



Down Syndrome
Association of Atlanta

DSAA Today

September / October 2008

1978-2008!

30th Anniversary

2008 Regional Conference
on Down Syndrome and Other Disabilities

*Celebrating the Journey:
Yesterday, Today & Tomorrow*

Sponsored by: DSAA
November 7-9, 2008

Atlanta Perimeter Marriott Hotel
246 Perimeter Parkway, NE
Atlanta, GA 30346

www.atlantamarriottperimeter.com

30th Anniversary Gala

Join us for an evening of fun and reminiscing. The evening will begin with a cash bar reception and silent auction at 6:30; followed by a delicious dinner at 7:00. The silent auction will continue through dinner until 9:00. End the evening by dancing to hits of the 70's and everyone's favorite deejay Play it Again, Sammy!

From 6:30 until 9:00 any school aged children (3-21) are welcome to enjoy their own special dinner in the Kid Zone. Children will be supervised by the respite team of Kool Kidz Foundation, have a special child friendly buffet and age appropriate movies. There will be separate rooms for pre-school/elementary school and middle school/high school. At the conclusion of the Gala Banquet, the children are free to go to the dance with their parents.

Tickets must be purchased in advance! We will not have the capability for on site sales as the hotel must know in advance the number of dinners to prepare. The Kid Zone will have limited space; so we must go by first come, first served.

Tickets for the Gala Banquet are \$65 each; Self-advocates \$40 each Kid Buffet \$20 each. Please look in the Conference brochure or go online to purchase tickets for this event.

The one event that you do not want to miss in November is the Fall Conference that DSAA is sponsoring. Not only will there be two and a half days of presentations and workshops, but also a 30th Anniversary Gala event on Saturday evening. Hard to believe, but DSAA was founded in 1978 and is celebrating 30 years of continuous service to individuals with Down syndrome and their families in the Greater Atlanta area. Whether you are an "old timer" or a new member, we hope that you will join us both for the conference and for the celebration of this joyous occasion: 30 years as an organization.

The conference opens at 8:00 a.m. Friday, November 7th and adjourns at 5:15 p.m. that afternoon. Friday's speakers include Mitchell Levitz, an awesome self-advocate, and Dr. Brian Skotko, who has done research on the families of individuals with Down syndrome, including issues that affect parents and siblings.

Saturday's sessions begin at 8:00 a.m. and end at 5:00 p.m. Saturday's program includes an inspirational address by author Kathryn Soper, a special track of activities for individuals ages 15 up who have Down syndrome (Self-Advocates' Conference), a track of sessions translated and/or presented in Spanish, two medical panels, and a wide array of workshops on topics that are of interest to our members.

Saturday evening is the 30th Anniversary Gala Celebration. Tickets will be sold for a special banquet with entertainment and speakers. There will be a separate dinner and activities for school aged children during the adult banquet. The Gala events start at 6:30 for the children, the banquet for adults starts at 7:00 p.m. and a celebration dance (free and open to all) will be from 9:00 - 11:00 p.m. In addition, there will be a cash bar reception open at 6:30 and a silent auction taking place from 6:30 - 9:00 p.m. Banquet tickets are \$65 for adults and \$40 for self-advocates; children's tickets are \$20 per child.

The conference opens again Sunday morning at 8:30 a.m. and runs until 12:30 p.m. The focus on Sunday is on family, friends, and faith communities. There will be a final address delivered Sunday by Pat Bauer, a well known journalist who is also the parent of a child with Down syndrome (you may read her online blogs . . .).

Costs for the conference depend on whether or not you preregister before October 15th and whether you plan to attend one day or all three. There also are different rates for self-advocates and families (related - 2 people maximum). Except for the Gala events Saturday evening, there will not be any child care provided.

If you are on the DSAA mailing list you should have received a brochure with more details and a registration form. A copy of the brochure is also posted on the DSAA website www.atlantadsaa.org. Note that tickets for the Gala Celebration events are separate. All registrations can be done through the mail (send your checks to DSAA) or online with a credit card.

This is a wonderful local opportunity for our families to learn from and interact with both national and local experts. DSAA underwrites a great deal of the cost of the conference so that the registration fees are affordable for families. We also have a limited number of scholarships available for those who cannot afford to attend otherwise. We hope that our members will register early and we hope to see all of you in November at the Marriott!

Nominations Call for Biannual DSAA Awards

Please submit your nominations by the **Deadline of October 1, 2008.**

—AWARD CATEGORIES ARE—

R. DWAIN BLACKSTON AWARD - honors an individual who has shown excellence and leadership in making a difference in the lives of individuals with Down syndrome.

JIM SANDERS AWARD - is presented to an individual who has promoted advocacy and equality for individuals with Down syndrome.

