

Heart of Texas Down Syndrome Network Newsletter

September/October 2014
Volume 2, Issue 4

Letter from the Editor

Dear Fellow HOTDSN-ers,

This month's issue is probably our most important read yet. Included in is the most current information on our upcoming Buddy Walk, as well as information to help you enter the new school year with an IEP.

Also I get lots of great articles and activities sent to me via email each month. Only a portion of them end up here as many of them are time sensitive and no longer useful come printing time. For this reason, I am going to start emailing the best of the best resources straight to you. Read them or delete them. It's your choice. If for some reason you do not want me emailing you, just send me an email at kimtorres@hotmail.com and I will remove you from the list.

Enjoy this issue and can't wait to meet you all at the Buddy walk!

Kim Torres

BUDDY WALK 2014

When: Sunday, October 19th 2-5

Where: Hewitt Park

801 S Hewitt Drive

Parking available at Hewitt Park or Castleman Creek Elementary.

The Buddy Walk is our biggest fundraiser with nearly all the money staying local and a small portion going to NDSS to support advocacy projects.

Please see the enclosed flier and registration form for more details.

Also, we encourage you to make a poster of your child to decorate our walk area with. It is a great way to personalize the event. Just bring it with you to registration that morning.

Festivities included dinner from BJ's and a silent auction! Good times, my friend!



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

DEAR ROSEMARY THE LORD JESUS CHRIST IS STILL WITH YOU
USE THE FAITH REST DRILL THE LORD GAVE YOU DOCTHERS
I WILL KEEP YOU IN MY PAYERS I CAN DO ALL THE THINGS THURGH
CHRIST WHO STRNGTHEHENS ME STAND STILL AND WANTCH THE
DEIVERANCES OF THE LORD THIS IS THE DAY THE LORD HAS MADE AN
REJOCE SERVE HIM IN HAPPINESS LOVE KATY

Katy



SPOTLIGHT CORNER

Child's name: Katy Siegmund

Age: 22

School (if any): Was homeschooled and graduated with the Greater Waco Christian Homeschool Educators in May of 2011.

Favorite activities: Swimming, basketball, field trips, watching Disney movies and musicals

Favorite Food: Hamburgers

Favorite Book: Curious George

Favorite Disney movie: Mary Poppins

Favorite Musical: Annie

One thing no one would know about me: I was made an honorary Aggie on Aggie ring day in April of this year.

Katy is very proud of her brother Mark who graduated from Texas A&M and is now serving as a 2nd LT. in the United States Marine Corps.

The person/character I would most like to have dinner with: George Strait

One thing about me that makes my parents so proud: Katy loves the Word of God and is very good at writing encouraging letters to others. We had a friend recently that underwent heart valve surgery and I ask Katy to write her a letter. I have attached what she wrote. She also wrote the sweetest note to my Mom after my Dad had passed away. I keep copies and put in a special file so I can make a book.

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

TECHNOLOGY NEWS

Ever wished there was a way to search for APPS by therapy or educational skill? Well, your in luck! The Easter Seals, a fantastic organization that needs to make its way to Central Texas, has created a search engine for us! To access it, simply go to:

<http://bridgingapps.org/> and search away!

Editor's Note: I found some great APPS on here. Most of them were low key without a lot of back-ground "noise".



BRIDGINGAPPS®

Antibiotic is potential Down syndrome treatment

July 23, 2014 SPECIALED POST

Using an inexpensive antibiotic, researchers have corrected many abnormalities in a group of brain cells associated with [Down syndrome](#).

The common genetic disorder is caused by the presence of a portion or entire third copy of chromosome 21, instead of the normal two copies, one from each parent. Down syndrome is marked by mild to moderate [intellectual disability](#), physical growth delays and characteristic facial features.

It occurs in approximately [one in 700](#) births in the United States.

Investigators at the University of California Davis School of Medicine and Shriners Hospitals for Children identified the group of cells in the brain which they say plays an important role in the syndrome's abnormal neural development. They are the first to show that an abnormal neural support from these [astroglial cells](#) is involved in Down syndrome.

The researchers induced patient-derived stem cells to develop into astroglial cells and neurons, creating a new model for studying the disorder. They found that an inexpensive antibiotic, called [minocycline](#), corrected flaws in the action between the cells and developing neurons.

The findings appear online on [Nature Communications](#).

