

CHILDREN FROM COUNTRIES OUTSIDE OF SOUTH AFRICA PROTOCOLS AND PROCEDURES FOR COCHLEAR IMPLANT BY TYGERBERG HOSPITAL-STELLENBOSCH UNIVERSITY COCHLEAR IMPLANT UNIT

Thank you for your interest in our Cochlear Implant Unit at Tygerberg Academic Hospital Stellenbosch University, Cape Town.

1. THE MIRACLE OF COCHLEAR IMPLANTATION

Cochlear Implantation is a wonderful technology which makes it possible for deaf individuals to access sound and is described by many as a modern-day miracle. It is also expensive to acquire and maintain, and requires dedication, high levels of motivation and family support in order to achieve the best possible outcome.

Successful cochlear implant use is dependent on full commitment from you, your family, and the team.

There are a number of assessments and visits to medical health professionals which are necessary in order to establish whether cochlear implantation is the best treatment option for your child. Ensuring that your child achieves his or our full potential in life is our goal, so our team is careful in selection of appropriate candidates for cochlear implantation by following assessment and selection criteria in keeping with internationally established protocols. It should be noted that the most critical factors determining a good outcome from cochlear implantation are the duration of deafness, previous use of hearing aids and the age of the child. Cochlear implantation is contra-indicated in the case of older children and adults who do not use spoken language as their primary mode of communication. Therefore, our unit generally does not implant children who have been born with profound sensorineural hearing loss and have not had previous hearing experience by the age of four. Other critical factors which need to be in place for consideration for implantation are that the child will have access to appropriate intervention and be placed in a supportive educational system which promotes the development of spoken language. Strong parental involvement and commitment are essential.

2. HOW DOES IT WORK ENABLING A CHILD TO HEAR WITH A COCHLEAR IMPLANT AT OUR UNIT?

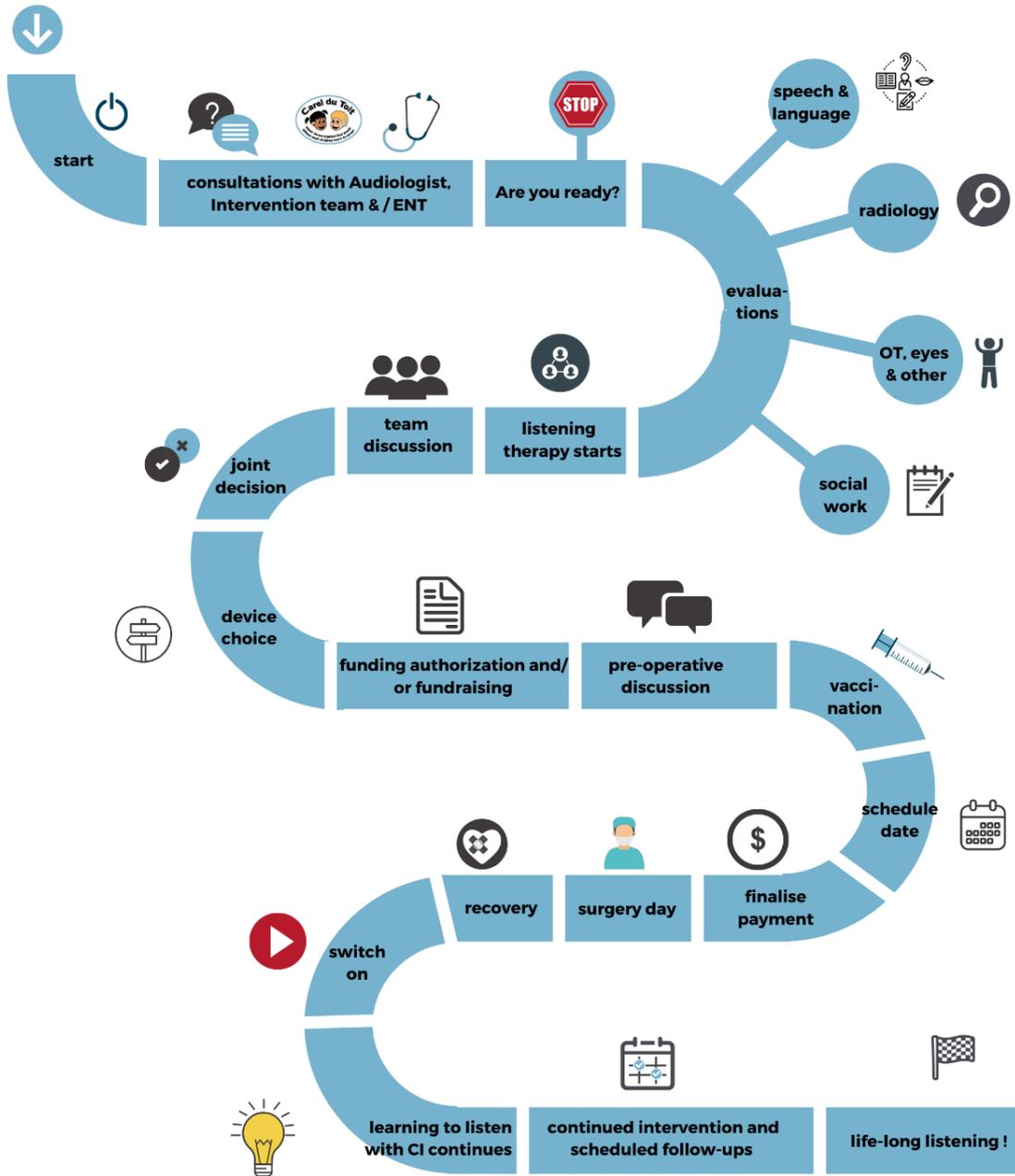
Figure 1 demonstrates the roadmap to hearing with a cochlear implant (page 2).