—PLEASE INDICATE—

R. Dwain Blackston Award -or- Jim Sanders Award

—PLEASE INCLUDE—

Name of nominee
Nominee's phone number
Nominee's email

Reason for nomination (one page essay)
Submitted by: Name/Phone/Email

—PLEASE SUBMIT YOUR NOMINATION—

via email to: executive_director@AtlantaDSAA.org
or U.S. mail to:

DSAA/Awards, 4355 J. Cobb Parkway #213, Atlanta, GA 30339

DSAA Executive Board

Executive Director:

Cynthia Jones
Executive_Director@AtlantaDSAA.org

President:

Morgan Allen
President@AtlantaDSAA.org

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Vice-President@AtlantaDSAA.org

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Vice-President@AtlantaDSAA.org

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Secretary@AtlantaDSAA.org

Newsletter:

Rick Raschke
Newsletter@AtlantaDSAA.org

WANT TO KEEP INFORMED OF ALL DSAA EVENTS AND ANNOUNCEMENTS?

Get on the DSAA Email List for Important Updates and Announcements right in your Inbox!
Email Douglas Quinby at
Public_Relations@AtlantaDSAA.org

Young Adults

Evan Nodvin 770.396.8056
Megan Sydney. 770.491.0155

Hispanic/Latino

Susy Martorell 404.931.6619

Korean/Asian

Erin Chun 678.777.7844
soccerchun@gmail.com

Alpharetta

Stefanie Baumblatt. 678.297.0992
Karen Wise 770.664.8141

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 Millsbaugh 678.364.0158

Heard/Troup Counties

Pamela Jones 706.675.1534

Henry County

Melissa Kendrick 770.826.6300
mbkendrick2@yahoo.com
Audrey Starace 678.245.0822
airens1@yahoo.com

North Fulton/South Forsyth

Gay Hall 678.455.9483

Gwinnett County

Jeanne Bond 770.736.6015
jeanjenie@aol.com

South Fulton County

Cathy Webb. 770.969.0238

Macon/Bibb County

Kim Wright 478.960.8597
Mandy Curlee 478.405.6083

Marietta/Cobb County

Cara Henley Plugge 678.560.4167
cplugge@comcast.net

Rockdale/Newton County

Melissa Kendrick 770.826.6300

Rome

Toni Puckett 770.748.5037

Letter from the Executive Director

“Speak Out And Educate”

I hope this finds all of you doing well and falling comfortably into the routine of the new school year. This is a really busy time for the Down Syndrome Association of Atlanta. We are working on the final details and taking registrations for both the Buddy Walk fundraiser and for our upcoming Fall Conference. You will find details about both of these events later in this Newsletter.

We also are participating in Macy's "Shop for A Cause" fundraising event this year. We are selling "tickets" for \$5 (all of which goes to our organization) which provide the ticketholders with a 20% or 10% (depending on items) discount on Saturday, September 20, 2008 at any Macy's department store, and also for a chance on a \$500 shopping spree drawing. Contact me or any other board member if you would like to buy (or sell for us) tickets.

By the time you receive this Newsletter we will have held our 10th Annual Golf Tournament. Russ Plugge and his committee did a fantastic job in organizing this event. We will have details in a later edition. Thank you Russ and all!

Related to all of this information about fundraising, I have become aware that many of our members would like more information about where the money from our fundraising events goes. I recently sent a message to those members on our regular email list that explained the DSAA activities and funding for them, but I will include that information in this Newsletter as well for those of you who are not on the email list. As an aside, if you have an email address and are not receiving emails from us, let us know. When we need to get information out quickly between Newsletters, the email blast is the easiest way. But it only works for you if you are on our list!

Finally—you will see an article in this Newsletter from Jennifer Carroll, our Advocacy Director, regarding DSAA's recent response to a new movie by Ben Stiller, "Tropic Thunder," which has language and scenes offensive to us. I am dismayed that critics would proclaim "the funniest movie of the summer" one that ridicules individuals with intellectual disabilities - spoof or no spoof. I encourage you to use the popularity of this movie as an opportunity to speak out and educate others about affirming the dignity of all people and to discourage the use of language that is demeaning.

As I continue to meet members of DSAA, I continue to be in awe of this incredible organization. I look forward to seeing ALL of you at the Buddy Walk and the Fall Conference! If I can be of assistance to any of you, let me know.

Regards,

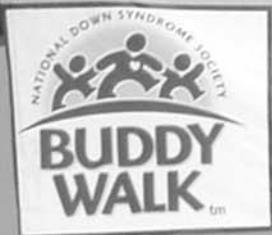
Cynthia

Attention Gwinnett Area Members:
Are you looking to meet other families in your area? We have a new exciting group that is forming! Jeanne Bond is mom to 9 year old Jacob and is excited about finding other families of all ages to share information, resources, and lasting friendships. Please contact Jeanne Bond for details 770.726.6015

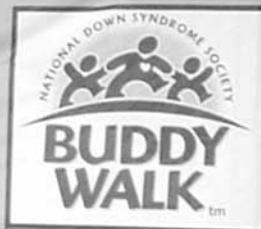
Networking Groups

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

The Down Syndrome Association of Atlanta
welcomes you to the



BUDDY WALK



Hello DSAA Members!

