

# TX Sense Abilities

A Quarterly Publication about Visual Impairments and Deafblindness for Families and Professionals

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*Texas School for the Blind and Visually Impaired, new main building*

A collaborative effort of the Texas School for the Blind and Visually Impaired  
and the DARS Division for Blind Services

## **This is What It Looks Like...**

By Catherine Allen, parent and blogger of Thoughts from the Positive Side, Plano

*Abstract: The author shares her daughter's experience turning what most people would see as a barrier into a detour for finding her unique talents.*

*Keywords: Family Wisdom, Self Determination, Recreation & Leisure, Charge Syndrome, deafblindness, sign language*

Editors' Note: Catherine Allen is the author of the blog, Thoughts from the Positive Side: For those who choose to live of the Positive Side on their Circumstances. She has graciously given us permission to reprint one of her recent posts that highlights what it means to live on the positive side of life. To read more, please visit her at [www.onthepositiveside.wordpress.com](http://www.onthepositiveside.wordpress.com).

As many of you know, my daughter is a Rock Star! Not only does she ROCK as an inspiring person, she literally wants to be a ROCK STAR...along the lines of Hannah Montana or Katy Perry.



photo of Rachel Allen dressed like a rock star

At the beginning of the Summer of 2011 Rachel decided to enter an idol contest at the International CHARGE Syndrome Conference. Of course, she decided she wanted to sing and dance! She had about 3 months to choose a song, create her dance moves and learn the song. She was so excited! We downloaded all kinds of songs onto her iTouch so she could learn and practice, practice, practice! She would get out her microphone stand, put on her Hannah Montana wig, get in front of the mirror and crank up the songs. This is what she does for fun. For years, she has carried her microphone with her everywhere...in the car, in church, to Camp Summit, to school, to the grocery store...just in case a song came on that she needed to rock out to.

Yes, she is an entertainer at heart and she has big dreams! If you know me and my daughter, you're aware that we just don't buy into the whole idea that something can't be done. I am a fan of fueling people's dreams. I'm very much a realist, but only so I can clearly see what the obstacles are and what I'm up against. Obstacles certainly have nothing to do with whether or not something is doable. Obstacles are more like road signs that say Detour: Go this way Instead. Yes, they are frustrating and can be time-consuming. They are often discouraging, especially when you really, really, really wanted to go that way. But, I believe even the obstacles that block my path are a gift to me. I will confess to you now, that as I watched Rachel practicing every day, I became concerned for her and her dreams.

For those who don't know, Rachel is functionally both deaf and blind. But her deaf/blindness wasn't an obstacle in this situation. The two areas that gave her problems were her balance issues and her airway/tracheal issues that cause her to need a trache tube. I think we could have eventually adapted her choreography so she could have successfully pulled it off. But when she sang, she just couldn't make it through the song without going into coughing episodes and spasms. I watched this for several months until one day after practice, I saw that she was so exhausted from coughing and also frustrated. I had decided that as long as she enjoyed herself and loved performing, that it was good enough. But this day, I knew that she was facing reality, her obstacles, and she had become discouraged. She sat in my lap and I told her that I didn't think she would be able to sing and dance at the conference. "Maybe you can just dance?" No, she wanted to sing. She wanted to sing like Hannah Montana, like all rock stars, she wanted to be like everyone else. We sat together for a long time; her limitations and her discouragement circling around us. I looked around the room and saw that she had set her Teletubbies in front of where she practiced, as an audience. I said, "Your Teletubbies are wondering why you're upset." So she started to explain to them in sign language. "I can't sing. It makes me cough, cough, cough, so I can't sing. I'm sorry. (shrugging her shoulders) I can't sing anymore." I thought I was going to cry. And that's when I saw the Detour sign.

"What if," I said to her, "you signed the song instead? Without using your voice. Your Teletubbies need an interpreter so they can understand the words." (so thankful the Teletubbies can become deaf when necessary.) She wasn't thrilled about the idea but she tried it. She made it all the way through the song without coughing. I said to her, *"That was beautiful! You know what? Almost everyone can sing with their voice, but you know a different language so you can also sing with your hands! Not everyone can do that! That's really special."* She started practicing signing songs every day and watching people sign songs on YouTube. She loved it!

You know, I talk about "Living on the Positive Side" because sometimes there are circumstances that we cannot change. Sometimes, we just don't get to be like everyone else. We have unique challenges that make us different. It's easy to give in to self-pity. It's okay, I encourage it, as long as you are aware of what you're doing and call it what it is. "I'm having a pity party today." It's all good. Because you recognize that it is a temporary condition. It's when you begin to tell yourself lies that I'm concerned with. "I'm not as good as them because I'm different." "I suck as a person because I can't do something." Living on the Positive Side is about choosing a perspective that supports your unique brilliance. It's about looking for the Detour signs and acknowledging them as a gift. Your limitations keep you from being average. They create obstacles that can lead you to the discovery of a talent, a service, a strength you didn't know you had. And that is something to be thankful for. Living on the Positive Side is about being thankful, even for the obstacles. I really think that's what the Thanksgiving season is really all about. It's great to be thankful for all the good stuff in your life. But if you really want to experience the power of gratitude, begin to recognize that most of the bad stuff we complain about can be seen as gifts that guide us to answers we may not have otherwise discovered.

The best part of this story is that Rachel has become somewhat of a role model for other girls with similar challenges. Rachel has given them the hope of being able to sing and perform, too. Something they might have dreamed of, but didn't know could happen. If a deafblind multi-handicapped child with CHARGE Syndrome can be such an inspiration just by choosing to Live on the Positive Side of her circumstances, imagine what you can do. Just this week, Rachel told me, "I don't sing with my voice anymore. I sing with my hands." There was no grief or discouragement in her words, only pride and confidence. She had faced reality and let it lead her to her brilliance.

Living on the Positive Side...this is what it looks like on YouTube:  
<http://www.youtube.com/watch?v=oO3TFT4RguA>

## **A Parent's Voice: What Should You Do if Your Blind or Visually Impaired Child Is Bullied**

By Susan LaVenture, National Association for Parents of Children with Visual Impairments (NAPVI) Executive Director, Watertown, MA

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<http://www.familyconnect.org/blog.asp?BlogID=1>

*Abstract: Susan LaVenture, NAPVI president, blogs about what it's like to be a parent, how to advocate for your child, what new resources she's found, and much more. Several disability organizations promote awareness of bullying during Bullying Prevention Month by offering resources on their websites.*

*Keywords: Family Wisdom, bullying, visual impairment, blind students*

Bullying, and how to prevent it, is an issue that has confronted schools and families across the country. It is especially a concern for families of children with disabilities, including those who are blind or visually impaired, who may be perceived as vulnerable and therefore a target for bullying and teasing by their peers. "What Should You Do if Your Blind or Visually Impaired Child Is Bullied" offers 10 guideposts for families and schools to address the issue. A copy can be downloaded at [http://www.dcmp.org/ai/bullying/blv\\_web.pdf](http://www.dcmp.org/ai/bullying/blv_web.pdf)

To promote awareness of the issue, the PACER Center's National Bullying Prevention Center has designated October as National Bullying Prevention Month. The National Bullying Prevention Center, whose goal is to engage and educate communities nationwide to address bullying through creative, relevant, and interactive resources has organized resources and events for this month. A listing of these resources and events may be found on its website in recognition of National Bullying Prevention Month. <http://www.pacer.org/bullying/nbpm/>

In addition, the Described and Captioned Media Program (DCMP) has made available several resources, including tip sheets and videos, for families and teachers on its website at [www.dcmp.org/bullying](http://www.dcmp.org/bullying).

