VOICES OF CHANGE

VOC

Transformation for PEOPLE with disabilities

DECEMBER 2011
VOLUME 19

Four years of inspiration
VOC celebrates a history of information and awareness

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Letter from the Editor:

DEAR READER

VOC, Celebrates its 4th year of existence and can look back at the impact that it has made on the lives of persons with disabilities. It has been extremely difficult in these times of economic depression to obtain the necessary funds to keep the newspaper going.

Our sincere appreciation goes out to Amore for her persistent efforts in selling advertising space in our newspaper.

The University of the Free State has become our mainstay in keeping the medico-social project alive and for that we are deeply indebted to the institution. This umbilical cord between the community and university is vital and clearly indicates to the universities willingness to involve itself with the man in the street especially persons with disabilities. Members of the Faculty of Health Sciences who sacrifice their time to make contributions to VOC are also acknowledged for their unselfish commitment. We would also like to thank all the other people who have supported VOC.

Prof. André Claassen
Editor-in-Chief
Chairperson

Mamma's en mangels

'n Spesialis antwoord 'n paar kwelvrae rondom mangels

Prof. André Claassen

DAAR is baie verwarring by sommige ouers omtrent die verwydering van mangels by kinders. Die volgende vrae duik gewoonlik op:

Moet my kind se mangels uitkom?

As daar 'n indikasie is, ja. Ongelukkig is dit nie altyd so eenvoudig nie. Die mangels en die adenoïede vervaardig antiliggaampies wat die liggaam help. Dus is dit 'n goeie orgaan wat in beginsel gespaar moet word. Gelukkig is daar in die wand van die dermkanaal van dieselfde weefsel wat ook antiliggaampies vervaardig sodat wanneer 'n adenotonsillektomie gedoen word, daar nie 'n noemenswaardige daling van antiliggaampies in die bloed aangetoon kan word nie.

Daar is egter onduidelike faktore. Die mangels en adenoïede is waghonde by die boonste deel van die spysverteringskanaal en lugweg onderskeidelik. Hoe betekenisvol is dit? Toets die mangels en adenoïede alles wat die liggaam binnegaan en vervaardig dan die regte antiliggaampies? Ons is nie seker nie. Een ding wat ons egter glo, is dat as die mangels en adenoïede kronies geïnfekteerd is en herhaalde akute ontsteking ondergaan, dan is die orgaan siek. Dan doen die mangels en adenoïede nie meer hul werk nie en kan dit uitgehaal word.

Is my kind te jonk om sy mangels te laat uithaal?

Daar is geen rigiede reëls rondom die ouderdom wanneer 'n mangeloperasie (tonsillektomie) oorweeg kan word nie. Onthou dat die adenoïede (agter neus mangel) saam met die tonsils verwyder word. So as daar 'n aanduiding of goeie rede is hoekom die operasie gedoen word, dan word dit gedoen. Uit die aard van die saak sal 'n mens nou nie graag klein babatjies wil opereer nie, want dit mag prakties moeiliker wees asook die risiko's hoër en verpleging moeiliker.

In die praktyk doen ons gewoonlik die operasie vanaf ± 2 jaar omdat pasiëntjies gewoonlik eers dan aangemeld word. Dus is ouderdom eintlik 'n relatiewe faktor.

Sal my kind nog siek word wanneer mangels uit is?

As die mangels siek was en herhaaldelik ontsteek het, sal jou kind minder siek word na 'n tonsillektomie. Ongelukkig is die paar honderd ander virusse nog teenwoordig wat gereelde boonste-lugweginfeksies kan veroorsaak (net soos voor die tonsillektomie).

Sal my kind beter eet na sy tonsillektomie?

Wanneer die keel gesond is mag hy 'n beter eetlus hê. Ouers sê gereeld "Die kind eet my nou uit die huis uit" nadat die mangeltjies uitgehaal is. As die mangels kronies siek is, sal die kind nie 'n aptyt hê nie. Hulle mag ook as gevolg van kroniese aantasting 'n lae graad gastritis (ontsteking in die maag) met swak eetlus hê.

Moet my kind elke keer antibiotika gebruik wanneer hy/sy verkoue en 'n seer keel kry?

Gesonde kinders wat in kinderkonsentrasie kampe is, word blootgestel aan honderde verskillende tipe virusse. Die meeste van die virusse kan lugweginfeksie en 'n seer keel veroorsaak. Dit is nie ongewoon vir kleuters om 8-10 keer per jaar siek te word nie. Daarvandaan die persepsie dat die kind "heeljaar siek is". Met ondersoek van hierdie pasiëntjies sal die hele keel rooi wees en die mangels mag geswel wees, maar dit beteken nie noodwendig dat die mangels die oorsaak van die probleem is nie. Die virus is wel en benodig nie antibiotika nie. Hoë-risiko kinders (kongenitale immuniteit, hart problem, ens.), asook kinders wat na ±72 uur nie beter is nie, mag antibiotika benodig.

Te veel antibiotika word voorgeskryf vir ongekompliseerde boonste-lugweg virale infeksies. Dit het geen effek teen virusse nie en daar is slegte nagevolge soos weerstandigheid wat ontwikkel.

Wat is dan die indikasies vir adenotonsillektomie?

Herhaalde akute ontsteking wat deur 'n kundige gediagnoseer is. Die hoeveelheid aanvalle is relatief en die graad van aantasting moet in ag geneem word (hoe siek was die kind).

Bogenoemde is aanduidend van 'n kroniese ontsteking wat dan akute opflikkerings veroorsaak. Mangels bly rooi afgeëts en kliere is tasbaar in die nek selfs wanneer die kind gesond is. Lugwegobstruksie wat veroorsaak word deur vergrootte mangels en adenoïede. Obstruktiewe slaapapnee mag ontstaan wat kan aanleiding gee tot hartversaking.

