



MedStar Georgetown University Hospital

Pediatric Cochlear Implant Program

Patient & Parent Information Packet



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Welcome to MGUH

Welcome to the Georgetown University Hospital Cochlear Implant Program!

Congratulations on taking the first step towards determining if cochlear implantation (CI) is right for you or your child! The aim of this packet is to provide you with important information as you begin the CI evaluation process. The decision to proceed with a cochlear implant can be challenging, and our goal is to provide you with information to help you make the best choices.

Within this handout, you will find details regarding the cochlear implant evaluation to determine candidacy, pre- and post-surgical information, and a timeline of follow-up visits. You will also be provided with information on how cochlear implants work. If you decide to move forward with implantation, specific manufacturer details will be discussed. Our team works with all three FDA approved cochlear implant companies: Advanced Bionics, Cochlear Corporation, and MED-EL.

Thank you for choosing MedStar Georgetown University Hospital (MGUH) to start this journey. We are looking forward to being a part of your team! Feel free to bring this packet to your upcoming appointments.

MGUH Cochlear Implant Team

Team & Clinic Information

SURGEONS

H. Jeffrey Kim, MD, FACS
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SPEECH LANGUAGE PATHOLOGIST

Outpatient Speech Pathology Program Coordinator
Physical Medicine and Rehabilitation Department
Phone: 202-444-3612

*The MGUH CI team works closely with local speech language pathologists.
Please ask your Audiologist for recommendations.

AUDIOLOGISTS

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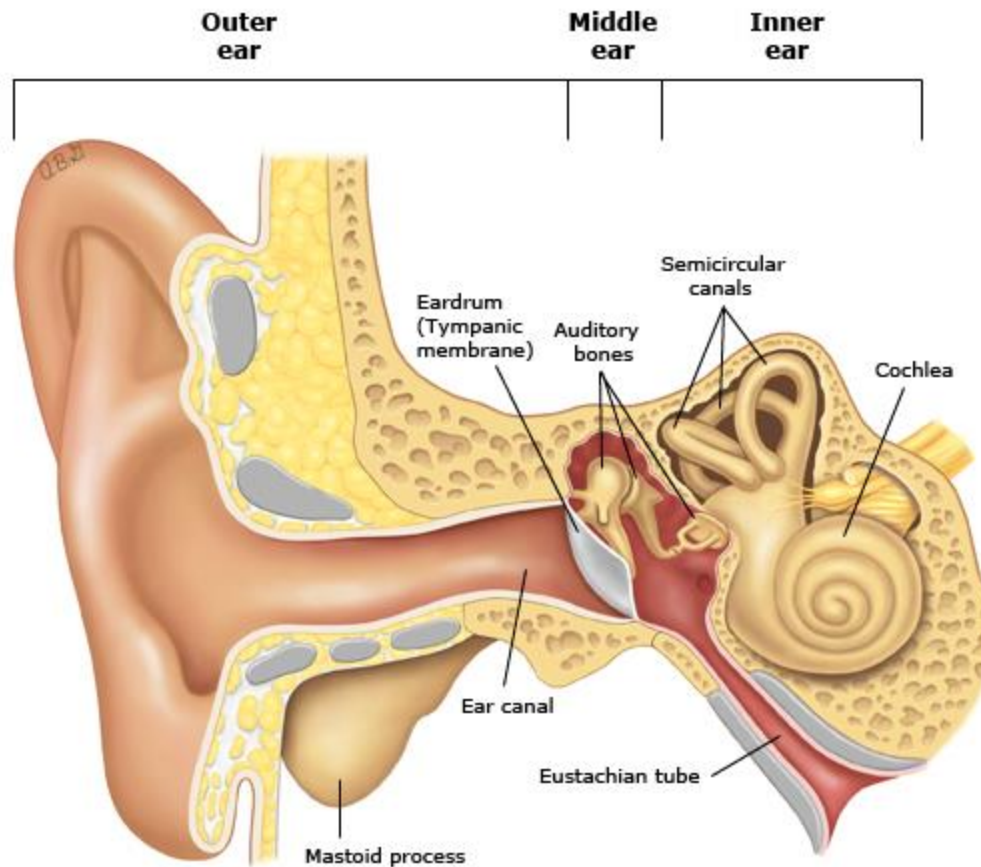
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How the Ear Works

