

# CONNECTIONS

*Newsletter for Self-Advocates, Parents & Friends*

It was wonderful to see so many new faces at the Winter Dance last month! As I absorbed the laughter and dancing, I knew a good time was had by all, which was exactly what we all needed on a cold Saturday evening in February. As the Board was planning the dance I was reminded of how support groups like DSNMC evolve and why. We grow out of the needs for our families to connect with each other. It is with events like these that we are able to provide that opportunity for everyone and I feel fortunate to be a part of making that happen for our families.

**Gena Mitchell**  
**President**  
Email: [gena@dsnmc.org](mailto:gena@dsnmc.org)

2011 is destined to be a year of growth for DSNMC, and I want to tell you about a few things that are occurring now and others that you can expect later this year. You may have noticed the new DSNMC logo on this newsletter. We have been fortunate to become a pro bono client of New Signature, ([www.newsignature.com](http://www.newsignature.com)) a creative technology firm based in Washington, DC. New Signature has been working for many months on a new website for us that is progressive and packed with

up to date information, resources and information about DSNMC and this includes our new logo. The DSNMC Board is dedicated to providing our families and our community with the resources that we need throughout our journey with Down syndrome. To do this, we saw the importance of building a website that is simple and easy to navigate for our members so that we can have a repository of quality information that is helpful to each of you. We value your feedback as well as information that you can share to be included on the site. I hope that once you are done reading the newsletter, you will take a few minutes to check us out online at [www.dsnmc.org](http://www.dsnmc.org).

We are awaiting the approval on our 501c3 - it is our hope to have this complete by the Buddy Walk in October 2011. Once again, we have been fortunate enough to become a pro bono client for the law offices of Patton Boggs ([www.pattonboggs.com](http://www.pattonboggs.com)) in Washington, DC and they have been working on this for us. Once we have completed the application process and our 501c3 has been approved, we will be able to continue to build on the foundation that we have created for DSNMC and expand our resources to educators, healthcare professionals and most importantly quality events like the winter dance that are so important to the health of our community.

The DSNMC Board of Directors have a responsibility to provide the core resources, like getting connected with the Infants and Toddlers program for early intervention, genetics contact information, potty training guidance, and so on. Just as important, if not more, is for us to create and nurture the platform for friends and families to gather and enjoy each other, or help each other, if needed. This is why groups like DSNMC evolve, because we as parents or family members or friends who are on this Down syndrome journey want and need the opportunity to talk to each other. I have never met another group of people who are connected by a common thread to be so giving. Everyone wants to share their story, their information, and really anything they can give. So I find it interesting that our kids are called "special" when really it's those around our children that are "special", and our kids, well, they are kids. It is this thought that guides me as the DSNMC President, and I hope that you will reach out to me with any questions, concerns, or ideas for changes. As the Board of Directors guide the path for DSNMC, we remain a grass roots organization that is driven by the needs of our community.

## Inside This Issue

Perspectives: A Young Babysitter

Film Review: Yo Tambien

Navigating the Insurance Maze

Advocacy News:

- Buddy Walk On Washington!
- Lorraine Sheehan Act

What is Self-Advocacy?

Education: Techniques for Success

Upcoming Events

# PERSPECTIVES

My name is Kelsey, and I am a senior at Our Lady of Good Counsel High School in Olney, Maryland. What started out as an obligation to fulfill service hours for my school has turned into a rewarding and fulfilling experience for me. When I was assigned to volunteer at the Marvatots program, to assist children with disabilities, I was a little apprehensive. I do not have any younger siblings, and I did not have a great deal of experience working with young children, especially children with special needs. With the help of the director, I was able to work with the children and I began to look forward to my time with them every week. It was through this program that I was introduced to a beautiful little girl named, Abby and her sweet little brother, Roman. Abby has Down syndrome. When the program ended, I really missed my time with the children, and I let Mrs. Dudish, the director, know that over the summer I would like to be available to babysit for any families that may need my services. From the first time I babysat for Abby's family I knew I had made new friends and would have a long-lasting rewarding experience ahead. My apprehension went away and I soon realized that Abby and Roman had a great deal to teach me. Abby is outgoing and honest with her feelings. She greets everyone with a bold hello and makes friends everywhere she goes. She is honest and inspires me to be a better person. Babysitting for a child with Down syndrome is so rewarding. I love the feeling of helping out others. I thought I would make a difference in the life of a child with special needs, but Abby is the one who has made a difference in my life.

**By Kelsey Mirkin**

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If we had no winter, the spring would not be so pleasant; if we did not sometimes taste of adversity, prosperity would not be so welcome.

~Anne Bradstreet

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WINTER DANCE  
Brookside Gardens  
2011

# FILM REVIEW

## Yo También

By Patricio Korzeniewicz

Pablo Pineda is an impressive young man. A citizen of Spain and 35 years old, he became the first person with Down syndrome to receive an university degree in Europe (a B.A. in Educational Psychology). He is a strong and outspoken advocate for people with disabilities. He is also the star of Yo También, a 2009 Spanish movie directed by Antonio Naharro and Álvaro Pastor.

