

Heart Strings



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

Volume 19 January-February 2015



UPCOMING EVENTS

January 16th Dad's Night Out 6:00 p.m. Diamond Lanes South Fun night of Bowling

RSVP no later than January 14th to Carla at info@gradsa.org or 270-925-0195

February 7th Sibling Day Out 2:00 p.m.—4:00 p.m. Edge Ice Center

Join the fun and ice skating RSVP to Carla at info@gradsa.org or 270-925-0195

February 21st GRADSA & SOKY Valentines Dance for Teens and Adults

OMS North Campus RSVP to Carla at info@gradsa.org or 270-25-0195

February 28th Mom's Night Out 6:00 p.m. BUNCO at Logsdon Center

Come play BUNCO RSVP to Carla at info@gradsa.org or 270-925-0195

March 5th Massage Therapy presented by Donna Kealin 6:00 p.m. Logsdon Center

RSVP no later than March 3rd to Carla at info@gradsa.org or 270-925-0195

March 21st Color Blast 5K 8:00 a.m. Moreland Park

More information inside newsletter Please support !

March 21st World Down Syndrome Day Social More details to come!

GRADSA Needs Your Help! Our goal is to have an Education Event every month. We are currently scheduling Apps Smackdown, Sleep Apnea, Continuing Education/Employment and some 15 minute speakers during socials. We need a plan of communication to be sure we reach everyone and have a good turnout. Please let us know the following information:

- 1) Most effective way of communication?
- 2) What events would you like to see?
- 3) How often should we have events?
- 4) Any other information that would be helpful to us.

Please send this information to Carla at info@gradsa.org, 270-925-0195 or any board member.

Are you on Facebook? Like GRADSA at www.facebook.com/GRADSA PLEASE send your emails to Carla at info@gradsa.org or 270-925-0195. A lot of our information is sent by email so let's get connected!

Comments from Carla...

Hello Everyone...

Welcome to 2015, so hard to believe! Can't believe I have been with GRADSA since 2010 and what a great time it has been. I hope everyone had a wonderful Christmas and New Year. Our Christmas Party was one of our largest yet and everyone seemed to have a really good time. Thank you so much to all of our families that were able to come. Of course there are some great pictures enclosed. Be sure to visit our FB page or website to see all of them. We had a good time at "Parents Night Out". I feel so blessed to spend time with your children and that you trust me with caring for them. 2014 was an awesome year and let's make 2015 even bigger and better. Hope to see you all at upcoming events. Have a fantastic year!

Board News...

The GRADSA Board and especially our Committee Chairs would like to thank everyone who has stepped up and joined the Programs, Fundraising or Buddy Walk Committee. We appreciate your help so much. Per our Strategic Plan we are planning to add more committees in 2015. We are looking to possibly add Education Committee, Grant Committee and Volunteer Committee. We are counting on our families, extended families and friends to please step up and volunteer. If interested or have any questions please contact Carla at info@gradsa.org, 270-925-0195 or any board member.

We are so sad to see Allen Sabins leave the board. Allen was a huge asset and will be missed. Please read Allen's email to Carla below:

As you may have heard - my family and I are moving back to CT. That said, please see the attached letter requesting my resignation from the Board of Directors. A big thank you to you, and the other members of the Board for welcoming me with open arms, and allowing me to serve alongside each of you. I didn't realize what an impact the organization would make on me, and I look forward to sharing my experiences with friends and family back home. Continued success to you, the organization, and most importantly - the families and individuals it serves. If I can be of any sort of assistance remotely - please don't ever hesitate to ask.

Color Blast 5K...

It's almost that time again! Color Blast 5K will be March 21st at Moreland Park. You can register at www.colorblast5k.org or contact Carla for a paper registration. If you register to walk please join GRADSA's Gifted team. There will be a place on the registration form to list the team name. Don't forget, GRADSA's Gifted! Please remember this is National Disabilities Month and World Down Syndrome Day! If you are unable to walk then please consider volunteering. We need lots of volunteers to make this happen. To volunteer please contact Carla at info@gradsa.org or 270-925-0195. Don't miss out on all the FUN!

