

Heart Strings



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



Volume 16 July-August 2014

UPCOMING EVENTS

July 24th Support Community Living Logsdon Community Center 6:00 p.m.-7:30 pm

Medicaid Waiver Program for moving to independence. Recommended for all parents as there is a long waiting list. Several providers will be present. Contact Carla at 270-925-0195 or info@gradsa.org to RSVP. No later than July 21st.

July 25th WBKR Cookout Box Lunches for sale. Also have raffle tickets for Big O Music Fest

We will sale box lunches and raffle tickets from 11:00 am—1:00 pm We need volunteers for set up, during event and clean up. Please contact Carla at 270-925-0195 or info@gradsa.org. Spread the word

August 1st Pack to School Swim Party Cravens Pool 5:30 p.m.—8:30 .p.m. This is always a fun event and you don't want to miss Gary & Jonathon Estes' grilling! YUM! YUM! RSVP to Carla at 270-925-0195 or info@gradsa.org no later than July 25th

August 9th Bluegrass in the Park Henderson, KY GRADSA will have a booth and provide a kids game. Come out and visit us. To volunteer to work the booth contact Carla at 270-925-0195 or info@gradsa.org

September 11th Dietician to speak on Healthy Heart, Celiac, etc. Join Beth Cecil from Owensboro Health

September 27th BUDDY WALK Smothers Park. Check out information in this issue!

October 17th Fall Family Fun Night. Trunnell's. More details to come.

October 26th Dad's Night Out Buffalo Wild Wings

November 13th Massage Therapy Class. Presented by Donna Kealin

December 6th GRADSA Christmas Party at Bellevue Baptist Church. More info to come

December 13th Parents Night Out

MOM'S NIGHT OUT WAS SO MUCH FUN!!!



EDUCATION FAIR

Educations Fair will be August 1st thru August 31st. Get your orders to Carla at 270-925-0195 or info@gradsa.org. The limit is 1 item per family and 1 item for teacher or therapist. No more than \$35 per item to include shipping.

Comments from Carla...

Hello Everyone...

I hope everyone is having a great summer. So happy with our Holiday World turnout. We had 51 families and had a great time. Thanks to all of you that came and I hope you had as much fun as I did. If you receive this newsletter in time I sure hope to see a lot of you at the WBKR Yard Party. Come show your support for GRADSA and share with your friends and family. Raffle tickets for Big O Music Fest and Box Lunches will be for sale. We will have the Balloon Twisters there and face painting. We have the Pool Party coming up August 1st so RSVP now. GRADSA is now in Buddy Walk mode. Check out the inside of this newsletter for more information. We had 5 families to go to the National Down Syndrome Conference this year and will share some of that great information with you in future newsletters. Love you all!

New Families...

GRADSA is excited to welcome the Peach Family. Richard and Kay Peach are the proud parents of Preston Peach. Preston was born March 4th. Preston has 3 siblings, Dalton 12, Reece 11 and Isabel 6. We look forward to getting to know all of them. Isn't Preston a cutie?



GRADSA is excited to welcome Anna Sue Maurice. Anna Sue is the precious daughter of Cindy Wimsatt And John Maurice. She was born May 26th. Anna Sue has one sibling, Haley. Can't wait to meet this wonderful family. She is so beautiful!



Are you on Facebook?

Like GRADSA at

www.facebook.com/GRADSA

PLEASE send your updated emails, phone numbers, etc. to Carla at info@gradsa.org or 270-925-0195. A lot of our information is sent by email so let's get connected!

Mail Chimp We are now sending emails thru Mail Chimp so please do not delete them.

GRADSA will soon have a new website. We hope you all will visit.

Children are valued for their Special Abilities... SpecialEDPost 07-14-14

By: Stephanie Pratico

Many parents have or will experience the joy of their high school senior receiving college acceptance letters. In my list of dreams for my children, that falls somewhere toward the bottom. When my son John, 20, and my daughter, Sara, 15, were born with Down syndrome, I knew the likelihood of receiving even one college acceptance letter may not be a reality. However, the day John received his letter of acceptance for Team New Jersey in the 2014 Special Olympics USA Games, I believe I experienced the equivalent. Over the years, I have spent countless hours in doctors' appointments, IEP meetings and on the phone with various State agencies, discussing my children's diagnoses, limitations and challenges. Fortunately, after shedding many tears, I realized early on that although it is important to recognize the areas of development that need support, those are not what define the wonderful people my children are. Although John was fortunate to reach some of his developmental milestones with minimal delays, Sara's road was much more difficult. John actually learned to walk at 16 months, and Sara was over three years old. In spite of their varying abilities, we were at home at Special Olympics. Special Olympics is where we go for sports training and competition. My children need to be in a place where despite their disabilities they are among their peers, can have the same experience as any other child and are valued for their special abilities. It is so wonderful to have a place in the community where we can be a 'typical' family. Regardless what sport or event they are in, our family sits in the stands, or often stands anxiously on the sidelines — cheering and jumping and sometimes praying — just like any other parent. It is hard to describe how that feels because it was never certain when they were born if they would live to see their first birthday because of their medical issues. When you begin to raise a child with special needs, especially one with chronic medical needs, it is very easy to get caught up in what is emergent, you almost simulate a firefighters approach. Then one day, someone walks into your life from Special Olympics and makes you remember that part of being a child is just that: being a child. Having fun, playing sports and building friendships. The people and programs at Special Olympics have enabled John and Sara to experience that.



