

A New Year, A New Look for Connections

DSG is thrilled to share our new look for Connections with our readers. With the help of our friends at Adoska, our goal is to professionalize the newsletter while making it easier for you to read all the great content.

Every issue of Connections is chock full of information, news, research and up to date best practices on supporting people with Down syndrome.

We hope you enjoy the changes and would love to hear your feedback on the new style and format. Send your thoughts to info@kcdsg.org. Let us know what you like, what you don't any topics or issues you would like us to cover in the future.

Many thanks to our friends at Adoska for their fantastic work on this project! Visit www.adoska.com to learn more about their great work.

World Down Syndrome Awareness Day

Down Syndrome International (DSI) has officially earmarked 3/21 as World Down Syndrome Day (WSDS). The date was chosen to signify the uniqueness of Down syndrome in the triplication (trisomy) of the 21st Chromosome. Commemoration of World Down Syndrome Day started in March 2006, it has now grown into a global celebration.

The annual observance of WSDS aims to promote awareness and understanding of Down syndrome and related issues and to mobilize support and recognition of the dignity, rights and well being of persons with Down syndrome.

The DSG will host a WSDS Celebration on Sunday, March 21, 2010 at the Westin Crown Center Century Ballroom from 11:00 AM-1:00 PM. We will feature self advocates on a main stage who will share their stories about their lives and have lots of fun and information available. This will be a **FREE** event designed to help you celebrate your loved one with Down syndrome. We encourage you to invite friends, neighbors, teachers and family members to come along to learn more. Watch your mailboxes and www.kcdsg.org for more information on this great event!

If you are unable to join us we encourage you to celebrate WSDS through any of the following activities:

- Write a letter /editorial to your local paper about Down syndrome.
- Send photos of your loved one with Down syndrome along with a celebratory message to educators, therapists, physicians, family members and friends.
- Host a presentation on Down syndrome at your work, church or civic group.
- Encourage your school or employer to host a Dress Down for Down Syndrome Day. to raise funds for the DSG. Contact us at info@kcdsg.org for materials.
- Provide a peer presentation at your child's school so his/her friends can learn more about Down syndrome.
- Donate a book on Down syndrome to your local school or library.
- Host an awareness party and invite family and friends to help you celebrate that extra chromosome.



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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.

BOARD of Directors

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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

Could it Really Be 35 Years? It doesn't seem possible but thirty-five years ago, a new baby boy was born into our family while we were living in Hong Kong. How excited we were and what a great son he is. Lee now lives in his own condo, works two jobs, teaches a fitness class, is a personal trainer and has become a fourth degree Knights of Columbus. There is so much I could say about Lee and about the events over the last thirty-five years, but then this column would be a book and probably bore you to death so I'll confine it to just a few areas.

When Lee was born, his mother and I didn't have a vision about how his life might be. We just wanted him to be happy, have a full life and have options that he could pursue. While we couldn't have expressed it at the time, it has turned out that the "I" words (Intensive, Inclusion, Independence) provided the best approach.

Intensive in terms of any program or therapy that was done. We decided that if we were going to put any effort into something, then we should do it completely and all the way. Carolyn's teaching Lee to read is a great example. We thought that if Lee could just read, his world would be expanded. So we used a sight-reading program developed by Glenn Doman in the early 70's. We have seen advertisements for new reading programs in the last few years and they seem to be based on the concepts developed by Mr. Doman almost forty years ago. Lee's reading program started when he was two and used flash cards that were shown to him about twenty times during each day, seven days a week. It worked. he was reading by age 3 and entered pre-school reading well above grade level.

Inclusion in that we wanted Lee to have the choice of living in his community so we selected activities and educational situations that were always inclusive. We believed that he needed to learn to live in a diverse community when he was young to prepare him to live there when he became an adult. In the early years, we had to go to private schools because the public schools were not equipped to do full inclusion but that changed when he entered middle-school. We wanted all his teachers not to change their expectations of what was required of him as a student and yet provide the support that was needed. Carolyn again did an unbelievable job in daily communicating with every instructor and working with Lee every night on his homework. The skills and discipline that he learned at home during those years were what equipped him to be successful in college on his own. Our approach meant that we passed on Special Olympics and instead did community soccer, karate and theatre. That was a mistake and we now wish that we had included Special Olympics with his other activities.



If living independently was an option for Lee, he needed to learn the skills he would need to do so. We thought that the best place to learn was at home. At an early age he became responsible for cleaning his own room, doing his own laundry, planning what to wear and cooking with his mom. Later, Lee added planning meals, budgeting and handling money. In looking back, he was much better prepared to live independently when he moved into his first apartment than I was at the same point in my life. . . and his checkbook and condo are proof of that! Does he still need support? Sure, but that's true of all the children of all of our friends, no matter how old the children are. That is just what parents do.

"...I am so proud of my son's accomplishments but even more pleased with the type of person he is."

Lee likes working at the Kauffman Foundation and at Sylvester Powell Jr. Community Center, and he still hopes someday to have one full-time job with benefits. Purchasing a condo last December fulfilled another of his personal goals so I'm betting he achieves his career goals too.

As is the case with any father, I am so proud of my son's accomplishments but even more pleased with the type of person he is. Lee has exceeded my expectations in every way and I'm so fortunate to have him as a son. I am also so fortunate to have a wife that is so talented and dedicated to supporting her son and his father.

My last bit of advice to other fathers is to listen carefully to their children. There have been times that I didn't listen carefully to Lee about his desires and in every case, the outcome would have been much better if I had. It is so easy to become judgmental about what is possible and not possible. I keep learning that the best approach is to put effort into how something could happen versus judging whether it could happen. The outcome with this approach has always surpassed my expectations.

