

TX SenseAbilities

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

A Girl with Optic Nerve Hypoplasia....A Beautiful Perspective

By Nancy L. Allen, Parent, Bastrop, TX

Abstract: A mother reflects on her daughter's first four years of life, which includes building community, going through multiple medical procedures, benefiting from early intervention, and enjoying life.

Keywords: Family Wisdom, Deafblind, Optic Nerve Hypoplasia, Early Intervention, Eye Medical, MAGIC Foundation, Texas Parent to Parent, DARS, Division for Blind Services, Hippotherapy, personal reflections

This is the story of my 4 year old daughter, Minerva. She was named after her Aunt Minerva, and we all have nicknamed her "Minnie". The name fits her perfectly, as the name "Minerva" is known as "the Goddess of love". Minnie was born with bi-lateral Optic Nerve Hypoplasia. In addition, she is also deaf in her left ear. Minnie has had a long journey already in just 4 years of her life so far. This little girl might be classified as a child with "special needs", but she is definitely special to me and her family. I want to share her incredible story with everyone, as a message of hope, encouragement, strength, and victory. My daughter Minnie is no ordinary child, as she has already taught me a wealth of knowledge. She is my teacher, and I am the student. I am just so thankful for God giving me the privilege to be her mother. I would never change a thing about her or how everything has evolved.



Minnie was born on April 23rd, 2007. It's a date that was etched into my mind, like my own birthday. That date will always stand out to me when I hear it, because it's the day that changed my life and God gave me another precious gift, a child. Previously, I had another daughter, Jocelyn. She was two years old when Minnie was born. Jocelyn had picture perfect health. So I thought I knew what to expect. I had no idea what was in store for me.

Shortly after Minnie was born, at the age of 2 months old, she was running a very high fever of 106, and I immediately took her into the local ER. The doctor's told me they wanted to do a "spinal tap" on my daughter and make sure what was going on with her. I was deeply concerned but felt comfortable exploring all options. Turns out at this point they found she had mild kidney reflux. She was hospitalized for a week. All seemed okay, and Minnie was prescribed a daily medicine to take for her kidney reflux.

All seemed normal, but I could feel something wasn't quite right. Soon after she was born, Juan and I noticed that both of her eyes would "dance" around at a very rapid pace. We were puzzled and didn't

know what that meant. We didn't have a clue that it was nystagmus. A family member noticed something strange about Minnie's eyes also. That person was Maguis, Juan's niece. She thought Minnie's eyes weren't normal—that her eyes didn't seem to focus on things. It took an outsider looking in to create a sense of concern. She was very perceptive and intuitive with Minnie's vision. Maguis observed the fact that Minnie didn't seem to have a good reflex reaction if an object (i.e.: a cotton swab, etc.) was placed close to her eyes. It struck me as very odd that it seemed Minnie would not blink normally, if at all. Maguis' observation confirmed our fear that there was an abnormality with our daughter. This was an entirely new territory for us as parents. Immediately, we became very proactive in getting all the help Minnie needed.

So soon thereafter I took Minnie to a pediatric ophthalmologist at Riley Children's Hospital in Indianapolis. This is our ground zero, where our lives changed as we knew it. I didn't know what to expect, I just wanted to know something. The doctor examined her eyes, and shortly after told me "She has Optic Nerve Hypoplasia, typically called ONH". He wrote the diagnosis's name down on a blank prescription pad and handed it to me. After he said those words, everything else he said seemed surreal. Part of me wanted to deny what he just said, that my precious little 4 month old baby girl isn't normal and something's wrong. I had my older daughter, Jocelyn with me too that day. I had no idea what an impact this diagnosis would be to our family.

Minnie was around 6 months old when she started to habitually scratch at her left eye. She never was bothered by her right eye, and left it alone. However, her left eye really seemed to bother her. It seemed I tried everything to help or remedy this. I tried putting socks on her hands, eye goggles, eye patches, arm splints, but nothing seemed to really help. At some point, Minnie found a way to poke, press, jab, and scratch at her left eye until it would bleed. It got so bad, that her left eye was scarred. You couldn't see her pretty brown eye color anymore. Instead her left eye was white, opaque and had a rippled texture to it. She was hospitalized for a week and a half from this when she was 6 months old. The doctors wanted to get the left eye calmed down, and they had to give her eye drops every 30 minutes. The ophthalmologist called this scarring on her left eye a corneal ulcer. And over the next couple of months, they performed two eye surgeries to stitch her left eye partially shut. This was done in an attempt to prevent her from scratching at her eye. The fancy term for this surgery is called tarsorrhaphy; and at this point these surgeries were just temporary. Eventually, the stitching was becoming loose; the eye had healed a lot. So the doctor decided to take the stitches out.

Right before Minnie's first birthday, we moved from Indiana to Texas, and by that time her eye scratching started up again and was relentless. I needed good help, and fast. I was terrified, the eye patches weren't working, and every possible remedy was hopeless on my end. I needed a strong, caring pediatric ophthalmologist. Being new to Texas, I didn't know anywhere to start but in the phone book. I discovered there were only 4 pediatric ophthalmologists in the Austin area at the time. I tried them all. All of them seemed to be not accepting "new" patients at the time, or had a long wait list, except for one ophthalmologist. That doctor was Hillary Onan. The receptionist was very empathetic with my concerns for my daughter's eye problems. She briefly consulted with Dr. Onan, and quickly called me back to let me know that the doctor could see Minnie immediately. I was thrilled! Minnie needed excellent care, and she received that. After our first appointment, Dr. Onan

didn't hesitate and had Minnie admitted to Dell Children's Hospital in Austin, Texas. I felt a sense of relief to get more answers for our daughter.

Ultimately, from a week long stay, Dr. Onan was able to bring comfort to Minnie's left eye through eye drop medications, etc. The doctor also implemented a metal eye shield (like an eye patch) to cover Minnie's eye to protect against the reoccurring scratching. It worked! This was just a temporary fix until we saw a pediatric cornea specialist in Houston. We wanted to examine her left eye thoroughly and see if she was a possible candidate for a cornea transplant, and also find out what her vision was like in that eye. Also, the doctor was deeply concerned about "saving" the left eye. The eye tissue had become very thin from all the scratching. The doctor was afraid of the tissue possibly becoming perforated, and no one wanted to see that happen.

The cornea specialist examined her eyes under sedation, and got a very good look at them. As soon as he was done with the exam, he walked in the waiting room, sat beside me and said, "Minnie has zero vision in her left eye. She has an 'anesthetic' cornea; meaning that she cannot 'feel' her left eye at all. Therefore, she's not a good candidate for a cornea transplant." This is because there would be no input from the new cornea to the rest of the eye. By Minnie having no feeling or vision in her left eye, this is a big reason she would scratch constantly at her eye. His recommendation was to have the left eye permanently closed shut. So therefore, now she would have a permanent tarsorrhaphy.

We went back home to Austin, and soon after had her left eye permanently closed shut by an oculoplastics surgeon. The surgeon did an amazing job and told me "After she's healed from the surgery, it will look like she's 'winking'." Once this surgery was done, Minnie could start to really take off. Everything was new all over again for her. She finally had free use of her hands to explore the world around her. To be able to finally touch, feel, and grab objects, and not be distracted by her left eye, was just amazing. She wasn't restricted by socks on her hands, eye patches, arm splints, etc. She could feel everything and she showed a vast improvement with her therapy sessions and daily living. It was a Godsend for her.

All of this happened by the time she was just over 1½ years old. Her therapy sessions continued and I was still searching for help from resources. I was able to attend The MAGIC Foundation's 2009 Conference in Chicago. (*Editor's Note: The MAGIC Foundation for children's growth is an American non-profit organization which helps families of children diagnosed with a wide variety of different growth impacting medical conditions through education, networking, physician referrals and numerous other services. To learn more about the MAGIC Foundation, please visit www.magicfoundation.org.*) I was so happy to be able to go and meet other parents like myself. It was more than I ever expected. I felt so welcomed and humbled by the entire experience. I met adults with ONH and other children with ONH. I walked away with a lot of valuable information and made some great friends too. I decided to "Run For MAGIC" in April 2011. I ran a half marathon in Nashville, Tennessee. This was done to help raise awareness and donations for MAGIC. I loved the entire experience and plan on training to run a full marathon for next year's MAGIC marathon! It was surreal to have the love and support of our family and friends in Nashville. Minnie's Aunt Minerva ran alongside me in the half marathon. That meant the world to me, to have that unconditional love for

this special little girl and for all the MAGIC children out there. I think it's so important to raise awareness about Optic Nerve Hypoplasia, since it is one of the leading causes of blindness in children.

That same summer in 2009, I was also blessed to attend the 5th Annual Texas Parent To Parent Conference. It was really amazing to be a part of such a wonderful experience. I learned so much from attending and have been blessed to attend every year since! I was exposed to a lot of vital information and resources here in Texas for my daughter. I love Texas Parent to Parent, and will be participating in their parent volunteer training program this summer. I am thrilled to do this and hope to help newly diagnosed ONH families, and possibly be an outreach speaker. I just want other parents and caregivers to know that they are not alone and there are great resources out there, like Texas Parent to Parent. So many individuals and organizations have helped both me and my daughter very much, like the Texas Department of Assistive and Rehabilitation services (DARS). I just want to give back and help other families as much as I can.

I was turned onto "hippo therapy" from some of the parents I'd met at the MAGIC Foundation Convention. I decided to really look into therapeutic horse riding when I got home to Texas. Since Minnie was still not walking yet (at the age of 2 ½ years), that was my first big goal for her with the horse therapy. We started the fall semester in late August 2009, and literally after one therapy session, Minnie started walking on her own! I know this wasn't completely from just one therapy session, but it definitely helped! We fell in love with the horse therapy and have been doing it ever since. It really opened up her vocabulary too. I can remember not too long after a couple more sessions, she would start to say "I rode a horse today!" It was awesome to see her vocabulary increase from her daily experiences.

Minnie is also hearing impaired. At birth, she failed her newborn hearing screening. After several follow up hearing tests, her right ear appeared normal, but her left ear showed no signs of hearing. So right before Minnie turned a year old, she had an Auditory Brain Response (ABR) test done, and ear tubes put in both ears. The ABR test showed that Minnie had profound sensorineural hearing loss in her left ear and the right ear was completely normal. At the time, I was unsure how a profound hearing loss would effect her overall development and progress. To help with her special needs, we began ECI services (Early Childhood Intervention). One of the services provided was for her hearing. Minnie had a wonderful Auditorially Impaired (AI) teacher. The teacher implemented the use of a hearing device, called an FM system. It would help Minnie with noisy environments (e.g., classroom settings, public places, etc.) and also in everyday use. The person that is speaking wears a microphone, and it sends speech signals to the listener (Minnie), and she wears a tiny FM receiver behind her ear. Overall, Minnie has greatly benefited from using this technology. Her vocabulary and level of communication is very high functioning and expansive. I can remember for the longest time, Minnie would not speak, or say little words. Then, after enough time, therapy, and a lot of love, Minnie began to speak. Now she's blossoming and developing her own special interests. She loves to read a lot of books, or just make up stories as she points to the pictures. Minnie has a great love of music, dancing, and playing different instruments (i.e., acoustic guitar and keyboard). I give all the credit to her wonderful father, Juan, as I have no rhythm. Minnie loves playing guitar and singing with her dad.

It's a wonderful way for her to express herself and bond with her dad too.

Currently, Minnie is 4 years old and is doing extremely well. A year ago, her urologist informed me that Minnie no longer has kidney reflux at all! I was floored by that and so thankful. That's a miracle in itself. She is being closely monitored for all of her hormone levels by an Endocrinologist. A month ago, we found out that Minnie has hypothyroidism and takes a simple daily medication for that. It has really helped bring down her thyroid levels to a normal range. Carefully monitoring all of her hormone levels are an essential and vital part of Minnie's development.

She transitioned to a public school setting from the ECI program last year and loves school. She's very social, loving, and accepting of others. Her PreK teacher told me one of the first days of school, she walked over to another child in the class, and sat down beside him and clearly said, "I'm going to sit down next to you, because you're my friend!" I couldn't be happier with her development and progress. Minnie will soon be fitted for a cane to use on a daily basis. I think that will be a great tool to help her navigate around the world more independently.

