

DSAA Today



The Newsletter of the Down Syndrome Association of Atlanta • November/December 2006

A big THANK YOU to our Buddy Walk Sponsors

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It Was a Record-Breaking Buddy Walk!

by Michelle Norweck, Executive Director, DSAA

I'm fortunate to work in an environment where opportunities to be inspired abound. Last month was no exception—people from throughout the metro Atlanta area and beyond participated in the largest record-setting fundraiser in the history of the Down Syndrome Association of Atlanta. Over 1300 people attended and over \$170,000 was raised in support of the Down Syndrome Awareness.

The revenue from the Buddy Walk is the largest source of income for the DSAA each year. The money raised supports the DSAA in its purpose to provide education and support for individuals with Down syndrome and their families, promote public awareness, and encourage a better understanding of Down syndrome. Ten percent of the revenue will go to the National Down Syndrome Society for education, research, and advocacy. The NDSS envisions a world in which all people with Down syndrome have the opportunity to realize their life aspirations, a mission that is shared by the DSAA.

There were many new features to the 2006 Atlanta Buddy Walk. The first being the NDSS Convio Fundraising Software that enabled over 900 participants to register online. Many of the participants commented on how easy it was to solicit donations from family members and friends with the secure online payment system. Many teams were created online by our members and

award baskets were presented to the top fundraiser in the category of team and individual. The top fundraising team was **Team Zoe**, who raised funds in honor of **Zoe Catherine Nelms** and brought in more than \$9,000. The top individual fundraiser was **Darden Glass** who raised more than \$3,500.



Michelle Norweck, Executive Director of DSAA and Buddy Walk Co-Chair Gabe Lyons present a \$10,000 check to the Murphy Family.

DSAA member and Buddy Walk committee Co-Chair, **Gabe Lyons** along with DSAA and Buddy Walk committee member **Tim Johannesson** participated in Convio Training beginning in January and created the Atlanta Buddy Walk website in May of 2006. From there the committee of seven core members solicited sponsors, obtained Silent Auction and Raffle items, and met twice a month to plan the event.

Continued on page 4

DSAA Executive Board

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Michelle Norweck

Executive_Director@AtlantaDSAA.org

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President@AtlantaDSAA.org

Steve Harrison

President@AtlantaDSAA.org

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Vice-President@AtlantaDSAA.org

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Vice-President@AtlantaDSAA.org

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Jennifer Durden

Treasurer@AtlantaDSAA.org

Secretary:

Susan TenEyck

Secretary@AtlantaDSAA.org

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sharonjbaron@comcast.net

Governor's Proclamation

by Susan Lumpkin, DSAA Proclamation Chairperson

Even though the crowd was small at the Proclamation signing, it was a great success. Due to the small number of members in attendance, we were invited into Governor Perdue's office to witness the actual signing that declared October Down Syndrome Awareness month in Georgia. As the Governor entered his office he noticed a new younger female Governor in his Chair. "Good Morning Madame Governor", he addressed DSAA member, Zana Lumpkin. Then he scooped her up onto his lap and signed the Proclamation to help increase the awareness about how wonderful and unique our children and adults with DS are.

Governor Perdue took the time to speak to each child in attendance. He held Miss Mary Claire Greig and Miss Lainey Carroll. He also visited with Jake King and Jack Jorgensen. Other parents and family members were in attendance in honor of their children. We were all pleased at the Governor's attempts to visit with young Christopher Norweck by showing him a small glass elephant on his side desk. When all else failed, the Governor got down on the floor with Christopher, cowboy boots and all!

The staff had told me on a previous occasion that they really looked forward to the visits that the Governor had with children. Indeed many of his staff were witness to our running around trying to keep our little ones' hands off of the Governor's room decor! The staff had said that visits with the children put the Governor in the best mood! I believe that is true as he really seemed to enjoy all those in attendance!



Governor Perdue gets assistance from Zana Lumpkin while signing the proclamation.

Area Networking Groups

Hispanic/Latino

Susy Martorell 404.931.6619

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

Cara Henley Plugge . . . 678.560.4167

Rome

Toni Puckett 770.748.5037

If you are interested in starting a Parent Network Group in your area, please let us know at contactus@AtlantaDSAA.org.

Dentistry for our Special Kids

by Kris Jorgenson, D.D.S. and DSAA Member

Does just the thought of going to the dentist raise the hairs on the back of your neck? Just imagine what the strange and sometimes scary new world of the dentist's office must do to our children with Down syndrome! There are some important things to remember, however, that can go a long way toward making any child's dental visit both productive and even rewarding.

