

DSAA Today



The Newsletter of the Down Syndrome Association of Atlanta • September/October 2006

Highlights from the NDSC National Convention

By Jennifer Carroll, NDSC Convention Volunteer Coordinator

Atlanta had the honor and privilege to host the 34th Annual National Down Syndrome Congress Convention in July. More than 1,800 attendees came from all over the world, including Spain, Canada, Mexico, South America, and 47 states.

During the three days of the conference having a child with DS felt like a common occurrence as parents and professionals shared stories of achievements and celebrations; challenges and solutions. More than 60 speakers, including world-renowned experts spoke about issues that affect our families. Attendees learned about the latest research, best practices in therapy, education, health, and numerous other topics.

Keeping with the spirit of Atlanta, celebrating diversity was a big theme. For the first time ever, Spanish-speaking families received translation services during several workshops. Zoila Martinez, DSAA's leader in the Hispanic community, led a sharing session specific to the concerns of Hispanic families. African-American families also met together to discuss their unique challenges and concerns.

Self advocates enjoyed their own conference where they shared many tips and traded e-mail addresses. Topics included healthy eating, planning a successful first date, the benefits of kickboxing, and many more. For many of the 218 self advocates who attended, the highlight of the conference was the dance on Saturday evening. Music was provided by Chris Burke and the DeMasi Brothers. A talent show on Sunday morning also was a huge favorite.

As usual, the Sibling Conference was a great success. Middle school and high school students, fortunate enough to have

Photos and article continue on page 4.



BUDDY WALK IS ALMOST HERE!

Saturday, October 14 at Duluth Town Square

Walk Day Event Schedule

REGISTRATION - 10:00A.M.

The registration area is at the back of the amphitheater at the Town Square. If pre-registered, go to the express line. When you register, you'll receive all your event materials and t-shirt.

WALK - 11:15A.M.

The one-mile walk (also a 1/4 mile distance offered) begins and ends inside the Duluth Town Square. All participants with Down syndrome crossing the finish line will receive a medal. Strollers and wagons are welcome.

LUNCH - 11:45A.M.

A box-lunch is provided for everyone who is pre-registered. Bring your blankets and chairs to enjoy this picnic-style celebration.

ENTERTAINMENT - UNTIL 1:00P.M.

Relax on the lawn and enjoy games, giveaways, music, and a gymnastics performance by the Murphy Family.

REGISTER ON THE WEBSITE

Go to the home page at www.AtlantaDSAA.org and click on the Buddy Walk link. You can register, get event information, view the sponsors, and get fund raising "tools and tips."

RAISING MONEY

Ask your family, friends, and co-workers to sponsor you by pledging to help support this local project of the DSAA. Be sure to see if your company has a matching gift program. All Buddy Walk donations are 100 % tax deductible.

CREATE A TEAM

Organize a group of buddy walkers from your workplace, school, or community. Use our on-line tool at www.AtlantaDSAA.org/buddywalk to set goals and track your team's progress and standing. Call Tim at 678.414.9260 for more information on setting up a Buddy Walk team.

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2006 Buddy Walk Title Sponsor

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From the Executive Director

in • spi • ra • tion (in' spə ra' shən)

The *American Heritage Dictionary of the English Language* defines inspiration as:

1. Stimulation of the mind or emotions to a high level of feeling or activity.
2. An agency, such as a person or work of art that moves the intellect or emotions or prompts action or invention.
3. Something, such as a sudden creative act or idea that is inspired.
4. The quality of inspiring or exalting: a painting full of inspiration.
5. Divine guidance or influence exerted directly on the mind and soul of humankind.
6. The act of drawing in, especially the inhalation of air into the lungs.

After having attended the 34th Annual National Down Syndrome Congress Convention in Atlanta, there is one word that comes to mind . . . inspiration! Meeting hundreds of parents from around the world who also have a child with Down syndrome was a truly inspirational experience. Meeting the authors of the books that we all have on our nightstands and shelves at home was a treat. Hearing directly from the physicians and therapists about the latest research and treatment options in Down syndrome was enriching.

