

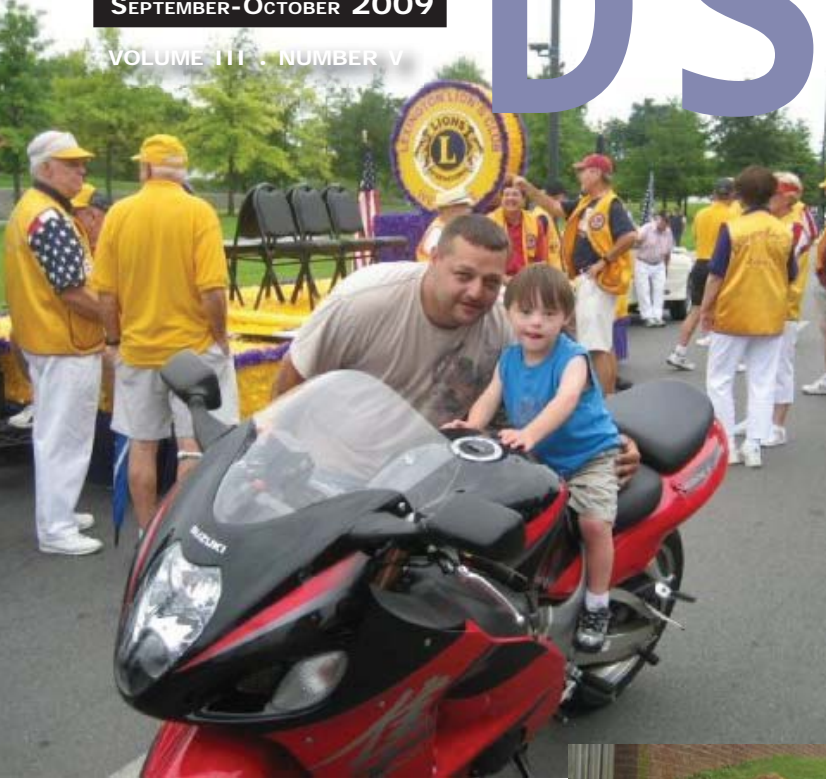


Beautiful Capable Loved

# DSACK

SEPTEMBER-OCTOBER 2009

VOLUME III NUMBER V



*see what a motorcycle poker ride and an inspired father have in common, story on page 4 & 5*

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## OUR VISION

**DSACK** celebrates that ALL people are beautiful, capable and loved.

## OUR MISSION

**DSACK** exists to: Celebrate our Down syndrome community  
Support individuals in Central Kentucky with Down syndrome and their families  
Educate the Central Kentucky community & Assist in local and national research efforts

## NEWS FROM THE BOARD

### Welcome Aboard New Board Members!

**Belva Collins? Harold Kleinert? Samantha Matthews? Brooke Reed? Who are these people?**

*Submitted by Traci Brewer*

These are four of DSACK's dedicated and hard-working Board Directors. I wanted to introduce them to everyone, so that you will recognize them next time you see them at a DSACK event. Make sure you pat them on the back and thank them for their advice, time and commitment to DSACK. I'm sure as you read their bio, you will be extremely impressed and understand why DSACK is so fortunate to have such outstanding individuals on our board.

**Belva Collins:** Earned her doctorate in severe disabilities from the University of Kentucky where she is currently a professor in the Department of Special Education and Rehabilitation Counseling and prepares teachers in the Moderate and Severe Disabilities program. Dr. Collins grew up in Harlan County, Kentucky, and later taught special education in rural Southwest Virginia. Her research interests include rural special education personnel preparation, systematic functional instruction for students with moderate and severe disabilities, and inclusion of people with disabilities in their faith communities. Dr. Collins regularly publishes and presents on these topics and is the author of a text, *Moderate and Severe Disabilities that focuses on best practices across the life span*. A former chair of the American Council on Rural Special Education, she now serves as editor of their journal, *Rural Special Education Quarterly*. Dr. Collins began serving on the board of the Down Syndrome Association of Central Kentucky in 2007. She also has organized and serves as chair of a committee on religious inclusion at Second Presbyterian Church in Lexington. Thank you, Belva, for your professionalism and passion for DSACK.

**Harold Kleinert:** Currently is the Executive Director of the Human Development Institute – University Center for Excellence in Developmental Disabilities Education, Research, and Service at the University of Kentucky. He has directed a broad range of federally funded demonstration and research projects, especially in the area of education of children and youth with severe disabilities, including research focused on alternate assessment, peer tutoring, and service learning for students with developmental disabilities.

Most recently, he has led projects designed to teach physicians, as well as medical, dental, nursing, and physician assistant students, how to provide high quality care to patients with developmental disabilities. His work with *Brighter Tomorrows* is designed to enable physicians to provide prenatal and newborn diagnoses of Down syndrome to patients with supportive, accurate, and up-to-date information. *Brighter Tomorrows*, developed in collaboration with families from DSACK and UK physicians, has also produced a Family Version (available in both English and Spanish) to support

families at this critical juncture in their lives. Harold has been involved with DSACK since 2002, when recruited by Karen Boudreaux, and he was DSACK's first recipient of the Karen Boudreaux "Something Extra Award". His unwavering commitment and expert advice have been invaluable to us.

**Samantha Matthews:** A certified MSD teacher, Samantha is currently employed with Jessamine County Schools as a special education teacher at Nicholasville Elementary. Samantha has designed and conducted various staff workshops for training on CBI, special needs, volunteer opportunities, Edmark reading program, data collection procedures and Safe Crisis Management. Her professional development includes Response to Intervention, Autism and PDD, Developmental Delays, Alternate Portfolio and Attainment Tasks, Alternate Portfolio Scoring, Safe Crisis Management, Occupational Therapy Integration in the Special Needs Classroom, and Sign language for Kids. She has been involved in several volunteer activities including the DSACK Buddy Walk, Lions Run for Sight, GRADSA picnic, Missing Piece March for Autism, and the Special Olympics Polar Bear Plunge. Samantha "Sam" is brand new to our Board and brings with her a bundle of energy and a ton of enthusiasm!

