



HEART STRINGS

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

March/April 2006

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

Message from Executive Director

I thought the last few months would be a reprieve from the hectic pace, but it has continued throughout the winter months. Haley has been playing Upwards basketball and has a game every Saturday at 8 a.m. As soon as she wraps up her season, Matthew will start on a Special Olympics bowling league on Saturday mornings. So much for sleeping in on the weekends! During the week, there are practices, church activities, scouts, and gymnastics. Matthew just finished up KinderMusik and will begin horseback riding and soccer soon. It seems we are always on the run - I'm sure most of you can relate.

GRADSA has kicked off the new year with a bang...3 educational workshops in the 1st quarter and a social event for teens and adults. We've expanded our newsletter to 8 pages and will soon launch a new website. And it won't be long until we start planning the 2006 Buddy Walk...if you would like to work on this committee, please let me know. It is a great way to become involved and know you are making a difference!

I received so much feedback from the last issue of *Heart Strings*. The personal stories submitted by siblings touched many of your hearts. Just a reminder that anyone can submit a story for the newsletter at any time - friends, grandparents, aunts, uncles, teachers - share how a person with DS has changed your life. Parents - share your child's accomplishments with other GRADSA members. Let's celebrate together!

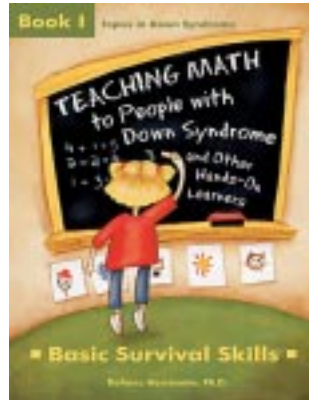
I hope you will find this issue informative - tips on IEP meetings and how to advocate for your child at school, information on therapeutic horseback riding and behavior issues. I could relate to several behavioral concerns mentioned in the Q&A. It can seem overwhelming but keep in mind that most behaviors subside over time.

We have several children facing medical issues so please keep them in your prayers. Ethan Smith, 5-month old son of April and Shawn, will be having heart surgery soon. Kyrstyn Randolph recently had surgery to replace the hardware in her neck and make space for her spinal cord. Luke Stone is finally home, after spending 6 weeks at Kosair with RSV; however, the doctors are still concerned with his heart and lungs. And there is a new baby, Landon, who is also struggling with heart issues.

Hope to see you soon!

Cindy Huston

Calendar of Events



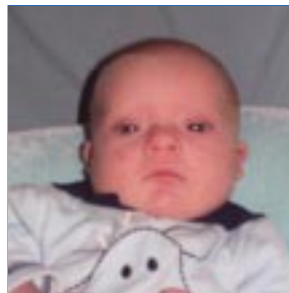
Saturday, March 4, *Teaching Math to People with Down Syndrome and other Hands-On Learners, presented by DeAnna Horstmeier, Ph.D., author of the book.*

This class will be held from 9 a.m. - 2 p.m. in Rogers Hall at Kentucky Wesleyan College's Winchester Center. The math program explained in *TEACHING MATH* has been successfully used with preschoolers, children, and adults with Down syndrome. Its success lies in capitalizing on the visual learning strengths using manipulatives, games, and activities to teach and maintain motivation.

DeAnna Horstmeier is an Instructional Resources Consultant at a special education regional resource center in Columbus, Ohio, where she assists parents and educators with teaching strategies and materials for their students. In addition, she has taught special education and speech, language and communication at Ohio State University. *Parents and teachers are invited to attend.* Lunch will be provided. *To sign up, contact Cindy Huston.*

Sunday, April 9, *Easter Eggstravaganza*, 1:30 - 3:30 at the Family Y. We'll begin with snacks and crafts then proceed (weather permitting) outside for an egg hunt. This event is open to children with DS ages 12 and under and their siblings. *Please RSVP by April 1.*

News



Joseph Zebediah "Zeb" Wells, was born on December 17, weighing 10 pounds, 9 ounces. Proud parents are John and Laura Wells. He was also welcomed by his sister, Lee Ann, 16, and brother, J.T., 13. We welcome them to the GRADSA family.