Submitted By, Buddy Jones

President's LETTER

Dear Members:

One of my favorite things about my son Jack is his ability to travel. Delays, traffic, lost luggage and long lines don't faze him. He packs most of his belongings into a backpack and resembles a pioneer headed across the plains to a new life. He is ready to settle in anywhere, any time.

This past weekend, Jack and my husband accompanied me to San Antonio, Texas where I was to give a presentation. First stop was the airport where Jack sailed through the security process. I on the other hand was singled out for my flowing skirt. No doubt the bulges near my hips were mistaken for contraband.

Strangers in the boarding line felt compelled to visit with Jack. He cheerfully explained to all that he would not be sitting with his parents. He was used to flying unaccompanied. At the end of the flight he complained that I don't spend enough quality time with him and could I carry his laptop?

We hold our breath as his suitcase is opened. Did the hair gel, men's shampoo, tube of moisturizer, body wash, shaving gel and toothpaste make it through the flight intact? Did he learn his lesson from the previous trip and not pack all of his charging apparatuses in the same Ziploc bag?

Is the playstation that emerges from his suitcase compatible with the hotel's television? It doesn't matter. If not, he goes to the front desk and asks for help. A team of AV specialists descend upon the room immediately, sometimes with a new television in tow.

I have learned to request hangars, towels and a clean room in a manner that suggests I am related to Jack. I receive these items only because management is coming to the room anyway to drop off a gift bag for Jack. Included in the gift bag is the information he requested regarding the Alamo and the history of the Coyote Ugly saloon. While I am busy presenting, the guys tour the Alamo, Madame Tussaud's Wax Museum, Ripley's Believe it or Not and a horror museum, spending five or six minutes at each venue.

The rest of the day is spent convincing me by way of cell phone pictures of wax figures that they spent the day with celebrities. Too bad I missed out. No vacation is complete without the hamburger and fries argument. At some point my husband tells Jack that he has to order something besides hamburger and fries. After much muttering and scowling, Jack relents and orders steak and fries.

The weekend is over. Jack returns the DVD's he borrowed from the concierge. The staff line up to hug him goodbye. He promises to come back for a visit. We arrive at the airport and start the boarding process all over again.

We arrive home safely. And we wait and wonder. Will he break his own record? Will he come in under two minutes on time elapsed between talking about this trip and asking about the next? We are no longer irritated by this practice. We marvel at how far he has come and how anxious he is to go. The journey continues.

Bridget Murphy

Dads Appreciating Down Syndrome

Fathers are encouraged to come and meet other dads who are parenting children, teens or adults with Down syndrome. Monthly meetings are held in various locations around the Kansas City Metro Area. Please contact Kevin Hight at 913-940-8377 or Robert Merritt at 816-419-9206 or via email at info@dadskc.org to RSVP for an event or if you have any questions or resources needs!

Thursday, March 18th 6:30 PM
Minsky's Pizza
427 Main Street, Kansas City, Missouri



Thursday, April 22 6:30 PM
Dinner at the DSG Center
10200 W. 75th Street, Suite 281 OP, KS

facebook

Using Facebook? Look for D.A.D.S of Kansas City and join our group or you can visit us at www.dadskc.org. At each site, you will be kept informed on upcoming events, post photos of you and your loved one with Down syndrome, and contact other Dads in the KC area.

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

B.E.S.T. Network

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

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

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

DS Group of the Ozarks

Second Monday of each month, meetings are held from 6:30-8:30 PM at High Street Baptist Church. Childcare provided with RSVP and a small donation. Call 417.885-9905 or visit www.ozarksdsg.org for more information.

DOTTE Friends

Saturday, April 17th at 10am
Dotte Friends will have some fun at DeAnna Rose Children's Farmstead, located at 38th St. and Switzer in southern Overland Park, KS. We will meet at the entrance at 10am and then enjoy almost 200 animals, a country schoolhouse and more!

At noon, We will meet up again for lunch at the goldfish pond so bring a sack lunch or you can purchase your lunch at the snack shop.

We are looking for more families to join us in the Wyandotte or surrounding areas. Please feel free to join us. Any questions and to RSVP to any events. Call Becky Mesler, 913-788-9013 or mobile 913-940-8512, or via e-mail to becky529@kc.rr.com.

Eastland FRIENDS

FUN FRIDAY at the Lee's Summit R-7 Aquatic Center. March 5th 6-8 PM. This night is open to persons with disabilities and their families. Admission will be paid by Eastland FRINEDS. NO refreshments being provided.

April 8th 6-8 PM MOM'S NIGHT OUT@ Potter's Haven in Lee's Summit. Join us for a much needed girl's night out. Appetizers, soft drinks, wine and sweets will be provided. Attendees responsible for their own pottery fees. RSVP to 816-347-0994 or kjmmmbryan@yahoo.com

FACES of Olathe

Events details are in the making and were not available at the time of printing. For more information on FACES of Olathe please contact Debbie Horn via phone at 913-768-6717 or send an email to debbie@horns4.com.

African American Friends

Saturday, April 24 at 4:00pm, Mom's Night Out! Join us at Peach Tree Buffet, 6800 Eastwood Tfwy, KCMO 641529. DSG will pay \$10 toward each MOM's dinner!

If you would like to be added to the email distribution list, learn more about African American Friends or to RSVP, please contact Petrice Welch at 816.531.7265 or via email to chelwelch@yahoo.com.

Johnson County FRIENDS

Monday, March 8th at 6:30pm. Come to the DSG office for an educational seminar with Scott Adams. He will review special needs planning at 7pm after we enjoy dinner. Childcare is provided!

