



In Touch

Spring Edition ~ 2005

News from the President



Since the last newsletter your organization has participated in the following events:

The past few months have been very busy for DBMAT. In January, the Welch family and the Rand family were invited to attend a family workshop “Through Your Child’s Eyes”, sponsored by DARS.

On February 15 , my dad and I attended the Capitol Day in Austin for the ARC of Texas. We joined Raylene Gill with her two children, and Denise Sewell. It was quite an experience. We met with legislators and told them about our “special kids”. We also presented them a packet on DBMAT. We wanted them to know that we are out there and what our children’s needs are. The media interviewed us on the steps of the Capitol and Raylene got to tell about her story. It was wonderful.

In February, my family and I also attended the Deafblind Task Force meeting and the Deafblind Symposium in Austin. Our BIG SURPRISE at the symposium was when our family received the “Trail Blazers” award!! Thank you all. We have always admired all the families and professionals that have worked so hard and received awards, but we just never expected to get an award for giving to families what has been given to us for our son. We appreciate all the help we have received from the professionals and parents to make DBMAT effective. The family social at the symposium was hosted by DBMAT. Two DBMAT “Screaming Almonds” – C.C. Davis and Steve Schoen entertained us. It was great to visit with old friends and make new ones. There were legislators and policy makers there that we could meet and talk with. It was a wonderful opportunity for us to visit and

support one another. I can’t wait until the next symposium!

Jacson, Susie and I were invited to participate in the West Texas Cluster Family Conference in March at Lubbock, Texas. We were on a panel telling parents about DBMAT and how to advocate for their children by getting in touch with their legislators. We also mediated a “Round Table” discussions group. We had a great time. They even had a dance on Saturday night and Jacson danced up a storm! We had a great time and would love to attend again.

Planning is already underway for our Family Conference in October. Anyone wanting to help us with the planning should contact me. We welcome any and all help. I also want to thank everyone who contributed to this issue of “In Touch” newsletter. It means a lot for each of us to share our experiences with one another.

Don’t forget the Family Conference - October 7-9. You will receive the conference registration “In Touch” edition in July. **Hope to see you there!**

Thanks, Paul Welch

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Field trip to TSBVI

Outreach

by Chris and Vivecca Hartman

Recently Vivecca and I went on a one day field trip to TSBVI with my son Christopher and his teachers. We had two goals in mind: one-that we would observe and learn about the systems the Deaf blind children were receiving from a home living perspective; two-the teachers were going to observe the daily school routines and integrate ideas they learned about into their school program for Christopher.

The field trip was very successful! Vivecca and I brought back several ideas we believe will help us help Christopher at home. Simple ideas, such as a larger chair for him to sit in when dressing in front of his dresser, and to use a 5-part calendar box when dressing in the morning. We used to think about what to start with and where. When we were at TSBVI we asked, “so what do you start with.” They said, “the underwear goes on in the bathroom and the calendar box starts with the 1) under shirt 2) shirt 3) pants 4) socks 5) shoes.” We thought it was great! Something so small as to start with the underwear in the bathroom! That freed up enough slots for us in the 5 part calendar box. Instead of an undershirt, we were needing a place to insert the cochlear implant. So now, underwear goes on in the bathroom and the implant is the first slot on the calendar box for us! It works great! He is well on his way to learn to dress himself independently. We are also going to make him and his sister do more around the house (chores are good for all children). We plan to have him help sort the silverware when it comes out of the dishwasher. (We will remove any knives.) Another topic we discussed is to back-up each task and realize that we need to show Christopher where things come from. For example, it would be a good idea to show him that we put our dirty utensils in the dishwasher, turn it on and let him feel it running. So that when we pull the clean ones out he will have a better understanding of what it was. This is a little cycle that we can fairly easily start to show him. We get clean utensils to eat with then we put them in the dishwasher then we put them away. This is just an example of picking a task that we think he can do and we can make entertaining by doing it with him. Another that we have been doing a little and probably should do more of is grocery shopping, letting him feel things at the store, bag them, bring them home and put

them away then going to find his own snacks. Another cycle that has meaning and interest to him. ☺

These are just a few of the ideas that can grow into many others, like a seed. These seeds came from having the opportunity to go to TSBVI and observe the deaf-blind children in their living and learning environments that are so well structured by the school staff and Outreach Team. I am sure our teachers got many great ideas as well!

