



DSACK

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DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY



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Celebrating

2010

Welcoming

2011



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WHAT'S GOING DOWN WITH

DSACK

NEWS

FROM THE BOARD

Presentation at Georgetown College



Thanks so much, again, for your visit to my class on Friday - it was really a wonderful experience for me, personally, and for my students. The children were such good examples of what individuals with Down Syndrome can learn and do. Thanks for the effort that you expended in bringing them to campus.

Thanks again
Susan Hart Bell, M. S., Ph.D.

Reflections

A few weeks ago, several members from the DSACK board met to review our strategic plan and reflect on the accomplishments our organization has seen over the last eighteen months. While we are extremely proud of our accomplishments, we are most pleased that DSACK has remained true to our mission statement which is to:

- Celebrate our Down syndrome community.
- Support individuals in Central Kentucky with Down syndrome and their families.
- Educate the Central Kentucky community.
- Assist in local and national research efforts.

Thanks to the efforts of many, DSACK has come to mean so much to so many families. We certainly have accomplished a tremendous amount in a short period of time, but we can't forget our humble beginnings. If not for the vision of a few mothers who felt the need to advocate for their kids and develop a support system in our community, none of this would have been possible. Countless hours have been spent by many board members to ensure that we stay focused, guard our excellent reputation in our community, and have complete transparency in our finances and decision-making.

Moving forward, we want to continue building our programs and meeting the needs of our DSACK community. We are working with other affiliates to build an advocacy network within our state legislature. Our program coordinator, Allison, is working on updating our current database program. We want our loved ones to form their own support system through our peer group meetings every month. These wonderful outings offer opportunities for families to build strong bonds as they face challenges in the future and as they celebrate accomplishments. They also encourage independence and give our loved ones opportunities to give back to others. We are planning our first conference for this February and have secured speakers who are experts in fields such as speech, self-advocacy, postsecondary education, exercise and physical therapy, individualized educational plans, and strategies for educating students with Down syndrome.

As you look over our list of accomplishments, I encourage you to think about our future, as well. What does DSACK mean to you? How has DSACK helped to make a brighter future for your child and family? What are your gifts or talents, and how can you use those to help DSACK meet our future goals? No one person has achieved the goals we established eighteen months ago. Rather, several people working together helped complete the picture. It will take fresh faces, ideas, and talent to keep DSACK moving forward. With all of us joining together, we will make a positive impact on our cities, schools, government, and most importantly, the lives of our loved ones.

Respectfully,
Traci Brewer, Chairperson

who are we?

BOARD OFFICERS

Traci Brewer, *Parent*
Michelle Gilliam, *Parent*
Regina Schmutte, *Parent*

TREASURER

Lee Ann Mullis, *Parent & Consignment*
Inventory Analyst/Accountant

PROGRAM COORDINATOR

Allison Kerschbaum

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Sally Miracle, *Central Kentucky Special Education Cooperative; Low Incidence Consultant*
Heather Stillwell, *Special Education Teacher*

ADVISORY COUNCIL

Caroline Boeh Baesler, *Parent & Attorney*
Karen Roof Boudreaux, *Parent*
Becky Lesche, *Parent & Educator*
Dr. James Riley, *Pediatrician*
Malkanthie McCormick, *Parent & MD Internal Medicine Physician*

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.

NATIONAL NEWS

National Statistics for Down Syndrome

The Centers for Disease Control and Prevention (CDC) and the National Birth Defects Prevention Network have published a study that updates national statistics regarding the prevalence of Down syndrome in the U.S. The study indicates that there are about 6,000 diagnoses of Down syndrome each year in the United States. One in every 691 babies is born with Down syndrome. This is an increase from the previously reported statistic of 1 in every 733. Based on the new study, the National Down Syndrome Society (NDSS) will cite the new prevalence estimates on its website and other materials.

National Down Syndrome Society Responds to American College of Obstetricians and Gynecologists' New Recommendations for Prenatal Testing

The National Down Syndrome Society (NDSS), a nonprofit organization with more than 250 affiliates nationwide representing the more than 400,000 Americans with Down syndrome and their families, issued a resolution today in response to the American College of Obstetricians and Gynecologists' (ACOG) recent recommendations that all pregnant women, regardless of their age, should be offered screening for Down syndrome. The resolution includes two call-to-action points:

- Challenging and strongly encouraging health care professionals and organizations like ACOG to partner with NDSS and other Down syndrome organizations to ensure the wide-spread proliferation of balanced, accurate and up-to-date information to expectant parents; and
- Urging health care professionals, policymakers, and the Down syndrome community to work together to ensure that expectant parents are not unduly influenced to undergo prenatal testing or to terminate a pregnancy after receiving a prenatal diagnosis of Down syndrome.

