Celebrating World Down Syndrome Day

World Down Syndrome Day (WDSD) is March 21, which falls on a Saturday this year. This year, seven national Down syndrome organizations (International Down Syndrome Coalition, National Down Syndrome Congress, LuMind Foundation, Global Down Syndrome Foundation, National Down Syndrome Society, International Mosaic Down Syndrome Society, and Down Syndrome Affiliates in Action) have come together to create a fun event to mark World Down Syndrome Day.

On Saturday, March 21st, they are asking DSAA members along with other local Down syndrome communities to come together with the “Spread the Love on WDSD: Random Acts of Kindness” project to elevate awareness and understanding of Down syndrome.

Here is how you can participate:

1. On March 21st, wear a shirt that identifies yourself as part of the Down syndrome community, such as a past Buddy Walk t-shirt or your Color Dash t-shirt.
2. Choose an act of kindness to share; 1-3 acts of kindness are suggested for WDSD15.
3. Cut out the enclosed WDSD postcard and give it with your “Random Act of Kindness.”
4. Post your photos of your “Random Acts of Kindness” to your social media accounts to help build awareness of the event, and be sure to tag DSAA and to use the hashtag #WDSD15 and #DSAA.
5. Lastly, be sure to join DSAA for our inaugural Color Dash 5K run on the morning of March 21! For more information on registration email us at info@dsaatl.org.
Happy New Year! I always love the beginning of a new year. I love looking forward to all the fun things that lie ahead, and 2015 will be no different for DSAA. We have many returning popular events and some new, exciting ones.

This March, on World Down Syndrome Day, which is Saturday, March 21, DSAA will host its inaugural 5K Color Dash to raise awareness of Down syndrome. The Color Dash is different from traditional runs in that you start the run with a white shirt and at every kilometer a new color blast of blue, green, pink, orange or yellow will add to your shirt until you come to the finish line with an explosion of colors. We cannot wait until March 21st! The dash will take place at Blackburn Park in Brookhaven. Be on the lookout for more details about the event and how to register.

We are also continuing our momentum of DSAA Education Days. We just had a very informative session on January 10 that consisted of a New Parent Seminar and a Potty Training Workshop. Our next Education Day is Saturday, April 18. We will be doing an IEP Workshop and another New Parent Seminar. For more details on the April 18th Education Day and to find out about more Education Days, visit our website at dsaatl.org/calendar.

Our annual summer party will be back the first Saturday in May, which is May 2, and by popular demand we’re bringing back the iCan Bike camp from June 14 – June 19 at Northview High School in Johns Creek.

Lastly, but certainly not least, our annual Buddy Walk will be back on October 18.

I can’t wait for all of these exciting events and more. Be on the lookout for further information!

Sincerely,
FINANCIAL SUPPORT
— $36k in Support to the Emory Down Syndrome Clinic
— $34k to the Adult Down Syndrome Clinic
— Sole funder of AHSDA, DSAA’s Hispanic Group
— Sponsorship of Disability Day at the Capitol
— Sponsor Bregman Conference and Dance
— Sponsor Habima Theatre
— Support to GiGi’s Playhouse, Corrigan Care, All About Developmental Disabilities and Habima Theatre

COMMUNITY PARTNERSHIPS
— Partnership with AMC to support Sensory Friendly Film nights
— Partnership with Emory on their Best Buddies program
— Partnership to establish dual-diagnosis support group
— Partnership with SkyView Atlanta for DS Awareness
— Supported “Spread the Word to End the Word” campaign in March
— Supported #GivingTuesday
— Partnership with Ghost Tours of Dallas for DS Awareness Days
— Support D.A.D.S.
— Facilitate DSAA networking groups across metro Atlanta
— Nine research and national studies from top hospitals and universities across the U.S. shared with our members
— Two (City of Atlanta and State of GA) proclamations denoting October as Down Syndrome Awareness Month, including a visit to the Capital and meeting with the Governor