Fit with Friends...

Our Fit with Friends group at the Health Park has been a great success. We are looking at extending the program if we get more individuals that are interested in participating. If we continue there will be a few changes but not sure what those are at this point. Carla will be meeting with the Health Park to discuss. If you are interested in joining Fit with Friends please contact Carla at info@gradsa.org or 270-925-0195. Please feel free to speak with the families of Dana Hamilton, Michael Smith, Matthew Cook, Taylor Palmer, Paige Roberts, Sam Winstead, Elizabeth Stickler or Larry Basham if you would like to get their input. They have all been faithful attendees and we appreciate them.

New Adult Group...

We are looking at starting a new group for 21 years and older. We are hoping this will be approved at the next board meeting. We will meet every 6 weeks. The first meeting will be a social and then the following meeting will be a community project. We feel it is important for our adult individuals to give back after seeing all the support and volunteers they have seen over the years. Please be thinking of a neat name for this group. We also would love to have a couple mothers/fathers to help lead it. This will be to help lead the meetings and events but we are hoping the actual ideas and input will come from our adult individuals. Please contact Carla at info@gradsa.org or 270-925-0195 if you are interested in participating and/or helping.

Sibling Saturday...

For those of you that have liked our Facebook page then you have probably seen the Sibling Saturday Posts. This is a great way to share photos with our families. If your child has not been featured with their sibling then we probably need a picture or two. Please contact Carla at info@gradsa.org or 270-925-0195 so that we can add them to this fun, social activity. There are a couple that have Facebook but no pictures on your page of the siblings together so please contact Carla. We do not want to leave anyone out. Thanks so much!

GRADSA's Updated Funding Policies...

Education Conference Funding

PURPOSE: To encourage individuals with Down syndrome, their families and GRADSA leadership to continue their education through conferences, seminars, and extra-curricular activities. Funds are to assist with registration, transportation and other associated expenses.

WHO CAN APPLY: An individual with Down syndrome, a parent or legal guardian of an individual with Down syndrome or a GRADSA board/committee member.

HOW TO APPLY: Submit the following to GRADSA, PO Box 2031, Owensboro, KY 42302 or email to info@gradsa.org.

- Completed application form
- Receipts for which reimbursement is being requested

ADDITIONAL DETAILS: All requests are subject to funding availability and must be approved by the board prior to reimbursement. Requests must be submitted within 30 days of the date printed on the receipts or within 30 days following the event date. GRADSA will only reimburse for actual expenses incurred after the event has begun or has taken place. In addition, GRADSA requests that the beneficiary or their family submit or present a brief summary to the board of how the event was beneficial. Any conferences or seminars must be specific to the Down syndrome or Special Needs Community. Scholarships will be awarded between \$150-\$500, with priority given to those that can most adequately share their experience with the GRADSA com-

Travel Reimbursement Funding

PURPOSE: To financially assist GRADSA families and board members when traveling out-of-town for special Down syndrome events or medical visits. Funds are to assist with gas, lodging, food and other travel related expenses.

WHO CAN APPLY: A family affiliated and involved with GRADSA whose primary purpose for travel is for the family member with Down syndrome; or a board member traveling for a Down syndrome event that will enhance the mission of the GRADSA community.

HOW TO APPLY: Submit the following to GRADSA, PO Box 2031, Owensboro, KY 42302 or email to info@gradsa.org.

- Completed application form
- Receipts for which reimbursement is being requested

ADDITIONAL DETAILS: All requests are subject to funding availability and must be approved by the board prior to reimbursement. Requests must be submitted within 30 days of the date printed on the receipts. GRADSA will only reimburse for actual expenses incurred. Limit of \$400 per family per calendar year.

Applications for these funds are available on www.gradsa.org. For a printed copy please contact Carla at 270-925-0195.

Kroger's Community Rewards...

