



# LISTEN UP!

Johannesburg Cochlear Implant News letter

Spring 2013



## JCIC ADMIN HOURS

Our office is open from Monday to Thursday between 8:00am and 4:00pm. **We close at 2:00pm on Fridays.** Please contact Gadija to book appointments and order batteries or spare parts. She is available at [admin@jcic.co.za](mailto:admin@jcic.co.za) or 011 482-6141 or 011 356-6198.

## MEDICAL AWARD

The **Lasker Awards** have been awarded annually since 1946 to living persons who have made major contributions to medical science or who have performed public service on behalf of medicine. The Lasker-DeBakey Clinical Medical Research Award was awarded this year to Graeme Clark; Ingeborg Hochmair and Blake Wilson for the development of the modern cochlear implant — a device that bestows hearing to individuals with profound deafness.

[http://www.laskerfoundation.org/awards/2013\\_c\\_description.htm](http://www.laskerfoundation.org/awards/2013_c_description.htm)



## WELCOME TO OUR NEW RECIPIENTS

Congratulations and good luck to our recipients implanted since our last newsletter:

**Adults:** Martha Mangale (2<sup>nd</sup> ear); Dana Blankfield; Andries Holliday (2<sup>nd</sup> ear); Jeanette Fineberg (2<sup>nd</sup> ear); Phillip D'Alebout; Anne English (2<sup>nd</sup> ear); Nigel Coote (2<sup>nd</sup> ear); Sophey Makgobi; Bawanile Nomandla; Neil Petersen

**Children:** Mohammed Abood (2<sup>nd</sup> ear); Demi Lever; Tawfeeq Sallie (2<sup>nd</sup> ear); Salmaan Angamia Ismael (2<sup>nd</sup> ear); Sebastian Christians (re-implant)

## BILATERAL FEEDBACK

A number of people took advantage of the discount offered on second implants. Bilateral implants may not provide perfect hearing and certain situations will continue to be difficult or frustrating but having sound coming to both sides can certainly enhance many of life's experiences. We asked for feedback from people regarding their views on bilateral implantation – the good, the bad and the ugly!

Some of the feedback came from long-term bilateral users and some from people who have recently received their second implants. The ease with which people adapt to a second implant will be influenced by factors such as length of hearing loss, period of time between the two implants, medical factors and motivation.

We do have some bilateral users who for various reasons have not adapted to the second implant and have chosen to use one side only, but the majority are using both implants.

*Note from Editor: Thank you for your contributions. We have selected the ones most relevant to the topic and have taken the liberty of editing in the interest of space.*



**Belinda Reynolds (1<sup>st</sup> implant 4/04/2000; 2<sup>nd</sup> 5/06/2000)**

Bilateral implants are definitely far superior to just ONE!

I've run out of batteries so I am currently having to cope with one and I can tell you I am really struggling! I can't even hear when an sms comes through, can't hear the TV at all either, at least with two I can hear "some" speech on TV.

When they are both switched on I can hear a lot more ☺

**Hiten Bawa is a 25 years old with bilateral implants for 7 years (1<sup>st</sup> 15/2/2006; 2<sup>nd</sup> 20/11/2006)**

I am on the brink of finishing my Master in Architecture degree at UCT. I would not have made it this far and coped with the rigors of tertiary education without the implants.

The best part is I can enjoy music concerts, learn to socialise, speak clearly, talk to my family on the phone, and play music on my iPod with a Neckloop.

The worst part is rechargeable batteries don't last longer than 12 hours and even worse is when I forgot to recharge them overnight. ....

The ugly part is that I cannot stand echoes because most buildings, especially classrooms, are acoustically poor that interferes with my microphones.



**Peter Hutchison (1<sup>st</sup> implant 1/03/2010; 2<sup>nd</sup> 14/5/2012)**

Well I've had my second implant for 16 months now and can only rave about it, can't think of one bad aspect – maybe one, you now have two devices to switch on and look after instead of one???!?