The number one thing we can do for our children (both those with Down syndrome and our typically-developing children) is to have a positive attitude about seeing the dentist, or at least to put up a good front as the case may be! Our kids take their cues from us as parents, both the positive and the negative. Demonstrating a comfort level in the dental office and with the staff members has a greater affect on our kids than many parents realize. We need to display this positive attitude as much as possible in both the way we act and in what we say about our own dental experiences. If we as parents are comfortable and relaxed in the dental office, odds are much greater that our kids will be, too. Pretending to be comfortable when you really are not is OK, too!

Choosing the right dentist for our children is another key to building a long-lasting relationship that can foster trust and will allow our kids to have a good experience each and every time they go to the dentist. Because many kids with Down syndrome thrive on routine, selecting an office that is smaller and less chaotic and has low staff turnover is one way to help ensure that the child is seen by familiar faces. The familiarity and rapport that is established will allow the staff members to get to know the child and make the visit more personalized, based on the the individual needs of our special patients. A pediatric dental office is where the only patients seen are children, usually up to the age of 18. Many pediatric and some general dentists have had additional training in behavior management and sedation techniques; some may even have hospital privileges that

allow them to see a broader range of patients that have different needs and/or more complex diagnoses.

Not all kids with Down syndrome need to see a pediatric specialist, however. One of the most important things to consider when choosing a dentist is how open he or she is to the individual special needs of our children. Having experience with, or at least a sensitivity to, the specialness of a patient with Down syndrome is a real plus. Ask about this when you call to make an appointment. Morning appointments are usually better for all kids, both those with special needs and typical children. The kids generally are fresher and more accepting of a new experience. A longer appointment time may be needed to get the child "warmed up" and introduced to some of the new materials or procedures that may be done that day. Sometimes having the parent in the room with the child is an advantage and sometimes it is not; this depends on the needs and sometimes the behavior of the child. Many typical children will tend to act out a bit more if mom is in the room because their attention is drawn away from the task at hand and they know how "far they can go" with mom (or dad, as the case may be). Therefore, many dentists prefer that the parent is not in the treatment room but close by in the reception room. Discuss this with the doctor and let them know a bit about your child and ask which way they think may be best in order to give the child the best experience possible. Don't underestimate your child, however; you cannot imagine the look of pride on a child's face when they come out of the treatment room and they were able to do everything "by themselves"! If your presence in the room is a calming factor for your child, discuss this with the dentist before your appointment to make sure you are both on the same page.

A large group practice can feel very rushed and may not be as willing to spend the extra time it may take to establish trust and get to know our children.

Procedures should be explained in a way that will be non-threatening and easily understood by the child. This method is more commonly known as the "tell-show-do" method where a staff member will tell the child what is about to happen, then show the child in a demonstrative way what will happen, and then with the child's cooperation, do the procedure. Being more focused on the total experience for the child rather than just "getting the procedure done" will really pave the way for less anxiety-producing dental visits in the future. The trust established in this way will carry over when more extensive procedures beyond routine care may be required and will help our kids be less afraid when they go to the dentist.

Let's face it, few people enjoy going to the dentist, but our kids (and us as parents) have enough to worry about without having every trip to the dentist turning into a battle. There are many things we can do to make the dental experience more enjoyable for us and for our kids. After all, our children really do give us a lot to smile about!

CORRECTION

In Memory



**Evan Michael Usher
June 7, 2005 - September 18, 2005**

Please note the corrected date that Evan passed away. The date was listed as September 10 in the previous issue.



Buddy Walk continued

Buddy Walk Co-Chair **Rebekah Lyons**, assisted by volunteers **Danielle Kirkland** and **Shannon Ujvagi**, set up a beautiful Silent Auction/Raffle area, coordinated registration, pledge prizes, and all of the logistical details. **Tamara Pursley** was the mastermind behind the excel spreadsheets that enabled us to convert mail-in registrations to online participants and professional image e-mails that gave participants up to date information. **Scott Jeffries** coordinated all the entertainment and children's activities and **Cindy Costello** was instrumental with sponsorships and donations.

A special thanks to each of our sponsors, especially McCar Homes who was the Platinum Title Sponsor of \$10,000 and brought in an additional \$15,800 in pledge donations that were matched by their corporate office for a total donation of \$31,600. McCar Homes also provided 45 employees who volunteered from 7:30 A.M. to 2 P.M. on the day of the event to help with the set-up and clean-up. Other innovative additions to this year's Buddy Walk was having a lunch instead of breakfast, Buddy-Walk bags, finish-line medals for all the children, and individuals with Down syndrome, and

the gymnastic performance by the Murphy Family.

