



# DSACK

*beautiful capable loved*

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JUNE  
2011  
VOLUME V  
NUMBER III

DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY

*celebrating kids issue*



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# DSACK

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## WHAT'S GOING DOWN WITH DSACK

### Mark Your Calendars!



#### DSACK Summer Picnic!

Sunday, June 26 at Whitaker Bank Ballpark, Pepsi Party Deck. Admission and dinner buffet are complimentary for immediate family of those DSACK members with T21. Legends game begins at 5:05 pm.

#### DSACK Community Night!

Thursday, August 4 at Whitaker Bank Ballpark. Come out and support the DSACK Community as we are the featured group for Community Night. One lucky child will be selected to throw out the opening pitch! Watch the Friday Blitz for contest details. Legends game begins at 7:05pm.



#### Kentucky Down Syndrome Advocacy Network (KDAN)



DSACK is one of five associations across the Commonwealth to join the newly created Kentucky Down Syndrome Advocacy Network (KDAN). At its first meeting in Frankfort, the group fashioned the new mission and vision: "KDAN is a statewide association that facilitates collaborative advocacy for government policies to serve the best interest of people with Down syndrome. Our vision is that Kentuckians with Down syndrome live and work in an environment where diversity is valued, strengths and interests are accentuated and opportunities equal those in the general community."

Self-advocates, family members, staff and volunteers from across Kentucky (including Lexington, Louisville, Owensboro, Bowling Green, Northern Kentucky and elsewhere) traveled to Frankfort to further the KDAN effort, and to spend time with our elected officials. KDAN members visited over a dozen representatives to start developing a rapport so that, throughout the coming years, KDAN and the state of Kentucky can work together to address the issues and concerns of 5500 + Kentucky families who are living with Down syndrome.

If you are interested in representing DSACK for KDAN, please email Traci Brewer at [tbrew67@hotmail.com](mailto:tbrew67@hotmail.com).

#### Kroger Cards

If you have a DSACK-issued Kroger gift card, please remember to reload the card each time you enter the store and then pay with the card when you check out! This process allows DSACK to receive 4% of your purchases. There are dozens of DSACK-issued cards out there that are not being reloaded, so consider this a friendly reminder! It is an easy way to support DSACK's programs. If you have sold any of the \$5 cards to friends or family members, pass along this reminder to them to please use their cards. DSACK still has more to Kroger cards to sell. Pay DSACK \$5 in order to receive a \$5 gift card with a serial number connected to DSACK. What an easy way for us to generate funds! Thank you!!



#### Lexington Family Magazine

Be sure to pick up a copy of the April issue of Lexington Family magazine! DSACK has a 1/2 page ad on page 21 AND a short article in the News to Use section on page 45. You can find a magazine at over 600 locations in 9 counties!

Also, grab a copy of Exceptional Family magazine to find DSACK Mom April Vernon's lovely essay.

We also spotted Olivia Miller in an article about Central Kentucky Riding for Hope, Conor Healy in an ad for Bluegrass Miracle League and Dr. Harold Kleinert in an ad for the Kentucky Council on Developmental Disabilities! Exceptional Family comes out once per year and is a resource guide for people with disabilities, their families and the professionals who support them. We have several extra copies at the office.

DSACK would like to thank John Lynch, Editor, and Gary Mazza, VP of Sales and Marketing, for being so great to work with on both of these projects.

#### It Finally Feels Like Home!

The first photos have been hung and we have space and frames for many more. Please send in your 8x10 black & white photo of your child with Down syndrome. The photo can include siblings, parents, or can be of the child alone. To make this project affordable for DSACK, we ask that you also include \$10 to cover half the cost of the mat and frame. We have a vision of filling the walls with dozens of beautiful faces - please help us do it!



## who are we?

### PROGRAM COORDINATOR

Allison Kerschbaum

### BOARD OFFICERS

Michelle Gilliam, *Chairperson*  
Regina Schmutte, *Vice Chairperson*  
Lee Ann Mullis, *Treasurer*  
April Vernon, *Secretary*  
Hans-Pete Healy, *Research Officer*  
Your Name Here, *Board Liaison*

### BOARD DIRECTORS

Susan Hart Bell, *M.S., Ph.D., Parent & Professor of Psychology & Coordinator of Child Development, Georgetown College*  
Traci Brewer, *Parent*  
Meada Hall, *M.S., Ed.D. Principle Investigator & Project Director for Community Based Work Transition Programs, UK*  
Harold Kleinert, *Ed.D., Executive Director of HDI*  
Joanne Luciano, *PT, MHS, Kids In Motion, Inc*  
Samantha Matthews, *Special Education Teacher*  
Matt Moore, *Director of Special Education, Jessamine County School District*

### ADVISORY COUNCIL

Caroline Boeh Baesler, *Parent & Attorney*  
Karen Roof Boudreaux, *Parent*  
Becky Lesch, *Parent & Educator*  
Malkanthe McCormick, *M.D. & parent*  
John Riley, *M.D.*

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

# DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY

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## NEWS FROM THE BOARD

### Behind The Scenes

**DSACK** is fortunate to have a group of encouraging, compassionate and sincere individuals who make up our Board of Directors. They all lead busy, full lives. They are all full-time professionals with personal and professional commitments, yet they make time to share their energy and expertise with our organization. They meet with the officers bimonthly and communicate with us between meetings as needed. That is not where their service to DSACK ends, though, as you can read below.