TRAINING AND ADVOCACY
— Launched bi-monthly advocacy e-newsletter
— Supported NDSS and other, for a successful passing of the ABLE Act in 2015!
— Participated in Buddy Walk on Washington
— Participated in DSAIA National Convention
— Participated in NDSC National Convention
— Participated in World Down Syndrome Day activities
— Participated in DSAIA Trainings
— Participated in NDSS Trainings
— Participated in ABLE Act Advocacy

844-DSAA-CARE | www.dsaatl.org | 3
Obstructive Sleep Apnea (OSA) is a common condition in the general population, with an even higher prevalence in patients with Down syndrome (DS). OSA is characterized by intermittent periods of reduced or ceased airflow through the upper airway when an individual is sleeping at night. Anatomy accounts for many of the reasons why there is a higher incidence of OSA in individuals with DS. Some, but not all, of those factors include poor muscle tone in the mouth and upper airway, poor airway movement coordination, narrowed airway passages in the upper and lower throat, a large tongue, enlargement of tonsilar tissue in the back of the tongue, throat and nose and obesity. All of these factors contribute to the collapse and obstruction of the oropharynx and hypopharynx that leads to a 50-100% incidence of OSA in individuals with DS. Moreover, the overall incidence of OSA increases as individuals with DS age, with almost 60% of children with DS having an abnormal sleep study by age four.

As most of you are aware, individuals with DS suffer from many medical conditions. OSA has been repeatedly and reliably been shown to affect cognitive abilities, behavior, growth and more serious health issues like cor pulmonale (right heart failure) and pulmonary hypertension (abnormally high blood pressure in the arteries of the lungs). Unfortunately, the ability of parents and caregivers to predict sleep abnormalities in their children with DS have been shown to be poor. Because of this poor correlation, the new American Academy of Pediatric health care guidelines recommends a baseline sleep study or polysomnogram (PSG) for all children with DS by age four. A PSG is the gold standard test for diagnosing sleep disordered breathing and sleep apnea. As you can imagine, OSA often goes undetected in both adults and children, which is why caregivers should monitor sleep patterns in individuals of all ages, especially when changes in mood, behavior or concentration abilities are noted.

Symptoms that suggest sleep abnormalities are numerous. The most obvious symptoms are those of uncommon sleep positions such as sleeping while sitting up and sleeping with the neck hyper-extended. Additional symptoms include restless sleep, snoring, gasping for air at night, heavy breathing, stopping breathing (apnea), frequent awakenings during the night, difficulty arising in the morning, daytime sleepiness and excessive napping. Sleep apnea can also cause behavioral changes including irritability, poor concentration and attention deficits.

Sleep apnea, and specifically OSA, has numerous causes. With respect to anatomy, the site of obstruction can generally be broken down into three areas: the nose, the upper throat (pharynx) and the lower throat (hypopharynx). Nasal obstruction tends to be from enlarged adenoids, chronic rhinorrhea and congestion, nasal septal deviation and nasal turbinate enlargement. Pharynx obstruction tends to be from enlargement of the tonsils and an excessively long palate. Hypopharynx obstruction tends to be from an enlarged tongue and obstructing tonsils on the back of the tongue.

If the primary care physician identifies any airway disturbances during sleep, a referral to an Otolaryngologist (ENT) should be made. As an otolaryngologist, our job is to determine if a sleep study and/or surgical intervention is required. Non-invasive treatment options include continuous positive airway pressure (CPAP) machines, weight loss and medications used to treat allergies and gastroesophageal reflux (GERD), both of which cause airway swelling and subsequent narrowing.

When it comes to surgery, removal of enlarged tonsils and adenoids is typically the first line surgical treatment. In individuals with DS, because of the shape of the bony facial skeleton and narrow nose, even mildly enlarged tonsils and adenoids can have a greater than expected effect on airway obstruction at night time. Although tonsillectomy and adenoidectomy (TA) is the most common initial surgical intervention, DS patients tend to show persistent OSA even after having their tonsils and adenoids removed, which is why all DS patients with OSA who undergo TA require a post-operative PSG. If residual obstruction is present despite TA surgery, it is typically due to the large size of their tongue and the relatively floppiness of their airway. Therefore, it is very common for additional interventions to be required, both surgical and medical. Medical treatments such as CPAP and continuous oxygen during sleep continue to be very useful and effective options. If an individual with DS fails TA surgery for OSA and cannot tolerate CPAP use, surgical options for persistent OSA need to be tailored to each individual’s specific pattern of obstruction. Typically, patients are then put to sleep in the operating room while their airway is observed with special endoscopes. This allows for the precise location of obstruction to be targeted surgically. Surgical approaches currently being used include lingual tonsilectomies, uvulopalatopharyngoplasty (UPPP), midline posterior glossectomy, tongue advancements, hyoid suspension, jaw surgery and tracheostomies.