**Brooke Reed:** Currently working on her doctorate in school psychology at the University of Kentucky. She holds a Graduate Certificate in Developmental Disabilities, M.S. in Educational and Counseling Psychology, and a B.A. in Psychology, Summa Cum Laude. Brooke has been a research assistant for the Collaborative Center for Literacy Development, University of Kentucky; teaching assistant for the Department of Educational, Counseling, & School Psychology, University of Kentucky; teaching assistant for Department of Psychology, University of Kentucky; Intern at World Food Programme, Walk the World Division, Rome, Italy; and a camp counselor at Urban Promise Ministries, Camden, NJ. Some of her professional development includes: Effective School Age Inclusion of Exceptional Children, Assistive Technology, *Brighter Tomorrows: Training to Deliver Prenatal and Newborn Diagnoses of Down Syndrome*, *The Role of Play in Children's Development*, *Response to Intervention Training*, and National Association of School Psychologists Annual Conference.

Brooke started with DSACK as a practicum student to establish our teen/young adult social group, which is currently meeting monthly and continues to grow. When her practicum was completed, she continued volunteering with DSACK in many different areas including the Buddy Walk. She is also brand new to our Board, and we are so delighted to have her!

*DSACK new Board Directors*



## LOCAL NEWS TO USE

### YMCA & Miracle League

#### Offers much more than Baseball!

Did you know that the YMCA & Miracle League offer much more than Baseball?! The Miracle League just kicked off its fall season this September. Did you know there are many other opportunities for involvement offered through Scott County YMCA and the Miracle League's Executive Director, Kevin Haury? Below are a few other sports and recreation activities being offered in Lexington for children with special needs.

For more information on these programs, please check the Toyota Bluegrass Miracle League website at [www.bluegrassmiracleleague.org](http://www.bluegrassmiracleleague.org) or the YMCA of Central KY website at [www.ymcaofcentralky.org](http://www.ymcaofcentralky.org). You may also contact Kevin Haury via phone: 502-863-4841 or via email: [khaury@ymcaofcentralky.org](mailto:khaury@ymcaofcentralky.org)

#### First Score Flag Football

First Score Flag Football is a football league for children with special-needs age 5-19. The league is a 5 on 5 non-contact program utilizing rules adapted from the popular NFL Flag Football Program. Players receive a reversible NFL team jersey. Games are played on Sunday afternoons at the University of Kentucky Seaton Center indoors from October 11 to November 15. Cost is \$50 per player.

#### Adapted Musikgarten

Musikgarten is a music and gross motor movement class very similar to the kindermusik program. This adapted program is designed for children 5-8 and is held at On The Move Pediatric Therapy on Tuesdays from 6-6:45 pm tentatively beginning September 15 thru November 17. Class size is limited to 6 participants. Cost is \$85 per participant per session.

#### Get Moving Wellness

Our newest program! Get Moving Wellness is a special-needs wellness class designed around the idea of keeping children with special-needs active in a gym setting. Participants will participate in stretching, light aerobics, games and core training aimed at keeping there children 8-19 active and healthy. It will be held at the North Lexington YMCA on Thursdays from 6:00-6:45 pm. This class begins September 17 and runs through October 22. A second session is tentatively scheduled from November 5 through December 17. Class size is limited to 20 participants per session. Cost is \$50 per session.

### Lexington Parks & Recreation Therapeutic Programs

#### Offers numerous recreational activities!

Lexington Parks and Recreation Therapeutic Programs offer numerous recreational activities for people with special needs. For more information about any of these programs, please call Brent Claiborne with Parks and Recreation at (859) 288-2908. Even if you do not plan to participate now, perhaps sign up for their notifications and schedule and such.

#### Adapted Aquatics

Beaumont Family YMCA  
Mondays (3:30pm-5:30pm)  
Dates: September 14-November 2

#### Bowling

Eastland Bowling Lanes  
Saturdays (beginning in September)

#### Drama

October 14-November 18  
Bell House  
13 years old and up

#### Fall Dance

Tates Creek Recreation Center  
October 23 (6:00 pm - 9:00 pm)

#### Holiday Dinner/Dance

Tates Creek Recreation Center - December 12

## DONATIONS RECEIVED

Thank you to **Dr. Czar Crofcheck** for her in-kind donation of a blackberry phone for DSACK's use!

DSACK received a very special donation and note from a very special friend and local author with national acclaim. DSACK would like to extend an enormous "Thank you" to **Kim Edwards**, author of *The Memory Keeper's Daughter*. DSACK has included her note below, and we are honored to receive her support.

*Dear Friends,*

*I am very happy to enclose [a generous donation] to the Down Syndrome Association of Central Kentucky in support of your fine work.*

*This gift comes with my thanks to the members of your organization who gave so generously of their time and wisdom as I was researching *The Memory Keeper's Daughter*. This was a novel I had never intended to write, in part because I knew so little about Down syndrome when I was given the idea for this book by my pastor. Though I read a great deal to educate myself, the one-on-one conversations with DSACK members really deepened my insights into the joys and complexities of loving a person who has Down syndrome. *The Memory Keeper's Daughter* has now been translated into almost 40 languages.*

*I have given to the National Down Syndrome Congress in support of their "We're More Alike than Different" campaign, and I'm delighted also to support your fine work in Central Kentucky.*

*Sincerely, Kim Edwards*

## WHO ARE WE?

### 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*

### 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 OFFICERS

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

## BIG BLUE BEACH BLAST!

**Please join us!**

DSACK is excited to announce that Annette Jett and Frank Bickel of "Franky and Annette's" have chosen DSACK as a recipient of the proceeds raised at their upcoming FUN community event! They are hosting a "Big Blue Beach Blast" and fundraiser in which partial proceeds will benefit DSACK. We are asking DSACK to help spread the word about this event AND show our appreciation to Franky and Annette's. DSACK will have an informational booth set up at the Big Blue Beach Blast, and we encourage DSACK members to attend this event! Annette and Frank plan to make this an annual event, so let's support them as they reach out to support us! Partnerships like this allow DSACK to unite with our local community in spreading the word that people with Down syndrome are beautiful, capable and loved! See you at the Beach Blast!