We have definitely struggled a lot to get here. I have dealt with a lot of judgment from strangers who don't know or understand her Optic Nerve Hypoplasia. I find a lot of comfort in putting my trust and faith in God. Anything is possible with God. There's a reason my daughter was born this way. I might never know exactly why or how. But I do know that I have accepted and embraced her special needs.

I pray and hope that other parents do not feel alone or that their weight is too much to bear. I suggest surrounding yourself with great, positive people that can help you. Also don't be afraid to ask questions, or seek a second or third doctor's opinion about your child. Don't ever let someone poison your spirit and say your child "can't" do something. Also, there is always a way to channel your raw emotions into something positive. I try to take it one second at a time, and accept the fact that I can't fix everything. The best thing I can do is to "show up in my life" and love myself, my daughter and everyone with all I have.

I have to be honest, and admit a lot of times during this journey, I thought I was lost and I didn't know what I was doing; but I was never lost, I was right where I needed to be. And now, when a stranger asks a familiar question: "What's wrong with her eye?," I have Minnie tell them "God doesn't make mistakes.". There are struggles that lie ahead, that is for sure. But as Fredrick Douglass said, "If there is no struggle, there is no progress". I am honored to take that challenge.

Luke...

By Lynn and Luke Novay,

Abstract: A mom and her teenage son with disabilities tell his story from their own unique perspectives. They describe how he learns, his interests and his participation in several sports.

Keywords: cortical visual impairment, ADHD, horseback vaulting, sports, Special Olympics

Editor's Note: This family has been involved with anything "VI" for many years at both the local and state level. From time of Luke's birth Lynn has searched for opportunities to volunteer in her son's school and in the community. She is currently on the Region 10 ESC Extended Core Curriculum planning committee. She recently completed the Family Leadership training series and created the following student introduction portfolio as an assignment. Then she encouraged her son to use his own voice in creating an introduction portfolio. Portfolios are an effective and creative way to share information about your child or yourself with teachers, classmates, or employers. There are several types of portfolios depending on your audience and your purpose. For ideas to get started go to www.texasprojectfirst.org/StudentIntroPort.html. When reading Luke's story, compare it with his mom's, and take a look at the similarities and differences in each of their perspectives. Both of them make it clear that Luke is a wonderful guy that you want to meet in person.

LUKE ACCORDING TO MOM BY LYNN NOVAY

Hello my name is Luke Cole Novay and I am 15 years old. I go by Luke or Captain Luke on my Vaulting Team. I have a vision impairment, epilepsy (although I have not had a seizure since 2006), language delay, ADHD and autism. I have several disabilities, but many more abilities.

My vision issue is my processing of what I see. It may take a little longer to see or focus on something. The teachers give me the notes for class instead of me copying them from the board. I'm slow and it's hard for me. In some classes I like to sit in the back but mostly I sit up front. The glare of the room can make it difficult for me to see. My vision teacher gets me large print books which I use sometimes. I have a line reader to help me follow when reading. I also have books on tapes and CDs.

I take things literally. I like it black and white, but I live in a home of black and white, gray and every color of the rainbow. So I have to adjust. My family and my speech therapist help me to understand the other colors. I like to kid around but I will behave. If I argue with you it is because I think you are attacking me.

I do get distracted but I do my best to stay on task. I use chewing gum when taking a test and need to focus it helps. I'm a very high functioning I am told. I just know I don't understand sometimes and I get tired. Direct teaching is the best way for me. If you want me to know something, teach it to me the right way the first time because I don't change. I also learn best if it is repeated to me several times.

My love is vaulting. I am told that when I was little I didn't know where I was in space. If I bumped into you or you bumped into me I would fall all the way to the ground. I could not stop myself. Now, with a lot of hard work and help, I can stand on a horse while it is walking!

When I graduate I would like to be a policeman, a stunt man, game designer and many other things. I'm still deciding. I plan to live with my family on the other side of my parents' land. That way my kids

can just run across the pasture to their grandparents' house.

I hope to have a good year in your class.

MR LUKE NOVAY: IN MY OWN WORDS

BY LUKE NOVAY



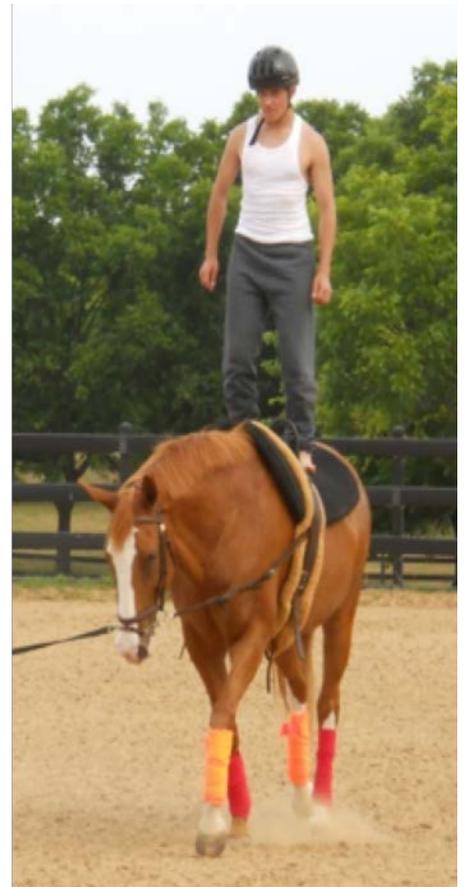
Hi, I'm Luke Novay a.k.a Captain Novay and/or Mr. Wonderful. I like Law Enforcement and Mixed Martial Arts. I look up to Chuck Norris a.k.a Walker Texas Ranger.

I'm visually impaired and I can do: basketball, soccer, and sports riding and vaulting on horseback with Special Olympics. I enjoy being an athlete of Special Olympics.

Vaulting is gymnastics on horseback. There are three of us that do vaulting. Bill, Nick and me are known as the 3 amigos. There are three positions:

Captain (me) Sargent (Bill) Lieutenant (Nick). There's two Queens: Sarah and Amy. We use handles attached to a pad wrapped around the horse (a surcingle) to vault with the tricks that two of us can do. They are: Around the World, Trot, Canter, Canter No Hands, and **STAND UP ON THE HORSE'S BACK** while it's **WALKING**.

I've played basketball for 8 seasons. I'm going on my 9th season. I was really fast my rookie year. I had "rookie" written across my team shorts my first year. I'm not as fast anymore. I think I should run the "tire drill" to help make me faster and to run light on my feet.



Luke standing on horseback.



I have performed with the 2004 Gymnastic Olympians. I am in the center front with the blue team shirt.

I've played soccer for seven seasons. I can play forward, middle fielder, defense, or goalie. For my team my position is middle fielder. I enjoy it even though I run the length of the field. That's tough!

I'm retired from gymnastics and track but I've been to the American Airlines Center in Dallas when the U.S. Gymnastics team toured after the 2004

Olympics. My spotter for the parallel bars was U.S. Gymnast Guard Young. I have his warm-up jacket still.

I'm going to come out of retirement and do gymnastics again. Two years in a row I missed the season because I was injured playing football in my yard. Then the next year in 2007 my appendix blew up inside me. Man that hurt! I'm a warrior and I fought through the pain and look at me now. That's a long story and it's better for me to tell it in person.



I love to play basketball and my nickname on my team is "Shutdown Defender!" This is me with my team. I am on the left dribbling the ball. My jersey number is #1.

I love doing all the sports in Special Olympics. My mom has taken me to all of them. Basketball was the first one she took me to. I'm classified in the top 5 players and I'm a leading defensive player for our team. I enjoy being the leading defensive player. Coach calls me the "shut down defender" or "the brick wall" or "road block". I'm most famous for reaching in to take the basketball from the other team. I'm proud of being famous for this but mad when the refs give me a foul. I tell them my opinion about the foul and always get in trouble with coach but I can't help it.

I'm in high school in 9th grade. I'm in weight lifting and I'm loving it. I got a hard headed coach that loves all of us. He's 6'4" and his name is Coach Wright. I call him Coach "Too Tall" Wright like Ed "Too Tall" Jones. I look up to Too Tall.

My future is to become a FAMOUS weight lifter and be in the Guinness world record books and be a millionaire. I want to own my own farm that is 1500 or more acres and have a 3 story house. I'll give mom and dad some acres and build my house on the other side as far away as I can. Not because I don't love them. I want to live my life near my family. Plus I have to give all the credit to mom for getting me this far.

Have a nice day and thanks for reading.

I Didn't See It Coming...Again (Part III)

By Sasha Y. Rangel, 25-year old, Austin

Abstract: The author continues her story about her journey of life with vision impairment. This article, which is a continuation of her previous articles published in the Winter and Spring 2011 editions, describes her adventures studying abroad, wrapping up her undergraduate career, and her initial introduction into her present-day internship.

Keywords: family wisdom, visually impaired, personal perspective, transition, adult life, studying abroad, vocational, self-determination, Orientation and Mobility, Retinitis Pigmentosa, success

“AYUDAME!” (“HELP ME!”) / HELP OTHERS

The title of this section is “Help me” in both English and Spanish. This is one of the first key phrases I learned when I traveled to Spain. It was right up there in “key phrases to remember” along with “bathroom”, “food”, and “please”. I was not able to coordinate flying into the country with the other student from my university, so ready or not, I went by myself. I had what little Spanish I knew, and a fearless guide dog who was only as semi-aware as I was about the adventures we were about to embark upon.

I went through the motions of asking for assistance from an airport employee to navigate through the Customs checkpoint in the Madrid airport and needed to take both a cab to the train station and then a train to the town I would be studying in called Valladolid (va-ya-doe-leed). After about 15 hours of travel total, I arrived at the train station in Valladolid to discover there was no host family that I would be staying with to pick me up. After my immediate reaction of tears, I called all the parties concerned and eventually ended up in my first Spanish home. I was only able to stay in this home for a week because not only was it extremely difficult to get to the university from where I was staying, but the children in the family were allergic to my guide dog. New country, new fears... and now another new place to live.

I was fortunate to be paired with an older woman who welcomed having myself and a guide dog live in her home. After the culture shock, adjustment to our new environment and a little orientation, Glori and I set out on our mile and a quarter walk to our first day of school.

The university and I worked diligently to figure out ways in which I could view the materials and learn right along with the other American students in my classes. We came up with computer documents and enlarged documents in order for me to see and hear the language. I took courses in Literature, Culture, Phonetics, Conversation, and Grammar. In addition to these courses through the university, we are also taken on day trips to different cities in the region of Castilla y Leon. The cities we got to visit were Segovia, Salamanca, and Burgos. The trip to Burgos is a trip I will never forget.

The day we were getting off the train coming back into Valladolid from Burgos, we had to quickly get off the train and sort of jump from the narrow stairway next to the train to the walkway. My guide dog was scared to make such a big jump from falling out of a truck before, so I tried as best as I could to encourage her to take the jump with me as safely as possible. A train assistant attempted to coax her out of the train but pulled on her leash too hard. Glori fell off the train, onto the train tracks and cut off some of her hair off during that fall. It was quite the traumatic experience for both of us, but after emergency veterinary care, she was able to fully recover.

On a lighter note, I was able to make a few friends along the way who showed me around other cities

that were not apart of the university field trips. My new friend Brooke (an American who studied in my same university program and later moved to Spain to teach English as a Second Language) introduced me to lots of wonderful people and took me to many Spanish nightlife events. I will always be grateful to her for all these lovely experiences.

Some of the other activities I experienced in my study abroad journey included meeting members of the large blindness organization in Spain called ONCE (National Organization for Special Blind Persons). Their welcoming demeanor allowed me to participate in a few of their meetings, cooking classes, and other activities that empowered their blindness community. These experiences taught me that while there are cultural differences worldwide, this country had many empowering connections and activities to promote the success and well being of the blind.

