56 DAYS TO GO TO THE NATIONAL ACADEMIC DISABILITY AWARDS

VOICES OF CHANGE

VOC

Page 8

Transformation for PEOPLE with disabilities

OCTOBER 2010
VOLUME 14

VOC is a non-political, non-religious, non-governmental and non-profit-making organisation in partnership with the University of the Free State. We give a voice to people with disabilities by giving different academic disciplines a chance to write about their news and views.

Come join us at the VOC Golf day!
Date: Saturday 27 November 2010
Place: Schoemanspark, Bloemfontein
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Amoré van Schalkwyk 072 0988 023 or
Samantha van As 072 0673 020

SPRINGBOKS SHARE IN OUR JOY

Cochlear implants are for people with hearing impairments who have a desire to interact with the hearing world and to communicate with spoken language

Emma Clipstone, a 3 year old cochlear implantee is granted the opportunity to sing the national anthem with John Smith, Captain, and the SA rugby team.

Photo: Provided

Magteld Smith
Cochlear Implantee from CI team, ENT, Universitas Academic Hospital, Bloemfontein

THERE are two camps with very different opinions about the cochlear implant (CI). On the one hand, there are those who see the CI as a gift and a miracle that will enhance the quality of life for some deaf individuals. On the other hand, there are those who see the CI, together with spoken language, as a threat to deaf culture. They view it as a tool that, based on the activist approach, considers deafness as a human rights issue.

Some hearing impaired people may have a desire to interact and communicate with the hearing world. This is a yearning for spoken language. It is recognized that this may, to a certain extent, form the foundation of surviving in the world.

Look at Emma Clipstone, who received a cochlear implant: she is aware of the fact that she is singing, she can hear everything around her, she is confident and, most of all she has a future – just like every South African rugby player next to her. She does not and might never really understand that she has received one of the biggest gifts made available by humans. Emma is saved from a lonely world where she is isolated from the people around her.

Being in the company of people who have no knowledge of deafness and speaking language may lead to problems. We should also remember that being in the company of parents of hearing impaired children may come with its own obstacles. This is because some parents, without even knowing it, compete against each other. They want their child to have the highest intelligence, seeing that society has the tendency to measure intelligence by the way we speak and pronounce words.

As soon as parents are confronted by the reality of the devastating impact deafness will have on the family, together with the fear of society thinking they have an unintelligent child, they turn to the natural path of sign language.

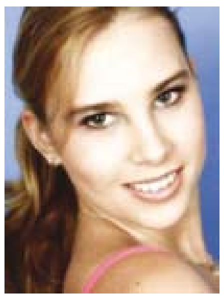
CONTINUED ON PAGE 6

Inserted in: Sowetan THE SOUL TRUTH Sunday Times THE PAPER FOR THE PEOPLE Sunday World

“I WANT TO ESCAPE FROM THIS SILENT WORLD”

“I find myself to be living in a glasshouse. I feel distant from everything and everyone.”

Yolandi Maritz


Natassja Buys
Photo: Provided

“I see things, but I can’t hear what is going on. My world is one of silence.”

This is how 21 year old Natassja Buys describes her life as a person with a hearing disability.

Thanks to her mom’s help, being deaf and having to attend Transoranje School for the Deaf in Pretoria never bothered Natassja.

“I grew up in a very protective home. My mom and grandmother are both deaf. At school, I never had a yearning to hear because all my friends were deaf as well. I was comfortable and content in my silent world.”

Natassja has since decided that she wants to break away from the silence.

At the moment, she is completing a diploma in Accounting from the University of South Africa (Unisa). As part of her training, she works as an Accounting Clerk in Pretoria North.

“At work, I was exposed to hearing people for the first time. I was expected to talk all of a sudden and all around me, people were talking.”

“I couldn’t hear anything they were saying. I was forever unsure of what was expected from me and this leads to your self-worth and confidence decreasing. I am only realizing now what I have been missing all these years,” she says.

Luckily, her impairment didn’t bother any of Natassja’s colleagues. They made her part of their group and learnt how to help her understand the topics of conversations.

Natassja smiles as she tells of the difference her colleagues made to her world.

“I am invited to social occasions. I love music, even though I can only feel the vibrations. I now have more hearing friends than deaf friends!”

All of this, combined with her dream to be successful at work, led to her decision to have a cochlear implant.

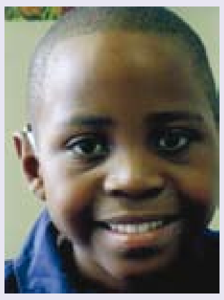
A team of doctors confirmed her to be a suitable candidate. Sadly, because of the costs of the implant, her medical aid did not cover the operation.

Meanwhile, a trust was founded to help Natassja. Golf days and concerts were organized to raise funds for the operation.

“I dream of waking up in the mornings of the noise made by my alarm. I want to hear the sea, the birds and the traffic. I can’t wait!”

It started with a headache...

