

UPCOMING EVENTS



- **EVERY FRIDAY:** New club for adults 18-50, Miller Park, 5:30—8:30 p.m. See page 8.
- **BEES**—Thursday, September 22 and October 27th, Amos Cottage. Look for email reminders.
- **BLUE GRASS BASH**—September 24th, see page 9.
- **CENTERPOINT DD ADVISORY MEETING**—Next meeting: October 6th, 5:30—7 p.m., CenterPoint, 4045 University Parkway.
- **NO LIMITS II DANCE:** Next Dance will be October 7th, 7-9 p.m.!(Note change in date.) See page 9.

Look for *part of your email address in this issue* to win free registration & shirts for Buddy Walk! Email ckelsey@triad.rr.com to say that you saw it!

PDSSN NEWS

VOLUME 4, ISSUE 4

FALL 2011

Buddy Walk 2011

SATURDAY, OCTOBER 15th, 8:30-NOON

WEST FORSYTH HIGH SCHOOL!

This year's Buddy Walk is going to be GREAT!

Please note the new location: West Forsyth High School, Clemmons.

A carnival theme will give it a little twist, and lots of fun attractions are in store for you and your family. There will be games, a train ride, talent show, fun walk, food, and lots of fun!

Get a team of walkers together from your workplace, church, or neighborhood. Invite everyone to join in this wonderful day of celebration!

If you haven't registered yet, be sure to take care of that today! (www.pdssn.com) The shirts are awesome this year, and with a family registration you get up to four of them (and can get additional ones for \$5 each).

Do you need brochures or flyers to help get the word out? Just send an email to info@pdssn.com.

If you have a corporate sponsor or can help in any way, be sure to let Barbie know. bbeawright@gmail.com

If you have talent, here's your chance to shine! Write Sherry today!
shjeffries5@triad.rr.com

SEE YOU AT THE BUDDY WALK, BUDDY!

DREAMS IN MOTION



Dreams in Motion at Extravadance in Kernersville is the name of dance classes for people with special needs. Several PDSSN family members participate and are very happy their children—young and older—are part of this fun activity. Here is the schedule:

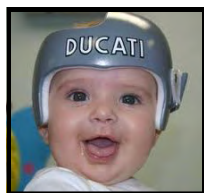
Tuesday, 5:00 pm - 6:00 pm, Ages 6-18

Tuesday, 3:00 pm - 4:00 pm, Ages 19 and older - starting on September 20

For more information, call Extravadance at 993-7766 or 996-4445. Their email address is info@extravadance.com Website is www.extravadance.com Address is: ExtravaDance & Tumble, 1239 Masten Drive, Kernersville, NC 27284 The cost is \$5.00 per class.

Bill says....

Be on the watch for a new movie titled: Up with Downs: The Peruvian Challenge. This Canadian film with English subtitles is a marvelous documentary about six young adults with Down syndrome who are accompanied by six special education graduate students to climb Machu Pichu in the Andes. The scenery is breathtaking, the challenge is enormous, the humanity extraordinary. It hasn't been released yet, but I have alerted RiverRun and Aperature to look for it. Maybe the most significant part of the movie, produced by Jeff Martin, the father and special ed graduate faculty member, is the few days the troupe spent with natives on the mountain. What a cross-cultural experience in language and humanity! This brought back so many memories of spelunking with Jeremy and the dozens of encouragers among peers and staff to get him in the bat cave! Thank goodness we didn't "harvest" guinea pigs for dinner in celebration! (Thanks to Bill Donohue for this review.)



CAN YOU HELP?

We have 3 requests for infant plagiocephaly helmets. If you have one that your child is no longer using please consider donating it to the Family Support Network. These helmets are expensive and often not covered by insurance. They can be refitted and used by another child whose family may not be able to afford the out of pocket expense. Thanks for your help.

Chris Gentry, Program Director
Family Support Network of Greater Forsyth
336-924-5301 www.fsngreaterforsyth.com

For Your Bouncers . . .

I was at "Bumper Jumpers" in Greensboro with Ben at a recent birthday party. Bumper Jumpers has bouncers for all age groups (check out their website or Facebook page). They made the effort to provide a great opportunity for families who have children with special needs. They offered all the bouncing you could want for \$4.75 a person plus free popcorn and pizza from 6:30pm to 8:00pm on Tuesdays, but they stopped it because no one came. They will start it back up again if there is interest. Please contact them and let them know if you are interested, it's great exercise and opportunity for our kids in a safe environment!! 336-855-0056 4217 High Point Road, Greensboro, NC 27407

- Sandy Sauer

Tidbits from the Top!

