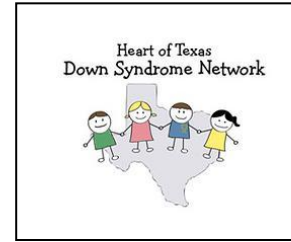


Providing Support for Families in Central Texas.

Board Members:

Alice Kingston –President
Erin Shank – Vice President
Angel Hux – Secretary
Open Seat –Treasurer
Kim Torres – Board Member



Letter from the Editor

Dear Fellow HOTDSN Families,

My name is Kim Torres. My family and I recently moved back to Texas after some time in Illinois and North Carolina. My husband, Scott, and I have two fabulous kids, Hayden (who has the extra chromosome or "Chromy" as we call him) is three and a half and Caroline is our extremely talkative fifteen-month- old.

After being blessed with great support through our local Ds group in Illinois, I knew I had to get involved in Waco. So...here I am...writing my very first newsletter!

It is my hope to publish a newsletter that is worth your time to read on a bi-monthly basis. In order to do that though, I would love to share your stories. Please feel free to email me when you attend a workshop, learn a new teaching technique, find the latest greatest therapy tool or just to share a great achievement. I want this to be a newsletter about US as we all journey down a highway that has some of the highest highs and lowest lows.

So, it is my pleasure to share with you our very first regularly published newsletter! Enjoy!

Kim Torres

Support HOTDSN on World Ds Day!

In this issue:

| | |
|-------------------|---|
| Member Updates | 2 |
| National Ds News | 3 |
| Local News/Events | 5 |
| Educational News | 7 |

Join us as we celebrate World Down Syndrome Day a day early (3/20) at BJ's Brewhouse in Waco or Temple!

World Down Syndrome Day (3/21) celebrates the uniqueness of Trisomy 21 and recognizes the unlimited potential and possibilities of all individuals with Down syndrome

15% of the profits will be given to HOTDSN.

Funds raised will be used to benefit the needs of our local members.

A flyer will be coming for you to present to the server that night.

BJ's locations:

Waco:

5929 W Waco Drive
254-776-0200

Temple:

3550 S General Bruce Drive
254-778-3300

Feel like exercising after you eat at BJ's? Well you are in luck!

The following day you can help raise money for Down syndrome cognitive research by running or walking your meal off in the first ever Virtual Run/Walk supporting Research Down Syndrome.

For more information, simply turn to page 3.



HAPPY BIRTHDAY!



3/9 BeccaBass

3/11 Tobin Davis

4/7 Cohen Williams

4/17 Michael Keathley

If we missed your child's birthday, please email it to kimtorres@hotmail.com and we will honor them in the next issue.

Spotlight Corner!

Meet **Joseph Barney!**
Our first ever Spotlight Member!

Age: 7

School: H.O. Whitehurst Elementary, Groesbeck, TX

Favorite Activities: Digging outside and playing in the rocks

Favorite Food: PIZZA!

The person/character I would like to have over for dinner: Woody from Toy Story

Favorite Book: Toy Story

One thing no one knows about me: I can figure out how to get into just about anything I want.

One thing about me that makes my parents so proud: The joy I find in the small things in life.



Parent Connection

Meet Charlotte Siegmund. She is a HOTDSN mom who works as a realtor in Waco. She has an amazing 21-year-old daughter with Ds who works with her in her office. She is very interested in helping families who have children with special needs find their next home. Give her a call!



Each Office Is Independently Owned And Operated.

CHARLOTTE SIEGMUND
REALTOR®

(254) 644-2149 CELL
(254) 776-0000 OFFICE
(254) 776-4417 FAX
CharlotteSiegmund@jsrwaco.com



JIM STEWART,
REALTORS®
500 N. Valley Mills Dr.
Waco, TX 76710



www.ColdwellBankerWaco.com

Come and Play!

Are you the parent of a young child with Down syndrome?

Would you like to meet other parents in your shoes?

If so, COME PLAY WITH US!

Our first Parents of Young Children Play Date will be March 25th from 9 to 11.

Snacks, drinks toys, fun and good conversation provided! Just bring yourself...and all your kiddos!

