

# Heart of Texas Down Syndrome Network Newsletter

July/August/September 2015  
Volume 3, Issue 3

## Letter from the Editor

Dear Fellow HOTDSN-ers,

Long time, no write! Literally! While I should have had this issue published nearly three weeks ago, I have found myself falling victim to the endless fun of summer time! Add in the fact that my kids no longer grace with a guaranteed two-hour-long nap time each day, and I find myself trying to get a July issue out by August! Let's just hope the wonderful information in this edition makes up for all the anguish you have felt over my lateness. :) Ha, ha, ha!

Anyways, here's to an edition filled with a Step Up for Down Syndrome Walk preview, Fall Buddy Up Tennis information, a new local column and many great stories!

Kim Torres (kimtorres@hotmail.com)

## Step Up for Down Syndrome Walk

HOTDSN is happy to announce that planning is already underway for the 2015 walk! The event will be held at Hewitt Park on **Sunday, October 11th at 2:30**. Friendship, music, Zumba classes, a local resource fair, free food, music and dancing, a silent auction, carnival games, jump houses and ice cold snacks are all in the works for this year's event. We are very excited to make this event even better than last year's wonderful event!



So, you may be asking, "Why the name change then?" The Buddy Walk, originated as a grass roots movement to raise money and awareness for the National Down Syndrome Society. The name change allows us to make this a 100% local event, giving the members complete control of the event and the funds raised through it.

The new name will be the same event, but with a new energy. The new name will encourage people to "step up" for Down syndrome in ways far beyond basic awareness. We will now be able to focus the event around the needs of our members through local events (like funding Buddy Up Tennis or the iBike Campaign) or supporting other national causes outside of basic awareness (to include cognitive research, Alzheimer's prevention, and educational programs like The Learning Program that help teach students with Ds to read.)

We hope you enjoy the event (and the name change)! If you have any further comments or suggestions, please do not hesitate to contact us!!!

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
- Kim Torres—Newsletter Editor
- Julie Willie—Social Media Director



## SPOTLIGHT CORNER

**Child's name:** Joseph Hoelscher

**Age:** 4

**School:** Holland Elementary School PPCD  
Holland, TX

**Favorite Book:** Turbo and anything Frozen

**One thing no one would know about me:** I go to bed all by myself, I am a big boy now!

**The person/character I would most like to have dinner with:** Any character from Frozen

**Sibing:** He loves his big sister, Jennifer, a bunch!

**Favorite activities:** watching his favorite movies, swimming, being outside, racing play cars and anything train related

**Favorite Food:** popcorn, cupcakes and yogurt/ice cream

**One thing about me that makes my parents so proud:** Joseph's speech is coming along beautifully and with his starting school last year he has improved so much in that area! We only hope to see more growth and better conversations to come!

*"The difference between ordinary and extraordinary is just that little extra."*



### **Join us for the fall season of Buddy Up Tennis!**

The new season starts Saturday, September 12th from 1:00-2:30.

All sessions are held at the Waco Regional Tennis Facility on Lake Shore Drive.

The cost is **FREE** and all athletes are provided a racket.

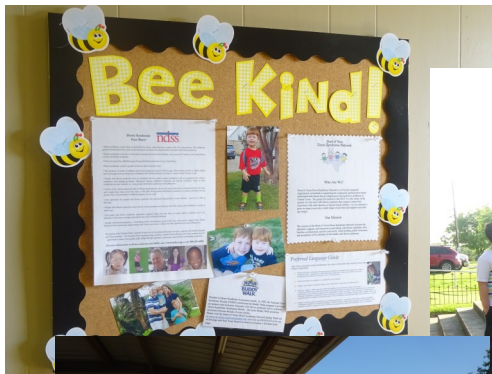
To sign up, email Charlotte Siegmund at [Waco@buddyuptennis.com](mailto:Waco@buddyuptennis.com).

Buddy Up Tennis is a weekly, high-energy 90-minute program focused on adaptive tennis, fitness, and fun for children and adults with Down Syndrome. For more information you can check out their web-site [www.buddyuptennis.com](http://www.buddyuptennis.com).

## Local Church raises money For HOTDSN!

From: The West News

"St. Martin's Church CCE (religious education class) in Tours started a service project this year called "Bee Kind" in which the children collected spare change to donate to a selected organization. The CCE decided to start the project as a way to show the children that small things matter just as much as something bigger and that a little can add up to a lot. St. Martin's CCE raised \$310 to donate to the Heart of Texas Down Syndrome Network in honor of Easton Kadlacek, son of Ronnie and Sherry Kadlacek and little brother of Parker.