Yo También explores the relationship between Daniel, the character played by Pablo Pineda, and his office co-worker Laura (played powerfully and tenderly by Lola Dueñas). Daniel has just begun working in a state agency providing social services to people with disabilities, and as in many other areas of his life, his skills and abilities constantly surprise those around him. Daniel is critical and humorously aware of the prevailing low expectations, and some of the funniest moments in the film come when he plays upon and mocks common stereotypes.

But while the movie has many funny moments, it also turns a critical eye on the impact of disabilities on love and sexuality. Daniel's and Laura's professional relationship gradually evolves into a deeper friendship: Laura is emotionally damaged, and both she and Daniel face both pain and happiness as they explore how far to take their love for one another. And here too Daniel must face the doubts of others who care about him (his family), as they question his judgment and his relationship with Laura.

This is a powerful film that raises important issues regarding the interplay between disability, difference, love and sexuality. It is also a humorous and touching movie, with great performances by both professional and non-professional actors (including other young men and women with Down Syndrome). Let's hope that it gets a similar wide distribution in the United States as it had, to broad acclaim, in Spain.



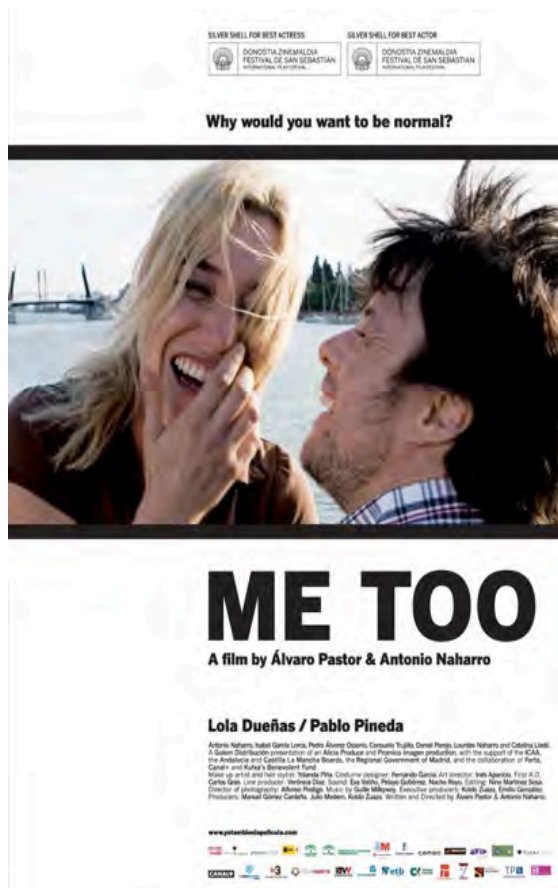
Source: [www.yotambienpelicula.com](http://www.yotambienpelicula.com)

## Yo Tambien/Me Too

By Adrian Forsythe Korzeniewicz

This movie is about a young adult named Daniel. He has Down syndrome. He just finished college and started a job in an office. Daniel develops a crush on a co-worker. This co-worker does not have Down syndrome, or any other intellectual disability, but had a troubled past. The end had a tender and heartbreaking moment. This movie brings up issues, like how much can people with disabilities mainstream in their communities? It also brings up issues like to promote healthy decisions, when having a love and sexual relationship with anyone. The lead star of this movie actually has Down syndrome and just graduated from College. He did not go to any special program. Instead he mainstreamed into general ed classes. He is an inspirational person that people with a disability can look up to.

*Adrian Forsythe Korzeniewicz is a self-advocate and student in the LIFE program at George Mason University.*



Source: [www.yotambienpelicula.com](http://www.yotambienpelicula.com)

# SACHS CAPITAL

# NAVIGATING THE INSURANCE MAZE

By Chiara Jaffe

Dealing with insurance companies can be frustrating and time-consuming. This is particularly true for parents of children with special needs who often have complex health and developmental issues that require ongoing medical care and therapies. One significant issue includes coverage of habilitative services, which are often misclassified as rehabilitative services by insurance companies.

## Habilitative Services vs. Rehabilitative Services

Habilitative services benefit children with congenital or genetic birth defects by enhancing functional skills such as eating, bathing, and dressing through the use of occupational therapy (OT), physical therapy (PT), and speech therapy. The goal of habilitative services is to develop functional abilities that were never present.

Rehabilitative services, on the other hand, include the use of PT, OT, and speech therapy to treat patients who have lost functional ability due to an injury or illness, such as a broken limb or a stroke. The goal of rehabilitative services is to reduce physical or intellectual disabilities and restore the patient to his or her best possible functional level.