PLEASE JOIN US  
SATURDAY, SEPTEMBER 19TH  
4 O'CLOCK P.M. AFTER THE UK-UL FOOTBALL GAME  
FRANKY & ANNETTE'S RESORT STYLE RESTAURANT  
AT THE SIGNATURE CLUB OF LANSDOWNE  
3256 LANSDOWNE DRIVE, LEXINGTON, KY



## Big Blue Beach Blast

PARTIAL PROCEEDS BENEFITING  
SPECIAL NEEDS CHILDREN'S CHARITIES  
RIGHT AFTER THE KENTUCKY - LOUISVILLE FOOTBALL GAME

### Live Music Line Up

**Featuring:**  
CONCH REPUBLIC 4PM-8PM  
JESSIE ROSE PENNINGTON AND CORY CROSS 8PM-9PM

AT 9:30 MOVE INSIDE AND DANCE TO  
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**EXTRA POINT PACKAGE \$15.00**  
ADMISSION TO THE BANDS AND CASH BAR ONLY



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## Paradise Cycles hosts Buddy Ride for DSACK!

**Grand Reopening promoting DSACK...**

Mike Lear's Motorcycle club joined DSACK in this year's July 4th parade. The motorcycle riders had so much fun, that Travis Teachy, owner of Paradise Cycles, decided to donate the proceeds of his Buddy Ride to DSACK! So, on August 15th, Paradise Cycles hosted a grand reopening with DSACK to promote awareness of the upcoming Buddy Walk on October 3, 2009 at Keeneland. Mike and Travis were instrumental in the planning and execution of the Buddy Ride, and numerous others offered time, talent and donations! Trisha and Thomas Spiller donated the food. An unbelievable amount of individuals and businesses donated other items for the raffle. Many DSACK families and friends came out to support Paradise Cycles, as they supported DSACK. The Buddy Ride was a huge success, and numerous DSACK families were honored and humbled at such a generous and thoughtful gesture...and also enjoyed getting our pictures taken on the motorcycles and jamming with the DJ. This event was not only about raising money, but about building community. Our community and the community of Paradise Cycles joined together to make this a fun filled day. This event not only raised awareness of the Buddy Walk, it built friendships and connections that DSACK hopes to keep in the

future. Thank you Paradise Cycles for this year's Poker Ride and we look forward to future Rides together!! Best wishes with your business from DSACK! Be sure to patronize our friends at Paradise Cycles for your motorcycle needs, and Thomas Spiller for your plumbing needs.

Mike shares his personal story about being Kaden's Dad on the next page. Thank you, Mike and Karen! What special people you are! DSACK appreciates you and your children who are beautiful, capable and loved!



Mike & Kaden



Buddy Ride 2009

Being a Dad

On Christmas Eve 2004, we finished opening gifts with family and were just sitting around talking. Out of the blue Karen made a remark about her stomach feeling weird. Joking around, as I always do, I made the comment of "Oh my goodness, your pregnant". We all laughed and carried on with the night. A couple of days later we were out grocery shopping and Karen again mentioned that she still wasn't feeling quite right, so we purchased a pregnancy test. We went home she took the test and immediately started talking about names. We were excited. This would be our first child together. The next few months were typical: doctors appointments, bouts of nausea, weird cravings and mood swings (at least that's what she called them). Then one day at a routine doctor's appointment it all started, trips to the high risk doctors, this test and that test and all along every possible scenario going through our heads. All the tests came out fine; the only thing we were told was he had a short femur bone, and even the high risk doctor stated "no biggie, neither of you are tall, he is just a short baby". By this time Karen is 34 weeks pregnant and we were at yet another doctor's appointment. We pretty much lived there. After doing our routine non stress test we were told Karen was being admitted to the hospital for what could possibly be for the rest of the pregnancy. The baby's heart rate was non reactive and not reassuring. After a week in the hospital and an amniocentesis to determine lung maturity, our OB decides its time for Kaden to enter this world. She feels he will be better out than in, since he wasn't tolerating it very well. The next day, July 28th, 2005 Karen was scheduled for a c-section. We were taken to this tiny room to wait for "our turn". At about 2pm they came and got Karen, took her back to the OR, up on the table, started prepping her and next thing we knew she was back in the room waiting again. We had been bumped for an emergency that had come in. About 2 hours passed and again it was our time. About 45 minutes pass and they finally come to get me so I can go back with her. After about 30 minutes he is here, all 4lbs 10oz. I am counting fingers and toes, eyes, limbs, the whole nine yards. He is screaming and everything is good. Happy Birthday Kaden Michael! We are then brought into our room where we will stay until we go home. About 2 hours have passed and they bring Kaden in. Karen is still rather groggy and slightly ill from the anesthesia, so I get to hold him first (as if I wasn't going to anyway). I know what it is like to hold a newborn, I had done it with my daughter, but something was different. He was so peaceful, it was like "life" was lifted off my chest and when he looked at me it was almost like he was trying to tell me something. Looking back, it was as if he was telling me everything was going to be

OK. Suddenly a group of people come into our room and just begin with "we think your baby has Down Syndrome". She then begins telling us about "our options". I have never wanted to hurt someone so bad, how dare they speak of my sweet baby that way. I proceeded to inform her that our only OPTION was to take him home, love him and raise him the best way we could; he was our son and he was not disposable. They told us he probably wouldn't walk until he was 7 or 8 (he was 1 1/2), possibly wouldn't talk until about 12 (he hasn't quit since he was a little over 2). Kaden can do anything he puts his mind to, and most of the time he tries things he probably shouldn't (you can thank his big brother for that). He is all boy and has many interests like tools, building, singing, dancing and motorcycles (he is Daddy's boy). Still to this day I can hold him and he just lays and stares up at me the way he has done since day one and all my stress and cares of the day seem to go away. I truly feel that he was sent to us for a reason and it gives me great honor to call myself Kaden's dad.