Finally, another experience I had during my stay in Spain was volunteering at a private elementary school to help teach children English. I was able to participate in their classrooms and help with different English speaking activities. In the midst of these educational activities, the students and I were also able to ask questions of each other about culture and daily life. The children learned as much from me about Texans who are vision impaired guide dog users as I learned about the youth of Valladolid that were future leaders of their country. One of the neatest things the children learned about me was that there was no need to be scared of service animals, plus learning that a blind person can be fully functional in society. I could hear the children talking to their parents on our walks home after school and explaining things about me and Glori that helped educate the community all the way around.

One final thing I took from that experience was the message the school conveyed about their theme for the year for their students. The theme of the year for the school was “Un mundo para compartir” which means in English “one world for sharing”. Because we had such a sharing exchange between myself and the students and staff of the school, I felt that this was a life long expression that I would carry with me always. About one year later, I received an award from Texas State University called the “Isis De La O Gomez Outstanding International Student Award” which the university had both printed and brailled the message on the plaque. This brought me many tears of joy because as I explained to the awards committee, whenever I do lose my sight permanently, I will always be able to remember the experience of the award and what it had to say.

VISION LOSS STRIKES AGAIN

I was told at a very young age that having Retinitis Pigmentosa would make my vision decrease over the years. I was also told that this vision loss would inevitably lead to complete blindness and the time of that blindness could not be determined until it happened. Because there are so many types of RP, it seemed that the message that was passed on unofficially was “you never know when you’re going to go”. I spent a good majority of my life preparing for the inevitable by learning different non visual techniques for different aspects of everyday life. And while I maintained a pretty positive attitude through it all, I must say that one experience of vision loss was a little more difficult than others in the past.

When I returned from my study abroad semester in Spain, I encountered signs of more fatigue than “normal” (normal being what I was accustomed to seeing for a certain period of time). It seemed that I was having an even more difficult time than usual determining how far away things were from me. I also noticed that it seemed my eyes were getting tired earlier in the day and more frequently. I figured that I would go through a typical visit to my eye doctor and figure out a solution to get things back to the way they were.

My eye doctor told me that my prescription had changed a little and that I did experience a little bit of field loss so that the tunnel I was seeing through had narrowed a little. She told me that the most subtle of differences according to visual acuities and field loss would be more apparent to someone who was in the lower ranges of functional eyesight and would be able to notice any sort of loss that much more directly than perhaps others. I intended on taking all of this information in stride and go on with things as normal, understanding that vision loss with my eye condition was “normal”. However, I was not prepared for my reaction soon after.

There was one day that I needed to speak to my vocational rehabilitation counselor about some adaptive equipment I needed for my college coursework. She was talking to me about the report she’d received from the eye doctor and said that normally it was quite a lengthy letter that went into great detail. The words she said to me thereafter are words that I will never forget: “She only wrote one paragraph and said you have one degree of field left”.

Just to give you an idea, one degree of field means you are looking through a tunnel that is even narrower than a drinking straw. I think my mind went into shock and numbness at the same time. I walked out of her office that day and initially thought that while the news was a little difficult to swallow, I thought all I would need was a Wendy’s chocolate frosty and that would solve my temporary “down in the dumps” syndrome. I found out as that day progressed that I needed just a little more support than that frosty.

I was very fortunate to have had all the training I experienced up to this point in hopes that non-visual skills would prepare me for the permanent vision loss and total blindness. I am forever grateful that I had these skills in place, but I don’t think that all the preparation in the world could prepare me for the difficult adjustment that I had to the villainous vision loss that struck once again. I can honestly confess that I felt as if my heart fell to my feet, my stomach was in knots, and my head was spinning all at the same time. I became so anxious that I was even having a hard time concentrating on my coursework. I began to doubt myself, and wondered if I really could be successful, and if I could live happily through a time when I foolishly felt like a sense of vision loss could mean life loss. While I wallowed in self pity for a brief period of time, I did come to the terms with the idea that I was not really dying.

I tell you this story to convey that while I have been very blessed with the beauty of life and all of its ups and downs, I told everyone I could think of that vision loss seemed to affect me so negatively at this point. I talked to friends, teachers, my counselor, my eye doctor, my family, other blind people—

anyone and everyone who would listen to my grief. I can comfortably say that with time, as well as the love and support of many, many people, I rose above the depths of distress and continued on the path to success.

TO GRADUATION...

As I entered my last semester of college, I realized that many things had to be in place for the final semester to go as smoothly as possible. At this point in my preparation for graduation, I had only the final hours of coursework to complete a double major in Sociology and Spanish. While both of those majors were the furthest from my mind when I began college, I was ecstatic to have come across those majors in my self-discovery, and grateful that these areas of educational expertise would soon be enshrined on my diploma.

I was diligent... I was focused... I was ready! I began my first few weeks of classes and was given my first writing assignment. By this point I had done several writing assignments, so to me, this seemed like a piece of cake! When I began this assignment I discovered that I was not as prepared for the culture shock of writer's block that struck me. For some reason (naturally I wanted to blame stress before the procrastination monster that lurks in my brain that was called "senioritis") I could not get started for the life of me. Time was drawing nearer to the deadline and I had nothing to work with. What was I supposed to do?

I remember sitting in front of my computer for hours and feeling like if I stared at the monitor long enough, the words that lurked deep within me would emerge eventually. As the hours passed, I could not develop a rhythm that would save me from the headache of trying to get all the ideas onto the metaphorical paper that is the word processing document. Fortunately, an angel in disguise emerged in the form of a graduate assistant in my class. Her name was Jamie, and she taught me one of the most valuable lessons in life... how to take a break!

I expressed my frustration with not being able to get started on my essay. She asked me if I had eaten that day and silly me, I hadn't. She decided to teach me how to pry myself away from the computer, grab a meal, and take a moment to breathe in order to clear my mind of stress. At first I thought Jamie was crazy for wanting to take me away from something so important. However, I'm glad she taught me the importance of collecting oneself in a relaxed state of mind. She taught me that with all the things we go through in life, only a balanced life will get you through the day as effectively as possible. I will always be grateful to her for that lesson and the loving friendship that evolved.

I had many more stressful days and few relaxing days, but I made sure that I practiced my important tool, gathering my thoughts together. I was able to finish my double major degree and walked across the graduation stage on May 14, 2010.

Great! I graduated!! Now what??

...AND BEYOND

The day after graduation I got involved with a volunteer opportunity to train in skills such as active listening and crisis intervention for a domestic violence hotline. I participated in this training for a little over a month with the hope that I could volunteer and possibly get a job somewhere along the way. The biggest barrier at the time was the compatibility issues with adaptive low vision software not working with their online resources. This turned out to be an on-going process to try and figure out a solution. A solution was never fully discovered and I missed out on a fantastic opportunity to get my foot in the door with this profession. Life obstacles like this happen to everyone.

I spent about six months after college in a stage of “relaxation” if you will. I looked for some jobs and spent the other time recuperating from the overwhelming hustle and bustle of college life. As time passed by, I began to feel a slight sense of worthlessness at the idea of having a degree and not having a job to put that knowledge into paid employment. This down feeling was mixed with the feeling of needing to convince myself that it was all right to have a little bit of time to pause and reflect on what the next steps of my future needed to be. All of these emotions mixed together ultimately just led to an enormous feeling of confusion during this six month period.

During my educational endeavors, I came across many groups of people and was able to make many acquaintances and friends who have all sorts of information and knowledge they have shared with me. One day, I received a call from a friend who asked if I could participate in a group panel to answer questions about our experiences in transitioning from high school to wherever our paths led us after graduation. I felt fortunate to have such an opportunity to learn from other panelists as well as to share my story, so I agreed. I made contact with the person from TSBVI Outreach who was arranging this panel group as a part of a conference for vision impaired high school students. Because time and life experiences were all I had at that time, I offered my time, energy, and brain to help wherever the specialist needed. As it turned out, I was grateful for the learning experience of helping to put together ideas and activities for this conference, participating in the panel, and assisting to co-facilitate a workshop for the students. I felt a strong connection to the people I worked with, and because my dream has always been to be involved with community education and outreach in a blindness field, I asked if it was at all possible to intern with the TSBVI Outreach Programs. Through lots of questions and support from both the Outreach programs and the Division for Blind Services, I was able to participate in the internship I am part of today.

This internship thus far has given me a vast wealth of knowledge and experience in working with and on behalf of students who are vision impaired. The beauty and the curse of being an intern is that you are expected to make mistakes and learn from them. It was very frightening but also enlightening to dive into the workplace atmosphere and learn things as I go. I must confess I was a little overwhelmed with my first exposure to a sort of panel interview I received from various members of the Outreach team asking what my skills were and if there were certain projects I could assist them with. Silly me for being young (and dumb), I said yes to them all! I had no idea what half of the terminology they were using even meant, but by golly, I was going to learn!

I have had the privilege of working with families in their training to become leaders and advocates for their children with vision impairment and other disabilities. I have also been able to work with and learn about various forms of adaptive technology. I have learned some methods of approach to transition planning for various students, as well as how a process of collaborative effort from various community members in a student's life can help provide support in preparation for future events. I have had the opportunity to hone my oral and written communication skills. These experiences and many others in this internship have hopefully prepared me for a future career in the blindness field as either a counselor or teacher... wherever the wind might take me!

I would like to leave one piece of advice to anyone who has read my story. I would like to emphasize the importance of starting to think about your future as a successful individual as early as possible. Understand and embrace the ideas that while plans may change throughout your life, your ability to grow and learn from any situation will help shape the successful person you are and will continue to become. We all have the right to information that affects us, and it is the responsibility of the community at large to learn about their surroundings and all that that they encompass. The world is full of questions to answer and lessons to be taught. I ask that those with vision impairment and/or other disabilities as well as those in this field of work, help us spread the positive message that having a disability does not mean that they are "not able" to do things in order for success to take place. Help the world to understand that a disability is really just a diverse opportunity.

Thank you, and love this day!

This Is Jack

by Marie Smith

Reprinted with Permission from *Future Reflections*, A Magazine for Parents and Teachers of Blind Children published by the American Action Fund for Blind Children and Adults in partnership with the National Organization of Parents of Blind Children. (Volume 29 Number 2, Special Issue: Blind Children with Additional Disabilities)

Abstract: The author of a blog about her son shares her positive and proactive approach for supporting people in getting to know her son with an atypical appearance.

Keywords: Family Wisdom, Blind, Personal Perspective, Apert Syndrome, Craniofacial Disorder, Dealing with the Public, Bullying, Atypical Appearance, Self-Determination

From the Editor: Any child who is visibly different will probably be teased, ignored, or even bullied by peers at one time or another. In her blog Marie Smith of Alabama described how she reacted when her son was bullied due to his atypical appearance. Her blog post expanded into an article for Future Reflections on this important and often painful topic. You can visit Marie Smith's blog at <http://allaccesspasstojack.blogspot.com>.



This is Jack. He is four years old. To me, he is the most awesome, brave, hardworking, self-motivated person who has ever lived. But if you walked by Jack in the grocery store, you'd probably take a second glance—and not for the reasons I've just mentioned.

The night Jack was born I distinctly remember hearing the words “Apert syndrome” for the first time. Apert syndrome is a rare craniofacial disorder. It causes a number of issues that vary from one affected person to another. At least three characteristics are seen in every person with Apert syndrome. The first is early fusion of the sutures in the head. The sutures are supposed to be open at birth to allow room for the brain to grow. Another characteristic is called retruded midface; the middle part of the face grows at only one-third the rate of the rest of the face. The third trait is fusion of the fingers and toes.

Children with Apert syndrome require a series of surgeries. Cranial surgery is necessary to make room for the child's growing brain. Eventually most children with Apert syndrome also need surgery to correct breathing issues by pulling the middle part of the face forward. (Jack hasn't had this surgery yet, but he has severe obstructive sleep apnea and requires a device to help him breathe at night.) Still more surgeries are needed to separate the fingers and toes of children with Apert.

Jack has not followed a typical Apert's pattern. In a two-year period he needed thirteen operations, most of them to reduce or prevent pressure on his brain. Somewhere along the way he also developed optic nerve atrophy. He is legally blind in his right eye and has only light perception in the left eye.

At nearly five years old, Jack is in the beginning stages of acquiring speech. He also has fine and gross motor delays. He is socially delayed and does not read nonverbal cues well, probably because he doesn't see them. Nearly constantly he has a runny nose due to very small nasal passages and what his allergist calls “vasomotor rhinitis”—his nasal passages overreact to irritants.

