

Owen's chance to hear the world clearly

Chevone Petersen

"WELL after all that, if he is only deaf, that's a miracle" says Brandon Oberholster after his son, Owen, failed his newborn hearing screening at four weeks old in 2010, after surviving an obstetrical emergency and spending four weeks in the neonatal intensive care unit.

Today Owen is a bright and mischievous 3-year-old who up until a year ago benefited from bilateral hearing aids.

Since then he has undergone many tests and evaluations which confirmed his candidacy for a cochlear implant for his left ear; surgery is booked for next month.

His audiologist has also confirmed that he needs a stronger hearing aid for his right ear (he is using hearing aids on loan from his school).

Behind every child with a hearing impairment is a parent/caregiver, pushing the boundaries, supporting and guiding that child.

I asked Owen's parents, Tasmyn and Brandon, about the impact hearing loss may have on family dynamics and how service providers, family and friends have an impact on the resilience of families raising hearing impaired children.

As a parent of a hearing impaired child, I often wonder whether parents receive counselling when their children are diagnosed with hearing loss. Did you receive any counselling from any of the medical professionals while Owen underwent all the hearing evaluations during his first year?

No. The test would be explained and thereafter the results would be explained, but we were offered no counselling or assistance. We just got on with what we had on paper. Our audiologist referred us to the Carel du Toit Centre after Owen was fitted with his hearing aids.

Did you at this point, after Owen was fitted with hearing aids, understand the implications hearing loss may have on your family - your dreams and hopes for Owen?

Yes, we did, and we were ready to tackle Owen's impairment as a family and do everything in our power to give him the best chance possible.

Owen is a confident, positive little boy and I thank our awesome family for helping to shape these qualities in him. I have no doubt he will grow up, be successful and he will help others.

Did you at any point consider sign language as Owen's main communication tool?

One of the first questions we asked was if Owen would need to learn sign language and we were told no. As a result we have never explored sign language as an option for Owen since he is developing beautiful language and listening skills. We have committed to helping him develop his speech and auditory skills.

I believe Owen was the first baby in South Africa to benefit from the Widex Baby440 hearing aids. Can you tell me more about this?

At eight months, Owen's audiologist suggested the Widex Baby440s. These hearing aids were new and very small and would provide him with the amplification



BREAKING THE SILENCE: Brandon Oberholster holds his 3-year-old son, Owen who was born deaf. Owen has been approved for a cochlear implant, which costs R235 000, next month.

he needed. When we found out the price (about R25 000 each) we asked if there was any way we could get financial assistance or a sponsorship.

Our audiologist then spoke to Widex and they agreed to fit Owen bilaterally in exchange for weekly/monthly tests and follow-up assessments to monitor how the devices were benefiting Owen.

Amplification can significantly improve a hearing impaired person's quality of life. How have hearing aids impacted on Owen's quality of life and his development?

Owen benefited hugely from his hearing aids from the first minute! I remember leaving the audiologist practice that day and on our way home a truck overtook us and Owen started turning his head as he followed the sound and when I saw his facial response to the noise I broke down in tears.

Owen became responsive to our voices, normal sounds and day-to-day noise and then the build up started to get him to say his first words.

Do you have any other developmental concerns for Owen?

Not at this point. Owen is a healthy child and receives weekly speech and occupational therapy. The Carel du Toit Centre encourages parent involvement during therapy sessions.

I attend speech therapy with Owen once a week and Tasmyn attends occupational therapy every alternate week since we both work full time.

Your audiologist referred you to the Carel du Toit Centre, what has this experience been like for your family?

For the first 14 months we attended parent guidance and Owen officially started attending the school on a daily basis during the week when he turned 2 years old.

The staff have been very sup-

portive and have equipped us with the knowledge and guidance needed to understand and help Owen develop to his fullest potential.

We have learnt so much from Owen, the children at his school are so strong and resilient, despite their impairment. To us Owen is a normal child, we just have a talk a little louder.

How did Owen's first year of life impact on his older brother Ethan and how would you describe their relationship?

Ethan was a 3 years old when Owen was born, he had no understanding of what was going on and the anxiety we were going through. He was very excited about his new baby brother.

Ethan was kept busy at school during the day and on weekends his dad made an extra effort to do fun things with him while I spent time with Owen.

Most tests and procedures were done during the week so as to not disturb his routine and he really proved to be the helpful "big brother" and adapted rather easily. We always kept Ethan informed about what was going on with his brother from the beginning.

Ethan loves Owen unconditionally and is always happy to play. Ethan often introduces Owen to his friends and helps him experience life in the most fun ways, like only children can.

Like all siblings they have their good and bad days and there will be a little fight now and again, but Ethan understands Owen's situation and he is happy in his role as the "big brother".

How do you maintain a balance between parenting Ethan and ensuring constant medical appointments, therapies, schooling and one-on-one time with Owen?

