

# DSAA Today



The Newsletter of the Down Syndrome Association of Atlanta • July/August 2006

## The Greatest Gifts Come In the Most Unique Packages

by Debbie Carlisle

Have you ever received a gift that was in a unique package but was not what you expected? That is what happened to us when our only child was born. When our son Bradley was born sixteen years ago we were told within a few hours that he had Down syndrome and a severe congenital heart defect. We had no idea what the future held but the one thing we knew for sure was that we would need to rely on our faith in God to get us through.

We tried to learn all we could about Down syndrome by talking with other parents. As we talked with other families the one thing that we learned was that our son did have a future and it could be very bright. We also began to realize what a very special child we had been given.

Bradley's health was our immediate concern. His heart defect was complicated and we were told that he would need surgery soon. Those first few months were terrifying. Against all odds Bradley began to grow and thrive



slowly, which allowed the doctors to wait until he was eighteen months old to perform open heart surgery. This was the greatest test of our faith we

have ever faced. The hardest thing we had to do was watch them take him to the operating room not knowing if he would come back to us. Once he was in the operating room the surgeon discovered that Bradley's heart defect was much more involved than what he expected. After five to six hours of surgery we were told it was a miracle that Bradley had survived to this age. We knew then that God definitely had a plan for Bradley. Not only was his surgery a huge success but he was released from the hospital five days later.

Bradley is now sixteen years old and he has faced many health obstacles over the past sixteen years. He overcame each one and continued to thrive.

When Bradley was five years old we wanted him to learn to swim for safety reasons. For some unknown reason Bradley was terrified of the water. Thankfully God sent me an

*Continued on page 7.*

### SAVE THE DATE

#### DSAA Educational Workshops

Saturday, September 30, 2006

in Atlanta at Peachtree Road

United Methodist Church

11 A.M. to 4 P.M. (Lunch at 12:30 P.M.)

**Keynote speaker from the Georgia Special Olympics**

### WHAT'S INSIDE DSAA TODAY:

Executive Director Letter .....page 2

Journal Article Abstract: Diversity Stories ...page 3

DSAA Recap .....pages 4 & 5

Emory Connection .....page 6

Buddy Walk .....page 6

New Birthday Format .....page 8

## DSAA Executive Board

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# From the Executive Director

## Special Report: Siblings of Children with Down syndrome

The birth of a child with Down syndrome is a very special time as each of us knows, but it can also have an impact on the other children in the household. The relationship between siblings can be a very important part of any person's life. Children who grow up together in the same family can form a unique bond, regardless of a brother or sister having Down syndrome. It's important to know that many factors affect how siblings relate to one another, not just the fact that one of them has a disability. In any family, good or bad feelings may develop between siblings or because of siblings. This is called old-fashioned sibling rivalry. However, according to Valdivieso, Ripley, and Ambler (1988) many siblings who have a brother or sister with a disability have reported some concerns, which may include:

- Guilt about not having a disability. Some siblings may feel they are to blame for their brother's or sister's disability
- Embarrassment of the sibling's behavior or appearance
- Fear that they may develop the disability
- Anger or jealousy over the amount of attention the brother or sister with Down syndrome receives
- Pressure to overachieve or overcompensate in order to "make up for" the areas that the sibling with a disability may not be able to do as well

If you observe clues that your child seems angry, embarrassed, or sad that his or her sibling has Down syndrome try giving them an opportunity to express

