

Heart Strings



Our children and adults with Down syndrome
are the heart of our organization and our most precious gifts.
Volume 22 July-August 2015



UPCOMING EVENTS

July 13th-17th Fit with Friends Summer Camp Healthpark

Registration for this event is over. We hope all participants have a great time!

July 31st Back to School Pool Party 5:30 p.m. -7:30 p.m. Cravens Pool

Don't miss our annual Pool Party. Lots of fun for everyone and great food. Please RSVP to Carla at info@gradsa.org or 270-925-0195 no later than July 29th!

August 1st thru August 31st Education Fair This is a great service so get your order in!

Pick out your Educational item and send info to Carla at info@gradsa.org Carla will place orders the first week of September. Remember there is a \$35 limit and this includes shipping. You may also order for teacher or therapist. If you are new to GRADSA please contact Carla at info@gradsa.org or 270-925-0195 to get more information on this great opportunity.

August 20th Think First and Stay Safe Webinar Logsdon Center 6:00 p.m.

A guide to prevent sexual abuse, abduction, bullying, school violence, etc. This is for parents. It is also for all individuals with special needs. Please help us spread the word. Presented by Sidney Hargrave from Holly's House. Don't miss! RSVP by August 16th to Carla at info@gradsa.org or 270-925-0195

September 4th WBKR Yard Party This was a great and fun outreach event last year.

We need volunteers for the day of and to help pass out flyers to businesses before the event. If you can help please contact Carla at info@gradsa.org or 270-925-0195. Thanks so much.

September 26th Buddy Walk McConnell Plaza Check out info inside.

We have a new fundraising website and it's awesome. We need lots of teams this year so please be thinking about this. For more information see inside of newsletter.

October 24th Fall Family Fun Night Reid's Orchard 6:00 p.m. -9:00 p.m.

This year it will be at Reid's Orchard. Lots of games, hayride, food, etc. Don't miss out on the fun! RSVP to Carla at info@gradsa.org or 270-925-0195 before October 21st!

December 5th Christmas Party Bellevue Baptist Church 6:00 p.m.

As you all know this is one of our biggest and nicest events. Make sure you attend for a great time and a wonderful opportunity to meet our families. RSVP to Carla by November 30th at info@gradsa.org or 270-925-0195.

December 11th Parents Night Out Logsdon Center 6:00 p.m. to 8:30 p.m.

We will have food, movies and games. Perfect chance for a nice dinner out or that last minute Christmas Shopping. Siblings welcome. RSVP to Carla by December 8th at info@gradsa.org or 270-925-

Comments from Carla...

Hello Everyone...

WOW, I cannot believe the year is half over. Where does the time go? Thanks to the families that went to the playgroup at Simply Therapy and a special thanks to Simply Therapy, we appreciate you so much! We are gearing up for Buddy Walk. There are some big changes this year so please read all the information inside, your emails and Facebook! Please remember this is our biggest fundraiser and we need your help! I hope everyone had a wonderful and safe 4th of July! I'm looking forward to Special Olympics softball. My favorite sport! Thanks to Christie Ashby and Heather Hensley for updating us on new families. Sure hope to hear from these families soon. We had a great meeting with the NICU at Owensboro Health so hopefully this will help in reaching out to new families also. Remember, if there is an educational event you feel we need, please let me know. Hope to see you all soon.

Board News...

The GRADSA Board would like to thank everyone who has stepped up and joined the Programs, Fund-raising, Communications, Grant and/or Buddy Walk Committee. We appreciate your help so much.

Per our Strategic Plan we are 'adding more committees in 2015. We are counting on our families, extended families and friends to please step up and volunteer. We cannot do this without you. If interested or have any questions please contact Carla at info@gradsa.org, 270-925-0195 or any board member.

We are excited to welcome new board member Ralph Blair. Ralph is the Director of Internal Audits at Owensboro Health. He attended Owensboro Catholic High School and Kentucky Wesleyan College. Ralph married Michele in 2009. They have 2 children Macie and Ross. We are extremely excited to have Ralph as he will be a great asset.