Dixie & Olivia Miller  
Kaden & Karen Lear



Sam Elbert, Sam Matthews,  
Kaden Lear



Kaden



Conor Healy & Emily Brewer



Mike, Karen, Kaden, Karson & Parker

## BUDDY WALK 2009!



### Buddy Walk News

#### Last opportunity to secure sponsorships!!!

This is our last opportunity to secure sponsorships for the Buddy Walk. If you know of any business that may want to sponsor the walk, let us know! We have letters and brochures already printed, and your personal connection will help secure sponsorships!!

The sponsorships will count towards your team's total. Please let us know any sponsorships that you secure so that we can make sure that they get all of the benefits! Go to [www.dsack.org](http://www.dsack.org) to print out a sponsorship brochure. Remember to ask businesses that you patronize every day!! The most they can say is no!!

#### Teams on the move

Watch out everyone...Marching for Mattie has already raised over \$3000, Megan's Team, Emily's team and Marie Claire's Miracle Makers, Team Tori and Trey's Troop are coming up close, with over \$1000 in donations. If you are not starting/joining a team, think about joining Amanda Jone's team! Her company National City Bank (Now a part of PNC), is going to match their sponsorships! This year we are going to award prizes in three categories! The prize will go to the team leader, or person, that achieves these goals; Most money raised, Largest team, and most creative sign. Each team can only win one prize, so if one team achieves two goals, second in line will get the prize!!

#### Thank you!!

Thank you everyone that has registered on line already! With just 9 active teams, we have already raised over \$15,000 and counting! Ten more teams have registered and are in the process of raising money. That does not include our sponsorships which is also over \$11,000!! Keep it coming!!

### On-Line Registration

Registering on line is as easy as 1,2,3! Just go to [www.dsack.org](http://www.dsack.org) and click on "register here". This will bring up our Buddy Walk page, and you can take it from there! Call Regina at 859-983-3754 if you need ANY help or have ANY questions! If you would like to print out registrations go to [www.dsack.org](http://www.dsack.org). If you would like to have registration hard copies mailed to you, email [remicale2@aol.com](mailto:remicale2@aol.com) or call 859-983-3754.

### Buddy Walk T-shirt Pick UP!

Buddy Walk T-shirt pick-up will take place on Thursday, October 1 from 12noon - 7pm. Stop by KFW (Kentucky Furniture Warehouse) to pick up T-shirts for you and your team, and to receive any last minute details and information about the big celebration! If you are not able to stop by on the 1st, then you may pick up your T-shirts at the T-Shirt Table the morning of the Buddy Walk.

KFW is located at 136 Commerce Drive, Nicholasville. Directions: Go south on Nicholasville Road towards Nicholasville. Once you cross over Man O War, go to the 5th traffic light (past Brannon Crossing). Kohls is on your right and KIA on your left. Turn left at the KIA onto Commerce Drive. KFW is 500 yards down on the right hand side. Look for a big warehouse that says KFW.

DSACK still needs volunteers to work 2 hours shifts beginning at 11:30am to work this pick up. For more information, contact Regina @ (859) 983-3754!

### Silent Auction and Door Prizes

*(Submitted by Amanda K Jones, Raffle/Auction Committee Chair)*

This year we will be added an exciting raffle to our Walk. Each walker will receive a free ticket with their registration to drop in the raffle box item of their choice. Different prizes will be available to suit all ages. In addition, we will be selling additional tickets so you can have even more chances for these great prizes. As a special bonus, we will have a few select items that will be auctioned in silent auction style. We will be posting these items on our website so you can start dreaming about them!



### Brand new baby boy in Lexington!!

*(submitted by Hudson's proud Grandfather, Brad Harris)*

Grandfather Brad Harris is delighted to announce that he has a brand new grandson, Hudson Harris, born July 27th at St. Joseph East hospital in Lexington, Kentucky.

"He weighed in at 9 lbs 7 ounces, so we immediately decided to appoint him Vice President in charge of Poopie Diapers!"

Hudson will have to get written permission from his mother and father: Bo and Geneva Harris of Lexington. They have already created the most delightful website for Hudson at <http://boandgeneva.blogspot.com>.

Brad said: "If you go to that internet location you will be delighted to find the most charming baby delivery photo-show created by their friend Kristin Tatem!"

Grandpa Brad went on to say, "We are delighted with the help and support we have already received from DSACK, particularly from Regina Schmutte and Michelle Gilliam. They immediately invited me to a wonderful meeting conducted by a gifted speaker Nicole T. Maher and her daughter, Darrah."

"I also enjoyed learning about all the networking and resources from people I met at the Buddy Ride - especially Lee Ann Mullis and Eileen Miot. I am looking forward to my children becoming a part of your network of friends and loved ones."

We are very pleased and excited to have so many sponsors and participants willing to help out with such a great cause. Helping these children is something that Central Kentucky takes seriously. A testament to that is such a wonderful list of donations that have been given to support our auctions. Some of the many items include overnight stays at the Hilton and Hyatt Regency in Lexington, dinner and overnight stay at the Horseshoe Casing (Caesars Indiana), handmade jewelry by Lynn Miles, a gift basket from Maker's Mark, a matted horse print from the Pyramid Society, tickets to the Lexington Children's Theatre, and great food from Malone's!

