

Heart of Texas Down Syndrome Network Newsletter

November/December 2014
Volume 2, Issue 6

Letter from the Editor

Dear Fellow HOTDSN-ers,

Welcome to our November/December issue of the HOTDSN Newsletter! While, I was unable to attend the Buddy Walk thanks to a lovely stomach flu that left me in bed with a 101 degree temperature, I have heard that it was the best one yet!!! Please take some time to look through the pictures and stats that are featured inside!

Also, as I have stated before, I am always looking for a good story. I would like to start two new feature articles. The first would feature an activity that you have done in the Central Texas area that you have very much enjoyed. It need not be disability related. If you have something, please consider emailing me about it. I will send you a form to answer a few quick questions about it. Throw in a picture for me and you are done!

The second one is to feature a doctor or therapist that you have found helpful in the area. I am starting this one with a personal recommendation for Hayden's child psychiatrist in this month's issue. If you have someone to add, please send their contact information my way!

Thanks a ton and Happy Holidays!

Kim Torres (kimtorres@hotmail.com)

BUDDY WALK 2014



Heart of Texas
Down Syndrome Network



INSIDE THIS ISSUE

Local, Regional, National and World News...all related to Down Syndrome.!!! Six pages full of glorious fun!!! :)

BOARD MEMBERS

- Alice Kingston—President
- Angel Hux—Secretary
- (Your name here) - Treasurer
- Kim Torres—Newsletter Editor
- Julie Willie—Social Media Director



SPOTLIGHT CORNER

Child's name: **Levi Daniel Poliquin**

Age: 14 months

Favorite activities: playing with balls, crawling and playing with my 6 brothers and sisters

Favorite Food: chocolate chip cookies!!

Favorite Book: all books! Loves animal books in particular

One thing no one would know about me: I am reserved at first to strangers but when I warm up its all smiles

The person/character I would most like to have dinner with: my sister Elle she is 15 and I Love when she feeds me and holds me

One thing about me that makes my parents so proud: I am strong and adventurous and full of giggles, smiles and kisses. I don't give up easily!



“The difference between ordinary and extraordinary is just that little extra.”

BUDDY WALK - BY THE NUMBERS!

250 -Number of walkers.

40 -Number of Volunteers.

\$6000—Money raised for HOTDSN.

\$700 money raised for RDS through silent auction.

Largest Team and Fundraiser: Easton Kadlecck and Family

**All numbers are preliminary estimates at time of publication.



Yes! Bullying Can be Addressed Through the IEP

By Special Education Advocate Julie Swanson and Attorney Jennifer Laviano

Below are a few practical tips regarding bullying in school. While the original article was written for parents of children with Autism (thus the ASD references below), the general idea applies to Ds. For more information visit their website at: www.SpecialEdJustice.com.

1. Ask for your school district's bullying policy and procedures.
2. Screen your child at home. Talk to him or her and explore what's happening at school and with peers. Set up a data collection system at home that tracks any changes in behavior.
3. Screen your child at school. Have a team meeting with your child's special education team (examples: the special ed teacher, regular ed teacher, case manager, social worker, guidance counselor, school psychologist, speech pathologist, principal) and make them aware of the situation. Ask the school team to monitor your child over a period of time and set up a data collection system among the team to track any changes. Make sure that monitoring takes place across all structured and non-structured school settings (the classroom, hallways, lunch room, bathroom, school bus and at recess).
4. Document the issue and request that the documentation be placed in your child's educational file.
5. Determine if what is happening is a reportable offense in accordance with school policies.
6. Put a (written) plan in place with the school team.
7. Recognize the difference between a school-wide approach to bullying and a child-centered approach. School-wide approaches include getting other kids involved in resolving the bullying issue like pairing the student with an ASD with a peer buddy. A child-centered approach involves the child with an ASD gaining a skill or learning to change their own behavior like recognizing a bully or having a bank of responses to say to a bully.
8. Consider what is making your child vulnerable to being bullied. If you don't identify the specific problem your child is having then it is more difficult to address it and help remediate it through the IEP. For example, is it your child's Inability to read / recognize social cues (shunning, teasing, gesturing, etc.), inability to respond effectively (lack of a strategy bank), or inability to self-advocate. Once you've identified these type of issues, you can argue that these social skill deficits should be addressed as social skill goals and objectives in the IEP.
9. Develop a plan targeting your child's level of ability. Set up a buddy system in unstructured settings (school-wide). Develop incentives for other kids to participate as buddies (school-wide). Develop classroom lessons to raise awareness of bullying, that will be taken seriously and there will be consequences when students bully (school-wide).
10. Develop IEP goals to address each individual social skill deficit (student-centered). Develop IEP goals to address each individual pragmatic language deficit (student-centered).
10. From a legal perspective, one of the most difficult challenges in addressing bullying in our public schools is that, while many states do have laws on the books regarding bullying, they generally do not include what is called a "private right of action." In English, and summarizing a very complicated legal premise, this means that while the law exists, there is no right to sue someone who violates it under that specific statute. Therefore, parents whose children are being routinely tormented at school who are faced with an administration who elects not to properly address the situation are left to utilize other state or federal laws if they want to find justice in our courts.

