

CONNECTIONS

WORLD DOWN SYNDROME DAY

By Christiane Aquino, DSNMC Parent

This is the second time the United Nations officially celebrates World Down Syndrome Day in recognition of a UN resolution proposed by Brazil and supported by 80 countries to designate 21 March annually as World Down Syndrome Day (WSD - A/RES/66/149). This year's motto was the "Right to Work", inspired by Article 27 of the UN Convention on the Rights of Persons with Disabilities (UNCPRD), which states: "States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities."

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BUDDY WALK ON WASHINGTON

By Allison Wohl, DSNMC Parent & Executive Director, CPSD

NDSS hosted its annual Buddy Walk® on Washington on March 13 – 14 in Washington, DC. The two-day advocacy event brought over 220 individuals from across the country to our nation's capital to advocate for legislative priorities that positively impact the lives of people with Down syndrome and their families. Advocates from the Down syndrome community met with more than 300 members of Congress to bring our issues to the forefront of their agendas. On Wednesday, March 13, NDSS hosted an advocacy training session to help advocates prepare for

their Congressional visits the next day. The training session included an exclusive event for self-advocates entitled NDSS Self-Advocates Speak Out hosted by the NDSS Self-Advocate Advisory Board (SAAB). During our training session, Jim Nussle, a current NDSS Board Member, former U.S. Representative and former Office of Management and Budget (OMB) Director, provided keynote remarks about "Making Your Voice Heard" in our nation's capital.



APRIL 2013

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Upcoming Events
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Winter Dance

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Board of Directors

Gena Mitchell, President
gena@dsnmc.org

Leslie Bisignano,
Vice President
leslie@dsnmc.org

Aaron Cohen, Treasurer
aaron@dsnmc.org

Vacant, Secretary

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christine@dsnmc.org

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adrian@dsnmc.org

Karen Gee
karen@dsnmc.org

Mimi Gehres
mimi@dsnmc.org

Chris Hicks
chris@dsnmc.org

Kathy Myers
kathy@dsnmc.org

Ricki Sabia
ricki@dsnmc.org

Heather Sachs
heather@dsnmc.org

Newsletter Editor:
Elizabeth Totah
elizabethwt@dsnmc.org

Administrative Support:
admin@dsnmc.org

Buddy Walk:
buddywalk@dsnmc.org

www.dsnmc.org
301-979-1112

President's Letter

In February, two board members and I attended the Down Syndrome Affiliate in Action conference where they had a wonderful speaker, Bill Clemente. Bill is a three-time Stanley Cup champion who has written a book about every day leaders. His discussion topics resonated with me as I reflected on our membership and our everyday lives.

Exude positive energy, not negative. Whether we are communicating with our children or handling service needs with the school system or county, positive energy breeds positive outcomes. DSNMC has had great success within our community by engaging other groups in a positive way. That does not mean we do not address conflict or issues that are in need of a solution. It simply means that we have the opportunity to make change, and it is more likely to occur when we do not focus on the negative but instead seek solutions.

Be a giver, NOT a taker. I think there are times that we fall on both sides of this; but, if we consistently exhibit behaviors of extreme giving or extreme taking, it causes unbalance. Always being a giver causes burn out and can lead to being taken advantage of. Always being a taker prevents the opportunity to share the positive energy and the personal reward of giving, and we can alienate ourselves. The balance of giving and taking helps us have a positive self-image, allows us the opportunity to maximize our membership of any community, and supports our ability of being a member of any community.

Focus on the shared bond. We all do this when we engage on our listserv, unite in a common discussion at a parent workshop, or socialize at community events such as the winter dance or summer picnic. I like to think we all do it when we see someone that we may not know, or recognize from DSNMC events. Do you walk up to that person and speak to them? Do you introduce yourself and ask them if they are DSNMC members? This could be your opportunity to give. Maybe they are unaware of our organization and in need of a group like ours - your positive energy will be welcoming to them.

Pull people vs. push people. Leaders that "pull" people use inspiration, accountability, structure and discipline to bring results. Those that push people are more likely to be pleading and use more negative tactics to get things done. As president of DSNMC, this resonated with me. I took much of this to heart and felt confident that DSNMC has been pulling our membership. As board members, we are committed to engaging our membership in this manner.

Bill was an incredibly dynamic speaker and I was invigorated at the end of his presentation. What I walked away with was that although we are all volunteers, I believe that as leaders of DSNMC, our obligation is to keep the balance, be positive and to provide the inspiration, structure and accountability for DSNMC. We have a reputation within our community as one that is a partner to service agencies, hospitals, the school system and so many more. Others respect our vision and how we seek to fulfill our mission. This is everyday leadership at its best and I am proud to be a part of such an organization, not to mention look forward to see where we are headed!

Gena

NEW BOARD MEMBER!

Ricki Sabia resides in Silver Spring, Maryland and is the mom of Steve, age 21 (who has Down syndrome), and David, age 24. She is a graduate of Georgetown University and the University of Maryland School of Law. Since 1994, Ricki has been involved in numerous volunteer activities for children with disabilities and their families. She was a Board member for the Arc of Montgomery County from 1994-98 and a co-President of Parents of Children with Down Syndrome of Montgomery County (PODS) for a couple of years in the 1990's. In addition, she volunteered on numerous local and state education committees, including as co-chair of the Montgomery County Public Schools Special Education Continuous Improvement Team from 1999-2005, which served as an advisory committee to the Superintendent. At the 2012 DSNMC Buddywalk, Ricki coordinated the activities for the teens and young adults.



