

Heart Strings



Our children and adults with Down syndrome
are the heart of our organization and our most precious gifts.
Volume 9 May-June 2013



UPCOMING EVENTS

May 10th and 11th BBQ Festival GRADSA is thrilled to have a booth
We are selling raffle tickets for UK, UL and WKU Corn Hole
Board Sets and a nice Gas Grill with 4 Burners.
Come see us at our booth!

June 1st Social in the Park Yellow Creek Park, Shelter #2
12:00 p.m.—3:00 p.m. Food and drinks provided
Food, fun and socialing. Don't miss the FUN!!!
Please RSVP to Carla no later than May 29th at
270-925-0195 or info@gradsa.org

July 8th—July 12th I Can Shine Bike Camp Sportscenter
Taking participants and Volunteers
Contact Carla at 270-925-0195 or info@gradsa.org

We are scheduling more social events and education events. This information will be mailed out separately in a few weeks. Watch your mail for more information. It may be a regular sheet of paper tri-folded so don't accidentally throw it away!

May 29th—31st Apollo Football team is offering a Free Flag Football Camp for High School ages 14-22 with special needs. For more information contact Amy at 270-302-6496 or ampayne@walnutmemorial.org Game on Friday night at 6:30 p.m. Come show your support!

Comments from Carla...

Hello Everyone...

I can't believe it's time for a newsletter again, time flies when you are having fun! Color Blast 5K was such a good time and a huge success. GRADSA is honored to be a part of such a great awareness event. Can't wait until next year's 5K! We have a precious new baby boy born on May 29th. Will have more info in the next newsletter. Can't believe school is almost out, didn't it just start??? I hope everyone had a great Easter. Can't wait to see everyone soon, I miss you all.

From the Board...

We will be having a Social in the Park on June 1st. We encourage everyone one to attend. Besides eating, socializing and having a lot of fun we also want to discuss GRADSA's future and what you want us to provide. We were very disappointed in having to cancel our last Social and our Sibling Round Table due to 2 or less families signing up. We will share what we see in GRADSA's future and have a questionnaire for you to fill out. Please try to come and show your support. If you are not able to make it please let Carla know if you would like for her to email you a questionnaire. We appreciate your support and love you.

We are so sad to accept the resignation of Brenda Walker. We want to thank Brenda for her many years of service. Please read letter from Brenda below:

Dear GRADSA family,

After much thought and soul-searching, I have decided to render my resignation to the GRADSA Board of Directors. As many of you know, the past year has been a tough one on my family health-wise. While I truly enjoy community service, family needs take priority and difficult decisions have to be made. Please know that I did not make this decision lightly.

It has been my honor and pleasure to be a part of the Green River Area Down Syndrome Association for many years. I have enjoyed serving our GRADSA families and seeing this organization grow and flourish. More importantly, I have been blessed by the friendships that I've formed with the members of our GRADSA family over the years, and I hope these relationships will continue. I still plan to support and participate in GRADSA activities as time and family needs allow.

I will forever be an advocate for our loved ones with special needs and a cheerleader for GRADSA, in particular. I know that Carla and the dedicated individuals currently serving as directors will take GRADSA to new heights. I wish this board, each family member, and God's sweetest angels the very best life has to offer. You will always be in my thoughts and prayers.

Sincerely,

Brenda Walker

Color Blast 5K...

The first Annual Color Blast 5K was a huge success. We had over 4,000 participants which set the record for the largest 5K ever in Owensboro. We were able to donate \$15,923 to WHAS Children Crusade and each of the 6 organizations that hosted received \$7,949!!! How awesome is that? A huge Thank You for all of you that participated and volunteered. We could not have done it without you.

Save the Date: 2nd Annual Color Blast 5K will be March 22nd, 2014

Registration will open after Thanksgiving

Friday After 5...

GRADSA is excited to share with you that we will have a booth at Friday After 5 to help raise awareness and share what GRADSA offers to our community. We will also be raffling off prizes. Show your support and stop by our booth on May 24th, June 21st, July 19th and August 16th. FYI: May 24th at Friday After 5 will be a non-profit block party so be sure to come and check out all the resources. We are looking forward to reaching out to the community and hope to see you there.

Self Advocate Corner...

