

# CONNECTIONS

## Take Me Out to the Buddy Walk

By Michael Piper, Connections Editor

Around the time of last year's Buddy Walk, the organizers of the event were brainstorming a theme for the 2013 walk. With the Washington Nationals cruising to a National League East Division title before falling just short against the St. Louis Cardinals in the playoffs and the Baltimore Orioles making their first playoff appearance since 1998, an obvious option presented itself.

"The whole Washington region seemed to be caught up in the playoffs around this time last year," Buddy Walk manager Susan Mordan said. "We thought it might be cool to tap into that playoff fever a little bit especially since we all thought the Nats would be right back there this year."

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## Techniques for Success

By Julie Ryan-Silva, DSNMC Parent & Executive Director, CPSD

Do you want to learn more about how to support the education of your child with Down syndrome? Do you want your child's teaching team to have new tools and inspiration for educating your child? Then it's time for you to register for Techniques For Success (TFS) for Parents and to invite your child's teachers to register for Techniques for Success for Educators.

In its fifth year, TFS focuses on practical strategies for educating students with Down syndrome as well as those with other special needs. TFS is sponsored jointly by DSNMC and F.R.I.E.N.D.S. of Frederick.

TFS for Parents will be held in the evening on Friday, Oct. 25. TFS for Educators, meanwhile, will be an all-day event held on Saturday, Oct. 26. Both informational programs will be held at the same location – the Hilton Washington DC/North Gaithersburg in Gaithersburg, Md.

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### SEPTEMBER 2013

Self-Employment

DSNMC Picnic Pics

Night at the Nats Game

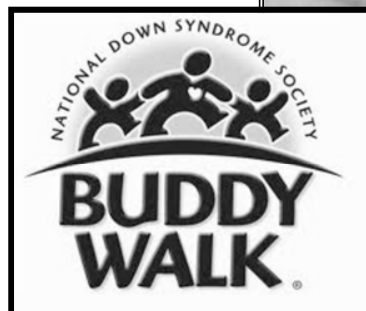
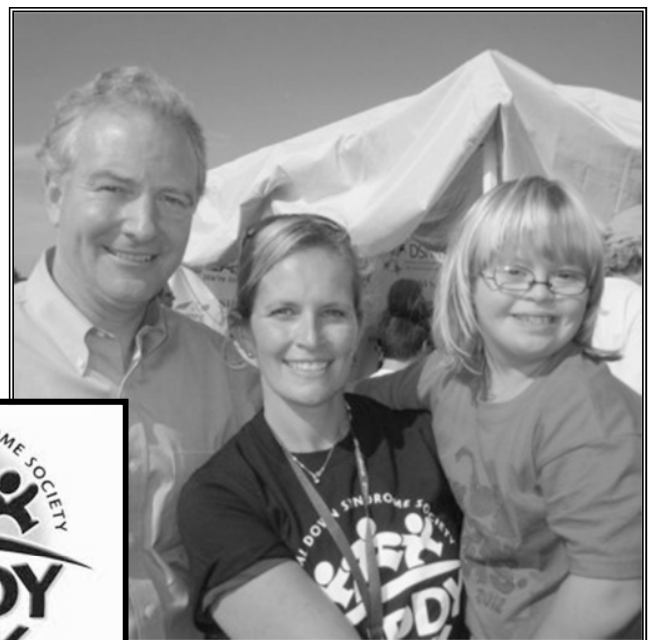
ABLE Act and Burden of Proof

Ethan Saylor Update

Upcoming Events

Call for Nominations

DSNMC Pool Party



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## President's Letter

Once again, I find myself asking, where has the summer gone? I love this time of year. It always feels like a fresh start, even more so than New Year's Day. The start of another school year with so many possibilities, a calendar of activities that has yet to spin out of control and so much enthusiasm from my girls about school – it is such a great feeling!

Even so, I find myself feeling sad about the fact that I am in the home stretch of my term as DSNMC President. Next month, we will be accepting nominations for my successor and subsequently announcing the results during the Buddy Walk at Hadley's Park on Saturday, Oct. 5. As excited as I am to have more free time, I find myself wondering what I will do with myself. I have spent the past seven years thinking about how we can grow and improve DSNMC. It has been exhilarating and exhausting all at the same time. Even so, I wouldn't trade it for anything.

I have had the great fortune to meet some of my dearest friends through DSNMC as well as so many wonderful people that I cannot wait to get to know better. The DSNMC family and the vision of what could be have been driving forces throughout my tenure. I was able to give for a significant period of my life to a community that I have passion for, and as rewarding as that is, I was also able to watch my own ideas blossom and grow and become real, tangible programs or services that helped people. As I move on, I wanted to share what I wish for - because it will take each and every one of you to make it happen.