Ricki's employment, since Steve's early years, has been focused on improving education for students with Down syndrome. She worked from 1999-2002 for the Maryland Coalition for Inclusive Education and from 2002 to the present for the National Down Syndrome Society (NDSS). Her current position is Associate Director of Education for the NDSS Policy Center. In April of this year, Ricki will be leaving NDSS to work as a consultant in the disability field. One of her consulting projects will be with a multi-state consortium that is developing a new alternate assessment tied to the common core standard. Maryland is a member of this consortium. Her role will be to work with states on efforts to inform families and respond to their questions about this new assessment and the instructional component that will accompany it.

WE REMEMBER THE LIFE AND DEATH OF

ETHAN SAYLOR

1987 – 2013



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DSNMC SUPPORTS IMPORTANT EDUCATION BILLS IN ANNAPOLIS

A BILL TO CREATE A POSTSECONDARY EDUCATION TASK FORCE AND A BILL SHIFTING THE BURDEN OF PROOF IN IEP DUE PROCESS HEARINGS

By: Heather Sachs, DSNMC Education Chair

DSNMC has signed on to letters of support drafted by the Maryland Down syndrome Advocacy Coalition (MDAC) in favor of two education bills introduced in the Maryland General Assembly during the 2013 legislative session: **HB 813, "Task Force to Study the Impact of Expanding Noncredit Courses for Students with Developmental Disabilities"** and **HB 1286/SB 691, "Due Process for Children with Disabilities – Burden of Proof."** DSNMC will keep you updated on the status of these bills. Please look for updates on the DSNMC listserv, and please take action when we request that you call your state delegates and senators to ask for support.

HB 813, "Task Force to Study the Impact of Expanding Noncredit Courses for Students with Developmental Disabilities," would create a statewide task force to examine and recommend more options for postsecondary education opportunities for students in Maryland with developmental and intellectual disabilities.

RATIONALE: Many of our families are disappointed by the lack of access to dual enrollment programs in the transition process, resulting in many Maryland students with Down syndrome, among other intellectual disabilities/developmental disabilities, attending postsecondary education programs out-of-state (such as in Virginia, Connecticut, New York and South Carolina). Postsecondary programs result in employment gains (wages and hours), communication skills, enhanced problem-solving and abstract thinking abilities, and self-esteem. DSNMC believes that a coordinated effort such as the one proposed by HB 813 is necessary to address the regulatory, legislative and institutional barriers that exist at a systemic level, and that effort should be focused on cost, accessibility, service coordination, transition, preparedness, and diversity of interests among students and families.

IMPACT: HB 813 will bring representatives from the 2-year and 4-year campuses together with self-advocates, advocates, service providers and the state agencies that fund and regulate services for adults with intellectual and developmental disabilities in Maryland.

HB1286/SB 691, "Due Process for Children with Disabilities – Burden of Proof," shifts the burden of proof in IEP due process hearings away from the parents and onto the school districts. This would rectify an injustice promulgated by the *Shaffer v Weast* U.S. Supreme Court case, which placed the burden of proof on the party that initiates a due process proceeding, unless the State law or regulations determines otherwise.

RATIONALE: Initiating due process proceedings is enormously time intensive, expensive, and emotionally draining for parents, but sometimes there is no other way to protect a child's educational rights. School districts have all of the resources and relevant personnel at their disposal, whereas parents must hire expensive private expert witnesses and evaluations to meet the burden of proof. Furthermore, under another U.S. Supreme Court case (*Arlington v Murphy*), States do not have to allow parents to be reimbursed for these expenses even if they prevail at due process.

IMPACT: If the burden of proof is shifted to the school districts, it would require them to do nothing more than prove that the IEP or placement they propose for a child meets the minimal standards of appropriateness imposed by the IDEA instead of requiring the parents, without the appropriate resources and witnesses, to prove the negative, that the school district's proposal is not appropriate. This bill would protect the educational rights of children and families by restoring fairness to due process proceedings.



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CHANGES IN PEP PROGRAM

By Dawn Piper, DSNMC Parent

As a parent of a 2-year-old with Down Syndrome the transition to Montgomery County Public Schools' (MCPS) Preschool Education Program (PEP) and the opportunities and education available for my son is at the forefront of my mind. As such I took the opportunity late last month to attend a Special Education Advisory Committee meeting discussing PEP and the changes and developments planned for 2014. A description of the current PEP program is available at <http://tinyurl.com/bmhs3uo>

After opening with testimonies and questions from parents, MCPS Special Education Director Gwen Mason spoke and began by addressing rumors that PEP would be eliminated. She confirmed that there are no plans to dismantle special education services and, in fact, MCPS plans to increase and improve services in 2014 since it has the largest number of children ages 3-5 who require services (2,482) in Maryland.

Felicia Piacente, director of the Division of Pre-K, Special Programs and Related Services, then addressed the meeting, emphasizing that MCPS' goal is to look at increased opportunities for special needs children and ensure these children are ready for Kindergarten. She further explained that the goal for our children is to have the Least Restrictive Environment (LRE), meaning the most inclusive class setting possible. She cited research that special needs children perform better in this environment and are more kindergarten ready when given more inclusive opportunities.

