

CONNECTIONS

OVERWHELMING RESPONSE TO THE ABLE ACT CALL TO ACTION = GRASS ROOTS ADVOCACY AT ITS BEST!

By: Heather Sachs, DSNMC Education Chair

Back in July, I posted a call to action on our listserv for members to call Senators Mikulski and Cardin to request that they cosponsor the Achieving a Better Life Experience (ABLE) Act. This important Act would establish tax-exempt 529 accounts for our family members with Down syndrome (or other disabilities) and would not count towards eligibility for public benefits. This piece of legislation is of paramount importance to the way we plan and save for our children's futures.

I am happy to report that YOUR efforts worked, and Senator Mikulski has signed on to be a cosponsor! Whether or not Senator Cardin follows suit remains to be seen. ***DSNMC members who took the time to make phone calls, send emails, and encourage their friends and family to do the same should be PROUD.*** I have never seen such an outpouring of grassroots advocacy in our community before! Within 2 days, there were dozens of messages on our listserv and my personal inbox stating that calls had been made, and thanking me for making it so easy for them to make their voices heard. Many of these messages were from members who had never before taken advocacy action, who perhaps had previously been intimidated by the prospect of calling Congressional offices, had erroneously believed that they had to possess detailed knowledge of the issues about which they were calling, and who had assumed that such calls would take a large chunk of time from their already busy schedules. It was heartwarming to read members' listserv posts encouraging other members to call, stating things like, "took me all of 3 minutes to call both offices," "they are keeping a tally of our calls, so please call and add to this tally," and "it was so easy – all I had to do was give my name and county!"

There are many other important issues affecting our families that DSNMC members can support now and in the future. I am confident that this was not a one-time deal, but rather a new trend of activism and empowerment within our membership. Together, we truly can make a difference!

To be fully informed about current legislation, please sign up for NDSS Action Alerts at:

<http://www.ndss.org/en/Policy/Get-Involved/>.

SEPTEMBER 2012

Playgroup Photos

Back-to-School Resources

ESEA Waivers

Advocacy Update: ABLE Act

Techniques for Success

Sibling Corner:
Brothers & Sisters
Conference

A D.A.B. of Neuroscience

BUDDY WALK

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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



PLAY GROUP

Summer 2012



UPCOMING PLAYGROUP

Saturday, October 27
10:00 AM - 1:00 PM
Butler's Orchard

And, see you at the
BUDDY WALK!



Children remind us to
treasure the smallest of
gifts, even in the most
difficult times."

- Allen Klein



DSNMC BACK-TO-SCHOOL RESOURCES

(1) DSNMC EDUCATION RESOURCE GUIDE: PRINT OUT THE DSNMC EDUCATION GUIDE AND GIVE A COPY TO EACH TEACHER AND PARAEDUCATOR WHO WILL BE WORKING WITH YOUR CHILD THIS YEAR

<http://www.dsnmc.org/resources/teachers/>

(2) BUDDY WALK (OCTOBER 6): ENCOURAGE YOUR CHILD'S FRIENDS, CLASSMATES, TEACHERS AND SCHOOL COMMUNITY TO ATTEND THE EVENT IN SUPPORT OF YOUR CHILD AND THE ENTIRE DOWN SYNDROME COMMUNITY. AN ADDED BONUS IS A DAY OF EXTREME FUN!

www.dsnmc.org

(3) TECHNIQUES FOR SUCCESS CONFERENCE (NOVEMBER 10): EMAIL THE REGISTRATION LINK AND FLYER TO YOUR CHILD'S PRINCIPAL, TEACHERS, THERAPISTS AND PARAEDUCATORS. PRINT THE FLYER AND POST IT IN THE SCHOOL'S MAIN OFFICE. FOLLOW-UP WITH REGULAR REMINDERS TO THEM – SPACE IS LIMITED AND TYPICALLY FILLS UP QUICKLY!

www.techniquesforsuccess.org

(4) TECHNIQUES FOR SUCCESS PARENT PROGRAM (NOVEMBER 9): REGISTER YOURSELF FOR THIS FREE WORKSHOP DESIGNED TO PROVIDE TECHNIQUES FOR SUCCESS RESOURCES TO PARENTS AT A FRACTION OF THE TIME COMMITMENT AND CUSTOMIZED TO PARENTS INSTEAD OF EDUCATORS.

www.techniquesforsuccess.org

(5) DSNMC LISTSERV: WE ARE A HELPFUL AND ROBUST COMMUNITY. IF ISSUES ARISE REGARDING YOUR CHILD'S EDUCATION (OR JUST ABOUT ANYTHING ELSE RELATING TO YOUR CHILD!), CHANCES ARE, ANOTHER MEMBER HAS ENCOUNTERED THE SAME THING. PLEASE POST FOR SUPPORT AND ADVICE.

