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2010 BUDS Buddy Walk Committee Needs YOU!

The Buddy Walk Committee is getting ready to kick-off a new season and that means that we are looking for some new members to come aboard and fill a few positions. After being with us for the past few years our Food Coordinator and Volunteer Coordinators have retired - so that leaves us looking for new faces to fill those positions.

If you are interested in finding out what the committee does and what you can do to help please come out to our 2010 Kick-Off Meeting that will be held on Monday, March 1, 2010 at Grooveground Coffee Shop in Collingswood. Come on out even if you're just curious, enjoy good conversation and good coffee and make a new friend or two.

We can use volunteers to not only fill those two positions but to help out in general with smaller self-contained tasks, such as making follow up calls to prize donors or dropping off brochures at area businesses. If you have an idea of something you would like to see at our Walk come out and tell us - we are listening!

I hope to see some new faces at the kick-off meeting.

**Are you on facebook?
The BUDS Buddy Walk is...
just search for it and join!**

Reminder

Join the National Down Syndrome Society for the Buddy Walk® on Washington | February 24-25, 2010

Government Affairs Committee (GAC) leaders, affiliate leaders in government relations, seasoned self-advocates and others will come together to "walk" right into the offices of their elected officials! Click here to learn more.

Preliminary Conference Schedule

Wednesday, February 24

2:00 p.m.-4:30 p.m.
Interactive advocacy training to unite and prepare for visits on the Hill

6:30 p.m.-9:30 p.m.
Buddy Walk on Washington Reception and Award Ceremony

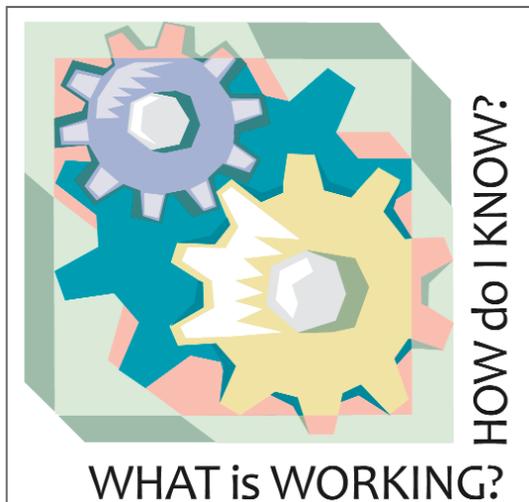
Thursday, February 25
8:00 a.m.-9:30 a.m.
Legislative Breakfast on the Hill

9:00 a.m.-5:30 p.m.
Meetings with Elected Officials

As a member of BUDS if any of you plan to attend please email Nancy Hennefer at golfforlife@comcast.net. If there are enough of us, we could possibly commute together.

Save the Date

NJCIE's 8th Annual Summer Inclusion Conference



Presented by:
New Jersey Coalition for Inclusive Education (NJCIE)
Location & University Partner:
Georgian Court University, Lakewood, NJ
District Partner: Lakewood Township School District

Featured Presenters:
Nationally known experts on inclusion:
Dr. Paula Kluth, consultant, teacher, author
Michael McSheehan, UNH Institute on Disability
Carol Tashie, inclusion facilitator, teacher, author

Plus:
Faculty members from Georgian Court University
Higher Education Faculty from NJ Universities
Classroom teachers from around NJ
Students

Featuring 21 workshops per day for teachers, administrators, families and others involved with education

Topics will include:

- Strategies for inclusive multi-cultural classrooms
- Co-teaching 1 & 2
- Using a consultative model to support inclusion
- Strategies for elementary and secondary grades in math, reading, science
- Early childhood inclusion
- Working with students with complex needs
- Facilitating friendships
- Integrating therapies
- Response to Intervention 1 & 2
- Using alternative assessment in inclusive settings
- Using New Jersey's Quality Indicators for Inclusion
- Hands on Demonstrations from the AssistiveTechnologyCenter



June 30 & July 1, 2010



Contact NJCIE
at 732-613-0400 or
NJCIE@njcie.net to be
added to the mailing
list for a brochure/
registration form,
available
February, 2010.

