

CONNECTIONS

Buddy Walk on Washington

DSNMC MEMBERS ON THE HILL

By Heather Sachs
heather@dsnmc.org

On February 29 and March 1, 2012, many DSNMC members attended the annual two-day advocacy event sponsored by the National Down Syndrome Society known as the Buddy Walk on Washington. We joined 350 advocates from 40 states to advocate for public policies that impact the lives of people with Down syndrome and their families. DSNMC was well-represented by Board Members and General Members. This was the third year that DSNMC participated in this event and our delegation was the largest we have ever had. We were also proud to have so many self-advocates join us this time.



After receiving advocacy training and issues briefings from NDSS on Wednesday February 29, the Maryland Delegation, composed of DSNMC members and members from other Maryland affiliate groups and the Maryland Down Syndrome Advocacy Coalition (MDAC), met with staff from the offices of Senator Barbara Mikulski, Senator Ben Cardin, Representative Andy Harris, Representative Steny Hoyer, Representative Donna Edwards and Representative Chris Van Hollen on Thursday March 1. We were also thrilled to present Representative Van Hollen with the Champion for Change Award on behalf of NDSS at the Down Syndrome Caucus Breakfast. Representative Van Hollen has recently become a co-chair of the Congressional Down Syndrome Caucus, joining his fellow co-chairs Representative Cathy McMorris-Rodgers (R-WA), Representative Pete Sessions (R-TX) and Delegate Eleanor Holmes Norton (D-DC). Many DSNMC members are constituents of Representative Van Hollen and we are grateful that he has become such a vocal and passionate voice on our behalf in Congress.

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MARCH 2012

Buddy Walk on Washington

Getting Ready for Kindergarten

Sensory Processing

Advocacy – NCLB/ESEA

Self Advocacy Perspective: Brain Study

A D.A.B. of Neuroscience

Annual Membership Meeting & Survey Results

Buddy Walk on Washington Continued from previous page

POLICY OBJECTIVES AT CONGRESSIONAL MEETINGS

The Achieving a Better Life Experience (ABLE) Act (H.R. 3423/S.1872):

The ABLE Act, introduced in November 2011, would utilize the 529 education saving accounts program to develop ABLE accounts, which could be held by people with developmental disabilities to fund a variety of essential expenses, including medical and dental care, education, community-based supports, employment training, assistive technology, housing and transportation. The ABLE Act provides individuals with disabilities the same types of flexible tax-advantaged savings that all other Americans have through college savings accounts, health savings accounts, and individual retirement accounts without jeopardizing their SSI and Medicaid benefits. This would enable parents and individuals with disabilities to have a savings tool to help them save for the future just as other Americans in the broader population. Developing assets is one way toward improving economic self-sufficiency, and savings will help people with Down syndrome to live full, productive lives in their communities.

WE ASKED the Senators and Representatives with whom we met to cosponsor this important piece of legislation (and we thanked Representative Van Hollen who is already a co-sponsor).

Reauthorization of the Elementary and Secondary Education Act (ESEA):

The Elementary and Secondary Education Act (ESEA), formerly the No Child Left Behind Act (NCLB), is currently being reauthorized by Congress. One positive aspect about NCLB is that it created accountability for schools and school districts by requiring academic performance assessments for subgroups, including a disability subgroup. If a subgroup did not meet annual performance targets, then specific interventions to bring about school improvements were required. For the first time, the *academic* achievement of students with disabilities became a focus for many schools. Unfortunately, the ESEA reauthorization bills that have passed committee and are coming to the floor of Congress significantly diminish this accountability. Additionally, they do not contain language to prohibit states (such as Maryland) from precluding students from getting a high school diploma solely because they took alternate assessments.

WE ASKED the members of Congress with whom we met to vote *against* the current ESEA reauthorization bills as they are currently written. We expressed our support for certain amendments to the bill that have been offered by Representative George Miller (D-CA).

Increasing Down Syndrome NIH Research Funding and Down Syndrome Research Infrastructure (Trisomy 21 Research Resource Act of 2011 – H.R. 2696/S.1841):

The landscape of Down syndrome research has changed drastically in the last several years, with new promising studies and trials being done to address cognition, adaptive behavior, Alzheimer’s disease and other medical conditions in people with Down syndrome. Most of these groundbreaking developments have been supported by private funding, but both government funding and clinical research infrastructure support are vital to our efforts to translate research into real treatments and therapies. However, the National Institutes of Health (NIH) funding for Down syndrome has steadily decreased over the past decade, with Down syndrome being the least-funded of all genetic and developmental disabilities. The Trisomy 21 Research Resource Act would expand and intensify programs of the NIH and Centers for Disease Control and Prevention (CDC) to create an infrastructure of Down syndrome tools, including a Down syndrome contact registry, research database and biobank.

WE ASKED the Senators and Representatives with whom we met to cosponsor this important piece of legislation (and we thanked Representative Van Hollen who is already a co-sponsor).



STAY INFORMED ABOUT ADVOCACY ISSUES BY SIGNING UP FOR ACTION ALERTS AND E-NEWSLETTERS!

National Down Syndrome Society

www.ndss.org

Sign up for Action Alerts on this website!

Disability Scoop

www.disabilityscoop.com

The Arc Action Alerts

www.thearc.org

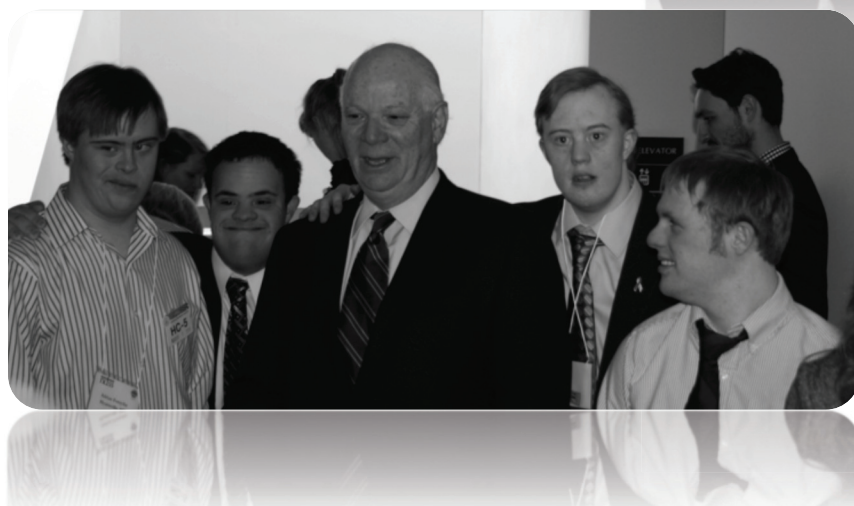


How Can YOU Get Involved in Advocacy?