Ms. Piacente presented the most recent data, from October 2011, on how MCPS education for 3-to-5-year-olds compares to the state and other counties in Maryland. She did not have handouts of the presentation available, but stated she would email the data to everyone who attended the meeting.

What changes can we expect in 2014?

Increase the number of PEP inclusion classes and expand them to other school sites. There was not a list of sites provided at the meeting, but here is a breakdown of PEP inclusion classes:

PEP Itinerant is specialized instruction and services provided at daycares and community preschools. MCPS is looking for more preschools willing to participate and provide inclusion and plan to increase the number of PEP Itinerant teachers from two to five. The ARC of Montgomery County's Karasik and Family, Infant and Child Care Center Nursery School in Silver Spring, for example, received a Building Bridges grant which will provide inclusion for students six weeks to 10 years.

PEP PILOT (Providing Inclusive Learning Opportunities for Threes) is slated to increase from 13 classes 16 classes. The program, which began as just a program for 3-year-olds now includes 4-year-olds. Students can attend two days per week and some may attend four days per week, depending on IEP outcome.

PEP Collaboration is offered to 4 year olds where the teacher and the special educator work together to teach the class. This is a more rigorous class, compared to a real Pre-K program. The county plans to increase the classes from 14 to 19.

New schools being added!

Weller Rd, Glenallan, Oakland Terrace and Travilah

Expanding programs at the following schools!

Glen Haven and Washington Grove.

Some Inclusion Data

- For inclusive classes, MCPS has (41%) in comparison with the state (48%) and with most other counties in the state. Howard County has the most (70%).
- For non-inclusive/separated classes, MCPS has (26%) compared to the rest of the state, which has (17%), and Howard County (0%), and includes the following classes: PEP Classic, PEP Beginnings, PEP INC, and PEP Comprehensive. Ms. Piacente stated that PEP Classic has the largest number of classes and has only increased slightly over the years, since inclusion classes continue to show the most growth.

BUDDY WALK ON WASHINGTON

continued from front page

Following our training session, NDSS hosted our Buddy Walk® on Washington awards dinner and celebration. NDSS recognized individuals and organizations from the Down syndrome community that fight tirelessly to advocate for people with Down syndrome year-round, including: the Down Syndrome Association of Jacksonville (DSAJ) with the Buddy Walk® of the Year Award,

Daniel Goodrow and Connor Long, Self-Advocate of the Year Award; Nikki Davis and Richard Peck, Advocate of the Year Award; Rick Kosmalski and Jawanda Barnett Mast, NDSS DS-Ambassador of the Year Award; and the Eunice Kennedy Shriver National Institute for Child Health & Human Development (NICHD), Organization of the Year Award.



We were honored to have Congressman Ander Crenshaw (R-FL) and Congressman Pete Sessions (R-TX) join us as award presenters.

Later that day, NDSS joined Senator Bob Casey (D-PA) and Representatives Ander Crenshaw (R-FL), Cathy McMorris Rodgers (R-WA), Pete Sessions (R-TX) and Chris Van Hollen (D-MD) at a press conference for the Achieving a Better Life Experience (ABLE) Act - one of its highest legislative priorities for the 113th Congress. John

Anton, NDSS DS-Ambassador and Self-Advocate from Massachusetts, spoke at the press event about how the ABLE Act will help him as a 47-year-old with Down syndrome. "There is no other bill in the US Congress that has as much bipartisan, bicameral support as the ABLE Act. It is time that Congress enacts into law the ABLE Act," said NDSS Board Chair Chip Gerhardt.

The ABLE Act has 27 cosponsors in the Senate and almost 100 cosponsors in the House. "Passing this landmark legislation will go a long way to help all people with Down syndrome (including my 13 year old daughter Natalie) and other disabilities realize and achieve their own hopes, dreams, and aspirations," said NDSS Board and National Government Affairs Committee Member Steve Beck.

Maryland had the largest number of families in attendance—37 families, representing each county in the state! Montgomery County made a very strong showing and our advocates visited both of our Senators, Mikulski and Cardin, and both of our Congressman, Van Hollen and Delaney. DSNMC's Allison Wohl awarded the NDSS Champion of Change award to Senator Ben Cardin, who was one of 20 members of Congress honored by NDSS.

As he does each year, Congressman Van Hollen met personally with the Montgomery County delegation, even in the midst of lengthy and tense negotiations on the House Budget Committee (on which he is the ranking member) and on a day when the president addressed the House Democrats!! Congressman Van Hollen, a co-chair of the House Down Syndrome Caucus, is a champion for our families. END





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DOES YOUR WORKPLACE HAVE A MATCHING OR GRANT MAKING PROGRAM?

DSNMC is launching a corporate fundraising campaign and would like to know if any of our members are employed at organizations that have matching and/or other grant making programs.

Since employers prefer to provide support to organizations that are important to their employees, your response to this request will allow us to target our efforts as we launch this campaign.

If your employer has a matching grant or other giving program, please contact Leslie Bisignano, Vice President, DSNMC at leslie@dsnmc.org or 703.628.0293.

