

March 2012 Newsletter

Issue No 10

HAPPY ST. PATRICK'S DAY

PLEASE JOIN US ON TUESDAY, MARCH 6th FOR OUR MONTHLY MEETING

The format of our meetings will be changing, the monthly meeting will become more informative in nature and the kids will be entertained in a separate section so the adults can focus on speakers and interact with each other. In order for this new format to be implemented, we need volunteers to help with the activities that we will have planned for the children. Light refreshments will be served. Please note the new time: **7:00pm**

Please allow some time for adjustment as the new transition takes place ☺

VOLUNTEERS NEEDED

F.R.I.E.N.D.S. is actively looking for sincere and responsible individual's ages 18 to 80 to help throughout the year in various meetings and activities. Volunteer responsibilities would range from child activities (as mentioned above), helping with fundraising events and mailings, and/or providing various professional expertises that would benefit our families. For more information on being a volunteer, please contact Denny Weikert at 703-928-2494 or email dweikert@friendsoffredco.org

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.



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A Down Syndrome Poem

Author Unknown

An extra little chromosome,
that's all it is, you see.
Where all of you were born with two,
I was blessed with three.

Down Syndrome as most call it,
Trisomy 21, if you please.
This extra little chromosome
Makes some differences, you see.

I love to run and sing and dance,
and tease my teachers too.
But when it comes to school work,
It's hard for me to do.

I need a little extra help,
as many of you do.
With all my friends and your support,
I know I'll make it through.

Just be my friend,
and I'll be yours.
It's as simple as can be.
Remember, you were born with two,
and I was blessed with three.

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HEALTH AND WELLNESS

POTTY TRAINING A CHILD WITH DOWN SYNDROME

As any parent knows, some children are easier to potty train than others. Children with Down syndrome are no exception, but require additional patience and understanding as their minds play catch up to their bodies. Some children with DS may never be potty trained depending on the severity of their disability. What works for one family may not work for another, but below is an encouraging website that may help some parents as they begin to tackle this seemingly daunting task, along with some personal tips from our group.

“First of all, accept that **ALL** children are different, and the timetable for wanting to use the toilet will differ for each one. Any time from 3 years to 8 years and upwards is 'normal' for a child with Down's syndrome. Wait for the cue to come from your child. Do they pull at their clothes or tell you when they are wet or soiled? Do they try to imitate older siblings or friends by trying to use a potty or toilet? Are diapers dry for longer periods of time? Then they are ready for your help to move them forward. This is just our experience, yours will be different. Let yourself be led by your child. (And burn any potty training manuals written by ladies who don't have children [with disabilities] of their own...” Retrieved from <http://www.downsideup.com/2012/02/ode-to-potty-training.html> on February 2012.

Tips from F.R.I.E.N.D.S. parents:

1. **PATIENCE:** Potty training a child with Down syndrome can take from months to years, so be patient and know that like anything else, they are trying their best
2. **DEXTERITY:** Ever noticed that your child may not have the best hand to eye coordination or those thumbs just don't want to help out as they should? Children with DS can have lowered dexterity in their fingers and decreased hand to eye coordination. Make being able to go to the bathroom easier on them by putting loose fitted clothing on or elastic wadded pants. (With our daughter, Kristen, we had her regular pants altered to have Velcro installed inside, so that on the outside, her pants looked normal and stylish, but she was able to go to the bathroom by herself, unassisted, without struggling with a zipper and button).
3. **PROMPT, PROMPT, PROMPT:** Children with DS benefit from consistent prompting and encouragement along with consistent routines, so make sure that you are constantly asking if they have to go, until they can make that distinction on their own, and try to get them on a schedule so their bodies adapt to the potty schedule as well.
4. **FAMILY EFFORT:** Mom and Dad can't always be around when potty time is needed, so get older brothers and sisters, grandparents, care-givers involved in the potty training process.
5. **ACCIDENTS WILL HAPPEN- BE PREPARED:** Even after you think your child has mastered the potty, they could be 8, 10, 12, even 16 years old or older and still have an accident. **BE PREPARED:** always have an extra set of pants and underwear in the car or nearby (or keep at school) so that an accident at any age is easily managed and minimize the embarrassment to your child. Disinfectant wipes and napkins come in handy if the accident occurs on the playground, in the mall, etc. (Because chances are, it will).
6. **GET THE SCHOOL INVOLVED:** You can't be with your child at school, so make sure the teachers and aids are aware of your efforts at home, and get them involved in the routine and encouragement of your child to use the potty.

