is** the donkey. After telling Paul Messner this story, and asking whether there is any possibility of Calum participating, Paul warmly and enthusiastically encouraged me to speak with their executive director and get the rehearsal times on our calendar. In short, Calum was invited to be a part of the show!

The Nativity story is told with puppets that are larger-than-life figures worn like costumes which move to the accompaniment of voiced parts and musical interludes. There are angels on high and sheep under foot, camels and wise men and biblical figures. The prophet Isaiah is about twelve feet tall! Calum wanted to be the donkey. Then he wanted to be Joseph. Then he suggested the ox.



"The people associated with The Nativity were wonderful and welcoming, and embraced Calum as a full and important part of the cast."

Many of the parts are particular in their timing, so we all determined that Calum would do well as a sheep, since sheep move in flocks and he would have friends to help him that way. Sheep also have shepherds, a good thing for a kid with lots of enthusiasm and not much sense of direction!

Calum was a sheep, and as his mother, I was proud to hear him "Baaaaa" his way up the aisles. He did catch some of us by

surprise, though, when in his deepening voice he came up the aisle "Baaaaaa Baaaaaa- Hi, Mom-Baaaaaa."

We had Sunday through Thursday rehearsals and five performances over three days. We had the challenges of transitions, of "Where's Calum?", of his insistence that he wanted to watch the show rather than stay hidden in the back.

Through it all, the people associated with The Nativity were wonderful and welcoming, and embraced Calum as a full and important part of the cast. Calum wanted to go, wanted to be a part of the show, and reveled in being a sheep. And when we performed the first show for a sold-out packed house of 590 people (mostly kids—it was a Friday morning), it was thrilling to be a sheep (Calum) and an angel (Mama) and to hear the giggles and the "Ahhhh!" from all in the audience.

Calum is already talking about next year, happy to be a sheep but keeping his eye on the part of the donkey. As he grows, and as his voice deepens, I wonder if he wouldn't be better as a sheep dog?

Submitted By: Machrina Blasdell

DSG Member Earns Eagle Scout Award

At 7:30 PM on Monday night, December 27, 2010, Daniel Camacho sat in an Eagle Scout Board of Review composed of adult scout leaders from his Scout Troop and local District Scout Council. It was the last requirement he had to meet on the trail to becoming an Eagle Scout. Michael, one of his older brothers, and an Eagle Scout himself, was given permission to sit with him during the Board of Review as a "friend of the scout."

After the Board finished questioning Daniel, he and Michael were ushered out and sat with other family members awaiting the decision of the Board. His mother, Linda, and I are proud to announce that at around 9:00 PM we were informed that Daniel has met all his Eagle Scout requirements and is now officially an Eagle Scout.

Daniel has been a Boy Scout for the past seven years. He is a Brotherhood member of the Order of the Arrow, and a Warrior in the Tribe of Mic-O-Say. He has camped with his troop every month (with very few exceptions) since becoming a scout, attended an extended summer camp every summer, and has earned 37 merit badges (only 21 are required to become an Eagle Scout). Nationally, only 2% of all boys who start Boy Scouts go on to attain the highest rank of Eagle Scout.

For his Eagle Scout project Daniel designed, and with the help of scout volunteers, built two stand-alone shelving units in one of the storage rooms located to the left of the altar in his church, Holy Trinity Catholic Church. The room is used for storage of



equipment and supplies used for the various religious church services. One unit measures 15 feet in length, 6 feet in height, 3 feet in width, and has two shelves. The second is 6 feet in length, 4 feet in height and 2 feet wide. Both are attached to the storage room's interior walls for stability.

We are, to say the least, as proud of Daniel on the occasion of this significant accomplishment as we were when his three older brothers became Eagle Scouts. The fact that Daniel has Down syndrome, yet never quit on his pursuit of this goal, speaks volumes about his extraordinary dedication, spirit, and courage. He is a true Eagle Scout in every sense of the word.

