

COCHLEAR IMPLANT UNIT KOGLEËRE INPLANTINGSEENHEID

HOSPITAAL • TYGERBERG • HOSPITAL



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*Stories van ons inplantgebruikers en hul ouers.
Hier is verkorte weergawes van hul stories. Die
volledige stories is in die foto-album in die KI Eenheid.*

At the end of 2014 the Tygerberg Hospital-University Stellenbosch Cochlear Implant Unit will have implanted 563 adults and children. Of this total 326 are children and 109 of the children were implanted when they were younger than 3 years old. This requires the implementation of appropriate intervention for this young group of children and their families that has necessitated a shift in the model of intervention. Read about our Speech Language Therapist, Barbara Kellett's account of the changes that have taken place in managing these young children and their families.

The changing face of speech language therapy for deaf children



BARBARA KELLETT

My undergraduate training focused on child centred, individual, remedial speech and language therapy within a preschool or school context.

Multidisciplinary teams comprised mostly of professionals usually without the parent present in the sessions.

Today, contemporary models of practice promote family centred intervention focused on broad communication skills, as key to good outcomes. Working with an ever younger population, with better access to sound technology, requires of professionals to shift focus towards intervention that skilfully observes and facilitates typical patterns of development at or very close to when they would occur.

Terms such as collaborator, coach, early interventionist and aural rehabilitationist now co-exist alongside the title of speech, language and listening therapist. Most clinicians and researchers, in the field of childhood deafness, agree that we are part of a new, revolutionary era for deaf and hard of hearing children and their families. Advances in hearing technology, the advent of newborn infant screening programmes, shifts to family-centred intervention, outcomes-based practice and the

clinical application of technology platforms for intervention all contribute to the changes that are occurring worldwide.

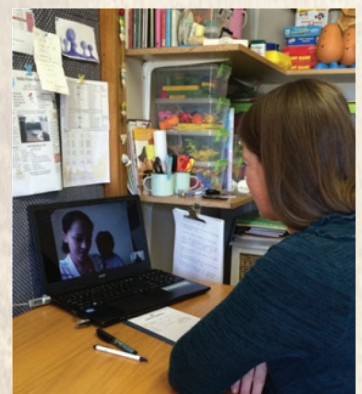
Within a working week I may find myself in dialogue with a mother of a 4 month old baby who is already wearing hearing aids, helping her recognise and respond to her baby's communication attempts; I may use technology such as Skype to connect with families over distance and coach a mom as she interacts with her 13 month old toddler who has already had a simultaneous bilateral cochlear implant; I may collaborate with an occupational therapist as we guide a dad of a busy 2 year old in ways that optimise listening and language; I may help a colleague facilitate a group of 2 year olds and their mothers as they move from messy play to music to book reading or I could be helping up-skill interested professionals across the country via distance learning....

In South Africa change has always been part of our ongoing professional commitment.

Eleven professionals graduated from a year long mentored programme in auditory verbal therapy and practice in 2010, going on to develop a postgraduate short course with the University of Stellenbosch in developing listening and spoken language. This mentored course, LSL-SA (Listening and Spoken Language, South Africa), forms part of a growing international body of specialised professionals who have the knowledge and skills that reflect the shift to parent-centred, norm-based intervention grounded in validated, outcomes based therapy.

These professionals have specialised to help families help their children develop spoken language through listening. We have the expertise; we draw on successful international models and research outcomes; we have specialised training programmes and systems of mentorship available. As David Luterman points out: most clinicians continue to grow and learn while "at the fringes of their clinical (in) competence." May we always embrace the philosophy of change to better serve those wonderful families that grant us our moments of grace.

*Read more about the
stories of our new implant
recipients, starting with our
youngest ones.*



Alekzandra Celestino (No 531)



Alekzandra was diagnosed with a profound hearing impairment at the age of 3 months. My husband and I were at a loss as we had no history of hearing loss in either of our families. We knew for certain that we wanted her to live out her full potential. Making the decision that she should get a CI wasn't easy, but we knew it's the best choice we could have made for our princess. Thankfully we had a great team who was with our family every step of the way, giving us all the information we needed to make an informed choice. The few hours she was in theatre for the cochlear implant operation were the longest and scariest for my husband and me. Looking back, 2 months post-surgery, seeing how she responds to different sounds and our voices, we have no regrets. We feel truly blessed that she was diagnosed early and that she has access to this amazing technology.