My name is Sinalo Ngolozana.


Sinalo Ngolozana
Photo: Provided

AS a little boy, I used to have excellent hearing ability. One morning in December 2008, I woke up with a terrible headache. I went to see a doctor about this, where I fell asleep in the chair. My aunt woke me when the doctor was ready to see me. He gave me an injection and some medicine. After that, my aunt and I went home.

Back home, I fell asleep again and rested until my aunt woke me to offer me some food. However, I didn’t feel like eating anything. I fell asleep again.

The next time I opened my eyes, I found myself in hospital. When looking around and seeing nurses, doctors and sick children, I realized I was also ill. I wasn’t sure whether the scene I found myself in was real. I fell asleep again.

The next time I woke up, I realized I was unable to hear. My head was quiet. Sadly, life around me didn’t stop and I was still lying in the same bed. I slept in that bed for a few months. I even started viewing the nurses around me as my mother! I spoke to the nurses, but I couldn’t hear anything. I just kept looking that their moving mouths.

January 2009 arrived and I saw my parents – I was so delighted! They took me home with them. In March 2009, however, I moved to Cape Town with my grandmother. This was where I attended Dominican Grimley School. I was still unable to hear anything and kept concentrating on the people around me and their moving mouths.

One day, I went to Tygerberg Hospital, where scans were done to check my hearing. The doctors told me I would never be able to hear again, but I would receive a cochlear implant.

Nowadays, I can hear speech and everything around me. I am incredibly happy with the fact that I can hear again.

Meeting between OSDP and organisations well attended

VOC raises awareness of National Academic Disability Awards

Lize du Plessis

THE meeting between the Office on the Status of Disabled Persons (OSDP) and disabled people’s organisations was held recently. Various institutions and organizations were represented at the meeting.

A few decisions were made and various announcements also made out a part of the meeting. Voices of Change (VOC) used this meeting to once again raise awareness of the very first National Academic Disability Awards, which is to be held later this year. The latest publication, together with an information sheet, was distributed amongst the attendees.

Everyone was encouraged to remember that the closing date for nominations is 29 October 2010. Please visit VOC’s website at www.ufs.ac.za/voc for more information, guidelines and the nomination form.


At the recent meeting between the OSDP and disabled people’s organizations, VOC informed attendees of the coming National Academic Disability Awards.

Photo: Amoré van Schalkwyk

INSIDE THE MIND OF THE HEARING-IMPAIRED

A hearing impaired post-graduate shares her innermost thoughts and feelings on obstacles she has to overcome on a daily basis.

Lize du Plessis

"I beg your pardon?"

"What did you say?"

"I'm sorry, can you repeat that?"

THESE and other requests for repetition are recurrent lines in the everyday life of Magteld Smith. "I've been called self-centred, a poor listener, deaf-dumb and a variety of other things," she says. While none of those labels accurately describe her, two words do: hearing impaired.

Being hearing impaired has shaped Magteld's personality, her relationships and of course, her confidence. While she has been blessed to experience some success in life, Magteld had to work three to five times harder than normal people to achieve it. Graduating from university did not happen to Magteld because she was smart. "It happened because I attended every class, sat in the front row of the classroom and read the entire textbook to compensate for what I did not hear in class."

We are very aware of how people attempt to define us by what they see. So much of our life experiences have been spent countering stereotypes and disproving myths. Magteld has been equipped to deal with society's misperceptions regarding deafness. "I developed a knack for progress - despite setbacks," she says. Nevertheless, being a human being and being a woman are things people can see; living with a hearing impairment and invisible disabilities cannot be seen with the naked eye.

Magteld explains she is not aware of any scholarly manuals, public service announcements or talk-show debates on academic achievements of deaf people making use of spoken language. "We just live with subjected unfair prejudges and frequent misunderstandings."

"I have become adept with perfectly timed, 'is that right', 'get out of here, 'I see', and other conversation fillers. Sadly, deep inside I know I have no idea what the other person is talking about," she explains.

Furthermore, Magteld has the tendency to tune out. This simply happens because she has to work very hard to tune into what is being said around her – tuning out is nearly a natural state. "My patience and understanding for others is high, because I hope that by being patient and understanding to them, they will return the favour," she says.

"Nonsense, there is no such thing as lipreading!" "Deaf people have the vocabulary of a child of seven years old; sign language is the only means for a deaf person to make communication possible." These are all things we hear often.

Sadly, for so many young children and people of other ages who have been practising on a daily basis to achieve spoken language, this makes them feel as if they are being accused of being a liar or of over-exaggerating their situation. Obviously, this can cause great strain on relationships between hearing people and hearing impaired people. It can also create conflict between hearing people who belong to the so-called "deaf culture" and hearing impaired people who choose to be part of "deaf culture".

There seems to be no room for hearing impaired people who cannot pull their own weight by using spoken language. All hearing impaired people had to work much harder than hearing people and, says Magteld, they get angry to think that others are drawing a good income out of their disability.

