

September 2011 Newsletter

Issue No 4

WELCOME F.R.I.E.N.D.S.

EARTH QUAKES, HURRICANES, BACK TO SCHOOL, OH MY!!!

What an interesting last few weeks it has been in our local area. Hopefully everyone was able to come out of these events unscathed. We have a jam-packed newsletter for you this month. There are a ton of activities going on, including the most anticipated, **10th Annual Buddy Walk on September 17th**- WE HOPE TO SEE EVERYONE THERE. Please make sure you have your First Giving page set up to maximize your donating efforts.

PLEASE NOTE: Our newsletter is in desperate need of photos and bios for our Kids Corner. If your child has not yet been featured, please make sure you send your child's information and picture to holly.mohler@yahoo.com. Please be sure to also send any Down syndrome related topics of interest that you would like to see featured in our social/political awareness or health/wellness sections.

MUMS for SALES: In a wonderful partnership with Chloe's Cause Foundation, F.R.I.E.N.D.S. will be selling mums this year. The order form is available online at friendsoffredco.org. Mums will be available for pick up at the Buddy Walk. Pre-orders are due September 9th. Contact Tracy Barnard for more information.

Buddy Walk Quilt: Pat has volunteered to make a quilt of all the Buddy Walk t-shirts from previous years, but we are missing years 2001, 2002, and 2003. If anyone has one of these t-shirts that they are willing to part with, please contact Tracy Barnard.

September is also a time to remember those who were lost 10 years ago in the 9/11 attacks. Please be sure to take a moment on Sunday, September 11th, to reflect on that day, remember those who made the ultimate sacrifice for our country and those that continue to sacrifice at home and abroad.

MAY WE NEVER FORGET



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HEALTH AND WELLNESS

MUSCULOSKELETAL DISORDERS IN DOWN SYNDROME

“Almost all of the conditions that affect the bones and joints of people with Down syndrome arise from the abnormal collagen found in Down syndrome. Collagen is the major protein that makes up ligaments, tendons, cartilage, bone and the support structure of the skin. One of the types of collagen (type VI) is encoded by a gene found on the 21st chromosome. The resulting effect in people with DS is increased laxity, or looseness, of the ligaments that attach bone to bone and muscle to bone. The combination of this ligamentous laxity, and low muscle tone, contribute to orthopedic problems in people with Down syndrome.

Spine: The major condition associated with the spine in Down syndrome is Atlantoaxial instability, which is the looseness between the first and second vertebrae of the neck. Another condition associated with the spine in Down syndrome is **scoliosis**, which is the curvature of the spine to the side. While it appears to be more common in people with DS, the exact incidence isn't known. In the era when almost all children with DS were institutionalized, scoliosis may have been seen in up to half of them as they became adolescents. Treatment of scoliosis remains the same as in other children, with bracing being the initial therapy, followed by surgical intervention if necessary.

Hip: Five to eight percent of children with DS will develop abnormalities of the hip. The most common condition is dislocation of the hip, which is also called **subluxation**. In this condition, the head of the thigh bone (the femur) moves out of the socket formed by the pelvis (the acetabulum). This dislocation may or may not be associated with malformation of the acetabulum. The dislocation appears to be due to a combination of laxity of the connective tissue that normally keeps the hip together along with the low muscle tone found in DS. Interestingly, hip subluxation in children with Down syndrome is hardly ever found at birth but instead is most common between the ages of 3 and 13 years. The most common sign is a limp, and pain may or may not be present. Treatment will often start with immobilization of the hip with a cast. Many children with DS will require surgical correction, however.

Instability of the patella (kneecap) has been estimated to occur in close to 20 percent of people with DS. The majority of cases of instability present only as kneecaps that can be moved further to the outside than the normal kneecap (subluxation); however, some people can have their kneecaps completely move out of position (dislocation), and some may even have a hard time getting it back into the right position. Mild subluxation of the kneecap is not associated with pain, but dislocation may be painful. While people with instability of the patella are able to walk, there is often a decreased range of motion of the knee, with an accompanying change in gait. The longer that nothing is done for the instability, the worse the condition will get over time. Orthoses (special braces) may be useful for mild cases, but severe cases require surgical correction.

Flat foot, also called pes planus, is seen in the vast majority of people with DS. In mild cases, the heel is in a neutral position. In severe cases, the heel rotates so that the person is walking on the inside of the heel. Flat feet result in heavy calluses of the feet, pointing of the front part of the feet away from each other (the opposite of being "pigeon-toed"), and even the creation of bone spurs in the feet. Many cases respond to orthotics, but severe cases need surgical correction.” (www.ds-health.com, 2011).

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SOCIAL AND POLITICAL AWARENESS

SPECIAL OLYMPICS OF FREDERICK COUNTY

“The mission of Special Olympics of Frederick County Maryland is to provide year round sports training and athletic competition in a variety of Olympic-type sports for all children and adults with intellectual limitations, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts and friendship with their families, other Special Olympics athletes and the community” (www.somdfrederick.org, 2011).