"At NDSS, we have always had strong, collaborative relationships with health care professionals, particularly through our advisory boards and our program Changing Lives: Down Syndrome and the Health Care Professional," said Pam van der Lee, Chair of the NDSS Board of Directors. "In cooperation with other Down syndrome organizations, we hope to expand and enhance these partnerships going forward, while continuing to be a voice and advocate for the Down syndrome community." Other Down syndrome organizations in the U.S. and internationally have issued statements in recent weeks about the ACOG recommendations. NDSS is committed to working with these groups to express our collective concerns about the new guidelines and address these pressing issues facing the Down syndrome community. Following is the full text of the NDSS resolution on the American College of Obstetricians and Gynecologists recommendations regarding prenatal testing for Down syndrome:

1. Whereas, The National Down Syndrome Society (NDSS) is the nation's largest organization devoted to helping people with Down syndrome and their families,

2. Whereas, NDSS strives to assist people with Down syndrome and their families through national leadership in education, research and advocacy,
3. Whereas, the NDSS and its members value the lives and contribution of people with Down syndrome, as well as all people with disabilities, and affirms a vision of a diverse and inclusive society in which human rights are respected and differences are celebrated,
4. Whereas, the American College of Obstetricians and Gynecologists has recently recommended that all pregnant women be offered prenatal screening for Down syndrome,
5. Whereas studies have shown that the information given pregnant women about Down syndrome is frequently incomplete, and often neglects to recognize the rich and fulfilling lives that are possible for people with disabilities,
6. Whereas the Board of the National Down Syndrome Society challenges and strongly encourages health care professionals and organizations like ACOG to partner with NDSS and other Down syndrome organizations to ensure the wide-spread proliferation of balanced, accurate and up-to-date information to expectant parents,
7. Whereas a prenatal diagnosis of Down syndrome does not mean that the fetus should be terminated,
8. Be it resolved, therefore, that the Board of the National Down Syndrome Society urges health care professionals, policymakers, and the Down syndrome community to work together to ensure that expectant parents are not unduly influenced to undergo prenatal testing or to terminate a pregnancy after receiving a prenatal diagnosis of Down syndrome.

continued on page 4

MAKING CONNECTIONS

GRADUATE STUDENT SHARES HER DSACK EXPERIENCE

(Board officer Michelle Gilliam recently received a letter from Patrice Fischer, who just completed her practicum with DSACK. Her letter made us smile and we wanted to share an excerpt. Thank you, Patrice!)



I wanted to use this time to thank you for all your help and guidance you have given me this semester. Helping get volunteers with the Buddy Walk, tutoring William and Kate, and helping with other various activities has allowed me to be more confident working independently and with many different people. I am so glad that you fostered me "not holding my hand" through this process, because I became a lot more confident in being a leader. I hope this can transfer to my career as a future school psychologist and that I can continue to initiate things myself without someone guiding me through the process. Working with everyone on the DSACK board has really been something that has touched me and changed my life, for your passion and determination to make a difference for people with Down syndrome is so contagious. I catch myself talking about the work I do with the students I tutor and the interactions I encounter with DSACK all the time. I have been so fortunate to be surrounded by leaders that volunteer their time, and work so hard to make a brighter tomorrow for people with Down syndrome. Even though I will not be on practicum next semester, I hope that I can still be involved with the DSACK community. I am glad I am going to continue to tutor, and I hope that one day when I am a school psychologist I could serve on the DSACK Board if I get hired here in Lexington.

Thanks for everything, Patrice



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NATIONAL NEWS

continued from page 3

NDSS Position Statement: Prenatal Blood Test

The National Down Syndrome Society is aware of the new prenatal blood test being developed by Sequenom and by Stanford University, which may have the potential to improve the safety, and certainty of results, for women who choose to undergo prenatal testing for Down syndrome.

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. Instead, they should be given balanced and accurate information so that they can make informed decisions.

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.

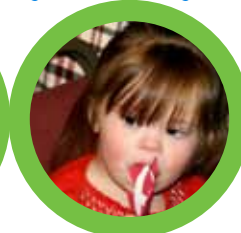
Finally, 81% of medical students say that they are not getting any clinical training regarding people with intellectual disabilities (3), and 45% of obstetric fellows say that their training on how to deliver a prenatal diagnosis is "barely adequate" or "nonexistent" (4). Before these new prenatal tests are made commercially available, the NDSS urges medical schools, residency programs, and fellowship trainings to educate their healthcare professionals on how best to deliver a prenatal diagnosis of Down syndrome to expectant families. Affiliates of the NDSS have been working with hospitals around the country to provide such trainings.

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."
3. Special Olympics. The health and health care of people with intellectual disabilities. <http://www.specialolympics.org/>. Accessed February 10, 2007.
4. Cleary-Goldman J, Morgan MA, Malone FD, Robinson JN, D'Alton ME, Schulkin J. Screening for Down syndrome: Practice patterns and knowledge of obstetricians and gynecologists. Obstet Gynecol 2006;107:11-17.

DSACK HOLIDAY PARTY

Thank you to all of you who joined us for the DSACK Holiday party! It was a cold and snowy day but our hearts were filled with warmth as we celebrated our loved ones. I so enjoyed meeting all of you and getting to spend time with your kids. We enjoyed a delicious lunch and incredible bread pudding as well as a beautiful new location at Second Presbyterian church. Callie Baesler offered a meal time prayer and Santa and Mrs. Claus arrived to bring goodies for all the girls and boys. I think a great time was had by all. Thank you for coming out to celebrate with us and a special thank you to all of you who helped make the Holiday party a success. Merry Christmas to you and yours!

Allison Kerschbaum,
DSACK Program
Coordinator



LOCAL NEWS

SPECIAL OLYMPICS YOUNG ATHLETES PROGRAM



Have you been looking for a fun family activity that will keep you and your child active and busy? The Young Athletes Program might just be your answer. The Young Athlete Program was designed by Special Olympics to meet the recreational needs of 2 to 7 year olds. This program is incredibly flexible and can work in a variety of

environments. Even though it was designed by a physical therapist and the primary focus is gross motor skills, the program is a valuable tool that can easily address social and pre-academic skills as well. The program focuses on isolated skills that are necessary to be successful in sports in a non-competitive way. The idea is to develop the skills at an early age in a fun, play group setting.