The Buddy Walk on Washington was an inspiring and empowering experience. We learned about issues that have the potential to directly impact our families and as well as the greater disability community. Please take the time to contact Senators Mikulski and Cardin, as well as your Representative, and ask them to support our positions on the legislation described on the previous page. (If your Representative is Van Hollen, please take the time to send a thank you email to his office).

Generally, when we post notices on the DSNMC listserv or in the newsletter asking our members to sign petitions or make calls to their Congressmen, please take a few minutes to do this. When we put out the call for people to attend hearings on Capitol Hill (or in Annapolis), please do this if you are so able.

Next year, when we open registration for the next Buddy Walk on Washington, please consider signing up as part of our delegation so that you can experience it firsthand. We will be more powerful in larger numbers and it is our responsibility as a community to band together to make our



SPECIAL THANKS TO THE FOLLOWING DSNMC MEMBERS who did a fantastic job representing our organization:

MaryAnn Dawedeit, Eli Lewis, Cami Fawzy, Adrian Forsythe, Cathleen Fromm, Karen Gee, Jeanne and Patrick Jones Amuthan Kannan, Shannon Lyons, Ricki and Steve Sabia, Penny and Jamie Veerhoff

DSNMC Board Members in attendance were:

Nancy Forsythe, Chris Hicks, Heather Sachs and Allison Wohl

IN HONOR OF MOTHER'S DAY ON MAY 13th

You've developed the strength of a draft horse while holding onto the delicacy of a daffodil...
you are the mother, advocate and protector of a child with a disability. (Lori Borgman)

LOVE,
DSNMC & ALL OUR CHILDREN

SACHS
CAPITAL

SHULMAN
ROGERS

GANDAL
PORDY
ECKER

Proud to support the
Down Syndrome Network of Montgomery County
2011 Buddy Walk

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

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

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



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President's Letter

It was my great pleasure along with four other board members to attend the DSAIA (Down syndrome Affiliates in Action) conference March 2-3, 2012 which was held in Crystal City, VA this year. DSNMC is one of 73 organizations who sent representatives to the annual event. Down Syndrome Affiliates in Action (DSAIA) is a national trade association composed of nearly 80 Down syndrome support organizations from across the country. DSAIA brings together all local Down syndrome affiliate groups like DSNMC, to collaborate, share and educate on all things related to Down syndrome. The conference is for affiliate leaders, board members and staff to share programs, ideas and professional development to best serve our communities. DSNMC has been a DSAIA member for four years and it has been a critical piece to our overall growth.

Deanna Tharpe, DSAIA Executive Director, states, "It is a priority to grow the capabilities of local and regional Down syndrome organizations and create a unified effort to increase the acceptance of and opportunities for individuals with Down syndrome." She adds that DSAIA "supports Down syndrome affiliates through a growing repository of programs and materials, regular training webinars throughout the year, and using DSAIA's economies of scale to broker benefits for local groups."

It is difficult to put into words just how amazing this conference really is. There is so much energy, passion and knowledge regarding Down syndrome in one place that it gives such an incredible perspective on what is possible. I always feel so focused and re-energized after a weekend with other affiliate leaders and I am thankful to be a part of DSAIA and to be able to attend their annual conference. It is a wonderful opportunity to learn from others who are running DS organizations across the country that operate with a budget sometimes quadruple that of DSNMC and to also be able to provide guidance and support to groups that are new and need help. No matter how many times I attend this conference, I am always blown away with the generosity and giving within this community!

In speaking with experts like Dr. Brian Skotko at the conference, I frequently heard a phrase that resonated with me, "the Down syndrome movement". As I reflect on these conversations, it drives home a significant point. We must all work together, toward a common goal for all of our children. Whether it is NDSS, NDSC, DSNMC, DSAIA, Global Down Syndrome Foundation or any other DS focused group, we must be a community that shares one voice on behalf of those with Down syndrome. We must work together to support research, employment opportunities, education, awareness as well as other issues. DSNMC's Board of Directors is committed to doing our part to support the Down syndrome movement, and we will continue to seek out organizations like DSAIA to be the best organization we can be. I am certain we have all used the phrase "it takes a village to raise a child," at some point in our journey with Down syndrome or even with our entire family. I hope to work with each of our members in one capacity or another to support DSNMC's mission, as our village supports the Down syndrome movement.

Gena Gena Mitchell
President

BUDDY WALK 2012
DATE: OCT 6, 2012
PLANNING IS UNDERWAY!

If you are new to DSNMC, this is a great way to get involved in something meaningful and fun.

Thursday, March 29th
7:30pm-8:30pm
5904 Carlton Lane
Bethesda, MD

Please RSVP if you plan to attend the meeting gena@dsnmc.org

Annual Membership Meeting

January 22, 2012 was DSNMC's first Annual Membership meeting. It was a great kick off to our journey as our own 501c3 organization. The Board of Directors discussed the current state of DSNMC. A brief overview of each committee was conducted which included their area of focus and current initiatives. We were fortunate to have some familiar faces as well as new ones to discuss perspective and what our membership is looking for from our organization.

During the meeting, we also took a look at the results from our membership survey. This was an incredibly helpful exercise that will enable the board of directors to target what our membership has asked for. For example, we know when to schedule meetings, what parent workshop topics are of most interest, where people live so we can cover all areas within Montgomery County when planning events - and that is just to name a few!

