DSNMC
DOWN SYNDROME NETWORK OF MONTGOMERY COUNTY

Newsletter for Self-Advocates, Parents & Friends

CONNECTIONS

Dynamic Buddy Walk Continues to Grow

By Michael Piper, Connections Editor

Back in 2007 Gena Mitchell was reading her emails when she came across a message on the Down Syndrome Network of Montgomery County listserv asking for volunteers to donate time to help set up the Buddy Walk – a fundraising event for the organization. Her response?

"That might be cool," Mitchell remembered thinking. "I thought it might be fun to help out. At the time it was a pretty small event. There were maybe 100 or 125 people and we just did a walk through Kensington. We had some food trays from Costco and some fruit from Giant and that was about it. It was a lot of fun."

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The Buddy Walk set a new record with over 700 attendees in 2013.

Techniques for Success: A chance to learn

By Jeff Flaherty, DSNMC Parent

When my wife first asked if I was available to attend this year's Techniques for Success for Parent's workshop I responded with an enthusiastic, "Of course!"

After all, we received a lot of terrific information at last year's program, so why wouldn't I want to learn more valuable parenting techniques?

However, when the evening of October 25 rolled around, I'd be lying if I told you I didn't have thoughts of "skipping class". The idea of leaving the office after a long day … and week … to sit in a hotel ballroom for three hours seemed less appealing at the moment than it did when I initially agreed to attend. But I had made a commitment to my wife to go and I wanted and needed to honor that commitment. It took just a few minutes into the program to realize the commitment I was honoring went well beyond the one I made to my wife.

As the parents of a special needs child, my wife and I often find ourselves

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President's Letter

This is the most difficult president's letter that I have written over the past seven years. Not because I don't know what I want to share, but I struggle with how to reflect on the past seven years in a few paragraphs. So much has happened and there are so many people to thank, not to mention all of the excitement that lies ahead. Thinking back, I had not intended to become president of a "support group."

When my daughter, Devin, was born 11 years ago, I thought having her integrated as a part of the community was what we needed. She would go to the store, the library, family outings – anywhere we all went as a family. I wasn't going to let a little thing like an extra chromosome deter me from going about business as usual. At the time, I didn't understand, and more likely could not comprehend, what an organization like DSNMC could give to our family because my perception was my reality. It wasn't wrong, I just didn't know any better.

Once I became involved with DSNMC as a member, it became quickly apparent that this community of parents had so much to offer to each other and it filled a critical need for each of us. I was hooked and I wanted to do more.

As president, I have been incredibly fortunate to have worked with many amazing people on the board of directors, wonderful members and parents who have simply offered their personal and professional expertise and even volunteers who have not had any direct affiliation with Down syndrome but simply want to help. I have seen 750 people gather to celebrate our children and young adults with Down syndrome.

I have also seen our members work together on Capitol Hill and in Annapolis and within MCPS to advocate for people with Down syndrome. As I think about what we have all done together I am blown away and I am incredibly proud and humbled to have participated in so many significant events with all of you.

Over the past several months, many have asked about how I feel about stepping down. My answer of course is filled with mixed emotions. DSNMC has been a significant part of my daily life for a very long time, and as with anything that comes to an "end" there is some sadness.

However, that is minimal for me because I feel very strongly that our new president, Kathy Myers, is the right person for the job. I feel confident handing the reigns over and am genuinely excited to see where she takes us.

I have been fortunate to have worked with Kathy on the BoD for the past three and half years. She has been a tremendous asset to DSNMC and I have no doubt she will exceed any expectations there may be. She is one of the most knowledgeable people that I know regarding Down syndrome. She is aware of all current topics that relate to Down syndrome and is not afraid to roll up her sleeves and get down to business, all with a smile and an easily approachable demeanor.

DSNMC is lucky to have Kathy and I hope you will join me in welcoming her and offering your support throughout her tenure!

