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Betting on the Future

By Becky Samitt, Event Chairperson

The First Betting on the Future Casino Night was held November 12th at the Atlanta National Golf Club in Alpharetta, Georgia. It was truly a great night, and I am honored to have been a part of the evening! We had 200 guests (not including the volunteers) and the event raised over \$20,000 - an incredible outcome for a first-time event. I want to share with you some of the excitement from the evening.



A Casino Night welcome from Heidi Moore and Lindsey Corbin.

As you walked in the double, wrought-iron covered doors of Atlanta National; you were greeted by volunteers, Heidi Moore and Lindsey Corbin. Every volunteer that evening wore a name tag with a photo of an individual they love who has Down syndrome.

Risa Nettles, Dale Greig, Paulette Acevedo, Katrina Washington, and Sarah Shay were waiting at check-in to assign silent auction bidding numbers, distribute programs, and hand out \$2000 in faux gaming money.

Once you passed through the foyer the main room was filled

with live piano music (we had a last minute fill in, for Darrell Smith). Darrell was an asset to the planning of this event and was truly missed!

There were white-gloved servers passing hors d'oeuvres of goat cheese with basil and sun-dried tomato crostini, bacon and scallop kebobs, and white bean and garlic chicken bruschetta. At the buffet was a carving station with a roast steamship round of beef, poached salmon with lemon dill, penne pasta, chicken satay with lime

sauce, vegetable spring rolls, spinach and feta wrapped phyllo, imported cheeses, assorted fruit and berries, and for dessert: miniature pastries.

The dining tables were placed all over the facility and were donned with red and black table cloths and decorations that consisted of playing cards, dice, and confetti. To me the most important decoration came in the form of information about Down syndrome. Displaying this information was very important to the committee because it was a way to educate

the public about Down syndrome. And it worked!! I received several emails from the guests who thanked us for the fact sheets. Some feedback included, "I went on the

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DSAA Executive Board

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Executive_Director@down-syndrome-atlanta.org

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From the Executive Director

In my role as Executive Director I have the privilege and honor to help create with you a vision for the Down Syndrome Association of Atlanta. Over the next several newsletter issues, I will outline for you some ideas about the enhancement of DSAA's current objectives and purpose. The DSAA has as one of its primary objectives to support new parents and families of children with Down syndrome through information, education, support, and advocacy. The majority of the members of the DSAA are families with children ages birth to age 8. There exists an opportunity to continue this support to families with children and teens entering adolescence and adulthood by targeting these age groups with additional programming, activities, and events. Here are some examples of how DSAA could provide support for individuals in older age groups with Down syndrome:

- Educational seminars focusing on independence with personal hygiene, guidance about sexuality and relationships, employment, education, and recreation
- Socials for teenagers and for young adults
- Advocacy for post-secondary education and help in obtaining adult services
- Caregiver support groups for parents and siblings of older adults

DSAA currently supports a community resource called the Adult Down Syndrome Program (ADSP) that serves adolescents and adults with Down syndrome. I recently had the opportunity to visit the Adult Down Syndrome Program and observe their staff in action as they met with adult clients with Down syndrome and their family caregivers.



Dr. Leslie Rubin at the Adult Down Syndrome Program with client Margo Doherty.

Continued on page 3.

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 770.945.0136

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

Advocacy Update

By: Heidi J. Moore, DSAA Advocacy Director



Due to our advocacy efforts, WE have been heard! I have been told that our advocacy and ongoing communication of concerns to the Katie Beckett Waiver denial situation has resulted in a lot of meetings taking place in the last two weeks between Dept. of Community Health, Dept. of Human Resources, Federal Medicaid, Legislators, Governor's office, etc.

At this point, this is what I know.....The Dept. of Community Health (DCH) has made "some" changes to the eligibility criteria and more changes are pending in the next two weeks. (Please go to the DSAA website to see the final version of the Katie Beckett eligibility criteria).

According to the DCH if you are in the process of being denied, requesting a fair hearing, etc.....try to stay in the "hopper" for as long as you can so your application will be reviewed with the new criteria. If you have received a final denial, you may want to wait to submit a new application until we get confirmation of when the new eligibility criteria will be fully implemented.

In addition, I have been told that the DCH/DHR is looking at other options for families that truly do not qualify for the Katie Beckett Waiver program. Other options may include the following: buy-in "Peachcare" insurance program, create an insurance risk pool, new waiver, and looking at increasing private insurance responsibility for Standards of Care for children in this State. I will keep you posted as I have more information!

