



DSACK

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DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY

DSACK Buddy Walk issue!!!

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WHAT'S GOING DOWN WITH DSACK

BEAUTIFUL, CAPABLE AND MOVED!



What did these capable DSACK families do? They came from all over the place (London, Richmond, Paris, Danville, Mt. Sterling, Nicholasville and Lexington), packed 6 vehicles and 2 trailers full of furniture and lots of STUFF - in 32 minutes flat - and then drove it all to DSACK's new home!

Thank you to Travis and Tonya McPhetridge, Brent Merritt, Scott Mandl, Herve Miot, Kathy Meurer and family, Wes Vernon, Meada Hall and Michelle and Grace Gilliam for getting everything safely to our new home. 340 LEGION DRIVE, LEXINGTON. See you soon!



Picnic In Paris

We are grateful to Tony, Karen and Blair Osborne for hosting the last picnic of the summer. What started out being a small event for the Teen & Young Adult Group ended up being a major party for any DSACK family who wanted to attend!

An estimated 60+ people (ages preschool through adult) showed up for swimming, basketball, cornhole, potluck dinner, smores in the firepit and awesome fellowship. It was a wonderful time of relaxing with old and new friends of all ages. Thanks to the Osbornes for their gracious hospitality!

Down Syndrome Conference In Lexington

Mark your calendars for Saturday, February 25th for DSACK's 2nd Annual Conference. This conference will target general and special education teachers, speech language pathologists, school psychologists, families and anyone interested in learning more about the following topics:

Social Integration Movement: Steps for Fostering Relationships with Typical Peers

Hands-On-Math For Your Students and Children Using the Philosophy and Methods of Piaget and Montessori

Developing Intelligible Oral Speech for Children with Down Syndrome

Supporting Behavioral and Emotional Issues in Children, Adolescents, and Young Adults with Down Syndrome

Presentation by Self-Advocate

Parent Panel

Details to follow in the next newsletter. If you have questions before then, please contact us at info@dsack.org!

SPECIAL THANKS TO YOU!!

Thank you to Dr. Susan Bell for submitting a grant request to Walmart to help offset some of DSACK's costs for 2012 Educational Conference

Thank you to Traci Brewer for submitting an application to the Better Business Bureau requesting membership on behalf of DSACK

thank you!

who are we?

PROGRAM COORDINATOR

Allison Kerschbaum

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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.

The DSACK Newsletter is published bimonthly by

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



NEWS TO USE

Down Syndrome Research May Untangle Mysteries of Alzheimer's

By Drs. Elizabeth Head and Frederick Schmitt, UK Sanders-Brown Center on Aging

As individuals with Down syndrome are living longer than ever before, they face increased risks of age-related conditions such as Alzheimer's disease. In fact, due to an extra copy of chromosome 21, people with Down syndrome produce extra Alzheimer's-linked proteins in their brains.



Like all people with Alzheimer's disease, people with Down syndrome develop plaques and tangles in their brain - but they do so at a younger age than persons without Down syndrome. Research has shown that virtually all individuals with Down syndrome have Alzheimer's-like changes in

their brains by age 40, although they may not develop dementia until age 50 or later, if at all.

During this approximately 10-year period, although the brain appears to have protein changes consistent with dementia, individuals continue to function at their usual level. This same phenomenon occurs in the general population, as many participants in the UK Sanders-Brown Center on Aging brain donation program come to autopsy with full-blown Alzheimer's pathology in their brains, but no record of clinical dementia symptoms during life.

Working to understand how the brains of individuals with Down syndrome adapt to aging may hold keys to unraveling the mysteries of Alzheimer's disease. If we as investigators learn how people can continue to function normally while their brains develop physical manifestations of Alzheimer's, we may be one step closer to heading off dementia in millions of people. Because the brain aging process is in many ways accelerated in people with Down syndrome, working with these individuals is an ideal way to study how we can prolong normal brain function for individuals with Down syndrome as well as the general population.

To this end, we are currently conducting a research study involving participants age 35 and older who have Down syndrome. This study is funded by the National Institute of Child Health and Human Development (NICHD). Participants are asked to come to the University of Kentucky every six months throughout the five-year study to give a blood sample, take thinking and memory tests, have a neurological exam, and undergo a MRI brain scan. Participants will benefit from a full evaluation of their brain function and monitoring throughout the course of the study. Our goal is to recruit 40 adults (over 35 years of age) with Down syndrome who do not have signs of dementia, as well as 10 to 12

CELEBRATIONS!