**Dr. Susan Bell** is, once again, chairperson of the Buddy Walk registration committee. In the past, she has recruited some of her college students to volunteer with DSACK. She also graciously offered to be a presenter at our 2012 conference and is willing to write much-needed grants for DSACK! We appreciate her efforts immensely.

**Traci Brewer**, previous board chairperson, has agreed to now be the DSACK liaison with Affiliates in Action as well as participate in the Kentucky Down Syndrome Awareness Network (KDAN). We are glad she is still willing to lend her time to DSACK.

**Dr. Meada Hall** was one of the fabulous speakers at our 2011 conference and has a true heart for advocacy. She assisted with interviewing candidates for the Program Coordinator position. Maybe you met her at our last summer picnic or at a Buddy Walk? As in the past, she will be working at the DSACK table at the Buddy Walk this year...stop by and say hello and thank you.

**Dr. Harold Kleinert** has been on the board longer than any of the current members. He is a huge source of encouragement to the officers and never fails to return calls or emails when we have a question for him. He continues to work with DSACK on many issues with wisdom and passion and we are so grateful that he shares his time and ideas with us.

**Joanne Luciano** joined the board and got right to work! She is very willing to help in any way she can and has already jumped onto a Buddy Walk committee for this year. She also contacted many of the state therapy boards and helped us be able to offer continuing education credits to professionals who attended the 2011 conference. She has presented to the New Parent Group about physical therapy issues and sees many DSACK children for P.T. She is a favorite among parents and children alike. We are so glad to have her.

**Sam Matthews** approached DSACK a few years ago and asked if she could be involved. She has been chairperson of the Buddy Walk sponsorship committee in the past and is now the wonderful leader of the DSACK Elementary Group. The group has flourished under her leadership and continues to grow each month. Her enthusiasm and love for our children is unmatched and we are so thankful to have her on the board.

**Matt Moore** was a great source of advice during the interview process for Program Coordinator and he assisted with actual interviews, as well. He was also very helpful during the planning of the 2011 conference and was instrumental in getting the conference registration information disseminated across the state. We truly appreciate his time and expertise.

When you see these people, please offer them your sincere thanks. They are, just like you, pulled in many different directions, personally and professionally – but they continue to make time for our organization. I am very grateful to each individual and feel honored to sit at the boardroom table with them.

*With Appreciation,  
Michelle Gilliam, DSACK Chairperson*

## NEWS TO USE

*continued on page 4*

### Preparing for the ARCs

A Few Suggestions for Parents as they Prepare for ARCs (Admissions and Release Committee):

1. Prepare notes about what they want to learn/find out at the meeting
2. Prepare notes about what they want their child to learn in school
3. Bring pictures of your child if they won't be attending
4. If this is your child...?-questioning strategy
5. Ask for additional time to consider important decisions if you're uncomfortable making them on the spot at the meeting or want to get additional input
6. Look for opportunities to express gratitude to teachers and related staff
7. Bring someone along as a source of support
8. In compromising, define how and when to evaluate if compromise is working
9. Try to remain clam
10. Say "I don't know what you mean" is a demonstration of confidence and competence

These questions and suggestions deal primarily with IEP meetings and do not cover all the activities that could happen at an ARC meeting.

*Submitted by Matt Moore, DSACK Board Member*

## d o n a t i o n s

Kentucky Housing Corporation

Dr. Doug Knight in memoriam of Jason Boyd

Shawn & Julie Gillen

Kids Place, in kind

Girl Scout Troop 881

The Dotsey Family

Sandra Green, MD, donated 50 brand new children's books to DSACK via Geneva Harris

Lee Ann Mullis painted a beautiful canvas for the DSACK conference room

A big thank you to April Vernon and Scott Mandl for photography donations! We very much appreciate your talent and your generosity!

*thank you!*

*The DSACK Newsletter is published bimonthly by the Down Syndrome Association of Central Kentucky, P.O. Box 910516, Lexington, KY 40591-0516.*



# DSACK

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## NEWS TO USE

*continued from page 3*

### Using the IPAD and IPHONES with great success!

**DSACK** is hearing more and more stories of our loved ones with Down syndrome using the IPAD and IPHONES with great success! The IPAD appeals to our loved one's typical learning style of visual strength. We are hearing stories of people using them to develop fine motor skills, make math concepts more concrete, provide visuals for schedules and behavior management, allow personalized flash cards and story development, and as incentives to promote learning and independence.

While this new technology is very exciting, there seems to be a learning curve as to which APPS are most effective and helpful. If you have any sites or information to add to this conversation in regards to IPAD and IPHONES and APPS, be sure to submit them to DSACK for inclusion in future newsletters! For instance, do you have a "favorite app" for developing handwriting skills? Do you have a list of Apps that you have found to be most helpful and affordable? Share your experience and help fellow DSACK members! Below, DSACK has included a few sites to get you started in your research about IPADS, as well as a personal story from Dusty Hanson about his son's Spencer's use of the IPAD. Thank you, Dusty, for sharing with our DSACK community!

