



LOCAL NEWS TO USE

• RESEARCH AND AWARENESS CONFERENCE JUST NORTH OF LEXINGTON!

The International Mosaic Down Syndrome Association and the Down Syndrome Association of Greater Cincinnati is planning an international conference to be held in Cincinnati, Ohio, USA on July 10-12, 2009 . IMDSA's conference provides many unique opportunities for the entire family including a "Kid Konference" for children ages 2-12, (including siblings), and a "Youth Conference" for those 13-adult (including siblings). The "Family Reunion/Silent Auction" is a relaxing time to get to know one another and a "Banquet/Dance" will be held Saturday evening with a variety of activities planned Exhibitors will be on hand for you to purchase products to help your child. Visit www.imdsa.org for registration, hotel information, and all the details.

• FIRST STEPS FAMILY ORIENTATION VIDEO

The First Steps Family Orientation Video is now available on the First Steps Website. The video last 13-17, and is very informative for families interested in First Steps. Visit the following link and click on the right hand side to see the video: <http://chfs.ky.gov/dph/firststeps/>



Nicole's family volunteering as librarians for the Lending Library at the Buddy Walk

• MAY MAHER HELP YOU? DSACK'S LENDING LIBRARY GETS AN OVERHAUL

Did you know that the DSACK library has 37 titles in our collection? We also have multiple copies of many of the books. If you stopped by

our booth at the Buddy Walk then hopefully you grabbed a book list. If you didn't get the chance to do so, please email Nicole Maher and she will send you a list. If you are interested in checking out an item, Nicole can either mail it

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Dixie Miller, Parent, Developmental Interventionist

John Riley, M.D., Pediatrician at PAA

Meg Steinman, Parent

an inspirational message of our shared humanity. Many have found that his works intellectually and emotionally enrich their own relationships with those with special needs.

Bérubé's book, *Life As We Know It: A Father, a Family, and an Exceptional Child*, is a moving account of his experiences with his son, Jamie, who has Down Syndrome. It was a New York Times Notable Book of the Year in 1996 and was chosen as one of the best books of the year by Maureen Corrigan of National Public Radio.

His lecture at Transylvania will discuss narratives of disability in American culture from philosophy to science fiction.

Sponsored by the Center for Liberal Education at Transylvania University Funded by the Bingham Program for Excellence in Teaching

For more information, contact Jeff Freyman, (859) 233-8273 or jfreyman@transy.edu

• DSACK HOSTS NATIONALLY KNOWN ENT DOCTOR, SALLY SHOTT!

(submissions by Tonya Merritt, Tracy Brewer and Michelle Gilliam were combined for this summary)

On Saturday, October 11th, DSACK was proud to host Dr. Shott from Cincinnati Children's Hospital's Ear, Nose, and Throat Clinic. This was a once-in-a-lifetime opportunity for DSACK, as Dr. Shott is known nationally for her research and treatment related to those with DS. Dr. Shott provided useful information regarding ear infections, tonsils, adenoids, sleep apnea, and sinus treatments. (Many children with DS suffer from these conditions due to their small facial features, airways, and ear canals.) Dr. Shott helped us to understand the causes of these various conditions and the best course of treatment. She also gave us excellent questions to ask our pediatricians and/or ENT doctor when we, as parents, are advocating for our children. Dr. Shott provided a detailed overview of the history of medical research addressing people with Down syndrome. She noted that, in the past, many medical studies identified conditions, such as hearing loss, that have a greater incidence in the Down syndrome community, but very few examined the effectiveness of specific protocols to improve the outcomes for those patients because they considered the conditions to be "part of Down syndrome". She also noted that the advances made in the medical treatment of people with

Down syndrome have come largely because parents have demanded them.

Thanks to parent, Dixie Miller for suggesting Dr. Shott speak to us, and for making the initial contact! In addition to providing wonderful information, Dr. Shott was extremely warm and gracious. Afterwards, we all enjoyed a delicious lunch of pizza, salad, and cake.

Dr. Sally Shott is a pediatric otolaryngologist (ENT) and professor of otolaryngology at Cincinnati Children's Hospital Medical Center and the University of Cincinnati Medical Center. She has won numerous national awards and honors and has authored many publications. She has a special interest in children with DS and the specific medical issues they face. She can be reached at 513-636-4355 or 513-636-0520.

• WATCH "READING ROCKETS" ONLINE FOR FREE!

A new PBS show, "Toddling Toward Reading," outlines the critical importance of language development and the crucial years before kindergarten. One show segment focuses on Avery, a preschooler who has Down syndrome, and how her language skills have improved in an inclusion model preschool. "Toddling Toward Reading," in many markets, will be paired with "A Chance to Read," another episode in the "Reading Rockets: Launching Young Readers" series that focuses on literacy programs for students with various physical or learning challenges. These two episodes will air on PBS stations across the country beginning in September (local listings vary). To find out more or to watch the shows online for free, visit this site: <http://www.readingrockets.org/shows/watch>.