On February 12th, from 10am to 12pm we have planned an informal session at the new DSACK offices that you won't want to miss! We will give a broad overview of the Young Athlete Program, and discuss the materials and equipment that is available. Special Olympics Kentucky would like to start a Young Athlete Program in Lexington and is in the need of a coordinator, facility and participants to insure its success and is hopeful that members of DSACK will be able to help.



B E I N S P I R E D !

Well Look At That (from the blog of Dave Hingsburger. Dave is a Director of Clinical and Educational Supports in Ontario, Canada. He lectures worldwide and his blog has won many awards.)

Everybody noticed.

Everybody stared.

Eventually even me.

We stopped at Petro-Can to fill up the car and had to wait until a lane cleared by the pump so we could pull in. We'd passed several other stations without line ups, but here we sat. Joe collects Petro-Points and refuses to gas anywhere else. It's one of his, um, quirks. I didn't notice anything at first. Then I saw a young guy about twenty staring intently at something. I put my eyes on his gaze and slid along to see the object of his attention. "Oh, stop," I thought to myself. He was staring at a man, about the same age as he was, with Down syndrome, who was pumping gas into a car. "Surely," I thought, "people are used to seeing the disabled amongst us being out and in the community doing every day things."

Then I noticed that everyone else was staring too. Really looking at this guy. This was more than "Wow look at the disabled guy pumps gas." This was something else.

So I took in the whole scene. He was pumping gas into a car. The car was empty. Forgive me for what I thought, but I thought that his mom or dad was probably in the service center going to the washroom. He finished pumping gas, went in to the little kiosk and paid.

Now, I understood what people were looking at. Staring at, seeing. He got into the car, on the driver's side.

Started the engine.

Drove off.

Even I reeled at that. I had heard of people with Down syndrome driving, but I'd never seen it before. My automatic assumption was that he was a passenger. That because he had Down syndrome he'd never ever be in the driver's seat.

They weren't staring at him. Those people at the gas station. I think that something different was going on. They were re-evaluating everything they ever thought about someone with Down syndrome. They were ripping apart pre-conceived notions. They were having prejudice challenged.

Admittedly, so was I.

Damn.

Just when I thought that I had it all together, some guy with Down syndrome drives me off the road. Makes me realize how deep my own prejudices run.

I wonder, though, about the effect he will have. On me, it was immediate. I reached inside myself and raised the bar - set expectations higher - not for them - for me.

But I wonder about that twenty something guy whose stare I'd noticed. Should he ever get the news that his wife is carrying a baby with Down syndrome, will he remember the guy with the car, pumping gas? The guy who drove off. The guy who is living a life, unpredicted. The guy doing things, unexpected. The guy who dreams, unencumbered.

I truly hope so.



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DSACK GROUPS

Why Go To A Meeting?

DSACK is beginning a brand new year of serving and supporting families and educating the community. One of the biggest efforts we make is providing peer groups for the families.

If you read the newsletter or browse the website, you know that DSACK offers monthly meetings for the following groups: 0-5 Parent Group & Playgroup, Elementary Group and Teen & Young Adult Group. There are many, many of you who have children with Down syndrome who have never been. I want to encourage you to attend a meeting this year! I can list dozens of reasons why you should, but found the following excerpt from Dave Hingsburger "hit the nail on the head." (see information about the author on page 5 of this newsletter).....

Last night I came out to use the computer and saw a young mother with a beautiful little boy of 8 months. We chatted briefly and his eyes grew huge while looking at me ... kind of like he was trying to fit all of me in. I didn't say anything to Mom 'cause I wasn't quite sure but he looked like he had Down syndrome. But it could have gone either way. So, I let it go and we just chatted. Smiling I went to work on the computer.

Afterwards I was thinking about her and the thought popped into my mind, "Gosh, I really hope he does." Forgetting for a second that we lived in a world that devalued kids with Down syndrome and disability, I just thought about the "ride" that mom was in for - the unexpected joys - the land that she was about to become a citizen of - the opportunity to relearn and redefine joy. I guess it was because I'd spent a couple days talking with some moms of kids with Down syndrome, maybe because I'd just spent some time talking to a young guy with Down syndrome who was with his family at a conference, maybe it's because I'm finally at the point of realizing that disability does not equal tragedy.

I know, I know, I don't have kids. I know, I know, I don't know what it's like - really.

But, but, but, there are so many people who I meet that have had their lives so fully enriched by parenting kids with Down syndrome. The look of the parents at the World Congress in Vancouver were like they'd been given a ticket to an exclusive club with it's own language, it's own sense of humor, it's own unique view of the world - I was surprised that there wasn't a secret handshake to go with all of it. Watching, I felt like an outsider - envious of the connection these parents had with each other and with their kids.

So forgive me, I'm not wishing Down Syndrome on some poor family, I'm wishing purpose and meaning and joy on some lucky family - because of Down Syndrome.....

