



HEART STRINGS

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

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

May/June 2005

Message from Executive Director

Spring is finally here and it is nice to see the trees and flowers blooming, the grass getting greener (even if it means mowing!), and everyone getting outside for some long awaited warmth and sunshine. I know our family seems happier now that we can get outdoors.

Since the weather has been nice, Matthew has his own little routine when he gets home from school. First he cups his hands around his mouth and yells "Bo want toast?" Bo is our 13-year old beagle who is nearly all the way blind and deaf. He meanders his way along the fence line toward the smell of bread. (We don't really toast it for him but that's the term Matthew knows since he eats it for breakfast.)

Then he moves on to the trampoline, swings for a while, slides a few times, then it's time for our nature walk out to the field. We blow a dozen dandelions along the way, then he says bye bye to the flowers (fowfers). An annoying weed to adults, but a beautiful "fowfer" to kids.

When it's time to go inside, I use Kool Pops as a lure. They aren't a significant source of calories or sugar so why not use them to help make this transition time easier for him . . . and for me. Did I mention that I get one too?

Spring also means sports have arrived and parents become chauffeurs and cheerleaders at their childrens sporting practices and events. Not that we mind, but it does provide for a busy schedule. On page 2, there are several photos of children and adults with Down syndrome participating in a variety of fitness activities.

Getting regular exercise is important to all of us, but especially those with lower muscle tone. Not only does it develop stronger muscles, but exercise actually helps with speech development too. If you do not get enough oxygen to the diaphragm, then it could affect your speech. On page 3, JoAnn Tessandori, Speech Pathologist, offers some suggestions on increasing abdominal/diaphragmatic (deep) breathing.

With all the responsibilities of family, work, volunteer, and church activities, why not take a break and enjoy the Mom's and Dad's outings in May? It is a relaxing time that gives parents the opportunity to visit with each other without having the kids tugging at your shirt. Mark your calendars now to attend - you deserve it! (Please note: Due to limited ticket availability on the 13th, Mom's Night Out has been changed to May 14. Dinner will be at Texas Roadhouse - table will be available at 5 p.m. so join us when you can.)

We are planning a Book Fair in June as part of our Education Outreach. GRADSA will pay for a book of your choice for each family. Please see the list of books available on page 3. If you have a specific book that you are interested in but is not on the list, please let me know.

Despite busy family schedules, I hope you will find time to participate in an upcoming GRADSA event. I look forward to seeing you soon.

Cindy Huston

Calendar of Events

Saturday, May 14, Mom's Night Out, 5:00 - 9:30 p.m. Join us for an evening of fellowship with dinner at Texas Roadhouse and a Theatre Workshop Play. GRADSA will cover the cost of dinner and tickets. Please contact Cindy Huston if you would like to attend.

Saturday, May 21, Dad's Day Out, Golf Outing at Ben Hawes, Tee times are at 9 a.m. but you should plan on arriving at 8:30 a.m. GRADSA will cover the cost of green fees, cart, and box lunches. Please RSVP to Matthew Williams at (270) 689-1695 or (270) 929-6348 (Email: Matthew.Williams@aleris.com).

Monday, June 20, Book Fair, 6 - 8 p.m., at the Family Y, Stop by to pick up your book and enjoy an evening of fellowship. Pizza and refreshments will be provided. Child care will be available but not necessary since it is a casual, family event. (Please review the list of books available on the third page and submit your order to Cindy Huston by May 31.)

News



The Buddy Walk Committee has begun planning the 2005 Buddy Walk, which is set for Sunday, October 2. We are pleased to announce that [Texas Roadhouse](#) is our *Exclusive Presenting Sponsor* for this year. We are currently soliciting additional corporate sponsors. If you know of a business who might be interested, please let us know and we will send them a sponsorship package.

GRADSA will be accepting [Board Nominations](#) until June 13 for the 2005-06 year for the positions of President and Vice President. Elected positions serve one year terms and meet bi-monthly. Elections will be held at the Book Fair on June 20. If you are interested in serving or would like more information, please contact Dwight Beyke at (270) 686-6433.