Candice and Mario Celestino

wat hul aanbied by die hospitaal en is Nina op dag 3 getoets. Die toets was nie suksesvol nie, en met die hertoets op 6 weke het sy weer die toets gefaal. 'n Breinstamtoets is gedoen toe sy 9 weke oud was. Die nuus was dat Nina 'n uitermatige gehoorverlies in haar linkeroor het en 'n ernstige gehoorverlies in haar regteroor.

Die skok en verslaenheid was oorweldigend. Dit het gevoel asof al ons hoop en drome vir ons dogtertjie, in 'n oomblik weggeneem was. Al wat oorgebly het was 'n gevoel van verlies en hartseer en baie vrae. Ons het egter besef ons moet sterk wees vir Nina en het ons fokus verander na oplossings.

Nina het haar inplanting in haar linkeroortjie gehad op 10 maande ouderdom. Dis nou al 'n jaar na haar inplanting en ons dogtertjie het so wonderlik ontwikkel te danke aan haar spraak- en taal terapie en natuurlik ons almal wat by die huis ook hard werk om haar soveel moontlik bloot te stel aan klank en taal. Dis die mooiste mooi om te hoor 'kom mamma speel' of 'pappa sit'.

Sy is lief vir musiek, dans en gesels en dis wonderlik om te sien hoe sy regtig luister as ons vir haar 'n storie lees. Sy kan nou hoor en ons kan haar elke dag vertel hoe lief ons haar het. 'Moenie wag vir die storm om oor te waai nie, leer eerder om in die reën te dans'.

Rindi en Jean Carstens.

Nina Carstens (No 504)



Ons dogtertjie, Nina, is gebore op 16 Oktober 2012. Soos enige eerste ouer wil seker maak hul doen alles reg, het ons dadelik ingestem vir die gehoorsiftingstoets

Allegra Lategan (No 484)



Allegra is prematuur gebore op 22 weke met 'n gewig van 500 gram. Om haar aan die lewe te kon hou, moes sy baie intensiewe mediese prosedures ondergaan.

Na 5 maande in die Neonatale Hoësongeenheid moes sy 'n gehoortoets ondergaan. Omdat sy so klein was, is aanbeveel dat sy na 3 maande weer getoets word.

Die ABR gehoortoetse het gewys dat sy 'n gehoorverlies het met ouditiewe neuropatie. In April 2013 het Allegra haar 1ste inplanting gekry. Ons het nie geweet hoe sy op die inplanting sou reageer nie. Die aanskakeling 4 weke later was 'n groot verligting toe Allegra kon hoor. Vanaf dag een het sy besef dat dit 'n goeie klank was, een wat haar help. Sy het aandagtig begin luister, en wys nou nog na haar oor elke keer as sy 'n nuwe klank hoor. Binne weke het sy geluister na opdragte, dit begin verstaan en dit uitgevoer. Sy het ook vir die eerste keer begin klanke maak, en 'n paar maande later het sy begin babbel. Sy het verander in 'n spontane, vriendelike kind wat mal is oor musiek en net tussen maatjies wil wees.

In Februarie 2014 het Allegra haar 2de inplanting gekry. Haar verstaan van taal word elke dag net beter. Allegra se nuwe "ore" het 'n hele nuwe wêreld vol wonderwerke oopgemaak.

Chantal en Hennie Lategan

Melanie Benjamin (No 492)



17 November 2009 a little girl at the age of 2 days old changed our lives completely. Without a doubt or consideration we took full control over this little bundle of joy.