*"Siblings" continued on page 3; more sibling photos on page 6.*



From top, counterclockwise, Joseph (9), Daniel (8), and David (4) Chun

## Area Networking Groups

### Grandparents

Ann Huffman . . . . . 770.781.3727

### Hispanic/Latino

Susy Martorel . . . . . 404.931.6619  
Zoila Martinez . . . . . 770.740.9204

### Young Adults

Evan Nodvin . . . . . 770.396.8056  
Megan Sydney . . . . . 770.491.0155

### Alpharetta

Karen Wise . . . . . 770.664.8141

### Americus

Valerie Moates . . . . . 229.924.4022

### Atlanta/Decatur/Tucker

Valerie Harrison . . . . . 770.939.8489

### Augusta

Wanda Miller . . . . . 706.855.7440

### Carroll County

Jennifer Turner . . . . . 256.568.9742

### Cartersville

Betty Schaaf . . . . . 770.383.9085

### Cherokee County

Alyssa Allen . . . . . 770.517.9970

### Fayette/Coweta Counties

Virginia Cook . . . . . 678.364.9131  
Nancy Millspaugh . . . . . 678.364.0158

### North Fulton/South Forsyth County

Gay Hall . . . . . 678.455.9483

### Gwinnett County

Shere' Owens . . . . . 770.967.4775

### South Fulton

Cathy Webb . . . . . 770.969.0238

### Macon

Leslie Hales . . . . . 478.471.9225

### Marietta/Cobb County

Laura Gray . . . . . 770.218.8844

### Rome

Toni Puckett . . . . . 770.748.5037

# Journal Article: Diversity Stories

by Susy Martorell

The *American Journal of Community Psychology* featured a special topic in their June 2006 publication entitled, "Diversity Stories". Twenty-two stories of diversity dilemmas encountered in community research and action around the country were detailed. "Bridging Uncharted Waters in Georgia: Down Syndrome Association of Atlanta Outreach to Latino/a Families" tells the story of the fantastic leap-of-faith DSAA took in forming the first Spanish-speaking Down syndrome support group in the country back in the fall of 2000.

**Read the abstract below for a summary of the article.** To get a reprint of the complete article, written by Susy and Gabriela Martorell, go to [www.sheridan.com/springer/eoc](http://www.sheridan.com/springer/eoc).

Receiving the news that your newborn child has Down syndrome is difficult for most parents; difficulties which are compounded by language and cultural barriers for immigrant Latino/a families. The metro Atlanta area has shown a large increase in this population in the last 10 years, and increasing numbers of Latino/a parents with children with Down syndrome are coming in contact with the health-care system. Experiences and observations regarding the formation of a Latino/a support group for parents of children with Down syndrome in Atlanta are described. In addition, efforts to integrate these Latino/a parents in to a parent education conference sponsored by the Down Syndrome Association of Atlanta are also recounted. Finally, reflections upon the lessons learned and individual and organizational changes that occurred as a result of the process are discussed.

## Executive Director *continued*

those feelings. One way to facilitate opening the communication is through stories. Woodbine House Publishers offers three books recommended by parents of children with Down syndrome: *We'll Paint the Octopus Red* and *The Best Worst Brother* by Stephanie Stuve-Bodeen, and *My Friend Isabelle* by Eliza Woloson. As parents, we also need to be aware of our own feelings, and ensure that we have an opportunity to express feelings and concerns through counseling, networking groups, or caring friends and family members.

The DSAA provides opportunities for parents to connect with one another through events, activities, and area networking groups. Frazier (2006) notes that children can pick up on their parents' worries and will benefit from clear communication. Additionally, if there are health or medical issues, it is important to answer questions and respond to their concerns in the most simple and precise manner. Children go to their parents for reassurance and security and parents can be role models for how to best handle stress. Frazier states: "Educate siblings on the needs of the family member with DS, and allow your children to feel a variety of conflicting emotions as new abilities and changes unfold. Expect that the children will adjust in a healthy and positive way, and have confidence

that the outcome will be a valuable and unique sibling relationship."

Research on siblings indicates that there are positive aspects of having a brother or sister with Down syndrome. Researchers have found that children in families where a sibling has a disability can become more mature, responsible, self-confident, independent, and patient. These siblings can also become more altruistic, more sensitive to humanitarian efforts, and have a greater sense of closeness to family (Lobato, 1990; Powell, 1993).

The DSAA supports parents of children with Down syndrome through advocacy, parent network groups, and education. You can look forward to more information and education about siblings with Down syndrome at our next Educational Workshops on September 30.

