

Down

Syndrome

Association of Central Kentucky



WHAT'S GOING DOWN WITH DSACK

VOLUME II – NUMBER III

JULY-AUGUST 2008



DSACK APPRECIATION DAY WAS A PARTY!

Submitted by Michelle Gilliam

DSACK held its first annual Appreciation Day on April 20th. Yes, we thought it was time for a party! Mostly, it was time to thank the individuals and businesses who have shown an interest in our children and families over the past year. The types of support we received were many, and a list of our supporters can be found on the website at www.dsack.org.

Special recognition was given to past Executive Board members Caroline Baesler, Karen Boudreaux and Meg Steinman for their years of dedication to DSACK. An award was created in honor of Karen Boudreaux, whose heart and energy took DSACK to another level when she became involved several years ago. The "Karen Boudreaux 'Something Extra' Award" will be given annually to an individual or business who has given that "something extra" to DSACK, above and beyond anything expected. It will be our version of the 110% Award.

A unanimous decision by the Executive Board was made to give this year's award to Harold Kleinert, Ed.D., Executive Director of the Interdisciplinary Human Development Institute. His tireless work on behalf of people with Down syndrome is known nationally and has helped our DSACK community immensely. We truly appreciate his passion and dedication.

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EXECUTIVE BOARD MEMBERS

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

ADVISORY BOARD MEMBERS

Executive Committee members plus:

Caroline Boeh Baesler, Parent

Karen Roof Boudreaux, Parent

Sandra Brock, Cabinet for Health and Family Services, Executive Director of the Ombudsman

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

Carolyn Bays, Chief, Division of Clinical/Biochemical Genetics & Dysmorphology, Dept. of Pediatrics, UK

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

Dixie Miller, Parent, Developmental Interventionist

John Riley, M.D., Pediatrician at PAA

Meg Steinman, Parent

DSACK ANNUAL SUMMER PICNIC A SUCCESS!

Submitted by Mary Mandl

A little rain didn't dampen the spirits of those who turned out for DSACK'S Summer Picnic at Southland Park in Lexington on June 1st! The brief rain shower actually cooled us off and brought us even closer together as we huddled under Shelter #2. This was my first picnic with DSACK, and I was warmly welcomed and excited to meet several new families and precious children. My 10-month-old daughter, Megan, who has DS, enjoyed being held and passed around by many parents, while her 4 year old sister Tracy played with her friends from DSACK on a great playground! This was a perfect location for our families to eat, mingle and share stories. The BBQ and side dishes were delicious, and the sun reappeared so we could enjoy more time together. My favorite take-home story came from meeting Jason, a 23-year-old young man with DS, who came over to say hi to my daughter. We discovered that we live in the same town, and Jason works at the McDonalds we often visit! How encouraging to see his smile, wonderful attitude, and good work ethic. His mom shared that Jason is their best employee. I am always encouraged as I meet more families involved with DSACK and look forward to more events such as this to bring us closer.

SUMMER PICNIC ALSO SERVED AS KICKOFF FOR BUDDY WALK

Submitted by Caroline Baesler

DSACK's Annual Summer Picnic was held Sunday, June 1st at Southland Park and was a big success, as usual. It was great to meet new families who attended and see lots of familiar "old" faces as well. Plenty of kids (and some moms and dads) enjoyed playing on the playground and everyone enjoyed good food and fellowship. A big thanks to Becky Lesch and other members of the DSACK Executive Committee for putting it all together.

The picnic also served as a kickoff for the 6th Annual Buddy Walk to be held September 27th. Now is the time to get your team together and start thinking of a fund-raising goal. The Buddy Walk, along with being our biggest event, is also our main fundraiser for the year and is the backbone of the many programs and supports that DSACK provides to our families. For information on forming a team, visit the website at www.dsack.org or email Martha Campbell at mcampbell@apscommunications.com.

DID YOU LEAVE SOMETHING AT THE SUMMER PICNIC?

Some individuals left personal items at the picnic, such as 2 umbrella chairs, a black umbrella, a yellow mixing bowl with large spoon and various other items. To claim your items, please call Becky and leave a message at (859) 252-9523.

