

# DSAA Today



The Newsletter of the Down Syndrome Association of Atlanta

• May/June 2006

## NEW DATE! GOLF TOURNAMENT 8th Annual

The DSAA Golf Tournament has been rescheduled for **Monday, June 12, 2006**. The tournament will once again take place at the Brookfield Country Club in Roswell. This private country club hosted our tournament last year and the feedback was excellent from all the golfers who participated. The weather did not cooperate for our original date of March 20. The good news is that this will allow additional time for more golfers to participate.

We have some wonderful sponsors this year. A sampling of our sponsors includes Coke N.A., Atlanta Beverage Co., PGA Superstore, Airtran Airways, and Loco's Deli.

Tournament registration starts at

10:30 A.M. with a noon shotgun start. Lunch and on-course beverages will be provided.

After the tournament there will be a barbeque buffet, raffle, and silent auction. We have some great prizes and hope to have a large turnout for this very important fund raiser.

The contact person for this event is **Russ Plugge**, RPlugge@comcast.net or 678.480.7537. You can read more about this tournament and download the registration form from the DSAA website at [www.down-syndrome-atlanta.org](http://www.down-syndrome-atlanta.org).

### Directions

Brookfield Country Club is located in Roswell. From GA 400 take Holcomb Bridge Road West and go approximately 5 miles to the light at Mountain Park Road. Turn right (there will be a Chick-Fil-A on your right) and drive one mile to the entrance of Brookfield Country Club community. Turn right on to Oakhaven Drive, go to the first stop sign, turn left and go 1/4 mile to the club entrance.

### Tournament Sponsorships



We have varying levels of golf tournament sponsorship available, as this type of support is always needed and very much welcome. Information concerning sponsorship opportunities can be found on the DSAA website. Click on "events" on the home page and the "Golf Tournament" will be a bullet item on the left side of the page. On the golf page you will find a download for the sponsorship flyer.

### Tournament Highlights

**Four-person scramble,  
three flights**

**Hole-in-one /closest to the  
pin contest**

**Longest drive**

The \$200 entry fee includes cart, greens fees, mulligan range balls, golf apparel, team photo, on-course beverages, lunch, dinner, and prizes.



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## DSAA Executive Board

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Executive\_Director@down-syndrome-atlanta.org

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Vice-President@down-syndrome-atlanta.org

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Treasurer@down-syndrome-atlanta.org

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Secretary@down-syndrome-atlanta.org

Newsletter Editor: Sharon Jones Baron

# From the Executive Director

In the March/April Issue of DSAA Today, I outlined for you one of the resources that DSAA supports, the Adult Down Syndrome Program. I described their program and my observations at a recent visit. I also outlined some examples of how DSAA can provide other services to adolescents and adults with Down syndrome. The other program that DSAA supports financially is the Emory Down Syndrome Clinic. In turn, they support the children and families of the Down Syndrome Association of Atlanta not only through the direct medical care provided at the clinic, but also through:

- Advisory to the DSAA Board
- Sponsorship of the Buddy Walk and Golf Tournament
- Volunteers at the Buddy Walk and Golf Tournament
- Education and Information through DSAA workshops and conferences

Dr. Sallie Freeman, Genetic Counselor and Dr. Jeannie Visootsak, Medical Director of the Down Syndrome Clinic, recently presented at the DSAA Educational Workshop on March 25th at the First Baptist Church of Smyrna. They provided a thorough description of the clinic, including demographics of clients served since it was founded in January 2003, an overview of the DS Healthcare Guidelines, and Principles of Developmental Milestones.

We, as members of the Down Syndrome Association of Atlanta, are so fortunate to live in a state full of so many resources right in our own back yard - resources such as the Adult Down Syndrome Program, the Emory Down Syndrome Clinic and the National Down Syndrome Congress. In addition to these programs, the Down Syndrome



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## 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 Southside

Cathy Webb . . . . . 770.969.0238

### 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

### N. Gwinnett/Hall/Barrow/Jackson Co.

Andrea Roberts . . . . . 770.995.9586

### Henry County

Jennifer Andrew . . . . . 770.897.0025

### Macon

Leslie Hales . . . . . 478.471.9225

### Marietta/Cobb County

Laura Gray . . . . . 770.218.8844

### Rome

Toni Puckett . . . . . 770.748.5037

### Vidalia

Patricia Blackstone . . . . . 912.538.1229

# Wrightslaw Special Education Law and Advocacy Training Program

By Diane Saliceti

On February 2nd, 2006 the Autism Society of America, Greater Georgia Chapter hosted the Wrightslaw Special Education Law and Advocacy Training Program in Duluth Georgia. The training was presented by Wayne Steedman, Esq. and Pat Howey. This conference provided valuable information pertaining to special education law, particularly pertaining to changes in the new IDEA (Individuals with Disabilities Education Act) 2004. The training also focused on how to be a skilled advocate for your special-needs child in the public school setting. More information on IDEA 2004 can be found on the website at [www.wrightslaw.com](http://www.wrightslaw.com).

