

Down

Syndrome

Association of Central Kentucky



WHAT'S GOING DOWN WITH DSACK

VOLUME II – NUMBER III

SEPTEMBER-OCTOBER 2008

EXECUTIVE BOARD WANTS TO THANK YOU!

Executive Board would like to acknowledge the following people and organizations with a special THANK YOU:

- DSACK has been awarded a grant from **Central Baptist Hospital** in the amount of \$2500.00. We are so excited for the opportunities this grant will create for our members. A portion of these funds will go to our scholarship opportunities for families to attend educational conferences. DSACK will use the remainder of this grant to send out Birthday Cards with important information, resources and reminders pertinent to our family member with Down syndrome. Be looking for these in the near future!
A HUGE “thank you” to Central Baptist and to Ted Collins, who was so instrumental in obtaining this grant for DSACK!
- **Ron Boudreaux**, of Paducah, KY passed away recently. Ron was the Father of Kerry Boudreaux, Father-in-Law of Karen, and Grandfather of Kala, Kelsey and Kate. At the request of his family, contributions were made to DSACK in his memory. DSACK is honored to be the recipient of such generosity and wishes the best to the Boudreaux family in this time of loss.
- In addition to the “This Little Piggy” fundraiser, **Mike Marks** and the **Bank of Lexington** allow DSACK to use their Board Room on a regular basis. Thanks to their generosity, the DSACK Advisory Board has a convenient and comfortable place to meet! Please stop by the Bank of Lexington at the intersection of New Circle and Harrodsburg Road for your banking needs, and thank them for their support too!
- **Judy Templar** and the **Child Development Centers of the Bluegrass** allow DSACK to use their facility for our monthly “2nd Saturday Parent Group” meetings and playgroup! Thanks to you, our group has been a huge success!
- **Nicole Maher** has volunteered to restructure and revitalize DSACK’s Lending Library. She has also

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

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

Dixie Miller, Parent, Developmental Interventionist

John Riley, M.D., Pediatrician at PAA

Meg Steinman, Parent

for the parade and came through with flying colors! DSACK had a truck decorated with new DSACK banners, a convertible, and dozens of walkers carrying Buddy



Walk signs and passing out candy and information. One wagon carrying children had a homemade sign that read, "Down Syndrome Rocks Baby!" Another had a sign saying, "More Alike Than Different". **The group was full of energy and excitement, and DSACK was selected for the Mayor's Award for the parade entry that best represented the parade theme, "Celebrate Freedom"!!** As awesome as all of that is, the best part of the parade was watching the crowd react to our group. As they read our banners and saw our beautiful children come by, their faces lit up and they cheered



and waved. One little girl near me said, while waving back to the crowd, "I am the Queen!" Thanks to all of the families who joined DSACK for the parade. A special thanks goes to Martha Campbell of APS for a great afternoon!



When asked about her experience at the Parade, Darrah Maher said, "I cannot wait to see the turn out at the Buddy Walk this year. It sure was a fun experience to be in the parade

with a bunch of other families who had kids with Down syndrome. I hope that people saw how kids with Down syndrome are just like the rest of us who do not have a disability."

PRESTIGIOUS E.N.T. DOCTOR TO SPEAK TO DSACK 2ND SATURDAY PARENT GROUP - ALL ARE WELCOME AND ENCOURAGED TO ATTEND ON OCTOBER 11TH AT 10:00.

Dr. Sally R. Shott is a pediatric Otolaryngologist (ENT) and practices at Cincinnati Children's Hospital Medical Center. She sees patients up to 21 years old. Dr. Shott has done extensive research on ear, nose, and throat issues and how they affect patients with Down syndrome. Some of her research includes the importance of sleep studies in children with Down syndrome to rule out and treat sleep apnea. Dr. Shott is a member of the American Board of Otolaryngology

and in 2006 she was elected the President of the Society of Ear, Nose, and Throat Advances in Children (SENTAC). For more information about Dr. Shott please visit, www.cchmc.org.

Dr. Shott will speak at 10:00 at Child Development Centers of the Bluegrass, 465 Springhill Dr., Lexington. Childcare is provided. DSACK will provide lunch following the meeting. For more information, contact: Michelle at mandm@pngusa.net or 859-223-4207.

MAKING PALS AT "CAMP PALS"

Submitted by Meg Steinman

"It was great". Those were the words that my daughter Julia said when asked about her experience at Camp Pals. "It was great" does not even begin to adequately describe this camp, or the people associated with the camp. Camp Pals is a week long camp housed at Cabrini College in Radnor, PA. The camp is geared for individuals between the ages of 14-21 who have Down Syndrome. Campers interested in the camp should be ready to thrive in a residential environment, work well in groups, and require minimal assistance with hygiene. Camper applications are screened and campers are selected. This year there were 63 campers selected. Each camper is paired with a volunteer counselor with similar interests, and they room together (in air conditioned dorms) for the week. Throughout the week all participants enjoy team building, develop friendships, fun activities and trips. In addition to the one on one camper/counselor ratio, there are additional counselors should a situation arise that additional supervision is necessary. This was Julia's first year at Camp Pals. She had 2 other friends from her dance team that attended this year as well that were from Lexington. Counselors are also carefully screened. Campers do pay tuition for the week. The counselors do not get paid for the week, it is totally voluntary.

Camp Pals was founded by Jason Toff and Josh Stein. The idea was born in Allentown, PA and grew out of a program that these young men participated in at high school that was called PALS (Peer Assisting Learning Support). Jason was the founder of the PALS program at his high school. Jason attended a leadership camp run by Julian Krinsky, and at this camp approached him about starting a camp for students with disabilities. Julian Krinsky agreed to sponsor the program, and agreed to start the camp the following summer. Later

that summer Jason and Josh attended the National Down Syndrome Congress Annual Convention and met Jenni Newbury. These three young people joined forces and Camp Pals was born.