Without a name or clothes, we immediately welcomed her into our home. We named her Melanie Benjamin, in memory of my husband's late daughter. Her mother could not take care of her. We continued to care for Melanie, and finally the adoption went

through. I quote the court's message to Alvin and myself: "Melanie is now yours as if she was born of yours, let no man tell you otherwise".

Things went smoothly until I discovered that Melanie, at the age of a year and six months, could not hear us. Melanie was found to be partially impaired in both ears and was fitted with little brown hearing aids in both ears. She started as a 2 year old at the Carel du Toit Centre. In 2013 she was a candidate for a cochlear implant.

She received the cochlear implant through Tygerberg Hospital. Ever since the operation Melanie has improved so much, that the team informed me that Melanie is only 6 months behind a normal child. She is loved by everybody and we could not ask God for better.

Retha and Alvin Benjamin

Shilo Rhoda (No 479)



Shiloh developed a progressive hearing loss, which needed hearing aids of increasing strength. She was finally diagnosed with Enlarged Vestibular Aqueduct Syndrome (EVAS). Cochlear implants were her only recourse if she ever wanted to hear again. She received bilateral cochlear implants in February 2013, at the age of 4 years.

On 10 April 2013, Shiloh had her big "switch on". It was only on that day, that I realized how much she'd been missing out on. She had been lip reading to compensate for her ever increasing hearing loss and had seemed to be coping very well.

When we got home after the switch on, we sat in the kitchen in silence, when she suddenly asked, "What is that sound, Mommy?" I replied with tears in my

eyes,"It's the kettle." For the first time I realized that my child did not know the sound when a kettle is boiling. Since then, her hearing has improved dramatically. She is much more talkative and inquisitive.

My husband and I are forever grateful to each and every person that has had a hand in allowing Shiloh to reach her full potential and still continue to do so.

Gail and Wayne Rhoda.

Oren Peters (No 475)



My son was born one of a twin. Oren and Julia arrived three months prematurely. Oren weighed 560 grams and although small, one could tell he was strong from the beginning.

The first six months of Oren's life were spent in the ICU. This early stage was characterised by problems associated with extreme premies, i.e. chronic lung disease, breathing problems, intolerance to feeding, low birth weight, lower grade brain haemorrhages, etc. Oren came home after six months. At a later stage, he was diagnosed with a severe hearing loss in both ears and auditory neuropathy and fitted with hearing aids in both ears.

Discovery Health made it possible for Oren to receive a cochlear implant last year. He has a hearing aid in his other ear. Oren has thrived with the hearing technology. Oren was mainstreamed at the age of six.

The success of the cochlear implant can be attributed to the dynamic support of his facilitator, his social worker, teachers, Herzlia's special needs facilitator, his speech therapists and audiologists. Learning new sounds is a process and not an automatic experience. It helps your child engage more with the

world around them. It will significantly increase your child's communication, social interaction, vocabulary and self-esteem. The list can go on!

Lyanne and Gavin Peters

Kaylin Johnson (No 377)



Kaylin wasn't born deaf. Her gift of sound was taken from her when, at 4 months old, she contracted bacterial meningitis. Kaylin's journey to sound started when she received a cochlear implant at the age of 1 year 2 months. The emotional impact of her illness and subsequent hearing loss was overwhelming and it took some time to come to terms with it. The final acceptance of her hearing loss led to the start of a personal blog called Kaylin's Journey to Sound. I hope by writing about our experience it will inspire other families who are on the same journey. Go to www.journey2sound.co.za. *Jonene Johnson*

Lorenzo Andrews (No 476)



Many people say that self-confidence is one of the greatest assets any human being can have. Well I believe that the cochlear implant helped me in building my self-confidence as before I was stuck

between two worlds: the hearing world and the deaf world. I am the only deaf person in my family.

Throughout my teenage years the most places I visited were hospitals and audiologists. I was spending less time with friends and family because I couldn't communicate with them properly. I became extremely silent in my high school. For grades 11 and 12, I went to Dominican Grimley School in Hout Bay. The school helped me improve my confidence but outside in the real world I still felt like an outsider. At the age of 17 I was encouraged to get a cochlear implant because I wanted to study further. In 2013 I received a cochlear implant. Ever since then I had improved hearing but it also helped me to improve my self-confidence. In matric I came second in the National Exams for special needs students. Today I'm a first year student at the University of Cape Town doing a Bachelor of Social Science degree.