## References:

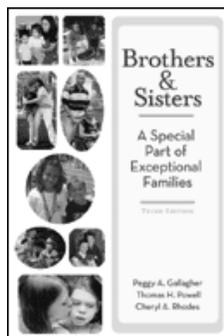
Frazier, L., "Siblings with Down Syndrome": *The Down Syndrome Center, March 2006. Jacksonville, FL: Hope Haven Children's Clinic and Family Center*

Lobato, D.J. (1990) "Brothers, Sisters, and Special Needs: Information and Activities for Helping Young Siblings of Children with Chronic Illnesses and Developmental Disabilities". Baltimore: Paul H. Brookes Publishing Co., Inc.

Sincerely,

*Michelle Norweck*

Executive\_Director@AtlantaDSAA.org

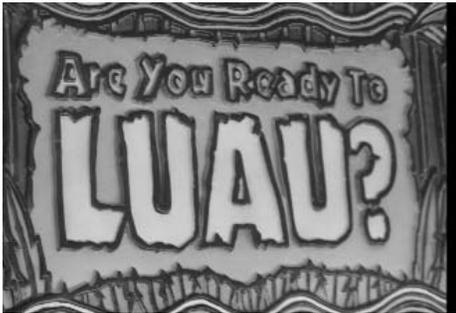


**Janice Nodvin**, Executive Director, ISDD recommends two new books. The first book ***Brothers and Sisters a Special Part of Exceptional Families*** is coming soon. This book is written by Peggy Gallagher, Ph.D., Thomas Powell, Ed.D., and Cheryl Rhodes, M.S. Both Gallagher and Rhodes are from GSU.

The second book is the second edition of ***Medical Care for Children and Adults with Developmental Disabilities***. This book is edited by I. Leslie Rubin, M.D. and Allen C. Crocker, M.D.

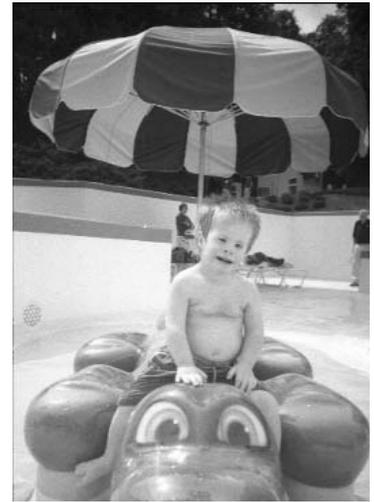
To view more information on both of these books go to [brookespublishing.com](http://brookespublishing.com). On the home page type in an author's name in the search field, and then select the book title from those listed.

# DSAA Recap



The 2nd Annual DSAA Spring Luau was held at Lake Lanier Islands on May 20, 2006. It was a beautiful sunny day filled with food, music, water, and fun. Special Thanks go to our valuable volunteers: **Shere' Owens** for planning this social event, **Katherine Henderson** and **Sara Beth Moody** for helping with set-up, and **Helen Smith** of the Emory Down Syndrome Clinic for helping with registration. The special surprise of the day was complimentary return tickets that were presented to everyone who attended. Sixty-one families representing

277 individuals attended this DSAA event. If you have pictures from the Spring Luau that you would like to add to the website, please forward them to [Executive\\_Director@AtlantaDSAA.org](mailto:Executive_Director@AtlantaDSAA.org). Please include your comments on a location for next year's Luau; Lake Lanier Islands, Stone Mountain, or somewhere else!



## AHSDA Picnic

On June 2, 2006 the 6th Annual AHSDA (Asociacion Hispana de Sindrome de Down de Atlanta) Picnic was held at Mason Mill Park in Decatur for our Spanish-speaking members of the DSAA. There was food, music, and a raffle drawing for prizes, and games for the children. The picnic was coordinated by **Susy Martorell**, Social Worker and **Zoila Martinez**, Hispanic Family Support Director. It was a fun-filled day for families of many cultures. The DSAA has approximately 151 members who are Spanish-speaking. Eight different countries are represented; a sampling includes Guatemala, Honduras, Mexico, and Spain.



