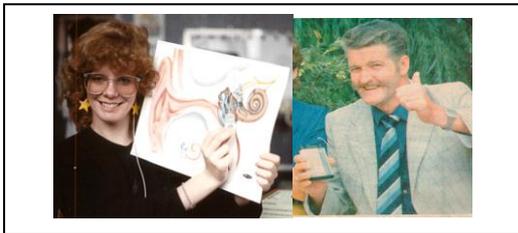


## **CELEBRATING 30 YEARS OF COCHLEAR IMPLANTS AT THE TYGERBERG HOSPITAL-STELLENBOSCH UNIVERSITY COCHLEAR IMPLANT UNIT**

Thirty years ago, on the 4<sup>th</sup> and 6<sup>th</sup> November 1986, Rinelma Wapenaar and Gerrie van Reenen became the first two profoundly deaf adults to receive a multichannel cochlear implant at Tygerberg Hospital. Prof Derrick Wagenfeld was the implanting surgeon and Lida Müller the audiologist.



To date (end 2016) we have implanted 657 adults and children with 153 having received a bilateral cochlear implant.

The Dept. of Ear Nose and Throat at Tygerberg Hospital has a longstanding history of rehabilitating deaf people to hear through the pioneering work of Prof Carel du Toit. He understood that medical and surgical treatment of hearing loss alone could not benefit all children and adults with hearing impairment. Early identification, early intervention and rehabilitation model was required to complement the medical treatment modality.

The first cochlear implant unit in South Africa was established at the Department of Otorhinolaryngology of the University of Stellenbosch at Tygerberg Hospital in 1986. It was placed at an academic hospital because this type of intervention requires a multidisciplinary team of ENT surgeons, audiologists, speech-language therapists, radiologists, paediatricians and educators. The aim was to set up a broad

geographic provision for cochlear implantation in South Africa, to develop evaluation materials, and to set standards for subsequent units. Being situated at an academic hospital ensures that the ongoing training of key professionals is provided as well as the long-term sustainability required for patient follow-up. Recipients all over South Africa had to travel to Cape Town for the service. Some families even relocated to be closer to Tygerberg Hospital. Now there are implant programs in other parts of the country including Pretoria, Johannesburg, Bloemfontein, Port Elizabeth and Durban.

Spoken language is an indispensable component of being human and without it we cannot describe things, ideas or feelings. Deafness has a devastating effect on the mental, emotional and social interaction of the affected person (Helen Zille, Argus, 2011).

In the case of mild and moderate hearing loss current hearing aid technology is very effective in overcoming the loss of hearing. However, when the hearing loss is severe-to-profound, hearing aids are often just not enough to give the adult or child access to hear the full spectrum of spoken language. When the loss of sensory cells in the cochlea, or inner ear, is too great, by making the sound louder with a hearing aid the hearing nerve will not be stimulated in such a way that speech sounds become recognisable.

The impact of severe-to-profound hearing loss on adults results in interruption of conversation, compromised social life and the inability to sustain gainful employment. Children born with a profound hearing loss have limited success to develop spoken language.

The initial attempts to help profoundly deaf people understand speech by electrically

stimulating the hearing nerve commenced in the 1950s and 1960s. Over the past three to four decades, the notion of restoring hearing to deaf people has progressed from the realm of science fiction to a commercially viable industry of cochlear implants. Cochlear implantation can be called a modern miracle and is now firmly established as an effective option in the rehabilitation of children and adults with severe-to-profound hearing loss. The cochlear implant has created a paradigm shift in the treatment of sensorineural hearing loss. The impact that the implant has had is far greater than one would expect considering the brief time over which its development occurred. In less than four decades, the cochlear implant progressed from the first attempts to elicit hearing via direct electrical stimulation of the auditory nerve to a commercially available device that has restored varying degrees of hearing to tens of thousands of deaf patients.

A cochlear implant is an electronic prosthesis that replaces the function of the damaged or absent hair cells in the inner ear by changing the sound energy into coded electrical signals to stimulate the hearing nerve directly. The electrodes stimulate the nerve fibres via a controlled electrical current which is recognized by the brain as sound. The primary goal of the cochlear implant is to provide the user with access to sound.

Historically, development of spoken language by children born deaf has been influenced by the technology of the time. Unlike many other congenitally or early-onset disabilities, infants with hearing loss have the prospect of outcomes potentially matching those of their hearing peers provided the loss is identified early and intervention in a rehabilitation program is initiated by 6 months of age. Children who receive cochlear implants before the age

of 2 years and engage in early auditory based intervention programs could enter 1<sup>st</sup> grade, with expressive and receptive spoken language skills that are close to those children with normal hearing (Kral & O'Donoghue, 2010).

Many parents seek cochlear implants for their deaf children because they want their children to hear and speak like normal-hearing children. This is not surprising given that most of these parents are hearing themselves, use spoken language at home, and would like their child to enjoy the same educational, social, and occupational opportunities available to them. Parents who have a child with profound hearing loss view childhood deafness as restrictive, limiting participation in a predominantly hearing world.

At the outset, cochlear implants generated considerable controversy among educators of the deaf and the Deaf culture, as well as the medical community, because few believed that the new technology would offer profoundly deaf children safe and reliable access to key elements of spoken language. Few would now argue with the ability of cochlear implants to deliver meaningful access to the speech signal and to offer the opportunity of developing receptive and expressive spoken language to many profoundly deaf children, thus transforming the life opportunities in ways that could not be imagined just a few years ago. (O'Donoghue & Pisoni 2014)

Spoken language is not the automatic outcome of early cochlear implantation. The children need to follow a therapeutic intervention approach based on developing listening skills that is focused on achieving normal developmental milestones in listening, speech, language, cognition and conversational competence.