The following are just a sample of the sports that are available to children and adults with disabilities in the Frederick SO: Year round gymnastics, cheerleading; Fall cycling, golf, flag football; Winter skiing, floor hockey; Spring basketball and duckpin bowling; Summer swimming, equestrian and softball. Up-to-date medical evaluations are required for participation in sporting events, and most children with Down syndrome are required to have a lateral x-ray of the cervical spine in hyper-flexion and hyperextension (especially if involved in diving or gymnastics events). **Musculoskeletal disorders** (see our health and wellness section) are the cause for concern and the reason behind these x-ray requirements.

Most if not all sporting activities are free to the participants thanks to local sponsors of the organization. One way our organization can give back is by supporting the local Spirit Night Out at Chick-fil-A. See attachment for more details (and also the Up-coming Events page).

The Frederick SO also works to promote social acceptance of all persons with disabilities with their support of the Spread the Word to End the Word campaign (www.therword.org).

There are many sporting events that are open to all ages- such as gymnastics. This sporting event will begin again this month starting at 4-5:30pm on Saturdays at the Frederick Gymnastics Club. If you have never been to this facility, it is a great place for children of all ages to run, play, jump (in the foam pit), increase their motor skills and just plain have FUN! Contact coach Anne MacDonald for more information.

Get involved in your local Special Olympics organization. It not only provides a safe place for our children to show case their talents, but it is also a great place for children and families to socially network with others.

“LET ME WIN. BUT IF I CANNOT WIN, LET ME BE BRAVE IN THE ATTEMPT”





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for Down Syndrome • Frederick County, Maryland



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UPCOMING EVENTS AND ACTIVITIES

Monthly Group Meeting for September- CANCELLED

Please come out for our 10th Annual Buddy Walk in lieu of our monthly group meeting.

Pre-sales of MUMS for the Buddy Walk- orders due by September 9th

Please visit our website: friendsoffredco.org to download the order form or contact Tracy Barnard for more information.

Maryland Mystics Fast Pitch Girls Softball Carwash- September 10th, from 9am-3pm at Mr. Bubbles located at Ballenger- 5930 Edenton Court, Frederick.

The Mystics have changed the date of their car wash event from September 17 to September 10 so that they can participate in our 10th Annual Buddy Walk. They will set up a clinic for our kids between 1:45-3:45 at the Buddy Walk- Field 1 at Baker Park. Show your support for this AWESOME sacrifice by this organization by coming out to their car wash event. Be sure to mention FRIENDS at the car wash!!! This is a great opportunity for our group to show our support of local organizations that sacrifice for our kids to hopefully make a difference in our community. It's a great way for us to give back!!!

Spirit Night-benefits SO of Frederick County- Chick-fil-A- September 14, from 4-8pm

Show off your multi-tasking skills by eating more chicken and supporting your local Special Olympic organization. Present the attached coupon at the Chick-fil-A in Frederick on Spirit Night and based on the evening sales, CF will make a donation to the Special Olympics of Frederick County.

10th Annual Buddy Walk- September 17th – Band Shell at Baker Park, Frederick MD

SET UP YOUR FIRST GIVING ACCOUNT NOW FOR OUR UPCOMING BUDDY WALK

ONLY TWO WEEKS LEFT

1. Check in/Registration begins at 11 am. When you check-in, you will receive your t-shirt(s).
2. Walk will begin at 1pm. The one block walk begins and ends at the band shell in Baker Park.
3. Key note speaker Brad Hennefer, a young man with Down syndrome, affiliated with Golf For Life: www.golfforlife.org
4. Featured artist Margie Smeller will have a table set up: www.margiesmellerart.com
5. KidzArt will be back again this year with a new mural for the kids to color.
6. Activities include petting zoo, moon bounce, ice-cream truck, food and much more.

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OUR KIDS CORNER- KRISTEN HOPE MOHLER



Kristen Hope Mohler is 14 years old, born May 31, 1997. She was born to Shannon Kellerman of Wolfsville, and Kenny Mohler of Smithsburg. Her step-mom is Holly Mohler, and she has 3 sisters and one brother (with another brother on the way- due in December). Her sibling's names are Jessica, Kylie, Anna Jo, and Kevin. Kristen is in the 8th grade at Middletown Middle School, in Ms. Brook's Learning for Life class. She is involved in the SO of Frederick County- participating in gymnastics year round, and occasionally basketball and swimming. She loves to color, read and swim. She has a pet dog named Kosar, and a cat named Charmin. She loves going to the YMCA kid's unlimited program during the summer months, where Ms. Kelly (the director) is her new best-friend (along with Sammie). Her favorite snack is popcorn. Her favorite dinner is spaghetti (or the occasional gluten free pizza from Toppings). She loves playing with her cousins, visiting her Nanny and Granddaddy, as well as Gramma and Grampa who live on a farm and have many cows and cats to play with. She still gets a little scared of the dark, but she says that when she is 16, she will no longer be scared. ☺ She is looking forward to getting her license and has stated that when she gets older she will work at Wal-Mart or McDonalds (probably because these are two of her favorite places to visit). ☺



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