As I said earlier, if you saw Jack in a grocery store, you would probably take a second glance. If you had children with you, they might point and say, “Mommy, that kid has a big head!” or “Daddy, look at his weird eyes!” Young children tend to let their thoughts spill out without any filter, using whatever words they know. I'm sure that one of these days it will be Jack's turn to embarrass me with some ill-placed remark, uttered innocently and entirely too loudly. He will be speaking his mind with whatever vocabulary he has.

My husband, David, and I do not attempt to shelter Jack from children's honest observations. We would rather that parents not try to hush their children and hurry them out of Jack's presence. We know that he has a big head and his left eye protrudes a bit. His fingers and toes look unusual, too. We think Jack is aware that he looks a bit different from other children, but we want him to know that

he is still essentially the same.



We realize children are bound to make honest observations. We would like parents to acknowledge their comments calmly and say, "Yes, that boy looks a bit different, but he is a little boy who might like to play. How about we go say hi?" Someday when Jack is on the playground and a kid says, "You sure do have a big head," I hope he'll say, "Yep, so do you want to play ball?"

What's really important to us is that parents and children not avoid us. We're just regular folks. Everyone has differences. Jack's differences are more readily apparent than some, and that's okay.

We want children to treat Jack the way they would treat any other child. Like any other child, he responds according to his mood. If he's in a good mood when a child approaches him, he'll flash a beautiful smile. Now and then he won't seem to care that anyone is there. Sometimes he wants to play, and sometimes he prefers to be by himself.

To answer the questions children ask about Jack, we explain that he was a bit different when he was born. He did not have separate fingers or toes, but we got the doctor to separate them for him. Also, he had some problems with his head that made it grow big, but the doctor took care of those problems, too. Jack does not see very well, so he often uses his hands to touch people and things. He is still learning to talk.

It's a lot of information for a child to take in, so we always finish with the fact that Jack is a little boy who likes to run and play as much as they do. Often children only remember the last part of anything you tell them, and that's the most important part. Kids will notice Jack's differences on their own. They may need adults to help them see that he is like them. He very much is, and he loves to be around other kids.

A few months ago we spent several days surrounded by lots of people we didn't know. At times like that we encounter a great deal of curiosity from others. We met the full spectrum of reactions.

Some kids did not seem to register Jack's obvious differences. They played happily beside him and with him. Some kids asked a couple of questions and then resumed playing with Jack. A few kids refused to go anywhere near Jack, even after I tried to introduce them to each other.

Heartbreakingly, there were some kids who (there's just no other way to say this!) were mean and

hateful. I tried to introduce Jack to them, but they would not listen to me. They called Jack a monster and told other kids to run away from him.

It was a shock to my system. I'm not going to lie; it hurt. It hurt real bad. The worst part was seeing how the mean kids influenced the others. I did not dare to react for fear that the pain inside me would burst out and injure those little people.

I wish I could believe this was an isolated incident. Sadly, I know there will be more to come in the months and years ahead. All kids get picked on for something from time to time, and Jack's unusual appearance will doubtless attract the attention of young bullies. If I'm around when it happens again, I will remind the child that he is being mean—if you call someone a monster, you know you are being mean!—and ask him to stop. Again I will try to introduce Jack. If that does not work, I will ask the bully to take me to his parent to discuss his behavior.

I wanted to believe that Jack did not hear what the kids were saying, but I'm sure he did. He asked to leave, although he'd been having fun. He started clinging to me. After that episode, we had a brief talk with him about how some people are mean. We tried to explain that meanness is a reflection on that person and what they are going through, not a reflection on Jack.

Why do some children play comfortably with Jack and why are some kids mean? What makes the difference? Is there inherent goodness in children, or do we need to be suspect of every second glance Jack receives?

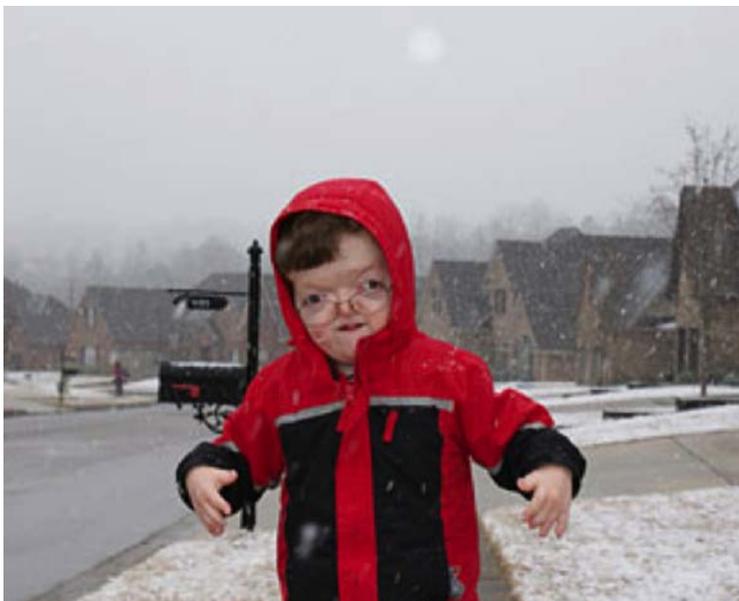
After a lot of prayer, thought, and discussion with my other half, I believe parents make the difference. If parents are uncomfortable with Jack and are busy processing their own thoughts about him, they cannot help their children feel at ease. They will not encourage their children to play with him if they cannot get past his differences themselves.

Some people live their entire lives surrounded by people who look and act more or less like they do. When they encounter someone who speaks a different language, has a different culture, uses

adaptive equipment, or has a craniofacial disorder, they absolutely don't know how to react. Sadly, lack of knowledge sometimes results in fear.

What can we do? How can we show these people that different is neither bad nor scary?

One thing we can do is to get out into the world. I truly believe that it helps for people to see Jack being the adorable little kid that he is.



To keep friends and family updated without overloading their email servers, I started a blog. I find it easy to write about how I think and feel. Fortunately, other people have found our life interesting, and we've spread a bit of awareness through my posts.

When we're out in public, I find I can connect with most kids, and these exchanges help me connect with the parents. However, that's not always a winning formula. In the live presence of other adults I tend to be rather shy. Out in the big wide world I have to take a deep breath, step up, and introduce myself and Jack a little more often. "Hi," I'll say when I meet you. "I'm Marie, and this is Jack."

Ready for Halloween?

Abstract: Three mothers of children with disabilities describe how they include their children in Halloween parties and traditions.

Keywords: Halloween, costumes, children with disabilities

Editor's Note: It's not too early to start thinking about how your child can be part of Halloween. Maybe thinking about fall temperatures will give you a break from the 100+ degree weather. Three creative moms share their ideas.

COSTUME IDEAS FOR WHEELCHAIRS

BY ISELA WILSON

Here are some fun ideas to cover wheel chairs for Halloween. All you need is card board boxes, a little glue, a little paint and a little imagination!



Captain Jack Sparrow aka Andrew. A pirate ship made from cardboard and painted surrounds his wheelchair. A sail is fashioned from a white curtain panel and is attached to the back of the wheelchair. Andrew is wearing a wig with long black hair tied with a red bandana.



King Andrew on his mighty steed! His wheelchair has a stuffed horse attached to the front and the back of the chair. Andrew is wearing a crown and a royal cape.



Race Car Driver, Lightin' McQueen aka Andrew. A red car made out of cardboard is attached to the sides and front of the wheelchair. Andrew is wearing a helmet and a racing shirt.

HALLOWEEN FUN!

BY IRASEMA RAMIREZ

My daughter Irasema "Irita" and I enjoyed the Halloween Party celebrated in October, 2010, organized by the Division for Blind Services in Laredo. The Haunted House was the best surprise for all the kids and young adults that participated in the event.

DARS-DBS employees, Astrid Hinojosa, Imelda Cortez and Mary Trejo, did an excellent job on the entertainment. We ate pizza, chicken salad sandwiches, cake, drinks and lots of candies. There was also two piñatas.



Irita is dressed in black wearing a witch's hat. She and her mom are both screaming and look scared.

TRICK OR TREAT WITH A TWIST: OUR ALTERNATIVE TO THE HALLOWEEN FRENZY

BY MICHELE CHAUVIN

Our daughter, Lauren, is 10 years old. She is blind due to ROP and has additional disabilities related to prematurity, including speech disorder, developmental delays, mild cerebral palsy, and other health impairment (one functioning kidney, heightened auditory sensitivity, and PVL).

In the past, Lauren has participated in church harvest festivals, community fall fun days, local pumpkin patches, and various Halloween parties. She rode camels, had her face painted, pet (and smelled) the animals, compared little/medium/big pumpkins, carved pumpkins, bobbed for apples, roasted marshmallows for s'mores, went on hay rides, danced to Halloween music and more. We are blessed in the Houston area with a variety of options provided by DARS-DBS Children's Program, The Lighthouse of Houston, the Houston Zoo, and various community and church organizations.

This past year we celebrated inside with family the night before Halloween. Lauren has 6 girl cousins ages 1-6 years old. They came over dressed in their Halloween costumes. Lauren dressed as a punk pirate. We ate pizza then watched or listened to *It's the Great Pumpkin Charlie Brown*. Luke and I took turns describing the video for her. I believe it helped that she had visited several pumpkin patches over the years. This provided a real world context for this story.

Next the girls went trick or treating inside, as the adults hid behind bedroom doors with baskets of candy. Lauren straggled behind the others, while the girls hustled through the hallway and revisited each door, until their treat bags and buckets were full. We took our time letting Lauren knock on each door and follow our model saying, "Trick or Treat," then holding out her bucket. She enjoyed the focused attention from the adults.

Meanwhile her cousins quickly tore into their candy in the living room. We named the candy as they placed each piece in her bucket, so she eagerly anticipated eating her treats, too. Having that many girls together in one space was fun and challenging. Lauren has truly grown in her ability to tolerate all the noise and confusion a large family brings. She remained calm, and she seemed to enjoy most of the evening, especially the treats. After she visited the final door she exclaimed, "Now you can eat your candy!" And, she did.

TAPVI Talks

By Christina Silva Suarez, Harlingen, TX

Abstract: The Texas Association for Parents of Children with Visual Impairments (TAPVI) is an affiliate of the National Association for Parents of Children with Visual Impairments (NAPVI). TAPVI members organize a variety of local events across the state. For information about these organizations, including how to become a member, go to www.spedex.com/napvi/chapters.html#5 or call 1-800-872-5273.

Keywords: family wisdom, visually impaired, blind, parent group, braille awareness

In January 2011, TAPVI participated in a Braille Awareness Day at the Harlingen Public Library. We invited Nancy, a blind student from Vela Middle School, to read to the children at the library. She read *Guess How Much I Love You* by Sam McBratney. The children enjoyed the story and after Nancy finished reading, she answered questions about how she learned to read Braille.



We also participated in Braille awareness at the Brownsville Public Library where Angel, a blind high school student was asked to read for the children at the library. The children and adults asked questions about how he learned to read Braille. Angel mentioned that he had attended Texas School for the Blind & Visually Impaired (TSBVI) for 5 years and that wants to be a teacher.

In April 2011, TAPVI was represented at the Children's Book Day at the Harlingen Public Library. This literacy expo features a variety of resources and games with a reading and writing focus. Rose Aleta Laurell, a Texas librarian, has a children's book written about her called *Librarian on the Roof*. Rose Aleta and some students performed the story, and then she signed copies for families in attendance.



A table with TAPVI information, Braille books and some candy was visited by those attending the expo. Both kids and their parents learned about Braille, TAPVI and support groups for families with special needs.

TAPVI was invited to sponsor an activity during the statewide family gathering at Morgan's Wonderland in June 2011. Morgan's Wonderland is a fully accessible amusement park located in San Antonio. Children and adults with and without visual impairments were able to explore and discover "treasure" by using their

senses of touch and smell. Gift baskets filled with summer fun activities including gift cards were raffled off to three lucky families.

ABC's of a Great School Year

By Elizabeth Eagan Satter, CTVI, Federal Way Public Schools, Federal Way, Washington

Abstract: the author gives a helpful list of important things for teachers and parents to remember when helping their students with visual impairments be successful.