When asked what her message to the outside world is, Magteld answers: "Let us not be like the general population of this ruthless world. We all need to realize that every person is valuable; despite the fact that they may not be physically able to function normally, look like everyone else or be a prominent figure in their society. What kind of people are we if we are judging someone by their outward appearances, their ability to contribute and what they are able to do in order to measure their value? Everyone has a gift, a purpose and the ability to impact other lives despite their physical condition – albeit visible or invisible."

Drawing done by Refematsure Setenare from Bloemfontein.
Photo: Magteld Smith

"Yes, there are people in this world who try to cheat the system. Because they do not want to work, they jump through a lot of hoops to get free money, free food and free housing. This lifestyle and attitude is appalling and abhorrent. Let us be careful not to treat everyone with an illness, injury or disability as if they belong in this group of unethical, indolent frauds."

The irony lies in the fact that it is not the visible impairments that are usually the culprit in someone being disabled or unable to work. "Yet, when our visible limitations do not seem that bad, people cannot understand why we are impeded. However, it is the invisible symptoms they cannot see that are keeping us from being able to function."

When a person has a visible limitation, we can see that they have impairments on the outside. This means we believe them when they tell us they cannot perform a task. For example, if a friend is vision impaired, we do not question them when they tell us they cannot go scuba diving alone. But when a person is debilitated by symptoms that are not visible, their integrity and intentions are often questioned when they declare they cannot participate.

According to Magteld, people with invisible disabilities are thankful and grateful for the invisibility of their impairment. Even so, it can also be a great burden to bear, with its unique set of challenges. Because people cannot see the limitations for themselves, they often show their disbelief with a hurtful statement. This causes the person with the illness or injury to feel as if their character and honesty is being judged. "Sadly, this cuts deeply, straight to the heart, when our virtue is being torn to shreds," says Magteld.

Refusing to believe what you cannot see will only make others feel isolated in their struggles. They will feel as though you do not see them as honourable, respectable and valuable to you.

Be mindful to value each person individually, because they are of great value to God. Whether we have a visible or an invisible disability, we are all striving for respect, understanding, accessibility and, most of all, belief. We do not want others to prejudge us and be unwilling to hear the truth. We want people to listen and treat us like valuable, contributing people with integrity, courage and strength.

In general, neither type of disabilities is worse than the other, because each person's degree of limitations is varied, despite their outer appearance. Some have visible disabilities, some have invisible ones and others fall under both categories. For some it is the visible disabilities that hinder them, for others it is the invisible ones and for others it is mutual.

Giving a helping hand to all

My name is Leon van Wyk.

I was born on 1 September 1968 in Welkom in the Free State. Unfortunately, I was born with Cerebral Palsy. That didn't keep me from finishing my school career at a public school in Welkom. After finishing my school career, I started working with my father as a store man. I got retrenched after a while.

I received the opportunity to attend Access College in Johannesburg, where I completed a Diploma course in Business Administration. After that, I started doing administration work for the Association for Persons with Disabilities in Bloemfontein.

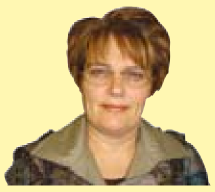
Today I am staying in the Jean Webber House in Park Road in Bloemfontein. We are currently setting up a computer centre, which will be managed by people with disabilities. The centre will mainly be used for the typing of any kind of documents. This will be done for anybody – it can be the young student or the old Chief Executive of any company who wants to make use of our services.

Leon van Wyk
Photo: Amoré van Schalkwyk

Prof. André Claassen
Project Manager and
Editor-in-Chief

Prof. Seedat
Assistant Project
Manager

Prof. Hennie Oosthuizen
Medical and
Consitutional Law



Magteld Smith
Project Coordinator
and layout

VOC Project Management Team

Samantha van As
Project Marketing
Manager

Dr Iain Butler
Managing Editor

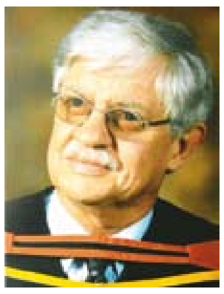
Frans Makhele
Sesotho Translator

Lize du Plessis
Editor

Amoré van Schalkwyk
Marketing Consultant
and Photographer

An equal opportunity, that's all

Ernest Wilson Kleinschmidt (Deaf)



Ernest Kleinschmidt

FOR DECADES, a substantial part of the hearing population have regarded deaf people as sub-normal humans - people with a very limited ability to use spoken language, and automatically, people with a very limited intelligence. According to these people, the ability to speak with a clear voice is the "alpha and omega" of a person's ability to live a normal life.

These opinions led many hearing people to believe that deaf people can only exist as a part of the community who needs to be cared for like other groups receiving welfare assistance. These views led them to believe that the main parts of assisting deaf people should be classified as "empathy" and "sympathy".

The hearing impaired are simply asking to be treated as equal to the rest of the world. Ernest Kleinschmidt explains why.