The confluence of early identification coupled with the sensory restoration by means of cochlear implantation, has transformed expectations for profoundly deaf infants and young children making faster and more age-appropriate language acquisition a realistic possibility, especially for those children with normal cognitive abilities. However, despite early intervention with cochlear implants, it is likely that there will continue to be some children for whom the assumption of complete access to spoken language via cochlear implantation will not be achievable, and implant teams need to be alert to the special communication needs of these high-risk children. Given the heterogeneity of deaf children, it is very unlikely that a “one size fits all” approach will ever be appropriate for their habilitation.

Although performance of adult patients following cochlear implantation can be variable and dependent on a number of factors, including age of onset of deafness, duration of deafness, age at implantation, use of hearing aids, and cognitive ability, there is no doubt that as the increasingly expanding adult population that achieves meaningful speech understanding grows, so are more cochlear implant recipients able to pursue professional careers and personal interactions that were previously unattainable.

Over the years since we started our cochlear implant program we have seen many changes in the candidacy criteria, surgical procedures, implant design, speech coding strategies, and the speech processors. Initially we could only implant adults with bilateral profound hearing loss who lost their hearing after they had developed spoken language. In 1988 we implanted our first child, at the age of nine years. Children younger than two years

could not be implanted until 1998. Stimulation of the hearing system in the brain during the sensitive/critical periods is central to normal development of hearing, speech and language development. In 1999 we implanted our first child at the age of 6 months.

The indications for cochlear implantation continue to evolve. In the past only those with profound deafness and no residual hearing were candidates. Today, individuals with significant residual hearing are being considered for cochlear implants. Preservation of residual low-frequency hearing during implant surgery is both achievable and desirable. Electrode designs aimed at hearing preservation have evolved developing shorter electrodes, manufacturing thinner and more flexible electrodes.

Socio-emotional support for CI users of all ages and their family members can be found online through social media networks, blogs, or websites of CI companies. In the years to come there will be a deeper understanding of how powerful the auditory access is that is provided by the state-of-the-art hearing technologies such as cochlear implants. (Estabrooks 2016)

Our Cochlear Implant Unit recently celebrated our **30<sup>th</sup> anniversary** at a function held on 5 November 2016 where cochlear implant recipients, their families and professionals involved in their care gathered together to enjoy the occasion.



HERE FOLLOWS THE SHORTENED VERSIONS OF THE STORIES OF SOME OF OUR IMPLANTEES.

Their full stories are kept in the photo album at the Unit.

**BELINDA BARNARD (No 550)**



Ek was sowat 8 jaar gelede met Mitochondriale-mutasie gediagnoseer. Na drie oog operasies was ek weer vol moed, want ek kon al die mooi dinge weer sien en waardeer. Die volgende probleem het opgeduik, ek het my gehoor heeltemal verloor. Dit was 'n geweldige skok.

Met alle eer aan my Hemelse Vader en sy meestersplan het ek by die Tygerberg Hospitaal uitgekom. Prof Loock en sy mediese span het my weer hoop gegee. Toe my man die oproep ontvang dat ek 'n kogleêre inplanting gaan kry was ek in die wolke. Na die operasie het ek weer die wonderlike wêreld van klank ontdek. Elke

nuwe geluid was kosbaar. Dit was wonderlik om weer met my kleinseun te kon gesels en deel van sy lewe te wees. Alhoewel dit soms nog bietjie moeilik gaan, weet ek dit gaan verbeter en dat ek weer 'n sinvolle lewe sal kan ly.



**BRAVERY MOLANGA ETIYA (No 624)**

Bravery was born 25 October 2013, a healthy and happy baby. In July 2015 she was diagnosed with meningitis which affected her hearing. I just noticed that my baby became very quiet and unhappy – no singing, no calling her sisters by name. Every word she was saying before disappeared. She had a profound hearing loss which could not be helped with hearing aids. Both cochleae had been damaged by meningitis.

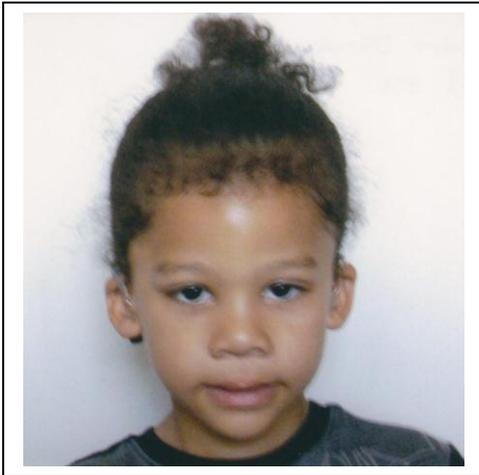
The only chance for Bravery to hear again was the cochlear implant. It was so difficult for us to make that decision, but finally we decided to give Bravery the chance to hear again. On 23 May 2016 Bravery received a cochlear implant, and on 14 June she was switched on

Since that time till now my girl is making a lot of progress, she can hear, dance when the music is on. She is very excited about any sound she hears. When I look at that progress since the implantation till now, my child is giving me so much strength. She is my very brave Bravery.

**BIBICHE MOLANGA ETIYA**

## DAVID JACOBS JNR (No 598)

My son was diagnosed with a profound hearing disability in June 2014 at the age of 2 years and 6 months. The news was devastating and evoked feelings of denial, disbelief and anguish for me and my wife. Accepting this reality raised many



questions in terms of the diverse challenges that we had to face coupled with a profound realisation of how vulnerable we really are.

