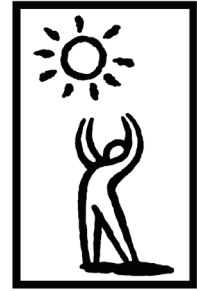


DOWN SYNDROME ASSOCIATION OF NORTHERN VIRGINIA



September, 2007

Buddy Walk 2007—It's Gonna Be Great!

Upcoming Events

details: www.dsanv.org

September 29

Communication Workshop

October 6

Annual Pumpkin Pick Numbers 13 Farm
numbersthirteenfarm.com

October 13th

Buddy Walk
Fairfax County Government Center

October 25

Autism Society Workshop

November 17

DSANV Fashion Show
Details to come

Have you put together your Buddy Walk Team yet? The Third Annual DSANV Buddy Walk will kick off at 10am on Saturday, October 13 at the Fairfax County Government Center Ellipse in Fairfax, Virginia. The event is a gentle, flat walk around the grounds of the Center, followed by a non-stop, fun-filled day of activities for all ages. The 2006 Buddy Walk was an enormous success, raising \$172,000, a 45 percent increase from 2005. Estimated attendance at the walk was 1,600. Let's keep up the good work!

The 2007 Walk will be loaded with as much fun and excitement as last year's. Cheryl Maynard, the DSANV Buddy Walk organizer, encourages everyone to come out and enjoy the fun. "We've got great activities and entertainment with lots more to enjoy for everyone, including older kids, teens and adults with Down Syndrome." This year's entertainment is Travis Tucker and his band, Millenium. Travis was one of the top 12 finalists on the 2004 season of *American Idol*. Walkers also will have the

chance to participate in a variety of new and exciting features: a five-person rock-climbing wall, two moon bounces, and a Special Olympics soccer station from 11 am to 1 pm. After the soccer station, there will be two scrimmages: girls with Down Syndrome against DSANV Moms, and boys with Down Syndrome against DSANV Dads. There also will be a nine-hole putt-putt golf course, run by local Special Olympians with an expertise in golf. In addition, walkers will enjoy performances by the VSA of Virginia, and the popular displays of law enforcement vehicles and equipment and race cars.

Most importantly, the Buddy Walk raises awareness and much-needed funds so that all people with Down syndrome in Northern Virginia can reach their full potential. Cheryl Maynard encourages everyone to join in. "Don't wait – grab some buddies and form your team today!" For information or to volunteer, contact **Cheryl Maynard** at cherylm@dsanv.org.

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Your Input Needed for Research

As separate inserts inside this newsletter, you'll find two surveys that will provide valuable input for ongoing research related to Down syndrome and medical care. Please read this letter from the researcher, and follow instructions accordingly.

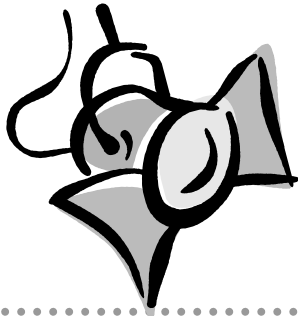
A Message from Researcher, Megan Lohr

(University of Virginia School of Medicine, Class of 2010)

The purpose of this research is to gain a better understanding of the experiences of individuals with Down syndrome and their families with regard to the transition from pediatric primary care to adult primary care medicine.

This research involves asking adolescents and young adults with Down syndrome and their families to answer survey questions about their transition experiences. By compiling the responses to the surveys, I hope to be able to identify several specific and practical ways in which primary care pediatricians and adult health providers can improve the transition process for their patients with Down syndrome.

(cont'd on page 2)



Two Local Kids Make the Big Time

Samantha Bates of Arlington and Logan Gross of Stafford, will appear in lights on Broadway on September 30, as part of the National Down Syndrome Society's video production to demonstrate that people with Down syndrome can be a vital part of their communities. Approximately 215 photos will appear in the video; Samantha and Logan were chosen from over 2,500 entries. The video will be shown on the larger-than-life Newscorp Astrovision by Panasonic, located in the heart of Times Square. Panasonic has donated 40 minutes of time on the Astrovision to show the video that will kick off National Down Syndrome Awareness and Buddy Walk 2007, which includes more than 275 walks in the U.S. and abroad.