Finally, it was brought to our attention that many members were interested in volunteering, but simply needed to know what needs we had. Please see the insert for a description of volunteer opportunities within each DSNMC committee. We have found that everyone has their own niche and we want to be certain that your time is spent doing something you are passionate about. We realize that not everyone is interested in planning social gatherings for example, and that some may have an hour a week, and some a full day to dedicate. That is the beauty of a volunteer organization- we need it all. DSNMC is also launching an online volunteer sign up. If you are interested in using this tool, please email admin@dsnmc.org

If you were not able to attend the Annual Membership meeting, we still want to hear from you! If you have any comments, questions or concerns we would love to hear from you. Please email gena@dsnmc.org.

New Board Members

TRACY DOUGLAS-WHEELER, VICE PRESIDENT

Tracy Douglas-Wheeler comes to DSNMC with close to 17 years experience working in the non-profit healthcare sector. She currently works for the Mid-Atlantic Association for Community Health Centers, a non-profit association, where she is the Director of Performance Improvement. She has worked in various capacities that have included overseeing the operations of a pediatric center of excellence, outpatient oncology, rehabilitation, and cardiopulmonary division, and facilitated the growth of a cancer education and screening program targeting uninsured and underinsured young women. Tracy is married to Louis Wheeler, Jr. and has two children, Alec and Caitlin.

CHRIS HICKS, BOARD MEMBER

Chris Hicks joined the DSNMC Board at the beginning of this year bringing with him almost 20 years of accounting and financial services experience. The majority of that time was spent serving in various roles in public and corporate accounting, including working in the audit, tax, SEC reporting and not-for-profit arenas. He now works as a consultant for Vision Consulting where he designs and implements strategic and comprehensive business solutions for a variety of startup and emerging growth companies. Chris is a graduate of Gonzaga College High School and Catholic University and is an avid hockey fan. He and his wife Kari live in Brookeville and have four children, Andrew, Erin, Elena and Bella. They are all proud members of "Team Chicka Bella" and look forward to seeing you at the Buddy Walk in October or the Polar Bear Plunge in January!

SURVEY RESULTS

THANK YOU for participating in the DSNMC survey. Your time is precious, and your input is valued.

DID YOU KNOW THAT...

- Almost half of our members live Down County (Bethesda, Silver Spring, etc). The remainder are evenly split by Mid County and Up County.
- Majority of responders had a child that fell in the birth to Elementary school age.
- Respondents expressed preference for playgroups, social gatherings for adults-only, and workshops on elopement and potty training
- About half of DSNMC members actually volunteered for DSNMC in some way

Check out the survey results with the raw data and graphics on our website at dsnmc.org. If you have difficulty locating it, please contact Dierdre at admin@dsnmc.org

Patton Boggs LLP
proudly supports the
Down Syndrome Network
of Montgomery County.

We salute DSNMC's mission to empower individuals with Down syndrome and their families, and to educate the community through awareness and advocacy programs.

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DSNMC EVENTS

Coffee and Conversation

2nd Tuesday of each month
 9:30am – 11:30am
 Montgomery Mall - Caribou Coffee
 (1st floor near Crate and Barrel)
 Contact Karen O'Connor at
 301-972-5138 or
 tkrbmo@verizon.net

Board Meeting

Wednesday, April 11
 7:30pm -9:30pm
 Contact Gena at gena@dsnmc.org

Play Groups

If you would like to join a playgroup, please email info@dsnmc.org, or you can call (301) 979-1112, which is our general number.

SAVE THE DATES!

Summer Picnic - June 13
Buddy Walk - Oct 6

***HAPPY HOURS**
 are happening!
 Stop by for a quick
 drink or spend the
 evening. Swing by
 after work, make it
 a portion of your
 date night, schedule
 it with a haircut or
 manicure. Bring a
 friend, a partner or
 come alone.*

*3rd Thursday of
 each month*

*Contact
admin@dsnmc.org
 for location and
 exact timing.*

PARENT WORKSHOPS

Co-sponsored by DSNMC, The Arc Montgomery County & The Autism Society of Montgomery County

All seminars will be held at The Arc Montgomery County located at 11600 Nebel Street
 Please register for one or more of these free presentations:

Haydee De Paula - [301-984-5792](tel:301-984-5792)
haydeed@arcmontmd.org
 Kathy Myers - kathy@dsnmc.org

*Sessions related to
 transitions to
 Kindergarten &
 Middle School are
 being planned!*

The IEP Process

Wednesday, April 11 from 7 - 9 pm.
 Presented by Josie Thomas, Executive Director of the Parents' Place of Maryland
 Parents will learn how to request an IEP meeting and evaluation, the meaning of a facilitated IEP meeting and how to request one, and team members. Parents will also practice writing goals and objectives and learn what to do when something goes wrong

How Will I Know if My Child is Making Progress?

Wednesday, May 2 from 7 - 9 pm
 Presented by Josie Thomas, Executive Director of The Parents' Place of Maryland
 Parents will learn how to gather information from special education and general education sources. Parents will learn how to use this information to help their child.

COMMUNITY EVENTS

Faith, Deafness & Disability Conference

Saturday, April 21
 8:15 AM – 4:45 PM
 Blessed Sacrament School, Chevy Chase
 Contact Peg Kolm at 301.853.4560 or mkolm@adw.org

Equipment Connections for Children (ECFC): Trike-A-Thon

Saturday, April 28, 2012
 Rain Date: Saturday, May 5
 11am - 2 pm
 Germantown Community Center
 18905 Kingsview Road, Germantown
 Minimum Fee: \$10

The **NDSC** conference will be held in D.C. this summer. DSNMC has designated money for scholarships for our membership to attend.

Email Deirdre at admin@dsnmc.org to request an application.

Potomac Community Resources, Inc.

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

PCR is a private, nonprofit organization that encourages and supports the inclusion of persons with developmental differences into the life of our community.

Register for programs now!

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

Are you part of the listserv?

DSNMC@yahoogroups.com... HOW MEMBERS OF DSNMC COMMUNICATE REGULARLY

Joining the DSNMC listserv is the best way to receive information on DSNMC news and upcoming activities. The listserv is an easy way to communicate with other families, ask questions and share information.