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SOCIAL AND POLITICAL AWARENESS

DAN MARINO STARTING A COLLEGE FOR THE DISABLED

Miami Dolphins Hall of Fame quarterback Dan Marino, and the Dan Marino Foundation, are planning a downtown Fort Lauderdale college for developmentally disabled students, according to a *Sun Sentinel* report. The college is looking to give student the real-world experiences necessary to prepare young adults with disabilities to make it on their own.

Marino's son, Michael, was diagnosed with autism in 1992 when he was two-years-old. Marino then founded the Dan Marino Foundation, focused on raising money for the developmentally challenged. Now, the foundation is looking to build the Dan Marino Foundation Vocational College, a first of its kind; post grade school institution for those with developmental challenges.

"We're here to teach the skills, provide the supports and reduce the supports as the program goes along," said Kerri Parmelee, the foundation's transition program director.

"We wanted to create something, much like a two-year community college, but it's totally focused on vocational," said Mary Partin, the foundation's chief executive officer.

The college would be located on the 400 block of North Andrews Avenue, and would utilize nearby apartments for students. The enrollment would cater to students from age 18 to 28, all of whom are diagnosed with autism, Asperger's syndrome, **Down syndrome**, or other developmental disabilities. The school is aiming to open in the fall of 2013, with a student body of around 60 for the first semester. The school anticipates an annual tuition of around \$7500 for the two-year program, and would be divided into trimesters.

Currently, federal and state public services for persons with developmental challenges are only available until age 22 - the Dan Marino Foundation Vocational School would assist would be open to students who were too old to receive further services from the state or federal governments, whether they graduated high school or not. The foundation plans on continuing the social and job skill development of these students.

The State of Florida has begun working on legislation to add the school to the State's higher education system, with the State Senate's high education committee already passing the bill. In the mean-time, the foundation is prepared to run as a private institution if they cannot get the designation.

Retrieved from <http://www.thephinsider.com/2012/2/8/2783770/miami-dolphins-legend-dan-marino-starting-college-for-developmentally> February 2012.

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SOCIAL AND POLITICAL AWARENESS (CONT'D)

LINK BETWEEN DOWN SYNDROME AND ALZHEIMERS

A recent study was done to find out why people with Down syndrome are at such a high risk of developing Alzheimer's in later life. With the exception of a few rare familial links to the devastating disease, Down syndrome is the only disorder known to correlate so clearly with dementia.

Professor Tony Holland, of the Cambridge Intellectual and Developmental Disabilities Research Group, the organization charged with leading the research, has stated that almost 100% of people with Down syndrome will go on to develop dementia. Even more worryingly for these sufferers and their families is Professor Holland's assertion that symptoms of dementia often manifest themselves up to 40 years earlier in those who have Down syndrome.

Recent medical advances may mean that those with Down syndrome are living longer and better lives, but this increase in life expectancy is leaving more and more sufferers at the risk of developing dementia, a consequence that Professor Holland described as a 'poisoned chalice' for patients. He is now urging those with Down syndrome to come forward as volunteers for this groundbreaking project.

The four-year study, funded through the Medical Research Council in partnership with the Down Syndrome Association intends to examine the role of beta amyloid in the development of Alzheimer's. Scientists are already aware that people with Down syndrome have more amyloid in their brains and hope that their findings will shed light on the causes of this specific form of dementia for the population as a whole.