Many traditional insurance plans claim never to have heard of habilitative services or that habilitative services are not a covered benefit. Instead, they cover a limited number of sessions for rehabilitative services (e.g., 60 sessions annually), to be shared between PT, OT, and speech therapy. Therefore, any child receiving multiple types of therapy on a weekly basis would likely exhaust the number of allotted sessions well before the end of the calendar year. **It is important to know that if you have a traditional insurance plan, it is illegal to deny coverage for habilitative therapies or to misclassify such therapies as rehabilitative, and therefore subject to a cap at a maximum number of sessions.**

Since 2000, traditional insurance plans are required to cover "Habilitative services, including occupational therapy, physical therapy, and speech therapy, for the treatment of a child with a congenital or genetic birth defect to enhance the child's ability to function" (Maryland Code Subtitle 8, Section 15-835). This Maryland statute applies to children with Down Syndrome who are under age 19 and mandates that these individuals be allowed to receive an unlimited number of sessions of PT, OT, and speech services. *Continued on next page*

### ***Rehabilitative Services***

Goal is to *reduce and restore* due to an injury or illness

### ***Habilitative Services***

Goal is to *develop* functional abilities that were never present. Particularly relevant to persons with Down syndrome seeking therapy.

### ***Know the Law!***

For **traditional** insurance plans, It is illegal to deny coverage for habilitative therapies or to misclassify such therapies as rehabilitative, and therefore subject to a cap at a maximum number of sessions. (Maryland Code Subtitle 8, Section 15-835)

## Traditional vs. Self-funded Insurance Plans

When my husband and I switched from my employer's health insurance plan to his employer's plan at the start of the 2011 calendar year, I assumed that my son, Jake's, weekly private OT, PT, and speech therapies would automatically be covered under the Habilitative Services Statute. What I was not aware of was that not all insurance plans are regulated by the state, and those that are not covered by the state are not required to follow state laws. My husband's health insurance policy turns out to be such a plan – it is referred to as a self-funded plan.

### Traditional Insurance

Traditional (also referred to as fully-insured) plans are established by an insurance company and regulated by either the state Department of Insurance, the state Department of Health, or by special state health insurance boards. (In Maryland, the regulatory body is the Maryland Insurance Administration). Claims are paid directly by the insurance company.

### Self-funded Insurance

Self-funded (also called self-insured or non-insured) plans are established by a plan sponsor, including a company, union, association, or a state municipal or government agency and claims are paid out of company assets by the plan sponsor. At first glance, self-funded plans may appear more appealing than traditional plans because they have lower co-payments and deductibles. However, self-funded plans are regulated through ERISA (the federal Employee Retirement Income Security Act), which is implemented by the Pension and Welfare Benefits Administration of the U.S. Department of Labor. **Therefore, self-funded plans are generally exempt from state laws and regulations related to benefits, including the habilitative services mandate.** In addition, state prompt payment rules and standards of network adequacy for providers (i.e., requirement that there are a sufficient number of geographically accessible participating providers in a network to meet the needs of members) do not apply to self-funded plans. *Continued on next page*



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## Questions to Ask When Selecting a Health Plan

In order to keep other families from making mistakes like the one that I made in selecting a health insurance plan, I have developed a list of questions to ask the insurance carrier that you are considering coverage under before enrolling in the plan:

- **Is this a traditional (fully-insured) plan or a self-funded plan?**

If your child is a high utilizer of habilitative services as our son is, it is probably most cost effective to participate in a traditional plan if you have the choice. If this is not an option, or like us, you chose to participate in a self-funded plan without knowing about its limitations with respect to coverage of habilitative services, there are other possibilities for funding (see section on funding sources).

- **Is this plan an HMO, POS, or PPO and are there out of network-benefits?**

Health Maintenance Organizations (HMOs) have lower out of pocket costs (i.e., lower monthly premiums and copayments) but they require you to seek care with providers in their network and do not provide coverage for services if you go out of network.

Point-of-Service Plans (POSS) are similar to HMO plans, but they do cover out-of-network providers. However, services for out-of-network providers are reimbursed at a lower rate and may be subject to higher deductibles. In addition, POS plans charge higher monthly premiums for providing the flexibility to go out of network.

Preferred Provider Options (PPOs) generally provide a large in-network provider panel and very few plan restrictions. However, they are the most expensive of the three options.

- **Do my family's providers participate with the plan?**

It is important to determine whether any providers seen frequently by each family member are part of the plan's provider network (i.e., group of providers who have agreed to provide services at negotiated rates). If there are a number of providers who are not in network, it may be necessary to switch to in-network providers or consider a plan with out-of-network benefits, if either of these options are possible for your family.

- **Do I need a referral to see a specialist?**

HMOs always require a referral from a primary care physician or pediatrician to see almost any type of specialist, while POS and PPO plans generally do not. However, it is always wise to check before you commit yourself to a specific plan. Also, keep in mind that referrals are generally valid for a specific number of visits over a set period of time (e.g., 4 visits over the course of one calendar year) so you need to ensure that you obtain a new referral before you exceed the number of visits or referral expiration date. In addition, you need to obtain a separate referral for each provider.