We are grateful for the organizations that have focused on the topic of bullying and worked on developing helpful resources for families. We'd like to invite families and children to share their experiences with bullying and their own tips and advice on how to

face their unique challenges by replying to this blog. To reply go to <http://www.familyconnect.org/parentsitetimehome.asp> and join.

## **WHAT SHOULD YOU DO IF YOUR BLIND OR VISUALLY IMPAIRED CHILD IS BULLIED? 10 GUIDEPOSTS TO HELP STOP BULLYING**

A child with visual impairments faces unique challenges in keeping pace with his or her sighted peers. Add bullying to the mix and you have a problem that can be overwhelming for the student, the parent and the school staff. The solutions are as varied as the classmates, schools and communities where the bullying occurs. Here are 10 guideposts to help stop bullying.

What is Bullying?

Bullying is when someone repeatedly hurts or threatens another person on purpose. Bullying comes in many forms. It can happen in person, in writing, online, on cell phones, in school, on the bus, at home — anywhere. Wherever it happens, it's NOT acceptable.

### **PREVENTION**

**1. Recognize that bullying happens to visually impaired kids:** Many people cannot conceive of the idea that a blind or visually impaired child would be the victim of bullying. Unfortunately, children with glasses are traditionally the first individuals to be marked by bullies. The University of Bristol conducted a 2005 study that showed children with glasses are bullied 35 to 40% more than children without glasses<sup>1</sup>. Bullies perceive those with any amount of visual impairment to be weak and therefore a prime target for their aggression.

**2. Be alert that bullying might be happening to your kid:** Since children with special needs often occupy a lower social standing among their peers, they lack a support system—which the bully recognizes. Bullying can go unreported because children with disabilities often struggle with self esteem issues. They may fail to report the abuse due to their feelings of intimidation, humiliation, or embarrassment. It's important to speak with your child about bullying. Tell your child in no uncertain terms that bullying should never be tolerated and there is no shame in reporting it.

**3. Make sure your child's school knows the specific problems your child faces when being bullied:** Establish a rapport with your child's teacher and principal. Educate them to the nature of your child's visual impairments and to your child's strengths and vulnerabilities. For example, if your child has had food thrown at him in the cafeteria, school staff should be on the lookout to prevent recurrences.

**4. Teach your child to be a self-advocate:** Teach your child that she has a lot to offer

both classmates and school. Encourage your child to get involved with her peers. The more friends your child has, the less likely bullies will target her, since bullies tend to victimize loners without a support network. Encourage your child to speak out when something seems wrong. If she is perceived as having a strong character, that is often enough to discourage a bully from targeting her.

**5. Beware of cyberbullying:** The cyberbully uses the Internet and social media tools to harass his victims. Matthew Kaplowitz, co-author of *How to Talk to Your Kids About Bullying and School Violence* and producer of digital media for students with disabilities, recommends that you oversee your child's computer activities. "Consider installing Internet security filters. They will help you regulate your child's online experience. Check text messages to make sure that offensive messages aren't being sent to your child. Teach your child never to reveal personal information online."

## **INTERVENTION**

**6. Be supportive:** If you discover that your child is being bullied, don't wait. Speak to her about it immediately. Listen to your child's feelings. Be understanding and supportive. Explain that they are not responsible for being bullied nor is there any shame in being bullied—bullying must never be tolerated. Share a story about how you or someone you know was bullied. You are also likely to have strong feelings in the matter, but try to generate an impression of calmness. This is your child's experience—and it's a very personal experience.

**7. Gather information:** Find out everything you can about the incident(s). Who was involved? What led up to the altercation? How long has the bullying been going on? Learn about the school's anti-bullying policy. Get all your facts organized so you can approach the situation efficiently and effectively.

**8. Communicate your concerns calmly with the school:** Positive communication is usually the key to getting results. Approach your child's teacher and the parents of the bully in a calm, objective manner. Let your demeanor show that you are just there to find a practical solution to an unfortunate problem. The other parties involved might respond defensively if they feel you are angry or judging them. You are all going to have to work together on a solution, so eliminate resistance before it begins by communicating calmly.

**9. Be persistent:** Bullying is not to be tolerated after it has been discovered and reported. If the bullying continues and your child's teacher doesn't rectify the problem in a prompt fashion, do not hesitate to take the matter to a higher authority. Alert the school's guidance counselor or principal. If this fails to bring satisfaction, notify the district supervisor. You probably won't meet such opposition but always be prepared to take your grievance up the 'chain of command'. Keep a written record of all the communications and conversations you've had with teachers and school staff or school

administration.

**10. Utilize your child's Individualized Education Program (IEP):** If the bullying of your child is based on his visual disability and the harassment is interfering with your child's learning, the school is legally obligated to stop the persecution. Your child's school is also required to provide supportive services that address the effects of the bullying. Set a meeting with the IEP team to collaboratively figure out an anti-bullying action plan.

Final Word: There is no quick fix to the problem of bullying. It is a serious situation that requires the ongoing involvement of family, school staff, and community members.

Once you have come to a resolution, share your experiences with the special needs community. We're all in this together and the more information that is available, the easier it is for everyone.

## **RESOURCES AND RELATED LINKS**

Bullying and the Child with Special Needs: A website that offers a comprehensive report and online resources regarding bullying and children with disabilities. <http://www.abilitypath.org/areas-ofdevelopment/learning--schools/bullying/>

Horwood J, Waylen A, Herrick D, Williams C, Wolke D, no shame attached to reporting it. ALSPAC Study Team. Common visual defects and peer victimisation in children. *Investigative Ophthalmology and Visual Science*. 46: 1177

National Bullying Prevention Center: A website created by PACER, a parent training and information center for families of children with disabilities, to address bullying through educational, creative, and interactive resources. [www.pacer.org/bullying/](http://www.pacer.org/bullying/)

Stop Bullying: Speak Up: A website, produced by the Cartoon Network that educates kids about the problem of bullying and encourages them to spread the word about bullying awareness and prevention.

[www.cartoonnetwork.com/promos/stopbullying/index.html](http://www.cartoonnetwork.com/promos/stopbullying/index.html)

StopBullying.gov: A website that provides information from various government agencies about how students, parents, educators, and community members can prevent or stop bullying. [www.StopBullying.gov](http://www.StopBullying.gov)

This article was prepared in collaboration with the National Association for Parents of Children with Visual Impairments (NAPVI), [www.spedex.com/napvi](http://www.spedex.com/napvi), Hands & Voices, [www.handsandvoices.org](http://www.handsandvoices.org), and Bridge Multimedia, [www.bridgemultimedia.com](http://www.bridgemultimedia.com).

## Living the Good Life

Jean Robinson, TSBVI VI Outreach Family Support Specialist

*Author's Note: This article is a combination of an article reprinted with permission from "Businessman receives award for motivating others" by David Ball, Reporter with The Orange Leader and from an interview with JoAnn Priddy, mother of Brett Simpson*

*Abstract: A young man with deafblindness wins The Christian Knapp Great Motivator award for his success owning and operating his own business. His involvement in his local community began as a high school student and has won him recognition. His mother shares her thoughts about their journey.*

*Keywords: Family Wisdom, deafblind, disability, employment*

Brett Simpson is one impressive individual. What's so impressive about Mr. Simpson is that he is blind and deaf, yet he goes to work every weekday. He owns and operates Brett's Place, a snack bar at the main entrance of the Orange County Courthouse in Orange, Texas. In October 2011, during the annual conference for the Deaf-Blind Multihandicapped Association of Texas (DBMAT), he received the "Christian Knapp Great Motivator" award for his work accomplishments. The award is named after a young man whose life was short but very motivating to others.