The cochlear implant gave me the hope I needed. So maybe the cochlear is the hope that we as deaf people need, it's not meant to give me perfect hearing, but it's there to create the hearing I never had. It would be very hard to have achieved everything I did without the cochlear implant.

Shannon Wilsnach (No 538)



By the age of one, I was diagnosed with a profound bilateral sensorineural hearing loss and wore hearing aids ever since. After mainstream schooling, I was accepted at Rhodes and completed my BSc. An FM system helped me follow what was being said in class. I decided to have a cochlear implant when I turned 25. It was a hard decision to make because I felt I did well enough with my hearing aids. The fact that my hearing loss is progressive pushed me to look into the benefits of a cochlear implant. I was worried about the effect it would have on my activities. These include diving and horse riding.

The surgery was a painless experience. Two weeks after switch on and I appreciate my new way of hearing. Most of the sounds are those that I did not hear before. I am still adjusting to the high frequency sounds that my hearing aids don't provide. Words sound more clear now that I pick up on the softer tones (eg: 's', 'sh', 'ch', 'f', 'g' and the list goes on). My pronunciations are more accurate.

Anene Engelbrecht (No 518)



Ek is heeltemal doof gebore en het my hele lewe lank 'n gehoorapparaat gedra, eers in beide ore, tot ek 18 jaar oud was en toe net in die regteroor vir die laaste 15 jaar.

Toe ek in 2012 swanger raak met my eerste baba, het ek agtergekom my gehoor begin verswak. Het eers gedink dis die apparaat wat probleme gegee het, maar nadat ek 5 verskillende aparate probeer het, het ek geweet, dit is nou tyd vir 'n kogleêre inplanting.

Ek het nie 'n keuse gehad nie, want ek kon nie meer my babatjie hoor huil of ander geluide rondom my nie. Dit het ook begin om my werk te belemmer. Na die aanskakeling van die inplanting was ek baie teneergedruk en bekommerd, want die klank was glad nie wat ek verwag het nie. Die klank was baie vreemd aan die begin, maar na elke afspraak vir die verstellings het dit al beter en beter gegaan. Nou 7 maande na die aanskakeling kan ek baie beter hoor as met die gehoorapparaat.

Daar is nog soveel meer wat ek sal kan vermag met die kogleêre inplanting in die toekoms. Mens moet tyd maak om al die klanke waar te neem en om luisteroefeninge te doen. Ek is dankbaar dat ek 'n 2de kans gegun is met my gehoor, en vir die tegnologie wat vandag beskikbaar is, en ek sien uit na die pad vorentoe!

Ntombizanele Mnyengeza (No 507)



I am 57 years of age and an educator. On April 21, 2013, after an emergency operation I realized I could not hear. I thought I would regain my hearing as I was recovering, but then was told that I was totally deaf.

Hearing aids did not help, and a cochlear implant was recommended, which I refused, because I believed that the Lord, the Healer would restore my hearing, as He has seen me through the illness. As the days went by and I was recovering I agreed to have the operation.

Everything went well and the financial cost was paid by GEMS medical scheme. There was excitement in my family for the 1st of October 2013 for the day of the switch-on.

Hearing sounds is a feeling that I cannot describe. The feeling of joy when I heard my sister and my daughter talking, and I could respond to the conversation. The different sounds became clearer every day.

I was emotionally coming back to myself. It is almost a year after my cochlear implant and I am no longer frustrated. I call people with my cell phone, and fit in socially. I realized that God has been with me all along, and He showed His love for me throughout the process. Thanks to the cochlear implant team for giving back my life.

Florus Herwels (No 489)



In ons familie aan moederskant het ons geskiedenis van oorerflike doofheid, nl. otosklerose. In my middeljare het my gehoorverlies vererger. Ek was aangewese op aparate. In 2012 was die sterkste gehoorapparaat nie meer sinvol nie.