Bogenoemde is by verre algemene indikasies en enige ander situasie moet liefs deur 'n ONK-spesialis geëvalueer word.

Bridging the cleft for a better life

Cleft lip and palate are very common birth defects in South Africa

Prof. Fred Jooste
Plastic and Reconstructive Surgeon

WHEN we speak about clefts of either the lip or palate, we mean the following: A cleft is an opening or a gap in either the lip or the palate or in both. Thus, a cleft lip is a lip with a gap in it, and a cleft palate involves an opening in the roof of the mouth.

Cleft Lip:

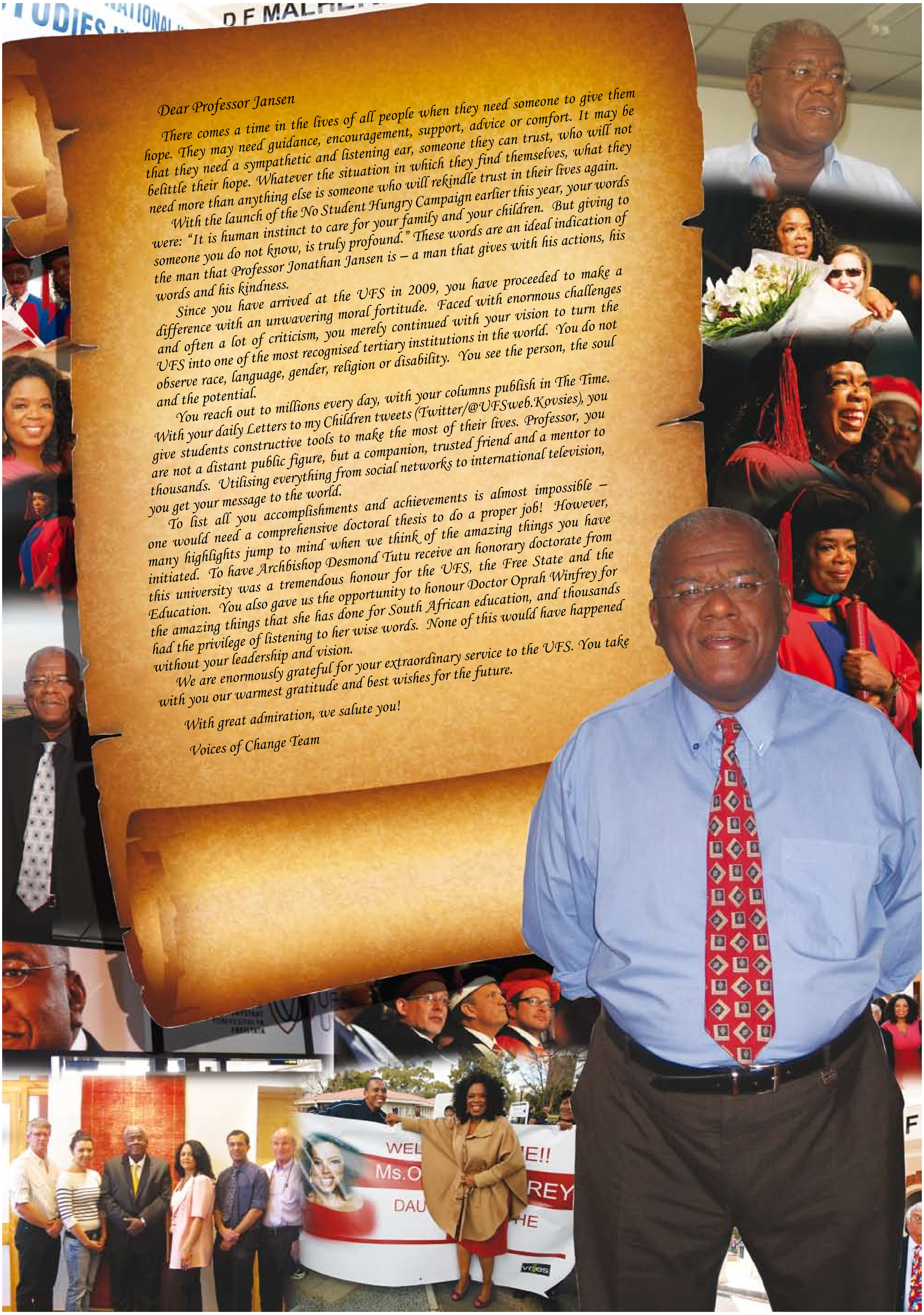
A cleft in the lip can either be incomplete or complete, and unilateral or bilateral:

- An incomplete cleft lip involves just a portion of the lip.
- A complete cleft lip involves the whole lip, and extends into the nose.
- A unilateral cleft lip involves one side, i.e. either the left or the right side of the lip.
- A bilateral cleft lip involves both sides of the lip, i.e., both right and left sides.

When a child is born with a cleft lip, the parents of the newborn may experience shock, disappointment and confusion, because their baby does not look like the other babies. They are usually quite anxious to have the lip repaired before the baby is seen by family and friends. But the lip repair is in no way an emergency procedure and it is definitely in the baby's interests to wait and have the operation done at three to four months of age. At this stage the baby is much more capable of handling a general anesthesia and the lip structures are also bigger, making the repair easier.

It is very important to explain this fact to the parents and to have them understand that their child is normal except for the cleft (which can be repaired), and that the child should be treated as normal. Thus, with a cleft lip, the disability is experienced more by the parents and not so much by the child. The parents may even feel anger at the doctor who gave them the bad news, or direct their anger at themselves (feelings of guilt), their spouse, society or even God. These feelings are normal and need to be resolved. The best way is for them to attend the cleft clinic at their nearest tertiary hospital, where parents with children with similar disabilities may share experiences, ideas and problems. In the Free State the cleft clinic is held every last Wednesday of the month in the Plastic Surgery Outpatients' Department at Universitas Academic Hospital.