Gena

Techniques for Success
Strategies for Educating Students with Down Syndrome and Other Special Needs

EXCELLENT EDUCATORS: 2013 TFS Honorees

The following individuals and schools were honored by parents as Favorite Educators at the 2013 TFS conference for their outstanding commitment to students with special needs:

Ashburton Elementary: Barbara Barr, Roxanne Bell, Becky Mangan, Pratima Mitra, and Judy Segal

Brunswick Elementary School Staff

Carderock Springs Elementary School: Principal Rock Palmisano and Staff

Cloverly Elementary School: Maneth Gravell and Catherine Najarian-Halpin

Damascus Elementary School: Wodoslawsky, Vogel, Sweeney, and the SCB/LFI Team

Flora Singer Elementary School: Kara Tymon and the Learning Center Staff

Kensington Nursery School: Helene Segal-Turner, Kathleen McNickle, and Debbie Wofsey

Oakland Terrace Elementary School Staff

Our Lady of Lourdes School Staff

Rosemary Hills Primary School: Neeta Lobo

St. John the Evangelist School Staff

Thurgood Marshall Elementary School: Peggy Hurkett, Janet Hilton, Carrie Smith, Ravinder Basi, Chris Shrake, and Jen Carter

Treetop House Montessori: Ms. Sau Fong

Wayside Elementary School Staff

Wood Acres Elementary School Staff

Photos courtesy of Julie Ryan-Silva

Attendees browse through the resources at the Techniques for Success Conference

VITORIA AIELLO JOINS DSNMC BOARD OF DIRECTORS

DSNMC Staff

Aiello

DSNMC welcomes its newest member of the Board of Directors, Vittoria Aiello. Vittoria and her husband, Massimiliano Albanese, serve as the coordinators of the DSNMC play group and Massimiliano handles the DSNMC Facebook page.

Born and raised in Italy, Vittoria earned a Masters of Arts in Business Economics from the University of Naples Federico II, one of the most ancient institutions of higher education in Italy. After graduation, she worked for the same University as a Financial Data Analyst. In this role, her responsibilities included budget management, and project financial planning and monitoring. Vittoria also holds a Master in Business Administration from the Robert Smith School of Business at the University of Maryland, College Park.

In the United States, where she moved with her husband in 2007, Vittoria has assisted the Liberian Development Foundation (LDF), a 501(c)(3) providing educational opportunities for the people of Liberia, in launching new programs and initiatives, including Books to Liberia and the Scholarship Program.

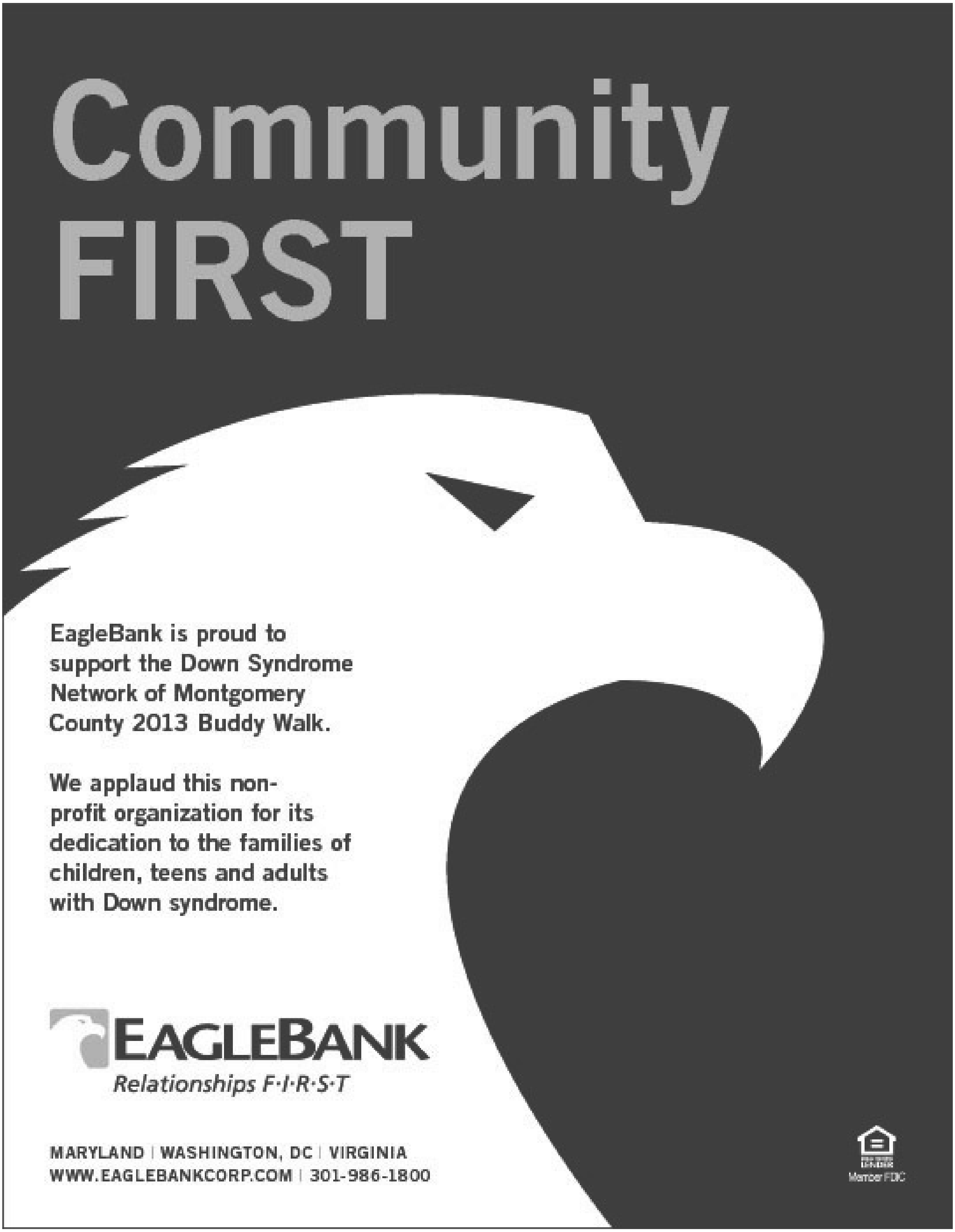
More recently, Vittoria has contributed to the creation and launch of the Laboratory for IT Entrepreneurship at George Mason University and is currently collaborating with the Laboratory as an Advisor for the creation and incubation of new IT ventures.