The Murphy Family is an amazing family with 23 adopted children; 18 have Down syndrome. The Murphy's live right here in metro Atlanta and their amazing story can be read by going to www.murphyhouseproject.com. A \$10,000 donation was made to the Murphy House Project on behalf of the Atlanta Buddy Walk.

Another presentation at the event was the first ever Buddy of the Year Award, which went to Patrick Essen. Patrick, who has served on the DSAA Board of Directors as a self-advocate, is an outstanding example of an individual with Down syndrome who is unlimited in his achievements, service to others, and leadership. He is an amazing individual in whom you can truly "See the Potential".

So on behalf of the Buddy Walk Co-Chairs, Gabe and Rebekah Lyons as well as the entire committee who served for 10 months, we say thank you to each and every one of you who volunteered, made a contribution, solicited donations on behalf of all children with Down syndrome, participated, sponsored, and helped to make this year's Atlanta Buddy Walk the most successful ever!

Buddy Walk Challenge Achievers will be announced in the January/February newsletter.

More Governor's Proclamation photos. Jake King takes the Governor's seat for a "test drive" (left). A candid moment with the Governor (below).



DSAA Collaborates with Peachtree Road United Methodist Church

Peachtree Road United Methodist Church hosted the DSAA's Fall Education Conference on September 30, 2006. More than 65 parents and 20 children attended. PRUMC provided a beautiful learning environment, a Mexican Buffet, and childcare. The children enjoyed lunch, arts and crafts, story time, outdoor play, and Music Therapy sessions by Jennifer Walker of Therabeat, Inc.



DSAA member Besty Glass collaborates with PRUMC Special Needs Ministry Director Betsy Lunz.

Highlights from the Conference included a keynote presentation from Debbie and Bradley Carlisle who shared video clips from Bradley's participation in the 2006 Summer National Special Olympic Games. Sibling Research Outcomes from Doctoral Candidate, Sarah O'Kelley, Transitional Workshops from Briggs & Associates and DeKalb County Babies Can't Wait, and an Educational Rights Workshop from GAO Attorney, Denise Quigley.

Overall, the Conference was well attended and well received. Workshop evaluation results indicated an overall satisfaction rating of 71% Excellent, 18% Very Good, and 11% Good rating. Plans are underway for the Spring Education Workshops in March 2007. To volunteer with the Education Committee or to recommend speakers, please email us at Education@AtlantaDSAA.org.

What's Coming Up

Unlock the Waiting Lists!

Conversations that Matter: Town Hall Meetings on Disability

The Teaching Museum North
791 Mimosa Blvd. Roswell, GA 30075
Tuesday, December 5, 2006
6:30 – 8:30 P.M.

6:30-7:00 Pre-Program Reception 7:00-8:30 Program

Please join other parents, professionals, legislators and self-advocates from North Fulton in a community discussion about services for people with disabilities in Georgia.

Our Special Guest for the evening will be

**Dr. Steve Hall, Director of the Office of Developmental Disabilities,
The Division of MHDDAD, Georgia Department of Human Resources**

Other Speakers include:

**Dr. Darlene Meador, Program Director, Office of Developmental Disabilities,
Georgia Department of Human Resources**

Dave Blanchard, Director of the Unlock the Waiting List Campaign!

For more information contact: **Jennifer Carroll** at jenniferofroswell@msn.com
or call 770.998.1703

*Directions: 400 N and exit onto Holcomb Bridge Rd (Exit 7) west.
Turn left onto Alpharetta St/GA 120/GA 9. Stay straight to go onto Magnolia St.
At first light turn left onto Mimosa Blvd.*

Ladies Night at The Chandlery

The Chandlery, located in historic downtown Roswell, at 950 Canton Street will be hosting the Ladies' Night out again this year on Friday, December 1, from 5 to 8 P.M. DSAA will be providing wine and cheese for your enjoyment while you complete your holiday shopping. The Chandlery is a unique gift store with many beautiful one-of-a-kind items for everyone on your list. The store generously donates ten percent of the evening's purchases back to DSAA. Hope you can join us and bring a friend! Please RSVP to Jennifer Carroll, 770.998.1703, by Tuesday, November 28.

Down Syndrome Association of Atlanta Annual Holiday Party

Saturday, December 9, 2006 10 A.M. to 12P.M.

Creekside United Methodist Church
673 Peachtree Parkway
Cumming GA 30041

What to bring? If your last name begins with

A-L Bring something sweet

M-Z Bring something salty

(Please bring enough to share with 10 or more;
DSAA will provide other snacks and beverages)

RSVP to 404.320.3233 or send an email to
Social_Committee@AtlantaDSAA.org.