**Submitted By Proud Parents of Daniel,
Mark and Linda Camacho**

Thursday March 17th

6:30 pm to 9:30pm

Minsky's Pizza

**River Market Location,
427 Main St. KCMO**

Pizza will be provided



Thursday, May 19th

6:30pm to 9:30pm

**Community America Ballpark
1800 Village West Pkwy
Kansas City, KS**

**DADS is going to see the
T-Bones take on the South-
Shore Railcats.**

**Limited number of Tickets
provided email/call today to
reserve your ticket!**

support

fellowship

action

DADS Upcoming Events

We hope to see you at one of our upcoming events. If you have any questions please contact us via email, phone, or on our FACEBOOK PAGE, D.A.D.S. of Kansas City.

**RSVP to
All events via Email
info@dadskc.org
Or call
Kevin Hight
913.940.8377**

**Robert Merritt
816.419.9206**

Johnson County Offers Take Me Home Program

The **Take Me Home** program is a database maintained by the Johnson County Sheriff's Office Communications Division for adults and children who may have difficulty communicating due to a developmental or cognitive disability. This database is only accessible to law enforcement personnel.

The database includes a picture, disability information, physical description and emergency contact information for all registered individuals. If a person in the Take Me Home program is encountered alone by a police officer, or is reported missing, the officer can access the database by the person's name or description to locate their information. With this information at hand, the officer can appropriately assist the person.

This is a FREE service offered to developmentally and cognitively disabled citizens who live in cities that are dispatched by the Johnson County Sheriff's Office. This program is currently available in the cities of:

... DeSoto	... Lake Quivira	... Roeland Park
... Edgerton	... Merriam	... Rural JO County
... Fairway	... Mission	... Spring Hill
... Gardner	... Olathe	... Westwood

Who can enroll in Take Me Home?

Any adult OR child who may have difficulty communicating due to a developmental or cognitive disability, while lost or in an emergency situation. These individuals tend to be at risk for wandering and may include people with disabilities such as Alzheimer's, Autism, Dementia, Down Syndrome etc.



We ask that anyone enrolling an individual is either a family member, legal guardian or is turning in a signed registration form on behalf of the individual's family with their permission.

Individuals who do NOT qualify for enrollment include people with ONLY physical disabilities, hearing impairment, vision impairment, anyone who can communicate via translator/interpreter and children who have not reached a developmentally appropriate age for speech.

Online you will find downloadable information about the program and how to register an individual. You will also find a registration form that you may download and fill out to bring to registration if you wish. This information will not be available on the Johnson County Sheriff's Office so please visit the website at: <http://www.jocosherriff.org/Index.asp?incl=tmh>

For any further questions, please contact the Johnson County Sheriff's Office Communications Division by phone at 913-782-0720 or e-mail at shr-disptakemehome@jocogov.org.

Deputy Alison Anderson
Johnson County Sheriff's Office, Communication Division

New Book Teaches Cooking to People with Down Syndrome

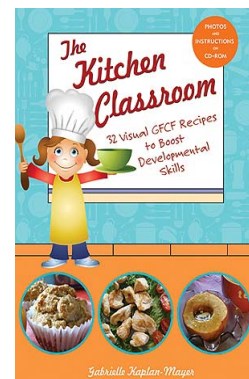
Cooking offers children with autism, Down syndrome, and other developmental disabilities a multitude of opportunities to learn and improve their communication, motor, sensory and social skills. The Kitchen Classroom shows how teachers, providers, parents and friends can make cooking a rich-learning experience.

This book includes sections about the process of cooking with young children with developmental disabilities, ingredient lists with step-by-step directions and photos of each of the prepared dishes. The Kitchen Classroom also includes a CD-ROM, where the same recipes listed in the book are presented in a format that is designed for the child to use. With tasty, easy-to-

prepare recipes for Funny Face French Toast, ABC Salad and many more appealing Gluten Free Celiac Friendly dishes, this unique cookbook helps children with their development and life skills, while teaching healthy eating habits that can last a lifetime.

Check this great resource out from the DSG lending library to help your loved one with Down syndrome learn to cook independently.

You can also purchase the book online at www.woodbinehouse.com





Lose The Training Wheels – Overland Park, KS Camp

Hosted by Ekklesia Church

- When:** March 14 – 18, 2011
Where: Johnson County Community College gymnasium;
12345 College Blvd
Cost: \$150 per attendee which includes a camp T-shirt.
Goal: Lots of kids riding on two wheels!