In November 2010, Vittoria's and her husband's lives were blessed with the birth of their daughter, Federica, born with Down syndrome. Since then, Vittoria has been very active in advocating for the rights of people with Intellectual Disabilities, by writing articles, participating in local and national events aimed at raising awareness about Down syndrome and other intellectual disabilities, and by running fundraisers supporting research on Down syndrome. Vittoria also heads DSNMC's Advocacy Committee.

Welcome Vittoria!

"When I give, I give myself."

Walt Whitman



BuddyWalk 2013!

Hadley's Park

October 2013

Photos courtesy of Bridget Conley


Buddy Walk
DSNMC
Special Olympics
Maryland
Montgomery County
"Be a fan!"
PALS

Techniques for Success 2013

continued from front page

wondering if our son’s behavior is a result of his disability, or is he simply being a “young boy.” After behavior analyst Stacy Taylor, M.A., B.C.B.A., delivered her brilliant presentation, Behavior Strategies, I realized it isn’t important if my son’s behavior is a result of his Down syndrome or not. Undesirable behavior is undesirable behavior in any child, a simple concept that can easily be overlooked when lost in the focus of a disability.

Taylor’s techniques of addressing undesirable behaviors have proven to be just as effective with our typical children as with our special needs child. These techniques are relatively simple and can easily be implemented at home as well as in the classroom. Taylor did a phenomenal job of breaking down some fairly complex theories into very understandable nuggets.

Additionally, Taylor introduced and explained the Competing Behavior Model and the “A-B-C” behavior analysis technique; two truly useful tools developed to better understand and more effectively address undesirable behaviors. Of course, these are just a few of the powerful tools and concepts Taylor discussed in the short time she had with us parents. I couldn’t take notes fast enough. On top of all the great information she provided, Taylor’s light-hearted, often comedic delivery could not have been more enjoyable. At times she was more an entertainer than an educator.

The world of assistive technology, learning resource Web sites, applications, blogs, etc., can be overwhelming. And if you’re at all like me, you find it hard to simply stay abreast of the latest smart phone release. Fortunately, there experts like Dr. Sean Smith.

Dr. Smith’s *Technology as a Tool for Implementing Universal Design for Learning* presentation was a wonderful, real-life example of how he and his special needs son used adaptive learning techniques to be successful in accomplishing a school project on U.S. Presidents. We were even treated to a video of his son’s classroom presentation. Smith shared the link to his Website (http://delivr.com/2ppec) where anyone can access what seems to be an endless list of resources on assistive technology and universal design for learning.

Tips for Addressing Undesirable Behavior

Behavior analyst Stacy Taylor broke down strategies for dealing with behavioral issues in her talk at the Techniques for Success Conference. Among the tips she touched on were the following:

Behavior produces consequences … the consequences either strengthen or weaken the behavior. We do nothing good for our children when we protect them from these consequences.