Reading Rockets is a national, multimedia initiative that provides information on teaching kids to read and helping those who struggle. The project is a service of public television station WETA in Washington, DC and is funded by a grant from the U.S. Department of Education, Office of Special Education Programs



Nicole with Paulette and Katie Apostolides. Katie & her mother presented a workshop on making friends.

• NICOLE MAHER ATTENDS NATIONAL DOWN SYNDROME CONGRESS CONFERENCE *(submitted by Nicole Maher at DSACK's Request)*

As I walked toward the Seaport hotel in Boston my heartbeat

quickened. Then my heart totally swelled as I entered the lobby. There I was greeted by the sight of hundreds of families who have a member that shares that extra chromosome with my daughter Tarenne. We were all there for the NDSC's annual national conference.

The conference title this year was "We're More Alike Than Different" and the validity of those words was evident as you watched the interaction of the self advocates. This year I noticed that there were many more couples exploring the hotel, and the surrounding area, unaccompanied than ever before. I attribute this to how far the movement for independence and self-actualization has come. It was refreshing to see young adults simply being young adults!

The conference itself can only be described as having the best of the best from our world of Down syndrome in one place. The breakout sessions offer instruction in every area of life for every stage of our loved ones lives. I attended sessions on Universal Design for Learning, Speech Therapy, Math curriculum and Making Friends. They were all extremely informative and if you would like to hear more about any of those sessions please feel free to email me!

The general sessions were packed full of engaging speakers. We heard about the latest in Down syndrome research, successes in post-secondary education, how to tell if a school is truly inclusive, and about delivering a neutral diagnosis to families. My favorite though was Mark Nasjleti. Mark is a self advocate who successfully lost over 100 lbs while in his thirties. He started "Go Voice for Choice" which promotes healthy living for people with disabilities. Mark was an incredible speaker and I thoroughly enjoyed his intelligence and wit.

There are vendors there selling so many neat things that next time I will remember to bring an empty suitcase for my purchases!

Going to a national conference is truly like a kid going to Disney World for me! I can not explain the high I get from being around so many people that have T21 and their families. I not only take away an immense amount of new knowledge but most importantly I return refreshed and ready to advocate anew! I strongly recommend applying for a scholarship if you cannot afford to make the trip. And if you can afford a vacation then I can't say enough about how much your family will gain from making this your destination!

NATIONAL & INTERNATIONAL NEWS TO USE

• STORY FROM BBC NEWS: DOWN SIGNS "SEEN IN STEM CELLS"

[HTTP://NEWS.BBC.CO.UK/GO/PR/FR/-/1/HI/HEALTH/7597761.STM](http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/7597761.stm)

The team from Barts and the Royal London say the changes to embryonic stem cells are caused by the presence of an extra copy of chromosome 21. The study, in the American Journal of Human Genetics, says the extra chromosome sets off a chain of genetic changes in the developing embryo...

Therapeutic potential:

The international team of researchers, which also included scientists from the US, Australia, Spain and Switzerland, looked at embryonic stem cells from mice which had been genetically engineered to carry a copy of human chromosome 21. They discovered that the presence of the extra chromosome 21, known as trisomy 21, disturbs a key regulating gene called REST, which then disturbs the cascade of other genes that control normal development at the embryonic stem cell stage. The scientists also found that one gene (DYRK1A) which is present on chromosome 21, acts as the trigger for this disturbance.

Dean Nizetic, professor of cellular and molecular biology at Barts and the London, said the work could one day lead to molecule-based therapies which could alleviate the effects of Down's syndrome. "We hope that further research might lead to clues for the design of new therapeutic approaches tackling developmental delay, mental retardation, ageing and regeneration of brain cells, and Alzheimer's disease. He said he believed the genetic effects continue throughout life. "I suspect that it's not just important for the development of brain cells but for their maintenance throughout life; how cells age and how they can cope with stress. That's an area that could be approached with regard to therapies."

"Extremely positive"

Professor Nizetic suggested future research should be directed into basic molecular mechanisms that could one day develop into treatments to children with Down's syndrome in the first few years of life when the brains are "plastic" and rapidly developing. And he said that the same areas of the human genome have been thought to play a part in Alzheimer's disease - so

research could also lead to treatments for that condition.

Carol Boys, chief executive for the Down's Syndrome Association said: "Any research that helps us to understand more about some of the complex medical conditions that are commonly associated with Down syndrome can only be a positive step forward. The development of therapeutic treatments for these sometimes complicated health problems that can be associated with the condition will hopefully lead to an improvement in the overall health of people of with Down's syndrome."

