

### Celebrating your Deaf or Hard of Hearing Child

I'm scanning my memory, reaching back to December 1981, when our daughter Emily was identified as profoundly deaf. It was September when I first suspected our 10-month old baby couldn't hear. Three months and many professionals later we had a definitive diagnosis of profound deafness. Celebrate? Impossible, I thought. I doubted I'd ever smile again, never mind feel joy or contentment.

This is written for parents in a similar place: discovering their child is deaf or hard of hearing. Today there are more options and new technologies available, yet I know the response in the hearts and minds of parents is not so very different. The knowledge that one's child will face difficulties is never easy to accept or welcome information. A thousand questions run through a parent's mind: How will my child learn? Can we communicate fully? How will this impact our family? How much will this cost, and where will the money come from? Where will I find the time to get my child to therapy? I don't have a car, how can I transport her to therapy and school? What will my child's life be like? Is she sad? Will I muster the strength cope? What about my other child or children? Why did this happen? Who is to blame?

The best advice I can give is to live one day at a time. Learn all you can about what it means to be deaf or hard of hearing. Make every effort to meet other parents with deaf and hard of hearing children. Make every effort to meet older children and adults who are deaf and hard of hearing. Be a smart consumer and seek professionals who will provide honest, unbiased information – consider what might motivate a provider to recommend one approach, treatment or therapy over another. Information leads to power, confidence and comfort for you as parents.

This spring my daughter will graduate from a state university and is applying to graduate schools. Twenty-one years ago I would have given anything to make her deafness disappear; today, her dad and I know we would not want her to be anything other than the deaf person she is. For us, sign language has been the most effective way to relate to each other and for her to learn. She showed us what she needed, what was best for her. It was our job as parents to pay attention to what she communicated. Falling in love with our child was easy, falling in love with the part of her that was "deaf" took some time, but it did happen. Learn, accept support, reject negativism and trust yourself above all.

Continue reading this section of your notebook for reflections from other Wisconsin families who have deaf or hard of hearing children. Be inspired and trust that you are exactly the parent your child needs.

Barbara Aschenbrenner Smiling Mother of Emily, born 11/80



### Personal Stories of Celebration

Here is your chance to meet a few Wisconsin families who have children who are deaf or hard of hearing. They have shared personal celebrations of their children.

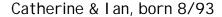
Jack, born 9/97



When our deaf son was very young, people would ask, "How's Jack?" We knew they were most curious about his progress relative to his hearing loss; however, we were bothered when the deafness overshadowed the fact that he was really just a healthy, normal little boy. So, in response to people's questions, we would tell a story about what Jack was doing. For example, we'd say, "oh, he walks now and is getting into

everything." We think of Jack as a child first, and his deafness is just part of who he is. We try to guide others into seeing him as we do. We must also add that when he was a year and a half old, Jack received a cochlear implant and is making fantastic progress in his speech, listening and language skills.

-- Paul & Molly Martzke, Green Bay





Our twins, Catherine and Ian, are deaf and we have two older boys who are hearing. We suspected first that Catherine couldn't hear. Ian had us fooled because when I (mom) would rock and sing to him, he'd hum back. Both were tested, and identified with profound hearing losses. Within minutes of the diagnosis, right there in the audiologist's office, we learned the signs for "ball" and "baby." I knew our children were ready for language; Catherine was already showing frustration at 13

months of age. We use CASE (Conceptually Accurate Signed English), speaking and signing at the same time in order to include everyone in our family. Within a week or two, the twins were signing back to us. Our older boys are proud to know sign language. Catherine leans more toward using ASL (American Sign Language) while Ian readily acquires English through signs and speech reading. They attend our neighborhood school with the accommodation of an interpreter and keep pace with their peers. At age seven, they were diagnosed with a heart condition called "Long Q-T Syndrome," which sometimes exists in conjunction with profound deafness. The syndrome is rare, but we encourage parents to speak with their doctor about ruling it in or out. More information can be found on this website: SADS.org

### Willa, born 5/97



Willa is our first child, our only child. She failed the newborn hearing screening, and was diagnosed with certain hearing loss a year and a half later. She uses hearing aids and has learned to speak. She does well in school, being mainstreamed into a regular kindergarten class. She loves books and qualifies to attend reading instruction in the first grade classroom at school. We go to the library one or two times per week and read with her every night. Willa even has her own library card! About six months ago,

she lost more hearing in her right ear and we hope she will receive a cochlear implant soon. Of course we worry about her future, her education and communication, but we've been through the hardest part. Her grandparents, the whole family, and we all love her very much. She's really no different than any other kid.

-- Allen Tsao & Aiping Gu, Milwaukee

### Emma, born 4/97



We've always believed that it's important for people to perceive the deaf or hard of hearing child as a child! So many consider deafness to be a disability. We don't see it that way – our daughter Emma will live a different way. She will require some special accommodations, but basically she just uses different ways to communicate and to learn or approach information and situations. When Emma was young, we

suspected that she couldn't hear and thought, "If all we have to do is learn sign language, that's no big deal." We participate in Wisconsin's Deaf Mentor Program and appreciate the education and encouragement we receive from our deaf mentor.

-- Don & Lori Menzel, Kewaskum

#### Claire, born 11/98



Our daughter Claire was diagnosed at 17 months with a moderate to severe hearing loss. It was hard to believe at the time because she is such a smart little girl who was already speechreading and focusing on visual cues. Once fitted with hearing aids and given access to communication through speech therapy and sign language, she made incredible strides. By age 3 years, her expressive speech was delayed by only six months and her receptive language skills

exceeded her actual age! Those are "clinical" statistics that provide a narrow view of Claire. In fact, she is an energetic, inquisitive and affectionate girl who often seems wise beyond her years. She has a sense of humor and loves "knock down hugs." She has taught us to appreciate little things. We'll never forget the look on her face when she realized that our cats, which she'd seen daily since she was born, made noises! She is like any other child is so many ways, yet just a little more special from our perspective.