My First Voting Experience, by Jenna Quigley-NDSC News Spring 2013

This year was my first time voting and it was in the presidential election. Let me tell you a little about myself. I am Jenna Quigley. I am 19 years old and a senior at Tucker High School and I want to tell you about my voting experience. At school, on Channel One News, I listened to the news broadcasters talk about the presidential election. They talked about both candidates and how they felt about things that matter to them and our country. I also watched the debates with my dad. This was not my first time at the polls. I have gone with my parents a lot of times over the years when they voted. This time was different because I was going to cast my own ballot! In order to prepare for this, my mother went on line to the Secretary of State's Office website and printed off DeKalb County's sample ballot so I could practice. I filled it out at home, so I could bring it with me in case I got too nervous when it was time to vote for real. On the day we went to vote, I was excited and nervous. I brought my State ID and my completed "draft ballot" with me. My dad had already voted early, so I went to vote with my mom. We decided to do early voting hoping we would avoid a very long wait, but we still had to wait in line with a lot of other people. The poll workers gave us some paperwork to fill out while we were in line and I could fill it out by myself because I practiced almost every day at school. After we filled out the paperwork and showed the poll worker our IDs, they checked us in. One of the workers asked me if it was my first time voting, I told her it was. She let me vote in a booth right next to my mom in case I had any questions but I didn't. After I voted, I put on my "I'm a Georgia Voter" sticker! Then when we were leaving, the poll worker made sure there was a big announcement to everyone still waiting in line that I was a first time voter. One of the workers even rang a pretend bell-saying, "Ding, Ding, Ding, first time voter" and pointed to me! I felt great. Everyone cheered for me as I left the building. I will definitely vote again!

About Jenna Quigley

Jenna Quigley has a business with her best friend, Donna Williams. They make greeting cards and sell them at conferences and online. She loves to sing, dance and perform. She has been in two productions with the Habima Theatre: *Happy Days* and *Guys and Dolls*. This year she will also be in a production of *Grease*. Someday she hopes to get a dance and music scholarship so she can be on stage and sing and perform in front of a big audience and have a solo.

To check out Jenna's business, visit www.justforyoucardart.com and become a friend on Facebook: Justforyoucardart!

First Climber with Down Syndrome Reaches Mount Everest Base Camp-specialEDpost, March 2013



A teen from Bend, Oregon made the history books by becoming the first person with Down syndrome to climb to the base camp of Mount Everest. Eli Reimer, 15, and his father arrived at Los Angeles International Airport to find a crowd of supporters waiting for him Tuesday night. The two returned to the states from Nepal after a successful mission to raise money and awareness for disabled children. Eli trained for a year before he and his dad set out on a two-week, 70-mile hike to reach the Everest base camp. The altitude was 17,600 feet. "I would say over 90 percent of the world's cultures don't accept disability and wouldn't think that somebody like my son would be able to attempt let alone complete something like this. So it was an amazing experience to do it with him. And like I said he actually led the way. We were dragging. We were experiencing our own sense of disability as we went up into the mountains and he led us all the way to base camp," described Eli's father, Justin Reimer. Eli is the first person with Down syndrome ever to stand on that spot.

Great Job Jenna and Eli!!!

Down Syndrome Fact Sheet...specialEDpost March 21, 2013

- ◆ Down syndrome is named after the British doctor John Langdon Down, who was the first to describe characteristics of people with Down syndrome in 1866.
- ◆ Down syndrome, or Trisomy 21, is a condition whereby there are three copies of the 21st chromosome instead of two.
- ◆ 25 was the life expectancy for someone with Down syndrome two decades ago. Today, the approximate life expectancy is 60.
- ◆ 1 in 691 births in the United States are affected by Down syndrome, making it the most frequently occurring chromosomal condition.
- ◆ More than 400,000 people in the U.S. have Down syndrome. It is estimated that 5 million people worldwide have Down syndrome.
- ◆ It is one of the leading clinical causes of cognitive delay in the world — it is not related to race, nationality, religion or socioeconomic status.
- ◆ Its probability increases with advanced age in mothers; however, 80 percent of those with Down syndrome are born to mothers younger than 35.
- ◆ 40 to 60 percent of children born with Down syndrome will have a congenital heart defect. More than 50 percent of those with Down syndrome will experience the early onset of Alzheimer's.
- ◆ It is extremely rare for a person with Down syndrome to develop a hard tumor cancer, to have a heart attack or to suffer a stroke.
- ◆ Despite its frequency, Down syndrome is the least funded of the conditions serviced by the National Institutes of Health receiving approximately \$17 million out of a total \$28 billion budget.
- ◆ Children with Down syndrome can read and are gifted visual learners. They have a predisposition to specific learning strengths and challenges that are not currently addressed in practice in special education.
- ◆ Improvements in care during the past 15 years have led to a 20-point increase in IQ for individuals with Down syndrome.

Don't Forget GRADSA Offers...

- ◆ Funding for Educational Conferences
- ◆ Traveling Reimbursement
- ◆ Resource Library

For more information and regulations on these services please visit www.gradsa.org or contact Carla Renfrow at 270-925-0195 or info@gradsa.org

GRADSA still needs your email addresses. Remember this is the best, quickest and most inexpensive form of communication. We also love to receive your stories and information so please send to Carla.

