Hi DSAA Families,

I hope everyone’s year is off to a great start, DSAA’s sure is! We are so excited to welcome Brian as our new President – he has already infused great energy into the role. Under his leadership, expect to see many new things from us as we work to better serve all of you. I’ll let him tell you more below and keep my comments short this issue.

As always, I am a call or email away. I love to hear your ideas, share stories and photos and just be a part of all your lives. I am thankful for this job every day, and I am so blessed to call all of you family!

Best,

Vanessa Champlin

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Hi DSAA members! I hope everyone had a happy and safe holiday season.

I’m excited and honored to have the opportunity to serve as President of DSAA for the next two years. I have gotten to know many of you throughout the years of our family’s involvement with DSAA and look forward to meeting many more families.

I first joined the DSAA board in 2011 as the IT and Advocacy Director. As IT Director, I migrated the DSAA website and Buddy Walk registration to a new platform. As Advocacy Director, I’ve been involved with the Partners in Policymaking program at All About Developmental Disabilities (AADD), as well at the National Down Syndrome Society (NDSS) Down Syndrome ambassador program, which includes representing Georgia at the annual Buddy Walk on Washington. Networking with advocates across the country has been an incredible experience. Helping get the ABLE Act passed, which would provide a mechanism for families to save money tax free, is a passion for me and as President I will continue to support that effort.

continued page 2
As the former group leader, D.A.D.S. also holds a special place for me. I’m proud to be part of what this great group of fathers has been able to accomplish over the past 3 years. I look forward to the continued growth of our group, as expand our meetings in order to engage more fathers in the Atlanta metro area.

As President, I look forward to working with our staff and board to focus on providing tangible value to our membership, as well as fostering a sense of community among our families and with other local organizations.

Some major areas I will be focusing on over the next two years are:

- Increasing DSAA’s presence, both locally and nationally.
- Increasing funding of DSAA and its programs through grants and corporate sponsorships.
- Improving existing DSAA programs and adding new programs or partnerships.
- Creating an opportunity for our members to have more direct involvement with DSAA through the creation of a Community Action Board, as well as providing more specific, targeted volunteer opportunities.
- Improving the Buddy Walk online registration experience, improving our membership management, and refreshing the DSAA website and mobile presence.
- Improving communication with our members, both electronically and through mailings, as well as improving the experience of reaching us by telephone. Expect to hear from DSAA more often and more consistently.

I have some innovative ideas and know many of you do as well. I want to give you the opportunity to be heard and work together to meet the needs of our members. Nothing has to be business as usual, and everything is on the table. DSAA is supposed to be an association of people working together in common cause, not just a staff, officers, and board members. It’s all of us. I cringe every time I hear DSAA referred to as “they”, so I want to challenge all of you to change that mindset and to help make DSAA an organization that we can all be proud to be a part of. Without you, DSAA doesn’t exist. I’m truly excited about the possibilities. Please email me your ideas, concerns, etc. at brian@dsaatl.org.

Sincerely,

Brian Moore
President, DSAA
AHSDA 13 years later…
Evan, “muy simpatico”

Asociación Hispana de Síndrome de Down en Atlanta (AHSDA) welcomed Janice Nodvin and her son Evan Nodvin, to the monthly parent support group meeting at the Chamblee Library late last year.

Parents and friends were charmed from the get go with Evan’s opening, “Buenas Dias, mi nombre es Evan Nodvin. Yo tengo treinta y cuatro años.”

Back in the year 2000 Janice served as President of DSAA and began an inspired effort to bring the DSAA to Latino families in our community. This unique outreach recognized the fact that Atlanta was witnessing the birth of many babies with Down syndrome to Latino families who could not speak English and were struggling to find out more about Down syndrome and how to be the best possible parents to their “bebes especiales”. AHSDA now supports over 180 families with six “Madres Guías” (Mother Guides), monthly educational/support meetings, Spanish Welcome Packets, hospital and home visits, and an annual picnic in the Spring.

Janice and Evan Nodvin

Janice and Evan guided the AHSDA parents into the world of a future adulthood for their children that was unimagined and enthralling.

Evan, 34 years of age, told his story to a roomful of parents, amazed at how well he spoke (with a sprinkling of Spanish to boot) and amazed at the range of activities he’s engaged in: YMCA Happy Club, Habima Theatre, Special Olympics, etc. He told of graduating from Chamblee High School in 2000, where he was a member of the marching band and participated at all the football games. Evan talked about his job at the Weinstein Senior Adult Day Center, his apartment, his girlfriend, his bowling team, his music, his friends.

DSAA’s Inaugural Cooking Challenge:
Money raised. Awareness boosted. Smiles built.

