

Explant and Update for 2015

Well, here we are in 2015! Many years have passed since I wrote the majority of what is available on the website www.deafchildrenspeak.com. The miracle of cochlear implantation is still prevalent; the miracle of a completely deaf child hearing and communicating just like everyone else still exists. Looking at the past seven years, the reality of cochlear implantation has also set in. What exactly do I mean by this? Even though Gabriella is twelve years old, is in seventh grade and does extremely well in class, she has a hard time hearing in many circumstances.

Let's look at the academic skills first. Gabriella gets excellent grades; she obtains 90% - 95% on most of her school tests, and about the same scores on all of the California State Exams. She reads extremely well, is good at math and also loves science. She has really good interactions with her teachers and has age appropriate academic skills. Most people who have worked with her or spoke to her feel she is above average in her IQ level. All of her teacher's really enjoy having her in their class. Many times I think, "How can a child do so well in school when she is having a hard time hearing?" Over the years we have used a SoundField system in the classroom and currently we are using a Phonak FM System. With this system the teacher wears a microphone, there are "boots" that are placed on the external processors and the teacher's voice is then transmitted directly into both of her implants. Another amazing technological achievement! So she hears each teacher very well, but the problem comes when the children ask questions in the classroom, when she is in the multi-purpose room, when she is at recess, having lunch etc. With this said, we have noticed her to be a little more reserved than most students in social situations.

As always, speaking clearly, concisely and reducing background noise definitely helps. She can carry on a very clear and articulate conversation with any person who speaks to her, inside the school or in the general population. In almost every circumstance it is impossible to know she is deaf. In the sound booth at the audiologists Gabriella receives scores of 15dB sound recognition and 20dB on pure tone testing across all frequencies. She even obtains a 96% word recognition and 96% sentence recognition (on her good ear.) So her hearing levels are very, very good, her articulation and conversational speech are also excellent.

So what does Gabriella like to have in place to help her hear even better, to hear more clearly and to make sense of what is being said? As we discussed, an FM system in the classroom is a necessity. It would be ideal if there was a specific tool that could help raise the voices of all the children in class when asking questions. It would be nice to reduce the background noise at recess and it would be nice to reduce the echoes and background noise in the lunch cafeteria. As hearing people we can adjust to all of these circumstances and hear pretty well. As an implanted child, there are still many challenges in these particular areas. After all, Gabriella is deaf and the implants are a miracle, but the reality is that they will never replace two normal ears. I am glad that these additional technologies exist to help implanted children hear better. There is even a product called the Rodger Microphone that can be pointed at a speaker and that person's voice will be transmitted directly into the processors! We are currently looking at using one of these devices to help with any speaker that does not have an FM microphone on.

With these excellent products that are on the market, with the correct mapping programs and frequent checkups by the audiologists, the hearing levels can be maximized and the frustration of “not hearing every word” can be reduced. We are even looking into a phone that will caption every word on the receiving end. I came to find out about these phones and the free captioning service at www.captel.com . Many states have programs that will pay for the phones and the monthly cost of the captioning.

Going beyond the classroom, there are many other technological wonders that help Gabriella hear at a more optimal level. At the movies she likes to have a captioning device to help understand every word. At home she likes to have captioning on the television. (There is even a device on the Nucleus 6 processor which will feed the television audio directly into the processors!) She also likes to use a plug in adapter to a cell phone, and her iPad to transmit the sound directly into her processors.

So are cochlear implants the cure for deafness? Absolutely. Are cochlear implants as good as human ears? Unfortunately not. With a little ingenuity a young twelve year old, a young teenager or even a young adult can get by just fine in this hearing world. Have the implants served their purpose to help my daughter gain speech, excellent articulation, above average cognitive skills and near perfect hearing? Absolutely YES! There is even a waterproof device sold by Cochlear Corporation that can be put over the external processors so she can hear while swimming. This use to be a problem when she took swimming lessons because the instructor could not communicate very well with her. Then the amazing research and development team at Cochlear Corporation came up with a waterproof rubber boot that fits over the processors. Too cool!