THIS IS VERY GOOD NEWS and I hope this shows you that our advocacy efforts paid off!.....UNITED....WE WILL MAKE A DIFFERENCE!

Recently I gave a presentation to FOCUS (Families of Children Under Stress) at their annual educational conference regarding the Katie Beckett Waiver and thought much of the information would be helpful to DSAA families as well. The theme of my presentation was the reality show: Survivor - Outwit, Outplay, Outlast. Please go to the DSAA website for the entire presentation; www.down-syndrome-atlanta.org/advocacy/advocacy.htm.

Jenna Quigley's Social Studies/Civics Project

By Jenna Quigley

Hi! my name is Jenna. I am twelve years old. I want to tell you how I raised \$600 for the American Red Cross for the kids who lost their toys and clothes because of Hurricane Katrina. My Mom and Dad were watching the news a lot and I heard them talking about the people who needed help because of the Hurricane. I asked my Mom, "what about the kids?"

My Mom told me that the kids lost their toys and their clothes because the water came into their house up to their knees, and then even higher. She told me they

could not take their toys or clothes with them, they just had to get out.

My Mom and Dad gave money to the American Red Cross so they could help people who did not have their homes anymore. I asked if I could give the kids some of my toys. My Mom said I could sell my toys at a yard sale and then give the Red Cross the money. I thought that was a good idea.

My friend Mary made four BIG signs for me that said "Yard Sale-All Proceeds to the American Red Cross Hurricane Relief Effort." Mom helped me send out emails

Executive Director *continued*

Their office provides a comfortable home-like setting that is staffed by a caring team of professionals who are extensively trained in the field of developmental disabilities. The depth in which the services were delivered and the genuine concern that was displayed by each and every staff member inspired me. The stories of the family caregivers and their personal testimony of how their lives have been enriched by the ADSP were unforgettable.

The Adult Down Syndrome Program is supported by the DSAA in collaboration with The Institute for the Study of Disadvantage and Disability (ISDD) and the Team Centers, Inc. ISDD is a private, nonprofit, United Way agency that provides specialty care for individuals with developmental disabilities. To find out more about this program's specific services, view staff profiles, and learn how to schedule an appointment please visit our website at www.down-syndrome-atlanta.org. and click on the Resources page. If you have any questions or concerns about how the DSAA can continue to support individuals and families of persons with Down syndrome and expand upon its current objectives, please contact me. I am open to exchanging ideas and creating a shared vision for our children at any age.

Michelle Norweek

Executive_director@down-syndrome-atlanta

about the yard sale to some of our friends. A lot of people gave me things to sell. Some people mailed me checks made out to the American Red Cross, and some friends helped me at the yard sale too.

We did not put any prices on things. People just took what they wanted and made a donation. That is how I raised \$600 for the American Red Cross.

My Dad took me to the American Red Cross office and I gave them the checks and money that I collected. The lady at the front desk took my picture!! That was very fun. I wrote a thank you note to everyone who helped me. A lot of people have told me they thought I had a great idea and they are proud of me.

Jenna and her family are members of DSAA. Jenna is currently being home schooled by her Dad, and she came up with this project herself. Jenna turned 13 this month, she has Down syndrome and a hearing impairment.

DSAA Recap



Betting on the Future cont.

internet,” “I never knew that,” and “Thank you, and it caused me to look some things up”.

Our silent auction gave everyone an opportunity to bid on cool items to benefit DSAA. The silent auction was maintained by **Tim Johansson**, **Kinsley Payne**, and **Kim Hanock**. Silent auction items included art, autographed memorabilia, themed baskets, fun stuff for children, entertainment, decorating, useful services, and travel. Each category contained anywhere between 10-20 items. Our ten most popular items were Reynolds Plantation golf foursome, Fiesta Gas Grill, Milton Dental laser teeth whitening, horse riding lessons, seven days at a private villa in Italy for 4 guests, Big Canoe cabin, ABCO security system installation with 6 months monitoring, Stevie Nicks signed tambourine, two nights in Beverly Hills and Ellen DeGeneres tickets, and D. Gellar and Sons .5 karat diamond earrings.

The evening opened with a few remarks from **Gabe Lyons** who welcomed everyone. Gabe was also responsible for the “Betting on the Future” logo, invitation flyers, programs, and sponsor signs. Self advocates,

Patrick Essen and **Cynthia Outman**, officially opened the casino.

