

UPCOMING  
EVENTS

- **ANNUAL MEETING** with Down Syndrome Update by Dr. Jewitt— January 23, 2009 at Allegacy
- **SURE-BET Poker Tournament**— February 28, 2009, 7-10 pm
- **LITTLE BUD-DIES** play-group: 12/13/08, 1/10/09, and check the web site for more dates!
- **CENTER-POINT DD ADVISORY MEETING**— First Thursday of the month.
- **BEES**— Building Exciting, Effective Skills for Parenting—Starts again in January 2009—on 4th Thursday of each month from 6-7:30.
- **NO LIMITS II DANCE:** 12/12/2008, 1/9/2009

# PDSSN NEWS

VOLUME 1, ISSUE 1

WINTER 2008

## Thoughts from the Conference - 1

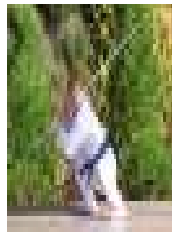
By Bill Donohue

It seems like I have been attending these national conferences most of my adult life. They remain interesting because our situations change as a family and the national landscape changes as well.

For many years I have heard the expression, “the unfinished child” in reference to our kids’ medical deficits. In Boston I was introduced to “the unfinished gift.”

The word play changed the meaning from victim to responsibility. It was underscored by Winston Churchill’s admonition that we make a living by what we get, but make a difference by what we give. Our children’s gift to us is the responsibility to give of our selves to them and others. From the DADS (Dads Aware of Down Syndrome) group, which seems to grow every year, to the breakout

sessions for moms and dads of children in certain age categories, I found this conference more engaging than most. I appreciated the growing number of assisted living alter-



**Jeremy Donohue demonstrates his skills with bo at the Buddy Walk.**

natives for adults, the dramatic impact of some support organizations across the country, and the extreme variance among state

services. Clearly the new neonatal testing for Down syndrome has the national organization at a crossroads.

North Carolina appears pretty average in terms of services for children and adults with disabilities, which calls up the glass half full/empty question. It is not unsimilar to the “gift” challenge. How do you accept the position in which you have been placed, as a father in North Carolina? As a member of the PDSSN? Each of the four PDSSN families in attendance this year will relate a different experience with the conference. But each family’s journey stands to enrich us all. I hope each of you will consider Sacramento, California, as a destination in your journey next year.

## Poker FUN-draiser in February!

This February, PDSSN will co-sponsor the 2nd Annual Celebrity SURE-BET Poker Tournament. The Tournament, which will be on Saturday February 28, 2009 at The Special Children’s School from 7 p.m. to 10 p.m., will support PDSSN and the Early Intervention program at The Special Children’s School.

Feeling lucky? Feeling like a

poker pro? There are several competitor categories and participant entry fee levels available, starting at \$25.00. Corporate representative, packages and sponsorships are welcome. There will be no gambling or monetary winnings—this is all for fun, and all entrance fees are a tax-deductible charitable donation. But there are some prizes!

Early intervention is a SURE BET when it comes to children with special needs, so come and support this cause AND the PDSSN AND have a great time!

**For More Information, see [www.pdssn.com](http://www.pdssn.com)**

# What's up with the Conference?



Making a REAL difference

PDSSN gives grants to families to attend national conferences. It helps strengthen our community and our organization by empowering our members with up-to-date knowledge. We encourage our families to go because of the great things that you bring back with you!

Sounds like a great deal, right? Well, all that PDSSN asks in return is that each person who attends a national conference with the help of a PDSSN grant write an article

for the newsletter about their experiences. We don't need anything fancy—just a statement about what you learned and what it means to you.

That way, in addition to you using your exciting new knowledge that you gained at the conference as you volunteer and interact with others in the PDSSN and others in the community, you get to share your experiences with everyone who looks at the newsletter—even if you don't

know them personally. It's a win-win situation.

PDSSN also helps with grants for local conferences—with the same requirement.

So, if you are interested in receiving one of these grants, and you're willing to commit to writing about what you learned, submit a request to the Board of Directors for a grant—there are details about the grant process on the web-site: [www.pdssn.com](http://www.pdssn.com)

*“Common sense should tell us that reading is the ultimate weapon—destroying ignorance, poverty and despair before they can destroy us.”*

*-Jim Trelease*

## Reading Tutors Needed

REAL, which stands for “READERS ARE LEARNERS” is a very good program that PDSSN supports. The program allows adults with developmental disabilities to receive tutoring to help them learn to read or improve their reading skills to levels that of proficiency to function on the job and in society.