In the end, OSA is a very common and serious disease in patients with DS. Diagnosing and treating OSA in patients with DS can help many of their chronic medical conditions in addition to improving their overall quality of life.

Reach Dr. Athavale at athavale.sanjay@gmail.com or (770) 292-3045.
Options are currently available to serve as a comprehensive consultative service to those who have a primary care physician in place or as a primary care medical home for those who wish to be served at Urban Family Practice Associates (UFPA). ADMH individuals and their families require extensive services which are not always fully covered through insurance — private, Medicaid or Medicare. Services involve detailed discussions with the individual, caregivers and family members centered around changes in functioning, medication management, increased medical symptoms, life planning, educational issues, behavioral management issues, transition to adult services, end of life issues, location of and consultation with primary care and specialty physicians, and assistance in access to the adult service delivery system. The interdisciplinary team provides an extensive history analysis, complete developmental and medical evaluation, discussions and recommendations for life planning, follow-up with specialists as needed and consultation with health and community-based services. Most persons have not had this type of service and coordination in a very long time. Our ADMH addresses families in a holistic approach covering medical, pharmacological, psychological, social and family issues, education and support.

Program Updates
Beginning in June 2014, the location, team physicians and core format transferred from Innovative Solutions for Disadvantage and Disability to Urban Family Practice Associates. These revisions accomplished our goals to provide more comprehensive services, to accept insurance including Medicaid and Medicare, and to offer a best practice patient model preferred by the medical community — that of a Medical Home. Since that time, our clinical slots have been completely filled and are currently booking into May 2015.

Developments noted since our enhanced format:
— Schedule is at full capacity with 6 to 7 patients per clinic (a full day of patient scheduling)
— Each patient time allotment from the interdisciplinary team ranges from 1 hour (follow-up) to 2.5 hours (new patients)
— Electronic medical records are utilized throughout the UFPA offices
— All patients are seen by our interdisciplinary team including medicine, nursing, social work, behavior analyst, long range counseling
— Insurance is provided so that most patients do not pay out-of-pocket expense. This is a major improvement for access to the adult medical system. Other costs not covered under insurance are covered through our grant and private donations and ‘minimal administrative co-payments.
— Laboratory and X-rays needed at time of service are now accomplished at the appointment

— Collaboration with clinical psychologists for basic psychological testing is in place to obtain waiver services and documentation of functioning levels
— Referrals are made to specialists as needed
— Medication management is provided by our medical team
— Referral is made to dietitians on a case by case basis
— Continued support to and collaboration with the DSAA and other community agencies by our Clinic Director
— Program has received a grant from Georgia Healthy Alliance for Family Practice that focuses on outreach and education tools of the Medical Home concept.

Forecast for 2015
There are a few major changes and developments in progress.
— ADMH has been approved by the IRS as a non-profit organization under the umbrella of Urban Family Practice Associates.
— ADMH has established a Board of Directors from a diverse background including law, accounting, medicine, community service, marketing and development. This board will be our guide in the development of a strong strategic plan.
— Access to services as individuals transition from pediatric to adult care is difficult and of paramount importance. In order to promote and reflect the best practice comprehensive care that is the hallmark of this program, we changed the name to ADULT DISABILITY MEDICAL HOME.
— Our focus remains serving adolescents and adults with Down syndrome and other complex medical issues.
— As funding increases, our goal is to offer services to other complex disabilities.
— Focus groups have indicated the need to increase our monthly clinical schedule. Within this next fiscal year we plan on adding one additional clinic per quarter increasing to 16 day long clinics.
— Our physicians have submitted an application to present at the National Down Syndrome Congress Convention 2015 and plan on meeting and networking with other physicians in the field.
— Increased educational materials and supports will be provided to patients and their families.
Managing Behavior in Children with Down Syndrome

How Understanding Leads to Intervention: Development and Cognitive Processing (Part 2)
By Mary Pipan, MD, Clinical Director, the Trisomy 21 Program at The Children's Hospital of Philadelphia

“No!” “Stop it!” “I don’t know.”