*~ Courtney Elbert, Sam's Mom*

1. Here is the link to HDI's recent seminar about iPads and they still have their presentations listed to peruse  
[http://hdi.uky.edu/SF/news/press\\_release/11-01-11/HDI\\_Seminar\\_Series\\_-\\_Universal\\_Applications\\_of\\_iPhone\\_and\\_iPad\\_for\\_Persons\\_with\\_Developmental\\_Disabilities\\_and\\_Communication\\_Disorders.aspx](http://hdi.uky.edu/SF/news/press_release/11-01-11/HDI_Seminar_Series_-_Universal_Applications_of_iPhone_and_iPad_for_Persons_with_Developmental_Disabilities_and_Communication_Disorders.aspx)
2. Here is a link via Kansas City's Down Syndrome Guild that has a list of 200 Iphone Apps  
[http://www.kcdsg.org/for\\_educators.php?show\\_child=80](http://www.kcdsg.org/for_educators.php?show_child=80)
3. Here is a blog that seems to have some good information also  
<http://teachingall.blogspot.com>
4. Here is another website to help sort through and look for APPS. It looks to be well organized and helpful:  
[http://www.oneplaceforspecialneeds.com/main/library\\_special\\_needs\\_apps.html](http://www.oneplaceforspecialneeds.com/main/library_special_needs_apps.html)

**When** we learned that the I-Pad was something that could help Spencer, we were having a bit of frustration with one particular aspect and that is communicating with him. I don't have the best hearing, his Mother is profoundly deaf since birth and has speech deficiencies of her own, then you add the low muscle tone of Spencer's Happy Gene and it's just easier to ask yes or no questions and guess at what he is trying to say if he doesn't know the sign for it. We surely didn't want that to be the normal form of communication. So we thought that we would ask around. We asked his teachers, his therapists and anyone that we thought might have been exposed to its practical application of the assistive device. What we found was a lot of reverberation and excitement, but not much exposure.

At that point I knew we were heading into new territory, but I also knew that there had to be something to it. So I got online and searched for assistive devices and searched for information about what works and what doesn't. Then I searched for programs that might be in the works or having success. I didn't find much. At this point, I was thinking, "Ok, I know that the I-Pad is an extremely popular item, it's an extremely solid operating system, it lends itself to the fingers of little kids in the way of touch screen. I remember seeing Stephen Hawking sitting in a wheel chair listening to a box speak for him, lecturing my father about time and space, so I know the power of assistive devices and computers. I know that even though technology is increasingly developing, the Apple devices are going to be around for the long haul. I concluded that the

I-pad will indeed be a viable device from a hardware standpoint that will be of benefit to Spencer. Now the question remains, to what end?"

I then used the app store to find things that people have developed for special needs and I found a few. I got excited and sloppy in my research and tried a few of them on my own, knowing somewhat about the particulars of Spencer's I.E.P. goals, and then tried to find some things that were on my own list. I got about ten items. As I was going to task on the implementation I found that I was getting ahead of myself a little because I really didn't have anyone to turn to that would give me the direction and way to handle the device. So I started to backtrack a little in my head. What I then decided is that we need the therapists and school teachers on board to use the device to help Spencer. I believe that this will always be a work in progress, and here is the key reason why. As the progress is made and the teachers change, so will the applications. With that key piece of the puzzle, I found that I couldn't just arbitrarily pick "assistive devices" out of the air and they would apply to Spencer, had to find the need and find a way to assist that particular need in a particular way or it wouldn't help.

I also came to the conclusion that we had to do everything possible to protect the device in every way, so I again got online and found the reviews for protection devices for the I-Pad and found a thing called an Otter box- Defender series. I also found that there is a free download that uses GPS to track an I-phone or I-Pad if it's lost or stolen.

So, to task we went. We talked to the teachers, showed them how it functions, we sent the I-pad with Spencer to school, and it came home and back and forth we went. Now in monitoring the going on and the possible progress, we found that we were successful in transporting and using it at school; however, checking the power usage on the device, we found that it was coming home at 80% battery and sometime more. We didn't say anything to the teachers as it then would no longer be a true and honest way to check up on its usage, but we inquired as to how much it was being applied and found that for Spencer to truly get the most out of it, it was up to us again. And here is one of the other keys that make this work. We knew from the start that we could shoot ourselves in the foot if we put games on it. It's not for the purpose of games. Spencer loves playing games, and he loves playing Xbox with his brothers, but in order for this I-pad to be an assistive device, then there has to be some restraint from confusing the purpose. So, we found that if Spencer would truly benefit from the I-pad, then we had to become Assistive/assistant Therapists and give him his therapy at home for the most part. So we leaned even more on the people that "work with him" to find the things that will help his development and his opportunity for the best possible quality of life.

We do have applications that are very specific to Spencer's presents needs, and as he develops and changes then we will address this accordingly. I also found that through the App Store on the I-pad, that they give the information to the developers. I strongly believe that if Spencer has a need that isn't being met, and there are app's out there that are close, but not useful, I can contact the developers, and partner with them to develop the things that will help not only Spencer, but others as well.

Now in conclusion I found that Medicaid won't reimburse because they are having reservations about the I-pads getting broken, and I understand that. That is why ours is encased and insured. I also know that since Spencer has been exposed to the device, his memory, attention, and SPEECH has improved substantially! Yes, it was a sacrifice in the short term; however, it is my opinion, that he will have this device and benefit from this device all of his life.