Brett and his family feel Orange County should share in his joy. The county employees played a big part in Brett achieving this award. He succeeds Burt Hardwick, a blind man who ran the snack stand for 30 years. The business was already set up for a blind person and it was a perfect place for him. He has an amplification device (FM system) that enables him to hear over environmental noise. He also has a wireless receiver in his pocket that vibrates if a customer has trouble getting his attention. The Orange County Commissioners' Court voted to give the contract to Mr. Simpson and he has been in operation for two years.

JoAnn Priddy, Simpson's mother, said that her son could stay home but he wouldn't like it. "His favorite part of the job is talking to people. He likes visiting and is very social. No matter what he's doing, he will always want to help other people. He's made a lot of friends. It's like a family here," she added. "He's always been independent. He was taught that at an early age," his mother said. He was involved in several activities growing up including his church youth group, a summer job with Camp Fire Boys and Girls and received the Best Camper award at the Lions' Camp in Kerrville. And if that

wasn't enough, Simpson also was given the prestigious Courageous Heart honor from the Diocese of Beaumont. After he graduated from high school in 2006, he attended the Texas School for the Blind and Visually Impaired (TSBVI) in Austin for two years. There, they taught him important skills such as using a tactile grocery list for supplies and reading simple Braille. The school made a video of him working at their snack bar. He also worked in the TSBVI library and at a food bank in Austin.

Mr. Simpson gets up on his own at 5:30 every morning and gets to work by 7:20. His morning routine includes a 30 minute walk on his treadmill. His co-worker, Amanda Dille, gives him a ride to work and he sings in the car the entire time. "I love him," Dille said. "He's a nice boss. He lines me out. He's structured and organized." You also can find him singing every other Thursday at The Barking Dog Lounge on open mike night. Last week, he sang, "It's Five O'clock Somewhere." He sang the same song at the 2011 Lions' Club convention in Beaumont. Simpson is a member of the Texas Federation of the Blind and attends their monthly chapter meeting in Orange. Priddy said the organization is seeking other blind people to join. He has become active in the Community Christian Church attending activities and services twice a week.

Upon reflecting on the last 25 years, Priddy noted that her biggest frustration was training and re-training vision teachers in her local district. Her son had 3 different vision teachers that were new to the field of blindness. Coordinating teacher training fell on Priddy and she felt that she was starting over each time a new teacher came on board. It took time for a new teacher to understand Brett's communication and learning style and for them to form a meaningful relationship. One of Priddy's best experiences was participating in Futures Planning several years ago with Deafblind Outreach Transition Specialist, David Wiley. "It opened my mind up and gave me the chance to dream about all the possibilities. I realized that Brett could do something he loves and have a happy life."



*Brett Simpson with Melanie and Gary Knapp of DBMAT*

## **Texas Chargers Sixth Annual Retreat and Conference**

Debika Ingham, Treasurer of Texas Chargers, Inc.  
and parent of a 4-year-old with CHARGE

*Abstract: The author shares highlights of the Sixth Annual Texas Chargers Retreat, which was held November 4-6, 2011 at Camp Allen.*

*Keywords: CHARGE Syndrome, Texas Chargers, family organization, retreat.*

Texas Chargers, Inc. is a group of Texas families, friends and professionals dedicated to helping children and young adults living with CHARGE syndrome. Our two key goals are to provide an annual retreat to help families access the information and resources specific to the state of Texas and to support the CHARGE Syndrome Foundation in everyway possible. This article serves to share our 2011 progress and some of our 2012 plans towards fulfilling that mission.

Texas Chargers held our sixth annual retreat and conference in Navasota, Texas in early November. We chose Camp Allen in Navasota for its relatively central location (Texas is a mighty big state so central is a big area in itself!), wonderful amenities and our now familiarity with holding a retreat of this size at this facility. This year, November gave us our first real respite from the heat, but temperatures climbed quickly during the weekend. This month also gives families who attend the National Charge Syndrome Foundation Conference some time to gear up for another family reunion – since most of the families of Texas Chargers (and many at the National level) consider one another extended family.

Approximately 30 families and 22 individuals with CHARGE gathered to share our trials and tribulations, to pose our questions, to provide a shoulder to lean on and, most importantly, to celebrate each and every one of our roles in supporting families and individuals with CHARGE. With over 150 people in attendance and 60 volunteers to help with childcare, activities, and other logistics, the 6<sup>th</sup> Annual Retreat was packed with great moments and lots of new approaches to our traditional events.



*Sally Prouty spoke to parents and professionals while kids participated in a variety of activities at the 2011 Retreat and Conference*

The traditional parent panel kickoff for the weekend changed into a CHARGE focus panel which included parents of children with CHARGE but also teen and adult individuals with CHARGE. The viewpoints offered by our younger panelists helped shape a broader and richer discussion about what parents and children go through over the years. With the benefit of hindsight, they also gave advice to parents on how to respect them as individuals first and to view CHARGE as one of many attributes that make them unique. We concluded the evening with a tough discussion about legislative updates. Texas, like many other states has gone through a brutal legislative session where budget cuts threaten to impact the services and support our families receive. We received updates on what changes have been made, what changes are looming, and ways to continue to influence the decision with our lawmakers in Austin. The importance of finding and keeping important resources on hand is something our keynote, Sally Prouty, is well aware!

Sally Prouty shared the story of her 30 year quest to ensure her son with CHARGE syndrome had access to quality medical, educational, and social services. She has been instrumental in defining, developing, and coordinating services for deafblind individuals including intervener services. After paving the road herself in many cases, she offered a presentation on “How to Get What Your Child Needs by Being Respectfully Demanding.” She stressed the importance of understanding and building relationships with the other stakeholders in your family’s success. The key is how to go about demanding what you and your child need without alienating those people that hold the resources in their hands.



*Sally Prouty highlights Minnesota, the last of many stops along the way to find and often create the right environment for her son's education and wellbeing.*

One of the great things about Texas Chargers is how vested the agencies themselves are in our mutual success. We have many individuals from the Texas School for the Blind and Visually Impaired (TSBVI), Texas School for the Deaf (TSD), the various Educational Service Centers (ESC) of Texas, the DARS (Department of Assistive and Rehabilitative Services) Division for Blind Services and the DARS Office for the Deaf and Hard and Hearing supporting us with outreach and information, financial assistance, sign language interpreters, and many of them attend the retreat and conference, too! Their presence helps to keep a pulse on the families and help ensure the families are knowledgeable of not only what resources are available, but how to obtain them.

A few other changes and additions to highlight were mostly geared towards thinking about the individuals with CHARGE and their needs, perspective and talents. We added a sensory room to allow those with CHARGE who were overwhelmed by the bustle of the conference a chance to have a peaceful place for respite. We added a visual simulation station so people could "see" for themselves what vision loss and impairment is like. We had a Cochlear representative on site to answer questions about hearing loss, devices and eligibility, and to demonstrate various conductive devices. One teen liked an upgrade to her bone anchored hearing aid (BAHA) so much she signed, "Everything is so clear, I'm happy now" and ran off with the demonstration device down the hallway! We celebrated the art of living in a world with CHARGE by asking those with CHARGE to enter an art contest.



*Lexi at work creating her first place art for the Texas Chargers Art Show*

The mom's support group turned its focus from the moms themselves and instead worked with a fabulous array of donated scrapbooking material to put together a portfolio for their children with CHARGE to share with educators, family, medical and other communities.

The culmination of our focus on the individuals themselves comes in a special presentation every retreat we call "Star Charger." This year's Star Charger, Rachel Gibson, gave a wonderful multimedia presentation which her mother voiced and she signed along. She shared about her family, her school, her likes and dislikes, and snapshot of the world according to Rachel. That evening, we all celebrated in a family social filled with dancing to a DJ, balloons, face painting, and a chance to smile. Last year's Star Charger, Rachel Allen, gave a encore performance that won her the best of the "Stage" category at National.