Select one of the options below, and follow the instructions. If you have questions please contact Deirdre Kelly at admin@dsnmc.org or 301-979-1112.

OPTION 1

Create a Yahoo account. If you already have one, make sure you are logged in. Go to <http://groups.yahoo.com/>.

Use the search box to find the DSNMC group (search on DSNMC).

Click on the DSNMC name/logo and you will be redirected to the group's main page.

1. Click on the "Join This Group" button, located in the top, right corner.
2. Verify that you are joining with your correct profile.
3. Select the email address that you would like to use.
4. Select your preferred options for frequency and format of messages. Type in the text for the word verification.
5. Press "Join."

OPTION 2

If you would prefer to have DSNMC send you an invitation to join the group, please send an email to: info@dsnmc.org

In the subject line of your email use the phrase "Request to Join Listserv." DSNMC will send you an invitation with a link to join the group.

OPTION 3

Subscribe to a group's mailing list only

If you're not sure you want to join the group, you can sign up to only receive email messages from the group. This option allows you to receive messages but will not allow access to the group's web features (photos, files, attachments, links, polls, and calendar).

To subscribe to the group's mailing list via email:

Send a blank email to: dsnmc-subscribe@yahoogroups.com

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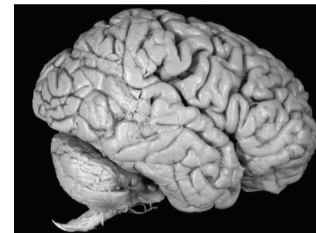
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DOWN SYNDROME AND THE BRAIN

A D.A.B. of Neuroscience



By Nancy Raitano Lee, Ph.D. & Jay N. Giedd, M.D.
Child Psychiatry Branch, National Institutes of Health

Over the past several years, researchers in the fields of neuroscience and education have been joining forces to advance knowledge about how the brain develops in children with typical development and those with learning differences, how children in both of these groups learn, and how the brain changes in response to educational programs.

This field, referred to as *educational neuroscience*, is only in its infancy, and thus, there is still very much to be learned. However, as scientists at NIH who study the developing brain, we wanted to reach out to the DSNMC and contribute to your newsletter with a neuroscience column that provides readers with information about the brain, what is known about brain development in Down syndrome, and what research tells us about the effects of educational programs on the brain. Also, as we learn more about how the brain develops in young people with Down syndrome through our own research, we will share this information with your community.

For our first *D.A.B.* column, we provide some fun facts about the human brain and its development. Stay tuned for future columns that will describe the brain and neuroscience research in more detail.

SIZE The adult brain weighs about 3 pounds, while the newborn brain weighs just under a pound.

PROCESSING UNITS The brain has over 75 billion neurons, which are the cells that process information.

CONNECTIONS These neurons make over 60 trillion connections. Neurons connect at a point called a **synapse**, which can be thought of as a relay station for neuron-to-neuron communication.

DEVELOPMENT

- By the 8th week of gestation, the very basic structures of the brain are established, but the brain has a long way to go before it reaches adult maturity
- During preschool years, the brain's size increases by four-fold!
- By age 6, a child's brain is 90% of the adult size
- Some brain structures do not reach full maturity until the early-to-mid 20s

Have questions about this column or the Down syndrome Brain Development Study at NIH, contact Dr. Nancy Raitano Lee

lnancy@mail.nih.gov
(301)435-4520

Want to learn more? Check out these websites:

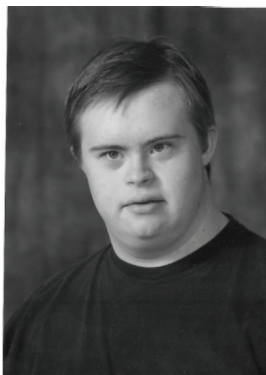
Society for Neuroscience: <http://www.sfn.org/index.aspx?pagename=brainFacts§ion=publications>
Neuroscience for Kids: <http://faculty.washington.edu/chudler/neurok.html>

References:

Blinkov, S.M. and Glezer, I.I. *The Human Brain in Figures and Tables*. A Quantitative Handbook, New York: Plenum Press, 1968.
Stiles, L. & Jernigan, T.L. (2010). The basics of brain development. *Neuropsychology Review*, 20, 327-348.



BRAIN STUDY



By Adrian Forsythe
Self-Advocate

The NIH Clinical Center is conducting a research on brain development and learning. This research is for children and adults from the age of 3-30 years old and must have a chromosomal diagnosis of Down syndrome. You would have to go through several tests on reading, math, computers, and problem solving. The people who are in charge will ask you if they can draw blood. For me, it was not really a big deal because they found a spot on my arm and it was that easy. Afterwards, they will say you can go to the cafeteria to get something to eat. Then it will be time to go through the MRI. MRI is very loud when you go in the machine. That can make you feel scared and so you will have earplugs. Also you can bring a DVD to watch but without the volume. You just lay down and relax. That is what I did and I felt great. This research will be held at the NIH Clinical Center. This research may be completed over 4 visits. Each of those visits will take about 4-8 hours. When I walked out I felt that I made a difference in understanding how my brain functions. I hope this article inspires children and adults with Down syndrome.

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

Researchers at the NIH are conducting a research study on brain development and learning in children and young adults with Down syndrome.

All procedures (including brain imaging, learning and memory testing) will be completed on an outpatient basis at the NIH Clinical Center and may be completed over 4 visits. Each visit will take between 4-8 hours.

Children and young adults may be eligible to participate if they are between 3 and 30 years old and have a confirmed chromosomal diagnosis of Down syndrome.

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

For more information, contact:

Nancy Raitano Lee, Ph.D. at **301-435-4520**

TTY: 1-866-411-1010

email: LNANCY@MAIL.NIH.GOV

<http://patientinfo.nimh.nih.gov>



NIMH National Institute of Mental Health, National Institutes of Health,
Department of Health & Human Services
Protocol No. 89-M-0006

Perseverance is not a long
race. It is many short races
one after another.