(So, come out and celebrate with some other DSACK families!)

submitted by Michelle Gilliam

0-5 PARENT GROUP & PLAYGROUP

In November, we had our 1st meeting in the new DSACK space! There were 15 children in the new playroom. (I didn't count adults in the front room, but there were plenty there, gathering information from the two Speech Language Pathologists who were presenting.) It was so fun to watch siblings tumbling around with each other, protecting each other and, when one found a new friend with whom to play, ignoring each other. I loved watching everyone flock to Levi, the youngest in the group. One of the best scenes was sweet 6 year- old Laney holding Jack (not her sibling!) while he slept.

Mary Mandl has taken the role of Childcare Coordinator, which involves hiring and training the sitters, organizing the playroom, and giving suggestions as to how we can make it safer and more accommodating. Mary has also offered to bring refreshments for the parents each month.

Mary Henson has taken the role of Program Coordinator, which involves scheduling speakers and topics for the parents.

Please let the appropriate Mary know if you can step up and help them with their volunteer responsibilities! Can you pick up breakfast one month (DSACK will reimburse you!) or help organize and set -up the playroom (still a lot to be done!). Do you know of an interesting speaker who might want to talk with the group? Would you be willing to organize a topic of discussion? At the very least, I encourage you to please give Mary Mandl and Mary Henson a big "thank-you" for their service to your family!

Elementary Group

The elementary group has had really grown over the last 3 events! I am excited to announce the upcoming events and share photos from October and November.

In October we went to Boyd's Orchard in Versailles. While there we enjoyed a petting zoo, slides, hayride, picking pumpkins, lunch and a hay maze. Everyone had a great time!



DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY

J A N U A R Y - F E B R U A R Y 2 0 1 1

In November our group went out to eat for an early Thanksgiving meal at Golden Corral. Not only did we eat, but the bakery manager taught us how to decorate and ice cupcakes!



In December we went shopping for Christmas gifts at the Dollar Tree. Look at the calendar on the back page for upcoming events!



Advocates in Motion (AIM) Teen & Young Adult Group

Hello wonderful DSACK Family!

I wanted to let everyone know what our AIM, young adult, group has been getting into these past few months as well as what is going to be going on in the future! We had a wonderful turnout at our last group outing. We went bowling at Southland Bowling Lanes in Lexington and the group rocked it! I have never seen such great bowling! We would love to have more young adults join our fabulous group! We have several things planned for the next few months. January 8th we will be at Madd Potter in Lexington, February 12th we will having our Valentine's Day party and in March, we will be going to Movie Tavern!

If you have any questions regarding AIM, please contact me through email at heatherstillwell0@gmail.com or 502-553-5514. See the DSACK calendar online or in the newsletter for more details.

Thank you for allowing me to be part of your young adult's life!! ~Heather Stillwell

thank you to our sponsors!



DSACK Mom's Night Out Schedule for 2011

Hello Moms!

I am busy scheduling this year's events for Mom's Night Out. Please, share your ideas with me and join us when you are able.

Eileen Miot erwky@yahoo.com

January 24, 2011, 6:30 pm, Dinner at Saul Good Restaurant & Pub. 1808 Alysheba Way, Lexington, KY 40509. (859)317-9200.

February 23, 2011, 12:30 pm, Lunch at Joseph-Beth Booksellers. 161 Lexington Green Cir # B1, Lexington, 40503 KY 859-273-2911.

March 14, 2011, 6:00 pm Good Scents Home & Body Shop. 123 N Broadway, Lexington, KY 40507. Free parking at Victorian Square Garage www.buygoodscents.com.

Events I am currently working on:

*Phil Dunn Cooking Class, *Sunset Painting Class, *Kim Edwards author of *Memory Keepers Daughter* latest novel *The Lake of Dreams* is due for release on Jan 4, 2011. Waiting to hear if there will be a local book signing we can all go to and finally.....*Your Idea Here!

The night of November 15 offered a thrilling opportunity for DSACK moms to meet Kim Edwards, author of *The Memory Keeper's Daughter*. DSACK moms and grandmothers sat around Eileen Miot's dining room table munching on pork tenderloin sandwiches and cookies as Ms. Edwards discussed the origin and development of the novel. She recalled her minister telling her about a man who had learned in adulthood that he had had a brother with Down syndrome who had died in an institution. Although she was intrigued by the story, Ms. Edwards initially decided that it was not hers to tell. However, an opportunity to teach a writing workshop for a group of people with special needs reignited her interest in the story. As she worked on writing the novel, which begins with the birth of twins – one with Down syndrome – she talked to many DSACK parents to ensure her depiction of the character was genuine. Over the course of the night, Ms. Edwards answered questions, led a writing exercise, and previewed her new novel, *The Lake of Dreams*, which will be released in January. Thanks to Eileen and Kim Edwards for a fabulous Mom's Night Out!

celebrations!

Jack Adams turned 2
Quote from his parents ~ "Happy Birthday Jackeroo, I can hardly believe that you are two. You've brought so much joy to our family, and know there's much more to come. So on your birthday, my sweet boy, I wish you happiness and joy times two!"



celebrations!