With all that said, I would like to tell you about our experience. We applied for admission in early February, and found out in March that she had been accepted. A week before camp started we were contacted by her counselor, Kelly, a delightful young woman from the Philadelphia area. This was her first year at Camp Pals as well. We arrived with Julia's gear on Sunday, June 15. All campers were treated to a rousing welcome from staff and campers. Kelly joined us immediately, and after completing the necessary paperwork we went to the girl's dorm. This year there were four units for the girls. Julia was in the Red Robins. When we arrived at Julia's room there were tie-dyes red t-shirts with Red Robins on the front. The counselors in this unit also decorated socks. This was the uniform for the sporting competitions. We helped Julia unpack, and Julia ushered us to the door-eager to being her week at Camp Pals. We were able to email Julia, and the email was printed out and delivered to her. Kelly graciously gave us her cell phone number as well-just in case we wanted to see how it was going.

The week was packed full of activities. The campers and counselors met in the cafeteria for breakfast each morning. It was time then for activities. Campers were placed in activities based upon their interests. Some of the activities included art classes, karaoke, aerobics, cooking, and other sporting events. It was time for lunch, and after lunch the activities tended to involve all the participants. Monday evening after dinner the campers and counselors went to see Kung Fu Panda. Tuesday evening was spent at the bowling alley. Wednesday was a day trip to the beach-Ocean City, NJ. Campers and counselors had fun in the sand and water, and each group had a surrey to ride up and down the boardwalk. One day the camp had lessons from a local golf pro, and then spent the afternoon playing miniature golf. One afternoon was spent learning about different instruments, and then practicing with them. There was also camp wide sporting competition and a camp wide water balloon battle.

Friday night after dinner was a formal dance at the college. Saturday was up early to enjoy the final breakfast, then off to wash clothes and pack to come home. We picked Julia up in the early afternoon on Saturday. We all attended the closing ceremony. After

the recognition there was an open time for comments from parents, counselors and campers. I do not think there was a dry eye in the auditorium. Parents spoke of how wonderful it is to have a place where individuals with Down Syndrome are valued for the person they have become. I felt as did others that it was so wonderful for us to not have to advocate for acceptance. Many parents commented how wonderful it was to enjoy a few days of vacation themselves, knowing that their camper was having a wonderful time. The campers all mentioned how much fun they had. The counselor comments were so touching, and the majority of the comments were about how much the week had changed their life for the better, and that they learned so much from the campers. Many counselors thanked the parents for letting their child participate. Real friendships had been born during the week, between campers, counselors, and between campers and counselors.

Camp Pals has a website: www.camppals.com. You can read more about the camp. Clicking on the link for the blog will take you to a site with pictures and videos.

YOUR CHANCE TO WIN \$100 GIFT CARD!!

There is still time for you to borrow a DSACK piggy bank and raise funds for DSACK to develop a new website. The pigs have traveled to school, work and to an ice cream social! Do you know of a business that would like to host a pig for a week or two? Will you be attending a special event or party that would welcome a pig? Would you like to take a pig to work or school, or for a walk around the neighborhood? The winner will be announced at the Buddy Walk on September 27th, so if you would like to participate, please act quickly by calling DSACK at (859) 494-7809

THE FIRST YEAR JUST FLEW BY!

The 2nd Saturday Parent Group wants to wish Happy 1st Birthdays to Joella, John and Megan!! Their parents happily agreed to submit photos and articles about their little blessings. These babies (and their families) have been coming to our monthly meetings since they were only a few weeks old. We are so happy to share them with the rest of the DSACK community. HAPPY BIRTHDAY TO EACH OF YOU!! What a treasure you are!



HAPPY BIRTHDAY, MEGAN! *(Submitted by Megan's Family)*

Megan Lee Mandl was born on August 4, 2007 to proud parents Scott and Mary Mandl and big sister Tracy. She has been a sheer joy to watch this year! Clapping is her most recent way of expressing excitement, and she loves to roll all over the house. Her favorite song is Twinkle, Twinkle Little Star, and she especially likes to turn up the volume on the stereo with her feet while no one is looking! She believes she is ready for crunchy foods, but having only two teeth somewhat limits her intake right now. She is sitting up for longer stretches of time now and can't wait till she can chase her big sis! Happy Birthday Meg!

We're looking forward to year two!



HAPPY BIRTHDAY, JOHN! *(Submitted by John's Family)*

There's a volunteer in our church nursery who asks every parent who drops off their child, "Any special needs?" He's asking about bottles and diaper changing instructions. Still, we do a double take almost every time he asks. Our baby son, John, has Down Syndrome.

We were surprised with the diagnosis when he was born last September. While the adjustment has not been easy, John himself has been a wonderful surprise to us. He is a source of light in our lives. John does not behave as we expected. We did not expect to have a baby who is happy 95 percent of the time.

Our older daughter says, "God makes everybody special." An extra chromosome makes you think about this in a new way. We've learned that parents of children with special needs and their children are "normal" in so many ways and "special" in important ways. We know that John is not only special because he has special needs.

1. John has a special smile and an irresistible laugh. Sisters and books inspire squealing with delight.
2. John makes a special effort to learn and develop. Holding up his head and sitting up have not come easy, but he never stopped trying.
3. John has introduced us to many special families through DSACK. When John was just weeks old, Tammy and Dave Carter invited us to their home for

cake and conversation. Several other people called and came by letting us know that having a child with Down Syndrome is wonderful, worth celebrating. The positive and informative monthly DSACK meetings for parents of young children have been such an encouragement.