- **Is pre-authorization or pre-certification required?**

Many procedures require pre-authorization (i.e., contacting the insurance company prior to hospitalization or surgery to receive approval for that service) or pre-certification (i.e., contacting the insurance company prior to treatment to determine whether the treatment meets medical necessity criteria). It is important to make this determination prior to receipt of services because since it is often not possible to obtain pre-authorization or pre-certification retrospectively.

Therefore, the claim for the service may be denied if you do not contact your insurance company beforehand. *continued on next page*



- **How much are deductibles and co-pays?**

A deductible is a fixed dollar amount that the covered individual must pay annually before receiving reimbursement for health care expenses, and a co-pay is the portion of the fee that the covered person pays. Deductibles and co-pays are generally higher for out-of-network providers because their services are reimbursed at a lower rate. In addition, because out-of-network providers do not have a contract with the insurance company, they can charge a higher fee. Therefore, it is important to contact the billing department of any out-of-network providers to determine how much they charge for a particular service or procedure beforehand.

- **Are preventive services covered?**

HMOs generally cover preventive care such as vaccinations, screening tests, and annual physicals. However, POS plans and PPO plans may not so it is important to ask whether such services are covered.

- **Is it possible to provide coverage for an out-of-network provider at an in-network rate if the participant was already seeing this provider?**

I would never have thought to ask this question, but when my husband and I switched insurance plans, a customer service representative informed me that a member could apply for this benefit if s/he had been seeing a provider for ongoing care before joining the plan and the new plan did not have any appropriate network providers available. It is not necessary for the provider to have been an in-network provider with the previous insurance plan. My son’s private OT and speech therapists do not accept any insurance plans so they were not in-network providers for my previous plan.

If the new plan denies the coverage request, ensure that they have an in-network provider who has experience working with children with Down syndrome, is located in a reasonable radius to your home, and is accepting new patients. If there is not an in-network provider who meets these requirements, then you should be able to appeal this decision. If the plan is able to identify an appropriate in-network provider and, therefore, will not cover your provider at an in-network rate, and you wish to retain your current provider, see the section on funding sources.

*Continued on page 11*

NOTES:

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**Claims Processing and Approval Issues**

Unfortunately, even after you do research to ensure that you select the best insurance plan for your family (if you have an option), and you feel knowledgeable regarding the benefits and the limits of the policy, it is not uncommon to run into claims issues. My family has run into problems related to getting claims processed and approved with both traditional and self-funded plans with which we have participated. Through my own experiences and advice that I have received from other families, I have put together a list of suggestions for dealing with claims issues:

- If a claim is denied initially, it should include the reason for the denial and instructions for appealing the decision. **When you write the appeal letter, include documentation from the relevant provider(s) explaining why the service should be covered, and if applicable, have the provider document why failure to cover the service will likely result in the need for more expensive procedures in the future.** Since insurance companies are most concerned with cost, this may provide incentive to cover the less expensive service.
- **If you are still unsure of why the claim was denied after review of the denial letter, contact the customer service department for your insurance carrier to obtain clarification. It is possible that the wrong diagnosis or billing code was used and you may need to make a call to the provider’s office to have them resubmit the claim with the correct code.** We had a situation in which a claim for an ophthalmology visit was not covered. When I contacted our insurance company, the representative informed me that the claim did not include an appropriate diagnosis so I contacted the ophthalmologist’s billing office. They resubmitted the claim with the diagnosis code for Down Syndrome, and the claim was then covered.
- **If you run into ongoing issues with processing of claims, and your insurance is provided through your or your partner’s employer, contact the Human Resources (HR) Department.** The HR office should have a representative from the plan who works with them directly. Because it is in the insurance company’s best interests to keep the contract with the employer, the plan representative will likely be helpful in facilitating the claims process. I had an ongoing issue with getting out-of-network claims processed. Our previous insurance carrier only allowed claims to be mailed in (rather than faxed) and never received any of the seven different claims that I mailed in, despite the fact that I used extra postage, confirmed the address multiple times, and re-submitted several claims. I finally discussed the issue with my HR department and they then had me fax my claims directly to their representative at the insurance company for processing. **Note: If your insurance is provided through the state of Maryland, contact your case manager for assistance.**

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- **If your claims issues cannot be resolved using any of the suggestions above, contact Congressman Chris Van Hollen's Office.** Complaints and appeals sent directly to the Maryland Insurance Administration (for traditional plans) or the Department of Labor (for self-funded plans) can take over a month to be processed and generally can only be made in writing. Congressman Van Hollen's Office has contacts at both of the Maryland Insurance Administration and the Department of Labor. I have spoken to his office regarding the issue of coverage of habilitative services under a self-funded plan and they have offered to submit my documentation directly to a representative at the Department of Labor should my appeal to our plan for coverage of habilitative services be denied.
- If all else fails, contact an attorney. Many attorneys do not charge for an initial consultation to determine whether or not you have a compelling case.
- Also, although it is best to apply for benefits as early in the fiscal year as possible to ensure that funds are available, there are periods of the fiscal year during which funds are replenished. Therefore, if you are applying later in the year, it is a good idea to contact Community Connection to determine the status of funds. For more information, call 301-583-8880 or 877-622-6688 or go to <http://www.marylandcommunityconnection.org/index.php/services/low-intensity-support-services-liss/>.
- **Maryland's Technology Assistance Program (MD TAP)** provides assistive technology services to Maryland residents with disabilities through equipment loans, a device-exchange program, low-interest financing programs, and cooperative buying discounts. For more information, call **1-800-832-4827** or go to <http://www.mdod.maryland.gov/MTAP%20Home.aspx>.