Our first meet-up will be at Kim Torres' house for simplicity sake. Please text her at 210-884-3608 to RSVP and get directions! Hope to see you there!



Virtual Run to Support Research

Research Down Syndrome's World Down Syndrome Day Virtual Run/Walk is an opportunity for people across the world to come together to advocate and self advocate for persons with Down syndrome.

Your \$30 registration fee will support research being conducted to develop drug treatments improve memory, learning and communication in persons with Down syndrome. Studies are also aimed at treatments to reduce the impact of Alzheimer's disease in individuals with Down syndrome. Learn more about Research Down Syndrome and the scientific studies the Foundation supports at www.researchchs.org.

The World Down Syndrome Day Virtual Run/Walk can be any distance you want, maybe its 3.21 miles or laps around your block, 321 yards or 21 miles. Get creative, have fun and celebrate WDS. Run/walk whenever or wherever you want. Then post photos of your run/walk and messages on our Facebook page,

www.facebook.com/wdsdrun.

Maybe you can't participate on March 21? You can still support the World Down Syndrome Day Virtual Run/Walk by making a donation at

www.researchchs.org. (Source: www.researchchs.org.)



New Drugs May Transform Ds

(From Scientific American. Jenni Laidman. March 1, 2014.)

“People born with Down syndrome have always been considered to be incurably developmentally delayed—until now. In the past few years a number of laboratories have uncovered critical drug targets within disabled chemical pathways in the brain that might be restored with medication. At least two clinical trials are currently studying the

effects of such treatments on people with Down syndrome. Now geneticist Roger Reeves of Johns Hopkins University may have stumbled on another drug target—this one with the potential to correct the learning and memory deficits so central to the condition.

Down syndrome occurs in about one in 1,000 births annually worldwide. It arises from an extra copy of chromosome 21 and the overexpression of each of the 300 to 500 genes the chromosome carries. “If you go back even as recently as 2004, researchers didn't have much of a clue about the mechanisms involved in this developmental disability,” says Michael Harpold, chief scientific officer with the Down Syndrome Research and Treatment Foundation. But all that has changed. “In the past six or seven

years there have been several breakthroughs—and ‘breakthroughs’ is not by any means too big a word—in understanding the neurochemistry in Down syndrome,” Reeves says.

This improved knowledge base has led to a series of discoveries with therapeutic promise, including the latest by Reeves. He and his team were attempting to restore the size of the cerebellum in mice engineered to show the hallmarks of Down syndrome. The cerebellum lies at the base of the brain and controls motor functions, motor learning and balance. In people with Down syndrome and in the Down mouse model the cerebellum is about 40 percent smaller than normal. By restoring its size, Reeves hoped to gain a clearer picture of the developmental processes that lead to anomalies in a brain with Down syndrome.

Continued on Page 4.

New Drug Therapy



(Continued from page 3)

Reeves's team injected newborn Down mice with a chemical that stimulates an important neurodevelopmental pathway that, among other things, orchestrates cerebellum growth. "We were not in fact surprised that we fixed the cerebellum. That was our working hypothesis," Reeves says. Yet he had not anticipated that three months after treatment the mice with a restored cerebellum would be able to learn their way around a water maze—a function of learning and memory thought to be controlled by another part of the brain, the hippocampus. The researchers do not yet know whether they inadvertently

repaired the hippocampus or whether the cerebellum might be responsible for more learning and memory functions than previously realized.

In fact, other investigational treatments for Down syndrome target the hippocampus—but none target this particular chemical pathway. Reeves's study, published recently in *Science Translational Medicine*, may point to a pharmaceutical intervention that could allow those with Down syndrome to live more independent lives. "The possibility of actually giving Down syndrome people the ability to improve learning and memory significantly—that's something I never thought I'd see in my entire career," Reeves says. "And it's now happening. The game has changed."

ABLE Act Making Waves



The national Down Syndrome Congress has announced that their push in Congress for the passage of the ABLE Act, a law that would, per their website, "amend Section 529 of the Internal Revenue Service Code of 1986 to create tax-free savings accounts for individuals with disabilities. The bill aims to ease financial strains faced by individuals with disabilities by making tax-free savings accounts available to cover qualified expenses such as education,

housing, and transportation. The bill would supplement, but not supplant, benefits provided through private insurances, the Medicaid program, the supplemental security income program, the beneficiary's employment, and other sources. "

To learn more visit www.ndss.org or follow the movement at #PasstheABLEAct.

