



# DSACK

*beautiful capable loved*

JANUARY-  
FEBRUARY  
2010

VOLUME III  
NUMBER VI

*Happy 2010!*



- 2** news board from the board  
DSACK groups
- 4** DSACK christmas party
- 6** local news to use
- 7** special olympics
- 8** national & international news  
celebrations
- 9** making connections
- 10** reaching out to support research  
wonderful websites  
donations received  
be inspired
- 11** soccer league
- 12** calendar  
submissions



**DSACK**

**NEWS FROM THE BOARD**

The DSACK Board expresses our deepest sympathy to Jeremiah Wray and Rachelle Lefever and family whose daughter Shelby Christine (7 months) died on November 26, 2009 as a result of complications following open-heart surgery.

The DSACK Board expresses our deepest sympathy to Jason and Emily Merrick and family whose daughter Gabrielle Rae (4 months) died on November 20, 2009 as a result of complications following open-heart surgery.

*Your two angels will be remembered by DSACK, and you will always be a part of the DSACK Family.*

**DSACK**

**GROUPS**

**0-5 Parent Group & Playgroup**

**\*TIME HAS CHANGED FROM 9-11 TO 10-12!\***

Faith Lutheran Church, 1000 Tates Creek Rd., Lexington

This group is for families who have a child with Down syndrome between the ages of 0-5 years old. Siblings and grandparents are welcome. Chidlcare provided. Contact Michelle @ 859-223-4207 or mandmgilliam@windstream.net

January 9th: Angela Folczyk, OTR/L, will be discussing occupational therapy for our children.

February 13: We will view "Megan's Story", a documentary about Megan McCormick which highlights her educational path ( which now includes college!) There will be a discussion afterward with the McCormicks.

**Elementary Group**

You are invited to join the 0-5 group parents on **February 13!** Please let Michelle know if you will be coming. Information about other events will be emailed to you. Contact DSACK with any questions.

**THANK YOU AND GOOD LUCK, Megan and Ashleigh!**

DSACK would like to say thank you and goodbye to Megan Thomas and Ashleigh Gray, who are graduate students at UK in the School Psychology Program. They started working with DSACK last summer to fulfill practicum requirements for their certificate in Developmental Disabilities. These ladies have been phenomenal to work with and have made a lasting impression on the DSACK board.

We are REALLY going to miss them. They enthusiastically and independently started the peer group for our elementary aged students and coordinated many fun outings for them and their families. They also, along with AIM leader and DSACK board member Brooke Reed, coordinated all of the volunteers for the 2009 Buddy Walk. Because of their diligence and attention to detail, we now have a database of over 150 volunteers! (They



even hand-wrote thank you notes to each one!) These ladies are beautiful inside and out. We feel blessed to have had Ashleigh and Megan with us these past several months and wish them all the best with their future endeavors.



**WHO ARE WE?**

**BOARD OFFICERS**

- Traci Brewer, *Parent*
- Courtney Elbert, *Parent*
- Michelle Gilliam, *Parent*
- Regina Schmutte, *Parent*
- Malkanthie McCormick, *Parent & MD*
- Internal Medicine Physician*

**TREASURER**

- Lee Ann Mullis, *Parent &*
- Consignment Inventory Analyst/*
- Accountant*

**ADVISORY COUNCIL**

- Caroline Boeh Baesler, *Parent &*
- Attorney*
- Karen Roof Boudreaux, *Parent*
- Becky Lesche, *Parent & Educator*

**BOARD DIRECTORS**

- Belva Collins, *Ed.D. UK, Professor of*
- Special Education*
- Harold Kleinert, *Ed.D., Executive*
- Director of IHDI*
- Samantha Matthews, *Special*
- Education Teacher*
- Brooke Reed, *UK School Psychology*
- Doctoral Student*

*DSACK Bylaws and financials are open for review, and the Board of Director Meetings are open to our community. Agenda items are determined well in advance.*

# DSACK

## A.I.M. (Advocates In Motion) Young Adult Group

The young adult group has had some fun events the past couple of months. We painted pottery at the Mad Potter where everyone had fun talking and painting together! In December, we baked and decorated Christmas cookies that we delivered to local fire stations. The firemen were surprised and excited about the cookies, and they let us get in their big truck!



On **January 24th**, we are going to see the UK women's basketball team play Auburn University at Memorial Coliseum at 2pm. Tickets are \$2 for anyone under 18 and \$5 for adults. We will meet at Memorial Coliseum at 1:30pm.

