

September - October 2004
“Boundless Horizons”
A Great Time was had by all at the NDSC Convention!

PHOTO COLLAGE FROM CONVENTION

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From the Executive Director

First of all, I wanted to take a few minutes and say a great big THANK YOU to Sue Joe. She has been dedicated to DSAA for over six years. Her efforts have helped form this organization into what it is today. Sue is moving on to work with the National Down Syndrome Congress here in Atlanta but I'm sure she will continue to be involved with DSAA. Thanks again Sue for all your hard work over the years!

After three years sitting on the Board of Directors of DSAA, I am now taking on the role as your new Executive Director. I look forward to this challenging position and to DSAA continuing to grow based on the needs of our members. I hope all of you have learned from the last legislative session that *United We Will Make a Difference* for individuals with disabilities and that you will get more involved in advocacy efforts in the future. DSAA will continue to grow and keep you up to date on the issues facing our families!

This is going to be another busy fall season! The Golf Tournament Fund Raiser will be held on September 27th at County Club of the South; our Buddy Walk awareness and fundraiser event is scheduled for October 16th at the Downtown Duluth Square; as well as our Fall Festival scheduled for November 7th and Holiday Party with Santa for December 5th. As you can see we have a lot planned and need your help. If you want to volunteer, help with fundraising or just attend the events, there are many to choose from.

The National Down Syndrome Congress Convention ÒBoundless HorizonsÓ was held on August 20-22 in Minneapolis. Those of us who attended learned a lot about other parent organizations, as well as, medical, educational, and general information that we hope to distribute to our members in the coming months and at our General meeting on August 28th.

I hope our organization will get involved in educating legislators on issues relating to our children and adults with disabilities. In the next few weeks, Candidate Forums will be held in Georgia to discuss these important issues with legislators prior to the election in November. Let's show our support, attend these meetings and let our voices be heard before they return to the Capitol in the coming year!

I look forward to meeting you at the upcoming DSAA events. If you have any ideas or suggestions, feel free to email me at Executive_Director@down-syndrome-atlanta.org. Thank you for your continued support of DSAA! Please visit us on the web www.down-syndrome-atlanta.org to stay up to date on the most recent DSAA events, activities and advocacy efforts.

Sincerely,

- Heidi J. Moore

“A Multicenter Vitamin E Trial in Aging Persons with Down Syndrome”

May South has been chosen as one of 27 sites in the US and abroad to participate in a multicenter Vitamin E trial in aging persons with Down syndrome. This project will be the first large-scale treatment study of Alzheimer disease in persons with Down syndrome. The granting project sponsor is the National Institutes of Health.

Dr. Leslie Rubin in collaboration with **May South** located at 1770 The Exchange, Suite 140, Atlanta, GA will be recruiting persons with Down syndrome over the age of 50 to participate in this important study.

It is known that people with Down syndrome over the age of 50 are more likely to get Alzheimer disease than other older people. Some of the changes that occur in people who develop Alzheimer disease include a decline in memory, thinking, working, and self-help skills. Vitamin E has been shown to slow the development of these changes in some people with Alzheimer disease in the general population. We do not know, however, whether it will help older people with Down syndrome. By giving some people a high dose of Vitamin E and other people inactive pills called placebos, we aim to find out whether Vitamin E really helps to slow the rate of cognitive/functional decline in older individuals with Down syndrome as they grow older.

Individuals with Down syndrome over the age of 50 with or without a diagnosis of Alzheimer disease will be recruited from their homes or from state and private service provider agencies. A Vitamin E regimen of 1,000 I.U. (international units) twice daily, plus a multivitamin will be compared to a placebo and multivitamin. The treatment period will be for three years, with study visits at six-month intervals and telephone contacts at 3-month intervals in between. For an individual to be considered, a “Consent to Participate in Research” form must first be signed by either the individual or their legal guardian. An initial Screening Visit will be scheduled close to where the individual lives to determine if he or she will be eligible. During this visit, basic information about the person’s health, medical, social, and work background will be gathered and a brief physical examination will be done. A blood sample (about 2 tablespoons) will also be collected, and the participant will be asked to perform a brief praxis test, which is a series of simple fine and gross motor