Emily Brewer turned 13 on December 5th
"I am thirteen! I went to see Tangled with my friends from school. It was a funny movie." - Emily





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WONDERFUL WEBSITES

http://chfs.ky.gov/dms/mpw.htm: Learn about the Michelle P. Waiver. This site will give you information on how to obtain it, as well as how it can help you, your family and your loved one with Down Syndrome achieve their fullest potential.

http://www.fcps.net/prc: The Parent Resource Center provides a place where parents of children with special needs can receive parent-to-parent counseling on special education issues and concerns. You will find some valuable resources listed on their website, including a child's notebook or teen's notebook designed to facilitate communication for everyone involved on your child's ARC team.

http://www.ndss.org/: Go to "My Great Story" you can view a story by Linda Hougland, Grandmother of Will Merritt here! The "My Great Story" you can view a new way of thinking about people with Down syndrome by showcasing and collecting inspirational stories told by people with Down syndrome as well as their family members, friends, colleagues, employers, and many others. These stories will be displayed in a beautiful online storybook for the next 12 months.

www.dsack.org: Browse our local web site. Learn what we are doing here in Central Kentucky to celebrate our loved ones with Down Syndrome and educate our community. Find out how you can be involved!

calendar

0-5 PLAYGROUP & PARENT GROUP

All meetings will be held at the DSACK office at 212 Two Oaks Road in Nicholasville from 10 a.m. until 12 noon. Child care is provided. Siblings and grandparents are always welcome. Call us at 859-494-7809 or email at newparentgroup@dsack.org.

February 12th, 2011 – Melissa Hardison of Special Olympics of Kentucky will discuss the Young Athletes program for children ages 2-7. This program helps build on physical skills for young children. Elementary families are welcome to join us for this presentation <http://www.soky.org/youngathletes.htm>.

March 12th, 2011 – Topic TBA (Watch www.dsack.org and emails for announcements, or call the DSACK office at 859-494-7809).

April 9th, 2011 – Topic TBA

May 14th, 2011 – Topic TBA

ELEMENTARY GROUP

RSVPs are crucial to planning a successful event. Bring your child out and meet Miss Sam and the other kids. It is for Kindergarten and up. Call 859-494-7809 or email info@dsack.org. Contact us to RSVP and to be added to this group's email list. All events are in Lexington or at the DSACK office in Nicholasville, unless specified otherwise. If you RSVP (and come) your child will receive a \$5 gift card to Dairy Queen.

February 12th, 2011 – Valentine Party, DSACK office, 212 Two Oaks Road, in Nicholasville, 3 – 5 p.m. We will decorate cookies and make cards. Students should bring a list of people to make cards for. Come and enjoy a day of crafts and cookies!

March 12th, 2011 – Kid's Place, 3993 W. Tiverton Court, Lexington. An Occupational Therapist will be there to talk about fine and gross motor activities and answer any questions you may have at this time. 11:00 a.m. - 3:00 p.m. Come out and play and eat lunch!

April 30th, 2011– Monkey Joe's, 1850 Bryant Road, Ste 120, Lexington 11:00 a.m.–3:00 p.m. Come and join the fun!

May 14th, 2011– Picnic at the park 1:00pm-3:00pm. A speech therapist will be present to answer any speech questions you may have at this time.

***Remember** that the 1st child to attend four elementary group events will receive a \$50 gift card to Target or Toys R Us (their choice). If more than one child reaches this goal, the gift card amount will be split.

TEEN/YOUNG ADULT GROUP (AIM – ADVOCATES IN MOTION)

RSVPs are crucial to planning a successful event. Come out and meet Heather and the other young adults. 859-494-7809 or info@dsack.org, contact us to RSVP and to be added to this group's email list. All meetings are in Lexington unless specified otherwise.

celebrations!

I am so excited that I want to share this in the Celebrations section of the newsletter. My son, Joshua, who is six years old and going to kindergarten at Clays Mill Elementary has been doing great in school. He took his first sight word test and spelling test a few weeks ago and got 100s on both. He was recognized in front of all the kindergartners for doing such a great job. Today he just took his second unit test of 24 sight words and 6 spelling words and had to read some sentences and only missed 4 sight words! His reward was a movie and popcorn so guess what we'll be doing tonight! I'm hoping many more movie nights are in store.



Thanks, Tammy Carter

donations

Thank you to Ann Lefever, for her donation to Erica's fund in memory of her littlest angel, Shelby Christine Wray.

Thank you to the Merritt Family who donated a brand new DVD player to the DSACK office.

All costs for young adults to participate in these events is paid by DSACK. If you RSVP (and come) you will receive a \$5 gift card to Dairy Queen.

February 12th, 2011 – Valentine Party, DSACK office, 212 Two Oaks Rd, in Nicholasville, 12:30-2:30 p.m.

March 12th, 2011 – Movie Tavern, 133 North Locust Hill, time and movie TBA.

April 15th, 2011 – Picnic at the Arboretum, 500 Alumni Drive, 12:00 – 3:00 p.m.

May 14th, 2011 – Surprise! The group member with the best attendance from November through April will choose this month's outing. He or she will be given several options and will have a part in planning the day's event.

February 26th – DSACK 's Educational Conference. See pages 9-12 for the enrollment and informational brochure. You won't want to miss this opportunity to hear from local and national experts!

Mom's Night Out (MNO)

January 24, 2011, 6:30pm, dinner at Saul Good Restaurant & Pub. 1808 Alysheba Way, Lexington Ky 40509. (859)317-9200

February 23, 2011, 12:30, lunch at Joseph-Beth Booksellers. 161 Lexington Green Cir # B1, Lexington, Ky. 859-273-2911

March 14, 2011, 6pm Good Scents Home & Body Shop. 123 N Broadway, Ky 40507. Free parking at Victorian Square Garage www.buygoodscents.com

submissions

Submission deadline is Monday, February 14th and can be sent to Allison Kerschbaum at allisonkerschbaum@insightbb.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 allisonkerschbaum@insightbb.com.

