

DSAA Today



The Newsletter of the Down Syndrome Association of Atlanta • January/February 2006

8th Annual DSAA GOLF TOURNAMENT

First and foremost, thank you to all of the wonderful folks that supported the Down Syndrome Association of Atlanta through participation and support of last year's charity golf tournament. We are excited to do it again!

This year's golf tournament, and important DSAA fund raiser, is scheduled for Monday, March 20th with a 12 noon shotgun start at the Brookfield Country Club. Feedback from last year's event at this private country club was very positive and we hope to have everyone back again for more. We will keep the number of golfers under 100 again this year to insure an enjoyable pace of play. (The bad news is that means we only have room for four additional foursomes!)

For individual players and foursomes, the cost for this year's tourney is \$200 per

player. This donation includes your mulligan range balls, box lunch at the start, drinks on the course, closest to pin/long drive contest, dinner, prizes, team photo, golf apparel, and more... See the registration information that will be posted soon on the DSAA website.

Please feel free to contact us if you have any questions or comments. We look forward to seeing everyone on March 20th!

DSAA Golf Committee:

Rich Carroll: rich.carroll@siemens.com
work 770.279.4818, cell 770.365.2523

Brent Maddux: bmaddux@bellsouth.net
work 404.386.1481

Russ Plugge: RPlugge@comcast.net
678.480.7537

Brookfield West 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 West community. Turn right on to Oakhaven Drive, go to the first stop sign, turn left and go 1/4 mile to the club entrance.



Sponsorships Available

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 at down-syndrome-atlanta.org. 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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From the Executive Director



It's the beginning of a new year and that means many new opportunities for the members of the Down Syndrome Association of Atlanta. The DSAA has had a remarkable 2005 filled with many accomplishments and achievements. The success of the Down Syndrome Association of Atlanta is directly related to you the members. Without active members who serve on the

Board of Directors, as Executive Officers, event chairpersons, event volunteers, and the many participants, we would not have all the wonderful things that DSAA has to offer. A special thank you goes to each of the immediate past officers of 2005:

- Executive Director - Heidi J. Moore
- Co-Presidents - Dale Greig and Jennifer Carroll
- Co-Vice Presidents - Kathy Everett and Steve Harrison
- Treasurer - Jennifer Durden
- Secretary - Cindy Stephens
- Membership/Fund Raising - Becky Samitt
- Programs Director - Sharon King
- Social Committee - Shere' Owens
- Education Committee - Stephanie Meredith
- Advocacy Director - Heidi Moore
- Grant Review Director - Morgan Allen

- Public Relations Director - Douglas Quinby
- Newsletter Editor - Sharon Jones Baron
- Buddy Walk - Diane Bromelow and Lauren Biggs
- Golf Tournament - Rich Carroll, Russ Plugge, and Brent Maddux
- Self Advocate - Patrick Essen
- Family Support Co-Directors - Karen Wise and Katherine Hunter
- Hispanic Family Support - Zoila Martinez

In addition to these individuals, there have been many others who have served on committees, participated and hosted local support groups and have contributed to the success of the DSAA in some way. To each of you I say thank you as well. This is one of the things that makes the DSAA so unique. The Association is volunteer-driven and is successful because of the personal motivation and unique bond that each of us have as members related to someone special with Down syndrome. There are many exciting events and opportunities for members to take advantage of in the upcoming year and here is a sneak preview:

The first quarter will bring another Educational Seminar for family members, and the Bregman Educational Series and Dance for adults with Down syndrome. Second quarter we will have our 8th Annual Golf Tournament, Spring Social, and a Young Adults Outing. The third quarter we will be the host city for the National Down Syndrome Congress Annual Convention and another local Educational Seminar. In the fourth quarter of 2006 we look forward to Down Syndrome Awareness Month, our Annual Buddy Walk, a Fall Festival, and our traditional Holiday Party. In addition to these major events there are always many opportunities for parents and families to socialize and identify resources through Area Networking Groups and play groups. Whether you are a new

continued on page 3

DSAA Executive Board

Executive Director:

Michelle Norweck

Executive_Director@down-syndrome-atlanta.org

Co-Presidents:

Dale Greig

President@down-syndrome-atlanta.org

Steve Harrison

President@down-syndrome-atlanta.org

Co-Vice Presidents:

Kathy Everett

Vice-President@down-syndrome-atlanta.org

Stephanie Meredith

Vice-President@down-syndrome-atlanta.org

Treasurer:

Jennifer Durden

Treasurer@down-syndrome-atlanta.org

Secretary:

Susan TenEyck

Secretary@down-syndrome-atlanta.org

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

North Fulton/South Forsyth County

Gay Hall 678.455.9483

Gwinnett County

Shere' Owens 770.495.6396

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

Newsletter Editor: Sharon Jones Baron

NATIONAL DOWN SYNDROME CONGRESS ANNUAL CONVENTION

July 21-23, 2006

Message from NDSC Executive Director, David Tolleson

How lucky for us that the NDSC convention will be in our home state this year! With over 50 presenters and 2,000 attendees - this is not only an educational opportunity - it is a family reunion! We will be able to offer best practice workshops covering issues for all ages regarding our families, schools, religious organizations, employers, and communities.

We try very hard to keep the costs as low as possible for our attendees. To assist with this we utilize a small army of volunteers. Would you be willing to help us recruit volunteers from your workplace, religious organization, civic club, fraternity/sorority, etc.? Here is a brief description of what is needed:

- Registration - assist at NDSC registration desk, 4 hour shifts, begins Friday afternoon through evening and again 7:30 am Saturday through late afternoon.
- Youth/Adult program - provide support for small groups of individuals with Down syndrome ages 15 and over, no experience necessary. Be prepared for the time of your life! Optimal to have the same volunteer throughout the day (multiple days are best) – all day Friday and Saturday, 5 hours Sunday AM.
- Brother/Sister program - assisting coordinators with the sibling program on Saturday (8 am – 5 pm), chaperones to attend the off-site field trip Sunday AM.
- Floaters - assist with unanticipated tasks and/or fill in for volunteers who don't show, staggered shifts, Friday through Sunday
- Silent Auction Support - help set up for auction on Friday afternoon or assist during the auction Friday 7:30 – 10:00pm, hand out programs, staff tables, etc.
- Family members should attend the workshops; we have several opportunities for you to volunteer before the convention.

Please call or email the following people to schedule a presentation for your group or for more information:

Jennifer Carroll, DSAA – jenniferofroswell@msn.com,
770.998.1703

Denise Dreyer, NDSC – denise@ndsccenter.org, 770.604.9500

Join the excitement!

Executive Director *continued*

parent member or have been with the DSAA for several years, we appreciate your membership and I encourage each of you to examine your ability to continue to be active or become more active by giving of your time and talent as a member of the Board. We currently have openings for new committee members in the following capacities: Fund Raising Director, Social Committee, Buddy Walk, and the Education Committee. Please contact me directly if I can answer any questions you may have on how to become more involved.

Being a volunteer on a committee is a great way to meet new people and learn more about the Association and its purpose. Only through the dedication of our wonderful volunteers are we able to offer so many opportunities for programming and events that further promote positive awareness about Down syndrome.

Thank you for your continued support of the DSAA, and please visit the website at www.down-syndrome-atlanta.org as upcoming events, programs, and advocacy efforts will be highlighted in greater detail. I look forward to working with you in 2006, and am open to your ideas and suggestions.

Sincerely,

Michelle Norweck

Executive_Director@down-syndrome-atlanta.org

New this year in *DSAA Today*

In addition to the wonderful articles pertaining to very young children from the Down Syndrome Clinic at Emory University, we will also feature articles from the Adult Down Syndrome Program; a collaboration between the ISDD and TEAM Centers, Inc.

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DSAA Today is available to you on-line. Sign-up to receive future issues delivered right to your computer.



DSAA Recap



Buddy Walk 2005 Pledge List

\$5000 and over

Mary Claire Greig

\$2000 and over

Alyssa Biggs
Ethan Bromelow
Megan MacArthur
Sean Reeves
Matthew Taylor

\$1000 and over

Sean Allbee
Elijah Adrien
Gibby Durden
Jacob Moore
Joey Storey
Carli Walters



\$500 and over

Alissa Allbee
Sara Baumblatt
Gavin Cook
Leigh Ann Kaman
Andy Meredith
Christopher Norweck
Courtney Owens
Harold Pietz
Ricky Raschke
Ashlynn Rich
Andrea Roberts
Michelle Welter

\$250 and over

Lainey Carroll
Jennifer Everett
Elijah Jones
Drew McClanahan
Heather Mabry
Kathy Schrader
Amy Sweet

Snapshots from the DSAA Holiday Party



What's Coming Up



2006 Bregman Conference

No Obstacles! Fitting theme for
Bregman Conference

Highlights include the Chris Burke Band
and World Special Olympian Katie Rouille



Adults with developmental disabilities are already looking forward to the 13th annual Larry Bregman, M.D. Educational Conference, March 11 and 12, 2006 at Georgia Perimeter College. This year's theme, No Obstacles! is a fitting legacy to the beloved Atlanta pediatrician, who wanted children with disabilities and their families to focus on their many abilities and on living life to its fullest.

