

July - August 2004

6th ANNUAL DSAA GOLF TOURNAMENT

The DSAA will be hosting the 6th **Annual Swing For The Children Golf Tournament** on Monday, September 27th at the Country Club of the South. This is our major fund raising event of the year. We have raised in excess of \$25,000 in previous years.

The tournament will begin with practice and registration from 10:30 - 11:30 AM. A box lunch, provided by Loco's Deli, will be on the carts for a shotgun start at noon. Following the tournament, we will host a Silent Auction and buffet dinner for the golfers. This dinner is available for DSAA member golfer families at a small fee per person.

Space is limited to a maximum of 100 participants. Please be sure to register early in order to guarantee yourself a spot.

If golf is not your game, but you would like to volunteer for the tournament; please contact Dale Greig or visit our website (contact information below).

Several sponsorship levels are available: **Executive Sponsor** (\$2,500); **Hole Sponsor** (\$1,000); and **Clubhouse Sponsor** (\$500). Each level comes with various benefits to the sponsor. If you or your employer has an interest in sponsorship, please contact Dale Greig for specific details.

The entrance fee is **\$250** per golfer which includes cart and green fees, range balls, a golf shirt, goodie bag, team photo, lunch, on-course beverages (provided by Pepsi and Coors), buffet dinner, and the Silent Auction at the conclusion of the tournament.

To register for the tournament or to volunteer visit our website at www.down-syndrome-atlanta.org or contact Dale Greig @ 770-509-7322. Come out and enjoy this fun-filled day and support the DSAA.

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From the Executive Director

Each summer, in the six years that I have been involved with the Down Syndrome Association of Atlanta, I have seen our parent volunteers “put it in gear” to prepare for our busy fall schedule. For those of you who are new to DSAA, you can look forward to our annual Golf Tournament Fundraiser September 27th; our Buddy Walk awareness event on October 16th (note the new location), as well as our Family Fall Festival and Carnival on November 7th, and our Holiday Party with Santa in December. These events all require a great deal of preparation and planning, and we are fortunate to have a dedicated group of parents working on all of these.

As we strive to make the rest of 2004 a big success, we also have many accomplishments to be proud of over the first half of the year. These include our regional educational conference in February, our annual adult social in April, and our inclusion practices workshop in May. We also had another successful membership renewal drive (it’s not too late to return your form!) and our New Parent Panel returned to Northside Hospital for a presentation to the regular care nurseries’ staff. In addition, we have a new look to our website, and welcome your suggestions. Please visit www.down-syndrome-atlanta.org often to stay up to date on DSAA events and activities.

If you have some free time this summer, and are still wondering if you should attend one of the national conventions, let me encourage you to do so. Both the National Down Syndrome Society conference in Washington, DC in July, and the National Down Syndrome Congress convention in Minneapolis in August promise to be an incredible source of information and empowerment. NDSS is celebrating their 25th year with a theme of “Empowering, Reaching, Achieving,” while NDSC’s “Boundless Horizons” will be their 32nd annual convention. I promise you will leave these conferences renewed and energized.

This will be my last message to you as DSAA’s Executive Director. In August I will be starting a new job, as resource specialist with the National Down Syndrome Congress, whose office is also here in Atlanta. I’d like to be the first to welcome Heidi Moore as our new Executive Director, and wish her much success as she begins a new path in her involvement with DSAA. Heidi currently serves as co-vice president on the DSAA Board of Directors, and will bring a great set of skills as a parent and a professional to this organization.

I look forward to seeing all of you at upcoming DSAA events. Thank you for your continued support of DSAA!

- Sue Joe

Meet The Wise Family

- by Karen Wise

Rich and I have 4 beautiful children - Eve 7, Gavin 5, Ian 2, and Mary Rose, 5 months. We homeschool our children and are a part of a nationwide homeschooling support group. Next year, Eve and Gavin will attend Bristol Academy 1 day a week to learn Science and Art with other homeschooled kids. They also were on the Springmonte Swim Team this summer and attended Vacation Bible School. We like to camp, hike, swim, and spend time on our boat. Rich and I teach fitness classes at the YMCA. We feel that staying active is important for all of our kids...for self-esteem and staying healthy, and we know that our actions speak louder than our words! Rich is a Project Manager and I am a homemaker.