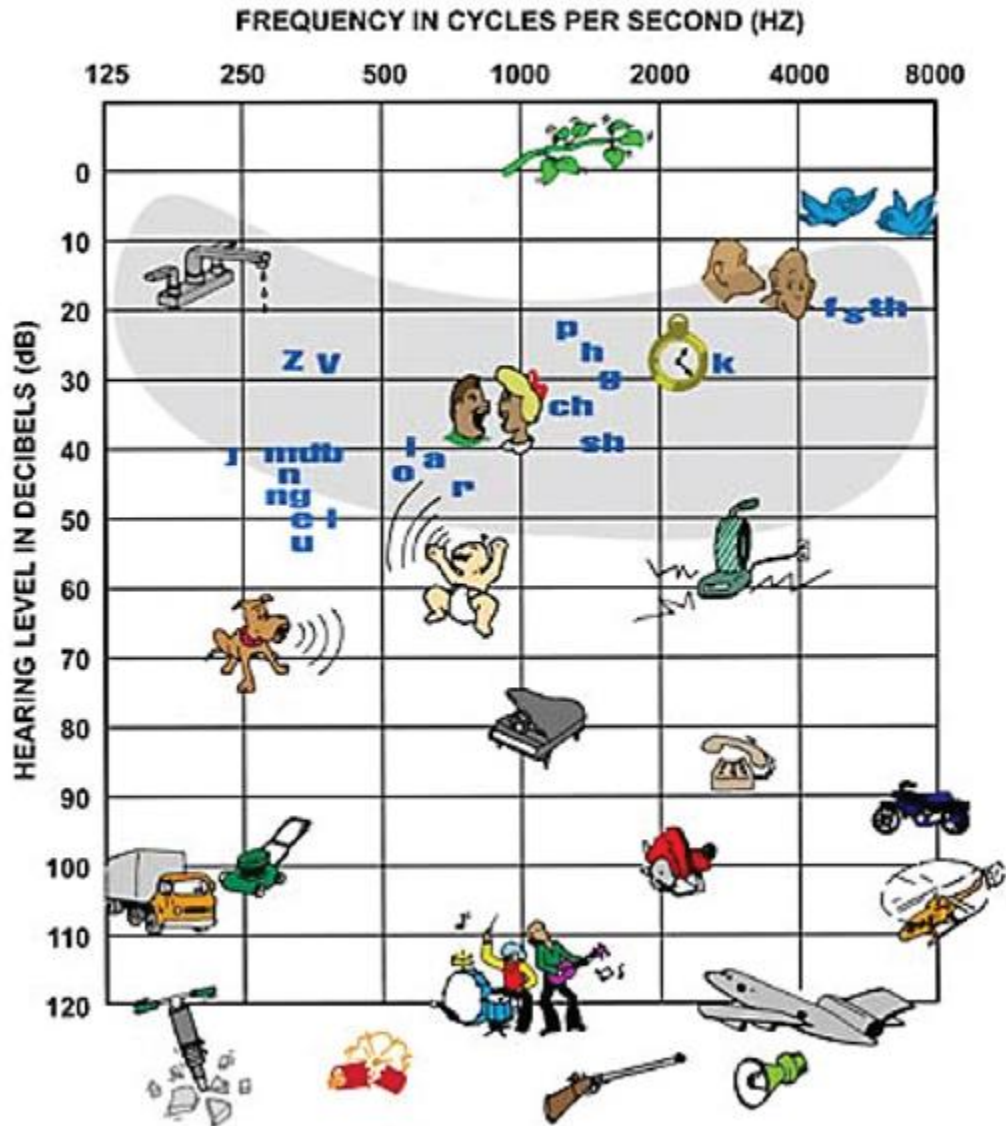


Outer Ear: The external part of the ear that you can see. The outer ear, known as the pinna, collects sound, which then travels down the ear canal and causes the eardrum to vibrate.

Middle Ear: The area behind the eardrum contains three small bones known as ossicles. Eardrum vibrations are transmitted to the ossicles, which deliver sound energy to the inner ear.

Inner Ear: The cochlea is a snail-shaped, fluid filled organ lined with hair cells. Mechanical vibrations from the ossicles cause pressure changes in the inner ear. The movement of fluid causes a reaction to the hair cells, which generates a signal from the cochlea to the hearing nerve up to the brain.

