



**THE EXECUTIVE COMMITTEE NEEDS YOUR HELP**

DSACK's newly-constituted Executive Committee has been hard at work tackling issues and meeting the needs of our families. In order to do this, they have provided a number of opportunities just waiting for the right person to take them on.

- Grant writing
- Community awareness
- Development of DS Clinic at UK
- Public speaking
- Membership drive
- Fund raising
- Future growth
- Parent groups
- Parties/social events
- Education/seminars
- New parent packet
- Newsletter
- Brochures
- Web master
- Press releases
- PowerPoint development

Please take inventory of your talents and interests and sign up to help. Call the new DSACK phone number: 494-7809, or email or call one of the EC members.

**DSACK HAS A NEW PHONE NUMBER... HOW ABOUT YOU?**

DSACK has purchased a cell phone and will be passing it along to Executive Committee Members to answer. DSACK's new phone number is (859) 494-7809. Has your contact information changed? If so, contact DSACK with your updated contact information, and we will update our file.

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## EXECUTIVE BOARD MEMBERS

Traci Brewer	523-3902
Courtney Elbert	879-2182
Ellen Fernandez	219-0023
Michelle Gilliam	223-4207
Becky Lesch	252-9523
Malkanthie McCormick	273-0632

## 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

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

Charles Hill, M.D., OB/GYN

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

Dixie Miller, Parent, Developmental Interventionist

John Riley, M.D., Pediatrician at PAA

Meg Steinman, Parent

Artist Community ([www.latitudearts.org](http://www.latitudearts.org)). We would also like to thank the various businesses that hosted the Piggy Banks for us: Lexington Seafood, George's Deli, Annette's on Vine, Third Street Stuff and Coffee, and the Drug Mart Pharmacy in Nicholasville. There were also two schools to whom we are grateful. Veterans Park Elementary and Tates Creek High School enthusiastically invited a DSACK Piggy to stop by and gobble up some of their students' generous donations!

**A BIG, BIG thank you to Veterans Park Elementary. The DSACK "piggy" dropped by for a visit, and the children of Veterans Park brought in their change in a huge way. In less than two hours, the children donated \$1,119.00. WOW!!!!!! Thank you to the children, teachers and staff of VPE, especially Judy Blakeman, for getting the word out. You have all truly made a difference!**

Finally, DSACK would like to thank the Bank of Lexington for hosting this wonderful event and helping DSACK to raise about \$1800!

## SUMMER CAMP OPPORTUNITIES - HURRY! REGISTRATION HAS ALREADY BEGUN!

Lexington Parks and Recreation offers Therapeutic Recreation Fun Camp and Camp Kearney, which offers a 2-week inclusive camp setting. Therapeutic Camp runs from June 9th-July 18th with three two-week sessions. Camp Kearney runs for two weeks July 21st -31st.

Therapeutic Recreation Fun Camp, which is designed for all youth and young adults with disabilities between the ages of 5 - 21, will be held at Castlewood and Woodland Parks. The camp will operate from 7:45 am - 4:30 pm, Monday - Friday. The Castlewood Camp is open to ages 5 - 12 while the Woodland Camp is open to those 13 - 21 years. The cost is \$150 per session and scholarships are available. Campers who qualify for free lunch through their school may be eligible for a reduced camp fee.

For more information, visit [http://www.lfucg.com/parks/summer\\_camps.asp](http://www.lfucg.com/parks/summer_camps.asp) or call 288-2928

## SECOND SATURDAY PARENT GROUP SITTER SPOTLIGHT

*Submitted by Michelle Gilliam*

The monthly parent group is also a monthly playgroup for our children. As the parents meet together for 2 hours, the children are cared for in a classroom by these incredible people. To my knowledge, no child has ever cried or asked for their parents while being cared for in this group. Some parents have been amazed at what their little ones have accomplished in there and nobody ever wants to leave! The parent group would not be so well attended month after month if it weren't for the quality childcare these ladies provide. They are a huge reason for the success of our "Second Saturday" meetings!