– W. Elliot

*Are you a self-advocate? Would like
to write a book or film review?
Would you like to submit a poem,
photograph, etc. the newsletter?*

*Please send submissions to
elizabethwt@dsnmc.org*

Please note any resources
that are listed in
DSNMC Connections
are not to be interpreted as
recommendations, but
resources.

STUDY PARTICIPANTS NEEDED... for a computer research study conducted by Libby Kumin (Loyola University), and Jonathan Lazar and Heidi Feng (Towson University)

We need 10 participants for a study about computer use with touchscreens by adults with Down syndrome. To qualify, you need to:

- Be 18 years or older
- Have experience using computers and the internet
- Have a facebook account and a web-based e-mail account
- Have at least a little experience using a touch screen-based tablet computer or smart phone, such as an iPad, iPhone, Samsung Galaxy, Blackberry Playbook, or Motorola Xoom

To participate, you will need to come to Loyola University Columbia Center for a one time (about 2 hours) session where we will ask you to show us how you do some things on the computer. This is not a test. We want to know what things are easy and what are hard, what you usually do and what is new. We will supply an iPad for you to use at the session.

Appointments are available on Monday, Wednesday, Fridays and Saturdays in March and April. You will be paid \$150 for participating. Send an email to Libby Kumin at [lkumin@loyola.edu] with the dates and times that are best for you.



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Real Estate Professional
Long & Foster
Buddy Walk 2011 Sponsor

240.606.4711

4733 Bethesda Ave
Bethesda, MD 20814

<http://JamesBegg.LNF.com>
Jim.Begg@LongandFoster.com

HELP WANTED!

Spanish Speaking Community

DSNMC is participating in a national initiative of the Down Syndrome Affiliates in Action to increase the involvement of Spanish-speaking families in the activities and programs of the Down syndrome community. If you are interested in helping in our area, or if you have questions, please contact Nancy Forsythe at 301.779.3462 or nancy@dsnmc.org.

Professional Outreach Committee

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

Newsletter

Contributions

Do have an idea for an article? Knowledge to share? Can you review a movie, book or conference? If you are interested in submitting a piece or helping with the newsletter, contact Elizabeth at elizabethwt@dnmc.org

Secretary & Treasurer for DSNMC Board/Executive Committee

Treasurer should be a CPA as required for non-profits. It is not necessary to have a child with Down syndrome to serve on the Board. Please contact gena@dsnmc.org if you are interested.

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

dsnmc.org

REMINDER!
DSNMC
EDUCATION RESOURCE GUIDE
AVAILABLE ON WEBSITE!



CONDO DOMAIN

Smart Agents. Smarter Clients.

At most banks, green means money.
 At Congressional Bank, green means even more – being good to our environment. We’ve made the switch to using clean energy and **green** power at our Maryland and DC branches. Now, we are proud to be the **first bank** in Montgomery County to become a Certified Green Business.



A truly “green” bank.
 (Now *that’s* distinctive.)



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www.congressionalbank.com

THE CLEANING AUTHORITY IS A PROUD SPONSOR OF THE DOWN SYNDROME NETWORK OF MONTGOMERY COUNTY



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 EVEN MOTHER NATURE.**

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- We’re reliable, thorough & affordable
- Our employees are bonded and insured
- Our cleaner training is comprehensive and we inspect our crews routinely
- We have upgraded our housecleaning products to include Green Seal Certified® cleaning products*



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Getting Ready for Kindergarten?

WHAT ARE YOUR OPTIONS?

By Heather Sachs
Education Chairperson
heather@dsnmc.org

This time of year, placement decisions for Kindergarten weigh heavily on the minds of parents who have children turning 5 years old by September 1. There is an array of special education programs available within your home (neighborhood) school, your cluster and your quad cluster (note that a “quad cluster” is a group of 4 neighboring high school clusters who are supervised together by a community superintendent). Most IEP placement determination meetings occur during the spring, and it is helpful to be familiar with the program options described below. Note that these programs vary by school and cluster. For example, the Learning Center program at your home school is not necessarily the same as the Learning Center program at another school. The best way to determine whether one is a good fit is to visit!

Whether your child is coming from a PEP program, private preschool, or Infants and Toddlers, there will be many educators and specialists who will express their opinions to you about where your child should be placed. While you should consider their opinions, you will need to do your own research to make the final determination. You know your child best! *You do not have to automatically agree to the IEP team’s placement recommendation.* You should go into the IEP Placement Meeting with your own idea of where you want your child to be placed, and be prepared to argue the reasons why. Is it important to you to have your child attend school with his or her siblings and neighborhood kids? Do you think your child would do well in a larger classroom with non-disabled peers, a para-educator and a general education teacher? Or, would the best placement for your child be in a small, self-contained classroom with other special education students and a special education teacher? You can only answer these questions *after* you do *your* homework!



Image Courtesy of: schoolbusdriver.org

MAKE AN APPOINTMENT TO OBSERVE ANY POTENTIAL PROGRAM

Call the principals of the schools you are considering, and set up a time when you can go into the actual classrooms to observe how things are done. If your child is in PEP, the Parent Educator at your PEP site should assist you in scheduling these visits. You should plan to view **at least two different programs**. Pay attention to the teaching methods, class size, discipline methods and make-up of kids in the class (and their types of disabilities). Ask whether there are any opportunities for inclusion with non-disabled peers in general education classes. *When you return home from your observations, record your thoughts.* Take notes on why you do or do not think that would be the best placement for your child (**don't forget to record dates and names of people with whom you spoke**). These notes could come in handy at an IEP meeting where there is a placement dispute, and you need to argue for or against a particular program.

THINK OUTSIDE THE BOX WHEN CONSIDERING PLACEMENT OPTIONS

If you do not feel that your child fits into a particular "box," it is possible to come up with a creative solution for placement. For example, your child could be in a general education classroom but get pulled-out to do academics with students from The Learning Center at the same school. Or, your child could officially be in an LFI program but you could try to write into the IEP that he or she would do specials and recess with a general education class so that he or she will have some interaction with non-disabled peers. Obviously, scheduling and staffing will ultimately determine the feasibility of unconventional solutions, but it does not hurt to ask. **If the team agrees to an unconventional service, make sure that it gets written into the IEP.** While it would be nice to take people at their word, **the IEP is the only legal document** that requires the school system to provide certain things for your child.

