



HEART STRINGS

A bi-monthly publication for families and friends enriched with the Down syndrome connection.

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

January/February 2008

Message from Executive Director

I hope each of you had a wonderful holiday! Just as the new year began, I came down with strep throat...again. As I complained my way through each ache and pain, I was reminded of the many children and adults with Down syndrome who must endure recurrent illnesses and major surgeries. Unfortunately, they are more prone to heart defects, respiratory problems, ear infections, hearing issues, sleep apnea, thyroid issues, dental concerns, and the list goes on. It can be overwhelming to the families who face these issues. On page 4-5, I have included the Health Care Guidelines for Individuals with Down Syndrome. Please review carefully and discuss any concerns with your health care providers. If you're like me, it's easy to put off those annual tests, especially when your child doesn't seem to have any symptoms, but it is so important to have them done.

Please keep the following individuals in your thoughts and prayers:

Tiffany Adams is 11 years old and lives in Morganfield. She was hospitalized on November 11 with pneumonia and influenza B. She spent nearly 6 weeks on a ventilator at St. Mary's and Kosair. She is currently in Rehab in Louisville. If all goes well, she will be home by the middle of January.

Heather Sutton is a 40-year old woman from Henderson. She has been hospitalized at St. Mary's in Evansville since December 26 with pneumonia.

Ben Pace is a 2-year old boy from Hopkinsville. He had open heart surgery to repair his Tetralogy of Fallot when he was just 4 months old. He requires a tracheotomy due to his pulmonary hypertension, tracheomalacia and laryngomalacia. Ben also has gastro-esophageal reflux disease, reactive airway disease, hypothyroidism, and requires a G-tube and nissen due to low weight gain and reflux. His mom hopes that the trach and G-tube will be removed within the next few months.

Jonah Edge is a 10-year old boy from Philpot who has heart issues and obstructive sleep apnea. Jonah had 3 surgeries in 2007 and may face additional procedures in 2008. His grandmother wrote a touching story (page 2) about the blessings Jonah has brought to her life.

Luke Stone, a 4-year old boy from Owensboro, who continues to require oxygen after a lengthy battle with RSV two years ago.

Robbie Sherrard, a 3-year old boy from Owensboro, who was recently diagnosed with sleep apnea.

Remember that GRADSA is here to help when your family is experiencing a medical crises. Please call if you know of someone with Down syndrome who is sick, hospitalized, or facing surgery.

I wish each of you a happy and healthy 2008!

Cindy Huston

Calendar of Events

Successful Learning Approaches, Saturday, January 19, 2008, 9:00 a.m. - 4:00 p.m. at Kentucky Wesleyan College (Rogers Hall in the Winchester Center). This workshop is co-sponsored by the Green River Area Down Syndrome Association and the Opportunities for Family Leadership/Department for Mental Health/Mental Retardation Services.

Presenter: Susan J. Peoples, an educator for 30 years, research clinician, author of **Stars of Success: Understanding How Children with Down Syndrome Learn**, and mother of a son with Down syndrome. This practical session will assist parents, teachers, and other service providers (OT, ST, DI) to understand the instructional needs of students with Down syndrome and other developmental delays. It will identify the instructional design needed to provide remediation for deficits in short and long term memory, transfer of learning, and concept development skills. **There are no registration fees to attend this workshop. We have applied for CEU's for Speech and Occupational Therapists. Teachers should request a certificate of completion. Please RSVP to Cindy Huston at (270) 771-4945 or email: info@gradsa.org.**

- 8:30 a.m. Coffee & Danish will be available
- 9:00 a.m. – 10:30 a.m. Identification of specific learning needs characteristic of children with developmental delays and their academic impact.
- 10:30 a.m. – 10:45 a.m. Break
- 10:45 a.m. – 12:00 p.m. Overview of six learning processes
- 12:00 p.m. – 1:00 p.m. Lunch (provided on-site)
- 1:00 p.m. – 2:30 p.m. Relating developmental stages to the scope and sequence of instructional design.
- 2:30 p.m. – 2:45 p.m. Break
- 2:45 p.m. – 4:00 p.m. Programming for individual student needs – handwriting, reading, and spelling.

Saturday, February 9, 7:00 p.m. - 9:00 p.m., Valentine's Dance, Owensboro Middle School Cafeteria, 1300 Booth Avenue (enter from side of building), Co-hosted by GRADSA and Special Olympics. Teens and adults with Down syndrome are invited to dance the night away.

