

The CIDSO News

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**"A Brighter
Tomorrow"**

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Lots of Surgeries by Abbey Heins

When I was a baby, I had a heart operation. It didn't work. I went back in the operating room to have another open heart operation. When I was recovering at the hospital in Peoria, I was sleeping in my baby crib. I was very excited and decided to climb out. My incision opened up. Blood was coming out everywhere. My mom, Sandy Ginther, was hysterical running down the hallway calling for my doctor to take me back in the operating room and sew it up. But the nurses were able to fix it and my mom was still crying. And my dad, Greg Heins, was there too. Because it all worked out okay, now its funny to think about my mom running like a crazy lady up and down the halls.

In my lifetime, I have 14 surgeries. The kinds I have had are: sinus, ears, nose, head, heart and tonsils. I have one extra chromosome. My extra chromosome had to do with everything except my tonsils. The chromosome affected my health but not the person I am. In that way, it didn't effect my lifetime.

I want to tell you my feelings before I go to sleep for surgery... nervous, scared. When I wake up, I am emotional crying with tears saying that I am sorry for the operation. Sometimes I get scared when I see blood coming out of my nose for my sinuses. The operations makes it better for me.

I had 40% chance to die and 60% chance to live for my open heart surgery. But I'm standing here today and telling you guys these things. Help your little kids to not be scared about these things. Maybe reading a book will help them. It helped me when I was a kid.

With School Around the Corner...

Parents are always looking for great tips to help their children be successful in school. Be it time management, organization skills, or just getting through the day. Here are some tips for teaching math to learners with Down syndrome.

In all learning it is important to avoid rote memorization of facts. It is better to learn to understand the concept through actual experience. Mathematics is a language of symbols which describes relationships between figures, forms and quantities. A better understanding of the below grouping processes and one-to-one correspondence is a vital concept in day-to-day use.

- **The ability to see similarities:** These similarities may be of any type or nature. They may be color, shape, size, taste, brightness, or even such a personally abstract things like favorite foods or music. Having repeated experiences seeing how things are alike.
- **The ability to group similar things:** In the beginning, actually placing the similar things side by side is necessary. Most things can belong to several different groups. A coat may belong to a blue group, a clothing group, a cotton group, and a buttonhole group. Organizing and reorganizing these groups is necessary in order to develop understanding.
- **The desire to count things in groups:** Even after things are grouped, there is frequently not a need to give a symbol name to the number of things in the group. Some languages do not have all the numbers that we are familiar with in the English language. They simply have a label for one and a label for many. Needing to make things even as with teams, is one of the more basic reasons to count.
- **The understanding of 1:1 correspondence:** It is difficult for some people to learn that for each number there must be something that is counted. It is important in early learning that students are actually counting objects. Some teachers have used small stones, blocks or other tangible objects. It is important that learners can handle these things themselves.
- **A purpose for comparison of the amounts in groups:** Abstract or arbitrary comparisons do little to enhance learning. Comparison between numbers of boys and girls, black shoes and white shoes or school lunches and sack lunches may be necessary in order for the learner to be interested in comparisons.
- **Some numbers may have no ordinal meaning:** Telephone numbers, street addresses and social security numbers have only arbitrary meaning; they are not "counting" things. It is necessary to memorize these numbers rather than to use them in computations.

The ABLE Act "Achieving a Better Life Experience Act"

On July 21, 2009 a briefing was held on Capitol Hill for staff of Members of the House of Representatives regarding the ABLE Act--Achieving a Better Life Experience Act--((S 493/HR 1205) which would allow individuals with disabilities and their parents to create a tax-advantaged savings account which would not jeopardize public benefits. The moderator of the briefing was Stephen Beck, a parent volunteer from the Down Syndrome Association of Northern Virginia who has worked closely with the staff of NDSS and NDSC. The briefing consisted of a series of presentations from individuals such Rick Hodges who is the parent of a child with Down syndrome and Alexander Reid who has a brother with Ds. Both Congressman Ander Crenshaw, the bill's lead sponsor, and Congressman Cathy McMorris Rodgers, co-chair of the Congressional Down syndrome Caucus and important supporter of the legislation, spoke.

Members of the NDSS Science Advisory and the NDSS Clinical Care Advisory and other professionals have provided expertise to the Policy Center staff regarding a proposed piece of legislation which will create centers of excellence to conduct basic, clinical and translational research. This piece of legislation is now being finalized by Member of the house of Representatives and is expected to be introduced soon.

Recommendations for person first language from the NDSS

Down vs. Down's. NDSS uses the preferred spelling, Down syndrome, rather than Down's syndrome. While Down syndrome is listed in many dictionaries with both popular spellings (with or without an apostrophe s), the preferred usage in the United States is Down syndrome. This is because an "apostrophe s" connotes ownership or possession. Down syndrome is named for the English physician John Langdon Down, who characterized the condition, but did not have it. The AP Stylebook recommends using "Down syndrome" as well.

People with Down syndrome should always be referred to as people first. Instead of "a Down syndrome child," it should be "a child with Down syndrome." Also avoid "Down's child" and describing the condition as "Down's," as in, "He has Down's."

Down syndrome is a condition or a syndrome, not a disease.

People "have" Down syndrome, they do not "suffer from" it and are not "afflicted by" it.

Don't Forget the Buddy Walk is Almost Here!!!

Just a friendly reminder of some important Buddy Walk details. The Buddy Walk is going to be September 26, 2009 at Carden Park, located behind Prairieland Elementary in Normal. Registration and fun will begin at 8:00 and the walk will start at 10:00. This is the 5th year of the CIDSO Buddy Walk and we have some very special things planned.

As mentioned in the previous newsletter, we will have a special guest walker this year. Bernadette Rasha, an artist with Down syndrome will join us in celebrating our 5th anniversary of the Buddy Walk.

CIDSO's online fundraising page is up and running! Visit www.firstgiving.com/cidso to help raise funds for CIDSO and the 2009 Buddy Walk. It is easy to create a fundraising page, simply click the "Get Started" button on the web site and follow the step by step instructions. You can also use this website to make a donation or search for fundraising pages of people you would like to sponsor.

As in past years, we are offering a free Buddy Walk T-shirt for those who pre-register for the event. That would be for people who register by September 4th. Since this is our 5th anniversary, we are also encouraging people to wear "retro" shirts from past years.

Team spirit is something that helps to add fun and energy to the walk. Please consider forming a team, coming up with a team name, and showing a "sign of support" for your team. There will be a sign making station available at the walk or you can make own in advance. The largest team (as reported to the registration table by the team captain) will be the Grand Marshalls for the walk and will have their photo featured on next year's registration materials. Hope to see you there!



Mark the Date

August 29th: Summer Picnic

September 4th: Last day to pre-register for the Buddy Walk

September 26th: Buddy Walk

October 19th: CIDSO board meeting

December 6th: Christmas party

Disclaimer Policy

The editor of this newsletter writes as a non-professional. CIDSO does not promote any therapy, treatment, institution or professional system, etc. Please discuss specific concerns with your health care professional.