

# **Cochlear Implant Center at Joe DiMaggio Children's Hospital**

*Division of Pediatric Otolaryngology – Head & Neck Surgery*

## **Patient & Parent Information**



RL 13193



## Table of Contents

Welcome .....	3
Important Contact Information.....	4
How do we hear?.....	4
How does a cochlear implant work? .....	6
Your Child’s Audiogram.....	7
Who is a candidate?.....	8
What to expect? .....	9
Meningitis Vaccination Information.....	10
Cochlear Implant Candidacy Profile .....	11
Cochlear Implant Candidacy Profile (continued).....	12
Surgery .....	13
Post-surgery & First Fit.....	14
Follow-up Information .....	15
Devices .....	16
What Things Cost .....	17
Communication Mode Considerations and Expectations.....	18
FAQ.....	19



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## Welcome

Welcome to **The Cochlear Implant Center at Joe DiMaggio Children's Hospital**. We are housed within the Division of Pediatric Otolaryngology and Head & Neck Surgery as part of the Memorial Healthcare System. The program is served by a team of healthcare professionals:

**Samuel Ostrower, MD, FAAP**

*Otolaryngologist, Medical Co-Director*

**Lawrence Grobman, MD, FACS**

*Neuro-Otologist, Medical Co-Director*

**Julie Verhoff, AuD, PhD, CCC-A**

*Pediatric Cochlear Implant Audiologist, Director of Audiology*

**Bianca Castro, AuD, CCC-A**

*Pediatric Audiologist*

**Ania Reyes, AuD, CCC-A**

*Pediatric Audiologist*

**Debra Stanley, LCSW**

*Social Worker*

**Lauren Rothstein, SLP-A**

*Speech Language Pathology Assistant, Aural Rehabilitation Specialist*

Your child has been referred to the center because he or she may benefit from an implantable hearing device called a cochlear implant. In the coming weeks we will evaluate your child and give you the necessary information to decide if a cochlear implant is appropriate for your child and your family. We are here to be a source of information and support. Please do not hesitate to ask questions at your appointments, via email, and over the phone.



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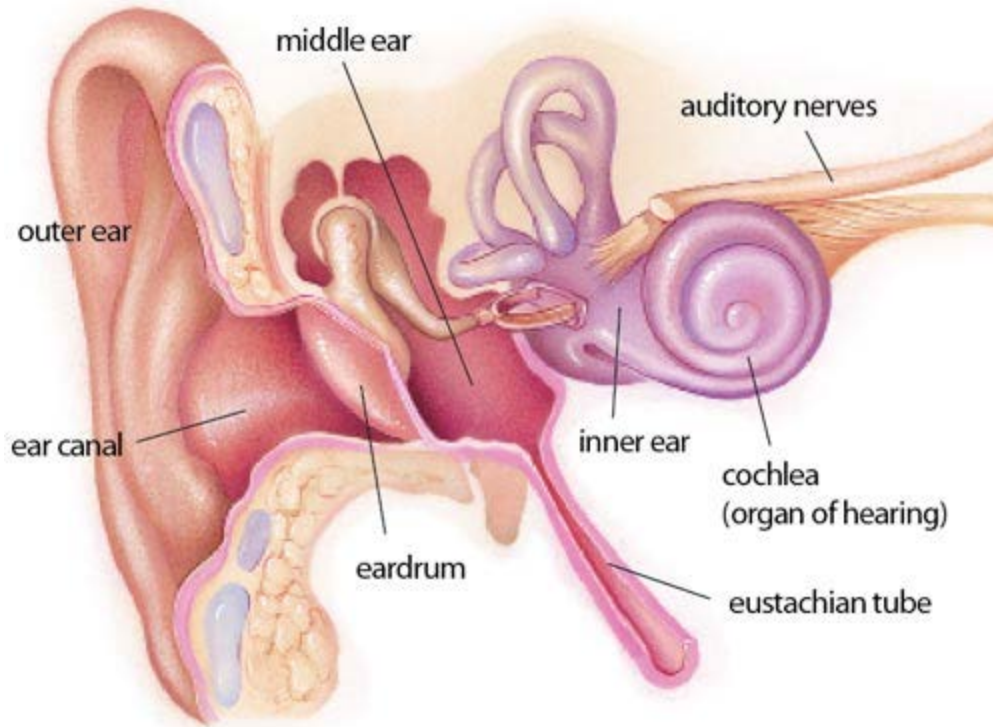