Keep in mind that everything just mentioned is to help a cochlear implanted child hear more effectively. In a quiet room my daughter still has the ability to discriminate rhyming words, to respond to a whisper, to answer any question auditory only, on her good ear of course. Unknown to us, one implant started to fail and we found that her excellent responses were becoming less frequent; her very good hearing was deteriorating.

Explant a Necessary Procedure

About twelve months ago we noticed that Gabriella would ask for words or sentences to be repeated on a more frequent basis. We took her to see the audiologist and the mapping was changed a few times. In regards to the mapping programs; Cochlear Corporation has four maps that can be stored in the processors. Currently Gabriella has a map for every day conversation and the classroom, a map for noisy places like a restaurant, and a map to hear music better. Her sensitivity level is set at 12 and the volume is set at 7. You can even change the mapping program, sensitivity and volume levels with a hand held device. We also use a Dry and Store box to remove excessive moisture from the external processors. Outside of replacing a battery here or a wire there, the processors have held up pretty well over the years. To reduce the chance of losing a processor and to reduce the chance of the processor falling off her ear and hitting the ground, we use fishing line and an alligator clip to secure the processor to her shirt so it will hopefully never be lost. Thanks to having a good insurance plan, we had the opportunity to upgrade the external processors a few times from the Freedom, to the Nucleus 5 and then to the Nucleus 6. Each new processor comes with more bells and whistles to help the recipient hear better. In reality, I am sure she would have done just fine with the original Freedom processors, but since we had the opportunity to upgrade we did.

So after trying out a few different maps to help my daughter hear better, nothing seemed to help. She then complained of the left processor “not sounding good.” Back to the audiologists where a word recognition test was done. She received 96% on her “good” right ear and only 70% on her left ear. The Cochlear representative was called and an integrity test was performed. They found that 25% of the electrodes on the left ear failed the testing. What this means is that those electrodes did not pass the impedance thresholds and they were outside of the normal readings for impedance and other technical criteria. With her word and sentence recognition falling on that one ear, we could not understand why her pure tone scores were still in the 20dB range on all frequencies. The audiologist said “yes, she can hear the pure tones pretty well, but she CAN NOT hear clearly.” With that said, I finally understood the severity of the problem. So pure tone testing does not give the whole story, it must be coupled with word and sentence recognition tests within the sound booth. The maps were changed again, a few electrodes were turned off and we took a wait and see attitude, hoping she would hear better over the next few weeks. There were a total of three integrity tests performed and many sound booth tests. On the most recent testing her word recognition was down to 40% on words and sentences. More electrodes had failed and about half the electrodes were not working properly on her left ear. All of these test scores were examined by Cochlear Corporation and our audiologist. The reality became that a re-implantation or explant was necessary.

During the first two implants when Gabriella was 14 months old and 25 months old, my wife and I had the greatest optimism that the surgeries were a necessary procedure that had to be done so our daughter could hear better. We were concerned with the surgical risk, but the benefit of having implants were too great and overshadowed any real concern we had. We knew she would be in good hands with our surgeon and support staff at Children's Hospital Oakland. Now that we were facing a third operation for our daughter, and since she was twelve years old, we had a decision to make as a family. Gabriella would be a full participating part of this decision process.

So as parents, the only thing that was on our mind was the surgical risk involved. We have all heard of the stories of surgeries going wrong. They take off the wrong leg, the person dies under anesthesia, and the surgery for whatever reason goes horribly wrong. This was what we were thinking about now. The optimism turned to frustration. Are we really in the 1% failure rate that the companies speak so highly of? Will the end result be better? Will she come through the surgery 100% O.K.? We did not know, but we did know that she had to have a new implant or else her ability to hear correctly would be compromised and with so many electrodes failing we might as well just turn the processor off. We didn't like that decision either. So we weighed the pros and cons and discussed everything with our little girl.

