

Heart Strings



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

Volume 4 July-August 2012



UPCOMING EVENTS

July 12th GRADSA Social 5:30 p.m. Guest Speaker: Allan Mills Dinner Provided
RSVP to Carla at 270-0195 or info@gradsa.org by Tuesday, July 10th

July 16th-July 20th Lose the Training Wheels

Openings still available

Contact Carla at 270-925-0195 or info@gradsa.org if interested

August 15th thru September 15th Education Fair Each family can request 1 educational item for their child with Down syndrome with a limit of \$35. Your child's teacher or therapist can also request 1 educational item that will help your child, It is then theirs to keep for future students. Please find your item and send information to Carla at 270-925-0195 or info@gradsa.org and she will order.

September 22nd Holiday World Hours 11:30 a.m.—8:00 p.m. Part of Halloween Weekend

Splashin Safari Closed

Contact Carla at 270-0195 or info@gradsa.org no later than Aug. 20th to reserve your tickets.

October 20th Buddy Walk Smothers Park on the Riverfront

Comments from Carla...

Hello Everyone...

We had a great turnout and a wonderful time at the Pool Party. It was so good to see everyone. Check out the pictures inside. I do not have all the information to share at this point but we do have another new family. Watch for more news in next newsletter. I know I sound like a broken record but please send me your email addresses. This is the best way for updates and prayer requests. I know there are a lot out there that I do not have. It's almost time for Lose the Training Wheels and I am so excited. I do believe it is going to be a wonderful experience. Be sure and check out our infomercial for it on Owensboro Cable 75. It is also on my Facebook page. I will be having knee surgery but should not miss any events except maybe Holiday World so please get your reservations in no later than August 20th as we may have to mail tickets this year. Love all of you so much.

GRADSA Board Meetings...

GRADSA Board Meetings are now the second Monday of each month. They will be held at YMCA at 5:30 p.m. Everyone is invited. Hope to see you there.

Buddy Walk 2012 News...

Huge typo in the last newsletter, Buddy Walk will be October 20th (not 22nd) starting at 11:00 a.m. More information along with sponsorship sheets will be coming soon. We are hoping for a great turnout .

Volunteers needed for Buddy Walk...

A huge thank you to Sherry Cook and Sara Vance for chairing the Silent Auction. They are off to a strong start by collecting several baskets and even a couple Corporate Sponsors. Great job ladies! We still need volunteers to make this happen. We need leadership and helpers in Fundraising, Food, Volunteers, Publicity, Games, Entertainment, and Vendors. Come on guys, we can do this!!! Call Carla at 270-925-0195 or info@gradsa.org or any other board member to get involved. We Thank You.

Newsletter by email...

We still need people who would be willing to get their newsletter by email. This is the only way we can continue to do the newsletters every other month. Our printer will only print 300 if we have newsletters this often. We have about 360 on the mailing list and only 3 have agreed to receive by email. If this works for you please let Carla know at info@gradsa.org. Thanks so much for your co-operation as we really do not want to go back to quarterly newsletters.

Like Baseball? SOUNDS Down Syndrome Awareness Night at Greer Stadium...

August 17 is Down Syndrome Awareness Night at the Sounds ballpark in Nashville
Special features will include :

Special Down Syndrome Awareness Announcements throughout the game.

Self advocates throwing out the first pitch.

Nashville Sounds team wearing Down Syndrome Awareness Charity Jerseys to play.

Silent Auction featuring the Sounds' Down Syndrome Awareness Jerseys - win & get the jersey right off your player's back!

An exciting fireworks show when the game ends.

Bring your family and friends!

For more information on this exciting partnership with the Sounds or to purchase tickets, contact DSAMT at 615.386.9002, visit

www.dsamt.org or www.nashvillesounds.com, or email teri@dsamt.org.

Please take the time to read this...

Who Wouldn't Want a Child Like This?

