

DSACK

Down

Syndrome

Association of Central Kentucky



WHAT'S GOING DOWN WITH DSACK

VOLUME III – NUMBER I

JANUARY-FEBRUARY 2009

LOCAL NEWS TO USE

• DSACK THANKS BECKY LESCH FOR YEARS OF DEDICATION

The DSACK Community and the DSACK Executive Board is indebted to Executive Board Member, Becky Lesch. As of 2009, Becky has decided to step down from the Executive Board. Her years of service, dedication and perspective are treasured and will be missed. DSACK asked fellow Advisory Board member Caroline Baesler to write a few comments about Becky to capture the many ways in which Becky has offered of herself to the DSACK community. Caroline's article will be included in the next newsletter. Becky, we look forward to many more years of growth for DSACK with you on the Advisory Board. Thank you for your dedication.

• BECKY LESCH ENDS LONG TENURE ON EB

After more than 20 years of very active involvement, DSACK is sad to announce that Becky Lesch will be stepping down from the Executive Board. I had a chance to chat with Becky about her service and unwavering commitment to the Down syndrome community and here's what she had to say.

Although she wouldn't admit it, Becky is essentially one of the founders of DSACK. Becky's family moved to Lexington in the 1980's and at that time, she met a woman who had obtained a grant from the March of Dimes on behalf of a group called "BUDS" – Beginning to Understand Down Syndrome. When the other woman left town, Becky took over. At the time, Becky worked at the Child Development Center, which let BUDS use its space, and the group focused primarily on family support.

While at CDC, Becky met Meg Steinman (who should probably be considered the co-founder of the modern-day DSACK). For the next 10 to 15 years, Becky and Meg were the face of the Down syndrome support community. They were extremely involved in going to hospitals, ICU's, homes, and surrounding areas, with an emphasis on connecting with parents first receiving a diagnosis. They

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CALENDAR

EXECUTIVE BOARD MEMBERS

Traci Brewer	523-3902
Courtney Elbert	879-2182
Michelle Gilliam	223-4207
Malkanthie McCormick	273-0632
Regina Schmutte	983-3754

ADVISORY BOARD MEMBERS

Executive Committee members plus:

Caroline Boeh Baesler, Parent

Karen Roof Boudreaux, Parent

Sandra Brock, Cabinet for Health and Family Services, Executive Director of the Ombudsman

Carolyn Bay, M.D., Chief, Division of Clinical/Biochemical Genetics & Dysmorphology, Dept. of Pediatrics, UK

Belva Collins, Ed. D., UK Special Ed. Professor

Harold Kleinert, Ed.D., Exec. Dir. Of IHDI

Becky Lesch, Parent

Dixie Miller, Parent, Developmental Interventionist

John Riley, M.D., Pediatrician at PAA

Meg Steinman, Parent

camaraderie that results from finding others who can immediately relate to what you are going through (or will go through in the future). She also has enjoyed seeing how different people handle the challenge of Down syndrome and grow, and sharing the positive and uplifting moments with friends. While talking with Becky, her dedication to DSACK was obvious. She felt her work with DSACK was a great way to give back and “pay it forward” for all the support she had received in Wisconsin when her son, Paul, was born.

But for all she has given to DSACK, she still insists that she’s gotten more out of it, calling it almost a “selfish” thing. She surprised herself that she could do what she has done within DSACK – Becky said she’s never pictured herself as well-organized or “in charge of things, but more as a behind-the-scenes resource. But, despite this, she has been interviewed on television and by a best-selling author, has taken charge of major aspects of the Buddy Walk – things she said she never would have done before Paul.

When asked what challenges she sees ahead for DSACK, as is typical, she couched them in the positive. Now that DSACK has a healthy budget and so many energetic people involved, she feels it might be time to look at the group’s mission, with a focus on goal setting, and ask some tough questions. And because the need in outlying areas is so great, she hopes DSACK will try to get satellite groups going by giving guidance, meeting with them, and providing support in the form of time and commitment.

As for DSACK, Becky decided now was the right time for her and her family to rotate off the Executive Board. While other long-time EB left a while ago, she stayed on to be a “transitional” person, to provide institutional memory and guidance on what has been done or tried in the past. But she has new challenges at work, so she had to make some tough decisions. While her guidance and wisdom will be missed, I am positive that Becky will remain as committed as ever to the Down syndrome community. Thanks, Becky, for your years and years of contribution, hard work, and dedication. DSACK would not be what it is today without you.