GRADSA NEEDS YOUR 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.**

Obama Signs Able Act... Dec. 22nd Disability Scoop

With his signature, the president has paved the way for people with disabilities to open tax-free savings accounts where they can amass more than \$2,000 without losing government benefits. President Barack Obama signed the Achieving a Better Life Experience, or ABLE, Act Friday before leaving Washington for the holidays. The new law will allow people with disabilities to open special accounts where they can save up to \$100,000 without risking eligibility for Social Security and other government programs. What's more, individuals can keep their Medicaid coverage no matter how much money is accrued in an ABLE account. Modeled after 529 college savings plans, interest earned on savings will be tax-free. Funds accrued in the accounts can be used to pay for education, health care, transportation, housing and other expenses. To be eligible, individuals must have a condition that occurred before age 26 and each person may only open one ABLE account. Under current gift-tax limitations, as much as \$14,000 could be deposited annually. People with disabilities may be able to start opening ABLE accounts as soon as 2015. However, some hurdles remain. While the new law alters federal rules to allow for ABLE accounts, each state must now put regulations in place — much as they have done for other types of 529 plans — so that financial institutions can make the new offering available. “We can't mandate that a state will create a 529, but given the lobby that we've seen, I think by the end of next year, I think we'll see this in every state,” Sen. Richard Burr, R-N.C., one of the measure's chief sponsors, said on a recent call with reporters. The law's name was amended in recent weeks to honor Stephen Beck, Jr., a longtime proponent of the bill who died unexpectedly in early December.

“Eli's Heart”, Organization...

GRADSA received an email form this organization and would like to share with our families:

I would like to introduce you to Eli's Heart, a 501 c3 organization that helps families with travel expenses associated with medical procedures. Our son Eli was born with Down Syndrome and has had several surgeries in his 2 years of life. We understand the future financial concerns for all families that have a child with DS, so we want to try to focus on supporting our community. For families that need to travel for surgeries, we provide plane tickets, hotel rooms, gas cards, meal cards, etc. Even though our website states our support is for heart surgeries, we are willing to support other procedures.

Casey Craig

President, Eli's Heart

Website: www.elisheart.org

Facebook: <https://www.facebook.com/pages/Eli-Heart/487016554665419>

Email: contact@elisheart.org

Special Education, Disability Programs Unscathed In Budget Deal...

Dec. 12th Disability Scoop

A spending plan making its way through Congress is a win for people with disabilities, advocates say, more for what it doesn't do than what it does. Most federal programs supporting people with disabilities will maintain level funding under the \$1.1 trillion budget deal, with a few areas seeing modest gains. The plan was approved by the U.S. House of Representatives late Thursday, as the federal government's existing budget was set to expire at midnight. Lawmakers also passed a temporary measure to give the U.S. Senate time to vote on the legislation that would fund most federal activities through Sept. 30, 2015. Following years of belt-tightening in Washington, advocates say that just maintaining steady funding for disability programs offers some relief. "Most of the programs that we track that support people with disabilities got level funding which we continue to say in this environment is a victory," said Jennifer Dexter, assistant vice president of government relations at Easter Seals. Under the deal, funding available to states under the Individuals with Disabilities Education Act will rise \$25 million and vocational rehabilitation will increase \$33 million. Other programs expected to see an increase include housing assistance, support for postsecondary programs for those with intellectual disabilities as well as autism and developmental disabilities efforts at the Centers for Disease Control and Prevention. However, most of the gains are too modest — generally less than 1 percent — to keep pace with inflation, warns Annie Acosta, director of fiscal and family support policy at The Arc. "Everyone is relieved when their programs don't get cut but this isn't just one year; it's been longer term," she said. "Even when you have level funding, you're losing money every year if you're not keeping pace with inflation."