In Sympathy

James Michael "Mikey" Castlen, 53, of Wendell Foster's Campus for Developmental Disabilities died Nov. 4, 2007. He was born Nov. 19, 1953, in Owensboro. He was preceded in death by his mother, Margaret Elizabeth (O'Bryan) Castlen. Survivors include his father, Joseph W. Castlen Jr. of Owensboro; a sister, Theresa O'Bryan and her husband, Charles, of Huntingburg, Ind.; five brothers, Joseph W. Castlen III and his wife, Kaye, of Owensboro, David L. Castlen and his wife, Barbara, of Boynton Beach, Fla., Thomas O. Castlen and his wife, Ann, of Owensboro, John G. Castlen and his wife, Michele, of Owensboro and Col. Stephen E. Castlen and his wife, Sue, of Fort McPherson, Ga.



A Grandmother's Love...by Judy Bittel



Almost 11 years ago, I walked into my daughter's hospital room, bursting with pride and love for her and my newest grandson. One look at Anji told me that something was amiss. She looked at me with pain in her eyes and said "Mom, sit down. There's something I need to tell you. But I need you to be strong. I'm barely holding on and if you break down, you'll take me with you. Mom, Jonah has Down syndrome."

Every negative emotion I was capable of feeling rose up to overtake me. Shock, denial, anger and hurt. How could something like this happen to our family? What cruel joke had fate played on my darling daughter, her husband and two other children? Why? What were we going to do? We didn't know anything about Down syndrome. I knew Anji needed me to be strong, but how was I to do that, when at any moment I felt I would collapse under the hurt. I hurt for Jonah. I felt he had been "cheated" of all the good things life could offer. I hurt for Anji, Larry and the other children, for I felt they had been "cheated" of their son and baby brother. I hurt for myself, because I feared I didn't have the strength that I knew Anji needed for me to have.

As we slowly became aware of Jonah's medical issues, I realized that only with strength from God could I hope to be what I knew Anji needed me to be. I asked God for the strength to be there for my precious grandson and his family. For the first time since Jonah's birth, I found peace with myself and with the fact that Jonah has Down syndrome. With this peace came the realization that Jonah's Down syndrome was secondary. Dealing with his medical

issues was far more important than Down syndrome. This was when I looked past the Down syndrome and saw just Jonah. Not Jonah with Down syndrome....but Jonah, the child. Needless to say, I fell hopelessly in love with this precious grandson of mine.

It hasn't been easy, with all the medical issues that Jonah has faced. But he has faced them, and conquered them. And with each new victory for Jonah, **MY** faith has been renewed. The medical hurdles aren't over yet, as he has many yet to face. I'm confident however, that with God in control, He and Jonah can conquer them all. Jonah is many things:

A challenge, because of his medical needs
A teacher, teaching us unconditional love and acceptance

Jonah has taught me to stop, see, and enjoy the beauty of simple, everyday things. To watch him splashing in the pool, to hear his gut-wrenching laughter, to see him watch in awe as a lightning bug flutters by, to see his total, unquestioning acceptance of everyone fills my heart to overflowing. And reminds me anew of the blessing that is Jonah. Yes, Jonah is a challenge, a teacher, and a wonderful blessing, but mostly....Jonah is just Jonah. Not Jonah with Down syndrome, just Jonah. With his big brown eyes, his sweet, trusting smile, and wonderful hugs and kisses. Jonah, who finds beauty in everything and in everyone.

Has Jonah been "cheated" of what life could offer? NEVER!! Jonah possesses things this world could never give to him, such as his ability to love and accept unconditionally, and the way he finds beauty in things that most of us never even take the time to see. No, Jonah hasn't been "cheated." Jonah's world is complete. Our family would have been cheated had God chosen not to send us the blessing of a little boy named Jonah.

Out-of-the-Box Reading Program

In November, GRADSA hosted an Out-of-the-Box Reading workshop presented by Denise MacDonald and Karen Evershed. Below are some key points from their website:

- * Studies have shown that children with Down syndrome can learn to read from a very early age.
- * Teaching your child to read early stimulates brain growth and instills the desire to learn.
- * Due to the fact that many young children with Down syndrome may experience significant hearing loss, many tend to become visual learners rather than auditory learners.
- * Reading enhances speech!
- * Teaching your child to read prior to integration in a school environment can ensure that they will not be left behind.
- * Increasing your child's vocabulary enhances their ability to succeed in social situations and facilitates their ability to express their wants and needs.
- * Teaching proper words and sentences via reading leads to the use of grammatically correct speech.

GRADSA paid for 50% of the program for the families who were present at the workshop. We have 2 programs in stock and can order additional programs if needed. If you are interested in finding out more about the program, please contact Cindy Huston.

