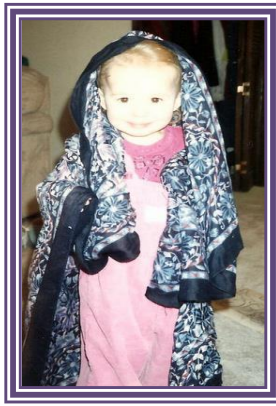




Hope! Dream!  
Achieve!



## My Story

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Parent Mentor

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Views and opinions in this article are presented as information only. Parent Links Hope! Dream! Achieve remains neutral and supportive of ALL choices.


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*I'm a parent of a beautiful girl named Erika. She was born profoundly deaf. I would like to share my story of how it was for me, the decisions I had to make and the perspective that I have gained.*

*I knew sign language before she was born.* At the college I attended in Dallas Texas I learned Signed Exact English and became fluent. I had many friends who were deaf and enjoyed learning about their Culture. I was also in a singing/signing group that did concerts in many churches across the US. While attending college, I met and married my husband of 23 years. We did not know at the time that his mother's family from the 1800's had many family members who were born deaf. We were young and even if we did know we would never even think that it would affect our children.



*Erika* was born in June of 1991 in Bend Oregon with no complications. At that time in Oregon, the hospitals did not have the hearing screening test. We had no idea that anything was different with her hearing until she was about 6 months old and only from observation from others. My friends who were deaf told me that she acted like a deaf baby; my hearing friends commented that she was very alert. I decided to do my own hearing test. One day while she slept in her car seat, I put headphones on her ears. I turned the music on at a very low volume; she did not respond. I turned it up louder, still nothing. Finally I turned it up so loud that I could hear it and still Erika slept on. She did not startle, wake up or acknowledge the sound in any way. I knew then that she had some sort of hearing loss and made an appointment with my pediatrician. I hoped that I was wrong.

 The pediatrician used a bell to test her. If she moved to look at the sound that would prove that she was hearing. She did move to look at the bell. The doctor told me that I was worried for nothing, that my exposure to the deaf community was causing me to be overly anxious about her hearing. "Just to stop me from worrying," she said, "I will make an appointment with the Oregon Health and Science hospital in Portland or a hearing test." The test was scheduled to take place in two weeks. My husband and I were greatly relieved by the doctor's comments. We wanted to believe that she had normal hearing and was just a heavy sleeper.

On the day of the test, they gave her medication that made her sleep and put electrodes on her head. This test was called an auditory brainstem response, (ABR) test that would test her response to sound neurologically. When the test was done the doctor came out to where I was waiting, handed me some brochures and told me that my daughter was not only deaf but profoundly deaf. The brochures were for support services available in our area as well as a local oral school. He said that he was sorry and walked away. At that moment, my world came crashing down around me. I had no idea what do, where to go for help. All I knew was that my world changed drastically that moment.

I went through many emotions but the first one that surfaced was being devastated. How could this happen to my baby? I went home and just sat. I felt numb. I still had to take care of my baby but cried often while I did. I didn't know it but I was going through the five stages of grief as depicted in Kübler Ross's model. The five stages are denial, anger, bargaining, depression and acceptance. These stages of grief are really for people who have lost a loved one. My daughter was not gone so why would I feel the same way? I learned later that I was grieving the loss of my hopes and dreams that I had for her. She was still the cute baby that I had before the ABR test, but still felt that this was my fault. I had done this to her. Needless to say this was a very difficult time but with the support of other families that I met I was able to move forward. I realized that my feelings were normal. Everyone may go through this process differently but it was OK to feel this way.



**Getting Help** Now I had to find out what to do to help her. We got the latest hearing aids hoping that she would receive some type of hearing from them and began to teach her signs; (her first sign was at 8 months old and was milk), began early intervention; first at my home and later at the school site. We were also interested in getting the latest hearing surgery for children, the cochlear implant but that would have to wait.

**Cochlear implants** in 1991 were approved by the FDA for children *only* age three and over. Even though we knew about her deafness early on, we could not get it earlier which would have given her more time. We were told that because she was receiving the implant so late that there may be limited results for her. We thought that if she could hear us call her name or the sound of a car that it would be worth it and began to the process of becoming a candidate. In June of 1994 Erika received her unilateral implant. We had no idea of the controversy that we were to be confronted with. If a child gets an implant, they can't sign, they must only learn to talk. That is what we were told. But she was three and already very fluent in sign, how could we take that away from her? We wanted her to be able to communicate to us and learn to use the implant. We wanted to try everything with her. If one thing did not work, we would try another.