After being fitted with hearing aids in August 2014 we were hopeful that Junior will now have access to sound and develop spoken language. During this period, we got to know some amazing people who, with a sincere desire to help Junior, guided and accompanied us with sensitivity, compassion and humility on the road ahead. This team discussed and evaluated Junior's situation and decided that he was a candidate for a cochlear implant. Junior had his first Implant in November 2015 and after that the switch-on. The results were so amazing. Within days he called me dad.

DAVID JACOBS SENIOR

## ELIZABETH GRAHAM (No 602)

My father always had poor hearing, which



worsened with increasing age and impacted negatively on his life. The accepted theory was that his ears had been damaged while serving

in the artillery during WW2. However, after two of his seven offspring tested positive to a recessive inherited form of hearing loss, we can assume that he, in fact, suffered from the same disease. My younger brother and myself, both now deaf, were labeled 'disobedient' and were frequently punished for 'ignoring' our parents when we were called

One day after my 40<sup>th</sup> birthday, while conversing with my husband, he turned his face away and I realized that I could not 'hear' him without seeing his lips. I immediately consulted a local ear, nose and throat doctor, who tested my hearing and informed me that there was nothing that they could do to help me. He then added his famous last words, "Don't worry, you are not going deaf." I found his optimism impossible to accept, so decided to improve my lip-reading skills while I still had the benefit of some hearing. Every day I spent some time in front of the TV with the sound barely audible, watching people speak. Ultimately, I became very proficient at lip-reading and could manage one-on-one conversations quite adequately. During the next 10 years, I completed my PhD and accepted a research position at the University.

Finally, in 1993, technology caught up with me and I was fitted with a hearing aid. This was the first miracle in my life! I especially enjoyed hearing my footsteps and birdsong, but was rather less enthusiastic about the clatter of cutlery and crockery and the engine noise in cars. Of course, the most important benefit was the ability to socialize and enter into technical discussions with colleagues.

Another 10 years passed, with several changes of hearing aid, before the audiologist said that the only route open to me was to have a cochlear implant. Unfortunately, our financial position was such that we could not consider that option at the time, so I was, once again, plunged into silence. This time, I did not face my plight bravely, but became angry, introverted, anti-social and finally withdrew from all but a few close friends who stayed the course and tried to sustain me. After my husband died in 2010, I managed alone for 5 years before moving to Grahamstown to live with my daughter and her family. By this stage, I needed assistance with visits to the bank, doctor, dentist etc.

Then the second miracle happened! My house was sold and I could finally contemplate having a cochlear implant. The Medical Aid agreed to partial funding, and I was implanted on the 16 November last year. When the processor was fitted on 7 December, I was able to follow speech immediately, in spite of the fact that everyone sounded like a dialect. My first conversation with my son was such an emotional event that he had tears of joy in his eyes. Regaining my hearing for a second time has been an unbelievable experience which I will treasure for the rest of my life. I have now made new friends, can socialize easily with strangers, and have successfully attended a lecture. However, I still battle with electronic sound from a TV or telephone. Incidentally, my

youngest daughter, who qualified as a doctor, also became deaf in her late thirties, was bilaterally implanted a few years ago. She has now been able to return to her chosen profession. Finally, I no longer worry about the possibility of my grandchildren experiencing hearing difficulties when they grow up because I know that cochlear implants will be there for them.

### **GAMIEM AHJUM (611)**



“We, as the Ahjum family would like to thank all the people that were involved in the miracle that happened to my son Mogamat Gamiem Ahjum.

Firstly I have to start with Carel du Toit Centre, Surida, staff and everybody that was involved with Gamiem. I, as a parent believe in miracles and believe that God works through people, then I met Gill at Tygerberg Hospital and some medical people for which my family are very grateful. They decided that Gamiem was a candidate for a Cochlear Implant but it is very expensive and I could not afford it.

One Thursday morning sitting and brooding of how I am going to raise R300 000, I received a call at 7:55am that changed our lives with the grace of God. It was Ryan O’Conner and they asked me if I would give them an interview. The Monday, a lady called, I still can’t remember her name, as I was too shocked with the best news of my life, and

said that Bidvest is going to sponsor the operation. In all my life and all the negative things I heard of big companies, my mind went back to what my mother said to me many years ago. She used to tell me that you get 3 types of people in life, the greedy, the selfish (this is what I thought all big companies was) and the good Samaritan, which is Bidvest.

You do still find people that care about communities. We as a family will always be grateful to all the people involved in Gamiem's future and will always be in our prayers. To all of them God bless and keep up the good work.

We appreciate what you have done for us as a family. God works through people and all of you are "angels". God bless".

#### **AIDAN WHITEHEAD (No 155)**



Aidan gave a talk at the recent Hear2Day meeting. They meet every second month to discuss issues related to hearing loss. Their website is [www.hear2day.co.za](http://www.hear2day.co.za). Here is what he had to say:

I have chosen to title my speech 'A deaf person can do anything but hear'. I want to illustrate this by talking about my experiences as a deaf person. I hope that

I can leave you with the message that anything is truly possible for a deaf person with the aid of cochlear implants and the right support.

My parents only discovered I was deaf when I was having a development test done at about nine months old. The results proved inconclusive so I had to have further testing, which indicated I was profoundly deaf. I was then put on a hearing aids for nine months.

At the age of two, I received my first cochlear implant. I started attending the Carel du Toit Centre in 2001 to catch up the hearing skills that my non-deaf peers would have developed. This entailed a lot of speech therapy and commitment from my parents, especially my mom.

