Transitioning to a Cochlear Implant with CART: Our Journey

by Kelly Klapstein

When our daughter Serena was born, we had no idea she was Hard of Hearing. She seemed to be developing normally according to our pediatrician and was communicating and responding as our first baby had. Then when she was around two years old, she contracted a bad ear infection.

At that time, her speech was coming along, but not as quickly as her older brother's had at the same age; however, we also knew he was an exceptionally verbal child. During her ear infection and cold, Serena and I were playing, and her grandmother called on the phone. I held the phone to Serena's left ear, but she shook her head and said, "No," moving the phone to her right ear. I thought this was unusual and after the phone call ended, I tried to whisper in her left ear. She said she couldn't hear me and moved so I could talk into her right ear. Off to the pediatrician we went, who referred us to an audiologist.

Serena was diagnosed with bilateral sensorineural loss, mild-moderate in her right ear and severe-profound in her left and began wearing hearing aids. That was the starting point of our journey with many appointments, heartbreak and assessments. However, we soon got over the heartbreak and moved into acceptance and understanding because we realized that many other children had more challenging issues and health concerns than our daughter.

I suppose we all want our children to be perfectly healthy and 'normal,' but eventually we adapted to our new 'normal,' and Serena happily experienced a typical childhood with gymnastics, soccer, piano lessons, skiing and mainstream schooling, where she used a personal FM system. In fact, I would have to admit we had become quite complacent about Serena being Hard of Hearing, and perhaps it was a form of denial that anything could or would change. But things did change.

In junior high school, Serena rebelled against her hearing aids and pretty much stopped wearing them. In grade 10, during the summer break, Serena expressed a newfound desire to return to the audiologist and get her hearing checked. We discovered that her hearing had dropped significantly in her right ear, and her left ear was profound. This time, Serena wanted a new hearing aid because she now could not manage without one.

The following summer, Serena was getting ready to leave on a trip to Germany to visit close family friends. Two days before her departure, she complained that her hearing aid wasn't working. It was the weekend, so we couldn't see an audiologist. Since my husband was flying there a week later, he planned to bring along the required parts and tools that the audiologist gave him to fix the broken hearing aid. After his attempts to fix the parts in Germany, Serena said she still could not hear. A visit to an audiologist revealed that it was not the hearing aid that wasn't working. Serena's hearing was gone. They called it "unexplained sudden deafness."

They gave her steroid shots in an attempt to revive the inner ear hair cells—to no effect. The German doctors began talking about the possibility of cochlear implants. Serena wanted to stay in Germany for the remainder of her trip, enjoying herself despite all that was happening.

I was at home in Canada, feeling horribly upset and trying to figure out what we should do next. I made appointments with her Ear Nose and Throat (ENT) specialist and audiologist. I felt desperate about her return to high school, which was in a few short weeks. Serena excelled in school. She had always lived in a hearing world, and did not know sign language. How could she continue as a Deaf student if she did not know ASL? The emotional upheaval was tremendous for all of us. It was heartbreaking. Amazingly, Serena was the strongest of us all, maintaining a positive attitude and looking forward to returning to school.

Many phone calls and online searches resulted in a contact at the Canadian Hard of Hearing Association Edmonton Chapter, who suggested that I look into CART (Communication Access Real Time). They put me in touch with Linda Hallworth, the President of the Alberta Shorthand Reporters Association. That

was the most important piece of information I received because with live captioning in the classroom, Serena could continue to study in her high school.

Although initially our high school attempted to implement DragonSpeak, a voice-to-text program, it failed miserably. After a demonstration of CART at the school, we all knew that was the only option to ensure Serena's success.

A second valuable contact was Alberta Hands & Voices, a parent-driven support group for Deaf and Hard of Hearing children. By connecting with this organization, I no longer felt alone and lost. There were other parents who were on similar journeys with their children too, and together we could make a difference for our children by sharing resources and our own stories.

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I attended a Coffee Talk organized by Hands & Voices in Edmonton, and explained to an audiologist at the meeting that Serena was feeling undecided about cochlear implant surgery. The audiologist suggested that I connect Serena with another teenager with a cochlear implant. Happily, Serena got in touch with this young man and they met to talk about everything over coffee. Shortly after, she agreed that proceeding with cochlear implant surgery was the right choice.

Our ENT immediately referred Serena to the Glenrose Hospital. Her new audiologist fitted new 'super power' hearing aids in both ears, just to provide some sound that would enable her to lipread better and also be aware of her environment. These hearing aids made a big difference and soon Serena seemed to be returning to her normal self. Her teachers commented that she was participating in class discussions again. It is exhausting to lip read all day, and she had terrible tinnitus and headaches. Her weariness by the end of the day was noticeable, but with her new hearing aids and even a little residual sound, she felt like part of the hearing world again.

The assessments involved with the cochlear implant evaluation seemed endless. It was difficult to juggle all the appointments, but Serena was finally deemed

eligible for implants in both ears. We met with the surgeon and just shy of one year after her sudden deafness, Serena underwent cochlear implant surgery in her right ear in July 2014. Other than being upset about so much of her long hair shaved off, the surgery and recovery went well. Activation took place in August 2014, and within a week, Serena was beginning to hear again. Technology is a miracle!

Most of us have memories of our high school years that are unforgettable, but Serena's experience is undoubtedly extraordinary. She is currently in Grade 12, was elected student council president, and plays on the senior basketball team. She is so excited about her graduation and plans to attend the University of Alberta. Her future is bright!