



# In Touch

The Newsletter of the Deafblind Multihandicapped Association of Texas

Winter Edition ~ February 2010



## In This Issue

by Steve Schoen Executive Director

## From the President's Pen



*I can't believe another year has ended. 2009 was a great and very busy year for DBMAT. We realized two of our goals. We got both of our bills passed and that was a major accomplishment. Hopefully, this year will be just as good if not better.*

*Our Family Conference was a great success. It was the first time that we completely filled the camp and had a waiting list. It made me feel so good to see camp full. I met so many new families this year. It was great to get see some of our old friends as well.*

*The following officers were elected at the annual business meeting:*

- Paul Welch - President*
- Vivecca Hartman - Treasurer*
- Alaine Hinds - Member-At-Large*
- Denise Sewell - Member-At-Large*
- Jillana Holt-Reuter - Member -At-Large*
- Rebecca Abrego - Member- At-Large*

*Three awards are given out every year at the Family Conference. Chris Palasota received the Christian Knapp Award for the great motivator. Gay Bellamy was awarded the Everett Bryan Award for the Professional who has gone "above and beyond" in her work with people with Deaf Blindness . The Olivia Cruz Award was given to the Khan Family for their dedication and efforts on behalf of persons with Deaf Blindness. Congratulations and thank you for all you do!*

*Don't forget to mark your calendars for the Christian Knapp Memorial Golf Tournament on May 14<sup>th</sup> in Friendswood, Texas. Hope to see you there.*

*We can always use more help on our committees. Anyone who would like to sign up for committees contact Paul @432-263-1658 ([pwelch@usaonline.net](mailto:pwelch@usaonline.net)) or Steve @512-336-7859 ([stephenschoen@sbcglobal.net](mailto:stephenschoen@sbcglobal.net)).*

Paul Welch

We are excited to get this issue to you. It means our long season of procrastination has come to an end! In this issue you will find the following:

- 1) President Paul Welch gives all readers a hearty welcome.
- 2) Robbie Caldwell writes about her family's decision-making process to obtain a quality education for daughter Gabby.
- 3) Vice President Wayne Thompson describes his feelings about this year's conference.
- 4) Rubina and Fareed Khan share their story about their decision to send daughter Tania to the Texas School for the Blind in Austin. You will see that the Caldwell's and the Khan's faced similar challenges and creatively sought out the best answer they could for their children.
- 5) Marcia Hartman shares a grandmother's view of life with a grandchild who is deafblind.
- 6) Steve Schoen (me) outlines DBMAT's progress in achieving our long range goals. This includes a hearty exhortation to continue striving till these goals are accomplished.

In our next issues you could see your own thoughts. Feel free to send any ideas you have for newsletter articles to me at [stephenschoen@sbcglobal.net](mailto:stephenschoen@sbcglobal.net)

### Table of Contents

President's Pen .....	1
In This Issue.....	1
My Daughter Gabby.....	2
My Time at Camp .....	3
Our First Camp Experience.....	3
Christian Knapp Memorial Golf Tournament .....	3
Five Years .....	3
My Time With Christopher.....	5
Updates on Our Legislative Projects .....	5
2009 DBMAT Conference Pictures .....	7

# My Daughter Gabby

by Robbie Caldwell

My husband and I are products of the best that Houston's public schools had to offer at the time: HISD's Vanguard Program. We were educated by teachers who loved their area of expertise, enjoyed children, and most of all, wanted to make a difference. I entered the Vanguard Program in 2<sup>nd</sup> Grade and this experience colored how I viewed teachers and the public school system. I viewed them through a lens of dedication, love, and excellence. (*Screeching sound at this point in the narrative.*) Imagine our shock, when our daughter entered the Deaf-Coop in our beautiful suburban school district. It was the complete polar opposite of my ideal, on so many levels. And let me preface this, so as to not sound like a letter of complaint about teachers and Texas public education. I think they are asked to do way too much, with very little, if any support from administration or adequate training for the vast array of challenges children with disabilities display in an educational setting.