## Important Contact Information

- Clinic Number/Scheduling: 954-265-1616
- Israel Gerena (Authorizations/Insurance): 954-265-1627
- Niriam Diaz (Surgical Scheduling): 954-265-1610
- Eduardo Reina (Medical Assistant): 954-265-1624
- Ania Reyes (Audiology): 954-265-1623
- Debra Stanley (Social Work): 954-265-6349
- Lauren Rothstein (Speech Pathology/AVT): Call Matt Morrison at 954-265-7674

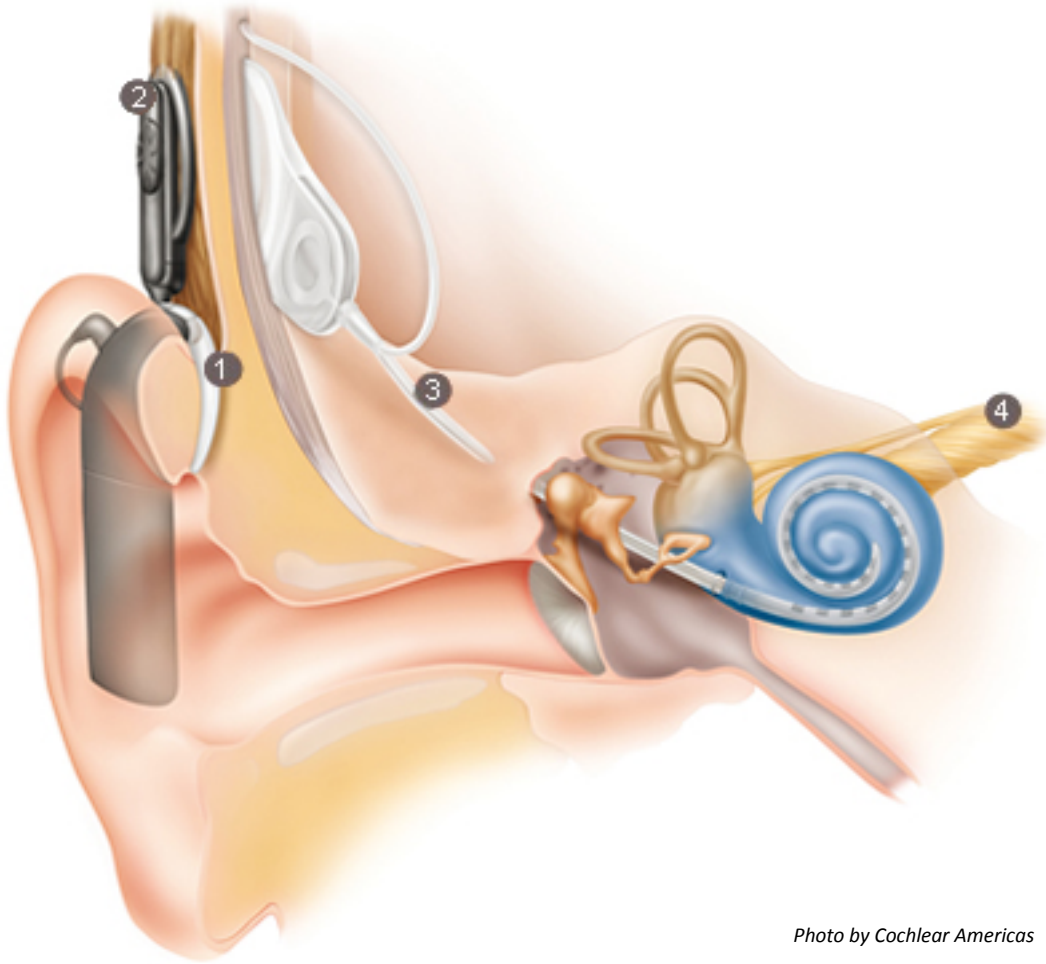


## How do we hear?



- Outer Ear (ear canal & ear drum): Sounds in the form of vibrations travel down the ear canal to reach the ear drum. This causes the ear drum to move/vibrate.
- Middle Ear (space behind the ear drum with the three smallest bones in the body): The vibrations of the eardrum cause movement in the chain of tiny bones that is connected to an opening of the inner ear. This movement causes the fluid in the inner ear to move as well.
- Inner Ear (cochlea): The movement of the inner ear fluid causes tiny hair cells inside the cochlea to change, firing electrical signals from the inner ear to the hearing nerve (auditory nerve) and then up to the brain.