Die moeilikste was wanneer die kleinkinders kom kuier en ek alleen was om hulle op te pas. Sou hulle onder die oog uit is wees en een begin huil, was dit 'n rondom trippel van my kant om te bepaal waarvandaan die klank kom.

By kerkdienste was dit dieselfde: by die sing van gesange moes my vrou menigmaal aan my stamp om aan te dui ons sing nog nie daar nie, of is lankal daar verby.

So 'n week na die inplanting se gesondraak periode is die apparaat aangeskakel. Dit was vreemd om die geluide te kon hoor. Die eerste geluide was 'n tip, tip, tip. Ek het gewonder of die apparaat foutief is, en ek het dit vir die oudioloog gesê, maar sy het vir my beduie om te wag. Weer die tip, tip, tip en die kantoor deur gaan oop. Tip, tip tip. En toe die persoon staan, die tip, tip ophou, registreer ek, dit was voetstappe wat ek kon hoor!

Dit het al beter gegaan en ek is nie meer bang om met mense te gesels nie. Selfs die telefoon en TV is nie meer aardsvyande nie.

Lionel van der Schyff (No 517)



I started to lose my hearing at the age of 26. Over the years my hearing deteriorated to the point where I was totally deaf in my right ear and had profound hearing loss in my left ear. My hearing loss began to have a deleterious effect on my work and social life. I started attending Hear2day meetings. After listening to what other deaf people had to say about cochlear implants I decided to explore the matter further.

I deliberately adopted an open mind with the cochlear implant and had no expectations about my “new hearing” – either good or bad. After switch-on everything I heard had a strange metallic sound to it. Initially I found this metallic noise rather irritating but noticed an immediate improvement in my hearing. I was now hearing sounds that I had not heard in years. Some of them were unrecognisable and I had to ask people to identify them for me. The “new hearing” can be summed up as good, bad and funny.

On the positive side, I can now hear in meetings at work and in lectures and seminars delivered in large rooms. I can even hear speeches delivered outdoors, something that would have been impossible in the past. I hear news broadcasts and documentaries fairly well on television but still struggle with films that have a lot of background noise. On the negative side, there are still challenges, with regard to the telephone and music.

On the more humorous side of my “new hearing” relates to where I work. Subsequent to getting the cochlear implant I now realise that there is a music shop over the road from where we work. The shop starts blaring out loud music from late morning which continues until early evening. In the four years of working in my office I had never realised this!

Lulu Dallman (No 511)



I was already losing my hearing during my school years. I can remember being sent from classes for chatting when I was merely asking my classmate what the teacher had said. It got progressively worse over the years.

At age 24 a colleague suggested I go for a hearing test as I was talking very loudly on the phone. The ENT guy thought it was otosclerosis so I underwent a stapedectomy in 1972 while living in Germany. On returning to South Africa in 1975 I was fitted with, first one and later bilateral hearing aids.

In 2000 I was no longer benefiting from hearing aids but at the time, though I was found to be a suitable candidate for a CI, my medical aid did not cover the cost. I was getting progressively isolated from society and suffering with depression.

When my medical aid introduced a benefit for CI implants I decided to go ahead even though I was petrified of the procedure. Everything went very well and 6 months after the activation of my CI I am able to hear as near to normal as science makes possible at this stage. Among the sounds I have regained birdsong, music and the voices of my grandchildren are very precious to me over and above other everyday sounds.

Cindi Norris (No 533)



I became deaf on the 21st June 2011 after the birth of my beautiful baby boy. I couldn't understand it; the shock of me not hearing only really hit me months later. At the time my baby was born, I was very sick and 3 months later my younger sister passed away.

I was very confused and hurt, losing my hearing, my sister, and my beautiful baby. As time went on, I became more withdrawn and lonely. It felt like no one understood what was going on in my head except my family. I was so lonely. I lost all my friends. I felt useless and disabled, so for a long time I kept to myself, living in silence. Eventually I accepted being deaf. After 3 years – you learn to live with it.