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## Sources of Funding

In situations in which you are unable to have a service covered (e.g., you have an HMO and your child is receiving PT through an out-of-network provider or you have a self-funded plan and have exhausted the benefit maximum for PT, OT, and speech halfway through the benefit year), there are other methods to help pay for these services (either through your own funds or through a public or private agency):

- **A Flexible Spending Account (FSA)** covers medical and dental expenses not covered by insurance, such as annual deductibles and copayments for office visits, procedures, and medications. Up to \$5,000 in pretax funds can be deducted annually from each wage earner's paycheck toward such expenses. Normally, you will be required to submit a form with the list of expenses incurred and a copy of the invoice or receipt in order to be reimbursed. However, some employers provide FSA debit cards that can be used at appropriate health care related merchants (e.g., doctor's offices, clinics, and pharmacies).
- **Low Intensity Support Services (LISS)** is a statewide program for individuals who meet the service requirements set by the Developmental Disabilities Administration (DDA). (A diagnosis of Down Syndrome meets the requirement). The program is administered through Maryland Community Connection and is able to provide up to \$3,000 per fiscal year (e.g., July 2010 – July 2011). Participants can apply for LISS more than once and there is NOT a financial requirement.
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- **The Mikel Foundation** is a public charity organization founded in 1997 to benefit children and families of children with genetic disorders. The Foundation provides money for the private purchase of wheelchairs, orthotics, gait trainers and various other types of adaptive equipment. There is NOT a financial requirement. For more information, go to <http://www.themikelfoundation.com/> and click on "Contact" to access the grant application.
- **The My Turn Program** is administered by the Community Support Network and provides financial assistance to families of children between the ages of 3 and 13 who have developmental disabilities. The program does not have a financial requirement but does take income into account in making determinations regarding level of assistance provided. For more information, call 240-777-1216 or go to <http://www.montgomerycountymd.gov/hhstmpl.asp?url=/content/hhs/ads/CSN/myturn.asp>
- **United Healthcare Children's Foundation** provides financial assistance toward the family's share of the cost of medical services. This program DOES have a financial requirement. For more information, call (952) 992-4459 or go to <http://www.uhccf.org/>.

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### Where to Go For More Information

- Full statute for provision of habilitative benefits in the state of Maryland:  
<http://www.michie.com/maryland/lpExt.dll?f=templates&eMail=Y&fn=main-h.htm&cp=mdcode/18257/193d2/19666/19716>
- Congressman Chris Van Hollen's Office: Call (301) 424-3501 or go to <http://vanhollen.house.gov/>
- Detailed explanation of differences between traditional and self-funded plans and procedures for appealing a denied claim under a self-funded plan. (Note: This information is provided by the Colorado Division of Insurance, but because self-funded plans are regulated by the Department of Labor, which is a federal agency, the information is applicable to Maryland residents as well):  
<http://www.dora.state.co.us/insurance/consumer/2009%20docs/consFaqERISA062209.pdf>
- Detailed procedures for filing appeals or grievances with the Maryland Insurance Administration (for traditional plans only): <http://www.mdinsurance.state.md.us/sa/jsp/consumer/Appeals.jsp>
- The Maryland Legal Aid Bureau, a private, non-profit law firm provides free legal services to low-income Maryland residents. For more information, call (240) 314-0370 or (888) 215-5316 or go to <http://www.mdlab.org/>

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# SELF-ADVOCACY

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## What is Self-Advocacy?

DSNMC is beginning to offer programs and events to enhance self-advocacy skills for transitioning teens, young adults and adults.

But what do we mean by self-advocate? And you might ask, am I, or is my child, a candidate for self-advocacy?

Self-advocacy is a set of skills that will help individuals with Down syndrome to know themselves better and to be able to communicate their interests and concerns to others. Self-advocacy includes skills in decision-making; listening and speaking; problem-solving; goal-setting; self-awareness; learning from mistakes; and helping others.

