



# 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.

November/December 2006

## Message from Executive Director

What an awesome day we had at the Buddy Walk! The weather was fantastic and everyone seemed to enjoy the festivities. My favorite part was seeing each person with Down syndrome as they crossed the stage, with a cheering crowd of over 1,000 people!!! I was in awe of the love and acceptance shown that day to our children and adults with Down syndrome. I am reminded of the quote by Margaret Mead - "Don't think a small group can't change the world. Indeed, it's the only way it has ever happened."

Not only did we have an amazing show of supporters, but because of the generosity of so many people, over \$43,000 was raised to support GRADSA!! With our growth comes a greater responsibility to serve our members. We want your input and feedback to determine the services you need. The board will be meeting in December to plan events and budget for 2007. If you have any ideas or suggestions, please let us know.

Included in this issue of *Heart Strings* is a thought provoking article by Kathie Snow entitled "No, Not Special...They are Ordinary Needs." She has a knack for putting issues into perspective with a little dose of humor. On page 4 is an interview with Dr. William Cohen concerning the Health Care Guidelines. Remember that all individuals with DS should receive a yearly thyroid test, hearing test, and vision exam (preferably from an Ophthalmologist). At age 3, it is recommended that children receive a cervical spine x-ray to rule out Atlantoaxial Instability. If your child is involved in any sports activities (Special Olympics, horseback riding, etc), this x-ray is required before participating. There is also a new recommendation that all children receive a sleep study around the age of 3-4, to rule out sleep apnea. Results of this study can be found on page 5.

GRADSA is hosting a Special Needs Estate Planning workshop on November 11. Don't miss this opportunity to get all your questions answered from our panel of professionals. To round out the year, we will be having our annual Christmas party on December 2. This is always a "jolly" event and I look forward to seeing everyone.

Please keep Landon Ashby and Jonah Edge in your prayers. Landon had heart surgery in July and must have another heart cath to close his PDA. Jonah will be spending at week at the DS Clinic in Cincinnati to undergo intensive sleep apnea testing. His mother, Anji, has created a journal at Caring Bridge that chronicles Jonah's medical history and provides updates on his progress. It can be viewed at: [www.caringbridge.com/visit/jonahedge](http://www.caringbridge.com/visit/jonahedge)

Hope to see you soon!

*Cindy Huston*

## Calendar of Events

**Saturday, November 11, Special Needs Estate Planning Workshop, 8:30 a.m. - 1:30 p.m. at Kentucky Wesleyan College (Rogers Hall in the Winchester Center), Lunch will be provided. Please RSVP to Cindy Huston.**  
Presenters include:

- **Carolyn Wheeler**, Project Director of Hope for Tomorrow, will present an overview of special needs estate planning.
- **Richard Bush**, an attorney from Louisville and father of an adult son with Down syndrome, will discuss wills, guardianship, and special needs trusts.
- **Marc Bosley**, a local financial planner, will discuss ways to fund a special needs trust.

**Saturday, December 2, Christmas Party, 4 - 7:30 p.m. at Kentucky Wesleyan College (Rogers Hall in the Winchester Center),** Crafts and activities will begin at 4:00 p.m., with dinner being served at 5:30 p.m. Santa will arrive after dinner with goody bags for the children. **Please RSVP to Cindy Huston by November 22.**



## Spotlight



Charity Loudon is a 26 year old woman with Down syndrome. She has learned to crochet and has made several beautiful afghans, shawls, and pillows. Charity is selling her items and will customize with your choice of color. Prices are as follows:  
Baby afghan - \$20; large afghan - \$50; pillow - \$5; shawl - \$15.  
To place your order, please call 729-9869, 993-3561, or 993-3560.

## No, Not "Special"...They are Ordinary Needs

To create this article, I needed a computer with the software that meets my needs. To learn to write and read, my son, Benjamin, has also needed a computer with the right software since the age of four.

To get to work every day, Richard needs a good set of wheels on his car. Holly also needs a good set of wheels to get from class to class on campus.

Miranda needs a clip-on wireless microphone before she can successfully deliver her keynote presentations. Jose needs a communication device before he can successfully express himself at home, at school, or in other environments.

