10 Things To Do For Down Syndrome Awareness

October is Down Syndrome Awareness Month! It is the perfect chance for you to take a few moments and educate others on what Down syndrome is and how loving someone with Down syndrome has impacted your life. The DSG hopes you will consider some of the following activities when you are thinking about celebrating Down Syndrome Awareness Month.

1. **Host an AWARENESS Day at your School or Office** -- Contact DSG for kid-friendly stories to read or check-out a copy of *Just Like You - Down Syndrome* to show. Request a Dress Down Kit or Band Together kit and raise awareness at your school or office.

2. **Eat Bread to Raise Dough!** -- Contact DSG with a date and Panera location to set-up a fundraiser! Panera will donate a portion of the proceeds. Email info@kcdsg.org

3. **“Me Too”** -- Submit photos of inclusion in action to info@kcdsg.org for a “Me Too” video to celebrate awareness in our community. (i.e. You like music? Me too!)

4. **Show A-Wear-Ness** -- and sport your DSG, Step Up Walk or other Down syndrome gear in the community. Send photos to info@kcdsg.org

5. **Join a DSG Committee** -- Help spread the mission of the DSG to the KC Metro area by volunteering on one of our 5 committees. Email info@kcdsg.org for an application to join Public Awareness, Public Education, Diversity, Development or Prom committees

6. **Register on DS-Connect** -- Participate in the national DS registry to help support research and share de-identified statistical data about your family member with DS through survey questions to further research. dsconnect.nih.gov (20 minute survey)

7. **Ask Your Local Library** -- to set up a display of up-to-date books about Down syndrome. If they don’t have a set, purchase a DSG Book Bundle for them! Request a letter from DSG to send to your local library.

8. **Pick Up a DSG Information Packet** -- and deliver it to your OB/GYN to share with patients.

9. **Social Media Blitz** -- Change your Facebook profile picture or cover photo. Visit www.kcdsg.org/Awareness.php for awareness photos. Post a picture-a-day of your loved one with Down syndrome. Share videos fostering awareness like “Just Like You” or “Don’t Limit Me.” Re-post, re-tweet, pin to Pinterest and hashtag #DSAM2014

10. **Visit a Local Restaurant or Business** -- that employs people with Down syndrome. Thank the manager and share the business with others. Contact the DSG for a list of businesses around the Kansas City Metro Area.

*Email info@kcdsg.org to request DSG materials to help with any of the above suggestions. Go forth and create awareness!!*
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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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.

### The “Meaning” of Meaningful Employment

As more young people with Down syndrome are completing school and being given opportunity to develop interests, skills and expertise previously denied to them, there is a steady increase in the number of people with Down syndrome entering further education and employment. Employment is not just about financial security but also about personal growth, being a contributing member of the community and living an ordinary life. Lack of meaningful employment has a significant impact on both physical and mental health.

Today there is recognition that people with Down syndrome can fulfill valuable roles within a wide range of workplaces. Initiatives have been developed in many countries to support young people with Down syndrome to move into the workforce with appropriate, individualized supports.

People with Down syndrome still face several challenges in regard to entering the mainstream workforce. Work opportunities are often limited by lack of flexibility in workplace culture and limited provision of support. And until recently there has been little emphasis on supporting people with Down syndrome to develop the skills they need to start work.

However, in the future, with increasing opportunity and appropriate support, there is no reason not to expect most young people with Down syndrome to transition successfully into the workforce with their peers when they complete their education.

If you are an employer (or know an employer) interested in employing a person with Down syndrome, please contact the DSG at info@kcdsg.org for information, resources and support.

Reprinted with permission from Down Syndrome Victoria and available to read online at: www.downsyndromevictoria.org.au/resources.html

### We are excited to announce that Hattie’s Fine Coffee recently hired a DSG teen with Down syndrome.

Consider visiting the coffee shop during the month of October to celebrate Down Syndrome Awareness Month!

Thank You Hattie’s for helping individuals with Down syndrome reach employment dreams!

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Hattie’s Fine Coffee, a family company owned and operated by Gretchen & David, has been providing Prairie Village, KS with the finest in fresh roasted coffee since 1999 and now it’s available online!

Hattie’s Fine Coffee
4195 Somerset, Prairie Village, KS 66208
913-648-BEAN

Hattie’s bakes many items from scratch, including several Gluten Free options like gooey chocolate chip cookies and banana bread. Hattie’s proudly offers real fruit smoothies and freshly squeezed juice with no sugar or fillers added, just wholesome ingredients!

Visit Hattie’s Online at: www.hattiesfinecoffee.com

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Visit Hattie’s Online at: www.hattiesfinecoffee.com
A Path To The Future -- What Are Your Hopes And Dreams?

When you learn your child has a disability, it often detours your dreams for your child’s future. As your child learns and grows, your aspirations change with them. How do you help your child have the full and meaningful life you have always wished for?

The Exceptional Student Education (ESE) Department of Indian River County Schools is committed to helping parents and their children make dreams a reality by improving our transitional services for students with disabilities. Working through our new Parent Advisory Committee, we have adopted curriculum and assessments to facilitate positive transition from school to college, career and community.

One method of planning for the future is completing and following a PATH. PATH (Planning Alternate Tomorrows with Hope) was developed in 1991 by Jack Pearpoint, John O’Brien and Marsha Forest. PATH is a powerful person-centered planning tool that assists families in identifying and reaching goals and dreams for their child with a disability. The family and their support network come together to develop an action plan for positive, desirable and possible future for the student. A trained facilitator assists the student, their families and representatives from support agencies to specifically define what the student wants for their future. Then the team develops and graphically displays the steps to reach the future goals.