## How does a cochlear implant work?



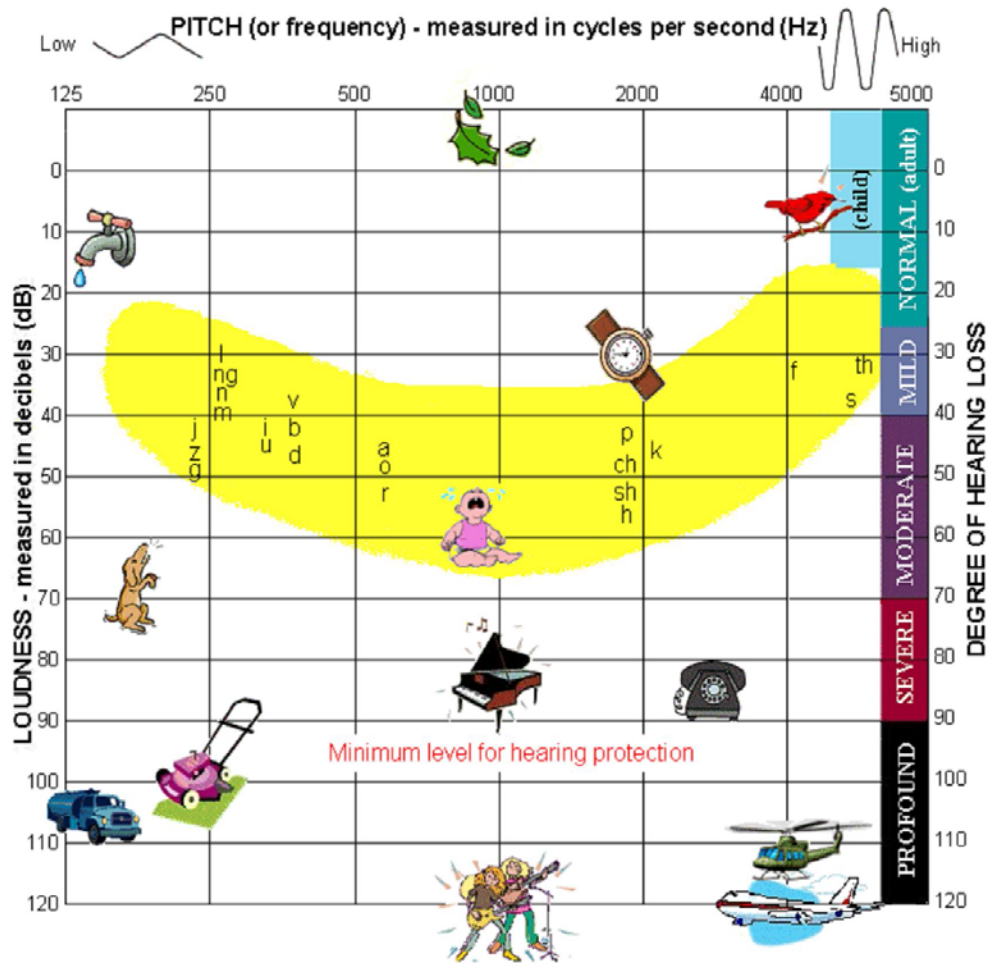
*Photo by Cochlear Americas*

A cochlear implant has parts that are surgically implanted and parts that are externally worn behind the ear and on the head. Follow the numbers in the diagram above to read about each part of the cochlear implant system.