[on the web]

Journey Toward Independence: How a Young Woman with Down Syndrome Became an Independent Adult

By Betsy Smith
with support from her mother

Betsy on graduation day My name is Betsy. I am a 25-year-old woman. I live in my own apartment, which is great because it gives me the privacy I want and a place to express myself. I can relax in my comfortable black leather lounge chair while I watch my favorite TV shows or I can pretend I am a rock star on stage at a concert. I have a great CD collection and my walls are papered with posters of rock stars. I enjoy experimenting with cosmetics and have created my own great make-up center. By the way, I have Down syndrome.

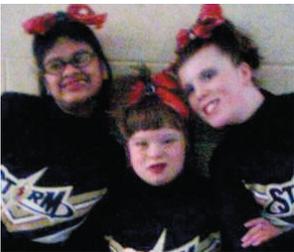
Having my own place has taught me how to be responsible for taking care of the things around me. I can travel independently in my community, and because of this, I am able to do the

things that I like to do, like singing at my church; taking dance, aerobics, Weight Watchers, and adult school classes; as well as enjoying buffalo wings at my favorite restaurant. People know and welcome me at my local supermarket, deli, bank, hair salon and video store. I serve on the Board of Directors of the Yogi Berra Baseball Museum. It feels wonderful to be supported and respected in the community where I have grown up. I really love my life.

My advice for parents is to listen to your kids' needs, wants, and dreams. Parents and kids need to work hard on their dreams if they want them to come true. Parents, stay focused on what you believe in and push for it with all your might.

To read more visit:
pbs.org/parents/inclusivecommunities/independence.html

Members Write In - From Amy Fitzgerald Spirit Soars for South Jersey Cheerleaders



Last September I was at the Pitman Craft Fair with Emily when a woman approached me, inquiring about Emily. How old is she, where does she go to school, etc... She started telling me about a Special Needs Cheerleading group that had just started up at a place called Sports and More on Rt 41 in Sewell, (about 1/4 mile east of the Five Points Diner). It's the home of the South Jersey Twisters Cheerleading team (formerly known as the South Jersey Lightning). The woman has a daughter with special needs, and two good friends, who also belong to Twisters. She said they had only had two practices so far and I could

come anytime, it was open and FREE to any and all kids under 18 with special needs. All I needed to do was show up.

We went to the very next practice which was held on Wednesday evenings from 6:30 - 8:30, which they quickly re-thought and made it til 8:00. Long night for our girls, especially on a school night. It was slow going at first but she soon we got to know everyone and began to really look forward to it every week. Practices are now on Fridays from 6:30 - 8:00 pm.

There were about eight girls with varying disabilities, two who had Down syndrome. Both are members of BUDS. I asked them if they had a flyer I could give to her school, Bankbridge Elementary (and Regional) in Sewell, for them to hand out to the students, and they gladly printed up about 20 of them for me. I sent them into school the next day, and the very next week about 5 new girls showed up! This year, many new girls have joined, and actually one boy! There are maybe 18 - 20 kids on the team now. The team is looking forward to two upcoming competitions.

Members of the other teams come and volunteer as our girls "helpers" and spotters. They develop wonderful, trusting relationships together and really look forward to seeing each other every week, and I mean both the volunteers and our kids!

For more information please contact Bonnie Melnick at bmeln50193@wildcats.wilmu.edu. or call 856-401-8111 ext. 208.

Are You Connected?

Sign up at these websites to stay informed on the latest advocacy issues that are of interest to your family.

NDSS | www.ndss.org
National Down Syndrome Society

The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.