As part of our Buddy Walk last fall, we invited Mitchell Levitz, a well known and nationally recognized self-advocate, to speak to a group of self-advocates from our area. Mitchell encouraged these self-advocates to become involved in local opportunities for self-advocates. For background, he recommended a group called Self-Advocates Becoming Empowered (SABE), a national organization started and still run by self-advocates. According to SABE, self-advocacy helps:

To ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends; and to learn from their mistakes. (Source: <http://www.sabeusa.org/>)

DSNMC recognizes the growing role that self-advocacy will play in the lives of transitioning youth and adults with Down syndrome. *We have announced our first training to be held in the spring.* (See p. XX of the newsletter and the website) Our activities will always be designed with three goals in mind: to build skills, to build friendships, and to have fun.

Individuals with DS and their families want greater capacity for self-advocacy, and federal law increasingly calls for it. Self-advocacy is written into major pieces of legislation supporting people with disabilities, including the Workforce Investment Act (and its predecessor Rehabilitation Act of 1973), as well as updates to the Individuals with Disabilities Education Act (IDEA). Starting with the 1990 reauthorization of IDEA, services for transition-age youth must be based on student needs and take into account student interests and preferences. IDEA mandates increased student involvement in transition planning, and students must be prepared to participate in planning for their future.

Moreover, research has demonstrated a positive relationship between self-advocacy and how well individuals fare when they leave school. Students with disabilities who have good self-advocacy skills are more likely to succeed as adults. They are more likely to have jobs, to earn higher wages, and to live independently.

*Continued on next page*



Self-advocacy is a set of skills that an individual acquires over time, and that an individual will likely express better in some situations than in others.

Self-determination is not an all or nothing set of skills. As youth with disabilities mature, it is likely that they will experience different levels of skill and ability with regard to self-determination. ... Healthy adolescent development requires a sense of belonging to a peer group, a sense of accomplishment or mastery of skills (academic, vocational, and social), a sense of having something of value to give back to others, and a sense of independence. (Source: <http://www.ncset.org>)

An important part of achieving success in self-advocacy is being surrounded by people and institutions that provide a context to learn, practice and master self-advocacy skills. We hope that our training and support activities will be an integral component of that process for DSNMC's community of self-advocates.

### **THREE (3) WEBSITES TO KNOW:**

[www.wrightslaw.com/info/self.advocacy.htm](http://www.wrightslaw.com/info/self.advocacy.htm)

This is a terrific collection of media - articles, websites, podcast. It is a great place to start looking into what people are saying about self-advocacy.

[www.ncset.org](http://www.ncset.org)

The National Center on Secondary Education and Transition (NCSET) coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities in order to create opportunities for youth to achieve successful futures. NCSET is headquartered at the [Institute on Community Integration](#) in the University of Minnesota's College of Education and Human Development.

[www.disability.gov](http://www.disability.gov)

An amazing resource with a tremendous breadth and depth of information. On this site, Americans with disabilities, their families, educators, and employers are connected to thousands of resources from federal, state and local government agencies, educational institutions and non-profit organizations. New resources are added daily across 10 main subject areas – benefits, civil rights, community life, education, emergency preparedness, employment, health, housing, technology and transportation.

Want to be a part of the Self-Advocacy & Leadership Network?

Join us! Develop your skills and have fun!

Contact Adrian Forsythe [aforsyt2@gmu.edu](mailto:aforsyt2@gmu.edu) or Nancy Forsythe.

# ADVOCACY

Would you pay an additional dime for an alcoholic drink to reduce Maryland’s budget deficit, lower state health care costs and crime rates, and to help individuals with developmental disabilities? That

proposal is gaining momentum in the State Legislature. Maryland’s alcohol excise tax rates are decades old. The current excise tax on hard liquor was set 56 years. The rate for beer and wine was set in 1972—39 years ago!

## LORRAINE SHEEHAN HEALTH & COMMUNITY SERVICES ACT OF 2011

By Penny Veerhoff

The Lorraine Sheehan Health and Community Services Act of 2011 (MD Senate Bill 168/House of Delegates Bill 121) aims to increase alcohol taxes by ten cents per drink, raising \$215.6 million in additional revenue. It is estimated that the act will save Maryland an extra \$225.2 million in alcohol and addiction-related health and crime costs.\* Together, that is more than \$430 million.

The Lorraine Sheehan Act will divide the additional income into funds for four areas of service: developmental disabilities support; alcohol and addiction treatment and prevention; mental health care; and the Maryland Medicaid Trust Fund.

Well beyond ten thousand people in Maryland with developmental disabilities are on a waiting list for services and many need help urgently. If nothing changes, the future for them and their caregivers is bleak and scary. The Down Syndrome Network of Montgomery County and the Maryland Down Syndrome Advocacy Coalition have signed on as supporters of SB 168 and HB121. Please take the time to contact your state senators and delegates and urge them to vote for these bills. It only takes a moment to send an email or make a call. Tell them that an additional ten cents per drink makes sense!