Families have expressed an interest in having a [GRADSA Directory](#) available. The Directory would list only families who have an individual with Down syndrome. Information included would be parents' name, address, phone number, and the child's name and birthdate. *If you do NOT want your families' information included, please let us know by April 15.* This directory will only be made available to families who have a person with Down syndrome.

GRADSA has a [Scholarship Fund](#) for parents who wish to attend conferences sponsored by other organizations. Please contact us to receive an application form.

[Graduates](#) - If you will be graduating this year, we would like to honor you in the next issue. Please send a photo and brief bio by April 15.

2005 ANNUAL REPORT

The families who have been enriched with the Down syndrome connection, and the community, have embraced the mission of GRADSA and enable us to serve more than 250 families, educators, and professionals. Below is a recap of GRADSA's activities for 2005, in which \$26,442 was allocated, as follows:

Administration (5%)

Office supplies, mailing expenses, NDSS dues, donation to Katrina Fund for the Down Syndrome Community

Buddy Walk (22%)

The Buddy Walk is the premier event hosted by GRADSA. The walk is held in October of each year, celebrating National Down Syndrome Awareness month. We surpassed our expectations with over 800 people in attendance and nearly \$32,000 raised, thanks to a dedicated committee and wonderful community support.

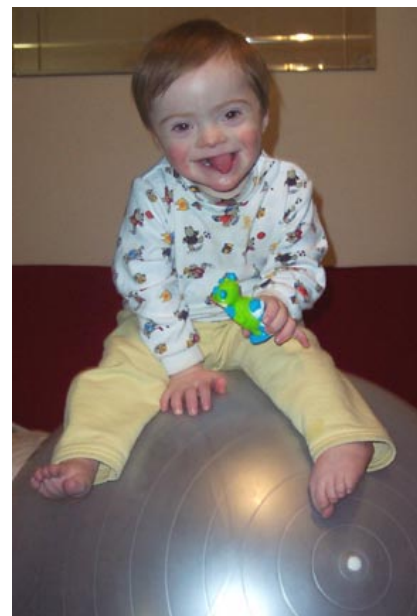


Education/Outreach (18%)

We hosted our first *Changing Lives: Down Syndrome and the Health Care Professionals* workshop, targeting obstetricians and pediatricians, to educate them on the medical and developmental needs of individuals with Down syndrome, and to equip them with positive tools for delivering the diagnosis in a positive and supportive manner. We also hosted workshops on Behavior and Teaching Reading, presented by educators from the Daviess County Public Schools. We held a Book Fair, which supplied books to nearly 20 families and teachers, as well as several additions to our Resource Library. GRADSA also granted 7 scholarships for parents to attend conferences sponsored by other organizations.

GRADSA publishes a bi-monthly newsletter, *Heart Strings*, which includes upcoming events, educational articles, medical news, and personal stories. Our mailing list has over 250 people, including member families, special education teachers and administrators, service providers (speech, physical, and occupational therapists), obstetricians, and pediatricians. A local company donates the printing of our newsletter, which keeps our cost at a bare minimum. We also maintain a website - www.gradsa.org

We are committed to helping new families adjust to raising a child with Down syndrome by providing information, support, and encouragement. In 2005, we served 12 families in the Birth-3 program. GRADSA assists new families by offering therapeutic items such as plexi-glass mirrors, therapy balls, boppy pillows, horn and straw programs, and educational books.



GRADSA also recognizes the health issues that may affect individuals with Down syndrome and supports families during medical crises by providing care packages, meals, and making hospital visits.

Social Activities (24%)

GRADSA hosts several social events throughout the year, including a Valentine's Dance, Easter Eggstravaganza, Family Movie Night, Holiday World Outing, Christmas Party, and Mom's and Dad's Night Outs. These activities are important to help families build friendships and share resources with each other.