I began mainstream schooling in 2004 at Kildare Pre-school along with a class of 20 hearing boys and girls. I do not recall having any issues in terms of hearing back then. There, however, was an instance when I did not hear the bell ringing calling us back to class. The teacher found me and was very understanding. She brought me inside and explained to my classmates that they should make sure that I did know that the bell had rung.

2005 marked the beginning of my formal schooling career. After a long process of evaluating different schools, my parents sent me to SACS Junior. Just prior to this I received my second implant.

My Grade One teacher Miss Ferrandi has an incredible passion for her learners and their individual needs. I think that this was crucial in setting a solid foundation for my time at SACS. At the time, I made use of an FM system, designed to direct spoken sound to my speech processors, which had to be worn around the neck of whoever was speaking.

My first year at SACS exposed me to many new people, some of whom were interested in my speech processors, some indifferent and some who tried to exclude me because of my difference; however, Alex, a very loyal friend of mine, would always stand up for me. By the end of the year, everyone accepted me. Alex also played a critical role in my adjustment to mainstream school.

From Grades Two to Four I made several strong friendships which I still enjoy today. I think that I can attribute this to them treating me as if I was a conventional hearing child and yet, even today, they still understand when I have to ask them to repeat themselves. They are also willing to repeat anything else that I may have missed (such as an intercom announcement or a teacher giving instructions).

Towards the end of junior school, I made an academic shift from a B student to an A student completing Grade 7 with an aggregate of 85%. Despite my love for reading my language subjects, English and Afrikaans, are my weakest. I am not sure if this is related to being deaf or if it is just the way I am. In other subjects, such as Visual Arts, Science and Mathematics I have performed well.

Entering the High school initially was a difficult adjustment for me. You are forced to forge your own path; there is no one to check up on you so you have to be extremely organised and self-motivated. Yet I managed to maintain my academic results which I think stands testimony to the fact that deaf children have the potential to excel in an environment with hearing peers.

I started rowing as a sport in Grade Eight and made my way up to the first crew over the last four years. Rowing is a very intensive and time consuming sport with

nearly two sessions a day for six days a week. Rowing taught me the importance of time management and helped me to settle me into a high school routine. It also complimented my academic goals well. My speech processors used to humbug quite a lot – which is understandable considering the damp conditions of rowing. Cochlear produced a zip-lock bag which protects the speech processors from sweat and water. This has been very effective in countering this problem.

I have been very privileged to have been recognised for my contributions to all spheres of school life (culturally, service, sport and academics) having been awarded a full blues for each. Full blues is the highest award level at SACS.

I have just finished my mock exams last week and will begin my final school exams in three weeks from now. It is a little daunting but I am looking forward to it.

Looking forward next year I have been accepted to study Chemical Engineering at both UCT and Stellenbosch.

Being deaf is a part of who I am but it does not define who I am. I say this because I do not consider myself deaf on a daily basis. It is only on a few rare occasions when both my devices stop working that I am reminded that I am deaf. I used to get frustrated by this inconvenience but now I treat it as a reminder of how amazing cochlear implants are and how cochlear implants have enabled me to realise my full potential.

Cochlear implants and a little hard work have the potential to transform the lives of all deaf children and adults who choose to use it.



### **GAEL GRAY (No 628)**

Since discovering in my early 20's that I had a high frequency hearing loss that made hearing lecturers at university very difficult, I have lived with a steadily decreasing ability to hear. This has affected my confidence and relationships with people. I have steadily become more and more socially isolated as my hearing deteriorated. I was running my own business and have found that extremely difficult, my business suffered as my hearing got worse.

In 2015 my audiologist referred me to Tygerberg for a cochlear implant evaluation. I had a growing feeling of excitement at the prospect of being able to hear better, but was overwhelmed by the cost and also a bit afraid of having to admit to myself and the world how little I actually heard. I felt quite safe in my quiet world although I was frustrated and lonely.

In February, this year my medical assurance finally gave a written commitment to funding a large portion of the procedure, implant and device.

The implant was done in June of 2016, my daughter came from Australia and was with me through the weeks of rehabilitation while my auditory nerve

learnt to interpret what I was hearing. It was a tremendous help having someone to work with during this time, doing the exercises with me, laughing with me and cajoling me when I felt despondent or overwhelmed by technology. It also helped to have someone to say 'you know you are no longer speaking too loudly' or 'I can't believe you heard what I said from the other room' continually reminding me of improvements in my hearing ability.

It is going on for 3 months since I received my external device, life has settled down, I am back running my business and my daughter has left. I don't hear everything that is said to me and do occasionally need to ask people to repeat what they said, but I hear very much better than I did. I am beginning to understand how much tension I lived with previously trying to work out what people were saying; my shoulders have dropped noticeably. I hear birds now although I have still to recognise which bird I am hearing. I have been given a CD of 'Bird sounds of Southern Africa' and am beginning to recognise a few of the more common sounds. I hear my 4-year-old granddaughters' stories. My confidence in social situations has improved considerably. There are many things I still have to master but I see an audiologist every few weeks and she gives me new things to try so I am moving forward all the time. For the first time in years I feel that my life holds potential for new interests and that the world is not such a scary place. What a wonderful gift this has been, my world is expanding and not contracting as it has seemed to do in the past.

**JEAN GRUNER (No 592)**



I am 76 years old. I have been going deaf since age 54 years. Over the last twenty years I have needed increasingly stronger hearing aids. Two years ago, I was told that hearing aids would no longer be of any help. It was then suggested that I should have a cochlear implant.

At first I was reluctant to go ahead with it because of the cost and it also seemed such an enormous procedure. A strong motivating factor was my deteriorating eyesight, and the fact that I faced deafness and practical blindness by the age of eighty. So, last year I had the implant operation.