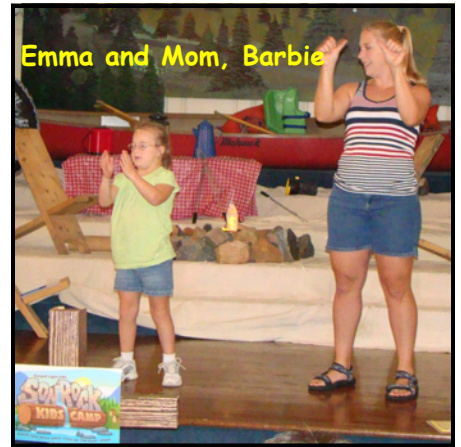


Emma, Biker Extraordinaire!

Go, Emma, go!

Practice makes perfect and leads to confidence in controlling and braking on her "big girl" bike! She's an awesome rider! Congratulations, Emma!

EMMA WRIGHT



Emma and Mom, Barbie

In addition, this summer Emma helped her mom lead music for their church's Vacation Bible School. (Or should we say that Mom was helping Emma?!)



DALTON COPE



Bobbie & Dalton

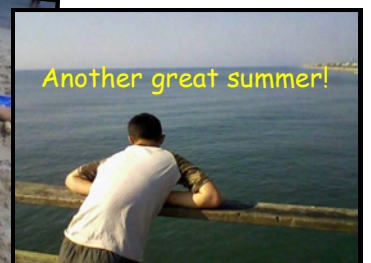
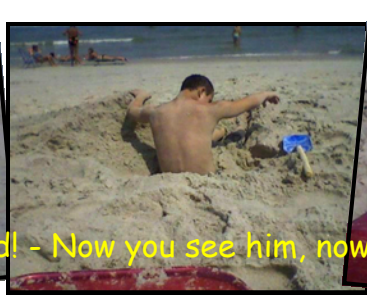


Lunch and Toons

Now you talk about a guy who had a fun summer, you must be talking about Dalton! He and his dad did their "summer thing" and have the photos to prove it. Though Dalton is now back at school (Stoner Thomas in Davidson County), he has fond memories of fun times at the beach. Dad Bobby Cope does quite a bit of volunteering at Dalton's school and recently was interviewed on Channel 2 News. Go to <http://www.digtriad.com/life/community/2twc/article/175065/184/2-Those-Who-Care-Paige-Wilhoit> to catch the interview and learn about the honor that parent Paige Wilhoit received from Channel 2's "Those Who Care."



Fun in the Sand! - Now you see him, now you don't!



Another great summer!

More Tidbits from the Top!

NDSC conference

San Antonio Texas August 5-7, 2011

Jeremy's Dream Trip

I went to Texas to the National Down Syndrome conference. I slept in a big beautiful hotel. I went down a water slide. My friends from New York came to the conference. I also saw some of my friends from college and friends from earlier conferences. My sophomore roommate Ryan was there because he is in charge of the Sibling conference. I ate at a nice Mexican restaurant. I went on the River Walk in downtown San Antonio. I did not go to the Alamo because I don't like fighting and wars. I went to sessions on Friday and Saturday on Self Advocacy, Exercise, and Finances.



Monica, David & Monica's cousin who directed the film *Monica and David* that won best documentary at the Tribeca Film Festival. & is up for an Emmy Award!



On Sunday there was a talent show. Friday and Saturday nights I went to the dances. We all learned a dance from YouTube before we went and did the moves together. It was cool. I was a greeter for the banquet on Saturday night. Lauren Potter, the cheerleader from Glee, won an award. I talked to Monica and David and Monica's cousin who directed the movie about them getting married. I saw their HBO movie last year at Chris Kelsey's house. They were both looking forward to returning home since they have been traveling with their cousin for 6 months promoting their movie. It is up for an Emmy award and won the documentary award at the Tribeca Film festival. Robert DiNiro gave them their award. They have been married for about six years. I can't wait to go to the conference next year in Washington and go to the classes and see all my friends.

-Jeremy Donohue

JOSEPH AND THE AMAZING TECHNICOLOR DREAM COAT



Jeremy and his fellow cast members at West Side Civic Theatre are pictured in the play that took place in Lewisville earlier this month. It was a lot of fun to watch, and even more fun to act in, apparently! Jeremy is happy to be back acting after being away for his four years at UNC-G/Beyond Academics.