By Beverly Beckham

The Boston Glove June 24th, 2012

She was born nine years ago on June 20, and it was the best of times and the worst of times. Lucy's being here was what we had prayed for, what we had begged for. But not exactly. Because she was not the child we had imagined. At first she was. Ten fingers, ten toes, blond hair and blue eyes. "Isn't she perfect, Mom?" my daughter said, cradling her new daughter. She is, I agreed. We were all smiles. It was the best of times. My daughter was happy. Life was good. Minutes later, everything changed. Trisomy 21, a doctor said. Down syndrome. And Paradise was lost. We had been in the Garden of Eden a mere 12 hours. Now we were in deep woods imagining quicksand and quagmires and animals ready to attack, our joy obliterated by fear. Where do we go? What do we do? How do we get out of here? Though not a single thing had changed. But we had changed. We now saw with different eyes. We saw what we were told to see. This was the worst of times. Nobody picked up Lucy and said, "Look at the miracle she is. Look at those fingers and toes. See how she stares at you. Watch how she kicks and coos. She will be fine. Your family will be fine." Nobody knew what to say. Friends hugged us. Nurses looked at us with sad eyes. The doctor unswaddled Lucy's blanket and pointed out the space between her big toe and her other toes, the single line on her palm and the skin folds near her eyes. All indicative of Down syndrome, he said. And where we had seen only perfection minutes before, we now saw only flaws. People with Down syndrome have low muscle tone, heart problems, hearing problems, digestive problems, and a higher incidence of childhood leukemia, he continued. When he finally left the room, we cried. Lucy did have heart problems. When she was 2 months old, she had surgery. Two months later, she was back in the hospital. She had a rough start. There have been other rough patches, not medically, yet hard, still, very hard, because it isn't easy being different. It takes Lucy a long time to learn. Her cousin, Charlotte, mastered doing a cartwheel last week in just one hour. It will take Lucy lots of hours. But she will do it. She's been singing "It's a Hard Knock Life" since she was 4. This year she sang it in a drama class. Last week she sang and acted it out on a stage with a group of children at a packed recital. Lucy does what she sets her mind on doing. It's hard to watch her work so hard at things that most kids learn by osmosis. But she plugs along, trying and trying, and succeeds just when we're about ready to give up, when we think she is never going to sip from this cup, say a full sentence, engage in a real conversation. And then she does. Lucy wakes up smiling every day. She always has. On long car trips, she sings away the miles. She knows when someone needs a hug. And when someone cries, she cries, too. If a child falls on a playground and wails in pain, Lucy sobs whether the child is a friend or a stranger. She is pure empathy. Who wouldn't want a child like this? Nine years ago, we shed a lot of tears worrying about the future. Now it is that future. And it is not a deep, dark, scary woods. Not always, anyway. Sometimes it's pink balloons and pink plates and pink napkins and a pink tablecloth and even pink frosting because it's Lucy's birthday and Lucy wants pink. Everybody's life has challenges. Lucy's has a few more. But Lucy's life is not a tragedy. Lucy's life is not a burden. Lucy's life is not what we were led to believe it would be: sad and joyless and not worth living. Her life is full of joy. Lucy is a happy child. She makes our lives worth living. She is not the child we imagined. Nine years ago we cried over this. Sometime we still cry. But not because Lucy isn't who we want. She is exactly who we want. We cry because Lucy is sweet and good and imaginative and kind and funny and caring, and the world doesn't see any of this. The world sees only a little girl with Down syndrome.

We cry now, not because of Lucy, but because of the world.

New Fund for GRADSA Families...Traveling Reimbursement Fund

To help GRADSA families financially when traveling out-of-town for a special Down syndrome event or medical visit. Funds are to assist in gas, hotels, food, etc. when traveling out-of-town for a special needs event or doctors appointment. GRADSA families with an immediate family member that has Down syndrome and the reason for traveling is for this person can apply. Submit the completed application form to GRADSA, PO Box 2031, Owensboro, KY 42302 or email to info@gradsa.org. All grants must be board approved and are subject to availability of funds. Limit of \$200 per family per year. Application on website or contact Carla at 270-925-0195 or info@gradsaa.org. GRADSA will only reimburse for actual expenses incurred. Please send receipts in and you will then be reimbursed. Must be submitted within 30 days of returning from trip.