[Kentucky School for the Deaf](#) offers services to children who are deaf or hard of hearing, from birth to 5th grade. In order to qualify, hearing must be 25dB or worse in the better ear and must have a bi-lateral loss. For more information, contact Andy Hensley at (270) 339-8376, Email: ahensley@ksd.k12.ky.us, or Laurie Parks at (270) 852-7250, Email: lparks@daviess.k12.ky.us.

The NDSS has provided affiliates with several copies of the book "[Making Plans: A Financial Guide for People with Down Syndrome and Their Families](#)." The purpose of the booklet is to help families move toward independence by making plans for the future, managing money, and learning how to use the resources and laws that enable individuals with disabilities to lead fulfilling lives. If you would like to receive a copy, please contact Cindy Huston.

[National Down Syndrome Society Annual Conference "I imagine"](#), July 7-10 in Chicago, Illinois. For more information, call (800) 799-4113 or check their website at www.ndss.org.

[National Down Syndrome Congress Annual Convention](#), July 29-31 in Anaheim, California. For more information, call (800) 232-6372 or check their website at www.ndsccenter.org.

Both of these conferences bring together parents, family members, professionals, teens and adults with Down syndrome, and siblings to learn best practices in education, health care, employment, community living, and inclusion.

GRADSA has a conference scholarship fund to assist parents with registration fees. Please contact Cindy Huston to obtain an application.

Spring into Fitness



Several children with Down syndrome are participating in TOPSoccer, a program for children ages 5-16 with mental and physical disabilities. Each athlete is paired with a member of the KWC men and women soccer teams who serve as game buddies.

(Left to Right: *Leland Isbill, Taylor Palmer, and Peyton VanMeter*)



Swimmers *Shannon Mahoney, Dana Hamilton, and Chris Hagan*, stay in shape by swimming each week. They compete in the Special Olympics.



Weightlifter *David Fogle* works out 3 days a week at the YMCA. He can bench press 235 pounds.



Volunteers from Dream Riders assist *Michael Smith* and *Matthew Huston* in their first ride of the season. Horseback riding increases balance and coordination.

Deep Breathing Techniques Help with Speech Development

JoAnn Tessandori, Speech Pathologist

Children with low muscle tone have difficulty coordinating all speech functions such as movement of the tongue, lips and jaw. Muscles of respiration also require fine coordinated movements for speaking. All speech production happens on exhalation, therefore, deep breathing is important in helping a person extend exhalation so that they can have efficient air support for speech.

The most efficient type of breathing for speech is belly breathing (abdominal-diaphragmatic breathing). This type of breathing is best described as a deep breath through the nose with little or no movement seen in the shoulders and chest area. The movement should be at the level of the abdomen/diaphragm. To fully understand this method lay on the floor with a book on your abdomen. You want the book to move up and down as you do deep breathing and you want little or no movement of the shoulders and chest area. A deep breath such as this will aid speech output on one breath. Recently, deep breathing has been associated with health benefits of providing more oxygen to the blood.

Exercises that I use to help children with low muscle tone use deeper abdominal breathing are some of the more difficult horns in the horn program that receive "big air" such as birthday blowers or the horn that requires you to blow up a balloon. I have also used blow pens with older children in art activities to emphasize deep breathing activities. Some of these deep breathing exercises are utilized with asthmatic children to develop abdominal/diaphragmatic breathing.

There is an interesting book available titled "Yoga for the Special Child" by Sonia Sumar. The author is a certified speech pathologist who is also trained in yoga. She utilizes yoga positions and techniques with children who have Down syndrome. Additional information can be found at www.specialyoga.com.

Note: GRADSA has a limited number of Horn Programs available. Please check with your child's Speech Therapist to see if he/she would benefit from the program.

Book Fair

As part of our Educational Outreach, GRADSA is offering families and educators a choice of the following books. Please review the list and submit your order to Cindy Huston by May 31. Pick-up will be on June 20 at the Family Y (see calendar for details).

