

Heart Strings



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

Volume 12 November-December 2013



UPCOMING EVENTS

December 6th Christmas Party Owensboro Christian Church 6:00 pm-9:00 pm

Don't miss our annual Christmas Party, always a great time with great families!

Great food catered by Moonlite. Door prizes and gift for each family.

RSVP to Carla at 925-0195 or info@gradsa.org no later than 11/30/13

December 13th Parents Night Out Logsdon Community Center 6:00 pm-9:00 pm

Last minute shopping? Nice, quiet dinner? A good ole nap without interruptions?

Bring the kids to the Logsdon Center for some fun. We will have games, crafts, food and a movie. Kids can bring a toy or game if they want to.

RSVP to Carla at 925-0195 or info@gradsa.org no later than 12/10/13

Watch for GRADSA's 2014 CALENDAR!

Comments from Carla...

Hello Everyone...

I am absolutely amazed that 2013 is almost over. Our next newsletter will be in 2014! I feel it has been a wonderful year for GRADSA and I am so excited to see what all happens in 2014. We have a wonderful, growing board which you will learn more about inside this issue. I want to thank the entire board for all they are doing to help GRADSA move forward. I also want to thank all of our families and their involvement in GRADSA. Our events this year have been our best attended since I have been with GRADSA. I so appreciate our new families and their enthusiasm. I can't wait until our Christmas Party. It is always one of our nicest events and very well attended. Again, thank you so much for allowing me to be a part of this great organization.

Merry Christmas and Happy New Year to You All!

Sincere Apology...

I want to give a huge, sincere apology to Jay Mahoney. I did not mention Jay in the last newsletter when thanking the Buddy Walk committee. I can assure you it was a complete oversight on my part and he is such a great asset. Jay is responsible for several of our corporate sponsors along with a lot of donations for the Silent Auction. I am so fortunate that he is a sweet and understanding man and will forgive me for my mistake, right Jay? Love you bunches!

From the Board...

As promised in the last newsletter we are excited to share how our board has been growing. We are proud to announce the following new members:

Amy Harper

Ashleigh Bottoms

Juli Stewart

Kyle Gorman

Helen Wright

Jessica Gorman

JC Jackson

Below are some bios on some of the new members. Hopefully we will have more to come in the next newsletter.

Amy Harper: I was born and raised in Owensboro, I graduated from OHS in 1992 and then went onto Western, where I have a degree in moderate/severe disabilities and learning and behavior disorders. I'm married to Todd Harper, we've been married for 10 years, and we have a precious son that will be 2 on October 9th. I am really excited about being a part of the GRADSA board, thank you!!!

Juli Stewart: My Name is Juli Wurth Stewart born and raised in Owensboro. 1992 graduate of Owensboro Catholic High School and 1997 Graduate of Brescia. Married to Kent Stewart and have daughter Izabella who will be 4 in December and expecting baby no. 2 any day now. I am accountant and have worked with my father at Clemens, Guthrie & Wurth, LLP in Owensboro since 2004.

Ashleigh Bottoms: Hello! My name is Ashleigh Bottoms and I'm very excited to be joining the board of GRADSA! I live in Owensboro with my husband, Sean and work as a School Psychologist for Breckinridge County Schools. Sean and I are from Burgin, a small town in central Kentucky. I attended Georgetown College for my undergraduate degree in Psychology, the University of Kentucky for my Master's degree in Educational Psychology and Specialist degree in School Psychology. While at UK, I volunteered for the Down Syndrome Association of Central Kentucky (DSACK) as Volunteer chair for the Buddy Walk and started and led the Elementary Age Social Group. In my spare time, I love to play with my dog, Ollie, read and go to the lake.

Jessica Gorman: My name is Jessica Gorman. I have been married to my husband, Kyle, for 8 years. We have two children, Lucas(6) and Lydia(3). I am a 1st grade teacher at Burns Elementary School. I am looking forward to serving on the GRADSA board along with my husband! I am excited to learn more about Down syndrome and ways that I can give back to my community.

On a sadder note, Sondra Gilbert has left the GRADSA board. Sondra has been a tremendous asset to the board and will be missed. Sondra has had to take on a lot more responsibility and new duties with the ACA starting and cannot commit the time needed to GRADSA. We will still be partnering with Sondra for trainings and workshops. We wish Sondra the best.

New Family...