April event information will be hitting your mailbox. To RSVP or for questions please contact Debbie Yost at, deb.opks@gmail.com or at 913.814.9739

FRIENDS of Joplin

Sunday, March 28 at 3pm, Join us for an Easter celebration at Alicia House, 5742 Hwy C, Joplin, Mo. Please bring a snack or dessert along with a dozen treat filled eggs per child. We will have an Easter egg hunt for all kids! Please RSVP by March 25 so I can know how many to expect.

Monday, April 12th at 6pm, Mom's Night Out at Del Rio Mexican Restaurant, 1802 W 32nd St. #A. Friends will pay \$5 toward each ladies meal. Please RSVP by April 10th.

If you have suggestions for meetings, or to RSVP to any event please contact Alicia Hammer, 417.499.3606 or via email at alihammer@sbcglobal.net.

Northland Buddies

Friday, March 12, at 6pm Kansas City Regional Center: Who, What, When, Where, Why, How?? Come find out more about KCRC at an informational meeting. Meet at North Cross United Methodist Church, 1321 NE Vivion Rd. KCMO 64118. Pizza will be served at 6:00 and meeting will begin at 7:00. Childcare will be provided to all who RSVP by March 8th.

Friday, April 23 at 6:30 to 8:00pm. Fun Run in Liberty, 1919 Industrial Drive Liberty, MO 64068. Have fun at this indoor inflatable center. There is a large obstacle course, moon bounce, inflatable slide, children's imagination village as well as a small arcade.

There are snacks available to purchase. Northland Buddies will pick up the admission price for children with Down syndrome and their siblings if you RSVP by April 21st.

To RSVP to both events contact Kris Plubell at 816-792-4671 or e-mail at kdkb@plubells.com.

St. Joseph Community Group

Sunday, March 7 at 11am. Come out to the St. Joseph Civic Arena to support the Down Syndrome Group's booth at the UCP's 24th annual Chili Cook-off

Saturday, March 13, 11:30 am. Join us for lunch at CiCi's Pizza, 2207 N. Belt Hwy. The Group will pay for the cost of the immediate family to have lunch.

Saturday, April 10, 2-3:30 pm. Join us for a swim party at the YWCA Aquatics Center, 802 N Jules. The pool is heated and life vests of all sizes are available. RSVP's and questions to Stephanie Mefford at (816) 364-0003 or e-mail mef4ds@stjoelive.com.

Rural Missouri FRIENDS

Event Details are in the making and not available at the time of printing. Please contact Kathy McCurry if you would like to know more about Rural Missouri Friends or for questions via phone: 660.258.7204 or via email kmccurry@shighway.com

Sibling Support Group

Thursday, March 11 from 7 PM to 8:30 PM at the DSG Center, Are you caring for an adult brother or sister who has Down syndrome? DSG invites you to attend bi-monthly meetings to connect with other siblings and to explore your needs at the DSG office!

Refreshments will be served. Your sibling with Down syndrome is welcomed! RSVP to Sarah Jurcyk, 913.677.1213 or via email at sjurcyk@kc.rr.com

Teen Club

Saturday, March 27th, from 10am to 2pm. Teen Club is still waiting for YOU to join us in our fun and fellowship. Anyone from the ages 13 and up to adults, Join us for FlipBooks at the Timothy Lutheran Church in Blue Springs, MO, 425 NW RD Mize Rd.

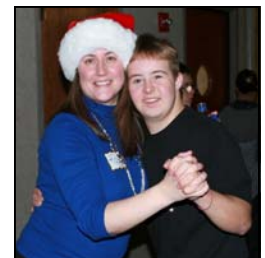
Visions Con Esperanza

Thursday, March 25 at 6:30pm, Monthly Support Group.

Thursday, April 29 at 6:30pm, Monthly Support Group.

All meetings held at Mattie Rhodes, 148 Topping Ave, KCMO. For questions contact Odily Rowland at 816.241.3780.

RECENT Events



MO GAC Education Survey

Missouri Governmental Affairs Committee (MO-GAC) for Down Syndrome is a coalition of parents representing Down syndrome affiliate groups statewide that was formed in December 2008. Their mission is to understand and act upon issues that impact all individuals with Down syndrome.

MO-GAC has created a short survey to determine how much time children with Down syndrome are spending in the regular/general education environment. There is currently no method to obtain this

information from the Missouri Department of Elementary and Secondary Education. The results of this survey will help MO-GAC know how to advocate for our children with legislators.



The survey is intended for those in Missouri who have children with Down syndrome between the ages of 5 - 21. Your answers are strictly confidential. No registering of your e-mail is required. No identifying information will be asked.

To complete the survey visit the DSG website homepage at www.kcdsg.org For more information, contact Petrice Welch, Co-Chair, MO-GAC, at chelwelch@yahoo.com or 816-531-7265.

A large, stylized white Easter bunny is the central focus of the graphic. It has long, upright ears with pink inner linings. The bunny is set against a light green background. To the left of the bunny is a large yellow flower with a pink center. To the right is a smaller pink flower with a yellow center. The text is arranged around the bunny.

**DSG Family
Easter
Eggstravaganza**

**Saturday, March 27, 2010
9:00 AM to 11:00 AM
Lee's Summit North High School
901 SE Douglas
Lee's Summit, MO 64086**

Bring the entire family and join us for breakfast, crafts, games, a visit with the Easter Bunny, and DSG's infamous Egg Walk! The 2009 event welcomed over 350 people and everyone had an EGGCITING time.

**Please RSVP to the DSG office
at 913-384-4848 by March 24th.**

Don't forget your cameras and Easter baskets!