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

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

ESTATE PLANNING WORKSHOP WAS OFFERED APRIL 26!

Submitted by Becky Lesch who attended the workshop

What do you want to have in place for your family when you are no longer able to care for them? How much money will it take? Where will the money come from? Who will decide how it is spent? What legal safeguards can be established now to protect your plan?

These are difficult questions to consider as we go about our busy lives with our families. It is possible to set up a plan NOW which will be beneficial to your family and the family member with a disability in your absence. Carolyn Wheeler, an estate planner with Mass Mutual, (www.ky.hope.org) 859-223-4141 warned us that her job was to make us a little uncomfortable by raising these questions. She also had some tips about finding answers.

Parents are encouraged to find out about Publicly Funded Resources by contacting the Kentucky Resource Market 1-877-293-7447. We also have a binder in our DSACK library filled with this information. The ARC of Kentucky is also an excellent source of information. 1-502-875-5225.

To avoid costly mistakes, consult an attorney with a specialty in this area that will make sure that your child's resources are protected within the legal framework. One attorney in our area who is very knowledgeable is Karen Perch, P.H.D., J.D. (859-224-0513). To save time and money, Nancy strongly recommended having critical questions

answered with your child's team before meeting with an attorney.

Dick Covert contributed the plan that his family has for his daughter, Nancy. She just had her 40th birthday. Nancy lives in an apartment, and runs her own computer-based business, called "Stay in Touch".

About twenty six parents and guardians attended this workshop sponsored by the ARC of Kentucky and the Down Syndrome Association of Central Kentucky. There was a wealth of knowledge and experience shared during this morning workshop. Please plan on attending when this workshop comes again. It is neither too late nor too early to consider your child's future.

LIVING WITH CELIAC DISEASE

Submitted by Nicole Maher

Tarenne was diagnosed with Celiac Disease (CD) when she was 3 ½ years old. We caught it because our doctor had the recommended medical guidelines for children who have T21 in her file. Tarenne was asymptomatic, but looking back we could see some signs that we had brushed off as 3 year old behavior (like refusing to eat chicken nuggets and only wanting the French fries).

In all honestly, this diagnosis was harder for me emotionally than when we had received her prenatal diagnosis of Down syndrome. After all, I knew how to love, but how in the heck was I going to cook without wheat? Rye and barley are also prohibited on a gluten free diet, but I assumed they would be easy to rid ourselves of. I was wrong.

Gluten is in everything! I soon learned that we had to be careful what toothpaste to buy, which spices were okay, and what products had hidden gluten, even though looking at their ingredient list, they appeared to be fine. This was 5 years ago. New laws were passed by the FDA this year, and companies have to list allergens directly and clearly on their packaging. Things have become much easier to detect!

Caroline Baesler (A DSACK friend) was the first person to come to my aide. She came over with a gluten free (gf) cookbook and had even gone to the trouble to make gf cookies for Tarenne. And they were great!

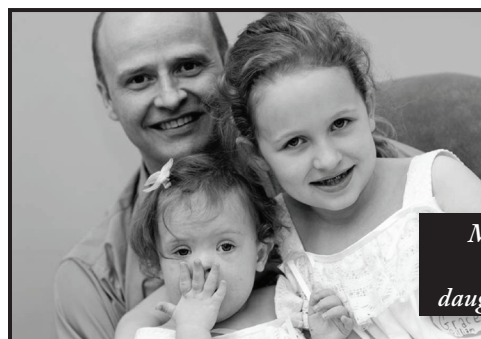
With that little bit of inspiration I moved forward with our new lifestyle. While it was a big adjustment, once I

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Approximately 100 people attended the event, which was complete with DJ, dancing, great door prizes and a catered buffet. Courtney Elbert created a beautiful video of our loved ones that was shown at the party.

Special thanks to the Child Development Centers of the Bluegrass for hosting the event, Drs. Jim and Malkanthie McCormick for sponsoring the catering, Regina Schmutte for securing door prizes from Baby Moon, Blockbuster, Ky. Furniture Wholesale, Portrait Shoppe, Rafferty's, Target and Victoria's Secret, and to Jacqueline Agentis for donating her time and talent photographing the party. Also, a BIG THANKS to all

who came and partied with us!