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



DSACK

beautiful capable loved

DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY
P R E S E N T S

HIGH EXPECTATIONS

Realizing the Possibilities

a conference about Down syndrome for parents and professionals



Saturday, February 26th, 2011
Marriott's Griffin Gate Resort
Lexington, KY
7:45 a.m. – 1:30 p.m.

Who Should Attend

- Parents
- Grandparents
- Self Advocates
- Teachers
- Physicians
- Case Managers
- College Students
- Physical Therapists and Physical Therapist Assistants
- Occupational Therapists and Occupational Therapist Assistants
- Speech Language Pathologists
- Social Workers
- Anyone with an interest in people who have Down syndrome

Conference Description

This conference will bring together outstanding educators, medical professionals, and researchers as well as disability advocates, self-advocates and parents to discuss subjects on a variety of issues related to Down syndrome.

Local and national experts will be speaking on topics including realizing your child's potential, early communication and speech, literacy and reading, health issues, postsecondary education, behavioral management ,family issues, inclusion and much more.

This is an ideal conference for all parents (regardless of your child's age), grandparents, educators, physicians or other health care professionals, students, self-advocates, and the community. Come learn how to set high expectations for those with cognitive disabilities and how to provide the proper supports to help them meet those expectations.



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C O N F E R E N C E S C H E D U L E

Registration and Breakfast – 7:45-8:10

Opening – 8:15-9:00 "Postsecondary Education is an Option for People with Intellectual Disabilities" by Jeff Bradford This session will report on success stories, discuss initiatives around Kentucky and the United States, share guidelines about funding and a new 5 year grant, and present the statewide plan.

Breakout Session 1 – 9:05-10:00

A. "Enhancing Language and Literacy with a Balanced Approach" by Donna Horn, Ph.D., M.S., CCC (SLP) This seminar presents ways to achieve balanced early literacy instruction. Approaches to combining code (decoding, phonological awareness, word recognition) and meaning (comprehension and functions of print) will be provided. Participants will learn a range of instructional options and different contexts that can be used to balance language and literacy instruction. Participants will gain knowledge in adapting texts and existing programs that can be used within school, home based, and intervention contexts for individualized early literacy programs. Both narrative and expository text contexts will be illustrated, and videos of early language literacy classroom and individual programs will be used.

B. "Helping Develop Motor Skills and Fitness in Children With Down Syndrome (Elementary School and Beyond)" by Beverly Durborow, PT, MS and Lisa Reynolds, MEd, OTR/L, ATP. This session will include the following topics: general motor development as it relates to the early school years, motor and participatory expectations of children at school (elementary through high school), what is generally offered by schools for PT/OT and why children with Down syndrome often do not qualify for school PT (but need to continue working on physical abilities), the benefits of developing fitness and recreational sports skills (and suggested activities), the importance of movement and social participation as the child grows into middle and high school years, and the importance of developing "lifetime" movement and activity habits.

Breakout Session 2 – 10:05-11:00

C. "Let's Get Talking and Let's Have Fun: Early Communication and Speech Ideas for Infants and Toddlers with Down Syndrome" by Jane Kleinert, Ph.D., CCC-SLP This session will focus on encouraging early speech/language development for infants and toddlers who have Down syndrome. The focus will be on fun ways to help children develop early vocabulary, turn-taking, first words and sentences. Video tapes of very young children using simple technology and interacting with their family will be shown. Emphasis will be placed on making language fun and useful to our children!

A B O U T T H E S P E A K E R S

**Jeff
Bradford,
MSW**

~ For the past three years, **Jeff Bradford** has been the director of the Postsecondary Inclusion Partnership (PIP) at the Human Development Institute at the University of Kentucky. The PIP is a model demonstration project aimed at including students with intellectual and other developmental disabilities in postsecondary education. Jeff will now become the director for the Supported Higher Education Project (SHEP) which will develop a comprehensive system of support for students with intellectual disabilities throughout the state of Kentucky. Jeff has a master of social work degree and has worked with children and adults with disabilities for over twenty years. In his spare time, Jeff enjoys hanging out with his family, riding his motorcycle and watching episodes of House on television.

**Traci C.
Brewer**

~ **Traci Brewer** is the mother of five children, including Emily who was born with Down syndrome. Traci began volunteering with the Down Syndrome Association of Central Kentucky in 1997, shortly after the birth of her daughter. She began by coordinating social events for families and went on to serve on the board. Traci is currently the chairperson of the organization. She often speaks publicly on topics associated with Down syndrome including best practices for educating children with Down syndrome, medical presentations at local hospitals and doctor's offices, peer presentations at schools and churches, panel discussions at local seminars, and is a regular speaker at a local college regarding faith inclusion. Traci has attended several national and regional conferences focusing on topics related to Down syndrome. In addition to serving the Down Syndrome Association of Central Kentucky, Traci has served on the Fayette County Special Education Advisory Council. She is an active member at Centenary United Methodist Church in Lexington and is leading the effort in starting a ministry for individuals with development delays. She is currently employed by Pediatric and Adolescent Associates.