This a great opportunity to

volunteer and to share YOUR talents with an individual who will really appreciate it.

Tutors receive training, and training sessions are held periodically throughout the year. Volunteers do not have to pay a fee for the training. REAL is looking for volunteers who are willing to commit to at least one hour each week.

If interested, please find information on the web site: [www.pdssn.com](http://www.pdssn.com), or contact Sarah Arras, who is with Monarch, at Forsyth Industrial Systems, 650 N. Highland Avenue, Winston-Salem, NC 27101. (336) 725-7527. Email: [sarras@monarchnc.org](mailto:sarras@monarchnc.org)

**VOLUNTEER—CHANGE SOMEONE'S LIFE AND YOUR OWN**

Who in their right mind would miss out on something this fun?



## Family Gatherings and Programs

Wonderful PDSSN families host three family gathering events each year. Usually in the summer, there is a pool party, which is a really great time for everyone. Please check the web site to find the

date for the next family gathering, and mark your calendar, because the family gathering is not to be missed.

### PDSSN LAUNCHES PRE-NATAL EDUCATION PROGRAM

This is a new program that will offer support to families

who have received a pre-natal diagnosis of Down Syndrome. We are providing high quality information to doctors' offices in the form of brochures, to give families who receive the diagnosis as much information as we can. In addition, one-on-one meetings with trained volunteers is available.

# THE BUDDY WALK IS AWESOME (even in rain)!



some things just can't be done, that some tasks are just too

Conventional wisdom would tell you that a rainy, chilly morning in September is no time to have a successful fundraiser. Conventional wisdom might also tell you that

hard. But conventional wisdom can be wrong.

A case in point is the 2008 Buddy Walk. Everyone who attended the walk was amazed and

inspired by the great turnout and the willingness of parents, friends, and community members to show their support for people with Down Syndrome and their families, regardless of the weather.

The Buddy Walk is a highlight of our year and does wonders drawing attention to our cause. Many, many thanks to all of the volunteers and participants who made this year GREAT, and special thanks to our Buddy Walk chairs—**Lisa Kennedy and Kathy Martin**.

*By taking a stand on important issues like this*

*one, we make our voices and the voices of our children be heard.*

## Tropic Thunder Boycott Efforts

In August of this year, the movie *Tropic Thunder* was released in our area. PDSSN called for a boycott of the movie, and our efforts received mention in several local media outlets. The movie made extensive use of the r-word and portrayed adults with developmental disability as the butt of jokes.

PDSSN issued a press release, and PDSSN member Bill Donohue

wrote a guest editorial in the *Winston-Salem Journal* highlighting the offensive nature of this movie.

But there is a bright side to this story—our efforts helped draw attention to the use of the r-word as a pejorative term. By highlighting the fact that using the r-word is just as insensitive as using the n-word. The more publicity that we have to show the world that people with

developmental disabilities must be treated with the same respect that any person is given, the more people realize that use of the r-word will not be accepted in our society.

By taking a stand on important issues like this one, we can make our voices and the voices of our children heard—we are making a difference.

## Thoughts from the Conference - 2

By Deborah Woolard

While Jeremy attended the Youth & Adult orientation, I attended the “Mothers Only - 22 and older” session. The list of concerns included post secondary programs, work, housing; weight control; immature behaviors, self talk; social opportunities ....

The next day we met with

the Canister Company to discuss the **new PDSSN prenatal education program**.

*Post-secondary Education for Youth with Intellectual Disabilities* reviewed the post secondary programs that are listed at thinkcollege.net and includes Beyond Academics.