Mr. Steedman emphasized that IDEA 2004 calls for a higher standard for our children in receiving a free, appropriate public education (FAPE). The phrase "to the maximum extent possible" was used in IDEA 1997 to refer to our children being included in the general curriculum and prepared for life after school. However, IDEA 2004 takes this phrase much further. Public schools are now required "to the maximum extent possible" to help our children meet developmental goals and challenging expectations that have been established for all children. Additionally, schools are to provide scientifically-based instructional methods "to the maximum extent possible" when teaching our children. Peer-reviewed and research-validated methods of instruction must be used. Mr. Steedman pointed out that we must counter low expectations for our children and strive to "close the gap" between disabled children and non-disabled peers.

According to Mr. Steedman the most important part of IDEA 2004 is the purpose of the law, "...to ensure that all children with disabilities have available to them a free appropriate public

education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living, and to ensure that the rights of children with disabilities and parents of such children are protected." This should be our "mission statement", or vision, when developing each IEP. Our goals should be written with this in mind.

Another change in IDEA 2004 is the elimination of short-term objectives when developing an IEP. Because this has been eliminated our goals can no longer be broad statements about what our children will achieve in a year. Goals must be more comprehensive, specific, and measurable; they must meet the child's academic and functional needs; and they must indicate how the child's progress will be measured.

Many other changes were included in the discussion of IDEA 2004. For more information please refer to *Wrightslaw: IDEA 2004* by Peter Wright, Esq. and Pamela Darr Wright.

Ms. Howey led discussions pertaining to tests and measurements, developing SMART IEPs, and how to negotiate and avoid obstacles in order to achieve successful IEP meetings. She emphasized the importance of testing for our children. Testing allows us to objectively identify our child's current levels of performance, including strengths and weaknesses. This provides a baseline to use when setting IEP goals for our child. Testing also allows us to compare scores in order to evaluate progress over time. If your child is not making sufficient progress changes in programming should be made. When your child is evaluated it is important for parents and other advocates to have a clear understanding of what those test scores mean. If you are unsure, please consult with the

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**Executive Director** *continued*  
Association of Atlanta has several Parent Network Groups throughout the State that meet on a consistent basis to provide support and information to parents of children with Down syndrome. If you have not had an opportunity to connect with one of these groups or are interested in starting a group in your area, I encourage you to do so. Contact information for these groups is listed in each newsletter.

Although the groups originally began with parents of newborns and infants, the groups today have families whose children are of all ages. Whether you live in Gwinnett, Cherokee, Forsyth, Fulton or Henry County, we want you to know that your Down Syndrome Association supports you. If there is not currently a group in your particular geographic area, I can guarantee there is at least one other parent that lives in your county who is also a member and would be happy to connect with you.

As a parent of a child with special needs, community resources and networking is vital. Please feel free to contact me if you would like more information on how to find a group, a fellow parent to connect with, or to start a group. Your willingness to share your experiences with others and help promote positive awareness about Down syndrome is what will help all of our children reach their highest potential.

Sincerely,

*Michelle Norweck*

[Executive\\_director@down-syndrome-atlanta.org](mailto:Executive_director@down-syndrome-atlanta.org)

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**Effective May 15, 2006** the DSAA website address is changing. The new address is **[www.Atlantadsaa.org](http://www.Atlantadsaa.org)**. You will be able to access the website using the old and new site addresses.





## DSAA Educational Workshops

By Stephanie Meredith

DSAA held Educational Workshops on Saturday, March 25 at the First Baptist Church of Smyrna. The workshops featured an array of interesting speakers and a presentation to Bill McElderry and Etowah High School recognizing their generous contributions to DSAA (read about how Mr. McElderry's students raised \$2,400 for DSAA on page 7 of this newsletter).

Our speakers appealed to a range of ages. For the parents of younger children, Dr. Sallie Freeman and Dr. Jeannie Visootsak spoke about the Emory Down Syndrome Clinic and the Down syndrome developmental milestones, Karel Dokken and Brent

Applegate shared the benefits of hippotherapy, and Lisa Nevitt discussed the benefits of play therapy and the services offered by Lekotek. Meanwhile, Kim Watt offered ideas for creating special needs activities or services at local recreation associations and Alyssa Allen led an IEP discussion with some particularly insightful information from her own experiences. For young adults, Janice Nodvin led a presentation about the Adult Down Syndrome Clinic that blossomed into a discussion about family and maturation issues.