The **Out of the Box Reading Kit** has been developed to make your job easy. It spells SUCCESS! It not only provides you with an organized plan, but it also provides you with everything you need to make it happen. You can learn more about the program and watch a video of Karen's daughter, Robyn, who has DS, reading (at 2 years old) at their website: www.outoftheboxreading.com

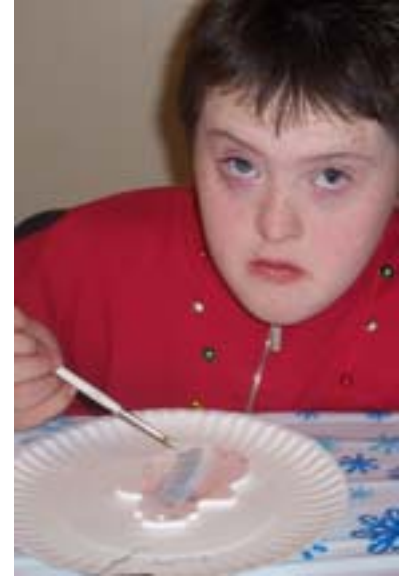
GRADSA members enjoyed the annual Christmas party with entertainment by Randy Lanham and Joe Christian.



Laura Whitfell played with her new whistle.



Cowboy **Mitchell Hensley** worked on his snow globe.



Kyrstyn Randolph paints a snowman ornament.



Buddies **Leland Isbill, Matthew Huston, and Sam Winstead** pose for a picture.



Ben Pace and his sister enjoyed their first GRADSA Christmas party.



Landon Ashby liked playing with the maraca.



Elliott Williams and Zeb Wells enjoyed playing with the drums.



Levi Wright colored a snowman with help from Dad.

Health Care Guidelines for Individuals with DS

The Down Syndrome Health Care Guidelines, compiled by the Down Syndrome Medical Interest Group, and specialized growth charts, assists families and medical professionals in providing appropriate medical and preventative care. They were designed to define for parents what is needed, so they can communicate with their primary care physician and say, "This is what is recommended. This is what we need to do." It is a helpful tool for physicians because it defines the medical vulnerabilities and the necessary screenings. Most pediatricians only care for a few children with Down syndrome in their practice, and although they may be knowledgeable about the current recommendations, they don't keep up-to-date in the same way as parents, who become experts about the needs of their children. In essence, parents need to be educated to be the educator for the physician.

Neonatal (Birth-1 Month)

- Chromosomal karyotype and genetic counseling, if necessary.
- If vomiting or absence of stools, check for gastrointestinal tract blockage (duodenal web or atresia or Hirschsprung disease.)
- Evaluation by a pediatric cardiologist including echocardiogram. Subacute bacterial endocarditis prophylaxis (SBE) in susceptible children with cardiac disease.
- Exam for plethora, thrombocytopenia.
- Review feeding history to ensure adequate caloric intake.
- Thyroid function test - check on results of state-mandated screening at birth.
- Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (at birth or 3 months).
- Pediatric ophthalmological evaluation (by 6 months) for screening purposes.
- Discuss value of early intervention (infant stimulation) and refer to enrollment in local program.
- Refer to local Down syndrome parent support group for family support and resources.

Infant (1-12 Months)

- General neurological, neuromotor and musculoskeletal examination.
- TSH and T4 - Thyroid Function Test (at 6 and 12 months).
- Evaluation by a pediatric cardiologist including echocardiogram, if not done at birth. Consider progressive pulmonary hypertension in patients with a VSD or atrioventricular septal defect who are having little or no symptoms of heart failure.
- Subacute bacterial endocarditis prophylaxis (SBE) as indicated.
- Well child care: immunizations.
- Feeding consult, especially if constipated. Consider Hirschsprung disease.
- Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (by 3 months if not performed previously or if results are suspicious).
- Ear, nose and throat exam (as needed), especially if suspicious of otitis media (ear infection).
- Well balanced, high-fiber diet.
- Vision exam (by 6 months and annually), earlier if nystagmus, strabismus or indications of poor vision.
- Discuss early intervention and refer for enrollment in local program (if not done yet).
- Application for Supplemental Security Income (SSI), depending on family income; consider estate planning and custody arrangements; continue family support.