It’s more productive to **focus on desirable (or appropriate) behavior** using positive reinforcement than it is to focus on undesirable (or inappropriate) behavior by using punishment.

Finally, hearing from self-advocates Jordyn Dannenbaum and Candace Whiting about their accomplishments and the challenges they face and overcome every day was not only incredibly inspirational, but equally emotional. I felt as if Jordyn and Candace, for a brief moment, became the voice of my son – allowing me to understand how he might be experiencing and processing his world today and how I might be able to empower him to navigate the road ahead. These beautiful, young women remind us of the infinite possibilities for our own children. I was so incredibly grateful for their willingness to give us such a personal glimpse of their lives as people with Down syndrome … once I got past the ridiculous envy I have towards their parents for their impressive parenting skills.

TFS FOR EDUCATORS RECAPPING 2013

By Julie Ryan-Silva, TFS Planning Committee Member

In late October 2013, DSNMC and F.R.I.E.N.D.S. of Frederick County hosted the fifth Techniques for Success (TFS) conference. TFS focuses on practical strategies for educating students with Down syndrome and those with other special needs. The conference aims to inform and inspire educators and parents. National experts discuss the latest approaches for educating students with Down syndrome and adult self-advocates share stories of their lives and educational experiences.

This year, TFS for Parents was held in the evening on Friday, Oct. 25, and TFS for Educators was all day on Saturday, Oct. 26. Almost 100 parents and 300 educators participated, the largest number to date. For the second year in a row, TFS for Educators filled up weeks before the registration deadline.

The specific topics and speakers for TFS change every year making it worthwhile to return. Almost 40 percent of this year's participants had attended TFS in the past. Based on past participant feedback, the 2013 conference had fewer speakers to allow for more in-depth discussion of their topic areas. This year's presentations were:

- **Technology as a Tool for Implementing Universal Design for Learning:** Dr. Sean Smith. Smith is an Associate Professor of Special Education at the University of Kansas and the father of four, including a son with Down syndrome. Smith's presentation and suggested resources are available at: **http://delivr.com/2ppec**
- **Behavior Strategies**: Stacy Taylor. Taylor is the owner and director of Advance Behavior and Learning in Central Florida and the mother of four, including a child with Down syndrome.
- **Self-Advocate Experiences:** Jordyn Dannebaum, Candace Whiting.

TFS is free to participants and is funded mostly by Buddy Walk donations. This year, Blackboard, Inc., an education technology company headquartered in Washington, DC, became a Platinum Sponsor of TFS with a $2500 contribution. For the first time, parents had the chance to become Favorite Educator Sponsors of TFS by donating $100 in honor of a favorite teacher, team or school. Favorite Educators from 15 schools were recognized during the conference by having their names announced and prominently displayed (**See Page 4**). The conference included a raffle with two iPad Minis as grand prizes. These prizes were donated by DSNMC parents Cathleen and Sean Fromm on behalf of the company G2SF, and by another parent on behalf of the Catholic Coalition for Special Education.

TFS could not occur without the support of these donors and those who raised funds for the Buddy Walk. Thank you! Much appreciation is also due to DSNMC members who served on the TFS Planning Committee: Co-Chair Heather Sachs, Kirsten Jones, Patti Klobus, Susie Lee and Gena Mitchell, along with Co-Chair Katie Routzahn, Shane Buckland, Doug Silvern, Bob Walsh and Denny Weikert from F.R.I.E.N.D.S. of Frederick County.

> "It is so wonderful to see how far students with disabilities can go. Inspired me to be a better teacher!"
>
> ***Unnamed educator from 2013 conference***

PLAN NOW FOR TFS 2014

TFS 2014 will take place in the fall and details will be posted on the TFS website as they become available: http://techniquesforsuccess.org/

Planning will begin soon and help is welcome with large and small tasks. The Planning Committee is particularly interested in finding someone to assist with writing grants and/or securing sponsorships for the conference. If you would like to discuss options for helping with next year's conference, please contact **Heather Sachs** at heather@dsnmc.org.

BUDDY WALK ON WASHINGTON '14

By Vittoria Aiello, DSNMC board member

The Buddy Walk on Washington is an annual two-day advocacy event sponsored by the National Down Syndrome Society (NDSS). The event will take place Wednesday, Feb. 26 and Thursday, Feb. 27.