It's that time of year again, with the weather cooling down it can only mean one thing . . . The Buddy Walk Is Almost Here!!!

My name is Jennifer Thanepohn (*Tenpin*) and I am the Down Syndrome Association of Atlanta's 2008 Buddy Walk chairwoman. The Buddy Walk will be on:

October 4th at the Duluth Town Green from 10:00am to 1:00pm

It will be a fun filled day with Jay Memory, the Cobb County Special Olympics Gymnastics Team and our Favorite Atlanta DJ Neal Howard performing. Throughout the Buddy Walk there will be activities including a trackless train, games and bounce houses, clowns and of course the 1/2 mile walk itself.

—Register Your Team Online Now—

Organize a group from your workplace, school or community and support people with Down syndrome while building team spirit. Use our online tool at:

www.AtlantaDSAA.org/buddywalk

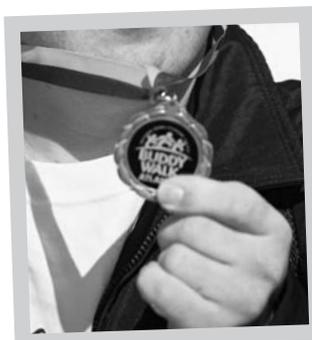
to set goals and track your team's progress and standing as your team competes in DSAA's biggest fundraising event of the year.

Also, the *Second Annual DSAA Buddy of the Year Award* will be given at the Atlanta Buddy Walk on Saturday, October 4, 2008. We welcome nominations of any individual with Down syndrome exhibiting the qualities and actions listed below. All nominees must be 16 years of age or older. This award is to acknowledge, celebrate and give recognition to an individual with Down syndrome who has demonstrated outstanding personal and community involvement:

- *Excels in their area of talent and interest*
- *Demonstrates leadership qualities among their peers*
- *Volunteers their time to enhance the lives of others*
- *Has made an important contribution to the community*
- *Is a great model of the potential of individuals with Down syndrome.*

To make a nomination, please email me at JenniferEMSGirl@yahoo.com for the Buddy of the Year Award Form and send back by email or U.S. mail to arrive no later than September 12, 2008.

by U.S. mail delivery please send to: Jennifer Thanepohn / DSAA Buddy Walk Chairwoman • Down Syndrome Association of Atlanta / Buddy of the Year Award • 4355 J Cobb Parkway #213, Atlanta, GA 30339



Down Syndrome Association of Atlanta *"2008 Buddy of the Year Award"*
Nominations Must Include:

- *Nominee's name:*
- *Parent's name:*
- *Home address:*
- *Phone number:*
- *Email address:*

Information on sponsor making the nomination:

- *Name:*
- *Relationship to nominee:*
- *Phone number:*
- *Email address:*

Background on nominee (providing information that will enable us to understand how they exhibit the qualities of "Buddy of the Year". In 1-2 pages, describe what makes your Buddy so special. Please provide any photos, stories or anecdotes that help illustrate your nomination.



**Down Syndrome
Association of Atlanta**

With every Buddy Walk, ***We Are Always In Need of Sponsors, SPONSORS and Did I Mention SPONSORS?*** If you know of a company or individual who would be interested in being a sponsor for the 2008 Atlanta Buddy Walk please let me know. This year we are in need of items for the Silent Auction and the Raffle tables. We are in need of donated items from places, where you would frequent most, like coffee houses, restaurants, hair salons, etc. in the form of gift certificates, coffee mugs with ground coffee, haircut certificate/hair care/beauty products, hotel accommodations, dinner gift certificate, art pieces, toys, etc. There are volunteer opportunities the day of the walk as well. Please email me if you think you can help at JenniferEMSGirl@yahoo.com

Thank you again and I will see **YOU** at the Buddy Walk! • Jennifer Thanepohn, DSAA Buddy Walk Chairwoman



The Emory Connection

An Overview of Clinical Research

by Jeannie Visootsak, MD

An important component in advancing our knowledge in Down syndrome is through “clinical research”. Although laboratory and animal research are essential, it is clinical research that answers the question “Does it work?” To answer this question, specific conditions or treatments are studied in a 1) Clinical research study or 2) Clinical trial in order to understand the nature of a disease or the effectiveness of a drug.

Research questions are typically initiated from literature review and/or our clinical practice. As an example, our interest may be sparked after learning that there are a lack of studies in the developmental patterns of children with Down syndrome who have a congenital heart defect. We may also derive our research questions from our clinical practice. For instance, if we recognize that our patients are reporting common medical concerns that have yet to be published in literature, we may be interested in conducting further research. Indeed, research strengthens anecdotal findings (e.g., testimonials and case studies) because it is based on a sound experimental design with a large number of participants and a comparison group.

