

CASE STATEMENT

STEVE BIKO ACADEMIC HOSPITAL BOARD-
ROBERT KERR TRUST HEALTH PROGRAMME

A BEAUTIFUL NOISE

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1. INTRODUCTION

Hearing is a basic sense - one of the first functions that a fetus develops and that helps the baby to bond with his/her mother. Hearing connects us to people, loved ones. It unites us with our environment. We play, talk, express, experience, learn and work in sound and words. We live and love by it. It even helps us to survive in certain circumstances.

Being such an obvious function, hearing is often taken for granted by most of us.

One can hardly imagine a world without sound. Hearing impairment is a sad reality that deprives about 47-million of the world population from obvious benefits that most of us enjoy. People with hearing disabilities are often lonely and isolated from the people around them and their environments.

However, a cochlear implant made it possible to restore some people's hearing. A cochlear implant can literally bring a whole new world to somebody who could previously not hear a thing. It can:

- enable the recipients to move forward in life with renewed confidence
- reconnect them to people and their environment
- give them the opportunity to develop/regain spoken language
- improve the quality of their lives
- empower them to attend a mainstream school and/or expand their career opportunities
- empower them to increase their income potential
- empower them to live and function independently
- encourage community involvement
- reduce their dependency on the state/social services

The Steve Biko Academic Hospital Board-Robert Kerr Trust Health Programme (SBAHB-RKT Health Programme) recently embarked on a Cochlear Implant project to turn deaf people's silence into "a beautiful noise"!

2. EXECUTIVE SUMMARY

The SBAHB-RKT Health Programme had its first cochlear implant successfully performed on the 24th of June 2009. In the words of the patient, the 68 year old Eersterust resident, Mr Arnold Henderson: "I cannot even begin to explain to people what it is like to hear properly again. To hear the birds in the morning - that is what I missed most". He had been unable to hear properly for 15 years.

The South African Government does not fund cochlear implants. As a government facility, the Steve Biko Academic Hospital is daily confronted with state patients who simply do not have the financial means to improve their health. However, being a leading state health and academic facility in South Africa that exists since 1927, consisting of state of the art medical equipment to the value of R270-million, the Hospital Board had reason to believe

that they could do more to help financially disadvantaged patients. The Board offered the hospital's medical facilities and expertise free of charge when it decided to establish a separate non-profit organisation (NPO), the SBAHB-RKT Health Programme, to address the immense physical and emotional needs that disadvantaged state patients often endure.

The Steve Biko Academic Hospital Board-Robert Kerr Health Programme was approved in principle in June 2009. The process of establishing this Programme as an NPO separate from the hospital started soon afterwards.

Among the many health needs that exist, The "Beautiful Noise" cochlear implant project was chosen to kick off the Board's Health Programme due to the huge need that exists and the **SUBSTANTIAL** difference it could make to the life of someone who has been excluded from the world of sound. Being deaf is not an emergency condition, but deprives people from a very basic function that is required to live a meaningful life. However, the Health Programme plans more projects to assist with even more crucial health needs in future.

3. VISION

The SBAHB-RKT Cochlear Implant Project reconnects clinically and socio-economically qualifying, disadvantaged hearing impaired people to the world of sound – a life changing intervention.

4. MISSION

Hearing is a basic sense, an obvious function that is often taken for granted. It connects us to people, our environment. We play, talk, express, learn and experience in sound and words. We live and love by it. For hearing impaired people, the world can be a silent, isolated place and life's options can be limited. The SBAHB-RKT Cochlear Implant Project restores the hearing of deaf people to enable them to live a meaningful life.

5. TARGET GROUP

This cochlear implant project will focus on clinically qualifying, hearing impaired people who do not have the financial or social means (mostly previously disadvantaged individuals) to attain a cochlear implant. Although not exclusive, preference will be given to young children. In the case of a minor patient, a stable conducive home environment and the ability of the parents to support their child with regard to post-operative rehabilitation and clinical follow-up as well as education, are of vital importance.

6. OBJECTIVES

- To create awareness on the SBAHB-RKT Cochlear Implant Project that can bring a whole new world to hearing impaired people.
- To create awareness on the need for resources to restore disadvantaged people's hearing.
- To mobilize resources and elicit public support, locally, nationally and internationally for the SBAHB-RKT Cochlear Implant Project.
- To raise funds to yearly restore the hearing of about four candidates who qualify for a cochlear implant in terms of this project.
- To communicate regularly with donors about the progress of the project.

7. HEARING DISABILITIES

7.1 Statistics

At least 7% (47-million) of the world population has some or other degree of hearing loss. Hearing loss is one of the most common impairments.