tasks that will evaluate one’s ability to make simple voluntary movements and handle two common objects (a padlock and a small jar). Each selected study participant will be seen every 6 months for 3 years. A 6-month supply of either Vitamin E or placebo pills that look like the Vitamin E will be supplied during each follow-up visit. A supply of multivitamin supplements will also be supplied as part of the study. During each 6-month visit, a brief praxis test and a few simple tests of memory, function, and everyday behavior will be given to measure the participant’s performance. Blood pressure, pulse, respiration and temperature will also be taken. The participant’s caregiver must be willing to accompany them to all of the study visits, make certain they are properly taking the study medication, and communicate any changes in their health status over the 3 years of this study. On the last visit (visit #7) a final physical exam and a final blood sample (about 2 tablespoons) will be collected and will be used for the same purposes as the blood tests during the screening visit.

There are no major side effects associated with taking Vitamin E supplements. However, mild gastrointestinal side effects such as upset stomach may occur. Because Vitamin E can worsen the problems of people who have blood-clotting disorders, we will not allow anyone to enroll in this study if blood-clotting problems are detected during the initial screening visit. Physical exams and cognitive testing present no risk. There might be slight pain during the blood drawing (venipuncture) and there is a risk that a bruise may develop at the puncture site. To reduce the chance of any risks, only experienced medical personnel will handle all the blood drawing procedures, and sterile conditions will be maintained.

This project is approved by the Institutional Review Board of the New York State Institute for Basic Research In Developmental Disabilities.

If you provide services to consumers with Down syndrome age 50 and over, or have a family member with Down syndrome who is over age 50 and would like to have him or her participate in this study, please call us.

Co-Principal Investigator, **Dr. Leslie Rubin** 404-303-7247
Study Coordinator, **Janice Nodvin** 770-956-8511, ext. 207

The Emory Connection

New parents want the best for their baby, and families who come to our Down Syndrome Clinic are no exception. They have many questions about what they should be doing for their new baby. We remind them that, just as for any child, one of the first steps is to find a pediatrician in whom they have confidence. A good pediatrician, accessible for routine care and those inevitable, frantic new parent calls, is essential. However, children with Down syndrome have some special needs, and we are fortunate that two different groups of professionals have developed guidelines that address these needs. The American Academy of Pediatrics published guidelines in 2001 (Pediatrics, 2001, vol 107:442-448) and the Down Syndrome Medical Interest Group produced their revised set of recommendations in 1999 (Down Syndrome Quarterly, vol 4, no. 3). These two sets of guidelines are very similar to each other and address such issues as cardiac evaluations, thyroid screening, hearing and vision testing, and other topics. The recommendations are tailored to the age of the child.

The two publications mentioned above are lengthy and primarily directed toward health care professionals. For example, we use the guidelines extensively in the Emory Down Syndrome Clinic. Parents who want to investigate the original publications can find the guidelines of the Down Syndrome Medical Interest Group on the internet at various sites (type "Down Syndrome Quarterly" into Google). The journal *Pediatrics* can be found in libraries including the Emory Health Sciences library.

Fortunately, these guidelines have been summarized in the form of various checklists and tables. These short versions can be very helpful to parents who can see at a glance the various recommendations. In the Emory Down Syndrome Clinic we give all new parents one of these checklists. We review the material with them and suggest that they keep a copy and give one to their child's pediatrician to attach to their child's chart. However, even in summary form, these guidelines can be somewhat technical. Therefore, we suggest that parents discuss them with their pediatrician or during a visit to the Down Syndrome Clinic. There are several sources for these checklists and tables. We often use the table found on Dr. Len Leshin's website <http://www.dshealth.com/> The National Down Syndrome Congress, headquartered in Atlanta, has another such summary which can be obtained by contacting them at 1-800-232-NDSC or 770-604-9500 or by email to: info@ndscenter.org

For information about the Emory Down Syndrome Clinic, please contact our Down Syndrome Clinic coordinator, Aimee Anido, MS (404-712-8232, aanido@genetics.emory.edu) or Sallie Freeman, PhD (404-727-0495).