We are looking for more in-kind donations. Anyone that can assist with this would be greatly appreciated. Just ask a local business that you frequent. Most will say yes to an in-kind donation! Email Regina for the in-kind donation form! Remicale2@aol.com

With contributions still coming in, we look forward to a day of fun, celebration, and promoting awareness.

### Buddy Walk Fun!

*(Submitted by Tracy Durham-Beall, Entertainment Committee Chair)*

This year's Buddy Walk promises to hold lots of fun and entertainment for all participants. Along with a variety of musical acts, there will be a DJ to keep the fun rolling throughout the walk. Rosie's Ponies has enthusiastically offered a petting zoo with a variety of farm animals, which was a big hit at last year's Buddy Walk. Inflatables, generously provided by Party Right Productions, will get the kids bouncing again this year. Capturing the essence of the event in pictures requires a professional with a heart for children, which we found in Karen Russell of Karen Russell Productions. A children's event just isn't an event without face painting, tattoos, and balloons donated by Oogles and Goggles. In addition to the above mentioned, there will be lots of other participants and donors that will help keep the day eventful. WTVQ, who is promoting the walk, will also be doing live coverage of the event that day. So, get your new walking shoes on as we make steps toward a brighter tomorrow!

### Great Ideas!

We will have a meeting place for teams this year! If you have over 25 walkers registered on line, there will be a designated "team meeting place" We will have a visible place for your banner, so that all of your participants can find you!

An idea from an experienced walker, Traci Brewer, is to bring a folding chair with you, that way you will always find a place to sit!

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### Big steps for little feet

*(submitted by Eileen Miot, proud mother of Marie-Claire)*

Marie-Claire Miot and Joella Mullis took a big step towards their independence last week. You see, on Aug 13 Joella and Marie-Claire had their first day of school at Providence Montessori. First steps are sometimes more challenging for Mommy's and Daddy's than for our little ones.

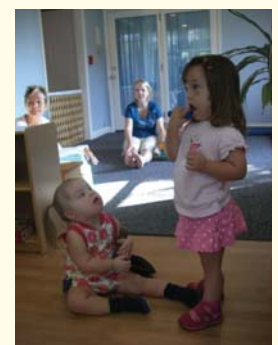
Letting go is never easy and is clearly a challenge for parents of typical children...but should it be so much more challenging for us with children with Down syndrome?

The girls did awesome on their first and second days! How do I know, you may wonder? Well, Lee Ann and I stayed the entire time. We were the only parents that did. Not sure why the others didn't?!? We stayed because we didn't want to miss the girls chatting with new friends, playing with peers, interacting within their new environment. We were mesmerized!

On day three we left them with four nurturing teachers. The only tears shed were by the mama's - not because it was really that hard letting go but because we were so very proud of our Big Girls.



### CELEBRATIONS!



## 2ND SATURDAY NEW PARENT GROUP

## "Keeping the Faith" with Scott Mandl

### What DSACK's New Parent Group Means to Me

**...every time I spoke with her I felt more at peace**

*(submitted by Eileen Miot)*

I have been blessed in countless ways by being involved with DSACK, specifically the 2nd Saturday New Parent Group for parents and their children ages 0-5. This group is full of people who are so generous with their time, knowledge and love. My relationship with DSACK started before I moved back to Paris, KY from Cebu, Philippines.

We were living in the Philippines away from family and friends when I had Marie-Claire. When she was diagnosed with Down syndrome I was searching for Mama's to connect with that could mentor me through the process. I found that in the DSACK 0-5 group.

I received Courtney Elbert's number from a mutual friend. I can't tell you how many times I called her for guidance and encouragement. Every time I spoke with her I felt more at peace. I started emailing other members, thanks to Courtney.

On at trip home, we attended a DSACK 0-5 meeting in which Nicole Maher was the speaker. I don't remember exactly what she said, but I do remember how I felt after she spoke. I was on fire! I needed to meet her amazing family. I needed Herve to meet Joe...I needed her faith, enthusiasm and peace to erase some of my fears and concerns. All of my needs were met when Courtney arranged for all of us to have a play date at her place.

Before we moved back to Paris, KY I once again reached out to DSACK 0-5 group members. I needed to learn the First Steps system, and who were good therapist and doctors to see. Once again, DSACK came to my aid.

Since moving back, we have attended many phenomenal meetings. Marie-Claire and Sebastien have a great time playing with their friends. Herve and I have a new extended family in which we can call on and share this beautiful journey. Thank you all!

**...a source of both wisdom and encouragement.**

"Why did our child have Downs? How can we know we are doing all we should for our child? How will our child make it through adulthood? How will we make it through this week!?"

Radio Shack says: "You've got questions, we've got answers!" While the Bible doesn't offer easy answers for everything, it can be a source of both wisdom and encouragement.

On November 14th, DSACK Dad Scott Mandl will be sharing how faith has helped his family on their journey with Megan, and how God can play an important role in your family as you deal with the many challenges and blessings of being a "Downs parent". This will be during the 0-5 parent meeting at Faith Lutheran Church, 9-11 a.m. but anyone from DSACK is welcome to attend.

A former journalist and associate minister, Scott is currently Executive Director of Christian Flights International, a Richmond-based mission to Haiti. He and Mary have two beautiful, capable and loved daughters, Tracy, 5, and Megan, 2.



## NATIONAL & INTERNATIONAL NEWS TO USE

### Toys R Us' annual "Toy Guide for Differently-Abled Kids"

Already thinking about Christmas presents? Check out Toys R Us' annual "Toy Guide for Differently-Abled Kids" for ideas. The guide is organized by skills such as fine motor, gross motor, tactile, social skills, etc. You can find it online at: <http://www.toysrus.com/shop/index.jsp?categoryId=326168>

## CELEBRATIONS!



Congratulations to **Kent Wallace** (age 8 years old) who was honored to be in his sister's wedding. What an incredibly handsome Junior Groomsman!