Scholarships for individuals with Down syndrome seeking Higher Education or Enrichment Classes. Deadline to apply July 31st

Ruby's Rainbow is a nonprofit organization supporting the higher educational needs of individuals with Down Syndrome. Their goal for 2012 is to award scholarships to individuals with Down syndrome seeking higher education or enrichment classes.

If you feel you or your child will benefit from this opportunity, please submit the application with the designated essay, written by the candidate, two letters of recommendation and Parent/Guardian Information sheet by July 31st, 2012. One can also include videos, pictures or anything that may help us get to know the candidate better. The scholarships will be issued for the fall semester of 2012. Please include an e-mail address as you will receive an e-mail confirmation that we received your application.

You can e-mail the application and essay to Liz@rubysrainbow.org. You can also mail your application and anything else you feel will help us get to know you better to P.O. Box 153095 Austin, TX 78715. We look forward to hearing from, and learning all about, these amazing individuals!

For the application and more information go to www.rubysrainbow.org and click on "How to Apply"

Free Conference...

September 15, 2012

9:00 am to 4:30pm (CDT)

3rd Annual Western Kentucky Mini Parent/Professional Conference

Murray State University

Curriss Center, 1500 Chestnut St., Murray, KY 42071

Join us to learn about special education, learning strategies, legal rights and advocacy. This **free conference** will tell you what you need to know for your child's/student's education, from early childhood transitions through transition from high school! The goal of this conference is to provide practical information and tools to help you help your child/student become successful in school. We'll also provide you with timely local resources and networking opportunities. Parents, grandparents, caregivers, educators, providers, and therapists are all welcome to attend.

Free Gas Card for Each Family who participates (handed out at the end of the day),

Meal and Refreshments Included

Information Booths and Exhibits, & Door Prizes!

You can register at www.mywkec.org or calling Rhonda at the 800 number below.

For more information about the conference contact Rhonda Logsdon (rhonda@kyspin.com) at KY-SPIN by calling 800-525-7746 or Susan Clifton of the West Kentucky Special Education Cooperative at 270-809-6980.

Apple To Become More Disability Friendly . . . Disability Scoop June 12th, 2012

The iPhone and iPad will soon be even simpler to use for people with a wide range of disabilities thanks to a new software update. Changes designed to make the popular mobile devices more accessible are expected in a forthcoming update to Apple's iOS software. A new feature called "Guided Access" will be especially beneficial for students with disabilities by helping users to "remain on task and focused on content." The offering allows parents and educators to limit access on a device to one specific app by essentially turning off the "home" button and restricting areas of the touch screen that respond to commands. "We've been surprised by the number of children with autism who've been flocking to our devices, especially our iPads, and we want to make that experience even better," said Scott Forstall, the Apple executive responsible for the new software, in announcing Guided Access. In addition, the new software will include added screen reader functions to allow those with vision impairments improved access to maps and other features. Apple's devices have long been regarded as ahead of the curve in terms of disability access. But in unveiling the new software at the tech-giant's Worldwide Developers Conference in San Francisco, company officials are becoming increasingly overt in their emphasis on the disability market. Accessibility was highlighted as one of 10 key areas that will see improvements in the new mobile operating system alongside hallmarks like phone, email and Web browsing functionalities. The new software known as iOS 6 is expected to be available this fall as a free download for the iPhone 4S, iPhone 4, iPhone 3GS, the new iPad, iPad 2 and iPod touch (fourth generation).

Help NDSS for the July ABLE Act Challenge . . . DSMAT July 22nd, 2012

The ABLE Act currently has 166 cosponsors in the House and 22 cosponsors in the Senate... but we still need more cosponsors to help us pass the bill.

