



**THE EXECUTIVE COMMITTEE**

Your DSACK Board and Executive Committee have been hard at work over the past couple of months to make DSACK the most effective all-volunteer organization it can be. There is much going on in the Down syndrome community locally and nationally!

The Board is working with NDSS, NDSC, and others to make "Brighter Tomorrows" available on the web for use by physicians nationally and possibly in medical school curricula. "Brighter Tomorrows" is a virtual training model developed by Board member Harold Kleinert, UK's medical team, and UK's IHDI in conjunction with local DSACK families, that focuses on teaching physicians a supportive and balanced method of informing parents that their child has Down syndrome. DSACK is also working to support a bill in Congress that would require physicians to provide accurate information, as well as offer referral information for local Down syndrome groups, to parents who receive an in utero diagnosis of Down syndrome - an occurrence that is likely to happen with more frequency given the ACOG's new screening recommendations. The Board is also in the very early stages of exploring the DS community's interest and desire for DSACK to work with physicians at Kentucky Children's Hospital and University of Kentucky to try to obtain funding for and establish a comprehensive clinic to serve people with developmental disabilities over their lifespan.

On a more local level, the Executive Committee has re-tooled to distribute responsibilities among all its members in an effort to become more efficient and share the workload. Going forward, Becky Lesch and Meg Steinman will be responsible for overseeing Programs and Outreach, including adult playgroups, new parents, quarterly workshops and socials, school outreach, medical outreach, and the lending library.

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## EXECUTIVE BOARD MEMBERS

Caroline Baesler	619-1392
Karen Boudreaux	219-3404
Ellen Fernandez	219-0023
Becky Lesch	252-9523
Meg Steinman	276-5518

## ADVISORY BOARD MEMBERS

Dr. Charles Hill, M.D., OB/GYN  
 Dr. John Riley, M.D., Pediatrician at PAA  
 Dr. Harold Kleinert, Exec. Dir. of IHDI  
 Dr. Malkanthie McCormick, Parent  
 Dixie Miller, Parent

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Karen Boudreaux will focus on Development (her passion), which includes obtaining grants and in-kind donations, securing annual giving and working on legislative and advocacy issues. Ellen Fernandez will handle Finance and Administration, which includes oversight of the budget, legal matters, assets and facilities, and acting as secretary for the corporation (all of which basically means she keeps everyone in line). And I will be working on Communications, including the newsletter, the website, establishing a volunteer bank, and working with APS Communications to get the word out on DSACK activities. In the near future, one or more EC and/or Board members will be attending regional conferences to bring back ideas to share and implement locally and, believe it or not, work will start in earnest on the Buddy Walk.

I encourage each of you to get involved in DSACK in some way. Consider your interests and passions and then call an Executive Committee member to offer your time and talents. The more people who are involved, the better DSACK will be. We also welcome –and need–your feedback, so feel free to call or email an Executive Committee member about any issue. And make sure to let us know what’s going on in your life so we can include it in the newsletter. We want to support, encourage, and celebrate our loved ones with Down syndrome!

Sincerely, Caroline Boeh Baesler (Callie’s mom)

## NEWS TO USE

### INTENSITY STUDY OFFERED

UK’s PT Department is seeking young children, age 8 months to 5 years 11 months, with a developmental disability that affects motor development, such as cerebral palsy or Down syndrome, who are not yet independently walking. The purpose of this study is to determine if providing intensive physical therapy intervention when a child with a disability is close to gaining a new gross motor skill, such as sitting, crawling, standing or walking, influences the rate and quality of gross motor development. There is no charge for participation; there will be no change in the current therapy program; and the intensive intervention will be standard pediatric physical therapy intervention. No experimental treatments will be provided, just an increase in the intensity (3 times/week) of routine pediatric physical therapy. If interested, contact Susan Effgen at (859) 323-1100, ext 80579, email: [seffgen@uky.edu](mailto:seffgen@uky.edu).

### COMPUTER USAGE STUDY

A group of doctors is studying computer usage in people who have Down syndrome. They hope to develop effective computing tools or software to help our children with Down syndrome use computers for learning, leisure and job skills. If your family member is between 6 and 21 years old and you have about 15 minutes to spare, you can help in this endeavor. Simply visit <http://www.surveymonkey.com/s.asp?u=750982588877> to make a difference!


### STANFORD UNIVERSITY RESEARCH

Scientists in the Garner laboratory at Stanford University have recently published some exciting findings regarding improved cognitive performance in a mouse model of Down syndrome. Using several different drugs, scientists were able to restore cognitive performance in mice to almost normal levels. To their surprise, improved cognitive performance persisted even after the drug treatment had been terminated.