Daniel, a doctor, needs voice recognition (VR) computer software to effectively dictate his daily notes. Samantha, an eight-year old, needs VR software so she can write stories and book reports in third grade.

Kate spends 50+ hours at her desk, but couldn't do so without her ergonomic chair and curved desk that holds her multiple terminals. Amelia also needs a desk that meets her work needs - a height-adjustable, curved desk with desktop cubbys so everything is within arm's reach.

Acme Widget Company has risen to the top of its field because the individual differences - including some behavioral eccentricities - of all employees are supported and valued. Mrs. Dahl's classroom is viewed as a model of success and all students are learning, because she's created a caring environment where all students - including those with significant differences and needs - are valued and supported.

Tyrone is a great "honey-do" hubby at home. But he can't do everything for himself, so he occasionally hires a plumber or an electrician. Oscar is thrilled to have his own apartment, but can't do everything himself - including getting dressed and undressed - so his family and neighbors pitch in and he pays for other assistance.

Maria cannot sit through the Sunday morning sermon without rhythmically shaking her right leg as it's crossed over her left, and she also doodles

on the Sunday program. Tony cannot sit through church without occasionally flapping his arms and rocking back and forth in the pew.

To be successful at home, school, work, and in other environments, to achieve our hopes and dreams, and/or to simply get through each day, **everyone** needs assistive technology (AT), accommodations, and supports. The examples above describe these **ordinary needs** of a variety of different people. And as you might have figured out by now, the second example in each description involves people with disabilities.

Too often, however, we say children and adults with disabilities have "special needs." In another article (*The Case Against "Special Needs"* available at [www.disabilityisnatural.com](http://www.disabilityisnatural.com)), I describe the dangers of using this term to describe individuals with disabilities, as in, "She has special needs." This descriptor generates pity, segregation, and worse.

But we need to take an even closer look at the consequences of the "special needs" mentality. For it seems that identifying the needs of a person with a disability as "special" and using the term "special needs" leads to the perception that these needs are different, extraordinary, expensive, and/or abnormal. This perception, in turn, results in these needs not being met, and the negative chain of events ends with exclusion and segregation, loss of opportunities, the presumption of incompetence, and more!

For example, Julia, a child with a disability, is not talking and cannot write with a pencil. Based on formal assessments, she's said to have an IQ of 50 (and is presumed incompetent). As a result, her teachers and parents believe she must be in the special ed room where her "special needs" can be met. Speech and occupational therapists will attempt to help Julia learn to talk and write. Based on her IQ, it's believed she can't learn academics, so she'll be taught life-skills. (But are we sure the assessment is correct? If one doesn't talk or write, how can a traditional assessment provide an accurate picture of one's abilities?)

Would Julia's parents and teachers go without

## No, Not "Special"...They are Ordinary Needs continued

their computers for writing, along with their cell phones which they use to communicate with others? Then why should they deny these tools to Julia?

It's time to recognize that the needs of children and adults with disabilities are ordinary - just as ordinary as the needs of people without disabilities. *Furthermore, AT, supports, and accommodations are the pillars upon which inclusion and success are built!*

Because when Julia is provided with a speech output device and a computer for writing, she can demonstrate her competence and abilities; be included in an age-appropriate general ed classroom, as well as typical community activities; make friends, and live a self-determined life of her dreams.

Stephen had been denied opportunities to get a real job because of "inappropriate behavior." But when he was provided with behavior supports and the environment was modified to meet his needs, his "innappropriate behavior" magically disappeared. There are certain work activities Stephen performs best with a co-worker, and others he does best alone. He needs the freedom to take frequent short breaks when stress builds up, and he needs only one "go-to" person when he needs help, instead of the multiple layers of staff used by co-workers. His employer is willing to do what it takes to ensure all of his employees are successful - for that's what makes his company successful. Similarly, teachers in inclusive classrooms are doing the same for students who need behavior supports and other accommodations.