Party All the Time provided a real-life casino experience. The gaming started with a brief explanation of all the games and then it was a no-holes-barred night of slot



Pictured from left to right Paulette Acevedo, Chairperson - Becky Samitt, Sarah Shay, Stephanie Meredith, and Katrina Washington.

machines, Texas hold'em, blackjack, roulette, big wheel, and craps. The high money winner of the night won a trip for two to Las Vegas with airfare included.

Thanks to volunteers **Kristie Kline** and **Camie Chirico**, DSAA sold drinking cups with an additional \$2000 in gaming money. This came in handy for those of us new to casino games.

When the casino gaming was over guests had an opportunity to play a charity game of heads and tails. For \$20 per person you had the chance to win four nights at the Old Key West Hotel (sleeps 12) on the Disney property. It was a simple game, buy your chance and **Janet Boyden** would flip the coin. If you chose heads, you placed your hands on your head. If you chose tails, you placed your hands by your side. With every flip of the coin, the numbers of players dropped quickly and before we knew it, we had a winner, who was off to Disney, for the amazing price of only \$20!

Thanks to a great response from our sponsors, we were able to give away three trips to Las Vegas. The top three winners for the evening each took home a big prize.

Michelle Norweck, DSAA Executive Director, closed the evening with a very big thank you to our volunteers. This was a nine-month project and everyone worked very hard leading up to this event.

In addition to the names of the volunteers I have mentioned throughout this article, I would like to also thank **Violet Smith**, the committee's significant others, and the DSAA Board of Directors. I want to add my personal thanks for the opportunity to be a part of the DSAA and this event.



Roulette, Craps, Slot Machines, Texas hold'em, and Black Jack were some of the big games of the evening.



The Greigs and guests enjoying dinner.



Cynthia Outman and her Dad trying their luck at the slot machines.

What's Coming Up

CONVENTION VOLUNTEERS NEEDED

Volunteer recruitment continues for the upcoming NDSC Convention at the Atlanta Marriott Marquis, July 21-23. Here is a description of volunteer duties:

- 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@ndscenter.org, 770.604.9500

DSAA MEMBER DIRECTORIES

The directories are coming, the directories are coming. . . March begins our annual Membership Drive; co-chaired this year by Alyssa Allen and Jenny Cudabac. Memberships may be renewed online through our website with a credit card, or you may mail a check made payable to DSAA to the following address: 4355 J Cobb Parkway #213 Atlanta, GA 30339.

For the first time in the history of DSAA, a membership directory will be made available to members who are current with their annual dues. Volunteers will be calling members to update their profile information and to obtain permission to be included in the directory. Members who became first-time members or renewed beginning March 2005 or after will receive a 2006 DSAA Membership Directory. For any existing member who has not paid their \$20 dues since March of 2005, please submit your payment to keep your membership status active.

Scholarships are always available; so enlist your family and friends to join as well. Membership dues, along with other generous donations, allow the DSAA to assist families in the following ways:

- Provide important resource information to new parents
- Host educational conferences and seminars
- Publish our newsletter, *DSAA Today*
- Maintain our website, www.down-syndrome-atlanta.org
- Advocate for all individuals with Down syndrome

Educational Workshops

DSAA will present six educational workshops on Saturday, March 25 at the First Baptist Church of Smyrna. The schedule is as follows:

- 1:30 - 2:00** Welcome and check-in
- 2:00 - 2:30** Presentation by Etowah High School and Bill McElderry "The Value of Community Fund Raising"
- 2:30 - 3:15** Workshop session #1
- 3:15 - 4:00** Workshop session #2
- 4:00 - 5:00** Katie Beckett Waiver Appeal Question and Answer Forum.

Participants can choose two workshops from the following:

For Younger Children

"Understanding What the Emory Down Syndrome Clinic Offers and Defining the Developmental and Health-Care Guidelines for Children with Down Syndrome"
Drs. Sallie Freeman and Jeannie Visootsak

"Off the Beaten Path - The Value of Hippotherapy, Play Therapy, and Innovative Technology"
Brent Applegate, Physical Therapist

For School-Age Children

"Getting Our Kids Involved in the Local Recreation Association"
Kim Watts, Cherokee Recreation Program Director

"Parent Roundtable - Sharing IEP Success and Horror Stories"

For Adults

"Nutrition A - Z"
Emory Department of Nutrition

"Understanding What the Emory Adult Down Syndrome Clinic Offers."
Janice Nodvin, Executive Director, ISDD

Childcare is provided, please RSVP to **Stephanie Meredith** at 770.704.9543 or education@down-syndrome-atlanta.org.

For directions, go to the DSAA website, from the menu bar select "Events" then scroll down to "Parent Education Conference" or call the church at 770.435.3231.