• TREASURING OUR DSACK TREASURER

The DSACK Community and the DSACK Executive Board is indebted to our Treasurer, Ellen Fernandez. As of 2009, Ellen has decided to step down from her role as DSACK Treasurer in hopes of focusing more of her “spare time” and energy on the Arthritis

Foundation. In regards to her decision to step down from her role as treasurer, Ellen said, “I love DSACK - and I am so proud of what we have accomplished in the last few years, but I am going to turn my focus to the Arthritis Foundation - in hopes that they will find a cure for the disease that still determines my energy levels on a day to day basis.” Ellen’s sister Sue recently celebrated her 44th Birthday and has Down syndrome. Sue is in great health, in her 9th year working at McDonalds, cheerleading, playing Bocci for Special Olympics and has a key role in helping care for their father with Alzheimers. DSACK Executive Board asked fellow Advisory Board member and past President of DSACK, Karen Boudreaux, to write a few comments about Ellen to capture the spirit of Ellen’s dedication to DSACK. Ellen, thank you for your selfless dedication, consistency, perspective, organizational skills, and heart.

DSACK is currently seeking a replacement for Ellen’s role as Treasurer of DSACK. If you are interested in this volunteer position that is of vital importance to DSACK, please call DSACK at (859) 494-7809. We prefer someone with experience in finance, accounting, and/or book-keeping.

• ELLEN FERNANDEZ – ADVOCATE, FRIEND, AND NEIGHBOR

(submitted by Karen Boudreaux)

The first time I ever met Ellen, was at a neighborhood Bunco party with her infamous “Bunco Babe” sweatshirt on, that had been given to her by her mother. She was modeling the crown that would be given away at the end of the night to the lady with the best score. Additionally, she presented a selection of appetizers, desserts and drinks that could not be matched by any 5 star hotel. She and her mother-in-law are AMAZING cooks, and if you have ever been to her house, you will see the incredible collection of cookbooks that she has acquired over the years, and I am certain tried several recipes from all of them. She makes her guests most welcome and the only rule she has, is that you will have fun!

Over the years, Ellen has become more like a sister to me as well as a neighbor with all the projects we’ve been involved in, etc. Many of you do not know, but Ellen was the person that I sat down with at my kitchen table when we decided to create a plan for DSACK and write a grant for the Jr. League in 2002. I remember her drawing a crescent moon over the top of 3 categories,

identifying the different groups we would be trying to reach, namely, new families, existing families, and the community/medical at large. Then we designed a plan to do just that. We were just to a point of needing to expand and grow our efforts as we began to realize that more babies were being diagnosed and several were going home without being diagnosed, and without information. It’s not because we had not tried, in fact Becky and Meg carried books and information around in their cars at all times, scheduled meetings, picnics, parties, etc., but the backing of the community was just not there to the degree it was needed. We all agreed, something more needed to be done. That’s where Ellen came in and helped us write grants, design a plan and work the plan. Her business background from Lexmark and University of Rochester, has TRULY helped DSACK and the community at large. She has been a volunteer on the Executive, Advisory and Buddy Walk committees as well as Brighter Tomorrows project through UK. Her sister Sue, has Down syndrome and Ellen has been a terrific example of a loving sister and advocate as well.

She has been our Treasurer for the last few years and has done a FABULOUS JOB! We truly appreciate her efforts and will miss her. The time and energy commitment has been second to none. We love her and appreciate her immensely! Ellen, good luck and only the best!!

We love you,
Karen

• DSACK WELCOMES NEW EXECUTIVE BOARD MEMBER!

The DSACK Executive Board welcomes new member Regina Schmutte, wife to Bob and mother to Emily (4) and Bobby (1). Regina is originally from Bethlehem, Pennsylvania but has been in Lexington for many years. She and Bob own and operate Kentucky Furniture Wholesale. Prior to that, Regina was Event Planner for the Lexington Marriott.

In the 12 months since Bobby was born, Regina has jumped right into the DSACK family to attend parent groups, research topics for discussion, write newsletter articles, solicit valuable door prizes for our events, gather a crowd to march in the Fourth of July Parade, provide videos for other parents, take a fundraising piggy to her place of business, procure a photographer for Appreciation Day, and the list goes on. She

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has become a champion for the Down Syndrome community and we are so excited to have her as a new Executive Board Member!

Regina will be the board liaison for the 2009 Buddy Walk and has some innovative ideas to make it the best ever. If you would like to hear more, call her at (859) 983-3754. Join our proactive new board member and get involved now. She is ready to get things rolling!

• BUDDY WALK 2008 CELEBRATION STORIES!

(Submitted by Martha Campbell, APS Communications)

Our biggest and best yet – the 2008 Buddy Walk was again a huge success thanks to a dedicated team of volunteers. We went in to this year's walk a little unsure of how the state of the economy would affect our efforts and we were met with abundant generosity and the willingness to offer monetary and physical support – allowing us to again meet and exceed our goals. We at APS Communications are proud to serve as the coordinators for a dedicated committee of volunteer chairs and we are always touched by the individuals with Down syndrome, their families and friends that we get to celebrate each year in this event. I think the day can be summed up for me in an exchange that occurred between myself and one of our friends from The Stewart Home who participates each year in the walk – I asked this young lady, who was decked out in her tiara and sash for the day's festivities – “How are you?” Her response was a beaming smile and one simple word – “Happy!” Why do we do this? That's why!

