

AUGUST 2012 Newsletter

Issue No 15

MONTHLY MEETING- TUESDAY, AUGUST 7TH, 7PM- MUMC

WE WILL HAVE 3 VOLUNTEERS AVAILABLE FOR OUR AUGUST 7TH MEETING

Thanks to the Rotary Club and Catherine Fairley's efforts, we now will have rotational volunteer staff at our monthly meetings to help out with the youth while the parents are able to listen to speakers, coordinate activities such as the Buddy Walk and socialize with each other.

SAVE THE DATE: 11TH ANNUAL BUDDY WALK DATE SET FOR SEPTEMBER 22ND, 2012:

Much preparation is going to be needed to accommodate our ever growing group and outreach programs, so PLEASE, if you have not been involved in previous years or are new to the group, we NEED YOU!!! There are many volunteer opportunities available and needed to make this day a HUGE success for our group and our Down syndrome awareness efforts. Committees are forming now, contact Denny for more information.

SET UP YOUR FIRST GIVING ACCOUNT NOW FOR THE 11TH ANNUAL BUDDY WALK

Below is the link for all online registrations and fundraising for this year's Buddy Walk.

<https://www.firstgiving.com/frederickfriends/buddywalk2012>

Remember, 100% of the funds received are invested into our awareness campaigns; So why wait, use the web address below and select the **"JOIN NOW"** button and get you and your team registered today.

KIDS CORNER

Every month we strive to showcase a different child from our group in our Kids Corner. If your child has not yet been showcased, please send a picture and a bio to holly.mohler@yahoo.com. We will also be showcasing siblings of our group, so please send in your bios and pictures.



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SOCIAL AND POLITICAL AWARENESS

HEALTH AND WELLNESS

DOWN SYNDROME RESEARCHERS SEE HOPE FOR A PILL TO BOOST MENTAL ABILITY

New studies are raising the hope of finding a pill to improve the intellectual abilities of people with Down syndrome.

One study, published online by the [journal Translational Psychiatry](#), is the first ever to show that a drug might improve the verbal memory of people with the disorder. Although the benefits appeared modest and the study was small, Down syndrome experts meeting last week in Washington called it a major development after more than a decade of research in mice and test tubes. Down syndrome patients could see intellectual abilities improve with drug Namenda.

The drug used in the recent study, Namenda, is approved for treating Alzheimer's disease. Although it has shown only a slim and temporary benefit for that condition, a 2007 study of mice with the genetic equivalent of Down syndrome showed that it almost entirely normalized their ability to learn and remember. The effects in humans appeared far less striking. Alberto Costa, a physician and neuroscientist at the University of Colorado in Denver, ran a test involving 42 young adults with Down syndrome, half of whom received a placebo.

After 16 weeks, most of the people who received Namenda performed better on tests of memory than they had at the beginning of the study. But the effect was statistically significant on only one of the 14 tests, which some researchers at last week's meeting said they considered disappointing. "It was a small improvement on a single measure," Costa, who began studying Down syndrome after his daughter was born with it, acknowledged. "But it's the first time in this business anybody saw anything. You can see it as a little study that had a little tiny effect, or as one of the greatest findings in Down syndrome over the past 10 years. Both are true." His trial was funded by the maker of Namenda, Forest Laboratories, and by the National Institutes of Health, the Linda Crnic Institute for Down Syndrome at the University of Colorado and the Coleman Institute for Cognitive Disabilities. While he and others emphasized that it is far too early to consider offering Namenda to people with Down syndrome, Costa said he is hoping to organize another, a larger study of the drug. He also wants to test it in people with Down syndrome younger than 18.

To read more- go to http://www.washingtonpost.com/national/health-science/down-syndrome-researchers-see-hope-for-a-pill-to-boost-patients-mental-abilities/2012/07/30/gJQA1ntvKX_story.html



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HEALTH AND WELLNESS

CHANGES IN MEDICAL ASSISTANCE DUE TO NEW HEALTH CARE LAWS PASSED

Note from the Editor: I just wanted to share this story with the group- it does not reflect the views of FRIENDS- and is just an FYI:

We, the Mohler family, received a letter in the mail from Kristen's primary physician (one of the largest pediatricians in Frederick County) stating that because of new healthcare laws being passed and changes being made to Medical Assistance coverage through those laws, they would no longer be able to treat her as a patient. As many of you are aware, children with disabilities are required in the state of Maryland to apply for a medical assistance card/number to be eligible for certain government benefits.