**Beverly
Durborow
PT,MS**

~ **Beverly Durborow** has worked as a pediatric physical therapist for 24 years in Kentucky and Mississippi. She has worked with the 0-3 population through Central Baptist Hospital, the First Steps Program, Child Development Center of the Bluegrass, Nurses Registry, Private Patient Clients, and the school systems in Fayette, Garrard and Pendleton Counties. She holds a Bachelor of Science degree from Mississippi University for Women, a Master's degree in Motor Learning and Special Education from Louisiana State University and a Master's degree in Physical Therapy from The University of Alabama at Birmingham.

**J.
Courtney
M. Elbert**

~ **Courtney Elbert** graduated from Bellarmine University with a Bachelor of Arts in English and Secondary Education. She earned her Master of Science in Educational Policy Studies and Evaluation with an Emphasis in Higher Education from the University of Kentucky. Courtney served as the Assistant Dean of Students and Director of Student Activities at Bellarmine University. She worked with Transylvania, Bellarmine and UK in developing various Leadership Programs, Conferences, and Workshops. She is currently a Title I tutor and is a blogger for the Lexington Herald Leader. Courtney has served as the Vice-Chair of the Down Syndrome Association of Central Kentucky and Chairperson of the Education Committee. She is also the Founder and Chairperson of St. Leo SPICE (Special People in Catholic Education) which raises funds and awareness about people with special needs within the St. Leo Parish School and beyond. She serves on a Lexington Diocesan-wide Inclusion Committee. Courtney is often asked to speak publicly on a variety of topics and panels such as education of people with Down syndrome, inclusion of individuals with special needs, the dignity of life, and leadership. Courtney and her husband have three children and their middle child, Sam, has Down syndrome. The Elbert Family was featured in the 2009 edition of Exceptional Family Kentucky.

**Meada
Hall
Ed.D**

~ **Meada Hall** is the Director for the Community Based Work Transition Program. She also teaches part time in the Department of Special Education at the University of Kentucky. She has 12 years of teaching experiences at the university level at the University of Kentucky and at Eastern Kentucky University and has over 25 years of experience working with individuals with disabilities. She began working as a recreation therapist for several adult agencies, and then began her career as a special education teacher across the K-12 setting. During this time, she developed and implemented the "College Connection", a program which provided opportunities for students with moderate and severe disabilities to participate in college life, courses, and employment as a means of transitioning into adulthood. Through the years of experiences, Meada has become an advocate for individuals with disabilities and their families. She has several publications in the area of working with students with disabilities and has presented at national, regional and local trainings and conferences. Meada received her doctorate in special education from the University of Kentucky.

H I G H E X P E C T A T I O N S

Realizing the Possibilities

D. "Navigating through the Individual Education Plan (IEP)" by Meada Hall, Ed.D This presentation will provide information on planning, developing and implementing the IEP as well as how to get the student involved in their IEP process. Participants will learn about; a) present level of performance; b) special factors considerations; c) goals and objectives; d) specially designed instruction and related services; e) participation in general education and least restrictive environment; f) progress monitoring; g) differentiated instruction and; h) transition planning.

Break 11:00 – 11:15

Breakout Session 3 – 11:20-12:15

E. "Obstructive Sleep Apnea and Ear, Nose and Throat Problems seen in Down Syndrome" by Sally Shott, MD This presentation will review many of the common Otolaryngologic (ear, nose and throat or ENT) problems seen in children and young adults with Down syndrome. This includes chronic ear infections and hearing loss, chronic nasal congestion, and airway problems, including sleep abnormalities and obstructed sleep apnea. Treatment options and outcome expectations will be presented. Ongoing research studies in these areas will also be presented.

F. "Best Practices for Educating Students with Down Syndrome" by Traci Brewer and Courtney Elbert This session will offer practical solutions to parents and educators regarding communication, cooperation, independence and inclusion. This session will include simple solutions to help parents and educators successfully instruct and enjoy their child/student with Down syndrome. These strategies are relevant for students of all ages from preschool to college. Topics discussed will include: a) better communication with happier outcomes; b) moving your child/student toward independence; c) behavioral management and; d) inclusion tips for home and school. This session is appropriate for ALL educators, including family members, paraprofessionals, therapists, facilitators, medical professionals and anyone who interacts with students who have Down syndrome.

Lunch with Speaker 12:30-1:30 "The Importance of Belonging, Relationships and Learning With Each Other" by Barbara McKenzie Since the early beginnings of the inclusive education movement many years ago, we seem to have lost site of our original vision of school communities where ALL are welcomed, diversity is celebrated, and we embrace our interdependence. Barb hopes to re-focus us to that importance by sharing stories gathered from the extraordinarily "ordinary" life of a person with a disability label, her daughter Erin. Conveyed in the form of keen observations, heartfelt surprises, and insightful reflections, the stories and images inspired by Erin's life demonstrate the rich connections and relationships that result from an inclusive learning community.



**Donna
Horn, PhD
MS,CCC-SLP**

~ **Donna Horn** holds a doctoral degree in experimental psychology in the area of cognitive/developmental psychology, as well as masters degrees in speech/language pathology and psychology. She has presented many national workshops and authored materials on interventions on school language and literacy issues, and has recently published a topics article on expository text comprehension. Dr. Horn is the owner/director of Horn and Associates in Rehabilitation, PLLC, a multi-specialty rehabilitation group.