1. **Sound Processor or Speech Processor:** converts environmental sounds (captured by the **microphone**) into a digital signal. This is where the implant battery lives.
2. **Coil:** The digital signal is transmitted to the internal implant through the **cable** and coil.
3. **Implant:** The implant converts the digital signal into electrical impulses that are sent to the cochlea via the **electrode array**.
4. **Auditory Nerve or Hearing Nerve:** The hearing nerve is stimulated by the electrical impulses from the electrode array. The brain then perceives the sound.

## Your Child's Audiogram

Audiogram Key	Right Ear	Left Ear
AC (unmasked)	○	×
AC (masked)	△	□
BC (unmasked)	<	>
BC (masked)	[	]
No response (on any symbol)	↙	↘
Sound-field (non ear specific)	S	



**Loudness Levels of Common Sounds (in decibels)**

-10 dB Leaves rustling	80 dB Rush hour traffic	120 dB Rock band
10 dB Breathing	90 dB Food blender	120 dB Airport
20 dB Whisper	110 dB Chain Saw	140 dB Shotgun blast
40-60 dB Conversation		

An **audiogram** is a type of graph that shows the softest sounds a person can hear across low to high frequencies/pitches. The audiogram in the picture above shows the degrees of hearing loss as well as the loudness and pitch of everyday sounds.

Developed for FIRST YEARS - <http://firstyears.org/>  
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## Who is a candidate?

Cochlear implants are recommended for patients who get little to no benefit from traditional hearing aids. The Food and Drug Administration (FDA) has approved the use of cochlear implants for children who meet the following criteria:

- Children who are at least **12 months of age**
- Children with **severe-to-profound hearing loss**
- Children who are **medically cleared** or healthy enough to undergo surgery
- Children who have **little to no benefit from traditional hearing aids** that are **appropriately fit and worn during all waking hours.**
  - Older children who are unable to understand at least 30% of the words presented with listening only tasks.
- Children whose families can provide the **support and follow-up** needed in order to succeed with a cochlear implant.



*Photo by hearingfirst.org*



## What to expect?

### **Evaluation Process:**

1. Otolaryngology
  - a. Decide if your child is medically a candidate for a cochlear implant
  - b. Look for the cause of hearing loss (genetic testing, MRI or CT scan)
  - c. Talk about surgery plans and risks involved
2. Audiology
  - a. Talk about your child's hearing health history and school/daycare arrangements
  - b. Evaluate hearing status with and without hearing aids
  - c. Provide information about cochlear implants and hearing loss
  - d. Talk about goals and realistic expectations for your child
3. Speech and Language Pathology
  - a. Asses your child's communication abilities
  - b. Set goals for pre- and post-cochlear implant
  - c. Provide assistance and support with your child's educational plan
4. Social Work
  - a. Determines the needs of your family and helps make the cochlear implant process as smooth and effective as possible

### **Evaluation Checklist:**

#### *Otolaryngology*

- ENT appointment
- MRI/CT
- EKG
- Healthy ears
- Meningitis vaccine
- Surgery overview and date
- Post-op follow-up scheduled

#### *Audiology*

- Case history
- Unaided & aided audiogram
- Minimum 3 month trial with appropriately fit hearing aids
- Basic understanding of hearing, hearing loss, hearing aids and cochlear implants
- ABR/OAE

- Speech perception assessment/parent questionnaire
- CI device overview and selection
- Follow-up schedule

#### *Speech Pathology*

- Speech and language evaluation
- Therapy/school services optimized
- Speech therapy trial (if not already completed)
- Early Steps/SHINE/Child Find referral (based on age)- IFSP/IEP

#### *Social Work*

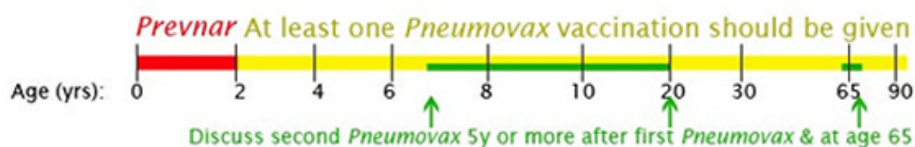
- Psychosocial evaluation to identify any social work issues or needs
- Maintain ongoing communication with social worker as needed

## Meningitis Vaccination Information

Bacterial meningitis is a life-threatening infection of the brain and the fluid around the brain. People with cochlear implants are at a higher risk for contracting bacterial meningitis. **Although the risk is small it is very important for anyone with a cochlear implant to be vaccinated.** After vaccination and post-implantation it is very important that your child see the ENT if an ear infection or fever of unknown cause develops. Untreated middle ear infections can spread and develop into meningitis.