Keywords: blind, visually impaired, study skills, self-advocacy, independence.

When the new school year has begun, summer is just a memory of the past and a wish for the future. As parents and teachers, we wish success for our children at school, with their new or old friends, and in the goals we've set for them. Here's an alphabetical guide to helping our students achieve success.

A = ATTITUDE:

Attitudes are everything to a student when learning something new, doing a task, etc. We have to help our students change their negative views to positive ones.

B = BREAKFAST:

Breakfast really is the most important meal of the day. If students come to school hungry, they will be less able to focus on learning. Their focus will be on the sounds or the aches in their stomach. Encourage them to eat breakfast; perhaps stick a breakfast bar in their backpacks for a boost if the students need it. Lunch time varies at schools from late morning to early afternoon making it difficult for hungry students to pay attention to anything but their hunger.

C = COMMUNICATION:

Communication is vital to a student's success. Encourage the student to acquire communication skills that include oral, written, and nonverbal (body language) modes. The student should learn that effective communication will help build trust and respect, accomplish goals, share ideas, express feelings, etc.

D = DREAMS:

Students have dreams for their future. They need assistance and guidance to reach their dreams. Parents, teachers, counselors, and others can assist students by helping them plan to take classes to reach their dreams or learn the skills needed to make those dreams become a reality.

E = ERASE:

Help students erase all the negative feelings that they may feel about themselves or their disabilities. Help them turn the negatives into positives. By erasing the negative, a student will be able to focus on the positives and move forward.

F = FRIENDS:

Friends help us get through the good times and the bad. They provide a feeling of belonging and companionship. Through friends, the student is often more willing to try new things. Friends provide valuable information on clothing trends, music, and so much more.

G = GRADES:

Students don't always realize that grades are important for anything other than making their parents happy and being able to move on to the next grade. We should teach the students that grades help them acquire admission into college, scholarships, school awards, and future jobs. Help them understand that doing well in class establishes a firm foundation in the subject matter that they can use and expand upon for better grades in other courses yet to come.

H = HOMEWORK:

While homework is not fun, it is a necessary beast, as it helps the student learn a skill or continue to practice a skill, so mastery is reached faster. Parents should share and support homework time by showing an interest in their child's work and offering assistance when necessary. Teachers must remember to applaud the student's efforts to complete their work and offer constructive criticism when errors are found in the homework.

I = INTERESTS:

What is the student interested in? Encourage those interests through research and further exploration. Consider ways to expand those interests by expanding the student's experiences.

J = JOKE:

Humor is a vital part of life. Teaching the student when and where it is appropriate to tell jokes is vital. Some students want so desperately to be liked and to fit in that they overdo the jokes and wind up

being ostracized instead.

K = KNOWLEDGE:

Every student walking into the classroom has a vast variety of experiences. Students with visual impairments may not have as many experiences, but also come with their own knowledge of different things. Encourage them to share. It is through sharing that others learn more about the student, and they can learn new things from each other.

L = LISTEN:

Listening is perhaps one of the toughest skill areas which is not commonly taught in school anymore. To listen, the student needs to focus on what is being said while blocking out the distracting background noise such as other people's conversation, car horns, or phones ringing.

M = MODIFICATIONS:

Students should carry a copy of their modifications in their backpacks, binders, or somewhere that they can easily access. Sometimes these are not distributed to teachers in a timely manner, or they are overlooked. Students should be familiar with needed modifications, and be able to access and discuss them whenever necessary.

N = NOISE:

The beginning of the school year is always noisy: lots of student chatter; chairs scrapping the floor; chalk tapping the board as the teacher writes; etc. This can cause the student to go into sensory overload. Encourage the student to talk to the teacher about moving to a corner in the room or just outside the door when needed to get a break from the noise level.

O = OBJECTIVES:

Students should be aware of their Individualized Educational Plan (IEP) objectives. It makes sense that the student be aware of what they are being held accountable to learn.

P = PLANNERS:

Many schools give out planners for students to keep track of assignments, and as a method to contact parents. Students with visual impairments need to keep a planner as well. Planners can be enlarged copies of what the school is using, a store bought large print version, or electronic. Planners are an excellent way to keep track of assignments, projects, school functions, and school holidays.

Q = QUESTION:

We often need to ask questions for clarification. Students may not ask questions due to self-consciousness around their peers. Students with visual impairments are no different. Encourage students to ask questions to understand a topic or task better.

R = READ:

The only way to improve a student's reading ability is practice, practice, and more practice. Encourage students to set goals for themselves in reading. They should read for at least 30 minutes

every night. Suggest they read to a sibling, parent, or even a calm family pet. Family pets can be a favorite as they typically give readers their full attention, and don't talk back or interrupt them.

S = SELF ADVOCACY:

Students need to learn the tools to be their own advocates. Parents, TVIs, or O&M Specialists won't always be handy when a problem or concern arises. Students should be able to tell their teachers that they need something repeated, or whatever else they may need to be successful.

T = TECHNOLOGY:

Students with visual impairments tend to have a lot of technology. They must learn to take care of their technology as well as how to use it. If the technology fails, and it will, the student should learn to call for assistance, be it the TVI or a technology helpline.

U = UNDERSTANDING:

Tell students that many times classroom teachers have never had a student with a visual impairment in their classrooms before. Students can learn to teach the teacher about their visual impairment and how to make necessary modifications. Teachers are willing to work with students with visual impairments, but they may be hesitant because it's a new experience for them. Students and teachers can learn what works and what doesn't together—a perfect partnership in education.

V = VOLUNTEER:

Students with visual impairments have many people willing to step up and assist them; volunteering gives students a chance to give back. At the same time, they get opportunities to explore the world of work, a brief taste of what a job entails, without being employed to do a job day after day.

W = WEATHER:

Students need to learn how to dress for all kinds of weather and be prepared for sudden and unexpected changes in the weather. A small retractable umbrella can go in the backpack for a surprise rain shower, or sunglasses or a ball cap for the sunny days. Be prepared is not just a Boy Scout motto, it should be a motto for our students as well!

X = XEROX:

Students need to label those Xerox copies as soon as possible. Pull out the slate and stylus to label them, or mark them with a dark pen/marker, punch a hole in the sides of the pages, and place them in a binder behind the correct tab for easy retrieval at a later date. This not only helps the student stay organized and find the pages more easily, but shows their teachers that the student is competent.

Y = YOGA:

Students need to exercise to help keep their bodies fit along with their minds. Yoga is merely one form of exercise designed to attain physical and mental control and well being. Student need to find what works for them and schedule it into their lives. Good health, both mental and physical, will aid them in the days ahead in their lives.

Z = ZOMBIE:

Students with visual impairments can frequently be compared to zombies, in that they go about the school day and do their best not to be recognized or to stand out. These students have many talents, thoughts, and ideas that need to be heard. They need encouragement and a safe environment to express them.

Did you notice that the ABC list is all from the Expanded Core Curriculum? The ABC list is just a starting point—a list to get one's mind thinking of the possibilities. Each student who enters the classroom deserves a chance at success. Students with visual impairments need to have tools in their tool boxes to aid them in gaining independence through those successes. Here's to a great start to the school year and a year full of successful triumphs!

Assistive Technology Evaluation Process Part 1: Gathering Information

Patrick Van Geem, Teacher of the Visually Impaired and Assistive Technology Consultant,
TSBVI Outreach

Abstract: Part one of a series on meaningful technology assessment for students with visual impairments focuses on collecting good information

Keywords: visually impaired, assistive technology, AT evaluation

ATTENTION TO THE NEED FOR AT EVALUATION:

In Texas, the Individualized Educational Plan (IEP) process includes a question about assistive technology. It asks whether the team has considered assistive technology for the student, and if not, why? It is important to always consider some type of assistive technology for students with visual impairments whether it is needed or not. However, a full evaluation of assistive technology is not always necessary. Questions of assistive technology for any student with a visual impairment can come from various sources and if solutions are not obvious then formal evaluation may be necessary. Here are some areas of evaluation for an assistive technology solution.

Student Driven

Your student is not keeping up or is failing his classes. A classroom teacher may ask the TVI if there is anything out there that could help this student. The student will ask if there is anything that could assist him. The student could indicate a need for assistive technology indirectly by complaining that a particular subject contains tasks that are too difficult to accomplish, or that he is not able to keep up with the class.

Home Environment

Parents may want their child to be more independent in the home. Some parents want their child to participate in the daily chores or to help in the kitchen or entertainment activities. They also may want support for a homework assignment. They are also worried about life and work after graduation.

Instructional Environment

The instructional environment may have changed, such as a transition from elementary to middle school. In third grade, the educational priority changes from learning reading skills to learning content. This usually means the instructional input is accelerated. At this point in their school careers, if the student has not mastered basic academic and study skills, the gap starts to widen between the student with a visual impairment and his or her peers. Classroom changes start happening as early as fifth grade. An average of six daily classroom changes occur in middle school. Once in high school, students work on a credit system in order to graduate. This creates an individual time limit for academic achievements, assignments, testing, and activities. The list goes on here.

Professional Inquiry

The teacher of students with visual impairment (TVI) knows that something is needed but may not know what it is. She does not have all the answers, nor should she. An assistive technology evaluation along with collaboration with other professionals could help her find the answers. Sometimes an assistive technology evaluation merely starts a conversation between professionals about the student. This collaboration is a good thing.

ASSEMBLE A TEAM OF THE STUDENT'S STAKE HOLDERS:

Professionals

Professionals in each of the student's disability categories should always be included in the team. Assistive technology issues may not always center around the student's vision. There could be motor planning issues or auditory needs. If a student receives direct or consult time from any related service such as Orientation and Mobility, Physical Therapy, Occupational Therapy, or Speech Pathology, their input is needed during the evaluation process.

Paraprofessionals

Paraprofessionals working with the student on a regular basis should be included on the team. These staff persons should always be included in the conversations. They know the student's needs because, except for the family, they often have the most frequent contact with the student.

Family Members

Family members are also an important part of the evaluation team. Parents and other family members should always be included in a discussion of assistive technology. They may know about uses for particular technologies that professionals may not have considered.

Outside School Support Services

Input from job coaches and rehabilitation teachers should be considered if needed, especially if the student is in a vocational program and near graduation from high school. A DARS Division for Blind Services (DBS) representative should also be a part of the team.

COMPILE STUDENT PROFILE INFORMATION:

Student profile information can come from various sources such as Low Vision reports, Functional Vision Evaluations, O&M reports, Full Individual Evaluations, OT/PT reports, Functional Behavior Analyses, Communication Assessments, Academic evaluations, etc. Information about the student can also be obtained by using a checklist. Several organizations such as the Georgia Project for Assistive Technology, Wisconsin Assistive Technology Initiative, University of Kentucky Assistive Technology Project and Onion Mountain Assistive Technology Assessment all have checklists. A checklist can give the professionals an overall snapshot of the student and how he functions in his learning environment.

The information needed:

- motor planning and capabilities
- functional vision
- functional hearing
- behavior
- social-emotional level
- instructional placement
- method of communication

Observe the Student in His/Her Learning Environment:

Observe the student in the environment where the assistive technology is likely to be used. Make sure to observe in the home if the family wants something to assist him with independent living or recreational leisure activities. Be sure to observe the student in math, science and language arts. If the student is in a life skills classroom environment, be sure to observe activity routines and the method of communication. You may want to also consider the time of day and whether an observation in special areas is necessary. It is important to see the most active and the most fatiguing parts of the day. The question you need to ask yourself is, how is the student accessing information in all instructional environments? It can be helpful to videotape activities.

Other questions to ask are:

- Is the student actively participating in the instructional task?
- What is he/she currently using?
- Do the tools meet the needs of the student?
- Is the student keeping up with the lesson/activity?

Other Things to Consider.

Pay attention to the lesson or activity. List behaviors that indicate active participation. Note who is interacting most with the student during class times. If there is a paraprofessional with the student, pay particular attention to how intervention takes place. Also note how ready the student is for today's lesson and how organized he is with storing and retrieving instructional materials.