Another aspect of research involves clinical trials. For example, scientists at Stanford University published a study in 2007 entitled “Pharmacotherapy for Cognitive Impairment in a Mouse Model of Down Syndrome”. The researchers studied Ts65Dn mice, which have extra chromosome 21 material, and a learning profile similar to individuals with Down syndrome. They wanted to see what effect a certain drug (called a GABA antagonist) would have on Ts65Dn mice. Ts65Dn mice given a GABA antagonist drug developed normal learning behavior after 17 days. They postulated that if the neurons of children with Down syndrome are similar to those in the Ts65Dn mice, then it may be possible to use a GABA blocking drug to improve learning in children with DS. So, how do we translate laboratory animal studies to human trials?

Clinical trials involving new drugs are classified into preclinical research and four phases. The drug development process proceeds through all four phases over many years. The path to drug approval includes 1) Preclinical research- does it work in animals? Once this phase is completed, the researchers inform the FDA by applying for a Investigational New Drug Application so that it may be tested in humans. 2) Phase I- Is it safe in humans both with and without disease. 3) Phase II- Does it work in humans and is it safe? Of note, only one-third of experimental drugs successfully complete both Phase I and Phase II studies. 4) Phase III- New vs. Old treatment in humans. This is a large-scale testing to get more thorough understanding of the drug’s effectiveness, benefits, and the adverse reactions. Phase III includes several hundred to several thousand patients and typically last many years. 5) Phase IV monitors the drug’s long-term efficacy in a large population, and further refine the safety information or dosing questions.

The most important person of all in every clinical research is the volunteer participants. Without your participation, no clinical research can be done.

MEMBERSHIP MEMO:

- Have you noticed that there is a renewal date on your address label that you receive from the DSAA?
- This is a new feature that the Down Syndrome Association of Atlanta is offering to their members.
- You will always know when your renewal date is for your membership just by looking at the address label on your DSAA mail.
- Membership dues are annual and are \$20.
- They can be paid online at www.atlantadsaa.org under membership renewals or by sending a check to DSAA, 4355 J Cobb Parkway, #213, Atlanta, GA 30339.
- Don't forget to renew today to reap the benefits of membership.
- We have a lot of exciting events coming up including the Buddy Walk, Regional Educational Conference and the Holiday party.
- If you have any questions on your membership status, contact Stefanie Baumblatt at sbaumblatt@bellsouth.net or 404-320-3233.



Book Fair On the Square

A meaningful life in the community for everyone is the Vision of the Department of Human Resources Division of MHDDAD. In support of this vision, the Division’s Office of Developmental Disabilities is pleased to be a co-sponsor of a unique community educational event entitled Book Fair on the Square.

The Book Fair will take place in Marietta (Metro Atlanta area) on Friday & Saturday, Oct. 3 & 4, 2008. The theme of the Book Fair is Opening Minds, Changing Hearts. The Book Fair will feature authors who have written acclaimed books fostering community inclusion for everyone including persons with disabilities. There will also be an art show and family activities.

Please visit the Book Fair website at www.bookfaironthesquare.org where you can learn about the events that will be taking place as well as about sponsorship opportunities, etc.

Joetta Prost, Ph.D.
Director, Policy & Training
DHR Division of MHDDAD
jprost@dhr.state.ga.us

Training On New Developmental Disability Waivers

The *Division of MHDDAD Office of Developmental Disabilities* is pleased to continue providing training regarding Georgia's "New" Waivers for Persons with Developmental Disabilities. Throughout Fiscal Year 2009, various training events about the waivers will be tailored for different groups of stakeholders.

Beginning in August, six Provider Transition Intensive sessions for DD Providers will take place in Clarkston (Metro Atlanta), Thomasville, Augusta, Savannah, Cartersville and Morrow. These Provider Transition Intensive sessions focus on specific subject areas critical to the successful implementation of the NOW and COMP Waivers that are administered by the Office of Developmental Disabilities and scheduled for implementation in November 2008.

The updated announcement which contains details about the training and how to register is available at the below website. IF YOU HAVE ALREADY REGISTERED USING THE ANNOUNCEMENT DISTRIBUTED EARLIER, THERE IS NO NEED TO REGISTER AGAIN. Registration is quick and easy online at:
www.cviog.uga.edu/training/dhr

The announcement will also be posted on the Division's training web site at:
<http://mhddad.dhr.georgia.gov/training>

For questions call: Mat Winer, Training Coordinator II, at 404-463-0796 or via email at:
RegistrationMHDDAD@dhr.state.ga.us

Web Surfin'?

Check out this site . . .

<http://www.brightertomorrow.org/>

Workin' On Sight-Words?

Try flashcards for your young reader—

Fundraising and DSAA Why the Buddy Walk Is Important—

The DSAA Buddy Walk is coming up quickly. It will be held October 4th at the Duluth Town Square and we are expecting a great day with lots of fun and excitement.

Buddy Walk was established in 1995 by the National Down Syndrome Society (NDSS) to promote awareness and inclusion. October is National Down Syndrome Awareness Month, and Buddy Walk is one of the celebratory events. Local groups like the Down Syndrome Association of Atlanta join with the national association to hold events across the country. NDSS offers resources to local groups to help them in planning and carrying out the events, including the use of the Kintera website to manage registrations and payments, and a variety of posters, brochure templates and other media and materials. DSAA has taken advantage of many of the resources that NDSS provides.