Mark your calendar for **February 20th** from 6-8:30pm! We are having a pizza and movie night at Drew Janoski's house (1001 Watermill Lane). Please RSVP to Brooke Reed by February 17th so we know how much pizza to order.

The group is continuing to grow and we always welcome new people, so if you are between the ages of 15 and 30 and have Down Syndrome, please contact Brooke Reed (321-507-0332 or [brooke.reed@uky.edu](mailto:brooke.reed@uky.edu)) to get involved! Families are always welcome and encouraged to attend!



## Sibling Group

**January 30**, 2:00 p.m. Initial meeting for DSACK siblings ages 8-12. Rebecca Smith plans for this to be a fun time of getting to know each other. Please RSVP to 859-494-7809 if you would like to come!

## Mom's Night Out 2010

If you are like me, I start off the New Year making resolutions. I am looking forward to accomplishing many of them including: getting more involved with DSACK, Knowing our membership, and feeding my interests: the arts, culinary, literary, musical, sport and creative. Planning MNO2010 is the perfect fit with my goals.

*Let's paint Pottery...*

It's creative fun for everyone! Come to the Mad Potter on **Monday, January 25th** from 6:00-9. I have reserved the private party room. Bring refreshments to share. Price of painted piece covers the piece, paint and firing. They range from an ornament \$5 to a kitchen sink for \$200. Please let me know if you can make it by 1-22 and if you have any suggestion for MNO2010 calendar. Eileen Miot 859-340-2771 or [erwky@yahoo.com](mailto:erwky@yahoo.com)

**The Mad Potter**  
Lansdowne Shops  
3385 Tates Creek Rd.  
Lexington, Ky  
859-269-4591  
[www.themadpotter.biz](http://www.themadpotter.biz)

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Cell (859)492-7971  
Fax (859)223-0499  
E-mail: [cwheeler@finsvcs.com](mailto:cwheeler@finsvcs.com)  
Insurance Representative of MassMutual and its affiliates. Carolyn B. Wheeler is a Registered representative of and offers securities through MML Investors Services Inc., a MassMutual subsidiary. Supervisory Office: 2365 Harrodsburg Road, Suite A300, Lexington, KY 40504-3392 (859)223-4141

DSACK

CHRISTMAS PARTY!

Ho! Ho! Ho!

*Ho!Ho!Ho! What a merry holiday party we had!!!*

DSACK once again held our annual holiday party at Trinity Hill United Methodist Church. This year we had the entire meal catered by Bons Temps Catering and it was absolutely delicious! So many of our families commented on how much more enjoyable the event was since they didn't have to prepare or bring food this year. Thank you Bons Temps for making this possible and making our party even more inviting.

We had record attendance with over 90 people! Many of our board members were present including Belva Collins, Samantha Matthews, Brooke Reed, Michelle Gilliam, Courtney Elbert, Malkanthie McCormick, and Traci Brewer. Of course, we had a visit from Santa, which is always the highlight of the day! Thanks, Santa, for taking time out of your busy schedule to visit with us! We know many, many children (and parents) went home happy because of seeing you! Thank you, Mary Mandl, for asking Santa if he could stop by during his hectic schedule!

DSACK would especially like to thank Sam Matthews and Stephen Greene who provided the children's activities. They went to A LOT of effort and the children had A LOT of fun! There were gingerbread houses and gingerbread cookies to decorate, clever coloring books and crafts, cookies to take home, and a fabulous Velcro gingerbread activity book that Sam created for each of the children to take home.

Many people contributed to the success of this year's Annual Christmas Party. This truly is a collaborative effort, and we appreciate everyone's help.

Because this is one of our biggest events every year, we have outgrown our space at Trinity Hill. If you know of any facility that would let us host our party on their site, please contact Traci Brewer at 859-806-8196. We need to reserve a place right away for next year. Maybe your church or workplace has a place we could use? Please put on your thinking caps and call Traci with suggestions.

We look forward to seeing all of you in 2010. We already have some exciting things in the works for DSACK! We hope all of you had a blessed and peaceful holiday season, and that 2010 is wonderful for you and your family!

~ DSACK Board Officers



# DSACK

## What Matters Most...



The DSACK Christmas Party has been a special part of our Christmas plans for the past three years since Megan came into our lives. It's always on the calendar, and I was so excited to dress the girls and bring them this year! The fact that my brother-in-law, sister, niece, and great niece would also be coming had me even more excited in a special way!

What I didn't plan on was little Megan fussing the entire party due to tummy ache, bronchitis, feeling overwhelmed by the crowd, or who knows! She cried and fussed, fussed and cried, refused to eat (even threw her Goldfish Crackers on the floor!), and made Mommy's time much less fun than usual.