**Find a way to support DSNMC.** Keep in mind that there are many ways to support DSNMC. Serving on the Board of Directors, volunteering at a key event, helping coordinate parent workshops, contributing to the list-serv with quality information, raising money for the Buddy Walk, getting corporate sponsors, personally donate ... I could go on and on. Some of these may seem impossible and unfathomable to you at this point in your life, but always keep an open mind. Life has a funny way of twisting and turning and what you cannot do now may be a possibility next year or the next. There is a time in this journey that we are on that we weigh heavily on the side of "takers" and then all of sudden we become the "giver". Embrace each one, and do not feel guilty, the opportunity will be there for both.

**Make suggestions and give feedback.** Everyone who serves on the Board of Directors is a VOLUNTEER. Show your interest so that they are inspired to serve the organization and in turn serve you and all of our members.

**Share information.** The Down syndrome landscape is ever changing and we all need to share information. Respectful, professional dialog is necessary on the list-serv and at events to keep us all informed. As we all say, it takes a village to raise a child, and that is especially true for all of us.

I am looking forward to seeing everyone at the Buddy Walk. It will be a sentimental day for me. The Buddy Walk was my first endeavor with DSNMC, eight years ago. Being a part of this organization has been inspiring, and I hope that you all are equally inspired by what lies ahead.

*Gena*

## ADVOCACY UPDATE: ETHAN SAYLOR

*DSNMC Members: Please take a moment to take action TODAY!*

**From the National Down Syndrome Society (NDSS)**

Down Syndrome Advocates:

On July 22<sup>nd</sup>, NDSC and NDSS issued a letter to Governor O'Malley which stated, in part, that Ethan's Fourth Amendment right to be protected against unreasonable seizure was violated by the excessive force used by the deputies and that his rights under the Section 504 of the Rehabilitation Act of 1973 were violated. While the letter called for numerous actions to be taken, the Governor has failed to respond to this letter.

Our organizations commend Maryland Delegate Heather Mizeur for joining our call on Governor O'Malley to launch "a full investigation and inquiry" into Ethan Saylor's death.

*We still need your help to continue to **email, fax, and/or call Governor Martin O'Malley of Maryland to demand an independent investigation into the death of Ethan Saylor.***

Please contact Governor O'Malley of Maryland **TODAY** by visiting the link below, and responding to this action alert with a phone call or letter/email demanding justice for Ethan. NDSS/NDSC are asking for action TODAY on the Ethan Saylor case. Below is the link to take action:

**[www.votervoice.net/NDSS/Campaigns/32591/Respond](http://www.votervoice.net/NDSS/Campaigns/32591/Respond)**

Please direct questions to:

Ginny Sessions  
 Grassroots & Development Programming Manager  
 National Down Syndrome Society  
[gsessions@ndss.org](mailto:gsessions@ndss.org)  
 (202) 465-3221

### REMEMBERING **ETHAN SAYLOR**



**1987 – 2013**

### Smile for the camera!

Any DSNMC parents interested in having their child's photos decorating **First Annual Tribute 21 Masquerade Ball** benefiting Research Down Syndrome (RDS) are welcome to attend a studio session with photographer Bridget Conley from 9 a.m. – 1 p.m. on Saturday, Sept. 14 at Studio Art in Rockville. The photos will be blown up and featured at the event and parents can purchase photos with the proceeds going to RDS.

To participate, contact Bridget at 240-731-5755 to set up a time.



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## SELF-ADVOCATE WORKSHOPS: PALS PROGRAMS AND ARTSTREAM

**By: Ricki Sabia, DSNMC Board Member**

DSNMC is collaborating with PALS Programs and Artstream to provide a two-hour workshop on public speaking in the Fall and a two-hour workshop on self-advocacy in the Winter for teens and young adults with Down syndrome and their friends, siblings and peers (ages 16 -30). Artstream has been hired to run the workshops, which apply the acting techniques taught in their drama classes to public speaking and self-advocacy. PALS Programs will provide peer volunteers to enhance the inclusive experience. Attendees will gain important communication skills and confidence while having fun and meeting new people! We hope some of the attendees will be interested in doing presentations at local schools or advocating with policymakers. However, all of the self-advocates will benefit by becoming more comfortable expressing themselves. There will be no fee to attend, but attendance is limited. Attendees at the Fall workshop will be given priority for the Winter workshop.

**PALS Programs ([www.palsprograms.org](http://www.palsprograms.org))** is a non-profit organization that has run summer camps and other activities to teens and young adults with Down syndrome for 10 years. PALS provides opportunities for independence and skill-building in fun, inclusive environments. There are Camp PALS summer programs at Georgetown University as well as activities arranged by PALS Adventures and PALS Fit throughout the year.