7.2 The hearing impaired person

People with hearing disabilities are people like you and me. We have the same needs, emotions, dreams and abilities. However, the disability can handicap and withhold them from living a meaningful life. As explained by a cochlear implant recipient who experienced both the silent and hearing sides of life:

- We deaf people lose touch with loved ones and our environment
- We experience high levels of frustration being unable to participate in ordinary, everyday activities; even as simple as responding to a door bell, telephone or alarm
- We often experience sorrow and grief being unable to hear cheerful sounds like laughter, music, birds
- We often have to endure people making fun of us
- We often simply withdraw from society to protect ourselves from the pain and difficulties it brings

8. COCHLEAR IMPLANTS

8.1 A Cure

Hearing loss is often irreversible. However, a cochlear implant can restore hearing disabilities that originated from damage to the inner ear (cochlea) which resulted of hair cells being damaged or missing. Such damage often results in a sensori-neural hearing loss and is usually permanent. Mild to severe sensori-neural hearing loss can usually be helped with hearing aids. Severe or profound hearing loss can only be helped with a cochlear implant. A cochlear implant cannot restore natural hearing, but is a very effective device that helps to reconnect a hearing impaired person to sound and spoken language.

Cure, i.e. restoring people's hearing and enabling them to live a meaningful life, becomes possible with a cochlear implant. It literally brings a whole new world to a person who previously could not hear anything!

8.2 History

The first cochlear implant in South Africa took place at Tygerberg Hospital in Cape Town in 1985. At the Steve Biko Academic Hospital, the first implantation was done in 1990. Due to a lack of funds, these operations were brought to a standstill for many years until the establishment of SBAHB-RKT Health Programme in June 2009. Today there are more than 120 000 cochlear implant recipients worldwide. More than a 1000 people in SA benefit from cochlear implants.

8.3 Benefits

The benefit of a cochlear implant extends far beyond being reconnected to sound. Recipients report that they feel they have been given an opportunity to "start over" and

move forward with renewed confidence in life. The quality of their lives can improve drastically. The merits include:

- reconnection to people, loved ones
- restoring of family unity and relationships
- restoring of their potential and dignity
- developing/regaining of spoken language
- reconnection to their environments and everyday sounds
- independence
- enhanced education and employment opportunities
- community involvement
- increased income potential
- reduced reliance on social services
- even personality changes, especially with children

8.4 Success rate

Not everybody with a hearing disability will benefit from a cochlear implant. To ensure a successful operation the Ear Nose and Throat team at the Steve Biko Academic Hospital performs meticulous pre selection tests on potential candidates. Only those who comply strictly with world-wide accepted clinical, social and psychological criteria qualify for an implant. The team starts with the selection and testing program as early as 6 months prior to the implant to ensure a successful and meaningful operation. Our success rate has currently been 100%.

8.5 Who qualifies?

Selecting appropriate candidates is of utmost importance. Patients have to undergo a series of medical tests to ensure they comply 100% with the clinical criteria.

This programme applies very strict socio-economic and clinical criteria in our patient selection. The selection is done by a multi-disciplinary team consisting of Ear Nose and Throat Specialists, Speech therapists, Audiologists and Social Workers of the Steve Biko Academic Hospital. We focus on financially and socially disadvantaged people (see Vision and Target Group earlier in this document) when a cochlear implant is considered. Although not exclusive, preference will be given to young children. In the case of a minor patient, a stable conducive home environment and the ability of the parents to support their child with regard to post-operative rehabilitation and clinical follow-up as well as education, are of vital importance. (See addendum for the comprehensive clinical criteria.)

Early implantation if somebody was born with a hearing disability is of utmost importance as it influences the child's ability to develop spoken language skills and adapt in a main stream school. An adult who lost his hearing later in life however also qualifies for an implant since he/she has a memory of language to draw from and can therefore still benefit from an implant.

Although these criteria exclude some candidates, it ensures that only those who will really benefit from the costly implant become recipients. These recipients then have an increased

chance of living a meaningful life and contributing socially and financially towards their communities.

9. IDENTITY AND GOVERNANCE

9.1 The Steve Biko Academic Hospital

Although a new Programme that only started in 2009, the SBAHB-RKT Health Programme works hand in hand with the Steve Biko Hospital that offered its medical facilities and expertise free of charge to support the Programme. The foundation of this hospital (then Pretoria General Hospital) goes as far back as 22 April 1927. It was renamed HF Verwoerd Hospital in 1967, which was changed to Pretoria Academic Hospital in 1997 and finally to the Steve Biko Academic Hospital in 2008. A Faculty of Medicine was established in 1943 that formed an academic institution with the hospital. This academic institution grew over the years to include other world standard facilities such as the Maternity Hospital, Ear, Nose and Throat Hospital and the Orthopaedic Hospital.