Across the UK, 700,000 people are diagnosed with dementia annually at a cost of £17 billion. Dementia is commonly associated with memory loss but is also responsible for changes in mood as well as communication and reasoning problems. The degenerative nature of the disease means that sufferers will inevitably end up needing round the clock care.

With the UK population set to rise to 70 million by 2027, it seems this funding boost has come at just the right time.

<http://www.ds-health.com/issues.htm> retrieved January 2012.

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UPCOMING EVENTS AND ACTIVITIES

MONTHLY GROUP MEETING: MARCH 6TH, AT 7:00-8:30pm (NEW TIME)

Light refreshments will be served- please bring a treat to share with the group (St. Patrick's Day themed treats would be great).

WORLD DOWN SYNDROME DAY- MARCH 21ST, 2012:

This is the 7th annual World Down Syndrome Day. There are many ways that we can locally show our support for this day: wear your Buddy Walk t-shirt, send our newsletter or website out to your friends and families on that day, or look into purchasing a F.R.I.E.N.D.S. license plate:

<http://www.mva.maryland.gov/Vehicle-Services/SpecialtyPlates/displayPlateDetails.asp?PLATEID=843>

DRESS DOWN FOR WORLD DOWN SYNDROME DAY:

This is a great way for F.R.I.E.N.D.S. to begin fund-raising outside of the Buddy Walk. Get your workplace, family and friends involved in celebrating this day with us by dressing down on the 21st (wear your Buddy Walk T-shirt). Minimum contribution to participate is only \$1. Flyer and contribution forms to be distributed later this week.

DINE OUT- MAMA LUCIA'S - MARCH 21ST - Partial proceeds of the night's sales goes to FRIENDS

So come out and show your support from 5:00-10:00 p.m. and enjoy a great meal at the same time!!!

TRANSITION PRESENTATION FROM THE ARC- MARCH 27TH AT 6:30-8:00PM MUMC

The ARC of Frederick County will cover what is available as far as program, resources, funding opportunities before, during, and after school and what to expect when your child has an IEP. Also included in this presentation will be information regarding transition to adult services when the child is no longer in school.

* *Please RSVP to Tracy at tbarnard02@gmail.com by March 15th.*

GET INVOLVED- JOIN A COMMITTEE TODAY

Committees are forming within the next few months to help our group be better organized and effective in our strive to support and advocate for families with Down syndrome in our local community. Please take some time to fill out the attached survey, and find a way to get plugged in and involved. WE NEED YOUR SUPPORT and HELP to make this group a continued growing success.

APRIL UPCOMING EVENTS (details to follow)

Annual Easter Egg Hunt

Dad's Night Out- Final 4 at Glory Day's- included in Dining for Dollars for the month of April

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OUR KIDS CORNER- GRACE FAIRLEY



Grace was born August 16, 2003; her parents are Catharine and Richard Fairley. She absolutely loves her big brothers Michael and Ian and their dog Jackson Boy, who just happens to be her best-friend. Grace attends Parkway Elementary, and is in the 2nd grade. She loves music, playing dress up and acting. Her favorite TV program is Sprout and getting on their online website. She is a talented cheerleader as you can see above for the boy's school in Hagerstown (St. Maria Goretti). She takes swim lessons at the YMCA and plays soccer with the Frederick City Soccer team. But most of all, she loves being with her family.

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AFFILIATED ORGANIZATIONS- IN THE NEWS

NDSC SUPPORTS WORLD DOWN SYNDROME DAY 2012

The National Down Syndrome Congress officially announces March 21st, 2012 as the 7th annual World Down Syndrome day. NDSC's website has some great ideas on how to celebrate the day, along with the national advocacy e-brief/e-mail alert. To receive this information and more, visit their website

<http://www.ndscenter.org/>



Newsletter Committee:

Holly Mohler (holly.mohler@yahoo.com)