



HEART STRINGS

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

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

November/December 2008

Message from Executive Director

It is with mixed emotions that I announce my resignation as Executive Director, effective December 31. I have accepted a wonderful job opportunity with the Wendell Foster Campus in the Assistive Technology Center. I am excited to be able to continue serving the disability community through an exceptional organization.

GRADSA will always be dear to my heart but I feel it is the right time for me to accept new challenges. It has been an honor and privilege to serve in this capacity. I have always taken seriously the duties entrusted to me. I am so proud of what we have accomplished together in these last 5 years. I am confident that GRADSA has the resources, talent and passion to continue moving forward.

I would like to wish Brett, Gail, and Kathleen Kight the best of luck in their move to Texas. We will miss them at GRADSA events but hope they will stay in touch!



This issue of *Heart*

Strings includes articles on the Peer Tutor program and Council for Exceptional Children at Burns Middle School, and personal experiences from a family retreat at the Center for Courageous Kids, plus lots of great pictures from recent GRADSA events. Also of interest is information on zinc levels for individuals with DS. Our pediatrician mentioned this at a recent visit because of Matthew's skin rashes. The multi-vitamin we were using did not even contain zinc so be sure and look at the label. Zinc is also very important for the immune system. And if your child has "rosy" cheeks (especially in the winter), try CeraVe, a moisturizer that was recommended by our dermatologist and has worked wonders for Matthew. It can be purchased over the counter at your local pharmacy.

Please remember these children in your prayers:

Krystyn Randolph - Krystyn flipped out of her wheelchair backwards at school on Sept. 30 and has been hospitalized at Kosair. She has endured 2 surgeries to repair damage to her spine.

Luke Stone will be having a heart cath on Nov. 18 in Louisville and may be facing surgery to repair a hole in his heart.

Robbie Sherrard will be having his lingual tonsils removed on November 25 in Cincinnati.

I hope you have a wonderful holiday season and many blessings for 2009!

Cindy Huston

Calendar of Events

Inclusion and Collaborative Strategies

Tuesday, November 11, 6:00 - 8:00 p.m. at the Family YMCA

Presented by Dr. Leah Hoover, Assistant Professor of Special Education at Kentucky Wesleyan College. Dr. Hoover is a former special education teacher and was previously Director of Special Education for Hartselle City Schools. She will discuss how to communicate effectively with your child's teacher, paraprofessionals, and outside agencies in an inclusive setting to make your child's education successful. Child care is available for children 10 and under. Sandwiches and refreshments will be served from 6:00 - 6:30 p.m. **Please RSVP to Cindy Huston.**

Christmas Parade

Saturday, November 22, 4:30 p.m.

Mike Murphy has generously offered the use of a semi and flatbed trailer for GRADSA to participate in the Christmas Parade. **Space is limited so if your family would like to ride on the float, please let us know at your earliest convenience. Thanks!**



Christmas Party

Sunday, December 14, 4:00 p.m. - 7:00 p.m. at Lourdes Parish Hall

Crafts and activities begin at 4:00 with dinner being served at 5:30 p.m. Santa will arrive around 6:30 with treats for all the kids. Texas Roadhouse will be catering the event. Adults will have their choice of entree - pork chop or chicken breast. Hotdogs and mac & cheese will be available for children. **Please contact Cindy Huston by Dec. 9 with the number of individuals in your family who will be attending, children's ages, and choice of entree.**

Executive Director position open

GRADSA is currently seeking a highly motivated, self-starter, detail oriented person to serve as Executive Director. Computer skills are a must. This person will maintain financial and administrative documents for the group as well as file required reports. This person would also work with all the committees and the Board to carry out the mission of GRADSA. **If you are interested, please call Stephanie Smith at 270-929-4742.**

Congratulations...

.... to Nilda Jorge Melendez on the birth of **Elias Gozman Jorge**. Elias was born on September 26, 2008. He is doing well and lives in Beaver Dam with his family.

Burns Middle School offers CEC and Peer Tutor Program

Burns Middle School has a brand new club this year called the **Student Council for Exceptional Children (CEC)**. The purpose of this club is to help foster relationships between kids with disabilities and kids without disabilities. It is modeled after the Apollo CEC club and is the first middle school club to be sponsored by the state CEC organization. Just like the Apollo chapter, the BMS chapter adopted the motto "developing friendships for life." To do this, members will attend a morning meeting every other week to hang out and learn about each other. Another thing members will do is plan after school activities such as a costume party, movie and popcorn party, and even a weekend fieldtrip. Club members will have many opportunities to learn about the differences of others but more importantly, we hope they learn about the things they all have in common. Everyone matters and our CEC club will set the example for what can be accomplished when young people come together and focus on their strengths and abilities as individuals and as a whole. -- **Rachael Clark, Special Education Teacher**



Jonathan Whittaker and Trey Whitt planted trees for the courtyard.