The SBAHB-RKT Health Programme has access to the hospital's state-of-the-art medical equipment to the value of R270-million. This is the only teaching hospital in South Africa that accommodates the hospital & University Clinical Department's offices in one building – which ensures a close relationship with its academic counterparts and continuous improvement of medical staff's technical skills that are to the benefit of the SBAHB-RKT Health Programme. The Steve Biko Academic Hospital is a leading state health and academic facility in South Africa.

9.2 Geographical influence

The SBAHB-RKT Health Programme operates from the premises of the Steve Biko Academic Hospital that offered its facilities and medical expertise free of charge to the Programme. The Steve Biko hospital is located in Pretoria, and mostly serves patients in the vicinity of Gauteng. However, being a referring hospital, patients from other provinces are also admitted if the need arises.

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9.3 The SBAHB-RKT Health Programme Board/Trustees

The Hospital Board, that initiated the cochlear implant programme, is a body established in terms of the Health Act 61 of 2003 to govern the hospital. Members are appointed by and report directly to the MEC (Member of the Executive Council) for Gauteng Health and Social Development. Besides governance, the body advises the hospital management on issues

such as finances, human resources, patient care, transformation and general management of the hospital. The Board ensures that the voice of the patients is heard and their issues are taken into account when service is delivered and decisions are made.

The Board consists of nine members. It comprises of all required skills and knowledge that include those of an advocate, judge, business people, nurses, doctors, human resources specialists, financial people and community leaders. Many of the board members have been working together for the past nine years and became a very active and energetic board that also support and guide other hospital boards in the Tshwane Region. These members and a few other people were appointed to also serve on the Board of the SBAHB-RKT Health Programme. The SBAHB-RKT Health Programme's Board comprises of a variety of members to include all skills and knowledge to manage an NPO. Members/trustees include:

Dr A de la Porte: Pastoral counsellor and part time lecturer University Pretoria

Mr LA Ebrahim: Accountant, businessman

Dr SM Grabe: Medical Doctor

Adv KK Kekana: Advocate, High Court Chambers Pretoria

Mrs GE Koekemoer: Nursing management

Mr OSN Lebeso: PR Councillor, Tshwane Municipality (Chairperson)

Judge LM Molopa-Sethosa: Judge, Pretoria High Court

Dr TSL Sizani: CEO, Dental Network Company

Dr ME Kenoshi: CEO, Steve Biko Academic Hospital

Mr SP Janssen van Vuuren: Director Finance, Steve Biko Academic Hospital

Mr R Baatsen: Robert Kerr Trust trustee

9.4 The cochlear implant team

The cochlear implant surgery is performed by highly qualified Ear, Nose and Throat specialists. The team under leadership of Prof M Tshifularo, is mentored by an expert, Prof JG Swart from the University of Pretoria's Cochlear Implant Programme, who started with the first cochlear implant operations in South Africa about 20 years ago. Prof Swart and Dr Burden from the University Program have performed more than 300 cochlear operations since their start. The surgery is however preceded by the intervention of a multi professional team that includes:

- Medical practitioners to evaluate the cause of hearing loss and patients' general health
- Radiologists performing DT and MRI scans of the ears
- Audiologists to evaluate patients' hearing and to do the cochlear device fitting, programming and follow-up testing
- Speech and Language Therapists that help with speech and language evaluation, rehabilitation and support
- Psychologists to assess patients' ability to cope with the surgery and participate in follow-up programs
- Social Workers that guide and manage family and patient expectations
- Educators/Teachers who assess their educational, learning and rehabilitation abilities
- Marketing and Resource Mobilization team to raise funds for disadvantaged patients

This team made a major effort to facilitate the commencement of the SBAHB-RKT Cochlear Implant Project. They are highly skilled people who are well prepared, equipped and enthusiastic about their work. They are in accord with our first cochlear implant recipient,

Mr Henderson, who said: "it is not about what you accomplish in life, but what you do for others that count" when he thanked the hospital for restoring his hearing after 15 years.

10. COCHLEAR IMPLANT REHABILITATION PROGRAM

Thorough records are kept of all recipients to ensure a successful program. Post operation sessions are scheduled as often as indicated to fit and adjust the cochlear device electronically and monitor patients' rehabilitation process. Patients often attend pre and post operation speech and/or other therapy sessions at the hospital to maximize the benefits of the implant and to assist them to adapt in the hearing community.

The Steve Biko Academic Hospital offered the SBAHB-RKT Health Programme its expertise and rehabilitation services to support the cochlear implant recipients for the rest of their lives. This is not a once-off procedure, but an ongoing process involving post-operative evaluations and ongoing rehabilitation and support.

11. COSTS

A cochlear implant device costs about R250 000, depending on the exchange rate (Nucleus device imported from Australia). Only a small part of the population is able to afford the implant and very few medical aids contribute towards the device and operation. These costs are totally out of reach of this programme's target group (financially and socially disadvantaged patients).