Mention the Family Holiday Party, give your name, how many will be attending and the ages of the children you are bringing.

We are going to have a wonderful time decorating cookies, drinking hot cocoa, listening to stories and music. You can also get your picture taken with Santa.



First Annual Ho-Ho-Ho Down

Make your reservations today!
Young Adults age 15 and up
please join us on

Saturday, December 2
11am to 2pm

Unity North Atlanta Church
4255 Sandy Plains Road
Marietta, GA 30066.

Dance to the live music of
Whippoorwhil Sound and
enjoy a BarBQ Buffet.

Cost is \$5.00 at the door.
Please RSVP to
contactus@AtlantaDSAA.org

THE EMORY CONNECTION

The Emory Down Syndrome and Congenital Heart Defects Study

by Lora J.H. Bean, Ph.D., Instructor, Department of Human Genetics,
Emory University School of Medicine

For several years researchers at Emory University in the Departments of Human Genetics and Pediatrics have been working together to understand why some children with Down syndrome are born with a heart defect. We have worked with the Sibley Heart Center and Children's Healthcare of Atlanta (CHOA) to identify children with Down syndrome who have an atrioventricular septal defect (AVSD or AV canal). This type of heart defect is rare in the general population but common among children with Down syndrome.

Our focused study of the causes of heart defects is possible due to a larger research initiative on the causes of Down syndrome directed by Dr. Stephanie Sherman in the Department of Human Genetics. Established in 1989, Dr. Sherman's work continues to offer families in the Atlanta area an opportunity to participate in important Down syndrome-related research. Although many of the children in these studies are also eligible for the heart study, we needed to include additional families in order to meet our goals.

In 2004, funding was granted by the Cardiac Research Committee at Children's Healthcare of Atlanta (CHOA) to identify and recruit additional children for the heart study. The response from Georgia families has been amazing. To date, 85 families whose child was treated at CHOA have enrolled in the study.

We have recently expanded our project to include families whose child is treated at Columbus Children's Hospital in Columbus, OH. In addition, more than 30 families have been recruited through our long-standing collaboration with Dr. George Capone at the Kennedy Krieger Institute Down Syndrome Clinic in Baltimore. This past July, representatives from our study attended the National Down Syndrome Congress convention in Atlanta. Nearly 30 families from around the country expressed an interest in participating in our study.

Overall, approximately 150 families whose child has Down syndrome and an AVSD are participating in our project. We have started to use various genetic methods to identify risk factors for heart defects. Our work includes a search for genes on chromosome 21 responsible for AVSDs. Understanding why heart defects occur in children with Down syndrome will also help us to understand why heart defects occur in persons without Down syndrome.

A research study cannot be successful without support from the medical community, intensive efforts by researchers, and, most importantly, the time and effort of families. We are continually impressed by and thankful for the willingness of busy families to make time for a study that will someday benefit others. Thank you to all who have participated.

For more information, contact Dr. Lora Bean at (404) 727-0485 or lbean@genetics.emory.edu.

The Down Syndrome Clinic staff wish to thank the Down Syndrome Association of Atlanta for its support. We couldn't do it without you! As always, we welcome your comments and suggestions (contact Sallie Freeman, sfreeman@genetics.emory.edu). To find out more about the Emory Down Syndrome Clinic contact Shelley Dills, Down Syndrome Clinic Coordinator at 404-778-8524.

Announcement!

DSAA Position

The DSAA is offering an excellent opening for a seasoned Executive Assistant or Office Coordinator seeking a unique work-from-home opportunity. This position is a key contributor to the smooth operation of DSAA. This position will require a maximum of 10 hours per week and reports directly to the Executive Director. Salary range is \$10 -\$15 per hour.

Areas of responsibilities include:

- Support the Executive Director by assisting with communications, scheduling, task tracking, reporting, as well as ownership of ad hoc assignments and projects.
- Maintaining, updating and tracking Membership and Volunteer databases.
- Scheduling Board of Director meetings.
- Creating and disseminating flyers and invitations for events.
- Other administrative assignments as directed by supervisor

Qualified candidates must have:

- Ability to complete assignments on schedule, sometimes under challenging circumstances
- Ability to work independently, but confident to ask for help when needed.
- Strong attention to detail; solid skills in follow-up and follow through.
- Ability to maintain confidentiality.
- Demonstrated capability to learn quickly and adapt.
- Strong, yet professional demeanor.
- Highly dependable with a proven ability to "get things done".
- Excellent written and oral communication; grammar and proofreading skills.
- Proficiency in all applications of Microsoft Office: (Word, Excel, Outlook Publisher and PowerPoint).