On the first day, participants will learn about NDSS key priorities for the 2014 Buddy Walk and will have the opportunity to connect with other affiliates and advocates. On the second day, participants will meet with Members of Congress and their staff on Capitol Hill to advance education, research and healthcare for people with Down syndrome. The event brings parents and advocates from across the U.S. together to advocate for public policies that impact the lives of people with Down syndrome.

If you have never attended, now is the time to do so. You do not need to be an experienced advocate to participate to this event! NDSS will provide you with all of the training you need. The ABLE Act will be one of the priorities on the agenda. To have it passed, we need to go to Capitol Hill *TOGETHER* and tell our Senators and Representatives that it matters to us now more than ever, and to encourage their support.

DSNMC will cover the registration fee ($30) for its members and will process your registration. To register, please contact DSNMC Administrator Deirdre Kelly at: **admin@dsnmc.org** .

Please feel free to email: **Vittoria.aiello@gmail.com** with any questions about the Buddy Walk or just to communicate your intent to attend.

Buddy Walk Details

For a schedule of events, visit:

http://tinyurl.com/keseubv

For an event overview, visit:

http://tinyurl.com/mroyspl

Self-Advocate Patrick Jones and Rep. Chris Van Hollen, D-Md.

Walk offers chance to mingle, make a difference

My name is **Patrick Jones**. I am 22 years old. My mom and I have gone to the Buddy Walk on Washington for the last two years. I liked meeting people from other places. I got to talk to representatives and Congress about important things.

I work at Dawson's Market. I would like to be able to save money to live in my own apartment or save money for vacations. We spoke to people about passing the ABLE act so I and others can do this without losing benefits.

If you get a chance to go to the Buddy Walk on Washington you should go. It's a lot of fun and important for people to see how many people are affected by their decisions.

BUDDY WALK: A YEAR OF GROWTH, TRANSITION

Continued from front page

Little did she know, however, that her involvement in that 2007 Buddy Walk was just the beginning of what became a passionate quest to grow the walk into a carnival-like event that was the cornerstone of the DSNMC calendar each year. Mitchell took over the lead in organizing the event the following year, drawing a much larger crowd and increasing the fund-raising from around $10,000 to nearly $35,000. This past October, the event drew close to 750 participants and DNSMC raised more than $90,000.

Political columnist and DSNMC father George Will introduces his son, Jon, a self-advocate at October's Buddy Walk. Jon spoke about his experiences working for the Washington Nationals.

As the Buddy Walk grew, Mitchell and her family became connected to it in a way she never imagined.

"My children think the Buddy Walk is their party," "Mitchell said. "It's been amazing. We were always getting deliveries to our house [for the Buddy Walk] – t-shirts or stickers and a ton of boxes. It became a significant part of our lives. My daughters are always surprised if they are talking about the Buddy Walk and people aren't familiar with it. They are like, 'What do you mean you've never heard of it?' It's become part of our identity."

Mitchell's dedication to the Buddy Walk is what made this year's event a bit more emotional as the DSNMC president handed over those responsibilities to incoming president Kathy Myers.

"I don't think I realized how much time we spent on the Buddy Walk," Mitchell said. "It's nice to have some of that time back but it's a strange feeling. It's really all my children have known. My oldest, Maddie, who's 13, was like 'What do you mean you won't be president?' It's just been something we've gotten used to the past six years."

Success in 2013

The ever-evolving Buddy Walk continued to grow and broaden its reach this year. The theme this year was 'Take Me Out to the Buddy Walk' which was particularly appropriate given the sunny afternoon that felt much more like August than October. The activities included the always-popular staples such as moonbounces, a pre-K tent for the little ones, face-painting but were expanded this year to include activities for the older children. Al Bidwick and his players from 5 Tool Baseball set up a variety of baseball activities and Fitness for Health provided activities designed to help improve coordination and motor skills.

Gena Mitchell, center, was honored as she steps down this year after her term as DSNMC president. With the help of countless volunteers, Mitchell spear-headed the growth of the Buddy Walk, from a leisurely stroll through Kensington to a full-blown carnival-like event in Hadley's Park. The event has raised some $190,000 for DSNM the past two years combined.