For each of you who had the opportunity to attend any part of the convention, you know what I'm talking about. The other very inspirational part about this year's convention was the number of DSAA members who not only participated, but also were an active part of the event. The Down Syndrome Association of Atlanta played a significant role in this year's annual convention. As the host city, the DSAA Board served as ambassadors to the hundreds of families from across the nation who attended at the Atlanta Marriott Marquis. Jennifer Carroll, DSAA's immediate past president served as the NDSC Volunteer Coordinator and recruited over 400 individuals who served in many capacities throughout the 3-day convention. Jennifer was recognized at the Award Banquet for her outstanding leadership and accomplishment. We had several DSAA members who served as Facilitators of the Parent Sharing Sessions: Alyssa Allen, Michelle Norweck, Adriana

"Inspiration" continued on page 7.

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

Advocacy ALERT - Therapy!

by Heidi J. Moore, DSAA Advocacy Director

Unfortunately the Department of Community Health (DCH) has decided to continue with their proposal that makes it more difficult for our children to receive therapy. We really need to push this issue with our legislators and with the Governor that this is WRONG and needs to be changed ASAP! DCH is stating that each therapy is only allowed 8 units per month (approx. 2 - 3 hrs. of therapy per month!) or a combined therapy (ST/OT/PT) of 16 units per month without getting a prior authorization (PA). In addition, each PA will have to be submitted every 3 months per therapy needed!

Please get involved and do the following:

1. Go to the following website (www.vote-smart.org) and input your five-digit zip code plus four digits (you can get the four digits from junk mail you receive if you don't know them) to find out the name of your State Senator/Representative. Send a quick e-mail or call them and let them know how important these issues are to you personally.
2. Also, contact Governor Sonny Perdue on line at: Georgia.Governor@gov.state.ga.us (he just needs to hear from us).

Here are some items to think about when writing your letters and making your phone calls:

In a recent interview on Fox 5 10:00 P.M. news, Mark Trail, Medicaid Director at DCH, indicated that the state must be "financially responsible" with how it spends it's money. While prior authorization is generally a good mechanism to ensure that services are properly administered, it can have several negative consequences if not administered properly (as anyone knows who has had an HMO). Therefore, we need to determine whether the proposal outlined by DCH is "financially responsible" in this circumstance.

The only rational explanation for implementing prior authorization requirements is that DCH believes par-

ents, doctors, and therapists are not qualified to determine the level of services necessary to meet a child's needs. Even though these caregivers see the child daily, weekly, and/or monthly, DCH apparently believes it is in a better position to determine the level of services for a child and believes that by reducing prior authorization levels, it will reduce the number of "unnecessary" therapies.

In order to be financially responsible, governments must determine whether reducing their programs will save money without causing other undesirable results. For example, the state could simply stop providing any services of any kind. It could discontinue police, fire fighters, etc. Although this would save the tax payers money, this would not be a "responsible" decision as it would have serious negative consequences. Similarly, the state can't just look at the cost of the program when making changes, it must look at all of the circumstances. It must determine whether the change will achieve cost savings without reducing the necessary level of care. Therefore, in order to make sure these prior authorization level changes are responsible, we must ask ourselves these questions:

1. What will the total costs be for increasing the number of prior authorization reviews?
2. What savings does DCH expect to see as a result of reducing what it believes to be "unnecessary" therapies?
3. Are the savings greater than the cost to implement the changes?
4. Are the pre-authorization levels set appropriately?
5. Are there any other non-monetary factors that must be considered?

Please get involved and write your letters and make your phone calls. Therapy needs to be viewed as an investment in our children's future! Due to the increase in paperwork, more and more providers are NOT accepting Medicaid. WE have to STOP the trend before it's too late. Medicaid is not going to be worth the paper it's written on if we can't find providers for the services our children need in order to become active, productive, tax paying citizens in society.

Help Unlock the Disability Waiting Lists for Georgia

by Heidi J. Moore, DSAA Advocacy Director

Please take a moment to send a quick e-mail endorsing the continued funding of the 2,000 MRWP waiver slots for children and adults with disabilities. The Department of Human Resources Commissioner is meeting with her staff right now to develop budget recommendations and we need your help!

Go to www.unlockthewaitinglists.com/actionalert.html to make this click of advocacy. Thank you for always deciding to act, it makes a difference.

Even if your child has the Katie Beckett waiver, we still need to continue to add disability waivers (someday your child may need this waiver too). As advocates, we need to stick together and help the cause.

UNITED... WE WILL MAKE
A DIFFERENCE!


In Memory



**Evan Michael Usher
June 7, 2005 - September 10, 2005**

Baby boy of Michael and Rose Usher. He was a child worth fighting for.