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PLAY GROUP

We are going to do another try at our HOTDSN Play group as there are so many new members and an expressed interest in the group!!!

Play group will be for kids birth through Pre-K.

Siblings are welcome to come!

This is a GREAT way to meet other moms and create life long friends.

We will meet in Waco on a weekday morning.

If you are interested in joining us, please email Kim Torres at

kimtorres@hotmail.com.

Include some days of the week and times that would best work for you and we will work on a date and time that works for everyone.!

BIRTHDAYS!



November

Brendan 11/6

Kannon 11/18

Bode 11/22

December

Derek 12/20

Parker 12/20

Aliza 12/31

HAPPY BIRTHDAY!

If I have missed your child's birthday it is because I don't have it. Please send it my way and I will note it in the next issue. Thanks!

A Growing Double Blow: As People Born with Down syndrome , Live Longer many Develop Alzheimer's

By Barbara Brotman <http://edition.chicagotribune.com/Olive/ODE/ChicagoTribune2/>

Jeff Malanoski sat in front of his bowl of cereal, watching "The Price is Right" and forgetting to eat his breakfast.

His sister, Marilyn Long, sat at the table next to him and repeatedly reminded him.

"Why don't you eat your cereal?" she coaxed, reaching over his shoulder to give it a stir. Her husband, Mike Long, sighed. "It takes forever," he said. It didn't used to. Malanoski has Down syndrome, but until a few years ago he ate without prompting, dressed himself and was relatively easy for the Longs to care for in their Elk Grove Village home, as they have for 26 years. For 20 years, he worked as a bagger at Jewel.

Now, however, his sweet smile is topped by short gray hair. He can't eat or dress by himself. He no longer works; he was forgetting how to bag groceries. He no longer knows how to tie his shoes.

Malanoski, 57, lives with a neurological double-whammy: In addition to Down

syndrome, he has Alzheimer's disease.

The two conditions are genetically linked. Even so, the combination was rarely seen years ago because people with Down syndrome usually didn't live long enough to develop Alzheimer's and other illnesses of aging.

But now medical advances have extended the life expectancy of people with Down syndrome, and families are encountering the reality spelled out in figures from the National Task Group on Intellectual Disabilities and Dementia Practices:

Adults with Down syndrome are at high risk for developing Alzheimer's disease, and at an earlier age than the population as a whole. At least 25 percent of those older than 40 have Alzheimer's, and more than 50 percent of those over 60 do, compared with 6 percent of those over 60 in the overall population.

*Continued to next page.

IDEA FULL FUNDING ACT INTRODUCED IN SENATE (SOURCE: CAPITAL INSIDER SEPTEMBER 22ND)

Senator Tom Harkin (D-IA) introduced [S. 2789](#), the Individuals with Disabilities Education Act (IDEA) Full Funding Act, on September 10. This bill would increase spending over the next decade to bring the federal share of funding for special education up to 40%, the amount promised when the law was first enacted in 1975. To date, the federal government has never covered more than 16% of these costs per year. The increased funding would be paid for through increased taxes on individuals earning over \$1 million per year. The House version of the bill, [HR 4136](#), was introduced in June by Rep. Chris Van Hollen (D-MD). Learn more at <http://www.help.senate.gov/newsroom/press/release/?id=49395c2f-ea55-4133-8556-827b2e521a62>

HOTDSN FUNDS HELP RDS GRANTS

Research Down Syndrome (RDS) has announced funding for six grants to support Down syndrome cognitive research.

The 2014/2015 RDS Research Program Grants include:

Johns Hopkins University School of Medicine: "A Down Syndrome Center for Fundamental Research"

Emory University School of Medicine: "The Down Syndrome Cognition Project"

University of California, San Diego School of Medicine: "Defining the Genes and Mechanisms and Treatments for Neurodevelopmental and Neurodegenerative Causes of Cognitive Dysfunction in Down Syndrome"

University of Arizona: "The Neuropsychology of Down Syndrome"

Stanford University School of Medicine: "Mechanisms Underlying the Roles of Sleep and Circadian Rhythms in the Learning Disability of Down Syndrome"

VA Palo Alto Health Care System: "Improving Adrenergic Signaling for the Treatment

The Adult Down Syndrome Center at Advocate Lutheran General Hospital in Park Ridge has been seeing so many families struggling to care for people with Alzheimer's that it recently started a support group, which is believed to be the only one in the country.

"It's clear that our patients are not just the patients, but the family trying to deal with it," said Dr. Brian Chicoine, the center's medical director.

This month, at the group's second meeting, family members sat in a circle and went around the room, describing the increasing toll Alzheimer's is taking.

