



In Touch

The Newsletter of the Deafblind
Multihandicapped Association of Texas
Winter Edition ~ February 2017

From the President's Pen



The definition of a President is "the highest elected or appointed officer or position within an organization".

It has been an honor to serve as President of DBMAT. But, the President is only as good as the people around her/him. I could not have dreamed a better group of people to support me and our unified mission and vision...to make lives better for our deafblind population.

Each one of you -whether you realize it or not- have continued to strengthen the foundation that DBMAT was built on by wonderful families more than 40 years ago.

I know there will always be challenges in our future. But what is most incredible about our organization is that we have proven time and time again throughout the years that our family members and friends that are deafblind are our priority.

You are their voice for change!

So...my DBMAT family...I thank you for your time, your work, and your unrelenting passion and drive.

So my only advice to you....when it comes to the Cogswell-Macy Act, or Interveners, or something you believe in so strongly....remind your legislative leaders.....

"It is the right thing to do"

Melanie Knapp

PS. I want to also thank my son Christian for being the drive behind our family. It all began with a young manChristianand his remarkable journey with his Intervener Ann.



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The next **Christian Knapp Memorial Golf Tournament** will be **Friday, October 20, 2017** starting at 12:30 p.m. at the **Quail Valley Golf Course** in Missouri City.

Please mark your calendars and invite all your golf loving friends. The Golf Tournament is our primary way to raise funds for our intervener initiative.



The Thompson's

By: Melanie Knapp

One of the best things about joining DBMAT is meeting and getting to know the people. Gary and I met Diedra and Wayne, Caleb, Dugan, and Kevin Thompson in 2004- the year we joined DBMAT.



Kevin was friendly and a sweetheart....now he is

away at college and I get the weather report from Him every now and then via Facebook. I imagine in a few years we will be getting the weather report from Kevin on a TV station!

Dugan and I are also on Facebook. I get to experience what a wonderful Mother she has become by watching her precious baby grow up. I have always felt Dugan's quiet and sensitive spirit, and her love for her family whenever I have been around her.

Our family will always be connected to The Thompson family. Unfortunately we share the same heartbreak. We both have lost a son and a brother that we loved beyond words.

We also share that we had two amazing young men, Caleb and Christian, whom were both "The Great Motivators".

Never wavering, Wayne believed that the Legislative arena should have the pleasure of meeting Caleb. Through his Dad's voice and determination....Caleb made friends in the legislative arena. His friendship with Representative Susan King led to bills that were passed for the DBMD Waiver in Texas in 2009.

Gary and I were so honored to present Caleb with The Great Motivator award in 2008.



Texas Workforce Commission Contacts

By: Susie Welch

Tammy Martin is the head of the Children's Program. The change with Transition Program moving to age 14 will be effective on October 1, 2017 – More to come in our next newsletter about what this will all mean. Here are some updates:

Blind **Children's** Vocational Discovery and Development Program is now under Texas Health and Human Services Commission. Any referral who is visually impaired or blind ages 0 through 9 can be sent to this program. For more info call 1-877-787-8999.

The Transition Program that served visually impaired and blind youth ages **10** through age **22**. This program is now under Texas Workforce Commission. For more info call 1-800-628-5115.

The Vocational Rehabilitation Program serves visually impaired and blind **adults at any age** who want to retain or gain employment. This program is under Texas Workforce Commission. For info call 1-800-628-5115.

The Older Individuals who are Blind program serves visually impaired and blind adults age **55** and older who want to maintain an independent life and are not interested in employment. This program is under Texas Workforce Commission. For info call 1-800-628-5115.

The Independent Living Services Program serves visually impaired and blind adults **under the age of 55** who want to maintain an independent life. This program is provided through local Independent living Centers and referral information can be accessed at:

<https://hhs.texas.gov/services/disability/independent-living-services>. A person can also call 1-877-787-8999.

For STAR Anything, you can also call HHSC Ombudsman office at 1-877-787-8989 or 1-866-566-8989! If you have a Care Coordinator include them.



Taking the Time to Talk

"Cogswell-Macy Act"

by Heather Withrow

In October 2015, Orion and I, during a NIH-NEI* deafblind gene research visit, we were blessed to be able to meet dear old friends from our Maryland days and pay a visit to a legislative aide in Senator Cornyn's office to share information about the Cogswell-Macy Act. Barbara Raimondo, the CEASD** government relations liaison, and an ASL interpreter met with me outside Senator Cornyn's office. We strolled Orion in with a local volunteer intervener as well. Orion knew that we'd do fine so he took a nap in his stroller at the table as Barbara explained to the aide about the Cogswell-Macy Act

and I shared examples of experiences of our Texas families of DeafBlind children.

