

WHAT NOW?

Building Bridges Among Parents of Deaf and Hard of Hearing Children



Are Deaf Children Afraid of the Dark?

December 2007

by Melinda Siler

I remember when Becca was a baby, she would not go to sleep at night. I would put her upstairs in her crib and she would cry and cry and cry! I knew that there was something wrong with her. She had been changed, fed, burped, and she was very tired, yet she refused to sleep. She would finally win me over and I would go get her. Usually I would rock her until she fell asleep in my arms and then I would lay her back down in her crib. If she woke up I would have to start all over again. If she didn't wake up right away, I could be sure that she would wake up sometime in the night, usually about 2 a.m. I would go into her room and rub or pat her back until she calmed down. As soon as I stopped and tiptoed out of her room, the crying would start again. Eventually I would put her in bed with my husband and me until she fell asleep or until I fell asleep first. My two older children experienced

normal, occasional sleepless nights, but never to this extent.

This tiring routine went on for over two years. I'm not kidding! Every night for over two very long years! Then one night Becca slept until morning! When I awoke, I was scared. I ran in and checked her. She was fine and still sleeping. I was amazed! She slept through the night! What was different about that night? I thought and I wondered as I stared at her. What could possibly have changed?

I slowly looked around the room and I realized that I had forgotten to turn off her nightlight. Wow! Could that really be it? I tried it the next night and she slept all night.

I finally figured out that when Becca woke up in the middle of the night to a pitch black room, it terrified her. If I was in the room with her, as long as I

had my hand touching her arm or back she was fine. She felt connected to me. As soon as I took my hand away she would panic. Needless to say, I left the nightlight on after that. She is six years old and still sleeps with her nightlight on.

I didn't realize how scary the dark can be for a deaf or hard of hearing child. It is even more scary than for a child who can hear. When a hearing child is in a dark bedroom, he or she can still hear the TV, or the clock ticking, or parents talking. The child knows he or she is not alone.

The deaf child loses two senses, sight and hearing, in the dark. If a child cannot hear familiar sounds, how does he or she know there are people close by?

Becca, actually, found a way around this problem. One night



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More Personal Stories Needed!

Thanks to everyone who sent stories to What Now. Do you have a story we could feature? Please send it. We'd love to share your experiences. Here are some suggestions for personal stories:

The form of communication you chose for your child and why.

The type of education setting you chose for your child—mainstream, deaf school, etc. Why you chose it and how it is working for your child? What are the positives and negatives to those settings?

Share your experiences to help another parent or family, no matter how trivial you think it may be (even a story about a nightlight).

Teachers of the deaf, audiologists, and deaf or hard of hearing adults are encouraged to write. Parents could benefit from your expertise.

Please send your personal stories to the address or e-mail on the front of this newsletter. Thank you.

Appreciation for the What Now Newsletter

My name is Allison Cunningham. I have a three-year-old daughter, Jenna. She is severely-profoundly deaf. She passed a newborn screening in the NICU three days before going home but then was diagnosed when she was 14 months old. After exploring our options, we chose to get a Cochlear Implant (CI). Jenna's surgery was on July 29, 2004, at Children's Hospital in Pittsburgh, Pennsylvania. She has progressed well and definitely likes to hear. She refuses to remove her implant. She even keeps it on when she is sleeping. Jenna attends a private preschool where her Speech Pathologist comes on Mondays and her Teacher of the Deaf comes on Fridays. There are definitely many obstacles having a deaf child and a lot of hard work, but we know that it will all pay off.

Jenna is the fifth child in our county, Harrison County, to receive a CI. We have teamed with another family to get an auditory-oral program developed in the Harrison County Public School system. Our goal is for our children to have spoken language.

We have also started a Cochlear Club that meets usually once a month. This is a time that allows families an opportunity to discuss concerns or get and receive advice from other families. We have guest speakers sometimes. The children enjoy being with each other. You should see their faces when they realize that other children have the same thing on their heads as they do.