GRADSA is excited to introduce Jenny and Louis Hayes. Jenny and Louis are the proud parents of Connor Hayes. Connor was born September 23rd and is doing great. Jenny and Louis, we are so happy for you to be a part of GRADSA and we can't wait to meet your precious little Connor. He is such a smart boy, I can't believe he already knows he is a UK fan!



GRADSA Presents "Fitness and Nutrition Program"...

GRADSA will offer nutrition classes once a week for six weeks and will have a cooking class and serve lunch the last week. These classes will be for the older individuals and all parents/guardians. We will also provide instructors for exercise classes twice a week for six months to a year for our individuals with Down syndrome. These will be held at the Healthpark or the YMCA. GRADSA will provide exercise supplies for individuals to keep once the program is over so that they can continue the fitness at home. We are very excited to offer this program and hope many of you will participate. We hope to make it a fun experience. We will be launching the program no later than January. Great New Years resolution, huh? GRADSA was provided this opportunity from a grant provided by Owensboro Regional Health. We will be sending out more information in the near future. Are you pumped?

New Registry aims to serve people with Down syndrome...

DS-Connect offers a centralized, secure online resource to store and share health information.

The first national Down syndrome registry in the United States has been launched by the U.S. National Institutes of Health. The DS-Connect web-based registry will serve as a free resource for people with Down syndrome and their families, as well as health care providers and researchers. Participation in the registry is voluntary. "The Down syndrome community has voiced a strong need for a centralized, secure database to store and share health information. DS-Connect fills that need, and helps link individuals with Down syndrome to the doctors and scientists working to improve their health and quality of life," Yvonne Maddox, deputy director of the U.S. National Institute of Child Health and Human Development (NICHD), said in a news release from the National Institutes of Health. The NICHD funded and developed the registry. People with Down syndrome -- or their family members on their behalf -- can sign up to create personalized profiles so they can anonymously compare their health information to other participants. The site has been designed to keep all personal information confidential so participants cannot be identified by other people using the site. If participants wish to be informed about research studies that might be of interest to them, they can give permission for the registry coordinator to contact them. "DS-Connect is for people of all ages, not just children," Maddox said. "Right now, we don't have much data on older individuals with Down syndrome, and that's been a problem. People with Down syndrome are living longer, and researchers and physicians will require information about the health issues and needs of these individuals to make recommendations about their health care." A public-private group called the Down Syndrome Consortium will play an important role in helping to spread information about the registry to the Down syndrome community. The consortium is made up of people with Down syndrome and their relatives, as well as National Institutes of Health scientists and representatives from professional societies and advocacy groups. "We've been fortunate to have so many experts and advocates provide input on this effort," Maddox said. "The establishment of this registry is a tremendous step forward for Down syndrome research, and the resource will become all the more beneficial as more individuals join in the months and years ahead."

For more info: <https://dsconnect.nih.gov/>

Debunking the Termination Myth...DSG, Nov/Dec 2013

For years, the myth has been spread that 92% of babies with Down syndrome in the U.S. are aborted; however, recent research shows the termination rate is much lower and dropping.

What is the actual termination rate?

According to a survey of 24 studies across the U.S. that were done between 1995-2011, we know the following:

The weighted average of the surveys from the Natoli study show that the termination rate is actually about 75% among those who get a confirmed diagnosis with an amniocentesis or CVS.** Only about 2% of women in the U.S. get an amnio or CVS, so any termination rate only applies to that group. Termination rates also vary significantly depending on the age of the mother, race/ethnicity, gestational age, and where the mother lives. Evidence shows "termination rates have decreased in recent years, which may reflect progress in medical management for individuals with Down syndrome and advances in educational, social, and financial support for their families."

Where did that termination myth come from?

The 92% termination rate came from an older summary of termination rates that only included U.S. studies from the 1980's and also included international figures where termination rates are higher.

Why is the termination myth harmful for expectant parents?

Quoting the inaccurate 92% termination rate is usually meant to elicit shock and revulsion that so many babies with Down syndrome are aborted. Sadly, many expectant parents say that when they hear that 92% of babies with Down syndrome are terminated, it actually makes them feel alone, as though they would be in a small minority by choosing to continue a pregnancy. Therefore, this myth actually runs the risk of prompting more terminations by making expectant parents feel isolated.

Why is the termination myth harmful for all of us?

This myth also infects our culture leaving many people saying in public forums, "If the vast majority of people terminate a pregnancy when they find out the baby had Down syndrome, then Down syndrome must be really, really bad." This leaves parents of children with Down syndrome feeling like they have to justify their decision to continue a pregnancy when questioned by those around them. Fundamentally, this myth risks creating a culture that is less likely to accept and value children with Down syndrome, and it's based on false information.