# DSAA Golf Tournament Highlights

The 8th annual DSAA golf tournament and fund raiser took place June 12th at Brookfield Country Club in Roswell. The weather was sunny and the course was in great condition. The day was a wonderful success and raised \$13,000 for DSAA.

Seventy-five golfers signed in and each person received a DSAA "Swing for the Children" golf towel, a golf glove with their favorite NCAA logo, and a \$25 gift card to the PGA Tour Superstore. Prior to the start time, a box lunch was provided to each golfer and volunteer by Locos Deli, and beverages were supplied by Coca Cola and Atlanta Beverage Company.

After the noon shotgun start, the golfers participated in some exciting on course games. There were four closest-to-the-pin contests, a long-drive competition, and a putting contest for a pair of Airtran tickets. Surprisingly six golfers sank the 50-foot sloped putt to force a putt off after the tournament ended. Brad Koontz of Locos Deli was the winner of the Airtran tickets by outlasting the other 5 contestants.

Dana Wright, Mike Valdez, and Norm Atkins all received \$100 gift certificates to the pro shop at Brookfield Country Club for their closest-to-the-pin victories. Terry Hogan won a very large George Foreman Grill supplied by Blue Ribbon Foods for his close in shot at hole #3. Corey Williams showed off some muscle to win a \$100 gift certificate for the long-drive competition.

After the tournament, golfers enjoyed a

barbecue buffet with all the fixin's. There was also a silent auction and raffle during the dinner.

The tournament winners with the overall low-gross score was the team from Ambush Boarding Company: Chuck Morrow, Adam Blank, Johnny Lee, and Joe Henry. They each received a round of golf at Brookfield Country Club.

The field was divided into three flights.



The first-flight winner was from JGA SRC: Mark York, John Holley, Nathan Spears, and Andrew Dalby. The second flight was won by St. Peter Chanel Catholic Church: Brian O'Neill, Billy Harrison, Billy Hughes, and Eric White. The third flight

was won by the Friends of Russ Plugge (Event Coordinator): Graham Cherrington, Frank McManus, Ray Szczepaniak, and DSAA's own self advocate Patrick Essen. All the flight winners took home a beautiful framed print of a classic golf hole with the DSAA golf logo imbedded in the matting. The PGA Tour Superstore graciously donated golf lessons to one very deserving team.

A special thank you is in order to all the volunteers who helped with the registration and silent auction. They include Michelle Norweck, Patti Greig, Katie Greig, Jennifer Carroll, Cara Plugge, Sharon Jones Baron, and Joan Essen. We look forward to seeing all the golfers and hopefully some new faces at next years tournament and fund raiser.



## Thank you to our Tournament Sponsors

Airtran Airways  
The PGA Tour Superstore  
Ambush Boarding Company  
Atlanta Beverage Company  
Coca Cola, N.A.  
Magarahan, Villines & Honis  
Locos Deli & Pub  
Capitol Indemnity  
Siemens Technologies

## Tournament Hole Sponsors

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**For what's coming up,  
check out the  
"Save the Date" box on the  
front page of this newsletter.**

# THE EMORY CONNECTION

By Sallie B. Freeman, PhD, Assistant Professor, Down Syndrome Clinic Director, Department of Human Genetics, Emory University

## Introducing Shelly Dills

We are delighted to introduce our new Down Syndrome Clinic Coordinator, Shelley Dills. Shelley joins our clinic team that includes Dr. Jeannie Visootsak, Developmental Pediatrician and Clinic Medical Director; Sallie Freeman, PhD, Director; Helen Smith, Nurse Researcher; and Elizabeth Sablon, Medical Interpreter.

Originally from North Carolina, Shelley received her undergraduate degree from Peace College in Raleigh and her Masters in genetic counseling from the University of South Carolina, School of Medicine in Columbia. Before coming to Emory in 2004, her experience included several years at the Center for Human Genetics at the Duke University Medical Center. Her special interests center on genetic counseling in a pediatric setting. DSAA take note, Shelley has a history of volunteering for Down syndrome-related events!