LFI Program Discussion

Due to the recent conversation on the DSNMC listserv regarding MCPS Learning for Independence (LFI) programs, DSNMC has begun a formal inspection to explore the content and treatment of students within these programs throughout the county. We would like to hear your experiences with this program, both positive and negative. Our goal is to use this information to create a rubric document which will describe the elements of a well run LFI program in order to minimize the risk of negative incidents in these programs. If we obtain sufficient response to this request for information, then the DSNMC leadership will meet with the MCPS Special Education leaders to discuss our recommendations.

Please email Gena Mitchell (gena@dsnmc.org) with the following information. The deadline is Wednesday, April 17.

Editor's Note:

If this deadline has been missed (due to the timing of the newsletter, please feel free to share your data, but keep in mind that it may not be officially included due to timing.) Thank you for understanding. – E.T.

- (1) Name of school (including elementary, middle, high)
- (2) Description of aspects of the LFI program or LFI activities that you believe to be beneficial (if any)
- (3) Description of any objectionable activities in the LFI program (if any)

Feel free to pass this request to other families who have students in an LFI program (regardless of type of disability). The more anecdotes we collect, the better informed our actions will be when we discuss this issue with MCPS. Names of students will be kept confidential.

HAPPY MOTHER'S DAY!



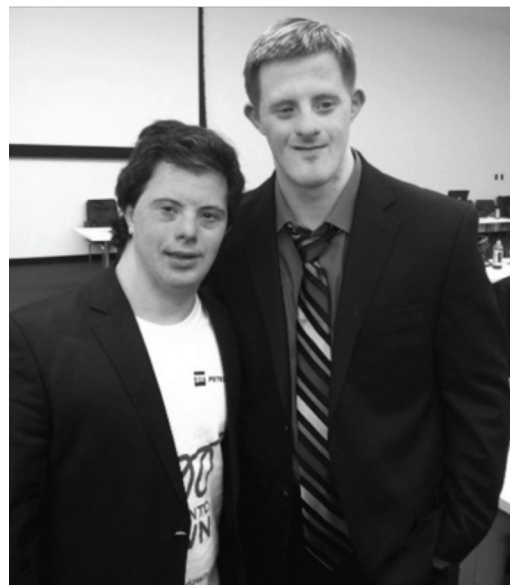
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Continued from front page

March 21, 2013 – World Down Syndrome Day at the United Nations

In order to discuss the tools to best achieve the right to work, the UN Conference featured 34 speakers sharing their best practices and experiences and representing over 10 countries, as well as 8 self-advocates, 6 companies (e.g. Walgreens, Holiday Inn Singapore and Wegmans) and international organizations such as the International Labor Organization, the UN High Commissioner for Human Rights, and UNICEF – the Children’s Fund.



From Brazil, Breno Viola (Coordinator of accessibility from Movimento Down) and Brad Hennefer, from New Jersey, worker of the year from Wegmans Food Market.

**THE FOUR FACTORS FOR SUCCESS
IN THE WORKPLACE**

1. Access to education and proper training (including accessible materials)
2. Partnership between public or private training centers and companies/ organizations interested in hiring people with Down syndrome. *Necessary to identify the skills needed to perform the specific job placement being looked for or offered, and the adequate training to acquire these skills*
3. Corporate philosophy that recognizes that hiring people with Down syndrome is not charity, but good business
4. Family involvement and support

From the experiences shared (in countries ranging from the Emirates to South Africa, Singapore, Australia, and the United States, among others), there were a few common points

(see Box) suggested as key for making the working experience of a person with Down syndrome successful for both sides (the employee and the employer).

Fulfilling the new spirit of Down syndrome advocacy is the theme, “Nothing about us without us”, self-advocate participation this year was even higher than last year. In every panel, there was at least one self-advocate speaking to the audience--John Anton’s lobbying U.S Congress experience; South Africa Sheri Brynard career as a Pre-K assistant teacher; Kazuzi Kobayashi’s dedication to his job at a French Bakery in Japan;

Breno Viola’s commitment to accessibility at work and great sports achievement (first black belt Judo athlete with Down syndrome); and Brad Hennefer’s enthusiasm about his job at Wegmans Food Markers. They were all very inspiring stories and webcast of all speakers presentations is available (see box on next page).

Although the participants celebrated the recent achievements for the inclusion of people with Down syndrome in the job market, it was recognized that they still face multiple barriers to gaining employment, including inadequate access to training opportunities, and discriminatory employment practices. Furthermore, many private and public sector organizations still lack the knowledge on the benefits of employing persons with disabilities, including Down syndrome. Other organizations understand this inherent value, but they lack the human resources policies and programs that prepare people with Down syndrome for success in the workplace.



Kazuki Kabauashi works at a French bakery, lives in his apartment by himself and wants to earn more money to be a taxpayer. He speaks English and Japanese. He and his family survived the tsunamis in Japan in 2011 by living on the attic of their house for 3 days with limited to no Food and water until being rescued by the emergency teams.