**ArtStream ([www.art-stream.org](http://www.art-stream.org))** is a regional organization whose mission is to create artistic opportunities for individuals in communities traditionally under-served by the arts. They have numerous programs for individuals with disabilities, including inclusive theater companies. Their Leadership Programs teach individuals with disabilities to communicate with confidence in fun, interactive sessions based in the arts.

## DSNMC THANKS ELIZABETH AND MIMI!

**THANK YOU** to Elizabeth Totah for her time and effort in making the DSNMC newsletter what it is today! A few years ago when Elizabeth took this critical task on for the organization, it was a simple document. Elizabeth has worked tirelessly to transform the newsletter into a solid piece of quality information for our membership. She coordinates with so many people to ensure we do not miss an activity, event, sponsor, or piece of news. Even moving to Malaysia didn't stop her! A few years ago when her husband was relocated by his job, she continued to support and produce the newsletter for us. Her commitment to DSNMC has been a gift to us all!

DSNMC would like to say **"So long and THANK YOU,"** but not good bye to Mimi Gehres, whose Board of Directors term ended in June. Mimi was an integral part of the foundation of DSNMC's growth over the last 3½ years and developed our medical outreach program. Mimi established relationships with local hospitals, genetic programs and genetic counselors to focus on delivery of diagnosis for new families. She coordinated speakers like Dr. Brian Skotko, to present at grand rounds at these hospitals in addition to parent presentations. DSNMC has been fortunate to have her expertise and talent during such a critical time. Mimi also chaired the Buddy Walk in 2011 which is the most critical event for DSNMC to maintain its services and programs. Thank you Mimi for all of your hard work and countless hours to make DSNMC what it is today!

### A DSNMC WELCOME

Dawn and Mike Piper have assumed responsibility for the DSNMC newsletter. Dawn and Mike live in Silver Spring with their three boys, Ryan, Colin, and Brendan. Dawn and Mike became members of DSNMC a little over two years ago when their youngest son Brendan was born.

We are grateful to Mike and Dawn for taking on this role. If you have any suggestions for articles or would like to contribute to a future edition of the newsletter, please contact Mike or Dawn at [dawn@dsnmc.org](mailto:dawn@dsnmc.org) or [mike@dsnmc.org](mailto:mike@dsnmc.org).

# Community FIRST

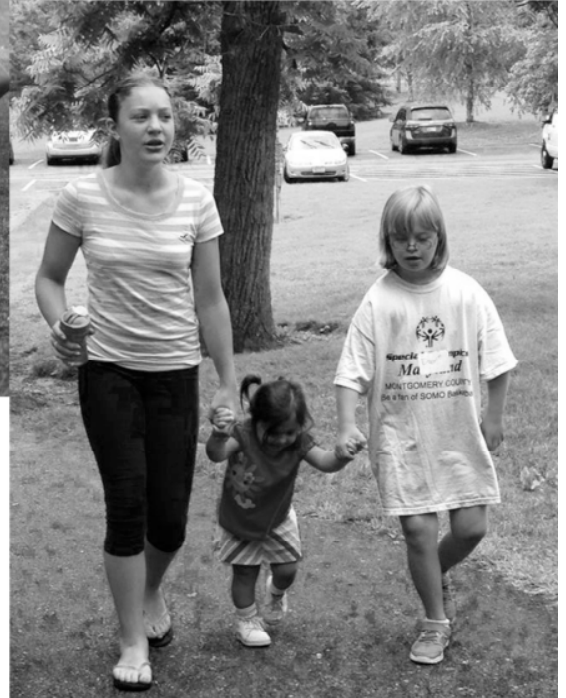
EagleBank is proud to support the Down Syndrome Network of Montgomery County 2013 Buddy Walk.