Deaf people very strongly object to these views, with a clear "no, thank you." This is because they have never seen themselves as welfare cases; neither do they want any person to feel sorry for them. Expressions like "shame" or "the poor deaf mute" are regarded as extremely degrading by the hearing impaired.

In the first place, deaf people are not ashamed of being hearing impaired. In fact, most of them are proud to say, "I am deaf". Secondly, deaf people have never been asking for gifts and handouts and would take strong exception when offered any. Thirdly, deaf people hate it to be called "disabled", because they most certainly do not need a wheeling chair or a white stick. The only difference between them and the hearing majority is that they use different ways of communication.

The only thing that most hearing impaired persons ask from the community at large is a fair and equal opportunity to prove themselves, with no special favours. They really want to become worthy citizens of their country. They long for an equal chance to prove themselves in any field or sphere of their own choice, and so to prove that pretended obstacles on the way to success is just what it says: pretended.

A deaf man once said that his greatest wish in life is to be treated as a normal human being, with all the opportunities and privileges afforded to other people, without the need to place unwanted obstacles in his way. Is this very simple request so difficult to understand?

LIVING WITH ALBINISM

A specialist explains how to handle, treat and live with albinism

Prof. Werner Sinclair
Dept of Dermatology
UFS

ALBINISM (oculo-cutaneous albinism) is a common inherited condition of the skin and eyes. The condition is seen in the Free State on a regular basis. Affected individuals have an inability to make pigment (melanin) in the skin and eyes. This leaves them with a very white skin, yellowish hair and very light brown or blue eyes. In some cases, the patient may develop dark brown freckles, which can cosmetically be very distressing. Apart from not being able to see normally, these patients are completely healthy and normal with normal intelligence and physical abilities.

The manner of inheritance (recessive) is such that the parents of the affected patient are usually not affected. The birth of the albino baby comes as a complete surprise.

The biggest problem with albinism is the fact that the skin of these patients have no defence against the sun and sun damage can be seen at a very early age. Precursors of skin cancer are usually already seen in teenagers and invasive skin cancer in early adulthood and even the late teenage years. This is a massive problem and almost all albino patients will sooner or later develop skin cancer. These growths are often multiple, very large and fast growing and are often untreatable and potentially fatal at the time of first diagnosis – especially in people who are also HIV-sufferers.

Advice to albino patients should be aimed at protecting the skin against all forms of sun exposure. The protection should be assured at all times, from birth to old age. These people should never go outside without a wide-brimmed hat (a cap is not good enough) or umbrella. Furthermore, clothing with long sleeves should be worn at all times and preferably also long trousers. These guidelines are applicable to both sexes. Girls with albinism should not even own dresses. Ideally, they should be allowed to wear long trousers al all times – even when they are going to school or church. This can play a huge role in reducing later complications.

Albino patients are advised to not rely on sun blocking creams. These creams make very little difference and are usually quite expensive.

Children with albinism should be seen by a dermatology clinic at least once a year so that early skin cancers can be detected and removed. Adults need to visit a dermatologist every three months for the same purpose.

We would like to hear from you!
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The difference between hearing and listening

Is there really a difference between hearing a listening?

Ilouise le Roux
Speech-Language Therapist and Audiologist

THE CONTINUED development and improvement in technology in early identification, diagnosis and intervention is giving hope to adults and children with hearing disabilities.

A cochlear implant is a device used to provide access to sound for children and adults with a profound hearing loss. The cochlear implant consists of an internal part that is implanted during surgery and an external processor worn behind the ear. Cochlear implantation has been called the modern miracle of our time.

However, the term *miracle* often leads to confusion with regard to what hearing loss entails. Furthermore, it can be misunderstood as a "quick fix" for a profound hearing loss. Providing technology in the form of a cochlear implantation is only the first step in the process of rehabilitation of a severe to profound hearing loss. We should not think of providing hearing technology in the same way as putting on glasses and seeing everything clearer.

Jean-Marie Pollock, Jenna-Lee Pollock and Ilouise le Roux
Photo: Provided

Cochlear implants provide access to sound, but it does not provide immediate understanding of speech. Remember: hearing is not the same is listening. Therefore, a person who is fitted with a cochlear implant needs to develop listening skills to benefit from their access to sound.

The first step in the development of listening skills is the ability to become aware of sounds. The next step in this process is being able to know where and what the source of the sound is and that sounds differ from one another. After this, a person should learn that a specific sound has a specific meaning. An example of this is a ringing sound – to us, this means the telephone must be answered. Following this stage, the patient learns to understand speech sounds, words, sentences, phrases and conversations.

Our brain interprets the sound and provides meaning to sound. Therefore, in simple terms, we hear with our ears but listen with our brains. When a person has limited exposure to sound, the brain loses its ability to interpret sound. When a person is fitted with a cochlear implant, the brain needs to learn how to interpret and attach meaning to the sounds. This requires extreme concentration, practice and time.