AUDIOGRAM OF FAMILIAR SOUNDS



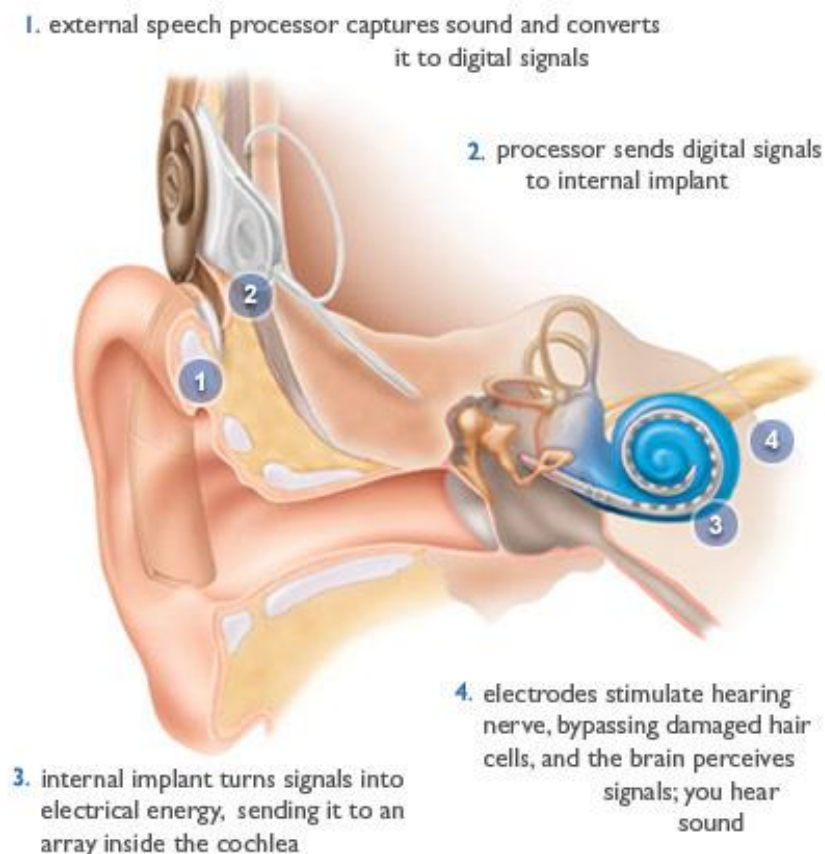
An audiogram depicts shows the softest sounds a child can hear from low to high pitch. The audiologist plots an individual's hearing on this graph. The pictures and speech sounds on the graph indicate where common sounds occur.

- X = Left ear
- O = Right ear

What is a Cochlear Implant?

Cochlear implants are medical devices designed to provide sound to individuals who do not benefit from traditional hearing aids. A traditional hearing aid picks up sound via a microphone and sends an amplified signal through the auditory system. This is an **ACOUSTIC** signal. A traditional hearing aid may not be powerful enough to provide audibility and clarity to those with significant degrees of hearing loss.

A cochlear implant uses an **ELECTRICAL** signal to stimulate the acoustic nerve and transport sound information to the brain via a surgically placed internal component. An external piece worn behind the ear or on the head picks up speech and environmental sounds via microphones and communicates with the internal implant. The image below illustrates how the processor and implant work.



Evaluation Process

WHAT IS THE GOAL OF A COCHLEAR IMPLANT EVALUATION?

- Determine if the patient is a candidate for cochlear implantation
- Provide information about cochlear implant device options, implantation process, and follow-up timeline
- The evaluation process consists of multiple visits

EVALUATION PROCESS

- **Audiologic Evaluation**
 - Test hearing sensitivity with and without hearing aids
 - Evaluate speech understanding with and without hearing aids
 - Discuss candidacy, expectations with a CI, timeline of appointments
- **Medical Evaluation**
 - A neurotologist, physician who specializes in ears and the brain and performs cochlear implantation, will review the patient's medical history
 - The patient will likely be referred for a CT scan and/or MRI
 - The surgeon will review the surgery, risks, and follow-up care
- **Speech and Language Evaluation**
- **Device Discussion**

IMPORTANT CANDIDACY INFORMATION

Who can have a cochlear implant?

Cochlear implants are suggested when a person has significant hearing loss and does not receive sufficient benefit from a well fit hearing aid.*

FDA Criteria

Children at least 9-months of age

Children with severe-to-profound hearing loss in one or two ears

Children who are not making progress with speech and language, even with a properly fit hearing aid

Children who are healthy enough to undergo surgery

Children whose families will use the device full time and receive speech therapy

**Current research demonstrates significant benefit for children who do not meet these evolving criteria. Each child is treated as an individual and will be evaluated based on the best available medical and clinical recommendations.*

Device Selection

Manufacturer: _____

Processor Model(s): _____

Implant Model: _____

Processor Color: _____

Please visit the corresponding websites for more information regarding a chosen manufacturer or to speak with a representative:

Advanced Bionics: <http://www.advancedbionics.com/us/en/home.html>

Cochlear Corporation: <http://www.cochlear.com/wps/wcm/connect/us/home>

MED-EL: <http://www.medel.com/us/>



Meningitis Vaccination

Bacterial meningitis is an infection of the brain, spinal cord, and surrounding fluid. People with cochlear implants are at a higher risk of developing bacterial meningitis. The risk is small but serious. The Centers for Disease Control and Prevention (CDC) recommends pneumococcal vaccination for adults and children who are scheduled to undergo cochlear implantation. The timing and type of vaccination varies with age and vaccination history.

