



HEART STRINGS

Our children and adults with Down syndrome are the heart of our organization - and our most precious gifts.

A bi-monthly publication for families and friends enriched with the Down syndrome connection.

September/October 2005

Message from Executive Director

Although it was sad to see the kids head back to school, I admit that it is nice to have a cleaner house and a little "quiet" time. It has also been good for everyone in the family to have some structure and routine back. Sleeping in (if 7 a.m. falls into that category) and splashing in the pool every day can become habit-forming, not to mention the added pounds that crept on over the summer. Of course, I blame it on my motherly duties of baking something homemade at least once a week...or was that twice a week?!

It's amazing how a child can change in a year. I was recently comparing the "first day of school" pictures from last year and I couldn't believe how they had grown, both physically and mentally. My daughter, Haley, is almost 8 years old and in 3rd grade. Matthew is almost 5 and will be starting kindergarten next year! He is becoming quite independent (and quite bossy). His response to anything is "I wanna try" - meaning "I want to do it myself!" Which is a good thing I guess, unless we happen to be crossing the road.

Don't forget to take advantage of our end-of-summer fling, the annual Holiday World outing, on September 17. GRADSA will pay admission and lunch for individuals with Down syndrome and their immediate families. Teens and adults with Down syndrome may also invite a friend.

With fall right around the corner, GRADSA is gearing up for the 9th Annual Buddy Walk on Sunday, October 2. We are anticipating our largest event yet. Don't forget to send in your registration form by September 15 so we can order enough Buddy Walk T-shirts for everyone.

GRADSA is excited to be hosting the *Changing Lives: Down Syndrome and the Health Care Professional* workshop on October 18. Although the target audience is obstetricians, pediatricians, and nurses, parents and service providers are also invited to attend. Service providers should check with their accreditation providers to determine if it is eligible for educational credits.

The Sign Language class has been postponed until January due to the YMCA being closed for maintenance. Our next education workshop will be in November with Reading Strategies presented by Valerie Neville, Special Education Teacher at Meadowlands Elementary School.

Hope to see you soon!

Cindy Huston

Calendar of Events

Saturday, September 17, Holiday World Outing, GRADSA will pay admission and lunch for individuals with Down syndrome and their immediate families. Call Cindy Huston with your reservations by September 1. Tickets will be mailed prior to the event.



Sunday, October 2, 9th Annual Buddy Walk, 11 a.m. - 3 p.m. at Moreland Park in Owensboro. Join us for a boot-stompin' celebration of Cowboys and Cowgirls who have Down syndrome. A picnic lunch will be provided along with activities for everyone to enjoy. **Don't forget to pre-register by Sept. 15 so we can place the T-shirt order.** If you need a registration form, contact Cindy Huston or download it at www.gradsa.org

Tuesday, October 18, Changing Lives: Down Syndrome and the Health Care Professional, Noon - 1 p.m., OMHS's Center Street Conference Center. See page two for more information.

November (Date TBA), Reading Strategies, presented by Valerie Neville, Special Education Teacher at Meadowlands Elementary School. More information will be provided in the next issue.

News

OC-TV will be airing a segment on the Buddy Walk featuring **Aaron Shoemaker**, employee of **Texas Roadhouse**, during the month of September. The segment will air on Cable Channel 51 on Tuesdays, Fridays, and Saturdays, at 10:30 a.m., 2:30 p.m., 6:30 p.m., 10:30 p.m., 2:30 a.m., and 6:30 a.m.

There will not be a fall session of **TOPS Soccer**. The organizers plan to be back in the spring. Watch the newsletter for sign-up information.

Special Olympics will be forming a **Bumper Bowling League** for children ages 5-8. If you would like to sign up, please contact Mary Dee Boemker at 800-633-7403 or mdboemker@soky.org.

If you missed the family movie "**Shorty**", it is available for loan. Please contact Cindy Huston if you would like to borrow it. Shorty is the true story of Walter Simms, a 55-year old man with Down syndrome, and the impact he made on his community.

The **Board of Directors** is in need of two additional advisors. An advisor can be anyone interested in improving the lives of individuals with Down syndrome -- a parent, grandparent, friend, professional, service provider, or physician. We are specifically in need of someone with an accounting background. Advisors do not serve a specific term. The Board meets bi-monthly. If you are interested, please contact Dwight Beyke.

GRADSA extends its sympathy to the family of **Anji Edge**, in the loss of her grandmother, **Ada Bittle**.

Changing Lives: Down Syndrome and the Health Care Professional



GRADSA will be co-sponsoring the *Changing Lives: Down Syndrome and the Health Care Professional* workshop to be held on Tuesday, October 18, 2005, at Owensboro Medical Health System's Center Street Conference Center. The workshop will be held from 12:00 - 1:00 p.m., with lunch provided.