I was told that the “wow factor” would not be as great as with the first.

I disagree as I've been amazed at the completeness and improvement of the quality of sound.

In fact my whole ability to hear improves so much when I have two switched on that I have difficulty (for a while) using only one.

So I highly recommend having a second implant done.



*Feedback from parents who have walked the road with their children:*

**Michael McKeen is a 20 year old (1st implant 4/12/2001; 2<sup>nd</sup> 19/6/2006)**

Michael has been much happier and more confident following the second implant. He still favours the left side which was done first as his stronger ear.

The awareness of surroundings and origin of sound is dramatically improved with the bilateral implants .

*Note from Mom:* Just an added mention, I recently purchased the alarm clock for him from Hearability and the independence this has given him is huge! (He loves it!) His mom is also happy as I don't have to wake up at all hours to make sure he is awake to study etc.



*Note from Editor: Remember that we have Assistive Devices available for trial and sale at JCIC.*

**Dakota Wood (1<sup>st</sup> implant 23/2/2010; 2<sup>nd</sup> implant 30/7/2012)**

The bilateral implants have completely changed Dakota's life from a little girl of 5 who had possibly 50 words in her vocabulary and made three word sentences to a 9 year old who brims with confidence, never stops talking and singing and is gearing herself to solve the world's problems by the time she is a “grown-up”, in particular she wants to save the rhino!! The only shortfall for her is still the telephone, but she got around that and wears headphones connected to her phone.

**Jordyn Manos (1<sup>st</sup> implant 19/1/2010; 2<sup>nd</sup> implant 8/03/2011)**

Jordyn was born deaf in her left ear with a progressive hearing loss in the right. Over a trying 8 years, she eventually lost all possible hearing and was implanted on her right ear. She was back in her main stream public school of 36 pupils in 2 months.

With the resounding success of the first operation and following many consultations the family opted to brave the second ear.

This too was a success and her parents report that Jordyn is now a bilateral dependant daughter achieving fabulous school results in very difficult hearing conditions. She is a horse-riding enthusiast, even with the occasional fall here and there, loves her singing and dancing with a more positive attitude toward life than ever. She adapted very well to her hearing disabilities by doing very interesting projects in class and embracing her “disabilities” and by grasping life in every possible way.



**Jeanne Gildenhuys is 18 years old. (1<sup>st</sup> implant 20/12/2001; 2<sup>nd</sup> 22/2/2006)**

Jeanne found it incredibly difficult in the beginning but persisted in using both cochlear implants. Today, as 18 year old she is very grateful that she did so.

With her new refined hearing in the updated processors she is far better able to distinguish word in songs etc.

Jeanne has just achieved 3 distinctions in her Grade 12 Prelims and very few people are even aware of her being differently “abled”.

She has coped in class accepting that she might miss finer communications and uses her smart phone to take notes from the board.

Jeanne finds it annoying that the batteries of the different ears go flat at different times and she is not able to plan accurately for when she requires batteries.

She still finds it hard to go to parties with her friends. She finds it difficult to join in going to the beach or swimming.

She finds it difficult to watch movies or DVD without subtitles and this has not much improved over the years.

In boarding her roommate has to wake her in the mornings.

She still sometimes mishears unfamiliar words and finds it difficult when different people speak at the same time.

She sits at the head of the table when in restaurants to better see different people.

*Editors Note: Hopefully all processors will become more water friendly in time. Jeanne is a good example of how you can manipulate your environment and use additional technology to assist you in your everyday life.*



*A slightly different experience:*

**Lassika Pillay (1<sup>st</sup> implant 18/3/2002; 2<sup>nd</sup> implant 3/5/2005 – explanted 2012)**

Lassika had bilateral implants but due to pain on the side of the second implant for close to 6yrs, the family elected to have it explanted last year. (The implant was functioning within specifications and no reason for the pain could be found). While she no longer has pain, the experience of her having had two implants to going back to one made “a massive difference for her”. She has had to adjust and so have the family. They feel that having both implants benefitted her and are considering a second implant again in the future.