The 2008 Buddy Walk could not have happened without the support of the following sponsors and teams:

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• FUND RAISING FOR BW...AN EXCITING CHALLENGE!

(Submitted by Megan McCormick, self advocate)

It all started when I went with Mackenzie Gathof to assist in child care for the DSACK “New parents group” in September. One of the parents asked me if I would like to take one of the decorated piggy banks and collect funds for the DS Buddy walk. So I brought Miss Piggy home.

I created a pledge list for potential donors on the computer and made about three copies. Each weekend I walked around the neighborhood going from door to door. I practiced my speech so that I could talk clearly. I said, “Hello my name is Megan McCormick, I live in the neighborhood. I am walking for the Down Syndrome Buddy Walk on the 27th of September. I am collecting pledges for my walk. You can make a check, which is tax deductible, or cash towards the “DSACK Buddy Walk” and put Megan's team on the memo section. Most people supported me, and a few didn't. I still gave all of them a coupon from Texas Road House

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Celebrations

* Chevy Chaser and Southsider are listing various community organizations for involvement in their first annual “Giving Back” issue. Among the nearly 70 groups included, DSACK will be featured. Look for it late December/Early January!

* We have a celebrity among us! DSACK's very own Kent Wallace (8 years old) is featured in the new book, *Helping Children with Down Syndrome Communicate Better: Speech and Language Skills for Ages 6-14* by Libby Kumin, Ph.D., CCC-SLP (Woodbinehouse.com)

BEHIND THE SCENES CELEBRATIONS FOR DSACK!

* Executive Board Member, Traci Brewer recently was asked to speak to Central Kentucky Riding for Hope. Read her excerpt in this newsletter!

* Executive Board Member, Courtney Elbert recently spoke at St. Leo Catholic Church about “dignity of life” in regards to people with special needs. She will soon be offering this presentation to other audiences also. She is also creating an “Everyone Counts” experience for the students at St. Leo School and Church.

* John Lynch, the editor from Lexington Family Magazine was impressed with our DSACK newsletter, and asked Courtney Elbert to write an article for the upcoming state-wide publication, “Exceptional Family KY: A Guidebook for People With Disabilities, Their Families and the Professionals Who Support Them.”



HAPPY 1ST BIRTHDAY, BOBBY!

(Submitted by Bobby's Family)

Here we are, a year later, and I can't even believe that the time has passed so quickly. It turns out that our son IS everything that we had hoped and dreamed about, and then some. Every thing he does amazes us, from the first time he rolled over, to his first drink from a sippy cup. He has brought so much joy into our lives. He is bright, Handsome, beautiful, funny, amazing, and so much more that I can't even put into words. We love him so much and are so grateful to everyone at DSACK and our therapists, for helping us to enrich Bobby's life, as well as our own! Happy Birthday Bobby! Love Mommy, Daddy and Emily



HAPPY 1ST BIRTHDAY, WILL!

(Submitted by Will's Family)

At one year-old, Baby Will is on a roll! In fact, he rolls everywhere: across the room, under the footstool, onto his floor gym. This little guy is on the move!

At nine months of age, Will's newfound ability to roll was a turning point for all of us. Certainly for Will it has vastly expanded his world. No longer is he confined to a lap or a bouncy seat; he is the master of his destiny. Like a little brother, he gleefully makes bee-line for Eli's toys the moment he hits the floor, leaving Eli uncertain whether to cheer Will's mobility or hide his entire car collection. Brent and I are simply amazed.

We had been anxiously awaiting Will's achievement of this milestone, the first that brings autonomy, for months. Finally, after much practice, and following his own timetable, he did it. Will rolled over. Repeatedly. Defying everyone's expectation, he first rolled back to front. After a few more weeks (and much coaxing from his therapists - what would we do without them), he mastered front to back. Now, he barrel rolls everywhere with such speed and skill you would never believe this was an area of concern.

Along with the rolling, Will has had an explosion of development. He can now sit up, babble using a variety of consonants, pick up veggie puffs to put in (or near) his mouth, and pass objects hand to hand. How exciting to see Will reach goals he's had to work so hard to achieve!

We understand that Will, like all children, will face many challenges in his lifetime, but we have learned this year that all Will needs to meet his goals is love, patience, support... and sometimes just a little more time. We're so proud of our baby boy and so grateful for the friendship, support and inspiration we've found in the DSACK community. It's been a wonderful year.

Have something you want to celebrate? An award, birthday, or some other achievement? Email submissions to Courtney Elbert at celbert@roadrunner.com with “Newsletter Item” in the subject line for inclusion in the newsletter.