Last fall the DSAA Buddy Walk made almost \$150,000 after expenses were paid. Of this, \$15,000 (10%) was donated to NDSS, specifically designated for their Washington, D.C. Policy Center. The remaining \$135,000 stayed in DSAA and has been used for the following activities:

• Grant to the Emory Down Syndrome Clinic	\$ 31,250.
• Grant to the Adult Down Syndrome Clinic	23,000.
• Funding for the Hispanic Support Group	4,200.
• Launching Down Syndrome Specialists Project in schools	3,200.
• Costs for bimonthly DSAA Newsletters	11,000.
• Costs for website maintenance	3,000.
• New Expectant Parent and Medical Provider Guides	25,000.
• New Parent Packets and Parent Liaison Program costs	1,000.
• Spring Educational Conference	800.
• Scholarships for members to attend conferences	4,000.
• Bregman Dance for young adults	1,000.
• Winter social and spring luau	17,000.
• Advocacy	2,200.
• Fall Conference Planning and Publicity	8,350.
TOTAL: \$ 135,000.	

Obviously DSAA has other fundraising events (Golf Tournament, Shop for A Cause, etc.) and obviously not all expenses are covered by the funds raised through the Buddy Walk (e.g., conference registrations). But, as you can see, Buddy Walk funds are critical to carry out many of the activities that DSAA provides in support of our families and young self-advocates.

DSAA provides information to expectant parents and their physicians; reaches out and provides information and support to new parents; supports four programs that offer critical and specialized supports to families at times of need (the Emory Clinic, the Adult DS Clinic, the Hispanic Support Group, and the new Down Syndrome Specialists Project that provides information and support to educators in public schools who are working with students who have Down syndrome); provides information through a website and bi-monthly newsletter; offers connections to other families through a member database and a network of local parent support groups; provides learning opportunities through DSAA conferences and scholarship support to help members attend other training events; offers social opportunities; and works with a wide array of other organizations to advocate for individuals with disabilities. We don't do it all perfectly, but we are trying hard to implement a balanced program of activities to reach all of our families.

Buddy Walk funds are not raised on behalf of NDSS, but rather on behalf of our local organization. Yes, DSAA contributes to the national organization, but that is the "cost" of participating in the event that they started and control. DSAA would have considerable overhead costs if it designed and did all of the publicity and registration itself.

DSAA puts many of our volunteer resources into the Buddy Walk; it will take all of our members to make it successful. We are in tough economic times right now and it is increasingly hard to raise funds from sponsors and businesses. We have a huge network of friends and family members and supporters—if each makes a contribution to this event we will collectively achieve our goal, AND have fun in the process.

“SHOP FOR A CAUSE” will be Saturday, September 20th.

If you purchase a ticket (by making a \$5 donation to DSAA), you will **SAVE 20% or 10%** (depending on the merchandise) all day with a special shopping pass AND be eligible to enter a chance to win a \$500 gift card (no purchase necessary). DSAA board members will be “selling” tickets, or you can contact Cynthia Jones at Executive_Director@AtlantaDSAA.org.

If you are willing to “sell” additional tickets, let Cynthia know asap. For a \$5 donation to DSAA, you, your friends, neighbors, family members, co-workers, etc. can support our organization, save money on purchases at Macy’s on September 20th, and enter a chance to win a shopping spree!



Carta a Ruth:

Te escribo esta carta por que necesito que conozcas tu historia, como llegaste a mi vida para cambiarla, para ser mejor persona, luchadora, perseverante, paciente y sobre todo me enseñaste a ser madre y te doy las gracias por eso mi Ruth.

Llegaste a mi vida el 09 de Enero del 2005, cuando tuve en mis manos la prueba de embarazo que me confirmaba que dentro de mí se estaba formando un ser, desde entonces soñé con tenerte en mis brazos, como toda espera fue difícil pero valió la pena, luego de 38 semanas de disfrutar tus movimientos en mi vientre, de tocarte a través de mi barriga por fin el 07 de setiembre del 2005 pude cumplir mis sueños de saber como eras, mis sueños de poder oler te y sobre todo de poder tocarte.

Recuerdo bien cuando te pusieron a mi lado y vi tu rostro hermoso por primera vez, sentí una emoción tan fuerte que no pude evitar llorar, pero era un llanto de alegría y desde ese día que por la noche te dejaron dormir a mi lado no nos hemos separado mi amor, TE AMO.

Ya sabía desde el cuarto mes de embarazo que nacerías con Síndrome de Down, pero esa noticia no me quitó ese sueño dulce de esperarte, al cuarto día que naciste recibí la llamada de la coordinadora de Babies can't wait, ahí viví la realidad de que tenía un niña especial, yo te veía como cualquier otro bebe, pero era importante que estuvieras también en manos de personas que conocían como ayudarnos para tu desarrollo.