SPREAD THE WORD TO END THE WORD

03.31.09

www.r-word.org

Spread the Word to End the Word is an ongoing effort by Special Olympics, Best Buddies International and their supporters to raise the consciousness of society about the dehumanizing and hurtful effects of the word retard(ed) and encourage people to pledge to stop using the R-word.

The campaign, created by youth, is intended to engage schools, organizations and communities to rally and pledge their support at www.r-word.org with a goal of reaching 100,000 pledges.



Our language frames how we think about others. Help eliminate the use of the R-word in every day speech by spreading the word to end the word. Visit www.r-word.org to pledge your support, download a toolkit of resources you can use to educate others and to learn more about this important day.

Create a Spread the Word event at your school or in your community. Hold a pledge drive, host a youth rally or come up with your own idea to get the word out!

Sonflower Bakery at Church of the Resurrection

Last February, I was meeting with my assistant and a parent about jobs that our students could do here at the Church of the Resurrection to help parents have some free time, to help the students develop more job skills, etc.

After determining that many of the jobs here at the church would require skills that our students did not have or would require too much supervision, the parent (Beverly Williamson) told us about a cookie baking program that her daughter participated in in TX. We decided to try it out by ordering frozen cookie dough and a small convection oven. Our thoughts were to provide our café, The Spring, with a few fresh baked cookies during the week.

In the meantime, I told some of our congregational volunteers about what were doing. We were encouraged to apply for grant monies, which we did and received. We were also given generous donations by some families that loved the idea.

We began researching this type of operation. Access House at Blue Valley Schools was most helpful in how they run their program and they supplied us with contact information on supplies we would need. 3

Women and an Oven also provided us with lots of helpful information. Many wonderful volunteers from the food industry have offered advice and have come in to help us.



We purchased a large convection oven and the necessary baking supplies to work in our very limited space. We only have a small galley kitchen in our church, but we are able to do breads, cookies, scones and cinnamon rolls. We only use frozen or premade products at this time. We do not have a commercial kitchen so we do not bake from scratch.

All of our products are sold through our café. We are not selling to make a profit. We are teaching the students job skills as well as giving them meaningful activities to do during the day. We have lots of adult and youth volunteers, so it is a very inclusive environment.

The bakers bake on M, W and F for 2 1/2 hour shifts. We have 20 bakers and 30+ volunteers that help at various times during the week. I also have a part-time staff person that is the bakery director. She handles orders, orders product, schedules and all of the operations.

Our grand opening weekend, we sold over 3,000 baked goods. Since the opening in June, we have made over 50,000 baked goods! The students are having a wonderful time and love their jobs! They do not get a salary but are able to take baked goods of their choice home with them at the end of each shift. We frequently have holiday and birthday celebrations for them. One parent told us that her son is the happiest he has ever been! Bakers have been very faithful in showing up for “work” and so have our volunteers.

We have been so blessed by this endeavor. Our staff loves baking days as the church smells wonderful! We have been able to make cookies for all kinds of special events held here, including the symphony. It just goes to show you, you do not have to spend a lot of money or have special spaces or equipment to make things happen.

Submitted By, Jennifer Ross

Calling All Graduates!

If you have Down syndrome and will be graduating from high school or college in May or June of 2010 we want to hear from you! Write us an article about your school experiences, share your future plans and send us a picture in your cap and gown so we can share it with our members. We can't wait to hear about what the future has in store for you!



Articles and images should be sent to info@kcdsg.org by June 1st. Selected pieces will be published in the July/August issue of Connections. Once published, DSG will send you extra copies for bragging rights!

DSG E-blasts

DSG E-blasts are a great way to stay in touch with us between issues of the Connections Newsletter.

Sent bi-weekly via email, DSG E-blasts are full of information and links for upcoming events, ongoing research, inspiring stories, legislative alerts, fundraisers and volunteer opportunities.



Opt in to receive email blasts from the DSG.

Visit www.kcdsg.org and scroll to the bottom of our homepage. Click the icon to subscribe to receive future DSG E-blasts today!

Looking at Metabolism

In the first weeks after our son with Down syndrome was born, my thoughts strayed to his health throughout his life. My impression was that all adults with Down syndrome were very obese. As a dietitian, most of my work had been in the weight management area. I had seen firsthand the effects of long-term obesity on a person's life. I remember emphatically explaining to my husband that we needed to be an aerobically active family. I asked him to consider cross-country skiing, and to plan for activities like family biking trips.

Now, years later, Andy is a slender, tall boy, like his brother. He eats well but not perfectly. He appears "active," but it's not very aerobic. And, when I look at other children with Down syndrome at conferences and in my community, there seems to be a mix of body types: some are slight and petite, some are thick and stocky, and some are overweight. Where did that early image of obese adults come from? Had I fallen for a myth? Could it be that this younger generation of persons with Down syndrome will not have as many obese adults? Has the increase in community inclusion changed the incidence of obesity?

Probably not. Research suggests children with Down syndrome are as active as their peers, yet use fewer calories overall. They appear to have a lowered Basal Metabolic Rate, which is the rate a person burns calories for fuel when completely at rest-or sleeping. Taking that information one step further, it means that they use fewer calories throughout the day to accomplish the same activities as their typical peers.

When Andy hangs out with his friend, and eats the same amount and kinds of foods, does the same activities with the same intensity for the same amount of time, he will burn up to 15% fewer calories than his buddy. Since he ate the same amount of food as his buddy, but needs less to do the job, he has calories leftover. These extra calories—even as few as 50 calories per day—can lead to an increase in weight.

For example, 50 calories is equal to a half of a large red delicious apple. The calories from half an apple leftover at the end of the day for one year will lead to about 5 pounds of increased weight. If that continues for 5 years, it becomes a troublesome 25 pounds. With this in mind, it is easy to see how slender children and adolescents with Down syndrome can change into overweight young adults.