Trey Whitt and Tyler Lamar enjoyed time together during a CEC meeting.

Peer Tutor Program

This year we started a pilot program for 8th grade students to become actively involved with students who have disabilities. At the end of last year we talked with 7th grade students about becoming a peer tutor during their 8th grade year. We explained what the class would be like and then had them fill out a questionnaire about why they would want to become involved in working with their peers with disabilities. We hand selected about twenty students to go through an application process, get teacher evaluations, and a signed permission slip from their parents. After going through this process we then selected four peer tutors for the first semester to start in two of the four classrooms. These selected 8th grade students took this peer tutor class in place of one of the other 8th grade electives (i.e., gym, music, band, etc).

During this class peer tutors will have assignments related to their peers with disabilities. For example, some of their assignments this nine weeks are planning a Community Based Instruction trip (one peer tutor is planning a trip to the zoo), write a letter to be used in their 8th grade portfolio (one peer tutor is writing a letter to future peer tutors, while another is writing a letter to the public getting them to participate in the Special Olympics), and they are responsible for turning in Friday Reflections about the week they experienced. They are graded based on assignments, but most importantly on their positive interaction with students who have disabilities.

There are a total of 3 peer tutors this 9 weeks, and it has been an extremely positive and uplifting experience. The students with disabilities have responded well to the interaction, directions, and positive correction they get from the peer tutors. They look to them as role models and they are so excited when they come in the room. Having their peers in their class has helped them build self-esteem, model their behavioral habits, and most importantly they call them their best friend. For the peer tutors it has been a class that has educated them to appreciate life, but most importantly understand different types of disabilities. They ask a lot of questions and this allows me to share an explanation of "why" or "how", so they can help educate other students in the building. The last pep rally we had, two of my peer tutors asked if the kids could come sit with them and their friends. This is the cycle we are trying to build here at BMS and it is working. Friendships are developing among all kids and my students with disabilities have made some wonderful new friends.

Amanda Owen, Special Education Teacher

Family Retreat Weekend at the Center for Courageous Kids

Four GRADSA families recently enjoyed a weekend family retreat at the Center for Courageous Kids in Scottsville, Kentucky. The hospitality and accepting environment was simply amazing! Upon arrival on Friday evening, families were escorted to their own private den and restroom/shower areas. Each den had 8 twin beds with a different quilt and the kids loved picking out which bed they would sleep in. Each family was assigned a counselor for the weekend - someone to help with the kids and provide a welcoming atmosphere. Three meals a day were served in the dining hall - not to mention a freezer with assorted ice cream bars that was available anytime. After every meal, a dance ensued as everyone pitched in to clean up. A campfire was held the first night around the fireplace where we learned several camp songs. The next day was filled with activities - horseback riding, swimming, woodshop, fun center (bowling, pool, air hockey, etc.), arts & crafts, cooking, pumpkin carving, and trick-or-treating around camp. On Saturday night, they held a dance for the kids and the parents spent some time alone at the fun center. Our camp experience ended around noon on Sunday with a slide show of the weekend and a warm send-off from the staff and counselors. It was an awesome weekend! -- **Cindy Huston**



Laura Whitfill enjoyed the weekend with her mom and sisters.



Kelsey Dueker spent time in the Arts & Crafts Center.



Matthew Huston and his sister, Haley, loved sleeping in the den.

Dear GRADSA Family,

There are a few sayings most of us have used at one time or another that go something like "You get what you pay for," "Nothing good is free," and "If it looks too good to be true it probably is." When you hear that the Center for Courageous Kids (CCK) has a free family weekend for families who have a child with Down syndrome, you tend to think free means cheap and



a waste of time. There are blessings in life that we miss out on that we never knew we missed. I am glad that I did not let the blessing of spending a weekend with Heather, Mitchell, and Katelyn at CCK pass us by because it was free, we were too busy, or I cannot do without my TV.

Let me tell you about the facilities that are there. They have a bowling alley that you can pre-program the bumpers to come out for people who need them and go back for those who do not need them. They have one of the nicest zero entry swimming pools I have ever seen that is indoors and stays at 84 degrees. They have horses to ride. There are arts and crafts, cooking, woodworking, and more throughout the weekend. The facilities, dining area, and dorm rooms are all top notch.

The staff and volunteers are super nice and a blessing to be around. It is a great weekend to slow down from all the grinds of life and relax with your family around other people who have an understanding of what you are going through. I do not want to over-hype this camp so remember it is camp with silly songs and silly games. It is also a good time to shut out all the noise of the world and just spend time with your family in a family-friendly environment.