There are eight steps to the PATH process:

1. **Dream**: The team identifies the dream (outcome) that the individual desires for the future.

2. **Goal**: Beginning with the dream, the team develops long-term goals for the student. With the help of the facilitator, the team develops a vivid, colorful display of the student’s future that is both positive and possible. The team selects a date for an end goal projecting out one to three years.

3. **NOW**: The team describes the present. This is a snapshot of the student’s current life.

4. **Enroll People**: The team identifies additional people to enroll in this change process. Who needs to be involved to make this goal attainable? If there are people needed who are not available, how do we get their support?

5. **Build Strength**: The team recognizes ways to build strength – the team members and the student identify what skills and knowledge the student will need to reach their dream, and how the student can get them.

6. **Action Steps**: With the facilitator’s help, the team breaks down the PATH into smaller parts. They develop concrete action steps toward the end result that can be completed in the next several months.

7. **Next Months Work**: The team then adds action steps that can be completed one month after the PATH process.

8. **Commitment**: The final step is commitment from the team to action on the PATH. The team identifies an action step that can be taken immediately, and participants sign the PATH as a visible sign of their willingness to support it.

Completing a PATH is not an easy process. Participants must come to the table prepared to listen and respect others’ opinions, and the focus must stay on the individual for whom the PATH is developed. A well done PATH will take three to five hours to complete and years to fulfill. The PATH should be a fluid working document and reviewed often to ensure that the team is on track in completing action steps. Some goals may need to be adjusted and timelines may need to be changed. Completing a PATH is an emotional and rewarding experience for all those that participate.

*Original article write by Luanne Betaux, Laura McGill and Mary Grace Hektner in “Parenting Special Needs Magazine.”*

Read more by visiting: magazine.parentingspecialneeds.org/publication/?i=192864&p=30
African American Friends

Contact group leader, Yinka Perry, at dsg.aafriends@gmail.com for more information about upcoming events.

We encourage you to attend DSG’s Family Day at Weston Red Barn Farm on September 7th and the Step Up for Down Syndrome Walk Sunday, October 19th from 12:00PM - 4:00PM at Arrowhead Stadium.

Central MO Ds Family Network

The Central MO Down Syndrome Family Network serves families living in central Missouri, who have children enhanced by an extra 21st chromosome.

Keep informed of our activities by email at centralmodsfamilynetwork@gmail.com or follow us on our Facebook page at www.facebook.com/centralmodsfamilynetwork.

Flint Hills DS Group

Flint Hills Family Group outing at A&H Farms Pumpkin Patch—October evening event, Date TBD. More information will be emailed or uploaded on Facebook. More information about A&H Farms’ Pumpkin Patch is available at http://www.aandhfarm.com/pumpkin-patch.

For more information, follow our Facebook page at Flint Hills Families Affected by Down Syndrome, call Briana at 785-456-2137 or email bnelson@ksu.edu.

Dotte FRIENDS

Dotte Friends will meet for dinner on Monday, September 29th at 6:00PM at El Potro Mexican Cafe. It is located at 13035 Cannan Drive, Bonner Springs, KS (913-721-3000). Bring the family for an evening of food and fellowship. Dotte Friends will pay $10 per person, up to three in a family.

RSVP to Becky Mesler by September 26th at abecky529@kc.rr.com or call/text 913-940-8512 or call 913-788-9013.

Eastland FRIENDS

Mom’s Night Out! Join us Tuesday, September 23rd at 7:00PM for dinner at La Fuente Mexican Restaurant (1255 NE Douglas St, Lee’s Summit). Eastland Friends will pay a portion of each mom’s meal.

To RSVP for events or be added to our Eastland Friends contact list email: eastlandfriends@gmail.com.

Friends of Joplin

Our Annual Harvest Party will be Friday, September 26th from 6-8 pm at Right Choices Corn Maze in Southwest City. There will be activities for everyone and s’mores to finish off the night! The cost will be $3/person and children 3 and under are free. We are unable to bring other food and drinks due to their snack shack so please bring some money for any food or drinks you may want. We must turn in a head count in by September 12th so please don’t forget to RSVP to Alicia (417)499-4614. Hope to see you all there!

Questions about FRIENDS of Joplin? Contact Alicia Hammer by email at alihammer@sbcglobal.net or by phone at 417-499-4614.

Johnson County FRIENDS

DSG Family Day at Weston Red Barn Farm Sunday, September 7th from 1:00-4:00PM Don’t miss this fun family event!

Be sure and join 10,000 friends celebrating life with Down syndrome at the Step Up for Down Syndrome Walk Sunday, October 19th from 12:00PM - 4:00PM at Arrowhead Stadium.

Make a personal page to register your family, friends or team online today at www.stepupfordowns syndromekc.org.

Go like Johnson County Friends facebook page to stay up on group events. Email group activity suggestions and ideas to dsgjocofriends@gmail.com.

Contact Yinka Perry at dsg.aafriends@gmail.com for more information about upcoming events.
DSG Family Day at Weston Red Barn Farm on Sunday, September 7th from 1:00PM - 4:00PM. Don’t miss this fun family event!

Are You Ready to Step-Up for Down Syndrome?!

Join other DSG families on Sunday, October 19th from 1:00PM - 4:00PM at Arrowhead Stadium, Lot C. Make sure your team is registered by September 19th to get your team name on the back of your walk shirts.