## Analysis Ranks Best States For Disability Services

Taken From: Disability Scoop By: Michelle Diamant July 16, 2015

A diverse group of states spanning the nation came out on top in an annual ranking of services for people with intellectual and developmental disabilities.

The [analysis](#) released Thursday by United Cerebral Palsy looks at Medicaid services offered across the 50 states and the District of Columbia.

For the fourth year in a row, Arizona took first place in the listing. Other states leading the pack include Maryland, Missouri, New York, Hawaii, Colorado, Minnesota, the District of Columbia, South Carolina and Ohio.

The ranking is largely based on data from 2013 and assesses a number of factors including how easily services are accessed, what types of environments people with developmental disabilities live in and how much they participate in the community.

Nationally, the report found that 14 states had no institutions, but the number of states where at least 80 percent of people and dollars are allocated to community-based settings fell to 32.

At the same time, waiting lists for home and community-based services grew to 322,000 people.

Top states included those that are both big and small as well as those with high and low taxes. The level of per-person spending on home and community-based services also did not appear to affect a state's odds of faring well in the ranking.

Mississippi came in dead last for the ninth year in a row. In addition, the report calls out Arkansas, Illinois and [Texas](#) for consistently falling at the bottom of the list since 2007.

### NEW AND NOTEWORTHY

Editors Note: The following article was published in the Peoria Journal Star (7/7/2015) and showcases one of my dear friend's son. Wouldn't it be WONDERFUL to get this program in Waco! They also have started iSwim and iDance!!! For more information visit: <http://icanshine.org>.

"Young bike riders get an assist as Easter Seals Central Illinois holds an ICan Bike program at the East Peoria Events Center using modified bicycles with special instructors. Tristen Sanchez, 8, of Dunlap gets help from spotter Dominic Tarantino as Elizabeth "Maggie" Silzer, 13, rides in the background. Participants attend one 75-minute session each day for five consecutive days where they learn to ride, accompanied by a volunteer spotter. After a week of training, most of the 75 students will be able to ride without training wheels .



## BIRTHDAYS!

### 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!

Olivia 7/3

Sam 7/3

Joshua  
7/4

James  
7/11

Michael  
7/12

Graciela 7/12

Katy 8/4

Adam 8/5

Brennan 8/13

Maya 8/18

Charlsie 8/18

Hayden 8/26

Rachel 9/7

Emily 9/19

Jalissa 9/26



## Texas ABLE Act

<http://www.txdisabilities.org/able-act>

The ABLE Act is a federal law passed in December of 2014 that amended the Internal Revenue Service Code to create a tax-advantaged savings option for people with disabilities.

On May 30, 2015, Texas enabled its version of the Act ([SB 1664, Perry](#)). For the first time in history, Texans with disabilities can save money (in their own name) to pay for certain disability expenses without the fear of exceeding the Medicaid individual resource limit of \$2,000.

After the program is implemented, a Texas ABLE account can help individuals lead more independent, self-directed lives and allow family members to help save for their loved-ones' futures.

**Who qualifies?** Any individual who has a significant disability that was diagnosed before the age of 26, regardless of their current age, qualifies for an account. Texans who meet the age criteria and are already receiving benefits under SSI and/or SSDI will automatically be eligible to establish an ABLE account.

**What does a Texas ABLE account do?** A Texas ABLE account is a hybrid savings account with limitations on how much you can save and what you can spend your savings on. Currently a person with a disability can only have a maximum cash savings of \$2,000 (individual resource limit) before they lose their Medicaid coverage. That's where Texas ABLE can provide the most benefit; by allowing an individual to exceed the \$2,000 asset limit and save as much as \$100,000 before having their Medicaid coverage suspended.

**How does the program work?** Each year, an account beneficiary can save a total combined amount of \$14,000 into an individual Texas ABLE account. The funds can come from earned wages, a family member, a friend, or any other source.

For example, a person with a Texas ABLE account might earn \$6,000 throughout the year beyond their personal expenses. They could save that money in their Texas ABLE account. In addition, a grandparent might wish to put another \$6,000 into the account, and the beneficiary's parents might add another \$2,000 to reach the \$14,000 maximum deposit limit. No more money could be deposited into that account that year.

These funds could then be used for a variety of disability related expenses (education, housing (with exceptions), transportation, employment training, assistive technology, personal support services, health prevention and wellness, financial management, administrative services, legal fees, funeral and burial fees and other expenses) to ensure financial stability and that the account owner can live a self-directed and independent life.