However, the unexpected blessing came from her five year old sibling Tracy this year. Tracy is terrified of Santa, but let me hand her the gift he had for her. When she opened it, she was so surprised to find a Sparkling Princess Snow White Barbie! "That's all I wanted!!!," she exclaimed! I wish Christmas surprises were all as simple and meaningful as that! It gets even better...

Tracy and I had been praying for all of the DSACK babies who recently had heart surgery. Together we were so sad when two sweet babies went to be in Heaven for Christmas. We were also excited to hear that baby Jack went home from the hospital. But at Saturday's Party, when I pointed out Jack's Mommy (who was holding Jack at the moment) to Tracy and said, "See that little baby?" She said, "Yes." I said, "That's Baby Jack!" Tracy looked at me with the biggest, happiest blue eyes ever and jumped up and hugged me as hard as she could around the neck! She got it! She knew that God heard our prayers and she got to see His Love in action. It doesn't get better than that!

I know God Has blessed our family so much by being a part of the DSACK community. He knows our hopes and dreams for all of our children. Thanks for being such a special part of our lives.



Mary Mandl, with Christmas Love from the entire Mandl family



## LOCAL NEWS TO USE

**Need Buddy Walk 2010 Members!**

Regina and the Buddy Walk Committee are looking for committee members and chair people for Buddy Walk 2010! We would like to form the committees by the end of February. Call Regina if interested 859-983-3754!

**Down Syndrome Awareness "Peer Presentation" Training Coming in 2010!**

Parents and professionals find that if classmates understand a child's disability, they may become allies in helping the child. The children may also be less likely to view accommodations or individual support as unfair advantages. One of the best ways to teach children about a disability is to talk to them at school. For many families, presenting at school is an annual event. Sometimes, an IEP team writes it into a child's

Individualized Education Program (IEP) document. The event is an opportunity to:

- discuss why a child may look or behave differently from other children in the class
- point out the many ways in which the child is like classmates
- offer classmates tips for interacting with the child

DSACK seeks to educate the community to breakdown stereotypes, provide positive images of individuals with Down syndrome and to support families to achieve success. One new way that DSACK is working hard to achieve this is through our newly offered "boxed up" Down Syndrome Awareness Peer Presentation kits, and training sessions for anyone interested in becoming a trained volunteer Peer Presenter for DSACK. Volunteers who go through the training session will be empowered to educate their loved one's school community and will also have the tools to do so through our Peer Presentation Kit. Those who attend the training will be able to check out the kits for use at schools of their choice and will also receive other support from DSACK such as personalized bookmarks for your child's class, etc. In order to assure the quality and consistency of these presentations that reflect on DSACK, only those persons who have attended a training session will be able to check out the presentation kit.

We plan to hold training sessions occasionally throughout the year as needed. **Our very first Peer Presentation Training Session will be offered on Saturday, January 23rd from 9:00-11:00a.m.** The location will be determined based on the number of people who sign up to attend, so **PLEASE RSVP!** If you have questions or plan to attend, contact Traci at 859-494-7809 or Courtney at 859-879-2182.

**Michele P. Waiver**

The Michele P. Waiver evolved as a result of a lawsuit regarding persons with intellectual disabilities or developmental disabilities and the lack of community based services available. It is designed for children and adults and the purpose is to help people remain in or return to the community. To qualify you must have a developmental disability or significantly sub average intellectual functioning. Here is how you can apply:

Contact your local Mental Health/Mental Retardation Board – This is done through Access in Fayette County – 859-272-7483. Tell them you want to schedule an appointment to have your child accessed for the Michele P. Waiver. Someone will give you a call back to schedule the appointment.

Services covered Case Management, Adult Day Training, Behavior Supports, Physical Therapy, Speech Therapy, Occupational Therapy, Respite, Personal Care and others...

For more information you can visit:

<http://www.chfs.ky.gov/dms/mpw.htm>

OR you can call Stella Smith at the Parent Resource Center for more information – 859-381-4229.

**Courageous Kids Family Camp Application Deadline!**

<http://www.courageouskids.org/>

Courageous Kids is a world class medical camping facility in the rolling hills of Scottsville, Kentucky providing a cost-free, safe, and fun camping experience for seriously ill and disabled children and their families. On Family Weekends the child with disabilities attends Camp with his or her entire family. Parents facing similar challenges immediately bond with each other. Healthy siblings of children living with serious illness know all too well how a childhood medical condition impacts the entire family. These children have lost some of their childhood as well as parents are **forced to focus their resources** and emotional energy toward the ill child. These children will learn they are not alone. The **weekend programs are designed** for the **entire family** including parents' night out and non-stop activity for the children. Adult only sessions with professional experts in the fields of counseling, medicine, and medical financial aid are provided.