On September 26, 1998, our beautiful Gavin Harris was born. Three hours after his birth, we were told he had Down syndrome. We were both in shock. Never knowing anyone with Down syndrome, we were scared and confused about what it meant. The birth was fine and he seemed fine to us. We thought they must be mistaken. But test results confirmed the diagnosis. We both cried on and off that whole day, just holding each other in that single hospital bed, and cuddling our new little baby boy. How would we handle this? This wasn't in our plans. How could this happen to us? I prayed that God would somehow make me feel all right about this. I remember wondering how I would do anything in life without crying. But as the days passed and our boy developed, I began to realize how much of a gift he really was, to everyone he touched! Weeks after his birth, Rich's company needed someone to work in Europe for 6 weeks. We took this as an opportunity to get away from all the phone calls and explanations, and to bond as a family in this time of crisis. So off we went. Each weekend, we took a trip to a different city. Our last weekend there was Christmas, and we were off to Rome.

We got tickets to midnight Mass with the Pope, thanks to our priest in Alpharetta. We walked in with a 2 year old and an infant, and immediately an Italian nun motioned for us to sit in the back. I protested, wanting to be closer to our Holy Father. Neither of us understanding the other, I finally agreed to sit where she insisted. As Mass began and the procession started, we realized, all the priests, bishops, archbishops, and finally our Holy Father, walked within 2 arms lengths of us! We were in awe, and as I looked over at our Italian nun friend, she gave me a look as if to say, "See, I told ya so!" Then, about midway through Mass, one of the Pope's guards tapped my shoulder and spoke in Italian. The only words I got were, "Finale.Mass.Papa" and he signaled for us to follow him. I said "OK" and looked at Rich, saying, "Maybe everyone with kids will have them blessed

by the Pope at the end of Mass." Then a French lady next to me grabbed my arm and said, "Can my daughter go with you to meet the Pope?" I said, "Of course" and looked back at Rich saying, "Maybe everyone doesn't get to go." Sure enough, as Mass was ending, this guard guided us, along with the little French girl, to the back of the church. We were the only ones. I felt as if I was floating above, watching all this happen. As the procession passed us, there were the priests, bishops, archbishops, and then sure enough, our Holy Father, Pope John Paul II humbly shuffled over, placing his hand on Gavin's head (sleeping through it all), then Eve's head, blessing them both. It was like an out-of-body experience! In astonishment, Rich and I agreed that this was God's sign to us, that everything would be all right. That He would give us the graces we need to be the best parents to Gavin. For Gavin is His child, only on loan to us.

Our journey since Gavin's birth has had it's ups and downs. But through it all, God has been so good. Gavin teaches us, everyday, to let go and let God. And to accept people of all abilities just the way they are. We remember that people are worthwhile because God made them special, not because of what they accomplish. We've also recently come to terms with the fact that Gavin was made by God by design! There's nothing to fix. There was no mistake. He's covered in the fingerprints of God. He's not broken! He has more in common with typical kids his age than differences. He will do everything other kids will do, just in his and God's time and with some extra help along the way. Through prayer and love, Rich and I have grown closer through all of this!

The best thing we did after Gavin was born was to communicate with other families. We now have a family support group that meets in our home several times a year for the camaraderie, sharing ideas, and allowing our kids to also foster friendships.

I joined the DSAA board in hopes of helping other new families, like we were helped when Gavin was first born. I also want to encourage advocacy for our children and support inclusion for our kids - in school, sports, community activities, etc.

A message that I would give to new parents is this: Make sure that you keep your "couple relationship" a high priority. Nurture the relationship. Do not get lost in the therapy merry-go-round. Let your child be a child, and enjoy your family times together. It is important to take time for yourselves and each other.

THE EMORY CONNECTION

News from the Down Syndrome Center, Department of Human Genetics, Emory University.

Congenital Heart Defects and Down Syndrome

Through a collaboration between Emory University and the Sibley Heart Center at Children's Healthcare of Atlanta, families who have a child with Down syndrome and a congenital heart defect are being invited to participate in a research study. This study will help us understand why some children born with Down syndrome also have a heart defect. For more information contact Lora Bean at (404) 727-0485 or LBean@genetics.emory.edu.