One example from my family's experiences was that we had to move to another state halfway across the country to Texas, to get Orion appropriate services, particularly intervener support, as he grows up through the educational system. We sure kept the aide busy writing notes in her notebook. Her pen even dried out during the process!



We need to make sure to bring extra DBMAT "ILY" (I love you) handshape pens for future opportunities like this!

Time has passed without a single senator in our nation stepping forward to sponsor the Cogswell-Macy Act. We need to continue to try even after our National Advocacy Day efforts at the US Capitol Building on March 2, 2016 with Melanie Knapp and Vivecca Hartman, the National Call-In Day April 14, 2016, and the Texas Call-In Day on July 28, 2016. It felt like a miracle that during fall 2016, U.S. Representative Sheila Jackson Lee (Houston area) stepped forward in support of the Cogswell-Macy Act. This may just be the first leak in the dam.

Another possible opportunity we have is when the Individuals with Disabilities Education Act (IDEA) needs to be re-authorized, we can specifically push

for the components of the Cogswell-Macy Act to be incorporated into IDEA at that time. Our US-level legislators will hopefully have prior knowledge from our tireless visits, e-mails and phone calls.

Keep it up, awesome and loving Texas families!

*NIH-NEI: National Institutes of Health's National Eye Institute
**CEASD: Conference of Educational Administrators of Schools and Programs for the Deaf



Alice Cogswell and Anne Sullivan Macy Act (H.R. 3535)

Shared from the www.intervener.org website

Named for the first deaf student to be formally educated in the U.S. and for Helen Keller's beloved teacher, respectively, the Alice Cogswell and Anne Sullivan Macy Act will strengthen the Individuals with Disabilities Education Act to improve results for deaf, hard of hearing, blind, visually impaired, and deaf-blind children, including those with additional disabilities.

On September 17, 2015, a comprehensive **Bill** to reform the education of deaf, hard of hearing, blind, visually impaired, and deafblind students was introduced in the U.S. House of Representatives. Sponsored by Congressmen Matt Cartwright (D) and David McKinley (R), H.R. 3535, the Alice Cogswell and Anne Sullivan Macy Act, the bill will amend the Individuals with Disabilities Education Act to address the unique needs of these populations. This is truly a historic event.

The Act includes 3 sections. Title I addresses issues specific to the education of children who are deaf/hard of hearing, Title II addresses issues specific to the education of children who are blind/visually impaired, and Title III addresses issues specific to the education of children who are deafblind. Click [Cogswell/Macy Act: https://www.congress.gov/114/bills/hr3535/BILLS-114hr3535ih.xml](https://www.congress.gov/114/bills/hr3535/BILLS-114hr3535ih.xml)

to read the full text of the Bill. [TITLE III: http://intervener.org/wp-content/uploads/2015/10/BILLS-114hr3535ih1.pdf](http://intervener.org/wp-content/uploads/2015/10/BILLS-114hr3535ih1.pdf)

begins on page 40 of the Act and includes wording which:

- Designates intervener services in the "related services" listing
- Reflects the need for the recognition of and training for teachers of the deafblind
- Adapts the federal definition of deafblindness
- Requires each state to specifically address deafblind issues in the development of its state plan

The Alice Cogswell and Anne Sullivan Macy bill now needs to gain the sponsorship of many more House members, and it needs to be introduced in the Senate. **Please take a few moments to contact your Congressional members to ask them to sponsor this bill either by phone or email.** You can find your state [Senators by clicking here; http://intervener.org/wp-content/uploads/2015/10/BILLS-114hr3535ih1.pdf](http://intervener.org/wp-content/uploads/2015/10/BILLS-114hr3535ih1.pdf)

and your [Members of Congress by clicking here; http://www.house.gov/representatives/](http://www.house.gov/representatives/)

If you choose to call, follow these steps:

1. Call the Capitol switchboard at [202-224-3121](tel:202-224-3121). The Leadership Conference on Civil Rights provides great information to help you in telephoning your Representative; http://civilrights.org/action_center/resources/calling-congress.html
2. When someone answers (or if you reach an answering machine) identify yourself and let them know you're a constituent.
3. Ask your member of Congress, and their staff whom you're likely to speak to, to co-sponsor the Cogswell-Macy Act – H.R. 3535, and ask him/her to get back to you with a response. For the full text, point them to the: [Cogswell/Macy Act:](https://www.congress.gov/114/bills/hr3535/BILLS-114hr3535ih.xml)

<https://www.congress.gov/bill/114th-congress/house-bill/3535/text>

If you choose to email, there are sample messages at the bottom of the article on Intervener.org:

<http://intervener.org/cogswell-macy-act/>

Be sure to tailor your message to your particular situation.

For more information contact Linda Alsop or Sally Prouty at 1-855-357-5571.