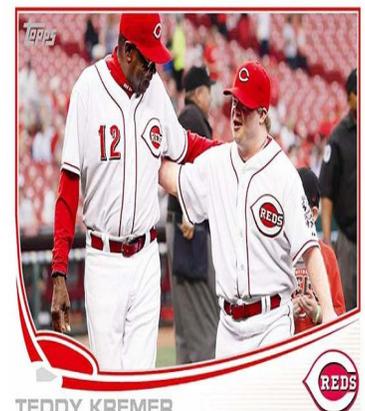
What can we do to make sure expectant parents get the support they need?

Down syndrome advocates and organizations can make sure expectant parents get accurate, up-to-date balanced information and support immediately after receiving a diagnosis. They can distribute the Lettercase "Understanding a Down Syndrome Diagnosis" books that have the credibility of being reviewed by the national medical organizations (lettercase.org); they can link to the National Center for Prenatal and Postnatal Down Syndrome Resources, including Down Syndrome Pregnancy, from their website (downsyndromediagnosis.org); and they can provide direct support and baskets to expectant parents. This insures that expectant parents receive materials immediately from their doctors or online which show the potential of children with Down syndrome, and they feel welcomed into a supportive organization as soon as they are ready.

**Natoli et al. 2012. Prenatal diagnosis of down syndrome: systematic review. *Prenatal Diagnosis* 32, 142-153

Batboy with Down syndrome gets his own card...YAHOO Sports, October 24th. 2013

Topps cards absolutely hit a grand slam by including Ted Kremer in its 2013 update set. Kremer, a 30-year-old man from the Cincinnati area who has Down syndrome, inspired anybody who heard about his time as a batboy earlier this season for the Cincinnati Reds. Kremer's card is a variant of another card in the set, so it won't be found frequently in packs, but it's out there for collectors — if they dig. It features Kremer and former manager Dusty Baker. A Kremer card sold on eBay for \$149.99. Another sold for \$82. There was only one on eBay today, it had an asking price of \$159.99 or best offer.



T. James Kimble was sitting at the railroad crossing he drove over every day on his way home. He was ready to stop his car on the tracks — there were no crossing gates, so it would look accidental. But as he heard the blast of the horn, he cried out, "Lord, please send someone who can understand what's going on inside of me and help me get better." The outburst surprised him so much he missed the train. Eighteen years later, he's alive and well — a fact he attributes mostly to his son, Joshua, who was born two years after the incident. He's sure Josh, now 15, was sent to help him understand what was going on inside of him and help him get better. Josh was born with Down syndrome. In the hospital, T.J. and his wife were told of all the things Josh wouldn't be able to do, but Josh showed the world what he could do. "My son Joshua had a disability more severe than mine, but yet still finds ways to live beyond his own disability," T.J. said. "The older he became, the more he inspired me to live beyond my own depression. I began to realize my son Joshua's Down syndrome had turned my depression upside down." On July 19, T.J., Josh and a group of supporters will arrive at the steps of the Capitol after a 96-mile walk from Radcliff to raise funds and awareness to empower others with disabilities. When T.J. was 6, he lost control of his bicycle and ran it into a moving car. Knocked unconscious, he awoke in a pool of blood bigger than he was. He said the compound skull fracture that resulted was the start to a lifetime of challenges. The complications began in first grade when he was moved to a special education classroom and was never put on the track for a high school diploma. "I had struggled all my life," he said. "I now know that was, in large part, due to my head injury." T.J.'s father was killed in a hit-and-run car accident in Dallas when he was 10. The stepfather who later became part of his life was nothing like his biological father, he said. "My stepfather was very abusive," he said. "I've had a loaded gun — he and his drug-dealing and drug-taking friends, they pointed a loaded gun at my left temple and cocked it." But he lived to tell about it. T.J. also lived to tell about the time he got into a particularly bad fight with his stepfather, which resulted in him having his head slammed against concrete multiple times. "I couldn't take it anymore," he said. ". I remember thinking, 'Whatever normal is, this isn't it. I think I'm just going to leave here.'" He jumped a fence and never returned to that house, despite being homeless for almost a year. T.J. wandered from trash bins to a campground to a trailer park when it got really cold. T.J. later moved in with the family that invited him to church and eventually went to school to become a minister. He met a woman named Liz, and they've now been married for 20 years. Despite the stability and security he found in his church and his wife, T.J. still didn't feel right. "I realized that something was still very wrong inside of me," he said. "I was clinically depressed, and I didn't realize it. I can't put into words the intensity and the gravity of the pain I felt." He remembers three distinct instances in which he tried to end his life, including the railroad incident. The suicidal tendencies stopped when Josh was born in 1997. "I began to feel the barriers and layers of insulation break down around me," T.J. said. "I began to feel these acts make me feel alive again." The little acts of love Josh displayed inspired T.J. to overcome his own disability, the clinical depression. He's working on a book, to be titled "The Joshua Factor Story," to compile the many ways Josh has touched not only his life, but others' too. "It just became infectious," he said. ". I found myself in a place of wholeness, and I was like, 'Wow, I want to help other people. I want to help them discover this.'" T.J. went to school to become a clinician, a time when he began to understand what happened in his own life. For two years now, T.J. has operated a practice, Your Best Life Now Counseling, from Lifeline Assembly of God in Radcliff. T.J. employs a faith-based counseling approach. Mostly, he counsels families with children with disabilities — he helps them see beyond the disability. He helps his clients realize the upside of disabilities, as he did with Josh. "We empower them to discover their own purpose and begin to live that with a passion," T.J. said.