We are doing our best to learn how to help John. At times the information and the weight of the new responsibility overwhelm us. We do not always feel up to the task. Fortunately, we're not alone. Friends, family, therapists and doctors are integral team members in raising John. John's place as the youngest of three gives us important perspective. Parenting generally is hard, but good. Comparing children is unfair. No matter what happens or how we feel personally, our children need us to be the best parents we can be. John is teaching us other important lessons in how to be his parents. He's shown us that love and care go a long way toward diminishing stress. We have found a sanctuary in being together.

As we help John blow out the candles, we'll think about growth. When we brought John home, he slept a lot, so much it frightened us. We undressed him to keep him awake for feedings. We worried he'd never play or learn. Now, he loves to play. He's curious and has a fantastic laugh. John has grown in many ways. And, so have the rest of us. We've grown in our perspective of the gift of life. We're growing in our understanding of ideas like disability, inclusion, opportunity, and hope. And every day, we grow more in love with a little boy who has added such sweetness and goodness to our lives because he's special.



HAPPY BIRTHDAY, JOELLA! *(Submitted by Joella's Family)*

WOW!!! It is hard to believe that 1 year has already passed by and how can we possibly be celebrating Joella's FIRST birthday. This year has definitely been a whirlwind for my family and the most descriptive word I can come up

with is "WOW!" Just one year ago, coming to terms with the diagnosis of Down syndrome is probably the single hardest thing that I, as a mother, had to do. As a mom, you want the best for your children and bam you are hit with "We suspect your baby might have Down Syndrome." just hours after giving birth and after the doctor telling you that your baby is in the NICU with respiratory problems. I look back on that now and reflect on the raw emotion that I felt. At that particular moment after the doctor told us, I didn't care about the "Down Syndrome", but was most concerned about if my baby was going to be okay. We anxiously awaited the results of the echo because I knew enough about Down syndrome that there can be problems with the heart. I wanted to know if she was getting enough oxygen and wondered how long she would have to be under that hood. She was one healthy baby though weighing in at a whopping 8lbs 10oz and she dwarfed all of the premature babies in the NICU. That experience truly opened my eyes. Each day she was in the NICU, she progressed and was making her way to being home. I watched as some of the other babies were truly struggling each and every day. My heart hurt for those mothers who would place their tiny babies under their shirts to create that bond and warm them up. How truly fortunate we were. After 6 days, our Joella was released to come home, healthy heart and all. Then the thoughts starting swirling through my head about caring for a child with a disability and how was it going to differ from my other daughter. I began feeling anxious about the future and how exactly was I going to handle this because right at that moment, it wasn't any different. Caring for Joella was no different than caring for my other daughter when she was an infant. Sure, I worried more about her breathing and keeping her warm after the stay in the NICU, but other than that she ate, slept, pooped, peed, just as my other daughter did. The days quickly passed and my

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CELEBRATIONS

- Welcome to new DSACK members Helen and Richard and baby Gracie Elaine born this April! Congratulations and welcome to the DSACK family!

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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love grew and grew for my precious girl. There would be days that I actually wouldn't even think about the "diagnosis" and maybe that really was all a bad dream, yep the doctors had to be wrong. Nope, that just wasn't the case especially after seeing the karyotype in black and white with Trisomy 21 staring me back from the page and maybe my safeguard to feeling was actually denial. Reality. Time to face it head on. I loved my baby girl far too much to not do my best for her, so it began, doctor's appointments, and First Steps processes to begin therapy and let the whirlwind begin.

Consequently, the past several months have been filled with therapists, wonderful therapists, that have helped us in many of Joella's successes and reaching these milestones. These milestones that we strive for to make sure that development is happening like it is suppose to. It is important, but I have a new take on it since passing by a plaque in a store that read "Life is not a matter of milestones, but of moments." I had to buy it. So now, we are blessed with wonderful moments, like when she sat independently by herself at 6 ½ months. When she began playing and manipulating her toys at 10 months, and exploring them with her mouth. Our latest moment, is her scooting on the floor by herself on her tummy. These are all wonderful moments in her life that we will remember forever. These little accomplishments that we can notch off for her. She has also developed quite the personality as well, and yes, Mama has made her ROTTEN! Who wouldn't, did you check out those cheeks, totally kissable!!! However, this is something her therapists aren't quite as thankful, the rottenness that is. She has a way of "putting on the lip" as we say when she has had enough or just doesn't want to do the task at hand. It is quite pitiful for anyone to witness and as her speech therapist states, "It can break anyone's heart." So she has mastered how to get compassion and to manipulate that at quite a young age. She has a quirky little sense of humor and a contagious giggle. Her big sister, Laney, is by far one of her favorite people, and my favorite thing to watch as a mother, is how Laney can make Joella laugh so hard by just being silly. No one can make Joella cackle like her big sister and my most favorite sound to hear is my girls giggling together. I look forward to hearing that sound for a long time.

So, WOW, one year has passed and we survived the whirlwind of the diagnosis, the revolving door of therapists, and the "moments" reached. Even with the whirlwind, I believe that in all I have come to appreciate so much more in this world and have a greater understanding and compassion for all. I am thankful to be a part of this family of friends in our DSACK community and believe that we wouldn't be as far as we are without the support of the Parent group and the programs like First Steps. I am so grateful to all with inspiring stories that encourage my family to press on and to continue to strive to do our best to help Joella become the best that she can be. The road ahead may be filled with uncertainty and may or may not be easy, but as always in anything that my family has faced, we have managed to overcome by pure love. So, Happy Birthday Baby Girl, We Love You!!!