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which said that a percentage of what was ordered would go to DSACK as a donation.

I even got permission from the priest at my church to make an announcement about the Buddy Walk and to request pledges. The priest not only gave me permission, he got a stool for me so that I could stand at the podium to make my request! The congregation applauded and stood in line after the mass to support me with donations.

I was very excited when it came time to count all the money in my piggy bank. I collected almost \$ 2000. It was \$1,873 and change to be precise!

I enjoyed the experience and I am glad a parent challenged me to raise funds with Ms Piggy!

• BUDDY WALK 2008: LOVE CAN BUILD A BRIDGE

(Submitted by Michelle Gilliam, parent)

OK, I stole that from Michael's Uncle Jimmy. He made a DVD of the Buddy Walk with that Judd's song in the background. It is amazing what music can do. But it's even more amazing what one extra chromosome can do! This was our first year putting a Buddy Walk team together and it was a blessing to see how many people came to walk in "Ava's Parade". We were humbled by the turnout. Michael and I both had dear childhood friends come with their own families. Grace's friends came. My parents' friends came. Ava's speech pathologist came with her family. Cousins. Work friends. Church friends. Other friends. This group of people would never be together in any other circumstance. So, why now? I would like to think it was because they all love my little girl. The little girl that I am so madly in love with. But, to be honest, some of them didn't even know Ava before that day. Like the group of Asbury students. A student named Hannah was quite taken with Ava after meeting her once, heard about the Buddy Walk and gathered a group of her college friends to come and walk with her in Ava's Parade. So, if some of our walkers didn't already love Ava, I believe they want to love her. And they want to love your kids, too. Just like everyone else at the Buddy Walk. That one little chromosome is bigger than we realize. And it brings people together. All that love in one place! Yes, love can certainly build a bridge.

BUDDY WALK 2008: A JOURNEY OF HOPE!

(Submitted by Lee Ann Mullis)



What an exciting day!!!! It was such a beautiful day on September 27th at the Keeneland racetrack and how wonderful a day to bring awareness about Down Syndrome. We were pumped up for this year, which is something that I couldn't honestly say last year. 2007 Buddy Walk was when we sat back in the shadows and took it all in, Joella, our daughter diagnosed with Trisomy 21, was only 7 weeks old at that time. Truthfully, it was a rather overwhelming experience but an experience that I was really grateful to have gone through. It helped our journey towards acceptance and gave us hope. So, when the Buddy Walk was gearing up for 2008, we definitely wanted to be a part of the fun day. We got our little team together compiled of family and friends (almost all coming from out of town, I might add), each one never attended a Buddy Walk previously. I feel that more than anything, we impacted them by sharing this day and isn't that what it is all about. One of my friends stated, "Thank you so much for inviting us to share this day with you. It was truly an amazing morning and don't forget us next year." It was sad that it ended shortly after noon, I personally was so energized that it just wasn't enough to celebrate these beautiful lives, so next year for 2009, we are going to try and make plans to extend the celebration within our family and do something special. So, I commend the organizers of the event and congratulate them for a job well done. Until next year...

JESUS PROM IS SPECTACULAR!

(Submitted by Brooke Reed, DSACK Volunteer)



Over 1200 people with physical and intellectual disabilities attended Jesus Prom for an over the top spectacular event! Jesus Prom is probably Lexington's largest party, thrown by Southland Christian Church, to show love to teenagers and adults with physical and intellectual disabilities.

I had the opportunity to volunteer as an escort this year which was an excellent experience! After arriving, I waited in line for about 30 minutes with the other escorts. As people arrived at the prom, they were greeted outside and matched with an escort for the evening. Everyone was wearing their fancy dresses and tuxes and looked wonderful! After finding my person to escort, we walked through hallways decorated with chandeliers and fountains to get to the dining room. Dinner was served to anyone who wanted it, and then it was off to the hair and make-up table! The guys weren't too interested in the make-up, but enjoyed having their hair fixed. We got our picture professionally taken and then headed for the dance floor! It was incredible to see the number of people dancing and singing! There were people everyone dancing to the music of a live band! After a couple hours of dancing, the access minister spoke for about 10 minutes and showed a video of Jesus. He reminded everyone there how much they are loved by Jesus and by the Southland community. All of the participants received a necklace with a cross on it to remind them of this love. After the gifts were handed out, we were back on the dance floor for another hour! I was sad to leave at the end of the prom, but also thankful for being able to experience such an amazing event.

PAUL PONDERES THE JESUS PROM

(Submitted by Mary Lesch, sister of Paul)

On November 14, 2008 my brother, Paul, attended the "monster blow out" called Jesus Prom. It was held at Southland Christian Church in the main sanctuary, from 6pm to 10pm. Planning started months ahead of time, and definitely showed during the dance. Let's go to Paul for a first hand account of the event.