Arms folded, body and face turned away. Sitting on the floor, refusing to move. Fondly and frustratingly, this is often called “stop, flop and drop.”

Psychologists refer to this behavior as “oppositional,” or maybe even “defiant,” but those descriptions often didn’t fit with the smiling child I saw in front of me, eager to please and generally compliant. From the hundreds of children and young adults I have assessed, and from studies on development and cognition, I came to realize that these refusal behaviors needed to be interpreted differently in individuals with Down syndrome (DS). What they often really meant was: “I don’t understand” or “I’m frustrated” or “I need help.” And sometimes they meant: “Give me a minute, I’m not ready yet” or “I need to know what’s happening next.”

Effective behavior intervention requires an understanding of where the behavior is coming from, taking into account:
— the context,
— the person’s level of abilities,
— their temperament,
— their experiences and how they learn best.

Individuals with Down syndrome are just that, individuals, and thus what works for some, may not work for others. The broad areas that help explain many of the behavioral challenges facing caregivers of individuals with DS include sensory processing (discussed in the previous issue of Down Syndrome News, Spring 2013), development and cognitive processing (the focus of this article), and communication and social and emotional functioning, which will be discussed in a future segment.

As children’s brains develop, they become capable of more and more complex movement and thinking. This development occurs in predictable sequences across the first 25 years of life. The timing of development varies widely among individuals with DS, and thus regular assessment of progress is necessary to help keep expectations reasonably challenging.

As parents and caregivers push a child to accomplish to the best of her ability, expecting outcomes beyond her capability will frustrate everyone, and may result in refusal behaviors. For example, if a child is just starting to draw lines and circles, expecting them to copy letters does not make developmental sense. Refusal behaviors will also occur if you underestimate the child’s capabilities. The child becomes bored and is ready to take on more challenging tasks. Another common cause of refusal is when a child is capable of a new skill on his best day, but because the skill is still emerging and is not quite solid, he is easily sabotaged by stress, anxiety or anger. Similar to all of us, children with DS have different levels of frustration tolerance. Some will happily fill out an entire math sheet, confidently writing numbers in the blank spaces. Others get to the first question they are unsure of, and put their head down, refusing to try anymore. For a child with a low frustration tolerance, tasks need to be approached carefully, starting with mastered tasks and then building momentum to try more challenging tasks.

Cognitive processing refers to how we take in information, put it together with what we already know, and then think through a response. Cognitive processing in individuals with DS is often characterized by longer processing times, more difficulty in flexibly switching from one thought to another, limitations in the amount of information that can be kept in mind at once, and difficulty with the organization of that information to make sense of the situation and then respond appropriately.

Some of us are visual learners, more effectively taking in information through what we see, while others need to read information, and others need to hear it. Individuals with DS tend to process visual information better than through language. Thus, we emphasize “talking in pictures” to help them process both simple information (what’s going to happen today), and more complicated problem-solving (what to do when a friend ignores you). Visual supports have also been used very effectively in children with autistic spectrum disorders, and often those same visually-based interventions can be used for individuals with Down syndrome.

Longer processing time requires that we wait longer for a response to what we’ve said or shown them. This is probably the most common situation where we see the “automatic no” response. Often, ignoring the refusal and waiting will work. “Patience is a virtue” is the needed mantra. Pressing too early may result in higher stress and more shut-down. We are all required to move our attention from one thing to another, literally thousands of times a day. For example, while reading this article, you may have glanced at the clock, then to the TV, then back to the article. For some, shifting from thought to thought, and activity to activity comes easily. For others, including many with DS, the shift is harder. This difficulty shifting may also result in “getting stuck” on certain things, and having difficulty moving on. Transitions between activities or thoughts require preparation, effort and time. This is probably the second most common cause of the “automatic no” response. This can often be eased by warnings that the transition is coming, with a countdown, or with a transition song. (Who doesn’t love Barney’s clean up song?) Giving a child a heads-up as to what will be happening next can also be very useful, with a visual schedule or a social story.