Happy FOURTH birthday to our wonderful **Will** on December 7. My, what a big boy you are! You make us proud every day. Love, Mommy, Daddy, and Eli



Happy 4th Birthday **Bobby Schmutte!!**
We love you! – Mommy, Daddy, and Emily

Xander Berry, 7 months old! I have been constantly surprising my family with all of my accomplishments! So far I have mastered smiling, jabbering, reaching, rolling over, eating with a spoon, holding my own bottle and saying my nanny's favorite word, "nan



man". With all the love and patience that they give me I will be sure to keep them on their toes. Every day my family tells me just how much I brighten their world, so watch out Sun, here I come!

With love,
Xander's family

adults with Down syndrome who have already been diagnosed with dementia. Those who already have dementia will only attend a single visit.

While adults with Down syndrome are predisposed to Alzheimer's disease, there is hope for the future. We are learning much from their experiences, and hope that our research will result in knowledge that can improve the quality of life for individuals with Down syndrome and their families, as well as all those who suffer from Alzheimer's and related dementia.

For more information, visit <http://www.uky.edu/DSaging/> or contact Roberta Davis, 859-257-1412 ext. 479.



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BUDDY WALK

What a fantastic Buddy Walk!

This year, I am in AWE!!! Not only did we raise \$90,000 and have 1600 walkers, and 200 volunteers, but the day itself was AMAZING!!! From our fabulous committee chairs, to our volunteers, entertainers, teams, walkers, and generous exhibitors and sponsors, I cannot thank everyone enough!



All of the money raised at this walk goes to helping our families in Central Kentucky. We are able to make presentations to schools, medical professional and many other community groups. We are able to offer scholarships to camps and conferences, put on our own conference and help families in the hospital with Erica's fund. We are able to celebrate at our summer picnic and Holiday party as well as support our monthly events for new parents, elementary students and AIM. Amazing!

For the past 3 years, I have been blessed to be a part of this day; I am in awe of this community of people. I am in awe of the love, acceptance, generosity, and joy that ALL of you EXUDE. This organization brings me such happiness and peace. I thank each and every one of you for every part that you play in making this day such a success and pure celebration of life! I cannot wait to see what next year, our 10th anniversary, brings! I can only imagine that it will be 10 times the joy!

All of you are Beautiful, Capable, and very much Loved!

Regina Schmutte, Buddy Walk Chair



Ethan (5 yrs) enjoyed being the conductor of the "Bourne Special" but his favorite part was looking at the creek. The whole crew waited on him so our team got to be the caboose of Buddy Walk 2011.

Joshua Carter,
7 years old:
"The Bubbles!!!"



Ava, age 5 - "Ava's favorite part of the Buddy Walk this year was definitely having her friends and family all together in one place! Also fun were the mini horses, Clifford and the mascots! Big thanks to everyone for a great day."

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Wade Mitchell

Quotes from the elementary group!

Thank you to our Sponsors, Exhibitors & Entertainment!



"Dancing with Clifford"
 - Trey Blair, 5 years old

Sydney, (sister to Sam) Ethan and Sam loved hanging out with friends and family and the bonfire at our house that night after the Buddy Walk.

Sam said his favorite part was seeing himself on the billboard. (6 Yrs) We stopped by before heading over to the Buddy Walk. When he saw himself, he said "Whoa - that's fancy!"

Kent (10yrs) if he could tell you, he'd say he sure loved the pool of balls & the blowup bouncy thing.



Ethan (brother to Sam) said his favorite part was when everyone got up on stage and were dancing and jamming and having such a good time.



Courtney (mother to Sam) "I loved getting to cross paths on the actual Walk with all the other Buddy Walk teams...and getting to wave and share that moment of empathy with each other for the immense joy, pride and love we share for our loved ones with Down syndrome!"

"My least favorite part was that we forgot Sam E Club's sign!" Attached is a picture of Ethan (9), Sam (7) and Sydney (5) looking at the DSACK Billboard featuring Sam! "People on New Circle were waving and honking and smiling when they realized that Sam and his siblings were so excited to see him up there looking so fancy!"





