



B.U.D.S.

Bringing Up Down Syndrome

www.bringingupdownsyndrome.org

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World of Words



Every Sunday evening, Michelle Dobry, a 10th grader at Eastern High

School, sits down to write her "Weekend News." She writes a story that details all the events of her weekend, and on Monday, she will read this article to her fellow students. In her spare time, Michelle likes to surf the net, looking up her favorite websites about Spiderman and reading about the latest teen topics.

There was a time when Michelle's parents, Tina and Ray Dobry, thought that these reading and writing activities would be impossible for Michelle to achieve. When Michelle was born with Down syndrome, Tina's training as a nurse gave her little hope for her daughter's academic future. Tina had been taught that children with Down syndrome are "trainable" and can never learn to read and write.

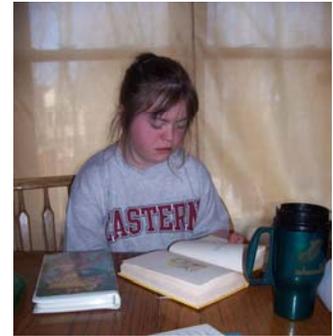
However, after meeting several young preschoolers with Down syndrome, Tina and Ray noticed that these children were recognizing letters

and beginning to read.

Inspired, they began to integrate a variety of activities into their daily lives to start Michelle on the path toward reading. They used strategies from Patricia Oelwein's book Teaching Reading to Children With Down Syndrome. Labels went up on items all around the house, stories were read constantly and Michelle began to read.

When she started school in Voorhees, however, Michelle's teachers discouraged the Dobry's from continuing these strategies, stating that Michelle was "just memorizing sight words, not reading." Her school reading curriculum for the first few years consisted of alphabet activities only.

The summer after third grade was a positive turning point in Michelle's journey to become an independent reader. Through her Extended School Year program, Michelle was taught by Eileen Nolan, a reading specialist. Eileen noticed right away that Michelle was beginning to sound out words. Because of her extensive training in the many theories of reading instruction, she was able to



help Michelle begin reading independently.

Using word families to see patterns was one way that Eileen helped Michelle to learn to read. Acting out stories such as "The Gingerbread Man" was a fun and engaging method. High interest materials such as books that have been made into movies were also very helpful. Michelle also enjoyed books on tape, reading aloud to stories that were of interest to her.



The Dobry's began using the "Hooked on Phonics"

program three times a week. After two years of instruction using all these strategies Michelle was reading independently. Her school program now became

Michelle's Remarkable Story is Continued on Page 7

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Food, Fun and Surprises at the *Bunco Potluck Dinner*



Paul & I finally made it to the a BUDS Potluck dinner. Every year we have "good intentions" to go, then somebody gets sick or we find ourselves out of town. Anyway, we're so glad we went.

First, it's always good to get out for a date without the kids (who we love so *dearly!* :D) and have some "adult time". It's both a pleasure and a necessity to get to talk to other adults once in a while.

Second, there's all the food-haha! That's ALWAYS a good thing, to be able to sit, sample and enjoy some home-made recipes along with great conversation. (I never once had to stop in the middle of a sentence say "get your shoe out of your brother's mouth" or "please get the cat off the trampoline!")



And last, we played Bunco, a nice surprise. It might sound silly at first, but once we got started it was really a lot of fun. I actually won a prize...and I don't care that it was for lowest score, I walked away with a nice prize that included CHOCOLATE!!! Also always a good thing!

I hope we can do it again, sooner and hope to see more of you there!

Amy Fitzgerald (mom to Emily-11)

Don't Miss
the Next
Bunco/
Potluck Dinner
for BUDS
parents
on
Saturday,
April 21st
RSVP by April 17th
to
Sue Orthey
(856) 751-7421

**We will be holding our semi-annual
Bunco/Potluck Dinner for BUDS parents on
Saturday, April 21st.**

We so enjoyed our last social evening that we are going to repeat and hope more of our members join us. The excitement of the prizes alone make the evening worth it.

**We will meet at the
Voorhees Community Center at Lions Lake at 7:00 PM.**

**Call Sue Orthey at (856) 751-7421 for a food assignment and directions. The group will provide the entrees, so we are only looking for appetizers, salads or desserts.
Please RSVP by April 17th.**



Be a Buddy—Join a Buddy Group

What's a Buddy Group, you ask? A Buddy Group is a group of about 8 to 10 families will each agree to host a gathering in their home for a group of individuals who have DS that will rotate each month.



To join the group, you must agree to host one of the events. You will agree among your group, via e-mail, etc. who will host which month, correspond with each other, and work as families to schedule your events.