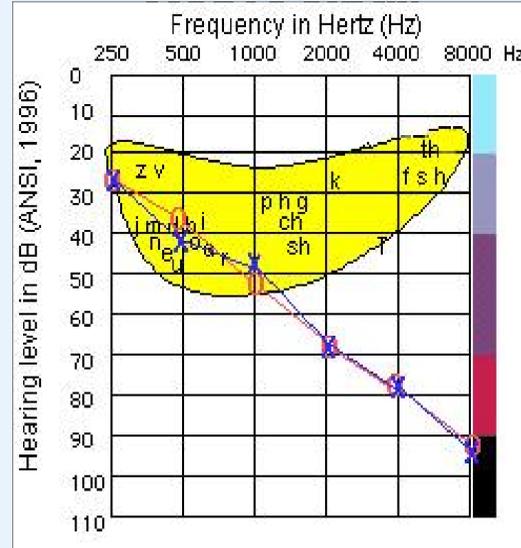
Ethan is at school from 8am to 1pm and then attends aftercare until 4pm. We try to keep Owen's appointments as early as possible in

SPEECH BANANA: HOW TO READ YOUR CHILD'S AUDIOGRAM

ACROSS the top of the graph are the numbers representing pitch/frequency from low to high. On the left side of the graph are the numbers representing loudness of sound. Your audiologist will be interested in measuring the softest sound your child can hear, this is referred to as your child's hearing threshold.

On the graph "x" charts the responses for the left ear and "o" the responses for the right ear.
15dB to 25dB represents a slight hearing loss
25dB to 40dB represents a mild hearing loss
40dB to 55dB represents a moderate hearing loss
55dB to 70dB represents a moderately-severe hearing loss
70dB to 90dB represents a severe hearing loss
90dB and above represents a profound hearing loss

Ensure that you understand your child's hearing loss and gather as much information as possible about his or her diagnosis and share these details with their teacher.



Educational Institutions for Hearing Impaired Children

SCHOOL	COMMUNICATION METHODOLOGY	ON-SITE SERVICES / SUPPORT
DE LA BAT SCHOOL Pre-school - Gr.12 Worcester - 023 342 2560	South African Sign Language	Audiology & Speech Therapy Psychology/Social Work Student Accommodation
DOMINICAN GRIMLEY SCHOOL Pre-school - Gr.12 Hout Bay - 021 790 1052 www.dominicangrimley.org	Oral-Aural	Audiology & Speech Therapy Social Work Student Accommodation
DOMINICAN SCHOOL FOR THE DEAF Pre-school - Gr.9 Wittsboms - 021 761 8046 / 7	South African Sign Language Total Communication	Audiology & Speech Therapy
MARY KIMM SCHOOL Gr.1 - 7 Observatory - 021 447 0310	South African Sign Language Oral-Aural	Speech Therapy
NOLUTHANDO SCHOOL FOR THE DEAF & HARD OF HEARING Pre-school - Gr.9 Vocational Training Khayalitsha - 021 381 1160	South African Sign Language	Also accommodates children with normal hearing who have other special learning needs.
NUWE HOOP SENTRUM Pre-school - Gr.9 Vocational Training Worcester - 023 348 2200	South African Sign Language Oral-Aural	Audiology & Speech Therapy Psychology and Social Work Occupational Therapy Staff Nurse Student Accommodation Also accommodates children with other special learning needs
THE CAREL DU TOIT CENTRE Pre-school - Gr.3 Tygerburg - 021 938 5303 www.careldutoit.co.za	Oral-Aural	Audiology and Speech Therapy Occupational Therapy and Physiotherapy Social Work and Psychology Parent Guidance Short-term accommodation for Families travelling from other Provinces/African countries

the mornings so one of us will still see to Ethan to not disrupt his routine while the other will see to Owen and then we will meet up for his appointments/procedures. This is working for us and also minimises absenteeism at work.

The same happens in the evenings, where one of us will sit with Ethan and the other with Owen to see to homework. Sometimes we do it together.

We spend a lot of time together as a family but we also have quality one-on-one time with each of the boys and we rotate so we both get time alone with them.

How did Owen's hearing loss diagnoses impact on your relationship?

Having a child can put strain on any relationship and having a child

with an impairment even more so.

It is physically, emotionally and financially demanding, but it's not by choice of the parent or the child or children, to be in this situation. You need to pull together as a family and support each other and do what is in the best interest of your family.

We have had a few emotional disagreements but ultimately we agree on what is best for Owen, Ethan, and us as a couple and then as a family.

I know from personal experience that raising a hearing impaired child can be financially exhausting. How has Owen's special needs impacted on the family financially?

I'm not quite sure how we manage but we do. We always seem to

make a plan and if not we adjust to make it work. We are blessed with amazing support from our extended families and they are always there for us when we need help.

Owen has been approved for a cochlear implant and his surgery is set for August 4. Is your medical aid covering this costs?

Owen was officially approved for a cochlear implant last month. We were then informed that the total costs of the operation is R235 000 of which our medical aid will cover R155 000. We still need to raise the excess of R80 000.

Initially we had to ensure payment of this before his surgery date, but thankfully we have been given an extension until the end of August to pay in any outstanding balance.



