

CONNECTIONS

Collaborative effort a success despite cold, rainy weather

By Gena Mitchell, DSNMC member

March 30th, 2014 marked the first annual Race for Respect 5K and Kids Dash for Down syndrome awareness! It was a wonderful beginning to a DC metro partnership between the eight surrounding Down syndrome parent groups.

The participating parent groups included: the Down Syndrome Network of Montgomery County, Northern Virginia Down Syndrome Association, DS connection (Ann Arundel), F.R.I.E.N.D.S of Frederick County, the Chesapeake Down Syndrome Parent Group, the Prince George's County Parent Group.

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The first annual Race for Respect 5K drew some 800 registered runners to Washington, D.C. despite cold, rainy conditions.

JUNE 2014

Mark your calendars for TFS

2014 Buddy Walk Update

Sights from the 2014 Winter Dance

News and upcoming events

The advocacy experience

Affiliates in Action conference

Buddy Walk on Washington: Strength in numbers

By Vittoria Aiello, DSNMC Board Member

The Buddy Walk on Washington is a powerful and inspiring experience. It is powerful because people from all across the U.S. join together in an effort to advocate for better life conditions and better health for people with Down syndrome.

And, as we all know, unity is strength. It is inspiring because it gives participants a chance to meet people who, although from different

backgrounds, are all motivated by the same passionate belief that making the world a better place for people with Down syndrome is not only necessary, but attainable.

One of the priorities on the 2014 legislative agenda was the Achieving a Better Life Experience (ABLE) Act.

The ABLE Act would allow parents of

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President's Letter

Guess who's turning 10 years old this year? That's right, this year marks the 10th anniversary of DNMC's annual Buddy Walk, and we hope that this year's celebration will be the biggest yet. The Buddy Walk will be held on Saturday, Oct. 11, at Hadley Park so make sure to save the date. The event is DSNMC's biggest fundraiser and is an opportunity for us to come together as a community with family and friends to celebrate our family members with Down syndrome.



Planning for this year is underway and we need a dynamic Buddy Walk Committee to make the walk happen! In honor of the 10-year anniversary we are asking if you can pledge 10 hours of service to help DSNMC. In addition to working with and getting to know other members better, all 10-hour volunteers will be recognized at the race. Below are some of the ways you can help:

- **Food donations** – Contact vendors to secure food donations for the event, contact various grocery stores/warehouse stores to see if they will donate gift cards, contact restaurants for food donations.
- **Media** – Do you have media contacts that would help us publicize the event or cover the day's activities? Help submit information to advertise in the "local events" sections of various papers. Help with social messaging.
- **Sponsors** – Contact existing sponsors to see if they will continue to support this year's event. Contact new sponsors to obtain their support. Get logos and other information from sponsors so we can recognize their support.
- **Prizes** – Contact organizations/individuals for donation of possible prizes such as tickets, electronics, gift cards, etc.
- **Vendor Tent** – Contact companies who may not be able to sponsor but would like to pay to present their services at the Buddy Walk
- **Race logistics** – set up; clean up; setting up activities for the teen, elementary and pre-k tents; stuffing race packets; helping with registration

The Buddy Walk Needs you!

To volunteer lend your support to DSNMC's most important fundraiser, contact Kathy Myers at: Kathy@dsnmc.org

The best way you can help is to plan to set up a team and raise funds. The Buddy Walk is vital to our success as an organization and allows us to provide the social, advocacy and educational opportunities we do throughout the year. There is no better feeling than knowing that you helped to bring over 700 people together as we did last year.

We look forward to celebrating with everyone on October 11!

Kathy

Affiliates in Action: Conference full of innovative ideas

By Leslie Bisignano, VP, Board of Directors

The 2014 Down Syndrome Affiliates in Action Leadership Conference was held in Washington DC, February 28 – March 2. The Down Syndrome Network of Montgomery County sent a delegation to the conference to discuss issues of concern and share best practices with leaders from Down syndrome groups across the nation with the shared goal to provide new and improved services to those affected by Down syndrome.

Sponsored by the Global Down Syndrome Foundation and the National Down Syndrome Society, the conference was attended by members of the more than 80 affiliated Down syndrome organizations. DSNMC's delegation included Board President Kathy Myers, Vice President Leslie Bisignano, Board Member and Education Committee Chair Heather Sachs, Board Member Vittoria Aiello, Board Member Ricki Sabia and Past President Gena Mitchell.

Topics of discussion included donor and volunteer retention, hiring and evaluation of professional staff, upcoming changes in state alternate assessments and instruction, strategic planning, various management software analyses and comparisons, Federal legislative updates, medical outreach best practices and customer service presentations.