In the next chapter I will tell you more about clefts of the palate.



Dear Professor Jansen

There comes a time in the lives of all people when they need someone to give them hope. They may need guidance, encouragement, support, advice or comfort. It may be that they need a sympathetic and listening ear, someone they can trust, who will not belittle their hope. Whatever the situation in which they find themselves, what they need more than anything else is someone who will rekindle trust in their lives again.

With the launch of the No Student Hungry Campaign earlier this year, your words were: "It is human instinct to care for your family and your children. But giving to someone you do not know, is truly profound." These words are an ideal indication of the man that Professor Jonathan Jansen is – a man that gives with his actions, his words and his kindness.

Since you have arrived at the UFS in 2009, you have proceeded to make a difference with an unwavering moral fortitude. Faced with enormous challenges and often a lot of criticism, you merely continued with your vision to turn the UFS into one of the most recognised tertiary institutions in the world. You do not observe race, language, gender, religion or disability. You see the person, the soul and the potential.

You reach out to millions every day, with your columns publish in The Time. With your daily Letters to my Children tweets (Twitter/@UFSweb.Kovsies), you give students constructive tools to make the most of their lives. Professor, you are not a distant public figure, but a companion, trusted friend and a mentor to thousands. Utilising everything from social networks to international television, you get your message to the world.

To list all you accomplishments and achievements is almost impossible – one would need a comprehensive doctoral thesis to do a proper job! However, many highlights jump to mind when we think of the amazing things you have initiated. To have Archbishop Desmond Tutu receive an honorary doctorate from this university was a tremendous honour for the UFS, the Free State and the Education. You also gave us the opportunity to honour Doctor Oprah Winfrey for the amazing things that she has done for South African education, and thousands had the privilege of listening to her wise words. None of this would have happened without your leadership and vision.

We are enormously grateful for your extraordinary service to the UFS. You take with you our warmest gratitude and best wishes for the future.

With great admiration, we salute you!

Voices of Change Team

‘n Ongelooflike reis van aanpassing

Die kosbare lesse van ‘n lewe in ‘n rolstoel

Freddie Pitts

OP 20 Februarie 2007, het my lewe ingrypend verander. Ek is daardie oggend oppad werk toe gedurende ‘n gewapende rooftog geskiet. Die koeël is deur albei my longe, asook my rugstring. ‘n Noodvoertuig het met my hospitaal toe gejaag waar ‘n noodoperasie gedoen is. Ten spyte hiervan is ek en my vrou later ingelig dat ek verlam is en nooit weer sou loop nie.

Dit was die begin van ‘n onvergeetlike reis van aanpassing. Ek moes leer om weer deel van die wêreld te word deur slegs die gebruik van my bolyf en wilskrag. Ek is elke tree van hierdie reis ondersteun deur my vrou, familie, vriende, kollegas en hospitaalpersoneel. Die herstelproses was ingewikkeld en lank, maar om dit op te som kan ek sê dat ek selfs moes leer om myself in ‘n bed om te draai – vandag kan ek heeltemal onafhanklik funksioneer.

Een van die belangrikste oomblikke in my herstelproses was ‘n gesprek tussen my werkgewer en my vrou. Hy het my vrou onmiddellik na ek in die hospitaal opgeneem is, verseker dat ons nie bekommerd moes wees oor finansies of my werk nie. Hy het geglo dat ek weer my gewone verantwoordelikhede sou kon behartig na my rehabilitasie. Ek kan nie genoeg benadruk hoe groot rol hierdie boodskap in my herstelproses gespeel het nie. Die feit dat soveel mense geglo het dat ek weer bo sou uitkom en die sekerheid van werk ná alles, het dit byna maklik gemaak om die uitdaging te aanvaar. Terwyl ek baie hard gewerk het aan my fisiese herstel, het my werkgewer reeds my werkplek omskep om 100% rolstoel-vriendelik te wees. Ek het een dag my baas gevra hoekom hulle soveel moeite met my doen en hy het geantwoord, “Omdat ons wil en omdat ons kan!”

Drie en ‘n half maande later is ek uit die hospitaal ontslaan het dadelik weer begin werk. My kollegas het my rondgery en my voortdurend gehelp. Almal by die werk, van die admin personeel tot die bestuur, het my ondersteun en nooit laat voel dat ek “gestremd” is nie. Nege maande later kon ek weer self ‘n motor bestuur (wat ‘n bevryding) en nou kan ek heeltemal onafhanklik regkom by die huis sowel as by die werk.

Ek kan getuig dat ek nou, vier jaar nadat ek geskiet is, volkome aangepas het. Fisies is daar sekerlik ‘n paar dinge wat ek nie kan doen wat ek voorheen kon doen nie, maar daar is soveel wat ek wel nog kan doen. My werk as produksiebestuurder doen ek so goed as wat ek dit voorheen gedoen het. My huis- en werksomgewing is só ingerig dat ek heeltemal onafhanklik by die huis kan bly, met my eie vervoer werk toe kan gaan en ‘n vol sosiale lewe kan lei. Ons kuier gereeld by vriende en almal vergeet sommer dat ek in ‘n rolstoel is.

Ek het in die laaste drie jaar ‘n paar belangrike dinge geleer:

- Die ondersteuning en vertroue van ‘n werkgewer is een van die belangrikste motiveerders om te herstel na ‘n traumatiese besering.
- Vriende, familie en sommer mense oor die hele wêreld was ‘n groot bron van ondersteuning en het my oortuig dat die mens van nature baie hulpvaardig en simpatiek is.
- Dit maak nie saak hoe sleg dit met jou gaan nie, daar is altyd baie ander in jou onmiddelike omgewing wat swaarder laste het om te dra en wat dit dikwels stilletjies op hul eie dra sonder dat iemand daarvan bewus is.
- ‘n Mens moet alles wat hy kan doen altyd waardeer asof dit môre weggeneem kan word. Moenie energie of emosie op negatiewe gedagtes en dinge mors nie. Die persoon waarop jy hierdie energie mors, weet dit gewoonlik nie eens nie en dit sou hom waarskynlik in elk geval nie pla nie. Jy is die enigste wat verloor.
- Daar is nooit iets wat onmoontlik is om te doen solank jy net voldoende energie, wilskrag en breinkrag gebruik nie.
- Die mens kan in alle omstandighede aanpas.