Congratulations to **Alex Greene** who recently celebrated his First Birthday!



## ELEMENTARY GROUP

### Off to a Great Start!

Thank you for helping us get this group off the ground.

*(submitted by Megan Thomas)*

The DSACK Elementary Group is off to a great start! Ashleigh Gray and I, both School Psychology graduate students at UK, have had so much fun planning events and getting to know our kids. Our first group session was held at the Brewer family home, and we all had a blast enjoying the pizza, movie, karaoke machine, and great company. For our second group session, we visited Fire Station #20 to meet the firemen, tour the fire trucks, and learn about fire safety. It was so fun to see our kids interact with the firemen, and I think we all had a great time! Afterwards, we all went to Graeter's for ice cream!



## AIM (ADVOCATES IN MOTION)

### Become a Leader!

#### lead the Buddy Walk!

Are you a teen or young adult with Down syndrome? Do you like being the "star" of the show? Then DSACK has big plans for you at the Buddy Walk! Members of Brooke's group, Advocates In Motion, will be driven around Keeneland in a limousine at 9:30 a.m., and will then be let out at the starting line to lead the Buddy Walk as a group. You will also receive a specially-designed T-shirt to wear, identifying you as a member of Advocates In Motion. If you would like to participate, you MUST reply to Regina Schmutte by Sept. 15th to assure a spot in the limo and a T-shirt in your size. Don't miss out on this fun part of the Buddy Walk - we really want you there! Contact Regina at (859) 983-3754 or Remicale2@aol.com.

#### ARC offers Leadership Training

The Arc of Kentucky is accepting applications for its 2009-2010 Advocates in Action/Self-Determination Leadership Training Academy. This training program is designed to train individuals with disabilities, family members, siblings of family members with disabilities, or professionals working with people with disabilities to be independent and to be the strongest advocate and self-advocate that they can be. It will provide state-of-the-art knowledge about issues relating to developmental disabilities and build competencies necessary for Advocates in Action participants to become advocates who can effectively influence public policy.

The Advocates in Action Leadership Academy will include two 2-day training events to be held in Frankfort. The first session will be November 13-14; the second one will be held in February, 2010. Participants will also have the opportunity to attend The Arc of Kentucky's Annual Conference on April 23-24, 2010 in Louisville. Travel expenses for lodging, mileage, meals, respite care and support services for program participants will be reimbursed according to individual needs.

If you have any questions or need additional information, please contact: Patty Dempsey/Linda Wainscott @ The Arc of Kentucky

(502) 875-5225 or (800) 281-1272

Congratulations to **Sam Elbert** who started kindergarten at St. Leo Catholic School thanks to the support of their newly established SPICE Program (Special People in Catholic Education). The Elberts are hard at work raising funds and awareness to support this new effort, and hope it sets a precedent for other private and/or religious schools.



## REACHING OUT TO SUPPORT RESEARCH

**Literacy Development Program****therapy & research that benefits our loved ones***(submitted by Donna Horn)*

DSACK would like to thank Donna Horn for investing her time and expertise in offering incredible therapy and research that benefits our loved ones through the quality therapy received through Horn Richardson and Associates. Thank you for believing that our loved ones with Down syndrome are indeed beautiful, capable and loved. Thanks to you and your staff for cherishing our loved ones exactly as they are, and supporting them in their individual development. Thanks for being our companions on this journey.

Donna G. Horn, M.S., CCC, Ph.D.

Horn, Richardson and Associates

2412 Greatstone Point

Lexington, KY 40504

Early literacy instruction is mandated across preschool programs, yet the nature of this instruction and the incorporation of appropriate daily and home instruction is often poorly or minimally addressed. The purpose of this group program is to increase literacy skills in young children with Down's Syndrome through the use of a well developed early literacy program in a small group, therapy program. The secondary purpose of this group is to include young adults with well developed reading skills and Down's Syndrome as group instructors. It is felt that this inclusion will both encourage abstract problem solving skills in young adults, but that the young adults will in turn, be inspirational in a population of young children and their families.

Systematic and Engaging Early Literacy Instruction (SEEL, Culatta, 2009) is a language and literacy project conducted across preschool and kindergarten classes including Head Start and Title I classrooms. Children with language delays or differences are exposed to salient examples of literacy targets in engaging activities. Instruction occurs in thematic units that support phonological and print awareness and comprehension and vocabulary skills. Instructors highlight targets as they interact in play and class routines. SEEL has been highly effective in improving early literacy skills. Engaging activities, fit within authentic context, permit instructors to control children's exposure to targets and keep them motivated.

**Introduction**

There is an ongoing current debate regarding types of reading instruction (see Kahmi, 2009 for thorough review). Combining instructional techniques may continue to be the most effective way to teach literacy skills (NIH Reading panel, 2000). Researchers have recommended that reading instruction for children at risk for literacy learning problems be systematic, engaging, and interactive (Lyon, 2000; Sweet and Snow, 2003; Justice and Kaderavek, 2004). Psychologists further add that there are basic principles in theories of learning that all teaching needs to incorporate (Pashler et al, 2007, IES, Grasser, 2009). These principles include the need to space learning over time, use multiple ways (as opposed to just verbal) to present concepts, connect and integrate abstract and concrete representation of concepts, and ask deep, explanatory questions. These basic principles must be used as we teach literacy, even within early literacy programs.

Children with Down syndrome are quite capable of learning to read, but often lack systematic instruction, and/or reading goals are secondary ones on their IEPs. Early literacy goals, although required for children enrolled in Early Start Programs, vary greatly both in their content, specificity, and success. Not all children even have phonological awareness goals as targets on their IEP's, and classroom instruction within inclusion may not include some of the basic psychological principles. Goetz et al (2008) document the effectiveness of training support staff to teach phonological awareness in an intensive program for children with DS. Clearly, children with DS benefit and need instruction from a very early age in literacy. Additionally, many of our young adults with DS are capable, effective readers who can offer supports and direct instruction for families and young children with DS.