We are also required to problem solve several times a day, quickly and efficiently. We take into consideration the pieces of information we deem relevant, usually from what we see and hear, keep that information in mind while we think about what we’ve experienced in the past, consider the consequences of what to do next, and finally respond, usually in the space of a minute or less. It’s complicated!
Individuals with DS may have difficulty paying attention to all the relevant information, focusing only on one or two things. Their attention may need to be drawn to the relevant details. (Look at her face, is she smiling or frowning?) This will then influence how they relate that to their experience, in order to interpret the situation. Guiding them through the process of how to think through situations can help them with the interpretation. (She is unhappy, you’re right. What could have happened?) They then may have difficulty choosing an appropriate way to respond, and have trouble considering the consequences of their actions, before they act. (What do you think you could do: ask her if she’s OK, or if she needs help? Bring her something to eat?)

Some individuals will struggle with answering open ended questions. It may be more effective to give them multiple choice answers from which to choose. The use of visuals to help understand, especially for these multiple step processes, can be very beneficial. Figuring out where an individual’s processing is breaking down takes detective work, but gaining this understanding will help problem-solve similar situations in the future. Also remember that problem solving gets even harder if stress or anxiety is present.

These differences in processing likely explain why so many individuals with DS thrive on predictable routines and structure. Indeed, they often impose their own routines and structure on the world around them, needing to control the physical structure (doors need to be shut, tables need to be clear), what happens next, or how activities must be done (I open the door and you walk through). We can optimize behavior and learning, and minimize stress, by structuring physical spaces appropriately, organizing activities in a predictable manner, and by building routines.

Within these comfortable environments, we can more effectively teach flexibility and problem solving, thus averting future frustration behaviors.

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**Resources**

**FOR VISUAL SCHEDULES**
- Visual Supports and Practical Tools: www.do2learn.com
- Visual Schedules
  - First+Then+Boards: lessonpix.com/articles/9/35/
- Good Karma Applications, Inc.: www.handsinautism.org
- Visual Schedules
  - Social Stories Workbook
  - Comic Strip
  - Conversations
  - Author: Carol Gray
  - www.thegraycenter.org

**FOR SOCIAL STORIES**
- www.handsinautism.org
- LessonPix.com
- Visual Schedules
- First+Then+Boards
- LessonPix.com/articles/9/35/

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**Study on Spoken Language**

If you have a son or daughter with Down syndrome between 6 and 23 years of age, you and your child are invited to participate in a research study being conducted by Dr. Stephanie Sherman at the Emory Down Syndrome Center in Atlanta, Georgia, and four other US sites.

The goal of this study is to learn more about how samples of spoken language can be used to measure change over time in the spoken language, problem solving and behavior of individuals with genetic syndromes. In the future, it is possible that measures of spoken language production may be useful as one way to learn whether different drugs can help individuals with genetic syndromes to learn and use language more effectively.

If you decide that you and your son or daughter would like to be in this study, we will ask you to visit one of the study sites three times over two years. At each visit, we will collect a sample of your son or daughter’s speech as s/he interacts with an examiner in three different settings: a conversation, looking at a picture book and participating in a series of interactive activities with an examiner. We will also give your child some tests that will measure his/her problem solving skills and how much language s/he understands and produces. We will ask you to fill out some questionnaires and participate in an interview about your child’s everyday living skills.

If you would like to learn more about this study, please call Helen Smith at 404-778-8477 or email hsmith3@emory.edu

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**DS-360 Study on Quality of Life**

The DS-360 study is a nationwide research study investigating all of the clinical conditions that may alter the quality of life for individuals with Down syndrome. To participate in this study, we would need to collect a small biological sample (blood or saliva) from the individual with Down syndrome and his/her biological parents. The blood draws can be done by our trained phlebotomists or we can also send a kit with you to piggyback on your child’s next medically necessary blood draw. We have saliva kits available as an alternative to a blood draw. We will do a phone interview with moms that covers family, pregnancy and medical history. Finally we will have you sign a medical record release form which allows us to obtain medical records related to DS.