THE EMORY CONNECTION

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

New Mouse Model

Three years ago I wrote an article for the DSAA newsletter reporting on mouse models of Down syndrome. Recently, those of us who study Down syndrome were excited to learn of an important new development in this area.

Because some of you may be new to the idea of mouse models, I'll start with a little background. Even though we have known for over 40 years that Down syndrome is caused by an extra chromosome 21, we still cannot explain why the presence of that extra chromosome causes an individual to have the constellation of clinical findings that we know collectively as Down syndrome. Within the past few years researchers have mapped the genes on all human chromosomes, and they now estimate that chromosome 21, the smallest chromosome, has only about 200-400 genes. Typically, each of us has two copies of these genes, but individuals with Down syndrome have three (trisomy). Having a third copy of some or all of these genes must be at the root of the developmental delay, characteristic physical findings, heart and gastrointestinal defects, and other conditions associated with Down syndrome. Scientists around the world are working to link the individual components of Down syndrome to specific genes. Establishing such links will help us answer questions about Down syndrome and offer hope of targeted treatment for some of the associated problems.

There are several ways to tackle these questions. First, researchers can work directly with humans. For example, Emory is one of many institutions worldwide enrolling individuals with Down syndrome in studies designed to identify important genes. At Emory, we are currently searching for genes significant in atrioventricular septal defects, the type of heart defect most commonly seen in Down syndrome. As a second approach, researchers can turn to traditional laboratory animals in their search for critical genes. In this regard, the common laboratory mouse has become a star.

Mouse chromosomes are similar but not identical to human chromosomes. Genes that are on chromosome 21 in humans are scattered over several mouse chromosomes. Even so, it has been possible to breed mice that have three copies of some of the mouse genes that are similar to genes on human chromosome 21. While these mice have been useful for selected studies, they are far from perfect models for Down syndrome. Recently, however, in what appears to be a great leap forward, Dr. Elizabeth Fisher and her colleagues in London, England reported success in creating mice that contain, in addition to all the normal mouse chromosomes, a nearly complete copy of a human chromosome 21. These mice, trisomic for most of the 200-400 genes on chromosome 21, show heart defects and problems with learning and memory. This new mouse model still has shortcomings, but the consensus in the scientific community is that these mice offer exciting new opportunities to learn more about the chromosome 21 genes important in Down syndrome.

Reference: Aileen O'Doherty et al. 2005. An aneuploid mouse strain carrying human chromosome 21 with down syndrome phenotypes. Science. 309: 2033-2037.

Those 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 (contact Sallie Freeman, sfreeman@genetics.emory.edu). To find out more about the Emory Down Syndrome Clinic contact Helen Smith at 404.778.8477.



Announcements

University of Georgia Research Project on Speech and Language Development

The Language Processes Lab, a unit in the Department of Communication Sciences and Disorders at the University of Georgia, invites children (ages 10 - 18 with no more than a mild hearing loss) with Down syndrome and their parents to participate in a current study. The purpose of the study is to examine how children with Down syndrome learn expressive language. UGA is also interested in learning how factors such as memory and word knowledge impact language development.

For more information on this study send an email to Dr. Yolanda Keller-Bell at langlab@coe.uga.edu or call 706.542.3037.

DSAA Today

We have had a few families sign-up for the e-mail reminder service to pick-up the newsletter on-line. Thank you, this is a tremendous savings to DSAA in terms of printing and postage.

By signing up for this service you will receive the newsletter one-week earlier than usual. As soon as the newsletter is ready to print, simultaneously we are able to post it on the website. By downloading the newsletter you don't have the delay of printing and mailing.

If you would like to be a part of our email reminder program, just send an email to contactus@down-syndrome-atlanta.org.

DSAA brings Chris Burke to Atlanta

By Jennifer Carroll

Thousands of metro Atlanta school children rocked out with Chris Burke and Joe and John DeMasi during Exceptional Children's Week. The tour, organized and sponsored by DSAA, included appearances at Mimosa Elementary, Bascomb Elementary, Sixes Elementary, Clayton County schools, Centennial High and Etowah High schools. The week concluded with a performance at the Larry Bregman Educational Conference.

The Chris Burke Band's performance combines music from their four albums and delivers a poignant message: "It's your abilities that count, not your disabilities!" The three men speak eloquently about the importance of inclusion, friendship, and believing in one's self. "Obstacles," says Chris, "are what you see when you take your eyes off your goal."

Burke, a Golden Globe nominee, is most famous for his role as "Corky" in the TV series "Life Goes On," but he has also starred in other TV movies and has had special appearances on "ER," "Touched by an Angel," and "The Commish." The first season of "Life Goes On" will be out on DVD on May 9th.