When communicating with someone with a cochlear implant you can help him or her to understand speech by speaking at a normal conversational volume, by reducing background noise such as the radio or television, by repeating yourself when information was missed and by sitting close to the microphone of the cochlear implant.

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Chabane shares her hobbies

My name is Chabane Chabane.

I am a resident at Jean Webber House. My hobbies include watching soccer on television and listening to classical music. My family lives in Welkom.

My implant has given me confidence!

My name is Faghire Hartley.


Faghire Hartley

IN 1999, I was diagnosed with mild hearing loss in my left ear. In the following years, until 2004, my hearing decreased dramatically.

I started wearing a hearing aid in 2005 but it didn't make a very big difference. I even stopped wearing the hearing aid, as it didn't help.

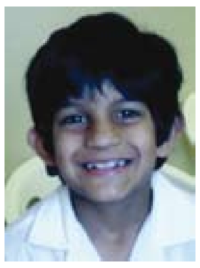
In 2008, I went to Tygerberg Hospital for an evaluation for a cochlear implant. The process consisted of a number of tests. It was established that I would indeed be a suitable candidate for the implant.

The operation was done in November 2009 and my speech processor was switched on in December 2009. Switching on the processors was a very moving moment, as I was able to start hearing and understanding what was said around me. After five years of complete silence, it felt as though a new life had begun.

The implant had a very positive impact on my confidence. I firmly believe the implant completely changed my life for the better.

Cochlear implant the reason for happiness

My name is Touheed Ismael.


Touheed Ismael

WHEN I was two years old, I still hadn't started talking. My parents took me to a clinic, where the nurse asked me a few questions. I didn't answer any of her questions.

The nurse then wrote the Red Cross Hospital a letter.

I was taken to the hospital, where both my ears were checked. It was then established that I was deaf in both ears.

In 2004, at the age of three years, I received hearing aids. At the age of six, I started attending classes at Carel du Toit Centre in Bloemfontein.

I was still unable to pronounce and hear some words. That was when I applied for a cochlear implant.

The application was successful and the operation was done in 2009. My hearing is so much better now! I am so incredibly happy and grateful to all the doctors at Tygerberg Hospital, who helped me during the entire process.

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Kids Talk

Kids, join us! We are learning some new words and what they mean.

A Glossary of MEDICAL words

Asthma

Say: **az**-muh

Someone with asthma might have trouble breathing because of problems in their airways. Airways are the tubes that carry air into the lungs. The airways can get irritated, swollen (puffed up) and narrow (like a pinched straw), which makes it difficult to breathe. Many things can trigger an asthma attack, like viruses, allergies, smoke and even exercise. Of course, breathing is really important, so someone who has asthma may need to see a doctor regularly. They will also have to carry special medicine to make it easier to breathe.

Dyslexia

Say: dis-**lek**-see-uh

Wha tifev eryth ingl oooked lik ethis whe nyo utrie dtoread?

Dyslexia is the name of a learning problem some kids have with reading and writing. It can make words look jumbled and make it difficult to read and remember what was read.

Cochlea

Say: **ko**-klee-uh

The cochlea looks like a spiral-shaped snail shell deep in your ear. It plays a very important part in helping you hear, because it changes sounds into nerve messages and sends them to your brain. After the eardrum “receives” a sound, the sound gets turned into a vibration that travels to the cochlea. There, the tiny hairs that line the cochlea move and shake, sending messages to your brain that you are hearing a sound. The amazing thing is: all of this happens in a very short moment!

Seizure

Say: **see**-zhur

You might hear a seizure being called a convulsion, fit, or a spell. Most people think of a seizure as someone shaking all over and losing control of his or her body. Remember: there are different kinds of seizures and all of them are caused by abnormal electrical activity in the brain. Your brain uses electrical signals and if those signals go a little haywire, a person can have a seizure. Some people may have only one seizure in their whole life. For other people, seizures may happen more often as part of a condition called epilepsy.

People with epilepsy usually need to take medicine to control their seizures.

Farsighted

Say: **far**-sy-tid

If you find it easy to see things that are far away from you but you have trouble seeing things that are close to you, you might be farsighted.

Many kids who have trouble reading books are farsighted. Being farsighted is the opposite of being nearsighted (which means you find it difficult to see things that are far away from you). Luckily, you don’t have to worry about being farsighted because some cool glasses will get you reading in no time.

Albinism

say: **al**-buh-nih-zum

Have you ever heard the word **albino**? It’s a word that’s sometimes used to describe a condition called albinism. Humans, animals, and even plants can have this condition. This means the person, animal, or plant doesn’t have the regular amount of pigment or colour.

You might know that albinism causes a kind of pale appearance. **But what exactly causes albinism?**

To understand albinism, you need to learn about melanin (say: **mel**-uh-nin). Melanin is a chemical in our bodies that colours our skin, eyes, and hair. It’s made by melanocytes (say: muh-**lah**-nuh-sytes), which are cells found in the bottom layer of your skin.