Slegte dinge gebeur met goeie mense en dit gebeur dikwels toevallig. Dit is nie dat God dit so wil hê nie, maar dit gebeur omdat die mens geskape is om sy eie besluite te neem , of dit nou goed of sleg is. Ek glo en het ondervind dat God altyd teenwoordig is om my te help om deur hierdie slegte tye te kom en sterker aan die anderkant uit te kom.

Sal ek eendag weer loop? Wie weet? Wat ek wel weet, is dat God natuurwette tot stand gebring het waarvolgens dinge op hierdie pragtige wêreld van ons gebeur. Een daarvan is dat senuwees nie vanself oor ‘n afstand van 50mm sal groei soos wat ek sal nodig hê om my rugstring weer heel te maak nie. God het ook die mens geskape om allerhande wonderlike maniere te kry om dieselfde natuurwette te gebruik om mediese wonderwerke te laat gebeur. Daar sal miskien ‘n manier gevind word (stemsel of elektronies) om later weer my onderlyf met my bolyf te laat kommunikeer, maar tot dit gebeur aanvaar ek dat ek nooit weer sal loop nie.

‘n Lojale, liefdevolle eggenoot aan jou sy is nie ‘n gegewe nie, maar ‘n ongelooflike voorreg waarvoor baie hard geveg moet word. Mense vra my en my vrou gereeld hoe het ons dit reggekry om aan te gaan teen sulke skynbaar reuse uitdagings. Ons antwoord is eenvoudig, “Wat sou die alternatief wees en waar sou ons nou gewees het?”

Freddie Pitts en sy vrou, Leoné Pitts.

Foto: Verskaf

Living with the two headed dragon

The difficulty of diagnosing bipolar disorder

Dr. Christo du Plessis

MOOD disorders are as old as the human race itself. In the Bible King Saul was jealous and depressed and tried to pierce David with his spear. Hippocrates used the terms mania and melancholia to describe mood disorders. Today we talk about depression and bipolar disorder.

The two parts of bipolar disorder are depression and mania (or hypomania). By definition mania is a constant elevated mood, which lasts for at least one week if not treated. The patient experiences sleeplessness, fast thoughts, increased goal directed activities, increased energy and has more pleasure seeking behaviour. Patients usually feel very good and do not think something is wrong. Their lack of insight is often a big problem, because the patients usually experience increased mental abilities and they tend to reason very well - to such an extent that they often convince people around them that all is fine and they do not need any treatment.

The behaviour of the manic patient can be erratic and can cause a lot of damage to relationships. Although they think that they are superior to other people, patients often have severe functional impairment at work, home and in other major areas of their lives. This often leads to people losing their jobs or deterioration in relationships with their spouses, family and others.

The manic episode is often followed by a depressed phase. This is experienced as incredibly bad and people often would rather die than go into a depression phase. During this phase, suicidal thoughts and even attempts are common. During the depressed phase, patients lose their love for life. They are often negative and have excessive feelings of guilt, difficulty to concentrate, to remember, to make choices or to reason well. They do not eat well and want to sleep more, but cannot fall asleep, or wake up in the middle of the night, unable to go back to sleep. They lose interest in life and this is difficult for the people around them to understand. Especially when the patient used to be cheerful and still looks healthy.

Bipolar disorder can start from as young as five years of age up to 50 years. Sometimes it is very difficult to diagnose, because it often presents at onset with a depressed mood. In retrospect the diagnosis will be made of Bipolar Disorder. This changes the treatment of the condition totally.

In Major Depressive Disorder doctors tend to give people antidepressants, while in Bipolar Disorder they use moodstabilisers. Often you will hear that people were wrongly diagnosed with Depression, but it is clear that this is an evolving condition. The important thing is that this disorder needs to be treated for life. Different modalities are used, but medication is the most important treatment modality. It is very important that the patients understand their condition.

People who has other medical illnesses, like Diabetes Mellitis for instance, have to take responsibility for their condition and they need life long treatment. The brain is also an organ and when abnormalities need to be treated, patients need to take the responsiblity and if needed make life changes and take treatment for life. The patient should know the symptoms and should have people (professionals and lay people) whom they can trust. These support systems should be utilised as soon as emerging symptoms are discovered. Psychotherapy for the patient and the family is extremely important. This disorder is treated in a team approach. The main player is the patient himself.

Congratulations with excellent work!

T: 051 401 2863 F: 051 401 2629
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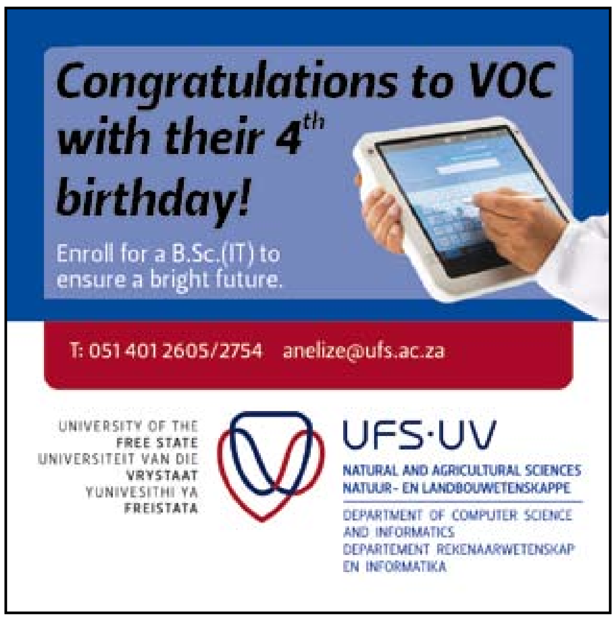

Congratulations to VOC with their 4th birthday!