Chris met the DeMasi brothers at summer camp over thirty years ago. The DeMasis tease Chris that they tried to get rid of him, but he just kept coming back. Eventually they included him in their band. Their lifelong friendship is a testimony for several of their songs, in particular, "Friend Forever," which Chris begins with the words "I may have Down syndrome, I may have a disability, but I still have the ability to be your friend." The audience gets it—students and teachers alike. Throughout the performance Chris demonstrates that he has so many



Hunter Estep and a fellow classmate join Chris on stage during the performance at Bascomb Elementary.

more abilities; he is quick witted, charismatic, and charming. He literally dances his way into the hearts of the audience.

astounding how much Chris knows about movies especially his current favorite, "Walk the Line." His future goals include starring in a biopic about an actor who has Down syndrome. He would like the film to be a true depiction of the challenges he faces, but for it to also highlight the abilities and accomplishments of individuals with Down syndrome.

When Chris is not on the road performing, he lives in New York City and works for the National Down Syndrome Society as a Goodwill Ambassador. Off stage, Chris is very warm and engaging. He and his friends talk about politics, music, and movies. It is

It's hard to say who the biggest hero among this group is. Is it Chris for being such an inspiration and excellent role model and never giving up? Is it Joe and John for their lifelong loyalty and dedication to their friend, and for seeing Chris' abilities and helping him achieve his goals? What about Frank and Marian, Chris' parents? They refused to institutionalize him at birth. They never stopped believing in their son; being insistent on providing an education



The Chris Burke Band, from left to right, John DeMasi, Chris Burke, and Joe DeMasi.

for him, and helping him to pursue his acting career. They have all made it possible for people with Down syndrome today to be included in schools, to be given job opportunities, and to be embraced by their families and communities. Through Chris, John, and Joe, millions of people around the world have had their eyes opened to the capabilities of people with Down syndrome.

DSAA thanks them for coming to Atlanta to spread their message in a highly-entertaining manner. The Chris Burke Band will be back in Atlanta for the National Down Syndrome Congress Conference in July.

One more thing . . . you can find out more about The Chris Burke Band and sample and purchase their music at www.chrisburke.org.



Chris and the band pay a personal visit to Gabby Allen's second-grade classroom.

BIRTHDAY GREETINGS TO

March 2006

Caden Adams
Amy Ballew
Taylor Barbee
Brett Barksdale
Sam Bryant
Shelton Broughton
Noah Buczek
Casey Carroll
Travis Cudabac
Isabella Decoufle'
Matthew Dowda
Katherine Eubanks
Elijah Edwards
Darden Glass

Francesca Guariglia
Dylan Hall
Amanda Hardin
Kayla Hendrix
Kristen Holland
Sofia Jones
Ross Kirby
Kevin Kuehn
Jackson Lingner
Luke McGrew
Anna Moates
Dane Moehring
June Morsberger
Reagan Murphy
Sallicia Parks
Emory Perry
Savannah Proctor
Jack Racker
Kennedi Robinson
Noah Schaaf
Zachary Schuetz
Kathryn Sims
Nicholas Stevens
Carter Tafelski
Joshua Sloman
Rodrigo Tortorelli

Karen Valentino
Devon Van Uum
Meera Wall
Anne Marie Ward

April 2006

Yvonne Almaraz
Ashley Underhill-Archer
Kristi Bernhardt
Todd Besmertnik
Megan Black
Thomas Blackwell
Khaliah Boyd
David Carlson
Joseph Chun
Tammy Dean
Evan Dewey
Marie Dreyer
Caroline Dukes
Gibby Durden
Jack Few
Kashiim Gibbs
Mary Claire Greig
Matthew Hardister
Samuel Paul Hurst
Carter Johannesson
Jessica Johns

Hunter Jones
David Kilbourne
Patricia Ledezma
Brooke Mackie
Ross McEarchern
Niah McGregor
Marin Melone
Kaitlin Meriam
Allie Mewbourne
Lauren Miskin
Lilly Moore
William Murtha
Brenna Newton
Rachel Nicholson
Evan Nodvin
Christopher Norweck
Orlando Olvera
Abbey Pickett
Taylor Powell
Jeffery Puckett
Reece Roberts
Sara Rogers
Joshua Ross
Hermona Samuel
Ali Sims
Brian Zifle

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DSAA Today

Hollywood actor Chris Burke with the Allens during a visit to Bascomb Elementary School; article 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.