Childhood (1-12 Years)

- TSH and T4 - Thyroid Function Test (annually).
- Echocardiogram by a pediatric cardiologist if not done previously.
- Behavioral Auditory Testing (every 6 months until age 3, then annually).
- Lateral cervical spine x-rays (neutral view, flexion, extension) to rule out atlanto-axial instability. Radiologist to measure atlanto-dens distance and neural canal width (at 3-5 years, then as needed).**
- General pediatric and neurological exam, including evaluation for signs of spinal cord compression: deep tendon reflexes, gait, Babinski sign.
- Use Down syndrome growth charts and head circumference charts, as well as growth charts for typically developing children.
- Eye examination (annually or more often as indicated).
- Screen for celiac disease IgA antiendomysium antibodies and total IgA (between 2 and 3 years).
- Question about obstructive sleep apnea; ear, nose and throat (ENT) exam as needed.
- Dental exam (2 years; follow up exams every 6 months after). Twice-daily teeth brushing.

Health Care Guidelines for Individuals with DS cont;

- Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) for cardiac problems (as indicated).
- Brief vulvar exam for girls.
- Well child care: immunizations, pneumococcal vaccine (2 years).
- Evaluation by a speech & language pathologist to maximize language development and verbal communication.
- Review parental concerns; current level of functioning; monitor for behavior problems.
- Continue speech therapy and physical therapy (as needed).

** Atlantoaxial dislocation refers to a weakness of neck muscles that affects approximately 10-20% of children with Down syndrome. Most cases are asymptomatic. A lateral cervical spine x-ray is recommended as a preventative measure against neck injuries for all children after age 2. If atlantoaxial dislocation is present, high-risk activities such as jumping, diving, etc. should be limited. In cases where symptoms are present, it can be surgically fused.

Adolescence (12-18 Years)

- TSH and T4 - Thyroid Function Test (annually).
- Auditory testing (annually).
- Cervical spine x-ray, as needed for sports participation.
- Monitor for obstructive airway disease and sleep apnea.
- General physical and neurological examination (check for atlanto-axial dislocation).
- Eye examination (annually).
- Monitor for obesity by plotting height for weight on the growth charts for typical children.
- Clinical evaluation of the heart to rule out mitral/aortic valve problems. Echocardiogram (ECHO) as indicated by clinical findings.
- Reinforce the need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adolescents.
- Adolescent medicine consult for puberty/sexuality issues; health, abuse prevention and sexuality education.
- Pelvic exam (only if sexually active).
- Low calorie, high fiber diet; regular exercise program.
- Smoking, drug and alcohol education.
- Psychoeducational evaluations (every 2 years) as part of Individualized Educational Plan.
- Begin functional transition planning (age 16 years).
- Monitor independent functioning.

Adulthood (More than 18 Years)

- TSH and T4 - Thyroid Function Test (annually).
- Auditory testing (every 2 years).
- Cervical spine x-rays as needed for sports participation.
- Ophthalmologic examination, looking especially for keratoconus and cataracts (every 2 years).
- Clinical evaluation of the heart to rule out mitral/aortic valve problems. Echocardiogram (ECHO) as indicated by clinical exam.
- Reinforce the need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adults with cardiac disease.
- Baseline Mammography at 40 years. Follow up every other year until 50 years, then annually.
- Pap smear and pelvic exam (every 1-3 years after first intercourse). If not sexually active, single-finger bimanual examination with finger-directed cytology exam. If unable to perform, screen pelvic ultrasound (every 2-3 years). Breast exam (annually).
- General physical and neurological examination (check for atlanto-axial dislocation); routine adult health care.
- Clinical evaluation for sleep apnea.
- Low-calorie, high-fiber diet. Regular exercise. Monitor for obesity.
- Health, abuse-prevention and sexuality education. Smoking, drug and alcohol education.
- Clinical evaluation of functional abilities (consider accelerated aging); monitor loss of independent skills.
- Neurological referral for early symptoms of dementia (decline in function, memory loss, ataxia, seizures and incontinence of urine and/or stool).
- Monitor for behavioral or emotional changes and/or mental health problems. Psych referral (as needed).
- Continue speech therapy and language therapy, as indicated.

* Based on Health Care Guidelines for Individuals with Down Syndrome: 1999 Revision (Down Syndrome Preventive Medical Checklist).

A Reason to Celebrate

GRADSA invites its readers to share their reasons for celebrating! Please send your submission to P.O. Box 2031, Owensboro, KY 42302, or email: info@gradsa.org



Congratulations to **Lela and Scott Hale** of Hopkinsville on the birth of their son, **Elijah**, who was born on November 10, 2007, weighing 4 pounds, 1 ounce and 15 1/2 inches long. Elijah was welcomed by siblings Shea, Cole and Michael Hightower, Kobie Simmons, and Alex, Zach and Gracee Hale.

Elijah was the hit of the Christmas party, dressed in festive attire and posing with his new teddy bear.

We welcome them to the GRADSA family.