[Classroom Language Skills for Children with Down Syndrome \(A Guide for Parents and Teachers\)](#) - This book covers a child's language needs through middle school.

[Early Communication Skills for Children with Down Syndrome \(A Guide for Parents and Professionals\)](#) - This book covers all aspects of early speech-language development and the impact of intelligibility issues, hearing loss, and apraxia (difficulty planning oral-motor movements).

[Fine Motor Skills in Children with Down Syndrome \(A Guide for Parents and Professionals\)](#) - This book describes fine motor development required for skills such as feeding, cutting, and handwriting in children with Down syndrome from birth through age 12.

[Gross Motor Skills in Children with Down Syndrome \(A Guide for Parents and Professionals\)](#) - This book covers how factors such as low muscle tone, increased flexibility, and temperament affect gross motor development. It features over 100 activities for parents and professionals to practice with their infants and children through age 6.

[Medical & Surgical Care for Children with Down Syndrome \(A Guide for Parents\)](#) - Easy-to-read and well-organized, this book covers medical conditions - from heart disease to skin conditions - that are common among children with Down syndrome, as well as dental care, nutrition, sexuality, and alternative therapies.

[Negotiating the Special Education Maze](#) - This book covers the Individualized Education Program (IEP), Americans with Disabilities Act (ADA), and the Individuals with Disabilities Education Act (IDEA).

[Teaching Math to People with Down Syndrome \(A Guide for Parents and Teachers\)](#) - This book, for children and adults with Down syndrome, is a guide to understanding computation, number concepts, measurements, place value, time, counting, addition, subtraction, shapes, and money.

[Teaching Reading to Children with Down Syndrome \(A Guide for Parents and Teachers\)](#) - This book offers easy-to-follow lessons to teach your child with Down syndrome to read.

[The Down Syndrome Nutrition Handbook](#) - This book covers all aspects of nutrition and healthy living for children and adults with Down syndrome. Topics include: Breast and Bottle Feeding; Basic Nutrition and Physiology; Celiac Disease; Diabetes; Alternative Therapies; Food and School; Weight Management; Fitness and Exercise; and Cooking and Menu Planning.

[The New Language of Toys: Teaching Communication Skills to Children with Special Needs \(A Guide for Parents and Teachers\)](#) - These sample toy dialogues show parents how to play purposefully with their child - using store-bought and homemade toys - to provide language learning opportunities and stimulate language development. Parents can help their child build receptive language skills (understanding), expressive language skills (communicating), and speech.

Heather's Hints

To improve cutting skills and imagination, let's think back to when we were children. My Grandma always helped us make paper dolls (a lost art). Take old magazines and find good pictures your child would enjoy cutting out. Provide them with good scissors (always supervised) to cut down on frustration with scissors that do not work well. They can either cut the magazine page as it is or you can glue the whole page on a piece of construction paper and then let them cut out the picture. The construction paper will provide a little more resistance and be easier to manage. Remember, as parents, you must be creative. Look for people first. Then find them clothes to wear, cars to drive, food to eat and even toys for their children. This activity does not have to end in one day. You can continually add to your paper doll family. Be sure to name them as well. The most important part is to have fun with your child building theirs and your imagination!

Heather Hensley, OTR/L, Kid's First Therapy Services, LLC (and mom to Mitchell, 3 years old, who has DS)

May/June Birthdays

Larry Basham - 26 years old on May 25
Joseph Clements - 3 years old on June 27
Amanda Eaton - 27 years old on May 25
Chris Hagan - 42 years old on June 18
Dustin Lee - 22 years old on May 31
Colin Powers - 6 years old on May 13
Jason Snell - 36 years old on June 15
Blake Spainhoward - 6 years old on June 26
Neal Sweeney - 47 years old on June 1

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 our children.

Services

GRADSA, an affiliate of the National Down Syndrome Society, 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.

Policy Statement

GRADSA does not endorse, recommend or support any specific regime, therapy, or editorial submitted for publication.

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.

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All board meetings are open to the general membership. The next meeting will be held on Monday, June 13, 6 p.m., at the Family Y.



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