Candidates should submit their resume and salary requirements to:

Executive Director
DSAA
4355 J Cobb Parkway #213
Atlanta, GA 30339

Or email:
Executive_Director@AtlantaDSAA.org

No faxes or phone calls please

Binational Health Week

by Susy Martorell

The DSAA Spanish-speaking support group, AHSDA, was front and center at the Binational Health Week celebrated at the Consulate General of Mexico on October 11th in Brookhaven. This annual health fair provides medical screenings, healthcare referrals, and prevention education throughout the United States, Mexico and Canada.

Five "Madre Guias" (Mother Guides) hosted our booth at the fair to promote public awareness and to encourage a better understanding of Down syndrome. This yearly event coincides nicely with our celebration of persons with Down syndrome each October. Andrea Cortes, Angelica Pale, Erenia Castillo, Irene Angeles and Lorena Lopez were all actively approaching parents at the fair with AHSDA brochures and "calabacitas" (mini plastic pumpkins). Their little ones, Nicole (2 ½) and Leslie (8 months), were great crowd pleasers and all enjoyed a sunny community day of sharing and relationship building.



Madre Guias Angelica Pale and Lorena Lopez, leaders in the Spanish-speaking support group, handed out DSAA brochures at the annual binational health fair.

Nicole, relaxes in her stroller while visiting with a new friend she made while representing DSAA at the health fair.



Special Olympics Georgia F.A.N. Needs Your Help

The Family Action Network (FAN) is seeking volunteers for the upcoming Special Olympics Georgia Winter Games. The games will be held January 19 - 21, 2006 in Cobb County. We need volunteers to help sell Special Olympic merchandise at the opening ceremonies Friday night and at various sports venues on Saturday and Sunday. Most volunteers only need to commit to a 2-hour time frame but if you can give more time it would be appreciated.

This is a great way to experience the games and volunteer at the same time. The Family Action Network (FAN) uses the funds raised from the merchandise

sales to donate sponsorships to Special Olympics Georgia, Sponsor the Spring Family Camp, Provide the Winter Games Family Social and provide help and support to SOGA families in general.

If you can volunteer for this wonderful event please contact Debbie Carlisle at 770.493.9240 and leave a message or email her at debcarlisle@bellsouth.net. Schedules will be flexible and any help you can offer will be appreciated. If you work for a company that would like to provide volunteers as well that would be a great opportunity for them to get involved with Special Olympics.

Get Involved

We are currently accepting nominations of qualified, energetic individuals to chair various committees for 2007. The committee chair openings are: Social/Spring Luau, Kid's holiday party, Young Adult holiday party; Advocacy/Health, Education, Job Placement; Public Relations/Press releases, Web site/E-mail communications; and finally Fundraising/ Casino Night, Shop for a Cause, and the Buddy Walk.

If you have a passion or talent or know of someone who does in one of those areas please submit a brief biography by going to the DSAA website and click on contact, then submit to president. Someone will call you within a short time to discuss the nominee for consideration.

Happy Birthday Wishes!



Johnathan Lanning, November 3



*Taylor Freeman,
December 11*

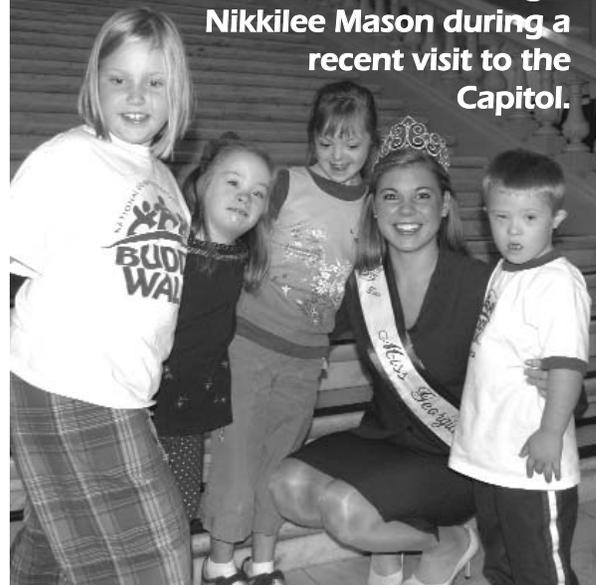
Down Syndrome Association of Atlanta
4355 J Cobb Parkway #213
Atlanta, Georgia 30339

Phone 404.320.3233
www.AtlantaDSAA.org



DSAA Today

**DSAA members visit
with Miss Teen Georgia
Nikkilee Mason during a
recent visit to the
Capitol.**



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.