<http://www.dsnmc.org/about/join-the-listserv/>

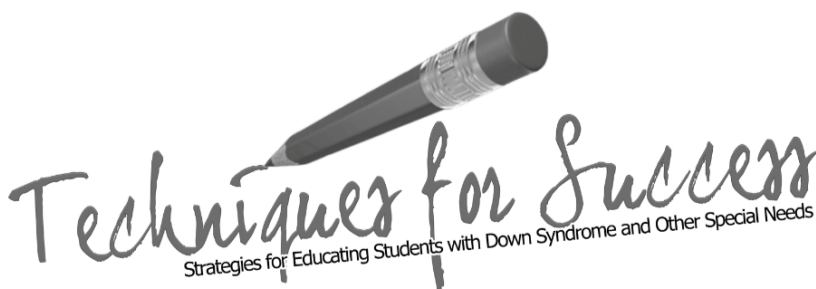
(6) PARENT WORKSHOPS: DSNMC PROVIDES FREE WORKSHOPS THROUGHOUT THE YEAR AT THE ARC MONTGOMERY COUNTY ON TOPICS RANGING FROM IEPs, TO BEHAVIOR PLANS, TO FINANCIAL PLANNING. CHECK FUTURE DSNMC NEWSLETTERS AND THE DSNMC WEBSITE FOR DETAILS.

www.dsnmc.org



PARENT PROGRAM

Friday, November 9, 2012 – 6 to 9 pm
Seneca Valley High School Cafeteria,
19401 Crystal Rock Dr, Germantown,
MD 20874



Event: Prior to the Teacher Program, on November 9th from 6-9pm, parents will get the chance to learn first-hand from experts on different aspects of educating students with Down syndrome. Topics will include “Technology Tools for Parents” and “Accommodations, Modifications and Strategies”. David Egan will provide “A Self-Advocate’s Perspective”. This is the 4th time that Techniques for Success is being offered for educators, but this is the first year that we are offering a parent-only program. The program is designed for parents who have children with Down syndrome or other special needs up to age 21. Adults only, please. We are unable to provide childcare.

Registration Info: Go to <http://techniquesforsuccess.org> under Techniques for Success for Parents for details and to register by October 20. The event is free of charge. However, space is limited and costs are incurred for all registrants. Therefore, we ask you to register only if you are committed to attending the conference. A light dinner will be provided.

EDUCATOR PROGRAM

November 10, 2012
8 am to 5pm
Gaithersburg Marriott Washingtonian Center

**Share the flyer insert with your
 child’s educators at school.**
*Educators from both public and private
 schools are welcome.*

Event: On November 10th, the Down Syndrome Network of Montgomery County (DSNMC) will partner with F.R.I.E.N.D.S. of Frederick County once again to hold the 4th Techniques for Success Conference. This day-long-event is designed to inform teachers and other professionals working in area schools about children with Down syndrome, and to share the latest practices and approaches that are conducive to success in classrooms. Included in the program will be an adult with Down syndrome, or Self-Advocate, who will share how he has reached his full potential. Experts from around the country will share practical strategies for educating students with Down syndrome and those with other special needs.

Conference topics presented each year vary and are based on requests from participants. This year’s topics include:

- Development and Behavior Concerns in School-Age Children with Down Syndrome
- Technology as a Classroom Tool for Teaching Students with Down Syndrome
- Accommodations, Modifications and Strategies
- Transition Processes and Preparation: Middle School, High School and Beyond
- A Self-Advocate’s Perspective

We are expecting 300 teachers from the area to come to the Washingtonian Rio Marriott Hotel. Please tell your child’s teacher about this event. Although they may hear about it through the school, hearing from you directly might be the push they need to attend. The majority of participants in the past have expressed their gratitude for the chance to learn more about children with Down syndrome. Some of the same educators attend regularly and new participants are encouraged. General educators, special educators, para-educators, administrators, counselors, therapists and home school parents will be in attendance.