Sometimes, a kid or an animal whose body can’t make a normal amount of melanin is born. This is what happens with albinism, which can show up as a lack of pigment (colour) in the skin, eyes, hair, fur, or feathers of that kid or animal. There are different kinds of albinism. Some kids with albinism might have pale skin or hair. Other types of albinism might affect only the eyes.

Most kids with albinism have blue eyes and others have brownish eyes. In some cases of albinism, a kid’s eyes might appear pink or reddish. This isn’t because the iris (the colored part of the eye) is pink or red. It’s because the iris actually has very little colour. The eyes appear pink or red because the blood vessels inside of the eye (on the retina) can be seen through the iris.

CONTINUED FROM PAGE 1

It is possible that the CI saved young Emma from children and adults making fun of her. It is also possible that people making fun of her might have caused her to withdraw from society in order to protect herself from the pain and difficulties it leads to. Emma is saved from high levels of frustration, because her CI enables her to take part in ordinary, everyday activities. Her parents decided to protect their child against experiencing possible sorrow or grief. How do we know this? It’s simple: we can see the satisfaction by simply looking at her facial expressions.

However, not everybody with a hearing disability will benefit from a CI. To ensure a successful operation the Ear, Nose and Throat teams in South Africa perform meticulous preselected tests on potential candidates. Only those who comply with the world-wide accepted clinical, social and psychological criteria qualify for an implant. The team starts with the selection and testing program as early as six months prior to the implant to ensure a successful and meaningful operation.

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

This programme applies very strict socio-economic and clinical criteria in their patient selection. The selection is done by a multi-disciplinary team consisting of Ear, Nose and Throat specialists, speech therapists and audiologists. The CI teams in South Africa work together, learn from one another and are internationally connected.

Furthermore, the rehabilitation is of utmost importance for all children with hearing impairment, but a person with a CI needs highly qualified, trained and skilled specialists. The surgical procedure follows the same routine as other operations, such as an appendectomy and tonsillectomy.

To enable your child to really benefit from a CI, you need to be close to a CI team, since your child will need speech and audiological therapy and “tuning in” on a weekly basis.

Parents of deaf children, remember: the choice is yours! Spoken language is on the one hand, with sign language on the other. Each of these comes with its own challenges, hardships and victories. Parents are expected to decide which of these two will have the positive impact on their child’s life.

It is up to the parents to make the call. Parents, you will make the decision and take responsibility for your child’s future and destiny. No one can make this decision on your behalf. You can’t blame anybody for you decisions – whatever they might be. The final decision is up to you, the parents. Do not make choices that will complicate your family life even more. Both sign language and spoken language is expensive, the question is this: which will help your child to survive in a hearing world?

Voices of Change Editorial Policy

THE articles and features published in Voices of Change undergo a rigorous editorial process. This includes extensive reviews by medical professionals and academics. This supplement, however, is not intended to provide medical care, jobs, financial aid to the public or to sponsor disability assistive devices. The information in this supplement is for educational purposes only. For specific medical advice, diagnoses and treatment, please consult your doctor.

The articles, photos, animations, and features found in VOC are created and revised by members, physicians, writers, editors, and graphic designers of the VOC team. Our goal is to make sure that all information is accurate, balanced, current and family friendly.

The VOC editorial members review all our readers’ comments on articles in this supplement and suggestions for possible improvements and corrections.

The VOC team makes every effort to be neutral and objective when focusing on different disabilities, sex, race, religion and age. Within the articles, VOC takes turns referring to human beings as “he” or “she”. Remember that, even when the author of an article refers to “he” or “she”, the information provided is applicable to both male and female readers, unless otherwise specified.

Although every effort is made to verify that the information provided by resources – which includes websites, organizations, books and contact particulars –is up-to-date and accurate, the information tends to change and not all of it was necessarily reviewed by Voices of Change. These resources are provided solely as a convenience to our readers and are not an endorsement by the Department of Otorhinolaryngology within the Faculty of Health Sciences at the University of the Free State (UFS).

Winston dreams of owning a computer

My name is Winston Choene.

I am a quadriplegic. I used to work at the Centlec electricity call center as an assistant coordinator. This was my job from 2001 until 2009. At the moment, I am unemployed. I would love to better my computer skills but sadly, I do not own a computer.


Winston Choene
Photo: Amoré van Schalkwyk

The ins and outs of Parkinson's

A specialist tells more about possible symptoms, treatment and living with Parkinson's disease

Dr Deon Greyling
Senior Lecturer and Internist
Internal Medicine, UFS


Dr Deon Greyling

PARKINSON'S disease (PD) is a common disorder that affects the brain's ability to control movement. It is a chronic, slow progressive disease with disability in the end stage. In fifteen percent of patients, Parkinson's disease exists due to genetic inheritance. The cause of the remaining patients' disease is possibly due to environmental causes.