*Rachel Gibson, this year's Star Charger, signs along with her presentation. Although she's in the limelight, she turns the focus back on us by taking pictures of the group. She shared that she would love to do photography professionally.*

For those families that could not attend National in Florida this year, Brownie Shott, a foundation board member, gave an overview of this year's conference, logistics for 2013's conference and a highlight of the key goals and plans for the CHARGE Syndrome Foundation.

### **OUTCOMES OF 2011**

As the families packed and made for home, The Texas Chargers board met on Sunday to review business but to also review the feedback from the members. While much of the feedback was positive, we took to heart the constructive criticism and have earmarked time to discuss how to further improve the retreat and conference. One of the most exciting decisions was ways to further our mission to support the CHARGE Syndrome foundation. We've decided to provide all families who attended our conference with family memberships to the National Foundation. We are certain this will provide our families with valuable information provided by the Foundation, help foster increased dialogue with our group on how best to serve the Foundation's goals, and will provide better "numbers" at a National level which helps draw attention to the need for research and additional financial support.

## **PLANS FOR 2012**

With the conference barely behind us, we are happy to announce the date for our 7<sup>th</sup> Annual Retreat: November 2-4, 2012. While planning details for the next retreat are a few months away, we have focused on several areas to help support growth. We have increased our focus on our outbound communication by encouraging our families to stay connected all year with Facebook and working on ways to update our website more frequently. We have a board member who is driving fundraising efforts beyond our traditional means to help grow the resources with which we can deliver a retreat, support our families, and support the CHARGE Syndrome Foundation. We are working with our growing population of teens and young adults to focus discussion on transition and transition planning. We are encouraging families to stay connected with the deafblind community including other Texas organizations like DBMAT, events, workshops, and ways to develop additional communication access. The Texas deafblind census has identified approximately 80 individual students with CHARGE Syndrome from birth to completion of public school in Texas alone. We know this doesn't count adults who are no longer counted on the census and the untold many who are either undiagnosed or who have not come forward for support. We are working with social workers, professionals and educators across Texas to share information on CHARGE Syndrome. Our goal is that none of the families in Texas with CHARGE will travel down this road alone.

## **LEARN MORE**

From the first day we heard of the syndrome (the day our younger son was born), we heard great things about Texas Chargers and the wonderful support group Cathy Springer, President, has created for Texas families with CHARGE. My first phone call with her put me on the path to great doctors, resources, and an open invitation to call anytime for support. My first retreat had me in a puddle of tears – overwhelmed by the fellowship, the stories, and renewed hope for the future. The following year, I watched as my husband experienced the same roller coaster of emotions. This last year, I've tried to give back by joining the board and helping to put together another wonderful retreat.

For more information on this incredible organization, visit our website, [www.texaschargers.org](http://www.texaschargers.org), or join our ongoing discussions and updates on Facebook under the group "Texas Chargers." Our contact information is also on the CHARGE Syndrome website under the "RESOURCES" tab. Feel free to contact myself, Debika Ingham [debikaingham@yahoo.com](mailto:debikaingham@yahoo.com) with comments, questions, or family or professional referrals or to contact any of the other board members listed on our website.

## **TAPVI Talks White Cane Safety Day 2011**

By Michele Chauvin, Houston and Irasema Ramirez, Laredo

*Abstract: Family members of the Texas Association for Parents of Children with Visual Impairments (TAPVI) participated in the national observance of White Cane Safety Day 2011. Hundreds across the state recognized the white cane as a symbol of blindness and a tool of independence. Two families describe their participation in White Cane Safety Day.*

*Keywords: Family Wisdom, white cane, blindness, low vision, TAPVI, parent association*

White Cane Safety Day began as a national observance in the United States in 1961, and it is celebrated annually in October. The event recognizes the achievements of individuals who are blind or have low vision and the important symbol of blindness and tool of independence, the white cane. In Texas, DARS Division of Blind Services sponsored White Cane Safety Day 2011, along with numerous agencies and organizations. The theme this year was "Growing Towards Independence". Several statewide events invited VI families to attend. TAPVI was grateful for the opportunity to help sponsor and support events in Dallas, Houston and Brownsville.

Houston celebrated with an event on Saturday, October 15th, 2011. Blind and visually impaired individuals of all ages and their families marched downtown along several city blocks ending at Discovery Green. The sponsors provided sack lunches, and the event was free. The celebration included music, activities for children, door prize drawings, and opportunities to gather information about valuable resources and services for people with blindness or visual impairments. The Presidential Proclamation was read, which declared October 15, 2011, as Blind Americans Equality Day.

### **HOUSTON WHITE CANE SAFETY DAY**

This year we attended this event as a family (Chauvin). We walked the route with our 10 year old daughter, Lauren, and cheered, "White Cane Day!" She walked confidently with her cane in front, and she paid close attention when crossing city streets. We felt proud of how far she has progressed with her O&M skills. I wondered what onlookers thought about our interesting group, including individuals in wheel chairs, on scooters, with guide dogs, and with white canes, as well as families with infants in strollers, senior citizens, and all ages in between. The group was culturally diverse, as well. What

united everyone was our common determination that despite any ongoing challenges



with blindness and low vision, we all continue growing towards independence.

*Lauren with her dad participating in White Cane Day in Houston*

While Lauren enjoyed a kayak ride on Kinder Lake and lunch with Dad, I visited with individuals and families seeking information. TAPVI had a resource table alongside various blindness and low vision agencies and organizations. Several families stopped and asked questions about their child's education and services. I also spent time visiting with friends and their children and exchanging stories about recent activities, events and achievements. Mostly, I enjoyed connecting families with one another. There is something satisfying about observing a parent while having an "ah ha" moment. When parents meet children who are like their own, they discover others who have similar postures, modes of communication, challenges, interests, and experiences. Suddenly they realize they are not alone, as they connect with lifelong resources for support and information, namely other families with children with visual impairment.

I look forward to next year's event, and I hope you have the chance to join the celebration. Please contact TAPVI and let us know if you have any comments or questions about this important event.

### **EAGLE PASS WHITE CANE SAFETY DAY**

Irasema and our family (Ramirez) participated in White Cane Day in Eagle Pass along

with employees from DARS Division of Blind Services in Laredo. We went to Eagle Pass to create awareness for traffic to stop upon seeing a person trying to cross the street using a white cane. The event was well attended with more than 200 people in Eagle Pass.

A group of students with visual impairments went to City Hall in Laredo to witness the proclamation made by the Mayor Raul Salinas recognizing White Cane Day.



*Irasema Ramirez, Laredo Community College student giving instructions during White Cane Day*



*Consumers participating in White Cane Day with the mayor of Laredo*

## **Becoming a Woman**

Kate Hurst, Statewide Staff Development Coordinator  
Texas School for the Blind & Visually Impaired Outreach Programs

*Abstract: This article provides information to parents and caregivers about preparing themselves and their adolescent daughters who are visually impaired or deafblind for their menses.*

*Key words: Menstruation, sexuality, sexuality education, hygiene, visually impaired, deafblind*

From time to time I get calls from parents who want to know what to do about their daughter's first period. They are often somewhat panicked and unsure what they can do to get ready for this big day. Still many of them have instinctively done exactly the right things to help their daughter be prepared. Here are some of the questions I am asked and some suggestions for what to do.

### **When Will Her Period Begin?**

Most young women begin their periods in the early teen years though some will begin much earlier and some much later. One factor that may help a mother know when their daughter's first period is approaching is the age when she or an older female sibling(s) experienced their first period. Other signs like budding breasts, growth of underarm or pubic hair or regular changes in mood can be another indicator that the time is approaching. The reality is you probably won't know precisely when it will occur. That is why it is a good idea to start as early as you can to prepare.