Congratulations to board member Ashleigh Bottoms. Ashleigh and Sean welcomed their first child on June 8th. Andrew Grayson Bottoms weighed 7 lbs. 9 oz. and was 20 1/2 inches long.



Congratulations to board member and GRADSDSA family member Haylee Hay. Haylee and Matt welcomed their 3rd child on May 31st. Parker Elizabeth Hay weighed 8 lbs. and was 20 inches long. Porter and Preslee will be great siblings!



Congratulation to GRADSA family member Jacklyn Goodall. Jacklyn and Jesse welcomed their 3rd son on July 1st. Holden Reed Goodall weighed 9 lbs. 4 oz. and was 21 inches long. Mason



Congratulations Graduates...



1. Peyton VanMeter
2. Tyler Lamar
3. Paxton Hocker

**GRADSA is so proud of you!
Way to go Class of 2015!!!**

Update on Anna Sue...

Sweet Anna Sue Maurice is doing great. She is off ventilation and is eating for the first time. Puree food but she is loving it! She had her 3rd dilation and her esophagus did not stay open as hoped. They injected steroids and will have another dilation the week of July 13th. On a good note, Anna Sue was moved to out patient on July 11th! Poor Cindy and Anna Sue have been in Boston since April 22nd. Cindy has shared so many pictures. Boston Children's Hospital does look like a great place and they have made lots of friends. Please keep this wonderful family in your prayers as Sweet Anna Sue continues to get better. Can't wait until they are home!



In our Community...

Big story in the newspaper about Puzzle Pieces on June 25th and guess who made the cover? Jonah Edge and Ethan Smith. We were so happy to see them. Great pics guys! Thanks for making our day and Good Luck to Puzzle Pieces on their Capital Campaign!



Did everyone see the great picture of Kim Johnson in the paper on June 20th? Kim is Special Education Director for the city schools and local coordinator of the Daviess County Special Olympics. It was a wonderful story for a special needs ministry they are starting at Owensboro Christian Church. Kim will be leading "Special Connections" which will serve children and teens with special needs and is open to the public. The first phase of the ministry launched in April and is called the Buddy Program. It partners volunteers with children that have special needs ages 3 through 12th grade. The volunteer takes them to the appropriate Next Gen group during the 9:45 a.m. worship service. Inclusion is their first priority and with the child having a buddy with them, they are able to participate and interact with their peers in many ways. The second phase coming in September, is the Growth Group for adults with special needs. Their Bible study classes will have modified curriculum geared to their needs and there will also be a social component. The third phase coming in January will offer respite care for parents every other month. As the ministry grows they want to find ways for the children to serve in the church. It is all about helping all children reach their full potential. Interested in volunteering? Volunteers must be eighth grade thru adult. They must attend training class and commit to partnering two to four times a month. Volunteers and individuals with special needs do not have to be members of the church to participate. For more information or to volunteer, call Russ Smith at 270-683-2706.

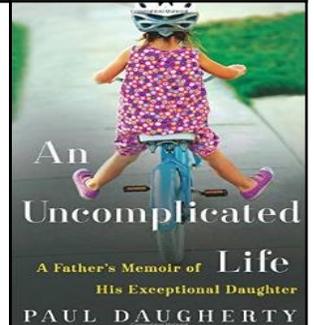


Photo by Jerry Seeb, Messenger Inquirer (jerry.seeb@messengerinquirer.com, 693.1724)
Kim Johnson is all smiles Thursday while talking about the new Special Connections ministry for children and teenagers with special needs at Owensboro Christian Church.

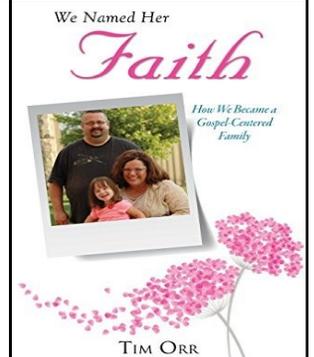
Recommended Books...