My eyesight (macular degeneration) has since deteriorated considerably and I am so thankful that I did decide to go ahead. I can now continue to live a fairly normal life due to this amazing technology. What also amazed me was that I was able to hear the words spoken to me from the moment of switch-on.

**LETICIA SCHARNECK (No 613)**



I am 23 years old. I received my cochlear implant only 6 months ago but the journey till now has been awesome. At first it didn't make sense but after focusing and putting my mind to it, I can now understand, make-out and listen without being told what it was. I never thought I will be able to listen to the radio or sing and dance to music. To me that seemed impossible.

Being part of a conversation is awesome and even to hear with my back turned to the one talking is so amazing. I have learnt a lot and still learning because every day is a lesson. I didn't expect that I would adapt to sound so quickly. At first I was very nervous and scared to hear but I believe miracles can happen and its life changing. We take life for granted but hearing is a blessing.

**KATE (No 344) and FAYE ALLWOOD (No 617)**, (with brother Liam, written by a proud Father, Anthony Allwood)



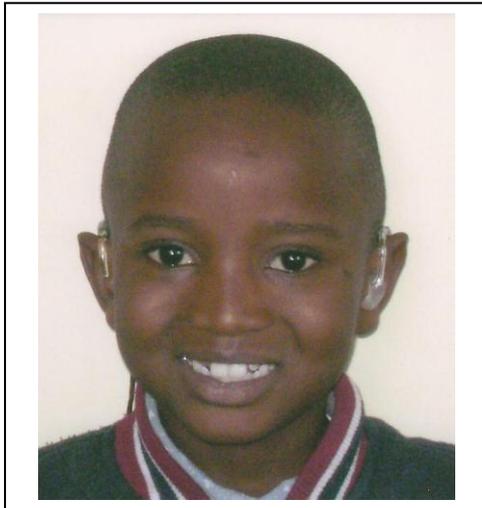
Eight-year-old Kate Allwood is in grade 2 at Somerset House Prep, Somerset West. She loves school and loves her friends. She reads and speaks perfectly. With her hair down while having fun with her many buddies, you would never be able to guess which child was born profoundly deaf. Kate was selected to sing in the junior school choir, and enjoys singing for friends and family alike. She is always keen to take part in any activity and sport, but loves her swimming the most. With summer, almost in full swing, she looks forward to the long happy afternoon swims with her brother, Liam, at home, and then the possibility of swimming for the school team as well. Her heart is huge, and she is confident in the fact that her disability does not define her, but she is just who she is - a happy, bubbly 8-year-old, keen to talk about her journey wherever she goes.

Liam, 5 years old, her younger brother, has normal hearing. He is always keen to entertain or be entertained by his noisy sisters; he is never one to shy away from

the limelight. He loves his sisters, superheroes and insects.

Baby Faye, now a speed crawler at 15 months old, also received bilateral implants after she too was born profoundly deaf. Faye had both implants done at 8 months old, while Kate's implants were done at 6 and 11 months old. Both sisters' hearing were screened at birth, and their profound hearing loss detected early. This huge advantage allowed both of them to be referred and enter the cochlear implant program at the optimal time. Faye is hugely loved, and a joy to the whole family. Her infectious, sunny, personality took a quantum leap from silence and smiles to chatter and beautiful sound from the moment she was "switched on". After just six months of getting access to sound she is already saying her first words "up" "dada" "mama", and understanding a whole lot more of the world. Her siblings are quick to involve her in everything, and as the smallest member of the family she wouldn't miss out on one noisy moment. Under the watchful guidance of Barbara Kellett, Faye's speech therapist, her mother Sarah, is again being expertly tutored on giving the best hearing and speech therapy at home. Kate was so chuffed at the news that there was someone "just like me" now in the family, and said "we'll have such fun doing the same stuff and putting on each other's ears". I am so very grateful for the many people involved in the miracle that has enabled both my girls an opportunity at living a normal life in our hearing world.

**LIYEMA XALABILE (No 622)**



Liyema born on the 28<sup>th</sup> July 2009 was declared at 3 years old that he is a deaf child at Tygerberg Hospital. Before being discovered deaf, we as parents were concerned about why he was not talking at his age and we arranged for his first appointment in Khayelitsha Hospital. He was then referred to Tygerberg Hospital where further hearing tests were conducted. With the correct hearing aids, he started to hear better and his speech improved slowly.

Then over time further hearing tests showed that Liyema's hearing was deteriorating and a cochlear implant was recommended. On the 9<sup>th</sup> May 2016, Liyema went through a successful implant surgery. Three weeks later with the switch-on, we observed a significant improvement in his speech and hearing. Liyema could hear and respond to very soft sounds, enjoyed his processor and could put it on-and-off all by himself. We are very grateful to have had an opportunity to have our lovely boy-child as a beneficiary of the cochlear implant. This has really changed his life for good and no one can imagine how grateful we feel when I see Liyema happy and enjoying to

hear us very clearly.  
GILBERT & SIPHOKAZI

**MANDIPHA NGCONJANA (No 593)**

Few years ago, I became deaf because of the TB medication (injection). It was not easy for me to go some places alone. I always had to ask someone to come with me. I had so many tests for my ears, later I decided to have the cochlear implant. My children didn't want me to do it but I made the decision that I will go through with it.

What is important now, is that I can go to the clinic by myself, go shopping, travel by public transport, go to church, and hear people when they talk.