Just wanted to share something that was helpful for us.



Chris's

Life

by Sheryl Palasota
~ Mother

Christopher Palasota (Chris) was born on January 1, 1974 (a New Year's Day surprise to his mother and father) after a night of partying and eating!

Even after our family doctor suggested we “terminate” him, his dad and I knew that he was always meant to be a part of our lives. I had rubella the first trimester of my pregnancy.

Chris had cataracts when born and we were sent to Houston to a specialist. Chris had them removed and was fitted with the hard contacts. The doctor said these were best. I put them on and off. He now wears glasses so that he can independently put them on, and they are much more comfortable.

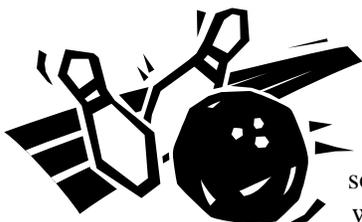
He also had an EEG, which was abnormal (the brain was affected some). Chris has some autistic traits. He can tell you what day of the week that your birthdate falls on. He loves doing this! He amazes us!

At age two, he wasn't making normal sounds or talking. We went to the MHMR, “First Steps Forward” program and he was diagnosed as deaf. We learned ways to work with him to stimulate his learning. At age three he started school – the Regional Program for the Deaf in Bryan, Texas (our city).

Chris was in the Deaf Program, Special Ed, and Life Skills. He really loved the life skills program. They went out in the community and did a lot of “hands on.” Chris can print, shop and even write checks.

The ARD’s were difficult, but we even got Chris his own teaching assistant. She is still with us as an intervener – part-time.

In 1996, he graduated from high school and the Deafblind Waiver became available – what a blessing!! The waiver has enhanced the quality of Chris’ life so very much. The TSBVI and TCB worked closely with his school and us.



Chris does Special Olympic bowling, league bowling and Special Olympic golf. He’s a member of our ARC. We have socials and dances monthly. He works ten to twelve hours a week

at Central Texas Orthotics and Prosthetics here in Bryan where he is highly accepted and admired for his abilities, not his disabilities. Chris also “speaks” through his intervener at a class at Texas A & M here in College Station. This is an education class for prospective teachers. Students come up to us in the community later and remember him.

Chris also goes to kidney dialysis three times a week. He is currently on a transplant waiting list. He has never complained about going there.

Chris loves life. He loves to swim, read, travel, go to the bookstores, libraries, camps, malls, and carnivals (Six Flags, etc.). He really enjoys when his younger brother, Jason gives him rides on jet skis!

Chris’ dad (who passed away in 1999) was always proud of him and advocated all of the time for his son. I know he would be proud now. When I count the many blessings in my life, Chris is one of them!



A TRIBUTE TO LEE

~ Goodbye to a Friend

Lee Alan Coughran, 40 passed away on April 25th in San Antonio, Texas. Lee was born deaf-blind multihandicapped. Lee was one of the first children to enter the Texas School for the Blind’s pilot program

for Rubella children in Austin at age 7. Prior to entering the school, Lee received therapy through the West Texas Rehabilitation Center in Abilene, Texas. Upon graduation from school at age 22, he moved to a newly opened group home in San Antonio, operated by Goodwill Industries. Gay Bellamy and Susan West recently assumed this program, under the name “HandsOn.” He was a huge part of the “HandsOn” family. We all were blessed to have been a part of Lee’s life but even more so to have him in ours. To know Lee was inevitably to love Lee. Many hearts are broken by this loss and oceans of tears will be shed. His footprints will forever be imprinted on the paths of our lives. His smile could brighten up an entire room and then have you smiling with him. No one could hug better than Lee. We will miss him. We were so lucky to have him in our lives.