The fun begins Saturday night with a dance sponsored by the Down Syndrome Association of Atlanta, featuring live music from international television star and musician, Chris Burke and his band.

Sunday morning, attendees will return to campus for breakfast and register for a full day of sessions, starting with a keynote speech by Katie Rouille, a World Special Olympics gold and silver medalist, who will discuss living life to its fullest. Program and skill sessions will include popular favorites from years past, such as computer skills, jewelry making, and line dancing, as well as new offerings such as resume writing and emergency preparedness. The conference and dance are open to all adults with disabilities, family members, and caregivers who are at least 18 years old. Advanced registration is \$18 per person, and financial assistance is available to assure that everyone can participate. Family members and caregivers are encouraged to participate in a concurrent conference designed to address their interests and concerns, such as navigating benefits and independent living.

The planning and outreach committee, comprised of conference alumni, staff, and more than a dozen service providers, is coordinated under the JF&CS Disabilities Services Division. Volunteers are needed throughout the weekend.

The Webb Spraez Award, which honors an outstanding individual who works behind the scenes to improve life and opportunities for individuals with disabilities, will be presented at the conference. Nomination forms can be found on the website at www.bregman.org.

For more information, contact Jody or Lisa at 770.677.9344 or bregman@jfcs-atlanta.org, or register online at www.bregman.org.

Educational Workshops

DSAA will present six educational workshops on Atlanta's north-side; exact location will be sent via a calling post and noted on the website. Mark your calendar for Saturday, March 25 to attend and take part in a wonderful variety of educational programs that pertain to ages birth to adult. Some of the topics include:

- *the benefits of hippotherapy and play therapy*
- *proper nutrition as your child grows*
- *keeping track of Down syndrome health milestones*
- *the benefits of social skills groups in schools*
- *understanding the Adult Down Syndrome Clinic, and more*

We will also be presenting a forum featuring parents who have successfully appealed the first Katie Beckett Waiver denial.

Child care will be provided for all children in a family, and they will be entertained with music, games, movies, and craft projects. Please RSVP to **Stephanie Meredith** by March 11 at education@down-syndrome-atlanta.org or 770.704.9543. There is no charge for these workshops, but we must know how many children are coming to plan for the appropriate number of child-care providers.



**8th Annual DSAA
Golf Tournament,
see the front page.**

THE EMORY CONNECTION

The Down Syndrome Clinic at Emory: Questions and Answers

By Dr. Sallie Freeman

The Down Syndrome Clinic at Emory University celebrates its third birthday in January 2006. We established the clinic with the initial objective of serving children from birth to three years of age and with the long-range goal of growing the clinic as the children grow. To date, our clinic has scheduled more than 200 family visits. For those of you who are not familiar with our services, we'd like to give you an introduction and answer some of your questions.

What age children are you currently seeing in your Down Syndrome Clinic?

While our long-range goal is to see individuals of any age who have Down syndrome, we currently have the following limits:

- New patients ~ birth to age three years
- Returning patients ~ we have raised our age limit so that children whom we first saw before age three years can continue to return to clinic after their third birthday.

How do I make a clinic appointment?

To make an appointment call Aimee Anido, Clinic Coordinator, at 404.778.8481. Spanish-speaking families can call Elizabeth Sablon, our medical interpreter at 404.778.8476. We think it is important that parents are the ones to make the appointment because that initial phone call gives us the opportunity to explain the clinic and determine if there is information about Down syndrome that the family needs immediately. If so, we can often provide it by phone or mail prior to their clinic appointment.

How is a visit to the Down Syndrome Clinic different from a visit to a pediatrician?

We are not a substitute for a pediatrician. As for any child, your goal should be to select a pediatrician whom you trust to provide all the best general pediatric care and who will be available for those inevitable midnight earaches! Our clinic combines genetics and developmental pediatrics. Please read on to find out more.

What does a clinic visit include?