The drug called PTZ (pentylentetrazole) offers new promise for the treatment of people with Down syndrome. PTZ blocks a neurotransmitter called GABA (gamma-amino-butyric acid), which is believed to be overabundant in people with Down syndrome. GABA seems to slow down the brain’s

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circuits, so a dose of PTZ speeds them back up. "This treatment has remarkable potential," said researcher Craig Garner. "So many other drugs have been tried that had no effect at all."

These research results shed new light on potential mechanisms underlying impaired cognition in Down syndrome and may provide novel strategies for therapeutic possibilities. While this is very encouraging news, it is important to keep in mind that these studies were carried out in animals. The safety and efficacy of the drugs will have to be carefully assessed.

For more information see <http://dsresearch.stanford.edu/community/index.html>.

### **CENTRAL KENTUCKY RIDING FOR HOPE**

With the annual running of the Kentucky Derby upon us, DSACK thought it would be appropriate to celebrate and share information about a unique program available right here in our own "Kentucky Home." "Central Kentucky Riding for Hope" is dedicated to enriching the community by improving the quality of life and the health of children and adults with special physical, cognitive, emotional and social needs through therapeutic activities using the horse.

#### *General Information*

CKRH originated in the fall of 1981 and has experienced continued interest and growth. It is a non-profit organization established to provide horseback riding for therapeutic purposes and social and recreational activities. The program has proved highly successful in helping people with a wide range of disabilities to develop self-esteem, confidence, coordination and a sense of achievement while learning horsemanship, tack and riding principles. CKRH is completely dependent upon community support. The program is operated at the renowned Kentucky Horse Park.

#### *Equine Facilitated Programs Offered at CKRH*

Every participant interacts with a trusted, accepting horse or pony and is supported by dedicated volunteers and experienced instructors and therapists. Why the horse? The horse's strength, warmth, soothing rhythm and three-dimensional movement pattern provides healthy exercise while improving

circulation and muscle tone. The responsibility associated with working with horses and the social interactions between peers benefit the participant physically, mentally and emotionally while raising self-confidence and increasing independence through triumphs. The honesty and unconditional love of the therapy horse is proven to encourage interaction and acceptance and to provide the moments where all involved are a part of great joy.

#### *May thru October, CKRH offers Therapeutic Riding, Hippotherapy and a seasonal Stable Management program.*

Therapeutic Riding lessons are structured with a team approach. Each team participates in a weekly, one-hour group lesson during an eight-week session. Four to six riders similar in either age or ability focus on individual riding skills while gaining therapeutic benefits. These therapeutic benefits include increased muscle tone and strength, decreased spasticity, improved hand/eye coordination, balance, mobility, sequencing, sensory integration, color-number-letter identification and task directives. Additionally, group lessons provide opportunities to enhance interaction and communication with peers, cooperation, turn taking, patience building, increased self-esteem and a heightened sense of well-being. Horseback Riding is highly motivating and FUN.

Goals are thoughtfully developed to foster independence and to provide challenging and educational activities. Input is from parents/guardians, rider, teacher and therapist - an instructor's lesson plan may include a wide variety of games and exercises designed to increase the rider's ability to listen, learn, and communicate. In addition, all riders work on improving their riding skills and a willingness to try new things and attain new goals. Riders not only improve their riding skills but there are opportunities for the whole horse experience such as grooming, leading, tacking, etc. Lessons may be held in the outdoor riding ring, trail rides, and in the barn.

An initial phone screening for registration and an on-site evaluation are required to determine the most appropriate program participation.

Stable Management provides an opportunity for participants to stay involved with CKRH during the winter months. This unique program partners CKRH participants with members of Keeneland Pony Club

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Together, this program provides hands-on, unmounted activities to learn about horses and stable management. Special guest speakers graciously share their knowledge, skills and experiences in the horse industry. Stable Management is a seven-week program, offered February and November on Sunday afternoon.

For more information regarding hippotherapy services provided by Cardinal Hill through CKRH, contact Angel Miron, PT, AHA Registered Therapist at Cardinal Hill Rehabilitation Hospital, (859) 367-7125. For more information regarding Hippotherapy or AHA contact [www.americanhippotherapyassociation.org](http://www.americanhippotherapyassociation.org). For more information on CKRH, visit [www.ckrh.org](http://www.ckrh.org).