There are three ways to adapt for this difference in metabolism: increase activity, limit calories or increase activity AND limit calories. Focusing on calories alone is one option. However, unless there are other medical reasons, it is risky to limit calories for children under 18 years of age without direct medical supervision. Children have great vitamin, mineral, protein, carbohydrate and energy needs while they are growing. Limiting calories may cause children to get to few of what they need to grow and develop well. For adults, a sole focus on calories becomes a battle of willpower and feels like a punishment.

As with everything else, focusing on positives and abilities has a far greater effect. Beginning with a focus on physical activity has many more positives. A person can choose from a variety of aerobic activi-

ties that are enjoyable. Additionally, regular aerobic activity has many health benefits; increased muscle tone, decreased resting heart rate, decreased blood pressure, a sense of well being, better sleep and an increase in metabolism.

Being physically active and focusing on aerobic activity doesn't mean you need to be an Olympic athlete. For the average person with or without Down syndrome, adding small amounts of aerobic activity on a regular basis makes a difference. Even small changes in daily activities can be beneficial.



People with Down syndrome burn up to 15% fewer calories than their peers.



Ideas for Adding Aerobic Activity for Parents, Adults and Children:

- *Park at the far end of the parking lot*
- *Take the stairs instead of the elevator*
- *Walk or bike to activities in your area*
- *When you go to the park, play tag for 10 minutes with the kids. Don't catch them, chase them around!*

Ideas for Adding Aerobic Activity for Teenagers and Adults

- *Use a push mower to mow the lawn*
- *Go for a long walk, hike or bike ride with a friend weekly*
- *Join a local recreation facility*
- *Join a walking club*
- *One hour of television watched=a walk around the block.*

Coming up with ideas to increase activity is the easy part. The hard part is choosing activities that are motivating. It is important that the person with Down syndrome make the choice of activity and be involved in setting goals.

Working together as a team in planning will help. Write your plans in a special place. Create a list of 2 small, but specific, activities to add in a week. Begin with things that are 99% achievable. Talk about when activities will be and who will participate. Write them on the calendar. Then create a way to track visually as goals are met with a chart or checklist. Remember to leave room for doing more than the goals you write down—a chance to over achieve!

For Andy, we hope to build habits that will last a lifetime and be fun—habits that will increase his overall activity and hopefully reduce the risk he will have to fight the battles that extra weight can bring.

By, Joan Medlen, RD, LD From FEDS News Today, October 2009, Vol 20 #6, newsletter of Families Exploring Down Syndrome.

Special Olympics Young Athletes Program

The Special Olympics Young Athletes Program is an innovative program which introduces young children ages 3-7 years old with intellectual disabilities to the world of sports.

The program focuses on the basics that are crucial to cognitive development: physical activities that develop motor skills and hand-eye coordination, and the application of these physical skills.

Improved social skills create a confidence boost which allows athletes to interact with other children on the playground, whether or not they have disabilities.



The Special Olympics Young Athlete Program builds confidence and brings families together!

JOIN US FOR PLAY TIME!

Shawnee Mission

Instructional Support Center/Gym
9700 West 96th Overland Park, KS 66212

Dates: 2/25, 3/11, 4/21, 5/19, 6/9

Time: 6:30 PM-7:30 PM

Parents and younger siblings are encouraged to participate as well.

RSVP's to Terri Price

(limited to 16 athletes per session)
pricet@ksso.org or 913-236-9290

Young Athletes is funded in part by a grant from Kansas State Council Knights of Columbus and Wal-Mart.

School's Out Guide

Are you already thinking about summer and wondering what to do to break the monotony of having kids home ALL DAY, every day? Kansas City offers lots of activities and camps for kids you should be aware of.

The Family Conservancy offers parents a wonderful guide to help them select appropriate camps for their children. "School's Out!: A Parent's Guide to Choosing Summer Care", is a wealth of information about metro area child care camps, recreational programs and enrichment programs that will help you begin your search.

While using this guide, don't limit yourself to looking only in your county of residence and keep in mind that not every program in the area is represented. Programs can be searched for by name, city, state, county or activity you check. *The guide also indicates which programs are prepared to support children with special needs.* Don't wait start researching great camps and programs online today!

The online version of the School's Out Guide is at www.thefamilyconservancy.org Hard copies will be at local libraries and child care centers soon! Call the Family Conservancy at 913-342-1110 for more information on where to obtain copies.



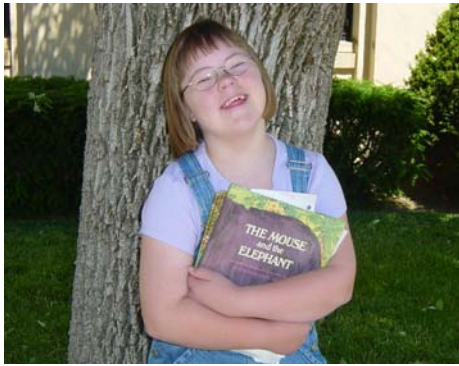
National Parks Pass Program

The America the Beautiful Passport is a lifetime entrance pass to national parks, monuments, historic sites, recreation areas and national wildlife refuges for citizens or permanent residents of the United States who are blind or have a permanent disability such as Down syndrome.

The Passport admits the pass signee and any accompanying passengers in a private vehicle if a park has a per vehicle entrance fee. Where a per person entrance fee is charged, the Passport admits the pass signee, spouse and children.