Program Description

The objective of Lose the Training Wheels is to teach individuals with disabilities to ride a conventional two wheel bicycle without training wheels.

Our program uses specialized equipment, coaching and encouragement to reach this goal. Through the use of our equipment, we gradually introduce the instability of the bicycle until the participant “discovers” how to ride a bike.

Trained staff from Lose the Training Wheels (LTTW) will conduct the program. The LTTW staff will supervise the progress of the participants and direct the work of volunteer “spotters”. They will also make necessary adjustments to the trainer bikes for each participant.

Participants will attend one session (75 minutes) per day for a total of five days. During the ses-

Space is limited! Contact Dave Krug at dkrug@jccc.edu for more information.

sion each participant will ride indoors on an adapted trainer bike or outdoors on a conventional bike once they have achieved that skill level. Participants are required to wear a properly fitting helmet when they are on a bike.

Bicycling involves a physical activity on moving equipment. It is inevitable that circumstances will arise when it is necessary to physically touch, hold, or even grab your participant. This often occurs as we place feet on pedals, lift a chin to improve forward vision, place a hand on the back to increase pedaling speed, or catch a participant who might be falling. These activities occur in a public setting and are for therapy purposes. If you or your participant objects to being touched you are advised to not enroll in this program.

In spite of extensive safety measures, bicycling involves the risk that a participant will fall or collide with an obstacle or another rider. The result of a fall or collision could be a mild injury such as a skinned knee or a serious injury such as a broken bone or head injury. By enrolling in this program you acknowledge that you are aware of, understand and accept this risk.

We strive to teach every participant to become an independent bike rider, but we are not successful in all cases. The outcome cannot be predicted and is not guaranteed. We do promise to make every effort to provide the best equipment, staff and environment to assure each participant's highest level of success possible.

Requirements for Participation

- Minimum of 8 years of age with a disability
- Able to walk without an assistive device
- Able to wear a property fitted bike helmet
- Able to sidestep to both sides
- Minimum inseam of 20"
- Maximum weight of 220 lbs



DSG is celebrating World Down Syndrome Day on 3/21 by recognizing community members who give dedicated 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, 2011 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 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?



Submit nominations to the DSG by March 10, 2011:

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:

Name of person with Down syndrome served by nominee:

STARS Program Upcoming Events for March/April



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 info@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. Unless otherwise noted, STARS activities are typically held in the DSG Center on Wednesday evenings from 6 – 8 PM

March 2011

March 2nd Movie Night at the Office

March 11th Spring Fling Dance at Parkville Athletic Center 7 PM-9 PM

March 14th, 16th and 18th Spring Break Camp -Details will follow in separate mailer

March 23rd Cultural Awareness Night—teens bring their favorite foreign food to share!

March 29th Rockhurst Bowling at Ward Parkway Lanes 3:30 PM-4:30 PM

March 30th Self Defense Class



April 2011

April 6th PowerPlay ***Transportation provided from DSG office***

April 13th Hannah Montana Movie and Game Night

April 20th Yoga & Healthy Relationships with MOCSA

April 27th Kickball and snacks ***Transportation provided from DSG office***

April 26th Rockhurst Bowling at Ward Parkway Lanes 3:30 PM-4:30 PM

April 30th Lunch with Friends at Blue Moose in Prairie Village *** Transportation provided from DSG office***

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; these details will also be provided in periodic mailers advertising STARS activities throughout the year.

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.

Inclement Weather Policy

As we move through winter months, please be advised the STARS Program maintains an inclement weather policy. 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.

Contact

To RSVP for an upcoming STARS activity please call 913-384-4848 or email info@kcdsg.org

THANK YOU PLATTE COUNTY BOARD OF SERVICES!

Platte County Board of Services for the Developmentally Disabled recently provided a \$5,000 grant to fund expansion of the STARS Program into the Northland area!

New Initiative Focuses on Adults with Down Syndrome and Families

Last month, DSG launched an exciting new initiative in caring for adults with Down Syndrome – and their siblings. Adults who found themselves caring for their adult brothers and sisters with Down Syndrome approached DSG for support. A community group called Siblings Are Great Advocates (SAGA), was formed so siblings could share information and resources.