Gina Clark joined us recently after calling DSACK offering to become involved with our children. It was perfect timing and we are so glad she is here. Gina is from Louisville and is a sophomore at UK majoring in Special Education, specifically moderate to severe disabilities. She became interested in this field after doing volunteer work at a special needs school in Louisville. In addition to being a student, she is employed at a Real Estate Institute doing clerical work. In her free time she enjoys friends and family, jogging and music.

Mackenzie Gathof has been with us since we started the group last October. She is from LaGrange and is a student at UK majoring in Communication Disorders with a minor in Family Studies. Her decision to pursue Communication Disorders and working with individuals who have disabilities has been influenced by her oldest brother, who has disabilities himself. Mackenzie says she loves working with a diverse group of individuals, especially children and plans to do so for the rest of her life! She currently tutors a student and close friend who has Down syndrome in a college algebra course at the community college.....and she loves every minute of it!

Coady Kleinert has also been with us since Day One! She is graduating from UK this May with a degree in Russian Studies. Next year she will be working as an inner-city special education teacher for Teach for America and will also be pursuing her master's degree in education. She will be leaving Kentucky for these new adventures, but assures us that she would like to come back as a guest sitter when she is in town! Coady's favorite things are reading, running and riding bikes. *Coady, we wish you all the best and know you will be a blessing everywhere you go! We will miss you!*

## TR POSITION IN JEOPARDY - YOU CAN HELP!

*Submitted by Meg Steinman*

The Fayette County Parks and Recreation, Therapeutic Recreation (TR) Programming Division has been providing programming for individuals with disabilities across the life span. A few examples of the programming offered includes swim lessons, exercise classes, floor hockey, bowling, summer camp, therapeutic horseback riding and social dances. In addition to programming for individuals with disabilities, this group also helps with programming for senior citizens. A position for a Program Specialist-Senior for the TR Division was created and posted. Before the interviews could occur, there was a hiring freeze and now there is a good chance that this position will be taken away. This position is critical to continue providing programming, as well as creating new programming for individuals with disabilities.

Please take a moment to write to the mayor of Lexington and the LFUGC council in support of this position. The email address for the mayor is: [mayor@lfucg.com](mailto:mayor@lfucg.com). Visit <http://www.lfucg.com/council/council.aspx> to email the members of the council. Please take a moment and email the council! We need to get enough community support to enable the TR program to grow!

## SPECIAL OLYMPIC DANCE WAS FABULOUS!

For the past several years, DSACK has contributed towards the annual Special Olympic Dance. This year's dance was held Friday, April 11 at Lexington Catholic High School. According to Karen Boudreaux, who attended the event and hosted a table for DSACK, "It was FABULOUS!! All of the kids had a great time, including all of us (Moms and Dads). Julia Steinman celebrated her 17th Birthday with everyone singing to her and she was just BEAUTIFUL with a smile from ear to ear. It made me want to cry tears of JOY! Megan was just as excited for Julia, as if it had been her own Birthday, and so was Kate and Christian. Jeremy was all smiles as well. I'm sure there were others from DSACK there, but we were so busy dancing and celebrating that we may have missed some of our good friends."

## "THIS LITTLE PIGGY" RAISES BIG, BIG MONEY AND WINS AWARD!



*Submitted by Traci Brewer and Courtney Elbert*

On April 17th, The Bank of Lexington officially wrapped up the "This Little Piggy" campaign! DSACK was one of several local charities chosen to participate. The charities were given four "Piggy Banks". Then each worked with local artists to decorate the piggies, and

collaborated with local businesses to "host" the piggy banks. **A BIG PIGGY congratulations and thanks to Latitudes Artist Community whose DSACK piggy won the award for "Most Creative". DSACK is honored to have worked with Latitude, and appreciates their passion, creativity, generosity, and advocacy for our group!** DSACK would like to again thank the artists who decorated our Piggy Banks: Theo Edmonds of Hillbilly Chic ([www.coollifekey.com](http://www.coollifekey.com)), Helene Steene ([www.helenesteene.com](http://www.helenesteene.com)), and Latitude

## GLUTEN-FREE RECIPES FOR THOSE WITH CELIAC DISEASE

*Recipe taken from epicurious.com.*

Celiac disease, often confused with an allergy to wheat, is a digestive disease that causes an immune reaction to a protein called gluten, damages the small intestine, and interferes with the absorption of nutrients with food. People with celiac disease cannot tolerate gluten, which is found mainly in foods such as wheat, rye, and barley, but is also in many products you would not expect (like stamps and envelope adhesive!). Approximately 5-10% of people with Down syndrome are diagnosed with celiac disease. The most effective treatment is a gluten-free diet, so we will try to highlight one or two recipes in every newsletter for our families that might benefit. For more information, visit [www.celiac.com](http://www.celiac.com) or [celiac.nih.gov](http://celiac.nih.gov).