"She doesn't know her numbers now," said Marian Harrington, whose daughter is 55.

"I was in shock; she could not write her last name," said Meg Kerber, whose sister is 54. "The letters threw her, even when I told her it was a 'B.' "

"I have to dress him. I have to make sure he eats," Marilyn Long said. "He doesn't even know how to change the TV (channel) anymore — and he used to do all that.

"He's losing the ability to do everything he worked so hard to do."

That seemed to encapsulate the sadness around the room. The skills being lost to Alzheimer's were hard-won. The disease was upsetting decades of carefully arranged services and living arrangements.

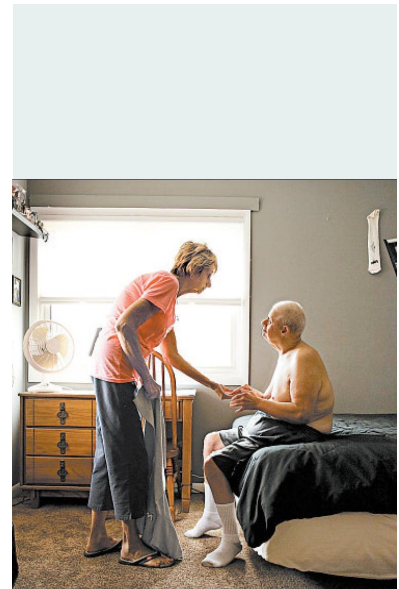
"He's forgetting how to do things that it took him 50 years to learn," said Bill Zermuehlen, father of 50-year-old Chris.

People with Down syndrome have an extra copy of the 21st chromosome, which carries a gene that produces one of the key proteins behind the changes in the brain characteristic of Alzheimer's.

The protein, beta-amyloid, damages brain cells and forms amyloid plaques, a hallmark of Alzheimer's disease, said Dr. Michael Rafii, director of the Adult Down Syndrome Clinic at the University of California at San Diego and a key researcher in the field.

And because people with Down syndrome have an extra copy of the 21st chromosome, he said, they overproduce betaamyloid.

By age 40, everyone with Down syndrome has the neurological pathology — plaques and tangles, which are twisted strands of another protein — characteristic of Alzheimer's. (Article continued online at sourced website.)



Mission Possible Cruise...More than a Boat Ride

The mission statement of Mission Possible Cruise is simple: "Our purpose is to create Down Syndrome Conferences, that are one of a kind, life-changing experiences. We aim to provide parents, caregivers, teachers, school aids, therapists and medical professionals an opportunity to learn proactive solutions to help our loved ones with Down syndrome. Our emphasis is on nutrition, bio-medical intervention and innovative therapies that address real issues and provide viable answers. The unique Cruise Ship environment offers all guests, including adults and children with Down syndrome and their siblings, the extended opportunity to network with like-minded families and professionals and have some fun. You can attend and discuss informative sessions, all while enjoying a fantastic vacation experience.."

But what is more exciting (especially for people like me who do not have the time, energy or money to hop on a cruise ship to learn about Down syndrome, is that most of the sessions are taped and then posted to their website for you to view for FREE!!!

I personally have seen Teresa, Linda and Norman speak in person and they have a wealth of knowledge to teach us...information that tradition mainstream pediatrician simply don't have time to research. For more information, visit: www.missionpossiblecruise.com.



DISCLAIMER - The purpose of this newsletter is to share items of interest relating to Down syndrome and other disability issues. It is sent published by Kim Torres for educational purposes and does not necessarily reflect the views of The Heart of Texas Down Syndrome Network (HOTDSN).

HOTDSN does not promote or recommend any therapy, treatment, institution, professional system, political affiliation etc. and any information contained herein shall not imply such.

MEDICAL SPORTLIGHT

DR. CHRISTINA CHEN

Child, Adolescent and Adult
Psychiatrist

Location: Waco,

Phone: 254-772-2006

While many physicians skip over the related psychiatric issues that come with Ds and many other brush them off as “just Down syndrome”, Dr. Chen has shown always been very concerned with dealing with issues such as ADHD and anxiety without minimizing them because of Down syndrome.

TECHNOLOGY TIPS

Down Syndrome Education International has released two new apps: [See and Learn Saying More Words](#) and [See and Learn Saying Later Words](#). Both are centered around the theme that we can help our kids with their speech by teaching them to read.

[HaveFunLearning](#) makes some awesome educational videos on youtube! We use the sight word, and letter videos regularly, but the science and math videos and songs are great too. The videos are not too flashy and the songs are up-beat popular pop tunes. My favorite is “What do the Letters Say” to the tune of “What does the Fox Say”!!!

IDEAS PLEASE!

Ideas are slowing coming in each month for this newsletter, but I am only as good as the emails I get. If you are interested in a certain topic, email me and I will find an article. If you find a good read, email that to me as well to share. This is after all, OUR newsletter and I so very much want it to reflect all of our thoughts and interests.

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