

- **ANNUAL MEETING**
with Down Syndrome Update by Dr. Jewett—
January 22, 2009 at Allegacy CU
- **CenterPoint “World Café”**
for strategic planning—
open to the public, 9-
Noon, January 22
- **SURE-BET**
Celebrity Poker Tournament—
February 20, 2010, 7-10 pm
- **CENTER-POINT DD ADVISORY MEETING—**
First Thursday of the month.
Next meeting: 2/4/10, 5:30,
Tise Cottage, Children’s
Home campus
- **BEES—**
Building Exciting, Effective
Skills for Parenting—Starts
again in January 2010—on
4th Thursday of each month
from 6-7:30.
- **NO LIMITS II DANCE:**
February 12
March 12
April 9
May 14
June 11

PDSSN NEWS

VOLUME 3, ISSUE 1

WINTER 2010

Buddies ‘R Us! The 2009 Buddy Walk



October 10, 2009 was a happy day for a lot of Buddies! It was the annual celebration known as the Buddy Walk.

Each year more people find their way to Tanglewood to celebrate the extraordinary gift to our lives that people with Down syndrome bring us.

It’s a time for “kids” birth to 100 to come together for a few hours of play and laughter. This year (as you can see from the photo above) was another great gathering. Everyone enjoyed walking or applauding the walkers, performing or admiring the performers, snacking, and most of all, visiting with old friends and meeting new ones. It’s a

wonderful occasion every year. This year Fran Sandridge & Chris Kelsey were awarded the honor of “Buddy of the Year.”

PDSSN sponsors a great many programs and forms of outreach during the year. The earnings from the Buddy Walk make that possible!

We are grateful to our sponsors—businesses and individuals that are listed to the right. Thank them when you see them and let them know that you are part of PDSSN and are appreciative of their support.

Again, Lisa Kennedy and her team of volunteers pulled off this extraordinary event with great style

DD Through the Lifespan: A Success!

October was eventful for PDSSN, and one highlight was a conference focusing on Developmental Disabilities. Co-sponsored by AHEC of Wake Forest University School of Medicine, Amos Cottage, CenterPoint, J. Iverson Riddle Developmental Center, Special Olympics of NC, and The Special Children’s school, this conference covered many aspects of life for a person with DD.

A highlight of the conference was the presentation by Chris

Burke and his sidekicks, Joe and John DeMasi. They proved that “Everyone Can Be A Singer with the Band,” by leading the attendees in song and laughter. Timothy Shriver’s keynote address was warm and inspiring. There were so many wonderful sessions and great presenters that it would be impossible to name them here.

The next time this conference is available, be sure to sign up! You’ll be so happy that you did!

Friends for Life

- ◆ Wal-mart
- ◆ Dr. Tina Merhoff & Associates
Pediatric Dentistry

Buddy

- ◆ Battery Tree, Inc.
Kernersville
- ◆ McDowell Family

Best Friend

- ◆ Anue, Inc.
CAP-MR/DD Services
- ◆ Mt. Pilot Drug
- ◆ Fuller Architecture, Inc.
- ◆ Corning (Cable Systems)
- ◆ McNeeley Pest Control
- ◆ Peters Family

Pal

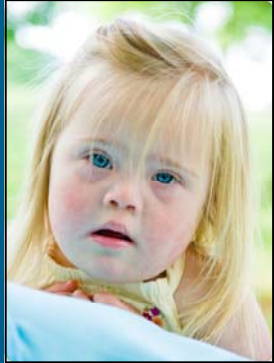
- Wheeler Family Dentistry
Kurt Klinepeter, MD
Tamison Jewett, MD
- Lindley Rehabilitation Service
Vroom Family
- A Divine Touch Massage Therapy
Bayada Nurses DD Service
Hip Chicks Boutique
Norma Woolard
Woolard-Donahue Family

I'm Down with You!

Do you need a smile,
and a warm feeling
today?