**The Family Camp for Down Syndrome is March 26-28, 2010 and the Application Deadline is Tuesday, January 19, 2010!**

# DSACK

## Bluegrass Technology Center

*(submitted by Mary Henson)*

The Bluegrass Technology Center has a variety of resources available to individuals with disabilities. Here are ten reasons to consider this center a long-term resource for your family.

1. Their mission is to support people with disabilities towards independence and productivity through technology. There are 4 such centers in Kentucky. The Bluegrass Technology Center serves Lexington as well as Central and Eastern Kentucky.

2. They have a large collection of switch-activated toys, which are adapted for children with developmental delays. Currently the rental cost of these toys is covered by a grant from WHAS, so this is a free resource to families. They can also instruct parents in adapting existing toys affordably to be switch-activated toys.

3. The BTC has special equipment like walkers, bikes and chairs for rental. People in the First Steps program may have these fees covered. BTC works with therapists.

4. On Fridays, the United Way sponsors an open computer lab there. If you have a specific goal for your child such as developing organization skills for school, you may call ahead to establish a time for the lab.

5. At BTC, you can review many different kinds of software, adapted computer mice, and adapted keyboards. Going for a tour would allow you to try these devices or perhaps rent them. We were given 2 CDs for a free software trial.

6. The Bluegrass Technology Center makes computers available (\$25 cost) to children with disabilities from low-income households who need a computer. BTC accepts donations of gently used computers to refurbish for this program. They are particularly interested in donations of computer mice and keyboards right now.

7. Fayette County Schools and other school systems work with the Bluegrass Technology Center. If you are interested in increasing your child's use and access to technology, center staff could provide a tour of their resources and demonstrate options for the school-age child.

8. BTC has a knowledgeable staff which is committed to helping people find technology that improves the quality of life for people with individuals. Our tour guide, Carol Moffett, is a specialist in Assistive Technology and a former special education teacher.

9. Many types of assistive technology and aids for communication are available from a simple three choice board to an intricate eye response unit.

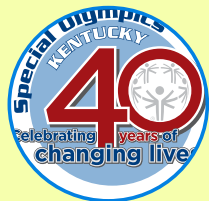
10. The center coordinates training activities throughout Central and Eastern Kentucky.

You can call them for an appointment at 859-294-4343. The website address is [www.bluegrass-tech.org](http://www.bluegrass-tech.org)

Personal Note: As a mother of a curious, busy two year old with Down's Syndrome, I can tell you that he thoroughly enjoyed the tour of Bluegrass Technology Center. He loved the dancing Grinch decoration and the Little Tikes computer unit. He tried very hard to get to the hard drive. He experimented with many of the switch-activated toys. We are looking into a switch for an adapted mouse. Learning of their resources for the broad community, I see the Bluegrass Technology Center as an important resource.



## Special Olympics – 40 Years of Changing Lives



**Special Olympics Kentucky** will be celebrating its 40th Anniversary in 2010! It's been an unbelievable 40 years with humble beginnings in 1970 as a small group of athletes gathered at Valley High School in Louisville to participate in the first Special Olympics Games offered in Kentucky. The courage and pride displayed by those participants and their families that day helped to lay the groundwork for the Special Olympics program we know today. Special Olympics has grown worldwide and serves over 1.2 million athletes annually. Here in Kentucky, over 6,000 athletes participate each year in sports and training programs and activities.

The mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for both children and adults with intellectual disabilities. No doubt that sport is the focus of the movement but it was quickly understood that through sports the lives of people with intellectual disabilities were impacted in many other ways. For Special Olympics athletes, sports provide a gateway to empowerment, competence, acceptance, joy and dignity. The "playing field" is also a classroom as the training and competition enhances focus and gives participants a structure for learning important life lessons about perseverance, endurance and setting goals.

Special Olympics has also had great impact on the public perception of individuals with intellectual disabilities. Part of the Special Olympics purpose is educating people about the dignity and gifts of all people! Most attitudes toward people with intellectual disabilities are formed by negative stereotypes and misconceptions. Yet when people see Special Olympics athletes in competition, they find their attitudes change. You see, through sports Special Olympics fosters and environment of acceptance, tolerance and inclusion.