All of the participants and speakers actively participated in the parent

panel and shared Katie Beckett appeal experiences, and we learned some approaches that can be particularly helpful when submitting a Katie Beckett renewal application or appeal.

We appreciate all the parents who participated since we can only gain insight by learning from each other. If anyone would like to receive a copy of the handout we used at the meeting that contains more detailed information about Katie Beckett appeal ideas, please contact **Stephanie Meredith** at [stephaniem@canisterco.com](mailto:stephaniem@canisterco.com).

The First Baptist Church of Smyrna provided a beautiful location in historic Smyrna at no charge, and we enjoyed the help of some kind volunteers and exceptional child-care workers. The children in child care enjoyed a music therapy session and a signing class.

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## Dance kicks off Bregman Educational Conference!



Every year DSAA looks forward to sponsoring the dance that kicks off the Bregman Educational conference. This year, the dance was made even more memorable by a special appearance from the Chris Burke Band. Many of the band's fans knew the words to all the songs and sang right along. The evening's participants were thrilled to meet Chris and get his autograph. Afterward, the crowd was able to rock out with "Play it Again Sammy" their favorite DJ, Sammy Rosenberg. It was an enjoyable evening for all.



# What's Coming Up



Dear Members  
and Friends of the NDSC,

An NDSC Convention is like no other event. When we come together, we literally transform the world. The spirit and enthusiasm of our youth is indescribable. Brothers and sisters shine with pride. Parents and professionals smile with deep satisfaction and beam with joy. The workshops are life changing, the speakers are inspiring, the unique exhibits are exhilarating, the networking with friends from across the country and around the world is phenomenal. If you've never come, you may think I'm exaggerating. If you've been before, you know of the miracle that can occur.

Make plans now to attend the NDSC's 34th Annual Convention on July 21-23, 2006 in the heart of southern hospitality, Atlanta, GA. It is the only national conference on Down syndrome to be held this year in the United States.

Our theme is "Open Possibilities" and during the weekend you will see the myriad opportunities open to you and your family. You will also have the chance to learn concrete strategies to make your vision a reality. And, you will be able to do it at an affordable price, because the NDSC works hard to make this convention accessible to as many families as possible.

I was sitting at a lunch counter during one of the first NDSC Conventions I ever attended. A stranger said to me, "This sure is a friendly city. Aren't there a lot of people with Down syndrome around here?" I replied, "I think this is such a friendly place because there are so many folks with Down syndrome here!"

Look forward to seeing you in Atlanta.

Sincerely,

Rich Robison, NDSC President

***The convention brochure and registration form are available on the DSAA website. Click on "Events" from the menu bar on the home page and then select "National Conference."***

## **NDSC Convention Souvenir Program Journal**

You can include a message in the souvenir booklet to show your support for the work the NDSC does to serve persons with Down syndrome. Messages may provide information, recognition, good wishes, or may memorialize an individual. Business logos and photos may be included.

Each of the expected 1,800 attendees will receive a copy of the souvenir journal. It is a wonderful keepsake.

The souvenir journal message application is available on the NDSC website at [NDSCCenter.org](http://NDSCCenter.org). Click on the words "Convention 2006" on the home page, then click on "Convention Details" then under "Opportunities for Involvement" select "Souvenir Journal". If you do not have access to the internet, contact the Convention Coordinator, **Denise Dreyer**, at 770.604.9500. The deadline for submission of message layout or copy is May 26. Message prices start as low as \$50.

## **NDSC Convention Volunteers Needed**

The volunteer application is now available on the DSAA website. From the home page click on "Events" and then select "2006 Conference". You can also contact DSAA member **Jennifer Carroll** at 770.998.1703 or **Denise Dreyer** in the NDSC office at 770.604.9500.

# THE EMORY CONNECTION

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

## CAM and Down Syndrome: "Hope, Reason, and Evidence"

Type "Down syndrome" into Google and the internet search engine immediately returns over 46 million entries! Narrowing the search to "treatment for Down syndrome" (21 million), "medicine for Down syndrome" (17 million), or "supplement or vitamins for Down syndrome" (3 million) doesn't offer much help. New parents, wanting the best for their child, have always sought out treatments and therapies, but the internet now presents a bewildering array of information directly to parents who, sitting in front of their computers, must try to make sense of it all.

