



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.

March/April 2007

Message from Executive Director

Parents of children with disabilities can relate to how exciting it is when your child reaches a goal, especially one that may seem relatively easy for a child without cognitive delays. Our family has been in celebration mode as Matthew has achieved a huge accomplishment that we have been working on for a long time - toilet training! He has been "halfway" there for about a year but we have been struggling with the "other" half. One day when we least expected it, things just "clicked." Finally, he understood what we've been trying to explain to him all this time...and acted on it! It reminded us that we need to always think positive and know that he WILL reach those milestones - maybe a little later than a "typical" child but he will get there nonetheless.

Many of you with school-aged children will be reviewing your child's IEP soon for the next school year. Included in this issue of *Heart Strings* are two articles from *Disability Solutions* on how to improve your relationship with school personnel. It is important to establish good communication skills as you will be working together for the next 12+ years to provide a quality education program for your child. On page 3, there is a checklist of questions for both parents and professionals to review.

Also included in this edition is GRADSA's Annual Report for 2006. We had a very productive year and are looking forward to another one in 2007. We are continually grateful for the wonderful community support that enables us to serve our members.

I hope you enjoy the pictures from the Valentine's Dance and Playgroup. Both events were fun-filled and enjoyed by all. Don't miss the Easter EGGstravaganza scheduled for April 7.

I am looking forward to the Medical and Behavior Workshop on March 24. This workshop is open to anyone interested in learning more about medical and behavior issues in individuals with Down syndrome. Please invite your child's doctor, teachers, and service providers to attend this informative workshop.

Be sure and check the calendar for more details on upcoming events. Hope to see you soon!

Cindy Huston

Calendar of Events

Saturday, March 3, Dad's Night Out, 5:30 p.m. at Johnny B's Pizza. All dads of children and adults with Down syndrome are invited to enjoy a relaxing night out. **Please RSVP to Cindy Huston.**

Saturday, March 24, Medical & Behavior Workshop, 9 a.m. - 12 p.m. at Kentucky Wesleyan College (Rogers Hall in the Winchester Center). Presentations will be made by Dr. Robert VanDervoort, MD, Medical Director at the Vanderbilt Down Syndrome Clinic, and Linda Ashford, PhD, Psychologist with the Clinic. Dr. VanDervoort will discuss medical issues common in individuals with Down syndrome and Dr. Ashford will discuss behavior concerns. Lunch will be provided. **Parents, physicians, teachers, and service providers are all invited to attend. Please RSVP to Cindy Huston by March 17.**

Saturday, April 7, Easter EGGstravaganza, 10:30 a.m. - 12:30 p.m. at the Family Y, Pizza and refreshments will be available. This event is open to children with Down syndrome & their siblings, ages 12 & under. **Please RSVP to Cindy Huston.**

Friday and Saturday, May 4-5, Fired Up for Down Syndrome Conference in Franklin, TN, Sponsored by the Down Syndrome Association of Middle Tennessee. This conference is for family members, health care professionals, educators, and community professionals. There will be many noted speakers, including Dr. Lawrence Leichtman, Dr. George Capone, and Dr. Brian Skotko, and a variety of topics presented. For more information, you can visit their website at: www.dsamt.org or call (615) 386-9002. **Remember, GRADSA offers funding for parents to attend educational conferences. Please contact Cindy Huston for an application.**

Saturday, May 19, Supported Employment Workshop, 9 a.m. - 12 p.m. at Kentucky Wesleyan College (Cox Conference Room in the Winchester Center). This workshop will be presented by Milton Tyree, Kentucky Supported Employment Training Project, Human Development Institute at the University of Kentucky. Lunch will be provided. **Please RSVP to Cindy Huston by May 11.**

My Hero

Heroes can be someone super,
Like Spiderman, or a Ninja Turtle.
They can be someone famous,
Someone live, or one deceased.
My hero may not have special abilities,
Or star in the greatest of films.
He may not make exciting art,
Or leap tall buildings in a single bound.
The one I hold in my highest regards,
Can't do any of that.
Laying in a hospital bed,
Or eating his favorite foods,
Sick, hardly able to move,
Or dancing to no tune.
My hero is a full ten years,
In the body of someone six.
He may be small,
With no stamina at all,
And he may be weak,
And look oh so meek.
But he's still my hero,
All the same,
And I'd never have it any other way.
I love you Jonah!