With over 15 sports offered, there is something for every Kentucky athlete from children to older adults to participate in.: Alpine Skiing, Aquatics, Basketball, Bocce, Bowling, Cheerleading, Equestrian, Golf Gymnastics, Ice Skating, Powerlifting, Snowshoeing, Soccer, Softball, Track & Field, and the Young Athlete Program.

Whether you participate, volunteer or support Special Olympics Kentucky you can change lives, including your own, inside and out. Contact us today and learn how you can be a part of Special Olympics Kentucky by visiting our website: [www.soky.org](http://www.soky.org) or call 800-633-7403.

*(submitted by Special Olympics Kentucky representative)*

NATIONAL & INTERNATIONAL NEWS TO USE

**Rising to the Occasion**

**Rising to the occasion again: Student with Down syndrome inducted into National Honor Society at Blue Valley North**

*By Grace Hobson*

**The Kansas City Star**

<http://www.kansascity.com/105/story/1567266.html>

"Sarah Sherman is no more special than any of the 141 other students inducted Thursday night into Blue Valley North High School's chapter of the National Honor Society. Her 3.75 grade-point average is high, yes, but they all have at least the required 3.5. Every one of the students worked hard to pull the grades while participating in school activities and logging at least 40 hours of community service. She is, however, the only one who has Down syndrome. As she was called to walk across the Blue Valley North stage at Thursday night's ceremony, her achievement was not singled out. Her name carried no extra weight on the program. She blended in. She belonged..."

*To read the rest of Sarah's story, visit the website mentioned above!*

**Celebrations!**

*Happy 7th Birthday to Brandy!*

Not only did you celebrate the Buddy Walk with your "Brandy Boo Team", but now you are celebrating a big Birthday too!



*Congratulations to our very own DSACK Movie Star!*

To watch the video about Megan McCormick of Lexington, visit the link below and follow these instructions: On the left side of the screen, click on the very last icon that says "PEPID (WMV)"... This will take you to a video stream of Megan's video.

<http://www.ihdi.uky.edu/belonging/>

The film, funded by the KY Council on Developmental Disabilities, focuses on postsecondary education for individuals with intellectual disabilities. It was shown in its entirety at the Kentucky Theatre on November 5th, 2009.

**Avoid Learned Helplessness**

**Tip of the month for Educators**

Students with Down syndrome are often presumed to need help in areas where they can actually be quite self-sufficient. It is best to presume competence and provide supports when the student requests assistance or proves it is needed. Avoid the pitfalls of OVER HELPING the student by examining the following practices.

**Promotes Learned Helplessness**

- Protecting the student from taking any risks
- Rescuing the student from anticipated outcomes
- Overlooking errors
- Constant reminders of what should be taking place
- Speaking for the student
- Simplifying assignments
- Giving inflated grades on work done
- Accepting of making excuses for the student
- Inconsistency in discipline or expectations
- Permitting inattentiveness to task at hand

**Promotes Independence**

- Setting clear limits on what is safe
- Enforcing agreed upon consequences in unemotional manner
- Discussing issues and creating solutions
- Giving clear directions and expecting follow through
- Student is encouraged to speak for him/herself
- Teaching at a challenging level using learning strengths
- Using rubric scoring honestly
- Using clear expectations and coaching the student on errors
- Consistency in discipline or expectations in all settings
- Holding the student accountable for attending to task

An educator's ultimate responsibility is to train a student to be a productive member of the community. Students with Down syndrome benefit from teaching interactions that will challenge them to be as independent as possible. Over helping the student actually sets them up to fail when they leave the classroom. Make sure the student's peers also understand that they should not do anything for the student with Down syndrome until they have asked for help with a task.

# DSACK

MAKING

CONNECTIONS

## Connecting With Ob Dept At UK: A Giant Step For Dsack!

*The American College of Obstetricians and Gynecologists recommend that all women be offered prenatal testing. More accurate blood tests to detect Down syndrome mean that it is even more essential to give expectant parents and medical providers reliable and up-to-date information about Down syndrome. The passage of the Prenatally and Postnatally Diagnosed Awareness Act (formerly know as the Kennedy-Brownback Bill), only adds to this importance.*

*For organizations such as DSACK who serve people with Down syndrome, these factors mean that the landscape will start to shift from parents with new babies to expectant parents with a prenatal diagnosis. It also means that medical professionals will need more support and reliable information during the diagnosis phase.*

*Currently 90% of all women who receive a prenatal diagnosis of Down syndrome choose to abort. This is astonishingly high! DSACK is trying to work with UK and other hospitals and departments to make sure that patients are receiving the most accurate information and are aware of other alternatives, such as adoption.*