### Gluten-Free Blueberry Corn Muffins

- 2 tablespoons tapioca flour plus 2 tablespoons for dusting pan
- 1 1/4 cups finely ground yellow cornmeal
- 2/3 cup white rice flour\*
- 1/4 cup cornstarch
- 1 tablespoon plus 1 1/2 teaspoons sugar
- 2 teaspoons baking powder
- 1 teaspoon baking soda
- 1 teaspoon fine sea salt
- 1/2 cup (1 stick) unsalted butter, melted
- 1/2 cup whole milk
- 1/4 cup plus 2 tablespoons pure maple syrup
- 4 large eggs
- 1 cup fresh or frozen (unthawed) blueberries (about 5 ounces)

\*Be sure to use white rice flour; brown will result in gritty muffins.

Special equipment: Muffin pan with 12 (1/2-cup) cups

Position rack in lower third of oven and preheat to 400°F. Butter muffin pan and lightly dust with tapioca flour, knocking out excess.

In large bowl, whisk together tapioca flour, cornmeal, rice flour, cornstarch, sugar, baking powder, baking soda, and salt.

In medium bowl, whisk together butter, milk, maple syrup, and eggs.

Using wooden spoon, stir wet ingredients into dry ingredients until fully combined. Gently fold in blueberries.

Divide batter among muffin cups, filling each cup 3/4 full. Bake until tops are domed and feel springy to the touch, and toothpick inserted in center comes out clean, about 15 minutes. Let cool in pan 5 minutes, then turn out onto wire rack.

## NEWS TO USE

### SURVEY OF RELIGIOUS PARTICIPATION

Researchers in the Department of Special Education and Rehabilitation Counseling at the University of Kentucky are conducting a survey of parents of children with disabilities and their experiences with their faith communities such as their church, synagogue, mosque, temple, etc. We are interested in finding out the factors that influence parents' participation, or lack of participation, in a faith community as it relates to their child with a disability.

We would appreciate it if you would take the time to fill out a survey. If you decide to participate, your answers will remain completely anonymous. Your name will not be known unless you choose to participate in a follow-up telephone interview that will occur at a later time.

The project is being done by Belva Collins, Ed.D. (professor and DSACK Advisory Board Member) and Melinda Jones Ault, M.S. (doctoral student), both at the Department of Special Education and Rehabilitation Counseling at the University of Kentucky. If you have any questions or comments, you can contact Belva Collins at 859-257-8591 or e-mail her at [bcoll01@uky.edu](mailto:bcoll01@uky.edu). You can contact Melinda Ault at 859-257-3759 or e-mail her at [mjault@uky.edu](mailto:mjault@uky.edu). If you have further questions or concerns, you can contact the University of Kentucky Office of Research Integrity at 859-257-9428.

Thank you very much for your time and support. Please note that by completing the survey, you are giving your consent to participate in the survey and you are giving us permission to use the results in written or oral presentations.

Please start the survey by going to <http://www.faithsurvey.org/>. If you prefer a paper version of the survey, contact Melinda Ault at [mjault@uky.edu](mailto:mjault@uky.edu) or 859-257-3759. It should take you about 15-20 minutes to complete.

## SURVEY OF GRANDPARENTS OF CHILDREN WITH DISABILITIES

As a doctoral student at the George Washington University Graduate School of Education and Human Development's Department of Teacher Preparation and Special Education, Margaret Dougherty is conducting a research study to investigate the needs of Kentucky grandparents of children age birth to 21 years with disabilities.

She would like to personally invite grandparents of children with disabilities to participate in this study by completing a survey online through the link listed below or by requesting a mailed pencil/paper survey.