My life became better with the cochlear



implant. It was like I was dreaming when I got my life back. Sometimes people don't have the patience to always take you where you need to go, or to repeat what they were saying. My advice to people who have the same problem as me is to get a cochlear implant so that you can have a better life and a better future ahead, because of the cochlear implant.



**MARIE CALITZ (No 467)**

Approximately 10 years ago I had this strange experience that I could not follow a discussion my husband and I had. Nor could I hear certain sounds like the chirping of birds in the garden and the barking of my dogs. It became worse as time went by and I decided to see an Ear Nose and Throat specialist. He suggested a cochlear implant on my left ear which eventually was conducted on 28 September 2009.

After a couple of weeks later the switch on took place and I could hear again. A week after this wonderful experience of being part of life again I was infected with the pseudomonas germ. Apparently, there is no cure for this germ and thus the only way forward was to have the implant removed. I was devastated to be deaf again. The psychological impact that this experience had on my life is indescribable. I became a stranger to my husband and friends because I did not want to socialise.

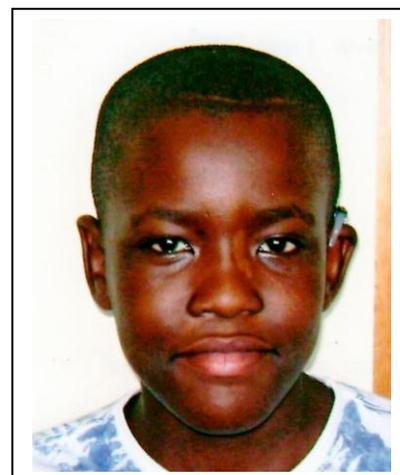
After a couple of years, I again went for a cochlear implant but that procedure was not successful. At that stage of my life I really felt that there was no sense living in isolation and lost all my interest in life. My audiologist later convinced me to have an

implant on my right ear because she thought at the time that it would be my best chance to be able to hear again.

On the 7<sup>th</sup> of July 2016, the switch-on took place at Tygerberg Hospital. I could hear again! I never realised that common sounds would give me so much satisfaction as you normally take everything for granted in life. As we drove to the guest house I could hear my husband's voice after a period of almost 7 years. I could also hear the ticking sound of the car's indicator. At the guest house, I heard sounds of birds in the trees and the sound of an aircraft and so the sounds went on and on. It was strange to hear word's that I haven't heard for years.

Our only way of communication over the last 7 years was by means of writing. My husband and friends had to write everything down as the only way of communicating with me. It was very frustrating and time consuming. It was amazing getting home to hear my dog bark, the sound of the sea, singing birds in my garden, to experience the wonder of nature again and the zest for life. Now I can communicate with friends again which is fantastic.

**CHUMA FASI (No 610)**



My name is Chuma. I had meningitis last year December 2015 and I lost my hearing. I was scared and I had doubts about the cochlear implant since the hearing aid would not help. It's been 7 good months since I got my cochlear implant, and I am very happy that I got the cochlear implant. It took me two almost months to get used to it.

The cochlear implant gave me my life back since I lost my hearing at the age of 11 years. I don't feel ashamed, shy or scared anymore. I am still in the same school and have the same friends thanks to the cochlear implant. The audiologists at Tygerberg were always nice, understanding and made me feel at ease whenever I had my appointments. They made me to look forward to my operation.

#### **NELLIE BURGER (No 623)**

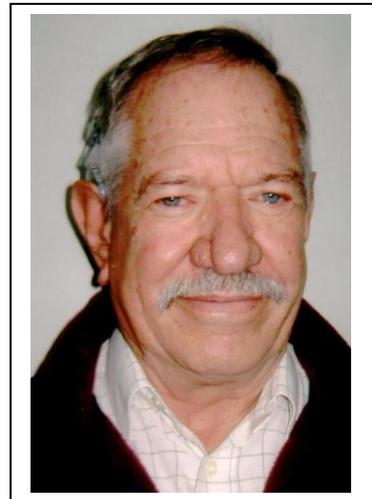


Na baie oorweging het my man, Johan en ek besluit ons moet die opsie van kogleêre-inplanting oorweeg. Ek is vir plus minus 30 jaar doof in my linkeroor en met my regteroor kan ek nog effens hoor met 'n gehoorapparaat.

Intussen het ek, wat 'n geselsmens is, stil geword. Ek het my feitlik aan alles en almal onttrek. Johan en ek het so graag saam gholf gespeel, maar dit het ook sy

tol geëis, want die sosiale verkeer het my beangs gemaak.

Ek is gekeur vir 'n kogleêre inplanting en met groot opgewondenheid is die operasie op 25 Mei 2016, deur Dr Wagefeld, by die Strand Mediclinic uitgevoer, 'n wonderlike ondervinding – geen pyn. Net voor die aanskakeling sterf my man skielik. Met my familie se ondersteuning en Lida Muller se optimisme gaan ek voort. Op 8 Julie 2016 is die groot dag – die aanskakeling. Ek is ietwat teleurgesteld oor al die harde by-klanke, maar met soveel aanmoediging kan dit net beter gaan. Die apparaat pas gemaklik. Ek kan nog nie op die landlyn telefoon hoor nie en die televisie wil ook nog nie goeie resultate lewer nie. Ek troos my daaraan dat dit nog net 2 maande na die aanskakeling is. Oor nog 'n paar maande vertel ek 'n meer positiewe storie. In die proses het ek so baie omgee mense ontmoet.



#### **NICK SWANEPOEL (No 621)**

My hearing problems started while we were working as missionaries in the desert in northern Kenya. I had a malaria attack as well as a virus in my left ear, which damaged the nerve badly. Then I experienced Meniere's syndrome, with bouts of severe nausea and dizziness.