I am writing to you in regards to the newsletter. I think this is a wonderful opportunity for people to hear from other people. I believe we have all faced challenges that if some other family may hear it could be a big help.



That's Dog-Gone Cute!

By Janean Oliverio

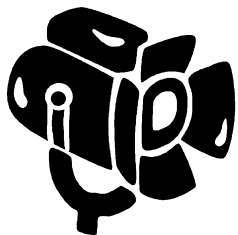


My son, Broc Oliverio, is now 4 years old and has developed spoken language after receiving a cochlear implant at 14 months old. He enjoys working at the Oliverio Farm where one day we

had to call the veterinarian. This was a new word for Broc and he caught on very fast with some difficulty pronouncing the word. When the veterinarian arrived, she responded to Broc's initiations of conversation. She commented on how much she liked Broc's dog, "Bruno." Now, "Bruno Oliverio" has always been a very important part of our family. The veterinarian asked Broc, "What kind of dog is Bruno?" Broc didn't reply. She said, "I think he is a boxer." Broc confidently replied, "Oh no Vetnarum, he's an Oliverio!"

Letters to the Editor

I just wanted to thank you for the newsletter I received earlier this year. I think this is a wonderful thing you have done. As a parent of a hard-of-hearing child, my resources for information have been limited and I loved reading someone else's story for the first time in six years. I guess I should introduce myself. My name is Lori Willey and I am the proud single-mother of a fabulous 10 year old girl, Kendall. Due to respiratory distress, premature birth, and other complications Kendall has moderate bilateral sensorineural hearing loss and now you can combine that with vision problems. My daughter's hearing loss is not severe yet it has presented its fair share of challenges, especially the last six weeks and now we are facing vision problems as well. So, thank you again for getting info out there! Small town West Virginia is frustrating when you are looking for help and resources.



**WHO
CAN
HELP?**

Children with Special Health Care Needs

I recently found out a tidbit of information that could be very helpful to some parents. For those of you who applied with Children with Special Health Care Needs in the past and were denied because of income, you may want to try again. I was recently told that the Federal Poverty Level periodically raises. Those levels raised on February 1, 2007. You may now qualify even if you did not qualify in the past.

For more information and for applications, call Cathy at 1-800-642-8522 or go to www.wvdhhr.org/mcfh and click on the Children with Special Health Care Needs link. The income guidelines are listed on their website.

**"QUOTES"
THAT
COUNT**

"The first step in establishing positive behavior in your child is by establishing a tranquil home environment. Environments filled with tension affect children, their emotional well being and their learning. Your disposition and mood are the first and foremost factors in creating a home that nurtures your child as a whole and creates positive feelings and behaviors in the child." -Keys to Raising a Deaf Child, by Virginia Frazier-Maiwald and Lenore M. Williams, MA



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around a year ago, I noticed that Becca was leaving her hearing aides in and she was sleeping with them. I reached for her ears to take her hearing aides off and she quickly covered her ears and shook her head "no." I asked her why and she responded, "cause I want to hear my Daddy go Buuuuuuh, Buuuuuuh, Buuuuuuh." (She was referring to her Daddy snoring). I smiled and left her hearing aides. I never thought I would see the day when my husband's snoring would be a comforting sound!



INDIVIDUALIZED EDUCATION PLAN (IEP)

If you do not feel (or if the school system says it cannot) provide an appropriate education for your deaf child and you must enroll your child in a different school (whether that is the West Virginia School for the Deaf in Romney or to a school in a different district that employs a teacher of the deaf), then the school is responsible for your transportation costs.

"The county school district is required to provide free appropriate transportation services to any exceptional child who requires special transportation because of his or her special needs. The State Board of Education has established regulations for the special transportation of exceptional children. These regulations apply to county school districts and outline the specific responsibilities of both the school district and parents for transporting exceptional children." - *from Hand in Hand with Special Education, A Guide for Parents*
