

Piedmont Down Syndrome Support Network News

Piedmont Down Syndrome Support Network
www.pdssn.com

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Are you ready to Walk? Buddy Walk 2007

It's time to get excited for this year's Buddy Walk. The walk will be **September 29, 2007 at Tanglewood**. This is an exciting time for everyone to get together and raise money for a great cause. This year's Buddy Walk is sure to be the best Buddy Walk yet. We will have a special guest: Chris Burke. Chirs will be leading our Buddy Walk, and it sure to be a

really fun event.

It's always good to remember the reasons for the Buddy Walk: (1) To promote acceptance and inclusion of people with Down Syndrome; (2) To raise funds locally for education, research, support, and advocacy; and (3) To enhance the position of the Down Syndrome community, enabling us to positively influence local and

national policy.

If you want to help, please get in touch with Kathy Martin or Lisa Kennedy.

With an event this exciting on its way, what are you waiting for? Let's get out there raising funds and get ready to rock!



What if Services are *Not* Going Well?

Thoughts to Consider

By Chris Kelsey

You have been getting services for your child for several months, and something keeps nagging at you. You're not sure that the coordinator is on top of things, or you're not sure that the therapist is helping. Or your child just doesn't respond positively to this person. You also may wonder, "Do these service providers *ever* talk to one another?"

Communication is a legitimate concern. All the people who provide services to your child, including his teachers, therapists, and case manager (or service coordinator) should be communicating with you and with one another on a regular

basis. You have the right to expect this.

If your child has a service plan, or an IEP, or both, there should be regular occasions when all of you sit down together to discuss progress, unmet needs, and goals. You have the right to call such a meeting whenever you believe there's a need for it.

What do you do if you are not satisfied with the services you are getting from a particular provider?

Well, first check your attitude: do you recognize that these people are your "employees" and are in your life because you have chosen them? Next, how do you approach them with a complaint? Here's an idea:

Figure out what you want. Picture how things would look if they were better. This will help you be clear.

Ask for what you want. You don't have to be demanding. You don't have to be accusatory or blaming. State what you want in clear terms.

Listen. (Don't be afraid of silence. The ball is now in the other person's court.) Listen not for excuses, but for whether or not the person truly "gets" what you are saying.

Discuss the changes that need to take place to reach your goal of being satisfied.

"But wait!" as they say in ads, "there's more."

What if you *have* tried to ap-

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Lend a Hand!

- To help with Buddy Walk: Lisa Kennedy (712-3448) or Kathy Martin (475-7774)
- Help with Family Gatherings:
- We Need Tutors

Important Dates:

- Friday, September 7 Education program on Sensory Integrations. Register ASAP—flyers on the website
- Friday September 29—BUDDY WALK

National Down Syndrome Congress 34th Annual Convention

By Deborah Woolard

It is always fun to check into the hotel at a National Down syndrome conference. It seems everywhere you look there are people with Down syndrome - adorable infants held by parents, toddlers crawling and walking in all directions as they explore their new surroundings, preteens standing shyly with their parents or sibs, and young adults greeting each other with a smile and a hug as they reunite after a years absence.

I started the conference the usual way – The Mother’s Only group. Over the years, I have moved up and now qualify for the 18-21 year group. Next year I will move to 22 and older and there I will stay. The mothers talked about transition from high school, living arrangements, dating, sexuality, and jobs. They decided transportation was too big an issue to even discuss. I was particularly interested in hearing about the program at Eastern New Mexico University-Rosewell. Several of the mothers had students enrolled in this program.

Next came the mixer. The mixer and the Saturday night dance are always fun and free spirited. I got to dance with Jeremy since he was missing Rachael (his favorite dance partner). Chris Burke still knows how to work the crowd as he DeeJays with his friends Joe & John DeMasi.

Saturday started with plenary sessions that included a reminder by Carol Mills of the importance of Language and our role as parents and advocates to encourage others to use Person First Language. David Koppenhaver from our own Appalachian State University spoke on Thoughtful Literacy and the importance of learning to read what is important and interesting to the individual. The new

“Golf for Life” program was presented before we broke into workshop sessions. I attended Dual Diagnosis: DS & neurobehavioral disorders in adults. I was overwhelmed by the issues many adults with DS and their families are facing. I hope none of our children have the complex mental health problems that I heard about in this session. Many parents described their difficulty in receiving accurate diagnosis and appropriate medical treatment.