On December 10, 2009 DSACK officers Michelle Gilliam, Traci Brewer and Courtney Elbert gave their presentation to the nurses at UK's High-Risk OB Department. Michelle, Traci and Courtney collaborated to create this unique, original, and impressive presentation geared towards medical professionals that seemed to strike the right balance of emotion and facts. This one-hour presentation included a power-point, research-based facts and statistics, emotional appeal, a comprehensive packet of accurate information, video footage, and audience participation. The purpose of this presentation to medical professionals was to:

- ~ Establish a relationship with the high-risk department
- ~ Provide national and local resources
- ~ Be available to answer any questions medical professional or patients may have
- ~ Be available to meet with parents who have received a prenatal diagnosis (if parents desire).
- ~ Provide a comprehensive packet of information to parents with a pre-natal diagnosis of Down syndrome
- ~ Shape the attitudes of healthcare professionals towards babies born with Down syndrome, and the image being portrayed to new parents regarding the future of their baby.

The audience was extremely receptive to the information they were given, all evaluation forms were positive, and all in attendance said they would recommend this presentation to others. They also requested that DSACK return to speak to the obstetricians, genetic counselor and residents! Thank you to Nancy Jennings, B.S.N., R.N., Nurse Clinic Manager, Department of OB/GYN at UK for allowing us this great opportunity! We look forward to future presentations and an established relationship!

## Baby Sign Language Classes

**When?** Monday evenings – February 1-April 5, 2010

**Where?** Tates Creek Branch Library, 3638 Walden Ave.

**Time?** 6:30 pm – 8:00 pm

The classes are free and will focus on teaching signs that are developmentally appropriate for parents/guardians to use with their children to enable them to communicate earlier.

To register please contact Michelle Gaines at 859-381-3456 or

email [michelle.gaines@fayette.kyschools.us](mailto:michelle.gaines@fayette.kyschools.us).

## New Support Group Forming in Fayette County

Beginning Tuesday, **January 12th** a new support group called **"Special Kids and Families"** will be meeting. This group is open to ALL families who have children with special needs and will meet at the **Tates Creek Public Library** from 6:30 pm – 8:00 pm. They will begin with "meet and greet" from 6:30 pm – 7:00 pm followed by a special speaker each month from 7:00 pm – 8:00 pm. For more information, please contact Stella Smith at the Parent Resource Center 859-381-4229. Some of the objectives of this group are:

- Share feelings and experiences
- Exchange information and resources
- Provide training for parents to increase skills
- Discuss ways to solve problems
- Offer support and help as needed
- Meet other families and begin to network

## The Woodford Wallabies, a Special Olympics basketball team

has 7 open roster spots. We are in the beginning division so players of any skill level or age are welcome. We practice in Versailles on Tuesdays from 6:30-7:30 at Hunteartown Elementary school - a short 10-15 minute drive from Bluegrass Airport. We plan to participate in a Lexington Special Olympics basketball league that will have 6 games at Jessie Clark Middle school. You are encouraged to attend a practice any to check it out. Call Will or Janine at (859) 879-7003 for more information.

REACHING OUT TO SUPPORT RESEARCH

**What is Important to You?**

**Most important things affecting people with disabilities in KY?**

The KY Council on Developmental Disabilities, the University of Kentucky Human Development Institute (HDI), and KY Protection and Advocacy (P&A) want to know your ideas about the most important things affecting people with developmental disabilities in Kentucky. Please take just a few minutes to complete this survey and tell them those things you want them to consider in making services better for the people they care about!

For English <http://www.kyddnetwork.org/surveys/survey.aspx>  
 For Spanish <http://www.kyddnetwork.org/surveys/surveysp.aspx>

**Social communication in young children with Down Syndrome**

Your child will participate in a free 2 day developmental assessment examining his or her cognitive, linguistic, and social communicative abilities. Eligibility: Children who have a genetically confirmed diagnosis of Down Syndrome aged 3 years, 6 months – 5 years 11 months. For more information please contact: Angie John, M.A. University of Louisville 502-852-4638. Principal Investigator: Carolyn B. Mervis, Ph.D.

WONDERFUL WEBSITES

**Free Special Needs Teaching Resources**

<http://www.senteacher.org/Home/>

SEN Teacher provides cost-free teaching & learning resources for students with special needs and learning disabilities.

All the resources available or listed are free for use in schools, colleges and at home.

The Printables Page has a selection of printable worksheets, handouts and teaching aids most of which can be customized to suit a range of learners. The Links Page lists websites which have been carefully selected for the quality of their information or because they provide further excellent sources of cost-free learning resources and software. The Files Page lists free educational software from many sources which has proved useful to teachers and parents of special needs students. Search Tools are custom Google search engines which make it easier to locate free resources and information from several different SEN related areas.