NDSC 2014 Convention...

The 2014 National Down Syndrome Congress Convention, "Setting the Pace" will be held in Indianapolis, IN on July 11th-13th. Registration opens March 3rd. For more info on convention visit: <http://convention.ndsccenter.org/general-convention/>
Don't forget GRADSA offers funding for conferences. Funding is limited to availability.

Trunnels and Halloween Dance...



In Our Community...



Daviess County High School Special Olympics bowling team participated in the area tournament on Oct. 19 at Diamond Lanes South. Pictured, back row, Nicholas Roberts, Zach Payne, Tiffany McDaniel, Nicholas Walker, Zach Lindsey, Jeron Brown, Brandon Kay and Attila Gray. Front row, Kelsey Dueker, Jonah Edge, Leland Isbill, Sheri Storm and Mackenzie Taylor.



Above: Several of our sweet individuals on the DCHS Special Olympics Bowling Team.

Left: Loving Shannon Mahoney kissing her mom. This was a great article, hope you all got to read it. It was in the Messenger-Inquirer on October 16th, 2013.

Happy Birthday!!!

November

04 Jonathon Whittaker
08 Ana Lila Desillo
10 Matthew Huston
10 Elijah Hale
18 Ben Pace
25 Joey McAtee
30 Steven Ballard

January

04 Landon Ashby
12 Shannon Mahoney
16 Raegan Brown
20 Erin Clark
21 Ashley Hagan
22 Ashley Dant
23 Isaiah Cruz
23 Elizabeth Stickler
24 Sherri Storm
24 Kathleen Kight
30 Zoey Doolin

December

02 David Leonard
04 Preslee Hay
05 Tasha Worman
06 Christina Martinez
08 Tammy Sears
15 Lukas Mahoney
16 Alan Wood
17 Zeb Wells
17 Clayton Eddings
22 Elysha Barrow
26 Paxton Hocker
27 Hannah Hardesty
28 Mark Vollman
28 Ann Switzer
30 Max Engineer

“This is the day which the
Lord has made:
Let us rejoice and be
glad in it.”

Psalm 118:24



Fazoli's Birthday Club:

Fazoli's, 5060 Frederica St., is treating individuals with Down Syndrome to a free meal to celebrate their special day. Children ages 12 and under can choose a kid's meal while teens and adults have their choice of a small spaghetti with marinara or meat sauce. To receive your free meal, show this column to the cashier during the month of your Birthday.



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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 individuals with Down syndrome.

SERVICES

GRADSA is an affiliate of the National Down Syndrome Society and the National Down Syndrome Congress. GRADSA is a non-profit 501(c)3 organization that provides its members with a bi-monthly newsletter, educational workshops, social activities, a website, a parent outreach program and a hospital outreach program. There are no membership fees to join.

POLICY STATEMENT

GRADSA does not endorse any specific therapy, treatment or educational setting. We provide a variety of information and viewpoints. However, each family must make an individual choice.

PRINTING OF ARTICLES

GRADSA welcomes articles from parents, professionals and other interested parties. Material for consideration should be sent to Carla Renfrow at info@gradsa.org. Articles written for *Heart-Strings* may be reproduced if credit is given to the original author and GRADSA. Permission to reprint articles not original to *HeartStrings* should be acquired from the original source.

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