*Michelle's Husband
Michael &
daughters Ava and Grace*

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knew what to buy things returned to normal. Tarenne adjusted really well and would even ask, "Mom I have this?"

When asked to share a recipe for the newsletter I realized that I really don't even use our g/f cookbooks at all anymore. I have simply become accustomed to using substitute items for the food that our family has always enjoyed. If you ever have any questions about gluten free living and celiac disease please feel free to use our family as a resource. Nicole and Joe Maher (859) 881-5423

These are the items that we could not live without:

Ancient Harvest Quinoa Pasta
Annie's Naturals Cowgirl Ranch Dressing
Betty Lou's Krispy Bites
Blue Diamond Almond Crackers
Bob's Red Mill All-Purpose Gluten-Free Baking Flour
Deboles Pasta Corn Spaghetti
Health Valley Corn Crunch-Ems Cereal
Mrs. Leeper's Gluten-Free Beef Stroganoff
Mrs. Leeper's Gluten-Free Creamy Tuna
Wheat & Gluten Free Rice Pecan Bread by Food for Life

THESE LITTLE PIGGYS DID NOT STAY HOME!

Submitted by Nicole Maher

The piggy bank fundraiser sponsored by Bank of Lexington is officially over, but our little piggys are still traveling! Two DSACK families have already taken the piggy banks on the road with them. As a result, they have raised lots of money, and, just as importantly, they have raised awareness about our Down syndrome community.

A HUGE thanks goes out to the Merritts and the Mahers who are proving that the Buddy Walk doesn't have to be our only fundraising effort. And it certainly doesn't have to be the only way to promote acceptance and inclusion of people with Down syndrome. Their stories are below.

Please join in the fun and adopt a piggy bank for a week or two. You can be creative with your fundraising and awareness efforts. Any amount raised will be very appreciated. The Executive Board has decided that funds raised from this effort will be used to design and develop a new DSACK website. We have high hopes

for the website endeavor and need all the help we can get. To assist with the website itself or to take a piggy bank, call 859-494-7809 or speak to a board member.

Submitted by Brent Merritt

On Thursday and Friday, May 8 & 9, The Scott County High School Choral Department held the 23rd Annual Ice Cream Concert in the school's Auditorium in Georgetown. During the concert, Brent Merritt, Scott County HS Choral Director and dad to 5 month old Will, gave a brief public announcement about DSACK and asked the audience to visit the uniquely decorated piggy bank conveniently located just outside the cafeteria where everyone would enjoy ice cream after the concert. Over \$1000 was donated by Scott County students and audience members alike! Brent, Tonya, Eli and Will would like to thank all the folks at Scott County H.S. for their generous support of DSACK.

Submitted by Nicole Maher

Our family volunteered to grab one of DSACK's artistic piggy banks to try to raise some money and awareness in our community. The pig's first stop was Darrah and Tarenne's elementary school, Rosenwald Dunbar in Nicholasville. Jonathan Hardy and Brady Taylor of DSACK are also students there. We went into this with the intention of raising more awareness than money. Poster were hung on the walls and flyers were sent home with every student in his/her backpack. The flyers included basic information about Down syndrome, as well as the fact that Rosenwald Dunbar has 3 students with that extra chromosome...and that they make great friends and classmates. Darrah, our oldest daughter who is in 4th grade, incorporated a piece about T21 and the fundraiser into her Enrichment program's newscast for the school, as well as in their school announcements! The class who raised the most money won a pizza party provided by our family. In the end, our school raised a lot of awareness about Down syndrome, as well as \$319 for DSACK! This is exactly the kind of response we had hoped to elicit! My favorite donation was a Ziplock bag full of a little boy's piggy bank money that included some lint, a candy wrapper, and some grass.

NEWS TO USE

LOUISVILLE "SIBHOPS" ARE BEING FORMED!

What are Sibshops?