For those who missed the fun, check out the video highlights from our Inaugural Cooking Challenge. Teams competed for the title of ultimate cook, completed with a chef hat and custom apron. Current Buddy of the Year Bess Winebarger and her team (including our ED’s husband who is still bragging) were crowned the winners before everyone sat down to enjoy the night’s creations.

http://www.youtube.com/watch?v=UDlyRAuAVyQ

Special thanks to our partner for making this fun night a reality!

Janice and Evan Nodvin

continued page 4
Janice followed Evan’s talk, leading a discussion with parents that began with the advice, “listen to the doctors, listen to your heart”. She urged parents to have a “vision for your child’s future” and to “involve the whole family in this vision”. “Teach your child to ride a bike”.

At this point, Evan reminded the audience that in the state of Georgia, “it’s the law, you must wear a helmet”. Janice encouraged the parents to keep their kids in school till they turn 22 years of age and talked about the benefits of getting a “Medicaid Waiver” that would support the young adult child throughout independent adulthood.

Janice and Evan guided the AHSDA parents into the world of a future adulthood for their children that was unimagined and enthralling. To imagine one’s child could one day, in Evan’s words, “do all the things a single man does like grocery shopping, cooking... and going out with my girlfriend.”

One new mother to the group was brought to tears as she related how she’d moved recently from another state and did not know how to get connected, how to find resources, and now she’d found AHSDA and this wonderful story.” Another mother told of her 14 year old daughter who wants to have a boyfriend. Mom told her she cannot have a boyfriend till she turns 16 years old. Each day “Gina” wakes up and asks, “am I 16 now, can I have a boyfriend”. Gina’s mother was encouraged by Evan’s remarks that it’s nice to be in love.

Janice and Evan brought their loving warmth and friendliness and sharing to our AHSDA parents and the parents paid it back with broad smiles, hugs, gracious thanks and a greater appreciation of how amazing the life of an adult with Down syndrome can be here in our grand city of Atlanta, GA!

Mil Gracias! Janice and Evan

Article contributed by Susy Martorell, AHSDA Networking Leader
A speech-language pathologist shows parents and caregivers that they don’t need to be experts to help kids communicate better. Use this uniquely designed book to improve the communication skills of young children—ages 3 through 7—who have delayed or ineffective speech due to autism, Down syndrome, cerebral palsy, cleft lip/palate, Childhood Apraxia of Speech, hearing loss, or another condition.

Talking Is Hard for Me! features a lively, full-color illustrated children’s story that follows a child and his family as they challenge, prompt, and support his communication efforts through:

- Natural need creation (change the environment)
- Sign language & AAC
- Communication turn-taking
- Choices
- Sentence simplification
- Music
- Reading

Adults can read the story on their own or with their child to empathize with his struggles to talk while learning practical ideas that help. The accompanying informational sections are full of accessible speech-language therapy strategies and instructions to improve communication and ease frustration.

Readers will be empowered when they see how easy it is to apply these practices throughout everyday life. Share this book with your child’s peers, family members, daycare providers, and teachers. It makes a great tool for speech-language pathologists to reinforce therapy outside of sessions.

“This is an amazing resource for any parent, teacher, therapist, family member, and friend of someone with communication difficulties.” Simply Speech blog

Available on Amazon, Woodbine House and at other retailers.
Kevin Mackey
Andrew David Barnes
Natalie Broeker
Taylor Will Carter
Kayla Evans
Kendra Vongsavath
Johnathan Lanning Mckinley
Jaydah Hector
Johnathan Robinson
Maya Corinne Oliver
Noah Alexander Chrystal
Griffin Brown
Jayden Gresham
Claire E. Lanham
Amy Rogers
Angela Clark
Jasmine Faichney
Jake King
Rylan Grace Turpin
Brennan Sharp
Jonathon (Alex) White-
man
Gavin Violante
Arianna Stevens
Haley Price
Addie Gunnells
Rachel Hunter
Joshua Roberts
Tabitha Hogg
John A. Harvey IV
Kareem Hakeem
Haley Price
Isaiah Remoe-Doherty
Linda Raschke
Emma Madison Austin
Russ Silver

Donna Williams
Emma Farrell Henley
James Riley Smith
Megan MacArthur
Matthew Hayes
Cristian Rogers
Adison Modly
Nevaeh Crowell
Rachael Campbell
Jeremy Ahn
Christopher Yancy
Joe Clark
Casim I. Joyner
Chanel Saffo
Karynmari Powell
Myah Miracle Warren-Bullock

Margaret “Maggie” Matheson
Jean Carr
Anari Sekumade
Monte Watts
Sara Bolet
Lukas Tang
Sophia Amirpour
AJ Leverett
Madsyn Foster
Landon Scholpp
Tucker Mitchell
Zachary Willingham
Ayoca Freeman
Kevin Nguyen
Adam Utterback
Hannah Marie Keith
Taylor Freeman
Jonathan Brown
Molly Montgomery
Drew McClanahan
Zoe Nelms
Kennedy Hines
Melissa Hoffman
Kholin Chen Phang
Bryson Bostedt
Emma Dymek
Annabella Lee Galamore

Zachary Seelbinder
aspiring chef, turned 4!