Then a miracle happened, I went to the Cochlear Implant Unit at Tygerberg Hospital and received a cochlear implant. "You have given me my life back". The operation was in June and I felt no pain, no dizziness, I felt alive again.

I can talk on the phone, watch TV and I understand when people talk to me quite clearly, it feels great. Music is still a bit hard. I played James Blunt in my room and I started to cry, because I heard him clearly, the song "You are Beautiful".

Before I went deaf, I used to listen to him all the time, so I thought, let me try and see if I can hear him, and I could not believe I heard him clearly. It was the first song I heard since I had the cochlear implant, and I could hear music clearly.

Johline Gerber (No 457)



Ek werk as instruktiese by die volwasse sorg se keramiekafdeling van die Nasionale Instituut vir Dowes (NID). Twee jaar gelede het my lewe ingrypend verander na 12 lange jare van erge doofheid. Ek het as kind gehoorapparate gedra na kinkhoes en masels. Ek was hardhorend en in 'n horende skool. Na my man se dood en toe ek 3 maande swanger was, het my gehoor baie vinnig verswak. Apparate het geensins meer gehelp nie, en ek het begin depressief raak. Ek kon dit net nie aanvaar dat ek heeltemal doof gaan word nie. Deur ons wonderlike Hemelse Vader het ek begin werk by die NID en kon vir my 'n mediese fonds uitneem, en die geleentheid aangegryp vir 'n kogleêre implanting. 'n Nuwe wêreld het vir my oopgegaan. Misverstande het verminder. Die mooiste is die wonder van musiek, die gefluit van voëls en die reën op die dak. Alles klink anders as waaraan ek gewoond was, maar is baie gemakliker as gehoorapparate. Ek het goeie bevordering in my werk gekry. Ek is baie rustiger en ontspanne en het baie self vertroue gekry.

Mariana Botha (No 499)



As baba het ek gesukkel met oor infeksies en my gehoor het progressief verswak. Op 6 jarige ouderdom is ek gediagnoseer met gehoorverlies. Toe ek ongeveer

12 jaar oud was, het ek 'n onsuksesvolle operasie in my regteroor gehad. My ma het my elke maand vir spraaklesse geneem. Hierna is ek na Mary Kihn skool vir hardhorendes. My gehoor het later soveel verswak dat gehoorapparate nie meer gehelp het nie.

My kinders en man se droom was dat ek 'n kogleêre inplanting moet kry. So het ek uiteindelik op 18 Julie 2013 die inplanting gekry. Die operasie was 'n geweldige sukses. Die dag van die aanskakeling kon ek elke woord hoor wat die oudioloog sê. Dit was werklik 'n wonderwerk en ek kon nie my trane keer nie.

Daar was dinge wat ek vir die eerste keer in my lewe kon hoor soos wanneer ek my kop krap, die hout wat in die vuur kraak, die reëndruppels op die dak en my man wat chips eet. Ek geniet my musiek en ek kan praat oor die telefoon. My spraak het ook aansienlik verbeter, en ek lees nie meer lippe nie.

My dogter is tans met vakansie in Thailand en ek kon met haar oor die foon gesels. Ek geniet nou eers my lewe met oorvloedige dankbaarheid in my hart wat ek nie kan beskryf nie.

Vicky Fourie (No 500)



In 2011 het ek opgetree as gasspreker by 'n fonds-insamelingsfunksie vir 'n baba wat 'n kogleêre inplanting sou kry. Ekself het gehoorapparate gebruik. By die funksie het my oudioloog my vertel dat ek eintlik ook 'n kandidaat vir 'n inplanting is.

Kort daarna moes ek my gehoorapparate opgradeer en selfs die sterkstes het my nie gehelp nie. 'n Inplanting was toe die enigste opsie. Vir 2 jaar het ek geworstel met die besluit om dit te doen of nie.