BUDDY WALK UPDATES

• SO MUCH MORE THAN A WALK!

Submitted by Martha Campbell

Come join us for the 6th Annual DSACK Buddy Walk which will be held on Saturday, September 27th at beautiful Keeneland Race Course. Registration begins at 8:30 a.m. and the Walk kicks off at 10:00. Last year our Master of Ceremonies, Megan Newquist of WTVQ, looked around and said to me, "I can't believe this! This is so much more than a walk!" She is right in so many ways – not only is the morning filled with activities and entertainment for the whole family – from music to balloons, face painting to a petting zoo – but the event also includes lunch and fellowship with some of the nicest people you'll ever meet.

As individuals and families whose lives have been touched by Down syndrome, we need to get the word out about this wonderful event! Send people to the website at www.dsack.org for information, form a team (remember our deadline is September 5th to be guaranteed a T-shirt), tell everyone you know that they can help support DSACK and have BIG FUN at the same time! If you know people who'd like to volunteer for the walk or donate a door prize or if you have any questions concerning

the Buddy Walk, please don't hesitate to contact me at mcampbell@apscommunications.com or at (859) 21-2017 EXT. 26.

See you at the BUDDY WALK!

• LOCAL ARTISTS AND TEXAS ROADHOUSE TEAM UP TO HELP THE BUDDY WALK

Submitted by Martha Campbell

"David Carter Fine Arts" has been painting murals for Texas Roadhouse since they first opened. Once the business started opening restaurants faster than David could paint, he brought on local Lexington artists David Soileau and Ted Hall. Now the artists and Texas Roadhouse on Richmond Road have teamed up to support the 6th Annual Buddy Walk!

David Carter, David Soileu and Ted Hall are producing and donating 4 new murals for the local Texas Roadhouse AND they have donated the money that Texas Roadhouse paid for the original artwork back to the Buddy Walk. How did all of this come about? David Carter's son, Joshua, has Down syndrome and the Carters have participated in the Buddy Walk with their team, "Joshua's Fanatical Family", for several years – so the Carters thought, "Why not bring these businesses together to support the 6th Annual Buddy Walk?" – David S., Ted and Texas Roadhouse all came on board!

Not only did the artists agree to donate their work, but Texas Roadhouse also agreed to donating 10% of purchases made on September 22nd and 23rd (with the enclosed voucher) back to the Buddy Walk.

Make your plans now to head to Texas Roadhouse on Monday, September 22nd for the "unveiling" of the new murals – a brief presentation will be made at 8:00 p.m. and you can meet the artists – and come back on Tuesday, September 23rd to enjoy the murals, have some great food and give back 10% to the Buddy Walk. Tell family and friends to make their plans to visit as well! Additional vouchers can be copied from this original or can be found at www.dsack.org.

• OH SAY WILL YOU SING?

Calling all singers (or even if you're not a singer)! To kick off the Buddy Walk this year we would love to have several of our beautiful children and adults with DS join Traci Brewer on stage to sing the National Anthem. We will coordinate several rehearsals to help everyone learn the words and get acquainted before the big event. If your child or adult is interested, please contact Traci at (859) 806-8196. DSACK is so excited about this and we hope to have a huge choir leading the walkers on our big day!

NEWS TO USE

• REVIEW BRIGHTER TOMORROWS FAMILY VERSION!

WWW.BRIGHTERTOMORROWS.ORG

It is with excited and grateful hearts that DSACK thanks our Advisory Board Member, Dr. Harold Kleinert and the Interdisciplinary Human Development Institute at UK for helping others to understand that people with Down syndrome are beautiful, capable and loved. The "Brighter Tomorrows Family Edition" is now up and running, and they are seeking input and reviews from DSACK. Please visit www.brightertomorrows.org to view the project and offer your feedback! It is important for DSACK members to offer feedback to individuals and groups that support us.

The purpose of the Family Version of Brighter Tomorrows is to provide accurate and balanced information to parents and prospective parents who receive either a newborn or in utero diagnosis of Down syndrome. The Family Version includes an extensive Resources Section with printable PDF files, specifically written for new or prospective parents. The Family Version also has a "video anchored" set of Q and As for parents. "Life Glimpses" of children are also featured. Each Life Glimpse was written by a parent of a child with Down syndrome and describes the journey of that child and his or her family.

Brighter Tomorrows, designed for national dissemination, was awarded to the University of Kentucky by the U.S. Centers for Disease Control. It was developed in full partnership with families from DSACK.

• TOP FIVE UNMET HEALTHCARE NEEDS OF KENTUCKIANS WITH DISABILITIES

"The Health and Wellness Forums for Kentuckians with Disabilities is funded by a grant from the Foundation for a Healthy Kentucky. The Foundation's mission is to address the unmet health care needs of Kentucky, by developing and influencing health policy, improving access to care, reducing health risks and disparities and promoting health equity."

Please take time to share your personal experiences in barriers to accessing health care in Kentucky. Please answer all questions as this survey is confidential and will not ask you for your name or any identifiable information.

Fill out this survey: http://www.surveymonkey.com/s.aspx?sm=nA2ydiEQbAPQ5uMLhR8_2fMw_3d_3d

• NDSS POSITION STATEMENT: SEQUENOM PRENATAL TEST

http://www1.ndss.org/index.php?option=com_content&task=view&id=2056&Itemid=233

The National Down Syndrome Society is aware of the new prenatal test being developed by Sequenom, that may provide improved safety and more accurate results for women who choose to undergo prenatal testing.