The Special Olympics State Bowling Tournament was held in Lexington on December 1, 2007. **Larry Basham** (middle) of Owensboro was a member of the team who came in 1st place. The local Special Olympics took a delegation of about 38 athletes from the Daviess County area for the competition. They were coached by Louise Brown and Genny Honeycutt.

Meadowlands and Burns Elementary Schools held their own Buddy Walks to honor students who have Down syndrome. Meadowlands raised \$216 and Burns raised over \$300 to benefit GRADSA. Thanks for your support!



Survey

Please take a moment to complete the survey below so that we can better serve our members. Your input is very important to us. You can mail the completed survey to P.O. Box 2031, Owensboro, KY 42302, or email your answers to info@gradsa.org, whatever is most convenient for you. We appreciate your feedback!

1. Which of the following applies to you? Immediate family of an individual with Down syndrome
 Extended family (grandparent, aunts, uncles, etc).
 Educator or Service Provider (OT, ST, PT, DI)
 Health Care Professional
 Friend

2. What are the issues most important to you? Education
 Medical
 Communication
 Social
 Recreational
 Independent Living
 Employment

3. What types of educational workshops would you like to see offered? _____

4. What social activities does your family enjoy most? Do you have any suggestions for improvement for current activities, including Moms and Dads Night Out? Would you like to see different social events added?

5. Have you ever been to our website? If yes, was it helpful? Comments: _____

6. Please rate your overall opinion of our newsletter: Excellent Good Fair Poor
Please list the sections you enjoy most: _____
What type of items would you like to see featured in Heart Strings? _____

7. What is your overall opinion of GRADSA and its impact on families and the community?
 Excellent Good Fair Poor
Comments: _____

Jan/Feb Birthdays

Landon Ashby, 2 years old on Jan. 4
Erin Clark, 31 years old on Jan. 20
Andrew Conway, 10 years old on Feb. 24
Isaiah Cruz, 4 years old on Jan. 23
Ashley Dant, 21 years old on Jan. 22
Jonah Edge, 11 years old on Feb. 3
Ashley Hagan, 11 years old on Jan. 21
Kathleen Kight, 4 years old on Jan. 24
Morgan King, 5 years old on Feb. 6
Caleb Lancaster, 10 years old on Feb. 18
Shannon Mahoney, 38 years old on Jan. 12
Michael Smith, 26 years old on Feb. 15
Lindsey Spain, 25 years old on Feb. 14
Elizabeth Stickler, 8 years old on Jan. 23
Sherry Storm, 11 years old on Jan. 24
Heather Sutton, 41 years old on Feb. 18
Cody Trotter, 14 years old on Feb. 17



Ashley Hagan will be 11 years old on January 21. She attends North Hancock Elementary School. She loves going to Holiday World and the movies. She also likes to swim and read.

Fazoli's Birthday Club - Fazoli's, 5060 Frederica Street, is treating individuals with Down syndrome to a free meal to celebrate their birthday. Children ages 12 & under can choose a kids meal while teens & 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, an affiliate of the National Down Syndrome Society and the National Down Syndrome Congress, is a non-profit, 501(c)3 organization that provides its members with a bi-monthly newsletter, educational workshops, social activities, a website (www.gradsa.org), a new parent outreach program, and a hospital outreach program. There are no membership fees to join.

Policy Statement

GRADSA does not promote or 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 Cindy Huston. Articles written for **Heart Strings** may be reproduced if credit is given to the author and GRADSA. Permission to reprint articles not original to **Heart Strings** should be acquired from the original source.

Board Members

Matthew Williams, *President*

Home: (270) 689-1695

Cell: (270) 929-6348

E-mail: Matthew.Williams@aleris.com

Stephanie Stickler Smith, *Pres.-Elect*

Phone: (270) 683-9100

E-mail: sticklersl@omu.org

Michele Cecil, Director

Steve Hagan, Director

Tony Hamilton, Director

Deanna Isbill, Director

Lori Marksberry, Director

Jamie Mullins, Director

Tonya Murphy, Director

Paul Puckett, Director

Brenda Walker, Director

Cindy Huston, *Executive Director*

Home: (270) 771-4945

Cell: (270) 314-3676

E-mail: info@gradsa.org

The next board meeting will be held on Monday, January 14, 5:30 p.m., at the Family YMCA. All board meetings are open to the general membership.

MOVING? Don't miss an issue of *Heart Strings* due to an address change! Please call or email us to update your information. Thanks!

To discontinue your subscription to this publication, please email: info@gradsa.org

P.O. Box 2031
Owensboro, KY 42302

GRADSA
GREEN RIVER AREA
DOWN SYNDROME ASSOCIATION