NDSC | www.ndsccenter.org
National Down Syndrome Congress

The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

SPAN | www.spannj.org
Statewide Parent Advocacy Network

The mission of the Statewide Parent Advocacy Network is to empower and support families and inform and involve professionals and others interested in the healthy development and education of children and youth.

SONJ | www.spannj.org
Special Olympic New Jersey

To provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.

[Lessons from the edge by Janet Wiedemann]

One Family's Adventure in Potty Training

When Ryan was about 2 1/2 years old, I went to a potty training seminar. I got some great information that I would save for when the time was right. Among the presenters, was a father of a young adult with Down syndrome that shared his experiences on this topic. Bottom line, after tons of strategies and professional interventions, at 12 his son was still not fully trained. He and his wife decided that maybe their son may just be a kid who will not be fully trained and they would just need to accept that. Of course, my first thought was, UGH....please don't let this be Ryan!

Around 3 years old, we started bringing Ryan to "the potty". This made sense because his sister was training and being a year younger he often did things when she did. They both walked around the same time and even this year's Christmas card featured both of them missing their front teeth. It wasn't unfamiliar territory. He had visited the potty many times to watch things flush. His potty experience ranged from him standing patiently in front of you waiting for you to finish, so he could flush for you, to managing to get a plastic bottle to go down the toilet. We are still not sure how he did that one, since plastics are not known for their "flushability". He was so successful that it took a plumber and \$150 to get it out.

Ok so Ryan was well versed in what the potty was and what to do when you are on it. However, he just didn't think that it applied to him. Sound familiar? We tried so many different strategies to encourage him. We tried to make going to the potty as fun and as pleasant an experience as possible. Most of the time, he would sit there and look at you like he was saying "Ok, now what?" He was just not ready yet.

We tried motivators. Food is not a motivator for Ryan, unless we are going to go to McDonald's drive thru for French fries. We attempted having the "secret prize box". So new plan, if he sat on the potty, even if he just went through the motions, he gets a secret prize. How fun, right? Nope. It then became a battle of wills because he would whine and cry to get a prize at all times of the day. In order to preserve what is left of my sanity, I put the prize box out of sight. He was just not ready yet.

We had heard so many successful stories about going cold turkey, so we figured we'd try it. At this point Ryan had visited the potty many times. The only successes we had were when we seemed to place him on the potty when the time was just right. All the hoopla and cheering in the world didn't seem to make him want to go on his own. It just didn't seem to register with him. He would stand in front of you with his eyes glazing over. You could ask him if he has to go potty and he would respond with a strained "No".

We planned it over a holiday break from school. We ceremoniously got rid of the pull-ups, showed Ryan his new big boy underwear. For the next 5 days, Ryan did not think twice about using his new Lightning McQueen and Buzz Lightyear underwear just like the pull-ups. Maybe I should have been more persistent, but after 5 days of 6 or more clean-ups a day I WAS DONE. D-O-N-E, DONE! He's just not ready.

We tried motivators. Yes, I know I said this before. Even though quite a bit of time had passed since the prize box, we figured we'd try it again. We moved onto prizes he would earn and pick out himself. We presented him with an array of higher end prizes to choose from. Starting with Wow Wow Wubbzy figures and Matchbox cars seemed to do the trick. It was starting to work! He would push until his entire head was red just to get one of those cars. I was elated that we finally found the key!

Could it be, an end to changing all those icky pull ups?! An end to wrestling a 50 pound kid who didn't want his pull up changed in the first place! An end to those sore, red and rashy bottoms. An end to arguing about who changed the last icky pull up and whose turn it was! If he used the potty, he got a prize. It was as simple as that. However, he still didn't seem to mind going in his pants, so there were many, many accidents. He's just not ready.

Life has to go on, you know? There is shopping, play dates, sports activities, scouts, errands. Cleaning up messes on-the-go gets OLD fast, so as much as we didn't want to go back to pull-ups, we did. The story of the man with the 12 year old son who wasn't potty trained always ran through the back of my head. Yup, this would be Ryan. I just need to accept the fact that he may not get there and move on. So, as hard as it was, I let it go and moved on.