The presentation will be made by Dr. Bonnie Patterson, MD, and Director of the Jane and Richard Thomas Center for Down Syndrome, Cincinnati's Children's Hospital Medical Center.

This program was created by the National Down Syndrome Society to educate health care professionals on the medical and developmental needs of individuals with Down syndrome and equip them with practical tools for delivering the diagnosis in a positive and supportive way.

Program Objectives: Upon completion, participants will be able to:

1. Describe the medical and developmental needs of individuals with Down syndrome.
2. Deliver the diagnosis of Down syndrome in a positive and supportive way.
3. Discuss local and national resources.

Target Audience: RN's, LPN's, Obstetricians, Pediatricians & their office staff

Accreditation/Course Credit

The Daviess County Medical Society is accredited by the Kentucky Medical Association to sponsor continuing medical education for physicians. The DCMS Consortium designates this educational activity for one credit hour in Category I credit toward the AMA Physician's Recognition Award. Each physician should claim only those hours of credit that he/she actually spent in the educational activity.

This offering provides 1.2 CNE for nurses. OMHS is a KBN Approved Provider of Continuing Education, Provider #4-0032-7-109-2-2-2. Exp. Date July 1, 2006. Participant must sign the attendance roster providing license number and SSN, attend the entire program and complete a program evaluation to obtain CNE credit. KBN approval of an individual nursing CE provider does not constitute endorsement of the program content. Please note that 50 minutes = 1.0 CNE. Kentucky Board of Social Worker credit approval pending.

Pre-registration is required. OMHS Employees may register in Registrar. Non-employees should call Debbie Goatee, Patient Services Education at (270) 688-3050. Deadline for registration is October 11, 2005.

The Importance of Delivering the Diagnosis

In March, senators Kennedy and Brownback introduced a bill into the senate called the "Prenatally Diagnosed Condition Awareness Act." This bill (S. 609) states as its goal: "To amend the Public Health Service Act to increase the provision of scientifically sound information and support services to patients receiving a positive test diagnosis for Down syndrome or other prenatally diagnosed conditions." This bill will establish a resource hot line and website for new parents of children with Down syndrome, establish a "clearing-house" of medical information about people with Down syndrome, establish a network of national and local peer-support programs, and set up awareness and education programs for doctors who provide the diagnoses of such conditions to parents. This is a remarkable bill and you can read it in its entirety by going to thomas.loc.gov and searching for bill "S.609".

Two groundbreaking studies by Harvard student Brian Skotko were published this year. The first report was published in the January issue of the medical journal, *Pediatrics*, and discusses the experiences of mothers who received the diagnosis of Down syndrome upon the birth of their child. The second report was in the March issue of the *American Journal of Obstetrics and Gynecology*, and explores the experiences of mothers who received a prenatal diagnosis of Down syndrome.

Both studies showed that physicians routinely failed to provide current information about Down syndrome, potential positive outcomes for their child, and referrals to parent support groups.

A summary of both reports may be found at the www.ndss.org under the News and Events tab - Science & Research News.

Meet the Buddy Walk Goodwill Ambassadors

David Fogle is the son of Lynn and Phil Fogle. He has an older brother, Brad, a younger sister, Carrie, two nieces, and two nephews. David is 34 years old and graduated from Apollo High School in 1991.



David is employed at the Opportunity Center in the woodworking shop. He participates in several Special Olympic sports, including basketball, bowling, and weight lifting. His passion is weight lifting and spends several evenings each week in the YMCA weight room.

He has been to three Special Olympic World Games and has four gold, two silver and one bronze medals from these games. He participated in Power Lifting at each of these World Games.

David also enjoys going out to eat and to the movies with his girlfriend, Shannon Peterson. He has lived in his own apartment with roommate Heath Logsdon for the past two years.

David and Chris will be arriving at the walk via limo at 11:30 a.m. They will greet the other "Cowboys and Cowgirls with Down syndrome" at 1:30 p.m. and present each person with a Texas Roadhouse cowboy hat and Buddy Walk bandanna.

Christina Marie Hagan, daughter of Linda and John Stavrakis, and Ron Hagan, is a graduate of the Mattingly School and has been involved with Special Olympics program over 20 years. She has received numerous honors and awards for swimming, her chosen sport, and also for her outstanding skills in bowling. Chris is an asset to any team with her strong leadership qualities and profound competitive spirit. Presently she is playing golf every Monday with her coach/partner, Pat Sturgeon. They are currently preparing for a golf tournament which will be held at Ben Hawes State Park, with awards going to the Special Olympian and partner posting the best nine hole score.

Chris' private life consists of hanging out in the loft section of her parent's home with occasional overnight visits from friends, but mostly just playing with her most prized possession, Benji, a miniature Yorkshire Terrier. Chris also enjoys listening to country music, working on latch hook rugs, and mastering her skills on her computer, which she uses to play games on.

