

Heart Strings



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

Volume 18 November-December 2014

UPCOMING EVENTS

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

Our Annual Christmas Party is always a nice and fun event. Sure hope to have a great turnout. We have moved venues this year! **RSVP by Nov. 28th** to Carla at info@gradsa.org or 270-925-0195

December 13th Parents Night Out 6:00p.m.-8:30p.m. Logsdon Center

We will have food, movies and games. **RSVP no later than December 9th** to Carla at info@gradsa.org or 270-925-0195

January 8th Massage Therapy presented by Donna Kealin Logsdon Center 6:00 pm

Don't miss out on this great workshop. **RSVP no later than January 3rd** to Carla at info@gradsa.org or 270-925-0195

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!**

GRADSA has a new website. Still have changes and things to add but check it out!

WATCH FOR OUR 2015 CALENDAR OF EVENTS !!!

Comments from Carla...

Hello Everyone...

Buddy Walk 2014 is over and we are already discussing Buddy Walk 2015. 2014 was a huge success, see more information inside this newsletter. We had a great time at Trunnell's again this year, thanks so much to everyone that came and shared their Friday night with us. Halloween Hoe Down with SOKY was a blast! We have some great pictures inside. We just had our first social in a while and it was really fun. Hoping to build these during 2015. I hope everyone is ready for our Annual Christmas Party. We will be at Bellevue Baptist Church this year. This event is always a great time. Can't wait to see everyone. Hey Parents, don't forget our Parents Night Out on December 13th. This is a great time for last minute Christmas shopping or just time to relax and have date night.

We are excited and looking forward to a great 2015 with our GRADSA family. The Program Committee is working diligently to plan the activities and events for the coming year. We are putting speakers in place and will include topics that will be of interest to both new parents and the seasoned parents of children with Down syndrome. We are also scheduling our Social events for 2015. If you have a topic or event you would like to see covered please let us know.

Most of all, we on the board would like for you to know that we are working for YOU, our families. Please email us at info@gradsa.org with any suggestions or concerns. We look forward to seeing you all in the coming year!

Special Thanks to our Buddy Walk Corporate Sponsors...

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Wells Health Systems
Growing Minds Learning Center

River Valley Behavioral Health
American Electric Power
Mandy Crawford Family Practice
Pediatric Dentistry of Owensboro
Commonwealth Family Pharmacy
Almost Home/Care Tenders

Best Buddy

Likens Plumbing
IGA
Simply Therapy

Beckman Tire & Auto Center
E.M. Ford & Company
DNJ Auto Parts & Sales

Audubon Federal Credit Union
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Woodard Cooling & Heating

New Board Member...

GRADSA Board is excited to welcome Mark Pfeifer.

Mark is an attorney with Jacobs & Pfeifer, PSC. Mark is married to Holly and they have 6 wonderful kids-Paul, Natalie, Annie, Maria, Luke and John. Mark serves or has served on the boards for Catholic Charities for the Diocese of Owensboro, St. Vincent De Paul and Immaculate Parish. Mark was advised that GRADSA was looking for an attorney to join our board and he knew GRADSA is a great organization.

WELCOME MARK!



We Are More Alike Than Different Awareness

GRADSA is happy to say we received 13 letters for our "Awareness Project". The following will have their picture on a billboard. The billboard will direct everyone to our website where there will be a 2-3 minute video of that individual. Congratulations to Mitchell Hensley, Michael Smith, Dana Hamilton, Matthew Huston, Leland Isbill and Sam Winstead. We will run two billboards per month from mid-February thru mid-May. The rest of our individuals that sent in letters will be featured in the big video. The big video will be 15-20 minutes and will be sent to all schools in our counties and to the police and fire departments. Thanks so much to everyone who sent in a letter. They were all wonderfully written.

Volunteers Needed...

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. We would love to have more committee volunteers. If anyone else is interested in helping please contact Carla at 270-925-0195 or info@gradsa.org

GRADSA's 17th Annual Buddy Walk...

2014 Buddy Walk was a huge success and THANKS so much to everyone that attended, volunteered, raised money, etc. We could not do it without you! We raised \$60,518.30 which is amazing! With the Strategic Plan this year our goal was to raise fundraising by 10%. We raised it by 23.2%!!! The majority of this increase was from our teams. We hope to build on that in the future. Again, THANKS so much to everyone! Enjoy just a few of the pictures below. You can see hundreds of pictures on our website www.gradsa.org or our Facebook page www.facebook.com/GRADSA. Please LIKE our page while you are there.



GRADSA has some t-shirts left. The colors were awesome and very popular. Because the event is now over we are selling them for \$10.00. Contact Carla or any board member if you would like to buy one.



Kroger's Community Rewards...

GRADSA NEEDS YOU HELP, PLEASE TAKE THE TIME TO DO THIS!

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.**

4 Apps to help teens and adults learn community skills ...

Does your older child need help improving their community and vocational skills? How about social skills in the community? Teenagers and young adults function better in their community by targeting literacy skills, social skills, expanding vocabulary, sequencing, problem solving and improving overall communication. With the use of the iPad, working on community skills has become even easier and more accessible than in the past.