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

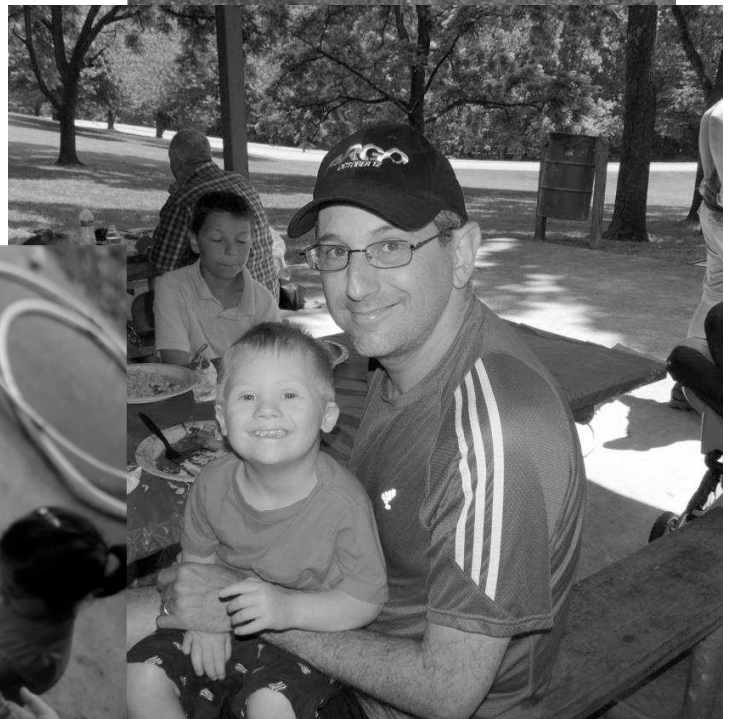


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**DSNMC Summer  
Picnic!**  
Black Hills Regional  
Park  
June 2013



## Techniques for Success 2013

continued from front page

### Topics for 2013

Based on past participant feedback, we're inviting fewer speakers this year to allow for greater depth in the presentations. 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 parents of children with Down syndrome as well as experts in their fields.

Participants will also hear from **self-advocates** Jordyn Dannenbaum and Candace Whiting about their educational experiences. All four speakers will present at both TFS for Parents and TFS for Educators.

### Registration

Online registration is now open at the TFS website (<http://techniquesforsuccess.org/>) and is free of charge. Please download a flyer from the website to share with your child's teaching team. The registration deadline is Friday, October 11, 2013. Be sure to register early, and encourage your child's teachers to do so also, as both conferences tend to fill up quickly and have waiting lists.

### Supporting TFS

This year, parents have the opportunity to support the TFS conference with a \$100 gift given in honor of their **favorite educator**. The favorite educator

could be an individual, group of teachers or a school. This is a wonderful chance to help improve education for students with Down syndrome in our area while recognizing those who have made a difference for your child. Details are on the enclosed Favorite Educator Sponsorship Form, which is due by October 1.

Beyond sponsorship, the TFS Planning Committee would welcome help with preparations for TFS. If you are interested in small or large tasks, please contact Heather Sachs, TFS Planning Committee Co-Chair, at [heather@dsnmc.org](mailto:heather@dsnmc.org).

**Know an educator you want to sponsor? Fill out the form on Page 18**



***It's time to register ...***

### ***TECHNIQUES FOR SUCCESS (TFS) CONFERENCE***

#### ***TFS for Parents\****

Friday, Oct. 25  
6 - 9:30 p.m.

#### ***TFS for Educators\****

Saturday, Oct. 26  
8 a.m. - 4 .p.m

*\*Note – There is a new location for both workshops. The Hilton Washington DC North/Gaithersburg will host the events. The facility is located at 620 Perry Parkway, Gaithersburg, Md.*





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## SELF-ADVOCACY STARTING A SELF-EMPLOYED BUSINESS

By Elliott Greher, DSNMC parent

A question most of us parents face as our children grow older is how they will spend their time and generate some income in the process. There are certainly jobs out there but often they are limited not only in terms of compensation but in scope as well.

One option that may not seem possible on the surface but in fact offers our children a chance at good compensation and a flexible breadth of responsibilities is running his or her own business. Self-employment generally requires the assistance of an aide – whether that is a third party or the parent is up to you. But it also offers a flexibility that allows for your child to handle as many roles and responsibilities as he or she is capable of performing. The aide can oversee some of the more complex activities as well as transportation, thus broadening the business opportunities. The disabled person is tasked with the duties he or she can handle depending on his or her strengths and abilities.

For the past seven years, my son Josh has run a vending machine business selling bottled drinks. With help from the State of Maryland, Josh owns two vending machines entirely, and manages a third provided by Pepsi Cola.

Getting started required a bit of leg work as Josh needed to procure \$14K in seed money. In order to acquire the money, Josh prepared a business plan to apply for funding from “Reach Independence through Self-Employment,” a program funded by Maryland’s Division of Rehabilitative Services (DORs).

In order to develop the plan we accompanied Josh to a few classes. The finalized draft was easily prepared and was accepted without incident. The resulting business was then listed as a minority/disabled business by both Montgomery County and the State of Maryland.

With the seed money in hand, Josh set out to purchase the vending machines. The two machines Josh bought cost \$6K new when the business began and, were he to discontinue the business, he could sell the machines and keep the proceeds. Selling vended drinks is a popular self-employed business for intellectually disabled persons in Maryland. Joshua received the \$6000 from the State Of Maryland plus \$8000 to buy bottled drinks, a sum that covered several refills to the machines.

The vending machines are located in the cafeteria of two separate schools and the business has a storage closet for extra drinks in one school. Twice each week, Josh travels to the schools to fill the machines and to collect cash from sales. His aide, funded by the Maryland Developmental Disability Association (DDA), provides transportation and guidance to Josh. We, his parents, order more soda and help with the paperwork. The business pays various taxes to the State of Maryland and a space rental fee to the schools. Josh makes about 12% for each dollar sold, a sum he reports to the IRS and the State of Maryland on his Federal and State Income Taxes.