• CLEMSONLIFE PROVIDES A HIGHER EDUCATION EXPERIENCE FOR STUDENTS WITH INTELLECTUAL DISABILITIES

New York, NY (September 8, 2008).

Clemson University's Eugene T. Moore School of Education will launch ClemsonLIFE in January 2009, a program designed to provide a college experience for students with intellectual disabilities. The College Transition Connection (CTC) is funding the development of this innovative model program, with financial support from the State of South Carolina. The CTC grant will total \$155,000 over three years. The National Down Syndrome Society (NDSS) is providing technical assistance and grant administration.

State Superintendent of Education Jim Rex joined Clemson faculty, state legislators, CTC board members, NDSS representatives, and prospective students with disabilities and their parents when the program was announced today at an event on the Clemson University campus. ClemsonLIFE (Learning Is For Everyone) is designed to provide a coordinated course of study that enables qualified students to experience college life while developing the employment and independent living skills necessary to participate fully in society.

"Clemson University's willingness to lead and innovate, the College Transition Connection's leadership, and the State of South Carolina's financial support will achieve 21st century outcomes for students with intellectual disabilities in South Carolina and a model for the rest of the country to follow", said Stephanie Smith Lee, NDSS Senior Policy Advisor.

The two-year program will provide academic instruction including financial literacy, decision making, business communication, and independent living skills, while also providing job internships and opportunities to be included in campus life, all focused around providing a

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Celebrations

"Celebrate Good Times, C'Mon!"

Do You Have a Buddy Walk Story to Share?

Buddy Walk 2008 was a huge success and celebration! With record attendance and dollars raised, DSACK is excited and humbled to see the support offered within - and to -our community! Do you have a story, photo, observation, reflection, etc. from the Buddy Walk to share with the DSACK Community?! The next newsletter will feature highlights, photos and stories from Buddy Walk 2008! Please send submissions ASAP to Courtney at celbert@roadrunner.com Let's celebrate together!



HAPPY 1ST BIRTHDAY, KENNEDY!

Our DSACK community has another 1st Birthday to celebrate! Sonya Gibson wrote this special poem for her daughter Kennedy (aka "Squeaker") who recently turned ONE!

Happy First Birthday Squeaker!

You're already one my Squeaker, I can hardly believe,
That an entire year has flown by since God gave you to me.

I am thankful and grateful to Him everyday,
For sending one of His beautiful angels my way.

The things you are doing now I can't believe my eyes,
You're rolling, sitting, and you've even learned some signs!

You roll around from place to place,
With that heart stopping smile always on your face.

And with every bridge we cross and with every
milestone we meet,

With every step we take and every odd we beat,

Remember, we got there with a little extra nudge,
A little work, some effort, and a whole lot of LOVE!

I love you so much my beautiful baby girl,

Happy 1st Birthday

Love "Momma"

HAPPY BIRTHDAY TO BERT HOLBROOK of Waseca, MN who celebrated his 80th birthday recently, and might just end up holding a Guinness World Record as the oldest living person with Down Syndrome. In 1929, one year after the birth of a son to Bert and Lillian Holbrook of Waseca, people with Down Syndrome lived to an average age of 9 years, according to experts. Institutions were the norm and medical care was minimal. But Bert Holbrook, Jr. was raised by his parents at home and helped them in the family's meat and grocery store where he "socialized with everyone," said Pat Foley, his nurse at Elm North, an intermediate care facility where he lives today. By 2005 the age expectancy of a person with Down Syndrome had risen to 55 years because of home care or smaller facilities and better medical treatment. When Foley heard that Peter Davison, the oldest man with Down Syndrome, according to Guinness World Records, died in December 2007 at age 68, she began to think that [Bert] may hold a longevity record. First she talked with his sister, now 90 years old and still in Indiana, and her family and got their consent. Last week, Foley received a message from Guinness asking for more paperwork ... a birth certificate, a letter from a doctor verifying Junior's diagnosis, a cover letter and a consent by his guardian. She will also send photos and newspaper clippings from his 80th birthday party. She thinks they may have an answer from Guinness in six to eight weeks. "He'll love the attention it brings because he is very social," Foley said about Junior. "He's just a cool guy," she said, and she's happy for the positive attention Junior's birthday may bring to him. To view the entire article, visit: <http://www.wasecacountynews.com/news.php?viewStory=515#>

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

successful transition to the work environment.

The pilot cohort of three students will be admitted in January, with six more students accepted each fall and thereafter. The students will learn independent living skills while taking part in various off-campus and on-campus activities. Program goals include academic enrichment, socialization, independent living skills and job training and career exploration. ClemsonLIFE is supported by a partnership between CTC, NDSS, and the Center for Disability Resources at the University of South Carolina. For more information visit: <http://www.clemson.edu/culife>.

