



HEART STRINGS

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

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

January/February 2007

Message from Executive Director

It is with great sadness that I submit my resignation as Executive Director of GRADSA. The past 3 years have been one of the most rewarding times of my life but my spirit tells me that it is time to move on to the next chapter. I appreciate the support and encouragement shown to me during this time. The best part of my job has been getting to know all of the children and adults with Down syndrome and their families. I look forward to continued friendships with those who share and value the special bond we have. Members of the board and I will do our best to make this a smooth transition and provide uninterrupted services to our members.

Included in this issue of *Heart Strings* are two medical articles on Pain Tolerance and Recurrent Boils. When Matthew was a baby, we noticed he did not seem to respond to pain. However, in the last few years, every time he barely bumps into something, he says "boo boo" and we have to kiss it! In all seriousness, this is something we should all be aware of. I have heard many moms and dads attest that their child with Down syndrome had an increased pain tolerance. I have even noticed that when Matthew gets sick, it usually hits him in full force, making me think he was not able to communicate the feelings of illness coming on, like most of us are able to do. It is very important to seek medical care on a timely basis.

On page 4, there is an informative article with tips on Communication. Until I read the book "Teaching Reading to Children with Down Syndrome", I did not realize the difference between "teaching" and "testing." I now understand that Matthew has to be taught the concepts prior to being tested on them. I simply can't hold up new flash cards and ask him what the word or picture is. This book is an excellent resource and is available in our Resource Library. There is also a great idea for homemade picture books to help your child adjust to new situations. We have tried these and they work great!

On page 5, Christie Ashby, mother of Landon, who just turned 1 year old, shares the trials and blessings of their first year together. Her testimony demonstrates how the joys our children bring to us far outweigh the challenges we may face in raising them.

GRADSA has a busy schedule for the 1st quarter of 2007! Be sure and mark your calendar for the events listed in the right-hand column. There should be something of interest for everyone.

Please keep Jonah Edge in your prayers. Jonah is scheduled to have the first of two airway surgeries on January 10. If all goes as planned, his second surgery will be about a month later. You can stay updated on his progress by visiting the following website:
www.caringbridge.com/visit/jonahedge

Hope to see you soon!

Cindy Huston

Message from the President

I hope everyone had a safe and happy holiday season. We have an exciting year ahead of us in 2007. Over the past few months, we have endured many changes. One in particular, our Executive Director and backbone of GRADSA, Cindy Huston, has decided to pursue a new career effective May 31. I would like to take this opportunity to personally thank Cindy for taking GRADSA to new heights. The passion and devotion she puts forth in planning all the events and opportunities for our members will be sadly missed. Please wish her well in her future endeavors.

With that said, GRADSA is currently accepting resumes for this position. We are seeking a highly motivated, detail-oriented self-starter with excellent computer skills, the ability to communicate with a wide range of constituents, including individuals with Down syndrome and their families, educators, service providers, physicians, media, affiliate leaders, and community supporters. Knowledge of Down syndrome and the disability community, specifically in the areas of health, development, education, and appropriate language guidelines, is required. This is a part-time position, approximately 20 hours per week. Applicants should submit a cover letter and resume with 3 professional references to me at: 2305 Ben Ali Court, Owensboro, KY 42301. Deadline is February 15.

Also, we are looking for anyone interested in serving as a Board Member. Please feel free to call or email me with any questions.

Matthew Williams

Calendar of Events

Thursday, January 25, Educational Advocacy Seminar, Presented by Leslie Lederer, Disability Rights Advocate with Protection & Advocacy, 6 - 8 p.m. at the Family Y (2nd floor). This seminar will discuss your child's rights through the Individuals with Disabilities Education Act (IDEA) and tips on writing effective IEP's. Sandwiches and child care will be available. **Please RSVP to Cindy Huston by January 24.**

Saturday, January 27, Play Group, 11 a.m. - 12:30 p.m. at Owensboro Gymnast, 3239 Alvey Park Drive East (off Hwy 54). This event is open to children with Down syndrome and their siblings ages 10 and under. There will be one hour of fun in the gym followed by pizza and refreshments. **Please RSVP to Cindy Huston by January 26.**

Saturday, February 10, Valentine's Dance, 7 - 9 p.m. at Owensboro Middle School (cafeteria). Teens and adults with Down syndrome are invited to dance the night away with DJ Dale Sanders. The dance is sponsored by GRADSA and Special Olympics. Pizza, refreshments, and cake will be served.