Assistive technology devices can be defined as anything that makes life easier or better - and they come in all shapes and sizes, and are used by everyone. A carpenter needs a good hammer; a busier carpenter needs a high-tech nail gun. A doctor needs the best and newest equipment - or would you prefer one who diagnoses with just a stethoscope? Look around your home and office. Could you get by without your computer, printer, cell phone, microwave oven, garage door opener, and . . . Make a list to see how dependent you are on all the AT devices in your life!

Supports - including behavior supports - come in many forms. Tobacco, caffeine, chocolate, shopping, daydreaming, whisker-pulling, crotch-rubbing, sports betting, hugs, sex, a comforting word, exercise, calling in sick when you're not, and many, many, many other things or activities that help us get through the daily grind. *Which of your supports would you be willing to go without? And haven't most of us exhibited "inappropriate behavior" when our needs aren't being met?*

Accommodations also come in a variety of shapes and sizes, including flex-time, a personalized workspace, music playing softly at bedtime, a boss or teacher who really listens and cares, an atmosphere that supports creativity, and much, much more. *What type and how many accommodations do you use at home, work, or in other environments? And which would you be willing to go without?*

Examine your own life with regard to needs that are ordinary, but crucial to your success. Now look at the individuals with disabilities in your life. Are inclusion and success in any environment being denied to them because their needs aren't being met? Can we continue to put the burden of failure on their shoulders? Isn't it time we took responsibility for our beliefs and actions, and our refusal to recognize that their needs are just as ordinary and important as ours?

It's time for swift and positive change to ensure children and adults with disabilities have the same opportunities and experiences most of us take for granted. And this will happen when their ordinary needs for assistive technology, supports, and modifications are met. Can we afford to do anything less?

*"We can believe what we choose. We are answerable for what we choose to believe."*

John Henry Newman

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## Health Care Guidelines for Individuals with Down Syndrome

An interview with William I. Cohen, M.D., NDSS Board Member and Chair, NDSS Clinical Advisory Board. William I. Cohen, M.D., specializes in developmental and behavioral pediatrics in the Child Development Unit of the Children's Hospital of Pittsburgh. He directs the Down Syndrome Center of Western Pennsylvania and is an associate professor of pediatrics and psychiatry at the University of Pittsburgh School of Medicine. Dr. Cohen is also co-founder of the Down Syndrome Medical Interest Group, and medicine editor for the Down Syndrome Quarterly.

**The "Health Care Guidelines for Individuals with Down Syndrome" were written for medical and health care professionals, as well as educators, but they also are designed as a resource for parents and other caregivers. Why is this document such an important tool?**

The importance of the document is to support parents in getting the screening tests done that we believe are important to keep children and adults with Down syndrome healthy. Pediatricians may have between three and five children with Down syndrome in their practice, and although they may be knowledgeable about the current recommendations, I don't expect them to be able to keep up in the same way as parents, who really become experts about the needs of their children. And even though we write about and present these issues in a variety of forums - at scientific meetings and continuing medical education conferences - the issue may not be as compelling for physicians as it is for parents.

The "Health Care Guidelines" are supposed to help 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, too, because it defines the medical vulnerabilities and the necessary screenings.

We designed the guidelines to come into physicians' offices through the professional circuit, but also through families. If I send out something to all the physicians in our area, it may or may not get filed in a place that's going to be useful. But when Mrs. Smith comes in with Billy and has the document in her hand, it goes into Billy's chart where it needs to be.

**What advice can you give to new or expectant parents about selecting a pediatrician and other health care professionals to work with their child with Down syndrome?**

That's a very interesting question, and it comes up very often when we see patients in the Down Syndrome Center. The notion that many folks would have is that they need to find someone who's very knowledgeable; that it really is going to help them to have somebody who is an expert on Down syndrome. In my experience, some of the people who believe they may be experts on Down syndrome may

not be current. They may be enamored of their expertise and fail to listen to parents about what may be different with their child.

A mother once came to me with a new baby and said, "My doctor is a family physician, and he said that he doesn't know anything about Down syndrome." I anticipated that she had reacted to this as if it was a problem, but she went on to say, "And so he told me that any information I could bring him would be so appreciated." He, indeed, is the kind of physician you want - one who is open to partnering with a family. The knowledge that someone has is necessary, but not sufficient. In fact, not having the knowledge is less of a problem than believing you have it.