Staff (31%)

Compensation for Executive Director

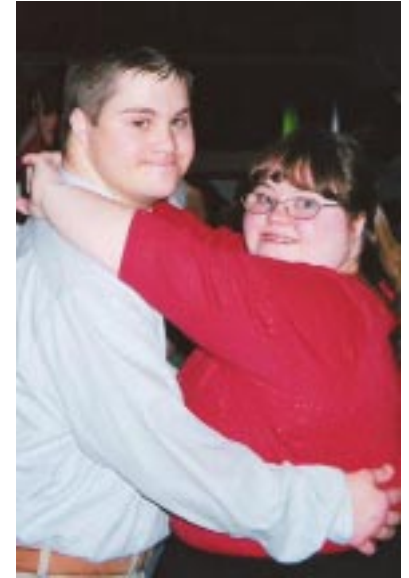
VALENTINE'S DANCE



Nearly 100 teenagers and adults with disabilities, including more than a dozen individuals with Down syndrome, enjoyed a night of dancing at the Valentine's Dance on February 11, sponsored by GRADSA and the Special Olympics.



Left to Right: Moggie Riney and John Head; Michael Smith and Chris Hagan; Shannon Peterson and David Fogle; Mark Vollman and friend, Dee; Peyton Van Meter and friend, Haley; Linda Murphy; Alan Wood; Shawn Riney and Dana Hamilton; Aaron Shoemaker and Adrienne Free



Therapeutic Horseback Riding

Therapeutic Horseback Riding is an alternative therapy for individuals with physical and cognitive disabilities. Therapeutic horseback riding is most effective in children because of the nature of mental, physical and social development. However, it produces very favorable improvements in riders of all ages. The motion of the horse, concentration needed, and communication between instructor and rider allows people with a variety of disabilities to benefit from riding. There are many advantages of therapeutic horseback riding.

Physical

The most obvious and often the most immediately recognizable benefit is physical. Just like physical and occupational therapy, horseback riding uses movement as a primary means of therapy. Instructors employ a variety of physical tasks that help improve balance, muscle strength, flexibility, joint movement, and posture.

Balance and Posture

Horseback riding requires balance and good posture for all riders. The connection between horse and rider is a fundamental element in building balance in riders. Instructors often employ various exercises that work on balance and posture, such as grabbing rings while riding, throwing a ball into a basket, riding with arms stretched out, riding with the eyes closed, riding backwards, etc. The combination of supporting as well as challenging the rider enables the rider to improve their physical capabilities both on and off their mount.

Muscles and Joints

The movement of the horse improves muscle tone and flexibility. Riders with low muscle tone and loose flexibility will work on strengthening and tightening the muscles primarily in the back, neck, buttocks and leg regions.

Cognitive and Sensory

Riding requires attention, reasoning skills and memory. Because therapy and riding both build knowledge as time progresses, simple tasks grow into complex skills that provide the rider with intellectual stimulation. The rider must interpret sensory information they are receiving from the horse, instructor, and environment, and use this information in a manner that is appropriate for learning riding skills.

Emotional, Social and Psychological

Riding helps the student interact with others, form meaningful relationships with the horse and instructors. They reap benefits of improved self-esteem, confidence, and self-image.

Source: Wikipedia - The Free Encyclopedia - <http://en.wikipedia.org/wiki>

There are two programs in this area that provide therapeutic horseback riding for children and adults with mental and physical disabilities - Dream Riders and Ohio County Equestrians. The typical age to begin is 3 years old. Individuals with Down syndrome must have a cervical spine X-ray to rule out atlantoaxial instability before participating.