The patient derived stem cells, which scientists say are superior to a less complex animal model of the human disorder, will allow them to test potential therapies for Down syndrome. The star-shaped astroglial cells play a role in the transmission of nerve impulses, as well as helping to form the brain's physical structure.

The Back-to-School Assignment for Parents of Special Needs Kids

By Lynne Arnold, From TACA, Talk About Curing Autism, www.tacanow.org, July 11,

It's time to get the kids ready for back to school with new clothes, a fresh supply of notebooks and maybe a cool new backpack. But what about you? Are you prepared for your special needs child to start school? Parents need to do their homework before school gets started.

Even if your child already has an IEP (Individualized Education Program), remember, it's just a "plan." For your child to get the full advantage (and hopefully significant progress) from the IEP, your participation in and preparation for its implementation is critical. Here are 10 homework assignments to help your child to make a successful transition into the new school year:

- 1. Read the IEP.** I know that sounds totally obvious, but many parents over rely on their understanding of what happened at the IEP meeting rather than the document. Like special education attorney Timothy Adams says, "Read it like a love letter and go over each and every sentence." Remember, an IEP is a legally binding document.
- 2. Photocopy the IEP document and go over it with a highlighter.** Make a list of anything ambiguous. Example: You recall the principal at the IEP meeting saying that your child would have a 1:1 aide but it is not in the services listing. Write a letter or email to the special ed director (or your child's case manager) asking for clarification. See www.aboutautismlaw.com for sample letters. Hopefully, you electronically recorded the IEP meeting so that you can transcribe the principal's statement to include in your letter.
- 3. Be sure that you understand how your child's progress is being measured.** Will data be taken on a daily basis? Are notes taken at every therapy session? How and when will you be provided with that information? Ongoing reports about your child's progress are critical for parents to fully participate in their child's education. For some kids, that might mean a daily log that is sent home in the child's backpack or a communication log in the classroom that parents can read daily.
- 4. Schedule a meeting with your child's teacher to review your child's IEP.** This is a great time to provide the teacher with special insight as to your child's learning style, ask questions about homework or provide information if your child is on a special diet. For many children, it is also a good idea for the child to meet the teacher as well as any other service providers. If your child will be attending a new school this is a great time for a tour of the campus to help ease any first-day-of-school anxiety.
- 5. If your child has challenging behaviors, he should have a behavior plan.** Now is the time to also meet with the principal and/or vice principal to discuss discipline (especially if your child is at a new school). It will likely be a lot easier to determine how the school can support your child's behavior needs in advance, than when administrators are reacting to a problem and meeting you and/or your child for the first time.
- 6. If your child is receiving services from an outside agency or vendor, be sure to confirm that a master contract has been signed with the district to avoid any gap in services.** Although your district can provide compensatory education later if any sessions are missed, your child is best served by consistent services from the first day of school. *(Comment, while this does not happen often in TX, it is a good idea to check that the school does not have any therapists' positions vacant. If you are taking your child to private therapy during the school day, inquiry about the district's policy for doing this. Cnoe)*
- 7. Districts are legally obligated to provide transportation if the child's unique needs require it (i.e., child cannot safely and effectively walk to school) and/or the child's IEP places him in a school that is not his neighborhood school.** Unless you prefer to do pickup and delivery yourself, contact the transportation department to ensure your child has been assigned to a bus route. Discuss any special needs like car seats, transitioning at the pick-up/drop-off location or whether an aide will be riding the bus with your child.
- 8. If you didn't accept the district's last IEP offer, the district is legally required to implement the last agreed-upon IEP in the new school year while allowing the child to advance to the next grade.** Your child has a federal right to stay put (with all services and placement) until you agree to a new IEP offer or until the district prevails in a due process hearing. *(Comment - this does not apply in TX. Here the school must offer you another ARD/IEP meeting in 10 days. If you decline that offer or after that meeting the school can implement an IEP over the parents' objection. Prior written notice must be provided to the parents. It is important to indicate on the paperwork, what you agree and disagree with. cnoe)*
- 9. Sign up to volunteer at your child's school (this may involve a background check and/or fingerprinting) even if it means taking off time from work.** This is one of the best ways to see your child's progress and challenges first hand (while providing support to your child's school). This is typically far more effective and insightful than simply doing an observation. Remember, you have the same right to volunteer at school and in your child's classroom as any parent of a regular education child. A district cannot create a volunteer policy that only applies to special education parents.
- 10. Keep up the good work and learn more about your child's right to a Free Appropriate Public Education (FAPE0).**