Visit
[http://
imdownwithyou.com/](http://imdownwithyou.com/)

You'll enjoy every
minute!



Making Buddies!

Ava & Lisa - "Down is Good"

Ava and Lisa Kennedy were featured in the September issue of Forsyth Family magazine. It was a great article and an opportunity for Lisa to get some publicity for the Buddy Walk. It also offered readers a glimpse into the life of a very typical family who happen to have a child with Down syndrome.

In the article, Lisa shared that Ava's diagnosis was not known until her birth, and so the intervening years have been full of change and learning

for the Kennedys.

It was obvious that the journalist, Kelly Melang, was captivated by Ava. In closing, she wrote, "Ava's smile is infectious and as I leave she wants to come with me. I've made a Buddy with a beautiful little girl who proves that Down is Good!"

It occurs to us that this is the way that stigma is erased: one person at a time. Relationships are the workshop settings of life. As we disclose ourselves to others, we learn

and grow, and offer others the same experience. It's through loving relationships that fear goes away and understanding and acceptance become part of who we are. We find that we are all more alike than different. Thanks, Lisa and Ava!



What could possibly be more joyful than to bring joy into another's life?

Reading Tutors & Students Needed

REAL, ("READERS ARE LEARNERS") brings adults with disabilities a great opportunity to improve their reading skills. No matter a student's current reading level, REAL tutors will work with the student and together they will make progress. Reading enhances a person's employment qualifications, supports independence, and brings a lot of

joy into the student's life.

The tutor will experience the deep satisfaction of making a truly significant contribution to someone's life!

This is a completely free program for both students and tutors who are willing to commit at least one hour each week. Volunteer tutors are trained and given the support they need to be effective. Are

you looking for a way to give back? Here is one way you can make a difference! Contact Stuart Egan at pdssnreal@gmail.com. Look for more information on page 3 of this issue and on the web site: www.pdssn.com,

VOLUNTEER!

CHANGE SOMEONE'S LIFE AND YOUR OWN!

BEES Schedule

- 28-Jan Debbie Allred
- 25-Feb Guest from Monarch
- 25-Mar Kurt Klinepeter
- 22-Apr Elizabeth Allen
- 27-May Mary Christiansse
- 24-Jun Sarah Kaplan & Kris Drum
- 22-Jul Sandy Sauer, behavior specialist
- 26-Aug Ramona Janelle & Judy Hoskins
- 23-Sep Gail Hounshell
- 28-Oct Loretta Arnn & Chris Kelsey

BEES is here for you!

BEES for parenting is a series of informational and support meetings for parents who would like to learn more about techniques for approaching behaviors that are becoming problems in relationships. It's also an opportunity to share what has worked for you, and to find out you are not alone!

Meetings are held at Amos Cottage on the fourth Thursday of each month, from 6-7:30 p.m. Childcare and a light supper are included, but you must RSVP in advance to Chris Gentry at 924-5301. The schedule for this year's meetings is in the box to the left.

This is one of PDSSN's most popular offerings.

A REAL OPPORTUNITY!

Dear Piedmont Triad Community Advocates,

I am writing you on behalf of the Readers Are Learners Program (REAL), a literacy program for young adults with developmental disabilities. As the liaison from the Piedmont Down Syndrome Support Network for REAL, I am asking for your help in recruiting volunteers to act as tutors for our next group of willing students. I may have contacted you last year, and I hope that you will be willing to help promote our program again this year.

We are seeking patient, qualified volunteers who are invested in helping some of our young adults build and maintain basic reading skills. In most cases, these students have specific goals in mind: reading a restaurant menu, navigating parts of the newspaper, or deciphering advertisements. REAL has been very successful in the past – so successful that some of our young adults in the three two years graduated to the Beyond Academics program at UNCG. But more importantly, what REAL has helped create are relationships that have fostered confidence in our students and fulfillment in our tutors.