However, when it comes to explaining the results of prenatal testing for Down syndrome, nearly 25% of physicians admit to emphasizing negative information or actively urging parents to terminate their pregnancies (1). As such, the NDSS urges policymakers, health care professionals, and the Down syndrome community to work together to ensure that expectant parents are not pressured to terminate a pregnancy after receiving a prenatal diagnosis of Down syndrome.

Further, research has shown that mothers who receive a prenatal diagnosis of Down syndrome are often given an inaccurate, incomplete, and sometimes offensive description of Down syndrome from their medical providers (2). The NDSS continues to partner with health care professionals to ensure that the wide-spread proliferation of balanced, accurate and up-to-date information about Down syndrome is provided to expectant parents at the time of diagnosis.

(1) "Wertz DC. Drawing lines: notes for policymakers. In *Parens E, Asch A, editors. Prenatal testing and disability rights. Washington, DC: Georgetown University Press; 2000, p. 261-287*"

(2) "Skotko, B (2005). Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics and Gynecology, 192: 670-7.*"

• NEW DRUG REVERSES ALZHEIMER'S DISEASE WITHIN DAYS IN MOUSE MODELS

Due to the chromosomal links between Down syndrome and Alzheimer's, DSACK often cites articles pertaining to Alzheimer's research, as this research may help us understand more about Down syndrome and also meet the needs of our aging family members that develop Alzheimer's.

ScienceDaily (July 10, 2008)

Scientists report a remarkable improvement in Alzheimer's transgenic mice following treatment with a new drug. The study provides the first demonstration that an ionophore, a compound that transports metal ions across cell membranes, can elicit rapid and pronounced improvement in neuropathology and cognitive function in mouse

models of Alzheimer's Disease. Recent research has implicated dysregulation of metal ions in the brain particularly copper and zinc, in the pathogenesis of AD and the damaging accumulation of amyloid beta protein that is characteristic of this devastating disease.

ADVOCACY ALERT

• "TROPIC THUNDER" MOVIE A TOPIC BLUNDER!

Patricia Bauer of "Patricia E Bauer News & Commentary on Disability Issues" (www.patriciaebauer.com) has followed the series of events involved with the release of the Dreamwork movie, "Tropic Thunder", which brought on protests by various groups such as the ARC, NDSS and NDSC. Numerous articles appeared in national headlines and other media coverage, and a joint position statement was released by NDSC and NDSS. Please educate yourself further about this movie and the issues at hand. Below are excerpts from Bauer's website and Tim Shriver's op-ed on 'Tropic Thunder' posted on August 11th, 2008:

Special Olympics Chairman Timothy Shriver writes in the Washington Post that he has not yet been permitted to see "Tropic Thunder." But on the basis of previews, excerpts and written accounts, he concludes that the film is "an unchecked assault on the humanity of people with intellectual disabilities — an affront to dignity, hope and respect."

Shriver objects to a world in which people with intellectual disabilities routinely face discrimination, abuse, insult and institutionalization, are denied medical treatment and excluded from social movements. He cites Gallup poll data that found most Americans don't want a person with an intellectual disability in their child's school.

The use of language, he says, perpetuates and amplifies the public view that these people are "hopeless."

Sadly, they're such an easy target that many people don't realize whom they are making fun of when they use the word "retard." Most people just think it's funny. "Stupid, idiot, moron, retard." Ha, ha, ha. I know: I could be too sensitive. But I was taught that mean isn't funny.

... So, enough. Stop the hurtful jokes. Talk to your children about language that is bullying and mean. Ask your friends, your educators, your religious leaders to help us to end the stubborn myth that people with intellectual disabilities are hopeless. Ask Hollywood to get on the right side of dignity. I hope others will join me in shutting this movie out of our lives and our pocketbooks. We don't live in times when labeling and humiliating others is funny. And we should send that message far and wide.

• ABC FAMILY CHANNEL "THE SECRET LIFE OF AN AMERICAN TEENAGER" STARS ACTOR WITH DOWN SYNDROME!

http://abcfamily.go.com/abcfamily/path/section_Shows+Secret-Life-Of-The-American-Teenager/page_Detail

"The Secret Life of an American Teenager premiered in July on the ABC Family Channel. The show features Luke Zimmerman, an actor with Down syndrome, in a recurring role as the lead character Amy's older brother.

Be sure to respond to ABC and let them know how much you appreciate the inclusion of a character with DS. Any notes of congrats to Luke can go through info@dsala.org.

• HOUSE VOTES TO EXPAND CIVIL RIGHTS FOR DISABLED

House Votes to Expand Civil Rights for Disabled

By Robert Pear as published in *The New York Times* on June 26, 2008

The House passed a major civil rights bill on Wednesday that would expand protections for people with disabilities and overturn several Supreme Court decisions issued in the last decade.

The bill, approved 402 to 17, would make it easier for workers to prove discrimination. It would explicitly relax some stringent standards set by the court and says that disability is to be "construed broadly," to cover more physical and mental impairments. Supporters of the proposal said it would restore the broad protections that Congress meant to establish when it passed the Americans With Disabilities Act that President George Bush signed in 1990.

The chief sponsor of the bill, the House Democratic leader, Representative Steny H. Hoyer of Maryland, said the situation was now bizarre. "An individual may be considered too disabled by an employer to get a job, but not disabled enough by the courts to be protected by the A.D.A. from discrimination," Mr. Hoyer said...