-- Jack & Christine Herden, Monches

### Erik, born 2/93



Erik has a severe to profound hearing loss, but with hearing aids, is able to hear in that "speech banana" range at 20-35 decibels. Erik has a fun sense of humor. If you ask him to describe himself he'll tell you he's good at video games. His positive, cheerful disposition was helpful for me as his mother when we first discovered his hearing loss at 13 months of age. He continued to be his happy, cheerful self and wondered why I was crying. Today he has a sign language interpreter in school to insure that he

doesn't miss curriculum content, but likes using his speech and hearing to communicate with friends. Erik is an above average reader, a skill we credit to early use of closed captions on television and videos. He's our third child, so it's been natural for us to see him as a "whole child" and look beyond the hearing loss to the young, smart, charming person he truly is.

--Frank & Angela Pintar, Wauwatosa

Janeva Mosher, born 8/01



We are deaf, and whether our child was deaf or hearing didn't matter. Neva is deaf and a true blessing. For us this is normal, she is normal, her development is normal and she proves that hearing and deaf children are very much the same. She achieves developmental milestones that are typical of most children. Our daughter is assertive, independent and a delight! A deaf child is a

child first and we advise parents of deaf children to relax and enjoy their kids. We love Neva and everyday feel thankful for all the great things she brings to our life, she is such a joy and lights up the world for everyone who meets her. We hope you will meet her someday! All that being true, raising a deaf child is still a process full of decisions - as much so for deaf parents as for hearing parents. We who are deaf may make different decisions, but make them we must, and we encourage parents to get support from other parents to make the process easier.

--Jeff Mosher & Amy Rowley, Franklin

Jennifer, born 9/98



We adopted Jennifer as a newborn, from the Marshall Islands. We knew she was tiny and might have some problems, but didn't know she was deaf until she was 15 months old. She also has cerebral palsy. People ask us if we'd have adopted her if we'd known about her medical concerns and deafness. Our answer is definitely, "yes! It would never have changed our minds." Around four months after identifying her deafness and starting to communicate using sign language it "clicked" for us that this

was a kind of special way to get to know Jennifer. We believe there's a reason for this to happen and that her being deaf is just a "different way."

--Brian & Tammy Hogan, Mukwanago

### Jacob, born 7/01



Our son Jacob's hearing loss was identified through a newborn hearing screening. At 13 months he received a cochlear implant. At 17 months he now runs around, pointing and grunting – his way to ask for the names of things. We're involved in a playgroup with hearing kids and observe little difference between him and the other children except that he seems much more expressive non-verbally and often gets his point across more effectively. He's in the oral playgroup at the Center for the Deaf & Hard of Hearing and receives speech therapy at Children's

Hospital of Wisconsin. We still use a few signs and if he knows the name of something in sign language, he uses it. It's fun to see the "wheels turning" in his head as he learns. Through Wisconsin's Deaf Mentor Program we've been exposed to Deaf culture, an awesome new experience for us.

-- Ron & Chris Jahnke, Wauwatosa

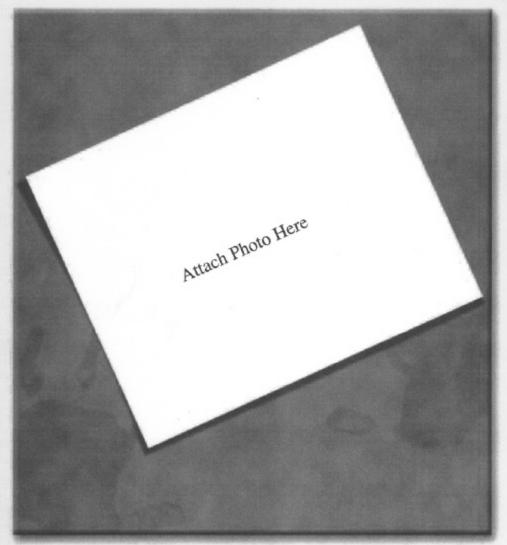




Some people say that a deaf kid is "just a kid." But, our daughter Tess is still a *deaf kid*; we can't separate the deafness from her. She also has Down Syndrome, so for her, things take more time. Moments to celebrate are when she shows that spark of understanding, then uses signs. She tells us a story, her hands flying, and we understand bits and pieces. When things "click" for her it's a thrill because it's taken us so long to get to that point.

--Dan Ruetten & Connie Stevens, Spring Green

# Celebrate your Child's First Word



Here is a place for you to describe your child's first word, signed or spoken:

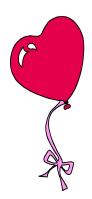
# Celebrating Your Child



	Likes	Dislikes
Food		
and		
Drink		



Likes	Dislikes	
		People
		People and
		Friends



	Likes	Dislikes
Toys,		
Blankets and		
other Things		



Likes	Dislikes	
		Games
		and
		Activities





	Likes	Dislikes
Books		
and		
Songs		

Likes	Dislikes	

	How does your child let you know what	How does your child let you know
	he/she likes?	what he/she doesn't like?
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When is your child the most	When is your child the least
cooperative?	cooperative?



	What frightens your child?	What soothes your child?
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# How do you and your child participate in the following daily routines together?



Feeding	Dressing	Bathing



Naptime/Bedtime	Playtime	Other



What do you do to help your child	What do you do to help your child
learn?	communicate?





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