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Baie geluk met jul 4de verjaarsdag. Hou aan met die goeie werk wat julle verrig.

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A hearty congratulations to VOC from the FEMS on their 4th birthday in this, the national and international month for people with disabilities!

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Geluk met 4 jaar se positiewe bydrae tot die gemeenskap!

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Veels geluk!

Hou aan met harde werk!

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Fereirra se entoesiastiese vooruitsigte

Mariné Jacobs

"OPGEE is geen opsie nie. Al wat sal bepaal of jy gaan kry in die lewe wat jy wil hê, is hoe graag jy dit wil hê." So sê Paul Ferreira, 'n sprekende voorbeeld dat 'n gestremdheid bloot so nadelig is as wat jy dit toelaat.

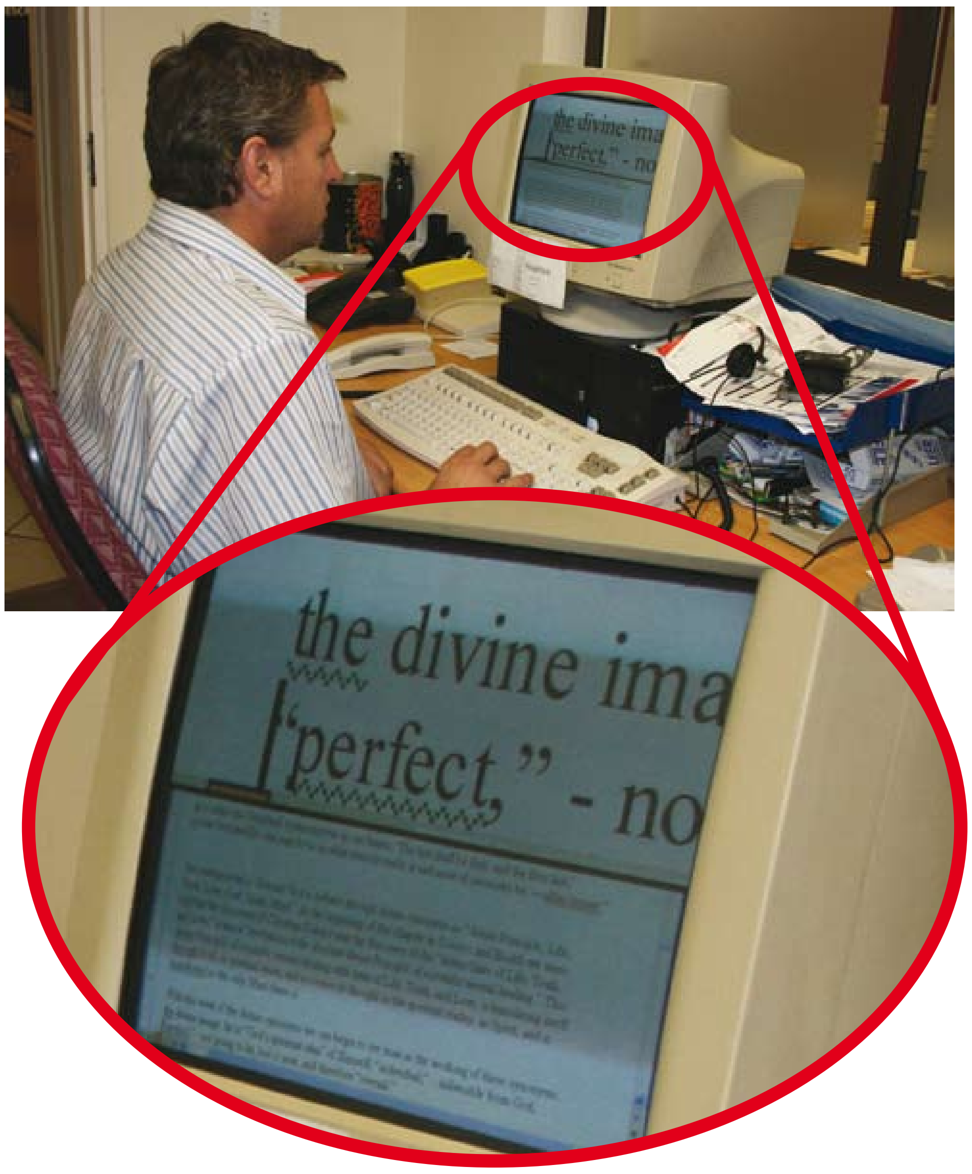
Paul is met normale sig gebore, maar toe hy 8 jaar oud was, het sy ouers agtergekom dat daar fout was. Hy sou in voorwerpe vashardloop wat reg voor hom staan. Die nuus was nie goed nie. Paul het makulêre degenerasie, 'n kondisie wat veroorsaak dat sy sig al hoe meer versleg. "Ek het geen sentrale visie nie, net kant-visie. Daarom moet ek verby mense kyk om hulle raak te sien," sê Paul. Daar is geen konvensionele behandeling vir hierdie kondisie nie, maar Paul sê dat hy wel na stamselbehandeling kyk. "Die dokters en die mediese fonds wil nie veel daarvan hoor nie en die prosedure sal my in die omgewing van R210 000 kos. Dit is nie so maklik om bymekaar te kry nie."