The disease affects the body's moment. Rest tremor, slowness of movement, stiffness and poor balance are characteristically affected. As symptoms worsen, patients may have difficulty walking, swallowing and performing daily tasks. In patients, walking is a shuffling movement with shorter steps and unsteadiness. In later stages, the freezing phenomenon can be seen. At this stage, the patient has difficulty in initiating walking.

Patients may also have masked facial expressions, decreased eye blinking, speech disturbances, swallowing difficulty and finding it difficult to look upwards. Furthermore, they sometimes experience a stooped posture and abnormal back curvature.

Dementia can be part of the disease and up to 80% of these patients develop dementia over a fifteen to 20 year period. Depression, anxiety, loss of motivation and fatigue are common mood disorders in people with Parkinson's disease. Some patients experience hallucinations and psychosis. Medication used to treat the disease may lead to psychosis.

Sleep disorders are also common and patients have difficulty falling asleep and staying asleep. Sleep disturbances can be related to difficulty turning over in bed, muscle cramps, dreams, urinating at night and pain. Patients also tend to sleep excessively during the day. Medication used to treat Parkinson's can contribute to daytime sleeping. Patients may also experience dizziness when standing up, abnormal sweating, urine leakage and sexual dysfunction. Loss of smell is one of the first symptoms of possible Parkinson's disease.

Parkinson's is usually a slow progressing disease. There is an increased risk of dying due to falls, choking and pneumonia. There is no cure for Parkinson's disease but symptoms can be well controlled with medication. Treatment must be individualised and treatment decisions should be taken with help of the caregiver, family members, the patient and the treating doctor. Help concerning this disabling disease can be obtained from a general practitioner, neurologist, Parkinson's Societies and support groups.

REGISTRATION AS A VOC MEMBER/
BOINGODISO JWALOKA SETHO SA VOC

VOICES OF CHANGE, PO BOX 38425, LANGENHOVENPARK, 9330
E-mail: voicesofchange@ufs.ac.za

APPLICANT DETAILS (PERSON WITH A DISABILITY)
DINTLHA TSA MOINGODISI (MOTHO YA NANG LE BOQHWALA

Full Names: / Mabitso ka botlalo:
Surname: / Fane:
Title: / Thaetlele: **Gender: / Bong:** Male / Botona ☐ Female / Botshehadi ☐
ID number: / Nomoro ya ID:
Residential Address: / Aterese ya bodulo:
Postcode: / Khoutu ya poso:
Postal address: / Aterese ya poso:
Postcode: / Khoutu ya poso:
E-mail address: / Aterese ya imeile:
Cellphone: / Nomoro ya selefounu:
Date of birth: / Letsatsi la tlhaho: DD / MM / YY Occupation: / Mosebetsi:

PERSON/S WITH A DISABILITY/TIES
MOTHO YA NANG LE BOQHWALA

Education / Thuto
Diploma / Diploma ☐ Degree / Dikri ☐
Postgraduate / Thuto ka mora dikri ☐ Certificate / Setefikeiti ☐ Primary school / Thuto ya motheo ☐
High school / Thuto e phahameng ☐ No schooling / Ho se be le thuto ho hang e telele ☐

Marital status / Boemo ba tsa lenyalo
Never married / Ho se nyale/nyalwe ho hang ☐
Married / O nyetse /O nyetswe ☐ Living together / Ho dula mmoho ☐ Missing / Lahlehile ☐
Divorced / O hladile/hladilwe ☐ Widower/widow / Mohlolohadi ☐

Employment / Tsa tshebetso
Employed fulltime / Mosebeletsi wa saruri/nako e telele ☐
Unemployed / Ho se sebetse ☐ Employed part-time / Mosebeletsi wa nakwana ☐

Run or do any kind of business, big or small, for yourself or with one or more partners? / Ho na le kgwebo eo o e etsang, e kgolo/nnyane, o le mong kapa le motho e mong ☐

PARENT OF A PERSON/S WITH A DISABILITY/TIES
MOTSWADI WA MOTHO/BATHO YA/BA NANG LE BOQHWALA

Education / Thuto
Certificate / Setefikeiti ☐ Degree / Dikri ☐
Postgraduate / Thuto ka mora dikri ☐ Diploma / Diploma ☐ Primary school / Thuto ya motheo ☐
High school / Thuto e phahameng ☐ No schooling / Ho se be le thuto ho hang e telele ☐

Marital status / Boemo ba tsa lenyalo
Never married / Ho se nyale/nyalwe ho hang ☐
Missing / Lahlehile ☐ Living together / Ho dula mmoho ☐ Married / O nyetse /O nyetswe ☐
Divorced / O hladile/hladilwe ☐ Widower/widow / Mohlolohadi ☐

Employment / Tsa tshebetso
Employed fulltime / Mosebeletsi wa saruri/nako e telele ☐
Unemployed / Ho se sebetse ☐ Employed part-time / Mosebeletsi wa nakwana ☐ Entrepreneur / akgwebo ☐