Below are 2 books that have been recommended. We will be ordering and adding to GRADSA's library. We usually add educational books so this will be a little different path. If you want to borrow once they come in just let Carla know at info@gradsa.org or 270-925-0195. Sure hope you enjoy them.

An Uncomplicated Life: A Book Review-IDSC 06/03/15. Oct. 17, 1989 was a game changer for Paul Daugherty. On this day his second child, a daughter that he and his wife Kerry would name Jillian, was born. Jillian was born with Down syndrome and would challenge everything that Paul knew about raising a child and being a father. A sportswriter by trade, Daugherty tells the story of raising Jillian in his new book. There is no shortage of memoirs on the market but there are not enough books out there from a father's perspective. Daugherty's memoir about raising his daughter Jillian is a moving and beautiful tribute that takes us from Jillian's birth (his family's "last bad day") up through today where Jillian is an independent and strong-willed young lady with a full life. The book is well written and full of perfect analogies and relatable anecdotes. The book delves into the world of therapies, special education, IEPs and helping his daughter transition to life as an adult. Telling a rare side of the story from a father's perspective, moms and dads alike will enjoy this well-written, funny and caring book from Paul Daugherty.



Tim Orr is the proud father of Faith, his adopted daughter, who happens to have Down syndrome. It has been an amazing journey for him and his wife as her parents. He has recently written a book entitled *We Named Her Faith* that has appeared on Amazon's best-seller list. It's a story of their lives before and after adopting Faith and shows how their life experiences prepared them to be parents of a child with special needs. Looking back, it is amazing the experiences that life will bring. Some of those experiences are memorable like the moment of your first kiss, the time you buy your first home, or the moments you welcome your children to this world. Other experiences are far more mundane like the daily routine of going to work or maintaining household responsibilities. All of our life experiences combine to form a story. In this book, he tells the story of their family which includes their beautiful baby girl. They share how God has guided their personal experiences every step of the way to prepare them to be Faith's parents. They hope their story will inspire you as it reveals the very hand of God orchestrating events serving His purposes and displaying His glory.



The majority of our information is sent by email and on Facebook so let's get connected! Don't miss out!!! Are you on Facebook? Like GRADSA at www.facebook.com/GRADSA
PLEASE send your emails addresses to Carla at info@gradsa.org or 270-925-0195.

GRADSA Buddy Walk...

GRADSA's Buddy Walk will be September 26th. We will be located at the McConnell Plaza across from the Hampton Inn. This will be a much more contained area so that we can have a better count of how many people we have plus the games, agencies, etc. will be together opposed to all spread out. We sure hope this is a great improvement.

Have you created your team page yet? Remember this is for families, extended family, friends, schools and businesses. Be sure and personalize your page with a picture and a story about your Down syndrome journey. Set a goal and watch it grow as you share your page on FB and through emails to colleagues, friends, family, therapists, teachers and medical professionals to help raise funds and awareness. Watch FB and your emails for more creative fundraising ideas to help reach your goals. And, of course, the website has ideas too. If you need any help setting up your page please contact board member Scott Sullivan at scott@ffponline.net or Carla at info@gradsa.org. Don't forget this website is www.ds-stride.org/gradsabuddywalk or you can link to it from the homepage of www.gradsa.org

We want to give a huge Shout Out to our teams that have already been created. Thank you so much for your support of GRADSA. We could not do it without you. Congratulations to Adrienne Free. Adrienne won tickets to ROMP for having her page created by June 15th! Congratulations to Mitchell Hensley. Mitchell won Holiday World tickets for having at least \$100 in donations by June 30th. Our other incentives are: Everyone that has a \$1,000 in donations by August 31st will be put in a drawing to be on the 2016 GRADSA Billboard and everyone that has \$4,000 in donations by September 21st will receive an iPad. Starting the week of July 20th we will be highlighting teams that have been created with a picture and short story thru FB and email so be on the lookout. Our Corporate Sponsor Packet is complete. If you have any company that is interested in supporting GRADSA the packet is available on our Buddy Walk website or you can contact Carla at info@gradsa.org.