*~Dusty Hanson, Spencer's Dad*

# DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY

M A Y - J U N E 2 0 1 1

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## Parent Resource Center-List of Summer Camps & Activities 2011

For children and teens with special needs

Submitted by Matt Moore, DSACK Board Member



For More information, Please call Vickie Shearer or email at [vickie.shearer@jessamine.kyschools.us](mailto:vickie.shearer@jessamine.kyschools.us) or call 859-887-2421 ext. 3728

All Abilities Drama Camp  
Campers will be a part of putting on a play & making new friends. The camp ends with exciting performance of The Hungry Caterpillar.  
To Register or more info, contact Anna Brannen [annaharkenbrannen@gmail.com](mailto:annaharkenbrannen@gmail.com) or Phone 402-203-5603  
sponsored by: Special People in Catholic Education

American Diabetes Association  
Camp Hendon—  
Carrollton, KY  
888-342-2383  
Ext. 6662

Bluegrass Miracle League  
Registration Forms available online at [www.bluegrass-miracleleague.org](http://www.bluegrass-miracleleague.org)  
(Every child deserves a chance to play baseball)  
To learn more contact Kevin Haury @ 502-863-4841

Camp Carnegie  
859-254-4175  
6 sessions in July with the 2 first sessions beginning July 6  
[www.carnegieliteracy.org/index.htm](http://www.carnegieliteracy.org/index.htm)

Camp Discovery  
Ky Hemophilic Foundation—for child with bleeding disorders  
July 12-15 Ages 7-15 yrs old  
Cedar Ridge,  
Louisville KY  
800-582-2873

Camp Freedom  
Children in Foster Care  
June 6th – 10th  
Lebanon Junction, KY  
[Lions-campcrescendo.org](http://Lions-campcrescendo.org)

Camp Happy Days  
For children with physical & mental difficulties  
Bowling Green, KY  
270-393-3480  
Ages 6 and older  
[www.bgky.org/bgpr/specialpopulation.php](http://www.bgky.org/bgpr/specialpopulation.php)

Down Syndrome of Louisville Camp  
Louisville, KY  
Michelle Bernard 317-415-5530

Cardinal Hill Easter Seal Camp KYSOC  
Multiple Disabilities—  
Carrollton KY  
502-732-5333  
Ages 6 & older  
[www.Cardinalhill.org/kysoc/camps](http://www.Cardinalhill.org/kysoc/camps)

Cardinal Hill Hospital—Camp  
Cardinal Hill  
Lexington, KY  
Camp Date July 13th & 14th  
859-367-7125 or  
[www.cardinalhill.org](http://www.cardinalhill.org)

Central KY Riding for Hope Therapeutic Riding  
Ky Horse Park  
Lexington KY  
859-231-7066  
4 yrs old to adult  
[www.ckrh.org](http://www.ckrh.org)

Diabetes Fun Camp for Children  
Masterson Station,  
Lexington KY  
859-323-5404  
ext. 269  
(Ask for Leslie Scott)

EKU & Office of Vocational Rehabilitation  
Planning to Win Summer Transition Programs  
Eastern KY University,  
Richmond KY  
859-622-2933

Explorium  
Lexington KY  
859-258-3253  
Available all summer  
Ages 3-13  
[www.explorium.com](http://www.explorium.com)

Jessie G Harris, Jr. Psychological Service Center  
Anger Management Group for Children  
OR Social Skills for Children  
University of KY,  
Lexington KY  
Both sessions 1 1/2 hr once a week for 12 sessions  
Call 859-257-6853

KY Lions Youth Camp—For Blind or Visually Impaired: Deaf or Hard of Hearing  
June 29—July 3 Ages 8-15 yrs old

Lexington Children's Theater  
Lexington KY  
859-254-4546  
Classes all summer  
[www.lctonstage.org](http://www.lctonstage.org)

Lexington Gymnastics & Cheerleading Camps—Lexington KY  
Ages 4 and older  
859-273-5880  
[www.lexingtongymnastic.com](http://www.lexingtongymnastic.com)

Life Adventure Center of the Bluegrass  
Versailles KY  
859-873-3271  
[www.lifeadventurecenter.org/](http://www.lifeadventurecenter.org/)  
Summer Equine Camp  
5 sessions

Living Arts & Science Center  
Lexington KY  
859-252-5222  
Grades K-12  
[www.lasclx.org](http://www.lasclx.org)

Summer Camps for Sensory Processing  
Owensboro KY  
270-689-1738

LYSA Topsoccer  
Central Kentucky's only soccer league for special needs athletes  
[www.lysa.org/youth/tops](http://www.lysa.org/youth/tops)  
859-223-5632

The Sharon School for Attention Deficit Disorders & Learning Disabilities Camps  
3-2 week sessions start June 6th  
multiple session attendance allowed.  
200 Oak Tree Lane,  
Nicholasville, Ky  
859-509-6892 or  
[email sharonschool@msn.com](mailto:sharonschool@msn.com)

Special Motor Fitness Clinic  
Eastern KY University  
Richmond Ky  
859-622-1891  
Ages 4-11 years old

Special Olympics (SOKY)  
St. Joseph Park,  
Lexington Ky  
[www.soky.org](http://www.soky.org)

Special Touch Ministry, Inc.  
Summer Camp Getaway  
Camp Crestwood  
Crestwood KY  
502-227-2557  
(Kusum Neal)  
[www.specialtouch.org](http://www.specialtouch.org)