INTERNET LINKS

OFFICIAL AGENDA and SPEAKER BIOS:

worlddownsyndromeday.org/sites/default/files/WDSYD%20UN%20Programme%202013.pdf

WEBCAST OF ALL SPEAKERS:

PART 1: webtv.un.org/search/part-1-world-down-syndrome-day-conference-2013-theme:-right-to-work/2243087015001?term=World%20Down%20Syndrome%20Day

PART 2: [webtv.un.org/search/part-2-world-down-syndrome-day-conference-2013-theme:-right-to-work/2243438023001?term=World Down Syndrome Day](http://webtv.un.org/search/part-2-world-down-syndrome-day-conference-2013-theme:-right-to-work/2243438023001?term=World%20Down%20Syndrome%20Day)

A video from Down Syndrome International called "**LET US IN - I WANT TO WORK!**" celebrated, in partnership with 62 countries, the joys and challenges of World Down Syndrome Day 2013:

youtube.com/watch?v=mg_NMCETiHc&feature=player_embedded

If you think you can or you think you can't, either way, you'll be right.

-Henry Ford



In loving memory of **AMANDA ELISE MAHMOOD** April 20, 1990 – December 28, 2012

By Rosemarie Castillo Mahmood, DSNMC Parent

Amanda Elise Mahmood was born on April 20, 1990, weighing 5 1/2 lbs, a survivor of an emergency c-section. Before I went under general anesthesia, I didn't know what was going to happen to my baby. How happy I was that she was born! It didn't matter to me that she was born with Down syndrome - she was here and I loved her from the moment I saw her. Amanda was also born with an uncommon heart defect (unbalanced a/v canal). This was going to affect what she could and couldn't do physically; however, neither of these conditions affected how she defined herself, nor how we lived our lives with her.

At the age of 11 months, Amanda had a heart catheterization and we were told by the doctors that she had pulmonary hypertension. In addition, this would only get worse as she got older and one day would cease life for her. It was always something in the back of my mind as she grew up, but never the thought so real as during the last 8 months of her life. Amanda passed away December 28, 2012 - a brave, amazing and courageous young woman who brought so much joy into our lives. She truly lived a happy life, so loved by her family and by all who knew her during her life on this earth.



Amanda was the center of our universe, sandwiched in-between her sister, Jessica, older by 22 months, and her sister, Sara, younger by 22 months. She tried everything she could, no one could tell her she couldn't do this or that. Once she discovered her limitations, it was just accepted by her and she was content to find something else to do. So instead of running around with the other kids at the park, she would draw or play imaginative games with dolls. She did eventually outgrow the Barbies, but she continued to enjoy dressing up and being a girly girl. She loved having her nails

done, buying a ring, now and then (a little bling), and there was nothing to compare to being with her sisters, just hanging out with them. Raising three daughter, and very strong-willed little girls at that, was a challenge, yes, stressful at times, oh yes, but I loved being a mom and there was nothing more rewarding to me than doing everything I could for them. I may not have always done the best, but I did my best, with love at the very heart of everything.

We loved how Amanda danced, laughed, smiled, said things that made us smile or laugh and did things that made us feel so proud of her. We have so many wonderful memories. There are sad memories too; however, I don't want to mention them now as this is a short note of remembrance. The Black-Eyed Peas and Lady Gaga were among her favorite pop artists. She loved ice cream, sour candies, pizza and french fries. When she was diagnosed with Celiac Disease, we needed to change her diet to gluten-free foods, but she still was able to enjoy these edible delights. Amanda could be quiet and reserved at times, but other times could be very chatty and animated. She was also so "in the moment" throughout her life that she would enjoy just about anything that the day would bring. We, as her family, provided her with the security of knowing that all of her needs were met, that we were always there for her and that she was loved beyond measure. I think she exuded a confidence in knowing these things. She seemed so trusting and saw only the good in all people.