TENDER TOUCH: Owen and Tasmyn enjoy fun times together with the tough times. A positive attitude and plenty of support from family, friends and experts has helped this family understand Owen's silent ability.

This, as you can imagine, has put immense strain on us as a family. We are so grateful for the support of our family and friends who have been very busy helping us raise funds, hosting fund-raising events and sharing Owen's #surgery2sound fund-raising appeal via social networks.

We have raised R41 000 thus far and we remain hopeful that we will raise enough funds to cover Owen's surgery costs and buy a stronger hearing aid for his right ear which costs R28 000 of which medical aid will cover 50 percent.

What has been your most proud moment as a parents on this journey to sound?

Every day is pretty much a special day, especially when Owen comes home with a new word, sen-

tence, song or story. Our mantra and the message to want to send to everyone reading this today is that "disability is not inability".

The Celtic meaning of the name Owen is "Young Fighter", apt for this little guy who made sure that everyone knew that he was not going to give up without a fight from the moment he came into this world.

If you wish to know more about Owen's #surgery2sound e-mail Tasmyn Oberholster, on tasmyn.1984@gmail.com. You can also follow Owen's journey on his Facebook Page, HEAR Today Trust Fund for Owen Oberholster.

Petersen is the founder of a parent support group Decibels of Love, visit www.facebook.com/decibels_oflove or www.decibelssoftlove.com

Hearing loss at birth may affect brain and language

Surida Booyesen

IT WAS Helen Keller who said that deafness is the worst misfortune as it means "the loss of the most vital stimulus, the sound of the voice that brings language, sets thoughts astir and keeps us in the intellectual company of man".

Every day 17 infants with hearing loss are born in South Africa, but most children h the problem are only identified at about the age of 3 years old.

If you believe that 3 is still early enough to address the problem before schooling age, you are mistaken. Most children miss out on the most opportune time for brain and language development and continue to have lifelong difficulty in understanding and using language and age appropriate literacy skills.

The Carel du Toit Centre runs a programme where "deaf children learn to speak". It offers hope, support and intervention to children up to Grade 3.

The centre offers a family-centred, child-centred intervention programme called CHAT (Children Hear and Talk) to children and their families living with paediatric hearing loss. This means that parents and family members have weekly sessions, where they are equipped with the knowledge and skill to support their child.

The CHAT Centre is excited that next month, a pilot project, starting with three families, within and beyond South African borders, will commence utilising tele-intervention (speech therapy and parent guidance services via Skype).

This means that 12-month-old Aleksandra Celestino, who received her two cochlear implants in Cape Town two months ago, and her parents, will still have weekly intervention sessions while they are in Angola.

Speech-language therapist, Barbara Kelleff, is excited about this project and believes that "once we have a corporate sponsor on board to assist with funding for the hardware, computer software and reliable broadband internet, this method of therapy and training will be preferred by many families, even those staying in Cape Town."

Aleksandra is not only one of the centre's first tele-intervention users, she is also one of the first babies, born

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In SA, less than 10 percent of infants have access to early hearing screening services

with a profound hearing loss, that has been diagnosed through the Carel du Toit's hearing screening initiative in community-based obstetric units. Aleksandra had access to early hearing detection and intervention services.

Tersia de Kock, audiologist and programme manager of the Infant Hearing Screening programme at Carel du Toit, explains: "In South Africa, less than 10 percent of infants have access to early hearing screening services."

"The international gold standard is for infants to be screened for hearing loss by one month of age, for the hearing loss to be diagnosed by three months and for family centred intervention services to commence by six months."

"Even when infant hearing screening services are available, waiting lists for ENT (ear, nose and throat) appointments and diagnostic assessments can be longer than six months..."

"In Aleksandra's case, her parents decided not to wait. They consulted a private audiologist to obtain results and the subsequent assessment. Not all families are this privileged."

"For this reason, the Carel du Toit Centre is partnering with government and are in the process of developing more accessible speech and hearing services for children in the province."

At Carel du Toit the goal is to help children achieve age appropriate speech and language development in a language rich environment while following a mainstream curriculum.

The family and child have access to support services, including speech language therapy, audiological support, occupational therapy, physiotherapy, social work and transport services.

These support services come at a cost and Ruth Bourne, principal at the centre, reports that they "only receive 19 percent of our annual budget from the government and need to source the other funds from private and corporate donors".

Three of the Carel du Toit staff were invited to present their approach and findings on the impact of early intervention in a South African context at the international HEAL2014 (Hearing Across the Lifespan) Conference and the FCEI Congress (Family Centred Early Intervention) in Europe.

Jenni Bester, speech therapist, reports: "Despite many of the challenges our children with hearing loss face, such as late diagnosis and inadequate hearing technology, the quality intervention they receive here is comparable to the best in the world."

Contact your nearest audiologist or hospital should you suspect that your child may have a hearing loss.

Contact the Carel du Toit Centre on 021 938 5303 or visit www.careldutoit.co.za