Continuing Education Units (CEU) Credit for Teachers and Other Info: Montgomery County Public Schools (MCPS) staff can earn 8 hours towards CEU credits for participating in the day-long program. Participants will also be given a flash drive full of educational materials as reference material to take back to their home schools. In addition, conference participants will be offered a continental breakfast, lunch, and snacks for the day. This year’s program will have a raffle and door prizes.

Registration & Details: Educators can go to <http://techniquesforsuccess.org> under Techniques for Success for Educators. (Parents may download a flyer from the website to share with their child’s teaching team.) The event is free of charge. Space is limited. Early registration is encouraged – the deadline is **October 20**. Please note that costs are incurred for all registrants once registration is complete. Therefore, we ask educators to register only if they are committed to attending the conference.

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State Waivers Lower Expectations for Students with LD

By Candace Cortiella

Smart Kids with Learning Disabilities

<http://www.smartkidswithld.org/hot-topics/state-waivers-lower-expectations-for-students-with-ld>

Candace Cortiella is Director of The Advocacy Institute, a non-profit organization dedicated to the development of products and services to improve the lives of people with disabilities, particularly learning disabilities.

On September 23, 2011, the U.S. Department of Education introduced an ESEA Flexibility Program which allows states to waive certain key accountability and funding allocation requirements of the Elementary and Secondary Education Act (ESEA—formerly referred to as NCLB, the No Child Left Behind Act). In exchange for these waivers, states must provide certain assurances that are supposed to improve academic achievement for all students, including students with disabilities.



Brought on by the inability of the U.S. Congress to formulate and pass an update to ESEA—now several years overdue—the ESEA waivers have been embraced by almost all 50 states and the District of Columbia. As of August 13, 33 states have applied for a waiver, several more are under review, and only a handful of states have not applied.

WHAT GETS WAIVED

States receiving ESEA waivers are no longer required to adhere to many provisions in current law. Most important among these are:

- Making Adequate Yearly Progress (AYP) by achieving annual measurable objectives (AMOs, specifying the percent of students required to be proficient) which must lead to 100% proficiency by 2014
- Required interventions in all title I schools failing AYP – primarily allowing students to transfer to another school or receive supplemental educational services, or tutoring
- Identification of every school's AYP status every year, by student subgroups (racial/ethnic/low income/disability/English proficiency)
- Several restrictions on how federal funds can be spent.

WHAT STATES MUST DO

States receiving ESEA waivers are required to commit to do several activities, including:

- Ensure students are college and career ready, by either adopting the Common Core State Standards or other approved standards
- Develop state-defined accountability systems to replace AYP, including new assessments aligned to new standards
- Enhance teacher and principal evaluation policies, such as developing systems that include student performance
- Reduce administrative burden on districts and schools.

Thank you to
Allison Wohl,
DSNMC
member, for
submitting this
article.

WHAT REALLY HAPPENED

LACK OF INVOLVEMENT. Despite a requirement that states “meaningfully engage and solicit input from diverse stakeholders and communities in the development” of a request, most states compiled their requests internally at state departments of education and asked for little if any stakeholder input. This lack of transparency and input was particularly acute with regard to the disability community.

LESS ACCOUNTABILITY. Accountability for student subgroups—such as students with disabilities—has been allowed to be marginalized in these new state-developed accountability systems. Several states created new “groups” of combined student groups. For example, Virginia created a “Proficiency Gap Group” that combines students with disabilities, English language learners and low income students. Since no student counts more than once in these new combo groups, states escape the impact of students who, in fact, belong to several student groups. Previously, under NCLB, students counted in every applicable student subgroup.

LOWERED EXPECTATIONS. The ESEA waiver allows states to set lower expectations (or AMOs) for low-performing students. Despite the fact that the purpose of ESEA is to “ensure that all children have a fair, equal, and significant opportunity to obtain a high-quality education and reach, at a minimum, proficiency on challenging state academic achievement standards and state academic assessments” states have been given the green light to continue the soft bigotry of low expectations once considered deplorable. Students with disabilities will be particularly hard hit by this new approach, which could be called the “start behind, stay behind” provision.