DSAA Recap



NDSC Convention continued

a brother or sister with DS, got to hang out with each other and share their experiences. They learned that their feelings are not unique to them but shared by others. The event was highlighted by a trip to the Georgia Aquarium on Sunday.

Behind the scenes, working tirelessly to make the event a success, were hundreds of dedicated, fantastic, volunteers. Individuals came from as far away as California, incurring personal travel expenses, for the privilege of serving. Several Atlanta companies, including Coke, Northside Hospital Foundation, Deloitte, Hands-on-Atlanta, St. Peter Chanel Catholic Church, Special Olympics of Georgia, Department of Genetics at Emory, and The Optimist Club supported with many volunteers. Parents, grandparents, and other family members volunteered as well.

The great spirit of Atlanta showed through. Hosting this event was not only an honor - it was a labor of love; like putting on a three-day wedding with two thousand guests. We are so very grateful to participants and volunteers alike who helped make it happen.



Above: Russ and Cara Plugge welcome convention guests at the DSAA exhibit. **Top right:** Cynthia Outman participates in a martial arts demonstration.



Above: The Hardister family is all dressed up and ready for the Saturday-night banquet.



Above: Joe Carroll is the Master of Ceremonies during the Friday-night silent auction **Right:** Johnny Eng greets convention guests during registration.



Above: DSAA Advocacy Director, Heidi Moore, was a speaker during a breakout session. Her topic was "Be a Survivor: Power of Advocacy for our Children".



Left: Douglas Quinby and Steve Harrison chat between sessions. **Right:** Lindsey Corbin greets convention speakers with a DSAA gift bag.



What's Coming Up

DSAA Fall Education Workshops

The workshops will be held on Saturday, September 30th, from 11:00 A.M. to 4:00 P.M. at Peachtree Road United Methodist Church in Buckhead (3180 Peachtree Road Atlanta, Georgia 30305; phone 404.266.2373). The workshops will be held in conjunction with the Special Needs Ministry of PRUMC.

The Outline of Topics on 9/30:

- 11:30 – 12:15 Transitioning
- 12:30 – 1:45 Special Olympics of Georgia (Lunch)
- 2:00 – 2:45 Sibling Study
- 2:45 – 3:45 Educational Rights

Schedule and Description 11:00 – 11:30 Check in/child care drop off

11:30 – 12:15 There will be two transition workshops during this time. One session will focus on younger children, while the other workshop will center on the 14+ age group. A representative from Babies Can't Wait will discuss transitioning from BCW to community services. The other workshop will feature a representative from Briggs & Associates regarding "Project Search", employment, vocational training, etc.

12:30 – 1:45 Lunch will feature speakers Debbie Carlisle with Bradley Carlisle and Josh Hanson on the Special Olympics. Bradley Carlisle recently competed in the National Games in Iowa. Josh Hanson is head of the Delegation for the National Games. Lunch will be provided at a cost of \$6 per person, which will be payable on the day of the event.

2:00 – 2:45 Sarah O'Kelley will discuss her recent study and research of siblings of children with Down syndrome and other developmental disabilities. Many DSAA members have participated in this study.

2:45 – 3:45 Denise Quigley will be on hand to share insight and address issues regarding educational rights of children with special needs.

To register for lunch and childcare, please RSVP by September 15th to Betsy Glass at 404.459.9923 or betsy.glass@comcast.net. Please indicate the number of adults, the number of children, and the children's age(s).

Directions to the church can be found at www.prumc.org.

BUDDY WALK, continued

SILENT AUCTION

There will be wonderful items to silently bid on from 10:00 A.M. to 12:30 P.M. On page 7 of this newsletter read about artist Michael Johnson who has donated an original painting for the auction.

BUDDY OF THE YEAR AWARD

The first annual DSAA Buddy of the Year Award is part of this year's festivities. This award will acknowledge, celebrate, and give recognition to an individual with Down syndrome over the age of 16. The nominee should excel in their area of interest, demonstrate leadership among his/her peers, volunteer in the community, and demonstrate the potential of people with Down syndrome. The official nomination form can be printed from the DSAA website; deadline is September 22.



ANYONE CAN BE A BUDDY!

We encourage people with Down syndrome to invite buddies -- everyone from friends and family to teachers, neighbors, legislators, and celebrities to join them on the Buddy Walk. Every participant helps promote the importance of awareness.