Saturday, February 24, Mom's Night Out, 5:30 p.m. at Olive Garden. All moms of children and adults with Down syndrome are invited to enjoy a relaxing evening out. **Please RSVP to Cindy Huston by February 23.**

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 by March 2.**

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. **Please RSVP to Cindy Huston by March 17.**

In Sympathy

Steve Paulson, 42, of Fordsville, passed away on December 11, 2006. He was the father of Raven Paulson, a delightful young girl with Down syndrome. We extend our deepest sympathy to her family.

Conner Merimee, 2, of Evansville, passed away on December 14, 2006. Connor was a precious child with Down syndrome who fought a courageous battle with leukemia. We extend our deepest sympathy to his parents, Steven and Gayle, and their family.

Marty Hubbs, 49, of Tell City, passed away on December 24, 2006. Marty was a lovely woman with Down syndrome who was a blessing to all who knew her. She is the sister of Meg Boswell of Owensboro. We extend our deepest sympathy to Marty's family.

Sports Issue

Calling all sports enthusiasts! The next issue of *Heart Strings* will feature children and adults with Down syndrome participating in all types of sports - soccer, softball, basketball, golf, tennis, gymnastics, bowling, karate, swimming, horseback riding, skating - whatever your sport is, we want to know about it! Please send your photos and stories to us by February 15.

Additions to Resource Library

The following items were donated by Carolyn Wheeler, director of Hope for Tomorrow, to help guide you in planning for the future of your loved one with a disability.

Safe and Secure by By: Al Etmanski with Jack Collins and Vickie Cammack

A Good Life By: All Etmanski

CD - Peace of Mind

Everyone Counts: Teaching Acceptance & Inclusion

This program is a curriculum to educate elementary-aged students about Down syndrome and encourage positive relationships between students with and without disabilities. It contains video clips for each grade level along with ideas for hands-on activities. GRADSA has purchased several programs for distribution to area schools. Please check with your child's school counselor about using this program. If they are interested in viewing the materials, please contact Cindy Huston.

Parent Professional Conference

The 21st Annual Parent/Professional Conference will be held March 2-4, 2007, at the Marriott Griffin Gate Resort in Lexington. The pre-registration deadline is February 16. For more information, call the Jefferson County PRC at (502) 485-3346 or (502) 485-3807. GRADSA has a fund for parents who would like to attend educational workshops. Please contact Cindy Huston for an application.



Congratulations to Joni Hidalgo and Alex Galindo on the birth of their daughter, **Elsa Ruby**. Ruby was born on September 20, 2006, and has 2 older sisters.



Luke Stone plays with his laptop as he rings in the new year. He has come along way since spending 6 weeks at Kosair with RSV a year ago. He still requires oxygen and receives his school services at home.

PAIN

Do people with Down syndrome have a greater pain tolerance than other people? Do people with Down syndrome have a normal pain tolerance but we misinterpret their complaints? The answer to both of these seemingly opposing questions is "yes."

Many families and care providers have commented to us that they think the person with Down syndrome they know has an increased pain tolerance. We have seen many examples that support these observations. Many patients have been seen with health problems that would seem to be quite uncomfortable but who had little or no complaint or discomfort.

Furthermore, a recent study provided supporting evidence in a "mouse model" for Down syndrome. Mice with a trisomy (extra chromosome) have been studied. They have been found to have similar health issues as people with Down syndrome. This mouse model was found to have a higher pain tolerance. The mouse had less response to painful stimuli.