Chris is currently employed by the Opportunity Center which has her placed at the Big Blue Bingo Hall. She works two days a week which allows her Saturdays to be open for bowling and spending quality time with her special friends at Martha's Outreach Program.

Chris' life is cushioned with loving parents and three attentive sisters. All who know Chris can truly appreciate her strong opinions and quick wit, which has done nothing more to endear her to everyone around her. Chris knows no stranger, and has the unique ability of befriending anyone willing to talk to her. It has been noted by many who have met Chris, "once you've met her, it's hard to forget her."

When Chris was asked to comment about her life, her reply was simple and direct: "I t's Great!" For those of us who know and love Chris, we know she means it!





Will Graves Beyke picks out his popcorn and snacks before the movie.

GRADSA hosted a Family Movie Night on July 30. Adults viewed the film "Shorty" while the kids enjoyed "Shark Tales."



Elliott Williams and Robbie Sherrard think playing is more fun than watching a movie.



Mitchell Hensley was all smiles!



Matthew Huston gets a hug from his buddy, Leland I sbill.



Nycheala posing for the camera!



Paige Roberts plays ball with Kathleen Kight.



Spotlight



"Having an individual with Down syndrome working for Texas Roadhouse has been an inspirational experience."

Chris Blythe, Managing Partner



GRADSA is thrilled that Texas Roadhouse is the Presenting Sponsor for this year's Buddy Walk. Chris Blythe, Managing Partner, loves being involved with the Buddy Walk because it focuses on the strengths and capabilities of individuals with Down syndrome. In addition, it is important to him that the funds raised are kept within the community to support local families. Of course, the added incentive is that they can support their own buddy, Aaron Shoemaker.

Aaron has been employed at Texas Roadhouse for over a year. Blythe considers Aaron to be the ideal employee. Not only does he have a positive influence on his co-workers, but has a strong work ethic too. He is always on time, dives right into his work, and finishes all his tasks. He brings energy and enthusiasm to the staff every day that he works. His sweet smile and big hugs are an extra bonus.

Buddy Walk and Advocacy

The Buddy Walk has established itself as the premier advocacy event for Down syndrome. The purpose of the Buddy Walk is two-fold: to promote acceptance and inclusion of people with Down syndrome and to raise funds for local and national education, research, and advocacy programs.



The Buddy Walk is a powerful tool to demonstrate that individuals with Down syndrome possess a wide range of abilities and are active participants in the community. The walks involve children and adults with Down syndrome, their families, friends, and thousands of local supporters. It is inspiring to see all these children and adults walking side by side.

Advocacy is as simple as joining forces to walk with others at the Buddy Walk or putting your name on a letter to Congress. Most people are already participating in advocacy every day without even thinking about it. Every time you are out in public doing the same things that every other family does, you are advocating the fact that individuals with Down syndrome deserve the same opportunities as everyone else. They deserve opportunities that will allow them to live up

to their potential: academically, socially, and financially. Other forms of advocacy are reflected in your everyday interactions with health insurance companies, healthcare providers, and educators.

As Ghandi said, "You have to be the change you wish to see in the world." These words convey the importance of advocacy efforts, large and small.

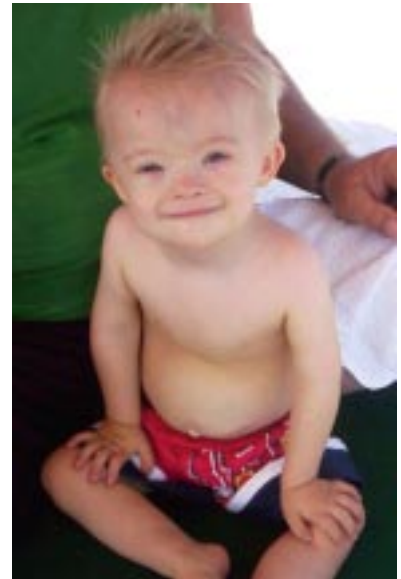
Source: National Down Syndrome Society



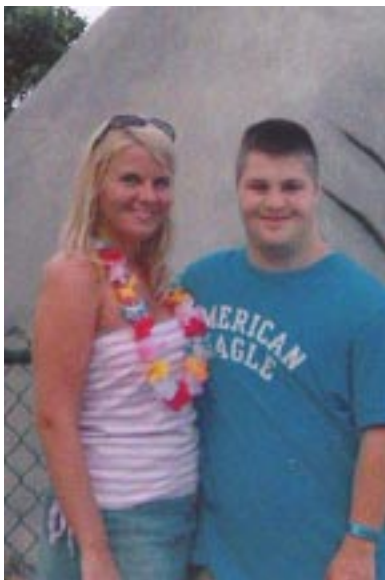
Robbie Sherrard enjoys the pool on a family vacation to Daytona Beach.