Shelley will be responsible for scheduling families for the clinic. As you may know, we ask that families call to make their child's appointment. This gives us an opportunity to get acquainted and explain what is involved in a typical clinic visit. The clinic currently serves children with Down syndrome from birth through age four. For questions or to schedule an appointment in the Emory Down Syndrome Clinic, please call Shelley at 404.778.8524.

## Announcements

## 14th Annual Lekotek Run

The Lekotek Run will take place on Saturday, September 9. Join your fellow runners for an exciting morning of events to benefit Lekotek of Georgia.

A fast four-mile loop and one-mile fun run will start and finish at Georgia Perimeter College-Dunwoody Campus. A judged four-mile race walk will also be part of this year's events. Strollers and baby joggers are permitted. For more information go to [www.lekotekga.org/run.htm](http://www.lekotekga.org/run.htm).

## Siblings



Make steps for a brighter tomorrow by taking part in the Buddy Walk on **Saturday, October 14, 2006** at the **Duluth Town**

**Square.** Each step you take and each dollar you raise will help provide the important services that enhance the quality of life for individuals with Down syndrome and their families.

Sign up now for the Buddy Walk by going directly to our registration site at [www.AtlantaDSAA.org/buddywalk](http://www.AtlantaDSAA.org/buddywalk). Here is the schedule:

- 10:00 Event, silent auction, and festivities begin
- 10:00-11:30 Registration opens
- 11:15 Walk begins
- 11:45 Lunch served
- 12:30 Silent auction closes
- 12:30 Final presentation
- 1:00 Event concludes

For more information, call **404.320.3233** or email [BuddyWalk@AtlantaDSAA.org](mailto:BuddyWalk@AtlantaDSAA.org).

*Mitch and Isabelle Dillon*



*Marissa and Marty Rasnick*



*Christopher and Calvin Norweck*



## Chat Rooms

DSAA Secretary, Susan TenEyck, has provided this list of chat rooms to visit, if you want to exchange thoughts and ideas in a bigger "arena". As with any internet communication, please be smart and be careful.

<http://groups.msn.com/DownSyndromeawholeneworld/>

<http://www.imdsa.com/>

[http://health.groups.yahoo.com/group/down\\_syndrome/](http://health.groups.yahoo.com/group/down_syndrome/)

<http://health.groups.yahoo.com/group/UpsNDowns/>

<http://health.groups.yahoo.com/group/MosaicDS/>

<http://health.groups.yahoo.com/group/homeschoolinganddownsyndrome/>

<http://health.groups.yahoo.com/group/downsyndromeguild/>

## Bradley, continued from page 1.

angel in the form of a swim coach.

Boni Powell had been teaching swimming for over 30 years when she took on Bradley as a student. She had more than 15 years experience with Special Olympics at the time. Boni took a terrified little boy and worked with him week after week until he began to trust her. Boni always worked at Bradley's pace, which contributes to his swimming success today. Five years after Bradley began taking lessons with Boni he



Bradley with his Olympic coach Joshua Powell.

swam in his first State Special Olympics Games at Emory University. At that time he was only able to compete in the 10 meter and 15 meter assisted division. He won two gold medals and that was the beginning of Bradley's swimming "career". He has competed in the State Special Olympic Games every year since and has won numerous medals and ribbons. Bradley now swims in the 50 meter freestyle, 50 meter breaststroke, 50 meter backstroke and relay competitions.

This past fall we learned that Bradley was chosen to represent the State of Georgia at the first National Special Olympics Games in Ames, Iowa this July. Bradley is one of eighteen athletes from Georgia attending the games.

Joining Bradley at the National Games as a coach is Joshua Powell. Joshua is the son of Boni (Bradley's long time swim coach) and David Powell. Joshua grew up watching his Mom teach Bradley how to swim and practiced with him over the years. Somewhere along the road the desire to coach Special Olympics was ignited in Joshua and he will fulfill that dream

with Bradley at the National Special Olympic Games this summer. Joshua's exposure to Special Olympics also helped him decide to pursue a degree in Special Education at Georgia College in Milledgeville.