• KENNEDY-BROWNBACK BILL DIES IN SENATE SPENDING SHOWDOWN

<http://www.patriciaebauer.com/2008/07/28/kennedy-brownback/>

July 28th, 2008

From *C-Span, CBS News, the Associated Press, the New York Times, the Washington Post, WashingtonWatch.com* and elsewhere:

A bill aimed at providing accurate and comprehensive information to parents who receive a diagnosis of a disability for their child, either prenatally or after birth, died today in a massive Senate showdown over federal spending.

Senate Bill 1810 was among a package of about three dozen bills that went down in a partisan vote, as Senate Majority Leader Harry Reid attempted to break a logjam created by Republican Sen. Tom Coburn of Oklahoma (above). Coburn, who has become known as the Senate's "Dr. No," had used a procedural device to block the bills, which included some \$10 billion worth of bipartisan legislation.

Reid had hoped to outgun Coburn by combining the three dozen bills into one massive "Advancing America's Priorities Act", but the measure failed to rally the required 60 senators needed to bring it to a vote. Coburn had threatened a filibuster if the measure were advanced.

What happens next was not immediately clear. The Senate is supposed to adjourn at the end of the week, but Mr. Coburn, who has blocked the programs by putting a personal "hold" on them, has said he would back most items if the lawmakers laid out ways to pay

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for them and did something about high gasoline prices. S. 1810, co-sponsored by Sens. Edward M. Kennedy (D-Mass.) and Sam Brownback (R-Kan.), has been promoted by a coalition of advocacy organizations as a way of providing support for prospective parents who are increasingly undergoing prenatal screening and testing during their pregnancies. Kennedy and Brownback, from opposite sides of the political spectrum, have been seeking to pass such a bill for several years.

As more and more parents postpone childbearing until later in life, they become statistically more likely to have children with Down syndrome or other disabilities. It is estimated that up to 90 percent of pregnancies in the United States in which Down syndrome is diagnosed end in abortion.



THANK YOU FROM THE FAMILY OF RON BOUDREAUX

by Karen Boudreaux

A HUGE thanks to everyone for their support over the summer when Kerry's dad passed away. Those of you who knew him saw the love in his heart for children with Down syndrome at our annual Buddy Walks. Upon his passing, a memorial in his name was created to benefit DSACK with has resulted in over \$600 in donations. We truly appreciate the thoughtfulness and generosity from everyone. Below is a list of current donors we would like to thank:

- Meg & Bill Steinman • Diane Bodin • Lynn & Joe Lech
- Tim & Judy Campbell • St. John Homemakers
- Mrs. Phyllis Willett • Mr. & Mrs. Bob Tackett
- Dale & Francis Mittendorf • Susan Parker
- Dan Rubin • Kim English • Bret Anderson • Karen Wilmeth
- Beth Jepson • Debbie Maren • Monica Poole
- Mike & Darla Sims • Colette & Don Rees
- Melanie & Chris Sturgis • Melissa & Andy Stephens
- Phil & Linda Roof • Bill & Nancy Sturgis
- John & Lena O'Nan • Kimberly & Sean Ferrera
- Tops 110 • Ron & Donna Hoskins
- Harmon Murphy • Kelly Stratemeyer
- Louis & Judy Roof • Brenda & Curtis Gardner

MAKING CONNECTIONS

• JUST GETTING STARTED

A support group in Louisville especially for families of infants and children presents a series on: "Understanding Government-Funded Supports and Services."

Kentucky Hart Supported Living Grant, Home And Community Based Waiver, Consumer Directed Option Date – Tuesday, September 9, 2008

Time – 6:30 to 8:30 PM

Place – The Council On Mental Retardation Centre, 1151 South 4th Street, Louisville, KY, 40203

Speakers – Bekka Krall, Seven Counties Services, Sandra Duverge, Parent, Casey Rusk, Res Care Home Health

Michelle P Waiver, and Supports for Community Living Waiver

Date – Tuesday, October 14, 2008

Time – 6:30 to 8:30 PM

Place – The Council On Mental Retardation Centre, 1151 South 4th Street, Louisville, KY, 40203

Speaker – Leslie Lederer, Parent and Protection and Advocacy Staff

Kentucky Impact, and Crisis Prevention/Response Grant

Date – Tuesday, November 18, 2008

Time – 6:30 to 8:30 PM

Place – The Council On Mental Retardation Centre, 1151 South 4th Street, Louisville, KY, 40203

Speaker – Seven Counties Services Staff, Kentucky Impact Staff

Call: Abby Ramser to confirm attendance at 584-1239 or email at aramser@councilonmr.org

• **THE ARC OF CENTRAL KENTUCKY HELD ITS FIRST MEMBERSHIP MEETING** on August 4, 2008 at the Beaumont Library. Bob Sterrett and Ann Smits presented information about resources in KY for persons with Developmental Disabilities.

• **DADS APPRECIATING DOWN SYNDROME**, or D.A.D.S., is an organization of fathers of children who happen to have Down syndrome. They hesitate to call themselves a "support group", even though in many ways, they do support each other. They prefer to think of D.A.D.S. as an "action group." "You won't find us in a church basement drinking warm coffee and whining about having children with Down syndrome. Instead, you'll find us out in the community coaching

our kid's sports teams, participating in our children's IEPs, volunteering at local Down syndrome fundraising events, and even sponsoring fundraising events of our own."

D.A.D.S. hosts regular meetings where members come together to share insights and experiences. Face it: there are certain responsibilities that generally fall on the shoulders of the father. Having a child with special needs often affects how we approach those responsibilities. We invite expert speakers to discuss medical, educational, financial, social, and many other issues that affect our children's lives. And of course, we share stories and experiences that are unique to fathers of children with Down syndrome.