Matthew Huston and his sister, Haley, at the Gulfarium in Fort Walton Beach.



Luke Stone smiles for the camera on the beach in Panama City.



Aaron Shoemaker and his sister, Melissa, take a break from playing miniature golf in Panama City.



Sam Fenwick hugs a deer at the Pittsburgh Zoo.



Andrew Conway and his sister, Mary Beth, play in the sand at Destin, Florida.



SUMMER

Everyone Counts: Teaching Acceptance and Inclusion

Nickelodeon has joined in the efforts to raise awareness about Down syndrome. The cable channel is airing three different NDSS public service announcements that feature young people with Down syndrome fully included in school and family activities. The PSAs, which are geared towards 8- to 12-year-olds, encourage positive relationships between kids with and without disabilities and emphasize the message "We're all different...that's what makes us the same!"



Nickelodeon produced the spots for the NDSS educational curriculum *Everyone Counts: Teaching Acceptance & Inclusion*. Executives decided to provide additional visibility to the spots by airing them in various national markets over the coming months. There is no set schedule, so check out Nickelodeon regularly to catch them. We expect that these PSAs will provide many opportunities for dialogues among teachers, parents and students about Down syndrome and the potential of children born with the condition.

Note: GRADSA is working to implement this program in all elementary schools.

Heather's Hints

In order to help build your child's finger coordination, strength and general creativity, try putting a twist to regular play-dough by making it edible. Mixing canned chocolate icing, creamy peanut butter and powdered sugar, will leave your child with a wonderful afternoon of fun and a delicious snack. There is no set recipe, simply mix equal portions of icing and peanut butter and then add the powdered sugar until you have formed play-dough consistency. You and your child can then make many exciting things with the dough and it's okay to sneak a bite every now then, because it tastes great. Provide your child with various cookie cutters and safety scissors to help shape the dough as well as enhance fine motor skills. Encourage your child to form letters, numbers, pictures, etc. to build creativity and imagination. Above all, have fun!

"OOH IT'S SO GOOD!!"

Heather Hensley, OTR/L, and mom to Mitchell, 4 years old
Kid's First Therapy Services, LLC

Kindermusik

Research has shown that participation in music offers numerous benefits for a child's cognitive, physical, and social development. Musical activities are a cross between logic/emotions, math/language and have been shown to enhance listening skills and increase attention span. It is acknowledged by the scientific and educational worlds as being the single best activity to improve success in and out of school, on tests, and throughout life.



Kindermusik classes are now being offered by Cathy Mullins, Licensed Educator. Classes are offered for infants through 7-years old and will be held at Good Shepherd Church on Bittel Road. An Open House is scheduled for September 4, from

2- 4 p.m. For more information, contact Cathy Mullins at (270) 688-8202 or (270) 316-9203.

September/October Birthdays

Trevor Brown - 16 years old on Sept. 27
Kelsey Dueker - 12 years old on Sept. 11
David Fogle - 35 years old on Sept. 10
Zander Haynes - 1 year old on October 12
Mitchell Hensley - 4 years old on Sept. 4
Denise Howard - 44 years old on Sept. 23
Tatum Parker - 6 years old on Sept. 1
Isacc Ramsey - 4 years old on Sept. 9
Jeff Rhinerson - 27 years old on Sept. 2
Paige Roberts - 3 years old on Sept. 21
Eli Rose - 3 years old on Sept. 18
Alec Skipworth - 5 years old on Sept. 21
Alyssa Toerne - 11 years old on Sept. 18
Kaleb Warman - 16 years old on Sept. 16



Correction from last issue: Charity Louden was incorrectly listed as Charity Wilkerson.

If this information is not correct or a birthday is not listed, please let us know!

Mission Statement

GRADSA's mission is to enable families enriched with the Down syndrome connection to share resources, build friendships and advocate together for the future of our children.

Services

GRADSA, an affiliate of the National Down Syndrome Society, is a non-profit, 501(c)3 organization that provides its members with a bi-monthly newsletter, educational workshops, social activities, a website (www.gradsa.org), a New Parent Outreach Program, and a Hospital Outreach Program. There are no membership fees.

Policy Statement

GRADSA does not endorse, recommend or support any specific regime, therapy, or editorial submitted for publication.

Printing of Articles

GRADSA welcomes articles from parents, professionals, and other interested parties. Material for consideration should be sent to Cindy Huston. Articles written for *Heart Strings* may be reproduced if credit is given to the author and GRADSA. Permission to reprint articles not original to *Heart Strings* should be acquired from the original source.

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All board meetings are open to the general membership. The next meeting will be held on Monday, October 3, 6 p.m., at the Family Y.



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