Bradley trains once a week with Boni or Joshua and loves the swim practices.

At the end of this year Bradley will graduate after 11 years of training with Boni. She will turn over some of Bradley's individual training to Joshua

when he is home from college. The rest of the time Bradley will swim with the DeKalb County Special Olympic swim team. This will be an end of an era for us all. Bradley is and will continue to be a very confident person because of the skills he learned with Boni over the past 11 years.

The closer we get to the National Games the more excited we all get. To see Bradley compete with other Special Olympic

athletes from all over the United States is a dream come true for all of us.

Bradley is finishing his first year at Tucker High School as a freshman and loves being a member of the Tucker High School community. His favorite thing this past year was attending the football games and getting involved in the football fever. He has made many friends and loves his class and teachers. The Tucker High School Key Club has also been a big supporter of Bradley's



this year. They started a fund raiser for his trip to the National Games and have also helped educate the THS community about Special Olympics.

My husband and I consider ourselves truly blessed. While some people have referred to Bradley as a special child in the past, we have always seen him as a child first and foremost who happens to be a very special person. Bradley has done well and succeeds at many things; however there have also been just as many struggles and tears along the way. But we believe that without the struggles the rewards would not be as important. Bradley will be faced with limitations at times for the rest of his life but because of his success through Special Olympics he knows he can overcome those limitations and succeed. He is a person who has some extraordinary abilities that far outweigh his disabilities.

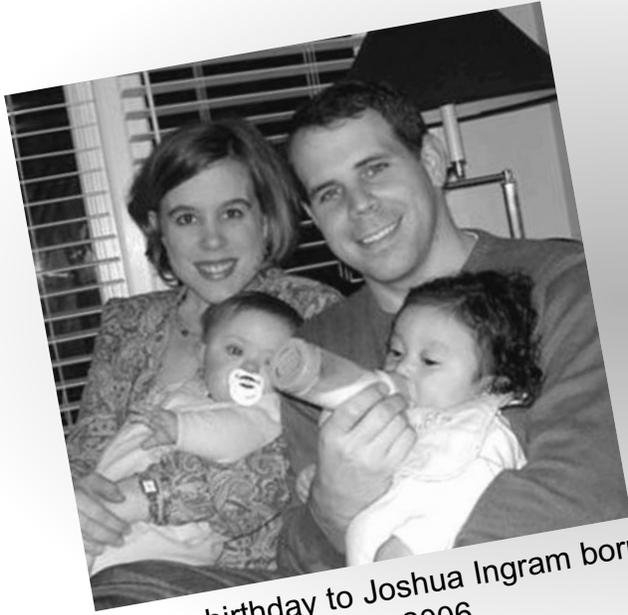
When we watch Bradley swim, gliding through the water with ease, it's

hard to remember him coming into this world struggling to breathe. When he raises his hands in victory and you see the pride on his face when he finish-

es you know that this is part of the plan God has for him.

So when you are given a gift that at the time may not be what you expected, just accept it and wait. God will show you, just as he did us, that the greatest gifts are those that we did not expect and they do come in the most unique packages.

## New Birthday Wishes Format!



Happy birthday to Joshua Ingram born  
June 2, 2006

Submit a photo of your child  
and we will print it on this  
panel of the newsletter. We  
will include your child's  
name and birth date. Submit  
photos for September and  
October birthdays by  
August 7.

Send digital photos to  
Sharon Jones Baron at  
[sharonjbaron@comcast.net](mailto:sharonjbaron@comcast.net)

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# DSAA Today



**Golf Tournament  
Highlights on page 5.**

*Statement of disclaimer: The editor of this newsletter writes as a non-professional. This newsletter reports items of interest relating to Down syndrome. The Association does not promote or recommend any therapy, treatment, etc. We wish to bring together those interested in Down syndrome.*