1. **Community Success** - This app includes many different categories including Getting Around, At Home, With People, Out Shopping and Around Town. Each category, includes subcategories with steps (for sequencing), a story and a video. For example, within "Getting Around," there is a topic about riding in a car. For that particular topic, there are the steps to riding in the car, story and video. Each story includes questions in the end. Community Success Free is available and allows you to try the app before purchasing it.
2. **Social Success** - Social Success is similar to Community Success in that the format is similar but it focuses more on the social interaction within the community, school and vocational program. It even has a topic named "Using Technology" which discusses cell phone and texting etiquette with videos and questions included. Within each category are several subcategories which include an introduction, steps, self-talk, a movie and problem solving questions. This is an excellent app to own and use for a variety of goals both in school, day habilitation/vocational program, and at home. Social Success Free is available and allows you to try the app before purchasing it.
3. **Read to Learn** - Read to Learn helps emphasize literacy within the community. If you have a child who struggles with reading, getting around the community can be difficult. With this app, keywords are emphasized and functional words are reviewed. The app is sectioned into three categories. Life Skills Readers, Focus on Feelings and Safety Skill Reader. Each category includes several stories that give you the option of reading to yourself or having the book read to you. This app can help build stronger community and literacy skills.
4. **Between the Lines Advanced (Apps for Speech, Language & Auditory Development)** - This app helps to improve abstract language, problem solving, interpreting social cues and inference skills related to vocational work and the community. The videos are age appropriate and functional which makes this app extremely helpful for teenagers and young adults who struggle with social skills, abstract language and interaction within the community and relationships. A Lite Version is also available for trial before purchase.

Obstructive Sleep Apnea and Down Syndrome...

Sally Shott MD at Cincinnati Children's Hospital...www.downsyndromensw.org

What is "Sleep Apnea"?

Sleep apnea occurs when you stop breathing as you sleep. In adults, an apneic event occurs if you stop breathing for 10 seconds or more. In children, an apneic event occurs if you stop breathing for two or more respiratory cycles. (The length of respiratory cycles varies for children of different ages.) "Obstructive" apnea occurs when breathing stops because of some type of upper airway obstruction, although the abdominal and chest muscles still move in an attempt to breathe.

Why do people with DS have a higher incidence of Obstructive Sleep Apnea than other people?

People with DS have a higher incidence of Sleep Apnea because of anatomical differences related to having DS. For instance, the hypotonia or poor muscle tone that may have been a problem during early childhood, also affects the throat muscles. For all of us, throat muscles relax when we fall asleep. However, this is more prominent in those with DS and more obstruction can occur. In addition, the obstruction tends to occur at multiple airway levels. Children and adults with DS also tend to have a smaller mouth and back of the throat, so that tonsils and adenoids take up more room, relative to the overall airway size. Because of the small oral cavity, the tongue takes up more room and easily falls back, obstructing the back of the throat. We have also found that the lingual tonsils, which are located at the base of the tongue, are often larger in those with Down syndrome. We all are born with lingual tonsils, but they are rarely a problem. They sit at the base of the tongue, just above the opening of the larynx, which is the top part of the windpipe. If the lingual tonsils are enlarged, they can obstruct the opening to the windpipe when sleeping, as the airway relaxes. There is also a higher incidence of adenoid re-growth, even if they have been removed before, in people with Down syndrome.

How is sleep apnea treated?

Sleep apnea treatment has made a lot of progress over the past 10 years and doctors continue developing better treatment methods. The most common surgical procedure is removing the tonsils and adenoids (T&A). This may cure the airway obstruction in most typical children and adults; however, this is not always the case for those with Down syndrome. My own experience shows that only one-third will have normal sleep studies after a T&A. Therefore, it is important to re-evaluate the sleep abnormalities with a post-operative sleep study.

If sleep abnormalities persist despite a previous T&A, the next step is determining where and at what level the airway obstruction still exists. Start with a good physical exam. In addition, at Cincinnati Children's Hospital, we use a cine MRI evaluation to evaluate the airway. We have found this to be very helpful in evaluating the child's airway, without radiation, during sleep and periods of airway obstruction. It is a dynamic evaluation of the airway that is useful in those with complex airway obstruction. Other ways to evaluate the residual obstruction include various x-rays as well as endoscopic examinations.

Further surgical treatment depends on the obstruction. Surgeries now can treat obstruction at the base of tongue, the lingual tonsils, the soft palate and even lower in the throat. Sometimes the adenoids regrow, even if they were removed in the past, and they need to be removed again. The results are sometimes quite good.

Nonsurgical medical options also are available. Weight loss is extremely helpful, especially if the child or adult is overweight. There are some oral appliances that help hold the tongue forward, but unfortunately children rarely tolerate them. There are also positive pressure treatments such as CPAP or continuous positive airway pressure. The positive airway pressure is supplied by either a facial or nasal mask or through nasal prongs. If used regularly, this treatment is very successful. However, it must be worn every night or it does not work.

Fall Family Fun Night at Trunnell's 2014...

Everyone had a wonderful time and what a beautiful night!



Halloween Hoe Down...



Happy Birthday!!!

November

08 Ana Lilia Sedillo
 10 Matthew Huston
 10 Elijah Hale
 18 Ben Pace
 25 Joey McAtee
 30 Steven Ballard

December

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

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

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

Happy Birthday!

Halloween Cuties...



Is that Dorothy or Hannah Hardesty?



Paige Jackson as Princess Anna!



Cowgirl Adrienne Free!



Fireman Landon Ashby with brother Dr. Parker!



Batgirl Lexxi Jones!

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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