Down Syndrome Clinic

The Down Syndrome Clinic continues to be incredibly busy. We look forward to July when we will increase our clinic days to twice a month. For information or to give us feedback and suggestions, please contact our Down Syndrome Clinic coordinator, Aimee Anido, MS (404-712-8232, aanido@genetics.emory.edu) or Sallie Freeman, PhD (404-727-0495; sfreeman@genetics.emory.edu).

- Sallie Freeman

Buddy Walk on October 16th

The Buddy Walk is a celebration of Down syndrome awareness as well as a fundraiser. This year the DSAA community will meet at the Festival Center in Duluth Square for fun, fellowship, food and fitness. We begin at 9AM with music, face painting and friends. The walk itself is a stroll around the Village Green. Strollers, wagons, wheelchairs and walkers will parade around the Green mid-morning (around 10:30 AM). We then return to the Festival Center for more fun and prizes.

This is a fundraiser for the DSAA and also our affiliate organization, the National Down Syndrome Society, which promotes advocacy and research studies on a national level. We are encouraging walkers to raise pledges for the DSAA and either mail them or bring them to the walk registration table. Visit the DSAA website at <http://www.down-syndrome-atlanta.org> to access the Buddy Walk page for further information (or see "Upcoming Events" in this newsletter).

Upcoming Events

July 22 - 25

NDSS National Conference in Washington, D.C. To register contact NDSS at 800-317-7554 or download the registration form at www.ndss.org

July 26

Celebrate the 12th Anniversary of the Americans with Disabilities Act!

August 20 - 22

NDSC 32nd Annual Convention in Minneapolis. To register contact NDSC at 800-232-NDSC or download registration form at www.ndscenter.org

August 27 - 29

A Family Fun Weekend through FOCUS at Camp Twin Lakes. Call 770-234-9111 for information and reservations.

October 7 - 10

The Arc of Georgia Annual Conference will be held at the Wyndam Conference Center in Peachtree City. Call 404-634-5512 for more information.

October 14

National Rehabilitation Association Annual Training Conference & Exhibit Showcase to be held in Philadelphia. Contact: 888-258-4295 or visit www.nationalrehab.organization/websitevents for details.

October 16

Mark your calendar for the Buddy Walk from 9AM until noon at the Festival Center in Duluth Square! We need sponsors! If you have any information please contact Lauren Biggs at 770-889-3030 or Diane Bromelow at 770-346-8586.

November 7

Save this date! A Fall Festival and Carnival is being planned for this Sunday afternoon. We still need volunteers! Please contact Shere Owens at 770-495-6396 for more information on volunteering. Details about location and activities will be forthcoming.

December 5

Save this date! Annual Family Holiday Party complete with a visit from Santa. Details about location and time will be in the next newsletter.

eligibility meeting. Have a general plan of what your child needs and how that plan should be implemented. It is helpful to have suggested goals for your child.

* Get copies of all evaluation results and new assessments prior to the meeting. Do read them prior to the meeting. Meet with the school psychologist prior to the meeting. This saves meeting time and avoids surprises.

* Bring evaluation results and other pertinent information from private professionals that work with your child.

* Be prepared. Organize your child's file, make an outline or agenda, list concerns according to their priorities. Come ready to negotiate.

* If you think the evaluation does not truly reflect your child's abilities, ask for an independent education evaluation.

* Note your child's strengths and weaknesses. This helps the IEP team select the best approach to teach your child. Be sure to focus on strengths. Bring a picture of your child.

* Write down goals that you have for your child. The goals should be easy to understand.

* Be sure to include the "related services" your child needs, such as therapies, assistive technology, or transportation.

* Think about the past school year. What worked well? Be proactive!

* If your child is attending the meeting, inform the IEP team and prepare your child. Make a list of what your child wants the IEP team to know. Help clarify his ideas.

* Bring someone with you to your meeting (i.e. an advocate, neighbor, grandparent). It is alright to tape the meeting. This can help you remember what was discussed.

During the Meeting - REMEMBER: BE AN ACTIVE IEP TEAM MEMBER

* Arrive on time, be well prepared, and dress like you were going to an important meeting.

child's meeting. Remember, you know your child better than anyone else. You are the expert!