ADVOCACY ALERT

• DOWN SYNDROME COMMUNITY CELEBRATES AN IMPORTANT VICTORY! CONGRESS PASSES THE KENNEDY-BROWNBACK PRENATALLY AND POSTNATALLY DIAGNOSED CONDITIONS AWARENESS ACT

New York, NY (September 26, 2008).

After three years of advocacy, the U.S. Senate and the U.S. House of Representatives passed S. 1810, the Prenatally and Postnatally Diagnosis Conditions Awareness Act, during this last week before Congress adjourns. The legislation has been an extremely high priority for the National Down Syndrome Society (NDSS) and the National Down Syndrome Congress (NDSC). These organizations and individuals with Down syndrome and their families across the country are convinced there is a need for physicians and other health professionals to provide parents who receive a prenatal or postnatal diagnosis with updated, evidenced-based information about Down syndrome.

U.S. Senators Edward Kennedy (D-MA) and Sam Brownback (R-KS), original co-sponsors of the bill, came together to pass S. 1810. The bill passed the Senate by unanimous consent on September 23rd and passed the House by a voice vote on September 25th.

The Prenatally and Postnatally Diagnosed Conditions Awareness Act ensures that pregnant women receiving a positive prenatal test result and parents receiving a postnatal diagnosis will be more likely to receive up-to-date, scientific information about life expectancy, clinical course, intellectual and functional development, and prenatal and postnatal treatment options. It offers referrals to support services such as hotlines, Web

sites, information clearinghouses, adoption registries, and parent support networks and programs specific to Down syndrome and other prenatally diagnosed conditions. The information that is all too often being provided in these situations is out-dated and inaccurate. The treatment options, functional development, opportunities and accomplishments of individuals with Down syndrome have improved dramatically over the years, yet decades old stereotypes still persist. It is critically important for healthcare professionals, families and society to update their knowledge and their perceptions about individuals with Down syndrome. NDSS, NDSC and affiliate groups across the country, have worked for almost three years to bring the bill to passage. J. David Hoppe, NDSS Governmental Affairs Committee Chair, worked tirelessly with Members of Congress to ensure the bill would be considered despite competing time demands in Congress. "With one small eight-page statute we have the power to brighten the future for people with Down syndrome and their families, by breaking stereotypes and dispelling myths", states Hoppe.

NDSC and NDSS appreciate the hard work of the Members of Congress who championed the bill in the Senate and the House of Representatives—Senators Edward Kennedy and Sam Brownback, Congressmen James Sensenbrenner and Tim Ryan.

Other members of Congress who provided invaluable assistance and support— Senator Harry Reid, Speaker Nancy Pelosi, Majority Leader Steny Hoyer, Senator Mitch McConnell, Congressman James Clyburn, Minority Leader John Boehner, Congressman Roy Blunt, Congressman John Dingell, Congressman Joe Barton, Senator Jon Kyl, Congressman Pete Sessions and Congresswoman Cathy McMorris Rodgers. NDSS and NDSC would like to thank the members of the Trisomy 18 Foundation and their leadership who were diligent and stalwart supporters in the effort to pass the bill.

NDSC and NDSS would also like to thank their affiliates and the thousands of individuals with Down syndrome, parents, families and friends who have worked tirelessly during the three-year effort to pass the legislation.

***DSACK encourages you to write a thank you note to our very own Republican Senator, Mitch McConnell for supporting this bill! (Maybe include a photo too!)**

**You can reach him at:
Mitch McConnell
361-A Russell Senate Office Building
Washington, DC 20510**

• THE HIGHER EDUCATION OPPORTUNITY ACT OF 2008 UNBOLTS DOORS FOR STUDENTS WITH INTELLECTUAL DISABILITIES!

The National Down Syndrome Society led a successful effort to expand post-secondary education opportunities for students with intellectual disabilities, and to add the principles of Universal Design for Learning (UDL) into the Higher Education Opportunity Act of 2008. After many years of effort, 14 extensions and months of intense negotiations, Congress has approved a bill to reauthorize the Higher Education Act. This bill, which sets federal higher education policy for at least the next five years, was signed by President Bush on August 14.

Summary of provisions for students with intellectual disabilities

Allows students with intellectual disabilities, who are attending programs designed for them in higher education, to be eligible for the first time for Pell Grants, Supplemental Educational Opportunity Grants and the Federal Work-Study Program. Authorizes the development and expansion of high-quality, inclusive model comprehensive transition and post-secondary programs.