Passes may be obtained in advance by contacting Kathy Everett at 678.230.6985.

There are some exclusions to this offer, please check with the store prior to shopping.

Macy's at Town Center, Shop for a Cause Shopping Pass Coupons - \$5.00 100% Benefits Charity on Saturday, September 16th, 2006 - 9AM-10PM

Join MACY'S in Kennesaw on 9/16/06 in a national day of support for non-profit organizations. Donate \$5 to get your shopping pass and receive 20% off all regular, sale, and clearance prices on women's, men's, and kids' apparel and accessories, fine and fashion jewelry, bed and bath items, housewares, frames, luggage, china, crystal, and silver. Receive 10% off all regular, sale and clearance furniture, mattresses, rugs, kitchen, electronics and technology items.

THE EMORY CONNECTION

9th World Down Syndrome Congress Conference Highlights

By Jeannie Visootsak, MD

It was great to meet clinicians, researchers, parents, and children from all over the world at the 9th World Down Syndrome Congress in Vancouver, B.C., Canada, August 22 - 26, 2006. The conference brought together families, researchers, therapists, and educators to share a wealth of information to help optimize the lives of individuals with Down syndrome. Here are some highlights from the conference:

1. **The one-day workshop of the Down Syndrome Medical Interest Group (DSMIG)** included Down syndrome clinic medical directors from every continent. The DSMIG is one of the groups responsible for the healthcare guidelines for individuals with Down syndrome. A steering committee is currently working to integrate these Down Syndrome Health Supervision Guidelines into every child's primary care visit with their pediatrician. There is also a plan to incorporate developmental and educational screening into the healthcare guidelines during well child care visits.

2. **Dr. Bob Hodapp from Vanderbilt University** reviewed findings from a large-scale national study of adult siblings of persons with Down syndrome. This study used a web-based survey to examine characteristics of siblings and siblings' relationships with individuals with Down syndrome and other disabilities. Based on 277 responses from adult siblings of persons with Down syndrome, these siblings have higher joint activity, closer relationships, and slightly better health/lower depression rate compared to siblings of persons with other disabilities. However, the level of interaction appears to decrease when the siblings with Down syndrome reach their 30s, 40s, and 50s.

3. **The Kohl's Center for Safety Transportation of Children and Indiana University School of Medicine** recently published a brochure on "Car Safety for Children with Down Syndrome". The recommendation suggests keeping the child rear facing for as long as possible. This keeps the child's head and back against the car safety seat and gives better protection from injury. You can order the brochures at www.preventinjury.org

The state-of-the-art in the field of Down syndrome continues to grow. The collaboration of parents and professionals is essential to increase awareness of Down syndrome and advance the scientific knowledge.

Those of us in the Down Syndrome Clinic thank the Down Syndrome Association of Atlanta for its support. We could not do it without you! As always, we welcome your comments and suggestions (contact Sallie Freeman, sfreeman@genetics.emory.edu).

The Emory Down Syndrome Clinic serves families of children from birth through age four. For questions or to schedule an appointment, please call Shelley Dills, Clinic Coordinator, at 404.778.8524.

Announcements

TOP Soccer

US Youth Soccer TOPSoccer (The Outreach Program for Soccer) is a community-based training and team placement program for young athletes with disabilities that is organized by youth soccer association volunteers. The program is designed to bring the opportunity of learning and playing soccer to any boy or girl, ages 4-16, who has a mental or physical disability. The TOP Soccer goal is to enable the thousands of young athletes with disabilities to become valued and successful members of the US YOUTH SOCCER family.

September 9 – November 11
Cherokee Impact will hold the
TopSoccer program at Hobgood
Park. For more information call
Morgan Allen at 770.517.9970.

DSAA Membership

DSAA is in the midst of its annual membership drive. Your 2006 membership form has been sent to you. Complete it and mail your check to DSAA today!

For the first time DSAA is creating a membership directory. Be sure to be included by sending in your membership form.

Another new program of membership includes the Supporting Parent Program. Families new to DSAA by birth, transfer, or just getting involved for the first time will be matched as closely as possible to an existing "mentor" family in their area.

DSAA wants to know how we can best meet the needs of your family. We need your input on the membership form so we can continue to support and educate DSAA families.