“There’s No Place Like Home for Sexuality Education:

Strategies for Teaching and Supporting Health Sexuality” by Terri Couwenhoven. **We have her excellent book in our PDSSN library.**

Dr. Capone discussed co: morbid conditions that **Cont’d on page 4**



# What PDSSN Needs from YOU

*This newsletter shows you why the PDSSN serves as an outstanding support group in the Piedmont. We have accomplished a great deal in the past eight years. We have amazing community support with outstanding professionals on our board, attendance at our buddy walks, cooperative programming relationships with other agencies, and family appreciation for all that we do.*

*Like many other support groups, a few PDSSN members are doing a majority of the work and we need to change this. Our organization would be much stronger and there would be less burnout of the leaders if every family member would volunteer for one task. Please take time to thank those who volunteered and use this opportunity to sign up to help in 2009. Some of the jobs that are most needed are:*

*Buddy Walk Assistant Chair*

*Buddy Walk Committee chairs (food, registration, entertainment, advertizing, sponsorships, etc.)*

*Family Gatherings (3 per year)*

*Notebook copying (several times a semester)*

*All the PDSSN programs – REAL, Little Buddies, BEES, Education/Community Outreach*

*Advocacy and brochure development*

*Annual resource updates to website*

*Website maintenance*

*Educational programs*

*Plus many other small tasks that are done by the officers or board members.*

*Contact Wayne Kennedy (PDSSN Chair) to volunteer for the PDSSN & Lisa Kennedy (2009 Buddy Walk Chair) to volunteer to help with the 2009 Buddy Walk (see what I mean)*

*Thanks for your support in helping the Piedmont Down Syndrome Support Network advocate for our children, educate or community, and support each other.*

*Deborah Woolard  
Board member*

**We have  
amazing  
community  
support.**

## PDSSN Dance! Dance! Dance!

COME AND DANCE THE WINTER BLAH'S AWAY

Here's a chance to work on those New Year's resolutions:

Spend some more time with your family

Get More Exercise

Catch Up with Friends

### PDSSN WINTER DANCE

When: Friday February 27, 2009, 6:30 –8:30 p.m.

Where: Pinedale Christian Church (Directions on PDSSN Web Site)

RSVP to Kathylyn Barnhill at [barnbetts@windstream.net](mailto:barnbetts@windstream.net)

Or 924-6434

Feel free to bring a friend but please RSVP

*We need help with set up and clean up, so please let Kathylyn know if you can help out*

## Piedmont Down Syndrome Support Network

4045 University Parkway  
Winston-Salem, NC 27106  
Phone: 336-714-9120  
E-mail: [info@pdssn.com](mailto:info@pdssn.com)

### UPCOMING SIBSHOPS:

Sibshops are active events for the brothers and sisters of children with special needs. Sibshops offer games, discussion, crafts, special guests and a light dinner in a fast-paced, recreational setting, giving kids the opportunity to:

- Meet other brothers and sisters of children with special needs
- Form new friendships
- Have fun
- Talk about life with their brother or sister with others who understand
- Learn about how others handle difficult situations
- See how much they have to offer to others

Siblings ages 4-14 are divided into appropriate age groups so they can connect with their peers in a smaller group setting. Sponsored by Parents Together/Family Support Network of Greater Forsyth, Sibshops are organized and coordinated by well-qualified professionals and volunteers – some of whom are adult “sibs.”

Sibshops are typically held six times a year at Redeemer Presbyterian Church. There is no cost to attend, but **registration is required**. Please call the Parents Together office for more information ~ **336-924-5301**.

**Steps for a Brighter Tomorrow.**



## Thoughts from the Conference—cont'd

accompany Down syndrome and increase with age.

The high incidence of **sleep apnea** and the importance of a sleep study was stressed. Sleep apnea can cause attention and distractibility. It does not cause OCD or anxiety which are common. OCD is so common that at some level it may “be a part of DS”. These symptoms become a disorder when they interfere with life. Common obsessions or recurrent thoughts and self talk are frequently about the weather or repeatedly asking about upcoming activities. Being tidy is a common trait for folks with Down syndrome. It becomes a compulsion when the environment has to be a certain way. If things are not “just so” there may be a behavior backlash. Hoarding items is not

uncommon. Skin picking or rubbing and repeatedly rewinding a DVD to the same scene over and over are common compulsive behaviors. Phobias and fears can accompany anxiety. Depression can be confused with symptoms of sleep apnea or other sleep dis-



turbance. Ten to twelve percent of adults with DS are depressed (2-5% above the general population).

The symptoms of these disorders are not usually textbook and the boundaries between disorders is blurred in our children and the combinations of symptoms can come and go. It is very difficult to find an appropriate medical provider for mental health issues in people who have Down syndrome.

I encourage all PDSSN families to attend a national conference. I always learn something and when I see Jeremy at his sessions I remember how important it is that our children have opportunities to join with their peers.