a. STEP 1 – ASSESSMENT

The assessment process that occurs in Cape Town for at least two weeks for the following procedures and appointments include the following:

Audiological Assessment	Other Assessments	Medical Assessment	Feasibility Assessment
<ul style="list-style-type: none"> · Comprehensive hearing assessment (with and without hearing aids), · Speech-Language assessment. 	<ul style="list-style-type: none"> · Occupational therapy · Neuro-developmental evaluation (paediatrician/psychologist/neurologist) · Physiotherapy 	<ul style="list-style-type: none"> · Ear, Nose and Throat Investigation · Radiology · Other 	<ul style="list-style-type: none"> · Access to rehabilitation · Access to educational options · Adherence to mapping schedule · Financial resources · Social work · Communication resources (stable internet, couriers).

ROADMAP TO ENABLING A CHILD TO HEAR WITH A COCHLEAR IMPLANT



www.cochlearimplants.co.za

Figure 1. a Visual representation of the journey to hearing with a cochlear implant at our CI Unit.

The Assessment process include:

- An appointment with an audiologist from Tygerberg Hospital Cochlear Implant Unit. A full history is taken, and the relevant information gathered. You will need to bring all relevant medical reports and history.
- Further hearing tests which will include behavioural and objective hearing tests. Your child may need repeat objective tests (ABR and ASSR). The tests may be able to be performed under natural sleep, but if not successful will need to be booked for another time under sedation. If possible and indicated, these may be done at the same time as the radiology.
- It is assumed that your child will have already been fitted with hearing aids in your own country. If not a trial period with appropriately fitted hearing aids will need to be arranged.
- Appointment with an ENT surgeon who will assess your child’s medical suitability for cochlear implantation and make arrangements for the radiological assessment.
- Radiology – this will be done during the first week. This is in order to assess whether implantation is anatomically possible and includes a CT scan and MRI scan of internal auditory structures and brain.
- Speech and Language assessment is necessary in order to establish your child’s speech and language level, and in order to support and provide you as caregivers with appropriate intervention goals.
- An appointment with the Social Worker at the Carel du Toit Centre.
- Other investigations will also be requested, including occupational therapy and paediatric neurology.
- A team meeting is held with all team members where the evidence is reviewed and a decision made as to whether cochlear implantation is recommended to be in the best interest of your child.
- To ensure successful use of a cochlear implant, adequate access to financial resources are a critical component in the long term, in particular for patients from outside of South Africa. We need to safeguard that a cochlear implant is in the best interest of you and your family.