Most importantly, Josh enjoys the work and the contacts he makes with the employees at the vending machine sites. The business also provides him a small annual income.

### Want to learn more?

There are plenty of on-line resources to help you on the path to self-employment.

Here are a few:

The **National Collaborative on Workforce Disability’s** guide to self-sufficiency:  
**[tinyurl.com/lac8p6m](https://www.tinyurl.com/lac8p6m)**

The **U.S. Department of Labor’s** disability resources page:  
**[tinyurl.com/kozmbx9](https://www.tinyurl.com/kozmbx9)**

Disability.gov’s self-employment page  
**[tinyurl.com/6tp92eh](https://www.tinyurl.com/6tp92eh)**

## At the Old Ball Game

By Kari Hicks, DSNMC parent

On a beautiful, warm July evening we had the pleasure of attending a Washington Nationals game with DSNMC and Camp PALS. Prior to the event, I had never heard of Camp PALS, an organization that runs week-long camps across the country pairing up college students and young adults with Down syndrome. The camps aim to offer a variety of new opportunities and activities while encouraging the more independence for, and awareness of the Down syndrome community.

The game was a chance for DSNMC families to meet some of the Camp PALS campers and their counselors who were attending camp at Georgetown University that week.

We got to our seats just as the game was beginning. There were three long rows filled with teenagers and young adults distinguished by the Camp Pals t-shirts they were wearing and another two rows of DSNMC members. Everyone was having a good time. I had the opportunity to speak with some of the counselors about how they got involved with Camp PALS. It was clear just watching the group's interactions that camp was fun and enriching for the campers and counselors alike.

I look forward to the day when my daughter, Bella (2), is old enough to be a camper and hopefully her sisters and brother can be counselors in a few years. Bella, for her part, loved the game, the fireworks and, like most kids, the concessions.



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**Continued from front page**

While it might have been a bit more timely had the Nats held up their end of the bargain, the 2013 Buddy Walk will indeed feature a baseball theme. “Take Me Out to the Buddy Walk” is the official theme for the event, which will take place on Saturday, Oct. 5 at Hadley Park in Potomac, Md. Registration begins at 10 a.m. and events will run through 2 p.m.

In addition to the standard events – the moon bounces and carnival-type activities – there will be a host of opportunities for all participants to get a little taste of October baseball.

“There is a lot that goes into baseball and we felt like there may be a lot of kids that haven’t really gotten any exposure to it,” Mordan said. “We’re going to have volunteers working with the kids to make sure everyone gets a chance to participate and we’ve reserved both fields so the kids can run the bases.”

DSNMC coordinated with 5-Tool Baseball to have some of the players come out as volunteers and partnered with Camp PALS ([www.camppals.org](http://www.camppals.org)) to organize a softball game and some other events to ensure there is something to appeal to each age group represented at this year’s Buddy Walk.

One of the event’s in-kind sponsors – Fitness for Health – is bringing equipment and providing some activities as well. The Rockville-based gym provides state-of-the-art fitness training and occupational therapy. The business uses new technology and play-based strategies to make what otherwise may feel like work, feel more like fun.

As always, raising awareness and money for the programs and services the Down Syndrome Network of Montgomery County provides is a key focus of the Buddy Walk. Last year’s record-setting year featured around \$100,000 in fund-raising. Bettering that mark is the focus this year, and the organizers have tried to make it even simpler for participants to help in that regard.

“Last year we had a few different links depending on if you were registering or setting up a team or fund-raising, but this year you can do everything in one place,” Mordan said. “We had a great year last year but some of our corporate sponsors aren’t participating this year so we are relying even more on our members to help generate fund-raising and find new sponsors as well.”

To register and create a team to help raise money, visit [www.crowdrise.com/BuddyWalk2013](http://www.crowdrise.com/BuddyWalk2013).

The money raised funds programs such as the Techniques for Success Conference, parent workshops and outreach to new families and medical professionals. It also helps fund social events such as the winter dance, spring picnic, monthly playgroups and coffees.

“We have grown tremendously over the past few years,” Mordan said. “But we know we can do more.”