FOLLOW-UP OF THE INTERNATIONAL RUBELLA SYMPOSIUM

by Dr. Ed Hammer

The International Rubella Symposium was held at the Helen Keller National Center on March 14-16 in Sands Point, Long Island, New York. C.C. Davis, Jeanne Reeves, and Ed Hammer attended from Texas. The symposium focused on several important events that concern rubella in the United States and worldwide. Countries from every continent presented the current status of rubella eradication in their country.

It was formally announced that the rubella virus has been eradicated in the United States. This is a major breakthrough for those parents who witnessed the rubella epidemic of the 1960s. Another event was a keynote speech by Dr. Paul Parkman, the physician who invented the rubella vaccine. Dr. Parkman spoke about the process he used to attenuate the rubella virus. He also pointed out that the rubella vaccine does not contain any mercury, the focus of a hot debate going on in regard to the increase of autism.

Dr. Joseph Icenogle of the Center for Disease Control (CDC) in Atlanta also presented his proposed study of the markers that are present in parents and persons with

Congenital Rubella Syndrome. He is seeking to identify the profile found in persons who experienced rubella and the late effects of this profile. He was asked to include Texas in his study that will be coordinated in partnership with the Helen Keller Center in New York. This study seems even more important since there has been one case of rubella reported in May 2005 in Canada.

One of the outcomes of attending the symposium is that Dr. Hammer is interested in doing an outcome study of those individuals, parents, and families of persons who are deafblind multihandicapped in Texas. This study will provide information about the functional skills, living arrangements, and continuing challenges that parents and persons with deafblindness face. Dr. Hammer is working with agencies and individuals in Texas to try to pull this study together. He would do the data collection and analysis if others would encourage participation.



DBMAT Members Takes Part in the 2005 Texas Symposium on Deafblindness

by David Wiley, Texas Deafblind Project, TSBVI

A large contingent from DBMAT participated in the 2005 Texas Symposium on Deafblindness on February 26-27 at the Hyatt hotel in Austin. The symposium was sponsored by TSBVI Deafblind Outreach, and was attended by close to 400 people from around Texas, including both family members and professionals.

DBMAT families took an active role in the symposium. In addition to attending presentations on a variety of interesting topics, DBMAT members served as hosts at the Family Social on Friday evening. Over 100 attended the social, to visit with one another, talk to invited guest dignitaries, and listen to the toe-tapping sounds of DBMAT's "house band", The Interveners (Steve Schoen & C.C. Davis). Two DBMAT families bravely presented closing keynote presentations to all the participants at the symposium. An inspiring talk about "The Great Motivator" Christian Knapp was given by

his mom and dad Melanie and Gary Knapp, along with Christian's brother Landon. Next, Lee Ann Bryan make a presentation about her life, past present and future, followed a video about her activities featuring her parents Jackie and Everett Bryan.

During the symposium, several awards were presented to people who have been leaders in the community,, demonstrating a commitment to improving the lives of Texans with deafblindness and their families.

The "Trailblazer Award" is given to family members who, through their actions in meeting challenges for their own children, provide an easier path for other families follow. DBMAT's own Welch family received this year's award. Paul and Susie Welch, as well as Paul's dad Leo, and their son Jaceson were pioneers at school in practices such as including a student with multiple disabilities in regular education classes and community-based instruction. Paul and Susie are still helping other families through DBMAT, with Paul serving as president, and as everyone knows, Susie right there with him every step of the way.

The "Intervener Award" was presented to Helen Porter. Helen began working as Lee Ann Bryan's interpreter and aide at school in Amarillo in 1978. She still works with Lee Ann in the community through the Deafblind Medicaid Waiver.

The "Marty Murrell Award" is presented to an educator, and this year went to Tish Smith. Tish has worked on communication with dozens of deafblind students at Texas School for the Blind and Visually Impaired for many years.

The "Ann Silverrain Award" is given for a long-term commitment to improving the lives of Texans with deafblindness. This year Steve Schoen received the Award. As DBMAT members know, Steve recently retired from his work with the Deafblind Medicaid Waiver, and helping to organize the annual DBMAT family conference. Steve has volunteered to continue being involved with DBMAT as their Executive Director for a period of time, to assist in trying to acquire additional funds for activities and hopefully a permanent paid executive director in the future.