Among the internet sites devoted to Down syndrome, a number present information about complementary and alternative medicine (CAM). CAM includes a wide array of therapies, supplements, and treatments that are not standard practice among conventional healthcare providers. Trying to evaluate the claims made by some sites can be daunting. Fortunately, there are other sites that try to examine these claims from an unbiased point of view.

The journal *Mental Retardation and Developmental Disabilities* recently devoted an entire issue to articles discussing the use of CAM in children with various developmental disabilities including Down syndrome, autism, attention deficit disorder, and cerebral palsy. The title of the opening article is very descriptive, "Introduction: Novel Therapies in Developmental Disabilities—Hope, Reason, and Evidence." The authors point out that parents of children with developmental disabilities may be more likely to seek CAM options. They often want to go beyond what is offered by the traditional medical community.

In her article "Complementary and

Alternative Therapies for Down Syndrome," Dr. Nancy Roizen of the Children's Hospital for Rehabilitation at the Cleveland Clinic, discusses a wide array of CAM options that have been offered or proposed for Down syndrome. These include nutritional supplements, medicines, and other therapies. She points out that some of the possibilities are either not well-grounded in fact or have been proven ineffective, while others may have enough science behind them to warrant further research. As she indicates, most CAM options for Down syndrome do not currently have adequate evidence to support their use. Lacking are large, controlled, double-blind studies in which neither the subject (or parent), nor the researchers knows which participant has received the treatment and which has received a placebo. To emphasize the sizeable number of subjects many studies require, Dr. Roizen points to the example that to detect a six-point IQ difference after a treatment, 170 individuals with Down syndrome would have to be enrolled; a difficult and very expensive undertaking. Also, many parents want to know about CAM for infants. There are ethical and practical problems in conducting studies of this type on the very young.

Traditional medicine is evidence-based. This means that the treatment healthcare providers offer should have sufficient scientific and medical evidence to support its use. For the health and safety of individuals with Down syndrome, CAM options that offer the possibility of improving lives should be carefully chosen for further study and subject to the same guidelines.

Hyman S, Levy S. 2005. *Introduction: Novel therapies in developmental disabilities—hope, reason, and evidence. Mental Retardation and Developmental Disabilities Research Reviews. 11(2):107-109.*

Roizen N. 2005. *Complementary and alternative therapies for Down syndrome. Mental Retardation and Developmental Disabilities Research Reviews. 11(2):149-155.*

To find out more about the Emory Down Syndrome Clinic contact Helen Smith at 404.778.8477.

## Announcements

### Research Study on Dental Practices

People who have Down syndrome and are 18 years of age or older are invited to participate in a study on dental practices. This study is endorsed and supported by the Institute for the Study of Disadvantage and Disability. Contact the Executive Director, Janice Nodvin, at 678.595.4854 or via email at jnodvin@aol.com. Participants will be paid for their help with this study.

### March was Membership Renewal Month

There is still time to turn in your membership renewal form. The renewal form can be obtained from the DSAA website. Send a check, payable to DSAA, for \$20 along with the form to the address on the mail panel of this newsletter.

### TOPSoccer

TOPSoccer (The Outreach Program for Soccer) is a national soccer program created to train young people with disabilities in a caring coaching environment. The TOPSoccer program not only gives young athletes with disabilities an opportunity to play soccer, it also serves to train players to participate in competitions like Special Olympics. Google "TOPSoccer" to find out about programs nationwide. TOPSoccer is available here in Atlanta, and DSAA will keep you posted when registration opens for the next session.

## Wrightslaw *continued*

school psychologist assigned to your child's school or other qualified professional who is trained in tests and measurements in order to have a clearer understanding of your child's current functioning and strengths and weaknesses prior to the IEP meeting.

Ms. Howey introduced developing a SMART IEP for your child. This stands for Specific, Measurable, use Action words, Realistic and relevant, and Time limited. In order to write appropriate goals you must have an accurate baseline of current functioning and start from that point. The goals must be based on the child's own unique needs, not some external standard. Progress toward goals must be monitored at regular intervals.

When negotiating an IEP with school personnel, Ms. Howey emphasized that it is important to come to the meeting prepared. Maintain a businesslike relationship with the staff. Do not become emotional during the meeting. Channel those emotions toward solving problems and always keep your focus on achieving an appropriate education for your child.

These are only a few highlights of Ms. Howey's presentation. Much of her information came from her own personal experiences and from the book, *Wrightslaw: From Emotions to Advocacy* by Pam Wright and Pete Wright.

## Special Olympics Update

DSAA is sponsoring special olympian, **Bradley Carlisle**. Bradley is representing the state of Georgia at the first ever National Special Olympics in Ames, Iowa July 1-8. He is competing in the swimming event.