Sibshops are a chance for brothers and sisters of children with special needs to meet other sibs through recreation with opportunities to hang out and also to talk about being a sibling of a brother or sister with special needs. (check out siblingsupport.org for more information).

There will be 2 groups:

- Children finishing 1st-4th grades will meet at Home of the Innocents (1100 E Market, Louisville)
- Children finishing 5th-7th grades will meet at the Council on Mental Retardation (1151 S 4th Street, Louisville)

When? What? Cost?

-June's meeting will be a classic Sibshop, and July and August meetings will be recreational outings.

-The cost is \$5 and there are scholarships available.

-**Saturday, July 12, 2008**

1-4pm
TBA Water activity

-**Saturday, August 9, 2008**

1-4pm
TBA Indoor Activity

How do I register or what if I have questions?—Call *Amanda Westmoreland at Home of the Innocents with any questions or to obtain a registration form: (502) 303-4409*

CONNECTION BETWEEN DOWN SYNDROME & ALZHEIMERS

Below is a link to an article in New York Times that discusses the connection between Down syndrome and Alzheimers. This article illustrates the importance of cognition research for benefit of the entire Down syndrome community.

To access the article, go to the New York Times' Article Archive from 1981-Present at their website: <http://www.nytimes.com/ref/membercenter/nytarchive.html> Just type in the article information in the appropriate boxes: "For People with Down Syndrome, Longer Life has Complications" by Sally Sara published June 1st, 2008.

SIGN LANGUAGE WEBSITES

Submitted by Courtney Elbert

DSACK often highlights resources for sign language because many of our loved ones with Down syndrome have had great success in using sign language to enhance their early communication and lifelong communication success. There is research supporting the use of sign language with all infants and young children, and even more reasons to use it with our children with special needs. Here are some websites for parents, families and anyone interested in learning sign language. (The first two sites are the ones we used regularly when learning and teaching sign language to our son, Sam. He used sign language as his primary

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CELEBRATIONS



Congratulations to Sam Elbert who recently became an official walker! Sam is now vertical and walking most all of the time with minimal assistance. He has even started to push our hands away when we try to hold his hand!

Congratulations to Nicole Maher who received a scholarship from DSACK to attend the National Down Syndrome Congress's national conference in Boston on the weekend of July 12th. We look forward to hearing about the experience and gaining valuable information for our families.

Congratulations to Julia Steinman who received a scholarship from DSACK to attend Camp Pals. We look forward to hearing about the camp experience. Because of your request, DSACK has

decided to create scholarships for camp opportunities in the future.

For updated information about conference and camp scholarships, please visit our website (www.dsack.org)! DSACK plans to develop and expand these opportunities in the near future.

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

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form of communication until he was almost four, and we still use it every single day. We believe sign language has been a vital part of his development, and we have enjoyed communicating with him. Sam's older brother and younger sister communicate with sign language too. Sam and his siblings LOVE the "Signing Time" series and we have purchased many of the DVD's. You can also find them at the library, or on PBS.). The New Parent group recently focused on Sign Language with a presentation by DSACK's very own Beth Ann Bourne, so stay tuned for additional information in our next newsletter.

- www.signingtime.com
- <http://commtechlab.msu.edu/sites/aslweb/browser.htm>
- www.hearmore.com
- www.rocketlanguages.com
- www.tinyfingers.com
- www.showsondvd.tv/baby.html
- <http://www.aslpro.com/>

ALASKA GOVERNOR BALANCES NEWBORN'S NEEDS, OFFICIAL DUTIES

Written by Steve Quinn, Associated Press Writer

"The results of Gov. Sarah Palin's prenatal testing were in, but the doctor's tone was ominous: "You need to come to the office so we can talk about it." Palin, known for a resolve that quickly launched her from suburban hockey mom to a player on the national political stage, said "No, go ahead and tell me over the phone." The physician replied "Down syndrome," stunning the Republican governor who had just completed what many political analysts called a startling first year in office. She had arrived at the Capitol on an ethics reform platform after defeating the incumbent Republican in the primary and a former two-term Democratic governor in the general election. Her growing reputation as a maverick for bucking her party's establishment and Alaska's powerful oil industry quickly gained her a national reputation. Now she said she is trying to balance caring for her special needs child and running the nation's largest state. The doctor's announcement in December, when Palin was four months pregnant, presented her with a possible life- and career-changing development. "I've never had problems with my other pregnancies, so I was shocked," said Palin, a mother of four other children. "It took a while to open up the book that the doctor