The Passport also provides a 50% discount on federal use fees charged for facilities and services such as camping, swimming, parking, boat launching and tours. In some cases where use fees are charged, only the pass signee will be given the 50% price reduction. The Passport is nontransferable and does NOT cover or reduce special recreation permit fees or fees charged by concessioners. A Passport must be obtained in person at a federal area where an entrance fee is charged. You may obtain a Passport by showing proof of medically determined permanent disability, or eligibility for receiving benefits under federal law.



Practical Solutions for Adapting Curriculum

Thursday, April 8, 2010

8:30 AM-11:30 AM

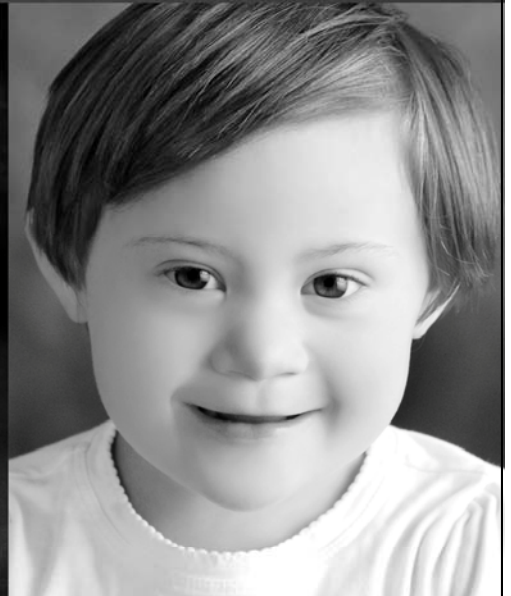
**Kauffman Conference Center
4801 Rock Hill Road, Kansas City, MO**

Adapting curriculum can be daunting even for the seasoned educator. The DSG wants to add to your toolkit of resources by providing tips, strategies and techniques that have proven successful in the classroom with students who have various disabilities. With creativity and initiative, the doors to many new experiences can be made available to students with exceptionalities. This access can be achieved through simple accommodations and/or modifications to the existing curriculum.

This three hour interactive seminar will help you better understand the nine different types of adaptations, when to use them and how to successfully implement changes to your current curriculum. Over 50 proven samples will be shared with attendees so you are guaranteed to go back to your class with some new ideas. This educator led session will cover adaptations that work for K-8th grade in various subjects and provide attendees the ability to

- Determine what is an accommodation and what is a modification.
- Obtain basic knowledge of how to provide opportunities to access the general education curriculum through modifications and accommodations that maintain the spirit of the curriculum. AND how to evaluate those assignments.
- Determine ways to evaluate adapted assignments and the learning that was intended.

**Don't miss this great FREE seminar being sponsored by the DSG!
TO RSVP contact info@kcdsg.org or 913-384-4848**



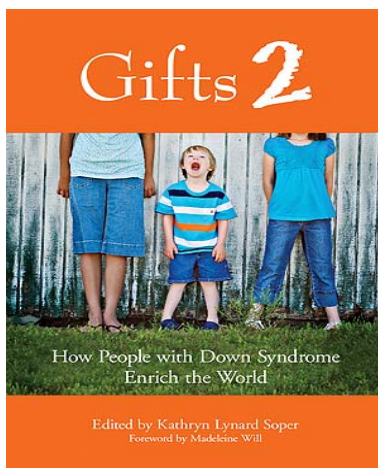
PHOTOGRAPHY
by Brandi

913.829.8539
www.photographybybrandi.com

New Addition to the DSG Lending Library

Acceptance, courage, friendship, awareness, and joy—these are the gifts recounted in more than seventy inspirational essays included in *Gifts 2*. Edited by Kathryn Lynard Soper, the follow-up to the best selling *Gifts* presents a broader perspective on Down syndrome and life by including passionate stories by siblings, grandparents, cousins, aunts and uncles, as well as mothers of older children. Friends, teachers, medical professionals, and coaches also share the joys of knowing and caring for someone with Down syndrome.

Like the previous book, *Gifts 2* helps us see that the hopes and dreams family and friends have for a child with Down syndrome are similar to the ones we have for any child. And, more often than, not expectations are fulfilled—if not always the way we anticipated they would be.



Gifts 2 makes a great gift for parents, family members, educators or professionals. To order, visit www.woodbinehouse.com

A grandparent, inspired by his grandson's strong will, discovers the ability to persevere and not give up a job. A brother who assumes he would be the person helping his sibling with Down syndrome describes how often it is the other way around. A young teacher remembers her first student with Down syndrome and it gives her strength and clarity when she is faced with her own child's diagnosis.

This heartfelt collection is a source of comfort to other families, and offers insight to anyone who wonders how people with Down syndrome live today. Give the ultimate gift, share both volumes of *Gifts* with family and friends, your child's teacher or pediatrician—help raise public awareness and provide others a point-of-view they might otherwise miss.



The STARS Program is Gearing Up for Springtime!

Spring Break Camp

The STARS Program will host a Spring Break Camp for those teens who will be in town on March 15, 17 and 19th from 9 AM until 12 PM. Lunch will be provided each day. This week was selected as it coincides with a majority of spring break schedules for school districts. Spring Break Camp details will be mailed directly to teens in our database and posted on the www.kcdsg.org calendar of events.

STARS Weekly Activities

In March and April we are looking forward to digital photography and movie making classes, a desert social, kickball night, bowling, a trip to the Toy & Miniature Museum and a scavenger hunt at Oak Park Mall. We will also introduce a new program called Circles which helps teens and adults with developmental disabilities better understand interpersonal relationships.

Rockhurst Bowling Continues Through April

If your teen would like an opportunity to experience positive peer role modeling, please consider joining us at a Rockhurst Bowling event. Seniors in the National Honor Society will bowl with your teen on the last Tuesday of each month from 3:30 PM-4:30 PM. At Ward Parkway Lanes. The following are the remaining dates for bowling: Tuesday, March 30th and Tuesday, April 27th.