FEWER INTERVENTIONS. States with waivers are now required to identify and intervene in only 15% of the state’s Title I schools – those with the very worst academic performance and graduation rates. All other schools will simply report their assessment results.

BOTTOM LINE

Unlike the many features of NCLB that applied to all states, now no two states’ accountability systems are alike. No commonality across states makes for impossible advocacy at the federal level. All of this makes state-level advocacy more important than ever before. Building coalitions, such as Wisconsin’s Survival Coalition (<http://www.survivalcoalitionwi.org/>) will be critical to protecting the rights of students with disabilities. So find out what’s in your state’s waiver. Do it today. All ESEA waiver requests and related documents are available at <http://www.ed.gov/esea/flexibility/requests>

WHERE DOES YOUR STATE STAND?

States with APPROVED WAIVERS: Arizona, Arkansas, Colorado, Connecticut, Delaware, Florida, Georgia, Indiana, Kansas, Kentucky, Louisiana, **Maryland**, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, **Virginia**, Washington and Wisconsin and the District of Columbia.

States with OUTSTANDING REQUESTS FOR WAIVERS: California, Idaho, Illinois and Iowa.

States (plus Puerto Rico) that have NOT YET REQUESTED WAIVERS: Alabama, Alaska, Hawaii, Maine, Montana, Nebraska, New Hampshire, North Dakota, Pennsylvania, Texas, Vermont, West Virginia and Wyoming. However, several states have received approval to freeze Annual Measurable Objectives (AMOs) for the coming school year—Alabama, Alaska, Idaho, Iowa, Maine, West Virginia.

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As a parent, I always find myself saying, “wow they have grown up so quickly, I cannot believe how fast the time has gone by.” We have all said it, and we have all felt it and I think this is the simplest way for me to sum up the past six plus years that I have been President of DSNMC. We have grown up, and it is hard to believe how many years have gone by.

President's Letter

It is difficult to think about my day-to-day life without there being some component of DSNMC. The time is coming when someone else will take my place, pick up the ball of activity and run with it. As much as I love this organization, my term is coming to an end and the Board of Directors is looking for a successor. That said, I will not vanish, but will remain as a Trustee and an advisor to both DSNMC, as well as the new President.

My presidency has been one of the most fulfilling and exciting experiences of my life. What began as a simple interest in helping Penny Veerhoff plan the first Buddy Walk in 2005, quickly became a “we can do this...and this...” drive that I could not walk away from. I was first driven by my daughter, Devin, to expand the organization to a level that embraced the many dynamic families involved and reach out to our community as an authoritative resource on Down syndrome. The ideas were endless and I found that when I asked other members to be involved, they were just as excited and passionate as I was. It was a clear a recipe for success that enabled DSNMC to grow from a budget of \$4,000 budget to one of \$130,000 along with new healthcare and educator outreach, advocacy initiatives, membership expansion and a more structured organization that has been able to sustain our growth.

On a personal level, I was able to utilize my business skill set and turn it loose in a way that was driven by passion for my family, which I knew would also impact so many other families with very similar needs. There are very few if any opportunities in life for one to do this, and I have been blessed with six plus years. I have also met so many incredible people both in the Down syndrome community as well as our community as a whole that have given me the gift of looking at one situation through many, many different glasses. Life in general can very easily sweep one up, and as President, the exposure I was given to so many different family situations, I was able to take a small piece of each one to guide the journey with my own family as well as fulfilling my duties as President. There is nothing more rewarding than a parent or a child or adult with Down syndrome thanking you for something you have done that has made an impact on their life. In the end, I am thankful to have had this incredible opportunity to serve all of our members and I am sincerely looking forward to seeing where my successor will take us.

If you have any interest in speaking about this in greater detail, I would be more than happy to. Please email me to coordinate. In the meantime, I am committed to building the foundation that DSNMC has so that the possibilities are endless.

Warm Regards,

Gena

BUDDY WALK 2012

The October 6th event will be held at Hadley Park in Potomac, MD from 10:00-2:30, and we look forward to making this Walk our best one yet. The theme for the walk this year is “We Are All Stars” celebrating the many stars among us with a little splash of Hollywood glitz and glamour. The Master of Ceremonies for this year’s Buddy Walk is Adrian Forsythe Korzeniewicz, a self advocate with ambitions to advocate for people with disabilities and to be an actor.