Upcoming Events

September 21

North Fulton Candidate Forum. A non-partisan forum for all north Fulton candidates for the Georgia State Senate and House of Representatives will be held on September 21st at 7 PM at East Roswell Park (900 Fouts Road) in Roswell.

September 27

6th Annual Swing For The Children Golf Tournament at the Country Club of the South. To register for the tournament or to volunteer visit our website at www.down-syndrome-atlanta.org or contact Dale Greig at 770-509-7322.

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

A Fall Festival and Carnival will be held at the Wildfire Paintball Field, 2641 Hestertown Road, in Madison. For directions go online to www.wildfirepaintball.com. The festival will be from 1 - 5 PM. A costume parade will be held at 3 PM. Game booths, prizes, concessions, music and fun guaranteed for all. We still need volunteers! Please contact Shere Owens at 770-495-6396 for more information on volunteering.

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.

Courtney Owens, age 3, is featured on the cover of the Abilitations Fall 2004 Catalog.

Resources

In Georgia, the Cobb Community Services Board, the Cobb County Micro-Enterprise Project and "CobbWorks!" - the local Workforce Investment Board, received a Department of Labor grant to remove barriers that many residents with disabilities encounter as they try to enter or re-enter the workforce, attain new skills, start a business or go directly into the career of their choice. These partners in the Customized Employment Project provided the financial and research support to initiate customizing the WorkWORLD benefits planning software to include a Georgia Benefits Information System (GABIS). This Georgia Information system is integrated into the WorkWORLD software program and website.

You can view the GABIS portion of the system at: http://www.workworld.org/wwwwebhelp/welcome_to_gabis.htm The non-profit WorkWORLD website offers free software and a Help/Information system that helps people with disabilities use work incentives in Federal benefit programs such as SSI, SSDI, Section 8 Housing, and Food Stamps to return to work or become more self-sufficient. They are a unit of Virginia Commonwealth University's School of Business and are funded by a number of Federal, State, and local grants, contracts, and cooperative agreements to offer these services on the Internet at no cost to users.

Gwinnett Playgroup will begin meeting in early fall on the last Friday of each month at 11:00 a.m. For more information, please call Shere' Owens 770-495-6396.

Vidalia Playgroup will begin meeting on September 20th at 7 PM at Grace United Methodist Church. Please contact Patricia Blackstone at 912-538-1229 for more information.

<http://www.groups.yahoo.com/group/GA-ParentNetwork>
Online discussion group for parents in Georgia who have children and adolescents with disabilities. They offer assistance, support and resources for education information, Medicaid and insurance issues, and other issues that parents of special needs children will find beneficial. This group also offers periodic trainings for parents concerning education issues. This group is moderated by a Babies Can't Wait Parent Educator and a member of the Governor's Council on Developmental Disabilities.

Latest in a Series of Court Decisions on I.D.E.A. Cases Goes Against Parents

In what is the latest in a series of court cases of its kind, the Fourth Circuit Court of Appeals in Richmond, Virginia has issued a decision that will make it even harder for parents to prevail in due process proceedings brought under the Individuals with Disabilities Education Act (IDEA). This case, filed by parents in Maryland who said that their middle school son had been denied a free appropriate public education (FAPE), went through two administrative hearings, two federal court decisions and two appellate court hearings.

The appellate court made the decision that instead of the school having to prove that they provided FAPE, as the lower court decided, the parents must show that the child was denied a FAPE. In law, this is called shifting the burden of proof and is an extremely important decision that will make it even harder for parents to win at due process hearings.

This Fourth Circuit Court of Appeals hears appeals from federal court decisions in the states of Maryland, Virginia, North Carolina, South Carolina and West Virginia. While the Fourth Circuit, along with the Fifth, Sixth, and Tenth Circuits have ruled against parents, some Circuits, including the Second, Third, Eighth and Ninth, have left the burden on school systems. As a result of these conflicting opinions, the U.S. Supreme Court will likely decide the issue of burden.