Ahora estas camino a cumplir 3 años y parece mentira como pasa el tiempo, y lo que en su momento parecia que eran tormentas que no se podrían superar hoy puedo mirar atrás y sorprenderme como con el favor de Dios hemos podido ir avanzando cada etapa de tu desarrollo y tu salud. Cuando a las dos semanas de nacida tuvimos que llevarte de emergencia al Hospital del Childrens Health Care de Egleston, sentí que mi mundo se colapsaba, jamás imaginé verte sufrir pero tuvimos que atrevernos ese camino para poder seguir avanzando y gracias a Dios, a los médicos, enfermeras y a cada persona que nos ayudó mientras estuvimos esos 35 días en el Hospital hoy ese corazoncito esta reparado, si bien es cierto saliste con un tubo en tu barriguita por que tenias reflujo y además los líquidos se iban a tus pulmones a los 4 meses esto era asunto superado, recuerdo perfectamente cuando en febrero del 2006 fuimos a Atlanta para que te hicieran los exámenes para saber si habías superado el problema del paso de líquidos a los pulmones, como siempre lloré de emoción al ver en la pantalla como el líquido que te deban a beber iba correctamente a tu barriguita !lo superó! grité de alegría por fin te vería comiendo y tomando leche por tu boquita, gracias a Dios otro obstáculo superado mi amor.

Vendrían nuevos retos como no, si la vida está llena de retos, pues ahora tendrías que aprender nuevamente a usar el biberon, te imaginas a los 5 meses aprender nuevamente?, tuvimos la bendición de tener un buen terapeuta que te ayudó a recordar lo que sabias hacer al nacer, luego vendrían nuevos retos, con sus respectivas esperas y como no, con mucho trabajo para lograrlo, pues hay que trabajar duro para lograr nuestros objetivos verdad mi amor?, y los resultados están ahí algunos serán excelentes otros quizá no, pero lo importante es no dejar de luchar y tu eres una buena luchadora te he visto y de ti he aprendido.

Es así como pude verte sostener tu cabeza, luego sentarte sola, después dar tus primeros pasos y poco a poco ir diciendo algunas palabras, quiero que sepas que me siento muy orgullosa de ti eres la mejor hija que me pudo haber dado Dios, ahora espero ansiosa el mes de setiembre para llevarte a la escuela y comenzar una nueva etapa de aprendizaje.

Te amo Ruth, juntas iremos avanzando por el camino que Dios ha señalado para nosotras, seré tu apoyo en cada paso, sabes que puedes contar conmigo mi amor, y se que de ti recibo mucho amor en cada abrazo y beso que me das.

Con amor
Mamá

A letter to Ruth:

I am writing you this letter because I need you to know your history, how you came into my life and changed it, how you made me a better person, a fighter, persevering and patient, but most of all you showed me how to be a mother and I thank you for that, my Ruth.

You came into my life on the 9th of January, 2005, when I first had in the hands the pregnancy test which showed that a new human being was forming inside of me, since then I dreamed about having you in my arms, and the wait was difficult as those things are, but worth it. After 38 weeks of savoring your movements inside of me, touching you through my belly, at last on the 7th of September, 2005 my dreams were answered, I came to know you, I could smell you, and most of all I could touch you.

I remember well when they put you at my side and I saw your beautiful face for the first time, I was so full of emotion I could not help but cry, but it was a cry of happiness and since that evening when you slept at my side we have not been separated my love, I LOVE YOU. I knew from four months along that you would be born with Down syndrome, but this news had no impact on my sweet dream of waiting for you. On the fourth day after you were born, I received a call from the service coordinator from “Babies Can’t Wait”, and with that I realized that I did have a special child even though I saw you the same as other babies; it was important that we would get help from people who would know how to support your development.

Now you are almost three years old and it seems a lie how fast the time has passed. Those things which at the moment appeared tortuous and insurmountable at the time, I am now surprised to see, through the grace of God, we have been able to progress past and still advance with each phase of your development and your health. When we had to take you to the emergency room at Children’s Healthcare, Egleston, at just two weeks of age, I thought my world had collapsed. I never imagined seeing you suffer, but we had to cross that road in order to move forward and thanks to God and to the doctors and nurses and each person who helped us during those 35 days in the hospital, this little heart was repaired and it’s true you left with a tube in your little stomach for the reflux that made liquids collect in your lungs. Four months later, this was another problem that had been turned around. I remember perfectly well in February of 2006 we went to Atlanta so they could do tests to see if you had overcome that problem of passing liquids to your lungs; as always I cried with emotion to see on the screen that the liquid they fed you was passing correctly to your little stomach, you succeeded! I screamed with happiness to finally see you eating and drinking milk with your little mouth, thanks to God another obstacle was overcome, my love.