**As she grew**, we stayed with the idea of trying all the different educational choices. She was in a total communication school program, had hours of speech therapy, private tutoring, counseling and even was on a deaf dance team. I made play dates for her and her class mates, introduced her to other deaf adults both with implants and spoke and those that did not have an implant and signed only. By the time she was going into 8<sup>th</sup> grade, we decided to send her to the California School for the Deaf in Fremont where she would live on campus and come home on the weekends. CSDF is a public school for children who are deaf or hard of hearing and would benefit from a rich American Sign Language environment. Many of the teachers are deaf and all of the staff signs in ASL fluently. She was so excited to be part of the school experience where she was just like everyone else. This was very hard for me; I wanted her here, not three hours away but for her sake, we made it work. It turned out to be a wonderful experience for her. In the total communication programs she was often left out of extracurricular activities but at CSDF, she was able to totally immerse herself. She was a cheerleader, volleyball player, actress in four plays, photographer and year book designer. By age fifteen, she did not want to wear the implant any longer. We felt that she was mature enough and allowed her to make that decision. Her language up to continues to be understandable but not perfect. Today, she will still wear it once in a while.



**Erika graduated** from CSDF and is now attending college. She is a smart, funny, beautiful adult with dreams and aspirations. She is a talented artist and hopes to someday teach art. Even though she is deaf, she drives, has her own apartment, votes, pays her own bills online, has a boyfriend and most importantly.... is happy.



**Advise to you?** I cannot tell you to sign or not, to get an implant for your child or not. Those are personal decisions that you the parent alone gets to make. The advice I give you the parent with a child who is deaf or hard of hearing is:

- Ask lots of question of the professionals, meet other parents and listen to your heart.
- If one way doesn't work, try another.
- Give yourself time to process your feelings. If you feel sad, give yourself time to feel that way for that then move on.

## Meeting other Parents

When a parent finds out that their child is deaf or hard of hearing, they often do not know what to do next. Of course the professionals direct them toward the early start programs, preschools, speech therapy, medical intervention and all of that is very important. But a professional cannot share in the parents experience as another parent can. Meeting another mom who also has a child can be very exciting. Another parent could able to answer the questions and relay their own personal experiences.



The benefits of meeting other parents include:

- mutual support through contact with other parents of a deaf or hard of hearing child with similar condition
  - sharing information which helps in caring for their child
  - building confidence
  - offers an opportunity to help other parents of children who are deaf or hard of hearing

*"Parents who frequently met with other parents of deaf and hard of hearing children reported less isolation, stronger emotional bonds with their child and greater acceptance for the child. Parents also emphasized the benefits of giving mutual practical help in coping with everyday challenges."* (Manfred Hintermair, 2000)

Offering support to parents is what Parent Links is all about. Each mentor is a parent of a deaf or hard of hearing child.

- Through email, phone and mail we are here to help answer the questions that parents may have about raising a child who is deaf or hard of hearing.
- Help parents find local connections.



## Listening Toys

Listening toys are now available to new families from Parent Links. If you or someone you know has a child between the ages of birth to three who has been diagnosed deaf or hard of hearing let us know! Toys are available to new referrals. For more information call Darla at 559-229-2000 x 208. Toys are free of charge.

## Parent Mentors

### Exceptional Parents Unlimited

Darla Schwehr  
Vicky Olea  
4440 N. First Street  
Fresno, CA 93726  
559-229-2000 x 208

### Counties

Alameda, Contra Costa  
Fresno, Kings  
Madera, Mariposa  
Merced, Monterey  
San Benito, San Francisco  
San Joaquin, San Mateo  
Santa Clara, Santa Cruz  
Stanislaus, Tulare

### Family Focus Resource & Empowerment Center

Irma Sanchez  
Cora Shahid  
Kristal Molina  
Edith Wysinger  
18111 Nordhoff Street  
Northridge, CA 91330  
818-677-6854 Office  
**Counties**  
Imperial, Inyo  
Kern, Los Angeles  
*Mono, Orange  
Riverside, San Bernardino  
San Diego, San Luis Obispo  
Santa Barbara, Ventura*

### Rowell Family Empowerment Center

Kat Lowrance  
Barb Ciukowski  
962 Maraglia Street  
Redding, CA 96002  
530-226-5129

### Counties:

*Alpine, Amador, Butte, Calaveras  
Colusa, Del Norte, El Dorado, Glenn,  
Humboldt, Lake, Lassen, Marin,  
Mendocino, Modoc, Napa, Nevada,  
Placer, Plumas  
Sacramento, Shasta, Sierra  
Siskiyou, Solano, Sonoma  
Sutter, Tehama, Trinity  
Tuolumne, Yolo, Yuba*



Check out our website: [www.myparentlinks.com](http://www.myparentlinks.com)

## Attention Counties.....

Parent Links is located in your area! For families we offer one on one support in person or by phone, free "listening toys" for their children, (new referrals). For professionals and parents we offer Key Parent, IEP, IFSP and Ask the Right Question training. We are now putting together a schedule for this coming fall. If you are interested in having one of the Parent Links staff come just let us know.