Closer to home, more than 2000 Special Olympics athletes from around the state of Georgia will descend on the Emory University campus to compete in Aquatics, Athletics, Soccer,

# Etowah High School students raise funds to benefit DSAA

By *Stephanie Meredith*

At the DSAA Education Workshops on March 25, DSAA recognized the generous contributions made to our organization by Bill McElderry and his Etowah High School students, including a contribution of over \$2400 this year. Truly, McElderry and his students are an inspiring example of compassion and dedication.

For the past few years, they have held the "Dimes for Downs" fund raiser. This fund raiser involves every class in the school as they compete to collect coins on behalf of DSAA, and the winning class receives a pizza party and homemade brownies to reward their efforts.

The truly inspiring part of this story is that the students running the fund raiser are members of McElderry's vocational training program. This means that these students have disabilities themselves and are learning different job skills that they can contribute to the community upon graduation. McElderry encourages his students to participate in these fund raisers so that

they can learn to give compassion since they are most often the recipients of compassion.

Bill McElderry comes from a long line of educators who are committed to teaching and enriching the lives of young people. It is clear that he genuinely cares for the students with dis-



*Etowah High School teacher, Bill McElderry presents a check to DSAA Executive Director Michelle Norweck*

abilities in his class, and his generosity of spirit extends to the community as he and students choose to donate to DSAA. Moreover, McElderry is willing to share his fund-raising techniques with anyone who asks so that they can make the same kinds of contributions.

We also want to thank the Etowah High School administration for their support of this program.

Volleyball, Tennis, Gymnastics, Table Tennis, and Badminton.

The Opening Ceremonies take place at 8:00 A.M. on Friday, June 2nd. All events are free to the public, so bring the whole family and "Come Be Inspired".

About 1000 volunteers are needed

over the course of this weekend to make this event a success. If you would like to volunteer as an individual, with your family, or with a group then the first step is to fill out a volunteer application. The application is available at [www.specialolympicsga.org](http://www.specialolympicsga.org) or call **April Aiken** at 770.414.9390 ext. 120.

# BIRTHDAY GREETINGS TO

## May 2006

Estafany Luz Abad  
 Elijah Adrien  
 Austin Bean  
 Gavin Blackstone  
 Jackson Bowers  
 Nia Bradley  
 Noah Burgamy  
 Donovan Canter  
 Grace Carter  
 Carly Craig  
 Corbett Dishman  
 Joshua Eaton

Hunter Estep  
 Jeremy Foster  
 Noah Gazaway  
 Caitlin Gleason  
 Pamela Gomez  
 Lindsey Hales  
 Lerone Howard  
 Carly Ingram  
 Jake Jeffries  
 Christina King  
 Michael Kozicki  
 Michelle Martos  
 Ariana Milagro  
 Carlos Pineda  
 Quinton Pressley  
 Estefania Ramirez  
 Angel Rodriguez  
 Katie Rouille  
 Manuel Ruiz  
 Megan Sanders  
 Claire Schell  
 Victoria Sparks  
 Sean Stevenson  
 Darby Taylor

Lily Von Schmeling  
 Javonni Washington  
 Paige Washington  
 Maddie Wright

## June 2006

Tuan Ameen  
 Trevor Beard  
 Katie Bender  
 Laura Benitez  
 Anders Bezanson  
 Mark Butler  
 Raaj Callendar  
 Nicholas De Barros  
 Kylie Dennis  
 Jennie Linn Dunn  
 Jim Foster  
 Iris Gonzalez  
 Dorian Gray  
 Noah Gray  
 Angelica Guitierrez  
 Karol Ann Hart  
 Abby Hendrick  
 Courtney Jones

PJ Keaveney  
 Andrew Kirkland  
 Jacob Knight  
 Daniel Knobloch  
 Kathleen Lewis  
 Araceli Martinez  
 Taylor Matyas  
 Mason McKenzie  
 Katie Norris  
 Christian Pate  
 Dale Potter  
 Cevin Prater  
 Mary Catherine Price  
 Antonio Rodriguez  
 Madison Sherrer  
 Julia Shriner  
 Daniel Skandera  
 Nathan Sykes  
 Lilly Turner  
 Hector Ubaldo  
 Evan Usher  
 Victoria Webb  
 Ciara Zachary

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[www.down-syndrome-atlanta.org](http://www.down-syndrome-atlanta.org)



# DSAA Today

**The Chris Burke Band is back! See them at the NDSC Convention in July. Don't miss this outstanding event. Convention information is available on page 5 and on the DSAA website.**



*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.*