There would be more challenges of course, life is full of challenges, now you would have to learn all over again how to drink from a bottle, imagine learning that all over at 5 months of age. We were blessed with the help of a good therapist who helped you remember what you knew how to do at birth. Soon there would be more challenges, each with a waiting time and of course requiring hard work, well one has to work hard to reach one’s objectives, isn’t that true my love? And the results are there for all to see, some will be excellent and maybe others not so great, but the important thing is to never stop fighting and you are a very good fighter; I have watched you and I have learned from you. This is how I have come to watch you hold up your head, then sit on your own, later take your first steps and little by little saying some words, I want you to know that I am very proud of you, you are the best daughter that God could have given me. And now I anxiously await the month of September to take you to school and start off on another new era of learning. I love you Ruth, together we will continue to advance on the road that God has shown to us, I will be your support with each step, you know that you can count on me my love and I know that from you I will receive so much love with each hug and kiss you give me.

With Love
Mama

A Message from the Adult Down Syndrome Program

How long has it been since your son, daughter or sibling with Down syndrome had an evaluation by experts in the field of Down syndrome? Is he or she transitioning from pediatric to adult health services or leaving the school environment and entering community resources? Have you seen changes in your family member's health, behavior or life skills? Do you feel you need help with long term goals for your family member and you? Do you feel your primary care physician may need some consultation with an expert in adults with Down syndrome?

The **Adult Down Syndrome Program (ADSP)** is a specialty health service for teens and adults with Down syndrome and their families. We are beginning our fourth year as a partnership supported by the Down Syndrome Association of Atlanta and have garnered a reputation as a leader in life long issues of persons with Down syndrome. It is the home of our research study on senior adults with Down syndrome as well where we are collaborating with experts in the field of Down syndrome all over the world.

Our team sees families regularly each month and is comprised of experts from various fields of health and wellness. Our program is led by Dr. Leslie Rubin, developmental physician, who shares his expertise with our nurse/social worker, our dietician/nutritionist and our family coordinator. The first visit to our program will cover an extensive discussion concerning past health records, educational programming and life skills. We want to know your concerns and what is important to the individual and family as far as long term goals. We are available to assist you with this individualized plan. Recommendations are made and resources in the community are provided. We are available to follow-up as needed with the family, the medical providers and community service providers in your community.

We are waiting to hear from you. If you have questions or wish more information, please contact our clinic director, **Janice Nodvin, at 678-595-4854** or email at jnodvin@aol.com.

Dr. Leslie Rubin, *developmental physician*
Janice Nodvin, *clinic director*
Susan Carney, *nurse/social worker*
Ria Bonaparte, *dietician/nutritionist*

DSAA Joins Protest of Movie and Use of "R-word"



DSAA joined with other disability groups across the state to protest the Ben Stiller movie "Tropic Thunder". On Monday, Aug 11th, DSAA hosted a conference call with the *ARC of GA*; the *Shepherd Spinal Center*; *GCDD*; and *JF&CS*; where all participating groups agreed to form the '*Disability Coalition of Georgia*'. The purpose of the coalition is to protest the movie because of its use of the 'R-word' and the negative depiction of people with intellectual disabilities.

Protests were held at three movie theaters in metro Atlanta, and additional sites in Macon, Savannah, Albany, Waycross and Newnan. At the time of this writing, we estimate over 100 advocates across the state participated in the protests. Many more DSAA members wanted to attend but were unable to. Additional protests were scheduled for the weekend. DSAA also signed a petition against the use of the "R-word" that is expected to be published in the NY Times.

Defenders of the movie contend that the movie is intended as a satire of the extremes of Hollywood. For those of you who haven't read the blogs or reviews, Ben Stiller plays an actor who tried to win the Oscar for his portrayal of 'Simple Jack', a man with intellectual disabilities. He is ridiculed throughout the movie, and repeatedly referred to with the "R-word". Robert Downey Jr. plays an actor who portrays an African-American. When he utters the 'N-word', another actor calls him to task and berates him several times throughout the movie for attempting to lump all African-Americans into certain stereotypical behavior. Defenders say that using the 'R-word' is simply meant to be humorous and that by eliminating offensive words there won't be anything left to laugh at.



This is simply not the case. The writers of this movie went out of their way to denigrate people with intellectual disabilities, treating them as the minority 'safe' to ridicule. It is our position that the movie will cause an increase in the use of the 'R-word' and will perpetuate negative stereotypes. David Tolleson, Executive Director of National Down syndrome Congress, put it succinctly when he stated that, "it would be different if there was protagonist to respond to (Ben) Stiller's antagonist in the same way there was for (Robert) Downey's character (but there isn't)".



There is a silver lining: disability groups across the nation are joining forces to speak with one voice. In Georgia we are planning to follow suit and collaborate on future issues. Hollywood, businesses and government must recognize that, people with disabilities make up the largest collective minority in the US. It is time to take a stand and speak out against the injustices endured by our loved ones.

If you were unable to attend a protest but still want to see the 'R-word' eliminated from everyday use, there is a way to help. The Special Olympics have set up a web site to take a pledge against the use of the word. It only takes a second to make your pledge and forward it to all of your family members and friends.

Go to: <http://r-word.org>. Also write your newspaper thanking them for their coverage or go to their blog sites as well as Pat Bauer's site at www.patriciaebauer.com.

by Jennifer Carroll



Hunter turns 1!