ASK FOR ADVICE FROM FRIENDS AND THE DSNMC LISTSERV

It is helpful to ask other parents to share their experiences with particular programs in particular schools. Post a message on the DSNMC listserv to ask for parents to share their advice and experiences at **specific schools and with specific programs**. We all want to help each other through this stressful process and other parents are generally very forthcoming with information and advice. At the same time, remember that the experience and perspective of another parent will not necessarily be the same as yours. So, gather opinions, but then decide what is best for your family.

Gather opinions, but then decide
what is best for your family.

CONSIDER HOLDING YOUR CHILD BACK A YEAR

Some parents of children with DS fill-out the MCPS Kindergarten Waiver and place their children in a private pre-K program for the year, after which they start in MCPS kindergarten. While cost may be prohibitive to some families, it is worth considering. Your child will have an extra year to catch-up developmentally, and can get a jumpstart on Kindergarten academics. Note that, if you do the Kindergarten Waiver, the only services you could get for your child through MCPS for that year would be Resource and Speech/Language services. You could post a message on the DSNMC Listserv asking members to recommend pre-K programs in the area if you are considering going this route.

CONSIDER ASKING FOR A GENERAL EDUCATION PLACEMENT WITH FULL-TIME SUPPORT

Many students with DS are fully mainstreamed (especially in the early grades) and tend to thrive in this environment. Our kids often model peer behavior. As a result, they can greatly benefit from typical peer models. To be successful, a student (and teacher) must be properly supported, so it is helpful to **ask for para-educator support for your child**. This support can range from "full-time, one-on-one" support to sharing a para-educator with another child or small group of children in the classroom. At times, other staff members or therapists may provide this support. **Placement in general education with a supporting para-educator is generally not offered at IEP meetings as the team's first choice – you have to ask for it to be considered.** It involves coordination by the school (to meet staffing demands) and increased funding from the cluster placement office. **This placement can be done, it happens frequently, and it can be very successful.** This placement will not negate any services your child receives (e.g., Resource, Speech/Language, PT, OT). All of these details will be written into the IEP.

MCPS SPECIAL EDUCATION PROGRAMS

ELEMENTARY HOME SCHOOL MODEL

Elementary Home School Services support students in grades K-5 as a result of a disability that impacts academic achievement in one or more content areas, organization and/or behavior. Students served by this model are assigned to age-appropriate heterogeneous classes in their neighborhood schools. Student access to the general curriculum during the course of the day is based on individual student needs and will encompass a variety of instructional models and may include instruction in a general education environment and/or a self-contained setting.

This option is only available for those people whose home school (neighborhood school) offers this model. In other words, if you live outside the boundary for this particular school, your child will not be able to attend.

LEARNING AND ACADEMIC DISABILITIES (LAD) PROGRAM

Learning and Academic Disabilities services are for students with disabilities that impact their academic achievement. Students served by this model have previously received a considerable amount of special education support in the general education environment, but require additional services to enable progress toward the IEP goals and objectives. These services are provided in a continuum of settings that may include components of self-contained classes, cotaught general education classes, and other opportunities for participation with nondisabled peers. Selected elementary schools provide LAD services within each cluster.

The LAD programs tend to be mixed grade classes (e.g., K-2) and provide some opportunities for inclusion throughout the day with age-appropriate non-disabled peers (e.g., the students may have specials, lunch and recess together).

LEARNING CENTER

The Elementary Learning Centers provide comprehensive special education and related services. The school-based learning centers offer a continuum of services for Grades K-5 in several self-contained classes along with opportunities to be included with nondisabled peers in the general education environment. These services incorporate the student's IEP with the general education curriculum through strategies such as assistive technology, reduced class size, and differentiated instruction.

Depending on the school, the opportunities for inclusion with non-disabled peers can be plentiful to non-existent. If inclusion is important to you, examine the inclusion practices at the school you are considering. Also note that MCPS no longer has Learning Centers at the middle-school and high-school levels, so students from Elementary Learning Centers will either need to transition to an LFI program at middle school or go into a general education setting at their home middle school.

LEARNING FOR INDEPENDENCE (LFI)

The Learning for Independence services are designed for students with complex learning and cognitive needs, including mild to moderate intellectual disabilities. Services support the implementation of the Fundamental Life Skills (FLS) curriculum, or a combination of the FLS and accommodated general education curricula. Students are provided with many opportunities for interaction with general education peers, including inclusion in general education classes as appropriate, peer tutoring, and extracurricular activities. They learn functional life skills and functional academics in the context of the general school environment and in community settings. Community-based instruction and vocational training are emphasized at the secondary level so that students are prepared for the transition into the world of work upon graduation or exit from the school system.

The LFI programs tend to be self-contained, with minimal or no inclusion with non-disabled peers. Some LFI programs are more academic than others, so check with your school. Note that placing your child in an LFI program will likely render him/her ineligible for a MCPS diploma as it is a non-academic track.

These MCPS education program descriptions were obtained from the MCPS website, www.montgomerycountyschoolsmd.org/departments/specialed/parents/services/schoolage-elementary.aspx.

IMPORTANT: Each elementary school tends to have one type of program.

This means that, if the program you want for your child is not offered at your home school, then your child could be bussed to another school in your cluster or quad cluster. To find which programs are offered at which schools in your cluster or quad cluster, see

http://www.montgomeryschoolsmd.org/departments/specialed/resources/Program%20Locations2011_2012.pdf



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SENSORY PROCESSING

One Mom's Experience

By Camelia Fawzy, Mom of Matei 11 and Marcu 8 (born with DS)

I started my Sensory Integration adventure a little more than one year ago. My younger son, Marcu (born with DS), went through a particularly bad Autumn. Once again, we were in the pediatrician's office to change the antibiotic. Most nurses know us and don't bother to cover the consultation bed with the paper anymore, but it does happen sometimes. We enter one of those small examination rooms - Marcu and I race to get to that paper first! If the nurse happens to be in my way and Marcu gets to it first, the disaster unfolds. I have to once again explain that Marcu loves the noise that paper makes and cannot resist unrolling it as much as he can before I manage to stop him.