Authorizes the establishment of a coordinating center for the new model programs. This center will provide technical assistance, evaluation, and development of recommendations for model accreditation standards as well as outreach and dissemination to postsecondary programs, families and prospective students. Ensure equal college opportunities for students with disabilities

Establishes a national center to provide support services and best practices for colleges, students with disabilities, and their families. Helps colleges recruit, retain, and graduate students with disabilities and improves education materials and facilities.

Universal Design for Learning (UDL)

The Higher Education Opportunity Act contains numerous provisions regarding the preparation of educators in early childhood, elementary, secondary and postsecondary education settings to use the principles of UDL in their instructional practices. UDL provides flexibility in the ways information is

presented, in the ways students respond or demonstrate knowledge and skills, and in the ways students are engaged. It also reduces barriers in instruction, provides appropriate accommodations, supports, and challenges, and maintains high achievement expectations for all students.

The recent UDL efforts were led by a task force headed by Ricki Sabia, Associate Director of the National Down Syndrome Society Policy Center, and 24 general education and disability organizations, including the National Down Syndrome Congress. For more information on the Task Force and Universal Design for Learning see www.udl4allstudents.com and www.cast.org.

The U.S. Department of Education Office of Special Education Programs (OSEP) has published a toolkit of information and resources that will help policymakers, education personnel and parents understand how to implement UDL strategies and practices. This toolkit is available at <http://www.osepideasthatwork.org/> and CDs will be available shortly through ED Pubs <http://edpubs.ed.gov/>

REACHING OUT TO SUPPORT RESEARCH EFFORTS

• VOCATIONAL REHABILITATION NEEDS ASSESSMENT SURVEY

Every three years, the Kentucky Office of Vocational Rehabilitation must perform a comprehensive needs assessment for the state plan required by the Rehabilitation Services Administration. We now have a needs assessment survey available on-line for the public. The link is below and is also available on the OVR and KATLC internet sites. I ask that you take time to complete the survey if you have not done so already. Please pass the link on to anyone or any group who you think might have an interest in completing the survey. I appreciate your help. <http://ovr.ky.gov/index.htm> or http://www.surveymonkey.com/s.aspx?sm=E28V1rjGEb1SphRrRvXIWA_3d_3d

Dave Matheis Office of Vocational Rehabilitation
209 St. Clair St. Frankfort, KY 40601
(502) 564-4440 Fax - (502) 564-1268

• **YOU ARE INVITED TO COMPLETE 2 SURVEYS FROM GRADUATE STUDENTS AT UNIVERSITY OF SOUTH CAROLINA.**

Dear Parents:

You are invited to participate in a Genetic Counseling Master's Thesis Project to define balanced information about Down syndrome. This study combines the complementary perspectives of parents and genetic counselors for the construction of guidelines to ensure that the first information parents receive about their child's diagnosis is balanced, accurate, and consistent. Participation involves completing an online survey. The online survey will be available until November 30, 2008 at midnight, and can be viewed at the following URL: http://www.surveymonkey.com/s.aspx?sm=4PH0aW70hR_2bgfvqxUJfwHw_3d_3d.

If you have questions or difficulty accessing the online survey, please call 919-522-6428, or email klberrie@gmail.com. Thank you for your participation!

Sincerely,
Katie B. Sheets,
BSGenetic Counseling Program

My name is Allison Bellomo and I am a senior Genetic Counseling student at the University of South Carolina School of Medicine. I am conducting a Masters thesis project entitled "The Perspective of Prenatal Genetic Counseling in the Down Syndrome Advocacy Community." The purpose of this study is to gain more information about the views and opinions of prenatal genetic counseling and prenatal genetic diagnosis within the Down syndrome community by surveying members of NDSS and NDSC. The goal of this study is to use the information to better serve patients within the prenatal genetic counseling setting and to encourage more communication between advocacy organizations and genetic counselors. I value your experience and believe that by completing the survey provided by the link below you can help others gain a better understanding of what you, a member of NDSS, think about prenatal genetic counseling. If you are interested in this research project, please complete the following survey:

Survey link: http://www.surveymonkey.com/s.aspx?sm=DjyB_2f5wJzjzuvNnEIzDfkQ_3d_3d

Thank you,

Allison Bellomo Genetic Counseling
Student University of South
Carolina marcpennterbellomo@yahoo.com

MAKING CONNECTIONS

Do you have time, information or items to share? Things such as information about a playgroup forming, a therapist looking for volunteers for a study, someone looking for a social network of Moms of children with DS, or maybe items like a walker or assistive devices that someone is no longer using or is seeking, or babysitting opportunities, etc.

Send them to Courtney at celbert@roadrunner.com and they'll be included here.

• NEW GROUP FORMING FOR TEENS AND YOUNG ADULTS!