An additional component to the study, if your child is between the age of 6-25, is the cognitive battery testing. We are trying to understand how kids learn and process information and what environmental and genetic factors may play a role. For this part of the study, your child would complete a series of tests — most on a computer similar to computer games. This usually takes about 2-2 1/2 hours with breaks.

If you would like to learn more about this study, please contact Tracie Rosser at 404-778-8474 or trosser@emory.edu

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**Past Participants**

Finally we need all past study participants to help us with a short follow-up questionnaire on medical issues. If you have participated in one of studies in the past: ADSP, NDSP, EDSP or CHD — please contact Tracie Rosser at 404-778-8474 or trosser@emory.edu. The questionnaire is a short 15 minute survey that you can complete over the phone, by mail or online. It covers all of your child’s medical history.
Birthdays

**JANUARY**

Gorge Antonio
McClain Ashworth
Gabri Berger
Jacob Bond
J.J. Briggs
Tysor Brown
Joseph Carter
Chandler Cash
Gavin Cook
Ethan Cornwell
Demeadra D. Obi Davidson
Camille Drake
Troy Jason Forrester
Alexander Freeman
Lucy Genske
Martha Haythorn
Teddy Heck
Amiya Hodge
Noal Larson Ingalsbe
Hayden Irving
Mullen Isaac
Omari Jenkins
Steven Joe
Kylie Johnson
James Kelly
Grace Key
Gracie King
Shannon Laffey
Philip Francis Lane
Gabe Martin
Noah McCallum
Elisha McKenzie
Jacob Moore
Sarah Grace Morris
Grace Key Nance
Michelle Norweck
Jenna Quigley
JC John Conrad Quinby
Darwin Ramos-Ignacio
Hunter Roach
Tucker Rowlett
Moriah Rozell
Zachary Seelbinder
Noal Slaton
Jennings Slaughter
Regina Thompson
Alexandra Thorman
Grant Tillman
Shirley Salazar Tobar
Katherine (Katya) Vazhenin
Charlie Ward
BreAnna White

**FEBRUARY**

Nathan Anderson
Hollis Todd Burke
John Chambliss
Katherine (Katie) Cohenour
Peter Cook
Sarah Costello
Paytun DaSilva
Cohen Echols
Ada Kate Enck
Debra Eubanks
Paloma Flores
Angelo Hector Galante
Jason Garcia
Gavin Geaman
Ndeye Modade Geisslinger
Suzanne Goossens
Mary Beth Hurst
Shane Jackson, Jr
Adama Jallow
Kim Johnson
Matthew Jones
Joseph Anderson Just
Ruby Lovelady
Sara Kate Mulligan
Layla Noor
Kathryn O’Keefe
Jacob Pitre
Rick Raschke
Felicia Roman
Hugh Rowling
Colten Rozier
Alexis Rutland
Lukas Staffanell
Colin Stephens
Preston Hamilton
Thanepohn
Maggie Tressler
Linda Valdez
Sonia Walker
Christian West
Joseph Williams
Cornti Wright

KIDS’ CORNER

Connect the dots from 1 to 19 and color the picture when you have finished.
MARCH