At best, we were floundering. I mean, all of us were floundering. As parents, we were in no way prepared to advocate for a complex special needs child in the maze of ARDs, IEPs, Deaf Ed Teachers, VI Teachers, PT, OT, Speech, IDEA, TEA rules and regulations, doctors orders, and medical considerations. Our parents had only to attend school games, performances and the occasional parent-teacher conference. These were our role models for parenting a vanilla child, but we had a tapioca, rocky-road, boysenberry mix child. Gabrielle (Gabby) was born at 23 weeks, weighing 350 grams (12 ounces). She spent the first 4 years extremely fragile, with a trach, ventilator, g-button, and more. As my husband likes to call her: our very own conundrum, wrapped in an enigma. She was and still is a child who can read and test at or near grade level, with limited expressive language. A child that is profoundly deaf with cochlear implants. She is blind with a severely reduced field of vision and acuity, but with her contacts on she appears to have pretty decent functional vision. However, her constant movement and looking around to "take it all in" only exacerbates her ADHD behaviors in the classroom. This was a classroom where they expected students to sit still, "listen" to a teacher, or attend to an interpreter for all instruction. The school felt they needed to prepare students for the TAKS starting in Pre-K. Quickly it became clear that our young energetic teacher and her trusty aid were overwhelmed with many children with varying degrees of hearing loss, as well as other disabilities. As many of you have experienced, the school was overwhelmed and in my opinion somewhat apathetic. This showed daily and was not at all what I had envisioned for my daughter. Gabby went from a child who was excited every time we said the word "school", to a child who cried uncontrollably when we were driving on any roads near her school. As I stated before, we were all floundering.

She was at the end of her Kindergarten year and we were at a crossroad. We were very dissatisfied with most of the aspects of Gabby's education. We knew that she shouldn't stay at the Deaf-Coop and she couldn't go back to our neighborhood school. We started exploring. We were looking for some place, any place that did at least one of the areas well. We looked at an area private school for children with neurological or developmental disabilities, but they couldn't handle children with a hearing loss or visual impairments. One day, I overheard another mother mention that the Texas School for the Deaf had a great elementary program. We scheduled a tour and got to visit Carolyn Gay's 1<sup>st</sup> grade class. Wow! That's my one word testimony for the impression this teacher made on my husband and I. If this is what TSD had to offer, we were pleased. Energetic, teachers who loved to teach. Gabby would learn sign language (ASL), which would help with her expressive language. However, there were still so many unanswered questions. Would this be a good fit for Gabby? Not to mention, that we lived in Sugar Land and the School for the Deaf is in Austin. Like all other overprotective parents, we were apprehensive about sending our 6 year old off to a residential school. We decided to give them a test drive during their two week summer program. We stayed in a hotel for two weeks and I drove her daily to the school. It was during the summer program that the school (on their own) paired her up with a one-on-one aide who voiced. Each day she wanted me to pick her up later and later. She loved it! (halting screech, again...*the good kind of screech!*) Could this be the place we were looking for? We were definitely willing to give them a try. With a lot of debating, I convinced my husband that this is was the best choice for our one and only Gabster. And we were blessed to be in the position to be able to move. We had no other children to consider and he worked all over the country. We could always come back home. He conceded and we packed up and moved the very next month.

Moving to Austin was the BEST thing we could have done for Gabby at that time. But, moving to Austin and having her attend TSD is not our "happily ever after." As most of you know, this is a long, long journey down a winding road. The level of professionals you meet in both the deaf and blind communities here in Austin are outstanding. They are some of the best professionals and individuals I know. We were even more lucky that TSD's VI Teacher Peggy Miller happened to be on the Texas DeafBlind Taskforce. She and the entire team, including the Principal and other administrators have been instrumental in Gabby's programming and progress. They are working with us to make creative solutions for Gabby's education, including partnering with TSBVI. My idealism is being restored bit by bit.



## *My Time at Camp*

*by Wayne Thompson*

It is always so great to attend our camp and conference each year. We are able to see our friends whom we have grown to love over the years. We also meet new families who we hope to see again.

I am inspired not only by the "old timers" but by the young families who are the future of DBMAT. I also missed many who were not able to attend this year. I hope I get to see those again soon.

The break out session for fathers did my heart good. I hope each father who attended heard something that was meaningful to them. I was particularly impressed by the young fathers who attended. Thank you so much for the opportunity to share with each of you.