All in all, the symposium went well, and hopefully all the participants learned a lot and had fun. DBMAT was able to spread the word about the organization, and find several new members. Deabind Outreach thanks all the DBMAT members who came for helping make the symposium a success.

“Through Your Child’s Eyes”

by Celestine Rand ~ Parent

On January 16th the Paul Welch family of Big Spring and the Riley Rand family of Odessa, attended the “Through Your Child’s Eyes” workshop. We were invited to attend this workshop by Janice Herrera of DARS (Texas Commission for the Blind). We met with a group of families of children with blindness and other disabilities in order to offer support and encouragement. We were able to share our lives as parents of older children. By describing experiences with our children, we hope we helped them realize we understood all the ups and downs of their journey.

Jacque Carrillo, sister to JoAnn Rand, also reflected about being a sibling. The normal reactions and questions a sib might have ranged from sadness to the unique bond that is created within a family. She believed being allowed as a child to become fully involved with the family helped her feel included and helped the family as a whole.

The families asked us various questions about responding to the needs of their children, and dealing with the maze of decisions families face. Finally, we stressed that the advocacy found with organizations like DBMAT were critical in helping families on their journey with their special child. Information on joining DBMAT was distributed also.



SCREAMING ALMONDS

by Riley Rand Jr. ~ Parent

I would like to thank the DBMAT family for the nice compliments from the last

newsletter, concerning the “Screaming Almonds”. We know that C.C. Davis, Steve Schoen, Tom Solis, and Linda Carter feel the same. All of the band members would also like to thank Paul Welch for the encouragement that he gave us many times to begin the DBMAT band.

We look forward to having more fun this year! The Rand family hopes to see all of you at Camp 2005!

Supplemental Needs Trusts – Your Planning is Essential

by June Griffith ~ Attorney at Law

Does your child receive Social Security Benefits and Medicaid? If so, you already know that they cannot continue to receive these if their income becomes high enough to cover their support needs.

If you die, and your family member inherits your property, they may lose benefits for a period of time until the inheritance is exhausted.

However, if you establish a Special or Supplemental Needs Trust, the trust may inherit property or money for their benefit, and still allow them to continue to receive the Medicaid and other government benefits. Your planning is essential so that these are set up by you during your lifetime.

You may find this form on the internet, or call your family lawyer. My telephone number is 972-569-9990 if I may be of service to you.

Someone I Love

by Lori Hickman

Someone I love relies on me in ways you will never understand. Someone I love endures pain and challenges that break my heart and renew my spirit at the same time. Someone I love is unable to advocate for themselves for things that most of us take for granted. Someone I love will never have the opportunities that every child should have. Someone I love will need unconditional love and support after I am gone - this frightens me to the core. Someone I love

encounters pity, stereotyping responses, and prejudice at every turn, because they look, act, and/or learn differently than others. Someone I love has needs that require me to allow "outsiders" to have power and input in areas that should be mine alone to meet. Someone I love will continue to look to me for everything in life long after other children are able to assume a place as part of the world. Someone I love has needs that require more time and energy than I have to give. Someone I love has needs that mean I am not able to meet basic needs of my own. Someone I love has needs that have become the driving force behind major decisions my family makes. Someone I love has changed me in ways I will never be able to describe. Someone I love has taught me about love and about the really important things in life...

And still others don't understand what it is to be me. They aren't living in my skin.