"Paul, what happened at the dance?"

"I went with two babes, and I just danced and had some supper, chicken nuggets. With the two girls, Kelsey and Candice we just walked and everything. I just danced."

"Did you sing to the music?"

"Yeah, you know it's a song 'Can't hear you' sing a long."

"What were your favorite parts of the dance?"

"I just danced and played hooky. Eric is a good drum player. He had a solo."

There were games like Deal or no Deal, party favors, formal photo opportunities, music and fun for all. Paul had fun hanging out with "babes", dancing and talking. He was encouraged to get jewelry for his mother as a party favor, but opted for a ceramic statue instead. ("Hee hee hee yeah." he commented.) Overall, Paul enjoyed hanging out with other young adults in a formal party atmosphere where his wonderful personality could shine. Planning is already underway for the next Jesus Prom, which will be held next November. There was talk that the next Jesus Prom will be a more casual atmosphere. It was a treat for me to help my brother get fitted for a tux, and see him heading out to a place where he could join people from all over the city close to his age and older. (Individuals are invited who are high school age and older to the monthly Jesus Parties and yearly Prom. They are held at Southland Christian Church, 5001 Harrodsburg Rd. in Nicholasville. For more information about Jesus Parties call Kara Moore at 224-1664. The next Jesus Party will be held on January 23, 2009 6:30pm to 9pm.)

Additionally if there are any older siblings out there that are looking for someone to talk to about having a sibling with a disability and how enriching that can be in your life, feel free to email me at mary.lesch@gmail.com. I'd love to get in contact with you.

JESUS PROM THANK YOU NOTE FROM SOUTHLAND CHRISTIAN

DSACK contributed to the Jesus Prom, and the following note of thanks was received from Access Ministry at Southland Christian Church:

To Down Syndrome Association of Central Kentucky,

On behalf of the Jesus Prom at Southland Christian Church, I would like to send a huge thank you to you for your generous donation to the 2008 Prom. We are so honored and humbled that you chose to support this ministry year after year in such a tremendous way.

It is our desire to see the Jesus Prom to continue to grow here at Southland as well as across the nation. We are thrilled that other churches across the country have the passion to begin hosting Jesus Proms of their own. It is because of donations like yours that we are able to host an event worthy of our special needs friends.

DSACK HOLIDAY PARTY WAS FESTIVE AND FUN! SANTA CLAUS CAME TO TOWN

DSACK held its annual Holiday Christmas Party on December 6th at Trinity Hill United Methodist Church. Many people braved the wintry weather (and over an hour of stand-still traffic on New Circle and Tates Creek Roads!) to make it to this lovely event. Santa felt right at home with all the snow, and he enjoyed the enthusiasm and awe of the DSACK community who attended. Over 75 people were present to eat and be merry during this festive time of year, as well as enter to win numerous door prizes that were donated to DSACK. DSACK would like to thank Traci Brewer for organizing this event, and Brooke Reed who helped to set up and clean up. DSACK also thanks all those businesses that donated door prizes, as well as Regina Schmutte who worked hard to obtain these. DSACK would also like to thank Vallerie Rice who was the caterer for this event. (Vallerie also catered DSACK's Spring Appreciation Event, and the DSACK Summer Picnic. If you are interested in contacting Vallerie for your catering needs, contact Malkanthie McCormick.)

NEWS & INTERNATIONAL NEWS



SENIOR WITH DOWN SYNDROME CROWNED HIGH SCHOOL QUEEN
Kristin Pass, 18, center, was named homecoming queen Friday night at her Texas high school, beating two

other finalists for the crown. Pass was born with Down syndrome. The crowd at the Aledo High School football stadium erupted into cheers and gave her a standing ovation during halftime at the game. (Photo Courtesy Chari Hust and Story by Emily Friedman – October 14, 2008)

REACHING OUT

• **WILL YOU REACH OUT AND SHARE YOUR STORY?**
(Submitted by Dr. Harold Kleinert)

The Human Development Institute at the University of Kentucky (HDI) is looking for families of children and young adults with developmental disabilities to share their stories in one-one-one experiences with trainees. These trainees may be graduate students working on a Certificate in Developmental Disabilities, Pediatric

Medical Residents, students majoring in social work, psychology or education, or students at the Lexington Theological Seminary. Residents and students gain insight and knowledge from families and individuals with disabilities, which help these students and practitioners prepare for their future careers.

The time commitment is minimal – either two or three visits during a month or a few visits over a semester. However this sharing makes a huge impact on the trainee's perspective of children with disabilities and their families. For example, it is critical that pediatricians in training understand the progress that children and young adults with Down syndrome are making with improved education and supports. As another example, future ministers need to understand the importance of faith inclusion, and the gifts that individuals with Down syndrome can bring to their faith communities.