To my surprise, while discussing the necessary operation and the benefits of having a new implant my daughter took the news pretty well. She knew she wanted to hear much more clearly. I was afraid that there would be extreme opposition on her part, but there was not. Her number one concern was “Will the doctor have to give me a shot?” She even said “I do not want the surgery if I have to get a shot!” I listened to her concerns and remembered when I was a child, my parents told me that I had blood poisoning, and I had the identical reaction. How coincidental! So we were all in agreement that a re-implantation was necessary and would be the best course to pursue.

With the decision made to move forward with a re-implantation, we talked to the audiologist again about insurance approval and all the needed steps to get the surgery done. Within a few

weeks we had the approval for the operation and a surgery date was set for February 6th 2015. About one week before the surgery we met the highly skilled surgeon who has implanted hundreds of children and now our daughter's life and future hearing was in his hands.

The evening before the surgery Gabriella was on a twelve hour fast so no food or liquids would be in her stomach the next morning. On the morning of the surgery we arrived to the hospital at 6:00 A.M. even though the surgery was due to take place at 7:30 A.M. The nurse put her on a bed; she changed into a hospital gown and all of her vital signs were taken. Everything looked good. The anesthesiologist came by to say hello and to meet Gabriella for the first time. Soon after this the surgeon and the audiologist showed up and it was getting closer to 7:30 A.M.

Gabriella was then wheeled a few floors down into an adjacent building and we all gave her one last hug and a big kiss before she went into the operating room. Our family then went to the hospital cafeteria to wait out the two hour operation. There were friends, grandmothers, aunts and uncles all who have joined us for this special day. Gabriella's grandmother even came all the way from Las Vegas for this very important operation! There must have been about eight people sitting around talking about anything but the surgery. This was to keep our minds focused on other things.

We were hoping and praying that everything would turn out good. A lot of nervous anxiety and three cups of coffee later, we looked at the clock and it had been about one hour and forty five minutes. We wanted to go to the operating area and find out how our daughter was doing. We got close to the security doors ready to pick up the phone and talk to a nurse and all of a sudden the audiologist came walking out and said "The surgery went great!" We were ecstatic and relieved, we hugged her, thanked her and tears of joy started to flow down our faces. She then explained that everything went well and Gabriella passed the ABR test which was performed after the surgery to make sure the implant was functioning properly. So we knew everything went well. We knew the implant was working. Now we just needed to see our daughter! A different nurse escorted us to a waiting room and she said it would be about 30 minutes before we could see our daughter and only two people at a time could be in the recovery room. That was going to be a minor issue due to the fact we had so many friends, relatives, grandmothers and others in our group.

A nurse walked into the waiting room and said Gabriella is in the recovery area and we could see her. So we walked into the room, vital signs registered on a monitor. One nurse was by her bed and she said "she is doing just fine and should wake up soon." About fifteen minutes later Gabriella slowly woke up, and within one and a half hours she was wheeled out of the hospital to our waiting vehicle. Yes, at age twelve this is an outpatient procedure which does not require an overnight stay in the hospital. We drove home and with a few pain pills she made it through the night and felt pretty good the next day. We were instructed not to get the incision wet for 10 days and no physical activity for three weeks. She did not need antibiotics at home because all the antibiotics she needed were in her I.V.

By day four after taking it easy this whole time, she felt pretty good. She could walk well and she also conversed well. She took a total of two weeks off of school and was excused from PE for a total of three weeks. Within the two weeks following the surgery, we went to the park, walked around, walked her dog and did many things except anything that could result in a fall

such as bicycling, riding her scooter, or skating. All of these activities needed to wait a few weeks or even a month until she was fully healed.

The recovery was going well. On day seven after the surgery we had an appointment with the surgeon to make sure the incision was healing well with no infections. Everything looked good and the doctor wanted to see Gabriella in six weeks to check her again for proper healing. We also made an appointment with the audiologist three weeks after the surgery to put on the new external Nucleus 6 processors and turn everything on. This is one of the most important and nerve wracking days. This is the tell-all appointment where we will know for sure how well the electrodes are hugging the hearing nerve.