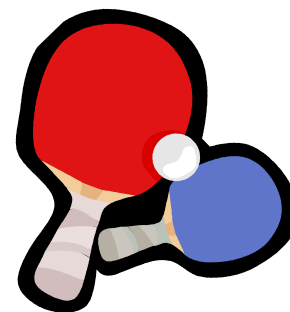
HANG TIME

**Open Basketball
for Adults with
Disabilities**

**Wednesdays, 9 a.m. to Noon
Miller Park Recreation Center
400 Leisure Lane
Winston-Salem, NC 27103
336/727-2831**

PING PONG, ANYONE??

If you are a table tennis buff, you can have fun at Miller Rec Center on Wednesdays! Call Leah (336-727-2831) for more information!



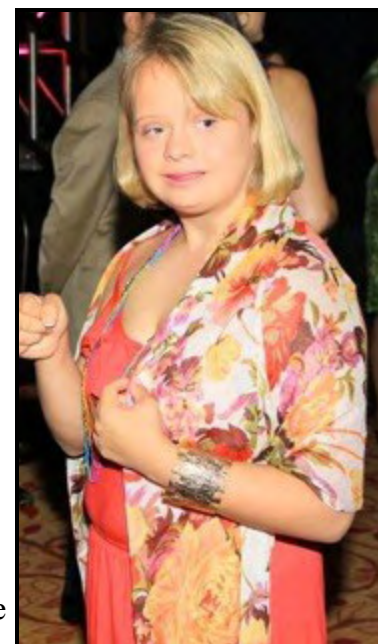
A NEW ROCK STAR AMONG US!

Two thousand hungry conference attendees were still a buzz, as the annual awards program was about to commence. The Master of Ceremonies flashed the easy smile of a television news anchor in welcome as the crowd began to settle. [Robin Steele](#) was honored for her tireless work in Cincinnati spearheading the National Down Syndrome Adoption Network. [Jason's Deli](#) of San Antonio was honored for creating and maintaining quality employment opportunities for individuals with Down syndrome and [Dr. Sally Shott](#) received the distinguished Pueschel Award for her research on sleep apnea and treatment of ear nose and throat issues for people with Down syndrome. [GiGi's Playhouse](#) won an award for celebrating diversity and enhancing the lives of disabled youth through theater. [Chris Scott](#) was applauded for his work with the More Alike campaign and national celebrities [Monica and David](#) were cheered for the movie which shared their quest for independence.

Still the uneasy, impatient feeling was there as eyes flashed from table to table and the bright smile of anticipation began to light the room.

"From Riverside, California," boomed the MC, knowing he had the audience in his hand, "please welcome [Lauren Potter](#)." Two hundred teenagers did what they do best, sounding like two thousand, roaring their cheers for the Glee star as she took the stage. A celebrity of neon proportions was welcomed by the NDSC. A new, though decidedly diminutive and blonde, rock star was born. No Academy Award actress was ever more glamorous or appreciative or adored than Lauren Potter in her five minute acceptance speech. Her reoccurring stardom on the Emmy Award winning production was the honor the crowd was waiting for and she did not disappoint. Chosen to play the now famous cheerleading cohort of Sue Sylvester the meanest of the mean, she spoke with confidence and enthusiasm. She was one of us. She was the new Chris Burke, noticeably absent from this year's convention.

For the kids, their evening was made and only the anticipation of actually meeting Lauren --- and OMG --- actually dancing with her at the dance in a few minutes held greater stock. For the parents, there was joy that amidst the challenges and uncertainty in their lives, a new face had arisen to spur hope and awareness for them and their children.



(Continued on page 6)

ROCK STAR, continued from page 5.

She was not only a positive role model for their children, she was taking a leadership role in the national campaign to “Spread the Word” (...to end the word), thus serving as a role model for parents, adult actors, and the whole world.

Even a seasoned banquet observer would admit this event had a little for everyone: the reminder to appreciate research going on behind the scenes, to celebrate medical practitioners who love our kids, to thank those who give generously and to honor our volunteers. And yes, even a rock star or two to bring some sparkle to the eyes of our children... and maybe a tear or two to most parents.

As I traveled back to Winston I couldn't help appreciate the many great things accomplished by the PDSSN in our community. From our own awards, generous contributors and civic hero's to our very own Buddy Walk talent show where a rock star is born every year, we are truly blessed.