* As the IEP team develops your child's goals, make sure that he is provided the appropriate educational opportunities and activities to work on those goals.

* Do not forget about additional supports or modifications the student needs in order to achieve his goals.

* Determine where your child will work on his goals with those supports and modifications.

* If the student is to be removed from the general education setting, document, in detail, why the student cannot be educated in the general classroom. This should be clearly stated in the IEP minutes.

* Sign the IEP only if you are in agreement with it. You may take time to think about it before signing.

* Before you sign, be sure to review the meeting minutes. Make sure they accurately reflect what occurred during the meeting. Correct any changes or additions as appropriate.

* If you do not complete the IEP after 2 hours, suggest that the meeting be rescheduled to finish it. Your concentration begins to fade.

After the Meeting

* Relax. IEP meetings are stressful regardless of how well the meeting went.

* Review the minutes and the IEP. If important discussions are missing write a letter "thanking" the school for their time, noting the information the school "forgot," and ask that your letter be attached as an addendum to the IEP document. Send your letter by certified mail and keep a copy.

* Be proactive. Make sure that your child's teacher receives the information and supplies she needs to adapt the curriculum.

* Consider ways that you can reinforce the IEP goals and objectives at home.

* Continue communication with school staff. Let them know if you are pleased or dissatisfied with the implementation of the IEP. Do not wait until the next IEP to voice your concerns. You can call an IEP meeting at any time.

Do We Need A DISABILITY AWARENESS Week?

Disability Awareness Week occurs yearly, yet the impact of a good PTA Special Needs Committee can last throughout one's lifetime. With the support of the Autrey Mill Middle School and Taylor Road Middle School PTAs in Fulton County and their respective principals, Ann Ferrell and Francis Boyd, Johnny Kelley was a featured speaker during Disability Awareness Week.

Johnny Kelley presented an eloquent speech about his life experiences. He is a 25-year-old man who was born with cerebral palsy. To enhance his communication he uses an augmentative communication device that talks for him. He uses a motorized wheelchair for mobility. All that said, what the students saw on March 8 was a man that had a lot to offer society.

One student spoke for many when he said, "This sort of gave a little spark in my brain that said that all people, no matter what they look like, can be smart, funny, fun to be with, and have dreams just like everybody else." Mr. Kelley's quick wit and demeanor allowed the students to see through and past the physical limitations they may have otherwise focused on. Another student told Mr. Kelley, "I really enjoyed hearing you speak to us. I feel very different about life now. You helped me understand that you are just like one of us." The students learned in one hour what some people never learn in their lifetime. Student James Lee said it well when he said, "I learned people with disabilities can do most of the things we can. I think we should not treat people badly because of their disabilities but help them and treat them like anyone else. He really changed my view toward people with disabilities, and I learned a lot from him."

Mr. Kelley described how he was discriminated against and what we can do to prevent that from happening to other people in the future. He talked about the need to help people now instead of taking care of them later. One student wrote about what he

learned, "Even if he is in a wheelchair that does not mean that he can't do what other people do. He follows his dreams just like we do. He went to college, got a job, and wants a Navigator with nice rims." Another student said, "I thought Mr. Kelley was cool because he wasn't different from everybody else. I learned that people with disabilities can do things like a regular [able-bodied] person."

One goal of Disability Awareness Week is to dispel misconceptions through positive education. People have certain perceptions based on their personal knowledge and experience. Programs to create awareness cause young and old alike to see that "People with disabilities can do most of the things we can. We should not treat people badly because of their disabilities, but help them and treat them like anyone else." (James Lee) The students were surprised to learn that Mr. Kelley lives independently, is employed, and has a girlfriend. They learned in one simple lesson that all people are equal.

They also learned that the federal and state governments do not always adequately support people with disabilities in education, housing and employment. People are routinely placed on "waiting lists" that have no funding and no foreseeable solution without advocacy at the grass roots level - families, self-advocates and providers.

Did you know that in Georgia, as in many other states, a person with a disability actually needs a "waiver" to receive government assistance and stay out of an institution? Yes, we still have institutions in Georgia. The "system" needs to be changed so that people with disabilities are truly thought of as people not entities to be warehoused. People with disabilities have much to offer society, but they need our support, not handouts.