### **When Should I Start Preparing My Daughter for Her Period?**

It is never too early to start teaching critical concepts and vocabulary such as body parts, private versus public behavior, clothing and hygiene related terms. Depending on the child's ability to understand representations, her visual skills and cognitive skills, a doll can be helpful in developing these concepts.

Ask your teacher of students with visual impairment (TVI) and orientation and mobility specialist (COMS) to include Individualized Educational Plan (IEP) goals that focus on learning critical vocabulary and concepts. Some of these terms may also be taught in health or biology classes, depending on the student's program. Either way, talk with your educational team about the importance of building language concepts that focus on aspects of biology, anatomy, health and hygiene, gender, safety, and sexuality in an

age appropriate fashion.

If possible, visit with parents of older female students with disabilities about their experiences. This will give you information to ready yourself for what is coming and how to deal with the challenges. Your Division of Blind Services (DARS) transition or children's specialist can help you connect with another parent and may also be able to provide ideas and information to you.

There are many materials available to teach young women about their menstruation cycle. Talk to your school's health teacher or nurse to see what they might share. If your child has multiple disabilities, you may want to download a book written by me and my colleague, Robbie Blaha, for DB-Link. It is titled *Introduction to Sexuality Education for individuals Who Are Deafblind and Significantly Developmentally Delayed* and may be downloaded for free. DB-Link also has a list of other articles and materials that can be found at <http://nationaldb.org/ISSelectedTopics.php?topicCatID=20>.

### **What Should I Do? Practical Strategies**

1. Provide instruction prior to your daughter's first period.

By starting in advance of the menses, parents and staff will have the opportunity to prepare the young woman in a positive manner. If your daughter's communication skills are good enough, sit down and talk with her about her period, let her know what to expect. Show her the materials she will use and explain how and when to change. Discuss the physical discomfort she may feel and what she can do to manage it. Help her pack a small supply bag that will fit into her purse or backpack.

If your daughter has multiple disabilities let her become familiar with the pad by wearing one for specific lengths of time on a daily basis. Try out different pads and select the one that is most comfortable for her. Allow her to learn about the pad without experiencing the added discomfort of being in her period for the first time. A young woman's period may bring some physical and emotional discomfort. Dealing with the unusual sensation of a pad may be unacceptable to her, and she may react by pulling off the pad repeatedly when it is first introduced. Should this happen, it will be less stressful for everyone if you are dealing with a dry pad in a private place.

Give your daughter time to practice the new skills involved in changing a pad (e.g. taking the paper strip off the back of the pad, attaching the pad to undergarments, disposing of the pad after it has been used, etc.). If you present these new skills only while your daughter is menstruating, she may not have enough opportunities in those

few days each month to learn independence in the routine.

## 2. Stay matter-of-fact when teaching menstruation management.

It is important to be positive, organized and relaxed. Address menstruation management as if you were teaching tooth brushing and hand washing. This can be a stressful time for your daughter, so try not to make this a big deal. If your daughter has multiple disabilities take care not to teach negative behaviors with this particular hygiene activity. If changing pads offends you or if you view training your child as a waste of time, your daughter may receive a negative message about the activity. Treating a young woman abruptly while helping her or changing pads can make her feel that she has done something wrong. This is not fair to her and certainly not beneficial in developing a good self-concept about her body.

## 3. Help reduce your daughter's confusion.

Sometimes individuals confuse their period with a toileting accident and become distressed. They may keep insisting they need to use the restroom. If your daughter feels the need to go to the bathroom more often, let her. For a young woman with multiple disabilities this is an opportunity to practice changing the pad. Let your reassuring manner tell her that she is doing the right thing. Praise her success and be proud of her independence.

Another area of confusion is related to pad disposal. Your daughter may want to flush it down the commode like toilet paper. Take special care to guide her, hand-over-hand if necessary, to dispose of the pad in the proper container near the commode. You may want to consider purchasing a small trash receptacle with a lid that is used exclusively for this purpose or a wall container like those that are found in most public restrooms. Parents should remember these skills should be practiced exclusively in the bathroom, especially if there are significant developmental delays. If your daughter experiences pad changing in other places at home, she may assume it is appropriate to remove the pad in other places that may not be acceptable. Help her to understand that taking off her sanitary pad is appropriate behavior only in the privacy of the bathroom.

## 4. Handle menstrual problems in a proactive manner.

Before your daughter has her first period, make an appointment to talk with your family doctor or nurse about premenstrual stress syndrome, the need for a gynecological examination and how to assist your daughter in going through that examination. Don't assume this examination is not really necessary. These young women are subject to the same health risks in this area as their peers who are nondisabled.

Keep a record of her periods to detect irregularities that may warrant medical attention. Also, following a round of antibiotics, have your daughter checked for yeast infections which can cause discomfort, especially during her period.

A weekly or multi-weekly calendar allows you to schedule her periods on the calendar. Help her to anticipate her period by going to buy pads at a grocery store. Talk about her upcoming period with her as you review the calendar together. If she does not use this type of calendar, use the bag with the pad as a topic of conversation during her usual hygiene activities. Make things easier for yourself by always having extra pads, latex gloves, and a change of clothing on hand. You can help her pack these items into a backpack for outings or trips to and from school.

Your doctor may suggest giving your daughter aspirin or a Tylenol-like product for the first several days of her period. This can help make her more comfortable, and may head off problems if her communication level prevents her from letting you know she has cramps. There are also birth control methods that can reduce the number of periods or make them milder. You may want to discuss these options with your family doctor or gynecologist. Make sure the school nurse has the necessary information she may need to help your daughter at school.

Some young women may need to change their daily routine during their period. Permission to avoid certain physical activities, opportunities to go to the ladies room or to visit the nurse may be needed. If your child has additional impairments, she may need more time to rest or to complete an activity.

5. Don't expect the day to go as usual.

If your daughter or one of your students is menstruating, both her schedule and your schedule may have to be adjusted. It is almost impossible to maintain the number of activities in a typical day and still find time to teach the critical skills of menstruation management, especially if the child has multiple impairments.

If you as a caregiver are too rushed, you will do most of the work yourself. When that happens an opportunity to gain independence has been lost.

6. When problems occur, try to see the situation from your daughter's perspective.

Find out what the problem is without adding to the young woman's stress. Did she forget her supplies? Has she stained her clothing? Is she teary or emotional? Is she in pain? Be kind and supportive, but also somewhat matter-of-fact. Let her know these are problems that occur for most women and can be handled. Help her find strategies

for herself.

Some young women who are multiply impaired may not want to participate in the management of their period. Consider whether this is a pattern of behavior she exhibits in other situations. Don't put any more emphasis on this activity than you would other types of hygiene activities. If you do, you may set yourself up for a power struggle. You might understand the cause for her unwillingness to participate by noting other activities she does not like. Are there similarities between those activities and the menstruation management routine? For example, does she dislike touching tape or other adhesive surfaces? Does she show some aversion to handling other things that are damp?

Consider the activity's design. Is she experiencing the same sequence of events every time she changes pads? Check with other caregivers that help her with this activity. If they are having the same problems you might help each other in finding solutions. If they are not having problems, you may want to adopt their approach.

7. Share knowledge of your child and the way you do things at home with the educational staff or other caregivers.

Probably the most important thing you can do to help your daughter become independent is to communicate with all of those individuals who support her or assist her in this activity throughout her day. The more everyone takes the same approach to menstruation management the better it will be for your daughter.

Work together to build strategies for supporting your daughter during this time. Most importantly, make sure school personnel are committed to making this experience a valuable learning opportunity for your daughter. Don't be shy about asking for their help. They may have experienced this many times before in their teaching career, while it may be your first time.