"It's the small things we do for our families that show our love every day — the sweet treat, the cup of tea, the hug and the "How was your day?"

DOWN SYNDROME RESEARCH & TREATMENT FOUNDATION



Mother's Day
Tea-21 Fundraiser

Because every mother hopes for a brighter future for her child.

In that spirit, and as part of the Tea-21 Mother's Day Fundraiser, we're compiling the Tea-21 Cookbook, an assortment of recipes from the kitchens of our favorite moms: you! We invite you to contribute your best recipes, savory or sweet, to be included in this collection. The cookbook will be sold on DSRTF's website to raise funds for cognition research.

Donating your special recipes to this effort is a simple, personal way to support the innovative research we fund. **All submissions will be entered into a special drawing to win a \$100 gift card**, as a small token of our thanks." (source: DSRTF)

Take advantage of the Children's Special Needs Network!

Our local chapter offers ALL of these great resources!

Saturday Afternoon Respite – CSNN offers four hours of free childcare to children with special healthcare needs and their siblings. We currently offer these center-based respites once a month in Killeen, Temple and Waco.

Diaper Closet – Children with special needs are eligible to receive two packs of diapers twice a month. Please call the CSNN office before you stop by to confirm that we have the size you need available.

In-Home Respite Assistance – If you have a trusted childcare provider to watch your children in your home, you may be eligible for reimbursement of those costs.

Resource Assistance – CSNN has funds available to help you cover medical costs not covered by insurance. These costs include copays, medications, etc. Contact the CSNN for a better idea of what costs may be eligible for reimbursement.

CSNN Library – We currently have many great books for caregivers of children with special needs. Feel free to stop by and browse through our selection. We also have a computer available to use to obtain further information or resources.

Camp Scholarships – Summer will be here before we know it and Central Texas has many great camps for children with special needs or chronic illness. CSNN has a list of camps and may be able to provide a camp scholarship for your child.

Recreational and Social Experiences – CSNN offers many fun recreational and social experiences throughout the year for families of children with special needs or chronic illness. Be sure to be added to our email list, like us on Facebook, and check our website (www.special-children.org) to get information on all of our exciting activities.

All resources and services require certain paperwork and some must be reviewed by our Allocations committee. Please feel free to call us at 254-933-7597 if you have any questions and for step by step instructions on how to take advantage of what we have to offer!

CSNN Upcoming Events:

- [Belton Sensory Friendly Movie \(Mr. Peabody\)](#) – **Monday, March 10, 10am** – Grand Avenue Theater at 2809 Oakmark Drive in Belton
- [Temple Bowling](#) – **Tuesday, March 11, 12:30-3:30 pm** – Spare Time Bowling at 5434 205 Loop in Temple
- [Cultural Activities Center Art Class](#) – **Thursday, March 13, 9:30am** – At the CAC at 3011 N. 3rd Street in Temple. – CSNN will be hosting a class in which each student will make and glaze a clay bowl.
- [Waco Bowling](#) – **Thursday, March 13, 1-3pm** – Westview Lanes at 4565 W. Waco Drive.
- [Play Day](#) – **March 29, 1-4**
Peaceable Kingdome Retreat Center. Killeen. Movies, games, miniature gold, hiking and so much more.

Registration for all events is required. Please register by calling the CSNN office at 254-933-7597.





HAPPY EASTER from the HOTDSN to you! We would love to share your pictures from the big day. Email them to kimtorres@hotmail.com to be published in our net newsletter.

BEHAVIOR MATTERS!

HOTDSN March Parent Support Meeting

We are happy to introduce Torey Lewis from Focus Behavioral Associates to present at our next Parent Support Meeting. Focus Behavioral Associates provide clinical-based Applied Behavior Analysis (ABA) techniques to treat and enhance the lives of children and adults with socially significant behaviors. Focus Behavioral Associates work to assess their client’s strengths and weaknesses—to learn what helps the client, and to understand the priorities—in order to establish the key goals of therapy. They then develop an individualized behavior program to address target behaviors and outline the skills that client needs to develop (e.g., compliance, communication, play skills, toilet training, cooperation and turn-taking, transitioning etc.).