gave me about children with Down syndrome, and a while to log on to the Web site and start reading facts about the situation. "The 44-year-old governor waited a few days before telling her husband Todd, who was out of town, so she could understand what was ahead for them. Once her husband got the news, he told her: "We shouldn't be asking 'Why us?' We should be saying 'Well, why not us?' "There was never any doubt the Palins would have the child, and on April 18 she gave birth to Trig Paxon Van Palin. "We've both been very vocal about being pro life," Palin said. "We understand that every innocent life has wonderful potential. "Down syndrome is caused by the presence of an extra chromosome in the fetus' cells. It's a genetic abnormality that impedes physical, intellectual and language development. The mother's age is a large factor in the chances of having a Down child. Once a woman turns 40, the chances of having a Down child is 1 out of 100, according to the Eunice Kennedy Shriver National Institute of Child Health and Human Development. During her first year in office, Palin distanced herself from the old guard, powerful Republicans in the state GOP, even calling on tightlipped, veteran U.S. Sen. Ted Stevens to explain to Alaskans why he was being investigated by federal authorities. She asked Alaska's congressional delegation to be more selective in seeking earmarks after Alaska's "Bridge to Nowhere" became a national symbol of piggish pork-barrel spending. She stood up to the powerful oil industry, and with bipartisan support in the statehouse she won a tax increase on oil companies' profits. She also found time to pose for fashion magazine Vogue while she was pregnant, and she has been mentioned among potential vice presidential running mates for John McCain. Three days after giving birth, Palin returned to work in her Anchorage office, accompanied by Trig and her husband. This was not a mother's typical visit to the office to show off the new baby; instead, she was serving notice that a child of special needs will not hinder her professional commitments. "It's a sign of the times to be able to do this," she said. "I can think of so many male candidates who watched a family grow while they were in office. "There is no reason to believe a woman can't do it with a growing family. My baby will not be at all or in any sense neglected. "Neither, Palin said, will the state, as she prepares to lead deliberations for a multibillion-dollar natural gas pipeline. That's the economic future of the state, a means of getting North Slope natural gas to consumers throughout North America. "I will not shirk my duties," she said. Other politicians have pressed forward with their careers

despite jarring personal news. Democratic presidential candidate John Edwards continued with his campaign despite the return of his wife Elizabeth's breast cancer, though he eventually dropped out. Another elected official who has a child with Down syndrome said Palin will likely have detractors, but that shouldn't change ambitions for the mother or child. U.S. Rep. Cathy McMorris Rodgers, R-Wash., has just celebrated the first birthday of her son Cole, her first child, who was born with Down syndrome. She is busy campaigning for a third term, and Cole often travels with her between Washington, D.C., and the Pacific Northwest. "Cole opened my eyes to the pain and trouble a lot of families endure," Rodgers said. "He's allowed me to see people and circumstance more deeply, and the generosity of people. "It's in human nature to focus on the negative, on what the person can't do. In our mind, we are focused on what he can do, what he will be able to do and do very well. "It's not unlike how Palin sees her child. "I'm looking at him right now, and I see perfection," Palin said. "Yeah, he has an extra chromosome. I keep thinking, in our world, what is normal and what is perfect?"

ADVOCACY ALERT

NDSS PARTNERS WITH REGAL CINEMAS

NDSS is excited to announce a new partnership with Regal Cinemas.

In 6,900 screens across America, several well-known public figures will speak about acceptance and inclusion for people with Down syndrome, highlighting our National Buddy Walk program and October as Down Syndrome Awareness Month.

The 30-second film will run from September 26-October 9, 2008 in all Regal Cinemas across the country.