The session entitled, *"Upcoming Changes in State and Alternate Assessments and Instruction: A Toolkit for Your Families"* was presented by DSNMC Board Member Ricki Sabia. IEP meetings will soon be held to make participation decisions regarding newly developed alternative assessments for the 2014-15 school year. This

presentation was developed to help families prepare for these assessments and understand how the new Common Core State Standards could impact children with Down syndrome. Attendees received a tool kit of parent-friendly documents designed to help families be informed advocates for their children as these educational changes occur.



A presentation entitled, *"Maximizing the Fundraising Potential of Your Donor Database"* presented by Firespring CEO Jay Wilkinson provided insights into the factors to consider in selecting a donor management tool, how to turn data into actionable efforts to increase

the donations to the organization, and strategies for how to really get to know your donors.

In addition to 2½ days of sessions, nearly 30 exhibitors whose customers include the Down syndrome community were on hand to share their resources and products.

Representatives from the National Institutes of Health were also on hand to present a session about DS-Connect, the web-based health registry that will serve as a national resource for people with Down syndrome, their families, researchers, and health care providers. The NIH representatives even assisted attendees in joining the registry while at the conference!

The DSNMC delegation returned from the conference energized with new ideas and approaches to continue to advance the mission of our wonderful organization!



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Race for Respect: Getting local DS parent groups together

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Southern Maryland Down Syndrome Association, and Greater Richmond Down Syndrome Association. This is the first time this many groups have collaborated on one initiative and what a success it was -- despite the chilly temperatures and rainy weather!

The goal for the Race for Respect (R4R) was to create AWARENESS for Down syndrome and what better way to do this than to stop traffic in our Nation's Capitol?

As a first year event, we were thrilled to have Laura Evans from Fox5 as our Mistress of Ceremonies. Laura's support of our community is incredibly appreciated and was evident in her kind and heartfelt remarks.

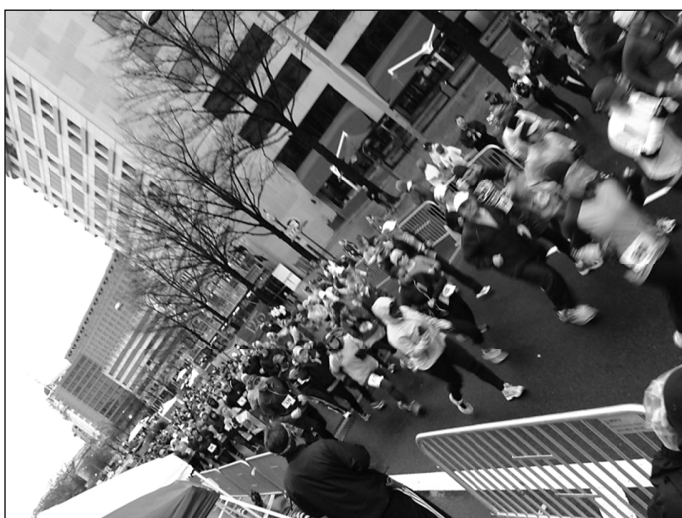
We were also joined by Congresswoman Eleanor Holmes-Norton from Washington, DC. The Congresswoman spoke to all of the hot topics such as The ABLE Act and community support and outreach. Her understanding as a parent off a child with Down syndrome was poignant and so very thoughtful. Not to mention that it was wonderful to hear from someone advocates for our children on Capitol Hill every day!



Our final speaker was Madison Essig. Madison is a sophomore at Woodrow Wilson High School in Washington, D.C., and her comments on what it means to treat someone with Down syndrome with respect and dignity will certainly remain with each of us! Jackie Zamora from ZAMDANCE gave us a killer warm up and right before the starting gun went off, Davis Gesteihr wowed us with his rendition of the national anthem and Davis' sister, Madison Gesteihr, signed the anthem beside him.


As the race director, I have been contacted by countless runners and volunteers, who have commented on the amazing atmosphere at the Race for Respect. Things like, "I have never seen such camaraderie at a race before." "As a volunteer, I was blown away by the kindness and appreciation by the runners." "I have never seen a group of people-volunteers and runners-with a more positive attitude under such harsh weather conditions." This speaks volumes of our community. I have to say that I was freezing by the time I went home, but without question I was elated with the success of the event. The view of the capitol and the monuments was amazing. We had close to 800 registered runners and even with the frigid temperatures, more than half showed up to run.

Believe it or not, we have already begun planning 2015's Race for Respect and I am certain the race will continue to grow each year. I look forward to seeing you next year!!