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Lori Hickman is a speech pathologist in Washington state. She is the author of [Living in My Skin, The Insider's View of Life With a Special Needs Child](#), and four other books on speech and apraxia



Hats

by Leslie Fansler

*"Hats that are old
hats that are new
some have one hat
others, quite a few"*

There is one thing that has been a long standing tradition in DBMAT, it separates the rookies from veterans. That one thing is HATS! Believe it or not, in the days of yore, some of us paid upwards of \$100.00 for a special DBMAT hat in the live auction. Not many will admit to it, but some of the veterans have whole trunks stuffed with DBMAT hats from as far back the 1980s. There are many members who remember, and cherish the memories of Olivia Cruz, the official DBMAT hat maker. Well, it is time to let that DBMAT pride shine. This year at the annual DBMAT Family Conference we will be sponsoring a DBMAT Hat Revival. We will be recognizing the oldest hat, the

newest hat, the dirtiest hat and the member with the most hats. Take part in the new DBMAT era by showing your support of the years gone by. Take out those hats, dust them off and wear them with pride. Looking forward to seeing you, and your hats, in October.



Advocacy, Inc. Update

by Chris Hartman

Working together to improve the lives of Texans with disabilities.

The mission of Advocacy, Inc. is to advocate for, protect, and advance the legal, human, and service rights of people with disabilities.

As some of you may know, the Board of Directors for Advocacy, Inc. are no longer appointed. This means D.B.M.A.T. no longer has a guaranteed seat on the board. All new board members must fill out an application and then the applications are reviewed and the applicant with the qualifications that fit Advocacy, Inc.'s needs at the time will be selected. As of April 24, 2005, I will no longer be on the board and would love to see another D.B.M.A.T. member take my seat.

Advocacy, Inc., the designated Protection and Advocacy (P&A) system for Texans with disabilities, welcomes all nominations for its Board of Directors.

TO APPLY: Go to Advocacy, Inc.'s website – <http://www.advocacyinc.org> or contact Shirley DeBerry at 512-454-4816 or 1 800-252-9108.

Some of the activities of DBMAT are supported by the Hilton/Perkins Program of the Perkins School for the Blind in Watertown, MA. The Hilton/Perkins Program is funded by the Conrad N. Hilton Foundation of Reno, NV. DBMAT acknowledges and appreciates this



MEMBERSHIP APPLICATION

Please check type of Membership:

Regular Associate

Annual Dues: \$10.00 per individual

Name _____

Address _____

Phone _____

Fax _____

E-mail _____



DBMAT is a non-profit organization for families with Deafblind Multihandicapped, or Deaf Multihandicapped, or Blind Multihandicapped and professionals.

When you join DBMAT, you join a group that has a large network of people throughout the state who will provide support and knowledge. It is your ticket out of the isolation of being the only family in town with a child who is deafblind. You can meet others who have some of the same issues and who can offer tips and listen with understanding. It also gives you the power as an advocate to change state policy and practice.

DBMAT allows you and your family to experience a fun annual weekend away with other families and professionals.

Please join our DBMAT family.



Child/Adult with Sensory Disabilities:

Name _____

Birth Date _____ Sex _____

Is s/he presently being served? Yes

No

Program Name _____

Address _____

As an Associate, my occupation is:

Program _____

Address _____

Phone _____

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As a Contributing Sponsor, I am interested in DBMAT because: _____

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Mail with application to:

C.C. Davis

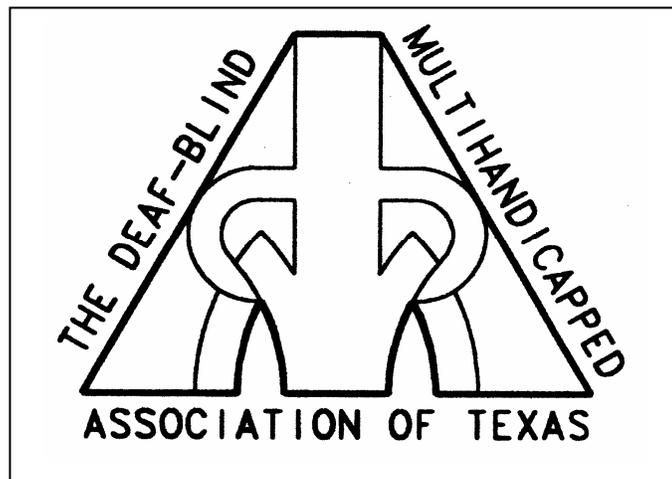
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In Touch is a Publication of the Deaf-Blind Multihandicapped Association of Texas (DBMAT)

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