Grandparent insights and perspectives are critical to the success of the study's objective, helping professionals to learn the needs of grandparents whose grandchildren have disabilities. If you know of any Kentucky grandparents of children age birth to 21 years who have disabilities, please share this survey information with them.

The survey will take approximately 20 minutes to complete. Your responses are anonymous. They will be used for research purposes only and will be pooled together for analysis. No identifying information will be collected or maintained.

*Continued on page 6*

## CELEBRATIONS

Did you see Julia Steinman on the front page of the Herald-Leader last month? Julia was the focus of an article discussing several recent developments that have shed a positive light on Down syndrome – The Memory Keeper's Daughter movie on Lifetime Television and the Brighter Tomorrows module developed by IHDI. The article showed Julia at school and at her job at Child Development Center. Way to go, Julia!

Did you see Megan McCormick in the Herald Leader also? Megan looked beautiful and athletic as she struck a pose with her fellow squad members of the Kentucky Elite Showcats! According to the Herald Leader, the Showcats are made up of athletes with special needs ages 11 to 43 and are seven-time national champions in their own right. Every year they've entered, the Showcats have won their division at the Cheersport Cheerleading and Dance Competitions in Atlanta, which annually brings in some 15,000 cheerleaders and 50,000 spectators. In recognition of their accomplishments, Cheersport is sending the Showcats on an all-expenses-paid trip to perform in exhibition at the Cheerleader Worlds Competitions in Orlando, Fla., in late April. It will be the first time a special-needs team has performed at the event, which annually draws the top cheer teams from throughout the United States and around the world, said Mary Fehrenbach, coach of the Kentucky Elite Showcats. Megan and her teammates will get to stay at Disney World Resort and visit the Disney parks!

Several of our families are involved in the Toyota Bluegrass Miracle League this year, which opened its season April 19th. Come on out and watch our kids PLAY BALL!

Happy Birthday to Kate Boudreaux, who celebrated a birthday in March, Julia Steinman, who celebrated a birthday in April, and Callie Baesler, who will be 10 this June!

Congratulations to Sam Elbert who participated in the "Win-O-Lympics" on April 13th. Sam participated in 4 events (bowling, commando crawl, bean bag toss, and barrel/tennis ball throw). In addition to a Gold medal, two Silver medals, and one bronze medal, Sam was awarded the "Win-O-Lympic Spirit Award". Sam enjoyed the opening ceremony where the athletes paraded around the Paul Lawrence Dunbar gymnasium while waving to all of the fans!

Have something you want to celebrate? An award, birthday, or some other achievement? Email submissions to Courtney Elbert at [celbert@adelphia.net](mailto:celbert@adelphia.net) with "Newsletter Item" in the subject line for inclusion in the newsletter.

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Your participation is greatly appreciated. Completion of the survey will be an indication of consent. A summary of the results will be made available through this survey source's future newsletter or listserv communication. Margaret is asking that you please complete the survey by June 1, 2008.

To access the survey, visit [https://www.surveymonkey.com/s.aspx?sm=yYzqDy8FGsDpqgorxKgRRA\\_3d\\_3d](https://www.surveymonkey.com/s.aspx?sm=yYzqDy8FGsDpqgorxKgRRA_3d_3d). If you have any questions or if you wish to have a paper copy of the survey with a postage paid return envelope sent to you, please contact Margaret Dougherty at (502) 893-8843 or [marg@gwu.edu](mailto:marg@gwu.edu). Further information regarding this study may be obtained by contacting Dr. Marian Jarrett, Principal Investigator at (202) 994-1509 or [mjarrett@gwu.edu](mailto:mjarrett@gwu.edu). Information regarding your rights as a research participant can be obtained through the George Washington University Office of Human Research at (202) 994-2715 (study identification number: 020873).

#### **SURVEY ABOUT POSITIVE ASPECTS OF PARENTING CHILDREN WITH DISABILITIES**

The study is being conducted by Teresa Ulman, M.S., as a dissertation project under the direction of Dr. Elisabeth Dykens, Ph.D. through the Vanderbilt Kennedy Center. Eligibility requirements are as follows:

- The parent must be 18 years or older
- The parent must have a child between the ages of 8 and 25 with a diagnosis of one (and only one) of the following: Angelman syndrome, autism or PDD-NOS, Down syndrome, Prader-Willi syndrome, or Williams syndrome.