Confirmed to speak in the film:

- Meredith Vieira, Co-Host of NBC's *The Today Show*
- Liam Neeson, Actor
- John C. McGinley, Actor and NDSS Buddy Walk Ambassador
- Albert Pujols of the St. Louis Cardinals
- Chris Burke, as well as other self-advocates

To view this entire announcement, visit NDSS webpage: http://www1.ndss.org/index.php?option=com_content&task=view&id=2052&Itemid=233

HOW DOCTORS BETRAYED HER BROTHER WITH DOWN SYNDROME

"If I am patient, it is because of him. If I don't judge people by appearance, it is because of him. If I have a mordant sense of humour, if I love a daft joke or a singing dog, if I shout at people who abuse disabled car parks, it is not because I was born like that, it is because I became David's sister, and loving him shaped me in a way loss can't erase."

In a heartbreaking account, Heidi Thomas, the screenwriter behind BBC drama "Cranford", tells, for the first time, the shattering story of her beloved brother David, a boy with Down syndrome who was repeatedly failed by the medical establishment during his short life – and then again after his death."

To view this article in its entirety, visit: <http://tinyurl.com/4hfdyz>

MAKING CONNECTIONS

The following letter was received from an Optician in the DS community who has worked to create eyeglasses that are custom designed to fit the unique facial features of children with Down syndrome – they have shortened temples (arms), extra wide frame fronts, and a lowered bridge. Portions of her letter and her contact information are below:

Dear Down's Advocate:

Hello, my name is Maria Dellapina and I am writing to inform you about an opportunity to enhance the lives of the children we spend our lives advocating for.

I am a mother of a nine-year-old daughter with Down Syndrome and have struggled throughout her life to fit her properly in eyewear. Being an optician for over 25 years, I was constantly searching for frames that fit her unique needs. After realizing early on that I was fighting a losing battle, I took it upon myself and my experience as an optician, to design and create a special line of frames that dramatically enhances her abilities to function in eyeglasses.

I am proud to say that recently I was able to partner with a manufacturer who has developed my design into a workable frame for children with DS and other special needs. SPECS4US Inc., Superior Precision Eyewear for Children who are Special, is my vision to bring specially formatted frames to enhance the life

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of not only my daughter, but the lives of all the special children struggling with this problem every day.

If you would like to speak with me directly, or have any further questions, please feel free to call me at 440.829.9888 or email me at INFO@SPECS4US.COM. Please check out my webpage, www.specs4us.com, which is nearing completion to learn more about my cause. Thank you in advance for your time and support.

Sincerely,

Maria Dellapina
Founder SPECS4US Inc.

DOES SOMEONE YOU KNOW NEED A "THANK YOU"?

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

SUCCESSFUL PARENT'S GROUP EXPANDING

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

DONATIONS RECEIVED

DSACK thanks you for your contribution! Your support enables DSACK to work towards our mission of enhancing the lives of individuals with Down syndrome throughout their lifespan!

- Knights of Columbus
- Rosenwald Dunbar Elementary School in Nicholasville
- Donation in memory of Sandy Anderson
- Nancy and Curtis Eskew of Corydon, IN
- Robert Anderson
- Laura Prather
- Robin Davis
- Scott County High School Choral Department

CALENDAR

BUDDY WALK MEETINGS

Tuesday, July 1st, 15th, 24th & August 12th & 26th 5:30 p.m.
APS Communications
3320 Clays Mill Rd.

36TH NDSC NATIONAL CONVENTION

July 11-13, 2008
Boston, MA

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

SECOND SATURDAY PARENT GROUP-

July 12th, August 9th, September 13th 9-11am
Child Development Center, 465 Springhill Drive

Moms and Dads, if your child who has Down syndrome is between 0-5 years old, you're invited to monthly meetings on the second Saturday of every month from 9-11 a.m. at the Child Development Center, 465 Springhill Drive in Lexington (behind Lafayette High School/SCAPA). We will begin with a presentation and childcare is provided. For more information, contact Michelle at 859-223-4207 or mandm@pngusa.net. The dates for the upcoming months are July 12th, August 9th, and September 13th.