Making Sense of a New Processor

So that day came March 2nd, 2015, the day to get the new external Nucleus 6 processor activated and turned on. We were told previously that when the new implant is turned on it could take upwards of three to four months for everything to sound normal and it may sound “funny” initially. In the audiologists office Gabriella was hooked up to a computer and each electrode was tested independently. There we were looking at the computer screen and all 22 electrodes came up, much like a bar graph. Gabriella could hear each electrode, so this was a very good start! The audiologist meticulously adjusted each T-Level and each C-Level on the processor until she was fully satisfied that each electrode would not be too loud or too soft. The T- Levels are set for the minimum input on that particular electrode and the C-Levels are set for the maximum input. This highly skilled individual then placed a map into program one with the identical map and louder volume placed in programs 2, 3, and 4. We were told to go to a higher program every two days which would increase the volume she was receiving. We were also told to let Gabriella use just her new implant independently for one to two hours each evening. We followed all directions given.

The audiologist explained some unique features of the Nucleus 6 processors. These processors have an external Mini Microphone that parents or other speakers can talk into so their voice will be transmitted directly into the processors. This works great at noisy restaurants or sporting events. This is somewhat like a mini FM System! There is also a Wireless Phone Clip that can be plugged into cell phones or iPads so the sound will be transmitted directly into the Nucleus 6, pretty neat and useful! In addition to these features, these highly advanced processors are self adjusting. What that means is that if a cochlear implant user is in a restaurant with a lot of noise or in a situation with multiple speakers or even trying to understand speech in a windy environment, the processors will take a reading of the “sound environment” and make an adjustment to give the user the best possible listening experience.

Before our next appointment, I decided to give Gabriella an open word recognition test. I would say 20 single syllable words in a quiet room, auditory only and see how well my daughter would do. So I covered my mouth with a piece of paper. I then clearly articulated 20 words and she got... 25% correct. This is crazy, only 25% correct what is wrong? Is there a problem with the implant? I was very concerned. I called numerous professionals to find out if this is normal. I asked many questions. There was no time to waste. We then set up formal auditory training at our local children’s hospital. I wanted two sessions per week, but the insurance only approved one session per week for one hour each.

In addition to using the newly implanted ear independently for one to two hours per day, we were also told to have my daughter visit and work on the following websites. These websites have very good listening exercises and in some cases are created by the cochlear Implant manufacturers. The following are the websites we were given:

www.medel.com/us/user-support-us/

www.medel.com/us/soundscape/

<http://hope.cochlearamericas.com/listening-tools>

<http://hope.cochlearamericas.com/listening-tools/telephone-training>

<http://thelisteningroom.com/lessons>

I then performed the same open word recognition test a few weeks later and my daughter got 66% correct. Now this is a little better, maybe things will improve over the next few months. Gabriella started her auditory therapy with the therapist, one visit per week. As time progressed her hearing got a little better gaining a 72% word recognition and her other ear was still at 96%. She did perform at 20 dB across all frequencies in the sound booth with both ears. Just like starting out teaching good listening skills, trying to enhance this one ear to discriminate, and make sense of what is being said was all we really concentrated on for the next few months.

At 120 days post activation Gabriella was performing at about 92% open word recognition. She had a pretty good handle on rhyming words and picking out word differences within a sentence. I did notice that it seemed a little more difficult to talk on the phone to her and the speech therapist just told us that it will take a while longer maybe six months or more. We were encouraged to keep going to the various web sites, read to our daughter and try to talk in an auditory only manner to enhance her hearing skills on her new ear. At this point, she hears a great deal better than with her failed implant, and can utilize all of the advanced features of the Nucleus 6 system. So we are very happy that everything worked out so well. I do realize that even though a child has two good working implants, nothing will ever replace two human ears. Again, I look at my daughter and I am amazed every day that a young child like her who is completely deaf, can communicate so effectively in this fast, loud and unforgiving world we live in.

Good luck in all of your hearing adventures.

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