Toymaker Wants Playtime To Be More Inclusive . . . Nov. 19th Disability Scoop

Mr. Potato Head is one of seven toys Hasbro is including in a new set of resources for kids with developmental disabilities learning to play. The maker of childhood classics like Mr. Potato Head, Play-Doh and Connect 4 is looking to ensure that kids with developmental disabilities know how to engage with its toys too. Hasbro Inc. said Wednesday it is introducing a series of online videos and other tools to help children with disabilities learn to play with seven toys in its lineup. The offering called "ToyBox Tools" is designed to help kids learn what each toy is all about, how to put the item together and presents children with alternative ways to engage independently or with peers. The initiative emerged from employees at Hasbro concerned that kids with developmental disabilities were losing out on valuable opportunities to connect with others through play, the company said. Hasbro officials described the effort as a pilot program and said they will continue to refine the tools, which are available online for free, based on feedback from experts and consumers. The company indicated that it may develop similar resources for additional visit www.toyboxtools.hasbro.com

Disability Champion Leaves Congress . . . Dec. 16th Disability Scoop

After 40 years on Capitol Hill, a U.S. senator who shaped the Americans with Disabilities Act is leaving his post. Sen. Tom Harkin, D-Iowa, is retiring at the conclusion of the year, after choosing not to seek re-election. The departure will leave disability advocates without their strongest ally in Congress. Often inspired by the experiences of his late brother Frank, who was deaf, Harkin has long prioritized the needs of people with disabilities, authoring the landmark ADA and pushing for legislation expanding opportunities for education, independent living, employment and physical accessibility. "Harkin's passion to create a world where people with disabilities live independently and are assured of basic equal opportunity has created a lasting and positive impact on the lives of millions of Americans with disabilities," said Mark Perriello, president and CEO of the American Association of People with Disabilities, who called Harkin the disability community's "number one champion in Congress." "I do not think anyone will replace Harkin, either in spirit or in actuality. I anticipate that many senators will take up various pieces of the disability agenda, but no one will take up the entire cause," Perriello said. Sen. Lamar Alexander, R-Tenn., who worked side-by-side with Harkin on the Senate's Health, Education, Labor and Pensions committee echoed that sentiment. "Sen. Harkin's legacy is secure," Alexander said. "He is the Senate's champion of Americans with disabilities. It'll be a long time before there's a greater champion of Americans with disabilities in this body and I salute him for that." Speaking on the Senate floor last week, Harkin urged his colleagues to continue his work. "We have made significant strides forward in changing America to fulfill two of the four goals of the Americans with Disabilities Act. These two are full participation and equal opportunity," Harkin said. "The other two goals — independent living and economic self-sufficiency — need more development." Specifically, he called on lawmakers to support expanded opportunities for competitive, integrated employment for people with disabilities, acknowledging that he hadn't done enough in that realm. And, he said more work is needed to further deinstitutionalization of people with disabilities by providing opportunities for "true independent living with supports." Harkin also lamented the Senate's failure to ratify the United Nations Convention on the Rights of Persons with Disabilities. "I don't think anything has saddened me more in my 30 years here than the failure of the Senate to ratify the CRPD," Harkin said. "I hope the next Senate will take this up and join with the rest of the world in helping make changes globally for people with disabilities." Noting that he once delivered an entire speech on the Senate floor in sign language, Harkin turned to just one sign to close his time in Congress, pausing to teach those in the chamber the sign for America. "All of us, interconnected, bound together in a single circle of inclusion with no one left out. This is the ideal America toward which we must always aspire," he said.

Christmas Party 2014...



Parents Night Out 2014...



Happy Birthday!!!

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

February

03 Jonah Edge
04 Levi Goodall
06 Lexxi Jones
06 Morgan King
07 Brett Duncan
14 Lindsey Spain
15 Michael Smith
17 Cody Trotter
18 Caleb Lancaster
18 Heather Sutton
24 Andrew Conway

March

04 Preston Peach
06 Tatum Edge
17 Matthew Cook
19 Elliott Williams
21 Adrienne Free
24 Sam Winstead
25 Brooklyn Griffith
28 McKenzie White

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

Happy Birthday!

Santa Cuties...



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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