## PATIENT PERSPECTIVE

# The Word is Good

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I was born with a hearing loss, but did not get my first hearing aid until I was 9 years old. With or without the hearing aid, music has been a big part of my life. As I got older, I lost more and more benefit from the hearing aid. A cochlear implant was the answer for me. It allows me to pick up the high-pitched sounds that I wasn't picking up with the hearing aid. My biggest thrills are recognizing words and songs on the radio. Being able to hear and understand music has opened up new activities for me.

Say the word and you'll be free,
Say the word and be like me,
Say the word I'm thinking of,
Have you heard? The word is love.
It's so fine, it's sunshine.
It's the word love.
In the beginning, I misunderstood.
But now I've got it, the word is good. (Lennon & McCartney, 1965)

At the age of 40, I went from hearing nothing to hearing more than I could ever dream. Who would have thought a person hearing-impaired since birth, would be able to enjoy the radio and hear the everyday sounds of birds singing? These are things I could never do with my hearing aid.

# "IN THE BEGINNING, I MISUNDERSTOOD ..."

I was my parents' first child and so they didn't know what to expect. My mother was only 19 when I was born a premature twin. I was 2 lb, and my sister Donna was 1 lb. She lived only 2 days. I spent the first 2 months of my life in

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the hospital. Because of my prematurity, the doctors were concerned about my vision. However, it was my hearing that was to be the problem. My earliest memory of this was when I was about 4 years old. One night while riding in the car, I reached up and turned on the dome light and said something like, "Turn the light on so I can see what you say." This unusual statement convinced my mom I had a hearing loss, and she confirmed it with a specialist. My parents were told I had a severe hearing loss in both ears.

No services were available in the small town in which we lived, so from age 4 to 8, I had to survive on my own. People tell me that I would watch my mother constantly. Even as a friend was holding me, I would intently watch my mother's face wherever she went in the room. Evidently, I was trying to watch her face for speechreading information.

When we moved to a larger town, I began speech therapy. For some reason, the professionals did not feel I was ready for hearing aids for several years. However, they wanted me to continue speech and speechreading training. I received my first hearing aid when I was 9, while attending a speech and hearing clinic during the summer. The professionals told my mom that I would never be able to go past sixth grade. She would tell them not to tell me that. My mother did not like my teachers or other professionals limiting my abilities. I credit her for motivating me to be my best. She helped me learn to communicate on my own by encouraging me from the beginning to buy my own candy bar and popcorn at the movies and the store.

#### "IT'S THE WORD LOVE ..."

My mom and I worked very hard to succeed in school. To help me learn to read, mom would act out the words in the book, so I could learn their meaning. Because I cared very much about my grades, I would stay up until all hours of the night to complete my homework assignment. Even though I was very shy, I managed to attend regular school until fifth grade by sitting in the front row of the class and letting the teacher know that I needed to read lips. I was good in math, and the teachers were often surprised that I could do so well given my hearing loss. Even though I passed the fifth grade, I had to repeat fifth grade at an oral school for the hearing-impaired. The professionals thought that two more years of training would help me handle junior high school. When I completed sixth grade, I was able to go back to regular school. As a senior, I got on the honor roll for the first time.

I grew up listening to '60s and '70s music. The Beatles' first appearance on *The Ed Sullivan Show* was the same year I got my first hearing aid. They caught my attention and I became an instant fan. I wanted to listen to no one but the Beatles! I would save up my allowance to buy Beatles albums. Sometimes I got lucky and the words would be printed inside. When the words were not there, I

did a lot of looking to find the words in *Teen* magazine. If I couldn't find the words, I would have great difficulty understanding them on my own. I would play the albums daily and memorize the words. I never missed an opportunity to see them on TV. The "bouncing ball" on the sing-along portion of *The Beatles Saturday Morning Cartoon Series* was very helpful.

After high school, I learned to enjoy other kinds of music. I went to weekly classical music concerts at the library and to the Mississippi River Festival with local rock bands. It was fun even though I didn't know any of the songs. I especially enjoyed when they played the drums. I learned about new singers and bands only from watching TV shows like *American Bandstand*. I could hear Johnny Cash and Tom Jones well because of their low-pitched voices.

I was gradually losing a little more of my hearing each year. I was getting fed up with my hearing aid, as it would feed back when I turned it up too loud. My busy life as a mother left little time for me to enjoy music. I had the Nucleus 22 implanted on October 18th, 1993. My hook-up date was November 15th. I was worried that I might not like the "new" sound. I wasn't sure if the cochlear implant would be successful and had a fear that I was taking a chance and may be giving up the joy of music. So the weekend before my surgery I took all of my Beatles music and listened to it over and over one last time, in case I would only have the memories.

I had heard in my own way for almost 40 years and it was just driving me crazy not knowing what to expect. You see, I thought that hearing with an implant would be more like "normal" hearing, but since I had never heard normally, I didn't know what that meant! At first, I was very disappointed with the way things sounded with the implant. My brain was only signaling me to hear one "bell" sound for every sound that was made. When people were talking it was just a repetition of the bell sound every time they opened their mouth. I worried that it would stay that way and thought that maybe I had made a mistake. It was no fun to hear one tone when I had picked up more than that with my hearing aid. I wanted to hear music but this was ridiculous! But it improved the very next day. Everyone sounded like Mickey Mouse. It was the first time I heard high-pitched sounds. With programming and therapy, we were able to adjust the processor to my satisfaction. It wasn't long before speech sounded more natural (whatever that means!) to me. I felt that having never heard normally, I was at a disadvantage when it came to making judgements about the sound quality of different programs, and knowing what to expect.