What Makes You Different is What Makes You Beautiful... Huffington Post 02-02-14 By: Megan Griffo

Tara McCallan wants her little girl to know that different is beautiful. Her 1-year-old daughter, Pip, has Down syndrome. Pip and her 2-year-old brother, Noah, are the stars of their mother's blog, [Happy Soul Project](#). This week, McCallan sent pictures of Pip to HuffPost Good News' Facebook page: "I think [this picture's] message is so very important," McCallan wrote. She told the Huffington Post that, with these pictures and her blog, she wants to spread awareness about Down syndrome and also "be a voice or open someone's eyes to how to approach others [who have loved ones] that are beautifully different." "I want people to know that my daughter is just that," McCallan said. "My daughter." Go to: www.HappySoulProject.com to see more great pictures!



Special Thanks...

The GRADSA Board and especially our Committee Chairs would like to thank everyone that has stepped up and joined the Programs, Fundraising or Buddy Walk Committee. We appreciate your help so much. If anyone else is interested in helping please contact Carla at 270-925-0195 or info@gradsa.org

Author with Down Syndrome publishes first book...SpecialEdPost 06-03-14 By: Jordan Gribble



Living with Down syndrome isn't easy, but 21-year-old Sean Adams is finding happiness through a positive outlook and a supportive family. The Larose resident tells that story his newly published book, "I am Happy to Be Me." "It talks about my life with Down syndrome and shows others what life is like with Down syndrome," said Sean, who lives with his parents, Melisa and John Adams. "Some people don't accept their disability. But I think everyone should know that I'm glad I have my disability. It's a gift from God that should not be taken for granted." Down syndrome is a condition that someone is born with that causes below average mental abilities and problems in physical development. Taking inspiration from the deaf and blind Helen Keller, who even with her disabilities was able to write 12 books during her lifetime, Sean says he too wants to give a voice to the voiceless. "Some kids with disabilities, they don't speak up, and they need a voice. I write to be a voice," he said. Sean began writing the book as a freshman at South Lafourche High School. It began slowly at first. But finally with hard work and the guidance of his godmother, who is also a published author, Sean was able to complete the book. "When he first started writing he wanted to write big novels like 'Harry Potter.' We told him that he'd have to narrow it down to a page at a time. We said that when he could write a couple of sentences that make sense we could move on from there. One day he was with his godmother, and they sent it off and the publishing house agreed to publish it," Melisa said.

FYI: GRADSA has ordered this book for our Resource Library. Please contact Carla at 270-925-0195 or info@gradsa.org to put your name on the list to check it out!

Winning Racer to fundraise for Down syndrome research...SpecialEdPost 05-27-14 By: Michelle Boudin

NASCAR driver David Ragan was of course on the track Sunday hoping for another big win. But we caught up with him as he got ready for the race to talk about something that's just as important to him – his big brother. The winner of Talladega last year, David Ragan seems most at ease with his family around – including big brother Adam – who has Down syndrome. "When I won the race at Talladega last year, Adam missed it," David told us. His brother chimed in, completing his sentence. "I missed it!" Mom Beverly says her sons have always been close, the whole family really. "We are and that's very important. We came from a small town, my husband always liked sports so we're just all in it together," Beverly told us. The Ragan brothers have both had success with cars. Adam works hard at the family dealership. "He stays busy selling cars," David says. Adam, again jumps in. "I was busy selling cars!" "How many cars or trucks have you sold this week," asks Adam. "Whole bunch of them," says Adam. "How many," insists David. "I can't count," replies Adam. Next month the brothers will hit the road together with their whole family – competing in a road rally to raise money for Down syndrome research. "Having an older brother with Down syndrome is something that we've had to live with our entire life and we've seen the good things and we want to share that with other families."



BUDDY WALK 2014...