\*Data from the End The Wait Campaign Fact Sheet. For more information, go to: [http://www.endthewaitnow.com/media/documents/FactSheet\\_%20Feb\\_2\\_2011.pdf](http://www.endthewaitnow.com/media/documents/FactSheet_%20Feb_2_2011.pdf)

### Join Our Team!

The DSNMC Advocacy Committee strives to enhance the lives of people with Down syndrome in Montgomery County and statewide, with a particular focus on educational and recreational opportunities. We provide education and support opportunities to parents to effectively advocate for their children, and work with other Down syndrome groups to achieve local and national policy objectives. We welcome your input and would love for you to join our committee.

**Heather Sachs**  
**Advocacy Chairperson**  
Email: [heather@dsnmc.org](mailto:heather@dsnmc.org)

## Buddy Walk on Washington!

The DSNMC Advocacy Committee organized members to participate in the Buddy Walk on Washington! Three (3) key discussion points were the topic of meetings with our representatives: Support of the Able Act, Maintenance of funding for Down syndrome research at NIH, and an invitation to join the Congressional Down Syndrome Caucus.

On February 7, interactive advocacy training was offered by NDSS followed by a dinner reception and award ceremony. The advocacy training covered policy priorities identified above, as well as expectations and guidance for meetings with legislative representatives. The following day, our group along with individuals from other parts of Maryland worked as team by visiting various members of Congress and the Senate. In addition to meeting with Representative Chris Van Hollen, we met with representatives from the offices of Senator Mikulski, Senator Cardin, Representative Steny Hoyer and Representative Andy Harris.



This is a fantastic opportunity if you ever have wanted to share your opinions with elected officials... and learn how to do it. We hope that you can participate next year!

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Proud to support the  
Down Syndrome Network of Montgomery County  
2010 Buddy Walk

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301-230-5202  
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# TECHNIQUES FOR SUCCESS

## DSNMC & F.R.I.E.N.D.S. of Frederick County

### hosting the second annual Techniques for Success Seminar for educators on April 2<sup>nd</sup>

Techniques for Success (TFS) was begun in 2009 to fill a need to provide our teachers with relevant and up to date information for teaching our children with Down syndrome. Our goal is to support the teachers and administrators of our children on how to have the most success within the classroom. We have brought in national speakers on behavior, subject experts such as teaching math to children with Down syndrome, self advocates and administrators who have success in building inclusive models across the country. Our first seminar in 2009 was incredibly successful and with the positive feedback we have received from those who attended, we are proud to make this an annual event!

**Cami Fawzy**  
**Board Member &**  
**Education Committee Chairperson**  
Email: [cami@dsnmc.org](mailto:cami@dsnmc.org)

This year, we are excited to have an excellent panel of speakers again including, Dr. Brian Skotko, Dr. Libby Kumin, Carol Crook, Erin Thompson (self-advocate) and Brad Henefer (self-advocate). We hope that you

will use the included flyer to forward to your child's school. There will be information for special educators, general educators, therapists, para educators, administrators and we will have a wait list for parents to join as well. Kindly distribute the flyer enclosed or go to the [www.dsnmc.org](http://www.dsnmc.org) website to get a pdf version. Also, if you have any questions regarding the seminar, please email Cami Fawzy at [cami@dsnmc.org](mailto:cami@dsnmc.org).

The Education Committee works to provide families, educators and communities including our children and young adults with Down syndrome access to information, education resources and networking opportunities to better enable them to reach their potential.

*We welcome your support, ideas and suggestions. Do you have a story about your experience with any educational programs in MCPS you would like to share with parents in our county? What worked, what you think could be improved if anything and why this particular program might benefit other children with Down syndrome?*



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Bonnie Connor, Centerville  
[bonjoe3@yahoo.com](mailto:bonjoe3@yahoo.com)

# Techniques for Success- 2011

Saturday,

April 2, 2011

8:00am to 4:30pm

Marriott Courtyard- Washingtonian @ Rio  
9751 Washingtonian Boulevard  
Gaithersburg, Maryland

## Who should attend...?

**General Educators**

**Special Educators**

**School Administrators**

**Home Schooling Families**

**Involved Parents**

(limited seating available)

**Register @: [www.dsnmc.org](http://www.dsnmc.org)**

*...This is a 100% FREE seminar, only your time is required!*

### Speaker Line-up:

- **Dr. Brian Skotko, M.D., M.P.P.**, a clinical fellow in genetics at Children's Hospital Boston, Massachusetts General Hospital, has dedicated his professional energies toward children with cognitive and developmental disabilities.
- **Dr. Libby Kumin, Ph.D.**, in speech-language pathology. She has been active in teaching, research, advising, and coding, professional, and community service. She has published four books, eight chapters, and numerous research articles in the area of communication skills in infants, toddlers, children, adolescents, and adults with Down syndrome. She founded the Down Syndrome Speech and Language Center for Excellence at Loyola Columbia Center.
- **Dr. Nancy Grace, Ph.D.**, is the Director of the Developmental Disabilities Clinic in the Dept. of Behavioral Psychology at the Kennedy-Krieger Institute and an Assistant Professor at the Johns Hopkins School of Medicine. Dr. Grace is a Child Psychologist with special interest and training of children with developmental disabilities and Autism Spectrum Disorders who are experiencing behavior problems.
- **Carol Quirk**, director of Professional Development Services, is one of the founders of MCEE. She received her Doctor of Education Degree from the Johns Hopkins University.
- **Erin Thompson** Erin "graduated" George Mason University and is on the Board of Directors of the Down Syndrome Association of Northern Virginia. Erin worked to get rid of the "k" word in Virginia's laws. She is also a Special Olympian, Best Buddies Ambassador, and plays the piano.
- **Brad Hennefer** is a young man who lives in Cherry Hill, New Jersey, with his family. Brad also works part-time for Anamark at CH East, as well as at Wegman's Supermarket. Brad enjoys listening to music, watching movies, hanging out with his many friends, and playing sports. He has participated in Special Olympics basketball, golf and weight lifting, winning several gold and silver medals.