While all that seems to support a higher pain tolerance, we also suspect that some of the apparent pain tolerance may be due to our inability to interpret the complaints of some people with Down syndrome. It may be an impairment of verbal communication skills or the absence of someone who understands the person's communication attempts. Another possibility is the reduced ability of some people with Down syndrome to appropriately self-assess where the pain originates and, thus, a limited ability to make others understand that he is experiencing pain. The person may be experiencing pain but we are just not understanding.

How can we avoid missing painful episodes?

Watch for subtle signs.

A grimace, pointing, a different spoken phrase, sweating for no apparent reason, and holding a limb differently can all be signs to note. There are probably many more that you have noticed as well.

Watch for behavioral changes.

Pain can often be expressed in a behavioral change. When I teach medical students or residents, I always emphasize that a change in behavior has to be viewed as a form of communication. This is true to some extent in all of us. People with Down syndrome are no different. However, the person with Down syndrome's ability to communicate verbally or non-verbally may be limited so he may end up telling us with a behavioral change. It could be less activity, more activity, seeking greater attention, seeking less attention, a sad affect, anger, emotional lability, reduced emotion, and many others.

Consider the possibility that a person with Down syndrome may have a reduced ability to perceive pain.

Remembering that the person with Down syndrome may also have a reduced ability to perceive pain is important as well. Keeping an eye on someone whom has what appears to be a minor complaint can help prevent missing something more concerning. If the pain persists longer than expected or there are other symptoms that could suggest something more serious despite

the person having little complaint, it could be time to have it further evaluated.

Remembering a few ideas about communication can help us avoid missing painful episodes.

A reduced ability to communicate symptoms may be the real cause of an apparent increase pain threshold in some people with Down syndrome.

A reduced ability to communicate may cause a misinterpretation of the symptoms.

What are the implications?

Pain tolerance may or may not be less. It is important to consider physical problems and optimize physical health when evaluating behavioral changes.

Communication: consider displays of behavioral changes as potential communication devices of physical or mental pain.

RECURRENT BOILS

Recurrent Boils are a common problem for adults with Down syndrome. The axilla (armpits), groin area, the buttocks, and the thighs are common sites where this problem occurs. We recommend the following:

1. Gently but thoroughly wash the area of concern daily with an antibacterial or anti-acne soap. A loufa sponge is often helpful.
2. Thoroughly rinse the area.
3. Gently but thoroughly dry the area.
4. Applying baby powder may help keep the area dry, particularly in hotter, humid times.
5. When a boil occurs, apply a triple antibiotic cream such as Neosporin.
6. A few studies have suggested that Zinc and Vitamin C may improve the immune function of some adults with Down syndrome. We recommend Vitamin C 1000 mg daily and Zinc sulfate 100 mg daily. This is in addition to a good one-a-day vitamin.
7. If the boils continue to be a problem, using the prescription soap Hibiclens on the problem areas has been helpful for some of our patients.
8. If the boils continue to be a problem, some of our patients have benefited from using a daily antibiotic (this is similar to the way acne is treated). A daily dose of amoxicillin, tetracycline, or other antibiotic may be helpful.

Both articles by Brian Chicoine, M.D., Medical Director of the Adult Down Syndrome Center, Advocate Lutheran General Hospital, Park Ridge, IL

COMMUNICATION TIPS

I have had the opportunity to observe many speech/language pathologists over the course of time. Sometimes, to me, it is not clear if they are "teaching" or "testing" the child. How many more times will they ask a child, "What's this?", before giving the child some sort of clue or help so the child can figure out how they are to answer or what they are to answer?

When meeting with your child's speech language pathologist, an important question to ask is, "How will you teach that?" If you know the strategy, you can carry over the teaching at home.