SAGA founders, noted that siblings had taken over guardianship when the parents died or were no longer able to handle the responsibility. The siblings with Down Syndrome were in their mid-40s on up, and each was exhibiting the accelerated aging symptoms unique to Down Syndrome. The SAGA team relied on each other for the latest news of the limited medical studies defining the connection between Down Syndrome and Alzheimer's.

The SAGA team approached the Down Syndrome Guild, which was receptive and already at work identifying needs of older clients and their families. Bridget Murphy, Board President of DSG, vowed action.

The first meeting

In addition to four members of SAGA and the DSG leadership, there was strong interest from the community, with participation of:

- ... Larry and June Rouse, founders of The Mission Project, a non-profit providing educational, social and fitness opportunities, based in Mission, KS.
- ... Dr. William Craig, President and CEO of Lake Mary Center, an organization providing residential services, treatment and community support for developmentally disabled persons
- ... Kirk Davis, program director at the Lake Mary Center residential facility in Olathe
- ... Merlin Butler, MD, geneticist at KU with expertise in Down Syndrome
- ... Jessica Hellings, MD, neuropsychiatry at KU, also with expertise in Down Syndrome
- ... Heather Anderson, MD, and Anne Arthur, NP, both of the KU Down and Dementia Clinic

The meeting focused first on the identifying the key issues facing the population, defined as adults age 30+ with Down Syndrome. The following issues came to the surface as needing to be addressed:

Medical challenges: Need health care guidelines and education for families, to monitor and understand changes; individual medical support plans, including neuropsychiatric assessments. The group also identified the need for specialized medical care, building referrals and developing research, including exploration of links between Down Syndrome and Alzheimer's, neurologic disorders and the remarkable absence of solid tumor cancers.

Family dynamics: Families need training and counseling to develop better skills for dealing with emotional pressures, conducting crucial conversations and making tough decisions. The group also identified needs for activities, respite care and a spectrum of placement options.

Financial challenges: Families need help navigating social support, managing finances and long-term planning.

Legal issues: Questions of guardianship and rights of siblings came to the forefront; families need to understand the potential minefields and prepare for them.

The ultimate goal was crystallized by Murphy, who quickly scribbled a sign: "January 2017" – a target date for groundbreaking on a new Center of Excellence for supporting adults 30+ with Down Syndrome in Kansas City.

Action plans

With opportunities clearly in sight, the group committed to action.

Regular meetings are scheduled at the DSG offices monthly to stay on course. Members brainstormed to identify additional stakeholders – others in the medical community, community service providers, other government agencies. Other actions include gathering more information about the potential needs in our region, and building awareness for the issues and SAGA.

What you can do: Do you know siblings of an adult with Down Syndrome? Encourage them to contact info@kcdsg.org and join the SAGA group.

Siblings Are Great Advocates

SAGA 2011 Meeting Dates

January 13th
March 10th
May 12th
July 14th
September 8th
November 10th

SAGA Meetings are from 6:30-8:30 PM at the DSG office.
For more information or to RSVP contact SAGAc@gmail.com or 913-677-1213

Are you the guardian/advocate/caregiver for your adult brother or sister who has Down syndrome? Join the DSG SAGA group to meet other siblings, share resources, provide support to one another and learn about new and exciting research and medical advancements to help your siblings with Down syndrome.

JOIN SAGA TODAY! SAGAc@gmail.com

DSG
Down Syndrome Guild
of Greater Kansas City
10200 West 75th Street, Suite 281
Shawnee Mission, KS 66204



The **plus15** campaign funds research at Johns Hopkins Medical Center, Stanford University, University of San Diego and University of Arizona to improve the memory, learning and speech of people with Down syndrome. **plus15** will make it possible for people with Down syndrome to live more independent lives – with more opportunities than ever before.

TELL 15 FRIENDS AND HELP SPREAD THE WORD

We need your help. Help us spread the word about the **plus15** campaign. Share the campaign with 15 of your friends! "I joined the **plus15** campaign to improve the learning ability of someone with Down syndrome. I'm sending you this message to help spread the word and encourage you to join the campaign too. If you have Down syndrome, **plus15** means living the life you want for yourself and your loved ones. It means new possibilities at school, on the job and the ability to lead a more active and independent life. Find out why, and how you can help."