With the support of the YMCA, REAL has literacy training to help tutors become prepared to help our students. Tutors would be trained by the Literacy Initiative of the YMCA, paired with a young adult, and assisted in finding a space to conduct tutoring sessions. We ask that potential tutors be willing to meet on a weekly basis with their students throughout the calendar year. Specific times would be arranged by the tutor and the student based on their availability.

Working with the Readers Are Learners Program would be a tremendous way to help those who want to help themselves. Available on the PDSSN website is a flyer that provides more information about REAL and contact information. We ask that you please post a flyer in your workplace, make copies for anyone interested, or pass one along to any volunteer or potential tutor. *Any and all information including applications for tutors and potential students can be found on the PDSSN website at www.pdssn.com/events/programs.htm. Please forward any applications to me, Stuart Egan, at 824 Chester Road, Winston-Salem, NC. 27104.*

Tutoring these young adults is a tremendously rewarding experience as well as a great way to be of service. As a parent of a child with developmental disabilities, I am grateful to be raising my family in the Piedmont Triad community. That is because people like you promote inclusion and advocacy for all community members.

Please contact me if I can be of any help. My email address is pdssnreal@gmail.com.

With warm regards,

Stuart Egan
PDSSN Liaison for REAL

Do you know that you were meant to SHINE? It's true!

Honors

- ◆ **Laura Laxton and Melinda Gentry** received the **Mayor's Council on Disabilities' Helping Hand Award!** The Mayor's Council award is also great recognition for PDSSN! Congratulations, Laura & Lisa!
- ◆ Fran Sandridge and Chris Kelsey have been buddies for many years, and so how much fun it was for each of them to receive PDSSN's first **Buddy of the Year award for 2009!** Fran and Chris thank PDSSN for this great honor and pledge their continuing support to this wonderful organization.

Sure Bet Celebrity Poker

When: Saturday, February 20, 2010
Where: The Special Children's School
Time: 7—10 p.m.

An evening of entertainment and plain ol' fun!
Benefit: Early Childhood Education

Questions? — Call Bill at 336-924-9309

Ask the Geneticist....

With this issue we add a new feature, "Ask the Geneticist." We thank Dr. Tamison Jewett, geneticist at Wake Forest University School of Medicine for her willingness to respond to questions posed by our readers. If you have a question you would like featured, please send it in an email to pdssn@gmail.com.

Dear Dr. Jewett,

I am confused about the recommendations for screening for abnormal neck flexibility in children with Down syndrome. Would you please clarify this issue?

Confused Parent

Dear Parent,

This is a confusing subject for parents and doctors, alike.

It is reported that up to 15% of people with Down Syndrome (DS) who are less than 21-years-old have lax ligaments holding the first cervical vertebra (top-most bone in the neck, also called the "atlas") in place on top of the second cervical vertebra (also called the "axis"). When this occurs, it is called "atlanto-axial instability" (AAI).

The concern about AAI is that if the two vertebrae can slip on one another, the spinal cord could be pinched and cause the child to lose function or, worse, become paralyzed. Screening for AAI is performed with xrays of the neck in forward, backward, and neutral positions.

In 1983, xray screening for AAI was recommended for all individuals with DS who wanted to participate in the Special Olympics. Soon thereafter, numerous health supervision protocols for children with DS adopted this recommendation as a universal screening measure at 3 to 4 years of age.

The recommendation for one-time, routine screening is controversial for a number of reasons. As with any test, measurements can be inaccurate. People who have normal measurement s early on may have abnormal measurements later. Not all people with AAI are at increased risk for spinal cord injury. Finally, most people with spinal cord injuries do not sustain them during athletic activity. For example, extension of the neck performed at the time of intubation for a surgical procedure is potentially more dangerous than sports participation. It is clear that more research must be done on this issue in order for us to know what the best plan should be.