Pulitzer Prize-winning political columnist George Will and his son Jon were on hand to kick off the walk with an inspiring speech that delved into Jon's job with the Washington Nationals – an opportunity that makes any parent of child with Down syndrome smile and allows all to

See Buddy Walk Page 14

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

Anonymous

BUDDY WALK: CONTINUED GROWTH GOAL FOR 2014

Continued from Page 12

And, any wrap-up of the event would be remiss if it failed to mention a significant highlight – Teddy Roosevelt (the Nationals racing mascot, not the former president) showed up to greet the walkers as they finished and mingle with the crowd for pictures.

How you can help

The growth of the Buddy Walk is something Myers can appreciate from her years on the DSNMC board and after taking a more prominent role in the organizational efforts this year, she was surprised and excited by how many new faces were in attendance. Among the hundreds of participants were more than 40 new ‘teams,’ many of which were among the top fund-raisers.

“We went to Jimmy’s [Myers’ husband] office holiday party and I was talking with several of the co-workers from his office that were at the Buddy Walk this year,” Myers said. “It was great hearing that they enjoyed it and that their kids had so much fun seeing Teddy and taking part in the whole event.”

But, as has been the case for the past nine years, Myers knows the dynamic Buddy Walk needs to continue to evolve. The $90,000 raised was impressive but represented a slight step back from the $100,000 raised in 2012. Efforts to match and exceed that number are a focus as is expanding the age range of activities for those that attend.

“I thought we were able to appeal to more age groups this year and I think that’s what we need to continue to do,” Myers said. “Some of the feedback we got in past years was that the event catered to the younger kids, but we had more events this year and we need to keep finding more activities and ways to reach out to the older participants and the self-advocates.”

That growth is going to require more man-power and so opportunities to get involved and volunteer continue to expand as well. A couple options for those interested include efforts to grow corporate sponsorship and to help expand the VIP aspect of the program.

“I would like to get a bigger VIP committee so that we can think of more VIPs to invite, contact them earlier and have more help greeting them when they arrive,” Myers said. “We also would love to grow our sponsorships so we’re looking for help identifying businesses that may be interested in participating and contributing.”

Anyone interested in helping with these or other initiatives can contact Myers at: Kathy@dsnmc.org.

TRIBUTE 21 EVENT RAISES $150K FOR RESEARCH

Connections staff

The First Annual Masquerade Ball, TRIBUTE 21, was held on Saturday, Nov. 9th at the Powerhouse in Georgetown. The event was spearheaded by DSNMC parents Brendan and Erin Fry and held in loving memory of Flynn Thomas Fry.

Due largely to the extraordinary efforts of the Frys, their extended family and a host of volunteers, this event helped to raise approximately $150,000 towards the efforts of Research Down Syndrome.

Dr. Yvonne Maddox, deputy director of the National Institutes of Health, and Dr. Robert Reeves of Johns Hopkins were guest speakers while Eli Lewis served as self-advocate host of the event.

The mission of Research Down Syndrome is to fund and support scientific research directed towards the development of safe and effective drug therapies that will improve memory, learning and communication in persons with Down syndrome and address the increased likelihood for Alzheimer's disease.

DSNMC EVENTS

Play Groups

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

Sunday, Jan. 19
Sunday, Feb. 9
Sunday, March 9

Location: TBD

*Meeting times and additional details will be shared via the listserv and Facebook.

Contact: Vittoria Aiello
P: 301-272-0311
email: vittoria.aiello@gmail.com

DSNMC Winter Dance*

Saturday, Feb. 1 from 5:30-8:30 PM

Location: Gwendolyn E. Coffield Recreation Center - Social Hall

2450 Lyttonsville Road / Silver Spring, Md. 20910

RSVP to: rsvp@dsnmc.org

*Please note this is a new location for the Winter Dance. The auditorium at Brookside Gardens, the previous location for this event, is closed for renovations.

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

Coffee and Conversation

Tuesday, Jan. 14
Tuesday, Feb. 11
Tuesday, March 11
Tuesday, April 8

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

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

Tools for Schools Workshops

Tuesday, Feb. 4
Alternate Assessment/FLS Curriculum

Presenter: Myra Byron, MCPS

Time: 7:00 PM

Location: The Arc Montgomery County

Wednesday, March 12
Special Education and the Law*

Presenter: Selene Almazan, Co-Director, Maryland Coalition for Inclusive Education (MCIE)

*Details will be posted to the DSNMC calendar and communicated via the listserv and Facebook at a later date.

Happy New Year!

2013 Buddy Walk Sponsors

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