INTERVIEW PROCESS:

The interview process should include the student (if possible), the classroom teachers, and the parents. Let the person being interviewed do most of the talking by asking open-ended questions (i.e., how, what, where, when). Do not ask "why" because this may put the person on the defensive.

Student Interview

Be sure to interview the student after observing in the classroom. Doing so can help you determine how the student advocates for himself. You may be able to find out if the student really understands his or her own needs. Try to determine what the student needs, as opposed to what he wants. Needs and wants are not necessarily the same. Make certain the parents or teachers are not present when interviewing the student. Answers might be skewed if they are present during the student's interview. Ask about the types of accommodations/equipment used in the instructional environment, and what are some difficult visual assignments. Ask also about suggestions he might have for accessing assignments.

Parent Interview

Interview the parents at home. Although parents may have issues related to school, many of the concerns parents have are with domestic access issues in the home, homework considerations, and outings. Usually this involves computer access. If the interview is done at the home, the surrounding environment may remind parents of needs and concerns they may have there. Ask the parent how the student does homework assignments, and about computer usage. Also ask the parents about other assistive technology used in the home, like a monocular, magnifier, or braille writer, etc.

Teacher Interview

Before interviewing classroom teachers, a few days in advance you might want to provide a question sheet to fill out and bring to the interview. Teachers are busy folks. They may not think of everything, especially if the interview time is after a long day. Some questions to ask teachers are:

- What are typical assignments and tasks in your classroom?
- What are the accommodations used by the student in your classroom?
- Is assistive technology listed in the student's IEP? (A classroom teacher may not know the answer to this).
- Does the assistive technology meet the student's need?
- How does the student problem-solve?
- Does the student advocate for himself?

NEXT ISSUE PART 2:

Based on the data collected, determine an assistive technology, set up activities for evaluating the technology, and write a report.

RESOURCE CREDITS

TSBVI VI Assessment: www.tsbvi.edu/technology/tech-assess.htm

Tech Related Links: http://www.csb-cde.ca.gov/Documents/technology_related_links.htm

Georgia Project for Assistive Technology, Vision Technology: www.gpat.org/Resources%20Main.htm

International Society for Technology in Education: www.iste.org/template.cfm

Quality Indicators for Assistive Technology Services: www.qiat.org

Texas Assistive Technology Network: <http://www.texasat.net/default.aspx?name=trainmod.home>

TEA: Technology Application Standards (K-12 TEKS): www.tea.state.tx.us/technology/ta/stustd.html

TSBVI: VI Technology Assessment: www.tsbvi.edu/technology/tech-assess.htm

Wisconsin Assistive Technology Initiative: www.wati.org/products/freematerials.html

AT Conference, CSUN 2006; Debra Leff, VI Educational Specialist, ESC Region 13 and Cecilia Robinson VI Educational Specialist, ESC Region 4

Making a Plan for the Future

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

Abstract: In this article, Superintendent Daugherty discusses the importance of family support and involvement during the high school years as the student prepares for the future.

Key Words: blindness, visually impaired, transition planning, power of the family, systems of support

A graduating class of 26 seniors walked the stage at the Texas School for the Blind and Visually Impaired (TSBVI) on June 1, and it was a great day in our new auditorium. The seniors clearly enjoyed the celebratory nature of the event in honor of all they had achieved and learned, and their teachers were visibly moved as they reflected upon the individual path of personal and academic growth each student represented. Parents and grandparents approached me during the day-long event to say how grateful they were for how their child had flourished during their time at TSBVI.

Some students had been with us as little as one year, and one or two had been enrolled for at least five. Like graduates in any high school, each of these students faces a somewhat uncertain future regardless of how much success they had in school. Some have developed compensatory skills and attitudes that almost totally neutralize the impact of visual impairment upon learning and upon independence. Others will have life-long challenges related to additional health or disability concerns. Within this entire range of individual differences, I think it is hard to accurately predict who will have the high quality of life we want for all of our kids, and who will struggle to approximate that goal. But if I was forced to select just one predictor of good life outcomes, the power of the family would rise above almost any characteristic a child might have.

Some students and their families that I have known over the years parallel my own experience with high school graduation: you get your diploma and then ask the question of what comes next. For me it was work, not college or really even the thought of college for several years until I happened upon the field of Special Education. Other families and their children I've met seem to have a plan when it comes to next steps, and it's this group, particularly those with children who have multiple disabilities, I'd like to focus on. The parent role in supporting adult children as they mature takes a lot of forms from financial resources to the collective social and emotional resources of the family unit. Some families have plenty of both of these, some have one and some almost none. Our job as a school is to collaborate with families and students in all of these situations, and our absolute best successes are with families who recognize early on that there needs to be plan. The socio-economic characteristics of the successful families range all over the map, but the commitment to making a plan is a consistent predictor of good things to come. The more the level of disability affects daily living, the more important is the plan.

A good plan likely has to differ from how families raised and supported their child before they graduated from high school. Regardless of maturation or level of independence, these children have become adults and need to be recognized as such. Regardless of family resources, the life of this young adult needs to expand to interaction with a larger community outside of the home. Friends of the family, local businesses and community resources all need to be looked at as a system of supports that can help a young adult with disabilities develop the work and social opportunities all of us value in our adult lives. There are systems in place to help parents, some of the most notable of which were developed by parents of children with disabilities, that can be used in transition planning work with school districts and DARS/DBS. Often referred to as Person Centered Planning, this process is a road map for how a family and child begin to put all of the pieces in place for moving into

adult life. Cyral Miller, Director of the TSBVI Outreach Program (512-206-9242, cyralmiller@tsbvi.edu) can put parents in touch with other parents and professionals who have great experience in this process. The Beach Center on Disability (www.beachcenter.org) at the University of Kansas is another excellent resource.

Destination Wonderland

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

Abstract: This article describes the joint project "Destination Wonderland" at Morgan's Wonderland Park.

Key Words: blind, visually impaired, disability, DARS Division for Blind Services, TSBVI, Education Service Centers, Morgan's Wonderland Park, recreation

Judging by the turnout, it was not only a hot idea, but, in spite of the heat later in the day, a great success! This was one of those special gatherings that give our consumers and their families an important opportunity to increase social skills, gain confidence, and network with other families, providers and resources. We are talking about "Destination Wonderland," the Morgan's Wonderland Family Conference, a two day event sponsored in partnership by DARS Division for Blind Services, Texas School for the Blind and Visually Impaired, and Education Service Center Regions 6, 9, 11, 13, 14, 15, and 20.



On June 16th, 1400 consumers and family members converged in San Antonio at Morgan's Wonderland. Three hundred families served by DARS Division for Blind Services were selected to attend the event. On Thursday evening, a Meet & Greet was held at each of the two hotels where the families stayed, and families took the opportunity to meet and share with other families. Name tags showing city of origin encouraged interactions. The Division for Blind Services

(DBS) prepared business cards with contact information for each family group so parents could easily exchange information. It was exciting to see parents connect with each other and make plans to stay

in touch, stating "I have your information and I will be calling you next week!" And a few lucky families won door prizes donated by various vendors and DSB field offices. The indoor swimming pool was a popular place for the kids and their parents after the Meet & Greet.

On Friday morning over 85 volunteers, consisting of DBS staff, TSBVI staff, Education Service Center Region 6 consultants and numerous teachers of the visually impaired from across the state showed up early to make sure everything was in place for the big event. Once the setup was completed, the volunteers helped with Spanish translation, special activities, and access to rides, providing information and park support.

There were also over 37 vendors and resource providers sharing information and helping families access and learn about additional services. The resource tables encircled the gym and continued into an adjoining room, resulting in a constant stream of visitors. There were, not surprisingly, more visitors as the thermometer crept up over 100 degrees!

In addition to all the attractions in the Park, families also had the opportunity to participate in a number of special activities planned by our partners. TSBVI had the gym filled with games and fun activities to challenge our consumers and their siblings. They also conducted an orientation and mobility (O&M) activity facilitated by TSBVI's Edgenie Bellah and O&M Specialists from across the state. Education Service Center Region 11, under the leadership of Olga Uriegas and Susan Trigg, provided a morning arts and crafts activity. In the afternoon Debra Leff and Jayme Wratchford from Education Service Center Region 13 provided Early Literacy activities. Texas Association for Parents of Children with Visual Impairments (TAPVI) facilitated a make and take project. And special guest 12-year-old Reed Deming, an up and coming local talent, provided a lunch time concert in the amphitheater. Then the stage was turned over to our very own DBS consumers, who entertained their parents and new friends with an outstanding talent show.

To pull off such a great event we had a number of wonderful sponsors and donors. The Lions Clubs provided a tasty lunch of hot dogs, chips, cookies and fruit for all the families, vendors and volunteers. COSTCO provided bottled water for the participants to keep everyone hydrated. The San Antonio Lighthouse for the Blind made sure all the families had a cloth bag to carry all their goodies and information. Embassy Suites assisted with hotel rooms and provided a pizza and movie deal for the families. Blue Bell made sure everyone got a much needed cold ice cream treat in the afternoon.

The record heat of 104 degrees did not seem to deter anyone from having a marvelous time. One parent stated "I have never seen my child smile so much, and he is still smiling!" Another parent was heard saying "My son just came alive today; this has been wonderful." A mom who had five young kids stated that Morgan's Wonderland was a park where her family could come and everyone got to participate, and this was the first time they could enjoy an amusement park as a family. Parents and kids alike expressed their appreciation to get to attend this event. Tara McKain, parent of Lexi, stated "We had the best time ever! Lexi had a blast and they had so many indoor things to do that we did not even get hot. She caught three fish in the lake and enjoyed every moment of it! We can't thank you enough! Thanks again!" At the end of the day, there were a lot of tired kids and parents but they

all reported that they had a great time! It was clear that many good things happened in the Park that day.

We know that an event like this is not possible without a team effort and DBS is pleased and honored to get to partner with such great agencies and organizations. Thanks to everyone for their hard work and especially to our families for participating!

AFB and NAPVI Announce Breakthrough Social Network for Parents of Visually Impaired Children

Information excerpted with permission from www.afb.org

Abstract: This article describes how FamilyFriends, a new dimension to the social networking site FamilyConnect, allows them to customize and personalize their online experience and connect with other parents and caregivers of children with visual impairments.

Key Words: blind, visually impaired, disability social network, American Foundation for the Blind (AFB), National Association for Parents of Children with Visual Impairments (NAPVI)

NEW YORK (March 10, 2011)—The American Foundation for the Blind (AFB) and the National Association for Parents of Children with Visual Impairments (NAPVI) today announced the launch of an innovative social network for parents and caregivers of visually impaired children.

FamilyFriends is the latest extension of AFB's web community, FamilyConnect. For the last three years, visitors to www.familyconnect.org have connected with other families through message boards and have explored resources related to raising children with visual impairments.

Now, FamilyFriends provides registered FamilyConnect users with new networking features and options to further customize and personalize their online experience. Users can create and post profiles that can be found by other parents based on such shared criteria as geographic location, a child's eye condition or a child's age.

"With only 94,000 visually impaired school-aged children in the U.S., over half of whom have additional disabilities, it's easy for families facing vision loss to feel alone," said Susan LaVenture, Executive Director of NAPVI. "FamilyConnect and its new social networking component, FamilyFriends, gives busy parents, grandparents and other caretakers an easy way to connect with each other and find support 24 hours a day."

"One of the most common questions I hear from families is 'how do I find other parents with a child who is coping with this diagnosis?'" said Scott Truax, FamilyConnect Program Manager. "The feeling

of isolation can be very strong and there is a real need to talk with other parents about the unique aspects of raising a child with special needs. FamilyFriends now provides a quick way to fill those needs.”

The FamilyFriends social networking features allow people experiencing vision loss in their families to come together in ways that are affirming and helpful. Users can also log into FamilyFriends for the same reason people go to other social networking sites—it gives people a real sense of community and connection. Registered members can send friendship requests, update their pages with news and photos, share links they like and follow their friends via e-mail alerts.

FamilyFriends adds a new dimension to FamilyConnect, the original web portal designed by experts at AFB and NAPVI for parents and caregivers of children with visual impairments. FamilyConnect gives parents access to message boards where they can talk to other parents, compelling videos featuring real-life families, parenting articles, a mom-authored blog, a glossary of more than 30 eye conditions and links to local resources. The site also features sections dedicated to multiple disabilities, technology, education and every age group from infants to teens.