Dream Riders is hosting a kick-off luncheon Saturday, April 8, 11:30 a.m., at the Daviess County Fair Grounds to honor volunteers and welcome back riders and their parents. Burgers, hot dogs, chips, and drinks will be available. There will be a brief program giving an overview of the new season. The horses and other animals will be on hand to be greeted and groomed. All rider physicals must be updated after three calendar years. For information about enrolling as a new rider or becoming a volunteer, contact Mike Clark at 929-8833 or Suzy Higdon at 993-5608.

Ohio County Equestrians contact is Rhonda Leach, (270) 274-9650.



My son will begin his 4th season with Dream Riders in April. Jonah is 9 and his list of disabilities is extensive. Through Dream Riders, Jonah has found an activity that he can take part in and call "his own". He has never been able to participate with his siblings in scouts, church, and sports and trying to explain to him why has left me in tears more than once. The pride Jonah feels in his accomplishments through Dream Riders, as well as the physical benefits of increased stamina, improved coordination and balance have been nothing short of amazing. Watching him gather his gear (vest, helmet and of course BOOTS) each week prior to his ride has taught me that every child, regardless of abilities, wants something of their own. Every child deserves that. Thank you Dream Riders for allowing Jonah this opportunity.

Anji Edge, Parent of a *Dream Rider*

"A" is for Advocacy: Defending your Child's Rights at School

If you have a child with disabilities, **A-D-V-O-C-A-C-Y** is the key. The following tips can make your collaboration with school personnel as smooth as possible.

A--Always know your rights. The first thing you need to do is learn all you can about special education law. Websites such as ED-LAW and Family & Advocates Partnership for Education are great starting points. In addition, there are several books available that help parents understand special education law.

D--Determine which services and accommodations are most important to your child's education. Choose your battles wisely. Arguing over minute details is exhausting and will not facilitate productive relationships with teachers, therapists and administrators. Keep in mind, however, that services your child needs to benefit from education cannot be denied because of cost or lack of qualified personnel.

V--Visit parent support groups in your community. You can get information, ideas and moral support from parents in similar situations. Locate a support group in your area through parent training and information centers.

O--Organize a notebook containing all relevant information about your child. Request a copy of your child's school records, add medical records and results of independent evaluations and keep a record of the date, contact person and important details of all conversations with school personnel.

C--Compose your thoughts before meeting with school personnel.

A--Attend a conference or workshop for parents of children with disabilities to keep current with legislation and learn new advocacy strategies.

C--Consult with an independent educational consultant to obtain an objective opinion of your child's strengths and needs. If you feel uncertain of your ability to effectively advocate for your child, ask an advocate or a trusted friend or family member to attend meetings with you.

Y--You are the best judge of your child's needs and have knowledge that school officials do not possess. Remember, you are an equal participant in the educational team!

G. Denise Lance, Ph.D.

A Successful IEP Meeting Happens When We...

- Work on building positive relationships with the school team.
- Know and understand what is in the student's IEP.
- Know rights and what to do if they are being violated.
- Keep good, organized records.
- Make sure what is needed and agreed upon is written down.
- Are good listeners...even when we disagree.
- Focus on the student's issues, not on personalities or district concerns.
- Set priorities - choose what things are most important to work on now.
- Share what you know works with the student.
- Go to meetings prepared and positive.
- Know when to stop using what's not working and try something else.
- Stay involved - set up a method of feedback.

From Emotions to
Advocacy: The Special
Education Survival Guide,
by Pam and Pete Wright

This practical, user-
friendly book teaches you
how to plan, prepare,
organize and receive
quality special education
services for your child.

Available in the GRADSA
Resource Library

Family Information Network on Disabilities - www.findoflouisville.org

Q: How does behavioral development differ in children with Down syndrome as compared to their peers?

A: The behavioral challenges that we see in children with Down syndrome are not all that different from those we see in typically developing children; they may occur at a later age and last a little longer. For example, temper tantrums are fairly common in 2 and 3 year olds. A child with DS may have temper tantrums that begin at 3 or 4 years of age. The behavior itself is really no different; neither are the techniques you would use to intervene. When looking at behavioral issues in children with DS, it is important to take into consideration the child's level of functioning. We have to evaluate behavior in the context of developmental age, not only chronological age.