The ENT specialist in Nairobi warned that this could be an ongoing problem leading to decreased hearing as time went on.

Over the years, I used various hearing aids. These would initially be helpful, but I kept needing more powerful helps. Finally, in November 2015, I lost the ability to hear.

It was during this time that I went to Tygerberg Hospital and made enquiries about having a cochlear implant. Plans went ahead and in May 2016 I had the first implant on my right ear.

I was so excited for the switch-on which took place on 30<sup>th</sup> May. Reading the experiences of other implantees helped prepare me for what to expect. Driving home, I was able to have a conversation with my wife! This was a very emotional time for me, as we had not been able to talk in the car for about twenty years! Progress was rapid. My brain would suddenly identify the cooing of the pigeons. Then I could hear the clock ticking on my wife's side of the bed. One of the greatest joys has been listening to music. YouTube gives you the opportunity to listen to a song while displaying the words at the same time. I particularly enjoyed guitar music and worship music as I have so much to thank God for. The results were truly amazing and I felt that I had gained 110% of my hearing.

The implant has transformed my life in countless ways. Now I need to break bad habits related to my life BH (Before Hearing.) I need to concentrate more instead of copping out of a conversation. I need to learn to hear the phone. I must ask people to speak slowly and clearly for me.

I have just had a second implant done and the switch-on took place on 30<sup>th</sup> September this time to the left ear which

has been without hearing for many years. The results have been very encouraging although I realize that I am still on the recovery journey.

What the second implant has given me is a sense of balance in my hearing. Although the device in the right ear had helped so much, I still was left feeling rather at a loose end. I was at the doctor's waiting room, with lots of noise and lots of people talking. It was very stressful because I had to be on the lookout in case someone called my name. The left ear device has taken this fear away and given me much more confidence in hearing in a variety of situations, being able more accurately to place where the sound comes from. Right after having the second device, I needed to make a phone call, which has been impossible for me up to this time. I phoned and was able to handle quite a complex situation all on my own for the very first time. Now when I take my left device off, I am left with a feeling of loss. Thank you to the dedicated team at Tygerberg for the amazing help!

### **TAUHURA AJAM (No 603)**



Tauhirah was diagnosed with hearing loss and cerebral palsy after she survived a blood infection after birth in 2009. During 2010 she was fitted with her first hearing aids but progress was slow due to her

being premature and continuous ear infections. In 2014 we were referred to Carel du Toit where progress really started to show. With their guidance and assistance, Tauhirah was slowly bridging the gap with speech development. She was identified as a candidate for cochlear implant in 2015. We had to make a decision as there were no guarantees that there will be improvement due to the fact that she has cerebral palsy too. We decided to take a leap of faith and what a blessing it was. Tauhirah showed major improvement with listening and speech development. Within the first year Tauhirah was able to identify the difference in sound from her cochlear implanted ear and her hearing aid ear. It was then decided that she will go for the second implant. She is now a bilateral cochlear implantee with cerebral palsy and is still improving in speech and listening. Her vocabulary continuously keeps on growing. She has an amazing team, from the audiologist, speech therapist, counsellor, teachers and us parents of course. It is hard work, definitely not a journey for those not willing to put in every bit of effort, but it is so rewarding when they show signs of improvement. I can still remember when Tauhirah's words became clearer, and the way she breaks things down herself when she realises she is having difficulty saying something. We are now able to have meaningful conversations with her, something that wasn't possible pre-cochlear implant. The first thing she does in the morning is to put on her sound processors. When she comes out of the shower and we are talking to her without the sound processors on, she very quickly shouts "I can't hear you, I need my cochlears first". It is truly amazing how my daughter has developed in the short space of time that she had them. The journey we are undergoing is such a blessing for us and her. (RASHIEDAH AJAM – Mother)



### **TRACEY LE ROUX (No 599)**

I was diagnosed with a bilateral hearing loss at the age of 4, and by the time I entered high school my hearing loss was severe-to-profound. I used an FM system and microphone to deal with mainstream high school and then university, where the Lord enabled me to cope with the lectures and studies. After graduating from UCT in 1997, I began working as a paediatric Occupational Therapist in a large practice, where the receptionist would make my phone calls for me. Because my conversations with the children, parents and teachers were focused and mostly directed by me, it was relatively easy for me to cope with the amount of lip-reading required.

I "retired" from OT work to focus on my family, eventually becoming a home schooling mom to my 3 kids. As my kids got older, I found myself getting more and more tired trying to keep up with the amount and complexity of lip-reading required. In recent years, I also found myself struggling to have the emotional energy to go to evening Bible studies and meetings, because I was just too tired to lip-read any more. In September 2015, I

apprehensively found myself on the journey to a CI, which took place in October 2015. The first period after switch on was intense and tiring, getting used to all the sounds that I had no idea existed. I especially struggled to get used to all the high-pitched sounds that I had missed before. But the end result has been amazing. Almost one year later, with a second CI in April 2016, there are no words adequate enough to describe the enormous change in my life! Listening to conversations has become a joy, hearing previously unknown sounds are a treasure I don't take for granted. I'm appreciating the music my kids listen to, I'm having easy conversations with my husband and kids, and I'm so much less exhausted at the end of each day.