A group for teenagers and young adults is starting now! The group will be structured to meet the needs of the families participating. An initial meeting was held Oct. 18th, and there are several fun events coming up soon!

-November 1st we will go to Boyd Orchards in Versailles, KY from 12-2 for the Harvest Festival.

You can pick apples & pumpkins, enjoy hayrides, corn maze, music food, playgrounds, pony rides, farm animal center, and more! You have the option of purchasing lunch at the Apple Blossom Cafe which serves sandwiches, soups, burgers, hot dogs, kids meals and freshly baked desserts!

-November 22nd we will attend a Georgetown College Men's Basketball game in Georgetown, KY. The game is at 2pm and the cost is \$5 per person.

-We will hopefully find a good Holiday movie to attend on December 12 or 14.

Moms and dads are both welcome and are encouraged to stay at these social events, think of it as a time to socialize with other parents who also have an adolescent with Down Syndrome! If your family is interested or if you have any questions, please contact Brooke Reed at 321-507-0032 or email at brooke.reed@uky.edu

• **SPECIAL OLYMPICS KENTUCKY** is recruiting youth ages 2 – 7 years with intellectual disabilities to "Play with a Purpose." This program will teach beginning skill development through games. For more information, contact Melissa at 1-800-633-7403 or mhardison@soky.org.

• CALLING ALL CELIACS!

Do you have a family member that has celiac disease? If so would you be interested in joining our family for a quarterly pot luck dinner or lunch? We could not only share the dining experience with one another, but could trade ideas and recipes. If you are interested please call me! Nicole Maher 859-881-5423

• SOUTHLAND CHRISTIAN CHURCH "JESUS PARTIES" AND PROM!

Those individuals who are high school aged and older are invited to come out to Southland Christian Church (5001 Harrodsburg Road– Nicholasville) for their monthly "Jesus Parties." These events will take place from 6:30 – 9:30 pm on the following dates:

Friday, October 24

Friday, November 14 (Prom)

For more information or to register, contact Kara Moore at 224-1664.

• LEXINGTON-FAYETTE URBAN COUNTY GOVERNMENT PARKS & RECREATION THERAPEUTIC RECREATION PROGRAMS (TR)

provides opportunities for persons with disabilities and others in the community to enjoy activities that use recreation, leisure and play to provide outlets for our multi-talented population. Contact Brent Claiborne at |859| 288-2908 or bclaiborne@lfucg.com with any questions or comments. Be sure to also visit the website at www.lfucg.com/parks/special_rec.asp to learn more.

Please be sure you sign up for programs as soon as possible. Classes fill up quickly. Please call (859) 288-2908 for registration information.

Holiday Dinner Dance

Bring your family and friends to our dinner dance and celebrate the holidays with good food and music.

Ages: 13 & over

Time/Date: 5 – 9 pm, Saturday, December 13 Location: Tate's Creek Recreation Center

Cost: \$5 (dance only) – Dinner Cost TBD

Adult Fitness

Come to the Dunbar Community Center Gym and get a great workout. We do a variety of fitness activities that will leave you either tired from your workout or tired from laughing! Limited transportation home will be provided.

Ages: 18 & over

Dates: September 16 – November 20

Time/Day: 12 – 2 pm

Tuesday/Thursday

Cost: \$30 per session

Bowling

Strikes, turkeys and spares are just part of the fun with the TR bowling league. Ramps are available for those who use wheelchairs or have limited mobility.

Ages: All ages welcome

Date: Saturdays, September 13 – November 15

Time: 12 – 2 pm

Location: Eastland Lanes

Cost: \$4.50 per week (payable to Eastland Lane)

• FREE LUNCHSHOPS!

Sponsored by the Fayette County Parent Resource Center in collaboration with the following agencies: Bryan Station Youth Service Center, the Commission for Children with Special Health Care Needs (Lexington Office), the Bluegrass IMPACT East Office, and the College for Technical Education. Check the Calendar section for specific topics and dates of the November Lunchshops Legal Series!

• FAYETTE COUNTY PUBLIC SCHOOLS : SUPPORT GROUP FOR PARENTS OF STUDENTS WITH ADHD

If you are the parent of a child with ADHD, you know the challenges that can be created at home, at school and sometimes in the community. In an effort to assist families, the Fayette County Public School is offering a free support group for parents of students with Attention Deficit Hyperactivity Disorders. A portion of each meeting will be used for support and another portion to acquire new information and share ideas. The group will come together the last Tuesday night of each month. If you want to come for informal social share time from 6:30 to 7 p.m. please join us at that time. The actual meeting will be held from 7-8 pm. We will discuss issues relevant to parenting students who are inattentive, impulsive and/or hyperactive.