Swak sig demp nie sy gees nie

Paul sê dat hy nie werklik meer onthou hoe dit voel om behoorlik te kan sien, maar sê dat sy sig drasties verswak het in die afgelope twee jaar. "Dit is vir my moeilik om die straat oor te steek, omdat ek glad nie die motors kan sien nie. Ek het ook geen idee van afstand nie," sê Paul. Hy sê dat trappe klim ook 'n reuse uitdaging is en dat skerp lig sy oë seermaak. "Omdat ek stukkies kan sien en stukkies nie kan sien nie, is dit baie frustrerend. My oë pyn heeltyd omdat ek probeer sien waar daar geen sig is nie." Die grootste aanpassing vir hom is beslis dat hy sy onafhanklikheid moes prysgee. Hy sê dat dit hom vies maak om stadig te moet beweeg en dat hy nie kan sien wanneer sy kinders vir hom iets wys nie. Hy kan byna glad nie meer skryf nie en sukkel om kleure uit te maak. "Ek kan ook nie meer werk toe stap nie en moet rondgery word. Dit laat my minderwaardig voel."

In teenstelling hiermee, sê Paul dat sy geheue 'n baie groot rol in sy lewe speel. "As ek eenmaal 'n pad geloop het, weet ek presies waar elke uitstaan-klip, walletjie, trappie en gaatjie is. Ek kyk nie na my beker as ek koffie maak nie, ek hoor wanneer die beker vol. Soveel so dat ek nog weet of daar genoeg spasie vir melk is!"

Hy erken dat sy gestremdheid hom by tye baie moedeloos en teneergedruk laat voel. "Veral as my kinders vir my vra wat iets is en ek kan nie sien wat hulle wys nie. Dan raak ek baie vies," sê Paul. Hy voeg egter by dat daar so baie is waarvoor hy dankbaar is. Sy kinders, die feit dat hy kan loop en rondbeweeg en godsdiensvryheid. "Die grootste van alles is dat daar altyd geleenthede is om jouself te verryk en te verbeter. Ek sien uit daarna!"



Paul in sy kantoor by sy spesiale rekenaar by Rosepark Hospitaal by skakelbord.

Foto: Amoré van Schalkwyk

Van die rugbyveld tot 'n rolstoel

Traumatiese ervaring gee hom nuwe perspektief

Mariné Jacobs

ARNÉ Gouws is 'n doodgewone man met 'n buitengewone verhaal. 'n Verhaal van moed, deursettingsvermoë en dankbaarheid. As 'n kranige rugbyspeler is hy na matriek vir die Sharks o/19 span gekies en 'n suksesvolle rugbyloopbaan het vir hom gewink. 'n Ernstige motorongeluk het egter binne 'n oogwink al sy planne verander. Arné se rug is op drie plekke gebreek toe die motor 'n lamppaal getref en oor hom gerol het. Sy werwelkolom is tot só mate beskadig dat Arné verlam was.

"My hele lewe het verander. Ek as mens het verander. Die manier hoe ek verskillende aktiwiteite gedoen het en hoe ek dit nou moet doen… Dit is 'n ongelooflike groot verandering en aanpassing," sê Arné. Hy sê dat sy besering hom nie net liggaamlik geraak het nie, maar emosioneel ook. "Ek is baie meer gevoelig en het begin om die lewe heeltemal anders te sien en te ervaar."

Arné erken dat 'n lewe in rolstoel baie uitdagings stel. Hy sê dat sommige mense hom nou baie anders behandel en dat baie plekke nie rolstoel-vriendelik is nie. Hy sê ook dat hy mal is om strand toe te gaan, maar dat dit nou baie moeilik is. Alhoewel hy oorwegend positief is oor sy gestremdheid, sê hy dat hy soms teneergedruk raak. "Dit is maar net menslik, die bitterheid haal jou een of ander tyd in. Dan huil jy so bietjie, vra Jesus vir moed en krag en dan gaan jy weer volmoed aan."

"Dit is maar 'n aanpassing vir my familie ook," sê Arné. Hy voeg by dat sy familie vir hom ongelooflike ondersteuning gebied het en dat hul gesin nog altyd wedersyds ondersteunend was. Sy lewe het verander en sy rugbytoekoms is iets van die verlede. Maar, sê Arné, hy het baie uit die ervaring geleer. Hy weet nou dat daar altyd iets is om voor dankbaar te wees en dat ander dikwels swaarder kry as jy. "'n Mens moet maar weer oor begin en nie gaan lê nie. Die wêreld daar buite wag nie vir jou nie." Sy boodskap aan iemand wat deur 'n soortgelyke ervaring gaan is eenvoudig, maar waardevol: "Byt vas. Met God is niks onmoontlik nie. Hy sal vir jou die moed en krag daagliks gee om aan te gaan!"

Arné Gouws

Foto: Verskaf

Musiek in my ore

Kogleêre inplanting is jong meisie se grootste geskenk

Lizanne Bell

MY naam is Lizanne Bell en ek is `n 21-jarige meisie van Queenstown in die Oos-Kaap. Ek was vier jaar oud toe my ouers vermoed het dat ek `n gehoorprobleem ontwikkel het. Hulle het my na `n kliniek in Oos-Londen vir toetse geneem. As kind was ek op daardie stadium veels te jonk om te verstaan waaroor dit alles gaan, terwyl my ouers redelik bekommerd was oor wat die toekoms vir my inhou. Oppad na die spreekkamer, terwyl ek bewe van angs en by die vreemde omgewing probeer aanpas, het my ouers my gerus gestel en gesê, “As ons op die Here vertrou, sal alles goed afloop.”

Na afloop van die toetse het die geneesheer my ouers meegedeel dat ek gehoorgestremd is en ` n gehoorstuk moes dra. Die gebruik van gehoorstukke was ‘n groot aanpassing en met die ondersteuning van my ouers kon ek die nuwe omstandighede verwerk. Gehoorapparate moes ten duurste aangekoop word. Op daardie stadium kon my ouers net een gehoorstuk bekostig. Die groot oomblik het aangebreek die dag toe die spesialis, Dokter Bak, die gehoorapparaat vir die eerste keer aan my regteroor aanheg. Ek kon vir die heel eerste keer my eie stem, die voetstappe van mense en my pa se bewerige stem hoor! Die geleentheid het ons almal oorweldig. Trane van vreugde het my ouers oorval. Die tweede gehoorstuk is die volgende jaar aangekoop, wat weereens `n positiewe bydrae gelewer het.