Want to help plan for Race for Respect 2015? Contact Gena at: gena@dsnmc.org

Community FIRST



EagleBank is proud to support the Down Syndrome Network of Montgomery County 2013 Buddy Walk.

We applaud this non-profit organization for its dedication to the families of children, teens and adults with Down syndrome.



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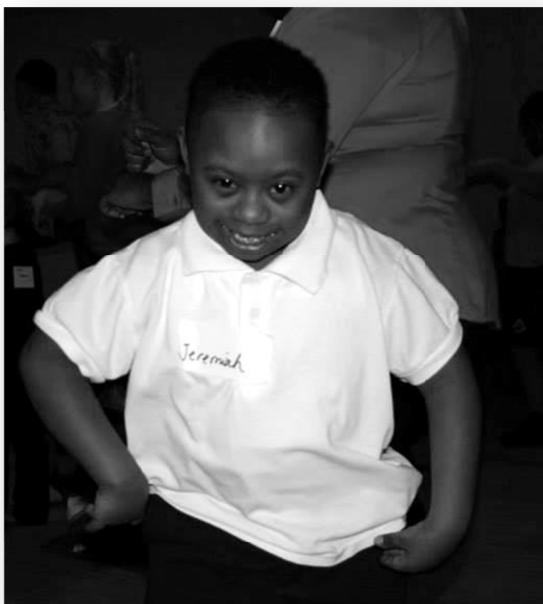
**Race for Respect
Washington, D.C.
March 30, 2014**





DSNMC
Winter
Dance

Feb. 1, 2014
Long Branch Community
Recreational Center



Techniques for Success 2014: Save the Date



Please save the dates for the 6th Techniques for Success (TFS) conference. TFS, sponsored jointly by DSNMC and F.R.I.E.N.D.S. of Frederick, focuses on practical strategies for educating students with Down syndrome and those with other special needs. TFS for Parents is scheduled for Friday, October 24, and TFS for Educators for Saturday, October 25. Both events will be held at the Holiday Inn in Frederick, MD. **Please save the date and ask staff at your child's school to do the same!**

For the past 6 years, TFS has spread up-to-date knowledge about Down syndrome and effective teaching practices within our school system. The specific topics change each year so it is worthwhile for past attendees to return. Almost 100 parents and 300 educators joined us for last year's conference.

The TFS Planning Committee is working to finalize the program of nationally-recognized speakers for the 2014 conference. We have confirmed that the dynamic **Stacy Taylor** will return to address behavioral challenges in educational settings. Participants will also have the opportunity to hear from **self-advocates** about their educational experiences. Watch the TFS website for details as they become available: <http://techniquesforsuccess.org/>. Registration will open in the late summer.

Parents will again have the opportunity to support TFS while honoring their favorite educators through the Favorite Educator Sponsorship. Watch the DSNMC listserv for details about how to become a sponsor.

If you have an interest in helping with TFS, please contact Heather Sachs, TFS Planning Committee Co-Chair, to discuss possibilities. Heather can be reached at heather@dsnmc.org. Help is needed and appreciated for large and small tasks.

TFS Save the date!

TECHNIQUES FOR SUCCESS CONFERENCE

When: Friday, Oct. 24 – Saturday, Oct. 25

What: Evening session for parents on Friday followed by a day-long conference for educators on Saturday.

Where: Holiday Inn Frederick
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DS Advocacy: Buddy Walk on Washington

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children with disabilities to save for their children's future. Currently, people with disabilities cannot hold more than \$2,000 in assets and their monthly income must be very low in order to qualify for federal benefits. The ABLE Act would create a new subsection (f) ABLE account within Section 529 of the Internal Revenue Code to allow families to create tax-advantaged saving accounts of up to \$100,000 for qualified disability expenses.

The ABLE Act has received unprecedented bi-partisan support in the Congress: at the time of this year's Buddy Walk, 401 congressmen had cosponsored it. The ABLE Act bill has also received significant media coverage with articles recently appeared on national newspapers, like the *New York Times* and the *Washington Post*:

<http://tinyurl.com/pymlz23>

<http://tinyurl.com/n8h5kfa>

Another priority on the legislative agenda was requesting the House Energy & Commerce Committee to convene a hearing on the intersections between Down syndrome and Alzheimer's disease. People with Down syndrome are at increased risk of developing Alzheimer's disease. Also, they develop it at a much younger age. By age 40, a full 40 percent of people with Down syndrome will develop the disease, and by age 50 that rises to 50 percent. While not everyone with Down syndrome develops the symptoms associated with

Alzheimer's disease, all develop changes in their brains (plaques and tangles) typical of the disease. Those changes start at a very early age in people with Down syndrome. One of the questions researchers are trying to answer is why 50 percent of those with Down


syndrome do not ever develop dementia even though they do develop plaques. Understanding the connection between the two conditions might help untangle the Alzheimer's puzzle and, thus, lead to more effective treatments for this dreaded disease. Thus, advocates at the Buddy Walk requested a House Energy & Commerce hearing on the intersections between Down syndrome and Alzheimer's disease in order to yield attention to these important issues for people with Down syndrome and ultimately ensure that the Department of Health & Human Services, the National Institutes of Health, industry, and other stakeholders provide appropriate investments in these areas.

