My experience with cochlear implant

My name is Gerald Andrew; I am 29 year old male Tanzanian. Last year (2009) was one of the most memorable for me. It's when I received my cochlear implant at Apollo hospital in New Delhi after more than three years of hearing loss. Everyone's experience with cochlear implant is a bit different therefore, am happy to share mine with anybody out there, from the moment I lost my hearing, my experience during my stay at Apollo Hospital and one year later on, after cochlear implant.

I was born with normal hearing and managed to receive a mainstream education normally, joined University in 2002; a four years course; I was 22 yr old then. Four years later everything seemed to be all right and I was on course to complete my first degree. Unfortunately, in my last semester when I was about to finish my thesis, I started to experience continuous loss of balance, dizziness and constant head pain. At that time my hearing was fine and I didn't notice any changes though I am not sure if it was decreasing slowly without me noticing so I kept on working on my research hoping that I can hold on for a couple of weeks until my last presentation. Unfortunately, on Friday 19th of May 2006, with just four weeks left until my final presentation I experienced suddenly major hearing loss in my left ear, if that wasn't enough, ten days later the same happened to my right ear. Things were happening so fast I didn't know what was going on. My family and I were devastated; we didn't know just what was wrong. After several tests, another blow hit me, it was discovered that I was suffering from chronic myelogenous Leukemia (CML) which, according to my doctor was the cause of Sensorineural or inner ear hearing loss.

Due to my deteriorating condition it was clear that I wouldn't be able to continue with my research so I had to postpone my last presentation so as to receive the treatment as soon as possible to save my life. Unfortunately, early medication I used (chemotherapy), helped in damaging my hearing even further. From there, life became very difficult, unable to communicate with my friends and family, no more phone calls, I relied heavily on lip-reading and the patience and understanding of those closest to me to help explain and re-explain what I didn't get. I felt isolated and lost my confidence. Most of us do not realize just how much we value something until it is taken away from us.

Three months later, as my condition improved my hearing was getting worse yet I was determined to finish my dissertation and graduate with my class mates that year. It took me almost a month to conclude and submit my thesis. I remember as I was standing in front of lecturers on my final presentation I couldn’t hear a word I was saying, at the end of presentation all the questions were written down and I would read and answer them one at a time. Almost forty minutes later I was done. It was such a relief and emotional day as I was able to finally complete my first degree in time to graduate with my classmates.

As my hearing continue to deteriorate, so was the increased trips to hospitals, I tried several hospitals, consulting several doctors; doing tests after tests, trying different types of hearing aids hoping that maybe my hearing was going to improve with time with no success. I remember sitting in the auditory room during one the tests with the earphones on waiting and thinking *"come on then you can start today a little bit"* and he was half way through!! it was clear that I had reached the point where hearing aids, no matter how powerful, may no longer help me much in any way. From that point, I knew I have to look for other alternatives available. It was the suggestion of one ENT specialist that I began exploring the possibility of a cochlear implant. At that time I didn’t know anything about it and unfortunately in my country there is no Hospital with such technology. I knew it’s going to be such an uphill struggle but I wasn’t going to give up easily and fortunately in 2008, Ministry of health came to the rescue and I was referred to Apollo Hospital in New Delhi at the end of the same year.

I remember the same day we arrived at Apollo hospital we were introduced to Dr Ameet Kishore, a Senior Consultant Surgeon (ENT and Neuro-Otology), who implanted me with a HiResolution cochlear implant one month later. Sitting there watching him talking with my mum I couldn’t understand much but I just knew he was a wonderful doctor, three months later and I thought ‘how right I was’!

As the process begun, the doctors had to make sure that I was able to withstand the surgery due to my condition (chronic myelogenous Leukemia), after which they were convinced and carry on with second test which was, cochlear implant candidacy process tests where I met this dear Audiologist and Speech Pathologist Ms. Neevita Narayan at SpHear (Speech and Hearing clinic). Prior to getting these test, I thought that maybe I still had enough hearing to be able to use hearing aids again but the series of tests further confirmed my candidacy for a cochlear implant, although I was disappointed it wasn’t unexpected.

Personally, the decision to get an implant was relatively easy. I thought, here is the choice of either a life of total silence and frustrations or taking a risk and be able to hear again. The thoughts of spending the rest of my life unable to hear again and thinking of all the obstacles I faced for over three years of being hearing-impaired and those lie ahead, terrified me and made my decision to go for it rather easy and there was no question in my mind that it was a correct decision. My family, friends and doctor wanted it to be a success. So was I. Given that I was staying in hospital the doctor’s daily visits gave me an opportunity to ask anything I wanted to know i.e. the whole procedure, risks, side effects and benefits of cochlear implant. By the time my surgery was scheduled I was ready and looked forward to it.

It didn’t take long and the surgery was scheduled on Wednesday January 7, 2009. It was undertaken without incident. *"The surgery was success"* said Dr Ameet Kishore soon after surgery. I woke up to find a huge bandage wrapped round my head, at first, the pain and noises (tinnitus) made me really uncomfortable but both subsided as hours went on. It was suggested that I stay in intensive care for couple of days for close monitoring as a precaution measure due to my condition (leukemia) so as to avoid any infections. The first few days after the surgery I felt a bit exhausted and it took me a week or so to feel almost back to normal. The wound had to stay dry for five days, by the time I was out of intensive care the wound seemed to heal nicely. Usually, before the next stage, (switch on) the wound site of the surgery needed to heal completely.