On the pathway down to the archery area, my son Kevin discovered a brick in honor of Caleb Thompson in 2001. We were not aware that this brick existed. We attended Camp John Mark twice that year; once with DBMAT and once with a group from Our Children's House at Baylor. The brick was placed there by someone from Our Children's House. It is a reminder of how our children impact the lives of others.

I am honored to have his name on that brick. At Camp John Mark I have met so many who have impacted our lives. We have also attained information at our workshops that has helped us get where we are today!

Congratulations to the deserving recipients of the awards this year! Thanks to each of you for being part of our lives. I am looking forward to seeing everyone again next year. I am also hoping to meet many new families next year.

**KEEP IN TOUCH WITH EACH OTHER !!!**



**We have booked the golf course for the Christian Knapp Memorial Golf Tournament. Please save the date:**

**FRIDAY, MAY 14, 2010  
SHOTGUN 0800 A.M.  
TIMBERCREEK GOLF COURSE  
FRIENDSWOOD, TEXAS**

**Of course we will need:**

- **golfers**
- **volunteers to help that day**
- **raffle items**

**Please let me know if you can help with any of these.**



**Thanks very much and look forward to hearing from you.**

**Melanie and Gary Knapp**



## *Five Years*

*by Rubina and Fareed Khan*

Five years. That is how long it took us to decide to send our "poor innocent deafblind child" to a different city to study. Tania was 15 and for the past several years our local schools were unable to meet her needs. We kept trying, fighting, begging for services to give our child the good (and, of course free and appropriate) education that she deserved. We met with the school district, we searched for interveners ourselves, we harassed the deafblind outreach team from The Texas School for the Blind and Visually Impaired (TSBVI) in Austin to come down and help the local schools. We almost went to litigation. A part of us recognized that TSBVI is better because the resources for Deafblindness are limited and by default the expertise is concentrated in Austin at the school. Our School district had wanted us to move to the Regional Day School that they had identified as the resource for deafblindness but we knew better. The school district was never interested in having a comprehensive program for deafblindness. Only TSBVI could do that.

While all these thoughts buzzed in and out of our consciousness, the years were passing. Tania was hanging in there getting some kind of education; she had interveners who were trying their best and some teachers who made an effort but were bogged down by having classrooms full of

multiple special needs children with varied, opposing needs, aides who were underpaid and overworked and a culture where folks did not show up. The substitutes were poorly prepared and downright inferior. If the teacher in the classroom was bad or did not know or care about deafblindness then the experience was even more miserable. And there were years of that sort of apathy. All the while, we had the Outreach team telling us over and over: She can do better, she deserves better, she needs more, think about other options. Just like a guardian angel sitting on your shoulder prompting, cajoling, prodding. We needed that sort of persistence because our fears were supreme over any rational thoughts. So we thought and thought.... for five years. It was not as if we had another option. The only option was sending Tania to TSBVI, where she would be in a more "restricted environment" but with experts who deal with her kind of disability daily. She would be with people who did not need to be taught; they were already trained in deafblindness. Only the students would teach these experts even more. These experts would now become Tania experts. We could not let that opportunity slip away, could we?

But how could we send our precious child away from us? We are such a close-knit family. We have always included Tania in every activity from mundane trips to the grocery store to exotic vacations in Morocco. We have always been hands on, reserving respite care only for times when we had to work. How could we now trust others to feed her, bathe her, hug her, say good night to her, and cater to her whims? How could we make her sleep in a dorm with strangers watching her? School there might be great, but could we risk estranging our daughter from us? Would it be worth it? Would we lose the close bonds we had with her? Would we hurt her feelings and make her believe we had sent her away from us? Would she understand the change? Or would Tania think she was being punished or worse abandoned?