Summer Camp Programs  
Jessamine Co YMCA  
Age 5-9 Starts June 6  
Age 10-17 Starts June 6  
Contact is Jennifer Bishoff 859-885-5013  
[jbishoff@ymcaofcentralky.org](mailto:jbishoff@ymcaofcentralky.org)

Summer Transition Enhancement Program (STEP)  
June 13—20 Camp prepare deaf or hard of hearing high school sophomores, juniors & seniors for life after high school  
Register by April 30th,  
Eastern KY University  
859-622-2568 or 859-539-2703

Systematic Treatment of Autism and Related Disorders (STAR)  
For children already diagnosed with Autism & who have language and reading abilities  
Louisville, KY  
Ages 4-7 and Ages 8-12 DAY CAMP  
502-852-3797 or  
[www.starautism.louisville.edu](http://www.starautism.louisville.edu)

Therapeutic Recreation Programs  
Parks & Recreation  
Lexington KY  
859-288-2928  
Several camps for different age groups  
[www.lexingtonky.gov/index.aspx](http://www.lexingtonky.gov/index.aspx)

Touched by Cancer  
Youth Day Camp  
American Cancer Society  
Presidents Park,  
Edgewood, KY  
800-227-2345 or  
859-372-7881  
Ages 6—12  
[www.cancer.org](http://www.cancer.org)

Wilmore Parks & Recreation  
Wilmore KY  
June 6 – July 29 2010  
Amy Fitch  
859-858-9031 or  
[email amy@wilm-orep@earthlink.net](mailto:amy@wilm-orep@earthlink.net)

YMCA Camp Piomingo (Overnight Camp)  
Children with ADHS & Food Allergies welcome  
[www.ymcacampio-mingo.org](http://www.ymcacampio-mingo.org)  
502-587-9622  
or 800-411-5822  
Ages 6 to 16

YMCA Central KY  
859-254-9622  
[www.ymcaofcentralky.org](http://www.ymcaofcentralky.org)

To apply for a scholarship to a camp or conference go to [www.dsack.org](http://www.dsack.org). Go to the dropdown menu on the RIGHT of the homepage, Under the Pages Tab, click on DSACK Community, click on Programs & Services, click on Conference & Camp Scholarship Applications.



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## DSACK GROUPS

# Elementary Group

**Wow!** The Elementary Group went to Kids Place and it was amazing! It was great to see the kids playing, Dads talking, and Moms catching up on it all! Huge thank you to all the volunteers and families that attended! I am so blessed to know you all and to get to see you each month! Enjoy the photos!!

*Thanks, Sam Matthews,  
DSACK Board Member*



### Elementary Group Summer Schedule

June 11, 10a.m. – 12 p.m

You are invited to join the 0-5 group for a presentation by KET's Kathy Day about art and science for our children. See details under the 0-5 group schedule

July Summer Party TBA

### Teen/Young Adult Summer Schedule

**Meet the Group:** Friday, May 20  
Frozen Yogurt Night at 7pm  
at the Orange Leaf at Fayette Mall, 152 W. Tiverton Way, Ste. 170

**Friday, June 10 Baseball**  
Lexington Legend's Game at 7:05 pm

**Saturday, July 30 Dress Up Dinner**  
Girls show up at the DSACK Office for a "Hair and Nail Party" at 4:00pm. Boys are welcome too! We will have snacks and music for everyone. At 7pm, we'll meet at an Italian restaurant TBD.

August-TBD Pool Party!!

Summer Party-TBD

Contact Patrice Fischer at [Patrice.Fischer@uky.edu](mailto:Patrice.Fischer@uky.edu) with any questions.

# AIM Group



# 0-5 Parent & Playgroup



## 0-5 Parent Group & Playgroup Summer Schedule

May 14, 10 a.m.-12 p.m.

"Show and Tell/Potluck Brunch" - This parent Show and Tell is an opportunity to find resources and share ideas. Bring books, games, toys, or photos to describe something that has been valuable in your child's development. Bring your favorite brunch dish. Come ready to share good food and conversation.

June 11, 10 a.m.-12 p.m.

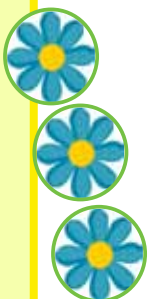
"Arts and Science for Everyone"

Kathy Day from KET, Elementary group is invited - KET's Kathy Day will discuss how families can use two KET resources, Art to Heart and Everyday Science. She will give us ideas on how our kids can be involved in the arts and how that will stimulate brain growth and development in other areas. The everyday science material shows how very young children can learn to love science through exploring the world around them. These are two excellent resources with tons of ideas for family activities and enrichment.

July 9, 10 a.m.-12 p.m.

"Megan's Story"

Megan and Malkanthie McCormick - Megan McCormick's story is one that every parent should hear. Her many accomplishments as a student and an athlete are impressive. Just in her early 20s, her attitude and poise make her a popular speaker. Megan also has Down syndrome and relates how she has met challenges along the way and continues to meet them and succeed in her college classes. Dr. Malkanthie McCormick, Megan's mom, will also speak from a parent's perspective.





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## BUDDY WALK

### BUDDY WALK 2011

The Down Syndrome Association of Central Kentucky's 9th Annual Buddy Walk presented by Bank of Lexington October 1, 2011.