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Buddy Walk 2011



Letter from Father John

Love was in the air at this year's annual Buddy Walk! It is such a Joy to see so many people who care about people in our Community. We gathered inside the Thoroughbred Center for information, directions and find our TEAM. We were inspired by speakers and a pep rally, singing and dancing! It seemed everyone was so happy to be there to show their support for a person with Down Syndrome or their family. As we walked in groups behind beautiful banners or signs, people lined the walking route and cheered as we walked by and we cheered back!

I think children offer adults a special gift. They remind us of that innocent inner child within each of us. We love kids because they help us to see the world in a new way, to be ourselves, with no pretention or mask. Children born with Down syndrome offer us this gift perpetually!

The Buddy Walk offers me this perpetual gift! I am inspired as I see people giving of themselves, loving others and receiving love. As a Catholic Priest, my walk with Jesus Christ, is all about encountering His Love in prayer, worship and in the relationships into which He leads me. This year's Buddy Walk was truly a walk with Christ for me. The Lord of Lords, the Savior of the World, the King of Kings, wants to be our "Buddy", our friend. I could certainly see Jesus in the faces of all those at this year's Buddy walk. This year's walk was a witness to me of God's love working through the leadership of DSACK, the families, the participants and the many sponsors. It was like a symphony of love; truly love was in the air!

Fr. John Moriarty

DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY

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Article by a Mom-to-be

It was a day that seemed like any other day. It was June and the sun was shining brilliantly. My husband had went outside to speak with the contractors who were working to add an addition to our house and I was trying to figure out if 13 weeks pregnant was the end of my first trimester or not. We were blissfully happy. We had waited and tried and tried and waited to get pregnant and finally we were expecting our biggest blessing. I had no idea at that moment how much the phone call I was about to receive could change my entire life. The Obstetrics Coordinator from my doctor's office called to give me the results of the first trimester screening we had undergone at their recommendation. Her words rang in my ears. . .the screening had come back positive for increased risk of a chromosomal disorder. The actual breakdown was 1 in 8 for Down syndrome and 1 in 29 for Trisomy 18. My doctor wanted to see us that afternoon to discuss the results. I calmly agreed and hung up the phone. It was then that the room seemed to spin around me. I looked helplessly out the window at the vivid green of the trees in my yard and the bright sun streaming down and willed my husband to come back inside. I was frozen. . .it felt like I physically could not move. After what seemed like an eternity he came through the front door. The moment he saw my face his grin faded. I tried to speak but the words would not come and when they finally did it was a jumbled mixture of sobs and broken speech. I cried and he cried with me. Somehow, I think we just knew that we were going to be 'the one.' We were incredibly fearful of what this meant for us and for our baby.

Fast forward nearly four months, much prayer, a Chorionic Villus Sampling, and one definite diagnosis of Down syndrome later, and we are in a much different place. Once again we are blissfully happy and so excited to meet our baby. We went through our period of adjustment and shock, we mourned for what we thought would be our future, and now we are ready to experience what will be our future. As I write this, I am currently 28 weeks and 5 days pregnant. I have had time to do much research, to make some new (very helpful!) friends, and come to terms with our baby's diagnosis. By the way, it is a boy and his name is Cooper! As scary as receiving the diagnosis was, we are in such a good place now. We feel as if January 4th (our due date) cannot come quickly enough. We know that the future will not be without challenges and uncertainties but we will face them as they come. We can't wait to raise Cooper, to share him with others, and to advocate for him and the Down syndrome community as a whole.

As part of our effort to learn as much as possible and embrace our baby boy's 'something extra' we recently participated in the Down Syndrome Associate of Central Kentucky's Buddy Walk. We were apart of the team Kylie's Krew in support of Kylie McPhetridge. We were both incredibly nervous as we made the drive up to Lexington. We chatted anxiously about what we were feeling and what we expected. From the moment we arrived it was nothing but a positive experience. Smiling welcoming faces abounded, not to mention the many precious and beautiful children. We took it all in. Someone pointed out a young lady with Down syndrome who is trying for her driver's license and is attending college. We saw children dancing, laughing, and playing. We entered our names in the raffle that was going on, perused the many booths, and received a good amount of helpful information. We even talked of having a team for Cooper in the future and what we might name it. The weather was cool and brisk but the warm enthusiasm that permeated the event was inspiring. I felt very emotional throughout the day as the spirit of encouragement and hope was shared but we left with our hearts full and light. I am already looking forward to next year's DSACK Buddy Walk when I can bring my little boy. He will be close to 10 months old at that time and I know it will once again be a positive experience for all.