Statement from Down Syndrome Organizations Regarding Robert Ethan Saylor . . . NDSC April 16th 2013

Global Down Syndrome Foundation (Global), International Down Syndrome Coalition (IDSC), International Mosaic Down Syndrome Association (IMDSA), National Down Syndrome Congress (NDSC) and National Down Syndrome Society (NDSS) continue to share deep sadness over the tragic and preventable death of Robert Ethan Saylor. Each organization is addressing this situation in a manner keeping with their particular mission and all the organizations have been in close communication regarding various initiatives. We are all united in condemning this tragic death and to working together to uphold the human and civil rights of people with Down syndrome and their families. NDSC and NDSS have taken the lead in this case and have met with the local Frederick County affiliate, members of the Saylor family, and the U.S. Department of Justice. Those interactions are ongoing and seek to support the Saylor family, while preserving all options available to them, and, at the same time, to prevent tragedies like Ethan's death from occurring in the future. Later this month, following another round of meetings with the Department of Justice and the family, NDSS and NDSC will present a joint "town hall" teleconference to share more information regarding initiatives and proposals to prevent this from occurring in the future. We hear you. We are listening. And we intend to work as hard as we can, together, to prevent this from ever happening again. We need to stay united as one Down syndrome community that is focused on the bigger picture and justice for Ethan. See what we are doing and how you can help.

National Down Syndrome Congress – www.ndsccenter.org

National Down Syndrome Society – www.ndss.org

International Down Syndrome Coalition – www.theidsc.org

Down Syndrome Affiliates in Action – www.dsaia.org

Global Down Syndrome Foundation – www.globaldownsyndrome.org

International Mosaic Down Syndrome Association – www.imdsa.org

Down Syndrome Affiliates in Action, working in its role as a trade association, continues to support and respect the efforts of the other national organizations as all work diligently to address this issue.

Book Reviews...

When Down Syndrome and Autism intersect: A Guide to DS-ASD for Parents and Professionals: by Margaret Froehle, R.N. & Robin Zaborek. **Families who have a child with Down syndrome and a co-occurring Diagnosis of an autism spectrum disorder have a place to turn for information!**

Luck Dogs, Lost Hats and Dating Don'ts- by Thomas Fish, Ph.D and Jillian Ober, M.A., CRC. Stories include, "How to Find a Girlfriend" and "Dirty Dishes", about roommates learning to live together. These are interesting, everyday stories that will engage readers with engaging topics and large format photos.

The Boys' Guide To Growing Up: Choices and Changes During Puberty: by Terri Couwenhoven, M.S. Not many parents look forward to explaining what's going on during puberty to any boy, including those with developmental disabilities. This will be a huge help in navigating this topic! It contains very realistic drawings and uses simple and unsophisticated language. This will be a true life saver for many families.

Try Reading Again: How To Motivate and Teach Older Beginners, Age 10 & Up- by DeAnna Horstmeier, Ph.D. Try Reading Again provides tools to create age appropriate stories which will tap your self-advocate's interests. Current research shows that students are most successful and motivated when reading about their own experiences.

In Our Community 2013...

Congratulations Kelsey Dueker and Peyton VanMeter 2013 Prom Queens



Peyton VanMeter
OHS Prom Queen 2013
with
Prom King Josh Hicks



Peyton VanMeter
with date
Matthew Cook



Kelsey Dueker
DCHS Prom Queen 2013



Jon Whittaker
Dancing before
Weight Lifting
Competition
at Special Olympics

Sam Winstead's
Bowling Birthday Party.
How FUN!!!

Matthew Cook, Lukas
Mahoney, Sam Winstead,
Matthew Huston,
RayAnna Hutchins,
Leland Isbill
and Merek Justice.



Happy Birthday!!!

MAY

01 Mason Clark
04 Emily Stone
13 Colin Powers
20 Levi Wright
22 Amie Morris
25 Larry Basham
25 Amanda Eaton
31 David Leonard

JUNE

01 Neal Sweeney
15 Jason Snell
17 Tina Miller
18 Zeriah Allen
18 Chris Hagan
27 Joseph Clements
28 Caleb Francis

July

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



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

Psalm 118:24

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
P. O. Box 2031
Owensboro, KY
42302

info@gradsa.org
www.gradsa.org
270-925-0195

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 *HeartStrings* may be reproduced if credit is given to the original author and GRADSA. Permission to reprint articles not original to *HeartStrings* should be acquired from the original source.

Jonathon Estes, Interim President

Phone: 270-313-2111

Email: jestes@emford.com

Board Members:

Sara Vance (Interim Vice President)

Gary Estes (Interim Treasurer)

Tony Hamilton

Carla Renfrow, Executive Director

Phone: 270-925-0195

email: info@gradsa.org

Beth Ewing

Lori Marksberry

Lance Morris

Renea Estes

Sondra Gilbert

Sherry Cook

Non-Profit Org.
U.S. Postage
Paid
Owensboro, KY
Permit No. 120