**Free Printable Behavior Charts**

<http://www.freeprintablebehaviorcharts.com/>

Designed and developed by a parent and family therapist, this site claims to provide a unique blend of expertise and practical parenting. We are committed to providing parents with information, education, and resources. Our behavior chart collection will be continuously growing so keep checking back as new charts will be added regularly.

DONATIONS RECEIVED

The following donations were made in memory of and in honor of loved ones:

*In memory of Gary L. Sampson, grandfather of Jack Thornbury, by Mr. & Mrs. James Martin, Anne Thompson, Susan Sampson and W.R. Brignon.*

*In memory of Shelby Christine Wray by Mr. Joe Graviss*

*In memory of Shelby Christine Wray by Roy & Bobbie Benson*

*In honor of Deacon Jim Paris, Director of Pastoral Life, Catholic Diocese of Lexington donated by his staff*

*In memory of Erica Nicole Jent Herald donated to "Erica's Fund" by her family*

*In honor of her daughter Jessie Birdwhistell who is Director of LYSA Top Soccer League donated by Janice Birdwhistell*

*In memory of Shelby Christine Wray by Steve Gay and Mary Ellen Rosebrough*

*In memory of Shelby Christine Wray by Sarah and Ed Winston*

*In memory of Shelby Christine Wray by Courtney and Dennis Elbert and Family*

**Be Inspired!**

*A Grandparent's Perspective: Other-Centered Love*

*Printed with permission from Cynthia McMillen of Tennessee, grandmother of Sam Elbert and mother of Board Officer and Newsletter Editor Courtney Elbert.*

How can a loving parent or grandparent adequately describe the love they have for their child or grandchild?

Verbalizing profound, other-centered love is difficult, if not impossible, because, I think, this love surely is a "portal" to where we are able to vaguely touch infinity. Where we experience in some way the infinite unconditional love that God has for the creatures He made in His image.

On May 30th, 2004, our grandson, Sam, was born in Lexington, KY. Our boy arrived a month early in a very unassuming, undemanding way, amidst tornados and raging storms.

# DSACK

## League for Special Needs Athletes Preparing for Spring Season



The Lexington Youth Soccer Association (LYSA) will again offer TOPSoccer (The Outreach Program for Soccer) to Lexington area athletes, youth to adult. TOPSoccer was created by the US Youth Soccer (USYSA) to meet the needs of children ages four and older with physical and/or mental disabilities.

Registration for the spring season opened Dec. 1, 2009, and will close March 1, 2010. The cost for participation is \$25 per player. Registration fees cover player insurance. Practice shirts and uniforms are provided. Players must provide their own shin guards and soccer cleats. To register go to: <https://active.leagueone.com/Olr/Pages/Welcome.aspx?ClubId=1192>

Jessie Birdwhistell is the LYSA TOPSoccer program director and a lifelong soccer player.

"During the fall season, we had 48 players sign up. It was a wonderful experience for the coaches, players and volunteers," said Birdwhistell. "The players learned soccer skills, had fun and made new friends."



Like all TOPSoccer leagues nationwide, LYSA TOPSoccer is a non-profit organization that is staffed and operated by volunteers and is primarily funded by charitable donations from area individuals and businesses.

"We had more than 85 volunteers and received great support from the community to help us purchase the uniforms and equipment we needed," said Birdwhistell. "I can't wait for the spring season to begin!"

Practices will be held on Sundays starting the week of April 10 and ending the week of May 22. Teams will be organized both by the player's ability and age.

In addition to practice and games, there will be social events for players and volunteers throughout the season. Last year, teams attended UK and Transylvania soccer games as well as an end-of-season tournament held at Kentucky Indoor Sports and Soccer. A special ceremony was held following the tournament to recognize both players and volunteers.



A family and volunteer information event is currently planned for April. Further information will be forthcoming about the event soon. If you are interested in coaching or being a volunteer or buddy for TOPSoccer, please contact Janice Birdwhistell at [jeb147@aol.com](mailto:jeb147@aol.com) or (859) 229-7670. If you have questions about LYSA TOPSoccer, please call Sherry Cook at (859) 223-5632 or by email at [info@lysa.org](mailto:info@lysa.org).