Caden Adams  Dylan Hall  Chase Riggott
Madison Leah Arnold  Michael Hamlett  Gracie Robinson
Amy Ballew  Katie Harwell  Victor Rosales
Jose Banos  Aidan Henson  Zahra Rowe
Taylor Barbee  Chase Walker Hilton  Rain Smith
Brett Barksdale  Kristen Holland  Sierra “Rain” Smith
Siena Brignola  Sofia Jones  Avery Stein
Caleb Campanile  Ross Kirby  Nicholas Stevens
Noelle Campbell  Kevin Kuehn  Ian Stewart
Will Clower  Wesley “Carter” Lucero  Carter Tafelski
Wyatt Burnell Corn  Will Markwell  Matthew Taylor
Sierra Crick  James Mathis  Bradley Thompson
Travis Cudabac  Gwyneth Maulsby  Rodrigo Tortorelli
Isabella Decoufle’  Kaleb A. Awoke  Karen Valentino
Benjamin DeGrazia  Mechegia  Kathleen Van Uum
Jacob Douglas  Anna Moates  Devon Van Uum
Elijah James Edwards  Jude Moody  Meera Wall
Katherine Eubanks  Amina Parker  Leah Kate Weatherby
Hannah Foy  Jonathan Perez  Jade Audrey Wynns
Darden Glass  Eliza Lauren Perkins
Francesca Guariglia  Emory Perry

GET FEATURED
Share your photos for a chance to be featured in upcoming newsletters! Send a high-resolution JPEG or similar file with your child’s name, age and birthday by April 1 to stephanie@dsaatl.org.

Happy birthday to JC Quinby (age 11), Zachary Seelbinder (age 5), McClain Ashworth (age 6) and Philip Lane (age 6)
DSAA Community Groups

AHSDA (HISPANIC GROUP)
Erenia Castillo
castillorigobert@bellsouth.net

ATHENS
Victoria Pressley
victoria@presley.us

CARROLLTON/VILLA RICA/DOUGLASVILLE
Nicole Mitchell
emmasmom0908@yahoo.com

COBB COUNTY
Regenia Guariglia
regenia.guariglia@gmail.com

COLUMBUS
Angels Among Us
Melissa Clark
melissaclark@synovus.com

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Alita Byrd
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facebook.com/groups/DSPlaygroup

GWINNETT/SOUTHWEST
Jessica Kelly
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facebook.com/groups/DSPlaygroup

HENRY COUNTY AND SURROUNDING AREAS
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or
Alison Utterback
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dcrick1@cox.net

MONTICELLO MIRACLES
Kelly Copelan
kmdcopelan@gmail.com

NORTH ATLANTA, FORSYTH/NORTH GWINNETT/JOHN’S CREEK
Margaret-Ann Hopper
erfaith@att.net
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PAULDING COUNTRY/SURROUNDING AREAS
Megan Maulsby
MeganMaulsby@gmail.com
facebook.com/groups/198321133569907

PEACHTREE CITY/NEWNAN/FAYETTE THE UPSIDE OF Downs
Katie Reyes
momwifeme914@gmail.com

SOUTH FULTON
Shining on Ds
Cathy Webb
cnwwebb@yahoo.com

If you are interested in starting a group in your area, contact us at info@dsaatl.org

DSAA Member, Evan Nodvin and Bob Saget at the Marcus Jewish Community Center of Atlanta Book Festival this past November.

Special thanks to our Platinum Sponsor, Superior Plumbing.

Swim Lessons

Interested in swimming lessons for your child? Two-time Olympic Swimmer Helmut Levy is a coach in the Gwinnett area. He is bilingual in Spanish and English. Student must provide access to a pool. He can be reached at 404-951-9989.
Andy Miyares is not your ordinary athlete.

At 31 he holds world records in swimming and has dined with former President Clinton at the White House. He has flown all over the United States to help build homes for Habitat for Humanity, he teaches swimming to children and he’s been featured in a television commercial. Andy Miyares also happens to have Down syndrome and is a Special Olympics athlete.

Andy has been participating in Special Olympics for over 23 years. Andy found in Special Olympics continual opportunities to develop fitness, demonstrate courage, experience joy and participate in the sharing of gifts, skills and friendship with his peers, families and communities.

Andy comes from a family of five children, all of whom were active in sports while growing up. Andy wanted to join in as well. He began participating in Special Olympics through his school.

Andy has participated in swimming, tennis, basketball, golf and bowling over the years. He has competed on local, state, regional and national levels, almost always finishing in first place, regardless of the sport. Swimming became his specialty. As a Down syndrome swimmer, he has competed in World Competitions of Down Syndrome in Ireland, Portugal and recently in Italy.