At this year's Buddy Walk, I lead the Maryland delegation, which was the most numerous delegation we ever had: 47 people. I was very impressed with the passion and determination showed by everyone, especially by the self-advocates: ambitious, young adults eager to let their representatives know about their passions, their needs and their dreams. I was also very pleased to see several siblings participating to the event. They talked to the congressmen about the positive impact the ABLE Act would have on their life as siblings of a person with Down Syndrome. It was truly inspiring. Siblings are a crucial part in the life of people with Down Syndrome: their support, advocacy and encouragement make all the difference in their life.

**By age 40, a full 40 percent of people
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by age 50 that number increases to 50 percent**

BUDDY WALK ON WASHINGTON 2014 sponsors



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Self-Advocacy: New Program met with rave reviews

By Ricki Sabia, DSNMC board member

In November 2013 DSNMC launched a series of inclusive self-advocacy and public speaking workshops for teens and young adults with Down syndrome and their peers (ages 15-30). These workshops are led by an instructor from ArtStream and were designed for the Artstream Leadership program (www.art-stream.org). They are fun, interactive sessions based in the arts and do not require participants to have prior experience or a particular level of communication skills.

The primary goals of the workshops are for participants to learn/practice skills and build confidence while having fun and making new friends. It is also our hope that most of the participants will become more comfortable and effective when communicating in their classes, at IEP meetings, at their jobs and in social situations. In addition, it would benefit the DSNMC community if a greater number of self-advocates felt comfortable talking to policymakers and/or groups of educators and students. There are self-advocates who have had these experiences and are mentors for the others.

During the two-hour workshops, the parents have the option of meeting for coffee and conversation. It is a great opportunity for parents of teens who are starting

their transition to adulthood and parents of young adults to share information and experiences. Funding for supported employment and numerous bills in the Maryland General Assembly were discussed at the most recent parent meeting. The program has been a success thus far, as the following email indicates:

What a wonderful program both for our young adults and for us parents (moms)! Charlie really enjoyed the activity and I think he probably learned a lot more than he realizes. I know I learned a lot and truly benefited from the interactions and info you provided. It's funny how some of us will make time to go out with our child when they have an event, but are more reluctant to go out without them. Nice, all around!

Thank you, thank you, thank you,

Nancy

Three more workshops will be held in 2014, as well as one or two social activities for this age group. Check the DSNMC listserv for details as they become available. For more information contact Ricki Sabia at: ricket@dsnmc.org

DSNMC Annual Egg Hunt



Federica Aiello, right, finds an Easter egg during the DSNMC play group's annual egg hunt at Cabin John Park in April. On the left, the group poses for a celebratory pic after a loading up on eggs filled with stickers, candy and other treats.





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is to be there for ourselves.

Anonymous

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Advocacy Update: Updates from D.C., Annapolis

DSNMC members' efforts help push key legislation through at state level

By Patricia Montilla Keeling

This past February I had the opportunity to be part of a couple of important advocacy efforts that will have a tremendous impact on the lives of people with Down syndrome. I participated in an effort to pass the SB 654 Down Syndrome Information Bill at the state level in Annapolis, Md., and attended the Buddy Walk on Washington to support the ABLE act at the Federal level. Both experiences were rewarding and allowed me not only to learn but to meet others passionate about improving the lives of individuals with Down syndrome.

When Heather Sachs, advocacy Chair for the Down Syndrome Network of Montgomery County (DSNMC), asked me if I would be willing to testify either in person or by writing my testimony for the SB 654 Bill, I jumped at the chance. Even though I am not the best at public speaking, I decided I would testify in person in front of a panel of senators assigned to hear about our bill.

This cause was very close to my heart because as a former Vice President and co-chair for the professional outreach committee for DSNMC, my focus was to develop a program designed to make sure health care professionals provided accurate information about DS to their patients. Having talked to many parents in the Down syndrome community and hearing their personal stories about how their diagnosis was delivered in an inaccurate and/or undesirable way, I knew firsthand the desperate need for this legislation.