GIVE \$15 TO INCREASE LEARNING AND INDEPENDENCE

Your contribution will help DSRTF to improve the cognitive ability of those living with Down syndrome a reality. Visit our website at www.plus15.org and complete the tribute information to make your donation in honor or memory of a loved one. Your honoree will receive a letter notifying them that you have made a gift in their name.

JOIN THE **plus15** COMMUNITY

Join the **plus15** campaign to help improve the cognitive ability of those living with Down syndrome a reality. As a member of the **plus15** Community you will be able to keep up to date on the latest research supported by the Down Syndrome Research and Treatment Foundation. You will also be able to connect with others and provide feedback through our discussion groups and surveys.

To learn more about **plus15** visit:
WWW.PLUS15.ORG WWW.DSRTF.ORG

Down Syndrome 101 Trainings Help Educators/Childcare Providers

DSG recognizes it can be stressful to send your baby or young child with Down syndrome into a child care center where they have no experience with the condition. We are pleased to announce a new training that is now available to educate childcare providers.

Down Syndrome 101 for Childcare Providers focuses on the common medical, social and communication issues which babies and small children with Down syndrome face. The many similarities between these children and their typically developing peers are also identified.

Childcare providers are shown a video of teens and adults and what their life is like so they will appreciate that people with Down syndrome have the same goals, dreams and hopes. Proper support in the center and strategies for working with staff and parents



Contact info@kcdsg.org or 913-384-4848 if you are interested in DSG facilitating a Down Syndrome 101 training in your child care center or school district.

are shared to provide a good foundation for open communication. Early intervention and working with therapists is also explored.

Down Syndrome 101 for Paraprofessionals highlights social, communication, behavioral and medical issues for people with Down syndrome which affect academic learning.

Strategies for encouraging independence rather than learned helplessness are highlighted. Examples of problem behaviors and how to alleviate them are discussed. The unique learning profile of a student with Down syndrome is shared along with best practices for teaching and overcoming challenges associated with speech, memory, attention span and communication issues.

A Special Thank You to Bank Midwest for Their Support of First Downs for Down Syndrome!

First Downs for Down Syndrome was awarded \$5,000 on Thursday January 27, 2011 at Blue Valley Northwest High School. Bank Midwest CEO, Tom Metzger presented the check to First Downs, along with Head Football Coach and team members.

Thank you Bank Midwest! We appreciate your support!



Pictured above from left to right:

Thomas LeManske- Blue Valley Northwest Student, Cooper Lund- Blue Valley Northwest Student, Amy Stoll- First Downs for Down Syndrome, Mike Zegunis- Head Football Coach Blue Valley Northwest, Tom Metzger-CEO, Bank Midwest, Jake Swalley-Blue Valley Northwest Student & Caitlin Soder- Blue Valley Northwest Honorary Football Captain.



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@dfds.org. You can also learn more by visiting our website at www.dfds.org





Fundraising Event Dates for 2011

8th Annual Private Cellar Wine Tasting & Auction

Date & Time: Wednesday April 13, 2011, 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.

9th Annual First Downs Golf Classic!

Date & Time: Monday July 18, 2011

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 2011

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 letters, kits and materials available for you to share with your high school.

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

The September 16, one day event, raised over \$10,000 for FDFDS!

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



Pictured above:

Claudia Sanchez- KFC, John Thomas- FDFDS , Amy Stoll-FDFDS, Tim Deves-FDFDS & Jesus Romero- KFC

Congratulations to all the 2010, high school participants for their participation in the FIRST DOWNS high school program. Overall, this program raised \$24,821 to support people with DS in Kansas City!

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



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 FDFDS at 913-722-2499 for info.



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

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DSG Easter Eggstravaganza
April 9, 2011
9:00 AM-12:00 PM
Kansas City Convention Center
Bartle Hall Room 2215



Bring the whole family and join us for a fantastic event which includes breakfast, games, arts/crafts, door prizes and a visit with the Easter Bunny! Don't forget your Easter baskets and camera.

Rachel Coleman of Signing Time will be our special guest. She will entertain kids of all ages with a wonderful 45 minute performance and will also participate in a meet and greet to sign autographs. Signing Time materials will be available for purchase at the event.