Snow bunny Natalie Broeker turns 5!

Former Buddy of the Year Jenna Quigley
turned 21!

Emlyn Moore
Jenna Dawson
Logan Garner
Anna Hill
Ithan William Kwei
Jamaal Cooper
Bowman Caldwell
Dylan Allen
Jamie Anderson
Catherine (Cate) Tyran
Wyatt Hartle
Kristina Brewster
Kelvin Starks
Jack Anderson
Maya Mathis
Elise Zylstra
Nathan Martin
Zaid Khader
Marti Grieco
Evan Long
Christian Watkins
Stephan Bilson
Madeline Knox
Makayla Thomas
Courtney Owens
John Gross
Noah James Malone
Andrew Kern
Maddie Harrison
Marc Piccolo
Reedus Rogers
Debbie Tauber, preschool teacher of DSAA Member Wyatt Corn at Riverview Elementary, took it upon herself to raise awareness throughout the school for what some of her students go through each day. “Our school has taken on the “S.P.A.R.K.” attitude, which stands for service, pride, attitude, respect and kindness,” Tauber said.

Tauber said she and her class went to each classroom in the school and put jars in the rooms to collect the dimes. “Our children went around and they took these jars to each person, we told them a little bit about Dimes for Downs and what Down syndrome was,” she said.

Riverview Principal Julia Mashburn said she noticed the students getting active right away. “Almost immediately, when the jars went out, students gave up their ice cream money for the day. They chose, themselves, to put their money in the jar rather than buy an ice cream treat,” she said. “They know they are giving to a good cause and they see the benefits of that cause in the building every day. It’s a relevant cause to them.”

DSAA thanks Ms. Tauber, Wyatt and his family and all the students at Riverview Elementary for their support!

Riverview Elementary gives Dimes for Downs!

Hayden Irving
Alexander Freeman
Omari Jenkins
Moriah Rozell
Ethan Cornwell
Teddy Heck
Martha Haythorn
Philp Francis Lane
Gabi Berger
Elisha McKenzie
Noah McCallum
Jacob Bond
JC Quinby
Sarah Grace Morris
Gabe Martin

Wyatt Corn stands in front of a “Dimes for Downs” poster at Riverview Elementary.

MORE BIRTHDAYS

Gavin Cook
Mullen Isaac
Daughter Fu
Joseph Carter
Grant Tillman
Regina Thompson
Amyia Hodge
Hunter Roach
Jennings Slaughter
James Kelly
Camille Drake
Steven Joe
Lucy Genske
J.J. Briggs
Jacob Moore
Darvin Ramos-Ignacio
Shirley Salazar Tobar

Demeadra D. Obi Davidson
Katherine (Katya) Vazhenin
Noal Slaton
Noal Larson Ingalsbe
Zachary Seelbinder
McClain Ashworth
Troy Jason Forrester
Charlie Ward
Shannon Laffey
Gorge Antonio
Kylie Johnson
Tucker Rowlett
Tysor Brown
Grace Key Nance
Gracie King
Chandler Cash
BreAnna White
Alexandra Thorman
Jenna Quigley

J.C. “Just do it!” Quinby turned 8!
America the Beautiful
The National Parks and Federal Recreational Lands Pass

Spring is just around the corner, take advantage of this free family resource! The Access Pass is a lifetime pass available to US citizens or permanent residents of the US who have a permanent disability. Find out more at: http://store.usgs.gov/pass/access.html

Join a DSAA Community Group

DSAA Networking Group Leader:
Emily Jones, emily@dsaatl.org

AHSDA (Hispanic Group):
Erenia Castillo, castillorigobert@bellsouth.net or Susy Martorell, smartor@emory.edu

Athens Area: Amy McCollum, amy_mccollum@bellsouth.net

Carrolton, Villa Rica, Douglasville: Nicole Mitchell, emmasmom0908@yahoo.com or Tina Holcomb, Tdarlene18@yahoo.com

Cherokee County: Amber Chase, tacadc@earthlink.net

Cobb County: Regenia Guariglia, regenia.guariglia@gmail.com

Columbus: Angels Among Us: Melissa Clark, melissaclark@synovus.com

Dekalb/Atlanta: Alita Byrd, alitabyrd@gmail.com and on Facebook http://www.facebook.com/groups/DSPlaygroup/

Gwinnett, Southwest: Lisa Brown, lisa@dscga.com and on Facebook http://www.facebook.com/groups/DSPlaygroup/

Henry County and Surrounding Areas:
Melissa Kendrick, melissa@dtpartners.com or Alison Utterback, nc_utterbacks@msn.com