### CDC Guidelines for Pneumococcal Vaccination in Children who have or are Candidates for Cochlear Implantation

- Children who have cochlear implants or are candidates for cochlear implants who have not received any previous doses of a pneumococcal conjugate vaccine (PCV7 or PCV13), should receive PCV13 as it is recommended routinely for all infants and children. In addition to receiving PCV13, children with cochlear implants should receive one dose of the pneumococcal polysaccharide vaccine (PPSV23) at age 2 years or older after completing all recommended doses of PCV13.
- Children with cochlear implants who have already completed the 4-dose PCV7 series and have not received PCV13 or PPSV23 should receive one dose of PCV13. PCV13 should be followed  $\geq 8$  weeks later by a dose of PPSV23.
- Children with cochlear implants aged 24 through 71 months:
  - Who have not received any doses of PCV7 or PCV13 previously should receive 2 doses of PCV13;
  - Who have received an incomplete schedule of  $<3$  doses of PCV (PCV7 or PCV13) before age 24 months should receive 2 doses of PCV13; or
  - Who have received 3 doses of PCV (PCV7 or PCV13) should receive a single dose of PCV13.
- Children 6 through 18 years of age with cochlear implants should receive a single dose of PCV13 regardless of whether they have previously received PCV7 or PPSV23. PCV13 should be followed  $\geq 8$  weeks later by a dose of PPSV23. Children aged 6 through 18 years with cochlear implants who have not received PCV13 and who previously received  $\geq 1$  doses of PPSV23 should be given a single dose of PCV13  $\geq 8$  weeks after the last PPSV23 dose, even if they have received PCV7.
- Timeline:



## Cochlear Implant Candidacy Profile

The following list (and chart on the following page) is a brief overview of various factors that can influence performance outcomes for acquiring speech and spoken language after cochlear implantation. It is not possible to predict if and when certain challenges may emerge that can directly affect performance outcomes, which is why it is critical to closely monitor each child for possible complicating issues that call for necessary revisions and accommodations to approaches, communication strategies, and overall plan of care. It is important to remember that members of the team who can provide valuable input about your child’s progress can include family, audiologists, therapists, psychologists, teachers, etc. The following list is not exhaustive, and not all of it may apply to your child.

- **Aspects of the Child:** anatomical, physiological, cognitive/intellectual, developmental, behavioral, language exposure, co-morbid factors, unknown conditions (ie: learning disabilities, autism, etc).
- **Hearing history:** etiology of hearing loss, onset of hearing loss, degree and type of hearing loss, age at diagnosis, previous listening experience, age of intervention pre-implant, age of intervention post-implant, unilateral implantation, bilateral implantation.
- **Family and Environment:** social, economic, cultural, commitment, resources, multi-lingual household or caregivers.
- **Educational and Therapeutic Methods:** consistency of therapy (auditory based, auditory-verbal, speech/language), expertise and experience, family support system, carryover and expansion, emphasis on audition as primary modality for learning, integration of audition for communication, adapted or modified approach regarding other communication modes (sign language, total communication, cued speech, PECS, etc), school placement/classroom setting, consistency of FM system usage.
- **Use of Technology:** age at fit, consistency of use, maintenance, ongoing audiological management.