Highlights of the CDC Recommendations

The CDC has issued pneumococcal vaccination recommendations for individuals with cochlear implants. These recommendations can be viewed in detail on the CDC website (<https://www.cdc.gov/vaccines/vpd/mening/hcp/dis-cochlear-gen.html>).

- Children who have cochlear implants or are candidates for cochlear implants should receive PCV13. PCV13 is now recommended routinely for all infants and children.
- Older children with cochlear implants (from age 2 years through age 5) should receive two doses of PCV13 if they have not received any doses of PCV7 or PCV13 previously. If they have already completed the four-dose PCV7 series, they should receive one dose of PCV13 through age 71 months.
- Children 6 through 18 years of age with cochlear implants may receive a single dose of PCV13 regardless of whether they have previously received PCV7 or the 23-valent pneumococcal polysaccharide vaccine (PPV23, Pneumovax®)
- In addition to receiving PCV13, children with cochlear implants should receive one dose of PPV23 at age 2 years or older and after completing all recommended doses of PCV13.
- Adult patients (19 years of age and older) who are candidates for a cochlear implant and those who have received a cochlear implant should be given a single dose of PPV23.
- For both children and adults, the vaccination schedule should be completed at least 2 weeks before surgery.

Vaccinations do not eliminate the risk of bacterial meningitis. Children and adults who received cochlear implants with an ear infection or fever of unknown cause should see their doctor immediately. If clear liquid drainage is observed to be leaking from the implanted ear, please see the cochlear implant surgeon.

Surgery Day

- CI surgery lasts approximately 3-4 hours. Children are often sent home the day of surgery. However, parents should be prepared to stay overnight if recommended by the surgeon.
- Your child will wear hospital clothes during surgery. Bring his or her own clothes to wear home. A shirt that buttons or zips up the front is best as the bandage may be too big for a pullover style shirt.
- General anesthesia is administered in the operating room.
- An incision is made in the crease behind the ear, which makes the scar inconspicuous once it has healed. A small amount of hair behind the ear is shaved, if necessary.
- A pocket is created under the skin to accommodate the internal receiver-stimulator portion of the implant. This part of the implant has a flat design so that it will not produce a noticeable shape.
- The surgeon creates an opening through the air-filled bone called the mastoid to the inner ear. The cochlear implant electrode is threaded through the spiral-shaped organ. Most cochlear anatomies can accommodate a full electrode insertion. If a cochlear abnormality is present, a partial insertion may be necessary.
- The implant function is tested in the operating room to ensure responses from the auditory system.
- The incision is closed with hidden absorbable stitches that do not require removal. A mastoid dressing is placed on the ear and remains in place for 1-2 days.
- Patients usually leave the hospital 2-3 hours after surgery is completed.

Risks with Surgery

RISKS ASSOCIATED WITH CI SURGERY

- Loss of natural (or residual) hearing in implanted ear
- Greater chance for infection around the brain and spinal cord (known as meningitis)
- Facial nerve stimulation resulting in involuntary facial twitching
- Swelling (inflammation) /
- Pushing or extrusion of internal device
- Soreness, redness, breakdown of skin in area around device
- Failure of implanted device, sometimes requiring re-implantation.

RISKS ASSOCIATED WITH ANY EAR SURGERY

- Numbness / tenderness around the ear
- Injury to the facial nerve / facial paralysis (drooping)
- Taste Change (dry mouth or metallic taste in mouth)
- Leak of inner ear fluid (perilymph) or fluid that surrounds the brain (cerebrospinal fluid)
- Dizziness or Vertigo
- Ringing in the ears (tinnitus)
- Local complications such as blood, fluid, or infection at or near surgery site
- Rashes (skin reactions)

GENERAL SURGERY RISKS

- Post-surgery pain, scarring, bleeding, and infection
- Risks associated with general anesthesia (e.g., problems with the heart, lungs, kidneys, liver, and brain)

FOLLOWING SURGERY

- Return one-week after implantation for a follow-up with the surgeon.
- Once healed, there is little to no visible evidence of the implant's presence.
- The incision can tolerate water 3 days after surgery
- Sports and strenuous exercises should be suspended for 3 weeks.