**GRAHAM KERLEY (No 596)**



For a mature person with a hearing-dependent career as a university academic, having unilateral sudden sensorineural hearing loss after 35 years of relying on that ear because of impaired hearing in the other ear, was particularly difficult to deal with. I was no longer able to communicate effectively with my students, participate in meetings, and undertaking research work became a challenge. Worse, however, was the effect

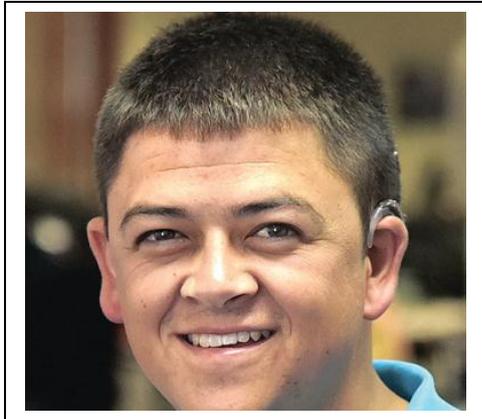
on my ability to communicate with family and friends. My ENT Specialist in Port Elizabeth recommended that I consider a Cochlear Implant and referred me to the team at Tygerberg. It was with considerable apprehension that I travelled to Cape Town for the assessment. The cochlear implant team did an amazing job explaining the technical aspects of the whole cochlear implant process, and answered my questions.

I was overjoyed to be offered the opportunity of a cochlear implant, and travelled to the Cape with my wife for the surgery, which took place in October 2015. This all proceeded smoothly, and it was an odd moment to see the X-rays of my head the next day, with the implanted device in place. Switch on (November 2015) was a revelation – simply the awareness of sound (no matter how insignificant) on that side was an amazing and deeply emotional moment. This is really science doing magical things, such as alerting one to rain on the roof, taps running and my daughters' precious laughter. My cochlear implant and hearing aid now work together to help me communicate, and the implant has given me renewed abilities and confidence in my family and work life. I can once again communicate with my daughters and wife, hear my students and even undertake field work on foot in "big five" habitats where I need to be able to hear the rumble of elephants or the snort of a rhino as warnings of danger.

Every morning when I fit my processor after a night of no sense of hearing on that side, I get a thrill of excitement as my senses return. This is accompanied by a sense of gratitude for the smart scientists who developed the technology, the funding sources who helped make it possible and the Tygerberg cochlear implant team who made it happen.

David Ritchie's award-winning pictures of

**CONGRATULATIONS TO DAVID RITCHIE WHO WON THE NATIONAL VODACOM JOURNALIST OF THE YEAR AWARD.**



Cape Argus photographer David Ritchie won the regional Vodacom Journalist of the Year award in the photography category. His series of photographs depicted the student protests at UCT's upper campus in February. During the protests over the lack of student accommodation, students burnt painting and other artworks.

David's images depicted the students burning the artworks and a plaque in the parking lot during the #Shackville protests.

Then he travelled to Johannesburg for the national awards on the 11<sup>th</sup> November and won the national overall journalism award. First time it's ever gone to a photographer. The awards are regarded as the highest accolade that journalists in South Africa can aspire to. The Vodacom Journalist of the Year Awards are a means of recognising and rewarding skill in the all-important arena of news and information dissemination. Winning an award has become a prestigious career achievement with the overall national winner receiving R100 000, along with professional acknowledgement.



protesters burning paintings and a plaque at UCT (Cape Argus, 17 February 2016) .

David (No 84) received his cochlear implant in 1996. He matriculated in a mainstream school in Plettenberg Bay and then went on to study photography in Cape Town.

**CONGRATULATIONS TO ALEXANDRA UKENA (50)**



Alexandra obtained her Master's Degree in Philosophy in the discipline of Bio-ethics from Stellenbosch University Cum Laude for her Thesis entitled "Moral Perspectives on the problem of elective D/deafness".

Alex received her cochlear implant in 1994 after she lost her hearing. She matriculated at the German School. She currently works at Hoërskool Stellenbosch as a teacher.

## **MEDICAL NOTES**

A few reminders:

### **Medicalert Disc**

It is recommended that all cochlear implant users should wear a medicalert bracelet. This is to warn medical personnel who may need to treat the cochlear implant user in an emergency situation that the person has a cochlear implant. This is important to avoid the potential risk of damage from various medical procedures to the implant.

You can contact your ENT surgeon for more details.

### **MRI scans**

No patient using a cochlear implant should have an MRI scan before consulting with their ENT surgeon. Those patients who use a CI22 implant may not have MRI procedure. Patients who use a CI24 implant may only do so under specific conditions which should be approved by your ENT surgeon.

There is no risk to CT scan, ultrasound imaging and X-ray procedures.

## **SPARES AND ORDERS**

Your cochlear implant processor has a 3 year warranty; most other parts have a one year warranty. Should anything break during the warranty period you should report it immediately to your audiologist.

Consumables (e.g. microphone protectors, batteries) and parts no longer under warranty can be ordered from Jacqueline

de Bruto (012 667 4460 / [customercare@southernear.com](mailto:customercare@southernear.com)).

You should always ensure that you have enough spare parts to replace what is needed in an emergency, and to replace microphone protectors and dry bricks every 3 months.

## **CHANGE OF CONTACT DETAILS**

In the case of changes in your contact details, please remember to inform your audiologist or Antoinette de Bruyn ([antoinettedb@sun.ac.za](mailto:antoinettedb@sun.ac.za)) or by What's App 076 387 7227

## **FACEBOOK**

Cochlear implantees in South Africa have started a Facebook group: South African Cochlear Implantees. You can request permission from the administrator to join should you so wish.

## **HEARUS**

HearUs is the charity arm of our programme and aims to support our unit and provide financial assistance to needy patients where possible.

[www.hearus.org.za](http://www.hearus.org.za)

To find the **Facebook** page go to:

HearUs – A South African Cochlear Implant Association.

By “liking” the page you will automatically follow updates. Your comments are welcome.