Mark your calendars for the 17th Annual Buddy Walk, Saturday, September 27th from 11:00 am to 1:30 pm at the beautiful Smothers Park. Contact Carla Renfrow at 270-925-0195 or info@gradsa.org to volunteer for this event.

GET INVOLVED BE INSPIRED

Help GRADSA and Start Fundraising Online-Form a Team for the 2014 Buddy Walk

Design

- *Register at www.active.com/donate/gradsabuddywalk2014
- *Customize your team page
- *Upload a photo of your Buddy
- *Set a Goal

Publish

- *Email link of your team page to friends and family
- *Get the word out on Facebook and Twitter
- *Send out email reminders to your team throughout the entire process

Manage

- *Keep people involved with Fundraising Goal
- *Encourage friends and family to donate online

Fundraise

- *Set a goal for yourself and your team
- *The team who raises the most money online this year will receive a Pop Up Tent with their own reserved spot at the BUDDY WALK**
- *Any questions on setting up a page on active giving or regarding fundraising please call Renea Estes at 270-791-8838

GET INVOLVED, BE INSPIRED

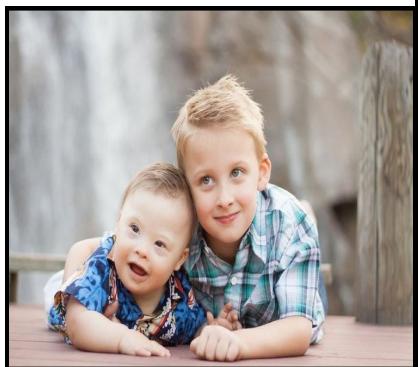
The Buddy Walk Silent Auction is a huge part of our fundraising. Would you like to help? We need GIFT BASKETS to be donated. If you can donate a Gift Basket please contact Carla at 270-925-0195 or info@gradsa.org

Thanks you so much for all you do.

My Son with Down Syndrome is Everything I Never Knew I Wanted...