Audiology Appointments

In order to allow the incision site to heal, the initial activation is scheduled approximately 4 weeks after surgery. At the activation appointment, the external cochlear implant equipment will be programmed (“mapped”) and the device will be turned on for the first time! This appointment can be both exciting and overwhelming. Our main goal on this day is SOUND DETECTION as we begin providing the auditory nerve and brain with new stimulation.

AUDIOLOGY TIMELINE

Following implantation, you/your child will return for multiple audiologic appointments, each 2 hours in length.

- Activation (~4 weeks post-surgery)
 - Fit the external sound processor
 - Create programming that is comfortable for the child as he/she adapts to the new sound.
 - Provide instruction on use and maintenance of the equipment
 - Complete paperwork and registration
- 1 Week Post-Activation
- 1 Month Post-Activation
- 2 Months Post-Activation
- 3 Months Post-Activation
- 6 Months Post-Activation
- 9 Months Post-Activation
- 1 Year Post-Activation
- Annual/Bi-Annual Follow-up Visits

MAPPING

- The cochlear implant is connected to the computer and programming software
- The internal implant is tested
- The processor is programmed using objective measurements and the child’s responses. Different techniques will be employed to determine when a child hears sound based on the child’s age: hand raising with older children, listening games with younger children, and parent/audiologist observation with the youngest children
- Every child is different. Reactions to sound include crying, smiling, or nothing at all

WEAR TIME

- For the best results, the CI sound processor should be worn during all waking hours. “Eyes open, ears on.”
- In order for the child to hear, the inside and outside magnets must be connected. Ask your audiologist for tips if retention of the device is an issue.

Aural Rehabilitation

The cochlear implant has been activated and your child beginning to listen. Your audiologist has programmed the settings to give your child adequate sound input.

WHAT HAPPENS NEXT

Your child will learn to hear and interpret the new sound to develop speech and language skills. Many children develop spoken language skills following cochlear implantation. However, we utilize a family-centered, team approach to determine appropriate goals for your child, which may include other modes of communication. A specialized therapist, called a speech-language pathologist, can help your child learn to effectively use sound provided a cochlear implant to communicate. This type of therapy may be called Auditory-Verbal Therapy (AVT).

KEEP IN MIND

- Children with normal hearing need more than a year to listen to sounds and learn to speak.
- Speech and language develop with time and practice.
- The more speech your child hears, the more they learn. Talk and read to your child every day.
- Speech therapists or other specialists help parents teach their children language.
- To learn speech your child must hear it. Keep the device on all waking hours.
- Be patient, learning language will take time.
- Every child is different!

Support and Resources

In addition to patient/technical support offered through the manufacturer, there are several helpful websites and online communities for individuals who have received or are considering a cochlear implant.

Advanced Bionics

- Bionic Ear Association (available through the AB website)
- Doug Lynch
 - Cochlear Implant Consumer Specialist
 - Phone: 304-876-1677 (office); 661-210-8528 (cell/text)
 - Email: Douglas.Lynch@advancedbionics.com
- Customer service: www.advancedbionics.com/us/en/support
 - Phone: 1-877-829-0026
 - Email: CustomerService@AdvancedBionics.com
- Advanced Bionics Store: shop.bionicear.com
- myAB Online
 - <https://advancedbionics.com/us/en/portals/consumer-portal.html>

Cochlear

- Cochlear Community (available through the Cochlear website)
- Cochlear Concierge for those considering cochlear implantation
 - Email: concierge@cochlear.com
- Martha Schley Smith
 - Engagement Manager
 - Phone: 1-804-914-0680
 - Email: MarthaSmith@cochlear.com
- Customer service: www.cochlear.com/US/Support
 - Phone: 1-800-483-3123
 - Email: customer@cochlear.com
- myCochlear: self-support available online
- Cochlear Store: www.cochlearstore.com
- Reimbursement & Insurance
 - Phone: 1-800-633-4667 (option 2)

MED-EL

- HearPeers: <http://forum.hearpeers.com/>
- Alexanna Rodgers, M.S., CCC-SLP
 - Consumer Engagement Manager
 - Phone: 919-717-1692 (call/text)
 - Email: alexanna.rodgers@medel.com
- Annie Patricia Rodriguez, Au.D.
 - Consumer Engagement Manager-*Spanish Language/Bilingual Programs Only*
 - Phone: 984-227-4599 (call/text)
 - Email: annie.rodriquez@medel.com
- Customer service: www.medel.com/us/user-support-us/
 - Phone: 1-888-633-3524
 - Email: implant.us@medel.com or customerservice.us@medel.com
- myMED-EL WebShop
 - <https://us.shop.medel.com>