*The carnival-style rides and games are always a big attraction at the Buddy Walk but this year’s theme should only broaden the event’s appeal, allowing participants to take part in a variety of baseball-related activities.*



*Last year was a record-setting Buddy Walk with participants and corporate sponsors combining to raise more than \$100K in funds, which go to support the Down Syndrome Network of Montgomery County’s events and programs. The goal is to eclipse that total this year.*



## ADVOCACY UPDATE

### ***Examining the ABLE Act and Burden of Proof***

By Vittoria Aeillo, DSNMC parent

As parents, we all have the same dreams and wishes for our children: that they can live happy and fulfilling lives and become independent and contributing members of the society. For parents of children with disabilities, these dreams and wishes are no different, but they might be more challenging to accomplish. Sometimes, federal and state laws and policies might prevent people with disabilities from obtaining the most appropriate education or becoming fully independent. Two important pieces of legislation that could play a crucial role in helping people with disabilities realize their dreams and ambitions are the ABLE Act (reintroduced in 2013 in the U.S. House of Representatives and in the U.S. Senate) and the bill on the Burden of proof (introduced in the 2013 Legislature of the State of Maryland).

#### ***Able Act – Background and current status***

Under current law, families in the U.S. have the opportunity to save for their children's education through tax-favored 529 education savings accounts. However, parents of children with disabilities do not have access to the same federal and state tax benefits 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. To overcome this discrepancy, the Achieving a Better Life Experience (ABLE) Act (H.R. 647/S. 313) was reintroduced with bipartisan support by Rep. Ander Crenshaw (R-FL) in the House of Representatives and by Sen. Robert Casey (D-PA) in the U.S. Senate in February 2013, in the 113th Congress. The ABLE Act had been introduced in the 111th Congress but time ran out before Congress could move the legislation forward.

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. These savings would supplement, not replace, the benefits provided through private insurance, the Medicaid program, the Supplemental Security Income (SSI) program, the beneficiary's employment, and other sources. Qualified disability expenses include health and wellness, education, employment support, housing, transportation, and miscellaneous expenses (e.g., financial management and administrative services, legal fees). The total assets on the ABLE account will only affect SSI benefits, which will be suspended if the assets reach \$100,000. However, the beneficiary will still be eligible for Medicaid, independently of the total assets in the ABLE account, and even if SSI benefits are suspended.

At this time, the ABLE Act is in the process of being considered in several committees in the House and in the Senate. If it receives favorable vote, it will go to the floor of the House and Senate. However, even if hearings are held, the committee may fail to take action. Thus, gaining co-sponsors is crucial to call attention to the bill and build the pressure necessary to move it through the legislative process. Currently, the ABLE Act has been co-sponsored by 250 congressmen in the House and 41 in the Senate. This is a good result, but more co-sponsors are needed.

Everyone is encouraged to support this crucial piece of legislation, by contacting their senators and representatives and urging them to cosponsor this bill. The names of representatives in a congressional district can be found by zip code on the House website: [www.house.gov/representatives/find/](http://www.house.gov/representatives/find/). The names of senators in each state can be found on the Senate website: [www.senate.gov/general/contact\\_information/senators\\_cfm.cfm](http://www.senate.gov/general/contact_information/senators_cfm.cfm).

#### ***Bills on Burden of proof***

Education is a life-long process and one of the most important processes in a person's life. It gives every individual the opportunity to reach their full potential. Appropriate and quality education for people with intellectual disabilities is especially crucial given the hardships and challenges these individuals face to gain independence and inclusion in their communities.

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## ADVOCACY UPDATE

*Continued from page 13*

Under the Individuals with Disabilities Education Act (IDEA), when parents of a child with disabilities and a local school district disagree over the child's individualized education program (IEP), either side has a right to bring the dispute to an administrative hearing officer for resolution. IDEA does not indicate whether parents or school districts have the burden of proof in special education hearings. If a statute does not specify which party has the burden of proof, the plaintiff typically has the burden of proof. A 2005 U.S. Supreme Court decision on the Schaffer v. Weast case established that the party filing a due process complaint about an individualized education program (usually the parents) bears the burden of proving to the Administrative Law Judge that the IEP does not provide adequate educational benefits. However, parents of disabled children are at a significant disadvantage in due process hearings for several reasons, including the lack of evidence required of the district, the legal resources a district has access to, and the fact that many of the experts testifying in a hearing are employed by the district.

‘The measure of  
a civilization is  
how it treats its  
weakest  
members.’

**Mohatma Gandhi**

As a consequence, placing the burden of proof on parents discourages many parents from challenging inadequate IEPs and, thus, compromises the opportunity for students with disabilities to receive appropriate educational

On the contrary, the burden of proof should fall to the school districts since, under federal law, the district is responsible for ensuring the appropriateness of the educational program. The district must be required to assume the accountability for the success of the program and should be working in collaboration with parents to assist in the process.

Two bills have been introduced in the 2013 Maryland State Legislature – House Bill 1286 and Senate Bill 691– to require public schools to bear the “burden of proof” in due process hearings between parents of students with disabilities and their school district. Broad support has been recorded around the bills. A total of 814 signatures supporting the measures were collected in an online petition on Change.org. The Maryland Disability Law Center and the Maryland Coalition for Inclusive Education also supported the bill by testifying at the hearing.