The mission of the Down Syndrome Network of Montgomery County is to empower and support individuals with Down syndrome, their families and the community through education, information, public awareness and advocacy. It is through our only fundraiser, the Buddy Walk, that we can achieve this mission. Money raised at this walk is used to support the many educational programs, public awareness and advocacy efforts throughout the year. Money raised at this event helps to fund DSNMC membership activities like the playgroups, winter dance, and parent workshops. As a grass roots organization, DSNMC counts on contributions to make this a strong resource for families of children with Down syndrome.

Our goal this year is to surpass the \$70,000 raised in 2011. Over the last year, we have upgraded our online registration and fundraising sites to make it easier than ever to create a team and start to raise money for DSNMC at <http://www.crowdrise.com/BuddyWalk2012> . To register for the walk, go to the DSNMC website <http://www.dsnmc.org> and click on the Buddy Walk logo.

New this year, top fundraisers will be awarded following prizes:

- First prize - a limousine ride to Buddy Walk and a Canon PowerShot camera
 - Second prize - a Canon PowerShot camera and movie night basket for 4
 - Third prize – Canon PowerShot camera
- Multiple winners per level are possible!

All prizes will be calculated based on monies raised by Thursday, October 4th at 12 noon. Prize amounts include sponsorships as well as online, check and cash donations, which will all be verified by an individual appointed by DSNMC. Board members are not eligible.

Keep an eye on the DSNMC list serve for ways to volunteer at this year’s Buddy Walk or to help in the planning. Contact Susan Mordan, Buddy Walk Manager, at buddywalk@dsnmc.org.

Schedule – October 6, 2012

10:00 am	On-site registration will begin
11:00 am	Opening Ceremonies, led by Adrian Forsythe Korzeniewicz
11:30 am	Walk begins- one mile loop around the park
12:00 pm	Carnival like festivities begin- Moon bounce, arts and crafts, teen/'tween area, face painting, refreshments and more
2:30 pm	Events close

Buddy Walk Volunteers

If you know of any groups or individuals who would like to be volunteers at the 2012 Buddy Walk, please email buddywalk@dsnmc.org

DSNMC EVENTS

Coffee and Conversation

2nd Tuesday of each month from
10:30 - Noon

Tuesday, October 9
Tuesday, November 13
Tuesday, December 11
10:30am – Noon

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

If you would like to attend a **Board Meeting**, please contact Gena at
gena@dsnmc.org

BUDDY WALK 2012

Saturday, October 6, 2012

See dsnmc.org or page 11 of this
newsletter for details.

HAPPY HOURS are happening the 3rd Thursday of
each month from 5:30 – 7:30 PM!

Thursday, September 20
Clyde's Tower Oak, Rockville

Thursday, October 18
Uncle Julio's, Gaithersburg

Thursday, November 15
Carraba's Grill, Germantown

Questions, contact admin@dsnmc.org

Play Groups

Saturday, October 27
10:00 AM – 1:00 PM
Butler's Orchard

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

PARENT WORKSHOPS related to
Kindergarten and Middle School
being planned! More information
to come via the listserv and
dsnmc.org These are co-sponsored by
DSNMC, The Arc Montgomery County &
The Autism Society of Montgomery



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

November 9 & 10
See dsnmc.org or page 5 of this
newsletter for details.

Please share the flyer insert with
your child's educators at school.



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COMMUNITY EVENTS & NEWS

PARENT-to-PARENT

Recruiting New Mentors

Are you a good listener? Have you had experience accessing resources for your child? Do you have some time to invest in helping another parent? If so, please consider becoming a mentor through SEEC's Parent to Parent (P2P) program. P2P is a free and confidential peer mentoring program in Montgomery County for the parents of children with a wide range of special needs, including developmental disabilities, complex medical conditions, and learning differences.

P2P connects parents looking for emotional support and/or information referral with experienced and trained parent mentors in a one-to-one match. The program serves families of children from birth to age 21, and contact can be made via email, phone and in person. In addition to its matching/mentoring service, P2P hosts several activities throughout the year, including mentor training, family get-togethers, and informational workshops.