- A review of your child's medical history. When parents schedule an appointment, we ask for permission to get their child's medical records. Information from the birth hospital, pediatrician, and any specialists helps us get to know your child. For example, we can make sure that all recommended tests such as a hearing screen, thyroid test, and cardiac evaluation have been completed adequately.
- A discussion of your child's chromosome report. Parents often want to know more about how Down syndrome occurs, what an extra chromosome 21 means for their child, and if there is an increased chance for another child with Down syndrome in the family.
- A physical exam. We complete a basic physical exam of your child and make a special effort to answer any questions you have about features characteristic of Down syndrome.
- A developmental evaluation. Our medical director, Dr. Jeannie Visootsak, is a board-certified developmental pediatrician. After conducting a developmental evaluation she discusses her findings with parents and makes recommendations for the timing and frequency of early interventional therapy (physical, occupation, speech/language). Each child is an individual with developmental strengths and challenges. Our goal is to identify these strengths and challenges and make recommendations to maximize each child's potential.
- An explanation of the Healthcare Guidelines for Children with Down Syndrome. These national guidelines provide parents and physicians with a concise outline of special items of care and their timing (e.g., cardiac evaluation, vision and hearing exams, thyroid tests.)
- Referrals. Based on each child's medical history, physical examination, and developmental evaluation, we suggest appropriate specialists if needed.
- Answer questions. This is perhaps the most important part of your visit. We urge parents to come with their ques-

tions. Each family who visits our clinic is in a different place in terms of their knowledge of Down syndrome and their understanding of what the diagnosis means for their child. We try to tailor visits to each family's needs.

Where is the Down Syndrome Clinic located?

The clinic is located in our new facility just off the Emory campus near the corner of North Decatur and Clairmont Roads. The address is 2165 North Decatur Rd., Decatur, GA 30033 and parking is easy!

How do I find out more about the clinic? Aimee Anido, Clinic Coordinator, will be glad to answer questions related to the clinic; her contact information is listed below.

All of us in the Down Syndrome Clinic 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.

Sallie B. Freeman, PhD

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sfreeman@genetics.emory.edu

Jeannie Visootsak, MD

Assistant Professor
Down Syndrome Clinic Medical Director
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Aimee Anido, MS, CGC

Clinic Coordinator
Genetic Counselor
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Helen Smith, BSN

Research Nurse
404.778.8477
hsmith@genetics.emory.edu

Elizabeth Sablon, BSW

Certified Medical Interpreter
404.778.8476
esablon@genetics.emory.edu

Jeannie Visootsak, MD, FAAP is a Developmental Pediatrician and Medical Director of the Emory Down Syndrome Clinic. For information about the clinic which serves children from birth to age 3 years, please contact our clinic coordinator, Aimee Anido, MS (404.778.8481, aanido@genetics.emory.edu) or Sallie Freeman, PhD (404.778.8484; sfreeman@genetics.emory.edu).

Announcements

Lekotek of Georgia

By Jennifer Carroll

Lekotek has openings at their Alpharetta and Duluth locations. This non-profit organization provides parents with information, education, and resources. Children with disabilities and their families participate in monthly hour-long play sessions where trained therapists provide adapted toys specific to a child's disability and interests. The family takes home a bagful of toys to borrow for the month and when they return the next month they exchange them for new toys. Lekotek is a Swedish word that literally means "play library." As a parent, I love this program because it gives me the opportunity to try out toys, software, switches, etc. before buying it. My daughter has participated in computer camps, Compuplay, and play sessions at Lekotek since she was an infant and looks forward to every session. Annual memberships are \$240 per year, scholarships are available and no family is denied services. For more information visit the website, www.lekotekga.org, or call 404.633.3430.

Disability Day at the Capitol Thursday, February 23, 2006

A day of advocacy for policy makers, people with disabilities and their allies. For more information on this upcoming event go to the Governor's Council on Developmental Disabilities website at www.gccd.org.



Adult Down Syndrome Program

Information provided from the ISDD brochure

Specialty health services are available for adolescents and adults with Down syndrome thanks to the collaboration between the Institute for the Study of Disadvantage and Disability (ISDD) and TEAM Centers, Inc. The Adult Down Syndrome Program offers a number of services to individuals with Down syndrome and their families, and accepts Medicare, Medicaid, and private insurance.