- Bill Donohue

A Family Experience

Our family always enjoys the opportunity to attend the NDSC conference. It seems like yesterday we attended our first conference and the youngest Donohue kept crawling under banquet tables where we couldn't reach him. Then there was the time he snuck out of the hotel room in Florida with his friend Steve so they could be the first one in the pool. Panicked parents and hotel security hunted for what seemed like hours before we located one who had walked up the stairs and one who had taken the elevator down. But times change, this year Jeremy had free reign of the hotel and conference center. I am fortunate to be part of the Down Syndrome Medical Interest Group that is mostly composed of staff from DS Clinics across the country as well as some international members. A lot of subjects were discussed during this eight hour session including the new healthcare guidelines for children with Down syndrome. Significant changes include elimination of routine cervical x-rays and celiac testing. Renal screening after birth is not recommended. They recommend not using Down syndrome growth charts which are outdated (data is presently being collected to create more updated DS growth charts). Additions include sleep studies on all children by age 4 years. They should have one now if they haven't had one in the past.



Deborah & Bill with Frank Murphy, former President of National Down Syndrome Congress

As usual I came back from the conference motivated by the sessions I attended and the people I met. And some new dreams for our organization:

- ♥ Hopefully the PDSSN will become an affiliate of The Next Chapter Book Club. Currently there are 145 book clubs in 4 countries. Let's make it 146 or more. There are 27 clubs in Columbus, Ohio where the concept originated. The goal is more about giving people with intellectual disabilities a chance to express their views and opinions than it is about reading. People of all reading levels are welcome, including those that require Echo reading.
- ♥ A presentation on Cool Club motivated me to look into a second Saturday Club. This one for those 20 and older. I met with some community folks to see how to best make this available. See page 8!
- ♥ I'd like self advocates to have a larger role in the PDSSN organization and activities after hearing about the role of self advocates in Canada's "Voices at the Table" program. They determined that many families drop out of support groups because there is little for adults who have DS and they are rarely asked their opinions.

- Deborah Woolard

Notes from Promoting Health, Independence, Safety, & Community for Teens & Adults with DS

by Drs. Chicoine & McGuire:

This session focused on the importance of creating independence, the relationship between mental & physical health, & why sex education is so important.

- ◆ Many teens and adults with Down syndrome are in a chronic state of mild dehydration.
- ◆ Photos of AM & PM routines are helpful - having a picture list tell them what to do rather than the parent is sometimes more successful.
- ◆ Speaking for some people with DS can be exhausting & can lead to fatigue. Speakers described the energy needed as similar to our being in a foreign country. Adults with Down syndrome are frequently left out of important communication. Visual expressiveness is a strength and some people with DS are drawn to drama.
- ◆ They tend to be perceptive and empathic - sometimes overly so because they have trouble blocking it. There is a tendency to absorb conflicts & stress & many pay the price.
- ◆ Self talk is common and can be useful. Many tend to think out loud, review events, express feelings and frustrations. Need to be taught to do it in private.
- ◆ This one will not come as a surprise to most of us. There is a tendency for stubbornness. They resist change and can get stuck in a “groove”. Grooves may help increase independence but if under stress a groove can lead to an obsession or compulsion. If you notice a tendency to get stuck in a groove, reduce the stressors in the persons life. Because people who have DS are very visual when you combine that with a groove they are “practically photographic” they remember exactly where an item is in a room and if you move it even an inch or two they will move it back to its previous location. This became very pronounced with Jeremy when he moved into his student apartment. Even when visiting us, he is troubled if we have moved something to a new location.
- ◆ There is a tendency to remember things as if they are happening right now. This is another thing we have seen with Jeremy - he has an amazing memory of previous experiences. The example they gave was one that fits him. If a person with DS had a traumatic experience with a dog in the past it remains very real and can turn into a phobia.
- ◆ We all know people with DS are visual learners. They don't forget what you Show them. They tend to love movies and tend to put themselves in the movie and watch it repeatedly - I'm guessing you've seen this in your kids.
- ◆ It is important to discuss sexuality and self protection with your children. Females on long term low dose oral contraceptives should have clotting factors checked.

- Deborah Woolard



PINS BY BRIGETTE

Here's a preview of items that Brigitte Parsons has created for sale at the Buddy Walk. All proceeds will go to PDSSN! Our thanks to Brigitte for sharing her time and talent to benefit our organization!

Are You a Great Detective??

Here's a way to prove it: see if you can find a partial email address buried in this newsletter! If it's yours, all you have to do is to write Chris at ckelsey@triad.rr.com. You will receive a free Buddy Walk registration and up to four T-shirts! Free!





The Friday Socialites

Who are the Friday Socialites: Anyone between the ages of 18 years and 50 years who has an intellectual or developmental disability who likes to socialize and spend time with friends.

Who are The Socialite Friends: Adults who do not have intellectual disabilities who like to socialize and spend time with friends. Friends at Wake Forest and at Winston-Salem State have joined the group.