LOUISVILLE SIBHOP MEETINGS

Saturday, July 12th, 1-4 pm
Saturday, August 9th, 1-4 pm

See article in newsletter for more information. Call Amanda Westmoreland at Home of the Innocents with any questions or to obtain a registration form: (502) 303-4409

DSACK's Advisory Board Meetings are held every other month from 9-11. The remainder of 2008's meetings will be August 2nd, October 4th, and December 6th.

SAVE THE DATE FOR BUDDY WALK 2008

Saturday, September 27, 2008
Keeneland Race Course

Interested in helping out?

Contact Martha at mcampbell@apscommunications.com.

FRIENDS BUDDY CRUISE

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

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

DSACK AT THE LEGENDS GAME

Date T.B.D.

BUDDY WALK UPDATES

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!

JOIN THE PARADE

DSACK will be participating in the Lexington 4th of July Parade to help promote DSACK and the Buddy Walk. We need as many walkers/riders as possible – we'll be handing out Buddy Walk brochures. If you would be available to join us, please contact Martha Campbell at mcampbell@apscommunications.com as soon as possible for details! The Parade begins at 2:00 p.m. on July 4th – HOPE TO SEE YOU THERE!

COURTNEY'S CONTEMPLATIONS



Happy Father's Day!

I have three brothers and no sisters. I'm not a feminist because I never saw the need to be. My Mom and I were outnumbered by the males in our household, and I have realized how much I appreciate and relate to the humor, interests, communication styles, emotions, and thought processes of males. As I contemplate, I know there are boys amongst us skinning knees, digging in the dirt, being occasionally rowdy, taking risks, and learning to separate from Mom in order to become honest, courageous, dependable, humble, just, compassionate, and good men one day.

Having a loved one with Down syndrome is, I imagine, something special for our dads, brothers, uncles, grandfathers, etc. I think because of our loved ones with Down syndrome, these males have the opportunity to become more well-rounded and more balanced – to embody MORE than the stereotypical traits involved in the gender divide. Because of our loved ones with Down syndrome, I believe they now experience emotions, vulnerability and fear with different eyes and different hearts. I believe that many of these unique males may now view winning and losing, and the "race" itself differently. I believe their lives now embrace something much deeper and more profound than who is captain of the football team, and yet they can still sit and enjoy a good football game on the TV or at the stadium, or in their fantasy football league. I believe because of our loved ones with Down syndrome, these males are more comfortable with hugs, love, tears and prayer. In a uniquely profound way, they have found depth in the simplicity of daily routines and small victories, as well as a simple clarity amidst the deeper issues that still confuse and challenge many men. These men work differently, think differently, act differently and live differently because of their love for a child with Down syndrome. Isn't that beautiful? These men are unique, amazing and inspiring.

Because of Sam, I believe Dennis (Sam's Dad) is even more incredible than when I first fell in love with him. Because of Sam, there is a richness in Dennis' soul that has emerged out of the depths of raw emotion and pure love for a son. Because of Sam, Dennis seems more aware of the many simple, golden moments in our life. I often watch Dennis and know he is totally alive in the present moment, breathing it in and etching it in his memory as "golden". His love for Sam permeates his being and his essence, and I think it is beautiful. I am more in love with my husband and children, and with life itself, because of this love between a unique father and a unique son.

Happy Father's Day to all of you Dads and Grandfathers (and uncles and cousins and brothers...) who are blessed because you have a loved one with Down syndrome! Thank you for being, and loving, and growing and influencing in your unique and special way.

SUBMISSIONS

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

Submission deadline for the next newsletter is Friday, August 8th and can be sent to Courtney at celbert@adelphia.net. Send us pictures of your family member who has T21 to be included in the banner of the newsletter. Digital photos are preferred. Photos should be of the individual alone – head & shoulders preferred.

Do you...

- know someone who might like to receive our newsletter?
- have an interest in placing an ad in our newsletter?
- want to receive the newsletter by e-mail instead of through regular mail to save DSACK mailing costs?

If so, please contact Caroline Baesler at (859) 619-1392 or baeslerjunk@alltel.net. 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.