For the past 10 years, we have not used Kristen's MA because she has been covered under our primary insurance that we carry for the rest of the family, which is Blue Cross Blue Shield PPO. So for the past 10 years, her primary physician has never submitted or received a claim/payment through her MA. But because she is required by the government to carry an MA card because of her disability, and because of the new laws recently passed, she is now being dropped from her primary physician. The letter stated that the new law does not allow their office to see patients that are covered under plans for which they do not participate.

We were told that we had one option: Find a new doctor that accepted her type of MA coverage (regardless of whether we use it or not) and that also participates with our primary coverage BC/BS.

This is just a heads up of changes to come for our children and our health care system. Feel free to share your story of how your child's healthcare has been positively or negatively affected by the recent healthcare laws.



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UPCOMING EVENTS AND ACTIVITIES

AUGUST

AUGUST 7TH- MONTHLY MEETING

AUGUST 8TH- BUDDY WALK MEETING- AT BAKER PARK 7PM- DISCUSS LAYOUT

AUGUST 15TH- BUDDY WALK MEETING- 7PM- PANERA IN FREDERICK

AUGUST 18TH- DAD'S DAY- BUILD CARNIVAL GAMES- 10-2PM- DENNY'S HOUSE

7211 Mt. Church Rd. Middletown, MD 21769

AUGUST 21ST- BUDDY WALK MEETING- 7PM- LOCATION TBD

AUGUST 28TH- BUDDY WALK MEETING- 7PM- LOCATION TBD

SEPTEMBER

WEEK PRIOR TO SEPTEMBER 22ND- STUFF THE BAG NIGHT- VOLUNTEERS NEEDED

SEPTEMBER 22ND- BUDDY WALK

OCTOBER

OCTOBER 2ND- MONTHLY MEETING- DRESS UP FOR HALLOWEEN PARTY

FAMILY DAY- HARVEST FARM- Saturday in October

NOVEMBER

NOVEMBER 6TH- THANKSGIVING DINNER

TECHNIQUES FOR SUCCESS CONFERENCE

DECEMBER

DECEMBER 4TH- CHRISTMAS PARTY

MISC:

F.R.I.E.N.D.S PHOTO SHARING- [HTTP://DOWNBUTUP.SHUTTERFLY.COM/](http://DOWNBUTUP.SHUTTERFLY.COM/) SHARE PHOTOS OF THE GROUP AND INDIVIDUALS WITH DOWN SYNDROME THROUGHOUT THE YEAR



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Save the date!

4TH TECHNIQUES FOR SUCCESS CONFERENCE

November 9, 2012 – Parent session

November 10, 2012 – Conference for educators

The 4th Techniques for Success (TFS) conference will take place in November 2012. TFS focuses on practical strategies for educating students with Down syndrome and those with other special needs. This year, there will be a special session for parents in the evening of Friday, November 9 (location to be determined) and an all-day conference for educators on Saturday, November 10, at the Gaithersburg Marriott in the Washingtonian Center.

Please save the date and ask staff at your child's school to attend!

Inviting your child's teaching team is a great way to show support for them and to spread up-to-date knowledge about Down syndrome within our school system.

The educators' conference is appropriate for general and special education teachers, paraprofessionals, therapists, counselors, administrators and homeschooling parents. The specific topics and speakers change each time so it is worthwhile to attend every year. This year's topics will include technology, behavior issues and an interactive session about accommodations, modifications and strategies.

The conference is offered free of charge, thanks to those Buddy Walk donations. Watch the DSNMC listserv and website for details about registration, which will open in the late summer.

TFS is a joint effort between DSNMC and F.R.I.E.N.D.S. of Frederick County. If you would like to become a part of the Planning Committee, please contact Heather Sachs, TFS Planning Committee Co-Chair, at heather@dsnmc.org.

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OUR KIDS CORNER

ANNA JO MOHLER



Anna Jo Mohler was born August 15, 2009 to Kenny and Holly Mohler. She has 2 sisters and 2 brothers, Jessica, Kristen (shown above), Kevin and Alec. She LOVES the color purple and her favorite show is Mickey Mouse Club House. Her favorite character from that show is Daisy- because she wears purple. She loves to copy her big sister Kristen in all that she says and does.



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AFFILIATED ORGANIZATIONS



Newsletter Committee:

Holly Mohler (holly.mohler@yahoo.com)