*I understand that the above list serves as a guideline for various factors that can influence performance outcomes following cochlear implantation. I understand that cochlear implantation does not guarantee development of listening skills, auditory processing, or speech and spoken language, and that multiple factors can affect the rate, duration, and mastery at which these skills are developed. I understand that the overall plan of care can include type of technology and amount of technology, educational placement setting, and primary communication modality based on team recommendations.*

**Parent/Guardian Name:** \_\_\_\_\_ **Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_



## Cochlear Implant Candidacy Profile (continued)

At your final appointment prior to surgery all of your child's information will be reviewed with you. This is a summary of the unique factors that will affect your child's outcome with a cochlear implant and ensure realistic expectations are developed. Please see the figure and notes below as a reference:

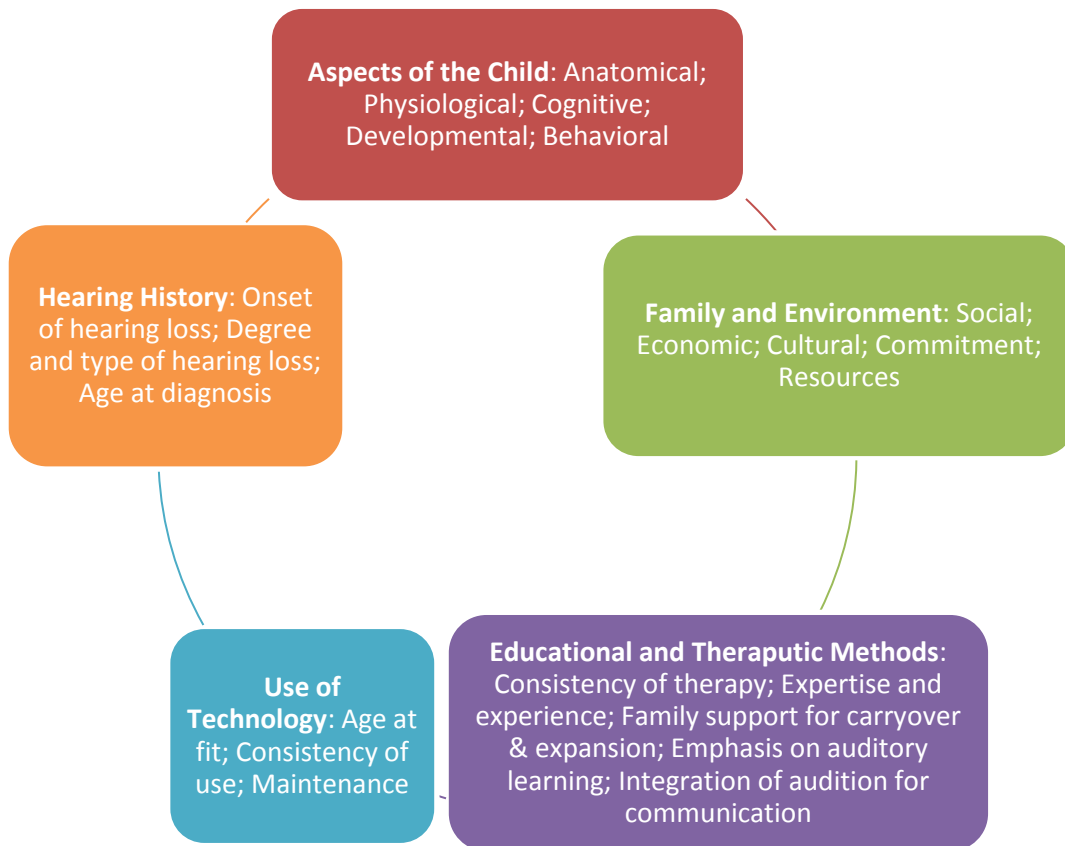


Figure adapted from: Teagle, H.F., Eskridge, H. (2010). *Perspectives on Individual Differences Affecting Therapeutic Change in Communication Disorders*. New York, NY: Psychology Press Taylor and Francis Group.

Notes: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_ cochlear implant candidacy profile has been discussed with me in detail.  
Parent/Guardian Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_



RL 13193

## Surgery

### **Before Surgery:**

- Your child's surgeon will work with you to schedule a surgery date.
- Insurance authorization is coordinated by the otolaryngologist and the hospital.
- Notify us of any signs of illness or temperature that occur within 3 days before surgery; Call: 954-265-1616
- Do not give your child aspirin or aspirin containing products anytime 2 weeks before surgery as it acts as a blood thinner.
- Your child should have nothing to eat after midnight the day before surgery and only small amounts of clear liquids the day of surgery.
- Cochlear implant surgery lasts about 3-4 hours. Children usually go home the same day but parents should come prepared to stay overnight if needed.
- Please bring your child a shirt that zips up or buttons up the front as the bandage may make it difficult to pull a shirt over the head.
- A nurse will teach you how to care for the stitches and bandages at home. Keep the area clean and dry until your child returns for their post-op appointment.
- Typically your child will see the otolaryngologist a week after surgery but please call immediately with any concerns: 954-265-1616
- Teddy Bear Tour prior to surgery- if you are interested in this please contact Niriam: 954-265-1610