### **WIN-O-LYMPICS**

The 2007 Win-O-Lympics took place on April 22 at Dunbar High School gym. We hope the event was successful, and a lot of fun for everyone involved! For the 2008 Win-O-Lympics, they are considering adding a series of events specifically created for people with Down syndrome who want to participate. In a future newsletter, DSACK plans to follow up with information about this addition to the 2008 Win-O-Lympics!

Win-O-Lympics is sponsored by the Parents of Children with Special Needs, Inc. which is an organization designed to provide Olympic type events for children/youth who are physically challenged. Win-O-Lympics was begun in 1987 when it was discovered that physically handicapped children who are not mentally handicapped could not compete in the Special Olympics. Some of the events offered this year were: commando crawl, log roll, scoot race, body bowling, scooter board race, putt putt golf, bowling, frisbee throw, bean bag throw, hockey shoot, tennis ball throw, soccer kick, and many more. For more information or questions about the Win-O-Lympics program, call or email Neil at (859) 523-2737 or at [winolympicky@yahoo.com](mailto:winolympicky@yahoo.com)

### **WALL STREET JOURNAL STORY**

The NDSC has been contacted by a reporter with the Wall Street Journal who is writing a story regarding nutritional/dietary supplements, and claims made that these supplements can improve cognition in individuals with Down syndrome. This reporter also

plans to address claims that these supplements have curative power in other medical conditions such as Cystic Fibrosis, ALS and Muscular Dystrophy.

If you have any experience in this area and would be willing to be interviewed for this story in the WSJ, please contact [sue@ndscenter.org](mailto:sue@ndscenter.org).

### **DSACK LENDING LIBRARY OPEN**

Please be sure to visit the DSACK Lending Library where you can sign out a book, use the computer, or make suggestions of resources to order. The Library is located at the Child Development Center, and it is open from 8:00-3:00 (during the hours of operation of the Child Development Center). 465 Springhill Dr., near Lafayette High School.

### **DONATIONS RECEIVED**

#### **Thank You To The Following Donors:**

Farmer's Bank & Trust  
Hurst Office Suppliers  
R. J. Corman

#### **In-Kind**

Argosy Hotel – Casino  
Ashland  
Cincinnati Zoo  
Cincinnati Symphony Orchestra  
Kentucky Horse Park  
Kentucky Railway Museum  
Malone's  
Radisson Plaza

#### **EASY DONOR OPPORTUNITIES**

- Did you know that if you make a donation to the United Way of the Bluegrass, you can designate your donation to go to DSACK? Even if DSACK is not on the list of "official United Way agencies," you can make your own designation to DSACK by writing it in on your United Way form. Please ask others to consider designating DSACK for their United Way contributions.
- Does your company have a matching program or a volunteer program? Many companies, especially larger ones, will match donations you make to charitable organizations such as DSACK or donate to organizations where their employees volunteer. Take advantage of these opportunities!

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## ADVOCACY ALERT

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### KENNEDY-BROWNBACK BILL NEEDS SUPPORT

The following is taken from the Joint Position Statement by the NDSC and the NDSS on the Prenatally Diagnosed Condition Awareness Act and is in reference to Senate Bill 609, known as the Kennedy-Brownback Bill. The statement responds to the fact that the bill, which requires certain information to be provided to families who receive a *prenatal* diagnosis of DS, does not take into account that families receiving a diagnosis after birth are equally in need of information and services.

- *The bill does not require that information and support services be offered to parents whose child receives a postnatal diagnosis of Down syndrome. It is just as important to provide these services to parents who choose not to undergo prenatal testing and have a child with Down syndrome. And as the recent studies by Brian Skotko of Harvard demonstrate, health care providers are not adequately delivering either the prenatal or postnatal diagnosis. We hope that this legislation will be broadened to address the need for information in a postnatal diagnosis.*
- *While we appreciate the consideration given to patient privacy concerns in the data collection sections of the bill, we would like to see an informed consent provision that requires a disclosure statement outlining how the patient's information will be used. This would further ensure privacy for patients.*
- *We recommend that decisions regarding distribution of funds provided by this bill place an emphasis on partnerships between health care groups and disability organizations.*
- *The bill does not specify how the information and support services provisions would complement the pre-existing programs for families already being implemented by NDSC, NDSS and other organizations.*
- *We strongly encourage Congress to consider how these successful existing programs and services can be expanded to increase their reach and impact, rather than creating entirely new programs and services that would be duplicative and not cost-effective.*

For additional information on Brian Skotko's studies, visit [www.ndscenter.org/news/advocacy.php](http://www.ndscenter.org/news/advocacy.php).