Let me give you some examples of some strategies that I use often. If I want to teach a child his or her phone number, I might use something called backward chaining with visual cues. Picture this. The phone number is laid out in front of the child using foam numbers or plastic magnetic numbers. Assuming the child knows numbers, have the child say the phone number with you several times while you both point to the numbers. After a while, say the numbers in order again, but cover up the last number so the child can't see it. Encourage the child to recall that last number from memory. When the child can recall the last number consistently, cover up the last two, following the same procedure. Once successful with the last two numbers, cover the last three and so on. Before you know it, over several weeks, the child will be able to recite the entire phone number from memory.

Some children have difficulty retrieving words. Rather than ask the child eight times, "What's this?", I use a technique called delayed modeling. For example, I may say, "keyboard - what's this?" and the child responds "keyboard." The interval between giving the answer and asking the question gradually increases. Another strategy to aide a child in recalling a word is to give the child the beginning sound or the beginning part of the word.

Some children with Down syndrome have difficulty putting the ending sound on words. They might say *bu* for bug; *di* for dish; or *u* for up. One of my strategies for teaching ending sounds is to stretch out simple words like Mom (Mmmooooomm) while driving a toy truck into a block tower. The tower comes down with the last *m* sound. I encourage imitation and use a variety of words as I emphasize the last sound while I am "driving" the truck.

When a given skill needs to be learned, there needs to be strategy for teaching it. Asking the same question over and over again is not going to elicit the answer miraculously. Doing the same thing over and over, hoping that the child will learn, is not an effective strategy. When no progress is seen over a period of time, it may mean the strategy is wrong for teaching that skill and perhaps there are some pre-requisite skills that need to be taught first.

Ann Nobis, SLP, Reprinted News and Notes, May/June 2006, newsletter of Aim High Down Syndrome, Albany, New York

HOMEMADE PICTURE BOOK

Some children with Down syndrome have difficulty going to new places or with new experiences. Here is an idea that may help all concerned with this transition. A homemade picture book will make the unknown more familiar and comfortable for the child.

For a new school, take photos of the outside of the building and of all the areas your child may use - the classroom, library, art room, music room, cafeteria, gym, playground, bathroom, front office, etc. You can label the rooms with words, if appropriate. Laminate each picture. Bind in a 3-ring binder or punch a hole in the upper left-hand corner and secure the pictures together with a ring. Then take a picture of your child, cut out the background so you have a silhouette, and laminate it. Now the picture of your child can "visit" each place in the school. You can talk about what he/she will be doing in each place and who will be there with him/her. The child can carry the book there.

This idea can be adapted for other circumstances - a school bus ride, relative's home, the mall, a haircut, a doctor or dentist appointment, or a plane trip. Additional pictures are available in magazines, brochures, or the Internet (i.e. Do2Learn.com). You can also ask siblings to draw pictures to contribute to the book.

You will be happy when your child is no longer dependent on the book and has adjusted to the new place or experience. This is a fun way to help our children grow.

By Ann Jonaitis, Reprinted from D.S. Press, Volume XXIV, Issue #6, Newsletter of the Down Syndrome Association of Cincinnati

A NEW MOM'S JOURNEY



Landon Charles Ashby was born January 4, 2006. Landon is our first child. After a difficult pregnancy we were relieved when he finally arrived. Travis and I had one hour to bond, cry and enjoy the moment. I think God had it in his plan for us to have that special hour. Landon was taken to the nursery to be checked over and everything would change.

I lost track of time but within a few hours we received a phone call from the pediatrician that a chest x-ray needed to be ordered. Landon was not breathing well and was being kept on oxygen. Landon was 4 weeks early. He was such a little guy weighing in at 5 lbs, 5 oz so we didn't think much about the difficulties. The x-ray came back clear but showed Landon had a rib missing. He also told us that Landon had facial features that may have been family traits but it could be Down syndrome and blood work needed to be drawn. We would have results in a couple of weeks.

The next afternoon Landon was sent to St. Mary's by ambulance. It was up to that point we had not held him since that special hour we had the day before. Travis and I, along with family and friends, drove to Evansville. We met with the neonatologist in the NICU. I never realized or thought about how the NICU was another world and I had no intentions of staying very long. That is when we were told Landon more than likely did have Down syndrome and to expect to stay 3 weeks. The amount of time spent in the NICU depended on how well he ate and his breathing. An echo was being ordered to verify he had no heart problems. I quickly told him I had numerous ultrasounds throughout my pregnancy and he did not have a heart condition.