Sarah Edge with her brother, Jonah. Sarah wrote this poem while Jonah was in the Cincinnati Children's Hospital recovering from airway surgery in January. You can stay updated on his progress by visiting his mom's online journal at: www.caringbridge.com/visit/jonahedge

KEEP YOUR EYE ON THE PRIZE!

Communicating Means Success

The following is an excerpt of the article "Keep Your Eye on the Prize! Communicating Means Success" by Michael T. Bailey, that was published in the Spring 2006 issue of Disability Solutions. To view the article in full, visit their website at: www.disabilitysolutions.org

Special Education guarantees every eligible child a free and appropriate public education. It also requires that the education be accomplished through specially designed curriculum modified from the general education curriculum to meet the unique learning style of that child. It is a great concept. It is simple to understand.

IDEA is a promise as much as it is a law. It is a promise full of egalitarianism and hope. It is a promise of optimism.

Why, then, are so many parents, students, and educators frustrated and angry so much of the time? Why do so many carefully crafted plans fail to deliver their educational promise?

Why is this so hard? What happens that too often sidelines and complicates the ingenious simplicity that underlies the law? Is someone at fault? If so, who?

My belief is that damage can, and often is, done to children in special education when adults feud over them. The significance of our children's education and happiness is too important to lose in a blame-game made-up and played by adults.

What happened to good faith and calm communication? What can we, as parent advocates, do to improve the situation? Is there a crucial step that we are missing? Have we done all we possibly can do?

Communication at IEP Meetings is Crucial

Families have asked me to be their advocate in over 200 IEP meetings. Those invitations come from families facing difficulty. The IEP meetings I attend are not routine and they are not easy. Still, many of them are a success. But even one that is a failure is way too many. Why do some succeed and some fail?

Parents and educators agree that communication is the key to a successful IEP. Both "sides" must take steps to acknowledge and address it.

There is an abundance of legal resources to help parents learn law and procedure. Every state has a Parent Training Center that teaches IEP advocacy. Many parents have a sophisticated knowledge of IEP procedure, related services, supplemental aids and services and the rest of the cacophony of terms we all learn.

College, graduate school, in-service training, and education system culture train and groom professionals in how to run the meetings, and curiously, how to deal with us. Most districts maintain advisory councils and other committees that include parents to promote collaboration and mutual respect.

But, in spite of our best effort, the meetings are often emotional, unpleasant and far from focused on the needs of one child at a time.

What's Missing?

What is lacking in many meetings, and crucial follow-up interactions with schools, are some fundamental communication skills. Are they listening? Often they are not. Is that entirely the fault of educators? Or do we shoulder our share of blame by being poor communicators? Before we condemn school personnel, it is entirely appropriate that we look to our own demeanor first. Are we doing something wrong? How can we improve?

Novelist Owen Wister offers some insight into real communication. "Smile when you call me that," is recognition that English is a language lacking in subjective verbs. To communicate our real meaning, we rely on gesture, body language, and timber of voice. A conversation is handled much differently than a written communication. And it is conversation that we have with school personnel. We must rely on more skills than just the use of words, even cool words that we learned in IEP trainings. We need to learn to listen both to ourselves and to them. Most importantly, both parents and school personnel need to listen to your child, their student. (continued on page 3)

A Checklist for Families

Do I believe that I am an equal partner with professionals, accepting my share of the responsibility for solving problems and making plans for my child?

Am I able to see a professional as a person who is working with me on behalf of my child?

Do I see my goal, when interacting with professionals, as the mutual understanding of problems so that we can work together to solve them?

Do I maintain a file of important documents and correspondence so that I have a complete history of services provided to my child and family?

Do I clearly express my own needs and the needs of my family in an assertive manner?

Do I clearly state my desire to be an active participant in the decision-making process concerning services for my child? Do I seek mutual agreement on ways to assure my involvement?

Do I take an assertive role in planning and implementing my child's plan?

Do I come to appointments having thought through the information I want to give and the questions I want answered?

Do I accept the fact that a professional often has a large load of families and students to deal with and not just mine?

Do I treat each professional as an individual and avoid letting past negative experiences or attitudes get in the way of establishing a good working relationship?

Do I communicate quickly with professionals who are serving the needs of my child when there are family changes or other notable events in my child's life?