Parents from other states and countries were seeking advise and appointments with Dr. Capone. My second workshop of the day was Research on Therapies by Dr. Priya Kishnani. The

good news is that people with DS now have a life expectancy of 56+ years with 50% living to 50 and 25% living to 65. Her investigation into potential therapeutic effects of cholinesterase inhibitors was discussed. This study is of particular interest since the brain changes of Alzheimer disease has been found to affect some of our children in very early and by age 45 years all individuals with DS have the brain changes found in Alzheimer disease. Jeremy participated in one of her studies and we felt he had mild memory improvement on the study drug. The bad news is funding has become all but impossi-

ble to obtain in the last few years. The night ended with the banquet and dance. Dr. Shott, the ENT doctor from Cincinnati who is collaborating with Dr. McGuirt on how best to manage Jeremy’s sleep apnea, won the Exceptional Meritorious Service Award.

Sunday’s Plenary Session included a presentation on celebrating abilities and a self advocate talking about her journey to college. The workshop I attended reviewed research related to understanding the causes and consequences of having an extra chromosome 21.

In-between sessions, I got to hear our friend Steven Sauter give a presentation about his job at the St. Lawrence University Bookstore to the Young Adult Section. I got his autograph on *Adults with Down Syndrome* by Sig Pueschel. I also got a preview of Steven’s Romeo and Juliet monolog with me playing the role of Juliet to his Romeo. Jeremy loved the applause he got when he performed a bo routine to Kung Fu Fighting. The talent show moved quickly from one enthusiastic entertainer to the next.

As always, I found it a joy to be in the presence of so many who care about people who have Down syndrome and for Jeremy to have the opportunity to spend a weekend with his DS peers. He has his calendar marked for Kansas City Aug 3-5, 2007.

“The good news is that people with DS now have a life expectancy of 56+ years, with 50% living to age 50 and 25% living to age 65.”

April at the Wheel - the pottery wheel, that is

April Anders attends the Enrichment Center. She spends her day learning dance routines, using the computer, attending art classes and she is in a physical fitness and wellness program.

April has just discovered a new passion and that is using the pottery wheel. Patsy her one-on-one and Stacey her art teacher saw the potential April has to use the wheel. April takes her new skill very seriously and is striving to improve.

April's pottery along with ceramic pieces and paintings by other artists are on display at the Gateway Gallery. All proceeds from the sale of exhibited work will benefit the individual artist. Stop by the Gateway Gallery at the Enrichment Center on Marshall Street and show your support for a budding



artist. They have wonderful pieces for your home or gifts for your friends.

Stacy helps April shape the clay.

What if Services are *Not* Going Well? (continued from page 1)

What if you *have* tried to approach this person and they listened, seemed respectful, but never followed through? Then you have a second problem. The first one is that things are not going well. The second one is that your attempts to facilitate change have been ignored. Now you must ask yourself if it's worth the struggle to work this through, or if you need to 1) address your concern at a higher level, or 2) find another provider for your child's service.

The system of services has instituted "consumer choice" so that you have options. To be fair about it, most providers want to make you happy with their services. They don't need to lose your "business," or to have the bad "PR" that results when someone is dissatisfied. So do

try to work with higher level people, if you can. Sometimes a simple change in worker can fix the problem.

Whatever you do, feel good about your efforts to maintain quality services and quality communication for the sake of your

"If your child has a service plan, or an IEP, or both, there should be regular occasions when all of you sit down to discuss progress, unmet needs, and goals."