## **RESOURCES**

Menstruation and Mental Disability: Advice for Parents of Adolescent Girls. About Kid's Health

website: <http://www.aboutkidshealth.ca/En/HealthAZ/DevelopmentalStages/Tweens/Pages/Menstruation-and-Mental-Disability-Advice-for-Parents-of-Adolescent-Girls.aspx>

Robbie Blaha and Kate Moss, 1999. "Preparing Your Daughter for Her Menstrual Cycle", P.S. NEWS!, Summer 1999, published by Texas School for the Blind & Visually

Impaired, Austin, TX.

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Schwier, K.M. and Hingsburger, D, 2000. Sexuality: Your sons and daughters with intellectual disabilities. Baltimore, MD: Paul H. Brooks Publishing Co.

Sexuality Education - <http://nationaldb.org/ISSelectedTopics.php?topicCatID=20> DB-Link Selected Topics.

## Performance Evaluations and VI Professionals

KC Dignan, Ph.D. Texas School for the Blind and Visually Impaired Outreach  
Professional Preparation Coordinator

*Abstract: A survey about performance evaluations for VI teachers and orientation and mobility specialists. Results indicate that VI professionals are not confident that evaluators understand what they do, nor use the results for program planning.*

*Keywords: performance evaluation, visual impairment professionals, orientation and mobility specialist, teacher of students with visual impairment*

Performance evaluations for all educators have been receiving increased attention in recent years. There are a myriad of approaches and methods for performance evaluations. Most existing systems have been developed around a classroom setting. Regardless of the system used, the primary prerequisite for relevant evaluation is for evaluators is to know what they are evaluating. This is a significant issue.

VI professionals present several challenges to the administrators who evaluate them. Not only are they itinerant, the range of their students and the scope of their job is substantial, well beyond most classroom teachers. Additionally, most administrators have little or no understanding of what VI professionals do. Given that the primary responsibility of evaluators is to know what they are evaluating, this is a significant issue.

Texas School for the Blind and Visually Impaired (TSBVI) wanted to understand whether accurate performance evaluations were perceived as a major issue for VI professionals and, if so, what was the nature of the issue. A survey was developed and posted on the TSBVI website for two weeks. Information about the survey was distributed via various email venues. Not all participants responded to all of the questions. The summary below reflects the data provided by the survey.

### Characteristics of respondents

269 Participants	Years of Experience
67% Texas	0 – 5 years: 23%
32% Non-Texas	6 -10 years: 19%
Certification area- overall	11 - 15 years: 16%

73% TVI  
 8% O&M  
 19% Dually certified  
 Certification area - Texas  
 77% TVI  
 8% O&M  
 15% Dually certified

16 – 20 years: 14%  
 21+ years: 27%  
 Number of VI Professionals in a District  
 1 25%  
 2-3 25%  
 4-6 23%  
 7-10 16%  
 11+ 12%

## RESULTS OF SURVEY

The respondents were asked about the degree to which they agreed or disagreed with a series of five statements and given the opportunity to add additional comments.

I am confident that special education staff who assess my performance understand what I do and why.	Slightly or strongly disagree: 53% Slightly or strongly agree: 47%
I am confident that building (or other non-special education) staff who assess my performance understand what I do and why.	Slightly or strongly disagree: 79% Slightly or strongly agree: 21%
I am confident that my performance evaluation samples the most important functions of my job.	Slightly or strongly disagree: 60% Slightly or strongly agree: 40%
My performance evaluation is a direct extension of my job description.	Slightly or strongly disagree: 55% Slightly or strongly agree: 45%
I am confident that my performance evaluation is used as a road map to help improve my skills and abilities, to prepare me for future and immediate needs and for recognition of excellence.	Slightly or strongly disagree: 63% Slightly or strongly agree: 37%

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Overall satisfaction with performance evaluation system	Slightly or strongly disagree: 62%
	Slightly or strongly agree: 38%

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Additionally, 178 comments generated 12 themes.

Knowledge of VI:	31%	Does own evaluation:	2%
Travel with me:	4%	Uses a VI-specific plan:	4%
Talk with me:	6%	Generally positive:	7%
Scope of job:	11%	Procedural recommendation:	13%
Misalignment with activity &/or instrument:	15%	Evaluation is not used for planning or improvements:	3%
No evaluation:	3%	Referenced testing or state standards:	1%

## REFLECTIONS AND IMPLICATIONS

Robust and appropriate performance evaluations are invaluable for guiding future practices, determining and justifying professional development and understanding where skill deficits and excellence exist. As more and more attention is paid to performance evaluations nationally, it is important that VI professionals receive valid and appropriate evaluations. Many evaluation systems like those used in Texas, focus on classroom teachers and not itinerant or specialized educators.

The survey intended to determine if VI professionals perceived performance evaluations as a challenge. The results overwhelmingly indicate that the majority of the respondents had concerns about their evaluation.

### **1<sup>st</sup> rule: Understand what you are evaluating**

The primary concern seems to be that evaluators are not familiar with the nature and scope of a VI professional's job. While no evaluator can have expertise in all educational domains, it seems clear that campus level and special education administrators are lacking basic knowledge of what, for example, an O&M specialist does.

Understanding what you are evaluating is the first prerequisite for performance evaluation. This seems to be a challenge. One comment from an O&M specialist can be used as an example. A building administrator told an O&M specialist that he only ever saw the O&M specialist working in the halls. Therefore, the hall was considered her classroom and the O&M specialist was assigned to decorate the bulletin boards in the hall. Districts seem unprepared to evaluate itinerant educators.

### **Taking an active role**

Educators have very little say about how they are evaluated. However, if valid and appropriate performance evaluations are to be completed, VI professionals will need to understand and take a more active role in the process. They may not be able to change the system used (PDAS in Texas), but they may be able to inform their administrators.

The Professional Preparation Advisory Group (PPAG) is a consortium of VI educators, administrators and others involved in recruiting, training and supporting new VI professionals. In November, this group started development on an auxiliary tool to empower administrators to be more effective when evaluating VI professionals. Once developed and tested, this guidance document will be posted on the TSBVI website and available to all VI professionals, hopefully in the 2012-13 school-year.

When it is complete it is hoped that VI professionals in Texas will be able to share it with their administrators. VI professionals from other states may also find it helpful.

## **Why Professionals Should Go to the Texas Chargers Annual Retreat**

Holly Cooper, Ph.D., Deafblind Educational Consultant,  
Texas Deafblind Project, Texas School for the Blind and Visually Impaired

*Abstract: a professional discusses her experience at the Texas Chargers Annual Retreat and why other professionals should consider going*

*Keywords: charge syndrome, family conference*

The first time I went to the Texas Chargers Retreat was four years ago when the conference was in its early years. I wanted to learn more about these fascinating students with CHARGE syndrome that I saw in classrooms in my work as a statewide deafblind educational consultant. I learned a lot, had a great time, and I've been back every year. If you are a teacher, therapist, orientation and mobility specialist, or other professional working with a student with CHARGE, I urge you to go to Texas Chargers, especially if a student you know will attend.

For the last three years Texas Charges has had their family conference in early November at Camp Allen, in the piney woods of Navasota, about 80 miles northwest of Houston. Camp Allen is owned by the Episcopal Church and looks like a summer camp which has gradually evolved into a retreat center. Each family has a motel quality room. The camp is wheelchair and stroller accessible, the food is good, and Texas Chargers arranges for child care and activities for the people with CHARGE and their siblings so adult family members are able to attend presentations and support groups.