Bank of Lexington

People who know *Banking.*  
People who know you.

Planning for our 9th annual Buddy Walk is starting! We have many volunteers who have committed to donate their time to help make our 2011 Buddy Walk a success. If you are interested in volunteering your time, or if you have a friend, relative, or co-worker who wants to get involved, contact Regina Schmutte at remicale2@gmail.com or 859-983-3754.

Meeting dates are as follows. All are welcome!

- o April 12
- o May 3
- o June 7
- o July 5
- o Aug 2
- o Sept 6, 13, 20 & 27 (weekly)

### Secure Auction Items!

We welcome all donated items for our Buddy Walk Auction! All proceeds from our auction are donated directly to the DSACK Buddy Walk. Is there a business you frequent regularly? Don't be afraid to ask! Most businesses enjoy giving to non-profits, and it is great advertising for them! Contact Regina for an auction form 859-983-3754 or remicale2@gmail.com.

**Our 2011 Buddy Walk** registration web site is up and running!! Register your team @ [www.buddywalk.kintera.org/dsack](http://www.buddywalk.kintera.org/dsack)! The first 3 families to sign up their team will receive a ticket for two to The Legends Ball Park for DSACK night! Go to [www.buddywalk.kintera.org/dsack](http://www.buddywalk.kintera.org/dsack) to start your Buddy Walk team now!

### BW Fun Facts

We are pleased to announce the Buddy Walk's 2011 Presenting Sponsor: **THE BANK OF LEXINGTON**. Thank you to the Bank of Lexington for continuing to support our organization. We appreciate your dedication!

**WTVQ** will be our media sponsor again this year! Thank you for your support WTVQ!

**We Heard You!!** The 2011 Buddy Walk T-shirt will be Kentucky Blue this year! We took a vote and Kentucky Blue came in first!!! **GO CATS!**

**Who will raise the most money for 2011????** We already have a team that is creeping up on \$2000!! Jordan's Team started raising money as soon as Buddy Walk 2010 concluded..... catch them if you can! The team with the most money raised, and the team with the most members this year, will win a sitting with a professional photographer and will be featured on next year's billboard! Thank you Kristen Tatem Photography!

**Thank you to our committed volunteers for the 2011 Buddy Walk!**

#### Registration Committee

Chair: Susan Bell  
Committee: Georgetown Psi Chi and Psy Faculty

#### Exhibitor Committee

Chair: Pete Healy

#### Auction Committee

Chair: Amanda Jones  
Committee: April Vernon

#### Entertainment Committee

Chair: Tracy Durham Beall  
Committee: Tammy Carter

#### Food Committee

Chair: Allison Kerschbaum  
Committee: Karen Andrasean and Vikki Healy

#### Sponsor Committee

Chair: Regina Schmutte  
Committee: Ashley Candalaria

#### Volunteer Committee

Chair: Erin Salmons  
Committee: Joann Lucinano

**Need Help with the Buddy Walk Web site? Want to register your team, but not sure how? Contact Regina at 859-983-3754 or remicale2@gmail.com. I want to help you succeed!**



If you had a Buddy Walk Team last year and want to re-create your team for Buddy Walk 2011, all you need to do is, click on the link at the top of the registration form that says:

If you have participated in any Friends Asking Friends event in the past, click here to autofill this form.

Then log in using your user name and password from last year and the rest of the form will be filled out for you and last year's history will be in HQ.

# DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY

M A Y - J U N E 2 0 1 1

## celebrations!

### "Pay attention. Be astonished. Tell about it." Mary Oliver, Poet

**Spencer** is highly functioning except speech, very animated, fun loving and sharp as a tack. He is friends with everyone from the janitor to the Principle. He is a character! Spencer loves playing guitar and performing in front of people. He loves anything Toy Story related or anything to do with pirates and treasure. Spencer loves doing anything his family is doing and he is our best cleaner if it involves a rag and a spray bottle. If you put a screw driver in his hand he will take things apart, which there is a picture of him fixing the vacuum head.

*Submitted by the Hanson Family*



**Kent Wallace** can't wait to go camping! His favorite camping pastime? Helping daddy start the fires!

*Submitted by the Wallace Family*



We have just started having to use cloth diapers and none of her pants fit over them so **Abrianna's** always pants less!


*Submitted by the Gonzalez-Clark Family*

I would like to congratulate **Conor** on making the Patriot Club at school for earning all A's and B's on his report card. He worked really hard and we're all SO proud of him!

*Submitted by the Healy Family*



### birthdays!


 **Raynard Coleman** celebrates a birthday May 6. Happy 15th Birthday, Raynard!

*Love, Mom*

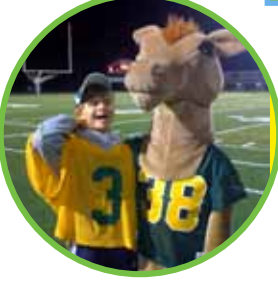


**Ava Gilliam** can jump!  
*Submitted by the Gilliam Family*

### birthdays!

 **Levi Vernon** turns 1 on May 27th. Happy Birthday Levi. We love you!

*Dad, Mom and Adam*



My son, **Christian Massie**, who is an 8th grader at Morton Middle School, was recently voted by his classmates as the student with the most spirit. He is a repeat honoree. Christian was on the sidelines for all the games to cheer on the team. He also was the manager in charge of the kicking tee, retrieving off the field after kick-offs he was on the bench for both the boys & girls basketball teams and he was part of the 8th grade celebration night at Morton. Way to go Mr. Spirit!