To learn more about LTF Friends, RSVP for an event or to be added to our email list please contact group leader Anne Martinez at 785-354-8243 or via email richard-anne@sbcglobal.net.

DSG Family Fun Day at Weston Red Barn Farm Sunday, September 7th from 1:00-4:00PM. Don’t miss this fun family event! RSVP to DSG by email at info@kcdsg.org or phone at 913-384-4848.

Bowling at Olympia Lanes (2414 N Belt Hwy) Saturday September 13th from 2:00 - 4:00PM. RSVP to Renee Sherman by September 12. We will cover $5.00 lane/shoe rental for immediate family members only.

Join our group for a Talent Show on Saturday, October 11th at 3:00PM at Rolling Hills Library Annex (1906A N Belt Hwy) to celebrate the talents of our loved ones with Down syndrome. Feel free to bring snack following program. If you play the piano, sing, dance, tell jokes, make funny faces, draw special pictures, or have a special talent that you want to speak about, then call Renee Sherman by October 10 so we can arrange a time for you to perform on the stage. Refreshments following the show.

For more information about St. Joseph Group contact Renee by email at grover_rar@hotmail.com.

Step Up for Down Syndrome Walk Sunday, October 19th from 12:00-4:00PM at Arrowhead Stadium. Form your teams now and get the fundraising going so our DSG can continue providing all the awesome services they do! NLB’s can make arrangements to set up near each other via the NLB Facebook page or the email northlandbuddies@gmail.com.

We are looking for someone to take over this community group. For information on how to become a group leader or for information about our group contact info@kcdsg.org.

Register online by visiting stepupfordowns syndromekc.org

Thursday September 18th from 6:30-9:30PM at 810 Zone in Lee’s Summit for dinner. $10.00 will be provided toward each DADS meal.

Thursday October 16th 6:30 to 8:30 DADS will support FDFDS by meeting at Old Chicago in Overland Park. DADS will purchase their own meal at this meeting.

Email, call or Facebook message another DSG dad and invite him to come with you to the meetings! RSVP by email to info@dadskc.org.
The Simplest Visual Schedule

What is a First Then Board?
A First Then Board is a visual strategy used to help children with language and/or behavior needs complete specific tasks. This strategy displays two pictures. The "first" is usually a picture of a non-preferred activity and the "then" is a picture of a preferred activity. The child must do the first before being able to do the second activity. It helps with both receptive and expressive communication. Children benefit by know exactly what is expected of them. In addition, by using pictures, the visual is there for the child to refer to even after the word is gone.

How does it work?
To help with specific task completion, the adult (teacher, therapist, parent) will place two pictures on a First-Then Board. These pictures may be a sequence (ie: first potty, then wash hands) or separate tasks (ie: first writing, then play trains), or a task and reward (ie: first math, then cookie). The pictures should be given along with the words and/ or signs.

Who can use this?
A First-Then Board is a visual strategy that parents, teachers, and therapist use to help a child complete desired tasks. Most children can be taught simple routines at a very young age with a First - Then Board. A child with Autism who has language and behavior needs will respond much better when the expectations are clear and simple as shown on a First-Then Board. A child with cognitive delays can refer to this simple schedule of what to do. A child with behavior needs can understand there is a set end to the non-preferred task and they can make it to the preferred choice. With the choices displayed, they become more concrete and almost contractual to both the child and adult, so the child knows if I first... then I will... (Keep in mind it is only effective if the adult follows through as well.)

First-Then boards can be purchased or homemade. Contact DSG for more information on where to purchase First-Then boards or to request a First-Then Kit to make your own!

First
Then

When can this strategy be used?
This visual strategy can be used to teach a new skill, manage challenging behaviors, or support a simple schedule / sequence. It can be used throughout the day from morning routines (ie: first dressed, then breakfast), to schoolwork (ie: first clean-up, then outside), to meal times (ie: first carrots, then dessert).

What do I need to make this strategy work?
There are many ways to create a simple First - Then Chart. Let’s start with the board itself. Start with a First - Then page with the words along the top. You may print this on cardstock or glue to a piece of cardboard and cover with contact paper. Another effective strategy is to slide the paper in the front clear cover of a three-ring binder (This is great because pictures can be kept inside in pencil pouches). Put soft velcro in each box so pictures can be easily attached and removed.

For the pictures, photographs of the task or the real items work very well. For example, use a picture of the child brushing his teeth and reading a story. You may also use simple clip art. LessonPix (www.lessonpix.com) provides an extensive library of clip art that is easy to print in the size needed. Laminate the pictures or cover with clear contact paper. Place a piece of the rough velcro on the back of each picture.

If you use an iphone, ipod touch, or ipad, there is an application called, “iprompts” that will allow you to import pictures and comes with a small library of pictures. It is an expensive application, however, it can be a tool that is easy to carry.

Reprinted from: lessonpix.com/articles/9/35/First+Then+Boards

1. Independence: The primary reason for using visual schedules is that they promote independence in many ways. If you have a schedule, you can transition and navigate your day without another person having to tell you where to go and what to do.

2. They help avoid power struggles. If I have a schedule that tells me what to do, I can’t argue with it. I can’t tell you how many times I have said, “Schedule says ___” and had the student follow the direction but if I said, “I need you to do ___” it wouldn’t happen. The schedule takes the “personal” piece out of it and makes it more objective.