Families are asked to meet with the trainee in a relaxed, natural environment, such as the home or in the community, and talk about the family's experience and day to day life. Additional visits usually occur in the community – at school, during therapy, or on a family outing. Due to the trainees' schedules, it is helpful if families live in Fayette Co. or in the surrounding counties. A small stipend is provided to participating families in recognition of the importance of their contribution to this effort. If you would like more information, please contact Marybeth Vallance, M.S.W., A.C.S.W. at (859) 257-3360 or at Marybeth.Vallance@uky.edu.

• **REACHING OUT TO CKRH WARMS A MOTHERS HEART**
(Submitted by Traci Brewer)

Last month, I had the honor of speaking to a group of volunteers and staff for Central Kentucky Riding for Hope (CKRH). CKRH is a wonderful program that offers equine therapeutic riding lessons to children and teens with disabilities.

My daughter, Emily, has participated in their program, and I cannot tell you the joy I see on her face every time she is on "her" horse, Socialite. During the hour she sits astride Socialite, she has a volunteer that leads the horse and two side-walkers that stand on either side to help Emily maintain her balance. She walks her horse, along with other students in her group, around a ring and learns how to hold the reins, turn the horse, and stop the horse. Along with learning how to ride a horse, it is also excellent therapy. She has increased her trunk stability, learned to follow instructions, take turns, and communicate clearly. However, Emily doesn't see this

as therapy at all. On the contrary, it is the highlight of her week! For that hour, she gets to be atop her horse and experience a sense of independence that she rarely gets to experience.

This organization is able to offer this program due to the efforts of their volunteers, who spend countless hours not only helping the riders, but taking care of the horses, the grounds, and the barn. They are also required to attend training before they can volunteer. That is why they asked DSACK to prepare a presentation.

I began my presentation with the wonderful DVD Courtney Elbert made for our Appreciation Reception last year. If you haven't seen this DVD, it is of the 2007 Buddy Walk and Holiday Party. It features our beautiful children and our families and demonstrates the joy our loved ones have brought to our lives. I wanted the staff and volunteers to understand that having a child with DS is challenging, but the rewards far outweigh the struggles. I went on to present some communication tips to help them better relay instructions to their riders. I also showed them examples of a visual schedule and visual cues and explained that because children with DS are usually visual learners, these are excellent ways to help the children to understand what is expected and also what to expect during their hour.

The staff and volunteers were very open to my suggestions and asked excellent questions afterward. They were so excited about the visual schedule and the fact that it would be helpful to all their children, not just those with DS, that they are going to have one in place next season. As if their taking time out of their busy schedules to attend a training session wasn't enough to show their huge hearts and compassion for children with different needs, they also took up a collection at the end and contributed over \$100.00 to DSACK.

As I walked out to my car in the blustery winter wind, my heart was warmed by the fact that there are so many caring people in our community. So often, it is easy to focus on the negative comments, the staring eyes, the indifference to our loved ones. However, this group of people reminded me that most people are understanding and willing to go the extra mile for those in need. What a blessing I received that night!

Learn more about Central KY Riding for Hope at: www.CKRH.org.

MAKING CONNECTIONS

Do you have time, information or items to share? Things such as information about a playgroup forming, a therapist looking for volunteers for a study, someone looking for a social network of Moms of children with DS, or maybe items like a walker or assistive devices that someone is no longer using or is seeking, or babysitting opportunities, etc.

Send them to Courtney at celbert@roadrunner.com and they'll be included here.



• TEENAGER YOUNG ADULT GROUP!

(Submitted by Brooke Reed, DSACK volunteer)

The group is off to a great

start! We have already attended a basketball game, pumpkin patch, and holiday movie! We would love for all teenagers and young adults to participate in the upcoming activities:

- Game night in January
- February Event TBA
- Look forward to some fun Spring activities also!

If you have any questions, please contact Brooke Reed at 321-507-0332 or brooke.reed@uky.edu

• **ASSISTANCE AND SUPPORT** has been provided for a DSACK family whose house burned. Our thoughts are with you.

• **ASSISTANCE AND SUPPORT** has been provided for a DSACK family involved in a serious car accident. Our thoughts are with you.

• **DON'T FORGET** about DSACK's Lending Library. To request a list of items in the library, or to check out items, contact Nicole Maher at nicjoe@roadrunner.com or at (859) 881-5423

• **"EXCEPTIONAL FAMILY KY: A GUIDEBOOK FOR PEOPLE WITH DISABILITIES, THEIR FAMILIES AND THE PROFESSIONALS WHO SUPPORT THEM"** is a unique new publication created in partnership between the Kentucky Developmental Disabilities Council and Lexington Family Magazine, "Exceptional Family KY" is a free, full-color, 48-page glossy magazine that will be distributed statewide and printed by Feb. 1, 2009.