You can help us reach over 200 cosponsors in the House and 35 cosponsors in the Senate by July 31 (August Recess)!

Please take a few moments and send an email to support the ABLE Act TODAY. It only takes a few minutes and makes a huge difference!

House Contacts:

- Jennifer Debes in Rep. Crenshaw (Jennifer.Debes@mail.house.gov)
- Karen Summar in Rep. McMorris Rodgers (Karen.Summar@mail.house.gov)

Senate Contact:

- Jennifer McCloskey (jennifer_mccloskey@casey.senate.gov) in Sen. Casey's office

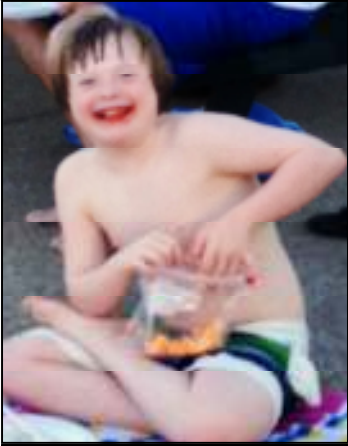
Important Announcement from NDSC & GDSF . . . NDSC June 15th, 2012

Since January, the National Down Syndrome Congress and Global Down Syndrome Foundation, in consultation with others, have been working on a "Down Syndrome Prenatal Testing Pamphlet." With the development of the early maternal blood draw screening test, the need for this information is greater now than ever.

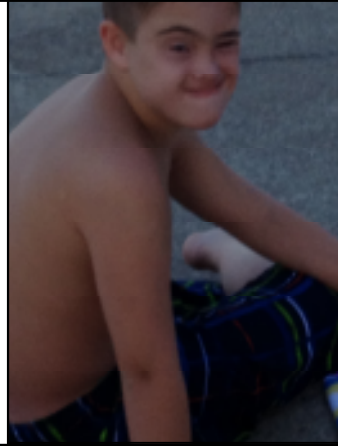
A draft of the pamphlet is available for review at www.downsyndrometest.org. Our goal is to have a final pamphlet ready to distribute by mid-July. Both print and online versions of the information will be free to physicians and patients.

This is very exciting news for the Down syndrome community. A 2003 Harvard research study revealed that a large majority of medical students and doctors feel unequipped to give a diagnosis of Down syndrome and know very little about the condition. Not surprisingly, many parents report that they have been given inaccurate information.

Pool Party was so much fun...



Matthew Huston



Sam Winstead



Landon Ashby



Paige Roberts



Elliott Williams



Andrew & Shelly Conway



Chapel Estes



Beth & Briley Ewing



Gary Estes



Michael Smith &
Dana Hamilton



The Ashby's



Sam Rutland

A Special Thanks to Jonathon and Gary Estes for cooking!!!

Happy Birthday!!!

JULY

5 Taylor Palmer
9 Shelby Crook
13 Abbey Garvin
14 Caron Posey
15 Shawn Riney
18 Sam Fenwick
19 Tyler Lamar
20 Dana Hamilton
26 Will Graves
30 Alan Bennett
31 Charity Loudon

AUGUST

3 Linda Murphy
10 Justin Hagan
11 Ethan Smith
20 Aaron Shoemaker
20 Beth Wilson
21 Sam Rutland
22 Luke Stone
23 Brent O'Nan
28 Keith Grant

SEPTEMBER

2 Jeff Rhinerson
4 Mitchell Hensley
9 Isaac Ramsey
10 David Fogle
11 Kelsey Dueker
13 Raven Paulson
16 Kaleb Worman
18 Eli Rose
20 Ruby Hidalgo
21 Paige Roberts
21 Alec Skipworth
21 Denise Howard
27 Trevor Brown

**“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 kids 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

Landon and Christie Ashby

Tea with Mom at Meadowlands Elementary School.
Such a precious picture and a wonderful family.

Please send me your pictures and stories for the newsletter. Look forward to hearing from you.





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.

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