It's interesting as an educator to watch children with CHARGE in non-school environments. These children and young people were active, curious, and social. Some of them knew one another from previous retreats, and sought each other out again. Many of them had favorite toys or topics that they wanted to talk about and get others to talk about. Star Wars characters, school buses, trains and other vehicles were favorite subjects of drawings, play, and discussion. The more relaxed atmosphere of the retreat allowed them freedom to choose some of their own activities in a setting where no one was trying to make them fit in to a regular routine and stay focused. They didn't have to sit in desks, work on the same task a long time, and they could rest or run whichever they needed to do. Special meals were not provided but it was common to see families tube-feeding their child with CHARGE at the table, or giving them foods like pudding, mashed potatoes, guacamole, or Ensure. During the evening social time, they danced

to loud music, watched strobe and light effects, had their faces painted, and drew pictures with me.

Something many of us who are teachers may not realize is the complexity of the medical issues that many children with CHARGE face during infancy and early childhood years. For most with CHARGE, these years are filled with repeated medical crises and diagnoses of one disability or disorder after another. By the time we see them in the classroom, many parents have been through a lot of grief and fear for their child and are happy to have them still in their lives. I saw this at Texas Chargers again and again. Parents are so happy to meet other people who have had similar experiences. They are glad to be able to talk about their child without having other people avoid them because they don't know how to relate to the experience of a parent of a child with a disability, especially a syndrome as complex as CHARGE. Grandparents are also a strong presence at Texas Chargers, and there are so many consistent grandparent attendees that they have their own T-shirts!

For a few years I have worked with the CHARGE children and youth to make a group quilt which Texas Chargers later offers as a raffle prize. I asked the kids to draw pictures on paper pre-cut to the size of the quilt block using iron-on transfer crayons. I came prepared the first year with a variety of materials, but now I only bring the crayons and paper because they are the favorite of the participants. They are clean, familiar to kids, you don't have to wait while they dry, and they don't make the fabric stiff. One young lady named was a fan of the Teletubbies, her favorite was Tinky Winky, the lavender one. Her friend drew a picture of Dipsy the green Teletubbie to be included in the group quilt. I never saw the Teletubbie fan's reaction to it, but when I realized the drawing was not made by the Teletubby fan, I thought it was really funny. Apparently the artist did too.



A drawing of the Teletubbie Dipsy in green crayon

A young adult woman named Sarah has been a big fan of anime for as long as I've known her, and I've watched her drawings change and become more sophisticated over the years. Last year she told me she had been awarded a trip to Japan to learn about anime from the Make A Wish Foundation. I later heard that her trip was cancelled due to the earthquake and tsunami. She told me this year that she was going to have the opportunity to do the trip to make up for missing it previously. I always like to get a drawing from her; she spends a lot of time making something really creative. The first time she drew for me, I told her not to write her name on the drawing because when I ironed it on the fabric it would be backwards. Since that time, she has always written her name backwards on her picture so it would come out right when I transferred it to fabric.



*An anime style drawing of a cat-like character with the artist's name written in reverse*

I encourage teachers and other education professionals to attend Texas Chargers and the National Charge Foundation conferences. I believe I have learned more that has helped me support students with CHARGE by going to family conferences than I would have learned just going to workshops for professionals. It's truly energizing and instructive to see the young people with CHARGE and their families who have been through so much, but learned to find joy in each other.

## **Big Things to Come at the Texas School for the Blind and Visually Impaired**

William Daugherty, Superintendent  
Texas School for the Blind and Visually Impaired

*Abstract: This article describes how changes at TSBVI's campus are improving and expanding services.*

*Key Words: Texas School for the Blind and Visually Impaired, blind, deafblind, visually impaired.*

For two weekends in November, all of us at the Texas School for the Blind and Visually Impaired (TSBVI) got a taste of what we want the future of our campus to look like. Hundreds of people gathered at the school to share and to learn more about the education of students who are blind, visually impaired, or deafblind. The first weekend attracted a record number of parents of TSBVI students, and the second weekend was the Southwest Orientation and Mobility Association conference—our first time hosting such a large meeting in our new facilities. Both events required exceptional extra effort by TSBVI staff to pull off well, but there was such positive feedback that it energized us and gave us a vision of our new campus as a place where we want there to be a lot of visitors and large gatherings of people with whom we share common interests and goals.

TSBVI is by no means the center of the universe when it comes to serving all of the many visual impairment related interests in Texas, but we are highly committed to do our part given the many resources we have been granted. As an educational field we are relatively small, often referred to as a low incidence disability group. As individual professionals we are often geographically scattered and have limited access to colleagues with whom we can readily share ideas and problem solve. And as parents, we often report that we are isolated on many levels. No other single organization in the state has been given quite the opportunity as has TSBVI to fill in some of the gaps that keep us from truly being a statewide learning community and support network of parents, professionals and individuals who are blind or visually impaired. At TSBVI we are trying hard to make sure everything we do is in service to this concept of statewide mission.

We had hoped that upon the completion of our new campus, scheduled to be in December of 2012, everything would be solidly in place to jump boldly into the future

with technologies that would assist in reaching out to the state with unprecedented efficiencies to address those gaps previously mentioned. In reality, we are still trying to figure out how to operate the lights and to make the water come out, and stop coming out, from our new automatic faucets. Nonetheless, we are closing in on putting into place the infrastructure to make the sharing of information, originating from TSBVI or from others, increase dramatically in quantity and quality. This has proved to be a big learning curve, and not a smooth one. In the meantime, we are putting our best foot forward—primarily our great new meeting spaces and our hospitality.

For most of TSBVI's history, we have been primarily known for the education we have provided to students enrolled at our Austin campus. This will always be one of our primary purposes, and students enrolled in record numbers with us last August. Over the years there has been a steady progression in the school's commitment to serving every student in the state, regardless of where they regularly attend school, as well as providing supports to the families and educational teams of these students. Our continuous growth in outreach services, short-term and summer programs, curricula, our website [www.tsbvi.edu](http://www.tsbvi.edu) and teacher-training partnerships with Texas Tech and Stephen F Austin universities are some notable examples of this progression. But our campus facilities and electronic communications infrastructure have often stood in stark contrast to our desire for our organizational appearance to reflect the quality of the people who work here. That appearance, both in form and function, is rapidly changing for the better. We'd love to have you visit, so give us a call and arrange a tour.

## **Working Together to Provide Quality Services**

Barbara J. Madrigal, Assistant Commissioner, Division for Blind Services

*Abstract: This article discusses the importance of partnership when planning services for Texas children who are blind or visually impaired*

*Key Words: Blind, visually impaired, DBS Blind Children's Program,*

The Blind Children's Vocational Discovery and Development Program (or Blind Children's Program, for short) believes that children who are blind or visually impaired have brighter futures today than at any time in history. The advances in technology makes it possible for them to live, learn and play alongside their peers. Laws are in place to protect their rights to education and access to their communities. There are many excellent resources to help children who are blind achieve their fullest potential. But our work is not done.

The mission of the Division for Blind Services Children's Program is to work in partnership with Texans who are blind or visually impaired to reach their goals. A Blind Children's Program Specialist works with each child and family to create a service plan tailored to their unique needs and circumstances. In order to do this, we must not only work closely with the family, but also with the child's educational/medical team. This is a partnership that includes many people, i.e., the consumer, their family, and educational partners such as VI teachers, O&M specialist, ECI, classroom teachers and other school personnel. It also includes medical partners such as the pediatric ophthalmologist, therapists and social workers.

The goal is for our consumers to reach their fullest potential and to know the joys of contributing to their community and/or their family. This is often accomplished through work—whether it is paid employment, volunteer work or performing appropriate chores in their home. Vocational discovery begins at a very early age. In order for children to grow into independent and productive adults, they need to acquire skills in the areas that we refer to as the Big Six. These areas include Adjustment to Blindness, Independent Living, Travel, Communication, Support Services and Vocational Discovery and Development.

The Children's Program lays an important foundation by providing the support, tools and training that will assist consumers to reach their habilitation goal and become successful adults.