What we need when we have a child with special health care needs is someone who will collaborate - who is open to listening to parents and seeing them as partners. We need to know how to identify someone with that style. One of the best ways to find a pediatrician is to ask families of other children with Down syndrome in the area. Going to parent support groups can be very helpful.

**The guidelines - even in their summarized form - are very complex and scientific. What is the best way for parents and other caregivers to educate themselves about the many issues they address?**

This may be a matter of formatting; it may have become too dense. We've already talked about a "Headline News" version for the next version, instead of "The MacNeil Lehrer Report." On the other hand, parents don't want to get half-information. They would rather have it all and then sift through it. When we see new babies, one parent may want all the information and will enjoy getting as much background they can, whereas another family member may be overwhelmed. We like to try and let people know that they can choose how much to read or not read. It's very rare that you get a baby with an owner's manual.

And there's good news and bad news in the guidelines. We talk about things that can happen, but rarely do occur. Dr. Allen Crocker from Boston Children's Hospital has talked about "ghosts," which terrify families. These are things that occur very, very rarely but do happen with a slightly greater incidence in children with Down syndrome. Still, they linger out there even though the likelihood is low.

We encourage parents to do what's comfortable for them. The important thing is that the information is there for them and they can choose to use it as they want. To say, "Well, we're going to dumb it down" would be insulting to the parents. There are a lot of sophisticated parents out there. It's fascinating how knowledgeable the family of a child around six weeks old can be about this condition. I point this out to the residents, but then I say to them, "Well, of course, all they have to learn is one disorder

## Health Care Guidelines continued

and you have to learn the whole textbook in pediatrics." But it is pretty impressive because the need to know is so great.

I am trying to foster in pediatric residents the idea that these parents are going to be their allies. They should learn to collaborate with them and listen to what they have to say, and also learn to prioritize based on what the family's issues are.

The guidelines have very specific recommendations for five age groups: newborn, infancy, childhood, adolescence and adulthood. Is it realistic to expect a health care professional to maintain such a high degree of diligence?

I don't think they're onerous. We're talking about hearing screening every six months to about three years, vision screening annually, thyroid function testing annually, celiac screening at about two years of age, neck x-ray between three and five. And then being aware that there are some vulnerabilities to some other conditions, and not saying, "Whatever it is, it's just the Down syndrome."

The whole point of the guidelines, in a sense, is to overcome the notion that "if anything is going wrong, it's Down syndrome" rather than a treatable and definable condition. That's unacceptable.

**What effort is being made to inform health care professionals about the need for specific and**

**proactive treatment for people with Down syndrome throughout their lives?**

The health supervision guidelines from the American Academy of Pediatrics are published in Pediatrics. Members of our group present this information at pediatric grand rounds locally and nationally whenever we get invited. A colleague, Dr. David Smith, has written an article for Family Physician about adult health care. There are presentations at continuing medical education conferences. I'm doing one for the American Academy of Pediatrics in Vancouver in September. There are big conferences about health care that are often held by parent groups. I caution parent groups that primary-care physicians are not going to take a day to learn about all the problems of kids with Down syndrome. It's just not that salient for them. There are regional conferences as well, and many of the members of the Down Syndrome Medical Interest Group are involved in this education. ***But I will tell you that the most effective thing we do is educate parents to be the educator for the physician.***

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***Please contact Cindy Huston for a copy of the Health Care Guidelines and a Record Sheet that lists specific medical issues and how often they need to be reviewed. These recommendations cover infancy through adulthood.***

## Abnormal Sleep Patterns Appear Common in Children with Down Syndrome

More than half of children with Down syndrome may have abnormal sleep patterns and obstructive sleep apnea syndrome, and parents may not be able to determine whether their children are among those with sleep difficulties, according to an article in the April issue of Archives of Otolaryngology & Head & Neck Surgery, one of the JAMA/Archives Journals.