The Thompson Family

By: The Hartman Family

In honor of Caleb Thompson and his family, I am writing this article about my families observations and admiration for their family!

The first time we met the Thompson's was at the DeafBlind Multihandicapped Association of Texas ("DBMAT") camp years ago! I think our son, Christopher was probably 2 years old, he is 19 now.

Caleb use to join us in the meeting room at the old camp location. His family has always impressed me with their love and adoration of Caleb. I have been so impressed with the family's dedication!

Wayne is an amazingly driven person to never let obstacles get in his way. If we ever had a challenge he'd always say "well, let's talk about this." and by the time we were done I'd wonder why I ever thought there was an obstacle to begin with.

Wayne is an honest person that speaks the truth and never judges. Everyone would benefit by having him in your corner.

Our daughter, Kaylina, has only ever liked going to DBMAT Camp! I've signed her up and taken her to other camps and she never wanted to go back, except for DBMAT Camp! She always wants to go and I am sure her friendship with Dugan Thompson has had much to do with that! They were inseparable during camp for years! Now they have grown and life has taken their paths, allowing us the opportunity to watch Dugan's precious baby girl grow up! Dugan

is as sweet and as nice as they come! She is like her dad in that she is easy to talk with and very approachable too :-)

Dierdra is such a caring mom, so full of love for her family! She is a person of few words, but heartfelt when she speak of her kids. The love shines through her! It is obvious to see that her love holds the family together!

The brothers, Kevin and JR are also important members of the family. Now Kevin is off to college and we all get reminded that our kids just keep growing!

The qualities I see in the Thompson family are admirable and I am honored to know them!

Our love and support will be here and ready to extend to them any time!



Finding an Intervener

By Susie welch

Have you ever tried to find a qualified intervener? It is very difficult to find one as there are not very many of them. DBMAT offers scholarships for the Intervener classes for people who work with our kids.

Here's a link to the scholarship info and application:

http://www.dbmat-tx.org/intervener/scholarship_letter.php

It's just very difficult to find that special person and then getting them to stay. The biggest problem is that the wages have not been increased with the cost of living and minimum wage since our bills passed around 10 years ago. Even if you go Consumer Directed, it is not much money for the experience they have to have. McDonalds in our city start paying at \$12.50 an hour. When the oil industry picks up more the wages will go up more! Money is a BIG incentive!

We all need to visit our State Legislator. Get to know them and their aids. Take your child to visit them in their office and let them get to know you. Write a one page story about your child and attach his or her picture to it. The more they get to know us...they will remember you next session. This session is not a good time to try to get wages increased since they have already cut all state agencies by four percent. If we get to know our legislators now, then next session we can approach them **to increase the Intervener wages.** This is how we accomplished getting our bills passed last time.

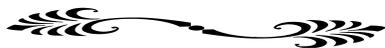
Here's how to find your State Legislators:
<http://www.fyi.legis.state.tx.us/Home.aspx>

We have to keep them aware of DBMAT and our kids.

So please visit your legislators. Tell them your story. Let them know you and your child! By doing it now, they will know you when the time comes to Vote for a Bill.

We have more power in numbers, so see them soon!

We CAN make a difference!!



Jason Lee Helmers

June 28, 1998 - April 4, 2016

Jason Lee Helmers was granted his angel wings on April 4, 2016. His days were spent surrounded by family and friends that Jason had touched in some way throughout his much too short, yet very memorable life.

Jason's life would seem too short to many, but those who were touched by him understood that the quality of existence far exceeds the quantity of time in which one lives. His wide smile could melt the hearts of those around him and though he never spoke a word, his voice and thoughts could always be heard.

Jason possessed strength, perseverance, and an ability to overcome incredible odds and physical challenges. With his courage, he led us to believe that each day is

a blessing and an opportunity to create lasting memories. He enjoyed communicating with everyone he met, even though he could not speak, he never met a stranger. When Jason met you for the first time or hundredth time he would ask "what is your name" and then he would want to know "what color is your house".

Jason was fortunate enough to attend the Texas School for the Blind and Visually Impaired from August 2008 to 2016. The TSBVI team of administrators, teachers, teacher aids, dorm staff and health center team created a "home-away from home" learning experience that let Jason flourish. They provided Jason with the necessary skills to learn how to read and write which opened his world of communication.

Whether Jason was enjoying a cup of coffee with milk and a "little sugar" and his 1 – 2 – 3 cookies or helping granny cook (if he could "lick" the spoon), he always had his cap on. He enjoyed spending the night at hotels and eating at his favorite restaurants. He could quickly finger-spell out his favorite places. He spent many summers at Camp Summit horse-back riding and swimming.