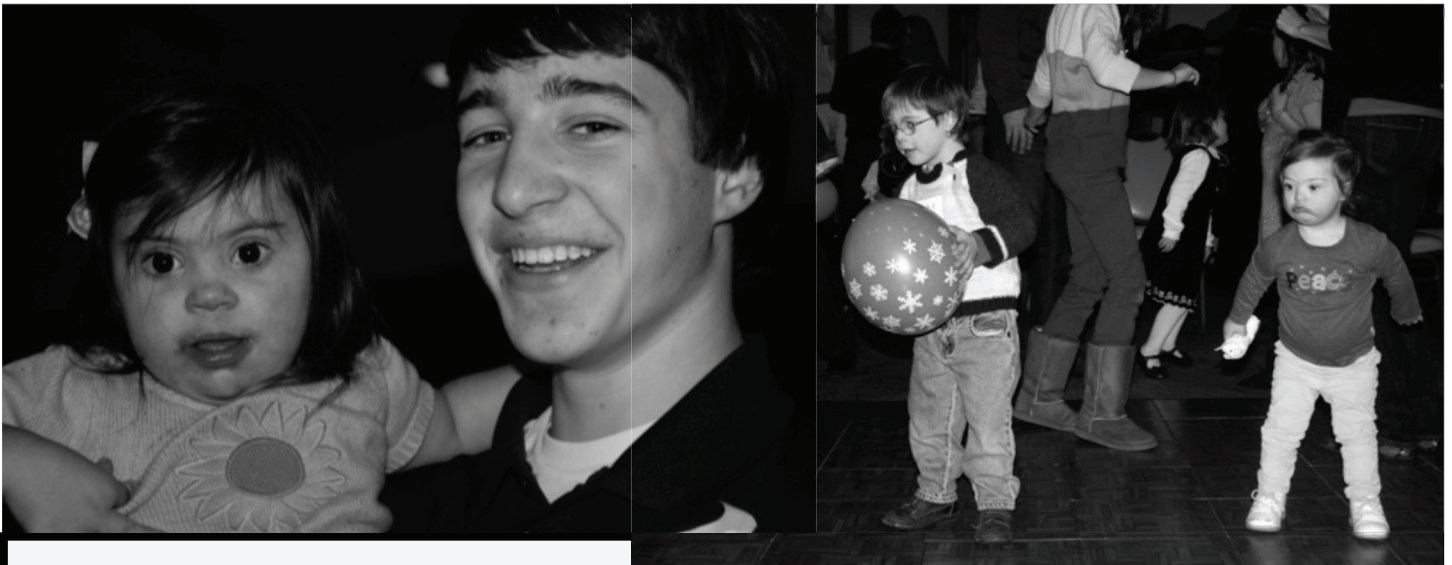


Throughout her school years, things went as smoothly as could be, from preschool at St. John's Lutheran, on Aspen Hill Road, to Weller Road Elementary to Barnsley Elementary (I transferred all three daughters so that they could all be at the same school when my oldest was accepted into a GT program there) to Homeschooling for 9 years (again all three daughters and beginning just 2 months after being at Barnsley) to Rock Terrace School, in Rockville. There were times I needed to advocate for Amanda. If I didn't, who would make sure she received what she needed and what was best for her, right? I was only too happy to do it any time, every time. Amanda "graduated" in 2011 and went to a day services

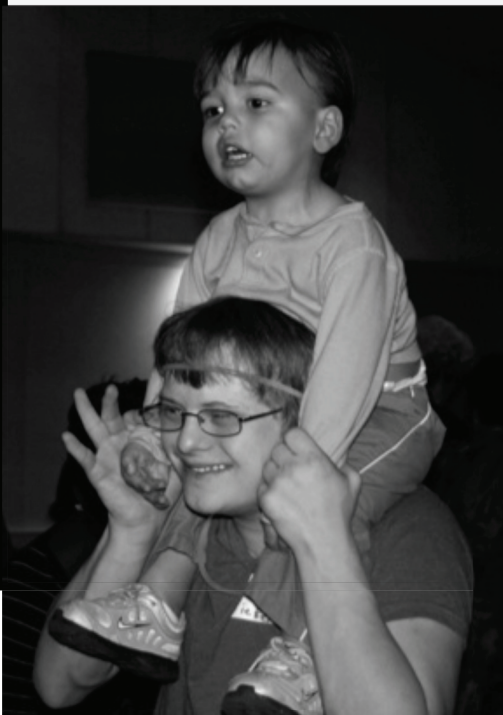
program at St. Coletta's of Washington, located in Rockville, MD, where she enjoyed working on-site creating glass works and helping with works to be fired in the kiln, until the end of April 2012. She spent the rest of the year at home, where we made the best of each day and did everything we could to make her days as happy as possible, going on outings, taking trips or just staying home to watch movies or dance in the living room.

She accomplished some things that some of us never do, such as "marry" a childhood friend (they were kids when they did this), visit Hawaii - because she wanted to go there, be crowned a prom queen, compete and win a bronze medal with Special Olympics as a JOY Cheerleader (2011) and have an Art Show at a gallery, Pyramid-Atlantic in Silver Spring, Md, complete with a limosine ride, rolled-out red carpet and media coverage. And what a lucky girl to have had a second chance at life, seven more years, following heart surgery in 2005, when she spent 5 weeks in CICU (the cardiac intensive care unit), Children's Hospital, before she went home a week or so before Christmas that year. That was truly a miracle and the best Christmas ever for us! We did have one more Christmas with Amanda before she passed away and I'm grateful for this. We are also very grateful for the kindness and generosity that we were blessed to receive from friends who knew us and those who didn't, but wanted to help in some way. I can't ever thank everyone enough for their donations, support and caring during a very difficult time. END





DSNMC
WINTER DANCE
2013





The only way we can be there for our children
is to be there for ourselves.

Anonymous

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PARENT PERSPECTIVE

USING RESPITE CARE IN MONTGOMERY COUNTY

Respite care is available as a service within Montgomery County. The service administrator is the ARC of Montgomery County, although the funding comes from the County. I have used respite for my son with Down syndrome (age 33), for over fifteen years. While respite was available before his eighteenth birthday, eligibility was determined by my income. As a mid-level Federal civil servant, he was not needy enough. At age eighteen, eligibility was determined by his income. Since his annual income has ranged from \$12000 to \$16000, fully funded respite eligibility is assured.

Respite is for the caregivers, his parents. We are the ones who should be getting the rest from our caregiving functions. Funds are made available to provide for his care so that the primary caregivers can get a break. We have always chosen to use this respite in chunks of days, from a minimum of three days to a maximum of ten days. But we try to make sure that the respite period provides unique experiences for him. Twice a year he would go away for a three or four day weekend. He would go to a youth activity in Baltimore, Wilmington, or other various locations in Pennsylvania or New Jersey. He would join several hundred other youths and fifty or more "advisors" in activities at a hotel. He usually would get a dedicated "advisor" to assure his safety and enjoyment. Once each year he would go to a camp or a travel program, either in New York or in Massachusetts. We chose a care provider who reliably monitors his safety and provides exciting things to do, good meals, and usually a hotel accommodation. While the respite funds do not pay the full price of my son's care on these weekends and camp, they often cover well over half the costs. In the meantime, we can enjoy dinner in a restaurant, a movie or concert, or just being alone together without being concerned about what and how he is doing.