These questions went over and over in our minds and we could not bring ourselves to send Tania to Austin (3 hours away by car). Then Tania herself started letting us know that she needed more. She started getting moody and emotional, having tantrums, throwing things, acting out at school. She was learning more signs, but getting bored with her activities. She needed more challenges than we could give her. So we decided to make the move. Tania was ready for a better school, better teachers. We talked to TSBVI, asked them if they could take Tania and give her the education she needed. They said "Yes!" We talked with her current school, they were only too happy to

make the referral. Meetings were held, paperwork was completed. Tania was approved to go to Austin, December 2008. But now there was no space in the classrooms there. So we waited. Six months passed. Tania got naughtier, more demanding, more moody. Guiltily we started looking forward to Tania going to Austin. Finally we were told that she had a place in the best classroom, with the best, most experienced teacher in deafblindness. She was to start in August with the new semester. We were so excited. August --- our whole family drove down to Austin to drop Tania to her new school. We had a truckload of her stuff. We had a long day of registration ahead of us. We were not sure if Tania knew what was happening though we had tried to explain the change to her. We went through all the formalities of registration dragging all our three kids with us. There was barely time to eat lunch. Finally evening came, Tania was in her dorm and it was time to leave. This was a very tearful goodbye. Tania looked confused, her siblings were sad and we were crying. We drove back to Houston in silence.

We were at work next day, getting regular reports from Austin. Tania went on a hunger strike. She refused to eat or drink anything for two days. She did not sleep all night. On the third day we started panicking. Her wonderful teacher promised us that by hook or by crook he would get some food into Tania. And he did! It was a slow start but he managed to persuade stubborn Tania to take a few bites of yogurt. He also managed to get her interested in school activities. Slowly, but surely Tania started to come around. We made it to Friday when the bus would bring her home.

What a homecoming! It was so great to see her back, though she did look a little stunned. Maybe it was the grueling four hour bus ride back to us. Maybe it was the emotions she could not express. Maybe she was angry. Maybe she was confused. We spent the weekend looking at her telling her we were "happy, happy Tania was home" hoping she understood. Hoping she would forgive. The first weekend with Tania back home was interesting. She was happy to be

back, but moodier than ever. Taking her back on Sunday was traumatic. We had made a commitment that we would let her come home by bus, but we would personally drop her back every Sunday, even if it meant an eight-hour venture for us every weekend. Tania refused to get in the car. The next week she got in but refused to get out at TSBVI. The week after she got out of the car but refused to walk in to her dorm.



The week after that she walked to the door but refused to ring the door bell. Little by little she learned how to separate from us. She gave us cues to let us know it was okay to leave. All along she has been letting us know. She has taught us that she understands the value of this move. She might not like the separation but she knows that this is for the best.

Tania had some rough weeks at first, especially in the evenings, with more free time. She has been doing better and better as time passes. She is communicating more freely with us, using symbols and sign language. She is making



demands; she is "listening" more, understanding more. She is making decisions and choices. She is maturing. She can independently entertain herself, no doubt a skill learned by Tania out of necessity of fighting loneliness. Not that TSBVI has let her be lonely. Independence is a skill we have all had to learn in our lives. Both Tania and we are learning to function independently of each

other. The car rides back are still tough. She gets used to being home on the weekends and does not like to travel back. But now, when we drop her off, she waves goodbye to us before we are ready. She is ready to disconnect from us every Sunday evening and to face the week ahead. Now, five months later we can clearly see that TSBVI has been fantastic for Tania. Every week as she has been getting more comfortable with her new routine she has been getting calmer and happier. We have had an excellent communication with her teacher and the other staff. Maybe we should have done this five years earlier. Maybe it takes five years to make such a monumental decision. Either way the decision has been made, the die was cast and the roll was a good one.

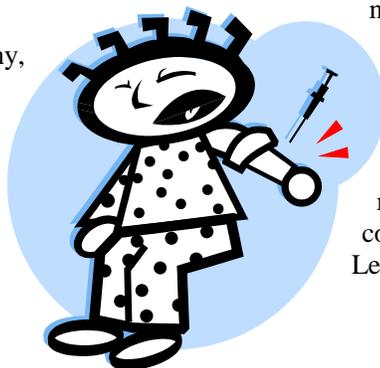
Here is to the next five years.



## My Time with Christopher

by Grandma Marcia Hartman

Hi, I'm Grandma! Christopher's funny, he's sad, and guess what...he's just like everyone else. Christopher's favorite time is playing with Dad. One day Dad took Christopher to the doctor to have two shots. When he got home he took my hand and put my hand on one



spot then took my other hand and put it on another spot, then I knew he had had two shots. He knows the doctor. He knows the place smells funny. The doctor's office is not his thing.