PLEASE TICK X THE APPLICANT'S PREFERRED METHOD/S OF COMMUNICATION
JWALOKA MOINGODISI, TSHWAYA KA X MOKGWENG WA DIPUISANO WA KGETHO YA HAO

English ☐ Sesotho ☐

Symbols and pictures: / Matshwao le ditshwantsho: ☐ Braille: / Mongolowa Braille: ☐ Telephone: / Thelefounu: ☐ Email: / Imeile: ☐ Mailing: / Poso: ☐ Audio: / Modumo: ☐
Deafblind signing: / Puo ya ditholo le difofu: ☐ Finger spelling: / Mopeleto wa menwana: ☐ SMS texting: / Puisano ka SMS: ☐ Large print: / Mongolo o moholo: ☐ Sign language: / Puo ka matshwao: ☐
Total communication: / Puisano ka botlalo: ☐ Other (please specify): / Mekgwa e meng (ka kopo hlalosa): ______

WHEN WERE YOU DIAGNOSED WITH A DISABILITY/TIES?
HO HLAHELLETSE NENG HORE O NA LE BOQHWALA?

☐ Birth / Tswalo ☐ Age / Dilemo

☐ Visual impairment (blindness) / Bofofu ☐ Speech impairment / Bothata ba puo ☐ Autism / Bothata ba ho kopana le batho ☐ Disabling hearing impairment (deafness) / Botholo (Na o ntse o na le bothata ba kutlo le ha o sebedisa dithusa-kutlo?)

☐ Do you have difficulty seeing, even if wearing your glasses? / Na o ntse o na le bothata ba pono le ha o sebedisa diborele?
☐ Do you have difficulty remembering or concentrating? / Na o na le bothata ba ho hopola kapa ho tsepamisa monahano?
☐ Because of a physical, mental, or emotional health condition, do you have difficulty communicating, (for example understanding or being understood by others)? / Na o na le bothata ba dipuisano, kapa hore batho ba utlwisise seo o se bolelang, ka lebaka la boqhwala mmeleng, kelellong, kapa tshetiso ya maikutlo?
☐ Do you have difficulty with self-care, such as washing all over or dressing? / Na o na le bothata ba ho itlhokomela, jwaloka ho tlhapisa hohle mmeleng kapa ho ikapesa?
☐ Do you have difficulty walking or climbing steps? / Na o na le bothata ba ho tsamaya kapa ho hlwa ditepisi?
☐ Do you have any difficulty joining in community activities (for example,festivities, religious or other activities) in the same way as anyone else can? / Na o na le bothata bo itseng ba ho nka karolo diketsahalong tsa setjhaba (mohlala: meketeng, bodumeding kapadiketsahalong tse ding) ka tsela e tshwanang le ya batho ba bang?

2010 National Academic Disability Awards

The very first South African National Academic Disability Awards function is to be celebrated in conjunction with International Day of People with Disability (IDPwD) on 3 December 2010.

Nomination Form

The nomination form should be read in conjunction with the 2010 National Academic Disability Award Nomination Guidelines. A copy of the nomination forms and guidelines can be downloaded from the Voices of Change website at **www.ufs.ac.za/voc**. Alternatively, you can send a sms with your name and postal address to 072 09 88 023. We will then send you hard copy of the nomination form and guidelines.

Nominating another person

You may nominate yourself or another person who you know is eligible for an Award.

Only complete nomination forms will be considered for an Award.

VOC intends to produce publications and conduct public awareness campaigns to promote the 2010 National Academic Disability Award.

Please email your nominations to voicesofchange@ufs.ac.za. Alternatively, you may send a hard copy of the nomination to:

P.O Box 38425
Langenhoven Park
Bloemfontein
9330

Nominations for the Awards should reach VOC **no later** than Friday 29 October 2010.

Successful applicants will be notified via sms or email.

Join VOC's group on Facebook for regular updates.

facebook

2010 International Day of People with Disability

www.ufs.ac.za/voc • voicesofchange@ufs.ac.za

Joining in the honour of 2010 National Academic Disability Awards

Kendall and Thobeka encourage VOC readers to take part in the prestigious awards.

The 2010 National Academic Disability Awards are getting closer! With the function being held on 3 December 2010 and nominations closing on 29 October 2010, there is much to be looking forward to.

Two beautiful ladies who will share in the winners' joy, are Kendall Daniel and Thobeka Shata. After being crowned Rag first and second princesses respectively of the University of the Free State (UFS) this year, they are both ready to help raise awareness for people with disabilities.

The two ladies are both enrolled for B.Sc degrees at the UFS. Between attending classes and studying, they like to, in true rag style, give to help others.

Be sure to visit Voices of Change's (VOC) website at www.ufs.ac.za/voc for more information on the 2010 National Academic Disability Awards. The nomination form, together with guidelines, can be downloaded from the website.

Kendall Daniel and Thobeka Shata

Photo: Provided