The next date for families with a child with Down syndrome is March 27-29, 2009. Don't let this blessing pass your family by and miss out on a great camp weekend. To learn more about CCK and sign-up for next spring's camp for Down syndrome, go to www.courageouskids.org or call (270) 618-2900.

**In Christ Alone,
Chad Hensley**

News

[Buddy Walk Sweatshirts for Sale](#)

Due to many requests, orders will be taken for Buddy Walk sweatshirts (navy with white imprint) @ \$10 each. Children and adult sizes are available. **[Orders must be placed and prepaid by November 28 with pick up at the Christmas Party on December 14.](#)** If you are not attending the party, other arrangements can be made. Please contact Cindy Huston to submit your order.

[Bike Camp Survey](#)

GRADSA has been working with the Wendell Foster Campus to host a "Lose the Training Wheels™" Bike Camp next summer for individuals with disabilities. The program gradually introduces the instability of a bicycle by using unique adapted bikes which allow children to ride conventional bicycles. It is a week long camp with daily sessions of 1 hour and 15 minutes. Cost will be approximately \$100 - \$150 with scholarships available. We are currently in the planning stages but need to determine how many of our members would be interested. **[At your earliest convenience, please let us know if your child would like to participate.](#)**

[Adoption Awareness Program](#)

If you have a child with Down syndrome already...consider loving another! The Down Syndrome Association of Greater Cincinnati (DSAGC) is looking for people who are interested in learning more about adopting a baby or child with Down syndrome. Since 1982, the DSAGC's National Adoption Awareness Program has been helping families and agencies across the country become aware of the many families who are interested in adopting a child with Down syndrome. Their mission is to ensure each child born with Down syndrome finds a loving home. If you want to know more, contact Robin at: rsteale@zoomtown.com, log on to <http://dsagc.com/dsagc-progs-adoption.asp>, or call 513-761-5400.

[Congress passes Prenatally & Postnatally Conditions Awareness Act](#)

After 3 years of advocacy from the National Down Syndrome Society, the National Down Syndrome Congress, and affiliates across the country, Congress recently passed S. 1810, the "**[Prenatally and Postnatally Diagnosed Conditions Awareness Act](#)**," which authorizes the Department of Health and Human Services to establish a grant program to collect and disseminate information regarding Down syndrome or other prenatally or postnatally diagnosed disorders and to coordinate the provision of support services for those who receive a diagnosis of one of those disorders. The act was signed into law by President Bush on October 8.

This Act will ensure 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.

[Zinc Levels in Persons with Down Syndrome](#)

Zinc levels can often be low in individuals with Down syndrome. The superoxide dismutase 1 (SOD1) gene is located on the 21st chromosome and the protein it codes for contains copper and zinc. Because individuals with DS have 3 copies of this gene instead of 2, more zinc is needed to produce the excess amount of protein coded for by this gene in DS than in children without this syndrome. In addition, individuals with DS have an increased risk of about 5% for celiac disease that may be associated with diarrhea and a lower zinc level due to poor absorption.

[Zinc is important to help maintain healthy skin integrity, regulate hormone function, and to support the immune system. Low zinc levels can be manifested by rashes/acne, mouth sores, loss of hair, problems with the sense of smell or taste, frequent illness, elevated thyroid stimulating hormone levels, and poor growth.](#)

The U.S. Recommended Dietary Allowance (RDA) for elemental zinc is 3 mg from birth to 6 months, 5 mg from 6-12 months, 10 mg from 1-10 years, and 15 mg for individuals 11 years or older. There are also several foods that are good sources of zinc including beef, pork, lamb, and dark meat from chicken (less zinc in white meat from chicken), peanut butter/peanuts, dark leafy vegetables, enriched whole grain wheat products, dried beans or peas, and lima beans.

Individuals with confirmed low zinc levels may require additional zinc supplements above recommended RDA levels as prescribed. Please talk with your health care provider and/or a registered dietitian about any health or dietary concerns you may have since individuals with DS usually have unique health care needs.

[Susan Hunter, RN, MSN, CS, PNP, FNP-C, CMH Down Syndrome Clinic Nurse Practitioner](#)

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Book Reviews

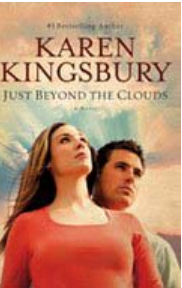
A THOUSAND TOMORROWS



Cody Gunner is a nationally renowned bull rider-cocky, brash, a legend among his peers. On track to the top, Cody has rejected everything about his past, including his famous father, his hurting mother, and every woman who ever came along. His heart only has room for his young brother who has Down syndrome. Ali Daniels is the most recognized horsewoman in her sport. She embraces life, making the most of every moment and risking everything for her passion. Along the way, Ali seeks to fulfill the dreams of her little sister, a girl who died before she had a chance to live. And so competing is all she needs until the day Cody discovers what Ali has been hiding so well. Reluctantly Ali allows Cody into her private world. Despite their fears, they bare their souls and love finds them in a way that it seldom finds anyone. In a breathless race for time, their love becomes the one part of them that will never fail, never die. In the end they find something brilliant and brief - a thousand tomorrows.