**Risks of CI Surgery** (your surgeon will talk with you about these risks in detail and answer any questions you may have):

- Loss of any residual hearing in the implanted ear
- Higher risk for meningitis
- Facial nerve stimulation/involuntary facial movement
- Inflammation/extrusion/swelling
- Failure of surgery possibly requiring removal of the implant
- Failure of implanted pieces requiring removal and replacement
- Numbness/tenderness around the surgical site
- Neck pain
- Change in taste
- Loss of feeling in face
- Cerebrospinal fluid leak
- Dizziness (vertigo)
- Tinnitus/ringing in the ears
- Skin reactions/rashes
- Anesthetic Risks

## Post-surgery & First Fit

### **After Surgery:**

- The initial stimulation is usually about 4 weeks after surgery. In the meantime your child can continue to wear his or her hearing aid in the opposite ear.

### **First Fit:**

- The initial stimulation is usually a longer visit (approximately 2 hours).
- The sound processor, microphone, and headpiece are fit.
- The first map or program will be created so that it is comfortable for your child, this may not provide too much sound stimulation, but there will be progressive maps to try out before the next visit.
- Programming
  - If old enough your child may report when a sound is heard or play a “listen and drop” game to indicate when a sound is heard.
  - For very young children we will all observe the child’s behavior for any evidence that sound is heard.
  - Responses can range from smiling, to crying, to no response at all.
- You will be counseled on device use, troubleshooting and equipment care
- Product registration and warranty will be completed



*Photo by Advanced Bionics*

## Follow-up Information

### Follow-Up Schedule:

- Initial Stimulation (3-4 weeks after surgery)
- Following initial stimulation:
  - 2 weeks
  - 5 weeks
  - 9 weeks
  - 3 months
  - 6 months
  - 9 months
  - 1 year
- After the first year, appointments will be in 6 month intervals (with added appointments if needed)

**Realistic Expectations:** Before typically hearing children learn to speak they have spent over a year listening. Keep in mind that this may be the first time your child is hearing. Speech and language takes time and experience to develop. The best thing you can do is ensure your child is wearing his/her device during all waking hours and expose them to a lot of spoken language. Reading to your child aloud daily is very important. Attending speech language pathology sessions and/or auditory verbal therapy sessions is necessary for your child to learn to listen and develop speech and language.



## Devices

There are 3 cochlear implant companies/manufacturers on the market today. We will review the companies with you, but encourage you to research on your own in order to make the selection that is best for your child and your family. There are successful cochlear implant recipients from all 3 manufacturers, and likewise unsuccessful recipients. The success of your child will depend on his/her cochlear implant candidacy profile rather than on the device you choose. Although they look different they all function in a very similar manner.

- All manufacturers offer a 10-year warranty for the internal portion of the cochlear implant system.
- Warranty on the external device: warranty goes into effect on the day of initial stimulation. Items under warranty are replaced due to normal “wear and tear” only.
  - Advanced Bionics, 5-years
  - Cochlear, 5-years
  - Med-El, 5-years
- There is a **one-time** replacement for loss and damage (beyond repair) during the users warranty period.
- After warranty expires:
  - Service contracts can be purchased from the manufacturer before the warranty expires.
  - Some families choose to cover the cochlear implant through homeowner’s insurance policies—coverage varies; this is for loss and damage only.
- Although devices are designed to withstand long term use, internal devices can fail due to a blow to the head. For this reason “high risk activities”, contact sports and bicycling/rollerblading without a helmet are not recommended.
- Repairs: Eventually your child’s CI will break due to normal wear and tear or an accident.
  - The first thing to do when you note the device is not working is to (reference your user guide) troubleshoot and find what part is broken.
  - Check if your device is still under warranty (based on the date of initial stimulation).
  - Call the cochlear implant manufacturer directly to receive help with troubleshooting:
    - **Advanced Bionics:** 1-877-829-0026
    - **Cochlear:** 1-800-483-3123
    - **Med-El:** 888-633-3524



## What Things Cost

**Cochlear implant surgery, the internal device, and external equipment costs about \$80,000.**

Most of this cost is paid by insurance. After your warranty is over you are responsible to determine what is covered by insurance or Medicaid and what will be your responsibility. It is very important to purchase extended loss and damage warranty on your device once it has expired or been used.