Torey will equip us with strategies for dealing with difficult behaviors. At the end of the presentation there will be Q&A time for any concerns you may wish to know more about.

When: Saturday, April 5th 2-4pm

Where: Hope Therapy (6701 Sanger Ave, Waco, TX 76710)

Child care provided with RSVP to 254-230-9782.



Challenger League Baseball

Who can play? Any mentally or physically challenged boy or girl who is eligible for school ages 5 – 18 (age 21 if enrolled in HS).

Teams are determined by skill level and ability, not age. Each player is placed on a team suited for his or her capabilities. The CHALLENGER DIVISION will allow the player to hit off a “tee”, play coach pitch or player pitch.

There is no registration fee. Each player should provide his own glove, shorts/pants, socks and shoes. The sponsor will provide a hat and shirt.

Tryouts will be on Saturday, March 22nd at the Challenger Field. If there is bad weather that day, tryouts will be March 29th. New Players Tryout at 9 am. Returning players tryout at 9:45 – 11 am.

Games are played at the Challenger/Don Deatherage field. This field is located at Lake Air Little League (behind Fields 4 & 5). It is close to the City of Waco Recycling Center.

For more information or registration packet, contact Coleen Ostrom at 254-723-3828.

Teach your child to read and improve SPEECH!

Having problems with speech? Try teaching your child to read!

It may sound crazy, but it works!

The Learning Program of the Down Syndrome Foundation of Orange County is a research based reading and math program that can not only help your child learn to read, but also to speak better.

The program is based around the idea that our kids learn to read FIRST

through sight words and then LATER through phonics.

We (this is Kim Torres speaking now) started using this program when Hayden was 16 months old. He was sight reading words before age two because of it. And while his expressive language skills kept him from saying all of the words, he was definitely building a lexicon of words in his brain to use later in life. Once the speech started flowing, we couldn't stop him from talking!

If you are interested in learning more, please visit their website at www.dsfo.org/learning-program. Here you will find great research-based tips for learning and TONS of free materials.

Still don't believe me, visit Hayden on youtube at <http://www.youtube.com/watch?v=cQj2bSDmpW0>. Here he is reading at 17 months old!

Sign Language classes in Waco at last!

My Little Play Place, located at Highway 84 and Hewitt Drive, is please to announce that it is now offering sign language classes based on the popular video series, Signing Time. Please give them a call for more information! 751-9600.



Homework Help One Click Away

Freebies are everywhere on the internet. This is one of the best sites I have found for quality educational materials on every subject you can find! Yes...that even includes our beloved Thomas the Train Engine!

The activities are designed as lap books for your kids, but if you have no urge to ever be a teacher, you can

simply print out the pages and give them to your kids to explore at their own pace. Beats spending money on store bought activities! Best part is that the author has listed activities for all levels of learning!

Check out the sight:

Homeschool Share

http://www.homeschoolshare.com/index_lapbooks_master_list.php



App of the Month

Story Creator
By: Alligator Apps

Create your own books on your iPad/iPhone. Use your own words, pictures, and voice! Great app for teaching reading, listening, speech and so much more.

All Ages.
\$1.99



Follow us at:

www.hotdsn.org

www.facebook.com/

[groups/hotdsn/](https://www.facebook.com/groups/hotdsn/)



Contact us at:

support@hotdsn.org

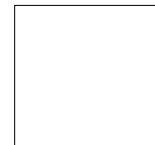
254-230-9782

We need your help!

In order to become the very best Down syndrome Network that we can be, we need your input. Find us new members, send us your stories and tell us about techniques/toys/lessons/games that have made a difference.

Feel free to contact Kim Torres at kimtorres@hotmail.com or Alice Kingston at 254-230-9782.

**HEART OF TEXAS DOWN
SYNDROME NETWORK**
PO BOX 21869
WACO, TX 76702



Believe in the
extraordinary!