*Feedback from a relatively new bilateral user:*

**Mark Bester (1<sup>st</sup> implant 2/11/2010; 2<sup>nd</sup> 23/4/2013)**

My experience with Bilateral so far:

1) I found that the sound interpretation came much quicker than the first ear done. I could understand the sounds almost immediately and the sharp sensations associated with the higher frequencies also disappeared quicker.

2) The second implant is a CI422, which is a thinner, shorter electrode. I'm not 100% sure as we still have a way to go on the mapping, but it seems as if the sound is somewhat “thinner” than the other ear. The sound in the first ear seems fuller.

3) Overall it has made my hearing much better in all environments especially in noise.

*Editor's note: We look forward to hearing how the sound quality changes with time and MAPping.*

*The views of an adult considering a second cochlear implant:*

**Emile van den Houte (1<sup>st</sup> implant 13/6/2012)**

My cochlear works fine.

I think where it can improve is to

-have better removal of background noise and

- better balance between the singer's voice and the background in music.

I do think that a 2<sup>nd</sup> cochlear will improve my hearing. It is under consideration to have it sometime in the future

Thinking if I wait a bit longer they might have it all under the skin?

*Note: Emiel chatted to Mark on Friday and is now motivated to go for the second side!*

*One size does not fit all:*

A number of our unilateral recipients still use a hearing aid on the other ear – sometimes because they still have sufficient residual hearing on that side or for financial reasons or from choice because they want to retain their acoustic hearing.

## GROMMETS



We have been told by many people that small changes to a device or a programme can have a significant effect on their ability to adapt and cope with how they are hearing. Middle ear problems can affect anyone - people whose hearing normally falls within the normal range; people with existing hearing losses and people with cochlear implants. The onset and treatment of these problems will affect how you hear.

The proverbial shoe was on the other foot when Estelle Roberts (JCIP Speech Therapist) had grommets last month and is now experiencing first-hand what she has always down-played in counselling parents about their children with grommets.

She shares her experience after 3 weeks.

**'Ten Things to Know about Grommets – in Adults':  
An insider's view...**

Getting grommets really isn't sore

Hospital stays aren't great...

With titanium grommets in situ, there is strange and intermittent 'crackling' and 'creaking' – a disconcerting physical and sound sensation

The hearing loss associated with a foreign body (titanium grommets) in the ear-drum is mild on paper – creating a minimal 20dB air-bone gap

In spite of this mild hearing loss, it's effect on day-to-day listening, as a deviation from 'regular hearing' is hugely disconcerting

The hearing loss associated with the foreign body in the ear-drum leaves the sensation of extremely blocked ears

The hearing loss associated with a foreign body in the ear-drum results in listening deprived of definition and crispness

Ten days on, there has been no adaptation to the 'new' hearing...

The sensation of blocked ears affects the sense of taste – it too seems dulled and lacking in definition

There is an extreme longing for the hearing that was... And inordinate sympathy for what at least some of our children might be experiencing – and unable to verbalize, with their grommets!

#### IN MEMORIUM



**BAXTER WAREING**

**13/05/1965 – 15/09/2013**

Baxter became part of the JCIP family in 2012. He had been hearing impaired from birth and received a cochlear implant in October 2012 at the age of 47 years. He was a very positive and motivated man who always brightened up our rooms with a cheery smile and greeting. Sadly Baxter passed away on 15<sup>th</sup> September 2013. Our thoughts and prayers are with his wife Heather and children Jonathan and Robyn.

We will miss you Baxter.

**Don't forget to send in your comments, questions and suggestions and stories! Please share them with us at [admin@jcic.co.za](mailto:admin@jcic.co.za) or 2711482-6141 and we will include them or reply to them in our next edition.**