Nou bietjie meer as een jaar na my operasie kan ek met oortuiging sê: "Ek is so bly ek het dit gedoen!" Toe ek my kat kon hoor miaau vir die eerste keer, was dit vir my 'n hoogtepunt. In die begin het die spraak-en-klank oefeninge my tot trane gedryf. Elke dag het ek saam met my ouers geoefen. Dit was so moeilik om nie te lip lees nie, en net te luister. Ek moes ook hard konsentreer op die klanke wat ek in my spraak uitgelaat het. Ek het bewus geraak van wat buite om my aangaan en het besef hoeveel ek gemis het. Elke dag is dit klein stappe, maar dit raak al hoe groter. My wêreld raak ook al hoe groter.

Portia Keet (No 524)



Ek is 32 jaar oud en het begin doof word op die ouderdom van 23. In 2007 moes ek gehoorapparate vir beide ore kry. Dit het in 'n mate gehelp, maar my gehoorverlies het my lewe, en my as mens verander. Ek het geen sosiale lewe meer gehad nie, en ek het ook baie afhanklik geword van ander en ek het nie daarvan gehou nie.

Gelukkig het van my werkskollegas aanbeveel dat ek uitvind van die kogleêre inplanting...en siedaar! My gehoor het so verbeter, daar is nog dae wat ek dink "WOW". Op 18 Oktober sal dit 7 maande wees wat ek gebruik maak van my kogleêre inplanting en dit word net beter en beter.

Op 1 Oktober het ek my eerste gesprek op my selfoon gehad. Ek kan nou lekker televisie kyk, 'n gesprek voer sonder om 2/3 maal te vra vir herhalings. Ek hoef nie te lip lees nie. Hierdie inplanting is verseker een van die beste uitvindings ooit. Dit het nie net my gehoor verbeter nie, maar ook my selfvertroue.

Amy Thomson (No 494)



As Amy is not able to read or write, she depends solely on her hearing to communicate, which has made this successful cochlear implant all the more important to us as a family.

Debbie Slabbert (No 506)



Amy was a healthy baby who appeared to be developing normally until the age of 8 months when she showed signs of balance problems. A shunt was inserted into the right lobe of her brain at 13 months in order to drain the fluid (Hydrocephalus) which had built up due to the drainage ventricles being blocked for some unknown reason.

CT Scans at 15 months showed that she had developed a tumour at the base of the brain stem. The neuro-surgeon at Red Cross Hospital managed to resect 90% of the tumour. This was followed by 6 weeks of radiotherapy which destroyed the remainder of the tumour, along with a whole lot of brain cells. The process has resulted in severely diminished brain function and Amy is mentally disabled as a result, with her ability to speak being the least affected function. As a result of the insult to the brain, she developed epilepsy from the age of 8 years.

Her hearing deteriorated slowly and she needed to wear hearing aids in both ears from the age of 10 years. The right ear stopped functioning 5 years ago and she relied totally on her left ear. This ear also suddenly stopped working in September 2012 at the age of 28 years and was quite a blow to us all as there was now no more aural communication with Amy.

Fortunately our ENT recommended a cochlear implant. The operation was performed in 2013. The big moment came when the cochlear implant was switched on and Amy started hearing sounds again.

She started to distinguish words and we were slowly able to communicate with her again. She gradually lifted out of the quiet world and began to enjoy hearing familiar stories being read to her. Her ability to converse with us and express her needs was also a big plus.

Never in my wildest dream did I think that I could have a cochlear implant as I was given the impression that it was more for younger people until my great friend Shirley Visser had a cochlear implant in November 2012. I was with her when she had her 1st switch on. It was awesome when she said she could hear the clock "ticking" and I was amazed.

There were lots of photos of those people who had a cochlear implant and I spotted one very old lady. I asked her age and was told she is 82! Shirley encouraged me to go for it and I thought, if I don't try, I will never know. In August 2013, I went for my switch on. I heard my audiologist's voice for the 1st time and I started laughing because it sounded just like a robot talking. From then on, I was picking up lots of amazing sounds that I had not heard before, e.g. hearing my dog's nails on the tiles when she was running and listening to my music on my cell phone. I am so excited as I am due to have a cochlear implant on my left side soon!