Despite having had the surgery I could still not hear and nothing more would happen for a few weeks. It's a difficult and anxious waiting time which fortunately I seemed to cope so easily so much that when the “switch on’’ day arrived, I felt a little bit unprepared for what I thought is going to be important moment in my life. I had not fully considered exactly what being able to hear again was ‘’really’’ going to mean to me. The clinic was few minutes away from hospital; in the car my mum was quite calm and lost in thought. So was I. I tried as much as I can to lower my expectations. By the time we arrived at the clinic the doctor was there and the audiologists were ready. As we were inside, I remember my mum and the doctor stand there facing me and the audiologist, I was anxious and nervous and my heart was hammering hard in my chest as the audiologist connected the external processor and prepared to "switch" me on.

I had been warned this could be disappointing and at first I thought, *"she's must have done it wrong I can't hear anything"* then slowly like being woken after a deep, deep sleep the sounds began, there were little beeps and cheeps and blips! As my audiologist, Ms. Neevita Narayan, and my Mom and another audiologist in the room continued to converse, the voices started to take on the sound of the cartoon character, Mickey Mouse! Then I heard someone saying ‘‘ *take it easy, take it easy*’’ did someone just said take it easy? I asked. They were all astonished on how fast I was able to catch on some words on the first day, it gave me such relief and joy I could ever imagined. One thing that couldn’t recognize was the sound of my own voice. I kept thinking *"who's that talking?"* only to realize it was me!! Being able to actually hear myself talking was just amazing. Few minutes later, when audiologist suggested that we go outside and see how I was copping, I remember standing there hearing the sounds of cars, motorbikes, people talking, simply the sound of life around me, for the first time in three years of silence it was one the amazing experience I will never forget.

Going back to hospital that day I felt like different person, more confident, ready to talk to anybody. As I closed my eyes and mum said some simple words or phrases and I repeated them to her again and again. Walking around, I could hear my own footsteps again and the noises coming from the television were indistinct but I could hear them. It had been a very long and emotionally exhausting day but I could not sleep. As I sat on my bed reflecting the events of the day, I knew the sound was not perfect, but it was SOUND and the journey out of silence had begun, there was no turning back.

Usually, the outcomes for each cochlear implant recipient are individual and the process may not be immediate, it needs patience, learning and adjusting and re-adjusting, one step at a time allowing your brain to adopt but more importantly the support of people around you. For that reason, soon after ‘‘switch on’’ day I knew the next few weeks were crucial and I had to work really hard. I started rehabilitation the following week in which the testing with the audiologist was such an encouragement. We started with a piece of paper with some words and sentences. Then she said she would say the words and I would have to tell her which ones. The immediate response in my mind was like saying *"Will I really hear the Words? “* She was very reassuring and convinced I would manage so we began. A few minutes later I had scored almost 100% and heard nearly every word she said.

As rehabilitation and mapping continue the robotic speech sounds of the first week slowly took a more natural form. Mum sounded like I remembered. Men and women's voices separated in to just that. The first four weeks post *"switch on"* were very intense, both exciting and exhausting. There were the weekly trips to see the audiologist. The general adjustment and re-learning is hard work but the rewards are worth it. I remember the day I was able to use my cell phone again almost two weeks after rehabilitation, talking to my father, brother and sisters' back home was the happiest moment in my life.

With the help and company of my mother I had wonderful experience throughout my stay in Apollo hospital, one that is going to stay with me for long, long time. The doctors, nurses and all the staff were just amazing. I remember when I arrived at hospital I couldn't understand when they were talking but my mum was there, trying to explain and re-explain to me, that really made my life more comfortable. Sometimes I used to sit back and reflect how life would have been if she wasn't there with me, I feel lucky to have a mother like her and I will forever be grateful for everything she's done to me. And when I was able to hear again it was such a pleasure to talk to them, it was such remarkable turn around.

It has been said that you never really appreciate something until you have lost it. Indeed that has been my experience with hearing loss and now, one year after implant, I feel I have regained it once again! Those sounds and voices that I remember before I lost my hearing are all back again! I no longer avoid gatherings, people and places. I actually look forward to them! I can now use the phone again to call anyone, anytime and chat!

My music records I saved are such a joy to listen to! I had forgotten how uplifting and fun music can be! Each day brings something new to be appreciated all over again! The wind blowing through the trees, Computer keys clicking, Water running, Dogs barking etc. The ability to hear voices and understand so easily and be able to respond. The sounds of life! What a blessing to be given the chance to hear it all again!

I know, I am still learning and getting used it but with the help and understanding of my family, relatives and friends I am coping really well, Not a day goes by that I don't think *"Wow I can* *hear again"* I will never take sound for granted. There is a moment first thing in the morning when I pause, take a deep breath before I *"switch on"* for the day. Having a successful implant cannot ever replace *"normal"* hearing but it comes pretty close. There are still times when it's not all great but the pros totally outweigh the cons and life in general is much easier to cope with.

It's a year since I had an implant but I feel like it's just like yesterday because life is made up by few big moments and a lot of little ones, I still vividly remember that day of ''switch on'' or the time I was able to use my cell phone again, talking to my family and friends, I still remember me and my mum's weekly visits to audiologist, the training sessions with Ms Neevita Narayan, I still remember chatting to nurses and ever smiling Dr Kishore every time he came to visit us. I still remember meeting and chatting to different patients some of them from my home country and I still remember the day I listened to my favorite songs I missed so much, the joy, the relief and no matter what, those memories are going to stay with me for the rest of my life.

The journey out of the silence was not an easy ride and at times, emotionally charged, still is, but it is a journey I am willing to go all the way. Nevertheless, it's unlikely to forget the those who made all these possible and I just don't know how to express my heartfelt thanks and appreciation for the wonderful care and treatment I received from Dr Ameet Kishore and Audiologist, Ms. Neevita Narayan and all Apollo hospital staff, you are all going to be in my heart always. From the bottom of my big heart I say thank you. You gave me a second chance, a chance that am going to take with both hands.