It's also important to know the child's language skills. Many of the behavioral concerns in children with DS are related to their frustration with communication. We often find that we can successfully address behavioral issues by helping children find verbal and/or non-verbal ways to express themselves and communicate more effectively.

Q: What are some common behavioral concerns in children with Down syndrome?

A: One behavior I am asked about frequently is temper tantrums, which are common to all children. Because the child with DS often has communication difficulties, temper outbursts may be more difficult to manage, particularly when out in public.

Toilet training is another area of frustration for parents because children with DS are usually a little older when they are interested in toileting - and, again, communication problems can be related to problems with toilet training.

Another big concern we hear from parents is their child wandering off - not because they're angry or running away, but rather, because they simply like to explore the neighborhood. Parents will report that their 6 or 7 year old goes out of the gate and over to the neighbor's house, but because the parents do not know where the child is, it's a very scary thing. The primary goal of intervention is to keep the child safe by doing things such as making sure there are good locks on the door and using alarms. Wandering is such a common concern that Joan Medlen, editor of Disability Solutions, dedicated a whole issue to the topic.

Another challenging behavior is the child who throws himself down on the ground when he does not want to do

something. This can occur in the grocery store, at home, in the classroom, or in the middle of the street. It is different from the temper tantrums because the child is not mad; he's simply saying "I'm not going." This stubborn, oppositional behavior can happen at any age. When children are 2 or 3 years old, it is easy to pick them up and carry them, but when they are 9 or 10, this is much more difficult to manage. It can also be dangerous behavior if it occurs in the middle of a street, so it is important for parents to get help with how to manage this type of behavior before it gets out of control.

Q: What are some behavioral concerns in teens and adults?

A: What we are seeing often in teens and young adults are problems with withdrawn and depressed behavior. They stop wanting to go to their jobs or participate in recreational activities, and they may be having sleep problems. There are so many transitions and changes happening in their lives - for example, school is ending, they are looking for jobs, and siblings are often leaving home. They can have the feeling of "Gee, I'm 18 or 19 and I should be on my own and I'm not. I'm still living at home with mom and dad." At this age, we also counsel the adolescent in regard to social skills and sexuality. We use Leslie Walker Hirsch's CIRCLES techniques when we work with our young adults in these areas.

Q: How should parents approach behavior issues in their child with Down syndrome?

A: The first step is to rule out a medical problem, as some behavior problems can be directly related to a medical issue. The child may have hearing loss, vision problems, a thyroid condition, sleep apnea or celiac disease. All of these things can initially present as a change in behavior. Parents should have their child's doctor evaluate the child to make sure there is not a medical problem. Once that has been done you should consider psychological or emotional stressors that may be impacting behavior, such as depression, anxiety, changes at home, a sibling moving away, or parents going through a divorce.

Once you've ruled out medical and psychological issues, you can work with a professional to help develop a behavior treatment plan. This involves looking at what we call the ABC's of behavior: the antecedent - what precedes the behavior - the behavior itself, and the consequences of the behavior. It is important to look at both positive and negative consequences. It is always preferable to use positive consequences to reward appropriate behavior. That is something we often forget to do. When our child is being good, we think, "Now's the time to wash

Behavior Q & A continued

the dishes or fold the laundry!" We really should be reinforcing the behavior, saying things like "I really like what you're doing now." Most of us are not used to doing this, and we have a tendency to reward negative behavior by giving children attention when they're doing something we don't like.

A lot of acting out behavior is actually done to get attention, so when we use positive consequences to reinforce good behavior, we can decrease negative behavior. Sometimes, however, there must be negative consequences, like "time outs", or in the case of an older child, taking away privileges for inappropriate behavior. It's important to remember that, particularly for younger kids, the consequence has to be delivered when the behavior happens. For example, it is often difficult for a child to make the connection between something they did wrong at school and the consequence they get for it at home.