Although the initial expense is high, cochlear implantation is a very cost-effective way of treating, rehabilitating and empowering patients with hearing losses. This especially applies to children who could be transformed into productive and fully integrated members of the society where they would otherwise have been financially dependent on the state.

12. FUNDING

Funding of cochlear implants for state patients is one of the biggest constraints.

12.1 Initial funding

Support funding from the Robert Kerr Trust enabled the Steve Biko Academic Hospital Board to fund and partially fund the first two cochlear implants at the hospital in June and October 2009. This trust is kept and managed by Trust Services Pretoria that is also a representative member on the SBAHB-RKT Health Programme. Robert Kerr was a member and subsequent chairman of the Hospital Board from 1917 to 1947, who donated his substantial estate to the hospital. However, the Robert Kerr Trust supports many other emergency hospital needs and the SBAHB-RKT Health Programme was initiated to extend the financial support function of the Trust.

12.2 Future funding: Fundraising strategy

The SBAHB-RKT Health Programme embarked on a forceful fundraising strategy to give more disadvantaged hearing impaired patients an opportunity to "a new start in life". The following fundraising actions are planned for 2010:

- Marketing and awareness raising campaigns – print and electronic media
- Mobilising of personal donations

- Annual Golf Day
- Volunteer campaigns involving educational institutions, general public, business owners, societies, clubs etc
- Internal staff fundraising projects
- Creating of an sms donation and competition line
- Clothing donation jumble sales
- Approaching of sport clubs to run/cycle/soccer/golf for cochlear implants
- Fundraising Spring Picnic with celebrities
- Corporate social investment requests

12.3 Projected budget

This budget projects values for the period January to December 2010.

Summary of projected values:

Activity	Projected income	Projected expenses
Marketing and awareness	R3 000	0
Mobilising of personal donations	R35 000	0
Annual golf day	R200 000	R40 000
Volunteer campaigns:	R150 000	
- Recruiting, training, rewarding		R5 000
Internal staff projects	R2 000	0
Sms donation/competition line	R10 000	
- Setting up of line		0 (sponsored)
- Advertising competitions		R5 000
Clothing jumble sale	R100 000	
- Advertising costs		0
Fundraising Spring Picnic	R60 000	
- Venue		R10 000
- Catering		R10 000
- Entertainment		R0 (sponsored)
Corporate Social Investment	R500 000	0
Salaries		R120 000
Travel and telephone costs		R15 000
Stationary, printing and diverse expenses		R10 000
Office rent, water and lights, equipment		0 (hospital premises)
TOTAL	R1 060 000	R230 000

Projected income: R1 060 000

Projected expenses: R 230 000

R 830 000

Aim: Implanting of 3 candidates at R250 000 per implant: R750 000

13. CLOSING

We sometimes go about life, accepting that some sad circumstances are a given. The SBAHB-RKT Health Programme however proves that change is possible. With the Beautiful Noise project, deaf people can “start over” - a life changing intervention.

Donors can make “a beautiful noise” to a hearing impaired child and be part of an event that can change a life forever!

We end off by quoting the joy of a mother whose child, Emma, age 3 received a cochlear implant:

I can now ...

Tell Emma jokes in the car

Teach her new songs and watch her dance

Talk to her from the next room

Read her stories when she's on my lap

Listen as she talks with her friends

Feel pride in her age-appropriate language skills

Understand exactly what she's saying

Marvel at her abilities in the classroom

Whisper “I love you” to her

Believe she can do and be anything she wants

ADDENDUM A

SBAHB-RKT HEALTH PROGRAMME

CLINICAL CRITERIA TO QUALIFY FOR A COCHLEAR IMPLANT

CHILDREN:

- Bilateral moderate / severe to profound sensorineural hearing loss
- Restricted or no useful benefit from hearing aids

Birth to 2 years	Restricted access to speech sounds with hearing aids (eg. Aided hearing thresholds outside the speech spectrum at 2000 Hz and above)
2 to 5 years	Failure to develop acceptable level of auditory skills (eg. Speech and language delay)
Above 5 years	50% or less open-set sentence discrimination

- No medical and or radiological contraindications

ADULTS:

- Bilateral moderate / severe to profound sensorineural hearing loss
- Pre- or post linguistic hearing loss with oral / aural communication skills
- Restricted or no useful benefit from hearing aids :
50% or less open-set sentence discrimination scores in the ear to be implanted
- Patients must have a desire to be part of the hearing world!
- No medical and or radiological contraindications

SOCIO-ECONOMIC CRITERIA:

CHILDREN:

- Adequate family support that will be sustainable
- Parents must be gainfully employed
- Audiological, educational and rehabilitation services must be accessible and available

ADULTS:

- Must have the skill to re-enter the work force
- Must be motivated to be gainfully employed
- Audiological and rehabilitation facilities must be accessible