3. They provide a permanent visual reminder. I can leave a schedule with you and you can check it throughout the day. When the teacher moves on to another student, the activity or the transition doesn’t stop.

4. They relieve anxiety. Imagine if I took your calendar away from you. Would you know when your dentist appointment would be? Do you know the location of your son’s soccer game? You might find you keep asking those questions when you don’t have a visual to refer to (i.e., your calendar). Ever have a child who engages in constant questioning? Sometimes it’s because they are anxious about what is going to happen next. A schedule allows them to check their schedule instead of checking with you and learn to independently moderate their anxiety. Reducing anxiety allows them to focus on the task at hand.

5. They communicate with students. They give children information about what is going to happen and what is expected. When I check my schedule and it tells me we are going to PE, I know to be prepared to go outside. If it tells me it’s time for lunch, I know to prepare myself to enter the loud cafeteria. This communication also helps children receptively to understand what is happening in their environment and eventually to communicate.

6. Individuals often understand visual information best. For many children, they comprehend information faster and more easily visually. So why not use a medium that uses their strengths.

By Christine E. Reeve, Ph.D., BCBA-D

Reprinted from: www.autismclassroomnews.com/2013/05/visual-schedules-series-7-reasons-to.html
Is Alzheimer’s disease an acquired form of Down syndrome? When neurobiologist Huntington Potter first posed the question in 1991, Alzheimer’s researchers were skeptical. They were just beginning to explore the causes of the memory-robbing neurological disease. Scientists already knew that by age 40, nearly 100 percent of patients with Down syndrome, who have an extra copy of chromosome 21, had brains full of beta-amyloid peptide—the neuron-strangling plaque that is a hallmark of Alzheimer’s. They also knew that the gene that codes for that protein lives on chromosome 21, suggesting that people acquire more plaque because they get an extra dose of the peptide. Potter, though, suggested that if people with Down syndrome develop Alzheimer’s because of an extra chromosome 21, healthy people may develop Alzheimer’s for the same reason. A quarter of a century later mounting evidence supports the idea.

“What we hypothesized in the 1990s and have begun to prove is that people with Alzheimer’s begin to make molecular mistakes and generate cells with three copies of chromosome 21,” says Potter, who was recently appointed director of Alzheimer’s disease research at the University of Colorado School of Medicine, with the express purpose of studying Alzheimer’s through the lens of Down syndrome.

He is no longer the only one exploring the link. In recent years dozens of studies have shown Alzheimer’s patients possess an inordinate amount of Down syndrome–like cells. One 2009 study by Russian researchers found that up to 15 percent of the neurons in the brains of Alzheimer’s patients contained an extra copy of chromosome 21. Others have shown Alzheimer’s patients have 1.5 to two times as many skin and blood cells with the extra copy as healthy controls. Potter’s own research in mice suggests a vicious cycle: when normal cells are exposed to the beta-amyloid peptide, they tend to make mistakes when dividing, producing more trisomy 21 cells, which, in turn, produce more plaque. In August, Potter and his team published a paper in the journal Neurobiology of Aging describing why those mistakes may occur: the inhibition of a specific enzyme.

Meanwhile University of Kentucky researchers have been collecting brain scans, blood tests and lifestyle surveys from dozens of adults with Down syndrome over the past five years. They aim to understand why—even though nearly all patients develop plaque—only 60 to 80 percent develop dementia.

National Institutes of Health director Francis Collins recently told a Senate subcommittee that there is “intense interest” in studying the two conditions together. And in 2013 the Alzheimer’s Association teamed up with the Linda Crnic Institute for Down Syndrome to fund work examining the link.

In general, by studying Alzheimer’s in a smaller population guaranteed to develop the pathology, scientists can learn more, faster, says Dean Hartley, director of science initiatives for the Alzheimer’s Association. He and others say it is too early to conclude that Alzheimer’s is indeed a form of Down syndrome: “But we need new ideas like this in the field to help us better understand the underlying pathways of the disease.”

Take the Down Syndrome and Dementia Survey created in conjunction with the DS and Dementia Clinic at KU at link below.

www.kcdsq.org/files/content/Down%20Syndrome%20Dementia%20Questionnaire.pdf

SAVE THE DATE ~ JUNE 26 - 28, 2015

NDSC ANNUAL CONVENTION

Convention registration opens March 2015
Visit www.convention.ndsccenter.org

DSG offers $500 scholarships to the NDSC Convention each year. Applications will be available online by January 2015
Facilitating Friendships in the Inclusive Classroom

Friendships are an important foundation in the inclusive classroom. Aside from being physically included in the curriculum and day-to-day activities, a child with special needs also needs to genuinely feel included. This feeling of inclusion stems from a sense of belonging and relating to other children in the class. The sense of emotional well-being and stability derived from friendships allows students to be more receptive and open to learning new concepts as suggested by recent research in the field of neuroscience. Teachers have an essential role in creating and maintaining the friendships amongst the students in the inclusive classroom.

1. Identify Interests
   By identifying the various interests of the class, the teacher is taking one of the first steps to helping the students identify with one another. Allowing the students to express their interests through discussion, surveys, games, and school clubs will help them discover other students who are like-minded.

2. Highlight Strengths
   Regardless of academic ability level, each student has strengths and skill sets that teachers can recognize and highlight. By doing so, students can feel valued and confident amongst his/her classmates. For example, a student who may not excel in math may be an exceptionally talented soccer player. Teachers can highlight student strengths during class discussions, projects, and leadership opportunities.