The same group of individuals with DS will then rotate each month to a different family's home for an event. Each family will incur the cost of the event which they host in their home. By the end of the year, you will hopefully have a core group of friends for your children as well as lasting family friendships.



BUDS Teen & Young Adult Pizza Party Buddy Group (ages 13 and up)
Contact: Nancy Hennefer at golforlife@comcast.net or (856) 354-0584

BUDS "Tweeners" After School Buddy Group (ages 7 to 12)
Contact: Nancy Scully at scullyclan@go.com or (856) 566-2487

BUDS "Young Child" Buddy Play Group (ages 6 and under)
Contact: Laurie Lausi at notes2lausi@comcast.net or (856) 424-2301

Reece's Rainbow

an International Down Syndrome Adoption Grant Ministry and Advocacy Group
www.reecesrainbow.com

The primary goals of Reece's Rainbow:

- 1) To raise awareness of the plight of these children and their availability to be adopted.
- 2) To locate new adoptive families for orphans with Down syndrome internationally.
- 3) To "de-mystify" the process and costs of international adoption...it IS affordable!
- 4) To encourage families to consider adopting a child with DS through education and financial help.
- 5) To raise money to place sizeable grants on WAITING CHILDREN.
- 6) To offer financial assistance to adoptive families through our Sponsorship Program



Sergey - from Ukraine

If there is anyone in the community that is considering adopting a child with trisomy 21, this website is so very helpful.

We have begun our home study here in New Jersey. We want to adopt Sergey from the Ukraine! (I included his picture above) He has the same spirit in his eyes that I saw in Tommy. It is in honor of Tommy that we want to adopt Sergey. www.caringbridge.org/va/tommy

The cost of the adoption is frightening!! Can we do this? I sure

Deb Dougherty
5414 A Scott Plaza
Fort Dix, New Jersey 08640
609.353.1006

Upcoming Events

April 21: Adult Potluck

7:00 pm, Lions Lake Banquet Facility, Voorhees

BUDS is hosting another adult Bunco evening! This time BUDS will provide all the food. Your only requirement will be to RSVP, as we will need a count in order to buy the food. A great time was had by all the attendees in January!

RSVP by 4/19: Sue Orthey (856)751-7421 or regan65@aol.com

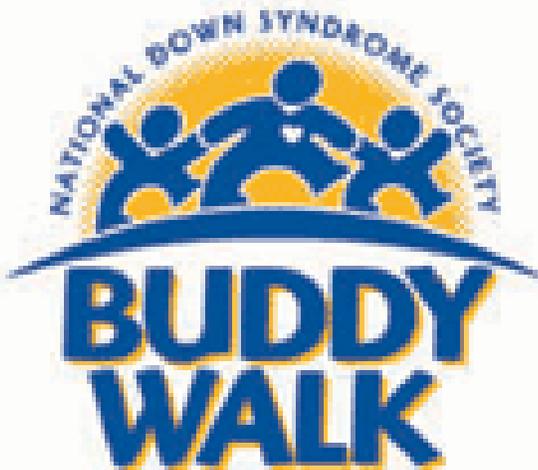
May: Golf for Life PGA Clinic

We haven't set a date yet, but there will be another Golf for Life clinic in May.

We'll email more information.

For more information, visit: www.golfforlife.org

MARK YOUR CALENDARS 2007 BUDDY WALK SUNDAY, OCTOBER 7TH 2007 IN WASHINGTON LAKE PARK



We need your help!

Our 2007 Buddy Walk Committee is looking for fun and energetic people that would like to help create another fantastic

Buddy Walk!

NO EXPERIENCE NECESSARY—Just the Willingness to Have Fun!

If you would like more information or wish to help out with this upcoming event contact budsbuddywalk@verizon.net

American Special Children's Pilgrimage Group Sponsored Trip

ASCPG is a non-profit organization that sponsors a trip to Lourdes, France, each Easter for special children (ages 9-18) and volunteer adult caregivers.

The group is based in North Jersey. They just formed a group in Philadelphia. They raise money all year long to take kids to Lourdes. Each child has 2 caregivers and there is also a doctor and 2 nurses in the group.

My daughter, Samantha, has gone three times She always has a wonderful time. Although Samantha's grandmother is one of the nurses, I would still send her again if my mother decided not to go. The people involved in the group are all volunteers and must pay their own way. They are a wonderful and caring group of people.