The first week I watched Michael Bolton on television and noticed the background music more than his voice; it wasn't pleasant. I also watched a '70s special, and it didn't sound as good as with my hearing aid. At my first therapy session, my therapist began helping me to learn how to enjoy music with the implant. She loaned a patch cable to me and showed me how to connect it to my Walkman. She also began working with me on recognizing some favorite Christ-

mas carols. She made a cassette recording of "Silent Night," "Jingle Bells," and "The Twelve Days of Christmas." I listened to the tape whenever I could, sang along with it, and memorized the words. At about the same time, I listened to all of my Beatles tapes with my Walkman and had the words with me to refresh my memory. It sounded pretty good, almost like I remembered it, but I had a few surprises. I noticed in the song "Love Me Do" that I had never heard the word "Please" ("So plea-ea-ea-ea-ease, love me do-oo"). I thought there was a long pause there because my hearing aid didn't pick up the high pitches!

## "SAY THE WORD AND BE LIKE ME . . . "

I immediately went out and bought more of their recordings, and I felt like a teenager all over again. I found the St. Louis Beatles Fan Club on the Internet and have been a member for 2 years. Activities with the club include club historian, Halloween parties where partygoers are supposed to dress in the Beatles theme, karaoke night (only Beatles songs, please), and field trips to Beatles celebrations and memorials. I've heard Ringo in concert three times. I now go every year to Beatlesfest in Chicago, where I can meet famous people associated with the Beatles. Before going to a concert of Beatles music, I will listen to the cassette every day for a week to refresh my memory of the words so I can sing along with them. It is the first time in my life that I feel at ease in a social club. I don't worry as much about being different because we like the same thing. I had the opportunity to have my story published in a collection of stories from Beatles fans like me, along with some famous musicians. All the authors have autographed my copy. It would be wonderful if I could meet Paul, Ringo, and George to show them why I may just be their biggest fan.

## "SAY THE WORD I'M THINKING OF..."

It was Christmas Eve and I was driving home from the grocery store. There was a slight covering of snow on the ground. While I was waiting for the signal light to change, I recognized "The Twelve Days of Christmas" on the radio. I couldn't believe the song we had recently been practicing was on the radio, and I was able to pick it out! With the hearing aid, the radio just sounded like a foreign language to me. Then right after "The Twelve Days of Christmas," "Silent Night" came on. With that song, I was struck by how far I had come, and I was overwhelmed with happiness at being able to recognize some of my favorite Christmas carols. I just broke down crying with joy. I felt like no one would understand what I was experiencing. "Silent Night" was the most beautiful song I'd ever heard, and I know no one appreciated it more than I did on that special Christmas Eve.

#### "SAY THE WORD AND YOU'LL BE FREE . . . "

I am enjoying music with my children, Jamie and J.J. We watch MTV together, and I have to admit some of it is not bad, like The Backstreet Boys and Mariah Carey. Jamie is teaching me all of the latest songs that she likes, but the Beatles are still my favorite. She went with me to Beatlesfest last year and was surprised to see me enjoy the concert. It touched my heart that she could see how much joy I get from music. My husband, Jim, and I have found that we both like Hootie and the Blowfish. I also enjoy hearing J.J. play the trumpet in his school marching band, especially his award-winning solo performance of "The Marine's Hymn."

It was such a thrill when I walked into Wal-mart and I could recognize my favorite song, "And I Love Her." It was exciting to be able to do something that people with normal hearing can easily do. I listen to KLOU 103.3 FM on my way to work, at work with my Walkman and patch cord, and on Sunday mornings when they play only Beatles songs from 8:00-9:00 a.m. During my lunchtime fitness class, being able to hear the music helps me enjoy the class more and motivates me to try harder. When I went to see *Titanic*, it was fun to hear the sound of the water rushing and I felt the music helped to build up the tension when the ship was sinking. I recently went to see an open-captioned movie. My battery burned out so I had to watch the movie without sound. It was hard to stay awake because I was not hearing anything!

Because of my "ear-opening" experiences with the implant, I have become very interested in educating others about the needs of the hearing-impaired. There are so many areas that need attention. For example, why can't records, tapes, and CDs have printed words enclosed? Also, it would be helpful if the packages were labeled to indicate that printed words are included, in the same way movie videos are labeled "closed-captioned." Having the words makes it easier for me to learn them, and knowing the words makes the music more enjoyable. I know of people with normal hearing who have difficulty understanding the words and would like to have a written copy as well. I have thought it would be fun to learn how to play "And I Love Her" on the piano and guitar. I never could whistle (except with my hearing aid!) – maybe I can learn how to do that!

## "BUT NOW I'VE GOT IT, THE WORD IS GOOD ..."

The song "The Word" has a double meaning for me as you can see. Since getting the implant, I can hear better, do more, and have learned it's O.K. to make mistakes. I am more comfortable and confident in asking for the assistance I need to hear, understand, and enjoy what life has to offer. Every night when I take off my implant, I am reminded of how much I appreciate music. I am de-

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lighted that I can respect and appreciate hearing without taking it for granted. Since I've received the cochlear implant, the word is good, very good!!!

## **ACKNOWLEDGEMENTS**

I would like to thank the Washington University School of Medicine Cochlear Implant Team (Susan Binzer, Laura Holden, Margo Skinner, and Dr. Gail Neely); my mom, Peggy Patterson; and the St. Louis Beatles Fan Club, for helping me hear, and enjoy what I hear.

## REFERENCES

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