P2P has been fortunate to have several parents of children with Down syndrome participate as mentors, but we are always looking to expand our pool of available support parents. If you are interested in learning more about what is entailed in becoming a P2P mentor, or would like to access its services, please contact Krista Middlebrooks at kmiddlebrooks@seeconline.org, or 240-472-7363.

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](tel:301-365-0561)

Help new medical students from The Uniformed Services University BE THE BEST DOCTORS THEY CAN BE!

This is a model program. The Department of Medicine and Pediatrics at Uniformed Services University are seeking special needs families that have a desire to share their stories and participate in the curriculum of the medical students at USU. We are always seeking families that would like to participate by hosting students for Home Visits! First we set up a brief orientation if you haven't already (to see you in person to make sure this is the right fit for you), and then you can host as many or as few as you'd want to for whatever weeks our home visit coordinator has available. This occurs in the very early fall. Two or three students would come for a pre-arranged date, time and timeframe that works for the host family. Students have met families for an outing, or just at the house to see "a day in the life". We ask you for what week(s) in the fall that you're available, then we have one of the students contact you directly to set up that time for one day during that week. It's as simple or as intricate as you'd like. This year, family visits are already underway, and we are mostly seeking help for next year. If interested in any of our programs or any further information, please do not hesitate to contact Rose Ann Stern, Patient & Family Coordinator at USUHS (Uniformed Services University). XArmyRN@aol.com, 703-232-4015

"The central struggle of parenthood is to let our hopes for our children outweigh our fears."

- Ellen Goodman

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>

National Institute of Mental Health, National Institutes of Health, Department of Health & Human Services

Protocol No. 89-M-0006

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

Jim Begg

Real Estate Professional
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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

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



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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 Institute of Mental Health, NIH

Part Two of 'Life is a journey, not a destination.'

-Ralph Waldo Emerson

In the June newsletter, we described the brain's 'developmental marathon' based on what is known about how the brain develops in typically developing children and young adults. As you may recall, we discussed the fact that brain development is a journey that begins well before a baby is born and continues into the early 20s. The recap below summarizes what we have learned about child brain development using **longitudinal MRI** (i.e., repeated magnetic resonance imaging or MRI scans of the same children scanned at multiple points during childhood) and other methods.

RECAP OF LITERATURE ON TYPICAL BRAIN DEVELOPMENT

→ As children grow and learn, long fibers that permit communication between different brain regions called **axons** become covered in a fatty material called **myelin**. Myelin wraps around axons and serves as a form of insulation, which helps to speed and synchronize neural communication. Myelinated axons appear white when captured using MRI and so they are referred to as **white matter**.



White matter increases throughout childhood and adolescence and is thought to contribute to more efficient brain functioning.

→ Gray matter, the neural tissue that appears gray when captured with MRI, is comprised of **neurons** (basic neural processing units), **dendrites** (branches that receive and conduct signals from other neurons) and **synapses** (gaps where neurons communicate with each other). Gray matter increases in early childhood (thought to be due to increases in the number and complexity of dendrites and synaptic connections) and decreases in late childhood and adolescence (thought to be due to **synaptic pruning** – that is, eliminating unnecessary neural connections).



Gray matter decreases during late childhood and adolescence likely due to pruning of unnecessary connections, resulting increased communication efficiency in the brain.

WHAT DO WE KNOW ABOUT GRAY AND WHITE MATTER DEVELOPMENT IN DOWN SYNDROME?

There have been very few MRI studies of the brain in children with Down syndrome and **no studies have been published using longitudinal MRI to describe the developing brain in Down syndrome**. So we will

summarize what is known about the brain in children with Down syndrome based on so-called ‘cross-sectional’ studies (i.e., one time ‘snapshots’ of the brain using MRI and other methods).



Total gray matter volumes are reduced in Down syndrome compared to typical children.



Total white matter volumes are reduced as well.



Myelination (the process by which axons are covered in a fatty sheath called myelin) is delayed in Down syndrome and this is noted as early as 6 months of age.



Certain brain structures appear to be particularly affected by Down syndrome. These will be discussed in our next issue. So stay tuned for details. However, here is a preview:

- The hippocampus, a part of the brain thought to be important for rapid learning of new information and for the formation of long-term memories (including autobiographical memories or memories about one’s own life) is reduced in size.
- The cerebellum, a structure at the base and back of the brain thought to be important for motor development but also attention and some other cognitive skills, is also reduced.
- The temporal lobes which are thought to be important for both language and social development are reduced in Down syndrome in many reports.
- Some research suggests that the frontal lobes, thought to be important for planning and higher-level cognition, are also reduced in size.