Communication Workshop

DSANV presents a workshop with Dr. James MacDonald, *A Communicating Partners Workshop — Social and Communication Development from Early Play through Civil Conversations*. The workshop will be held on Saturday, September 29, from 8:30 am to 4:30 pm at Immanuel Bible Church – Terrace Rooms, 6911 Braddock Rd, Springfield, VA 22151.

Dr. MacDonald, Professor emeritus in Communication Disorders and Developmental Disabilities at the Ohio State University, has been researching, teaching and developing evidence-based programs for communication disorders and delays for over 30 years. He has clinically served over 1000 families of children with Autism, Down syndrome, Aspergers, Apraxia and other "late-talking conditions". In Dr. MacDonald's view, social isolation and failures in building relationships are the major consequences of many communication disorders. Come hear how over 1,000 parents and professionals have helped to ensure that each child has life-long communicative relationships that are interactive, verbally and nonverbally communicative, conversational, and socially appropriate.

Register early as seating is limited. A certificate of attendance will be available for those who need documentation for continuing education purposes. No childcare will be provided. If you require special accommodations or have other questions, email educationcommittee@dsanv.org or call (703) 621-7129.

Dr. MacDonald has written six books and directs the Communicating Partners Center and invites families for individualized program planning. For more, see www.communicatingpartners.com.

Research Project *(cont'd from page 1)*

If you would like to participate in this research, please complete the surveys following this introduction. There are two surveys, one is specifically for parents and the other is for adolescents and young adults with Down syndrome. If you think that your son or daughter would like to participate, and you feel that would be appropriate, please have them complete their survey after the parent survey has been completed. If they request your assistance with the survey, please feel free to assist them. Both surveys are completely anonymous and participation is voluntary. You can mail the completed surveys to:

Megan Lohr, 122 Oakhurst Circle #4, Charlottesville, VA 22903

The surveys can also be completed online by going to the website <http://people.virginia.edu/~mel5b>

Ultimately, this research will greatly benefit those with Down syndrome, their families, and their primary care physicians. If pediatricians were more aware of the unique needs of their patients with Down syndrome, they could better prepare them for the transition to adult care. Similarly, with more information, adult health providers could better anticipate the needs of their new patients, making the transition smoother.

Thank you very much for your time and assistance with this research. If you have any questions or concerns, please don't hesitate to contact me at meganlohr@virginia.edu.

National Down Syndrome Congress National Convention—My

Experience by *Heather Trammell, DSANV
Board Member*

I recently attended the National Down Syndrome Congress National Convention in Kansas City. What a great opportunity to gather information, network and be inspired! I attended the all-day Pre-Conference called "Creating Classroom Success for Students with Down Syndrome" by Susan Peoples, whose seminar content reminded me how Down syndrome affects **every** area of learning for our students.

For our opening session on Friday evening, the attendees were treated to a western welcome! Carlene Matson, second vice president, captured a great goal for us parents: "We are making the world a better place for our children because our children are making the world a better place". Self advocate Audrey Wagnon expressed what is surely a common goal for our kids: "Every day is the best day of my life". Later that evening, I went to the silent auction where I met really nice people, among them Karen Gaffney and her mom, who were so generous to share their time and thoughts with me in preparation for our recent Non-Public School Options program.

Saturday morning's first keynote speaker was Ann Turnbull of the Beach Center on Disability. She spoke on "Enhancing Family Quality of Life: Thinking and Acting Wisely". She was very well received discussing the important pieces of the puzzle for our disabled family members: research, family quality of life, family support, evidence-based action, communities of practice, and partnership with national organizations like NDSC. Then Karen Gaffney spoke about her swimming adventures, particularly her next adventure: swimming Lake Tahoe. Her desire is to be a part of "rewriting the data" on the too often accepted limitations that accompany Down syndrome.

I attended a breakout by Ann Turnbull on the Communities of Practice idea that the Beach Center is developing. It was a lively and enlightening roundtable discussion of how this online resource could be enhanced to be the most supportive place for families in need. My afternoon session was on "Moving from the Elementary to the Middle/Junior High School: Transition Tips and Other Strategies." It's important to think through this transition earlier than most schools. This session identified challenges and gave tips on how to meet those challenges.