Tara Wagers





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- “Chase”ing Butterflies
- Adoring Abrianna
- Anna’s Fantastic Family
- Ava’s Parade
- Bank of Lexington
- Bean’s Team
- Bella’s Blessings
- Bobby’s bunch
- Bourne Special
- Bri Bri’s Bees
- Chad’s Champions



A Huge thank you

- Conor’s Crew
- EKU Best Buddies
- Elijah’s Construction Crew
- Emily’s Entourage
- Harley
- Horn & Associates
- Hudson’s Homies
- J’s Crew
- Jack Attack
- Jeremy’s Crew
- Joella’s Joys
- John’s Jammers
- Jordan’s Team
- Joshua’s Fanatical Family
- Kate’s Team
- Kylie’s Krew



DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY

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Levi's 321 Genes
Marie-Claire's Miracle Makers
Massie
Megan's Team
Olivia's Village
Omarion's Bouncing Ballers
PC's Pack
Roger Dale Brown Jr.
Sam Elbert's Sam E's Club
SOTA
Tanners Tapestry

to ALL of our

TEAMS!

Team Alex
Team Cameron
Team Lilly
Team Raylan Gauge
Team Rinker
Team Sailie
Team Spencer
The Kidz Club
Tori's Tornados
Treasuring Tarenne
Trey's Troop
Walk for Miles
Walking with Will
Will Power
Wisdom Wonders





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BUDDY WALK CONTEST WINNERS!



Congratulations to all of you! You are all **winners!!** But....

the **prizes** this year go to.....

Will Power...with the most walkers!! We will have the pleasure of seeing handsome Will Merritt lighting up Lexington streets next year on our billboard!! GO WILL POWER !! Brent and Tonya, YOU ARE BOTH AWESOME!!! Little known fact, the Merritt's were also the couple responsible for the AWESOME program of "Born this Way". Thank you to both of you! You work tirelessly every year to help make DSACK a success!



Jordan's Team.....

Jordan's team has raised the most money of all of the Teams... over \$7,000! Sara Ball worked hard all year round, and, with the help of her family, friends, and adorable son. Jordan's beautiful face will grace the streets of Lexington next year on our billboard!!

Starting off the Walk....

Most creative sign was judged by our WTVQ emcee, Christine, and the honor goes to Elijah's Construction Crew!! Darlene Penn, you did a wonderful job with over 115 walkers, and the determination to raise money for DSACK. You are so appreciated! Next year you will lead off our walk, as a team in honor of your MOST CREATIVE SIGN!!!!



Thank you so much for all the effort put into to **building teams**, and **raising money**, and just making this years Buddy Walk a fantastic event!! We appreciate you all!

MAKING CONNECTIONS

Making strides for DSACK

DSACK welcomes Jeanne Miller, President/Owner of MarketLinks, Inc., a locally owned marketing and fundraising company located in Lexington, Kentucky. Jeanne will assist DSACK in furthering its mission in central and eastern Kentucky by developing relationships and educating members of the community.



As a certified facilitator, Jeanne led the DSACK board through the process of developing its vision and defined the focus for the organization over the next five years.

Her background in non-profit fundraising will be an asset in engaging members of the community and telling the DSACK story.

Jeanne is passionate about those with special needs and is blessed with a daughter who has autism. She and her husband, Jonathan, are strong advocates for their daughter and live the DSACK motto daily that all children are beautiful, capable and loved.

Jeanne, her husband Jonathan, and their three daughters, ages 15, 12 and 9 reside in Lexington, Kentucky.



Thank you to Mayor Jim Gray, for celebrating this day with us!

"Look What Some Dsack Parents Have Been Up To!"

Several DSACK parents have been making positive waves in the classrooms - from elementary to college.