Recently Respite Care in Montgomery County has changed. It is still available up to ten hours per day. It is now available up to 164 hours/year where before it was 140 hours/year. It now pays up to \$14.50 per hour where before it paid no more than \$7.50 per hour. (We are now using two respite caregivers, one charging \$14.50 and the other charging \$10.00, while before it was always \$7.50.) Now the respite care provider must have completed a criminality check (which was not needed before). This requirement may prevent us from using the kind of out-of-state care providers we used in previous years.

One of our current care providers comes forty Sundays each year and is teaching our son new skills. He is learning to cook and bake with a stove and oven, two kitchen fixtures he previously refused to use. He is learning how to express himself artistically, where we formerly emphasized musical expression. He is taking exercise walks in the neighborhood. The other care provider has a varied program of recreation for about ten developmentally delayed adults in a Montgomery County community center. This program meets for five hours each month for ten months each year. (We expect our son will miss one or two sessions.)

Our son looked forward to camp and his weekends away, and so did we as it provided an extended period of respite (24 hours of respite where ten hours were funded, for fourteen days each year). We hope our son will like the new approach to respite, even though the activities are different from the recreational ones he was used to receiving. As parents, we will also have to adjust to this different approach where respite is delivered in smaller amounts.

Elliot Greher is a retired Federal employee who spent nearly 30 years with the U.S. Nuclear Regulatory Commission (Rockville, MD). Mr. Greher is 70 years old, been married for nearly 50 years, and has lived in the same house in Silver Spring for 36 years. He has 4 children -, the youngest is 33 and has Down syndrome. Mr. Greher helps manage his funding by the State of Maryland, Montgomery County, and various non-governmental and religious programs.

SAVE THE DATE!

TECHNIQUES FOR SUCCESS CONFERENCE

Friday, October 25, 2013 – Evening session for parents

Saturday, October 26, 2013 – Day-long conference for educators

The Techniques for Success (TFS) conference will celebrate its 5th year in 2013! 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 25, and TFS for Educators for Saturday, October 26. 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!** Inviting your child's teaching team is a great way to show support for them and to spread up-to-date knowledge about Down syndrome within our school system.

Based on past participant feedback, we're inviting fewer speakers this year to allow them to go more in-depth in their topic areas. Dr. Sean Smith will be back by popular demand to discuss rapidly-expanding **technology resources** that can support students with Down syndrome, with a focus on how technology can support **Universal Design for Learning**. Stacy Taylor will address **behavioral challenges** in educational settings. Both Sean and Stacy are experts in their fields as well as parents of children with Down syndrome. Participants will also have the opportunity to hear from **self-advocates** about their educational experiences. Watch the TFS website for details: <http://techniquesforsuccess.org/>. Registration will open in the late summer.

If you would like to join the TFS Planning Committee, please contact Heather Sachs, TFS Planning Committee Co-Chair, at heather@dsnmc.org. Help is welcome for tasks large and small!

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Down Syndrome Network of Montgomery County
2012 Buddy Walk

Don Rogers
301-230-5202
don@shulmanrogers.com

Scott Museles
301-230-5246
smuseles@shulmanrogers.com

Shulman, Rogers, Gandal, Pordy & Ecker, P.A.
12505 Park Potomac Avenue 6th Floor Potomac, Maryland 20854
ShulmanRogers.com

DSNMC EVENTS

Coffee and Conversation

May 14 and June 11
2nd Tuesday of each month
10:30 – Noon

Caribou Coffee
Westfield (Montgomery) Mall

Contact Karen O'Connor at
301-972-5138 or tkrbmo@verizon.net

Summer Picnic

June 23
11:00 AM-2:00 PM
Black Hills Regional Park (Picnic Site 1)

Volunteers Welcome for the Professional Outreach Committee

If you are interested in reaching out to the medical community and other healthcare professionals, contact Mimi Gehres at mimi@dsnmc.org

Play Groups

Saturday, June 8
11:00 AM – 1 PM
Potomac Community Center

Please email info@dsnmc.org, or call (301) 979-1112 for more information.

DSNMC MEMBERSHIP MEETING

May 19
4-6 PM
Potomac Community Center

For the latest information and details on all DSNMC events and news

dsnmc.org

If you would like to attend a **Board Meeting**, please contact Gena at gena@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
TTY: 1-866-411-1010
email: LNANCY@MAIL.NIH.GOV
<http://patientinfo.nimh.nih.gov>

COMMUNITY EVENTS

Potomac Community Resources, Inc.

PCR provides innovative therapeutic, recreational, social, and educational programs for teens and adults with developmental differences.