FamilyConnect also serves Spanish-speaking families. Visitors to the FamilyConnect homepage can now choose the “Read this article in English” link or the “Leer este artículo en español” link and access more than 300 articles in Spanish. Spanish-speaking families can access the site’s Spanish language content by logging in directly to <www.familyconnect.org/Spanish>. In addition, screen reader users can hear text pronounced correctly in both languages.

“For parents who are raising children with visual impairments, there is tremendous value in discovering that there is no challenge or experience related to vision loss that is unique to them,” said Carl R. Augusto, AFB President and CEO. “With FamilyFriends and the addition of Spanish language content, this community is not only growing closer, it’s becoming richer, more diverse and better informed.”

FamilyFriends was developed under a grant from the Lavelle Fund for the Blind, Inc., which was a lead sponsor for the FamilyConnect web site. The Conrad N. Hilton Foundation was also a lead sponsor for FamilyConnect and, additionally, funded development of the Spanish-language version of the site.

ABOUT AFB

The American Foundation for the Blind (AFB) is a national nonprofit that expands possibilities for people with vision loss. AFB’s priorities include broadening access to technology; elevating the quality of information and tools for the professionals who serve people with vision loss; and promoting independent and healthy living for people with vision loss by providing them and their families with relevant and timely resources. Headquartered in New York, AFB is proud to house the Helen Keller Archives and honor the more than forty years that Helen Keller worked tirelessly with AFB.

ABOUT NAPVI

The National Association for Parents of Children with Visual Impairments (NAPVI) is an international membership organization serving families in the U.S. and in 55 countries. NAPVI helps parents to find information and resources for their children who are blind or visually impaired, including those with additional disabilities. NAPVI provides leadership, support, and education to assist parents in helping children reach their potential.

MEDIA CONTACT:

Adrianna Montague-Devaud
AFB Communications
(212) 502-7615
amontague@afb.net

Texas Guide By Your Side program

By Debbie Kopp, Texas GBYS Program Coordinator

Abstract: This article describes the Texas Guide By Your Side, a program that has specially trained parents of children who are deaf or hard of hearing and adults who are deaf or hard of hearing who will serve as a guide and offer resources, information, encouragement, and an opportunity to network with other families.

Key Words: Deafblind, deaf and hard of hearing, parent support

Guide By Your Side is a parent support program within the national organization of Hands & Voices. Hands and Voices is dedicated to supporting families with children who are deaf or hard of hearing without a bias around communication modes or methodology. It is a parent-driven, non-profit organization providing families with the resources, networks, and information they need to improve communication access and educational outcomes for their children. Outreach activities, parent/professional collaboration, and advocacy efforts are focused on enabling deaf and hard of hearing children to reach their highest potential. Hands & Voices believe that "What Works For Your Child Is What Makes The Choice Right"

www.handsandvoices.org

Texas Hands and Voices is the state chapter of national Hands & Voices. The chapter offers parents and families with children who are deaf or hard of hearing a variety of services including: direct parent to parent support through the Texas Guide By Your Side (GBYS) program, opportunities for families to network and share resources while attending workshops and trainings, social events and gatherings, and through the Chapter website, e-newsletter, and Facebook page.
www.txhandsandvoices.org

Texas Guide By Your Side (GBYS) is a parent support program offered free of charge to parents and families with children who are deaf or hard of hearing throughout the state of Texas. Texas GBYS is available through a partnership between the Texas Hands & Voices chapter and the Educational Resource Center on Deafness (ERCOD). ERCOD, located on the campus of the Texas School for the Deaf, serves as a Texas statewide resource center for deaf and hard of hearing children (birth to 22), their families, and the professionals who serve them. <http://www.texasdhhresources.org>. Texas GBYS embodies the mission of Hands & Voices, which is to provide information and support in an unbiased manner to families with children who are deaf or hard of hearing. www.txgbys.org

Texas GBYS has twelve “Guides” serving families throughout the state. There are nine “Parent Guides” who are specially trained parents of children who are deaf or hard of hearing. They work directly with families in need of the unique support that comes from someone who has walked the path him/herself and can share from direct experience and wisdom. Parent Guides can provide support and information at the time of screening and/or confirmation of a hearing loss, as well as provide a continuity of support to families throughout the child’s life, especially at times of transition. Guides offer resources, information, encouragement, and an opportunity to network with other families.

Parent Guides may provide:

- Direct parent-to-parent emotional support, encouragement, and guidance.
- General information and resources in an unbiased manner.
- Assistance in understanding early intervention and the unique educational needs of infants and youth who are deaf or hard of hearing.
- Basic information regarding communication options or methods and amplification and technology.
- Workshops, trainings, and events for parents and children.
- Networking opportunities with other families.
- Referrals to other programs that serve deaf or hard of hearing children

Texas GBYS has three “Deaf/Hard of Hearing (DHH) Guides” who are specially trained to provide families and children with the invaluable perspectives that come from personal experience. Their role is not the provision of service (i.e., to teach families sign language or to share oral training techniques), but to provide helpful examples drawn from direct experience of life as an individual who is deaf or hard of hearing. Like Parent Guides, DHH Guides are often an important link for extended family members who do not have direct contact with service providers, but do need to increase their understanding of the unique needs of a family member who is deaf or hard of hearing.

DHH Guides may provide:

- An invaluable perspective that comes from direct, personal experience.
- Exposure to a variety of communication options.

- Information regarding Deaf culture and the Deaf community.
- Awareness of and sensitivity to issues faced by individuals who are deaf or hard of hearing.
- A comfortable setting in which to ask questions about hearing loss or deafness.
- An important link for extended family members who do not have direct contact with service providers but need to increase their understanding of the unique needs of a family member who is deaf or hard of hearing.

Texas Guide By Your Side serves parents and families (including extended family members) with children who are deaf or hard of hearing:

- Living in the state of Texas
- From the age of birth to 22
- With any degree of hearing loss
- Attending any kind of educational setting
- Using any type of communication mode
- Wearing any or no amplification

To request services, parents can self-refer by completing a short on-line form. Professionals can also request services for staff or families they serve.

English: <http://www.formstack.com/forms/GBYS-request>

Spanish: <http://www.formstack.com/forms/GBYS-requestSP>

For more information, contact: Debbie Kopp, Texas GBYS Program Coordinator

512-462-5738 (voice)

512-410-1198 (videophone)

512-462-5661 (fax)

DKopp@txgbys.org

Sports Competition Invites Blind and Visually Impaired Students

Press Release from Reg. 10 Education Service Center

www.region10.org/ssvi/documents/SprtsRel.pdf Contact: Christy Householter

christy.householter@region10.org

Abstract: The 2011 Sports Extravaganza provides opportunity for students with visual impairments to compete.

Key Words: News & Views, blind, visually Impaired, sports, track and field, goal ball, competition

Blind and Visually Impaired Students who would never consider competing in a sports event are not only winning medals but also succeeding in their every day activities. October 21-22, 2011 in Irving,

Texas more than 300 visually impaired athletes will compete in the 13th Annual Sports Extravaganza. Students with Visual Impairments will participate in Paralympic type and national sports such as Track and Field, Goalball, and Beep Baseball.

A student said, "Sports Extravaganza increases my hope for the future. I got to practice some coaching skills by showing a friend how to warm up." A parent remarked "It is awesome to see the number of volunteers, especially young people, and the organization it takes to put this on. Mere thanks doesn't do all of you justice." "These students participate in Sports Extravaganza for fun, friendships and competition, and at the same time, develop skills that prepare them for life", says event coordinator, Christy Householter.

At this momentous event, students from all over the state of Texas and the United States are welcomed to compete October 21-22, 2011 at Nimitz High School in Irving, Texas. (Previous years have seen visually impaired students from Colorado, Oklahoma, and New Mexico participate.) In addition, the Lone Star Classic Goalball Tournament will be held in Irving, Texas in March, 2012.

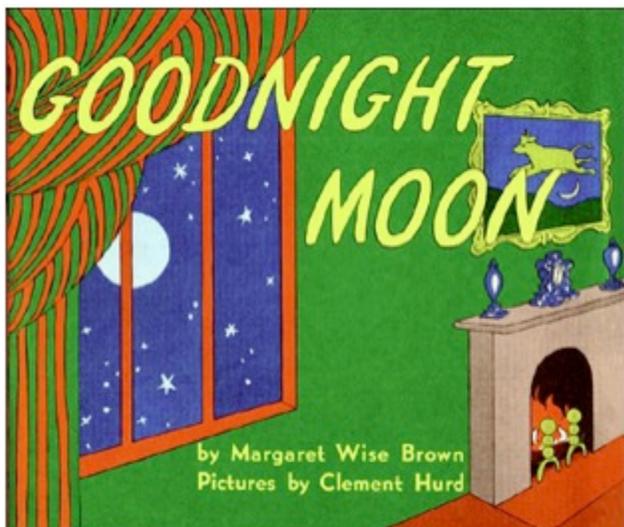
Sponsored by Region 10 Education Service Center and Lions Clubs District 2-X1 and 2-E2, the Sports Extravaganza encourages physical fitness among children with visual impairments from infants to 22-years-olds. The application, volunteer forms and more information can be found at www.region10.org/ssvi/Sports_Extravaganza.html

Goodnight Moon to Touch

Information excerpted from <http://www.nbp.org/ic/nbp/GOODMOON.html>

Abstract: This article describes the Goodnight Moon set that includes tactile graphics.

Key Words: Blindness, visual impairment, literacy, Braille, National Braille Press



Goodnight Moon has delighted children and grown-ups since 1947, and now blind children and adults can explore the "great green room" by touch!

Precious few picture books for blind children actually contain pictures. Those that do are often special books with special graphics rather than beloved classics. So we decided to challenge ourselves and make *Goodnight Moon* a real picture book. Clearly most pages were too busy to replicate in full, so we asked artist Irma Goldberg (Creative Adaptations for Learning) to re-create only those images mentioned in the text - the

bowl of mush, the comb, the mittens, and so forth. If you've ever wondered what the pictures look like in *Goodnight Moon*, you're in for some surprises—at least that's what we heard from those who got a preview.

There are three pieces to the set:

- 20 tactiles
- a guide for navigating around the images as well as more descriptive text about the pictures in the book
- a print/braille edition of *Goodnight Moon*

This set can be purchased for \$30.00 from the National Braille Press. You can contact the National Braille Press at <http://www.nbp.org/ic/nbp/publications/index.html>, or by phone at 1-800-548-7323.

2011-12 SWOMA Conference: Out of the Box and On a Shoe String

by Kate Hurst, TSBVI Statewide Staff Development Coordinator

Abstract: The 2011-12 SWOMA conference will provide training about Orientation and Mobility Instruction.

Key Words: News & Views, SWOMA, O & M, travel, Blind, Visually Impaired, training, conference

The SWOMA Planning Committee is pleased to announce the upcoming SWOMA Conference. It will be held November 10th-12th at the Texas School for the Blind & Visually Impaired Conference Center in Austin, Texas.

COMS need information about serving a wide range of individuals that include infants and toddlers, individuals with multiple impairments, elderly clients, and returning veterans. The challenges of serving all these differing needs, keeping up with advancements in technology, and being sensitive to the emotional aspects of each individual are rarely covered in most O&M training programs. Thus the need for on-going inservice opportunities, like SWOMA. COMS really need to learn how to think “outside the box” and with our current budget restrictions and reduced release time for training, we have to do it on a “shoe string”.

In order to make this year's SWOMA and time and cost effective as possible, the SWOMA Planning Committee has made some unique plans for this year's event. We will be holding the conference on the TSBVI campus in their new Conference Center. A block of rooms has been saved at the Hotel Allandale which has rooms that can accommodate up to 8 people, many rooms include a kitchenette to allow participants to save on food and rooming costs. Though the cost of the conference will be greatly reduced, the quality of the conference has not.

Tentatively scheduled speakers include:

- Diane Barnes;
- Dr. Anne Corn;
- Jim Durkel;
- Dr. Nora Griffin-Shirley;
- Joleen Kinzer;
- Ruth Ann Marsh;
- Scott Meyer;
- Dr. Richard Templeton;
- Melanie White;
- Marjie Woods;
- Representatives of the Veterans Administration;
- And panels that include COMS, teachers, PT, OT, students, and adults.