However, due to the strong opposition of the teachers’ union, the bills have been withdrawn, in order to avoid that an unfavorable vote would prevent the bills from being presented again in this legislative session. The main argument conveyed by the teachers’ union in opposition to the bills was that the burden of proof on school districts would result in increased paperwork for teachers. However, this argument was totally unfounded as schools are already required to maintain records to show compliance with IDEA.

Advocates, support groups, organizations, and parents play a key role in the process of providing legislators, teachers and districts accurate information on the burden of proof relative to ensuring that a minority group of disabled individuals receive equal treatment in hearings and the educational process as a whole.

Continuing to build and expand support is also critical. When the bill will be reintroduced, support can be provided by contacting the state delegates and senators and letting them know about the importance of the bill on the burden of proof. The names of state delegates and senators in each district can be found on the website <http://mdelect.net/> by simply entering a street address.

Everyone has the right to reach their full potential. Parents of children with disabilities have the same rights as any other parent to obtain appropriate quality education for their children. If we allow injustice and disparity toward the weakest to exist in our society, we can rest assured that one day it will adversely impact all of us.





DSNMC  
Play Date  
Cedarbrook Swim  
and Tennis Club  
July, 2013







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

Anonymous

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**Techniques for Success: Favorite Educator Sponsorship**

We invite you to consider donating \$100 to the 5<sup>th</sup> Techniques for Success (TFS) conference to become a Favorite Educator Sponsor to support the conference scheduled for Saturday Oct. 26, at the Hilton Washington DC North/Gaithersburg. By becoming a Favorite Educator Sponsor, you will be helping F.R.I.E.N.D.S. and DSNMC provide educators in Frederick, Montgomery and neighboring counties with strategies to effectively teach students with Down syndrome and other special needs. You will also be letting your child’s educators know that you appreciate their efforts.



The names of educators who are designated as Favorite Educators will be displayed on placards on the TFS conference tables. Additionally, the Favorite Educator will receive notice of your donation in his or her honor. You may recognize a single individual, or a group of individuals, or a school team. Please complete a separate form for each individual, group or school that you wish to recognize. Please contact Heather Sachs ([heather@dsnmc.org](mailto:heather@dsnmc.org)) or Katie Routzahn ([krouzahn@friendsofredco.org](mailto:krouzahn@friendsofredco.org)) with questions.

*Please see [www.techniquesforsuccess.org](http://www.techniquesforsuccess.org) for more details about the Techniques for Success conference. Techniques for Success is co-sponsored and hosted by F.R.I.E.N.D.S. of Frederick County ([www.friendsofredco.org](http://www.friendsofredco.org)) and the Down Syndrome Network of Montgomery County ([www.dsnmc.org](http://www.dsnmc.org)). Both F.R.I.E.N.D.S. and DSNMC are 501(c)(3) tax-exempt organizations, and all sponsorships will be tax-deductible to the extent permitted by law.*

Please complete entire form (Print or Type)

Your Name: \_\_\_\_\_

Your Address: \_\_\_\_\_

Your Phone: \_\_\_\_\_

Your E-mail: \_\_\_\_\_

Name of Educator(s) being honored: \_\_\_\_\_

School Affiliation of Favorite Educator: \_\_\_\_\_

E-mail Address of Favorite Educator (If not known, please provide mailing address.):

\_\_\_\_\_

Please return this form by Tuesday, Oct. 1, along with a check for \$100 made payable to:

**Down Syndrome Network of Montgomery County**  
P.O. Box 10416  
Rockville, MD 20849



(Please include “TFS 2013 – Favorite Educator Sponsorship” in the memo line of the check.)



## Call for Nominations for DSNMC Board of Directors

### President

DSNMC is seeking a new president to join its Board of Directors at the end of 2013. The president's general duties include but are not limited to: acting as a spokesperson for DSNMC, overseeing the day-to-day operations of the organization, working with the part-time event manager to plan the Buddy Walk (an annual fundraiser and advocacy event), and organizing and attending bi-monthly meetings of the Board of Directors and Executive Committee. The president also will work closely with the part-time administrator on details related to operations, communications, finances and membership. And to help DSNMC achieve its goals, the president will establish working and/or collaborative arrangements with other organizations.

### Secretary

DSNMC is seeking a secretary to join its Board of Directors. The secretary is responsible for attending meetings of the Board of Directors and the Executive Committee, drafting minutes and related correspondence, and working with the part-time administrator to oversee DSNMC's administrative functions. This person will also assist with the newsletter and will be involved in key decision making on day-to-day operations and the overall strategic direction of DSNMC.

Contact Gena Mitchell at [gena@dsnmc.org](mailto:gena@dsnmc.org) for more information.