Hosted By:

**F.R.I.E.N.D.S.** and the **Down Syndrome Network of Montgomery County**

Sponsored in part by:



# NEWSLETTER

Thank you for the positive comments regarding the look and feel of Connections, our newsletter. We see this publication continuously improving and evolving to meet your needs.

**Elizabeth Totah**  
**Secretary & Newsletter Editor**  
Email: [elizabethwt@dsnmc.org](mailto:elizabethwt@dsnmc.org)  
Mobile: 215.680.9046

Readers and members of DSNMC are submitting their perspectives, knowledge and experiences to share with one another. Think about what you have learned, your area of expertise and consider writing a feature article... or submit an idea for one. We would appreciate perspectives, informative articles, film and book reviews, etc. We want to hear from self-advocates, professionals, parents, caregivers and others. Please email or phone me with all constructive comments and ideas.

The English and Spanish versions of the newsletter are the same great format and content - now it is two (2) separate documents. In doing this, production time for the newsletter will decrease, money and natural resources will be saved, and ads from our Buddy Walk sponsors will be more visible. Spanish readers will receive a copy of the Spanish version of this newsletter in the mail. In addition, the pdf of this newsletter is available in both English and Spanish on [www.dsnmc.org](http://www.dsnmc.org) and will be distributed on the ListServe.

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# DSNMC EVENTS

## March

### **Financial Planning Workshop Speaker & Panel Discussion**

Thursday, March 3  
7:00 – 8:30pm  
The Arc of Montgomery County  
Contact Kathy at [kathy@dsnmc.org](mailto:kathy@dsnmc.org)

### **Coffee and Conversation**

Tuesday, March 8  
9:30am – 11:30am  
Coffee Kiosk at Montgomery Mall (1st floor near Crate and Barrel)  
Contact Karen O'Connor at 301-972-5138 or [tkrbmo@verizon.net](mailto:tkrbmo@verizon.net)

### **Monthly Board Meeting**

Wednesday, March 16  
7:30pm – 9:30pm  
Contact Gena at [gena@dsnmc.org](mailto:gena@dsnmc.org)

### **Advocacy Workshop Speaker & Panel Discussion**

Thursday, March 24, 7:00pm,  
The Arc of Montgomery County  
Contact Heather at [heather@dsnmc.org](mailto:heather@dsnmc.org)

### **Fire Station Tour & Safety Tips**

March 26  
3-5pm  
This is a tour and fire safety tips presentation. Pizza & drinks will be served.  
Kensington Volunteer Fire Station  
(intersection of Connecticut Ave and Plyers Mill)

## April

### **BIG EVENT! Techniques for Success**

April 2, 2011  
8:00am – 4:30pm  
Marriott Courtyard - Gaithersburg  
See insert for details

### **Coffee and Conversation**

Tuesday, April 12  
9:30am – 11:30am  
Coffee Kiosk at Montgomery Mall (1st floor near Crate and Barrel)  
Contact Karen O'Connor at 301-972-5138 or [tkrbmo@verizon.net](mailto:tkrbmo@verizon.net)

### **Monthly Board Meeting**

Wednesday, April 20  
7:30pm – 9:30pm  
Contact Gena at [gena@dsnmc.org](mailto:gena@dsnmc.org)

## May

### **Advocacy Workshop**

Thursday, May 5, 2011

### **Coffee & Conversation**

Tuesday, May 10  
9:30am – 11:30am  
Coffee Kiosk at Montgomery Mall (1st floor near Crate and Barrel). Contact Karen O'Connor at 301-972-5138 or [tkrbmo@verizon.net](mailto:tkrbmo@verizon.net)

### **Monthly Board Meeting**

Wednesday, May 18  
7:30pm -9:30pm  
Contact Gena at [gena@dsnmc.org](mailto:gena@dsnmc.org)

### **Play Groups**

For information on monthly playgroups please contact Brooke Levey at [markandbrooke1@verizon.net](mailto:markandbrooke1@verizon.net) or Lisa Annulis at [lannulis@verizon.net](mailto:lannulis@verizon.net)





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O manda por correo esta porción de la pagina a: Tali Moscovitz  
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