The purpose of this program will be to use procedures designed to systematically teach key literacy skills-story comprehension, rhyming, alliteration, sound blending, and letter knowledge, letter-sound association and early phonics or decoding for diverse learners of later preschool and kindergarten age. The goals are:

1. to highlight specific literacy targets within an array of interactive and engaging activities,
2. to teach parents and caregivers the process of generalizing specific goals within their home environments, and
3. to provide a backdrop for young adults to learn the teaching process within early literacy while encouraging their own individual problem solving abilities.

## MAKING CONNECTIONS

**Dsack Mom's Night Out (DMNO)**

DSACK MOMs, Be sure to mark your calendar for future DMNO every 4th Monday of the month! There has been a great turn-out and we have had a great time! Thanks to Eileen for organizing DMNO!

Tonya Merritt (Mommy of Will) has graciously offered to host the first of many DMNO potlucks on September 28 at 7pm. Tonya picked Wine-Cheese-Dessert as the potluck theme of the night. Bring your favorite Red or White, Brie or Camembert, Cheese Cake or Fruit Plate.

Tonya's friend Dana Bernard will be selling Premiere Jewelry. Dana will donate 20% of the sales to DSACK! Tonya will also donate her hostess gifts to the Buddy Walk Auction. Thanks you two!!! Please bring your pocketbook, a friend and a dish to share to Tonya's home at 769 Willow Oak Circle, Lexington.

Lets all buy some new bling bling we can sport at the Buddy Walk!

Please RSVP to Eileen by September 24 with an idea of what you will share. (1-859-340-2771)

## Instructional Approach

Children will be seen in a small group setting, twice weekly in 1 ½ hour blocks, for 8 weeks, with no more than 5 children in a group, and one speech language pathologist and one instructor. A formal meeting will be held with parents before the group is initiated in which goals, teaching strategies and techniques, and required home involvement will be explained.

Children will be exposed to curriculum developed from the SEEL project and specifically adapted. Activity formats will include games, story enactments, play scripts, exploration of hands-on materials, interactive routines, cooking and the arts (movement, art, drama), or essentially the activities that make up later preschool and kindergarten programs.

To support story comprehension, story grammar elements will be highlighted during the dramatic telling and enacting of stories. Language demands will be altered and implicit information will be made salient and explicit. During story enactments, instructors and the Speech Language Pathologist will guide the children's participation and highlight important story information as they take on character roles and carry out story actions.

The major focus will always be, however, on increased phonological awareness and letter knowledge skills. To do such, instructors will expose children to targets as the children act on pros and materials. For example, to teach rhyming with 'ake', children will be exposed to 'ake' rhyme pairs as they participate in a story about a woman who bakes and decorates a cake. During the telling and enacting, the instructor will highlight rhyme pairs as the children plan the activity (make a cake), put ingredients in a bowl (take, shake in cake, and break), stir the ingredients (make the cake), put the cake in the oven (bake the cake), decorate the cake (make, flake, make snakes), eat and describe the actions (ate the cake, break the cake, take the cake) and clean up (rake the cake). At the kindergarten level, rhyming and alliteration will move to sound blending at the onset + rime level and to the reading of word family words. Decodable texts, based on children's experiences with hands-on activities will be read using shared reading supports.

Additionally, a young adult with well developed reading skills and a diagnosis of Down Syndrome will be used as an instructor, under the guidance of the speech/language pathologist. She will both act as an aid within the group and as a facilitator/instructor of early literacy skills. She will be given explicit training in the selection of curricular materials based on designated literacy targets, and in direct work with young children on those specific targets. She will be taught to model, demonstrate, and elicit specific language/literacy responses. Additionally, she will be taught initial data collection and analysis.

## Outcomes

Qualitative and quantitative analyses will be used to document children's engagement and participation in instruction, and actual progress in early literacy skills. Pre and post measures will be obtained, including language sampling with computerized scoring, pre-literacy and literacy direct measures. Family feedback regarding the success and suggested improvements will be solicited.

Families that are interested in participating can contact Donna Horn, M.S., CCC, Ph.D. at 224-4081.

## Parents, what do you think?

### about the efforts of your school district to promote and support parent involvement?

The Kentucky Department of Education, Division of Exceptional Children Services (KDE/DECS) has developed a survey to ask a random sample of parents whose children receive special education services about the efforts of their school district to promote and support parent involvement.

They have contracted with the Human Development Institute at the University of Kentucky (HDI/UK) to collect and analyze the results of the survey and to consult with them in regard to improving services to parents with disabilities.

The information from these surveys will help KDE/DECS identify and target specific training, services, and programs that may improve school facilitation of parent involvement. **The survey will be available on line August 21st.**

There are two options for completing the survey:

1. Complete the survey online by typing the following into your web browser: <http://tinyurl.com/KYParent> **OR**
2. Complete the paper survey you will receive in the mail (if you are in the random sample selected) and then return it in the enclosed envelope.

Thank you

## Emerging Issues & Trends

### affecting the Lives of People with Disabilities

The National Council on Disability (NCD) is gathering public input for a study of emerging issues and trends affecting the lives of people with disabilities. Information gathered will be used in the development of NCD's next annual progress report to the President and Congress, National Disability Policy: A Progress Report, which is required by Section 401(b) of the Rehabilitation Act of 1973. Please send your input by September 15, 2009. Comments can be emailed to [ncd@ncd.gov](mailto:ncd@ncd.gov). Type "Emerging Trends" in the subject line and ask for the link to the survey.