Houston County/Warner Robins:
Donna Crick, dcrick1@cox.net

Monticello Miracles:
Kelly Copelan, kmdcopelan@gmail.com

Milton, Alpharetta, North Metro, North Fulton:
Maggie Moore, maggie@mooretimes.com and on Facebook https://www.facebook.com/groups/DSCconnectionNorthMetro

Paulding, Acworth, Hiram, Dallas:
Megan Maulsby, meganmaulsby@gmail.com

Stone Mountain/Lithonia Bright Beginnings:
Lisa Lewis-Peck, dsgroupofga@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.
Adult Down Syndrome Program

Team consists of (l to r):

Janice Nodvin – Center Director
Ria Bonaparte – Nutrition Consultant
Laura Wells – Clinical Social Worker
Leslie Rubin – Medical Director
Wendy Gray – Clinical Developmental Physician
Manuela Woodruff – Behavior Analyst

DSAA partners with Innovative Solutions for Disadvantage and Disability to provide financial support for the Adult Down Syndrome Program. The Adult Down Syndrome Program offers a multidisciplinary team of physicians, psychologists, nutritionists, social workers and others who evaluate and provide program planning guidance for adolescents and adults with Down syndrome. For more information, contact Janice Nodvin, Program Director at 678-595-4854.

Education Sessions:
Saturday, July 19: Movin’ Up – Planning Your Child’s Successful Transition at Age 3,
Peace - Love and Harmony
Emory University Medical School

Saturday, September 13: New Parent Seminar, full walk through on filling out the Deeming Waiver application, educational session will run concurrently
Emory University Medical School

Saturday, November 15: Educational Seminar, topic TBD
Emory University Medical School

DSAA Events:
Spring Social, May 3rd
Railroad Pavilion, Stone Mountain GA

AHSDA Summer Picnic, May 31st
Mason Mill Park

2014 Buddy Walk, October 19th
Centennial Olympic Park

D.A.D.S Annual Golf Outing, October 24th
Bears Best Atlanta

Holiday Party, December 7th
Mt. Paran Church, Great Hall

Community Events:
Disability Day at the Capitol
Thursday, February 20

Bregman Conference and Dance
Saturday, February 22nd

Habima Theatre, February 27 - March 9
Approximately 100 parents, educators, and therapists from the Southeast region gathered on October 19, 2013 at Emory University School of Medicine for the Down Syndrome Research Conference. The conference was sponsored by the Down Syndrome Association of Atlanta and the Down Syndrome Clinic at Emory University. We were fortunate to have leading experts in Down syndrome from Colorado State University join us in providing an update on current research and intervention therapies used to enhance the quality of life for individuals with Down syndrome and their families.

The keynote speakers, Dr. Deborah Fidler & Dr. Lisa A. Daunhauer, from Colorado State University, presented on “Executive Functioning in Down syndrome: Implications for education and intervention.” Their most recent work focuses on the development of executive function in children with Down syndrome, including working memory, planning, shifting (cognitive flexibility), and inhibition using goal-directed behavior.

Elizabeth Will, M.Ed., Board Certified Behavior Analyst gave a very engaging presentation on “Behavioral Therapy for Children with Down syndrome”. She discussed the importance of reinforcement, incidental teaching, visual support, and behavior management utilizing the Applied Behavioral Analysis (ABA) approach in targeting behavior challenges in children with Down syndrome. Dr. Lillie Huddleston presented on “Planning for Educational Success: Practical Strategies for Children with Down Syndrome”. Her presentation included information about school placement, IEP’s, and tips on navigating the school system.

The day ended with Dr. Jeannie Visootsak providing an overview of how clinical trials work along with an update on the current clinical trial (Roche Pharmaceuticals) on a psychopharmacology treatment targeting memory, cognitive, and behavior in adults with Down syndrome. Phase I safety study has been completed, and currently Phase II is being conducted at 10 sites in the U.S. to determine the safety and effectiveness of the study medicine.

Although there is much excitement about the potential this study medicine could have on enhancing the lives of individuals with Down syndrome, Dr. Jeannie Visootsak reminded the audience that medications alone will not reverse learning problems in individuals with Down syndrome and it is important to combine medication with targeted educational interventions, behavioral strategies, and other resources.

It was exciting seeing the collaboration between parents, caregivers, and researchers. We hope with continued collaboration and support, resources for individuals with Down syndrome and their parents continue to grow and improve.

Please do not hesitate to contact Jean Luan-McColl, Down Syndrome Research Coordinator, if you have any questions or if you would like additional information about the Roche R0518658 Phase II trial.

For information about our Down Syndrome Clinic, please call Jean Luan-McColl at (404) 778-8619
The frog would love to leap along the path to get to the lily pad at the end. Please show the way to get there.
New President Brian hard at work at The Pigs and Peaches BBQ Festival last year!