Don't forget you can also register on our Buddy Walk website to avoid lines the day of event. You will have to register to receive wristband which will be required to eat. We will have our usual hot dogs and grilled bologna sandwiches plus we will have pork burgers this year.

T-shirts will be \$10. We will not have very many the day of event so be sure and reserve yours when you register. Volunteers may also sign up online. You will then be contacted by our volunteer co-coordinator. A special thank you to all of our volunteers, we could not do an event of this size without you.

IRS Proposes New Rules for ABLE Accounts... Disability Scoop 07/05/15

Six months after a federal law paved the way for tax-free savings accounts for people with disabilities, officials are providing details on how they expect the new program to operate. In a proposed rule issued Monday, the Internal Revenue Service unveiled guidelines for the Achieving a Better Life Experience, or ABLE, Act. The federal law is designed to allow people with disabilities to save money without risking their government benefits. The proposal offers specifics for the first time on how the new accounts should function and clarifies what types of expenses money saved in an ABLE account could be used for. Advocates say they're pleased that the IRS took a lenient view in determining what counts as "qualified disability expenses" under the law. Though the ABLE Act mandates that money can be used for specific purposes including transportation, housing and education, the law also allows for "other expenses" and it is up to regulators to determine what should qualify. "The Treasury Department and the IRS conclude that the term 'qualified disability expenses' should be broadly construed to permit the inclusion of basic living expenses and should not be limited to expenses for items for which there is a medical necessity or which provide no benefits to others in addition to the benefit to the eligible individual," the proposal states. The view that expenses must merely offer a quality of life benefit for a person with a disability — rather than be of medical merit — is significant, said Heather Sachs, vice president of advocacy and public policy at the National Down Syndrome Society. "We're glad to see that a person with a disability would not have to justify the purchase of an iPhone or something similar as a medical expense," Sachs said. Other details within the proposal are causing concern, however. The reporting and oversight requirements outlined go beyond those governing 529 college savings plans that the ABLE accounts were modeled on and could make the disability savings vehicles onerous to administer or utilize, advocates and state officials say. "As I read the proposed regulations, every time individuals with disabilities want to spend even a single dollar of their money, from their own ABLE accounts, they have to file paperwork with the state demonstrating that each is a 'qualified disability expense,'" said Nebraska State Treasurer Don Stenberg. "This is a slap in the face of Americans with disabilities, is an unreasonable and unnecessary burden on them, and will create administrative burdens that will increase the costs qualified individuals will need to pay to use the program." The proposed rules will be up for public comment for 90 days before the IRS issues final regulations. In the meantime, several states are working to make the ABLE Act a reality for their residents. Despite the federal law, each state must put their own regulations in place before making the accounts available. Currently, the ABLE Act has been enacted in 22 states, according to the National Down Syndrome Society. Each of these states, however, is still working out details related to administering the program. Sachs said she expects that states will likely wait for the final IRS rules to be issued before allowing financial institutions to begin offering ABLE accounts.

Sleep Apnea . . . Cincinnati Children's Hospital

This LIVE event online is a great opportunity to learn more about Sleep Apnea from experts in the field. All you have to do is go online and RSVP then join in on July 23rd at 6:00 p.m. The online address is: <https://liveevent.cincinnatichildrensblog.org/events/uac-sleep> or you can also look for the post on GRADSA's FB page on July 10th and connect there. Make sure you RSVP soon!

About This Event

Cincinnati Children's offers this live, online question and answer session on chronic obstructive sleep apnea in children with Down syndrome, Pierre Robin syndrome or micrognathia. During this event, our co-hosts, Raouf Amin, MD, and Stacy Ishman, MD, will answer questions from you and other families online, in real time.