What type things do the Friday Socialites and Friends do:

They:

Eat pizza

Watch movies Bowl

Swim

Putt Putt Golf Potluck dinners

Picnic

Attend sporting events

Volunteer as a group

Attend community events

... And they want to hear about your interests & ideas

When do they meet: Third Friday of each month, 5:30 - 8:30 PM

Where do they meet: Miller Park Recreation Center

400 Leisure Lane

Winston-Salem, NC 27103

RSVP: Leah Friend at Leahf@cityofws.org or 336-727-2831
or Danielle Dobbs (danielled@cityofws.org)

Sponsor: Special Olympics of Forsyth County

If Socialite needs one:one support to participate, a support person should accompany them to the event.



PROMOTION IDEA!

Another idea for promoting this year's Buddy Walk is to **wear shirts from past Buddy Walks**. Unplanned, but like these girls to the left, both of my kids decided to wear their Buddy Walk shirts and boy, what free advertisement. A lot of people noticed and commented on their shirts all day long. ringera_400@ Great way to get the word out!



Blue Grass Bash



Riverwood Therapeutic Riding Center's annual Blue Grass Bash is Saturday September 24, 2011 @ Riverwood TRC beginning at 5pm, tickets are \$30.00 include BBQ and 2 Blue Grass Bands and an awesome silent auction. More info @ www.riverwoodtrc.org.

For those of you who won't be able to attend this year, there is still a way you can support Riverwood and possibly win a "delightful Disney Vacation". This includes a 5 night 6 day stay @ Disney's Old Key West Resort in Lake Buena Vista, FL located near Epcot Theme Park, Disney's Boardwalk Area and Downtown Disney. <http://www.riverwoodtrc.org/documents/2011%20Florida%20Fundraising.pdf>

Please see the above link for all the wonderful details about the raffle. You do not need to be present to win, Tickets are only \$10 each or 6/\$50.00 and the vacation package is valued @ \$2500 The winner will be announced @ the Blue Grass Bash.

(Thanks to Kathylyn Barnhill for this article.)

Dance! Dance! Dance!

Time: 7—9 p.m.
Where: Pinedale Christian Church
 (Get directions at www.pdssn.com)

No Limits II

Spend some more time with your family
 Get More Exercise
 Catch Up with Friends

NEXT SEVERAL DATES:

October 7, 2011 (note change)
November 11, 2011
December 9, 2011

No Limits II is for adults 18 and over who have mental and physical challenges.



NEED A WAY TO KEEP TRACK OF HEALTH RECORDS?

If you need a handy system for keeping track of your child's health and treatment records, Sandy Sauer wants to share some valuable information with you.

Interested? Contact Sandy at her email address: snbsauer@aol.com.

DAVIDSON COUNTY FESTIVALS

- ♥ Snacks with Santa—Saturday, December 3rd, 9:30—Noon, Davidson County Fairgrounds
- ♥ Itty Bitty Kiddie Festival—Saturday, April 21, 2012 10 a.m. to 2 p.m., Davidson County Fairgrounds



**"NICE, HOW WE NEVER GET DIZZY
 FROM DOING GOOD TURNS."
 - George Bengis**

**Piedmont Down Syndrome
Support Network**



4045 University Parkway

Phone: 336-714-9120

E-mail: pdssnemail@gmail.com

Website: www.pdssn.com

PDSSN is a non-profit organization



Support PDSSN!! Join Today!!

PDSSN friends—if you are not yet a member of PDSSN, consider joining, please. You can print the membership form you'll find on our website and mail it with your \$10 family membership annual dues to:

PDSSN
Helen Johnson, Treasurer
PO Box 91
Pffafftown, NC 27040

PDSSN News Publishing Schedule

- ◆ Winter (January, February, March),
- ◆ Spring (April, May, June),
- ◆ Summer (July, August, September)
- ◆ Fall (October, November, December)

Contributions, including photos, may be sent to pdssnemail@gmail.com in early December, March, June, and September (the month prior to each publication) or earlier. Share your thoughts and proud moments in *PDSSN News*!

It's Time for an Update!

A message from Lori Dahlin:

It's time to update our PDSSN Notebook. Most of you have received a notebook and value it because it gives you resource information, personal stories that you can really relate to, and other wonderful articles that come in handy!

The last time we did a big revision was in 2009. Of course, the notebook is on our website in PDF format so that you can access it any time, and recently we have put it on a disk, so it's available in digital format, too.

Resources change, more families wish to share their journey, new medical information becomes available - so these are our inspirations for a revision.

Would you like to serve on this short-term but intensive committee? We'd love to have your ideas, your perspective on what is important, and your energy!

Please contact Lori at dahlin.lb@hotmail.com, or at 769-0325.

Thanks!