Questions and Contact Information

To RSVP to an event, request information, sign up to volunteer or to be added to the STARS parent email list please contact Rose O'Dell at rose@kcdsg.org. To learn about exciting ways you can sponsor STARS activities contact Amy Allison, Executive Director at amy@kcdsg.org.



STARS participants made goody boxes and delivered them to a homeless shelter during the holidays to help families in need.

YMCA Challenger Program For People With Special Needs

Challenger is for boys and girls 5-30 years old, with physical, intellectual and developmental disabilities. The fundamental goal of the Challenger program is to give everyone a chance to participate regardless of any limitations they may face. Athletes with a wide variety of disabilities, Autism, Asperger's syndrome, Cerebral Palsy, Down syndrome, spinal injuries, etc. are placed on teams with peers and coached by volunteers. Challenger is about more than playing a game. It's about making new friends, building self-esteem and being part of a team. To help athletes, we use a "buddy" system and pair each player with a volunteer that is at least 9 years of age or older. All participants receive a team shirt and person award for their participation.

YMCA Mission

The YMCA of Greater Kansas City was founded on Christian principles, as a charitable organization with an inclusive environment committed to enriching the quality of family, spiritual, social, mental and physical well being.

Young Adult Programs

Social events are planned by a youth advisory council. Supported by volunteers, participants interact and engage with peers and friends. Future events include YMCA Fun Nights, Kansas City Royals Games, T-Bones Games.

Swim Lessons

This program is designed to teach your child how to swim. Swimmers will be grouped by ability with two to three peers and taught by a certified instructor. Please contact your local YMCA Aquatics Director for details.

For more information please contact Raegan Schurr at 913-642-6800 or email her at raeganschurr@kansascityymca.org. You can also register for these programs by visiting www.KansasCityYMCA.org/adaptive



DSG Mind Your Marriage Retreat a Great Success!

Forty one couples joined us on Saturday, February 13th for DSG's 6th Annual Mind Your Marriage Retreat. Scheduled during the week of Valentine's Day each year, the retreat provides couples a chance to get away for an overnight stay at a local hotel and spend a few hours learning how to reconnect and re-energize their relationship.

Couples shared stories about their courtship, challenges they have faced, embarrassing and humorous anecdotes from their marriage all while learning how to open lines of communication and refocus on being a couple. DSG extends a sincere thanks to Rory Rowland, DSG dad and facilitator, for his efforts in making the retreat a success.

A few "overachiever" husbands in the room had the Central Standard Barbershop Quartet to come in and serenade their wives during the seminar portion of the retreat. The race is on now to "one up" this at next year's event. The seminar was followed by a cocktail hour and couples heading out to dinner at the Power & Light District. Watch Connections for details about the 2011 Mind Your Marriage Retreat!



Keep Our Children Safe in Schools

BACKGROUND—On Wednesday, December 9, 2009, Congressman George Miller (D-CA) and Congresswoman Cathy McMorris Rodgers (R-WA, who is a parent of a 2 year old son with Down syndrome, introduced legislation that would protect all children in schools from harmful uses of restraint and seclusion. *The Preventing Harmful Restraint and Seclusion in Schools Act (H.R. 4247)* would establish the first federal standards to protect students from misuse of restraint and seclusion and ensure the safety of everyone in the classroom. This bill would apply to public schools, private schools and preschools receiving federal education support. Senator Chris Dodd (D-CN) has introduced similar legislation in the Senate.

At the press conference announcing the introduction of the bill, Rep Miller thanked the APRAIS coalition, a group of national disability organizations whose efforts in the past several years have led to the introduction of this bill. Congresswoman McMorris Rodgers, who is a co-chair of the Down Syndrome Caucus stated: “As a parent, when I send my son Cole to school, my husband Brian and I send him with the expectation that he is safe from danger. We entrust him to teachers, principals and aides. And we know those school personnel have done an outstanding job to help him and keep him safe. Yet, we know this has not been the case for other children, particularly children with disabilities who are the most vulnerable and need the most protection.”

The DSG does not endorse the use of seclusion rooms or restraints on any child. Please contact your representative today to ask him/her to co-sponsor this important piece of legislation. Talking points are below to assist you!

Dear Representative (fill in name here): I am writing in support of the *Preventing Harmful Restraint and Seclusion in Schools Act (H.R. 4247)*. I encourage you to co-sponsor this bill to protect all children in schools from the harmful use of restraint or seclusion rooms. I want to protect my child with Down syndrome and children with other disabilities who are most often the victims of these types of punishment. See the details of the bill listed below and please consider becoming a co-sponsor!

This bill would:

- Establish important minimum federal safety standards in schools similar to the protections already in place in hospitals and other non-medical community based facilities; and
- Limit physical restraint and locked seclusion, allowing these interventions only when there is imminent danger of injury, and only when imposed by trained staff;
- Outlaw mechanical restraints, such as strapping kids to chairs and prohibit restraints that restrict breathing; Require schools to notify parents after incidents when restraint or seclusion was used;
- Call on states, within two years of enactment, to establish their own policies, procedures, monitoring and enforcement systems to meet these minimum standards; Encourage states to provide support and training to better protect students and prevent the need for emergency behavioral interventions; and,
- Increase transparency, oversight and enforcement tools to prevent future abuse.

Please contact Fred Jones at the House Education and Labor Committee (202-226-2068) with any questions or to Co-sponsor the bill.



Image by www.MistyWoodward.com

Help keeps schools safe for all children! Call or write your representative today.