Something funny happened once. Dad and Christopher went out in the backyard to hang a hammock and Dad didn't see the rotten part on the rope. The hammock was hung. Dad and Christopher jumped on, both laying on their backs having a great time – then boom!! They both hit the ground. Well, Dad fixed it. It took Christopher a few weeks before he would get on the hammock again but he got back on it and he loves it.



One day, Mom was playing with Christopher. He was sitting on a spinning top, Mom was spinning him fast and slow teaching him the signs. Christopher loved it. He signed fast. It was great watching him learn to play. At school he is signing more, learning Braille, making gifts for family, cooking, and counting. He's making good progress. All his teachers are great. Summer time is fun. Christopher loves to swim. He is a fish in the water, very natural.

My time with Christopher is precious. He has his own mind just watching him grow and learn makes me happy.



## Update on Our Legislative Projects

by Steve Schoen

The DBMAT vision is for all people who are deafblind to have the skilled interveners they need throughout their lives. We are making significant progress toward this goal. But continued efforts will be necessary over a long time to see this goal turn into a reality for every deafblind person in Texas. We should be satisfied with nothing less. So this little article is to summarize where we are now, where will be shortly, and what needs to happen next.



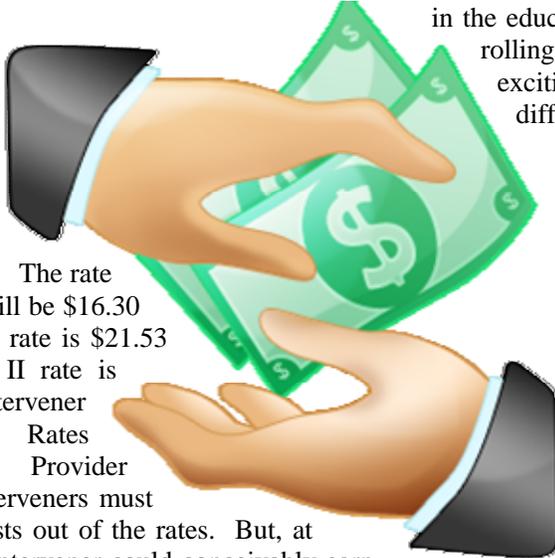
**Where we are now:** The Texas Department of Aging and Disability Services (DADS) has been doing a great job updating the rules for the Deaf-Blind Medicaid Waiver to correspond with SB 37 (the Bill we championed in the Legislature last year to serve children in the Deaf-Blind

Medicaid Waiver DB-MD) and to correspond with SB 63 (the bill to create a career ladder for interveners in the DB-MD waiver). The new rules are now officially “proposed rules”, which were presented to the Medical Care Advisory Committee (MCAC) two weeks ago. Children are already eligible to be served in the DB-MD waiver at this time. At the same time, HHSC has set tentative rates for the Intervener career ladder. These rates were formally proposed to the public on January 26<sup>th</sup>.

**Where we will be**

**shortly:** The rules for the DB-MD waiver should be official by May of this year. The new rates for interveners should also go into effect at that time.

The rates are very exciting! The rate for beginning interveners will be \$16.30 per hour. The Intervener I rate is \$21.53 an hour. The Intervener II rate is \$25.61 an hour, and the Intervener III rate is \$29.69 an hour. Rates are different than salaries. Provider agencies which employ interveners must pay their administrative costs out of the rates. But, at the Intervener III level an interverner could conceivably earn \$50,000 a year for full time work. This accomplishes our goal of seeing interveners able to support a family on their earnings.



intervener ladder, people need to take deaf-blind related college courses. DBMAT is funding scholarships for tuition for the online interverner college courses from Utah University. Direct people to our web site for the scholarship forms:

[http://www.dbmat-tx.org/intervener/scholarship\\_letter.html](http://www.dbmat-tx.org/intervener/scholarship_letter.html)

There is even more to do, especially concerning interveners in the education system, but for purposes of getting the ball rolling, let's focus on 1, 2 and 3 right now. It's an exciting time, and the opportunities to make a difference are immediately in front of us.