3. Emphasize Social Skills
   In addition to creating classrooms where students feel welcomed and friendships are encouraged, there is an effort to maintain these friendships. This is often done by embedding a social skills component in the curriculum. Within this curriculum, students are taught skills such as how to communicate and problem-solve. In addition, there are activities scheduled in the day when the students are encouraged to use their social skills such as during a class meeting or group discussions.

4. Provide Opportunities
   Above all, teachers need to provide students with opportunities within the school day to create and maintain friendships. Despite the heavy emphasis on academics in today’s education system, students should have the chance to be social with one another. Allowing time in the early grades for centers, giving older students group projects, or designing lessons, which encourage student interaction all facilitate connections and relationships amongst one another.

Reprinted from: www.friendshipcircle.org/blog/2014/07/22/4-tips-to-facilitate-friendships-in-the-inclusive-classroom/
Thomas recently celebrated his birthday. In lieu of gifts, he asked that family and friends donate items for the Down Syndrome Guild’s Baby Baskets. Thank you Thomas and Friends!

Our baskets are filled with accurate and up to date information, books, videos and some baby gifts which help parents start their journey on a positive note. DSG welcomes approximately 50 new babies with Down syndrome each year. Our welcome baskets are is one program we know changes lives and brings joy as DSG becomes a lifeline and trusted partner to parents. Contact DSG to make a donation or find out more about this program.

DSG would like to recognize and thank Kevin Hight and Robert Merritt for their service as community group leaders of the D.A.D.S. (Dads Appreciating Down Syndrome) over the last several years. DSG serves a HUGE geographic area and thanks to the leadership of Kevin and Robert, DSG is able to have a greater presence. We are grateful for all of the hard work you do to provide support, education and fellowship to DSG dads.

Help DSG extend a warm welcome to our newest leaders John Kille and Seth Norton who will be filling some big shoes as the next community group leaders of DADS! For more information visit www.dadskc.org or email info@dadskc.org to join an upcoming event!

In Lieu of Birthday Gifts...

Thank You D.A.D.S!

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BATTER Up!

Pujols Family Foundation
Family Cooking Experience

INDIVIDUALS WITH DOWN SYNDROME
15 YEARS OF AGE OR OLDER ARE INVITED TO BRING A FAMILY MEMBER OR FRIEND TO SPEND SOME QUALITY TIME LEARNING TO COOK IN A FUN, HANDS-ON SETTING.

 Reserve your space by contacting info@kedg.org or 913-384-4848.
Please indicate which class(es) you wish to attend and if there are any food allergies. Space is limited so sign up today!

LIBERTY HY-VEE
109 Blue Jay Dr. * Liberty, MO
Wednesday Nights from 6:30 pm - 8:00 pm
September 3rd and 17th
October 1st and 15th
November 12th and 26th

OLATHE HY-VEE
18101 W. 119th Street * Olathe, KS
Thursday Nights from 6:30 pm - 8:00 pm
September 4th and 18th
October 2nd, 16th, and 30th
November 6th

INDEPENDENCE HY-VEE
4545 S Noland Road * Independence, MO
Friday Nights from 6:30 pm - 8:00 pm
September 5th and 19th
October 3rd and 17th
November 7th and 21st

Please sign-up for 3 dates when you RSVP so that we can make sure plenty of people can participate.
You can be put on the waitlist for the remaining dates if you would like.
Easing Back-To-School Challenges for Your Child with Ds

The back-to-school season is a time when children are surrounded with new classrooms, new people, and new expectations. For students with special needs, immersion in all this change can make the fall an especially challenging season of adaptation. Parents can support their children at home and take steps to build good relationships with the adults who work with their children at school. By communicating, being flexible and sharing information, parents and school staff can improve the beginning of the new school year for students.

1. Help children track new routines. Special needs children often need more preparation to be ready to take on the school year. Visual ways to keep track of their daily and weekly schedules provide a boost. A wall calendar at home can be marked with special events, extracurricular activities, half days of school, vacations, holidays and of course assignment deadlines. Pasting a chart of the child’s daily school schedule inside a notebook or locker can also be helpful.

2. Team up with school staff. Establish a team relationship early on with your child’s teacher and any other adult who has contact with your child during the school day including the lunchroom aide, the playground supervisor, and the bus driver. Encourage each of them to feel invested in your child’s success at school.

3. Brief teachers on your child’s strengths. With all the attention paid to special needs children’s difficulties, teachers may overlook your child’s strengths and interests. Brainstorm with the teacher about ways to adapt assignments to include the child’s interests or to let the child’s special strengths shine.

4. Clarify your child’s needs. Your child may have an individual education plan (IEP), typically a complex document. The teacher may benefit from having a quick one-page reference sheet from you summarizing your child’s needs and accommodations as identified in the IEP. Background materials explaining your child’s disabilities may be helpful as well. Keep it short.

5. Set up continuous communication. Email messages, meetings or phone calls are options. These communications let you inform teachers about what may be happening at home with your child that affects him or her at school, such as changes in sleeping or eating patterns, anticipation of family events, or homework assignments that were problematic.

6. Seek opportunities for your child to work and play with other kids. Getting along with other children is an important element of success in school. Regularly discuss with school staff ways to bring your child together with others to help form friendships. These could include finding good partners for your child when the class works in small groups, identifying peer “buddies,” as helpers or suggesting extracurricular activities or clubs with students who share similar interests.