With Jason's passing we remind others that his life is one to be celebrated. Although we will miss him everyday, especially his winning smile, he will forever remain in our hearts. Through his teachings about life, we were able to create wonderful memories and it has been a privilege to be his granny and grandpa. Jason leaves behind many wonderful caregivers and teachers that provided love and support that enhanced his quality of life. All of these special people, too numerous to mention, provided Jason with love and caring in his life and also in his death.

Jason is survived by his loving grandparents, Ellis and Lynda Helmers; brother Jacob Helmers and sister Hannah Chavez; father Cody Helmers; uncles Tanner Helmers and Tye Helmers. Tye's girls Taylor and Gracie shared special memories with Jason. Tanner's family loved and enjoyed their visits with Jason; Robyn, Ryann, Adda, Georgy, Hyder. Other special members of Jason's family Wayne, Tammy, Dryden and Hunter.



DBMAT Committees

By The DBMAT Board

DBMAT Committees: DBMAT loves to have new ideas and other people’s involvement! We are most effective, when we divide and conquer our time and talents! In order to assist us in being able to do this, we have focus group committees that you can select one (or more ☺) to join. They are not all as active as others. The purposes of these committees are briefly defined as follows:

Legislative: To obtain and share legislative (both state and federal) information that affects people who are deaf blind and multihandicapped with the whole group. When there is action to be taken, where DBMAT may have an impact, this committee can organize and plan an approach for all to be able to participate.

Fundraising: To organize and communicate fund raising tips for all to participate in.

Conference Planning: To organize and plan the annual conference. The majority of the work for this committee is via conference calls starting 6 months prior to each annual conference.

Education: To organize ideas that are good for sharing amongst our families. Based on each family’s experiences and tips and tricks learned, one of the goals of this committee is to have a web-based place for knowledge sharing.

Regional Coordinators: To have a DBMAT member in each region of Texas as a contact person for any new locals that want to reach out and talk to someone close by.

vocational and independent living opportunities of these individuals for all ages.

Vision — DBMAT recognizes that people who are deaf-blind multihandicapped will benefit from the provision of Quality Intervener Services lifelong. When intervener services are provided from the age of diagnosis, the person who is deaf-blind multihandicapped is most likely to develop to their full potential with an abundance of “Moments of Joy”, (as defined by Dr. Jan van Dijk). As the person who is deaf-blind grows, his/her needs will change, but quality intervener services will always be required.

The DBMAT Board recognizes their primary goal is to advocate for quality Intervention to be available to all deaf-blind individuals who could benefit from it, until it is a viable option legally allowable to all who want to request it. The commitment to this goal began during their Board meeting, held on June 9, 2006 and continues to be a primary focus today. In addition to the primary goal, we advocate for all deaf-blind individuals to have access to the services applicable for their individual needs.

It is DBMAT’s vision to provide to individuals who are deaf-blind multihandicapped, as well as their families, access to other members, training opportunities, social events, as well as resources for which we maintain or have the ability to direct our members to.

Principles — We promote family education and understanding of our deaf-blind multihandicapped family member's abilities and disabilities. We offer resource information and referral to families, professionals, state agencies, and provider agencies serving people who are deaf-blind multihandicapped of all ages.



DBMAT 2012 Updated Mission, Vision & Principle Statements

By The DBMAT Board

Mission — The mission of DBMAT is to promote and improve the quality of life for all Texans who are deaf-blind multihandicapped. We support the establishment of educational, rehabilitative,



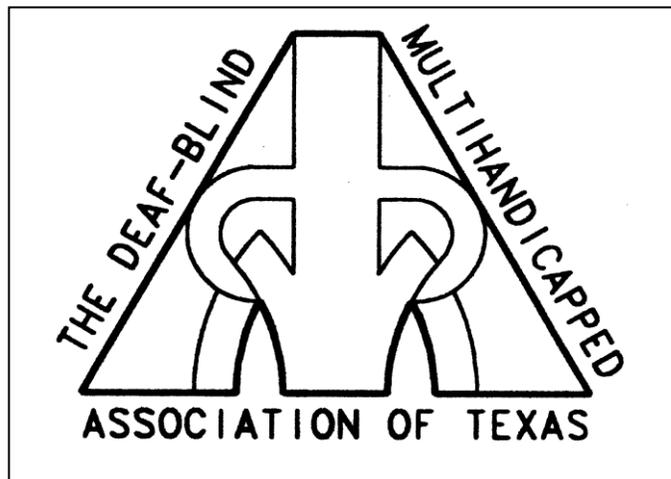
We had to say goodbye

By The DBMAT Board

We want to say a farewell **Thanks** to some founding members we lost this year: Riley Rand & Larry Clark. We appreciate all you did to help us get where we are today!

The Deaf-Blind Multihandicapped
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If you would like to be dropped from DBMAT mailing list or have a change of address
please contact: Paul Welch – Big Spring, TX.