Q: What advice would you give to parents who feel overwhelmed because of behavioral issues?

A: I would advise parents to remember that they cannot work on all the challenging behaviors at the same time. For example, we may have a child who comes in to the clinic whose parents say: he is having temper tantrums, we cannot get him to bed at night, he throws food, and so on. There may be 5 or 6 different concerns, but you have to target a specific behavior on which to focus your energy. As parents develop skills around managing that particular behavior, they will find that those skills carry over to management of the other behaviors.

It is important to remember that the challenging behaviors we see in children with DS are behaviors that are seen in all children. They may occur at a later chronological age and last a bit longer. If you need extra help, there are people you can turn to, including your pediatrician, school psychologists, therapists, and Down syndrome clinic staff.

Dr. Bonnie Patterson, director of the Jane and Richard Thomas Center for Down Syndrome in the Division of Developmental Disabilities at Cincinnati Children's Medical Center. Her specialties include Down syndrome, learning disabilities, and autism, with a focus on behavioral issues.

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Language Guidelines

Adapted from the Down Syndrome Society
of Rhode Island

The correct name of this diagnosis is Down syndrome. There is no apostrophe (Down). The "s" in syndrome is not capitalized (syndrome).

An individual with Down syndrome is an individual first and foremost. The emphasis should be on the person, not the disability. Down syndrome is just one of the many words that can be used to describe a person. Do NOT say, "That child is a Downs". A child with Down syndrome, an adult with Down syndrome, or a person with Down syndrome is a more appropriate way to discuss a person with this condition.

Words can create barriers. Try to recognize that a child is "a child with Down syndrome" or that an adult is "an adult with Down syndrome". Children with Down syndrome grow into adults with Down syndrome; they do not remain "eternal children". Adults enjoy activities and companionship with other adults.

Encourage people to use person-first language, i.e. "The person with Down syndrome", NOT "The Down syndrome person." I identify individuals with Down syndrome as an individual, a friend, a student, or a family member.

It is important to use the correct terminology. A person has mental retardation, rather than "suffers from", "is a victim of", "is diseased with", or "is afflicted by". A person with Down syndrome is NOT "a Downs".

Ask yourself if using the words "poor", "pitiful", or "unfortunate" when referring to an individual with Down syndrome is in his/her best interest.

Each person has his/her own unique strengths, capabilities and talents. Try not to use the clichés that are so common when describing an individual with Down syndrome. To assume all people have the same characteristics or abilities is degrading. Also, it reinforces the stereotype that "all kids with Down syndrome are the same."

Most important, look at the person as an individual—your child, your family member, your student, your friend. Proudly acknowledge their individuality and their accomplishments. Remember, persons with Down syndrome are more alike us than different. They have feelings too and are hurt by cruelty, stares and name-calling. They want to be included in your groups, not excluded.

How we, as parents, respond to our child and our child's disability has a greater impact on the child's life than the diagnosis. --- Kathie Snow

March/April Birthdays

If this information is incorrect or a birthday is not listed, please let us know!

[Matthew Cook](#) - 8 years old on March 17
[Adrienne Free](#) - 19 years old on March 21
[Judy Haggard](#) - 53 years old on April 7
[Leland I sbill](#) - 8 years old on April 30
[Seth Johnson](#) - 4 years old on April 13
[Robbie Sherrard](#) - 2 years old on April 13
[Roy Taylor](#) - 13 years old on April 2
[Jonathan Uhr](#) - 12 years old on April 25
[Peyton VanMeter](#) - 12 years old on April 13
[Elliott Williams](#) - 2 years old on March 19
[Sam Winstead](#) - 6 years old on March 24



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 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, April 10, 6 p.m., at the Owensboro Family Y.

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GRADSA
GREEN RIVER AREA
DOWN SYNDROME ASSOCIATION