Landon stayed at St. Mary's for 5 weeks. He did have a heart condition and feeding issues. The blood work did confirm Trisomy 21. I felt like such a failure. How could I have a son with so many issues? I had his entire life planned out from birth till he got married and had children. All of that had been destroyed. I felt distant from Landon since we were only allowed short visits a few times a day. I was afraid I would never have that mother and son bond.

Landon just celebrated his 1st birthday on January 4. Our lives have definitely changed but have changed for the better. I still worry, but what parent doesn't worry about their child. He will be able to accomplish anything but it will be at his pace. That is fine as long as he is happy. If you are around Landon long enough you will definitely see he is VERY HAPPY! I am also proud to say I have that special bond that I desperately wanted.

Christie Ashby

You can stay updated on Landon's progress by visiting the following website: www.caringbridge.com/visit/landonashby

*The following is an excerpt from "My Gift - The Magic of a Special Child"
by Daniela Geracitano Vance*

I love you because you provoke thought.

You are challenged.

You are a challenge.

*And you challenge without making a sound or lifting a finger - with your eyes alone
you make people think.*

*With your eyes alone you teach the truth about life and love - this is the awesome gift
you give to me and the gift you give to the world.*

You challenge people's preconceptions and help them build new ones.

You teach that beauty cannot always be seen and must be discovered.

You teach people not to prejudge.

Force them to look past appearances.

Explore beyond the tangible.

See the soul.

Play Group

The younger crowd enjoyed a play date at Kids First Therapy Services in Henderson. There were many fun things to do, including a ball pit, inflatable bouncer, slide, and train. Thanks to Heather Hensley for providing this opportunity!



Kathleen Kight and Sam Winstead play together.



Leland Isbill takes a ride on the train.



Levi Wright honks the horn on his bus.



Mitchell Hensley takes a break to pose for a picture.



Sam Fenwick relaxes in a sea of brightly colored balls.



Robbie Sherrard enjoyed the ball pit.



Matthew and Haley Huston zoom down the slide.

Christmas Party

GRADSA families enjoyed another fun-filled Christmas party, with crafts, games, cookie decorating, and Santa! A highlight this year was a video shown during dinner that featured photos from GRADSA events throughout the year. Thanks to Sid Rose for putting this video together. If you would like to see the video, please contact Cindy Huston.



Hannah Hardesty sure is a cutie!



Eli Rose and mom color a Santa magnet.



Krystyn Randolph plays holiday bingo.



Laura Whitfell tells Santa what she wants for Christmas.



Dana Hamilton checks out her goody bag.



Seth Johnson visits with Santa.



Elliott Williams flashes a big smile.



Zeb Wells sits in Santa's lap.

January/February Birthdays

Landon Ashby, 1 year old on Jan. 4
Erin Clark, 30 years old on Jan. 20
Andrew Conway, 9 years old on Feb. 24
Isaiah Cruz, 3 years old on Jan. 23
Ashley Dant, 20 years old on Jan. 22
Jonah Edge, 10 years old on Feb. 3
Ashley Hagan, 10 years old on Jan. 21
Kathleen Kight, 3 years old on Jan. 24
Morgan King, 4 years old on Feb. 6
Caleb Lancaster, 9 years old on Feb. 18
Shannon Mahoney, 37 years old on Jan. 12
Michael Smith, 25 years old on Feb. 15
Lindsey Spain, 24 years old on Feb. 14
Elizabeth Stickler, 7 years old on Jan. 23
Sherry Storm, 10 years old on Feb. 24
Cody Trotter, 13 years old on Feb. 17



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 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

Owensboro, KY 42302
P.O. Box 2031

GRADSA
GREEN RIVER AREA
DOWN SYNDROME ASSOCIATION