Meeting dates are as follows: Sept 30, Oct 28, Nov 25, Jan 27, Feb 24, March 31, April 28

All sessions will be held at the It's About Kids Support Service building (central board of education office) at 701 East Main Street in conference room C or D. Upon entering the building, take the elevator to the second floor and look for signage. Parking is available behind the main building at the entrance off Walton Avenue.

For more information contact Dr. Bobbie Burcham at 859-381-3308 or bobbie.burcham@fayette.kyschools.us

WONDERFUL WEBSITES

Do you have a wonderful website to share with DSACK? Send the web address to Courtney at celbert@roadrunner.com. Be sure to include a sentence or two describing why you think it's wonderful.

This website contains a beautiful presentation to counteract the recent publicity surrounding the movie, "Tropic Thunder": DSACK liked it so much we linked to it from our webpage. <http://www.blueberryshoes.com/psa/index.html>



COURTNEY'S CONTEMPLATIONS

Our loved ones with Down syndrome sparkle and glisten and shine! Below are some excerpts from our Buddy Walk letter we sent out this year.

SHINE ON!

Life with Sam continues to bring constant reminders of radiance – his, ours, yours, God's, and the radiance of human nature. This year brought countless moments of interconnectedness with others and with the optimism and hope that human nature embodies. Sam glitters and shines in remarkable ways and seems to act as a prism that reflects the glow of others' inner beauty. Dennis and I often comment to each other that we could watch Sam for hours. It's as if one could bask in his golden nature. There are many golden moments with Sam that may seem simple or miniscule to some, but will shine eternally in our hearts – two parents in love with a special boy...and more in love with life itself because of him. Whether it's Sam singing the UK Fight Song with his best friend at preschool, or telling some women at the beach how smart he is after counting to 20, Sam radiates joy and contentment. Whether it's the way he got the entire crowd at Ethan's T-ball game high-fiving with him and singing songs, or how he got the crowd at the local orchard clapping to live music with him as he tapped his toes and eventually got to join the band in strumming the guitar...Sam sparkles and glistens in his everyday existence...

Sam's unique radiance and the way he reflects our own inner light and beauty reminds me of a Thomas Merton book I read in college, "Conjectures of a Guilty Bystander", where Merton speaks of the epiphany he had at the corner of 4th and Muhammed Ali in Louisville. Merton said that he was, "suddenly overwhelmed with the realization that I loved all these people, that they were mine and I theirs, that we could not be alien to one another even though we were total strangers. It was like waking from a dream of separateness, of spurious self-isolation in a special world...This sense of liberation from an illusory difference was such a relief and such a joy to me that I almost laughed out...As if the sorrows and stupidities of the human condition could overwhelm me, now I

DONATIONS RECEIVED

Morris J. Sammons

OUR BUDDY WALK SPONSORS WILL BE HIGHLIGHTED IN A SPECIAL BUDDY WALK SECTION IN THE NEXT NEWSLETTER!

realize what we all are. And if only everybody could realize this! But it cannot be explained. There is no way of telling people that they are all walking around shining like the sun..."

We continue to come across serendipitous situations and wonderful people who are willing to see the light our son shines. Many have been open to working with us to create exciting and stimulating opportunities for Sam to grow and learn with peers his age. This is important to us for Sam, just as it is for Ethan and Sydney too. With a bit of guidance and support, Sam can participate in most anything his siblings and peers can do; but without that, he is often lost or unknowingly left out. We will forever be indebted and grateful to the individuals who are open to Sam joining in; who are willing to learn a little, or try a little, or go a little bit out of their way to help a little guy shine. Although he doesn't always have the words or capability to express it, we can see and sense when Sam feels good about himself and the world, and his place here in it. When Sam is feeling confident and proud, his arms swing excitedly, his eyes sparkle with delight, and his whole body exudes confidence in a special way...

As we've expressed since Sam was first born, we feel a sense of responsibility to help others understand more about the journey of raising a child with Down syndrome. Because of Sam, there are many opportunities for us to challenge and encourage others to live life more deeply and purposefully, rather than to walk around with vacant stares, or blissful unawareness of people with special needs, or even harsh glares. People with Down syndrome and other special needs are shining brightly if one takes the time to notice them and empathize with them, and to be open to helping them shine in their unique and important way. How can you help people to see Sam (and others with special needs) as if they are "walking around shining like the sun"? How can you help them to spread their special light to people still in the dark about their unique gifts and beauty?

We are thankful for Sam and the way he sparkles, and glistens, and shines. We are thankful we see Sam walking around shining like the sun. We are thankful Sam helps us to see others walking around shining like the sun. Shine on!