Topics include:

- Brain Injury;
- GPS: An overview of devices and hands-on;
- Structured Discovery Method;
- Using Movement Routines for Infants and Toddlers;
- O&M for Wheelchair Users and Individuals with Multiple Impairments;
- Functional and Standards-based IEPs;
- Intersection Rating Scale;
- Cochlear Implants and Impact on Travel in a Variety of Environments;
- APH O&M Product Showcase;
- Panel of Young Adults: Motivation through Recreation and Leisure;
- Getting Wheels;
- Happy Tapping: Beginning Cane Skills to Toddlers;
- O&M with Seniors;
- and more.

SWOMA will also include opportunities for blindfold practice, an update on legislation, resources, and news critical to COMS, a Dinner/Dance at Threadgill's Restaurant, and vendors.

To get more information about SWOMA and to gain access the registration website, go to www.tsbvi.edu/Outreach and follow the link to the Workshops and Conferences page. You may also email Kate Hurst at katehurst@tsbvi.edu or Carrie Keith at carriekeith@tsbvi.edu with any questions.

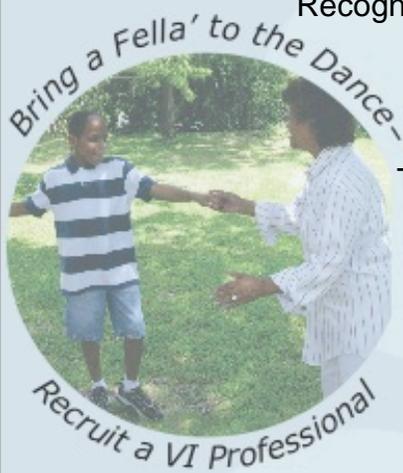
Early bird registration opens August 15th for those wishing to register at the special reduced rate and,

continues until October 1st. Registration closes on October 31st. Seating is limited so register right away!

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

TEXAS FELLOWS

Recognizing VI Professionals in their Role as Recruiters



Texas Fellow

Carol Rimka
Tressie Schindler
Sara Baker
Theresa Taylor
Kathy Krenek
Karla Cantu
Tashia Garcia
Lani Simonton
Brian Jones
Emma Lee Wilson
Mary Kainer
Cecilia Cox Hayes
Myleah Rhynes
Pat Harper
Barbara Kline
Carol Dancy
Bonnie Rudel

Candidate

Elizabeth Meek
Charlotte McKinney
Stacy Vance
Tammy Averitt
Julie Stanfield
Guadalupe Garza-Brown
Karen Baker
Cathryn King
Trish Duke
Harriet Page
Kathleen McGann
Gayla Brown
Beth Wallace
Shonda Prater
Julia Sohns
David Carabajal
Norma Freimark



For more information about becoming a Texas Fellow or working as a VI professional contact KC Dignan at

kcd@tsbvi.edu.

Bulletin Board

Announcements / Regional, State, and 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.
An up-to-date Statewide Staff Development Calendar is posted at
www.tsbvi.edu/Outreach/vi.htm.

2011 Introduction to the Intervener Team Model

September 23–24, 2011

**TSBVI Outreach Conference Center
Texas School for the Blind & Visually Impaired, Austin, TX**

Join Texas Deafblind Outreach for our annual training for new interveners (or those who have never attended this introductory training) and their teams.

Early registration for professionals / family:

\$35.00; Late Registration: \$50.00

Out of State Registration:

\$50.00; Late Registration: \$50.00

Interveners / paras:

Free; Late Registration: \$50.00

Learn more or register online:

www.certain.com/system/profile/web/index.cfm?PKwebID=0x256254b3ee

For further information please contact:

Brian Sobeck - Admin Assistant

Phone: (512) 206-9217

Email: briansobeck@tsbvi.edu

Jenny Lace - Education Specialist

Phone: (512) 206-9389

Email: jennylace@tsbvi.edu

13th Annual Sports Extravaganza For Blind and Visually Impaired Students

**Nimitz High School
100 W. Oakdale; Irving, TX**

October 21 & 22, 2011

Friday: Beginners Goalball Tourn. (5–10 p.m.)

Saturday: Individual Events (8:30 – 4:30)

For students with visual impairments, ages 0-22

There are no entry fees, but families will need to pay their own expenses for transportation and lodging if needed. (Some financial assistance may be available from your local Lions Club. Please call for more details.)

Lunch on Saturday will be provided by Lions Clubs International District 2-X1 and 2-E2.

Hotel: Country Inn & Suites – Irving, Texas

For information, or to get on the mailing list, please contact:

Christy Householter

972-348-1634

christy.householter@region10.org

Visit our web site for more information: www.region10.org/ssvi/Sports_Extravaganza.html

Registration packets available late August, 2011

The Deaf-Blind Multihandicapped Association of Texas



DBMAT: Making A Sweet Life

39th Annual DBMAT Family Conference

October 14-16, 2011

Camp John Marc, near Meridian, TX

A relaxing, fun-filled, learning weekend for all of our conference participants in a pleasant rustic environment. This conference is designed for families of children & adults who are deafblind multidisabled, deaf multidisabled, blind multidisabled and the professionals who serve them.

Featuring another wonderful opportunity to hear from Dr. Jan van Dijk and from Cheryl Ramey, an Instructor for the Intervener program at George Brown College in Canada

and a consultant for school teams as well as families.

While participating in the conference, parents & guardians are encouraged to place all their children/family members with our child care workers for fun activities, excitement and care throughout the conference activity time.

Space is limited so send in your registration early!!!

Deadline: September 5, 2011

For information and registration materials, check the DBMAT website at:

<http://www.dbmat-tx.org/newsletters/newsletter.html>

Mark your Calendars

6th Texas Chargers Annual Retreat

November 4 -6th, 2011

Camp Allen, Navasota Texas

The Texas Chargers, Inc. is a group of Texas families, friends, and professionals who are dedicated to helping children and young adults who live with Charge Syndrome. Our organization is to support the emotional and educational needs of the people with Charge Syndrome and the families and professionals working with them, to provide them with a better quality of life.

Watch for more information at:

<http://texaschargers.org>

2011-12 SWOMA Conference

Out of the Box and On a Shoe String

November 10–12, 2001

Texas School for the Blind & Visually Impaired Conference Center, Austin, TX

For more information about SWOMA and to access the registration website, go to www.tsbvi.edu/Outreach and follow the link to the Workshops and Conferences page.

Questions? You may also email:

Kate Hurst at katehurst@tsbvi.edu or Carrie Keith at carriekeith@tsbvi.edu

TSBVI Sponsored Workshops & Conferences

Outreach Programs sponsor and co-sponsor a variety of workshops and conferences on and off campus throughout the year. We also collaborate with a number of organizations to help support their annual events. Many of these events are available for as little as \$35 (Early Bird) or \$50 (Late Registration) which includes the cost of materials and two breaks.

Limited registration and/or travel stipends may be available for parents, paraprofessionals, and new teachers for select events. Check each event's on-line registration to learn more, and see if this assistance is available: www.tsbvi.edu/workshops.

Collaboration Skills: Meeting the Needs of Students with Visual Impairments in General Education Classes

Ann Adkins, VI Outreach Consultant and Outreach Staff

September 29, 2011

TSBVI Conference Center, Austin, TX

This workshop will examine the roles of itinerant Teachers of the Visually Impaired (TVIs), Certified Orientation and Mobility Specialists (COMS), and general education teachers in order to identify effective ways to meet the needs of students who are visually impaired and served in general education classrooms. We will stress the importance of developing good collaboration skills and provide suggestions and strategies to help teachers support students who are visually impaired in inclusive settings.

Audience: COMS, TVIs, ECI professionals, parents.

Using Routines with Non-Ambulatory Infants & Preschoolers to Encourage the Development of Purposeful Movement

Marjie Wood, COMS, AER Chair Division 9

October 6, 2011

TSBVI Conference Center, Austin, TX

This session will share routines that have motivated infants and preschoolers to start moving and develop purposeful movement. This session is highly interactive and will include activities with baby dolls carried out on the floor, so be sure to wear comfortable clothing. Participants will be able to develop specialized routines for their students after the discussion on effective methods, materials and goals. This session is limited to 20 participants and is designed primarily for Certified Orientation and Mobility Specialists (COMS) and Teachers of the Visually Impaired (TVIs).

Audience: COMS, TVIs, ECI professionals, parents.

Adaptive PE for Students with Visual and Multiple Impairments

Elina Mullen, Ed.D. CAPE, Adapted Physical Education Teacher,
Texas School for the Blind and Visually Impaired

October 27, 2011

TSBVI Conference Center, Austin, TX

Like their peers, students with visual impairments, including those with significant additional impairments benefit greatly from learning recreational skills and fitness activities. Elina will share information about the impact of visual impairments and other disabilities on these students access to physical education and discuss strategies for including them in a variety of physical activities. She will emphasize adapting commercial products and modifying sports to allow for participation.

Audience: APE instructors, Teachers of the Visually Impaired (TVIs), Teachers of the Deaf, Certified Orientation and Mobility Specialists (COMS), parents.

Teaching Braille Music

Sharon Nichols, Outreach Technology Consultant, and Brian Sobeck, BA in Music Composition

December 1, 2011

TSBVI Conference Center, Austin, TX

Want to help your student learn to read braille music? This hands-on workshop will provide you with strategies and resources for doing just that.

Audience: Teachers of the Visually Impaired (TVIs), Music Teachers.

Interesting Facts About Skin and the Importance of Good and Safe Touch in Brain Development

Gigi Newton, Early Childhood Consultants, TSBVI Outreach Program

January 13, 2012

TSBVI Conference Center, Austin, TX

Studies have shown how important good and safe touch is for an infant's survival, growth, and development both emotionally and physically. Information will be shared why good and safe touch is vital for all human beings and what techniques can be done to promote this type of touch.

Audience: Early childhood instructors, Teachers of the Visually Impaired (TVIs), Teachers of the Deaf, Certified Orientation and Mobility Specialists (COMS), parents.

Assessment of Students with Visual Impairments: New Tools, Successful Strategies

Marnee Loftin, Psychologist, Texas School for the Blind and Visually Impaired

January 20, 2012

TSBVI Conference Center, Austin, TX

Blindness is a very low incidence disability area, and most evaluation staff have irregular opportunities for assessing students with visual impairments. Time-tested tips and strategies will be shared. A new braille edition of the Woodcock Johnson and a new tool from Dr. Joan Chase offer improved options.

Audience: School psychologists, Diagnosticians, Teachers of the Visually Impaired (TVIs).

TX SenseAbilities

Published quarterly: February, May, August, and November

Available in Spanish and English on TSBVI's website at

<www.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

If you no longer wish to receive this newsletter, please call Beth Bible at (512) 206-9103

or email <bethbible@tsbvi.edu>.

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

Production Staff

Editor-in-Chief

David Wiley (512) 206-9219

<davidwiley@tsbvi.edu>

Editor's Assistant

Beth Bible (512)206-9103
<bethbible@tsbvi.edu>

DARS-DBS Editor

Beth Dennis (512) 377-0578
<Beth.Dennis@dars.state.tx.us>

Website Editor

Jim Allan (512) 206-9315
<jimallan@tsbvi.edu>

Spanish Edition Editor

Jean Robinson (512) 206-9418
<jeanrobinson@tsbvi.edu>

Braille Transcriber

B.J. Cepeda (512) 377-0665
<Bj.cepeda@dars.state.tx.us>

Section Editors

Family Editors

Edgenie Bellah (512) 206-9423
<edgeniebellah@tsbvi.edu>
Jean Robinson (512) 206-9418
<jeanrobinson@tsbvi.edu>

Programming Editors

Stacy Shafer (512) 206-9140
<stacyshafer@tsbvi.edu>
Holly Cooper (512) 206-9217
<hollycooper@tsbvi.edu>

News and Views

Beth Dennis (512) 377-0578
<Beth.Dennis@dars.state.tx.us>

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Outreach Program
1100 W. 45th Street
Austin, TX 78756