By Jamell White, Ph.D., LCSW-C, Clinical Director, Special Needs and Deaf Services www.jssa.org/easing-back-to-school-challenges-for-children-with-special-needs/

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Transition Boot Camp Sessions

**Session 1: The Nitty-Gritty: What Do I Need to Know Today?**
Wednesday, October 8th 6:00pm-8:30pm
This session will cover the following topics:
- Transition Plan from High school to adult living
- Decisions to be made while still in school
- Differences between high school and the adult world
- Funding for what comes after school

**Session 2: What Happens After the Bus Stops Coming**
Wednesday, December 10th 6:00pm-8:30pm
This session will cover the following topics:
- Work Options
- Post-Secondary Education
- Volunteer Opportunities
- Day Programs
- Living Options
- Self-determination
- Resource Session

**Session 3: Moving Toward Independence**
Wednesday, March 4th 6:00pm-8:30pm
This session will cover the following topics:
- Supported Living
- Independent Living
- Group Homes
- Intentional Communities
- Guardianship

**Session 4: Building A Social World for Your Child**
Wednesday, May 6th 6:00pm-8:30pm
This session will cover the following topics:
- Person centered planning
- Paid and unpaid supports
- Dating, sexuality and relationships
- Provider fair for social, recreational and leisure opportunities

For Parents and Teens (ages 12-18). RSVP to info@kcdsg.org or 913-384-4848
Help DSG spread awareness and ensure accurate up to date information available regarding Down syndrome.

Purchased separately, the titles listed below would cost $107.00 plus shipping and handling. DSG believes in this important program so we are offering our members a greatly reduced price of

Down Syndrome Awareness Month
Book Bundles

Unfortunately, many libraries, schools and hospitals have inaccurate and outdated resources on Down syndrome— or worse, don’t have any information at all. In recognition of October being National Down Syndrome Awareness Month, DSG is selling book bundles at a greatly reduced price. We need your help to stock shelves with accurate information and portrayals of people with Down syndrome. You can help “spread the word” and celebrate Down Syndrome Awareness month by purchasing and donating bundles.

Purchased separately, the titles listed below would cost $107.00 plus shipping and handling. DSG believes in this important program so we are offering our members a greatly reduced price of

- Just Like Other Daughters - Alicia Richards
  loved her daughter from her very first breath. Days later, when tests confirmed what Alicia already knew—that Chloe had Down syndrome—she didn’t falter. Now twenty-five, Chloe is sweet, funny, and content. Alicia brings her to adult daycare while she teaches at a local college. One day Chloe arrives home thrumming with excitement, and says the words Alicia never anticipated. She has met someone—a young man named Thomas. With-

- Targeting Language Delays - Many school-aged children with developmental and communication challenges need help with their listening, language, and reading skills. Targeting Language Delays explains how to teach these skills in sequential steps using more than 100 goals and activities that can be incorporated into an IEP or used for home practice. Thorough enough for SLPs, yet accessible enough for parents and teachers, this manual

- All About Tests & Assessments - Will help demystify the assessment process and make it less intimidating. You will learn: about psychological, academic, and neuropsychological tests and what these tests measure; about selecting evaluators; how to request a special education evaluation and how to provide parental consent; about speech-language, physical and occupational therapy, processing, adaptive behavior, and functional behavior assessments; test terms and the important realities about tests and as-

- Gross Motor Skills for Children with Down Syndrome - In parent-friendly language, the author explains the many physiological reasons that children with Down syndrome experience delays in their gross motor development and presents a physical therapy treatment plan for birth to age 6. Over 400 photos accompany step-by-step instructions to help readers assess a child’s gross motor readiness and teach skills for head control, sitting, crawling, standing, walking, using stairs, running,

- Inclusion in Practice - Educating Children with Down Syndrome in Primary School - The film examines the range of issues for children with Down syndrome, including learning in the classroom, planning and support, and social inclusion. Drawing on years of practical experience of supporting children with Down syndrome in mainstream schools, the film offers advice and information that is also supported by extensive scientific research into the children’s needs. This comprehensive film is an important resource for parents, teachers, assistants and anyone involved in educating children with Down syndrome.

Purchase bundles for personal use or donate titles to a local library, hospital or school for Down Syndrome Awareness Month.

Offer is valid for Missouri and Kansas residents.
Out of state orders may be filled if there are any remaining bundles on October 1st.

Don’t wait, limited bundles available! Offer expires September 15.
It’s been said you can’t choose your family. However, as I’ve grown and matured I’ve realized that I wouldn’t want to. I’m amazed to be blessed with a family as supportive as mine. Through all the hard decisions I’ve made, and the numerous times I’ve changed my mind, my parents have stuck by my side through anything life has put me through. Although at times I can be a handful, my parents have proved to love me no matter what. I was born on July 17th 1998. My mom always told me I was a ‘perfect baby’; I had no complications whatsoever after being delivered. I don’t remember much of the first years of my life, only what my parents have told me repeatedly years later. I rarely cried, I had a giggle that was contagious, and I was reading at moderately high levels at a young age. I was the only child for about Eighteen months, and my life was pretty normal. My baby sister was born, on January 31st 2000. This time it was different.

At my age, not everything told to me was easy to understand. I was heartbroken and confused when I couldn’t stay with my parents for three months because they were in the hospital with my baby sister. I was even more heartbroken and confused when all of my cousins, aunts, and uncles would visit me desperately trying to hide their tears after they visited the hospital to see the new baby. I had no idea what was going on, but the lack of attention I got was driving me off the wall. My mom told me that I refused to talk to her for a long time after my sister was born. For 18 months, I was used to being the center of attention throughout my entire family. I didn’t like this change, but it has affected my life all the way up until today.