Karen Boudreaux recently spoke to 180 5th graders and their teachers at Rosa Parks Elementary School about Down syndrome, what effect the extra chromosome does and does not have on people, how to be a good friend and teacher, and what the Buddy Walk is all about. She was also able to place 2 DSACK piggy banks at the front of the school for 1 week and called it "Dollar for Down Syndrome". All of the students were receptive during her talk and were excited to receive BW shirts from years past.

Brent and Tonya Merritt have made the rounds at Scott County HS and Paul Lawrence Dunbar HS, speaking to hundreds of students at both schools, including Beta Clubs, Drama Club and many others, plugging the Buddy Walk and giving general information about Down syndrome. Tonya recently spoke to the Heredity class at PLD about what Ds is (how it occurs & manifests itself throughout life), prenatal testing, services available for people with Ds, the "r" word, and family & social issues. Tonya shared, "We're so blessed to be able to share Will with so many of our students. They always receive him with open hearts".

Susan Bell opened a door for DSACK. She asked Scott Mandl and Lee Ann Mullis speak to about 30 PSI CHI students (honorary psychology group) at Georgetown College about DSACK, Down syndrome and the Buddy Walk. Both Scott and Lee Ann had their beautiful 4 year old girls there, Megan and Joella, to help with the discussion. Several in the audience volunteered to help at the BW following the presentation!

Regina Schmutte spoke with more than 50 3rd graders at Seton Catholic School about the importance of inclusion and how children are more alike than different.

Karen Boudreaux and April Vernon spoke to a kindergarten class at Children's Montessori in Georgetown about inclusion and how all children are more alike than different!

Thank you Karen, Brent, Tonya, Susan, Scott, Lee Ann, Regina and April for educating and advocating on behalf of ALL of our children.



thank you to our sponsors!



859print.com, the producer of our newsletter and the Buddy Walk bumper stickers, is offering 20% off to all DSACK members for their Buddy Walk banners! Contact 859print.com at (859) 231.0388 or 859Print@gmail.com.





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calendar

0-5 PARENT GROUP & PLAYGROUP

All meetings are held on the 2nd Saturday of the month at the DSACK office from 10 a.m. until 12 noon. Our new address is 340 Legion Drive in Lexington. Child care is provided. Siblings and grandparents are always welcome. Call us at 859-494-7809 or email at newparentgroup@dsack.org.

December 10th, 2011 –No meeting due to the Christmas party December 3rd.

ELEMENTARY GROUP

November 19th, 2011 from 4-6 meet at Golden Corral in Nicholasville to share in a Thanksgiving feast and make a list of what we are thankful for. One adult and one child will be covered by DSACK.

RSVP to Samantha Matthews @ 270-256-2002 or Samantha.d.Matthews@gmail.com

December 10th, 2011 from 11-2 meet at Target on East Reynolds Road in Lexington (by the mall) to Christmas shop for family members. Each child with Down syndrome will be given \$15.00 to shop for family members. Please send a list of people to buy for with your child. We will be shopping in the dollar aisle as well as Christmas gift sets isle. RSVP to Samantha Matthews @ 270-256-2002 or Samantha.d.Matthews@gmail.com

AIM GROUP

December 2nd, 2011 from 6-9pm at Chad Bell's home in Paris. Save the date for a Holiday Party. Directions and details to be sent via email.

SOMETHING FOR EVERYONE!

DSACK Holiday Party, December 3, 2011 at Marriott's Griffin Gate Resort. Luncheon 11:00am-1:00pm.

Please RSVP to dsack.org@gmail.com. Santa and Mrs. Claus will be passing out a baked goodie to each boy and girl. No need to bring a gift for your child or a dish to share. Just bring yourself, your loved one with Ds and your holiday spirit! DSACK will cover the cost of your loved one endowed with Ds, as well as their immediate family members. If for any reason you are unable to make the party, please let us know as DSACK will be responsible for covering the cost of those individuals that do not show.

DSACK Annual Conference, February 25, 2012 at Marriott's Griffin Gate Resort

Meetings for all groups are being planned for 2012, so watch the calendar!

submissions

Submission deadline is Monday, December 5th and can be sent to Allison Kerschbaum at 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.

Let's get the word out about DSACK and our loved ones with Down syndrome who are beautiful, capable and loved!