As courts continue to make it harder for parents to win challenges to their child's educational program, NDSC continues to urge legislators not to impose additional burdens in the reauthorization of IDEA. To read the court decision discussed above, go to <http://pacer.ca4.uscourts.gov/opinion.pdf/031030.P.pdf>.

New Newsletter for Self-Advocates

The Self-Advocate Leadership Network, part of the organization called Self Advocates Becoming Empowered (SABE), a national self-advocacy group for individuals with disabilities, is publishing a newsletter written for self-advocates. This newsletter is called The Riot! It will come out every four months in July, October, January and April. You can read the first issue at: <http://www.hsri.org/leaders/theriot>.

DSAA is proud to sponsor an Adult Down Syndrome Program serving families throughout the southeast

May South in collaboration with TEAM Centers takes the lead in providing this needed service to our community. The Program is now seeing individuals with Down syndrome of adolescent and adult ages. They accept insurance, Medicare/Medicaid and private pay. They are staffed by leaders in the field of Developmental Disabilities including specific medical issues and other complex chronic conditions associated with Down syndrome and the aging process.

Although there are many services for children with Down syndrome in Atlanta, there is currently a void in specialty health care services for adults with Down syndrome. It is well known that health, well-being and life expectancy are directly related to the quality of health care. This is related to availability and quality of health related services and supports. In addition, the healthcare needs of adults with Down syndrome are more complex in that there are increased frequencies of many common and uncommon conditions such as Thyroid disease, eye conditions, skin conditions, gastrointestinal conditions as well as increased risks for Atlanto-axial Subluxation, and most significantly there is a greater risk of Alzheimer's Disease with aging. There is also limited knowledge about the health care needs of adults with Down syndrome among health care professionals.

Mission of the Program:

Improve quality of healthcare for adults with Down syndrome by:

- ¥ Helping to identify health profile of adolescents and adults who have Down syndrome
- ¥ Providing coordination of health care for adults with Down syndrome
- ¥ Providing families resources for accessing primary and specialty health care in and around Georgia.
- ¥ Reviewing the environmental and social aspects in a Developmental model of service delivery

Staff:

Medical Director: Leslie Rubin MD

Dr. Leslie Rubin is a developmental physician who has been active in the field of Developmental Disabilities for more than 20 years. He is Medical Director of May South, Medical Director of TEAM in Chattanooga and serves as Co-Investigator of the Southeast Pediatric Environmental Health Specialty Unit. He has recently joined the faculty of Morehouse School of Medicine.

He is a sought after internationally known speaker and has co-authored books and journal articles. **Since making Atlanta his home he has developed connections with Universities, Hospitals and other agencies serving children and adults with developmental disabilities and has the vision of promoting awareness, knowledge and empowerment for people with developmental disabilities and their families in the Southeast.**

Center Director: Janice Nodvin, BA

Janice Nodvin is Director of Special Projects at May South where she serves as Project Manager of a research project on the use of Vitamin E on senior adults with Down syndrome. She serves as the project administrator and educator on the Southeast Pediatric Environmental Health Specialty Unit at Emory University and is a consulting editor of Making A Difference magazine, a quarterly magazine of the Governor's Council on Developmental Disabilities. Ms. Nodvin has been conference director of several regional and national conferences. Her volunteer experiences include President of Down Syndrome Association of Atlanta, Chair of the DeKalb Developmental Disability Council and Chair of Developmental Disabilities Department of Marcus Jewish Community Center of Atlanta.

Nurse/Social Worker: Susan Tiessen LCSW

Susan Tiessen brings a unique medical perspective to the team. She is a licensed registered nurse and clinical social worker. Her experience spans in many areas of developmental disabilities and clinical practice.