My little sister was born with Down syndrome. If you have never taken biology, Down syndrome is a genetic disorder in which a person is born with 47 chromosomes instead of the usual 46. Down syndrome gives the child physical characteristics that are not like that of other children. I, still at 18 months, did not recognize these right away. However, what I did observe was the way she struggled with things. It was hard for her to talk, and it took her longer than it took me to learn how to walk. I started to realize that she was different, but I didn’t quite understand why yet. At one point, I believed I had the same thing she did. This didn’t last long though.

As I grew older, I decided to try out for dance. I loved dance, and I still do. Although I’m not the best at it, I enjoy getting better and using it as a time to get away from my routine life and bond with friends. As I was figuring out what I liked and disliked, I noticed my sister slowly but surely improving. At first, we were trying to get her to use sign language. I learned the alphabet and some basic words and phrases in sign language, but as she got older, we noticed that she had a desire to speak. Her words slurred and her pronunciation was a little difficult to understand. But I always understood it. At first people had to ask me what she was saying, occasionally that does happen still today, but not as often as before.

During Carly’s early years, my parents spent numerous times at the hospital for Carly’s surgeries and check-ups. A lot of time was dedicated to scheduling and rescheduling meetings and appointments to see how Carly was improving. They still continue to take her to numerous appointments. Not only does Carly have Down syndrome, she also has ADHD, and lots of other problems. This involves problems focusing, hyperactivity, and the inability to control your actions. She has to take certain prescribed medicine during different times of the day. This is a huge hassle, and anyone who gives it to her has to do it right, or Carly will not behave appropriately during the day.

Carly and I have gone through tons of babysitters in our early ages of life. Some came and went, others left along with a piece of our heart. Each one of them I can assure you have learned some kind of life lesson while working with my sister. Carly may be a nuisance at times, but she leaves a lasting impression on everyone she comes into contact with.

Sometimes I believe I learn more from being with my little sister than I could ever teach her. She has taught me things such as how to accept others, and having the ability to accept yourself as well. I don’t think I would be who I am today if Carly wasn’t a part of my life. I’ll admit that it’s sometimes hard to relate and understand things when I try to communicate with Carly, which is frustrating for me especially because I like being in-depth with people. But I wouldn’t have it any other way. I also know I don’t spend as much time as I should working with her and supporting her. I seem distant at times, but it’s difficult for me as well due to my patience levels. I’m working on trying to build a stronger relationship with my sister.

I remember visiting Carly’s school for her school related musicals, carnivals, and the occasional holiday parties. Each time I’ve gone I would see her classmates, friends, and teachers come up to her and give her a big hug and ask her how her day’s been. From what I’ve seen they all have accepted her and treated her like anyone else, which is a big deal. I’ve been told awful stories of kids bullying and making fun of children with special needs, but with Carly it’s different. Being the wonderful influence I am, I’ve taught her things that have made her into the complete goofball she is today.

I have to be careful about what I do and say around her because you start to notice that some of my involuntary habits and my phrases have slipped into her vocabulary. But aside from being humorous, Carly is also very compassionate towards others as well. I remember one night I wasn’t in the best mood and I felt like everything was going downhill so I just threw a temper tantrum. Carly comes into my room with a box of tissues, sits on my bed, and hugs me for what felt like hours. She always hated to see me cry, and whenever I cried, she did the same. It was times like those when I realized Carly is a blessing. I know that no matter what I do, or how badly I screw up, Carly will be sitting on my bed with a box of tissues and open arms.

...Continued next page...
An occurrence that affected Carly was the death of my grandfather in 2009. My grandpa used crutches and spent his last few years sitting in his chair for most of the day. We all called it “grandpa’s chair” because nobody else sat in it besides the man himself. I’ll admit that I wasn’t as close to my grandfather as I was my grandma, but for Carly it was the opposite. Every time we visited Grandma’s farm, Carly would prop herself right on Grandpa’s lap. Grandpa didn’t mind it at all, and Carly loved it.

She would read him stories and color on coloring books, and even bring hats and sunglasses from the dress up bin and put them on Grandpa. There’s not one picture that has been taken of Carly and Grandpa where she was not on his lap. When Grandpa passed, Carly was heartbroken. She didn’t understand at first and she would occasionally ask where he was. It was difficult for the entire family to explain where Grandpa was, and when Carly would ask why he passed away, well, some of us didn’t even know the answer to that ourselves.

“Carly has taught me a lot but the best thing she’s taught me by far is the meaning of love.”

She’s taught me that love is expressed in many different ways and forms. The way she asks me how I’m doing each day, when she puts a warm cloth on my forehead when I’m sick, and when she randomly asks me if I’m happy are all simple ways that one may show their care and affection. She’s taught me to look for these simple but meaningful ways in other people. She’s taught me to find the good in people, because there is good in everyone. Carly has taught me that the little things mean the most. That no dollar amount could ever compare to the love and happiness that you can radiate to others. It’s amazing how one person can affect your life, and I’m truly blessed to have the honor to love someone with Down syndrome. Without my little sister and who she is, I wouldn’t be the kind of person I am, a person who looks beyond what people portray to find good and value within everyone.

Written by DSG Sibling, Katlin Othmer, April 2014
Are You Ready To
www.stepupfordownsindromekc.org

Team t-shirt deadline is **Friday September 19**. This is the last day to register to have your team name printed on the back of the t-shirt.