For more information about this national group, visit <http://www.dadsnational.org/>

For information about the D.A.D.S. Group in Louisville, KY contact Mark Leach with Down Syndrome of Greater Louisville at (502) 938-4864 mleach@stites.com

• DID YOU KNOW THERE IS A WAITING LIST OF PEOPLE WHO WANT TO ADOPT A CHILD WITH DOWN SYNDROME?

Yes! Many people in our society understand and value the fact that people with Down syndrome are beautiful, capable and loved. Many people have adopted a child with Down syndrome, and/or are hoping to adopt a child with Down syndrome!

Information about adoption of a child with Down syndrome in the United States is found at the Down Syndrome Association of Greater Cincinnati's website: <http://www.dsagc.com/adoption.asp>

Their website states the following: "The Adoption Awareness Program has provided information and

support to birth parents, adoptive parents and adoption agencies throughout the United States since 1981. The goal of this program is to ensure that every child born with Down syndrome has the opportunity to grow up in a caring family. Children of all ages and abilities are served by this program. We are contacted by a variety of individuals including genetic counselors, social workers, birth families, and families interested in adoption. An average of 4-5 calls are received each week requesting information on making adoption plans for a child with Down syndrome. There are presently over 200 families on the waiting list with completed homestudies waiting for children with Down syndrome. (Families who wish to adopt a child must have a homestudy completed by a licensed agency in their home state. An approved homestudy is required before an adoption can be finalized in a court of law. Families may wish to register with us while their homestudy is in process however.) Most of the adoptive families registered with us have had some connection or experience with an individual with Down syndrome sometime in their life. They may be a birth parent themselves. They may have a sibling with Down syndrome. Their decision to adopt is directly related to a positive life experience." To learn more about adoption, contact Robin. at rsteale@zoomtown.com

The website for international adoption of a child with Down syndrome is as follows: <http://www.reecesrainbow.com/>

DONATIONS RECEIVED

Central Baptist and Ted Collins

Ron Boudreaux's Family and Friends

United Way



COURTNEY'S CONTEMPLATIONS

Everyone in our DSACK community has contemplations, words, and stories to share. People with Down syndrome are beautiful, capable and loved. For this issue, I decided to ask other people to share their contemplations, and I would be quiet and still...while contemplating the undersides of my own eyelids!

Dixie serves on the DSACK Advisory Board and is involved in DSACK in many ways. The Executive Board asked Dixie if she would tell the story to our DSACK members of how she and Olivia became a family. This story speaks volumes and assures us that Olivia and others with Down syndrome are loved beyond many people's wildest imaginings! Dixie and Olivia are both special people and we are honored to have them in our DSACK community.



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HOW OLIVIA AND DIXIE BECAME A FAMILY

Submitted by Dixie Miller

Where to begin when writing the story of how Olivia and I became a family, I guess the best place to start is at the beginning. This is a story of how God truly works in our lives and if we are willing to follow his lead, how blessed we will become. The story begins when I was thirteen and God placed into my life a wonderful lady by the name of Judy Harrison. Judy was a medically fragile foster mother and not only is that remarkable in its self, when I met Judy, she had around ten children, all with significant medical needs in her home. Judy and her children started coming to our church and one Sunday morning during worship I held a baby that had been born addicted to cocaine. I came home that day and said that I wanted to go and play with Judy's children. My parents made the very wise decision to insist that if I was going to spend time with the children that it had to be on a weekly basis. So began my career as a volunteer at Judy's and began my love for children with special needs. All through middle school and high school I volunteered in Judy's home. After my freshman year of college, I started working for Judy.

It was while working for Judy in college that God first placed in my heart the desire to foster and adopt children with special needs. Though I knew, I would have to wait until after school and when I became financially stable. All through college and getting my masters I would dream about that day. However, there were times in my life that the dream would get buried deep down.

Then one day, I found myself standing in my house that I owned, with a job, and car and this dream came back and hit me like a ton of bricks. I had this sudden realization that I was financially stable and there was nothing stopping me in making this dream come true, and it scared me to death. I started praying and asking the Lord for signs that this was the path He wanted me to take. Over the next weekend God provided those signs over and over again. To the point of me calling social services on Monday to find out just what I needed to do to become a foster parent, and surprisingly there was an information meeting that night.

In May of 2005, I was certified to foster medically fragile children in my home. Soon after becoming certified I got a call asking if I would take a little boy straight out of the NICU. Around that same time, Olivia had come into care (though I did not know it yet). I took this little guy home hooked up to oxygen and a heart monitor and as quickly as he came so set in the panic. After a couple of days of no sleep, trying to work, and crying all the time, I made the decision to have him removed from my home. I was devastated. Why would God Put me through all of this just for me to fail? My minister counseled me and said, "Maybe there is another child God has planned for you." Were those words ever true! I took some time away from the foster care system to figure out just what I needed and wanted to do.

During this time, Judy kept telling me that my little girl was at her son's foster home. I had heard about Olivia and I knew that she was very sick. Her heart was so weak that the doctors did not think she would live long enough to make it to or through surgery. I also knew that if I went to Tony and Michelle's to meet Olivia that I would fall completely in love and I did not know if I could put myself in the situation of loving a little girl that was not suppose to live.

The day came that I finally decided to go and meet Olivia. However, when I called, I found out that Tony's brother and Judy's son, Justin, had just passed away. Judy had adopted Justin, a child placed in her home due to his cystic fibrosis. He lived until right after his sixteenth birthday. Justin adored Olivia and I truly have a feeling that he is the reason for my change of heart in going to see Olivia. I imagine him now entering the gates of heaven asking, "God, what is taking so long down there? Get these two together." I met Olivia for the first time the day of Justin's funeral. I will never forget that bitter sweet day with so many emotions attached to it. Walking into Tony and Michelle's and seeing her lying on the living room floor, her beautiful pale face and big dark blue eyes. As I held her, I knew I was holding my baby girl.