Little did his parents, or anyone, know that his early arrival would be the beginning of a lifetime of surprises he had in store. Sweet Sam (as I like to call him) arrived with 1 extra chromosome in each of his cells, three holes in his heart and some characteristics we didn't anticipate. In his unique way, he seemingly set out to surprise everyone. He learned to eat and thrive, he learned to smile and mesmerize adults, he learned all the important things that babies need to learn, including how to love and torment his older brother. He learned volumes of sign language and how to charm and flirt, how to welcome and love a little sister, and eventually even repaired his own heart!

He is now able to do most all the things that typically developing little boys do – all he needs is love, help and practice – the same things we all need. Sam was blessed with loving, caring parents who set out to learn about his particular needs, and continue to find the best ways they can to meet them – just as they do with their children with typical needs. I truly admire their loving patience, shared joy and tenacity in raising our grandchildren.

During this time that Sam has accomplished so much, he also taught us. To paraphrase a website about Down syndrome: He demonstrates a beautiful spontaneity, honesty, warmth and acceptance of others. He inspires us to step back and enjoy life itself with his unabashed belly laugh that prohibits any straight faces. At the same time, he is gentle, patient and tolerant. I have also learned that he gets frustrated with himself at times and his actions warrant a time-out by parents, or teachers, or even grandparents! He seems to thrive on consistent reinforcement of good behaviors and occasional time-outs.

The most important thing that Sam is teaching us as he grows, gets back to that profound, other-centered love that I have been trying to describe in this note.

HE LIVES IT! Sam demonstrates it – his open, vulnerable, forgiving acceptance of family, friends, strangers! I think our Sweet Sam is God's reminder to all of us how we are all capable of loving



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## CALENDAR

### 0-5 PARENT GROUP & PLAYGROUP

\*TIME HAS CHANGED FROM 9-11 TO 10-12!\*

Faith Lutheran Church, 1000 Tates Creek Rd., Lexington

This group is for families who have a child with Down syndrome between the ages of 0-5 years old. Siblings and grandparents are welcome. Childcare provided. Contact Michelle @ 859-223-4207 or [mandmgilliam@windstream.net](mailto:mandmgilliam@windstream.net)

**January 9th:** Angela Folczyk, OTR/L, will be discussing occupational therapy for our children.

**February 13:** We will view "Megan's Story", a documentary about Megan McCormick which highlights her educational path ( which now includes college!) There will be a discussion afterward with the McCormicks.

### ELEMENTARY GROUP

You are invited to join the 0-5 group parents on **February 13!** Please let Michelle know if you will be coming. Information about other events will be emailed to you. Contact DSACK with any questions.

### PEER PRESENTATION TRAINING SESSION

**Saturday, January 23rd** from 9:00-11:00a.m. Location will be determined by the number of people who sign up to attend! If you have questions or plan to attend, contact Traci at 859-494-7809 or Courtney at 859-879-2182

### A.I.M. (ADVOCATES IN MOTION) YOUNG ADULT GROUP

#### January 24th

UK women's basketball team vs. Auburn University at Memorial Coliseum at 2pm. Tickets are \$2 for anyone under 18 and \$5 for adults. We will meet at Memorial Coliseum at 1:30pm.

#### February 20th from 6-8:30pm

Pizza and movie night at Drew Janoski's house

RSVP to Brooke Reed by February 17th so we know how much pizza to order.

### SIBLING GROUP

**January 30,** 2:00 p.m. Initial meeting for DSACK siblings ages 8-12. Rebecca Smith plans for this to be a fun time of getting to know each other.

RSVP to 859-494-7809 if you would like to come!

### DSACK MOM'S NIGHT OUT

**January 25.** Mad Potter on Monday, **January 25th** from 6:00-9. RSVP by January 22 to Eileen Miot 859-340-2771 or [erwky@yahoo.com](mailto:erwky@yahoo.com) (see page 3 for details)

## SUBMISSIONS

**Do you** want to submit information for inclusion in the next DSACK newsletter?

**Submission deadline** is **Wednesday, February 17th** and can be sent to Courtney Elbert at [celbert@roadrunner.com](mailto:celbert@roadrunner.com)

**Send DSACK pictures** of your family member who has T21 to be included in the banner of the newsletter. Digital photos only. Photos should be of individual alone – head and shoulders preferred.

**Do you...** \* Have an interest in placing an add in our newsletter?

\* Want to receive the newsletter by email instead of through regular mail to save DSACK mailing costs?

\* Know someone who might like to receive our newsletter?

If so, please contact Courtney Elbert at (859) 879-2182 or [celbert@roadrunner.com](mailto:celbert@roadrunner.com)

*Let's get the word out about DSACK and our loved ones with Down syndrome who are beautiful, capable and loved!*