**Jane
O'Regan
Kleinert
PhD,CCC-SLP**

~ **Jane Kleinert** is an Assistant Professor in the Division of Communication Sciences and Disorders in the College of Health Sciences at the University of Kentucky. She is a licensed Speech/Language Pathologist with over 35 years of experience specializing in services to children with multiple disabilities, oral feeding disorders and early intervention. Dr. Kleinert's research and grant work focuses on intervention for speech and augmentative communication for students with significant disabilities. Her teaching areas at the University of Kentucky include speech sound disorders, pediatric feeding and motor speech disorders and early intervention. Jane and her husband Harold are life-long Kentuckians and have three adult children. Jane's younger sister, Ruth, has Down syndrome.

**Barbara
McKenzie**

~ **Barbara McKenzie** is an advocate, author, presenter, and organizer of gatherings about the importance of creating inclusive communities. In college during the late 60's she considered herself a social justice activist, but when Erin was born and diagnosed with Down syndrome, she realized how much she had to learn about welcoming everyone and discovering the gifts in each of us. Over the last two decades she has continued to learn with dear friends and leaders in the movement for full inclusion. Throughout Erin's all too short life, Barb shared observations, surprises, and reflections inspired as Erin and her family made new connections and relationships. Some of those narratives and a few new ones, thoughts from Erin's friends, and a collection of photographs tell this story of inclusion in her book, "*Reflections of Erin; The Importance of Belonging, Relationships, and Learning with Each Other*". This is not the story of an extraordinary person with a disability; rather what is extraordinary is that Erin had the opportunity to have an ordinary life. Continuing this vision of welcoming, inclusive communities where ALL are valued and participate is the message that Barb conveys in her conversations, workshops, and presentations.

**Sally
Shott
MD**

~ **Dr. Shott** is a Pediatric Otolaryngologist and Professor of Otolaryngology. She is affiliated with a private practice, in addition to her duties as an associate professor at Cincinnati Children's Hospital Medical Center and the University of Cincinnati Medical Center. Dr. Shott treats children with otologic disease, sinus disease and provides airway management. She has a special interest in children with Down syndrome and the specific medical issues they face. Her research includes ear, nose and throat issues and how they affect patients with Down syndrome. In 2006, Dr. Shott was elected President of the Society of Ear, Nose and Throat Advances in Children. She was awarded "Best Doctors in America" in 2004, 2005 and 2008. Her publications and professional organization memberships are numerous.

**Lisa
Sparks
Reynolds
MEd,OTR/L
ATP**

~ **Lisa Sparks Reynolds** has been licensed as an occupational therapist in Kentucky since 1996. She has a bachelor's degree in occupational therapy from Eastern Kentucky University and a master's degree in special education with an emphasis in assistive technology from the University of Louisville. Since 2002, Lisa has been employed as an occupational therapist for Garrard County Schools. She works with children with disabilities ages 3-21 in the school setting to help them develop and enhance delayed skills or accommodate for missing skills using various forms of technology. At home, Lisa is a wife and mother of two great children, ages 12 and 10. Their daughter, age 10, is diagnosed with Down syndrome. With their faith in God, as well as support from professionals, family, and friends, she and her husband strive to help both of their children reach their full potentials each day.

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HIGH EXPECTATIONS – REALIZING THE POSSIBILITIES

A Conference About Down Syndrome For Parents And Professionals

Copy as needed for each attendee or print additional forms at www.dsack.org.

Name _____ Profession/Job Title _____

Organization _____ Email address _____ Phone _____

Address (street, city, state, zip) _____

All attendees will be able to attend the opening and luncheon sessions, but you will need to choose between concurrent breakout sessions. Please circle which breakout sessions you will attend:

Session 1: A or B Session 2: C or D Session 3: E or F (we must have this information in order to process your registration)

Registration fee : \$25/person, \$40/couple, \$15/college student, with name of school and signature of advisor here _____

Registration includes breakfast, lunch, handouts and a copy of the book by Barbara McKenzie.

A limited number of registration scholarships available to DSACK families. If you require the registration fee be waived, please contact DSACK @ 859-494-7809 or info@dsack.org.

Send payment and completed registration form to DSACK, PO Box 910516, Lexington, KY 40591-0516 no later than **February 15th**.

We have reserved a block of rooms at Marriott's Griffin Gate Resort at a reduced rate of \$109 each. Please mention that you are attending this conference in order to receive this rate. A limited number of lodging scholarships are available to DSACK families. If you are a DSACK family living more than 75 miles from Lexington and require assistance paying for lodging the night before the conference, please contact DSACK @ 859-494-7809 or info@dsack.org and a scholarship form will be sent to you.

C O N T I N U I N G E D U C A T I O N C R E D I T S

All attendees will receive Certificates of Completion that reflect the actual number of contact hours.

This conference qualifies for 4.5 continuing education hours as required by many licensing boards and professional organizations. If your discipline is not listed below, save your course outlines and certificate of completion and contact your own board or organization for specific filing requirements.

Teachers – submit certificate to your school.

PTs and PTAs – This course has been submitted to the Kentucky Physical Therapy Association for approval.

Social Workers – This course has been submitted to the Kentucky Board of Social Work for approval.

SLPS – This course has been submitted to the Kentucky Board of Speech Language Therapy for approval.

Please contact DSACK for updated approval status.