Partners Resource Network • 1090 Longfellow Dr., Beaumont, TX 77706 Toll Free: 800.866.4726 • FAX: 409.898.4869 • website: www.partnerstx.org

INTERESTING AND TRUE

The oldest confirmed case of Down syndrome has been found: the skeleton of a child who died 1500 years ago in early medieval France. According to the archaeologists, the way the child was buried hints that Down syndrome was not necessarily stigmatized in the Middle Ages. (For more information read Colin Barras' article in New Scientist.

UPCOMING EVENTS

September 19—Mom's Night Out at Painting with a Twist

September 20—Texas Angels Pageant at Midway PAC (see email sent out to register)

October 4—CSNN inKida-ble Conference—Belton (see email sent out for registration)

October 13—BUDDY WALK T-SHIRT PICK UP

October 19—4TH ANNUAL BUDDY WALK—HEWITT PARK

BIRTHDAYS!



September

Jalissa

Emily P.

Rachel S.

October

Rebecca E.

Dylan V.



INCLUSIVE CLASSROOMS PROVIDE LANGUAGE BOOST, STUDY FINDS

BY MICHELLE DIAMENT JULY 29, 2014 DISABILITY SCOOP

For young children with disabilities, the key to mastering language may be surrounding them with their typically-developing peers, researchers say.

Over the course of just one school year, a new [study](#) finds that preschoolers with disabilities who attended mainstream classes with highly-skilled peers were using language on par with their classmates without disabilities.

By comparison, kids with special needs who were surrounded by children with weak language skills remained far behind their typically-developing peers at the end of the school year.

The findings come from a study of 670 Ohio preschoolers, slightly more than half of whom had a disability like autism, language impairment or Down syndrome. All of the kids' language skills were measured in the fall and spring using a standardized assessment.

Children with disabilities in classrooms with highly-skilled peers outperformed those surrounded by the lowest-skilled

youngsters by 40 percent in the spring testing, according to findings published online in the journal Psychological Science.

"In a sense, the typically-developing children act as experts who can help their classmates who have disabilities," said Laura Justice, a professor of teaching and learning at The Ohio State University who co-authored the study.

While kids with disabilities saw a big boost from attending class with children with strong language skills, researchers note that the kids with the greatest abilities did not see any downside from interacting with those who were not as advanced.

"The biggest problem comes when we have a classroom of children with disabilities with no highly-skilled peers among them," Justice said. "In that case, they have limited opportunity to improve their use of language."

The findings highlight the importance of inclusion for young kids with disabilities, researchers say.

CONGRESS WEIGHING TAX-FREE DISABILITY SAVINGS ACCOUNTS

BY MICHELLE DIAMENT JULY 24, 2014 DISABILITY SCOOP

A long-stagnant bill that would establish a new way for people with disabilities to save money without jeopardizing their government benefits is starting to make its way through Congress.

The legislation known as the Achieving a Better Life Experience, or ABLE, Act would allow people with disabilities to create special accounts where they could save up to \$100,000 without risking eligibility for benefits like Social Security. What's more, under the plan, individuals would not lose Medicaid coverage no matter how much money is deposited in the proposed accounts.

A U.S. Senate hearing Wednesday marked the first step in Congress for the bill which has been under consideration since 2006.

Under the proposal, individuals with disabilities would be able to create ABLE accounts at any financial institution. Modeled after the popular 529 college savings plans, funds deposited in ABLE accounts could be used to pay for education, health care, transportation, housing and other expenses. Interest earned on savings within the accounts would be tax-free.

Editor's Note: For full article visit: <http://www.disabilityscoop.com/2014/07/24/congress-weighing-savings/19545/>

COUPLE WALKS THE LENGTH OF ENGLAND TO IMPROVE EDUCATION FOR CHILDREN WITH DS

On June 14th, Sir Christopher and Wendy Ball completed a remarkable walk from the south coast of England to the border with Scotland, covering over 400 miles to raise funds to improve education for children with Down syndrome. Source: Down Syndrome Education International

Craniosacral Therapy Shows Benefits

Craniosacral therapy is a light touch manual therapy that addresses restrictions of the body's central nervous system. The craniosacral system is membranes and fluid that surround and protect the brain and the spinal cord. This vital system extends from the bones of the skull, face, and mouth, which make up the cranium, down to the sacrum, or tailbone area. The craniosacral system directly impacts the central nervous system, and imbalance could cause any number of sensory motor or neurological disabilities. Craniosacral therapy helps correct those restrictions so the body can release the effects of stress naturally. Children who could benefit from craniosacral therapy include those with brain dysfunctions, central nervous system problems, traumatic birth processes and developmental delays, just to name a few.