The **SENSORY SYSTEMS** are responsible for detecting **sights, sounds, smell, tastes, temperatures, pain** and the **position and movements of the body**. The brain then forms a combined picture of this information in order for the body to make sense of its surroundings and react to them appropriately. The ongoing relationship between behavior and brain functioning is called sensory integration (SI). **Sensory integration provides a crucial foundation for later, more complex learning and behavior.**

Source: www.brighttots.com/sensoryintegration

That day, was one of those. I finally got the paper away, hid the rest under the bed and rushed to offer him a couple of tissues (thankfully, every doctor's office has a nice box of tissues available and they save my sanity during those consultation moments). Marcu loves playing with tissues he has always loved tearing them into small pieces, rolling them, stashing them, talking with them while watching a video, throwing them in the air ready to catch them falling. When we cannot take the paper mess anymore, we replace it with socks. We no longer have a single pair of matched socks and have no idea where they end up. Marcu was having great fun with the tissues, said a quick "Hi" when the doctor came in and went back to his business. I was happy, finally able to focus on a good discussion with the doctor about next steps, medicines,

keeping sinuses open, improving sleep, etc. When I thought I received all the information to help me feel in charge with Marcu's care, Dr. Jones asked the magic question, "Do you know anything about sensory processing disorder?" He had been observing Marcu playing with the tissue papers while talking with me. He kindly suggested two books for me to read – the holiday reading as the season was approaching. Thanks Dr. Jones!

I came home, got on Amazon. Two days later my husband and I were reading **Sensory Integration and the Child** by A. Jean Ayres with a great sense of anxiety as we recognized issues in almost all sensory areas, but also excitement as we were finally able to explain some things we have been struggling to understand for years. We spent the holidays reading the second book Dr. Jones recommended: **Is It a Big Problem or a Little Problem?: When to Worry, When Not to Worry, and What to Do** and watching lots of YouTube videos such as:

SENSORY PROCESSING (sometimes called "sensory integration" or SI) is a term that refers to the way the nervous system receives messages from the senses and turns them into appropriate motor and behavioral responses. Whether you are biting into a hamburger, riding a bicycle, or reading a book, your successful completion of the activity requires processing sensation or "sensory integration." Sensory Processing Disorder (SPD, formerly known as "sensory integration dysfunction") is a condition that exists when sensory signals don't get organized into appropriate responses. Pioneering occupational therapist and neuroscientist, A. Jean Ayres, PhD, likened SPD to a neurological traffic jam" that prevents certain parts of the brain from receiving the information needed to interpret sensory information correctly. A person with SPD which creates challenges in performing countless everyday tasks. Motor clumsiness, behavioral problems, anxiety, depression, school failure, and other impacts may result if the disorder is not treated effectively.

Source: www.sinetwork.org/about-sensory-processing-disorder.html

<http://www.youtube.com/watch?v=z3vI0nHpXNM&feature=related>

<http://www.youtube.com/watch?v=QDaj4daRWJc>

<http://www.youtube.com/watch?v=qCqevZrnw5w&feature=related>

I took the books and as much info I retained in my brain to Marcu's education team as soon as school started and tried to explain why we suspect he is so "stubborn" and refuses to go to lunch and recess, why he tries to keep some more space between himself and those around him and why we thought it would be great if during the breaks we had included in his IEP it would be good if he could do some things that would help with his sensory overload.

A few months down the road, more books and videos and two OT evaluations, the latest with a sensory diet, and we are set to help Marcu's mind learn how to integrate his sensory inputs and give him less troubles.



in which his brain reaches the overload stage if we do not take some measurements to prevent the meltdowns, which really is not possible all the time. Richards, W; 2009; *Managing Meltdowns*)

Unfortunately, not many parents and OT specialists think about sensory processing issues if the child is not on the autism spectrum. And more unfortunately, not enough OTs are trained in sensory processing integration although many do work with kids on the autism spectrum for whom sensory disorder is well known to be a significant challenge. I wish we had known about this and started to work on these challenges much earlier. We are certainly no experts and still continue to learn every day

We see a long road ahead of us since we started to work with those issues so late but we can already see improvements. Marcu was diagnosed with Auditory Processing Disorder before we heard of Sensory Processing Disorder. Now, we know that the areas causing him most troubles are related to auditory, visual, vestibular and proprioceptive systems. His visual and auditory systems cause overload as his brain is not yet able to block sights and sounds we are normally able to ignore. We believe Marcu will often hear everyone in the class/room but is not be able to "hear" or differentiate an instruction addressed to him specifically all the time. If I want to make sure he understands what I say or ask him, I have to get down at his level and make him look at me while talking rarely and repeating what I say. If not overloaded he would be able to follow a short direction that starts with his name but this is not consistent and depends on what is going on in the environment. He is also wearing a weighted vest during school and sleeps better under his weighted blanket giving his proprioceptive (proprioceptive) system the extra input it needs.

A **MELTDOWN** is "an extreme emotional/behavioral response to stress or overstimulation. It is triggered by a 'fight or flight' response, which releases adrenaline into the body, creating heightened anxiety and causing the individual to switch to an instinctual survival mode. This is a common human reaction to stress." (Lipsky, D and Richard, W; 2009; *Managing Meltdowns*)

Parties are very difficult for Marcu because of his visual and auditory overload. Most of the time they end up with a sensory meltdown. School transitions, school cafeteria and recess,

what works and what doesn't and when but we feel that at least we are on the road to making things better for him and us. In the mean while, we will continue to fight over the TV volume and try to keep our while, we will continue to fight over the TV volume and try to keep our sanity while he tries to block all other sounds around him in order to focus on watching his favorite movies.