But many questions remain! Some are listed below:

(1) What do gray and white matter trajectories look like for kids with Down syndrome? (2) Do they look the same as those found in typical kids? (3) Do the same patterns of growth apply but at a slower pace? (4) Or do they occur at a faster pace? (5) Is there an age at which gray and white matter trajectories start to look more or less like those found for typically developing kids?

Gray & white matter trajectories for typical kids are shown below.

Research still needs to be done to describe what these curves look like in Down syndrome!

Figure 1.
White Matter Trajectory During Childhood & Adolescence

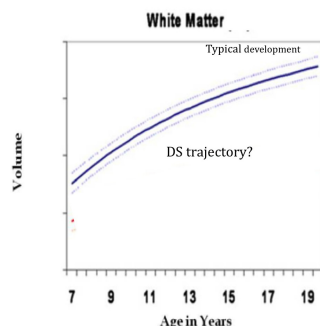
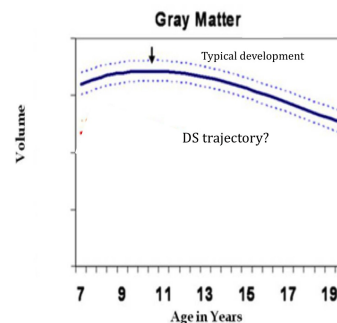


Figure 2.
Gray Matter Trajectory During Childhood & Adolescence



Images above modified from Giedd, J.N. & Rapoport, J.L. (2010). Structural MRI of Pediatric Brain Development: What have we learned and where are we going. *Neuron*, 67, 728-734.

For a review of brain and behavioral development in Down syndrome, see: Fidler, D. & Nadel, L. (2007). Education and children with Down syndrome: Neuroscience, development, and intervention. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 262-71.



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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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leave footprints on our hearts, and
we are never the same."

- Franz Peter Schubert



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SIBLING CORNER

BY MADDIE MITCHELL

THANK YOU to Maddie Mitchell for being the originator and first contributor to the SIBLINGS CORNER of this newsletter. All SIBLINGS of individuals with Down syndrome are invited to email contributions (including a photo) for consideration. Please email submissions to Maddie Mitchell at sing.act.21@gmail.com

NDSC Brother and Sisters Conference

My name is Maddie Mitchell, I am 11 years old. This past summer was the first time I went to the NDSC brothers and sisters conference as I have a younger sister with Down syndrome. Her name is Devin and she is 9 years old. Devin is very important to me.

What I Learned at the Conference

At the conference I learned many things. I learned more about what Down syndrome is and how to protect my sister if she is ever being bullied. Not to hurt the person bullying her mentally or physically, just to speak up and say “Hey, I don’t like what you’re doing to my sister, you shouldn’t bully people because they look or learn differently. You just shouldn’t be bullying in the first place. So, just back off.” I also learned some new character traits she has but I never thought of them. I already knew she was kind, sweet, frustrating, silly, and caring, but she’s a lot more than that. She’s shy, protective, serious, smart, understanding, mischievous, and a lot more.

I loved going to this conference! It’s cool to go somewhere when all the people in the room have a sibling with Down syndrome just like you. Nobody looks at you funny when you tell a story, instead, they smile, laugh, and they understand unlike this little story. So one day I went to school and I was frustrated with Devin and my friend asked me what was wrong. I said something about how Devin was bothering me or something like that. Then my friend said “Oh I totally understand. My brother does that all the time! I totally know what you’re going through. I can totally relate.” It’s not my friends fault, but the reality is she doesn’t understand because she doesn’t have a sibling with special needs. This time it was different, all the other sisters and brothers understood what I was talking about and I felt really comfortable.

Going to the conference also taught me that my younger sister Devin really does know what Emily (our little sister) and I are talking about. She definitely understands more of what we are saying than I thought. This is what I learned at the NDSC Brother’s and Sister’s Conference. I had a blast! I made new friends, learned new facts, and had an amazing experience! I can’t wait to go again!



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