Do I take the opportunity to communicate with other parents? Do we share stories and successes? Do we support each other in reducing isolation? Do I generously share with others the expertise I have gained?

Do I encourage professionals to communicate with one another and to keep me informed as well?

A Checklist for Professionals

Can I imagine myself in this parent's place? Have I mentally reversed roles to imagine how I would feel as the parent of this child?

Do I see this child as a little human who is more than one-dimensional? Can I look beyond the diagnosis, labeling, and disability?

Do I remember that this child about whom we are talking is someone the parent loves?

Do I really believe that parents are equal to me as a professional and, in fact, are experts on their own child?

Do I constantly value the comments and insights of parents and make use of their reservoir of knowledge about the child's total needs?

Do I communicate hope to parents when I judge their child's progress?

Do I listen to parents, communicating with words, eye contact, and posture that I respect and value their insights?

Do I ask parents questions, listen to their answers, and respond to them?

Do I work to create an environment in which parents are comfortable enough to speak candidly to me?

Am I informed about the child prior to a meeting? Do I place equal value on the parent's time and my own?

Do I treat each parent I come in contact with as an adult who can understand a subject as well as I can?

Do I speak plainly, avoiding the jargon of medicine, sociology, education, psychology, or social work?

Do I make a consistent effort to consider the child as part of a family, consulting parents about the important people in the child's life and how their attitudes and reactions can affect the child?

Do I distinguish between fact and fiction when I discuss a child's problems and potential with parents?

Continued from page 5:

I believe forgiveness strengthens my ability to advocate effectively. By letting go of resentment and anger, people are more willing to talk and problem-solve. They are less likely to worry the discussion will become a battle with an angry parent. Remember, forgiving someone does not mean they are not accountable for their actions. No one loses their rights by forgiving an injustice.

Learning forgiveness has given me a lot to think about. Have I truly forgiven every situation I am resentful over? No. But I am working on it. I am learning that it is harder to forgive those things that I have held onto for a long time - such as the IEP I mentioned earlier - than events that are recent. Perhaps our response to situations becomes so ingrained that changing how we feel about it takes time and work. After all, forgiveness is not meant to be easy, if done correctly.

These days I am not as easily upset in meetings about my son, though I have my moments. I am working on remembering to truly examine the situation, tease out the lessons, and then work on forgiveness. It feels much healthier. And I am much happier for the work.



Shannon Peterson and David Fogle snuggle for a slow dance.



Linda Murphy danced the whole night long!



Mark Vollman gets a hand from a friend.



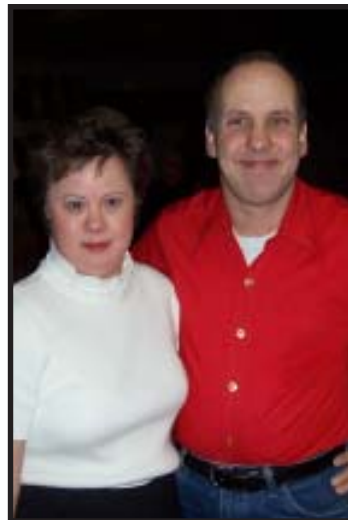
Alan Woods and Shannon Peterson show off their fancy moves.



Dana Hamilton and Shawn Riney enjoyed dancing to "YMCA."



Adrienne Free and Aaron Shoemaker enjoy a slow dance.



Chris Hagan poses with a friend.



Michael Smith and Shannon Mahoney ham it up.

An Effective Complement: Advocacy & Forgiveness

Living the life of a disability advocate can make the world seem like a very adversarial place. Of course, it depends on your experience. Most of the time, parents of children in early intervention services feel nurtured by their early childhood specialists. Everyone is concerned about the development and health of your baby and looks for the typical milestones along with you. Parents feel supported as specialists suggest strategies to keep the baby from sliding out of the high chair, to finally get up on all fours to crawl, or to sign their first word, "more," which everyone regrets later. I hear many parents describe Early Intervention services as a type of cocoon, protecting them from what lies ahead just around the corner: school-aged services.

Over the years, I've had to advocate staunchly for my son. I remember walking into a "brainstorming meeting" to find it was a full-blown IEP review with no notice. Seventeen people sat around a table smiling pleasantly at me, reassuring me there was nothing to worry about. He was only five at the time. In those early years I was devastated after every meeting. I felt exhausted - like one of the "Dementors" from Harry Potter had sucked all but a last breath from me. In just a short time, "advocacy" became synonymous with anger and frustration.