Nurturing and educating a family member with disabilities can be a challenging and sometimes

overwhelming responsibility. Just identifying the specific needs and finding the right services and support to meet those needs can be difficult and time-consuming.

The mission of "Exceptional Family KY" is summed up in one word – Empowerment. This magazine will provide the information, support and resources people with disabilities and their families need to connect with the services and opportunities that can enrich their lives.

The content of "Exceptional Family KY" will consist of a comprehensive, statewide resource list plus stories from people like you. John Lynch, Editor of Lexington Family Magazine says, "We are excited about 'Exceptional Family KY' and think it can play its part in making connections for people in Kentucky."

• YMCA OFFERS SPECIAL NEEDS BASKETBALL

The YMCA of Central Kentucky is offering Jump Start Basketball, a new program for children and youth with special needs. The program will be held at the North Lexington Family YMCA on Saturdays for five weeks beginning January 17 through February 14. Games will be held from 2 p.m. to 4 p.m. This unique program is open to all special needs children and youth ages 5-19. Each player will receive a t-shirt and end-of-season award.

Jump Start Basketball will be organized by the same administrators who oversee the operations of the Toyota Bluegrass Miracle League and the YMCA's First Score Flag Football program for children with special needs.

Registration is on-going and the cost is \$45. To register or ask questions, contact Kevin Haury at 502-863-4841 or at khaury@ymcaofcentralky.org. To download a registration form, visit: <http://www.ymcaofcentralky.org/>

• THE KIDZ CLUB PEDIATRIC MEDICAL DAY

TREATMENT FACILITY located on Alexandria Drive offers fully inclusive daycare for children who are medically fragile. The Kidz Club's mission is to provide the safest, most inclusive, and cost effective medical day treatment for infants and children up to school age. For more information, call (859) 224-0799 or (888) 902-KIDZ (5439) or visit their website at: www.thekidzclub.cc.. Please note that currently, if you wish for your child to attend this daycare after school and you cannot provide the transportation, you will need to address this transportation in your child's IEP!

WONDERFUL WEBSITES

Do you have a wonderful website to share with DSACK? Send the web address to Courtney at celbert@roadrunner.com Be sure to include a sentence or two describing why you think it's wonderful.

• <http://www.downsed-usa.org/>

Down Syndrome Education USA is a new nonprofit organization established to create new opportunities for young people with Down syndrome. They are with and work closely with Down Syndrome Education International - a leading research, information and education services organization. Down Syndrome Education USA will develop and evaluate education programs, offer conferences for families, teachers and other professionals and support scientific research.

COURTNEY'S CONTEMPLATIONS



Happy New Year! New beginnings often bring excitement, enthusiasm, and renewed energy and hope. With the current state of our economy and society, I am sure many of us feel unsettled and unsure about what our futures will hold. I hope 2009 brings you serenity, joy, and moments that are worth cherishing for a lifetime. Having a loved one with Down syndrome often helps us to remember what is most important.

The DSACK Executive Board is excited about 2009 and what we hope to accomplish for our DSACK Community. The Executive Board will be attending an all-day Strategic Planning Retreat on January 17th, 2009. Please keep us in your thoughts as we take some time to reflect, prioritize, strategize, create specific goals and priorities for DSACK, and create specific action plans to achieve these visions. We will then hold a half-day planning session with our DSACK Advisory Board to discuss and solidify these plans further. Remember that your DSACK Executive Board and Advisory Board Members are people just like you – people that have a billion places to be, and a billion things to do, and a billion things tugging at their time and hearts... yet they have committed to offer their time and talents to DSACK. **We ask that you please complete the survey included in this newsletter, and also please consider stepping up to get involved with DSACK in 2009!**

Our DSACK Community is in an exciting state of growth, energy and hope as we celebrate and support our loved ones with Down syndrome who are beautiful, capable and loved! There are SO MANY exciting things going on within and because of our DSACK Community! 2009 will be an exciting year for DSACK! Stay tuned in our next newsletter for more details!

DONATIONS RECEIVED

Please see our Buddy Walk 2008 Celebration section for a list of donors!

Every effort is made to assure the accuracy of this section, which reflects donations made since the previous newsletter. If an error has been made, we offer our sincerest apology and ask that you bring it to our attention by contacting (859) 494-7809

CALENDAR

2ND SATURDAY PARENT GROUP

Saturday, January 10th, 9:00-11:00 a.m.

Child Development Centers of the Bluegrass

465 Springhill Drive, Lexington

Verity Mathews, M.A. Ed. CCC/SLP will discuss speech pathology issues and will have a Q&A session

2ND SATURDAY PARENT GROUP

Saturday, February 14th, 9:00-11:00 a.m.