Happy Birthday! PDSSN Birthdays coming up

August

Juan Pablo Trejo 8/05/03
Rachel Rushing 8/06/93
Juan Trejo 8/6/03
Vanessa Silvar-Zamora 8/9/02
Kevin McGee 8/13/95
Leah Godaire 8/16/96
Rebecca Mustin 8/18/83

September

Dawlton Lawson 9/01/01
Greg Silvernail 9/1/68

Lucas Paynter 9/11/02

Sophia Smith 9/15/00
Jacob Allen 9/17/04
Evan Jeffries 9/19/03
"Ali" Alejandra Aguilar 9/19/00
Julio Chevez 9/25/04
Stephen Reeves 9/26/75

October

Justin Eaton 10/2/01
Cooper King 10/08/01
Richard Allen 10/22/77
Isaac Garber 10/27/01

November

Gerald Nunley 11/8/95
Noah Lemm 11/12/04
Rose Hodges 11/18/98
Zoe Mejan 11/21/02
Jeremy Donohue 11/29/84
Luke Bissell 11/29/01
Lindsay O'Donnell 11/29/99



Vippee for Birthdays!

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We're on the web:
www.pdssn.com

- Sign up for the BUDDY WALK today!

Congratulations!

- Jack Rice won a blue ribbon for FIRST PLACE in his heat in the Fall Special Olympics games in bowling. Jack also won a couple of ribbons at the spring games
- Austin Barnhill won an award for MOST IMPROVED STUDENT for the entire year from Team Eagles at Jefferson Middle School. He also won with award for the first quarter
- Jeremy Donohue moves into his new apartment in Greensboro this month in preparation for starting the Beyond Academics program at UNC-G.

Ten Reasons to Support PDSSN

1. **Only you** truly know what it is like to walk in the shoes of a parent of a child with Down syndrome. You are somewhat rare and you are special. The PDSSN is 100% volunteer, parent driven and dedicated to you and your family.
2. Over \$30,000 is raised by the **Buddy Walk** and given back each year to the programs and services that support the network's mission. You have already benefited this year and will in the years to come in ways you may never know.
3. Every family who has a child born with Down syndrome in the Piedmont receives a **PDSSN Resource Notebook** that has been estimated in actual value to be worth \$70. Our written family stories and pictures - that give us hope and perspective - are priceless.
4. The organization receives its vibrant leadership from a continuing education that comes, in part, from **NDSS** and **NDSC** - two national organizations who hold conferences and provide literature, intranet and program services. The PDSSN budgets \$6,000 each year for **Conference Stipends**. The value to attendees is huge, and the PDSSN enjoys dividends in many ways as well.
5. Children with special needs attract special challenges. From dual diagnosis to the associated behaviors growing up with developmental delays, PDSSN has teamed to sponsor **BEES**, a monthly family program to assist with parenting skills. Each year we also sponsor **Educational Seminars** for those issues directly impacting us, such as sensory integration, genetic research, and ENT challenges. We open these free to our family members, teachers and medical professionals, as well as the community at large.
6. As our children grow up they are absorbed in different ways in our schools, community and families. Some fall short in our public schools and some excel. **ReAL** is a catch up program for high school graduates to gain literacy skills. The **Beyond Academics Fund** helps high school grads attend a special residential collegiate program at UNCG. Both are funded by your PDSSN dollars. Each of us must look beyond childhood and the defined architecture of public schooling.
7. Social networking is the salve that allows us to share with protection, to celebrate without embarrassment, to listen and to help our fellow families. This is where we share experiences, celebrate successes and support one another on the "really hard days." **Ladies Night** out, **Guy's Night** out, and our **Family Gatherings** are an important connection - budgeted to make your participation easy, fun and welcome.
8. **Community Advocacy** impacts all of us, from simple community awareness and understanding, to legislative support. PDSSN supports a highly successful **Buddy Walk** for 1000 friends, a **No Limits** (monthly) Dance for nearly 400 adults with disabilities, a **Children's Play Group**, an **Adult Advocacy Group**, advertising, and many more things that help people walk in our shoes.
9. **Triad First and Families** is a state supported community chest for families with financial challenges. PDSSN happily allocates money each year to TFIF for Down syndrome families.
10. The **Sunshine Fund** is a small allocation, symbolizing a big, central idea in our network. We try to support our families when they are in the hospital. Our kids are frequently hospitalized and draw us from their siblings and our work in ways most other parents cannot appreciate. We do.

Special

He was born special
Therefore he is not able
To limit his love
-Ivan Mahlonovich