We know parenting a child with a disability is hard. But many people find that the experience has led to personal growth in unexpected ways. Surprisingly there are almost no studies that look at the ways the experience can strengthen people, while there is plenty of research that looks at negative outcomes for parents. This study will provide for a more balanced understanding of how having a child with a disability can change a person's life.

Benefits of the study include an opportunity to reflect upon the positive psychological growth that you may have experienced following the birth of your child with a disability.

The survey will take approximately 45-60 minutes

to complete and consists of a series of questionnaires about you and your child. At the end of the study you will have the opportunity to write your thoughts in an unstructured format. For further information, you may contact Teresa Ulman by email at [Teresa.ulman@vanderbilt.edu](mailto:Teresa.ulman@vanderbilt.edu) or by phone at 615.414.9665 or 1.888.322.5339. You may begin participation in the study immediately by visiting:

<http://kc.vanderbilt.edu/parentstudy>

#### **BARNES & NOBLE CEO**

Melissa Ann Riggio, 20-year old daughter of Barnes & Noble CEO Steve and his wife, Laura, and sister to Laura and Christina passed away on April 7th.

Melissa was diagnosed with leukemia last summer and since that time she fought long and hard to overcome the disease. Last June, she graduated from Bernards High School in Bernardsville, New Jersey, where she was crowned Prom Queen.

Although Melissa was born with Down Syndrome, she lived a full and extraordinary life. Melissa worked at the YMCA in Bernardsville and recently talked about entering a post secondary program so that she could become a counselor at the YMCA. She loved to read and listen to music, and she loved to write. Melissa was a poet and songwriter. Melissa was taking voice, drama, and dance lessons as she also aspired to become a singer one day. Some of Melissa's songs were recorded by singer/songwriter, Rachel Fuller.

In her song entitled, "The Ring," Melissa expresses her thoughts on being a woman and her purpose:

*I'm in the Ring outside  
I'm following my belief  
I'm looking at the sky  
I saw God following my heart  
I'm an ordinary woman*

*The Ring is falling down my way  
The wind is blowing me away  
The Ring is falling down,  
Down my way  
The wind is blowing me away*

*And so I came back to  
The center of the Ring  
Am I just a broken angel?  
God has sent me here to heal  
To be an ordinary woman.*

In lieu of flowers, the family has asked that donations be made to The Valerie Center at Morristown Memorial

Hospital, Morristown Memorial Health Foundation, P.O. Box 1956, Morristown, N.J. 07962.

When making a donation, please indicate that it is in memory of Melissa Riggio. People can send their expressions of condolence to Steve Riggio directly at his office:

Stephen Riggio, CEO  
Barnes & Noble, Inc.  
122 Fifth Avenue  
New York, NY 10011

#### **MEMORY KEEPER'S DAUGHTER LIFETIME MOVIE AIRED APRIL 12TH**

*Submitted by Nicole Maher*

If you read the book "Memory Keeper's Daughter" then you most likely waited with great anticipation for the Lifetime movie adaptation which premiered April 12th. If you read the scathing review in the Herald Leader then you may have also watched with a bit of apprehension as well.

Knowing full well that Lifetime movies are not high budget films I was pleasantly surprised by the movie. All in all it was an enjoyable film that promoted the positive aspects of those who have Trisomy 21. While it did not have the character development or the subtleties of the plot that made the book a best seller, it definitely will make viewers rethink their preconceived ideas about those born with Down syndrome and the lives that they lead.

If you have time to watch it when it airs again I think you will enjoy it. If you have not read the book by Kim Edwards, a local author, then I highly suggest you make the time to do so. You won't regret it!

#### **ADVOCACY ALERT**

##### **SPECIALTY LICENSE PLATE FOR DOWN SYNDROME**

The Green River Area Down Syndrome Association (GRADSA) is collaborating with other DS groups in Kentucky to apply for a specialty license plate promoting Down syndrome awareness. Before being approved, a group must receive 900 applications, along with a \$28 fee for each. If you and/or your family would be willing to order a plate, please send an email to Caroline Baesler at [baeslerjunk@alltel.net](mailto:baeslerjunk@alltel.net) with "Specialty Plate for DS" in the Subject line and the number of license plates your family would order. NOTE: The \$28 fee must be paid annually when you renew your car tags.