Health care professionals have a responsibility and duty to provide their patients with the best care. That means providing the most up-to-date and accurate information about Down syndrome should be a requirement. When Gov. Martin



DSNMC members Patricia Montilla Keeling (far left), Heather Sachs (middle left) and Gena Mitchell pose with Rep. Cathy McMorris Rodgers (D-Wa.).

O'Malley signed this bill into law on May 7, healthcare professionals were now required by law to provide accurate information.

My experience going to Annapolis was not only an advocacy effort to support a good cause, but also a very enriching and learning experience about the legislative process and how it works. It was very gratifying to see how as constituents, we have a voice and can make changes if we work together to advocate for our community.

Andrea Garvey from the Maryland Catholic Conference, and Heather Sachs from The Maryland Down Syndrome Advocacy Coalition and DSNMC were leading this effort and did a phenomenal job explaining to me the bill and the process it had to go through to pass as a law.

As my time came to testify, and with only 3 minutes to make my case in front of the panel, I spoke with conviction about my personal experience and made a strong case about the importance of this law and the impact it would have in our community. To my satisfaction, I felt I had stated my case and the senators seemed to be receptive. I can't emphasize strongly enough the importance of working together as a community to produce positive change -- I witnessed it firsthand.

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Advocacy Updates: A First-Hand Account

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Being part of the Buddy Walk on Washington sponsored by the National Down Syndrome Society (NDSS) was also a wonderful experience. I enjoyed meeting other parents and self-advocates from all over the country and learning about the ABLE Act and the impact it will have on my son's future if it passes as a law. The passing of this act will allow individuals with Down syndrome to save money and be active contributing members of the community without jeopardizing their disability benefits.

As a member of the Maryland delegation I had the opportunity to meet with our congressmen to ask them to co-sponsor our bill or thank them if they had already done so. I particularly enjoyed meeting with Congressman Chris Van Hollen because he continues to champion the Down syndrome cause.

I had the privilege to be present when he was given an award on behalf of NDSS and our delegation for his work and support serving the needs of the disability community. The ABLE act has so much bipartisan support in Congress and in the Senate that I am very optimistic it will pass fairly soon.

Undoubtedly, advocacy requires time, effort, and patience, but to see the hard work pay off when the bill finally passes makes it all worth it. I urge you be an active participant too. Trust me, there is nothing more gratifying than helping to pass a law that will impact the future of our children with DS.

To learn more about SB 564, the details of the vote and what it means for the Down syndrome community, visit:

openstates.org/md/bills/2014/SB654/

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DSNMC EVENTS

Play Groups

The groups will meet from 11:00 a.m. - 1:00 p.m.

Play groups meet once a month and details are posted on Facebook and available via the listserv. For more information, contact:

Vittoria Aiello
P: 301-272-0311
email: vittoria@dsnmc.org

DSNMC Summer Picnic

Saturday, June 29 from 11 a.m. - 2 p.m.

Location: Black Hill Regional Park, Picnic Site I

Contact: admin@dsnmc.org

For the latest
information and details
on all DSNMC events
and news
dsnmc.org

Coffee and Conversation

Tuesday, June 10

Time: 10:30 a.m. - 12:00 a.m.
Location: Caribou Coffee, Westfield
Montgomery Mall
Bethesda, Maryland

Coordinator: Karen O'Connor
301-972-5138 or tkrbmo@verizon.net

SAVE THE DATE

Buddy Walk 2014

Saturday, Oct. 11

Falls Road (Hadley's) Park, Potomac, Md.

Contact: Kathy@dsnmc.org

Techniques for Success

TFS for Parents - Friday, October 24

TFS for Educators - Saturday, Oct. 25

Holiday Inn - Frederick, MD

Contact: heather@dsnmc.org

Children and Young Adults with Down Syndrome Have a Story to Tell!

Researchers at the NIH are conducting a research study on brain development and learning in children and young adults with Down syndrome. All procedures (including brain imaging, learning and memory testing) will be completed on an outpatient basis at the NIH Clinical Center and may be completed over 4 visits. Each visit will take between 4-8 hours. Children and young adults may be eligible to participate if they are between 3 and 30 years old and have a confirmed chromosomal diagnosis of Down syndrome.

Volunteers will be compensated for their participation. Parent or legal guardian, child, and young adult must agree to participation. There is no charge for research procedures and evaluations.

For more information, contact:

Nancy Raitano Lee, Ph.D. at 301-435-4520 or TTY: 1-866-411-1010
email: LNANCY@MAIL.NIH.GOV



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