Olivia came into the state's care at the age of two months. Due to her heart condition, she was placed with a nurse that could look after her health care needs and attempt to fatten her up for surgery. Olivia had open heart surgery about a week after I met her, right before she turned six months. Olivia's road to recovery was a long and difficult one. She had many complications and stayed in the hospital a little over a month. I would sit with her in the hospital as much as I could during this time. On October 19th, I got the call from Tony that she was coming home.

During the next couple of months, as Olivia continued to recuperate, we started the transition process from Tony and Michelle's home to mine. I was blessed to be able to have Olivia during our Thanksgiving celebration, where her new family got to meet and hold her for the first time. She also got to spend her first Christmas with my family. On January 13, 2005, I traveled to Tony and Michelle's for the last time as I picked up my little girl and took her home. Olivia was nine months old.

The rest is history, as they say. Her adoption was finalized on September 11, 2006, such a strange date, now for me to have such

happiness attached to it. However, if you ask me, our anniversary will always be our "Gotcha Day" on January 13th and will be the date we will always celebrate. Olivia is now four and as I am writing this, the flood of memories that arise. I cannot believe how far she has come in such a short amount of time, when I look back on just how sick she was. I laugh, every time we go and visit her previous foster family and watch the amazed look in her foster father's eyes, this beautiful preschooler that he worked so hard on keeping alive as a baby.

Like I said in the beginning, this story is about how listening to God and following the dreams that he has planned for your life may be difficult at times but the blessings are bountiful. I had to make the decision on whether or not I wanted to stay in my comfort zone. I was single with a great job and lots of friends to enjoy life with. I went out when I wanted to, ate when I wanted, watched what I wanted on television. I now mainly stay home (occasionally calling in the troops to baby-sit), I eat a lot of chicken nuggets and fries now, watch a lot of Signing Time and Noggin shows, and chase after Olivia until I fall exhausted on the couch. However, I would not trade this life for the world. People say to me all the time, how blessed Olivia is to have me as a mother. They don't understand. I am the one that is blessed. The Lord has blessed me with the most precious gift. I only hope that I can do right by her and give her all that she needs and deserves. your life may be difficult at times but the blessings are bountiful. I had to make the decision on whether or not I wanted to stay in my comfort zone. I was single with a great job and lots of friends to enjoy life with. I went out when I wanted to, ate when I wanted, watched what I wanted on television. I now mainly stay home (occasionally calling in the troops to baby-sit), I eat a lot of chicken nuggets and fries now, watch a lot of Signing Time and Noggin shows, and chase after Olivia until I fall exhausted on the couch. However, I would not trade this life for the world. People say to me all the time, how blessed Olivia is to have me as a mother. They don't understand. I am the one that is blessed. The Lord has blessed me with the most precious gift. I only hope that I can do right by her and give her all that she needs and deserves.

CALENDAR

2ND SATURDAY PARENT GROUP BREAKFAST SOCIAL

Saturday, September 13th, 9-11 a.m.
Child Development Centers of the Bluegrass
465 Springhill Dr., Lexington

Come join the popular 2nd Saturday Parent Group (for those whose children with DS are 0-5 years old), and get to know each other better without an agenda. DSACK will provide food but you are welcome to bring something to share! Childcare provided. Siblings and grandparents are welcome too! More info: Michelle at mandm@pngusa.net or 859-223-4207

BUDDY WALK!!

Saturday, September 27th, 10 a.m.
Keeneland

Join the Celebration!

2ND SATURDAY PARENT GROUP

CHANGE OF TIME AND EVERYONE IS INVITED!
October 11, 10 a.m.

Child Development Center
465 Springhill Drive, Lexington

Sally Shott, M.D. from Cincinnati Children's Hospital will speak about Ear, Nose and Throat issues in children with Down syndrome. She sees patients through age 21. Meeting is at 10:00 at Child Development Centers of the Bluegrass, 465 Springhill Dr., Lexington. Childcare is provided. DSACK will provide lunch following the meeting. More info: Michelle at mandm@pngusa.net or 859-223-4207.

"JUST GETTING STARTED" SUPPORT GROUP IN LOUISVILLE

especially for families of infants and children presents a series on: "Understanding Government-Funded Supports and Services." Call: Abby Ramser to confirm attendance at (502) 584-1239 or email at aramser@councilonmr.org SEE "MAKING CONNECTIONS" SECTION FOR DETAILS ABOUT TOPICS, LOCATIONS, ETC. All presentations are located in Louisville.

September 9 6:30-8:30: Kentucky Hart Supported Living Grant, Home And Community Based Waiver, Consumer Directed Option

October 14 6:30-8:30: Michelle P Waiver, and Supports for Community Living Waiver

November 18 6:30-8:30: Kentucky Impact, and Crisis Prevention/Response Grant

The Center for Accessible Living (CAL) is presenting a series of community discussions about healthcare and disabilities in KY, specifically about "Barriers to Healthcare and Unmet Healthcare Needs for People with Disabilities." CAL is a disability resource center which promotes equal access with the ultimate goal of equal and independent status by encouraging awareness, involvement, and support for the rights of all people with disabilities by the entire community. A forum was held in Louisville on July 29th. The Lexington Forum was held August 26th. There are other forums across the Commonwealth in Bowling Green, Florence, Murray, Harlan, and Thelma. For more information about the forums, visit dsack.org or call DSACK!

SUBMISSIONS

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

Submission deadline for next issue is Wednesday, October 15th 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.