#### **MAKING CONNECTIONS**

##### **MENTOR FAMILIES NEEDED**

The Human Development Institute at UK (HDI) is looking for families of children and young adults with developmental disabilities to share their stories in one-on-one experiences with pre-professional trainees. These trainees may be University of Kentucky graduate students working on a Certificate in Developmental Disabilities, Pediatric Medical Interns/Residents, medical students, social work students, or students in Lexington Theological Seminary's Pastoral Care and Counseling Class.

The time commitment is minimal—usually either two visits during a month or a few visits over a semester—but makes a huge impact on the trainees' perspectives of children with disabilities and their families. Families are usually asked to meet with the trainees 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. If you would like more information, please call 257-3360.

##### **CHILD DEVELOPMENT CENTER LOOKING FOR STORIES**

2008 marks 50 years of service for the Child Development Center of the Bluegrass. The staff are looking for stories to use as part of the recognition of the years of service. If you have a story you would like to share please contact Judy Templar at (859) 278-0549.

##### **DOES SOMEONE YOU KNOW NEED A "THANK YOU"?**

The Executive Board needs your help in making sure all supporters of DSACK – support of any kind, financial or otherwise – are thanked in a timely manner. If you know someone who should receive a note of thanks, please contact DSACK at 494-7809 or contact an EC member.

##### **DAYTIME OPPORTUNITIES FOR CHILDREN NEEDED**

A DSACK Parent is looking for summer, daytime options for her son who is 13 years old, as both parents work during the day. Do you know of any summer daytime opportunities for children 14 – 21? If so, please contact DSACK at 494-7809.

## SUCCESSFUL PARENT'S GROUP EXPANDING

DSACK's Second Saturday New Parent Group has been SO successful that the Executive Board is considering the interest and feasibility of creating groups for older children and teens. If you are interested in stepping up to help coordinate the group, have ideas to share as we form the group, and/or if you are interested in participating, contact Courtney with your thoughts at celbert@adelphia.net with subject "Older Child Group" or DSACK at 494-7809.

## DONATIONS RECEIVED

**TOYOTA MOTOR MANUFACTURING-  
Thanks for being our first 2008 Buddy Walk  
Sponsor!**

## CALENDAR

### BUDDY WALK MEETINGS

**Tuesday, May 9th & 20th, June 3rd & 17th 5:30 p.m.**  
APS Communications  
3320 Clays Mill Rd.

### DSACK ANNUAL SUMMER PICNIC

**Sunday, June 1st 4:00 p.m.**  
Southland Park Shelter #1 on Hill-N-Dale Dr.

DSACK will provide the main dish and drinks. Please bring an appetizer, salad, side dish, or dessert to share, along with chairs and blankets, and any outdoor activities you would like to play and/or share.

### PARENT GROUP - May 10th, June 14th, & July 12th 9-11 am

Child Development Center, 465 Springhill Drive

Moms and Dads, if your child who has Down syndrome is between 0-5 years old, you're invited to monthly meetings on the second Saturday of every month from 9-11 a.m. at the Child Development Center, 465 Springhill Drive in Lexington (behind Lafayette High School/SCAPA). We will begin with a presentation and childcare is provided. For more information, contact Michelle at 859-223-4207 or mandm@pngusa.net. The dates for the upcoming months are May 10, June 14, and July 12th.

### DISASTER PREPAREDNESS FOR KENTUCKY'S AT-RISK POPULATION

**June 16-17, 2008 4:00 p.m.**  
Lexington, KY

A conference to improve the effectiveness of first responders and service providers. More information to come.

### 36TH NDSC NATIONAL CONVENTION

**July 11-13, 2008**  
Saturday, September 27, 2008  
Boston, MA

For more information,  
visit <http://ndscenter.org/news/events.php>.

### SAVE THE DATE FOR BUDDY WALK 2008

**Saturday, September 27, 2008**  
Keeneland Race Course

Interested in helping out?  
Contact Martha at [mcampbell@apscommunications.com](mailto:mcampbell@apscommunications.com).