For appointments or information, contact: Janice Nodvin, Center Director
770-956-8511, extension 207
jnodvin@mayinstitute.org

October is National Down Syndrome Awareness Month

This provides an excellent opportunity to create a positive atmosphere promoting nationwide awareness and acceptance of the potential of people with Down syndrome. For example, it offers an occasion to generate "good press" about educational issues to counter the negative media campaign around the Individuals with Disabilities Education Act (IDEA) reauthorization.

During this election year, promote public awareness and advocacy by meeting with local and state candidates, as well as elected officials, and let them know what programs and services are most important for our children and families. No project is too big or too small. Every piece of advocacy sends a message.

To highlight "National Down Syndrome Awareness Month," parent groups all over the country have used a variety of creative strategies to promote public awareness locally and statewide. Here are some successful ideas from previous years.

- * Press Conference (capitalize on proclamations)
- * Public Service Announcements
- * Articles for newspapers and magazines

- * Posters (libraries, schools, doctor's offices, churches, malls)
- * Presentation of awards to teachers, employers, writers, etc.)
- * Interviews on radio and television
- * Talks at schools and other community organizations
- * Fund Raisers
- * Donations of good books on Down syndrome to libraries
- * Special promotional calendars, notecards, etc.
- * Concerts, book fairs, and information booths at shopping malls

As a kick off for the events celebrating October, 2004 as "National Down Syndrome Awareness Month," you are invited to use this proclamation form as a strategy for regional and local public awareness. You can ask your elected state and local officials, such as the mayor of your city or the governor of your state or school board president, to sign on to this proclamation. Every signing creates an opportunity for media coverage and heightened public awareness. These events also provide an opportunity for people with Down syndrome to represent themselves.

PROCLAMATION in recognition of National Down Syndrome Awareness Month

WHEREAS, citizens who have Down syndrome are active citizens who contribute much to the overall quality of life in this community; and

WHEREAS, greater public awareness and acceptance of these persons will increase their access to education, community housing, employment, and social and recreational opportunities; and

WHEREAS, it is the desire of our community to create a place where all people can explore and develop their various abilities, can enjoy productive work, and can contribute by meaningful participation in the life of the community; and

WHEREAS, _____ (person of local organization), on behalf of the Down Syndrome Association of Atlanta, has worked to secure this proclamation; and

WHEREAS, it is the goal of _____ (state, county or municipality) to instill positive perceptions of people with Down syndrome;

NOW THEREFORE, I _____ (official) do hereby designate OCTOBER 2004 NATIONAL DOWN SYNDROME AWARENESS MONTH

and enjoin all our citizens to promote positive awareness and greater opportunities for persons with Down syndrome and challenge the citizens of our community to look beyond a person's particular disability and focus instead upon each person's diverse abilities and varied contributions to the community,

In Witness Whereof I have set my hand and seal this ____ day of _____, 2004.

(Editor's Note: This proclamation has been adapted from the sample proclamation of the National Down Syndrome Congress printed in October 1996)

September Birthdays

Nicholas Abrams	Jordan Huffman	Kendall Salmon
Caroline Albee	RJ Jennings	Jack Samitt
Lainey Carroll	Cameron Kindree	Nicholas Stubbs
Amber Dawn Clifton	Nicholas Lee	Kimberly Villanueva
Skyler Corliss	Zana Lumpkin	Justin Walker
Gracelen Easterwood	London Mayo	Carli Walters
Cameron Fernandez	Simon Mireless	Gavin Wise
Harry Gilcreast	Santino Monroe	
Jonathan Gross	Patrick Morrow	
Caleb Guy	Paul Partus	
Andrew Hall	Lauren Peterson	
Miles Henderson	Samuel Pearl	
Corey Hodge	Cole Plugge	
Audrey Huddleston	Bruce Riley	

October Birthdays

Gabrielle Allen	Patrick Essen
Bobby Aniekwu	Elizabeth Griner
Alfredo Arredondo	Erin Jarrell
Lou Bontempo	Mary Elizabeth Jarvis
Daniel Bryant	Olivia Kennedy
Bradley Carlisle	Lauren Maddux
Benjamin Collins	Mary Jo McElwe
Jessica Davidson	Mike McLemore
Lailana Duncan	

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