These challenges interfere with a child's ability to speak, learn reading, writing, often leading to behavior and self esteem challenges as well as social interaction difficulties. (DSNMC Education Resource Guide, page 7)

If you have any suspicions that your child might have difficulties due to the way his/her sensory perceive the environment or the brain organizes the information, please the resources, or contact the following:

Susan R. Tieche OTR/L
ITS: Developmental Therapy Services, INC.
10605 Concord Street, Suite 102
Kensington, Maryland 20895
301-933-7880 ext. 4
www.its-dts.com

Leaps and Bounds (*For Younger Children*)
4906 Wisconsin Ave. NW
Washington, DC 20016
Phone: 202-237-8737

Disclaimer: We have not worked with any specialists/organizations mentioned above but have been recommended as excellent service

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ADVOCACY UPDATE

THE STUDENT SUCCESS ACT & ENCOURAGING INNOVATION AND EFFECTIVE TEACHERS ACT... What does this mean for you?

By Allison Wohl
Advocacy Chairperson
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On January 6th, the House Committee on Education and the Workforce released two draft bills, *The Student Success Act* and the *Encouraging Innovation and Effective Teachers Act*. The goal of these bills is to drastically weaken the federal role in schools and to eliminate the accountability measures that are the hallmark of No Child Left Behind (NCLB). NCLB is the name given to the version of the Elementary and Secondary Education Act (ESEA), which became effective in 2002.

NCLB amended the Elementary and Secondary Schools Act of 1965 by requiring all government-run schools receiving federal funding to administer a state-wide standardized test annually to all students. Among other factors, students' scores determine whether the school has taught the students well. NCLB emphasizes equal access to education and establishes high standards and accountability. The law authorizes federally funded education programs that are administered by the states.



ESEA must be reauthorized every ten years, and there has been heated debate in the world of education policy, Congress and schools over the past several years as to how to “fix” NCLB when ESEA comes up for reauthorization. Congress had hoped to pass a reauthorization bill in 2011, but much controversy surrounds several provision of the bill; these particular provisions significantly impact how students with disabilities are accounted for and how achievement gaps are both measured and remediated.

While NCLB was not a perfect law, it represented the first time in history that academic achievement data was required to be collected for students with disabilities, in addition to the following vulnerable “subgroups”: English language learners, economically disadvantaged students and students from major racial and ethnic groups. More importantly, it was the first time that schools, districts and states were held **accountable** for the academic achievement of students with disabilities and other subgroups. The NCLB accountability provisions ensure that school districts and the public are informed of achievement gaps and that schools are required to implement specific interventions that address those gaps. In addition, NCLB has mandated that expectations for academic achievement extend to all students, including those with intellectual disabilities. As a result of these raised expectations, there has been tremendous academic progress for students who historically received little academic instruction.

There are a number of specific concerns that relate specifically to students with disabilities:

Lack of Accountability

The House draft bill that relates to state and local accountability, the *Student Success Act*, eliminates nearly all Federal Requirements that were included in NCLB to ensure that States set high academic performance goals for all students, work to close achievement gaps and help improve struggling schools.

Elimination of Maintenance of Effort (MOE)

The Students Success Act eliminates the longstanding ESEA Maintenance of Effort (MOE) requirement that, at a minimum, the same amount of State and local funding must be spent from year to year unless a couple of specific exceptions are met. The MOE requirement is in place to ensure that there is adequate funding to meet student needs.

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Through humor, you can soften some of the worst blows that life delivers. And once you find laughter, no matter how painful your situation might be, you can survive it.

- Bill Cosby



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Continued from page 25

We are greatly concerned about the funding problems that may be caused by the elimination of MOE from ESEA. In addition, we are concerned that when IDEA is reauthorized, there will be an effort to eliminate MOE from that law, if the effort is successful in ESEA reauthorization.

Highly Qualified Teacher Provisions

The *Student Success Act* eliminates requirements that teachers meet highly qualified teacher requirements that are currently in NCLB. These requirements determine whether teachers have the necessary credentials and core content knowledge to teach their students. It is important to ensure that teachers are not only highly qualified, but also to determine if they are effective.

Alternate Assessments Based on Alternate Achievement Standards (AA-AAS)

Students with disabilities, including those with intellectual disabilities, must have access to grade-level general education curriculum and must be expected to demonstrate achievement on the college and career ready academic content standards set forth by their State. Children with disabilities should be educated in inclusive general education classrooms. A number of provisions in the *Student Success Act* undermine these goals. The main provisions are discussed below:

Elimination of the Cap

In order to ensure the validity of student achievement data and high academic expectations for all students, there must be a cap on the number of students who take an alternate assessment on alternate academic achievement standards, instead of the current 1% cap on the number of proficient and advanced scores that can be counted from those assessments. Currently, the proficiency rate for students who take the AA-AAS is far higher than it is for students with disabilities in other assessments, so there is an incentive to place students in these assessments.

Limits on Access to General Education Curriculum

The *Student Success Act* takes language from current regulations, which can be read to limit the right of students who take the AA-AAS to be provided access to the general education curriculum. The language requires States to demonstrate that these students are included in the general education curriculum "to the extent practicable." The Act also includes problematic regulatory language stating that the alternate academic achievement standard on which the assessment is based must merely **promote**, not **provide**, access to the general education curriculum.

States May Preclude the Opportunity to Earn a Diploma

The *Student Success Act* also takes language from the regulations, which permits States to preclude students who take the AA-AAS from the opportunity to earn a regular high school diploma. **The only requirement is that schools inform the parents that participation in the AA-AAS will preclude their child from completing the requirements for a diploma.** Congress should override these regulations and provide students who take the AA-AAS with the opportunity to try to meet the requirements for a regular high school diploma. An additional problem with the *Student Success Act* is that it allows these students who have been precluded from earning a regular diploma, to be counted as if they received a regular diploma, for purposes of calculating graduation rate, as long they received a diploma based on meeting IEP goals. At the very least these students should earn a diploma based on the State content standards, not IEP goals, before they are counted towards the graduation rate.

If these issues are setting-off alarm bells, they should. Please make sure to contact your Representatives and Senators on both the state and local levels, as well as the Department of Education, to make your voices heard. While it is unlikely that this legislation will pass this year, it is important to advocate at all levels of policy-making sure that legislators understand that our kids not only have a right to a public education but that they also deserve to succeed.

Special thanks to Ricki Sabia from the NDSS Policy Center, for providing her input and expertise to this article.





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