### FRIENDS BUDDY CRUISE

**October 17, 2008**  
Royal Caribbean's Sovereign of the Seas

FRIENDS-Support, a Florida-based Down syndrome support group, will be hosting the first ever cruise to raise awareness for Down syndrome. We are teaming up with Royal Caribbean for an exciting 3-night cruise to the Bahamas! To join this one-of-a-kind adventure, visit [www.cruisesforu.com/ccs/20857](http://www.cruisesforu.com/ccs/20857) or contact FRIENDS-support at [joinus@buddycruise.com](mailto:joinus@buddycruise.com).

### DSACK AT THE LEGENDS GAME

Date T.B.D.

## BREAKING NEWS

**TWO BILLS MAKE PROGRESS IN CONGRESS - CONTACT YOUR SENATORS & REPRESENTATIVES TODAY!**

### • PRENATALLY DIAGNOSED CONDITION AWARENESS ACT

Contact your Representatives and Senators today. Ask them to cosponsor HR 3112 and S 1810.

### • FINANCIAL SECURITY ACCOUNTS FOR INDIVIDUALS WITH DISABILITIES (FSAID)

Contact your Representatives and Senators today. Ask them to cosponsor HR 2370 and S 2743.

### • Congressman Ben Chandler

Phone: (202)-225-4706  
Fax: (202)-225-2122

### • Senator Jim Bunning

Phone: (202)-224-4343  
Fax: (202)-228-1373

### • Senator Mitch McConnell

Phone: (202)-224-2541  
Fax: (202)-224-2499

FOR MORE INFORMATION ON THESE BILLS -  
GO TO [WWW.DSACK.ORG](http://WWW.DSACK.ORG) OR [WWW.NDSS.ORG](http://WWW.NDSS.ORG)

## COURTNEY'S CONTEMPLATIONS



Spring is a time of hope. A time of courage and resilience in a world that can often dampen spirits, blow winds of indifference, and create climates that are harsh and cold. Spring is a time to bloom. A time to take action and exclaim in a bold way, "I am beautiful and worthy and good!"

Recent events have troubled me as a person and as a parent of a child with Down syndrome - troubled me deep down to my roots. Changed me.

Internationally, I felt disgust deep at my core on February 2nd when the world thought a terrorist attack in Iraq involved a remote detonation and the unknowing participation of two women with Down syndrome. I cannot surmise something more purely evil and cowardly. (It was later revealed that the individuals did not have Down syndrome. I

seeped a small sense of relief amidst the evil).

Just a week later on February 11th, on a national level, it was reported that UNC professor Albert Harris told students in his embryology class, "In my opinion, the moral thing for older mothers to do is to have amniocentesis, as soon during pregnancy as is safe for the fetus, test whether placental cells have a third chromosome #21, and abort the fetus if it does." (Thankfully, Lara Frame was in Harris' class and happened to have a brother with Down syndrome. She, and others in the T21 community, challenged Harris and the Ivory Tower of UNC. They courageously took action and sprouted seeds of hope.)

On a personal level, I've been disheartened and deceived by the actions of the Administration of a non-profit, community-based charitable organization who claims to support and serve people with disabilities. (In response, a group of parents have bonded together with courage, hope and action).

The winds of the times can be harsh. The climate can be cold. It would be so tempting to hole up, pull back, hide, recoil within, give up hope, rot. But, spring reminds me of the tiny flower miraculously growing in a sidewalk crack. A tiny miracle beautifully and silently screaming out hope through action - regardless of its surroundings or its chances.

Our loved ones with Down syndrome have an optimism, resilience, courage, patience, strength, trust, beauty and hope that makes me less afraid to take actions fertilized by hope and courage.

What hopeful actions are you sharing with our DSACK community? What hopeful attitudes and actions are you broadcasting across the lawns of our society? It's time for you to bloom!

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## SUBMISSIONS

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

Submission deadline for May/June Issue is Wednesday, June 11th and can be sent to either Courtney at [celbert@adelphia.net](mailto:celbert@adelphia.net) or Caroline at [baeslerjunk@alltel.net](mailto:baeslerjunk@alltel.net). 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 Caroline Baesler at (859) 619-1392 or [baeslerjunk@alltel.net](mailto:baeslerjunk@alltel.net). 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.