It is the job of the Blind Children's Specialists to assess and plan services for the consumers. We recognize that no two children are alike; therefore, the planned services provided by DBS are based on the individual needs of that child. A good assessment is the key to planning services that benefit the consumer. It provides information on the child's current level of functioning and indicates areas that need additional attention. The Blind Children's Specialists are also thinking ahead to how the child can build on their current skills to reach the next step of their development.

During an assessment, the Blind Children's Specialist will request input from members of child's team. While the parents and family members know the child best, educational partners have the opportunity to see and work with the child in a structured setting, and they have excellent insight into how the child learns and deals with frustrations. Our medical partners have a keen understanding of the physical challenges and medical obstacles the child may face. Everyone comes to the table with their own perceptions and points of reference. Often an individual, viewing the child from their particular point of reference, may miss some of the child's strengths or areas that might need improvement. Perhaps we do not see ways to tweak the plan that will allow opportunities for the child to grow and develop new skills. It is through collaboration with the different team members that all of us are able to put the puzzle together and get a clear picture of the child's needs.

The services that the Division for Blind Services provides are designed to fit the child's individual needs. The range of services is very vast. These services include, but are not limited to: counseling and guidance, individual and group training for children and families, developmental toys and assistive technology, referral to other resources, and educational support which may include classroom observations, and consultations with teachers and attendance at Admission Review and Dismissal (ARD) meetings.

DBS and the Blind Children's Program is committed to building strong bonds with our consumer's educational team. We do this in many ways including routine contacts, collaborating on joint projects, the statewide partner survey and regional partner meetings. To maximize the greatest potential for the child's success, the team needs to work in a cohesive partnership that includes the family, school and DBS. It is important that we work together to clearly focus on enhancing the child's services and ensuring that we do not duplicate services or work at cross-purposes.

We understand and share the belief that school is responsible for the child's educational program as outlined in IDEA. Our agency policy does not allow us to pay for any

service or provide equipment that is the school's responsibility under the Individuals with Disabilities Education Act (IDEA). We are able to provide services and support in non-academic areas of the Expanded Core Curriculum. An example of this is an O&M lesson in the summer so a child can socialize with friends at the mall. When we purchase developmental toys and/or adaptive equipment for consumers, it is with the intention for these items to be used in the home. If DBS has purchased equipment which would be useful in a school setting, we strongly encourage the parent to have discussions with the school personnel to ensure that these items fit into the child's IEP and will be allowed on the school campus.

Only by working closely with our consumers, their family and our partners are we able to design and deliver world class services that encourage and enable our consumers to reach their fullest potential.

**Texas School for the Blind & Visually Impaired – Outreach Program Honors**

**TEXAS FELLOWS**

Recognizing VI Professionals in their Role as Recruiters



<b>Texas Fellow</b>	<b>Candidate</b>
Carol Rimka	Elizabeth Meek
Tressie Schindler	Charlotte McKinney
Sara Baker	Stacy Vance
Theresa Taylor	Tammy Averitt
Kathy Krenek	Julie Stanfield
Karla Cantu	Guadalupe Garza-Brown
Tashia Garcia	Karen Baker
Lani Simonton	Cathryn King
Brian Jones	Trish Duke
Emma Lee Wilson	Harriet Page
Mary Kainer	Kathleen McGann
Cecilia Cox Hayes	Gayla Brown
Myleah Rhynes	Beth Wallace
Pat Harper	Shonda Prater
Barbara Kline	Julia Sohns
Carol Dancy	David Carabajal
Bonnie Rudel	Norma Freimark



For more information about becoming a Texas Fellow or working as a VI professional contact KC Dignan at [kcd@tsbvi.edu](mailto:kcd@tsbvi.edu).

## **American Foundation for the Blind (AFB) 2012 Scholarship Program 2012**

AFB administers seven post-secondary education scholarships for up to 11 deserving students who are legally blind. The following is a list of the scholarships offered. The application deadline for AFB's 2012 scholarships is April 30, 2012.

### **The Delta Gamma Foundation Florence Margaret Harvey Memorial Scholarship**

One (1) scholarship of \$1,000 to an undergraduate or graduate student in the field of rehabilitation or education of persons who are blind or visually impaired.

### **The Ferdinand Torres Scholarship**

provides one (1) scholarship of \$3,500 to a full-time undergraduate or graduate student in any field. Strong preference will be given to new immigrants to the United States, and to those residing in the New York City metropolitan area. To be eligible the applicant must reside in the United States, but need not be a citizen of the United States.

### **The Gladys C. Anderson Memorial Scholarship**

One (1) scholarship of \$1,000 given to a female undergraduate or graduate student studying classical or religious music.

### **The Karen D. Carsel Memorial Scholarship**

provides one (1) scholarship of \$500 to a full-time graduate student in any field.

### **The Paul and Ellen Ruckes Scholarship**

Provides one (1) scholarship of \$1,000 to a full-time undergraduate or graduate student in the field of engineering or in computer, physical, or life sciences.

### **The R.L. Gillette Scholarship**

Two (2) scholarships of \$1,000 each to women who are enrolled in a full-time four-year undergraduate degree program in literature or music.

### **The Rudolph Dillman Memorial Scholarship**

Provides four (4) scholarships of \$2,500 each to undergraduates or graduates who are studying full-time in the field of rehabilitation or education of persons who are blind and/or visually impaired.

Visit [www.afb.org/scholarships.asp](http://www.afb.org/scholarships.asp) for further information and to fill out the application form.

Please direct questions and comments to:  
American Foundation for the BLind Information Center  
Toll-free telephone: (800) 232-5463  
email: [afbinfo@afb.net](mailto:afbinfo@afb.net)

# Bulletin Board

## Announcements/Regional, State, National Training and Events

Mail or email your items for the Bulletin Board to Beth Bible:  
TSBVI Outreach, 1100 W. 45th Street, Austin, TX 78756; or [bethbible@tsbvi.edu](mailto:bethbible@tsbvi.edu).  
An up-to-date Statewide Staff Development Calendar is posted  
at [www.tsbvi.edu/Outreach/vi.htm](http://www.tsbvi.edu/Outreach/vi.htm).



*Back-to-Back*



**TAER/TEXAS FOCUS**  
**March 29-30 and 30-31, 2012**  
**Omni West Hotel, Houston, TX**

This year, in an effort to make both events more convenient and cost effective, TAER and Texas Focus have collaborated to host a combined conference. A single registration site is established so you may opt to attend all or part of the event and pay accordingly.

More information and online registration Google **Texas Focus 2012** or go to:  
<http://www.certain.com/system/profile/web/index.cfm?PKwebID=0x2939696a26&varPage=forms>



## **NATIONAL FAMILY ASSOCIATION FOR DEAF-BLIND**

NFADB 2012 Symposium  
July 13-15, 2012  
"Preparing Leaders for Today and Tomorrow: Leadership in the 21st Century"  
Location: Austin, Texas

Everyone will learn new skills, receive invaluable resources, meet families from around the country and return home with new ideas to help them, their child and their community.  
Parent Leaders are encouraged to apply

## TX SenseAbilities

Published quarterly: February, May, August, and November

Available in Spanish and English on TSBVI's website at <www.tsbvi.edu>.

If you no longer wish to receive this newsletter, please call Beth Bible at (512) 206-9103 or email <bethbible@tsbvi.edu>.

Items to be considered for publication should be submitted by email to the section editors at the addresses listed below, or mailed to:

TSBVI Outreach  
1100 West 45th Street  
Austin, Texas 78756

Deadlines for Submitting Articles  
December 1st for the Winter edition  
March 1st for the Spring edition  
June 1st for the Summer edition  
September 1st for the Fall edition

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