Be sure and read *A Thousand Tomorrows* first as it gives you insight into the family history. I thoroughly enjoyed both books. I could easily understand the concerns that Cody and his parents faced as Carl Joseph sought independence as an adult. These are issues that every family struggles with. -- Cindy Huston

JUST BEYOND THE CLOUDS



Still aching over his wife's death, Cody Gunner can't bear the thought of also letting go of his brother, Carl Joseph, who has Down syndrome. Cody wants his brother home, where he will be safe and cared for, not out on his own in a world that Cody knows all too well can be heartless and insecure. So when Carl Joseph's teacher, Elle, begins championing his independence, she finds herself at odds with Cody. But even as these two battle it out, they can't deny the instinctive connection they share, and Cody faces a crisis of the heart. What if Elle is the one woman who can teach Cody that love is still possible? If Cody can let go of his lingering anger, he might just see that sometimes the brightest hope of all lies just beyond the clouds.

HALLOWEEN PARTY



Aaron Shoemaker's family came dressed as a group of athletes.



Sam Winstead (Sulley), Matthew Huston (Batman), and Leland Isbill (Harry Potter), enjoyed the festivities.



Ashley Hagan took her turn at the Limbo.



Luke Stone looked comfy & cute in his costume.



Trevor Brown participated in the 4-H Horse Show at the Hancock County Sorghum Festival in September. He won a first place ribbon, two second place ribbons, and three fourth place ribbons. Way to go Trevor!



Aaron Shoemaker was part of the Texas Roadhouse line dancers who performed in the DCPS Opening Day Round Up. He loves his job at Texas Roadhouse and line dancing is an added bonus.



START A NEW HOLIDAY TRADITION

Send a holiday card with a photo of your child to your obstetrician, genetic counselor, or other physicians. Do this each year to update them on your child's growth and successes and thank them for their help in making this wonderful life possible. This simple awareness effort is an easy way to enlighten the medical community to the joyful possibilities open to a life with Down syndrome.



GRADSA held its first Sibshop in August. The sibs had fun playing games and sharing what it's like to have a sib with special needs. Each participant received a T-shirt that said "I'm Special Too." Special thanks to Melissa Jackson and Kristin Blanford for facilitating this workshop!



Thank you to Lewis Lane Baptist Church for sponsoring a Buddy Basketball League this fall. Participants pictured above are: **Sam Winstead, Lukas Mahoney, Kelsey Dueker, Merrick Justice, Leland Isbill, Matthew Huston, and Amie Morris.**

HOLIDAY WORLD OUTING



Landon Ashby enjoyed the carousel with his mom Christie.



Beth Wilson gives her mom a hug during lunch at Holiday World.



Sam Rutland didn't let a broken leg stop him from having a good time with his family.



Amie Morris gave Santa a preview of what she wanted for Christmas!



Elijah Hale checked out the Holiday World brochure to see what he wanted to do next.



Colin Powers, Elizabeth Stickler, and their sibs enjoyed a fun moment together.



Adriane Free enjoyed the day with her family.

Nov/Dec Birthdays

Steven Ballard, 42 years old on Nov. 30
Elijah Hale, 1 year old on Nov. 10
Hannah Hardesty, 4 years old on Dec. 27
Paxton Hocker, 13 years old on Dec 26
Matthew Huston, 8 years old on Nov. 10
Lukas Mahoney, 9 years old on Dec. 15
Christina Martinez, 5 years old on Dec. 6
Joey McAtee, 23 years old on Nov. 25
Ben Pace, 3 years old on Nov. 18
Tammy Sears, 40 years old on Dec. 8
Ana Lilia Sedillo, 17 years old on Nov. 8
Ann Switzer, 8 years old on Dec. 28
Mark Vollman, 48 years old on Dec. 28
Zeb Wells, 3 years old on Dec. 17
Jonathan Whittaker, 14 years old on Nov. 4
Alan Wood, 37 years old on Dec. 16
Tasha Worman - 28 years old on Dec. 5

Fazoli's Birthday Club - Fazoli's, 5060 Frederica Street, is treating individuals with Down syndrome to a free meal to celebrate their birthday. Children ages 12 & under can choose a kids meal while teens & 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.

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, an affiliate of the National Down Syndrome Society and the National Down Syndrome Congress, 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 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 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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The next board meeting will be held on Thursday, November 20, 5:30 p.m., at the Family YMCA. All board meetings are open to the general membership.

If you have an address change or would like to discontinue your subscription to *Heart Strings*, please contact us!

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