Craniosacral therapy is performed on a fully clothed body using light touch, generally no more than the weight of a nickel. The therapist uses delicate manual techniques to release problem areas and relieve undue pressure on the brain and spinal cord. The therapist monitors the rhythm of the craniosacral system to detect potential restrictions and imbalances. Craniosacral therapy sessions for children can last from 15 minutes to 60 minutes, depending on the child's tolerance and need. An initial evaluation is conducted and often the problem can be corrected in 4 to 6 treatment sessions. (An initial evaluation can often be enough to correct a problem). The optimal result of craniosacral therapy is a central nervous system free of restrictions and a body that is able to return to its greatest level of performance.

Craniosacral therapy is often very beneficial with children who have self-regulatory and modulation problems. Conditions that may be improved in newborns treated with craniosacral therapy are colic, seizures, strabismus, torticollis, chronic otitis, dyslexia, aphasia, spasticity, Down syndrome, Autism and failure to thrive syndrome, as well as many others. Craniosacral therapy is a non-invasive and soothing technique to help restore function to the central nervous system and help children function to the best of their ability.

Source: <http://kidspeech.com/specialized-treatment-methods/craniosacral-therapy.html>



Nordstrom Spotlights Models With Disabilities

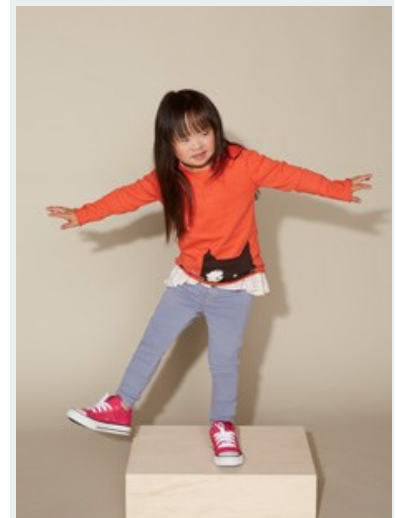
By [Shaun Heasley](#) July 18, 2014 From Disability Scoop Newsletter

To hype its trendiest looks for fall, Nordstrom is turning to models with various disabilities clad in everything from designer boots to kids' fashions.

Four people with disabilities grace the pages of the upscale department store's current anniversary sale catalog promoting the retailer's biggest sale of the year.

Among those pictured in the 88-page book are 7-year-old Emilia Taguchi, who has Down syndrome, and Jillian Mercado who models boots while seated in her wheelchair. Alex Minsky, a veteran with a prosthetic leg, is featured sporting Nike running shoes and Shaholly Ayers, who was born without her right arm below the elbow, spotlights a Dooney & Bourke bag.

For the retailer, inclusion is simply good business, said Tara Darrow, a Nordstrom spokeswoman who indicated the company has used models with disabilities since 1997.



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

HOTDSN
is spreading...socially!!!!

Julie Willie, fellow HOTDSN member and mother to Liam is taking on the role of social media director for HOTDSN!

We could not be more excited! You will now be able to follow us on Facebook, Twitter and Pinterest.

Stay tuned for more information coming your way!

HOTDSN MAKING A DIFFERENCE ONE SCHOOL AT A TIME

This month HOTDSN handed out its first ever grant to Waco ISD's, Crestview Elementary. The Rebecca Ellis Educational Grant, named after one of our newest members, is given to a school each year to increase the school's knowledge of inclusion. Crestview chose to use their \$500 grant to purchase a set of books for professional development. The book entitled, The Blind Advantage, by Bill Henderson, details how his journey as a principal who goes blind and how this experience changed his view on the importance of inclusion. The staff is excited to get started!

If you are interested in your school winning the 2015 grant, or if your school may be interested in completing the above book study when Crestview is done, please email Kim Torres or Alice Kingston for more information.



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Network

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