Since then, I've learned that being an effective advocate for my son, who has significant disabilities, means having impenetrable skin. It also means not thinking of him as my son, or me as his mother, during the meetings or at school. Rather, it becomes a business deal from my perspective. I force myself to sit back and watch the interaction of the team, listen to their comments, and then ask for the time I need to process the information. All must be done with as little emotion as possible. Sometimes I am more successful than others.

There are times when my feelings get the best of me and I am overwrought with anger, hurt, resentment - every negative feeling we have words to describe and some we do not. It is easy, perhaps too easy, for parents to fall into a constant pattern of righteous indignation. One of the best things about the years Andy was included in elementary school was being able to spend time with other parents who were constructively involved with the school community rather than being surrounded by anger and frustration all the time. This is because the school did not have a "special education room." When he moved on to middle school, I cried when I met some parents in his homeroom, a visually based classroom. The first meeting I attended was filled with anger, bitterness, and blame. I felt like I was being poisoned.

How did this happen? I agree that more often than not parents have a lot to be frustrated and angry about. Constantly maneuvering to find someone who sees your child as a great kid (rather than being told all the things he can't do) is not easy. Living under the microscope of special education without feeling judged at some point is impossible. The "evaluation" is not limited to academics, school situations, or your child's strengths. Folks tend to want to know just what it is we're doing at home to teach our children.

I've been doing some reading on forgiveness over the past year. I am increasingly convinced it is the missing link in advocacy efforts. Not being able to forgive eats away at us and breeds bitterness. The injustice takes on a life of its own; it is all-consuming. It becomes a part of daily life. That means your adversary wins.

My first introduction to this concept came from the book, "How Good Do We Have To Be?" by Harold Kushner. He tells the story of asking a woman whose husband had an affair, left her, and fell chronically behind in child support payments to forgive her husband. When asked how he could suggest such a thing, he replied, "I'm not asking you to forgive him because what he did wasn't so terrible; it was terrible. I'm suggesting that you forgive him because he doesn't deserve to have this power to turn you into a bitter, resentful woman." For me, that was a new spin on forgiving someone.

The last thing my children need is a bitter, resentful, angry mother, nor do I want to be that person. I enjoy life and like to revel in the good things, large and small. I love watching my children learn and grow, each at their own pace. I enjoy being helpful and looking for constructive solutions or steps to overwhelming situations. I like to laugh. I want to be a nice, warm-hearted person, not a sour, negative, cross one. I want to be able to walk into my son's school community and be the person I was before special education entered my life.

Like many people, I wondered if I forgive people who have hurt me - whether it was intentional or not - I also agree that nothing wrong happened. What I have learned is I do not. I had to learn what forgiveness is, and what it is not. Here is some of what I have learned.

Forgiveness is:

- letting go of the anger and resentment you feel.
- looking for the good in a situation.
- restraint from seeking revenge & harboring resentment.
- a freely chosen gift.
- a personal decision. It only takes one person to forgive.
- a way of healing your wounds from the injustices and hurts you have incurred.
- healthy. Research suggests forgiving those who offend you may ease depression, high blood pressure, backaches, muscle tension, and even heart disease.
- brave. It takes a brave person to forgive someone who has hurt them without asking for anything in return.

Forgiveness is not:

- forgetting what happened. In fact, it is better to forgive *without* forgetting. "You can forgive the bully and still watch your back." (Bob Enright, International Forgiveness Institute). We can learn from every experience and make corrections. This strategy seems the best for advocacy work. Learning (and remembering who you can trust) without hanging on to the bitterness.
- letting the other person or people off the hook. You can forgive someone and still hold them accountable for their actions. This is especially true in legal situations, including IEP meetings. Rules are rules.
- a guarantee there will be a reconciliation. Forgiveness is a gift we choose to offer to another person. They may not reciprocate. It takes two people to reconcile.
- overlooking what happened. In fact, in order to forgive, a person must truly understand the offending event.
- condemning someone. Back-handed forgiveness doesn't do anyone any good. In other words, offering forgiveness to show how hurt you are defeats the purpose.
- a means to justice. Forgiveness does not demand compensation first. You choose to give it or not, no strings attached.