### DIRECT SUPPORT WORKER BILL – NEED CO-SPONSORS

In order to live independently, people with Down syndrome and other disabilities rely on direct support workers to help them manage daily life. The degree of assistance required depends on individual need. For example, these workers assist people with daily medications, dressing, preparing and eating meals, other appointments and generally handling daily affairs.

Unfortunately, direct support workers have a very high turnover rate – reportedly as high as 75% each year -- because of poor wages and high job demand. This seriously threatens the opportunities for our sons and daughters to live successfully in the community.

One of the important steps being taken to address this issue is the introduction of the Direct Support Worker Bill (H.R. 1279) in the U.S. House of Representatives by Lois Capps (D-CA) and Lee Terry (R-NE) on March 1, 2007. The purpose of H.R. 1279 is to provide funds to States to enable them to increase the wages paid to targeted direct support professionals in providing services to individuals with disabilities under the Medicaid Program.

Action Needed: Urge your House members to Support H.R. 1279 by co-sponsoring the bill.

For more information visit the National Down syndrome Congress at <http://www.ndscenter.org>.



### 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.



## 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 [celbert@adelphia.net](mailto:celbert@adelphia.net) or Nicole [nicjoe@adelphia.net](mailto:nicjoe@adelphia.net) and they'll be included here.

## CELEBRATIONS

Do you have a celebration to share? Send your information to Nicole [nicjoe@adelphia.net](mailto:nicjoe@adelphia.net) or Courtney [celbert@adelphia.net](mailto:celbert@adelphia.net).

## COURTNEY'S CONTEMPLATIONS

*Like a colt*

*You dart*

*Free and playful*

*Neighing giggles trailing your romps*

*Frisky bounding*

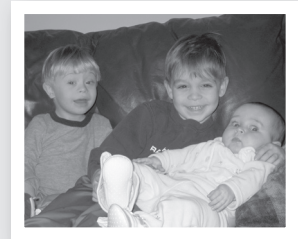
*Carefree galloping*

*Coltish confidence*

*Winds of freedom blowing your mane*

*Once wobbly-kneed boy*

*Draped in roses*



### COURTNEY'S KIDS

SAM 2½ YEARS

ETHAN 4½ YEARS

SYDNEY 7 MONTHS

With the first Saturday in May comes the annual running of the Kentucky Derby – the “Run for the Roses”! As I reflect on this unique fervor that lives in our very own “Kentucky Home,” I’m pensively drawn to connect the Derby with my son, Sam, and with others who have Down syndrome. As I watch the Derby, a race for three-year-old thoroughbreds, I’ll think about Sam who turns three-years-old this May. While the Derby hopefuls’ very first breaths begin with wobbly-kneed steps, we are still anxiously anticipating the day that Sam will dart off walking on his own! It is usually easy to be patient with Sam, and yet I long for him to feel the freedom and confidence of wind in his mane...

The horses that run for the roses in the Kentucky Derby will have trained for hours upon endless hours for this special moment, just as those who have Down syndrome have worked so hard to earn their various personal “roses.” Maybe that rose is taking a first step, or reading a book, or swimming a lap, or making a friend, or playing a piano, or being thoughtful, or accepting a job offer, or not giving up, or learning to let go...

While the beauty and thrill of the Kentucky Derby is “the most exciting two minutes in sports,” being the parent of a child with Down syndrome has helped me to cherish the preparation, dedication, and perspiration that precede the actual race. I am also now more aware of who often doesn’t win society’s “roses.” I know that life should not be a race governed by appearance or social etiquette, nor by productivity or profitability...or even roses. Being the parent of a child with Down syndrome has helped me to wholeheartedly cherish and celebrate more victories. It has helped me to unabashedly laugh or cry sometimes. And it has reminded me that we are all after various roses, in various ways, for various reasons, with various abilities and challenges.

Don’t think of life as a race necessarily, but identify roses that are worth striving to earn (as well as those that are not), and then work hard to earn those roses. Celebrate victories along the way. Cherish the beauty of simple moments that will gallop away before you know it. Imagine your once wobbly-kneed children draped in roses... because, one day, they will take off running!

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## CALENDAR

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### TRANSITION AND SUPPORTS FOR THE CHANGE FROM SCHOOL TO ADULTHOOD

May 19, 2007

10:00 am – 12:00 pm at the Child Development Center  
Doug Riddell from ARC of KY will hold a workshop for parents regarding “Transition and Supports for the Change from School to Adulthood.” He will be covering services available to individuals with disabilities in the state of Kentucky. People can join the group for information. For more information, contact Becky at (859) 252-9523.