Jackson turns 3!



Ruth turns 3!



Zana turns 7!

Happy Birthday!

October

Neshawn Adams
Gabrielle Allen
Bobby Aniekwu Jr.
Alfredo Arredondo
Sara Baumblatt
Lou Bontempo
Brianna Boyden
Daniel Bryant
Bradley Carlisle
Benjamin Collins
Katie Elzey
Patrick Essen
Kasey Frady
Elizabeth Griner
Tyler David Hall
Erin Jarrell
Mary Elizabeth Jarvis
Jack Jorgensen

Araceli Juarez
Elijah Kendrick
Brandon Leyva
Lauren Maddux
Kasie Martell
Mary Jo McElwe
D'Jaylon McKee
Beth McMurry
Tracy Moon
Oluwatamilore Omolabi
Cynthia Outman
Amanda Parrish
John Michael Patton
Jackson Pursley
Ricky Raschke
Ashlynn Rich
Ryan Daniel Schael
Ryan Stampfli
Sawyer Stricklin
Gray Tapache
Brian Thibodaux
Mike McLemore Turner
Erica Vallecillo
Audrianna Williams
Jameson Ray Woods
Danny Zakaria

September

Nicholas Abrams
Bryan Aguilar
Caroline Allbee
Sofia Lemos Alvarez
Benjamin Reece Bandy
Lainey Carroll
Jason Castillo
Amber Dawn Clifton
Colin Cooperider
Melissa Cordoba
Skyler Corliss
Christopher Cramer

Maria de los an Dewendt
Gracelen Easterwood
Cameron Fernandez
Harry Gilcreast
Myles Henderson Green
Jonathan Gross
Caleb Guy
Sophia Marie Guyer
Andrew Hall
Audrey Huddleston
Jordan Huffman
Khadijeh Jalloh

Elijah (E.Z) Jones
Cameron Kindree
Nicholas Lee (Nicky) Lee
Guadalupe Lopez
Zana Lumpkin
London Mayo
Nathan Peter McGinnis
Courtney Medrano
Simon Mireles
Santino Monroe
Gabriella Joy Ospina
Paul Partus

Lauren Peterson
Cole Plugge
Nathaniel S. Poll
Bruce Riley
Jonathan Rodriguez
Kendall Salmon
Jack Samitt
Ava Jones Sanders

William Standridge
Hunter Stephens
Wade Strite
Nicholas Stubbs
Robert Todd
Justin Walker
Carli Walters
Gavin Wise

If you would like your child's November/December birthday photo featured in the newsletter, **please submit by October 20th to contactus@AtlantaDSAA.org**



**Down Syndrome
Association of Atlanta**

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www.atlantadsaa.org

!DSAA Today



**Alpharetta
Advocacy**
story on page 7

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.



2008 Conference Registration

Register Online at www.atlantadsaa.org or by Mail
Registration Deadline 10/15

Attendee information (Print Clearly or Type)

Name (First) _____ (Last) _____

Name (First) _____ (Last) _____

Mailing Address _____

City _____ State _____ Zip _____

Contact Phone Number _____ email address _____

Name and Age of family member with Down syndrome _____

Must be at least 15 years of age to attend Saturday's self-advocates track which includes sessions on dancing, art, nutrition and job interviewing skills.

GENERAL CONFERENCE REGISTRATION:		After 10/15	
Full Conference—Family (two adults)	\$90	\$ 140	\$ _____
Full Conference—Individual	\$60	\$ 85	\$ _____
One Day Only—Individual	\$45	\$ 70	\$ _____
Self-Advocates Conference	\$25	\$ 50	\$ _____
Certificate of Attendance	\$10		\$ _____

30TH ANNIVERSARY CELEBRATION BANQUET:

	# of Adults _____ X \$65	\$ _____
	# of Self-Advocates _____ X \$40	\$ _____
<i>(please indicate if any of the follow choices are needed)</i>		
Vegetarian _____	Kosher _____	Gluten free _____
Child Friendly Buffet (Separate room/supervised)		
	# of children age 3-5th grade _____ X \$20	\$ _____
	# of children 6th-12th grade _____ X \$20	\$ _____

Members Grand Total \$ _____

PAYMENT OPTIONS:

____ Check enclosed Charge: ____ Visa ____ Mastercard

Card # _____ Expiration date: _____

Signature _____ Today's date _____

If registering by mail, return this form in an envelope or simply fold this self-return mailer and seal with tape securely on all three sides and affix stamp.

seal with tape securely

STAMP



**Down Syndrome
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4355 J Cobb Parkway #213
Atlanta GA 30339

seal with tape securely

seal with tape securely

fold



*Celebrating the Journey:
Yesterday, Today & Tomorrow*

2008 Regional Conference on
Down Syndrome and Other Disabilities

November 7-9, 2008

Atlanta Parneter Marriott Hotel



**Down Syndrome
Association of Atlanta**

DOWN SYNDROME ASSOCIATION OF ATLANTA
FOUNDED 1978

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