Costs include:

PRE-IMPLANT COSTS	IMPLANT COSTS	POST -MPLANT COSTS	VISIT COSTS	POSSIBLE UNPLANNED EXPENSES
<ul style="list-style-type: none"> • Audiological Assessments • ENT appointments. • Other assessments • CT and MRI • Anaesthetic for radiology and audiology assessments 	<ul style="list-style-type: none"> • Theatre, hospital ENT surgeon, Anaesthetist, medicine, • Cochlear implant system 	<ul style="list-style-type: none"> • Mapping and Audiology appointments. • ENT appointments. • Maintenance costs (replacements and repairs) • Upgrades 	<ul style="list-style-type: none"> • Accommodation • Visa • Transport • Interpreter costs and arrangements 	<ul style="list-style-type: none"> • Courier fees • Visits • Retention options • Insurance • Internet

Added to the implant system specific costs, you will need to be able to demonstrate intent and resources to allow for:

- a. Costs of assessment process and hospital visits (see attachment for estimated costs)
- b. Cost of the device (approximately R230 000- 300 000.00 for one system)
- c. Costs and ability of travelling, accommodation and visa requirements for the
 - assessment,
 - surgery,
 - subsequent programming of the device (every **3 months** for first year, **annually** thereafter assuming no problems arise between visits).

- Early intervention at the Carel du Toit Centre.
- d. If the patient or the primary carer is not fluent in English, an interpreter is required (not a family member) and the arrangements and costs of this will need to be borne by the family.

b. DECISION ABOUT COCHLEAR IMPLANT

A monthly team meeting is held with all team members where the evidence is reviewed and a decision made as to whether cochlear implantation is recommended.

c. STEP 2 - SURGERY

The surgery is when the internal cochlear implant electrode array is inserted. This is arranged by the ENT surgeon and audiologist. It is approximately a 3-hour procedure (if one implant is being done). An overnight stay in hospital may be required.

d. STEP 3 - PROGRAMMING OF EXTERNAL SOUND PROCESSOR

- Approximately 2-3 weeks after the surgery activation of the external device is done, where the sound processor is fitted. You will need to be in Cape Town for a minimum of 3 weeks from the day of activation for the fitting process and rehabilitation.
- Follow up visits are every 3 months for the first year. The primary caregiver will need to be in Cape Town for **1-2 weeks** during these visits. For the 3rd and 4th year post device activation, six monthly visits are required, then annually thereafter. The visits include appointments with the other team members.
- It is possible, with suitable internet connection that some speech and language therapy sessions can be done via video calls, e.g. Skype. If there is a speech-language therapist where you stay, the therapist on our team will work together with him / her.
- In the case of older congenitally deaf children we recommend that the family / a family member move to Cape Town for optimal progress. Your child will then attend the Carel du Toit Centre on a daily basis.
- The Carel du Toit Centre fall under the Department of Education. In order to attend the school, it will be necessary that the requisite paperwork for visa and educational legal requirements are in place. This will be explained by the Social Worker at your first visit there.
- Each child's rehabilitation needs (daily vs weekly vs visit) will be assessed individually.

3. ASSESSMENT FOR COCHLEAR IMPLANTATION AT THE TYGERBERG HOSPITAL-STELLENBOSCH UNIVERSITY COCHLEAR IMPLANT UNIT - OUR TEAM

Our unit was established in 1986 and is comprised of a highly skilled, professional medical and rehabilitation team who endeavour to provide the most appropriate management of your hearing loss within a multidisciplinary context. Figure 2 demonstrates the depth of our team with team members including Ear Nose and Throat Surgeons, Audiologists, Speech and Language Therapists, as well as other health professionals. Younger children managed in our programme are also referred to the Carel du Toit Centre (www.careldutoit.co.za) for appropriate rehabilitation by a skilled and experienced team.