DSG's A Night in the Orient Prom

We are gearing up for the annual DSG prom which is guaranteed to be one of the year's best events! The prom is an opportunity for teens and adults with Down syndrome, Autism, Spina Bifida, Cerebral Palsy and other developmental disabilities to dance the night away in a safe and accepting environment.

Attendees enjoy a plated dinner, gift bag full of goodies, floor show and 2.5 hours of sheer joy on the dance floor!



With 400 guests and 150 volunteers, our 2009 Prom was a blast! View images at dsgphotos.smugmug.com/

We are currently seeking sponsors and volunteers for *DSG's A Night in the Orient Prom* which will be held on Saturday, April 3rd at the Overland Park Convention Center.

Contact the DSG at info@kcdsg.org or via phone at 913-384-4848 to request an invitation for a special guest, to sponsor or to volunteer for this great event.

DSG Families Enjoy an Evening at the Roos Game to Help Raise Funds for First Downs for Down Syndrome!

A special thanks to the UMKC Athletics Department for their support of First Downs for Down Syndrome. Our families enjoyed a great game of UMKC Roos basketball on **Thursday January 21, 2010**. FDFDS will receive a portion of the ticket sales from that game.



DSG Members Noah Harrison, Keeley Krushall, Eli Harrison, Max Crawford & Sam Rogers stand on the court with the UMKC players during the National Anthem.



DSG members Keeley Krushall, Noah & Eli Harrison enjoying the game from the stands.

FDFDS Spokesperson Brian Waters Named NFL Man of the Year



The Kansas City Chiefs have struggled on the field the past few years but they have always gone above and beyond to give back to the community off the field. For the fifth time in the history of the NFL Man of the Year Award, a Chiefs player has won for his generosity off the field. This year's winner is Chiefs All-Pro Guard and FDFDS spokesperson Brian Waters.

Waters established his Brian Waters 54 Foundation back in 2005 which provides opportunities for underprivileged children and low income families. Brian also gives generously of his time to attend FDFDS fundraisers and events to help spread awareness and raise much needed funds to support individuals with Down syndrome. CONGRATULATIONS BRIAN and thanks for all you do to help families in Kansas City!

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 and the services of DSG and the Down Syndrome Clinic. Area Corporate Sponsors also support First Downs for Down Syndrome by donating money based on the number of first downs the Chiefs score in the season! We thank them for making a huge impact on our organization. For information regarding events or other fundraisers, 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



Mark your Calendar for these upcoming FDFDS Events



7th Annual Private Cellar Wine Tasting & Auction Thursday April 15, 2010

Join us for an evening of fun and great wine as we celebrate those with Down syndrome at Shook Hardy & Bacon Law Firm, 2555 Grand.

Taste wines from around the world & the opportunity to bid on unique wines from Kansas City's foremost private collectors.

For further details, please call our office at 913-722-2499

14th Annual Huddle Time Sports Auction June 2010



Gaining Ground for a Winning Cause!
Bid on one of a kind sports memorabilia and rub elbows with members of the KC Chiefs football team!

Celebrate Down syndrome at your work or school by hosting a Dress Down Day!

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!



For more information about our events, please log on to our website, www.fdfds.org



Celebrate Down syndrome at the
NEW Outlaw Cigar Company
13700 Metcalf Avenue, OP, KS 66223
-GRAND OPENING-
Saturday March 6, 2010 9am-10pm

A great BBQ lunch for \$5, raffles, meet the world's best cigar makers and so much more. Proceeds from the lunch benefit First Downs for Down Syndrome. For more details visit www.fdfds.org or call our office at 913-722-2499.

Go on a Civic Adventure with Family and Friends at T-Rex Café...



Tuesday March 2, 2010
from 5:00-8:00 p.m.

Join us for a dino-mite dinner, good times and family fun!
10% of your food bill will be donated back to FDFDS.

T-Rex 1847 Village West Parkway, KCK

For further details- call FDFDS at 913-722-2499

Happy New Year!
We hope you will save the date and join us this Year.

**First Downs for
Down Syndrome**
7TH ANNUAL
**Private Cellar
Wine Tasting
& Auction**
B E N E F I T

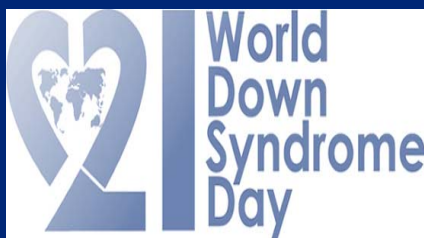
Thursday, April 15, 2010
6:00 p.m. to 9:00 p.m.
Shook, Hardy & Bacon Law Firm
More details at www.fdfds.org



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

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*Celebrate with the DSG!
Sunday, March 21st (3/21)
11:00 AM-1:00 PM
Westin Crown Center
One East Pershing Road
Kansas City, MO*



*Don't miss this family friendly,
fun and FREE event!
Invite your family, friends,
neighbors, co-workers, walk team
members to join us as we celebrate
life with Down syndrome!*

We have lots of great activities waiting for you at the World Down Syndrome Day Celebration:

- *Self advocates on the main stage sharing their personal stories of what life is like with an extra chromosome*
- *Vendors and exhibitors who have products and programs which support people with Down syndrome*
- *FANTASTIC door prizes*
- *Moonbounces, clowns, strolling entertainment*
- *Poppin Joe's delicious Kettle Korn*
- *Radio Disney spinning some tunes and giving away prizes*
- *Stay and Play area so you can visit with other attendees*



No need to RSVP, just drop in and join the fun. Parking is free in the Crown Center Mall parking lot on the weekends. The event is stroller friendly. Hope to see you there!