If you would like more information about Samantha's trips to Lourdes, please call

Jane Conolly (856-985-4756)



USEFUL WEBSITES

Websites

www.kidstogether.org
www.ndss.org
www.ndscenter.org
www.nads.org
www.tash.org
www.spannj.org
www.trisomy21online.com
www.downsed.org
www.21down.org
www.kiids.info
www.njea.org
www.specialolympics.org & www.sonj.org

Inclusive Websites

www.inclusion.org
www.inclusion.com
www.uni.edu/coe/inclusion
www.inclusive-education.com
www.tash.org/education

Helpful Products?

www.superduperinc.com
www.disabilitytraining.com
www.adcohearing.com
www.loveandlearning.com
www.enablemart.com

INCREASED PRENATAL SCREENING FOR DOWN SYNDROME – IMPACT IS SERIOUS

BY NANCY IANNONE

The American College of Obstetricians and Gynecologists has issued new practice guidelines for prenatal testing. They now recommend that all women, not just women over 35, be offered the non-invasive screening test called the **nuchal translucency screening test** (also called the nuchal fold scan, or first trimester screen).

This screening test reportedly catches 80% of babies with Down syndrome (Trisomy 21) and other chromosomal anomalies as well as some babies with heart defects. My daughter had both Down syndrome and a heart defect and we passed this test with flying colors. Her issues were picked up later by the QUAD screen, level 2 ultrasound, amnio, and fetal echocardiogram.

I believe foreknowledge can be an amazing benefit to a family preparing for the birth of a baby with issues. That foreknowledge was of immense help to me and my family in a number of ways. We were able to educate ourselves on Down syndrome, clearing away a lot of misinformation and assumptions. We were able to speak to other parents whose children had Down syndrome and whose children were born with the same heart defect. We toured the cardiac wing of the Children's Hospital of Philadelphia and met with a cardiac lactation consultant (which was of enormous benefit). We changed our insurance, saving ourselves thousands of dollars. We joined support groups and I found a great mentor. We were able to grieve and recover so that her birth and newborn stage were a time of celebration rather than shock.

Foreknowledge, however, does have a cost. Having known people with Down syndrome (although in retrospect not all that well), I thought I would take the news in stride. I was shocked by my own very deep and very sad reaction. With no baby to hold, that news is in some ways more damaging. I felt emotionally distant from the pregnancy. Despite my very strong pro-life beliefs (not based on religion), I found that I had to think the issue of abortion through, especially because I was reminded of my option to terminate by each of my four health care providers. It only took a few moments to realize that there was no way I could participate in my baby's demise, but those few moments are very painful to remember. There were times when I had thoughts that a miscarriage would avoid my having to deal with any issues. In some ways, I was pregnant with a diagnosis, not a baby. There were also several people who made casual remarks about abortion options without any idea that post-diagnosis the word "abortion" had a new power to hurt. At one point I felt like I had the word "expendable" stitched across my maternity shirt.

I found myself on an emotional roller coaster. I was traveling two parallel paths, one of sadness and one of hope. The sadness ended the day I saw my baby, and I was glad I did not deal with that sadness after her birth. But I did pay a price for that benefit of "hitting the ground running."

There is a bigger price as well. This test "catches" 80% of all babies with Down syndrome, other chromosomal anomalies, and some with heart defects. For women who would not otherwise be considered at risk, more babies will be caught in the prenatal testing net. More women will have amnios. With an estimated 90% termination rate for those who choose an amnio and receive news they would rather not hear, more babies will die.

As thankful as I am to have had that foreknowledge, I am sad that so many children like my daughter will never live to see this world, will never be given the chance to change their families in a positive way. It has nothing to do with "judging" the woman making this difficult choice, and everything to do with loving my beautiful child and watching all she can accomplish.

My sadness comes from many levels, and is not two dimensional. I am not simply sad because my daughter will have fewer peers. That is only a small part of the equation. If there were some "cure" for Down syndrome which could be administered prenatally, I would experience some sadness as well, for very selfish reasons (selfish meaning thinking of me and my daughter and its impact on her). But I certainly would not have the level of sadness I feel now. I certainly would not be resisting the idea. I would also be experiencing happiness that so many lives would be saved.

This sadness goes deeper. There is no cure for Down syndrome. Termination is not a cure for Down syndrome. Mothers who choose to terminate their pregnancies may describe their choices as unselfishly pure, hoping to avoid the "suffering" they believe to be in store for their children. Their reasons may be "selfish" as well, or a mixture of motivations. Regardless of their reasons, from my perspective, witnessing the pleasure my daughter experiences from living her life, increased prenatal deaths of people with Down syndrome and other chromosomal issues is a sad turn of events.

To me, experiencing this on a very personal, basic level, it is faces disappearing from family photos (whether it is the blood family or adoptive family), but only those faces with almond-shaped eyes. It is children disappearing from playgroups, teens vanishing from teen night, the adult Keith who loves country music and

Story is continued on Next Page

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gives lectures to parents and caregivers - disappearing. Peter, who as a teen came over my house to help me with the kids, who teaches classes every year to the biology students on what it is like to have Down syndrome, who wears a big obnoxious cartoon character costume every year at the buddy walk to entertain the kids - never drew breath. The older woman with Down syndrome gambling with her sister at the casinos in Atlantic City, both of them using walkers and pulling those slot machine levers - fading from the fabric of this world.