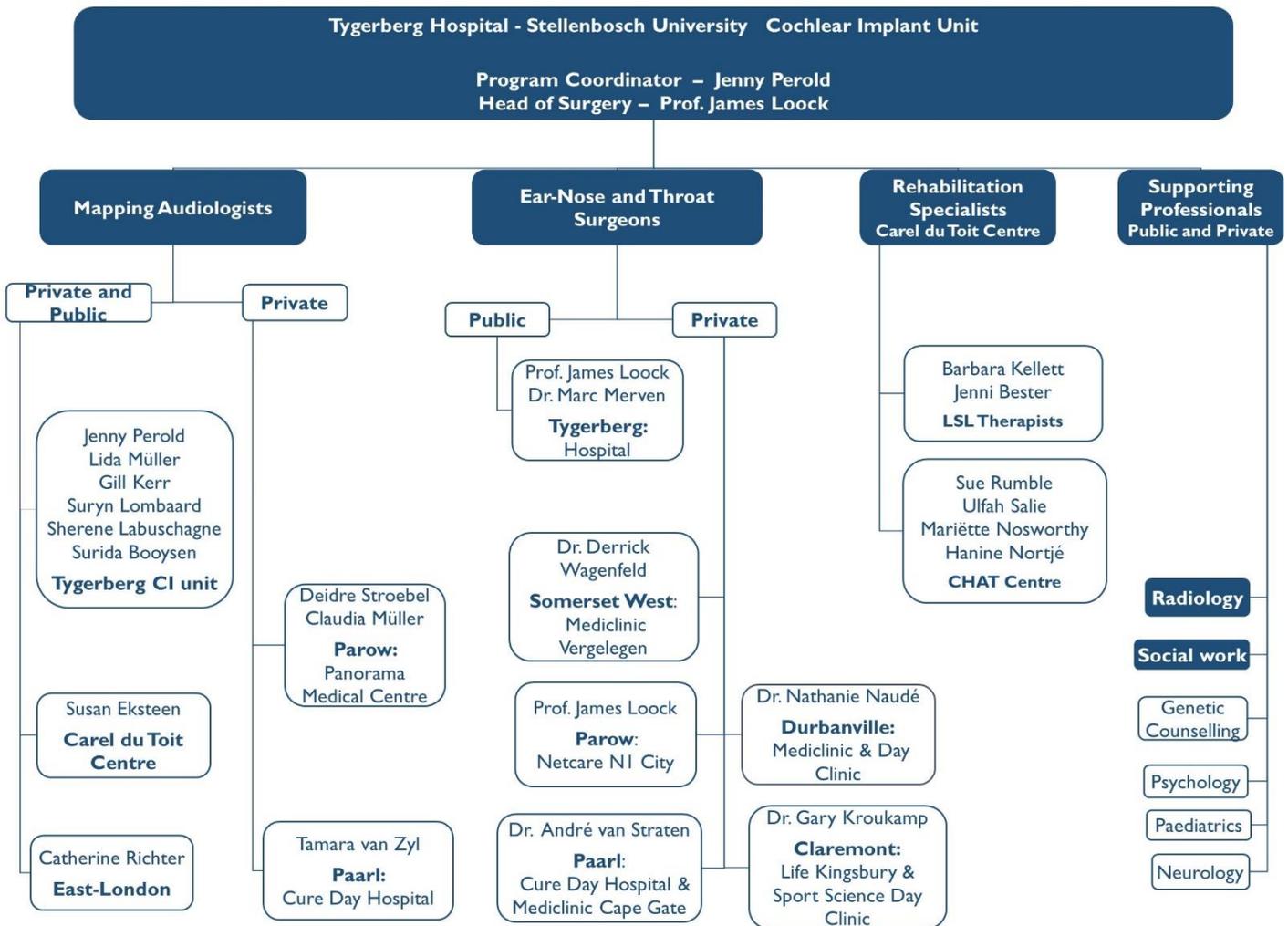


Figure 2. Core members of the TBH-SU- CIU team.

4. STILL INTERESTED?

If you feel the above-mentioned factors are possible for you, we encourage you to make contact with us for an assessment appointment.

For more information, please look at our website: www.cochlearimplants.co.za. If you would like to make contact with other parents who are in a similar situation please let us know. We are able to put you in touch with other families.