**Is a Texas ABLE account for me?** Not everyone needs a Texas ABLE account. Other useful estate planning tools exist that may better suit your personal needs. As regulations become clearer and implementation gets underway, families and estate planners will be better able to weigh which savings method would be best for each individual.

**Where and when can I apply?** The program is still in the early implementation stage. This is a new concept with a series of challenges. Implementation must be cautiously and purposefully planned to best serve Texans. The Texas Comptroller and the Prepaid Higher Education Tuition Board will have their hands full, but we all hope that qualified Texans with disabilities will be able to use the program by mid 2016.

The Texas Comptroller will create a website to educate Texans and to apply for the program. Be sure to watch their website or CTD's website for forthcoming information.



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.



## Five Steps to Becoming Your Child's Best Advocate

### **Start with the assumption that you are an equal partner in your child's education.**

Parents of children with special needs should be involved as equal partners in their child's educational planning. Unfortunately, many parents say, "How can I be an equal partner? I am just a mother or father. I don't know enough to work with all those professionals!" And a parent who feels this way will not "speak up" and be the best advocate for their child.

### **Deal with your perceptions or feelings about yourself as a parent of a child with special needs.**

Understand the grief process and don't let feelings of anger or denial get in the way of your ability to negotiate.

### **Acquire knowledge.**

You don't have to memorize everything about your child's disability, laws, etc. You just need to be aware and know enough to ask questions. You also need to know the resources available that can answer your questions.

#### **YOU SHOULD:**

- know about special education laws including the Individuals with Disabilities Education Act;
- know that special education programs must follow state regulations and that not all issues are controlled by the local school system;
- know how your school system operates, how decisions are made, the people, etc.; and know the sources of information and support in your state including your parent training and information center

### **Improve your skills.**

You need skills to become a better advocate for your child. You need to know how to communicate with others and be "assertive." And you definitely need to know how to ask questions. To become more effective you may also need to write letters and document issues. These skills are important and you can learn them – they just take practice.

### **Participate.**

Finally, the most important thing you can do for your child is to participate. Attend teacher conferences, parent group meetings, school functions. And always go to PPT meetings, give your ideas and suggestions, and negotiate an Individualized Education Program (IEP) that is truly individualized for your child.

### **REMEMBER YOU ARE AND ALWAYS WILL BE YOUR CHILD'S BEST ADVOCATE.**

Article by Connie Hawkins, Project Director, Exceptional Children's Assistance Center, North Carolina

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### **Nike Unveils Show for People with Disabilities**

(Disability Scoop, Shaun Heasley, July 15, 2015)

Thanks to a plea from a teen with cerebral palsy seeking shoes he could put on his feet independently, Nike is introducing sneakers designed specifically for people with disabilities.

Matthew Walzer, then 16, wrote an [open letter](#) to Nike in 2012 [asking](#) the athletic-wear giant to make a more accessible line of shoes that would still provide the support people like him need.



The company said this week that after working with Walzer for three years on testing prototypes, they are introducing an "easy-entry footwear system."

Limited quantities of the LeBron Soldier 8 FLYEASE will be available on [Nike.com](http://Nike.com). Additional FLYEASE styles are in the works, the company said.

## MEDICAL SPORTLIGHT

### MIGHTY TYKES

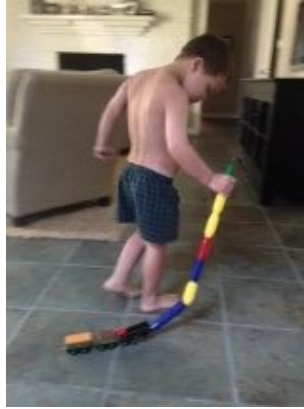
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## You Did It! A Celebration of Local Moments of Pride!

This issue ends with a new beginning! Last week I took this picture of Hayden:



Here, he has just created his first invention ALL BY HIMSELF! I titled it: "How to Pull My Train Around the House Without Sitting Down Using Some Old Toys I Never Play With". Then I thought...how many of us have these moments all the time! These moments that make the hard ones worth it. These moments that make us feel like the luckiest parents around because we know all the hard work that went into it. So, our new column will showcase just that. When you have a moment, simple text (210-884-3608) or email ([kimtorres@hotmail.com](mailto:kimtorres@hotmail.com)) me your picture with your child's name and a "title" for your big event. I will publish as many of them as I can in each issue.

Heart of Texas Down Syndrome  
Network

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