Here is a sampling of services:

- creating a health profile for adolescents or adults
- providing coordination of health care for adults
- providing families with resources for accessing primary and specialty health care in and around Georgia
- assisting families with transitional and long-term planning

This program is supported by the Down Syndrome Association of Atlanta, and DSAA member Janice Nodvin is the ISDD Executive Director. She has extensive knowledge in community resources, advocacy and issues related to Down syndrome and other developmental disabilities.

Janice is currently serving as a Project Manager on the research of the use of Vitamin E on the progression of Alzheimer's disease in adults with Down syndrome. It is known that people with Down syndrome, who are over 50, are more likely to develop Alzheimer's disease than the typical population. ISDD is participating in a national research study on the effects of Vitamin E and is looking for local participants over the age of 50 with Down syndrome. If you know someone who would be interested in participating, please contact **Janice Nodvin** at 678.595.4854 or go to the website at www.disadvantagedisability.org.

DSAA Today

The current and many past issues of *DSAA Today* are always just a click away on the website. As a matter of fact, we are offering a new service this year to inform you when the latest newsletter is ready

to view and/or print on your own. Help us save on postage and printing by signing-up for this new email reminder service. Just send an email request to: contactus@down-syndrome-atlanta.org, and you will be set to pick-up your next newsletter on-line.

BIRTHDAY GREETINGS TO

January Birthdays

Emmanuel Alvarez
Andy Beraki
Jacob Bond
Kayleigh Bridges
JJ Briggs
Ginny Burton
Grace Margaret Carroll
Abbigale Carson
Joseph Carter
Chandler Cash
Edwin Contreras

Gavin Cook
Zyon Cooks
Alexander Freeman
Bethanie Henderson
Steven Joe
Kylie Johnson
Grace Key
Shannon Laffey
Lillian McIntyre
Elisha McKenzie
Andrew Meredith
Jacob Moore
Isaac Mullen
Breana Ortiz
Jenna Quigley
JC Quinby
Hunter Roach
Tucker Rowlett
Shirley Salazar
Jennings Slaughter
Jesus Solis
Jayda Stokes

Alexandra Thoman
Davis Tillery
Susan Wellons
Brett White
Armando Zarza

February Birthdays

Joseph Anderson
Colby Andrews
Conner Cartihers
John Chambliss
Payton Cheek
Katherine Cohenour
Nicole Cortez
Dwayne Helms, Jr.
Paloma Flores
Philip Flores
Amber Lynn Foskey
Suzanne Goossens
Seth Higgins
Myles Howard

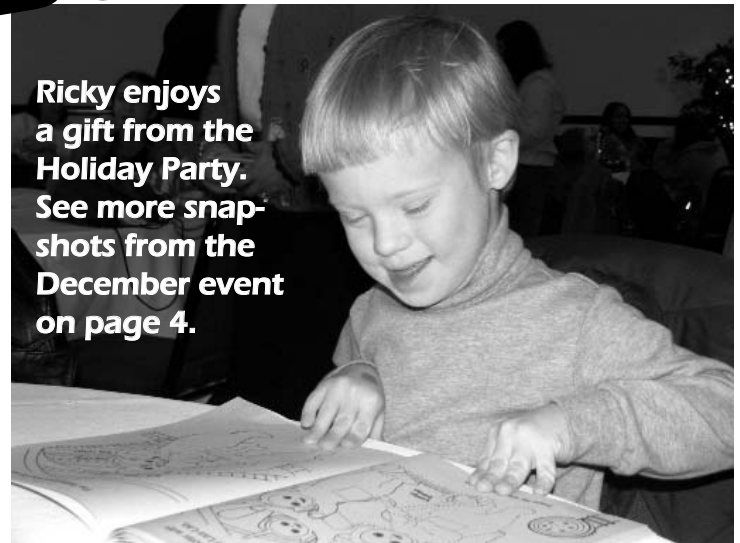
Mary Beth Hurst
Ross Matthew Johnson
Ereonna Jones
Matthew Jones
Kaitlyn Knauber
Payton Mabry
Matthew McCoy
John Perner, Jr.
Sydni Porter
Nolen Robison
Felicia Roman
Preston Rosell
Hugh Rowling
Alexis Rutland
Colin Stephens
Corte Tripp
Linda Valdez
Neddy Vignos
Lashawn Washington
Halli Yarbrough
Michele Zarate

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DSAA Today



Ricky enjoys a gift from the Holiday Party. See more snapshots from the December event on page 4.

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.