His idol is Michael Phelps, and similar to Michael, his favorite events are the 100 and 200 Butterfly. He is also a 1500 meter freestyle world record holder and swims the open water. Determination, dedication and courage have made it all possible for him, something he has acquired with his participation in Special Olympics.

But more than being an outstanding athlete, a mentor to younger athletes and an inspiration to everyone who meets him, Andy is an “ambassador” for Special Olympics athletes and people with disabilities, just like him. He frequently speaks to the community about people with special needs, so that people will understand that people with special needs are not that different from anyone else - they have abilities and skills and just need the chance to share them!

Andy is an International Global Messenger and has traveled the World telling everyone that “Andy is his name, swimming is his game and Special Olympics is his LIFE.”

Andy says, “Sports has given me the ability to know that I can do anything I want to do. I know I have Downs (Down syndrome), but that only makes me try harder to succeed. Special Olympics took me to the White House and to meet the Kennedy Family. I am always trying my best. I meet lots of people, and I have a lot of friends.”

Andy’s Mom, Ana Maria Miyares believes that Special Olympics has played a big part in Andy’s development as an athlete and a young man: “Special Olympics and Andy go hand in hand in our lives. We have learned with him, through sports, how limitations only exist in our minds. Special Olympics has shown us love, competition, perseverance and courage beyond anything we ever imagined.”

Andy is bilingual in English and Spanish and is currently working in the offices at Our Pride Academy in Miami. He also works at the Hilton Airport Hotel and is a Hilton Team Member. He is a registered United States Swimming Coach and is presently studying to be an official.

Andy has achieved what no other athlete with Down syndrome has done. He has been ranked in the top ten of United States Masters in his zone in individual events like the 200 fly and the 1500 meter freestyle. Andy is currently ranked as one of the best Down syndrome swimmers in the world.

When he’s not at work or training for a competition, Andy believes in giving back to the community. He volunteers at a summer camp at the Miami Rowing Club, teaching young children how to swim. He is a Swimming USA Coach and assists with Special Olympics swimming coaching, and he has helped build four homes for Habitat for Humanity across the country and volunteers at Project Drive, a local school for special needs children.

To learn more about the World Special Olympics taking place in Los Angeles this summer, visit www.la2015.org, and for the local chapter, log onto www.specialolympicsga.org
<table>
<thead>
<tr>
<th>Event Date</th>
<th>Event Description</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>February 21/22</td>
<td>Bregman Conference and Dance</td>
<td>The Selig Center</td>
</tr>
<tr>
<td>March 5</td>
<td>Disability Day</td>
<td>State Capitol</td>
</tr>
<tr>
<td>March 21</td>
<td>5K Color Dash</td>
<td>Blackburn Park in Brookhaven</td>
</tr>
<tr>
<td>April 18</td>
<td>Education Day&lt;br&gt; <em>New Parent Seminar and concurrent IEP Workshop</em></td>
<td>Emory University Medical Education Bldg&lt;br&gt;Rms 153A &amp; 170A</td>
</tr>
<tr>
<td>May 2</td>
<td>Summer Social</td>
<td>Location TBD</td>
</tr>
<tr>
<td>June 15 – 19</td>
<td>iCan Bike</td>
<td>Northview High School</td>
</tr>
<tr>
<td>July 18</td>
<td>Education Day&lt;br&gt; <em>Topic TBD</em></td>
<td>Emory University Medical Education Bldg</td>
</tr>
<tr>
<td>August 21/22</td>
<td>D.A.D.S Pigs and Peaches BBQ Competition</td>
<td>Adams Park</td>
</tr>
<tr>
<td>September 19</td>
<td>Education Day&lt;br&gt; <em>Topic TBD</em></td>
<td>Emory University Medical Education Bldg</td>
</tr>
<tr>
<td>October 18</td>
<td>Buddy Walk</td>
<td>Centennial Olympic Park</td>
</tr>
<tr>
<td>TBD October</td>
<td>D.A.D.S Annual Golf Outing</td>
<td>Bears Best Atlanta</td>
</tr>
</tbody>
</table>

DSAA Today’s Family Connection is a benefit of your annual membership. To renew or join today visit [www.dsaatl.org](http://www.dsaatl.org)