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**What needs to happen next:**

1) We need to be sure that all deafblind children are on the DB-MD interest list. If for some reason you know of a child who is not on the “interest list” for the DB-MD waiver, call 1-877-438-5658 and get them on the list. You can also call this number to check where you are on the list.



2) We need to ensure that people who are on the interest list, don't have to wait too long before services begin. The Legislature will need to increase “slots” in the waiver, and increase funding to DADS to fill these slots. DBMAT will need to contact their Legislators starting next year, to make this happen.

3) We need to make sure interveners in the DB-MD Waiver get the training they need to move up the career ladder. If you have a loved one in the DB-MD waiver, talk to your provider agency. Explain that they can find the proposed draft rules relating to the steps on the interverner career ladder by going to: <http://www.dbmat-tx.org/documents/QualificationsforanIntervener.pdf> Be sure they understand how advantageous it is for interveners to climb the ladder. Inform interveners about the DBMAT interverner scholarships. To climb the

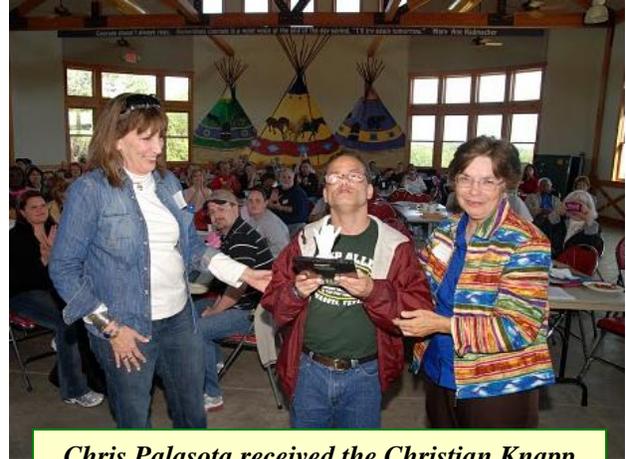




# 2009 DBMAT Conference Pictures



*The Olivia Cruz Award was given to the Khan Family for their dedication and efforts on behalf of persons with Deaf Blindness*



*Chris Palasota received the Christian Knapp Award for the great motivator*



*Gay Bellamy was awarded the Everett Bryan Award for the Professional who has gone "above and beyond" in her work with people with Deaf Blindness*



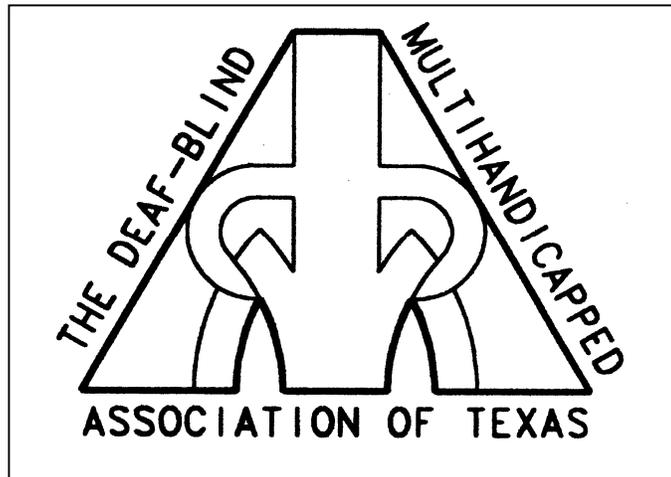
**DBMAT Board Members**

**Back Row (L-R): Cyndi Hunley, Melanie Knapp, Jackie Carter, Paul Welch, Steve Schoen, Jillana Holt-Reuter, Wayne Thompson, Alaine Hinds  
Front Row (L-R): Rosa Douglas, Denise Sewell, Vivecca Hartman, Rebecca Abrego**

To see many more 2009 conference pics go to:  
[http://www.dbmat-tx.org/annual\\_conference/a\\_c.html](http://www.dbmat-tx.org/annual_conference/a_c.html)

The Deaf-Blind Multihandicapped  
Association of Texas (DBMAT)  
909 Mountain Park Drive  
Big Spring, TX. 79720

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If you would like to be dropped from DBMAT mailing list or have a change of address  
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