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## DSNMC EVENTS

### Play Groups

Saturday, Sept. 14  
Croydon Creek Nature Center  
Rockville, MD

Saturday Oct. 19  
Woodend Nature Center  
Chevy Chase, MD

\*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

## Buddy Walk 2013

Saturday, Oct. 5  
10 AM - 2 PM  
Falls Road (Hadley's) Park  
Potomac, Md

Register or donate at [www.dsnmc.org](http://www.dsnmc.org)

Buddy Walk Manager: Susan Mordan  
email: [buddywalk@dsnmc.org](mailto:buddywalk@dsnmc.org)  
p: 301-263-0419

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

[dsnmc.org](http://dsnmc.org)

### Coffee and Conversation

Sept. 10 and Oct. 8  
2<sup>nd</sup> Tuesday of each month  
10:30 - Noon

Caribou Coffee  
Westfield (Montgomery) Mall  
Bethesda, MD

Contact Karen O'Connor at  
301-972-5138 or [tkrbmo@verizon.net](mailto:tkrbmo@verizon.net)

### Techniques for success

#### TFS for Parents

Saturday, Oct. 25 from 6 -9 p.m.

#### TFS For Educators

Saturday, Oct. 26 from 8 a.m. - 4 p.m.

Location: Hilton Washington DC North/Gaithersburg  
Register at: [www.techniquesforsuccess.org](http://www.techniquesforsuccess.org)

## COMMUNITY

### 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](mailto:LNANCY@MAIL.NIH.GOV)  
<http://patientinfo.nimh.nih.gov>

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[301-365-0561](tel:301-365-0561)



# National Down Syndrome Congress Convention

*A chance to learn, share and connect with fellow DS parents*

**By Valerie Williams, DSNMC parent**

On March 2011 at approximately 8:30pm, the nurse leaned down as I lay on the table, still open from my planned C-section, she said, "Mom, he's showing soft markers for Down syndrome so we're going to run some tests." She walked off, leaving me to wonder what is Down syndrome, how will this affect him, and why couldn't she just leave me a few moments to enjoy the birth of my child in peace? From that moment on my life has never been the same.

Soon we were off and running: meetings with the geneticist, cardiologist and pediatrician, and beginning therapies with the Infants and Toddlers Program. I soon realized that we were not alone. Many had come before and had valuable information to share. I began asking parents of other children with Down syndrome, "If you knew then (when your child was younger), what you know now, what would you do differently?"

I received many helpful answers and we put into place as much as we could. One piece of advice was to attend the National Down Syndrome Congress Convention. The what? They have one of those? It turned out the 2012 conference was conveniently being held in Washington, D.C. The icing on the cake was that the director and two teachers from our son's new daycare decided to attend as well.

If you've never attended the convention, you are doing yourself a great disservice. It's enlightening, fun, full of information and emotional ... sometimes all at the same time!

The seminars are broken down by age: if your child is 2, there's something for you; if your child is leaving high school, you'll be very interested in the increasing number of seminars on transition, independent living, employment and a host of others. There is, quite literally, something for every age.

That doesn't include the seminars that are applicable to everyone such as guardianship, financial issues, advocacy and anything related to federal funding and upcoming bills related to our families.

2014 NDSC Convention info

**Where:** Indianapolis

**When:** July 11-13, 2014

For more information and/or recordings of 2013 sessions, visit <http://convention.ndscenter.org/>

Most noteworthy are the sharing sessions and general plenary sessions. Sharing sessions take place in the afternoon on the first day. Generally speaking they're for adults, and encompass a wide range of interests.

The general plenary sessions are heavy on hearing from the heads of organizations who are doing fabulous work for our community and self-advocates who remind us to dream big. As the mother of a 2-year-old, it warmed my heart and brought tears to my eyes to hear self-advocates speak about obtaining a driver's license, living independently, owning their own businesses, being employed, and interacting with their peers.

For many of the self-advocates and children the highlight of the weekend is the fabulous awards ceremony and dinner, followed by Let's Dance!, an old fashioned party for those of all ages; pretty much anyone who wants to have a good time.

Don't think you can get away? Not a problem because the Convention is a "Cause-cation". That's a vacation with a cause and a purpose. There's a camp for typically developing children and teens that occupies the other family members while you go enjoy the rest of the convention. In addition, there are sibling only events, and this year a Down syndrome-Autism track of seminars was added.

I am extremely grateful for something of this magnitude taking place to validate and verify that my parenting skills are more than "good enough" and the future is bright and promising.

Next year's convention is in Indianapolis. Decide right now that you and your family are worth the trip and look forward to having the time of your life!

**Happy Halloween!**

“People have only as much liberty  
as they have the intelligence to want  
and the courage to take.”

- Emma Goldman



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O manda por correo esta porción de la pagina a:

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