Register for programs now!

www.pcr-inc.org
301-365-0561

NDSC Conference
July 19-21, 2013
Hyatt Regency Denver,

Colorado Convention Center, Denver

<http://convention.ndsccenter.org>

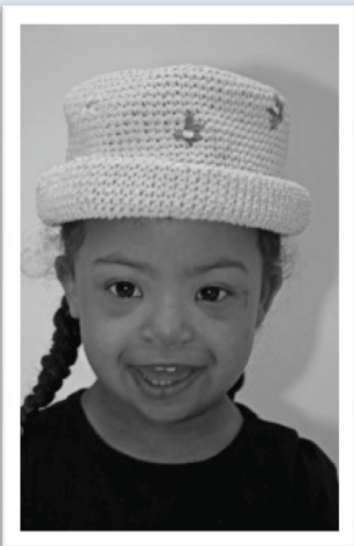
WHO'S WHO in DSNMC

This little glimpse inside the lives of our members is sure to educate, enlighten and inspire.

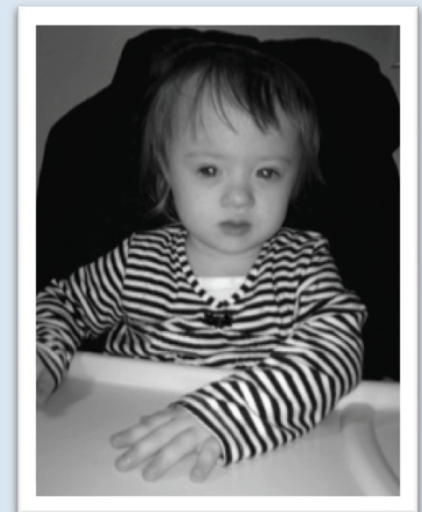


Gaithersburg . . . **Shannon Hughes** (9) attends Fields Road ES. She loves to move! Music, dancing, cheerleading . . . that's Shannon!

Kensington. . . **Delaney Dunigan** (14) is big sister to Patrick (7). She attends Tilden MS where she is one of the Best Buddies Directors. Delaney swims, dances, plays the piano and enjoys just hanging out with friends. Performance Credits: SO basketball and cheerleading, and Dream Allstars cheerleading.

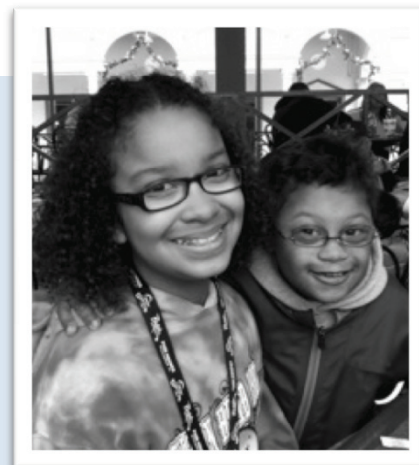


Ariana (4) is a student at Karasik where she enjoys reading, dancing, riding bikes and playing with friends. Ariana loves singing and playing the piano. Fave Act: The Fresh Beat Band! Ariana's star shined in the 2011 *Toys R Us Toy Guide for Differently Abled Kids*.



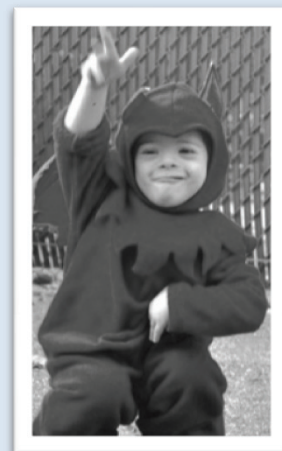
Potomac. . . **Federic Albanese** (2) attends St. James' Children's School where she loves finger painting, story time and finger play. She can also be found at the gym, kicking in the pool, or hitting the play-date scene. Star Quality: comedy. She wants to make you *laugh!*

Rockville . . . Cristian Villatora (9) totally adores his sister Adriana (11) and she just loves him to bits back! They spend lots of time together. Cristian especially loves playing soccer, swimming, playing with his slinky and visiting hotels. Cristian shares his star qualities with his classmates at Dufief Elementary.



Gaithersburg . . . Andrew Lee (3) is little brother to Connor (5). Andrew loves taking the bus to school at Thurgood Marshall PEP. Anything that has to do with music and books—that's for Andrew! He also works diligently on his rock star persona playing drums and strumming guitar in front of the mirror.

Kensington. . . Davide Kushner (5) is little brother to Teresa, Francesco and Gabriella. He attends Ashburton PEP, ECDC, and NIH preschool. Davide loves is an aspiring drummer who loves music. He also enjoys basketball—really, any game with balls! What he's *really* good at is giving his Mom hugs and kisses.



Kensington. . . Jamie Veerhoff (21), a Walter Johnson grad, attends MOST, is part of JFGH, and takes courses on music/movies at Montgomery College. Recently Appeared: As Mighty Moo for WJ pep rally, and to present an NDSS award to Congressman Van Hollen. Sports, politics, history, theater, Facebook!



Kensington. . . Will Veerhoff (21) is a WJ grad who thrives in the social scene! An outdoorsman, Will likes construction sites and firefighter parades, keeps fit at SO tennis and basketball, KEEN, and the BCC-Y. He loves jazz (especially Louis Armstrong), knows every instrument in the orchestra, but *loves that sax!*



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www.dsnmc.org
(301) 979-1112

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P.O. Box 10416
Rockville, MD 20849