About Chronic Obstructive Sleep Apnea

Children with Down syndrome, Pierre Robin syndrome and micrognathia are more prone to chronic obstructive sleep apnea due to structural issues associated with these conditions, such as a small jaw, low muscle tone or an enlarged tongue. Chronic obstructive sleep apnea means that your child's breathing may start and stop during sleep. This is treatable, but should be addressed as soon as possible, as undiagnosed sleep apnea can lead to delayed growth, behavioral problems and other medical issues.

There are a variety of surgical and non-surgical treatment options for children who experience sleep apnea as a result of Down syndrome or a craniofacial abnormality. Treatments may include CPAP ventilation therapy, medication and / or surgery to correct the cause of the sleep apnea. We encourage parents to consider further evaluation if their child continues to experience sleep issues after treatment.

The Upper Airway Center at Cincinnati Children's is one of the only centers in the country that focuses on sleep issues in children with craniofacial anomalies and Down syndrome. Our team specifically focuses on complex cases to improve the quality of life for these patients. Our specialists come together from different disciplines, including ENT, pulmonology, radiology, plastic surgery, genetics and developmental and behavioral pediatrics. Specialists attend a weekly meeting to review each child's case and discuss the care plan.

Presenters

Raouf Amin, MD, is the director for the Division of Pulmonary Medicine.

Stacy Ishman, MD, MPH, is the surgical director for the Upper Airway Center

PLEASE, PLEASE, PLEASE—Kroger's Community Rewards...

Kroger Cares Reloadable gift-cards are being replaced with Kroger Community Rewards. This is a wonderful change and if everyone will register it can produce big rewards for GRADSA. All you have to do is have a Kroger's reward card which I think 95% of us do. Go to www.kroger.com/communityrewards. If you already have an online account just enter your User ID and password then you will type in Green and one of your options will be Green River Area Down Syndrome Association. Click it and submit. If you do not have an online account simply register then search for Green and when Green River Area Down Syndrome Association comes up, click it and submit. If your information for your rewards card is not current you can update it at www.kroger.com or call 1-800-krogers, option #3. **You will have to go in on a yearly basis to update your organization or GRADSA will no longer receive rewards from your card.** This is a wonderful and very easy fundraiser for GRADSA. Please register your card and share with friends and family. If you have any questions or need any help please contact Carla at info@gradsa.org or 270-925-0195. Go get on those computers and register your card NOW! **GRADSA thanks you in advance.**

Holiday World 2015...



So proud of everyone at the State Olympics 2015...



Happy Birthday!!!

JULY

03 Abbey Garvin
 05 Taylor Palmer
 09 Shelby Crook
 14 Caron Posey
 15 Shawn Riney
 18 Sam Fenwick
 20 Dana Hamilton
 26 Will Graves
 30 Alan Bennett

August

10 Justin Hagan
 11 Ethan Smith
 20 Aaron Shoemaker
 20 Beth Wilson
 21 Sam Rutland
 22 Luke Stone
 23 Brent O'Nan

September

04 Mitchell Hensley
 09 Isaac David Ramsey
 10 David Fogle
 11 Kelsey Dueker
 11 Ashley Pinkston
 13 Raven Paulson
 16 Kaleb Warman
 18 Alyssa Toerne
 20 Ruby Galindo
 21 Denise Howard
 26 Elias Jorge
 27 Trevor Brown

“This is the day which the
 Lord has made:
 Let us rejoice and be
 glad in it.”
 Psalm 118:24

Happy Birthday!

If your child's birthday is not in the newsletter then please let Carla know the date at info@gradsa.org or 270-925-0195. We are missing several birth dates. We honestly hate to leave anyone out. Thanks so much.

GRADSA's Cuties Summertime Fun...



Pool fun with Colin Powers, Elizabeth Stickler and Jonah Edge! Looking good!



Paige Jackson got to go to the ocean. Hope she had a great time!



Matthew Cook with Mickey Mouse at Disney World. FUN!



Lexxi Jones went to the beach! Such a Diva!



Leland Isbill got to meet Morgan Freeman at Blues Camp. What an honor!

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.

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.



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