### POST-SECONDARY EDUCATION CONFERENCE: “OPENING DOORS TO STUDENTS WITH INTELLECTUAL DISABILITY”

Sponsored by the Ohio Down Syndrome Advocacy Network

May 19, 2007

Ohio State University in Columbus, OH

For more information, contact Janet Gora at DSAGC (513) 761-5400 or [dsagc@dsagc.com](mailto:dsagc@dsagc.com).

### SPECIAL OLYMPICS STATE SUMMER GAMES

When: June 1-3, 2007

What: Track and Field, Swimming, Gymnastics, Powerlifting and Soccer Championships

Where: Eastern Kentucky University; Richmond, KY

Volunteer Opportunities: timers, event stagers, awards stations, soccer officials.

Registration: Varies by sport. Swimming has the earliest registration date. Call (800) 633-7403 for details.

### DSACK NIGHT AT THE LEXINGTON LEGENDS GAME

June 24 at 6:00p.m.

We have free tickets to the game! Call Becky Lesch at 252-9523 if interested in attending! Kids run the bases after the game! This is a great family event!

## BUDDY WALK 2007 - THE TIME IS NOW!

DSACK needs energetic, motivated, and dedicated volunteers to step up and serve in a variety of positions on the Buddy Walk Committee. We will soon begin to hold regularly scheduled meetings. A variety of opportunities (Sponsorship Help, Volunteers, Food, Activities, etc.) are available to fit just about anyone’s schedule. Please consider this IMPORTANT volunteer opportunity. Contact [kboudreaux@insightbb.com](mailto:kboudreaux@insightbb.com) or [jblakema@lfucg.com](mailto:jblakema@lfucg.com) for more information.

SPONSORS NEEDED – Know an individual or business that might support the Buddy Walk? Please send that information to [mcampbell@apscommunications.com](mailto:mcampbell@apscommunications.com) and we will contact them. Thanks!

### INTERNATIONAL MOSAIC DOWN SYNDROME ASSOCIATION CONFERENCE

June 29 – July 1, 2007

Virginia Commonwealth University in Richmond, VA

For information or to register contact the IMDSA at [www.imdsa.com](http://www.imdsa.com) or (888) MDS-LINK.

### 18TH ANNUAL APSE NATIONAL CONFERENCE

July 16-18, 2007

APSE: The Network for Employment is holding an event focusing on supported employment in Kansas City. For more information, or to register, visit [www.apse.org](http://www.apse.org).

### NATIONAL DOWN SYNDROME CONGRESS

35th National Convention

August 3-5, 2007

Kansas City

[www.ndscenter.org/news/convention.php](http://www.ndscenter.org/news/convention.php).

### DSACK ANNUAL SUMMER PICNIC FOR FAMILIES AND FRIENDS/BUDDY WALK TEAM KICK-OFF

August 11, 2007

11:00 am – 2:00 pm

Located at Shelter 5 at Shilito Park. Please bring a dish to share, and enjoy fellowship with our great families!

### SPECIAL EDUCATION LAW AND ADVOCACY TRAINING BY PETE WRIGHT OF WRIGHTSLAW

Sponsored by DSACK, the Autism Society of the Bluegrass, and CRISIS

August 22, 2007 at Cardinal Hill Rehabilitation Hospital

To register, visit [www.wrightslaw.com](http://www.wrightslaw.com), early bird until 7/31/07. For information, contact Melanie Tyner-Wilson [tynerwilso@aol.com](mailto:tynerwilso@aol.com) or Sara Spragens (859) 299-9000.



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## SUBMISSIONS

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

Submission deadline for July/August Issue is Wednesday, June 6 and can be sent to either Courtney [celbert@adelphia.net](mailto:celbert@adelphia.net) or Nicole [nicjoe@adelphia.net](mailto:nicjoe@adelphia.net).

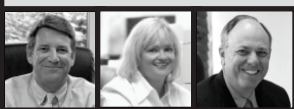
Send us pictures of your family member who has T21 to be included in the banner of the newsletter. Digital photos are preferred. Photos should be of the individual alone – head & shoulders preferred.

*Do you...*

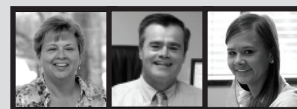
- know someone who might like to receive our newsletter?
- have an interest in placing an ad in our newsletter?
- want to receive the newsletter by e-mail instead of through regular mail to save DSACK mailing costs?

If so, please contact Caroline Baesler at (859) 619-1392 or [baeslerjunk@alltel.net](mailto:baeslerjunk@alltel.net). Let's get the word out about DSACK and our loved ones with DS!

**Let us show you what a friendly neighborhood bank is like.**



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