These are people, a vital part of the spectrum of humanity. They have lives, and relatives, and families who love them. And I can't separate them from the many unborn babies on their way. I can't. And I see the terminations as the same as those people vanishing. As much as I want to understand both sides of this issue, I cannot see it as any other way. It feels like a science fiction movie someone created, but it's real. And it weighs on my heart.

I don't think people who terminate are bad. I don't think they are any more selfish than the rest of us. I think that women who terminate have motivations, reasons, knowledge, experience, prejudices, family support, doctor's input, life perspective, religious beliefs, and other factors that are as varied as the people of this county are. I think in many ways they are doing the best they can, trying to make a decision during a very difficult time, and they have precious little time to decide in the midst of shattered dreams and expectations.

Despite the laundry list of reasons women can recite in favor of terminating, there is a component to choosing life many simply cannot appreciate until they hold their child in their arms. I have personally met many women who would have terminated had they known their unborn babies had Down syndrome, women who were angry at their doctors for not picking up the issue during the pregnancy. These women were later so happy that they did not know the diagnosis prenatally, so grateful their children are alive. And they will be gone. It is not that those moms won't exist, but the person they are, in as much as our experience shapes who we are, will not exist. They won't be the parent of that living child, sometimes sad and worried, sometimes happy and excited, learning from their child as much as they teach her - they'll be someone different, with perspective shaped by different experiences. And their children from my vantage point will be gone, vanishing faces in the world that never knew them.And I can't get over that. And I never will.

Nancy Iannone is the mother of four young girls. Her youngest, Gabriella, was diagnosed prenatally with Down syndrome and serious heart defect. Despite initial abortion option reminders, Nancy's doctors were wonderfully supportive, and Gabriella's birth was a joyful, relaxed experience due in large part to her obstetrician, cardiologist, and the labor and delivery staff. Gabriella had open heart surgery at Children's Hospital of Philadelphia when she was 5 months old and was home three days later on Tylenol. She is now a happy, healthy 2 year old.

Knowing that pregnancy post-diagnosis can be an emotional roller coaster, Nancy has written several essays to help newly diagnosed parents. Her short essay "A Hopeful Future" appears in the recently published book Gifts: Mothers Reflect on How Children with Down Syndrome Have Enriched Their Lives, edited by Kathryn Lynard Soper. This book is a collection of essays by parents with pro-life and pro-choice views who have united to assure newly diagnosed parents that lives with their children will be happy and exciting. The book will be published by Woodbine House and will be available in July of 2007 in bookstores. To preorder a copy of the book, log on to <http://giftsds.sequallah.org/>.



★ **World of Words –Michelle 's Remarkable Story (Cont from Pg 1)** more appropriate, with a literature based English class in middle school. Michelle especially enjoyed *Time Magazine for Kids* which was used as part of her reading curriculum.

★ Now in high school, Michelle has just completed reading Charlotte's Web with her reading class. Her speech therapist collaborates with the reading teacher to facilitate comprehension (the who, what, when where, why) of materials read in class. Michelle uses an augmentative communication device called the Vantage made by Prentke Romich. This has been beneficial in increasing her reading and writing skills. The device permits her to write complete sentences on her own, look up words and check spelling.

★ Many factors came together to assist Michelle in becoming an independent reader. Eileen Nolan's expertise as a reading specialist allowed her to use a variety of techniques that apply to the learning styles of students with Down syndrome. Her parents were untiring in their efforts to provide her with a rich and literature filled life. Michelle's own temperament and abilities also were a factor in her eventual success.

★ Michelle's story inspires us to reach for the stars academically for our youngsters with Down syndrome, even when professional educators try to discourage us. Children with Down syndrome have the capacity to learn. For some, reading will be a constant struggle, something that will take years to accomplish and maintain. Trying as many techniques as possible affords every opportunity for success. Even if reading remains an elusive goal, the efforts to get there are not in vain, for some learning is taking place whenever we expose our children to the world of words.





B.U.D.S

Bringing Up Down Syndrome

Return to:

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We're on the web!
www.bringingupdownsyndrome.org

Contact BUDS

Want some more information about BUDS? Want to get involved? Have questions or concerns?

You can reach BUDS via snail mail at:

BUDS PO Box 1085

Marlton, NJ 08053

856-985-5885

Or by email at:

information@bringingupdownsyndrome.org