Nicolene Julius (No 508)



Ek is 37 jaar oud en het drie seuns. In Oktober 2001 het ek siek geword en toe ek wakker skrik was ek in die hospitaal a.g.v. meningitis. Ek was vir 'n week in 'n koma. Toe ek daar wakker skrik kon ek nie hoor nie. Die dokter het my meegedeel dat ek doof is.

Dit was vir my baie swaar as horende persoon om nie te kon hoor nie. Niemand het my verstaan nie en ek het baie depressief geword. Ek moes ook van vooraf leer loop. My familie het my bygestaan en by Tygerberg Hospitaal is ek as 'n geskikte kandidaat gevind vir 'n kogleêre inplanting.

Ek het 23 September 2013 my operasie gehad. Die eerste keer toe die apparaat aangeskakel word, was dit vir my soos 'n nuwe wêreld wat weer oopgegaan het. Dit is lekker om weer te kan hoor.

Abraham Jarvis (No 480)



My hearing started deteriorating in the early 2000s. Because of the hearing loss I withdrew myself from people, even my own family and friends. Going out to do the simplest things such as going to a shop

to buy bread was torture. Misunderstanding people was at the order of the day and I started to say "yes" to everything because I could not understand what people were saying or being so embarrassed to ask them to repeat what they were saying. Being able to lip-read helped a lot, but only if people spoke clearly.

Even though I was surrounded by family and friends, sometimes I was lonely. My disability was invisible but was I? If someone told a joke I might manage to lip-read the first line. I never got the punch line but would laugh anyway when everyone else did. In many respects this behaviour sent the wrong message. How then was anyone to know the extent of my hearing loss or just how much I was struggling when it appeared that I understood everything?

In 2011 my audiologist suggested a cochlear implant. I received my cochlear implant in February 2013. The "switch on" day arrived on 21 May 2013. I felt unprepared for what I thought was going to be such a momentous occasion. From the moment the device was activated the journey out of silence began.

I walked down the passage and was delighted to hear my own footsteps. I started singing softly to myself just to determine whether I could hear my own voice. I organized a lift with my niece, Abigail, and just sat quietly in the car. The music played and I was tapping my feet to the tune. Overjoyed, she said "Boeta you can hear!" I don't know who was more delighted about my hearing – me or Abigail. I never thought I would be able to hear again.

I was overwhelmed and could not praise God enough. I remember being at a workshop in June 2013 when one of my colleagues said to me "Mr. Jarvis jy kan hoor!" The joy in her voice and her hug let me believe that my condition was just as difficult for her and others, than it was for me.

My positive attitude began to return. The return of music in my life has been a huge bonus. To hear the words of a song and feel the beat and move in time - it's euphoric. It is difficult to articulate the depth of feeling I have about being able to listen to music once more. I am playing "catch up" with life and experiencing all the sounds again; though this time through different eyes and ears and with a much greater appreciation.

The journey out of the silence was not an easy ride and at times, emotionally charged, but it is a journey I would not have missed for anything.

DECIBELS OF LOVE

Decibels of Love is a family driven initiative, providing parent-to-parent support for families raising hearing impaired children.

Parents need to have access to information, support, resources and knowledge and be empowered; they after all need to make the life changing decisions for their hearing impaired children. The group hosts monthly family resource mornings, topics and discussions.

Join us Decibels of Love for their next family resource morning.

www.decibelsoflove.com or www.facebook.com/decibelsoflove

THEY ARE TEENAGERS NOW

A get together was held on 6 October 2014 for a group of older high school teenagers with cochlear implants where common difficulties, challenges and solutions to coping with hearing loss were shared. Elana Solomon and Lorenzo Andrews shared their experiences of high school and university.



*Back: Jenny Perold, Shemorné Bedja, Alex Petersen, Jana Pretorius, Eddie Tippet
Front: Lorenzo Andrews, Wico Els, Elana Solomons, Lonwabo Yaya, Laetitia Veldsman,
Sinalo Ngolozana*