*Submitted by the Massie Family*





# DSACK

*beautiful capable loved*

## B E I N S P I R E D !

### THE ONE O'CLOCK ROLLOVER

*By Dave Hingsburger*

The one o'clock rollover determines the fate of the evening's sleep. It has for years now. When I fall asleep, I always fall asleep lying on my left side. At around one every night - that's every night - I come to a little bit and roll over onto the other side. On the rollover a memory pops into my mind. The other night, it was a memory of a betrayal by a really close friend. And that was it. The end of sleep. Usually, though, my mind is more positive and picks something nice, a warm memory to send me back to sleep.

Last night, the one o'clock rollover over was accompanied by a beautiful memory. This surprised me because I spent yesterday telling a lot of people about Brent Martin and the image of his last moments were burned deep into my mind with each telling. But Brent wasn't there, this morning at one.

Instead ...

Many years ago I worked at an agency where a youngish single woman had put in to adopt a child with Down syndrome. She specifically, only, wanted a child who had been cast away because of her disability. She felt that she had something to contribute to a child with a disability. And indeed she did. I have met many people who work in the field of intellectual disability who are good at what they do - she went a little further than good. Her caring came out in her voice. The kind of caring that doesn't patronize, it was the kind of caring that wrapped hurt in a warm blanket and gave it tea.

She told me that she had got the call and was going to be a mother with awe in her voice and barely concealed glee. She arranged to take time off work and was heading to the hospital that very afternoon to meet her daughter. The social worker kept wanting to

tell her stories about the parents, she refused to listen to the negativity, 'This is a day of 'hello', she's already had her day of 'goodbye,' she said to me.

I went to visit a few days later when she was at home with her little girl. Oh my, she was small. I don't think I'd ever seen a newborn before and didn't realize that they were so tiny. So fragile. She gave me the baby to hold and I did. I wondered if that tiny creature could feel my heart beating wildly as I held her. The enormity of holding life in my arms was huge; the automatic sense of wanting to protect and keep safe took me over. I was terrified that I wouldn't be up to the trust - I gave her back.

And then the baby roused a little bit. Mom leaned down and kissed each eye. "You have the most beautiful eyes in the world, don't let anyone ever tell you different," she said. Then she smoothed out these tiny perfect hands and kissed each one saying, "People will tell you that these hands won't be able to do much, don't listen to them you have perfect little hands." I got tears in my eyes and tried to discreetly wipe them away.

After baby was back in bed we had tea and she told me that she has decided that since her little girl is going to get a lot of negative messages about who she is and what she looks like, she will be full of positive messages first. So full that there will be no room for hopelessness, despair or self-hatred.

I don't know where she is now, either mother or child. But I imagine them doing well.

And I thank them for a wonderful night's sleep.

And for waking - smiling.

Every human life is a *beautiful* gift.

People with Down syndrome are *capable* of living full lives and dreaming big dreams.

People with Down syndrome are *loved* beyond your wildest imaginings.

### MAKING CONNECTIONS

#### DSACK Board Spotlights

##### Joanne Luciano

I have been a pediatric physical therapist for 13 years and have been practicing for almost 16 years. I thoroughly enjoy working with children and helping them reach



their potential. I have had the great fortune to work with so many wonderful children with Down syndrome and their families over the past 13 years. Recently I was asked to sit on the board for DSACK and decided it was a great opportunity for me to contribute in a different way, to the children and their families that I serve. DSACK is a tremendous organization, providing support, knowledge and guidance to children, families and the community, and I am honored to be a part of it.

~Joanne Luciano, PT, MHS

##### April Vernon

April Vernon works for Appelbaum Training Institute, training teachers across the country. She has a degree in Elementary Education and a Master's degree in Curriculum and Instruction. She has presented in 48 states (Montana & Alaska are the two she is missing in case you're wondering). She has done consulting work with schools, helping the teachers with the inclusion of children with special needs and guiding them through classroom management.



She currently trains child care teachers and directors twice a month, and writes and researches for Appelbaum Training Institute from home. Her two boys are Adam (2) and Levi (10 months). April's husband Wes is an elementary school assistant principal. They have been happily married for 14 years. April enjoys photography and scrapbooking in her spare time. April has joined the DSACK Officers as Secretary.

Check out April's blog at <http://secondtimearound-vernyvern.blogspot.com>.

#### DSACK Has A Library For You!

Did you know that DSACK will mail books and DVDs? If you can't make it in to the office to browse the titles, check the list online at [www.dsack.org](http://www.dsack.org), click the New Families link and then click Lending Library. There you will find a list of books and DVDs along with a brief description of each. Just email or call DSACK and we will put your borrowed materials (along with a postage-paid return envelope) in the mail. It's easy!

#### Sensory Rebound

It's wonderfully fun sensory stimulation in a supportive atmosphere.

#### SENSORY Rebound Night! BIG KICKOFF!

There's no place like BounceU to get sensory stimulation, and our monthly Sensory Rebound provides a fun-filled opportunity for children with special needs to bounce, socialize, and be themselves in a supportive environment.