By: Smoyer July 21st, 20014 Idaho

Colton was born on September 12, 2012. He was a big baby. But I already knew that. He had a full head of hair, and after months of heartburn, I knew that too. He also had Down syndrome and that, I did not know. Over the course of Colton's life thus far, I have learned so many things. I have met; I have inspired; I have been inspired; I have cried; I have been mad; and I have cherished, with everything that I possess in me, my son, who has Down syndrome. When we first started this journey together, there was nothing that could have prepared me for the heartache, the fear, or the suffering that would take hold of me when the doctor first spoke those words. And neither could the speaking of those words ever prepare me for the beauty, the joy, or the overwhelming love that I feel for my child. The first things I think about when I wake up in the morning are my sons, and the last things that wonder across my thoughts as I am drifting off to sleep at night are my sons. They are the light of the universe to me, though they are as night and day to one another. It was only after reflection however, that I was able to overcome the pain that Colton's diagnosis brought to me and to my family. I had to fight to regain control of everything that I thought mattered most importantly in life. It felt as if I had simply been struck down, flattened by some impossibly large tide that swept me far, far away from the place I thought I belonged to. But I was wrong. Once I climbed out of that maelstrom, I found myself standing in stranger waters. But there was something different there. The light was just a little bit softer, the sounds a little bit louder. But the imagery, the landscape was constantly changing. In one moment everything was clarity and sunshine, and in others it was hail and furious storm clouds. I spent weeks shouting myself hoarse, screaming, pleading, begging with...the air maybe, to come and rescue me. I hid from the colors and I hid from the powerful landscape that was all around me because it was so fierce in comparison with where I had come from. But eventually I had to stop hiding, I had to come out or I would have sat in the dark forever, never understanding or fully realizing what had just happened to me. So I stepped out, and I faced the storm. I clambered out of that dark pit and I brought myself up to face whatever dark and terrible thing was going to ruin my life for good here, in this strange place. But nothing ever came. No terrible monster ever shot out of the dark, no big bad beast ever showed its face. There was nothing in the dark places, nothing at all, but me. I was putting myself there, and if I wanted to be free of them, I just had to walk away. So I did. I realized that there would be stormy days with my son, as there would be stormy days with his brother. I also had to force myself to realize that there will be just as many sunny days, and I cannot abide by slinking about, sad-dening myself over an idea that has passed me by. Particularly when the one that stuck was so much better. I will raise my son to the best of my ability, with my entire family at my back. Together, we will give Colton everything that he will ever need in life, and in return, we will get his smiling face, his big brown eyes, and his love and affection. Is this not what every parent expects of their children? Remi will have the same opportunities, the same love and devotion, the same wonderful memories, and some of them will be exclusively between the two of them. I could not have asked for a better family, we fit like pieces to a puzzle. There are some days when I look at my sons, either of them, and ask myself how I got along without them in my life. It's stunning to think that Remi is already in school, and Colton is already nearing two years old! My heart feels as if it were about to burst sometimes, picturing the road we have taken, and imagining the journey yet to come. I know that one day soon these moments will just be memories, and I will find myself astonished, horrified, breathless and out of words as I realize that my boys are grown up. Then I have to laugh, because this means that one day I will be saddened at the loss of these days. How ironic that I will soon covet the memories that we made here when not so long ago I was a hopelessly emotional wreck, sobbing my fears and sadness that my youngest was just a little bit different. With time comes wisdom, I suppose. I have taken such a winding journey that I wonder if everyone does this, or if I happened to take the scenic route. So many ups and downs and confusing states of mind that I cannot count them all, but as I look back over them, I realize they were all leading to one place. I was always going to be okay. When I gave birth to Colton all I could think about, over and over, was how his life was going to turn out. How my life was going to be. Everything seemed so terrible, dark and ugly. I could not wrap my mind around the situation; much less fathom a happy story for us. I understand now that it was only the shock talking. Almost two years later I am the happiest I have ever been in my life, and my sons are entirely to thank for that. My husband has stood at my side and we have grown closer and stronger than ever before because of the fear we faced together. Is this not what we strive for in life? I am today a much stronger, wiser, educated individual, and I would never have made it this far without the shove that Colton's birth gave me. I would never have dreamed of creating a platform like Special Miracles, not in a million years. But now that I have, I am saddened to think that if Colton had been born as anybody else, I would never have done it. I would never have met all of the wonderful people that have become a part of my life, or made some of the friendships that only happened because I was thrown into that circle of people by his diagnosis. It would be like losing a limb. How has this never been a part of my plan to begin with? Life, certainly takes some strange and unexplainable twists, but where you wind up is half the surprise, I suppose. It has been a magnificent journey for me thus far. It doesn't make a lot of sense. How could something that started out so terrifying become this, which is so delightful that I simply do not have the words to describe it? I don't have an answer for that, but I do have some words for any other parent who is going to go through it, or is in the process of going through it now. That feverish, crushing despair will end. You will be happy again. Your child will light up your world, even if it takes time for you to see it. Some events in life far outstrip the others when it comes to how deeply they affect us, and Down syndrome is high on that list, but it doesn't bring the world to a stop. Take it as a new direction, a fork in the road where you have a choice. You can be defeated, or you can defeat it. However you do that is entirely up to you, but there's a reason that medical advances, medications, and laws pertaining to Down syndrome and other conditions like it are improving. More and more parents are choosing to fight, and along the way they are making strides in overcoming the stigmas and setbacks associated with raising a child with special needs. The diagnosis does not define your child, they will define what it means to have Down syndrome as they grow. And when the day comes where you wake up and realize that it just doesn't matter as much as you thought it would, walk with your head high because you've done something many people claim they could never do themselves. You've beaten the most frightening monster of all. Your own fears.



HOLIDAY WORLD 2014...



GRADSA's AWESOME FAMILIES AT HOLIDAY WORLD

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
27 Joseph Clements
31 Charity Loudon

August

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

September

02 Jeff Rhinerson
04 Mitchell Hensley
09 Isaac Ramsey
10 David Fogle
11 Kelsey Dueker
11 Ashley Pinkston
13 Raven Paulson
16 Kaleb Warman
18 Eli Rose
18 Alyssa Toerne
20 Ruby Galindo
21 Denise Howard
21 Paige Roberts
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!

Hometown Cuties...



Sweet Preslee Hay and awesome big brother Porter. GRADSA siblings are the BEST!

Send your pictures to Carla.atfo@gradsa.org



What a beautiful young lady Adrienne has grown into. If she loses any more weight there will be nothing left of her. Love you Adrienne!



WOW, wasn't it just yesterday that Levi was an infant??? Look how big and cute he is now! Miss you Levi!

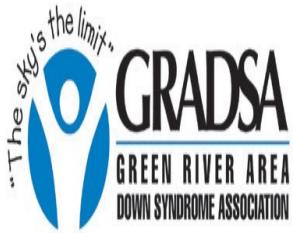


Paige Roberts became an Aunt to Emmet Gabriel Roberts on July 1st. Emmet is one lucky guy to have Paige for an Aunt. According to Kathy, Paige's mom, Paige loves and kisses on Emmet all the time but does not like his crying. She told her sister Brett to "fix it!"

**CONGRATS
TO
PAIGE
ROBERTS**

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.



GRADSA
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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.

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