(cont'd on page 4)

President's Letter

Dear Friends and Family,

It's that time of year again—the Buddy Walk is almost upon us. On Saturday, October 13, we will walk in the Northern Virginia Buddy Walk to show our support for the more than 350,000 individuals with Down syndrome in the United States. Every step we take, every dollar we raise, will help ensure that each individual with Down syndrome in the United States will be able to reach his or her full potential. Last year alone, over \$6.5 million dollars was raised nationwide for local and national education, research, and advocacy programs.

This is our largest event of the year and a time for us to show off what our group does and, more importantly, what individuals with Down syndrome are truly capable of. We hope you can join us to walk as guest stars, politicians, cartoon characters, Board Members, Special Olympians, friends, and family there to support us. You can make a difference for people with Down syndrome in our community and help the Down Syndrome Association of Northern Virginia.

This year we are trying to set new records with our larger than life fundraising target so we can expand our programs again in the coming year. Together we can support ALL of the individuals with Down syndrome, and their families who live in Northern Virginia.

But that takes money, volunteers, education, programs, etc. The money raised by the Buddy Walk will enable us to meet the community's needs. We need your help. Form a team, donate money, give your time. We can't wait to see you on the 13th.

Phil, Adrienne, Lena, Caleb, and Ethan Pedlikin

Phil Pedlikin, *President, DSANV*
philp@dsanv.org

CONTACT US

P.O. Box 364, Lorton, VA 22199
703-621-7129 www.dsanv.org

Autism Society Workshop

The Autism Society will host a special education law and advocacy workshop featuring Pete and Pam Wright of Wrightslaw.com. The workshop will be held on Thursday October 25 at McLean Bible Church from 9 am to 4:30 pm. The Church is located at 8925 Leesburg Pike, McLean, Virginia. The workshop will be in Conference Room C. Early bird registration fee is \$75 for parents/advocates, \$105 for couples, and \$90 for professionals. The fee includes two books by Pete Wright and lunch. Exhibiting opportunities are available for \$75. For more information, visit the ASA-NV at www.asanv.org.

Taken Out to a Special Ball Game

In June, Meredith Cripe, a DSANV member from Chantilly, met President Bush in a ceremony on the White House lawn, in recognition of special needs sporting opportunities.

Meredith assisted the President in throwing out the first pitch for the softball game on the lawn; she also thoroughly enjoyed her private tour of the White House and a lunch reception. Meredith has played second base for the Chantilly Youth Association Challenger's Tee Ball team since 2004 and is now a fifth grader at Willow Springs Elementary school.

Send us your news!

We want to hear from you, our members. Send us news -- learning to sign, toilet training, graduations, first steps, first jobs -- you name it. We want to share with the DSANV community your accomplishments and triumphs. Email the editor at newsletter@dsanv.org

Conference (cont'd from page 3)

Our afternoon plenary sessions included a presentation by the author of "The Memory Keeper's Daughter" along with a passionate review of how current IDEA laws affect our kids by Chicago attorney, Matt Cohen. Our self-advocate address was from author Creighton Wall (Holdredge, NE). He captured a little piece of my Beth. "Without music my life would be boring. I don't do boring."

Sunday morning's keynote speaker, Pat Bauer, spoke on the ethical implications of prenatal diagnosis. She gave some good action points we could take as well as some wonderful quotes (see two in the box below). My noon breakout discussion was led by NDSC staff on responding to the new ACOG guidelines on prenatal testing. Way too small a room for the impassioned discussion going on. The NDSC really wants to put together a task force to help implement some key strategic responses.

Memorable (and re-usable) quotes from the conference

"I graduated from the University of [insert your child's name]."

"No child is normal, and neither are we."

Nuts and bolts-wise, the conference seemed to run smoothly: registration was well organized, great hotel and hotel staff, and volunteers were easy to identify and friendly. The Down Syndrome Guild of Greater Kansas City did a good job of recognizing their conference sponsors. Babies were everywhere (NDSC is very accommodating this way)! I was most impressed by the simultaneous translation of the plenary sessions into Spanish. NDSC has increased their participation of Latino families by 84 percent this past year.

If you're looking to network with professionals in the field, other families, and learn the latest about Down syndrome, consider attending the 2008 NDSC conference in Boston.

DSANV's Mission...

...to ensure that all individuals with Down syndrome and their families receive the support necessary to participate in, contribute to, and achieve fulfillment of life in their community.