Please remember to bring your speech processor with you to ALL appointments to ensure that it is up to date.

**Surgery/Implant: \$70,000**

**External Speech Processor: \$8,500**

**Accessories: \$5-\$1500**



*Photo by Cochlear Americas*

## Communication Mode Considerations and Expectations

Ongoing changes in cochlear implant candidacy criteria have led to a varied population of CI users. Today, children with multiple delays in addition to hearing loss are being considered for cochlear implantation. The communication goals for these children may be very different from a typically developing child who has a diagnosis of hearing loss. This is important to consider when developing realistic expectations for outcomes with a cochlear implant. Please make sure to discuss this with your CI team members. The goal is for each child to reach his or her full communication potential.

Communication modes recommended may include:

- Cued speech
- Sign language
- Augmentative communication
- Visual aids to support independent communication

## Resources

- **Early Steps** – early intervention services for children from birth to three years. Must be referred by your physician or audiologist.
  - [http://www.floridahealth.gov/alternatesites/cms-kids/families/early\\_steps/early\\_steps.html](http://www.floridahealth.gov/alternatesites/cms-kids/families/early_steps/early_steps.html)
- **Center for Hearing and Communication:** Tracy Perez, *Psy.D.*  
Director of Mental Health Services  
2900 W. Cypress Creek Rd.  
Ft. Lauderdale, Florida 33309  
(954) 601-1930 (voice) extension 316  
(954) 601-1399 (fax)  
(954) 601-1938 (TTY) (954) 642-2351 (VRS)  
[www.CHChearing.org](http://www.CHChearing.org)  
*Must be a Broward County resident to receive services*
- **Deaf Service Center**
  - <http://www.fadcentral.org/deaf-service-center-association.html>
- **My Baby's Hearing-** online resource for all things related to newborn hearing screening and follow-up (English and Spanish)
  - <http://www.babyhearing.org/>

## FAQ

### **1. What is a cochlear implant?**

- a. A cochlear implant is a surgically implanted device that provides a sense of sound to a patient who is deaf or hard of hearing.

### **2. Who is a cochlear implant candidate?**

- a. Adults and children who meet the FDA criteria for implantation and who are healthy enough to undergo surgery are CI candidates.

### **3. How long have cochlear implants been available?**

- a. Cochlear implants have been approved by the U.S. FDA since 1985 for adults and 1990 for children.

### **4. Will a cochlear implant restore normal hearing?**

- a. No. Although a cochlear implant will provide a sense of hearing to a patient it does not “cure” hearing loss. The patient will need to learn to listen and use the electrical stimulation for communication. Speech and language will take time and experience to develop. Auditory verbal training and therapy can help the patient develop the needed listening skills to get the most benefit from his or her implant.

### **5. Will my child receive one implant or two?**

- a. One cochlear implant can provide the child with access to sound. Two cochlear implants will improve the ability to hear speech in noise and help with localization (knowing what direction sounds are coming from). Most children will receive one implant to start, unless there is a medical reason for obtaining two. Once the first implant is being used successfully we can discuss implanting the second ear if appropriate.

### **6. Can the implant be worn while playing sports?**

- a. In most cases, yes. Some devices are waterproof as well, but make sure you ask your audiologist if the device you have chosen may be used in the water. Deep water diving is not recommended as it may harm the implanted device.

### **7. Can the processor be removed at night?**

- a. Yes. The processor should always be removed while sleeping/at night to let the scalp rest and to charge the processor’s batteries. The processor should be stored in a dry-n-store container (this will be provided) to remove moisture.