

Protocols and procedures for children referred to the Tygerberg Hospital-University Stellenbosch Cochlear Implant Unit from countries outside of South Africa

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Your child has been referred to our Cochlear Implant Unit at Tygerberg Academic Hospital-University of Stellenbosch, Cape Town. Our unit was established in 1986 and is comprised of a highly skilled, professional medical and rehabilitation team who endeavor to provide the most appropriate management of your child's hearing loss within a multidisciplinary context. Members of our team include 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 re/habilitation by a skilled and experienced 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.

Our team is careful in selection of appropriate candidates for cochlear implantation in order to ensure as far as possible the best outcome. The assessment process and selection criteria we use are in keeping with internationally established protocols.

It should be noted that the most critical factors determining a good outcome are duration of deafness and the age of the child. Therefore, our unit generally does not implant children who have been born with profound sensorineural hearing loss and have not by the age of 3y acquired any speech and language.

Other critical factors which need to be in place for consideration for implantation are that the child will have access to appropriate re/habilitation and be placed in a supportive educational system which promotes the development of spoken language. Strong parental involvement and commitment are essential. Financial considerations are also a critical component (initial costs as well as long term maintenance, travelling and accommodation costs). Initial costs include

- Assessment process at Tygerberg Hospital
- Ear Nose and Throat surgeon appointments
- Radiological assessment

If your child is found to be a suitable candidate for cochlear implantation, the cost of the surgery, device and long-term costs (including upgrades, spares and maintenance) will need to be paid for by the child's family.

THE PROCESS:

If you feel the above-mentioned factors are possible for you, your family will be given appointments for the evaluation by the cochlear implant team. Part of this assessment will be at Tygerberg Hospital and part in the private sector.

ASSESSMENT

The following needs to be in place for the assessment process:

1. You will need to be in Cape Town for a period of at least two weeks for the following procedures and appointments:
 - 1.1 an appointment with an *audiologist* at 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.
 - 1.2 further *hearing tests* which will include behavioural and objective hearing tests. Your child may need sedation for the 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 with an audiologist who will perform the tests under sedation. If possible and indicated these may be done at the same time as the Radiology.
 - 1.3 It is assumed 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.
 - 1.4 Appointment with an *ENT surgeon* who will assess your child's medical suitability for cochlear implantation and make arrangements for the Radiological assessment.
 - 1.5 *Radiology* – this will be done at Panorama Mediclinic during the first week. This is in order to assess whether implantation is possible and includes CT scan, MRI scan of internal auditory structures and brain.
 - 1.6 *Speech and Language* assessment is necessary in order to establish your child's speech and language level, and in order to support and provide parents with appropriate intervention goals.
 - 1.7 An appointment with the *Social Worker* at the Carel du Toit Centre.
 - 1.8 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.
 - 1.9 Financial costs can be determined once a decision has been made as to whether your child will receive unilateral or bilateral cochlear implantation.

FINANCIAL CONSIDERATIONS

1. Costs of assessment process
2. Cost of the device (approximately R250 000.00 for one system)
3. Costs of travelling (for assessment, surgery, programming of the device (every 3 months for first two years, six monthly for the 3rd and 4th years after activation, annually thereafter assuming no problems arise between visits)
3. Accommodation
4. Visa requirements
5. Audiologist visits and tests
6. Appointments with the early intervention team at Carel du Toit Centre.
5. Should an interpreter be needed the costs of this will need to be borne by the family
6. Long-term maintenance costs (replacement of battery, cables, coils and upgrades over time of the external sound processor).

COSTS – See attachment

Should the above conditions be met and possible for the family, arrangements can be made to book surgery and order the cochlear implant device. The cochlear implant system needs to be paid for prior to the surgery.

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 being done). An overnight stay in hospital is usually required.

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 for the fitting process and rehabilitation with the early interventionist / speech and language therapist.

Follow up visits are every 3 months for the first two years. You / your partner 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, annually thereafter.

The visits include appointments with the intervention team (Speech-Language therapist / interventionist and if required other team members)

It is possible, with suitable internet connection that the speech and language therapy sessions can be done via 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,

Cochlear Implantation is a wonderful technology which makes it possible for deaf children to access sound and therefore provide the possibility of learning to speak. However, it is expensive to acquire and maintain, requires dedication, high levels of motivation and parental input in order to achieve the best possible outcome. Successful cochlear implant use is dependent on full commitment from the family, staff in the educational environment (where relevant), and the rehabilitation team.

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.