## WONDERFUL WEBSITES

<http://www.disability.gov/>

The U.S. Department of Labor has launched **Disability.gov**, a redesigned federal Web site that connects more than 50 million Americans with disabilities to thousands of trusted resources on disability-related issues, programs, and services. Formerly known as [DisabilityInfo.gov](http://DisabilityInfo.gov), the site has been redesigned and updated with new social media tools, such as a blog and a Twitter feed, to encourage feedback and interaction among visitors. [Disability.gov](http://Disability.gov) is not just for Americans with disabilities, but also for parents of children with disabilities, employers, workforce and human resource professionals, veterans, educators, caregivers, and many others.



Down Syndrome Association of Central Kentucky  
P.O. Box 910516  
Lexington, KY 40591-0516

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## CALENDAR

### 0-5 Parent Group & Playgroup

Saturday, September 12th, 9-11 a.m.

Faith Lutheran Church, 1000 Bates Creek Rd., Lex  
"Parent Roundtable" Submit topics you would like to  
share or have discussed to Michelle @ 859-223-4207  
or mandmgilliam@windstream.net

This group is for families who have a child with DS  
between the ages of 0-5. Siblings, grandparents  
welcome. Childcare provided.

### 0-5 Parent Group & Playgroup

Saturday, October 10, 9-11 a.m.

Faith Lutheran Church, 1000 Bates Creek Rd., Lex  
Jennifer Royalty, MS, RD,LD will discuss "Meeting the  
Challenges of Feeding Your Child" Jennifer worked  
for 15 years specifically with children who have  
special needs and has worked the last 4 years at UK  
in the neonatal intensive care unit. She will tailor her  
lecture to your interests - please submit topics/questions  
to Michelle ASAP. mandmgilliam@windstream.net or  
859-223-4207

### 0-5 Parent Group & Playgroup

Saturday, November 14th, 9-11 a.m.

Faith Lutheran Church, 1000 Bates Creek Rd., Lexington  
"Keeping the Faith" DSACK Dad Scott Mandl will share  
how faith has helped his family on their journey with  
Megan. More details on page 8.

### 0-5 Parent Group & Playgroup

December meeting is cancelled. We will see you at the  
Christmas Party instead!

### AIM Social Group (Formerly Teen/Young Adult Group)

For event information, contact Brooke @ 321-507-0332 or  
brooke.reed@uky.edu

### How To Enroll In a Medicaid Waiver Program

(open for all of DSACK!)

Saturday, November 7, 9:00

Faith Lutheran Church, 1000 Bates Creek Rd., Lexington  
Celeste Collins, BSW, Case Management Coordinator at  
Bluegrass Area Agency on Aging will discuss the 3 different  
Medicaid Waiver Programs and instructions on how to enroll.  
(If you previously were denied Medicaid for your child,  
attend this seminar and learn how you might do things  
differently next time. Also, learn what to do about therapies  
if your child is over 3 years old.)

### Elementary Social Group

For event information, contact DSACK @ 859-494-7809,  
or Megan at megan.kk.thomas@uky.edu or Ashleigh at  
Ashleigh.gray@uky.edu

### DSACK Mom's Night Out

Monday, September 28th, 7:00 p.m. @ Home of Tonya  
Merritt - 769 Willow Oak Circle in Lexington

Wine, Cheese & Dessert Potluck along with a Premiere  
Jewelry Party, 20% of proceeds (+ Tonya's hostess gifts)  
donated to DSACK! More details on page 10. RSVP to Eileen  
by Sept. 24th, 1-859-340-2771.

### DSACK Mom's Night Out

Monday, October 26th, 7:00 p.m.

Contact Eileen for details, 1-859-340-2771

### Buddy Walk Meetings

Tuesdays, September 15, 22, 29, 6:30 p.m.

Panera in Brannon Crossing, Nicholasville

These are organizational meetings to make this year's Buddy  
Walk the best ever. It is not too late to join us and lend a  
hand! Contact Regina at Remicale2@aol.com or 859-983-  
3754.

### Buddy Walk Registrations Due

Tuesday, September 25

This is the last day to register to be guaranteed a T-shirt. Mail forms to  
DSACK or give to Regina.

### Buddy Walk T-shirt Pick-Up

Thursday, October 1 from 12noon - 7pm

KFW (Kentucky Furniture Warehouse)

136 Commerce Drive, Nicholasville

Directions: Go south on Nicholasville Road towards Nicholasville. Once  
you cross over Man O War, go to the 5th traffic light (past Brannon  
Crossing). Kohls is on your right and KIA on your left. Turn left at the KIA  
onto Commerce Drive. KFW is 500 yards down on the right hand side.  
Look for a big warehouse that says KFW.

We need volunteers to work 2 hours shifts beginning at 11:30am to work  
this pick up. For more information, contact DSACK @ (859) 983-3754!

### BUDDY WALK

Saturday, October 3, 10:00 a.m. @ Keeneland Racetrack, Lexington

For more information, contact DSACK @ 859-494-7809 or visit [www.dsack.org](http://www.dsack.org)

### DSACK Board of Directors Meeting (Officers and Directors)

Monday, October 19th at 7:00 p.m. @ Bank of Lexington

### Lexington Parks and Recreation Therapeutic Program's

#### FALL DANCE Friday, October 23rd (6:00 pm - 9:00 pm)

Tates Creek Recreation Center

For information, call Brent Claiborne with Parks and Recreation at (859) 288-2908

### Lexington Parks and Recreation Therapeutic Program's HOLIDAY DINNER/DANCE

Saturday, December 12th @ Bates Creek Recreation Center

For information, call Brent Claiborne with Parks and Recreation at (859) 288-2908

### ARC of KY 55th Annual Conference

Friday and Saturday, April 23-24, 2010 @ Louisville Marriot East

Best Practices for People with Intellectual and/or Developmental

Disabilities & their Families

For more information, contact the ARC of KY @ 1-800-281-1272 or [www.arcofky.org](http://www.arcofky.org)

## SUBMISSIONS

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

**Submission deadline** is **Wednesday, October 22nd** 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 and 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!*