CALENDAR

THE HUMANITIES AND THE BOUNDARIES OF THE HUMAN:
LECTURE BY MICHAEL BÉRUBÉ

Tuesday, October 28, 2008 at 7:30 p.m.
Transylvania University -
William T. Young Campus Center Gym
Corner of North Broadway and Fourth Street

For more information, contact Jeff Freyman, (859) 233-8273 or jfreyman@transy.edu

2ND SATURDAY PARENT GROUP
PHYSICAL THERAPIST JOANN LUCIANO WILL BE THE SPEAKER FOR OUR NOVEMBER MEETING!

Saturday, November 8th, 9:00-11:00 a.m.
Child Development Centers of the Bluegrass
465 Springhill Dr., Lexington

Come join the popular 2nd Saturday Parent Group (for those whose children with DS are 0-5 years old). Childcare provided. Siblings and grandparents are welcome too! For more information, contact Michelle at mandmgilliam@windstream.net or 859-223-4207

**There will NOT be a 2nd Saturday Parent Group during the month of December. Please join us for the DSACK Christmas Party instead!*

SOUTHLAND CHRISTIAN CHURCH JESUS PROM!
FRIDAY, NOVEMBER 14, 6:30-9:30

Those individuals who are high school aged and older are invited to come out to Southland Christian Church (5001 Harrodsburg Road- Nicholasville). For more information or to register, contact Kara Moore at 224-1664.

INCLUDING PEOPLE WITH DISABILITIES:
A CALL TO ACTION FOR COMMUNITIES OF FAITH
Tuesday, November 18, 11:30-3:30
Lexington Theological Seminary
631 South Limestone Lexington, KY

A Community-wide education and resource seminar brought to you by the Lexington Theological Seminary and the Human Development Institute at the University of Kentucky designed to bring clergy, professionals, and families together to learn about establishing faith communities that are truly inclusive of all people, including children and adults with disabilities.

For additional information about the seminar or to make special arrangements, contact Loretta Bowling at lbowling@lextheo.edu OR (859) 280-1233.

DSACK's ANNUAL HOLIDAY PARTY!
Saturday, December 6th, 11:00-1:00
Trinity Hill United Methodist

Our special, annual Holiday Party will be potluck with DSACK providing meat and drinks. Parents should bring a WRAPPED gift for their children which will be handed out by a "special guest". RSVP to DSACK at (859) 494-7809 so we can plan food accordingly. *Anyone who can help cleanup afterwards, it would be much appreciated! (Trinity Hill is located on the corner of Tates Creek and Armstrong Mill, (not to be confused with Chapel Hill Presbyterian directly across the street).*

***There will be NO Advisory Board meeting in December! Advisory Board members are invited to the DSACK Christmas Party instead! The next Advisory Board meeting will be Saturday, February 7th.**

FREE NOVEMBER LUNCHSHOPS LEGAL SERIES:

• GUARDIANSHIP FOR PERSONS WITH DISABILITIES

Date/Time: November 11, 2008 from 11am – 1 pm

Description: During this informative session, participants will learn about the Guardianship process and whether guardianship is something your family will need to do for your child.

Presenter: Karen Perch, Ph.D. Attorney at Law

Location: Bryan Station High School; 201 Eastin Road; Lexington, KY 40505

Phone: To sign up for Lunchshops or get additional information call: (859) 381-4229

• WILLS AND SPECIAL NEEDS TRUSTS...

IT IS NEVER TOO LATE TO START PLANNING!

Date/Time: November 18, 2008 from 11am – 1 pm

Description: Planning for the future can never be too late! During this informative session, participants will learn about wills and special needs trusts.

Presenter: Kevin Johns, Attorney at Law with Wyatt, Tarrant & Combs, LLP

Location: Bryan Station High School; 201 Eastin Road; Lexington, KY 40505

Phone: To sign up for Lunchshops or get additional information call: (859) 381-4229

LEXINGTON-FAYETTE URBAN COUNTY GOVERNMENT PARKS & RECREATION THERAPEUTIC RECREATION PROGRAMS
HOLIDAY DINNER DANCE FOR AGES 13 AND OLDER
Saturday, December 13, 5:00-9:00 pm
Tates Creek Recreation Center

Cost: \$5 (dance only) – Dinner Cost TBD

Contact Brent Claiborne at 859-288-2908 or bclaiborne@lfucg.com with any questions

SUBMISSIONS

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

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

Do you...

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

If so, please contact Courtney Elbert at (859) 879-2182 or celbert@roadrunner.com. Let's get the word out about DSACK and our loved ones with DS!



OUR MISSION!



The mission of Down Syndrome Association of Central Kentucky (DSACK) is to enhance the lives of individuals with Down syndrome throughout their life- span by providing support, information and education to families, professionals and the communities that make up the Central Kentucky region.

With proper supports and services, people with Down syndrome will be productive members of the community.