Obstructive sleep apnea (OSA) occurs when, during sleep, an individual's upper airway becomes blocked, resulting in a temporary cessation of breathing. OSA occurs in an estimated 30 to 60% of the Down syndrome (DS) population, according to background information in the article. Children with DS also are at greater risk for the development of obstructive sleep apnea syndrome (OSAS), a broader term for sleep abnormalities that includes complete and partial airway obstruction, chronic obstructive hypoventilation (inadequate ventilation with not enough air getting into the lungs) with hypercarbia (excess of carbon dioxide in the blood) and hypoxemia (lower than normal amount of oxygen in the blood).

Sally R. Shott, MD, and colleagues from Cincinnati Children's Hospital Medical Center performed sleep studies on children with DS to determine the occurrence of OSAS. Fifty-six children with DS (ages 4 to 63 months, average age 42 months) completed overnight polysomnography (PSG), a test of sleep studies that monitors brain waves, breathing, stages of sleep and oxygen levels in the blood, among other variables. The children's parents also completed a survey about their child's sleep patterns.

Thirty-two (57%) of the children had abnormal PSG results and evidence of obstructive sleep apnea syndrome. When the researchers included an elevated arousal index (ten or more disturbances in sleep per hour), 80% of the children had abnormal results. Rapid eye movement (REM) sleep should make up 25 to 30% of sleep time in children younger than 5 years old, and in this group, only 9 children spent more than 25% of their sleep time in REM. Of the 35 parents who completed surveys, 69% of them reported that their child had no sleep problems, however among that 69% of children, 54% had abnormal study results. 36% of the children of parents who reported sleep problems in their children had abnormal PSG results.

***"Because of the high incidence of obstructive sleep apnea syndrome in young children with DS, and the poor correlation between parental impressions of sleep problems and PSG results, baseline PSG is recommended in all children with DS at age 3 to 4 years old," the authors write.***

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## A Day in the Life of GRADSA Members...



Kathleen Kight, Taylor Palmer, & Elizabeth Stickler, participated in the Arts workshop in August.



Aaron Shoemaker spent time with Willie Nelson at the Texas Roadhouse Golf Tournament to benefit the Special Olympics.

Shannon Peterson & David Fogle enjoyed a night at Goldies.



GRADSA members David Huston, Jeff Winstead, and Eric Sherrard, participated in a Golf Scramble sponsored by the Owensboro Association of Insurance & Financial Advisors. \$2,100 was donated to GRADSA.

Kindergarten students from Meadowlands Elementary held their own Buddy Walk on October 6, collecting \$372 for GRADSA. Guests of honor were Amie Morris, Jonah Edge, Taylor Palmer, and Leland Isbill.

## Holiday World Outing

30 GRADSA families enjoyed a beautiful day at Holiday World in September.



Colin Powers enjoyed the waves at Splashin' Safari.



Paige Roberts was all smiles, as usual!



Joseph Clements loved the wave pool.



Amie Morris had a BALL at Holiday World!



Laura Whitfell was ready to get wet on the log ride.



Elliott Williams jumped in the bouncer.



Elizabeth Stickler had fun on the water slide.



Beth Wilson and her family prepare to get wet on Ragin' Rapids.

## November/December Birthdays

**Steven Ballard**, 40 years old on Nov. 30  
**Michael Castlen**, 53 years old on Nov. 19  
**Hannah Hardesty**, 2 years old on Dec. 27  
**Paxton Hocker**, 11 years old on Dec. 26  
**Matthew Huston**, 6 years old on Nov. 10  
**Lukas Mahoney**, 7 years old on Dec. 15  
**Christina Martinez**, 3 years old on Dec. 6  
**Joey McAtee**, 21 years old on Nov. 25  
**Tammy Sears**, 38 years old on Dec. 8  
**Ana Lilia Sedillo**, 15 years old on Nov. 8  
**Ann Switzer**, 6 years old on Dec. 28  
**Mark Vollman**, 46 years old on Dec. 28  
**Zeb Wells**, 1 year old on Dec. 17  
**Jonathan Whittaker**, 12 years old on Nov. 4  
**Alan Wood**, 35 years old on Dec. 16



**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](http://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 editorial, therapy, or article printed in *Heart Strings*.

## 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, December 4, 6 p.m., at the Owensboro Family Y.

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