#### April 26th FREE!

- The Last Tuesday of every Month, 5:00-8:00PM
- Kick off is Free!/Regular Admission is \$7.95
- Socks and Reservations are Required
- Safe, Secure and Supportive Environment!
- Call today to make your Reservation

Limited space Available!

859-BounceU 859-268-6238

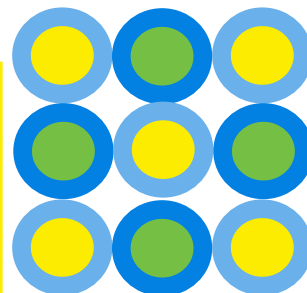
The Last Tues. of the Month!

\*\*\* RESERVATION REQUIRED \*\*\*

BounceU of Lexington  
3644 Boston Road, Suite 130  
Lexington, KY 40517

DSACK extends condolences to the family of David Littrell, who passed away on March 31st.

t h a n k   y o u   t o   o u r   s p o n s o r s !





# DSACK

*beautiful capable loved*

**NON-PROFIT**  
**U.S. POSTAGE**  
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**LEXINGTON, KY**  
**PERMIT NO. 114**

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



## c a l e n d a r

### 0-5 Parent Group & Playgroup

All meetings are held on the 2nd Saturday of the month at the DSACK office at 212 Two Oaks Road in Nicholasville from 10 a.m. until 12 noon. Child care is provided. Siblings and grandparents are always welcome. Call us at 859-494-7809 or email at [newparentgroup@dsack.org](mailto:newparentgroup@dsack.org).

**May 14th, 2011** – “Parent Show & Tell/Potluck Brunch” – Opportunity to share ideas and find resources. Bring books, toys, games and photos to describe something that has been valuable in your child’s development. Bring your favorite brunch dish, too. Come ready to share good food and conversation!

**June 11th, 2011** – “Arts and Science for Everyone” – KET’s Kathy Day will discuss how families can use two KET resources, Art to Heart and Everyday Science, to help stimulate brain growth and development. Young children can learn to love science by exploring the world around them. Lots of ideas for family fun and enrichment! Elementary Group is welcome to attend this program, but must RSVP to [newparentgroup@dsack.org](mailto:newparentgroup@dsack.org) 1 week prior.

**June 26th, 2011** (Sunday) – Summer Picnic for the entire DSACK community at a Legend’s game. 5:00 p.m. See page 2 for details.

## s u b m i s s i o n s

**Submission deadline is Monday, June 13th** and can be sent to Allison Kerschbaum at [dsack.org@gmail.com](mailto:dsack.org@gmail.com).  
**Send DSACK pictures** of your family member who has T21 to be included in the banner of the newsletter. Digital photos only. Photos should be of individual alone – head and shoulders preferred.  
**Do you...** \* Have an interest in placing an add in our newsletter?  
\* Know someone who might like to receive our newsletter?  
If so, please contact Allison Kerschbaum at (859) 494-7809 or [dsack.org@gmail.com](mailto:dsack.org@gmail.com).  
*Let’s get the word out about DSACK and our loved ones with Down syndrome who are beautiful, capable and loved!*

### Teen/Young Adult Group (Advocates In Motion – Aim)

New leaders this summer! Come out and meet Patrice Fischer and Mallory Marshall and plan on having lots of fun! As always, DSACK pays the cost for group members to participate in activities. For more information or to be added to the email list, contact [Patrice.fischer@uky.edu](mailto:Patrice.fischer@uky.edu) or call DSACK at 859-494-7809.

**May 20th, 2011** (Friday) – 7:00 p.m. Frozen Yogurt Night @ Orange Leaf behind Fayette Mall (152 W. Tiverton Way, Suite 170).

**June 10th, 2011** (Friday) – 7:05 p.m. Lexington Legends Game for Teen/Young Adult Group only.

**June 26th, 2011** (Sunday) – Summer Picnic for the entire DSACK community at a Legend’s game. 5:00 p.m. See page 2 for details.

**July 30, 2011** (Saturday) Dress-Up Dinner. Girls show up at DSACK office for hair and nail party at 4:00. Boys are welcome to come during this time as we will have music and snacks. We will meet at an Italian restaurant TBA around 7ish.

**August** – POOL PARTY! TBA!

**August 4th, 2011** (Thursday) - DSACK Community Night at Whitaker Bank Ballpark. Come watch the Legends play and help us celebrate our DSACK Community! Game starts at 7:05pm.

**July 9th, 2011** – “Megan’s Story” – A story every parent should hear. Her many accomplishments as a student and an athlete are impressive. Just in her early 20s, her attitude and poise make her a popular speaker. Megan has Down syndrome and will relate how she has met, and continues to meet, challenges and will discuss her college classes. Her mother, Dr. Malkanthie McCormick will speak from a parent’s perspective.

**August 4th, 2011** (Thursday)-DSACK Community Night at Whitaker Bank Ballpark. Come watch the Legends play and help us celebrate our DSACK Community! Game starts at 7:05pm.

### Elementary Group

**June 26th, 2011** (Sunday) – Summer Picnic for the entire DSACK community at a Legend’s game. 5:00 p.m. See page 2 for details.

**July 23rd, 2011** - POOL PARTY! TBA

**August 4th, 2011** (Thursday)-DSACK Community Night at Whitaker Bank Ballpark. Come watch the Legends play and help us celebrate our DSACK Community! Game starts at 7:05pm.