Child Development Centers of the Bluegrass

465 Springhill Drive, Lexington

Nicole Maher, DSACK Parent and Parent Liaison for Kentucky Partnership for Families and Children, will present "Building a Team for Your Child's IEP/IFSP"

Come join the popular 2nd Saturday Parent Group (for those whose children with DS are 0-5 years old). Childcare provided. Siblings and grandparents are welcome too! For more information, contact Michelle at mandmgilliam@windstream.net or 859-223-4207

BI-ANNUAL CONFERENCE: FIRED UP!

FOR DOWN SYNDROME IN TN

Friday & Saturday, April 24-25, 2009

Down Syndrome Association of Middle Tennessee presents a statewide conference on Down syndrome every other year.

Fired Up! for Down Syndrome brings together disability advocates, researchers, parents, educators and medical professionals for a two-day conference on a wide variety of issues related to Down syndrome. Past conferences have included workshops on Art and Music Therapy, Fitness and Weight Management, Educational Planning, Conservatorship, Sibling and Family Issues, Nutrition and much more. The conference also includes a portion for Self-Advocates, including presentations by and for individuals with Down syndrome on topics including employment, self-expression and conflict resolution.

If you have suggestions or questions regarding the 2009 Fired Up conference, email DSAMT at dsamt@bellsouth.net or call 615.386.9002.

FREE LUNCHSHOPS sponsored by the Fayette County Parent Resource Center in collaboration with the Bryan Station High School Youth Service Center, Bluegrass IMPACT East Office, the Commission For Children with Special Health Care Needs and the College for Technical Education.

The focus of the sessions are to provide information about a wide range of disability and non-disability topics to families of children with disabilities, agencies and school staff. To get more information call the Parent Resource Center at 859-381-4229.

To register for Lunchshops, call (859) 381-4229 or email stella.smith@fayette.kyschools.us or anita.jones@fayette.kyschools.us.

You may also register on-site at each session.

INTRO TO ON-LINE SAFETY AND DIGITAL CITIZENSHIP

February 26, 2009 from 11:00 a.m. – 1:00 p.m.

Bryan Station High School, 201 Eastin Rd, Lexington

Internet Safety has become a major concern for families and others in recent years. This session discusses Internet Safety tips and information families, students, school staff and community providers can learn to help keep students safe in the school and home settings.

SAFE AND SECURE: AN OVERVIEW OF ESTATE PLANNING:

ISSUES FOR FAMILIES WITH CHILDREN WITH DISABILITIES

March 10, 2009 from 11:00 a.m. – 1:00 p.m.

Bryan Station High School, 201 Eastin Rd, Lexington

Estate Planning provides a great opportunity to think pro-actively about the future of one's child with a disability. Participants will develop a "to do" list that will help them develop a letter of intent and help prepare legal documents.

TRANSITION ISSUES WITHIN THE SCHOOL AND COMMUNITY

April 14, 2009 from 11:00 a.m. – 1:00 p.m.

College for Tech Education; 1165 Centre Pkway #120

This Lunchshop will explore issues related to transition planning. All grade levels of transition will be discussed from elementary to high school to post secondary.

"YOU ARE AN IMPORTANT PIECE OF THE PUZZLE"

TRANSITION FAIR!

FITTING IT ALL TOGETHER: SUCCESSFUL TRANSITION FOR STUDENTS WITH DISABILITIES

Thursday, March 19, 2009, 9:00 a.m.—1:30 p.m.

UK Student Center, Lexington

The Central Kentucky Regional Interagency Transition Team is sponsoring a Transition Fair for 11th & 12th grade students with disabilities, parents, high school staff, post-secondary educators, and regional/state agencies in Kentucky. The purpose of this

regional event is to connect students with disabilities and their families with successful post secondary opportunities. Over 20 informational tables and breakout sessions will be provided by agencies and central Kentucky businesses along with DOOR PRIZES!

For additional information, about the Transition Fair visit: www.cksec.org or call (859) 257-4314

SUBMISSIONS

Want to submit information for inclusion in What's Going Down With DSACK?

Submission deadline for next issue is Friday, February 6th and can be sent to Courtney Elbert at celbert@roadrunner.com. Send us pictures of your family member who has T21 to be included in the banner of the newsletter. Digital photos are preferred. Photos should be of the individual alone – head & shoulders preferred.

Do you...

- know someone who might like to receive our newsletter?
- have an interest in placing an ad in our newsletter?
- want to receive the newsletter by e-mail instead of through regular mail to save DSACK mailing costs?

If so, please contact Courtney Elbert at (859) 879-2182 or celbert@roadrunner.com. Let's get the word out about DSACK and our loved ones with DS!



OUR MISSION!



The mission of Down Syndrome Association of Central Kentucky (DSACK) is to enhance the lives of individuals with Down syndrome throughout their life-span by providing support, information and education to families, professionals and the communities that make up the Central Kentucky region.

With proper supports and services, people with Down syndrome will be productive members of the community.