(continued on page 3)

Play Group

GRADSA members enjoyed a fun morning at Owensboro Gymnast on January 27.



Kathleen Kight tries out the balance beam.



Leland Isbill and Taylor Palmer pose for a picture.



Luke Stone plays with a bouncy ball.



Matthew Huston swings on the rings.



Mitchell Hensley rolls in the tumbler.



Jonathan Whittaker liked playing with the balls.



Sam Fenwick rides on the scooter.



Elliott Williams and dad play in the foam pit.



Sam Winstead climbs up the slide.

2006 ANNUAL REPORT



The Green River Area Down Syndrome Association is a non-profit organization whose 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 and adults with Down syndrome. GRADSA also seeks to provide the entire community with information and education to broaden awareness and foster positive attitudes regarding people with Down syndrome. Below is a recap of services provided in 2006:

Published 7 issues of *Heart Strings*, including a Buddy Walk special edition, that were mailed to nearly 300 families, professionals, and educators.

Launched a new website - www.gradsa.org - with a fresh, user-friendly design.

Held 6 educational events - Workshops on Sign Language, Brain Gym, Teaching Math to People with Down Syndrome, VSA Arts, and Estate Planning. We also hosted a Book Fair, which provided 24 titles on Down syndrome to parents and teachers.

Provided funds for seven parents to attend educational conferences.

Purchased 10 books/videos and copies of the *Everyone Counts: Teaching Acceptance and Inclusion* for the Resource Library.

Created and distributed Teacher Information Kits to help educators support students with Down syndrome in the classroom.

Served 12 children in the Birth-3 program, which provides therapeutic items such as plexi-glass mirrors, therapy balls, boppy pillows, horn and straw programs, and educational books. Provided new parent packets to 3 families.

Supplied copies of the book "Babies with Down Syndrome: A New Parent's Guide" to Methodist Hospital in Henderson for distribution to new parents.

Provided support to 10 families who were facing medical crises.

Offered 8 social activities for families - Valentine's Dance, Bowling Party, Mom's and Dad's Night Out, Easter EGGstravaganza, Holiday World Outing, Playgroup, and Christmas Party



Hosted the annual Buddy Walk, a community event that promotes acceptance and inclusion for individuals with Down syndrome. Over 1,000 people attended the walk, including 56 who had Down syndrome. The Buddy Walk is also our only fundraiser. We are fortunate to have many loyal supporters who contribute to our mission.

Administration/Board Expenses - 12%

Office supplies, mailing expenses, NDSS dues, liability insurance, and volunteer appreciation gifts.

Buddy Walk - 18%

T-shirts, pledge incentives, Showmobile rental, awards, and other miscellaneous expenses.

Education/Outreach - 22%

Educational workshops, resource library, conference fund, newsletter postage, website development & hosting, new parent outreach and hospital outreach.

Executive Director's Fee - 27%

Included a monthly fee and incentive plan.

Social Activities - 21%

Valentine's Dance, Bowling Party, Mom's and Dad's Night Out, Easter EGGstravaganza, Holiday World Outing, Playgroup, and Christmas Party.

March/April Birthdays

Matthew Cook, 9 years old on March 17
Tatum Edge, 1 year old on March 6
Adrienne Free, 20 years old on March 21
Judy Haggard, 54 years old on April 7
Leland Isbill, 9 years old on April 30
Seth Johnson, 5 years old on April 13
Robbie Sherrard, 3 years old on April 13
Roy Taylor, 14 years old on April 2
Peyton VanMeter, 13 years old on April 13
Elliott Williams, 3 years old on March 19
Sam Winstead, 7 years old on March 24



Tatum Edge



Matthew Cook

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 and adults with Down syndrome.

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 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.

Board Members

Matthew Williams, President

Home: (270) 689-1695

Cell: (270) 929-6348

E-mail: Matthew.Williams@aleris.com

Stephanie Stickler, Vice President

Phone: (270) 683-9100

E-mail: sticklersl@omu.org

Michele Cecil, Director

Carrie Colbert, Director

Steve Hagan, Director

Tony Hamilton, 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, March 12, 6 p.m., at the Family YMCA. All board meetings are open to the general membership.

Owensboro, KY 42302

P.O. Box 2031

GRADSA
GREEN RIVER AREA
DOWN SYNDROME ASSOCIATION