Meet Artist Michael Johnson

By Robin Johnson

Michael Johnson is 33 years old and works hard everyday. This year he has had some great jobs! He did nine illustrations for a book of dog stories including the cover. A children's hospital decided they wanted Michael to decorate the ICU and requested 20 large paintings of children and animals. The hospital is currently contacting donors so they can hire Michael for the job. While waiting for the funding to come through Michael did some watercolors for dog shows, two small portraits of baby boys, and a large portrait

of nine dogs on a beach for a family who admired his painting from the November 2005 cover of the *American Journal for Public Health*. Currently he is working on an acrylic portrait of a pony with a carriage and driver, and an oil painting of a dachshund.

In 2001 Michael had a solo exhibition at Vanderbilt University. In 2002 Michael won a national art contest sponsored by the AVMA (American Veterinary Medical Association). In 2003 his painting "Pets Make A Difference" was reproduced on posters and t-shirts for National Pet Week. Some of his paintings are owned and treasured by movie stars, famous authors, the owner of an NBA team, and even a U.S. Senator.

Michael loves animals and he paints from a cheerful and innocent point of view. He finds inspiration in his community and at the Evanston Dog Beach. His paintings are celebrations of life.

This gifted artist was born with Down syndrome. For 16 years he attended Park School, a public school that serves children with special needs and incorporates

the arts into their curriculum.

When Michael graduated at the age of 21 he decided that he was going to be an artist. All of his friends from school had jobs in the community, but Michael's family was committed to support his dream of being a full-time artist. Michael has been painting almost every day since graduation. Art is his job, not his hobby. He works hard every day. In twelve years he has developed his own cheerful style of painting animals with bright colors and happy faces. He has completed more than 800 paintings and illustrations. He has painted more than 200 commis-

sioned portraits of pets and children from photographs. Michael has become a hero for children who have Down syndrome and an inspiration to their families.

Local children with Down syndrome often visit his studio with their families and watch Michael

paint and enjoy the happy animal artwork on the wall.

The internet has helped Michael to mainstream his art. After 9/11 more people discovered a refuge of peace and happiness on his website. People who love animals send Michael photographs of their pets and children so he can paint their portraits in colorful landscapes from his imagination. Michael just likes to paint every day.

A special note from DSAA

Michael is donating one of his paintings to the Buddy Walk silent auction that will take place in Duluth on Saturday, October 14. To view Michael's work check out his website. Google Michael's full name "Michael Jurogue Johnson"; we had problems finding his website by the address we were given.



"Kids and Pets 4", an original painting by Michael Johnson

Executive Director, continued

Melone, Karen Wise, Denise Quigley, Kathy Everett, Jane Shaw, Joan Essen, Joe Carroll, and Jim Outman. The following members were part of the elite100 presenters at this year's convention: Heidi Moore, Kathy Everett, Zoila Martinez, and Susy Martorell. Cara Plugge coordinated the DSAA Exhibit table of volunteers that included: Russ and Cara Plugge, Michelle Norweck, Yvonne Pierre, Julie Anderson, Mary Anne Blackwell, Yanna Rodriguez, Debbie Hibben, Shere' Owens, Susan TenEyck, and Johnetta Harris. Diane Saliceti single handedly created special thank you bags for each of the 100 speakers. Matt Rasnick created and produced a video, which highlighted the DSAA's purpose and objectives. Stephanie Meredith coordinated volunteers who introduced the 100 speakers, and many of our members were selected to make these introductions and served as the A/V liaison. There are so many more of you who contributed in many other ways, and to each of you I say THANK YOU.

The NDSC presented an award to the DSAA in appreciation for the support and assistance with the 2006 convention. I was asked to receive the award on behalf of the DSAA. I wish to repeat here the words that I spoke from my heart that evening: "It is an honor and a privilege to represent the DSAA as Executive Director. I know I speak for our Co-Presidents, Dale Greig and Steve Harrison when I say this award is dedicated to each of our board members, self advocates, families, and volunteers. Thank you."

So thank you DSAA members and know that you exemplify the very essence of the Down Syndrome Association of Atlanta: Inspiring Strength, Understanding and Success!

Sincerely,

Michelle Norweck

Executive_Director@AtlantaDSAA.org

Happy Birthday Wishes!



Lainey Carroll, Sept. 1



Elijah "EZ" Jones, Sept. 1



Jason Castillo, Sept. 25

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DSAA Today



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.