Die volgende groot uitdaging in my lewe was die dag toe ek die laerskoolterrein betree. Daar het op daardie stadium groot onsekerheid by my ouers geheers of ek in ‘n hoofstroom-skool tussen kinders sonder gehoorprobleme sou aanpas. As kind was ek vasberade om deur te druk, alhoewel ek self baie onseker was. Met die genade van die Here het ek ook hierdie toets geslaag en my laerskoolloopbaan suksesvol voltooi. In die tussentyd het my gehoor verder verswak. Dr Burger, ons huisdokter, het vir my ‘n afspraak by Prof. André Claassen in Bloemfontein gemaak, met die moontlikheid van ‘n kogleêre inplanting. Prof Claassen het die nodige toetse gedoen en bevind dat ek ‘n geskikte kandidaat vir ‘n kogleêre inplanting was.

Die volgende drie maande het ek my voorberei vir die grootste operasie van my lewe. Die operasie was suksesvol uitgevoer en daarvoor sal ek en my ouers, Prof Claassen, Dr Butler, hul kollegas en die personeel van die Universitas Akademiese hospitaal, ewig dankbaar wees vir die onbaatsugtige diens wat hulle gelewer het.

Die oomblik van waarheid het aangebreek toe die kogleêre inplanting aangeskakel moes word. Na die stilte van die senutergende oomblik, het ek gebid, “God, U is in beheer.” Die volgende oomblik was onbeskryflik. Ek kan my opgewondenheid nie in woorde omsit nie. Ek het dadelik klank gehoor, maar moes spraakterapie kry om my brein te leer luister om te hoor. Mettertyd het die klank aansienlik verbeter. Ek kon na twee jaar die geluid van ‘n kriek onder my kamervenster hoor, sonder om te konsentreer. Wat ‘n wonderwerk!

Ek het in 2008 sonder enige moeite gematrikuleer en my eie motor as geskenk gekry. Die inplanting het ook gehelp dat ek my motorlisensie-toets baie maklik kon slaag. In 2009 het ek vir ‘n rekenaarkursus geregistreer, wat ook weer nuwe uitdagings gestel het. Ek moes weer aanpas omdat dit nie dieselfde is as in die skool nie. Ek het al die vakke suksesvol voltooi en is tans besig met verdere studies.

Graag wil ek hierdie geleentheid gebruik om die Universitas Akademiese Hospitaal, Prof Claassen, Dr Butler, llouise le Roux, Marianna van Heerden en almal wat betrokke was, te bedank vir hul bydrae om my lewensbaan te vergemaklik.

Lizanne Bell saam met haar ouers

Foto: Verskaf

Diagnosing autism and hearing loss

The impact of autism and hearing impairment on language development

Anri Olivier

AUTISM is a neurodevelopmental disorder with difficulties in various areas. Autism is no longer thought to be a rare disorder, with one in every 150 children being on the autism spectrum. A spectrum means that there are degrees of the disorder. Some children may only have mild symptoms of autism while others display much more severe symptoms. A child with autism can have difficulties in the following areas:

- Social interactions (getting along with people; knowing what to do in a group situation; difficulty handling social settings).
- Communication (talking; understanding; learning new words).
- Stereotyped and repetitive behaviour (flapping of hands and fingers; doing the same things with their bodies over and over; special interest in one toy or object so that it keeps the child from playing with or learning new things).

When diagnosing autism it is important to know that professionals will not look for the presence or absence of something (for example can he or she make eye-contact), but will rather look at the quality and way the child does things (for example how, when and for what reason does he or she make eye-contact). The diagnosis of hearing loss with autism or autism with hearing loss is increasing. When a child is not developing speech and language like other typical developing children, parents often firstly worry whether their child is able to hear well. This is a good place to start, as ruling out hearing loss can start the process of finding out what else is causing the delay in speech and language. In children with autism, the hearing assessment itself is very difficult. They often get referred to obtain a specialized test, where the patients are not required to participate and a machine determines hearing levels. This test is called a BERA (Brainstem-Evoked-Response-Audiometry). In many of the cases where hearing loss and autism are both present in a child, the hearing loss gets diagnosed first. However, it can be that the child with autism has a hearing loss that we are unaware of, because we think that the child is not responding to his name or not listening because of the autism. Both of these impairments have severe impact on the child’s communication and language development and use.

When the child is diagnosed with autism and hearing loss, it is very important to use a multi-modal approach (more than one way is used to teach the child) in speech therapy and every-day life. Language and speech need to be made visual by using natural gestures, sign language, pictures, facial expressions and sometimes special machines that work on a picture or symbol system (alternative communication systems). Verbal language (talking) should also be used together with the mentioned areas to develop listening skills and speech. We should do whatever we can to make it easier for the child to understand what he or she should do in a structured and organised way. Your speech therapist will also help you to find an appropriate school for your child that will be able to accommodate both the autism and the hearing loss.

The ins and outs of Parkinson's

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

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 movement. 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 15-20 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 slowly progressive 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.