We are not sure when it started but every once in a while, we would see Ryan run to the bathroom and use it, still while wearing his pull ups. Ok. Here's a prize. Great job. We'll see....still thinking he was just teasing us. But then it started becoming more frequent. No way, I thought....it's gotta be a fluke, has he made the connection? Still not over the trauma of the amount of messes and clean ups from the last trial, I was not ready to abandon the pull ups again.

School had decided to do only underwear there. Maybe they had "taught" him to make the connection. The bag of wet clothes that occasionally came home from school became less frequent, and at the encouragement of his teacher, I tried again at home. He would wear underwear at home, but if we had to go out, on went a pull-up. It had better work this time or I was headed for nice quiet vacation in a private padded room.

One night at Friendly's I realized I forgot to put a pull up on him. I took him to the bathroom, just in case. He used it! Ok, then. We still needed to run to Walmart...do I dare attempt it without the pull up? Feeling brave and encouraged by the Friendly's success, I moved on. Off to Walmart we went. First things first, right to the bathroom! Didn't have to go but at least he tried! We were there for about 30 minutes, and no accident. Wow! For the next few days, I attempted short outings in underwear.

At home he was using the bathroom much more consistently now. There has only been two accidents since and I still can't believe that the time has finally come. Every time I see my little man running to the bathroom, I am overcome with that warm, fuzzy feeling! He is ready!

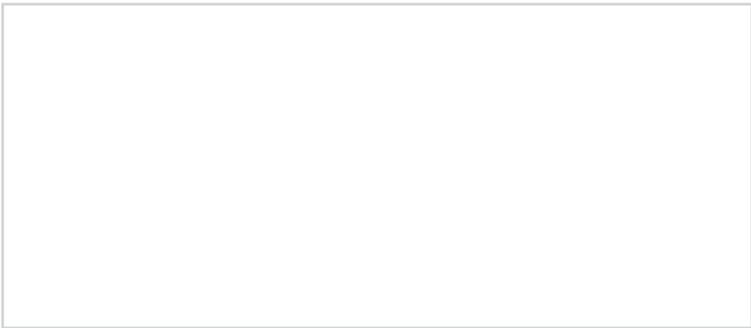
Once AGAIN, Ryan has taught me that he will do things in HIS time, when HE is ready. All the rushing, pushing and bribery in the world will not change anything. He has taught me that patience and perseverance are true virtues. And isn't that true with anything in life worth waiting for? Isn't it funny how it takes my seven year old to remind me of what is really important? I remembered that the man with the 12 year old son was also potty trained soon after they "let it go". Another lesson learned.

Note to self: apply these virtues when Ryan exits the bathroom with pants around his ankles announcing to the world he has pooped.

Give me strength.....



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The information contained in this newsletter is provided as information for our readers, and is not necessarily the opinion of the editor, or endorsed by the support group.

Conference Reimbursement

BUDS will reimburse members for conference fees. The conference must be disability related- education issues, medical issues, behavior issues, communication issues, etc. You will need to complete an application form, which you can get from the website – www.bringingupdownsyndrome.org

Our preference is to write the check to the conference holder. Please

submit your request in plenty of time, so that we can send you the check for the registration fee. BUDS will review all requests and will only pay for the registration fee, if approved. BUDS will only pay conference fees for the parents and/or the individual with Down syndrome. If you do not hear from us in a timely manner after your submission, call the BUDS phone number to make sure that we received your application.

Contact BUDS

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

You can reach BUDS via mail at:
BUDS PO Box 1085, Marlton, NJ 08053
or via phone at (856) 985-5885

www.bringingupdownsyndrome.org

Seeking Articles

**We are seeking articles for
the next newsletter.**

If you or someone you know would like to write for our newsletter please contact Kim Brooks at (865) 854-6517 or email kim@himandkim.com