Support is imperative in order to include people with disabilities in all aspects of their community.

Community support can be found in every person young and old, rich and poor. People helping people - isn't that what we want our children to learn? People with disabilities are people first.

Every human being has something to offer society; we just need to give them the opportunity. By introducing the students to Mr. Kelley, they were able to see how much one individual person can change their perceptions. Ethan Merbaum was correct when he said, "It's sad that people are judged by their appearance and not their ability." The students listened intently and heard Mr. Kelley's message. One student summed it up well when she said, "When you told us not to feel sorry for you because you are just like us, it gave me a new way of dealing with people with disabilities. Since I met you, I am now going to treat people with disabilities like everyone else!"

These students can't help but have a different outlook on people with disabilities as a result of seeing and hearing Mr. Kelley. They will not be afraid to work with, live by or employ someone with a disability. They don't need to be afraid of people with disabilities, but need to ask how they can help them to reach their full potential. You

can find out how you can help people with disabilities by calling the Governor's Council on Developmental Disabilities, the Atlanta Alliance on Developmental Disabilities, Unlock the Waiting List, Georgia State PTA or the Georgia ARC.

Disability Awareness programs are not only needed today, but should be required in all schools. While the Civil Rights movement of the 60s has had a positive affect on some, for people with disabilities the discrimination can still occur at an alarming rate. People with disabilities are denied education, housing and employment in many areas of the state and country. In Georgia there are over 4,000 people with disabilities on a waiting list for services and more than 1,000 of those are in "critical need." By educating children today, our future leaders will be more sensitive to the needs of people with disabilities. These leaders will not be apprehensive to be friends with, live by, and employ people with disabilities.

This article was written by Kathy Everett, M.A., parent, teacher and advocate. Kathy lives in Alpharetta, GA with her husband, Chris and their two daughters, Jennifer, 16 and Sarah, 13. She can be reached at <KathyEverett@comcast.net>.

Prepare Now for the New School Year: A Checklist for IEP/504 Meetings
by Lori von Schmeling of Project Bridges and Leslie Lipson of the Georgia Advocacy Office

With school starting in August, it is not too early to begin thinking about your child's Individual Education Plan (IEP). In fact, the IEP is a fluid document that can be changed at any time. Now is a good time to take out your child's IEP and review it for any updates you may want to make in the Fall.

After your child has had an opportunity to be in his new classroom situation, if you feel he is not achieving the goals that are stated in the IEP, is a good time to schedule an interim IEP meeting with your IEP team to review goals and objectives for the year.

The following is a checklist in preparation of your child's IEP meeting. This checklist would also be helpful for a 504 meeting.

Before the Meeting - HELPFUL HINTS TO CONSIDER BEFORE YOUR CHILD'S MEETING

* Do your homework! Be fully informed, and have a plan. If the child was evaluated by the school system, the meeting may be an eligibility meeting as well as a meeting to develop next year's IEP or 504 plan. An eligibility meeting determines whether or not a child is eligible for special education services under 504 or IDEA and which services a child needs. You must be included in the

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July Birthdays

Paula Amoss	Landon McGlaun
Andres Devia	Julian McKnight
Ian Dillard	Michael Moore
David Duron	Charlie Moylan
Brandon Edmonds	Karen Murphy
Jennifer Everett	Marqueze Perry
Gabriela Gomez	Marty Rasnick
Daniel Harman	Jose Santiago
Hannah Hibben	Chloe Simms
Michael Jarvis	David Smith
Luke Kurtz	Cody Wilbanks
Michael Lewis	Albert Williams
Shanice Matthews	Keron Whitters

August Birthdays

Alan Acosta	Marina Martinez
Zachary Beddington	Troy Millikan
Alyssa Biggs	Aleksander Perez
Ethan Bromelow	Katie Petersen
Marquis Browning	Stephanie Powell
Timothy Casey	Pierce Ruck
Angelica Cuevas	Bryan Salazar
Michael Hendrick	Rachael Shelp
Katie Holt	Abby Strietelmeier
Cooper Lilienthal	Polly Vettraino
Eva Lopez	Manolo Villanueva
Abigail Malone	Joshua Vogler
Tate Marti	Hannah Welter

If we have missed your child's birthday, please let us know. We want to correct our records.