Team t-shirt pick up day is **Saturday, October 11** from **9:00AM-1:00PM** at the DSG offices.

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18th Annual Huddle Time Sports Auction

It’s not too late to get your tickets to Huddle Time. Current members of the KC Chiefs offensive line will be present, along with former players and few special guests!

This fun filled evening will take place on **Monday, September 15** at **Shadow Glen Golf Club, in Olathe, KS** from **6:00-9:00 p.m.**

Huddle Time will feature one-of-a-kind sports memorabilia and items with Chiefs players. A night you won’t want to miss. Food, drinks, Monday night football (will be shown) and the opportunity to meet Chiefs players.

To order tickets and find further details, please visit [www.FDFDS.org](http://www.FDFDS.org)

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KFC’s team with FDFDS for Down Syndrome Awareness Month!

Area KFC restaurants & FDFDS are gearing up for the annual fall fundraising promotion, which will begin **October 1** and run **through October 31, 2014**. All 49 KFC stores in the Greater Kansas City and St. Joe areas will be participating.

Customers can purchase a KFC coupon book valued at $40 in savings for just $1. All proceeds from the sale of the coupon book will benefit First Downs and help raise awareness and funds for First Downs for Down Syndrome. Tell your family, neighbors and friends about this wonderful offer.

**Thank you KFC for helping the Kansas City Down syndrome community!**

First Downs for Down Syndrome teams with the Kansas City Chiefs Offensive Line to raise money for the Down Syndrome Guild, the Down Syndrome Clinic at Children’s Mercy Hospital and other Down syndrome organizations. A number of fundraising events are held each year to raise money and provide awareness of Down syndrome.

Area Corporate Sponsors also support First Downs for Down Syndrome. We thank them for make for their generosity. For information regarding events or other fundraisers, please contact Amy Stoll, Executive Director, at 913-722-2499 or email stoll@fdfds.org. You can also learn more by visiting our website at [www.fdfds.org](http://www.fdfds.org).
Calendar of Events

Golf Tournament
September 15, 2014 at 12:00PM
Shadow Glen Golf Club, Olathe KS
The four man shot gun start will tee off at 12:00 Noon with registration, browsing the gift salon and BBQ lunch (provided by Texas Roadhouse) beginning at 10:30 a.m. All golfers will enjoy meeting and playing against celebrity golfers, hole contests with premium prizes, the opportunity to win a car from Aristocrat, food and drinks on the course and meeting our self-advocates. At the conclusion of the golf tournament, golfers can stay for Huddle Time. Food, drink and both silent & live auctions. Bid on unique auction items and also meet current and former players of the Kansas City Chiefs.

Huddle Time Sports Auction
September 15, 2014 at 6:00PM
Shadow Glen Golf Course, Olathe KS
Huddle Time guests will enjoy fabulous food and drinks and the opportunity to bid on unique sports memorabilia as well as ‘unique experiences.’

Step Up for Down Syndrome Walk & Family Festival!
Sunday October 19, 2014 at 12:00PM
Arrowhead Stadium - Lot C
Food and Family Fun for all ages! Join us for a fun filled Sunday afternoon for the whole family– KFC lunch, inflatables, bungee pods, rock climbing wall, tattoos, pony rides, carnival games Happy Face entertainment on stage and so much more…The walk is a one mile walk around Arrowhead Stadium. For more information about the walk, please visit www.stepupfordowsyndromekc.org

A SPECIAL BENEFIT CONCERT for Mission Project & FDFDS
Friday, December 12, 2014 at 8:00PM
Helzberg Hall | Kauffman Center
Kansas City’s very own Oleta Adams and Wichita, KS native Chris Mann, together, promise a soulful and uplifting evening of memorable music. Tickets start at $52. A limited number of Gold Circle tickets are available for $125 each, which include a special reception and exclusive meet-and-greet on stage. This concert benefits the Mission Project, a local group helping young adults with developmental disabilities to live and work safely in the community with minimal support; and First Downs for Down syndrome, which raises money for the Kansas City Down syndrome community, in partnership with the Kansas City Chiefs offensive line.

FIRST DOWNS FOR DOWN SYNDROME
HIGH SCHOOL FUNDRAISER
The following schools are on board for the 2014 football season
Blue Springs Olathe Northwest
Blue Springs South Pleasant Hill
Blue Valley Northwest Raytown
Hardin Central Shawnee Mission West
Kearney Smithville
Leavenworth St. Pius X
Maryville St. Thomas Aquinas
Olathe East Turner

The above schools will participate in the joint fundraising efforts between high school football teams & FDFDS. The program is designed to create awareness and provide additional resources to benefit individuals with Down syndrome, while also raising money for the football teams. If your school is not on the list, we would like to get them involved. Please call the FDFDS office at 913-722-2499 for more information.

Host a Dress Down for Down Syndrome Day
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 more information.

“Without First Downs for Down Syndrome, the Kansas City Down syndrome community wouldn’t be as strong as it is today.”
- First Downs Parent

www.fdfds.org
Please Join Us!

Sunday, September 7, 2014 • 1 PM - 4 PM
16300 Wilkerson Road • Weston, MO 64098

Bring the whole family for a fun day on the farm with activities for all ages.
- Visit the animals
- Enjoy a hayride
- Fun family games
- Check out the pumpkin patch
- Food
- Hamster balls
- Watermelon eating contest
- Moon bounce
- Booger wars

RSVP by September 4th to info@kcdsg.org or 913-384-4848