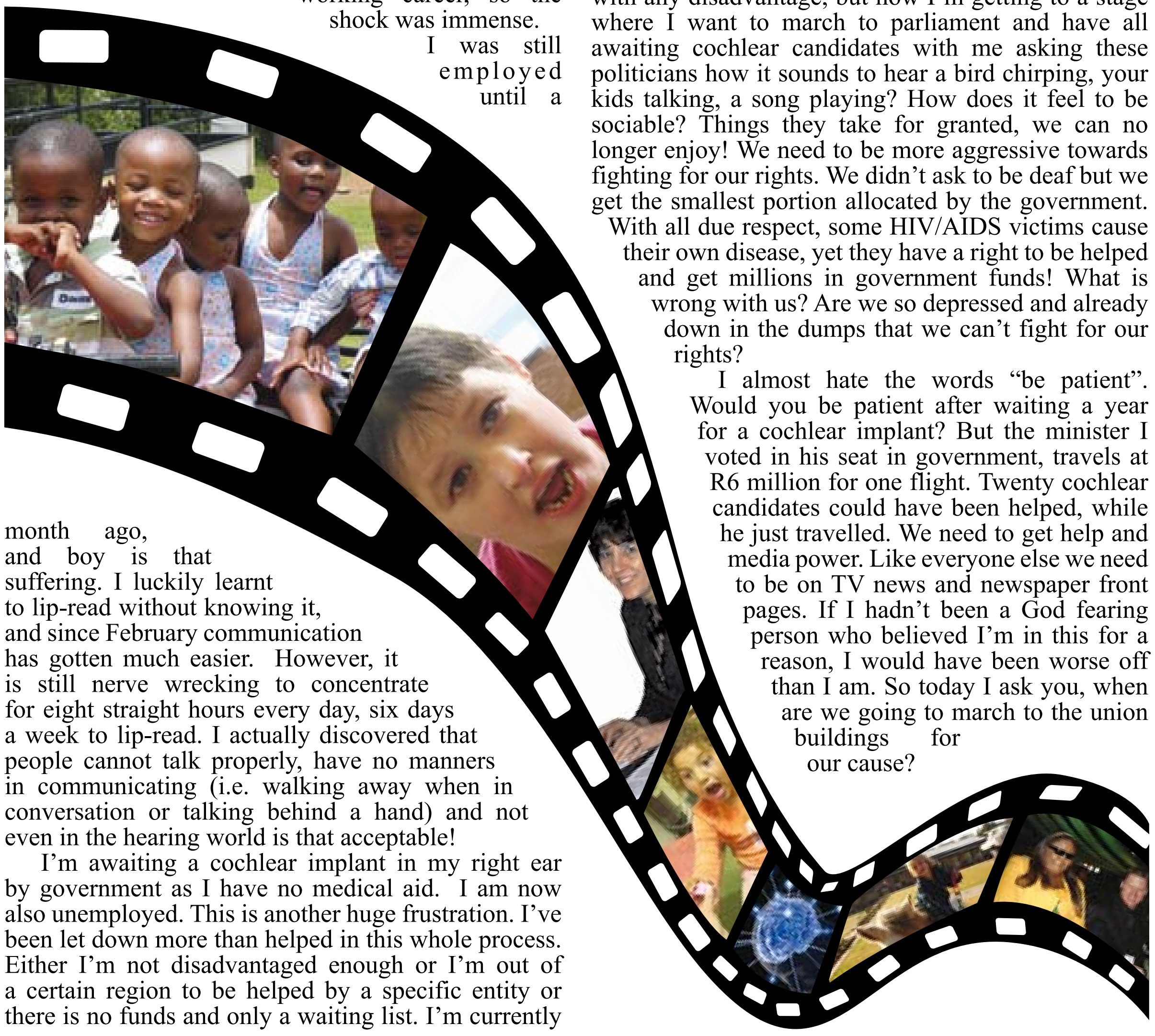
The land of silence

A hearing impaired woman demands to be heard

Karen Steffen

HI there all my deaf brothers and sisters. I'm Karen Steffen, age 45 and a white South African female. Until February this year I was still in the land of the hearing. I was born deaf in the left ear, but went through normal schooling till grade 12. About twelve years ago I lost a lot of hearing and had to start wearing a hearing aid. February 2011 was the last of that luxury! I've been a salesperson most of my working career, so the shock was immense.

I was still employed until a month ago, and boy is that suffering. I luckily learnt to lip-read without knowing it, and since February communication has gotten much easier. However, it is still nerve wrecking to concentrate for eight straight hours every day, six days a week to lip-read. I actually discovered that people cannot talk properly, have no manners in communicating (i.e. walking away when in conversation or talking behind a hand) and not even in the hearing world is that acceptable!



I'm awaiting a cochlear implant in my right ear by government as I have no medical aid. I am now also unemployed. This is another huge frustration. I've been let down more than helped in this whole process. Either I'm not disadvantaged enough or I'm out of a certain region to be helped by a specific entity or there is no funds and only a waiting list. I'm currently officially on three waiting lists at three different institutions. I receive an unemployment grant due to my retrenchment and even there I have to fight my way through a terrible system that has no patience and no compassion. Remember, I speak in a normal way and I lip-read, so if I don't announce that I'm deaf, you wouldn't know. Often normal hearing people think that I'm cheating.

I have always been compassionate towards people with any disadvantage, but now I'm getting to a stage where I want to march to parliament and have all awaiting cochlear candidates with me asking these politicians how it sounds to hear a bird chirping, your kids talking, a song playing? How does it feel to be sociable? Things they take for granted, we can no longer enjoy! We need to be more aggressive towards fighting for our rights. We didn't ask to be deaf but we get the smallest portion allocated by the government. With all due respect, some HIV/AIDS victims cause their own disease, yet they have a right to be helped and get millions in government funds! What is wrong with us? Are we so depressed and already down in the dumps that we can't fight for our rights?

I almost hate the words "be patient". Would you be patient after waiting a year for a cochlear implant? But the minister I voted in his seat in government, travels at R6 million for one flight. Twenty cochlear candidates could have been helped, while he just travelled. We need to get help and media power. Like everyone else we need to be on TV news and newspaper front pages. If I hadn't been a God fearing person who believed I'm in this for a reason, I would have been worse off than I am. So today I ask you, when are we going to march to the union buildings for our cause?