In the meantime, we in the U.S. continue to recommend neck xrays to screen for AAI at 3 to 4 years-of-age. If an abnormality is detected, further studies are recommended, such as MRI of the neck. It is important for all of us—parents and physicians, together—to recognize that just because the neck xrays have been normal, it doesn't mean that a problem can't develop. With each physical exam, children and adults with DS should have a careful neurological exam to look for changes in tone, movement, or reflexes that could signal a problem. It is also suggested that neck xrays be done prior to surgeries that require intubation if they have not been done in the previous year.

Hope this helps!

*Yours truly,
Dr. Jewett*

UPDATES

- ◆ **Ashlyn Rippey** underwent surgery on her cervical spine 11/18 due to instability that was discovered on routine xrays to allow her to continue in horseback riding. Her mom shares with the PDSSN membership that surgery went well, Ashlyn is recovering nicely (with no complaint of pain!).
- ◆ **PDSSN** has transferred nearly a dozen new publications to its **lending library**. Inspiring stories, educational materials, and a host of references are available for you to borrow at your leisure. See **Bill** at **The Special Children's School**.
- ◆ **The Winston-Salem Youth Hockey league** is sponsoring a program for boys and girls ages 8-18 who have disabilities. The program will be offered at little or no cost to families. Call Paul Hoppood at 706-464-8099.
- ◆ **The Buddy Walk** attracted more than 1,000 people in October, and raised about \$22,000 that is being put into programs and services that benefit people with disabilities, and especially those with Down syndrome. Said Leader **Lisa Kennedy**, "During the talent show, I looked out at all the people that were there. Everyone was having a great time. I that's what this day is all about... individuals of different races, religions, abilities coming together to enjoy a special day. Our Walk is about inclusion and acceptance. By the faces of those attending... I think we met our goal!"

Piedmont Down Syndrome Support Network



Piedmont Down Syndrome Support Network

4045 University Parkway
Winston-Salem, NC 27106

Phone: 336-714-9120

E-mail: pdssnemail@gmail.com

Website: www.pdssn.com

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

No Limits II

When: Second Friday of each month, 7—9 p.m.

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

Support PDSSN! Join Today!

PDSSN Members and friends,

It's that time of year again. Time to re-new your membership in PDSSN, or if you are not a member yet, time to become one! Please print the membership form you'll find on our website and mail it with your \$10 family membership dues (what a bargain!) to:

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



When our kids with Down syndrome grow up....

PDSSN is dominated by the cutest children in the world and historically our organization's vibrancy has come from parents of our youngest kiddos. However, as our national organizations have spread the word and our adults have become better served, we see increasing attention on adult services beyond public schools and new living arrangements beyond group homes. Times are changing for our kids....and for us.

The Boston conference provided several sessions on the funding and planning of diverse adult living arrangements, from apartments and condominiums and federally supported disability communities to more creative parent-driven assisted living opportunities. As one parent said to me, "I was a pioneer parent, keeping my child from an institution....now I'm 70 and she's 50...and we both need institutions to care for us!"

All across the country "intentional communities" are popping up, funded by multiple families with varying degrees of supported living. Using federal financial supports for your adult children, there are models with moderate costs and unique financing. Similar to Beyond Academics, there are states which see unique ways to partner with public and private groups to reduce or share costs with all involved. For some it involves part time work within or near the community,

For others there are continuous care components.

Several parents mentioned success with adult foster homes for their adult children, providing the rhythm of family life, without the all-for-one demands of a group home. Still others offered shared living arrangements and community cooperatives, born out of frustration with group homes. And from the wisest of the parents with experience, we heard thoughts about roommates, pets, marriage, house management and financial controls.

Here are a couple references to get you started: www.Camphill.org and www.pathfindervillage.org. The first is a world-wide organization for adults with disabilities, the second begun by some parents in Central New York specifically for their children with Down syndrome. One of the newest facilities, designed in 2006 by a parent of an adult with Down syndrome is in Missouri, www.stlouislife.org.

While it is never too early to check out our own estate planning, guardianship and adult care issues, our kids deserve the forethought and creativity for them as well. We have much to learn.

"Don't Be Afraid to Dream"